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DESIGN & TECHNOLOGY FUTURES

DIETARY INCLUSIVITY

SUPPORTING FOOD PREFERENCES IN SOCIAL- AND SERVICE-BASED INTERACTIONS

KAASAV TOITUMINE: TOIDUEELISTUSTE TOETAMINE SOTSIAAL- JA TEENUSPÕHISTES SUHTLUSTES

MASTER THESIS

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Tallinn 2021

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THESIS TASK

Student: Harm Jan Grinwis,
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Thesis topic:

English Dietary Inclusivity: supporting food preferences in social- and service-based interactions

Estonian Kaasav toitumine: toidueelistuste toetamine sotsiaal- ja teenuspõhistes suhtlustes

Thesis main objectives:

1. Understand the biology and lived experience of food intolerances
2. Explore design opportunities to support pain points in the experience
3. Design a concept that provides this support

Thesis tasks and time schedule:

No	Task description	Deadline
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2.	Concept finalization	10.05.2021
3.	Thesis finalization	24.05.2021

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SUMMARY

Dietary diversity is on the rise: vegan and vegetarian diets are becoming more popular, food intolerances and -allergies are increasing in first-world countries, and cultural diversity is decoupling dietary habits from geographical locations. When organizing food in social settings, or when offering options through (digital) food services, it should be assumed that people may have dietary restrictions or preferences.

But in reality, communicating dietary preferences often causes social friction for those that are seeking support. Whether the interaction is personal or professional, the conversation around food remains difficult, while food service platforms tend to offer limited support for facilitating special diets. These challenges in inclusivity are rooted in communication. We lack a shared understanding and framework to discuss our dietary preferences outside of our close social circles. Even if the information is freely shared, food organizers have little access to tools to help them find and provide suitable food. Meanwhile, digital systems lack a standardized protocol to share this information in the first place.

This thesis proposes a digital platform that aims to facilitate communication about food and diets. Users create a food profile that stores their dietary preferences and restrictions, which is then used to connect with other users and services. The platform enables the creation of social connections for personal and professional use, which helps food organizers create an inclusive environment for all participants. Food services can utilize the food profile to offer customers accurate recommendations, filtering options, or automated services. The platform has standalone web- and mobile applications, and is designed to be integrated in other online systems, aiming to create a network of dietary inclusivity.

The project is informed by research, interviews, and co-creation sessions. The resulting concept is presented through schematic maps and user journeys, and the platform is illustrated through wireframes.

EESTIKEELNE KOKKUVÕTE

Toitumisdieetide mitmekesisus on kasvamas: veganlus ja taimetoitlus saavad üha populaarsemaks, toidutalumatus ja allergiad on muutunud läänemaailmas üha tavalisemaks ning kultuuriline mitmekesisus on sidunud traditsioonilised köögid lahti oma geograafilistest hällidest. Organiseerides sellises situatsioonis toitlustust sotsiaalsetele üritustele või pakkudes (digitaalseid) toidukulleri teenuseid, peaks üha enam arvesse võtma, et inimestel on erinevad toitumispiirangud ja eelistused.

Tavaelus tekitab isiklike toitumiseelistuste väljaütlemine inimestele, kes tuge vajavad, tihtipeale sotsiaalset ebamugavust. Sõltumata, kas vestlus toimub isiklikus ringis või professionaalsetel alustel, on see alati keeruline, kuna toiduvahenduse teenuseid osutavad platvormid pakuvad minimaalset tuge spetsiifilistele dieetidele. Inimeste kaasamise välistamine algab kommunikatsioonist. Meil puudub ühine arusaam ja raamistik, kuidas oma toitumiseelistustest väljaspool isiklikku suletud sotsiaalset ringi rääkida. Isegi kui informatsiooni vabalt jagada, puudub toitlustuse organiseerijatel enamasti ligipääás vahenditele või informatsioonile, mis lubaks sobivat toitu valida. Samuti ei ole digitaalsetes süsteemides kasutusel standardseid protokolle, mis võimaldaks seda laadi informatsiooni jagada.

Magistritöö pakub välja digitaalse platvormi, mis võimaldab pidada süvitsi minevat kommunikatsiooni toidust ja dieedist. Kasutajad loovad süsteemis oma toidu profiili, mis sisaldab nende toitumiseelistusi ja -piiranguid ja mida saab rakendada teiste kasutajate või teenustega ühinedes. Platvorm võimaldab luua sotsiaalseid suhteid personaalses ja professionaalses kasutuses, toitlustuse organiseerijad saavad võimaluse luua kaasav toidulaud kõikidele ürituse osalistele ning digiteenused saavad profiile automatiseeritud filtritena kasutades teha klientidele täpseid personaalseid pakkumisi. Platvorm sisaldab eraldi kasutatavaid webi ja mobiili rakendusi. Süsteem on disainitud integreeruma teiste online süsteemidega, võimaldades nii luua kaasavat dieedi võrgustikku.

Projekt toetub uuringutele, intervjuudele ja koosloome töötubadele. Loodud kontseptsioon on esitletud skemaatiliste kaartide ja visualiseeritud kasutajateekonna kaudu. Platvormi tööpõhimõte on kirjeldatud *wireframe*'i näeol.

CONTENTS

LIST OF TERMS AND ABBREVIATIONS

Food Challenge

A supervised clinical test where a patient consumes a fixed or increasing amount of a suspected symptom-inducing ingredient. Symptoms can appear immediately, or can be monitored over the following 24-48 hours.

Elimination Diet

A (supervised) diet that aims to exclude suspected symptom-inducing ingredients for diagnostic purposes.

(Low)-FODMAP

Fermentable Oligosaccharides, Disaccharides, Monosaccharides, and Polyols, or Fermentable Carbohydrates. A group of carbohydrates that are known to cause distress in the bowels in certain people.

NCW/GS

Non-Celiac Wheat/Gluten Sensitivity.

GDPR

General Data Protection Regulation, a European data protection and privacy regulation.

CAM

Complementary / Alternative Medicine

WAO

World Allergy Organization

ASCIA

Australasian Society of Clinical Immunology and Allergy

1 INTRODUCTION

Food has many aspects. What we eat, how we eat, where we eat, and with whom we eat, are all highly social considerations. But what we eat also impacts our personal health and wellbeing, and has an influence on global supply chains, our ecosystem, and many people we will most likely never meet. What we choose to eat is an important decision, with serious consequences.

But in some cases, we relate more strongly to what we choose *not* to eat. There are many reasons why we wouldn't eat something. Maybe it is not in our culture, and therefore we consider it strange or unappealing. Or we choose not to consume certain products or ingredients out of ethical or environmental considerations. Sometimes, we eat to reach certain goals, or maintain a healthy standard. And sometimes, our body simply disagrees with certain items, and we are better off avoiding them.

Not eating something is a deliberate decision that we need to express and facilitate, out in the world. Not buying something in a supermarket is fairly easy, but not eating something at an event becomes slightly more difficult, and not eating something at a dinner party requires careful planning and communication, to avoid going hungry or disappointing the host.

This thesis explores the topic of not eating things. Or, in more suitable terms, the topic of dietary limitations and -preferences. It does so through the lens of food intolerances at first, but expands to a broader understanding of preferences later. It argues that dietary preferences could use more support, both in social environments and service interactions. Dietary inclusivity, if you will.

What we eat, or choose not to eat, is highly personal. At the same time, food is such a great thing to share. This project proposes a new way to communicate about food and facilitate inclusivity, to encourage sharing. Diversity and inclusiveness do not exclude each other. Instead, they can be brought together for the best of both worlds.

2 METHODOLOGY

2.1 Defining the Topic

This thesis project started out with the intention to find a design project at the intersection of food and health. The effect of nutrition on our health and wellbeing is a topic that has always fascinated me. I also think it can be an overwhelming or confusing topic to many people, so I wanted to explore ways to make the subject more approachable.

Nutrition is a multi-faceted topic with a rich history and many strong beliefs. Even within scientific research, there is a lot of conflicting information about the best way to eat. Our collective understanding of how food affects our body is still rapidly developing. In the past decades, we have seen the rise and fall of the low-fat diet, mostly popular in the United States to combat heart disease (La Berge, 2008). At the moment, US and Estonian government recommendations focus on a diverse diet of whole foods, rich in fruits, vegetables, whole grains, protein and dairy (FAO, n.d.; USDA, n.d.). There are also strong research-based voices advocating for the Mediterranean diet (Harvard School of Public Health, 2018) and a whole-foods plant-based diet (NutritionFacts.org, 2019) as the best way to prevent lifestyle diseases and maintain long-term health.

At the same time, the field of nutrigenomics is exploring how our genetic makeup determines how we respond to different diets (Kirkpatrick, 2020). The understanding that different people do best under different types of diets is not a new discovery in itself. Ayurvedic- and Chinese medicine traditions have long recognized different categories of people, with customized dietary recommendations for each. Nutrigenomics seems to be reviving this ancient knowledge, backed up by modern scientific standards.

Other developments include our understanding of the complex biological systems that affect our bodies. For example, the understanding that gaining or losing weight is simply the result of the net amount of calories consumed, a long-standing 'truth' in nutrition, is finally being replaced by a more complicated yet accurate model that acknowledges the extensive influence hormones have on our weight[2].

The way food is sourced, combined and prepared inherently influences how it affects us. The fiber, vitamins and carbohydrates in an apple impact us differently when consumed as extracted compounds. Generally, the whole food is a better source of nutrition. At the same time, isolating food compounds is necessary for our understanding of them, and our ability to manufacture them for supplements or medicine. While scurvy has been prevented using citrus fruits since 1747

[2] A great example of this can be found in author and self-proclaimed 'human guinea pig' Tim Ferriss' book *The 4-Hour Body* (Ferriss, 2010). In one experiment, Ferriss consumed 6214 calories in 12 hours. Using strategic timing, some light exercise and some over-the-counter supplements, he not only managed to not gain any weight, but even dropped his bodyfat from 9.9% to 9.6% in the 48 hours after the experiment.

(Challem, 1997), vitamin C was only discovered in 1912 and first synthesized in 1933 (Squires, 2011).

While I feel that we are making major breakthroughs in our understanding of nutrition, I also think this information is slow to reach people, and can be confusing or contradictory. The diets we eat are also much more dictated by our cultural and familial habits than by medical information. For my thesis project, I was hoping to discover a design opportunity to help people find a healthy and sustainable diet.

But this topic quickly proved to be too large. Nutrition and health are large fields with many factors, stakeholders and challenges, and approaching this field as a whole would be a herculean task. Instead, I took the advice of my supervisors (and everyone else I discussed this topic with), and narrowed my field of research.

Food Intolerances

To narrow down in the field of food and nutrition, I decided to explore the topic of food intolerances. I liked that this approach would allow me to frame the topics of food and health in an objective way. What being healthy actually means is a difficult subject with many considerations, both from biological and social perspectives. Focusing on food intolerances would provide an approach that excludes these considerations. Instead, success can be measured by improving noticeable symptoms.

I also have personal experience with food intolerances. My direct and extended family has various intolerances to different foods, some of which have only been discovered in the past couple of years. I noticed that in most cases these intolerances were discovered as a surprise, without being suspected before the diagnosis. On insistence of my mother, I also got tested just before moving to Estonia, and found out I have gluten intolerance, which is something I did not expect at all. I describe my own experience later in this chapter.

2.2 Methodology and Theory

Research Question

I did not start this project with a clear goal in mind. As described earlier, I picked the topic of food intolerances as a specified topic in the field of food and health. While I had some assumptions about the challenges in dealing with food intolerances (mostly from my personal experience), the final goal of the project revealed itself through the process, as is the case with many open-ended design projects.

I started the project with learning about the biology of food intolerances, while conducting interviews with various people that have personal or professional experiences in the field. Their input helped me understand the lived experience of handling food intolerances, starting with the recognition of the problem and ending in the daily management of an altered diet.

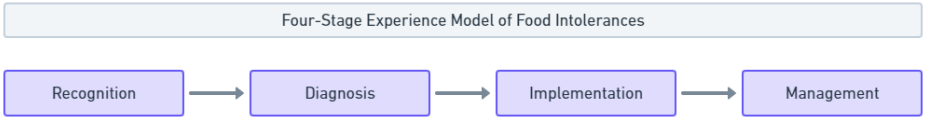

Figure 2.1. Four Stages of Experiencing Food Intolerances

In the end, I decided to focus my design solution on the final stage of this model. At that point, I also realized that managing a specific diet is not a challenge that is limited to those with food intolerances, but also includes people with allergies, religious restrictions, health considerations, and ethical preferences. While I narrowed my target user group at the start of this project, my current direction made me open it up again.

Because of the way the project developed, it can be seen as being driven by two separate research questions.

The research phase was led by the question:
How might we support people with food intolerances?
The design phase was led by the question:
How might we enable inclusivity for people with dietary restrictions in social situations and in services?

Model: Constructive Design Research

The model of Constructive Design Research, as presented by Bang, Krogh, Ludvigsen and Markussen (Bang et al., 2012), provides a framework to structure a design research project in a way that allows for the process to be adjusted as new information is discovered and understood. The authors pose that the development of design projects are often far from linear, something which I saw clearly reflected in my own process. In this model, experiments are placed at the center of the process, and are expected to take place at various stages in the project. The findings

from these experiments shape the understanding about the overall project, allowing for a reframing of the project when suitable.

Employing an iterative approach to my project allowed me to start the research without a fully specified problem. Instead, I could develop my understanding of the situation over time, and adjust my goal as new information presented itself.

The process of the thesis represented through the Constructive Design Research model:

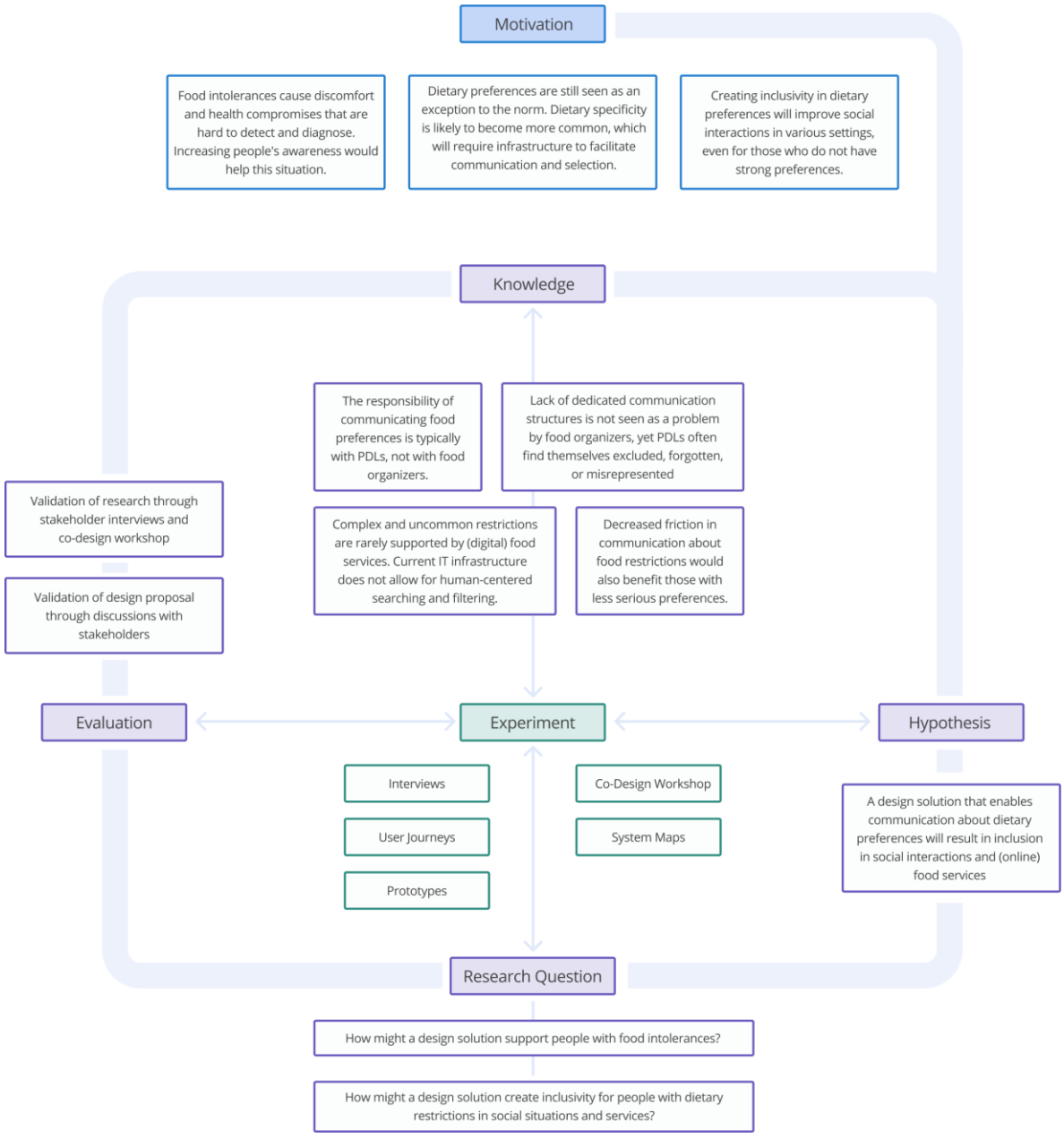

Figure 2.2. Constructive Design Research Model

2.3 Research Process

Food intolerances present a wide and very personal challenge. The topic can be approached from various areas of expertise, including biology, medicine, physiological and psychological impact, the impact on social relations, and even our current food industry. To create a comprehensive understanding that covered as many subjects as possible, I combined several desktop- and design research methods.

Literature Research

To understand the biology of food intolerances, I mostly focused on scientific journal articles. As the field of food intolerances is still rapidly developing and full of uncertainties, scientific papers were a reliable yet frequently updated source of information. Another useful source were informational websites for specific intolerances, meant to educate patients.

Survey

Before the topic of food intolerances was fully defined, I used an online survey to gather information about eating habits, people's opinion of their own health, and their feeling about the relationship between the two. The survey was shared through personal social media and on Reddit, both in English and in Dutch for maximum coverage. The survey was filled in by 99 anonymous participants.

The information from the survey gave interesting insights in the way people regard their personal health and their diets. While some comments were specifically related to dietary restrictions and food intolerances, most of the information in the survey was not directly related to the final thesis topic.

Interviews

While there are some articles online describing the lived experience of dealing with food intolerances, my main source for this information was interviews with people that have experiences with food intolerances themselves. I also interviewed a nutritional therapist and a holistic health practitioner, who both support people in diagnosing and managing food intolerances. To understand how food is handled in the workplace, I conducted interviews with two HR managers, from Estonian and Dutch companies, respectively.

The interviews were semi-structured to accommodate for the personal experience of the interviewees. Some identifiable information has been removed to maintain the privacy of the participants. Both medical professionals agreed to be mentioned by full name, and were invited to review the work prior to publication. The information shown in this report has been published with informed consent.

A full list of interviewees and topics discussed is available in appendix A.

Personal Experience

While I was careful not to rely too much on my personal experience with dietary restrictions and food intolerances, it did provide me with important knowledge about the lived experience. It also helped me integrate new information, and gave me a starting point to compare to when listening to others.

My first experience with severely changing my diet was when I decided to switch to a vegan diet in September 2018. This choice started from a motivation to have a healthier diet, and I made sure to properly study the nutritional requirements for a healthy vegan diet. This change in diet made me feel noticeably better. After some adjustment period I felt lighter, more energetic, and I felt like my immune system was stronger.

At the same time, I was battling some serious issues with fatigue and muscle tightness. These complaints started before changing my diet, and didn't change afterwards. Some days would be completely fine, while on other days I could barely get out of bed. On the worst days, I would feel like I could barely think at all. I didn't know what the cause of my complaints was, but I had been working with several therapists to correct my spine and posture, and assumed it could be related to that.

Before moving to Estonia, my mother had me do a food intolerance test, since in the months before both herself and my sibling had been diagnosed with several intolerances. I was skeptical of the used method but figured I had nothing to lose. I got diagnosed with an intolerance to dairy, which I hadn't consumed for the past 1.5 years, and an intolerance to gluten, which my diet was full of. When the therapist explained that gluten can cause muscle tightness[3], I realized that my unexplained fatigue and muscle cramping could be entirely food related.

I started removing gluten from my diet in the same period I moved to Estonia. This gave me the valuable experience and challenge of navigating a foreign supermarket with a newly restricted diet. The first Estonian words I learned where *piim, vadak, muna and nisu* (milk, whey, egg, wheat). It also gave me a lot of experience with being the person with the complicated diet.

These experiences undoubtedly shape my understanding of the topic and introduce a strong bias. To counter this, I tried to base my insights solely on information I received from others, and validated my insights with multiple people that were not involved with the project before during the co-design workshop. On the other hand, I believe my own experience helped me empathize with interviewees and participants.

Co-Design Workshop

A co-design or co-creation workshop is a collaborative session between designers and participants. The participants are often part of the group(s) that is being designed for in the project, which makes it a good way for the designers to get input from real future users (Mozilla, 2020). At the

[3] Another therapist later told me it is actually inflammation in the joints. I don't have conclusive proof excluding either hypothesis.

same time, a community is more likely to adopt a solution they have helped shape, which can be valuable in some situations (IDEO, 2009).

A co-design session often consists of exercises that allow the participants to create alongside the designers. This can be done by creating mockups, storyboards, designing a city layout, using roleplay, and many other exercises that get the participants actively involved. By giving participants a voice, designers can find valuable new information, and confirm their previous findings.

The Role of Co-Design in this Project

In this project, I used the opportunity of the workshop to challenge my insights from the research, and to gain input for the design process. Due to covid-19 restrictions, the workshop was held online, using a video call and an online whiteboard tool, in which exercises were set up beforehand. During the workshop I shared my personal experience freely, both as a way to give examples during the exercises, and to avoid creating a strict distinction between the roles of participants and facilitator.

The participants of the workshop were:

Liis Salus[4] – Nutritional Therapist, celiac disease, lactose intolerance
Linnea – Irritable Bowel Syndrome, low-FODMAP diet
Eliis – University lecturer, nutritionist, health promotor, vegan
Fiona – Former Pediatrician, chronic pain patient, anti-inflammatory diet
Myself – Vegan and gluten intolerance

The main insight taken from the workshop was that the personal experience of dietary limitations was very similar between all participants, regardless of the nature of their limitations. This became an important point in formulating the final design brief. The workshop was also used to get feedback on the first draft of the design.

[4] Liis participated in an interview one month before the workshop.

3 THE BIOLOGY OF FOOD INTOLERANCES

3.1 Adverse Food Reactions

This project concerns itself with food intolerances. Food intolerances can be confused with food allergies, and many regulations and considerations group them together for practical purposes. Another related term is food sensitivity or hypersensitivity. Sometimes the terms are used interchangeably, and sometimes they are meant to indicate different conditions.

Food allergy, -(hyper)sensitivity and -intolerance all fit in the broader spectrum of Adverse Food Reactions (AFR). AFR can be defined as "any abnormal clinical response that occurs following ingestion of a food or food component" (Washabau & Day, 2012)5. Abnormal, in this setting, means that these foods do not cause a reaction in most people. A burning sensation in the mouth after eating chili peppers would not be regarded as an AFR for clinical purposes, getting abdominal pain from a glass of milk would.

