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From Information Delivery to Patient Understanding

A Design Thinking Study of IVF Care Communication

Master's thesis in Industrial Engineering and Management

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SUMMARY
Patient information in fertility care is central to how patients understand, navigate and participate in their treatment. Despite this, information practices in IVF care remain understudied from a human-centered design perspective. This study investigates how patient information is currently created, communicated and experienced across the IVF care pathway at the Reproductive Medicine Division at Sahlgrenska University Hospital, and identifies challenges and breakdowns in the Current information flow.

The study was conducted in parallel with an ongoing innovation initiative, and draws on design thinking as its methodological foundation. Data was collected through thirteen semi-structured interviews with patients and healthcare professionals, a micro-ethnographic orientation including a stimulated patient journey and clinical observations, a participatory session with staff, and complementary sources including quantitative patient satisfaction data, social media and website review.

The findings show that patient information is distributed across a fragmented multichannel landscape without a shared structure for ensuring continuity across the care pathway. Information is often available in technical sense but not always accessible, timely or emotionally aligned with patient's capacity to receive it. Breakdowns in the information flow emerge at the intersection of emotional overwhelm, structural misalignment and inequitable access. Further finding concerns the consistent exclusion of partners from the information process, despite the system formally recognizing the couple as a unit of care.

The study concludes that meaningful improvement in patient information practices require not only clearer content or better communication, but a systematic commitment to designing the information environment around the patient journey. The findings contribute to an understanding of how information practices in IVF care are shaped by organizational and structural conditions, and lay groundwork for the next phase of the ongoing innovation initiative.

Keywords: Patient information, IVF care, health literacy, design thinking, information practices, human-centered design, patient communication, information flow

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Table of Content

List of Figures and Tables

1. Introduction

Recent demographic projections indicate that Sweden is experiencing a continued decline in birth rates alongside an ageing population. In 2024, the total fertility rate reached a historic low of 1.43 children per woman, and the birth rates are expected to remain at similarly low levels in the upcoming year (SCB, 2025).

At the same time, the number of older individuals is expected to increase significantly. By 2030, the population aged 80 and above is expected to rise by more than 160,000 people, contributing to an increased demand for healthcare and elderly services (SCB, 2025). Although the overall population is projected to grow, this growth is expected to occur at a slower pace and driven primarily by migration rather than natural population increase.

These demographic developments imply a shift in the balance between working-age individuals and those in need of welfare services, placing increased pressure on healthcare systems. In this context, supporting individuals and couples seeking fertility treatment becomes increasingly relevant, not only from an individual perspective, but also in relation to broader societal challenges.

This relevance has recently been acknowledged at the political level. In April 2026, the Swedish government proposed, as a part of the spring amendment budget, a significant expansion of publicly funded IVF treatment, with an allocation of 327 million Swedish crowns, and to increase the number of state-financed attempts from three to six (Regeringen, 2026). The proposal reflects a broader recognition that access to fertility care is not merely a medical question but a matter of demographic and social policy. For this reason, receiving and processing information throughout the IVF pathway has become increasingly consequential; expanding the access to treatment without addressing information gaps, risks leaving a growing patient population inadequately supported.

Infertility is a global phenomenon affecting approximately 10-15% of couples, with relatively similar prevalence across different societies. However, the underlying cause of infertility differs depending on the context. In high-income countries like Sweden, increasing age is one of the primary factors contributing, while in other parts of the world infertility is more commonly related to infections or complications from childbirth (Karolinska Institutet, 2025).

At the same time, the demand for assisted reproductive technologies, such as in vitro fertilization (IVF), has increased significantly over time. Advances in medical technology, along with changing social and legal conditions, have made fertility treatments more accessible to a broader range of individuals and couples.

Importantly, infertility is not only a medical condition but associated with psychological and social challenges. Individuals undergoing fertility treatment may experience stress, uncertainty, and emotional strain, particularly in cases involving repeated unsuccessful treatment attempts. This highlights the importance of understanding how fertility care is organized, experienced, particularly in relation to how information is communicated to patients throughout the IVF process.

1.1 Background

IVF is a form of assisted reproductive technology in which fertilization occurs outside the body, followed by the transfer of the embryo into the uterus as a part of the treatment process (1177, 2026). The process typically begins at the Reproductive medicine division to identify the cause for involuntary childlessness and assess whether IVF treatment is appropriate for the patient (Västra Götalandsregion, 2026). The IVF treatment typically involve several stages, including hormonal treatment, egg retrieval, fertilization, and embryo transfer, and requires the patients to engage with healthcare services over an extended period.

In Sweden, the national care guarantee regulates the maximum waiting times patients should experience when seeking publicly funded healthcare. The care guarantee states that patients should receive contact with primary care the same day they seek care, a medical assessment by licensed healthcare personnel within three days, a first visit to specialist care within 90 days if specialist care is deemed necessary, and treatment within 90 days from the decision to treat. The purpose of the care guarantee is to strengthen patients' access to timely care, although patients with the greatest medical need should always be prioritized first (1177 Vårdguiden, 2025a).

If a healthcare provider cannot offer specialist care within the guaranteed time limit, the patient should be offered care at another clinic, either within the same region or in another region. However, the patient cannot freely choose which clinic to be referred to under the care guarantee. Patients also have the right to receive information about how the care guarantee works, expected waiting times, changes in waiting time, and the consequences of different choices while waiting for care (1177 Vårdguiden, 2025a).

Although the care guarantee is intended to ensure timely access to healthcare, access to publicly funded IVF is not determined by waiting times alone. Before treatment can be initiated, patients must also meet specific regional eligibility criteria. This is examined during the fertility investigation, and eligibility may depend on factors such as age, relationship status, and whether the couple has a shared child. For example, in Västra Götaland, treatment is typically offered to individuals or couples who do not have a shared child, meet age requirements, and are considered to have conditions necessary to care for a child (Västra Götalandsregionen, n.d.-a). For couples, additional requirements may include being in a stable, long-term relationship and cohabiting. Furthermore, both medical and psychosocial assessments are conducted as part of the evaluation process.

Patients are typically offered up to three publicly funded IVF attempts. Each attempt refers to a complete treatment cyclic including hormonal stimulation, egg retrieval, fertilization and embryo transfer (1177, 2026). In April 2026, the Swedish government proposed an expansion of this entitlement to six publicly funded attempts (Regeringen 2026). The proposal reflects a national commitment to reducing financial barriers to fertility treatment and is framed explicitly in relation to Sweden's declining birth rate. This expansion would imply an increase in the number of patients entering and navigating the IVF care pathway in the coming years, which in turn amplifies the

importance of ensuring that patient information is structured, accessible and adapted to individual needs.

The most recent annual report from Q-IVF (2025), the national quality registry for assisted reproduction, presents a total of approximately 24,500 treatment cycles that were initiated across the country 2023. Among the clinics participating in this study, figure 1 illustrate the clinics in Gothenburg's numbers: Sahlgrenska University Hospital (SUH) initiated approximately 2,228 cycles, Livio Göteborg approximately 1,254 cycles, Nordic IVF Göteborg approximately 684 cycles, and Göteborgs IVF Klinik approximately 125 cycles during the same year. The figure underscores the volume and complexity of the care pathways through which patients move and situate the present study within a clinical context of considerable scale.

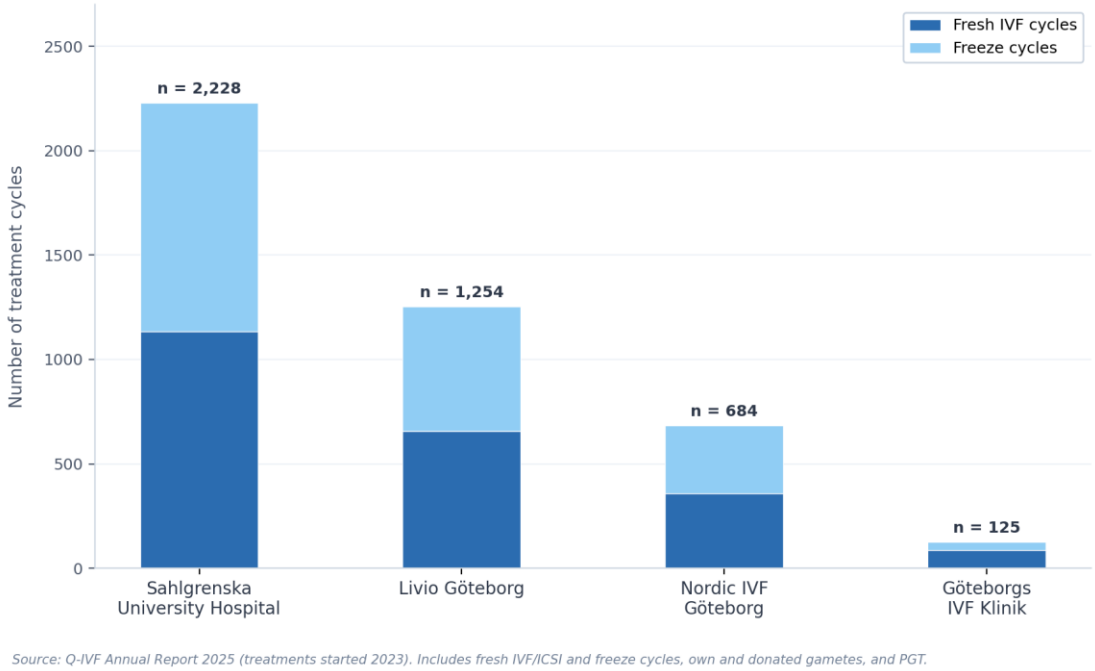


Figure 1 : Total cycle treatments at Gothenburg clinics 2023.

Following the investigation, patients may face waiting times ranging from approximately three months to up to two years before starting their IVF treatment. The waiting time depend on clinical prioritization, including whether the patient's case is assessed as falling under the Swedish healthcare guarantee (1177, 2025a).

Given the complexity of IVF care and the significant role of information throughout the treatment process, patient information constitutes a critical component of IVF services.

1.2 Problem Description

Despite the importance of patient information, several challenges have been identified in the current practice. During the waiting period between assessment and the first treatment-related consultation, patients are often expected to independently seek information regarding IVF care. In addition, patients are provided with verbal information and written information prior to their first IVF consultation with a

physician. This information is intended to provide the patient with general information and an overview of the IVF process.

However, engaging with this information requires patients to understand complex medical concepts, which can be difficult in emotionally demanding situations. Furthermore, as IVF treatment takes place over an extended period, patients are expected to retain and apply information across multiple stages of the process.

At the same time, the IVF journey is often experienced as long and emotionally overwhelming, and many patients might feel unprepared. This leads to repeated questions and misunderstandings, requiring substantial time investments from healthcare professionals. In many cases, these questions concern general information that has already been provided at earlier stages of the care process. As a result, healthcare professionals spend time reiterating standardized information rather than focusing on patient-specific needs and individual concerns. Although the information has been communicated through written and verbal channels, patients continue to seek clarification, for instance through follow-up calls to the Reproductive Medicine division's midwives or administrative staff.

As a result, both patients and healthcare professionals experience inefficiencies within the current information process. The absence of an integrated and pedagogically coherent approach to patient information (one that aligns patient with clinical workflows) results in information loss, repeated work for the clinic, and unmet patient needs. Therefore, this highlights the need for a systematic analysis of how patient information currently is created, communicated, and experienced within IVF care, and how it might be improved.

1.3 Purpose

This study is conducted in parallel with an ongoing innovation initiative funded by the Västra Götaland innovation fund. The purpose of this study is to develop an in-depth understanding of how patient information is created, communicated, and experienced across the IVF care pathway at SUH within the Västra Götaland region. The study aims to identify gaps, information breakdowns, and opportunities for improvement to better support both patients and healthcare professionals and to provide a foundation for recommendations that can guide the innovation initiative in its next steps within the design thinking process.

1.4 Research Questions

To address the purpose, the study is guided by the following questions:

1. How is patient information currently created, communicated, and managed across the IVF care pathway from the patient's perspective?
    - How do patients, healthcare professionals and the organization experience and navigate the current information flow?

- How do different stakeholders present and adapt information to support patient understanding?

2. What challenges and breakdowns can be identified in the current information flow between patients and stakeholders in IVF care?
    - Where do patients and stakeholders experience misunderstandings, repeated questions, and information gaps?
    - What organizational and structural conditions contribute to these challenges?

3. What opportunities for improvement can be identified based on the findings?

The research questions are structured to first establish an understanding of current information practices and subsequently identify challenges and inefficiencies in the information flow. This requires capturing both patient experiences and the perspectives of healthcare professionals involved in communicating IVF-related information.

1.5 Scope

This study draws inspiration from external contexts, including digital solutions and other domains that manage complex information flows. Insights from these contexts are used as analytical input to explore how coordination, communication, and process transparency can be improved within healthcare settings. However, the application of these insights is limited to the IVF-care process at SUH University Hospital's Reproductive Medicine Division. Specifically, the scope of the study focuses on the stage following the completion of the fertility investigation, where patients have received a referral for IVF treatment.

Due to the timeframe of the project and its position within the early phase of a large innovation initiative at SUH, the study focuses on analysis and the development of evidence-based recommendations rather than design or implementation of a complete solution. The aim is to provide a structured understanding of the current process and to generate recommendations that can inform future development work at SUH.

2. Theoretical Framework

This chapter presents the theoretical perspectives that underpin the analysis of patient information practices in IVF care. Drawing on literature within healthcare communication, health literacy, shared decision-making, and human-centered design, the chapter introduces key concepts for understanding how information is created, communicated, and experienced within complex care processes. Together, these perspectives provide a foundation for analyzing challenges related to patient understanding, information flow, and interactions between patients and healthcare professionals. The chapter concludes with an analytical framework that shows how these perspectives work together to guide the analysis.

2.1 Healthcare information practices and professional responsibility

In Sweden, the provision of patient information is not only a practical activity but also a legal obligation. According to Swedish healthcare legislation (Patient Act, 2014:821), patients have the right to receive individually adapted information regarding their health condition, treatment alternatives, risks and expected care processes. This places formal responsibility on healthcare professionals to ensure that information is not only delivered, but comprehensible and meaningful to the patient.

The legislation thus defines a normative standard for patient communication within healthcare. In addition, patients are entitled to timely access to care, which further reinforces the importance of clear and effective communication throughout the healthcare process (1177, 2025). However, the requirement that information should be individually adapted and comprehensible raises important questions about what understanding entails in clinical practice. In particular, the ability of patients to access, interpret, and use health information cannot be assumed. This highlights the need for theoretical perspectives that explain how patients engage with health information.

2.1.1 Health literacy and patient understanding

The concept of health literacy provides a useful lens for understanding how individuals engage with healthcare information. According to Nutbeam (2006), health literacy is defined as cognitive and social skills that determine individuals' ability to gain access to, understand and use health information in ways that promote and support health. Nutbeam (2006) distinguishes between three levels of health literacy: functional health literacy, involving basic skills in reading and understanding health-related materials; interactive health literacy, involving more advanced cognitive and social skills that enable individuals to actively engage wit health professionals; and critical health literacy, representing the ability to critically analyze information and expert greater control over life event and situations.

Extending this perspective, Sørensen et al. (2012) conceptualize health literacy as a set of four interrelated competencies: accessing, understanding, appraising, and applying health information. These dimensions highlight that comprehension is not a

single-step process, but a sequence of cognitive and social activities influenced by both individual capabilities and the quality of communication.

Further, these dimensions illustrate the complexity of comprehension, emphasizing that understanding health information depends on the interaction between logic, language, and prior experience. This interaction is crucial for accurate interpretation of information provided to patients, such as discharge instructions, consent forms, patient education materials, and medication guidelines.

Together, these perspectives emphasize that understanding healthcare information requires more than basic literacy. It involves the ability to engage in dialogue, interpret complex information, and to apply it in emotionally and cognitively demanding contexts. While health literacy explains patients' ability to understand and use information, it primarily focuses on individual capabilities and does not fully account for how information is structured, organized and delivered within healthcare systems.

2.1.2 Shared decision-making in healthcare

While health literacy explains patients' ability to understand information, shared decision-making (SDM) addresses how this information is used in clinical interactions. SDM is defined as an approach in which healthcare professionals and patients share the best available evidence and work together to make decisions that reflect informed patient preferences (Elwyn et al., 2012). This approach moves beyond viewing information as a one-way transmission and instead emphasizes a relational process in which patients are supported to engage with information, deliberate about available options, and express their values and preferences. SDM highlights that patients may experience uncertainty, emotional stress, and difficulty interpreting complex medical information.

As such, the responsibility of healthcare professionals extends beyond providing access to information, toward actively supporting patients in making sense of that information in ways that are meaningful for decision-making. While SDM emphasizes interaction and shared decision-making between patients and healthcare professionals, it does not fully address how information is designed, coordinated, and managed across different stages of the care process.

Together with the preceding perspectives on health literacy and patient motivation, SDM underscores that effective information practices in healthcare are shaped not only by what information is provided, but by conditions such as cognitive, emotional, and relational ones, and how these are received and acted upon.

2.1.3 People-focused healthcare and Motivational Context of Fertility Treatment

Traditionally, healthcare systems have been structured around a biomedical and repair-focused logic, where the primary objective has been to diagnose and treat disease. Focus has, in other words, been to determine what is the matter with the patient (Patrício et al., 2020). In contrast, the concept of people-centred healthcare,

promoted by the World Health Organization (WHO) (2009), calls for a broader understanding of care that goes beyond disease management to consider what matters to the person. This perspective emphasizes attention to physical, cognitive, emotional, and contextual aspects of wellbeing. It represents a shift from focusing solely on illness to acknowledging the individual's lived experience, values, and social situation as integral to care delivery.

This perspective is relevant in the context of fertility treatment, where patients enter care in state of considerable emotional and motivational intensity. Maslow's (1943) theory of human motivation is useful here, not as a comprehensive psychological mode, but for specific insight it offers about unmet needs. Maslow argues that when a deeply felt need remains unfulfilled, it tends to monopolise attention and redirect cognitive capacities toward its fulfilment. As Aanstoos (2024) describes the absence and desire for parenthood is an unmet drive, that occupies the individual's attention. For patients in IVF care, this means that cognitive availability needed to absorb, interpret and retain complex information significantly reduced – not because of a deficit in general capacity, but as a predictable consequence of a deeply activated motivational state. While Maslow's hierarchical model has attracted criticism for being difficult to test empirically and for reflecting individualistic norms, its score insight testing explanatory value for understanding the emotional and motivational vibrations patients bring to the IVF care pathway.

2.2 Human-Centered Approaches to Service Improvement

Traditionally, efforts to improve services have been oriented toward optimizing systems, processes and organizational structures. While such approaches offer efficiency and consistency, they risk overlooking what is most central to service quality: the lived experience of those receiving the services. Rather than asking how a system can be made more efficient, these approaches ask how a service is experienced. This particularly places the perceptions, emotions and needs of users at the heart of improvement efforts.

In the context of IVF care, where patients navigate a complex and emotionally demanding process over an extended period, this orientation is particularly relevant. The following section introduces three related frameworks: design thinking, service design and experience-based co-design. Although distinct in their origins and emphasis, all three are united by a commitment to understanding people's experiences as the starting point for meaningful improvement in service.

2.2.1 Design thinking

Design thinking (DT) has emerged as a widely developed approach to innovation that emphasizes a human-centered perspective on problem solving. As Brown (2008) describes, DT applies designers' sensibilities and practices to align human needs with technological disability and viable business strategies. Rather than focusing solely on predefined outcomes, DT emphasizes the process through which problems are explored, framed and addressed. This makes it particularly relevant in context characterized by uncertainty and complexity, often described as fuzzy front end of innovation (Carlgren et al., 2016).

The Stanford d. School (2010) represents the DT process as five iterative phases: empathize, define, ideate, prototype and test. These phases are not linear but flexible and circular, with insights from later stages often prompting the reframing of earlier assumptions. Carlgren et al. (2016) describe DT as characterized by five core principles: a focus on people, openness to reframing problems, an experimental and learning-driven mindset, the use of visible representations, and collaboration within diverse teams. DT provides both a methodological orientation and a framework for understanding how information practices in IVF care might be redesigned around patient needs and experiences.

2.2.2 Service design as a human centred approach

Service design emerged as a human-centred discipline grounded in understanding people's experience and translating these insights into improve services and customer journeys. Rather than optimizing existing processes, service design seeks to generate deep qualitative insights into individuals' contextual and holistic experiences (Patrício et al., 2020). It is recognised as a systemic discipline, focusing not only on individual user experience but on the broader configuration of actors, processes, infrastructures, and organizational arrangements that together constitute a service.

Patrício et al. (2020) argue that service design contributes to healthcare transformation through three complementary approaches: human-centred and participatory approach, a creative and transformative approach, and a service systems perspective. Applied to IVF care, service design provides a framework for understanding how the information environment across channels, roles and stages can be redesigned to better support patient understanding and participation.

2.2.3 Experienced-based Co-Design

Experience-based Co-design (EBCD) emerged as a critique of traditional management-centric change processes, popping that improvement efforts should be guided by the experiences of service users (Bate & Roberts, 2007). EBCD proposes a treason relationship between consultants, staff and patients, in which the user's experience become central. Rather than prioritizing initial organizational outcomes alone, the emphasis shifts toward improving the lived experience of those receiving the service.

Central to EBCD is the concept of touch points which are key moments in a service journey that stand out emotionally or cognitively for users (Bate & Roberts, 2007). These moments often represent intensified experiences and shape the overall perception of a service. Additionally, the touch points strive to achieve an informed vantage point to provide parallel insights into the bigger picture, allowing for a deeper understanding of how fragmented service encounters are experienced.

Specifically, touch points involve:

- Critical interactions
- Moments of uncertainty
- Emotional highs or lows
- Points of transition or handover

The touch points strive to achieve an informed vantage point that shapes the overall perception of a service and represents the primary sites for improvement. Bate and Roberts (2007) argue that services must not only be safe and effective but also be experiences as safe and supportive. This is a distinction that is significant in emotionally demanding care contexts such as IVF.

2.3 Change Management and Innovation Readiness

For organizations to remain relevant, continuous adaptation is necessary. In public healthcare systems, which are state-funded, this often translates into a sustained focus on cost-effectiveness and quality improvement. Buchanan and Huczynski (2023) argue that organizational change is inherently complex and rarely achieved through isolated efforts rather, it requires coordinated action across multiple levels. External pressures, including political decisions and societal crises, may accelerate change processes, while internal barriers such as functional silos, hierarchical decision-making and established cultural norms tend to reinforce stability and slow adaption.

While traditional change management frameworks emphasize structured and sequential implementation processes (Buchanan & Huczynski, 2023), large-scale healthcare transformation requires an understanding of healthcare as a complex adaptive system (Best et al., 2012). In such systems, change is nonlinear, context-dependent, and shaped by interactions among multiple actors, rather than driven solely by top-down directives.

Resistance and readiness are critical factors at the individual level. In healthcare systems, Best et al. (2012) emphasize that physician engagement plays a crucial role in enabling large-scale transformation. Without their support, change initiatives risk lacking intimacy and failing to translate into everyday clinical practice. At the psychological level, Fredberg and Pregmark (2018) demonstrate that urgency can function as double-edged sword – when framed primarily as crisis or threat, it may create anxiety and defensive behaviour rather than sustainable transformation, aligning with Yerkes-Dodson principle that excessive pressure undermines performance.

2.3.1 The Fuzzy Front End of Innovation

Reid and de Brentani (2004) conceptualise the fuzzy front end (FFE) as the early and often ambiguous phase of the innovation process that precedes formal development activities. This phase is particularly critical in context of discontinuous or radical innovation, where problems and opportunities are ill-defined and characterised by elevated uncertainty. The authors argue that decisions and sense-making processes at this stage fundamentally shape subsequent trajectories. At the individual level, the FFE is driven by actors who identify emerging patterns, evaluate their potential relevance and decide whether to bring ideas into the organization. At the organizational level, mechanisms enabling knowledge sharing and collective sense-making are essential for transforming emergent ideas into viable innovation projects.

2.4 Analytical Framework

Together, these theoretical perspectives form a complementary analytical framework for this study. Health literacy and shared decision-making provide lenses for

understanding how patients engage with and act upon information at the individual level. People-centred healthcare and Maslow's motivational theory ground this in emotional and experiential conditions specific to IVF care. DT, service design and EBCD offer frameworks for understanding how information practices can be improved through human-centred design at the organizational level. Finally, change management and FFE provide tools for analysing the organizational conditions that enable or constrain improvement at the institutional level. Applied together, these perspectives allow the study to move from describing the current information practices to understanding why they take the form they do, and what conditions would need to change for them to better serve both patients and staff.

3. Methodology

This chapter outlines the methodological approach of the study, including research design, data collection methods, sampling strategy, analytical process and ethical considerations.

The study adopts and explores a qualitative-dominant mixed methods design through qualitative data collection which constitute the primary empirical basis of the study. Qualitative methods are particularly suited to capture the complexity of lived experience, professional practices and organizational conditions that shape patient information in IVF care.

Quantitative data plays a complementary role to provide contextual support for the interpretation of qualitative findings rather than serving as a basis for statistical inference. Together, these sources enable a more comprehensive understanding of information practices across the IVF care pathway as part of the early-stage concept development. Table 1 presents all the data collected, its purpose, participants, and the number of sessions/episodes/reports/hours for each activity.

Data Source	Participants	Amount	Purpose
Ethnographic Observations			
Simulated patient journey	Doctor, midwives, nurses, researchers	1 session	Experience the patient pathway at SUH and understand how information is structured and provided
Observation in waiting room	Researchers	2 sessions	Experience the physical information environment and atmosphere prior to appointments
Participant observation — egg retrieval	Doctor, midwives, nurses, embryologist, researchers	2 sessions	Observe the emotional dimension and coordination between professional roles at a critical procedural moment
Participant observation — embryo transfer	Doctor, midwives, nurses, embryologist, researchers	2 sessions	Observe the emotional dimension and information communicated during the transfer procedure
Participant observation — ICSI, IVF and lab work	Embryologist, researchers	1 session	Understand the embryologist's role and the laboratory dimension of the IVF process
Participant observation — Wednesday information meeting	Researchers	2 sessions	Observe internal communication structures and information sharing practices
Participatory Session			

Data Source	Participants	Amount	Purpose
Workshop — stakeholder mapping	Doctor, midwives, researchers	1 session	Identify actors directly or indirectly involved in IVF patient information
Workshop — Mentimeter participatory session	Healthcare professionals, researchers	1 session	Collect real-time staff reflections on patient information practices across the IVF pathway
Interviews			
Healthcare professional interviews	Healthcare professionals, researchers	9	Develop organizational and patient understanding of information practices at SUH
Patient interviews	Patients, researchers	3	Capture patient perspectives and points of view on the IVF information experience
Interview — head midwife, Copenhagen University Hospital	Healthcare professionals, researchers	1	Develop comparative understanding of information practices at an international clinic
Complementary Data			
Quantitative data from SUH	Patients	2 reports	Contextualize qualitative findings with patient-reported satisfaction data
Documentary — Barnmakarna	Researchers	1	Early understanding of the IVF patient experience and emotional journey
Podcast	Researchers	2 episodes	Understand how experienced IVF patients describe their journeys informally
Instagram and TikTok	Researchers	2–3 hours	Understand how IVF is communicated and experienced through social media channels
Website review — Nordic IVF, Livio, 1177	Researchers	3 websites	Analyze how IVF information is structured and presented across formal digital channels

Table 1: Overview of empirical data collection.

3.1 Researcher role and positioning

This study is conducted by two master's students within the field of Innovation and R&D management. The researchers do not have a professional background in healthcare, nor any prior affiliation with SUH before the initiation of this study.

During the research, the researchers have been present on-site at the hospital and engaged in ongoing interactions with healthcare professionals. This position provided access to everyday practices and facilitated a deeper understanding of the different professional roles within the organization.

As a result of the researchers' presence in the field, they were also granted to access additional settings within the organization. This included participation in laboratory environments alongside clinical staff, as well as attendance at internal departmental meetings, such as weekly lectures. The researchers also presented at one of these lectures to present about their point of view in the ongoing work as part of the broader innovation initiative project.

This level of access provided further contextual understanding of clinical practices, internal communication, complementing data collected through interviews and observations. At the same time, it may influence the researchers' position in the field, as increased familiarity with the organization could affect critical distance.

The researchers' external outside position may influence both data collection and interpretation. On the one hand, it allows for a distinct perspective on existing practices, enabling the identification of taken-for-granted assumptions. On the other hand, it may limit the researchers' understanding of clinical routines and medical terminology.

To address this, efforts have been made to ensure clarity during interviews, to validate interpretations with participants when possible, and to remain reflexive throughout the research process.

3.2 Research Approach

This study is grounded in an interpretive research paradigm. Given the study's aim to understand how patient information is experienced, communicated and organized across the IVF care pathway, this orientation is appropriate as the researchers' interests lie in how people make sense of their world and their experiences (Bell et al., 2021).

The study follows an abductive approach, moving iteratively between literature and empirical evidence to develop an analytical understanding (Bell et al., 2021). Rather than beginning with a fixed theoretical framework and testing it against data, insights from the field have continuously informed and refined the theoretical direction of the study.

In addition, this study uses DT as a methodological foundation and analytical approach, emphasizing close engagement with users and their everyday practices as the starting point for understanding complex problems (Brown, 2008; Carlgren et al., 2016). DT aligns well with an ethnographic approach, as it emphasizes close researcher involvement in everyday practices and with a goal to understand the insider's perspective. Due to the limited timeframe, a micro ethnographic approach is applied (Bell et al., 2021). This approach was chosen because information practices in healthcare are deeply embedded in everyday routines, professional roles, and organizational structures that are difficult to capture through interviews alone. The

micro-ethnographic orientation allowed the researchers to observe these practices in context, complementing the interview data with direct situational knowledge.

3.3 Data Collection Methods

The study uses a mixed methods data collection approach, where the primary methodological foundation is the qualitative approach, complemented by existing quantitative data from the hospital. By combining these two, the study supports the DT process and enables a more comprehensive understanding of information practices in IVF care. Given the sensitive nature of this study's topic, the use of qualitative and quantitative aspects enables participants to articulate experience and insights that may otherwise remain implicit or difficult to express. Together, these sources support the DT process and enable a more comprehensive understanding of information practices in IVF.

The qualitative data was collected through three main approaches: semi-structured interviews with patients and healthcare professionals, ethnographically inspired observations at the Reproductive Medicine Division, and a participatory session with clinical staff. These are described in sections 3.3.1, 3.3.2 and 3.3.3 respectively.

In addition, complementary data was gathered through quantitative patient satisfaction surveys, social media and documentary material, and a review of publicly available digital information sources. These sources were not used as primary data but to contextualise and support the interpretation of qualitative findings. They are described in 3.3.4.

3.3.1 Semi-structured Interviews

The primary source of empirical data in this study consists of semi-structured interviews. This format was selected for a structured thematic focus while preserving flexibility for participants to elaborate on their experiences and perspectives in their own terms. As Bell et al. (2021) describe, semi-structured interviews combine predefined topic with open-ended questions, enabling the researchers to follow unexpected directions that introduce insights that are not anticipated in the interview guide.

A total of 13 interviews were conducted across three participant groups. Nine interviews were conducted with healthcare professionals at the Reproductive Medicine Division – 2 physicians, 2 secretaries, 2 midwives, 2 embryologists and 1 nurse. In this study, the terms embryologist and laboratory staff are used interchangeably to refer to the same professional group, which includes biologists, embryologists, and additional staff working in the IVF laboratory. Three interviews were conducted with patients who had personal experience of IVF treatment at a clinic in Västra Götaland region. One interview was conducted with a senior midwife at Copenhagen University Hospital's fertility clinic, which provided a comparative perspective on information practices in a comparable Scandinavian public healthcare context.

All interviews were conducted in Swedish, except for the Copenhagen interview which was conducted in English. The interviews were recorded with participants' consent and transcribed using Microsoft Teams transcription software. Subsequently,

the transcripts were reviewed and verified by the researchers through listening alongside the recording to ensure accuracy. Therefore, the quotes in this thesis have been translated from Swedish to English by the authors.

The interview guides were developed prior to each interview, tailored to explore information practices, communication challenges, and experiences of the IVF care pathway from each participant's perspective. Prior to each interview, all participants were informed of the study's purpose, their right to withdraw at any time, and that their responses would be anonymized in the final report.

3.3.2 Ethnographic orientation

To complement the interview data, a micro-ethnographic approach was adopted. Given the time constraints of the study, full ethnography was not feasible. Instead, the researchers immersed themselves within everyday practices and activities at the Reproductive Medicine Division over an extended period, attending the division on a regular and weekly basis. This approach enabled the researchers to develop a grounded understanding of how care is organized and delivered in practice, and how information is encountered, interpreted and navigated throughout the IVF process.

As part of this orientation, a simulated patient journey was conducted in collaboration with a physician and midwife at the division. The researchers received the same written materials that patients typically receive prior to their first consultation, attended a simulated first appointment, and followed the pathway through subsequent stages of care. This provided direct experiential insight into how information is structured and delivered from the patient's perspective.

The researchers were also granted access to laboratory environment and clinical procedures, where live observations were conducted across multiple stages of the IVF treatment process. This included observing an egg retrieval procedure, during which the researchers were present in the room alongside staff from multiple professional roles (physician, midwives, nurses, and embryologists), as well as the patient undergoing the procedure. This provided direct experiential insight into how different roles coordinate in practice during a critical and emotionally sensitive setting, and how information is communicated to the patient in real time.

Following the egg retrieval, the researchers observed the subsequent laboratory assessment process, including evaluation of retrieved eggs, the use of methods such as ICSI (*intracytoplasmic sperm injection*), and the selection of embryos for transfer or cryopreservation. Sperm and egg cells were also examined under microscope alongside embryologists. Additionally, the researchers were also present during an embryo transfer procedure.

