

Gluten, Pills And Talk:
Assessing Emergent Technologies
From A Patients' Perspective

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This research was conducted under the auspices of the
Mansholt Graduate School for Social Sciences.

Gluten, *Pills and* Talk

Assessing emergent technologies
from a patients' perspective

Mario Veen

Thesis

submitted in fulfillment of the requirements for the degree of doctor

at Wageningen University

by the authority of the Rector Magnificus

Prof. dr. M.J. Kropff,

in the presence of the Thesis Committee

appointed by the Academic Board

to be defended in public

on Wednesday 18 May 2011 at 1.30 p.m. in de Aula.

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Gluten, Pills and Talk: Assessing emergent technologies
from a patients' perspective, 196 pages

Thesis, Wageningen University, Wageningen, NL (2011)

With references, with summaries in Dutch and English

ISBN 978-90-8585-823-2

ACKNOWLEDGEMENTS

I would like to thank first of all the participants in this study. The creative ways in which celiac disease patients deal with their difficult condition has been inspirational. And the rigorous devotion of medical researchers to improve their lives strengthened my ambition to offer them a complimentary perspective. With their combined efforts, celiac disease may one day be a thing of the past.

Throughout this research I was fortunate to have three supervisors. Bart Gremmen, Hedwig te Molder and Cees van Woerkum, your different approaches to supervising have contributed greatly to the rich and valuable learning experience of the past years, which extended, to use academic parlance, “beyond the scope of this research”. I have at times not been the most easily superviseable PhD candidate, and I thank you for encouraging me to see it through. Hedwig, I admire your rigor and devotion to discursive psychology; Cees, your comments have added much value to my work; and Bart, I very much enjoyed our philosophical discussions. Thanks also to all my colleagues at META for creating a warm as well as intellectually stimulating environment.

I dedicate this thesis to my grandparents, who have always been an inspiration in my life. Gon en Joop, I am lucky to have such wonderful parents. Thank you for always standing by me and making an academic career possible in the first place. Lidwien, Simon and Eva, thank you for being part of this happy family; Mark and Jessica, thank you for making them happy.

Thank you fellow members of Dr. Funk – Kris and Tris – for providing often much needed musical relief from thesis-related activities; my friends Ties, Herman, Zuzanna, Aquara and David, thank you for everything. Sathanama, your love and example helped me place the process of completing this thesis in a larger perspective. Thank you for the beautiful moments we shared. Masha, you are my best friend and you and Jorge always inspire me.

Finally, thank you Catherine, Ties and Zuzanna for proofreading. Johanna, thank you so much for doing the lay out of this thesis. You have done a wonderful job!

Mario Veen
April 2011

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Maria Bronnikova, 2010

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CHAPTER 1

GENERAL INTRODUCTION

GENERAL INTRODUCTION

1.1 Introduction

Sometimes it is necessary to take a detour to arrive at your destination. In the film *Stalker* by Andrei Tarkovski, a writer and a scientist hire a guide to lead them to “the Zone,” a desolate area that contains a room where presumably all one’s wishes will be fulfilled. Early on in the film they stand in clear sight of this room and are ready to run straight to it, but their guide informs them that in “the Zone” things are not that simple. What seems the most direct way actually takes the longest, and one might never get there.

This research deals with such a topic where a linear, straightforward path might seem the most efficient way, but actually does not get us to where we want to be. The question is how to involve the perspective of people who are likely to be impacted by a future technology in the development of that technology.

In the past, product developers excluded users from the innovation stage. Users only came into the picture after the product had already been developed. The public’s role was limited to receiving information and choosing between the ready-made options offered to them. Since the onset of technology assessment (TA) in the 1980s, there has been more emphasis on engaging prospective users upstream in the innovation trial (Schot & Rip, 1997; Oudshoorn & Pinch, 2003). This is especially relevant in the case of emergent technologies, where there is a long innovation trial and many opportunities to involve prospective users.

At their most basic level, technologies need to be functional and safe: they need to do what they are expected to do, and not explode or be poisonous. From a marketing perspective, they need to be products that people want – or at least think they want or can be convinced to want; but besides these perspectives, there are also social and ethical concerns connected to technology. There is a difference between technological feasibility and social acceptability (Wolfe et al., 2002). This has become apparent with novel technologies such as genetically modified organisms (GMOs) and nutrigenomics, where it is often a question of how specific groups or society at large will be impacted. It is also particularly relevant

in cases where products of innovation processes emerge over periods of years or even decades, rather than appearing ready-made on the market. This allows us to recognize at an early stage that developments in a certain research field will most likely eventually lead to products that will impact the lives of certain groups of people.

In these initial development stages of emerging technologies it may not be possible to tell exactly what these products will look like, when they will be ready, and how they can be used. However, at the very least there are three factors present: expected innovation in a certain area, prospective users of those innovations, and a certain period of time over which technologies are emerging. This last factor is crucial because it provides a window of opportunity for intervention, meaning that there are a number of in-between stages in which they can be evaluated and the course of innovation can still be adjusted. This is different from a situation where there is a technological invention, for instance GPS, that is developed into a consumer application relatively fast, in which case consumers are confronted directly with a final product. The question addressed in this thesis is how to incorporate the view of prospective users of new technologies in the innovation process in such a way that the introduction of these technologies actually leads to an improved quality of life for them.

When something is being developed, and there is a question about whether and how those people for whom it is being developed will use it, and what possible adjustments can be made to suit their specific situation, just asking them about it may seem to be the easiest way to find out. However, there are some complications with this. It means asking people to assess a technology that does not yet exist. The technology might turn out differently, people's wishes or other circumstances might change, and there might be blind spots that turn out to be of crucial importance. In addition, it assumes that people will act as they expect to act, or to be more precise, as they *say* they expect to act. To name but one example, the telephone was originally intended to be used only for business transactions and broadcasting concerts. When asked about buying a mobile phone, only fifteen years ago most people would have rejected the idea, characterizing it as expensive or redundant. Now most people have (at least) one.

The paradox is that, although one wants to know about future impacts of technology, one can only examine current presentations and expectations. When asked to give their opinion about an emergent technology, what people are assessing is not the actual technology, but the

innovators' presentation of it, which is contingent on their particular circumstances, agendas, assumptions, and interests. Therefore, simply asking users is not sufficient, and a "detour" is needed.

This detour consists of examining users' everyday life. The approach offered in this thesis studies the social actions that are performed in the course of everyday interactions. It is this network of social actions that forms the arena into which new technologies are introduced and integrated. Insight into this arena through examination of prospective users' discursive practices can be used to involve their perspective in the development of these technologies. This approach is applied in this thesis to assessing emergent medical technologies in the field of celiac disease research.

1.2 The field: the patient central in celiac disease research

This thesis examines the case of emergent medical technologies for celiac disease (CD) patients. CD is a complex phenomenon, and not much is known about the exact way in which patients cope with it in their daily life. Therefore it is not immediately clear which medical technologies could help improve patients' quality of life.

Celiac disease is a digestive disease that causes an intolerance to gluten. In pre-historic times, there were no celiacs because our diet consisted mainly of fruits, nuts, vegetables, and meat. The transformation of our eating habits by the agricultural revolution introduced, together with lactose intolerance and diabetes, a condition that the Greek physician Aretaeus of Cappadocia described in the following way around 250 AD:

If the stomach be irretentive of the food and if it pass through undigested and crude, and nothing ascends into the body, we call such persons coeliacs (Adams, 1856: 256).

In the 18th century, Dr. Matthew Baillie (Baillie, 1815) discovered that a rice diet helped reduce CD patients' symptoms. Samuel Gee noted in 1888 that a Dutch child had no problems in the mussel season, but that his symptoms returned when the season was over. At the beginning of the 20th century, Sidney Haas recommended a banana diet. However, besides the fact that whatever was making celiacs ill was not in rice, mussels, or bananas, the precise trigger was still unknown.

A breakthrough in CD research occurred when Dr. Karel Dicke noticed that during the bread shortages in World War II the number of CD

patients reduced, and increased again after bread drops by the Allied forces. He was the first to link CD with the ingestion of wheat proteins. Nonetheless, it was only in the 1990s that CD was officially recognized as an autoimmune disorder caused by the interaction between gluten and the patient's small intestine.

In CD, the problem is now identified as an inflammatory reaction of the small intestine when it comes into contact with gliadin, which is a gluten protein mainly found in wheat, barley, and rye. For CD patients, gluten intake causes a flattened intestinal epithelium, leading to poor absorption of nutrients. This can result in abdominal pain, diarrhea, malabsorption, and poor growth as well as serious complications such as osteoporosis, infertility, miscarriage, low birth weight of children born to mothers suffering from CD, non-Hodgkin's lymphoma, and dermatitis herpetiformis (DH) (Gilissen et al., 2005).

Even though CD is estimated to affect up to 1% of Indo-European populations, relatively few people are aware of the disease. Herein lies its hidden threat to public health. Studies show that about 5 out of 6 patients are misdiagnosed, diagnosed at a later stage, or not at all. This means that of the at least 80,000 patients in the Netherlands, only about 10,000 have been identified. In addition, for many patients who have been identified, it has taken years for them to discover the cause of their ailments.

For CD patients, there is a striking time lapse between experiencing symptoms and their first visit to a medical expert (patient's delay), and between that visit and the correct diagnosis (doctor's delay). On average, the former is four years, and the latter ten years (Hekman, 2006). This may be due to the vagueness and broadness of symptoms associated with CD, and the fact that it is still relatively unknown. In recent years, however, there has been more awareness of CD, and this is likely to increase identification of patients and decrease the doctor's and patient's delay.

CD has a big impact on patients' lives, practically, socially, and psychologically (Hallert et al., 2002; Ciacci et al., 2002; Nijholt, 2006). Gluten is difficult to avoid because it is commonly found in the diet of most societies around the globe. Wheat is a staple food in many countries and used widely in the food industry. Although the market is substantial – with at least 1% of the population having CD – there is still a limited availability of gluten-free food (which is strange from an economic perspective). Besides this, the social dimension of food plays a role: eating is traditionally a shared social activity. Special dietary requirements can complicate or even be a barrier to participating. This is especially the

case for CD patients, for whom even one molecule of gluten can cause symptoms to occur (Olsson et al., 2009). Because CD is relatively unknown in society, explaining the condition to others can also be difficult. Finally, not being recognized or taken seriously is an issue.

CD patients who follow the diet in most cases no longer experience any symptoms. They may be labeled as patients officially, since they have been diagnosed with CD, but this may be hypothetical in the sense that *if* they eat gluten, they become ill. However, they would not be considered patients had their diets been gluten-free from the start. In countries where gluten is not such a prevalent part of the cultural diet, there may be people that would have developed CD if they had come into contact with gluten. Whether those people can be called CD patients, even if they have never experienced any symptoms and there is no way of telling their gut apart from a “healthy” person’s, is perhaps a philosophical question.

To summarize what makes CD interesting in the study of patient-technology relations: It is prevalent in society yet it is under-diagnosed. The patients that are diagnosed have often had to wait a long time for the diagnosis. Furthermore, it has a big impact on the everyday life of patients but no real therapy exists. The only available “therapy” is the avoidance of the allergen in diets. And when this therapy is successful, patients in most cases experience no symptoms and (physiologically at least) cannot be distinguished from a healthy person. Therefore it is not immediately clear from the outset what a medical innovation that would contribute to CD patients’ quality of life would look like, and more insight into everyday concerns of CD patients is needed.

1.2.1 The Celiac Disease Consortium (CDC)

In the past decade, research has shed new light on CD. The nature of the disease-inducing components of gluten and related proteins has been identified, the role of the enzyme tissue transglutaminase has been established, and the role of CD-associated HLA-DQ2 and HLA-DQ8 molecules is now fully understood. It has become evident that CD is a multifactorial disease that involves a variety of genes (most of them still unidentified) and environmental factors (particularly diet). Despite progress in understanding the disease, many problems remain unresolved. The Celiac Disease Consortium (CDC), founded in 2003 as a collaboration of different universities, patient associations, and industries in the Netherlands, aims to address key problems surrounding CD using a multidisciplinary approach focused on the needs of CD patients:

safer food, better diagnostics, and new treatment methods (Businessplan CDC, 2003: 5–13).

Three research clusters have approached these needs from different perspectives. The *Human Genomics* cluster focused on the identification of (aberrant) molecular pathways leading to disease development in order to improve diagnostic procedures, design a screening program to identify children at risk of developing CD, and generate leads for novel therapies based on fundamental insight into the role of particular molecular pathways in the onset of CD. The *Food Genomics* research cluster concentrated on reduction of gluten intake by improving means for detection of toxic gluten peptides in food products, evaluating novel approaches for the degradation of gluten in food, and generating tools to aid future breeding programs for the generation of safer wheat strains. A *Societal Research* program evaluated the impact of the disease and outcomes of the Food and Human Genomics clusters on patients and their families. The research undertaken in this thesis is part of the Societal Research cluster of the CDC.

The CDC research may result in innovations that have a far-reaching impact on the life of celiac disease patients. Some possibilities are an enzyme pill that would allow patients to eat gluten safely for a few hours, testing kits to be able to test if food contains gluten, wheat races that contain gluten which are safe for CD patients to eat, and a wider variety of gluten-free products. A clear understanding of patients' wishes, needs, and concerns regarding these research developments is crucial to guide and implement the CDC's work. This project was designed to explore the ways in which patients make sense of their illness and dieting practices, so as to help translate these everyday concerns into both relevant technology characteristics and effective communication about these new technologies (cf. Businessplan CDC, 2003: 52–53).

The innovators explicitly formulated in their mission statement their commitment to the patient as the central focus of their research (Businessplan CDC, 2003). This willingness to actively involve the patient in the innovation process is not always in evidence. It is the CD patient who is confronted with the diagnosis and the personal and social consequences of the lifelong gluten-free diet. It is quite obvious that the diagnosis and diet have a strong impact on the everyday life of patients and their families. Therefore it is clear who the prospective users of the emergent technologies are – a factor that is not always obvious in other areas of research.

1.2.2 Managing deficit models and Collingridge dilemmas

Science and technology studies (STS) have elaborately dealt with the question of how to include users' perspectives in innovation. STS was born out of the recognition that new technologies impact society at large, have social and ethical implications, and that not being aware of these implications may get in the way of public acceptance. In the past, innovators just developed science and worried about getting user acceptance later. If the user criticized the innovation, this was seen as resistance to change. The focus was on trying to get the technology accepted, and the innovation process itself was treated as a given (as critically described by Rip, 2009; Deuten et al., 1997). From the 1990s onwards, there has been more emphasis on involving users in innovation. Domestication theory showed that early user involvement improved successful integration of technologies in users' everyday life (Silverstone & Hirsch, 1992). Constructive technology assessment (CTA, see Rip et al., 1995; Schot & Rip, 1997; cf. Oudshoorn & Pinch, 2003) was developed as a method to stimulate dialogue amongst actors early in the innovation process.

Most notably, two problems have been identified as threatening the truly participatory nature of innovation processes. First of all, experts' think about users or the public in terms of a *deficit model*. The model denotes a way of thinking in which users are involved in the innovation process, but from a perspective that views them as laypeople that need to be educated about science and technology before they can make valid judgments about it. When innovators perceive resistance to proposed innovations, this is mainly described in terms of knowledge or trust deficits on the part of the public, and the intrinsic value of user involvement is still in question (Wynne, 2001).

With the *Collingridge dilemma* (Collingridge, 1980), the timing of user involvement is raised as a problem: either it is too early, and there is no concrete innovation to which users can react; or the technology is at an advanced stage, at which point it is no longer possible to make fundamental adjustments due to path dependency. These two problems are critically discussed in the STS and TA literature, and various solutions are proposed (see for instance Schot & Rip, 1997). Most current STS approaches, however, examine situations in which the innovation itself already plays a role: they concentrate on evaluations either of (partly) developed technologies or of future scenarios of what the innovation is expected to look like. However, in doing so, they fail to pay attention to participants' existing everyday concerns that seem unrelated to the tech-

nology at first sight but subsequently may determine whether it succeeds or not.

The contribution of this thesis to this body of literature is twofold: we propose to examine the current practices of prospective users in the situation that the innovation is expected to impact, i.e. the default situation in which there is no innovation yet, and to study users' talk in its own right, rather than only as an evaluation or assessment of various possible uses of the technology. The assumption is that new technologies are confronted with everyday problems and concerns that, to a large extent, are already there but often remain unnoticed, even by current and possible future users. These concerns are not necessarily technology related or, rather, will predominantly not be constructed as such by users. The aim is not to capture users' future ways of dealing with the technology per se. Rather, the goal is to bring patients' relevant interactional concerns to the surface (for example matters of identity, personal accountability, and blame attribution) so as to provide for a better *articulation* of patients' needs and expectations about future technological developments.

In the traditional approach to medical innovation, patients have a particular medical problem that impacts their quality of life (Holzman et al., 2004). Here, the patient is treated as an object of medical research, having primarily a physiological problem, and an intervention at this level – a therapy – is supposed to remove the cause of the reduction in quality of life experienced by the patient. A problem with this approach is that, as already mentioned, CD is not a “traditional” medical problem, in the sense that patients who follow the gluten-free diet in most cases experience no symptoms. A new therapy, for instance a pill that would allow patients to eat gluten without harm, would not constitute a medicine in the traditional sense, but an alternative to the existing practice of the gluten-free diet. Another point is that, in this approach, the patient is targeted as an individual, and there is evidence that social factors play an important role in coping with CD, and CD is interwoven so intimately in the fabric of everyday life and everyday actions such as shopping or going on holidays. We propose that, to make the patient central in medical innovation, it is not the individual patient that needs to be the object of research, but the patient in context, that is, in their everyday life.

1.2.3 Coping behavior of patients

In the case of CD patients, not much is known about how they treat the gluten-free diet in everyday life. Our research focuses on studying

the ways in which patients currently cope with their disease and diet, as the environment into which future innovations will be introduced. A lot of research has been done on the impact of particular diseases on patients' lives, mostly from a *social psychological* point of view. For example, pain coping strategies in fibromyalgia syndrome (Raak et al., 2003) and the role of social support in rheumatoid arthritis (Holtzman et al., 2004) have been examined by using questionnaires to reveal attitudes. In-depth interviews have been conducted to explore the effect of support groups on cancer patients (Yaskowich & Stam, 2003) and coping with HIV infection immediately after the diagnosis and later on (Reeves et al., 1999). Lee (2001) presents a narrative analysis of one patient's story of surviving cancer. With respect to celiac disease, this social psychological research tradition has also emerged. De Rosa et al. (2004) and Ciacci et al. (2002) make use of standard questionnaires such as the Illness Behavior Questionnaire (Pilowsky & Spence, 1983) and the Eysenck Personality Questionnaire (Eysenck & Eysenck, 1964).

What these research perspectives have in common is that they are essentially *cognitive* and are designed to map cognitions that lie behind behavior and conversation. The researchers aim to make inferences from patients' responses or draw conclusions from what they report in interviews. What is typical for these cognitive approaches is that researchers ignore the *rhetorical* and *interactive* context of accounts (cf. Horton-Salway 2001: 249). They do not look at the interactional business being performed in the course of natural interaction. However, these social actions are crucial for understanding patients' talk in the context of technology development. When technologies are introduced into society, they do not emerge into a void but into a social context in which people have an established way of coping and are used to performing activities in a certain way. If and when users adopt a new technology or treatment, it is in the context of these social goals. Likewise, when they respond to presentations about technologies, their arguments are embedded in, and can only be understood by examining, this social context. By just looking at the arguments themselves as isolated from this context, or viewing people's talk as isolated utterances expressing attitudes, emotions, and cognitions, and ignoring coping mechanisms as an integrated part of everyday practice, this action aspect, which is so vital, is overlooked. The *discursive psychological* approach can bridge this gap by shifting attention to *actions* and viewing patients' accounts from an interactional rather than a cognitive perspective.

1.3 Approach: discursive psychology

Discursive psychology (DP) is a form of discourse analysis developed from an approach outlined in *Discourse and Social Psychology* by Potter and Wetherell (1987). Further developed by Edwards and Potter (1992), discursive psychology draws on ethno-methodology and follows principles of conversation analysis through analysis of the structure of text and talk. The foundation of the status of language in DP is inspired by Wittgenstein's later work. Particularly in *Philosophical Investigations* (1953), Wittgenstein rejected the idea of language being a factual or cognitive representation of a state of affairs outside of language. According to this idea, our words, sentences, or conversations are neither a picture of the world outside us, representing an external reality, nor a window to our thoughts, feelings, and attitudes, describing inner cognitive mechanisms. Instead, language is seen as performing social activities in the context of our everyday lives: requesting, inviting, measuring, ordering, negotiating responsibility, and so on. When I request someone to pass me a hammer, for instance, I am not so much expressing an internal wish to have the hammer as participating in a particular "language game" in which performing a request could be followed by an action on the other person's part, such as handing me the hammer, or refusing to do so.

Whereas Wittgenstein worked mainly with these kinds of hypothetical examples, the object of analysis in discursive psychology is actual written or spoken discourse, usually recorded and transcribed, and subjected to close empirical analysis of the interaction that takes place. Discursive psychology is interested in discourse because it is in and through language that social action takes place. Rather than as an abstract system of meanings and interpretations, discourse is seen as the arena within which human beings perform interactional business. This orientation towards action sets it apart from both cognitive traditions of psychology and semiotic types of discourse analysis.

Discursive psychology examines how people construct worldviews in the course of their interactions, and the way these versions are established as solid, real, and independent of the speaker (Potter 1996). It aims to reformulate cognition from an analyst's category (the focus of social psychology) into a participant's resource. In everyday conversation, people perform all kinds of actions with their language, such as creating and presenting an identity, making judgments, and displaying neutrality. Likewise, attitudes or motives are an integral part of participants'

interactional work, rather than simply reflecting their inner world. From a discursive point of view, they are no longer private mental states but social phenomena that are locally produced and managed.

In each of the chapters of this thesis, we discuss the theory of discursive psychology more in depth, in relation to the particular topic of that chapter. For this introduction, a short sketch of three aspects of discursive psychology suffices. First of all, discursive psychological research focuses on interaction in context. Everyday conversations are the object of research: discourse that would have been produced even without the presence of a researcher and their recording equipment. This allows us to study CD patients' practices in their natural environment, i.e. everyday life, rather than isolating them and studying them in an artificial environment. This also means that the specific interactional context in which CD patients' talk is embedded is taken into account, rather than examining isolated sentences.

Secondly, discursive psychology focuses on social action rather than cognitions. A lot of the value of what people say lies not so much in the content of what they say, as in the social actions that are being accomplished by saying it in a particular way at a particular moment in the interaction. This also plays a role in patient interaction. For instance, patients may reject a certain treatment in conversations with others to avoid coming across as a bore, or as displaying deviant behavior. Another example of this is a study that found that a "scientific" self-diagnosis of CD was preferred by patients because it allowed them to create more credibility about their illness identity in conversations with non-patients than in cases of non-scientific self-diagnosis (Copelton & Valle, 2009).

Thirdly, discursive psychology takes *participants' concerns* as a starting point. The analysis is guided by what patients and other participants in the interaction bring up, and by the way in which they do so. It is not the researcher who makes inferences about what is going on in a conversation. People use the turn-by-turn development of a conversation as a resource to make sense of the social activities that are accomplished. These publicly displayed and continuously updated understandings of what is being said and done are an important "proof procedure" for the analyst.

Two specific areas of discursive psychology are interesting for the research proposed here. The first research field is in its early stages and takes discursive psychology as a perspective to examine the impact of a specific disorder on patients' behavior. Horton-Salway (2001, 2004) and Lamerichs (2003) have explored how the discursive psychology approach

can make a general contribution to the analysis of illness narratives. The discourse of people suffering from ME (chronic fatigue syndrome) (Horton-Salway 2001, 2004) and online support groups on depression (Lamerichs 2003) were examined on functions of utterances. It became clear that both ME and depression patients did a lot of interactional work establishing a specific patient identity. For instance, in online support groups on depression, patients showed a pervasive concern about establishing the kind of person they were (Lamerichs 2003). ME patients were found to make references to being an active person before the onset of the disease, creating a contrast with the current situation to stress the impact of the disease on their life.

A second interesting focus of discursive psychology is the issue of eating habits, food, and identity. Since after diagnosis CD patients have to radically adapt their diet, it is expected that conversational practices around food and eating are important. Wiggins (2002; Wiggins & Potter, 2003; Wiggins & Hepburn, 2007) and Sneijder and te Molder (2004, 2005, 2006, 2009) examined mealtime conversations within families and online forums on veganism, hedonism, and obesity. Mealtime conversations and online forums have proven to be contexts in which people often construct and refer to eating habits, food and health evaluations, and identity. However, there has been no research on these topics in a context where participants follow a medically imposed diet.

Another contribution that this thesis aims to make is to develop discursive psychology as a tool that can be used in technology assessment. This is a new area to which this kind of analysis has not yet been applied, and we hope to develop this use through applying it to the case of innovations in CD research. Doing so may offer interesting avenues for further research in the context of technology development, including but not limited to medical technologies. The aim in this is to develop discursive psychology as a practical tool that can be used in collaboration with all stakeholders involved in the innovation process to enable better communication and ultimately technological development that contributes to people's quality of life. Discursive psychology is a suitable approach to do this, because it directs our focus to prospective users' talk, and the actions performed in and through it, in its own right.

1.4 Problem formulation

The research products of the CDC may have far-reaching consequences for CD patients. The goal of the CDC is therefore to involve patients'

perspectives in the research, so that eventual new technologies may be integrated by them in a way that contributes to their quality of life. To design innovations that contribute to CD patients' quality of life, and communicate about these technologies effectively, it is essential to consider the current general concerns in the daily life of patients. However, very little is known about how CD patients currently deal with CD and the diet. Although there have been studies that address this issue, none has examined the actual everyday practices of patients. In the development of new technologies, a lack of knowledge of the everyday concerns of prospective users may lead to poor communication and failure to integrate these technologies into their established practices. Therefore, this research focuses on patients' accounts of the impact of CD and diet on their everyday life.

By using discursive psychology, we examine how CD patients present themselves in different social contexts and what social goals they achieve with this. Specifically, we examine how celiac disease-related topics are treated by patients in interaction with others. The natural setting in which patients are involved with dietary practice is the area that future CDC research products are most likely to affect. We examine discussions on an online forum in which patients discuss the diet with other patients, and interactions with family members. In addition, the research focuses on patients' reactions to preliminary results about emergent technologies. This emergent stage, when innovation is already somewhat developed but where there is still room for adjustment, is a crucial point in time to involve patients in the innovation process. It is important to examine, as soon as possible, issues that are important for celiac disease patients with respect to current diagnosis and therapy (i.e. dietary products).

Examining the everyday interactions of patients will lead to a better understanding of the way they cope with their condition. This, in turn, will provide insights that allow these concerns to be translated into relevant technology characteristics, and into a way of communicating and deliberating about these technologies that takes the patients' perspective into account.

1.5 Data collection: studying three kinds of interaction

Of course it is impossible to examine all of everyday life discursively. This would imply a "Big Brother" (or "Philips House") setting in which the patient is recorded twenty-four hours a day. By selecting discursive

psychology as our research tool, we have already restricted it to studying talk-in-interaction, or *conversations*. Even so, studying conversations is too broad an area, since it encompasses everyday talk between peers, telephone conversations, e-mail and online chat, and so on.

As a guiding focus to select the source of our data, we have to ask ourselves which areas in patients' lives are impacted by CD, and are therefore relevant to this study. This could include, for instance, conversations with the doctor when the patient is diagnosed, talk about shopping and food products, explanations of CD to friends or co-workers, discussions with other patients, meetings of patient associations, conversations between waiters and patients who are explaining that they cannot have gluten, consultations with dieticians, and so forth. All of these are potentially very interesting research objects. A guiding principle, however, is to choose a couple of different areas that can give us a richer picture of patients' everyday practices.

However, we are not just examining CD patients' everyday interaction from, for instance, a medical ethnography perspective, or a purely medical perspective, but from the perspective of innovation. The aim is to explore those areas of everyday life that will potentially be impacted or be relevant for future CDC innovations. Therefore we have to identify areas in which it is likely that issues that are relevant from an innovation perspective will be discussed.

We first divided patients' discourse broadly into three different social contexts: interaction with other patients, with non-patients, and with CD experts. Then we added to this the different interactional environments that play a role: everyday face-to-face conversations, internet conversations, and institutional conversations. Taking into account the innovation perspective, and asking where these kinds of issues were likely to be discussed, resulted in the following three data sets:

Patient–patient: interaction on online forums where patients discuss CD and diet

Patient–non-patient interaction: mealtime conversations of CD patients with family members

Patient–expert interaction: meetings between patients and CD researchers where developments in CD research are discussed

These data sets are described in more detail below.

1.6 Research questions and thesis outline

Aim of the thesis: To examine the everyday discursive practices of celiac disease patients in order to gain insight into how emergent technologies can contribute to their quality of life.

The problem formulation has been concretized in the following sub-questions:

How is the gluten-free diet treated amongst patients, and what does this mean for innovations that aim to provide an alternative or addition to the diet?

Examining patients' interactions with each other may shed light on how the only currently available practice for dealing with CD, the gluten-free diet, is treated amongst patients. Dietary practice is the background against which CD-related innovations will be introduced, and the way patients currently manage dietary practice shapes how any innovation will be received. The way the diet is embedded in patients' lives will have an effect on how innovations could affect, provide an alternative to, or even completely replace it. Since the internet is an important medium of communication for CD patients to gather information and exchange ideas about their disease (Lee & Newman, 2003), examining online talk allows us to get an insight into that part of their lives. CHAPTER 2 examines patients' online interactions with each other. The most used online environment for CD patients is the Gluten-free Celiac Disease Forum (www.celiac.com). A wide range of topics is discussed here, ranging from suitable restaurants, to how patients feel after starting with the diet, to the participation of young patients at children's parties.

How do CD patients and their family cope with disease and diet during family mealtimes?

One of the most important social environments in people's lives is family; and one of the most basic social rituals is eating together. Since this is also precisely the area that is affected by CD, and for which new innovations are being developed (a pill that allows one to eat gluten, gluten-safe wheat races, tests that can determine whether food is gluten-free), examining patient-non-patient discourse follows a recent tradition of investigating *mealtime conversations*.

Examining patients' interactions with non-patients may lead to a better understanding of CD as a collective phenomenon that has implications for patients' social environment. It is clear that being diagnosed with CD and changing one's habits of shopping, cooking, eating, avoiding gluten contamination, explaining to colleagues, and so on, affect not only the patients themselves but also their social environment. Therefore it can reasonably be expected that innovations that have an impact on those practices will also have an impact on interactions between patients and non-patients. CHAPTER 3 examines patients' mealtime conversations with close relatives.

How do patients and researchers discuss current developments in CD research? What does this say about expert–patient communication, and patient involvement in the innovation trial?

Examining interactions between patients and innovators about emergent CD research products will not only help to better understand patients' concerns and wishes with respect to these research products, but also allow for critical reflection on communication between the CDC and the patient community. CHAPTER 4 examines interactions between patients and experts in meetings where they discuss current research developments in the area of celiac disease.

On the basis of a series of meetings organized by the CDC, which we are allowed to record, we examine how patients respond to presentations by CD researchers about emergent medical technologies. This allows us to study not only the reactions of patients to these presentations, but also the way proposed innovations are presented to them by experts.

How can discursive psychology be further applied as a technology assessment tool?

To explore the methodological consequences of the findings from the research in this thesis, CHAPTER 5 discusses discursive psychology as a technology assessment tool, on the basis of the preceding analyses, and how it could be applied to other situations – i.e. not only to medical innovation, and in other contexts.

In CHAPTER 6, the main implications of this research for assessing emergent technologies from the user perspective are formulated, and the results are discussed.

CHAPTER 2

**QUITTING IS NOT AN OPTION:
AN ANALYSIS OF ONLINE DIET TALK BETWEEN
CELIAC DISEASE PATIENTS**

Published as Veen, M., te Molder, H., Gremmen, B. and Van Woerkum, C. (2010) "Quitting Is Not an Option: An Analysis of Online Diet Talk between Celiac Disease Patients," *Health (London)* 14(1): 23–40.

QUITTING IS NOT AN OPTION: AN ANALYSIS OF ONLINE DIET TALK BETWEEN CELIAC DISEASE PATIENTS

2.1 Introduction

This article examines how celiac disease (CD) patients cope with the risk of dieting lapses in their day-to-day living. Celiac disease is a disorder of the small intestine caused by abnormal responses to gluten proteins, and affects approximately three million patients in the Western world (Celiac Disease Consortium, 2008). Once developed, CD is a lifelong ailment that can lead to a variety of symptoms, including mal-absorption, diarrhea, growth retardation, osteoporosis, reduced fertility, miscarriage, low birth weight, and lymphoma. Currently, the only available treatment is a lifetime of gluten-free eating, a difficult prospect because gluten is found in wheat, barley, and rye, and is therefore common in many daily foods. Once gluten has been eliminated from the diet, the symptoms disappear after some time. Upon ingestion, however, these symptoms instantly return.