Adverse Food Reaction is a blanket term for reactions with a wide variety of causes, effects, and diagnostic methods. There is no single correct way to understand and categorize these reactions. Each website, institute or research paper seems to categorize AFRs in its own way. For the purposes of this project, we will do the same.

3.2 Classifying Adverse Food Reactions

Allergies and Intolerances

In an article describing a new recommendation for the nomenclature of allergies, the World Allergy Organization (WAO) proposes the term *hypersensitivity* to describe "objectively reproducible symptoms or signs initiated by exposure to a defined stimulus at a dose tolerated by normal persons" (Johansson et al., 2004). This definition is meant to cover the whole scope of allergies, including those unrelated to food. Hypersensitivity, in this context, would be one step up from adverse food reactions.

The article then specifies that in the context of food-related sensitivities (or AFRs), a distinction should be made between *IgE-mediated food allergy* and *nonallergic food hypersensitivity.* However, the article does not provide further details on what constitutes as a nonallergic hypersensitivity, or what mechanisms are involved.

[5] From the book *Canine and Feline Gastroenterology*. Although cats and dogs are out of the scope of this project, it might be interesting to note that 49% of cats with chronic signs of gastrointestinal problems improved when fed an elimination diet (Guilford et al., 2001). Elimination diets will be discussed in a later chapter.

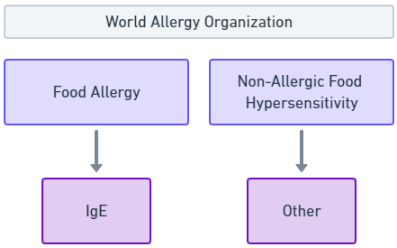

Figure 3.1. Adverse Food Reaction Classification of the WAO

IgE-mediated food allergy is the classic food allergy that most people are familiar with. People with these allergies can experience severe reactions from exposure to a very small amount of food (National Institute of Allergy and Infectious Diseases, 2012). This type of allergy involves IgE antibodies, which are mistakenly treating a harmless food particle as if it were a threat to the body. The results of this immunological reaction range from tingling and red skin to anaphylactic shock, which requires a shot of adrenaline from an Epi-Pen and support from a healthcare professional. The nomenclature of the World Allergy Organization distinguishes between this type of allergic reaction, and any other reaction caused by the consumption of food.

The model used by the Australasian Society of Clinical Immunology and Allergy (ASCIA) is slightly different, and splits adverse food reactions into two main groups: Immune Mediated and Non-Immune Mediated reactions (Australasian Society of Clinical Immunology and Allergy, 2019). Here, the distinction is made based on the biological mechanism responsible for the effect. Immune Mediated reactions include IgE, Non-IgE, Mixed IgE-and-Non-IgE, and Cell Mediated reactions. The other category contains Metabolic, Pharmacologic, Toxic and Unidentified reactions, which are reactions unrelated to the immune system. The meaning of these categories will be discussed later. Interestingly, the ASCIA and WAO use different models to classify allergies.

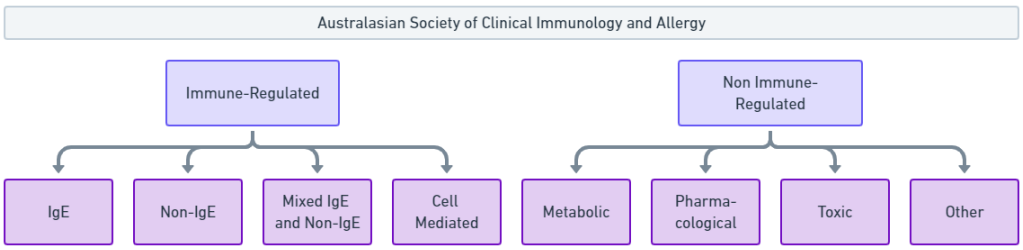

Figure 3.2. Adverse Food Reaction Classification of the ASCIA

Additional layers of biological distinctions are introduced in the paper The Differential Diagnosis of Food Intolerances (Zopf et al., 2009). The model proposed by the authors distinguishes between two main categories: functional intolerances and structural intolerances. Functional intolerances are caused by a single biological mechanism, like a lack of enzymes for a certain food component. Structural intolerances are the result of anatomical problems in the gastrointestinal organs, which makes them the secondary result of primary dysfunction.

In this model, IgE allergies are not a primary category, but are instead classified as a functional, non-toxic immunological food intolerance, which is very different from the models used by the WOA and ISICIA. The model used by Zopf et al. will be relevant later in this chapter, but it provides a good example of how different classifications can change the understanding of what food allergies and intolerances are.

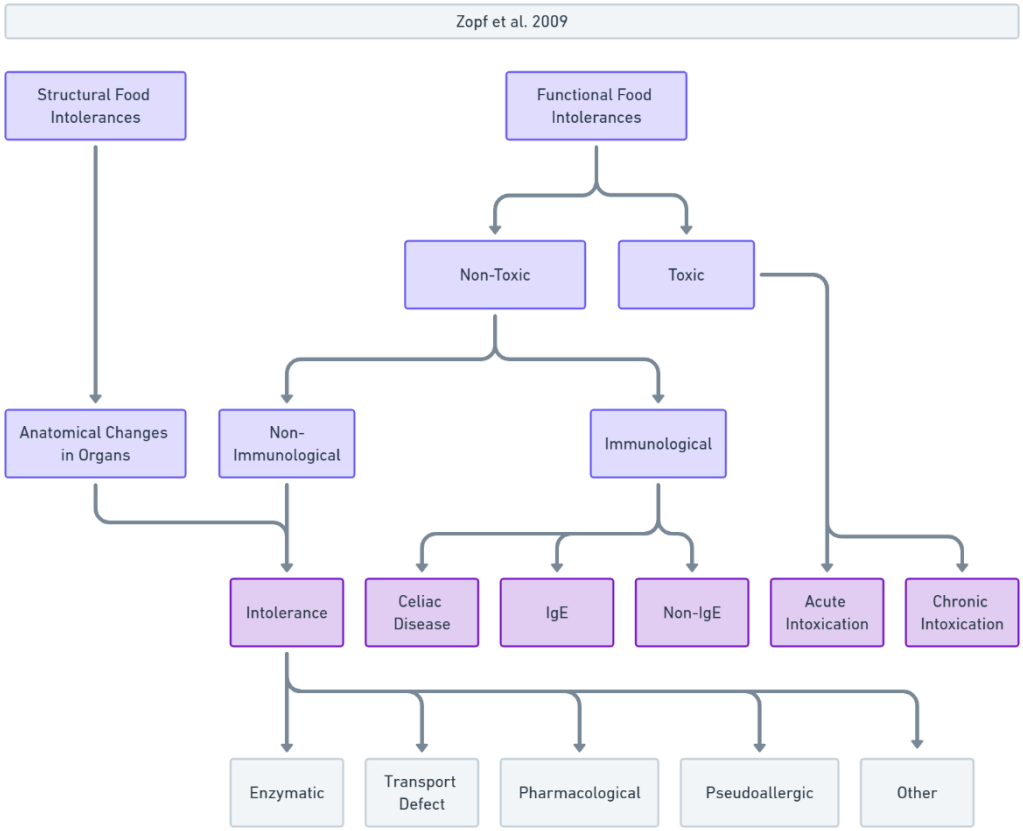

Figure 3.3. Adverse Food Reaction Classification. Credit: Zopf et al. (2009), modified by author.

Food Sensitivity and Food Intolerance

While the terms Food Sensitivity and Food Intolerance are both commonly used to describe non-allergic reactions to food, it can seem unclear whether they can be used interchangeably or are used to indicate separate pathologies.

In the scientific literature, intolerance seems to be the most commonly used term to refer to non-IgE mediated reactions. Some older papers use the term food sensitivity (Anderson, 1991; Young et al., 1994), but the term seems to have been replaced by intolerance. One exception is the cases of specific conditions, such as Non-Celiac Gluten Sensitivity.

Some articles on the internet use the term *food sensitivity*, but this simply seems to be a stylistic choice. However, two important exceptions stand out. An article publish in January 2020 by Harvard Health Publishing explains food intolerances as "..the inability to process or digest certain foods." (Campos, 2020). In the same article, food sensitivities are described as "symptoms that are not related to food intolerances, food allergies, or celiac disease". The article mentions that

there is some controversy regarding the exact mechanism, but that it might be an immunological reaction to foods that cause a variety of symptoms. Based on the model of Zopf et al. (2009), we can conclude that this explanation of intolerances and sensitivities is most likely overly simplified, and has no biological bearing.

The second important example is on the website of Everlywell, a US company offering various at-home testing kits and laboratory services for consumers (*Everlywell - About [LinkedIn Page]*, n.d.). On their page "Food Sensitivity Explained", Everlywell distinguishes between intolerances and sensitivities in way similar to the article published by Harvard (Campos, 2020). Intolerances are explained as a lack of enzymes causing gastrointestinal distress, and IgE allergies are mentioned as a separate category. However, food sensitivities are described as a "..poorly understood reaction to food that may be associated with levels of certain IgG class antibodies that are reactive to that food" (Everlywell, n.d.).

The article mentions that people may "go a lifetime without ever knowing they have [a food sensitivity] due to a delayed reaction time and vague symptoms that mirror common ailments", and links to their sales page offering an at-home food sensitivity diagnostic test. While the description of symptoms is somewhat correct, the distinction between intolerances and sensitivities seems to mainly serve as a marketing tool, promoting Everlywell's testing services. Testing services and the surrounding marketing will be discussed later.

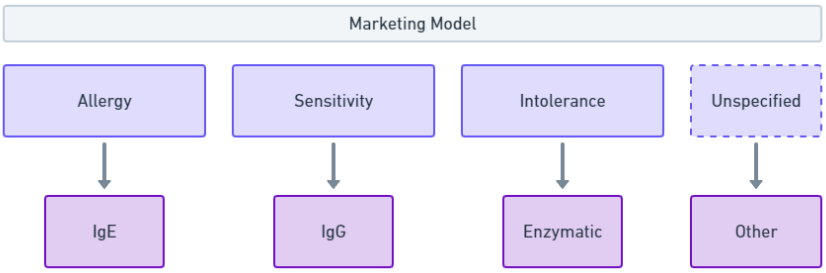

Figure 3.4. Adverse Food Reaction Classification for Marketing

For the purposes of this thesis, we will use the more scientifically accepted and distinctive term *intolerances*.

An Experience-Centered Model

Various institutions and researchers have developed models to classify food allergies and -intolerances. Depending on the interest, intention, or field of expertise of the publisher, these models divide Adverse Food Reactions into categories based on biological mechanisms, symptoms, or marketing potential.

What these models do not necessarily accommodate is the experience of the person facing these symptoms. To approach food intolerances from a point of view that puts the user first, and addresses their needs in their medical journey, we need a model that is centered around their experience.

For this purpose, we can make the distinction between reactions that are quick and potentially life-threatening, and reactions that are delayed and vary from mild to severe symptoms. When solely focusing on the experience of these symptoms, we can remain agnostic of the actual biological mechanism that is causing it. The symptoms and potential effects constitute how the person feels, what precautions they might need to take, and how their symptoms can be treated.

In practice, this approach brings us very close to the model the World Allergy Organization proposes. Immediate and potentially life-threatening effects are typically only caused by IgE-mediated allergic reactions. An exception to this could be food poisoning, but this is a separate issue since it would affect anyone, not just those with allergies or intolerances. What remains can be classified as food intolerances: delayed adverse reactions to regular foods that can cause various mild to severe symptoms, through a myriad of biological processes.

Because this distinction is so close to the WAO's model, we can keep using the term allergy to indicate IgE-mediated reactions. The other reactions can be classified as intolerances for this project.

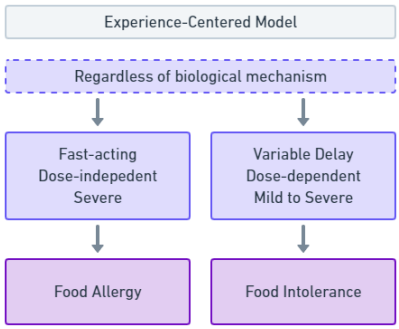

Figure 3.5. Adverse Food Reaction Classification based on Patient Experience

3.3 Allergies vs Intolerances

Now that we have explored the various ways to classify allergies and intolerances and have chosen a model that is relevant for this project, we can define the characteristics of allergies and intolerances. This will give an introduction to what intolerances are, and what they are not.

Allergies

As mentioned before, in this model allergies refer to IgE antibody mediated immune response to specific food particles. The main characteristics of an allergy is that the reaction can be triggered by a small amount of food, happens quickly, can induce a life-threatening anaphylactic shock (National Institute of Allergy and Infectious Diseases, 2012).

In an allergic reaction, the body's immune system mistakes a common food particle for a pathogen, and induces an immune reaction in response. The likelihood of developing an allergy is relatively low, and the chance seems to be influenced by a person's genetics (National Institute of Allergy and Infectious Diseases, 2012). Cow's milk, eggs, wheat, soy, peanuts, tree nuts, fish and

shellfish are the eight most common allergy-inducing foods (B. I. Nwaru et al., 2014; Sicherer & Sampson, 2014).

The National Institute of Allergy and Infectious diseases states that people with a food allergy can experience a fast-acting immunological reaction when exposed to a trigger food through digestion, airways, or skin contact (2012). The reaction typically occurs within a few minutes to several hours, and symptoms can include a tingling feeling in the mouth, swelling of the face, lips, tongue or throat, and hives and irritated skin. In extreme cases, anaphylaxis can cause a lowered heart rate and blood pressure, which may result in death if not treated immediately by a medical professional. The institute recommends people with food allergies to carry an epinephrine autoinjector (2012), commonly known as an EpiPen.

Intolerances

Where the biological mechanism responsible for allergies is well-documented and -understood, the category of food intolerances contains a wide variety of food-related complaints that cause a plethora of symptoms. These symptoms range from gastrointestinal distress to fatigue, respiratory issues, and can even lead to heart- and fertility problems (Kubala, 2018). However, before focusing on the differences between different food intolerances, it is important to consider the similarities.

The effects of food intolerances are typically dose-dependent, and occur up to 48 hours after consumption (Ozdemir et al., 2009). In this, they drastically differ from allergies. While some food intolerances can cause very specific symptoms, they mostly cause general discomfort that can be associated with many common complaints. This makes the symptoms hard to identify as food-related. Sensitivity and delay in reaction also vary from person to person, making it even harder to properly diagnose the problem. An intolerance might present itself as seemingly random bloating and stomach pain, or as a rash that sometimes mysteriously gets worse or disappears. Alternatively, someone might eat a food they are intolerant to so frequently the symptoms never really go away.

At the same time, symptoms are often not drastic or threatening enough to be taken seriously by healthcare professionals, or even by patients themselves. Vague stomach complaints that occur from time to time are hard to treat. Often, the complaints are not recognized as food-related at all, as Heleen Furster experiences regularly in her clinical practice (*Heleen Furster (Personal Digital Interview)*, 2020). She recounts the story of an older patient struggling with incontinence, which did not respond to any of the medication her GP prescribed her. When Furster detected the patient was intolerant to lactose, treating the incontinence was as simple as removing dairy products from the patient's diet, without requiring further medication.

Healthline lists the eight most common foods causing intolerances as dairy, gluten, caffeine, salicylates, amines, FODMAPs (fermentable carbohydrates), sulfites, and fructose (although fructose is technically part of the FODMAPs) (Kubala, 2018). The article also mentions aspartame, eggs, monosodium glutamate, food colorings, yeast, and sugar alcohols (another FODMAP). While

the article itself does not provide any data about the prevalence of these intolerances, it does provide scientific sources for most of its claims.

Finding exact data about the prevalence of intolerances and allergies is difficult, as will be discussed later in this chapter. However, it is important to recognize that the most common food allergies and food intolerances are not triggered by the same foods, although there is some overlap. Intolerances are not simply a milder type of allergy, but are a separate group of pathologies with different characteristics and biological mechanisms. To empathize with the situation patients find themselves in when dealing with a (potential) intolerance, it is important to acknowledge their variations and complexity.

3.4 Common Food Intolerances

Some food intolerances are more common than others. A few are well-known to most people, like lactose and gluten intolerances. In fact, 70% of the population technically has a lactose intolerance (Lomer, 2015; Suarez et al., 1995), although many may not even be aware, or only show mild symptoms[6]. Gluten-free eating has even become a somewhat popular diet over the last years (Doheny, 2016), and more and more people are claiming they don't tolerate it well.

There are many different foods that are known to cause a reaction in some people. Before we discuss these however, we first need to understand the mechanisms that are responsible for generating symptoms in the first place.

Biological Mechanisms

Food intolerances are not caused by one single biological mechanism. Instead, there are many ways in which food can cause uncomfortable symptoms. These symptoms can originate from processes in different organs, although they typically start in the digestion tract.

The understanding of the mechanisms of food intolerances has developed a lot in the past decades. While there is still a lot to learn, we now have a better understanding of the individual mechanisms that can produce symptoms. The model of Zopf et al. (2009) shows a good breakdown of the categories of biological mechanisms that are involved in food intolerances.

[6] alternatively, someone might limit the amount of dairy they consume, but would never associate themselves with the term 'lactose intolerant'.

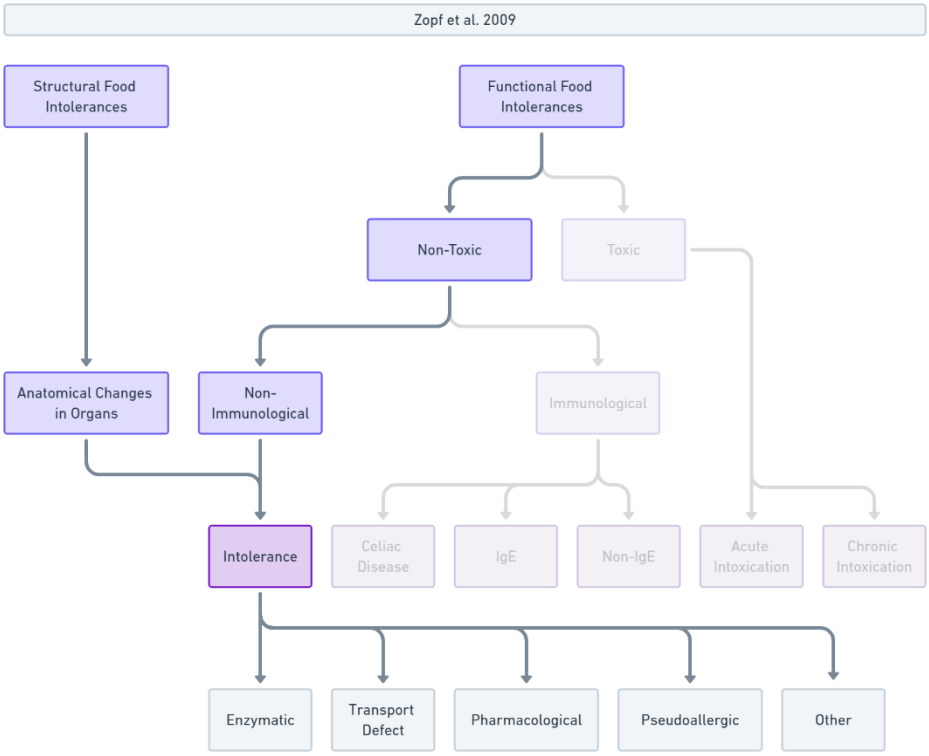

Figure 3.6. Adverse Food Reaction Classification. Credit: Zopf et al. (2009), modified by author.

Structural Food Intolerances
Food intolerances can be the result of structural abnormalities in the digestive system. A deformation in the small intestine, for example, can cause bacterial overgrowth, which then in turn causes fermentation. This can result in bloating or diarrhea when eating certain foods.

However, this is only one way that can lead to food intolerances. Most mechanisms are classified as functional intolerances, meaning that a single specific disorder is responsible for creating symptoms.

Enzymatic Intolerances
Enzymatic intolerances are caused by a lack of enzymes for a specific ingredient. Enzymes are a necessary component for digestion, and different compounds require different enzymes to be broken down. For example, lactose (milk sugar) requires the enzyme lactase to be digested. If there is not enough lactase available, the lactose will pass through the small intestine undigested, which causes problems in the large intestine. While a decrease in lactase production is completely normal in most humans (Lomer, 2015), enzyme deficiencies are usually not helpful. In some cases, it is possible to consume enzymes as a supplement.

Transport Defect
Similar to enzymatic problems, a transport defect is a problem in the intestines. When certain compounds can not be properly absorbed, even after proper digestion, they remain in the intestines. Transport problems can cause malnutrition, but the remaining compounds can also cause problems in the intestines themselves.

Pharmacological
Another mechanism of food intolerances is a pharmacological reaction to certain compounds in foods. These can be chemicals that naturally occur in some foods, or are added in the manufacturing process.

Pseudo-allergic
Pseudo-allergic reactions are reactions that look like (mild) allergic reactions, but are not caused by an immune-mediated system. This can occur when chemical react directly with the mast cells and trigger the release of the reaction that occurs when the body is having an allergic reaction.

A food intolerance may be caused by a combination of any of these mechanisms. These mechanisms are still only broad descriptions of the exact chain of reactions that can cause symptoms. Some intolerances are better understood than others.

Common Intolerances

As mentioned earlier, Healthline lists the eight most common food intolerances as dairy, gluten, caffeine, salicylates, amines, FODMAPs (fermentable carbohydrates), sulfites, and fructose (although fructose is technically part of the FODMAPs) (Kubala, 2018). Despite being a fairly comprehensive list (compared to other online sources), it is not exactly clear how common these intolerances actually are. The complications of determining the exact prevalence are discussed later in this chapter.

The following is a list of common food intolerances. The selection of these intolerances is based on their online presence in various articles, and the availability of scientific evidence in the scientific literature. For each intolerance, a description is given of the offending food components, the suspected biological mechanisms, and the symptoms they can cause. However, it should be noted that food intolerances can express themselves in different ways in different people.

FODMAPs
Fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (FODMAPs) are a selection of carbohydrates that are known to trigger digestive issues such as bloating and stomach pain. FODMAPs occur in a wide selection of foods. This includes dairy-based products, wheat-based products and related grains, beans and lentils, and a selection of fruits and vegetables. When avoiding FODMAPs, the diet should be focused around eggs and meat, cheeses, grains like rice and quinoa, and a selection of low-FODMAP fruits and vegetables (Veloso, n.d.).

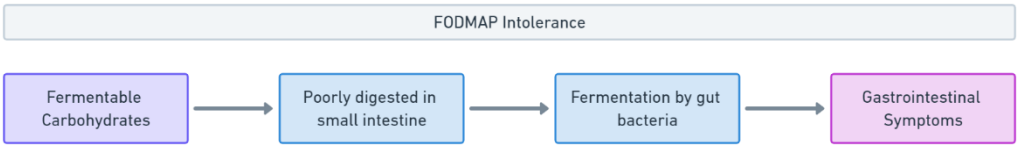

Figure 3.7. Mechanism of FODMAP Intolerance

FODMAPs are often linked to Irritable Bowel Syndrome. IBS is a blanket statement for a group of symptoms related to digestion, which can include bloating, constipation, diarrhea and bowel pain

(NIDDK, 2017). A low-FODMAP diet can reduce these symptoms by taking out the carbohydrates that are likely to trigger symptoms, and has been shown to be effective for roughly 50-84% (Lomer, 2015) or 75% (Halmos et al., 2014) of the population. Liis Salus confirms that in her experience, roughly 60% of her patients with an IBS diagnosis show improved symptoms on a low-FODMAP diet (*Liis Salus (Personal Digital Interview)*, 2021).