This level of access provided contextual understanding of the clinical complexity of IVF care. Observing these procedures across various stages of IVF process provided a grounded understanding that prior information or knowledge of such procedure is not merely a formal requirement but also meaningful condition for patients to feel prepared, safe, and able to participate in their own IVF journey. Being present at these critical touch points, and meeting patients within that context, reinforced the

emotional weight of IVF process and illustrated why clear, timely and sensitive information at each stage of care is essential for patient understanding.

3.3.3 Participatory session

In addition to interviews and ethnographically inspired observations, a participatory session was conducted in connection with a presentation held at the Reproductive Medicine Division at SUH. The presentation was a part of the ongoing innovation initiative, where the researchers together with the project manager, introduced the purpose and scope of the study.

During this session, an interactive digital tool (Mentimeter) was used to collect real-time input from attending healthcare professionals across different roles at the division. Participants were invited to provide written reflections on three guiding questions: (1) where in the IVF care pathway do you perceive the patient to be the most receptive to receiving information, (2) where in the IVF care pathway do you perceive the patient to be the least receptive to receiving information, and (3) what are the expectations and concerns regarding the development of information practices in relation to this project.

This approach enabled the collection of perspectives from multiple stakeholders simultaneously in a structured yet open format. The responses were documented and used as supplementary qualitative data, contributing to the identification of patterns related to information flow, timing, and patient understanding within the IVF care process. The insights are presented under section 4.5.3.

The participatory nature of the session aligns with the human-centred principles of DT, where insights are generated through engagement with relevant stakeholders in the context of their everyday practices.

3.3.4 Complementary Data Sources

In addition to the primary qualitative data, three complementary data sources were included to provide contextual support for the qualitative findings.

Quantitative patient satisfaction data was provided by Reproductive Medicine Division at SUH. The data consists of survey results administered through IMPROVEIT, a standardized measurement tool used across Swedish IVF clinics. As the data was received as secondary data, the researchers had no influence over the questionnaire design, distribution method, timing or response rate. SUH's sample consisted of 25 respondents during the 2024 survey period, compared to significantly higher response rates at the three private Gothenburg clinics. This limits the representativeness of the SUH data, and the quantitative findings are therefore treated as indicative and contextual rather than conclusive. The data is presented in section 4.5.2.

Social media platforms and documentary material were also examined to explore how IVF is communicated and represented in informal digital spaces. The purpose was not to conduct a systematic analysis but to develop a broader understanding of how patients experience and narrate the IVF journey outside formal healthcare channels.

The platforms reviewed included TikTok and Instagram, where creators share personal stories through short-form video and written posts. Two to three hours were spent reviewing content across these platforms. In addition, two podcasts were listened to, and the documentary *Barnmakarna* (2026) by Kalla Fakta on TV4 was reviewed as it provided insight into the emotional and psychological dimensions of fertility treatment from a patient perspective. These sources were not used as primary data but as contextual material to support the interpretation of qualitative findings. The insights derived from these sources are presented in section 4.5.1.

A review of publicly available digital information sources was also conducted to examine how IVF-related information is structured and presented across formal online channels. Three sources were reviewed: The websites of Nordic IVF and Livio (two private clinics) and 1177 (the official Swedish healthcare information platform). The review focused on how the IVF process is presented, what type of guidance is provided and how clearly the patient journey is communicated. The findings from this are presented in section 4.6.

3.4 Sampling Strategy

Given the sensitive nature of IVF treatment, different sampling strategies were applied for each participant group. The study includes participants from both patient and healthcare professional groups to capture multiple perspectives on information practices within IVF care.

For patient participants, a snowball sampling strategy was applied. Snowball sampling is particularly suitable when the research focuses on specific networks or groups that may be difficult to access (Bell et al 2021). Initially, a small group of participants relevant to the research questions was reached through networks of individuals who have undergone IVF treatment, such as the "*Riksförbundet för ofrivillig barnlöshet"* (the National Association for Childlessness). These participants were then asked to suggest additional individuals with relevant experience. This approach enabled access to participants with direct experience of IVF, while also supporting trust and willingness to participate in a sensitive research setting. Direct recruitment of patients currently undergoing or having undergone treatment at SUH was not pursued, as this would have required formal ethical approval beyond the scope of the master thesis conducted within a clinical setting. Patient recruitment therefore took place through independent external channels, ensuring that the study remained within appropriate ethical boundaries.

For healthcare professionals, a purposive sampling strategy was applied. This approach is strategic and aims to include participants with relevant experience within IVF care context and involvement in patient information practices (Bell et al., 2021). Access to healthcare professionals at Reproductive Medicine Division facilitated through the project manager, a reproductive specialist physician at SUH, who served as an initial contact person and assisted in identifying potential participants. This form of access can be understood as a type of gatekeeping, where the project manager functioned as an intermediary between researchers and potential participants. While this enabled efficient access to relevant professionals, it may also have influenced

which perspectives were represented in the study. A total of nine professionals were interviewed across five professional roles. A detailed breakdown is provided in section 3.3.1.

An interview with a senior midwife at Copenhagen University Hospital was identified separately through purposive sampling, selected specifically to provide an external comparative perspective on information practices in Scandinavian public healthcare context.

This combination of recruitment strategies allowed the study to include both internally facilitated and independent sources perspectives, contributing to a broader understanding of information practices in IVF care.

3.5 Stakeholder Analysis

To support the exploratory nature of the study and ensure that relevant perspectives are included, a stakeholder analysis is conducted. The purpose of the analysis was to identify and map key actors involved in the IVF information process and understand their roles, process responsibilities, and interactions across the care pathway.

In this study, stakeholders are understood as individuals or groups who affect or are affected by the creation, communication, and management of patient information within IVF care (Zimmer, 2021). Given the complexity of healthcare services and the interdependence between professional roles, a broad understanding of stakeholders is necessary. This will also support the purpose of sampling decisions for interviews and workshops to help identify critical points in information flow.

The stakeholder analysis is conducted through a stakeholder mapping workshop together with a physician and a quality and patient representative, who is also a midwife. During the workshop, relevant stakeholders are identified and discussed in relation to their involvement in patient information. The mapping of the actors focuses on direct or indirect contact with patient information, including physicians, midwives, nurses, administrative staff and patients themselves, as well as organizational roles that are connected to service development and coordination of information.

3.6 Thematic Analysis

The data analysis in this study, guided by the principles of DT, particularly the *empathize* and *define* phases, focuses on understanding the user experiences and synthesises insights into clearly defined problem areas. The process is iterative, where insights from ongoing interviews continuously inform subsequent data collection and interpretation. This iterative logic aligns with the double diamond model, which emphasise cycles of divergence and convergence throughout the innovation process (Design Council, 2005).

The qualitative data collected through semi-structured interviews were analysed using a thematic analysis approach, following the framework outlined by Braun and Clarke (2006). Initially, interview transcripts were reviewed to gain familiarity with the data.

Relevant segments were then coded inductively focusing on aspects related to how patient information is created, communicated and experienced within the IVF care pathway. Coding was conducted collaboratively by both researchers, with codes discussed and reconciled in joint sessions to reduce the influence of individual interpretation and strengthen analytical consistency.

The codes were subsequently grouped into broader theme representing recurring patterns across participants, such as misunderstandings, repeated information needs, and breakdowns in information flow between stakeholders. A pattern was considered sufficiently robust to constitute a theme when it recurred across multiple participants and was identifiable in accounts from both healthcare professionals and patients, suggesting it reflected a structural feature of the information process rather than an isolated individual experience.

Additionally, the quantitative data from the hospital were added to complement the qualitative findings. Rather than aiming for statistical generalization, this data was used to contextualise and support patterns identified in the qualitative analysis.

Throughout the analysis, brainstorming sessions were conducted to collaboratively interpret the data and identify both explicit and implicit meaning by participants. Explicit insights refer to clearly articulated experiences and statements, while implicit insights capture underlying needs, emotions, and assumptions that are not directly expressed but can be inferred from the data. These insights were used to deepen the understanding of patient and healthcare professional experiences and to identify key challenges and opportunity areas within the IVF information process.

To support this analytical work, post-it notes were used as a visual and tangible analytical tool, consistent with the DT principle of making thinking visible and concrete (Carlgren et al., 2016). Insights, observations and emerging patterns were written onto individual post-its in different colours to represent different aspects aligning with what was currently analyzed. This was physically and digitally using the collaborative tool Miro. Subsequently, this allowed the researchers to cluster related insights, identify recurring patterns across participants, and begin grouping observations into broader thematic areas. The Miro boards presented in chapter 4 are direct outputs of this analytical process, documenting how insights were organised and interpreted.

In several brainstorming sessions, the process surfaced questions and areas of uncertainty that required further investigation, prompting the researchers to return to the data or deepen their observations. This reflects the iterative nature of DT as an analytical approach in which insights and questions generated at one stage can inform subsequent stages of the innovation process.

3.7 Triangulation

To capture and ensure trustworthiness, the study applies triangulation. Triangulation allows the study to capture various levels of reality by examining the same phenomenon from multiple perspectives and through different types of data (Bell et al 2021). This is relevant in a DT concept, where understanding complex situation requires integrating diver point of view and source of insight.

In this study, data triangulation is achieved by including different stakeholders' perspectives, such as patients and healthcare professionals via interviews. This enable cross-checking of qualitative data and allows experiences of the IVF process to be compared across roles. Furthermore, methodological triangulation is applied through a combination of qualitative and quantitative methods. Semi-structured interviews provide an in-depth insight into experience, perceptions, and underlying challenges, while quantitative data from the hospital will offer measurable indicators related to process flows, waiting times or resource use. The integration of these data sources supports a more comprehensive understanding of the current situation.

The combination of triangulation and DT reinforces the iterative and exploratory nature of the research. While interviews contribute to empathic understanding and problem framing, the quantitative data help ground insights in measurable realities. Together, these approaches enhance the robustness and trustworthiness of the study.

3.8 Ethical Considerations

This study is conducted within a healthcare context involving sensitive topics related to infertility and IVF treatment. Ethical considerations have therefore been central throughout the research process. In addition, the researchers have signed confidentiality agreements with the hospital, to ensure that all sensitive information encountered during the study is managed according to institutional and legal requirements.

During the egg retrieval and embryo transfer procedures, patient consent was obtained before the researchers were allowed to be present as observers. The request was communicated to the patient by the responsible physician, and participation was entirely voluntary. No personal data, images, recordings, or other sensitive information that could identify the patient was collected or stored. The observations focused only on the clinical setting, communication practices, and information flow related to the care process.

In line with Bell et al. (2021), particular attention has been given to the following areas: harm to participants, informed consent, privacy and anonymity, deception and data protection. All participants were informed about the purpose of the study, the use of data, and the right to withdraw at any time without consequence. Participation was voluntary and no deception was used.

To ensure confidentiality, the researcher has signed confidentiality agreements with the hospital, to ensure that all direct information gathered at the hospital during the study is handled in accordance with institutional and legal requirements. Additionally, all data has been anonymized, and no identifiable personal or sensitive health-related information has been collected. Given the specialized context of IVF care, care has been taken to avoid indirect identification of participants.

Interviews and interactions were conducted with sensitivity, particularly considering the emotional nature of the topic and the professional responsibilities of healthcare staff. All data has been securely stored and used solely for research purposes.

3.9 Social and Organizational Considerations

Due to the study's context of being an ongoing innovation initiative at SUH, and that it is conducted at hospital, there are both social and organizational considerations that need to be addressed. Research in such settings is embedded in existing structures, stakeholder interests, and power relations.

The study involves multiple stakeholders, including healthcare professionals, patients and organizational representatives, each with different roles and degrees of influence. The hospital, as the host organization, provides access to participants and internal processes, which creates inherent power asymmetries between the organization and the researchers.

To address this, the study has aimed to maintain academic independence in defining research questions, selecting methods, and conducting analysis. Transparency in methodological choices and clear delimitation of the study scope have been central to ensuring research credibility.

Additionally, the study addresses aspects related to healthcare professionals' work environment, such as workload and coordination challenges. These aspects are approached with sensitivity, with the aim of understanding structural conditions rather than evaluating individual performance. By acknowledging the social and organizational context, the study seeks to conduct research in a reflector and responsible manner.

3.10 Use of Artificial Intelligence Tools

Throughout the study, AI-based tools such as Claude (Anthropic), ChatGPT (OpenAI) and Notebook LM (Google Gemini) have been used in supporting capacity at several stages of the research process. The use of the tools has been limited to tasks that assist the researchers without replacing their judgement or analytical responsibility.

In the early stages of the study, AI tools were used to support the orientation toward relevant theoretical domains, such as healthcare. As the researchers are not specialists in fields such as health literacy or shared-decision-making, AI tools were consulted to identify potentially relevant literature and theoretical frameworks that could be applied in this study. All suggested sources and concepts were subsequently reviewed and assessed independently by the researchers before incorporating the content into the theoretical framework to confirm that it aligned with the study. AI tools also assisted in the structural organization of the report, including maintaining coherence and a clear narrative thread across chapters. This also included checking the clarity of expression regarding language and grammar.

The interview scripts were generated with AI support, using built-in transcription functionality in Microsoft Teams. All recordings were retained and subsequently reviewed by the researchers, who listened to each recording while simultaneously reading the generated transcript to verify its accuracy. Any discrepancies were corrected before the material was used in the analysis. All personally identifiable

information was redacted from the transcript prior to processing, according to the ethical commitments outlined in section 3.8.

In the thematic analysis phase, AI was further used to support an initial reading of the interview material and to surface patterns in what each participant had expressed. This was done both to support a more systematic reading of the data and to reduce the risk of overlooking recurring patterns. However, for ethical reasons and to maintain analytical responsibility, all AI-generated outputs were reviewed and validated by the researchers before any themes were confirmed or adapted. All analytical conclusions, interpretations, and thematic decisions remain the responsibility of the authors.

In all instances where AI tools were applied, the output was reviewed at least by one researcher before being used in the study. No AI-generated content has been included in the thesis without human verification and independent source checking.

3.11 Limitations

A central limitation of this study concerns the ability to recruit participants. As IVF is a sensitive and highly personal topic, it has not been possible to contact patients directly through healthcare institutions. For example, it has not been possible to recruit participants by distributing information materials within facilities such as SUH or other clinical settings, as this would require ethical approval and access to patient groups that are not available to researchers as students.

Participants have been identified via relevant associations, social media, and through personal contact within the researchers' network who have experience with IVF. This means that the sample can be characterized, to some extent, as a convenience sample, which may affect the generalizability of the study. This recruitment strategy may also result in a certain bias in terms of which perspectives are represented. For example, individuals who are more open about their experiences or more active in social contexts are more likely to be included. At the same time, this approach has been necessary to conduct the study in an ethically responsible manner, with respect to participant's integrity and personal circumstances.

Due to the complexity of SUH as an organization, the recruitment of healthcare professionals focused primarily on staff directly involved in the IVF care pathway at the Reproductive Medicine Division. This allowed the study to capture perspectives from professionals engaged in patient-facing work and everyday information practices. However, this also means that the study mainly reflects the local clinical context. Perspectives from interesting actors defined in the stakeholder analysis further removed from the daily IVF process, such as higher-level management, regional communication functions, or those responsible for platforms such as 1177, are less represented. This may limit the understanding of broader organizational and structural conditions affecting patient information.

As discussed in section 3.1, the researchers approached this study as outsiders to the clinical context without prior affiliation or professional background in healthcare. While positioning supported an open and exploratory orientation, it also means that certain aspects of organizational culture and professional dynamics may not have been fully accessible. The researchers' presence during observations and interviews

may further have influenced how participants chose to present themselves in their experiences and practices.

As described in section 3.3.4, the quantitative data was received as secondary data by Reproductive Medicine Division and not collected or administrated by the researchers. This means that the researchers had no influence over what type of questions were measured, distribution method, timing or response rate.

The notably lower response rate at SUH compared to the private clinics limits the representativeness of this data, which is treated as indicator and contextual rather than conclusive. Furthermore, the geographical scope of the quantitative comparison is limited to IVF clinics within Gothenburg region. While this delimitation is consistent with the focus of the study, it means that the findings cannot be generalized to IVF care provision at a national level. However, the study's broader environmental analysis draws on perspectives beyond this geographical boundary, including practices at other Scandinavian clinics and patients' narratives shared through social media, which partially compensates for this limitation.

Regarding the timeframe, a planned whole-clinic process mapping involving staff across the Reproductive Division was planned as part of the broader innovation initiative and would provide a collective organizational perspective on the IVF care process. The session was initially planned for April but postponed to June, which fell outside the timeframe of the study. As a result, this activity could not be included in the data collection. This also represents a limitation in terms of capturing the shared institutional understanding of the process. Similarly, a planned visit to Nordic IVF Gothenburg, which would have provided an additional comparative perspective on information practices at private clinic operating within the same geographical context, was also postponed and could not be included within the study period. The absence of this data limits the depth of the comparative analysis between public and private IVF care.

The interviews conducted with the professionals and patients were carried out in Swedish, while the thesis is written in English. All quotes have been translated by the authors, which introduces a degree of interpretive influence over how participants' words are rendered in the final context. Therefore, some nuances may have been lost in translation even though the researchers have tried to preserve the meaning and tone of original statements.

Finally, this study draws on DT as its methodological foundation rather than traditional qualitative research logic. In conventional qualitative research, sample size and participant selection are typically guided by principles such as theoretical saturation or purposive sampling aimed at representativeness. While the recruitment of healthcare professionals in this study followed a purposive logic (selecting participants on their direct involvement in the IVF care), the patient sample reflects a DT orientation. In contrast to conventional qualitative research, DT prioritizes depth of insight over breadth of coverage and does not require predetermined sample size to achieve analytical validity. The three patient interviews were not intended to represent the full diversity of patient experiences but provide rich and contextually grounded perspectives that could inform the study's understanding of how information is experienced across the care pathway. However, it should be acknowledged that the

range of patient perspectives represented in this study is a limitation, and future research would benefit from engaging a larger and more diverse patient sample.

4. Empirical Context: IVF Information Practices

This chapter outlines the empirical context of the study and provides an overview of the data collected throughout the research, including the structure of IVF care at SUH, the key stakeholders involved, and the different channels through which patient information is communicated. It also presents the findings of the study, focusing on information practices within IVF care, based on three main sources of data: ethnographically inspired observations, semi-structured interviews with healthcare professionals and patients, and complementary quantitative and participatory data.

4.1 The IVF care pathway

This section presents the empirical mapping of the IVF care pathway at SUH, based on a simulated patient journey, observations in the clinical and laboratory setting, and collected patient-facing information materials. The purpose is to describe how patients encounter information across different stages of the process, from the first written appointment material to treatment preparation, clinical procedures, and home-based responsibilities. The section also documents where information is provided, in what format, and which professional roles are involved. Together, this mapping provides a structured overview of the current information flow and forms empirical foundation for the thematic findings presented in section 4.4.

To develop this understanding, a simulated walkthrough of the IVF pathway was conducted in collaboration with a physician and midwife at Reproductive Medicine Division. As part of this session, the researchers were introduced to the initial stage of the IVF process by receiving written materials as patients typically receive prior to their first consultation. These materials included multiple documents containing information about the IVF process, practical instructions, and consent-related content that patients are expected to read and sign (see section 4.1.7). This step provided insight into the volume, structure and complexity of information that patients encounter at the initial stage of their IVF care pathway. It also highlighted the expectations placed on patients to independently engage with and understand medical and peculiar information prior to the direct interaction with healthcare professionals.

4.1.1 Mapping the IVF journey

The insights were translated into a visual process map using the digital tool Miro. Figure 2 shows a structured representation of the IVF care pathway, including key stages, interactions and points at which information is provided to patients. The map also includes annotations reflecting different types of information assumptions, and perceived gaps identified during the walkthrough session.

Figure 2: An overview of the initial stages of the IVF patient journey without additional notes.

To support the analysis, different types of information and reflections were categorized using color-coded labels. Blue notes represent information provided by the healthcare provider, green notes refer to verbal information from healthcare professionals, pink notes reflect the researchers' (as patients) thoughts and interpretation and red notes highlight missing or unclear information, and black notes represent assumptions identified during the mapping process (shown in figure 3**)**.

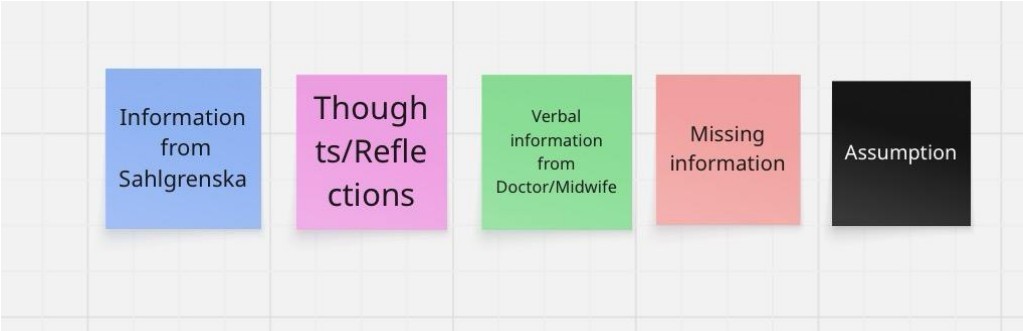


Figure 3: Notes in different colors that are placed in the mapping of IVF treatment

4.1.2 Initial stage: pre-consultation and information receipt

As illustrated in figure 4**,** the stage receiving the summons to the Reproductive Medicine Unit marks the transition from fertility investigation to IVF treatment. Prior to this stage, patients receive the outcome of the fertility investigation and are referred to IVF care. However, the mapping indicates that there is limited or no clear information provided regarding expected waiting times. In some cases, the cause of infertility remains unexplained, which may contribute to further uncertainty at this stage.

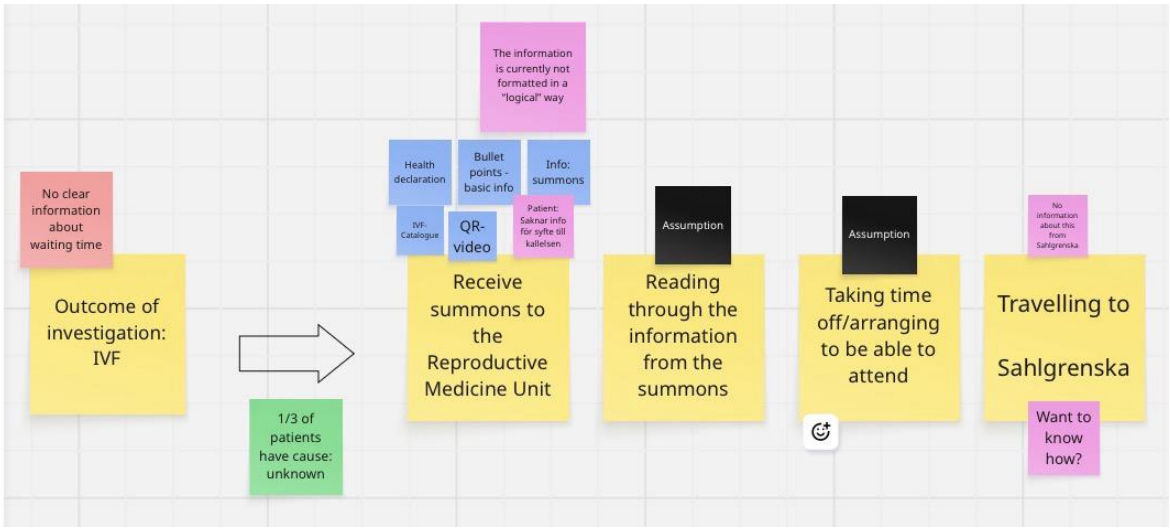


Figure 4: First steps after fertility investigation and having received the first letter home.

Following this, patients receive formal appointments from the Reproductive Medicine division. This appointment is accompanied by a set of written materials, including general information about IVF treatment, practical instructions, health declarations, and consent-related documents. In addition, patients are provided with supplementary material such as an IVF information booklet and digital content accessible through QR codes.

The mapping indicates that information at this stage is delivered through multiple sources, including written documents, structured bullet-point summaries, and digital

resources (section 4.1.5 and appendix A for full set of materials sent to patients prior to their first appointment). While this provides patients with access to extensive information, it also introduces complexity in how the information is structured and presented. Several elements appear to be repeated across formats, while other aspects are perceived as unclear or insufficiently explained, such as the purpose of the appointment and how different steps in the process are connected (section 4.1.5 and appendix A).

The mapping also highlights that the information is not always perceived as logically structured, which may make it difficult for patients to navigate and prioritize the content. In addition, certain practical aspects like preparing for the visit, when to take a day off from work, how to organize transportation and what to expect during the consultation, are not always explicitly stated.

Furthermore, the mapping includes several assumptions (represented by black notes), indicating that patients are expected to interpret and act upon the provided information prior to their first interaction with healthcare professionals. This includes understanding the purpose of the appointment, preparing necessary documentation, and making practical arrangements for the hospital.

Overall, the initial stage is characterized by a high volume of information combined with limited opportunities for clarification. This may affect how patients engage with and understand the IVF care pathway from the outset. As such, this stage is critical in shaping patients' initial understanding of the IVF process and their ability to engage with subsequent stages of care.

4.1.3 First clinical interaction

Figure 5 illustrates the patient's initial meeting after the investigation at SUH, and this begins when the patient arrives at the Reproductive Medicine Division and checks in for their scheduled appointment. This marks the first direct encounter between the patient and healthcare professionals within the IVF treatment process.

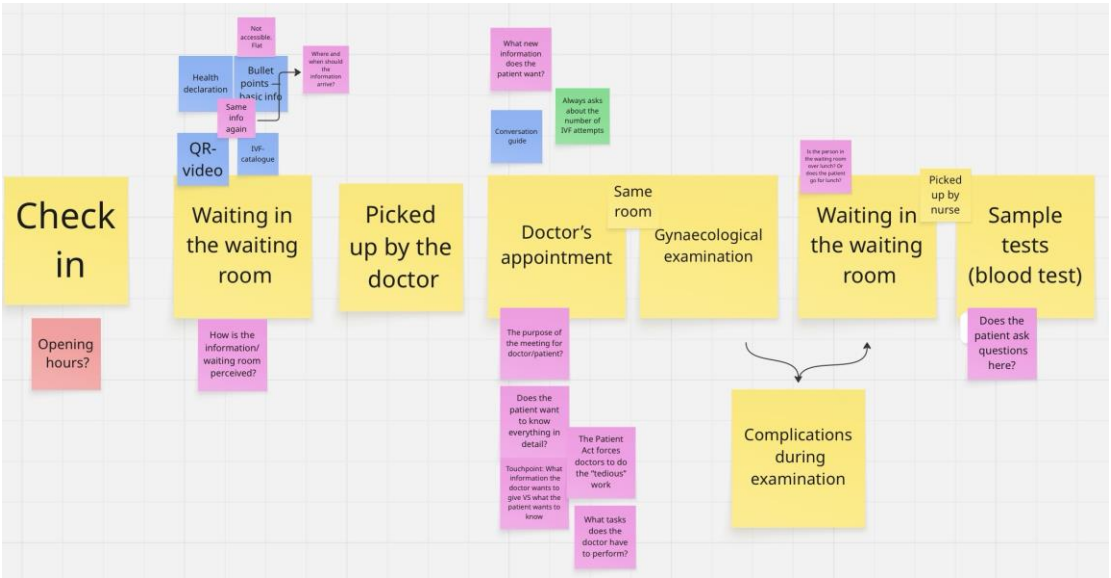


Figure 5: The first interactions between the physician and the patient.

Upon arrival, the patient typically spends time in the waiting room before being called in by a physician. The mapping indicates that, during this period, patients may encounter information materials that were also accompanied in the formal invitation; however, it remains unclear how this information is perceived or whether it supports patient understanding at this stage.

The consultation with the physician constitutes a central interaction in this phase. During this meeting, patients receive verbal information regarding their specific situation, potential treatment options, and the IVF process. The meeting lasts for approximately 1 hour. In addition, a gynecological examination is often conducted as part of the visit. These activities take place within the same clinical setting, contributing to a concentrated and intensive encounter with information.

The mapping highlights that patients are expected to engage with complex and detailed medical information during the consultation. At the same time, several reflections (the pink notes) indicate uncertainty regarding how much information patients can or expected to absorb in this setting. For instance, questions arise regarding whether patients seek comprehensive detail or primarily need clarity on key aspects of the treatment process.

After meeting with the physician, the patient is yet again expected to wait in the waiting room for the next step in the treatment process, which includes procedures such as blood sampling. That transition from consultation to examination, to this stage may introduce additional points of uncertainty, particularly in relation to where patients can ask questions and how information is communicated across different healthcare professionals.

The mapping identifies this stage as a critical point for potential misunderstandings, as it combines high informational complexity with emotionally demanding circumstances. As such, the first clinical interaction represents a key moment in the IVF care pathway, where patient understanding, expectations and engagement are shaped through direct communication with healthcare professionals.

4.1.4 Treatment preparation and home phase

As shown in figure 6**,** the next step of the IVF care pathway involves preparation for treatment, during which patients transition from the clinical setting to managing parts of the treatment process independently at home. This step begins with a consultation with a midwife, where patients receive detailed verbal and written information (green and blue notes) regarding the upcoming treatment process. The meeting is also approximately 1 hour, where the midwife instructs about hormonal stimulation, medication, and practical aspects of the IVF procedure.

Figure 6: Meeting with the midwife and guidance before home phase.

This stage represents a transition from physician-led consultation to more detailed procedure-oriented guidance, where the focus shifts from preparing the patient for active participation in the treatment. The mapping indicates that this interaction plays a central role in explaining how the treatment is to be carried out, including how to administer injections and how to follow treatment schedules.

Following the midwife consultation, patients transition from a clinical setting to managing parts of the treatment process independently at home. During this phase, patients are expected to follow detailed instructions regarding medication, including administering hormonal injections over a specified period. While this information is introduced during clinical interactions (blue and green notes: figure 6), opportunities for clarification become more limited once the patient returns home.

At the same time, reflections captured in the mapping and identified, from the patient perspective (pink notes, figure 6**)**, this highlight uncertainty related to practical aspects of the treatment. In particular, these questions arise regarding how to correctly administer injections, how to interpret bodily responses, and how to manage potential side effects. These uncertainties suggest that patients are required not only to understand the information provided but also to translate it into correct actions in a home environment without direct supervision from health professionals.

In addition, patients at this phase must follow specific schedules and timing for medication and appointments. The mapping indicates that this may create additional pressure, as patients are expected to coordinate treatment-related activities with their everyday lives. This coordination is primarily guided by the treatment schedule (*stimuleringsprotokoll*) which is personalized provided by the midwife during the consultation (see section 4.1.6 and appendix A).

The transition from clinic-based interaction to home-based responsibility also highlights a shift in the role of the patient, from recipient of information to active executor of the treatment. While support mechanisms such as written instructions or digital resources are available, the mapping suggests that patients may still experience uncertainty regarding whether they are performing the treatment correctly.

Overall, this stage is characterized by a combination of detailed clinical instruction and individual responsibility, which may influence patients' confidence in managing the treatment process and their overall experience of IVF care.

4.1.5 Treatment Continuation

As shown in figure 7, the next stage of the mapping of the IVF care pathway involves the initiation of treatment at home, followed by patients engaging with the healthcare system to progress their IVF process.

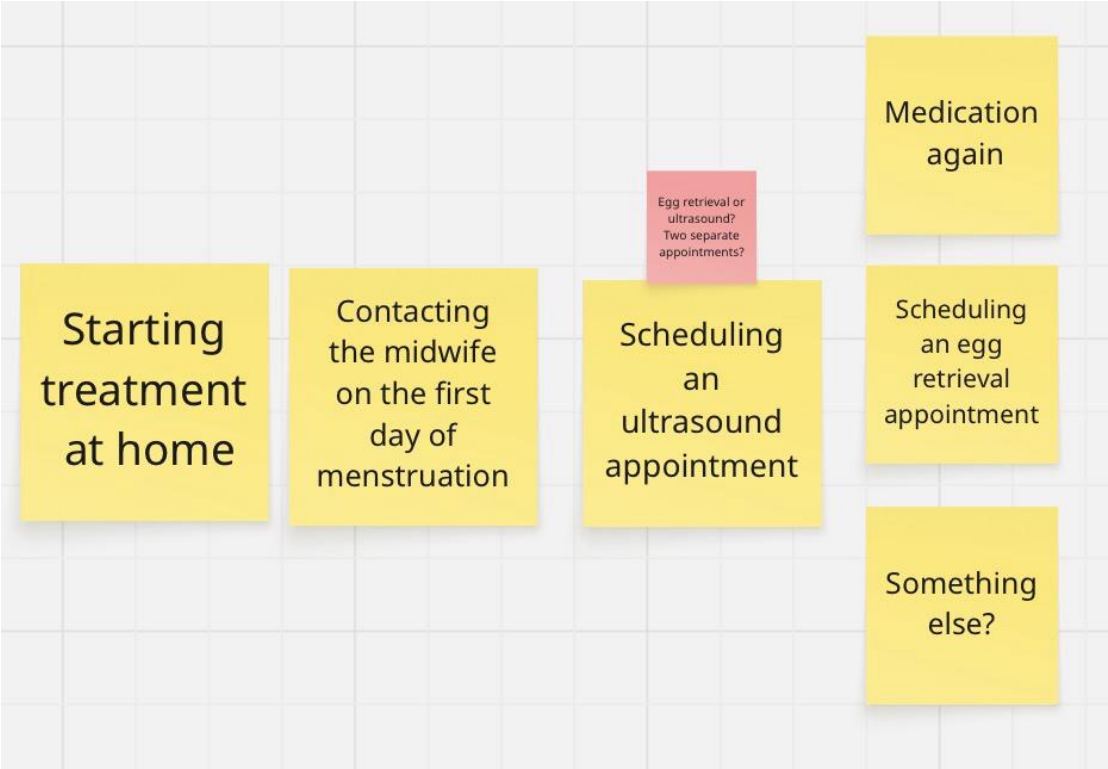


Figure 7: Stages before egg retrieval or if anything else happens toward the end of the hormonal treatment.