In theory, this means refraining from food derived from wheat, rye, and barley. However, this apparently straightforward solution meets with significant difficulties. Because most modern foods are processed, even products that appear safe to CD patients actually are not, as they are routinely contaminated with gluten from other sources (Celiac Disease Consortium, 2008). There are also psychological and social sources of dietary non-compliance (Ciacci et al., 2002; Hallert et al., 2002). The difficulty of total exclusion of the allergen in everyday life means, first of all, that CD patients have to deal with being constantly at risk, and, second, that they do experience the effects of gluten intake, no matter how strictly they keep to the diet.

Besides the food industry adding gluten to food products without this always being clear, there are also psychological and social sources of dietary non-compliance (Hallert et al., 2002; Ciacci, Iavarone, Siniscalchi, Romano and De Rosa, 2002). In practice, therefore, it is nearly impossible to exclude toxic gluten from the diet completely. This difficulty of total exclusion of the allergen in everyday life means, first of all, that CD patients have to deal with being constantly at risk, and, secondly, that they do experience the effects of gluten intake, no matter how strictly they keep to the diet.

Although still a speculative scenario, it is possible that in the future specific novel therapies will provide an alternative to or even abolish the gluten-free diet. These innovations will be introduced in an environment where CD patients have already established ways of coping with the gluten-free diet, the risk of gluten intake and occasional diet lapses. Insight into patients' current dietary practices will aid CD researchers in translating patients' concerns into relevant technology characteristics, and in designing innovations that patients can easily integrate in their daily life. Conversely, a lack of knowledge of this environment may lead to miscommunication and a problematic integration (te Molder et al., submitted).

Since the gluten-free diet is currently the standard therapy followed by CD patients, the focus of this article is on how CD patients construct dietary (non-) compliance in their interactions. We will take a discursive psychological approach to examine a CD patients' Internet support forum. Nowadays, the Internet is marked as the primary source of information for CD patients.¹ Up until now, however, there are no studies available that shed light on the ways in which CD patients *interact* with each other on the Internet as to, for example, construct their experience with the diet. Our analysis draws on naturalistic² data, that is, data collected without the use of methods such as interviews or surveys in which the researcher necessarily interacts with the participants in one way or another.

2.2 Coping with disease and diet

According to Lazarus (2005: 10), 'coping [with disease] is concerned with our efforts to manage adaptational demands and the emotions they generate'. In the current literature, the tendency is from understanding coping as an individual defense mechanism toward models that aim to incorporate both situational and individual determinants. This tendency can also be found in research on diseases that bear some resemblance to CD, not so much in causes or medical consequences but in terms of dietary challenges, such as food allergy and diabetes. In their study on food allergy with children, Dunn-Galvin et al. (2008) for example include the role of parental concern for the child's health, and the impact of family stress. Lawson et al. (2005) take the opinions of significant others regarding diabetes into account as one of the factors that would influence the self-care behavior of the person with diabetes.

However, as some coping researchers themselves point out, the shift toward contextual determinants has not yet been translated into perspectives and tools for analysis. Danoff-Burg et al. (2000: 184) highlight the limitations of standardized coping checklists to measure actual coping strategies: 'Missing from the critiques are data demonstrating how participants in studies interpret the concepts that are commonly accepted among stress and coping researchers.' Their finding that researchers and participants do not label coping in the same way 'add[s] to a growing body of literature warning that the current gold standard of coping measurement is failing to capture or may misrepresent the complexity inherent in the coping process' (Danoff-Burg et al., 2000: 193).

Coping studies on celiac disease are no exception in this respect, despite the interesting insights some of these studies offer on how the diet is perceived by patients. Svenker et al. (2005: 178) found that CD patients experience a 'strong emotional loading connected to meals'. Their participants reported feelings of isolation, shame, fear of becoming contaminated by gluten and worries about being a bother to others. They faced dilemmas of unwanted visibility of their condition, their possible neglect of the diet in the face of others, fear of being forgotten and taking more risk. The most pertinent dilemma reported was being unable to forget about the diet restrictions, and having to be constantly vigilant. In a study examining the effects of the gluten-free diet on members of the Westchester Celiac Sprue Support Group, Lee and Newman (2003: 1534) conclude that 'the great dilemma for those with CD is that although dietary non-compliance might be easier socially, the increased risk of acquiring diseases such as lymphoma, osteoporosis, and anaemia needs consideration'. They stress the need for more attention to the emotional and psychological impact of the diagnosis and the diet.

Although the social context of dieting behavior is mentioned and declared important, in actual studies the context remains a static factor influencing patients' internal psychological states from the outside. When, however, patients provide accounts of their ways of coping with their disease and diet they do not simply reflect their inner world. Responses are interactionally embedded discursive actions that are a reaction to questions and categories constructed by the researchers. To understand the patients' life world, it is crucial to start from the categories they use in their everyday life instead of those imposed by the researcher, and to look at the interactional business attended to in the course of patients' natural interaction. Our focus on actual interac-

tions among CD patients in an Internet support forum allows us to show the dietary management regime to be constructed as a collective rather than as an individual issue. This outcome may shed a different light on the common portrayal of dietary control – although riddled with conflicting moral practices (Balfe, 2005) or influenced by family or professional support (Maclean, 1991) – as an ultimately individual accomplishment or decision.

2.3 A discursive perspective on coping

In everyday conversation, people perform all kinds of actions with their language, such as creating and presenting an identity, offering judgments and displaying neutrality. Likewise, ‘attitudes’ or ‘motives’ are an integral part of participants’ interactional work, rather than simply reflecting their inner state. From a discursive point of view, they are no longer private mental states but social phenomena that are locally produced and managed.

The discursive psychological approach, developed in the 1990s by Derek Edwards and Jonathan Potter (1992; see also Edwards and Potter 2005; Potter, 1996; Edwards, 1997), shifts attention to conversation as it naturally occurs, and shows how direct and indirect appeals to mental states *do* things in the interaction, such as accusing, defending, building expertise, complaining and complimenting (see te Molder and Potter, 2005 for a discussion on the role of cognition in interaction research). Horton-Salway (2001, 2002) and Lamerichs and te Molder (2003) have explored how discursive psychology can make a contribution to the analysis of illness narratives. The discourse of ME patients (Horton-Salway, 2001, 2004), for example, showed a constant referral to an active life before the onset of ME so as to refute personality explanations for the disease. A study of online support groups for depression (Lamerichs, 2003) revealed different discursive strategies negotiating a ‘depressed but competent’ identity. Wilkinson and Kitzinger (2000) showed how breast cancer patients reported thinking positive while simultaneously resisting the moral prescriptions of this adage.

Since our specific focus is on how CD patients discuss their diet, discursive studies on how people deal with eating are particularly relevant. Wiggins and Hepburn (2007: 279) argue that seemingly private categories such as ‘tastiness’ and ‘appetite’, about which only the person in question can make claims, are in fact ‘part of a delicate web of social and interactional concerns’. Often, there is a tension between

treating food as a strictly individual matter or as a group matter. In family mealtime conversations, parents were found to negotiate between their responsibility for their child's eating habits, and treating their physiological state (e.g. whether they are full or not) as a private matter (Wiggins and Hepburn, 2007: 269). As we will see, the delicate boundary between dieting as a private and as a social matter is an important discursive resource, and area of negotiation, for CD patients.

Peel et al. (2005) specifically looked at how patients constructed dietary non-compliance. They presented themselves as faithful diet followers that were overcome by external circumstances. Peel et al.'s study shows that disease-related diets may have identity implications. However, it does not focus on actual interaction but derives its observations from semi-structured individual interviews. Moreover, the focus is on the relation between patients and the outside world, rather than on how patients present themselves among themselves. In this respect, research on Alcoholics Anonymous (AA) meetings offers an interesting area of comparison. Arminen (1998, 2001, 2004) showed that AA group members use various interactional devices to construct their experience as 'shareable', such as invoking mutual intimacy by making references to prior speakers (1998), and closing their turns with expressions of gratitude to construct the felicity of AA interaction (2001). Most importantly, AA members organize their talk through the use of 'second stories', as to coconstruct their experiences (2004). Second stories are responses to an account in which the recipient relates a parallel experience, so as to prove their understanding of it. Arminen (2004) distinguishes four different but related functions of second stories: re-contextualization of topics introduced in first stories, providing support for first speakers, offering new perspectives on parts of first stories, new interpretations of the problems discussed and contributing a worldview that can serve as a sense-making device for group members.

We will examine the use of second stories in an Internet support forum. The accessibility and anonymity of Internet discussion groups provide a way to form online communities of people coping with similar phenomena (Davidson et al., 2000). Studies on online support forums overwhelmingly focus on the role of these platforms in sharing information and providing support. Comparatively scant attention is being paid to other, perhaps more adverse, mechanisms at work in self-help group participation and support (but see Sandaunet, 2008, on non-participation and withdrawal from an online support group for breast cancer patients and Gavin et al., 2008, for the role of online

forums in normalizing pro-anorexia thoughts and behavior). In our study, we will explore the ways in which sharing information and giving support contributes to establishing dietary compliance as a matter of course.

2.4 Methods and material

Studies drawing on the perspective of conversation analysis have mainly paid attention to web-based chat, focusing on turn-taking and sequential organization (for example Garcia and Jacobs, 1999; Herring, 2004). Interestingly, these studies emphasize the similarities rather than the differences with face-to-face interaction. In their study of web chats, Schönfeldt and Golato (2003) show that people copy practices from face-to-face communication in such a way as to suit the technical specificities of the medium. Whereas just like in oral interaction self-completed repair is preferred in chats, the positions on which repair can be initiated are different in an online environment. Other examples are the practices of quoting (Reed, 2001) and ‘addressivity’ (starting a response by naming the recipient) by which participants – in the absence of face-to-face phenomena such as interruption, overlap, gaze and continuers – preserve a sense of sequentiality. From a discursive psychological perspective, Guise et al. (2007) compared the construction of ME in face-to-face interaction with that in non-synchronous online environments. It appeared that in all media similar themes emerged, and people were attending to the same interactional concerns.

Antaki et al. (2005) show how a user exploits the structural features of the medium as to make her message safe in interactional terms. In the self-selecting environment of a discussion forum, a first-in-a-thread is a comparatively non-accountable position even if that message is ‘private’. Other accountability issues in online interaction (see also Lamerichs and te Molder, 2003) concern response and non-response. The anonymous audience and the availability of technical reasons explaining non-response, make the failure to respond to a first pair part of a so-called adjacency pair (such as a question not being answered) a potentially different matter in terms of accountability than in face-to-face conversation. Conversely, responding to a message in an anonymous and selfselecting environment may also generate accountability for the responding participant (why you?).

This article starts from the assumption that the influence of the medium on the interaction is an empirical issue (see also Hutchby,

2001). Although a comparison between oral and online interaction is not our prime analytic focus, we will take the structural affordances of the medium into account in so far as these features are made relevant for particular purposes. More specifically, we will be interested in how participants exploit these features as to meet the challenge of being an ‘appropriate’ diet follower or more generally, an ‘appropriate’ CD patient.

We performed a single-case analysis,³ because this type of analysis is best suited to providing the groundwork for revealing participants’ understandings of the norms and rules that are at play in interaction. A single-case analysis is based on the assumption that one can extract certain data-internal understandings of the participants that reflect the order to which they orient themselves (Robinson, 2007). As such, it delivers indications of interesting research phenomena that may inform further analysis of a larger data corpus.

We chose the Gluten-free Celiac Disease Forum at Celiac.com, the biggest Internet discussion forum in the United States, to collect our data. For our analysis, we selected a sub-forum with the title ‘Celiac Disease – Coping with’. At the time, this sub-forum contained around 4000 topics, and around 38,000 replies. This means that on average every topic receives about 10 replies, but in reality this ranges between three and 20 replies per topic.⁴ Since we were interested in coping with the glutenfree diet we opted for the discussion thread ‘I want to quit the diet’, which generated 34 replies in only two days and was viewed 943 times. The case can be marked as extreme since it radically calls dietary compliance into question. The focus was on how a CD patient resists a medically motivated compliance, and how other patients treat this challenge. We also wondered whether there was a recurring structure in the way the responses were framed, whether the message was treated as interactionally appropriate and what, if any, mental state or reasons provided validation to quit the diet.

2.5 Analysis

The first post

Once the subject title, which reads ‘I want to quit the diet’, is clicked, the initial message and the responses to it are shown on the page. This is the initial message as it appears on the screen:

Fragment 1 (Drew)

Post#1

2 January 2007, 08:17 PM

New Community Member

Posts: 4

1 I am so fed up with this
 2 diet. I hate the fact that
 3 I have to think before I
 4 eat. Think before I eat.
 5 There is no freedom in that
 6 and it is making me angry,
 7 which is increasing my
 8 depression.
 9
 10 Has anyone ever decided to
 11 bag it in and just go back
 12 to a gluten filled diet?
 13 What happened? I have been
 14 strictly gluten-free since
 15 being diagnosed but I am
 16 ready to quit.

In the preface to her questions, Drew reports on being fed up, feeling hatred and anger, and being depressed. These are all terms that refer to an emotional state. At the same time, the way this emotional state is described as being caused by the diet is rather rational. In an argumentative fashion, being fed up is attributed to having to think before eating, and the lack of freedom that that creates. Drew first justifies quitting the diet by being emotional and resists being characterized as an irrational, unstable person by being rational about being emotional. She thereby defends herself against these accusations before they have been made. In a similar vein, she suggests that her questions do not stem from an *inability* to follow the diet, but rather from *wanting* to quit (13–16). The fact that she does shows that she treats the interactional environment as requiring that of her.

In lines 10–13, Drew asks whether anyone has ever decided to ‘just’ go back to a gluten-filled diet, and what happened when they did. These

questions are designed to prefer descriptive experiences over more evaluative options such as advice giving ('what happened?' rather than 'do you think this is the right thing to do?'; see also Clayman and Heritage, 2002). We will see recipients managing this issue in their responses. On the whole, the message displays urgency. Drew constructs herself as being 'ready to quit' (16), with only one barrier in the way: she does not know what will happen if she actually quits.

First response

The first response to the initial post appears almost half an hour later:

Fragment 2 (Devon)

Post#2

2 January 2007, 08:41 PM

Advanced Community Member

Posts: 520

1 Every now and then I get a
 2 little fed up and start to
 3 stop being so attentive,
 4 and it usually ends up with
 5 me being horribly ill for a
 6 week. I don't ever 'cheat'
 7 specifically, but I'll get
 8 fed up with wait staff and
 9 chance it and it usually ends
 10 badly.

((20 lines omitted))

31 It can be hard to make a
 32 conscious effort to take
 33 the time to take care of
 34 ourselves, I for one am
 35 much better at taking care
 36 of other people, but its
 37 worth it.

Fragment 2 treats the first post as an invitation to share one's own experience about dietary non-compliance. One asset of second stories is

that individual experience is treated as sharable and that this sharing is treated as a group contribution. However, as we will see, this post does more than just share experience. The softeners ‘every now and then’ (1), ‘a little’ (1–2), ‘start to stop’ (2–3), and ‘so’ (3) in relation to the dieting lapse stand in stark contrast to the extreme formulation ‘horribly’ (5) connected to its effects. Moreover, the indirect and passive way in which the dieting lapses are accounted for – ‘start to stop being so attentive’ (2–3) – achieve the effect of avoiding being fully responsible for the diet lapse. This minimization of responsibility for noncompliance, together with the dramatization of its effects, show that it is handled as a controversial topic. In stressing that she never specifically cheats (6–7), Devon shows her disapproval of intentional gluten intake and stresses again that she was at the receiving end rather than being the cause of the dieting lapse. Finally, her definition of the diet as an act to ‘take care of ourselves’ (33–34) resists an image of dieting as a matter of ‘negative’ discipline, and prevents the first poster from being blamed for lack of discipline.

The next responses contain the same elements that this post portrays, and their similarity to each other is in striking contrast to their departure from the first post. All posters start by sharing the experience of a dieting lapse, then report on their emotions as a reason for transgression, and, in an act of self-blame, construct that past experience as a foolish mistake: ‘and it usually ends badly’ (9–10). Finally, they argue for the value of the diet, or offer practical solutions to make it easier. All posts resist the possibility of being read as explicit advice. In some posts, members even explicitly dissociate themselves from the role of advisor (see Fragment 3, 21–24).

Except for one member who responds that ‘I want to quit too’ (Post#20, 1 – and then explains why she is not going to act on this desire), none of the others adopt the term ‘deciding’ that Drew uses. Also, none of the members endorse quitting the diet as a valid option. Members seem to exclude quitting decisions as an interactionally appropriate option. This raises the question of why the option of quitting the diet is entertained at all. In the following section, we discuss two interactional devices, used in all but a few of the responses, that resist the validity of quitting in different ways.

2.5.1 Interactional device 1: scripting frustrations with the diet as ‘too’ recognizable

In Fragment 2 Devon starts with ‘Every now and then’ (1). She thereby scripts her frustration with the diet as something that occurs regularly rather than being a one-time event (Edwards 1994; Sneijder and te Molder 2005).

By scripting (periods of) dieting lapsing and describing their own reasons to nonetheless maintain the diet, members presented the experience that is related in the first post as a matter of routine. In this way, the reasons for ‘wanting to quit’ are reformulated as ‘too’ recognizable and thus insufficiently ‘unique’ to quit. By providing their own reasons to continue the diet rather than directly undermining the desire to quit, they also offered advice without affecting the first poster’s experiential territory.

Fragment 3 (Morgan)

Post#3

2 January 2007, 08:49 PM

Advanced Community Member

Posts: 320

1 I do get very frustrated
 2 and depressed at times. I
 3 feel like the disease has
 4 taken away my freedom to
 5 eat where I want, when I
 6 want, and to not read a
 7 label EVERY time I buy
 8 something. Having said that
 9 I have never cheated (I have
 10 been accidently
 11 glutened). Not because I am
 12 perfect or live in a
 13 bubble, more because I
 14 found a will to stay
 15 gluten-free. For me it was
 16 my kids. If they someday

17 get this disease I want
 18 them to see me as a
 19 positive example. I want to
 20 be healthy for them and my
 21 dh.⁵ I am not saying that
 22 you should do the same,
 23 only what I have done to
 24 deal with it.

In lines 1–8 Morgan performs discursive work to agree with Drew’s experience of the diet by showing her frustration about it. She does this by repeating the elements of the first paragraph of the initial post, but formulates them differently. For example, whereas Drew uses repetition to illustrate her frustration (‘...have to think before I eat. Think before I eat’, Fragment 1, 3–4), Morgan uses capitals (‘EVERY’, 7) to achieve the same effect. In the next sentence, signaled by ‘Having said that...’ (8), she eliminates these emotions connected to following the diet as a valid reason to quit. She attributes this ability to stay gluten-free to a will, rather than being perfect (11–15), and then goes on to construct a context for being faithful to the diet (15–21). By writing that she found ‘a’ will to stay gluten-free (instead of ‘the’ will), Morgan constructs finding a will as a context for following the diet that is subjective and should be found by each individually. ‘*For me* it was my kids’ in line 15–16 suggests that *for you* there is another reason to stick to the diet without this implication being overtly available.

Another example is found in the following fragment: ‘In my experience, when I get frustrated I go shopping and see all the different options that there are for me TO eat’ (Jamie, Post#6, 26–30). This is another way of recognizing Drew’s reported frustration without turning it into a reason to actually quit. Instead, the experience is scripted as something for which there is a solution.

In confirming Drew’s mental state as something routinely encountered by faithful diet followers, the other members also nullify it as a justification to quit. Since her experience is now no longer unique, and others who had the same experience did not transgress, the act of transgression is constructed as something that, although it may happen accidentally (being ‘accidentally glutened’, Fragment 3, 10–11), is not a justifiable choice to make. Whereas Fragment 1 shows an orientation to an individual and unique problem (her emotional state) and points

to a general solution with which others may have previous experience (quitting the diet), the responses reverse this into a general problem of dealing with the frustration of the diet, which should be met with an individualized solution (This is mine – what is yours?). By providing plenty of reasons to remain faithful to the diet, they make it clear that there are no valid reasons to quit, and that Drew’s case is no exception to this. On the other hand, there is always a reason not to quit.

This interactional device manages a particular dilemma. Recipients of Drew’s message cannot simply discard her reasons and tell her to follow the diet, because one is not allowed access to the emotional and mental state of the other. Individual experience is treated as something private to which only the subject of experience has access (Sacks, 1984). By relating their own experience in a second story, they imply that, since they feel or felt the same as Drew, she should also act similarly. So this device enables members to avoid giving advice by scripting experience of frustration with the diet as something for which (only) a context of manageability needs to be found.

2.5.2 Interactional device 2: reformulating the individual decision to quit as an action *within* the diet

Drew constructs the diet as something that one can decide to quit. This presents a world in which there is a binary opposition: either one is ‘strictly gluten-free’ (Fragment 1, 14), or one eats gluten. In response, members construct a world in which ‘cheating’, ‘testing’ and being ‘accidentally glutened’ can be part of the everyday life of a diet follower. In this way, the desire to quit, or even actual gluten intake, are mitigated as reasons to stop the diet altogether.

In Fragment 2 Devon writes: ‘I don’t ever “cheat” specifically, but I’ll get fed up with wait staff and chance it and it usually ends badly’ (6–10). In Fragment 3 Morgan writes: ‘Having said that I have never cheated’ (8–9). These fragments show that the term ‘cheating’ is constructed as designating a controversial and condemnable action. Devon shows this by putting quotation marks around the term, Morgan by formulating it as something which she has not done despite there being emotional grounds on the basis of which she might be expected to do so. This is another example from a post further on in the thread where Eric constructs cheating as a foolish action by describing it as something he would have done in the past (but no longer now): ‘Oh yes, your messages cause me to recall the days when cheating seemed like the thing to do!’ (Eric, Post #25, 2–5).

The act of cheating carries with it associations of intentionally acting dishonestly or violating rules to win an advantage or profit at the expense of others. When Drew's category 'deciding to quit' is reformulated into mere cheating, the diet is constructed as a set of rules that should not be violated. The placement of 'having said that' in Morgan's message pre-empts a possible implication of the preceding account, namely, that it could be a motivation to transgress. The fact that she then asserts that she never cheated shows her orientation to transgression as something that could have interactional implications for other diet followers.

The following fragment confirms this pattern. Dylan first acknowledges the desire to quit (1), and then presents cheating as a motivation to want to 'quit' (4):

Fragment 4 (Dylan)

Post#20

4 January 2007, 05:31 PM

Community Member

Posts: 63

1 Yes -- I want to quit too!
 2 Today I was hungry and there
 3 was no one in the house but me
 4 (to see if I was cheating) and
 5 I looked at the pizza full of
 6 gluten, cheese and tomato with
 7 pepperoni (nitrates). I LOVE
 8 pizza!
 ((6 lines omitted))
 15 Anyway, I just looked at it and
 16 thought about how sick I would
 17 be. Would it be an hour till I
 18 get sick or maybe a couple? I
 19 did not eat the pizza.

Cheating is here constructed as an action that one is tempted to perform when others are not checking on you. By recontextualizing her own desire to quit as something that could lead to cheating, but can be resisted

when the proper context is provided (in this case thinking of how sick she would be if she did eat gluten, and later in the post by referring to her family), Dylan provides at the same time a second story for Drew's experience and labels the action that could flow from this desire, if one does eat gluten, as a condemnable experience. Furthermore, in opposition to cheating she constructs dietary adherence as a matter of responsibility to herself. In these ways, diet lapses are constructed as something foolish, thus also implicitly condemning Drew's intention to quit the diet. The willingness of some of these members to 'confess' having cheated in the past could be a discursive strategy to show that, in the start-up phase of learning to deal with the diet, it is interactionally appropriate to have diet lapses as long as they are condemned when one speaks of them. The significance of the use of this term is therefore not so much its reproachful aspect as the fact that it is an action within the diet, after which one returns again to being gluten-free.

In a discursive analysis of interviews with diabetics, Peel et al. (2005) found dietary non-compliance to be a highly accountable activity. Similarly, the CD patients account for cheating, and either deny having done it or contextualize it. However, whereas the diabetics in Peel et al.'s study 'localize' their diet lapses in specific external contexts such as holidays or menstruation, and build a positive identity in relation to that circumstance, CD patients construct them as dependent on failures of one's personal ability to deal with the difficulty of the diet. Sharing having cheated in a confessional way, and showing that now they can deal with it, also presents dietary adherence as a victory over the past.

The CD patients use 'cheating' to negotiate the terms of discussing the diet. They make quitting an inappropriate category and establish cheating as a category to situate diet lapsing as an action within the diet. For the CD patients in this forum there is no such thing as an accountable lapse except previous ones that ended badly, and from which the lapses learnt the value of dietary compliance. (See Maclean, 1991, for a very different account of 'cheating' by people that suffer from insulin-dependent diabetes. Dietary flexibility including planned cheating is portrayed as an important way of enhancing well-being.)

There are two other ways in which the members reformulate quitting. Besides cheating, and being accidentally glutened – which we encountered earlier as a way of accounting for a diet lapse without being responsible for it (Fragment 3, 10–11), they also construct the category of 'testing'. The following is the beginning of Post#6:

Fragment 5 (Jamie)Post#6

2 January 2007, 10:05 PM

Community Member

Posts: 50

1 I've gotten really fed up
 2 with having to be gluten
 3 free too. Just when I
 4 start feeling better, I
 5 'test' myself (purposely
 6 eating gluten). I'm not
 7 officially diagnosed yet,
 8 so I always seem to
 9 second guess when I start
 10 feeling a little better.

Jamie stresses that he tests himself when he starts 'feeling better' (4), and that he is not 'officially diagnosed' (7). Testing is constructed as an action performed in the absence of proof that he has CD or the certainty that a diagnosis provides. Although not as strong as the use of 'cheating', Jamie portrays testing as a foolish action that could lead to disastrous consequences. Later on in the fragment he mentions that: 'The last time before this when I 'tested' myself ... I ended up in the ER' (lines 16–19 of the same post).

Together, cheating, testing and being accidentally glutened form a set of categories that members use to justify their dieting lapses and incorporate gluten intake as an everyday life phenomenon in the world of a faithful diet follower in which quitting is not an option. What they have in common is that they are formulated as temporary actions – as opposed to a permanent decision to quit. They allow the members in this thread to safely share their dieting lapses, and at the same time offer Drew a way back in, since she can now label her decision to quit as an act of cheating or testing.

There appears to be a hierarchy in these categories. Cheating is generally dealt with as an intentional action where one knows the rules are being broken. Testing, however, is an action that flows from uncertainty.

On the one hand it is done purposely, but, on the other hand, it can be justified as being necessary to find out if one still really has CD. On this scale of descending intentionality, being accidentally glutened comes last. It is something that happens *to* you, even when you do not intend it to happen.

What we see here is that members are negotiating the context in which gluten intake is talked about. Drew proposes a context in which gluten intake is inconsistent with the diet. In response, the others construct it as something that, although not desirable, tends to occur within the context of being a diet follower. Again we can observe that the recipients are careful not to violate Drew's primary rights to assess her own mental state, or contest her reasons for action. Instead, they propose an alternative framework in which the desire to quit is treated as something that may lead to a *temporary* dieting lapse.

2.6 Discussion and Conclusion

In our analysis we found that patients' accounts of the diet are constructed in such a way as to exclude quitting as an option. By telling second stories, patients provide an alternative interpretation to one patient's experience of the diet. They mutually agree on this interpretation, and thereby reject the other.

The problem that Drew reports on is the perceived lack of freedom when adhering to the diet. Her proposed solution for this is to *decide* to quit: 'Has anyone ever *decided* to bag it in and just go back to a gluten filled diet?' In the responses to this message, the term 'decision' does not reappear, except in this message (Post#8, 15): '...everyone has to *decide* the reason they are going to stay gluten-free.'

Fragment 1 constructs a context in which the patient can decide whether or not to follow the diet. The formulation as a question reflexively shows awareness that there are consequences to the latter action, and that those consequences should be weighed against the difficulty of the diet. The second fragment establishes the diet as a matter of course. It presents a world in which the agency of the patient is to be found not in deciding *whether*, but *how* they are going to stay gluten-free. As we saw in our analysis, this second version is the dominant one.

Peel et al. (2005: 789) state that 'we need to move past prescriptive advice about what is a "good" diet and understand the internal and external barriers patients face, and assist them in addressing them'. In the analysis we saw that CD patients use several interactional devices to

deal with one such barrier: managing the risk of gluten intake in their day-to-day living. By scripting bad emotional experiences with the diet they discard these experiences as a valid reason to quit the diet, and by reformulating quitting into three categories of diet lapsing that can occur *within* the diet, they propose an alternative way of dealing with and interpreting dietary transgression. In this way, they can manage occasional diet lapses without putting the validity of the diet itself at stake. This finding is different from Peel et al.'s (2005) study, where diabetics are found to be externalizing responsibility for diet lapses and presenting themselves as a good diabetic at the same time. In our analysis we found patients co-constructing experience of the disease through second stories in order to establish the diet as a matter of course. They normalize diet lapses in order to construct them as an action within the diet as opposed to a reason to quit: quitting is not an option.

It is particularly interesting how the responses, which are similar to each other, differ from the first story. Whereas in the case of AA meetings this may be done in order to achieve the effect of 'being all in the same boat' (Arminen, 2004: 338), in the thread that we examined it seems that members are negotiating what exactly that boat looks like. Drew presents her situation as a black/white situation: either one is faithful to the diet or else decides to quit. The second stories establish quitting as a non-option and construct a new situation in which gluten intake is an exceptional action within the diet. This adds another dimension to Arminen's analysis: besides offering support, second stories can also be used to correct deviant cases. Without challenging the validity of the experiences related in the first story, in the second stories parallel experiences are used to show recipients how to put these experiences into the 'proper' context.

Two interactional features seem co-constructed by the medium. First of all, the initial poster did not return to the discussion. Whereas in face-to-face interaction this would be a highly accountable matter, in online interaction it is possible for a rich discussion to unfold without the first poster reappearing. Second, through the use of second stories, the members of (at least) this discussion forum do not need to be in discussion with each other, or even refer to each other (as in AA meetings, see Arminen, 1998). There is no explicit agreement between them, but the abundance of similar second stories establishes their account of the diet as the dominant one. Apart from the fact that stories are a type-conforming response to the question 'What happened?' in the first post, members can accountably tell the same kind of story over and over again

without necessarily having to add anything new. In this environment, it is not clear to whom they reply or whether or not they have read the other posts. Our findings are also relevant for CD researchers developing new solutions that would have an impact on the gluten-free diet. They need to be aware that these new options will be introduced in an environment where the gluten-free diet is constructed as being the only option available. Currently, the diet as an option in addition to something else is constructed as being impossible. Although medically there are different scales of CD for which occasional gluten intake may be permissible, participants construct the situation as being black/white. Either one has CD and follows the diet, or one does not. Future innovations will bring about a change in this situation and blur this distinction, since it may become possible to take, for example, a pill that allows one to eat gluten for a few hours, or new wheat strains that contain gluten but are not toxic (gluten safe) may be introduced. In both cases, gluten intake occurs, and this may be problematic in the current situation where the diet is constructed as a matter of course. Since the now discrete choice of following the diet or not will be replaced by a probabilistic choice from a range of solutions in the future, the question arises as to how CD patients will integrate the new therapies into their everyday life. Our study supports the case for approaching dietary compliance as a collective phenomenon rather than a mere individual accomplishment.

1 The Internet is the primary resource for information on diet and contact with fellow celiac disease patients. Lee and Newman (2003) report that while only 17 percent and 13 percent of the participants received information from a doctor and dietician respectively, more than 70 percent of the CD patients in the survey obtained diet information from sources such as the Internet. Although gatherings such as conventions and baking classes are common, there is no face-to-face community comparable in size with an Internet discussion forum such as Celiac.com, which has over ten thousand members and contains hundreds of thousands of posts.

2 The term 'naturalistic' (vs. 'natural') data makes clear that participants are always in some sense affected by their involvement in a research process. In this sense, it is never the case that data are strictly natural. (See also Potter 2002.)

3 Here a single case is one discussion thread, which includes the first post and all the replies to that post.

4 For every message it is indicated whether the poster is an 'advanced community member' (+75 posts on the forum) or a 'regular community member' (25 -75 posts on the forum). Before conducting the research, we requested permission to use the forum topics for our research; this was given by the webmaster since Celiac.com is a public site. To guarantee anonymity, all names and dates in the presented extracts have been changed.