Another reason why low-FODMAP diets can be very effective is because the carbohydrates in milk and grains are also FODMAPs. Someone with an intolerance for dairy or wheat (and related grains), without any problems with other FODMAPs, may still benefit from the broad elimination of trigger foods in this diet.

Because a diet excluding FODMAPs covers such a large group of foods, concerns have been raised about the long-term health impact. Such a strict limitation in foods may result in lowered calcium and iron levels, and a reduction in microbiota of 47% (Molina-Infante et al., 2015). Instead, a low-FODMAP diet should always be paired with reintroduction of potential trigger foods after several weeks, to find out which exact foods need to be avoided and which can be (partially) tolerated (Lomer, 2015; Veloso, n.d.). This is not only important for physical health; an extremely limited diet also decreases the quality of life of patients by interfering with social activities.

Symptoms associated with an intolerance of FODMAPs include constipation, bloating, gas, diarrhea, abdominal pain, nausea, stomach cramps, and even vomiting.

Celiac Disease

Celiac disease is one of the most severe forms of food intolerances. For someone with celiac disease, gluten trigger an autoimmune response that damages the villi, the small finger-like protrusions in the lining of the small intestine (Celiac Disease Foundation, 2017). This causes problems with the absorption of any foods, which is why celiac disease can have such debilitating effects. Only when gluten are completely removed from the diet can the villi start to heal. Gluten are naturally found in wheat, rye, barley and spelt.

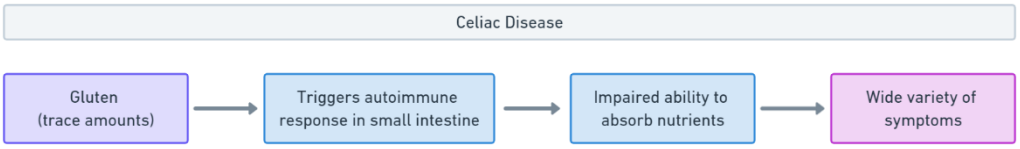

Figure 3.8. Mechanism of Celiac Disease

The amount of ingested gluten that is needed to trigger a reaction in celiac disease is much lower than that of many other intolerances. In this, celiac disease is closer to an allergy than a food intolerance. However, the reaction is only triggered when the gluten reach the small intestine, and there is no immune response similar to that of IgE allergies.

The symptoms of celiac disease include constipation, bloating, gas, diarrhea, abdominal pain, vomiting, and rashes or flushed skin, brain fog and mental health problems. Because of the

impaired ability to absorb nutrients, long-term effects can include anemia, menstrual/fertility problems, joint stiffness, fatigue, and even various cancers.

Non-Celiac Gluten/Wheat Sensitivity

As the name suggests, NCGS or NCWS are intolerances to gluten or wheat in people that do not have celiac disease. NCG/WS is a relatively new diagnosis, that did not gain much traction until the 2010s (Molina-Infante et al., 2015). Because NCG/WS lacks a testable biomarker, the diagnosis is often the result of the exclusion of other problems. Liis Salus specified that in Estonia, it might be next to impossible to receive this diagnosis since it's not recognized (*Liis Salus (Personal Digital Interview)*, 2021).

The symptoms and mechanisms of NCG/WS can have a lot of overlap with an intolerance of FODMAPs, as discussed above, since the carbohydrates of wheat and gluten-containing grains are also part of the FODMAP category. However, symptoms can be caused by a variety of mechanisms, each through a different component or pathway. It is not always clear if the symptoms are caused by wheat (and the related grains rye and barley) itself, or specifically by gluten. The combination of an intolerance of different compounds through different mechanisms results in a wide matrix of possible causes for NCG/WS.

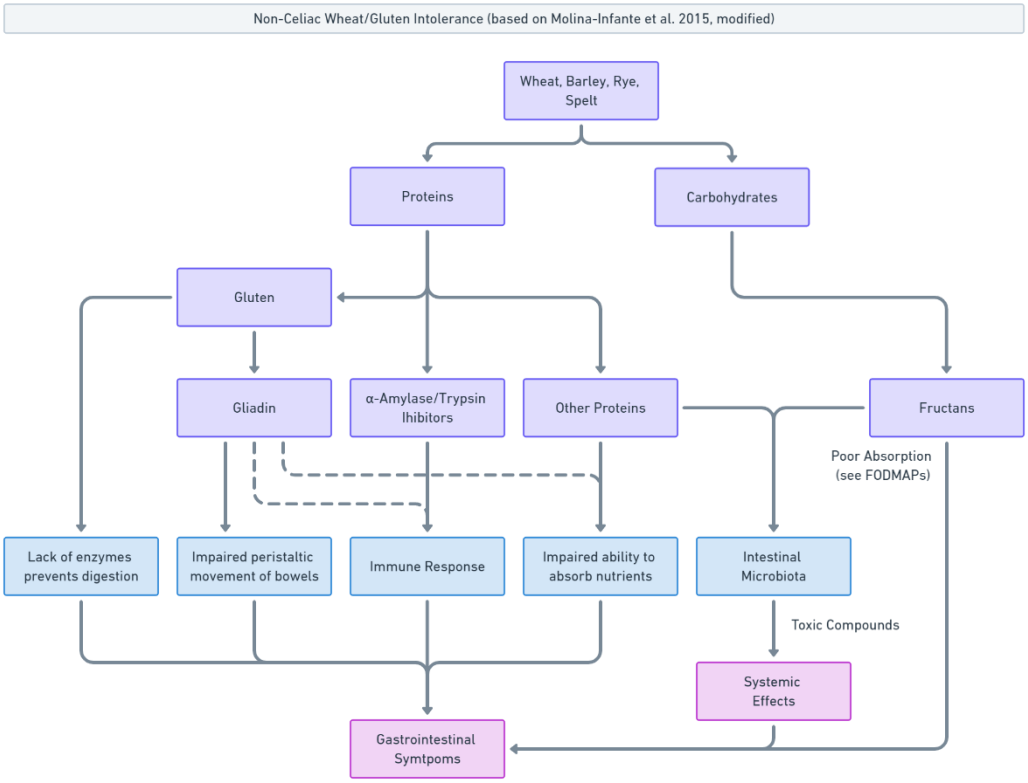

Figure 3.9. Mechanisms of NCW/GS. Credit: Molina-Infante et al. (2015), modified by author.

[7]

NCG/WS can cause damage to the intestines, although usually not as severe as celiac disease (Uhde et al., 2016). This shows that long term exposure to wheat or gluten can cause serious damage, even when the patient does not test positive for celiac disease. The symptoms of NCG/WS show considerable overlap with that of celiac disease, but do not typically result in reproductive complaints or cancer.

Lactose Intolerance

Lactose intolerance is by far the most common and commonly known food intolerance. It affects 65-70% of adult population (Lomer, 2015; Suarez et al., 1995), and is generally well-understood[8]. Lactose is a sugar found in all mammalian milk (Lomer, 2015). Lactose intolerance is caused by a decreased production of the corresponding enzyme lactase, which naturally happens in all human beings after they pass the age of breastfeeding (although there is some ethnic variance (Lomer, 2015)). A decrease in lactase production can also be caused by stomach problems or celiac disease, in which case the lactose intolerance is a secondary effect (Lomer, 2015).

Unabsorbed lactose in the bowels can cause several effects, according to Lomer (2015). The increased osmotic load can pull water into the bowels, resulting in watery stool or diarrhea. The undigested lactose can also cause fermentation, resulting in gas or bloating.

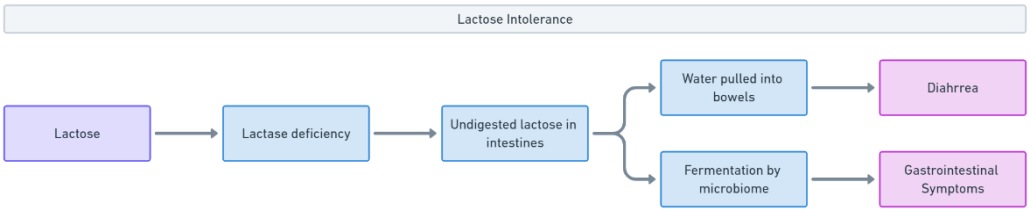

Figure 3.10. Mechanisms of Lactose Intolerance

While these effects can be unpleasant, they are seldom life-threatening. Sensitivity varies greatly between people, and many people may recognize that they are somewhat lactose intolerant but can still consume small amounts on a daily basis.

Milk Protein Sensitivity

Mammalian milk can also cause problems through its proteins, mainly casein and whey. Although a milk protein allergy is more common, mostly in babies (Mayo Clinic, n.d.), intolerances in adults can result in skin problems or stomach pain.

While some of the ingredients that can cause intolerances are well known, many of the chemicals that can be responsible for complaints are more obscure.

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[7] The presentation of the complexity of biological mechanisms for NCG/WS has the unfair advantage of the detailed work done by Molina-Infante et al. (2015). This flowchart is an excellent illustration of the many different systems that can be at play in any given tolerance.

[8] An expanded theory on the effects of the consumption of lactose when lactose-intolerant is discussed later in the chapter.

Some intolerances involve specific ingredients or components that are well known. Others are caused by the effects of certain chemicals, some of which people do not typically think about. Examples of this are histamine, sulfites, salicylates, glutamates, and caffeine.

Histamine

Histamine is a chemical that is naturally produced by the body, and also occurs in certain foods. Histamine is a neurotransmitter, and is also involved in gut regulation and stomach acid (Anthony, 2019). It is also released during an injury or allergic reaction (including IgE mediated allergies).

Histamine is coupled with a metabolizing enzyme called diamine oxidase. When the levels of diamine oxidase are too low, the amount of histamine in the body can not be properly regulated. A diamine oxidase deficiency can be the result of medication, gastrointestinal disorders, foods that trigger the release of histamine, or foods that contain large amounts of histamine themselves (Anthony, 2019).

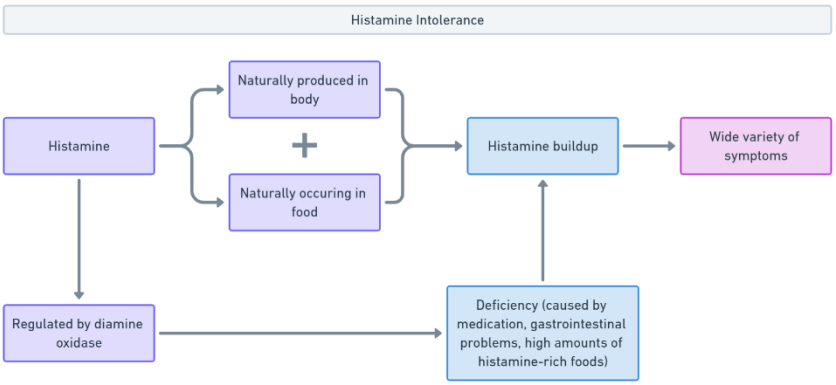


Figure 3.11. Mechanisms of Histamine Intolerance

In food, histamine is mostly rich in products that are aged or fermented, such as cheese, wine, beer, processed meats and canned foods. Spinach, avocado and eggplants are also high in histamine, while bananas, tomatoes, chocolate, citrus fruits and nuts can trigger a histamine release. On top of that, alcohol and tea can block the production of diamine oxidase. (Manos, 2020).

When the body has trouble regulating the amount of histamine, consuming foods that bring in large amounts of it can result in symptoms. Because histamine is a chemical that regulates many functions in the body, too much histamine can result in a wide variety of symptoms. These include headaches, flushed skin and itchiness, an increased heart rate, asthmatic symptoms, sneezing, nausea and stomach cramps, bloating, abdominal pain, diarrhea, irritated eyes and feelings of anxiety, as well as menstrual problems.

It is not exactly clear how many people have a histamine intolerance. Zopf et al. mentions that 1% of the German population is affected, 80% of which are middle-aged women (2009).

Salicylates

Another chemical that can cause problems are salicylates. Like histamines, salicylates occur naturally in a variety of foods. They can also be added as a preservative in foods and cosmetics, and are an ingredient in aspirin.

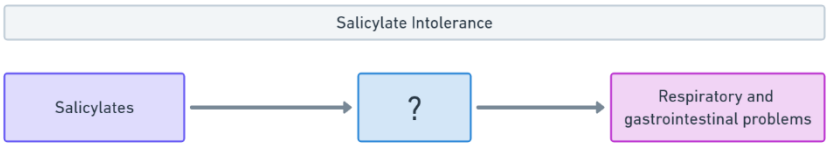


Figure 3.12. Mechanism of Salicylate Intolerance

The mechanism that causes the reaction is not fully understood (WebMD, 2017), although one possible explanation may be the overstimulation of mast cells, resulting in pro-inflammatory reactions and smooth muscle contractions (Lomer, 2015). Salicylates occur in a variety of fruits and vegetables, as well as herbs and spices, coffee, wine, beer, tea, nuts, ice cream, and some mint flavored candies. The reaction is mainly focused on the airways (Zopf et al., 2009), resulting in a blocked or runny nose or asthmatic symptoms. It can also cause gastrointestinal problems. Zopf et al. mentions that the prevalence in Europe is roughly 2.5% of the population (2009).

Sulfites

Sulfites are a third category of chemicals that occur naturally in foods. Like salicylates, they can also be added as preservatives. Again, the mechanism by which the intolerance operates is not fully understood, but sulfite intolerance seems to be more prevalent in people with asthma (Cleveland Clinic, 2020). The symptoms are also mostly organized around the respiratory system, including asthma attacks, a stuffed or runny nose, sneezing and coughing. Symptoms can also include skin problems and diarrhea.

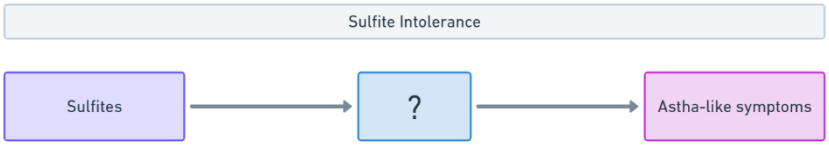


Figure 3.13. Mechanism of Sulfite Intolerance

Sulfites are found in beer, wines, dried fruits, pastry dough, canned foods, bottled citrus juices, pickled foods, and many condiments and soup- and sauce mixes.

Caffeine

A hypersensitivity[9] to caffeine actually exists, although it doesn't cause much more trouble than the average feeling of drinking too much coffee. There are two main mechanisms that can be responsible for a caffeine hypersensitivity. The first is a high sensitivity to the effects of caffeine,

[9] In this context, the term hypersensitivity is more fitting.

which is dependent on variations in the ADORA2A gene (Landolt, 2012). The second is a slower metabolism, which depends on the levels of the CYP1A2 enzyme in the liver (Sulem et al., 2011).

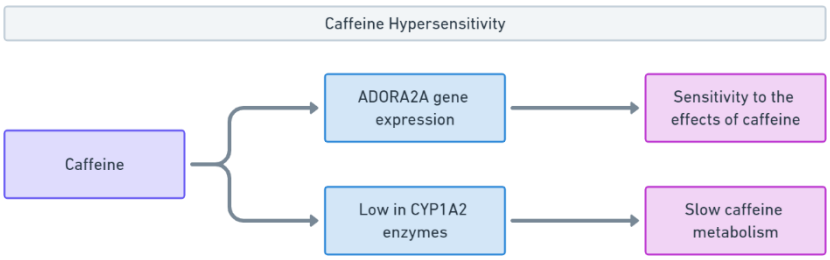


Figure 3.14. Mechanisms of Caffeine Hypersensitivity

As expected, the symptoms of caffeine hypersensitivity are an increased heart rate, slight anxiety, restlessness, insomnia and jitters, produced at a lower caffeine intake than most people[10].

Other Intolerances

The list mentioned so far is by no means exhaustive. Many other foods are known to cause intolerances in various capacities. Eggs (Caubet & Wang, 2011), food dyes (Kobylewski & Jacobson, 2012), lettuce, brewer's yeast, pork, tuna, rice, sole and asparagus (Caselli et al., 2017) have all been documented as triggering a reaction, as have many other foods[11]. In addition, an internet search of practically any ingredient followed by the words 'intolerance' or 'allergy' will give at least some positive results.

For the purposes of this project, the analysis above should be enough to illustrate the wide variety of combinations food intolerances can occur in.

[10] In contrast, roughly 10% of the population has caffeine hyposensitivity, which means the effects are reduced and go away faster. This is the result of a higher amount of CYP1A2 enzymes. (Sulem et al., 2011).

[11] It should be noted that specific ingredients commonly found in these foods could also be the cause of the reaction. Pork and tuna may contain high levels of histamine (depending on age and preservation method), while asparagus has high levels of salicylates.

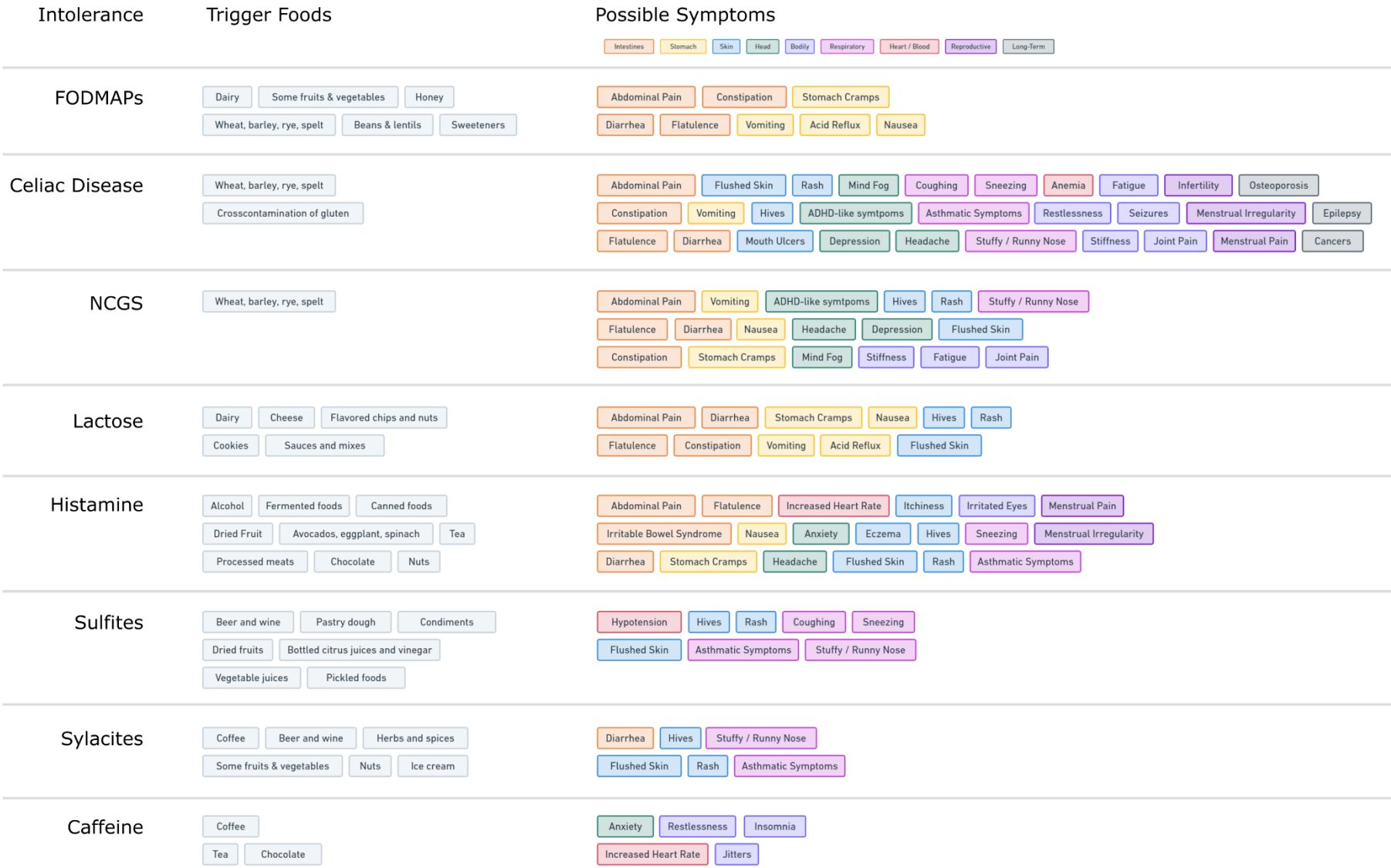


Figure 3.15. Common Food Intolerances and their Symptoms

3.5 The Prevalence of Food Intolerances

The exact amount of people that deal with food intolerances is hard to determine. As mentioned before, it is not always clear in scientific literature which symptoms and mechanisms are included when discussing food intolerances or allergies. Another major complication is the large difference between self-reported numbers from patients, and proven intolerances in medically supervised food challenges. On the other hand, it is possible that people technically have an intolerance, without noticing or acknowledging their symptoms.

Over-Estimation

The prevalence of adverse reactions to food is likely to be suffering from over-estimation and under-estimation, depending on the situation and source. People tend to self-diagnose food intolerances and allergies in themselves and their children, which can often be misguided and lead to unnecessarily limited diets. In a study of people with a self-diagnosed wheat or gluten intolerance (NCG/WS), 30% received a different diagnosis when tested by a professional (Tavakkoli et al., 2014).

The prevalence of food intolerances can also be overstated in marketing material. One website providing testing services for food intolerances mentions up to 45% of the population suffers from food intolerances (sportsgene.ee, n.d.).

Under-Estimation

On the other hand, intolerances that are diagnosed or confirmed for the purposes of scientific research have to be tested using higher standards. This usually involves some form of food challenge, where the patient consumes a type of food and monitors their symptoms for a period of time. The challenge can be combined with an elimination diet beforehand, that excludes any foods that are expected to cause a reaction. To increase the accuracy of the analysis, the food challenge can also be placebo-controlled. In this case, the participant does not know whether they are consuming a suspected food or a placebo.

This process is very resource-intensive and time-consuming. It is usually also designed to investigate a specific type of intolerance. Someone self-reporting stomach pain after eating bread might fail a controlled food challenge if they are only tested for one specific component (wheat or gluten), or if they were simply mistaken about what was causing their problems. While they might not be considered as an accurate positive for this research, something is still giving them a bad reaction. For this reason, it is likely that the strictest standards for intolerance testing might actually produce a prevalence rate is that is lower than is representable for the population[12].

[12] On the other hand, participants might experience a reaction when consuming a placebo food in a controlled test, simply because they believe they will react to it. This is called the nocebo effect.

Prevalence Rates in the Scientific Literature

These challenges in determining the actual prevalence make it hard to find reliable statistics. The academic field is quite honest about the lack of trustworthy prevalence rates (Madsen, 1997; B. I. Nwaru et al., 2014). Most papers opt for stating that their numbers are estimations, or provide a reasonable range. This challenge is not a new one, and if anything, the methods and classifications have only become more precise over time. A literature review from 1991 still groups allergies and intolerance as a single medical phenomenon, with an estimated prevalence of 1-2% (Anderson, 1991).

This mixed classification is another common challenges when comparing research papers. While Anderson reports a prevalence of 1-2% for allergies and intolerances, Zopf et al. states that 10-20% of the population suffers from adverse reactions to food (Zopf et al., 2009). The large difference in numbers could be explained by a change in our understanding of what counts as an allergy or intolerance, or in the willingness of Zopf et al. to consider self-reported numbers to be legitimate up to a degree.

