



# MUMMIBODIES. EATING DISORDERS, PREGNANCY AND POSTPARTUM.

1st of May 2020. VERSION 3.

## STUDY PROTOCOL

Approved by REGINAL COMMITTEES FOR  
MEDICAL AND HEALTH RESEARCH ETHICS  
(REC) 20<sup>th</sup> of May 2020, Reference 92665



## **Mummibodies**

### **Eating disorders, pregnancy and postpartum period**

A qualitative Study of Women With eating Disorders in Pregnancy and Post-Partum Period

#### **Background**

The purpose of this study is to gain better knowledge about how pregnancy and postpartum are experienced by women with eating disorders. There are well-known risks in people with eating disorders both during and after pregnancy (1, 2) and an increased risk of relapse (2). The strength of the study is the inclusion of users' own experience. It is necessary that health professionals understand the experiences of pregnant and new mothers with an eating disorder. This knowledge will form the basis for later development of adapted help and follow-up. The study will identify the course and experiences when women with eating disorders encounter pregnancy and childbirth. We will study three areas: 1) pregnant women and mothers' subjective experiences of the course and change in relation to food, body and weight during pregnancy and postpartum; 2) women's subjective experiences of emotional, cognitive and relational core experiences during and after pregnancy; and 3) women's own perceptions of what is the best help through pregnancy and childbirth.

Pregnancy and childbirth represent a major challenge for women with eating disorders. The body's shape, scope and functions change. Strange appetites can occur. The woman is often presented with a number of advices on diet and exercise. Eventually, breastfeeding will begin where the baby sucks nutrients out of the woman's own body. The woman's experience of her own body and the way she handles these changes can affect her care and be a risk factor for the newborn's development both physically and mentally. Studies show that low weight and poor nutrition during pregnancy can lead to premature birth (3-5), low birth weight (3-7) or cardiovascular malformations in the baby (4-7). Other studies show that mothers with eating disorders have difficulty breastfeeding and challenges related to the transition to solid foods (5,8,9,10,11). Several studies describe that postpartum depression occurs more frequently in women who have or have had an eating disorder (1, 5, 11, 12).

The risk of getting worse appears to be high after birth (1, 2, 12-15). Eight to ten months after birth, a Swedish study found an eating disorder in 11 percent of mothers (13). Another Swedish study found 5.2 percent in 10-12. week in pregnancy, which then increased to 12.8 percent 8-10 months after birth (15). The incidence of eating disorders among pregnant women is significantly higher than previously thought and increases throughout childbirth.

We know too little about how women with eating disorders relate to their body and food during and after pregnancy. What is the woman's relationship with the body in the "fourth trimester"? It has been documented that women with a previous eating disorder experience great difficulty with the physical changes during both pregnancy and childbirth (1, 2). Body dissatisfaction plays a crucial role in both the development and maintenance of eating disorders (16). Results from existing research are somewhat varied, but give a strong indication that pregnancy is associated with increased body dissatisfaction and recurrence of symptoms in those who have previously had an eating disorder (2, 14, 17, 18). Probably the eating problems take several paths through pregnancy and childbirth. Clinical experience and some studies suggest that in some cases, eating problems will decrease during pregnancy (15). For many, these positive changes seem to be temporary. Scientifically, we know far too little about these processes and whether the positive change with better help could have been lasting.

There is a great need for research that promotes expertise on how to understand and help women with eating disorders during pregnancy and in childbirth. Vestre Aker Health station contacted the Department of Eating Disorders because they experience increased concern and dangerous practices related to body image and self-image in pregnant and new mothers. Nurses and midwives believe they lack expertise in the field. They say they do not address this. They are afraid of making mistakes and hurt worse (personal communication, Leader at Vestre Aker health station).