5 Presumably 'dh' stands for 'dear husband'

CHAPTER 3

**IF YOU CAN'T EAT WHAT YOU LIKE,
LIKE WHAT YOU CAN:
HOW CELIAC DISEASE PATIENTS AND THEIR FAMILIES
CONSTRUCT DIETARY RESTRICTIONS
AS A MATTER OF CHOICE**

IF YOU CAN'T EAT WHAT YOU LIKE, LIKE WHAT YOU CAN: HOW CELIAC DISEASE PATIENTS AND THEIR FAMILIES CONSTRUCT DIETARY RESTRICTIONS AS A MATTER OF CHOICE

3.1 Introduction

By analyzing mealtime conversations, this paper examines how celiac disease patients and their close relatives deal with the gluten-free diet in everyday life.

Celiac disease (CD), an autoimmune disorder of the small intestine, is estimated to affect about 1% of all Indo-European populations. Currently, a lifelong gluten-free diet is the only way to avoid the occurrence of symptoms, which include chronic diarrhea, failure to thrive, fatigue, and mal-absorption. Studies show that CD affects patients not only physically, but also socially and in terms of personal wellness (Hallert et al., 2002; Ciacci et al., 2002; Nijholt, 2006). Even its medical diagnosis may be highly charged with conflict (Copelton & Valle, 2009). CD also has an impact on patients' social environment, including for example close relatives during practices such as preparing food, and avoiding gluten contamination in setting the table and washing up (Svenker et al., 2007). Currently, research on CD is beginning to produce new prevention, treatment, and diagnostic tools that could have an impact on the quality of life of CD patients. For these innovative efforts to be successful, they will need to take into account the context into which they will be introduced, i.e. the everyday life of patients (Veen, Gremmen et al., 2010). For example, lack of sensitivity to the practices CD patients have already established to deal with their condition can lead to miscommunication about innovations (te Molder et al., submitted).

To understand the needs and wants of patients who are restricted to a medically imposed diet, it is crucial to start thinking in the terms and categories that they are using, rather than categories conjured up by researchers. Moreover, it is important to realize that dietary practice is a social practice that can only be established and maintained in interaction with others. For example, Gregory (2005) found that practices relating to dietary management were seen by all family members as a shared family practice rather than an individual responsibility.

Earlier studies show that social and interactional factors such as moral conflicts (Balfe, 2005), family, and professional support (Maclean,

1991) have an influence on health-related dietary practice, but these studies still treat the diet as an essentially individual accomplishment. There are studies that pay some attention to the discursive and interactional dimension of disease-related dieting (Peel et al., 2005; Lawton et al., 2008; Gregory, 2005), but these studies focus on the patients' understanding of why they developed their disease rather than how they treat their disease during the course of everyday life. Also, their focus is mostly on adult patients.

Other studies show that relaxing dietary restrictions is sometimes beneficial (see for instance Maclean, 1991). Patients tend to attribute lapses to external circumstances so as to maintain the identity of a faithful diet follower, are faced with the difficulties of resisting a "spoiled identity", and portray themselves positively (Broom & Whittaker, 2004). Also, they negotiate the tension between being normal and being ill and try to preserve a sense of normality despite disruptions in routine due to dietary requirements (Gregory, 2005). Overall, these studies show the challenge of living with dietary restrictions and the diversity of practices invented to cope with this challenge.

Gregory identifies family as important not only as a location where much of everyday life takes place, but also for its constitutive role in constructing how one deals with disruptive events such as being diagnosed with a chronic illness. This is not a one-time event, but rather an ongoing "process of normalising family practices which are construed as predictable and stable, whilst encompassing change and uncertainty" (Gregory, 2005: 389; see also Hall et al., 2005). By analyzing dinner conversations between CD patients and their close relatives, we hope to gain more insight into how people deal with dietary restrictions on an ongoing basis in their everyday life.

3.1.1 A discursive psychological approach to family mealtimes

Focusing on families dealing with chronic illnesses, Gregory (2005: 376) highlights the privileged role of language at mealtimes: "Within families the language of food and eating derives its strength through the repetition of the routine and the expected." Previous studies of family mealtimes, not related to disease and diet, have already provided valuable insight into the pivotal role of talk in the organization of eating practices, using discursive psychology as an analytic perspective (Wiggins, 2002, 2004a, 2004b; Wiggins et al., 2001; Wiggins & Potter, 2003; Hepburn & Wiggins, 2005; Wiggins & Hepburn, 2007; Aukrust & Snow, 1998;

see also Mondada, 2009). Discursive psychology, an approach developed in the 1990s by Derek Edwards and Jonathan Potter (1992; see also Edwards, 1997; Potter, 1996; Edwards & Potter, 2005), examines how talk is used to perform actions, such as constructing one's identity, negotiating the rights to assess situations, and claiming or denying responsibility for (descriptions of) actions and events.

The merit of this approach is that it is able to analyze discursive practices as they occur in the context of everyday life (see Potter, 2002, on analyzing naturalistic data). Although the diet-related studies discussed earlier have produced a better understanding of how patients cope with their disease, these studies usually draw on interviews with patients about their condition. A first limitation of this approach is that it analyzes patients' accounts as a window on the world and their minds, instead of looking at how descriptions are used to achieve actions, such as turning the ostensibly individual choice of being faithful to a gluten-free diet into a collective matter (Veen, te Molder et al., 2010). Furthermore, there is a difference between such descriptive talk of patients as they reflect on their practices after the fact, and that which takes place while patients are performing these practices – just as there is a difference between the players' talk during an event such as a soccer match, and the descriptions and accounts that are constructed after the match, reflecting on thoughts, feelings, and actions after they have already taken place. In the first instance, our speaking is an integral part of the action and determines and shapes not only our experience but also our practices (e.g. by shouting directions or warnings), whereas talk after the fact performs actions such as selecting, evaluating, judging the action. The way patients evaluate their own experience may be an interesting topic of study in itself, but analyzing the interactional business that is performed during these practices will probably be more informative of the patients' life world. It is for this reason that our study focuses on CD patients' everyday interactions with their close relatives while having dinner. By examining family eating practices directly, rather than family members' reconstructions of them, we hope to gain more insight into how CD patients deal with their condition in the course of everyday life situations, so that CD researchers and professionals can attune their efforts better to patients' needs.

Discursive studies on mealtime talk reveal that families often negotiate categories that are usually regarded as individual bodily experiences (Wiggins et al., 2001). Wiggins and Hepburn (2007) have shown how parents continuously manage the tension between the child's primary

rights to make assessments about his/her own physiological condition, such as being full, being hungry, or whether the food tastes good or not, and their responsibility for the well-being of the child. Parents construct these internal states as observable through external sources, thus allowing them to make assessments about it. Seemingly private issues such as the food's tastiness and appropriate quantity appear part of a web of interactional concerns.

In analyzing family mealtime conversations including child CD patients, we examine whether and how parents manage the tension between the child's primary rights to assess the food and their concern for the child's well-being, in relation to offering gluten-free food and denying food that contains gluten. In a situation where food choice is limited, and eating food (just) because one likes it is more unlikely, this tension seems even more acute. Although a comparison between "healthy" families and families dealing with CD is not the first aim of this article, we will point out noticeable differences where this improves our understanding of the interactional patterns distinguished.

As mentioned before, this research takes place in the context of emerging medical innovations in the field of CD research, such as for instance diagnostic tools and gluten-safe wheat species. By using discursive psychology to analyze family mealtime conversations, we hope to give CD researchers a better insight into the way patients and their families currently cope with their condition, so that these innovations can be better integrated into the current practices of CD patients, and researchers can communicate about them more effectively.

3.2 Data

To account for childrens' dietary management, the role of parental concern for the child's health and the impact of the diet on family stress need to be taken into account (Dunn-Galvin et al., 2008). We have chosen to focus on parent-child interaction for several reasons. First of all, and especially when the child is recently diagnosed, we assume that there is an environment of teaching the child to deal with CD, making dilemmas explicit that might otherwise be dealt with more indirectly. This allows us to see how particular descriptions are preferred over others, and how participants deal with breakdowns and disruptions in routine as they are learning about them. Secondly, a case where the child has CD, and the parents do not, offers the interesting situation where the child is the one suffering physically from the condition, but the parents are the ones

who are responsible for the child's well-being and have authority over the child. Thirdly, and relating to this latter point, we were able to gather data from families with children ranging from very young to adults, thus allowing us to see – in an explorative manner – whether particular interaction patterns change or remain the same when children grow up.

Although we would have liked to have recorded more family meal-time situations, we have restricted the recordings to supper because it is generally a shared mealtime.

3.2.1 Selection and analytic procedure

Families were recruited through a call for participation on the website of the Dutch CD association (NCV). In this announcement, families were asked to self-record their family supper on an audio recording device supplied by us. Out of the many families that we interviewed, we selected seven with children on the basis of our criteria: age and regularly eating together. The children in these families were CD patients between 2 and 20 years old, and had been diagnosed between eight years and three months previously (see Appendix, p. 80).

Once they fully agreed with the conditions for participation in the research, the families were given an audio recording device that they were instructed to switch on before every supper and switch off afterwards. After a month, the recording device was collected, and we listened to all the audio recordings and made a word-level transcription of potentially relevant data. These data were analyzed with the analytic procedure outlined, for instance, in Potter and Hepburn (2005b). We first looked for data sections in which gluten played a role. These were sequences in which food was being offered, accepted, or denied. The emphasis on turns and sequences rather than isolated spates of talk is both a theoretical and a methodological starting point. People use the turn-by-turn development of a conversation as a resource to make sense of the social activities that are accomplished. These publicly displayed and continuously updated understandings of what is being said and done are an important proof procedure for the analyst. Close sequential analysis suggested for example that food offering sequences in families with young children were completed with repeated Yes/No (Y/N) taste queries (“Do you like it?”). We became interested in what exactly was being achieved in doing so. Comparison with other mealtime conversations (such as Wiggins 2004a) indicated that this finding was different from the situation in families without a child with CD.

The data set resulting from this procedure was transcribed in detail using Jeffersonian transcription (Jefferson, 2004; see Appendix I, p.170). Fragments discussed in this article were translated into English with the help of a native speaker, trying to capture the literal meaning as closely as possible (see Appendix II, p.171 for the original Dutch fragments). All the data used were anonymized by changing the participants' names.

3.3 Analysis

Out of the seven participating families, four were found to touch upon issues related to CD during supper. In two of the other three families, CD sometimes came up as a topic of conversation, but it did not seem to concern or affect supper itself. In the third family (Family 6 in Appendix), it was not discussed at all, perhaps due to the young age (2) of the child. In the four families found to deal frequently with CD issues during supper, it turned out that this was only the case in situations where gluten-free food was being offered, food containing gluten was being denied, and situations where the gluten content of the food was in question. By exploring the sequential relationships within these situations, we found that in situations where food was being offered, tastiness queries were persistent, and always used as a topic closer. In cases where food was being denied, this denial was softened by constructing it as a practice previously agreed upon. Finally, even in situations where the gluten content of food was initially treated as uncertain, the exchanges were followed by taste evaluations. In the following sections, these findings are elaborated upon.

3.3.1 Taste queries as a way to secure ultimate acceptance of (safe) food in terms of its tastiness

Offering gluten-free food was systematically followed by often repetitive queries about, and confirmations of, the tastiness of the food, as in Extract 1:

Extract 1

Family 1

1 **Moth:** Say I also have eh^h
 2 bought those
 3 ↑crackers (.) that

- 4 grandma always has for
 5 you (.) If it's
 6 [goo↓]
 7 **Pasc:** [Yea:h↑]
 8 **Moth:** Would you like a
 9 gluten-free cracker?
 10 **Pasc:** Yea:h^{hhh}
 11 (1.2)
 12 Which gra:ndma
 13 (0.3)
 14 **Moth:** Grandma Barbara
 15 ((30 seconds omitted. Speaking
 16 about grandmother's visit))
 17 **Moth:** Look at ↓this one
 18 (1.4)
 19 Do=you ↑like that?
 20 **Pasc:** Yes I want [↓one of]
 21 [((Sound
 22 opening crackers))]
 23 **Moth:** Yes of those °you can
 24 have ↓one. °

In line 7, Pascal displays excitement when his mother mentions that she has bought the crackers that his grandmother always has for him. Although he has demonstrated a positive attitude toward the food, the mother goes on to ask confirmation of its tastiness (lines 8–9). Pascal produces a type-conforming response in line 10. Yet in line 19, the mother again requests confirmation of the tastiness of the food. After an affirmative answer, Pascal requests a cracker, which is given to him. The Dutch word *lust* (translated as “Would you like,” line 8) simultaneously signifies liking and wanting. In this verb, liking a certain food is equated with wanting to eat it. In this context of dietary requirements for CD patients, however, liking food does not automatically mean that the food is allowed, because it could contain gluten. The mother shows an awareness of this by using *lust* in combination with “gluten-free”.

Note the negotiation going on in lines 17–25. After his first “Yes”, the child re-negotiates the field of constraint set by the question by not remaining indexically tied to it. He reformulates “Do=you ↑like that?” into “Yes I *want* ↓one,” thereby re-establishing his own right to decide on

the matter. The mother subsequently responds with: “Yes of those °you can have one°,” re-taking the initiative. Both the child and the mother claim to be in charge of the food: the child by evaluating its taste (his territory), and the mother in terms of the child being allowed, or not, to have it (her territory). This shows that there is more to these repeated requests than just evaluating the food. They are also used, and resisted, to negotiate the child’s epistemic privileges, and that of the mother.

In this sequence, the “allowability” of the food is constructed as a result of the food being tasty, and Pascal wanting it. The food is offered to Pascal only after his mother has pursued confirmation of its tastiness on multiple occasions, even after Pascal has already spontaneously stated that he likes the food (line 7).

Elaborate offering on account of tastiness of food occurred frequently in our data. In Extract 2, in which Pascal and his mother are discussing the gluten-free cereal that she has bought, we can observe a similar pattern. Notice also how the food is actually offered by the mother only after re-requesting a positive evaluation of the food from the child (lines 11–12).

Extract 2

Family 1

-
- 1 **Moth:** That is also ↓tasty.
 2 ((*She means the muesli they*
 3 *bought*))
 4 **Pasc:** Huhh↓
 5 (0.3)
 6 all of tho:se
 7 (1.5)
 8 **Moth:** 0↑kay?
 9 ((*sound of opening crackers*))
 10 (2.4)
 11 **Moth:** °Do you find those
 12 tasty, honey?°=
 13 **Pasc:** °=yeah=°
 14 **Moth:** °Well take that one
 15 out°
 16 (1.7)
 17 H↑mm?
-

In line 1, the mother makes an assessment of the food, after which the child confirms and upgrades it, that is, extends the assessment to all other products (“all of tho:se” in line 6), thereby claiming independent (and broader) access to the food’s taste (cf. Heritage & Raymond, 2005). Even though both the mother and son have already confirmed the tastiness of the food in lines 1–6, the mother seeks renewed confirmation of its tastiness in lines 11–12 before actually offering the food. The question is constructed in such a way that liking the food is the preferred option. In almost all cases, tastiness queries take the form of questions requiring a yes or no answer. Yes/no type interrogatives (YNI; Raymond, 2003) are a way to allow the recipient to formulate his/her own response, while simultaneously exerting agency in terms of the kind of response that is required. YNIs maximally exploit agenda setting by setting the terms within which recipients’ responses are to be constructed, and designing the question for a confirming response. The yes/no tastiness query in lines 11–12 is not a neutral informative question, but elicits a yes/no response, in which the preferred option is yes. In this case, the preferred option has already been established by the mother by having evaluated the food as tasty earlier on in the conversation (line 1).

Food evaluations during mealtime conversations, such as with gustatory “Mmms”, are often thought of as a spontaneous reaction to a physical sensation of the food, and are also interactionally built as such (Wiggins, 2002). Surprisingly, in all the mealtime conversations that we analyzed, we found almost no spontaneous tastiness confirmations in relation to gluten-free food. What stands out is the repeated solicitation for confirmation of tastiness and its interactional effect: a) the mother in the previous fragments formulates questions so as to anticipate a yes, thereby constructing “tasty” as the preferred option over others; b) the mother seeks an affirmative response before the food is actually offered; c) tastiness (and not the “allowability”) of the food works as an account for offering it; and d) the child’s repeated confirmations often do not seem to satisfy.

In another family, the mother requests confirmation of tastiness after having first established that the child is allowed to have the food by looking at the label.

Extract 3
Family 2

-
- 1 **Moth:** ↑Tasty?
 2 (1.5)
 3 **Zuza:** That ↑pi:nk one is the
 4 ↓tastiest
 5 **Moth:** That one is ↑sweet uh
 6 (.) the other one is
 7 yoghurt
 8 (0.7)
 9 **Zuza:** Yes↓
-

After the tastiness query in line 1, there is a long pause without a response from the child. In lines 3–4 the child, instead of simply confirming the food's tastiness, points out the piece of food that is the tastiest, thereby comparing the food items' relative tastiness. The mother responds by relating tastiness to sweetness (of the food that the child likes best), and naming the other option: yoghurt (lines 6–7). She does not challenge the child's food evaluation directly but through the more or less objective qualities of the food that can be established without having tried it (sweet vs. yoghurt – implying: the non-sweet character of the latter one). The mother thereby seems to turn the reason for liking the food into a predictable feature of likable food, so there is no reason not to try the other one.

In this fragment, the mother can be seen to challenge the child's food evaluation only indirectly. Wiggins (2004a) showed in a study on family mealtimes – without dietary restrictions – that evaluations of the food were open to direct challenges, since the food was available to all speakers. In contrast, in our corpus we found almost no challenges to the child's food evaluations, and if available, they were done indirectly. This shows that the boundary between the child's and the parents' territory is treated as delicate.

Again, a YNI is used to manage the tension between the child choosing her own food, and being restricted by her mother to only certain types of food in the face of health requirements. By using this kind of interrogative, the mother on the one hand concedes self-determination to the child by letting her confirm the tastiness of the food, but on the other hand exerts agency in terms of the kind of response that is ap-

appropriate. Wiggins and Hepburn (2007) found that in family mealtime conversations parents avoid coming across as forcing the child to eat, for example by treating the child as having greater access to its own appetite. At the same time, however, they continue to offer food in ways that manage to respect the privileged epistemic access of the child to its own physiological condition. Taste is a positive, commonly accepted subjective assessment. One is not entitled to decide for someone else what that person likes or does not like – to each his own taste. At the same time, it is a way to recommend or offer food (Extract 2, line 1). When the mother asks “Do you/would you like a gluten-free cracker” (Extract 1, lines 8–9), or “Tasty?” (Extract 3, line 1), these are not simply informative questions, but ways of offering food while managing the child’s epistemic access to its own taste.

However, there are also differences between the way tastiness queries are managed in our data and in Wiggins’ research on food evaluations in non-diet families, as illustrated by the following extract from her study (Wiggins, 2004a: 34):

1 (1.0)
 2 **Jane:** >right what do you< think-
 3 (0.4) make of ↓that then
 4 **Susi:** °nice°
 5 **Jane:** hmm? (0.4) lovely >isn't it<
 6 (1.2)
 7 **Matt:** don't ↑know
 8 **Jane:** you don't ↓know then (0.2)
 9 you haven't tried↓ it yet

In lines 2–3 there is a food evaluation request from Jane, the mother, in the form of an open-ended question. In our mealtime conversations of CD patients and their families, such open-ended tastiness queries were not found, and only done through YNIs or first assessments, which exert a stronger pressure for affirmation. In line 9, Jane points out that Matt, who says he does not know what he thinks of the food, has not tried it *yet*. The word “yet” is significant here, as it suggests that he will be required to try the food at some point. Since there are no dietary requirements, the food is available to all speakers and so evaluations of food are open to direct challenges. In our data, tastiness queries always occur only *after*

the safety of the food has already been established. In this way, the topics of tastiness and allowability are kept separate, perhaps to be able to positively complete the food assessments, and in a way that shows that the child's acceptance of the food has nothing to do with its allowability. The way in which positive answers to tastiness queries are pursued, and repeated even when the child has given evidence of its positive stance toward the food, is not found in Wiggins' mealtime conversations data. Finally, whereas Wiggins found that evaluation requests may be ways of making sure that children have eaten their food and continue to eat it, in our data, tastiness confirmation is frequently requested *before* the food *has* been offered – as a way to stimulate eating rather than making sure that the children have eaten it. In these instances, it makes sense to use only YNIs rather than open-ended questions because a negative answer would entail rejecting eating the food (in the same way that a positive answer implies that now the child has to eat it).

We found a pattern in which, after elaborate offering and requests for confirmation of tastiness, the parent tells the child he can have food, even after he has indicated that he wants and/or likes it. Together with food evaluations not being directly challenged, this shows that the matter of food choice is handled as a delicate issue and a matter that may be “in question”. In addition, by first pursuing confirmation from the child that he wants the food, and then saying that he is allowed to have it, the mother establishes that the child can have the food he wants. Compare this to a reversal of the sequence, i.e. first the mother offers gluten-free food to the child, and then asks if he likes it. In this latter case, tastiness is a subsidiary quality of the food. In fact, the child is restricted to eating gluten-free food whether he likes it or not, so in this case food evaluations are irrelevant to the choice of food. But when the child is allowed to have the food only after confirmation of its tastiness, tastiness – i.e. the subjective self-determined assessment of the child – is built up as the reason for eating the food. This is not only restricted to young children, but can also be seen with adolescents. The “child” in the following fragment is 20 years old, which of course creates a different dynamic between parent and child. For instance, trying to get the child to eat is naturally no longer part of the conversation, and more deliberation between parent and child was found.

Extract 4
Family 3

-
- 1 **Mash:** We also just=have to
 2 watch out for that
 3 garlic butter
 4 Friday
 5 (0.7)
 6 Perhaps I=could also
 7 just make that myself.
 8 **Moth:** Ye:ah ↓make it yourself
 9 **Mash:** Even ↑tastier too
 10 (1.0)
 11 **Moth:** Yes↓ have to lo:ok what
 12 we ↓need
 13 for=it=ourselves
-

In Extract 4 the mother and the daughter are discussing an upcoming dinner party. The daughter says in lines 1–7 that they should watch out for the garlic butter that will be served, and that perhaps they should make their own. They are making the garlic butter themselves to make sure it does not contain gluten, so the food being gluten-free is used as an account for making the butter. However, even though making the butter has explicitly been constructed as a health-related activity in lines 1–3, in line 9 an additional account is offered – tastiness. Here, a tastiness food assessment is used to manage self-determination. By describing self-made butter as “*even tastier too*” than other garlic butter, making this butter is presented as something that is done because it has an advantage (tastier), and is done by choice, rather than as something that is *required* because of not being able to eat gluten.

This tastiness assessment with the use of “even (...) too” shows how tastiness is drawn upon as completing the food choice sequence. The medical aspect of the food is treated, but in a very short and factual way, as a *necessary* condition for eating the food. The fact that the food is safe is not, however, a *sufficient* condition. It is treated as a requirement that has to be dealt with but is not a big matter. This is shown by the use of the Dutch word “even” (line 1, translated as “just”), a word that is used to designate the action (in this case being careful with the garlic butter) as something that is required but requires little effort.

This is yet another way in which taste is used as a category to manage self-determination. Besides managing parental responsibility versus children's agency by Y/N tastiness queries, participants use tastiness themselves to construct food choice as a function of their personal preferences rather than of dietary prescriptions and restrictions.

3.3.2 Softening denial by constructing denying food as a joint practice

In situations where gluten-free food is recommended, we see that tastiness rather than the food's safety is used as an account for offering and accepting it, constructing the eating of gluten-free food as a choice rather than something externally imposed. In situations where food is being denied due to its gluten content, tastiness is not used as a criterion to reject food, e.g. as in "I don't want it (anyway) because I don't like it". Tastiness, however, still plays a role, as Extract 5 shows. In this extract, the family is discussing the problem of their daughter putting her fingers in her mouth after playing with clay (which contains gluten).

Extract 5

Family 2

-
- 1 **Moth:** What did we now
 2 agr↑ee (.) that we
 3 would not ↓put your
 4 things (.) fingers in
 5 your mouth
 6 (0.5)
 7 Yes she finds
 8 that ↑tasty
 9 **Zuz:** °I find that ta:sty.°
 10 (4.6)
 11 **Moth:** What could ↑be=there=
 12 again on your fingers
 13 (0.6)
 14 after playing with
 15 cla::y or pai::nt?
 16 **Zuz:** °I didn't play with
 17 ↓clay°
-

In lines 7–8, the mother accounts for the daughter’s putting fingers in her mouth, despite her agreement not to, by referring to the food’s tastiness, which is confirmed by the daughter in line 9. Accounting for her daughter’s food choice to someone else (in this case the father) in terms of taste shows that she treats eating food with gluten as an accountable activity. The daughter, right away, draws upon this as a reason for performing an activity that she had agreed not to perform. Now the mother cannot disagree with her daughter without violating the child’s primary rights to assess taste. Interestingly, in lines 1–2 the account the mother gives for why the food is not allowed is not by alluding to the fact that it contains gluten, but by referring to a previous agreement between her and her daughter. By referring to a self-made agreement rather than an external source, the mother manages the agency of her child. At the same time, however, she constructs the child as being responsible for avoiding gluten, and accountable for violating an agreement she made herself. By establishing denying food as a matter of agreement, the mother simultaneously avoids responsibility for denying food to her child directly. Contrary to what we saw before in cases where food is accepted, now the gluten content of food is constructed as an external restraint that dictates food choices. This can be explained by the interactional goal in both cases being different: in the former it has to do with managing self-determination, whereas in the latter case the mother avoids constructing herself as the only source of the denial.

By using “we” twice in lines 1–2, denying is constructed as a joint practice and a cooperative activity for which her daughter is co-responsible. However, the daughter resists this responsibility. Although she does not deny having made the agreement, she treats tastiness as a quality that is superior to gluten content, repeating the mother’s allusion to tastiness in lines 7–8. We could say that the practice of using taste to manage self-determination in situations where food is being recommended backfires in a situation where food is being denied.

Notice how by asking a question in lines 11–15, the mother avoids either downgrading her daughter’s account of tastiness, or directly denying the food to her daughter. Instead, she puts her in a sequential position where it is impossible to give a type-confirming response without answering the question, whereas answering the question would result in confessing that, since she knew that the food contained gluten, she did something while being aware that it was not allowed. This question is a learning-type question, in which the preferred response is the “correct” one. Moreover, she refers to the previous agreement by using “could...

again" (lines 11–12), suggesting that her daughter already knows the answer.

Now the daughter resists this by denying the activity altogether (lines 16–17), and thereby avoids taking responsibility. Interestingly, she manages to resist this while still giving a type-conforming response to her mother's turn. Pointing out that the premise of the mother's question (the child having played with clay) is invalid is used as an account for not answering the question. Consequently, the mother's attempt to establish denying food as a shared activity and making the child jointly responsible for this denial fails, and the child succeeds in making her mother responsible for denying the food to her. This resistance, however, shows that the child is also oriented toward denying as a shared activity. Let us look at another extract in which the parent succeeds in acquiring agreement on choosing not to eat the food. In Extract 6, the mother has looked up whether the food contains gluten on an Internet database used by CD patients called Livaad. The product turns out not to be included in the database, so that the family does not know whether the food contains gluten or not.

Extract 6

Family 1

-
- 1 **Moth:** And but Li↑vaad
 2 (0.5)
 3 didn't see it on there
 4 (.) Could not find it
 5 (.) They just did not
 6 put it in there (.)
 7 Pfff
- 8 **Pasc:** Yes↓
 9 (2.6)
- 10 **Moth:** If we do not know for
 11 ↑sure right Pa↑scal (.)
 12 if there is gluten in
 13 it then we do not do
 14 it=right?
- 15 **Pasc:** °↓No°
 16 **Moth:** Myeah↓
-

In lines 5–6, the mother constructs the reason for not being allowed the food as caused by an external source – “they”, who have not included the product in the database. She thereby orients to refusing food as an activity that requires an account. In lines 10–14, she refers to a previous agreement about not eating food if one is not sure whether it is gluten-free. As in the previous family, she uses the first person plural “we” to establish denial as a shared activity. The mother’s question is formed as a negative declarative statement, followed by the Dutch tag “hè” – translated here as “right?”, line 14 – that seeks confirmation of the negative. The declarative component formulates the denial of the food as corresponding with a rule to which the child has equal access.

Consider an alternative way in which the mother could have dealt with this, e.g. explicitly denying food by saying “I don’t know if the food contains gluten, so you cannot have it.” She then would be responsible for denying food to her child; this would put the child in a position where he could disagree with her assessment – or simply accept or reject her statement. Once again we see how the diet as a restrictive and prescribed condition is resisted, and an alternative version of the diet as a matter of choice is established. By constructing the diet rule as something shared and already agreed upon, but also as something that needs confirmation from the child, the mother manages to bring off the rule as a joint decision. Resisting the rule would make Pascal act against his own decisions.


Arguably, calling children’s attention to their previous agreements is restricted to a certain age group. In our corpus, at least, it does not occur in families with very young children and with adolescents. In families with adolescents, we found a more indirectly managed tension between being (co-)responsible for the well-being of the family member with CD while also dealing with her right to self-determination.

Extract 7

Family 4

-
- 1 **Mari:** I want the real
 2 chocolate
 3 **Sist:** Then do you have to (.)
 4 then would you like the
 5 one with ↑nu:ts?
 6 **Mari:** Yeah with n[uts]
 7 **Moth:** [Oh yes]

8 **Mari:** yea:h I also find them
 9 tastier than the other
 10 kind



In line 4, the sister of the CD patient performs self-repair to manage the self-determination of her sister – taking the food instead of having to take it. Her sister responds with accounting for taking the food by emphasizing its tastiness, rather than the fact that this is the gluten-free kind. The YNI with self-repair reflects the sister’s concern with Maria’s right to self-determination, by stressing choice rather than obedience to a rule. This framing also corresponds with Maria’s use of “want” in line 1. This is a way to manage self-determination, as well as to demedicalize dietary requirements. If food is treated as something that one has to take – i.e. as medicinal – then the pleasure repertoire is no longer possible. In lines 8–10, Maria offers an extra account (besides real chocolate): she likes chocolate with nuts much better. This account is in terms of what she likes rather than what she is allowed to eat. Here we see how both the question and the response orient to self-determination by Maria: it is choosing rather than having to, and liking rather than being allowed. Both Maria and her sister reveal that they do orient to dietary requirements – her sister by using “have” in the first instance and Maria by using the word “also” in line 8. The difference is that the dietary context is used as a necessary condition, and tastiness as a condition sufficient in itself. Maria’s account suggests that, even if she did not have CD, she would have made the same choice.

The fragment shows how both patients and non-patients orient toward dietary requirements but keep it unspoken in the background, so as to be able to share the enjoyment of food in the face of potentially separating dietary requirements. In other words, they mitigate the fact that food choice is partly dictated by a health requirement that affects only one individual so as to be able to perform shared mealtime activities. Softening denial of food, then, is an important way in which participants demedicalize the diet and are able to perform normal family mealtime practices.

3.3.3 Gluten content as an explicit topic in situations of uncertainty

Where self-determination is managed with tastiness queries when gluten-free food is being recommended, and as a joint practice when food

containing gluten is being denied, it is interesting to see how it is managed in situations where it is uncertain whether the food contains gluten.

First of all, we look at a rather dramatic situation where, after offering a dessert to her two children, the mother starts to doubt whether it is gluten-free.

Extract 8

Family 1

-
- 1 **Moth:** I (.) I ↑thought that
 2 we looked this up
 3 already before=mummy
 4 wants=just to be sure
 5 look up whether you can
 6 really have it Pa↓scal
 7 **Pasc:** I can (.) I can ↑really
 8 have it
 9 **Moth:** Yes I think so too (.)
 10 but I first have to (.)
 11 you should not open it
 12 just now (.) I thought=
 13 that you can ha↑ve it
 14 just for a little bit
 15 leave it closed mummy
 16 is now going to °look
 17 it up again°
 18 **Pasc:** But it is ta:sty
 19 **Moth:** °Yes=it=is=tasty=but=
 20 you=should=not touch
 21 it°
-

In lines 1–6, the mother accounts for not allowing Pascal to eat his ice-cream by saying that she wants to know for sure that he can have it. Refusing food is not only an accountable activity on the part of the recipient, but perhaps even more on the part of the person offering the food – especially if the refusal takes place after the food has already been offered. The mother shows this by portraying distress (“I (.) I”, line 1), softening the denial of food with “just” (line 4), and stressing the importance of being certain of the safety of food with the extreme case formulation (see

Pomerantz, 1986) “really” (line 6). Something that is normally only conditionally in the background is now in question.