The mapping indicates that this phase begins with the patient contacting the midwife on the first day of menstruation, which serves as a trigger for the next steps in the treatment process. Following this, patients are scheduled for clinical procedures such as ultrasound examinations and egg retrieval.

This stage is characterized by multiple scheduled interactions, where patients move between different appointments and treatments steps. In addition, patients may be required to resume or adjust medication, further reinforcing the ongoing and cyclical nature of the treatment process.

The red **(**figure **7)** note when scheduling an ultrasound appointment highlights an uncertainty regarding missing information about what is being scheduled. For example, questions arise whether certain procedures, such as ultrasound and egg retrieval, are part of the same visit or require separate appointments. This suggests that patients may experience difficulties in understanding how the process unfolds over time.

Furthermore, the mapping indicates that patients are responsible for initiating certain actions, such as contacting healthcare professionals and coordinating appointments. This reinforces the active role of patient involvement in navigating the treatment process and highlights the need for clear and accessible information regarding next steps.

Overall, this phase is characterized by coordination, sequencing of appointments, and continued patient responsibility. While the process is structured from a clinical perspective, patient reflections indicate that the connections between different steps may not always be fully clear, which contributes to uncertainty in navigating the treatment pathway.

4.1.5 Ethnographic Observations in the Clinical and Laboratory Setting

The observations described in this section were made possible through the researchers' sustained presence at the Reproductive Medicine Division over an extended period. Due to the opportunity of receiving an office location on one of the laboratory floors, the researchers were present in shared spaces within the division on a regular basis. During these interactions, staff conversations frequently centered on recent research findings related to IVF, new studies, information regarding the organization, or relevant media such as podcasts and documentaries, all which reflect a culture of professional curiosity and continuous learning among the clinical team.

This ongoing presence also facilitated a collaborative dynamic between the researchers and the staff. In some cases, the researchers received materials to explore, such as patient-facing information documents and media relevant to the IVF information landscape. Several data sources collected during this study, including the patient-facing information materials documented in 4.1.6 and the laboratory day described below, emerged directly from staff suggestions rather than from the researchers' initial data collection plan. This reflects both the openness of the division to the research process and value of sustained field presence as a method for accessing data that would not have been available through structured or time-limited approaches.

The researchers spent one day observing the work of laboratory staff at the Reproductive Medicine Division. During this day, the researchers were present during several parts of the IVF process, including egg retrieval, embryo transfer, and ICSI preparation for the following day.

Egg retrieval

The egg retrieval procedure began with the laboratory staff preparing the necessary equipment, including a transport container used to transfer the retrieved eggs to the laboratory. When the patient arrived with the midwife, she and her partner were seated opposite the laboratory staff member. The laboratory staff introduced themselves, checked the patient's identification, and explained that the patient would receive information about the number of retrieved eggs after the procedure. The patient was also informed that the laboratory staff would later show what an egg looks like.

Before the procedure started, it was important that the patient had emptied her bladder, as a full bladder could make it more difficult for the physician to perform the procedure. Although the patient had visited the toilet beforehand, the bladder still had to be emptied during the procedure. During the egg retrieval, another physician entered the room to assist and provide support.

Throughout the procedure, several healthcare professionals were present and involved, including physicians, midwives, nurses, and laboratory staff. The physician communicated continuously with the patient and asked how she wanted certain parts of the procedure to be handled. Information was also provided during the procedure about the number of eggs retrieved and about circumstances that affected whether the procedure could continue. The midwife also communicated with and involved the partner during the procedure.

Embryo transfer

The researchers were also present during an embryo transfer. The patient appeared open and prepared for the procedure. During the interaction, the patient asked questions about what she should do after the transfer and whether she could continue living as usual. The physician responded to the patient's questions and explained that this information would be repeated later.

ICSI preparation

During the same observation day, the researchers also followed laboratory staff during preparation for ICSI procedures planned for the following day. This provided insight into the laboratory work that takes place outside the direct patient encounter and how laboratory staff prepare material and procedures as part of the IVF process.

Additional observations

The room where patients provide sperm samples is located on a different floor from the laboratory. Although the laboratory is situated on the same floor as the Reproductive Medicine Division, the laboratory staff do not share the same break room or other common staff areas with the clinical department.

During the observation day, one patient who was scheduled to provide a sperm sample had forgotten to bring a valid driver's license. As a result, the patient had to travel back to collect the identification document, which took approximately 1.5 hours. A member of the laboratory staff commented that this was understandable, especially since many people today are used to having identification or other documents available digitally on their phone. However, the hospital's identification control still required a physical identification document.

From an ethnographic perspective, the observation day at the laboratory provided insight that goes beyond what can be captured through interviews alone. The laboratory environment was characterized by a high degree of precision and quiet concentration, in contrast to the more communicative and emotionally visible work taking place in the clinical rooms nearby. Observing the clinical team working with focus and minimal verbal exchange reflects the technical demands of the procedures they were performing. At the same time, the moments of patient contact were managed with deliberate care,

as staff shifted from technical to communicative mode when introducing themselves, checking identification and explaining next steps. As an observer of the procedure it made it more clear how professional the clinical team is, and that each moment is managed with care.

The egg retrieval procedure was striking in its emotional intensity. Despite the clinical setting, the room held a palpable sense of significance for the patient and her partner. Continuous communication from the physician and midwife appeared to serve not only an informational function but an emotional one, to maintain a sense of safety and agency for the patient during physically and psychologically demanding moments.

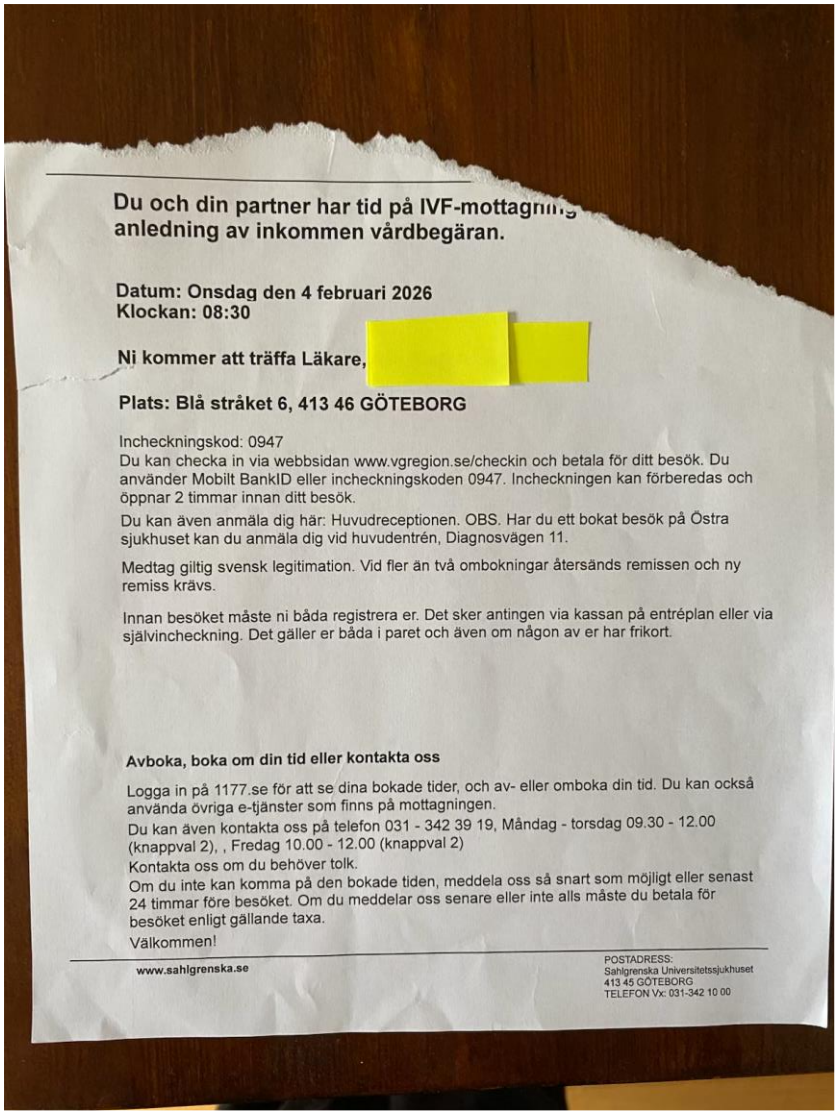
4.1.6 Patient-Facing Information Materials Across the IVF Pathway

To complement the mapping of the IVF process and observation in sections 4.1.1-4.1.4, this section documents the written and visual information materials patients receive and encounter across the IVF pathway. These materials were collected as part of the ethnographic orientation of this study, during which the researchers participated in a simulated patient journey and were present at multiple stages of the clinical process.

The materials span the full IVF pathway, from the initial appointment letter received before the first visit, through the waiting room environment, the midwife consultation, and the instructions provided ahead of egg retrieval and embryo transfer. Together these provide a concrete illustration of the volume and format of information which the patients are expected to engage with, much of that is delivered in written form and intended to be read and acted upon independently at home.

The figures in this section represent a selection of materials chosen to illustrate key characteristics of the information landscape at each stage of the pathway. The complete set of materials collected is documented in appendix A, organized by stage to allow the reader to examine the full scope of patient-facing information without disrupting the analytical flow of the main text.

Figure 8 shows the appointment letter sent to patients prior to their first visit, which includes practical information about the appointment, check-in procedures and contact details. This is the patient's first point of contact with the Reproductive Medicine Division following the completion of their fertility investigation. This letter and the enclosed information are addressed only to the woman who is the patient in this case.



Du och din partner har tid på IVF-mottagni
anledning av inkommen vårdbegäran.

Datum: Onsdag den 4 februari 2026
Klockan: 08:30

Ni kommer att träffa Läkare, [redacted]

Plats: Blå stråket 6, 413 46 GÖTEBORG

Incheckningskod: 0947
Du kan checka in via webbsidan www.vgregion.se/checkin och betala för ditt besök. Du använder Mobilt BankID eller incheckningskoden 0947. Incheckningen kan förberedas och öppnar 2 timmar innan ditt besök.

Du kan även anmäla dig här: Huvudreceptionen. OBS. Har du ett bokat besök på Östra sjukhuset kan du anmäla dig vid huvudentrén, Diagnosvägen 11.

Medtag giltig svensk legitimation. Vid fler än två ombokningar återsänds remissen och ny remiss krävs.

Innan besöket måste ni båda registrera er. Det sker antingen via kassan på entréplan eller via självincheckning. Det gäller er båda i paret och även om någon av er har frikort.

Avboka, boka om din tid eller kontakta oss

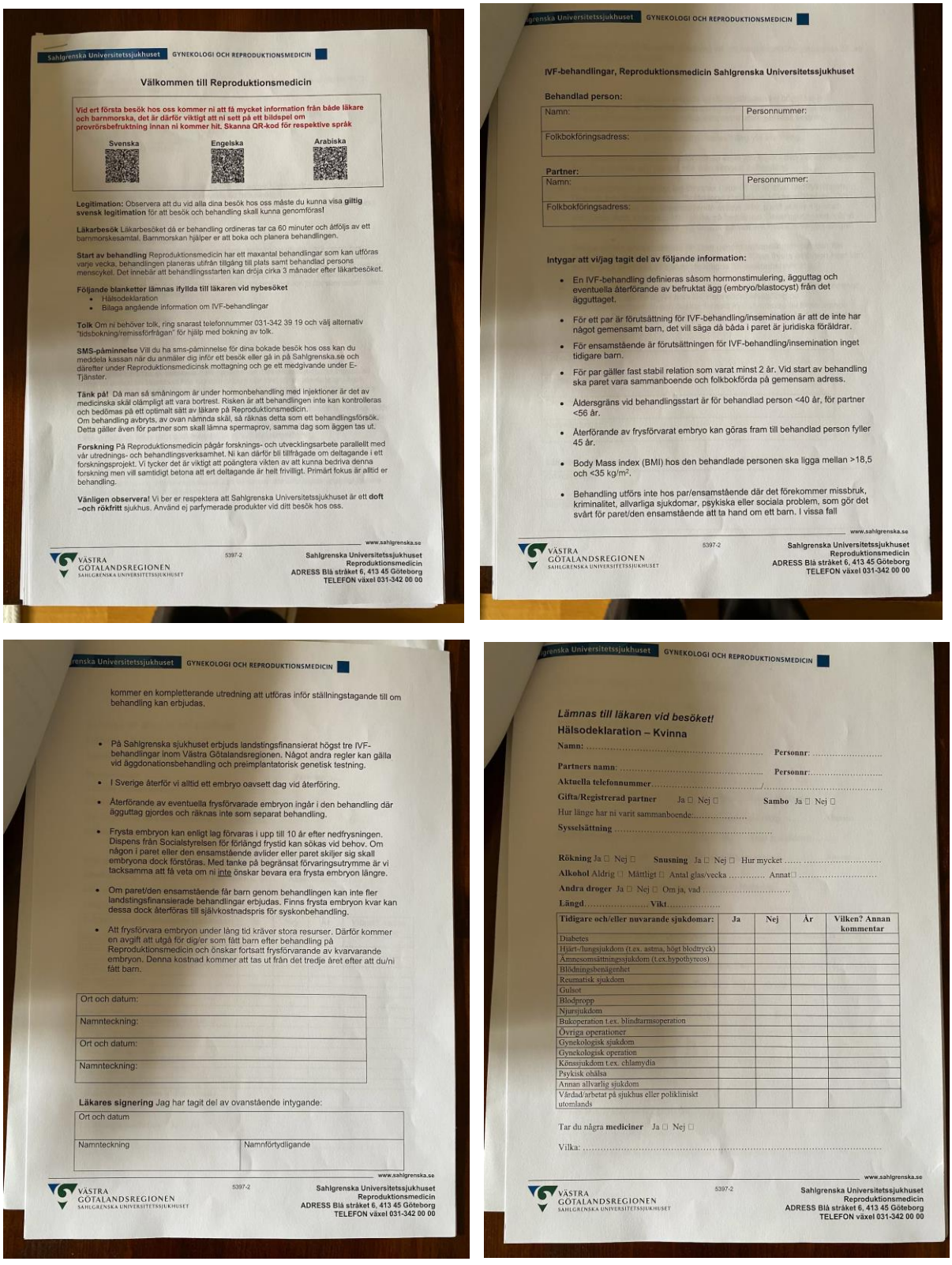
Logga in på 1177.se för att se dina bokade tider, och av- eller omboka din tid. Du kan också använda övriga e-tjänster som finns på mottagningen.
Du kan även kontakta oss på telefon 031 - 342 39 19, Måndag - torsdag 09.30 - 12.00 (knappval 2), , Fredag 10.00 - 12.00 (knappval 2)
Kontakta oss om du behöver tolk.
Om du inte kan komma på den bokade tiden, meddela oss så snart som möjligt eller senast 24 timmar före besöket. Om du meddelar oss senare eller inte alls måste du betala för besöket enligt gällande taxa.
Välkommen!

www.sahlgrenska.se

POSTADRESS:
Sahlgrenska Universitetssjukhuset
413 45 GÖTEBORG
TELEFON Vx: 031-342 10 00

Figure 8: Appointment letter.

Figure 9 shows the welcome letter included in the pre-visit information package, which introduces the IVF process and directs patients to watch an information video via QR code before their first appointment. The letter also outlines what documents patients are expected to bring and what forms need to be completed prior to their appointment. Additional documents sent in the first welcome package are provided in appendix A.



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Välkommen till Reproduktionsmedicin

Vid ert första besök hos oss kommer ni att få mycket information från både läkare och barnmorska, det är därför viktigt att ni sett på ett bildspel om provrörsbefruktning innan ni kommer hit. Skanna QR-kod för respektive språk

Svenska Engelska Arabiska

Legitimation: Observera att du vid alla dina besök hos oss måste du kunna visa **giltig svensk legitimation** för att besök och behandling skall kunna genomföras!

Läkarbesök Läkarbesöket då er behandling ordineras tar ca 60 minuter och åtföljs av ett barnmorskesamtal. Barnmorskan hjälper er att boka och planera behandlingen.

Start av behandling Reproduktionsmedicin har ett maxantal behandlingar som kan utföras varje vecka, behandlingen planeras utifrån tillgång till plats samt behandlad persons menscykel. Det innebär att behandlingsstarten kan dröja cirka 3 månader efter läkarbesöket.

Följande blanketter lämnas ifyllda till läkaren vid nybesöket
- Hälsodeklaration
- Bilaga angående information om IVF-behandlingar

Tolk Om ni behöver tolk, ring snarast telefonnummer 031-342 39 19 och välj alternativ "tidsbokning/remissförfrågan" för hjälp med bokning av tolk.

SMS-påminnelse Vill du ha sms-påminnelse för dina bokade besök hos oss kan du meddela kassan när du anmäler dig inför ett besök eller gå in på Sahlgrenska.se och därefter under Reproduktionsmedicinsk mottagning och ge ett medgivande under E-Tjänster.

Tänk på! Då man så småningom är under hormonbehandling med injektioner är det av medicinska skäl olämpligt att vara bortrest. Risken är att behandlingen inte kan kontrolleras och bedömas på ett optimalt sätt av läkare på Reproduktionsmedicin.
Om behandling avbryts, av ovan nämnda skäl, så räknas detta som ett behandlingsförsök. Detta gäller även för partner som skall lämna spermaprov, samma dag som äggen tas ut.

Forskning På Reproduktionsmedicin pågår forsknings- och utvecklingsarbete parallellt med vår utrednings- och behandlingsverksamhet. Ni kan därför bli tillfrågade om deltagande i ett forskningsprojekt. Vi tycker det är viktigt att poängtera vikten av att kunna bedriva denna forskning men vill samtidigt betona att ert deltagande är helt frivilligt. Primärt fokus är alltid er behandling.

Vänligen observera! Vi ber er respektera att Sahlgrenska Universitetssjukhuset är ett **doft –och rökfritt** sjukhus. Använd ej parfymerade produkter vid ditt besök hos oss.

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ADRESS Blå stråket 6, 413 45 Göteborg
TELEFON växel 031-342 00 00

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IVF-behandlingar, Reproduktionsmedicin Sahlgrenska Universitetssjukhuset

Behandlad person:

Namn:	Personnummer:
Folkbokföringsadress:	

Partner:

Namn:	Personnummer:
Folkbokföringsadress:	

Intygar att vi/jag tagit del av följande information:

- En IVF-behandling definieras såsom hormonstimulering, ägguttag och eventuella återförande av befruktat ägg (embryo/blastocyst) från det ägguttaget.
- För ett par är förutsättning för IVF-behandling/insemination är att de inte har något gemensamt barn, det vill säga då båda i paret är juridiska föräldrar.
- För ensamstående är förutsättningen för IVF-behandling/insemination inget tidigare barn.
- För par gäller fast stabil relation som varat minst 2 år. Vid start av behandling ska paret vara sammanboende och folkbokförda på gemensam adress.
- Åldersgräns vid behandlingsstart är för behandlad person <40 år, för partner <56 år.
- Återförande av frysförvarat embryo kan göras fram till behandlad person fyller 45 år.
- Body Mass index (BMI) hos den behandlade personen ska ligga mellan >18,5 och <35 kg/m^2.
- Behandling utförs inte hos par/ensamstående där det förekommer missbruk, kriminalitet, allvarliga sjukdomar, psykiska eller sociala problem, som gör det svårt för paret/den ensamstående att ta hand om ett barn. I vissa fall

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kommer en kompletterande utredning att utföras inför ställningstagande till om behandling kan erbjudas.

- På Sahlgrenska sjukhuset erbjuds landstingsfinansierat högst tre IVF-behandlingar inom Västra Götalandsregionen. Något andra regler kan gälla vid äggdonationsbehandling och preimplantatorisk genetisk testning.
- I Sverige återför vi alltid ett embryo oavsett dag vid återföring.
- Återförande av eventuella frysförvarade embryon ingår i den behandling där ägguttag gjordes och räknas inte som separat behandling.
- Frysta embryon kan enligt lag förvaras i upp till 10 år efter nedfrysningen. Dispens från Socialstyrelsen för förlängd frystid kan sökas vid behov. Om någon i paret eller den ensamstående avlider eller paret skiljer sig skall embryona dock förstöras. Med tanke på begränsat förvaringsutrymme är vi tacksamma att få veta om ni inte önskar bevara era frysta embryon längre.
- Om paret/den ensamstående får barn genom behandlingen kan inte fler landstingsfinansierade behandlingar erbjudas. Finns frysta embryon kvar kan dessa dock återföras till självkostnadspris för syskonbehandling.
- Att frysförvara embryon under lång tid kräver stora resurser. Därför kommer en avgift att utgå för dig/er som fått barn efter behandling på Reproduktionsmedicin och önskar fortsatt frysförvarande av kvarvarande embryon. Denna kostnad kommer att tas ut från det tredje året efter att du/ni fått barn.

Ort och datum:
Namnteckning:
Ort och datum:
Namnteckning:

Läkares signering Jag har tagit del av ovanstående intygande:

Ort och datum	
Namnteckning	Namnförtydligande

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Lämnas till läkaren vid besöket!

Hälsodeklaration – Kvinna

Namn: ..... **Personnr:** .....

Partners namn: ..... **Personnr:** .....

Aktuella telefonnummer: ...../.....

Gift/Registrerad partner Ja ☐ Nej ☐ **Sambo** Ja ☐ Nej ☐

Hur länge har ni varit sammanboende:.....

Sysselsättning .....

Rökning Ja ☐ Nej ☐ **Snusning** Ja ☐ Nej ☐ Hur mycket ....

Alkohol Aldrig ☐ Mättligt ☐ Antal glas/vecka ..... Annat: ☐ .....

Andra droger Ja ☐ Nej ☐ Om ja, vad .....

Längd..... **Vikt**.....

Tidigare och/eller nuvarande sjukdomar:	Ja	Nej	År	Vilken? Annan kommentar
Diabetes				
Hjärt-/lungsjukdom (t.ex. astma, högt blodtryck)				
Ämnesomsättningssjukdom (t.ex.hypothyreos)				
Blödningsbenägenhet				
Reumatisk sjukdom				
Gulsot				
Blodpropp				
Njursjukdom				
Bukoperation t.ex. blindtarmsoperation				
Övriga operationer				
Gynekologisk sjukdom				
Gynekologisk operation				
Könssjukdom t.ex. chlamydia				
Psykisk ohälsa				
Annan allvarlig sjukdom				
Vårdad/arbetat på sjukhus eller poliklinikt utomlands				

Tar du några **mediciner** Ja ☐ Nej ☐

Vilka: .....

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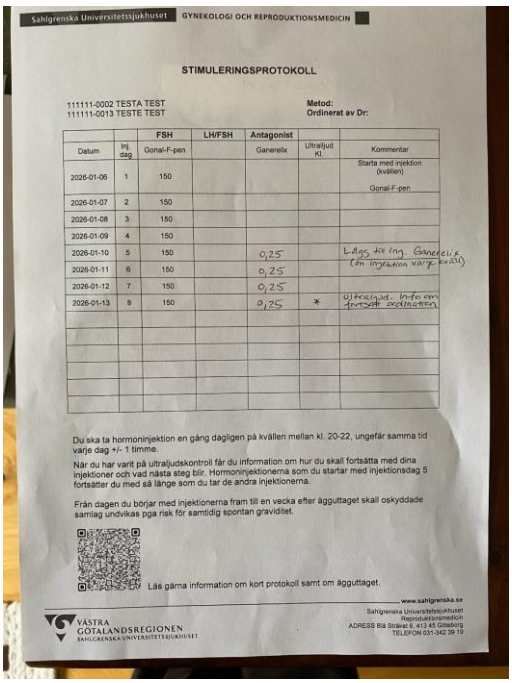
Figure 9: Welcome letter with QR codes and forms that need to be completed.

Figure 10 shows the waiting room at Reproductive Medicine Division, where patients encounter additional information through a TV screen displaying patient information, as well as a physical information station containing printed materials and QR codes.

More materials and what can be found in the waiting room are provided in appendix A.

Figure 10: Waiting room with TV screen and station with physical information.

Figure 11 shows the treatment schedule which is provided to patients during the midwife consultation. This document serves as the primary reference tool for patients managing hormonal injections at home, specifying the type, dose, and timing of each medication across the treatment cycle. The additional materials provided at this stage are documented in appendix A.



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STIMULERINGSPROTOKOLL

111111-0002 TESTA TEST
111111-0013 TESTE TEST

Metod:
Ordinerat av Dr:

Datum	Inj. dag	FSH Gonal-F-pen	LH/FSH	Antagonist Ganirelix	Ultraljud Kl.	Kommentar
2026-01-06	1	150				Starta med injektion (kvällen) Gonal-F-pen
2026-01-07	2	150				
2026-01-08	3	150				
2026-01-09	4	150				
2026-01-10	5	150		0,25		Lägg till inj. Ganirelix (en injektion varje kväll)
2026-01-11	6	150		0,25		
2026-01-12	7	150		0,25		
2026-01-13	8	150		0,25	*	Ultraljud. Info om fortsatt ordination

Du ska ta hormoninjektion en gång dagligen på kvällen mellan kl. 20-22, ungefär samma tid varje dag +/- 1 timme.

När du har varit på ultraljudskontroll får du information om hur du skall fortsätta med dina injektioner och vad nästa steg blir. Hormoninjektionerna som du startar med injektionsdag 5 fortsätter du med så länge som du tar de andra injektionerna.

Från dagen du börjar med injektionerna fram till en vecka efter ägguttaget skall oskyddade samlag undvikas pga risk för samtidig spontan graviditet.

Läs gärna information om kort protokoll samt om ägguttaget.

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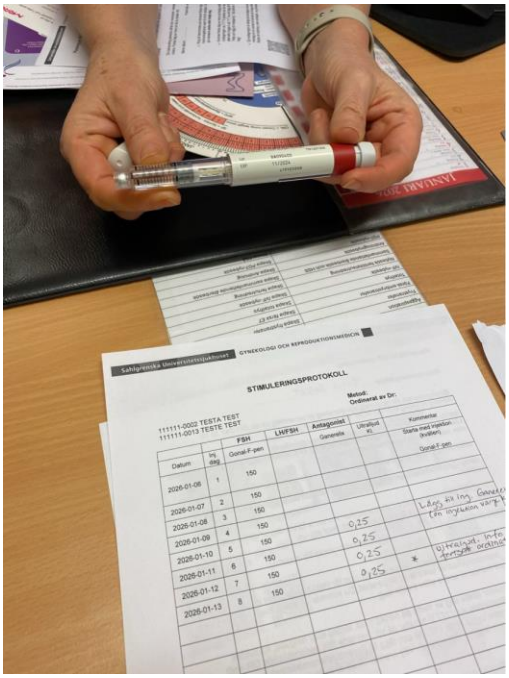
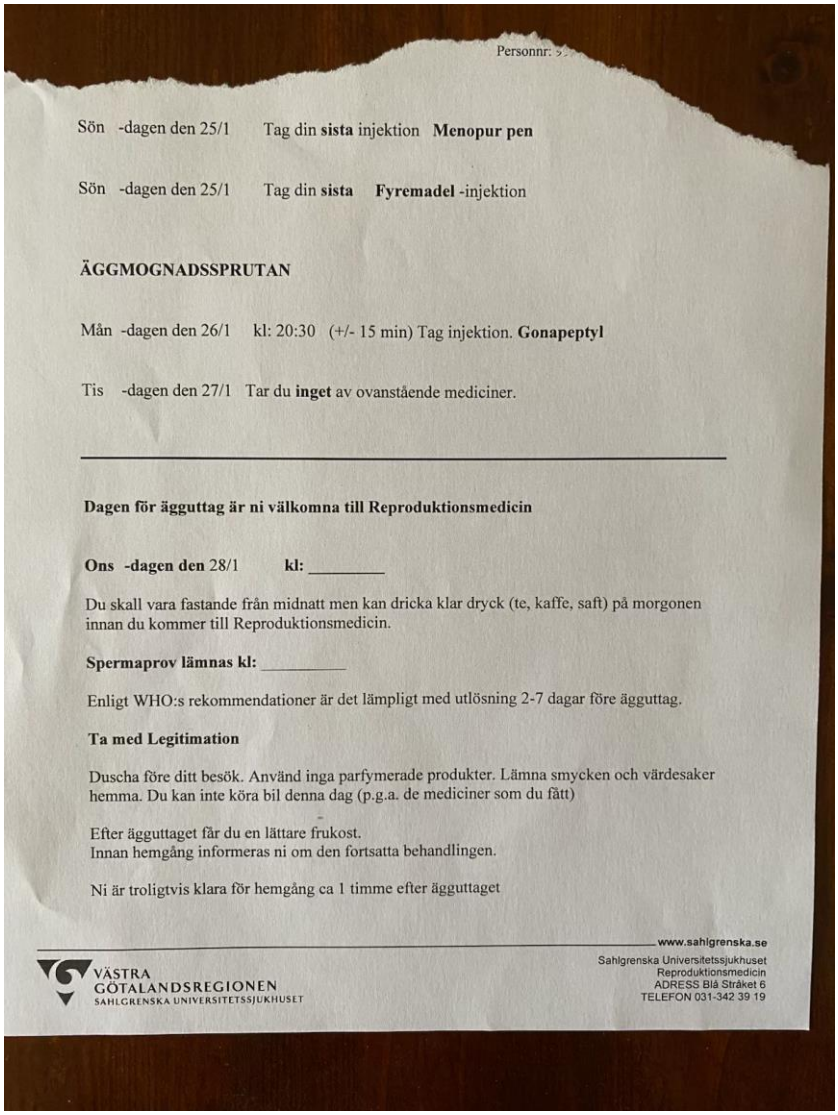


Figure 11: Treatment schedule and consultation with midwife.

Figure 12 shows the written instructions provided to patients ahead of the egg retrieval procedure. More information when preparing for this day is provided in appendix A.



Personnr: >>

Sön -dagen den 25/1 Tag din **sista** injektion **Menopur pen**

Sön -dagen den 25/1 Tag din **sista** **Fyremadel** -injektion

ÄGGMOGNADSSPRUTAN

Mån -dagen den 26/1 kl: 20:30 (+/- 15 min) Tag injektion. **Gonapeptyl**

Tis -dagen den 27/1 Tar du **inget** av ovanstående mediciner.

Dagen för ägguttag är ni välkomna till Reproduktionsmedicin

Ons -dagen den 28/1 **kl:** _____

Du skall vara fastande från midnatt men kan dricka klar dryck (te, kaffe, saft) på morgonen innan du kommer till Reproduktionsmedicin.

Spermaprov lämnas kl: _____

Enligt WHO:s rekommendationer är det lämpligt med utlösning 2-7 dagar före ägguttag.

Ta med Legitimation

Duscha före ditt besök. Använd inga parfymerade produkter. Lämna smycken och värdesaker hemma. Du kan inte köra bil denna dag (p.g.a. de mediciner som du fått)

Efter ägguttaget får du en lättare frukost.
Innan hemgång informeras ni om den fortsatta behandlingen.

Ni är troligtvis klara för hemgång ca 1 timme efter ägguttaget

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Figure 12: Egg retrieval day instructions

4.2 Stakeholder Mapping

To develop an understanding of which individuals and departments may influence and/or be influenced by the project, a stakeholder analysis was conducted as mentioned in 3.5. The central question guiding the analysis was: to what extent can different healthcare areas and departments influence, or be influenced by, the information distributed by SUH department of reproductive medicine.

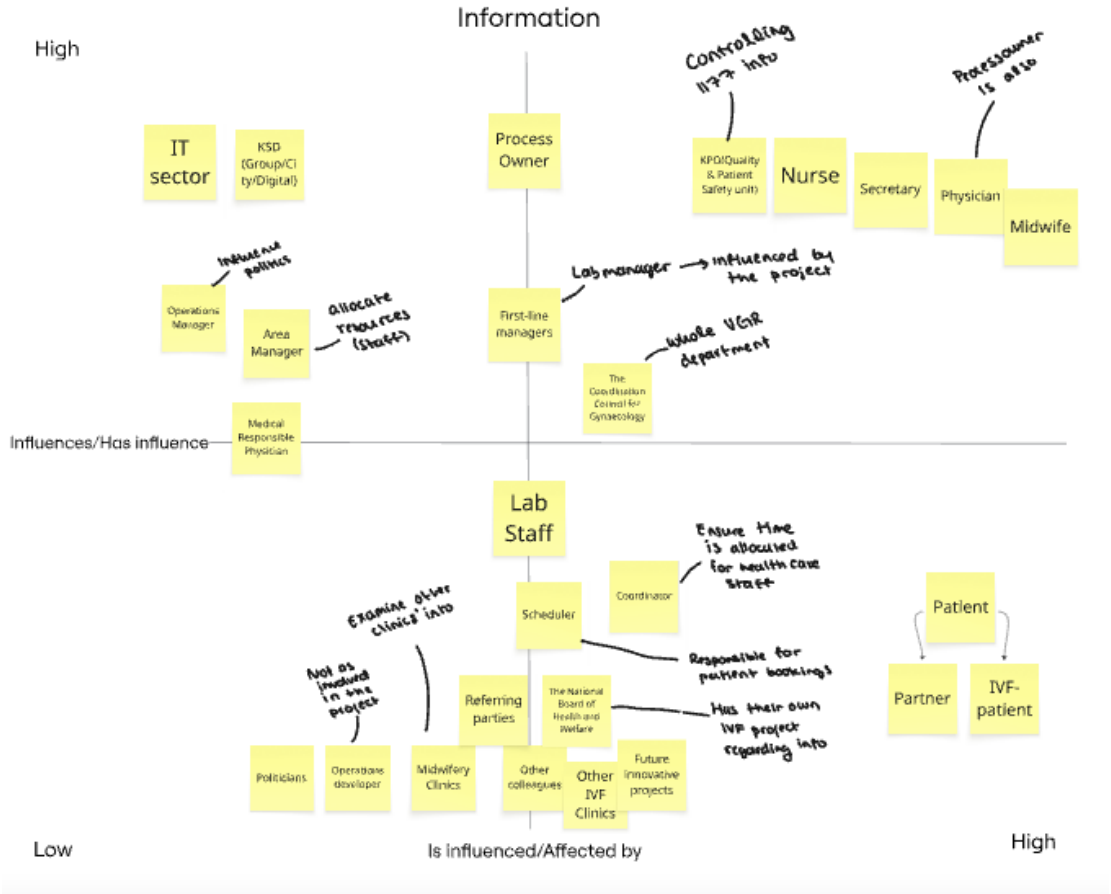

Figure 13: Mapping out the stakeholders in this project

Given their extensive insight into the organization, these participants contributed to mapping various healthcare areas onto a stakeholder matrix. The mapping assessed both the degree of influence (low or high) and the degree to which each area is affected (low or high). The result of this mapping is illustrated in figure 13**.**

The healthcare areas and departments identified as most relevant for interviews were those with high influence and high impact, as well as those with low influence but high impact. This selection enabled a deeper understanding of both how key actors who strongly influence information reason about and shape it, and how those most affected receive and interpret it.

