Master's Thesis

Cultural Anthropology: Sustainable Citizenship

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Resilience and Risk related to Mobile Health Applications

A case study of the G-Moji app

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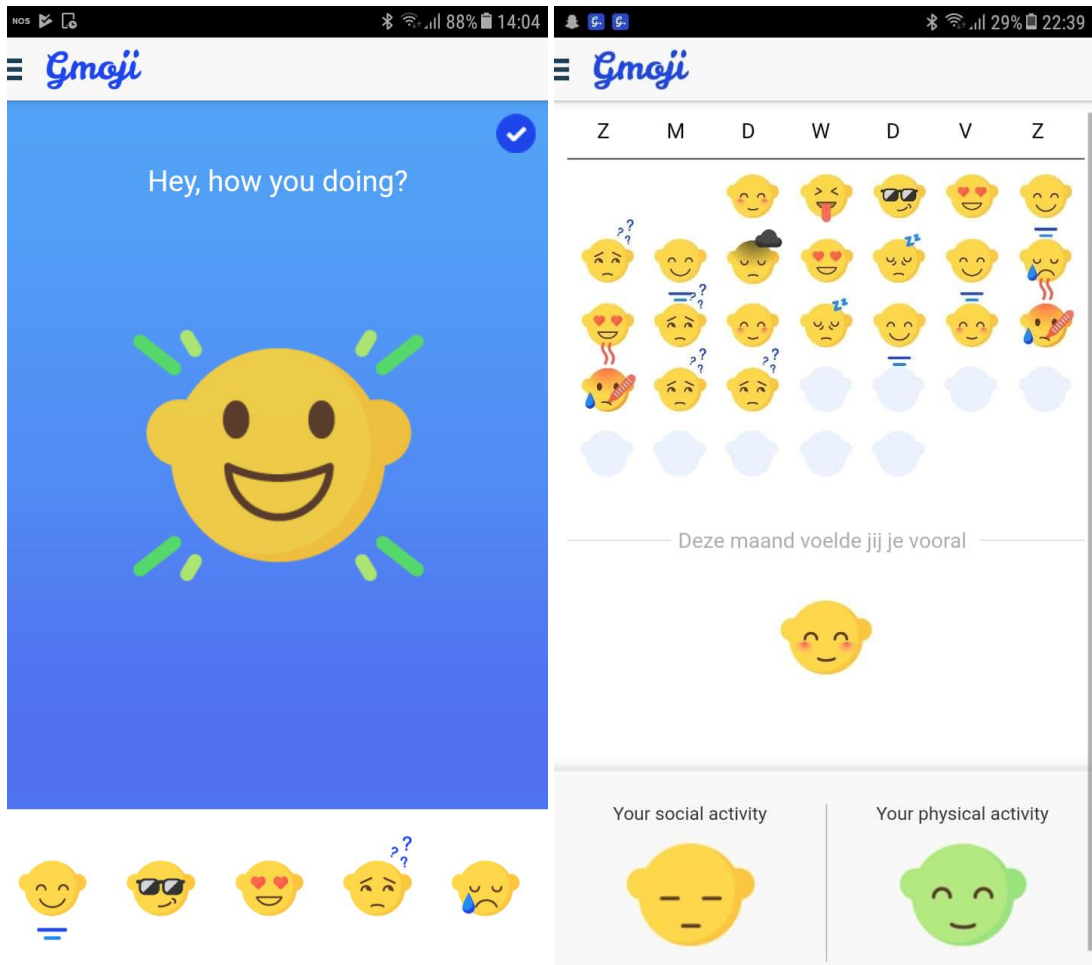
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Abstract

Garage2020 is planning to develop the G-Moji application for youngsters in youth care with the aim to improve their mental health. This app will be able to predict the mood of users by collecting passive (your location, phone status, charging) and active (social interaction, sleep, physical exercise) data. In order to develop this predictive app, 35 youngsters are testing a research app for three months. This research app is not able yet to predict the emotional state of the user. Everyday users are asked to choose an emoticon that suits their mood. This thesis is the result of a three-and-a-half month ethnographic research at Garage2020, answering the question 'How are resilience and risk related to the datafication of health experienced by users of the G-Moji app and approached by organisations providing this care?' I interviewed 11 experts who are involved in the pilot and 10 youngsters who are receiving youth care or psychiatry and testing the research app. In my research I will reflect on the G-Moji app as well as mobile health applications in general. Since 2017, 325000 mobile health application where downloadable worldwide and this number is increasing every year. However, many of these apps are not scientific validated, might be unreliable and lack privacy policies. On the other hand, mobile health technologies have the potential to offer great opportunities, regarding to an increase of self-awareness and autonomy. Therefore, it is of great importance to examine resilience-based aspect and risk-based effects of mobile health technologies, in understanding their possible benefits and pitfalls.

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1. Introduction

1.1 Datafication of health

Anthropologists Ruckenstein and Schüll 2017, 262) illustrate that "over the past decade, the capacity to gather, store, and analyze individuals' physiological, behavioral, and geolocational data has come to affect a wide array of everyday life domains, from policy making to policing, corporate marketing to electoral forecasting, entertainment to education, urban planning to epidemiology". This growing trend of turning many aspects of life into quantified data is called datafication. In the health care domain datafication is evident with the increasing use of digital health devices and applications. In 2017, 325,000 mobile health applications were downloadable worldwide on well-known app stores of which the largest are Google Play Store and Apple App Store. This is the largest number of health apps ever counted: 78,000 more than last year.[1] Mobile health apps are available for many mental and physical illnesses such as asthma (Kenner 2016), diabetes (Årsand, Frøisland, Skrøvseth, Chomutare, Tatara, Hartvigsen and Tufano 2012), bipolar disorder (Matthews, Abdullah, Murnane, Voida, Choudhury, Gay, and Frank, 2016), posttraumatic stress disorder (Rodriguez-Paras and Sansangohar 2017) and obsessive-compulsive disorder (Whiteside, Ale, Douglas, Tiede and Dammann, 2014).

Mobile health applications are to a greater extent used for self-care practices, because they can enable patients to monitor their own health at home without seeing a doctor (Rodriguez-Paras and Sasangohar 2017, 1827). These self-managing practices question the traditional patient and doctor roles, as patients have more access to their own data. Before the widespread use of such applications, patients were dependent on doctors who could obtain their medical results and give a diagnosis. Today, patients can interpret their own medical record and diagnose themselves, before they have seen a doctor (Lupton and Jutel 2015, 129). However, many mobile health applications do not provide any information in their descriptions about how the app was developed and how its conclusions are generated. It is often unclear if an app has been clinically validated and therefore if its results are reliable (Lupton and Jutel 2015, 131; Rodriguez-Paras and Sansangohar 2017, 1828).

In my thesis I will explore one particular mobile health application named the 'G-Moji app'. This app is an example of the ongoing datafication of health. The aim of the app is to improve the mental health of the user by predicting his or her state of mind and giving advice

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[1] https://research2guidance.com/product/mhealth-economics-2017-current-status-and-future-trends-in-mobile-health/ (30-12-2017)

on how to feel better. Youth care organisation Garage2020 is eager to develop the G-Moji app for youngsters in youth care, because this organisation believes that the G-Moji app has the potential to empower youngsters by giving them a tool to work on their own health, without being dependent on social workers. In chapter 2.3 I will elaborate on this autonomous effect of mobile health technologies. Garage2020 coordinates the development of the G-Moji app in Amsterdam, The Netherlands. Garage2020 designs alternative solutions on already existing problems in youth care from a youngster's point of view with the use of technological innovations.[2]

The purpose of this research is to explore the concepts risk and resilience, and relate them to the datafication of health by focussing on one particular mobile health application: the G-Moji app. Medical anthropologist Catherine Panter-Brick (2013, 2015) describes these two concepts as the following: "..risk is defined as a situation involving elevated odds of undesirable outcomes and resilience as the process of harnessing key resources to sustain well-being" (2015, 432). She argues that risk-based perspectives tend to focus on the vulnerabilities of humans, while resilience-based approaches attract attention to the capabilities of people (Panter-Brick and Leckman 2013, 133). In my analysis of academic literature about the datafication of health I recognise these two theoretical currents. Panter-Brick applies risk and resilience theories to medical anthropology, whereas I will relate them to the datafication of health.

When applied the concepts risk and resilience to the datafication of health, scholars with a risk-based approach discuss the exploitive and oppressing effects of the datafication of health: their focus tends to be quite negative. In chapter 2 I will examine some of their arguments. Scholars with a resilience-based approach explore its mobilizing and opportunity giving aspects: their focus tends to be more positive. In chapter 3 I will explore some of their arguments. Despite the differences between these two approaches, I do not regard risk- and resilience-based arguments as opposites. Rather I agree with Ruckenstein and Schüll (2017, 263) that these "..clusters do not represent debates or disagreements so much as they represent parallel conversations that place weight on different themes, sites of inquiry, and analytical frameworks; considering these conversations alongside one another makes salient their strengths as well as their shortcomings and suggests ways in which their elements might be productively combined". The intertwining of both resilience-based and risk-based arguments became evident regarding themes, covered in this thesis. In chapter 4 I will elaborate on these themes and present these two approaches as parallel conversations.

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[2] http://www.garage2020.nl/ (30-12-2017)

In order to answer my central question '*How are resilience and risk related to the datafication of health experienced by users of the G-Moji app and approached by organisations providing this care?*' I did an internship at Garage2020. During my internship I had the opportunity to conduct a scientific relevant independent ethnographic research. Several tasks related to my internship, such as recruiting and assisting youngsters during the pilot, helped me to gain trust of my respondents and conduct participant observation. I also tried the G-Moji app myself during the pilot. My ethnographic research is based on participant observations, 11 unstructured interviews with professionals and 10 unstructured interviews with youngsters who tested the G-Moji app while receiving youth care or psychiatric care. This thesis is the result of a three-and-a-half-month ethnographic research at Garage2020.

In the following section I will describe Garage2020 and the G-Moji app further by explaining the difference between the research app and future app.

1.2 Garage2020, G-Moji research app and future app

Garage2020 was born two years ago out of its mother organisation Spirit: an organisation that offers specialised youth care and pedagogical assistance to youngsters and families in Amsterdam and surrounding municipalities. Garage2020 was founded because Spirit wanted to establish an external facility that would come up with new ideas to improve youth care and criticise its mother organisation whenever needed. It is called Garage2020 because it is a working place for innovation and in 2020 Spirit will exist 500 years. Its aim is to improve youth care with technological innovations that reaches the perspective of youngsters in this rapidly changing society. Garage2020's ultimate goal is captured in its slogan: "Making youth care unnecessary" [3]. So, Spirit established an external organisation that has the goal to make its mother organisation unnecessary. Garage2020 works together with people from all sorts of different backgrounds: some have their expertise in youth care, others are for example developers, design-thinkers, data-scientists or tech-experts. Besides Amsterdam, Garage2020 is also situated in four other cities in the Netherlands. In every city Garage2020 is related to a youth care organisation. Garage2020 is planning to establish more of its organisations in the Netherlands.

Garage2020 is eager to develop a medical health application that is be able to predict the mood of users by collecting passive (your location, phone status, charging) and active (social interaction, sleep, physical exercise) data in order to develop the G-Moji app

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[3] http://www.garage2020.nl/ (15-08-2018)

Garage2020 started a pilot in April 2018: 35 youngsters from the age of 16 until 24 tested a research app for three months. This research app is a predecessor of the smart G-Moji app of the future. It does collect passive and active data, but it is not smart enough yet that it is able to predict how participants are feeling based on this collected data. Participants are asked every day by the research app how they are feeling. They can choose from a range of fourteen different emoticons and answer the question by picking an emoji that suits their mood at that moment. The research app gives users a monthly overview of chosen emojis.

When the pilot is over, the passive and active data collected by the research app will be combined with the daily filled in emoticons. Participants can fill in at least one emoticon (more than one if they desire) on a daily basis: all selected emoticons will be registered. All gathered information will be used to find correlations and to develop a predictive algorithm that will be able to predict the mood of users for the smart G-Moji app. The research app was derived from the Media Lab at the Massachusetts Institute of Technology. Garage2020 is the coordinator of this project in the Netherlands and works together with people from other organisations and universities that have their scientific expertise in mental health, artificial intelligence, forensic psychiatry, forensic orthopedagogics.