Measures that ensure high motivation and good follow-up should preferably be based on the woman's own motivated motivation (19-22), be individually adapted (19, 23) and preferably harmonize with - at least not come into conflict with - what the woman herself thinks will be the best help for herself and the child. This presupposes in-depth knowledge of how the eating problems through pregnancy and childbirth look from the woman's point of view. We need to know how she perceives the process. We need to know how she experiences and reacts to the changes in her body, appetite and weight. And we need to know what the woman herself thinks would have helped her and the baby best through these periods. Today we lack scientific knowledge on all these topics. Both clinicians and researchers therefore recommend that health authorities pay greater attention to the importance of eating problems during pregnancy and childbirth (24).

### **Aim**

To promote understanding of how pregnancy and childbirth are experienced by women with eating disorders in order to prevent relapse and develop measures for this vulnerable group.

### **Research questions**

We have formulated three key research questions.

1. Can characteristic processes be identified in relation to their own body, food and weight when women with eating disorders encounter pregnancy and childbirth? Here we will try to identify and describe different prototypical processes, any common features, characteristic separators and drivers.  
Delivery: Empirically based hypothetical model for prototypical processes.
2. Can it be identified that clinically or preventively important cognitive, emotional, behavioral and relational core experiences that the woman herself believes have been central in determining the course? believes has been critical of the course of the eating problems during pregnancy and during childbirth.  
Delivery: Categorization, characterization, identification of possible dimensions and experiential descriptions of assumed critical, typical and atypical experiences.
3. Can measures be identified that the woman herself believes have or would have led to her eating disorder having a less negative, possibly more positive, development during pregnancy and childbirth? Here we will describe what the women themselves as reflected as possible believe have helped and would have helped them.  
Delivery: Linked to the various identified processes and critical experiences, a list of potential measures that women themselves believe will contribute to better development for women, infants and immediate family.

## Method

### Design

The epistemological approach is empirical realism (not constructivist) where we assume that experiences are real and that the woman is an expert on her own experience. The strategy is to utilize the woman's experience as a source of knowledge. The point of view is the woman's, where we try to formulate, categorize, characterize and analyze dimensions in eating problems in the face of pregnancy and childbirth as the woman sees it.

There are three reasons for this choice: (1) The woman's experience is an underused source of knowledge in this area. (2) Therapeutic and indicated preventive measures are dependent on an alliance with the woman. Alliance formation is normally based on the woman's experience. (3) The woman's subjective presentation of the course may deviate from what an external observer would have reported. The measures the women themselves launch may run counter to what research and experienced clinicians recommend. But objective measures that neglect the user's own experience are unlikely to have a particularly lasting effect.

The issues require two qualitative research designs. For the first problem, we will use the method Grounded Theory (25, 26) because the purpose is to model processes. Grounded Theory is a method for developing concepts and theoretical understandings that are rooted in data through theoretical sampling, identification of similarities and differences between categories, open coding and focused coding. The aim is to construct a theoretical model for characteristic processes, anchored in empirical data from informants in the study. For the other two issues, we will use the method Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research method that is particularly suitable for psychological topics (27). The aim of IPA is to analyze and systematize the informants' experience and understanding of a phenomenon. Through this method, overall meaningful themes can be identified. At the same time, one can bring out nuances and variation in the material and look for any dimensions in the experiences.

### Reference group: User representatives as co-researchers

In the pre-project phase, we will establish a reference group with relevant personal experience. In collaboration with the user organizations Counseling on Eating Disorders and the Eating Disorders Association, we have recruited a group of mothers who have had or have an eating disorder. The focus will be on experiences they themselves have had during and after pregnancy. The purpose is to get input to the interview guide and help to later validate the results. Research questions, analyzes and results will be discussed with the group during and finally during the project period.

### Informants

We will use a heterogeneous sample. This has several causes. We currently know too little scientific to identify one scientifically and clinically interesting homogeneous group. Our clinical experience indicates that there can be great variation between different women in this life situation. In this round, we seek to identify different experiences one may have. Varied diagnoses have been chosen because we want to describe different courses, because these diagnoses are often unstable, and because we want to identify possible measures with different experiences and courses. Such diversity has great clinical relevance and has not been previously described scientifically. In practice, it facilitates the recruitment of informants. A disadvantage of using a heterogeneous sample is that each individual informant becomes relatively important. This is a small problem as long as the purpose is to identify different

experiences. The limitation lies in the cases where a supposedly important experience is described in only one or very few informants and at the same time there is basically little depth and nuance in the descriptions. This is compensated to some extent by very high demands on the quality of the way we interview the informants. We know that some of those who have an eating disorder during childbirth may not have shown a symptomatic level during pregnancy. There can be many, and maybe even mean a different problem. Therefore, we have defined two groups of informants. We define one group of informants in pregnancy and follow longitudinally with two measurement times: in pregnancy and after birth. Another group of informants is defined after birth and interviewed about current and past experiences.