Interestingly, the mother appeals to external authority – “look up whether you can really have it” (lines 5–6) to account for her refusal of food. In response, Pascal asserts his right to self-determination by saying that he can really have it, treating his own *judgment* as being sufficient to resolve his mother’s uncertainty. The mother’s response, “I think so too”, reveals that she takes this as a subjective assessment, and that this is not sufficient – there needs to be confirmation from an external source: “I *thought* that you can have it”, mummy is now going to *look it up* again.” She also uses strong language in urging Pascal not to open the ice cream wrapper: “you should not open it” and “leave it closed”. Self-determination to assess food choice is temporarily suspended until there is certainty. Pascal’s appeal to an established routine by referring to the food’s tastiness (“But it is ta:sty,” line 18) is also resisted. The mother’s confirmation of tastiness, and the instruction that the child “should not touch it” show the conditional relevance of the food being gluten-free – this has to be established before resorting again to the routine.

Fortunately, after looking up the product on the computer, it is established that it is gluten-free:

Extract 9

Family 1

-
- 1 **Pasc:** Can I have↓ (it) now?
 2 **Moth:** Yes (.) you can have it
 3 (.) otherwise mummy
 4 wouldn’t have bought it
 5 if I thought that
 6 you=could=not ↓have it
 7 (0.7)
 8 But I just wanted
 9 to know for sure (.) come
 10 (.) Shall I ↑open it?
 11 (4.5)
 12 Mummy also really
 13 ↓likes this one
-

Right away, after giving an account for why she had to look it up (wanting absolute certainty) the sequence is completed with – again – a taste evaluation: “Mummy also really ↓likes this one” (lines 12–13).

In families with adolescent children, the checking is done in a much more indirect way:

Extract 10

Family 4

-
- 1 **Mari:** Oh but I also ate some
 2 Ma:rs a while ago
 3 **Sis:** I have had so much candy
 4 ↑lately .hh
 5 **Moth:** Ma:rs?=
 6 **Mari:** Yes I am allowed Mars.
 7 (1.6)
 8 **Moth:** I found it very nice when
 9 also had taken Mars from
 10 the:h tennis
 11 (0.6)
 12 [Tha-]
 13 **Mari:** [Yes]
 14 But I just=cut=off=a=piece
 15 every time
-

The mother’s question – “Mars?” (line 5) – challenges the preceding utterance and is treated by the daughter as being a query about whether she is allowed to have Mars. The mother portrays sensitiveness to the daughter’s right to self-determination by checking whether Mars is safe, without making the full question explicit. The daughter’s emphasis on “allowed Mars” (line 6) is a claim to her right to assess food, and the mother takes this up by pausing, and then moving the topic into safer waters by saying that she has taken Mars from the tennis club and that she likes it – somewhat awkwardly formulated. Once again, the conversation proceeds to tastiness confirmations of various types of candy (not shown in this extract). Just as within the conversations of the families with a young child, the sequences that foreground uncertainty over the gluten-free status of the food were systematically followed by and completed with taste evaluations.

3.4 Discussion and conclusion

With the insights from this analysis we hope to make a contribution on three levels: practical insights into the everyday life of CD patients for researchers developing innovations that will affect these patients' lives, more general insights into how people cope with dietary restrictions for research focusing on parental feeding strategies, and expanding the body of research on food that uses discursive psychology.

We expected health to be a primary assessment criterion of food for CD patients and their families, but surprisingly we found that it played a role only as a necessary condition. Although the food's safety was always established first, its tastiness was constructed and positioned so as to ultimately account for eating it. In the families with a young child, the persistent taste queries, even after the child had shown a positive stance toward the food, marked the offering and acceptance of food, and the basis on which this was done, as a delicate and uncertain affair.

More generally, patients and their families showed an orientation toward demedicalizing the diet by constructing eating particular foods as a matter of choice rather than mere restriction. In situations where food was being denied, the child's self-determination was managed by referring to previous agreements, so as to remind the child of a joint decision. In both recommending and denying food, various types of questions were used to manage the tension between choosing one's own food and being instructed on it in the face of health requirements. In situations where the allowability of food was presented as uncertain, self-determination was temporarily suspended. As soon as the food's safety was established, family members started utilizing the pleasure repertoire again.

Although further research on this topic is needed, these results may be explained as a way of normalizing eating practices in situations where medically imposed health criteria restrict patients' food choices. Interactionally speaking, if medical criteria are constructed as the primary food assessment criteria, it becomes difficult to account for eating practices as a matter of choice. If the food is tasty, this is an added value or a way to soften the burden no doubt, but in this context food evaluations are also irrelevant in the sense that one is restricted to certain foods whether one likes them or not. If food is a choice, however, one eats it because one likes it – whether it is for tastiness, enjoyment, health promotion, or some other reason.

In communicating new innovations to CD patients, their orientation toward self-determination rather than toward being seen as a pas-

sive patient constrained by dietary restrictions should be taken into account. This finding is in line with a study that shows what happens when this self-determination is challenged by researchers in communications about a new pill for CD patients (te Molder et al., submitted). It is important for experts who are developing new innovations to know that CD patients orient toward demedicalization in their daily life, at least during mealtime conversations. From their professional perspective, it makes sense to think of CD as a disease to be cured, and to relate to patients in their identity as patients. But perhaps “patients” may resist being related to as people suffering from a medical problem and might prefer to be approached a different way, e.g. as consumers or as conscious eaters (paradoxically, if after diagnosis CD patients become ‘good’ consumers and eat consciously, their symptoms disappear, the small intestine usually recovers, and they are no longer identifiable as patients except for their genetic makeup).

Our analysis also shows that matters other than food and diet determine how the diet is dealt with. Rather than concentrating on just technical aspects of innovations, more research is needed to examine how these innovations affect identity issues and other everyday life concerns that are negotiated by patients in cooperation with their social environment. In line with a previous study of patient-patient interaction (Veen, te Molder et al., 2010), in which patients were found to construct the diet as a black/white situation in which one either follows the diet faithfully or not at all, patients and their families provide accounts for dieting other than medical ones, and in far more complex ways than the simple recommendation of avoiding gluten suggests.

Regarding more general application of our study, we can say something about the kind of strategies parents use to influence their children’s eating habits. Different types of parents report using different control strategies, some covert and some more coercive (Brown et al., 2007; Sullivan & Birch, 1990). However, little is known about how these strategies are employed by parents in specific contexts, and how children react to them (Moore et al., 2007). Our analysis shows how these strategies are part of everyday interaction in which family members perform interactional business to normalize the gluten-free diet under restrictive conditions. We found that YNIs were used so as to secure ultimate acceptance of the food in terms of its tastiness rather than because of its “allowability”. Parents also avoided being treated as the (only) source of denying food that is disallowed according to dietary prescriptions by asking instructive questions, or by using tags so as to put the child in a

position where he/she has to formulate his/her own, previously agreed upon, account for not eating the food.

Our study indicates that strategies such as modeling and invoking a positive socio-affective context for the child are a function of interaction rather than cognition. So rather than seeing parental feeding strategies as trying to influence the attitudes, cognitions, and behavior of their child, they can just as easily be explained by looking at interactional requirements. What a Y/N tastiness query does in terms of managing the child's self-determination while exerting parental control by restricting the type of responses can explain the potential effectiveness of this strategy more easily than looking at its influence on the child's cognitive taste framework. For instance, as we have seen, the interactional properties of such a query make it effective in the sense that it becomes harder for the child to refuse the food. Although this was not within the scope of our study, discursive psychological analysis of naturalistic parent-child interactions could be used to test the effectiveness of certain feeding strategies in practice, and for example explain why covert strategies may be more effective than forceful and direct ones.

This study adds to the body of discursive psychological analysis of mealtime interactions (cf. Wiggins et al., 2001) by examining how medical requirements affect mealtime interaction. It shows that psychological categories such as normalization are actually container concepts for a range of discursive strategies that are used to manage the tension between being normal and being ill (Gregory, 2005). We also found differences in the food talk by young CD patients and their families, and other mealtime talk (cf. Wiggins, 2004a). Tastiness confirmation was repeatedly sought even after this confirmation had already been given; food evaluations were not challenged directly; taste queries were made after the safety of the food has been established, and never in the form of open-ended questions. The combination of a strong pressure for affirmation of the food's tastiness while also persistently claiming it as uncertain, constructs the offering and acceptance of food as a tricky business. More research is needed on how medical contexts actually influence eating practices; this will yield valuable results in terms of concrete advice to families who find themselves in these situations, and experts who assist them.

Concerning the limitations of our research, it has to be noted that, of the seven participating families, there were two in which the gluten-free diet did not come up in mealtime conversations, or only occasionally. In one family, this can be explained by the fact that the child was

about one year old and not yet talking. However, the fact that it did not arise in another family points to a limitation of our research. By focusing on one specific type of setting, other settings in which CD is discussed are excluded. And because of the labor-intensity of the transcription and analysis of data, the number of participating families was limited to seven. Therefore it is recommended to conduct further studies of both mealtime conversations and other types of settings. That the gluten-free diet seems to be a major issue in mealtime conversations of one family and not at all of another is itself an interesting observation. However, explaining this anomaly at this point would be mere speculation, and further study is needed.

Finally, this research on mealtime interactions of CD patients and their families highlights an existential issue that is usually discussed under the heading of agency: people's need to exert their freedom of choice in the face of externally imposed conditions – whether it be illness or something else. The way in which CD patients construct dietary restrictions as a matter of self-determination shows that, although certain human behavior may be regarded objectively as being a function of imposed restrictions, people may still or, more precisely, then, construct a context that accounts for this behavior in terms of freedom of choice.

**APPENDIX:
PARTICIPANTS' INFORMATION**

	<i>Participants (age)</i>	<i>Age CD patient</i>	<i>Time since diagnosis</i>	<i>Time of recording*</i>
Family 1	Pascal Sister (3) Mother Father	5	2 years	15:50
Family 2	Zuzanna Brother (7) Mother Father	5	3 months	10:32
Family 3	Masha Mother	20	10 months	5:31
Family 4	Maria Mother Sister (18)	20	1 year	10:44
Family 5	Edith Brother (14) Mother	16	4 years	5:10
Family 6	John Mother	2	6 months	1:20
Family 7	Erika Sister (2) Mother Father	4	4 months	13:15

* hours : minutes

CHAPTER 4

**COMPETING AGENDAS IN UPSTREAM ENGAGEMENT
MEETINGS BETWEEN
CELIAC DISEASE EXPERTS AND PATIENTS**

COMPETING AGENDAS IN UPSTREAM ENGAGEMENT MEETINGS BETWEEN CELIAC DISEASE EXPERTS AND PATIENTS

4.1 Introduction

Traditionally, the end-user was mostly regarded as a passive recipient of products of scientific research, but after the “participatory turn”, more active involvement of these users in the innovation process has been sought (Jasanoff, 2003; Bäckstrand, 2003; Felt, Fochler, Müller, & Strassnig, 2009). For an adequate social embeddedness of scientific innovation, and an increase in public trust, it is necessary to take into account the perspective of non-expert stakeholders rather than just focus on technical and scientific features (Oudshoorn & Pinch, 2003; Felt et al., 2009). Upstream engagement exercises, such as public debates, focus groups, and interviews are supposed to open up the innovation process to incorporating future users’ needs and wants before it is too late to make fundamental adjustments.

Although upstream engagement is a contested notion, a workable definition is “dialogue and deliberation amongst affected parties about a potentially controversial technological issue at an early stage of the research and development process and in advance of significant applications or social controversy” (Rogers-Hayden & Pidgeon, 2007, p. 346). This implies that upstream engagement exercises need to be well-timed. Early on in the innovation process everything is still potentially open to users’ feedback, but on the other hand there may be too many uncertainties and too little concrete information on which they can base their feedback. This information may become available more downstream in the innovation trial, but then the product has become so entrenched in institutional commitments and decisions regarding its techno-scientific development that it is too late to make any drastic changes.

This problem has been termed the Collingridge dilemma (Collingridge, 1980). In addition, innovators and non-expert stakeholders may have different ideas of what counts as well-timed. For innovators, this may be directly after a proof-of-principle for a particular innovation has been achieved. Then there is a concrete cause for involving affected parties. For users, however, this may be beyond a point where

decisions that are relevant for them are still open. For them, well-timed may mean even before any research has been undertaken.

In this article we show that fruitful upstream engagement is not just a matter of timing but also of what issues are included on, or excluded from, the agenda. Experiences with novel technologies such as GMOs reveal that publics tend to address wider and more fundamental questions such as why use this technology at all, under what conditions, who is accountable, and who is in control (Macnaghten, Kearnes, & Wynne, 2005; Grove-White, Macnaghten, & Wynne, 2000). If technology is treated as a given, or if its beneficial role is assumed a priori, input from public deliberation is marginalized. In discussions where this happens, publics may be left unsatisfied because their fundamental concerns have not been addressed and are discarded as belonging either to an earlier stage that has already passed, or to an imaginary later point in time where “more facts will be available” (cf. Felt et al., 2009, p. 368). The scientists or policy experts, for their part, may be left wondering why they have not received straightforward answers to their questions relevant to the present technical design stage.

As a response to the Collingridge dilemma, a perspective of co-evolution of science, technology, and society – rather than a linear innovation model – has been proposed (e.g. Silverstone & Hirsch, 1992; Gremmen, 1993; Rip, Misa, & Schot, 1995; Oudshoorn & Pinch, 2003), such as in constructive technology assessment (Rip et al., 1995; Schot & Rip, 1997). Technological objects are an intersection of material and social factors (Latour, 1992; MacKenzie & Wajcman, 1999). Therefore even in the development phase, where implicit assumptions about social uses of technology are made, the user plays a role (Akrich, 1992; Woolgar, 1991; Guston & Sarewitz, 2002). These approaches give precedence to the importance of socio-technical issues in technological innovation. However, since the main focus is still on the technology in question, in most cases users are restricted to taking that *technology as a central reference*. What is lacking is an additional perspective in which everyday-life issues that are not necessarily related to technology, but nonetheless influence its reception, can come to the foreground (see for example Blume, 2000; Veen, Gremmen, te Molder, & Van Woerkum, 2010). In this article we show by means of a study of expert-patient interaction that a technology orientation cannot be imposed in public engagement exercises, and that other issues that are not allowed onto the agenda are still at play, even if they are not made explicit.

This shows the importance of how the *topic agenda* is managed. Even if the timing of engagement meetings is right, there is still the question of which themes gain access to the discussion, and which are excluded a priori or receive only marginal attention (Swierstra & te Molder, 2009). Experts tend to focus on “hard” impacts such as health, environment, and safety, whereas publics raise issues concerning political, cultural, and moral, or “soft” impacts. Because they are considered private and harmless, soft values tend not to be taken into account (Swierstra & te Molder, 2009). Topic agendas of engagement meetings are inextricably bound up with the timing, such as when users question issues for which, from the innovators’ point of view, the stage in which these can be addressed has already passed (Wynne, 2001; Macnaghten et al., 2005). The implication is that often, when innovators do involve users, they pose issues that should have been addressed at an earlier stage, at which stage from the innovators’ perspective there was too little concrete information available and too many uncertainties to substantiate non-expert involvement (Veen, Gremmen, et al., 2010).

A third issue in public engagement concerns the *quality of the interaction itself*, and how it is connected to policy implications. The fact that a dialogue between innovators and prospective users (in our case, patients) takes place does not mean that there is any real participation of non-expert stakeholders in the innovation process (see for example Van der Sanden & Meijman, 2008). For instance, even if lay views on proposed innovations are invited, in public debates scientific expertise may still trump experiential expertise (Kerr, Cunningham-Burley, & Tutton, 2007; Felt et al., 2009). A lack of attention to the discursive processes at play, and interpreting the discussions in terms of recommendations and outputs may cause the real value of these meetings to be missed (Walmsley, 2009). It has been noted that instrumental approaches such as evaluation questionnaires miss the extent to which the positions, values, outcomes, decisions, and so on are constructed during the moment-to-moment negotiations that take place during these events (Harvey, 2009). Instead, we need to pay attention to the social worlds in which participants develop their reactions to proposed technologies (Scott & Du Plessis, 2008), or rather the social actions they perform with their reactions. Therefore an understanding of public engagement meetings requires insight into how they are shaped by the interactional process that is taking place.

In our analysis of discussions between innovators and patients about proposed medical technologies we find that these three issues – technol-

ogy orientation, the topic agenda, and the quality of the interaction – are related. The questions raised by innovators in these meetings, which are primarily technology-oriented, establish a restricted topic agenda, and this is a barrier to fruitful dialogue.

We examine a case in which upstream concerns are raised at a downstream stage and show that the success of upstream engagement is not just a matter of when to involve the end-user in the design process, but also of establishing topic agendas, such as what kind of questions and domains the facilitators make themselves accountable for during the discussion. We find that where experts try to restrict the discussion to topics that are immediately relevant for current technical and policy decisions, participants still address basic concerns – ones that are taken for granted by the experts – such as whether the technology is desirable at all, and under what conditions. This happens despite the best intentions of the discussion participants and the seemingly well-timed and open nature of the event.

4.2.1 Discursive psychology

We examine this dialogue from a discursive psychological perspective (Edwards & Potter, 1992; Potter, 1996; Edwards, 1997), a form of discourse analysis that analyzes talk with regard to social actions being performed, and identify obstacles to interaction between innovators and prospective users in engagement exercises.

This requires detailed examination of the social actions performed in interactions between participants. The questions raised, and the answers given, are not so much reflections of participants' mental states as ways in which participants manage social relations between speakers regarding what each party knows, can know, or is responsible for knowing. These social actions are indicative and formative of the innovation process and the relationship between innovators and patients.

The discursive psychological approach, developed in the 1990s by Derek Edwards and Jonathan Potter (Edwards & Potter, 1992; Potter, 1996; Edwards, 1997), focuses on the analysis of text and talk as social practice. It examines what people *do* with their talk rather than what their talk *reflects*. This approach is fundamentally different from regarding what people say as a window to their cognitions, emotions, and attitudes. Reference to being tired or upset, for example, can be used to avoid responsibility for a particular action. A neutral description can be used to build credibility of one's claims, a bad memory to account for forgotten actions.

Although discursive psychology has rarely been applied as a technology assessment tool, there are a few exceptions. For example, a study of people's talk about notions of health and risk that are central to nutrigenomics highlights the tension between the assumption that people will simply avoid unhealthy eating habits when informed about the health risks and the remarkable finding that people have to account for *healthy* behavior in their everyday interactions (Komduur & te Molder, submitted). In another study, analyses of CD patients' interactions with other patients, family members, and experts are used to gain insight into patients' everyday-life practices on which innovations of CDC research will have an impact, with the aim of incorporating patients' concerns and wishes into the development trial (Veen, Te Molder, Gremmen, & Van Woerkum, 2010; Veen, Gremmen, et al., 2010; Veen, te Molder, Gremmen, & Van Woerkum, submitted; te Molder, Bovenhoff, Gremmen, & Van Woerkum, submitted).

Discursive psychology highlights the constructed and rhetorical nature of accounts. Saying that talk has a rhetorical dimension means that the selection of one particular description over others resists potential alternative versions. For instance, "I'm a man" undermines being a woman, and this could in certain situations (e.g. transsexuality) be treated as a defense. Another distinguishing aspect of discursive psychology is that it examines these descriptions as part of the sequence in which they are embedded, and on the basis of which participants make sense of what is being said at a particular moment in the interaction, rather than looking at isolated sentences. Therefore the development of the interaction before and after these sentences always has to be part of the analysis.

This perspective has consequences for understanding users' reactions to emergent technologies because, first of all, its focus on discursive action allows for a better understanding of users' reactions to technology on their own terms, and secondly it takes into account the role of the expert and moderator as part of the interactional context (see also Myers, 2004, 2007). The findings of analyses can reveal blind spots about the interaction between users and innovators that can be used as a basis for improving and adjusting the process of co-creation of technologies (Veen, Gremmen, et al., 2010).

4.2.2 Question design

Specifically, we focus on the kind of questions that the innovators pose to patients, and how patients respond to these. Question design mirrors

human relations and is an index of the social relations between speakers and recipients (Raymond, 2009). Question design has been a topic of conversation analysis, which has studied question design in many different contexts such as news interviews, health visitor interactions, and physicians' history taking (Clayman & Heritage, 2002; Heritage, 2007; Raymond, 2009).

Heritage (Heritage, 2007; Boyd & Heritage, 2006) identifies three unavoidable features of questions: (1) they set topic agendas and action agendas for the response, (2) they embody presuppositions, and (3) they incorporate preferences concerning possible answers.

In relation to the first feature, insofar as questions can be designed to exert control over the terms of the responses, they establish topic and action agendas (Heritage, 2007; Clayman & Heritage, 2002). The question "what's for dinner?", for example, establishes a topic agenda that makes relevant answers concerning food, and an action agenda in that the respondent is expected to provide a particular kind of response, i.e., a menu. Questions construct which responses are relevant, but also provide freedom. For example, Yes/No-type Interrogatives (YNIs) make relevant a response with the type-conforming tokens "yes" or "no", which may then further be qualified or elaborated upon (Raymond, 2003).

Examining the question agendas of the innovators reveals what they construct as relevant knowledge or feedback from the patients, the "deficit" patients can fill, what they make patients accountable for knowing, and what not. On the other hand, it shows what the innovators make themselves accountable for, and how they construct patients' role or part in the innovation process.

The second feature of questions is that they always embody presuppositions – at the very least that the respondent is in a position to answer the question. In the previous example, there is the presupposition that the recipient has access to the information, or can decide, what is for dinner. Examining these presuppositions provides insight into what is treated as given by innovators – which also precludes these givens from being "in question" – and how these presuppositions are treated by patients. These presuppositions can shape patients' responses (Clayman & Heritage, 2002), and patients can confirm or disconfirm them.

Each question establishes an "epistemic gradient": the degree to which it invokes the claim that the questioner lacks certain information to which the respondent has access (Heritage, 2007). An epistemic gradient is a distinctive gap in knowledge between questioner and respondent. Generally, tag questions invoke a flatter epistemic gradient than, for

instance, open questions. YNIs acknowledge the epistemic rights of respondents, but also tend to restrict the exercise of those rights. On the one hand, a YNI implies that the speaker does not know which of the two alternatives is the correct one, but on the other hand it implies that there are only two alternatives, excluding, for instance, a third possibility. In other words, the recipient is free to respond, but the terms in which the response is to be made are decided upon beforehand.

The final feature of questions is that they incorporate preferences for certain types of responses. YNIs particularly incorporate preferences (Heritage, 2002). In interactions between health professionals and patients, they have been shown to “severely limit the contributions that patients may make to the interaction” (Boyd & Heritage, 2006, p. 156).

4.3 Data and method

4.3.1 Background to the meetings

Our case study is a series of meetings between celiac disease patients and experts about emergent medical technologies in this field. Celiac disease (CD), or gluten intolerance, is an autoimmune disorder of the small intestine. For CD patients, gluten intake can lead to a variety of symptoms such as digestive problems, mal-absorption, growth retardation, osteoporosis, and chronic fatigue. Currently, the only available therapy is excluding gluten-containing foods from the diet completely. This lifelong gluten-free diet is a difficult prospect since gluten is found in wheat, barley, rye, and many other daily foods. Because most modern foods are processed, even products that appear safe to CD patients may have been contaminated with gluten from other sources (Celiac Disease Consortium, 2008).

The Celiac Disease Consortium (CDC) is a Dutch innovative genomics cluster consisting of representatives of scientific research, patient associations, social science, dieticians, general practitioners, and industry. The goals of the CDC are the development of improved diagnostic procedures, novel therapeutics, and safer foods for CD patients. Since the research of the CDC is likely to drastically affect patients’ lives, a clear understanding of the attitude of patients toward research developments is needed to guide and implement the CDC’s work (Businessplan CDC, 2003). As part of this aim, the CDC engaged in dialogue with patients about recent research developments.

In 2008, the CDC organized a series of information meetings between patients and CD experts to inform patients about current research developments and receive feedback on those developments. The topics they discussed were diagnosis and screening, gluten-safe wheat and oats, and a gluten-neutralizing pill. In this article, we examine how patients and experts discussed the latter topic of the gluten-neutralizing pill, because of both its revolutionary potential and the controversy surrounding it.

The possibility of the gluten-neutralizing pill (henceforth simply “the pill”) is based on the discovery of an enzyme that can work in the stomach to degrade gluten peptides into very small fragments before reaching the small intestine and triggering the inflammatory autoimmune response of CD patients (Stepniak et al., 2006 et al.). The presence of this enzyme in the stomach of CD patients would therefore potentially allow them to eat food containing gluten without becoming ill. If this pill in fact worked for all types of food, and all patients, it would provide the first alternative therapy to the current practice of CD patients avoiding gluten altogether.

It is still doubtful whether this scenario is in fact technically possible. The meetings took place while clinical trials were still being conducted, and at the time of writing the pill is still at the research stage. It is as yet unknown whether the enzyme will work equally well in a human stomach as in the laboratory, for how long, which types of food, and which dose would be required. The implication is that, whereas innovators were in the first instance talking about something that could completely replace the diet, a more likely result for the near future is a pill that can be taken once in a while alongside the diet. This pill could be used in situations such as emergencies, on special occasions, or for instance to alternate between gluten-free meals at home and a regular diet at work or in school. Innovators still expect that this would improve the quality of life for CD patients (Koning, 2007; Stepniak et al., 2006; Veld, 2007). The first reactions of the Dutch CD association (NCV) to this development were mixed, because it would reduce patients’ dietary compliance. Also, research shows that there is a group of patients that are satisfied with the diet and would not want to eat gluten-containing foods (Koning, 2007).

Four meetings were held, to which members of the Dutch CD association were invited by the CDC. On average, there were six patients per group, of which 70% were female and 30% male. The age range was spread equally from young adults to older persons, and education from high to low. At each meeting, two members of the CDC were present. To

ensure the consistency of information offered to patients, the first was a member who was aware of all research developments and present at all the meetings. Although this member also acted as a moderator, we found that in practice he was mainly treated by patients as a CDC researcher. The other member, who varied from meeting to meeting, was a scientist with a particular expertise such as the pill, genetics, or food genomics. In practice, both members were treated equally by patients, and were asked and answered questions about all facets, from scientific details to design or insurance coverage.

All the meetings followed the same general pattern. First, patients read the information sheet about the pill and listened to a short introduction by the expert. Then they asked clarifying or information-seeking questions about the pill and its developmental context. This meant that the innovators had to initiate the part of the meeting in which patients gave their feedback on the pill. Since without exception this stage of the discussion was initiated by a question, we examined the way the question design framed the discussion, and how, by doing this, a particular social relation between patients and innovators was implied. We were interested in this because, as had been seen in previous research (te Molder et al., submitted; Veen, Gremmen, et al., 2010), introducing an innovation always entails certain presuppositions, and the kind of response this elicits is to a large extent dependent on these presuppositions.

4.3.2 Data collection and analysis

The meetings, which lasted approximately seven hours in total, were audio recorded. These recordings were transcribed to word level accuracy by the first author of this paper, and relevant passages were subsequently transcribed in more detail, including pauses, overlap, and speech errors (see Jefferson, 2004; Appendix I, p.170). All transcripts were analyzed, and, from this initial analysis, sections that stood out were selected to be transcribed and analyzed in more detail.

Although due to space limitations we are only able to discuss a few fragments, the analysis presented in this paper is based on a much larger corpus of data. The fragments were translated into English with the help of a native speaker. Since this activity of translation involves interpretation as well, it should be noted that the analysis was performed on the Dutch fragments, and the translated fragments aim to capture the literal meaning as well as the analysis as closely as possible (see Appendix II, p.171 for the original Dutch fragments).

As stated above, in our analysis we focus on how patients design their discourse to accomplish various social goals rather than on the *content* of what they are saying. We also pay attention to how the innovators – who in this case are also the facilitators and moderators of these meetings – shape the unfolding interactional process, and the social goals that they are accomplishing with this. Rather than seeing patients' talk as isolated reactions to the pill, we regard it as occasioned by the interactional environment, which in this case is the way in which the innovators construct descriptions and accounts of the pill, and the way in which they design their request for patients' responses to this.

Rather than working with pre-established hypotheses, discursive psychology aims to develop explanations for patterns found in the data and deviations from those patterns. The burden of proof is on the analysts to demonstrate their claims on the basis of participants' own understandings displayed in the data (Potter & Hepburn, 2005a). The two main principles that guide the analysis are sequential analysis and the rhetorical nature of talk. Sequential analysis means that, rather than looking at isolated segments of talk, statements and accounts are examined for their function in their sequential context, for example, to counter or support a previous speaker's claim. Hypothesizing what other version the speaker might just as well have selected is a way to gain insight into the interactional business being performed by opting for one particular version (cf. Edwards, 1997).

4.4 Analysis

In the first part of this section, we examine what is constructed by innovators as a relevant response for patients, and how patients respond to this. We find that the innovators restrict the topic agendas to discussing use of the pill and that their questions establish a strong preference for an affirmative answer. Their questions embody presuppositions about the patients' everyday life, which are challenged by patients. In the second part, we examine how patients approach the proposed technology in the subsequent discussion. We find that the presuppositions embodied in the innovators' question design about the everyday life of patients, such as celiac disease being a restrictive condition, are a topic of negotiation for patients themselves.

4.4.1 Restricting topic and action agendas through question design

In the following, we examine the moment in the discussions when there is a transition from innovators as *providers of scientific information* and answering questions about the pill, to innovators who want to *know from patients* what they think about the pill. In all cases, the innovators initiate this part of the discussion by asking patients a question.

In our analysis of the way innovators introduce the problematic to patients, we find that their questions incorporate the presupposition that the pill is accepted by patients, and confine the topic agenda to discussing possible uses of the pill. These questions embody a strong preference for an affirmative answer. An example of this pattern is shown in the following extract that takes place after an elaborate answer to a patient's question about the pill.) Here, it is one of the patients who signals the transition from information giving to requiring patients' input:

Fragment 1

Group 1, 24:26–26:20

-
- 1 P1 So you really want to know what we ↓think of such a pill.
 2 (1.5)
- 3 Ex Yes for us that is a eh very relevant question. (.)°Yes°
 4 (0.7) I can imagine ↑right. What I hea:r here is of course
 5 like yes, the diet is fine but it is hard. Hard to accept.
 6 Eh hh↓hh. (.) Holiday a drag. Eh hh well the question is
 7 just (1.8) say such a pill is coming. And this pill turns
 8 out to be completely safe. (2.1) Will patients then ↑use
 9 it or eh hh (.) are we just sitting around here eh hh
 10 developing [some-]
- 11 P4 [I guess we'll see] how it ↑turns out,
 12 hehehehhh
 13 ((laughter))
- 14 P4 Yea[hhh]
- 15 P2 [Yes] I think it that it really depends on how you use
 16 it. Because I think that the diet in the sense of eh (.)
 17 excuse me not right now, that (0.4) seems much harder to me
 18 than that you (.) know, well, >not ↑allowed< that's clear,
 19 ↓done. So I will eh hh yes, for convenience's sake, that is
 20 (.) for yourself it's difficult, °because something like°
 21 yes you don't really need to, I don't need to be so-g loyal,

22 because I have an alternative, that feels different than I
 23 know what I'm up against I cannot ↓eat it because >if I eat
 24 it< I get sick. (1.0) So then I'm like if there is something
 25 then I would like to have something that helps me get rid
 26 of it ↑across the- because eh () >once in a
 27 while< tha- that doesn't do it for me. (1.0)

28 **Ex** Yes.

29 **P3** Yes all the time or not all the time.

30 **P2** Yes all the time or not at all.

The patient's turn establishes what patients "↓think of such a pill" (1) as a new topic agenda, but "really" (1) casts doubt on whether this is actually relevant for the experts. Although acknowledging the relevance of this question (3), after a preface (3–6) the expert ends up asking a different set of questions (6–10) that shift the topic focus to patients' *use* of the pill. This reformulation is achieved by a description of dietary practice as a burden ("hard to accept," "a drag"). Furthermore, this description is presented as something the patients *themselves* have said ("What I hear: here"). So the question the expert finally asks is accounted for as occasioned by the patients' own presentation of the diet as difficult.

The action agenda is constructed in different ways in the question the patient proposes to answer and the one the expert actually asks. In the first, patients are invited to share their thoughts, and in the second they are offered a choice between either affirming use of the pill, or affirming that the innovators are developing something useless. The epistemic gradient is much steeper in the question offered by the patient, because it explicitly constructs the innovators as requiring information from the patients (*you* want to know what *we* think) and asserts no knowledge concerning a likely answer. In the question the expert poses, this information gap is much smaller. It is prefaced by a description of the situation of the addressee, implying that the questioner knows their situation, as well as the possible reactions they might have to it. It is just a matter of knowing which one. This leaves much less room for epistemic maneuvering on the part of the respondent.