According to the project leader of the G-Moji app Nick, the future app might have two functions. One is spotting trends in the life of the user such as a bad sleeping cycle, low level of physical or social activity. This function doesn't need to be predictive, spotting trends might be enough for a youngster to change his behaviour and feel better. The other function is predicting the emotional state of the user on the basis of passive data. According to him, the app is not meant for lifetime use. The goal is to learn from the app, but once you learned to modify certain behavioural patterns you might not need the app anymore.

In my thesis I will reflect on the two different versions of the G-Moji app: the app used in the pilot (this one exists) and the future smart predictive app (this one does not yet exist). To keep it simple I will name the first one research app and the second one future app.

In the following section I will elaborate on the research methods I used, such as unstructured interviews and participant observation.

1.3 Participants, unstructured interviews and participant observation

I conducted 11 unstructured interviews with professionals and 10 unstructured interviews with youngsters who tested the G-Moji app while receiving youth care or psychiatry.[4] In my thesis I will use fictive names in order to maintain the anonymity of my respondents. I choose to conduct unstructured interviews because I believe, following sociologist O'Reilly's (2012, 119, 120) argument, that structured interviews do not enable participants to elaborate on their own perspectives concerning certain issues as the questions are predetermined. During the interviews I gave participants room to introduce new themes, enabled myself to add new questions based on my respondents replies and stayed critical towards my own observations. Working with unstructured interviews however, does not mean that I did not prepare beforehand. At every interview I brought a list of topics I wanted to address,[5] but I didn't had fixed answers in mind and leave it up to the participant to responds.

During my ethnographic fieldwork I conducted participant observation at Garage2020. Sociologist O'Reilly (2012, 97), stresses that "if you are simply being there, hanging around, taking part, you are no more than a participant (as we all are in our daily lives); but as a participant *observer*, you are someone who is observing as well taking part". I participated by taking part in the research team. I assisted Garage2020 in organising the pilot, finding participants and I tested the app myself for three months. Experiencing what my respondents went through during the pilot helped me to sympathise with them and enabled me to reflect on my own experiences. I also conducted intakes with most participants face-to-face before the start of the pilot. These intakes usually took one hour and consisted of a privacy agreement, a power bank and four questionnaires. According to anthropologist Tedlock (1992, 70) it is not an easy task to maintain an observing role while participating. He explains that some ethnographers become so familiar with their research location that they internalise appropriate behaviour learned from their informants. As a result, the ethnographer may frame certain happenings and moral codes as common sense, which obstructs a researcher's ability to pick up subtle details. In order to overcome this problem, I needed to distance myself mentally from my participatory activities in order to perceive all details in different contexts. I distanced myself physically from my research location and population in the weekends and on Tuesdays. I used these days for reflection. These days of physical distance helped me to distance myself mentally as well, so I could maintain an observing role while participating.

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[4] In Appendix A I will introduce my respondents
[5] In Appendix B I will provide the reader with the topic list

2 Resilience

Heidi suggests that the future app could be used to support youngster who have been put on a waiting list. Developing an app that may assist youngsters who need to wait to get help was the reason why she joined the pilot. Almost all youngsters I spoke to told me they had been put on a waiting list. Heidi needs to wait for two months in order to get therapy. She states that "everything can happen in two months if you are only feeling worse as time passes. Before you know it is too late, it is true, it happens a lot."[6] Fleur was put on a waiting list for intensive trauma therapy and needs to wait for 10 weeks. "I need a crisis time out, but that it is a crisis doesn't matter, I just need to wait for two months."[7] She has a difficult time in waiting and would like to have some support, because in the mean time she can't really do anything. "You wait and survive."[7] She explains that an app is at least something if you don't have any support at all. "It is not much, definitely not a human, but it might help."[7] James describes that he was in locked ward for depression and suicide. After he was discharged it took him two months to get a therapist. In the meantime he needed to get through the days by himself. "This was pretty hard, because time seemed to go very slowly and days seemed to be weeks".[8] Kim just returned from her doctor because of a self-harm injury when I spoke to her. She was feeling terrible. They would probably raise the dose of her medication in 5 weeks, because only then her psychiatrist has time to see her. "Normally I never call my psychiatrist and I called and they told me that they could help me in 5 weeks. I thought are you kidding me? Which is pretty lousy."[9] Six weeks later she texted me that she was admitted in locked ward.

The possibility of helping youngsters during a waiting list procedure is an example of a resilience aspect of a mobile health application. I will elaborate on this further in chapter 2.3. In the following sections I will provide the reader with some primary resilience-based arguments of scholars writing about the datafication of health and use these frameworks to positions my ethnographic material.

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[6] Interview with youngster Heidi, participant of the pilot, 14 May 2018
[7] Interview with youngster Fleur, participant of the pilot, 25 April 2018
[8] Interview with youngster James, participant of the pilot, 25 April 2018
[9] Interview with youngster Kim, participant of the pilot, 26 April 2018

2.1 Increase of self-awareness

A resilience-based argument of professionals I interviewed is that the ability of apps and devices to give direct feedback on tracked behaviour has the aim to raise awareness among users about their own behavioural patterns. All professionals stress that this increase in self-awareness has the potential to motivate users to change their lifestyle in favour of their wellbeing. Sara, who is a board member of youth care organisation Spirit, describes this as the following: "You get feedback, you learn your stress is rising, you learn which traps to avoid when you are stressed and as a result you may prevent excessive behaviour".[10] In this example, Sara illustrates that the feedback of apps and devices might help users to manage difficult situations and overcome problematic habits. All professionals agree with Sara and argue that an increase in self-awareness about behavioural patterns has the potential to prevent problematic behaviour.

Scholars writing about the datafication of health confirm that mobile health applications and devices have the potential to increase self-awareness among users about their own behavioural patterns. Researchers Williams, Price, Hardinge, Tarassenko and Farmer (2014) for example, conducted a qualitative study on an app for chronic obstructive pulmonary disease and conclude that patients considered their symptoms more on a daily basis with the app. Patients responded to be less tended to ignore their symptoms, as they would often do (ibid., 295, 296). Scholars Morris, Kathawala, Leen, Gorenstein, Guilak, Labhard and Deleeuw (2010) examined the effects of a mobile health application on which users could report their mood and practice mental and physical relaxation exercises. Morris et al. argue that self-tracking increased the awareness of users about their feelings. Furthermore, Morris et al. state that self-tracking motivated users to incorporating relaxation exercises on the app in their daily life and change their behaviour in favour of their wellbeing (ibid., 1). Although the studies of Williams et al. (2014) and Morris et al. (2010) show that mobile health technologies have the potential to enhance self-awareness and motivate users to modify behaviour, scholars have questioned the effectivity of many apps. In chapter 3.1 I will elaborate on this matter and question the reliability of many mobile health applications.

Many professionals proclaim that mobile health technologies are able to give users objective feedback on tracked behaviour. They explain that an app is not judgemental: it collects behavioural patterns for 24 hours and it is up to the user to interpret this information and take action. The feedback is a direct result of what the user is doing at that particular moment. Many professionals argue that feedback from an app or device is more objective than advice from a

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[10] Interview with professional Sara, board member of Spirit, 19 March 2018

social worker and regard this as a great advantage of mobile health technologies. Social worker Hugo for example expects that youngsters will take feedback from an application more objectively than advice from a social worker, because "an app is not someone you dislike or like".[11] He states that youngsters will only take advice from someone they like and that a successful intervention requires a good connection between social worker and youngster. He argues however, that with an app a youngster doesn't need to build a relationship in order to follow up its advice. According to Hugo, the reason for this is that an app is able to base its advice on objective measurements and is therefore more neutral than a social worker. Developer and strategist Bob proclaims that mobile health technologies are objective, because they don't give socially desirable answers. He illustrates that people often reply to others that they are doing well, while they are not. "If you ask people on the street or you ask your friends, how are you? Good. That's the standard answer".[12] According to him, mobile health technologies are more reliable than individuals themselves, since apps don't lie about someone's functioning. The perception of algorithms as objective technologies often proposed by professionals was discussed by many scholars in the field of cultural politics and algorithms such as Lupton and Jutel (2015), Cheney-Lippold (2011) and Irani and Lee (2016). Unlike professionals however, these above-mentioned scholars question the objectivity of algorithms and regard this perception as problematic. In chapter 3.3 I will examine the arguments of Lupton and Jutel (2015), Cheney-Lippold (2011) and Irani and Lee (2016) and explore the objective power of algorithms.

The objective aspect of mobile health technologies was not discussed by youngsters I interviewed, but apart from this they argued something quite similar. Like professionals, all youngsters proclaim that mobile health technologies have the potential to raise self-awareness and prevent excessive behaviour. Furthermore, youngsters add to this resilience-based argument that the future app could give them a sense of control. They explain that by receiving a warning or a suggestion of their emotional wellbeing you might consider your own feelings and take a moment to decide for yourself what you are going to do next. "Most of the times I do not pay attention to how I was feeling over the month, but now you can do something about it, because the app shows you the overview", explains James.[13] Jade illustrates that you may take into account a warning of the app, "by for example slowing down with work and school

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[11] Interview with professional Hugo, social worker of Spirit, 12 February 2018
[12] Interview with professional Bob, strategist and developer of No Worries Company, 23 May 2018
[13] Interview with youngster James, participant of the pilot, 25 April 2018

and taking more time for yourself". [14] According to her this is a different way of learning than listening to a social worker, because a device teaches you to take care of yourself and to develop this skill on your own. Many youngsters argue that the future app might confront you with how you are really feeling, because it will be able to predict your mood. They explain that when you are running away from your emotions, you may experience a sudden burst of negative emotions and that this might be prevented with the future app. Carmen and Kim illustrate that running away from your emotions could have serious consequences, as they both struggle with self-harm. Kim explains that she feels empty if she has a hard time with tracing back her emotions. At such moments "it might be helpful if the app could give could give me a suggestion with how I'm feeling, such as you could be sad or angry".[15] During the pilot her self-harm problems became so bad that she was admitted into a locked ward. In her crisis she texted me that she would stop choosing emojis for a while because her head was too full. Filling in emojis in her state was too much for her to handle.

This feeling of control argued by youngsters was pointed out by scholars Matthews et al. (2016) and Swan (2009). Mattews et al evaluated an app for bipolar disorder and conclude that self-tracking "..may give patients whose disorder makes them feel very out of control and who have been told there is nothing they can do to control their moods except take their medication, some sense of control" (ibid., 479). Scholar Swan (2009, 509) gives a similar conclusion about self-tracking. Youngsters complement the studies of Matthews et al. and Swan by elaborating on this feeling of control. Furthermore, youngsters add to the arguments of these two scholars, that besides a feeling of control, a mobile health application has even the potential to confront users with how they are really feeling.

Youngsters proclaim that if you track your emotions you might think about your emotions more carefully and become more aware of your own feelings. In the research app youngsters are tracking their emotions by choosing an emoji once a day that suits their mood at that particular moment. However, when I asked what effects this practice has on them, most youngsters answered that they didn't consider their feelings more than usual with the research app. It takes them a few seconds to fill in an emoji and after that they didn't really think about it. "It is an emoji and that's it, it feels like almost nothing", illustrates Jade, but she notes that if the app has a predictive and warning function in the future you will probably consider your

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[14] Interview with youngster Jade, participant of the pilot, 11 May 2018
[15] Interview with youngster Kim, participant of the pilot, 26 April 2018

emotions more. [16] Only two youngsters, Julia and Heidi, answered that they learned something about themselves by tracking down their emojis with the research app. Julia for example experienced a decrease in her social anxiety during the pilot and noticed this by filling in lots of positive emojis. Heidi explains that the overview started to make her think about why she filled in a certain emoji and what had happened that day. Regarding the low number of only two youngsters that considered their emotions more with the research app, it can be doubted if self-tracking with the research app would significantly increase self-awareness.

Some youngsters found it hard to express themselves in the emojis of the research app. They missed a more neutral emoji for example. Julia expresses the reason why the project leader of the G-Moji app Nick and I decided not to put a complete neutral emoji in the research app. She isn't sure if a neutral emoji would be a good idea because "a lot of people would soon think I'm feeling neutral, while deep within they are not feeling neutral".[17] Selecting a neutral emoji could be an easy way for youngsters to run away from their emotions and just select neutral, instead of really thinking about how they are feeling. Some youngsters found it difficult to express themselves in just one emoji, because you may experience a lot of different emojis during the day or at the same time. A couple of youngsters picked just one emoji a day on the basis of their average feeling during the day. Other's filled in more emojis a day if they felt their mood changed a lot.