The number of informants for problem 1 will be determined on the basis of a saturation criterion where we include informants until after at least ten interviews, three subsequent interviews follow which do not add anything significantly new to the answer to the problems (30). Based on previous experience with similar surveys, the number of informants for each issue is expected to be somewhere around 20 informants, ie about 40 informants. From these, a strategic choice will be made on issues 2 and 3. Strategic choice can mean looking for differences in order to obtain different prototype experiences. Recruitment of informants will take place continuously from the start of the project via a network. The project period has been extended to four years to get a sufficient number of informants.

Before further inclusion in the study, eating disorders are mapped with a revised version of the Eating Disorders Examination Questionnaire, EDE-Q adapted to pregnant women and women immediately after birth (16). The form is scored by the research fellow before further inclusion. EDE-Q is a self-completion form based on the "Eating Disorder Examination" (EDE) interview. EDE-Q measures the core symptoms of eating disorders. EDE-Q adapted to pregnant women and women immediately after birth is based on factor analysis. If the informant satisfies diagnostic criteria for a cut-off equivalent to  $\geq 2.8$  for an eating disorder, we will conduct a researcher-based interview, Eating Disorder Examination (EDE), for diagnosing the informant, and obtain standard background information. EDE is designed to assess the current condition, as well as to generate an operationalized defined eating disorder diagnosis. The interview is conducted after the experience interview.

The informants' background will be thoroughly documented. Background information will include data on age, gender, diagnosis, type of eating disorder, weight before, during and after pregnancy, onset of illness, first contact with the support system, relationships, first-time or multiple births. Background information is filled in by interviews after the experience interview.

Inclusion criteria will be that the woman is aged 20-40 and satisfies diagnostic criteria for anorexia nervosa, bulimia nervosa, overeating disorder or unspecified eating disorder (DSM-5). Exclusion Criteria will be people with additional problems related to ongoing psychosis, drug addiction or organic brain damage / disease because this will make it difficult to answer the research questions in this study.

### **Data collections**

Information about the project will be disseminated, both orally and in writing via the network (see below). Before further inclusion in the study, eating disorders are mapped with a revised version of the Eating Disorders Examination Questionnaire, EDE-Q (28, 29) adapted to pregnant women and women immediately after birth (16). The questionnaire is completed by the informant with a representative from the network. The form is scored by the research

fellow before further inclusion. EDE-Q is a self-completion form based on the interview "Eating Disorder Examination" (EDE). EDE-Q measures the core symptoms of eating disorders. EDE-Q adapted to pregnant women and women immediately after birth is based on factor analysis (15). If the informant satisfies diagnostic criteria for a cut-off equivalent to  $\geq 2.8$  for an eating disorder, we will conduct a researcher-based interview, Eating Disorder Examination (EDE), for diagnosing the informant, and obtain standard background information. EDE is designed to assess the current condition, as well as to generate an operationalized defined eating disorder diagnosis. The interview is conducted after the experience interview.