In another study, participants were first screened through a survey (Young et al., 1994). People with self-reported food intolerances were asked to participate in a double-blind placebo-controlled food challenge. In the survey, 20% of participants reported food intolerances. Of those willing to participate in the food challenge, only 20% actually showed symptoms in a controlled setting. After accounting for those who did not participate, the researchers calculated the prevalence of food intolerances to be 1.4% of the population.

This number corresponds to Anderson's range (1991), but is far from the estimations of Zopf et al. (2009). However, Zopf's estimation was used in a review article (Lomer, 2015), which promotes the idea that this range is considered acceptable in some contexts as well. The same problem exists in the world of allergies. Nwaru et al. compared data from 42 studies for self-reported and tested prevalence rates for the eight most common food allergies, and found that self-reported numbers are consistently higher than the tested prevalence, with a difference of up to 15 times (B. I. Nwaru et al., 2014).

Why are people consistently reporting such much higher rates of intolerances? A study in 1999 sought to find out if people who self-reported intolerances were more likely to have psychiatric disorders[13] (Knibb et al., 1999). The study surveyed people with perceived food intolerances (PFI) and a healthy control group. While they did find higher rates of neuroticism and psychological distress (as well as "outgoing personalities") in the PFI group, they did not find any evidence for psychiatric disorders.

[13] The authors state: "In most adults who believe themselves to be food intolerant there is no objective supporting evidence. It has therefore been proposed that the misperception of intolerance to food is linked to psychiatric illness or personality disorder". The statement indicates a speculation from a study from 1985.

Perhaps getting a proper diagnosis is simply not worth it. 7.3% of Australians avoid wheat in their diet, while only 0.5% of Americans test positive for Non-Celiac Gluten Sensitivity[14] (Skypala & Vlieg-Boerstra, 2014). NCGS is a fairly new diagnosis that is mostly based on the exclusion of celiac disease (Molina-Infante et al., 2015), which can be hard to get acknowledged by a medical professional. Testing for this in Estonia would require the patient to consume gluten for several weeks, which is highly uninviting for someone who experiences complaints from them and has already removed them from their diet (*Liis Salus (Personal Digital Interview)*, 2021). However, a review article from 2015 places the upper estimation of NCGS prevalence at 13%, making it a significant cause of food-related complaints (Molina-Infante et al., 2015).

The most common reported numbers of food intolerances seem to be either in the 1-2% or 10-20% range. This seems to be based on whether self-reported statistics are taken into account or not. What is interesting here is that lactose intolerance is quite confidently reported to be present in 65-70% of the population (Lomer, 2015; Suarez et al., 1995). However, while most people are technically lactose intolerant (meaning their lactase enzyme levels have decreased after childhood), many of them will not experience severe enough symptoms to acknowledge it as a problem.

The total prevalence of food intolerances remains hard to determine. However, both self-reported and scientifically confirmed rates of intolerances are increasing (Skypala & Vlieg-Boerstra, 2014), and allergies are on the rise as well (Marrs et al., 2013). But knowing the exact numbers is not necessarily important for this project. Whether or not someone can be proven to show symptoms for a specific food group in a clinical setting is does not say anything about the actual human experience. A yes-or-no statement provides no insights about the severity of the symptoms, the exposure necessary to trigger symptoms, and how complicated this component is to avoid in daily life. It also does not address the psychological aspects of managing a food intolerance, which will be discussed in the next chapter.

For scientific research, it might be preferred to err on the low side to make sure no false positives are reported. However, to support people with food-induced complaints, it is probably better to include everyone that might benefit from a solution. For this project, we will assume 10-20% of people experience intolerance-like symptoms when consuming certain foods.

[14] Because statistics are often missing or incomplete, different regions may need to be compared to form a conclusion.

3.6 New Developments in the Field

Scientific research in the world of food intolerances is still rapidly developing. Where research from 30 years ago does not even distinguish between allergies and intolerance (Anderson, 1991), we are now at a point where we understand multiple biological mechanisms that can be responsible for the various symptoms caused by different foods. Single diagnoses are split down further into distinct categories, as we learn to better understand what exactly is causing the symptoms to occur.

Recognizing New Conditions

Non-celiac gluten sensitivity (NCGS) was first described in the literature in 1976 and 1978, but has only been getting clearly defined and recognized as a separate disorder since roughly 2010, as described in a review article by Molina-Infante et al. (2015). Liis Salus confirmed that at least in Estonia, the diagnosis NCG/WS is not recognized, and would be hard to find support for (*Liis Salus (Personal Digital Interview)*, 2021). Besides, the diagnosis of NCG/WS is mostly based on the exclusion of celiac disease, by testing for antibodies and damage to the villi[15] (Molina-Infante et al., 2015). The review article also mentions that as of 2015, there has not been a re-challenge study of NCGS that used isolated gluten. Instead, gluten-containing foods like bread were used. But wheat, barley, rye and spelt also contain other compounds that can trigger a reaction, both in the form of proteins and carbohydrates (Molina-Infante et al., 2015). This raises the concern that even in specific NCG/WS studies observations may have been mixed or misinterpreted[16].

Recognizing New Mechanisms

Another recent development is a shift in focus from single compounds or pathways to the broader consideration of the body and digestive tract. As is often the case in biology, the whole is more than the sum of its parts. The way food is delivered, and the system that awaits it, influence how the process of digestion and absorption take place. This idea is also represented in two new theories, presented by Campbell et al. in 2010, and Skypala & Vlieg-Boerstra in 2015 respectively.

Campbell et al. (2010) propose that improperly digested carbohydrates would pass on from the small intestine to the large intestine, where a large number of bacteria in a low-oxygen environment awaits them. This would create a metabolic process that is different from the digestive process in the small intestine. During this process, the byproducts of the breakdown of these carbohydrates would consist of various alcohols, diols, aldehydes, ketones, and acids, some of which in turn have been proven to elicit cellular changes and gene expression.

This could result in the wide variety of seemingly unrelated symptoms we have come to associate with food intolerances, such as headaches, fatigue, eczema, and cognitive dysfunction, as opposed

[15] The finger-like protrusions in the small intestine, which are damaged when exposed to gluten for those with celiac disease.

[16] This is the flipside of the consideration described earlier regarding overly strict food trials for scientific research. If the conditions are too strict, people with valid intolerances can be filtered out of the results. If the conditions are not strict enough, as is the case here, newer research might make older results less useful.

to the gastrointestinal problems which might seem more obvious. The authors pose that the malabsorption of carbohydrates in the small intestine could be the result of a lack of enzymes, or a dysfunction in the transport to the blood.

According to the authors, this could be the answer for some people with unexplained wheat or gluten sensitivities. They also pose that this is likely to be the case for people consuming lactose, as ⅔ of the population does not produce enough lactase to break down the amounts present in the contemporary western diet (Lomer, 2015; Suarez et al., 1995). Understanding that this mechanism could be responsible for many various symptoms might be helpful to the many people that are diagnosed with Irritable Bowel Syndrome, which is the most common condition seen by gastroenterologists in the UK (Campbell et al., 2010) and which is often used as a blanket diagnosis for intestinal discomfort (*Liis Salus (Personal Digital Interview)*, 2021).

This more holistic approach is also represented in a review paper by Skypala & Vlieg-Boerstra (2015). They pose that the approach of researching food intolerances is shifting to a more systemic approach of the whole diet. They wonder if the increase in food allergies and intolerances (both self-reported and scientifically checked) could be the result of bad dietary habits.

The authors speculate that a bad diet could lead to the development of allergies and intolerances. Alternatively, a diet that does not support good digestion could show intolerance-like symptoms, perhaps in a similar mechanism as described above. The authors point to the fact that children in Hong Kong show higher rates of food allergy than those born in mainland China, which might be caused by the more 'Western' diet in Hong Kong. A similar concern was raised in 2009, when it was noted that the Westernization of the Chinese diet had resulted in an increase in the consumption of animal protein and fat (Zhai et al., 2009). As a result, undernutrition declined, but overweight and obesity increased in the whole population, including children. The authors warned that the burden of chronic noncommunicable diseases (lifestyle diseases) had grown in the same period.

The health of the gut microbiome has been proven to have serious effect on our overall health. Early childhood may be a crucial developmental period for our gut. It has already been shown that children with allergies show distinguishable differences in their gut microbiome compared to healthy kids of the same age (Ling et al., 2014), and that having siblings reduces the risk of developing allergies, unless those siblings have allergies themselves (Koplin et al., 2013). Besides, children delivered through a caesarean section have an increased risk of allergies, while being sent to daycare at a younger age reduces the risk (Marrs et al., 2013). Based on these findings, it seems clear that early exposure to a wide variety of pathogens actually increases resistance and health in later life.

Another key factor is variety of nutrition, as three separate studies found that a high food diversity in early life leads to a lower rate of food allergies (KE et al., 2014; Bright I. Nwaru et al., 2014; Roduit et al., 2014). Gut microbiome health is not only related to allergies, researches were even able to correctly predict childhood obesity based on stool samples of young children (Kalliomäki et al., 2008). Antibiotics use before reaching 6 months of age have also been associated with a

higher BMI in later childhood, due to a less diverse microbiome that does not recover in time (Trasande et al., 2013). This sentiment was even echoed recently in a publication about Estonia's centenarians, who tend to have a more diverse and robust microbiome than younger people, most likely due to their exposure to animals and the countryside from a young age (Tambur, 2021).

The world of research is always ahead of the world of clinical practice, while the adoption into culture may come even later or not at all. But these examples make it clear that our understanding of food intolerances is far from complete, and that our theories are still developing.

4 THE EXPERIENCE OF FOOD INTOLERANCES

As the previous chapter has shown, food intolerances consist of a wide range of symptoms, caused by a wide variety of ingredients. The degree of sensitivity is also different for each person. This makes food intolerances a very personal experience.

We are still discovering new mechanisms of food intolerances, and important factors that influence them. While the latest research can take some time to reach individual patients, information about intolerances is easily found online, with concrete advice about foods to avoid and how to best replace them. These developments are helpful. But the personal point of view of the patient is often neglected in scientific studies or informational articles.

To learn about the lived experience of food intolerances, I conducted interviews with various stakeholders, found personal blog posts and stories online, and hosted a workshop. I also relied on my own experience. As I collected these stories, I saw that just like the symptoms, the journey of each patient is personal and unique. The condition itself, the diagnostic process, the person's surroundings, and their attitude all contribute to the overall experience.

I also found some important similarities between these different journeys. This helped me define four main phases that most people go through: recognition, diagnosis, integration, and management. Each phase has a particular character and comes with its own challenges. These four phases are explored in detail in this chapter.

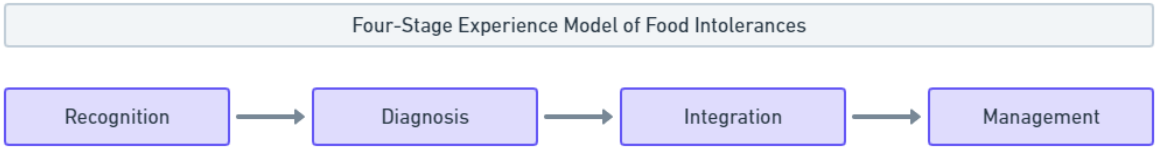


Figure 4.1. Four Stages of Experiencing Food Intolerances

This journey has strong social and emotional elements, that extend from the patient to their surroundings. Food is a core part of our culture, and has a role in many social interactions. Besides, when we are battling chronic complaints, they inevitably influence all aspects of our lives. The journey also connects to the medical sphere, as it often involves interactions with doctors and nutritional experts. The diagnosis leads to changes in diet, which then result in broader lifestyle changes and new considerations for social interactions. Overall, food intolerances tend to touch many aspects in the patient's life.

Because this journey spans different stages, it can contain a wide variety of stakeholders. At the core is the patient, who interacts with three main categories of other stakeholders: social relationships, service-based relationships, and medical relationships. How the patient relates to these groups can change over time, as the diagnosis and management of food intolerances influences the way we interact with others. These topics will be further explored in this chapter.

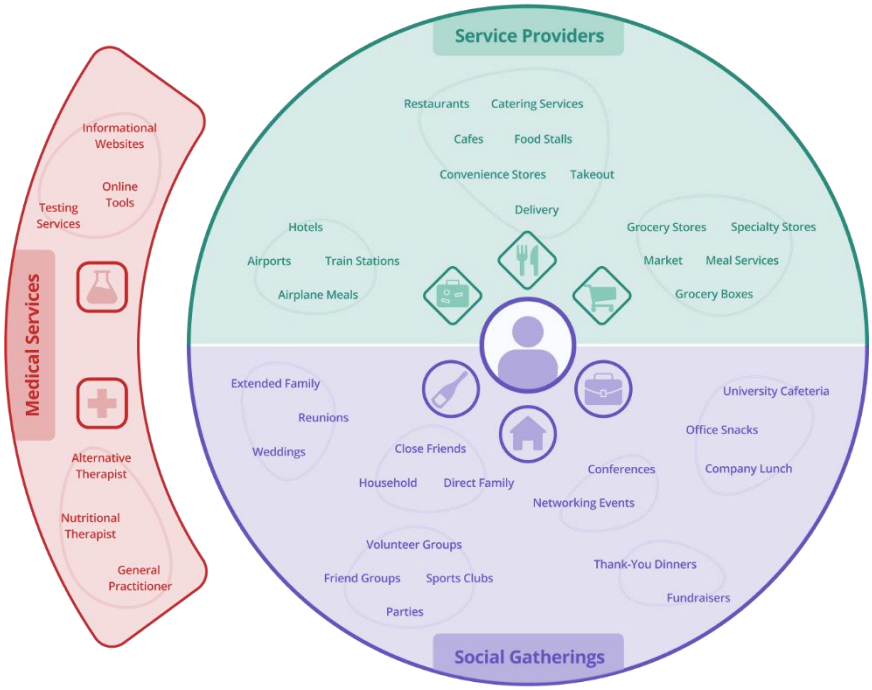


Figure 4.2. Stakeholder Map for the Lived Experience of Food Intolerances

4.1 Recognition

The first step of working with food intolerances is recognizing them for what they are. This is typically the first major challenge. Food intolerances tend to develop slowly over time, while the symptoms can vary in type, location, and intensity. Mild symptoms are often dismissed as temporary discomfort or being slightly sick, and are expected to resolve over time.

Going to see a doctor for these vague symptoms can be uninviting, especially for those that don't have strong relationships with their GP in the first place. If the discomfort persists on a tolerable level over time, it can also simply be accepted as the status quo, or a sign of getting older. For this reason, it is not unthinkable that many people live with unrecognized food intolerances that are unlikely to get diagnosed. In her interview (2021), Hannie shared that she had felt vaguely bad for years, but simply attributed her symptoms to stress.

The Impact of Chronic Symptoms

While food intolerances may not automatically be associated with chronic disease, even mild chronic symptoms can have a severe impact on our quality of life, both physically and emotionally.

In two blog articles, Unmana Datta describes her experiences with the chronic fatigue she experienced as a result of undiagnosed food intolerances (Datta, 2017, 2018). She expresses her guilt for relying on her husband to take care of her and their household, after being so sick she needed to quit her job. She recounts how she was described as lazy by her parents and teachers, until she internalized the criticism and simply accepted this apparent truth. This was the reality of her life, until she realized she was intolerant to dairy and wheat and started cutting them out of her diet.

While this may sound like a miracle story, it is close to my personal experience. Around ages 19 through 21, I was battling chronic fatigue, combined with stiffness and muscle tightness. On some days, I would be unable to wake up for hours. Despite eating a healthy diet, working out multiple times per week and having a stable rhythm, I felt lethargic and weak. At the time, I attributed these problems to spinal work I was doing with a physiotherapist. While I always felt better after a session, I also realized I was becoming dependent on them, which was a very scary feeling. But I accepted that this might simply be a medical condition I could not influence. Then, when I got diagnosed with a gluten intolerance and removed them from my diet, these symptoms completely disappeared, and I felt better than I had thought possible.

Visiting the General Practitioner

The decision to visit a doctor can be motivated in several ways. Even mild symptoms are worth investigating if they persist for long enough. Sometimes, symptoms get worse over time, either slowly or quickly. Another influence can be new information found by the patient, or hearing about experiences from someone else.

When people do visit a doctor, they might hope to find a clear answer about their mysterious symptoms and be advised on how to treat them. But in practice, this seems to rarely be the case. Food-related problems are often misdiagnosed, or only treated by suppressing the symptoms themselves.

Heleen Furster recalls how one of her clients showed increased inflammation markers in bloodwork done by the GP (Interview, 2020). The client was told this was probably the remnants of a cold or flu, which would go away by itself. Heleen also described the case of a middle-aged client, who was challenged with incontinence. The medication her doctor prescribed was only partially successful, and the problem remained. When the client visited Heleen's practice (on her own initiative) and was tested for food intolerances, it became clear that certain foods she was regularly consuming were the cause of her problems. Removing these foods from her diet was far more effective than her medication.

4.2 Diagnosis

Once the symptoms are recognized as being caused by food, the goal becomes to determine which exact foods should be restricted or completely eliminated from the diet, and which can remain. Finding this balance is important. Cutting out food unnecessarily makes the diet harder to follow, which decreases the patient's quality of life. Restricted diets also have a higher risk of resulting in malnutrition.

Diagnosing food intolerances can be done using different tools, and with the help of different professionals. The participants of this project showed a large diversity in the methods they used. For some participants, the diagnostic process was very positive, while others had disappointing or frustrating experiences.

Professionals

As discussed in the previous chapter, self-diagnosis of food intolerances and -allergies often leads to questionable results. People often completely misdiagnose their (perceived) intolerances, or get the details wrong. In most cases, professional help leads to a better result, although this path is not without its challenges.

General Practitioner

The general practitioner is often the first professional that is consulted for any medical issue. In Estonia, the GP's role is to provide basic consultations and treatments, and refer the patient to other experts if necessary.

While GPs are trained to have a broad medical knowledge, several concerns have been raised about their knowledge about nutrition. U.S. medical schools have been criticized for providing inadequate education about nutrition (Adams et al., 2010; Bruer et al., 1994), and a study from 2019 found that these skills are lacking in medical students worldwide (Crowley et al., 2019)[17]. For this reason, GPs might not be the best source of information in the diagnosis of food intolerances[18].

Liis Salus (Interview, 2021) described her personal experience with getting diagnosed with celiac disease. She recalls feeling extremely tired, and staying sick with the flu for four or five months before recovering. Her doctor was not sure how to treat her, and proposed she might have Irritable Bowel Syndrome[19]. After trying a low-FODMAP diet without result, Liis requested test for celiac disease from her doctor. The first test came back negative, but a follow-up exam confirmed her suspicion. Getting this diagnosis took roughly seven months, and the tests were only done because she insisted herself.

From the GP, the patient is typically referred to an expert in the field of nutrition. In Estonia, this is invariably a nutritional therapist.

Nutritional Therapist

In Estonia, a nutritional therapist is a recognized medical professional that can diagnose, test and guide people with dietary challenges for various diseases. Nutritional therapists can be referred to by a GP for heart problems, cancer, gout, arthritis, osteoporosis, celiac disease, and lactose intolerance. While nutritional therapists are the only officially licensed professionals in the field of medical nutrition, their services are always paid privately and not covered by the Estonian Health Insurance Fund (haigekassa)[20]. Besides taking referrals from GPs, nutritional therapists can also

[17] A commentary piece on this article mentions that incoming students often show a high motivation to learn about nutrition, but that this motivation decreases over time. The author hypothesizes that this might be because students do not see examples of how the knowledge could be applied in practice during their studies (Devries, 2019).

[18] However, 61% of U.S. citizens considered GPs a trustworthy source on nutrition (Starkey & Ryan, 2000).

[19] From her professional point of view, Liis described IBS as a blanket diagnosis that is often given to patients to be able to name their condition, without actually specifying what is the cause of their symptoms.

[20] A session with a nutritional therapist in Estonia typically costs around 60 euro. While this is not overly expensive, it does limit the availability of nutritional advice in those with low financial means.

be hired privately. Estonia currently has 24 nutritional therapists[21] (Eesti Toitumisteraapia Assotsiatsioon, n.d.).

A nutritional therapist typically assesses the patient's medical history and discusses their complaints in an intake process. It is also standard practice to use a food log for at least a couple of days, to see what the diet of the patient looks like. By analyzing the patient's symptoms and their diet, the nutritional therapist tries to identify common foods that may be causing problems for the patient.

In some cases, the therapist can use food intolerance tests to help the diagnostic process. Whether or not these tests are used depends on the patient and the therapist. In some cases, having concrete test results can provide a feeling certainty for the patient. However, Liis Salus warns that the tests are far from conclusive, and should only be seen as a supplement to more robust methods like elimination diets and food challenges (Interview, 2021).

From there, the therapist typically suggests some form of an elimination diet. Depending on the nature and severity of the complaints, and the analysis of the results so far, the diet can exclude some specific items, or exclude most common trigger foods at once. In the latter case, the low-FODMAP diet provides a reliable way of excluding many ingredients that can cause symptoms[22].

After some days, the effects of the diet are evaluated. If the intervention is successful, foods can slowly be added back to see which exact ingredients cause symptoms, and what amounts are tolerable. The process of assessing the medical history, keeping a food log, and following an elimination diet can be a slow process of trial and error that spans several weeks. However, it is scientifically supported as the most reliable method of diagnosing food intolerances.

Working with a nutritional therapist does have limitations. Liis Salus explains that some conditions are not officially recognized, or can be hard to find support for. Less common intolerances such as sulfite- and salicylate intolerances are not always included in regular education, and might require help from a professional specialized in this area. Getting an official diagnosis when the patient has already taken certain foods out of their diet might also require them to re-introduce the food for several weeks to see the results. This is highly unmotivating for anyone who already knows they experience symptoms, and may discourage them from getting an official diagnosis.

While nutritional therapists are the officially recognized way to diagnose and treat food intolerances, their support is limited to a controlled field with certain pre-defined practices. While they may be a good fit with scientific backing for most people, some may look for alternatives.

[21] Nutritional Therapists should not be confused with Nutritionists, who – In Estonia – are also trained in the field of nutrition but do not give medical advice. The name of this profession varies between countries. In many countries, a licensed nutritional expert that treats medical issues is called a Registered Dietician, and the title Nutritional Therapist is used for someone providing alternative treatments (Second Nature, 2021).

[22] The low-FODMAP diet is described in more detail in Chapter 3.

Alternative Therapists

The field of Alternative Medicine covers a wide variety of practices that are not officially recognized by the scientific medical system. For food intolerances, these practices include bioresonance testing, kinesiology, acupuncture, reiki, herbal healing, Ayurveda, and technically any other practice that claims to be beneficial in the diagnosis or treatment process.

There are good arguments that support the use of alternative medicine, as well as solid arguments against it. The field of alternative medicine hosts a variety of practices that is too broad to judge as an individual method, and different modalities may be more suitable for different situations.

One of the benefits of alternative medicine is that it tends to be focused on a holistic view of the body, the mind, and the systems in which the person lives. Where Western medicine can be critiqued for being reductive and too focused on individual symptoms, many alternative medicine practitioners focus on the symptom as an indication of a bigger trend. The patient's mental state, stress levels, lifestyle, overall fitness and sometimes even spirituality are considered to be influential too. This holistic view is well-suited for food intolerances, which can be caused by a wide variety of problems.

