Federica Lucivero

too good to be true?

appraising expectations for ethical technology assessment

Too good to be true?

Appraising Expectations For Ethical Technology Assessment

Federica Lucivero

Promotion Committee:

Prof. dr. P.A.E. Brey, University of Twente, promotor
Prof. dr. T.E. Swierstra, University of Maastricht, promotor
Dr. M. Boenink, University of Twente, assistant promoter

Rector Magnificus, chair
Prof. dr. ir. P.P.C.C. Verbeek, University of Twente
Prof. dr. ir. J. Eijkel, University of Twente
Prof. dr. F. Brom, University of Utrecht
Prof. dr. ir. H. van Lente, University of Maastricht
Prof. Dr. A. Nordmann, Technische Universität Darmstadt

The research for this thesis has been financed by the 3TU. Centre for Ethics and Technology (<http://ethicsandtechnology.eu>)

The printing of this thesis has been financially supported by the *Netherlands Graduate Research School of Science, Technology and Modern Culture* (WTMC, <http://www.wtmc.net>) and the Department of Philosophy, University of Twente

Printed by: CPI Wöhrmann Print Service, Zutphen, The Netherlands

Cover image: downloaded from

http://24.media.tumblr.com/tumblr_lj9moo3ntp1qzs56do1_1280.jpg

Cover design: Tjerk Timan

© Federica Lucivero, 2012

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without prior written permission of the author.

TOO GOOD TO BE TRUE?

APPRAISING EXPECTATIONS FOR ETHICAL TECHNOLOGY ASSESSMENT

to obtain
the degree of doctor at the University of Twente,
on the authority of the rector magnificus,
Prof. dr. H. Brinksma,
on account of the decision of the graduation committee,
to be publicly defended
on Thursday the 19th July 2012 at 14.45 hrs

by

Federica Lucivero
Born on 4th July, 1982
in Napoli, Italy

This dissertation has been approved by promoter(s):

Prof. dr. P.A.E. Brey

Prof. dr. T.E. Swierstra

Dr. M. Boenink (assistant promoter)

© Federica Lucivero, 2012

ISBN: 978-90-365-3389-8

CONTENTS

PREAMBLE	1
Outline of the book	
5	
PART 1	7
CHAPTER 1: Technology assessment and ethics	9
1.1 Appraising emerging technologies	10
1.2 Resources and limitations in traditions assessing technologies	16
1.3 Bridging the gap: pragmatist ethics	27
1.4 The contribution of this study	34
CHAPTER 2: ASSESSING THE PLAUSIBILITY OF SOCIO-TECHNICAL FUTURES	37
2.1 Expecting future science and technologies	38
2.2 The social construction of the future	41
2.3 The guiding normativity in technological visions	44
2.4 Technologies are not a means to an end	48
2.5 Assessing the plausibility of expectations: a proposal	52
PART 2	57
CHAPTER 3: The mechanism in the pill	61
3.1 Promises of emerging artifacts	62
3.2 Rhetoric and black-boxes	63
3.3 A note on methods	65
3.4 The Nanopil: tales of an emerging object	67
3.5 From the lab “details” back to the big picture	74
Chapter 4: The doctor in the pill	77
4.1 Expectations of artifacts in use	78
4.2 (Fictive) scripts and actor-worlds	78
4.3 Research design	83
4.4 The Nanopill: tales of an emerging practice	85

4.5 Conclusions	92
CHAPTER 5: The good in the pill	95
5.1 Visions of desirable worlds	96
5.2 Different expected artifacts and different values	98
5.3 Plurality of values among actors	102
5.4 Impacts of technologies and the moral landscape	104
5.5 Conclusion	112
PART 3	119
CHAPTER 6: Expecting diagnostics Diagnosing expectations	119
6.1 Immunosignatures and the healthcare revolution	120
6.2 Research design	122
6.3 Immunosignatures: a “simple” concept	124
6.4 The expected context of use	130
6.5 Immunosignatures and a desirable world	138
6.6 Discussion	145
CHAPTER 7: SCENARIOS AS “GROUNDED EXPLORATIONS”	149
7.1 Discussing the desirability of emerging technologies	150
7.2 Scenarios as tools to foster moral imagination	152
7.3 Plausibility assessment for “grounded explorations”	155
7.4 Techno-moral vignettes and scenarios in action	157
7.5 Discussion	168
POSTSCRIPT	171
ANNEX 1: Images of Nanopil and Immunosignatures	181
ANNEX 2: Techno-ethical scenarios and techno-moral vignettes	187
BIBLIOGRAPHY	199
SUMMARY	213
SAMENVATTING	219

A Nonna Luisa

ACKNOWLEDGEMENTS

It is widely acknowledged that the value of a PhD lies in the journey to becoming an independent scholar. Certainly, in the last four years I have witnessed and enjoyed this journey, feeling that I was indeed growing as a researcher. However, this development as an academic is not what I value of the process that culminated in this thesis. Instead, what I treasure is my growing as a scholar who is satisfied and able to be *dependent* on others: the ability to exchange ideas, the skills to listen, the will to collaborate in working out problems, the aptitude to brainstorm, the trust of sharing, the generosity to offer help, and the humility in asking for it. I like to think of my dissertation as the product of this journey.

I couldn't write this thesis independently from others. In particular, the contribution of my promoters and supervisor was fundamental. My first promoter, Philip Brey, has thoroughly supervised the process of writing my dissertation with poignant comments on the whole approach coupled with the ability of looking at details. My co-promoter, Tsjalling Swierstra, and my daily supervisor, Marianne Boenink, have both been crucial actors in this process. Having two supervisors who work together as a team and complement each other in such a way is a luxury for a PhD student. The creative brainstorming, the lively discussions, the numerous outlines, the sensible wisdom, the careful reading, the caring support, together with the enjoyable conference travels, dinners and drinks: collaborating with them has been a wonderful experience that has contributed not only to writing this dissertation and to growing as a researcher, but also to my personal development.

My research would be all 'head' and no 'body' without the availability and generosity of the people I interviewed in conducting my case studies. In particular, I wish to thank the BIOS group at Twente University and the Centre for Innovation in Medicine at Arizona State University. These groups are working on the two emerging technologies that I used as case studies for this research project. I wish to thank all the members of these groups, especially those who have spent long hours discussing their research with me. The expertise, patience and enthusiasm that they showed in our conversations and through their participation in the activities that I organized have been crucial for this whole study.

Several communities of scholars have added to my research. The 3TU Centre for Ethics and Technology has financially supported this project. The "WTMC" Science Technology and Modern Culture graduate school has initiated me into the field of Science and Technology Studies and has made me understand that belonging to a community of scholars goes beyond disciplinary boundaries. The small Ethics and Politics of Emerging Technologies (EPET) group has been

growing out the geographic boundaries of Twente. This working group has provided me with valuable inspiration and fun discussions. Participation in the Nanoned meetings have been highly influential for my research. I wish to thank Arie Rip for including me in this “nano”-interested community. The Consortium For Science, Policy & Outcomes at Arizona State University has welcomed me during the warmest winter of my life in 2010. The Socio-Technical Integration Research (STIR) folks have been a great source of inspiration and, although it might not be evident by looking only at this thesis, the discussions with Erik Fisher and his supervision during my stay in Arizona have played an enormous role in the way I approached my case studies and in defining my research questions. Last, but not least, the department of Philosophy at the University of Twente has been a great place to work: the sharing of ideas, sorrows and joys with the PhD/Post-Doc crowd have cherished long working days and late partying nights.

Thanks to Lise Bitsch, Yvonne Cuijpers, Pierre Delvenne, Erwin van Rijswoud, Willelm Halffman and Lucie Dalibert for their comments on previous versions of the chapters. Also, I would like to thank my friends Dirk Haen for the elegant translation of the summary in Dutch and Tjerk Timan for designing the beautiful cover of this book. Finally, I am grateful to Clare Egan-Shelley, Sarah Davies and Aimee van Wynsberghe for carefully editing chapters of my thesis and tailoring my winding and wordy Italian style into a more concise Anglo-Saxon style. Of course, I take full responsibility for every mistake or imperfection still present in the text.

Somebody says that a PhD is a lonely activity. I had the privilege of being in great company through the all process. At the University, at the bar or at home. Ana, your pragmatic wisdom and sense of humor has often been very inspirational for me, showing me what does it mean to be a woman while being an engineering scientist. I am very honored I could be an active witness of your achievements in the last four years. The discussions with Lucie on embodiment, gender and “post-stuff” at the breakfast table together with the jokes and complaining about sorrows about the PhD life have been incredibly valuable for me. I *hope* we will write that one paper together. Aimee, sharing this all process with you has been a wonderful and fun experience. We have been colleagues, we have been collaborators, we have been housemates, and most importantly we have been friends. What I have learnt about sharing and generosity in doing research comes from you. Now that we are both done with our thesis, I am *sure* we will write that one paper together. Together with many other chapters of our lives.

Finally, a PhD thesis is hard to accomplish without the love and the patience of our beloved ones. I wish to thank Paul and my family for their steady support. But the biggest role in the finalizing phase of this process was played by my beloved grandmother – an extraordinary woman – who, passing away a few weeks ago, reminded to me that life is much more than a PhD thesis. Cara Nonna, this thesis is for you.

Enschede, 27th April 2012

PREAMBLE

Appraising the plausibility of
expectations

It is not enough to change the world. That happens anyway and generally beyond our control. What matters is to interpret this change, specifically in order to lead it. So that this world does not change further outside of ourselves, ultimately becoming a world-without-us.

(G. Anders. Die Antiquiertheit des Menschen, vol 2)

New File. The blank page is scary. Open recent > Notes for Chapter 1. Ctrl+A, Ctrl+C. Better to start with this. Now, Ctrl+V on the blank page. This paragraph is a good start for my book. Ctrl+X, Ctrl+V, select paragraph, move up. Uhm, no... Ctrl+Z. A tag pops up in the bottom right corner of my screen: This is your rest break. Make sure you stand up and walk away from your computer on a regular basis. Just walk around for a few minutes, stretch and relax. I can check my Facebook page in my break. Or perhaps I shouldn't. I should install the software that limits my access to Facebook during working hours. This is killing my productivity! A walk might be better. Oh, wait: Ctrl+S.

These lines capture my daily activities while writing this book. Yet, 30 years ago they might have sounded like science fiction to the average academic. Writing a book in 2011 is a very different practice from writing a book in 1982, the year I was born. In fact, it was in 1982 that WordPerfect Corporation introduced WordPerfect 1.0 “that will become one of the computer markets most popular word processing programs”¹. With new technologies come new innovations: new tools are available, new skills are necessary, old abilities are superfluous, new problems emerge, old problems are redefined and addressed with new technical solutions and, new moral obligations arise together with new needs and desires. This is just one example among the many possibilities showing how the introduction of technologies deeply affects our daily practices by altering our knowledge, habits, perceptions, capabilities, and values.

Would it have been worthwhile to reflect on the impacts of computing and word processing on the writing practices of 30 years ago? Would such a reflection have affected the development of new hardware and software to avoid the occurrence of Repetitive Strain Injury syndrome? Would such a reflection have impacted policy makers and managers to grasp the sudden changes of writing and working practices? Would such a reflection on potential impacts have helped parents to better understand their children? Finally, would such a prospective reflection on a future practice even be possible at all? As the Italians say: “history cannot be done with ‘if’ and ‘but’”. That is, retrospective speculations on how things could have been different 30 years ago are not purposeful. Rather, what *can* be done is a prospective investigation of the relevance of such reflection on current emerging technologies.

The importance of a reflection on the desirability of emerging technologies has been addressed in the tradition of Technology Assessment. If we look to the etymology of word “assessment”, “assess” comes from the Latin *ad-sedēre*, meaning *to sit*, referring to the sitting position of judges comparing and estimating the “value of (property or income) for the purpose of apportioning its share of

¹ <http://www.computerhope.com/history/198090.htm>

taxation"². An assessment is an act of determining an amount (for example properties or income) and estimating (or comparing) its value with respect to a quality standard (for example spending or purchasing power). In this sense, assessing emerging technologies is an *evaluative* activity: it doesn't simply describe what impact a technology might have, it also suggests whether this impact is good or bad according to some "value". Although Technology Assessment activities are always evaluative of the desirability of technologies, the meaning of "desirability" has been interpreted in a variety of ways. A technology may have desirable consequences when it enhances the economy of a country, when it improves people's health, or the environment or when it eases people's everyday lives. Different economic, scientific, social or moral values can be mobilized to assess the desirable impacts of a new technology. We can define this evaluation as *normative* when a technology is assessed with respect to an explicit norm or authoritative standard. Such standards may be a legal or a moral norm. Philosophy and ethics have always been concerned with questions concerning desirability, good and/or values. Applied ethicists appraise whether some technologies are good or bad on the basis of established moral norms and principles. In this sense, they engage in a *normative* assessment of technologies.

But, prospective evaluation is not easy. In our daily lives, we have a hard time anticipating the consequences of our own actions. The task becomes even harder when the consequences depend on a large network of interacting players. The greatest challenge comes when we want to evaluate the desirability of these future consequences. Should we then give up with the attempt of meaningful discussions about the potential role that future technologies may play in our lives? Some policy analysts, sociologists and philosophers have argued that this is not ideal given that the expectations of how emerging technologies will change our lives, the promises of their benefits as well as the threats of potential losses determine our present decisions. Visions of future technologies guide our decision-making processes, they justify our choices, and they exclude alternatives. This happens on multiple levels: when politicians deliberate on investing public money for the research and development of new technologies; when healthcare managers decide how to re-organize the system for efficiency; when researchers select the focus of their research; when entrepreneurs consider what to invest in; when adolescents decide a course of study; when patients exclude certain treatments but accept others; when doctors empower their patients in the decision-making process. Reflecting on both the potential desirable and undesirable impacts of future technologies enables our society to understand current technological developments and their role in our practices in the near-

² "assess, v.". OED Online. September 2011. Oxford University Press. <http://www.oed.com/view/Entry/11849?redirectedFrom=assess> (accessed October 06, 2011).

future. This understanding allows us to interpret them and hopefully to make more cognizant decisions in the present.

Besides the question of “what” assessment means and “why” we should assess, comes the question of “who” should assess the desirability of emerging technologies. In the early days of Technology Assessment, experts in science, technology and economics were the best candidates for this task. Later on, the argument was made that, if technology plays such a big role on citizens’ lives, everyone in society should participate in decisions about technologies. Thus, not only the experts, but also citizens should have a say in assessing the potential impacts of emerging technologies. If emerging technologies should be democratically assessed, then the values and understanding of desirability should be clarified and openly discussed.

This thesis contributes to the question of “how” the desirability of emerging technologies can be assessed. In particular, it addresses the question of how to deal with “expectations” on emerging technologies when assessing their desirability. Emerging technologies are, by definition, “not there yet” and we can only assess their desirability by looking at the current expectations of their future development. Yet, these expectations do not provide stable grounds for philosophers and ethicists to ask moral questions about the desirability of emerging technologies. Why? The grammar of expectations clarifies this point. If I say that I expect to finish my book in a few months, my expectation communicates that: I *believe* and I *hope* that I will finish my book in a few months. In the act of expecting there is an element of belief that something *can* happen, for example I have enough chapters written. There is also an element of interest that something *should* happen, for example I want to finish my book. Furthermore, I can utter this expectation *in order to* convince my supervisors to settle the defense date soon. Since my expectation depends on my beliefs and interests, and can have a specific function, it cannot be taken as a starting point from which the value of my book can be assessed. The same line of reasoning applies to expectations of emerging technologies: are they *too good to be true*?

Philosophers of technology and applied ethicists cannot take expectations surrounding emerging technologies as descriptions of states of affairs. In the case of technologies that are still emerging, the *normative* assessment of the desirability of emerging technologies has to start by appraising the quality of expectations on emerging technologies.

How can the epistemological robustness of expectations on emerging technologies be assessed in view of a normative reflection on their desirability?

This methodological question is the central focus of this study. The goal of this dissertation is to articulate, implement and justify the approach to assess the plausibility of expectations on new and emerging science and technologies.

Outline of the book

The **FIRST PART** of this book presents the problems and research questions and the approach that is taken in order to address them. **Chapter One** introduces the general debate on the assessment of emerging technologies. It focuses on two academic traditions used to assess technologies, namely Constructive Technology Assessment and Applied Ethics/Moral Philosophy. The former tradition fails to deal with questions about the desirability of emerging technologies, while the latter lacks an empirical sense of the context. To account for these shortcomings, the tradition of pragmatist ethics, addresses these lacks by providing context-sensitivity and normative interest. Pragmatist ethics aims to improve the conditions for democratic deliberations on emerging technologies. However, it doesn't directly address the epistemological question of how to assess expectations. **Chapter Two** expands on the topic of "expectations" and the need to assess their quality. Using the Human Genome Project as an example, I reinforce my initial claim of assessing the quality of expectations of emerging technologies. In this chapter, I present the insights from the scientific and philosophical literature that is necessary to develop a methodology for assessing the quality of expectations. I turn to the literature on the sociology of expectations to investigate their social construction. According to the literature, expectations should not be taken at face value, because they have a strategic and performative role. The literature on "visions" emphasizes that it is indeed important to assess the desirability of the values and norms implied in visions of future technologies. Since this normative content is not always explicit, it should be disclosed before it can be assessed. These analyses of expectations are enlightened by the literature on empirical philosophy of technology. This literature points out that technologies often do much more, and very different things, than they were intended to. Consequently, I will argue that before asking whether these implicit norms and values are desirable *one had better check how plausible it is that they will indeed be realized*. To address this question, I develop an analytic and methodological approach which I refer to as "plausibility assessment". This approach is based on a three-step process that requires the articulation of three elements of these expectations: the expected *artifact*, its potential *use* and the anticipated *valuable impacts*.

Such an analytical framework is further described in **SECOND PART** of this book where the expectations of a specific emerging technology are used as an exemplary case: the "Nanopil", an ingestible device for in vivo screening of intestinal cancer. **Chapter Three** illustrates how to go about analyzing expectations about a future artifact. After introducing public expectations surrounding the Nanopil, I explain why further analysis is needed and how it can

be done. Then, I present my research design and the analysis of expectations of the Nanopil, explaining how this analysis helps to address the question of the plausibility of expectations. **Chapter Four** has a similar structure. It addresses the question of how to analyze expectations of the potential use of an emerging technology. Using the example of the Nanopil, I explain why they need to be assessed and what conceptual and methodological tools help with this. Based on these considerations, I discuss the findings of my analysis. These preparatory analyses set the stage for addressing the main question pertaining to the plausibility of visions in **Chapter Five**. In this chapter, I return to the question of how plausible it is that certain values and desirable worlds will indeed be realized by a new technology. The plausibility of the expectations of the Nanopil is assessed on three levels: how likely is that the artifact will promote the expected values? To what extent are these values desirable? And how likely is that a technology will instrumentally bring about a desirable consequence?

The **THIRD PART** of this book will discuss the possibilities for discussing and implementing the three-step approach developed in Chapters Three, Four and Five with respect to the Nanopil example. In **Chapter Six** I apply this analytical and methodological framework to another technology: the Immunosignatures. At the end of the chapter I discuss how my approach has been adjusted to this different case and what remains the same. **Chapter Seven** shows how my “Plausibility Assessment” can improve the debate on the desirability of emerging technologies. The insights gained help to develop plausible techno-ethical scenarios. These scenarios can then be used as tools to foster stakeholder discussions on the desirability of emerging technologies. The analysis of two pilot workshops, organized with the scientists and engineers developing the Nanopil and the Immunosignatures, points out the opportunities and limits associated with these tools.

How does my proposal for plausibility assessment contribute to the goal of assessing emerging technologies? The **Postscript** returns to the discussion outlined in Chapter One. It discusses the contribution of the proposed approach to assess expectations plausibility to the fields of applied ethics and Technology Assessment. In conclusion, I explain how this study contributes to the Ethical Technology Assessment goal of improving the conditions for democratic deliberation on the desirability of emerging technologies.

PART 1

1

Democratic appraisals of future technologies

Technology assessment and ethics

O most ingenious Theuth, the parent or inventor of an art is not always the best judge of the utility or inutility of his own inventions to the users of them (Plato, Phaedrus)

This chapter introduces the general issue of assessing the desirability of emerging technologies and points out certain trends in its social mandate (§ 1). These trends are then analyzed within two academic traditions: constructive technology assessment and applied ethics (§ 2). Whereas one tradition –being process-oriented – lacks a substantive assessment of the desirability of emerging technologies, the other tradition – exploring normative questions – is detached from the innovation process and, thus, too speculative. Pragmatist ethics is particularly apt to bridge this gap and take up the challenge of assessing emerging technologies (§ 3). This approach is process-oriented and context sensitive. It also articulates and explores substantial issues on the desirability of emerging technologies bringing them into the public discussion. Within this context, one question needs to be addressed (§ 4): if emerging technologies do not yet exist, we only have expectations of them, how can we guarantee that an assessment of their desirability is epistemologically robust? The contribution of this book lies in addressing this question.

1.1 Appraising emerging technologies

The myth of Theuth – told by Socrates in the Platonic dialogue *Phaedrus* – introduces the topic of this thesis: the prospective appraisal of the quality of emerging technologies. Theuth – the god “inventor of many arts, such as arithmetic and calculation and geometry and astronomy and draughts and dice, but his great discovery was the use of letters” – talked in front of Thamus, the king of Egypt, and

[...] showed his inventions, desiring that the other Egyptians might be allowed to have the benefit of them; he enumerated them, and Thamus enquired about their several uses, and praised some of them and censured others, as he approved or disapproved of them. It would take a long time to repeat all that Thamus said to Theuth in praise or blame of the various arts. But when they came to letters, This, said Theuth, will make the Egyptians wiser and give them better memories; it is a specific both for the memory and for the wit. Thamus replied: O most ingenious Theuth, the parent or inventor of an art is not always the best judge of the utility or inutility of his own inventions to the users of them. And in this instance, you who are the father of letters, from a paternal love of your own children have been led to attribute to them a quality which they cannot have; for this discovery of yours will create forgetfulness in the learners' souls, because they will not use their memories; they will trust to the external written characters and not remember of themselves. The specific which you have discovered is an aid not to memory, but to reminiscence, and you give your disciples not truth, but only the semblance of truth; they will be hearers of many things and will have learned nothing; they will appear to be omniscient and will generally know nothing; they will be tiresome company, having the show of wisdom without the reality. (Plato, *Phaedrus*)

Thamus is a scrupulous governor, carefully assessing the praise and blame of new inventions, and extensively approving and disapproving of them. Thamus claims his legitimacy of appraising Theuth's inventions because he can pick up on qualities that would otherwise remain hidden in the inventor's enthusiastic eyes. The technology under examination, the alphabet, is new and emerging, never been seen or used by any Egyptian before. The distinction between the role of the evaluator and inventor is clear-cut: on one side there is Theuth enthusiastic about how his technologies will benefit Egyptians, on the opposite side there is Thamus weighing the possible detrimental impacts on society. This “Technology Assessment” *avant la lettre* clearly distributes responsibilities between scientists and society.

1.1.1 From the myth to the history: the evolving social mandate of Technology Assessment

The idea that society should assess the desirability of technologies is fairly recent. Even in the aftermath of WW2, when the images of the atomic bomb in the Japanese skies were still vivid in people's eyes, the contribution of scientific research to societal progress was still widely acknowledged. The faith in the

endless frontier of scientific research, whose progress would inevitably reward society with goods, used to guide investments in basic research in the US (Bush 1945). Society trusted scientists who worked according to a mandate in order to contribute to social progress. According to the influential work of sociologist Robert Merton (1973 [1942]), science as a social institution has a normative structure and is self-regulated by an intrinsic *ethos*³. If in science there is an intrinsic control mechanism that regulates its development and the impact of research outcomes, there is no need for interfering or steering scientific development from the outside.

Only around the 1960's –while advancements in scientific research and new technologies were a key component of Cold War public narratives⁴– did the increasing fear for technologies' potential negative consequences begin to surface in the policy and media discourse. Such a fear resulted in a destabilization of the faith in the internal control mechanism within the scientific community⁵. Assessing the technological impact on society became a major task for policy makers. This new attitude is reminiscent of Thamus in Plato's myth: since technology developers are not fit to assess the potential benefits and damages of their inventions, institutions should take over this task. Considered as a management tool, the general aim of Technology Assessment (TA) was to reduce the costs of technologies' detrimental effects by anticipating potential impacts. Such activities were expected to help governments and parliaments to mobilize the most appropriate financial, political and regulatory resources in the governance of technologies. For this purpose, in 1972 the Office of Technology Assessment (OTA) was established to support the US Congress in dealing with cutting edge science and technology in many fields like medicine, telecommunications, agriculture, materials, transportation, and military defense.

In this tradition, TA was an instrument for policy analysis to inform the Congress and to orient strategic decision-making. The expected output of such assessments was a factual and neutral expert-based report. This model has been

³ In particular, four moral norms of behavior guide the appropriate scientific practice: universalism, communism, disinterestedness and organized skepticism (Merton 1942). Science serves the social function of providing certified knowledge since scientists conform to the four norms and provide society with sincere and accurate information about the given world and future forecasts. Within this view, scientific knowledge is, on the one hand, objective and neutral with respect to interests and values and on the other hand, science is intrinsically guided by ethics with respect to the four norms.

⁴ In 1957, the Soviet Union launched *Sputnik 1*, the first artificial satellite to be put into the Earth's orbit. This event, initiating the so-called "Space Age", triggered many reactions of the western scientific community contributing to the shift away from an "endless frontier" model in science and technology governance.

⁵ Emblematic in this respect is the prominent role of Aérospatiale research and war technologies in the filmography of the later 60s (see for example Stanley Kubrick's *2001: a Space Odyssey* and *Dr. Strangelove*). In these imaginary narratives, new technologies, supposed to celebrate the evolution of the human species and its progress, turn against human beings in a chaotic and uncontrolled way.

described through the effective metaphor of “watchdog TA”: technology assessment was established with a centralized “top-down” approach that would provide a systematic early warning evaluation of potential impacts of new technologies (Smits and Leyten 1991). In this model, technology is conceptualized as a given, a static autonomous entity which has direct impacts on society. Such impacts can be prospectively traced by a group of experts and controlled by governments. The unwanted impacts of technology were mostly conceived in terms of risk for health or environment. For example: the harmful influence of gas and toxic metal emissions from vehicles combustion on environment; or alternatively the negative social and psychological consequences of increasing computerization and automation in the workplace.

The OTA’s mandate was rescinded in 1995. By then, however, the institutionalization of TA had already arrived in Europe. In the late 80s and early 90s several TA organizations were established in many European states and at the super-national level of the European Union: the Office Parlementaire d’Evaluation des Choix Scientifique et Technologique (OPECST) in France, the Parliamentary Office of Science and Technology (POST) in UK, the Technikfolgenabschaetzungsbuero Deutscher Bunsdestag (TAB) in Germany, the Danish Technology Board (DTB), the Netherlands Office for Technology Assessment (NOTA)⁶, and the Scientific and Technological Options Assessment (STOA) at the European Union level. The European counterpart of OTA presented a different approach from the American institution. As Smits et al explain:

TA was viewed in a broader and more sophisticated way, not simply avoiding negative effects but pursuing a better integration of science and technology in society (2008: 7)

Thus, the goal of TA shifted from one of early warning to one of providing options for policy development⁷. Furthermore, the European TA offices were not exclusively geared to produce a robust, factual and objective report. Some offices in particular, like the Danish Board of Technology and the Dutch NOTA, building on ideas of participatory democracy, adopted an interactive and participative form. A growing number of stakeholders were involved in the assessment process in different interactive activities such as: awareness initiatives, consensus conferences, scenario workshops, citizen hearings, and deliberative mappings, among others (Klüver et al 2000). Instead of focusing on the report as a “product” of TA, the “process” of TA is considered as valuable in itself (van Eijndhoven 1997).

⁶After being evaluated in 1993, the mission of the NOTA is readjusted, emphasizing the role of the organization to support decision-making and societal debate. To mark this shift, since 1994, the name of the office changes to the Rathenau Institute.

⁷ Van Eijndhoven (1997) points out that this goal was already embraced in the last years of the OTA.

Besides these parliamentary TA institutions, other types of TA communities have emerged: industrial, academic and executive⁸ communities have developed a variety of TA concepts in the European landscape (Smit et al 1995). In general, these approaches cluster a number of bottom-up activities done *by* and *for* different actors involved in the development, management and usage of new technologies. TA was not embodied in one institution, but was multiform and decentralized. Smits and Leyten characterize this generation of TA with another metaphor: the “tracker [dog] TA” (1991). This metaphor captures the idea that, rather than a one-time assessment, TA became a process of ongoing dialogue that supported actors’ decision-making process.

From the early days of TA, an increasing number of participants and perspectives are included in the process of assessing technologies. In addition, the type of issues or impacts that are qualified as important to be assessed is broadened. If, at the dawn of TA, only health risks and economic impacts were assessed, later on “broader societal concerns” became central. The increasing interest of institutions for evaluating a broader range of implications of emerging technologies is evident in the evolution of institutional ethical committees. A quick glance into the history of the Presidential Commission for the Study of Bioethical Issues in United States⁹ and the European Group on Ethics in Science and New Technologies to the European Commission (EGE)¹⁰ is enough to see how the topics of interest of these committees have shifted over time.

This shift of interest is particularly evident in the European case. This transnational (European) independent body was appointed by the European Commission the task of providing recommendations to institutions on moral conflicts triggered by new technologies. Established in 1991 as Group of Advisers on the Ethical Implications of Biotechnology (GAIEB), the European ethic committee is replaced in 1997 by the European Group on Ethics in Science and New Technologies to the European Commission (EGE)¹¹. The broadening of the sphere of competence of the Group beyond the sphere of biotechnology is especially evident in the third and fourth mandate (2000-2005 and 2005-2010) when the reports are issued on ICT implants in the human body, agriculture technologies, and nanomedicine, among others. The broadening of the competences of the Group European embodies the broadening of European institutions’ interest for the broader set of implications of emerging technologies concerning cultural, societal, political and ethical issues.

⁸ The executive TA communities are exemplified by non-governmental organizations.

⁹ See <http://bioethics.gov/cms/history>.

¹⁰ See http://ec.europa.eu/bepa/european-group-ethics/archive-mandates/index_en.htm.

¹¹ See http://ec.europa.eu/bepa/european-group-ethics/archive-mandates/mandate-1998-2000/gceb_en.htm.

In the late 90s the public interest for developments in genetics and medicine contributed to re-adjusting the focus of the institutional and political attention on early assessment of ethical and social issues in Research and Development projects. This interest was triggered by the success of the Human Genome Project and the images and dystopian scenarios of human cloning and genetic enhancement that it carried along. As a result, funding agencies sought to support research on “ethical, legal and social issues/aspects” (ELSI/A) of genetics in North America and Europe¹². These programs had the aim of promoting education, guiding researchers’ conduct and directing medical and public policies. This idea of integrating ethical and social reflection early on in the innovation process has been developed further by governments at the national level and institutions at the European level¹³. The focus of early ELSI/A projects ranged from issues of privacy of genetic information to questions about potential misuses of genetic data (for example in workplaces or schools) or even the impacts of genetic research on concepts of race and humanity. Although the initial focus was on genetics, this ELSI/A trend has spread in other scientific and technological fields, for instance nanotechnology (Fisher and Mahajan 2006), food technologies (Mephram 2001) or synthetic biology (Pei et al 2012).

1.1.2 Two trends in assessing technologies

In the institutional approach to the assessment of the potential social and ethical implications of emerging technologies, commentators have pointed out multiple trends, two of which I will focus on: 1. a process-oriented trend and, 2. an ethics trend. Regarding the first trend in institutional activities and calls for assessing emerging technologies, a dominant top-down, centralized and technocratic governance of the impacts of emerging technologies is challenged. This is sometimes replaced by a bottom-up approach to governance of the innovation process. This trend is characterized by the emergence of interactive and participatory forms of TA, in which diverse stakeholders are involved in the process of assessment at an early stage of technological development. In this way evaluating technological innovation is increasingly democratized.

¹² On the Human Genome Project website, it is stated: “The U.S. Department of Energy (DOE) and the National Institutes of Health (NIH) devoted 3% to 5% of their annual Human Genome Program budgets toward studying the ethical, legal, and social issues (ELSI) surrounding availability of genetic information. This represents the world’s largest bioethics program. It has become a model for ELSI programs around the world”.
http://www.ornl.gov/sci/techresources/Human_Genome/research/elsi.shtml

¹³ Other examples of this trend can be traced in political discourse on “responsible development” (cf Rip and Shelly-Egan 2010), “codes of conduct” for responsible research, and the increasing importance of criteria of “broader impact” (National Science foundation, see Holbrook 2005) or the “societal relevance” (see VSNU, KNAW, NOW 2009) in the funding proposals’ evaluations.

Institutional TA has always been considered a way to empower democracy. For example by supporting the Parliament's deliberations. Science and technology policy reports proposing, or evaluating, technology assessment activities have endorsed a more participatory character¹⁴. In some cases, like Denmark, participatory TA brings the decision-making process from citizens' representatives in the Parliament, to the citizens themselves. To do this, citizens participate in "consensus conferences". In this sense, TA progressively endorses a deliberative democratic model. According to deliberative democratic theories, institution's policies are legitimized by their accountability, that is the justification and articulation of public policy by giving reasons for it (Dryzek 2000, Gutmann and Thompson 2002). In this "talk-centric democratic theory" (Chambers 2003), debates and discussions are expected to make the decision-making process more democratic and pluralistic. They create the conditions for participants to produce reasonable and well-informed decisions in which they take into account the positions of the other participants¹⁵.

In line with the normative stance of deliberative democratic theories, a number of policy reports (UK¹⁶, EU¹⁷, US¹⁸) have claimed that emerging science and technology assessments should be a democratic exercise in which users and citizens are offered a say in decision-making on technology and innovation. A broader social participation and a more active role of users also foster an integration of different perspectives into the discussion of emerging technologies. This also broadens the scope of these discussions. In addition to questions concerning health, environmental and safety issues, more uncertain and ambiguous social and ethical issues are brought up. The second trend in the technology debate can therefore be referred as an "ethics trend".

Whereas ethical and social aspects of emerging technologies in the past were taken into account at the end of the innovation process (if at all), they are now increasingly seen as an important ingredient of early stage TA. According to Swierstra (1997), this change in the issues to be discussed is recognizable in the media and in the political discourse on technologies and presents three elements. First, the discourse moves from questions of survival in relation to technology to good-life issues. Second, the classic dichotomy between society, values and culture on one hand and technology, facts and instrumental logic on the other, is

¹⁴ This was in line with the shift from an expert-based model to a participatory model in public policy (Fischer and Forester 1993).

¹⁵ Participatory TA needs however to overcome many challenges to achieve in practice such a democratization of deliberations on new science and technology (see Blok 2007; Jensen 2005).

¹⁶ See HM Treasury/Department of Trade and Industry/Department of Education and Skills 2004 *Science and innovation investment framework 2004/2014*. HM Treasury, London (quoted in Kearnes and Wynne 2007)

¹⁷ See EC 2004.

¹⁸ See Sclove 2010.

abandoned in favor of an idea of “technological culture”. Third, there is an increasing interest for attributing responsibility in the process of technological development. Therefore emerging technologies are assessed with respect to a wide-ranging scope of issues in which not only safety and health-related impacts, but more broadly defined ethical and societal aspects are deemed relevant.

1.2 Resources and limitations in traditions assessing technologies

Most policy makers, and scientific TA authors agree about the desirability of these two trends of broadening the process of democratic deliberation thereby widening the type of “social and ethical impacts” that are considered to be relevant. However, there is no consensus on how this should be done in practice. Because the institutional mandate translates into funding and research programs dedicated to TA or ELSI activities, the methodological and normative disagreements on what, how and why to assess emerging technologies reappear in academic discussions. Hoeyer (2006) refers to “ethics wars” to indicate the antagonism between two different scholarly traditions: ethics and social science. Not only do these two disciplinary fields rely on different theoretical backgrounds, they also use divergent methodological approaches. As such each of these two have differing attitudes or “ethical code”. This metaphor of “ethics wars” can also be used to describe how these two disciplinary fields approach the task of assessing technologies. In general, social scientists have addressed technology assessment as an “operational” endeavor to develop the best approach for engaging stakeholders and for intervening in the process of technological innovation. Ethicists, on the other hand, have interpreted TA as a normative project to assess the moral value of the technology in question (Grunwald 1999). In the following subsections, I will articulate some contentious issues in this disciplinary “ethics war” by discussing work from both disciplines and their respective critiques (often from members of the “enemy” scholarly field).

1.2.1 Constructive technology assessment

As explained above, the practice of technology assessment focuses on the question of how to include the analysis of emerging technologies in the actual processes of innovation. For example, classic institutional TA aimed at producing reports in which new technologies were reviewed and their potential direct and indirect consequences were described. Implicit in the early TA approaches was the assumption that a value-free description of facts (about technologies and

consequences) could be provided in order to guide political action. However, soon it became clear that forecasting the future effects of technology was difficult and controlling them almost impossible. The Collingridge dilemma (1980) points out the impasse in the attempt to control technological development at an earlier rather than later stage. At this stage technology is easier to direct, but uncertainties are higher and effects more unpredictable. The uncertainties and challenges in anticipating effects of emerging technologies are even higher if a non-linear perspective on innovation is considered. As shown by innovation studies and social constructivist approaches, technologies do not affect society according to a linear logic of cause and effect. Instead, society and technologies shape one another and co-evolve. This perspective has been taken up within the scholarly community of sociologists working on TA and in particular in the tradition of “Constructive Technology Assessment” (CTA) (Rip et al 1995; Schot and Rip 1997).

CTA stimulated a reflection on the role, theories and methods of technology assessment. This approach belongs to a second generation or “paradigm” of TA (van Eijndhoven 1997). Originated in the mid-1980s in the Netherlands, CTA has a long theoretical and applied history¹⁹ that has inspired more recent approaches such as Real-Time TA in the USA (Guston and Sarewitz 2002) or, the interactive learning and action approach (Broerse and Bunders 2000). All these approaches aim at a more “symmetrical” version of participatory technology assessment by engaging in an early-stage dialogue with different actors. The application of CTA in a number of projects has contributed to the development of a consistent methodology. Such a methodology consists in: “anticipating potential impacts and feeding these insights back into decision making, and into actors’ strategies” (Schot and Rip 1997: 251).

CTA moves beyond the value/fact dichotomy directly or indirectly present in TA approaches. This shift is inspired by the extensive literature from the fields of Science and Technology Studies (STS) and innovation studies that describe how interests, power-relations, and social structures play a role in scientists and engineers’ work. This STS-oriented TA draws on a range of studies: Bruno Latour’s reflections on the social dynamics in the laboratory (1987); Latour’s work with Callon and Law (1986) on the roles of human and non-human “actants” in complex techno-social systems (Actor Network Theory); the social construction of technological artifacts and the co-shaping dynamics between technology and society (Bijker 1995); and, research on the role of users in technological

¹⁹ Numerous CTA activities and studies have been carried out by PhD students involved in the TA NanoNed Flagship under the supervision of Arie Rip, one of the brain-fathers of CTA (<http://www.nanoned.nl/ta/research-projects.html>). Such implementation of the CTA approach within interactive workshops and other kinds of feedback activities have promoted a constant definition, implementation and revision of the initial methodology. For recent studies on concepts and methods for CTA cf. Robinson 2010 and te Kulve 2011.

innovation (von Hippel 1988; Akrich 1992, Oudshoorn & Pinch 2003). As a result, rather than aiming at controlling the technological end-product and expecting to steer it in one direction or another, these scholars draw attention to the process of technological innovation as a space and object of assessment. In doing so, they have developed various tools to engage a wide range of stakeholders in reflecting on diverse aspects of technological innovations. Such tools include, among others, building roadmaps and/or scenarios to anticipate and deliberate on future developments.

CTA's focus shifts from the "assessment" of emerging technologies typical of early warning TA to the "modulation" of the ongoing process of technology development and stakeholder' transactions by providing them with feedback about techno-social dynamics and patterns. Studies of technology dynamics provide a fundamental theoretical tool to analyze and identify possibilities to modulate technology development at an early stage (Rip et al. 1995). The key insight is that technology and society mutually influence each other – they co-evolve – therefore their dynamics cannot be studied in isolation. Another key concept is that actors, actions and practices become entangled and at some moment stabilize. This stabilization produces long lasting interactions in which actors and activities become mutually dependent. Structures emerge which enable some actions and constrain others. Let me give an example of this. When technology developers initiate a project they have a certain context of application in mind, for example a medical or military application. Therefore they are "allied" with doctors or governments. These early alliances close up the possibility for other interactions and lock the development of the technology according to a certain path in which interactions with other stakeholders (say, food industry) are constrained. In the vocabulary of Innovation Studies, socio-technical configurations are "entrenched" in "lock-ins" that constrain technological developments within some specific paths. A sociological analysis of innovation dynamics and stakeholders' interactions points out "emerging irreversibilities" and "path dependencies" at an early stage of technological development, (Robinson and Merkerk 2006, Robinson 2009, Rip and te Kulve 2008). This allows stakeholders and analysts to point out futures that are already present (or "endogenous") in some present configurations and choices.

This analysis of patterns of socio-technical dynamics is integrated in the preparation of interactive sessions (CTA-workshops) in which relevant stakeholders are invited to participate. These heterogeneous settings offer a "protected space" to stakeholders to reflect on technological developments, and to position themselves with respect to others. Socio-technical scenarios are fictional narratives informed by the analysis of patterns of socio-technical dynamics. They are used as tools to broaden stakeholder's understanding of socio-technical dynamics and to help them to become reflexive with regard to their own role in

shaping future configurations and to their interdependence with other stakeholders (Robinson 2010, Rip and te Kulve 2008). Such an understanding is expected to broaden actors' perspectives and enable them to play an active and more aware role in the innovation process. Furthermore, during a CTA workshop, stakeholders are in a deliberative setting in which they have to articulate their position, defend their arguments, criticize and learn from others. This interactive exercise is supposed to enhance stakeholder reflexivity and learning.

The fact that the CTA approach "should not be partisan and identify with particular actors' goals and interests" (Schot and Rip 1997: 257) doesn't mean that it is not reflexive about its implicit normativity. In particular, three normative criteria for desirable development are specified. Firstly, CTA assumes that it is better to *anticipate* possible paths of technological development, but emphasizes that such prospective thinking should be translated from the grammar of technological impact to the vocabulary of co-producing techno-social dynamics. Secondly, "*learning* must occur". Schot and Rip talk about "broad learning" to refer to the possible connections "between a range of aspects such as design options, user demands, and issues of political and social acceptability". Learning can also occur in the form of "deep learning". Deep learning can happen at two levels: a first-order learning improves actors' capacity to work s given goals and a second-order learning that requires a clarification of values. Finally,

reflexivity is needed about the co-production of technology and society, to avoid to fall back into a naïve concept of impact, and about the role of the different actors in technological development (*ibidem*)

Anticipation, learning and reflexivity are presented as important conditions for improving the agency and deliberation of actors in a socio-technical world. These improvements are expected to lead to the regulative ideal of a "better technology (in a better society)" (*ibid*, 256). By creating an idealized space of inquiry in the protected setting of interactive workshops, CTA operationalizes the normative ideal of deliberative democracy within the process of technological innovation. However, this normative ideal is often left implicit; CTA seems to have a strategic aim of smoothening the introduction of technologies in society. In fact, its method empowers stakeholders, endowing them with enabling tools for more effective decision-making. In this sense, CTA methods are "facilitating interfaces between supply of science and technology and the demand for useful applications" (Merkerk and Smits 2008: 316).

Although it is not always explicitly stated, CTA has a normative dimension, even just in the goal of creating a "better technology (in a better society)". However, the problem of TA's "normative deficit", identified by Armin Grunwald (1999) with respect to participatory forms of TA, also seems to apply to CTA. (C)TA focuses on stakeholders' *factual acceptance* and dodges evaluative exercises on the *normative acceptability* of technologies. In this way, it prohibits the space for "trans-subjectivity" of evaluations on emerging technologies. This means that

value-related positions are restricted to the subjective sphere and when normative positions of stakeholders emerge, their acceptability is not assessed.

Bargaining takes the factual preferences and values of the concerned parties as valid merely because they are factually given – a kind of naturalistic misconception, which neglects the necessity to argumentatively legitimate actions, and decisions [...] factual acceptance is, indeed not sufficient to allow conclusive decision as to the normative acceptability. (*Ibidem*, 175)

Indeed, interactions among stakeholders are described in CTA analyses as “negotiations” and an evaluation on their acceptability is not the main focus. The CTA analyst is more focused on evaluation of *how* the exercise has contributed to broadening the capacity of stakeholders’ to make decisions by taking into account socio-technical dynamics.

In principle, CTA aims at a “second-order deep learning” that requires stakeholders to clarify their firmly held values to each other. Although CTA declares that its methodology creates a space for different actors to challenge each other’s positions, worldviews and values; however, in practice, it offers neither tools nor concepts to unravel and explicitly discuss normative conflicts among stakeholders²⁰. Descriptions of discussions in CTA workshops (cf. Robinson 2010) do not show an explicit exploration of the normative assumptions, values and norms when moral conflicts occur. Rather than focusing on values and norms, CTA workshops and analyses concentrate on alliances, linkages, de-alignments and the possible innovation paths that they can open up or close down. In this sense, it becomes clear how Grunwald’s critique of the “normative deficit” in TA applies to CTA too.

The “normative deficit” of CTA also emerges in the gap between the practice and the declared goal to create opportunities for “broad learning” in which “a range of aspects” are addressed. Political philosopher Richard Sclove in a recent report evaluating the work of the US Office for Technology Assessment (OTA) proposes a quasi-hypothetical example that shows how moral issues tend to be excluded from the discussion in an expert-based assessment.

During the previous century a number of technologies –including window screens, private automobiles, sidewalk-free residential suburban streets and home air conditioning – contributed to the decline of face-to-face socializing and neighborliness in American residential communities. Now imagine a conventional, prospective, OTA-style study of one or more of these technologies, conducted at an appropriate date in the past. Let’s suppose that the study is advised by a committee including – in addition to outside technical experts – representatives from organized stakeholder groups, such as leaders from a consumer organization, a labor union, an environmental group and several business trade organizations. The consumer representative would predictably focus on the potential cost, convenience and safety of these technologies. The worker representative would likely dwell especially on wages, job security and

²⁰ An exception is provided by the “argumentative scenarios” used by (Shelley-Egan 2011) in order to provide scientists with a tool to clarify their arguments on responsible innovation. Chapter Seven will elaborate more specifically on these tools and their opportunities and limitations.

safety in the production process. The environmentalist might call attention to air pollution and the depletion of non-renewable resources. A representative of realtors might be concerned to prevent heavy-handed zoning or other regulations governing the development of suburban housing tracts. These are all reasonable concerns that merit inclusion in a TA study. But notice that no one on such a study advisory committee would be likely to shout, "Hey! What about the fact that all of these innovations could inhibit neighbors from talking and socializing with one another?" Absent any consideration of the possible effect of these technologies on social relations in daily life, there would presumably also be no attention to the follow-on question of how the technologically altered quality of community relations bears, in turn, on the basic ideals, structure and functioning of a democratic society. This is an example of how combining the views of even a very diverse range of organized stakeholder representatives, while helpful, can be insufficient to ensure that a TA study addresses the full range of significant social impacts and concerns. (Sclove, 2010, 17; also see Sclove 1995, pp. 3-9, 37-44 and 61-82)

This example shows how the interests of the public are unlikely to have a voice when only "organized groups" are engaged in the assessment of technologies. This critique can also be applied to CTA. By shifting the focus from impacts to the process of technological innovation, CTA runs the risk of excluding some "lay" questions on the good-life from the debate. As Sclove points out, there are some values that are systematically neglected in transactions and negotiations among stakeholders with specific interests. Along the same line, Swierstra and te Molder (2012) explain that some concerns about emerging technologies raised by citizens (for example, the question of "naturalness" in food industry) are discarded and minimized by technology developers. These concerns, typically non-quantifiable and ambiguous, are considered less important "soft" impacts that do not deserve attention. Currently, CTA lacks the tools to include issues concerning the "greater good" in the debate or to discuss "soft" impacts, like for example the impact of air-conditioning on neighborhood face-to-face social relations or the naturalness of food technologies.

1.2.2 Applied Ethics and Moral Philosophy

Ethicists address the question of the assessment of emerging technologies as a normative enterprise. In doing so, they often build on the methodological grounds of applied ethics and bioethics. As a branch of applied ethics, bioethics is considered a discipline that applies theoretical reflection in ethics to concrete moral problems pertaining to biotechnologies. Traditionally linked to the field of medical ethics dealing with the doctor-patient relationships and the virtues of the good doctor, bioethics goes beyond the scope of medical ethics (Kuhse and Singer 2012). It emerged in the 1960s as a reflection on the ethical controversies raised by "revolutionary developments in the biomedical sciences and clinical disciplines" (*ibidem*: 3). The field of bioethics comprises a piecemeal of disciplines and theories. Since the 1970s a "principle approach" by Beauchamp and Childress (2009 [1979]) has dominated bioethical reflection. This approach attempts to include both consequentialist and deontological ethical theories to identify principles and rules that can be applied to particular judgment about cases. The

utilitarian (Hare 2012), virtue ethics (Oakley 2012), and care ethics (Manning 2012) approaches have also been proposed and employed in the field of bioethics. Institutional bioethical committees refer to this tradition in their reports assessing the ethical implications of emerging technologies.

Let's consider again the case of the European Group on Ethics (EGE). The group is an independent body of fifteen experts designated by the European Commission. Its mission is to examine legal and ethical questions raised by emerging technologies and to write reports (or Opinions) that provide the European institution with a preliminary study to prepare and implement European legislation and policies²¹. EGE's reports usually comprise an extensive literature review describing the state of the art in a specific field of science and technology, and a sketch of the relevant legal background along with the relevant ethical and social issues. After this short review, the Opinion is provided in a prescriptive form specifying how European institutions should direct their policies. The legal and ethical principles to which the EGE appeals for justifying its normative position are drawn from the European official documents regarding the protection of fundamental rights (like the Charter of fundamental Rights or the Convention on Human Rights and Biomedicine)²². In their reports different normative approaches are used to evaluate emerging science and technologies: a "deontological" approach that refers to some prior universally accepted moral principles; a "consequentialist" normative analysis evaluating technology's potential implications for the total welfare; and "virtue ethics" arguments intended to address how technologies affect people's goal of conducting a good life.

Given the rigid structure of these reports the level of analysis remains too abstract. The scientific and technological review lists a very diverse range of technologies without characterizing their specificities. The evaluation of these technologies through philosophical concepts and ethical theories remains on too general a level. For example, emerging Information and Communication implants in the human body are evaluated in Opinion 20 (EGE 2005). These technologies are evaluated using the philosophical concepts of "autonomy" or "personal integrity". As I have shown elsewhere, the idea of what is personal integrity has changed in time depending on studies of biology and neuroscience about the relation between body and mind (Lucivero and Tamburrini 2007). Therefore, brain implants cannot be evaluated without an account of the way they interact with the human cortex and how this changes human perception or action control. EGE reports lack a thorough analysis of concrete science and technology and

²¹ For more information, cf. http://ec.europa.eu/european_group_ethics/index_en.htm.

²² "These rights are rooted in the principle of human dignity and shed light on the core European values, such as integrity, autonomy, privacy, equity, fairness, pluralism and solidarity" (EGE, 2007: 53)

remain too entangled in the abstract theoretical framework. For these reasons, they miss out on specific ethical issues raised by emerging technologies.

The proliferation of ELSI/A funding programs has fostered the study of ethical aspects of emerging technologies. In the case of the most novel scientific fields, like nanotechnology, the contributions of ethicists (sometimes co-authoring with scientists) consist in reviews of ethical issues (some examples are: Moor and Weckert 2004, Ebbesen and Jensen 2006, Lenk and Biller-Andorno 2007). In these reviews attempts are made to define and differentiate the technological applications and distinguish the ethical issues that they raise. These contributions compile inventories of ethical issues raised by emerging technologies. Despite they have the merit of providing a broad overview of basic concerns of emerging scientific fields, these reviews fail to address specific concerns and remain on a general level.

According to social scientist Adam Hedgecoe, not only ethicists fail in identifying new ethical issues associated with emerging technologies, they also lack a critical challenge of scientific practice and discourse. In reviewing bioethicists' discourse around pharmacogenetics, he notices that

it seems as if bioethicists have tended to provide broad, but "thin" reviews of potential ethical issues that stay within the boundaries of ethical discourse set by academic and industry scientists (Hedgecoe 2010 p. 176)

Often technology developers themselves, being aware of the importance of ethical debates around new technologies have strategically contributed to the ethical discussion. In doing so, they have "mapped out" the limits of ethical discourse (*ibidem*, 177). Bioethicists step into this discursive field without criticizing the scientists' factual claims. Bioethicists' discourse on pharmacogenetics "mirrors" the discourse of scientists promoting this technology²³. Bioethicists in this way fall in an "intellectual capture" in the sense that they "begin to share the ideas, beliefs and goals of the group they are meant to be regulating" (*ibidem*, 178). Hedgecoe concludes that bioethicists thus allow a "smooth assimilation of pharmacogenetics in the clinical practice", rather than asking whether there *should* be such assimilation.

This presupposition that technologies need to exist, if only in a promissory sense, before their ethical aspects can be debated, has led bioethicists to avoid discussion of issues beyond the pre-constructed discursive boundaries. (*ibid.* 179)

Thus bioethicists accept uncritically scientists' expectations on the technology as an unquestioned premise of the ethical debate. Philosopher Alfred Nordmann

²³ In particular, Hedgecoe and Martin (2004) analyze the role of bioethical commentators in the co-construction of future scenarios around pharmacogenetics. They conclude that bioethics debate plays a role in creating visions, mobilizing resources and "anticipatory negotiation" over what is acceptable and what should be regulated. Bioethicists "through the anticipation of social and ethical problems and a critical engagement with the process of innovation, are also helping construct and shape the future" (*ibidem* 357)

raises a similar point. He argues that philosophers, social scientists and ethicists are strategically employed by institutions as a resource to manage potential resistance and facilitate the process of adopting technologies (2007a)²⁴. In particular, by discussing the ethical and societal implications of “nanotechnology” or “converging technologies”, ethicists have been “recruited” by institutions to make these abstract categories meaningful for a lay audience. The adopted principle is “if it has social impact, it must be real” (*ibidem*, 224). The blindness to what is new in emerging technologies and the incapacity to come up with creative suggestions, together with the lack of a critical stance towards scientists’ claims are the main criticisms against ELSI reflection. Nordmann suggests that such “entanglement” of ethics of emerging technologies partially depends on the institutional background. By creating a demand, institutions have indirectly encouraged scholars to engage with ethical issues of new science and technologies without questioning the basis of such a demand.

