

New opportunities for eating disorders: developing a treatment delivery tool to help patients  
to communicate with each other

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## Abstract

This paper aims to find opportunities in a new medium that could support treatment for eating disorder (ED) patients. This research is based on the study of previous scholars, expert interviews, a focus group workshop (part of an iterative design process) and cognitive mapping method. Major findings from the literature review are that ED patients have poor social networks and their family caregivers struggle with helping the patients during the treatment. Nevertheless, several studies mention the positive power of peer support for patients. Secondary research has resulted in user-focused service design requirements to develop a new mobile platform. Its design requirements are based on real users' need, as found via focus group workshops. They want new technology that could help them to grow their self-esteem and confidence by taking the place of caregivers. Patients could, also, eat food with other patients in an interactive and secure environment through this platform. This will help them to know they are not alone and they have somebody who can understand them and motivate them to solve a problem. Currently, there is no mobile application which connects patients to other patients. This mobile application is not only a new approach to patient's networking system but also for the digital mental healthcare industry.

*Keywords: Eating disorder, Anorexia, Bulimia, Binge eating disorder, Mental illness, Psychotherapy, Treatment support, New medium, Network, Caregivers, Service design, mobile platform, New technology, Digital mental healthcare*

## New opportunities for eating disorders: developing a treatment delivery tool to help patients to communicate with each other

Eating disorders (EDs) are mental illnesses that often come back after treatment and complete recovery is hard (Steinhausen HC et al., 1999, 2002). There are different types of EDs, such as anorexia nervosa (AN) and bulimia nervosa (BN) and binge eating disorders (BED). These could be diagnosed by symptoms of being concerned with body shape and weight constantly. These disorders include extreme emotions, attitudes, and behaviors surrounding weight and food issues. Eating disorders are serious emotional and physical problems that can have life-threatening consequences for females and males (National eating disorders, NEDA). With AN, patients have an intense fear of gaining weight or becoming fat as well as the possible misperception of their body as being fat despite emaciation (American Psychiatric Association, 2000). Patients who have BN are also extremely conscious of gaining weight, but they have uncontrollable binge eating. People with BN are characterized by a cycle of bingeing and compensatory behaviors such as vomiting by themselves or extreme calorie losing exercise - unlike BED patients, who only can not control their eating.

Based on these symptoms, the research aims to find better opportunities to help ED patients and support ED treatment by connecting patients with other patients through technology.

The main research goal is to investigate technological opportunities for supporting the treatment of eating disorders: to develop a treatment delivery tool that helps various patients communicate with each other.

Sub questions:

- What technology will be the most relevant for the treatment tool / service as a new networking medium?
- What kind of support patients would like to have, in terms of experience and treatment, from a tool?

Constant care and support from the people around ED patients is often needed because EDs are accompanied by other psychological problems, such as depression or anxiety. A few studies were conducted by asking patients with other mental disorders to choose the most

important aspects of their life and requesting them to rate themselves on the aspects. Based on these co-morbid symptoms, in a study, thirty-five patients with serious mental disorder chose the most important keywords of their life quality as family, social support, love / relationship, friends, creativity, home, financial, work / job, health and pet (Prince PN et al., 2001). In another study, eighteen patients with depression mentioned the most important domains as mental health, family of origin, marriage / relationship, friends, leisure and work (Moore M et al., 2005). These results show that patients' social surroundings and relationships influence their mental illness. This could mean that these domains can bring effective interventions to ED recovery.

Even though ED patients' social networks can give effective support during the treatment, several researchers found that they generally report having a poor social network. In a study with 146 patients who had intensive day or in-patient treatment, some researchers found that recovery in ED patients is associated with seeking social support (Blok et al., 2004). However, research of social support shows that family caregivers of ED patients reported negative responses. They were substantially affected by ED patients' emotional disorders and felt anxious, powerless, sad or desperate and this had an impact on the relationship with the ED patients (de la Rie et al., 2007). To support effective intervention into EDs, it seems patients need different methods of enhancing their social relationships which could have a positive influence during the treatment.

On the other hand, there are still 70 million people who suffer from EDs in the world who cannot currently access treatment, due to lack of adequate insurance, incomes and different geographic aspects (Project HEAL, 2016). This study points out that numerous people in the world do not even have a chance to get treatment to improve life and consider social support. They struggle with their mental health issues by themselves without any social connectivity. However, Project HEAL mentioned that technology can be employed to bridge the gap (2016). This could bring treatments that are inexpensive and approachable to all kinds of people. Interventions could be tailored to reach under-treated groups (people of color, males, sexual and gender minorities, etc.). Further research found that internet-based treatment was superior to waiting lists in reducing ED psycho-pathology, frequency of binge eating and purging and in improving (ED-related) quality of life (J. Aardoom et al., 2013) This means E-mental health is becoming an efficient way to provide anonymous and convenient treatment with less cost and time.

The literature considers that both peer support and e-mental health are opportunity areas for supporting treatment of EDs. Therefore, this research helps to understand patients' requirements and needs for the tool which could deliver treatment support. Specifically, I will focus on how peer context and social networking affect the EDs patients' eating life and what makes their eating habits differently by considering technological implication.

## Literature review

### **Lack of support from the network around the patients.**

EDs patients' negative emotionality and perfectionism mean that they can be easily influenced by their social environment. In a 10-year follow-up longitudinal study, Keel et al. show that how roommate dieting frequency affects patients. By living with other roommates, their drive for thinness grows, as they share bulimic symptoms and purging status. This dieting frequency in college continues in their 30s, regardless of substantial changes in social environments. Ironically, this ED patients group, who are easily socially influenced, has poorer social networks than people who do not having eating disorder. Research from Tiller et al. (1997), with AN (n=44), BN (n=81) and 86 non- EDs university students, found that patients had less constant social support than people who don't have eating disorder. The average of the number of support figures was 4.5 for AN patients, 4.8 for BN patients, and 5.4 for the non-EDs comparison group. (See table 1)

Table 1. Sample characteristics for anorexia nervosa (AN), bulimia nervosa (BN), and reference groups

	AN(n=44) M(SD)	BN(n=81) M(SD)	Reference(n=86) M(SD)
Age(years)	25.3 (6.6)	26.3 (6.3)	22.0(3.7)
Duration of illness(years)	7.9(7.1)	8.8(5.7)	
Self-concept	90.5(33.5)	93.8(31.2)	
Body mass index(kg/m <sup>2</sup> )	16.4(2.7)	23.1(5.4)	21.5(2.5)

In this study, AN patients report that they receive lower levels of actual emotional and practical support from friends and BN patients show that they receive lower levels of support

from the partners, parents and siblings than the comparison group. It means they are not fully supported by their social network and a lack of social support could be the main aspect of the patients' behaviors in the EDs.

### **Family caregivers often struggle with ED family member.**

Despite the lack of support from the caregivers, the most cited domains in the patients to maintain quality of life (QOL) is sense of belonging (93%) with in 286 number of frequency. 'Family (44.4%)' and 'Partner (53.4%)' are 269 times mentioned in total under a sense of belonging. (see table 2).

**TABLE 2. The domains mentioned by the participants to contribute to the quality of life**

	Frequency (N = 286)	%
Sense of belonging	266	93.0
Family	127	44.4
Partner	142	53.4
Children	33	11.5
Friends/other	219	76.6
Work/education	184	64.3
Health	114	39.9
Well-being	109	38.1
Sense of self	92	32.2
Self-image	63	22.0
Self-efficacy	38	13.3
Disease-specific psychopathology	84	29.4
Leisure activities	84	29.4
Life skills	63	22.0
Sense of purpose or meaning	37	12.9
Financial situation/living condition	31	10.8
Pets	11	3.8

This shows family caregivers still occupy a huge role in the ED patients' perception of QOL. However, caring for someone with a mental illness can elicit strong emotional reactions including guilt, shame, despair and anger. These emotional reactions can be associated with change in expressed emotion (EE), in particular, criticism and hostility and over-protection (Hooley, 2007).

Some research shows that patients' families struggle many times while trying to help patients. According to Simon de la Rie et al ., 40 caregiver participants in the Netherlands responded that they felt anxious, powerless, sad or desperate as a caregiver. Also, in the same study, EDs were reported as affecting the caregiver's life substantially in 16 cases (40%), to some extent in 22 participants (55%). Only two participants (a father and a partner) did not feel their lives were being affected by the ED. Families mentioned that the presence of the ED led to worries and concern, loss of trust and an increase of conflict. The relationship tended to become more uneasy with less openness and spontaneity.

“I am always worried if she drinks and eats enough.”

“I did not trust her anymore, especially with regards to what she told us she was eating.”

“There is a lot of tension and conflicts. Everything seems to revolve around her.”

“She can be very distant. She is afraid that I meddle with her affairs. Our relationship lacks openness. I am afraid to say anything wrong.”

The comments above show how family caregivers' thoughts about ED patients have changed negatively. They have a willingness to help ED patients, but ultimately they are affected by the patients and start to feel powerless towards them. It can be difficult to understand the patients and see the problem from the patient's side of view.

This means that patients need treatment support from something that could occupy their weaker social network. This support should be such that it is not affected by feelings of loss of power, disappointment or anxiety while helping patients. This support should be different than that of therapists, but more like a family member to whom the patients feel close.

### **Peer context may be a key opportunity for intervention.**

At the beginning of literature review, patients were described as often being influenced by roommate dieting frequency. However, some researchers discovered a new opportunity from this finding by seeing it in a different way. Several research results show that peers of ED patients might affect the patient's eating habit positively. A study from Keel et al., suggests that peer environment in late adolescence may present an important opportunity for intervention (2013).

In their study, Pamela and Jean Forney (2013) assert that peer context may represent a key opportunity for ED intervention as peer groups represent the nexus in which individual differences in psychological risk factors shape the social environment and social environment shapes psychological risk factors. They add that peer-based interventions which challenge internalization of the thin ideal can protect against the development of eating pathology.

Moreover, from the another study, 83 undergraduate sorority members served as peer-leaders for an eating disorder prevention program in which they had previously participated. Peer-

leaders attended 9 hours of training and then led to 2-hour sessions (Figure 1) [1]<sup>1</sup>. Leaders showed decreases (beyond participation in earlier studies) in dietary restraint, bulimic pathology, body dissatisfaction, and thin-ideal internalization from pre-training through 7-week follow up. Results from this exploratory study suggest that peer-leaders who participate in a program and subsequently lead it may experience additional benefits compared to participation in the program alone (C. B. Becker et al., 2008).

Another study from Anna et al., shows how effective using peer leaders is for ED risk reduction. In the study, ninth grade girls (n=50) received a peer-led program about pre-intervention and post-intervention of ED. As a result, peer-leaders frequently aim to support ED intervention based on the tailored manual from the peer-led program.

These studies prove that peers could influence the ED patients dieting frequency even if the patients become older, but, ironically, they could support ED patients to stop eating abnormal way. Moreover, peers of ED patients with enough knowledge about the problem could be the best caregivers who could take the place of patients' family caregivers, who may be struggling. Patients could be more open about themselves to their friends, sharing their problem and stories about their ED.

### **Patients and therapists' different views of treatment quality.**

There is further evidence that ED patients' peers might be the best supporters for treatment. Simone de la Rie, Greta Noordenbos, Marianne Donker and Eric van Furth (2007) compared the therapist's and patient's perspective. In this study, seventy three therapists, one hundred fifty six current ED and a hundred forty eight former ED patients were asked about the qualities that affect them the most during the treatment.

Both therapists and patients most often mentioned focus on treatment, therapeutic alliance and communication skills as important aspects affecting treatment quality. However, patients and therapists valued similar topics differently. Therapists more highly valued the focus on

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[1] Cognitive dissonance

The state of having inconsistent thoughts, beliefs, or attitudes, especially as relating to behavioural decisions and attitude change.

ED symptoms and behavioral change, whereas patients underscored the importance of the therapeutic relationship and addressing underlying problems (See table 3 and table 4).