Because of the wider variety of modalities and backgrounds in alternative medicine, practitioners may have a more diverse background and 'toolkit' to work with when treating their patients. This can be a benefit in the treatment process, but also creates less consistency between different practitioners. Because of this, the quality of treatment can be very dependent on the practitioner.

The lack of scientific evidence can be a turn-off for many people. Since alternative therapists are not often referred to by doctors, their patients have to find them by themselves, either through the internet or recommendations from others. Furster's practice, for example, gets its clients mostly through recommendations from others, and from being locally known (interview, 2020). While she employs a mixed modality of methods (one of which is bioresonance testing) to diagnose and treat a wide variety of problems, many of her methods lack the scientific backing that would be required for her to be considered a valid option in the eyes of the medical system. At the same time, her track record of anecdotal evidence is very good, and she has a positive reputation in the area.

In contrast, Stan received a diagnosis from another practitioner that used bioresonance testing, and was discouraged by the lack of scientific backup for the claims she made (interview, 2021). He indicated a strong preference for scientific methods, although ultimately the alternative therapist's recommendation to switch to a vegetarian diet proved helpful, with even more improvement of his symptoms after he went vegan. Hannie had the opposite experience with an alternative therapist (interview, 2021). Her diagnosis proved mostly correct after a single consultation, and she experienced major improvements from following the advice of her therapist.

Finding scientific evidence for the effectiveness of alternative medicine can be difficult. In a survey-based study from 2006, 380 families with various food allergies in the New York area were asked about their use of Complementary and Alternative Medicine (CAM) (Ko et al., 2006).

Approximately 1 out of 5 respondents had used an alternative modality to diagnose and treat their allergies. The most common types were chiropractors, homeopaths, and acupuncturists. Overall, the participants judged the effectiveness of these methods as low[23].

Alternative therapies and diagnostic methods may be beneficial for patients, perhaps more when the modality matches the way the patient likes to work. For people who require strong scientific evidence to feel comfortable in their diagnosis, nutritional therapists may be a better fit.

Common Tools

Testing Services

Several types of tests exist to help diagnose food intolerances. While these tests have questionable scientific evidence for their accuracy, they are used by both professionals and consumers. The test typically collects a sample of saliva, blood, or hair, which is sent to a lab for analysis. While the test results can be helpful, they should not be taken as conclusive results. Instead, the results can be helpful to determine which foods should be tested in an elimination diet.

Liis Salus explains that she typically does not even recommend the use of tests, as they usually do not add much to the diagnostic process (Interview, 2021). If the patients has old test results, she includes them in her process, but older test results often prove less applicable to the current situation. Services that offer tests directly to consumers, either through clinics or using an at-home testing kit, should state that the test results are not a perfect indication of food intolerances, but this information is not always clear.

Forums and message boards that discuss food intolerances show a variety of reactions to testing services. One user under the name *keyboardqueen90* posted a message saying their test showed a sensitivity to eggs, yeast, dairy products, coconut, and gluten, and expressed her fear of how these severe limitations would be impossible to adhere to, as every supermarket product contained at least one of those items ([keyboardqueen90], 2018).

Another user called *linsage* ([linsage], 2016) on a similar forum explained how their various medical issues improved after taking gluten and dairy out of their diet, but their problems redeveloped over time. *Linsage* then saw an ad for a food intolerance test, which they describe as "..expensive, but my curiosity and anxiety got the best of me, and I am SO glad that it did." While their results seem to consist of unrelated food groups (salmon, chickpeas, lemon and cantaloup), *linsage* had anecdotal evidence for each of these items.

Several commentors under both posts pointed out the limited evidence for the accuracy of these tests, and tried to temper the strong emotions experienced by *keyboardqueen90* and *linsage*.

[23] As discussed in the previous chapter, it can be hard to find information specifically about intolerances, because they are both less studied and often combined with allergy data. As the mechanisms of intolerances are very different from those of intolerances, the low effectiveness of these methods for allergies may not translate to the field of intolerances.

These warnings align with the view of doctor Andre Sommer in his article about the IgG tests (Sommer, n.d.), where he warns that testing services often profit from scaremongering. He claims that IgG tests can not accurately detect food intolerances at all, and that the changes people make in their diets as the results of these tests are often overly restrictive and rooted in fear.

But despite the lack of scientific evidence, testing services are increasingly popular. Besides their strong marketing tactics (including sponsored articles (PaleOMG, 2018) and videos (Natural Kaos, 2020)), promising quick and reliable results from the comfort of your own home, they also fit a modern view on medical analysis. For many people, taking their health and wellbeing into their own hands through independent services that work on their terms is a sign of empowerment. The results of the tests are often shared through pleasant and modern digital platforms, or even come with impressive apps and personalized health recommendations. These factors, understandably, attract the interest of many people.

But it seems that these tests are not very helpful at best, and make misleading claims that lead to extreme emotions at their worst. This adds more confusion to the diagnostic process, and shows how the help of a professional can be beneficial.

Food & Symptoms Diary

The food diary is a staple tool in the identification of food-related complaints. For a period of several days or weeks, the patient logs everything they eat throughout the day. The diary can contain ingredients, preparation methods and the amount of food. For the use of medical diagnosis, symptoms that are felt throughout the day can be logged as well. The patient or a medical professional can use the log to look for patterns.

Food diaries are a very accessible tool for most people, with very little downsides. Several templates and apps can easily be found online, many of them completely free. Nutritional experts also often have their own version that they give to patients they are working with.

The main downside of food diaries is that they are time-consuming, and can be seen as boring[24]. The other limitation of food diaries is that they are only the first step, and still require interpretation to formulate a follow-up plan. This often includes a diet that eliminates suspected foods.

Intuition

Perhaps the most important element during the whole process of diagnosis is the patient's intuition. As vague and unidentified symptoms take shape and start being understood, the patient can start to understand how they respond to certain foods, and what might make their symptoms less severe, or worse. This skill is essential in the daily management later. A strong intuitive sense

[24] On the other hand, constantly tracking food may result in compulsive behavior in some people. In one study, a group of 106 participants aged 18 to 25 were surveyed about their use of fitness apps to track their food intake (Honary et al., 2019). Almost half of the participants experienced negative feelings from the use of those apps, including feelings of guilt, social isolation as the result of restricted diets, and fear of failing to reach their targets. While the use of food trackers for diagnosing food intolerances is less likely to have these results, it is important to note that these problems exist.

of what foods and amounts are acceptable and which should be avoided can help the patient to make decisions in daily life without the need for other tools. This greatly improves the quality of life.

As Hannie shared in her interview (2021), she can tolerate certain amounts of oil and gluten without feeling strong effects. She also makes sure to carry medicine for acid reflux, in case consuming too much oil is unavoidable. I personally learned to estimate how much gluten I can tolerate without feeling symptoms, and how much of the symptoms I can mitigate using supplements[25]. If that is not enough, I can anticipate I will require more sleep and be more tired, and plan accordingly. Liis Salus has a similar experience (Interview, 2021), and knows that her sensitivity to gluten will result in at least a couple of days of feeling fatigued each month, as avoiding cross-contamination is almost impossible.

One important consideration is that this intuition needs to be based on some reliable findings. As discussed in the previous chapter, people are likely to misdiagnose themselves and attribute their symptoms to the wrong causes. This can cause them to remove more ingredients from their diets than necessary, which may alleviate their symptoms but make their diet more complicated to follow than necessary. This is especially likely when using testing services without professional support.

A well-developed understanding of which ingredients cause reactions in what doses help the patient understand their condition, and are a huge improvement over the previous experience of unexplained symptoms. It can also help them anticipate symptoms, or make informed decisions about what they choose to eat. Anticipated symptoms are more pleasant to deal with than surprises, and this already results in a major win in the experience of the patient.

Conclusion

Diagnosing a food intolerance is far from straightforward. The process can be done alone, although professional help can make the process more reliable and pleasant. While tests are available, their results are unlikely to be accurate and require professional interpretation.

Most people interviewed for this project described this part of their journey as complicated and frustrating. They often felt misunderstood, couldn't find the answers they were looking for, or felt uncomfortable with the care they were receiving. While the successful diagnosis of a condition can be relieving, it can take a lot of time and testing before the answer becomes clear.

It should also be kept in mind that symptoms can change over time, and that the examination of symptoms and trigger foods is an ongoing process. Some intolerances never fully go away, while others may get worse or resolve themselves over time. Since intolerances can be secondary results of other problems, fixing the root cause may remove the intolerance too. Poor gut health,

[25] Whenever I do consume gluten, I use magnesium citrate to mitigate the resulting muscle tension and fatigue. I haven't been able to determine through which exact mechanism this works. Various conflicting theories exist, including the fact that it might be a placebo effect.

as the result of a general poor diet, can result in digestive problems. Improving the quality of the diet (which may include removing foods that trigger the intolerance) can give the gut microbiome time to heal, which in turn can result in the intolerance being resolved.

This brings us back to the importance of developing an intuition for our health. When people develop the ability to judge their sensitivity to certain foods and recognize changes over time, they are better able to adjust their diet without relying on medical professionals. Of course, drastic or unexpected changes will still benefit from professional intervention.

4.3 Integration

After the diagnostic process, the patient will end up with a set of recommendations to change their diet. Whether this completely changes their diet or only requires some specific interventions depends on the intolerance and the current diet. Cutting out lactose will be easier for someone who occasionally eats cheese than for someone whose meals regularly contain milk, yoghurt, butter, sauces, and processed foods.

Some ingredients are easier to spot than others. All milk products need to be clearly marked on ingredient labels, but these laws don't exist for histamine-rich foods. In most cases, people will need to memorize which types of foods contain the ingredients they should be avoiding. During the co-design workshop, Eliis shared that she mostly buys the same products that she knows to fit with her vegan diet. This was echoed by Linnea, who mostly relies on whole foods and has a hard time finding processed items that do not give her trouble.

During this period, the challenge for the patient is dual. They have their own adjusted diet to integrate, which may include cutting out some foods that they truly enjoy eating but must now learn to give up. On the other hand, food ingredients are suddenly split into two categories that did not exist before: things that are bad for you, and things that are okay. This is an important distinction that was typically not considered before.

During the integration period, the patient needs to start evaluating and adjusting their lifestyle in all areas that interact with food. This includes groceries, cooking, ordering food or eating out, social situations, workplaces, travel, etc. While some interventions may not be very serious, the combined effort of evaluating and adjusting each of these areas can be a serious challenge.

Direct Household

The people that are affected most besides the patient are the people they live with. This can be the direct family or housemates, or a romantic partner. As the transition to a new diet happens, the household (hopefully) supports the patient, and adapts with them.

An important step is to decide on which products may get cut out, replaced, or bought in separate versions. The whole household can switch to drinking lactose-free milk, or they can decide two buy two types. This consideration also applies to shared meals. Hannie describes how she and her son eat a vegan diet, but her husband prefers to stick to the food he is used to (Interview, 2021). Her

daughter is on middle ground. In some cases, they all eat the same meal, but often dinner will contain some vegan and some non-vegan elements, or consist of two separate meals altogether. To avoid mixing foods, they keep labeled bins in the pantry and freezer. At the same time, the whole household uses sunflower oil, which is one of the few oils Hannie can tolerate.

In contrast, many younger participants in the survey shared their desire to go fully vegetarian or vegan, but said they were limited by living with their parents. They indicated they would make different dietary choices if they were living alone, but being part of a family unit, they felt like they should sometimes put aside their morals to fit in and avoid making things complicated.

Adopting a new diet often creates a learning curve for the whole household. However, most patients indicated feeling supported by their friends and family.

Groceries

The new distinction between food that is alright, and food that should be avoided, carries through in doing groceries. It suddenly becomes important to read ingredient labels on almost every product, which is a new experience for most people.

Many products now have versions for people with restricted diets. Gluten free bread and cookies, lactose free milk and plant-based alternatives, wine without sulfites, and vegan meats can be found in every major supermarket, and even in smaller convenience stores. Liis Salus even recommended an Estonian gas station chain, mentioning that their fresh food selection is remarkably suitable for a gluten free diet (Workshop, 2021).

But the availability in supermarkets is not perfect, as is the logic of the shelves. Of course, supermarkets benefit from having their customers wander around the store (Rupp, 2015), but finding foods for a restricted diet can be a hassle. Participants of the project expressed their frustration with the placement of vegan and gluten-free products on multiple occasions. In many cases, one clearly marked shelf holds most of the products, but many individual items are spread throughout the store. These individual items are often poorly labeled, which makes finding the right groceries a time-consuming treasure hunt.

Dutch supermarket chain Albert Heijn announced the addition of shelf-labels for over 600 vegan products in 2019 (Albert Heijn, 2019), specifically meant to combat this problem. These initiatives are extremely helpful for those looking for vegan products. At the same time, they don't do much for people on a gluten-free diet, people avoiding sulfites, or someone looking for an egg-free baking mix[26]. These store-driven labeling efforts reflect consumer behavior, but are not universally applicable.

In the workshop (2021), Linnea expressed her struggle with finding any processed foods that she would be able to eat. With the large number of ingredients she needs to avoid, she barely bothers

[26] In defense of Albert Heijn, they do use individual labels for vegan, vegetarian and biological products, and their website has an educational page about gluten-free diets with suitable products (Albert Heijn, n.d.).

trying to find new products. She sticks to the foods that she knows, something that was echoed by Eliis for her vegan diet.

Social Eating

Eating Out and Ordering In

Changing your diet also means rethinking your favorite restaurant meals. Restaurant meals are typically more rich than homecooked food, and can result in more discomfort for people with a sensitive digestive system. Most restaurants nowadays have gluten-free and plant based options, or can modify a menu item to suit specific needs. Still, some participants to the project indicated that they stick to their favorite restaurants that they trust, some of which are specifically marketing themselves to certain diets.

Eating out in groups also extends the impact of the situation beyond the patient themselves. While most restaurants have suitable options for special diets, this is not always the case. This means that the selection of the restaurant will be limited by the least flexible person in the group. Being this person can feel like a burden, especially when the patient themselves is not used to their new dietary restrictions yet. At the same time, not standing up for their own needs will result in feeling discomfort later.

Food in the Workplace

Food in the workplace presents an intricate balance between a professional environment and social interaction. Many workplaces offer snacks, some even organize a daily lunch. Events and anniversaries are celebrated with dinners and cake, and meetings and conferences often involve food in some way.

For someone with a newly limited diet, announcing this change can feel unnatural. Especially when just starting out, this change is not yet integrated for the patient themselves, and exposing it to the outside world can be a challenge. This challenge is even bigger when someone is the first one to bring a certain diet into a workplace. Being the first comes with the responsibility of educating the food organizers, and uncertainty about receiving support from them. It is much easier to be the third gluten-free person in a team than being the one that needs to introduce the concept.

As a university researcher, Eliis (Interview, 2021) has become involved in organizing the policy for the university cafeterias. She is strongly advocating for reliable vegan options, something that is lacking in the university now. Despite helping shape the policy of the cafeterias, she can rarely find food there herself. When she does, it’s usually a combination of side dishes.

To gather more information about how workplaces organize food, I interviewed two HR managers, Antoinette (2021) and Kätlin (2021). Both order groceries for teams of roughly 60 people. Antoinette’s company offers lunch to the team every day, while Kätlin’s workplace mainly keeps a supply of snacks.

According to Antoinette, the meaning of the daily lunch is more than just the food: it’s a moment where the whole workplace comes together, and different teams and ranks can socialize. She

knows which people have vegan, vegetarian, and gluten-free diets, and tries to order groceries to suit them. At the moment she simply remembers who eats what, since the team is not that big. She admits that when she started as HR manager, she had no idea about these specific diets, but she has learned over the years and now brings up the topic with new hires during job interviews.

Kätlin has a similar policy: she knows who has a specific diet and takes them into account, and adjusts the weekly groceries upon request from the team. According to her, the team is very direct and comfortable with requesting new items. The company offers drinks, ice cream, dairy and almond milk, yoghurt and cereals, fruit, chocolate, cookies and nuts to the employees. During special events, the company orders food and drinks, during which they make sure there are vegetarian options available.

Both HR managers mentioned that they can remember who has special dietary requirements in the team, but might struggle if the team was much larger. Both want to be responsive to requests of the team, and hope people don't feel afraid to bring up requests.

When this topic was brought up during the workshop, some participants discussed the delicate social situations specific diets can present in workplaces. In some cases, it's not clear which foods are supposed to be for everyone, and which foods are meant for people with special diets only. Seeing people finish the vegan or gluten-free food and then move on to other items, while leaving nothing for those that relied on those options, was a common experience. Cases of being unintentionally left out were also shared by multiple participants. Sometimes HR simply forgets to include a vegan option. At the same time, the fear of being seen as nagging or annoying prevents people from constantly asking and checking in. These moments of uncertainty can make the situation more complicated.

The Social Challenge of Changing Diets

Integrating a new diet brings a dual challenge. The patient has to change their diet and find a new way of eating that works for them. This will take some experimenting and finetuning. At the same time, there is now a new external challenge in finding and receiving the food they need, with the social friction of asking for this treatment.

Returning to the story of Unmana Datta (2017, 2018), we see that changing the diet is only a small part of the process. Datta describes how she was always self-conscious, and now felt like her social interactions were made even more complicated by needing to watch out for eating 'forbidden' foods. Having to say no to a friend who offered her homemade food or having to decline invitations created a new anxiety.

She also describes how she had to learn that she shouldn't feel ashamed of her condition. Over time, she felt more comfortable explaining her situation to people, and recognized that she was doing herself a disservice by ignoring her body's needs.

In the survey, someone shared the comment "I am always in control of what I eat, although sometimes that means not eating." Switching to a new diet and sticking to it sometimes means

that there is no suitable food available. For those that experience serious symptoms from their intolerances, that means choosing between being left out, or accepting that they will feel the consequences later. While this highlights the importance of intuition and understanding personal limits again, it is not a pleasant decision to make.

4.4 Management

Over time, the newly adjusted diet integrates into the habits of the patient, and becomes a normal part of life. New standard groceries and favorite restaurants are found, and friends and family know about the diet. At this point, the challenges of the diet are no longer internal: the patients knows what to do, and how to achieve these results. Instead, the challenges become external. Adhering to the diet depends on the availability of options, the possibility to find them, and social situations.

In her interview, Hannie (2021) mentioned she adjusted to her new diet rather quickly, because she had already switched to a vegan diet a couple of months before her diagnosis. Changing again was not that hard, it just meant going through the ingredient lists again and finding new staple products. In contrast, Liis took three years to fully settle in her diagnosis (2021), mainly because she underestimated how careful she needed to be with her celiac disease.

Social Friction

One continuing challenge in the management of food tolerances and restricted diets is how they work out in social situations. At this point, close friends and family are usually informed, and can make sure options are available. But this quickly becomes more complicated in larger groups and more distant relationships.

The participants of the research often expressed how they don’t want to feel like a burden, and can feel uncomfortable bringing up the subject of their diets. Even when food organizers are happy to help, it can be difficult to constantly ask for special treatment, or check to make sure they won’t be forgotten. On the other hand, food organizers do actually forget, which can be an awkward and disappointing experience.

In other cases, well-intentioned gestures can simply be mistaken. Having to turn down food that someone made specifically for you because they misunderstood what you needed is an uncomfortable experience for both parties.

Despite the fact that the patient gets more comfortable with their intolerances and their diet over time, these social frictions don’t really go away. While food organizers are often happy to help out, the burden of communication is still with those that have specific requirements, and they often feel uncomfortable bringing up the subject.

This leaves people with dietary restrictions in social situations with several options. They can be provided with special food options, either just for them or extended to all guests. In situations with a variety of foods and snacks they can pick the foods that are suitable for them. They can also

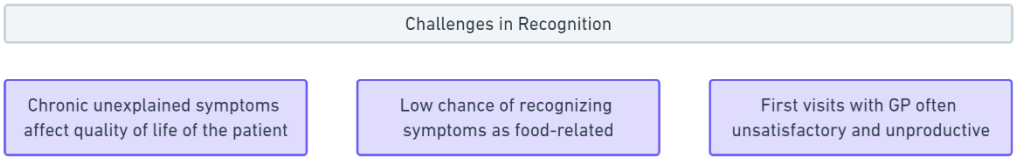
choose to bring their own food, either just for themselves to share with the party. In some cases, they might also decide that eating something that's not the best for them is worth it in this situation, either because they will enjoy the food, or because they don't want to cause any trouble. If those options don't work out, they may also simply choose to skip the meal.

None of these options are inherently good or bad. Each of these options can be a suitable arrangement, depending on the situation. The overall experience is mostly dictated by the attitude of those involved, and the communication surrounding the event. It's possible to feel seen and understood while declining a meal, just as it's possible to eat something to avoid confrontation while dreading how it will make you feel tomorrow.

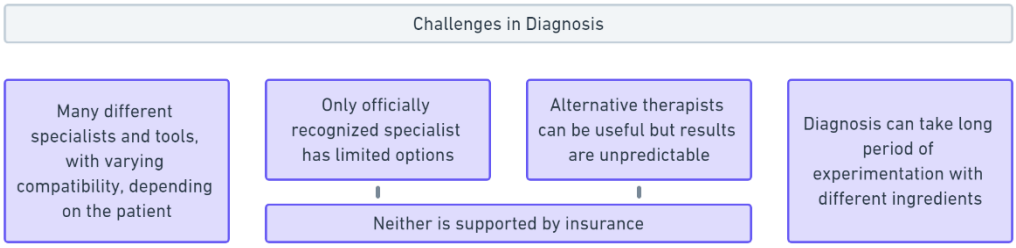
4.5 Pain Points in the Journey

The user journey described in this chapter is long and multifaceted. The challenges exist in overlapping emotional, social and medical domains, and manifest differently for each patient. The overarching pain points that stood out in the research are summarized here.

The main challenges in the recognition phase are in the effects of chronic complaints and in understanding that these complaints are food-related. First visits to the GP often fail to identify the cause of the problems.

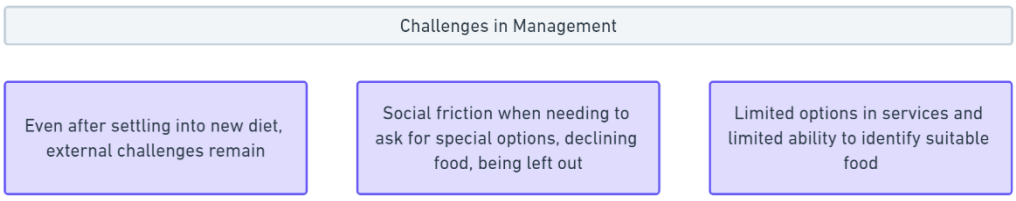


In the diagnosis phase, it can be difficult to find suitable professional support. Different tools and professionals suit different people. The diagnostic process can be long and ineffective.



During integration, there is a combined internal and external challenge of making the new diet work. While the patients are trying to settle into their new restrictions, they are faced with new social interactions to navigate, and new limitations in food services such as grocery stores and restaurants.

In the long-term management of the diet, the patient settles into their own system, but still faces friction arising from social interactions and services. These challenges never really go away.



5 RECONSIDERING THE PROBLEM SPACE

5.1 Defining the Problem Space

The design research described in the previous chapter showed a complex and personally unique lived experience. The total journey can span several years, resulting in the management phase, which continues indefinitely. The four phases described in the chapter – recognition, diagnosis, integration and management – introduce changes into the lives of the patients, and each come with unique challenges.