Ethicists’ reflections on emerging technologies are not always abstract or intellectually captured. An example of this is provided by the work of political philosopher Michael Sandel²⁵. Inspired by the discussions on genetic enhancements in 2004 he writes a short essay for the *Atlantic Monthly* entitled “The Case against Perfection”, extended into a short booklet in 2007. In this book, Sandel reflects on the promises in the field of genetics of treating and preventing debilitating diseases and their claims of enhancing human beings. Departing from the promises of genetics of treating and preventing diseases, the philosopher engages in a reflection on what is morally upsetting in the promises of genetic engineering for enhancement. He discards the usual arguments appealing to the principles of autonomy, fairness and individual rights, because “this moral vocabulary is ill-equipped to address the hardest questions posed by genetic engineering” (Sandel 2004)²⁶. Moving away from this vocabulary he tries to look at genetic enhancement from a different perspective. He explains the moral stakes as, “[technologies for genetic enhancement] transform three key features of our moral landscape: humility, responsibility, and solidarity” (*ibidem*). He gives the example of pre-natal engineering. Promoting the desire of controlling offspring goes against the value of humility that is the basis of parents’ unconditional love. This excess of mastery fails to acknowledge the “giftedness of life” and the

²⁴ A similar point has been raised by Tallacchini (2007), who shows how bioethical bodies at the institutional level are often a way to dismiss political debate on emerging technologies through soft law mechanisms.

²⁵ Famous in Harvard for his course in political philosophy entitled “Justice”, Sandel co-teaches also a course on “Ethics and Biotechnology” considering the ethical implications of number of biotechnologies. Although he doesn’t consider himself a professional ethicist, in 2001 he was invited to join the American President’s Council of Bioethics.

²⁶ The full article is available at: <http://www.theatlantic.com/past/docs/issues/2004/04/sandel.htm> as an html version: page references are not available on this version

“openness to the unbidden” that are important in our society. Emerging genetic engineering is assessed against values that are important for our society, but whose importance is often undermined. Sandel’s conclusions are that genetic engineering’s “promise of mastery is flawed. It threatens to banish our appreciation of life as a gift, and to leave us with nothing to affirm or behold outside our own will” (*ibidem*).

Sandel discusses the desirability of the values and worldview promoted in techno-scientific promises. In questioning them he mobilizes the tradition of “virtue ethics” (or “good-life” ethics), rather than the more common deontological or utilitarian traditions. In his ethical and conceptual reflection, Sandel points at issues that rarely appear in bioethical analysis. This work eludes the critique of “intellectual capture”: he is not aligning with the enthusiastic hype of technology developers and instead raises critical voices. However, Sandel’s reflections are still taking the promises of scientists and engineers as a starting point. Even if it is able to go beyond the scientists’ limited discourse and introduce some novel discussions, this type of ethical reflection uncritically supports the most optimistic of scientists’ views on technical possibilities.

This last point is raised in a two-page commentary published in *Nature Nanotechnology* where Nordmann and Rip (2009) warn that often ‘ethics leaps ahead of science’. Building on a previous article, they refer to the ‘*if and then*’ fallacy (Nordmann 2007b) as the tendency of ethicists to begin their analysis by hypothesizing futuristic, visionary technologies and then to conclude with the hugely existential ethical issues raised by these new technologies. In doing so, the hypothetical stance (“if”) is usually downplayed and speculative scenarios are presented as imminent and pressing. The ethical debates related to brain-computer interfaces provide an illustration of this fallacy. These ethical arguments begin with postulating that such interfaces might become widespread in society, to turn immediately to discussing ethical concerns regarding the enhancement of human nature. In the process, this type of ethics fails to address the feasibility of the technology in question. Furthermore, it discards the hypothetical status of the premise: “might” becomes “will”. While feeding unjustified hopes and fears, these discussions neglect more pressing ethical issues. By drawing the public gaze towards unrealistic scenarios, ethicists unwittingly contribute to turning strategic promises about technologies into generally shared expectations. In this manner, the ethicist, rather than acting as a critical force, ends up supporting specific interest groups.

According to Nordmann and Rip, in order to bridge the gap between futuristic ethical speculation and actual technology development, ethicists should precede an ethical evaluation of (nano)technology with “reality checks”. Such “reality checks” consist in assessing the quality of scientific expectations in order to establish whether they refer to feasible technical developments worthy of ethical reflection. This would close the gap between ethical scenarios and current science.

As Nordmann explains in another article, “nanotechnological and other technoscientific prospects suffer from the failure to distinguish physical possibility (all that does not contradict outright the laws of nature) and technical possibility (all that humans can build)” (Nordmann 2007b: 4). By assessing the quality of expectations, the ethicist would critically appraise the conditions of technical possibility rather than taking them for granted.

Nordmann and Rip’s commentary elicited several responses about the legitimacy and desirability of “speculation” in ethical reflections on emerging technologies (Lucivero et al 2011, Michelfelder 2011, Ferrari and Grunwald 2011). Grunwald (2010) argues that it would be a mistake to cluster all the reflections on the ethics of emerging science and technology under the same label. “Nano/gene/robo/computer/bio/neuro-ethics” are umbrella terms that include different types of studies. Under this label, there are studies that belong to “applied ethics” which deal with concrete questions to be considered in the context of regulating emerging technologies. For example whether nanoparticles should be included in food or, what are the equity issues in benefitting from nanotechnologies. These studies come later in the technology development process, when all the relevant decisions have already been made. Therefore they have less of a role in shaping technological development. However, other types of studies are also included in this generic “ethics” label, like philosophical work on human enhancement or human-technology relationships. These studies have joined the STS move towards upstream engagement and they have different purposes and methodologies from applied ethics. Rather than addressing concrete and existing ethical problems, this “explorative nano-philosophy” contains philosophical reflections of different types: epistemological, anthropological and hermeneutical. Whereas applied ethics aims at directing policy makers or other social actors towards some actions (for example, regulating a technological field) and must, for this reason, be concerned with concrete problems of the “here and now”, *explorative* nano-philosophy has a more diverse set of purposes. For example,

early thoughts about synthetic biology or human enhancement serve rather to promote the conceptional understanding and clarification of the issues from a normative perspective or to facilitate the development of clear terminology and ethical alternatives, but without there being anything immediate to be regulated. (*Ibid* 96)

Explorative philosophy can: prepare science and society for issues that could emerge in the future, draw attention to conceptual or normative gaps in today’s visions of tomorrow, and provide interpretative tools to “learn something ‘about and for us’ today” (*ibid.* 97). The purpose of an ethical/philosophical reflection on emerging technologies is not only to account for contextual and existing ethical dilemmas, but also to engage in more “explorative” reflections. As Grunwald

points out, explorative philosophy is in itself an emerging field and as such needs a methodological and epistemological foundation.

1.3 Bridging the gap: pragmatist ethics

The considerations thus far leave us with a gap. On the one side there is a “second generation” STS-oriented TA approach, Constructive Technology Assessment that strives for an inclusion of all the relevant stakeholders in the deliberation of emerging technologies. In this approach, the broad/deep learning and reflexivity of actors in the innovation process is a major issue. In line with a (more or less explicit) ideal of deliberative democracy, different groups are involved in the discussions. This approach focuses on the process of technology development rather than its product. Furthermore, it aims to improve it by making stakeholders more aware of dynamics of the co-evolution of technology and society in the innovation process. This type of TA approach puts *empirical acceptance* before *normative acceptability*. In doing so, it does not create the space for an in-depth analysis of normative claims and assumptions. By focusing on techno-social dynamics in the *process* of technological development, it overlooks a critical discussion of the normative aspects of the technology at stake. Furthermore, some issues about the desirability of emerging technologies are at risk of being systematically dismissed as “soft” by the stakeholders.

On the other side of the gap, applied ethics aims at an explicit normative assessment of emerging technologies. It assesses their desirability with respect to some moral principles or the way they endanger a vision of the good-life. In pointing out the potential moral conflicts fostered by future technologies, applied ethics tend to overlook the specificity of technologies. Bioethicists’ assessments risk being far removed from the actual state of the art in science and technology. Even when they do not align with the enthusiastic voices of technology promoters – as in Sandel’s case – their distance from the actual process turns the debate into a speculation about some technology that might never come into existence. These studies are unable to feed the actual process of technology development because they fail to interact with actors in the real world and they fail to play a role in modulating morally relevant decisions during the innovation process.

The debate on speculative ethics unfolds in opposing directions. On the one hand, critics indicate a risk of questioning the desirability of emerging technologies that will never be there. Such a speculative ethical reflection would reinforce the hype surrounding the development of a technology and could be instrumentally used to raise fear or enthusiasm in the public domain. On the other hand, it is emphasized that a reflection that goes beyond a here-and-now discourse is important. Such reflection should be able to explore scenarios of the

future with the goal of assessing the normative acceptability of present choices and decisions. Whereas the critique of speculative ethics points out the need for “reality checks” in order to draw attention to the “here and now” issues, the “explorative (nano)philosophy” argument indicates that speculative reflections on emerging technologies can still be valuable.

Striving for “better technologies in better societies”, both CTA and ethics bring important elements to the early reflection on emerging technologies. Several authors plead for a productive learning between these two traditions and have reflected on how integration could take place in practice (Grin et al 2000, Palm and Hansson 2006, Roelofsen et al 2008, Brey 2012). Such integration would encourage both an early and an empirically grounded assessment of real-world actors’ normative claims about the desirability of emerging technologies. This would contribute to a debate on normative acceptability of emerging technologies that explores issues and impacts that would otherwise be strategically discarded. Basically, this would include Sandel’s type of reflection in the context of stakeholders’ and public deliberation on the normative acceptability of emerging technologies. Keulartz et al (2002) claim that pragmatist ethics provides a normative and conceptual framework for this purpose. This is because pragmatist ethics focuses on concrete problem contexts, it embraces an evolutionary approach to morality, and it holds a pluralist approach based on a normative ideal of deliberative democracy. Let’s see.

1.3.1 Context sensitivity

Although pragmatist philosophers²⁷ are hard to bring under a common denominator, some similarities can be pointed out. In pragmatist ethics, values are not understood to be universal and transcendent rather, they are understood as situated in cultures, practices, times, and spaces (James [1897]; Dewey [1929]; Rorty [1989]). In this sense, pragmatists share a sense for context. There are no prior universally valid normative principles on which we can ground and justify our actions. On the contrary, some values are considered as “right” because they work in a particular context²⁸.

According to John Dewey’s pragmatist philosophy, norms and values are solutions to practical problems [1929]. In particular, morality is the set of values, norms and standards of good behavior that are shared in a certain society. Ethics is “reflective morality”, that is, the explicit discussion and questioning of the moral principles and models (Dewey [1922]). To explain this distinction, Swierstra and

²⁷ For an overview of the classic pragmatist philosophers see (Ayer 1968; Rorty 1982; Murphy 1990; Putnam 1987).

²⁸ This has been referred to as the anti-foundationalist thesis that is shared in pragmatist ethics as well as in pragmatist epistemology (see Peirce [1877, 1905])

Rip (2007) use the metaphor of the iceberg. Below the sea level, a consistent set of values, norms and standards of good behavior define the landscape of an unquestioned array of principles, models and virtues shared in a certain society. This invisible part of the iceberg, embedded in habits and routines, often undefined and ambiguous, represents morality. The visible tip of the iceberg is ethics, considered as the study of morality. However, ethics and ethical discussion is not only a field of philosophical inquiry. Ethical controversies and debates happen in the “real-world”²⁹ when actors explicitly discuss, question or defend moral principles and values, often in heated debates or controversies. In this sense, the authors refer to *ethics* as “hot morality” and *morality* as “cold ethics”. In line with a pragmatist philosophy, norms and values are solutions to practical problems. Dewey’s contextualism emphasizes that morality is the uncontroversial ground of our behavior and is questioned only in situated real *problematic situations*. When a concrete problem emerges, the guiding principles of our actions need to be discussed and eventually adapted to the new situation. This means that “morality” is not always the same.

1.3.2 Changing morality

Moral elements like principles, values or norms are often transposed beyond their original context of invention into other areas where similar problems play a role³⁰. An historical example will help me explain this point. The etymology of the word ‘morality’ comes from the Latin *mos-moris*, custom. In ancient Rome, the *mos maiorum* (in English, ancestral custom or fathers’ custom) was an unwritten code of habits, principles, behavioral models and practices that affected the private, political and military life in Rome³¹. The virtues and values prescribed by this code were accepted by the community because of the authority of the tradition. Furthermore, the written social norms were derived from this code. Despite coming from uncertain origin, the traditional values in the *mos maiorum* were considered as a stable basis for Romans’ identity. Some authors like Cato vehemently argued that observing the fathers’ custom was essential to the

²⁹ The distinction between ethical debates and “real world” ethics is the starting point of the EU funded project “DEEPEN”. Its declared aim is to reach an “integrated understanding of the ethical challenges posed by emerging nanotechnologies in real world circumstances” (see <http://www.geography.dur.ac.uk/projects/deepen/Home/tabid/1871/Default.aspx>). On this topic see also Shelley-Egan 2011.

³⁰ An example of the transposition of concepts beyond their original context is provided by (Swierstra et al 2009b). The meaning of the principle of “autonomy” has changed and has been transported to different problem areas: “This principle was first coined to elucidate the precarious political status of the fifteenth century Italian city-state, played an important role in religious controversies, resurfaced in Rousseau’s political philosophy, was elevated by Kant to take central stage in morality, and has in the last decades finally reached public prominence in the field of medical ethics” (132)

³¹ The content of this paragraph is partially based on http://en.wikipedia.org/wiki/Mos_maiorum and http://it.wikipedia.org/wiki/Mos_maiorum retrieved on the 16.10.2011.

wellbeing of the Roman Republic. However, in later years of the Republic, the lower (plebeian) social class undermined the conservative principle of the *mos* in order to achieve social and political reforms. Furthermore, when the Roman Empire demanded to manage a large conglomerate of different populations with very different customs, practices and values, the *mos regionis* (regional custom) was set alongside the *mos maiorum*. Beside this variability in the social and geographical dimensions, the traditional custom was also challenged in the temporal dimension. For example, in the first century AD, the values of Roman identity (exemplified in the virtues of *Fides*, *Pietas*, *Majestas*, *Virtus* and *Gravitas*) were gradually replaced by the values of Christian identity, namely liberty and equality.

This brief historical example shows how morality is a dynamic process characterized by continuous adjustments. Legitimized tradition and historical continuity, some values, principles and customs are taken for granted in a certain society. However, they are continuously evolving because of cultural and social interactions: the changes in the written social norms in ancient Rome reflect a reassessment in the interpretation of the values and their role in society. *Ethical* discussions on the legitimacy of some values, their meaning and their priority, trigger adjustments in the morality.

The morality shared by a community is thus expressed in the routines and habits of this community. These habits are not questioned unless there is a problem. For example, when a decision is hard to make or a conflict occurs among different values. In cases like these, a community becomes more aware of the “background of convictions”, experienced as unproblematic up to that point. Values are discussed, new vocabularies and concepts are created, a “workable solution” is constructed, and a new order is established (Keulartz et al 2002: 13). Pragmatist ethics emphasizes that the critical examination of generally accepted norms and the creative articulation of new moral vocabularies are necessary in order to deal with emerging problems.

According to pragmatist ethicists, applied ethicists consider technology in purely instrumental ways and give priority to values, principles and norms as cement holding society together. Applied ethicists should learn from the lessons of Science and Technology Studies that have shown the normative significance of technological artifacts. In doing this, ethicists should abandon their “anthropocentric prejudice” that prevents them from deeply understanding the dynamic character of our technological culture.

On the one hand, our modern technological culture has a highly dynamic character: old ways of life are continually being replaced by new ones, norms and values are constantly being put up for discussion, and we regularly find ourselves confronted with new moral problems. On the other hand, however, neither philosophy nor ethics seems to possess a vocabulary that can accommodate this dynamic character adequately. (Keulartz et al 2002: 4)

Emerging technologies are an important cause of “problematic situations” that challenge our morality. Keulartz et al. examine the well-documented case of the birth control pill. The pill’s success is attribute to the user’s self-discipline who has to remember to consume it. While endowing women with more power in family planning, it also makes them more responsible (and blameworthy) in the case of unwanted pregnancy (Oudshoorn 1995). In re-distributing responsibilities and power relationships, artifacts also change our mentality and morals. For example, by separating sexuality from reproduction, the introduction of the pill goes alongside a sexual revolution. It became easier for couples to engage in sexual activities outside wedlock, but it also promoted a birth planning mentality (Ketting 2000). The birth control pill nicely illustrates the impacts a technology can have on people’s concepts, meanings and values, which travel across practices and situations and are transported in several areas of moral deliberation. For example, the idea that a pregnancy must be planned is transported into the practice of abortion and plays an important role in people’s decisions. Technology has the innovative and creative power to generate new morally problematic situations that require old convictions, concepts, meanings and values to be criticized and revised. Pragmatist ethics, with its dynamic and co-evolutionary theory of morality, accounts for this creative aspect and the role that technologies have as moral agents.

1.3.3 Democratic deliberation as the normative ideal

This contextual and dynamic approach to morality and ethics distinguishes pragmatist ethics from other (traditional) ethical approaches in the assessment of technologies. The normative evaluation of traditional approaches in applied ethics consists in an appraisal of new technologies on the basis of normative ethical theories (deontological, consequentialist or virtue-ethics based) and the moral principles on which they are grounded. The outcome of such an appraisal is in the “shall/shall not” form. Pragmatist ethics doesn’t offer a grand substantive moral theory that can be used to evaluate emerging technologies; however, that doesn’t mean that “anything goes”. Pragmatist ethics is pluralist without being morally relativist. The concept of “right” is set as a regulative ideal in the practice of democratic deliberation (Habermas 1990). The process of finding workable solutions for problematic situations is a process of collective learning aimed at a regulative ideal of “creative democracy”. Such a process is the focus of pragmatist ethics. Indeed,

a pragmatist ethics is more process – than product – oriented. It is not a matter of offering solutions, but rather of facilitating public debate and political decision-making on emergent moral problems (Keulartz et al 2002: 15).

Pragmatist ethics aims at contributing to the process of deliberating on emerging technologies by facilitating the public and political debate and by ensuring that all relevant groups contribute to the discussion by bringing their position. The

underlying model is the Habermasian idea that a fair and non-coercive moral discourse creates the best conditions for participants to account for their positions, defend them, respond to critiques and learn from the positions of others.

However, some authors reflecting on the potential of pragmatist ethics for a technological culture also point out the limitation of this Habermasian perspective. In fact, the ideal space of inquiry is an abstraction that is in practice actualized in interactions among subjects that are dominated by power-relations and ideologies. Building on this Foucauldian tradition, some authors emphasize that such “pragmatist ethics” should articulate the reasons, make the meanings explicit, and show “to what people who use and apply concepts are committed” (de Vries 2002: 154). This stresses both the importance of collecting different perspectives as well as the need for critical analysis of foundational presuppositions. Such a philosophical approach should be considered as a “diagnostic practice”, a screening of the problem, rather than as a treatment (Zwart 2002). Rather than aiming at making the right decision, this insight assumes that the process of articulating the problems and analyzing the epistemological conditions for deliberation is important and desirable because it triggers a challenging of moral assumptions. Such critical and creative analysis is crucial for deliberation.

By studying the conditions that allow certain problems and solutions, as well as certain principles and concepts to emerge, we may become more aware of the factors that actually guide our thoughts and actions in the present, and this may prepare us for making our own concrete choices with regard to the present, although the choices are never determined by our philosophical principles, nor can they be deduced from them or warranted by them (Zwart, 2002: 39).

Furthermore, the improvement of the process of democratic deliberation is not only concerned with the inclusion of different groups, but it also requires a broadening of the issues discussed in the deliberative process. As (Thompson 2002) remarks, pragmatist ethicists should help in maintaining the balance between a “liberal” approach that focuses on the procedures for decision-making and aims at compromise or consensus among participants, and a “republican” approach focusing on the formation and quality of opinions and interests. In the republican approach, consensus for decision-making is a secondary goal. The main interest lies in the discussion of all relevant arguments and alternatives. Added to this, differences and confrontations are kept lively in order for the process of preference formation to be more robust. In this sense, pragmatist ethics offers a normative background that promotes deliberation of emerging technologies in which different perspectives and groups play an active role and in which a broad range of issues and topics are explored.

Pragmatist ethics also promotes a more substantial intervention in the process of moral deliberation on emerging technologies. Such an intervention can be done

in three ways (Keulartz et al 2002). First, the pragmatist ethicist can help define the nature of the problem. In doing this, the ethicist pays attention to how a solution in one problem area can be transposed and translated in another area (as we saw in the case of the birth control pill). In doing this, it is important to look at the two sides of the technology-morality relationship: on the one side, technology shifts the perception of moral problems, and on the other side moral ideas influence the perception of technological problems. Second, the pragmatist ethicists can help in sketching possible future scenarios. Such scenarios provide a narrative context for identifying emerging “problematic situations” at an early stage of the technological development. Furthermore, they help in anticipating how problems addressed by an emerging technology may create other “problematic situations” in different contexts. In doing this, the ethicist should look at problems beyond the current accepted values promoted by the technology and propose scenarios that address questions like:

which possible future worlds are disclosed by certain technologies? How do they change our view of nature, each other and ourselves? What shifts in patterns of responsibilities and in relations of power do they bring about? (*ibid*, 260).

These scenarios make actors more reflexive about their normative vocabularies and question whether these morally accepted ways of speaking require to be revised. This last point is linked to the third substantive intervention of the pragmatist ethicist in the deliberative process on emerging technologies: the ethicist can engage in the development of new moral vocabularies. This role of the ethicists helps to avoid dichotomous and polarized positions in ethical debates. This is done by articulating nuances and degrees rather than proposing ontological categories to analyze moral conflict. At times, the ethicists may be required to redefine concepts by looking at the problem from a different perspective.

In conclusion, pragmatist ethics provides an approach that can bridge the gap pointed out at the beginning of this section. It refuses to offer overall normative frameworks and instead is sensitive to specific contexts aiming at situated workable solutions. This approach is in line with the process-oriented, pluralist and democratic approach of CTA³². In addition to CTA, pragmatist ethics also puts issues regarding the desirability of emerging technologies on the agenda, because of its focus on the relations between technology and morality and the normative assumptions that are hidden within the deliberative practice³³.

³² Indeed, CTA too embraces pragmatist ethics (cf Shelley Egan 2011, and Krabbenborg forthcoming).

³³ A similar type of normative oriented Technology Assessment has also been referred to as “discursive or argumentative TA” (Est & Brom 2010).

1.4 The contribution of this study

In Plato's myth, Theuth presents his inventions explaining why they are desirable; however, King Thamus claims a legitimate authority to assess the desirability of these inventions, because the inventors are not the best judges of their brainchildren. What the best practice is for assessing emerging technologies varies across times, societies and disciplines. It can be argued that two trends have been dominant in modern Western societies: a democratization of the process of assessing technologies, and an inclusion of "broader" ethical concerns in such assessments. As some commentators point out, an assessment of the desirability of emerging technologies has a normative significance that has to be explicitly addressed. Technology Assessment activities and theories are sometimes lacking in this respect. The fields of applied ethics, bioethics and moral philosophy do address normative questions in the evaluation of emerging technologies, but they are often insufficiently critical of the empirical grounds of their analysis.

Pragmatist ethics offers a normative framework that bridges the gaps between the other traditions. Its general aim is to improve the process of stakeholders' and public deliberations by improving its conditions in three respects: 1) including different perspectives in the deliberative process; 2) articulating the reasons, meanings and assumptions behind a problem; and 3) exploring possible scenarios of how new technologies change our moral concepts and vocabularies. In this way, pragmatist ethicists encourage a substantive reflection on the desirability of emerging technologies and trigger a discussion among social actors about the normative acceptability of emerging technologies. Like CTA, pragmatist ethics *modulates the process* of developing emerging technologies by providing tools for enhancing stakeholders' reflexivity, triggering learning, and anticipating future dilemmas. Pragmatist ethics is also in line with philosophical studies *exploring substantial normative questions* about emerging technologies. In doing this, however, it maintains the focus on actual contexts and the normative positions of the real-world actors rather than imposing an overarching normative theory. Because of its affinity with the TA and ethics tradition, pragmatist ethics provides a conceptual, methodological and normative framework for an "ethical Technology Assessment".

If the focus of pragmatist ethics is to improve the conditions for a democratic deliberation on emerging technologies, then it is important to assess the quality of the information about the technology in question. This is of paramount importance because the object of the assessment consists of technologies that are still emerging and exist only as "expectations". Until now, the pragmatist ethical reflection has not explicitly addressed the issue that the epistemological

foundation of the expectations of novel technologies is problematic. To understand this point, let's go back to the Platonic myth we started with. Thamus hears about the alphabet directly from its inventor; how can Thamus understand how the alphabet works? How will Egyptians use this "invention"? How can Thamus anticipate what it will do once it is embedded in Egyptian society? At an early stage of a technology's development, many variables and uncertainties make it difficult to anticipate the final technology as a product, let alone to evaluate its desirability. The fundamental question here is: how to deal with these uncertainties while technologies are still emerging?

Technology assessment is an attempt of modern societies to manage uncertainties and contribute to strategic governance of the process of innovation. In this context, a future that has not yet been realized turns into an object of analysis and modulation. This upstream assessment is difficult because it concerns expectations of a future technology, not yet realized. These expectations are visions of a future set of affairs in which a certain artifact is integrated in social practices and interacts with human beings. An epistemological analysis is needed in order to analyze the possibilities for knowledge that are implied in technoscientific expectations. The aim of this study is to point out the relevance of this aspect and to offer an approach to deal with it. In particular, this discussion raises a question:

How can the epistemological robustness of expectations on emerging technologies be assessed in view of a normative reflection of their desirability?

As the discussion on speculative ethics (cf. § 1.2.2) has made clear, it is important to establish "criteria and procedures for better being able to distinguish between mere speculations and more plausible futures" (Grunwald 2010, 95). This appraisal of the epistemological foundations of expectations, while assessing their viability, should also transcend the logic of "here and now" and explore novel and distinctive issues raised by the expectations of new technologies. This study will show that the requirements of grounding hype and avoiding mere speculation can be coupled with an explorative reflection on the future. In other words, these two tasks are not mutually exclusive. On the contrary, they are both necessary criteria that should guide the upstream discourse on the ethical and social aspects of emerging technologies. This book presents a methodological approach for analyzing and articulating the moral reasons, meanings and commitments implied in expectations concerning emerging technologies. I claim that such an approach is a pre-condition for *any* ethical Technology Assessment.

2

Promises, expectations and visions

Assessing the plausibility of socio-technical futures

We are like sailors who have to rebuild their ship on the open sea, without ever being able to dismantle it in dry dock and reconstruct it from the best components
(Neurath O, 1932 [1983] p 92)

The example of the promises of genetics at the dawn of the Human Genome Project (§ 2.1) introduces the main topic of the chapter: the need to assess the quality of expectations on emerging science and technologies. The rest of the chapter will discuss insights from the scientific and philosophical literature that may help to develop a methodology for such an assessment. § 2.2 presents the literature on the sociology of expectations and points out the socially constructed nature of expectations. This literature shows that expectations should not be taken at face value, because they have a strategic and performative role. § 2.3 introduces the literature on Leitbilder and vision assessment. It emphasizes that it is indeed important to assess the desirability of the values and norms implied in visions of future technologies. Since this normative content is not always explicit, it should be disclosed before it can be assessed. I will argue that before asking whether these implicit norms and values are desirable, however, we had better check how plausible it is that they will indeed be realized. In § 2.4 I discuss insights from empirical philosophy of technology to point out that technologies often do much more, and very different things, than they were supposed to achieve. Technologies engage human beings with a rich array of relationships. To judge which values a technology will likely promotes (or diminish), a good view of both the artifact and the practices of use is needed. The final section of the chapter (§ 2.5) recollects what can be learned from this literature review. I argue that it is indeed important to assess the desirability of emerging technologies, but that we should not take for granted claims that a technology will realize certain values. We need to assess the plausibility of such claims. I propose that such a plausibility assessment could proceed by reconstructing and assessing three dimensions of specific expectations: the expected artifact, its use and its value. This approach will be further expanded and exemplified in chapters 3-5.

2.1 Expecting future science and technologies

When a technoscientific³⁴ field is still emerging, promises of its social relevance and desirability and warnings about its potential negative effects are wide spread. The dawn of the Human Genome Project (HGP) is an exemplar case in this respect. In the early 90s, the hope of mapping the entire human genome by 2005 sustained the American Congress' decision of allocating \$3 billions to this goal. In June 1998, when the working draft of the human genome sequence was announced by Francis Collins, the director of the HGP, the enthusiasm for mapping, sequencing and determining the function of human DNA were so high, the project was promised to end 2 years before the expected date (Collins et al., 1998). In the often quoted Shattuck lecture on the "Medical and societal consequences of the Human Genome Project" the HGP director describes in a prophetic tone how "the history of biology was forever altered" by a "bold" decision to initiate the enterprise that had the goal of characterizing "in ultimate detail the complete set of genetic instructions of the human being" and concluding that "the genetic revolution in medicine is under way"

Once the contributing genes and their disease predisposing variants have been identified, diagnostic tests can be developed to predict future risk — but these tests are most effective when a preventive strategy is available to reduce the risk in persons found to be predisposed to a particular disease. Another rapidly developing application of diagnostics is pharmacogenomics, the prediction of responsiveness to drugs. Ultimately, the real payoff of genetic research will be the development of new gene therapies and drug therapies, but they will generally require many more years of intensive research (Collins, 1999).

At the end of his lecture, after explaining the repercussions of the HGP in medicine and the ethical, legal and social issues that could rise from them, Collins provides a short narration, a story or, as he calls it, a "scenario" describing medical practice in 2010. This scenario describes a fictional character, Mr. John, testing his DNA and receiving detailed information (Collins even provides a table showing how this information would look) about risk association and disease predisposition and explains how Mr. John decides to act upon it³⁵.

³⁴ "Technoscience" is a concept used within actor-network theory (see Latour 1987) to blur the difference between scientists and engineers. According to this theories science and technology involve the same process of creating larger and stronger networks of human and non-human actors. In the following, I will use the terms "technoscientific" or "technoscientists" to refer to scientists and engineers working on new and emerging science and technology.

³⁵ In Collins' words: "As genome technology moves from the laboratory to the health care setting, new methods will make it possible to read the instructions contained in an individual person's DNA. Such knowledge may foretell future disease and alert patients and their health care providers to undertake better preventive strategies. In the wrong hands, however, that same information could be used to discriminate against or stigmatize a person. In response to this concern, the Human Genome Project has catalyzed the development of policy options for lawmakers to

Collins' vision was not an isolated case. Many voices rose from the fields of genetics showing hopes of the medical opportunities associated with DNA research. Not only could genetic research be applied to pre-natal and post-natal screening to identify babies at risk of developing certain diseases, but it could also lead to personalized medicine and better tailored preventive medicine. Chronic diseases could be managed, increased risk identified and preventive measures taken. Also the individual susceptibility to common disorders could be determined. Some also pointed out the enormous potential for a new field of pharmacogenomics, in which not only diagnoses, but also treatments could be personalized by determining individual susceptibility to drugs (Epstein, 2004; Richards, 2001). These hopes were accompanied by fears about potential ethical and social implications. These fears were partially addressed by allocating 5% of the annual budget of the HGP to explore the Ethical, Legal and Social Issues (ELSI) related to this scientific enterprise. ELSI research focused mainly on questions of data privacy, informed consent, inequality and stigmatization induced by the association of genes with behavioral traits and social or racial differences³⁶. These studies addressed these ethical and social implications of wide spread use of genetics in healthcare. Independent from whether these implications were appraised as positive or negative, these studies took for granted that the promises on genomics would be fulfilled.

The enthusiasm of the promoters of the project was balanced by many "skeptics" who doubted whether genetics would actually revolutionize medicine (Richards, 2001). According to these skeptics, mapping and sequencing the human genome could only lead to the identification of genes causing monogenetic diseases, but this would benefit only a small percentage of the population (Holtzman & Marteau, 2000: 141). Furthermore, effective treatment would lag behind. In the following years, several studies confirmed the skeptics' positions. For example, the hope that the association between a gene variant and a certain disorder could lead to a diagnostic test to identify people who carry the variant gene was soon disappointed by scientific evidence. In fact, common multifactorial disorders are determined by "complex gene-gene and gene-environment interactions" (Janssens & Khoury, 2006) that are not captured by generic risk profiles and require increasing reference to susceptibility and risks estimates³⁷.

consider in their efforts to prohibit genetic discrimination and to protect the privacy of genetic information. The stage is set to solve these vexing problems with effective federal legislation, but this window of opportunity will not stay open indefinitely." (Collins, 1999)

³⁶ For more information on the type of ELSI project conducted within the HGP see http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml

³⁷ On the basis of a simulation study—conducted to evaluate the predictive value and inheritance patterns of generic profiles and comparing the results with genetic tests for Huntington's disease and hereditary cancers – (Janssens & Khoury, 2006) shows how actual data on risk estimate in genetic variation carriers are only slightly higher than that in non-carriers. Even if research has been conducted in improving multiple genetic testing (genomic profiling), neither the predictions

Also in the case of monogenetic disorders, like Huntington's disease and breast cancer, evidence has shown that 1) there might be not only one, but more genes associated to the disease (for example BRCA 1 and 2 in the case of breast cancer) and 2) when the associated risk is estimated on a larger population scale (and not only in families with a high incidence of the disease) the associated risk estimate is much lower and therefore less informative (Burk et al. 2002). Finally, for pre-natal tests, where the predictability of predisposition seemed quite reliable, studies have shown that prospective patients and clinicians often had to deal with uncertain "grey results" that complicated rather than facilitated clinical decisions (van Zwieten, 2008).

The high expectations from the early stage of genomics research have been drastically deflated while the field further developed. Difficulties, uncertainty and unanticipated constraints arose at later stages of research to challenge the initial expectations of scientists, investors, policy makers, clinicians, patients and other social groups. The initial "genohype" (Holtzman, 1999) has required reconsideration in light of the little progress that has been achieved in translating scientific advances to the clinic, let alone in to health gains.

ELSI research on genomics was also assessed as hyped. Holtzman introduces the term 'ethereal debates' to point out that the ethical, legal and social issues about behavioral genetics and the possibility of genetic enhancement "are built on a house of cards"³⁸. ELSI research on genomics had (and has) the mandate of exploring the moral desirability of the futures proposed by scientists and proponents of the genomic revolution. However, in doing so, this research is bound by scientists' hopes and expectations and might even contribute to the genohype.

As the case of the Human Genome Project suggests, ethical reflection on emerging technologies has to deal with uncertain objects: the expectations on new science and technology; the promises of how emerging science will create better futures; the hopes of innovative solutions to current problems. Expectations of genomics are diverse and have spread to different social actors, including not only molecular biologists, chemists, medical geneticists, but also policy makers, pharmaceutical companies, mass media, insurance companies, diagnostic laboratories, and prospective parents. Each social actor holds different expectations, hopes, visions and projections about the future of genetics in the medical practice. These projections into the future describe an individual or

provided by these tests are informative, since "the most of individuals have disease risks that are only slightly higher or lower than the average disease risk in the population"

³⁸ This quote is taken from an interview with Neal Holtzmann, director of genetics and public policy at Johns Hopkins University a skeptic voice during the debate on the revolution of genomics in medicine (in Richards 2001).

collective belief in the possibility that a certain state of affairs will come into being.

An upstream ethical debate on emerging technologies based on this hype may result in “ethereal debates”. Indeed, by inquiring and reflecting on issues such as privacy or discrimination in the field of genomics, bioethicists intentionally or unintentionally presuppose the plausibility of a certain technological development. Chapter 1 has already introduced the criticisms against speculation in ethics and the risk for ELSI research to address questions that go beyond the limits of technical possibilities. According to this criticism, ethical debate should start from an assessment of the plausibility of technoscientific expectations, a “reality check” (Nordmann and Rip 2009). However, here I want to explore the question: what kind of objects are technoscientific expectations? And what is their role? Recent studies in the sociology of expectations have addressed these questions and explain why expectations on emerging technologies are more than just beliefs or representations of future technological worlds.

2.2 The social construction of the future

In the last twenty years, a number of studies have investigated how expectations play a strategic role in the dynamics of innovation (van Lente, 1993; Brown et al. 2000; Hedgecoe and Martin 2003; Michael and Brown 2000; Merkerk and Robinson 2006; Selin 2007). In these studies, at the interface between the tradition of social-constructivism (Bijker et al 1987) and innovation studies, it emerges that expectations guide actors’ decisions, legitimize their actions, attract interest or raise worries (Borup, Brown, Konrad, & Van Lente, 2006)

Van Lente (1993) in a pioneering study shows that expectation statements circulate at different levels and stages of the technological innovation process with different functions. Expectations at the “macro-level” are general *promises* on the technology, “broad, diffuse, general expectations, which have the form of scenarios” (*ibid.*, 184). An example of this type of promises van Lente provides is: ‘Memory chips will be of growing importance in all kinds of industry’. These macro-level expectations are the ones most visible for lay people, and probably also for ethicists. They are used by spokespersons to legitimize certain technoscientific domains when the social importance of a technology is not yet taken for granted and needs to be justified. Such expectations outline scenarios of technological and societal trends and are usually considered by social actors as “taken for granted background” (*ibid.*, 184) rather than as issues for discussion.

At a “micro-level”, expectations circulate among experts in a laboratory, in which they are expressed as quantitative *specifications* about future artifacts. These “search-expectations” “contain specifications for the artifacts, systems, or

processes to be developed. One example of micro-level expectation is: "The breakthrough value of Tenax paper will be 50% better" (*ibid.*, 181). These expectations are used as "heuristics" or "guiding search processes" and set requirements for the local agenda, for example within a research group.

At an intermediate (meso-)level, expectations are qualitative statements about the *functions* that the technology will presumably fulfill (*ibid.*, 182). They are general statements used by actors outside their own research context to position themselves within a certain field, but also to show the opportunities of a field (e.g. "cleaning waste water has great potential") and guide decisions for funding allocation. The boundaries between the macro, meso and micro level are fuzzy. Van Lente stresses that statements, agendas and actions among different levels are "nested": the acceptance of a broader promise requires the acceptance of other expectations associated with it.

Van Lente's multi-level analysis points out that expectations can have different forms and functions depending on the actors, contexts, and time. Other authors emphasize that they can be "inscribed" in actions, material, and machines (Borup et al 2006, Michael 2000). Material artifacts, practical decisions, and courses of actions embody expectations. Therefore, beyond the explicit discourses, expectations manifest themselves also in these material practices. To use the example of the Human Genome Project, expectations on the role of genetic science in healthcare materialized in research proposals, conferences, funding programs, policy decisions and ethical reports. These statements about technological futures are not (only) epistemic constructs on future state of affairs. Instead, expectations "do something: advising, showing direction, creating obligations" (van Lente 1993, 190). Actors in technological development use expectations as a "resource" when they need to "legitimize" their arguments and actions. They can also be used as a resource to convince other actors to act, for example to attract the interest of the investors, to mobilize funds or to achieve the consensus of the public opinion. By mobilizing support and ensuring funding, expectations play an important role in the innovation process, because they allow the development of protected spaces for an emerging techno-scientific field to grow.

In this sense, expectations are *performative*: they are not merely *representations* of the future but they *do something*. (van Lente 1993, Michael 2000). Expectations on new and emerging technologies allocate roles to social actors. For example, Collins' expectations on the genetic revolution attributed a role to pharmaceutical companies to invest into pharmacogenomics or to the American Congress to allocate money for research in the Human Genome Project. In Collins' expectations different social actors (biologists, politicians, pharmaceutical companies, etc...) performed a role in view of the success of the promise of the "genetic revolution". Expectations create a "promise-requirement cycle" (van Lente 2000, Geels and Smits 2000), in which protected spaces (or

niches) for innovative technology are created (Konrad 2006), stakeholders position themselves and others in a certain techno-social system, and funds are allocated. Once these expectations are shared they acquire autonomous force and set demands on actors³⁹. These expectations are not produced by an intentionally well-designed overarching plan or by a determined chain of necessary steps; instead they take shape through a contingent, bottom-up, decentralized process. The competition among heterogeneous visions also allows space to discuss, negotiate and construct new configurations (Arnaldi 2010).

Expectations not only vary “vertically” with respect to the level of the innovation process, they also vary “horizontally” among different actors. In the case of early expectations, the degree of involvement of actors in technoscientific practice influences their assessment of how plausible expectations are. Expectations appear more authoritative to those who exert little influence over the outcome of a promise (a broader public, for example). Researchers conducting research, in contrast, are more aware of the uncertainties and challenges involved (Michael and Brown 2003)⁴⁰.

The strategic and performative role of expectations in techno-social dynamics suggests that they are more than just experts’ statements on the future: they are rhetorical constructions (van Lente 1993). Scenarios and promises have a legitimizing role for new and not-yet established fields. Scenarios of future technologies aim to convince an audience to do something: for example, funding a research proposal, lobbying for a research field in a policy making environment, welcoming a future technology in a clinical practice, or using such technology. The use of rhetorical strategies is crucial especially for scientists who deal with issues that are unfamiliar to the audience: rhetorical tools are then mobilized to convince the audience that they are dealing with something real. Promotional rhetoric (Guice 1999), “hope” discourse (Brown 2006, Moreira and Palladino 2003), and hype (Michael and Brown 2000) have often been pointed out as a means to persuade the audience of scientific peers, funders and the larger public by appealing to their emotions.

To sum up, the literature from the social studies of Science and Technology shows, first, that there are different types of projections of images of the future,

³⁹ They have an active role in creating agendas and in “interlocking” activities. Promises are, in fact, taken up in the agenda and allow the creation of new interactions and new roles for stakeholders, who gather around the promise. The interlocking of these positions creates a requirement that demands some action. In this way, expectations create obligations among the stakeholders and establish objectives that become constraining: they create *emerging irreversibilities* (Merkerk and Robinson 2006).

⁴⁰ The analysis of these dynamics also illustrates a temporal dimension of techno-social expectations (Borup et al 2006). They change over time: while early on in the innovation journey promises are essential to attract attention and create niches for innovation to develop, later on these promises will likely be disappointed, giving way to disillusionment (Michael and Brown 2000).

with a different role and function in the process of technological development. It further points out their *vertical* variability across the levels and stages of technology development, their *horizontal* variability across actors and contexts, their *performative* character in directing actions and creating requirements, and their *strategic* and *rhetorical* component. These aspects all have to be taken into account when reflecting on the ethical desirability of emerging technologies.

2.3 The guiding normativity in technological visions

Despite their rhetorical and strategic character, expectations remain an important access point to such a reflection, because of their normative content. Technoscientific expectations are *visions* that carry and promote an ideal of a *desirable* world. In particular, macro-level expectations or promises (Quist 2007) have been addressed by German authors as *Leitbilder* or guiding images (Dierkes et al 1996, Grin and Grunwald 2000). These “images” of attainable futures are shared by different actors and “guide” their action and interactions (Grin 2000). Rather than focusing on the dynamics of interactions in the innovation process, studies on *Leitbilder* emphasize and analyze their normative content. *Futuribles* (Grin 2000) or visions of desirable futures carry the values, worldviews, and deep preferences of the holders. This literature on visions suggests that expectations are not only projections of techno-social configurations; they also project *moral* configurations.

The moral character of these scenarios can be understood when we think of the literary tradition of utopias and dystopias. This tradition has played an important role not only in modulating public debates, but also in framing scientific research within a particular universe of meaning. For example, Aldous Huxley's novel *Brave New World* (1969 [1932]) provides a tale of how the utopia of a healthier society implied in technologies for pre-natal genetic screening might turn into a dystopia of social re-organization. This dystopian turn questions the desirability of the quality of life, human relationships and self-perceptions resulting from these technologies, as well as the quality of democratic processes. The novel describes the values implicit in utopian visions on pre-natal genetic screening and explores the (un)desirability of its worldview. In doing this, it offers a scenario different from the one offered by Collins, about the future of medicine in the year 2010. Different though they are, the comparison shows that both visions are value laden. Collins' vision of how the patient in 2010 manages his health through genetic screening and adopts preventive measures to balance his risks is not a neutral description of the future. Instead, it is a wishful image of a

desirable state of affairs, in which every individual is in control of her health condition.

Visions are rooted in culture, its morality and traditions. In this sense, they are stable or “culturally coherent” (Grin and Grunwald 2000). Visions relate the past to the future, acting as carriers of cultural repertoires and shared meanings. Berne (2006) explains that some “old myths”, like the idea of mastering the physical universe or the perpetual self-improvement, dominate the discourse of nanotechnologists. These old *archetypes* are drawn upon because they provide descriptions of the place of human beings in the world that still seems still viable in our technological culture. In this way they support the technological innovation. These visions are vehicles for interaction and communication among actors since they carry some general meanings allegedly shared by different stakeholders (Dierkes et al 1996). However, because of their general and suggestive reference to a shared cultural repertoire, these visions can be carriers of different meanings and interpretations among different stakeholders.

However, visions are also transformative and challenging because they can propose alternative future scenarios as more desirable for a broader set of stakeholders (Grin and Grunwald 2000: 176). A vision of a techno-scientific future guides technology developers, policy makers, industrialists and the larger public towards a state of affair which is different from the current one. A scenario of an alternative and more desirable future motivates actors to act in order to realize it, or to raise opposition in order to prevent it from happening. In fact, future scenarios described by scientists, media or science fiction writers inspired by technology play a role in social actors’ decisions at different levels. For example, the high impact images of Crichton’s novel *Prey* (2002), depicting predator nanorobots escaped from human control, are mentioned in policy documents about nanotechnology (Selin 2007: 205). The tension between “old” and “new” in the dialogue between past, present and future emerges also in the ambivalent discourses of actors who selectively emphasize the continuity of their innovation with the past or its novel purport (Swierstra and Rip 2007, Shelley-Egan 2011)⁴¹.

The concept of “leitbilder” emphasizes that visions of the future are intrinsically normative; they describe a desired world and future state of affairs within a specific value framework. This normative content of visions clearly appears in the literary genre of Science Fiction as utopias or dystopia, but it is also present in technology developers’ guiding visions. The emphasis on the normative content of these guiding images adds another aspect to the discussion on the desirability of emerging technologies. Not only the strategic and contextual role of expectations should be taken into account and addressed, but also their normative content should be assessed. As approached by Grin and Grunwald (2000), a *vision*

⁴¹ Selin (2007) shows how nanoscientists know both how and when to mobilize Drexler’s visions on nanotechnology, and how and when to dismiss them as science fiction.

assessment aims at a democratic discussion of the normative content of expectations on emerging technologies. As these authors notice, a vision is "the world described by someone who is asked why particular technologies are desirable" (*ibid.* 53). However, the normative meaning of visions is not always explicitly stated. Some preferences, worldviews and value systems are implicit in the technological visions.

Reuzel and der Wilt (2000) make a case for vision assessment. The authors point out that the Dutch Investigative Medicine Program assessed cochlear implants for deaf people from a (dominant) clinical perspective according to which deafness is a handicap. Deaf Organizations critically responded to such an assessment, pointing out that "the perspective on deafness as a handicap is not shared by all" (*ibid.* 58). Therefore, the authors argue that an assessment of new and emerging technologies should uncover assumptions and perspectives in technological development that are presented as universal, but are instead shared only by some stakeholders. Instead of taking the dominant perspective, technology assessors have to include the perspectives and visions of all the relevant stakeholders in the deliberation process, bringing their voices in, creating spaces for confronting, communicating, arguing with other stakeholders on questions of what is important. The authors therefore address the question of how technology assessment can help to "uncover and critically examine visions, expectations and perspectives underlying the development and use of the technology" (p. 62). With "vision assessment", they propose an interactive approach that consists of broad consultations with the expected users of the technology and compare them with the visions of the technology developers'. In these exercises, stakeholders are asked to debate standards and criteria of merit of the technology, to discuss problem definitions and possible solutions, to envision the contexts of use of the technology, and describe the "desirable final state". This discussion should aim to make explicit the different needs of various stakeholders, considering them to be legitimate and scrutinizing them towards reaching some form of agreement.

The Vision Assessment approach addresses the "normative deficit" diagnosed in TA (see Chapter 1) by proposing to disclose and discuss the normative content of visions on emerging technologies. According to this approach, "expectations for the future reflect the values, worldviews and deep preferences of those who hold them" (Grin and Grunwald 2000: 11) and they contain assumptions on what is a "desirable" world. In the preamble, I refer to the etymology of the word "assess" and I explain how it is related with the idea of "evaluating" something or "comparing it with some values". The vision assessment approach points out the need for making the values that guide the assessment of emerging technologies explicit and discuss them, rather than giving them for granted. This is an important point that broadens the discussion of expectations. Not only does it

elucidate the rhetorical and strategic role of expectations in guiding towards *normatively* connoted goals, but it also offers some analytic tools to disclose the implicit normative assumptions intrinsic to actors' technoscientific expectations. In this way, normative assumptions hidden behind metaphors, vague concepts and criteria of desirability are opened up and critically addressed. Although this approach has the merit to claim a space to discuss the desirability of technoscientific expectations, it doesn't address the question of the *plausibility* of these expectations. The attention is on why/for whom/whether these descriptions are *desirable* and not on whether they are *plausible*. The difference between these two questions is very important. Let me explain this.

A vision on an emerging technology is "the world described by someone who is asked why particular technologies are desirable" (*ibid.* 53). Take as an example Collins' promising scenarios on how genetics will revolutionize medicine. Why is genetics desirable? Because it will provide diagnostic tests. These tests will offer knowledge that "alerts patients" and provides care providers with "better preventive strategies". These consequences are presented as good and valuable for society. The *desirability*-question asks why are these consequences good and valuable. The vision assessment approach aims at disclosing and assessing the desirability (D) of the vision that "genomic-based healthcare is good". However, the visions on genomics suggest not only that a genomic-based healthcare is good, but also that it is plausible, that there are good reasons to believe that this vision will happen/succeed. The *plausibility*-question asks whether genetics research can indeed be expected to produce these good consequences. In this sense, the P-question is a pre-condition to assess the D-question. Assessing the normative content of visions on emerging technologies requires to some extent an assessment of the plausibility of these normative visions. The aim of this thesis is provide some conceptual and methodological reflections on how to address the *P(plausibility)*-question.

Next section introduces some philosophical considerations on the interaction between technology and morality. This reflection carried out in the broad disciplinary field of philosophy of technology doesn't refer directly to "expectations" or "visions", however it provides some conceptual tools to address the P-question. In short, it broadens and enriches our expectations on the "good consequences of technologies": technologies are not tools or means to an end, but they embody some values, direct human actions, and alter human practices and values.

2.4 Technologies are not a means to an end

During the first half of the XX century several philosophers reflected on the role and essence of technology. Some of these philosophers like Jacques Ellul, Kar Jasper, Martin Heidegger, and Gunter Anders engaged in transcendental reflections on the conditions of the possibility of technology. “Technology” with capital T was often considered either as a neutral means to an end or as an autonomous entity in stark contrast with the human sphere of meaning and culture. Towards the end of the 90s, European and American philosophers of technologies pointed towards a shift away from this attitude (Kroes and Meijers 2000, Achterhuis 2001). Contemporary philosophy of technology – exemplified in the work of Andrew Feenberg, Alfred Borgmann, Don Ihde, Carl Mitcham, and Joseph Pitt – reflects on the concrete empirical manifestations of different technologies, moving the focus from the meaning and consequences of Technology, as an abstract entity, to actual technologies: diagnostic devices, communication technologies, scientific or medical instruments, or virtual realities. These become the new focus of philosophical inquiry, implying a different conceptualization of the functional and instrumental view. Technology becomes a human-controlled tool to reach a pre-determined end⁴².

Many authors in contemporary philosophy of technology defend an anti-instrumentalist conception of technology. They argue that artifacts are not simple tools or extensions of human organs. On the contrary, “there is a flux of possibilities that you suddenly envisage when you handle a hammer” (Latour 2002: 250). This is exemplified in Stanley Kubrick’s *2001*, when the monkey comes to realize that a dinosaur jawbone, initially used as an hammer, can be also used as a club to kill. In this sense, technologies “are not innocent”. Their use *translates* or *displaces* our initial goal because “*we have changed the end in changing the means*” (*ibidem*: 253). In *mediating* our actions, artifacts change our goals, in the same way the installation of speed bumps in the street does not

⁴² Philosophy of technology is a diverse and broad scholarly field that is hard to define in a systematic way. In a way, even Plato’s myth at the opening of Chapter 1 can be considered as a philosophical reflection on the role of artifacts and technologies. In the last 20 years some self-proclaimed philosophers of technology have largely drawn on sociological studies on science and technology (or Science and Technology Studies, STS) making the attempt of defining the disciplinary fields difficult, if not pointless. Furthermore, it is hard to draw a clear-cut distinction between philosophical reflection on scientific method, activity and role from philosophical reflection on technology. It goes beyond the scope of this book to provide a fair description of the field of philosophy of technology that would do justice to the wide diversity of the authors who have contributed to this field. In particular, Mitcham (1994) distinguishes a “humanities philosophy of technology”, which is continuous with social sciences and humanities, as opposed to an “analytic philosophy of technology” that seeks continuity with philosophy of science. (<http://plato.stanford.edu/entries/technology/>)

simply fulfill the function of calming the traffic. Instead, their introduction in towns and villages initiates a complex network of social interactions in which drivers, police agents and city halls are involved. Technological systems are “opaque black boxes” in the way goals intentions and outcomes are connected.

The post-phenomenological approach to technology (Ihde 1991) has highlighted that technologies are part of the human condition. They are embedded in the way we perceive the world, similar to how a pair of glasses or a thermometer help us in relating to the external reality and constituting our own. Technologies mediate both our meanings and actions (Verbeek 2005). This is clear for example in the case of the monitoring device for blood sugar measurement. When this device was introduced in the routine of diabetic patients, it didn't simply fulfill a function of measuring the level of sugar in the blood, but it created a practice of self-monitoring. This new practice implied not only different actions, behaviors and routines, but also new standards of normality and different relations between a patient and their own body (Mol 2000).

Technologies have a political dimension because they shape and determine power-relations. Langdon Winner asks, for example, if artifacts *have politics*. His answer is that they do. Robert Moses' design of Long Island Bridge, for example, was intentionally low to prevent buses and therefore the poor black minority to pass under it. Similarly, nuclear power plants presuppose a hierarchical political structure for their security management. Andrew Feenberg gives another example. He explains how the controlling ideology embedded in the Minitel technology in France (a precursor Internet) was reshaped by the users who - opposing the intent of the designers and policy makers - adopted it as an instant messaging device (1995). Feenberg welcomes user creativity as a democratic force, as opposed to an authoritative technocratic design. The example shows that it is possible to democratize technologies, a task Feenberg prescribes to philosophers of technology.

The examples of the speed bumps, the blood sugar meter and the Long Island Bridge show that artifacts are designed to make people behave in some particular way. The speed bumps *prescribe* drivers to slow down; the blood sugar meter *requires* diabetic patients to monitor the level of glucose several times a day; the Long Island Bridge *forbids* non-car owners to reach Long Island. In this sense, technologies are moral agents because they discipline people's behavior and distribute roles among stakeholders (Akrich 1992, Latour 1992).

The notion of “script”, articulated in the context of the Actor-Network Theory by Bruno Latour and Madeleine Akrich, captures the idea that “like a film script, technical objects define a framework of action together with the actors and space in which they are supposed to act”. For example, the cumbersome shape and weight of some hotel key-chains encourages the users to return the room key to the reception before leaving the hotel (Akrich and Latour 1992). The key-chain contains a “program of action” inscribed in it (Latour 1992): a non-written

instruction of how it should be used and by whom. While defining their technical objects, designers make assumptions about the world in which these will be inserted. Technologists' visions of the world are "inscribed" in the new object.