It is important to note that stakeholders positioned in the middle of the matrix may also play a significant role. However, this study focuses primarily on the extremes to develop a clearer understanding of the dynamics surrounding the information flow.

What could also be interesting would be to conduct interviews with departments that have high influence but low impact, as they are responsible for shaping and distributing information through channels such as 1177. Additionally, these departments may already be involved in similar initiatives aimed at improving information provided to patients.

4.3 Information mapping from SUH

By reviewing the materials sent to patients by post, as well as the information communicated via IVF section 1177, which serves as the healthcare system's official communication channel, patterns could be defined. This was done by mapping what information is distributed, through which channels, and in what formats. This mapping helped identify the extent to which information is repeated across these channels, as illustrated in figure 14. When one or more post-its are tagged on each other, it indicates that the same information is shared across the different channels. Post-its marked with a circle represent unique information that is communicated only within that specific channel.

Figure 14: Mapping of information from SUH

The different color for the post it stands for:

- Yellow is for information from 1177
- Black is for information from "*The Little Book about IVF*" (appendix A)
- Pink is for information sent to patients from SUH
- Orange is info from SUH own video reach by using QR-codes

The materials sent to patients follow the structure illustrated in the picture above. They consist of eight pages of text, including the appointment notice, Q-IVF information, QR codes linking to a self-recorded video presentation delivered through

PowerPoint, selected key information from the clinic, a signed declaration confirming that the patient has read the material, and health declarations for both the woman and her partner. In addition, a booklet titled *"The Little Book about IVF"* (appendix A) is included in the envelope to the patient.

The mapping revealed that the same information is communicated in multiple ways, at different stages, and with varying levels of explanation. For instance, the mapping presented above uses the physical documents as a baseline, from which it can be identified where information is repeated and where new information is introduced.

- The most detailed information was identified in SUH's video and *The Little Book about IVF (appendix A).*
- Some information is repeated across several channels, while other information is only communicated through one source.
- Practical and administrative information is mainly found in the written material from SUH.
- Medical and process-related information is distributed across the video, the IVF booklet and 1177.
- Patients are expected to combine information from several formats to understand the full IVF pathway.

This mapping demonstrates that substantial portions of the information are repeated across the four communication channels. However, certain elements stand out as being communicated exclusively through the written paper materials (pink post it):

- the duration of the first meeting with the physician
- instructions for signing up for SMS appointment reminders
- information that SUH is a fragrance-free and smoke-free environment
- the requirement that individuals undergoing IVF must not have substance abuse issues e.g., and that further assessment may be required to be able to continue
- information that couples must not already have a shared child from a legal standpoint
- the requirement of a relationship of more than two years, cohabitation, and registration at the same address
- the out-of-pocket cost for sibling treatment attempts
- information regarding Q-IVF

All other information is communicated through at least one additional channel.

4.4 Thematic Findings from Interviews with Healthcare Professionals and Patients

The following section presents the thematic findings derived from semi-structured interviews conducted with healthcare professionals at the Reproductive Medicine Division at SUH, former patients that have gone through their own IVF journey and a senior nurse at Copenhagen University Hospital.

Through thematic analysis, recurring patterns were identified across the interview data and organized into seven overarching themes: A multichannel information landscape, standardized information through a stepwise approach, patient responsibility in navigating information, information breakdown, the patient experience, structural incompatibilities between care and everyday life and organizational conditions. Each theme is presented in turn, supported by participant accounts and direct quotations. A separate section is dedicated to comparative perspectives from Copenhagen University Hospital, drawing from the themes, which offers an external point of reference for the challenges identified at SUH.

4.4.1 A Multichannel Information Landscape

Patient information within the IVF care pathway is communicated through a combination of channels, including telephone consultations, the digital platform 1177, written materials, in-person meetings, and digital resources such as instructional videos. This multimodal communication structure is intended to ensure accessibility and flexibility for patients, allowing them to receive and revisit information in different formats and at various stages of the treatment process. At the same time, the use of multiple parallel channels contributes to a fragmented information landscape, where responsibility for navigating and integrating information often falls on the patient.

The main patient-facing communication channels include:

- **1177 (digital platform):** Used for written communication between patients and healthcare providers, including messaging (48h reply time), follow-up questions, and access to general healthcare information. It also functions as a central, though sometimes limited, information source, replacing previous clinic-specific webpages that enable patients to access information independently and repeatedly outside clinical encounters.

- **Telephone:** Primarily used for real-time communication, including counselling, follow-up, clarification of instructions, and handling urgent or sensitive questions.

- **Face-to-face interactions (F2F):** Occurs during clinical visits such as consultations, examinations, and treatment procedures. These interactions are key for delivering complex information and enabling dialogue.

- **Written materials (paper-based):** Include appointment letters, treatment schedules, and informational leaflets sent to patients. These materials are often used as a reference throughout the treatment process.

- **Digital educational resources:** Include instructional videos, QR codes, and external websites used to explain treatment steps, medication use, and the IVF process. These resources enable patients to access information independently and repeatedly outside clinical encounters.

4.4.1.1 Communication as a Shared Professional Responsibility

Different professional roles contribute to patient communication in distinct ways. Midwives act as the primary communicators throughout the treatment process. Their communication with patients takes place across multiple channels, including telephone consultations for counseling, follow-up, and acute concerns, written communication via 1177, and face-to-face interactions during information sessions, treatments, and ultrasound examinations. Midwife B described that a significant part of their work consists of "*telephone counselling… many questions… a lot of worry.*". In addition to conveying information, midwives also have a pedagogical role, guiding patients through treatment procedures and medication use, often structured around standardized materials: "*I base everything entirely on the treatment schedule… all the information they need is there.*".

Secretaries function as coordinators within the information flow and are often the first point of contact for patients. According to secretary A, they mainly communicate via telephone and through 1177, which is considered a primary channel for managing patient inquiries: "*1177 can be considered the highest priority*.". Their responsibilities include distributing practical information, such as appointment letters and documentation, as well as managing incoming communication. A large part of their role involves answering recurring patient questions, often linked to missing or inaccessible information Secretary A describes it as "*Now I've answered three such questions… which used to be available on the website.*"

The secretary also explains that she does not "own" the attachments and text that are sent and published on the information webpage 1177. If she wants to change something, or even have full oversight of what they contain, she has to contact a system administrator for the entire "Area 1" and wait for them to administer the changes.

Physicians primarily communicate with patients during key clinical encounters, such as consultations involving diagnosis, treatment decisions, and care planning. These interactions are typically conducted face-to-face, while documentation in medical records serves as an important form of internal communication within the care team. Compared to other roles, physicians have more limited direct contact with patients throughout the process. Instead, much of their information is mediated through other professionals, particularly midwives.

Embryologist A describes how they contribute to patient communication, although their contact with patients is more limited and concentrated around specific treatment moments. Their role becomes visible during procedures such as egg retrieval and embryo transfer, where they may meet the patient, confirm identity, and provide information related to eggs, sperm, fertilization, or embryo development. As embryologist A described, being present during these moments makes the patient more than *"just a name on a paper or on a screen."*. The same interview also suggests that patients may value seeing that the laboratory exists and being able to ask questions directly, even if the time for such interaction is limited. In this sense, laboratory staff function as a bridge between the technical, often hidden, part of IVF treatment and the patient's understanding of what happens to eggs, sperm, and

embryos outside the body. Their communication is therefore not continuous, but it can be important for making the laboratory process more tangible and less abstract for patients. *(*embryologist 1)

4.4.1.2 Internal Communication Systems and Backstage Coordination

Communication within the IVF clinic is facilitated through multiple internal channels, involving both digital systems and interpersonal interactions. These channels support coordination between professional roles but also introduce complexity into the information flow.

- **Electronic health record systems (e.g., Elvis, WinIVF, Selma):** Used for documenting patient information, treatment plans, and clinical decisions. These systems function as the primary medium for formal, traceable communication between healthcare professionals, although they are not fully integrated and require manual transfer of information between systems.

- **1177 (internal handling):** In addition to patient communication, 1177 is used internally to receive, review, and distribute incoming patient messages. Administrative staff often triage and forward messages to the appropriate professional, by printing out the information or handing over a case in 1177. Making it a central node in both external and internal communication flows.

- **Verbal communication (face-to-face):** Occurs continuously in the clinical environment, for example between midwives, physicians, and administrative staff when coordinating patient care, clarifying information, or resolving issues in real time.

- **Telephone (internal use):** Used for quick coordination between staff members, particularly in time-sensitive situations where immediate clarification is required.

- **Paper-based workflows:** Certain administrative processes, such as referrals, consent forms, and documentation handling, still rely on physical paperwork, which is manually processed, scanned, and transferred between staff. These documents also serve as legal proof that the patient has received required information.

- **E-Mail and internal messaging systems:** Used for scheduling, coordination, such as staffing, planning, and administrative updates.

- **Visual planning tools (midwife scheduling board):** A shared physical board used by midwives to coordinate daily activities, patient flow, and task distribution. This tool supports real-time situational awareness within the team and enables quick adjustments during the workday.

4.4.2 Standardized Information Through a Stepwise Approach

The information provided to patients is largely standardized and structured around predefined materials, such as treatment schedules, brochures, printed documents, and digital resources. Healthcare professionals, particularly midwives, rely heavily on these materials when communicating with patients. The treatment schedule functions as a central tool for explaining treatment steps, medication, important dates, contact information, and timelines. As Midwife B explained: *"I base everything entirely on the treatment schedule… that is where all the information they need is."*.

At the same time, the way this information is communicated is not only a matter of handing out written material. The midwives appear to work according to what can be understood as a "next step principle", where they emphasize what is most important for the patient at that specific moment. This may include highlighting key dates, underline important phone numbers, and guide the patient through the printed material they have already received. In this way, the written documents are used both as a reference point and as a tool for structuring the conversation.

From the patient perspective, however, the first consultation can be experienced as information heavy. Patients 2 who attend their first visit describe receiving a large amount of information at once, which can create a feeling of being overwhelmed. One patient described the experience as being "fed" with information, almost like being a *sponge* trying to absorb everything. This illustrates a tension between the clinic's need to provide standardized and comprehensive information, and the patient's ability to process that information in an emotionally demanding situation.

The communication of information is typically distributed over time rather than delivered in a single instance. Patients receive different types of information at different stages of the IVF process, and key aspects are repeated across several interactions. This stepwise approach is partly shaped by time constraints and by the complexity of the treatment process. As midwife B explained: *"If we were to go through all the written information… we would never manage it in ten minutes."*. Instead, healthcare professionals prioritize the information that is most relevant at the current stage of treatment, while expecting patients to read the remaining written material themselves.

However, from a patient perspective, this structure may also create a lack of real-time dialogue and support. Several patients describe situations where they are left to interpret information, wait for the next step, and act independently without immediate access to clarification. Patient 2 expressed this uncertainty by saying: *"You just sit there waiting… you have no idea how this kind of thing works."*. This suggests that even when information is technically available, it may not always meet the patient's need for reassurance, interpretation, or emotional support in the moment.

Some patients also expressed a need for more direct access to the clinic in urgent situations, particularly outside office hours (patient 1). Rather than being referred to 1177, patients described a wish for an emergency number or a direct callback function for acute questions.

Digital tools have become an increasingly important complement to traditional communication. Instructional videos and QR codes are used to allow patients to

access information at home and at their own pace. From the staff perspective, this has improved patient preparedness. As midwife A noted: *"Most patients are very well prepared; they have read the material and watched the film."*. The possibility to revisit information several times at home may reduce stress compared with receiving all instructions during an in-person consultation.

Nevertheless, the reliance on asynchronous communication also has limitations. While videos, QR codes, and written information can support preparation, they do not replace the need for dialogue. For example, Patient 1 did not use the QR code before the meeting, partly because there was a long time between receiving the material and attending the first physical appointment. In this case, the timing of the information reduced its practical value. The patient also described a mismatch between expectations and reality when returning for treatment. After being told that they would be "first in line", they expected the process to start quickly. Instead, it took another six months before they had their first physical appointment at the clinic. This created frustration and a sense that the meaning of being "first in line" was unclear from the patient perspective.

The availability and accessibility of digital information also appear to have changed over time. Patient 3 described not finding relevant information on SUH's own website, which had been closed down, and also not finding sufficient information through 1177. This aligns with secretary A's descriptions of an information gap after the clinic-specific webpage was removed. Information that patients could previously find independently was no longer as easily accessible, which contributed to more recurring questions through 1177. As a result, 1177 became an important communication channel, but not necessarily a sufficient replacement for more specific and clinic-adapted information. This is further discussed from the staff perspective in section 4.4.3.

Overall, the findings show that patient information in the IVF care pathway is structured, standardized, and distributed across several formats and moments. This creates consistency and allows healthcare professionals to manage a complex process within limited time. At the same time, the patient experience reveals several challenges. Information may be available but not always accessible, understandable, timely, or emotionally supportive. Communication therefore depends not only on what information is provided, but also on when it is given, how it is explained, and whether the patient has the opportunity to ask questions when uncertainty arises.

4.4.3 Patient Responsibility in Navigating Information

Different stakeholders within the IVF care pathway contribute to patient communication in distinct but interconnected ways. Rather than being handled by one single professional group, information is distributed across midwives, physicians, administrative staff, digital platforms, printed materials, and the patients themselves. This creates a communication structure where several actors contribute to the patient's understanding of the process, but where the overall responsibility for navigating the information can become unclear.

Midwives play a central role in patient communication, both in face-to-face meetings and through telephone consultations. They are often responsible for explaining treatment steps, medication, timelines, and practical instructions. Although they rely

on standardized materials, such as treatment schedules and written information, the interviews show that communication is not fully consistent across individuals. As midwife A described: *"In general, we are supposed to say roughly the same things, but we probably still do everything quite differently."*. This suggests that standardized material provides a common foundation, while the actual communication is shaped by each midwife's way of explaining, emphasizing, and adapting the information to the patient.

In addition to delivering information, midwives also take on a role in validating and correcting information that patients bring from external sources. Since many patients search for information before or during treatment, they may arrive with knowledge from online forums, podcasts, social media, or acquaintances who have undergone IVF. This information can be useful, but it may also be incomplete, emotionally charged, or not applicable to the patient's specific medical situation. Healthcare professionals therefore need to guide patients toward more reliable and clinically verified information, while also helping them interpret what is relevant for their own treatment.

Patients themselves are active participants in the information process. They do not only receive information from the clinic but also seek additional knowledge outside the healthcare system. Patient 2 described this by saying: *"You had to search a bit yourself... podcasts and things like that, that you listened to."*. The same patient also explained that external information could be difficult to manage because IVF experiences vary greatly between individuals, making it hard to know what to trust or what to expect. This illustrates how patients often try to compensate for uncertainty by seeking information elsewhere, while at the same time risking exposure to conflicting or anxiety-inducing narratives.

Patient 3 also described difficulties related to finding clear entry points into public fertility care. The patient experienced a lack of clear guidance regarding where to turn for information within the public healthcare system, which contributed to a sense of distance and reduced trust. This was reinforced by the perception that communication from SUH was more focused on the organization's internal routines than on the patient's individual situation. As Patient 3 explained: *"There was never a single time when I called and they were like, 'Hi Patient 3, how are things going for you?' There was no personal contact; the focus was always on them and their organization, not on me as a patient."*. This highlights how information is not only about factual content, but also about whether the patient feels seen, guided, and supported.

Administrative staff, particularly secretaries, also play an important role in the communication flow. They often function as the first point of contact for patients and manage a high volume of questions related to waiting lists, referrals, bookings, and digital messages. One secretary emphasized the importance of 1177 as a communication channel: *"You could say that 1177 is the highest priority."*. At the same time, the secretaries described that the number of recurring questions increased after SUH's clinic-specific webpage was closed. The same secretary explained: *"Sometimes you just feel now I have answered three questions like this, questions that patients used to be able to find the answers to themselves on the website."*. This shows how changes in available information channels can shift the communication

burden from self-service information to direct contact with administrative staff (see figure 15 for reference).

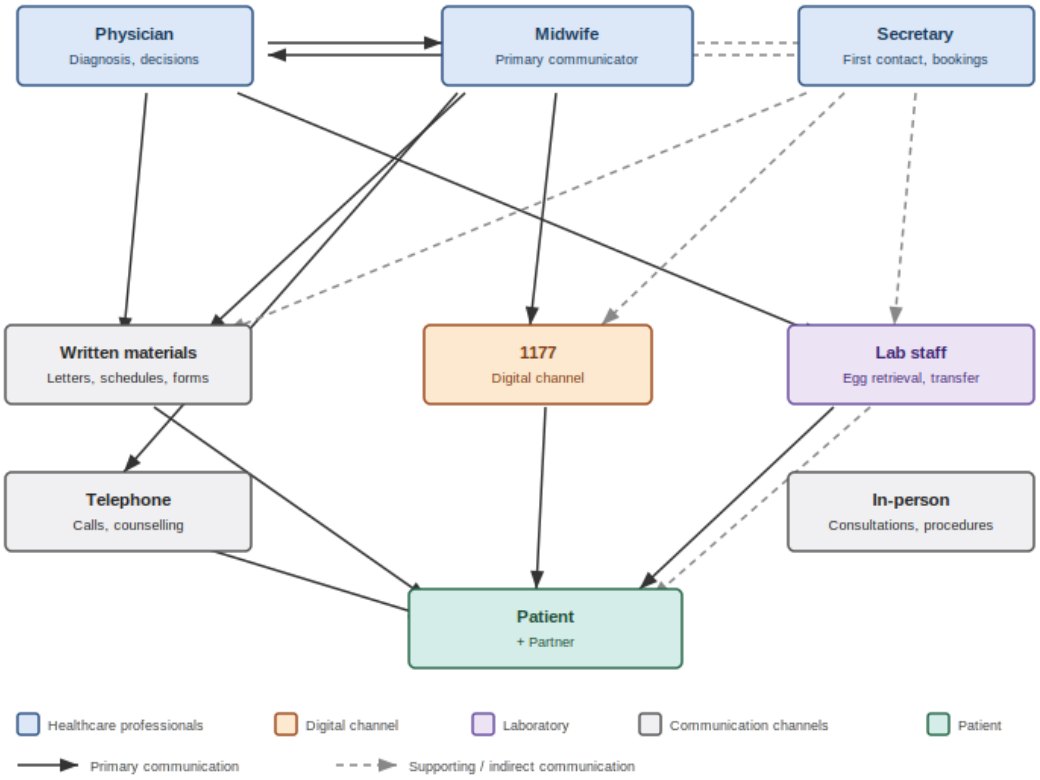

Figure 15: Information flow overview at SUH.

The role of the secretary is therefore not only administrative, but also relational. Secretaries help patients navigate the system, clarify waiting times, direct questions to the right professional group, and handle frustration caused by uncertainty or delays. However, their ability to provide answers is limited by the complexity of the system and by factors they cannot control, such as available appointments, medical prioritization, medical questions and resource constraints. This makes them an important interface between the patient and the organization but also places them in a position where they often need to manage dissatisfaction that originates elsewhere in the care pathway.

4.4.4 When Information Breaks Down: Repetition, Timing, and Mismatched Needs

Mismatch in communication contributes to misunderstandings, even when the factual information is correct. For instance, staff may explain why a treatment step is medically necessary, while patients may still feel unprepared for what it means in practice. Patient 1 described having many questions even after receiving written information, especially because the written material mainly explained what should happen next, rather than providing a broader understanding of possible scenarios.

Patient 1 explained that it would have been helpful to receive a short summary at each stage: *"I think I would have appreciated it if, every time we met, someone just gave a brief overall summary: this is what we have gone through, and this is what will happen next."*.

Another example of how staff attempt to support patient preparation is the practice of sending material home in advance. According to embryologist A, secretaries can send envelopes containing instructions and a sample tube before the patient's visit. This allows the patient and the partner to prepare at home and become familiar with the practical steps in a calmer setting, rather than receiving all instructions during the first meeting, as highlighted by midwife B.

The interviews with physicians, midwives, and embryologists also indicate that information gaps remain, despite general information being communicated through printed information sheets and digital resources. These gaps appear in relation to both administrative and medical details, such as the definition of "three attempts", the difference between method forms and standard forms, and the use of QR codes linking to IVF information videos. From the staff perspective, these issues are often already covered in the material. From the patient perspective, however, the early stages of the process can feel overwhelming, with many links, forms, and instructions introduced at the same time.

Patients described the beginning of the process as particularly information-heavy and difficult to organize mentally. Patient 1 explained that before starting IVF, the knowledge of this about this process limited: *"I probably did not know much more than that there would be an egg retrieval and an embryo transfer… but there has been much, much more in between."* This shows that patients may enter the process with a simplified understanding of IVF, while the actual care pathway contains many more steps, decisions, waiting periods, and possible deviations than expected.

Cost-related information was another area where misunderstandings occurred. The clinic may describe IVF as "free" in relation to the actual cost of the treatment, which can contradict patients' expectations. From the patient perspective, this wording can be misleading if other expenses are not clearly explained. Patient 1 described being told that the process was free, but later encountered costs for medication, appointments, and tests. This became particularly clear when collecting medication: *"I was completely confused when I picked up injections for 4,000 SEK and thought I was going to pick up free injections."* The patient reflected that it would have been clearer if the clinic had explained that the IVF treatment itself was publicly funded, but that other costs, such as medication and blood tests, still had to be paid by the patient.

The way this misunderstanding was handled also affected the patient's experience. Patient 1 described receiving an unpleasant response from staff when questioning the costs: *"I got quite an unpleasant answer from someone at the reception who basically said: 'Do you realize how expensive this actually is?' No, I do not, because no one has ever told me."*.

Patient 2 described a similar experience of being surprised by costs, although the dominant feeling was still gratitude for receiving publicly funded treatment. This

suggests that patients may simultaneously feel thankful for access to IVF and frustrated or shocked by costs they did not expect.

Misunderstandings are also linked to the timing of information. Patients may receive information early in the process, but the long waiting times mean that it may no longer be remembered when it becomes relevant. Patient 1 described that the information itself may have been good, but that the length of the process made it difficult to retain: *"The information has probably been really good if it had been a shorter process, but when the process is sometimes over a year, it is difficult to keep track of everything that is said."* This creates a need for repetition, reminders, and short summaries throughout the care pathway, rather than relying on information given once at the beginning.

This need for repetition contradicts with the staff perception that information is already repeated throughout the process. Midwives described that they return to the same written material at different stages and guide patients through the parts that are relevant at that moment. However, from the patient's perspective, repetition is still needed because the information becomes meaningful only when the patient reaches that specific stage. This shows that repetition is not only about saying the same thing again but about making information relevant at the right time.

The emotional context of IVF further affects how information is received. Information that is intended to create clarity may instead create anxiety if it arrives unexpectedly or without enough explanation. Patient 2 described receiving a message through 1177 in the middle of the summer stating that the IVF process could begin and asking whether they wanted to remain at SUH or be referred to a private clinic. Rather than creating reassurance, the message triggered panic because the patient thought that treatment might need to start immediately and feared missing the opportunity for care. The patient described the reaction as: *"For us, it was a bit like panic… Now we are going to start this, and it was in the middle of the summer. How do we do this now?"*. It was unclear how quickly they needed to respond and what consequences the decision would have for their treatment process. After seeking further information, the patient realized that there was still time before treatment would actually begin. In retrospect, the patient suggested that a phone call could have provided clarification and reduced the stress of the situation: "*With hindsight, I think the best thing would probably have been if someone had just called and talked a little*".

A similar issue was described by a physician, who explained that information that seems small from a clinical perspective can be experienced as major by the patient. For example, if an embryo cannot be thawed successfully and therefore cannot be used for transfer, staff may see this as one possible event within the treatment process. For the patient, however, it can mean the loss of a planned and emotionally significant treatment opportunity. This highlights the importance of not only communicating what has happened but also recognizing the emotional meaning of the information for the patient.

4.4.5 The Patient Experience: Identity, Emotion & Participation

The following three sections present the subjective dimensions of the IVF experience as described by patients and clinical staff. Together, they examine how patients navigate their own identity within the care system, how emotional strain shapes the reception and processing of information, and how involvement or exclusion affect the experience of treatment. While these dimensions are analytically distinct, they interconnect in practice through a patient's sense of identity, their emotional state, and the degree to which their partner is included, all of which influence how information is encountered, interpreted and acted upon, throughout the IVF journey.

4.4.5.1 Emotional Strain and Information Needs

The interviews show that IVF treatment is not experienced as a neutral medical process, but as an emotionally charged journey shaped by uncertainty, waiting, hope, fear and repeated moments of vulnerability. Patient 2 describes the process as difficult to fully understand before being inside it, partly because the outcome is uncertain and partly because each step carries emotional weight. One patient described the waiting period as a time where they had limited understanding of what would happen next and felt dependent on the clinic: "*You kind of feel like they have your life in their hands.*" The same patient explained that this made information especially important: "*You really need information in order to understand*".

This emotional state affects how information is received, remembered and interpreted. Patients are often stressed, worried or uncertain, which increases the need for repeated and carefully timed communication. Patient 2 described the first treatment attempt as marked by constant worry: "*It was almost a constant anxiety the whole time. Have I done this right? How should I do this?*". Patient 1 explained that the length of the process itself made it harder to retain information, stating that "*you become a bit crazy during the journey because it is so long*" and that information which may have been sufficient in a shorter process becomes difficult to keep track of when the process stretches over more than a year.

Embryologist A also emphasized that patients in IVF treatment are often stressed and worried, which requires a more thoughtful approach and clear communication. This means that communication cannot only be technically correct; it also needs to be adapted to the patient's emotional state. Midwife B describes guiding the patient through the treatment as an important part of their role. By explaining what happens next, what the patient needs to do, and when they need to act, they reduce the cognitive burden placed on the patient. This guidance appears to have a calming function, especially because patients are expected to manage several parts of the treatment from home.

Healthcare professionals appear aware of this emotional burden and describe communication as something that must be adapted to the patient's state. Midwives explain that anxiety often leads to more questions, and that patients who feel unsafe or uncertain tend to need more support. Midwife B noted that questions often arise from worry, and that "*the more treatments they have done, the more trust decreases and anxiety increases*". This makes communication not only a matter of transferring

information, but also of creating calm and helping the patient manage the treatment step by step.

The interviews also show that bad news requires a particularly sensitive communication structure. When no embryo can be transferred, midwives describe patients as often becoming too shocked to absorb information. Midwife B explained that in these situations, "*it is not possible to inform them; the patient is shocked in the moment,*" and that many patients start crying immediately and become "*completely blocked*" As a response, the clinic has developed a way of separating emotional and medical communication: the midwife first calls to give the immediate message, the doctor calls later the same day to explain the medical details, and the midwife follows up again after about a week to check how the patient is doing and to plan the next step.

The emotional burden is also visible in how patients interact with administrative staff. Secretary A describes themselves as the first point of contact and therefore often the ones who receive frustration that may be directed at waiting times, medical decisions or the system as a whole. In the interview material, patients are described as being in a crisis rather than being ill in a traditional sense, and as sometimes becoming passive-aggressive, angry or deeply sad because they are dealing with what is perceived as one of the greatest sorrows of their lives. This places secretaries in an emotionally demanding role, where they must provide clarity and reassurance while also managing expectations they cannot always influence.

Patients also describe IVF as physically and psychologically destabilizing. Patient 3 explained that hormonal treatment affected both mental state and emotions: "*You expose your body to such hormonal disturbances that you become completely crazy, just psychologically, and it affects your mind and emotions so much*." For this patient, the need for support was strongest at the very moment when the partner was not allowed to be physically present due to pandemic restrictions, making the clinical environment and the staff's ability to see, support and confirm the patient especially important.

Emotional instability is also connected to the physical effects of treatment. Patient 2 described how the hormonal treatment, waiting and uncertainty made it difficult to maintain a normal façade in everyday life. Similarly, a physician A noted that hormonal stimulation can intensify an already vulnerable emotional state, which healthcare professionals need to consider in their communication and care.

At the same time, the interviews show that emotional support is not only provided by healthcare professionals. Patients 2 also find support through partners, colleagues, friends and acquaintances who have gone through IVF themselves. One patient described how opening up about IVF made the process feel less shameful, as they discovered that many people around them had similar experiences: "*Then it became much easier. It became almost a happy thing instead of something shameful*". However, patients also distinguish between support from people they know and information from social media. While shared experiences can create comfort and normalization, social media may also increase fear because negative stories tend to be more visible. Patient 3 further described IVF as a process shaped by uncertainty and lack of control over the outcome. This means that information is not received

neutrally, but interpreted through longing, fear, previous experiences and the patient's current emotional state.

4.4.5.2 Partner Involvement and Exclusion

Although IVF treatment is centred on the woman's body, health, and experience, several participants across staff and patient interviews highlighted the importance of treating the process as a shared experience for both partners. At the same time, a recurring tension appeared between the intention to include partners and the practical reality that communication and information were directed at the female patient.

Among the healthcare staff, there was a clear awareness of this dynamic and a conscious effort to counteract it. Midwife A described her approach: "*You should see them as a couple. The important thing is, what I think is, that both of their names are on the paper. For that reason, he is included and they do it together.*". In practice, this meant ensuring the partner's name appeared on all documents, addressing both parties during appointments, and explicitly including the partner in key procedural moments such as egg retrieval, where the partner is asked to provide a sperm sample, and is guided through what that involves. Partners were described as welcome at all appointments, though this presence was only actively required at the initial visit and the egg retrieval, a pragmatic flexibility designed to accommodate work-life tensions described in section 4.4.6.

Despite these efforts, midwife A acknowledged that partners frequently reported feeling peripheral to the process: "*Interviews have been conducted to explore couples' experience, and many of them identify, or the man says that: 'Well, the experience is good, and the information is good and everything else is good, but I still feel left out, because this somehow still doesn't regard me'."* . This sense of exclusion appears to stem from the structural logic of IVF itself. Due to medical procedures, monitoring appointments and medication are tied to the woman's body and cycle, the way information is designed and delivered tends to address the female patient as the primary recipient.

This was also reflected by the patient, particularly patient 2 who described the clinic's way of communicating was almost exclusively to her. Communication and materials were primarily addressed to the female patient, which meant that her partner was left to read and interpret information second-hand. Patient 2 explicitly noted that she felt the partner should be addressed more directly in clinical communication to increase his sense of participation and ownership in the process. Rather than the partner being a passive recipient of filtered information, he had in this case become an active interpreter of it: "*It was my husband who had to explain to me, that: it is three attempts, three attempts with hormonal syringes"*. This role, where the partner fills gaps in the patient's understanding, emerged from the asymmetry in how information was distributed rather than from any deliberate design, suggesting that the current information model places an additional interpretive burden on partners.

The emotional exclusion was further amplified in cases where circumstances prevented physical presence altogether. Patient 3 described undergoing significant stages of the treatment process without her partner due to pandemic restrictions, an experience that increased the emotional burden of an already demanding journey. The

absence of her partner at these critical times, which was not by choice, underscored how much emotional support the partner's presence provides and how its removal compounds the vulnerability patients already feel.

4.4.5.3 Patient Identity and Diversity of Experience

Across the interviews a consistent theme emerged that IVF patients do not constitute a homogeneous group. Their prior experiences, professional backgrounds, level of health literacy, and reasons for undergoing treatment all shape how they engage with information how they position themselves within the care system, and how they experience their own identity as patients.

Clinical staff across different roles described IVF patients as a distinct group, not traditionally ill, which one of the secretaries characterised as a life crisis. Despite this vulnerability, the patient group was broadly described as highly engaged and well-informed. Physician B captured this duality as: "*This group is in general competent overall, with exceptions of course. I believe that longing for a child is like being hungry or thirsty – something that your whole body wants. It is a desire that is difficult to switch off".*This tension between being knowledgeable and emotionally overwhelmed by a deeply personal longing shape how information needs to be timed and delivered throughout the treatment process.