Some youngsters found it difficult to interpret the emojis of the research app. For David, the titles under the emojis are confusing, because his interpretation of the picture didn't always correspond with the given title. He explains that youngsters are used to emojis through WhatsApp, but in WhatsApp emojis are open for interpretation. An emoji in WhatsApp explains the message of a written text and may express multiple messages in different texts. The emojis in the research app on the contrary are not open for interpretation, because the titles under the emojis explain the meaning of every emoji. Julia on the other hand really likes the titles under the emojis, because on WhatsApp she frequently misinterprets messages due to the open interpretation of emojis. During my field work the complexity of WhatsApp emojis was evident when I asked 20 participants of the pilot to express themselves in 5 negative emojis and 5 positive emojis. The emoji with his face upside down was by some youngsters categorised as positive emoji, while by others this emoji stood in the list of negative emojis.

Upside-down face emoji

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[16] Interview with youngster Jade, participant of the pilot, 11 May 2018

[17] Interview with youngster Julia, participant of the pilot, 9 May 2018

Scholars Miller, Thebault-Spieker, Chang, Johnson, Terveen and Hecht (2016) and Kelly and Watts (2015) confirm that emojis can be interpreted in multiple different ways. Researchers Miller et al. asked participants through an online survey to interpret the most common used emojis and discovered that many emojis where differently defined. Even "in the cases in which participants rated the same emoji rendering, they disagreed on whether the sentiment was positive, neutral, or negative 25% of the time" (ibid., 259). Scholars Kelly and Watts argue that the interpretation of emojis depends on the relationship of the speakers. A kiss face emoji for example might have a different meaning when it is sent to a best friend than towards a potential lover (2015., 5). Regarding the ambivalence of emojis, outlined in the studies of Miller et al. (2016) and Kelly and Watt (2015), it is no wonder that some youngsters had a hard time in interpreting the selected emojis.

In the next section I will elaborate on how care could be personalized with mobile health technologies.

2.2 Personalized care

A resilience-based argument of scholars writing about the datafication of health, is that mobile health technologies are valid in real-world settings, because they monitor users every minute of the day. Scholars Matthews et al. (2016, 478, 479) and Collins (2012) stress that apps and devices provide a unique insight in the daily life of individuals and make it easy to collect a large amount of real-time data. Both studies argue that this opens up possibilities for scientists, since scientists might discover new correlations by interpreting this large amount of unique data.

Most professionals I interviewed, agree with Matthews et al. (2016) and Collins (2012), that mobile health applications give a unique insight in the daily life of individuals. Many professionals stress that the information collected by a mobile health application gives a richer understanding of the life of a youngster than previous methods such as questionnaires and observation, since an app is able to measure the behaviour of a youngster for 24 hours, while questionnaires and observations are just snapshots. Professionals often illustrate that with an app you might be able to map the bubble in which youngsters live in more detail and indicate what change in behaviour takes place on the basis of the mood of the user. Technologist and epidemiologist Luke for example states that the advantage of technology is that it is able to collect fine grained behaviour of individuals, because the human brain cannot keep track of those types of things: "like I can't remember what I wore three days ago and I can't remember

what I ate for breakfast". [18] According to him, predictive apps, like the future app can be used to collect this all-encompassing data and help predict when people experience a particular event of health outcome and increase our wellness. Most professionals share these thoughts of Luke about the future app. Social worker Hugo even hopes that in the future it would be possible to track the location of youngsters, because this opens up the possibility to explore at which spots a youngster feels save and which locations have a disordering effect. Tracking down location however, also raises questions about privacy. In chapter 3.2 I will explore this privacy aspect further. Many professionals agreed with Matthews et al. (2016) and Collins (2012) that scientist may discover new correlations with mobile health technology and state that this unique data should be used to improve youth care by examining the effectivity of interventions.

Besides the unique insight of individuals, scholars also argue that the implementation of mobile health applications in real-world settings makes it possible to adapt care to the personal demands users. Scholars Peng, Kanthawala, Yuan and Hussain (2016, 6) conducted a qualitative study on user perceptions of mobile health app and conclude that "..many participants liked apps with personalized coaching and guidance with specific plans". Peng et al. illustrate that many apps incorporate a goal setting function in which users fill in personal information, like their weight, and a personal goal, like losing weight, they want to achieve. On the basis of this personal information, apps are able to provide the user with a tailored plan to achieve these goals (ibid., 6, 7). Scholars Heron and Smyth (2010, 20-22) add to this argument that the moments of receiving feedback may as well be tailored to the specific needs of users. Users might for example initiate difficult situations in which they would be willing to receive extra support from the app (ibid., 20-22). The importance of self-chosen goals was showed by scholars Scheldon and Elliot (1999). These scholars argue that individuals are more likely to attain goals that are self-concordant.

Professionals I interviewed often stress that mobile health technologies have the potential to offer care that fit the personal needs of users. Many professionals explain that apps and devices give a richer understanding of the personal life of youngsters than previous methods and that the collected data should be used to adapt an intervention to the unique characteristics of a youngster. Many professionals stress like scholars Peng et al. (2016), and Heron and Smyth (2010) that mobile health applications make it possible to work on the personal goals of youngsters. Professor of forensic orthopedagogics Olaf for example states that an intervention will only be able to succeed if people are motivated to reach their own goals. This argument

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[18] Interview with professional Luke, technologist and epidemiologist at MIT Media Lab, 19 February 2018

was confirmed by scholars Scheldon and Elliot (1999). Olaf states that in youth care this is often not the case: people work with goals that do not have any meaning to them, because they are imposed by a social worker or proposed in such an abstract language that it loses meaning. Olaf proposes that "with a mobile phone, like the G-Moji, it might be possible to really work on your own things".[19] Many professionals share the thought of Olaf that a mobile health application makes it possible to work on your own goals and that this would have a positive effect on youngsters. Professionals Jack, who is a youth-initiated mentor of his best friend (see Appendix A) and Bob explain that a personalized app with a personal touch makes an app attractive to use. "In Snapchat you have bitmoji, in Facebook you have your own profile picture, on Twitter you can be who you want to be", illustrates Jack.[20] Jack and Bob suggest that youngsters should be able to customize the future app in order to make the app more personal. Scholars Dennison, Morrison, Conway and Yardley (2013) stress the importance of enabling users to customize mobile health applications according to their wishes. Dennison et al. conducted a qualitative study in order to explore the experiences of young adults with mobile health applications and conclude that many of their participants "..wanted to be in control of settings and to personalize the app during setup (and review and edit settings later on) depending on what suited them." (ibid., 7).

Most youngster proclaim that besides the predictive function of the future app, the app should also give advice on how to feel better and stress the importance of personalising this advice. Heidi for example suggests filling in activities you like to do in the future app, so that when you are sad, the app can use your own personal hobbies as a suggestion to feel better. Many youngsters explain that the future app could help them to reach their personal goals, as argued by scholars Peng et al. (2016), and Heron and Smyth (2010). Julia for example illustrates that the future app might help her with putting her fears in perspective, because she finds this difficult to do on her own. "Normally I ask my friends if my fear is qualified in a certain situation. However, they are not always available, and I feel like a burden if I'm always talking about my problems. Asking an app for advice would be great".[21] All youngsters found it important to personalize the future app by being able to customize the background and colors, compile a selection of own chosen emojis and design emojis themselves. This confirms the study of Dennison et al. (2013). In the research app customizing the app was not possible. Almost all youngster wished to have a writing function in the future app, so they could explain

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[19] Interview with professional Olaf, professor of forensic orthopedagogics at the UVA, 26 April 2018
[20] Interview with professional Jack, YIM of his best friend, 26 March 2018
[21] Interview with youngster Julia, participant of the pilot, 9 May 2018

why they were feeling in a certain way and write down what they did at a bad day to feel better as a reminder. Jade for example would love to add emergency numbers and a personal safety plan in which she can add warning signs, coping strategies and reasons to live for if she is in a crisis situation. Jade already has this function in another app and it really helped her in coping with difficult situations. All youngsters would like to receive tailored information from the future app.

Scholars Glazer, Mieczakowski, King, and Fehnert (2014, 221) analysed the development of a home-based telehealth system and conclude that "..the effect on patients was tied to caring relationships and a warm affinity to the technology in itself, welcomed for its comfort and promise to heal". Youngsters didn't experience yet a warm affinity to the research app, but they illustrated how the future app could be developed in order to accomplish this. All youngsters suggest that the future should not only focus on negative emotions but that positive messages are equally important and if not, more important. "The app is not for someone else, except a social worker or a friend sometimes, but it is really for yourself. So it needs to give you a good feeling', explains Jade.[22] She proposes that the future app could give reminders for positive activities, such as taking a shower for relaxation and green checkmarks of small daily activities such as I went to school today may also help youngsters in feeling better about themselves. Scholars Peng et all. (2016) and Dennison et al. (2013) confirm that users of mobile health application don't like to receive continuous feedback.

In the next section I will examine the autonomous effect of mobile health applications on users.

2.3 More autonomy

A resilience-based argument of scholars writing about the datafication of health is that mobile health technologies have the potential to decrease face-to-face meetings between patients and doctors, since patients can be supported at home by an app or device. Scholars Whiteside et al. (2014) examined a mobile health application for obsessive compulsive disorder and conclude that digital feedback might be enough for patients with mild symptoms and improve the care of more difficult cases. He states that "decreasing face-to-face meetings has the potential to lower the costs associated with attending appointment borne by the patient, including co-pays, parking, transportation costs, parent missed work, and child missed school" (ibid., 90). The

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[22] Interview with youngster Jade, participant of the pilot, 11 May 2018

reduction of costs due to less clinical visits was also pointed out by scholars Gega, Marks and Mataix-Cols (2004, 155), and Dobkin and Dorsch (2011, 788). Besides this practical benefit, scholars Vaart, Witting, Riper, Kooistra, Bohlmeijer and Gemert-Pijnen (2014, 4) and scholars Wentzel, Vaart, Bohlmeijer, Gemert-Pijnen (2016, 4, 7) stress that online sessions also improve the self-management of patients, as they are encouraged to implement therapy in their everyday life outside of face-to-face sessions. Despite the above-mentioned advantages of online therapy, Vaart et al. and Wentzel et al. stress that face-to-face guidance might be needed in order to discuss difficult matters and conclude that blended therapy has the best of both worlds.

All professionals agree with Whiteside et all. (2014), Gega et al. (2004), Dobkin and Dorsch (2011), Vaart et al. (2014) and Wentzel et al. (2016) that mobile health application have the potential to decrease face-to-face meetings and enhance the self-management of users. Professionals illustrate that a mobile application has the ability to give youngsters more control about their treatment, because they have the possibility to monitor themselves and work on their own health, without being dependent on social workers. Game-developer and strategist Dilan explains that health care is still based on a system in which the medical specialist is worshipped like a god and the patient is the passive receiver of care. He states that in order to improve health care we should change this system by for example empowering patients with tools that enables them to step out of their old role as victim. If patients keep acting like patients and doctors like doctors, the old system will never change, he argues. The idea of giving youngsters more autonomy in their therapy was shared by all professionals.

Youngsters proclaim that for most youngsters actual face-to-face meetings with a social worker should never be replaced with advice from a mobile health application. Most youngsters explain that people need a real conversation in order to get better and that this is something crucial you can't accomplish with an app. "You can ask SIRI, but then you get weird answers, not a real conversation. Furthermore, a social worker can help you with self-reflection, an app can't do that of course. A social worker can meet your needs, an app can't. Or it becomes really scary. No, let's not do that", illustrates Jade.[23] Youngsters however share the idea that a mobile health application could be really supportive for a youngster, certainly if it would be included in therapy and the therapist would work with it too. Julia suggests that an app might assist youngsters outside therapy, because people often need assistance when they are not sitting face-to-face with their therapist. She explains that it is not always easy to remember on you own what to do when you are not feeling well and proposes that if you try to stop therapy with less

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[23] Interview with youngster Jade, participant of the pilot, 11 May 2018

meetings, a mobile health application could be very useful to bridge the gap between having a psychologist and zero assistance. Julia is in the process of bringing down therapy herself. Most youngsters prefer blended therapy that incorporates both face-to-face and online sessions, just like scholars Vaart et al. (2014) and Wentzel et al. (2016).