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Information about the issues is collected through a semi-structured, interactive face-to-face interview. The aim of the interviews is to get descriptions as precise and close to the participants' own experiences as possible. A semi-structured interview guide is designed in advance. The Interview Guide is developed in close collaboration with user representatives in the reference group and ensures that relevant input from the reference group is covered in the interview. The interview guide contains all the topics we want the interview to cover in advance. The interview guide is primarily a thematic guide and aims to prepare interviews as an instrument. It is also used as a summary and checklist for interviews at the end of the interview to ensure that all relevant topics are touched upon. The informants are thoroughly informed in advance about what the interview will be about and why, and how it will proceed. The better informed the informant is in advance, the better founded the voluntary participation. The actual interview takes the form of improvisation on the topics as it is natural from the dynamics that develop in the conversation. The informant can introduce their own relevant topics independently of the interview guide. The supervisors have published a double-digit number of scientific articles and trained thousands of clinicians and researchers with this method, which is informally called the "Experience Interview" developed by Arne Holte (19, 21-23). The interviews are quality assured by a professional who is not directly involved, continuously listening through randomly selected sections of randomly selected interviews and providing guiding comments. The purpose of this is to ensure that consistency and validity in the interview format is maintained.

### **Data-analyze**

All interviews are transcribed verbatim, stored, organized, coded and analyzed in the electronic software NVivo version 11. Data for problem 1 will be analyzed according to the Grounded Theory method (25, 26). The analysis involves eight phases such as categories, theoretical sampling, identification of similarities and differences between categories, open coding, focused coding, negative case analysis, theoretical sensitivity, theoretical sampling, theoretical saturation, memo writing. The analysis will be regularly discussed in the research group and continuously monitored by the main supervisor to ensure reliability and credibility. Data for issues 2 and 3 will be analyzed according to the IPA method (27). Repeated listening and reading of each interview is carried out to get an overview and context. Each text is then explored using open thematic coding according to the "bottom-up principle". Each interview is divided into text excerpts that are given a definition based on the content of meaning and

distributed in a tree structure. The definitions of potential constructions are finally tested against the text by confirmation and selective coding according to the "top-down principle".

Validation of the results will take place through focus group interviews with informants from the survey with varying stories. The number and selection of focus group participants depends on the results. The participants will be briefly presented in advance with the most important results in writing. The results will then be presented orally to the group. The group will be asked to comment on the presentations. The purpose is to investigate whether the informants recognize their experiences as they have been analyzed, presented and illustrated, and possibly adjust and correct this. We make audio recordings of the focus group interview so that a person who is not directly involved in the project will listen through and check the conclusions the research fellow makes from the focus group interview.

### **Procedure**

The informants will be asked orally and in writing for consent to participate as described above: EDE-Q, EDE interview, "Experience interview" with audio recording, summary check according to interview guide and background information. Based on previous experience, the experience interview is expected to take 90-120 minutes. Total time spent per informant is calculated for a total of 140-180 minutes of interview hours (EDE interview, experience interview and background interview). The text is printed verbatim and stored electronically in NVivo 11. Audio recordings are deleted immediately after electronic storage. The electronically stored text is deidentified so that names and other clear characteristics cannot be recognized. After the data has been analyzed and before the completion of articles, validation is carried out using focus group methodology. All data is deleted when the survey is completed in accordance with the agreement with REK.

### **Organization –cooperations**

The project will have academic, professional and administrative roots at the non-profit foundation Department of Eating Disorders / Villa SULT (Sommerfeldt, Skårderud, Clinton). The project is also affiliated with the Department of Psychology, University of Oslo (Holte). Department of Eating Disorders / Villa SULT has strong clinical and academic expertise in the area. The choice of supervisors covers different aspects of the project. All three supervisors have cutting-edge expertise in qualitative research. If the main supervisor cannot complete the main supervisor role, Skårderud will take over as main supervisor.

PhD candidate: Psychologist specialist Bente Sommerfeldt has broad health professional and clinical expertise and cutting-edge expertise in the treatment of eating disorders. Sommerfeldt currently works at the Department of Eating Disorders as a professional director and clinical psychologist. She is a co-author of several articles and textbooks. She has communication skills and has given a number of courses, educations, lectures and supervised a number of departments within child welfare, child and family services, psychiatry and intoxication on eating disorders, mentalization, parental mentalization and treatment, both nationally and internationally. See CV.