Designers thus define actors with specific tastes, competences, motives, aspirations, political prejudices, and the rest, and they assume that morality, technology, science, and economy will evolve in particular ways (*ibidem*, 2008)

Thus, on the one hand, the "composition" of a technical object constrains the social actors⁴³ and their mutual relationships and, on the other hand, these actors reshape the object and its use. The design process, by defining the components of the artifact, also defines the relationships among actors. Indeed artifacts *prescribe*, oblige, allow or forbid specific behaviors and distribute roles and responsibilities among users.

The concept of "script" emphasizes how designers intentionally inscribe a moral agency in the artifacts. The way the designers imagine and determine the user in the technical object, her relations, and the context of use, may be quite different from the actual ones. Akrich emphasizes that "the world inscribed in the object" might be different from "the world described by its displacement". The script analysis suggested by Akrich and Latour consists in providing "thick descriptions" of the artifact design and the artifact in a social practice. The comparison between these two descriptions shows the mismatches and sketches the *geography of responsibilities* around technical artifacts.

Technologies do not only impose a conduct of actions to its users. They interact with our morality at a broader level. Swierstra (2009) remarks scholars' inclination for a one-way analysis emphasizing either the adaptation of morality to technology or the moral and normative construction of technologies. He argues that the interplay of technology and morality should be understood in a symmetric way. This non-linearity of techno-moral dynamics is emphasized in the metaphor of morality as a "force field" in which different norms and values stand in relation to each other. In the force field of morality, different vaguely defined values are in tension one with the other. These tensions are usually solved through compromise, by creating a hierarchy among values, or by distributing them in different spheres of application. The force of these values can be only assessed relative to other values, i.e. when an individual is forced to choose between two values. In these cases, "one norm pulls harder than the other"..

Morality can best be understood as a force field wherein conflicting norms and values compete for hegemony. In this competition, technology can sometimes tip the scales. The [birth control] pill created new conditions that enable more people than

⁴³ Latour 1987 introduces the concept of "actant" borrowing it from the field of semiotics. It refers to human and non-human entities whose agency is mediated by a spokesperson. Since for the purpose of this study I will not engage in a thorough semiotic analysis, I will keep the "actor" vocabulary to avoid unnecessary complex jargon. For a definition of the term "actant" see also Akrich and Latour 1992.

previously to take the dominant norms and values less seriously. At the same time, previously marginalized norms and values now come to the fore and gain societal acceptability. (*ibidem*, my translation)

Clarifying this last point is the example of the telephone, which was first sold as a business device. Even when they reached private households, they were only for functional use. For example, wives could order groceries. Only later did the telephone become a device for social interaction (despite telephone companies at the time trying to hinder this “improper” use) (Fischer 2011). Practices and routines have been profoundly changed by the telephone, with mobile phones adding further changes. However, it soon emerged that the value of “sociability” embedded in the telephone was in conflict with the values of “privacy” and respect of other people’s private space. With a phone call people were intruding into their friends’, family’s and (potential) customers’ lives. This threat to the value of “privacy” is exacerbated with mobile phones that allow to invade a person’s private life everywhere and at any time. The clash between “sociability” and “privacy” becomes manifest in the fact that people have started a new routine of not picking up the phone to be undisturbed by a phone call. At the same time, calling somebody without emailing first is progressively felt like “rude” or “awkward”⁴⁴. Telephone companies register a decrease in the voice spending, while text and surf spending increases. This change of habits goes alongside a different priority relation between the value of sociability and privacy in the context of calling. The privacy value “pulls harder” than the sociability value. Therefore, not only technologies mediate our actions and redistribute responsibility, affect our routines, perceptions, standards, concepts, but they also influence which values we prioritize in the “force field” of morality and how we interpret them. Technology and morality mutually shape one another (Swierstra 2009).

The literature from empirical philosophy of technology, then, shows the inadequacy of the view that technology is simply an instrument to achieve a fixed goal. Because of its material hermeneutics and agency, an emerging device can be expected to engage in a complex array of relationships with its users. Within these relationships some values or power-relations are promoted more than others and roles and responsibilities are distributed in a specific way. Values and assumptions on the user are inscribed in the design of artifacts. Furthermore, technologies modulate what we value and how much we value it. When an emerging technology is described as a means to achieve specific values, as most expectations do, these aspects are neglected. Before questioning whether the values associated with an emerging technology are desirable, then, we need to ask

⁴⁴ Paul P, (2011) Don't Call Me, I Won't Call You <http://www.nytimes.com/2011/03/20/fashion/20Cultural.html?pagewanted=all>, retrieved on 17/10/ 2011

how plausible it is that an emerging technology will instrumentally and linearly produce those (un)valuable consequences.

2.5 Assessing the plausibility of expectations: a proposal

This chapter has started with the case of genomics, showing how the outcomes were much more modest compared to the initial hype. Commentators recommend that before engaging in an ethical reflection on emerging technologies, ethicists should assess the viability of the technological possibilities (cf Chapter One). In fact, sociology of expectations points out that technoscientists' expectations are not objective representations of scientific facts, but projections of broad techno-social configurations. They have a strategic role of protecting innovations by securing funding and support. The context of utterance, the actors involved, their positioning and interest should be taken into account when addressing expectations on emerging technologies.

Their rhetorical and strategic character is not a reason to discard expectations as objects of ethical discussion. In fact, promises on emerging technologies are visions of desirable futures. Their normative content guides the actors' decisions in the innovation process, justifies their choices, and mediates their communications. This normative content adds a meaning to actors' projections of the future by rooting them in the past. As claimed by some authors, these visions should be assessed: their implicit values, preferences and worldviews should be made explicit and their desirability openly discussed in a democratic setting.

However, I argue that assessing visions means not only to make their normative content explicit, letting stakeholders discuss its *normative* acceptability, but that assessing visions also entails making explicit and discussing the *epistemic* justification of this normative content. An assessment of the plausibility of technoscientific expectations should address the claims that emerging technologies will produce desirable worlds. As the tradition of philosophy of technology points out, the materiality of technological artifacts embodies some values, promotes or forbids some actions, distributes responsibilities and affects our value system. The interaction between technology and morality contradicts the instrumentalist expectations that a certain technology will "simply" do something good.

The approach I propose builds on these considerations. I contend that a precondition of a "vision assessment" is a "plausibility assessment", an assessment of the epistemological foundations of these visions. For example, in the visions of

genomics where desirable outcomes for medicine are realized, a linear link is drawn between the technology and the attainment of these desirable outcomes

(Emerging Technology → Desirable Consequences)

or

($T \rightarrow D$)

I will refer to these as visions of desirability or D-Visions. As explained in the previous sections, technologies do much more in interacting with human beings and their morality. Before addressing questions on the desirability of emerging technologies the plausibility of these D-Visions should be assessed. How to do this?

In order to address this question I propose to break it up into three subquestions:

1. How likely will the expected *artifact* promote the expected values?
2. To what extent are the promised values *desirable for society*?
3. how likely is that a technology will *instrumentally* bring about a desirable consequence?

The first question focuses on the “T” component of the vision. As explained above, in the materiality of technologies values are “inscribed”, roles/responsibilities are distributed among stakeholders, programs of actions are suggested and new interpretations of the world are promoted. To address this question, the expectations of the *future artifact* should be analyzed. Once again, in the case of expectations surrounding genomics, it means to analyze the science and technology and its conditions to succeed. Assessing the plausibility in this case means to analyze these expectations and to compare them with the current scientific and technological practice supporting them. It means to point out challenges and uncertainties and rule out scenarios that turn implausible given the current state of the art. Furthermore, such assessment can have a constructive role of adding new material details and aspects about the technology at stake that can enrich the initial expectations.

The second question focuses on the “D” component of the vision. As the authors of the Vision Assessment approach point out, preferences and ideas of what is desirable are not the same for everyone in society. Different actors will have different perspectives on what is a problem and what is the best solution to address it. Since the new technology is expected to be included in a contextual social practice, with some actors using it in a specific way, the perspectives of these actors are important. Therefore, assessing the plausibility of expectations surrounding emerging technologies also requires to gather different stakeholders’

perspectives and expectations pertaining the use of an emerging technology⁴⁵. Such assessment has the goal of ruling out some scenarios of use as implausible from the perspective of stakeholders. There is also a constructive aspect in this assessment that can add new perspectives and new details about the practice.

These analyses set the groundwork for addressing the last question that pertains the “→” component of the vision. As emerged in the discussion of the literature in the field of philosophy of technology, technologies are not simply instruments to solve a problem. Instead, they change a number of practices, concepts and values. Therefore assessing the plausibility of emerging technologies requires to explore the interaction between technologies and morality. Such assessment has the goal of overcoming a naïve instrumentalist logic according to which a technology will have a desirable impact.

The approach I propose addresses these three questions. In order to do it, three interlocked steps are necessary:

- First, the expectations of the artifact should be investigated. In this way, the conditions for the technology to work can be explored together with its implications for the context of use.
- Second, the expectations of the context(s) of use should be analyzed. In this way, the social practices together with the values attached to them can be investigated. This helps to explore how the new technologies can be embedded in such practices and systems of values.
- Third, based on these analyses, the plausibility of the expectations that a new technology will realize some values can be assessed. This assessment concerns the three aforementioned questions: what values an expected artifact promotes?; to what extent are the promised values desirable for society?; and how likely is that a technology will *instrumentally* bring about a desirable consequence?

These are not isolated phases of analysis, but they build on one another. As it will emerge in the next chapters, what I am proposing is a flexible framework that can be adapted to different contexts, technologies and stages of technology development. There are, however, some strategies that are transversal to my analysis and that remain stable despite the variability of the approach.

First, assessing the plausibility of expectations requires *thickening* them. Details are added to their prospective descriptions of how an artifact will operate, how it will be used or how it will have socially desirable impacts. When the general public reads or hears about new technologies through journalists or from the scientists themselves a big, but quite general picture is presented before their eyes. The new technology is introduced as a solution in a context where there is a

⁴⁵ Interestingly, the term “stakeholder” indicates somebody who has something “at stake”, some interest, value or (idea of) good to protect.

need or a problem. For example, the Human Genome Project offers a solution to satisfy the need for more precise and individualized medicine. This new science and technology is expected to enable the production of innovative diagnostics and therapies targeting specific genes. More generally, early diagnostics enables early and more successful interventions that improve people's health conditions and decreases unsustainable high costs in national healthcare programs. In van Lente's terminology, these macro-level broad scenarios are *nested* with micro-level expectations: they are connected with other expectations that might be not explicitly referred to, but are nevertheless implied in the broader scenarios. For example, the scenario of better diagnostics might entail that genetic information has to be broadly exchangeable and comparable among researchers. The plausibility assessment that I am proposing here turns the philosopher's sight away from the broad scenarios circulating in the public domain. Instead, the philosopher is invited to evaluate the plausibility of these broad scenarios by focusing on the expectations that are nested within them.

The metaphor of the "mosaic" might help to understand what I mean. The broader scenarios offer a big picture. From a distance the tiles that form the mosaic appear as an appropriate component that contributes to the consistency of the overall image. However, the closer we move towards the picture, the more separate tiles we see and the more details appear. The mosaic tesserae acquire different colors, shapes or textures and the apparent uniformity gives way to inconsistencies and idiosyncrasies. The details of the tiles make the spectator lose the big picture and this is when a step back is beneficial. Now aware of the single tiles, the whole picture can be re-evaluated. Zooming in on the smaller tiles that compose the bigger picture is a recurrent element in my assessment of the plausibility of expectations.

Second, learning the lesson from sociology of expectations, I adopt the perspective that expectations of technological futures vary among different social actors. The *plausibility* of expectations of a future state of affairs is judged against the background of their beliefs and values. The lay audience might deem some expectations on the feasibility of emerging technologies as plausible, while a group of experts is more aware of the uncertainties and challenges. For example, within an audience consisting of molecular biologists, geneticists, general practitioners and patients the expectations of the Human Genome Project appeared more or less plausible depending on their epistemic background. The audience will assess the expectations with respect to their knowledge of physics and electronics, medical practice, self-testing practice or advising patients. Furthermore, we do not neglect that these expectations are visions of desirable futures and are carriers of values and ideas of good. Therefore, the judgment of plausibility will also depend on how these different audiences are mobilized by these values.

These beliefs and values change according to the position of the actors. Whether we talk of scientists, policy-makers, doctors, or patients, we can talk of different *epistemic and normative cultures*. They will have different knowledge, situated and dependent on their background, “expertise”, interests and system of values. An exploration of the judgments on these expectations from inside a specific epistemic and normative culture helps in analyzing these expectations. What is plausible for a certain epistemic and normative culture sharing a certain background might not be so for another culture. For this reason, my approach will consist in discussing the expectations of stakeholders belonging to different epistemic and normative cultures and point out controversies and clashes among these expectations. Clashes between visions of future technologies in society within different communities bring up new perspectives. Pointing out alternative perspectives among social actors is important to assess the likelihood of some expectations. When a scenario of a techno-socio-moral future is reconsidered from different “situated knowledges” (Haraway 1988) and interests, some aspects of the vision might be re-evaluated as unlikely while others might be added as important. New features enter and enrich the initial picture. Assessing the plausibility of expectations surrounding emerging technologies is like fixing a ship while sailing in the open sea; one cannot abandon ship to look at it from a distance and determine the best means of reconstruction. Such assessment can only occur from within the situated perspectives of social actors in the process of technology development.

PART 2

[...] It is the idea of the oncologist Prof. Emer. Pinedo, who approached us with the question of whether it would be possible to develop a Lab on a Chip system that can be used for the early diagnostics of colorectal cancer. This disease is the second most common cancer in men and women and is often only picked up at a (too) late stage. (Berg 2009: 38, *my translation*)

This quote is taken from a speech given by Albert van den Berg, professor of Miniaturized Systems for (Bio)Chemical Analysis at the University- on the occasion of the annual ceremony commemorating the founding of the University of Twente (the Netherlands) – during which he introduced one of the projects conducted within his research group. On being awarded a few weeks earlier with the prestigious Spinozaprijs (Spinoza Prize)⁴⁶, Prof. van den Berg elaborated on one of the anticipated outcomes of this research: an innovative device for the early detection of colorectal cancer, the Nanopil⁴⁷.

⁴⁶ The Spinoza Prize “is an honorary award for what the winners have achieved in their scientific career”. It is awarded by the by the Nederlandse Organisatie voor Wetenschappelijk Onderzoek (Netherlands Organisation for Scientific Research) and it comprises an award of 2.5 million euro to spend on research http://www.nwo.nl/nwohome.nsf/pages/NWOA_4XLB5_Eng?Opendocument&su=no

⁴⁷ Since expectations on the “Nanopil” have mainly circulated in a Dutch context, I will keep the Dutch form “Nanopil” rather than the English “Nanopill”. Some English reviews of the project

Between 2009-2011, TV, national newspapers, magazines, and a children's book⁴⁸ presented images of the Nanopil (NP). This device was expected to perform the task of a miniaturized lab within the human body and to transmit the result of the test to an outside receiver. Although the development of such a complex pill may appear futuristic, Professor van den Berg remarked at the time that there was already a so-called "Camera pill" (PillCam), with which pictures of the interior of the gastro-intestinal channel could be generated and sent to the outside (2009). Professor Pinedo, the oncologist who conceived of the Nanopil idea, anticipated (in 2009) that in 5 to 10 years doctors would be able to use the pill in hospital settings (Melchior 2009). Public debates were organized to discuss the opportunities of and concerns about this device⁴⁹.

Initially circulating in personal communications, funding proposals, or patenting applications, the expectations of the Nanopil travel across environments and circulate within public speeches, science cafés, and the media. The NP is not reality yet, but it already exists as an object of people's praise, desires, fears, investments, decisions, research; in short the NP exists as the object of a broad range of expectations. These expectations directly or indirectly refer to the desirability of this device for early screening of colorectal cancer. A democratic discussion (see Chapter One) about the desirability of an emerging technology like the NP cannot take these expectations at face value, because they are strategic and context-dependent (see Chapter Two). In order to discuss the desirability of the Nanopil in a meaningful way, we should assess the plausibility of the visions that this technology will realize certain values. This assessment aims at ruling out some improbable scenarios and at exploring other scenarios that remain implicit.

The promise is that the Nanopil will be a device enabling early, inexpensive and reliable screening for colorectal cancer. As outlined in Chapter Two, the success of such a promise requires that three broad conditions be met. First, the Nanopil will be a functioning artifact: it will detect the presence of markers for colon cancer *in vivo*, within the intestinal tract, and will communicate the result to the external world. Second, this artifact will be used in the practice of colorectal cancer screening by healthy individuals. Third, the use of this device in the expected social context will be desirable for society. In order to assess the plausibility of the expectations about the value of the Nanopil, these three conditions have to be analyzed. The next three chapters will outline how such an analysis can be performed. In order to assess the plausibility of these visions, the expectations of the artifact and of the context of use have to be assessed. Chapter

circulate on the web, but they are mainly quotations of press releases from the University of Twente.

⁴⁸ "Een pil met een lab erin" by Martine Letterie was published by Uitgeverij Zwijsen, Tilburg, 2009

⁴⁹ Debat Nanotopia: <http://www.lux-nijmegen.nl/debat/nieuws/2010/06/10/goed-idee-niet-de-nanopil-gaat-er-komen-dat-zeker>

Three and Chapter Four will address the question of how this can be done using the case of the Nanopil as an example. Based on these analyses, Chapter Five addresses the main question of the plausibility of the visions of the desirability of the Nanopil.

The choice of the Nanopil as a case-study was partially motivated by logistical reasons. First, the research on this device was conducted at the University of Twente and it was initiated at the same time that I started my PhD. This allowed me to follow the emergence of a technology concept from the beginning and in discussion with the actors who initiated it. Moreover, the NP received significant public exposure from a very early stage of the project. This public exposure of the technology, and its presentation in terms of its impact on people's lives and medical practice, makes it an ideal candidate for early ethical reflection. Most interestingly, while I was investigating the possibility of working on this case, I observed that this public interest and optimism was counterbalanced by a skeptical attitude on the part of engineers working at the lab-bench with regard to the medical application of their research on NP. This clash between the expectations of insiders and outsiders makes the Nanopil an interesting example of an emerging technology that triggers the imagination of the public and yet requires critical assessment.

3

The mechanism in the pill

From abstract images to detailed
descriptions

Caress the details, the divine details. (Nabokov V, Lectures on Literature, 1980)

Using the “Nanopil” as an example, this chapter discusses how to go about analyzing expectations about a future artifact. Following an introduction of the public expectations about the Nanopil (§ 3.1), I explain why further analysis is needed (§ 3.2). Specifically, these descriptions obfuscate the development process of the artifact and present the new technology as a perfectly working mechanism. By looking at the process of construction of the artifact, the alternative designs, components and conditions of its functioning can be grasped. This is important in order to assess the plausibility of the expectations with regard to this artifact. These considerations inform my research design (§ 3.3). § 3.4 presents the analysis of expectations on the Nanopil based on in-depth interviews with scientists and observed their laboratory practices. It transpires that such analysis rules out implausible scenarios and adds details to the initial expectations. § 3.5, I explain how this analysis helps to address the question of the plausibility of expectations.

3.1 Promises of emerging artifacts

Before a tumor is visible, it is possible to detect some changes in the DNA of the intestine cells. We can develop a pill with special nanowires to which the changing (methylated) DNA in the intestine liquid can bind. The information of the nanowires is sent to a receiver, for example a mobile phone (Van den Berg 2009: 38, *my translation*)

The Nanopill contains a minuscule lab that can sample and test intestinal fluid within the intestine. Descriptions of the expected artifact emphasize its overall function: diagnosing for colon rectal cancer. This description is provided in a lecture for a University celebration. As such, it is addressed to a broad audience. Some images from a short 1'22" animated video are shown to demonstrate the inner functioning of the pill (see Annex One) ⁵⁰.

In this video, a 3D animated middle-aged man stands against a dark grey background, holding a pill in his right hand. His eyes stare into the void and with an automatic gesture he leans his head back while bringing the pill to his mouth. In the next shot, the pill travels through his esophagus to his stomach and from there to his winding bowel. Then, the image zooms inside the pink cavity of the intestinal tract. Now, the white pill swims in a transparent fluid. Yellow strands floating in the intestinal tract (some of them with red dots attached) enter through a "sampling intake" hole inside the pill. In the interior of the pill, the yellow strands swim in a white corridor towards a chamber in which many pillars are perfectly aligned. The strands with red dots stick to these pillars. Following a sudden flash, the strands detach from the pillars. They swim to another compartment in which there are railway-like tracks with some strands attached to them. Each entering strand with red dots winds itself around one of the yellow strands on the tracks in a locked embrace. The image zooms out, showing that these tracks are linked to an area in the pill that emits waves. The image returns to the middle-aged man who now has a smart phone in his hand. He looks at it and then holds up the telephone screen to the spectator "Pill status received: result 4.7. Result automatically sent to the physician".

This video offers a scenario of the expected working mechanisms of the Nanopill. From the outside to the inside of the human body, the shooting angle of the camera travels through the intestine and then brings the spectator into the interior of the pill, disclosing the architecture inside the pill. This scenario

⁵⁰ This video (<http://vimeo.com/11547349>) was commissioned by the BIOS group at the University of Twente to a small Dutch company with expertise in science visualization (<http://www.utwente.nl/ewi/bios/>).

describes a complex and yet perfectly operating and stable mechanism in which every piece performs a function for the overall purpose: detecting biomarkers for colorectal cancer. The expectations that the Nanopil will realize a desirable world are based on expectations of how this device will operate. How, however, to assess the plausibility of these expectations? In order to assess the plausibility of these visions, a critical analysis of the expectations on the artifact is needed: why can we not rely on the video? And how to go about analyzing these expectations?

3.2 Rhetoric and black-boxes

The Nanopil sounds like a futuristic project, however this is not the case. The video has the function of making the Nanopil a reality. Presented in science cafes, included in online news or presentations, this visual tool is a rhetorical device that aims to show a broader audience that the Nanopil is not science-fiction. Promotional rhetoric (Guice, 1999) is crucial for scientists dealing with unfamiliar topics to convince audiences that they are dealing with something real (Brown, 2006; Moreira & Palladino, 2005). The linear simplicity of the NP system, the causal interaction between its parts and the functionality of its components that appear in the video should not be taken as a description of an existing mechanism. Instead, these features have a strategic function in deleting complexities in order to convey the message to a lay audience that the Nanopil is a feasible device.

However, this clean and perfectly working image is not a faithful representation of the “dirty” messiness of the development of new technologies. In fact, during the phase of production of technological artifacts, when science and technology are still “in the making”, artifacts are unstable processes of inquiry, inviting heated discussion (Latour, 1987; Latour & Woolgar, 1979). An example of this process is the “construction” of a scientific fact that is now viewed as the basis of the central dogma of molecular biology: the double helix structure of the DNA molecule. In the early 1950s, when Watson and Crick were discussing the configuration of the DNA molecule, the double helix was not a fact, let alone a dogma. Questions, claims, arguments, pictures, enthusiasm or frustration were the only “facts”. This process of construction resulted in a scientific “fact”: the triple helix became shared knowledge and its process of construction was concealed. Similar to scientific facts, artifacts are also constructed through similar processes; it is only when an agreement is reached that the artifacts stabilize in one specific shape and function. At this end point, they cease to be part of “heated” discussion and become “cold” objects. The process of construction is hidden (or “black-boxed”) and its product is presented as an abstract token without a history: an unquestioned and necessary dogma.

The promotional video black-boxes the actual process of construction of the Nanopil. At such an early stage of development, a device like the NP is an emerging artifact, still in the process of being constructed. In the video, such a constructive process is “black-boxed” while the expected outcome is presented in its simplicity. The process of simplification (Callon 1981; Law 1984) has a strategic role in the public space because it shows that the NP is a feasible object. Assessing the plausibility of these expectations about the artifact means looking beyond this simplified rhetoric and disclosing the messy constructive process of artifacts in the making.

This process comprises questions, frustrations and controversies around alternatives. Studies in the history of technology show that, in the emergent phase of technological innovation, different design alternatives coexist. For example, in the early days of the bicycle (Bijker and Pinch 1987), differently designed artifacts co-existed: a model with a front wheel bigger than the back wheel competed with the model with two wheels of the same size that we use today. This second model stabilized as a result of social negotiations and controversies in which different interests were at stake. As Feenberg (1995) remarks, design choices carry a specific vision of the world and system of values. Taking again the case of the bicycle, the model with equally sized wheels was considered to be safer by women and elderly people, while the other model aligned with the interests of young men because it was faster. The fabrication of technical artifacts is a process of “closure” of some controversial and value laden alternative designs within a final design choice. As the case of the bicycle shows, this process of artifact construction unfolds in time and in space: not only do design choices change over time, they are also shaped by controversies and negotiations among actors. This constructive process has been described by reconstructing the history of the artifact and articulating controversies (Bijker and Pinch 1987; Latour 1987). How can this process be analyzed in the case of emerging technologies?

The laboratory offers an excellent site from which to observe: the practices of making science and technology unfold (Knorr-Cetina 1981, Pickering), the controversies and compromises take place (Latour & Woolgar, 1979), and the manner in which “accuracy” of a new device is “invented” (Mac Kenzie 1990). Emerging artifacts exist not only in the form of oral or written discourses, like expectations, controversies or patents; in the laboratory, the materiality of emerging artifacts can be observed in experimental setups, biological samples, microscope images.

The laboratory is not only a site to reconstruct the social and material making of the artifact. It is also a site where an emerging artifact can be understood in the epistemic practices of scientists and engineers. In fact, studies of philosophy of science in practice have pointed out that emerging artifacts exist in the laboratory as “models” in which “knowledge of the relevant operations, physical properties, phenomena or properties” are built (Boon and Knuttila 2009). These models are pragmatic tools with which engineers can

intervene in reality. In order to predict the behavior of the mechanism which composes the final product, engineers make use of abstract models with which they “seek to gain understanding of the behavior and properties of various devices and materials” or to produce them. By abstracting from several features of the real device, these idealizations of devices allow engineers to conceptualize a certain phenomenon and to work with it. These pragmatic tools allow engineers to specify a function that a certain device has to fulfill and to highlight functional sub-components. When idealized models are used in the research practice, the relations between the expected overall function of the device and the function of its subcomponents adapt to material and physical conditions. Understanding the idealized model gives a key to access the artifact, as engineers conceptualize it. However, it is also important to go beyond this and look into the materiality of these components.

As Akrich points out, a focus on the “function” of the artifact erroneously suggests that the new technical object is doing the same as the old one in a better (more efficient, precise, sustainable, faster) way. In contrast, by describing some specific aspect of the artifact material design, attention can be drawn to how an object operates. In particular, she shows how the design process, by defining the components of the artifact, also determines the definitions of actors and relationships among actors. Therefore, in order to focus on what an object does in a social practice, Akrich suggests constructing thick descriptions of the artifact design rather than focusing on the function of the new technology.

In order to address the question of the plausibility of expectations on emerging technologies, we have to go beyond the “cold” simplification of the artifact’s mechanism offered to a broader audience, as exemplified by the Nanopil video. In the next sections, I will show how I build on these considerations in addressing the case of the Nanopil.

3.3 A note on methods

My methodological approach to the analysis of the Nanopil artifact was based on the above considerations. Because the Nanopil is still emerging, descriptions of this device in research proposals, patents, personal communications or controversies are still fictional. However, the NP also exists in the materiality of experiments, components and a patent. I reconstructed the history of the NP and focused on the controversies and negotiations around different design choices. In doing this, I pointed out how these choices were linked to the overall idea of the function of the artifact and its context of use. Through a close understanding of the designers’ models and laboratory practices, I articulated the different functional components of the artifact. I focused my attention on the physical characteristics of these components and described the material conditions of operation.

Over a 6 month duration, I visited the BIOS group every two weeks. In this time period, I interviewed all the researchers participating in the project with different roles: the project leader, 2 senior researchers, 1 post-doctoral student and 1 graduate student. I conducted a first round of semi-structured interviews with each researcher. Although I always began by communicating my interest in understanding more about the Nanopil and its technology, the interviews proceeded in different directions depending on the researcher's interest and attitude. Recurrent questions concerned the role of the researcher in the project, challenges experienced and reasons for concern and hope. Several researchers started narrating the story of their involvement in the NP project. A researcher brought the original project proposal of the NP - and the subsequent interview centred on the proposal. One senior researcher offered to guide me through the science and technology of the NP. We initiated a series of bi-weekly meetings. Starting with an in-depth explanation of every scene of the promotional video, ever more scientific and technical aspects were addressed. Given my fundamentally humanistic education, I did not have the sufficient disciplinary background to understand all of these aspects; for this reason, I immersed myself in self-study following every meeting. Back at my desk, I listened to recordings of the meetings, transcribed them and collected more information on the scientific and technical aspects that I was unable to understand. When Internet searches or scientific articles could not provide the information I required, I would ask further questions during the next meeting. Some of these meetings took place in the researcher's office and others in the laboratory, where experimental setups were shown and discussed. I also interviewed a molecular biologist from a different institution who was initially contacted by BIOS researchers to provide expertise on biomarkers. One year after these meetings, I interviewed the same researcher and the project leader again about the further developments of the project⁵¹.

In these interactions, my role alternated between the "interviewer", the "student", or the "philosopher". At the outset, I approached the researchers as respondents of semi-structured interviews, while maintaining sufficient leeway to facilitate elaboration and digression. During the meetings with the senior researcher, I approached the interaction as a student who needs to learn more about the science and technology of the Nanopil. When I became acquainted with the science and I started interviewing other actors⁵², I introduced the inputs of other parties to the conversations, allowing space for critical discussions.

These interactions with technology developers aimed to explore the complexities of an emerging artifact beyond the simplifying strategies of public

⁵¹ The description of my research design demonstrates that patient collaboration and the availability of researchers at the BIOS group were crucial. I wish to thank them for sharing their knowledge, reflections and time with me.

⁵² See Chapter Four.

science. In eliciting techno-scientists' expectations on the artifact in the situated context of the laboratory practice, I focus also on the materiality of the research practice: on the problems that researchers encounter in their everyday bench research (experimental setup, type of machines, practical challenges). Furthermore, my conversations with techno-scientists aimed to reconstruct the components, functions and aspects that are expected to contribute to the overall functioning of the final artifact. Such reconstruction aimed to "thicken" the description of the artifact that is "black-boxed" in the video. The analysis presented in the following sections describes this type of work. As the last section of this chapter emphasizes, this type of analysis rules out some implausible expectations and enriches the current visions of the Nanopil with new details that are important for the way in which the artifact operates in a social practice.

3.4 The Nanopil: tales of an emerging object

Although all the interviews and meetings were recorded and transcribed, I will not always report their exact transcription, for reasons of readability. At times I will use short narratives that are either summaries of long interviews, or my observations of laboratory practices. These narratives are typographically marked by the *italic font* and indent. They are not meant to be used for close discourse analysis. Instead, following the tradition of "empirical philosophy" (Mol 1998, 2000, 2002), these philosophical narratives have a "heuristic" function; they alert the reader to some observations, interpretations and considerations that guide the plausibility assessment of expectations on emerging technologies.

3.4.1 From an idea to a project

The story of a project is a good place to start exploring the complexity of an emerging artifact; in fact, it introduces the temporal dimension and provides a reference point to understand the present stage of research. Nanopil is a special project for researchers working at the BIOS. Its concept sprung from the will and mind of an oncologist looking for a technological platform for a specific diagnostic application. Doctor Pinedo was looking for an innovative diagnostic to detect tumors at an early stage and he had the idea of placing this diagnostic in a pill. Pinedo contacted the BIOS group at the MESA+ Institute for Nanotechnologies because of their expertise on lab-on-a-chip systems. These miniaturized platforms perform complex electrochemical analysis of micro-quantities of biological samples and can fit inside a capsule. In this sense, Nanopil can be considered to be a technology "on demand"; the oncologist explains what is needed and the technologists provide the solutions. In practice the roles are not so dichotomously

distributed. Since the beginning, in fact, the oncologist had a clear idea of how the device was supposed to work. A researcher explains:

One day in December 2007, I received a phone call from the head of the department, he wanted to hear what I thought about this idea of the oncologist. He mentioned this idea of having a diagnostic device that would detect an abnormal state of DNA from inside the body. To enter the body, the diagnostic system had to be small enough to fit into a capsule, like a pill. There are already some laboratories detecting this abnormal state of DNA (hyper-methylation) using some optical methods. However, they need a whole laboratory to do this, it wouldn't fit in a pill. An electrical signal, instead, could be miniaturized in a pill. There are several techniques that can be used, but nanowires seemed a good tool to us. From this overall idea of detecting hypermethylated DNA on a miniaturization platform, we started developing the idea of the Nanopil.

The innovative idea is to detect a specific marker for cancer (hyper-methylated DNA) *in vivo* and *in situ*, in other words the pill detects cancer biomarkers inside the human body rather than in the laboratory. These aspects are clearly stated in the application submitted by the oncologist and the medical director of the Dutch Institute for Prevention and Early Diagnostics to the European and US patenting offices. The patent, issued in February 2009, protects the invention of a “device for detecting a medical condition of disease”⁵³. The inventors want to combine an automated miniature analysis system, or lab-on-a-chip system, for the molecular detection of medical conditions, with a signaling method to notify a subject if a test result is abnormal. They call this combination “in situ lab-on-a-chip signaling (ISLOCS) device”. The “embodiment” of the device that performs an analysis *in situ* by “entering the body” is a central claim, together with the signaling system of the test result to the user. The capsule containing the device can be embodied in different ways, not only by swallowing it, but also by inserting it in the vagina, or in the nose, or ear. Once in the body, the capsule will collect bodily fluid, purify it, detect some marker of a certain disease and transmit the results of the detection to the outside world in various ways (either by releasing a colored dye, or radio frequency or acoustic signals)

In order to be easily introduced in the human body, the device needs to be small, “miniaturized”, so that it can be housed in a “capsule” small enough to “enter the body”. In the application for patenting, the manner in which the capsule can be embodied is broadly described (it could be by ingestion via the oral cavity or other types of insertion in other cavities, as long as the subject can do it herself). In addition, the type of disease that can be detected is not strictly limited to cancer or colorectal cancer. The “Bolus Smart pill System”, a device to detect colo-rectal cancer, is an example of “ideal ISLOCS application”. It can be

⁵³ “Device for detecting a medical condition or disease” by Pinedo H. M. et al. United States patent application, February 24, 2011, US Patent and Trademark Office, <http://appft1.uspto.gov/netacgi/nph-Parser?Sect1=PTO1&Sect2=HITOFF&d=PG01&p=1&u=/netahtml/PTO/srchnum.html&r=1&f=G&l=50&s1=20110046458.PGNR>.

swallowed, travel through the gastro-intestinal tract, collect intestinal fluid, purify a DNA sample and detect the presence on DNA molecules of an abnormal methylation specific for colorectal cancer. In the event of a positive detection, the integrated electronic system commands the release of a blue pre-stored dye that is pumped into the intestine, coloring the stool that can be observed after defecation.

The Nanopil is a device that has the function of detecting diseases in the human body. The novelty of this invention lies in the detection of markers for diseases inside the body by an automated device, which communicates with the external world. Colorectal cancer is an ideal disease to be diagnosed with this technology because the capsule can easily be embodied by ingestion. Travelling through the digestive tract, the device can detect cancer biomarkers in it. The application of the “nanopil” idea for the detection of colon-rectal cancer is possible because the device is small enough to be ingested, and that the digestive tract is continuously unfolding from the mouth to the anus. Thus, the “Bolus smart pill system” is made physically feasible due to a physical characteristic of the device, together with a physical characteristic of human bodies⁵⁴.

This story of the initial idea of the NP is interesting because it articulates its “core” concept. This story provides a narrative background for the researchers to justify or explain their research. As the following shows, these ideas of what the device should do are implemented and translated in research practice.

3.4.2 An idealized system and its building-blocks

When I first entered the lab, two researchers were setting up a complex machine sitting on the lab bench. They wanted to optimize the signal detection of the nanowires and compare it with other detection systems. In their interactions, the researchers did not mention the Nanopil or its use. Afterwards, they explained that the Nanopil as such is mentioned in the lab only when doctor Pinedo goes to visit them: or when people, like me, ask explicitly about the pill. During their daily activities, conferences, and in posters or presentations, they talk about the nanowires and not about the Nanopil *per se*.

The Nanopil as final device was the subject of communications to a broader audience, but it appears not to be a “plausible subject” in lab-talks or scientific conferences. In these research contexts, the researchers’ activity and discourse focus on NP components and sub-components. The artifact-in-the-making is

⁵⁴ It is interesting to note that, in the context of the research proposal, an additional reason is put forward to support the application of the pill for the detection of colon-rectal cancer. This second reason concerns the high benefits deriving from the early detection of this type of cancer, since it is a relatively slow-growing cancer and the surgical intervention for the removal is relatively easy. Therefore, claims about the technical feasibility of the pill are intertwined with claims about its social desirability. I will come back to this point in the next chapter.

discussed in a variety of ways in which the initial abstract Nanopil-object and activity is replaced by other objects and activities. Researchers' attention is directed towards the suitable temperature for the DNA molecule for proper hybridization; or to investigating the appropriate salt concentration; or to inquiring into the working mechanism of the pumping system.

When I first asked about the technology of the Nanopil, a senior research showed me the dissemination video. Afterwards he explained that, in order to understand this complex system, it had to be "broken up" into "building-blocks". During that meeting and subsequent meetings, drawings and further elaborations enabled me to understand that these functional chambers or compartments within the pills allow the following activities:

1) Sample collection and purification: *When the capsule reaches the bowel through the digestive tract, the intestinal fluid is sampled through a hole at one extremity of the pill. A pump brings the intestinal fluid into the pill. The pill is then directed into a chamber with glass pillars. Only DNA molecules with hypermethylated regions groups on some distinct areas stick to the pillars. The rest is washed out of the pill via another pumping mechanism. Then, the hypermethylated DNA is detached by the glass pillars and transported to the detection chamber.*

2) Detection of marker: *The hypermethylated DNA is conveyed to a chamber where complementary single stranded DNA molecules are attached to the silicon nanowire sensors. These DNA molecules present a complementary base sequence to the gene associated to the tumor that has to be detected. These nanowires are similar to electrical wires, but at the nano-scale. A certain voltage is applied to the nanowire. If the hypermethylated DNA retrieved from the intestinal fluid presents the gene mutation, it hybridizes with the complementary DNA molecule on the nanowire, and it produces a change in the electrical current in the silicon nanowire sensor.*

3) Result notification: *The change in current in the nanowire sensors is sent via electrical circuit to a chip (similar to a computer chip) which controls the whole mechanism. It sends electrical signals to a belt that the user has to wear in order to amplify the signal that is then sent to an external device (like a mobile phone), which translates it into numeric data on a read-out.*

4) Electronic interfacing: *or the chip, that provides the "brain" of the system*

5) Electrical power supply: *or the battery, which constitutes the "engine" of the device"*

The images in Annex One illustrate the different chambers that will compose the Nanopil. These boxes are viewed by researchers as signposts for the main components of the device. These signposts are "abstractions" in the sense that the detail and the exact working mechanism are still unknown and need to be explored. Therefore, after the overall function of the NP has been defined, engineers' expectations focus on the specificity of the single functional components. In this sense, both this image and the video of the NP do not have to be taken as representing the exact way the pill will work. On the contrary, they have an "intervening and constructive character" (Boon and Knuuttila 2009): they are pragmatic tools.

This distinction in functional components constitutes a pragmatic tool with which to manage such a complex and big project. For example, each one of these functional steps has become a research project with specific sub-goals and steps. By highlighting the most important functional components in the project, researchers set priorities. They may decide to focus on those parts of the project for which the feasibility needs to be

demonstrated in order to prove that the Nanopil is feasible *in principle*. As emerged during a conversation with the senior researcher, the sensing function is a prior goal for proving that the NP works in principle. Such a priority is determined by researchers, based on the fact that the defining characteristic of the device is its reliability, providing a marginal rate of false positives and, most importantly, false negatives. Such reliability can only be demonstrated by the appropriate functioning of the component detecting the cancer's marker. Since researchers establish that the main function of the NP is to perform highly selective and specific detection of a molecule, the proof of principle for the NP consists in providing evidence that the marker detection with nanowires is possible, reliable and sensitive.

The functional diagram of the Nanopil is only an idealized abstraction that provides a working tool for engineers. This abstraction of the "important" features and functions of the real device has the function of making things easier to handle in a research setting in which engineers can focus on one function at a time⁵⁵. In daily scientific work, the final expected artifact, the Nanopil, is only an end goal, while the researchers' focus is on single sub-problems. While addressing these questions on specific problems, through literature reviews, trial and error at the lab bench, frustrations and successes, it emerges that what was considered feasible in the first functional diagram becomes implausible.

When Doctor Pinedo pays his monthly visit to the laboratory, in December 2011, a researcher explains that the original idea of having molecules stand vertically on the nanowires proved difficult to implement. In order to have optimal conditions for these molecules to hybridize they have to lie horizontally on the nanowires.

The positioning of the nanowires can be adapted in order to ensure that the main function of the NP is performed in the optimal way. The initial concept of the NP and the idea of the overall function of the device is not directly discussed by researchers, however it informs their research practice. This aspect is even more evident when the design choices of NP developers are compared with the perspectives of other researchers in different disciplinary fields that are complementary for the realization of this device.

While the BIOS group maintains acknowledged expertise in the miniaturization field, the researchers have to rely on the expertise of molecular biologists with regard to the choice of the relevant markers and their statistical relevance for screening purposes. I went to visit a researcher working on tumor biomarkers. She is in contact with the Nanopil developers; at the beginning of the project she provided them with information on cancer biomarkers. She explains the complexity of the tumour formation to me: "we will always need to detect a panel of biomarkers, one is not sufficient". I go back to the laboratory, where the researchers explain to me that they are working on the detection

⁵⁵ In the philosophy of science, these abstractions are conceptualized by the notion of *ceteris paribus* clauses: "the study of some group of tendencies is isolated by the assumption that other things being equal" (Alfred Marshall) "the more the issue is narrowed and the more it can be handled: but also the less closely it corresponds to real life".

of one biomarker: the DNA hyper-methylation. What if molecular biologists think that a single biomarker is not enough, but you need a panel that comprises several of them? "Well, multiple biomarkers would increase the sensitivity and specificity, but then you would lose in terms of miniaturization and velocity of the system. If the idea is to have a system that everyone can have, then we have to go for an innovative system like the Nanopil. Our goal right now is to assess the efficacy of the detecting system - the marker that we use for this is not our main focus"

The molecular biologist focuses on the complex interplay of different mechanisms and aspects that need to be taken into account in order to ensure the sensitivity and specificity of the test. Instead, the engineers at BIOS concentrate their activity on the assembly of a miniaturized and fast device for in vivo analysis. It seems that the two researchers' divergence of opinion goes beyond a scientific question of which biomarker is more predictive; rather the difference in opinion concerns the overall goals in the research on diagnostics: the portability of the device versus the sensitivity and specificity of the result.

3.4.3 The functional components and their material conditions

Researchers are focused *inter alia* on their experimental setups, handling wires, locating glass supports, making calculations, designing circuits, reading scientific articles, and discussing their ideas. They focus their attention on specific sub-components of a bigger system. However, even when working on concentrations, binding events and micro-pumps, the link with the final product is still visible to the attentive eye. A researcher is in the lab -he is in charge of the pumping component; beside his work bench is an A4 sheet with three drawings of capsules of different sizes.

This is the real challenge of the project, we know that we will manage to do something with nanowires, but having a pump that is so small and so powerful, is difficult. We need the pump to be fast enough to sample the required amount of intestinal fluid in a relatively short time. We managed to make it work in 15 hours, but this is too long. The pill has to collect a relevant amount of samples and detect it in few hours, when the sampling conditions are good.

The optimal pumping time is defined by the digestion time of the user. Despite the focus of researchers on single components and sub-functions, as explained before, the optimal criteria of the mechanism are dictated by the overall function of the artifact of which these components are part. However, the opposite is also true: physical conditions might shape the performance of the Nanopil in the context of use. As explained by the project leader:

In order to be able to sample the intestinal fluid, the viscosity of the fluid should be low enough so that the pill doesn't get stuck into solid feces. The stool has to be softened. A laxative would do the trick. It is the same procedure that they have before a colonoscopy.

The pill needs to be able to swim through a fluid substance. This is not always the case in the human intestine. In order for this condition to be satisfied, the user has

THE MECHANISM IN THE PILL

to swallow a laxative. On the one hand, the overall criteria for the optimal performance of each component are established in relation to the final overarching function of screening for colon-rectal cancer. On the other hand, the decisions at the lab bench - while shaping the performance of (a) single sub-(sub-sub-)component - also define the performance of the NP. Even if the models used by engineers are abstractions of real, concrete situations, they set a standard for the behavior of the artifact in normal conditions. For example, engineers focus on physical/technical conditions for the NP to sample intestinal fluid at low viscosity. Such a condition is satisfied by the use of a laxative by the user that softens the stool in the intestine. These models set some conditions of normality that should be respected in order for the mechanism to work as expected. Some of these conditions are likely to be embedded in the design of the artifact and determine the use of the final artifact, even though they do not clearly appear in the broader scenarios on the NP.

Similar to this example, other technical “details” related to the feasibility of the artifact require modification of the initial expectations concerning the Nanopil.

Two researchers show me their experimental setup. They want to measure the electrical signal of the nanowires. At the moment, they don't have any DNA probe on the nanowires; it will take a few days for the probes to stabilize, before they can measure the electrical signal. “But in the pill, the probe will be already on the nanowire, it will be sold that way, they will have a protective layer that has to be removed before you do the detection”, they point out. So can the probe stay on the nanowires for a long time? “No, these molecules that are on the surface have a relatively short lifetime. But this is not a problem. Let's say, for example, that you have the pills on the shelf and then you have sent the probes for different types of cancer. Then somebody orders 10 pills and before you ship the pill you can put different probes on it. This way, you don't have to worry too much about the life time of the probe, because you know that it will be used in 2 weeks or so, so you can put the probes as you need them”.

The short life span of the DNA probes on the nanowires requires them to be added to the pill just before use. This technical condition implies that the pill cannot be stored for long periods in a pharmacy. One way of addressing this requirement is to assemble the Nanopil on demand, just before the pill has to be used. Once more, the technical conditions for the pill to work redefine the scenario of its use in a social context, adding relevant aspects that are excluded in the original expectations.

The set up equipment that is used to measure the electrical signal is cumbersome, it occupies half of the space on the lab bench, thick wires are all around it. How can such a big machine be miniaturized in a chip? “The system to measure the electrical current can be made very small with a computer chip”, they explain, “the reason why we have to have these external special cables is to protect the signal from external influences.. On a chip it is easier, everything is located in a small place within a few micro-meters. The reason why we do it this way now, with such big machinery, is that everytime you have a special chip made, it's around...anywhere from 10.000 to 15.000 euro. To have one or two chips made, if you are mass-producing you can have them for 2 euro. But for only one chip, it is very expensive.”

The computer chip, which constitutes the main platform of such a miniaturized system (lab-on-a-chip), is too expensive to be manufactured in small amounts. For the final pill to be cheap, chip production should be high.

Finally, at such an early stage alternative subprojects might run in parallel in order to develop the most efficient mechanism to perform a certain function. Take, for instance, the mechanism of notification of the test's result: two alternative systems are currently explored by researchers at BIOS. Doctor Pinedo's original idea (articulated in the patent) was to have a blue dye stored in the pill that would be released in the event of a positive result (cancer) and be visible in the stool of the user. This mechanism is being explored by engineers at BIOS. However, engineers propose an alternative mechanism for the notification of the test result: a radio-signaling system that sends the signal to an outside device, like a computer or a mobile phone. This system is preferable for the engineers because it would allow the integration of a technology that is already in place for other devices (like the PillCam). The blue bolus system, by contrast, requires the design and miniaturization of another pumping system, a task which is seen as a burden for the researchers.

In the patenting application, the blue dye system is emphasized whereas the video discussed above demonstrates the radio-signaling system. While broadly targeted discourses on emerging technologies tend to provide a unified vision of the technically possible artifact, an analysis of researchers' activities and decisions discloses the different designs. As in the case of the radio-signaling, one design might be preferred over another because it seems more feasible, however, as the next chapters will show it is not only a matter of feasibility. In fact, these two designs acquire a different meaning in a different context of use.

3.5 From the lab “details” back to the big picture

Assessing the plausibility of visions of the desirability (D-visions) of emerging technologies requires an analysis of the expected object of these expectations: the material artifact. The descriptions of the expected artifact aimed at a general public are often simplified abstractions of these objects. Whereas these public expectations describe the future artifact as an accomplished cold device, the laboratory offers interesting access to expectations, in which the history and making of the artifact is still visible. Within this space, researchers' choices, uncertainties, challenges, controversies and doubts, concealed in public expectations, become visible. Furthermore, in research practice, alternative design choices co-exist and are discussed and some design aspects that were too complicated to be explained to a broader audience- emerge.

Thus, in addressing the case of the Nanopil, my strategy involved diving into the midst of the techno-scientific practice in which the techno-scientists are “in action”. I presented some considerations collected during my study of the pill-in-the-making within the laboratory. My approach to the analysis of the emerging artifact was based on the two strategies introduced in the previous chapter: situating and thickening. I elicited the expectations in the situated practice of the artifact making, where expectations are embodied in experimental setups and research tasks. New aspects of the expected artifact, collected during the situating exercise, were added to the original expectations, while others were removed, resulting in “thickened” descriptions of the artifact – to - be. This type of analysis highlights uncertainties, scientific controversies and additional challenges that might constrain or redirect the development of the technology. While some scenarios of use can be ruled out as implausible given the current state of the art, others can be enriched with details of how the artifact will work. In any case, the temporal dimension of the technology development process has to be taken into account. When looking at this process, it is evident that there are many variables at stake. The Nanopil might transpire to have different components and functions from the one expected now. Furthermore, it might transpire that the device itself is unfeasible. Should we just avoid talking about the Nanopil as the end product of research? I argue that we should not; as I explained in the previous section, the end product plays a role in making choices in designing physical components or in research practice.

Reconstruction of the history of the project proposal and patenting application allows the main concept and overall function embodied in the Nanopil to be highlighted. These general ideas on the function of the end product play a role in defining its functional components. In their daily research, researchers deal with the problems, challenges and uncertainties involved in single sub-projects. In doing this, they are influenced by general ideas regarding the end-function of the entire artifact. This investigation of the expectations on an emergent technology in the laboratory provides a different angle to the one offered by public promises. In this way, uncertainties, difficulties and challenges emerge and initial hype is reduced to more humble expectations. Furthermore, when exploring the material aspects and conditions for the artifact to work, some aspects can be elucidated that transcend techno-scientific considerations. For example, in order for the NP to work the user has to ingest a high amount of laxative. The conditions for the adequate performance of the artifact also set a standard of use, determining how the pill should be used. An investigation of these conditions can contribute to re-adjusting the macro-expectations and public discourses related to it. Take as an example the observation that DNA strands located on the nanowires have a short lifespan. This technical condition has relevant social implications for the expectations regarding retail of the Nanopil. Greater attention to “technical

details” rebalances the discourse on the expected or desirable use of the Nanopil on less speculative grounds: what’s the point of having heated debates on the desirability of an improbable scenario in which the Nanopil is available on the shelf at the grocery store like a pregnancy test?

Finally, the stories from the lab floor suggest that the description of the artifact is not given once and for all. On the contrary, it develops over time and across actors. Whereas broader promises tend to depict the expected artifact as a “cold” established product, in the laboratory the expected artifact takes the form of an unsettled “warm” process. Several artifact designs compete or co-exist. As the following chapter will show, these artifact designs entail a different context of use. An assessment of the plausibility of these expectations can contribute to this research practice by making these scenarios of the Nanopil more robust. This will be further explained in the next chapter, which delves into an analysis of the expected context of use of the Nanopil. The Nanopil is expected to be used within a certain clinical practice. But what are the working conditions of this practice? How do actors in this practice consider the plausibility of the expectations on the use of the Nanopil?

4

The doctor in the pill

From “technical” details to social practices

Right from the start, technical, scientific, social, economic, or political considerations have been inextricably bound up into an organic whole (Callon 1987, 84)

This chapter addresses the question of how to analyze expectations pertaining the use of emerging technologies. Following a brief description of expectations concerning the use of the Nanopil, I explain why they need to be assessed in the context of the general research question introduced in chapter 2 (§ 4.1). To address this question, I recall the concept of “fictive script” (introduced in ch2) in order to point out that the expectations on the use of an emerging technology should be compared with the script in the emerging object (§ 4.2). Furthermore, these fictive scripts held by designers should be compared with the “world” as conceived by other actors. Following a short explanation of the research design used for investigating these questions in the case of the Nanopil (§ 4.3), the findings of this analysis are presented (§ 4.4). § 4.5 offers a discussion of how these findings address the research question.

4.1 Expectations of artifacts in use

Expectations concerning the Nanopil are more than descriptions of how a computer chip inside a small capsule is able to detect a biomarker for colon rectal cancer. These descriptions are framed within a social context in which a need or a problem is identified.

Colonic cancer is one of the most common cancers in people over the age of 50. The Dutch Health Board has already advised endoscopic or colonoscopic screening for people in this age group. But this is a painful and uncomfortable experience. Moreover, it presents a logistical nightmare and nothing is found in 95% of cases. What we need is a simple first-line test. The only alternative at present is a faeces test, but eventually, a nano-pill will provide a much more patient-friendly alternative.⁵⁶

The new device is expected to be employed within this broader social framework: a social context is introduced, a medical practice is described and the role of institutions or specific social groups/actors is proposed.

Albert van den Berg clearly imagines the use of this pill: a population screening program in which, for example, every three years all people aged over 50 are invited to swallow a nanopill. In the event of a positive result, a colon examination will follow. "I heard from the medical specialists that in this way the number of examinations, surgeries and deaths from colon cancer will decrease sharply. After all, the sooner something is found, the easier it is to treat the tumor." (Melchior 2009)

The Nanopil is introduced as a screening device, its context of use is sketched and the plausibility of the overall vision is supported by the opinion of other professionals, medical specialists for instance. The expectations that the Nanopil will realize a desirable world are based on expectations of how this device will operate in a certain social context and how it will be employed by users. But how can we assess the plausibility of these expectations of future use?

4.2 (Fictive) scripts and actor-worlds

The concept of "script" was introduced in Chapter Two; it explains how the design of artifacts not only "embodies" some assumptions about use and users but also "prescribes" how they should be used. I employed this concept as a means of underlining the importance of looking at the design choices and assumptions of technology developers when assessing the plausibility of visions of emerging

⁵⁶ A Pill with a Lab Inside <http://www.azonano.com/news.asp?newsID=15039> Posted December 8th, 2009

technologies. Depending on the choices made in designing the artifact and on the assumptions inscribed in it, the final product will “prescribe” different behaviors and “correct” uses. The previous chapter has shown how some of these assumptions of use can be identified in the current research on the Nanopil. There is yet another aspect of Akrich/Latour’s script analysis that is interesting for my study: the assumptions of designers about users and uses do not always correspond to the “real” users/uses.