There is a difference in the presuppositions set up by the patient's turn and the innovator's. Wanting to know "what patients think of such a pill" (1) presupposes that patients have an assertable opinion about the pill, but does not make any assertions about how to frame this opinion or what it means for the development of the pill. The expert, on the other

hand, asks patients to assume in their answers that a particular pill is on its way. The preface to his question (3–6) is set up as a first part of a contrast in which either the pill will be used by patients or it will have been a waste of time for its designers. In terms of action agendas, the patient's turn invites patients' responses in terms of *asserting opinions*, the innovator's turn in terms of making a *choice*. This invokes a fundamental difference in the relationship between patients and innovators. In the first case, patients are involved in terms of their thoughts and opinions about the innovation process in general; in the second case, in terms of choosing between available options that have already been decided.

To see how the questions differ in terms of their preferences for a certain type of answer, consider possible responses to the question the patient offers to answer, and the question the expert asks:

1. What do you think of such a pill?

I think that ...

I like it, because ...

I don't like it, because ...

I would prefer a pill that ...

Etcetera

2. Will patients use it or are we just sitting around developing something that ...

Yes, we will use it.

No the pill is useless.

The first question allows for any kind of answer that is constructed as an opinion about the pill. In the second case, two questions are linked together. The first is a YNI, with a preference for an affirmative answer, given that in the question preface the diet is constructed as a problem for which the pill could offer a solution. This is enhanced by the second question in which the alternative to accepting the pill is constructed as an affirmation of the innovators having developed something useless. The YNI “will patients then ↑use it” (8–9) is embedded between a preface that establishes a positive response as affirming the pill as a solution to an unpleasant situation (4–6), and a postscript (9–10) that frames a negative response as reducing the innovators' efforts to a waste of time. The preference is therefore clearly for a “yes” answer.

The first response to the expert's question (11–12) is constructed jokingly, and followed by her laughter and that of others, including the

expert. P4 displays reluctance to answer the question by not providing a type-conforming response. This reluctance can be seen as resisting the constraining character of the expert's question. The joke is, of course, that this patient gives a literal answer to the question "will patients use it," by taking it up as a request to make a prediction about the future of patients' behavior. By withholding an affirmative response to the expert's question, she points out what the expert constructs as being at stake in the question of use of the pill: the way the expert formulates this – "are we just sitting around" – suggests that if the pill is not accepted, it is the innovators who will be negatively impacted.

The second response (15–27) starts with a type-conforming "yes," but proceeds to qualify this affirmation by making the response to the question contingent on another factor: "it really depends on how you use it" (15–16). P2's description of a pill alongside the diet as "much harder" than the current situation challenges the presupposition in the expert's question that the pill would make things easier for patients. Her account is a departure from what was asked for – namely whether patients would use the pill or not. Rather than taking the pill as a given, and evaluating it, P2 poses conditions on the *kind* of pill that she would want: "if there is something, *then* I would like to have something that..." (24–25). She treats the version of the pill that the expert is presenting as only one of more possibilities, thereby challenging the terms of the expert's question, in which the only choice is between affirming the option presented by the innovators, or discarding it entirely.

This pattern of a restricted topic agenda, presuppositions about patients' dietary practice, and a preference for affirming use of the pill was found in all the groups. In the following extract, a similar question design (3–5 and 7–8) is used, in that it gives patients a choice between either affirming or rejecting the particular use of the pill that the expert proposes.

Fragment 2

Group 2, 16.43–17.09

-
- 1 P1 What was that question?
- 2 (0.4)
- 3 Ex The que:stion was (.) would you always want to ta:ke that?
- 4 If the eh-pill was available, and it is safe and works a
- 5 ↓hundred percent.
- 6 P2 °And therefore just eat gluten [then.]°
- 7 Ex [Would] you take a pill each

- 8 day before eating something, say. So that with >three
 9 meals a day< you take a pill in advance thrice a day.
 10 **P2** Only if it is with ↑gluten.
 11 (0.9)
 12 **P1** No I cook very ↑tastily, >nothing not< much will change.
 13 (1.4)
 14 **P2** No but °for (0.4) yes°

As in the previous extract, the expert asks the patients to assume in their answers that the pill is already available and sets a topic agenda in terms of discussing *use* of the pill (3–5). The question of the expert is a YNI, with a preference for an affirmative answer. This is enhanced by presenting the pill as unproblematic: available, safe, and works a hundred percent. It is important to note that in line 3 the emphasis is on “take” rather than on “always”. Casually including “always” in this way constructs it as obvious and avoids thematizing it as something to be considered in the response (compare: “would you always want to take that?”). This reinforces the notion that, if they took it, it would be all the time. In addition to that, the question also constructs a specific way of using the pill: “always”, “each day”, eat “three meals a day”, and “take a pill in advance thrice a day”.

As P2 makes explicit in line 6, this formulation assumes that patients would *want* to eat gluten if they *could*. “Only if” (10) qualifies the question, thereby exerting agency with respect to its terms. In line 12, P1 provides a type-conforming but dispreferred answer to the expert’s question. The answer is type-conforming in the sense that “no” is an interactionally appropriate response to the YNI, but, of the possible interactionally appropriate alternatives, it is the dispreferred answer. This is also shown by the fact that she gives an account for not wanting to always use the pill. In this account, eating gluten-free is dismissed as being a problem (“I cook very ↑tastily”). So, in both responses, the implication that the diet is a problem (for which the pill would provide a solution) is dismissed.

The assumption that, if a pill were available, patients would eat gluten with every meal disregards patients’ already established dietary routine. A negative answer to the question of the pill may therefore be seen as not so much a negative evaluation of the pill itself, but of the assumptions that the question introduces. In the following extract, this becomes clear as patients initially respond with agreement tokens while the expert

is asking the question (1–3, 7–8), until he adds the presupposition that patients would take the pill each day (9). This extract occurs after a discussion about different physical properties of the enzyme used in the pill, in which it was established as safe and reliable.

Fragment 3

Group 4, 9.50–10.20

-
- 1 **Ex** If we could return [to] that- to that pill [for] just a
 2 **P1** [yes] [yes]
 3 **Ex** moment. (0.4) Would you just eh^h buy it?
 4 (0.9)
 5 **Ex** If i:t was just safe, ↑right, let's ↓say it is [safe]
 6 **P1** [Oh definitely]
 7 **Ex** It- [it is] available, and would
 8 **P2** [Yes]
 9 **Ex** you take (.) each day then?=
 10 **P1** =That I don't think. (0.7) I think I would take it when
 11 (.)↓well eh if you want to eat special sometime or when I
 12 go: visit someone or (1.2) but just for daily li:fe I don't
 13 think I would ↓use it every day. (1.5) But (.)°who am I.°
 14 **P2** It's about the spontaneous things, in my opinion, that
 15 (.) are hard.
-

In lines 1–9, the expert constructs a YNI, which just as in the previous extracts contains assumptions about the use of the pill. The “just” (3) constructs the emphasized “buy” (3) as uncomplicated and self-evident. The patients are responding with agreement tokens until line 10, where there is a break with the preference structure. P1’s “That” (10) rejects the specific kind of use of the pill proposed in line 9. With the subdued qualification “who am I” (13), P1 downgrades his answer, thereby orienting to the preference for an affirmative answer that makes a negative answer accountable. In line 14–15, P2 problematizes the assumption that the problem for which the pill would be a solution is clear by further qualifying the response.

In all the meetings, the discussion about patients’ potential use of the pill was opened by the innovators asking closed questions, mostly YNIs:

1. “Will patients then ↑use it or ehhh (.) are we just sitting around here ehhh developing something... (Group 1, see Fragment 1)
2. “Would you always want to ta:ke [the pill]?” (Group 2, see Fragment 2)
3. “Who would just stick to the diet?” (Group 3, fragment not shown)
4. “Would you just ehhh buy it?” (Group 4, see Fragment 3)
5. “Would you take it each day?” (Group 4, see Fragment 3)

At their most basic, these questions serve to elicit information that the innovators can use to inform technical and policy decisions regarding the development process. In order to do so, however, the innovators need to leave the familiar scientific domain and pry into the patients’ everyday life. These questions presuppose the use of the pill, and therefore ask patients to affirm or deny a specific use rather than allowing the more fundamental possibility of using it at all, or discussing reasons for using or not using it. By asking patients to imagine that the pill is already available, the question of whether a pill is desirable in itself is excluded from the topic agenda. The type of questions the experts ask are questions about *how (often)* patients would use the pill. The prefaces to these questions contain presuppositions such as that the diet is hard, patients want to eat gluten, or that they want to use the pill every day. Although use is (theoretically) treated as “in question”, there is also a strong preference for “yes”.

An interesting aspect of the way these questions are formulated is the use of emphasis. Vocal emphasis highlights or directs the hearer to the speaker’s “point” (Clayman & Heritage, 2002). In the second question, “always” is not emphasized, but “ta:ke” is, and the response is positive. In the third question, however, “just” is emphasized, emphasizing the matter-of-course nature of continuing the diet in the light of the pill, and thereby constructing it as being in question. After this, a negative response instantly follows (“I would quit instantly”, fragment not shown), and this is followed by agreement from other patients (“me too”). Similarly, when the emphasis in the fifth question is on “each day” rather than “take” (as is the case in the second question), there is softened disagreement (Fragment 3, line 10). So when a particular way of use or a qualification is highlighted (as in questions 3 and 5), there is a tendency towards disagreement.

The innovators’ questions are formulated in such a way that patients are restricted to affirming or denying a particular way of using the pill. Interestingly, by establishing a restricted action agenda, the questions exclude giving substantive information.

By taking the pill as the starting point, it is assumed that patients have a problem and that the problem is clear. However, it is precisely this presupposition that is challenged by patients in their responses. In the following we will see that patients treat the pill as having implications not just for their current diet, but also for their identity.

4.4.2 Turning oneself into the initiating party: talking technology on the basis of everyday life

After the innovators' questions and the patients' initial responses, there followed a more general discussion that took place mainly between patients, and in which the innovators played only a marginal role – usually only as providers of information. What stood out in these discussions was the prevalence of descriptions of everyday situations, and that these were taken as a basis to discuss possible medical solutions. We found that patients approach the technology on the basis of their everyday life, and that they do so primarily in terms of social implications and identity issues. Take P2's turn in Fragment 1, where she says that an implication of using the pill as an alternative to the diet is that "I don't need to be so-g loyal, because I have an alternative, that feels different than I know what I'm up against I cannot ↓eat it because >if I eat it< I get sick" (21–24). Here she uses an account of an everyday-life situation to reject the particular use of the pill proposed by the innovator.

The following extract occurs after a discussion about the expected price of the pill, in which P1 makes a case for making the pill affordable by providing insurance coverage for it (this is what "that" in line 3 refers to).

Fragment 4

Group 3, 10.53–12.46

-
- 1 P1 And we will have to join together (1.0) and take an uh.
 2 stand to make them understand somehow uhhh that we need↑
 3 that.
 4 ((group agrees))
 5 P1 And not have to always spend three times the amount of
 6 time in the kitchen as others.
 7 ((group laughs))
 8 P1 And have to spend much more money on health care.

- 9 ((group laughs))
- 10 P5 On the other hand, () if you just make you:r-
 11 simply cook your vegetables and your potatoes and your
 12 [piece of meat] (.)well then you don't really ↑need it.=
- 13 P2 [yes that's also] true.
- 14 P1 =No but suppose you have three kids.
- 15 P5 Yes but then eh (1.2) there is a whole lot you ↑can eat.
 16 Even if you have a gluten allergy there are a lot of
 17 things that you can eat.
- 18 P1 Yes but also a ↑lot that you ↓can't.
- 19 P5 Yes but, [but]
- 20 P1 [If you] eat two bread meals a day what a
 21 most=people ↓do. (0.7)
- 22 P5 Yes ok that- you can- I'm still not so. I have never been a
 23 fan of bread even before I started eating eh (0.3)
 24 gluten-free. I (.) yes I still eat breakfast with eh (0.4)
 25 bowl of ↓yoghurt (0.4) and some fruit. ↑Yeah. (0.6) It's
 26 just what you make yourself ↑u:sed to, you know.
 27 (1.0)
- 28 P2 It will mainly become easier=
- 29 P1 =°Yes°=
- 30 P2 =I agree it is possible to eat very tastily nowadays even
 31 if you eat gl[uten-free.]
- 32 P1 [Hm hm]
- 33 (0.7)
- 34 P2 Only you co:nstantly (.) have to thi:nk about it and plan
 35 ahead a little. And well that is also (.) manageable. But
 36 in that light such a pill I=would=think ↑well (.) that
 37 might also be ↑good for a change.
- 38 ((group agrees))
- 39 P6 Then I could for instance if I am cooking in time start
 40 prepa:ring bread for my children (.) without eh having to
 41 wash my hands twice. (2.1) Everything around it. (1.2) The
 42 contamination.

In this extract, patients discuss the pill amongst themselves. Although the experts can still be considered as playing a role as addressees (cf. Myers, 2007), it is interesting that in this part of the discussion they are apparently not required or invited to play an active part.

Instead of taking the pill as the starting point and then asking how it can be integrated in their everyday practices, here patients take their everyday life as the starting point and ask what kind of pill would be required from inside this context, or rather, if it is needed at all. P1's attempt to mobilize patients (1–8) is challenged by P5 (10–12). This is followed by a discussion between them (14–26). After an intervention by P2 (28–37) a group consensus is reached, and they go on to discuss different scenarios for using the pill (39–42 and further).

At first sight it seems that the disagreement between P1 and P5 is about whether the gluten-free diet is hard to maintain or not. P1 first gives a description of the diet as a burden (1–8), to which P5 counters that it is relatively easy to eat well without gluten (10–12, 15–17, and 22–26), and is then resolved by P2 with a description (lines 28–37) in which eating well without gluten and the diet as a burden are consolidated.

However, besides determining what the “correct” characterization of the diet is, these descriptions are also used to perform social actions. P1's description of patients being unjustly burdened by the diet in terms of time and money is used as an account that patients “need” (2) the pill, and thereby establishes patients as having the right to make demands about its price. This marks a shift from producing a response to the expert's question of how patients would want to use the pill, to a position where patients are the initiating party. Rather than something offered to them that they can then take or leave, describing patients as unjustly burdened constructs the pill as something that is *demande*d by patients, and something about which they have the *right* to make demands on account of their everyday circumstances. P1's description is therefore used to reject the identity of a passive, receiving party of medical innovation.

“On the other hand” (10) signals a confrontational stance on the part of P5 with respect to the previous turn. By constructing the diet as uncomplicated, and rejecting P1's claim that patients “need” a pill, P5 resists the construction of CD as an encumbering external circumstance beyond patients' control. Instead, she makes whether the diet is a problem or not contingent on the patients' agency: “there are a lot of things that you can eat” (15) and “It's just what you make yourself ↑u:sed to” (25–26).

Although there is apparent disagreement, P1's turn performs a similar action as P5 with respect to the innovators' presentation of the pill: using a description of everyday life, both reject being a passive recipient of something that the innovators offer. P1 accomplishes this by establishing patients as having the right to make conditions about the pill, P5

does so by reflexively constructing the pill as redundant. P1 and P5 are negotiating the place of agency for CD patients: is it to have the right to make conditions about the pill, or to be able to dismiss the pill entirely because you can live a perfectly fine life without it?

In line 28, P2 constructs the pill as mostly making things easier, and so as something that can be of help, but not a necessity. She carefully negotiates P5's claim about CD patients being able to lead a normal and independent life ("eat very tastily nowadays", 30), and P1's claim that CD is an unfair burden. She reformulates this burden in terms of agency, using both extreme case formulations and softeners ("*constantly* have to think about it and plan *a little*"). After constructing this disadvantage of CD, she instantly adds that it is nonetheless "manageable" (35), and then carefully constructs the pill as a luxury that "might also be good for a change." Her careful ("would") and indirect ("then I would think, well...") way of formulating and the use of softeners show that she is orienting towards these issues as delicate and potentially controversial topics. This is followed by agreement from the group, including P1 and P5.

P2's version seems to succeed because it manages both the self-determination of patients and their right to demand and make conditions about the pill rather than being passive recipients of it. She acknowledges both that patients are unfairly burdened and that, in the face of this burden, they can get by. So they are exerting agency *despite* difficult external conditions.

As opposed to the experts' questions, where the pill is taken as the starting point and the problem for which it is a solution is presupposed, patients take everyday social situations as the starting point, and from there construct the kind of solution the pill would be. In this case, for example, the pill is constructed not as an alternative to the diet as such, but to "constantly having to think and plan ahead". So it is not so much the diet in itself that features as a concern of patients, but the set of everyday practices of which dietary routine is an integrated part, and which consist of more than just its technical aspects. Furthermore, they are exploring a way to formulate the pill in such a way that it is consistent with the identity of an ordinary, active person. P2's construction of the pill as a welcome but optional comfort for CD patients allows patients to discuss its use without affirming the identity of a passive patient leading a troublesome life, and by constructing the pill as something desired from within and on the basis of everyday-life practice. So first of all, patients take everyday life as the starting point and construct the pill as required in a particular way on the basis of everyday practice, and, secondly, pa-

tients construct themselves (rather than the innovators) as the initiating party, and negotiate social and identity implications of the pill amongst themselves.

In the way the innovators subsequently responded to this, we found a similar technology-oriented agenda as in the initial questions. Due to space limitations, we give just one example of this. At the start of the following fragment (1–2) the expert refers back to a statement made by P5 a few minutes earlier in the discussion, in which she said that a pill alongside the diet would be “confusing”, that she “can’t imagine eating a pizza with a pill like that,” and that it would “feel (...) as if you are fooling yourself or your body” (data not shown here).

Fragment 5

Group 1, 33.52–34.41

-
- 1 **Ex** You said that (.) emotionally you would have a lot of
 2 problems with taking a pizza with a (.) pill.
- 3 **P5** Yes.
 4 (0.7)
- 5 **Ex** [But that]
- 6 **P5** [But I] think that ↓ehh (0.6) look if you have a
 7 medicine that allows you to always eat gluten again
 8 (1.2)
 9 yes (.)°that.° (0.4)
- 9 **Ex** That cancels it out again.
 10 (1.0)
- 11 **P5** That’s another thi:ng=but I would ↑not ehhhh (0.3) be
 12 able to one day eh take a gluten-free meal and the next day
 13 a pizza that is like (.) stuffed with gluten.
- 14 **Ex** Hm [hm]
- 15 **P5** [Be]cause (1.8) no I think I would the:: I would still
 16 just ↓skip the pizza.
 17 (1.6)
- 18 **Ex** Bu:t does this perhaps also have to do with the fact that
 19 you: well (.)↑are conditioned for certain thi:ngs, that’s
 20 a no-go, shouldn’t do that?
 21 (1.0)
- 22 **P5** ↑Yes I think so. Just eh (0.6) yes (0.5) that would also
 23 just be (.)scary to eat.
-

Although there are more interesting issues at play in this fragment, for our purposes we are interested in the expert's use of a Y/N *declarative* (18–20), in which a speaker claims to know about the matters formulated in it (or assume them, or treat them as established), and thereby makes relevant its confirmation (Raymond, 2009). Here, the patient's rejection is reformulated as resistance to change, i.e., the source of the rejection is located in the patient rather than in the technology. Even if the patient confirms his assertion, it is interesting that he formulates it as something that he claims to know, rather than something that is in question. This kind of response was found in all the groups and is further proof of the technology-oriented agenda.

4.5 Discussion and conclusion

In our analysis of upstream engagement meetings between CD patients and innovators, we looked at the social goals that were being achieved rather than at the level of arguments. Our analysis shows how the innovators' question design constrains the discussion to use of the pill, in which its desirability is taken for granted, and that there is a preference for an affirmative response from patients. Patients, however, nonetheless raise fundamental concerns and call the benefit of the pill itself into question. This shows the importance of the way the topic agenda is managed for the quality of the interaction. Furthermore, we found a tension between the way the proposed innovation was introduced with a central orientation toward the technology, and the way patients in the subsequent discussion gave primacy to everyday-life situations. Whereas the innovators take the proposed innovation as their starting point and inquire into whether patients would adapt their lives to it, patients treat their everyday-life practices as a fixed context and explore what kind of pill would be required from there. We could say that there is a difference in orientation between the two parties to what is considered the basis or justification of the proposed innovation, and what it is expected to change. For the innovators, it is the technical possibility of an innovation that could solve a medical issue, potentially requiring changes in dietary routine and other everyday practices. For the patients, in contrast, it is precisely this everyday practice and identity issues that are taken as the basis to which any potential innovation would have to be adapted. We could say that in general users are concerned with technology from inside the context of everyday life, whereas innovators are concerned with users' everyday life from inside the context of technological possibilities.

Due to the competing agendas of getting a technology accepted on the one hand, and social concerns on the other, during these discussions both parties are speaking about different issues and do not connect. The innovators thematize the technology, then the patients their everyday life, and this in turn is picked up by the innovators by locating the problem in the patient rather than in the technology, e.g., as resistance to change.

The thematization of different issues between experts and patients was also found by Blume (2000) in the discussion around cochlear implants for deaf people. Cochlear implants were framed by experts as a solution to a tragic condition, but this view caused considerable resistance in the deaf community. Those who were born deaf, in particular, had been socialized into a distinctive deaf culture. Besides not viewing deafness as a handicap, the possibility of being able to hear again would have profound social impacts for them and was constructed as having to abandon one's deaf identity. Blume (2000) describes how these kinds of discussions around cochlear implants were mainly technical in nature, and there was little attention to everyday life issues.

Interestingly, the thematization of different issues is not made explicit by any of the participants in the discussion, including the moderator. We might speculate that one of the reasons why the issues remain under the table is because of the particular setting of these kinds of public engagement discussions. For both the CD experts and the patients this is an unfamiliar setting, and there are no protocols or scripts for how they should behave themselves, what kind of relationship is established between them – such as exist, for example, for regular doctor–patient interactions. The setting was not completely institutionalized, as in for instance surveys or interviews, but on the other hand not completely informal either, since one of the aims of the discussions was to use the gathered information for the development of medical innovations. A large part of our findings may therefore perhaps be explained by the unfamiliarity of both parties with this kind of conversational setting.

One of our recommendations is therefore a call to make participants in upstream engagement exercises conscious of these kinds of issues. It is unfeasible and unpractical to train the participants in these kinds of settings, because they usually concern once-off or infrequent events, but at the same time it is important to bring to the table the kind of issues that none of the participants explicitly addresses, but which profoundly shape the interaction. In addition, since the quality of the interaction depends to a large extent on the way in which the topic agenda is managed, and the centrality of everyday life and the identity of users as the

initiating party, we emphasize the importance of facilitating the space to explore social implications of proposed technologies. The possibility of a technological innovation is of course the incentive to engage in a conversation with patients, but if the primacy of the technological perspective is not at least temporarily suspended and if space is provided for patients to explore different ways of relating to different solutions from the context of everyday life – as opposed to starting with a focus on the technology and then asking if and how it could be used – these issues will come up anyway.

Recent literature has described how users often raise upstream concerns at a downstream stage (for example, Macnaghten et al., 2005; Grove-White et al., 2000). The contribution of our study is that it goes beyond diagnosing that it happens and shows how it comes about in the unfolding interactional process. First of all, the topic agenda is actively but implicitly limited to discussing issues that are directly relevant to the innovators. This means that a number of presuppositions are already made about the users' life, which may then be challenged by these users. In this respect, Garud and Ahlstrom's (1997) distinction between enactors and selectors is relevant. Insiders to the technology process are described as having the end-product in mind and see the outside world – including public acceptability – as barriers to be overcome. Outsiders, on the other hand, are described as “ranking technologies on a common set of criteria [that] provides outsiders with a means to exercise control over insiders' processes” (Garud & Ahlstrom, 1997, p. 42). Our study shows how this plays out in a real life situation and is embodied in grammatical and social features of the interaction. The innovators, on the one hand, frame the discussion in such a way as to engender endorsement of the proposed technology by patients, whereas the patients return time and again to accounts of everyday life as selection criteria. This results in competing agendas: one geared towards completion of the current technological development, the other towards (critical) selection, where precisely the course of this development is in question. For instance, users may resist particular presuppositions or preferences that the innovators' questions incorporate. Most importantly, we show the persistency with which this happens, and that, if it is not addressed, it profoundly impacts the quality of the interaction.

Secondly, despite efforts to limit the discussion to *how* the proposed innovation will or will not be used, patients continue to address the question of *why* use it at all? This is not just a question of the timing of the meetings; or rather, it may be that the timing is different for different

parties. The way the innovators formulate their questions and respond to patients implies that the proposed innovation will come in any case, and it is just a matter of adjusting it to patients' wishes. This suggests that the exploration stage has already passed. Patients, however, still address wider issues such as what exactly the problem is for which the pill could potentially offer a solution, and whether there is such a problem. This is something that the innovators treat as being clear already. We argue that unresolved matters will continue to be addressed by patients, even at later stages of the innovation trial. Therefore it is important to address these matters as early as possible. The problem in our case study is that, from the innovators' perspective, these meetings did take place at an early stage, since it was right after the first concrete research finding about the pill – the discovery that an enzyme that was already used in other products could be used to neutralize gluten in patients' stomachs. However, as our analysis shows, it may be worthwhile to meet with patients still earlier – even before any concrete research findings. A lot of questions, which are now still unresolved, could possibly be addressed in meetings like that. For example, questions such as what patients consider a desirable improvement of their situation; what kind of conditions have to be met by innovations that aim to contribute to their quality of life; and what exactly they experience as problems in their daily life, could have already been addressed in a much earlier stage. If this had happened, the meetings that we investigated might have had a different character. For instance, the pill could have been formulated as a response to issues raised by patients in earlier meetings.

As social scientists, it is partly our role to convince innovators of the value of investing in the relationship with prospective users at as early a stage as possible. Although it may not seem directly relevant to them when there are as yet no concrete results, it pays off – especially in cases where the innovations emerge over the span of years or even decades – to make it the first order of business to gain insight into the lives of those whose lives the innovations are likely to impact. When there is already an initial relationship between innovators and prospective users, the presentation of, and request for, feedback on proposed research finding takes place in a context where there is already some degree of mutual understanding of each others' social goals. From a purely technical perspective, the pill is simply a tool that would allow patients to eat gluten; but from the perspective of the patients themselves it is not the eating of gluten itself that is desirable, but the social purposes of a technology, concerns such as “thinking and planning ahead” or “visiting friends”. It

is not the diet itself that is the issue, but the diet as a social practice in the arena of everyday life. How the technical aspects that medical innovations could change feature in the everyday-life context is what innovators can find out about by conducting these kinds of meetings, particularly if they have them analyzed from a discursive psychological perspective, or play a more active part in the analysis by using for instance the discursive action method (DAM, see Lamerichs, Koelen, & te Molder, 2009) in which participants are assisted to reflect on their own discourse to become aware of how they talk about everyday issues, such as their own and each other's interactional problems and strategies.

Finally, our study contributes to the question of how to regard the status of the discussions in these meetings. It has been noted earlier that claims and statements made by participants are a product of the unfolding interactional process and that a focus only in terms of outcomes may miss the real value of engagement meetings (Harvey, 2009; Walmsley, 2009). We saw that the innovators' orientation to patients is formulated mainly in terms of outputs, e.g., "how would you use this pill?" The way the problematic is introduced and the questions are formulated makes relevant responses that provide a ready-made answer – in this case, a statement of how one would or would not use the pill. The way the patients subsequently discuss the topic, however, is completely different. We saw them orienting to the discussion more in terms of a process of exploration, of negotiating and discussing different constructions and implications of CD and the proposed innovations. Rather than providing a clear-cut answer to the innovators' question, patients were negotiating the terms on the basis of which this question could be addressed at all. This means that just taking patients' isolated statements about the pill as representative of patients' attitude would completely misjudge the character of their discussion. Addressing themes of how to use the proposed innovation in daily life requires patients to resolve more fundamental questions of identity, agency, and responsibility (see Blume, 2000). The participants in focus groups use these meetings as a way to explore different options, i.e., arguing aloud rather than stating ready-made opinions (Myers, 2004, 2007). It is the process of discursive exploration and negotiation that is important, as well as the specific content of what people say. This shows the need not only for a discursive space in the innovation process in which innovators and prospective users discuss issues such as risks or desirability of a product, but also for space for negotiation about how to discursively construct it, rather than presenting prospective users with one particular construction as a *fait accompli* and then asking

whether they want it or not. Most of all, it shows that co-construction of technology is a creative activity that can – and should – be done purposefully. Discursive psychology can be used as a tool to aid this process, promoting mutual understanding of parties from different backgrounds by providing insight into each others' social actions and goals. The results of these analyses can be used as a basis for improvement and furthering of the aim of involving those whose lives innovations are likely to affect.

CHAPTER 5

**EMERGENT TECHNOLOGIES
AGAINST THE BACKGROUND OF EVERYDAY LIFE:
DISCURSIVE PSYCHOLOGY
AS A TECHNOLOGY ASSESSMENT TOOL**

Published as Veen, M., Gremmen, B., te Molder, H., & van Woerkum, C. (2010). Emergent technologies against the background of everyday life: Discursive psychology as a technology assessment tool. *Public Understanding of Science*. Prepublished 13 April 2010, DOI:10.1177/0963662510364202.

**EMERGENT TECHNOLOGIES
AGAINST THE BACKGROUND OF EVERYDAY LIFE:
DISCURSIVE PSYCHOLOGY
AS A TECHNOLOGY ASSESSMENT TOOL**

5.1 Introduction

In 2005, scientists started to speculate about the possibility of a pill that would let celiac disease patients eat a normal diet. Whether such a pill could actually be produced, and whether patients would be able to use it, was not known at that point. As social scientists, we were asked to find out whether such a pill would be welcomed by celiac disease patients.

Celiac disease (CD) is an affliction of the small intestine that causes intolerance to gluten. For CD patients, even a single grain of gluten can wreak havoc with their digestive system. The complete exclusion of gluten from their diet is currently the only way to avoid this. This is no easy task, as gluten is found in products containing wheat, barley, and rye, and added to many others, so that recognizing sources of gluten can often be tricky. Following the strict gluten-free diet is found not only to complicate practical food-related tasks, but also to have a social impact (Hallert et al., 2002; Ciacci et al., 2002).

One would expect that the possibility of a pill that temporarily neutralizes gluten would be met with excitement by CD patients. When we explored this issue by looking at how it was discussed amongst patients on online discussion forums however, we found that initial reactions of patients were mixed. This is just one example of a proposed innovation that from a scientific perspective would constitute a breakthrough, but is met with mixed reactions from prospective everyday users. Such lack of acceptance is still often explained by experts in terms of a knowledge or trust deficit regarding the science and technology involved (Wynne, 1992, 2006). This article deals with the question of how to understand people's responses not from a technology-oriented perspective but *on their own terms*, that is, as social actions performed in the arena of everyday life.

A detailed analysis of the CD patients' responses showed that the problem was in the assumptions that were implicit in the way the pill was communicated to them (see section 4, this article; te Molder et al., submitted). What seemed to be a case of CD patients rejecting a pill that would allow them to temporarily eat gluten on closer inspection was

revealed to be a product of the presentation of the technology as a panacea – something that would solve all their problems. So rather than an outright rejection, it was a critical assessment of the innovators' construction of the proposed technology in the light of their day-to-day dealings with CD and the diet.

This example illustrates how the response to innovation may largely be determined by socio-interactional factors rather than just people's understanding of its techno-scientific qualities. In reacting to emergent technologies, people are responding from a context that encompasses more than just technological issues (Silverstone and Hirsch, 1992; Oudshoorn and Pinch, 2003). In this article we propose that, to understand prospective users' reactions to emergent technologies, it is important to know and examine the interactional contexts within which these reactions take place.

In this article, we specifically focus on situations in which the technology has only been partially developed. Our aim is to find out whether proposed innovations match with users' current interactional practices. Take, for example, identity-related issues. Whether CD patients present themselves as patients, healthy eaters, or "just ordinary" people in interaction with others has consequences for the kind of products that appeal to them. If someone presents him/herself as a health conscious individual, treating him/her as ill may lead to irritation; and if someone defines him/herself as suffering from a serious disease, treating this person as just health conscious may lead him/her to feel that he/she is not being taken seriously. In this case, rejecting a proposed technology is socially significant in the sense that one can resist or affirm a particular label, or a way of being treated.

The challenge is to get insight into the everyday life of prospective users in such a way as to be able to incorporate these observations into the innovation trail at the relevant point in time – usually as early as possible. The approach could also be applied to update such insight when people actually start using the technology. In this paper however, we restrict ourselves to an earlier stage in which a/the technology is foreseen or in the making.

Of course it is not feasible to map people's entire everyday life. That would imply a researcher shadowing persons to observe every single action they perform. We focus on a specific part of everyday life: people's conversations, and how these are designed to perform social actions in selected areas. Particularly, we examine talk-in-interaction that takes place during everyday-life practices on which the proposed technology

is expected to have an impact, or about which it makes assumptions. In our illustrative example of CD patients, we examine not only how they react to a researcher that introduces the pill to them, but also how they talk amongst themselves about the gluten-free diet, and their mealtime conversations with family members.