One of the key findings and distinctions drawn from the clinical staff concerned the difference between active and passive patients: those who take personal responsibility for understanding their treatment and those who rely entirely on the clinical team. Physician A articulated this tension through a vivid metaphor: "*I don't think they should be dissatisfied or have these questions – in that case they should be that patient who order home pizza and don't care about it (the process) and just let us do our job. In that case, they should not question things".* This framing, the "the person who wants pizza ordered," captures a perceived contradiction between passivity and expectation, where patients who do not engage with information are nonetheless frustrated when outcomes do not meet their hopes. The same physician noted that patients who had already undergone multiple treatment cycles at other clinics tended to arrive significantly more informed: "*Many of them who come are well-read on the subject, especially those who have already gone through these treatments before.".* In this sense, experience functions as a form of health literacy, the repeated exposure to the process builds a stable knowledge base that shapes how patient navigate the next step in the treatment process.

The active patient identity was also expressed from the patient 3's own perspective. This patient described her approach to participation in care as a deeply held value: "*It is you who is going to live with these consequences based on your decisions, for the rest of your life, and that is something worth investing. Patient participation is incredibly important, and there are no reasons to gamble it.".* Her sense of agency extended to actively choosing providers she trusted and disengaging from those she did not: "*When I feel like the clinics is not letting me be a part of my journey, or if I feel like I am not seen, I know I have the choice to say no and choose something else"*. Additionally, she also mentioned that her own comfort level and capacity for self-advocacy were not representative of all patients, which points to the awareness of the uneven distribution of health literacy across the patient population.

This unevenness is further illustrated by the contrast Patient 3 drew between her experiences at SUH and at a private clinic. At SUH, she described feeling anonymous: "*There was not one time I called them and they were like: 'Hi, there! How are you doing?' There was no personal contact, but a focus on them and their organisation, and not me as a patient".* At a private clinic, by contrast, the experience of being recognised and remembered created a sense of being seen as an individual: "*Each time I was in contact with the privet clinic, it was the same voices, same person we talked with – they were engaged in my process and was more like: 'Oh, but how is it going?' And there was always the sense of humanity/empathy in those dialogues"*. While this contrast partly reflects structural differences between public and private healthcare, it also illustrates how relational continuity shapes the patient's sense of identity and belonging within the care system.

The economic dimension of private care was also framed through the lens of identity and agency. Patient 3 described the decision to pursue private IVF not as a financial burden, but as a deliberate investment: "*We also felt that this was worth it even more – an investment in our lives"*. The predictability of a fixed price structure was described as a reducing psychological strain: "*The benefit with the privet clinic and our midwife was that we had set a price/package, and you knew what procedures/treatments that was included – the economic stress also affects this process"*. This suggests that financial transparency is not merely a practical matter but contributes directly to the patient's sense of control and emotional stability during treatment.

Patient 3's professional background also shaped how she experienced the clinical environment itself. Her familiarity with healthcare settings gave her a framework for understanding why care can sometimes feel impersonal or system focused. She also acknowledged the fact that patients without similar professional background may require more proactive support and guidance from clinical staff.

One of the more significant expressions of identity mismatch came from patient 1, whose reason for undergoing IVF was genetic rather than related to infertility. Having undergone the process through a gene diagnosis in her partner's family, she found that the clinic's information materials and communication consistently framed IVF as a response to involuntary childlessness, which did not reflect her situation: "*It has sometimes felt like I am a patient in wrong division. Because the priority is about: 'you can't have children,' there are few who talk or point out that it could be about other cases as well*". This experience of being misplaced and receiving information designed for a different kind of patient, highlights that the diversity of reasons for undergoing IVF is not yet fully reflected in how information is designed and delivered at the clinic.

4.4.6 Structural Incompatibilities Between Care & Everyday Life

Another recurring theme across patient and staff interviews was the tension between the demands of IVF treatment in the often of everyday working life. For patients, the

IVF process emerged as structurally incompatible with certain forms of employment, while clinical staff mentioned the time pressure during critical procedural moments which adds a layer of occupational strain that extends beyond the clinical setting itself.

The patients described how logistical requirements of treatment such as strict medication schedules, fixed times for hormone injections and sudden appointment callouts were difficult to reconcile with working life. Patient 1, working a rotating three-shift schedule, described the tension vividly: *"I felt like this isn't going to work for me. They call during the days, and I don't know if I have the time to answer and I also sleep on irregular times.".* The combination of irregular working hours and strict timing requirements of hormone injections and sudden callouts created what the patient described as an "*imprinted logistical challenge"* where the unpredictability of shift work collided directly with the rigid timetable of the treatment process. The patient continues expressing her fear of missing calls from the clinic during working hours by describing that the clinic usually calls from an unknown number, meaning that she could not call them back when she would have the time: *"The whole process have been like this: when did they call, when do they call, will they call tomorrow, can I answer then or will I miss it? Because they call from a private number, meaning I can't call them back"*.

The short notice list presented a particular challenge: patients on this list are expected to rearrange their entire day at minimal notice, an expectation that is not always clearly communicated in advance. This was noted by one of the secretaries (secretary A) that many patients have not received adequate information about the intention of being on the list entailed: "*The ones who have not received that type of info, they usually are like: oh, that came out of nowhere*". This creates an emotional strain for both patients and staff, as the uncertainty and confusion many times leaves the patient frustrated, and results in the staff needing collegial support after difficult those types of calls: "*Many of the patients become passive aggressive, so that you sometimes have to go and talk with the colleague".* The operational logic of the short notice list and its equity implications are discussed further in section 4.4.7.1.

Beyond scheduling, conflicts between the clinic's operational calendar and patients' personal lives could result in significant delays to treatment. Midwife B described a patient who became frustrated when treatment could not start immediately after her first appointment: "*She got the opportunity to begin the month after, but then the problem was that she had two vacations booked – the first month and the second, and suddenly the start time were three months away, and she thought it was our (clinics') fault".* This illustrates the intersection of personal and institutional calendars could produce delays with real emotional consequences, often perceived by patients as a failure of the care system rather than a result of their own circumstances.

A broader structural observation emerges from these perspectives: the patients experience that the care pathway is designed for people with standard daytime working hours. For those outside this norm (working shifts, irregular schedules, or employment with limited flexibility and so on) create a feeling of not fitting into the social system, having to adapt their lives around the clinical operational logic rather than the other way around.

In contrast, having a flexible employer was described as a meaningful protective factor. Patient 1 noted that her employer's willingness to accommodate short notice changes considerably reduces the stress of navigating treatment alongside work: "*My work helped me. I was honest with what I was going through, and they helped me change my work shift, so I was able to remove some of them. "*. Similarly, the long-standing relationship patient 3 had with her employer made the flexibility possible: "*He has been very generous and given me the freedom, so if I needed to go to the clinics for an appointment, if I needed to come to work earlier or later – it never was a problem*". These quotes suggest that the burden of accommodation falls unevenly depending on employment context, and that the clinic's current scheduling model implicitly assumes a degree of workplace flexibility that not all patients have access to.

For clinical staff, time pressure surfaces most acutely during procedurally critical moments. Embryologist A described working under time constraints during egg retrieval providers, where pace and precision requirements affect both the working environment and stress levels. This operational pressure left limited size for the kind of reflective practice or collegial exchange that might otherwise support staff wellbeing.

4.4.7 Organizational Conditions

The following two sections examine the organizational conditions under which IVF care is delivered at SUH, drawing on observations from clinical staff across different professional roles. Two interrelated dimensions presented: day-to-day working practices that shape how care is structured and delivered, and the conditions under which innovation and improvement work takes place within the organization. Both sections are indirectly or directly affecting the overall patient experience.

4.4.7.1 Working Practices

A consistent picture appears across staff interviews of a department managing significant administrative complexity with limited structural support. Several participants described working environments characterized by fragmented systems, unclear responsibilities and manual workarounds that consume time otherwise available for patient-centered work.

One of the prominent operational challenges concerned the management of patient referrals. Physician B mentioned receiving up to 100 referrals per week, each potentially accompanied by extensive documentation from prior investigations: "*It can be around 20 pages attached to a referral, from the investigations conducted during fertility assessments, and those take time to screen through. We get 100 referrals a week".* This volume of administrative tasks places considerable pressure on physicians, with the risk that urgent referrals, such as those involving fertility preservation ahead of cancer treatment, could go unreviewed for days. This is further amplified by the absence of standardized guidelines for what information is communicated with the patient during the first appointment, meaning that the content and depth of patient consultation vary depending on which physician the patient encounters.

The coordination of patient bookings is further complicated by the multiple digital systems operating in parallel without interrelating with each other. Secretary B described a daily task by the one that is responsible for that kind of task during that day where that person has to manually transferring bookings between systems: "*She has a fun task ahead of her by manually transferring all the visits from WinIVF to Elvis – they don't interact with each other, so you have to manually move over all the bookings*". This kind of duplicated work reflects a broader pattern of administrative friction across department, including the continued use of physical mail, fax machines for urgent referrals, and paper-based tracking of patient lists. This affects the patients directly when prescriptions are missed or overlooked due to the administrative load. As result, the patients spend time and energy contacting the clinic or submitting requests through 1177, an experience described by one of the physicians (physician A) as frustrating and unnecessarily burdensome for patients. Additionally, the rotational nature of physician schedules across different departments meant that errors such as those mentioned, or missing referrals, occur at points of handover which create gaps and are sometimes difficult to trace and resolve.

A further dimension of administrative complexity concerns the management of patient waiting lists. The secretaries are responsible for overseeing the multiple and separate waiting lists simultaneously, each corresponding to different patient groups or treatment pathways: standard IVF, PGT (preimplantation genetic testing), donation, andrology, endometriosis and uterine abnormalities. Each list carries its own scheduling logic, as certain patient groups could only be seen by specific specialists s*ecretary A* describe it as "*PGT-patients can only be seen by doctor number 1 or number 2 as of now, while all patients in the IVF queue can be called by any doctor, meaning that all patients are fighting for the same time slots".* This creates an additional layer of complexity where prioritization decisions are made continuously, often without formal guidelines for how to balance competing demands across patient groups.

The short notice list itself exists in response to a practical reality: due to the work-life balance tensions described in section 4.4.6, patients frequently decline or cannot attend appointments at short notice due to work or personal circumstances. Secretary B noted that patients on the list often do not answer when called and are subsequently removed: "*Not everyone on the short notice-list who actually can attend or answer the phone when we call. Like, if we call maybe three times without an answer, then we remove them from this list, because then they can't do short notice*.". To minimize wasted appointment slots, the clinic maintains this list of patients who have indicated willingness to attend at short notice, allowing staff to fill cancellations efficiently.

However, an equity concern emerged from the secretary's account of how short notice slots are filled in practice. When a slot becomes available at short notice, the secretary described a tendency to contact patients who have been most proactive in following up on their position in the queue, as they are perceived as more likely to be reachable and willing to come in at short notice. This pattern was explicitly acknowledged by the physician B, who noted: "*I also sense that when there is a patient who is calling and pushes enough, because it is the secretaries who decides who they pick to come to an appointment, the patients get a short notice time. They choose the patient who is very engaged and shown interest – then they would not need to call four other people*

to fill this slot again, so I would call the most engaged one. And that's not really fair. It is not necessarily the one that is the most nervous who needs the treatment first. ". This raises significant concern about equal access, as the ability to navigate and advocate within the system becomes an unintended factor determining who receives care and when.

Internal communication between the staff also relies heavily on a physical planning board, specifically midwives and physicians. This serves as the primary coordination tool for daily scheduling. While functional in stable conditions, this system proved fragile when last-minute appointments arose without relevant staff being informed. This can result in a patient arriving without assigned or staff not being aware, as mentioned by midwife A: "*It can happen that a doctor just had a visit and tell us: I just had a patient – and we don't know about it, because it did not reach us".* The physical nature of the board means that notifications are dependent on someone physically walking across to inform colleagues, a process that is fragile during stressful times. Additionally, the lack of structured feedback between physicians and midwives, following patient consultations, sometimes affects the waiting times for the patient. Midwife A described situations where they would wait up to 20 minutes without knowing whether a physician had finished with a patient, because no notification had been passed on.

The responsibility for individual patients was identified as a source of ambiguity, particularly around the role of the designated responsible physician, or PAL (*Patientansvarig läkare*). Due to the rotational nature of physician schedules, a patient's PAL could be unavailable, and questions arising between treatment stages could go unaddressed or handled inconsistently. This creates a gap in continuity of care that staff recognizes but finds difficult to resolve within current staffing structures.

The organizational fragmentation is further affected by the current physical layout of the department where the Reproductive Medicine Division is located. With the laboratory and clinical areas located on separate floors, embryologist A describe how the distance between units reduces opportunities for spontaneous exchange and informal collaboration. Additionally, sample transportation requires physical movement between floors, and the separation means that laboratory and clinical staff rarely interact outside formal procedures

At the laboratory, a different but related inefficiency was observed. Embryologist A describe spending approximately three hours on the manual replenishment of liquid nitrogen tanks, which is necessary but a non-specialist task that displaces time from core scientific work: "*We put a lot of hours per week just to go and fill these tanks. Me and my colleague counted how many hours we do, and it's approximately three hours per week which makes up to about two egg retrievals".* The current hiring freeze limits the redistribution of support to tasks of administrative and logistical nature and instead falls on the biologists by default.

Despite the structural constraints, adaptive practices had emerged that reflected the staff effort to maintain quality within limited conditions. Midwife A described a daily end-of-shift planning meeting where the following day's responsibilities were collectively mapped and distributed, with deliberate rotation across tasks to sustain

engagement among the staff: *"We plan day by day, so every afternoon we together look at what tasks we have for tomorrow and ask each other: what did you do today, and what would you like to do tomorrow? And we try to vary the tasks, so no one is doing surgery every day or stuck with the phone".* Additionally, the midwives described iterative improvements to patient-facing information, for instance, updating instructions to place the most misunderstood items prominently after noticing recurring errors such as patients forgetting to bring identification documents.

A further proactive approach concerned the prevention of cancelled treatment cycles. One of the midwives described how staff sought to be deliberately precise about ovulation testing instructions, by specifying both the timing and the type of test to use. The reason is that they have encountered repeated situations where anxious patients tested multiple times daily with different sticks. This could sometimes produce unreliable results that forced the cancellation of planned embryo transfers, and such situation represents both a clinical setback and significant practical and emotional cost for the patient. This pattern was described as one of the common sources of avoidable clinical disruption.

4.4.7.2 Innovation and Change Processes

While there is a clear awareness among staff that certain areas require improvement, the conditions in which innovation and development work takes place at SUH are significantly constrained. The findings suggest that improvement efforts are driven by individual initiative rather than structured organizational support, and that systemic barriers (regulatory and infrastructural) limit the pace and scope of change.

The most illustrative example of this came from one of the physicians, who also performs tasks within standard IVF pathway outside contracted hours. When asked whether these duties were her primary tasks, she was direct and noted: "*I don't have much time for this. It is more something I do by the side of everything else. I wish I had more scheduled time for this. It is more reasonable to schedule during work hours and not free time.".*

Among the improvement initiatives physician described was a project to restructure the existing patient information video, "*I feel like the patients might have seen the beginning, but not the whole (video) and that they might have seen it once but that there is too much information for them to remember it afterwards. A lot of things that are being said in the movie comes as a surprise, during the first meeting with the doctor.".* The fact that this development work which directly affects patient understanding and experience is being carried out in personal time, reflects a broader organizational gap between the recognized need for improvement and the resources allocated to support it.

One recent structural initiative is the introduction of the role *medical director* (*ledningsläkare*) which is a designated physician available during working hours to handle questions and decisions that would otherwise fall on colleagues simultaneously managing patient appointments. Physician B described this as an important development, compared to how it was previously; decisions were resolved in parallel with ongoing clinical work, creating significant strain. The impact of this

role is currently evaluated through a staff survey conducted before and after its implementation.

However, the organizational gap is further compounded by external regulatory constraints, where the organization VGR's regulations govern what information can be published on the clinic's website. This significantly limits the clinic's ability to communicate with patients digitally and physician B state that "*Before, we had a website where we could decide and specify what type of information we should publish, but that has changed, instead, there is minimal information on the site. So, we need to find other solutions."* As a workaround, the clinic resorts to downloadable Word documents, a solution that is neither user-friendly nor easily supported. This regulatory constraint effectively creates a barrier between improvement intentions and the clinic's ability to reach patients with timely and accessible information.

At a structural level, decisions regarding physical premises were identified as a further limiting factor. Embryologist A described how the current facilities constrain the clinic's capacity to expand or improve: "*When I started working here 8 years ago, they had already started to plan the move, and you never know, there could be other needs. It is physically difficult to do more than what we are already doing".* A planned relocation to new facilities has still been under discussion for several years without resolution, illustrating how slow institutional decision-making can stall operational development even when the need is clearly identified. Beyond stalling expansion, the current physical layout also constrains collaboration between divisions, as some staff across different units have limited visibility into each other's work and limited opportunity for spontaneous coordination.

Beyond exiting constraints and infrastructural limitations, resistance to change also emerged within the organization. Secretary A expressed concern that automation of administrative tasks could threaten existing roles, reflecting an awareness among staff that improvement initiatives carry personal implications and may not be universally welcomed.

The challenges described across 4.4.7.1 and 4.4.7.2 are further contextualized in section 4.4.8, which examines how a comparable Scandinavian fertility clinic has approached similar organizational and informational challenges through systematic structural investment.

4.4.8 Patient Information Practices at Copenhagen University Hospital

To contextualize the findings from SUH, an interview was conducted with a senior nurse at Copenhagen University Hospital's fertility clinic. The Copenhagen clinic operates within a comparable Scandinavian public healthcare context yet has developed a distinctly structured approach to patient information and care delivery that offers a useful point of reference. The data was collected to develop an understanding of how IVF information practices may be organized in other clinical settings, and to provide an example of how patient information can be structured and communicated in an alternative way. The purpose was therefore not to make a direct comparison, but to broaden the understanding of possible approaches to information delivery within IVF care.

A central finding from the interview is the *Copenhagen model* with its structure of the first patient appointment. Rather than separating clinical assessment from patient education, every new patient meets jointly with a doctor and a nurse for a full hour: "*One doctor and nurse will be together in the room for one hour – the doctor will go through their medical history and scan the patient, and the nurse will talk them through the practicalities ".* This team-based approach ensures that medical and informational needs are addressed simultaneously, and that the patients leave their first appointment with both a clinical assessment and a thorough understanding of the treatment process. The presence of two professionals in the room also allows each to complement the other, reducing the risk of missing or not communicated important information.

Prior to the first appointment at the Copenhagen hospital, patients are also required to watch a comprehensive information video covering the fundamentals of IVF treatment. This means that the initial consultation can build on a shared baseline knowledge rather than starting from zero, allowing the appointment time to be used more efficiently. According to the senior nurse, watching the video is considered obligatory before beginning treatment. If the patient arrives at the clinic without having watched it, they are asked to go home and look at it before signing up for treatment. Additionally, the patients are also offered a quarterly webinar, attended by 200 patients simultaneously. This provides a cost-efficient channel for addressing recurring questions on a scale without requiring individual consultations. As the head nurse described, this model significantly reduces the informational burden on clinical staff during appointments while ensuring patients have access to consistent and thorough information.

For self-administered medication, the clinic uses a dedicated digital platform providing detailed instructional videos on injections and techniques, allowing the patients to prepare at home at their own pace and revisit instructions as needed. This reduces both patient anxiety and the need for individual guidance appointments, freeing clinical time for more complex patient interactions.

Beyond information delivery, the Copenhagen clinic also takes a proactive approach to scheduling. The staff explicitly advise patients against beginning a treatment cycle during particularly demanding times at work or in their personal lives, encouraging them to wait a month or two until they have sufficient space and stability: "*We tell them: the clinic will still be here, it is better to wait one or two months until you have*

room in your life". This reflects the understanding of work-life tensions described in section 4.4.6, and positions scheduling guidance as a clinical responsibility rather than a personal matter for the patient to manage alone. Furthermore, the head nurse emphasizes their commitment to preventing unnecessary stress by debunking myths regarding the impact of stress on fertility outcomes, which helps remove the burden of guilt from the patient.

The results demonstrate a clear ambition to individualize information for each patient, where communication is adapted to the couple's specific health journey and emotional needs rather than relying solely on demographic or standardized data. The interview indicates that the clinic employs a communication strategy that prioritizes individual hope over general success and failure statistics. Rather than initiating consultations by emphasizing the mathematical probability of failure, the clinic's approach is rooted in the conviction that "as long as we make a treatment, then we actually believe it can happen".

Partner involvement is also structurally embedded in the Copenhagen model. Unlike experiences described by some patients at SUH (see section 4.4.5.2), the Copenhagen clinic frames IVF as a couple's project. Both partners are registered by name and personal identity number at every appointment, and the physical setups of consultation rooms are always equipped with two chairs, expecting both parties to come. Partners also receive their own dedicated information folder containing clear and specific information instructions tailored to their role in the process: "*We always make sure that there are two chairs in the room, because we want them both to feel that this concerns them equally, it is their project together.*". This structural approach to partner inclusion stands in contrast to the more implicit efforts described at SUH, where staff members consciously make efforts to include partners but without the same degree of institutional support or standardization.

The Copenhagen model illustrates how deliberate structural choices regarding appointment design, information sequencing, digital tools and scheduling guidance can address many of the challenges identified at SUH. While direct comparison is limited by the differences in organizational context, scale and governance, the Copenhagen findings should not be understood as best practice model or as directly transferable to SUH. Rather, they offer a concrete reference point for what alternative approaches to patient information in IVF can look like in practice, and demonstrate that challenges identified at SUH are not inevitable features of public IVF care.

4.5 Complementary Findings

In addition to the qualitative and ethnographic data presented above, complementary insights were obtained through social media, quantitative patient data and a participatory session with healthcare professionals. While these insights do not offer the same depth as the interview data, they contribute to contextualizing and supporting patterns identified in the qualitative findings. The participatory session insights, described in section 3.3.3, are presented here in terms of the substantive reflections gathered, rather than the methodological approach. Together, these complementary sources provide additional indications of how information is perceived, timed and experienced across a broader range of patients and healthcare professionals.

4.5.1 Social Media

One way to understand what kind of information patients encounter and how they experience it is through social media. Platforms such as podcasts and short-form videos on apps like TikTok offer patients a window into other people's IVF journeys, where individuals are open to and share both the positive and challenging aspects of their experiences with IVF. On TikTok, users are exposed to a mix of information from both Swedish and international creators. Women frequently share their personal journeys, often through relatable or emotionally driven formats, such as:

- "*POV: My brain 24/7 while doing IVF and just trying to survive*"
- "*5 things I wish I had known before IVF…*"
- "*My journey together with my partne*r"

However, there is no formal verification of the accuracy of the information being shared. Content can vary widely in reliability, and some stories depict experiences that differ significantly from what is legally permitted or practiced within publicly funded IVF care in Sweden.

4.5.1.1 Media Representations of IVF Experiences

The documentary *"Barnmakarna" (2026)* by Kalla Fakta on TV4 highlights another side of IVF, illustrating the desperation that can arise from the desire to become a parent, and how this can lead individuals to consider options that fall outside established regulations.

The documentary illustrates how patients struggle and go to great lengths to become parents, sometimes even putting their own health at risk. It highlights the emotional and psychological impact of the IVF journey, showing how individuals reflect on the person they became during this process – and how, when the outcome does not go the way they hoped, the emotional toll can be profound and destabilizing.

In interviews, patients expressed feelings for the IVF-process such as: "*I was very bitter, and I was afraid of who I was becoming*," and "*I couldn't bear to see anyone else become pregnant.*"

4.5.1.2 Patient-Narrated Journeys as Informal Information Sources

Many individuals that today share their journeys and can simultaneously build a platform through social media. One example is the account *thepursuitofkicki* on Instagram.

The account documents a long IVF journey and currently describes a conclusion where the couple has decided not to pursue further treatment. They have undergone a total of ten IVF attempts, including treatments using their own gametes as well as donations.

The couple describes IVF as an emotionally demanding process, and at the same time share information about the IVF process they have gathered throughout their journey. Their account thus functions both as a personal narrative and as a space where

practical information about IVF is shared, for instance: treatments, different stages of the process, and what patients can expect.

The information is communicated through a combination of formats. Stories are used to share shorter updates and information, while feed posts are used for more extensive reflections, summaries of experiences, and to create discussions with followers. The account has just below 9,000 followers, and posts typically generate between 2–50 comments, where other users often share their own experiences or ask questions.

This illustrates that, from a patient perspective, IVF-related information is not only created and communicated within the healthcare system, but also through patient-driven channels. Here, information is produced through individual experiences that are then shared and collectively interpreted. Followers use the comment sections to ask questions, confirm information, or compare their own situations, meaning that information is continuously developed through dialogue.

At the same time, this type of content highlights certain challenges in the information flow. Many of the questions raised in the comment sections concern fundamental aspects of the IVF process, indicating that patients in some cases perceive a lack of sufficient or clear information from healthcare providers. The content also shows that patients often seek confirmation and clarification of information they have already received, suggesting uncertainty or difficulties in fully understanding it.

Furthermore, it becomes evident that information often needs to be translated from medical terminology into more everyday language to be understandable. The account serves a function here by presenting information in a more personal and concrete format, connected to lived experiences.

In addition, the account shares detailed information about medical treatments, including different IVF protocols, medications, and procedures, primarily based on personal experience. This information is presented without reference to scientific sources or clinical guidelines and is instead grounded in what the couple has encountered throughout their own treatment journey. As a result, some of the information reflects specific practices from the clinics they have interacted with and may not necessarily correspond to current standards or variations in practice across different clinics. At the same time, previously shared content remains available on account, meaning that information from earlier stages of their journey continues to circulate regardless of potential changes in medical practice or recommendations.

4.5.2 Patient Satisfaction Result

The quantitative data is drawn from standardised patient satisfaction surveys administered by IMPROVEIT across Swedish IVF clinics in 2024. As described in 3.3.4, the data was received as secondary data and is treated as indicative and contextual rather than conclusive. In line with the geographical delimitation of this study, the results focus on four IVF clinics operating in Gothenburg area: SUH, Göteborgs IVF Klinik, Livio Göteborg and Nordic IVF Göteborg.

According to the data presented in these charts, the patient satisfaction was measured across five dimensions: medical care (*medicinsk vård*), accessibility (*tillgänglighet*), information, staff interaction (*bemötande*) and patient participation (*delaktighet*).

The scores reflect the proportion of respondents indicating full or substantial agreement with each statement. When reading the comparative figures, it should be noted that SUH's sample size consisted of 25 during the 2024 survey period, compared to 72 at Göteborgs IVF Klinik, 168 at Livio Göteborg, and 126 at Nordic IVF Göteborg.

Across all five categories, SUH scored below the other clinics as well as the national average. The widest gap is seen in the *patient participation* category (Figure 16), where SUH registered 55% compared to 78% at Göteborgs Klinik, 63% at Livio Göteborg and 75% at Nordic IVF, against the national average of 73%.

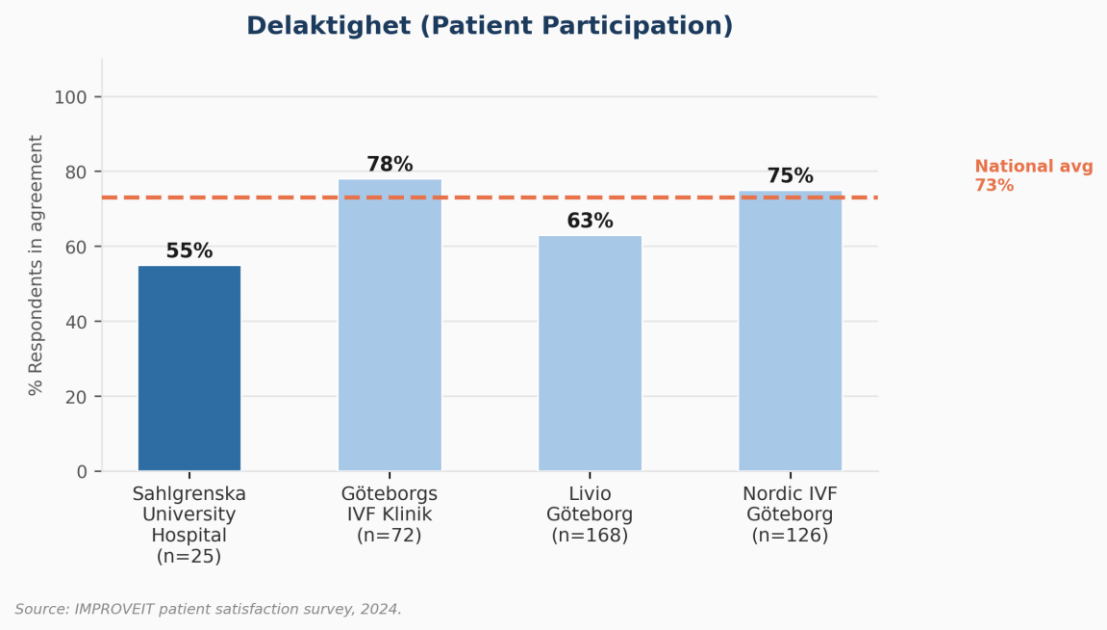

Figure 16: Patient Participation in Gothenburg.

The *information* dimension scores SUH at 79%, while Göteborgs IVF Klinik reached 94%, Livio Göteborg 84%, Nordic IVF Göteborg 89%, and the national mean stood at 88% (Figure 17).

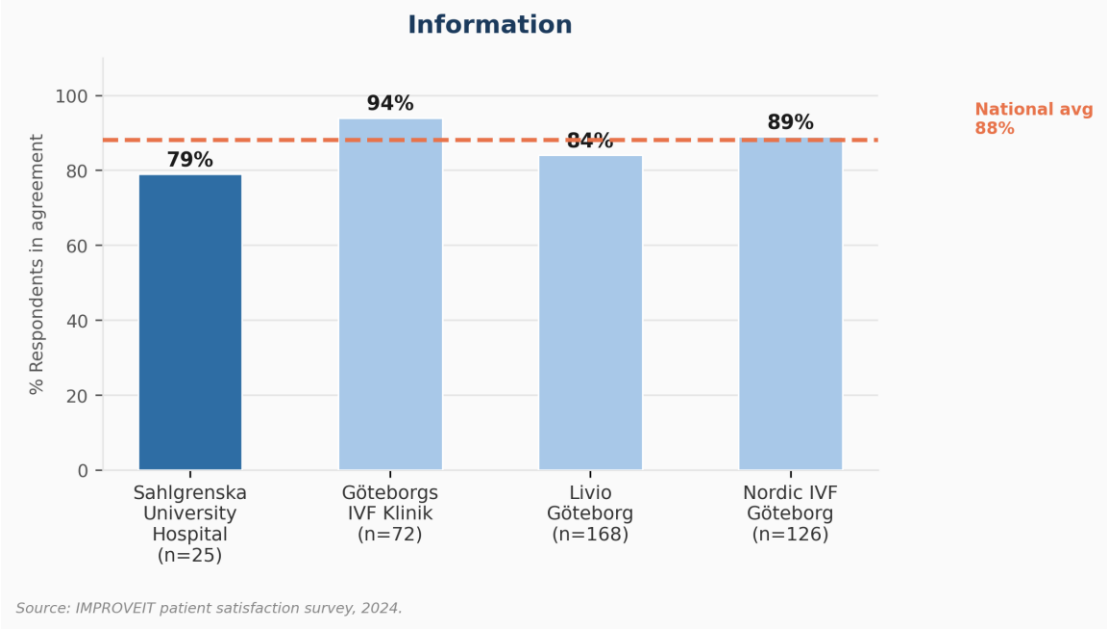

Figure 17: Information dimension comparison in Gothenburg.

Accessability (Figure 18) showed a comparable pattern, with SUH at 67%, Livio Göteborg at 81%, Nordic IVF Göteborg at 91%, and a national figure of 89%.

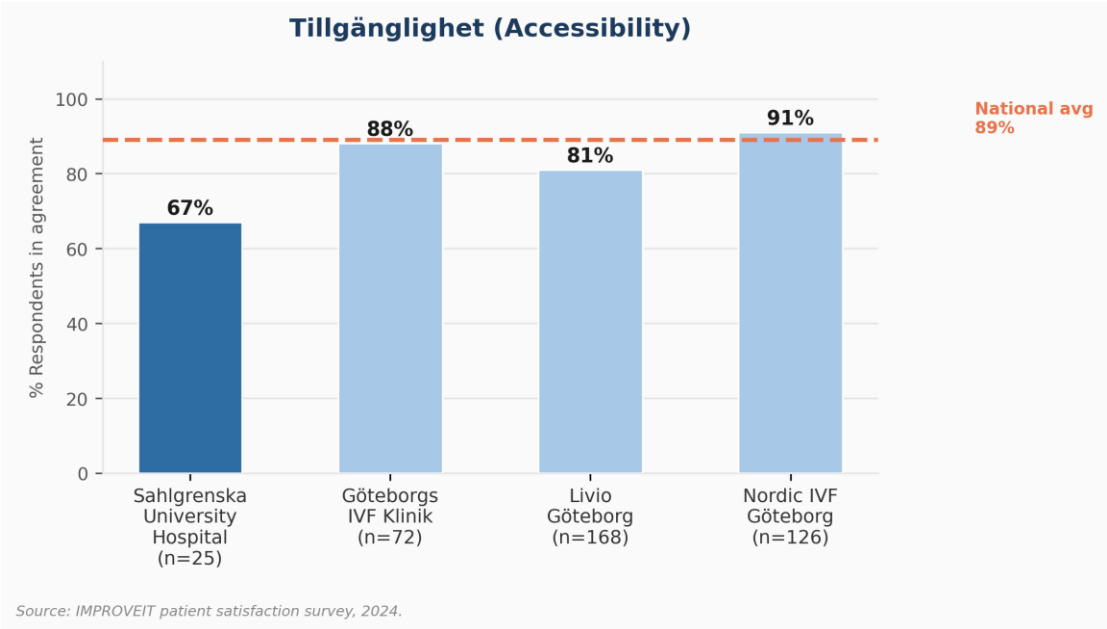

Figure 18: Accessability at IVF clinics in Gothenburg.