**TABLE 3. The ranking of the weighed criteria on the quality of treatment of eating disorders of therapists**

Weighed Criterion
1. Being respected
2. Learning to take your own responsibility
3. Learning how to eat normally
4. Focus on recovering weight
5. Focus on improving your body image
6. Being taken seriously
7. Trust in therapist
8. Explanation or information on EDs
9. Keeping a(n) (eating) diary
10. Being able to talk about eating behaviors

**TABLE 4. The ranking of the weighed criteria on the quality of treatment of eating disorders of current and former eating disorder patients**

Weighed Criterion
1. Trust in therapist
2. Being taken seriously
3. Treatment that addresses the person
4. Being able to talk about feelings
5. Focus on self-esteem
6. Being respected
7. Being able to talk about thoughts
8. Addressing underlying problems
9. Being able to talk about eating behaviors
10. Being accepted as you are

This result not only shows that therapists and patients held different values but also shows people who value the same quality could support the differing opinions of therapists and patients. Therefore, this shows further potential for using a communication tool between patients as a treatment support tool.

### **Internet and new technologies can be acceptable vehicles for delivering ED treatment**

By using new technology, E-mental health comes with numerous benefits: it can reach individuals who would otherwise be hard to reach, for example, individuals living in remote areas, or those who do not seek help out of shame or fear of stigmatization (Burns JM et al.,

2009). Also, numerous technology-based programs have been developed to treat and prevent ED.

Research has taken place into using virtual reality for enhancing the cognitive behavioral treatment of obesity with binge eating disorder (BED) (Cesa et al., 2013). Ninety obese (BMI >40) female patients with BED had sessions in the VR scene by wearing devices. First, each patient described negative thoughts and situations (eg, “being teased by my boyfriend at home”). The clinician then reproduced the event in VR from a first person perspective and discussed this situation and feeling. After that, the patient was asked to re-experience the event in VR from a third person perspective and they were asked to reassured and calm their virtual avatar. This proves that VR-based treatment can help to unlock negative memories of the body and modify behavioral and emotional correlates of negative memory. This could improve the long-term outcome of obese BED patients’ treatment.

Another study found that Internet-based treatments were superior to waiting lists in reducing ED psychopathology[2]<sup>2</sup>, frequency of binge eating and purging, and in improving (ED-related) quality of life (J. Aardoom et al., 2013). In this study, researchers collected relevant studies in electronic databases and evaluated internet-based treatment for ED from those eligible studies. Twenty-one studies were included and, as a result, the use of innovative methods for the prevention, intervention, and treatment of ED appeared promising.

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[2] Psychopathology

Psychopathology is a term which refers to either the study of mental illness or mental distress or the manifestation of behaviours and experiences which may be indicative of mental illness or psychological impairment.

## Methodology

### Participants

The sample of patient's for this study consists of patients with current and former ED recruited from the online/offline ED communities in the Netherlands. An email was sent to each patient inviting them to participate in a co-creation workshop. Participants could take part in the workshop once they had answered a questionnaire about their personal ED.

### Cognitive mapping and expert interview

After the literature review, 'persona cognitive mapping' and 'expert interview' based on 'Proud2Bme'(P2BME), an existing ED community website were completed . P2BME is one of largest ED online community in the Netherlands. Insight into the main values of P2BME was the goal of the interview. Exploring the website as a persona would be give helpful insight to understand what other patients think about online ED community system and how they behave when they first start using it. For this reason, persona cognitive mapping was completed by a former BN patient. This intense cognitive mapping session lasted for one hour, with the former BN patient writing down every thought which came while checking information and forums on the P2BME website.

Scarlet Hemkes, Head Director of P2BME, answered questions on the following topics during an interview.

- Structure and system of P2BME and the reasons of final concept of website
- Interaction and communication methods with P2BME members and website managers
- Vision and reference of the design solution

This interview was organized as a Skype meeting which was transcribed.

### Workshop with patients

The workshop research method was delivered through an iterative design process. Iterative design is a design methodology based on a cyclic process of prototyping, testing, analyzing,

and refining a work in progress. In iterative design, interaction with the designed system is used as a form of research for informing and evolving a project, as successive versions or iterations of a design are implemented (Zimmerman, 2003). An iterative design process is used as a service design method, as it will give enough feedback from users while it is being designed.. Therefore, this iterative design process was the best method to continuously improve the concept based on the users' opinions. ED is an emotional problem which needs a lot of specialized information as there are so many different types of patients and reasons for ED. Using an intuitive design process without user testings would bring a huge risk that could confuse or distract users. Therefore, an iterative design process diminishes the risk of misunderstanding what exactly patients need from the design solution. Moreover, as a BN patient, the researcher of this study had already devised intuitive design requirements. Therefore, designing quick prototypes first and asking the patients for feedback was the best approach to get clear research results.

On 3rd of December 2016, a workshop lasting 90 minutes was organized with 3~4 ED patients and people with eating problems. It was planned to have more workshops during the research phase, but there were some difficulties inviting patients to be in one place on the same day. Therefore, only one workshop was organized. The idealistic (but not realistic) first plan was to do three workshops with patients.

So, the workshop I did during the research phase helped to come up with specific design requirements and prototype ideas to develop further. The second and third workshops are planned for the design phase. These workshops will be organized to improve prototype details based on research results and design requirements. Next workshops will be organized through online group video call or individual interview. Patients will be asked to talk about their opinions for the prototypes and be involved in an idea generation and prototype development session. At the end of the workshops, an open discussion about the idea generation will be planned for the design solution.

## **Materials**

To warm up, participants were asked to draw an apple, enhancing quality and details of their drawing to practice their creative drawing skills. The workshop's main session was 'Agile UX sketching and scrum'. There is a determined process for Agile UX sketching and scrum

method, but this time, each step was changed slightly to accommodate eating disorder patients.

Sketching is an efficient way to collect abstract ideas in a short period of time while cultivating shared understanding across people. First, they were asked to come up with their own eating scenario by answering in what situations they ‘feel hunger’, ‘how do they think and behave when they feel hunger’ and ‘eat something’. These became inputs to understand and answer the questions (Networking, communication and sharing meal with other patients). Participants were asked to sketch their ideas based on the inputs. These ideas and information were labeled and critiqued in an open discussion.

The workshop ended with a test of technology devices and an open discussion. Participants put on virtual reality (VR) glasses and compared VR media screen to normal Skype video. After that, the facilitator asked them how they felt about wearing VR glasses and to discuss the advantages and disadvantages of each item.

## Result

### 1. Cognitive mapping

From the cognitive mapping session, additional requirements for the product came up. For this requirements, a former BN patient wrote down instant thoughts about the P2BME website while exploring every function there (Appendix 1). Classification was done by matching the requirements with keywords that ED patients often use in social media.

The additional requirements:

- Tools that could grow patients’ self-esteem and self-confidence
- Easy to approach to information that patient needs
- Tools that could help patients have a healthy diet and eat clean everyday (Give motivation and cheer them up)
- Tools that could help patients set their own meal plan and easy way to know how to eat right
- Tools that give a positive way of thinking about the patient’s body image
- Tools that make patients feel comfortable and secure while they are not eating in a hidden place

Key words: Negative perfectionism, Loss motivation in 3 days, Unsure how to describe themselves (dissatisfied with ego), Low self-confidence, Struggling, Afraid of gaining weight, Affected by peers, celebrities with ideal body

These results were used to form interview questions (with P2BME) for the next step.

## **2. Interview with Proud2bMe.nl (P2BM) head director**

The interview with Ms. Hemkes (Head Director of P2BME) gave new insights about how online networks could connect ED patients in an efficient way and how they could help each other (Appendix 2).

There are 375,000 visitors a month to the P2BME website. There are about 5,000 followers on the P2BME Instagram page. She mentioned that members in the website help and motivate each other by asking questions and facing problems together. This makes them to go further everyday in small steps. Ms. Hemkes started her own social network service before building P2BME, as there was no website for EDs people to communicate eight years ago.

P2BME differs from other diet / meal planning websites and communities by having professional psychologists and nutritionists who support the members. All activities are monitored by P2BME staff. These factors make people feel safe and comfortable. The website is not only about food, but more about EDs people's self-building support. P2BME members focus on their real problems behind the food. They share personal information such as photos of themselves or their meals and people support each other at the same time. Even though members are anonymous, they encounter someone who understands them and their problems. This helps people to build their self-confidence and self-esteem. Therefore, advice from people who have recovered from eating disorders and professionals are the main value of the website.

In P2BME, there are three main features: blogs, forums, and chatting. Ms. Hemkes pointed out that in 24 hours, an average 3500 people see every blog post from P2BME editors. They write useful information about EDs and give topics that people could discuss or comment on. In forums, people share their own information and get feedback from other members.

Furthermore, a live chat takes place every day from 7pm till 9pm based on different age group. About 40 people join each day, asking problems to moderators in the chatroom or sharing with other people. She added that people in the chatroom are very supportive of each other and they share their eating plan or their daily goals for the next day. This makes people motivated about their goals and life.

Ms. Hemkes mentioned that there are many online tools that help people's mental problems, but they only focus on advice from professionals. This is sometimes too far from the target group. She said people need to feel comfortable about sharing and P2BME tries to keep relationships with the website's members.

This interview shows that P2BME is already working on the aspects that patients valued the most and this could make the website successful (e.g., focus on self-esteem, being able to talk about feelings and being taken seriously) (see table 4).

**TABLE 4. The ranking of the weighed criteria on the quality of treatment of eating disorders of current and former eating disorder patients**

Weighed Criterion
1. Trust in therapist
2. Being taken seriously
3. Treatment that addresses the person
4. Being able to talk about feelings
5. Focus on self-esteem
6. Being respected
7. Being able to talk about thoughts
8. Addressing underlying problems
9. Being able to talk about eating behaviors
10. Being accepted as you are

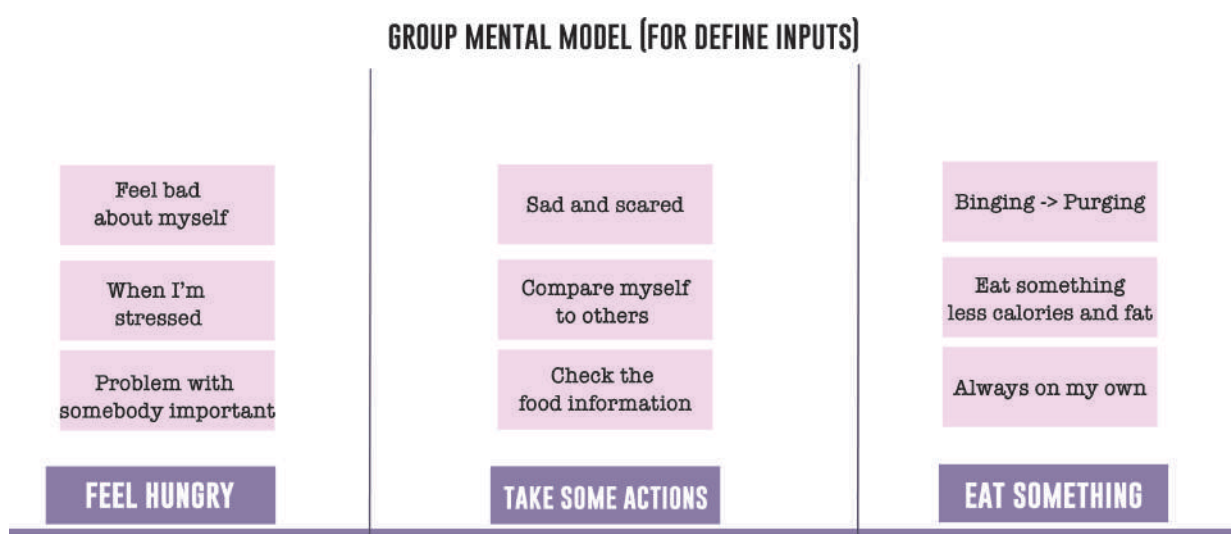
In summary, P2BME could be successful, since they focus on motivating patients to be positive about themselves. Facing the problem together with other ED members in P2BME is another main reason of the success. It is interesting that people in P2BME are willing to help each other in the chat rooms actively. This summary shows that the design solution should focus on raising patients' self-esteem, comfortable atmosphere, secure user network and a function so each patient can show deep understanding of other patients - more than dieting or meal planning products.

### 3. Workshop with patients

### 3-1. Group mental model generation

When the workshop was planned, five to eight participants were expected to attend, but there were huge difficulties to ask them to join in one place at the same time. Therefore, the workshop went ahead with three people who has EDs / eating problems. After finishing a warm-up sketch phase (Appendix 8, #1), a group mental model was created to make a scenario about participants' behavior and thinking process (Appendix 8, #2,3 and 4). The process was divided into three sections based on the patients' actions changing (from feeling hungry to having eaten something). This mental model was constructed by asking patients to choose which situation was most influential for them in each section. They were allowed to choose other participants' answers. After people chose their situations, they had a short discussion about whether they agree with the decision and the reasons for this. At the end, the final three situations were selected for each section (see Figure 1).