We now discuss some of the technology assessment (TA) literature that has taken into account users' talk in relation to emergent technologies. We then introduce discursive psychology, an analytic perspective that allows for the kind of research we propose, and illustrate that it can yield valuable results with a few illustrative examples taken from our research on CD patients' everyday talk.

5.2 The status of laypeople's everyday talk in relation to emergent technologies

Technology assessment, and later constructive technology assessment (CTA), recognized the importance of involving the user, in our case patients, in the innovation process to encourage integration of new technologies in users' everyday life (Silverstone and Hirsch, 1992; Rip et al., 1995; Oudshoorn and Pinch, 2003). There has also been a tendency to take into account the role of users' and scientists' discourse in the interaction between science and society (Silverstone and Haddon, 1996; Locke, 1999, 2002; Oudshoorn and Pinch, 2003), mainly as a result of the way in which information and understanding are constructed as part of scientists' and users' use of language.

With others, Wynne (1992, 2006) has argued that scientific and policy experts often operate under a knowledge deficit model, that is, they see themselves as having access to sound reasoning and laypeople as deficient in that respect. This model envisages a rigid demarcation between scientific and popular ways of knowing, between experts and laypeople. In contrast to what the deficit model presupposes however, the public's way of reasoning does not seem fundamentally different from scientific reasoning, although it utilizes different standards (Locke, 1999; Wagner, 2007). The case has been made that technologists need to study public responses to science in order to learn from them (Levitt, 2003), and to discover missing propositions in their own reasoning (Locke, 2002). Everyday-life concerns that inform people's responses to emergent technologies may be at odds with scientific standards, but can and should be understood on their own terms.

The lack of fundamental differences between scientific and lay methods of reasoning is reflected in the fact that, in practice, exemplars of both methods are drawn upon by experts and non-experts simultaneously, although they serve different interactional goals. According to the seminal study of Gilbert and Mulkey (1984), scientists draw on different repertoires in different settings. In public, they use an empiricist repertoire, painting a picture of an objectively knowable world being discovered using reliable instruments; but when talking privately amongst *themselves*, or when their own experiments fail, they adopt a contingent repertoire describing a world where facts and validations are human constructions and could have been otherwise. In conditions of controversy, the empiricist repertoire is used to legitimate their scientific practice, and the contingent repertoire to discredit others (competing scientists, the public, the media). Critical voices are constructed as being caused by influences of external sources such as the media, whereas the scientists' work itself is portrayed as flowing from an objective reality. Burchell (2007) showed that the more scientists are working in conditions of controversy, the more they design "empiricist selves" and "contingent others."

Although laypeople can be shown to make use of similar hybrid constructions, in which they combine scientific argumentation with everyday-life concerns, scientific expertise still dominates in the end (Kerr et al., 2007). Expert speakers include and even "colonize" layness (Kerr et al., 2007: 407), whereas lay speakers are less successful the other way around. Recent studies found that scientists viewed lay interpretations as an intrusion on their discursive terrain (Cook et al., 2004; Young and Matthews, 2007). In other cases, participants were found to construct themselves as "also a citizen" to suspend their primary identity as an official or expert and create the interactional space for displaying personal concern while preserving the authority of their official identity (Padmos et al., 2006; cf. Kerr et al., 2007).

A number of recent studies (e.g. Locke, 1999; Horlick-Jones et al., 2007; Harvey, 2009) recommend using discourse analysis to reveal the continuity between scientists' and laypeople's discourse. This leads to laypeople's discourse being taken much more seriously and seen as an important source of information in the innovation process. Our research builds on these studies, and encourages more detailed analysis of laypeople's discourse to understand it on its own terms. This entails letting go of a bias towards the innovator's perspective that is still present – for example, by gathering data from focus groups or public debates in which innovators set the agenda. The technology perspective, with its scientific

assumptions, is the point of departure for the focus and data collection methods still used in most studies, rather than what people demonstrably do in their everyday talk. We discuss two related reasons for this asymmetry – neglect of the interactional process and a lack of focus on everyday talk – and propose discursive psychology as an alternative way of looking at prospective users' talk in relation to emergent technologies.

5.2.1 Not considering the interactional process through which results come about

The first critique amounts to taking the results of public engagement exercises for granted, without considering how these results are constructed through a contingent discursive process. In these kinds of exercises, such as public debates or focus groups, participants state positions, offer evaluations, and express values in relation to emergent technologies. Quantitative and quasi-experimental approaches to evaluating these outcomes simply take them as reports of the participants' real positions, evaluations, and values, instead of a product of a unique social process (Harvey, 2009). Reported views about emergent technologies are constructed during the course of interaction and not simply results of individual cognitive processes (cf. te Molder and Gutteling, 2003). Evaluation approaches that focus only on the outcomes of questionnaires, focus groups, and public debates, ignore the process by which they came about, and run the risk of misunderstanding these results. It is a filtering process that can lead to a self-fulfilling prophecy, for example, by ignoring or distorting data that are not consistent with one's evaluation routines (Garud and Ahlstrom, 1997). Therefore it is crucial to examine the way the results are produced in the social interaction (Harvey, 2009).

One example is the future scenario that is used in questionnaires, focus groups, or interviews. In these scenarios, the innovators present a particular description of how the proposed technology may affect consumers. Often the reactions of the participants to the scenario are taken at face value. It is rarely examined how they are a product of the way the scenario is formulated, and the way the interaction between the participants, the moderator, and each other unfolds. For example, in public debates about genetics, participants used personal experiences with the subject matter – e.g., as being color-blind due to a genetic disorder – to counter the claim that, because they do not have technical expertise, they have less authority or credibility to speak on it (cf. Kerr et al., 2007). So the dominance of accounts of personal experiences in these debates

should not simply be understood as a reflection of participants' feelings or opinions, but how they were used in this context to counter the authority of scientific claims to expertise. Felt et al. (2009) found that, in public debates, ethical issues that participants treat as potentially controversial to the other party, or that others could treat as a direct critique, were discussed in intimate settings but often not carried into the plenary. An interpretation that does not take into account the interactional context of these events could conclude that apparently these issues were deemed not important enough for participants to bring them up in a more public setting. However, Felt et al. suggest that the social goal of maintaining a consensus environment, and avoiding directly critiquing others, plays a role here. These are examples of the importance of taking into account how negotiations and discussions during the process itself help shape the final outcome (Harvey, 2009).

5.2.2 Lack of focus on everyday talk in its own right

The second critique concerns research that gathers data in artificial settings and then takes these data to be reflective of everyday circumstances (cf. Van Herzele and Van Woerkum, 2008). The purpose of participation exercises is usually for the researchers to extract information from the prospective users; but in working with hypothetical situations and future scenarios, participants are not as committed as they would be in their everyday-life interactions. Thus, the evaluations they make could change once the technology is actually there. Accounts of emerging technologies proposed by innovators already imply particular versions of the prospective users' worlds, and exclude others. The position of the prospective users is usually limited to evaluating or countering these particular constructions of technology and does not allow for the study of the spontaneous constructions of these technologies as they emerge in the areas of everyday life that they may apply to, for example, evaluating future scenarios presented by innovators.

Although these kinds of settings may help to involve people in the innovation process, and give them a voice in the development of technologies that will affect their lives, they also disconnect them from their local everyday-life resources (cf. Van Herzele and Van Woerkum, 2008). So people are engaged with science and technology, but on the innovators' and innovation's terms rather than their own.

The focus of most studies in relation to emerging technologies that do take account of laypeople's discourse (e.g. Locke, 1999, 2002; Hor-

lick-Jones et al., 2007; Kerr et al., 2007) has primarily been on ways in which laypeople can agree with, argue, or dispute claims made by scientists. This focus already presumes a scientific way of approaching technology that prospective users do not necessarily adopt in their everyday-life practices. On the other hand, approaches that study users' interaction with technologies in their everyday circumstances, such as Silverstone and Hirsch's (1992) domestication theory, explicitly thematize discourse that occurs when users engage with the technology. This is still reasoned from a technological perspective and ignores discourse that may occur when people are not busy with technology, but that will ultimately influence its reception.

We propose instead to study participants' talk in its own right, and focus on how it is used to achieve socio-interactional goals. This can be done either by examining discourse areas to which the technology will apply or draw from, or by taking into account the interactional setting in which technology-related issues are being discussed, such as during interactions between experts and laypeople. To do this, we recommend using discursive psychology as an analytic perspective and additional technology assessment tool.

5.3 Discursive psychology and technology assessment

Discursive psychology is the empirical analysis of text and talk as social practice. The focus is mainly on naturalistic materials such as casual conversations, but institutional talk and written texts can also be analyzed by taking into account the interactional environment and by paying attention to the social goals participants aim for in the interaction. This type of discourse analysis was developed in the 1990s by the British social psychologists, Jonathan Potter and Derek Edwards, and is still being expanded and applied to new research areas.

Discursive psychology examines how traditional psychological topics such as attitudes, emotions, and scripts are made available by people themselves, as part of the social actions they perform in and through talk (te Molder, 2008). It is interested in the categories and preconceptions mobilized by the participants rather than by the researcher. A crucial methodological characteristic of discursive psychology is that it looks at talk with respect to what it *does*, rather than what it *reflects*. Instead of trying to determine what people really think or feel, it focuses on how appeals to mental states, descriptions, and accounts are used to accomplish social and interactional goals (Potter and Wetherell, 1987). A display of

anger can be used to establish sincerity, a neutral description to build credibility of one's claims, and a bad memory to account for forgotten actions. Because of its action orientedness and focus on participants' categories, discursive psychology focuses on detailed empirical analysis of data gathered in natural settings, such as casual conversations, phone calls, or counseling sessions. This analysis does not look at just isolated segments of talk, but always at the interactional context and sequential organization. When people offer their evaluation of something, this is generally regarded as an expression of what they really think about it. Discursive psychology, however, recognizes that it is also part of the specific argument, possible alternative evaluations, and thus the interactional setting (cf. Edwards and Potter, 2001).

Discursive psychology has been applied to such diverse topics as racial discourse, courtroom cases, coping with cancer or diabetes, and family mealtimes. Recently, online talk, such as in chat rooms and internet discussion forums, has proven to be a valuable topic for analysis (see e.g. Lamerichs and te Molder, 2003; Antaki et al., 2005).

Discursive psychology has rarely been applied to the relationship between prospective users and emergent technologies. An exception is a study about the interactional uses of concepts central to nutrigenomics (Komduur and te Molder, submitted; see also Bouwman et al., 2009). The study concludes amongst other things that *healthy* behavior has to be accounted for in everyday life, implying a possible mismatch between the assumption in current nutrigenomics that people will readily avoid eating unhealthily once informed about its risks, and current everyday practices. Furthermore, it shows that genetic explanations for being overweight are received reluctantly rather than easily accepted as appropriate accounts.

Our own studies, which we discuss below in more detail, aim to contribute to the integration of emergent medical technologies into CD patients' current practices.

5.4 Discursive psychology in relation to emerging technologies: illustrative examples

As mentioned in section 5.1, this research started at a point where a Dutch innovative genomics cluster called the Celiac Disease Consortium (CDC) considered the possibility of creating a pill that would neutralize gluten in the stomach, thereby allowing CD patients to eat a regular diet without suffering. The question was whether CD patients would

welcome such a pill. Given the difficulties of following a lifelong strict diet where even a slight transgression could cause symptoms to occur, the assumption was that patients would be anxiously looking forward to such a solution. This, however, was an unchecked assumption, and the CDC wanted to know whether patients would in fact welcome such a treatment. As part of the societal research program of the CDC, we were asked to examine this. The following are three illustrative examples taken from a larger project that included discursive psychological analysis of online material, mealtime conversations of patients, and meetings between researchers and patients (Veen et al., 2010, submitted; te Molder et al., submitted).

5.4.1 Quitting is not an option: how CD patients construct the diet as the only available option

For CD patients, internet forums are among the prime locations for interaction with co-patients (Lee and Newman, 2003). The CDC was exploring the AN-PEP pill and other medical technologies that could provide an alternative to, or even completely abolish, the gluten-free diet (Stepniak et al., 2006). At the time, this was still a speculative scenario¹, but, since these innovations would be introduced into an environment where the gluten-free diet was still the only option available, we examined interactions between patients to gain insight into their already established practices and ways of coping with the diet (Veen et al., 2010).

The analysis focused on an exchange between patients that stood out because of the unusual number of responses (34 replies and 943 views in only two days), indicating that it might concern a controversial topic, and because of the pattern of similarity in the way the responses were formulated. In this thread, one patient writes that she is “so fed up with this diet” and “ready to quit.” She asks whether “anyone ever decided to bag it and just go back to a gluten filled diet? What happened?”. A content analysis of the responses would suggest that patients were simply answering her question in various ways, by sharing their experiences with diet lapses, and how they dealt with them. However, a discursive psychological analysis showed that there was much more going on, and that the respondents were performing more interactional business than just sharing.

Sequential analysis of the replies showed that they were all structured in much the same way. First, they would describe frustration with the diet, then how this led to a diet lapse, and then how they dealt with

that in a positive manner. The responses to the first message all contained elaborate sharing of individuals' experience with the diet. And curiously, the initial poster did not return to the discussion.

We found that, in their messages, patients used two discursive strategies to exclude quitting the diet as a valid option, without explicitly telling the first poster not to do so. First of all, they used a device called "scripting" that constructs an event as something that occurs regularly (Edwards, 1994; Sneijder and te Molder, 2005). This approach to scripting differs from script theory in cognitive psychology and the method of script analysis proposed by Akrich and Latour (Akrich, 1992; Akrich and Latour, 1992). In discursive analysis, scripts are not approached as expressions of underlying cognitions or design features, but for what they do in the interaction (cf. Edwards, 1994). The following excerpt from one of the replies is an example of this:

Drew (Jan 2, 2007, 08:17 PM)
New Community Member

1 Every now and then I get a
2 little fed up and start to
3 stop being so attentive,
4 and it usually ends up with
5 me being horribly ill for a
6 week. I don't ever 'cheat'
7 specifically, but I'll get
8 fed up with wait staff and
9 chance it and it usually ends
10 badly.

"Every now and then" (1), "start to stop" (2-3), "usually" (4) and "I'll" (7) script the frustration of the diet as something that occurs regularly. With "a little fed up" (1-2) she contrasts with the first poster "so fed up with this diet." Then she says that even though she sometimes has diet lapses, she nonetheless maintains the diet, and goes on to give reasons why. This is an example of what occurred in almost all of the responses: scripting diet lapses and thereby presenting them as a matter of routine that is no reason to quit the diet.

The second device that patients used was to reformulate the individual decision to quit as an action that takes place *within* the diet. They use

terms such as “cheating” (see previous example, line 6), “testing” and “being accidentally glutened” when speaking of their own diet lapses. Thus the desire to quit is mitigated as a reason to stop the diet altogether. In this way, patients are negotiating the *interactional* context in which gluten intake can be talked about. Although the first poster constructs a lapse as inconsistent with the diet, the respondents instead treat it as something that, although undesirable, does occur – albeit temporarily.

These two devices contribute to the diet being constructed as the only option. The diet in addition to something else is constructed as being impossible. From a medical perspective, there are different scales of CD, for some of which occasional gluten intake can be considered less harmful than others. But our analysis showed that patients construct the gluten-free diet as a black/white scenario: either you follow the diet or not, there is no in-between option. The AN-PEP pill, and other proposed solutions, would therefore not just introduce a new technology but a new interactional possibility as well. It would be a transition from a deterministic to a probabilistic environment, in which there would be many gradations between following the diet and not following the diet – for example, taking a pill when eating out with others and eating gluten-free at home. This is something that needs to be taken into account in introducing alternatives to the gluten-free diet to CD patients.

5.4.2 Resisting straightforward acceptance of a future pill

The next example is taken from a thread in which an unknown “researcher” asked a question that generated a huge response from patients (te Molder et al., submitted; in total 152 posts were examined). Whether s/he is, in fact, a researcher is immaterial because what we are interested in is how this question is treated *interactionally* by patients, and how this correlates to the way the question is constructed. This is the researcher’s post:

Researcher (Sept 6, 2004, 09:38 AM)
Newbie²

1 I am doing some research on
2 developing potential new thera
3 pies for celiac disease and am
4 wondering, how much would you be
5 willing to pay each day if you
6 could take a pill that would let

7 you eat a normal diet? How much
8 would you pay per year?

The researcher, obviously an outsider to the discussion forum, asks a seemingly straightforward question. This is one of the responses:

Sammy (Sept 9, 2004, 08:04 PM)
Member

1 I wouldn't give one red cent for a
2 pill. I have taken pills all of
3 my life because of this disease. I
4 would just keep on with the diet
5 as is. I feel better than ever and
6 have more energy than most 60
7 year olds should have.
8 Pills? Thanks any way. Sammy

This exchange seems simple enough: a researcher polls prospective users of a future medical technology about how much they would be willing to pay, and a patient responds that she rejects the proposed innovation altogether. However, this conclusion changes when we look at this exchange from an interactional point of view.

When we look closer, the researcher's question, which is typical of the kind of questions that are used in consumer research, is far from neutral (as no question ever is). Questions set agendas. They invite particular types of responses and establish which kind of answers will be interactionally relevant (Clayman and Heritage, 2002). As the first turn of a sequence, this question introduces certain assumptions and sets the terms on which the question needs to be answered. This means that an unmarked answer, that is, one that responds uncritically to the question with a monetary value, not only answers the question but also affirms its presuppositions.

First of all, the question contains the assumption that CD patients would unquestionably accept the pill. Asking someone how much they would be willing to pay for something already assumes that they want it in the first place. Secondly, the pill is presented as an easy solution to a problem. "Would let you eat a normal diet" (6–7) constructs the gluten-

free diet as an abnormality that should be solved. Finally, it constructs the pill as something that CD patients would take daily (“each day,” line 5), for a long period of time (“per year,” line 8).

Sammy’s response challenges each of these assumptions. The extreme case formulation (Pomerantz, 1986) “one red cent” (1) does more than just answer the researcher’s question with “\$0.” It challenges the presupposition that the pill would be accepted by CD patients and calls the value of *any* pill for CD patients into question. “I feel better than ever and have more energy than most 60 year olds should have” on the one hand disputes the assumption that the gluten-free diet is abnormal or somehow a problem, and on the other hand constructs her identity as a healthy individual.

In their analysis of the other posts in this thread, te Molder et al. (submitted) found that the majority of these posts challenged the presuppositions of the researcher’s question that patients would unquestionably accept a pill. Only a minority answered the researcher’s question in terms of monetary value, but usually added conditions they would impose on accepting the pill. Just a few patients responded unconditionally positively.

An analysis of this internet forum that paid attention only to content would conclude that the majority of the patients on this forum prefer the current diet to a possible future pill. From an interactional point of view, however, this conclusion misses the point. What the patients are rejecting is not the proposed medical technology, but the *way* it is proposed to them: as something they should accept without question and as a panacea for their problem. For example, another thread in which a patient introduced the pill more carefully, as a suggestion that something like that might be developed (“If they found a pill that would neutralize the effects of gluten on your body [...], would you use it?”), did not evoke reactions as strong as the one shown above. For example,

Betty (May 3, 2004, 01:01 PM)

Advanced Member

1 The thought of someday being able
 2 to take a pill that would allow
 3 us to eat gluten is amazing. At
 4 the same time, like a lot of you,
 5 questions are raised to my mind.
 6 What about possible side effects?

This finding suggests that ways of communicating innovations to CD patients that construct their current dietary practices as downright problematic will not go over well. Presenting new possibilities as cure-alls reflexively constructs the gluten-free diet as unnecessary, a hardship, and undermines the complexity of the disease.

In addition, the patients are not only busy with evaluating or understanding the product in question. People's reactions to innovations, whether they accept or reject them or anything in between, are socially significant actions, that is, they accomplish goals in the arena of everyday life. Sammy, for example, rejects being characterized as a passive patient and presents herself as a healthy individual who is able to maintain her vitality in the face of adverse circumstances. By resisting the notion that they would straightforwardly accept the pill and carefully formulating and imposing conditions on its potential use, patients construct themselves as proactive, thoughtful people with an already healthy way of life. This is a cue to the innovators of the CDC to approach patients in a way that respects their current way of life, and treat them as active partners in the innovation process rather than as passive patients waiting for a cure.

This example illustrates how discursive psychological analysis can reveal some of the necessary conditions about communicating with prospective users in the future. It also shows how the way an innovation is introduced to prospective users correlates to the way they respond to it, and that matters seemingly unrelated to science or technology – such as identity – play an important role in how people react to innovations.

5.4.3 Constructing price as a condition to take the pill

As a third illustration, let us look at a fragment where patients are discussing the price of a future pill in a face-to-face meeting with experts. This fragment is part of a corpus of about eight hours of recordings of meetings between experts and patients. Although this is an example of institutional talk where innovators organized meetings with future users, it is analyzed with attention to the social actions being performed, and the interactional context in which it takes place. This interaction took place during a series of information meetings organized by the CDC in 2008. The purpose of these meetings was twofold. On the one hand, patients were informed about the latest developments in CD research, and the possible innovations that might result, and were able to pose their questions to the researchers themselves. On the other hand, it was organized as an opportunity for the researchers to engage with

patients and receive direct feedback about innovations in the pipeline.

First, let us look at the fragment where patients are asking the expert what the price of the pill will be.³

-
- 1 P1 What kind of price=is it one Euro per pill or five Euros
 2 per pill?
 3 Ex That is [com-] (.) That is completely unknown.
 4 P1 [Yes, yes]
 5 Well, there are of course multiple enzyme preparations
 6 and when this is mass-produced (.) it will become cheaper,
 7 of course.
 8 Ex Yes↑, that uhm
 9 P2 But is it three Euros per uh, pill or is it ten Euros? That
 10 also makes a difference=
 11 Ex =Yes that is pretty difficult. That is very difficult to say
 12 but I (.) don't think it will be ten Euros.
 13 (2.0)
 14 P2 And it will probably become chea:per after a whi[le.] If
 15 then it.
 16 P1 [°Yes°]
 17 The need will increase.
 18 P3 And we will have to join together (1.0) and take an uh.
 19 stand to make them understand somehow uhhh that we need↑
 20 that.
 21 ((group agrees))
 22 P3 And not have to always spend three times the amount of
 23 time in the kitchen as others.
 24 ((group laughs))
 25 P3 And have to spend more money on health care.
 26 ((group laughs))
-

Notice that the issue of price is raised here by the patients themselves, and in the context of expected use of the pill. This is very different from how it was raised from a researcher's perspective in the previous example: in the context of how much patients would be willing to pay for a possible pill.

The question we ask from a discursive psychological point of view is not what price patients are willing to pay, but when and how the issue

of price is drawn upon in the interaction, and with what interactional effects. Before this fragment starts, a number of patients have indicated that they would use the pill to replace the diet completely (not shown in this fragment). After the issue of price has been raised, one of these patients (P2) presents it as a reason for a change of mind, thus constructing it as a potentially decisive factor between “keeping the diet as it is” (the expert’s words), and using the pill. Price is not treated as an *additional* consideration to the question of using the innovation, but as something that could *determine* whether they would use it at all.

The question is *what action is being performed* by treating the issue of price in this way. By formulating price as a condition for accepting the pill, patients establish themselves as the party that decides, rather than for example displaying themselves as hopeful that the price will not be too high, thus assigning themselves a more dependent position.

First they bring up factors that may lower the price. The first one (5–6) is still from the perspective of the innovation: mass-production, but “the need will increase” (17) and “we will have to join together” (18) shifts the agency to the patients themselves. In addition, the expert from this point onwards no longer takes an active part in the interaction, as patients discuss amongst themselves. The shift from a position in which patients are dependent upon the expert for the innovation into constructing themselves as the decisive factor in shaping it is reflected in the *interactional* features of the conversation.

Next, the pill itself with this necessary condition attached is constructed as something to which CD patients have a right (accounted for by having to spend more time and money than others on cooking and medical treatment, lines 22–25). This is fundamentally different from presenting it as a panacea, an easy solution that patients are waiting for and will accept no matter what (example 2). In addition, it builds on our conclusion from example 1 that the pill will introduce new interactional possibilities and shows how patients negotiate the status of such a possibility.

On the basis of our study of which this interaction was one example, we recommended CD researchers to also explore and present the future status of the pill from a perspective that is related to the embedding of the pill in patients’ daily life. Discussing price should not be treated as an isolated and solely economic issue of how much patients are *willing* to pay, but involves issues of agency, and the status attributed to the pill in relation to the patient’s identity as an autonomous, initiating actor.

5.5 Conclusion

In this article we asked the question of how to gain a better understanding of people's reactions to emergent technologies, recognizing that these are often explained by scientists and policy experts as determined solely by (a lack of understanding of) the technical and scientific properties of the proposed technology (Wynne, 1992, 2006). We focused on this issue as being at least partly determined by the status of people's everyday talk in relation to emergent technologies and by the lack of a perspective that is able to understand prospective users' reactions to emergent technologies on their own terms. Although recently more attention has been given to the social dimension, this has been done mostly from the vantage point of the technology. We call attention to the importance of taking into account the fact that users are already talking and have established socio-interactive practices that are not necessarily related to the technology but do influence its reception, or rather, construction. By looking at CD patients' reaction to a researcher's question in its original interactive context, we suggested that one alternative to understanding people's response to emergent technologies as a response to those technologies themselves is to understand them as reactions to the way these are proposed by scientists and policy experts. In addition, we proposed to study prospective users' everyday talk in circumstances that the future technologies are likely to affect, but without those technologies necessarily having to be present. This translates into studying the discursive devices that are used in the contexts that emergent technologies are likely to impact and the understanding that people already have of their current practices – in other words, studying the background of everyday life against which new technologies will appear.

We recommend a discursive psychological approach to technology assessment for two main reasons. First of all, it focuses on naturalistic settings. Rather than taking them out of their everyday context into an artificial environment, in order to then find out how they would act in their everyday life, discursive psychology can examine users' practices directly by studying their *discursive use*. Here, it is the everyday concerns of the users that guide the analysis, rather than what the innovators think those are. Issues that are not necessarily related to technology, but will play a role in its reception, can therefore come to the surface; and this reveals prospective users' wants and needs that are blind spots from the perspective of innovators. The users themselves are often not discursively aware of these wants and needs, so they are not able to explicitly address

them in, e.g., interviews or focus groups. Assessment of needs can take place at any point in the innovation process, since it is not dependent on the presence of the actual technology (although the technology may of course change some of these needs).

Secondly, the focus of the approach on discursive action rather than on the content of people's talk allows it to understand locally produced "lay-understandings" of technology on their own terms. When, for example, a user presents a technology in a way that is inconsistent with scientific accounts of it, rather than being concerned that such a person has a mistaken understanding of technology, we should investigate what kinds of interactional work such utterances may perform, how and when they may occur, and what they are used in contrast with. By selecting a particular version of the technology, people may accomplish certain interactional goals that may be important for innovators to take into account, such as, for example, avoiding being characterized as a passive or needy patient.

The contribution of this approach to current TA research is that it highlights the way people *use* descriptions and accounts – of, for example, technology, their circumstances, their identity – to accomplish social goals. These social goals are difficult – if not impossible – to see if approached solely from the perspective of the innovator or technology, and seeing them requires empirical study of people's everyday interactions. A reference to genetic makeup can be used to negotiate responsibility for being overweight, but that such an account is found to be treated reluctantly by people in their everyday interactions is crucial information for nutrigenomics innovators, since they are working on a technology that aims to link these two factors (Komduur et al., 2009; submitted). The finding that people use descriptions of their healthful eating habits to resist the idea that they are too rigid about pleasure or too loose about health is relevant for innovators working on personalized nutrition, since they are introducing a technology that emphasizes health in relation to eating (Bouwman et al., 2009). And the fact that CD patients use the issue of price to negotiate conditions for using the pill in a particular way that maintains their identity as an independent, thoughtful person (rather than being a passive patient needing medicine) can help CD researchers to approach patients in a way that furthers fruitful communication.

The most important question, of course, is how to use these insights. This leads us to make a few observations about using discursive psychology as a technology assessment tool. There are two possible limi-

tations to this kind of research. The first is that discursive psychological analyses require a broad approach and detailed empirical study of conversational data. This may be laborious. However, the depth of the analysis and the detail of the transcriptions depend very much on the scope and purposes of the research, and can be adapted to be more practical. In the discursive action method (DAM) approach, for example, participants were fed back rough transcriptions of their own conversations and made into analysts of their own language (see Lamerichs et al., 2009).

Another point of attention concerns the issue of translating the findings from the analysis into policy decisions. It would be too naïve to conclude that, since CD patients reject the idea of the pill as a regular medicine, it should therefore not be introduced as a medicine but as, e.g., a food additive. However, the finding that by this rejection they are establishing themselves as independent and initiating actors, rather than patients waiting for an indispensable pill, is something that can inform policy decisions on how to involve patients more in the innovation process. Discursive psychology studies discourse in detail – making observations about what participants *currently* and *demonstrably* do in the interaction – rather than trying to reach a conclusion on general outcomes (Potter and Wetherell, 1987; Harvey, 2009). Conclusions from detailed analysis of case studies can to a certain extent be generalized, as the same discursive strategies often lead to similar interactional patterns (Goodman, 2008). At all times however, discursive psychology should be applied cautiously, considering in particular the contextual nature of all interactional business at hand.

In addition, we recommend the use of discursive psychology primarily as a *practical* tool. It can reveal blind spots about what is going on in the interaction between all parties involved in the innovation process. It can help to make people discursively aware of issues that play an important role but go unnoticed, so that these issues can then be dealt with. Most of all, it can be used to gain a deeper understanding amongst all parties about the kinds of issues, concerns, and strategies that are used by the other parties, and promote fruitful interaction that contributes to an integrated innovation process.

- 1 The CDC has conducted clinical trials to test the working of the pill in the human stomach. The test results are as yet inconclusive.
- 2 This forum makes a distinction between “newbie,” “member”, and “advanced member”, depending on the number of posts a member has contributed to the forum in the past.
- 3 Notation: P1, P2, etc. are patients; Ex is the CD researcher; [text] means overlap; underlined emphasis; ↑raised intonation; (x.x) pause of x.x seconds; (.) short pause; text=text no pause between words; and ((text)) analyst’s comments. Different levels of transcription can be used depending on the setting in which the transcripts are used. For example, one may decide to work with less detailed analysis and transcription for practical purposes (see Lamerichs et al., 2009).

CHAPTER 6

CONCLUSION AND DISCUSSION

CONCLUSION AND DISCUSSION

6.1 Introduction

This study has examined the everyday-life discursive practices of celiac disease (CD) patients in order to gain insight into how emergent technologies can better contribute to their quality of life. The central idea from which we started is that, in order to involve prospective users' perspectives in the development of emergent technologies, one has to study their everyday lives.

The research aimed to contribute to the goal of making the patient the central focus in the development of medical technologies in the field of CD. After summarizing the results of this research, I evaluate and discuss three aspects of this research more in depth. Specifically, I reflect on what making the patient (or user) central means with regard to technological innovation, and what role innovators play in this. What conclusions can be drawn from the analysis of CD patients' discursive practices in three different fields?

Secondly, I reflect on the application of discursive psychology (DP) in this research. The use of discursive psychology as a technology assessment tool has been discussed extensively in CHAPTER 5. Here, I concentrate on the benefits and drawbacks of using this approach in practice, in an interdisciplinary setting with medical researchers. On the basis of this experience, I make recommendations for future use of discursive psychology in technology assessment (TA) settings. Particularly, I share some insights that could be useful for moderators of discussions concerning technology development.

Thirdly, I address the benefit of studying patients' everyday life separate from concrete innovations, but with an innovation perspective. How does this contribute to user involvement in the development of emergent technologies?

Finally, I make suggestions for future research.

6.2 Results

To gain insight into the everyday life of CD patients, three types of interaction have been studied: patient–patient, patient–non-patient and patient–expert interaction. To study patient–patient interaction, I used online discussions amongst CD patients. For patient–non-patient interaction, in contrast, mealtime conversations between patients and family members were used. For patient–expert interaction I concentrated on discussions between patients and CD researchers about emergent medical technologies. In this section, I discuss the answers to the research questions posed at the start of this thesis:

How is the gluten-free diet treated amongst patients, and what does this mean for innovations that aim to provide an alternative or addition to the diet?

How do CD patients and their family cope with disease and diet during family mealtimes?

How do patients and researchers discuss current developments in CD research? What does this say about expert–patient communication, and patient involvement in the innovation trial?

How can discursive psychology be further applied as a technology assessment tool?