Akrich emphasizes that “the world inscribed in the object” might differ from “the world described by its displacement” (1992): the user’s environment that is specified and configured by the technical object may not match the actual object-user environment. In order to compare the projected use/user with the real one, Akrich travels to countries (specifically, less developed countries) where the new technical object (a photovoltaic generator) is used and interviews users. Specifically, she asks the users how the practice around electric generators functioned before and after the photovoltaic generator was in place. In fact, the “program” inscribed in an artifact does not determine the behavior of the user in a linear way. Mechanisms of adjustment between the real and imagined user may occur or the “program of action” inscribed in the object may conflict with an “antiprogram” of some users⁵⁷. The users can define roles by themselves or can resist the design. Take the example of the program of action inscribed in the design of new cars, whereby the alarm starts beeping when the car moves while the seatbelt is unbuckled (see Latour 1992). Users can resist this program by, for example, jamming something in the seatbelt buckle, or by buckling the seatbelt but passing it through the back of the driver’s seat rather than from the front⁵⁸.

These considerations emphasize that not only the artifact and its design but also the users’ behavior shape social practices in which new technologies are introduced. According to the researchers in the field of *Users Studies* – which builds on history of technology, innovation studies, feminist studies and social constructivist theories – the simple adaptation of users to a new technology is a simplification that is highly problematic. Technologies are re-inscribed by consumers in different logics from the ones they were conceived by designers. A differentiation in the product-user relation should replace a top-down ideal of users’ adaptation. This literature blurs the distinction between production and consumption (Oudshoorn and Pinch 2003) emphasizing that potential users (and social groups) play a role in the design of a certain technology (like the case of the bicycle (Bijker and Pinch 1987) or that of the scientific instrument industry (Hippel 1976)), and contribute to major innovations of the new products and

⁵⁷ In the script-vocabulary, if a user refuses to do what is “prescribed” by the artifact, s/he refuses to “subscribe” to the artifact’s prescription.

⁵⁸ I have personally witnessed drivers in the city of Naples (Italy) adopting this type of “anti-program”.

instruments they use. Besides the phase of technology development, users also play an important role when the product is on the market. Furthermore, when the technology is stabilized, the user will embed the technology in a certain practice, creating new practices and processes of appropriation sometimes unexpected by the designers (Silverstone et al 1992).

While the concepts of script, script analysis and user focus on existing objects, whose actual use can be described, de Laat (1996, 2000) notes that this concept can also be referred to expected objects. In the case of emerging technologies, designers also assume that users and other actors will relate in a certain way. As for scripts of material objects, there might be some gaps between the designers' assumptions and the present situation in expectations on emerging technologies. However, since the objects of expectations are still under construction, these assumptions cannot be de-scribed by analyzing material design choices. Emerging objects often exist as *texts* in funding proposals, public oral communications, interviews or patents; for this reason their "description" can only have a "fictive" character. In developing an analysis of "scripts of the future" or "fictive scripts", the author refers to Michel Callon's concept of "actor-world".

Callon introduces the concept of "actor-world" as a means of explaining the fact that techno-scientists' expectations on new and emerging technologies are constructions of entire worlds rather than descriptions of a technology. This is illustrated through the example of the electrical car (1986, 1987). In 1973, the engineers at the French electricity production/distribution company EDF (Electricité de France) wrote a plan for the introduction of an electric car. In a society dominated by the traditional automobile, EDF engineers described not only the technical characteristics of the electric vehicle (VEL), but also the social universe in which it would function, with the groups composing it and its trends of change. Different types of "entities" were included in this plan⁵⁹. Indeed, the components or "ingredients" of the VEL were non-human entities, like the catalysts to be used in the batteries, and human-entities, like the automobile company Renault that was expected to invest in the production and distribution of vehicles or the emerging environmental groups, that were expected to support the VEL project as a symbol of a post-industrial society.

⁵⁹ The socio-constructivist tradition emphasizes that technological innovations are not simply physical artifacts, but more complex "technological systems", made of different components, including also legislative artifacts (regulations), social or political organizations and institutions (Hughes 1983, 1987). In this sense, regulations, social groups and institutions are not part of the social environment –or the context – of a technological system, but they are part of the system itself. An analysis of these systems should reject the distinction between the inside (technology) and the outside (society) (Bijker et al 1987). The concept of "actor-networks" (Callon 1981) emphasizes that these systems are composed of both human and non-human elements and a distinction among them is not productive.

In an actor-world, several actors, human and non-human, appear together in “heterogeneous associations”⁶⁰. In Callon’s terms, the techno-scientists *juxtapose* different entities in the context of their visions by *simplifying* them. “Simplification” implies that entities like towns are reduced by EDF engineers to some limited aspects such as city councils in charge of developing non-polluting transport systems. Such simplification is necessary as a means of accounting for an “infinitely complex world” (Callon 1986, 29). Thus, by reducing entities to a few properties that make them compatible with other inter-related entities, the “actor-world” appears consistent and coherent.

In an “actor-world”, a particular actor (say a technoscientist) imbues other entities with a certain identity, task, or concern; in addition, some roles are attributed to them⁶¹. This attribution of identity and role is an expression of the interest of the actor who is designing a certain world. In the case of the electric car, the roles and identities attributed to social groups, Renault engineers, or catalysts to be used in the batteries were an expression of the interest of the EDF engineers. These constructed worlds were dependent on the knowledge and interest of a particular actor and can differ from the ones that other actors, say the engineers at Renault, would depict.

The proposed associations, and by consequence the project itself, would hold together only if the different entities concerned (electrons, catalysts, industrial firms, consumers) accepted the roles that were assigned to them” (Callon 1987: 93)

The success of these actor-worlds depends on the collaboration between the components that they assemble: these components might refuse to collaborate or their interests and positions might not have been appropriately assessed, or these scenarios might have been grounded in some misconceptions. For example, in the case of the electric car, the environmentalist social group did not take up the role of lobbying for a less polluting transportation system, while the construction of the battery proved to be more difficult than expected. When catalysts for the construction of the battery “refused” to collaborate and social groups proved to be weaker than expected, Renault engineers proposed another scenario in which the electric car was not included. The network of human and non-human actors described by the EDF engineers for the electric car did not concretize in real enrollments of actors.

Callon’s concept of “actor-world” emphasizes that technology developers’ “worlds” are simplifications of a complex reality that depend on their assumptions and interests. Furthermore, different actors might hold very different expectations, depending on their interests and assumptions. The success of

⁶⁰ Callon describes “these heterogeneous associations and the mechanisms of their transformation or consolidation” using the notion of “actor networks” (1987, p 93).

⁶¹ In Callon’s words, actors are “enrolled” (Callon 1986)

technology developers' expectations depends on other actors' willingness and ability to collaborate. These considerations illuminate the case of the Nanopil. Several actors are mobilized in technoscientists' expectations of the Nanopil - it is not just nanowires, pumping systems and computer chips that figure in the Nanopil's developers-world. By mobilizing the context of national screening programs, the government and Ministry of Health are also enlisted in the vision, a monitoring role is attributed to the doctors and to people over the age of 50, and a system of remote care has to function to allow the communication of the pill's test result to the doctor. The success of the screening program depends on the radio-signaling system to send the result to the user, and on the installment of a social infrastructure in which the doctor receives the message and communicates (it) to the patient. These expectations on the Nanopil are consistent because they build a context in which all the entities mobilized are linked up. But how to go about assessing the plausibility of these expectations?

De Laat's aforementioned "fictive script" analysis provides some methodological tools with which to address this question. It devises three exercises to make fictive scripts explicit and to describe the users, the actors, and the roles that are assumed in emerging technologies. Because they are based on expectations rather than on material objects, these descriptions have a fictional character and have to be considered as "thought experiments" (2000: 194).

The first exercise is a "100% thought-experiment". It involves describing how the world would be if the emerging object would deliver exactly as expected. By employing this exercise, "the general characteristics of the object in question" can be quickly grasped and described together with the "barriers" that exist in today's world and that constrain the realization of this object; for example, if the object is the battery for an electric vehicle, this experiment would lead to the statement that gas stations should deliver electricity, which is not the case today. The second exercise is a "black boxing" experiment. It involves black-boxing the object as it is conceived by its designers and analyzing it as an "input-output device". In this way, the actors connected to this device can be identified; for example, Renault engineers building the battery in electric vehicles or the users of this vehicle. The third thought experiment involves analyzing the "relationships between actors incorporated into the object". In this way, a description can be offered of what is expected from future *users*. Taking again the electric vehicle as an example, de Laat explains that

If the battery is designed as a single module, it may be rapidly exchanged for a new, fully charged one. If however it is divided over different places in a car (which for instance was the case with the first electric Peugeot's 106) it necessarily will have to be recharged at home or at an electricity station. (*ibid.* 194)

These three exercises are complementary and "provide a preliminary description of the future world the object defines" (*ibid.* 195). Such descriptions enable a

comparison between different anticipated futures as well as an eventual deliberation on emerging technologies.

These scripting experiments were originally elaborated with the purpose of enhancing the actors' reflexivity on structural and social difficulties and to facilitate the process of innovation. The concept of "fictive script" has also been applied by (Boer, Rip, & Speller, 2009) with the aim of bridging the gaps between promises of emerging technologies and "the realities of product development". Different "actor-worlds" are reconstructed in this methodology. Then, the different expected networks of actors and enrollments are mapped in order to point out the gaps in their expectations of the involved actors as well as in their roles and relationships. The next section provides an elaboration of how I included these conceptual and methodological tools in my research design to address the question of the plausibility of expectations about the use of the Nanopil.

4.3 Research design

My approach to the analysis of the expectations on the use of the Nanopil was based on the conceptual considerations presented above. I assessed the plausibility of the NP developers-world by comparing it with the "actor-worlds" of other actors. This was done in several stages and using different research instruments.

First, I constructed the actor-world of NP developers. As the overarching goal of my study is to assess the plausibility of the visions that the NP will realize some values (or a desirable world), I focused on the roles that are ascribed to users in defining the actor-worlds. This was done in several ways during the laboratory engagement presented in Chapter Three. My semi-structured interviews were partly based on the three thought experiments described above. I explicitly asked researchers to describe a world with the Nanopil as they envisioned it. In probing their answers, I asked them to define the actors involved in this world, along with their role. I also asked them to reflect on the users and the tasks that they are expected to perform. In doing this, I did not follow a strict protocol; rather I conducted the interviews in a conversational way. In some cases, these questions were not asked in one interview but on different occasions, including during my observation of their experiments, when judged appropriate. Because the inventor of the Nanopil is an oncologist, this type of interview was also conducted with him. This exercise allowed me to: 1) construct some fictive scripts of the Nanopil; 2) map a network of actors, as expected by the developers of the Nanopil.

The next step was to contact and interview these actors. In chronological order, I interviewed: one of the founders of the Dutch Institute for Prevention and Early Diagnostics (NIPED) who was also involved in the Nanopil patent application; an officer of the Dutch Health Council (Gezondheidsraad, GR) who supervised the Council's report on the necessity and availability of colorectal cancer population screening in the Netherlands; the officer of the Dutch Ministry of Health Welfare and Sport (VWS) who participated in the committee preparing this report; a staff member at the National Institute for Public Health and the Environment (RIVM), a specialized Dutch government agency in charge of the implantation plan for national-screening programs; a gastroenterologist⁶² at the Erasmus Medical Centre, Rotterdam; the head of the oncology department at the Vrij University Medical Centre, Amsterdam; a General Practitioner; the contact for the patient group for intestinal cancer at the SPKS, Stichting voor Patiënten met Kanker aan het Spijsverteringskanaal (Foundation for patients with cancer of the digestive tract). The aims of these interviews was to 1) collect details about the current social practices that technoscientists expect the NP to be part of and; 2) to ask those actors who might be affected by Nanopil to assess the plausibility of NP developers-world from their situated perspective. It should be noted that these actors are not neutral judges; instead they should be seen as "stakeholders". They had some interest at stake in their judgment of the plausibility of expectations on the Nanopil.

Furthermore, the interviews with these actors left room for digressions. I first asked them to describe their position and their role in the practice of colorectal cancer diagnostics, screening, management, prevention, information, etc. For example, I asked the gastroenterologist to describe the current practice of colorectal cancer diagnosis, while I asked the RIVM researcher to describe current screening implementation. In order to gain a better understanding of how the diagnostic practice for colorectal cancer is performed (Mol 1998), I also conducted participant observation in the colonoscopy room for one day at the Vrij University Medical Centre, Amsterdam. Furthermore, document analysis was conducted in order to understand the history of population screening programs in the Netherlands, as well as patients' perceptions of the current diagnostic and screening practice.

During the interviews, I also asked actors to elaborate on their expectations regarding future trends in their field. At some point in our conversations, I added the Nanopil to their "world". While some of these actors were aware of the NP project, others were not; , I explained the working principles of the device and, building on my previous conversations with engineers, I answered subsequent

⁶² The gastroenterologist was a member of the GR committee working on the CRC screening and an organizer of one of the feasibility trials for the screening tests for colorectal cancer.

questions on more technical details. I also presented the “fictive scripts” constructed by and with the technology developers. Again, my questions were inspired by de Laat’s experiments. First, I asked the respondents to “quickly grasp the general characteristics of the object in question, and especially the ‘barriers’ existing in today’s world to realize the object of concern” (2000, 194). In doing so, special attention was given to the expected “antiprograms” of the users and to the relationships between actors that are inscribed into the NP (what does it prescribe, allow, forbid, stimulate, etc.). In addition to the barriers, I investigated the opportunities that actors associate with this emerging technology.

In the following section, I present some findings of this study. In doing so, I show the kinds of considerations that emerge from this analysis and the way in which they contribute to addressing the question regarding the plausibility of expectations of the Nanopil. Since close discourse analysis was not a goal of my data collection, I will not always provide exact quotes although I do indicate the source of these considerations.

4.4 The Nanopil: tales of an emerging practice

4.4.1 Nanopil designers-world

Let’s consider again the script of the video introduced in Chapter Three. The Nanopil is a micro-system that can perform elaborate analyses of biological samples. This system is small enough to be contained in a capsule. The capsule will travel through the intestine, collect some intestinal fluid, and detect abnormal DNA through changes in the electrical current of nanowires. Then, the pill will inform the user of the result: “The result of the measurement can then be sent via radio signals to a receiver (e.g. a mobile phone) that can send the result directly to the doctor” (Berg, 2009). This script is included in a broader vision of portable devices for health diagnosis and monitoring:

There are great expectations of micro-fluidics and Labs on a Chip. An important area is that of biomedical applications. You can think of a variety of Point of Care systems that can be used both for early diagnosis and patient monitoring. The wireless network-communication plays a major role. Thus, for example, an iPhoneMed unit could be developed that links the Lab on Chip Devices to the mobile phone (ibid., *my translation*)

According to its inventors, the Nanopil functions as a screening test for colon rectal cancer. This means that this device does not determine whether the user has colorectal cancer, but whether there are some conditions that are worthy of further investigation using techniques like colonoscopy. The NP is expected to replace other tests that are used for screening healthy people. In many

descriptions and expectations, there is reference to the NP's possible use within a national screening program in which people over the age of 50 would be asked to take a Nanopil (*ibidem*; Melchior 2009).

As I mentioned in the previous chapter, the Nanopil is a project initiated by an oncologist. According to the technology developers, Dr Pinedo provided the social context and need for the Nanopil.

The problem in cancer treatment is that too many patients are too late. For example, you have complaints but you don't go to the doctor. Then, you have the doctor's delay, when the doctors misinterpret the complaints. Then you have the general practitioner's delay, like the waiting list. And so finally, when the patient is ready for treatment he cannot be cured. So the general thing, you see it with breast cancer, when I started 30 years ago, three out of four women died from breast cancer. Now only one out of four dies, because of early detection of breast cancer. The same is true for cervical cancer. Since you have the pap smear and a good checkup like in Holland, only a few patients die. But in many cancers you don't have these tests. For colon cancer you have the test of the stool but it is not very reliable. Often you have false positives and false negatives. So many people will still be lost because they are not tested. Also people do not like to bring the stool to the lab. (Interview on April 12, 2010)

The brain-father of the Nanopil envisions the Nanopil as a tool with which people can monitor their health. He stresses that the Nanopil is not aimed at patients entering the doctor's office with a symptom, but to healthy people or "clients": "We are not talking about patients but about normal human beings", he stresses. He also points out that as a society, "we are going towards the age of prevention" and the Nanopil is the tool of the future for engaging in preventive practice. He envisions that Nanopil could be used by healthy individuals in the privacy and comfort of their home as a component of a prevention and self-monitoring routine.

Engineers involved in the development of the NP frequently refer to Doctor Pinedo's observations in order to justify their assumptions on the user and context of use. However, as the previous chapter has shown, conditions and contexts of use are also inscribed in the artifact during the research practice. This is the case for the laxative that enables the capsule to travel in the intestinal tract. Similarly, the sampling and analyzing operation is expected to be much longer than the one minute shown in the video. Researchers expect that the whole operation will take between 7 and 15 hours. Also, the original design of the NP was based on a Blue-Bolus result communication through the release of blue-dye coloring the stool. The program of action of this design choice had the individual or client as the only witness of the test result. However, the existing state of the art (e.g. the PillCam) and the technical challenges of including a blue-dye pumping system in the pill have led engineers to explore another system, namely a wireless radio-signal. In the program of action inscribed in this design, the results are communicated not only to the client but also to his/her doctor. Furthermore, the client will have to wear a receiving belt that can amplify the radio signal from the pill and send it to an external device such as a mobile phone or a computer.

THE DOCTOR IN THE PILL

Other aspects, not directly linked to the functioning of the artifact, shape the fictional description of the Nanopil's context of use. For example, a central element in the description of the NP is that it will be a cheap diagnostic device. However, as reported in the previous chapter, microchips are cheap only when they are produced on a large scale. Therefore, the description of the NP as a cheap diagnostic device assumes that it will be sold in high quantities.

Finally, a certain behavior is assumed by the users: the users will clear their intestine by drinking liquid laxative the day before the NP ingestion (as when patients prepare for a colonoscopy). They will swallow the pill and wait for it to perform the *in vivo* test. In the case of the radio-signaling configuration, after a few hours they attach a belt and keep their (smart) mobile phone nearby. In these descriptions, different contexts, actors, institutions and conditions are imagined to cooperate. The following sections, based on interviews with other actors and document analysis, will thicken, articulate and/or question the technology developers' descriptions of the context of use, the practice and the user of the Nanopil.

4.4.2 Comparing actors' worlds: current screening practice and future trends

The Dutch Health Council report on colorectal cancer screening is mobilized in the Nanopil developers-world. The Dutch Health Council officer who supervised the report spoke about the story of the report. To date, the Netherlands has successfully implemented two national screening programs: breast cancer and cervical cancer. These screening programs have proven successful in decreasing the mortality rate for these two diseases. The debate on the national program for screening in the Netherlands was triggered by the results of a European survey in which citizens' awareness about colorectal cancer was explored. In comparison with other Europeans, Dutch citizens appeared to be less aware of the danger and symptoms of colorectal cancer. The results of this survey initiated a debate on the introduction of a screening program in the Netherlands⁶³. Indeed in 2007, the Dutch Minister of Health, Welfare and Sport (VWS) asked the Health Council to produce a report on the necessity and availability of colorectal cancer screening in the Netherlands. The expert committee set up by the Health Council judged unanimously that a screening program for colorectal cancer was desirable. Subsequently, several pilot studies began in the Netherlands to test the sensitivity and specificity of available tests for CRC⁶⁴. The iFOBT (immunochemical fecal

⁶³ While in other European countries like France, the UK and Germany there was some form of national program for population screening for CRC, this was not the case in the Netherlands.

⁶⁴ Namely, gFOBT (the "guaian" fecal blood test), iFOBT (an immunochemical fecal blood test, specific for human blood and more sensitive than the guaian), colonoscopy (considered as the

occult blood test) was selected by the committee as the most suitable test for a population screening program. This self-test (conducted by a healthy individual by collecting stool samples and sending them to the laboratory) would reveal the presence of occult blood in the feces, which is a symptom of a potentially bleeding tumor. Although the test has a relatively low sensitivity (65% against the 97% for the colonoscopy test), an analysis of its costs and benefits during the trials showed it to be the best available solution at the moment (Health Council of the Netherlands 2009)⁶⁵. A subsequent colonoscopy would however be necessary to diagnose the eventual presence and type of tumor.

While the Dutch Minister of Health at the time endorsed the final opinion of the Health Council, he highlighted the difficulties of implementing such a screening program in the short-term in a letter to the Parliament in November 2009; reasons included the lack of immediate capacity, in terms of staff and infrastructure, to guarantee a diagnostic examination (i.e. a colonoscopy) to every individual with positive results⁶⁶. While working on increasing the capacity of training nurses and other clinical personnel to conduct endoscopic investigations, the RIVM (the National Institute for Public Health and the Environment)⁶⁷ defined the implementation plan.

How would the Nanopil fit in this context? The officer of the Dutch Ministry of Health, Welfare and Sport responsible for the colorectal cancer screening program envisions it as a possible replacement for the iFOBT.

With the iFOBT, we invest in an infrastructure that we can easily adapt when we get a better test. Because we know that we will have a better test in the foreseeable future.

She goes on to explain that the implementation plan of this program was based on the idea of creating an infrastructure that is flexible enough to adapt to newer, more reliable self-tests than the iFOBT. However, the description of the screening practice provided by the staff member at the RIVM sets some conditions on this vision.

golden standard and always performed in any trial as control), CT colonography (or virtual colonoscopy), sigmoidoscopy (similar to a colonoscopy, but examining only the final part of the colon), molecular test (detecting specific biomarkers in stool or blood).

⁶⁵ In order to evaluate the introduction of a population screening programme, the Health Council drafted a normative framework in 2008 based on the ten principles of screening that were formulated by Wilson and Jungner in 1968. This normative framework comprises five criteria: 1) screening is directed at important health problems; 2) screening results in health gains or other benefits of the test subjects in question; 3) the screening method is reliable and valid; 4) participation in screening and follow-up examinations is based on an informed and voluntary choice; 5) efficient use is made of resources (Health Council of the Netherlands 2009, 27)

⁶⁶ On May 25, 2011, the Dutch Minister of Health, Welfare and Sport (VWS) decided to introduce screening for bowel cancer. The programme is expected to start between 2013 and 2019 (http://www.rivm.nl/Onderwerpen/Onderwerpen/B/Bevolkingsonderzoek_darmkanker).

⁶⁷ <http://www.rivm.nl/en/>

With respect to its implementation, colorectal cancer screening is different from the other existing screening programs because it involves a larger number of people (men and women over 50) and it implies a self-test. Indeed, while the smear test for cervical cancer and the mammography for breast cancer are conducted by medical personnel in a medical setting, the iFOBT requires that the stool sample collection is carried out by the healthy individual undergoing a screening program (or “screenee”) at home. The sample is then analyzed in the laboratory. In the currently running national screening programs, the general practitioner (GP) is a focal point. In case of an unfavorable test the GP receives the result of the test from the screening organization, informs the screenee and refers him or her to hospital. For that reason the GP is informed several days before the screenee receives the letter with the result. In the case of cervical cancer, the GP is also responsible for performing the smear test. As the RIVM staff member explained to me (at the time of the interview), the ongoing debate at RIVM centered on whether (in the future CRC screening program) the GP should also play a role in referring a screenee - in the event of a positive result - to hospital. For reasons of quality and in order to speed up the appointment process this task could be performed probably better by the regional screening organizations. In fact, in describing the implementation plan for screening programs, he pointed out how the Centre for population screening within the RIVM organizes the “logistics” and the “coordination” of the program. These screening programs aim at balancing “health improvement” and “autonomy” (as self-determination) for the involved individuals. Within this perspective, a screening program in which individuals are the only recipients of the result of the test is unconceivable because it would be impossible to “organize the screening”. This sets some conditions on the use of the Nanopil for population screening.

As explained above, the Nanopil developers are exploring two alternative designs for informing the user of the test result. These two designs are not equivalent in view of the use of the Nanopil as a test in a population-wide screening program. If the Nanopil communicates the result via radio signal and if the notification can be sent not only to the user’s device (i.e. a mobile phone), but also to the GP’s, it could be received instantaneously by the doctor and the user. In the blue bolus pill, instead, the subject is informed of the result of the pill via the release of the blue dye visible in her/his feces. In the “Blue bolus pill” scenario, the screening subject is the only witness and monitoring by medical personnel is not possible. The program of action inscribed in the “Blue Bolus pill” seems not to be compatible with the program of action inscribed in the screening programs. The details introduced by the RIVM representative enrich the image of the current population screening practice and challenge the consistency of the Nanopil developers’ world.

The scenario is different in the case in which the Nanopil is conceived in a “self-test” context; the Blue-Bolus pill is considered as absolutely plausible for such a context. One of the founders of NIPED (the Dutch Institute for Prevention and Early Diagnostics) and an applicant for the Nanopil patent, explores the possibility of having the “Blue bolus pill” as a component of the Prevention Compass. This is a prevention kit for personalized risk profiling, developed at NIPED.

The Prevention Compass [is] a patented, web-based, knowledge and decision support (KDS) system for evidence-based personalized prevention [...] It aims to empower professionals and individuals by delivering state of the art scientific insights while facilitating task-delegation, health education, self-management, quality assurance and shared decision making.⁶⁸

This “@home lab-box” provides the tools for the home collection of heterogeneous data such as questionnaires, biometrical data, and biological samples that will subsequently be sent to the laboratory for analysis. The web-platform integrates these data and measures a personalized risk profile for several health conditions (cardiovascular risk, mental disorders and colorectal cancer). The main idea is that this prevention platform should be personalized, that is, able to collect sufficient information from the individual and to provide a personalized response concerning the risk profile and the type of intervention required. Such a kit is expected to be sold directly to the consumer or to be used in healthcare practice as a management tool⁶⁹. In this context, the Blue-Bolus design is a viable option.

The Nanopil does not constitute a more reliable test that can replace the iFOBT in the future and simplify the screening procedure. On the contrary, the final design of the Nanopil will contain a script that will allow some social configurations and exclude others. Currently, several design options that hold different fictive scripts co-exist. Some of them are more plausible than others not only with respect to their technical feasibility (“the radio-signaling system is easier to reproduce because it already exists on the market/it is easier to miniaturize”), but also because of the social context in which they are expected to operate. In light of the program of action held by the screening organization, the expectations that Nanopil will be used in a screening program are plausible only if the developed design for the pill involves a communication system that sends the result to a monitoring structure (i.e. the GP or the regional screening Center).

4.4.3 Users’ preference and resistance

The designers have a certain idea in mind with respect to how the user behaves, what s/he wants, how s/he looks. These assumptions shape the technology.

⁶⁸ See the website:

http://www.preventiekompas.nl/HomepageRedesign.aspx?menu_id=9&page_id=136

⁶⁹ In fact the Prevention Compass motto is: “knowing, measuring, doing” (weten, meten, doen)

However, these assumptions can be misleading, failing to address the real users, who differ with regard to their fears, preferences, education, interests and values. In order to assess the plausibility of the expectations of the user's acceptance of the artifact, the fictive script inscribed in the design can be compared with the user's preferences and interests. In this way, deviance of the user's behavior from the expected one and resistance to the program of action inscribed in the pill can be taken into account.

Although agreeing in principle with the importance of prevention, the general practitioner and the gastroenterologist responded to the "home-kit" vision by describing some aspects of the current practice of colorectal cancer diagnostics that cannot be reduced to a self-test. In the view of the gastroenterologist, the practice of making a diagnosis is much more than just performing a test:

Making a differential diagnosis is not different from making a hypothesis. When you make a hypothesis, you take a few things into account. One is the *probability* of your diagnosis: the more probable, the higher you put it on the list of the differential diagnoses. The second is the clinical *relevance* of the diagnosis: if a physical condition is totally irrelevant, you put it low on your differential diagnosis. And the third is the *ease* and *certainty* with which you can test it. So sometimes you can have a wonderful option in your hypothesis, but if you don't have any test to prove or disprove it, or if it is a very difficult test, it is not very useful. So if you take this into account, and you go back to the patient with blood in the stool, a differential diagnosis of colorectal cancer, if the patient is 60 years and has blood in the stool is quite *probable*. It is also *relevant* to the patient to prove or disprove. But the blood in the stool test is not a good test for the symptomatic patient: the test may be negative, but there is still a chance that the diagnosis is correct. So then the test doesn't help in that setting. A doctor seeing a patient with symptoms should not test the stool. What he can do is test for anemia, and do some type of imaging of the colon with which you can truly corroborate or exclude the diagnosis of cancer. (*My emphasis*)

When a patient walks into the doctor's office with some symptoms, a screening test is not an option. "The history of a patient says much more than any test", echoes the general practitioner. The verbal interaction between the doctor and the patient plays a central role at this stage: the patient's family history, the description of the symptoms, and observation help the doctor in choosing one diagnostic tool over another. Moreover, it helps the GP to guide the patient in making decisions. For example, in the colonoscopy room where I carried out participant observation, the gastroenterologist carefully read the history reported by the GP, and based on that history, made decisions related to how to perform the colonoscopy (whether to use anesthetics, the desired width of the scope, etc). The NIPED-world seems to conflict with the gastroenterologist and general practitioner's world.

Furthermore, the NanoPil developers-world conceives this device as a more user-friendly alternative to the existing screening test; this is because the Nanopil does not require people to collect a sample of their own stool in order to send it to the lab. In this way, technology developers assume that the lack of early screening

is due to people's unwillingness to collect their stool sample. However, the GP and the patient advocate do not view the stool collection as a problem; rather they point to the lack of awareness on the part of the Dutch population regarding the risks and symptoms of colon rectal cancer as a reason for late intervention.

Furthermore, the literature shows that the bowel preparation preceding the examination is often considered to be the most burdensome and unpleasant aspect of the colonoscopy (Ristvedt et al. 2003; van Gelder et al 2004, Beebe et al 2007). The laxative has the purpose of clearing the intestine of feces in order to allow good visibility of the intestine walls during the endoscopy. Patients complain that the consumption of the laxative compels them to spend the day before the colonoscopy ingesting 5 liters of liquid laxative and "sitting on the WC". A special diet, poor in fibers, has to be ingested and the treatment causes nausea and sickness. A similar "bowel preparation" condition is embedded in the NP design, in order for the pill to freely move through the intestine and sample intestinal fluid. The user is expected to ingest a laxative and prepare the bowel before swallowing the pill. In this respect, the pill does not offer an easier and more user-friendly alternative to the FOBT since it requires the user to ingest the laxative.

Finally, the patient advocate and the general practitioner emphasize new aspects. Mistakes, fears, and "irrational" behaviors play a central role in the current diagnostic practice and are even more noticeable in the case of self-tests. The GP, for example, remarks that self-tests need to be extremely clear and easy to interpret. This remark is based on his experience with people's interpretation of the pregnancy self-test: although the result notification seems to be rather straightforward (+/-), users are often unable to interpret it correctly.

4.5 Conclusions

Expectations on emerging technologies are projections of a future world in which the new artifact is described within a social context. Technology developers tend to sketch coherent worlds in which the artifact, user groups and other stakeholders entertain simple and clear relationships. Assessing the plausibility of expectations about use is both a critical and a constructive activity. By discussing the envisioned technology with other actors, it is possible to identify where developers' visions collide with other actors' views and beliefs. But it also adds new perspectives and thickens the initial visions by exploring how current practices might change and adapt, in addition to new problems that might surface.

The concepts of script and actor-world suggest that technology developers hold some assumptions about the prospective users and other actors around a

certain innovation. As the fictive script analysis suggests, these constructions can be analyzed by shifting from one actor-world to another in order to map the displacement between them. This can be done through involving different potential social actors and users in future-oriented experiments and sketching the context of use, as well as the roles of these different actors; these conceptual tools have guided my research design.

Following the construction of Nanopil developers-worlds, I emphasized that some entities in the techno-scientists' world need more elaboration through the exploration of other actor-world. Additional details on a social practice, like the population-screening program, exclude some visions of the Nanopil and make others more plausible. When compared with the world of the National Institute for Public Health and the Environment (RIVM), the expectation of the use of the Nanopil within the context of a population-screening program is plausible only if the Nanopil features a system that allows the screening Centre to monitor the result. The scenario of the Blue bolus pill is not consistent with that of the population screening program. The assessment of expectations on the Nanopil has also highlighted the potential for resistance and controversies, as for example in the case of general practitioners or screenees required to ingest liquid laxative.

The analysis of the expectations of the Nanopil followed the double strategy of thickening and situating. Details were added to the picture, by exploring the situated perspective of actors in the practice in which the emerging technology is expected to operate. Furthermore, the assessment of the plausibility of expectations of the Nanopil was situated in the perspective(s) and practice(s) of the actors I interviewed. As pointed out, these actors are not neutral judges, but "stakeholders": their interests played a role in their judgment of the plausibility of expectations on the Nanopil. Therefore, their assessment and description should not be taken at face value. I have not engaged in the assessment of the plausibility of these views; rather my interest was in positioning one world in relation to the other.

One final remark: it is only upon leaving Paris for Africa – where she is confronted with the actual use of the artifact – that the significance of some technical components occurs to Akrich. "It was only in the confrontation between the real user and the projected user that the importance of such items (...) came to light" (1992, 210). I share this observation: it was only following the encounter with the current cancer diagnostic practice and the expectations of potential users that some "technical" components of the Nanopil stood out. For example, only during the interview with the RIVM researcher did I understand the extent to which the choice between a radio-signaling and a Blue-Bolus system affects the potential context of use. The comparison between the expectations of the Nanopil's developers within the laboratory and the expectations of other actors highlighted the significance of some "technical components" and design choices. In

this sense, the story narrated in the previous chapter was written *a posteriori*, following my interviews with other actors and potential users. Similarly, the story narrated in this chapter aims to address the question of the plausibility of the visions on the desirability of the Nanopil. The next chapter will explain how this can be done.

5

The good in the pill

Assessing the plausibility of visions of desirable worlds

There is no one best way to paint the Virgin; nor there is one best way to build a dynamo. Inexperienced engineers and laymen err in assuming that there is an ideal dynamo toward which the design community Whiggishly gropes. Technology should be appropriate for time and place; this does not necessary mean that it be small and beautiful. (Hughes, 1987: 68)

This chapter elaborates how the analyses provided in Chapters Three & Four contribute to assessing the plausibility of the normative visions that an emerging technology will bring about a desirable world. § 5.1 introduces the expectations of desirability in the case of the Nanopil and reformulates the questions outlined in Chapter Two. The plausibility of the expectations of the Nanopil are assessed on three levels. § 5.2 highlights the importance of assessing the plausibility of the expectation that an emerging technological *artifact* will realize specific values. § 5.3 expands on the importance of assessing the plausibility of the expectation that these values are *desirable for society*. In § 5.4 I discuss another aspect of these expectations that needs to be assessed, namely the *linear causal relation* between an emerging technology and a (desirable) consequence. § 5.5 concludes by highlighting the heterogeneity of expectations at three different levels s: it encourages us to distinguish artifacts, normative positions, and relations of mediations/co-production with morality rather than clustering them together in implausible scenarios.

5.1 Visions of desirable worlds

Expectations of emerging technologies describe innovative artifacts and project the way in which they will be used in a social practice to do something “good” or “desirable”:

“Doctors will be able to use the pill in five to ten years only ” says Pinedo. “But then you have something very special: early diagnosis without the use of stool samples. With the signals revealing the results, physicians may determine the need for a colonoscopy. Patients no longer need to stand with a jar of stool in the corridor of the hospital laboratory for an initial test. If you can determine whether people have a high risk of colon cancer with a pill, then affordable and less burdensome colon cancer screening is possible.” (Melchior 2009, *my translation*)

Expectations on the Nanopil address the question of “why the Nanopil is desirable (or good) for individuals and society”. These expectations describe the “good” in the pill: how the Nanopil provides a desirable means to address a social need, that is, detecting colorectal cancer at an early stage.

Dr Pinedo, oncologist and father of the Nanopil, explains in an interview⁷⁰ that the need for a Nanopil occurred to him during his observation of existing screening practices. In particular, he refers to the decrease in mortality rates for cervical and breast cancer following the invention of reliable screening tests and their introduction to a large target population. This observation reinforced Pinedo’s idea that more screening tests of this sort are needed to intervene earlier and to have greater chances of success of eradicating a growing tumor. In order to be effective, these screening tests have to be reliable in determining the risk of cancer, but they also have to be affordable in order to be broadly distributed in society. Finally, in order to be successful, screening practices must be friendly for the patient and not taxing⁷¹.

Dr Pinedo emphasizes that, in the case of screening, the people who use the test should not be viewed as patients, since they are monitoring their health without experiencing any symptoms. The autonomy of these asymptomatic clients is a priority in the oncologist’s opinion. The test should also be easily incorporated into clients’ normal routine and should respect their cultural background. This

⁷⁰ From the interview I conducted on April 12, 2010.

⁷¹ See also a previously quoted expectation by Prof van den Berg, the head of the BIOS group developing the Nanopil: “Colonic cancer is one of the most common cancers in people over the age of 50. The Dutch Health Board has already advised endoscopic or colonoscopic screening for people in this age group. But this is a painful and uncomfortable experience. What is more, it presents a logistical nightmare. And nothing is found in 95% of cases. What we need is a simple first-line test. The only alternative at present is a faeces test, but eventually, a nano-pill will provide a much more patient-friendly alternative”. (Berg 2009)

might imply that one has to adapt the screening practice to the local culture. For example, Dr Pinedo describes the good practice employed in the introduction of mammographic screening in South American villages. In order to come to terms with the local culture of shame around such an invasive test requiring women to have their breasts monitored, the screening practice was organized via a specially-arranged transportation system. By driving the “screenees” to other villages in which their anonymity was preserved, the screenees were spared the “shame” of being exposed to the prying eyes of the local community. As in the case of breast cancer screening, there is also a kind of taboo to be circumvented in the case of colorectal cancer screening.

As the nanotechnologist Prof van den Berg explains, the available methods for detecting colorectal cancer are painful and expensive, like in the case of endoscopic investigations. When simple screening tests are available, like the Fecal Occult Blood Test (FOBT), they are not user friendly. The latter is uncomfortable because it requires the screenee to collect a stool sample and to send it to the laboratory to check for blood traces: this is “not the best hobby” as the oncologist remarks, or, as a scientist exclaims, it is “a medieval practice!”⁷². The Nanopil proposes a “technological” solution to this discomfort. The promise is therefore to provide the users (both the screenee and the GP) with a means to effectively monitor bowel condition in an easy and comfortable manner. The NP offers a way for people to monitor their health and to detect abnormal statuses at a very early stage since it tests for the molecular causes of cancer and it is a “clean”, non-“medieval”, modern way of testing and receiving results.

The promises of Nanopil emphasize cost-effectiveness, the increased chance of saving human lives, the increased autonomy of the user, and a decrease in discomfort as valuable expected outcomes of the introduction of the Nanopil in the colorectal cancer screening and diagnostic practice. In chapter Two, I pointed out the strategic and rhetorical character of expectations. Mobilizing values, placing emphasis on needs and proposing desirable futures prompt public support and interest around a new technology. However, I have also shown that technoscientific expectations guide societal decisions in the direction of envisioned desirable worlds. In the visions of the Nanopil, for example, a linear link is made between the technology, the clinical practice and the attainment of these desirable outcomes. The Nanopil is expected to be a means to (better) promote and protect some values, the desirability of which is taken for granted in Dutch society. In chapter Two, I gave a *prima facie* argument that *in order to assess the desirability* of emerging technologies it is not enough to articulate the normative content of these visions. Rather, *the plausibility of these visions has to be assessed*. I said that three questions have to be addressed:

⁷² From an interview I conducted on April 15, 2010.

1. How likely will the expected *artifact* promote the expected values?
2. To what extent are the promised values *desirable for society*?
3. how likely is that a technology will *instrumentally* bring about a desirable consequence?

To address these questions, I have critically analyzed the expectations of the technological artifact as well as the expectations of its context of use, respectively in Chapters Three and Four. On the basis of these analyses, I address the questions about the plausibility of the Nanopil visions: whether the artifact is likely to realize the claimed values (§ 5.2), whether values are indeed considered valuable by everybody (§ 5.3) and, which other values might be affected.

5.2 Different expected artifacts and different values

In his book *Alternative modernity*, Andrew Feenberg refers to technologies as “meaningful objects” (1995: 155). He explains that technologies have two types of meaning: 1) a function that the technology is supposed to perform 2) and some connotations that “associate technical objects with other aspects of social life independent of function” (*Ibidem*). For example, the automobile has a function of transportation and some connotation about the social status of the owner. Feenberg argues that, in new technologies that are still emerging, the function and connotations are not clearly distinguished and a potential technological object might have a variety of functions and connotations. Referring to a classic example in the Social Constructivist approach to technologies (Pinch and Bijker 1984), he explains how, in the early development of the bicycle, different designs coexisted depending on the connotation that users attributed to bicycling. In some cases bicycling was considered a competitive sport and therefore the “velocity” function was privileged. In other cases, bicycling was viewed as a means of transportation and therefore the “safety” function was the priority. These two bicycle designs are functionally and connotatively different. According to Feenberg, the “ambiguities in the definition of a new technology must be resolved through technical development itself” (1995: 156). In the process of technical development, one design choice will prevail and the struggle of meaning will be covered up (the process described by Latour 1987 as technological “closure”⁷³). Such a process of “closure” is consolidated in a “technical code”. For Feenberg, “technical codes define the object in strictly technical terms in accordance with the most general

⁷³ See also Chapter Three.

social meanings it has acquired" (*ibidem*). However, these codes are the result of some social struggles or negotiations, and the meanings, in terms of the functions and connotations that they convey, reflect the ideology of one social party⁷⁴. For example, in the case of the bicycle, the accepted morality at the time, according to which women dresses were long and fully covering, prevented them from safely biking the faster bicycle with a wider front wheel. In this sense, current morality has a role in the consolidation of a technical code.

Also in the case of the Nanopil two alternative technical codes can be pointed out. Although "the" Nanopil appears to be a well-defined artifact in the public promises, the emerging state of this technology blurs this definition. As I explained in Chapter Three, techno-scientists' expectations on *one* emerging technology might in fact entail a *number* of different competing designs. For example, developers propose two technical alternatives for how the user can be informed of the result of the test. According to the first one, in the event that an abnormal DNA state is detected in the intestinal fluid, the pill releases a blue dye into the bowel, which is visible in the users' stool, once they evacuate. According to the second alternative, the pill sends a numeric result via radio signal to an external device, namely a mobile phone or a computer. As explained in Chapter Four, the expected use of the pill within a population-screening program for colorectal cancer excludes the blue-dye system, because the result has to be supervised by a care provider in a screening context. If the developers opt for the blue dye solution, it is unlikely that NP will be considered to be an appropriate test for a population screening program by the Ministry or Health Council. In addition, alternative technical options might not only influence the expected social context of use of a future technology, but also its moral meaning.

The alternative technical codes that surround expectations on the Nanopil assume different functions of the device. The apparatus can function as a self-test, the result of which is manifested to the user who observes the (blue) colored stool. Otherwise, it can function as a screening device controlled by a medical professional who receives the numeric result of the test on an electronic device, such as a computer or tablet. These different technical codes and functions also carry different "moral" connotations. To clarify this, let's look at how the connotation of the "moral status" of the expected users of the Nanopil differs in each of the two functions attached to the device. In the case that the Nanopil has a self-test function, the users will voluntarily and periodically test themselves in the comfort of their own homes. In expecting so, users are understood by technology developers as human beings who value prevention and are able to control their health by themselves. They consider health monitoring to be important and are

⁷⁴ This analysis brings Feenberg to draw attention on the fact that the ideologies and power struggles are settled down in the consolidation of a certain technological design.

willing to monitor their health. They are also physically, intellectually and economically able to monitor their health. The Nanopil is expected to empower these users' autonomy because it allows them to decide if, when, where and (partially) how to monitor their health condition.

By contrast, if the Nanopil is expected to function as a screening device, users will be part of a control-system. In this system, the public healthcare organizations will take care of them by offering them the opportunity of undergoing a colorectal cancer test, depending on their demographic or their risk-profile. The public healthcare system motivates users to test themselves by providing them with a comfortable, easy, and "clean"⁷⁵ test. In this case, it is not the autonomy of the test's user from the external care provider that is emphasized. Rather, the efficiency and the quality of the care process are privileged. The quality of the care process is strengthened through augmented control over the result by the medical practitioner via a tele-care system, that is, a system that can provide care in the physical absence of care personnel (for example via a computer).

Claims about the desirability of the Nanopil mobilize values such as "autonomy", "efficiency" and "comfort". However, these values are promoted differently in alternative technical codes. As a self-monitoring test, the Nanopil is primarily expected to promote the user's autonomy in dealing with her health decisions. As a screening device, the Nanopil is primarily expected to improve the quality of care in colorectal cancer clinical practice by providing an efficient system for the early diagnosis of colorectal cancer. These two technical codes assumed in expectations on the Nanopil embed different conceptions of what is "good" care.

I use a broad definition of "value" as a "judgment of an individual or a certain community about what is important" in life or more specifically in a specific social practice. The comfort of a medical examination is a value in the sense that it is considered as important, good or worth to strive for within a certain community, society, practice. It can be claimed that patients' privacy, screenees' autonomy, the robustness of diagnoses, and patients' care are all interrelated values in the current practice of diagnosis of colorectal cancer. However, if one looks at how these values are inscribed in different technical codes, these values may conflict. For example, if the Nanopil is used for screening purposes, the result of the home-test has to be monitored. This can be done via a radio-signaling system. During a public debate on the Nanopil⁷⁶ and a follow-up interview⁷⁷, an advocate of the

⁷⁵ NP is supposed to be a "clean" test as opposed to the Fecal Occult Blood Test which requires the user to collect a stool sample and send it to the laboratory for analysis.

⁷⁶ Debat Nanotopia: <http://www.lux-nijmegen.nl/debat/nieuws/2010/06/10/goed-idee-niet-de-nanopil-gaat-er-komen-dat-zeker>

⁷⁷ I conducted this interview on July, 1 2010

Dutch organization for patients with cancer in the intestinal tract⁷⁸ voiced her fear that such a system endangers the patient's privacy. Therefore, the home-screening test is expected to enhance the *autonomy* of users who can self-administer the test, but it does not necessarily protect users' *privacy*. Giving priority to the value of autonomy might also endanger the *effectiveness* of the screening. The GP makes this point: the remoteness of the test's practice does not allow the GP to face the patient in person during the delivery of the result, possibly leading to undesirable misunderstandings. If radio-signaling systems are avoided in order to secure the user's *privacy*, the users are the only actors in the healthcare chain who know the result of the test. Their privacy is promoted, in addition to their autonomy, because they can decide to take no action in the event of a positive result (abnormality detected). However, the *efficiency* of the screening system is diminished because a control-system is missing. Depending on the functions and technical codes that will stabilize, different values for the colorectal cancer diagnostic practice will be privileged.

The idea of morality as a "force field" (Swierstra 2009) can help explain this value-tension in different technical codes. In the force field of morality, "conflicting norms and values compete for hegemony". Similarly, the values of efficiency and comfort of a tele-care system compete with the value of privacy of the patient. In order to use the Nanopil as an efficient screening system for colorectal cancer, the patient's private data has to be sent via radio-signal to an external receiver and from there to a communication network of which the GP is part. Privacy, together with the value of interpersonal relations in care, are played down while the value of efficiency gains more force.

In this sense, paraphrasing Feenberg, we can say that expectations on emerging technologies are ambiguous with respect to their moral connotation. Eventually, some technological closure occurs and one moral connotation dominates the others. It is unlikely that the Nanopill will realize all the promised values equally. Some technical codes will prevail and with them some values will be privileged at the expense of others. In order to reflect on the desirability of emerging technologies⁷⁹, it is important to make explicit and articulate the moral content of expectations at a stage in which the technology is still fluid and a technical code has yet to prevail. I have done this by singling out the alternative expected designs of "one" technology. Instead of reflecting on the Nanopil and its desirability, different artifacts (NP1, NP2, NP3,) are distinguished in these expectations. The moral content of these different expectations is then articulated with reference to the technology's expected context of use and function. The assessment of the plausibility of expectations of emerging technologies that I

⁷⁸ Stichting voor patiënten met kanker aan het spijsverteringskanaal (<http://www.spks.nfk.nl/>).

⁷⁹ This is what I referred to as Desirability-Question (or D-Question) in Chapter Two.

propose diversifies expectations on the artifact rather than clustering them together under an empty “black-box”.

5.3 Plurality of values among actors

Values, interests and ideas of what constitutes a desirable world vary among social actors. The case of the high-wheel bicycle once more provides an illustration of this point.

The using practice of the social group of “young men of means and nerve,” that is, racing, showing off and impressing the ladies, constituted the macho machine, whereas the using practice of the social groups of women and elderly men, that is, touring, falling off, and “breaking limbs and bones”, constituted the unsafe machine, the macho machine led to a design tradition with larger wheel radius, and the unsafe machine gave rise to a variety of designs with, for examples, smaller wheels, backward saddle, or smaller wheel in front. Thus different using practices may bear on the design of artifacts, even though they are elements of technological frames of nonengineers. (Bijker, 1987: 172)

Members of a social group share one meaning of the artifact (or, “technological frame”). This meaning varies from group to group according to their interest, their role and value system. As pointed out within the Vision Assessment approach⁸⁰, expectations on the future depict “the world described by someone who is asked why particular technologies are desirable” (Reuzel and der Wilt, 2000: 53). In this sense, visions “reflect the values, worldviews and deep preferences of those who hold them” (Grin and Grunwald 2000: 11). According to this approach, diverging normative perspectives of different stakeholders should be explicitly articulated, standards and criteria of merit of a technology analyzed, needs spelled out, problem definitions discussed, and “desirable final states” envisaged. This articulation is important in order to assess the plausibility that a technology will have “desirable” consequences. For whom are these consequences desirable? Diverging worldviews and normative positions of stakeholders should be articulated rather than clustered together in a supposedly homogeneous desirable future.

In addressing the case of the Nanopil, I have elicited the normative positions of different stakeholders by interviewing them and exploring their perspective around a certain social practice and the way in which the emerging technology is expected to change it⁸¹. The promises of cost-efficient, comfortable and painless screening attached to the Nanopil suggest a common social problem and a shared normative framework among actors. Different stakeholders have diverse, and

⁸⁰ The Vision Assessment approach was introduced in §2.3.

⁸¹ The design of my interviews is described in Chapter Four.

sometimes *diverging*, views of the problem that the Nanopil should address. The same diversity emerges in their judgment of the potential value and drawbacks that the Nanopil might have. For example, when asked to define the problem addressed by the Nanopil, engineers respond that colorectal cancer is usually discovered too late, with the implication of low chances of successful intervention. Their solution is to build a tool for early diagnostics of colorectal cancer in order to enable early surgical interventions with a higher chance of success. For this reason, the Nanopil is presented in scientists' expectations as a screening device that smoothenes a cumbersome, time - consuming and expensive diagnostic practice based on colonoscopy. This novel technology is presented as a more reliable test that can detect the subject's susceptibility of developing colorectal cancer. Furthermore, as the developers explain, the Nanopil is a more user-friendly alternative that does not require people to collect a sample of their own stool in order to send it to the lab. Implicit in this perspective is the view that part of the problem of late surgical intervention rests on the unwillingness of people to collect their stool samples for early screening. However, from my interviews⁸² it emerged that the General Practitioner and the patient organization identify different types of problems that have to be addressed in the practice around colorectal cancer. According to these actors, the reason for late intervention in colorectal cancer diagnosis stems from the lack of awareness of the Dutch population regarding the risks and symptoms of colorectal cancer. From their perspective, a desirable solution to this problem involves an awareness campaign on colorectal cancer. Differences in the problem definition among stakeholders entail differences in the way in which the problem is addressed. The desirability of the Nanopil as a solution to problems in the diagnostics of colorectal cancer is less straightforward when different actors elaborate on what they think to be the cause of problem(s) with a certain practice.

This diversity of visions appears also when stakeholders are asked to identify possible future concerns around the Nanopil⁸³. For example, the gastroenterologist imagines a limited use of the pill, because it does not enable a discriminative diagnosis; such a diagnosis is necessary when a symptomatic patient presents him/ herself. The GP is concerned about the fact that the Nanopil allows users to test themselves in the private space of their home without the assistance of a care practitioner. The patient organization fears that people's privacy is endangered when the result of the test is sent to the user's or her doctor's mobile device. These visions on the concerns around the Nanopil are related to different values and depend on the stakeholders' position and epistemological and practical access to the colorectal cancer diagnostic practice.

⁸² See § 4.3.3.

⁸³ *Ibidem*.

When collecting the visions of different stakeholders on an emerging technology, we come across a richer variety of views on what is valuable or not valuable.

Furthermore, the judgments on the value of the technology might conflict with one with another. For example, the developers express their enthusiasm for the possibility of communicating the result of the sample analysis from the pill to an external device via radio-signal because this makes the development of the device easier and the whole system faster. However, an advocate from the patient organization is wary of such a system in which the result is sent to a mobile device by radio signaling, as it poses a possible threat to the patient's privacy. Even though engineers explain that this concern is irrational and unfounded because the system can be secured, for the patient organization, the privacy of the patient needs to be safeguarded even at the expense of the efficiency of the system. Matters of importance for patient advocates differ from those of engineers. For the former, privacy is more important than efficiency. This conflict among values at stake in visions of the Nanopil emerges when comparing expectations of different stakeholders. Explicit or implicit conflicts of values about the desirability of a specific emerging technology can be traced at an early stage in the expectations of current and future stakeholders

In contrast with the general claims of the Nanopil promoters' about desirability, the visions of different stakeholders on the technology at stake are much more diverse and sometimes in conflict. In order to assess the desirability of emerging technologies, these divergences in visions have to be made explicit and discussed when investigating the desirability of an emerging technology. Instead of taking the general claim of the desirability of the practice introduced by the Nanopil, I have emphasised diverging problem definitions, concerns and values of different social actors. The assessment of the plausibility of expectations that I propose broadens the space for alternative heterogeneous views, rather than privileging (even if in a critical way) a dominant, supposedly homogeneous perspective.

5.4 Impacts of technologies and the moral landscape

Thus far, I have argued that assessing the plausibility of expectations on the desirability of emerging technologies implies disentangling their unifying discourse. In this way, general claims on desirable futures can be contextualized and specified, while additional aspects and moral connotations are highlighted. The previous sections have drawn attention to how such disentanglement can be

carried out by differentiating the variety of moral connotations that are muddled in expectations on the value of the technology, and by articulating the plurality of normative visions among stakeholders that remain hidden in general claims of apparently uncontested desirability. In this section, I contend that expectations on emerging technologies have to be assessed also with respect to the expected linear instrumental relation between the technology and its desirable consequences.

An example from history of technology will clarify this point. In the context of an analysis of historical lessons on scenarios of technological futures, Geels and Smits (2000) examine expectations about the social consequences of ICT tools on teleworking. The two authors explain that there is a gap between the expected and the actual consequences of these technologies: it was only when society was confronted with practical problems involving real users and real contexts that the speculative futures proved not to work overly well.

For example, employees that are willing to try tele-working at home find that their houses lack space to set up an ergonomically acceptable workplace. Employees discover that they miss the informal and social interactions with their colleagues. The fading distinction between work and private life results in psychological problems in the family. Employees feel that tele-working reduces their career opportunities, as they have less contact with their superiors. On the other hand, managers feel that they have less control over their employees, as the latter are working out of sight (Geels and Smit 2000: 875-876)

The authors conclude that teleworking is not simply a replacement of an existing practice of localized working. On the contrary, teleworking introduces new practices that re-adjust and change the old practices. The reality of the “social-embedding” of teleworking is more nuanced than the way in which it is positioned when the expectations were emerging. Teleworking does not simply enable employees to work from home; moreover, it does not simply reduce costs for employers. Multiple elements have an impact on the success of teleworking: the aspects employees “miss” of the previous practice; the way in which they conceptualize the difference between private and working life; and the feelings of managers “.. However, this particular impact of ICT on working practices was not taken into account in the early days. Expectations on teleworking were flawed by a linear and instrumental conception according to which technology is a means to a (desirable) end.