Main supervisor: Professor of Health Psychology (UiO) Arne Holte is previously a full professor of Health Psychology (UiO), Clinical and Personality Psychology (UiT) and Medical Behavioral Sciences (Med. Fac. UiO). He is one of the country's foremost experts on prevention and on advanced qualitative research methods. He has more than 140 international publications, 10 of which are qualitative studies of eating disorders, H-rating 28. Holte has supervised 16 completed doctoral degrees, as well as one in progress, in Norway and the USA

and a three-digit number of master's and master's degree candidates. Holte is still a very active researcher and research communicator. Holte's main role will be to guide on method in all stages of the process, as well as to guide scientific writing and ensure progress.

Co-supervisor I: Professor, Ph.D. with Finn Skårderud is a psychiatrist, founder of Villa SULT and professor at the Norwegian Sports Academy. Skårderud has a doctorate in a series of qualitative studies of eating disorders. He is an internationally recognized expert on eating disorders with a large international network in both treatment and research in the field. He has supervised 11 completed doctoral degrees and has been an opponent in a number. He has supervised two completed PhD projects on mental illness and early parenthood. He is on the Editorial Board of the Journal of Eating Disorders. Skårderud's main role will be to guide on eating disorders, monitor the interview processes and interpretation of data.

Co-supervisor II: Psychologist specialist, Dr. psych Ingela Kvaalem is a psychologist and researcher at Oslo University Hospital.

We have established a network that will collaborate in the form of recruitment, implementation and dissemination throughout the project period. The network is a direct collaboration with the users themselves. The network includes:

- Foundation Institute for Eating Disorders, Villa SULT ([www.spiseforstyrrelser.no](http://www.spiseforstyrrelser.no)). The doctoral candidate Sommerfeldt and supervisor Skårderud are affiliated with Villa SULT.
- The health station Vestre Aker has entered into a collaboration with Villa SULT because they want increased competence in the field.
- Advice on eating disorders (ROS), [www.nettros.no](http://www.nettros.no).
- The Eating Disorders Association (SPISFO), [www.spisfo.no](http://www.spisfo.no).

### **Time schedule**

**Before project start (December 2019):** The reference group is contacted. Literature search and review. Apply for funding. Develop and test data collection procedures and methods. Reference group meetings.

**By funding (2020):** Apply for admission to a doctoral program at the Department of Psychology, UiO. Apply for approval REK. Register the study in [clinicaltrials.gov](http://clinicaltrials.gov).

**First period (Spring 2020):** Updating literature. Include mothers. Data collection before birth. Data collection after birth to group 2. Processing and coding of data continuously. Reference group meetings. Write the first draft of the introduction and method section of articles.

**Second period (Autumn 2020 / Spring 2021):** Follow literature. Further data collection before birth and start data collection after birth for group 1. Data processing, coding and analysis. Reference group meetings. Adjust article drafts.

**Third period (Autumn 2021 / Spring 2022):** Complete data collection after birth to group 1. Continued data processing, coding and analysis. Reference group meetings. Article draft adjustment.

**Fourth period (Autumn 2022 / Spring 23):** Reference group meetings. Focus group interview, final writing and publication of articles.

**Fifth period (Autumn 2023):** After completing a doctorate: Academic and popular communication.

### **Publishing**

**Scientific.** We will publish three scientific articles that are sent to "open access" journals registered with the Directory of open access journals (DOAJ) such as the Journal of Eating Disorders, the European Eating Disorder Review or equivalent international journals.

Working titles:

1. *Trajectories of eating disorders through pregnancy, birth and early motherhood.*
2. *Eating disorder and emerging motherhood: Emotional, cognitive and relational experiences.*
3. *Helping women with eating disorders during emerging motherhood: Perceptions and experiences of support.*

**Other.** The Department of Eating Disorders / Villa Sult will produce videos that are posted on websites, Facebook and distributed via the network described above. We will write an article on the topic of the Norwegian Journal of Nursing Research and the Journal of Midwives, and an article in the Journal of the Norwegian Medical Association. We will try to get the most important results into Nordic textbooks in gynecology and obstetrics. We will offer lectures and courses on the topic of medical education at the University of Oslo and we will offer the Norwegian Directorate of Health text for a brochure that can be posted in GPs' waiting rooms and at health stations. Workshops, conferences and educations will be developed and implemented.