Figure 1.



At the beginning, patients wrote down scenarios about the situations when they start feel hungry. After that, they were asked to talk about the behaviors and thoughts they could do before they eat something. This step is important, since this could be defined as a problematic phase for ED patients. After that, patients were asked to choose what for them was the three most influential situations for their eating behavior. Participants feel most hungry when they feel bad about themselves, when they stressed and when they have a problem in their social

life. After feeling hungry, they become sad and anxious of bingeing eating, comparing themselves to others and checking food information such as nutrition factors and calories. Regardless of their will-power self-control, they start to eat a lot and purge with different severe compensating behaviors. Patients also showed that they are afraid of eating with other people and try to eat on their own.

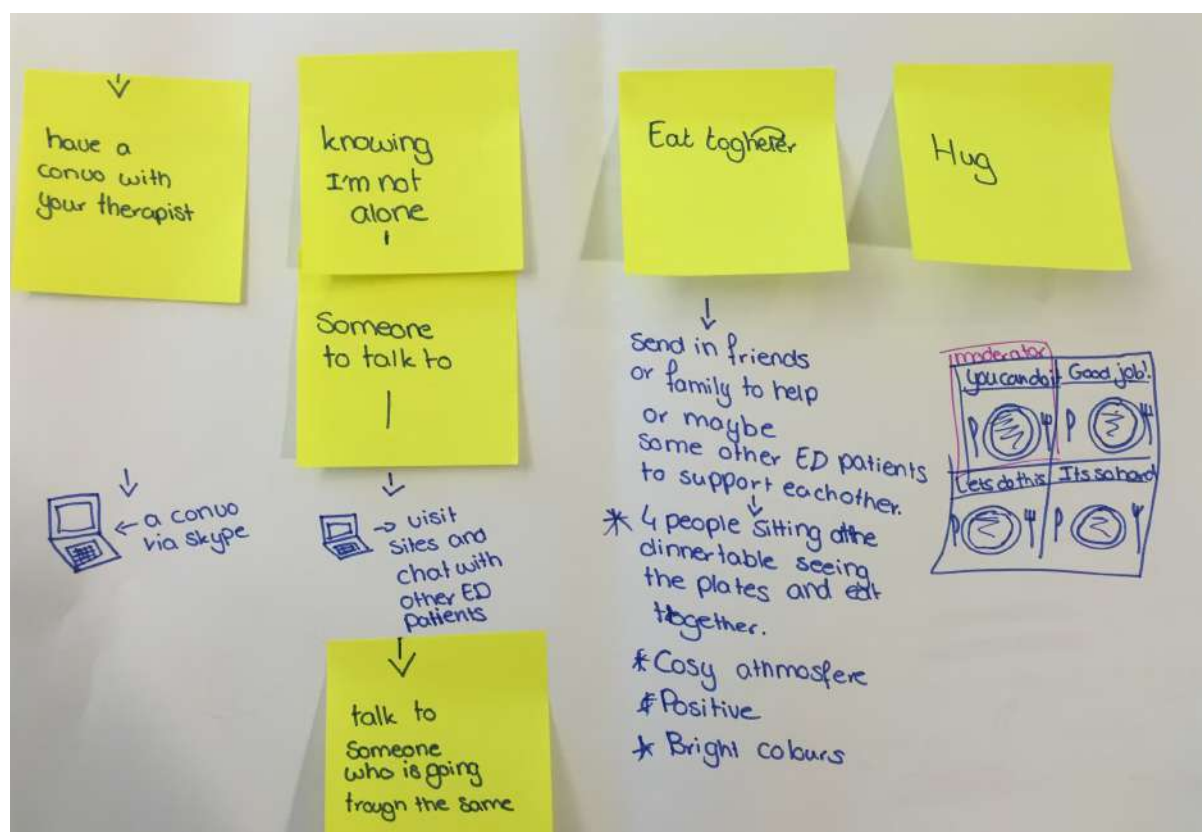
### 3-2. Ideas and detailed requirements

Based on the mental models, participants came up with ideas to solve the negative influences they mentioned. At first, the facilitator asked them what kind of wish they would ask a fairy to solve the negative eating situations. The participants were women under 25 years old, so a fairy is a familiar and iconic object that participants could focus on while imagining something creative. After that, the facilitator asked them how, instead of a fairy, technology could solve this problem. The participants came up with several ideas and these ideas could be classified as three big main ideas below.

#### **Conversations that let patients know they are not alone**

This idea shows participants want to communicate with others and technology could support them directly with this. In the workshop, participants mentioned they need hugs and constant attention from other people (see Figure 2). One idea that everyone liked was to share their plate screens with other people. Participants said it would be also nice if there's an expert as a moderator who guides people while they eat together online.

Figure 2.



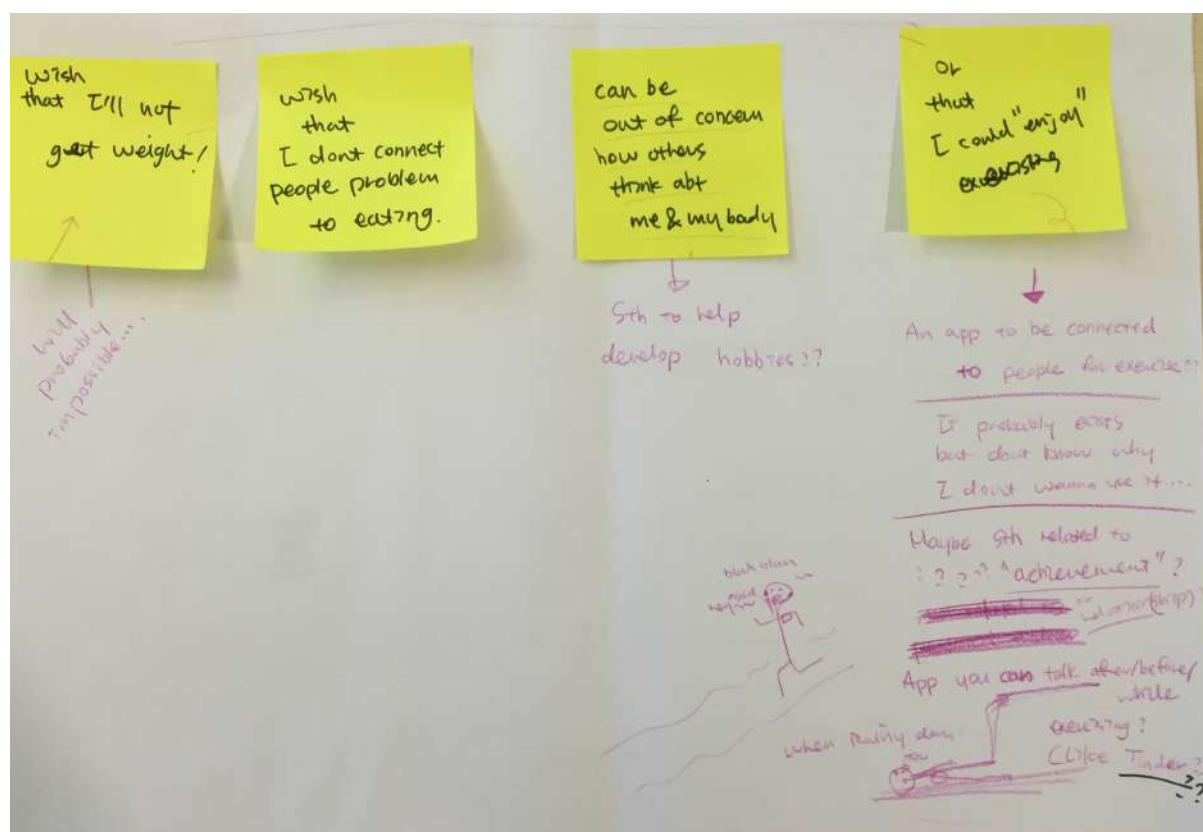
Participants said it would be nice if cheerful comments on the screen could support them. The atmosphere should be cozy and positive, giving each patient a brighter mood. However, they did not agree on showing their face on the screen, since there could be people who only do this session for once. Participants were happy with hearing voices. The most important point is they would like to share their face with people who can trust (Appendix 8, #6, 9 – 15 and 22 - 25). ED patients prefer to have eating session at dinner time. Because when they have constructive eating session in lunch time, they would think about eating something more. But after dinner, they go sleep in several hours (Appendix 8, #6, 19 – 22).

### Daily achievement and motivation tool through connecting online

Patients also added that they need somebody who can do some activities together when they feel emotional hunger. There are many service tools for exercise or weight loss, but the patients focused more on their feelings of achievement after exercising or losing weight. This is not necessarily focused on weight loss and exercise, but more like a challenge to meet a daily task. As a result, people will be motivated and self-confident about their achievements (see Figure 3).

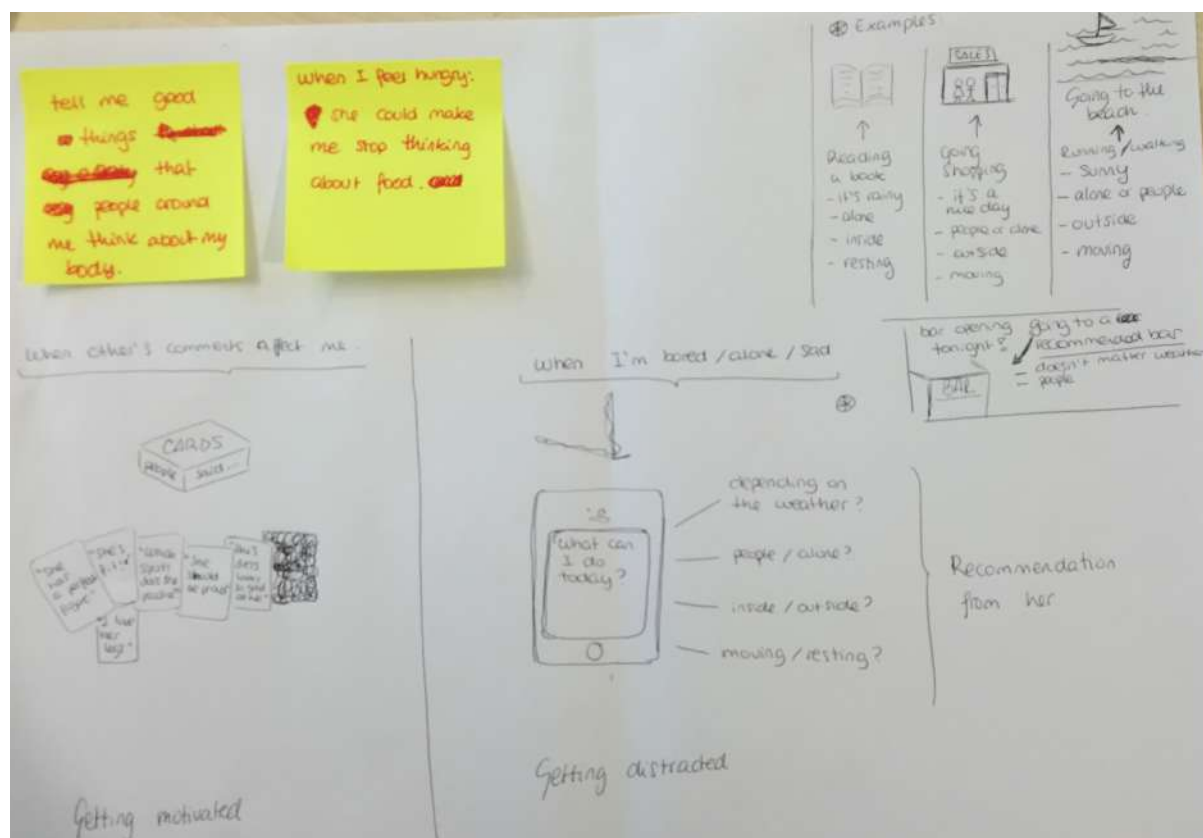
Networking with another person also plays an important role in this service. Patients mentioned that it would be nice if they could talk with someone before and after exercising or activities about how they feel. Tinder, the social network dating service, was mentioned as an example, as people could see other profiles and choose who to talk to based on brief personal information (Appendix 8, #6, 16 – 17).