These challenges arise from personal symptoms, but quickly extended themselves into the social sphere of the patient. Food is an incredibly social activity, and many of our social interactions involve food in some way. While the way food intolerances influence our social interactions changes over time, the issue remains throughout the whole user journey.

Part of the journey touches on elements in the medical sphere. Getting a proper diagnosis can be difficult, and this process was described as unpleasant by multiple participants of the project. Misunderstandings about the nature of food intolerances and questionable diagnostic methods further complicate the field.

There is also a personal internal struggle, as the patient learns to adjust their diet and lifestyle to their new diagnosis. It can be difficult to change a diet and give up favorite foods, although the relief of finally solving the medical puzzle outweighed the struggle in all participants of the project.

The whole spectrum of challenges that came up in the design research is too broad for a single design project. I decided to focus this project on the final stage of the journey, the long-term management of an intolerance.

The complete spectrum of challenges that came up in the design research is too broad for a single design project. To select a concise problem space for this project, I decided to focus on one area of challenges in the user experience. Since the challenges in maintaining a restricted diet over time never really go away, and the influences of food intolerances on the social life of the patient seemed underrepresented in the existing tools and research, I decided to focus my efforts here for this project.

5.2 From Food Intolerances to Dietary Limitations

While the research so far has been focused on people with food intolerances, it slowly became apparent that many of the challenges faced by the participants also applied to people with other dietary limitations. To confirm this, the workshop was set up to include people with different backgrounds, including diets excluding animal products and diets adopted out of medical considerations. The interviews with the HR managers also discussed dietary restrictions as a whole, without specifically focusing on food intolerances.

Specifically the phases of integration and management, as discussed in the previous chapter, showed considerable overlap in all people with dietary limitations. All participants recognized the challenges of finding suitable food and navigating social situations, whether their diet was motivated by health, biology, or ethical considerations.

Since the focus of the design project will be in the daily management of food intolerances and the social challenges that arise there, and these challenges are experienced by all people with dietary restrictions, it seems logical to represent their point of view too. This creates a design solution that can benefit more people, and creates a more widely applicable project.

5.3 Dietary Limitations in a Social Context

As described in the previous chapter, the challenges in managing a limited diet mostly arise from external interactions. At this point, the person has learned which foods they can eat, and has settled into a new diet. They have adjusted their weekly shopping list, found new foods they enjoy, and have found a way to make the situation work with their household and close friends.

The challenge becomes to maintain the diet. This is often not a problem of willpower and internal motivation. Instead, the challenge is in finding suitable foods. In the design research, this problem seemed most prominent in social situations where a person with dietary limitations depends on someone else to organize their food.

This situation exists in a variety of social situations. In close social circles this can be having dinner with friends or attending a birthday party. It can also be the lunch or snacks provided by a workplace, the food at a conference, the options in the university cafeteria, a thank-you dinner for volunteers, or any other social interaction that involves food.

The problem also exists in the service industry. While larger supermarkets have options for almost any diet, the selection of ready-made foods is considerably smaller for limited diets. Restaurants often include some vegan or gluten-free options, but this is typically a small selection of the menu. Finding these foods can be challenging too. Incorrect or missing labels, mixed supermarket shelves and lack of support in online environments all complicate the issue. The fact that most places have something suitable also makes it that much more disappointing and frustrating when certain places have no options available at all.

An increasing amount of our interactions with selecting food is happening online. We order food through delivery apps, order groceries from websites, and we sign up for events using digital forms. In these situations, our ability to communicate about our diets is limited to the options provided by the environment. In some cases this is too limited, or it can be completely non-existent.

5.4 Future Trends

The challenges explored in this research have strong connections to the social and cultural sphere. Food is extremely cultural, and many social interactions involve food. What we eat, the way we prepare it, and the circumstances under which we consume it have always developed throughout history. These changes have become even more rapid since the industrial revolution.

The past century provided us with a global transportation network and industrial solutions that has provided richer countries with access to a much wider variety of foods and a year-round supply of items that have historically been seasonal. We have also seen a productization of food. Food is no longer simply food, but a product with a message. The types of food we buy tell us something about ourselves and our lifestyles. The rise of processed foods has also created a series of brand-new items that never existed before.

Of course, these developments are not stopping. The foods that are available to us, the way we get them, and the way we consume them, are all under constant development. So are the attributes of our society and our culture.

Similarly, the challenges that are being addressed in this project will develop over time. Depending on how the future develops, they may become more relevant, or they could disappear completely. Given the project's the connection to our cultures and lifestyles, it makes sense to analyze current trends and create an understanding of what the future might look like.

This trend analysis is not meant to be exhaustive, or to make an attempt at accurately predicting the future. The goal is to analyze where the future *might* go. In the terms of Speculative Design, as described by Dunne and Raby in their book *Speculative Everything*, this analysis explores the sphere of plausible futures (Dunne & Raby, 2013). Analyzing this scenario can help us find what challenges or demands would arise from the future. These can then be used to help shape the design project, and create a more robust solution.

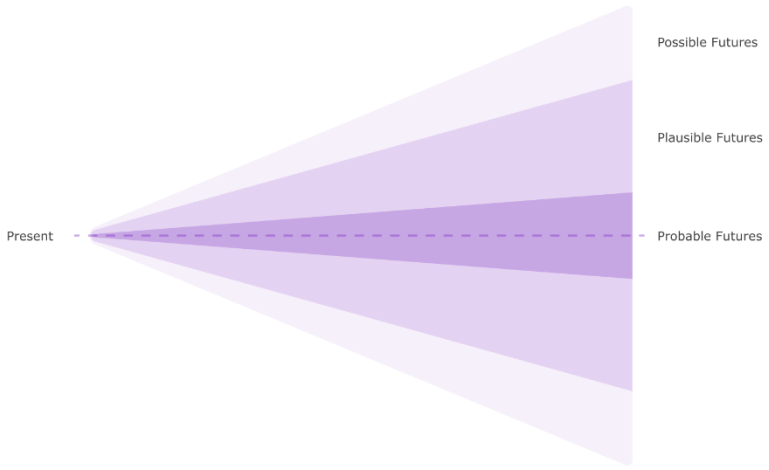


Figure 5.1. The Future Cone. Credit: Dunne & Raby (2013), modified by author.

The trend analysis is based on various articles, predictions and trend reports available online. To select relevant material, trends were considered that shape the way we create, prepare and consume food. Predictions and analysis from different sources about similar topics were compared and combined, and examples were found to support these. This resulted in two main insights that were relevant to the project, which are described below. The full map is available in appendix B.

Changing Food Sources and Giving up Control

Several trends and developments are supporting a move towards more convenience food, meal delivery, and eating out more. With the exception of the covid-19 pandemic, we spend more time out of our homes. The food delivery market has also grown in recent years, even resulting in delivery-first or delivery-only restaurants.

In dense urban areas, kitchens have become smaller, and are moving from a separate room to integrated in the living space. In smaller apartments, kitchens have been reduced to kitchenettes with just enough space and utilities to facilitate basic cooking. In some speculative architectural designs, kitchens are completely removed from the personal living space, and are used as a community commodity instead. This provides a new way to see the role of the kitchen, but also creates a new way of urban communal living.

Workplaces are also using food as a way to create a better atmosphere in the office, as a way to bring the team together, or even as a major perk that attracts and retains employees, from office snacks to complete meals. While this may seem like an arbitrary quality, it has very real consequences[27].

Finally, convenience foods are becoming healthier and more versatile. Pre-made food is moving away from the stigma of a 'TV dinner', but can provide a healthy and nutritious meal with reduced effort and preparation time. Healthy snacks have also become more popular, and fit in an on-the-go lifestyle where cooking utilities are limited for most of the day.

All of these trends support scenarios in which we move away from our ability to have full control over our food. Smaller kitchens, finding meals in restaurants or in supermarkets, and spending less time at home all inhibit the resources we have to create our food from scratch. This is not necessarily a bad thing, as long as we can find foods that are nutritionally, emotionally and financially sustainable for us. How well we can find these, depends on the options that are available, and our ability to find them.

[27] Malcolm Gladwell explores the role of food quality in universities in his podcast episode *Food Fight* (Gladwell, 2016). In his comparison between two universities, he concludes that the superior food quality in one of them is a decision that reflects their priorities. The money spent on 'luxuries' such as high-quality cafeteria food could have gone to accepting low-income students with tuition waivers. This is exactly what he claims the other university does, which, as a result, has less tuition money to spend on high quality lunch options, resulting in a decreased interest from high-income students, which further perpetuates the cycle. The poor university can't attract rich students, and the rich university won't enroll the poor. The quality of the cafeteria food has a real impact on which students are willing to enroll, and therefore on the budget and character of the university.

Getting More Specific

Multiple trends are supportive of us getting more specific about the things we eat. This can be motivated by our biology and health, or to optimize for ethics or experience.

Optimizing for Biology

It is now easier than ever to measure personal health factors. Any smartwatch or sports band can check our heart rate, activity, and sleeping patterns. Some more advanced devices can also measure heart rate variability and blood oxygen levels. The software supporting these sensors is getting more advanced too, creating extensive reports about our health and fitness, and providing us with insights that should help us perform best and stay healthy. With it comes the promise of a happier, healthier and longer life.

The hardware that enables these functions is constantly getting smaller and less intrusive, while being able to tell us more about ourselves. This self-quantification is already extending to areas that typically require extensive equipment in a medical facility, such as affordable Continuous Glucose Monitors.

At the same time, specific tests are also getting more accessible. Intolerance testing has already been described extensively in the previous chapters. Similarly, DNA tests can now be done affordably by sending in a sample from home. Our growing understanding of the human genome enables to interpret this data more accurately.

This combination of understanding our core biology and tracking our daily vitals creates the opportunity to easily fine-tune our diets. We can optimize for the foods we should be eating according to our biology, and work out the details based on our goals and daily activities. Many of these calculations can be automated, without the need for professional help. Combined with a growing response to lifestyle diseases by actually treating the lifestyle instead of the symptoms, this supports a future where we are much more aware of the impact our food has on us, and therefore much more considerate of what we eat.

Optimizing for Ethics, Preference or Experience

Globalization and digital (social) media has resulted in a much higher awareness of what is happening in the world, and a way for ideas to spread further and faster. This also allows for the spread of dietary ethics in a way that was not possible before. The rise of diets excluding certain animal products, as well as the exclusion of palm oil, endangered species, or certain brands that are deemed unethical, are supported by our ability to quickly communicate information and ideas online. This higher awareness of the source of our food, combined with an abundance of options, allows us to select for ethics in a way that was not possible before.

The biological optimization as described above is also being used to create personalized experiences. DNA analysis can be used to create ‘the perfect food’, based on personal tastes and preferences. While this is mostly linked to high-end restaurant experiences for now, this could become a more mainstream trend in the future.

These trends also support specificity in our food choices, although with a different motivation. Together, these ideas may change the way we select food, and may shift the market from a mass production of different options to more specific facilitation of personalized options.

Bridging the Gap

The two trends described above have conflicting interests. One the one hand, we are moving towards situations where we have less control over what we eat, and we rely more on getting food from 'external' sources. On the other hand, we are getting more specific about the things we eat, and we are exploring the benefits of doing so.

I propose that this conflict of interest can be mitigated through customization. When we create the food we consume from scratch, we have full control over the ingredients, the quantity, and the preparation method. By introducing customization and personalization in our outsourced food production, we would be able to reclaim control over what we eat, and create solutions that are sustainable long-term. This can be achieved by customizing our food as we select it, or by offering pre-determined personalized items.

In both cases, it is key that we are able to communicate about what our needs are. Without the infrastructure and shared understanding to discuss what we need from our food, it is impossible to facilitate the personalization that we need to trust a widespread outsourcing of our foods. In the same way we can not design products for an average user, we can not create meals for the average person. Food is too personal and too critical to generalize. If we are to give up control over what we eat, we need to be able to rely on a system that keeps this safe and sustainable for us long-term.

5.5 Conclusion

The design research resulted in a wide spectrum of challenges for people with food intolerances. After selecting a more defined problem space by focusing on the long-term management of intolerances, it became clear that a wider user base would benefit from a design solution in this area.

The target users of the project have been expanded to include anyone with a restricted diet, whether the restriction is based on health, nutrition, biology, ethics, religion, performance, or simply strong preference.

To support the design research that evaluates the current situation, a future trend analysis was used to evaluate plausible future scenarios that are related to the topic. This analysis shows that specificity in our dietary choices is likely to become more common over time. It also shows might replace more of our homecooked meals with (partially) pre-made food in the future. To bridge the gap between these two trends, we need a way to communicate about food and ask for the things we need. This reinforces the findings from the previous chapter, and shows that the challenges discussed there may become relevant for an even wider userbase.

6 DESIGN BRIEF

The research so far has shown that handling food intolerances comes with challenges at every stage of the process. In the final stage of the journey described in the design research, in the long-term management of the intolerance, the challenges are mostly external to the patient. Now, the ability to eat the food that is best for them is mostly impacted by their social interactions and the availability of those foods in various circumstances.

As discussed in the previous chapter, these challenges are shared by people with allergies or other medical considerations, or people who restrict their diets out of ethical or religious reasons. In fact, any restriction or strong preference in dietary choices brings these considerations. And, as seen in the previous chapter too, these restrictions and preferences are likely to become more common and more specific in the future.

But while it may sound like all of these rules and considerations threaten to take the fun out of food, what we are ultimately looking for are positive experiences. Most of us want to enjoy our food, either for the taste or for what it gives to our body, and preferably for both. And often our interactions around food are incredibly social. Every meal is a small expression of our identity and tastes, our heritage, and our exposure to other cultures. This effect is multiplied when we share it with others, in social-, professional-, and service-based experiences.

People with limited diets do not wish to be excluded from these experiences, but they do face challenges. These challenges mostly arise when they need to navigate social situations where they depend on someone else to organize their food, or when services do not adequately support their needs. In many cases, exceptions can be made, and food organizers are happy to help out. But misunderstandings, forgetfulness, or the fear of standing out or being a burden still complicate these situations.

The challenges described here seem to share common themes: inclusivity and communication. Inclusivity for dietary choices and our human differences, and open and easy communication about them to reach a shared understanding. This insight led to the exploration of Inclusive Design.

6.1 Inclusive Design

Inclusive Design can be summarized as the process of designing for the outliers, with the aim of benefitting everyone. More formally, it is defined as "The design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible [..] without the need for special adaptation or specialised design" (University of Cambridge, 2018).

Products and services are designed to suit certain circumstances and levels of ability. In this process, there is always the risk of creating a separation between 'normal users' and 'less abled users'. This categorization does not reflect reality. In practice, the different circumstances and levels of ability that people experience create a fluent continuum. At one end of this spectrum, there are users who have no problems whatsoever in using the design. At the other end, there are users who cannot use the design at all. Between those two extremes is a diverse set of people with unique user experiences.

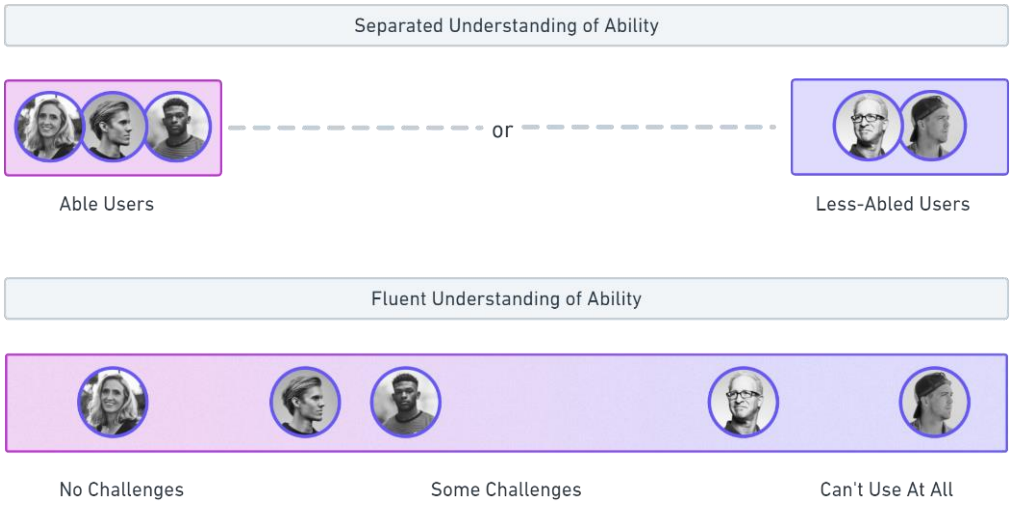


Figure 6.1. Understanding User's Abilities. Figure contains resources from unsplash.com.

In inclusive design, the starting point is the assumption that people are different and have different needs and abilities. By designing with diversity in mind, the resulting product or service becomes more widely accessible. While the design may be optimized for users with specific needs, the whole userbase tends to benefit from this inclusivity.

While this may sound similar to accessibility adaptations in products, there is an important difference. Accessibility is a feature of the product, while inclusive design is a method that embeds usability in the product philosophy. The result of good inclusive design benefits all users of the product, without creating a stark distinction between 'normal' use and extended accessibility.

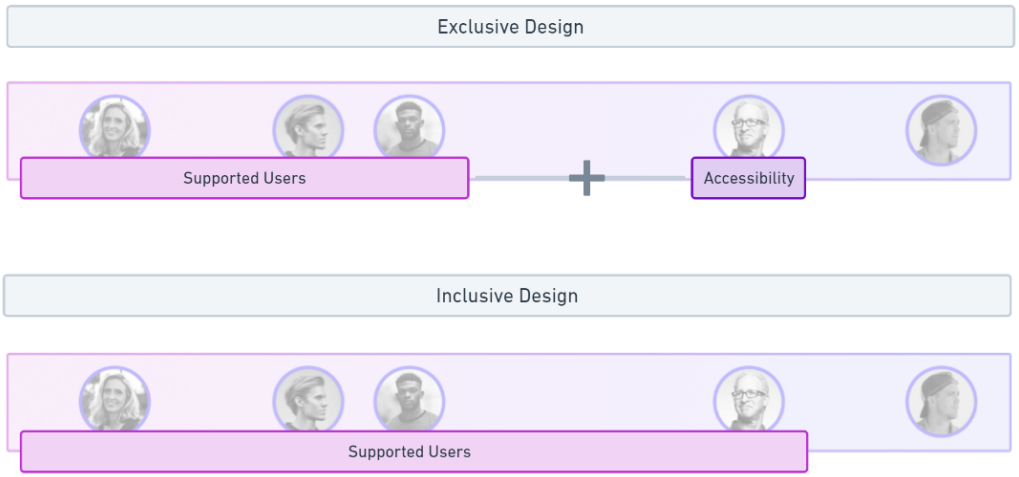


Figure 6.2. Traditional versus Inclusive Design. Figure contains resources from unsplash.com.

A great example is the sidewalk ramp, which became widespread in the US as the result of a campaign to increase accessibility for veterans with disabilities (Brown, 1999). While the design was intended to help people with disabilities, it quickly became clear that they helped people with bikes, strollers, crutches and joint pain just as much. As a result, they have become the new normal over time. In the digital realm, Microsoft presents inclusive design as one of its main design drivers, and even provides educational resources (Microsoft Design, 2016).

Inclusive Design and Food

The challenges that are addressed in design projects through inclusive design share a lot with the challenges of organizing food. Incidentally, they would also benefit from a similar treatment.

Let's consider a non-inclusive design process. The designers assume a certain level of ability of the users, and therefore anticipate a certain compatibility. Only when necessary, users are invited to share the limitations in their abilities, after which the designers can introduce accessibility options.

This sounds oddly familiar to the way we organize food. The assumption with food is that some people may have special diets, but most of them eat everything. People with specific requests are often welcome to speak up, but the responsibility is still theirs. This puts them in a position where they are usually the ones to ask, which causes friction in the communication.

Our online interfaces give us limited options (or sometimes, none at all). We can filter our results to exclude certain ingredients, or show results compatible with a specific diet. But what we are able to filter on is decided by the developers of the interface. In the best case, this gives us support for the most 'popular' diets and intolerances. In the worst case, the selection options are limited, or the results are incorrect and incomplete.

Now imagine our interactions with food were designed according to the principles of inclusive design. We would start from the assumption that everyone is unique and has different tastes. Some people have stricter criteria for what they eat, and where possible these can be

accommodated by the organizers. To organize food, we would start with involving the 'users' upfront, and try to understand their personal needs as well as possible. From there, we can create a solution that suits as many people as possible. In some cases, this means making sure all the food is suitable for everyone. Another option is introducing flexibility and customization, or providing an alternative for one element of the meal.

In online environments, we would make sure the infrastructure is adaptive enough to support our unique circumstances. This enables us to understand each other, and interact with digital services in a meaningful way.

While this may seem excessive, the amount of effort this communication takes largely depends on the tools and communication channels that are available to us. In practice, people with dietary limitations now usually rely on personal communication or limited online interfaces. Inclusivity doesn't have to be hard, if there is a pleasant an efficient way to facilitate it.

6.2 Industry 4.0 and Digital Twins

Our current industrial paradigm, also known as industry 4.0, is characterized by automation, ICT solutions and connectivity. This development builds on the introduction of mass production in industry 3.0.

This digitization and connectivity is not limited to industrial applications, but has already started integrating into our personal lives. We are all connected to the internet through our computers and mobile devices. At the time of writing, we are at the cusp of the widescale adoption of the 5G network, which promises a new wave of rapid advances. It also comes with the prediction of an expanded Internet of Things network, enabling the digital connection of many everyday objects to the internet.

Our expanding digital presence has also made its way into the world of food. A full thesis could be written on this topic alone, but the applicability for this project is in the way the end user experiences these changes personally. More and more, our food services can be found online, from supermarket inventories to restaurant menus and bespoke grocery boxes. For now, the way we interact with these online environments is through the interfaces we use on our screens. To interact with these worlds, we have to translate our needs and intentions into a compatible format first.

But our compatibility is limited by the information the system accepts. The richness of our experience can only be captured at the level of detail that is programmed into the system. In practice, this results in limitation in our ability to explain ourselves to the system, or our ability to receive information about our food.

A key concept in Industry 4.0 is the digital twin, a digital model that accompanies an artifact in the physical world. These can be models of factories, 3D files of products, or approximations of our personality used to optimize advertisements and social media engagement. The accuracy of this

digital twin is limited by the systems that support it, and the amount of information that is available as input.

While this system comes with its inherent limitations, the concept of digital twins is applicable to this project. To drive the inclusivity we would wish to see in our dietary preferences, we must have a way to communicate about what our preferences are. In a digital world, these must be translated into a format we can then share with each other, and with the interfaces we encounter.

A digital profile of ourselves will not capture the full complexity of our lives. But at the same time, the systems we employ today are overly simplistic. The technology we use should be able to support a more nuanced understanding of our preferences, and supporting this model will allow us to communicate more clearly and effectively.

6.3 Formulating the Design Brief

Framing the problem in terms of enabling inclusivity leads to the following research question:

How might we enable inclusivity for people with dietary restrictions in social situations and in services?

Platform Goals and Tasks

Based on the challenges that were highlighted in the design research and the goal of creating inclusivity for dietary preferences, within the ecosystem as described above, we can define a set of goals and specific tasks for the platform.