The discourses on the desirability of the Nanopil articulated in § 5.1 suggest that this device offers a solution to the problem of effective and comfortable/clean monitoring. However, as in the case of ICT, one can expect that, in addition to comprising a tool with which to improve the current state of affairs, the Nanopil creates *new* meanings and practices. Therefore, in order to assess the plausibility of expectations of desirability of emerging technologies, it is important to take into account this broader impact of the technology in different areas of life. The notion

of “mediation”, already introduced in Chapter Two, provides a conceptual tool to address the question of the plausibility of the expected relations between emerging technologies and desirable consequences.

5.4.1 Mediation

In order to explain how artifacts influence and determine human epistemologies and practices, Peter-Paul Verbeek explores the concept of “mediation” within the post-phenomenological tradition, drawing on Don Ihde (2005). Technologies “mediate” our relationship with the world in two respects. First, let’s consider imaging instruments introduced to the obstetrician’s room. By allowing parents to see the fetus with greater precision, these technologies alter the way the world is present for future parents. The images of the fetus invite parents to perceive, experience and understand the world in a different way than a non-technologically-mediated perception would allow. This is a form of “hermeneutic” mediation. Indeed, new ways of perceiving and experiencing involve “opening” up the world in a different way and changing the universe of meaning; for example, by being able to see the fetus and its human resemblance, prospective patients may attach a new meaning to it. Re-articulation of meanings and interpretations of reality also affect the values attached to aspects of that reality. For example, being able to see the human figure in a fetus might influence the importance that parents attribute to it or the moral status that they ascribe to it.

Building on script theory⁸⁴, Verbeek emphasizes a second type of technological “mediation” that he refers to as “pragmatic”. The technology has a program of action inscribed in it. To use the “script theory” vocabulary, “technical objects define a framework of action together with the actors and the space in which they are supposed to act” (Akrich 1992: 208). In this space, roles and responsibilities are allocated to actors in a way that re-designs the previous practice. The moral connotation of this relation emerges in the delegation of moral actions to the technology. The alarm system integrated in modern cars is activated when the seat belt is not buckled. The artifact’s design mediates human actions in the world in such a way that some actions will be allowed and others forbidden. In this sense, the artifact prescribes, obliges, permits, prohibits and disciplines users’ behavior. This is what Akrich defines as the “moral” content of objects (*ibidem*: 219).

The expectation that the Nanopil is a tool to improve screening of colorectal cancer reflects an instrumentalist view that assumes a linear relation between a technology and some consequences. Assessing the plausibility of these expectations implies bringing attention to this instrumentalist misconception and emphasizing the expected mediating character of emerging technologies. In order

⁸⁴ Script theory has been already introduced in Chapter Two and Chapter Four.

to do this, I looked closely at the existing practice that the new technology is expected to “improve” (in the case of the Nanopil screening practice) and I analyzed how responsibilities and tasks are distributed, in addition to the way in which knowledge is gained and interpreted. Then, I considered the fictive scripts of the Nanopil developed in the preceding analyses and I explored the kinds of responsibilities, tasks and epistemic practices that are expected to be inscribed in this device. In doing so, I explored how the Nanopil might enter into a relationship with human beings, alter their perceptions of the world and themselves, revise the meanings and values related to them, distribute roles among stakeholders, and re-distribute moral responsibility among actors.

The practice of screening

The importance of monitoring oneself is not an emerging practice; in fact, it is quite rooted in our society; the idea that our body manifests some signs that inform us about our health condition is not new to us. My grandmother learned it from her mother and she is still worried when my cheeks look rather pale or there are white stains on my nails. My grandmother also knows that if there is blood in her stool matter, there is something wrong going on in her body and she should contact the doctor. The practice of observing abnormal signs appearing on our body involves noticing something that should not be present. . This practice can involve routine self-checking and relates to some feeling of repugnance on the realization of signs of decay on our body: we see pimples, blood, cuts, leakages or crusts, we sense bumps or nodes or we feel pain or tingling.

This routine self-checking differs however from systematic and scientifically informed self-monitoring. When women are instructed to palpate their breasts as routine self-monitoring for breast cancer, they are taught how to *look for* eventual nodes. Nodes do not appear on the body; rather women are asked to search for indications that something might be wrong with their health. The presence of blood in the stool, a change in bowel habits, diarrhea, constipation or a feeling that the bowel does not empty completely, abdominal discomfort, smaller stools than usual, and constant fatigue are symptoms of colorectal cancer⁸⁵ which a GP might ask patients to investigate in a daily practice of self-monitoring.

Tests like the Fecal Occult Blood Test are similar to breast palpation in the sense that the users are asked to interact with their body (or a product of it). However, these tests differ: while the subject of breast palpation can experience the problem herself by sensing a node under her fingertips, the subject of the FOBT does not have direct experience of the problem. Her interaction with her body (or its product) ends with the act of collecting the sample. Subsequently, the responsibility of monitoring is transferred to the lab and eventually to the GP who

⁸⁵ See http://www.testsymptomsathome.com/mtl01_colon_facts.asp.

communicates the result. In this practice of monitoring, the subject is detached from the experience of her health condition.

The Nanopil: Allocating actions and responsibilities

The Nanopil is a form of “mediation” between the screening subjects and their experience of their health condition. As I explain in the following section, this mediation is both “pragmatic” and “hermeneutic”. First, the Nanopil mediates the actions of the monitoring subject by discouraging or inhibiting actions in which the subject has to pay attention to her own health condition. The discourses about the Nanopil propose a “comfort trend”, emphasizing the desirability of a test that is acceptable, easy and patient-friendly. By being able to test yourself in the comfort of your own home, whenever you want, and by freeing the user from being dependent on laboratories for results, the Nanopil is expected to fulfill this promise. Furthermore, this device is presented as a clean modern test that saves the user from the unpleasant task of sampling her feces.

These ideas are inscribed in the Nanopil’s design. The miniaturization of the analyzing platform and its integration into a capsule allows the user to ingest it. The manual collection of samples becomes superfluous, since the pill gathers the sample and analyzes it from within. In this sense, the pill takes care of the whole monitoring process. The screenees are left with information on their mobile phones rather than having to involve themselves in an active and unpleasant practice. The screenees do not have to move and touch their body as in breast or testicular cancer self-screening; they are relieved from the task of peering at their skin to map new and abnormal moles; and they do not have to bend over the toilet to collect feces samples. The technology is expected to liberate people from the discomfort of monitoring, the distaste of dealing with their body, and the embarrassment of describing repugnant signs and symptoms to their GP. The pill liberates users from this awkward link with their diseased body.

However, the NP can also be expected to allocate some tasks to the users. This practice of self-monitoring requires the screenee to perform some tasks. In contrast to the FOBT, the Nanopil does not require the user to interact with her stool matter, to sample it and send it to the lab. However, the user is expected to perform other tasks, like ingesting a laxative before taking the pill. This task is inscribed in an artifact, since one of the main conditions for the pill to work is the ingestion of a laxative to clear up the bowel and to allow the pill to traverse it. Moreover, depending on the interface chosen to communicate results to the user, the user is either required to put on a belt and receive a text on her mobile phone or to look at the color of the stool. Such a test requires strong self-discipline and clashes with some standards of wellbeing and user-friendliness that the user might have.

The user has to perform some tasks, but this work remains “invisible” (Star 1991; Oudshoorn 2011) in the expectations of the Nanopil. The NP does not simply improve a current practice, but creates a new practice⁸⁶. Within this new practice, responsibilities are re-distributed among actors and technologies. For example, adequate performance of the preparatory tasks prior to ingestion of the capsule becomes the user’s responsibility rather than the responsibility of the medical personnel or the device itself. The adequacy of the sample collection is a responsibility of the pill (or its manufacturer).

The Nanopil: Changing meanings and epistemic responsibility

The NP also “mediates” in the same way a thermometer would do. Reading off the pill is like reading off a thermometer in the sense that the device tells something about ourselves without resulting in a direct sensation. The idea that the pill will be better than other available screening devices (excluding the colonoscopy) is grounded on the promise of molecular diagnostics. Recent trends in molecular biology support the view that self-monitoring, such as “peering into the toilet”, is not enough to detect early disease stages: there are some phenomena that cannot be observed by the naked-eye. A currently available screening device as the Fecal Occult Blood Test (FOBT) detects the presence of blood in the feces that is hidden (“occult”) to human beings, but visible when a sample of stool matter is analyzed in the lab. The Nanopil brings this observation to a new level of molecular investigation. By detecting molecular markers in the intestinal liquor, the Nanopil seeks a different type of “sign” than the FOBT does. The latter detects the presence of blood in the feces. This could be interpreted as a sign of the presence of a tumor that causes the intestinal walls to bleed. The FOBT provides information about a disease in a stage that might be already advanced. Furthermore, the presence of occult blood in the stool could also be a sign of something else, for example the inflammation of anal veins (hemorrhoids). Finally, the absence of blood does not necessarily indicate the absence of a tumor: indeed, the tumor might be growing but not bleeding. The Nanopil provides information that differs from that of the FOBT; it provides information about a cancer that does not yet exist, but has the molecular triggering conditions that can lead to its development. In fact, the pill detects an abnormal status before any (visible or occult) symptom occurs. By analyzing the molecular mechanisms that underlie the disease, the pill enables detection of the disease at a much earlier stage, when it is still invisible. In this way, a therapeutic or surgical intervention can take place at an even earlier stage, increasing the chances of survival and reducing health care costs.

⁸⁶ See also Annemarie Mol’s analysis of the role of the blood sugar measurer in changing self-monitoring practices of diabetes patient (Mol 2000).

Molecular knowledge is considered to be superior, because it is more accurate than the behavioral knowledge; it offers a means of returning to the subcellular, molecular level⁸⁷, a level that is expected to be more informative. Our visible body is less informative than our invisible cells according to molecular medicine. It contains less information about ourselves, or it gives us information at a stage at which we cannot intervene with the same efficiency. "The pill knows you best", better than you know yourself even.

Thus, on one hand, the pill is presented as desirable within a "monitoring" discourse in which health monitoring is presented as a moral responsibility towards ourselves and society at large. On the other hand, trust in the pill builds on a molecular trend that indirectly implies the incompetence of the user to effectively monitor her body. The technology is presented as a more efficient way of self-monitoring that transcends our physical body; in this way, while still burdened by some practical responsibility towards ourselves, we are relieved of what we can refer to as "epistemic responsibility" (Code 1987). We are not responsible for the resulting information regarding our health condition because the device does not facilitate the collection, information, processing, and understanding of information.

The expectation that the Nanopil will make screening practices more reliable does not take these aspects into account. The Nanopil can be expected to contribute to a change in the way we self-monitor our health, in addition to the way in which we relate to our body. It has an impact on our practices of being ill, being healthy, and being concerned about our health. In this sense, the practice of self-monitoring introduced by the Nanopil affects several dimensions of our beliefs and perceptions on our personal identity and relations to others.

5.4.2 The co-production of technology and morality

By altering meanings and prescribing behaviors, the Nanopil can be expected to redistribute responsibilities among actors in a social practice. However, the Nanopil is not a direct cause of these changes, instead it is part of and reinforces ongoing "trends". Along with other technologies, the public discourse on health and early diagnosis, social infrastructures and current morals, Nanopil helps to sustain and expand, for example, trends towards monitoring, comfort, and molecularization. In this sense, new and emerging technologies interact with morality in a symmetrical way: current morality and values justify expectations on emerging technologies and are inscribed in their design, but technologies also change this morality.

⁸⁷ A similar remark is made by Nordmann (2007a) on the assumptions behind the idea of efficiency of nanomedicine.

Technologically induced moral change is more than adaptation to the new technology; it reflects deep changes in individuals' and societies' network of values, perceptions, concepts, standards, norms, and habits (Swierstra 2010). This occurs because the innovative force of new technologies creates *problematic situations* for which new normative solutions are required (Keulartz et al 2002). Take for example, organ transplantation technology.

The development of transplantation technology received important support from the optimistic belief that technological progress is an important moral value in itself. Furthermore, as soon as the technological opportunity to help people appeared on the horizon, it created the moral obligation to further pursue this technological trajectory. [...] From the moment this crucial technological innovation made it possible to help patients, the corresponding moral obligation was quickly established. But this techno-moral obligation raised new moral concerns. (Swierstra et al 2010)

On the one hand, morality is modified to adapt to the new situation, for example, the concept of "death" needs to be redefined with the development of technology for organ transplantation.. On the other hand, the technology is modified and technological solutions are sought and proposed to address the moral concerns that other technologies have created. For example, when transplantation technologies created the possibility of saving many people's lives, they also created the moral concern of extracting living organs from a donor. The concept of "brain death", together with new devices to measure the brain activity, offered a solution for establishing whether a person is dead and whether it is possible to proceed with organ transplantation. However, these solutions raised new moral problems with respect to the scarcity of organs and the need for criteria for their fair distribution.

The desirability of the Nanopil is legitimized by the mobilization of values that are supposed to be shared, and non-controversial in current Dutch society: autonomy, comfort or affordability. However, as explained above, the expectations of the Nanopil assume that people can monitor their body and look for signs (markers) of disease before an individual is aware of them. Boenink (2009) has observed that molecular medicine introduces new epistemologies that reformulate the traditional concepts of "health" and "disease". New epistemologies also lead to change in normative definitions, as the meaning of "diseased" is debated in cases of reimbursement.

The expectations that NP will improve the current state of affairs in the diagnostic practice of CRC underestimate an important aspect: the meaning of the values against which the desirability of the NP is *now* defined will change over time, *also* because of the NP. Technology and morality interact at a deeper level than techno-scientists seem to expect. Assessing the plausibility of expectations on how emerging technology will achieve some desirable social goals implies a critical revision of the linear instrumental assumption on which they rest. New technologies will not have *one* desirable consequence. They will be part of more

complex practices in which epistemologies, moralities and normativity will be adjusted.

5.5 Conclusion

In order to address the question as to whether the Nanopil is a good/desirable technology, the question of the plausibility of expectations on Nanopil has to be addressed. To that end, I analyzed the expectations of the artifact (Chapter Three) and its expected context of use (Chapter Four). Building on these analyses, this chapter has shown that general claims regarding the desirability of an emerging technology draw on a superficial unifying rhetoric of supposedly shared values. These discourses on the desirability of the Nanopil implicitly or explicitly refer to some values (autonomy, care, comfort, efficiency) that the technology is supposed to promote. The Nanopil “offers a solution for a social problem”, “addresses a need” and “improves our current clinical practice”. My analysis demonstrates the ambivalence and contradictions inherent in these expectations.

Specifically, I emphasized that a plausibility assessment of the expectations that a technology will realize desirable consequences (T → D) involves:

1. distinguishing the alternative artifacts muddled in one single expectation of a certain technology and highlighting the different moral connotations of these artifacts;
2. comparing the suggested homogeneous normative vision of technoscientists with the plurality of visions among potential stakeholders and indicating potential future controversies;
3. broadening techno-scientists' expected dynamics of interaction between the technology and morality.

The kind of assessment I propose responds to the need, articulated in Chapter One, to create the conditions for an exploration of the desirability of emerging technologies that is not merely speculative. This type of assessment is based on a three-step analysis in which each step builds on the preceding one. First, the analysis of the expectations of the artifact is conducted in the situated context of the laboratory. This analysis thickens the descriptions of the artifacts. Its goal is 1) to rule out some scenarios that are not plausible given the current design process and 2) to enrich the expectations with new conditions and contexts of use that are inscribed in the artifact design. Second, the analysis of the expectations of its use is conducted by retrieving the situated perspective of social actors about the expected practice of use and comparing it with technology developers' perspective. This analysis thickens the description of the practice of use. Its goal is again 1) to rule out some scenarios of use as implausible in the current social

structure and 2) to enrich expectations with conditions and contexts of use expected by other stakeholders. The third step has been described in this chapter and involves assessing the plausibility of expectations that an emerging technology will have desirable consequences. Based on the findings of the previous analyses, this assessment rules out vaguely homogeneous and linear scenarios and points to the need to distinguish, diversify and describe the heterogeneity in expectations of emerging technologies.

The Nanopil has provided an exemplar case of expectations the plausibility of which needs to be assessed. I have elaborated on why such an analysis should be carried out and shown how it can be done. Since what I am proposing is a methodological and analytical framework, in which theories, epistemologies and methods intertwine, it is necessary to demonstrate that this framework can be applied to other cases besides the Nanopil. Thus, in the following chapter I will elaborate on how I assessed the plausibility of expectations on another emerging technology for diagnostics, namely Immunosignatures.

PART 3

Emerging technologies exist only as projections of potential futures. As a result, they are only available for ethical assessment in the form of expectations. Such expectations provide unstable ground for ethical reflection because they often play a strategic role in the innovation process, functioning as guiding visions which depict a desirable world. Although assessing these visions of desirable worlds is important for democratic deliberation on emerging technologies, such normative assessments should be underpinned by an assessment of their *plausibility*. How can the plausibility of these visions of technology-induced-desirable-futures be evaluated? To address this question, in Chapters Three to Five I presented a three-step strategy:

STEP 1. Analyzing expectations of the technical artifact. Through interviewing technology developers, reviewing scientific literature, and observing laboratory practices, I collected information about: the origins of the concept, the arguments given for its feasibility; the uncertainties and challenges faced by researchers; and the different components of the future artifact. This situating strategy enabled me to

thicken the original vague expectations on the Nanopil. This analysis allowed me to point out alternative, co-existing designs (wireless/blue bolus), to rule out some implausible scenarios on the basis of the current state of the art (the Nanopil at the grocery store), and to point out some conditions for the artifact to work (the laxative).

STEP 2. Analyzing expectations of the context of use of the emerging technology. Using interviews with a broad range of social actors and a literature review on colorectal cancer diagnostics (clinical practices and policies), I collected information about: the current practice in colon rectal cancer diagnosis and screening, the considerations of actors, and the problems they face. In this way, I was able to thicken the descriptions of the context of use. I then asked the interviewed stakeholders to comment on the plausibility of technology developers' scripts, from their situated perspectives. This detour allowed me to dismiss some scenarios as implausible, given current practices (for instance the blue Bolus pill in a national screening program), and to point out possible resistance and controversies (doctors against point of care devices and users against laxatives).

STEP 3. Assessing the plausibility of the visions of the desirable world that an emerging technology will bring about. Based on the previous analyses of the expectations of the artifact and its use, I first showed that coexisting alternative designs have *divergent* moral connotations. Then, I pointed out that ideas of what is desirable in a certain social practice varies according to *different* stakeholders. Finally, I stressed that the expected linear relation between technologies and their desirable consequences neglects the *various*, mutual and complex relations of technology and morality. This analysis allowed me to emphasize the importance of teasing out heterogeneous scenarios of emerging technologies, rather than clustering them together in vague unifying promises.

Chapters Three to Five thus explained and exemplified the plausibility approach through the case of the Nanopil. This approach was presented in Chapters One and Two as a response to the need to improve the conditions for a democratic deliberation on emerging technologies. The plausibility framework developed so far addresses this need by offering a methodology to include relevant distinctions for deliberating the desirability of emerging technologies. Therefore the plausibility framework:

- Provides a general methodology to assess expectations on emerging technologies;

- Enables the design of tools to foster a democratic discussion of the desirability of emerging technologies.

The chapters included in this part will build on these two points by putting this plausibility framework into practice. Chapter Six shows how the methodology of plausibility assessment is applied to another emerging technology (Immunosignatures). In this way, the applicability of the methodology is discussed. Chapter Seven describes two exercises aiming at fostering a discussion of the desirability of the two emerging technologies assessed in this study (the Nanopil and Immunosignatures). This chapter indicates how I built tools for these discussions using the findings of the plausibility assessments.

6

Expecting diagnostics Diagnosing expectations

The plausibility framework in use

The quest we undertake is as down to earth as it goes below surface. (John Grin 2000: 28)

Chapters 3-5 developed a framework for assessing expectations of emerging technologies, using the Nanopil as an example. In order to show the general applicability of this framework, this chapter applies it to a different case: expectations of *Immunosignatures* (ImSg). After an introduction to the promise of this technology (§ 6.1), I present my research design to address this case (§ 6.2). The following two sections analyze expectations of this technoscientific project (§ 6.3) and of its context of use (§ 6.4). Based on these analyses, § 6.5 assesses the plausibility of expectations that the ImSg will bring about desirable outcomes. A short conclusion (§ 6.6) discusses the plausibility assessment framework through a comparison of the cases of the Nanopil and Immunosignature.

6.1 Immunosignatures and the healthcare revolution

The Center for Innovations in Medicine (CIM) is one of ten research centers within the Biodesign Institute at Arizona State University (ASU) devoted to the development of “purposeful research to solve urgent societal challenges”. The Center’s mission is to develop

innovative research that attempts to transform our understanding of diseases. In many cases, innovation requires that we put aside what we think we know and start fresh.⁸⁸

The CIM co-director confidently asserts that they aim at creating “a world without patients”. This is also the motto of the spinoff company that he has founded to manufacture microchips for research on “Immunosignatures”. This is how, in a recent video from 2010, the lab director describes this technology for “harnessing the immune system’s diagnostic power”:

One of the power project in my Center is to have well people monitoring their health in a comprehensive way so that they can detect early any aberrations, anything that starts to go wrong with their health and they can do it early, and act early. We think that this is probably the most important thing that we do around the health ...economics in United States also. [...] We realized that we have to develop a system that is cheap, very simple and very comprehensive, so that well people can use it all the time. There is a very powerful aspect of that, because it means that you are always normalizing your health with respect to yourself. Right now in the biomarker world in medicine, as we live right now, we are normalizing our markers to the whole population, generally not to ourselves, because we don’t take them frequently enough to do that. So, this was our goal. We were trying to figure out how to do that and we knew that it had to be a *technological revolution* in order to be able to do these kinds of things. We finally came on this really *simple concept* and that was: you have millions, billions of antibodies in you and if those antibodies were always registering your health status and we had to look at that whole repertoire, and get a signature of your antibodies *in a simple way, we might be able to revolutionize diagnostics*. We used those same arrays with peptides that we were using to develop synthetic antibodies, and we said what happens if you put a drop of blood from somebody on there, and you wash it off and detect the antibodies? Well, it turns out that you get this signature; you get 10000 spots lighting up at different levels that basically finger-prints your antibodies. We said, may be there is a change when something goes wrong. And sure enough we have tested over 20 different diseases now. Everyone shows *its own distinctive signature*. So we can normalize to yourself and when something happens, that signature changes. The beauty of it is that *measuring antibodies is so simple*. We can literally take less than a drop of blood, put it on a little filter paper, send it through the mail, even in Phoenix in the summer, take that filter paper and measure the antibodies on it. The signature is just as good as if we had measured the blood directly. So what we envision now is a health monitoring system where people are regularly sending in [...] a little thing of saliva or a drop of blood, goes to a central place, they monitor, that information goes back to people and they can tell what the health status

⁸⁸ From the Centre for Innovation in Medicine website:
<http://www.biodesign.asu.edu/research/research-centers/innovations-in-medicine>

is. And that's the big "we are gonna go" that we are shooting for with this. What we show in this first publication is that this works very well to monitor infectious diseases, although we have other projects on cancer and Alzheimer that are going on.⁸⁹

Immunosignatures are a "technological revolution" able to transform diagnostics and improve the American healthcare system. The desirability of such a system is that it will relieve the national economy of healthcare costs – costs which are unsustainable given that technology, hygiene standards, and healthier lifestyles have prolonged life expectancy and standards of medical care. On the one hand, people live longer and this ageing population requires more medical care; on the other, new biomedical research offers new, increasingly effective, but often expensive, treatments. Frequent personal monitoring is expected to prevent people from becoming chronically sick and thus permanently expensive for society. In this context, ImSg provides a system "to have well people monitoring their health in a comprehensive way and detect early any aberrations, anything that goes wrong with their system, and act early". This is done in a "simple" way: immune system activity can be disclosed by the detection of antibodies. The user will put a drop of blood on a piece of filter paper and send it by mail to a laboratory; the laboratory will analyze it; and the information will then sent back to the user, providing her with information about her personal health condition at a certain moment in time.

The concept behind ImSg has existed at CIM since 2007, when the project was known as "Doc-in-a-box". This doctor in a box was expected to develop as a portable device, standing on the kitchen table and used to monitor people's healthcare status. Although the idea of Immunosignatures originates from the concept of "doc-in-a-box", researchers believe that the kitchen table device is a long-term vision, while "Immunosignatures" will come in the near future. The Center's co-directors founded a spin-off company to support this project and to inquire into possibilities for marketing it as a direct-to-consumer test. Small kits have been assembled with a filter paper, a lancet to prick the finger, and instructions on how to send a biological sample to the CIM in order to have personal Immunosignatures detected⁹⁰. ImSg is an emerging technology and many promises circulate about its feasibility and desirability. In Chapter One I argued that initiating an explorative reflection on the desirability of this technology at this stage is important in order to improve a process of democratic deliberation. However, because of the uncertain status of expectations, this reflection has to be anchored to solid epistemological grounds. The framework that I have developed so far provides a methodology to assess the plausibility of these expectations.

⁸⁹ Video available on <http://vimeo.com/12370576>. Transcript and *emphasis* are mine.

⁹⁰ This kit had only been used for research purposes at the time of my fieldwork.

In the context of this book, expectations of ImSg are particularly interesting to address because 1) as with expectations around the Nanopil (NP), expectations are raised in an academic context and embedded in an application-driven culture; 2) thanks to the previous engagement of the group in an earlier workshop, it was possible to track the evolution of these expectations over the last three years, from a stirring vision of a “doc-in-a-box” to the current idea of “signatures of health status”; 3) the focus on diagnostics, personalized medicine and self-monitoring provides a common theme with expectations on NP that will be the focus of ethical reflection in the next chapter.

6.2 Research design

The main goal of this case study was to test, in a different context, the plausibility framework developed and exemplified in the case of the Nanopil. To do this, I designed my research methods to assess the plausibility of the case of ImSg by building on the experience gained during fieldwork on the Nanopil. In designing my fieldwork, I had to consider that the two projects were different. For example, Nanopil started with a very well defined project promoted by an oncologist with a specific vision of the practice and context in which the technology should be used. In contrast, ImSg was conceived of by a scientist as a way to “revolutionize health”. In this second case, different possible applications and contexts of use are explored by researchers.

In this second case my interviews with technology developers and observations of laboratory practices were also extended, to a longer and more intensive engagement. This allowed an analysis of expectations of the emerging technology which could be more firmly situated in laboratory practice. I was involved at the CIM from November 2010 until January 2011 as “embedded philosopher”. I was provided with a desk, introduced during a lab meeting to the whole group, and had access to all facilities, meetings and activities. I attended laboratory and project meetings twice a week, reviewed and discussed scientific papers and project proposals with researchers, and conducted participant observation during meetings and laboratory activities. I also held semi-structured interviews with several members of the research group: in some cases I had up to five interviews with the same person. Besides attending outreach events in which ImSg was presented to a lay audience, I also participated in informal activities (lunch conversations, the Christmas party). Finally, I presented my research twice at weekly laboratory meetings.

This interaction with researchers was initially aimed at understanding the science and technology of ImSg and their role in the project. When I became more

acquainted with the scientific and technological aspects, it became clear that the context of use for the ImSg was more broadly defined than in the case of the Nanopil. Different applications were explored by researchers. For this reason, I created some additional instruments to engage CIM researchers in exploring their expectations of the context of use of these technologies, organizing two focus groups with researchers. The first focus group engaged eight participants around the topic of “the challenges and promises of immunosignatures”. The goal of this discussion was to collect researchers’ discourses of the feasibility and challenges of ImSg. The second focus group engaged fourteen participants and focused on “the applications and practices of Immunosignatures out of the lab”. The goal of this second discussion was to collect researchers’ ideas about potential applications and to invite them to articulate their descriptions of possible contexts of use.

In a second stage I interviewed actors who were partially acquainted with the ImSg project in order to elicit their fictive scripts on ImSg. I interviewed experts who had participated in a former workshop organized by CNS-ASU/Consortium for Science, Policy and Outcomes (CSPO) in 2007, about the societal aspects of the doc-in-a-box (the original project on which the ImSg idea was grounded)⁹¹. The goal of these interviews was to gain a “helicopter” view of the current American healthcare system, trends in it, and expected challenges and opportunities for ImSg. The interviewees included the scientific chief director of the Biodesign Institute, a professor of law and ethics specializing in the legal aspects of emerging molecular medicine, an expert in business models acquainted with insurance company perspectives, and the director of Innovation and System Design department in a well-known medical clinic.

I also selected and interviewed actors who collaborated with the CIM, or who were pointed out by researchers as potential future collaborators. The goal was to elicit their interest in and doubts about the project, and their beliefs about its (im)plausibility. Among the interviewees were a biologist doing research on Neuro-Oncology and Neurosurgery in a clinic in Phoenix, who provided the CIM with samples of patients with brain cancer; a doctor who specialized in Valley Fever, who was involved in the ImSg diagnostics; an employee at the C-Path institute (which facilitates innovations in exiting the university and entering the market), who offered insights into regulatory procedures for diagnostic devices; and the president of a diagnostics company, whom CIM researchers expect to collaborate with in the future. Finally, I interviewed the directors of two centers at the Biodesign Institute involved in the “Partnership for Personalized Medicine”, a multi-institution effort that includes the translational genomics research institute (TGen) in Phoenix and the Fred Hutchinson Cancer Research Institute in Seattle.

⁹¹ See Selin 2007b and Selin 2008

One of these directors has a background in business and extensive knowledge of business models for health care and personalized diagnostics. The other director was trained in oncology and is involved in research on personalized diagnostics. These interviews often required preparatory desk research or provided new literature to review.

In the rest of this chapter I will analyze expectations of Immunosignatures by applying the plausibility framework delineated in Chapter Two and exemplified in the case of the Nanopil. First, I will analyze expectations of Immunosignature as a material artifact. Then I will analyze expectations regarding its use. These analyses prepare the ground for the third step: assessing the plausibility of the visions that ImSg will bring about a desirable world.

6.3 Immunosignatures: a “simple” concept

ImSg are presented as a “technological revolution” that is founded on a “simple concept”: our immune system mirrors our health. In fact, our immune system produces antibodies as a response to the presence of foreign bodies in our system. A read-out of the antibodies in a biological sample would thus provide information about the activity of the immune system. This would reveal information about the health condition of the subject providing the sample⁹². ImSg provide this read-out together with an interpretation of it. In the following discussion, I will reconstruct the origin and history of this revolutionary “simple concept” within the CIM, pointing out the reasons for its novelty and feasibility (§ 6.3.1). I will then examine this concept within research practice and point out co-existing platforms with different expected uses (§ 6.3.2). Finally, I will stress the conditions necessary for the ImSg concept to work in a context of use (§ 6.3.3).

6.3.1 Reconstructing the history of the concept

According to the CIM co-director, the whole project started as a way to support another research project being developed within the center: the cancer vaccine. The researchers needed to find a way to validate the vaccine and demonstrate that something had indeed changed within the organism. So, as a senior researcher explained, they started with the question: “Can we make an array to measure 1000 *things* in the blood?” They thought about measuring 1000 proteins, as biomarkers of health conditions, and they wanted to use antibodies, on an array,

⁹² “Our basic premise is that the antibody profile from an individual reflects their health status. If this profile can be displayed on a sufficiently complex array, the particular responses to chronic diseases will be apparent” (Stafford et al 2012)

which could catch the presence of these proteins. However, during the testing phase they realized that the different antibodies had recognizable binding patterns. Researchers wondered “what happens if we put a mixture of the two antibodies on the array?”: they tried it, and could see a mixture of the two patterns on the array. This finding made them believe that they could retrieve this information from antibodies within the body. They tried with human blood on the array, and saw a pattern that they interpreted as a mixture of the patterns of the different antibodies present in the blood. Antibodies thus became the things in the blood that they wanted to measure, while the proteins (in fact a form of simplified protein, “peptides”) became the “catchers” on the array. “This is what started the immunosignature array and we scaled it up to 10 000 peptides (simplified proteins)”. They ran samples of the same person before and after a vaccination and saw big changes for the same person. In fact, these results showed that: 1) it is possible to distinguish the signatures of different diseases in samples from the same individual; and 2) the signatures of different individuals are dissimilar. A senior researcher who has been working at CIM for several years explains:

And the group at that point split up and this became its own project. Before we thought that you had to scan every single protein in your body, but if we find a way to read this out we don't need to know every single protein, but your antibodies contain enough information.

The original idea has evolved in such a way that what is registered in ImSg is not the presence of certain proteins in the blood, but instead the presence of particular antibodies. These antibody patterns are now considered to have meaning for the health condition of the tested subject.

CIM researchers were therefore originally looking for something else: they wanted to use antibodies as biomarker catchers, without considering that antibodies can be even more informative than biomarkers. The history of the Immunosignature idea is described, by researchers, as a “paradigm shift” in their understanding of the relationship between the detection platform and biological information: what was initially the platform (the antibodies) became the information being sought, and what was the information (the proteins) became the detection platform.

This paradigm shift was accompanied by a second novelty: the use of random peptides (chains of amino acids) on the microarray. As the researchers explained, the current paradigm in immunology is that antibodies are antigen-specific; that is, antibody *x* will bind to specific foreign body, antigen *y*. According to this paradigm, in order to “catch” the antibodies in a biological sample, specific proteins should be used in the detection platform (a glass microarray). However, this is not the case on the CIM platform. Figure 4 in Annex One of this book (first presented by a graduate student during a laboratory meeting) shows randomly assembled chains of amino acids (peptides) co-located on a glass array (step 4).

These peptides are *randomly* generated, in the sense that they present some of the “bricks” (amino acids) which make up specific antigens, but that these bricks are erratically arranged. This means that no one specific antigen is on the glass array. When researchers put a drop of human serum on the array, they expect that the antibodies in the serum will bind to the peptides on the glass plate (Fig. 4 step 5). By expecting antibodies to bind to random chains of amino acids, researchers at CIM challenge the paradigm in immunology of antibodies as antigen-specific.

This second paradigm shift is recurrent in researcher discourse. When a researcher returned from a conference, he shared with his group the resistance of the scientific community to what he thought was a simple concept: the group's use of “randomly generated peptides”. His audience couldn't grasp how, on their array, they had chains of amino acids randomly generated by a computer, rather than using chains of amino acids corresponding to a specific pathogen. The innovation the CIM team presents doesn't fit into the current state of the art, and therefore encounters resistance from the scientific community. During the first focus group I organized, a researcher reflects on possible hurdles for ImSg:

Another big hurdle, leading to why these arrays wouldn't be useful, is that everybody thinks that antibodies see one thing, except maybe a few weird ones that might see multiple targets, but in reality all AB can see multiple targets [...] people get in ingrained that the pathogen gets into the body, the antibody are generated against it and just it. Prof. [expert in the field] attended one of our meetings and Stephen asked her “what would you say about monoclonal that recognize a lot of targets” and she replies “well it is a very poor monoclonal” [...] eventually things will start clicking...I don't know it might be too big of a comparison, but it is like trying to show that the Earth is round and not flat!

According to the current paradigm in immunology, antibodies are antigen-specific. Monoclonal antibodies are considered able to bind to only one specific antigen. Within this paradigm, it is hard to explain how antibodies can bind to randomly generated peptides that do not correspond to any antigen. The only plausible explanation is that it is a malfunctioning antibody (“a poor monoclonal”). The need to overcome the resistance of the scientific community, “ingrained” in the traditional paradigm of immunology, emerges in many conversations with CIM researchers⁹³.

⁹³ However, sometimes this controversy lurks in the discourse of researchers working at CIM. For example, CIM researchers talk about “real” peptides to refer to known sequences that are recognized as being the target of specific types of antibodies. They call “artificial” the peptides randomly assembled that they use on the immunosignaturing array. “In science nobody believes you if you don't show that actual stuff in the body. Here you show random stuff, artificial, harder to convince scientific society who only believes in real stuff” or “this is more real...random peptides is a sort of artificial”. This dichotomy “REAL *versus* ARTIFICIAL” suggests a hierarchy in the ontology of the researchers. The peptides synthesized in the lab from random amino acid sequences are less valuable, or less trustworthy, than ones traceable in nature. On one hand, researchers think that the ImSg concept does make sense and that the “conceptual hurdle” for the scientific community can be overcome by showing data that support this unconventional view of how the immune system works: hence publishing, showing evidence, producing results, winning grants, etc. On the

6.3.2 Concepts and components in research practice

“Immunosignature” is a concept that has been coined at CIM. It refers to the fact that it is possible to retrieve specific patterns, unique to each individual, by catching the antibodies in a serum sample. In the first focus group one researcher defines “immunosignaturing” as

a general *method to ‘immunosignature’* the antibody repertoire of an individual [...] a readout of antibodies’ profile on a random space.

According to this definition, an immunosignature is the actual “image” (or “snapshot”) of spots on the array obtained when the glass plate, with antibodies on, is scanned (Annex One, Figure 5). The specificity of ImSg with respect to other immunoassays is that they do not provide information about the presence of specific antigens, but show general patterns of antibodies. As a researcher explained to me:

With traditional tests, you’re only analyzing the immune response to very defined things. The question addressed by IMS is not “is there a particular disease or infection going on?”, but “what is going on?”

ImSg doesn’t provide information about the presence of a specific disease, but about the comprehensive condition of health. Thus ImSg should be the technique, method or platform for identifying immunosignatures concerning a general health situation, rather than detection of a specific antigen.

However, this apparently clear-cut concept turns out to be much more diversified within research practice⁹⁴. Researchers at CIM do not always use arrays on which random peptides are placed –sometimes they study the antibody patterns specific to particular diseases, and thus obtain an “immunosignature” for a specific disease. For example, a group of researchers were working on a project on biosecurity aimed at testing soldiers for specific bio-threat agents. They had to select specific pathogens (for instance anthrax or smallpox) and place them on the chip. The same procedure was done by a researcher working on an infectious disease typical of Southwestern States (Cocci, or Valley Fever) who had to place specific pathogens onto the array.

Random peptide microarrays are an “unbiased” way to test antibody repertoires, such that researchers do not need to have a “pre-conceived idea” of what peptide (and thereby pathogen) they should use to detect a specific antibody. In this way they can look at “patterns” on the array without needing to

other hand, by speaking of “real” or “artificial” peptides, the researchers embed in their daily language the skepticism of the scientific community. There is more. This distinction between “real” and “artificial” epitopes also discloses a difference in what the concept of “immunosignature” means.

⁹⁴ “Immunosignature” can here be considered as a “boundary object” (Star and Griesemer 1989) plastic enough to adapt to different needs and yet robust enough to maintain a common identity, and allowing negotiation and co-operation of actors around them.

know the pathogen. According to them, this is a good way to know whether there is any disease present, rather than pointing out a specific pathogen and how it can be treated. However, in some projects this more specific information is relevant, and therefore a different platform will be used. These considerations are important to this analysis because the concept of “immunosignature” clusters these differences in material practice and application under a homogeneous label. Differentiating amongst these might not change the practice of research, since researchers seem to communicate effectively⁹⁵. However, by analyzing these differences and assumptions in the basic concepts of new science and technology, alternative platforms and applications can be pointed out. For example, ImSg based on a “random space” provides information on comprehensive health status, while chips with specific pathogens on provide information on a specific health condition. As I will show (§§ 6.4-6.5), distinguishing these technologies and applications is an important step in assessing the plausibility of expectations in ImSg.

6.3.3 Some conditions for ImSg to work

One more aspect of the feasibility of ImSg should be mentioned. This technology is expected to provide information about the health condition of a person at a certain moment in time. As the co-director explains in the video mentioned above, it is truly personalized information, a “finger-print” of antibodies:

There is a very powerful aspect of that, because it means that you are always normalizing your health with respect to yourself. Right now in the biomarker world in medicine, as we live right now, we are normalizing our markers to the whole population, generally not to ourselves, because we don't take them frequently enough to do that. So, this was our goal. [...] Everyone shows *its own distinctive signature*. So we can normalize to yourself and when something happens, that signature changes. (My emphasis)

How do correlations among signatures appear? According to researchers, the similarity between today's or yesterday's patterns is shown by analysis of data collected on the glass plate: samples are clustered in graphs according to similarity between patterns, which depend on the intensity of a peptide – as shown by its illumination within the array – in a certain position (Annex One, Figure 6). Samples of individuals with the same disease are expected to show a similar “pattern”. Differences between people with a disease, and those who are healthy, show that there is a pattern of normality and a pattern of aberration. Differences in analyses of different individuals' samples show that there is a personalized pattern, or individual signature.

⁹⁵ However, after I shared these considerations with the CIM staff during a laboratory meeting, one of the co-directors admitted that this made him reflect on the direction that the center is taking (for an elaboration of how my analysis can play a role in the development process see Chapter Seven and the Postscript).

However, it seems that researchers are not primarily concerned about individual signatures, but rather with standard signatures. During my conversations with researchers, the importance of having a baseline to describe when a signature is normal, when it is abnormal, and when it is going towards a pattern indicating cancer or Alzheimers often emerged. In order to make these differences legible, researchers need to gather enough information about the baseline of normality. In fact, signatures are consistent for the same healthy individual but are very different among different individuals. In the case of a disease, the signatures of more individuals change, and they have a similar configuration, for instance in terms of a “common signature of influenza”. Identifying such configurations requires huge statistical effort, given that researchers are looking at differences both between people and between diseases. As one graduate student explained at a laboratory meeting, they need to identify a “standard normal signature”, that is

a reference line of Immunosignaturing, a range which gives an idea how normal individuals (free from any common chronic disease, irrespective of gender and age) respond to a particular peptide on an average. This line has the potential of contributing to baseline any class and also filter peptides which can act as controls, since their overall behaviors is known: a giant step towards ‘usage’ chips.

The final goal is to differentiate individual signatures, but in order to do so they have to find some common patterns. So “personalized signatures” might be a long-term goal, while standard normal signatures are the short-term goal most researchers are focusing on in their daily activity.

In conclusion, the analysis of expectations about ImSg science and technology has first of all articulated the novelty of the concept of “immunosignatures”. By using antibodies as a source of information about condition of health, and randomly assembled peptides to catch them, ImSg challenges two “paradigms” in the microarray and immunology world. For this reason, according to researchers, it triggers the disbelief of their peers. This analysis has also disclosed different ways that ImSg is done in research practice, and suggested that alternative technologies, with different expected uses, co-exist behind the idea of ImSg. Finally, moving beyond the rhetoric of the promise of a “personalized monitoring system normalized with respect to yourself”, I highlighted a condition for the success of ImSg, namely the definition of a “standardized normal signature”. When situated in the actual scientific practice of “doing immunosignatures”, the promise of ImSg acquires new dimensions.

6.4 The expected context of use

Researchers claim that ImSg is inspired by societal needs and purposes. Expectations around its social embedding circulate during CIM meetings and group reunions. Some of these expectations of use are based on the vision that originally triggered the project as a whole: the “doc-in-the-box”(DiB). DiB was conceived as a portable box with a reader, which would sit on the breakfast table as part of a family morning routine. It was expected to analyze small biological samples (such as a drop of blood or sputum), compare them with the history of the personalized signature and other biological information from the subject, and show an immediate result on its reader⁹⁶. According to the lab director and CIM researchers, ImSg is a more scientifically mature version of DiB, which remains the long-term vision for and ultimate end point of their research. Like DiB, ImSg will provide comprehensive monitoring for healthy people. However, closer analysis of research practice shows that expectations of the use of ImSg are more divergent than these visions suggest. Not only is the “fictive script”⁹⁷ of ImSg different from the DiB one, but researchers also use more than one fictive script (§ 6.4.1). When assessed through the situated perspective of other actors, some of these contexts (and scripts) are ruled out, while other possible contexts of use are pointed out (§ 6.4.2).

6.4.1 The many applications of ImSg

Despite the claimed overlap of the two visions, expectations of the context of use of ImSg and DiB differ in many respects. The idea of using detection antibodies solved the technical challenges of building a box that could analyze data on the kitchen table. In fact, antibodies (the target of the analysis) appear to be very stable molecules which are not easily affected by the environment and do not have to be analyzed immediately. That’s why, in 2010, the center’s director specified that the samples can be sent by mail “even in Phoenix in the summer”. Replacing the idea of the “box” with a shipment system affects the context in which this

⁹⁶ This is the CIM co-director’s vision of Doc-in-the-box in 2007, compiled for a workshop on the future social and ethical implications of personalized medicine. “Vision: It is Monday. After taking my HEPs (health enhancement pills) I put the lavager to my nose. It takes a painless wash of the nasal cavity and captures it in a module that is put into the BioSignaturer on the corner of my breakfast table. As I am fixing breakfast the screen on the BioSignaturer comes up. It notes that there are 19 significant variants from my signature last Monday. Looking at my history of signatures and integrating my genotype it warns that I am in the first few hours of an adenovirus infection. This information has also been relayed to my HIM (health information manager), Edith. Edith emails in a few minutes to recommend a course of Zn+Adeno inhibitor that will arrive at my workplace in two hours”. (in Selin 2007b)

⁹⁷ For an explanation of the concept of “fictive script” see Chapter Four.

technology is used. In fact, DiB was expected to be used for DAILY monitoring of ANY kind of health status, while ImSg can be done only REGULARLY because it requires the user to do more work (shipping the sample). The time frame assumed by researchers is “once a week/month”. Furthermore, whereas the DiB was expected to detect infections before the symptoms would appear, the current vision of ImSg does not portray it as suitable for detecting infections. Indeed, the researchers note that a typical infection lasts for one week, and that the time between the test, the shipment of the sample, and the result arriving is also likely to be one week. By that time, symptoms may already have been expressed, and the result of the ImSg is useless. In this sense the usability of ImSg is circumscribed to pre-symptomatic monitoring for chronic and long-lasting diseases. Thus while the visions of ImSg and DiB become assimilated, one into the other, important differences are kept out of sight.

Other differing visions of the context of use can be found in CIM researchers’ expectations of ImSg. ImSg is presented by researchers as a revolutionary technology and a “disruptive” innovation rather than an “incremental” solution to existing problems. According to this view, “incremental” solutions to a problem are ones that invest in newer, more effective and cheaper treatments for diseases. In contrast, a “disruptive” approach offers a revolutionary solution to problems in healthcare by addressing the stage when people are still healthy, and preventing them from becoming chronically ill. ImSg is not a diagnostic test for telling whether people *are* sick, but a system for pre-symptomatic monitoring of healthy people that tells you whether people are *in the process* of becoming sick. This system is thus expected to enable therapeutic interventions at a stage when no symptoms have emerged.

As such, the CIM directors and one graduate student are exploring possibilities for introducing ImSg onto the market as an online direct-to-consumer (DtC) test. They have been exploring the business models of successful companies, such as 23andMe, that provide DtC genetic tests⁹⁸. In doing this, they have to address the problem of the regulatory constraints that the FDA⁹⁹ has placed on online sales of diagnostic genetic tests¹⁰⁰. Companies like 23andMe have found creative solutions to these constraints, including offering these kits for “personal genetic information” rather than “diagnostics”. One possibility for marketing ImSg at this early stage would be to follow this model and offer “raw data” to consumers about their immune system activity. The users would receive

⁹⁸ See the website where this direct to consumer genetic profile is sold: <https://www.23andme.com/>

⁹⁹ Food and Drug Administration, the American agency responsible for protecting and promoting public health through the regulation and supervision of, among other things, pharmaceutical drugs, medical devices and vaccines. See <http://www.fda.gov/>

¹⁰⁰ See Little 2006

information about their immune system activity, without any interpretation of their meaning.

While some researchers address these kinds of questions, most CIM activities seem to focus on defining the “patterns” for specific diseases: infectious diseases, influenza, diabetes, breast cancer, Alzheimers disease. Focusing on pathogens and disease patterns does not necessarily mean that ImSg is expected to be a diagnostic tool for that disease. For example, when researchers talk about the influenza virus, they may be more interested in its value as a discovery tool and model because:

influenza is a great model system, that only has 8 proteins and it is easily being associated with the patterns that we see on the random array to what the actual sequences are.

However, in some cases ongoing research is overtly focused on specific diseases. One graduate student collaborates with a medical doctor and expert on Valley Fever. She explained to me how the doctor has provided samples from patients who have been checked for the fungus that causes the disease. Her project aims at exploring the possibility of early diagnosis of this infectious disease; preliminary results in this are promising. Within research practice at CIM, several applications for ImSg are being explored. The most successful current projects at CIM actually focus on its application as a diagnostic tool for specific diseases: ImSg is therefore not only a “disruptive” innovation, but also provides a platform for more “incremental” applications. The unifying vision of a system for monitoring asymptomatic people’s general health doesn’t do justice to this variety of research.

In the second focus group I organized (see § 6.2), I explored this variety of potential applications. I asked participants to list and describe short-term applications that they envisioned for ImSg. After some discussion amongst themselves, they agreed that it is more likely that in the short term the ImSg platform will be applied to enhance current diagnostic practices for specific chronic and infectious diseases, rather than being a tool to comprehensively monitor asymptomatic people’s health status. For example, they suggested that they can identify specific patterns for the Valley Fever infection, which might offer more accurate, cheaper and easier diagnostic tests than are currently available. Other short-term applications envisioned by researchers were: use within vaccine trials; as a diagnosis for cancer, autoimmune diseases, infectious diseases, and chronic diseases; clinical monitoring of cancer recurrence and effectiveness of vaccination; and tools to assess if a certain population (e.g. soldiers) have been exposed to a particular agent.

One of the “fictive” descriptions articulated during the focus group focused on the ImSg as a platform for the diagnostics of a specific chronic or infectious disease. In the case of Valley Fever, researchers drew parallels between this potential system and the current US procedure for testing for strep throat. A

symptomatic patient will be asked by their medical practitioner to perform the test through the collection of a drop of blood. The test will then have to be sent to the laboratory for analysis, and, in the case of positive results, the patient needs to go back to the primary care doctor in order to receive treatment.

A second fictive description elaborates a general vision of ImSg as a tool for the comprehensive monitoring of healthy people. Asymptomatic, healthy people will regularly send a biological sample to a central laboratory and receive their results by e-mail. An online system could be in place, in which people can log in, order the testing kit, and receive it at home. After putting the drop on the filter paper, the sample will be shipped, probably in a post office, so that an officer can write down the content and the reason that they are sending a biological sample. A central laboratory can analyze the sample and upload the result onto the online platform, so that users can have online access to their immunosignatures. This fictive script presents two phases. In the short-term, while research on correlation between immunosignatures and health status is still going on, this system is expected to provide information about your immune response, without providing any interpretation. This information could be openly shared and “people” with computational skills might be able to find some correlations. In the long-term, it could be uploaded on some platform (such as Google Health) where people collect and manage their own personal health records.

These fictive scripts discussed by researchers are interesting because they flesh out different ways of envisioning the future of the healthcare system, and the place of ImSg in it. They illustrate how an apparently unitary expectation of a technology opens up very different contexts, with different kinds of questions. The vision of ImSg as a “comprehensive monitoring system for healthy people” thus competes with a vision of ImSg as a “diagnostic tool” for specific health condition in symptomatic patients. Many more details could be added to these descriptions¹⁰¹; however, these fictive scripts offer a starting point for exploring the plausibility of expectations of the use of ImSg as expressed by other social actors and experts.

¹⁰¹ For example, where is IMS done? At a primary care consultation every year? Or by individuals in their homes? Exploring the site assumed in researchers’ expectations of ImSg is not a secondary matter because different sites define different contextual features: the actors involved (a doctor, a nurse, the pharmacist or a laboratory employee?), the frequency (once a year at the primary care, whenever symptoms occur, according to a personal routine at home), the communication system for the result (face to face, by snail-mail, by e-mail), information storage (in the patient’s virtual or paper-based personal medical record, at the GP’s office, in an online database), and the purpose of the test (diagnostics, prevention, education, profiles databank building). In each of these contexts, the network of actors changes, as do their relations. Thus each one of these expectations carries a different “script” of how the ImSg system will look and work.

6.4.2 Assessing and enriching fictive scripts from situated perspectives

If researchers believe that ImSg can most easily enter the market as a diagnostic device for specific health conditions, other stakeholders and experts assess the plausibility of this expectation differently. One of my interviewees works at the Critical Path institute, an independent, non-profit organization launched by the FDA in 2004 to play a mediating role between scientists, regulatory agencies and industries in order to facilitate the drug development process¹⁰². He explains how FDA regulations on biomarker tests require specification of the sensitivity and specificity of each element of the test in order to establish the precise accuracy of the test. To date there is no diagnostics test done using “patterns”.

It can be expected that you will have to convolute that pattern and specify for each component what is the specificity and sensitivity

Since 2006, FDA has introduced a class of assays, IVDMA (“in vitro diagnostic multivariate index assays”), which need more regulation than other tests (Little 2006). These tests screen for thousands of markers in order to predict the likelihood of a certain disease state, disease progression, or response to a therapy, by using an algorithm that gives different weightings to different markers. The impossibility of the physician interpreting the test without the algorithm makes the FDA wary. ImSg, which will use algorithms to interpret patterns, can be expected to raise similar problems. The expert in legal aspects of emerging biotechnologies that I interviewed explains:

Would FDA’s attempts of strengthening regulations be successful, we might wonder whether any company would invest in such the high costs of regulatory approval for a diagnostic test for a specific infectious disease, say Valley Fever, whose potential return might be too low.

The director of the Center for Personalized Diagnostics at the Biodesign Institute similarly shared their experience training as a medical doctor in oncology:

if you screen for some proteins, you can say that together all these signatures are signs for that disease [...] people might have similar patterns, so we are going to classify these people as type a or type b. This is very different from when a person enters your office and you want to classify her has type a or type b, but this is different because the person is different from the population you have tested it [...] You know that some people belong to a class or another. But is this test good for a patient? NO! Because what if the value of an individual falls in between? What do you tell to the patient? What you want is having no space between the two curves, otherwise you have too much variation and you don’t know what to tell to the patient.

If ImSg are conceived as a “tool for the doctor”, then they are expected to address the problems that doctors encounter when they need to diagnose a patient. The test has to provide them with the information they need to make a diagnosis –

¹⁰² See <http://www.c-path.org/>

information which will enable them to say something to a patient. In the current regulatory and clinical climate, patterns and algorithms do not provide a trustworthy source of information for giving a diagnosis. Thus the application of ImSg for specific diagnostics may encounter resistance from clinicians.

What about the plausibility of the second vision of Immunosignatures as a pre-symptomatic monitoring platform? As far as it concerns the online, direct to consumer model, from a legal perspective:

At the moment, there is an ongoing legal action in which FDA evaluates 23andMe, Inc.'s product as a diagnostic test and expects the company to apply to FDA for market approval. The way this legal act will evolve will seal the fate of other products as IMS-based tests for health and wellness monitoring.