Figure 3.



One another idea that is related to the main idea is, when they feel bored or sad, artificial intelligent is advising them to visit somewhere or to find their hobbies based on the big-data information (Appendix 8, #6, 9 and 26). Patients need something that could stop them to think about food, so this could help them replace food thoughts by making them to do something. The advices will be generated based on many private details such as distance, weather, situation and feeling. When they feel bored and lonely, this tool is analyzing the people's emotional and environmental factor and suggest them friendly to go new bar near their place. So this is like recommendation from 'Her'/'Him' (see Figure 4) (Appendix 8, #6, 8 – 9) (Ex. Hey, it's good evening there is a good bar so you could chill and have a good mood).

Figure 4.



## Remove negative concerns from other people about my body shape

Often, patients compare their body to other people, even if other people might not be interested in the patients' body shape. Therefore, participants tried to think about products that do not make them think too much about other people's negative thoughts on the patients' body shape. One idea is a card collection with other people's positive personal opinions about the patient's body shape. This will positively motivate patients about their life and how they think about their appearance. (see Figure 4).

Another idea is to share meals with fun nutritional information on the package. This package is designed for more than one person, so people could get ideas how to share the meal or cook together with other people. Participants added that this should satisfy the eater's mind, hunger and reduce guilt and worries about gaining weight. The meal package could have specific portions, therefore allowing people to control their meal portions better than when they suddenly eat a lot or less.

All in all, the entire workshop results show that participants are looking for help from something that they could do with other people. They showed a serious need for support from other people. Furthermore, interacting with strangers online is not a big problem for the participants if they could trust them. This means designing trustful product through which patients could make friends with strangers securely is an important issues. The results also show participants prefer help from others' rather than treating (or recovering?) themselves through their own hobbies or work. Finally, participants wanted to have something that helped them to not have negative image about their body shape.

### 3-3. Technology review

Figure 5. Expected scenario of using technology devices



At the end of workshop, participants tried different types of technological devices and gave their opinions. It was expected that they would choose virtual reality devices the most, since

it is new technology and interesting to watch interesting scenes virtually (see Figure 5). First, people showed interesting reactions to the virtual reality videos from 'NY Times VR' through smart phone.

However, participants claimed that other people would think them strange if they wear the device in public spaces such as a restaurant. They said they would only use it when they are alone. It could be used before and after eating, but not while eating. Another device - glasses made out of cardboard were considered inappropriate for the duration of a long online session, since the edge of the glasses make them quickly feel tired. They compared VR technology to Skype, preferring Skype as they did not need any further devices for Skype. . They can use Skype everywhere and anytime. The most significant reason is they are familiar with using Skype and this applies also for other people too. A disadvantage of using Skype is that they often have connection problems.

As a result, people chose Skype as the best method for sharing what they eat. They showed interest in using VR glasses and experiencing new technology but felt awkward using something new. Hence, this shows they are willing to use something that could replace Skype video calling which has more interactive functions and is also comfortable to use in public places.

## Conclusions and recommendations

An eating disorder is not a mental illness that individual can treat by himself / herself easily. Even though they are in therapy, therapists suggest that patients ask for support from the caregivers around them. However, there are many struggles during treatment between patients and their caregivers which can lead to misunderstanding and hurting each other inadvertently. Therefore, this research aims to dig down to find new technological opportunities that could support ED patients who are on treatment. Patients would communicate by becoming a caregiver to each other and this will accelerate their recovery to the normal life.

Several methods of design research have been used to find the best technology and requirements to support this new networking experience for ED patients. The results show that, simply, the target group wants to have ‘conversations that let patients know they are not alone’, ‘daily achievement and motivation tool through online connection’, and something that could ‘remove negative concerns about their body shape from other people’.

In the end of primary research, virtual reality was the technology with most potential to be used in an innovative way to support treatment. However, what users want was revealed from the focus group workshop. Patients do not want to wear VR glasses, as they are not comfortable yet and they do not want to buy additional devices.

According to the summary above, new technology opportunities that support treatment should help patients to grow self-esteem and confidence by doing what existing caregivers cannot do for them. This could be possible when the tool lets patients know that they are not alone and there is somebody who understands them and motivates them to solve problems. The patients could share their meals but should be in a more interactive and secure way than normal video calling.

## Plan of implementation or design

After the research, design requirements have been set-up. There are three different categories for the design requirements.

First, this tool must possess the following features as design criteria:

**Data security:** All sensitive data must be encrypted before being passed between the patients and server. Patients privacy should be protected strictly.

**Real-time response system:** Patients should always be able to get a real-time response or guidance from other patients and caregivers when they ask for help.

### Soft requirement

**Comfortable approach:** Patients should always find the tool approachable and feel comfortable and secure while they are connecting to other people online.

These are the design (soft) requirements for the product. However, as this tool is for the treatment of mental health issues, some requirements are hard to define as hard / soft requirements because each patient has different preferences. Therefore, I categorised the requirements with three questions: ‘What effect should this have on the patients?’, ‘What this tool should do when using it?’ and ‘How it should work?’.

### What this effect should be on the patients?

- This service helps people, so they are not afraid of eating with others.
- This service will do something therapists cannot do for patients while not in treatment sessions.
- This tool will encourage patients do activities together with other people.
- This tool can help patients to get compliments from other patients or caregivers easily.

### What this tool should do when using it?

- This service makes patients feel comfortable when they share their information or daily activities with other patients.

- This tool has trusted networking building system to enable patients to be open with strangers.
- Patients will not feel that using this tool is a mental health treatment or shameful.

### **How it should work?**

- This tool should use modern technology but not so new which is not available.
- This tool offers guides from nurses or expert patients.
- This tool will have a new profile building system only for mental illness patients.

Feasibility, viability and desirability of the product have been considered just before concept generation phase.

**Feasibility:** This tool will use technology which every type of eating disorder patients could approach, but by considering the target group age range (18 ~ 30) the technology will be modern and easy to access every time. That is why this tool can feasibly bridge the gap between treatment and eating disorder patients.

**Viability:** This tool is viable, since the number of eating disorder patients all over the world is increasing every year. Patients' demand for this tool will increase in the future. This tool could be developed into further types depending on patient demand.

**Desirability:** Recent eating disorder treatment has difficulties observing patients continuously after the treatment. Due to lack of adequate insurance, incomes and different geographic aspects, many people cannot receive medical care at hospitals even if they suffer with symptoms for long time. This is another reason why many people will desire to use this tool for their own clinical treatment approach.

By considering every aspect from the design brief, the design solution decided upon was to develop a mobile application that could build a narrow and private network between patients. This will facilitate people to share their meal online in the most interactive atmosphere. This will help users to motivate themselves and other patients by doing small challenges together.



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## Appendix 1

### **Persona : Proud2Bme (P2M) exploration cognitive recording**

Name: Claire

Age: 23

Date: 2016/10/5 15:15 start - 16:15 finish

By starting exploration of P2M website, I wrote my instant thought about my eating problems and with this process, I could see how I'm thinking about ED problem I have and about myself. After this process, I could come up with some extra requirements and main keywords. These requirements and keywords represent how, in general, patients think about the problem, therefore I would use these as a base of interview and workshop questions.

#### **Requirements**

- Tools that could grow patient's self-esteem and self-confidence
- Easy to approach to information that patient needs
- Tools that could help patients do healthy diet and eat clean everyday (Give a motivation and cheer them up)
- Tools that could help patients set their own meal plan and easy way of right eating knowledge
- Tools that gives positive way of thinking about patient's body image
- Tools make patients feel comfortable and secure while they are not eating in a hidden place

#### **Key words**

Negative perfectionism, Loss motivation in 3 days, Confusion to describe themselves (non-satisfied with ego), Low self-confidence, Struggling, Afraid of gaining weight, Affected by peers, celebrities with ideal body, No something 'special' except for appearance

#### **Questions to myself**

- How can I grow my self-confidence and self-esteem?
- What if I could get this information easily?
- Why I can't control what I eat everyday and why I always fail on a dieting?
- Then what is perfect meal plan for me and what is perfect body for me?
- What is my ideal body image?
- What is other people's ideal body image?
- What I want to achieve in the future?
- Hmm... too long information... Is there another method that I could get information?

#### **The way how I'm seeing myself**

- It's hard to see (myself) positively.
- There are already so many people who are better than me in area where I want to work, study and do something
- There are some real examples around me in the school, roommates and friends
- I often lose my motivation in 3 days.
- I feel like people who have fit body is loved by many people and if they have good personality even, then it's game over.
- Because I don't have something 'special', that's why I might want to have a 'fit' body that could change myself and it's, actually, the fastest way.

- Because I don't have something 'special', that's why I might want to have a 'fit' body that could change myself and it's, actually, the fastest way.
- Well, I could talk to others, but I ate food by hiding from others.
- I watched TV when I had food, I felt lonely at that moment but also it made me feel comfortable and secure.
- I really don't want to get weight back. I lost weight so hard and still I'm struggling
- Sometimes I think I might die because of throwing away and I think why I'm living by struggling this moment.

How did I approach to P2M website

-----Exploring started 3:15PM

1. Started from reading about what is different with Eating problem & Eating disorder  
“I had ED problem before, but now I'm struggling with EP problem”

2. Self-image tab

“I don't know about myself clearly”

“I'm confused when I describe myself”

“How can I grow my self-confidence and self-esteem?”

3. Beating self tab

“What if I could get this information easily? It's too much text with long information.”

“Even though this website says I should see myself better, **it's hard to see (myself) positively.**”

4. Compare self tab

“How can I think me in a bright side?”

“**There are already so many people who are better than me in area where I want to work, study and do something.**”

“I'm probably more lazy than them, that's why I'm not good at it?”

5. Media tab

“I use Instagram and there are people who really show-off their body and effort to make their body fit. Probably they did some photoshop, but not all of them did.”

“**There are some real examples around me in the school, roommates and friends.**”

“Why I can't control what I eat everyday and why I always fail on a dieting?”

6. Diet tab

“I tried every different kind of diet, but I cannot see the result soon. Therefore, **I often loss my motivation in 3 days.**”

“When I go on a strict diet, it's even harder for me because of binge eating disorder as a rebound”

“Then what is perfect meal plan for me and what is perfect body for me?”

7. Perfectionism

“Yes, I think I'm kind of perfectionist because if I do some mistake on the beginning or while on a diet, I go back to strict diet again and fail to loss a weight again.”

“I can't continue.”

“What is my ideal body image?”

“What is other people's ideal body image?”

“Even though people say ok, and my boyfriend says ok, but still I feel it’s not enough to compare with other fit body people.”

**“I feel like people who have fit body is loved by many people and if they have good personality even, then it’s game over.”**

“True I want to have a fit body.”

#### 8. Self image tab

“Yes, I always blame on myself when diet doesn’t go well. I feel guilty after that.”

“When I see the people on the instagram, they eat clean and live healthy. But I like instant food and it feels like I’m addicted to it.”

**“Yes, I have negative perfectionism.”**

“Probably this perfectionism is not only because of my body image.”

**“Because I don’t have something ‘special’, that’s why I might want to have a ‘fit’ body that could change myself and it’s, actually, the fastest way.”**

#### 9. Clicked my symptom category -> Clicked What should you do now category

“Yes, I just started therapy 3years after realizing my problem. The reasons are time, money, lack of confidence, lack of trust and mood swings.”

**“Well, I could talk to others, but I ate food by hiding from others.”**

**“I watched TV when I had food, I felt lonely at that moment but also it made me feel comfortable and secure.”**

“If I tell about this problem to my boyfriend, I wonder what he would think about me. Would he think me I have a psychic problem?”

#### 10. Clicked Tips tab

“ Really? Should I throw away the weight scale?”

“ I tried once, but I was under the anxious what should I do if I got some fat?”

**“ I really don’t want to get weight back. I lost weight so hard and still I’m struggling”**

**“What I want to achieve in the future?”**

#### 11. Clicked How do I tell and Experience expert tabs

“What my mom told about to me about the problem is, she actually just can’t do anything for me. First, she didn’t take it seriously. But after I got a diagnosis from the hospital, she changed her mind that I could take the treatment.”

“I hate feeling that I’m SO full after eating until I eager to vomit, and I decide to go on a diet in that day. This thought goes away quickly next day morning, because I feel hungry.”

“I forget what happened the day before.”