Platform Goals	Platform Tasks
1. Understanding and storing food preferences Creating a comprehensive and flexible system to understand the user's dietary preferences in terms of ingredients, preparation methods and sources. This becomes the 'digital twin' that allows the user to communicate their preferences with other people and services.	1.1 Take customizable and specific input regarding dietary preferences 1.2 Store user data in personalized profile 1.3 Enable sharing of personalized profile through various channels with different compatibilities
2. Enabling communication in social interactions Giving a platform to enable and encourage the sharing of food preferences to help organize social gatherings that involve food. By creating a broad compatibility with existing services and various use cases, food preferences can become a standard consideration.	2.1 Enable social sharing of personal food preferences with individuals and groups 2.2 Help food organizers understand the diets of participants to facilitate suitable food for everyone 2.3 Control of privacy in various settings
3. Enabling personalization in service interactions By creating a framework to communicate food preferences to the level of detail that accurately reflect the user, (online) services can be personalized in a truly meaningful way. This enables filtering options online and showing customized indicators or warnings with certain foods.	3.1 Use food profile to customize online experiences 3.2 Use food profile to guide decisions in physical-environment interactions

Other Considerations

Allow for flexibility and privacy

It is important to understand that how people choose to present their dietary preferences is personal and situational. The design should allow for flexibility in what is shared on each occasion, which in turn provides privacy to the user.

It should also always be clear what information is shared for each connection or event, and the user should have the ability to edit or remove a shared setting. The design will also need consider broader data safety regulations.

Avoid Unnecessary interactions

The core tasks of the platform are to record and store the user's dietary preferences, and use this data to communicate with others. Whenever applicable, similar interactions should be able to be repeated to avoid unnecessary input.

The platform is not meant as an educational tool or news feed, with varied articles or constantly updated content. It is also not a database for recipes or ingredients. Instead, it should be used to connect with other services that provide this information, and use the food profile to customize them for the user.

Wherever possible, the platform should fade into the background and enable more pleasant interactions in the real world, or in other digital environments.

7 DESIGN CONCEPT

The design brief, as stated in the previous chapter, shows a need for a platform that enables people to record their dietary preferences, which they can then share with each other and with services, to enable communication about food and personalize experience in food services.

The design phase of this thesis project, informed by the brief, led to the creation of FoodPass. FoodPass is a platform that enables people to communicate about food, and helps to organize their social and service-based experiences around it. The platform consists of a web interface and mobile app, with a strong emphasis on integration in other digital systems.

The three core components of FoodPass are the food profile, the tools offered to facilitate social interactions, and its connections with other food service platforms. These components fulfill the platform goals and tasks as discussed in the design brief in chapter 6.3.

Each of the components of the platform is discussed in detail below. Each use case is illustrated with a scenario in this chapter. Detailed user journeys and system maps are available in appendices D, E and F.

7.1 FoodPass in the Ecosystem

FoodPass serves as a platform that hosts the conversation about dietary preferences from user to user and user to service. As seen in the design research, people with dietary limitations or preferences typically have the responsibility to bring these up themselves and communicate directly with food organizers. Digital services offer little tools in terms of selection, communication, and filtering.

FoodPass situates itself between users and services. While this may seem like a barrier, a dedicated platform actually sends a clear signal that opening this conversation is welcomed. By using FoodPass as a filter for digital services, a wide range of personalized opportunities become available to the user.

A simplified system map is shown below. A fully detailed map is available in appendix C.

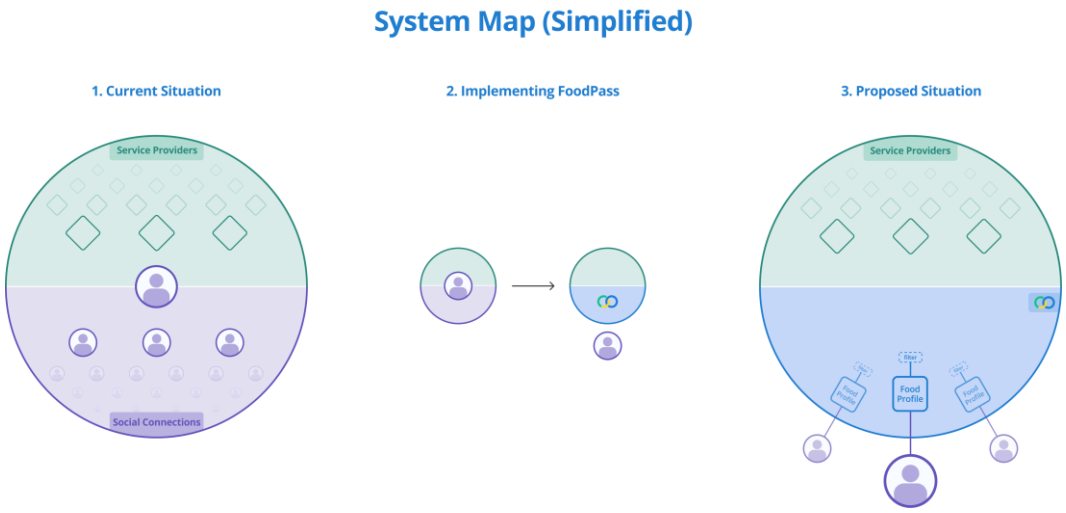


Figure 7.1. Systems Map (Simplified). Figure contains resources from thenounproject.com.

7.2 Food Profile

The food profile is the first interaction users have with FoodPass, and a cornerstone of the network FoodPass enables. The profile allows users to create a 'dietary digital twin[28]', by storing their food preferences in an online record. This record can then be used to share with other people and food services.

By creating an online environment that stores this information in a standardized way, FoodPass facilitates a shared understanding that can be used by people and digital systems. In the same was as email addresses and bank account numbers are created under shared protocols to ensure

[28] See chapter 6.2

compatibility, FoodPass allows users to translate their dietary preferences to a format that can be understood by both humans and digital platforms.

Formatting Food Data

One important challenge is that humans and digital systems have fundamentally different ways of understanding information. In digital systems, the information that is shared needs to consist of mutually understood building blocks. Information sent as a string of text, a numeric value or a date needs to be interpreted in the same way on the receiving end. When trying to digitize our understanding of food, we need to understand what the building blocks of this information ecosystem are.

In the food industry, ingredients are the fundamental building blocks we communicate with. Regulations require that every food product lists the ingredients it consists of. Other qualitative properties such as the origin, nutritional content, preparation method and overall quality of the ingredient are optional pieces of information. These qualities are usually conveyed through the packaging and marketing of the product (biological, free range, single origin, first harvest). These types of labels are less strictly regulated, and are often used in comparison to other similar products, as opposed to a global standard.

The way people relate to food is fundamentally different. When we communicate about food, we relate to the food itself, not a list of ingredients. We also use labels to quickly convey meaning and navigate a complex set of rules in principles in an understandable way. All major dishes, diets and cuisines have names, with an approximate understanding of what they are.

Using labels to communicate does have downsides. People using the same label to indicate their diet might not share the exact same set of rules and values. Two vegetarians can have different opinions about factory-farm eggs, shellfish, or how strictly they avoid meat when traveling. When we use labels as shortcuts to communicate, we inevitably lose some detail.

In service environments, we often see labels used to categorize and filter products. Supermarkets typically have indicators for major diets and intolerances, both online and in stores. But these labels have two problems. First, they are only available for popular or well-known limitations that represent big customer groups. Anyone with more obscure requirements is excluded from this system. Second, they are often only used for products that might not seem to fit in these categories at first glance. A gluten free croissant deserves a label, but a vegan carrot is a pleonasm.

Digitizing Preferences

Understanding that humans and digital systems have fundamentally different ways of understanding information is key in developing the food profile, which needs to be usable by both. The profile accommodates for these differences in three ways:

1. The buildings blocks from which FoodPass works are ingredients names, as these are the standardized units that the food industry uses to communicate. However, to increase ease

of use, users can also search for categories of food and popular diets, which will then load the corresponding ingredients for them. These can then be customized if needed to accurately reflect the preferences of the user.

2. Users can indicate three levels of preferences in the system: no restriction, avoiding, and excluding. Excluded ingredients are treated as unacceptable at all times, while avoided ingredients are seen as a mild restriction. These two levels allow for nuance in both social interactions and service integrations.
3. Users create one base profile, which can be customized every time it is shared. This allows users to communicate different preferences in different situations.

This flexibility helps create a human-centered experience within the rigid compatibility standards of a digital system.

The food profile creates a shared understanding of dietary preferences, which facilitates new ways to communicate about food. This in turn creates a starting point for a new type of digital network that connects people and services, in a wide variety of settings.

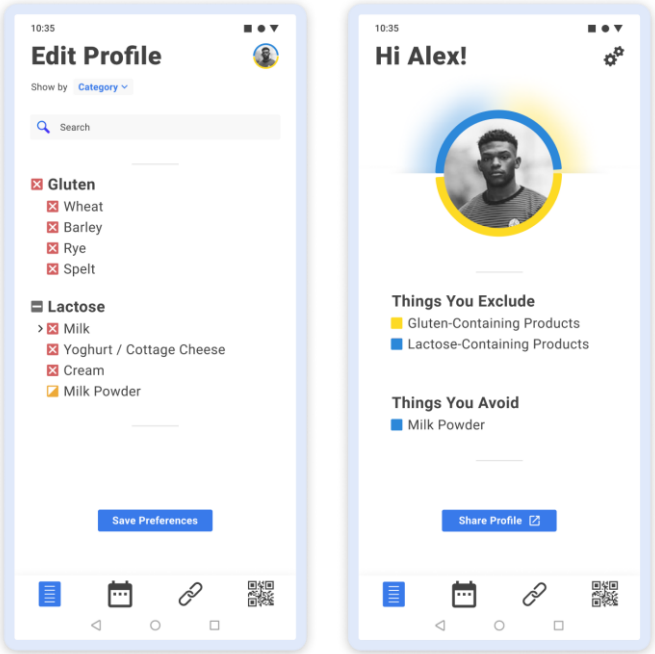


Figure 7.2. FoodPass Food Profile. Figure contains resources from thenounproject.com and unsplash.com

Each food profile is personalized by a colored ring around the profile picture of the user. The colors and elements of the ring give an abstract representation of the user's preferences. The colors provide a fun way to showcase something that is often either hidden or perceived as serious and limiting. The different segments of the ring can also serve as an indicator for food organizers that a participant seen in a filtered view may have additional requirements.

7.3 Organizing Social Gatherings

As seen in the design research in chapter 4, many of the challenges in managing dietary preferences show up in social interactions. Many social gatherings, from deeply personal to professional, involve food in some capacity. While food provides a source of pleasure and a ritual that helps us connect, engage, and relax, it can also be a source of stress for those that are maintaining a certain diet.

These frictions typically arise from the fact that the people who have these dietary preferences or limitations often rely on someone else, the food organizer, to facilitate this for them. At parties, in workplaces, or when participating in events, we are typically not in full control of the food that is provided for us. Arranging suitable food requires communication with the food organizer, often without a predetermined social protocol. As seen in the design research, people often feel uncomfortable or are afraid as being perceived as difficult when they need to bring up these topics. At the same time, the food organizer can lack the knowledge or tools to properly handle these requests.

One of FoodPass' core goals is to help streamline this process. By providing a system in which participants can easily communicate their dietary preferences, FoodPass helps create an inclusive environment. At the same time, the system helps food organizers keep track of people's preferences in a central location, instead of using personal messages, emailed surveys, or even in-person comments in the office kitchen.

FoodPass can be used to facilitate food in social settings in various capacities, from one-on-one interactions to large gatherings. Its ability to connect with different services helps food organizer arrange food at different scales.

Personal Gatherings

At the smallest scale, FoodPass can be used to organize personal gatherings. Birthday parties, Christmas dinner with the family, or a meal with an extended friend group can all benefit from clear and inclusive communication about dietary preferences.

In these situations, the biggest area of resistance is how quickly the system can be used without adding extra 'paperwork' to an otherwise light and fun social gathering. Sharing dietary preferences should not take more work than simply telling someone in a chat message or in real life, and the formality of the system should match the formality of the event.

For these types of events, FoodPass can be used as a standalone platform, or it can easily integrate with other social media platforms that are used to host events, such as Facebook or calendars. When used as a standalone platform, one FoodPass user can create an event and share a link with others. The link allows participants to log in and share their profile, or simply add their name and preferences to the event. When used in combination with other platforms, a FoodPass dialog will be integrated there, encouraging users to share their details.

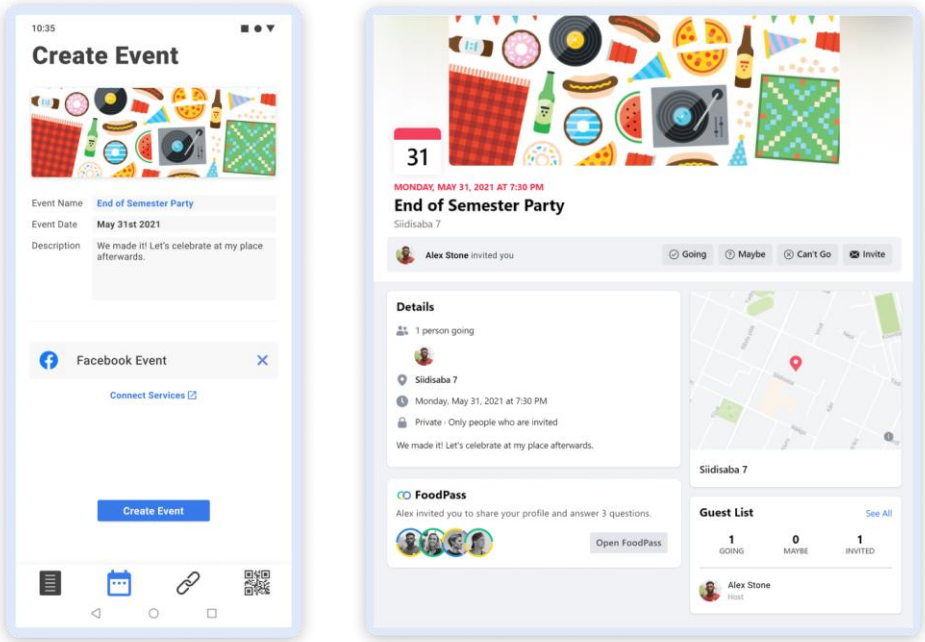


Figure 7.3. FoodPass Event in App and Facebook. Figure contains resources from thenounproject.com, unsplash.com and facebook.com.

The food organizer for the event receives a detailed overview of the preferences of the participants. They can quickly see which guests can not eat certain ingredients, and if any conflicts may have serious consequences. They can also look up ingredients and see if these are compatible with the participants.

Another benefit of using FoodPass is that the food organizer can add questions to ask the participants in the same environment. This allows the organizer to quickly gain information on the participant's favorite drinks, preferred cuisine, or any other information that might be relevant to the event.

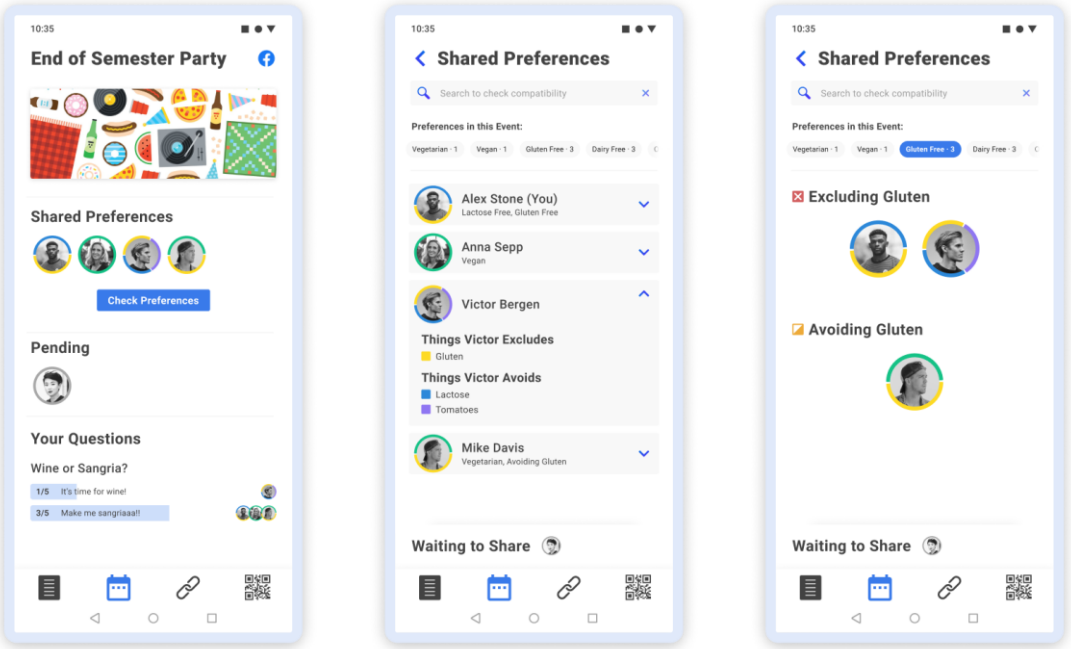


Figure 7.4. FoodPass Social Event Interface. Figure contains resources from thenounproject.com and unsplash.com.

A full user journey of using FoodPass to organize a personal event is shown in appendix F.

Use Case: Christmas Dinner

In Anna's family, Christmas is the one time of the year where the whole family comes together. Everyone looks forward to spending a week at her grandparents' house. The whole family enjoys the countryside and catching up with the family. Of course, the whole week is filled with shared meals, family recipes, and socializing in the kitchen.

But organizing food for such a big family has gotten more complicated. Some of the grandchildren refuse to eat meat now, and their parents are not fully convinced that's such a bad idea. Older family members are starting to take more care of their health. Aunt Marianne discovered her migraines were caused by lactose, and avoids it at all costs now.

But last year, Anna introduced FoodPass to the family. All 26 of them created a food profile and shared it with the Christmas Week event Anna set up. Together with her dad and aunt, the designated cooks in the family, she can now easily check who eats what, and if anyone changed their preferences since last year. They can now make sure each meal has suitable options for everyone. Most of the family members don't really use FoodPass for anything else, but it's a huge relief when Christmas comes around.

Figure: freepik.com

Teams and Workplaces

Teams and workplace environments create a mix of social and professional relationships that can be difficult to navigate. We typically know the people well, but the relationships are different from our private ones. In these situations, the topic of food and dietary preferences can be less comfortable to bring up, especially when we are new members.

In professional environments where food is freely provided in the form of snacks or full meals, the food is part of the compensation and value the team members get out of the company. In this case, being left out of this situation due to unmet dietary requirements is a negative experience, while being included is extremely positive.

In these situations, the food organizer is typically an HR- or office manager who is responsible for the team. While it may be possible to just remember which team members have certain dietary preferences, this is not a trusted long-term solution. It also make the facilitation completely dependent on the willingness and skills of the food organizer.

Instead, using FoodPass as a dedicated platform creates a framework for the team to communicate their preferences, and sends a clear signal that they are encouraged to do so. This removes the burden of communication from the team members. It also provides a system to store and use this information for the food organizer, who can benefit from having a dedicated environment. From there, FoodPass can also be used to connect with supermarket websites or catering services, to help order the correct foods to provide for the whole team. This removes the guesswork for food organizers.

A full user journey of using FoodPass to organize food in an office environment is shown in Appendix D.

Use Case: Football Team Summer Camp

Mike is a trainer for a local youth football team. His team plays national competitions and takes their work seriously. Mike has always been an advocate for performance-based nutrition, and instructs his team to eat as healthy as possible. He also likes to keep up with the latest science, and passes this information along to his team.

Each year, the team goes on a two week summer camp. They relax and recharge, but they also train daily and try out new plays and techniques, as a preparation for the upcoming season. During the camp, Mike still wants his team to perform as well as possible.

Some of the team members are vegan and vegetarian, while others have food intolerances that they need to keep in mind. One player is very allergic to peanuts. Mike used to keep this information in a spreadsheet. The team cooks their own meals while they're camping, so Mike would spend weeks preparing the meal plans and finding the correct groceries.

But now, Mike has moved the team into FoodPass. All players share their food profile with him, which gives him a clear overview of each player's needs and preferences. But what's even better is that Mike has found a website that will generate meal plans based on this information, with options for everyone. Mike can customize the results and export the meal plan to place an order at a local supermarket. The team is still getting amazing food, while Mike cut out most of the effort.

Figure: freepik.com

Enterprises, Conferences and Large Events.

Even further removed from personal relationships are enterprise-scale operations and large conferences or events. In these situations, food organizers typically have no personal relationship with the participants, and there are often too many participants to personally know them at all.

In these situations, FoodPass can scale up to help organize food on a much larger scale. When large events organize food, they typically rely on digital forms to collect information about dietary preferences, often in pre-determined categories. Instead, by using FoodPass, they can offer a more detailed and customizable experience for participants. This data can then be used to help organize catering services, and ensure all participants are able to find suitable food.

For large companies, having this data available can help organize food at a strategic level. Many of the world's largest corporations provide extensive food options in their workplaces, often spread over multiple cafeterias or restaurants. By understanding the employees' (anonymized) preferences, the company can make sure everyone is included. This also applies to Christmas giftboxes, team events, or even organizing company travel.

As briefly discussed in the previous chapter, organizing food in a high-quality and inclusive way can actually provide a strategic advantage for events, conferences and companies. Creating a supportive environment that makes participants or employees feel included is a major value that can be hard to replicate. This level of hospitality can encourage employee retention or encourage participants to return for next year's event.

Use Case: Business Conference

Ellen is an organizer for one of the most exclusive business conferences in Northern Europe. Each year, hundreds of high level executives travel to the conference to connect with each other. The conference hosts an outstanding lunch buffet, and various coffee breaks each day. Ellen used to send out a simple survey to ask people about their dietary preferences, and made sure to include plant-based and gluten free options for all meals. Despite her efforts, she still received some comments from people who had trouble finding suitable foods.

This year, Ellen decided to invite attendees to send their information through FoodPass. In the welcome message, she actively encouraged people to share all their details. FoodPass automatically generates a report for her to show which options she needs to consider. Not only was she surprised to see many people with combined restrictions, such as vegan *and* gluten free (something the didn't consider before), she also found some intolerances she had never heard of.

Ellen forwarded this information to the catering company, and made sure that they could provide various options for everyone involved. The catering company planned out a new buffet plan that includes options for everyone, and even proposed some bespoke items for people with very specific requests. Ellen then emailed these guests to let them know a special meal would be available for them in the lunch hall. The conference reviews have never been higher.

Figure: freepik.com

7.4 Service Integration

FoodPass' own platform and social sharing system enable a wide range of tools to enable dietary inclusivity in social events. Combined with existing social tools, such as email, shared calendars and social media, the system becomes even stronger. But the possibilities of using FoodPass' food profile are not limited to social gatherings.

A digital profile that accurately reflects the user's dietary preferences can be used in any food-related service, from supermarket websites and food delivery apps to high end restaurant- and hotel experiences. FoodPass creates the possibility for a vast network of food-related services.

Online Food Filters and Customization

One example of this is customizing the options to filter, categorize or highlight items in digital interfaces that sell food products. When ordering groceries or meals online, users are constricted by the filtering options and categories that are provided by the system they are using, if they are available at all. Typical options include vegan, vegetarian, lactose-free and gluten-free filters, as those are some of the most 'popular' restrictions. While these are helpful for those that fit this category perfectly, anyone with any variation in these categories has limited use for them.