Of the five categories, *staff interaction* represented SUH's strongest relative performance at 88% (Figure 19). However, this number remained below Göteborgs IVF Klinik (97%), Livio Göteborg (89%), and Nordic IVF Göteborg (93%).

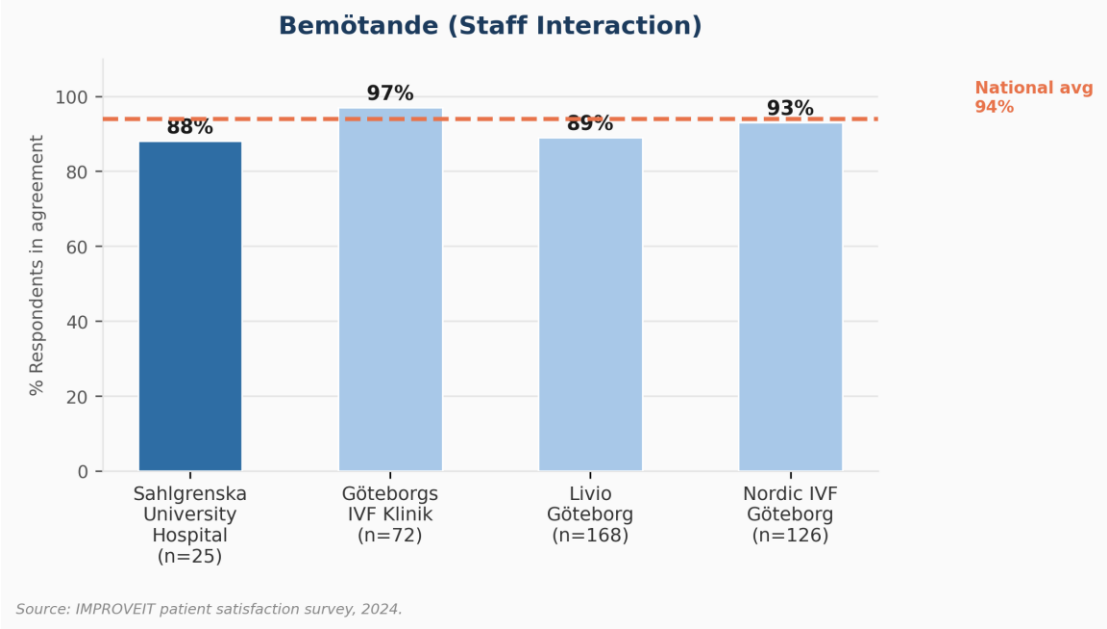

Figure 19: Staff interaction with patients in Gothenburg.

Similarly, the *medical care* result shows the result with SUH at 80%, Göteborgs IVF Klinik at 94%, Livio Göteborg at 90%, Nordic Göteborg at 93% compared to a national average of 92% (Figure 20).

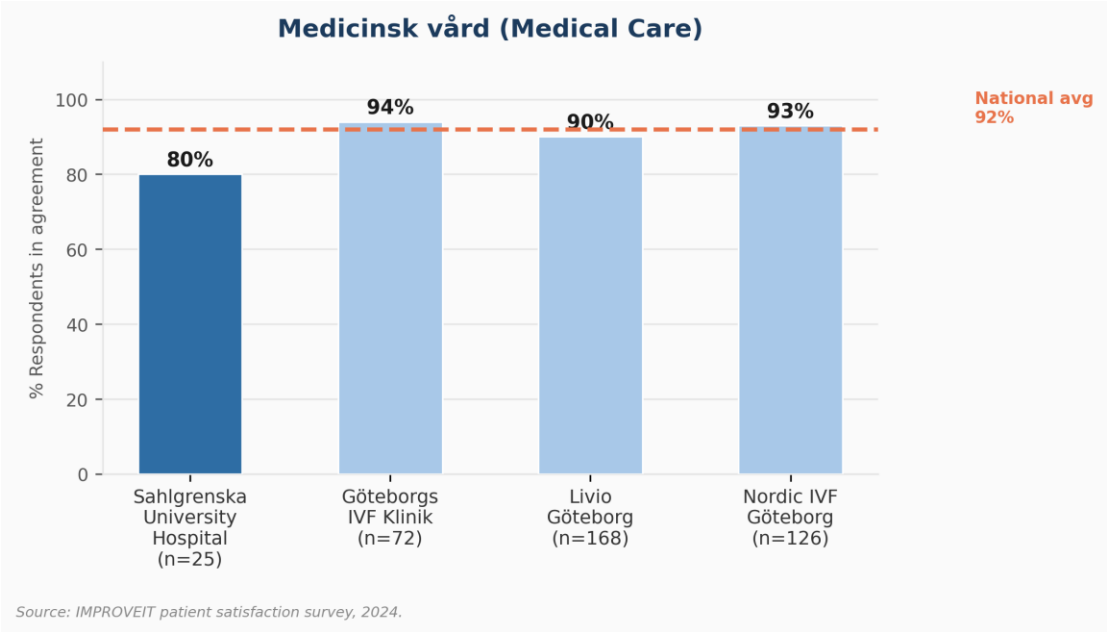

Figure 20: Medical care comparison in Gothenburg.

4.5.3 Participatory Session Insights

Building on the participatory session described in section 3.3.3, insights were collected through Mentimeter from healthcare professionals at the Reproductive Medicine Division. The responses, presented in Appendix B, capture real-time reflections on patient information practices across the IVF care pathway.

Based on the three questions posed during the session, the responses indicate that healthcare professionals perceive patients to be most receptive to information during calmer and more structured phases of the care process. In this regard, receptivity appears to be higher in situations where patients have time to prepare, reflect, and process information prior to treatment initiation. Information delivered in predictable settings and in a clear format was described as more likely to support patient understanding.

In contrast, healthcare professionals perceive patients to be least receptive to information during emotionally demanding or stressful stages of the IVF process. This includes moments characterized by uncertainty, time pressure, or clinical procedures. The responses suggest that patients' ability to absorb and retain information may be reduced in such situations, particularly when complex or detailed information is provided.

The responses to the third question, concerning expectations and reflections on information practices, highlight a need for more structured and patient-adapted approaches. Specifically, healthcare professionals emphasize the importance of improving the timing of information, reducing information overload, and ensuring consistency across different communication channels. There is also an expressed need to better align information delivery with patients' emotional and cognitive readiness throughout the IVF care pathway.

These observations contribute to supporting patterns identified in the interview data and process mapping, particularly regarding the relationship between timing, emotional state, and patient understanding.

4.6 Findings from Website Review

To understand how IVF-related information is communicated to patients, three publicly available sources were reviewed: Nordic IVF, Livio and 1177. These sources were analyzed to examine how information is structured, what type of guidance is provided, and how clearly the IVF journey is presented. The following sections describe the findings from each source.

4.6.1 Nordic IVF

The review of Nordic IVF's website showed that the information is presented through two main formats: a process-oriented treatment page and a topic-based information section (figure 21). The treatment page, An IVF Treatment, describes IVF as a sequence of steps, while the Facts & Advice section gathers articles on fertility,

infertility, IVF and related treatment questions (Nordic IVF, n.d.-a; Nordic IVF, n.d.-b).

Figure 21: Front-page of Nordic IVF with red marking on treatments and frequently asked questions categories. Source: Nordic IVF (n.d.). Retrieved May 4, 2026, from https://www.nordicivf.se

The page An IVF Treatment was found to be structured as a step-by-step description of the IVF process. The treatment is divided into six phases: investigation, hormone stimulation, egg retrieval, fertilization, embryo transfer and the waiting period. The heading of the page frames the content as an explanation of how IVF treatment is carried out, and the page therefore presents IVF as a chronological care journey (Nordic IVF, n.d.-a).

The review showed that the treatment page provides information about what happens during the different stages of IVF and in what order these stages occur. Each phase is described separately, which gives the reader an overview of the process from the initial investigation to the waiting period after embryo transfer. The page therefore presents the treatment as a connected sequence rather than as separate medical concepts (Nordic IVF, n.d.-a).

The treatment page also includes practical information about specific parts of the treatment. For example, in the section about egg retrieval, the website states that the procedure takes approximately 15 minutes, that pain relief is provided, that the patient is offered refreshments afterwards, and that a partner is welcome to be present (Nordic IVF, n.d.-a). The page therefore includes both medical and practical information about what the patient may experience during treatment.

The review also identified that the page includes statistical information about IVF outcomes. For example, Nordic IVF states that approximately 50–70 percent of eggs are usually fertilized and that around 70 percent of couples or women have had a child within three treatments (Nordic IVF, n.d.-a). These figures are presented as general information about treatment outcomes, rather than as individual prognoses.

In addition, the treatment page contains a section on what patients should consider during treatment. This section includes information about exercise, alcohol, medication, bleeding, miscarriage and over-stimulation (Nordic IVF, n.d.-a). The page therefore provides guidance not only about the treatment steps, but also about practical considerations and symptoms that may arise during the treatment period.

The review of the Facts & Advice section showed that this part of the website functions as a knowledge bank. The page presents itself as a collection of relevant information on topics such as fertility investigations, IVF, infertility, fertilization and involuntary childlessness, and states that the pages are updated continuously. The information is organised into separate articles and grouped under categories such as childlessness, fertilization, fertility, infertility, insemination and IVF. The page also includes a search function that enables readers to find specific information (Nordic IVF, n.d.-b).

The Facts & Advice section was found to be more topic-based than process-based. Many of the articles focus on specific questions or concepts, such as what IVF is, how egg retrieval is performed, what affects the chance of success, what regionally funded IVF means, and which rules apply (Nordic IVF, n.d.-b). The information is therefore broad and searchable but distributed across several separate articles.

4.6.2 Livio

The review of Livio's website showed that the information is presented through both a question-based format and treatment-specific process pages. The Frequently Asked Questions page functions as a broad entry point for common patient concerns, while the treatment pages provide more specific information related to particular fertility treatments, such as IVF, insemination, ovulation stimulation and donation treatment (Livio, n.d.-a; Livio, n.d.-b; Livio, n.d.-c; Livio, n.d.-d; Livio, n.d.-e).

Figure 22: Frontpage of Livio's website. Source: Livio (n.d.-a). Retrieved May 2026, from https://livio.se/fertilitetskliniker/goteborg

The Frequently Asked Questions page was found to be structured around common questions that patients may have before contacting or visiting the clinic. Livio introduces the page as a place where common questions have been gathered for patients to feel as safe as possible before visiting the clinic (Livio, n.d.-b). The page therefore presents information in a preparatory format, aimed at users who may still be considering whether, when or how to seek fertility care.

The FAQ page includes information about several early-stage concerns in the fertility care journey. It provides guidance on when to seek help, when to stop using contraception, whether to track ovulation, and how to understand the difference between insemination and IVF. Livio states that people under 35 are recommended to seek help after one year of trying to conceive, while people over 35 are recommended to seek help after six months. The page also includes a checklist of reasons to seek help, such as irregular cycles, previous ectopic pregnancy, testicular surgery, sexual problems, medication that may affect fertility, and general concern about fertility (Livio, n.d.-b).

The review showed that Livio's FAQ page is organized around concrete patient questions rather than around a chronological care pathway. The questions address practical, medical and lifestyle-related issues that may arise before or during fertility treatment. For example, the page explains how treatment choice is made and states that factors such as age, fertility investigation results, cause of infertility, previous treatments and personal preferences are considered. It also states that a specialist doctor makes an individual assessment and proposes the most suitable treatment (Livio, n.d.-b). In this way, the page provides answers to specific concerns, but it does not guide the reader through the full treatment journey from first contact to completed treatment.

In addition to the FAQ section, Livio's website includes treatment-specific pages that present process steps for different types of fertility treatment (see figure 23). For example, the IVF page provides information about IVF as a treatment and includes practical guidance about waiting time, investigation, how the patient may feel during treatment, and how treatment may affect everyday life and work (Livio, n.d.-b). The website also includes separate pages for insemination with a partner's sperm, ovulation stimulation and different forms of donation treatment (Livio, n.d.-c; Livio, n.d.-d; Livio, n.d.-e; Livio, n.d.-f).

Figure 23: Step by step explanation. Source: Livio. (n.d.-c). Livio — IVF. Retrieved May 4, 2026, from https://livio.se/fertilitetsbehandlingar/ivf

A central finding was that Livio's treatment pages are more adapted to specific patient situations than the FAQ page. These pages separate information according to treatment type and present content that is more closely related to a particular care pathway. For example, the page on insemination with a partner's sperm explains when this treatment may be relevant, how it can be carried out, and what happens after the insemination (Livio, n.d.-d). The page on ovulation stimulation explains that the treatment can be used when ovulation is irregular or absent and presents the treatment as a less invasive option that may be tried before IVF (Livio, n.d.-e).

The donation pages were also found to provide more patient-specific information. Livio has separate pages for IVF with donated sperm, IVF with donated eggs, insemination with donated sperm and double donation. These pages describe who may be eligible for each treatment and include sections such as "Who can undergo treatment?", "Your treatment journey" and cost-related information (Livio, n.d.-f). For example, the page on IVF with donated sperm states that the treatment may be relevant for heterosexual couples with reduced sperm production or unexplained infertility, same-sex couples, single women in need of donated sperm, or couples and women for whom previous insemination or IVF treatments have not been successful (Livio, n.d.-d).

Overall, the review showed that Livio's website combines general question-based information with more treatment-specific guidance. The FAQ page provides a broad overview of common concerns and is useful for readers looking for answers to specific questions. The treatment pages provide a more structured and patient-adapted form of information by separating content according to treatment type. However, the information is still distributed across several pages, which means that the reader needs to navigate between the FAQ section and the different treatment pages to form a complete understanding of the care journey.

4.6.3 1177

The review of 1177's infertility page showed that the website provides a collection of information related to involuntary childlessness and available fertility treatments. The

landing page states that the reader can find information about involuntary childlessness and the support available, and it includes links to several subpages, such as involuntary childlessness, fertility investigation, insemination, stimulated ovulation, IVF treatment step by step, and treatment with donated eggs or sperm (1177, n.d.-a). The information is therefore gathered in one place but divided into several separate sections.

The landing page was found to function mainly as an information overview rather than as a personalized guide (see figure 24). All categories are presented on the same level, regardless of the reader's individual situation. There is no initial filtering based on whether the reader is seeking care as a single person, as part of a heterosexual couple, as part of a same-sex couple, or with a need for donated eggs or sperm. As a result, the reader needs to enter the different subpages to determine which information applies to their own situation. For example, information about becoming pregnant with donated eggs or sperm is presented as a separate subpage, but the reader must actively enter this section to understand whether it applies to their situation (1177, 2025a).

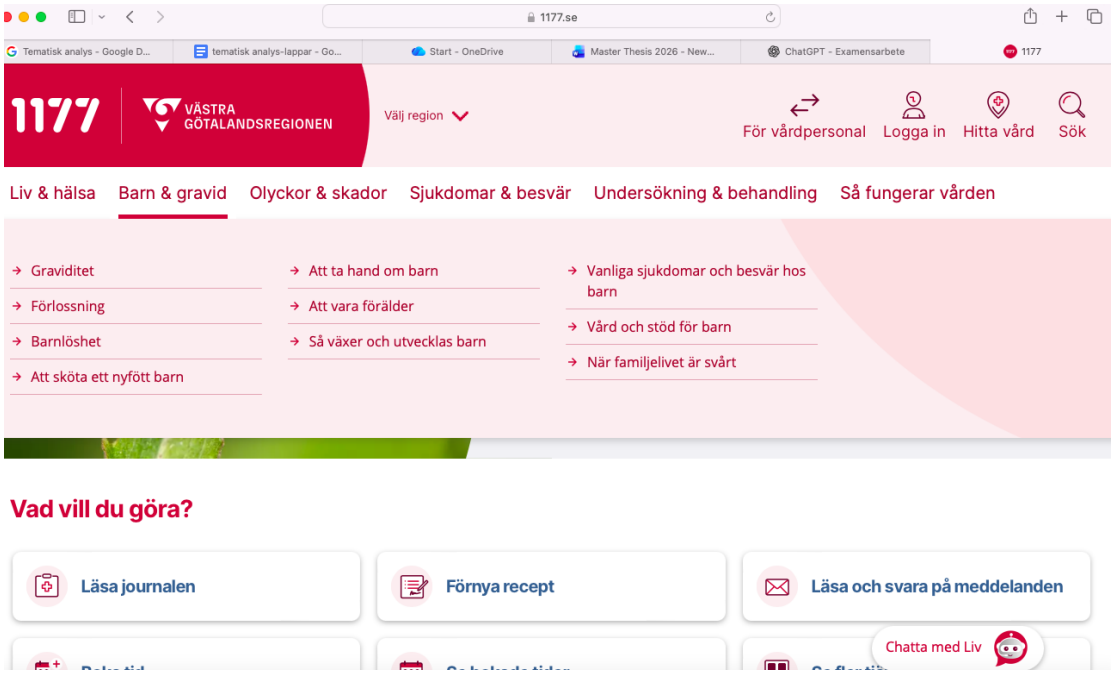

Figure 24: 1177 website when clicking on" Children & Pregnancy" roll-down. Source: 1177 (n.d.-b).

The review also showed that the page assumes a certain level of prior knowledge from the reader. A person who already knows what type of information they are looking for can use the page to find relevant content. However, a person who is at an early stage of the process may need to navigate between several pages to understand the differences between investigation, insemination, IVF, stimulated ovulation and donation. The structure therefore places responsibility on the reader to identify which pathway is relevant.

Another finding was that the distinction between main categories and supporting information is not always clear. For example, "stimulated ovulation" is presented as one of the main categories on the infertility page (1177, 2024). At the same time, hormone stimulation is also included as part of the IVF process on the page "IVF

treatment step by step" (1177, 2025c). This may make it difficult to understand whether stimulated ovulation should be interpreted as a separate treatment, as a step within IVF, or as both.

A similar pattern was identified in the way IVF information is divided. The website separates information about "IVF, test-tube fertilization" from "IVF treatment step by step". The first page describes IVF as a treatment method, while the second presents the treatment as a sequence of steps (1177, 2025c). Both pages contain relevant information, but the relationship between them is not made explicit on the landing page (see figure 25).

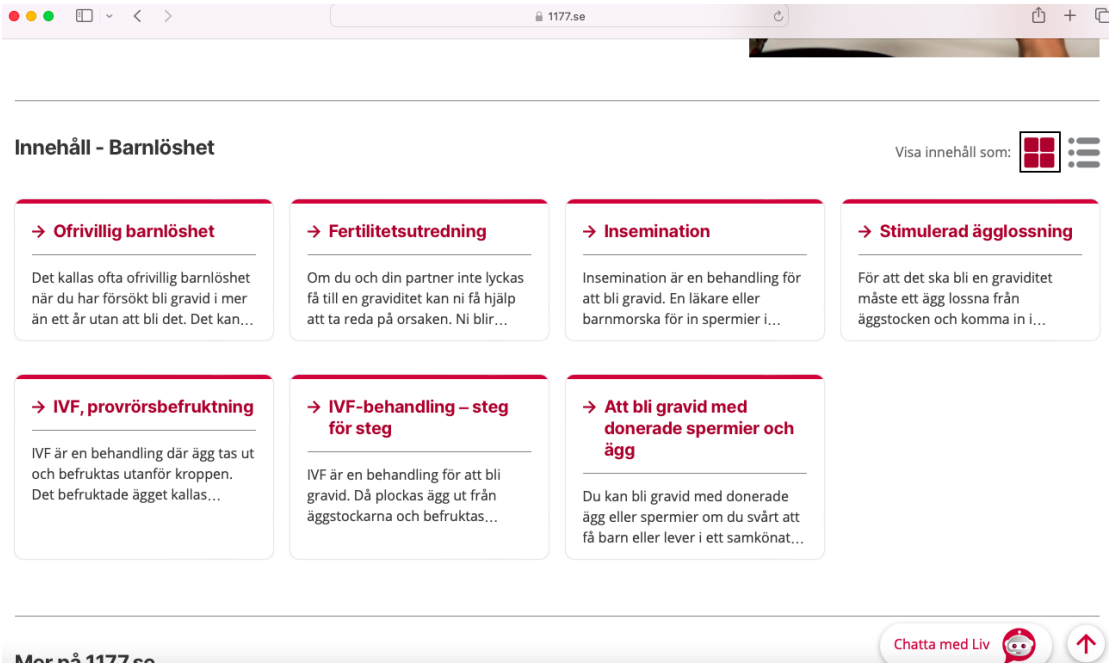

Figure 25: 1177's page with content about childlessness.

The review also showed that some related information is only found after entering specific subpages. For example, links to information about donating eggs or sperm are available through related content, but "donating eggs or sperm" is not presented as a category on the main infertility landing page. Instead, information about donation as an act, meaning how to donate eggs or sperm, belongs to another section of the 1177 website under healthcare donation rather than under the infertility category (1177, 2025d). This creates an additional layer of navigation for readers who may not know that this information exists or where it is located.

5. Discussion

This chapter discusses the empirical findings presented in chapter 4 in relation to the study's theoretical framework and research questions. The discussion is structured around three interconnected dimensions. Section 5.1 examines how information is currently created, communicated, and managed across IVF care pathway, addressing the first and second research question. Section 5.2 identifies the challenges and breakdowns that emerge in the information flow, addressing the second research question across three analytical dimensions: the emotional and psychological, the structural and design, and the equity and access dimensions. Section 5.3 presents an overarching argument about how organizational structure shapes the patient experience, connecting both research questions by demonstrating that many of the challenges identified are not incidental but structurally embedded.

Together, these sections aim to move beyond description toward an analytical understanding of why information practices in IVF care take the form they do, and what conditions would need to change for them to better serve both patients and staff.

5.1 Information Practices Across the IVF Care Pathway

This section examines how patient information is currently created, communicated and managed across the IVF care pathway at SUH, drawing on interviews with healthcare professionals and patients, as well as the process mapping, website review and participatory session findings. First, the multichannel landscape through which information reaches patients and the challenges this creates for coherence and usability. Second, the stepwise approach through which information is structured and delivered across treatment stages, and its limitations in supporting broader patient understanding. Third, the distribution of information across professional roles and the consequences this has for continuity across the patient journey. Together, these dimensions reveal a system that provides extensive information but does not always ensure that it is accessible, coherent or timed in ways that support patient understanding and participation.

5.1.1 A divided information landscape

The findings show that patient information in the IVF care pathway is communicated through a multichannel landscape, including written materials, 1177, telephone contact, in-person meetings, videos, and informal sources. Patients described relying on informal sources, such as family members, colleagues, friends or previous experiences, to understand what IVF could involve. While this provides several entry points to information, it also fragments the patient's informational experience. Information may technically be available, but patients are still required to locate, compare, remember, interpret, and apply it across different stages of the care pathway. This shows that the central challenge is not only information availability, but information coherence.

This finding addresses the research question by showing how patient information is currently communicated and managed across several separate channels rather than through one coherent information structure. From a health literacy perspective, this increases the demands placed on patients. Health literacy concerns individuals' ability

to access, understand, appraise, and apply health information in ways that support health-related action (Nutbeam, 2006; Sørensen et al., 2012). In the IVF context, patients must use these four abilities in an emotionally demanding and medically complex process. As a result, fragmented information does not only create practical confusion but may also increase uncertainty and cognitive responsibility for patients.

In relation to the research question, by showing where breakdowns occur in the information flow. Staff described that patients often contact the clinic with repeated questions about information that has already been provided, while patient interviews showed that patients may feel unsure about what information applies to them, what will happen next, and when they should act. This suggests a tension between the formal delivery of information and the patient's actual ability to understand and use it at the right time. In practice, responsibility for creating coherence is partly shifted from healthcare organization to the patient. This is important in relation to the Swedish Patient Act, which states that healthcare providers are responsible for giving patients individually adapted and comprehensible information about their care, treatment alternatives, risks, and expected care process (Patient Act, 2014:821).

This can also be understood from a service design perspective. Service design emphasizes that services are experienced across multiple interactions, actors, and touchpoints, and that the quality of the service depends on how these interactions connect into a coherent journey (Patrício et al., 2020). The comparison with private fertility clinics shows that clinics such as Livio and Nordic IVF present IVF information in a more consolidated and patient-oriented way, for example through chronological process descriptions and topic-based information banks. This does not imply that private clinics provide better care, since they operate under different organizational conditions. However, it illustrates how the structure and visibility of information shape the patient's experience. This shows that the issue is not necessarily a lack of information, but how information is organized and made accessible. In service design terms, clearer frontstage interfaces can help patients understand how different parts of the care pathway are connected.

Taken together, the analysis suggests that SUH's main challenge is not to produce more patient information, but to organize, sequence, and present existing information in a way that better supports patient understanding across the IVF journey. This represents one of the study's central contributions: information gaps in IVF care do not only arise from missing content, but from a mismatch between how information is distributed by the organization and how patients are able to engage with it over time.

5.1.2 The Stepwise Approach and its Limitations

The findings also show that information in the IVF pathway is often structured through a stepwise approach, where patients receive different types of information at different stages of the treatment process. For example, staff describe how patients receive information at the first clinical interaction, during treatment preparation, in connection with medication instructions, before egg retrieval, and later during treatment continuation. In theory, this approach can support patient understanding by reducing the amount of information given at once and by aligning information with the moment when it becomes relevant. This is particularly important in IVF care, where patients are required to understand and act on complex instructions related to medication, timing, test results and treatment decisions. By showing that patient

information is currently communicated and managed as a staged process, where different types of information are introduced at different points in the IVF pathway this connects to research question.

From a health literacy perspective, a stepwise approach may make information more usable by supporting patients' ability to access and apply information at the right point in the care pathway (Nutbeam, 2006; Sørensen et al., 2012). It may also support shared decision-making by creating repeated opportunities for patients to ask questions, clarify uncertainties and engage with healthcare professionals as the treatment progresses. Shared decision-making requires that patients are not only informed, but supported in understanding options, consequences and preferences in relation to their own situation (Elwyn et al., 2012). This is reflected in the empirical material, where staff describe that patients often need information repeatedly and that questions may arise at different moments depending on where the patient is in the treatment process.

However, the findings suggest that the stepwise approach does not automatically lead to patient participation. While information is divided across stages, patients do not always understand the overall structure of the process or how one step relates to the next. This finding addresses question two, as one patient described that it can be difficult to keep track of information when the process stretches over a long period of time, and that information that may be sufficient in a shorter process becomes harder to remember when months pass between different stages. Similarly, another patient described the waiting period as difficult to understand and expressed a need for information to make sense of the process.

Although the IVF process is medically structured as a sequence of steps, the communication around these steps does not appear to be equally standardized. Midwives use the treatment schedule as a basis for patient information, but the interviews show that information may be communicated differently depending on the professional, the situation, and the handover from physician to midwife. This means that patients may receive the core information, but not always in a consistent or coherent way. As a result, the stepwise structure may help patients understand what to do next, but not necessarily how the full IVF pathway fits together.

In practice, the stepwise approach therefore appears to support operational participation more than reflective participation. Patients are guided in what to do next, when to call, when to take medication or when to attend appointments. This can be effective from a workflow perspective, but it may leave limited room for patients to understand alternative pathways, ask informed questions or prepare emotionally for later stages. This is especially relevant because the patient interviews show that IVF is not experienced as a neutral medical sequence, but as an emotionally charged process shaped by uncertainty, waiting and vulnerability. In this way, the stepwise approach can reduce information overload while still maintaining a dependency on professionals to explain the meaning of each step.

5.1.3 Informational continuity within internal patient information

While the multichannel landscape distributes information across different media, the professional role structure distributes information across different actors. Together,

these two forms of distribution shape the patient 1 and 2 responsibility to create coherence.

The findings show that professional roles contribute differently to patient information across the IVF care pathway, which addresses research question. Health professions at the clinic and coordinators all provide or mediate information at different points in the process. This distribution is necessary in a complex and resource-intensive care pathway such as IVF, where medical decisions, practical instructions, laboratory results, booking systems and waiting lists need to be coordinated across professional boundaries. IVF treatment itself consists of several stages and requires patients to engage with healthcare services over an extended period (1177, 2026; Västra Götalandsregionen, 2026).

However, the main challenge identified in the findings is not primarily that patients do not understand who does what. Rather, the challenge concerns the lack of a shared and visible structure for what information has already been given to the patient, when it was given, by whom, and through which channel. Information is distributed across professional roles, but it is not always systematically traceable across the patient journey. As a result, informational continuity becomes dependent on individual professionals, local routines, and the specific situation in which the interaction takes place.

This is visible in how healthcare professionals describe their own information practices. Midwives describe that they aim to communicate the same core information, but that they still do it in different ways. Some of the staff spend more time with patients, others are more concise, and the way information is explained may vary between individuals. One midwife also reflected that after a short meeting, she could wonder whether she had really said everything she should have said. This relate to the research question, since the findings suggests that the issue is not a lack of professional commitment, but that information delivery is partly dependent on individual judgement rather than being fully supported by a shared system for ensuring informational continuity.

From a service design perspective, this points to a gap between touchpoint performance and journey coherence. Each professional interaction may function well in itself, but the transitions between interactions are less clearly designed. Services in the IVF pathway are shaped through multiple touchpoints across time, and the user experience depends not only on individual interactions but on how these interactions connect into a coherent journey (Bate & Roberts, 2007). Patients may receive information from several competent professionals, but the organization does not always have a clear overview of how these information moments connect over time.

The issue can therefore be understood as a design problem rather than only a communication problem. The system appears to be organized around professional and operational information channels, and who dose what. makes medical decisions. This organization is understandable from an operational perspective, especially in a resource-constrained environment. However, it does not necessarily create a patient-facing structure where information is coherent, traceable and timed according to the patient's experience of the care pathway. This aligns with a human-centred design perspective, where problems should be understood from users' needs, experiences and

contexts rather than only from internal organizational structures (Brown, 2008; Stanford d. school, 2010).

Rather than relying on the same professional to follow the patient throughout the IVF pathway, the findings point to the need for a clearer way of tracking what information has been given, when it was given, and through which channel. From a service design perspective, this means identifying key touchpoints in the patient journey and making visible what informational needs arise at each stage (Bate & Roberts, 2007). Such a structure would help staff understand whether the patient needs new information, repetition, clarification, or emotional support. In this way, informational continuity would not depend only on individual professionals but be supported by the design of the service itself.

The comparison with private care further illustrates the value of relational continuity. Patient 3 described SUH as lacking personal contact, while Livio was experienced as more personal because she encountered the same voices and felt that staff were familiar with her process. This does not prove that private clinics provide better medical care, but it shows how continuity and recognition can shape trust, agency and the feeling of being seen as an individual patient rather than as one case among many (WHO, 2009). This is also consistent with the website review, where private clinics such as Livio and Nordic IVF presented information in a more consolidated and patient-oriented format than the information available through 1177.

A more patient-centred service design would therefore not only clarify which profession is responsible for which type of information. More importantly, it would create a shared structure for documenting, coordinating and following up what information the patient has received and what information the patient may need next. This would support both patients and professionals by reducing repetition, preventing information gaps, and making the IVF pathway easier to navigate as a coherent service rather than as a sequence of separate professional interactions (Bate & Roberts, 2007).

5.2 Challenges and Breakdowns in the Information Flow

While section 5.1 establishes how information is currently structured and communicated across the IVF care pathway, this section turns to where that structure breaks down. The findings reveal a range of challenges and breakdowns in the information flow, from timing mismatches and emotional barriers to equity concerns and structural misalignments. Together, these prevent information from reaching its intended purpose. The challenges are examined across three analytical dimensions: the emotional and psychological conditions under which information is received, the structural and design factors that shape when and how information is delivered, and the equity and access concerns that determine who benefits from the current information model and who does not.

5.2.1 The Emotional and Psychological Dimension

Patients in IVF care seek help to conceive a child, a motivation rooted in Maslow's (1943) hierarchy of needs, specifically the higher-order need for love, belonging and the fulfilment of parenthood. When this need remains unmet, as is the case for

patients entering fertility treatment, Maslow argues that consciousness redirects entirely toward its fulfilment, as one physician described: the longing is the same as feeling thirsty or hungry. This deeply motivational state colours every interaction and piece of information encountered throughout the process. This is reflected across multiple sources such as the documentary *"Barnmakarna",* the social media account *thepursuitofkicki,* and the interviews conducted both with healthcare professionals and patients. All which describe the emotional intensity of IVF journey as recurring and defining feature of patient experience, from angry patients calling to know their position in the system, to the difficulty of absorbing information when receiving unwanted news, to the anxiety of not knowing the process (and having to repeat it several times). The healthcare professionals know this emotional burden is something the different professions need to address in their day-to-day work, as patients are undergoing hormonal treatment that intensifies their emotional state.

The overwhelming emotional state described above has direct implications of how patients receive and process health information. Sørensen et al. (2012) describe health literacy through four interrelated competencies regarding health literacy: accessing, understanding, appraising and applying health information. When a patient is emotionally overwhelmed, such as uncertain about outcomes, anxious about timing, or processing difficult news, their capacity to move through these four competencies is compromised. A patient may technically receive information but be unable to understand, appraise or apply it meaningful in that moment. As Nutbeam (2006) notes, health literacy reflects an individuals' cognitive and social skills to access, understand and use health information in ways to promote and support health-related actions. This underscores the importance of not only what information is provided (instructions, consent forms, treatment schedules, and medication guides) but also how and when it is delivered in relation to the patient's psychological readiness.

How information is delivered across professional roles is further amplifying the emotional burden felt by the patients. The findings suggest that the way information is emphasised and adapted depends significantly on the individual delivering it, meaning that two patients at the same stage of treatment may receive different explanations of the same process. For a patient already in an emotionally vulnerable state, this inconsistency can add another layer of uncertainty rather than reduce it. Because when information varies between encounters, patients may question what is correct, feel unsure about what to do next, or lose confidence in the care they are receiving.