In the case of a direct to consumer test, ImSg should be expected to be a freely purchasable product, since reimbursements from insurance companies are unlikely. This was explained by the respondent from the health care business, who is in contact with US insurance companies. From her perspective, a device for the regular monitoring of healthy people which would recognize if you are incubating a flu virus is not likely to be paid for by insurance companies. She explained that insurance companies "are not much of futurists" when making decisions about which treatments and diagnostics to reimburse: the decision whether to invest in a new technology is based on the current situation, including economic utility and clinical validity. The utility outcome of the use of ImSg for healthy people (and the preventive measures that it would entail) should be clearly comparable with the costs of letting the subject have the disease. If ImSg detects early stages of chronic diseases, insurance companies would likely not reimburse the service for the whole population. The respondent seemed more keen on the prospect of insurance companies being available to cover expenses for high risk groups, such as elderly patients, pregnant women, and people with cardiac risk or diabetes – population groups that are 'expensive' because of their high risk of getting sick. Monthly monitoring can be justified and accepted only if the benefits are clear:

For example, cancer patients are very expensive for insurance companies; therefore a system that would keep them out of the hospital would save a lot of money to payers and would therefore be welcome. But knowing if I get the flu or not, is not of much interest for them, it doesn't save them enough money to be worth it. It is a lot easier to present prospective studies that show that Immunosignatures can be convenient for a group of high-risk patients than for the population in general.

The "world without patients" motto is too futuristic for "payers" who would not see the long-term benefits and focus instead on short-term gains. The idea that patients are in charge of themselves might also, the respondent explained, encounter resistance:

Payers have reduced hospital time significantly in the last 20 years. There is less hospital and more outpatient care. Hospitals, cancer centers have contracts (incentives) with the insurances that they have less clinicians and having a better

quality. But they always want a clinician to interpret results for the patient. They don't want self-medications. That's the big issue.

A condition for ImSg to be taken seriously by payers is that information about the result should pass through a clinician. In this regard, ImSg could be integrated into the new concept of the "medical home" that has recently been incentivized by many payers. This is the idea that primary care physicians (or general practitioners) keep track of the patient's complete medical history across visits to different specialists. Payers are incentivizing general practitioners to set up an information management system that enables them to administrate patients' medical records in an efficient way. In this sense, according to the respondent (expert in designing business models for healthcare), ImSg could

allow the general practitioner to have more awareness of what is going on with the patient (in a high risk group) and this would be much appreciated by the payers

Based on the perspective of insurance companies, a third vision emerges. In this vision, ImSg is not an enabling tool for the patient's self-care and control, but a system that makes the general practitioner more aware of what is going on with patients in a high-risk group.

This third vision of ImSg as embedded in a broad system, in which self-monitoring functions to improve the quality of the health provider's service: this is also the vision of the director of the Innovation and System Design Department at a major American clinic. He explained that the mission of his department is to integrate predictive and information technologies to manipulate historical data and develop predictive profiles for patients who are about to face a surgical intervention. This would help anticipate what kind of care the patient will need and how long she will be in the hospital. In this context, it is important to have enough information about patients in order to reduce their hospital stay and thereby reduce costs. According to this stakeholder, ImSg might be a helpful tool in retrieving more information about patients or prospective patients and making the system more effective.

This actor explains how his clinic is investing in programs of home care or tele-medicine, such as the "Heart Care at Home" program, which has drastically reduced patients' stays in the clinic.

The distinction between doctor's office and home medical care will blur in the future [...] It has a huge benefit in the healthcare system: the healthcare stops being episodic and becomes continuous.

In this vision of ImSg in a "home medical care" context the technology could produce information that joins a large information stream that the system can analyze. The connection of remote technologies changes the relation between the provider and the consumer: ImSg as a point-of-care test, carried out by patients at home, could be part of this home care system and help to make contact between patients and care providers "less episodic" and "more continuous". This

respondent also refers to a trend of care providers helping patients to think about their health future and being proactive about it. In their programs, they integrate traditional medicine with complementary approaches around prevention and education about managing the effects of chronic disease through lifestyle modification (nutrition, exercise and stress management). ImSg could provide a tool for raising awareness of the connection between people's immune response and lifestyle.

Similarly, the Director of the Center for Sustainable Health at Arizona State acknowledged the importance of educating people for improving health business and management. He stressed that a change in citizens' attitude towards their health management is a key condition for improving healthcare at a national and international level. In his view, institutions have to invest in order to modify citizens' ideas about their personal responsibility towards society for keeping themselves in a good condition of health. Educational programs, awareness campaigns, and simple game-based persuasive technologies that enhance people's awareness of or control over their health are possible paths in this direction. This respondent envisions ImSg as a tool for changing citizens' ideas of responsibility by making them more aware of their health conditions.

The same technology, then, can be envisioned by scientists as acting in a non-medical context to promote a "world without patients" and by care payers/providers as being embedded in a more controlled context of use. According to this vision, the decentralization of care provision (which will be relocated into the patient's home) brings about a more effective system, which in fact involves more systematic control. The individual's home becomes an outpost of the doctor's office.

This analysis of expectations of the use of ImSg thickens generic visions. Some scenarios and contexts of use can be ruled out, such as monitoring a developing flu. New scenarios also emerge such as, for example, the use of Immunosignatures as diagnostic tools for specific diseases. Furthermore, the fictive scripts articulated by researchers have been assessed by other experts and stakeholders. This assessment points out some barriers to the social embedding of ImSg based on current social configurations (FDA regulations, the role of insurance companies). This assessment also indicates opportunities and contexts of use for ImSg based on experts' and stakeholders' interpretation of ongoing trends (for example, "medical home" initiatives by insurances and hospitals).

6.5 Immunosignatures and a desirable world

The previous sections have set the stage for assessment of expectations of the desirability of ImSg. When asked about the value of the doc-in-a-box, one of the CIM co-directors explained that its value was threefold: economic, for treatment, and for empowerment and education.

Economic: The health care system now is largely focused on taking care of ill people. This is where most of the dollars are spent. We currently spend \$2.2T dollars (19%GNP) on health care and are projected to spend \$4T (25% GNP) by 2015. This is not sustainable. One way to avert this crisis is to convert to a pre-symptomatic versus post-symptomatic medical system. We need to have a longer lived, better healthed population. **Treatment:** Early detection of disease would allow more effective use of even current medications. It would also open the opportunity to develop new classes of medications that act at an earlier, and presumably easier to treat, stage. **Empowerment and Education:** Each individual could see their own biosignatures and the implications of these signatures on a regular basis. This should empower them to take more responsibility for their own health and stimulate their own scientific education on what this means.

The ImSg inherits these values from the doc-in-a-box. As pointed out in the video, this innovation is desirable for the American economy. A health care problem is outlined in financial/economic terms: health care costs are unsustainable for the US economy. ImSg addresses this problem because it enables a “cheap”, “comprehensive” and “regular” monitoring system for healthy people. In this way “well people can monitor their health in a comprehensive way and detect early any aberrations, anything that goes wrong with their system, and act early”. Frequent personal monitoring would allow doctors to intervene early in the case of any aberration and thus to prevent people from becoming chronically sick and permanently expensive for society. Together with this economic value, ImSg is also desirable because it is assumed that early detection makes existing treatments more effective and fosters the development of new treatments that address the early stages of disease. ImSg provides a mechanism for earlier, and therefore more effective, treatment and helps achieve better health. Finally, by displaying information about an individual's health parameters, and showing how these parameters are linked to health conditions, ImSg enables individuals to “see” these correlations. This understanding empowers people because it makes them more scientifically literate and therefore better able to control the health of their body. Individuals are thus empowered to take responsibility for their health. In conclusion, IMS is desirable because it has a money-value for society, a health-value for patients, and a control-value (both as knowledge and as autonomy) for individuals.

The analysis below assesses this general expectation by pointing out alternative moral connotations of the different technological platforms and

applications of ImSg (§ 6.5.1). It also points out how the desirability of the expected outcome can be differently appraised by different stakeholders (§ 6.5.2). Finally, it shows how expectations of ImSg neglect the way that this technology mediates our understanding of reality and actions in society (§ 6.5.3).

6.5.1 Articulating moral connotations in different technological platforms

ImSg is expected to solve the problem of high healthcare costs. However, we can ask *which* ImSg is expected to have this desirable consequence. In fact, as explained in § 6.3.2, research on ImSg is currently going in different directions. For example, researchers “do immunosignatures” in at least two ways: 1) they use an array with 10,000 random peptides; or 2) they use arrays displaying only some specific epitopes of known pathogens. These two ways of doing ImSg are not only different stages of the validation of a scientific hypothesis: they also address different clinical questions. In the first case, ImSg answers the question “what’s going on?”; while in the second case, it answers the question “is there a particular infection or disease going on?”. Section 6.4.1 explored the plausible contexts of use of these platforms. The first platform is expected to be used in the context of comprehensive pre-symptomatic health monitoring, where there is no suspicion of a specific syndrome. Some researchers at CIM are also investigating the possibility of following the example of other companies, and offering this comprehensive pre-symptomatic monitoring as an online, direct-to-consumer test. According to the stakeholders I interviewed, this platform is likely to be enrolled into a “medical home” program for high-risk subjects (§ 6.4.2). The second ImSg platform, which addresses specific diseases or infections, is expected to be used in a clinical context in which a diagnostic decision has to be made. These different types of ImSg are placed by researchers on a temporal axis: the use of ImSg for specific diagnostic purposes comes before its use in comprehensive monitoring. However, these visions are not different phases of the same technology. There are, in fact, three expected technologies: 1) do-it yourself (DIY) health monitoring; 2) disease diagnostics; 3) medical home monitoring. Immunosignaturing platforms are therefore diverse both in their techno-scientific components and in the clinical (or more generally, social) context in which they are expected to operate. These emerging “technical codes” (Feenberg 1995) carry different moral meanings.

This is evident if we analyze and compare what each one of them does. The DIY online comprehensive monitoring system is expected to provide online customers with information about their immune system activity. In the short-term vision, this information is provided to clients but no interpretation of its meaning is given (see § 6.4.1). Based on the business model used by other direct-to-consumer test

providers, it is assumed that individuals own such information about themselves, and that what to do with this information is up to them. In this “patient-centered” healthcare vision, the liberty of individuals and their self-determination are therefore central values. Individuals will not be dependent on doctors, and they will be able to take care of their health in an autonomous manner; ImSg is seen as empowering individuals in this respect. Interestingly, these “libertarian” values of freedom – based on the concept of personal property – are combined in researchers’ scripts with “communitarian” values¹⁰³. In fact, CIM researchers explicitly point to e-healthcare platforms in which users share their personal health information and data with other users in order to maximize the availability of interpretation tools¹⁰⁴. This sort of open-source tool doesn’t aim at accurate interpretation, but its value would be to provide a platform for healthy people to share information and knowledge concerning the relationship between data on immune system activity and the meaning of such data in terms of condition of health. The assumption is that people, while owning their personal information, need to share it with others in order to make sense of it. The moral connotation of this envisioned technology is therefore an interesting combination of libertarian ideas of freedom and autonomy together with a communitarian ideal of “sharing”. Let’s compare the moral meaning of this vision with the others.

The vision of ImSg as a tool for the diagnosis of disease enables a system in which doctors play a central role. Here ImSg is considered an empowering tool for the doctor, rather than the individual user. As explained by one respondent, a test is useful for doctors when it provides them with relevant information to make a clinical decision or to inform a patient (see § 6.4.2). ImSg is expected to provide a clear-cut outcome that answers the questions of the doctor. In this context, ImSg is a good test not if it promotes individual autonomy or freedom, but if it promotes accuracy and salience within clinical practice.

Between these two visions there is a third vision, of ImSg in a “medical home” context. Here the same platform of DIY ImSg is embedded in a medical context: the technology is envisioned as a platform for monitoring the health of subjects from high-risk categories, such as old people, pregnant women or patients with chronic illnesses. In this scenario, the key users are not healthy people, but hospitals or primary care services. In fact, information provided by the system would help reduce costs for the care provider/payer (as explained by the director of the Innovation department, see § 6.4.2). Controlling the health of those in high-risk groups is expected to result in measurable economic benefit. In this vision, ImSg is good not because it provides an accurate diagnostic test, but because it contributes to the profit of care providers and care payers (insurance companies).

¹⁰³ For a short introduction to libertarian and communitarian values see Swift (2001).

¹⁰⁴ See for example: www.patientslikeme.com

In this case, it is not the specificity of the test that is desirable, but the fact that it allows comprehensive, cheap monitoring. Furthermore, this vision aims at a “remote, but tighter” relationship between patients/citizens and care structures. The values of autonomy and personal freedom promoted in the first vision have here been replaced by the value of “controlling” patients in their homes.

The moral meaning thus substantially changes according to different contexts of use of ImSg. The differences in the moral connotation, however, are lost in general expectations of ImSg. By referring to the economic value of a health monitoring system for asymptomatic people, other moral connotations that are inscribed in co-existing technical codes remain unarticulated. Articulation of these diverse moral connotations shows that it would be a mistake to assess the desirability of ImSg as such; instead, the multiple artifacts, applications and values should be distinguished before the question of the desirability of ImSg can be addressed.

6.5.2 Stakeholders and normative divergence

Different technical codes have different moral connotations. Furthermore, stakeholders and social actors have diverse interests, values and preferences, which do not necessarily align with those of the ImSg developers. One example is that FDA regulation requires statistics on the specificity and sensitivity of each protein used in a biomarker test, in order to ensure that the test is accurate. According to this view, placing an entire protein on an array, rather than a randomly assembled peptide, is more accurate, because the protein is expected to reproduce the exact target of the immune system. However, as CIM researchers note, these protein arrays are both more expensive and more time consuming. Peptide arrays might be less accurate, but they are cheaper and faster to assemble, and can therefore be distributed more widely and – if they are to be used by healthy people – will be more cost-effective. This controversy is therefore not about the accuracy of the test, but is a question about what application is desirable. In this sense, ImSg is a good test for monitoring healthy people and a poor (inaccurate) test for use in specific diagnostics. However, the desirability of the test might also depend on the context. In some contexts, in which low cost is a significant added value (for instance, in a developing country), ImS may even be a desirable diagnostics test.

At a more general level, the question of whether “disruptive” or “incremental” innovations are better for society depends on what value systems are held by actors. On the one hand, some CIM researchers propose a new way of looking at problems in health care by addressing healthy populations. On the other, the NIH evaluates CIM work as irrelevant for current medical practice, because it provides information that is too general and which doesn’t address clinical questions.

These two ways of assessing impacts on health care are based on normative differences. In one case, scientists should provide tools to address clinical needs: the clinical need comes first, inspiring research that addresses a specific question relevant to medical practice. Scientists – as one respondent with a clinical background explained – should look at the “differences that matter” for doctors in a clinical context. Here, “one size fits all” solutions are not desirable, and general patterns measured through whole populations might be misleading. In the other case, such patterns are valuable because they allow asymptomatic people to become aware of the status of their health and thus might guide them to change their lifestyle, or to take measures to improve their health condition. Ultimately, different actors hold divergent visions of what is desirable for society.

Finally, the three visions of ImSg described in the previous section (ImSg as DiY comprehensive monitoring, ImSg as diagnostic tool, ImSg in the medical home) raise different ethical and legal questions. In the case of the vision of ImSg as an online system of shared information, privacy issues may arise. In fact, in order to build a robust statistical correlation between antibody binding patterns on the array and a specific health condition, an extensive database has to be created by the ImSg developers. This database should include not only a sample and its analysis, but also environmental, geographical and personal data. How should this information be protected in the context of scientific research on ImSg?

In the case of the vision of ImSg as a tool for doctors, controversies could emerge around the liability of the physician in the case of a mistaken diagnosis. New genetic tests change the responsibility of the physician and the scope of her expertise. The doctor is now responsible for knowing and using the best available diagnostic tools for investigating her patients’ symptoms and susceptibilities. However, genetic tests, marker interpretations, and risk probabilities are currently a very limited part of the training of medical doctors. What kind of skills would ImSg demand from a medical doctor? In the absence of any symptom in the patient, what kind of liability for offering a pre-symptomatic test can be imposed on a physician? Would a person who goes on to develop a chronic disease be successful in suing her GP for not having prescribed ImSg monitoring before the symptoms occurred? Such questions highlight not only that different technological platforms promote different systems of values, but that different stakeholders and social actors hold different systems of values. The plausibility of expectations of the desirability of ImSg should be assessed with respect to this diversity. Expectations of the desirability of ImSg tend to unify social actors under an abstract category of “American society”. However, when this abstract category is opened up, different values and ideas of what is desirable emerge.

6.5.3 The interactions between ImSg and morality

The promise of ImSg is to solve the problem of high health care costs, empower individuals and doctors, and create a world without patients. However, ImSg will be more than a tool to solve social problems. Depending on the way they are designed, the interpretations provided around them, and their eventual context of use, Immunosignatures can be expected to do different things than those articulated in their “function”.

In the vision of ImSg as a comprehensive monitoring system, scientists expect that the goal of ImSg is to reduce costs in health care through “educating” people. Sometimes the value of ImSg for educating individuals is articulated as a goal in and of itself because it contributes to “empowering” people. By displaying information about an individual's health parameters and showing how these parameters are linked to health, ImSg is expected by scientists and other experts to enable individuals to “see” these correlations and thus to become aware of them¹⁰⁵. Thus ImSg appears to foster individual responsibility by providing users with relevant information about their body and general state of health: this information is then expected to “empower” people to take charge of their health. ImSg is considered a catalyst for changing people's mindsets about individual responsibility for health care. Just as people have changed their understanding of what is “private” in response to online social networks, they are similarly expected to adapt their daily habits to the use of a health monitoring system.

This line of reasoning builds on several assumptions. The first is that more information on their immune system makes people more knowledgeable. The second is that this knowledge empowers people to take action. The third assumption is that taking action allows you to take charge of (or responsibility for) your health, and that this enables people to be more in control of their lives (empowered). However, if we take into account that ImSg can be expected to “mediate”¹⁰⁶ the user's understanding of and action in the world, we can point out some rather richer dynamics of the interaction between morality and technology than found in the instrumental model in which ImSg is a means to empower people. In this context, the plausibility of these developments becomes less straightforward.

First, the information provided by ImSg does not simply increase knowledge regarding an individual's health condition. How the information retrieved through the use of the peptide array (see Annex One fig. 5) will be interpreted is still uncertain. This uncertainty also emerges in discussion of the best way for this

¹⁰⁵ “Each individual could see their own biosignatures and the implications of these signatures on a regular basis. This should empower them to take more responsibility for their own health and stimulate their own scientific education on what this means” (From Selin 2007b)

¹⁰⁶ See Chapter Five.

information to be communicated to potential customers or clients. How will an average person “make sense” of this information? The problem, according to scientists, is that the concept of “immunosignatures” refers to a type of information that is fundamentally different from similar, currently available types of personalized information (for example genetic profiles). An “immunosignature” identifies an individual’s health status at a particular point in time. In this respect, “immunosignatures” differ from “genetic signatures” (or genetic profiling): “genetic signatures” provide stable, constant information about an individual’s genetic make-up, while immunosignatures vary in time and are “dynamic” in the sense that they reveal a snapshot of information about a continuously changing condition (the individual’s immune response). In some ways the concept of *immunosignature* is closer to the concept of “signature” in our everyday usage. Like a handwritten signature, authenticity is not granted by absolute permanence and identity but by a *sameness* that is preserved over time. That sameness guarantees the link between a changing *token* and an immutable *type* or individual subject behind that. In this sense, the ontology introduced by the concept of *immunosignature* differs from the ontological assumptions of the concept of “genetic signature”. Genetic information offers information about an individual’s genetic make-up that can lead to a deterministic acceptance of character and behavioral traits. What does the personalized and yet *changing* immunosignature say about the *permanent* individual? ImSg introduces new concepts and perspectives on the relationship between bodily information and condition of health. The way in which ImSg “mediates” our way of experiencing health is therefore much richer than that suggested by an instrumental relationship (i.e. that ImSg information entails knowledge on health conditions).

These questions bring me to the analysis of the second assumption, according to which knowledge about immune system activity will enable people to take action. ImSg detect abnormal activity in your immune system, indicating that you are asymptotically sick. Experts envision this knowledge as empowering people to become proactive and therefore engage in lifestyle changes. However, it is not clear to what extent a person has power to take individual action. For example, clinical experts might be needed in order to prescribe a treatment. Furthermore, ImSg, as a comprehensive monitoring system, can be part of a toolbox for improving the efficiency of care providers. Here, then, the third assumption is questioned. In fact, when used in the context of the “medical home” ImSg is a tool for hospitals rather than a tool for individuals. Therefore it *doesn’t empower* individuals to be more in control of themselves, but is *a tool to control* individuals. In this sense, ImSg prescribe some form of social responsibility rather than enhancing individual empowerment.

Questioning the plausibility of linear expectations of how a technology will be a means to a desirable goal (or a solution to a problem) is important in order to

avoid speculation. ImSg cannot be simply understood as a tool for achieving desirable goals: it carries specific ideas and concepts of health, disease, information and personalized diagnostics. These concepts will interact with existing concepts such that ImSg can be expected to do different things. Looking at the relations between this emerging technology and our current concepts and values is important when assessing expectations of Immunosignatures and their desirability.

6.6 Discussion

The analysis of expectations of Immunosignatures described in this chapter applies the three-step framework delineated in Chapter Two and previously exemplified in the case of the Nanopil. This framework unfolds in three steps, each building on the other. Descriptions of the expected technology have been thickened. Fictive scripts describing the context of use have been sketched out and then assessed by actors (or experts) working with these contexts. These analyses have provided a ground for disentangling the multiple conflicting values implicit in different technological platforms, the heterogeneity found in normative visions across different stakeholders, and the different interactions the technology-in-use has with morality.

This analysis aimed to show the applicability of the three-step plausibility framework. Instead of providing a “one-size-fits-all” method, the framework is tailored to each specific case study. As discussed in § 6.2, I made different research design choices in addressing the Nanopil and Immunosignatures cases. These choices were dependent on a number of differences between the two cases. For instance, the Nanopil is an artifact developed by engineers under the guidance of an oncologist. The context of application is clearly specified (screening for colorectal cancer) and clinical practice is taken into account in the design of its different components. In contrast, Immunosignatures are “fingerprints” of the immune system retrieved through a specific array or microchip. The clinical application of this innovation is not yet fully defined, and different directions are being explored. In the first case, engineers are aiming to test and assemble different functional components; in the second, molecular biologists, biochemists and statisticians analyze biological samples and look for meaningful correlations. The different “epistemic cultures” (Knorr-Cetina 1999) of the two research groups require different methods for the analysis of expectations of the technology. If in the case of the Nanopil interactions with scientists were relatively limited – being based on a reconstruction of the different components and “pieces” of the artifact – for the Immunosignatures a longer and more intensive laboratory engagement

was required in order to get acquainted with the science and technology. This longer laboratory engagement also allowed me to explore in more detail different possibilities for clinical applications, which were less well articulated than in the case of the Nanopil. In general longer experience within the laboratory (two or three months) better served the aim of analyzing expectations of the artifact. These differences between the two cases are also reflected within the findings. In fact, while in the case of the Nanopil discrepancies between the engineers' fictive script and current clinical practice were emphasized, in the case of Immunosignatures discrepancies within research practice were the center of attention.

It is important to stress that both cases presented in this book concern emerging technologies for molecular diagnostics. Can the plausibility framework that I am proposing here be applied to different types of emerging technologies? This framework is certainly not only meant for diagnostics or medical technologies, but could be applied to other technologies. The comparison between the Nanopil and Immunosignatures has shown that the specificity of the technology, its stage of development, and the context of innovation have to be taken into account. Despite this context dependence, three features are important for any case:

1. Two levels of analysis of expectations (of the technology and of its use) are conducted as a basis for an assessment of the plausibility of visions of the desirability of an emerging technology;
2. These two levels of analysis are approached with the same main strategies of "thickening" and "situating": expectations are explored within a situated (research, clinical or other social) practice, with the aim of enriching them with details that did not appear in widespread promises;
3. These analytic strategies aim to disclose the heterogeneity that is hidden within general visions. This assessment teases out different aspects of the scientific and technological platform, its usage, and the values rendered invisible in broader scenarios communicated to lay audiences. This unraveling fulfills the function of assessing the plausibility of these expectations, rather than evaluating their desirability.

Such plausibility assessments can be considered to have an "epistemological" rather than a "prescriptive" role because they aim to improve the conditions for developing knowledge about emerging technologies rather than offering a judgment on whether they are good or bad. This epistemological assessment is itself not value-free. As explained in Chapter One, my approach holds a normative agenda of integrating reflection on the moral acceptability of emerging technologies into public deliberation on such technologies. According to this normative agenda, such reflection should be anchored in the current state of the

art and in social practices and the wider moral landscape and yet be able to explore the ways in which emerging technologies might alter symbolic orders (see Chapter Two). Such an agenda is achieved by offering the plausibility assessment as an analytical tool for ethicists who want to engage in discussion on the moral acceptability of emerging technologies. Furthermore, the plausibility assessment can also help to build tools to facilitate stakeholder interactions within *ad hoc* spaces for deliberation, for instance in the context of technology assessment activities. The next chapter will elaborate on this aspect.

7 Scenarios as “grounded explorations”

Designing tools for discussing the desirability of emerging technologies

We assume the most of the time that these others are here with us, but really are only able to and need to question our basic assumptions in the moment when we collide with an element of the complexity of our life, a tear in the routine of experience that requires us to rethink things in order that we might progress along our current (or any other alternate) course
(McGee 2002: 112)

This chapter shows that the plausibility assessment of expectations proposed in this study can be used to construct tools for discussing the desirability of emerging technologies. First I explain why, from the perspective of pragmatist ethics, future scenarios are good tools for assessing the desirability of emerging technologies (§ 7.1). I then review some of the types of scenarios that have been developed as tools for discussion of the social and ethical issues of emerging technologies (namely, “socio-technical” scenarios and “techno-ethical” scenarios and vignettes), indicating some of their limitations (§ 7.2). I clarify why my approach helps to address these limitations by tailoring scenarios for “grounded” and “exploratory” discussion of the desirability of emerging technologies (§ 7.3). Section 7.4 discusses how I designed two exercises in order to engage with the developers of the two technologies analyzed so far, the Nanopil and Immunosignatures. In particular, I describe how I constructed grounded, exploratory scenarios and the role that these played in the exercises with technology developers. Finally, I discuss the merits and drawbacks of the proposed tools (§ 7.5).

7.1 Discussing the desirability of emerging technologies

In Chapter One, I introduced pragmatist ethics as providing a desirable middle ground in current approaches for the ethical assessment of emerging technologies. Unlike traditional normative ethics, pragmatist ethics does not aim at providing prescriptive judgments on emerging technologies. On the contrary, its purpose is to foster democratic debate about the desirability of emerging technologies – debate in which diverse communities of stakeholders can present their normative positions. Unlike modernist practices of technology assessment, pragmatist ethics does not aim to facilitate the introduction of new technologies into society. It instead aspires to provide tools to explore the normative positions at stake in deliberation on emerging technologies, to articulate implicit moral issues, and to foster discussion of the interplay of new technologies with moral vocabularies. In such pragmatist approaches to the ethics of technology the question of methods is pivotal. Traditional methods of normative ethics and bioethics insufficiently address pragmatist anti-foundationalism and anti-skepticism¹⁰⁷: in particular, if no normative framework can be taken as given, on the one hand, and current morality is the starting point for ethical reflection, on the other, how can emerging technologies be assessed with respect to their desirability?

Pragmatist ethics aims at “facilitating public debate and political decision-making on emergent moral problems” rather than offering solutions. In this sense, it is based on a “formal” approach of

developing procedures to ensure that all interested parties have an equal chance to participate in ethical debates and to influence their course effectively (Keulartz et al 2002: 15).¹⁰⁸

However, interventions should also be “substantial” if they are to facilitate public debate and political decision making. In particular, pragmatist ethics seeks to help overcome impasses caused by tackling new moral problems with old concepts and tools. In order to do this, perspectives should be opened up and moral conflicts explored.

The notion of a “moral imagination”, inspired by John Dewey, plays an important role in this more substantial type of intervention. Moral imagination is

¹⁰⁷ See Chapter One for more explanations on these aspects.

¹⁰⁸ This approach is inspired by the field of “discourse ethics” developed by Jürgen Habermas.

a cognitive human competence important for making decisions (Fesmire 2003; Coeckelbergh 2007); specifically, it is significant when we make decisions according to particular epistemic and moral criteria. We decide (not) to do something on the basis of what we (think we) want, on what we know about the world, and on what we think is right to do. In this sense, deliberation is a process of moral reasoning, and therefore making the moral content of this reasoning explicit should improve the process. Moral imagination plays an important role in this process, because it allows people to project themselves and their actions into the future and to “feel” how it would be. This capacity for “putting yourself in someone’s else shoes” – imagining how you would feel and act in a potential future situation – is a key reflexive skill for moral reasoning.

Moral imagination is therefore an important skill to develop in those who deliberate emerging technologies (Burg 2009 and 2010). Technology developers, policy makers or investors need to make daily decisions that concern future technologies, and which determine their nature and applications. Let’s take again the case of Immunosignatures. When researchers explore different possibilities for applying this scientific and technological innovation in a clinical context, they have to discuss these possibilities and make a decision on what is the best direction. In such a decision making process, different values and considerations play a role – for example questions of feasibility or profit. For instance, the expectation that Immunosignatures will change people’s standards of privacy guides scientists’ visions of how it will become embedded into society. Here the ability to imagine how you would feel and act in the future is an important skill¹⁰⁹.

Future “scenarios” constitute suitable tools for training and triggering the moral imagination so as to help deal with decisions on emerging technologies. Scenarios are “creative redescriptions” (Keulartz et al 2002) of “various competing possible lines of action and courses of conduct”. They offer a plurality of possible futures and, in this way, present a number of alternative ways to address problems. Within the pragmatist perspective, scenarios are particularly appropriate to use when deliberating emerging technologies because we have to deal with “new problems, for which existing rules and routines are not adequate” (*ibid*: 259). Scenarios are useful tools for stakeholder reflection on the desirability of emerging technologies because they enable them to try out different plans in their minds, and to imagine the consequences of their choices and actions. More specifically, scenarios enable stakeholders to imagine how concepts, systems of values, and responsibilities (in a word, our morality) can evolve together with new technologies. In this way, the desirability of emerging technologies is not

¹⁰⁹ It has been argued that since broader social and normative considerations play an important role in decisions made on the laboratory floor, then making scientists reflexive about the role of this type of consideration in their decision making process is important in order to modulate technology development in a desirable way (Fisher 2007).

discussed using old concepts and vocabularies, but in a manner that enables their novel and creative role to be explored.

Which possible future worlds are disclosed by certain technologies? How do they change our view of nature, each other and ourselves? What shifts in patterns of responsibilities and in relations of power do they bring about? Next, it can then be investigated whether our normative vocabularies - our usual, morally accepted and socially sanctioned ways of speaking- are still adequate in light of these changes and shifts, or whether they require revision. (*ibid.*, 260)

Scenario narratives require stakeholders to step out of their current routine and engage with moral dilemmas and problems. In these hypothetical “problematic situations”, stakeholders are asked to reflect on their moral vocabularies and to adapt them to new problems. Pragmatist ethics acknowledges the importance of scenarios, but doesn’t provide a toolkit for writing and using them. These aspects have been investigated in the context of Technology Assessment.

7.2 Scenarios as tools to foster moral imagination

Several types of scenarios have been developed in order to help trigger discussion amongst stakeholders in the context of Technology Assessment. Constructive Technology Assessment (CTA)¹¹⁰ has developed several tools in this direction. CTA aims to improve the conditions for technology development at an early stage of the innovation process. This is done by providing stakeholders with tools to incorporate knowledge about socio-technical dynamics into decision making processes (Schot and Rip 1997). CTA workshops are interactive, heterogeneous settings that create a “protected space” for stakeholders to reflect on technological development, position themselves with respect to others, probe each other’s worlds, articulate their perspectives, and listen to other points of view. Stakeholders therefore have to be able to articulate their position, defend their arguments, and criticize and learn from others.

Socio-technical scenarios can be used as inputs into these discussions. They are fictional narratives that, starting from an existing socio-technical configuration, describe potential future developments and dynamics triggered by decisions by different stakeholders (Rip and te Kulve 2008). Building on previous analytic research on socio-technical dynamics, these scenarios describe how technological innovation breaks up the existing socio-technical order and requires actors to “re-align” in different combinations (Robinson, 2010). Scenarios are used as tools to broaden stakeholder understanding of socio-technical dynamics and to develop reflexivity on one’s own role in shaping future configurations, as well as of

¹¹⁰ For an extensive explanation of Constructive Technology Assessment see Chapter One.

stakeholder interdependence. In this sense, they offer both a window of opportunity for modulating decision-making and a strategy for moving in a desired direction (Robinson 2010): “broadening perspectives and providing insights in sociotechnical dynamics enables actors to do better in their normal working environment and can eventually contribute towards more desirable paths” (van Merkerk and Smits 2008, 329). Although a discussion of the desirability of an emerging technology can be triggered by this interactive exercise, this is not its primary aim. As has been noted: “Scenarios offered entrance points for ethical discussion, but these were rarely taken up in the workshops; other issues such as start-up firms and regulation dominated” (Shelley Egan 2011, reporting Robinson 2010).

In order to foster ethical reflexivity among scientists, other tools, namely *argumentative scenarios*, have been developed and implemented (Shelley-Egan 2011). Based on Stephen Toulmin’s Model of Argumentation and on interviews with scientists, these scenarios show how a *claim* is justified by a *warrant* (based on an ethical theory), and is counter-argued with a *reservation*. These tools have been introduced into focus groups with scientists in order to develop their understanding of the argumentative structure of moral dilemmas around scientists’ responsibility and accountability. These tools share with socio-technical scenarios the goal of stimulating scientists to discuss their positions, specifically by focusing on ethical arguments. As schematic representations of the functions of and relations between claims, warrants and reservations, these tools can enhance actor reflexivity about the discursive structure of ethical arguments. However, they do not trigger actors’ moral imaginations.

This goal is met in the narrative form of *techno-ethical scenarios* (Swierstra et al 2009, Stemerding et al 2010, Boenink et al 2010). These are fictional narratives of future ethical controversies around new science and technology. These scenarios are built according to a three step approach in which 1) the current moral landscape is outlined; 2) the technology is introduced and some potential ethical controversies are played out; and 3) some closure to these controversies is given through (fictive, but plausible) technical, regulative or organizational solutions. These three steps can be repeated several times so as to articulate further future controversies and closures. These scenarios provide a tool for the anticipation of ethical controversies around a new technology and for the exploration of the dynamics of interaction between current morality and new technologies. These tools have been used in CTA workshops to initiate a discussion on the roles and responsibilities of different stakeholders in the development of a specific technology (Lithium Chip and BAN technology).

*Techno-moral vignettes*¹¹¹ have been used as tools to initiate discussion of potential “soft impacts” of emerging technologies; that is, the impacts of the technology on forms of life, concepts, and morality. These impacts are considered important by the lay public and should therefore be included in democratic deliberation on emerging technologies. However, some social actors consider these impacts “soft” because they are not clearly quantifiable, objective risks (Swierstra and te Molder 2012). For this reason, such impacts are often neglected in public discussions. Like scenarios, vignettes are narratives that focus on potential impacts of new technologies on ways of life and which give accounts of techno-moral change. However, unlike scenarios they do not “offer a line of action and course of conduct”. In fact, scenarios, like movies, are a narrative form that describes a temporal unraveling of events. In this way they draw attention to alternative pathways and dilemmas that can emerge as a consequence of particular decisions. In contrast vignettes are more similar to photographs: they are “snapshots” of the future (van Notten et al 2003). Unlike scenarios, vignettes do not show causal connections between events or explanations of how a certain situation occurs. While scenarios take stakeholders by hand to show the potential co-evolution of technology and morality step-by-step, showing causal pathways between events, vignettes describe a future state of affairs.

Techno-ethical scenarios and techno-moral vignettes provide useful tools for pragmatist ethics’ goal of improving the deliberative process by triggering the moral imagination. An important aspect of these scenarios is that they are “controlled speculations” (Rip and te Kulve 2008); that is, the scenarios do not claim to have predictive power, but are based on empirical study of the context and dynamics of the innovation process. The “controlled” or “grounded” character of scenarios makes them a good tool for triggering discussions in which participants are “experts” or stakeholders who have been asked to reflect on the development of a specific technology. However, scenarios have also a speculative aspect, because they “explore” a potential future in order to trigger discussion¹¹². Assessing the plausibility of expectations contributes to the aim of constructing techno-ethical scenarios/vignettes as “grounded explorations” of future problematic situations.

¹¹¹ These tools were initially developed within the project “Vignettes and scenarios”, funded by the Nanopodium program (initiative of the Dutch Committee for the Societal Dialogue on nanotechnologies). See

http://www.nanopodium.nl/CieMDN/projecten/overig/vignetten_en_scenarios. Vignettes were further elaborated within a project coordinated by the Rathenau Institute: Synbio Futures. This project aimed to engage youth political organizations in debate on synthetic biology. Vignettes were developed and employed as a tool to trigger such debate. For more information on techno-moral vignettes and their role in this project see <http://www.rathenau.nl/themas/project/synthetische-biologie/synbio-futures.html>

¹¹² The discussion of speculative ethics and the middle ground between “here and now” ethics and “exploratory ethics” was introduced in Chapter One.

7.3 Plausibility assessment for “grounded explorations”

The three steps of the plausibility assessment help in writing scenarios that are grounded in the current state of the (technical) art, social practices, and moral landscapes, and yet explore possible future interactions between technology and morality. First, analysis of expectations of the artifact articulates the current state of the art, including technical challenges and scientific uncertainties. Description of the artifact's technical components provides better understanding of the technology (for example, the laxative condition, in the case of the Nanopil), and excludes some scenarios (for example, DNA molecules' short lifespan excludes scenarios which envision the Nanopil being available at grocery stores). Furthermore, the articulation of competing technical alternatives allows the selection of a potential future “fork” in the decision making process (for example the wireless vs. blue bolus signal communication). Upstream discussion of the moral acceptability of these two alternatives might support a future deliberative process around them.

Second, the analysis of expectations of use articulates the “fictive script” of technology developers such that it can be compared to perspectives of other social actors. In this way, current practitioners point out conditions for the success of the emerging technology in a particular context, and highly speculative scenarios of widespread and unconditional social use are avoided. Description of current practice articulates existing social arrangements which might hinder some design choices and promote others (for example, some existing practices of the national screening program are not compatible with the blue bolus system).

These analyses guide the assessment of the plausibility of expectations that an emerging technology will bring about a desirable world. Such assessments explore possible value conflicts and divergences which can then be the starting point for storylines for techno-ethical scenarios/vignettes. Firstly they can point out the conflicts between values inscribed in different designs for the same artifact. This distinction is important in terms of not clustering different ideas of the artifact into one scenario. Second, differences between systems of values shared by technology developers and those of other social actors are articulated. In this way, scenarios can explore the ethical controversies that might arise around a certain technology. Third, such analysis examines the mediating role an emerging technology may take in a certain social practice. Scenarios can thereby point out the potential future interplay between technology and morality. In general, the plausibility assessment that I proposed excludes some scenarios as implausible

while at the same time identifying conditions, conflicts and options that affect the desirability of the emerging technology.

Vignettes and scenarios are vehicles for feeding the results of the plausibility assessment back to stakeholders and thus triggering a discussion of the desirability of emerging technologies that is both grounded and exploratory. This balance between the goal of groundedness and exploration deserves some attention. Assessing the plausibility of expectations requires one to analyze the state of the art in technology and research practice, social practices, and the normative positions of different stakeholders. This exercise provides a solid ground for non-speculative scenarios and vignettes; however, this type of grounding is not enough. In fact, scenarios and vignettes are not *predictions* of possible futures, but tools to trigger the moral imaginations of discussants in *ad hoc* exercises (such as workshops) such that they encourage a discussion of the desirability of emerging technologies. In order to achieve this goal, scenarios should be considered plausible by their readers. Scenarios that are considered implausible by the discussants will be easily dismissed. However, the plausibility of these scenarios is not an objective criterion. When writing them, the epistemic background of the target readers or discussants should be taken into account. What do they know about the technology at stake, or about the social context? What will they consider plausible? Scenario plausibility has to be measured with the yardstick of the target audience. Furthermore, the scenarios/vignettes should be anchored to what is considered relevant and important by target readers. In this way, they will trigger the interest of the discussant. However, it is important to highlight that if the goal of the whole exercise is to broaden discussion and explore potential problematic situations, then vignettes and scenarios also have to be capable of stretching the borders of what is considered relevant. An ideal intervention should therefore broaden the topics and issues considered relevant by stakeholders to deliberation on emerging technologies.

The plausibility assessments of expectations of the Nanopil and Immunosignatures presented in Chapters 3-5 and Chapter 6 respectively have guided the construction of techno-ethical scenarios and techno-moral vignettes based on these technologies. These scenarios/vignettes should be considered tools for the facilitation of stakeholder exploration of the desirability of emerging technologies while avoiding highly speculative discussion. I implemented two exercises to investigate the utility of these tools, which were developed in the context of the plausibility assessments. In this study, scenarios and vignettes based on the Immunosignatures and Nanopil were used to broaden discussion of ethical concerns with technology developers of these two technologies.

7.4 Techno-moral vignettes and scenarios in action

The main goal of the two exercises was to explore the possibilities of using plausible techno-ethical scenarios and techno-moral vignettes in the context of the protected space of an interactive stakeholder workshop. My research question was: how do these tools foster discussion of the desirability of an emerging technology?

In order to answer this question I organized two workshops with the developers of the Nanopil and Immunosignatures in which the potential ethical and social implications of these technologies were a central focus of discussion. The techno-ethical scenarios and vignettes were used as tools for broadening participants' ethical considerations. Since these exercises were conceived as a pilot, to help understand the feasibility of the use of plausible scenarios and vignettes in an interactive context, I opted for a homogenous group of participants. Another reason for this was the reluctance of the developers to engage in multi-stakeholder workshops given the early stage of technology development.

These two exercises had different set-ups. Because the context for Immunosignature use is not yet well defined, with technology developers swinging between two very different visions of its application, the scenarios seemed a good tool to explore these different paths. In the case of the Nanopil, context of use – as screening for colorectal cancer – was more clearly defined, and could be described and explored within the short narrative of a vignette.

The success of these tools in facilitating discussion of the desirability of emerging technologies depends on how plausible they appear to workshop participants and on their effects on discussion. In evaluating the exploratory role of the vignettes/scenarios I have therefore addressed a number of questions: do they succeed in creating suspension of disbelief amongst participants? Are participants willing to discuss the issues that are raised in the scenarios and vignettes? Did scenarios/vignettes trigger/broaden discussion of the desirability of the technology at stake? If so, in what ways? And what were their ultimate effects on participants?

7.4.1 Immunosignatures Workshop

The first workshop engaged some of the scientists involved in developing Immunosignatures (ImSg) at Arizona State University. One year after the beginning of my three-month laboratory engagement at the Centre for Innovations in Medicine (see Chapter 6), I invited the researchers involved in the ImSg project for an afternoon workshop. Amongst the participants were the

director of the center, three senior researchers (assistant/associate professors), four graduate students, and two technicians. A colleague, also involved in the composition of scenarios, participated in the workshop so as to share the function of probing participants. As preparation for the workshop participants received two scenarios exploring two possible paths in the development of ImSg. Both scenarios had two parts: a first phase exploring the short-term future, and a second phase covering a longer-term future. The workshop was organized in five rounds. During rounds 1 and 2, participants were invited to read and discuss phase 1 of the two scenarios. During rounds 3 and 4, phase 2 of both scenarios was distributed and discussed. The last round was devoted to the evaluation of the workshop and scenarios.

7.4.1.1 *Techno-ethical scenarios*

The two scenarios (reported in Annex Two) are explorations of potential pathways for the co-evolution of ImSg (and their social embedding) with values, obligations and responsibilities. In particular, they aim to explore the differences between the two visions around ImSg pointed out in the plausibility assessment of chapter 6: a patient-centered vision, and a doctor-centered vision. At the end of my laboratory engagement I had presented this double vision to the Center's researchers during a group meeting. The Center's director found this distinction helpful – even “inspiring” – because it pointed out a “fork” for a decision that they have to make. For this reason, I thought it relevant to explore this fork further in the scenario workshop. Rather than taking the visions as two phases in the development of ImSg (as researchers at the Center tended to do), the two scenarios explore them as different developments. Both scenarios begin with a similar description of the current situation, in which preventive and personalized trends in healthcare appear as desirable solutions to unsustainable healthcare costs. The two storylines then develop in different directions, showing how the two visions held at the Centre might trigger different dynamics of interaction between technology, society and morality. They also suggest ethical dilemmas and controversies which might emerge along each path.

Scenario 1 focuses on the “patient-centered model”, in which pre-symptomatic diagnosis is expected to empower individuals. According to this vision, people do not need doctors and are able to control their health autonomously. By enabling individuals to become more aware of their health, ImSg is expected to make them more responsible towards it. The scenario shows how these promises can be integrated with the promises of existing online platforms for information sharing among patients. This scenario thus explores the possibility that the system is used to promote “community” and “solidarity” values rather than only “liberal” and “private” ones, as the promise of “empowering the individual” might suggest. This ambiguity is expressed in a controversy about privacy rights around personal

information. Closure is provided by the decision, by the authorities, to make patients' personal information available online for scientific research purposes. Phase 2 of the scenario describes how ImSg, conceived as a way of empowering individuals through freedom from doctors and hospitals, might instead become a tool for exerting control over them. By its inclusion in healthcare programs, ImSg can be used by institutions to invite citizens to take up responsible, healthy behaviors, with the goal of reducing costs in healthcare. However, this also burdens individuals with new responsibilities and duties.

Scenario 2 develops the vision of a "doctor-mediated model", in which personalized diagnostics are expected to improve healthcare services. Here ImSg provides a tool for improving current diagnosis practices. Because it aims to improve current practice, researchers expect that this vision will be easier to realize in the short-term. The scenario shows that the promise of personalized diagnostics can have its own development, rather than merely being a phase of development of tools for pre-symptomatic diagnosis. The scenario shows ImSg – when used by physicians to diagnose specific health conditions, such as Valley Fever – changing medical practice. In this context, ethical questions arise around criteria for a "good" diagnostic examination. Conflict between traditional diagnostic techniques (based on discussion of symptoms and physical examination) and molecular diagnostics are voiced by primary care doctors, who are burdened with new responsibilities for interpreting results and for acquiring scientific knowledge, while also being increasingly time limited. Phase 2 of this scenario describes how ImSg for tracking cancer recurrence becomes included in hospital remote-care programs. These programs, driven by the economics of cost reduction, raise the question of what "personal care" is when clinical personnel disappear. While the autonomy of patients is fostered, and they are free to decide how to act with respect to their own health, they are left on their own without human contact with their physician.

7.4.1.2 Opportunities for exploration

The discussion started with comments on scenario 1. One participant reflected on the fact that if you have to pay every time you want to have your immunosignature tested, "this can hinder the development of the technology". ImSg should become open-source in order for people to become acquainted with it, as in the case of social networks such as Facebook. Questions of privacy and the possible misuse of data were addressed by another participant. Later on, the same participant explains that;

I wouldn't want to have my immunosignatures public [...] it's a personal choice; maybe some people want and some other people don't

The example of the social network Facebook was again brought up to point out how people's attitudes and behaviors around privacy issues change over time.

Another participant explained that, in this way, “everyone can work on this information” and “people can co-operate” to interpret information. Besides keeping costs low, this strategy would enable a “massive database” that would help make immunosignature interpretation more reliable (because it will be grounded on a large statistical base).

Another participant explained that he had never thought about the issue of privacy: for him, the issue is that people should have the right to access information about their own health. In this way, they can do their own risk assessment:

Because if you just put this out and say, here is what the system is [...] you make a decision about what you want to do just right now [...] they make decisions if they want this product, if they don't want it, they can share information or not [...] People already do it with 23andMe, there are so many companies out there providing direct information. This would do it ten times more. And I thought that it is good that people make their own assessment.

In line with this idea of the desirability of autonomous assessment of health, the role and importance of physicians in diagnostics was explored during discussion of scenario 2. One participant critically reacted to the idea of “depersonalization of medicine” articulated in the scenario, claiming that computers can do everything better and that there is no “particular value for personal contact”. Not everyone agreed with this view. One participant explained that it depends on the type of disease and the exact situation: “some talk can be very useful”. Another noticed that “patients do not know their symptoms for sure” and that “doctors can help understand”. Later on, during discussion of phase 2 of this scenario, another participant pointed out:

I think you have to be very careful about how the technology is introduced...they have the data, but to interpret it, I don't think should be the patient's task...that has huge implications for the patient...one has to stop and think about, how does that person respond to that information? Doctors would rather not give you a diagnosis rather than give you a wrong diagnosis, for example, if I suspect that the patient has prostate cancer, I will order for the test and I will wait until the test arrives before I say anything to the patient, because if the patient doesn't have symptoms, you do not have the expectation that you have prostate cancer, not even remotely, so if you introduce this technology you also have to provide it with an interpretation....

This controversy amongst participants around the desirability of patient-centered versus doctor-mediated practice continued such that the discussion eventually moved on to the issue of “how much people really care about their health”:

P1: this is a product and the first thing you have to do is to look for the market...we assume that our consumers are all people in US. How many people are willing to pay? How many people smoke? Or eat at mc donalds? The people who really care about their health on a regular basis are only a few and only those people, like 20% are our consumers. And then you have to design the controversies only on those people....in that case you won't see the scenario 2.2

P2: unless part of the incentive for your insurance is that you participate in this test

P1: if you define the consumer, you know the mentality and you can address these issues

Participants agreed that “many people simply do not care”, but while some of them thought that “You have to create the structure to motivate people to do it” (for example through an insurance system that benefits people who attend regular check-ups), others believed that a system like ImSg should just address “people who take vitamins”.

This discussion opened up another topic: the relationship between information, empowerment and desirability:

P1: because more people have information, more widespread, the better...more knowledge about health

P2: me and you might do something with the information, but the other people...they want the doctor to tell them what they have to do...it depends on the individuals

P3: you think that information leads to better decisions but this is not necessary the case

Participant 3 explained this point further:

P3: because you empower people, it doesn't necessarily mean that is a good thing. If people have a big problem with patients who do not take care of themselves, and they go to the doctor...because ultimately somebody has got to pay for that, right? And so, you go to the doctor and it's expensive and somebody has to pay.... Because ...it costs... for somebody who takes responsibility to do it in an early stage, then this is part of the conflict, how you handle a situation like this....we pay those cases one way or the other, because people do not take responsibility...that's why I was wondering whether it would be possible to have some kind of virtual game to observe how people interact...just to see whether you can shape the debate, so that you can prepare people for this. Because the technology is gonna come one day, either it's immunosignature...or...I am wondering whether you can shape the attitude at an early stage....attitudes change really quickly

The proposal of an online database is phrased in terms of being a “sociological experiment”. However, this experiment doesn't aim to learn about potential consumer demand, as other participants had mentioned through reference to marketing strategies. Instead, this experiment has the interventionist aim of shaping people's attitudes.

One participant also came up with a third scenario and a number of ethical controversies that they felt were missing in the two scenarios provided:

When I was reading this stuff, I think the main issue of this technology in scenario one and scenario two that you mentioned...you always focused on the post-symptomatic, but I was expecting some controversy or some scenario 3 in which you actually state that, since we are moving back towards the pre-symptomatic, we are telling people that you might get the disease earlier, something like that. So xyz [...] he or she finds out that she might be showing some part of the pancreatic cancer or some cancer signature so she freaked out and she went out and spent like 10,000 dollars and then later it turns out, you know, that it was just a little warning for the glute system [...] So I would see more that the controversy would occur in the early stage [...] if your dealing with cancer or diabetes stuff, there's a big window of 10 years and 5 years that you develop the cancer and there are so many early signs, so many early warnings there. At what point in time do you wanna decide what you wanna do. And at every time point there's a cost involved. So at what time point you can decide what you want to do and at what price [...] so i was thinking more over that would be a bigger controversy. [...] At what time should I seriously consider myself as a candidate for

pancreatic cancer. You start going to tell me very early and it starts very late. and nobody knows the proper time. You don't want to freak me out telling me that i might and you don't want telling me that it's too late. But no one actually knows the proper time to tell a person. So that's, i think, the biggest hurdle there is, not this FDA approval of taking the misclassification, or errors or all this.

7.4.1.3 The role of scenarios

How did the scenarios contribute to discussion of the desirability of Immunosignatures? As noted above, evaluation of these “grounded explorations” depends on their ability to broaden debate whilst still being considered plausible by discussants. Generally speaking, participants felt that the scenarios were extremely realistic and detailed. Although they didn't contest the plausibility of the scenarios, they often questioned their desirability. One participant was particularly critical of them:

you know what bothers me about these scenarios? They take the whole technology and follow one event. The implication here is that we should make a decision on this one single event, even though in the context you cannot make this judgement, because there are other things...

As he explained later, “without numbers, without quantification it is difficult to make judgments. Here it is a psychological decision, it is very hard to do”. Quantifications and numbers should be there in order to judge the desirability of an emerging technology. However, this discussion doesn't concern scenario plausibility; instead, the participant is making a normative point. As they explained:

unfortunately, it is probably a realistic scenario...that single events will have big influences and there is difficulty in having people doing a cost/benefit analysis...yes, there will be bad things happening, but there will be also good things happening

What the participant is saying is that a quantitative cost/benefit analysis *should* guide decisions on the desirability of new science and technology, though *in fact* this is often not the case. This normative judgment is also evident when the timeline of the scenarios is commented upon:

yes it might be that by 2017 we are going to be in trouble but I hope it is going to be faster than that. [...] I think it's too slow, I hope it's too slow.

Scenarios were often used by participants to articulate their own, normative views, and to discuss these with other participants. For example, one participant expressed their preference for scenario 1, in which data are available to all end users via websites, because he thinks that greater understanding and knowledge can be gained through this approach. Later in the discussion another participant said:

P1: scenario 1 is my worst nightmare

P2: really? I liked it so much!

P3: Scenario 1 is the Immunosignatures nightmare. Because yes, you enable people and you give them their information, but how you interpret is really really important.

This participant continued by explaining the ways in which the interpretation and mediation role of the doctor is important, particularly when dealing with healthy people who might not be ready to hear that a cancer is growing in them.

Commenting more explicitly on the outcomes of the discussion, participants agreed that interesting issues were tackled, because “when you present the scenarios everyone starts looking from different angles at what might happen”. Although some of them (especially the junior researchers) added that “this doesn’t change the way we do things...it is for later on”, other perspectives emerged from the more senior researchers:

before I was more into the scenario 2 mindset, I thought that a diagnostic analysis (...) would be better, but now I think screw it, let’s just make something that people can use, we can put the data out there and let’s just see what happens....because there are very irrational ways to look at things that we as scientist can never anticipate. We never think, never anticipate what people will do with things...you can have an app store, or I pad, maybe a pharmaceutical company cannot make profit out of it, but....there might be more additional value that we cannot anticipate, there is a lot of additional value that can come up from an information platform that we cannot anticipate.

Participants were not only willing to discuss the issues contained in the scenarios, but found them of interest, with the capacity to spark animated discussion. The normative content of the scenarios was discussed and reasons given to support or dismiss particular normative positions. Furthermore, as shown in the last quotation, discussion triggered by scenarios succeeded in broadening the considerations and evaluations of participants (“Before I was [...] but now I think...”).