As mentioned in the vignette, in the begin of chapter 2, youngster Heidi suggests that the future app could be used to support youngster who have been put on a waiting list. Almost all youngsters I spoke to told me they had been put on a waiting list and illustrate their struggles while waiting without having professional support. Scholars also stress that mobile health technologies might be used to support patients who have been put on a waiting list. Scholars Sieverdes, Raynor, Armstrong, Jenkins, Sox, Treiber (2015, 26) for example explored a personalised mobile health program that supports patients who are waiting for a kidney transplantation in doing physical exercises. Sieverdes et al. explain that this program might prevent that people are being removed from the waiting list or dye while being on the list, due to low physical activity. Scholar Gega et al. (2004, 155) explored online cognitive behavioural therapy for anxiety and depressive disorders and conclude that this online therapy decreased the waiting list for face-to-face therapy a little, since some patients where sufficiently supported by online sessions. Regarding the examples of Sieverdes et al. (2015) and Gega et al. (2004), the future app might as well support youngsters in youth care who are waiting to receive professional assistance.

Scholars point out that less face-to-face appointments also have certain advantages for health care providers. Whiteside et al. (2014, 90), Gega et al. (2004, 155) and Steinhubl, Muse and Topol (2013) argue that by replacing some of the simple tasks by a mobile health applications, providers will have more time to help more patients. Steinhubl et al. stress that this changes the role of providers and has the potential to improve the relationship between patient and provider, since "..clinicians might be able to spend more time with the patients who need them most in their transformed role as diagnosticians and educators.." (ibid., 2396). According to Zvárává, Heroutová Grünfeldová, Zvára, Buchtela (2009, 684), and Dival, Camosso-Stefinovic and Richard Baker (2013, 17), mobile health applications might also assist clinicians in making though decisions, by providing personal information about patients.

All professionals agree with youngsters that mobile health applications should not substitute social workers completely, but that they could complement social workers by replacing some of their tasks. Like scholars Vaart et al. (2014) and Wentzel et al. (2016), professionals prefer blended therapy over online therapy. Many professionals explain that technology has the advantage of being able to work independently of time and location.

Thomas, who is a policymaker of the municipality of Amsterdam, and Luke for example illustrate that some technologies such as facetime support face to face interactions and may reduce the number of times that a person has to meet face-to-face with an individual. Most professionals stress like Whiteside et al. (2014), Gega et al (2004), Steinhubl et al. (2013) that by using mobile health technologies, social workers might not need to visit all clients and save time. Sara foresees that the role of social workers will change like the role of doctors are changing now, since patients have the ability to measure and look things up for themselves. She discusses the new role of clinicians, proposed by Steunhubl et al. (2013), and suggests that a new task of a social workers might be supporting youngsters with how to deal with so much collected knowledge about themselves. The arguments of Zváravá et al. (2009) and Dival et al. (2013) that mobile health technologies might support clincans in making though decisions, was not discussed by professionals.

Professionals support the idea that youngsters will have more autonomy with a mobile health application but stress the necessity of human interaction on top of it. All professionals stress the importance of sharing the personal data of a youngster collected by a mobile health application with someone the youngster trusts. This person involved might assist a youngster in using the application correctly, guide a youngster in interpreting the feedback and intervene if necessary. Hugo states that if the personal data of a youngster is accessible for a confident, the research app and the future app can be used as a preventive tool. He clarifies that with a mobile health application the confidant might notice sooner if a youngster is not doing good and might be able to undertake action before the situation of a youngster escalates. According to professionals this confident involved doesn't have to be a social worker, since a youngster might be quite reluctant in sharing their personal information with a social worker. Youngsters should choose their own confident and this person involved can be for example a friend, a family member or a YIM. "Someone with who you have a trusting relationship and who will not tell everything straight to the parents and youth care", illustrates board member of Spirit Nadia.[24] All professionals share this thought of Nadia.

All youngsters replied in interviews that sharing personal data with a social worker could be really helpful during therapy. Heidi for example explains that "together with a social worker you are be able to figure out like so many days you were sad for example and then suddenly you were happy, how does it come and how can we make sure that you feel more often that way [happy]".[25] James explains that by giving a social worker access to your personal

[24] Interview with professional Nadia, board member of Spirit, 19 March 2018
[25] Interview with youngster Heidi, participant of the pilot, 14 May 2018

data, you don't have to remember all the things you did, because the app keeps track of your behaviour. All youngsters however stress that they should be in control of what to share, since they were not willing to give social workers access to all their personal data.

There doesn't seem to be a consensus among youngster about giving someone out of their social network access to their personal data collected by a mobile health application. Some would never share this information with any friend, others only with real close friends. Jade doubts if she would ever show the future app to a friend, because "it is your own thing, your own problems and I find it hard sometimes to bother someone with that".[26] Heidi would feel more comfortable to show the future app to her mom than to a friend. James on the contrary would never give his mother access, because she will be to worried about him with all the collected information.

According to professionals Nick, who is the project leader of the G-Moji app, and Hugo, a mobile health application has the potential to relieve youngsters from having to tell their story all over again towards new social workers. Since some tasks can be replaced by an app, less social workers might be involved in the intervention of one youngster, or might be shorter involved, and the app can be used as a tool to save and share the story of a youngster. Many youngsters I interviewed were very annoyed about having to tell their story all over again towards people they do not know. David of 18 for example, already had had 18 different social workers. "For multiple times I had to tell 7 times a year the same story".[27] Heidi explains that it was not helpful for her to see only new faces all the time, because she needed someone with who she could build a relationship with. "The more often you bring it [the story] up, the more it becomes stuck in your head". [28] Many youngsters where like David and Heidi very annoyed of having to bring up their personal story again and again. The future app might support youngsters in sharing their story, as proposed by professional Nick and Hugo.

In the next section I will provide the reader with a brief summary of the resilience-based arguments described in chapter 2.

2.4 In conclusion

A resilience-based argument pointed out by all professionals and youngsters is that mobile health technologies have the potential to increase awareness among users about their own behavioral patterns and to motivate users to change their lifestyle in favor of their wellbeing

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[26] Interview with youngster Jade, participant of the pilot, 11 May 2018
[27] Interview with youngster David, participant of the pilot, 29 April 2018
[28] Interview with youngster Heidi, participant of the pilot, 14 May 2018

(see chapter 2.1). This argument was confirmed by scholars Williams et al. (2014) and Morris et al. (2010). Many professionals proclaim that apps and devices are able to give objective feedback on tracked behaviour and that their feedback is more objective than advice from social workers. Professionals regard this as a great advantage of mobile health technologies. The objective aspect of apps and devices was not discussed by youngsters. Instead, youngsters stress that the future app could give them a sense of control This feeling of control was pointed out by scholars Matthews et al. (2016) and Swan (2009). Youngsters add to these studies that mobile health technologies have the potential to confront users with how they are really feeling. Despite the idea of youngsters and professionals that self-tracking has the potential to increase self-awareness, most youngsters replied that they didn't considered their feelings more than usual by tracking their emotions in the research app. So, it can be doubted if self-tracking with the research app would significantly increase self-awareness among users. Some youngsters found it hard to express themselves in the emojis of the research app, because they missed certain emojis. Some youngsters found it difficult to express themselves in just one emoji a day or to interpret the emojis of the research app. Scholars Miller et al. (2016) and Kelly and Watts (2015) elaborate on the ambivalence of emojis and confirm that emojis can be interpreted in multiple different ways.

A second resilience-based argument, stressed by scholars writing about the datafication of health, is that mobile health technologies are valid in real-world settings (see chapter 2.2). Scholars Matthews et al. (2016, 478, 479) and Collins (2012) argue that scientists may find new correlations with the use of apps and devices, since the large amount of collected data provides and unique insight in the daily life of individuals. Many professionals share the same thoughts as Matthews et al. (2016) and Collins (2012) and add to their studies that mobile health technologies gives a richer understanding of the life of a youngster than previous methods in youth care such as questionnaires and observation. Scholars Peng et al. (2016), and Heron and Smyth (2010) argue that the implementation of mobile health applications in real-world settings makes it possible to adapt care to the personal demands users, since users can work on their own goals. Scholars Scheldon and Elliot (1999) state that individuals are more likely to attain goals if they are self-concordant. All youngsters prefer to receive tailored information from the future app and most youngsters stress that besides the predictive function, the app should also be able to give personalised advice. Many youngsters stress that the future app could help them to reach their own goals. All youngsters found it important to customize the future app according to their wishes. This was confirmed by scholar Dennison et all (2013). Youngster didn't experience yet a warm connection to the research app, as described by Glazer et al.

(2014), but they illustrate that if the future app would also focus on positive emotions, this might be accomplished. Peng et all. (2016) and Dennison et all. (2013) confirm that users of mobile health apps don't like to receive continuous negative feedback.

A third resilience-based argument examined by scholars writing about the datafication of health is that that face-to-face meetings between patients and doctors might become decreased by the use of self-monitoring devices. Scholars Whiteside et al. (2014), Gega et al. (2004) and Dobkin and Dorsch (2011) point out that this reduces the costs borne by patients, due to less clinical visits. Scholars Vaart et al. (2014) and Wentzel et al. (2016) add to this argument, that apps and devices improve the self-management of patients. Despite the advantages of online therapy, Vaart et al. (2014) and Wentzel et al. (2016) prefer blended therapy: a combination of online and face-to-face sessions. All professionals share the same ideas as the above-mentioned scholars. Like professionals, most youngsters stress that mobile health applications should not substitute social workers completely and prefer, like Vaart et al. (2014) and Wentzel et al. (2016), blended therapy. Scholars Sieverdes et al. (2015) and Gega et al. (2004) show that mobile health technologies have the potential to support patients who have been put on a waiting list. Regarding these studies, this might be an idea for the future app, since almost all youngsters I spoke to expressed their difficulties while waiting for professional care. Scholars Whiteside et al. (2014), Gega et al. (2004) and Steinhubl et al. (2013) stress that that less face-to-face appointments have the possibility for clinicians to save time. This argument was confirmed by most professionals. Scholars Zváravá et al. (2009) and Dival et al. (2013) argue that mobile health applications might as well support clinicians in making though decisions. This argument was not discussed by professionals. All professionals stress the importance of sharing the personal data of a youngster collected by a mobile health application with a confident. All youngsters replied in interviews that sharing personal data with a social worker could be really helpful during therapy. There doesn't seem to be a consensus among youngster about giving someone out of their social network access to their personal data collected by a mobile health application. According to some professionals a mobile health application has the potential to relieve youngsters from having to tell their story all over again towards new social workers. This could be an idea for the future app, since many youngsters where very annoyed about having to tell their story all over again towards people they do not know.

In the next chapter I will provide the reader with some primary arguments of

3 Risk

Professionals are concerned about the possible controlling effects of mobile health technologies. Nick for example is worried that youngsters might experience the future app as a controlling mechanism and feel unempowered if their behaviour is being measured for 24 hours. He explains that youngster could behave according to what the application is saying to them by thinking ".. the system is telling me that I'm depressed, so yes that means that I'm depressed".[29] According to Nick, a mobile health application is hard to ignore since it gives real time feedback on your functioning. Professional Sara confirms this and explains that in conversation with a social worker there is more room to take advice not seriously by thinking "as if you know what you are talking about". [30] She states that "it [a mobile health application] can be really helpful, but .. it can also work really confronting and oppressive".[31] Professional Olaf stresses that for some youngsters the future app might work, but that maybe a severe traumatised youngster needs trauma therapy instead of a phone. "Can you imagine that someone like that [a severe traumatised youngster] is walking with such a mobile phone, totally lost in monitoring himself while his trauma is not been dealt with?."[31]

The above-mentioned concerns of professionals are examples of possible risk aspects of mobile health technologies. I will elaborate on this controlling effect in chapter 3.3. In the following sections I will provide the reader with some primary risk-based arguments of scholars writing about the datafication of health and use these frameworks to position my ethnographic data.

3.1 Wrong prediction

A risk-based argument of scholars who write about the datafication of health is that it is often unclear if self-monitoring outcomes, predictions and advice from mobile health applications are reliable, because most mobile health applications lack a scientific validation. This was demonstrated in the study of Donker, Petrie, Proudfoot, Clarke, Birch, Christensen (2013). These scholars searched the literature for studies that examine the effects of mental health apps while using certain scientific validation methods. After a screening of 5092 abstracts and the full text of 197 articles, Donker et al. could only identify 8 articles that incorporated a scientific

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[29] Interview with professional Nick, the project leader of the G-Moji app, 9 May 2018
[30] Interview with professional Sara, board member of Spirit, 19 March 2018
[31] Interview with professional Olaf, professor of forensic orthopedagogics at the UVA, 26 April 2018

validation of a mental health app. These 8 articles described 5 evidence-based mental health apps, compared to more than 3000 mental health apps available to download at the time of their study. In these articles, the effectivity of the applications seemed to be proven in reducing mental health related complains. However, after reviewing the 8 selected studies, Donker et al. conclude that these validation studies where of poor quality and that their promising results should be questioned. The effectivity of mobile health applications was also explored by scholars Abroms, Padmanabhan, Lalida Thaweethai and Phillips (2011, 279). These researchers examined 47 application for smoking cessation and discovered that most of these apps did not advice users to evidence-based treatments outside of the application. According to Abroms et al., mental health apps should incorporate scientific proven strategies in order to be effective. The studies of Donker et al. (2013) and Abroms et al. (2011) reveal that the effectivity of mental health applications should be doubted, since most mental health applications lack a scientific validation method and amongst the ones that are evidence-based, the evidence is not very convincing.