**Media.** The videos will be open and accessible to everyone. We will inform about this in various Facebook groups and central channels such as Podcasts such as "Foreldrepodden", "Babyverden" ".:.". Through these forums, we will reach both the general public and various relevant user groups. In addition, we will offer a column and interviews to the Norwegian media where some of the supervisors are well known.

#### **Etichs: Etske betraktninger og godkjennelser**

The study is approved by the Regional Committee for Medical and Health Research Ethics (REK). Ethical reflections permeate the entire research process. Participation is voluntary. A well-understood information letter is presented to the informants. For other advance information, see Data Collection above. We follow the usual rules for informed written consent, withdrawal, deletion of material, de-identification and assessment of the consequences of participation.

Researching mothers' thoughts and experiences about their own health, body and self-image requires a high level of ethical awareness in the meeting with the informants themselves, as well as interview and text material. The theme of this project is occasionally sensitive. All participants in the project group are regulated by their respective professions' legislation on ethical conduct. The project group's clinical experience and experience with similar projects is as far as possible a guarantee for a safe and respectful situation where mothers can feel safe sharing personal information and talking about sensitive topics. Experiential conversations about difficult experiences in life can activate difficult thoughts and feelings. This requires professionalism from the researchers. This is taken care of by the fact that the interviewer is a specialist in clinical psychology with extensive experience in dealing with eating disorders and in that all the supervisors are very experienced with this type of conversation. Informants will not be their own patients.

Audio recording involves significant amounts of potentially personally identifiable material. All audio files are transcribed immediately and deleted after transcription and electronic loading. Before electronic loading, we will change personal names and all other easily identifiable characteristics. Should there exceptionally occur delays between interview and transcription or transcription and electronic loading, the data material is stored in a locked burglar-proof safe in Villa Sult. All findings published are anonymised. Quotes in published text will not be able to be linked to a person.

### **Budget and financial plan**

Due to the project's time frame, it is desired that the project funds be spread over four years from January 2020 to December 2023 to ensure a sufficient number of informants and time to conduct interviews six months after birth (measurement T2). We are mainly applying for salary for a three-year PhD position spread over four years (75% position) for psychologist specialist Bente Sommerfeldt with a view to qualifying for the academic title PhD. See attached budget in application form.

### **Vitenskapelig betydning og praktisk nytteverdi**

#### **Scientific utility**

As described several times here, this is by far an unexplored field. The survey will be able to help fill knowledge gaps about birth and the body in the fourth trimester. Closing knowledge gaps and being an initiator and contributor to knowledge development and research on women's health is central to the strategic plan of the Norwegian Women's Health Association and this study could contribute to this. There is an obvious need for more knowledge, and not least knowledge based on the users' own experiences. Thus, this is typically demand-driven research. Research findings will not least clarify issues for further research projects.

#### **Practical utility values**

*Prevention.* The project is especially important because it promotes women's health and living conditions and provides an offer to women in a vulnerable phase of life. The project already complements the Sanitary Women's existing research on eating disorders, the body and the "beauty tyranny" and also pregnancy and postpartum depression (Mamma Mia). Increased knowledge of such phenomena, such as early clinical signs, and what is perceived as useful by the users themselves, opens up opportunities for information, information activities and campaigns. The study will also form an important basis and experience on what can help women to strengthen the bond with the child already from the fetal stage. This applies not least under the auspices of public health stations, user organizations and of organizations such as Sanitetskvinnene and Villa SULT.

*Competence-enhancing measures.* Through research findings, the study will lay the foundation for establishing competence-enhancing measures for health personnel who work with pregnancy, childbirth and childbirth. By placing the user as an expert on their own experiences, the survey will be particularly relevant for competence development among users, relatives and health personnel. Specifically, this means courses and content in educations. An important focus will then be how to promote well-being and health in mother and child during pregnancy and after birth.

*Early intervention.* Knowledge of risk factors and signs will promote security among health professionals to more actively and purposefully ask the woman more directly about the relationship to food, body and weight. Being asked will lead to a lower threshold for

requesting and receiving help from the user himself. It will promote interventions at an earlier stage.