**“Sometimes I think I might die because of throwing away and I think why I’m living by struggling this moment.”**

#### 12. Clicked P2M logo again and went to main page

#### 13. Clicked one blog post on the main page

Title: 10 confessions of bulimia – by Scarlet hemkesin

Title: What did you eat today? – by Laura

“Can I write this post often? It’s a bit annoying for me to write a diary about meal and take a picture of them.”

13. Followed P2M instagram -> Followed one girl's instagram who is fighting from the Anorexia

"But still I followed strict dieters and clean eating dieters also such as 'Kayla Itsines'."

14. Clicked healthy and beauty tab

"Hmm... too long information... Is there another method that I could get information?"

15. Clicked forum

Exploring finished 4:15 PM -----

## Appendix 2

### Expert interview question with Scarlet Hemkes (Head director of Proud2BMe NL)

Hello, my name is Claire. Now I'm doing research to design a new tool that delivers eating disorder treatment to various patients through networking between patient. Therapists will be involved in this tool for the supporting patients while on a treatment. This interview will be helpful to get base resource and data for the design result.

With this design aim, I would like to ask you about

- **Structure and system of P2BM website and the reasons of final result**
- **How do you run P2BM website based on what kind of research and data.**
- **What kind of services and contents the new medium could offer to the patients and what could be the limitations of this tool**
- **How patients are communicating and networking in the website**

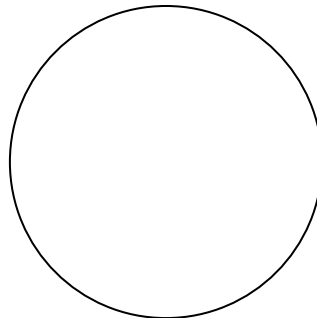
We are having open conversation interview and I specified some topics that you could talk to me.

#### Research and data

1. How this **current feature** of the website has been set-up as a **best result**?
2. What is the most **popular** and **influential** section?
3. Who is **target group** of this website? How did you do the research about target group?

#### Contents and layout

4. Can you tell me the **main value** on the website? Networking and interaction (%), Information (%) and treatment support (%)



#### Interaction and communication with P2BM members

5. What important parts of P2BM make **patients comeback** to the website continuously? (ex. Amount of information, forum, instant reaction)
6. Can you tell me about how members in P2BM get helps from other members in there?
7. How do you manage the **privacy issue** in P2BM? Are there offline meetings happen sometimes?

#### Influence as a former patient

8. How did you raise your **self-esteem and self-confidence**?
9. Did your **past experience** affected a lot on building up concept of the website? How your experience affected to building it ?
10. If you suppose you are former patient, how do you think about **sharing with others? (Confronting the problem and treatment)**
11. What are the differences with other dieting or meal planning community/website/app and P2BM?

## Appendix 3

### Interview script with expert (Scarlet Hemkes)

C: Me

S: Scarlet

C: Can we talk about the Proud2beMe (P2BM) website, how did you build up this website and how people in P2BM are communicating in the website? Also, can you tell me how the website is affecting on the people?

S: Well, When I started it, I started it through social media, because I had a lot of people who supported me on social media. I was doing campaigns against the Anorexia for the website, so I had a lot of people already who knew me who made me easier to get a lot of visitors at once when I launched the website and... What was your question? Sorry.

C: Hmm, how did you build up this website and how your past experience affected for the website construction?

S: Yeah, well, because I had an eating disorder myself and knew lots about it. Everything I wrote for the website was written from experiences so it was totally different than everything you can find on Google about Anorexia and Bulimia. So, that made difference for a lot of people. There was no modern safe place for young people to connect each other, that's why I wanted a forum on the website where they can post 24/7 which is, also, monitored by us. So, they feel safe and not triggering in that kind of things. And I, also, wanted to chat, so people can chat every night with professional psychologists and nutritionists. And that worked.

C: Does it mean that social networks such as Facebook or Instagram didn't work enough for you to treat an eating disorder problem? So, you thought it's good to have another community?

S: No, because 8 years ago, there were not many activities on the Facebook. It wasn't even popular.

C: No, not really.

S: No, that's why there was not that much, but now there are so much social media like Instagram, Facebook and now you see that a lot of people write their stories on the Instagram. It's easy to write in other places right now. But, 8 years ago, there was only P2BM.

C: But you are, also, using Instagram and Facebook like a P2BM. I also follow it and keep the track of them. It's actually helpful when I see some pop posts on the Instagram about courage or meal you upload, then I think I can try this meal or I can eat hamburger whatever.

Do you think those media are affecting a lot on the P2BM website now? Since social network is huge now, so people could communicate through them.

S: Yes, actually a lot of people are communicating through those social media. So sometimes, instead of posting their stories on the forum in P2BM, they post their story under the photo and say how their day was.

C: What do you think is the main value of the website, if you suppose there is no Facebook or Instagram or other social networks?

S: The main value is that recommendation between people who are recovered from the eating disorder and the professionals. So they are working together. So, visitors can very easily and anonymously ask for help to each other, but also to professionals and also someone who had eating disorders who understand that. I think that's the main value of P2BM.

C: Is that completely anonymous? How do you deal with the privacy issue? Because members need to build their trust about the website, then they can ask their problem.

S: Yeah, but you can register on the website only with your E-mail address. If you make a fake email address, then they don't know who you are so you could be totally anonymous. But, it's also possible to upload your own photo or write your own name

C: Do you think they care about a lot? For example, for me, I also have an eating disorder and I take therapy now, but my style is spreading out about my problem to other people. Because I think it's not a problem or something wrong with me. Now I'm not shame of it. But I'm wonder how other people who have an eating disorder think about their problem. Do they really care about their privacy or anonymity?

S: Yeah, I think that they don't consider that much because there are a lot of people who have neighborhoods already know the members have eating disorders. But there are, also, a lot of 14 years old young girls their mothers know that they are struggling with foods and losing weight. Also, old people who are shamed of it, because they have normal job and they don't want other people know they have psychological issues.

C: Yes, it's, anyway, psychological issue for people who don't have an eating disorder.

S: Yeah, maybe it's because of everybody only has an eating disorder, but also they have depression or personality disorder. I don't think lots of people every body to know that problem.

C: Well, there is a forum on the website and they talk about their issues with other people but how that community is working? Do they know each other or do they have some off-line meetings individually? Do you know something about it?

S: Well, I think some people know each other, and two or three people meet together so the older group where the women are 35+ years old sometimes meet, but most of them talk online. They don't really know each other in a real life. Because sometimes they put their contact number on their P2BM forum but not that often.

C: Because they don't want to show up themselves on the website?

S: Well, that's scary and I don't think that much about in groups. I'm not totally sure, because they are normally anonymous so sometimes they talk to each other on the online only on the forum and they send each other private message 'What is your facebook and then, they connect through Facebook and meet up. I think there's a lot of contacts out side of the forum but I don't know how close it is and how often they meet in real.

C: What I'm thinking about is design solution that people could share their meal with other patients but it's not like taking picture and post it on the online network, but more like doing skype or talking to other people when they are eating something. Now virtual reality and augmented reality are quite big issues and what Eric and I thought about is what if technology can connect the patients and patients. When they feel emotional hunger, then they can cheer them up each other. So, it is kind of futuristic way to connect the people.

S: If they would like that, they already have done that through Skype.

C: Yes, but the thing is it's different with other apps or bootcamps and that part I need to make it differently than those things.

S: Maybe you can eat with groups,,

C: Yes, it's like a virtual dinner table. So many people can join but they don't see each other or they can see each other.

S: Yeah, you want to see each other. Because, if you don't see each other, then you still think you are not eating, so I'm not going to eat then. So you want to see other person is also doing is best they can.

C: Yes, so it would be different with other media already exist probably.

S: Now in P2BM, every 7 O'clock they can chat in a group. Well, lots of people appreciate that and they talk about their day and make an live appointment, but not like appointment, they tell something like 'Ok, tomorrow, I'll do this and this'. This really helps a lot of people, so maybe it's possible to do this with some kind of app instead of going to chat but going to eat together.

C: So you mean, mentioning eating plan to other people before I eat during the chatting?

S: In the chat they also do things like that. Chat group really supports them each other. Eating together could be supporting them also.

C: Oh, yes, so not just chatting but seeing them and talking each other while they are eating. If there is that kind of session, I would enjoy.

Umm, you said they support each other really, how many people normally join the chatting?

S: We have about 4 chatrooms per evening and every chat room can have maximum 14 members. It's a little bit less busy now because of the social media. I think about 8~10 people per chat room. So like about 40 people per evening.

C: Do you know the age or...

S: The chat room is separated based on the age, but most of them are around 19~20.

C: Do you set the target group of the website? Such as P2BM is aiming 19~35 people or 19~25 yrs old people?

S: Well, when it was launched, the targets were a little bit too young. It was really pink. The style I wrote in was too simple, but now the age range is older so it's more difficult stuffs. So yeah, 20 years old or older but girls who are 16 years old don't understand something on the website. So it's just normal talks. So we to write like everybody can read and understand.

C: I read a lot of information in the P2BM website, and I wondered those lots of important information about eating disorders takes the huge role of the website? Do you think that makes the people visit the website again and again?

S: Yeah, but not because of the information, but the blogs we write everyday. That's why people come back together with the forum. But there are a lot of people who don't visit the forum do read the blogs.

I think like the blog of yesterday evening, 3500 people visited and read the post. Lots of people come to visit through Facebook, because we promote their to the website.

C: How many members are their in P2BM? I think I heard as 200,000?

S: In forum, 25,000 I guess and but P2BM has about 375,000 visitors a month. From Belgium and some other countries where Dutch people are living.

C: I also saw the American version.

S: Yeah, it is very different with Dutch version.

C: And I couldn't find any forum in the American version.

S: They have a forum but it's not really active.

C: If you suppose you are former patient, how do you think about sharing your dietary plan or problems with other patients? Do you think you treat yourself by sharing and helping other patients who are in the same situation or you will be helped from others and treated because of them?

S: Well, I don't think it's only helping somebody else, because it's not good way to deal with your own problem by focusing on somebody else's problem. So I think the best is somewhere inbetween. Helping people and telling your own story and yeah.

C: Yeah, so it's like a keeping balance between those two behaviors, actions.

S: Yeah, because when there is a balance there can be a community if only people ask for their help then, nobody is going to help them except for person who works for P2BM.

C: And, before you didn't have P2BM, I think low-selfesteem and low-confidence are take big part of having eating disorders. How did you raise them by yourself. It's a quite difficult question.

S: Well, I had therapy so, I raised it I worked and I did study. I think working and studying doing normal things in life, you build up self-esteem.

C: Yes, like getting self-responsibility.

S: Yeah, taking risks and facing the things you afraid of.

C: Did you think you were changing at that moment until the recovery stage?

S: Taking more self-responsibility makes me feel more worthy.

C: So, P2BM makes people to feel that.

S: Yes, we help them to ask questions and help face the problem and take little steps. We try to motivate people everyday.

C: What are the different things with other dieting or meal planning community/website/app with P2BM? Well, one thing is you are focusing on eating disorder.

S: Yeah, it's not that much about food. Because I think the problems are not really about food. It's far behind of the food where the problem is. So, we try to focus on the real problems and the difference is there are not so many websites like P2BM in the Netherlands. There was one who tried to copy P2BM and they made only by professionals. Sometimes it's too far from the target group. So it's not really personal stuff. Because we tell a lot of personal stuffs and try to help with photo of ourselves and that really makes difference.

C: SO, you are trying to focus on individual stuffs more deeply than others. Eric and I found that psychological therapy applications. And those were not talking about their own issues inside, but those are more about like instant talking with therapists. I thought it might work but also not, because, as I know, I need therapeutic alliance with my therapist for long time. That makes my life better and they will raise my self-esteem more and more. And you are also thinking like that? Do you think therapeutic alliance with therapists and patients connection is really important?

S: Yeah, I think because if I didn't have a connection with therapist then I'm not going to do anything.

C: Yeah, but P2BM is not only about therapy but it's more like helping people by working as a therapists but it's more like online....

S: Yeah, it's little bit more like an online friends with yeah... friend with a therapist.

C: My last question is how this feature of the current website has been set as the best result? Like a layout, forum, chatting or many functions. You said blog is the most important role of the website.

Do you think blog posting makes the P2BM as the current look like? P2BM is working well now and do you think the blog posting is the most important part?