The argument of Donker et al. (2013) and Abroms et al. (2011) that most mobile health applications are not evidence-based was confirmed by speakers during a conference I attended about mobile health technology. Various speakers including academics in the field of health care and technological research expressed their concerns about the absence of evidence of most self-tracking devices and wished to validate all of them. However, the speakers argued that this is impossible to do so, since there are simply too many of them: every day new devices and apps are put on the market that are not validated.[32]

Most professionals and youngsters I interviewed complement the doubts of Donker et al. (2013) and Abroms et al. (2011) about the effectivity of mobile health application by giving examples of inaccurate devices and apps. They express their concerns about the reliability of the future app by telling stories about the inaccuracy of other devices and applications they have used. Professional Sara for example takes the stairs a lot at work and is frustrated that her smartwatch has difficulties in measuring her steps while doing so. Youngster Fleur used two apps simultaneously to track her steps and discovered a big difference in the results of both apps. She explains that this made her really upset due to her neurotic complains. Professionals and youngsters are worried about the reliability of the future app, because of experiences with inaccurate mobile health devices and apps. According to them, a big risk of the future app is that it might give users a wrong prediction of their mood. All youngsters and professionals

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[32] Participant observations, conference about mobile health technology, 6 April 2018

proclaim that the future app should be able to predict the mood of users as accurate as possible and therefore needs to undergo a scientific validation.

According to many professionals, the reason why most devices and apps are not evidence-based is because a scientific validation is a big investment for a developer: it costs a lot of money and it takes a long time. Board member of IJsfontein Robert compares an evidence-based device with a validated drug. "If you want to bring a pill on the market it will take you 20 years".[33] He also states that even if a device is validated, there has to be invested in marketing and sales as well, "because a good product is not selling itself".[22] Many professionals state that most devices and apps are launched with the goal to entertain consumers and not to measure behaviour accurately. This explanation for the lack of evidence-based apps and devices, corresponds with the argument of scholars Martínez-Pérez, Torre-Díez and López-Coronado (2013). Martínez-Pérez et al. conclude in their study that "..the development of mHealth apps has a commercial and economic motivation more than a research motivation" (ibid., 13). Both professionals and scholars Martínez-Pérez et al. (2013) argue that most developers are not interested in validating their devices and apps due to high costs and commercial interest.

Scholars writing about the datafication of health not only question the reliability of mobile health application due to a lack of evidence-based research: scholars also stress that the majority of these apps are developed without the involvement of medical professionals. Scholars are concerned that these unregulated apps might cause harm. Researchers Rosser and Eccleston (2011, 309, 311) for example explored apps for pain management and discovered that of the 111 identified apps, at least 86% had not stated any medical professional involvement. Scholars O'Neill and Brady (2012, 530) conducted a similar study on colorectal disease themed apps and reveal that only 32% of the 68 examined apps reported to have a medical professional involved in the design. Both studies recommend a stronger regulation of mobile health application and state that medical professionals are essential in the development of these apps in order to prevent users from possible harm. However, neither Rosser and Eccleston (2011) nor O'Neill and Brady (2012) elaborate on the possible negative consequences of unregulated mobile health applications.

Youngsters I interviewed enrich the studies of Rosser and Eccleston (2011) and O'Neill and Brady (2012) by describing what harm an unreliable mobile health application might cause. According to all youngsters, a wrong prediction of the future app, could enforce a bad feeling. They illustrate that if an app says you are sad or you are going to be sad, you might interpret

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[33] Interview with professional Robert, board member of IJsfontein, 16 March 2018

this feedback as the feeling that you should have and as a result you will feel sad, even though the prediction might be wrong. This resembles what sociologist Robert K. Merton (1948, 195) called a self-fulfilling prophecy:

> "The self-fulfilling prophecy is, in the beginning, a *false* definition of the situation evoking a new behavior which makes the original false conception come *true*. This specious validity of the self-fulfilling prophecy perpetuates a reign of error. For the prophet will cite the actual course of events as proof that he was right from the very beginning."

The future app functions as a self-fulfilling prophecy when people falsely assume that the future app is able to predict the mood of users correctly, while the opposite could be true. A situation could occur wherein a user didn't feel bad at first, but an erroneous prediction of a bad feeling made them feel bad nonetheless. Following Merton's definition, people will keep the self-fulfilling prophecy alive by misinterpreting the wrong prediction as correct and perceiving the user's consequential bad feeling as proof of the prediction's validity.

However, a wrong prediction does not always turn the future app into a self-fulfilling prophecy as some youngsters illustrate. Julia for example explains that she wouldn't mind a wrong prediction much if she is feeling really happy, but if she on the edge it might make her a bit sadder because she will doubt her happy mood. So, following Julia's story, a wrong prediction of a bad feeling, might negatively affect the happy mood of a youngster if the youngster is not feeling that happy beforehand. Julia explains this situation as the following: "Sometimes you are just happy and you don't want to think about why you are happy. Or what it the matter. Then you just want to enjoy that feeling."[34] Under this condition the future app might function as self-fulfilling prophecy. Yet, a wrong prediction of a bad feeling might not function as a self-fulfilling prophecy when a youngster is in a really happy mood, since the youngster might be less likely to doubt his or her happy feeling. Another example comes from David. He foresees that "if you are depressed and your phone says that you are super happy, then it will actually go worse."[35] In this case, the future app does not function as a self-fulfilling prophecy, because the wrong prediction of a happy feeling does not affect the mood of the depressed youngster in a positive way. Nevertheless, like a self-fulfilling prophecy, the wrong prediction in the example of David enforces a bad feeling. Youngsters stress that in some cases a wrong prediction could become very risky and worry that it might even become fatal for youngsters with suicidal thoughts.

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[34] Interview with youngster Julia, participant of the pilot, 9 May 2018
[35] Interview with youngster David, participant of the pilot, 29 April 2018

Most professionals share the concerns of youngsters that a wrong prediction of the future app might cause harm by enforcing a bad feeling. Like youngsters, professionals argue that the future app might function as a self-fulfilling prophecy. Jack illustrates this self-fulfilling prophecy effect of the future app by stating that if the app doesn't predict correctly "and it says you are feeling bad, you are going to feel bad automatically because you think that that thing is right".[36] Olaf explains that we don't know yet what effects a self-monitor device or app has on youngsters, because we are still just at the beginning of this trend and we didn't explored it yet. According to Olaf, we should be very careful with new methods: even if it turns out it doesn't help youngsters, it still might harm them. All professionals stress, like scholars Rosser and Eccleston (2011) and O'Neill and Brady (2012), the importance of having social workers involved in the development of the future app in order to prevent youngsters from possible harm.

In the next section I will elaborate on privacy issues regarding to mobile health technologies.

3.2 Privacy

Scholars writing about the datafication of health stress that users of mobile health application risk their data being sold to third parties, since many apps lack privacy policies that protect sensitive information of users. This was demonstrated in the study of Sunyaev, Tobias Dehling, Taylor, Mandl (2014). These researchers analysed 600 of the most popular apps in use and discovered that privacy policies were absent in 30.5% of the apps. Furthermore, they revealed that 66.1% of the privacy policies did not secure sensitive information from users. Moreover, these policies where not even directed to the app itself but focussed for example on the protection of other services of the developer (ibid. 30). The privacy of users of mobile health applications was also questioned by researcher Ackerman (2013). She examined 43 health and fitness applications of which 23 were free to download and 20 were paid apps. 26% of the free apps and 40% of the paid apps turned out to not have any privacy policy at all. Besides the lack of privacy policies, Ackerman stresses that "..while almost all privacy policies say they protect the privacy and security or integrity of your data, we found that many did not use the most basic security for data transmission.." (ibid., 22). She even discovered that 39% of the free apps and 30% of the paid apps sent personal information from the user to an unknow third party that was not named in the app or in the privacy policy if the app had one (ibid., 5). Both scholars Sunyaev

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[36] Interview with professional Jack, YIM of his best friend, 26 March 2018

et al. (2014) and Ackerman (2013) conclude that the privacy of users of mobile health application is at risk, not only because many apps lack a privacy policy: even the ones with a privacy policy tend to fall short of guarantying the security of personal data. However, Sunyaev et al. (2014) and Ackerman (2013) do not elaborate in their studies on the possible consequences of data being available to others.

Most professionals I interviewed share the concern of scholars Sunyaev et al. (2014) and Ackerman (2013) about the privacy of users of mobile health application and that users risk their data being sent to third parties. Olaf for example argues that the safety of sensitive data is of extra importance in the case of a mobile health application, because an app is able to collect more information about a youngster than previous methods such as questionnaires and observations (see chapter 2.2). He adds to the argument of scholars Sunyaev et al. (2014) and Ackerman (2013) that users of mobile health application risk their privacy, because of the ability of a mobile health application to collect a larger amount of sensitive data than previous methods (see chapter 2.2). Sara describes a situation in which personal data is available to others and questions what could possible happen. She explains that "when you're having an operation in the hospital and you are being monitored during the operation and it [the monitor] gets hacked, yes, than you're dead and that is of course a big risk."[37] Sara complements the studies of Sunyaev et al. (2014) and Ackerman (2013) by giving an example of a possible consequence of data falling into wrong hands: it might even cause death. Hugo shows that privacy issues might not only be present on the level of data being available to unknown third parties, since a social worker's access to certain personal information such as location, might as well disrupt the privacy of a youngster. He foresees that his idea of being able to track down the location of youngsters with the future app (see chapter 2.2) will cause resistance among youngsters, because youngsters don't like to be watch all the time, certainly not if they skip school. Hugo stresses that in the case of the future app, personal data being available to social workers might also enforce privacy issues. All professionals stress that people involved in self-monitoring apps and devices should be really careful in saving and using collected data in order to keep sensitive data secure.

Some professionals I interviewed have a more nuanced view on privacy. Nick for example wonders why it is generally accepted for a therapist to dive into people's private lives by unravelling sensitive trauma's and in the case of a smart app this becomes a privacy issue. He questions how much different a mobile health application is from face-to-face therapy

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[37] Interview with professional Sara, board member of Spirit, 19 March 2018

besides the app's ability to collect real-time data, since both methods are used for the same goal: improving people's lives. He illustrates his doubts about the safety of the real world in comparison to the internet: "In the past, I think it is even still not allowed to send a treatment plan by mail for example. Instead you are allowed to send it by post though. How much safer is it then? If it then always arrives? And if the postman can't rip it open or post it in someone else's letterbox."[38] Although Nick agrees with scholars Sunyaev et al. (2014) and Ackerman (2013) that users of mobile health application risk their privacy, he questions if this commotion around online privacy is justified, since in face-to-face therapy, the privacy of youngsters is just as well at risk. Therefore, Nick states that the future app should be permitted to go really far in collecting personal information about individuals, just like face-to-face therapy, because both methods are used to improve people's lives. Luke stresses that protecting the privacy of individuals is of great importance in the development of future app, just like being transparent towards participants about what data is being collected. "We get a level of their social interactions about how frequent they are making phone calls, or sending text messages, but it is metadata, so we don't know what they are talking about, we don't know the content of their conversations and we do not know who they are talking to", elaborates Luke.[39] He explains that also the geographic location of participants remain undisclosed, since their physical activity is tracked without the use of GPS. Luke is like scholars Sunyaev et al. (2014) and Ackerman (2013) concerned about the privacy of users of mobile health applications. These scholars however argue that the privacy of users of mobile health applications is at risk, while Luke on the contrary demonstrates that the privacy of users of the research app is being guaranteed. According to Luke, personal information of users is safe, since the research app does not collect details about users that can be traced back to individuals: it only collects metadata about their social activity and also the location of users remains unknown.