These types of categories are also inherently binary. Items are either shown or not. This does not reflect reality in many cases. Most people do not strictly adhere to any diet 100% of the time, but will make educated exceptions or tolerate a certain amount of some types of foods.

Instead, the detail that FoodPass provides in its platform, combined with the flexibility of Excluding or Avoiding ingredients, can be used to create personalized filters in online environments that actually suits the user. By connecting their platform to FoodPass, food-service providers can improve their users' experiences. The service provider can choose how Excluded or Avoided ingredients are best represented through their platform. This can result in customized filters, icons that indicate a product's suitability for the user, or in selectively hiding products that contain Avoided ingredients.

In recipe websites, FoodPass can help find suitable recipes, and show warnings for certain ingredients. The platform can then suggest alternative ingredients. Another option is to add the ingredients for a recipe to a supermarket order, which can then be checked by FoodPass.

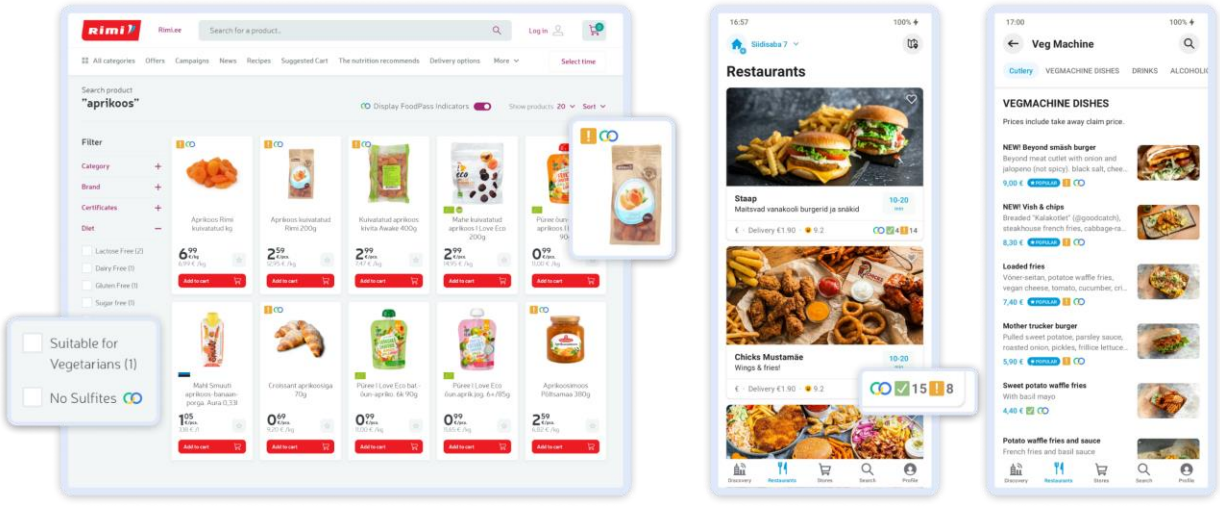


Figure 7.5. FoodPass integrated in Services. Figure contains resources from thenounproject.com, rimi.com and Wolt android app.

Use Case: Supermarket Website

Tina found out she's intolerant to sulfites, so she tries to avoid them in her grocery shopping. But while sulfites are usually indicated on ingredient labels, there is no filter available for them on grocery websites. However, by adding sulfites as an ingredient to Avoid in FoodPass, and linking her profile to her supermarket account, she now sees a symbol for foods that contain sulfites. This makes it much easier to select groceries online.

Figure: freepik.com

Bespoke Services

This extended personalization and compatibility is considerably easier to facilitate online than in real life, but real-life applications can create a lot of value in high-end services.

Experience-based food services, such as (high-end) restaurants, hotels and travel concierges, aim to create special high-value experiences for their customers. This is in part achieved by the quality or novelty of the experience, but also from the hospitality and personal care that goes into creating the setting. Sharing a FoodPass profile as part of the preparation allows services to discreetly integrate their client's preferences, and ensure that each experience is not only unique, but also compatible.

Use Case: Bespoke Travel

Eric likes to travel to luxury hotels. He always contacts the hotel before his arrival to introduce himself and receive the best possible service. The hotels he visits have extensive concierge services that can help him plan his travels, make recommendations, or even get reservations and tickets.

During his latest trip, Eric sent a link to his FoodPass profile to the hotel, which indicated that he can't have gluten, and doesn't eat meat. Despite those restrictions, he loves to check out the local cuisine. FoodPass automatically translated his preferences for the hotel's kitchen, and Eric has been enjoying excellent food in the hotel. Even better, when the hotel concierge made a reservation for him at a local restaurant, the concierge immediately forwarded Eric's food profile. When Eric arrived at the restaurant, he was presented with various vegetarian options that could be prepared gluten free.

Figure: freepik.com

Personal chefs and nutrition coaches can use FoodPass to quickly create a baseline understanding of the needs of their patients. This not only helps them to tailor their services from the start, FoodPass also provides them with a dedicated framework to store this information and connect to other services. This way, a meal plan can be turned into a fully compatible grocery list automatically through a supermarket website, or recipes can be automatically adjusted to suit clients.

A full user journey of using FoodPass to organize food in an office environment is shown in Appendix E.

7.5 Future Use Cases

FoodPass is intentionally built as a platform that flexibly connects to other services. While FoodPass can help organize social events and represent people's dietary preferences there, it can enable a much wider functionality by connecting food profiles and events to other services. This flexibility ensures FoodPass can create a growing network in the future, as more systems adopt its protocols and make use of the possibilities it provides.

Physical Environments

At the moment, the service integrations of FoodPass are mostly focused on digital environments. These digital environments then result in actions in the physical world, such as grocery orders or restaurant meals that selected specifically for the user. But the physical integration of FoodPass can be extended by using the digital information to inform physical indicators.

One example would be the use of light in grocery shelves or food displays, which could indicate suitable foods or show warnings when users activate their food profile. Amazon Go stores already have the technology to identify which grocery items is taken from the shelves, and charges customers' accounts automatically when they leave the store without having to scan the items (Garun, 2016). The same technology would allow customers to receive real-time physical feedback about the contents of a salad as the reach out their hand to grab it. University cafeterias could quickly highlight suitable items at the tap of a phone, without the need to read ingredient labels.

Quality, Genetics and Macros

As discussed at the start of the chapter, FoodPass distinguishes ingredients by what they are. This is the standard that is currently used in the food industry. The origin, quality and processing of ingredients is not logged in any standardized format. But while this system does not exist now, it could exist in the future. This would allow for new ways of indicating preferences, such as only buying vegetables of a certain quality level, or avoiding processed foods that do not comply with certain health standards. FoodPass should remain open to these changes in the future, to integrate a wider range of options.

As our understanding of biology develops, we will most likely find new knowledge that can be utilized to inform our choices about food. We are already learning how genetics play a role in the way we process food, and we are learning different diets work best for different people. This type

of information could be used in FoodPass. Alternatively, an external service could help generate food profiles based on a genetic analysis, which could then be synced to the platform.

Another dimension that is not touched in the scope of project is the amount of food people should eat. When eating for specific goals such as weight change, muscle gain or even general health and longevity, the amount of food and the breakdown of carbohydrates, fats and proteins has a serious effect on the body. These considerations could be a future extension of the FoodPass system. Until then, FoodPass' sharing and flexibility should enable some use cases through third parties, that can combine information from the food profile with their own calculations of optimal calorie intake and macro breakdown.

7.6 Development and Monetization

One important consideration of a network like FoodPass is how it is financed. FoodPass is an independent service with free market applications, and most likely won't be financially supported by a government or NGO.

One way to bring FoodPass into reality is to have it developed by a larger food-related company that sees a market for helping their customers communicate their needs. However, this may cause conflicts of interest with other services, and there is no clear incentive for the company to not use FoodPass for their own strategic advantage.

Since FoodPass is in part a social network system, an existing social media network may be interested in developing FoodPass. The strategic advantage of offering a new way to enable inclusivity may be interesting for existing social media networks, although in this way, the service is most likely too niche to be widely adopted.

It seems more likely that FoodPass would be developed by an independent company. This company could champion the needs of anyone with dietary preferences, while promising more engagement to food services and organizational tools to food organizers in professional positions. From this perspective, a FoodPass company could find support from multiple fields.

To make FoodPass a profitable company and platform, some earnings models will be necessary. While individual users will likely experience many benefits from the platform, they will also be the least willing to pay. Individual users would need to receive a lot of value from the service in return for a subscription price, and the network would need to be widely adopted to be usable enough to justify the price.

Instead, it is more likely that professional users would be willing to pay to use the service, when they are convinced the value they get from FoodPass makes them money too. Professional sports teams would be able to organize better food for their players, conferences and the hospitality industry would have better tools to create a unique experience for their guests, and companies could have happier teams, and in return, better talent retention. Hospitals would be able to manage the dietary requirements of hundreds of patients from one central platform. Websites and

apps that implement FoodPass' food profiles could offer personalized services to their customers, which will make them far more attractive than systems with conventional filters.

Professional users could be charged a price based on the amount of users that are connected to their platform, or the amount of interactions that flow through their system. Another option would be to charge a fixed price for a professional workspace or integration, regardless of the amount of users. Charging a reasonable but profitable price for a place in the network FoodPass enables may be a convincing way to get professional users to adopt the service.

7.7 Data Management and Privacy

The network that FoodPass aims to create relies on the sharing of personal data. In smaller social applications, this information will be shared with a food organizer, who will be able to identify individuals and see their preferences. In bigger social settings and service integrations, the information might not be evaluated by human operators, but that does not make privacy less of a concern.

However, FoodPass has been designed from the start to provide privacy to individual users, and favor data control of individuals over that of institutions. The platform should comply with Europe's General Data Protection Regulation (GDPR), as well as other local and international data protection standards. Specific features that help maintain privacy and data safety in the platform are described below.

Limited Information in FoodPass

FoodPass carries personal information that can be linked back to individual people. This poses a risk for privacy, either through connections to other platforms or through hacking attempts and data breaches. This risk applies to FoodPass' internal servers, as well as personal accounts or organizational accounts that carry information from groups of users.

These risks are mitigated in several ways. First, FoodPass accounts can only be set up with an email address and a sufficiently strong password. Users are also encouraged to set up two-factor authentication when they create their account.

The type of information that is stored in FoodPass is also limited. FoodPass does not store addresses, social security numbers, or any login information for services the account is connected with. The account also does not have any bank account- or credit card information for individual users on free accounts. Information stored in FoodPass should also comply with modern end-to-end encryption standards.

Privacy in Social Connections

In social contexts, FoodPass is a system that requires some trust and social vulnerability. We open up about ourselves, in hope of being understood and receiving support. Discussing our dietary preferences, and what it would take to support these, should not require anonymity. At the same time, users should be able to stay in control of what they share.

The first step to this is the ability to customize which part of the food profile is shared in each event. Whenever the user sets up a new connection, they can choose which settings they would like to share. The shared profile can also be edited at any time, and any connection can be revoked by the user. When a user changes their shared food profile, the food organizer for that event will be notified of the changes, without being able to see previous versions. If the connection is revoked, the information is lost to the food organizer. This complies with the 'right to be forgotten', as specified by the GDPR (European Union, 2018).

Within a FoodPass event, dietary preferences are only linked to users within FoodPass itself. If event information is used to customize a recipe or check a grocery list in an external service, the service itself only has access to the collective dietary preferences, without personal identifiers. This ensures that identifiable personal data does not go any further than those it was directly shared with.

Privacy in Service Connections

In service connections set up by one user, where a FoodPass account is linked to the account of another service provider, identities can not be anonymous. However, FoodPass does not share any other information than the food profile of the user. The platform of the external service provider determines how this information is processed, and how it is used in their platform.

Each connection to an external service shows a prompt that clearly lists what information the service receives, and how this information will be processed. As with social connections, the user can terminate a connection to an external service at any time. Since the food profile is only accessed directly through FoodPass, terminating the connection also removes this information from the other party's servers.

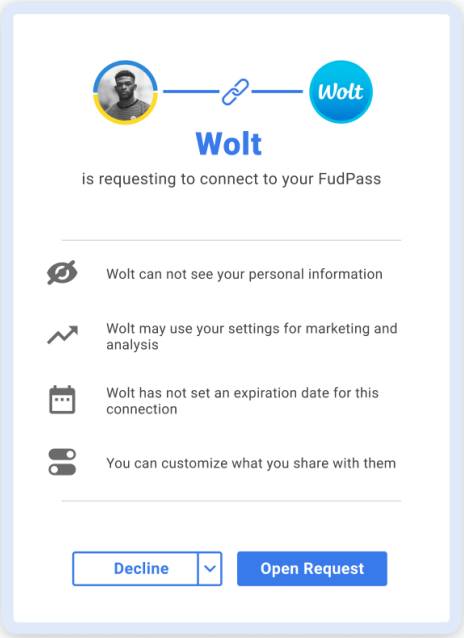


Figure 7.6. FoodPass Service Connection Interface. Figure contains recources from thenounproject.com and unsplash.com.

8 CONCEPT EVALUATION

8.1 Informal Evaluation

Because of the highly social applicability and broad userbase of the project, there were many opportunities to informally test the concept in informal social situations. Candid reactions and feedback were an important influence for the development of this thesis project, and brought out interesting ideas and use cases that I had not personally considered.

The reaction this thesis project elicited was generally positive. Different functionalities of the FoodPass platform appealed to different users, but most people agreed that a platform like this would be beneficial for them. A film director explained that FoodPass' social sharing would help him organize food for the cast and crew, something he wanted to do well but struggled with now, despite keeping different diets in mind. Another person mentioned that this platform would be great, because her boyfriend doesn't eat sauce on anything, which is a struggle when ordering takeout. This type of food preference was not even considered in the thesis, although it probably should have.

These types of input showed that there are many more opportunities for a platform like FoodPass. The platform has been designed to take advantage of this collective creativity, by freely and securely integrating its functions into other services.

8.2 Formal Evaluation

For a more formal evaluation of the concept, the service maps and wireframes were presented to Fiona, one of the participants of the co-creation session. This presentation took place over video call, where it was easy to share the digital prototype.

In this evaluation session, Fiona referred back to her comments in the co-creation session. She mentioned how it was time-consuming and difficult to translate ingredient labels in supermarkets as an expat. A digital food profile connected to the supermarket website could help her in this process, at least online.

She also commented on the colored rings around people's profile pictures in the app as a useful 'shorthand' to provide context and information. Overall, she found the flow of the app to be understandable and logical, and thought the integration with other services would create interesting opportunities.

8.3 Further Development

FoodPass, as presented in this project, is already an extensive platform with many use cases. Future development opportunities have been discussed in chapter 7.5, which details new types of information and areas of implementation that could be considered.

While data management and privacy have been discussed briefly, this topic deserves a much more thorough research process. In our current digital ecosystem, privacy is scarce and constantly at risk. Data is a highly valuable commodity, and is being extracted from our digital and physical presence wherever possible. My personal hope is that FoodPass would not participate in this frenzied obsession with data hoarding, but would work in discrete and secure ways that respect its users.

A topic that has not been touched in this thesis is the legal framework of a platform like FoodPass. Besides data and privacy laws, FoodPass might need to comply with legislations that apply to social media platforms, customer rights, and food- and health regulations. Additionally, FoodPass could help represent global standards in the field of food, such as food allergy ISO standards, or the global Gluten-Free Certification Program.

9 CONCLUSION

The world of food has changed drastically since our time as hunter-gatherers. Since then, we have moved to agriculture-based societies, and have experienced modern agricultural and industrial revolutions. Much of the food we consume today is far removed from what our ancestors used to consume, even up until a couple of centuries ago.

Today, we are at the cusp of several important breakthroughs that may shake up the world of food again. Genetic modification is becoming easier and cheaper than ever, which paves the road for newly modified crops, highly technically advanced food products, and experimental foods that may be unlike anything we've seen before. Our understanding of the human genome is increasing, and it's not unlikely that the rise of precision medicine will also bring us precision nutrition. Meanwhile, even our cheapest tracking devices are capable of highly advanced measurements, allowing us to make complex calculations regarding our health, activity, and nutrition requirements.

Despite all these incredibly exciting opportunities, our relationship with food is far from perfect, even highly problematic in some cases. Our constant abundance, easy access to calorie-rich but nutrient-poor food, and our insistence to add sugar to nearly anything, are starting to show its marks on the world. Lifestyle diseases have become an expected and accepted part of growing older, despite the fact that they are heavily influenced by our nutrition[29].

But the answer to this problem lies in its source: nutrition is one of the strongest daily influencers of our health and longevity. In time, we will hopefully reach a conclusive agreement on how to use food to promote our health. The answer to that question will most likely be different for everyone, depending on our genetics, lifestyle, and goals.

FoodPass was born out of a need for inclusivity in dietary diversity. The social system opens up a new channel to discuss food, and creates a framework that easily allows us to care for each other and our dietary needs. The service integrations aim to upgrade an outdated digital ecosystem, and help us personalize our online experiences.

In time, as the development of food provides us with new products and opportunities, and our increased understanding of our bodies helps us define our needs and best practices, a platform like FoodPass may very well be a necessary component to navigate the dazzling world of food.

Until then, my hope is that, at the very least, it will bring us a bit closer together, and add some inclusiveness to the colorful world of food.

[29] Please refer to the comparison of children in Hong Kong and mainland China by Zhai et al. (2009), as described in chapter 3.6. Another compelling example are so-called Blue Zones, areas with noticeably high rates of centenarians, described in the book by the same title by Dan Buettner (Buettner, 2007).

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LIST OF FIGURES

Figures may contain resources from freepik.com, thenounproject.com and unsplash.com, as indicated in the report. All resources are used under the creative commons license.

APPENDICES

A. Interviewees and Discussed Topics

Interviews with people with food intolerances included:

Stan, 25, Netherlands – February 8th, 2021
Stan's complaints included eczema and stomach pain. He received several allergy tests through a dermatologist, but was unsatisfied with the results. He visited a kinesiologist for bioresonance testing to find any food intolerances, after which he was advised to switch to a vegetarian diet. Afterwards, he moved to a vegan diet, which made him feel better and helped his skin clear up more. While his complaints have improved over the past few years, he is still not sure which specific foods were contributing to his symptoms.

Topics discussed: self-testing for intolerances, DNA tests, bioresonance testing, non-scientific testing methods, elimination diets, vegetarian and vegan diets as treatments for food-related complaints, allergy testing, skin condition as a measure of health.

Hannie, 48, Netherlands – April 15th, 2021
Before being diagnosed with her food intolerances, Hannie dealt with unexplained symptoms such as stomach pain, acid reflux and fatigue. After switching to a vegan diet, she decided to get tested for food intolerances as well, as her daughter was diagnosed with some intolerances around the same time. Hannie's intolerances include dairy, gluten, almonds, and most oils – mainly olive and rapeseed.

Topics discussed: food intolerances in immediate and extended family, misdiagnosis, vegan diet as treatment for food-related complaints, dealing with restricted diets in social settings, settling into a new diet, finding suitable products in online environments, stress-eating while sticking to a diet.

Interviews with medical experts included:

Heleen Furster, Holistic Medicine Practitioner, Netherlands – November 6th, 2020
Heleen Furster is an expert in holistic medicine and bioresonance[30] therapy, and has her own practice in Middelburg, The Netherlands. The aim of the interview was to learn how her work complements traditional Western healthcare, and what misconceptions people tend to have about her health. Furster has an extensive experience in working with food intolerances and -allergies.

Topics discussed: latent infections, Irritable Bowel Syndrome, food intolerances, the role of food quality in nutrition, digestion and enzymes, stress, the important of understanding personal and

[30] Bioresonance therapy is a diagnostic- and healing system based on the detection of wavelengths emitted by the body, either by itself or under influence of another compound (e.g., a suspected allergen). Practitioners use a machine, connected to the patient by electrodes, to analyze energy patterns in the body, and in some cases use the machine to manipulate these patterns to treat the detected condition (Hersh, 2019). Furster's practice uses Bioresonance therapy to detect nutrition deficiencies, allergies and intolerances, and infections, amongst others (Praktijk voor Natuurgeneeskunde & Bioresonantie, n.d.). There is no conclusive scientific evidence for the effectiveness of bioresonance therapy in either diagnosis or treatment of any condition (Hersh, 2019).

familial medical history, being proactive in relationships with medial professionals, listening to the body.

Liis Salus, Nutritional Therapist, Estonia – March 1st, 2021
Liis Salus is one of Estonia's 24 Nutritional Therapists. In Estonia, a Nutritional Therapist is the only officially recognized professional that treats medical complaints through interventions in nutrition and lifestyle. Salus was also diagnosed with celiac disease and lactose intolerance herself.

Topics discussed: unexplained symptoms and the difficulty diagnosing them, elimination diets, the accuracy of intolerance testing services, settling into a new diet, the challenges in receiving accurate diagnoses within the medical system, eating out and ordering food with dietary restrictions, finding support for lesser-known intolerances.

Interviews with HR managers included:

Antoinette, HR Manager, Netherlands – March 15th, 2021
Antoinette is an HR manager for a Dutch company, with a local team of roughly 70 people. The company organizes a daily free lunch for the team, which serves as an important social meeting point. The company has several vegans and vegetarians, as well as people who can't eat gluten.

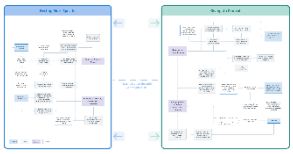
Topics discussed: knowing the diets of team members and providing suitable options, employees feeling comfortable bringing up requests, the effect of free lunch on the company culture, being the first for a specific diet in the workplace.

Kätlin, HR Manager, Estonia – March 15th, 2021
Kätlin is an HR manager for an Estonian company, with a local team of 55 people. The company provides several types of snacks and small meals for the team in the company kitchen.

Topics discussed: knowing the diets of team members and providing suitable options, employees feeling comfortable bringing up requests, birthday parties in the workplace, receiving feedback on available options from the team, giving employees freedom in organizing food for social gatherings.

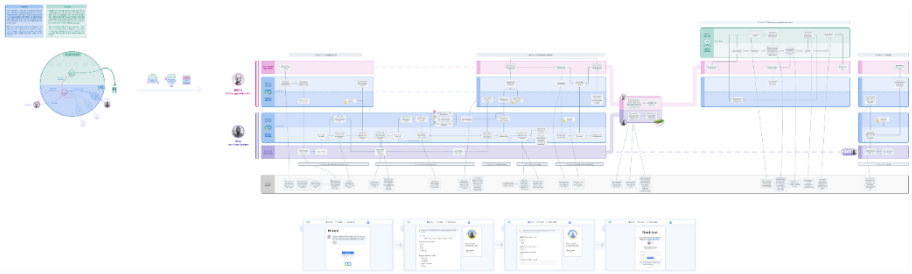
Due to page size differences, appendices B through F are available in full in a separate file. If this file is missing, please reach out through harmjangrinwis@outlook.com.

B. Future Trend Analysis Map

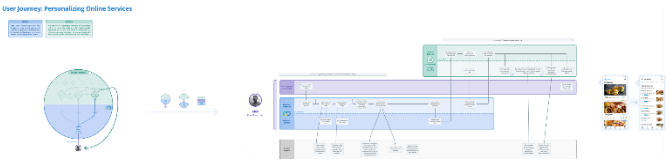


C. System Map

D. User Journey: Professional Social Event



E. User Journey: Personalizing Online Services



F. User Journey: Personal Social Event