S: Well umm, combination of the blog posting and the forum. Because if there is only blog posting, then people will find ask for help and getting contact to each other and that's really important.

C: It's like a networking or interaction?

S: Yeah, the interaction and the blog posting?

C: Blog posting is also interaction between editors and people.

S: Yeah, Interaction then, between the members each other and members and us.

-----Recording end

## Interview analysis **Interview Grounded theory**

<i>0. How this current feature of the website has been set-up as a best result?</i>
<i>Labels</i>
<b>Help and motivate people</b> <ul style="list-style-type: none"> <li>• to ask questions</li> <li>• to face problems</li> <li>• Take little steps</li> </ul> <b>Forum and blog posting</b>

<i>1. How did you build up this website and how people in P2BM are communicating in the website?</i>
<i>Labels</i>
<ul style="list-style-type: none"> <li>• I started it through social media</li> <li>• I had a lot of people who knew me</li> <li>• I was doing campaigns against Anorexia</li> <li>• I had an eating disorder myself</li> <li>• Knew lots about Eds</li> <li>• No modern safe place young people connect</li> </ul>

<i>2. What are the differences with other dieting or meal planning community/website/app and P2BM?</i>
<i>Labels</i>
<b>Managing website</b> <ul style="list-style-type: none"> <li>• Monitored by us</li> <li>• People can chat</li> <li>• Professional psychologists and nutritionists</li> <li>• Written from experiences</li> </ul> <b>Not about food</b> <ul style="list-style-type: none"> <li>• Behind of the food where the problem is</li> <li>• Focus on real problems</li> <li>• Personal stuffs</li> <li>• Photo of ourselves</li> </ul>

*3. Can you tell me the main value on the website?*

*Labels*

**Recommendations**

- People who are recovered from the eating disorder
- The professionals
- Ask for help each other
- who understand
  
- Easily
- Anonymously

*4. How do you manage the privacy issue in P2BM? Are there offline meetings happen sometimes?*

*Labels*

- Only with E-mail address
- Totally anonymous
- Own photo
- Own name
- Fake

*5. How target group is thinking of their privacy about eating disorders?*

*Labels*

- A lot of 14 years old young girls' mothers know
- Neighborhoods already know
- Struggle with foods and losing weight
  
- Old people who are shamed of it
- Normal job
- Colleague
- Psychological issues

*6. How target group is thinking of their privacy about eating disorders?*

*Labels*

**Teenagers**

- A lot of 14 years old young girls' mothers know
- Neighborhoods already know
- Struggle with foods and losing weight

**Old people**

- are shamed of it
- Normal job
- Colleague
- Psychological issues

**Combination of psychological problem**

- Everybody only has an eating disorder
- But also have depression or personality disorder

*7. How members in Proud2BMe are communicating with each other?*

*Labels*

**Communication in a real life happens but not that much**

35+ years old women sometimes meet  
most of them  
talk online  
don't know each other in a real life  
lots of contact outside of forum

**Negativity of show up themselves**

Scary  
No meeting in groups  
Talk each other on facebook

8. *What is the most popular and influential section? What makes people comback to Proud2BMe?*

*Labels*

375,000 visitors a month

**Group chat**

Every night 7 O'clock  
lots of people appreciate  
talk about their day  
make a live appointment  
really helps a lot  
really supports each other  
40 people per evening

**Blogs**

Write everyday  
3500 people visited for yesterday evening post  
Comback to forum  
Networking  
Interaction

9. *If you suppose you are former patient, how do you think about sharing with others? (Confronting the problem and treatment)*

*Labels*

- Tell your own story
- Help people
- Somewhere in between

10. *How did you raise your self-esteem and self-confidence?*

*Labels*

- Therapy
- Take risks
- Face things afraid of
- Take more self-responsibility
- Feel more worthy
- Connection with therapists
- Friend with therapists

## Appendix 4

### Workshop invitation letter

# DEAR PEOPLE WHO HAVE EDS, LET'S DESIGN SOMETHING TOGETHER :)

Have you ever joined design workshop?

DATE: 03/DEC/2016  
TIME: 14:00 (it could be changed)  
PLACE: GGZ Rivierduinen in Leiden

As you can see on the picture next, it's about getting ideas and inspirations for product/ service design. In the workshop, you are making brief and fun sketches about ideas and do brainstorming together with other people.



I'm Claire, industrial design student, who came from South Korea and I'm doing design research about the *eating disorder treatment support tool development* under the supervision of Professor Eric van Furth. This tool will help eating disorder (ED) patients communicate with other patients in a better way than before. For example, imagine that there is a tool that you could have a dinner with other people in virtual world!

I want to invite you to a creative workshop to understand patients better and to know what you want, with 5-8 people who have ED. I will send you workshop contents later, but in general I would ask you what do you want from your social network and how do you want to communicate with other people.

The workshop will take 1 to 1.5 hour maximum and there will be a little compensation too .  
If you live far from Leiden, I, also, could support train ticket.

Are you interested and you have time to come and visit GGZ Rivierduinen in Leiden?  
Please send me an E-mail [clairec09h18o@gmail.com](mailto:clairec09h18o@gmail.com) or text me through my number +31 6 8585 1750 .  
I'll contact you soon with workshop plan. I hope to see you in the workshop!

## Appendix 5

### Instagram advertisement

It took so long time to find participants for the workshop and there were difficulties to gather them in one place at the same time, I made an advertisement to post on the instagram. I also sent individual messages to more than 30 patients to ask their availability. This activity became one of main parts of the research by communicating with patients and get some ideas how to deal with patients participants.



Hello dear person with an eating disorder in the Netherlands,

I'm Claire from South Korea and I study design/innovation at the Haagse Hogeschool. I'm doing design research about eating disorder treatment product under the supervision of Professor Eric van Furth at GGZ Rivierduinen.

To understand patients better and to know what you want, I want to invite you to a creative workshop with other patients.

We are having fun drawing and idea generation time in the workshop. There will be a little compensation too. Are you interested and have time to come and visit GGZ Rivierduinen in Leiden? Please send me a message or E-mail [clairec09h18o@gmail.com](mailto:clairec09h18o@gmail.com) . I'll contact you with more information. Thanks!

## Appendix 6

### Workshop schedule

#### 1st workshop plan with patients

5mins

Explanation time

My research shows people have a communication and my aim is develop communication tool between other patients and therapists.

3mins

Squiggle bird

20~30 sec doodle and 2~3 mins birds drawing

Agile UX sketching and scrum

TOTAL 45 mins +/- 10

Inputs defining time ; total 15mins

1 min

Explanation and ask them to think about when, where and what situation they feel hungry

2~3 mins

Write down on the sticky note

1 min

Ask same thing in the problematic stage of patients

What do you think and behave?

2~3 mins

Write down on the sticky note

1 min

Same with feel hungry question for eating something stage

2~3 mins

Write down on the sticky note

2~3 mins

organizing time

3mins

Ask patients to pick the 3 most influential situation for the eating disorder

They can pick other's idea also.

1 mins

Ask people if there is a magic or fairy, how it could help patients to solve and help the situations what they chose? (it doesn't matter it's unrealistic)

Ex. You want to run away? You want this reality changes?

3 mins

Write down ideas

2 mins

“Now, imagine there is no fairy or magic but you have to do with something in reality that could help you to solve your wishes. What kind of tool could help your wishes?”

“Can you draw them down briefly, sketch quality doesn’t matter if I could understand your ideas”

5~10 mins

Drawing time

15 mins

Organizing the sticky notes based on the mental model scenarios, and review about them

5 mins break and Q&A

Technology review

10~15 mins

Wear expensive VR glasses, cardboard glasses, phone VR and try skype

After that, ave a short think aloud discussion

Ask people “how do people feel about it” and “what parts do they like of each method” and “what parts they don’t like on the each product?”

## Appendix 7

### Workshop activity pictures



## Appendix 8

### Workshop recording script

Workshop with patients transcript and result pictures

Date: 3<sup>rd</sup> of December. 2016 Place: GGZ

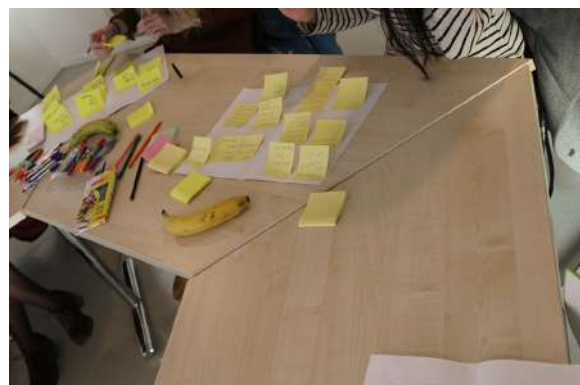
Rivierduinen Ursula clinic Time: 14:00 – 15:30

Me

Patient 1

Patient 2

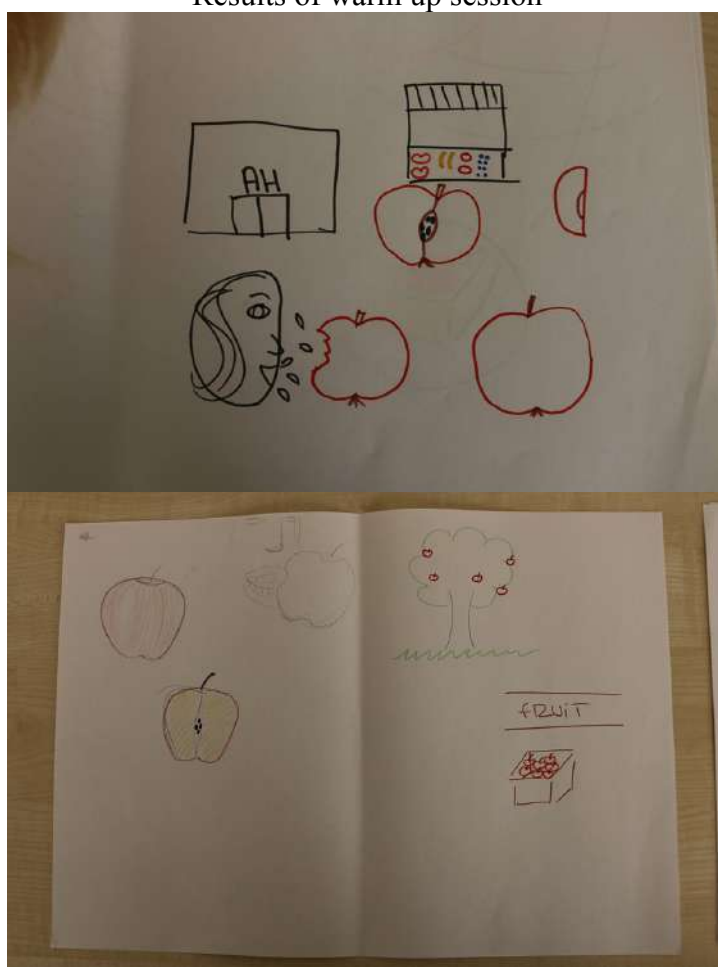
Patient 3



### #1

Me: Thanks for coming to workshop, this is about an eating disorder treatment tool development. I'm doing design graduation research now.