Scholars writing about the datafication of health have explored why people are willing to download mobile health application, despite a lack of privacy policies that secure sensitive information of users. Researchers Cranor, Guduru and Arjula (2006, 135) for example argue that "most people do not often read privacy policies because they tend to be long and difficult to understand". As a result, many people skip online privacy policies and are unaware that their privacy might be in danger. Cranor goes further in this argument with scholar Mc.Donalds (2008) by arguing that for many people, spending time on reading privacy policies feels like a price they are unwilling to pay. They calculated that a regular internet user in America would

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[38] Interview with professional Nick, the project leader of the G-Moji app, 9 May 2018
[39] Interview with professional Luke, technologist and epidemiologist at MIT Media Lab, 19 February 2018

spend about 201 hours a year by reading the privacy policies for each site they visit just once (ibid., 19). Researcher Sunyaev et al. (2014) and Ackerman (2013) stress that even if people would be willing to read privacy policies, they would still have no clue what would happen to their data, since privacy policies are often incomprehensible for users and incomplete. Scholars Dennison et al. (2013, 7) interviewed youngsters about their experiences with mobile health applications and show that although many of their respondents expressed their fears regarding to their privacy, some didn't care much about how their data was being used. These individuals didn't worry about their data being sold to third parties, because they believed for example that the app collected only unimportant information.

Youngsters I interviewed are not that concerned about their privacy as professionals. They believed that their data was unsafe anyway on the internet and that the research and future app wouldn't be less safe than other apps. This became evident when youngsters signed a privacy agreement of 3 pages before the pilot started. Most youngsters signed the agreement without reading, some even complained about the amount of pages. The argument of Cranor et al. (2006), Mc. Donalds and Cranor (2008), Sunyaev et al. (2014) and Ackerman (2013) that people are often not willing to read privacy policies, was being confirmed. Most youngsters didn't care much if their data was being sold to third parties. David for example isn't worried about his privacy on a self-tracking app, since the app only has unimportant information like his profile picture, his weight, length and heartbeat. Julia shares art on Instagram and follows tattoo artists. "So I think it is really innocent, so I wouldn't be scared if my information would be shared [with third parties] or something like that, because there isn't something interesting anyways."[40] Most youngsters share the same thoughts as David and Julia and confirm the study of Dennison et al. (2013) by stating that their data wouldn't be interesting enough for third parties to cause harm.

In the following section I will examine possible controlling effects of mobile health technologies.

3.3 Controlled by an app

Scholars stress that the datafication of health has certain negative controlling effects. Sociologist Lupton (2012) for example applies the ideas of social theorist Foucault (1975) about the 'panopticon' to mobile health technologies. The panopticon was used by Foucault as a metaphor for a new form of power in society in which individuals discipline themselves. The

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[40] Interview with youngster Julia, participant of the pilot, 9 May 2018

panopticon is described as a round prison, in which one single inspection house in the middle is surrounded by cellblocks. From this house, one single guard monitors all prisoners, since the windows of the cellblocks are directed to the inspection house. Despite the fact that one guard would not be able to observe all prisoners at the same time, prisoners in the panopticon feel as if they are being monitored the whole time, because they don't know when they are being watched. As a result, Foucault argues that prisoners will discipline themselves voluntary by practicing self-management strategies in order to perform desired behaviour. For Foucault the guard represents the small number of people in society with power, that are able to control a large number of individuals.

Scholar Lupton (2012, 235, 236) applies the panopticon of Foucault to mobile health technologies by stating that mobile health technologies function as controlling tools, because apps and devices monitor the behaviour of users continuously. Moreover, apps and devices encourage users to change behaviour that contribute to an unhealthy lifestyle in healthy practices by developing self-management practices. The ideas of Foucault about self-management are also evident in the study of medical anthropologist Soo-Jin Lee (2017). She states that citizens are encouraged by commercial enterprises and governments to act as 'good citizens' by managing their own health. According to Soo-Jin Lee this shift to good citizens is problematic because it implicates that all people are equally responsible for their own health by managing their risk through self-care practices, while some people are more privileged than others. Marginalised citizens have often not the ability to become good citizens, mobile health technologies are expensive. As a result, these vulnerable individuals are discriminated and excluded from society for not contributing to the common good as "good citizens" (Soo-Jin Lee 2017, 39-43).

Most professionals I interviewed are concerned about the ability of self-monitoring devices and applications to monitor the behaviour of individuals for 24 hours. They stress, like scholars Lupton (2012) and Soo-Jin Lee (2017) that youngsters might feel unempowered if they are constantly watched by the future app. Olaf even names Foucault literally and compares self-monitoring tools with the panopticon. According to him, an advantage of an app is that it collects more information about youngsters than previous methods such as questionnaires and observations and that this data is real-time (see chapter 2.2). However, the risk of knowing more about individuals, he states, is that society will also gain more knowledge of how to influence individuals better. He explains that on the one hand the goal of having all this information is to be able to improve society by knowing how to change people's behaviour. On the other hand, this has the risk of going at the expense of people's freedom since people might be manipulated

and controlled by society. Hugo wonders if social workers have the ability to track the location of youngsters and check if they attend school then "in what way is this not a virtual prison?".[41] The stories of Olaf and Hugo illustrates the controlling effect of the panopticon of Foucault clearly: Hugo even uses the same metaphor, a prison. In both examples, social workers represent the guard of Foucault's panopticon and youngsters the prisoners, who are being controlled by the social workers. So, the mobile health application can be seen as the framework of how this power is distributed, like the architecture of a round prison. Sara is concerned about how far youth care might go in controlling people. She wonders until what limit it is still responsible to correct people with feedback. She explains that the risk of such a tool is that individuals might be forced to use it, because they are blamed by social workers of not having their emotions under control. Sara illustrates the concern of Soo-Jin Lee about 'good citizens' by explaining that youngsters who are not using self-management tools, might be discriminated by social workers from society since they don't act as 'good citizens'. Many professionals share similar stories as Olaf, Hugo and Sara. This was also illustrated by professionals in the vignette at the beginning of chapter 3.

Scholars who explore the controlling effect of mobile health technology are worried about the increasing power of algorithms in society as objective technologies. Researchers Irani and Lee (2016) for example state that algorithms have a growing influence on human decision making by demonstrating how severe computer codes have penetrated everyday life. They illustrate that algorithms are present in various domains of society, such as "..curating news and social media feeds, evaluating job performance, matching dates, and hiring and firing employees' (ibid., 1057). The increasing power of algorithms in society is what they call 'algorithmic authority'. Sociologists Lupton and Jutel (2015) stress that people often regard computer codes as if they exceed human capabilities, while forgetting that computer codes are created by humans. These scholars argue that many people consider mobile health application to be able to give a more neutral and objective advice than a medical professional in person. As a result, people tend to regard self-monitoring devices and applications as truth makers by believing every outcome of these tools. According to Lupton and Jutel, this is a big risk of the datafication of health, since devices and apps can be wrong about your health, just like your own doctor in person (ibid., , 129, 131, 133). Scholar Cheney-Lippold is concerned about the categorising effect of algorithms on individuals. He explains that algorithms are used to make predictive assumptions about human behaviour and by doing so, algorithms simplify society by

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[41] Interview with professional Hugo, social worker of Spirit, 12 February 2018

placing people in certain premade categories. Algorithms determine for example people's race, purely based on online behaviour. According to Cheney-Lippold algorithms might have an oppressive effect on people, because individuals have no control about the category in which they have been determined to. People can't interact with the algorithm and correct it if they feel they do not belong in a certain category. In this way, individuals are not regarded as complex human beings, but reduced to premade categories.

The concerns of scholars Lupton and Jutel (2015), Cheney-Lippold (2011) and Irani and Lee (2016) about the perception of algorithms as objective technologies was being confirmed by my data, since many professionals proclaim that apps and devices are able to give objective feedback on tracked behaviour and that their feedback is more objective than advice from social workers (see chapter 2.1). Professionals regard this as a great advantage of mobile health technologies. This objective aspect of apps and devices was not being discussed by youngsters I interviewed.

Some youngsters stress the controlling effects of mobile health technologies. Fleur for example is concerned that users of mobile health applications might only listen to their app, instead of their own feelings. According to her, "it is certainly a danger that emojis generated by the computer might determine our emotions". [42] The concern of Cheney-Lippold (2011) about the categorising effect of algorithms is evident in her example, since the emojis generated by the future app might become oppressive computer-made categories.

Two respondents, professional Jack and youngster David are firmly against the future app. According to Jack, an app that predicts the mood of users, is threating the user as a robot. He explains that emotions are what distinguishes a human from a robot and if an app is acting like he is the boss about your emotions by predicting your mood, you are no more than a robot. "When an app or whatever is telling you how you are feeling … do you even feel like a human anymore?"[43] He is also not interested in smartwatches or other devices that are focussed on enhancing physical activity. He illustrates that people don't think for themselves anymore with these tools: people don't walk because they enjoy walking, they walk just to count steps. Like Jack, David was also annoyed by the idea that a computer was going to tell him how he was feeling, since he would certainly know this better than an app. Both respondents felt oppressed by computer-made categories, as described by Cheney-Lippold (2011).

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[42] Interview with youngster Fleur, participant of the pilot, 25 April 2018

[43] Interview with professional Jack, YIM of his best friend, 26 March 2018

In the next section I will provide the reader with a brief summary of chapter 3.

3.4 In conclusion

A risk-based argument pointed out by scholars writing about the datafication of health is that it is often unclear if mobile health technologies are reliable, because many apps and devices are not scientific validated (see chapter 3.1). This was demonstrated in the studies of Donker et al. (2013) and Abroms et al. (2011) and confirmed by speakers on a conference I attended about mobile health technologies. Most professionals and youngsters I interviewed complement the studies of Donker et al. (2013) and Abroms et al. (2011) by giving examples of inaccurate devices and apps. All professionals and youngsters proclaim that the future app should undergo scientific validation in order to be as reliable as possible in its mood predictions. Many professionals argue that most devices and apps are not evidence-based, because they are launched with the goal to entertain consumers and not to measure behaviour accurately. This argument was confirmed by Martínez-Pérez et al. (2013). Scholars Rosser and Eccleston (2011), and O'Neill and Brady (2012) show that many mobile health apps are developed without the involvement of medical professionals and are concerned that these unregulated apps might cause harm. Youngsters and professionals complement the studies of Rosser and Eccleston (2011) and O'Neill and Brady (2012) by elaborating on what harm an unreliable mobile health application might cause. All youngsters and most professionals explain that a wrong prediction of the future app, could enforce a bad feeling and might turn the future app into a self-fulfilling prophecy, as described by sociologist Merton (1948). Youngsters and professionals are concerned that in some cases, like when a youngster has suicidal thought, a wrong prediction might become fatal. All professionals stress the importance of having social workers involved in the development of the future app, just like scholars Rosser and Eccleston (2011) and O'Neill and Brady (2012).