As discussed in section 5.1.3, relational continuity and the quality of personal encounter shape how much patients trust the information they receive and how confidently they act on it. When patients feel anonymous or interchangeable, as one patient described at SUH, where communication felt focused on the organization rather than her as an individual, the emotional distance created reduces their sense of agency and willingness to engage with clinical information. Relational quality is therefore not peripheral to information delivery but a condition that determines whether information reaches its intended purpose.

Given the emotional intensity of the IVF process and the volume of information provided across the care pathway, patients frequently seek additional information outside the healthcare system, through social media accounts, podcasts, reading articles, going through different clinics' webpage, and having conversations with

others who have undergone IVF. As discussed in 5.1, the limited availability of clinic-specific digital information at SUH, compared to the ones offered by the private ones, means that patient seeking to understand their journey beyond what is communicated in appointments have few official digital resources to turn to. While this reflects patients' active role in trying to understand and prepare for their journey, it also introduces risk. As Aanstoos (2024) describes, an unfulfilled need occupies the individual's attention and colours their interpretation of all incoming information. In a hormonal and emotionally heightened state, patients may be particularly drawn to negative narratives, such as stories of failed cycles, unexpected complications, or difficult experiences. This could intensify anxiety rather than support informed preparation. Furthermore, this suggests that external information seeking is not merely gap-filling behaviour but a symptom of unmet informational and emotional needs within the care pathway itself.

A further tension emerges in the IVF care pathway between how healthcare professionals and patients perceive the repetition of information. Staff describe information as already communicated across multiple stages of the process through written materials, treatment schedules, telephone consultations and in-person meetings. However, from the patient perspective it has not necessarily been received. This is partly due to the limited availability of clinic-specific digital information, reflected in the quantitative data from 2024 by IMPROVEIT, where SUH scored the lowest on accessibility among the clinics in Gothenburg. As one patient mentioned, information that may have been sufficient in a shorter process becomes difficult to retain when the pathway stretches more than a year. Returning to Maslow (1943), when a patient is overwhelmed, their cognitive capacity to absorb complex information is reduced. Repetition is therefore not merely about saying the same thing again but about timing information to moments of emotional readiness, as one of the key factors shaping patient receptiveness to information.

As Bate and Roberts (2007) argue, services must not only be safe and effective, but they must be experienced as safe and supportive. This is perhaps most visible in how the clinic manages moments of shocking news. When no embryo can be transferred, midwives describe patients as becoming too shocked to absorb medical information. This reflects what Sørensen et al. (2012) describe as a collapse of the competency chain, meaning, the emotional state prevents entry into information process at all. Health literacy is therefore not a fixed capacity but a context-dependent one, shaped by emotional conditions under which information is delivered. This dynamic was illustrated by patient 2, who described her partner interpreting information when she had not fully absorbed it herself. Rather than being a sign of disengagement, this reflects a coping mechanism that emerges when patient's health literacy is compromised by emotional overwhelm. It underscores the importance of the partner's involvement in information delivery as a functional one: when the patient cannot fully process information alone, the partner's presence and informed participation become a practical necessity rather than an optional addition. Patient 3 further described how the absence of the partner during pandemic restrictions intensified the emotional burden of an already demanding journey and reinforced how much the partner's physical presence contributes to the patient's sense of safety and stability at critical moments.

In response, the clinic has developed a structured approach that separates emotional and clinical communication: the midwife calls first to deliver the immediate message, the doctor follows later the same day to explain the medical details, and approximately a week after the midwife follows up to check on the patient and plan the next steps. This recognition aligns with Maslow's (1943) hierarchy of needs, when the patient's emotional needs are not met, the information from healthcare professionals cannot be received and processed. From a shared decision-making perspective, this structure also reflects what Elwyn et al. (2012) describes as a necessary condition for meaningful patient participation; understanding their options, consequences and preferences before decisions are made. Decision-making after receiving bad news – to attempt another cycle, what to do with remaining embryos, or whether to consider alternative pathways – requires cognitive and emotional readiness. These cannot be assumed immediately after a difficult conversation, as midwives describe avoiding detailed explanations in these moments out of concern for making the situation worse. The midwife's follow-up call functions not only as emotional support but as a delayed second opportunity for shared-decision-making, when the patient is emotionally more stable and can engage with upcoming opportunities.

The importance of emotional readiness for meaningful participation was also reflected in patient accounts. Patient 3 described active participation as a deeply held value, noting that the decisions made during IVF have lifelong consequences and that patients should not simply accept what they are told but engage as informed participants in their own journey. This further aligns with Elwyn et al.'s (2012) goal of shared-decision-making - supporting the patients' capacity to deliberate and decide. However, this level of participation presupposes a degree of emotional stability and health literacy that not all patients have access to equally. For patients who are emotionally overwhelmed, the conditions for meaningful and shared decision-making may not be present regardless of how much information has been provided.

One way of addressing this challenge of emotional readiness concerns the tone and framing of clinical communication. Copenhagen's approach is shaped by an ambition to meet patients with hope rather than probability-based discouragement. The hospital focuses on the individual possibility of becoming pregnant rather than general success rates, as reflected in the statement "*as long as we make a treatment, then we actually believe it can happen*". A similar ambition can be identified at SUH, where communication is described as something that should meet patients at their current level of understanding and emotional readiness. From a DT perspective, this reflects an empathy-driven communicative orientation, rather than only asking what information patients need, they also consider how patients receive it. Both Copenhagen and SUH reflect an aspiration toward this shift, though the degree of which it is structurally embedded differs between the two contexts.

A further dimension specific to IVF care is the physical effect of hormonal treatment on the patient's emotional and cognitive state. Patients describe how hormonal stimulation affected not only their bodies but their mental state and emotional stability, which made it difficult to maintain a normal facade in their everyday life and intensifying an already vulnerable psychological condition. One physician noted that hormonal stimulation can intensify an already vulnerable emotional state, which healthcare professionals need to consider in their communication and care. This is

significant because the barriers to information reception are not static, they fluctuate with the patient's treatment stage. A patient who absorbed information clearly at the first appointment may be in a significantly more compromised state during the hormonal stimulation, yet this is precisely the phase when patients are expected to independently manage complex medication schedules, interpret bodily responses and make timely decisions about contacting the clinic.

5.2.2 Organizational Mismatches in Information Access and Delivery

A central finding in this study is that information gaps in the IVF care pathway are not only created by missing information, but also by a mismatch between when information is provided and when patients are able to understand, remember, and apply it. The results show that patients receive extensive information early in the process, often before they have entered the treatment stage where the information becomes practically relevant. This creates a timing mismatch: information may be formally available but functionally inaccessible at the moment the patient needs it.

This is particularly important in IVF care because the treatment pathway is long, emotionally demanding, and divided into several stages. Patients may receive information at the beginning of the process, but due to long waiting times, emotional stress, and the complexity of the care pathway, it may no longer be remembered when it becomes relevant. One patient explained that the information may have been sufficient if the process had been shorter, but that when the process stretches over more than a year, it becomes difficult to keep track of everything that has been communicated. This suggests that the issue is not necessarily that information is absent, but that the system relies too heavily on patients being able to store and retrieve information over time.

From a health literacy perspective, timing becomes a crucial part of patient understanding. Health literacy is not only the ability to read information, but the ability to access, understand, appraise and apply health information in a specific context (Nutbeam, 2006; Sørensen et al., 2012). Information provided too early may technically fulfill the requirement of having informed the patient, but it does not necessarily support the patient's ability to use that information when decisions or actions are required. Therefore, patient information needs to be synchronized with the patient's position in the care journey rather than delivered as a one-time transfer of knowledge.

A tension also exists between the staff perspective and the patient perspective. Healthcare professionals describe that information is repeated throughout the process and that midwives return to the same written material at different stages. However, patients still express a need for reminders, summaries, and clarification when they reach a new phase of treatment. This indicates that repetition alone does not solve the problem, because what matters is whether repetition is meaningful in relation to the patient's current situation. Information becomes useful when it is connected to an immediate need, such as starting medication, preparing for egg retrieval, understanding test results, or deciding about the next treatment step.

Mismatch in information timing

The emotional context of IVF further strengthens the importance of timing. One patient described receiving a message through 1177 stating that the IVF process could begin, asking whether they wanted to remain at SUH or be referred to a private clinic. Although the information itself was relevant, it was experienced as stressful because the timing, framing and the next steps were unclear. It created panic rather than reassurance, which illustrates how communication about waiting times and queue position becomes emotionally significant in IVF care. When patients have waited a long time to access care, a message indicating that the process can begin may be interpreted as an opportunity that must be acted upon immediately, regardless of the patient's actual readiness. The lack of clear reassurance regarding time, choice and queue position contributed to fear of losing access to treatment, resulting in a message not only interpreted information but also about referral options which serves as a decisive moment in the patient's care trajectory.

By contrast, Copenhagen explicitly reassures patients that they will not lose their place if they wait until they are ready to start treatment. This positions the patient's readiness as a clinical consideration rather than an administrative one. At SUH, communication appears to focus more on administrative movement through system than on reducing emotional uncertainty created by long queues, leaving patients to interpret the consequences of waiting on their own. This is further discussed in section 5.3, which reflects on a broader structural difference in how two clinics have designed their patient-facing communication.

From a human-centered design perspective, this points to a gap between the system's internal logic and the patient's lived experience – one message from the clinic can be perceived as a high-stake decision after months or years of waiting. A more patient-centered approach would include not only factual information about the next step, but also explicit reassurance about what happens if the patient needs time or is not yet ready to start (Brown, 2008; Stanford d. school, 2010)

Digital accessibility and organizational mismatch after the website closure

Another organizational mismatch identified in the study concerns the closure of SUH's previous local website and the shift towards 1177 as the main digital information channel. Before the website closure, the clinic had greater control over what information could be published and how it was presented. After the closure, however, the available digital information became more limited and less tailored to the local IVF process. One of the physicians described that the clinic previously had a website where they could decide and specify what type of information should be published, but that this changed, leaving only minimal information online and forcing the clinic to find other solutions. This indicates that the organizational decision to remove the local website was not matched by an equally functional replacement through 1177. The clinic is expected to rely on 1177 as the official digital information channel, but staff describe the process of changing or adding information there as slow, complicated and difficult to influence. Hence, meaning that even when healthcare professionals identify the informational gaps, they do not have the tools or mandate to control.

The consequences are visible in daily work. Secretaries described an increase in repeated questions after the website was removed, as patients could no longer find information independently. This shifted the informational burden from self-service to

direct staff contact, which increases the administrative load on already pressured professional groups. None of the interviewed patients referred to 1177 as a central source of IVF information, which suggests that the platform was not a meaningful support in their journey. This is further supported by the website review. When comparing with the websites of private IVF clinics, the 1177 information structure appeared less process-oriented and less clearly connected to the patient journey, showing a clear difference in structure, amount of information and ease of navigation. From a health literacy perspective, access to information is not only about whether it exists, but whether it is findable, understandable and usable in context (Nutbeam, 2006; Sørensen et al., 2012). If information is technically available on 1177, but difficult to locate or disconnected from the local care pathway, it remains functionally inaccessible from the patient's perspective.

The closure of the local website shifted control over information away from the clinical unit, while responsibility for answering patient questions remained with the same staff. This creates a tension between responsibility and authority – the staff are responsible for helping patients understand the process but have limited ability to shape the digital information environment that could reduce misunderstandings. As a result, it further limits the clinic's capacity for continuous improvement, since identified problems cannot easily be translated into updated patient-facing information.

5.2.3 The Equity and Access Dimension

Based on empirical findings, three personas were developed to represent different information behaviors in the IVF care pathway. These personas should not be understood as fixed patient categories, but as design-oriented abstractions of patterns identified in the interviews, process mapping and participatory session. The findings show that patients differ in how much information they seek, when information becomes meaningful to them, and how much responsibility they are able or willing to take in navigating the process. Some patients actively search for detailed information and try to build control through understanding, while others need information to be provided step by step when it becomes practically relevant. A third pattern concerns patients who want the clinic to provide clear guidance and reduce the burden of self-navigation. Translated to IVF care, these personas illustrate three different ways of relating to information, responsibility and uncertainty.

Rebecka represents the patient who actively searches for information and wants to understand the process in detail. Information creates a sense of control for her – she wants to know what will happen, why it happens and how different steps connect. If information feels fragmented or inconsistent, she will search elsewhere, compare sources or contact the clinic for confirmation.

Hanna does not need to understand the full process in advance but wants to take treatment step by step. Information becomes meaningful for her when connected to the stage she is currently in. Too much information too early becomes difficult to use when the relevant moment arrives. She benefits from short summaries, reminders and clear instructions about what happens next.

Amanda wants the clinic to take a stronger guiding role. She does not want to navigate large amounts of information independently but wants to know she is in safe hands and that the clinic will tell her what to do and when. She needs simple, prioritized and action-oriented information that reduces cognitive load rather than increases it.

From a health literacy perspective, this reinforces that patient understanding is not only about access to information, but about the ability to understand, appraise and apply information in context (Nutbeam, 2006; Sørensen et al., 2012). Equal information delivery does not necessarily create equal understanding, because patients have different levels of prior knowledge, emotional readiness, need for control and capacity for self-navigation. From a DT perspective, this also supports the need to design patient information around user needs and behaviors rather than around a single assumed patient journey. Brown's human-centered view of DTand the Stanford d. school's emphasis on empathy both suggest that services should be designed from an understanding of people's lived experiences and contexts (Brown, 2008; Stanford d. school, 2010).

The personas therefore contribute to the discussion on equity and access. If patient information is designed as one standardized package, it may unintentionally favor patients who are already able and willing to search, interpret and organize information themselves. Patients who need more guidance, reassurance or stage-based support may be disadvantaged, even though they have formally received the same information. A more equitable information model would therefore not only provide the same information to all patients but offer different ways of accessing and engaging with it. This could include layered information for patients like *Rebecka*, stage-based reminders for patients like *Hanna*, and simplified checklists or guided next steps for patients like *Amanda*.

In this way, the personas show that patient information in IVF care should not be understood as a static package of documents, but as a flexible support system. The goal is not to create separate care pathways for every patient type, but to design an information structure that can accommodate different ways of understanding and navigating IVF. This would support patient participation while reducing the risk that understanding depends on the patient's own ability to compensate for gaps in the system.

The equity concerns identified in this study extend beyond information design to access to treatment itself. One significant finding concerns the short notice list, which emerged as an operational solution to reduce wasted appointment slots. On the other hand, this illustrates how system pressures can produce unintended inequities in who receives care and when. As the findings show, patients who are more proactive in following up on their queue position, are more likely to be contacted when a short notice slot becomes available, not because they are medically prioritized but because they are perceived as easier to reach and more likely to attend. This is explicitly acknowledged by the process doctor as unfair and noting that the most anxious patient is not necessarily the one who needs treatment first.

From a health literacy perspective, this reflects what Sørensen et al. (2012) describe as the unequal distribution of health literacy across patient populations. Patients who can navigate the system, meaning those who know how to call frequently, who

understand how the queue works, and who have the flexibility to attend at short notice, are implicitly advantaged. Meanwhile, patients who are less able to do so – lower health literacy, limited workplace flexibility, language barriers, or less familiar with how to advocate within healthcare systems – are structurally disadvantaged, even though they have formally equal access to the same waiting list. This directly connects to the persona framework above, specifically *Amanda*, who relies on the clinic to guide her rather than actively navigate the system herself. Therefore, she is less likely to receive a short notice slot than a patient like *Rebecka*, who calls frequently and demonstrates visible engagement.

From a service design perspective, this is an unintended consequence of a system under pressure. The short notice list was not designed to disadvantage certain patient groups but emerged as a practical response to cancellations and capacity constraints. However, as Patrìcio et al. (2020) argue, service design requires attention to the broader configuration of actors, processes and organizational arrangements that together constitute a service. When a system is designed primarily around operational efficiency rather than equitable access, informal patterns emerge that reflect existing inequalities rather than clinical need. Addressing this would require not only a clearer protocol for how short notice slots are allocated, but a broader commitment to designing access mechanisms that do not inadvertently reward self-advocacy over medical priority.

A further dimension of inequity concerns how the IVF care pathway is structurally designed around the female patient, with partners occupying a peripheral role in the information flow. The treatment pathway, the information materials, the booking systems, and the communication channels, is all oriented toward the female patient as the primary recipient. Meanwhile, the partner's involvement is treated as supplementary rather than integral. This is not simply a matter of individual staff choices but reflects how the service has been architecturally configured. When one partner is systematically less informed than the other, the distribution of emotional and cognitive labor within the couple becomes unequal. The female patient not only carries the physical burden of treatment but also the primary responsibility for understanding, remembering, and communicating information to her partner. As Patrìcio et al. (2020) argue, service design in healthcare should adopt a human-centered and participatory approach that considers the full range of actors involved in the service experience.

In IVF care, the couple is the natural unit of such care – both are affected by the process, have a stake in the decisions made, and benefit from being informed participants. This is further reinforced by the clinic's own eligibility criteria which require patients to be in a relationship of at least two years, cohabiting and registered at the same address. The partner is therefore not an optional presence but a formally recognized part of the treatment context. Logically, the information should be directed toward both partners rather than exclusively to the female patient, if the system acknowledges the couple as a prerequisite for treatment. This was reflected by patient 1 in section 4.4.6, who described situations where she was unable to take calls from the clinic during working hours. In such cases, a partner could have received and relayed time-sensitive information, reducing the risk of missed communication and the anxiety associated with it.

Designing the information system around the individual female patient rather than the couple therefore represents a structural misalignment between how the service is organized and how patients experience and navigate it. By contrast, the Copenhagen model demonstrates that partner inclusion can deliberately be embedded in the structural logic of care, through joint registration, two chairs in every consultation room, and dedicated partner information folders. This suggests that integrating the partner inclusion does not necessarily compromise operational efficiency, and that the current misalignment at SUH is not an inevitable feature of IVF care but a consequent of design choices that can be made differently.

5.3 Organizational Structure as a Determinant of Patient Experience

In 2023, 2228 treatment cycles were initiated at SUH, making it the largest IVF provider in Gothenburg. The organizational conditions under which these cycles are delivered are therefore not a matter of internal operational concern alone but have direct consequences for a substantial patient population navigating one of the most emotionally demanding processes in their lives. The findings of this study suggest that many of the challenges patients experience across the IVF care pathway are not incidental but structurally embedded, rooted in how the organization currently manages information, coordinates care, and approaches improvement work.

When looking at the current day-to-day workload, physicians receive up to 100 referrals per week, embryologists spend approximately three hours filling nitrogen tanks, and bookings are manually transferred between systems - all of which consume time and attention that could otherwise be directed toward patient-facing work. These conditions are not invisible to patients. In the 2024 IMPROVEIT survey, SUH scored lower across all categories compared to the other Gothenburg clinics and the national average. The widest gap appeared in patient participation at 55% compared to the national average of 73%. This suggests that the administrative and organizational conditions described above have measurable impact on how patients experience their own involvement in care.

The tension between operational demands and patient centered design is a central challenge identified in this study. As Bate and Roberts (2007) argue, designing a set of experiences will be more successful and fulfilling for patients than focusing on organizational efficiency alone. This is reflected in the IVF pathway at SUH, where several moments are identifiable: the first appointment where patients receive large volumes of information, the egg retrieval procedure conducted under time pressure, and the moment of receiving news about embryo quality or failed transfers. As mentioned above, the organizational conditions affect the quality of these critical moments – the inconsistency of fragmented systems, rotational staff and administrative burden all depend on the staff capacity rather than structural design.

A related dimension concerns the continuity of care. Specifically, this regards the physical planning board that acts as the primary coordination tool for the midwives' daily scheduling. The planning tool proved fragile under pressure, with last-minute appointments sometimes going unnoticed by the assigned midwife, and patients waiting without clarity on the next steps. This further illustrates the lack of structured feedback between physicians and midwives, which amplifies the uncertainty, as midwives described having to wait up to 20 minutes without knowing whether a

physician had finished with a patient. At a broader level, the rotational nature of physician schedules means that the designated physician, or PAL, may be unavailable when questions arise between treatment stages, creating gaps in continuity that staff recognize but find difficult to resolve within current staffing structures. As Patrìcio et al. (2020) argue, service design contributes to healthcare transformation through three complementary approaches: human centered and participatory approach, a creative and transformative approach, and a service systems perspective. Applying this at SUH, the current organizational conditions constrain all three: patient participation in design is limited, creative improvement work happens in personal time, and the service system remains fragmented across disconnected roles, tools, and processes. This was also reflected by one patient who described feeling genuinely known by her care team at a private clinic - recognizing the same voices across appointments and experiencing the care as a personal investment in her life, while patients at SUH described feeling anonymous and interchangeable. It is therefore not a matter of personal preference but a structural condition that shapes how patients receive, trust and act upon information throughout the treatment process.

From an innovation perspective, this reflects what Reid and de Brentani (2004) describe as fuzzy front end: the early exploratory phase of innovation where the need for change is recognised but the path forward remains unclear and there are limited resources. At SUH, improvement initiatives exist, such as the physician's assignment and the planned information film restructuring, but these are carried out largely through individual initiative rather than structured organisational investment like the medical director implementation. The physician's assignment outside contracted hours is the clearest illustration of this: the organisation recognises the need for improvement but has not yet created conditions for it to happen systematically, instead, assignment is conducted in personal time.

As Buchanan and Huczynski (2023) describe, efforts to change require coordination across multiple levels of organisation as well as individuals' capacity and willingness to adapt. This is further complicated by the regulatory constraints that limit what can be changed. In the case of SUH, VGR governs and limits digital information publishing, the physical relocation has been under discussion for eight years, and a hiring freeze prevents the redistribution of administrative tasks to support staff. These are not internal choices but externally imposed constraints that narrow the space available for improvement. At the same time, resistance to change also emerges from within, as some staff expressed the concern that automation of administrative tasks could threaten existing roles, reflecting a dynamic that Buchanan and Huczynski (2023) identify as a natural but significant barrier to organisational transformation.

By contrast, the Copenhagen University Hospital illustrates what becomes possible when an improvement is treated as structural commitment rather than individual responsibility. The team-based first appointment, mandatory pre-visit information video, dedicated partner information folder, and proactive scheduling guidance are not ad hoc solutions but deliberate design choices that address the same challenges identified at SUH through intentional service design. Through the DT lens, Copenhagen has moved through the fuzzy front end and operationalised its improvement initiatives into the structure of care itself. This does not mean that Copenhagen's model is directly transferable to SUH, due to the difference in scale, governance, patient population, and other factors that must be acknowledged. Instead,

it demonstrates that the organisational challenges SUH faces are not inevitable features of IVF care but consequences of organisational choices that can, in principle, be approached differently. Moving from the current reactive and individually driven approach toward a systematic model of improvement would not only require dedicated resources and time for development work, but also a structural commitment to placing the patient journey at the centre of how information is designed and delivered.

The need for structural improvement in information delivery is not limited to individual staff members at SUH. Addressing these conditions is therefore not peripheral to the study's research questions, but central to them. The awareness of the problem is widespread as the healthcare professionals across roles collectively identified timing of information, emotional readiness of patients, and consistency across channels as key areas requiring improvement. However, awareness alone is insufficient because information practices and breakdowns identified throughout the study cannot fully be understood or improved without the attention to the organizational structure that shape them.

6. Conclusion

The purpose of this study was to develop an in-depth understanding of how patient information is currently created, communicated and experienced across the IVF care pathway at SUH. This research is in parallel with an ongoing innovation initiative to identify gaps and challenges in the current information practices, and to explore what opportunities for innovation exist to better support both patients and healthcare professionals.

The findings show that patient information in IVF care is not communicated through one coherent system but through a fragmented multichannel landscape, distributed across professional roles without a shared structured for ensuring continuity across patient journey. Information is often available in technical sense, but not always accessible, timely or emotionally aligned with the patient's capacity to receive it. Breakdowns in the information flow emerge at the intersection of emotional overwhelm, structural misalignment and inequitable access. This means that information fails not because it is absent, but because the conditions under which it is delivered do not support its reception, understanding or application.

A central finding of this study is that these challenges are not incidental but are structurally embedded and rooted in the organizational conditions under which IVF care is delivered. Administrative burden, fragmented systems, limited digital infrastructure and constrained improvement capacity collectively shape what patients receive and when. This suggests that meaningful improvement in patient information practices requires not only better content or clearer communication, but a systemic commitment to designing information environment around the patient journey rather than operational convenience.

A further central finding concerns the role of the partner in the IVF care pathway. The study identifies a consistent structural misalignment between how the system formally recognizes the couple, requiring a relationship of at least two years as an eligibility criterion, and how information is designed and delivered exclusively to the female patient. Partners frequently receive information secondhand, creating an unequal distribution of emotional and cognitive responsibility within the couple. From a DT perspective, involving the partner more actively and deliberately in the information process not only reduces this burden but also strengthens the couple's collective capacity to navigate the treatment process, make informed decisions together, and support each other at emotionally critical moments.

Based on these findings, the study identifies several concrete opportunities for improvement, including redesigning the first clinical encounter, strengthening the partner involvement in information delivery, and clarifying the role of digital information channels. These are all elaborated in the recommendations chapter.

The study has several limitations, which are discussed in detail in section 3.11, including the small patient sample and the micro ethnographic scope of fieldwork. Together, the findings contribute to a broader understanding of how information practices in IVF care are shaped not only by individual communication choices but by the organizational and structural conditions within which care is delivered.

7. Recommendations

Building on the empirical findings and the design thinking process, this section responds to the study's final research question by presenting recommendations for how the project grope can move forward in the innovation process and further develop patient information across the IVF care pathway. We recommend that SUH continues the innovation work within three areas: the first meeting, information channels, and the partner perspective. Together, these areas have the potential to reduce strain on healthcare professionals, strengthen patient involvement, and support a more informed and coherent IVF journey.

1. Redesign the first meeting

We recommend that the innovation project group further explores the structure and content of the first clinical meeting. This could include drawing inspiration from Copenhagen University Hospital, where both a physician and a midwife are present during the first meeting, as well as from private clinics that use medical instructional videos for practical treatment steps, such as administering hormone injections at home.

The purpose would be to create a clearer and more patient-centred first meeting, where medical assessment, practical treatment information, and the patient's own questions are connected without making the meeting too long or overwhelming. This could also reduce the risk of missing to communicate essential information.

As part of this, the clinic could develop a shared internal guideline for the first meeting. The internal guideline could guide professionals to first address the patient's individual situation, questions, and emotional readiness before moving into general information about the IVF process.

A possible prototype could be to test a combined first meeting with both a physician and a midwife present. Another option could be to build on SUH's current use of instructional videos, which are already sometimes used instead of in-person instruction for hormone injections. This could help shift standardized practical information outside the meeting and allow more time for patient-specific questions and treatment planning.

The test should involve physicians, midwives, and secretaries, since all three groups are affected by how information directly is communicated, followed up, and administratively handled. One risk is that a combined meeting could reduce flexibility for the short-notice list, due to several professional resources would need to be available at the same time.

The effect could be followed up by coding and tracking patient questions received through phone calls and 1177 after the first meeting, for example questions about egg retrieval, hormone injections, or the next steps in the treatment process. A decrease in these questions could indicate that the first meeting has created a clearer understanding of the IVF process.

2. Strengthen the partner perspective

We recommend that the innovation project group further explores how the partner can be more actively involved throughout the IVF journey. The findings indicate that the process is often structured around the woman's body and treatment, and that information is primarily directed to her, while the partner's informational and emotional role risks becoming secondary.

This could be prototyped by developing partner-specific information, such as a separate information map, and by sending key information to both parties, addressed to each person's role in the process. Partner-specific QR-code links could also be used to track whether partners access the material and which information they use.

The prototype could be tested at key touchpoints where the partner is expected or required to participate. At these meetings, the clinic could ask a simple follow-up question, such as: *"Do you feel that you understand your role in the next step?"* This would provide both quantitative and qualitative indications of whether the partner feels more informed and involved.

The test would need to involve laboratory staff, physicians, and midwives, since these groups meet or communicate with the couple at different stages of the process. A potential risk is that patients may experience the information as duplicated, but this could also help clarify which information is important for both parties to understand.

A stronger partner perspective could support shared understanding, reduce the informational and emotional burden placed on the woman, and improve the couple's ability to navigate the IVF process together.

3. Clarify the role of information channels

We recommend that the innovation project group further explores a strategic decision about which communication channels should be used, for what purpose, and how they should relate to each other. The current information landscape requires patients to combine information from several formats, including written material, video, booklet, and 1177, which may make the IVF pathway harder to overview.

One possible prototype could be to use the material sent before the first meeting to clearly refer patients to 1177 as the main channel for general IVF information. This could allow the printed or sent material to be made shorter and more focused on the process that is specific to SUH, rather than repeating general information already available elsewhere.

To address the organizational challenges of working with 1177, SUH could explore collaboration with other departments, the wider organizational area, or other public IVF clinics. This could help create stronger support for improving shared information, adding a clearer process flow, and developing a place where patients can return to previously asked questions and answers.

The test would need to involve the local owners of patient information at SUH and the responsible actors for 1177. A potential risk is that development through 1177 may involve long processes and be difficult to influence, especially if several organizational levels are involved.

The effect could be followed up by tracking how many patients access 1177 through QR codes included in the information material. SUH could also compare current use of the 1177 landing page for involuntary childlessness with usage after a clearer information bank has been developed. A higher number of visits, together with fewer repeated general questions through phone calls or 1177 messages, could indicate that patients are finding and using the information more effectively.

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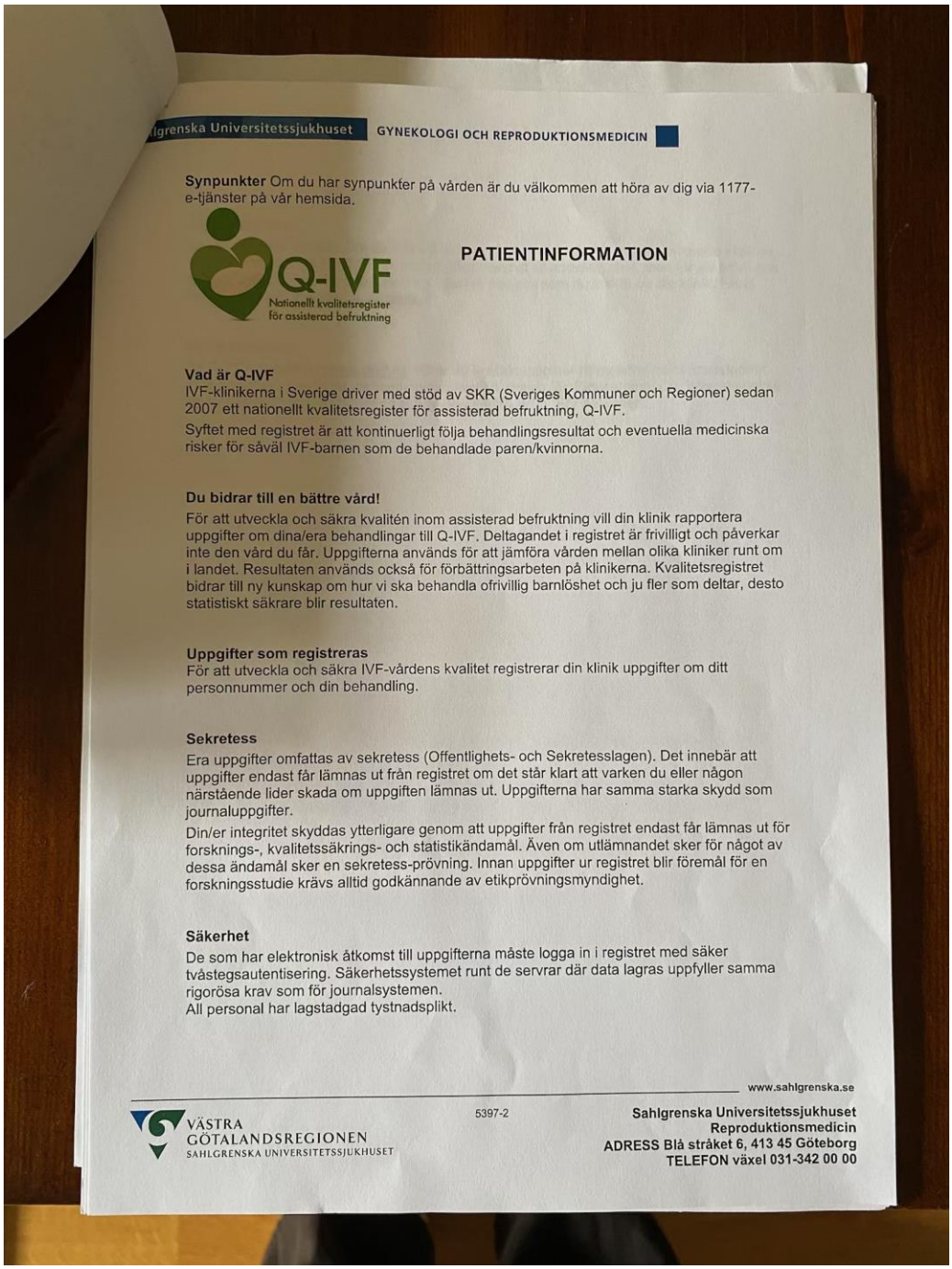
Appendices

Appendix A: Patient-Facing Information Materials Across the IVF Pathway

The following materials were collected during the ethnographic phase of this study, as part of the stimulated patient journey conducted at Reproductive Medicine Division at SUH. Materials are organized by stage corresponding to sections 4.1.1-4.1.4 of the empirical chapter. Selected materials appear as figures in sections 4.1.5.