- **Explanation time 5 mins –**
  - **Warm up session: I'm an alien, what's an apple? 6 mins –**
- Results of warm up session





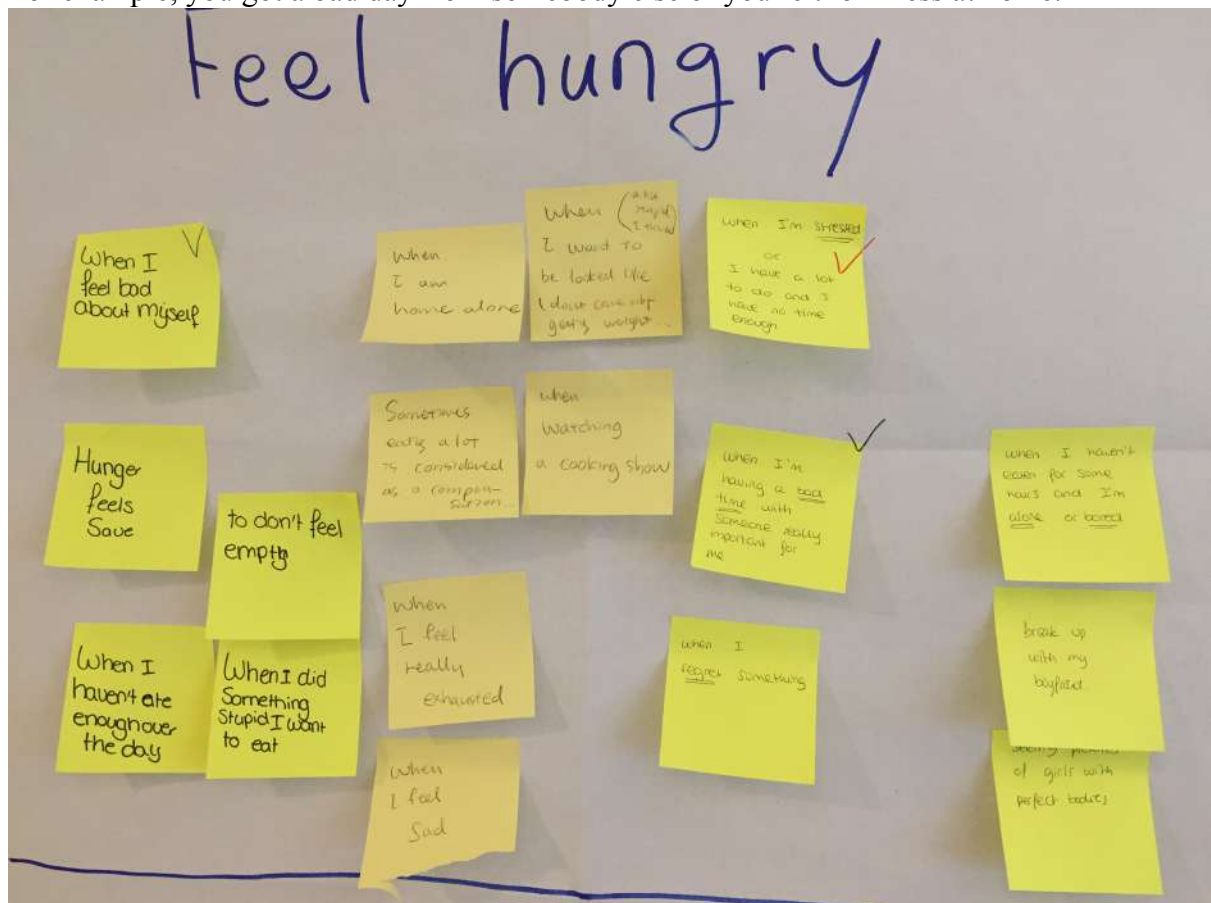
## - Agile UX sketching and scrum session 45 mins -

Inputs defining time ; total 15 mins

#2

Me: When, where and what kind of situations you **feel hungry?**

For example, you got a bad day from somebody else or you felt loneliness at home.

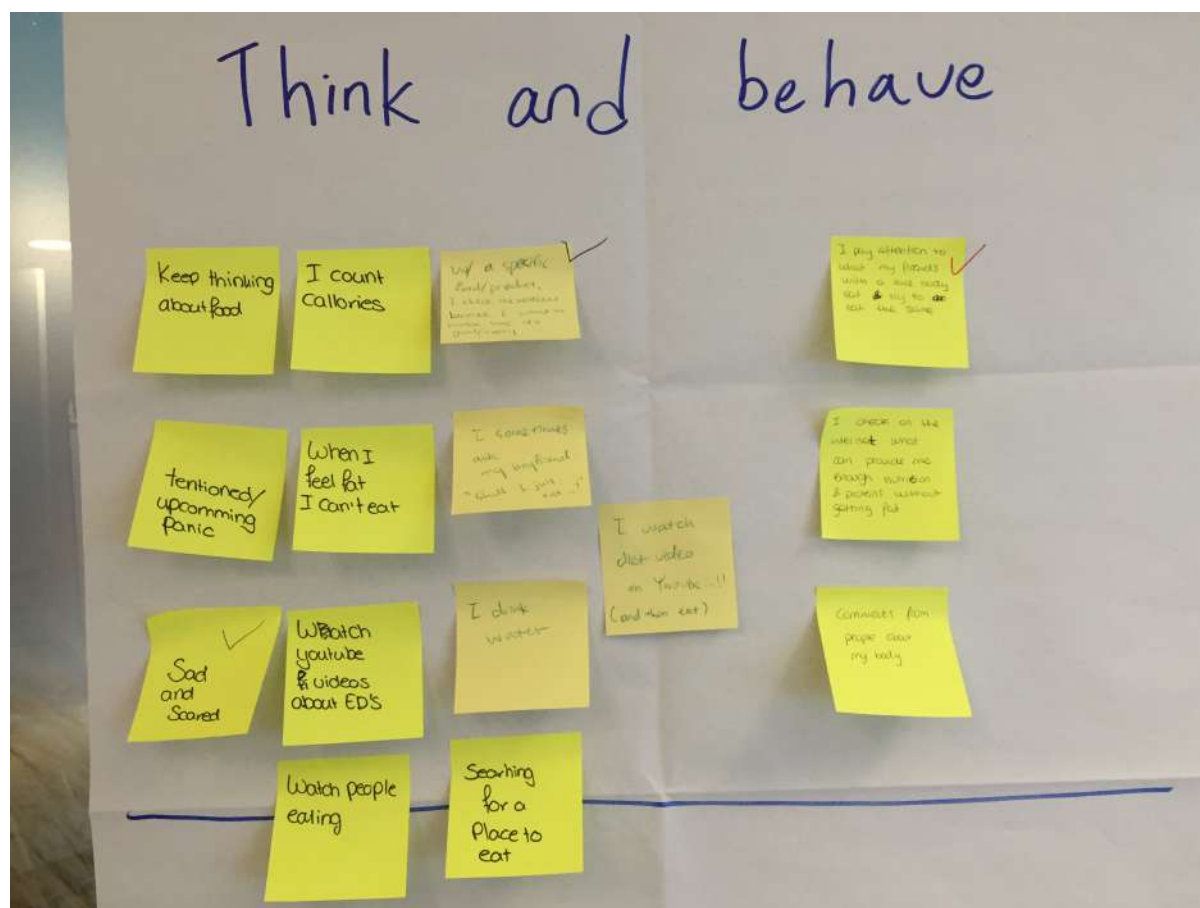


When I feel bad about myself  
Hunger feels save  
When I haven't ate enough for the day

To don't feel empty  
When I did something stupid  
When I'm home alone  
Eating for compensation  
When I feel really exhausted  
When I feel sad  
When I want to be looked like I don't care about getting weight  
When I watch cooking show  
When I'm stressed (there is something a lot to do)  
When I'm having a bad time with someone really important for me  
When I regret something  
When I haven't eaten for some hours  
When I'm bored  
Seeing pictures of girls with perfect body

#3

Me: **What do/did you think and behave before you eat something (take action)?**  
(ex. Checking calories)



Keep thinking about food  
Tensioned/ upcoming panic  
Sad and scared  
I count calories  
When I feel fat I can't eat

Watch youtube video's about Eds  
Check the review of the specific food product (good/tasty)  
I sometimes ask to my boyfriend "shall I just eat?"  
I drink water  
Watch people eating  
Searching for a place to eat  
I pay attention to what my friends with a nice body eat and try to eat the same  
Check what can provide me enough nutrition and portions without getting fat  
Comments from people about my body