A second risk-based argument of scholars writing about the datafication of health is that many apps lack privacy policies that protect sensitive data of users and users risk their data being sold to third parties (see chapter 3.2). This was demonstrated in the studies of Sunyaev et al. (2014) and Ackerman (2013). Most professionals share the concern of scholars Sunyaev et al. (2014) and Ackerman (2013) about the privacy of users of mobile health application. Some professionals I interviewed have a more nuanced view on privacy and question if the future app would increase privacy issues. Scholars Cranor et al. (2006), McDonalds (2008), Sunyaev et al. (2014) and Ackerman (2013) stress that many people don't read privacy policies, because these

policies are often too long and difficult to understand. This argument was being confirmed during my research, since most youngsters signed a privacy agreement without reading. Youngsters turned out to be not that concerned about their privacy as professionals and didn't care much about how their data was being used. Most youngsters resemble some participants in the study of Dennison et al. (2013) by regarding their collected data as not important enough that it could be used in a harmful way by thirds parties

A third risk-based argument of scholars writing about the datafication of health is that mobile health technologies might have negative controlling effects. Sociologist Lupton (2012) argues that mobile health technologies resemble the panopticon of Foucault, since apps and devices have the ability to control users for 24 hours and encourage users to modify behaviour and develop self-management practices. According medical anthropologist Soo-Jin Lee (2017), commercial enterprises and governments encourage citizens to manage their own health and act as "good citizens". Soo-Jin Lee is highly critical about this transformation of citizens into "good citizens", since marginalised citizens have often not the ability to manage their own health. Most professionals are like Lupton (2012) and Soo-Jin Lee (2017) concerned about the controlling effect of mobile health technologies. The stories of most professionals resemble the implementation of the panopticon of Foucault (1974) by Lupton (2012) on mobile health technologies and the description of "good" citizen by Soo-Jin Lee (2017). In the stories of professionals, social workers represent the people in power: symbolically presented by Foucault as the controlling guard. The youngsters in the stories of professionals, represent the prisoners, who are being controlled by social workers. The mobile health application is merely a tool to control these youngsters and can be seen as the prison. Scholars Lupton and Jutel (2015), Cheney-Lippold (2011) and Irani and Lee (2016) are worried about the increasing power of algorithms in society, because computer codes are regarded by many individuals as objective technologies, whilst they are not. Their concerned was being confirmed in my research, since many professionals proclaim that apps and devices are able to give objective feedback on tracked behaviour and that their feedback is more objective than advice from social workers. Professionals regard this as a great advantage of mobile health technologies. Lupton and Jutel (2015), Cheney-Lippold (2011) and Irani and Lee (2016) are worried about this perception of many individuals

4 Resilience and risk intertwined

4.1 Less intrusive or more intrusive?

There is no consensus among scholars if mobile health technologies are less intrusive or more intrusive for users. Some scholars argue that apps and devices have the potential to be less intrusive, as these technologies have the potential to decrease face-to-face meetings with clinicians. (see chapter 2.3) Scholars DeMaio, Schwartz, Cooley and Tice (2001, 2083) for example examined a digital health device for tuberculosis that assists patients in taking medications. DeMaio et al. conclude that patients experienced the device as less intrusive than regular face-to-face assistance, because they didn't need to go to the health care department that often. Scholar Bursell, Brazionis and Jenkins (2012, 312, 314) explored a digital health device that enables local general practitioners to do routine eye screenings for patients with diabetes. The device is by patients regarded as less intrusive, because they didn't need to visit an eye care specialist in order to get an eye examination.

However, other scholars argue that apps and device might be more intrusive, due to the large amount of collected sensitive data and received messages. Scholars Ramanathana, Swendemanb, Comuladab, Estrina and Rotheram-Borus (2013, 44) analysed a mobile health application for HIV and conclude that users regard the app as more intrusive, because of the collection of images and location. Scholars Årsand, Frøisland, Skrøvseth, Chomutare, Tatara, Hartvigsen, Tufano (2012, 1199) studied a mobile health application for diabetes and report that some users "commented that the messages were intrusive, arriving too often and at inconvenient times."

Some professionals I interviewed reflect on the intrusiveness of mobile health technologies. Professionals argue that the future app could be less intrusive than other forms of therapy, because it provides the user feedback without needing much input from the user. The future app collects data and predicts the mood of the user without needing the user to take any action, except downloading the app. Olaf explains that on the one hand, the future app has the potential to be less intrusive, since it enables youngsters to monitor themselves and work on their own health, without being dependent on social workers. This argument falls in line with scholar DeMaio et al. (2001) and Bursell el al. (2012). On the other hand, the future app could be more intrusive, since youngsters might be controlled by the app for 24 hours just like in the panopticon (see chapter 3.3). This statement resembles the arguments of scholars Ramanathana et al. (2013) and Årsand et al. (2012). Nick illustrates that less user input and sense of control is difficult to balance. He is concerned that if the app become too simple, if it's only predicting

the mood of the user without asking the user anything, it might become scary and people might lose their sense of control and as a result quit. Youngsters might on the contrary experience a sense of control if the app asks them questions, but you don't want to ask them too much questions, because than the app becomes too intrusive. Bob illustrates that it is difficult to balance how often an app should ask users for input. "..what is the boundary between [sending a message to users] exactly on the right moment with a good feeling and when is a wrong moment that causes irritation?".[44] Bob stresses than the app can be improved by asking users feedback on certain predictions and that in the development of a predictive application, user input is needed in order to learn from users if the app's predictions are right.

According to Dilan devices and application should learn people with direct feedback loops to get lost and find a way back, instead of telling them what to do. He explains that if a device motivates users to make their own choices, users will blame themselves when they make a wrong decision. However, when a device tells users what to do and the feedback turns out wrong, the devices disqualifies itself and users will blame the device and stop using it. He states that this often means that you need to make the content more difficult instead of easier and that the devices also needs to be able to say I don't know. This is illustrated by Nick when he describes how he learned from his step counter that his physical activity was higher if he went to work with public transport. "If my girlfriend had said to me, if you go by car you will move less, you should go with public transport, I wouldn't listen to her. I would go by car instead because it is way easier". [45] His step counter on the contrary motivated him to keep his car at home, because the device didn't tell him what to do. It was up to him to see the correlation between the amount of steps and his mobility and to change his behaviour.

All youngsters confirm that if the future app would be only predictive, users will lose their trust in the app and might delete it after a couple of wrong predictions. Therefore youngster stress that the future app should not become completely predictive. Instead they argue that users should be given the possibility to fill in the right emoji themselves if the application predicts their mood wrongly. Youngsters explain that by being able to correct the future app when necessary, the future app will learn from the user and becomes better in its predictions. Two youngster, Carmen and Fleur are concerned that giving user input, might become a compulsion for youngsters with neurotic tendencies. Carmen explains that she used an app in which she kept a record of daily activities and combined these activities with an image that resembled her mood. This app became a compulsion for her, because she became obsessed with tracking every

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[44] Interview with professional Bob, strategist and developer of No Worries Company, 23 May 2018
[45] Interview with professional Nick, the project leader of the G-Moji app, 9 May 2018

activity and finding the perfect fitting image. For Fleur, her step counter became too much: at one point she was compulsively walking as much as possible. Both youngsters suffer from neurotic complains.

So regarding the theme intrusiveness, parallel conversations are present of resilience-based and risk-based arguments. In the next section I will illustrate this intertwinement by elaborating on the theme connection.

4.2 Connection or distance?

Scholars stress that mobile phones have the ability to support connection. Scholars Walsh, White, Young (2009, 235) for example explored the experiences of youngsters with their mobile phone and conclude that a phone connects people regardless of distance. Youngsters felt reassured to be able to contact others and used their phone to share experiences. Scholars Mosa, Yoo and Sheets (2012, 1) explain that mobile health applications simplify communication for clinicians, as they need to communicate with a lot of different people in different settings: with patients as well as other colleagues at different health care departments. They conclude that "smartphones support several means of communication including voice calling, video calling, text messaging, email messaging, multimedia (text, image, and video) messaging, and conferencing through the cellular phone service provider" (ibid., 7). Multiple locations, communicating colleges as well as patients. Scholars Fiore-Silvast and Neff (2013, 83, 86) conducted two years of ethnographic research in data-intensive health and wellness communities and conclude that shared data has the potential to connect patients to their care managers.

However, scholars also stress that the quality of online conversations might be less than face-to-face conversations. Scholars Mallen, Day and Green (2003, 160) for example examined the communication between people who didn't know each other before in a face-to-face conversation and an online chat program. Mallen et al. conclude that participants developed a better relationship with each other in face-to-face conversations than online and state that "counselors and clients should be aware that their online relationships might take more time to develop when compared with face-to-face sessions" (ibid., 160). Scholars Alsosas, Dasb and Svanæsa (2012, 12) compared face-to-face meeting between patient and doctor, either supported with a paper chart, a personal digital assistance or a laptop. Alsosas et al. conclude that with the paper chart, patient and doctor had better eye, verbal and non-verbal contact,

compared to meetings with a personal digital assistance or laptop. Both studies show that online contact is of less quality than face-to-face contact.

Professionals agree with scholars Walsh et al. (2009), Mosa et al. (2012) and Fiore-Silvast and Neff (2013) that a mobile phone has the potential to support communication and illustrate that the research and future app may help youngsters to talk about their problems. According to most professionals, youngsters find it often hard to inform others about their difficulties. For youngsters it might be more easy to communicate their feelings with an app than to say it out loud, because they are nowadays so familiar with their phone.

However, some professionals stress that a mobile phone might as well create more distance between people, as described by Mallen et al. (2003) and Alsosas et al. (2012). According to Bob, the main challenge of mobile health applications is preventing that it will lead to distance between people, since people are nowadays so fixed on their phone that they tend to forget to meet individuals face-to-face. Jack is highly critical about implementing the future app and giving youngsters who need help an app instead of face to face assistance. He states that an app isn't going to help youngsters to feel better, since it isn't able to give youngsters personal attention, understanding or the hug they need. He foresees that youngsters will feel not be taken seriously if they need help and get a free app instead, since it almost looks like people don't have time for them. According to him, a mobile health application should always be combined with face-to-face assistance of someone the youngsters trusts.

Scholars point out that mobile health applications have the ability to create online communities. Scholars Kreps and Neuhauser (2010, 330) for example stress than an app might enable people with the same complains to chat with each other. Researchers Frost and Massagli (2008, 7) explored an online community in which patients exchange personal information and ask each other advice. Frost and Messagli show that shared information might foster the relationship between users. Scholars Rodriguez-Paras and Sasangohar examined a mobile health application for post-traumatic stress disorder and discover that half of their participants expected the app to share their story anonymously with other users (2017, 1826).

All youngsters, apart from James, would not make use of a chat function themselves that would connect them with other users, because they were not interested in meeting new people. Youngsters however foresaw that other youngsters would like to have the ability to share their story with other users and proclaimed that this chat function should be optional. Julia, Heidi and Ellen explain that youngsters with the same issues might support each other through a chat function. However, according to some youngster this could also easily go wrong, since youngster might assist each other in planning dangerous activities, such as suicide attempts.

This fine line between opportunities as well as risks, regarding online communities was being illustrated by some professionals.

In the next section I will provide the reader with a brief summary of chapter 4.

4.3 In conclusion

The intertwining of both resilience-based and risk-based arguments became evident in the debate about the intrusiveness of mobile health technologies. The studies of scholars DeMaio et al. (2001) and Bursell et al. (2012, 312, 314) show that mobile health technologies might be less intrusive for patients than face-to-face therapy, since patients don't need to visit specialists that often. This is a resilience-based argument. However, scholars Ramanathana et al. (2013) and Årsand (2012) argue on the contrary that apps and device might be more intrusive, due to the large amount of collected sensitive data and received messages. This is a risk-based argument. Some professionals where not sure if mobile health technologies would either decrease the intrusiveness of therapy, argued by DeMaio et al (2001) and Bursell et al. (2012), or rather increase the intrusiveness of therapy, demonstrated by Ramanathana et al. (2013) and Årsand (2012). Some professionals stress that if the future app would become completely predictive, without asking users for input, users might lose their sense of control and might even delete the app after a couple of wrong predictions. This was confirmed by all youngsters. All youngsters stress that the future app should not become completely predictive, since users should be given the possibility to correct the future app when necessary. However, some professionals argue that if the app asks too much questions, the future app risks to become too intrusive. Some youngster confirm this argument and even stress that if the future app asks too much user input, filling in information might become a compulsion for youngsters with neurotic tendencies

The intertwining of both resilience-based and risk-based arguments became also evident in the debate concerning communication support of mobile health technologies. Scholars Walsh et al. (2009), Mosa et al. (2012) and Fiore-Silvast and Neff (2012) stress that mobile phones have the ability to support communication. However, scholars Mallen et al. (2003) and Alsosas argue that the quality of online conversations might be less than face-to-face conversations. Professionals share the thought of Walsh et al. (2009), Mosa et al. (2012) and Fiore-Silvast and Neff (2013) by illustrating that the research and future app may help youngsters to talk about their problems. Some professionals stress that mobile health technologies have the possibility to connect people more easy, but might create more distance between people as well. Scholars Kreps and Neuhauser (2010), Frost and Massagli (2008), and Rodriguez-Paras and Sasangohar

(2017) point out that mobile health applications have the ability to connect users with each other by the creation of online platform in which users can chat with each other. None of the users, except James, where interested in such a chat function described by Kreps and Neuhauser (2010), Frost and Massagli (2008), and Rodriguez-Paras and Sasangohar (2017) and state that this chat function should become optional. Youngsters however foresaw that other youngsters might like to have the ability to share their story with other users. Some professionals and youngsters argue that an online platform for users might be really helpful for some youngsters since they can support each other through difficult times. This is a resilience-based argument. However, some professionals and youngster stress that an online community might also have negative consequences, since youngsters might support each other for example in doing dangerous things. This is a risk-based argument.

In the next section I will answer my main question.