It is important to note that the scenarios were not sufficient for broadening participant discussion. In fact, participants often tended to fall back into strategic thinking about how to make the technology more successful and to increase demand for it. In this workshop, reflection on the desirability of ImSg was often driven by a market logic. The role of the moderator was crucial in encouraging respondents to articulate and discuss the moral values implied by their arguments.

7.4.2 Workshop on the Nanopil

The second workshop was organized with the developers of the Nanopil (NP) technology. The workshop was organized over a year after the fieldwork described in Chapters 3-5, and took place on the day when the oncologist, the initiator of the NP, paid his monthly visit to the BIOS group at the University of Twente, the Netherlands. Besides the oncologist, all the researchers who were involved full time on the project participated in the workshop: the group therefore comprised one PhD student, two post-doctoral researchers, one assistant professor and one full professor. Furthermore, I invited another full professor

who had acted as a speaker during a public debate on the NP. I had the role of chair, while a colleague of mine, aware of my agenda, intervened in the discussion whenever she felt that probing was needed. The workshop consisted of five rounds of about 20 minutes each. In the first, participants were asked to reflect on why the NP is a good technology and on potential unwanted consequences. In each of the following three rounds a vignette was distributed and discussed. In the fifth round, participants were asked to evaluate the discussion.

7.4.2.1 Techno-moral vignettes

Analysis of expectations of the desirability of the Nanopil suggested a number of existing (implicit) value conflicts ripe for exploration. I selected topics relevant to the NP developers so that they (could) engage them more into the discussion. I then composed short narratives in which the selected topics played out.

Vignette 1 is about a 22 year old girl who complains about having to take a laxative for the NP to work. This vignette, based on the considerations which emerged in Chapter 4 around current practice in colonoscopy investigations, compares the NP with the stool test (FOBT). The vignette was expected to provoke researchers by questioning their claim that NP is desirable because it is more user friendly than the stool test that is currently available. Its goal was to provoke discussion of whether user-friendliness was indeed built into the design of the NP and of the trade-offs embedded in that design.

Vignette 2 is about a man who is waiting for results from the pill whilst carrying on with his normal routine; however, anxiety and nervousness about the result distracts him so as to cause a small car accident. This vignette was based on the concerns of the general practitioner, presented in Chapter 5, about the desirability of self-testing. This vignette's goal was to instigate discussion of the desirability of NP's promise to allow users to test themselves anywhere at any time. The vignette also aimed to trigger participant reflection about the most desirable system for sending results to patients (blue bolus vs. wireless).

Vignette 3 is set in a doctor's office, where Mr Smit, who has been diagnosed with cancer, complains that when he did the screening using the NP two years earlier he didn't receive a result. The doctor observes that the assumption of the screening test is that people are responsible and autonomous: Mr Smit holds some responsibility for not taking action when he didn't receive the result of the test. Vignette 3 was designed to trigger participant reflection about the fact that, though NP is expected to empower people, it also creates new worries, obligations and constraints: 'can' becomes 'ought'. In particular, it focuses on a shift in the responsibility attributed to patients for their health and in consequent increases in personal obligations. It aimed to foster participant discussion about the desirability of this broader social trend, to which they are contributing with the development of the NP. These three vignettes are fully described in Annex Two.

7.4.2.2 Opportunities for exploration

During the first round, participants were asked to articulate their expectations of the desirability of the NP. The voice of the oncologist was prominent in this part of the discussion. The topics were the same that emerged from the media sources and previous interviews: the suffering due to late discovery of cancer, the life-saving opportunities offered by screening techniques (exemplified in the cases of breast and cervical cancer), the burdens and unreliability of currently available screening techniques for colorectal cancer (the stool test), the high costs of colonoscopy-based screening, and the expected affordability and reliability of the NP. Participants were then asked to articulate potential unwanted consequences of this technology. This part of the discussion presented more heterogeneity. Issues that respondents mentioned included: potential fear of ingesting a piece of electronics; the possibility that users could trust the pill to the point that they neglect other signals of disease; privacy concerns because users might fear that the pill detects other types of information about the body and send it to interested parties; and, finally, false positives and false negatives.

In rounds 2-5 a broader range of topics was tackled. Throughout these rounds, the discussion often touched upon the theme of responsibility. Commenting on vignette 1, one participant observed that that:

this person [in the vignette] doesn't want to face reality. The question is: Do you want to know? This is a difficult question. It's a matter of choice.

This comment opened up a discussion about whether people have the right to decide not to know about their health condition or if, instead, society should encourage them to test themselves. Reduced insurance premiums were proposed as a way that society could introduce an incentive for self-testing. A participant pointed out that this might not be desirable, and could in fact be considered another unintended consequence of the NP. This conflict between knowing and not knowing opened up the question of the information and education that would be provided to potential NP users. In the context of this discussion one participant noted that:

doctors should always explain to patients that they went through it [the test] themselves. If you have never experienced pain, if you don't know what pain is, you cannot tell to the patients...

So: doctors should try the NP themselves. Interestingly, the role of the doctor and her responsibilities turned to be quite relevant. In the fourth round, discussing the case in which the result didn't arrive to the patient, some participants agreed that responsibility should *never* be put on the patient. However, a participant reacted to this:

I am not in favor of putting all the responsibility on the physician, I like if some responsibility is also on the patient. Because I see many cases in which the clinicians

make mistakes and things eventually go right only when the family of the patients makes them notice it, or they ask them to look again.

Interestingly, another participant observed that in the case of a screening test, we should not talk about “patients” but “clients”. Because they do not present symptoms, and consider themselves healthy, clients are less tolerant of undergoing complex procedures. For this reason, responsibility for the good quality of the screening procedure should not be put onto clients but onto the organizers of the screening program:

it is also true that in general it is good to have everything, data information and files, under control. But in the case of the pill, you have to be perfect. Because you are asking people to come to you when they are healthy, you are asking them a lot and you cannot take any risk.

This question of responsibility in the case of a malfunctioning system brought the discussion back to the earlier point regarding the responsibility of the individual for testing her health condition, and the role of insurance companies in this:

P1: the way I see it is: as insurance company client you have the choice of buying a package and if you go for one in which you pay less, then you accept to take responsibility

P2: well I was wondering whether this is fair [...]

P1: [...] this is their economic model

P3: but this is not a nice model...it is big brother like.

This unsettled controversy shows how the cases introduced by the vignettes did indeed spur debate on moral issues. Issues such as that of attribution of responsibility for individual health were largely discussed after the introduction of the vignettes. In this sense, the vignettes succeeded in putting new issues on the discussion table.

Besides opening up ethical controversies, participants were probed during the vignette rounds to address problems in a constructive fashion, such that discussion explored potential solutions to the problems raised in the vignettes. The NP was often acknowledged as being part of a broader techno-social system. This is shown in many of the responses participants gave, such as: “this is a matter of management of information”, “this is a question of organization”, “this is a problem of how the test is distributed”, or “this is a broader (bigger) problem”; similarly, it was said to be “an issue of informing” or “educating”. By emphasizing that good use of the NP depends on societal configurations, the role of design choices and development decisions (and consequent responsibilities for them) was played down. However, at some points “technical solutions” were pointed out. For example, while discussing the case of the user not receiving the results of the test, one participant underlined that in such a case the initiative to check that everything is going right “should be part of the organization”. Another participant pointed out that the user might also not have taken the pill. The first participant responded with another type of solution:

I think you can also have something on the pill that detects the temperature...if the pill is not at a body temperature the thermometer we see so...we can check whether the pill was taken.

In this way, the moral problem of ascribing responsibility for pill malfunction is partially addressed through a technological solution.

Finally, on several occasions participants reflected on the video that they use when they want to show a broader audience how the Nanopil works (see chapter 3). At several points in the discussion, participants commented on the inadequacy of the video as a promotional tool. For example, during the discussion of vignette 2, one participant commented that:

it is not the best video, because it doesn't give you an idea of the time dimension, it is very different from reality, it takes 10 or 20 hours before you receive the result [...] this [idea] should be incorporated in the video somehow, maybe a little clock.

And later on:

P1: for me the message is that it is beneficial to have such a pill and that the education that we have done up to now is insufficient, it should be done better...the movie should be changed in various way to make it more clear to the clients. We got used to the movie, but now we know that many things do not work

P2: also the doctor should be involved when making the movie, because now, the doctor was not involved...

P3: yes, I think it was a good approximation, at the time it was done, but we should fine tune it a bit more, but now we have to improve it and refine it.

P2: I think it is also good to show that it allows a clean surgery

P3: but of course a movie is always an approximation of reality, how much detail do you put in it?

P2: it depends on who is your audience...it has to be such that the patient understands the background, because half of what you tell a patient they don't hear.

What is interesting in this exchange is that the participants, who have previously referred to the importance of good “education” and “information” on the Nanopil, reflect on the way in which they have been educating and informing. The participants thus re-evaluate the means that they have employed to communicate to a lay audience, and propose some strategies for improvement.

7.4.2.3 The role of vignettes

Vignettes contributed to fostering discussion of the desirability of Nanopil in different ways. First, because of their thick narrative, the vignettes provided a concrete reference point during discussion. By recalling “this person” or “this case” in the vignette, participants contextualized their arguments, for example by saying “You might say ‘what the hell, I am not doing it, I prefer to go the *movie*’”. Potentially abstract ethical questions are thereby tackled in a more concrete, contextualized way.

This detail rich character of the vignettes also has a further consequence: it makes some ethical concerns appear very situated, and therefore easy to dismiss – for example by suggesting that “this seems like a bad story of a bad laxative. It is

not so bad to take the laxative". Similarly, the argument of vignette 1 can be disregarded as a function of the girl's personal attitude, rather than being addressed as a legitimate moral question. The narrative details of the vignettes, while contributing to the consistency of the story, therefore have the drawback of including variables that can be used by discussants to dismiss the argument by undermining its relevance. The plausibility of the vignettes and their grounding in concrete technical, social and moral aspects, which are acknowledged by stakeholders, here plays an important role. In fact, in order for discussion to proceed and the vignettes not to be considered far-fetched, it may be necessary to explain that the "bad story of a bad laxative" is in fact the current story for patients who have to undergo a colonoscopy.

The vignettes, by proposing a snapshot of a problematic situation, were also found to trigger discussion of some useful topics not explicitly tackled by participants in the first round: for example, the burden on users, the anxiety of a portable/ingestible test, and where responsibility lies in the case of malfunction. Furthermore, the discussion also included other aspects not explicitly addressed in the vignettes, for example the quality of the video on the Nanopil. They therefore achieved the intended goal of broadening technology developers' discussions of the desirability of the Nanopil.

7.5 Discussion

This chapter has shown that the plausibility assessment not only provides an analytical tool for the ethics of emerging technologies, but that it also can support the creation of tools for intervening in the process of technology development. In particular, the plausibility assessment can help in building techno-ethical scenarios and techno-moral vignettes. In the context of interactive workshops, these scenarios and vignettes are a tool for triggering the moral imagination of participants and facilitating a grounded but exploratory discussion of the desirability of emerging technologies.

These tools were employed in two exercises that I designed with the goal of triggering the moral imaginations of technology developers around the desirability of the products of their research¹¹³. These exercises aimed to explore the use of vignettes and scenarios in such contexts, and to point out lessons for further use of these tools. In §§ 7.4.1.3 and 7.4.2.3, I have already shown that

¹¹³ An in-depth comparison between the two workshops should take into account the differences between visions of the Nanopil and the Immunosignatures, the disciplinary background of the participants, and cultural divergences in tackling ethical issues between the Netherlands and United States.

scenarios and vignettes did indeed trigger technology developers' discussions of the desirability of the Nanopil and Immunosignatures. In particular, they were taken as a plausible point of departure and acted to broaden their discussions and considerations. I have also already pointed out where there is room to improve these tools. For example, scenarios do not necessarily direct discussion towards issues of moral desirability – participants may be more focused on issues of profit, or economic desirability. As explained, a moderator can play a role in pointing out value conflicts in participant discourse. Similarly, narrative details and structures have the advantage of triggering participants' imaginations and making the stories more plausible. However, they may also confine a normative argument to a specific context.

These exercises have also contributed to knowledge about the design of these kinds of tools. Firstly, in building vignettes and scenarios it is important that the elements of moral reflection should not be too numerous, in order to avoid discussion going in too many different directions. Because these elements of moral and ethical reflection are the outcome of a previous (plausibility) analysis, they may require more background and explanation than the narrative form can offer; the result therefore may be too complicated for readers who are not aware of the previous analysis. In this sense, vignettes provide a better tool because they provide only one or two issues for discussion. Second, the fact that I was well acquainted with the context, the participants, and their research allowed me to refer to specific cases and situations, not only in the vignettes and scenarios, but also during the discussion. For example, I could refer to specific projects or problems that I observed during my fieldwork. This helped to make the ethical discussion more concrete and relevant for participants. Third, scenarios and vignettes trigger the imaginative capacity of participants by thickening ethical considerations with concrete details. Details from interviews and fieldwork give a voice, sex, age, time and place to otherwise abstract and disembodied ethical arguments. These details, together with the consistency of the story, contribute to the plausibility of the scenario and discussants' suspension of disbelief.

Another point to be mentioned is that the two workshops were attended by relatively homogenous groups of stakeholders: other than the oncologist in the Nanopil workshop, the participants were all scientists/technology developers. As has been previously pointed out (Robinson 2010), heterogeneity is important in interactive workshops, especially in enabling the "heating up" of moral perspectives (Shelley-Egan 2011). The role of the oncologist in the Nanopil workshop was indeed important for bringing a different set of interests, values and principles to the discussion. However, the homogeneity of the group may also be functional; for example, it is logistically easier to gather a uniform group of participants, and this could encourage the use of such exercises on a more regular

basis (especially at an early stage of technological development, when there is less at stake).

A final reflection concerns the timing of this type of exercise. What is the right time for these exercises in moral imagination? ImSg and the NP are at an early stage of development. At this stage, technology developers feared that discussion of their desirability with a heterogeneous group of stakeholders would boost both hopes and hype. For this reason, the exercises were limited only to technology developers. Such exercises offer an opportunity to bring discussion of the desirability of emerging technologies into the laboratory, and to affect research decisions at this early phase. As one of the participants in the workshop on the Nanopil announced at the end of the session: "Next time, we will have the Nanopil lying on the table". However, it also emerged that some of the problematic situations introduced by the vignettes and scenarios were discarded by participants because they were considered to be too far along in the technology development process. In evaluating these exercises a graduate student commented: "I'm not sure whether it will actually affect any of my actions over the next year or two of my PhD research". We might ask, then: do these exercises positively contribute to modulating the process of technology development?

I think they do. The two workshops I organized may (or may not) have directly traceable consequences for the development of the Nanopil and Immunosignatures. However, they do show that spaces can be created in which the desirability of emerging technologies are explored in a grounded manner. The plausibility assessment of expectations presented in this study plays a fundamental role in doing this. In fact, it points out implicit value conflicts in expectations of the artifact and between potential actors regarding its use. Furthermore, this assessment dismisses the instrumentalist misconception that a new technology will have predetermined, desirable consequences. In this way, the rich interactions between technologies, societies and morality are brought into upstream discussion of the desirability of emerging technologies. Embodying this analysis in a narrative form, techno-ethical scenarios and techno-moral vignettes are "grounded explorations" that trigger the moral imaginations of their readers. On the one hand, they encourage discussion of future technologies that is not futuristic, because it is based on analysis of current practice. On the other hand, they also avoid foundationalism in their exploration of present decisions by assuming that our ideas of desirability and morality co-evolve with our social structures and technologies. In the spirit of pragmatist ethics, the approach that I am proposing contributes to the goal of improving conditions for democratic deliberation on emerging technologies. It does this by providing a methodology for the exploration of the desirability of emerging technologies in a grounded way, and thereby adds to the creation of a toolbox for ethical technology assessment.

POSTSCRIPT

Building-blocks for Ethical Technology
Assessment

The subjects of our deliberation are such as seem to present us with alternative possibilities: about things that could not have been, and cannot now or in the future be, other than they are, nobody who takes them to be of this nature wastes his time in deliberation.

(Aristotle- Rhetoric [1357a])

Between “grounding” and “exploring”

Having arrived at the end of this book, I now return to my initial question: *is it worthwhile to engage in a prospective reflection on the desirability of emerging technologies?* Traditionally, this kind of question is addressed in the context of Technology Assessment. More recently, ethicists have also joined the debate stressing the normative character of such a prospective assessment. Some authors have pointed out that reflections on emerging technologies are often too speculative and should instead be *grounded* on the “here and now” (Nordmann 2007b; Nordmann and Rip 2009). Other authors have remarked that a philosophical *exploration* of the meanings and implications of current promises is valuable to prepare society for future challenges as well as to interpret the present (Grunwald 2010). With this study, my aim is to find a balance between “grounding” and “exploring” the desirability of emerging technologies.

In approaching this challenge, I have articulated the *epistemological* problems that emerge when one deals with expectations surrounding emerging technologies. I pointed out that, at an early stage of technological development, these expectations are uncertain, strategic and embedded with normative connotations. For these reasons, an explorative reflection of their desirability requires a preliminary assessment of their *plausibility*. How likely are the expectations that a technology will realize certain desirable worlds? To address this question, I proposed an analytical and methodological framework. According to this framework, an analysis of the expectations of the *artifact* and of its *use* provides the ground for assessing the plausibility of the expectations that a technology will have a social *value*. Through analyzing expectations surrounding the Nanopil and Immunosignatures, I explained the theoretical and methodological aspects of this framework as well as showing the types of analysis it enables.

Consequently, my study offers normative ethicists a methodological and analytical framework to address questions about the plausibility of emerging technologies. By analyzing expectations surrounding the emerging artifacts and its context of use, ethicists can make their normative assessments of new and emerging technologies more grounded, and therefore less speculative. Such an analysis also addresses the “normative deficit” of Technology Assessment. My analysis encourages societal reflection on the morality implicit in deliberations on emerging technologies by: eliciting the beliefs and values that are inscribed in the materiality of an artifact; pointing out the interests and normative positions of actors involved in the expected context of use; and, accounting for the non-linear impacts of emerging technologies. Such an approach overcomes the “normative” deficit of technology assessment. By articulating the moral values and norms in

expectations on emerging technologies, the normative positions of stakeholders can be both explored and discussed.

Towards Ethical Technology Assessment

The main contribution of this study goes beyond the current approaches to the assessment of novel technologies. The assessment of expectations' plausibility that I propose promotes early (explorative) democratic deliberations on the desirability of emerging technologies that are epistemologically grounded (not merely speculative). In so doing, it contributes to a pragmatist-inspired form of Ethical Technology Assessment. This ethical technology assessment is based on the normative ideal of deliberative democracy. The core of this ideal is that everyone who will be affected by a technology should be able to have a say in the assessment of its desirability. Improving this process requires including a variety of stakeholders and different perspectives in deliberations, as well as improving the quality of the discourse on emerging technologies. The quality of the discourse is not improved in abstract and ideal deliberations in which a community exchanges judgments and reasons. Rather, in concrete contexts in which strategic considerations, interests, and negotiations among stakeholders take place. The plausibility assessment proposed in this book improves the conditions for democratic deliberations about emerging technologies in a plethora of ways:

- First, my analysis of the plausibility of expectations contributes to a reduction in speculations about the desirability of implausible contexts. For example, it can be clarified that controversies about the sale of the Nanopil to a larger public are irrelevant at the current stage. In fact, the Nanopil will not be stored on the shelves of the grocery store, since the DNA molecules that are attached to the lab-on-a-chip within the pill have a very short lifespan (see § 3.5). Similarly, in the case of the Immunosignatures, researchers currently investigate possibilities for samples to be sent to a central laboratory rather than analyzed in users' homes by a point-of-care device. This implies that scenarios of the device lying on the kitchen table should be abandoned (see § 6.4.1). An assessment of expectations anchors the reflection on the impacts of emerging technologies to the research practice and reduces speculations about the desirability of emerging technologies.
- Second, the analysis of the (technical) specifications of an expected artifact rules out misleading assimilations to other technologies. For

example, it is important to point out that the type of information about one's health condition provided by the Immunosignatures is epistemologically different from the one provided by genetic tests. For the former, the information is contingent on a current state, whereas for the latter test provides information of a disposition. As a result, the information resulting from a genetic test that an individual belongs to a risk group will accompany them for life, while the signature of one's immune system may change continuously (see § 6.5.3). Immunosignatures share certain aspects with genetic tests, but it would be misleading to raise exactly the same ethical concerns for both tests. Comparisons between these technologies should be cautious and should take into account the relevant differences.

- Third, this analysis of expectations articulates assumptions that are often hidden from the actors involved in the innovation process. For example, when I fed my analysis back to researchers from the Centre for Innovations in Medicine in Arizona, I pointed out how their expectations of Immunosignatures seemed to swing between, on the one hand a scenario in which they were used as a traditional diagnostic tool, and on the other hand a scenario in which they were used as an innovative tool for personalized and preventive medicine (see § 6.4.1). I showed them how these expectations imply different contexts of use, stakeholders, roles to take up and ultimately different visions of the world. After my presentation, one of the Center's co-directors acknowledged the unintentional ambiguity of their rhetoric and expressed the need for a more focused and clearly defined position about the path that they want to take. Similar observations can be made in the case of the Nanopil. In fact, Nanopil developers hold two models of how the result can be communicated to the user, by radio signal or, by releasing a blue dye. Engineers point out the technical difficulties associated with releasing a blue dye and relative feasibility of the radio signaling. By analyzing the potential context of use of the Nanopil, I was able to point out that a decision regarding the best design should also take into account the expected context of use of the Nanopil. In fact, the blue dye system could work for a self-test, but it would prevent the Nanopil from being suitable for a national screening program for colon rectal cancer (§ 4.3.1). The analysis of expectations can improve technology developers' decisions and make them more sensitive to the social context in which a technology is expected to be embedded

- Fourth, the plausibility assessment makes explicit the systems of values embedded in technology design and compares them with the system of values shared by other communities of stakeholders. For example, in the case of the Nanopil the patient organization may value privacy more than efficiency. Alternatively for patients, the disgust of taking a laxative is worse than collecting stool (§ 5.3). Pointing out implicit conflicts between and among stakeholders' values is important in order to foster a pluralist democratic debate about these values at an early stage of technological development. In such a debate, diverging ethical stances and value systems are given the space for articulation. These moral disagreements are made explicit when the technology development is still ongoing and can therefore be included in the development of new technologies. For example, in the case of the Nanopil's system to communicate results, technology developers might be asked by other stakeholders to take into account not only considerations of efficiency, but also considerations of privacy. This could imply that they have to spend more resources on the development of a technologically more difficult, yet more private, Blue Bolus system. This early consideration of potential moral controversies could avoid polarizations later in the ethical debate, when design choices have already been made.

As I said, every technology assessment is an evaluation and as such is based on some criteria or values. In these evaluations, moral values and norms play a role. The judgment that a desirable diagnostic technology should be cheap can refer to values of distributive justice, according to which public resources should be equally distributed in society. It can also refer to values of profit and economic return for the producer. Both judgments are based on a more or less explicitly articulated idea of "good" and in this sense they are moral values. An assessment of expectations' plausibility makes explicit the moral values and norms that are often implicit in judgments about the desirability of emerging technologies. Such increased awareness of the normative assumptions makes the debate more straightforward about what is really at stake and who the actors are which should be involved in the debate (because they have something at stake). In this way, the most relevant voices and perspectives are brought to the discussion table in order to have their say in the deliberations of emerging technologies.

- Fifth, the assessment of plausibility of expectations broadens the discourse on impacts of the expected technology. According to the instrumentalist logic, a technology is designed to have a clearly defined, valuable impact. My analysis points out that emerging technologies can be expected to achieve much more than the intended effect because they

change practices, standards, concepts, values and responsibilities at the same time. For example, I have discussed how expectations of the Nanopil carry a particular normative vision of the relation that we should have with our body (§ 5.4). The epistemic distance implied in the practices of monitoring ourselves with the Nanopil might then affect the relationship we have with our body. These types of scenarios are not predictions but rather they maintain a fictional character. They hold the potential to show that by addressing one problem the device might create a new practice with new problems. This analysis helps to create new descriptions of practices introduced by novel technologies. For example, it can affect technology developers' decisions about the best system to communicate the result to the user: the release of a dye in the feces instead of the radio signaling system would help the user to be more in touch with her body. However, these considerations can also be taken up on a different level. For example, the patient organization or the Ministry of Health may decide to foster a campaign to raise people's awareness and educate them that when using the Nanopil they should also learn how (as one of my interviewees said) to "feel their gut". Therefore, they help to avoid the misconceptions of linear expectations. Furthermore, they suggest new conceptual tools that can help to address problems raised by novel technologies

An exercise of imagination on the potential impacts on morality that a technology may have also allows stakeholders to reflect on questions of the good life. To reassess norms, re-evaluate priorities, and to re-define concepts as well as values. It helps in imagining how technologies affect our concepts, value systems, and the way we conduct our lives –in short, our morality. In this dynamic process some values will be demoted in favor of others, some practices will change their meanings, some forms of life will extinguish. These are matters that are worth discussing because they concern the whole of society. In this way, not only more perspectives, but also more issues and questions become debatable and become the object of deliberation.

- Finally, the plausibility assessment points out the heterogeneity in expectations: different artifacts, a variety of users, diverging values and a plethora of impacts and ethical controversies. As I have argued above, at an early stage of technology development some ethical conflicts might still be latent which covers up a potentially problematic situation by optimistic and ambiguous expectations. Such expectation might gather stakeholders together in an abstract illusion of agreement. Therefore, it is important to understand the nature of the problem explicitly presented in

expectations and to critically reconstruct it, making explicit any hidden problems.

By showing the diversity and heterogeneity of claims in expectations, the plausibility assessment questions their apparent universality, it points out problems and creates space for deliberations to start. It provides alternative visions of futures that improve deliberation. As Aristotle nicely illustrates:

The subjects of our deliberation are such as seem to present us with alternative possibilities: about things that could not have been, and cannot now or in the future be, other than they are, nobody who takes them to be of this nature wastes his time in deliberation. (Aristotle- Rhetoric [1357a])

We deliberate only on what can be different from how it is when we have a range of possibilities for our actions. The plausibility assessment presented in this book shows that multiple futures may be implicated in a single expectation. In particular, it shows how some roles, responsibilities, concepts and values are contingent: they can be different from how they are now and from how they are expected to be. It makes the values and the moral concepts explicit in the discourse and includes them in the process of deliberation, rather than leaving them as an unquestioned background. In this way, the plausibility assessment opens up the space and the scope of the deliberative process.

In the context of emerging technologies, a democratic society should expand the space of what is plausible to discuss and deliberate on, and include more perspectives and issues for discussions. The plausibility assessment provides the conditions for realizing this goal. It does so by mediating between two extremes of 'everything is possible' on the one hand, and 'false necessity' on the other. It grounds the discussion on values and impacts in the research and social practices, excluding some scenarios and discussions as implausible. At the same time, it points out that the values inscribed in expectations of future socio-technical systems depend on specific value judgments and worldviews and are therefore contingent and questionable. Technological futures are not inevitable. Since alternative futures are plausible, democratic deliberation on them should be encouraged.

Interpreting and intervening

The ethicist, philosopher, or social scientist engaged in this type of Ethical Technology Assessment has the role of improving the conditions for deliberation in which social actors, who have something at stake, take part to give reasons about the desirability of emerging technologies among stakeholders. To this aim,

an *analytical* and an *interventionist* phase are necessary. The *analytical* phase consists in assessing the plausibility of expectations about the artifact; its use and its desirability. Such an analytic phase is not an activity for “armchair” philosophers. In fact, it requires fieldwork and mingling with stakeholders in the “real world”. This fieldwork provides the grounds for a re-describing of the expectations of emerging technologies. The goal of these re-descriptions is to elicit the morality that is sometimes implicit in the expectations of the artifact and its use. This is important in order to uncover the heterogeneity in these expectations and to point out alternatives within present visions of futures. The *interventionist* phase consists of feeding this analysis back to stakeholders. In order to do this, specific tools have to be designed. The scenario workshops with technology developers, presented in Chapter Seven, are examples of these tools. Multi-stakeholder workshops or public debates are other examples of how this analysis can be fed back into society. Generally speaking, these tools need to be able to foster deliberation rather than having a report-like form.

The expertise of the Ethical Technology “assessor”, doesn’t concern normative contents; that is, the ethicists do not have a priority in judging what is good or bad about emerging technologies. Instead they have the role of safeguarding and improving the conditions for a democratic deliberation on the desirability of emerging technologies to occur among stakeholders. This doesn’t mean that ethical technology assessors are neutral mediators of the process or that they hold a normative-relativist position. As explained earlier, the normative framework comes from the ideal that democratic deliberations lead to better decisions. This ideal also resonates with a form of “occasional philosophy” (Thompson 2002). As problems are contextual - time and space dependent rather than fundamental and radical - also conclusions might be contextual and provisional. This approach promotes conclusions that might work for the moment, without reaching the ideal endpoint of absolute “moral correctness”. The contingent conditions of space, time, and cultures are seriously taken into account within this perspective. Despite the fact that moral norms have to be shared for functional cooperation in any society, their contingency is and should be made clear and legitimate.

To conclude, can we control technology development for the better? Technology Assessment says that we can. However, many variables are difficult to anticipate. In addition, as philosopher Gunter Anders says: “the world changes anyways often beyond our control”. However, this does not mean we should just wait and witness these changes passively. What we can do is interpret them: philosophy helps to achieve this goal. In the Hegelian tradition, philosophy is a reflection on our times. As owls spread their wings at dusk at the end of the day, so too do philosophers as they look back at the ages passed to interpret it. However, this interpretation is not necessarily retrospective. What I showed with this study is

that philosophers can help interpret our current time on the basis of an understanding of the past and an imagination of the future. A philosophical reflection helps society to be reflexive about its past and become aware of the directions it is taking. In this way philosophers can contribute to improving society. The role of the philosopher I propose here is not like the one of the Hegelian owl, who has a perspective from above. Instead, philosophers need to be “grounded explorers” who enter laboratories, collect details on social practices, gather the preferences and visions of stakeholders and critically probe them. Whether these analyses will change the future remains to be seen, but they do contribute to making sense of the present.

ANNEX 1

Images of Nanopil and Immunosignatures

Figure 1 from (Berg 2009: 39)

Figure 2 From the patenting application, available at <http://www.wipo.int/patentscope/search/en/WO2009104967>

Figure 3 Drawn by a researcher from the BIOS group during an interview

Figure 4 The Immunosignaturing process: read from bottom left (Courtesy of Muskan Kukreja)

Figure 1: Image of the peptide arrays: These peptide arrays have evolved from self-spotted low-volume arrays to a highly reproducible and commercially printed microarray printed in the

Figure 5 From (Stafford et al 2012) scan of the random peptide microarray (each colored spot correspond to a peptide previously printed on the array. The color depends on the intensity of the binding between each peptide and the antibodies in the sample—that has been run on the array).

Figure 6 (From Stafford et al 2012) Five analytical representations of the data retrieved by the quantification of data showed in fig. 4. After the measurement of the intensity with which the peptides lighten up, these data are analyzed with another software (also used for DNA microarray). Such software produces heatmaps, PCA and other graphs (see fig. 3) which highlight different correlations and visualize patterns in the data. The blue color indicates a low binding of peptides and antibodies and the red indicates an high binding.

Techno-ethical scenarios and techno-moral vignettes

1. Techno-ethical scenarios on Immunosignatures

Scenario 1 part 1

Current situation

Partly due to science and technology advancement, we are currently experiencing an increase in the longevity of the American population. This larger demographic of elderly persons, implies an increase in the amount of sick people, since are more prone to get sick or diseased. These costs are not sustainable in the long run.

A conspicuous number of experts from diverse fields points out that in order to address this problem, the adopted healthcare model has to move away from a symptomatic “one size fits all” treatment-based approach. A more affordable and effective model should lead towards 1) personalized and targeted care, 2) early and individualized diagnostics and 3) preventive risk predisposition.

These trends are visible in a broader landscape of actors operating within the sector of innovation in the American healthcare. To point out a few examples, hospitals promote innovative wellness programs in which patients are motivated to change their lifestyle; FDA encourages pharmaceutical companies to develop companion diagnostics; national and local policies of health educations raise citizens’ awareness with prevention information campaigns.

The Biodesign Institute at Arizona State University is active in supporting science and technology contributing to this broader purpose. Immunosignature research, at the Centre for Innovations in Medicine, aims at developing a tool for early, pre-symptomatic and personalized detection of diseases. This preventive healthcare model promotes a **“patient-centered” approach**.

In a patient-centered vision of healthcare, people do not need doctors and are able to be in control of their health in an autonomous way. In the long term, this vision implies that people commit to a healthier lifestyle and are responsible for their health without the mediation of a doctor. Some online platforms like patientslikeme.com, curetogether.com, inspire.com are already heading in this

direction: they create social networks in which patients can compare their data and support each other. The concept behind Immunosignaturing (IMS) is to contribute to this aim. It enables individuals to become more aware of their health and invites them to perform daily monitoring. With Immunosignaturing, as Dr Stephen Johnston explains, “Each individual could see their own biosignatures and the implications of these signatures on a regular basis. This should empower them to take more responsibility for their own health and stimulate their own scientific education on what this means”.

2012-2017

CIM directors decide to pursue the patient-centered vision and they contact different online platforms in which patients interact. In January 2013, the R&D director of the for-profit organization “patientslikeme.com”, which provides a platform for patients to exchange information and “converts their stories in computable data”, contacts the directors of the Centre for Innovation in Medicine. He has read about Immunosignaturing from their website (in which CIM recruits people who want to donate biological samples and share their health information to contribute to the IMS research). The two agree to sponsor the IMS project on the “patientslikeme” website in return for free immunosignatures for their users. In a video interview published on patientslikeme.com, CIM co-director Neal Woodbury explains the difference between IMS and genetic testing: “Genetic tests tell you about your genetic make-up, that you share with your family. Immunosignatures tell you a story that is unique to you. This is the story of the places you have visited, the food you have been eating, the things you have been doing. Your immune system stores all this information as a big book and by reading its pages day after day you can understand the implications of your daily choices on your health”. A disclaimer on the website explains that IMS is still a developing technology and the data and its interpretation is still uncertain. After few months of collaboration, JameX, a diabetic user on “patientslikeme”, compares his IMS with that of JulieD and comments on the blog about the surprising similarities between their condition and the IMS picture “These images are helpful beyond words... I feel connected to people who are suffering from the same symptoms as myself. And we know we can do something to change them. You have made me feel empowered...”. Some smokers start an online support group on patientslike.me in which they motivate each other to quit smoking.

In September 2014, the behavioral psychologist Dr Shannon Kyle comments on the phenomenon of health social networks in Time magazine, “the IMS images are constantly changing and when patients see this they feel that they can control their health. Therefore they are motivated to change their smoking habits. The fact that they can openly share this information with other users commits them to a healthier behavior. Solidarity and community values play an important role in

this". In February 2015 Google Health offers to have IMS has an available test on their website. Health Tell company, owned by Stephan Johnston and Neal Woodbury, starts doing IMS.

In December 2015, the Office of Privacy and Civil Liberties comments on the flow of sensitive data that endangers privacy. "Furthermore, information like that provided by IMS is not really robust. They show a picture with different colors that changes day after day, but what this means with respect to people's health is still unclear. Researchers are still working on this and the whole point of this website is to have free samples. It's just a business at the expenses of users, who should be protected". Some voices are raised by the community of patientslikeme.com against these accusations "People have the right to know about themselves, and IMS enables them to do so" "the whole idea of patientslikeme.com is to create a community in which people share stories and learn from each others, transforming their individual stories into a learning experience for others like them. IMS simply works in making people aware of the consequences of their lifestyle. Even if the meaning of the information is not clear yet, it does something good for people. And this is what matters".

In April 2016, Sally Meine a 19 year old girl from Ohio is admitted to the Cleveland Clinic in a coma, and is diagnosed with extreme malnutrition. When she regains consciousness, she explains to the doctors that she was experimenting with her friends to see how her immunosignature would change if she ate only fruit. The parents of Sally sue patientslike.me and Health Tell for liability for not putting in place enough failsafe to prevent misuse of IMS technology. In May, Sally's case is brought up in FDA discussions about the large availability to a broader public of sensitive medical data that is still not reliable.

In December 2016, the CEO of a famous pharmaceutical company criticizes the FDA intervention. In an editorial, he highlights that collaboration between HealthTell and patientslikeme.com are promising because they enable profiling of a large number of people with high degree of statistical relevance, advancing risk assessment and steering the direction of company research: "these experiments are nothing new, they happen every day with Google. Why shouldn't we use the same tools to develop our knowledge of health conditions and ultimately make our healthcare system more effective?"

FDA objection on the disclosing of Immunosignatures to patients on online platforms is legally reinforced due to the "current lack of reliability" of the information provided. However, an increasing consensus in industry and political environment acknowledges the importance that research on personalized signatures could have for national healthcare. Following a political controversy on the desirability and feasibility, in November 2017, policy agreements are made: patients' medical histories and biological samples analysis will be stored online.

This information is openly available to researchers, while maintaining patient anonymity. Educational campaigns are promoted to encourage people to contribute to this database: “Do it for your future. Do it for your children. Do it for a world without patients”.

Scenario 1 part 2

2018-2024

This decision boosts the development of IMS analysis. In 2020, a normalized “healthy” signature is established (including an algorithm to account for individual variation), leading to an improved detection and determination of illness. In 2022, local governments start some programs of wellness, educating citizens to adopt a healthier behavior. IMS is proposed as a good tool for educating healthy citizens to take more responsibility for their health.

In January 2023, in the state of California programs are initiated to provide people with lower incomes access to IMS at home. This is undertaken as an experiment to see if they engage in a healthier lifestyle. To make it more compelling, people are offered public Medicare in exchange for monitoring themselves with IMS on a weekly basis. Eligible citizens have to pick up the test at the closest Urgent Care clinic and send a biological sample to be tested with IMS. They receive the results via email and they can check their medical record online. They are told if they should inform the Urgent Care in case of serious and continuous abnormal signature.

In August 2026, the case of Francis Caine raises the public interest. In June 2024, she had received a message that she had to go to the urgent care clinic, but she hadn't. After 1 year she was diagnosed with cancer. The hospital had contacted the governmental Medicaid and they discovered that she was in the program but she had never acted on it. After the surgery, she is required to pay, because she didn't contact the urgent care immediately. In an interview Francis explains: “I didn't have any symptom back then, I felt good, I just didn't think that it could be serious”. Her neighbor comments, “She was already lucky not to pay for the medical insurance, but she didn't care that the government and other citizens are paying for her. She was given the chance of being proactive, but she decided not to...now she has to pay”. However, patient advocates take the side of Francis: “Discovering that something is wrong with you, that you might have a disease, that your life is threatened is overwhelming. We cannot expect that a single individual can cope with this information alone and simply act as others have told her to act. With this IMS idea, institutions are unloading their responsibility onto the patients rather than providing them with guidance and care”

Scenario 2 part 1

Current situation

Partly due to science and technology advancement, we are currently experiencing an increase in the longevity of the American population. This larger demographic of elderly persons implies an increase in healthcare costs, since the elderly are more prone to sickness or diseased. These costs are not sustainable in the long run.

A conspicuous number of experts from diverse fields points out that in order to address this problem, the adopted healthcare model has to move away from a symptomatic “one size fits all” treatment-based approach. A more affordable and effective model should lead towards 1) personalized and targeted care, 2) early and individualized diagnostics and 3) preventive risk predisposition.

The Biodesign Institute at Arizona State University is active in supporting science and technology contributing to this broader purpose. Immunosignature research, at the Centre for Innovations in Medicine, aims at developing a tool for early, pre-symptomatic detection of diseases. This preventive healthcare model promotes a **personalized diagnostics**: “you are compared with yourself yesterday”. This long-term vision of pre-symptomatic and personalized diagnostics is expected to go through an earlier phase of personalized (symptomatic) early diagnostics. The application of IMS in a clinical context presupposes a system in which doctors play a central role and in which technology is expected to offer a tool for them to improve their practice. In this sense, IMS is considered as a tool to improve the current diagnostic practice.

Ongoing research at CIM focuses on screening and diagnostics for chronic diseases (i.e. Alzheimer), monitoring for cancer recurrence, and diagnostics for infectious diseases like Valley Fever. The potential diagnostic tools arising from this research are expected to be used in a clinical context.

Half of those affected by Valley Fever in the U.S. are in Maricopa County. Two-thirds are in Arizona. Fungus in the soil, especially during the dry, windy season, becomes airborne and settles in the lungs to cause the disease. In 2006 Tucson-based C-Path also helped UA scientists receive Orphan Drug Status from the U.S. Food and Drug Administration, which would allow scientists to apply for grants to help pay for the development of the drug.¹¹⁴

In 2011, coccidioidomycosis (Valley Fever) is reported by the Council of State and Territorial Epidemiologists (CSTE) as a nationally notifiable disease. This increases the publicity and mindshare in the public health community.

¹¹⁴<http://www.bizjournals.com/phoenix/stories/2006/05/01/story4.html?page=all>

2012-2017

In June 2012, a study of the Centre for Disease Control highlights the healthcare costs of Valley Fever treatment for the State of California. In this study, the costs of absenteeism and presentism in the workplace due to Valley Fever are emphasized. At the end of 2012, Valley Fever Therapies LLC forms a partnership with the state of Arizona to take the drug to the market. "The state of Arizona thinks that this is an important enough public health issue" says Dr Galgiani, director of the University of Arizona Valley Fever Center for Excellence. Under these circumstances a diagnostics for Valley Fever becomes critical. Dr Galgiani and Dr Johnston, the CIM co-director and Health Tell CEO, investigate Clinical Laboratory Improvement Amendments (CLIA) certification for an immunosignature test.

In December 2013, the American Medical Association (AMA) includes the Immunosignature test for Valley Fever in Current Procedural Terminology in Category III¹¹⁵. As a member of the board of trustees of the American Medical Association explains: "Primary care physicians in Arizona have been encouraged to enroll in educational programs about early diagnosis of Valley Fever. AMA considers this of utmost importance in the Valley area in order to improve patient care by reducing patient anxiety and unwarranted use of antibacterial agents. Moreover, serious complications requiring treatment might be identified sooner."

In May 2014, the state of Arizona initiates a public campaign to raise people's awareness of symptoms and potential treatments for Valley Fever. "My friend Karen died of complications from Valley Fever while she was pregnant. She was not diagnosed in time. This was at the beginning of 2000" explains Mia Valdivia patient advocate for Valley Fever Survivors "since then, many things have changed. In this last year, I have received so many letters from people who go to primary care with few symptoms, are diagnosed with Valley Fever within 1 week, are quickly treated and keep on living normal lives".

In December 2015, Mr Carl Carlson was admitted to the Mayo Clinic in Scottsdale with advanced lung cancer. "He was diagnosed with Valley Fever one year ago with one of those tests. The doctor prescribed him some drugs, but the symptoms never left. Now they say that for all this time the cancer was growing. I want to understand who is responsible for this case of malpractice, the laboratory

¹¹⁵ Current Procedural Terminology (CPT®) is a listing of descriptive terms and identifying codes for reporting medical services and procedures. The purpose of CPT is to provide a uniform language that accurately describes medical, surgical, and diagnostic services, and thereby serves as an effective means for reliable nationwide communication among physicians, and other healthcare providers, patients, and third parties. CPT is also used for administrative management purposes such as claims processing and developing guidelines for medical care review. The assignment of a CPT Category III code to a service does not indicate that it is experimental or of limited utility, but only that the service or technology is new and is being tracked for data collection. <http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/cpt/cpt-process-faq/code-becomes-cpt.page>

or the doctor?” says his wife, interviewed by a local radio channel. “The fact is that these immunosignature tests are optimized on some statistical data, the physician should examine the patient carefully and provide a more personalized diagnostics” the PR of a diagnostic company explains.

Following up this case, the National Center for Ethics in Health Care (NCEHC) issues a report on the use of laboratory diagnostics in primary care practices and emphasizes the importance of traditional diagnostics. “Primary care medical clinics in Arizona are financially benefiting from the introduction of IMS diagnostics in the CPT. For each of these tests they get a service fee, but they do not take time to actually visiting the patient, ask about the symptoms, provide high quality care and information. But of course these tests are never 100% reliable. They should spend more time looking at the personal history and situation of the individual patient”.

In April 2016, The association of American Physicians responds to this report explaining the worsening of their working conditions “primary care doctors earn much less than other specialists and have to work in more difficult conditions. We can afford just 20 minutes per patients. How do you think we can provide good quality care? Furthermore, the spread of new diagnostic tests and new procedure demand a lot of preparation and retraining. Often these tests do not give a yes/no answer, but a grey result that needs to be interpreted. This is the responsibility of the doctor. If we spend all of our time learning about the possibilities for personalized diagnostics, when can we actually provide more personal care?”

In January 2017, the Centre for Medicare and Medicaid discusses the possibility of moving the Valley Fever diagnostic procedure to retail clinics (located inside retail/grocery stores) and staffed by non-physician providers, such as physician assistants and nurse practitioners, with remote physician supervision. This would release primary care doctors from the burden and decrease the service fees. However, due to its serious consequences the AMA points out that Valley Fever cannot be considered as a minor illness and should therefore be treated by physicians.

Scenario 2 part 2

2017-2025

In 2017, there is a breakthrough in the collaboration between CIM and Mayo clinic: statistically relevant differences between immunosignatures of esophagus cancer patients and patients whose esophagus cancer has been eradicated are established. This enables researchers to optimize a test to monitor the recurrence of the cancer.

In 2020, the test receives CLIA certification, however the previous controversies rose with the valley Fever makes the AMA wary about inserting this test into the CPT lists. "This test opens the possibility for a cheap monitoring of cancer patients, but who should read these signatures? The oncologist or the GP? It is too delicate for GP, but the benefit of the test is to alleviate the work of oncologists." The test does not take on with GP's, but is taken up and appreciated by oncologists.

In 2023, Cleveland Clinic is interested in using the immunosignaturing test for cancer recurrence in their "health care at home" program. This program was initiated by the innovation department of the clinic as an attempt to respond, on one hand, to pressures of private insurance companies for reducing patients' visits to the outpatient clinic, and on the other hand to the pressure for a more continuous and effective connection between the patients and the care provider. With this program of remote healthcare patients are connected to the clinic via online facilities on a daily basis and the costs of visits to the clinic are kept lower. IMS is introduced as a home test for cancer patients to monitor eventual recurrences. Every 3 months patients are sent at home a kit from the hospital and asked to send a biological sample by mail.

The head of the innovation department of Cleveland Clinic explains that this program makes healthcare a continuous and daily process, rather than an episodic one, "We offer a better quality care". "This is the future of healthcare, continuous monitoring of vitals and other values". You don't need to go to the hospital anymore. Payers are satisfied for the reduction of the costs.

However, George Carter cancer patient, 58 years old, is found dead at home by a friend. In a letter he describes how he knew that his tumor was growing, but he was too afraid to go through the surgery again. He stopped collecting samples. "he was missing the personal relation with his doctor, when you don't have a person on the other side who is taking care of you, what do you do? Do you really call it personal care? Where is the person here?". The hospital responds that results of the test were returned to the patient with an advice to contact them, but were not actively followed up by the hospital. "We put the patient autonomy on the first line. It is our core value to respect the decision of our patient, whether they decide to go for a treatment or they decide to decline it."

2. Techno-moral vignettes on Nanopil

Vignette 1

"I am not gonna do this again, it's disgusting!"

"Listen, Nya, I'm tired of this. Try to behave like an adult, you are 22 now! You know why you have to drink this laxative."

"Yes, for the stupid pill to work...."

"This 'stupid' pill is an easy way to check that everything is fine. Your dad's family has a history of Colorectal cancer so you had to start screening early. Consider yourself lucky, 20 years ago people had to collect a sample of their stool, smear it on a sample card, compile it with their information, seal it and mail it to the lab. The pill makes this much more simple, comfortable and clean!"

"SIMPLE, COMFORTABLE, and CLEAN???? Why don't YOU try drinking this crap? And this unbearable nausea. Blech. I feel like I have to throw up after every sip. Having to run to the toilet every half an hour is clean? Joyce wanted to go to the cinema with me, but I can't! I have to be at home, drinking laxative, feeling sick and running to the washroom every 10 minutes. I feel like I am spending the whole day in the bathroom. I would rather spend 1 minute collecting samples and forgetting about it. But instead, I have 2 more liters of laxative to go. ARGH..."

"Hun, you are behaving like your grandma! Just drink it, the doctor said..."

"I don't care about the doctor, I am not gonna drink it all"

"And if the pill isn't going to work then?"

"Even better, then they will think that I am fine and they will leave me alone"

Vignette 2

Policemen: "Your identification and car documents, please"

Mr Watson: "Oh sure, I am really sorry, I am still in shock. The car is really damaged"

Policemen: "Can you explain what happened?"

Mr Watson: "Yes, but I guess I have to explain it from the beginning. As every Wednesday, I am free from work to take care of the children. But today I was also supposed to screen for colorectal cancer. You know, I am over 50 and they sent me a test for checking if I have cancer. It is one of those pills that you swallow and it checks your intestine from inside and sends a report of the test to your mobile phone and to the doctor. Anyways, I was really eager to take this test, because lately I experienced some pain in the lower abdomen and I feared that there could be something wrong. The fact is, I was very nervous about the result of the test. So after swallowing the pill I waited and waited and I couldn't accomplish much besides imagining the pill floating within my intestine. But the message hadn't arrived yet, when it was time to leave home and pick up the children from school. So I went.

Policemen: "Are you allowed to drive, when you take this pill?"

Mr Watson: “Well, it is said that with the pill you can test your health everywhere and once you have the signal-receiving belt on and your mobile phone close to you, it’s just fine. However, while driving, I felt again a stinging pain in my abdomen, so when I felt the vibration of my mobile phone finally notifying me about my health status, I was distracted from observing the street. So I didn’t see that the car in front of me was so close. I am terribly sorry, but how can you focus on the street, when you are afraid that your health is at stake?”

Vignette 3

Doctor Jansen smiled while the next patient walked through his office’s door. This should be Mr Smit. He opened Mr Smit’s personal record on his computer and glanced into it. He was there because the result of colonoscopy was positive and a neoplasm had been found. He told him about the advanced status of the cancer and the need for an immediate intervention.

“I don’t understand, doctor, 2 years ago I participated in the national screening program and I took a pill to check whether everything was fine...”

“Yes, actually, I can see it on your record, but there is no result associated, are you sure you did the test?”

“Yes, I am, I remember quite vividly because I abhorred having to take this laxative! I don’t think I heard anything about the test afterwards, but I simply assumed that it meant I was OK. So how is it possible that this tumor is so big already? It must have been there two years ago! It would have been smaller then. What’s the point of a screening that doesn’t work?”

Doctor Jansen was dubious, what went wrong 2 years ago? The pill, or the network? Maybe Mr Smit did something wrong? Or maybe he himself did something wrong. But with all those screening tests around, how to keep track?

“Mr Smit, please calm down, what did you do when you didn’t receive a message? Did you call here to know more? That would have helped in tracking the problem at the time.”

“Doctor, how could I have known? I took the test, nobody contacted me, so I thought I was fine, I thought I was under control. That’s what I think when I am in a screening program, when I perform such an innovative test, sent to me by this screening organization. I think that everything is under control.”

“I am sorry Mr Smit, but I have to correct you. This screening program, like other do-it-yourself-prevention programs, presupposes that you are a responsible and autonomous person, who can take care of monitoring his own health condition. But this also means that you are expected to be more proactive. You have been quite negligent, Mr Smit.”

BIBLIOGRAPHY

- Achterhuis, H., 2001. *American philosophy of technology: the empirical turn*, Bloomington: Indiana University Press.
- Akrich, M. & Latour B., 1992. A Summary of a Convenient Vocabulary for the Semiotics of Human and Nonhuman Assemblies. In (W. Bijker and J. Law 1992).
- Akrich, M. 1992. The description of technological objects. In (W. Bijker & J. Law 1992).
- Anders, G., 1980. *Die Antiquiertheit des Menschen 2, Über die Zerstörung des Lebens im Zeitalter der dritten industriellen Revolution.*, Munchen: Beck.
- Aristotle, 2010. *Rhetoric*. (Edited by Roberts, W. R., & Ross, W.D.) New York: CosimoClassics.
- Arnaldi, S., 2010. Ordering technology, excluding society: the division of labour and sociotechnical order in images of converging technologies. *International Journal of Nanotechnology*, 7(2), 137-154.
- Ayer, A.J., 1968. *The origins of pragmatism: studies in the philosophy of Charles Sanders Pierce and William James*, San Francisco: Freeman, Cooper and Company.
- Beauchamp, T.L. & Childress, J.F., 2009. *Principles of biomedical ethics* [1973] ed., New York: Oxford University Press.
- Beebe T.J., Johnson C.D., Stoner S.M., Anderson K.J., Limburg P.J., 2007. Assessing attitudes toward laxative preparation in colorectal cancer screening and effects on future testing: potential receptivity to computed tomographic colonography. *Mayo Clinic Proceedings* 82, 666–671.
- Berg, A. van den, 2009. De kunst van het kleine, in Brinskma and van den Berg, *De kunst van de wetenschap, Redevoeringen 48ste Dies Natalis*, Universiteit Twente.
- Berne, R.W., 2006. *Nanotalk: conversations with scientists and engineers about ethics, meaning, and belief in the development of nanotechnology*, Mahwah, NJ: Lawrence Erlbaum.

- Bijker, W.E., 1995. *Of bicycles, bakelites, and bulbs: toward a theory of sociotechnical change*, Cambridge, Mass.: MIT Press.
- Bijker, W.E. & Pinch T.J., 1987. "The social construction of facts and artifacts: or How the sociology of science and the sociology of technology might benefit each other in (Bijker, W.E., Hughes, T.P. & Pinch, T.J., 1987).
- Bijker, W.E., Hughes, T.P. & Pinch, T.J., 1987. *The Social construction of technological systems: new directions in the sociology and history of technology*. In Cambridge, Mass.: MIT Press.
- Bijker, W.E. and Law J., 1992. (Eds.) *Shaping Technology, Building Society: Studies in Sociotechnical Change*. Cambridge, Mass, MIT Press.
- Blok, A., 2007. Experts on public trial: on democratizing expertise through a Danish consensus conference . *Public Understanding of Science* , 16 (2), 163-182.
- Boenink, M., 2010. Molecular medicine and concepts of disease: the ethical value of a conceptual analysis of emerging biomedical technologies. *Medicine, Health Care and Philosophy*, 13(1), 11-23.
- Boenink, M., Swierstra, T. & Stemmerding, D., 2010. Anticipating the Interaction between Technology and Morality: A Scenario Study of Experimenting with Humans in Bionanotechnology. *Studies in Ethics, Law, and Technology*, 4, 1-38.
- Boer, D. de, Rip, A. & Speller, S., 2009. Scripting possible futures of nanotechnologies: A methodology that enhances reflexivity. *Technology in Society*, 31(3), 295-304.
- Boon, M. and Knuuttila T., 2009. Models as Epistemic Tools in Engineering Sciences: A Pragmatic Approach in *Handbook of the Philosophy of Technological Sciences*. A. Meijers (ed.). Amsterdam, Elsevier Science, 687-719.
- Borup, M., Brown, N., Konrad, K., & Van Lente, H., 2006. The sociology of expectations in science and technology. *Technology Analysis & Strategic Management*, 18(3-4), 285-298.
- Brey, P., 2012. Anticipatory Ethics for Emerging Technologies. *NanoEthics*, 1-13.
- Broerse, J.E.W. & F.G.Bunders, J., 2000. Requirements for biotechnology development: the necessity for an interactive and participatory innovation process. *International Journal of Biotechnology*, 2(4), 275-296.
- Brown, N., 2006. Shifting tenses—from "regimes of truth" to "regimes of hope." In *SATSU Working Paper No 30 2006*.