*Better interactions between actors and levels in the health care system.* The pregnant, giving birth and maternity mother necessarily meet many actors in the health care system, such as health stations, midwives, GPs and maternity wards, and occasionally also mental health care. Increased competencies also promote the opportunities for better collaboration and more targeted communication between the various parties involved. This also applies to family members.

*Manualized programs and national guidelines.* The results of the research project as well as experiences that accumulate in its wake will together form a competence basis for further development of these parts of our health care system. This can be expressed in the content of health education and later establishments of local and national guidelines for how these women and their families meet.

*Tidlig intervensjon.* Kunnskap om risikofaktorer og tegn vil fremme trygghet hos helsepersonell til mer aktivt og målrettet spørre kvinnen mer direkte om forholdet til mat, kropp og vekt. Å bli spurt vil føre til en lavere terskel til å be om og ta i mot hjelp fra brukeren selv. Det vil fremme intervensjoner på et tidligere tidspunkt.

*Bedre samhandlinger mellom aktører og nivåer i helsevesenet.* Den gravide, fødende og barselmoren møter nødvendigvis mange aktører i helsevesenet, som helsestasjoner, jordmødre, fastleger og fødeavdelinger, og tidvis også psykisk helsevern. Økte kompetanser fremmer også mulighetene til bedre samhandling og mer målrettet kommunikasjon mellom de forskjellige involverte. Dette gjelder også overfor familiemedlemmer.

*Manualiserte programmer og nasjonale retningslinjer.* Forskningsprosjektets resultater samt erfaringer som akkumuleres i dens kjølvann vil samlet danne et kompetansegrunnlag for videreutvikling av disse delene av vårt helsevesen. Dette kan komme til uttrykk i innhold i helsefaglige utdannelser og senere etableringer av lokale og nasjonale retningslinjer for hvordan møtes disse kvinnene og deres familier.

### **User participation**

We take care of the user perspective as follows:

1. A reference group with eating disorders with children who do not participate in the study participates in the method development. The reference group has been established in collaboration with the user organizations.
2. The very purpose of the survey is to bring out the users' experience. We interview face-to-face, personally pregnant and mothers are interviewed about their subjective experiences.
3. The experience interview is specially designed to cultivate in one's own words, as little as possible influenced by the researcher, precisely the users' own formulations of their feelings, thoughts and experiences.
4. IPA and Grounded Theory are used to refine user experiences and develop models based on these.
5. Focus group interviews are used to validate the findings among the informants before publication.
6. The project is a direct and close collaboration with health stations in Norway (which are users of the results) and two central user organizations for eating disorders. Findings in the project will be discussed with the user organizations during the project period

### Plan for continuation

The study will form the basis for information, information and campaigns at health stations and user organizations of N.K.S and Villa SULT. Increasing the action skills of nurses and midwives is an important next step. Based on knowledge from the study, we will develop a training program for nurses and midwives. The training program can be used at all health stations in Norway via e-learning. Such a program will have a strong focus on how to understand and meet women with eating disorders in a vulnerable phase of life and what can help women to strengthen the bond with the child already from the fetal stage. Based on the results, we will also in collaboration with health stations and user organizations create a guide for health stations on how to meet women with strained relationships with food, body and weight during pregnancy and childbirth. This guide and the training will be an important supplement to the guidelines for maternity care in Norway. The new guidelines for maternity care that came in 2018 have a greater focus on living habits and diet. It is therefore the midwife's task to ask about these topics, but it is probably different from midwife to midwife how she asks. One thing is that health professionals ask how the woman is doing. But just as important is that they know what to do with the answer that comes. Increased competence is in demand. Leader of the midwives' association Kari Aarø has stated that midwives have not been good enough at detecting eating disorders.

The results also form the basis for an intervention program for women with eating disorders who face pregnancy and childbirth. The intervention program will be a low-threshold offer for women with eating disorders during pregnancy and childbirth and a practical and simple tool to use at health stations in Norway.

Relevant further studies after completing the PhD may be on the interaction between mother and child and the relationship.

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