5 Conclusion

In this thesis I explored the question '*How are resilience and risk related to the datafication of health experienced by users of the G-Moji app and approached by organisations providing this care?*' I examined both risk-based arguments and resilience-based arguments about mobile health technologies pointed out by scholars, professionals and youngsters. I regard this research as very relevant nowadays, since I already mentioned in the introduction, since 2017, 325000 mobile health application where downloadable worldwide and this number is increasing every year. However, many of these apps are not scientific validated, might be unreliable and lack privacy policies. On the other hand, mobile health technologies have the potential to offer great opportunities, regarding to an increase of self-awareness and autonomy. Therefore, it is of great importance to examine resilience-based aspect and risk-based effects of mobile health technologies, in understanding their possible benefits and pitfalls. However, the resilience-based arguments and risk-based arguments should not be regarded as oppositions, as they are intertwined, as showed in chapter 4. In the following section I will summarize the most important arguments of chapter 2, 3 and 4 and reflect on them by presenting some arguments from different chapters as parallel conversations.

A resilience-based argument pointed out by scholars, all professionals and youngsters is that mobile health technologies have the potential to increase awareness among users about their own behavioral patterns and to motivate users to change their lifestyle in favor of their

wellbeing (see chapter 2.1). Scholars and youngsters stress that mobile health applications could give users a sense of control. Youngsters add to this argument that mobile health applications have the potential to confront users with how they are really feeling. However, it can be doubted if mobile health technologies are effective, since scholars have pointed out that many apps and devices might not be reliable due to a lack of scientific validation. This risk-based argument was confirmed by speaker on a conference about mobile health technologies I attended and illustrated by most professionals and youngsters. Scholars also stress that many apps lack the involvement of medical professionals in the process of development and are concerned that these unregulated apps may cause harm to users. According to all youngsters and most professionals the future app might cause harm by giving a wrong prediction, since this could enforce a bad feeling and might turn the future app into a self-fulfilling prophecy. All professionals stress the importance of having social workers involved in the development of the future app in order to prevent youngsters from possible harm. All professionals and youngsters proclaim that the future app should undergo scientific validation in order to be as reliable as possible in its mood predictions. To put it briefly, the possibilities of mobile health technologies regarding to an increase in self-awareness and behavioural change can be doubted, since many apps lack a scientific validation and as a result might be unreliable.

A second resilience-based argument, argued by scholars and many professionals is that mobile health technologies give a unique insight in the life of individuals and that this collected data could be used to improve care. Scholars, many professionals and youngsters illustrate that mobile health apps make it possible to adapt care to the personal demands of users, since users can work on their own goals for example. All youngster prefer to receive tailored information from the future app. Scholars argue that users like to customize mobile health technologies, don't like to receive continuous negative feedback and might develop a warm relation with the app or device. Youngsters confirm these arguments. Youngsters didn't receive yet a warm connection to the research app, but illustrate that this could be accomplished by personalising the future app. However, scholars show that the collection of a large amount of sensitive data might enforce privacy issues, since many apps and devices lack privacy policies that protect this information. Most professionals confirm this risk-based argument and are concerned about the privacy of users of apps and devices. Some professionals I interviewed have a more nuanced view on privacy and question if the future app would increase privacy issues. Scholars argue that many people are not willing to read privacy policies and that some users regard their data as not important enough for thirds parties to cause any harm. These statements where confirmed by most youngsters as they signed a privacy agreement without reading and didn't care much

about how their data was being used. In sum, the collection of a large amount of sensitive data, might have the opportunity to provide a unique insight in the life of individuals and personalised care, but could as well have downsides regarding to the privacy of users.

A third resilience-based argument stressed by scholars is that mobile health technologies might decrease face-to-face meetings between patients and doctors. Scholars and professionals show that this might reduce the costs borne by patients and might improve the self-management of patients. Some scholars, all professionals and all youngsters stress that mobile health technologies should not substitute social workers completely and prefer blended therapy. Scholars and some youngsters suggest that apps and devices have the potential to support patients who have been put on a waiting list. This could be an idea for the future app, since almost all youngsters I spoke to had been put on a waiting list and expressed their difficulties regarding this experience. According to some professionals an app has the potential to share and save the story of a youngster. This could be an idea for the future app, since many youngsters where annoyed by having to tell their story all over again to new social workers. Scholars and most professionals stress that a decrease in face-to-face sessions has the possibility for clinicians to save time. However, the ability of mobile health applications to monitor users continuously, even outside face-to-face appointments with clinicians, could have negative controlling effects. Scholars argue that apps and devices resemble the panopticon metaphor of Foucault and that citizens are disciplined by commercial enterprises and governments to manage their own health. The stories of most professionals fall in line with these arguments. Scholars express their concerns about the perception held by many individuals that computer codes are objective technologies and question this objective aspect of algorithms. Their concerned was being confirmed in my research, since many professionals proclaim that apps and devices are able to give objective feedback on tracked behaviour and that their feedback is more objective than advice from social workers. As a result, the continuous support of mobile health technologies has its possibilities regarding to decrease in face-to-face meetings, but might as well pose some risks concerning the controlling effect of apps and devices.

The intertwining of both resilience-based and risk-based arguments became evident in the debates about the intrusiveness and the connection support of mobile health technologies. Among scholars and some professionals there is no consensus whether apps and devices might would either decrease the intrusiveness of therapy or rather increase the intrusiveness of therapy. Some professionals and all youngsters stress that if the future app would become completely predictive, without asking users for input, users might lose their sense of control and might even delete the app after a couple of wrong predictions. All youngsters suggest that

users should be given the possibility to correct the future app and therefore, should not be completely predictive. However, as mentioned by some youngsters, too much some user input might result in compulsive behaviour of youngsters with neurotic tendencies.

Among scholars and some professionals there is no consensus whether apps and devices would either support the connection between people or rather increase distance between people. Some scholars stress the ability of mobile phone to connect individuals, regardless of distance, while others argue that online conversations are of less quality than face-to-face conversations. Some professionals stress that mobile health technologies have the possibility to connect people more easy, but might create more distance between people as well. Scholars point out that users have the ability to connect with each other thought the creation of an online platform. However, most users where not interested in such a chat function. Some professionals and youngsters argue that an online platform for users might be really helpful for some youngsters, while some professionals and youngsters stress that this connection might as well have negative consequences.

Future research is needed in order to explore the risk and resilience aspect of the G-Moji app once the future app has been developed.

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7 References

7.1 Appendix A

Nick: Project leader of the G-Moji app. Nick works at Garage2020 and was two years ago involved in its establishment. He tested the research app before the pilot started for three months. During the pilot he will be testing the research app again for three months.

Luke: Technologist and epidemiologist at MIT Media Lab. The G-Moji app derives from him and his team of data scientists and researchers at the MIT Media Lab. The pilot is very similar to other studies they are conducting where they have a mobile application that senses the behaviour of individuals. MIT media lab collects this data to help predict when people might experience a particular event or health outcome. They developed for example an application that is able to predict if the user is more likely to be infected with the influenza virus.

Thomas: Policymaker of the municipality of Amsterdam. Thomas is associated with Garage2020 in general, but not specifically on the G-Moji project.

Nadia: Board member of Spirit. Nadia was involved two years ago in the establishment of Garage2020. She is associated with Garage2020 in general, but not specifically on the G-Moji project.

Sara: Board member of Spirit. Sara was involved two years ago in the establishment of Garage2020. She is associated with Garage2020 in general, but not specifically on the G-Moji project.

Hugo: Social worker at Spirit, specialised on the guidance of Youth-Initiated Mentoring (YIM). A YIM is someone a youngster with youth care choses out of his or her social network, like a family member, a friend or a teacher. A YIM has a trusting relationship with the youngster and functions as his or her representative towards parents and professionals. Hugo tested the app before the pilot started for 1 month.

Jack: YIM of his best friend. Jack tested the app before the pilot started for 1 month.

Olaf: Professor of forensic orthopedagogics. Olaf is going to analyse the collected passive and active data after the pilot.

Robert: Board member of IJsfontein. IJsfontein designs and develops playful (digital) learning, like serious games and gamification projects, 'based on the belief that people are naturally curious and intrinsically motivated to develop themselves'. Some of their projects are related to health and have the aim to learn users to modify behaviour that contribute to an

unhealthy lifestyle. Robert is involved in the G-Moji project by giving Garage2020 strategic advice on how to coordinate this project.

Dilan: Game-designer and strategist at IJsfontein. Dilan is involved in the G-Moji project by giving Garage2020 strategic advice on how to coordinate this project.

Bob: Developer and strategist at No Worries Company. No Worries Company is developing an application that is called Unit Victor. This application is similar to the G-Moji app in that it collects passive and active data and hopes to be able to predict the mood of users in the future. However, Unit Victor is meant for veterans and has as goal to make the step towards help easier, while the G-Moji app is meant for youngsters with youth care. Bob is not familiar with Garage2020 or any of their projects.

The 10 youngsters I interviewed tested the G-Moji app as part of the pilot while receiving youth care or psychiatry. Since not every youngster in the pilot had a social worker or therapist, I focussed on the ones who received any form of assistance, because it is the intention of Garage2020 to develop the future app for this target group. In my thesis I named the youngsters I interviewed:

Jade, Kim, David, Carmen, James, Julia, Amy, Heidi, Fleur and *Ellen.*

7.2 Appendix B

Interview topic list #1 (users of the G-Moji app)

Ice breaker questions

- How do you like the G-Moji app so far?
- How long have you been using the G-Moji app?

Risk

- How do you experience the G-Moji app?
- How do you experience the results of the G-Moji app?
- How do you interpret the results of the G-Moji app?
- What could be possible negative outcomes of the G-Moji app, according to you?
- How do you think your data is collected, stored and distributed?
- How do you reflect on that?
- Who do you consider as the owner of your data?

- Why do you consider that (particular person or organisation) as the owner of your data?
- Can you tell me something about self-diagnosis?/What do you know about self-diagnosis?
- Nowadays healthy people may know they are at risk of a disease through genetix self-tsteing without actual illnesses necessariry manifesting themselves. What is your opinion about this practice?
- Would you do it your self? (genetic testing)
- Do you know someone who did it? (genetic testing)
- Why did you stopped using the G-Moji app? (if someone did)

Resilience
- Can you describe me your relation with the G-Moji app?
- What could be possible possitive outcomes of the G-Moji app, according to you?
- How do you compare the advice from the mobile phone to actual face-to-face meetings with a social worker/doctor?
- Do you prefer either?
- Do you think both are necessary?
- Can one substitute the other?
- What do you think about sharing your data with others?
- If it was possible to share your data with your social worker/doctor, would you share it?
- How do you reflect on that?
- If it was possible to share your data with your best friends, would you do share it?
- How do you reflect on that?
- If it was possible to share your data with other users who have the same results as you, would you share it?
- How do you reflect on that?

Datafication on other aspects of life
- What do you think about other self-tracking practices such as counting your steps?
- Do you know other people who use self-tracking devices?

- How are you involved in self-tracking practices in your personal life? Do you track your health for example, besides the G-Moji app or do you track other parts of your life?
- How are you involved in self-tracking practices at school/work?
- How do you experience these other self-tracking devices?
- How do you experience the results of these other self-tracking devices?
- How do you interpret the results of these other self-tracking devices?
- What could be possible negative outcomes of such practises, according to you?
- What could be possible positive outcomes of such practices, according to you?
- How do you compare other self-tracking devices with the G-Moji app?
- Why did you stopped using this self-tracking device? (if someone did)

Interview topic list #2 (people of cooperating organisations)

Ice breaker questions

- How long have you been working at (name of the organisation)?
- How do you know Garage 2020?
- How have you heard of the G-Moji application?

Risk and resilience

- What could be possible negative outcomes of the G-Moji app, according to you?
- What could be possible negative outcomes of the G-Moji app, according to (name of the organisation)?
- What could be possible positive outcomes of the G-Moji app, according to you?
- What could be possible positive outcome of the G-Moji app, according to (name of the organisation)?

- Nowadays healthy people may know they are at risk of a disease through genetix self-tsteing without actual illnesses necessariry manifesting themselves. What is your opinion about this practice?
- How do you think (name of the organisation) would reflect on this practice?

Involvement

- How are you involved in the development of the G-Moji app?
- Why are you involved?
- How is (name of the organisation) your working at involved in the development of the G-Moji app?
- Why is (name of the organisation) involved?

Future

- How do you see the future of digital health devices in general?
- How do you think (name of the organisation) would see this future?
- How do you see the role of the G-Moji app in the future, in healthcare?
- How do you think (name of the organisation) would see this future?
- How do you see the role of the G-Moji app beyond healthcare?
- How do you think (name of the organisatio) would see this future?