- Brown, N., Rappert, B. & Webster, A., 2000. *Contested futures: a sociology of prospective techno-science*, Aldershot: Ashgate.
- Brown, Nik & Michael, M., 2003. A Sociology of Expectations: Retrospecting Prospects and Prospecting Retrospects. *Technology Analysis & Strategic Management*, 15(1), 3-18.
- Burg, S. van der, 2009. Imagining the future of photoacoustic mammography. *Science and engineering ethics*, 15(1), 97-110.
- Burg, S. van der, 2010. Ethical Imagination: Broadening Laboratory Deliberations. In S. Roeser, ed. *Emotions and Risky Technologies*. Springer Netherlands, 139-155.
- Burke, W. Atkins D., Gwinn M., Guttmacher A., Haddow J., Lau J., Palomaki G., Press N., Richards C.S., Wideroff L., Wiesner G.L., 2002. Genetic Test Evaluation: Information Needs of Clinicians, Policy Makers, and the Public . *American Journal of Epidemiology* , 156 (4), 311-318.
- Bush, V., 1945. *Science, the endless frontier: a report to the President*, Washington, D. C.: Govt. Print. Off.
- Callon, M., 1986. The Sociology of an Actor-Network: the Case of the Electric Vehicle. In (Callon et al 1986): 19-34.
- Callon, M., 1987. Society in the Making: the Study of Technology as a Tool for Sociological Analysis. In (Bijker et al. 1987): 83-103.
- Callon, M. and Law J., 1982. On Interests and their Transformation: Enrolment and Counter-Enrolment. *Social Studies of Science* 12: 615-625.
- Callon, M., Law, J., & Rip A., (Eds.) 1986. *Mapping the Dynamics of Science and Technology: Sociology of Science in the Real World*. London, Macmillan.
- Chambers, S., 2003. Deliberative Democratic Theory. *Annual Review of Political Science*, 6(1), 307-326.
- Code, L., 1987. *Epistemic responsibility*, Hanover, N.H.: Published for Brown University Press by University Press of New England.
- Coeckelbergh, M., 2007. *Imagination and principles: an essay on the role of imagination in moral reasoning*, Basingstoke [England]; New York: Palgrave Macmillan.
- Collingridge, D., 1980. *The social control of technology*. Open University Press.
- Collins, F.S., 1999. Medical and Societal Consequences of the Human Genome Project. *New England Journal of Medicine*, 341(1), 28-37.

- Collins, F.S., Patrinos A., Jordan E., Chakravarti A., Gesteland R., LeRoy W., 1998. New Goals for the U.S. Human Genome Project: 1998-2003. *Science*, 282(5389), 682-689.
- Crichton, M., 2002. *Prey*, New York: Harper Collins Publishers.
- Dewey, J., 1922. *Human nature and conduct; an introduction to social psychology*, New York: Holt.
- Dewey, J., 1929. *The quest for certainty: a study of the relation of knowledge and action*, New York: Minton, Balch.
- Dewey, J. 1981. *The later works, 1925-1953*. Edited by Boydston, J.A., Carbondale; London: Southern Illinois University Press ; Feffer & Simons.
- Dierkes, M., Hoffmann, U. & Marz, L., 1996. *Visions of technology: social and institutional factors shaping the development of new technologies*, Frankfurt/Main; New York: Campus-Verl.
- Dryzek, J.S., 2000. *Deliberative democracy and beyond liberals, critics, contestations*, Oxford; New York: Oxford University Press.
- Ebbesen M. & Jensen T.G., 2006. Nanomedicine: Techniques, Potentials, and Ethical Implications. *Journal of Biomedicine and Biotechnology*: 1–11
- EC, 2004. Towards a European strategy for nanotechnology. Commission of the European Communities. Luxembourg
- EGE, 2005. *Ethical aspects of ICT implants in the human body*. Opinion 20. Available at http://ec.europa.eu/european_group_ethics/docs/avis20_en.pdf
- EGE, 2007. *Ethical aspects of nanomedicine*. Opinion 21. Available at http://ec.europa.eu/bepa/european-group-ethics/docs/publications/opinion_21_nano_en.pdf
- Eijndhoven, J.C.M. van, 1997. Technology assessment: Product or process? *Technological Forecasting and Social Change*, 54(2-3), 269-286.
- Epstein, C.J., 2004. Genetic testing: hope or hype? *Genetics in medicine: official journal of the American College of Medical Genetics*, 6(4), 165-172.
- Est, R. van & Brom, F., 2010. Technology assessment as an analytic and democratic practice. *Encyclopedia of Applied Ethics* 2e Chapter 10 on "Technology assessment".
- Feenberg, A., 1995. *Alternative modernity: the technical turn in philosophy and social theory*, Berkeley: University of California Press.

- Ferrari, A. and Grunwald, A., 2011: Visions and Ethics in Current Discourses on Human Enhancement, Third Annual Conference of the Society for the Study of Nanoscience and Emerging Technologies (S.NET), Tempe, Arizona/USA, November 07-10 2011.
- Fesmire, S., 2003. *John Dewey and moral imagination: pragmatism in ethics*, Bloomington, IN: Indiana University Press.
- Fischer F. & Forester, J., 1993, *The argumentative turn in Policy Analysis and Planning*. Durham, NC:
- Fischer, C.S., 2011. *Still connected: family and friends in America since 1970*, New York: Russell Sage Foundation.
- Fisher, E., 2007. Ethnographic Invention: Probing the Capacity of Laboratory Decisions. *NanoEthics*, 1(2), 155-165.
- Fisher, E., Mahajan, R.L. & Mitcham, C., 2006. Midstream Modulation of Technology: Governance From Within. *Bulletin of Science, Technology & Society*, 26(6), 485-496.
- Geels, F.W. & Smits, W.A., 2000. Failed technology futures: pitfalls and lessons from a historical survey. *Futures*, 32(9-10), 867-885.
- Gelder, van R.E., Birnie E., Florie J., Schutter M.P., Bartelsman J.F., Snel P., Laméris J.S., Bonsel G.J., Stoker J., 2004. CT colonography and colonoscopy: assessment of patient preference in a 5-week follow-up study. *Radiology* 233: 328-337
- Gilbert, G., & Mulkay, M. J., 1984. *Opening Pandora's box: an analysis of scientists' discourse*. Cambridge [Cambridgeshire]: Cambridge University Press.
- Grin, J. & Grunwald, A., 2000. *Vision Assessment: Shaping Technology in 21st Century Society Towards a Repertoire for Technology Assessment*, Springer.
- Grin, J. 2000, Technology assessment as a tool for political judgment. In (Grin and Grunwald 2000), 9-33.
- Grunwald, A., 1999. Technology Assessment or Ethics of Technology? *Ethical Perspectives*, 6(2), 170-182.
- Grunwald, A., 2010. From Speculative Nanoethics to Explorative Philosophy of Nanotechnology. *NanoEthics*, 4(2), 91-101. Springer Netherlands.
- Guice, J., 1999. Designing the future: the culture of new trends in science and technology. *Research Policy*, 28(1), 81-98.

- Guston, D.H. & Sarewitz, D., 2002. Real-time technology assessment. *Technology in Society*, 24(1-2), 93-109.
- Gutmann, A. & Thompson, D., 2002. Deliberative Democracy Beyond Process. *Journal of Political Philosophy*, 10(2), p.153-174.
- Habermas, J., 1990. *Moral consciousness and communicative action*, Cambridge, Mass.: MIT Press.
- Haraway, D., 1988. Situated knowledges: the science question in feminism and the privilege of partial perspective. *Feminist studies*, 14(3), p.575-599.
- Hare, R. M., 2012. A Utilitarian Approach. In (Kuhse & Singer 2012).
- Health Council of the Netherlands, 2009. *A national colorectal cancer screening programme*. The Hague: Health Council of the Netherlands; publication no. 2009/13E.
- Hedgecoe, A. & Martin, P., 2003. The Drugs Don't Work: Expectations and the Shaping of Pharmacogenetics. *Social Studies of Science*, 33(3), p.327-364.
- Hedgecoe, A., 2010. Bioethics and the Reinforcement of Socio-technical Expectations. *Social Studies of Science*, 40 (2), p.163-186.
- Hickman, L., 2002. Pragmatic resources for biotechnologies. In Keulartz et al 2002
- Hippel, von E., 1988. *The sources of innovation*, New York: Oxford University Press.
- Hoeyer, K., 2006. Ethics wars: Reflections on the Antagonism between Bioethicists and Social Science Observers of Biomedicine, *Human Studies*, 29(2), 203-227.
- Holbrook, J.B., 2005. Assessing the science-society relation: The case of the US National Science Foundation's second merit review criterion. *Technology in Society*, 27(4), 437-451.
- Holtzman, N.A. & Marteau, T.M., 2000. Will Genetics Revolutionize Medicine? *New England Journal of Medicine*, 343(2), 141-144.
- Holtzman, N.A., 1999. Are genetic tests adequately regulated? *Science*, 286(5439), 409.
- Hughes, T.P., 1983. *Networks of power : electrification in Western society, 1880-1930*, Baltimore: Johns Hopkins University Press.
- Hughes, T. P., 1987. The evolution of Large Technological Systems. In (Bijker et al 1987)
- Huxley, A., 1969. *Brave new world* [1932] New York: Harper Perennial.

- Ihde, D., 1991. *Instrumental realism the interface between philosophy of science and philosophy of technology*. Bloomington, Ind. : Indiana University Pres
- James, W., 1956. *The will to believe and other essays in popular philosophy, and Human immortality*. [1897], New York: Dover Publications.
- James, W., 1981. *Pragmatism*, [1907] Indianapolis: Hackett.
- Jensen, C.B., 2005. Citizen Projects and Consensus-Building at the Danish Board of Technology . *Acta Sociologica* , 48 (3), 221-235.
- Kearnes, M. & Wynne, B., 2007. On Nanotechnology and Ambivalence: The Politics of Enthusiasm. *NanoEthics*, 1(2), p.131-142.
- Ketting, E., 2000. De invloed van orale anticonceptie op de maatschappij. *Nederlands tijdschrift voor geneeskunde*, 144(6), p.283-286.
- Keulartz, J., M.Schermer, M.Korthals, T.Swierstra (Eds.) (2002). *Pragmatist Ethics for a Technological Culture*. Deventer: Kluwer Academic Publishers.
- Knorr-Cetina, K., 1981. *The manufacture of knowledge: an essay on the constructivist and contextual nature of science*, Oxford: Pergamon.
- Knorr-Cetina, K., 1999. *Epistemic cultures: how the sciences make knowledge*, Cambridge, Mass.: Harvard University Press.
- Konrad, K., 2006. The social dynamics of expectations: The interaction of collective and actor-specific expectations on electronic commerce and interactive television. *Technology Analysis & Strategic Management*, 18(3-4), 429-444.
- Krabbenborg, L. *Forthcoming*. Dramatic Rehearsal on the societal embedding of the lithium chip. In: T. Swierstra and S. Van der Burg (eds): *Ethics on the Laboratory Floor: Towards a cooperative ethics for the development of responsible technology*. Palgrave/MacMillan
- Kroes, P. & Meijers, A., 2001. *The Empirical turn in the philosophy of technology*, Amsterdam; New York: JAI.
- Kuhse, H. & Singer, P., 2012. *A companion to bioethics*. Blackwell. Oxford, UK; Malden, Mass., USA
- Kulve, H. te, 2011. *Anticipatory interventions and the co-evolution of nanotechnology and society*. Proefschrift Universiteit Twente, Enschede
- Laat, B. de, 1996. *Scripts for the future : technology foresight, strategic evaluation and socio-technical networks: the confrontation of script-based scenarios*, Thesis (Ph.D.)--Universiteit van Amsterdam

- Laat, B. de, 2000. Scripts for the Future: Using Innovation Studies to Design Foresight Tools. In (N Brown, et al 2000)
- Latour, B., 1987. *Science in action : how to follow scientists and engineers through society*, Cambridge, Mass.: Harvard University Press.
- Latour, B., 1992. Where are the Missing Masses? Sociology of a Few Mundane Artefacts. In (Bijker and Law 1992): 225-258.
- Latour, B. & Venn, C., 2002. Morality and Technology . *Theory, Culture & Society* , 19 (5-6), p.247-260.
- Latour, B., & Woolgar, S., 1979. *Laboratory Life. The social construction of scientific facts*. Sage Publications Inc.
- Lenk, C. Biller Andorno, N., 2007. Nanomedicine-emerging or re-emerging ethical issues? A discussion of four ethical themes. In *Medicine, Health Care and Philosophy*. 10: 173–184.
- Lente, H. van. 1993. *Promising Technology: The Dynamics of Expectations in Technological Developments*. Universiteit Twente, Faculteit Wijsbegeerte en Maatschappijwetenschappen.
- Lente, H. van. 2000. Forceful futures: from promise to requirement. In (Brown et al 2000).
- Lie, M., & Sørensen, K. H., 1996. *Making technology our own? : domesticating technology into everyday life*. Oslo; Boston: Scandinavian University Press.
- Little, S., 2006 . FDA regulations and novel molecular diagnostic tests *Clin Lab Int*, 7 48-49.
- Lucivero, F. & Tamburrini, G., 2007. Ethical monitoring of brain-machine interfaces. *Ai & Society*, 22(3), 449-460.
- Lucivero, F., Swierstra, T. & Boenink, M., Assessing Expectations: Towards a Toolbox for an Ethics of Emerging Technologies. *NanoEthics*, 5(2), 129-141.
- Mackenzie, D.A., 1990. *Inventing accuracy : a historical sociology of nuclear missile guidance*, Cambridge, Mass.: MIT Press.
- Manning, R. C. 2012. A Care Approach. In (Kuhse and Singer 2012).
- Melchior M. 2009. "Doctoren met nanotechnologie" in *Medisch Contact*. 64 nr 49: 2032-2035.
- Mephram, B. 2001 Novel Foods in Chadwick, R.F. *The concise encyclopedia of the ethics of new technologies*, San Diego, Calif.: Academic Press.

- Merkerk, R. van & Robinson, D., 2006. Characterizing the emergence of a technological field: Expectations, agendas and networks in Lab-on-a-chip technologies. *Technology Analysis & Strategic Management*, 18(3/4), 411-428.
- Merkerk, R. van & Smits, R., 2008. Tailoring CTA for emerging technologies. *Technological Forecasting and Social Change*, 75(3), 312-333.
- Merton, R.K., 1973. "The normative structure of science" in Merton [1942] *The Sociology of Science. Theoretical and Empirical Investigations*, ed. Storer. N.W. Chicago: University of Chicago Press.
- Michael, M., 2000. Futures of the present: from performativity to prehension. In Brown et al 2000
- Mitcham, C., 1994. *Thinking through technology : the path between engineering and philosophy*, Chicago: University of Chicago Press.
- Mol, A., 1998. Missing Links, Making Links: the Performance of Some Artheroscleroses. In A. Mol and M. Berg (Eds.) *Differences in Medicine: Unravelling Practices, Techniques and Bodies*. Durham, N Ca., Duke University Press: 141-163.
- Mol, A., 2000. What Diagnostic Devices Do: The Case of Blood Sugar Measurement. *Theoretical Medicine and Bioethics*, 21(1), 9-22.
- Mol, A., 2002. The body multiple : ontology in medical practice. Durham: Duke University Press.
- Moor, J. & Weckert, J. 2004. Nanoethics: assessing the nanoscale from an ethical point of view. In Baird, D., Nordmann, A. & Schummer, J., 2004. *Discovering the nanoscale*. Amsterdam; Washington, DC: IOS Press.
- Moreira, T. & Palladino, P., 2005. Between truth and hope: on Parkinson's disease, neurotransplantation and the production of the "self." *History of the Human Sciences*, 18(3), 55-82.
- Moreira, T. & Palladino, P., 2005. Between truth and hope: on Parkinson's disease, neurotransplantation and the production of the "self." *History of the Human Sciences*, 18(3), 55-82.
- Murphy, J.P., 1990. *Pragmatism : from Peirce to Davidson*, Boulder u.a.: Westview Press.
- Neurath, O. [1932] Protocol Statements. In Neurath O., 1983. *Philosophical Papers 1913-1946*. Ed. and trans. by R.S. Cohen and M. Neurath. Dordrecht: Reidel.

- Nordmann, A., 2007a. Knots and strands: an argument for productive disillusionment. *The Journal of medicine and philosophy*, 32(3), 217-36.
- Nordmann, A., 2007b. If and Then: A Critique of Speculative NanoEthics. *NanoEthics*, 1(1), 31-46.
- Nordmann, A., & Rip, A., 2009. Mind the gap revisited. *Nature nanotechnology*, 4(5), 273-4.
- Notten, van P.W.F., Rotmans J., Asselt van M.B.A., Rothman D.S., 2003. An updated scenario typology. *Futures*, 35(5), 423-443.
- Oakley J., 2012. A Virtue Ethics Approach. In (Kuhse and Singer 2012).
- Oudshoorn, N., 1995. Technologie en zorg: Vrienden en vijanden. Het voorbeeld van nieuwe anticonceptiemiddelen voor vrouwen en mannen. *Gezondheid* 3 (3): 278-89.
- Oudshoorn, N., 2001. *Telecare Technologies and the Transformation of Healthcare*. Basingstoke [England]; New York: Palgrave Macmillan.
- Oudshoorn, N., & Pinch, T. J., 2003. How users matter: the co-construction of users and technologies. Cambridge, Mass. MIT Press.
- Palm, E. & Hansson, S.O., 2006. The case for ethical technology assessment (eTA). *Technological Forecasting & Social Change*, 73(5), 543-558.
- Pei, L., Gaisser, S. & Schmidt, M., 2012. Synthetic biology in the view of European public funding organizations . *Public Understanding of Science* , 21 (2), 149-162.
- Peirce, C.S., 1960. The fixation of Belief [1877] 5.358-387 Eds. Hartshorne and Weiss P. *Collected papers of Charles Sanders Peirce*, Cambridge: Belknap Press of Harvard University Press.
- Peirce, C.S., 1960. What pragmatism is [1905] 5.411-437. Eds. Hartshorne and Weiss P. *Collected papers of Charles Sanders Peirce*, Cambridge: Belknap Press of Harvard University Press.
- Perelman, C., & Olbrechts-Tyteca, L., 1969. The new rhetoric: a treatise on argumentation. Notre Dame, [Ind.]: University of Notre Dame Press.
- Pinch, T. & Bijker W., 1984. The social construction of facts and Artifacts: or how the sociology of Science and the sociology of technology might benefit from each other, in *Social Studies of Science*.
- Plato. *Phaedrus* in Thompson, W.H., 1973 *The Phaedrus of Plato*. New York: Arno Press.

- Putnam, H., 1987. *The many faces of realism*, La Salle, Ill.: Open Court.
- Quist, J., 2007. *Backcasting for a sustainable future : the impact after 10 years*, Delft: Eburon.
- Reuzel R., & der Wilt G.J., 2000. Technology Assessment in the Health Care Area. A matter of Uncovering or Covering up?. 53-71. In (Grin and Grunwald 2000).
- Richards, T., 2001. Three views of genetics: the enthusiast, the visionary, and the skeptic. *BMJ*, 322(7293), 1016.
- Rip, A., 2009. Technology as prospective ontology. *Synthese*, 168(3), p.405-422.
- Rip, A., Misa, T.J. & Schot, J., 1995. *Managing Technology in Society: The Approach of Constructive Technology Assessment*, Pinter.
- Rip, A. & Kulve, H., 2009. Constructive Technology Assessment and Socio-Technical Scenarios. *The Yearbook of Nanotechnology in Society, Volume 1: Presenting Futures*. E. Fisher, C. Selin and J. M. Wetmore, Springer: 49-70.
- Rip, A. & Shelly-Egan, C. 2010. Positions and responsibilities in the "real" world of Nanotechnology. Schomberg, R. von., Davies, S.R. & European Commission. Directorate General for Research., 2010. *Understanding public debate on nanotechnologies : options for framing public policy : a report from the European Commission Services*, Luxembourg: Publications Office of the European Union.
- Ristvedt, S.L., McFarland E.G., Weinstock L.B., Thyssen E.P., 2003. Patient preferences for CT colonography, conventional colonoscopy, and bowel preparation. *Am J Gastroenterol*, 98: 578-585.
- Robinson, D.K.R., 2009. Co-evolutionary scenarios: An application to prospecting futures of the responsible development of nanotechnology. *Technological Forecasting and Social Change*, 76(9), p.1222-1239.
- Robinson, D.K.R., 2010. *Constructive technology assessment of emerging nanotechnologies experiments in interactions*. Proefschrift Universiteit Twente, Enschede.
- Roelofsen, A. Broerse, J. E. W., Buning, T.D. & Bunders, J. F. G., 2008. Exploring the future of ecological genomics: Integrating CTA with vision assessment. *Technological Forecasting and Social Change*, 75(3), 334-355.
- Rorty, R., 1982. *Consequences of pragmatism : essays, 1972-1980*, Minneapolis: University of Minnesota Press.
- Sandel, M., 2004 The case against perfection, in *Atlantic monthly*, vol 293 No. 3; 51-62.

- Schot, J. & Rip, A., 1997. The past and future of constructive technology assessment. *Technological Forecasting and Social Change*, 54(2-3), 251-268.
- Schot, J. W., 1992. Constructive Technology Assessment and Technology Dynamics: The Case of Clean Technologies. *Science, Technology & Human Values*, 17(1), 36-56.
- Sclove, R., 2010. *Reinventing Technology Assessment: A 21st Century Model* (Washington, DC: Science and Technology Innovation Program, Woodrow Wilson International Center for Scholars.
- Sclove, R., 1995. *Democracy and technology*, New York: Guilford Press.
- Selin, C., 2007a. Expectations and the Emergence of Nanotechnology. *Science, Technology & Human Values*, 32(2), p.196-220.
- Selin, C. 2007b. *The Future of Medical Diagnostics*. Scenario Development Workshop Workbook. Center for Nanotechnology in Society, Arizona State University, Tempe, AZ.
- Selin, C. 2008. *The Future of Medical Diagnostics*. Scenario Development Workshop Report, CNS-ASU Report #R08-0001. Center for Nanotechnology in Society, Arizona State University, Tempe, AZ.
- Shelley Egan, C., 2011. *Ethics in practice: responding to an evolving problematic situation of nanotechnology in society*. Proefschrift Universiteit Twente, Enschede.
- Silverstone, R. & Hirsch, E., 1992. *Consuming technologies : media and information in domestic spaces*, London; New York: Routledge.
- Smits R., Merkerk R., van, Guston D. H, & Sarewitz, D., 2008. "The role of TA in Systemic Innovation Policy," Innovation Studies Utrecht (ISU) working paper series 08-01, Utrecht University, Department of Innovation Studies.
- Smits, R., Leyten, J. & Hertog, P., 1995. Technology assessment and technology policy in Europe: New concepts, new goals, new infrastructures. *Policy Sciences*, 28(3), 271-299.
- Smits, R.E.H.M. & Leyten, A.J.M., 1991. *Technology Assessment: waakhond of speurhond? : naar een integraal technologiebeleid*, Zeist: Kerckebosch.
- Stafford, P., Halperin, R., Legutki, J. B., Magee, D. M., Galgiani, J., & Johnston, S. A., 2012. Physical Characterization of the "Immunosignaturing Effect". *Molecular & Cellular Proteomics*.

- Star, S.L., 1991. Invisible Work and Silenced Dialogues in Knowledge Representation. In *Women, Work and Computerization*, eds. I. Eriksson, B. Kitchenham and K. Tijdens K. Amsterdam: North Holland: 81-92.
- Star, S. L., & Griesemer, J. R., 1989. Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science*, 19(3), 387-420.
- Stemerding, D., Swierstra, T. & Boenink, M., 2010. Exploring the interaction between technology and morality in the field of genetic susceptibility testing: A scenario study. *Futures*, 42 (10): 1133-1145.
- Swierstra, T., 1997. From Critique to Responsibility. *Society for Philosophy and Technology* (3) 1, 68-74.
- Swierstra, T., 2010. Het huwelijk tussen techniek en moraal. In: Marli Huijer & M. Smits (Red.) *Moralicide. Mens, techniek en symbolische orde*. [Jaarboek Civis Mundi i.s.m. Rathenau Instituut]. Rotterdam, Lemniscaat, 17-35.
- Swierstra, T., Bovenkamp, H. van de & Trappenburg, M., 2010. Forging a fit between technology and morality: The Dutch debate on organ transplants. *Technology in Society*, 32(1), p.55-64.
- Swierstra, T., Est, R. van, & Boenink, M., 2009a. Taking Care of the Symbolic Order. How Converging Technologies Challenge our Concepts. *NanoEthics*, 3(3), 269-280. Springer Netherlands.
- Swierstra, T. & Molder, te H. 2012. Risk and soft impacts, in S. Roeser, R. Hillerbrand, M. Peterson & P. Sandin (Eds.) *Handbook of risk theory* (pp.1050-1066). Dordrecht: Springer.
- Swierstra, T., & Rip, A., 2007. Nano-ethics as NEST-ethics: Patterns of moral argumentation about new and emerging science and technology. *NanoEthics*, 1(1), 3-20.
- Swierstra, T., Stemerding, D., & Boenink, M., 2009b. Exploring Techno-Moral Change: The Case of the Obesity Pill. In P. Sollie & M. Düwell (Eds.), *Evaluating New Technologies* (Vol. 3, pp. 119-138). Springer Netherlands.
- Swift, A., 2001. *Political philosophy : a beginners' guide for students and statesmen*, Oxford: Polity.
- Tallacchini, M., 2007. Ethics between Law and Politics : The Case for Human Biological Materials. *Public Policy*, (December), 1-15.
- Tenner, E., 1996. *Why things bite back: technology and the revenge of unintended consequences*. New York: Knopf.

- Thompson, P.B., 2002. Pragmatism, Discourse Ethics and Occasional Philosophy. In (Keulartz et al 2002).
- Verbeek, P., 2005. *What things do: Philosophical reflections on technology, agency, and design*. University Park, Pa. Pennsylvania State University Press.
- Verbeek, P.-P., 2011. *Moralizing technology: understanding and designing the morality of things*, Chicago; London: The University of Chicago Press.
- VSNU, KNAW & NWO. 2009. *Standard evaluation protocol 2009-2015. Protocol for research assessment in the Netherlands*. Available at www.knaw.nl/sep
- Winner, L., 1999. Do artifacts have politics? In D. MacKenzie & J. Wajcman, eds. *The Social Shaping of Technology*. Open University Press, pp. 28-40.
- Zwart, H., 2002 Philosophical tools and technical solutions. In (Keulartz et al 2002)

SUMMARY

Science and technology are paramount in defining our social practices. Computers and word processors define the practice of writing books differently from how ink and paper do. Similarly, molecular analyses of blood samples characterize the practice of diagnosing diseases differently from how an oral explanation of symptoms to a doctor does. If new technologies have a role in changing social practices, then they should be politically and socially governed. The governance of science and technologies requires a future-oriented assessment of how currently emerging science and technology will reconfigure social practices and what type of consequences they will have. Such an assessment allows society to make appropriate decisions and modulate developments towards desirable goals. This exercise entails many uncertainties and variables. Not only is it uncertain how emerging science and technology will develop; their social embedding is also hard to predict. Finally, when assessing emerging technologies we should be explicit about the values that are used to evaluate their desirability. In a democratic context, opportunities should be created for stakeholders to discuss these values and the moral acceptability of emerging technologies. This study ultimately aims at improving the conditions for such an assessment of the desirability of emerging technologies.

Chapter One introduces the rising and development of technology assessment practices in Western societies. Two approaches for assessing emerging technologies are discussed together with their merits and limits: Technology Assessment and applied ethics. Technology Assessment (TA) aims to increasingly broaden the space for democratic deliberation on emerging technologies. Some of these approaches have the merit of designing tools for making the actors in the innovation process more aware of other stakeholders' perspectives. However, TA approaches have been criticized because of their "normative deficit": TA fails to articulate the interests, preferences, values and create a space for a discussion on what a society should/shouldn't do (i.e. a *normative* analysis is missing). Ethical reflection on emerging technologies contributes to this aim. In fact, mainstream applied ethics focuses on appraising the desirability of a broad range of impacts of emerging technologies on human lives according to moral theories. However,

ethical reflection on emerging technologies has been criticized for being too speculative: ethicists do not question the *plausibility* of technological promises and support the hype of technology promoters. In this sense, ethicists fail to articulate the knowledge conditions of their analysis (i.e. an epistemological analysis is missing).

Pragmatist ethics fills the gap between TA and mainstream applied ethics. Pragmatist ethics holds that an assessment of emerging technologies should take place within the context of a democratic deliberation. In particular, it spells out some criteria for the quality of democratic deliberation and develops tools to improve the conditions of such a process. In this sense, pragmatist ethics sets the stage for “ethical technology assessment”. It enables a future-oriented exploration of the desirability of emerging technologies while looking in *contextual* “problematic situations”. However, such future-oriented exploration should be based on solid epistemological grounds rather than on mere speculation.

Based on these considerations, this study addresses the question:

How can the epistemological robustness of expectations on emerging technologies be assessed in view of a normative reflection of their desirability?

This appraisal of the epistemological foundations of expectations, while assessing their viability, should also transcend the logic of “here and now” and explore novel and distinctive issues raised by the expectations of new technologies. This study shows that the requirements of grounding hype and avoiding mere speculation can be coupled with an explorative reflection on the future. In order to address this question, I focus on the epistemological problem of assessing the desirability of technologies that are not there yet, and as such only exist as *expectations*.

Chapter Two articulates why *expectations* do not offer a steady ground for reflecting on the desirability of emerging technologies and how, instead, their *plausibility* can be assessed towards this aim. The literature explains that these projections of future states of affairs often have the strategic role of protecting innovations. Furthermore, they are not descriptions of future worlds, but normative visions of desirable worlds that guide towards their realization. Based on these considerations, I claim that the *plausibility* of the expectations that emerging technologies will bring about desirable worlds and promote desirable social values should be assessed. Such an assessment should take into account that values will be embedded and promoted in emerging artifacts and that they will be realized in social practices.

I propose an approach to assess the plausibility of visions that consists of three interlocked steps:

- First, the expectations of the artifact should be investigated. In this way, the conditions for the technology to work can be explored together with its implications for the context of use.
- Second, the expectations of the context(s) of use should be analyzed. In this way, the social practices together with the values attached to them can be investigated. This helps to explore how the new technologies can be embedded in such practices and systems of values.
- Third, based on these analyses, the plausibility of the expectations that a new technology will realize some values can be assessed. This assessment concerns: what values an expected artifact promotes; how likely it is that they are desirable; and how likely the technology will *instrumentally* improve a social practice.

Two analyzing strategies that are common to these three steps consist in *thickening* prospective descriptions of technologies in use and collecting *situated* judgments of their plausibility. These three steps are further described in the following chapters using the example of the expectations surrounding the Nanopil, an ingestible device for early detection of intestinal cancer.

Chapter Three discusses how to go about analyzing expectations of a future artifact. After introducing public expectations about the Nanopil, it is explained why further analysis is needed. Specifically, these descriptions obfuscate the development process of the artifact and present the new technology as a perfectly working mechanism. In-depth interviews with scientists and observation of their laboratory practices allowed me to look at the process of construction of the artifact and to investigate the expectations of an emerging technology. In the case of the Nanopil, this was done by collecting the details about the story of the project; its key concepts and how they are translated into a functional model; the different components of the Nanopil and how they are expected to work; and, controversies about alternative designs. This type of analysis enabled me to thicken the original descriptions of the Nanopil as a means of grasping the foundation of the expectations. As a result, I was also able to: identify alternative, co-existing designs in the system to communicate the test result to the user; underline possible required conditions for the Nanopil to work, like the consumption of a laxative to clear the bowel; rule out implausible scenarios on the basis of the current state of the art, such as the use of the Nanopil at the grocery store.

Chapter Four addresses the question of how to analyze expectations on the use of emerging technologies. To address this question, I use the concept of “fictive script” in order to point out that the expectations of the use of an emerging technology should be compared with the script in the emerging object.

Furthermore, these fictive scripts held by designers should be compared with the “world” as conceived by other actors. Following a short explanation of the research design used for investigating these questions in the case of the Nanopil, the findings of this analysis are presented. First, based on the analysis provided in the preceding chapter, some technical conditions for the pill to work that affect the way it can be used are pointed out. Then, using interviews with a broad range of social actors and a literature review on colorectal cancer diagnostics (clinical practices and policies), information about current practice in colon rectal cancer diagnosis and screening is collected. In this way, some scenarios of use are better defined. For example, it emerges that not every design choice is equivalent with respect to the context of use. A Nanopil that communicates the result to the user by releasing a blue dye in the intestine is unlikely to be used in the context of a screening program, in which the results of the screening have to be controlled in an efficient way. Furthermore, preferences, interests and perspectives on what is desirable in a certain context are gathered: how patient organizations are concerned with questions of privacy, how doctors are doubtful about/resist the use of self-tests for diagnostics, and how patients dislike the bowel preparation that is necessary for an endoscopic examination and that is still necessary in the case of the Nanopil.

Based on the previous analyses of the expectations of the artifact and its use, **Chapter Five** assesses the plausibility of expectations that the Nanopil will realize desirable values (such as early, reliable and user-friendly diagnostics). First, it is shown that for each artifact design, *competing* (or even conflicting) *values* are promoted. Expectations of the desirability of the Nanopil tend to cluster these distinctions into unifying visions without making the design differences explicit. As a result, expectations of the technology fail to address conflicting values related to a specific context; competing values are overlooked. Thus, it is claimed that they should be distinguished in order to more solidly ground the discussion of the desirability of this novel technology. Second, it is explained that different stakeholders have *divergent* beliefs about what is desirable in the practice of colorectal cancer screening. These moral divergences point to issues that may lead to future controversies. Once again, a grounded discussion on the desirability of the Nanopil should articulate these different positions, rather than group them under a common denominator of “societal desirability”. Chapter Five ends with a reflection on the potential “impacts” of this technology. I explain that the expectation of the Nanopil as enabling early detection of colorectal cancer suffers from a naïve instrumentalist logic. In fact, the Nanopil ‘mediates’ users’ understanding of themselves and their actions. Such a novel technology will not simply solve a problem; it should also be expected to change *a number of* practices, concepts and values. This interaction between technologies and

morality should be taken into account when assessing the desirability of this device. This analysis allowed me to emphasize the importance of teasing out heterogeneous scenarios of emerging technologies, rather than clustering them together in vague unifying promises.

Chapter Six provides another example of how the three-step framework can be applied to assess the plausibility of expectations surrounding an emerging technology. To begin with, the promises of ‘Immunosignatures’ are introduced: this emerging science and technology is expected to provide a tool for comprehensive health monitoring of healthy people that can revolutionize healthcare. Then, these expectations are analyzed in three steps. First, the description of Immunosignatures, its key-concepts and challenges are thickened. From an analysis of research practices in the laboratory, it emerges that the technical platforms and prospective applications of Immunosignatures is much more diverse than the initial promises seemed to suggest. Some conditions for this technology to work are also pointed out, together with its differences from other technologies. Second, the ‘fictive scripts’ describing the context of use are sketched out. This analysis thickens generic visions. Some scenarios and contexts of use can be ruled out, such as the use of Immunosignatures to monitor a developing flu. New scenarios also emerge such as, for example, the use of Immunosignatures as diagnostic tools for specific diseases. Furthermore, the fictive scripts articulated by researchers have been assessed by other experts and stakeholders. This assessment highlights some barriers to the social embedding of Immunosignatures based on current social configurations (for example, FDA regulations, or insurance companies). This assessment also indicates opportunities and contexts of use for this technology based on experts’ and stakeholders’ interpretation of ongoing trends (for example, the use of Immunosignatures in “medical home” contexts). These analyses provide a ground for disentangling the multiple conflicting values implicit in different technological platforms, the heterogeneity found in normative visions across different stakeholders, and the different interactions the technology-in-use has with morality. This chapter concludes with a comparison between the assessment of plausibility in the cases of the Nanopil and the Immunosignatures, elaborating on the differences in methodological choices.

Such plausibility assessments can be considered to have an “epistemological” rather than a “prescriptive” role because they aim to improve the conditions for developing knowledge about emerging technologies rather than offering a judgment on whether they are good or bad. **Chapter Seven** illustrates how this type of analysis contributes to develop tools for improving social actors’ deliberations on emerging technologies. In particular, the assessment of

expectations' plausibility guides the composition of "techno-ethical" vignettes and scenarios. These tools can be used as tools to trigger the moral imagination of participants during interactive workshops (inspired by Constructive Technology Assessment). This chapter explains how two exercises were designed in order to engage with the developers of the two technologies analyzed in this study, the Nanopil and Immunosignatures. In particular, it is described how grounded and exploratory scenarios were constructed and what role they played in the exercises with technology developers. These are promising tools for triggering an upstream discussion on the desirability of emerging technologies that is both grounded and explorative.

As explained in the **Postscript**, my proposal for such an assessment has a twofold outcome. First, it grounds the visions of futures technologies in situated practices, knowledge and values of stakeholders, avoiding in this way unwanted speculations. Second, it articulates the normative assumptions in expectations and explores their interaction norms, responsibilities, concepts and values. Such an assessment is preliminary to any Ethical Technology Assessment. Such a philosophical exploration of the meanings and implications of current promises can prepare society for future challenges and provide a tool to interpret the present.

SAMENVATTING

Wetenschap en technologie hebben een cruciale invloed op de aard van onze sociale praktijken. Het schrijven van een boek met computer en tekstverwerker gaat wezenlijk anders dan met papier en inkt. Het diagnosticeren van ziektes door middel van een moleculaire analyse van bloedmonsters verschilt van diezelfde diagnose door een arts die mondelinge toelichting geeft bij de symptomen. Als nieuwe technologieën deze invloed op sociale praktijken hebben, vraagt dat om politieke en maatschappelijke sturing.

Het (be)sturen van wetenschap en technologie vereist een toekomstgerichte beoordeling van hoe opkomende wetenschap en technologieën onze sociale praktijken zullen veranderen en welke consequenties ze met zich meebrengen. Een dergelijke beoordeling stelt de samenleving in staat om passende besluiten te nemen en ontwikkelingen bij te sturen richting wenselijke doelen. Maar deze onderneming brengt veel onzekerheden met zich mee. Het is niet alleen onzeker hoe opkomende wetenschap en technologie zich zullen ontwikkelen; hun maatschappelijke inbedding is eveneens moeilijk te voorzien. Uiteindelijk zullen we expliciet moeten maken op grond van welke waarden we hun wenselijkheid beoordelen. In een democratische samenleving moeten betrokkenen de kans krijgen om zowel deze waarden als ook de morele aanvaardbaarheid van opkomende technologieën te bespreken. Deze studie stelt zich als uiteindelijk doel om de voorwaarden voor een dergelijke beoordeling te verbeteren.

Hoofdstuk Een introduceert de opkomst en ontwikkeling van *technology assessment* praktijken in westerse samenlevingen. Voor het beoordelen van opkomende technologieën worden twee benaderingen besproken, met elk hun verdiensten en beperkingen: *technology assessment* en toegepaste ethiek. Het doel van *technology assessment* (TA) is het verbreden van de ruimte voor democratisch overleg over opkomende technologieën. Sommige vormen van TA zijn aantrekkelijk omdat ze instrumenten aanreiken om actoren in het innovatieproces zich meer bewust te maken van het perspectief van andere betrokkenen. Bepaalde vormen van TA zijn echter ook bekritiseerd om hun “normatieve tekort”: TA slaagt er niet in om specifieke belangen, voorkeuren en waarden te articuleren en de discussie aan te gaan over wat de samenleving wel/niet zou moeten doen. Dat

wil zeggen: een *normatieve* analyse ontbreekt. Ethische reflectie over opkomende technologieën draagt daar wél aan bij. De gangbare toegepaste ethiek richt zich juist op het beoordelen van de wenselijkheid van een breed scala van gevolgen van opkomende technologieën voor het menselijk leven, aan de hand van morele theorieën. Echter, zulke ethische reflecties zijn bekritiseerd om hun speculatieve karakter: ethici nemen de *plausibiliteit* van technologische beloften voor lief en dragen bij aan de hype die in het leven wordt geroepen door voorstanders van een bepaalde technologie. In die zin gaan ethici voorbij aan de kennisvoorwaarden voor hun analyse. Met andere woorden: een *epistemologische* analyse ontbreekt.

De lacune tussen TA en gangbare toegepaste ethiek wordt opgevuld door een pragmatistische ethiek. Deze stelt dat een beoordeling van opkomende technologieën moet plaatsvinden in de context van democratisch overleg. In het bijzonder reikt ze een aantal criteria aan voor de kwaliteit van dat overleg en ontwikkelt ze instrumenten voor het verbeteren van de voorwaarden van een dergelijk proces. In die zin dient pragmatistische ethiek zich aan als een perspectief voor “ethische *technology assessment*”. Ze maakt een toekomstgerichte verkenning mogelijk van de wenselijkheid van opkomende technologieën door de blik te richten op *contextuele* “probleemgevallen”. Een dergelijke verkenning moet echter wel gebaseerd zijn op degelijke epistemologische gronden in plaats van slechts speculatie.

Op basis van deze overwegingen staat in deze studie de volgende vraag centraal:

Hoe kan de epistemologische robuustheid van verwachtingen over opkomende technologieën worden beoordeeld in het licht van een normatieve reflectie op hun wenselijkheid?

Het op waarde schatten van de epistemologische gronden van verwachtingen bestaat niet alleen uit het beoordelen van hun levensvatbaarheid, maar moet ook de logica van het “hier en nu” overstijgen en wezenlijk nieuwe kwesties aankaarten die voortkomen uit verwachtingen van nieuwe technologieën. Deze studie toont dat het aan banden leggen van de hype en het voorkómen van speculatie samen kan gaan met een verkennende reflectie op de toekomst. Om de hoofdvraag te kunnen beantwoorden richt ik mij op het epistemologische probleem hoe je de wenselijkheid kunt beoordelen van technologieën die er nog niet zijn, maar alleen nog bestaan in de vorm van *verwachtingen*.

In **Hoofdstuk Twee** wordt beargumenteerd waarom *verwachtingen* geen solide basis vormen voor reflectie op de wenselijkheid van opkomende technologieën, en hoe ze op *plausibiliteit* kunnen worden beoordeeld. De literatuur leert ons dat zulke vooruitzichten vaak een strategische functie hebben in het beschermen van innovaties. Bovendien zijn ze niet zozeer beschrijvingen van toekomstige

werelden, als wel normatieve visies die richtinggevend zijn naar wenselijke werelden. Op basis van deze overwegingen beweer ik dat de *plausibiliteit* moet worden beoordeeld van verwachtingen ten aanzien van opkomende technologieën die wenselijke werelden zouden voortbrengen en maatschappelijke waarden zouden ondersteunen. Een dergelijke beoordeling dient in acht te nemen dat waarden zijn ingebed in opkomende artefacten en dat die waarden zo ook gerealiseerd worden in sociale praktijken.

Mijn voorstel is een benadering om de plausibiliteit van visies te beoordelen aan de hand van drie onderling afhankelijke stappen:

- Stap een: verwachtingen ten aanzien van het artefact moeten worden onderzocht. Zo kunnen de voorwaarden worden verkend waaronder een technologie zijn werk kan doen, in samenhang met de implicaties voor de gebruikscontext.
- Stap twee: verwachtingen ten aanzien van de gebruikscontext moeten worden geanalyseerd. Zo kunnen sociale praktijken en bijbehorende waarden in kaart worden gebracht. Dit helpt bij het verkennen hoe de nieuwe technologie kan worden ingebed in deze praktijken en waardesystemen.
- Stap drie: op basis van deze analyses kan de plausibiliteit worden beoordeeld van de verwachting dat een nieuwe technologie bepaalde waarden zal realiseren. Deze beoordeling omvat: (1) welke waarden een artefact zou kunnen bevorderen; (2) hoe waarschijnlijk het is dat deze waarden ook wenselijk zijn; (3) en hoe waarschijnlijk het is dat de technologie ook *instrumenteel* bijdraagt aan het verbeteren van een sociale praktijk.

Twee analyse-strategieën die terugkomen in elk van de drie stappen zijn het *verrijken* van toekomstbeelden over het gebruik van technologieën, en het bijeenbrengen van *gesitueerde* oordelen over hun plausibiliteit. In de volgende hoofdstukken worden deze drie stappen nader toegelicht aan de hand van verwachtingen ten aanzien van de Nanopil, een pil die geslikt kan worden voor het vroegtijdig opsporen van darmkanker.

Hoofdstuk Drie laat zien hoe het analyseren van verwachtingen ten aanzien van een toekomstig artefact in zijn werk gaat. Publieke verwachtingen over de Nanopil worden geïntroduceerd, maar er wordt ook uitgelegd waarom een verdere analyse eigenlijk nodig is. Zulke beschrijvingen van het artefact ontnemen ons het zicht op het ontwikkelproces en presenteren de nieuwe technologie als een perfect-werkend mechanisme. Diepte-interviews met wetenschappers en observaties van praktijken in het laboratorium stellen ons in staat om meer zicht te krijgen op de constructie van het artefact en de verwachtingen die daarbij horen. Het geval van de Nanopil zijn de volgende elementen in kaart gebracht: het

precieze verhaal van het project in detail; de sleutelbegrippen in dit verhaal en hoe die worden vertaald naar een functioneel model; de verschillende componenten van de Nanopil en hoe ze geacht worden te werken; en controversen over alternatieve ontwerpen. Dit type analyse stelde me in staat om oorspronkelijke beschrijvingen van de Nanopil te verrijken, en daarmee grip te krijgen op datgene waarop de verwachtingen gebaseerd zijn.

Dit leverde me het volgende op. Ik identificeerde alternatieve, co-existerende ontwerpen van het systeem dat testresultaten communiceert naar de gebruiker; ik wees op mogelijke voorwaarden voor de werkzaamheid van de Nanopil, zoals de inname van een laxeermiddel om de darmen schoon te maken; en ik kon onwaarschijnlijke scenario's uitsluiten op basis van de huidige stand van zaken, zoals verstrekking van de Nanopil bij de drogist.

Hoofdstuk Vier gaat over de vraag hoe verwachtingen over het gebruik van opkomende technologieën kunnen worden geanalyseerd. Om deze vraag te beantwoorden gebruik ik het concept "fictief script" om duidelijk te maken dat verwachtingen over het gebruik van een opkomende technologie vergeleken dienen te worden met het script van een nieuw object. Deze fictieve scripts, onderschreven door ontwerpers, moeten bovendien vergeleken worden met de "wereld" zoals die door anderen wordt gezien. Nadat een korte toelichting is gegeven op de onderzoeksopzet die gebruikt is voor het onderzoeken van deze kwesties in het geval van de Nanopil, worden de resultaten van deze analyse gepresenteerd. Eerst worden een aantal technische voorwaarden geschetst voor het slagen van de pil, en die relevant zijn voor het gebruik ervan. Vervolgens, op basis van interviews met een breed scala van sociale actoren en een literatuuroverzicht over darmkanker-diagnostiek (klinische praktijk en beleid), komt de belangrijkste informatie over huidige praktijken in darmkanker-diagnostiek en -screening op tafel. Op deze manier kunnen scenario's over de toepassing van de pil beter worden gedefinieerd. Niet iedere ontwerpkeuze heeft bijvoorbeeld dezelfde implicaties voor de gebruikscontext. Een Nanopil die resultaten aan de gebruiker communiceert door een blauwe kleurstof in de darmen te verspreiden is waarschijnlijk onbruikbaar voor een screening-programma, waarbij de resultaten op een efficiënte manier moeten worden gecontroleerd. Ten slotte worden voorkeuren, belangen en perspectieven over de wenselijkheid van een bepaalde situatie verzameld: hoe patiëntenorganisaties aankijken tegen privacy-kwesties, in hoeverre artsen twijfelen aan de toepassing van zelftests voor diagnostiek, en hoe patiënten opzien tegen het reinigen van de darmen, hetgeen noodzakelijk is voor endoscopisch onderzoek maar ook in het geval van de Nanopil nog steeds nodig is.

Op grond van eerdere analyses van verwachtingen over het artefact en het gebruik ervan, geeft **Hoofdstuk Vijf** een oordeel over de plausibiliteit van de verwachting dat de Nanopil bepaalde wenselijke waarden (zoals vroegtijdige, betrouwbare en gebruiksvriendelijke diagnostiek) zal verwezenlijken. Allereerst wordt aannemelijk gemaakt dat in iedere context *concurrerende* (of zelfs *conflicterende*) *waarden* worden onderschreven. Verwachtingen over de wenselijkheid van de Nanopil hebben de neiging om zulke verschillen glad te strijken tot overkoepelende visies die de gebruikscontext achterwege laten. Verwachtingen over de technologie slagen er daardoor niet in om tegenstrijdige waarden te voorzien; concurrerende waarden worden over het hoofd gezien of onder het tapijt geschoven. Ze moeten dan ook worden onderscheiden om discussies over de wenselijkheid van een nieuwe technologie van een solide basis te voorzien. Ten tweede wordt inzichtelijk gemaakt dat verschillende belanghebbenden *uiteenlopende* opvattingen hebben over wat wenselijk is in de praktijk van darmkanker-screening. Deze morele divergenties wijzen op kwesties die tot toekomstige controversen kunnen leiden. Ook hier geldt dat een grondige discussie over de wenselijkheid van de Nanopil deze verschillende posities zou moeten ophelderen, in plaats van ze te scharen onder de gemeenschappelijke noemer “maatschappelijke wenselijkheid”. Hoofdstuk Vijf eindigt met een reflectie op de potentiële “impacts” van deze technologie. Ik beargumenteer dat de verwachting van de Nanopil als een middel voor vroegtijdige opsporing van darmkanker zich zondigt aan een naïeve instrumentalistische logica. De Nanopil “bemiddelt” hoe gebruikers zichzelf en hun handelingen interpreteren. Een dergelijke nieuwe technologie lost niet alleen maar een probleem op; het zal ook een aantal praktijken, begrippen en waarden veranderen. Wanneer de wenselijkheid van het middel wordt beoordeeld, zal de wisselwerking tussen technologie en moraliteit moeten worden meegerekend. Deze analyse onderstreept het belang van het uitlokken van heterogene scenario’s over opkomende technologieën, in plaats van ze te clusteren in vage, alomvattende beloftes.

Hoofdstuk Zes reikt een ander voorbeeld aan waarbij het drie-stappen-plan kan worden toegepast om de plausibiliteit van verwachtingen over een opkomende technologie te beoordelen. Allereerst worden de beloftes over “Immuno-signatuur” ten tonele gevoerd: van deze opkomende wetenschap en techniek wordt verwacht dat ze het gereedschap bieden voor een alomvattende monitoring van gezonde mensen – wat een revolutie in de gezondheidszorg zou betekenen. Vervolgens worden deze verwachtingen geanalyseerd in drie stappen. Een: de beschrijving van het Immuno-signatuur, en de bijbehorende kernbegrippen en uitdagingen worden verrijkt. Uit een analyse van onderzoekspraktijken in het laboratorium wordt duidelijk dat technische platforms en toekomstige

toepassingen van Immuno-signaturen veel meer diversiteit kent dan de aanvankelijke beloftes suggereerden. Er worden bepaalde voorwaarden voor de werking van deze technologie uiteen gezet, ook in vergelijking met andere technologieën. Twee: de “fictieve scripts” over de gebruikscontext worden geschetst. Deze analyse verruimt algemene visies. Sommige scenario’s en gebruikscontexten kunnen worden uitgesloten, zoals het gebruik van Immuno-signaturen om de ontwikkeling van een griepvirus te monitoren. Daarnaast ontstaan nieuwe scenario’s, zoals bijvoorbeeld de toepassing van Immuno-signaturen als een diagnostisch instrument voor specifieke aandoeningen. Drie: de fictieve scripts die door bepaalde onderzoekers worden onderschreven, worden door andere deskundigen en belanghebbenden op waarde geschat. Deze beoordeling brengt barrières voor de sociale inbedding van Immuno-signaturen aan het licht, uitgaande van de huidige maatschappelijke instituties (zoals bestaande wet- en regelgeving en verzekeringsmaatschappijen). Deze beoordeling wijst ook op kansen en mogelijke gebruikscontexten, afgaande op de interpretatie die deskundigen en belanghebbenden geven van maatschappelijke trends (zoals het gebruik van Immuno-signaturen in de context van een “medische thuisbasis”). Deze analyses bieden een basis voor het ontrafelen van de veelvoudige conflicterende waarden die impliciet aanwezig zijn in verschillende technologische platforms, de heterogeniteit die zich uitdrukt in normatieve visies onder verschillende belanghebbenden, en de verschillende interacties die technologie-in-gebruik heeft met moraliteit. Dit hoofdstuk eindigt met een vergelijking tussen de beoordeling van plausibiliteit in het geval van de Nanopil en het geval van Immuno-signaturen – waarbij verder wordt ingegaan op de verschillen in methodologische afwegingen.

Dergelijke plausibiliteits-beoordelingen vervullen een “epistemologische” en niet zozeer een “prescriptieve” rol. Ze stellen zich ten doel om de voorwaarden voor het ontwikkelen van kennis over opkomende technologieën te verbeteren, en geenszins om te bepalen of ze goed of slecht zijn.

Hoofdstuk Zeven licht toe hoe dit type analyse bijdraagt aan de ontwikkeling van instrumenten voor het verbeteren van maatschappelijk beraad over opkomende technologieën. In het bijzonder geeft de plausibiliteits-beoordeling van verwachtingen enige richting aan het opstellen van “technisch-ethische” vignetten en scenario’s. Deze instrumenten kunnen worden ingezet om de morele verbeelding van deelnemers te stimuleren tijdens interactieve workshops (in de geest van Constructieve Technology Assessment). Dit hoofdstuk geeft inzicht in de ontwikkeling van twee oefeningen om met de techniekontwikkelaars van de Nanopil en het Immuno-signatuur samen te werken. Het beschrijft hoe gegronde en verkennende scenario’s tot stand zijn gekomen en welke rol deze hebben gespeeld in de oefeningen met techniekontwikkelaars. Dit zijn veelbelovende

instrumenten voor het stimuleren van een discussie over de wenselijkheid van opkomende technologieën in een vroeg stadium, die zowel gegrond als verkennend is.

Zoals ik uitleg in het **Postscript** heeft mijn voorstel tot een dergelijke beoordeling een tweevoudig resultaat. Ten eerste legt het een basis voor visies op toekomstige technologieën door gesitueerde praktijken, kennis en waarden van belanghebbenden mee te wegen, en daarmee ongewenste speculatie te voorkomen. Ten tweede verheldert het de normatieve aannames van verwachtingen en verkent het hun wisselwerking met normen, verantwoordelijkheden, begrippen en waarden. Een beoordeling als deze moet het vertrekpunt zijn voor welke ethische technology assessment dan ook. Een filosofische verkenning van de betekenissen en de implicaties van huidige beloftes kan de samenleving klaarstomen voor de uitdagingen van de toekomst, en een aanknopingspunt bieden voor het duiden van het heden.