CHAPTER 2 explored interactions between patients on an online discussion forum about the gluten-free diet. We found that the way patients currently treat the diet has consequences for innovations that blur the distinction between following or not following the diet. Amongst themselves, patients construct the diet as being the only option available. This may seem obvious, as no alternative therapy exists. However, the importance of analyzing the way patients stick to dieting is to emphasize that they have already established routines that comprise the context in which any CD-related innovation will be introduced and thereby place innovations in a broader framework consisting of diet and non-diet practices.

For patients, this context consists of strategies to sustain their diet routine. One such strategy used by patients to maintain adherence to the diet is to establish it as a matter of course by creating a scenario in which

one either follows the diet or does not. Some of the potential innovations being developed by the Celiac Disease Consortium (CDC) are inconsistent with this black/white scenario: for instance, a pill that patients could occasionally use, or gluten-safe wheat that is not gluten-free but is not harmful for patients. Since these innovations may blur the distinction that patients now make between following and not following the diet, they will not land in a void, but in an established way of life. This is especially so given the long patient's delay and doctor's delay among CD patients (the time between first symptoms and the first visit to the doctor, and between that first visit and the correct diagnosis, see section 1.2). Contrary to expectations, the research in CHAPTER 2 revealed that dietary adherence is treated and maintained by patients as a collective phenomenon rather than a private practice.

In a study of mealtime conversations between patients and their close relatives in CHAPTER 3, we found that properties such as tastiness are given priority over categories of health and safety. Although the food's safety was always established first, its tastiness was constructed and positioned so as to ultimately account for eating it. In the families with a young child, the persistent taste queries, even after the child had given evidence of his positive stance towards the food, marked the offering and acceptance of food, and the basis on which this was done, as a delicate and uncertain affair. More generally, patients and their families showed an orientation towards demedicalizing the diet by constructing avoiding gluten as a matter of choice rather than restriction. This is an important finding, since experts who develop innovations for celiac disease patients tend to relate to such patients solely in their patient identity, rather than their consumer or family member identity. In spite of the prevalence of these latter identities in day-to-day circumstances, they are overlooked in research products. This study, too, emphasizes that diet-related matters are treated by patients and their social environment as a collective rather than an individual issue, and that this social context should therefore also be taken into account in the innovation process.

In CHAPTER 4, we started looking into interactions between patients and celiac disease experts during organized discussions about emergent technologies. In the analysis we found that there was a fundamental difference in orientation of both parties. During the discussion, the researchers took the proposed innovation as a starting point and treated the everyday life of patients as something that could be adapted to that. The patients, in contrast, treated their everyday-life practices as a fixed context to which any innovation would have to be adapted. These com-

peting agendas caused parties not to engage with each other, and affected the quality of the interaction. However, this difference in orientation between getting a technology accepted and patients' concerns about identity, agency, and responsibility did not become an explicit theme of discussion.

CHAPTER 5 presented discursive psychology as a technology assessment tool in the field of science and technology studies, based on illustrative examples from the preceding research. To understand prospective users' reactions to emergent technologies, it is crucial to examine the interactional contexts within which these reactions take place, as people's reactions are shaped by issues that are not necessarily related to science or technology. This research has aimed to bring forward these issues, as they are often overshadowed or remain blind spots when descriptions or scenarios of proposed technologies are thematized as being the core objects of reference. Consequently, the study recommends also examining prospective users' everyday-life practices in their own right, and in naturalistic settings. Insight into the social actions that people accomplish in their everyday talk, such as establishing a particular identity, can help innovators translate prospective users' concerns into relevant technology characteristics.

6.3 Limitations of the study

Due to the time restrictions and labor-intensiveness of the method used in this thesis, one of the limitations was that the number of interactions that could be analyzed was of course restricted. It would have been interesting, for instance, to examine interactions of patients in restaurants to examine how they communicate with waiters and how these respond, or in their professional environment, e.g. at lunchtime with co-workers. Exploring more situations that are common to the life of CD patients may therefore be a fruitful continuation of this research. This could include other angles besides the innovation perspective; for instance, with the aim not just of improving the health-related quality of life of CD patients with medical innovations, but also of improving healthcare specific to CD patients, communication about or marketing of gluten-free products, and identifying other ways in which patients and their families can be helped to cope with CD, such as for instance ways to communicate effectively with waiters or school teachers about the special care needed to avoid contamination with gluten.

Another limitation of this study is that it concentrated only on a specific part of everyday life, namely, conversations. Focusing on audio recordings as the principal method of data collection meant that there were no visual cues on patient behavior. We could not take into account this non-verbal part of, for instance, the family mealtimes, and the discussions between patients and experts. It could be that there were facial expressions, gestures, or other actions that were relevant for the interaction but that we missed. Apart from the choices that needed to be made based on resources and time available, and the fact that we can never capture every single part of everyday life, an argument could be made that in these kinds of situations it would be valuable to have a camera present, so that a visual analysis of the interaction could also be part of the research. One consideration not to do this in the case of the mealtime interactions had to do with the invasiveness of the research on the everyday-life situation. I gave the families a little digital recording device that could be switched on and off easily, and was moreover relatively invisible. Of course a situation that is recorded or measured in some way for research is never a natural situation in the strict sense – there is always some influence of the research on the object of research, even if it is a little recording device. However, including video does substantially increase this influence because it is never enough to just record the situation from one angle, and two or three cameras are necessary. I stress this point because in discursive psychological research this seemingly technical issue is an extremely important part of the research to consider. It may mean the difference for the participants' experience of the situation as "natural" or as a "Big Brother" situation. Besides these practical points, the relation between (nonlinguistic) action and language, the status of each of these, and whether or not it is necessary to include one or the other in one's research, is a fundamental and philosophical question that goes beyond the scope of this thesis. Suffice it here to stress the need for careful reflection on whether or not to include video data in one's research, depending on the specific situation.

6.4 Discussion

In the following, I reflect on 1) the problematic nature of patient-centered medical technology development in situations such as that of the CDC; 2) the application of discursive psychology in this situation, and its development as a practical instrument in technology development; and 3) insights about user involvement in technology development.

6.4.1 The patient central

Patients' everyday communication is a domain to which innovators have very limited access. For them, the patient features mainly as an object of medical research, through informal conversations or representatives such as patient associations. This thesis put forward the idea that approaching patients as a subject requires understanding their actual everyday practices in relation to the disease.

The research presented in this thesis has been carried out as part of the aim of the CDC to make the patient the central focus of their research. "The patient central" is a term increasingly found in the mission statement of medical research institutions. However, this centrality may carry different meanings. The patient is of course the central focus of the CDC's research as an *object* of medical study – for instance, in studying patient material to discover genetic markers that are indicative of CD. The patient is also the *goal* of the research, which aims to improve the quality of patients' lives. In a third sense, the patient features as a central focus in that patients are *stakeholders* in the research that is being carried out. This mainly expresses itself in communication with the Dutch CD patient association (NCV), and in conducting surveys and interviews to measure patients' attitudes towards certain issues, such as for instance their satisfaction with current gluten-free products like Teff. In a more informal sense, many CDC members encounter and communicate with patients in the course of their work, for instance, as general practitioners or dieticians. These personal contacts with patients were also often referred to in meetings that I attended and interviews that I conducted with CDC members.

This thesis starts from the premise that performing patient-centered research means centralizing the patient's *everyday life*. This approach means a departure from a clinical, non-contextual approach that characterizes medical research where one tries to isolate situations that are directly related to physical symptoms and gluten intake. Instead, this study looks at CD in a broader context, such as cooking, eating, visiting the doctor, talking about CD. This is the context in which people actually apply knowledge or technologies, and the social functions these applications perform deserve further scrutiny.

The slogan "the patient central" invites one to approach CD patients as individuals, and approaches these individuals only as patients. One thing that has become clear from the discursive analyses of actual interaction, however, is that in everyday life everything is related with every-

thing else. First of all, the everyday-life practices relating to CD include more than just the individual patients themselves. The analyses both of interactions between patients on an online discussion forum about the gluten-free diet (CHAPTER 2) and of mealtime interactions between patients and their families (CHAPTER 3) revealed that diet-related matters are treated as a collective issue rather than as an individual phenomenon. When one patient considers quitting the diet, this is taken up as affecting other patients as well, and not just that individual patient. The analysis of mealtime conversations revealed that the diet affects not only patients themselves, but also those around them. Eating is a shared practice, so when a condition like CD affects eating practices, the consequences are also shared. When a family with a CD patient is having dinner together, and everyone is eating gluten-free, for the eating practices it does not matter so much which one of them is physically affected by it. This means that not just patients as individuals, but also those around them will be affected by any changes in their way of coping with CD.

The social environment of a CD patient plays a crucial role in the goal of avoiding gluten intake. For children with gluten intolerance, parents make sure their diet is gluten-free; but in other cases as well, it is often family, friends, colleagues who do the shopping, read the labels, prepare meals, and take precautions not to contaminate the patient's food when their own food is not gluten-free. In addition, persons who bear no close relation to the patient – often unknowingly – play an important part in their day-to-day health-related quality of life. One story that particularly struck me was that of a patient who participated in the discussions with CD researchers. It is mostly the simple things that are the problem, she said. When she orders something in a café or restaurant, she always communicates that she cannot have gluten, but still it often happens that she gets a biscuit with her coffee. When she requests a waiter to take it back and bring a coffee without a biscuit, while taking the biscuit away, some crumbs could fall into the coffee. Since she cannot tell whether this has happened or not, she does not take the risk and cannot drink the coffee. This example illustrates that, when it comes to the health-related quality of life of CD patients, it is not just the patients themselves who influence this, but also the actions of strangers.

Increased public awareness of gluten-free diets would go a long way to improving a patient's quality of living. A possible way to improve awareness would be, for instance, a national communication strategy about CD. Here, again, it is not the patient as an individual who is the central focus, but patients in their lifeworld, where others, and with that

interactional concerns, play a role. My suggestion is therefore to put more emphasis on the interactional context, as the theme “the patient central” is too narrow.

Besides the collective rather than individual treatment of CD-related matters, and the inclusion of others (non-patients), the focus on “the patient” is limited also limited because it highlights only the patient identity. A human being affected by CD does not have one particular section of their life reserved for being a patient, as distinct from everything else. If we trace the word *patient* to the Latin verb *pati*, which means to suffer, we could say that this description is limited in two senses. Firstly, the patient is not just a patient, but also, for instance, a consumer. Practices relating to CD, especially eating practices, are related and overlap with all those other identities as well. We could even say that the only therapy currently available for CD – the gluten-free diet – mainly involves being a good, pro-active consumer, involving strategies to make sure that the products one buys and eats are gluten-free.

Secondly, a patient might be a technically correct label for human beings with CD, but it might not be how they present themselves. In the case of CD, a patient might not treat his condition as part of his identity, or only in particular situations, such as going for a check-up or explaining his condition to someone. In CHAPTER 3, we found that the diet is demedicalized in everyday interactions, and properties such as tastiness are given priority over categories of health and safety. This is an important finding, since experts developing innovations for celiac disease patients are prone to relate to celiac disease patients solely in their patient identity, rather than their consumer or family member identity, which may gain precedence in the day-to-day circumstances in which the research products will eventually have to be used.

This may seem a theoretical or abstract discussion, but the way a patient is approached, and the discursive practices that construct this identity, directly affect a patient’s quality of life. The paradox is that human beings afflicted with CD benefit from relating to themselves as a CD patient, but do so precisely in order to avoid having to be considered as such. In the period leading up to a CD diagnosis, a patient experiences symptoms such as for instance fatigue, but does not attribute this to CD, and perhaps does not attribute it to any medical condition at all, but to, for instance, “just being a moody person,” or “a person who tires easily.” This may adversely affect social relationships, and in some cases even lead to depression. After correct diagnosis, the patient can now attribute these symptoms to gluten intake and formulate a strategy aimed at a glu-

ten-free way of life. If the patient succeeds in adopting new practices that eliminate gluten from the diet, in most cases the symptoms completely disappear. When the gut recovers, there is no easy way of distinguishing this person from a non-patient. The only indicative factor may be the gluten-free diet.

Dietary practice is ingrained with other habits, precisely *not* to be a patient, not to have to think about it. In CHAPTER 2 we saw an example of a patient who expressed her frustration with the diet as constantly having to think before she ate anything. When one is always a patient, always preoccupied with CD, it is a difficult predicament to deal with. Still, this is a reality for many CD patients. As was also emphasized in CHAPTER 2, occasional diet lapses are common for patients. Even if it says on the label that a product does not contain gluten, it could still be contaminated from other sources. These kinds of mistakes can have serious consequences, e.g. a patient may suffer for months because of inadvertent gluten intake.

Since the problem of CD is so complex, and so interwoven into the fabric of everyday life, the solution for it cannot be simple, as in e.g. a “traditional” disease that can be treated with a medicine. Since gluten is part and parcel of our food culture, so is having to avoid it. CHAPTER 4 shows that CD patients put innovations in a broader context and orient towards the social goals in which these innovations could play a role. Importantly, although any solution for CD starts with “just” a therapy, these social goals could form a critical avenue for future research.

Such research is placed alongside medical innovations like the anpep pill. As an alternative to the diet, these innovations have implications not just for CD patients’ everyday practices, but also for how they manage their (patient) identity. Faced with new medical and technical possibilities, it is not just a matter of retaining or discarding that identity. An identity is not a fixed “thing” that one can put on or take off like a jacket, but rather a set of concerns that is continuously invented, adapted, and improvised in response to ever-changing circumstances, and which itself can change in the process – what Oudshoorn calls co-creation of identity and technology (Oudshoorn, 2003). One of these concerns that the analysis of mealtime conversations with family members reveals is CD patients’ orientation towards self-determination. Given this orientation, it is important for innovators to respect the patients’ domain of everyday life as their own – to shape and make judgments about.

Health is an integrated concept, rather than something that is solely connected to a medical problem. From the patients’ perspective, it is not

separate from the rest of everyday life. As a result of investing a lot of time and effort, there is a group of patients who are happy with the diet and the patient may feel healthier than the doctor. So it is not only a solution for a narrow medical problem, but can also be a lifestyle, and just a way of living healthfully rather than a response to a disease. A diet can be a solution to a particular medical problem such as CD, but it can also be a boost for overall healthy living, consuming less alcohol, and increased exercise. In CHAPTER 4 we saw that patients construct for instance the an-pep pill not just as a solution for CD, but for everyday-life problems related to CD. For instance, the impact of not being able to eat the same as everyone else can affect one's relationship with co-workers.

Making the patient central is something that at the start of this thesis was still a slogan, has been developed in the literature, but is still a black box in terms of conceptualization. What exactly does it mean? Often innovators look at the patient from a technology-oriented perspective. This is a "contaminated gaze," a designer-oriented gaze. Science and technology studies (STS) offer solutions, but in most cases these solutions entail evaluations of (partly) developed technologies or of future scenarios. Therefore the detour taken in this thesis was required: *also* examining the patient in a situation where there is no question of innovation yet. And also in these situations, a close look at patients' talk in its own right, and the social goals it achieves, can lead to revealing insights. The study further looked at patients in deliberation exercises with innovators. Although this is an institutional setting, the focus on participants' talk in its own right revealed striking social actions that were performed by both patients and innovators, and the inherent structure of this kind of institutional setting. In other words, rather than taking the setting for granted, and treating patients' reactions to innovators' presentations of proposed medical technologies as expressing their attitudes or opinions, we also took into account the way in which these presentations were designed by the innovators to perform certain interactional activities. What we found was a persistent technology orientation: the focus was on offering technical solutions to patients rather than starting with the long-term identity and agency-related goals towards which patients orient. As we have seen, insight into these social goals by examining patients' talk in its own right is vital for delivering patient-centered care through medical innovation.

Recommendations

These insights suggest clear recommendations on the way the research perspective used here could supplement the traditional research on patients' centrality. The first is for CD researchers to become aware of their own assumptions about what constitutes a solution for CD patients. For instance, from a medical perspective, it may make sense to treat a disease as requiring a therapy. However, as we have seen, this is not something that can be taken as a given in the case of CD. Therefore, more discussion and study with CD patients about what exactly would constitute an improvement in their quality of life for them, and how innovations could contribute to this, is required. As we saw in CHAPTER 4, this could start with becoming aware of the technology orientation that seems to accompany being a medical researcher or a scientist. In everyday life, it may not be the medical or technological context that prevails for CD patients, but rather other social-interactional concerns that are not (yet) known to the researchers.

The second recommendation is not only to engage with patients on the basis of concrete research perspectives. Early interaction by engaging in explorative conversations with patients, even before any concrete research goals have been set, may provide invaluable insights about patients' everyday life and their long-term social goals. A quick scan could possibly contribute to innovations in CD treatment. Of course there is no neutral situation, and we always build on prior research, and the kind of research that can be done also depends on research in other fields; for instance, genetic markers that are found in genomics research or an enzyme that is already used in other products but now turns out to have a neutralizing effect on gluten.

One discussion in CD research that has been excluded from the research agenda concerns possible alternatives to a gluten-free diet. This discussion is particularly relevant as competing alternatives are emerging, such as a pill that allows patients to temporarily eat gluten, and new wheat races that are safe for patients to eat. As we saw in CHAPTER 4, these issues do come to the surface even if not part of the official agenda. This is particularly easy to see in the case of cochlear implants, for example (Blume, 2000). Deaf people at first rejected these because being able to hear would exclude them from the social environment in which they presently lived. The innovators in this case had not paid sufficient attention to the social world of the prospective users of this technology. For CD patients of course this is different, but potential alternatives still need to be examined and taken into account.

If the mission of the CDC is to improve the health-related quality of life of CD patients, they must find out first what exactly constitutes quality of life for CD patients. In this thesis, I have given some clues to this, but much more interaction with patients is necessary on this point. This question could also be embedded within the CD community, for instance within the association, amongst patients. Based on their discussions, these institutions could then offer valuable advice to the CDC about what for them would constitute real solutions.

Finally, there is the issue of how to involve patients in medical research. The call to make the patient central of course does not mean simply interviewing patients about what they want and letting this determine the research agenda. Medical research is not a deliberative process carried out by patients. However, when the goal is improving health-related quality of life, the patient needs to have a role in that. Medical researchers should have a sense of what motivates patients, how it is for them to have CD, and what would constitute an improvement in their health-related quality of life. As was said in the introduction to this thesis, sometimes it is necessary to take a detour to reach your destination.

Taking patients seriously does not mean taking what patients say at face value, but looking beneath the surface and taking into account the conversational context and background conversations. In this thesis, we did not just look at the level of arguments, but at the level of social goals. Patients do not so much “have” goals, but orient towards them as resources that they make relevant, or no longer relevant, in accounting for their actions, for instance in the light of technological and societal developments.

An example of this is the an-pep pill, which is currently in development and could potentially allow patients to safely eat gluten. Although a pill that would offer a permanent alternative to the diet is currently outside the realm of technical possibility, a pill that would allow patients to eat gluten once in a while, for a certain amount of time, is more likely to be the result of this innovation process. The assumption on the part of the innovators was that patients would want to use this pill on special occasions, for instance to take a break from the diet or for special occasions such as holidays. In the meetings with patients, which were the subject of CHAPTER 4, this did turn out to be the case for some patients, but a more pervasive concern emerged that for other patients would be a reason not to accept this once-in-a-while pill. One of these concerns was that the current situation in which patients simply do not eat gluten is clear, but that a situation in which the possibility exists to safely eat

gluten once in a while makes it complex. So in this case, one of the patients' social goals to which innovators assumed the innovation could contribute – to enjoy being able to eat gluten once in a while – is overridden by other social goals such as coping strategies having to be consistent and simple to execute. This point illustrates that everyday-life practice is a complex ensemble of social goals that are not easily accessed from the outside, even from the position of an involved and experienced medical professional. One may be able to see one goal that an innovation or treatment could contribute to, but fail to see another, superseding goal – such as having a treatment that does not make one stand out from one's social environment.

6.4.2 Evaluating discursive psychology as a technology assessment tool in practice

In CHAPTER 5, discursive psychology was presented as a technology assessment tool, a way of analyzing interactions with a focus on social action. Since this topic has been treated extensively in that chapter, here I would like to reflect on my own experiences of using discursive psychology in practice. During the research I gathered internet forum data, made recordings of CD patients' mealtime conversations, and of meetings between patients and CD researchers. As mentioned before, discursive psychology has not yet been used in this kind of setting. Discursive psychology is in development, and over the last years has been applied to new fields. It has been applied, for example, to medical interaction, such as doctor–patient talk, and to health-related contexts such as depression, obesity, or ME. However, as a technology assessment tool it has not yet been used, and it is one of the purposes of this thesis to do so. As with any new approach, there are challenges to be met.

One such challenge that I encountered while conducting this research was how to introduce this method in a primarily medical science environment. Discursive psychological analysis examines not just what people say, but what they *do* with saying what they are saying, i.e. the social actions they perform with their talk. This is different from cognitive approaches, in which what people say is treated as a window to their thoughts, feelings, and attitudes (Edwards & Potter, 2005). Discursive psychology is not so much interested in what people “really” think or feel, as in the particular function that their expressions fulfill within the interaction of which they are part. For instance, whereas from a cognitive perspective an utterance such as “I don't like this” is seen as an expres-

sion of that speaker disliking something, a discursive psychologist would ask why this person is saying this in the particular way it is said, at this particular moment in the interaction, and would proceed to examine the sequence of which this utterance is part, i.e. what has been said before and what is said after.

Another challenge that I encountered was on the level of presenting the results of discursive psychological analysis, which are multifaceted, and often have a different character than results that scientists are used to. For example, we were unable and did not want to formulate conclusions such as “X% of patients want Y innovation.” Instead, the conclusions were of a more subtle and fundamental level, pertaining for instance to the way of communicating with CD patients, their social goals. The results may help researchers to form a more complete picture of the environment in which they want to introduce their innovations and gain a deeper understanding of patients’ concerns.

For future discursive psychological research in these kinds of settings, I would recommend, first of all, making it clear from the start the kinds of results that discursive psychological analyses aim to achieve. Secondly, it is important to assess what happens if negative conclusions arise, or if unexpected results come up. For instance, one of the main insights deriving from the research in this thesis is that a lot more effort needs to be put into building up relationships with the patient community. This may not have been a result that was expected from this research.

Related to this point, my experience was that, as a DP researcher, I was also treated as a consultant and asked questions that were not directly related to this particular thesis research, for instance, being requested to find out what patients think about this or that CDC research product. The reason I usually could not answer those kinds of (immediate) questions, although I could see that they were very relevant for the particular situation at that moment, was not only that they were not within the scope of this project, but also because the kind of discursive psychological analysis that we used would be too “heavy” a tool for these kinds of relatively straightforward questions. Usually, my recommendation was to refer to another part of the societal research cluster of the CDC (see CHAPTER 1), e.g. to do a survey. However, I did experience the dilemma of being a researcher concerned with longer-term questions, and coming up often with subtle and fundamental points after a detailed analysis, which naturally takes some time to complete, and of being confronted with ad hoc questions from the field that I could see would be very relevant and interesting to answer. The methodological rigor and attention to detail of

discursive psychology is precisely what enables it to go beneath the surface and come up with results that are not discovered by other methods, and that are often about fundamental issues in communication. Yet, to be adaptable and relevant to changing situations that often occur in the field of emergent technologies, and to the actors operating in this field, a kind of discursive psychology “light” is required – one that is easier and quicker to use, while preserving its academic quality.

For the future of DP as a TA tool, I see two interesting ways in which it could be further developed and applied besides the way we have done in this research. The first is to use an adapted version of the discursive action method (DAM, see Lamerichs et al., 2009), in which participants in the interaction become analysts of their own discourse. Meetings between experts and prospective users could be recorded, and afterwards the parties could reflect together on the discursive strategies used. In this way, they could get more insight into their own and each other’s social actions, so as to come up with ways to improve the quality of future discussions. This can be done, I think, if beforehand there is a discussion in which a shared goal for all parties is established; in our case, for instance, maximizing the contribution of the CDC’s research to the improvement in CD patients’ quality of life. Given that communication between different parties is an essential element necessary to reach this goal, a series of meetings could be organized in which the DAM also has a place. In this case, the participants themselves – under the supervision of a DP specialist – become analysts.

The second strand in which DP could further be applied is the training of moderators for upstream engagement meetings, first and foremost taking into account that innovators come from a technology orientation, whereas users come from (their) everyday life. Such a moderator could intervene in the discussion, thematize these kinds of issues, and play a role in making each party understand and make explicit each other’s social goals. In the meetings examined in CHAPTER 4, it was the CDC members themselves who moderated the discussion. However, as we have seen, even the kind of questions that are posed shape the discussion: they co-define the relationship between the participants. Therefore it would be good to have someone trained in leading discussions about emergent technologies who has no interest in a particular outcome, and who focuses not so much on the content of the discussion as on the process.

6.4.3 Emergent technologies and prospective users: adding a discursive psychological perspective

Although users of proposed technologies usually come into the picture only at the very end of the innovation process, in the past decades the emphasis has been on upstream engagement: including prospective users at a stage where the technology is still being developed, preferably as early as possible. It was recognized that users do not only play a role after the product has already been developed and needs to be marketed, but that different versions of prospective users are already inscribed in technologies from the very beginning of the innovation trial. In this thesis, examining the everyday life of prospective users, by examining their interactional practices in situations that would be impacted by the introduction of these technologies, was presented as a method to gain insight into the user perspective at an earlier stage.

In CHAPTER 1, two barriers to upstream engagement have been described. The first is the Collingridge dilemma. Early on in the development stage, the technology is still too abstract and uncertain for prospective users to give meaningful feedback. The product could develop in many different ways, and it is too early to tell which way is the most probable. But when the technology has been more developed and is more concrete, due to path dependency there is little room to make adjustments, so at this stage user involvement would be futile.

The second barrier is the persistence of a deficit model of public understanding of science. From the point of view of innovators, involving the public at an early stage of the development of new technologies can be beneficial in the sense that it increases public trust and the legitimacy of these technologies. However, it also exposes the assumptions, values, and visions of science to criticism. In response to this criticism, scientists often respond with the argument that non-experts know too little about science and technology, or trust them too little, to make valid judgments, and that this should be left to technologists and ethicists. Before non-experts can participate in innovation processes, they first need to be educated. In this view, the main purpose of public engagement is to validate a proposed innovation, e.g. by gaining public trust or relieving concerns. Resistance to technology is explained as irrational resistance to change, or lack of understanding and expertise.

In recent years, many efforts have been made either to criticize these barriers as fictional, self-fulfilling prophecies, or to find solutions for them where they proved to be empirical realities. In many of these

studies, the importance of discourse has been emphasized, and various discourse analytic approaches have yielded valuable insights. The research undertaken in this thesis aimed to make a contribution to this debate in three ways:

1. The field: examining emergent technologies in a setting where there were different innovations at various stages of development, where there were resources to undertake interdisciplinary research of a medical problem, and willingness and initiatives to include the patients' perspectives. In addition, the medical problem had a unique character that made it a complex problem for which no ready-made solutions were available.
2. The research setting: rather than taking the proposed innovations as a starting point, the approach taken in this thesis was to start with the everyday life of prospective users – in this case patients – even without the technology necessarily having to be thematized. This is different from previous approaches, which mainly concentrated on the technology in use or as an explicit topic of conversation.
3. The approach: using a discursive psychological approach allowed the research first of all to be guided by the everyday concerns of stakeholders in the innovation process and, secondly, to focus on the social actions performed by participants, highlighting the way descriptions and accounts (whether technology related or not) were used to accomplish social and interactional goals.

The pilot study conducted for this thesis (te Molder et al., submitted) and CHAPTER 4 showed some interesting insights relating to the deficit model. These analyses showed that the way innovators approached patients also made relevant a certain kind of response. A researcher who asked how much patients would pay for a potential pill that would allow them to eat gluten received mixed responses; this could be seen as indicative of resistance to change. However, the analysis of this discussion revealed that the patients resisted the implication that patients would accept such a pill without question, and other assumptions implicit in the researcher's question. The analysis of discussions between researchers and patients showed that seemingly factual introductions of a proposed technology to prospective users by scientists already contained certain assumptions about patients and the way they would use it, and preferences for the kind of responses to the technology. Again, the response

could be explained as a response to the way scientists approached patients rather than to the technology itself.

In previous literature, the deficit model has been described as a manner or cultural attitude by which scientists approach the public, namely, as lacking the necessary expertise or trust. The public may resist the technology orientation of the scientists, and this may then be treated by scientists as a criticism of the proposed innovations, on irrational grounds. The public, for their part, may deploy their own deficit model in which the scientists are seen as lacking the everyday-life expertise necessary, for instance, to understand what it is like to be a CD patient every day. This cycle may be broken if attention is paid to the social goals of both parties. Interaction between members of science and of society in different settings has already been examined, but this thesis contributes to the literature by looking at the level of social action rather than the level of arguments.

The interesting thing about the situation that we examined was that the members of CDC did not fit the stereotype of traditional scientists in an ivory tower/laboratory. They initiated this research themselves, and were open and involved in taking patients' perspectives into account. Despite this, we found a persistent technology orientation. This shows how embedded and fundamental this is, and that it is not necessarily (just) a matter of having the best intentions to actually involve users.

As a response to the Collingridge dilemma, which problematizes involvement of users in the development phase of innovations, we have suggested studying prospective users' everyday life separate from the particular technology in question. In CHAPTERS 2 and 3, we examined natural interaction where the technology did not yet play a role. This allowed us to get a sense of patients' everyday practices without the presence of the technology. Not only is it impossible to ask questions or ask for reactions to a proposed innovation without introducing certain framings and assumptions, but also doing so acts as something around which the discussion converges, almost as an "attractor" in systems theory. Naturally people get excited or at least are interested in new technological possibilities, especially if these may affect them personally and possibly even improve their quality of life. This may be compared to the moment at which a teacher mentions that the class will have a break in five minutes, after which he will find that his has lost the students' attention and may as well take a break right away. Therefore, taking a detour by examining situations in which the technology is not present can show things that we would normally not see.

The benefit of studying patients' everyday life separate from the technology that is intended to be used is that one can get a sense of the background in which it will be introduced. In Chapter 4, the technology existed or was anticipated, and we saw right away a different orientation on the part of both experts and patients. There was a focus not on the technology as such, but on a specific presentation of it. What exactly it was in that technology that might constitute an innovation from the perspective of prospective users had already been defined by the experts in a particular way. One cannot avoid introducing certain assumptions about the technology, suggesting or preferring certain uses. It is not just the technology itself, but also the many assumptions that come with it and to which patients then react. This is not to say, however, that these scripts cannot be resisted and reformulated by users. In cases that orient towards the technology, it is crucial to treat participants' talk about the technology as talk in its own right, with a view to assessing what social goals can be achieved by patients' reactions to the technology. When people reject a certain technology, this should not be taken simply as a reflection of their state of mind, i.e. as proof that people do not want this technology, or that they have a negative attitude towards it. Rather, we should consider the social goals that these kinds of rejections are designed to achieve. As we have seen, a medical technology can be rejected, for instance, not necessarily because people do not like the technology in itself, but because they reject the way it portrays them as passive patients, or the way it suggests that their problems are uncomplicated because they can be solved with a simple technology. Treating participants' talk about technology as talk in its own right therefore means not treating their talk *only* as a reaction to a technology, but also as a speech act performing actions in the context of everyday life.

6.5 Suggestions for future research

The research presented in this thesis has opened new avenues in three ways. Firstly, it has established a tentative agenda for research on CD and ways in which CD patients and researchers can cooperate to come up with ways to improve CD patients' health-related quality of life. Secondly, the research points to the possibility of discursive psychology being developed further as a technology assessment tool and applied in other settings with other innovations. In this respect, it has to be noted that in the particular situation examined in this thesis it was obvious who the prospective users of the innovations were. However, this is not always – and perhaps not of-

ten – the case. Many emergent technologies, such as for instance nanotechnologies, are being developed without it being clear who the users of this technology will be. The approach we have taken requires the analyst to select some specific everyday-life situations that are expected to produce relevant data. When it is not clear who exactly the prospective users are and what situations of their lives proposed innovations are expected to impact, choosing these situations will not be as relatively straightforward as in the research presented in this thesis. We have seen that for CD patients the social environment – strictly speaking nonusers of the medical technologies – is very relevant. Concentrating only on users is also essentially a technology-oriented perspective, in which people not using a technology but still impacted by its consequences are neglected. An example of this is also found in controversial technologies such as cloning or stem cell research. In this case, there can be ethical considerations for society as a whole, and resistance from those who are practically speaking not impacted by this technology. Therefore in future research, two questions that must be considered are, how to examine the everyday life of prospective users if it is not clear who these users are, and what kinds of interaction to study if one wants to take nonusers into account.