#### #4

Me: Where, when and what kind of situations **you eat something?**

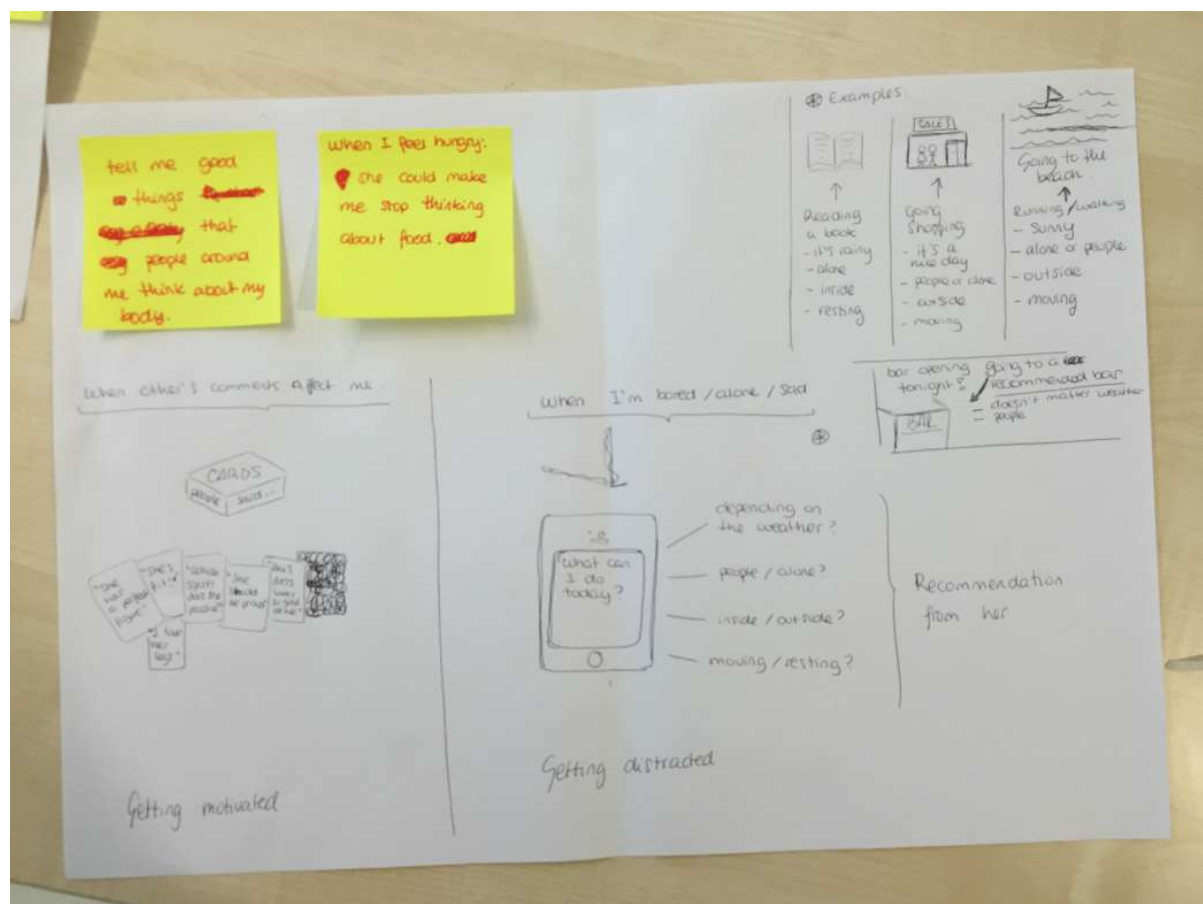


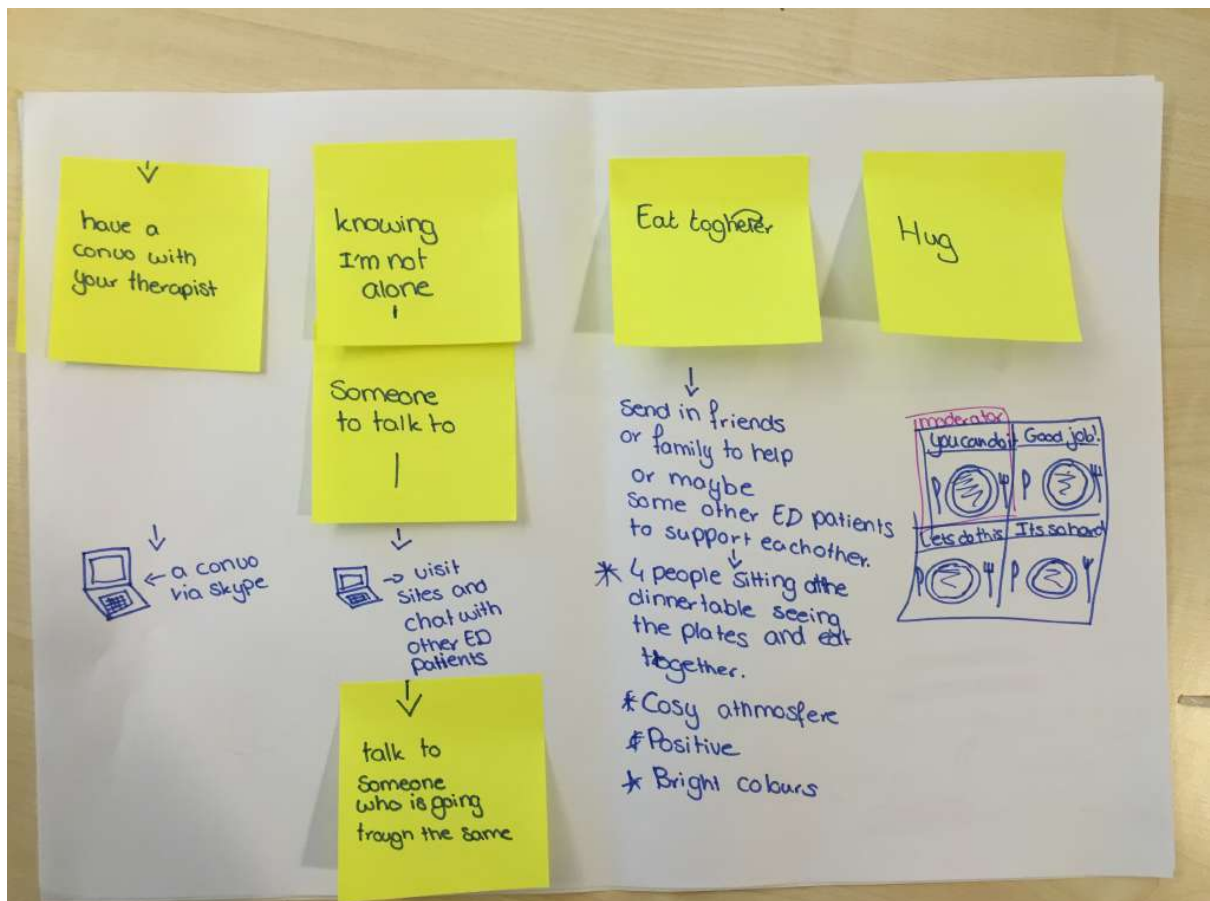
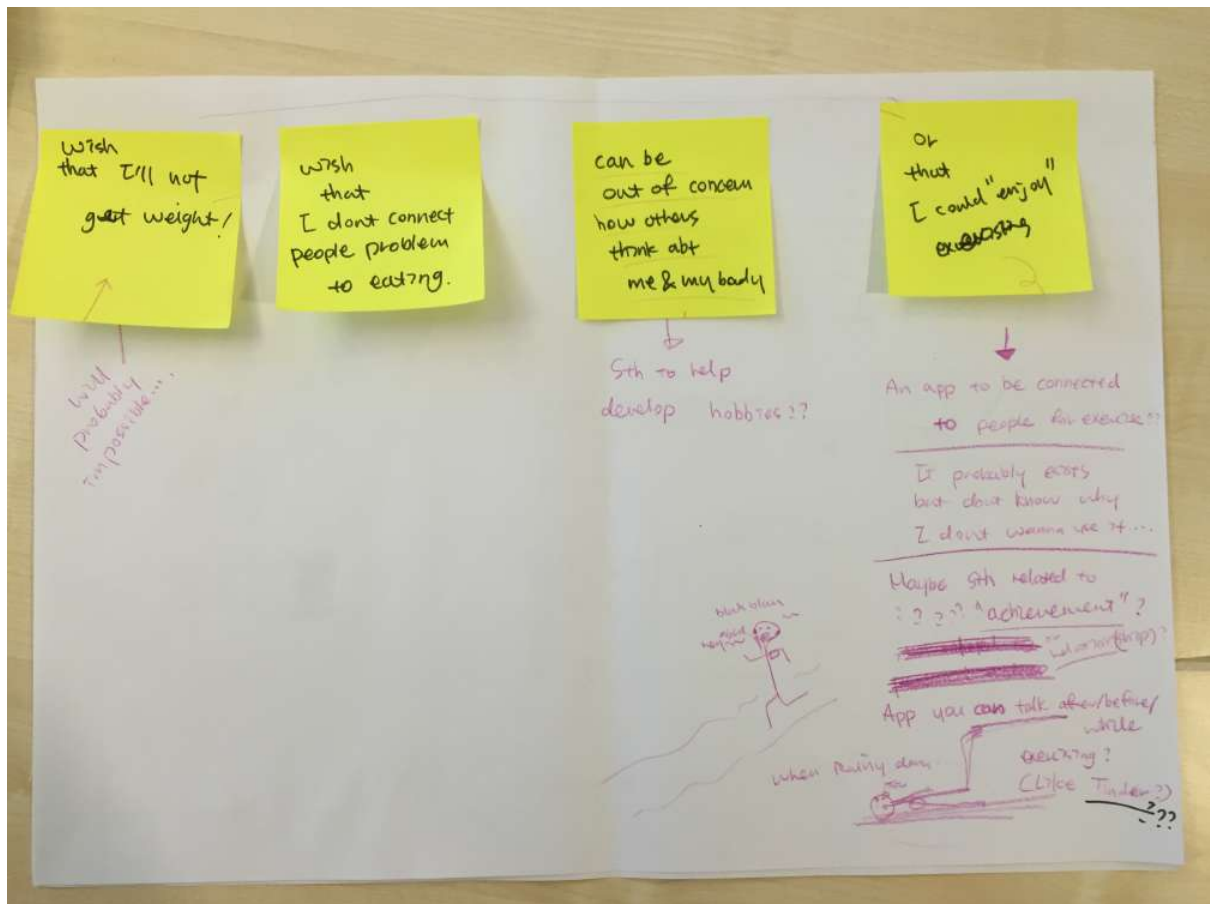
Guilt  
Stop eating  
Binging -> purging  
When I'm with a lot of people, I can't eat  
Fruit like kiwi, watermelon  
Jut tea and water  
Instant noodle at night  
Left over from dinner  
Depending on how I feel, it can be something really fat or just a kiwi  
Eat yogurt but no milk  
Eat something with less calories  
Ric+Chicken or vegetables or soup

#5

Me: If there is a magic, or fairy, how it could help patients to solve and help the situations what they chose?

And, if there is no fairy or magic but you have to do with something in reality that could help you to solve your wishes. What kind of tool could help your wishes?





## #6

Transcript discussion Agile UX sketching and scrum session

1 About conversation through skype idea

2 Patient 2: It can get therapist and friends. This is Skype sessions. Chatting also. People support each other.

3 Me: Can you maybe add more details on your idea? Like do you want to see face of them or sitting on a chair?

4 Me: 'Wish that I'll not get weight' is impossible to solve? It's possible, if you imagine. I'll help you maybe, you can meet your own personal trainer in your room.

5 Patient 1: Ok, let me think about more. And my another idea is for how can I enjoy exercise.

6 Me: Enjoying exercise?

7 Patient 1: Yeah,

8 Patient 3: My idea is when I don't like my legs and I don't want people say something about them, I wish there is a collection of cards with people's positive comments about my body. Or voice from someone you don't know

9 Patient 3: And another idea is when I feel hungry and if I think there is something that could stop thinking about food, there is an AI (Artificial Intelligent) app that could decide what I can do today. That AI app could suggest or make a decision for myself what I can do with details (Ex. Hey, it's good evening there is a good bar so you could chill and have a good mood.)

10 Me: Four people are sitting on a dinner table?

11 Patient 2: Yeah, it's on the computer screen. This is virtual actually you see. You don't see the faces. You just only see the meal of people. And you can put support messages to each other.

12 Me: Supporting message, also people can see on the screen?

13 Patient 2 : Yeah, so we can all see and support each other.

14 Me: Do you think you need a guide? And do you think they should appear also?

15 Patient 2: Yeah, maybe one of the screen they show on.

16 Patient 1: On my idea, I'm running while I'm talking. And I can do exercise with people I know a bit by seeing their profile online. I also got some ideas from the apps that you can loose weight (Ex. Bootcamp diet).

17 Patient 3: Tinder for workout (Hi, now I'm doing this this kind of exercise and do you wanna join with me and check the status through online?).

18 Everybody: Yeah, exactly haha

19 Me: When do you think it's good time for eating together? For me, I often feel bingeing food around 15:00 ~ 15:30.

20 Patient 3: Probably dinner time with warm meal.

21 Patient 1: I'll also go for dinner, because for lunch you have to move around and you also could control a bit after eating dinner together.

22 Patient 3: I don't want to eat that much in the lunch time because weather often affects to me. I don't want to feel I'm sweating after eating a lot and running during the lunch time. I'm from Spain.

23 Me: One more question is, do you think people will like to hear other's voice when they eat together?

24 Patient 2: I think yes, it's more good.

25 Everybody: After getting to know more, then seeing face will be Ok. Because this could be the one time session.

26 Patient 1: Also, something that could recommend something to do like hobbies.

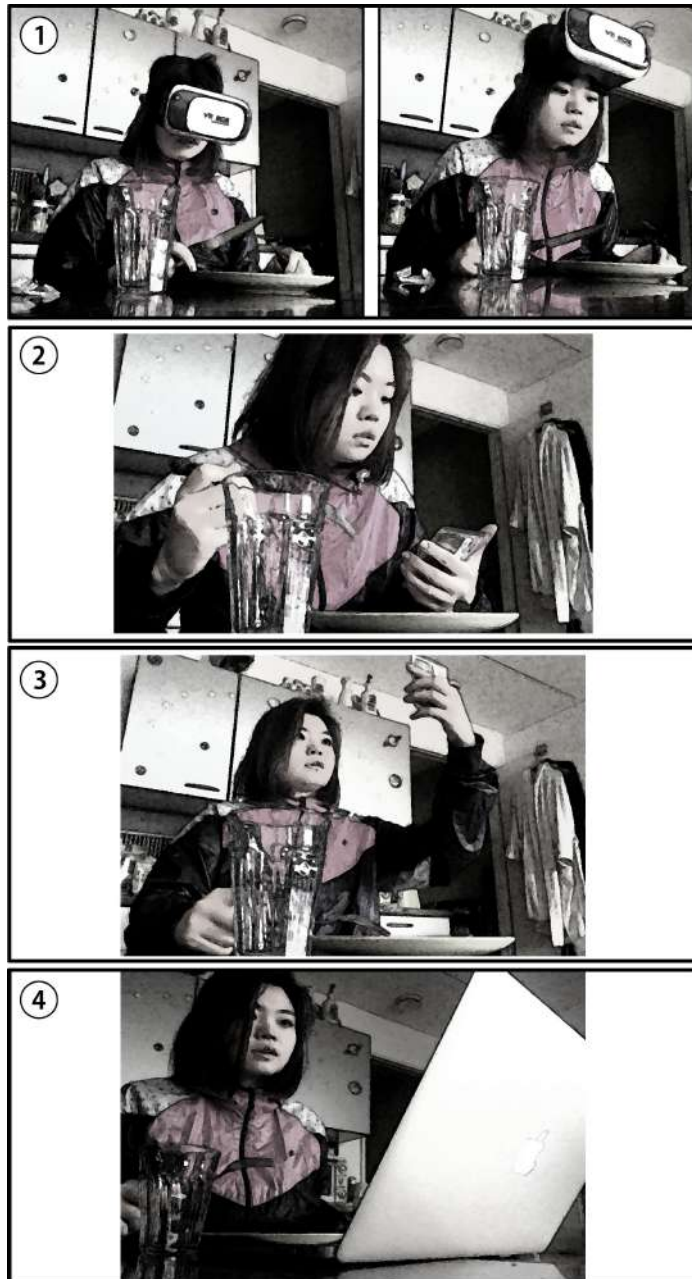
#7

### Technology review session

Tested

Virtual reality glasses, Cardboard glasses, Virtual reality on phone and Skype

### Expected scenario



#8

Opinions from people

### VR glasses



It isn't that heavy, wearing band is a bit uncomfortable and strange.

How can I wear this while eating?

If I could control video by myself, then it could be ok to see.

It's ok.

I want to use this before I eat.

### Cardboard glasses

I think this would be uncomfortable when I continue the eating session more than one time.

The edge of cardboard is too sharp.

For short time, it can be solution but during the whole session it will be uncomfortable.

### VR video on phone



How do they record this?

It's crazy to see through this.

I couldn't use this in the café. People will think it's strange that I'm using in there.

Eating at home, it will be ok.

### Skype

You don't need to buy extra kit.

You can do everywhere, even if you are not at home.

When connection is not very good, it becomes a problem often.