Thirdly, there is more discursive psychological and conversation analytical research that could be done on the basis of the studies presented in this thesis. The importance of language for technological innovation has been demonstrated in a variety of ways. We have seen, for instance, that something as seemingly simple as the framing of a question may embody the social relationships and the quality of interaction between innovators and users. The way question design indexes the relationship between different stakeholders in the innovation process is an area that needs to be further explored, as well as how other discursive strategies construct the innovation process. Language shapes the world, including technological innovation. A concept such as “gluten” may be associated with completely different actions for a CD researcher and a patient. The extent to which this happens is not always immediately obvious, as language is to us as water to the fish. Therefore a “detour” is needed, consisting of a close investigation of what actually goes on in the conversations through which the innovation process is conducted, including the everyday conversations of prospective users. This thesis has illustrated how there may be a field of fruitful future study somewhere between fundamental questions about the use of language that are addressed in discursive psychology and conversation analysis, and the issue of how to incorporate the view of prospective users in the innovation process.

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**APPENDIX I:
TRANSCRIPTION NOTATION**

**APPENDIX II:
ORIGINAL DUTCH FRAGMENTS**

APPENDIX I

TRANSCRIPTION NOTATION

[text]	Overlapping speech
(x.x)	Pause of x.x seconds
(.)	Micropause, less than 0.2 seconds
(text)	Speech unclear
()	Unintelligible speech
↑word, ↓word	Onset of noticeable pitch rise or fall
wo:rd	Colons show that the speaker has stretched the preceding sound
word	Louder and emphasised
>text<	Fast speaking
° text °	A passage of talk noticeably softer than surrounding talk
((text))	Transcriber's remarks
=	No pause between words, latching of contiguous utterances
.hh	Audible breath

The transcription notation employed for the data fragments presented in this thesis is an adapted version of Jeffersonian Transcription Notation (Jefferson, 2004).

APPENDIX II

ORIGINAL DUTCH FRAGMENTS

Fragments from chapter 3

Extract I

Moth: Zeg ik heb nog ook eh hh van
die ↑crackertjes gekocht (.)
die oma altijd heeft voor jou
(.) Als het [goeh↓]

Pasc: [Jee:h↑]

Moth: Lust jij glutenvrij
crackertje?

Pasc: Ja:haah
(1.2)
Welke o:ma
(0.3)

Moth: Oma Barbara
(*(30 seconds omitted. speaking
about grandparent coming to visit)*)

Moth: Kijk eens ↓deze
(1.4)

Vind=je=die ↓lekker?

Pasc: Ja ik wil [↓eentje van]
[[*(Sound opening)*
crackers]]

Moth: Ja daar °mag je der ↓eentje
van°

Extract 2

Moth: Die is ook ↓lekker
 ((*She means the muesli they bought*))

Pasc: Huhh↓
 (0.3)
 die allemaa:hl
 (1.5)

Moth: Okay?
 ((*sound of opening crackers*))
 (2.4)

Moth: °Vind je die lekker schat°=
Pasc: °=jah°
Moth: °Nou pak die maar deruit°
 (1.7)
 H↑mm?

Extract 3

Moth: ↑Lekker?
 (1.5)

Zuza: Die ↑ro:ze is het
 ↓lekkerste

Moth: Die is wel ↑zoet he (.) de
 andere is yoghurt
 (0.7)

Zuza: Jah↓

Extract 4

Mash: We moeten ook=even
uitkijken met die
 kruidenboter vrijdag
 (0.7)
 Misschien kan=ik die ook
 wel zelf maken

Moth: Ja:hh zelf ↓maken

Mash: Zelfs ook nog ↑lekkerder
 (1.0)

Moth: Jah↓ Moet even kij:ken wat
 we=er=zelf voor nodig
 ↓hebben

Extract 5

Moth: Wat hadden we nou
 afgespro↑ken (.) dat we niet
 spullen (.) niet je vingers in
 je mond zouden ↓stoppen
 (0.5)

Ja dat vindt ze ↑lekker

Zuza: °Dat vind ik le:kker°
 (4.6)

Moth: Wat kon=er=ook=alweer aan
 je vingers ↑zitten dan
 (0.6)

als je geklei::d of
 geve::rfd hebt?

Zuza: °Ik heb niet ge↓kleid.°

Extract 6

Moth: En maar Li↑vaad
 (0.5)
 zag ze niet derop. (.)
 Kon ze niet vinden (.)
 Hebben ze=der maar niet
 ingedaan (.) Pfff

Pasc: Jah↓
 (2.6)

Moth: Als we het niet ↑zeker
 weten he Pa↑scal (.) of er
 gluten inzitten dan doen we
 het niet=he?

Pasc: °↓Nee°

Moth: Mjah↓

Extract 7

Mari: Ik wil de echte chocolade.

Sis: Moet je dan (.) neem=je dan
 met ↑noo:tjes?

Mari: Jahh met no[otjes]

Moth: [Oh ja]

Mari: ja:h die vind=ik=ook lekkerder
 als die andere

Extract 8

Moth: Ik (.) ik ↑dacht dat we dit
al eerder hebben
opgezocht=mama wil=even
voor de zekerheid opzoeken
of jij het echt mag hebben,
Pas↓cal

Pasc: Mag ik (.) mag ik ↑echt
hebben ↑ho::or

Moth: Ja dat denk ik ook (.) maar
ik moet eerst (.) je moet het
nog even niet openmaken (.) Ik
dach=dat jij het mag he↑bben
nog even dichtlaten mama gaat
het °nu weer nakijken°

Pasc: Maar het is le:kker

Moth: °Ja=het=is=lekker=maar=je=
moet=er afblijven.°

Extract 9

Pasc: Mag ik (hem) nu ↓hebben

Moth: Ja (.) je mag hem hebben
(.) anders had mama hem
niet gekocht als ik dacht
dat je=hem=niet=mog
↓hebben
(0.7)
Maar ik wilde het toch even
zeker weten (.) kom=maar
(.) Zal ik hem open↑maken?
(4.5)
Mama vindt deze ook heel
erg lekk↓er

Extract 10

Mari: Oh maar ik heb laatst ook
Ma:rs geg[eten.]

Sis: [Ik] heb de
↑laatste ↑tijd echt
gesnoept .hh

Moth: Mah:rs?=-

Mari: =Ja ik mag Mars.
(1.6)

Moth: Ik vond dan wel leuk als
ook Mars had meegenomen van
de::h tennis
(0.6)
[Da-]

Mari: [Ja]
maar ik deed ook gewoon
telkens=een=stukje=der=
afsnijen

Fragments from Chapter 4

Fragment I

P1 Jullie willen dus werkelijk weten wat we daarvan ↓vinden van zo'n pil. (1.5)

Ex Ja dat is voor ons een eh hele relevante vraag. (.)°Jah° (0.7)
Ik kan me voorstellen=↑heh. Ik ho:or hier natuurlijk van jah, het dieet gaat prima maar het is moeilijk. Ehh. Lastig om te accepteren. Eh hh↓hh. (.) Vakantie vervelend. Eh hh nou=ja de vraag is gewoon (1.8) stel dus nou dat er zo'n pil komt. En zo'n pil blijkt helemaal veilig te zijn. (2.1) Gaan de patienten die dan gebr↑uiken (.) of eh hh zitten wij gezellig iets teh hh te ontwikkele[hhh]

P4 [Dat zien we] van↑ze:lf
wel, hehehehh
(*laughter*)

P4 Jah[ahh]

P2 [Ja] ik denk dat het heel erg uitmaakt hoe je hem gebruikt. Want ik denk dat het dieet in de zin van eh (.) nou sorry hoor nu e:ven niet, dat (0.4) lijkt mij veel la:stiger dan dat je (.) weet van nou, >mag ↑niet< da's duidelijk, ↓klaar. Dus ik zal eh hh ja, voor het gemak dus even, dat is (.) voor jezelf is het lastig, °want, zoiets°, ja het hoeft net niet, ik hoef niet zo-g zo trouw te zijn, want ik heb wat anders, dat geeft een heel ander gevoel dan ik weet nu waar ik aan toe ben ik moet het niet ↓eten want >als ik het eet< word ik ziek. (1.0) Dus dan heb ik zoiets van als er iets is dan zou ik graag iets hebben wat me nou over de hele ↑linie ervanaf- want eh () >zo nu en dan< da- ja daar heb ik niks mee.
(1.0)

Ex Ja.

P3 Ja altijd of niet altijd.

P2 Ja, altijd of niet.

Fragment 2

P1 Wat is die vraag? (0.4)

Ex De vraag:g was van (.) zou je dat dan altijd willen ne:men? Als eh=die pil er was, en die is – die is veilig en die werkt ↓honderd procent.

P2 °En dus maar gluten eten [dus.]°

Ex [Zou] je dan elke dag voordat jehhhh iets ging eten die pil nemen, stel. Dat je bij >drie keer per dag< eten drie keer per dag dus die pil vantevoren neemt.

P2 Alleen als het bij ↑gluten is.(0.9)

P1 Nee ik kook hartstikke ↑lekker, er gaat >niks niet< zoveel veranderen.
(1.4)

P2 Nee maar °voor (0.4) ja°

Fragment 3

Ex Als we even teruggaan [naar] die- naar die pil [van] (0.4)
Zouden

P1 [jah] [jah]

Ex jullie die gewoon ehhe kopen?
(0.9)

Ex Als die: gewoon veilig was, ↑he, ↓stel, hij is [veilig.]

P1 [oh zeker]

Ex Hij- [hij is] beschikbaar, en zou

P2 [ja.]

Ex je die ook (.) elke dag dan? =

P1 =Dat denk ik niet. (0.7) Ik denk dat ik hem zou nemen als (.)↓nou ja eh als je een keer bijzonder wil eten of als ik op bezoek ga: of (1.2) maar gewoon voor het dagelijks le:ven denk ik niet dat ik hem elke dag zou ge↓bruiken. (1.5) Maar (.)°wie ben ik.°

P2 Het gaat om de spontane dingen, vind ik, die (.) moeilijk zijn.

Fragment 4

- P1 En we zullen ons ook met zijn allen hard moeten maken (1.0) om dat eh^h op een of andere manier eh^h te laten doordringen dat wij dat no[↑]dig hebben.
(*group agrees*)
- P1 En dat we niet altijd achter het aanrecht hoeven te staan drie keer zo lang als een ander.
(*group laughs*)
- P1 En veel meer geld hoeven uit te geven in de gezondheidszorg.
(*group laughs*)
- P5 Aan de andere kant, () als jij gewoon je:- netjes je groente en je aardappelen en je [vleesje erbij] maakt (.) ja dan heb je het ook niet [↑]nodig.=
- P2 [ja dat is ook] zo.
- P1 =Nee maar je zal drie kinderen hebben.
- P5 Ja maar, maar dan eh^h (1.2) er is heel veel eh wat je [↑]wel kan eten. Ook al heb je een glutenallergie er zijn heleboel dingen die je wel kunt eten.
- P1 Jawel maar ook een [↑]heleboel [↓]niet.
- P5 Jawel maar, [maar]
- P1 [Als je] twee broo:dmaaltijden per dag eet wat de meeste=mensen [↓]doen.
(0.7)
- P5 Ja goed dat- daar kun je- ik ben zelf nog steeds niet zo. Ik ben nooit een fan van brood geweest ook niet voordat ik eh^h glutenvrij (0.3) at, zeg maar. Ik (.) ja ik ontbijt nog steeds met een eh^h bakje [↓]yoghurt (0.4) en wat fruit erin. [↑]Jah.
(0.6) Het is ook net wat je- wat je jezelf aan [↑]we:nt zeg maar.
(1.0)
- P2 Het zal vooral voor mij gemakkelijker worden.=
- P1 =°Ja. °=
- P2 =Ik ben het eens je kunt inmiddels gewoon heel lekker eten ook als je gl[utenvrij eet.]
- P1 [Hm hm]
(0.7)
- P2 Alleen eh^h je moet co:nstant (.) erover na:denken en een beetje vooruit plennen. En nou is dat is ook wel (.) te doen.
(0.6) Maar in dat licht zo'n pil >zou ik denken< [↑]goh (.) dat zou wel eens een keer [↑]lekker.

((group agrees))

- P6** Dan zou ik ook bijvoorbeeld als ik aan het koken ben in tijd de boterhammen vast voor mijn kinderen kunnen sme:ren (.) zonder eh twee keer mijn handen te moeten wassen. (2.1)
Alles eromheen.
(1.2)
De besmetting.
-

Fragment 5

- Ex** Jij zei dat je (.) gevoelsmatig heel veel problemen zou hebben met het nemen van een pizza met een (.) pil.
- P5** Ja.
(0.7)
- Ex** [Maar dat]
- P5** [Maar ik]denk dat dat ?ehh (0.6) kijk als je een medicijn hebt waarmee je altijd weer gluten kan eten (1.2) ja (.) °dat.°
(0.4)
- Ex** Dat heft dat dan weer op.
(1.0)
- P5** Dat is weer wat a:nders=maar ik zou ↑niet ehhhh (0.3) de ene dag eh een glutenvrije maaltijd kunnen nemen en de andere dag een pizza die vol dus (.) met gluten zit.
- Ex** Hm [hm]
- P5** [Wa]nt (1.8) nee, ik denk dat ik toch de::, ik zou dan toch de pizza gewoon laten ↓staan.
(1.6)
- Ex** Maa:r heeft dat ook een beetje te maken met het feit dat je: zeg maa:r (.) geconditioneerd ↑bent op ehhe bepaalde dinge:n, dat is gewoon taboe, moet je niet doen?
(1.0)
- P5** ↑Ja, dat denk ik wel. Gewoon eh (0.6) ja (0.5) dat zou ook gewoon (.) eng zijn om te eten.
-

SUMMARY

SAMENVATTING

SUMMARY

This thesis deals with the question of how to incorporate the perspective of those who will be affected by a certain technology in the development of that technology. Common approaches either invite prospective users to take on the role of the innovators and assess presentations of future technologies from that perspective, or examine how technologies are used by people in their everyday context. Instead, our approach starts with the everyday life of prospective users and examines the practices on which technologies will be expected to have an impact. In this way, issues that shape users' perspectives on new technologies, but that are in themselves not related to those technologies, can be uncovered. To illustrate our approach, emergent medical technologies in the field of celiac disease are examined.

Celiac disease is an affliction of the small intestine from which about 1% of Indo-European populations suffer. At the time of writing, the only available treatment for celiac disease is a lifelong gluten-free diet. Celiac disease can have a profound impact on patients' lives not only because of its physical symptoms, but also because of the social and psychological difficulties of avoiding gluten in an environment in which it is a common ingredient in many foods.

The goals of the Celiac Disease Consortium (CDC) are the development of improved diagnostic procedures, novel therapeutics, and safer foods for celiac disease patients. To guide and implement the CDC's work, a clear understanding of how patients are affected by celiac disease is needed. However, although there are studies about general social and psychological consequences, little is known about how celiac disease actually affects patients in the course of their everyday life.

The research presented in this thesis aims to gain insight into this issue by means of a detailed examination of patients' conversational practices. Examining how patients construct disease and diet in interaction with others reveals deeper concerns that will play a role in the development and implementation of CDC research products. Therefore we examine patients' internet discussions with fellow patients, mealtime conversations with close relatives, and discussions about new research developments with CDC innovators.

The data collection and analysis in this thesis is based on the discursive psychological approach developed in the 1990s by British social psychologists, Derek Edwards and Jonathan Potter. Discursive psychology examines how the accounts and descriptions of the world that people construct in the course of their interactions are used to accomplish social goals. It analyzes talk from a perspective of its function in the interaction rather than what thoughts, feelings, or opinions of the participants it might reflect.

Chapter 2 is a study of how celiac disease patients treat the risk of gluten intake in an internet discussion with fellow patients. Since gluten is present in many daily foods, often undetectably, gluten contamination and the occurrence of symptoms attached to it are a daily reality for most patients. Coping studies on celiac disease provide interesting insights on how the diet is generally perceived by patients, but it is mostly viewed as an essentially individual accomplishment, and not much is known about how patients actually cope with the diet in their daily practices. Knowledge of these practices is crucial for innovations that aim to provide an alternative to, or even completely replace, the gluten-free diet. Data were gathered on naturally occurring discussions between celiac disease patients on internet discussion forums, because the internet is one of the primary sources of information for celiac disease patients.

Our analysis shows that patients treat dietary practice as a collective rather than an individual phenomenon. In response to a patient who threatens to quit the diet, they narrate their own experiences with frustration in a way that suggests that it is an insufficient reason to quit the diet altogether and instead a context of manageability needs to be found. In addition, they construct occasional diet lapses as occurrences within dietary practice rather than something that is inconsistent with it. In this way, the diet is established not only as a matter of course, but also as a black/white scenario in which one either follows the diet or does not, and there is no in-between option. Some of the innovations that might result from CDC research, such as a pill that temporarily allows patients to eat gluten, or wheat races that contain gluten but are safe for celiac disease patients, will blur this distinction, which is now clear-cut. If these issues are not properly addressed, there might be problems in integrating these innovations into daily life because they are inconsistent with the current context of coping with celiac disease.

Although it is recognized that the gluten-free diet has many social implications for celiac disease patients, not much is known about how they actually manage these implications in their everyday interactions.

Chapter 3 examines how dietary restrictions are treated by patients and their families. Data were taken from recorded mealtime conversations of seven families with children suffering from celiac disease and analyzed using discursive psychology. We found two main discursive strategies by which patients and their families manage the diet during mealtime interactions. Tastiness, rather than health aspects of the food, was used as an ultimate account for eating it; and by softening denial of food, the diet was normalized and treated as a shared family practice. The analysis shows that the gluten-free diet is demedicalized and treated as a matter of choice rather than prescription. We conclude with practical implications of these findings.

Chapter 4 examines expert–patient discussions about emergent medical technologies in the field of celiac disease. Using a discursive psychological approach, we analyze these meetings with regard to the social actions performed by both experts and patients. We find that, whereas the innovators treat the proposed technology as a given and restrict the topic agenda to discussing possible adaptations, patients address wider questions such as how to construct the proposed technologies in terms of implications for their everyday life. We conclude that, even if innovators are willing to engage in discussions with prospective users about proposed innovations, a persistent technology orientation may stand in the way of fruitful interaction.

In contrast to the preceding chapter, Chapter 5 explores the methodological possibilities of discursive psychology as a technology assessment tool. To understand prospective users' reactions to emergent technologies, it is crucial to examine the interactional contexts within which these reactions take place as people's reactions are shaped by issues that are not necessarily related to science or technology. These issues are often overshadowed or remain blind spots when descriptions or scenarios of proposed technologies are thematized as being the core objects of reference. We therefore recommend also studying prospective users' everyday-life practices in their own right, and in naturalistic settings. Insight into the social actions people accomplish in their everyday talk, such as establishing a particular identity, can help innovators translate prospective users' concerns into relevant technology characteristics. We propose discursive psychology as an analytic tool to do this and show its merits with a few illustrative examples based on the preceding analyses in this thesis. In Chapter 6 we discuss conclusions, points of discussion, and implications of the research presented in this thesis for the question of assessing emergent technologies from a users' perspective.

SAMENVATTING**GLUTEN, PILLEN EN GESPREK:
HET BEOORDELEN VAN OPKOMENDE TECHNOLOGIËN
VANUIT EEN PATIENTENPERSPECTIEF**

Dit proefschrift behandelt de vraag hoe het perspectief van degene wiens leven door een nieuwe technologie beïnvloed wordt, in de ontwikkeling van deze technologie betrokken kan worden. Bestaande methoden nodigen ofwel beoogde gebruikers uit om de rol van innovator op zich te nemen en vanuit dat perspectief een technologie te beoordelen, of ze onderzoeken de technologie als deze al in gebruik is. In contrast met deze methoden begint onze benadering met het alledaagse leven van beoogde gebruikers en onderzoekt de praktijken die nieuwe technologieën naar verwachting zullen beïnvloeden. Op deze manier kunnen zaken worden ontdekt die het perspectief van gebruikers op nieuwe technologieën vormen, maar die zelf niet direct aan technologie gerelateerd zijn. Deze benadering wordt vorm gegeven aan de hand van opkomende medische technologie op het gebied van coeliakie onderzoek.

Coeliakie is een aandoening van de dunne darm waar ongeveer 1% van Indo-Europese populaties aan lijdt. Op dit moment is een levenslang glutenvrij dieet de enige beschikbare oplossing voor coeliakie patiënten. Coeliakie kan een grote invloed hebben op het leven van patiënten, niet alleen vanwege lichamelijke, maar ook vanwege sociale en psychologische problemen bij het vermijden van gluten in een omgeving waar het een veelvoorkomend ingrediënt is.

De doelstelling van het Celiac Disease Consortium (CDC) is de ontwikkeling van verbeterde diagnostische procedures, nieuwe therapieën en veiligere voeding voor coeliakiepatiënten. Hoewel er echter studies zijn gedaan gericht op de algemene sociale en psychologische gevolgen van coeliakie, is er weinig bekend over hoe coeliakie patiënten daadwerkelijk in hun dagelijkse leven treft.

Het onderzoek dat in dit proefschrift wordt gepresenteerd heeft tot doel inzicht te krijgen in deze kwestie door middel van een gedetailleerd onderzoek naar alledaagse gesprekken van patiënten. Onderzoek naar hoe patiënten ziekte en dieet construeren in interactie met anderen leidt tot diepere vraagstukken die een rol zullen spelen in de ontwikkeling en uitvoering van onderzoeksproducten van het CDC. Daarom onderzoeken we internet gesprekken van patiënten met medepatiënten, maaltijdgesprekken met naaste familie, en discussies met

innovatoren over nieuwe ontwikkeling op het gebied van coeliakie onderzoek.

De methode van datacollectie en analyse in dit proefschrift is gebaseerd op de discursieve psychologische benadering die in de jaren '90 is ontwikkeld door de Britse sociaal psychologen Derek Edwards en Jonathan Potter. Discursieve psychologie is een manier van het analyseren van gesprekken die bestudeert hoe verklaringen en beschrijvingen van de wereld die mensen tijdens hun interacties construeren worden gebruikt om sociale doelen te bereiken. Discursieve psychologie analyseert hoe mensen spreken vanuit het perspectief van de *functie* die het heeft in de interactie, in plaats van wat voor gedachten, gevoelens of meningen van de sprekers het zou kunnen weerspiegelen.

Hoofdstuk 2 is een studie naar hoe coeliakiepatiënten het risico van gluteninname behandelen in een internetdiscussie met medepatiënten. Aangezien veel alledaagse voedingsmiddelen gluten bevatten, vaak zonder dat dit vermeld wordt, zijn glutenbesmetting en het optreden van klachten een dagelijkse realiteit voor de meeste patiënten. Hoewel studies naar de manier waarop patiënten met coeliakie omgaan inzicht verschaffen over hoe het dieet in algemene zin door patiënten wordt behandeld, wordt het dieet in deze studies meestal gezien als een individuele kwestie, en er is weinig bekend over hoe patiënten daadwerkelijk in de praktijk met het dieet omgaan. Kennis van deze praktijken is van cruciaal belang voor innovaties die beogen een alternatief naast, of voor het dieet te bieden. De gegevens voor deze studie bestaan uit discussies tussen coeliakiepatiënten op internet discussie forums, omdat internet een van de belangrijkste informatiebronnen is voor coeliakiepatiënten.

Onze analyse laat zien dat patiënten het dieet als een collectief fenomeen behandelen, en niet als een individuele kwestie. Als reactie op een vraag van een patiënt die dreigt te stoppen met het dieet delen ze hun eigen ervaringen met dieetfrustraties op een manier die suggereert dat deze onvoldoende redenen zijn om te stoppen, en dat in plaats daarvan een werkbare context moet worden gezocht. Daarnaast formuleren ze incidentele afwijkingen van het dieet als deel van dat dieet, in plaats van als iets dat ermee in strijd is. Hiermee wordt het dieet niet alleen als een vanzelfsprekende zaak geconstrueerd, maar ook als een zwart/wit scenario waarin men ofwel het dieet volgt of niet, en waarin geen tussenoptie bestaat. Een aantal innovaties die zouden kunnen voortkomen uit CDC onderzoek, zoals een pil die patiënten in staat stelt om tijdelijk gluten te eten, of tarwerassen die gluten bevatten die veilig zijn voor coeliakiepatiënten, zullen dit nu duidelijke onderscheid vertroebelen. Als hiermee

niet goed rekening wordt gehouden kunnen er problemen ontstaan bij de integratie van deze innovaties in het dagelijks leven, omdat ze strijdig zijn met de context waarin nu met coeliakie omgegaan wordt.

Hoewel het bekend is dat het glutenvrije dieet vergaande maatschappelijke implicaties kan hebben voor coeliakiepatiënten, is er niet veel bekend over hoe ze met deze gevolgen omgaan in hun alledaagse interacties. Hoofdstuk 3 onderzoekt hoe dieetbeperkingen worden behandeld door patiënten en hun familieleden. De onderzoeksgegevens bestaan uit opgenomen maaltijdgesprekken van zeven gezinnen met kinderen die lijden aan coeliakie, welke werden geanalyseerd met behulp van discursieve psychologie. We vonden twee belangrijke strategieën waarmee patiënten en hun families het dieet werkbaar maken tijdens maaltijdinteracties. De smaak, en niet het gezondheidsaspect van het eten, werd gebruikt als de uiteindelijke reden om het te eten. Daarnaast werd door het weigeren van voedsel af te zwakken het dieet genormaliseerd en behandeld als een gezamenlijke familie activiteit. De analyse toont aan dat het glutenvrij dieet wordt gedemedicaliseerd en behandeld als een kwestie van eigen keuze in plaats van een gezondheidsvoorschrift. Wij concluderen met praktische implicaties van deze bevindingen.

Hoofdstuk 4 onderzoekt discussies tussen experts en patiënten over toekomstige medische technologieën op het gebied van coeliakie. Met behulp van discursieve psychologie analyseren we deze bijeenkomsten met betrekking tot de sociale handelingen die worden verricht door zowel deskundigen als patiënten. De analyse laat zien dat de innovatoren de voorgestelde technologie als gegeven behandelen en de agenda beperken tot het bespreken van eventuele aanpassingen, patiënten bredere vragen stellen zoals hoe de voorgestelde technologieën te construeren in termen van de gevolgen voor hun dagelijks leven. We concluderen dat zelfs als innovatoren wel bereid zijn om over innovaties in gesprek te treden met beoogde gebruikers, een hardnekkige technologieoriëntatie in de weg kan staan van een vruchtbare interactie tussen beide partijen.

In tegenstelling tot de voorgaande hoofdstukken onderzoekt hoofdstuk 5 de methodologische mogelijkheden van discursieve psychologie als een technology assessment tool. Om reacties van beoogde gebruikers op opkomende technologieën te begrijpen is het cruciaal om de interactionele contexten waarbinnen deze reacties plaatsvinden te onderzoeken, omdat deze reacties worden gevormd door zaken die niet noodzakelijkerwijs verband houden met wetenschap of technologie. Dit soort zaken worden vaak overschaduwd of blijven blinde vlekken wanneer beschrijvingen of scenario's van toekomstige technologieën worden gebruikt als

centraal referentiepunt. Wij adviseren daarom ook de huidige dagelijkse praktijken van beoogde gebruikers in hun eigen recht, en in naturalistische settings, te bestuderen. Inzicht in de sociale acties die mensen bereiken in hun dagelijkse gesprekken, zoals het in stand houden van een bepaalde identiteit, kan innovatoren helpen in het vertalen van de overwegingen van beoogde gebruikers in relevante technologie kenmerken. Wij bieden discursieve psychologie aan als analytisch instrument om dit te doen en laten op basis van de voorgaande analyses in dit proefschrift een aantal illustratieve voorbeelden zien. In hoofdstuk 6 bespreken we de conclusies, discussiepunten, en implicaties van dit onderzoek voor de vraag hoe opkomende technologie beoordeeld moet worden vanuit het perspectief van de gebruiker.

LIST OF PUBLICATIONS

**CURRICULUM
VITAE**

**COMPLETED TRAINING AND
SUPERVISION PLAN**

LIST OF PUBLICATIONS

Journal articles

Veen, M., te Molder, H., Gremmen, B., & Van Woerkum, C. (2010). Quitting is not an option: An analysis of online diet talk between celiac disease patients. *Health (London)* 14(1), 23–40.

Veen, M., Gremmen, B., te Molder, H., & van Woerkum, C. (2010). Emergent technologies against the background of everyday life: Discursive psychology as a technology assessment tool. *Public Understanding of Science*. Prepublished 13 April 2010, DOI:10.1177/0963662510364202.

Veen, M., te Molder, H., Gremmen, B., & Van Woerkum, C. (submitted). If you can't eat what you like, like what you can: How celiac disease patients and their families construct dietary restrictions as a matter of choice.

Veen, M., te Molder, H., Gremmen, B., & Van Woerkum, C. (submitted). Competing agendas in upstream engagement meetings between celiac disease experts and patients

Abstracts in conference proceedings

Veen, M. (2009). *A discursive approach to celiac disease*. Mansholt PhD Day, Wageningen, 5 juni 2009.

te Molder, H., & Veen, M. (2009). 'Do you like those sweetie?' Parental responsibility vs. the child's autonomy in CD patients' mealtime talk. Annual meeting of the International Communication Association, Marriott, Chicago, IL, May 20, 2009

te Molder, H., & Veen, M. (2008). *Recommending tasty foods or avoiding forbidden fruits? An analysis of question design in celiac disease patients' talk*. Social Life and Meaning Construction, proceedings LCM 2008, Odense, Denmark, 14 - 16 July, 2008.

Veen, M. (2008). *The role of genomics in the everyday life of celiac disease patient*. Genomics & Society Conference, 17 april 2008.

Veen, M., & te Molder, H. (2007). *On recommending what you are 'allowed to eat'*. 9th AWIA Symposium, Groningen, 14 december 2007.

Veen, M. (2007). *Coping with the default risk of gluten intake: An analysis of online interaction between celiac disease patients*. 16th Society for Risk Analysis Conference, Amsterdam, 19 juni 2007.

Veen, M. (2006). *The social side of celiac disease innovation*. Celiac Disease Consortium, 16 november 2006.

CURRICULUM VITAE

Mario Veen was born in Den Haag on 9 May 1982. In 2003, he completed his undergraduate education at University College Utrecht, with a major in Social Science and a minor in Philosophy. His undergraduate thesis focused on Heidegger and Adorno's conception of metaphysical experience. He developed an interest in the interdisciplinary analysis of contemporary cultural objects, especially through the philosophy of technology and everydayness. In 2005, he graduated with a research Master Cultural Analysis from the University of Amsterdam.

In 2005, he started his PhD study at the department for Methodical Ethics and Technology Assessment (META) and the Communication Science Group of Wageningen University, with the aim of examining the everyday life of celiac disease patients by studying their conversational practices. During this time, he further developed his interest in the relation between language, metaphysics, technology, and everyday life.

In 2010, he started a new research project at the University Medical Center in Rotterdam. In this research project, he examines how the sharing of experiences from practice contributes to the general practitioners' training, while further exploring the relation between everyday language and metaphysical questions.

COMPLETED TRAINING AND SUPERVISION PLAN

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Name Mario Veen
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Completed Training and Supervision Plan



Wageningen School
of Social Sciences

Description	Institute / Department	Year	ECTS*
<i>Courses</i>			
Mansholt Introduction course	Mansholt Graduate School of Social Sciences (MG3S)	2006	1
Ways of writing	Amsterdam School for Cultural Analysis	2006	3
Ways of knowing: a renewed commitment to knowledge	Amsterdam School for Cultural Analysis	2006	3
Gastcollege Advanced Communication Science: Applying Discursive Psychology	Wageningen University	2008	1
Gastcollege Advanced Communication Science: Discursive Psychology in Action	Wageningen University	2009	1
Science and Technology Studies PhD reading group	Science and Technology Studies, University of Amsterdam	2006	2
Philosophy of Technology Colloquium	Radboud University Nijmegen/ Wageningen University	2007– 2009	4

GLUTEN, PILLS & TALK

Mondelinge Interactie	University of Utrecht	2006	5
International Conference on Conversation Analysis	ICCA 2006, Helsinki	2006	1
An Introduction to the Methods of Conversation Analysis	University of York, UK	2006	1.5
Celiac Disease Consortium Meetings/Presentations on current Celiac Disease Research	Celiac Disease Consortium	2006	4
Presentations at conferences and workshops:			5
Mansholt Multidisciplinary seminar		2009	1
Society for Risk Analysis Conference, Amsterdam		2007	1
Conversation Analysis Conference, AWAI Groningen		2007	3
Poster presentation Society & Genomics conference		2008	3
Presentation Celiac Disease Consortium		2007	1
Total (minimum 30 ECTS)			31.5

This research was financially supported by the Netherlands Genomics Initiative and conducted under the auspices of the Mansholt Graduate School for Social Sciences, the Celiac Disease Consortium, and the Center for Society and Genomics

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Graphic Design: Johanna Bayerlein