Pre-visit materials (4.1.1)



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Synpunkter Om du har synpunkter på vården är du välkommen att höra av dig via 1177-e-tjänster på vår hemsida.

Q-IVF
Nationellt kvalitetsregister för assisterad befruktning

PATIENTINFORMATION

Vad är Q-IVF
IVF-klinikerna i Sverige driver med stöd av SKR (Sveriges Kommuner och Regioner) sedan 2007 ett nationellt kvalitetsregister för assisterad befruktning, Q-IVF.
Syftet med registret är att kontinuerligt följa behandlingsresultat och eventuella medicinska risker för såväl IVF-barnen som de behandlade paren/kvinnorna.

Du bidrar till en bättre vård!
För att utveckla och säkra kvalitén inom assisterad befruktning vill din klinik rapportera uppgifter om dina/era behandlingar till Q-IVF. Deltagandet i registret är frivilligt och påverkar inte den vård du får. Uppgifterna används för att jämföra vården mellan olika kliniker runt om i landet. Resultaten används också för förbättringsarbeten på klinikerna. Kvalitetsregistret bidrar till ny kunskap om hur vi ska behandla ofrivillig barnlöshet och ju fler som deltar, desto statistiskt säkrare blir resultaten.

Uppgifter som registreras
För att utveckla och säkra IVF-vårdens kvalitet registrerar din klinik uppgifter om ditt personnummer och din behandling.

Sekretess
Era uppgifter omfattas av sekretess (Offentlighets- och Sekretesslagen). Det innebär att uppgifter endast får lämnas ut från registret om det står klart att varken du eller någon närstående lider skada om uppgiften lämnas ut. Uppgifterna har samma starka skydd som journaluppgifter.
Din/er integritet skyddas ytterligare genom att uppgifter från registret endast får lämnas ut för forsknings-, kvalitetssäkrings- och statistikändamål. Även om utlämnandet sker för något av dessa ändamål sker en sekretess-prövning. Innan uppgifter ur registret blir föremål för en forskningsstudie krävs alltid godkännande av etikprövningsmyndighet.

Säkerhet
De som har elektronisk åtkomst till uppgifterna måste logga in i registret med säker tvåstegsautentisering. Säkerhetssystemet runt de servrar där data lagras uppfyller samma rigorösa krav som för journalsystemen.
All personal har lagstadgad tystnadsplikt.

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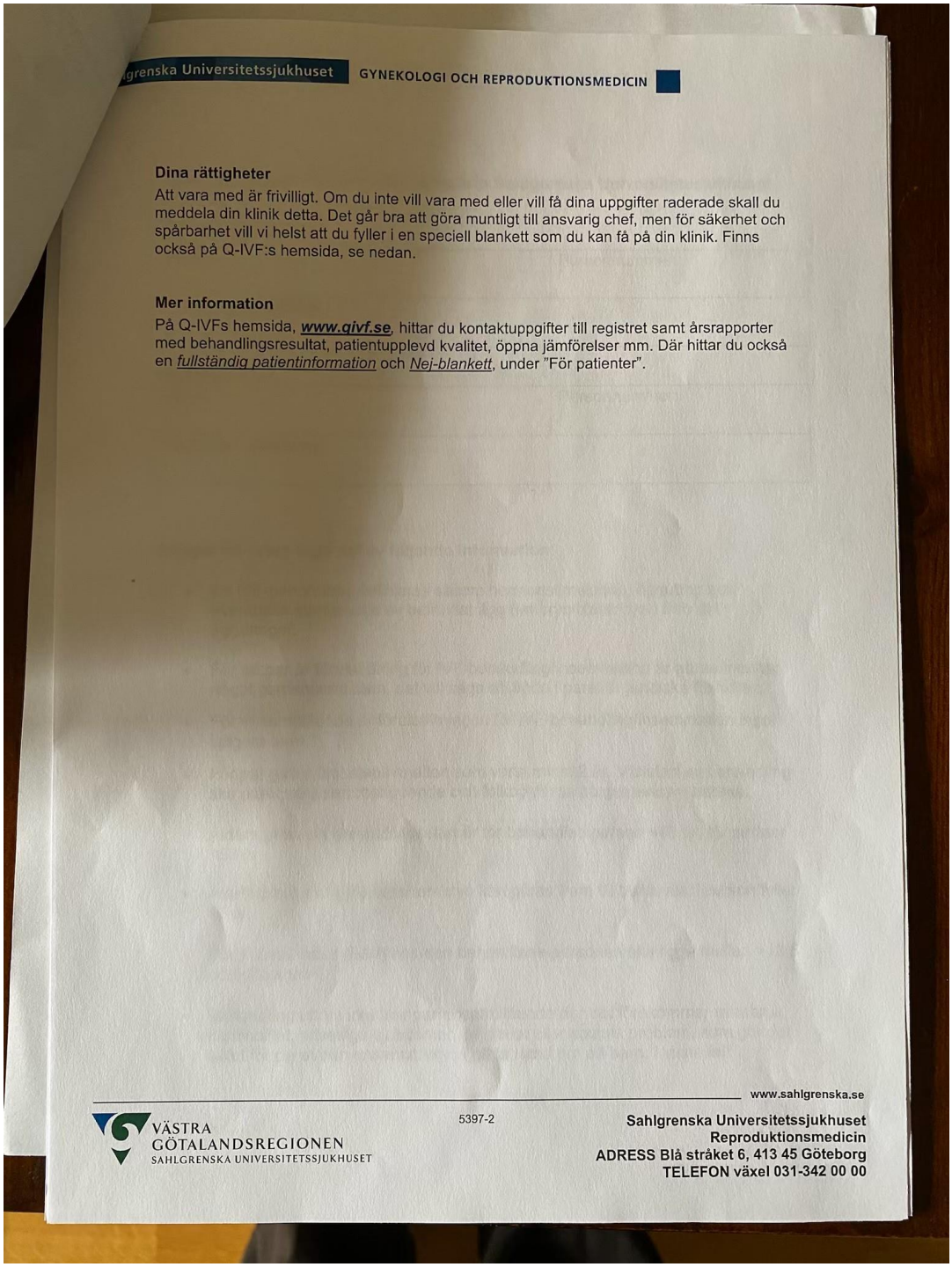

Dina rättigheter

Att vara med är frivilligt. Om du inte vill vara med eller vill få dina uppgifter raderade skall du meddela din klinik detta. Det går bra att göra muntligt till ansvarig chef, men för säkerhet och spårbarhet vill vi helst att du fyller i en speciell blankett som du kan få på din klinik. Finns också på Q-IVF:s hemsida, se nedan.

Mer information

På Q-IVFs hemsida, ***www.qivf.se***, hittar du kontaktuppgifter till registret samt årsrapporter med behandlingsresultat, patientupplevd kvalitet, öppna jämförelser mm. Där hittar du också en *fullständig patientinformation* och *Nej-blankett*, under "För patienter".

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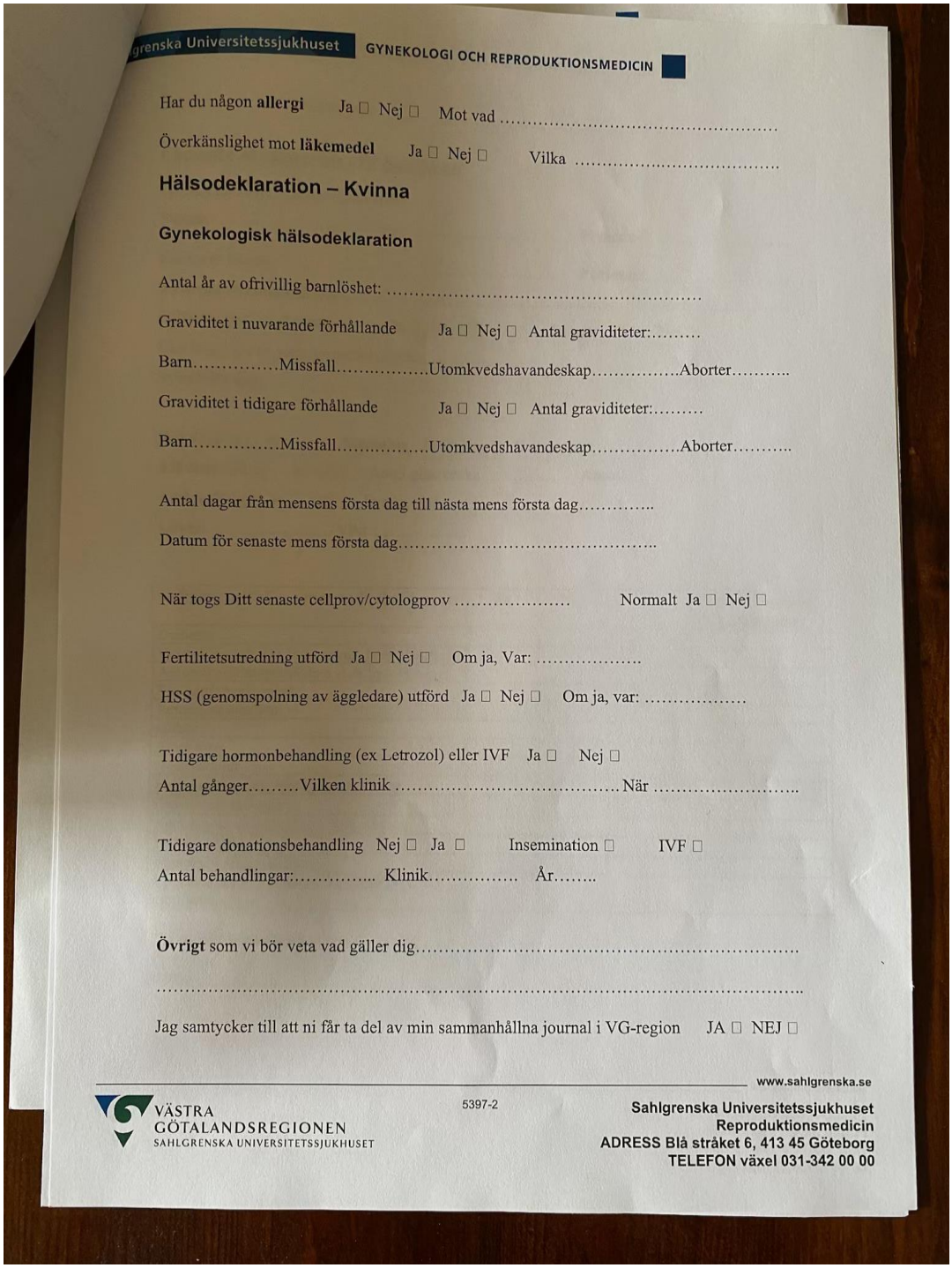

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Har du någon **allergi** Ja ☐ Nej ☐ Mot vad ……

Överkänslighet mot **läkemedel** Ja ☐ Nej ☐ Vilka ……

Hälsodeklaration – Kvinna

Gynekologisk hälsodeklaration

Antal år av ofrivillig barnlöshet: ……

Graviditet i nuvarande förhållande Ja ☐ Nej ☐ Antal graviditeter:……

Barn……Missfall……Utomkvedshavandeskap……Aborter……..

Graviditet i tidigare förhållande Ja ☐ Nej ☐ Antal graviditeter:……

Barn……Missfall……Utomkvedshavandeskap……Aborter……..

Antal dagar från mensens första dag till nästa mens första dag……..

Datum för senaste mens första dag……..

När togs Ditt senaste cellprov/cytologprov …… Normalt Ja ☐ Nej ☐

Fertilitetsutredning utförd Ja ☐ Nej ☐ Om ja, Var: ……

HSS (genomspolning av äggledare) utförd Ja ☐ Nej ☐ Om ja, var: ……

Tidigare hormonbehandling (ex Letrozol) eller IVF Ja ☐ Nej ☐
Antal gånger……Vilken klinik …… När ……..

Tidigare donationsbehandling Nej ☐ Ja ☐ Insemination ☐ IVF ☐
Antal behandlingar:…….. Klinik…… År……..

Övrigt som vi bör veta vad gäller dig……

……..

Jag samtycker till att ni får ta del av min sammanhållna journal i VG-region JA ☐ NEJ ☐

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Datum…….. Underskrift……..

Lämnas till läkaren vid besöket!

Hälsodeklaration - partner

Namn: …… **Personnr**: ……

Partners namn: …… **Personnr**:……..

Aktuella telefonnummer……/……

Gifta/Registrerad partner Ja ☐ Nej ☐ **Sambo** Ja ☐ Nej ☐

Hur länge har ni varit sammanboende……

Sysselsättning ……

Rökning Ja ☐ Nej ☐ **Snusning** Ja ☐ Nej ☐ Hur mycket …… ……

Alkohol Aldrig ☐ Måttligt ☐ Antal glas/vecka …… Annat☐ ……

Andra droger Ja ☐ Nej ☐ Om ja, vad ……..

Längd…… **Vikt**……

Tidigare och/eller nuvarande sjukdomar:	**Ja**	**Nej**	**År**	**Vilken? Annan kommentar**
Diabetes				
Hjärt-/lungsjukdom (t.ex. astma, högt blodtryck)				
Ämnesomsättningssjukdom (t.ex.hypothyreos)				
Blödningsbenägenhet				
Reumatisk sjukdom				
Gulsot				
Blodpropp				
Njursjukdom				
Bukoperation t.ex. blindtarmsoperation				
Övriga operationer				
Andrologisk operation t.ex. ljumskbråck				
Psykisk ohälsa				
Annan allvarlig sjukdom				
Vårdad/arbetat på sjukhus eller polikliniskt utomlands				

Tar du några **mediciner** Ja ☐ Nej ☐

Vilka: ……

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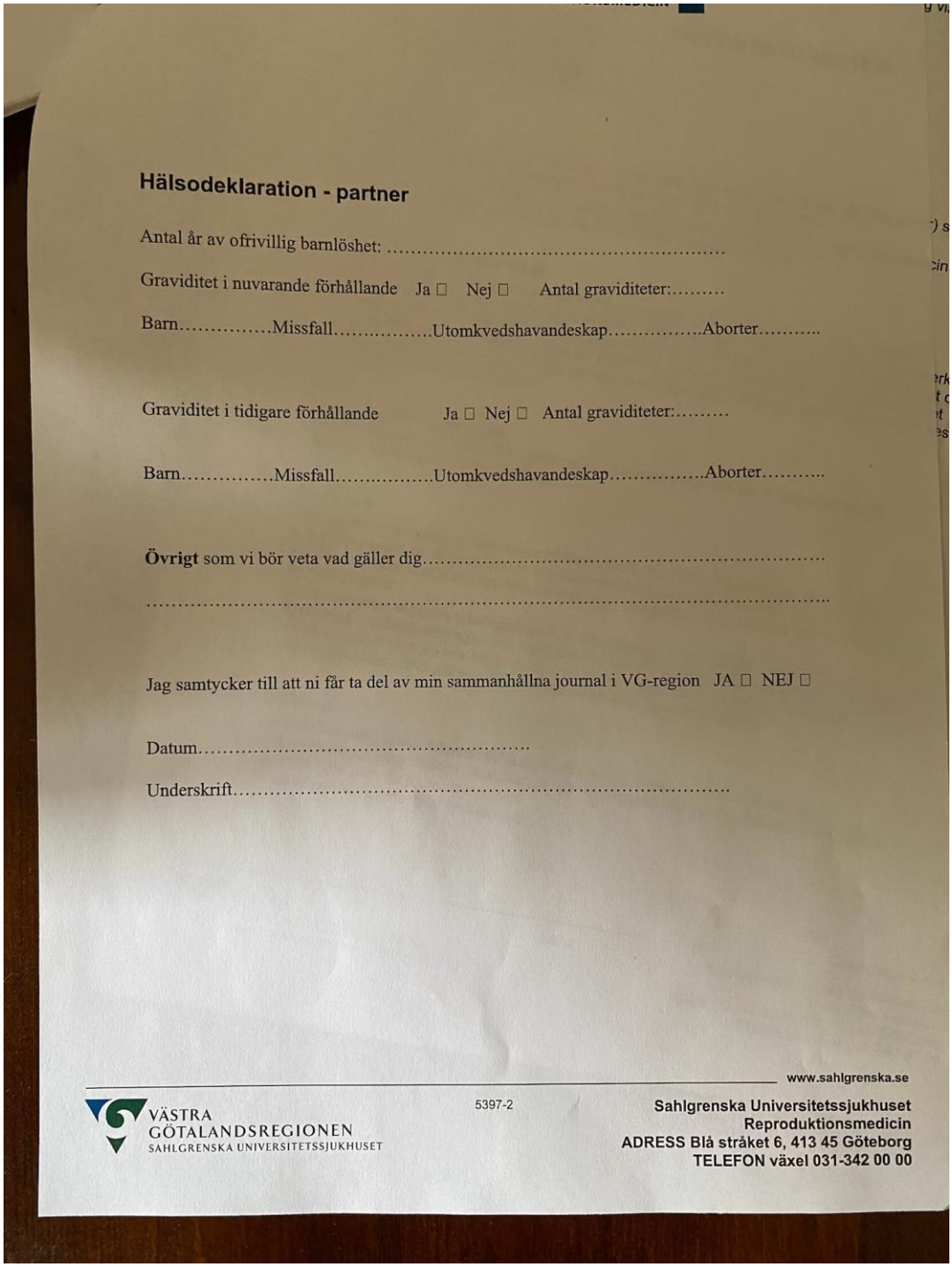

Hälsodeklaration - partner

Antal år av ofrivillig barnlöshet: ……

Graviditet i nuvarande förhållande Ja ☐ Nej ☐ Antal graviditeter:……

Barn……Missfall……Utomkvedshavandeskap……Aborter……..

Graviditet i tidigare förhållande Ja ☐ Nej ☐ Antal graviditeter:……

Barn……Missfall……Utomkvedshavandeskap……Aborter……..

Övrigt som vi bör veta vad gäller dig……

……

Jag samtycker till att ni får ta del av min sammanhållna journal i VG-region JA ☐ NEJ ☐

Datum……

Underskrift……

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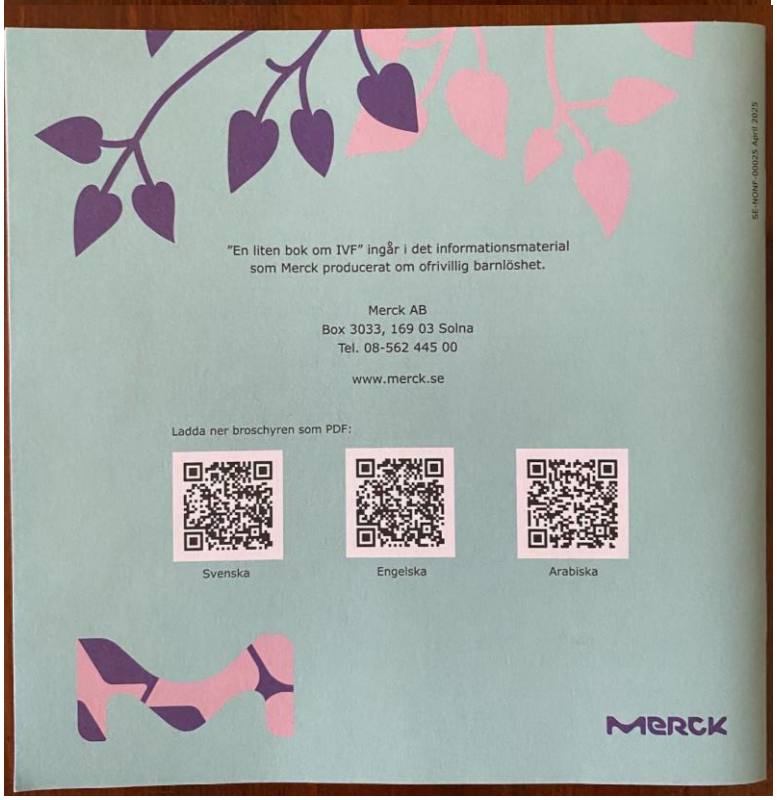
EN LITEN
BOK OM IVF
Merck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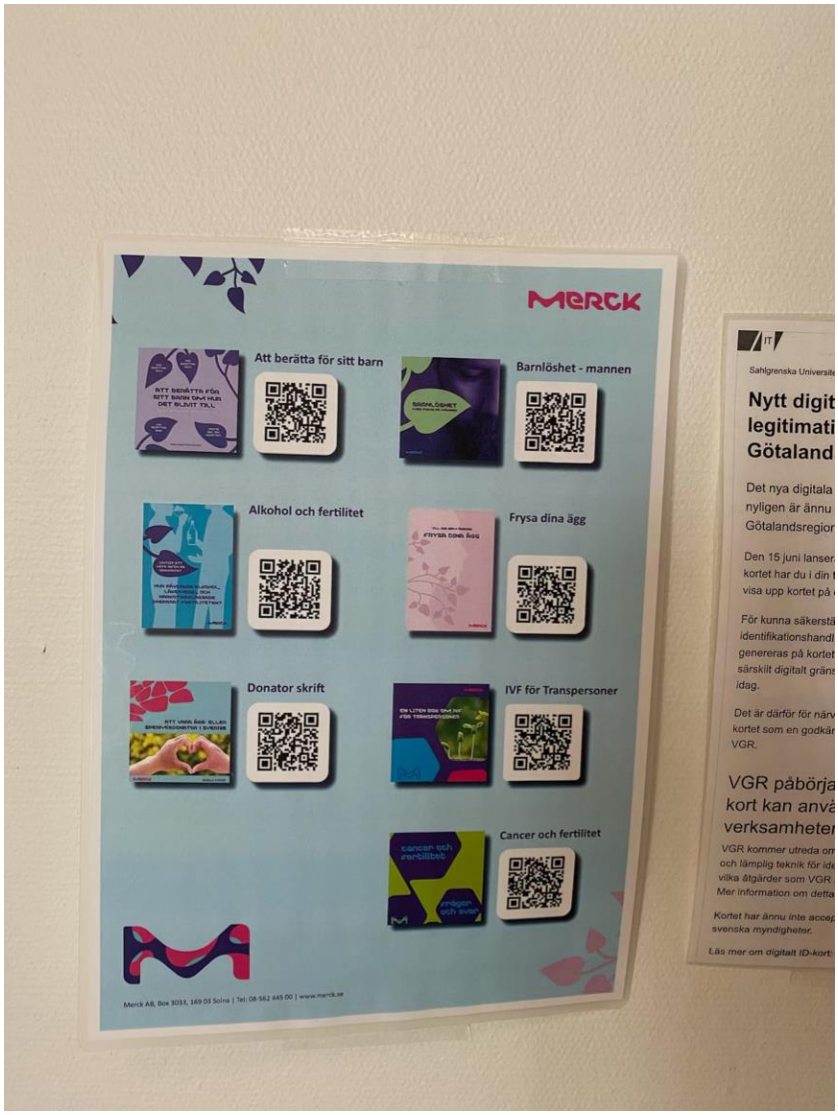
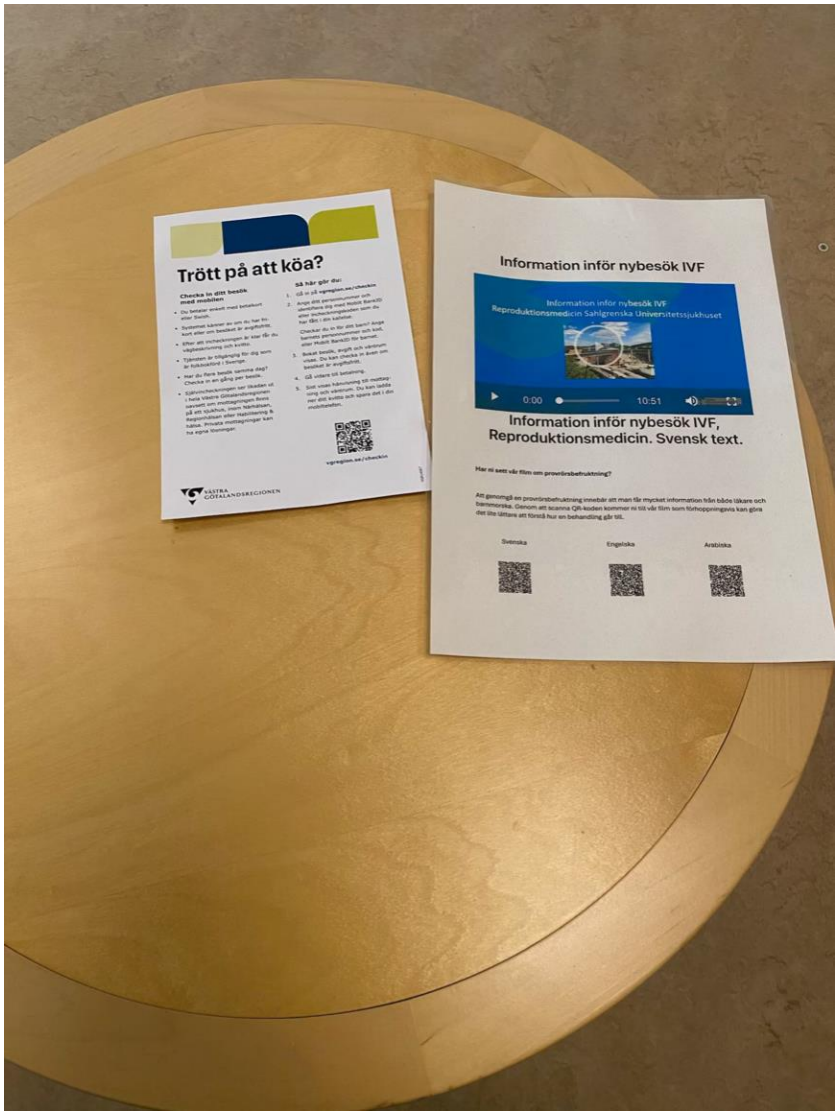
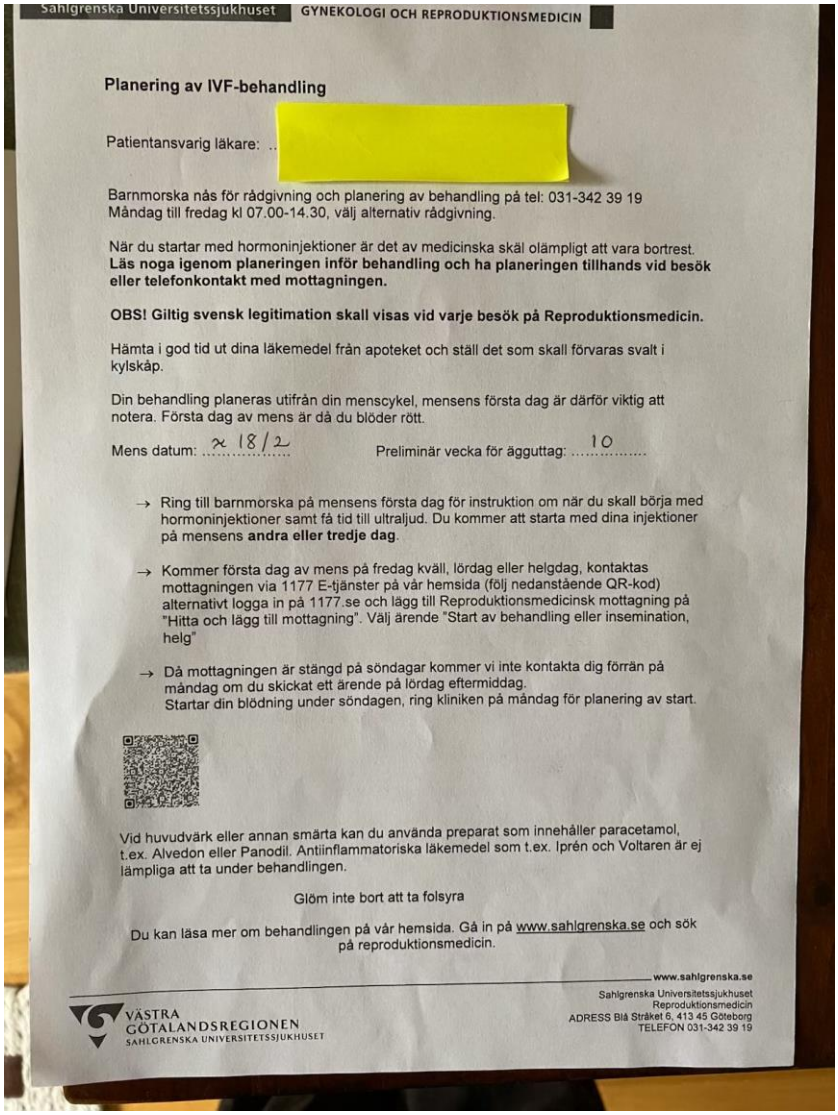
Waiting room (4.1.2)





Midwife Consultation (4.1.3)



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Planering av IVF-behandling

Patientansvarig läkare: ..

Barnmorska nås för rådgivning och planering av behandling på tel: 031-342 39 19
Måndag till fredag kl 07.00-14.30, välj alternativ rådgivning.

När du startar med hormoninjektioner är det av medicinska skäl olämpligt att vara bortrest.
Läs noga igenom planeringen inför behandling och ha planeringen tillhands vid besök eller telefonkontakt med mottagningen.

OBS! Giltig svensk legitimation skall visas vid varje besök på Reproduktionsmedicin.

Hämta i god tid ut dina läkemedel från apoteket och ställ det som skall förvaras svalt i kylskåp.

Din behandling planeras utifrån din menscykel, mensens första dag är därför viktig att notera. Första dag av mens är då du blöder rött.

Mens datum: ..18/2.. Preliminär vecka för ägguttag: ..10..

→ Ring till barnmorska på mensens första dag för instruktion om när du skall börja med hormoninjektioner samt få tid till ultraljud. Du kommer att starta med dina injektioner på mensens **andra eller tredje dag**.

→ Kommer första dag av mens på fredag kväll, lördag eller helgdag, kontaktas mottagningen via 1177 E-tjänster på vår hemsida (följ nedanstående QR-kod) alternativt logga in på 1177.se och lägg till Reproduktionsmedicinsk mottagning på "Hitta och lägg till mottagning". Välj ärende "Start av behandling eller insemination, helg"

→ Då mottagningen är stängd på söndagar kommer vi inte kontakta dig förrän på måndag om du skickat ett ärende på lördag eftermiddag.
Startar din blödning under söndagen, ring kliniken på måndag för planering av start.

Vid huvudvärk eller annan smärta kan du använda preparat som innehåller paracetamol, t.ex. Alvedon eller Panodil. Antiinflammatoriska läkemedel som t.ex. Ipren och Voltaren är ej lämpliga att ta under behandlingen.

Glöm inte bort att ta folsyra

Du kan läsa mer om behandlingen på vår hemsida. Gå in på www.sahlgrenska.se och sök på reproduktionsmedicin.

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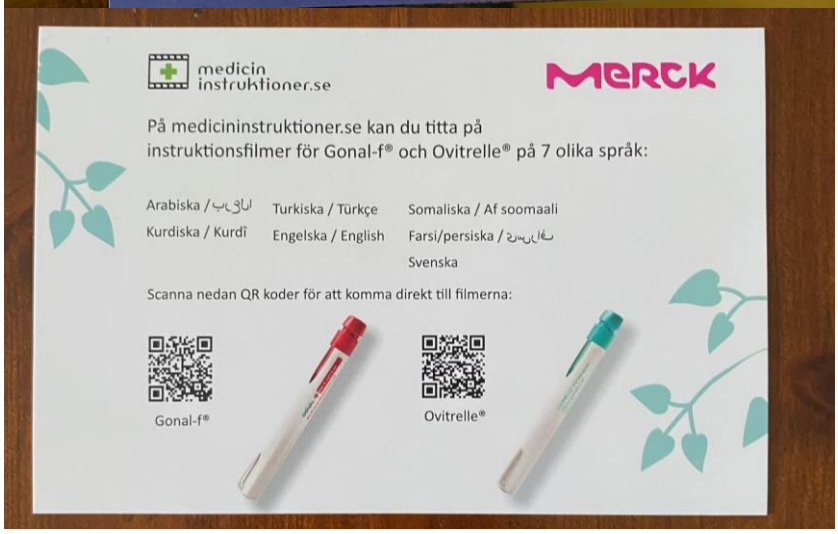
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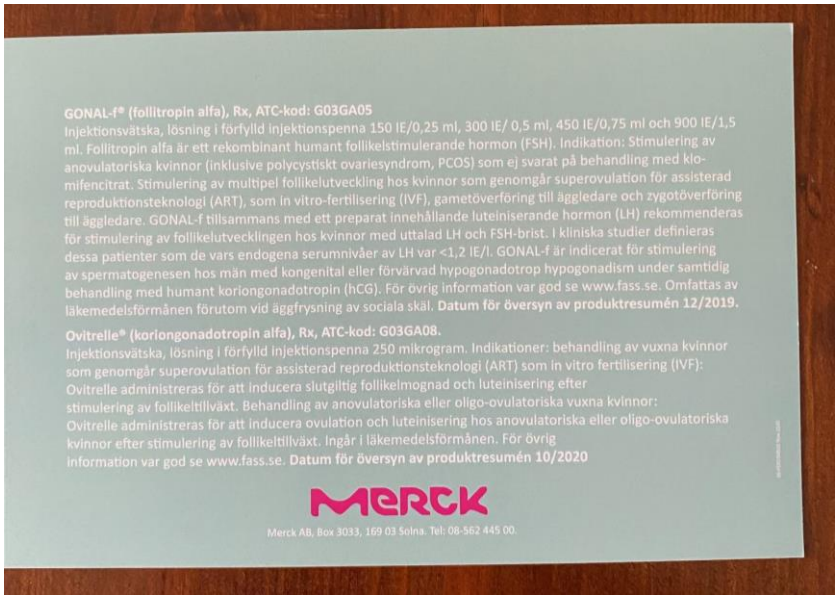


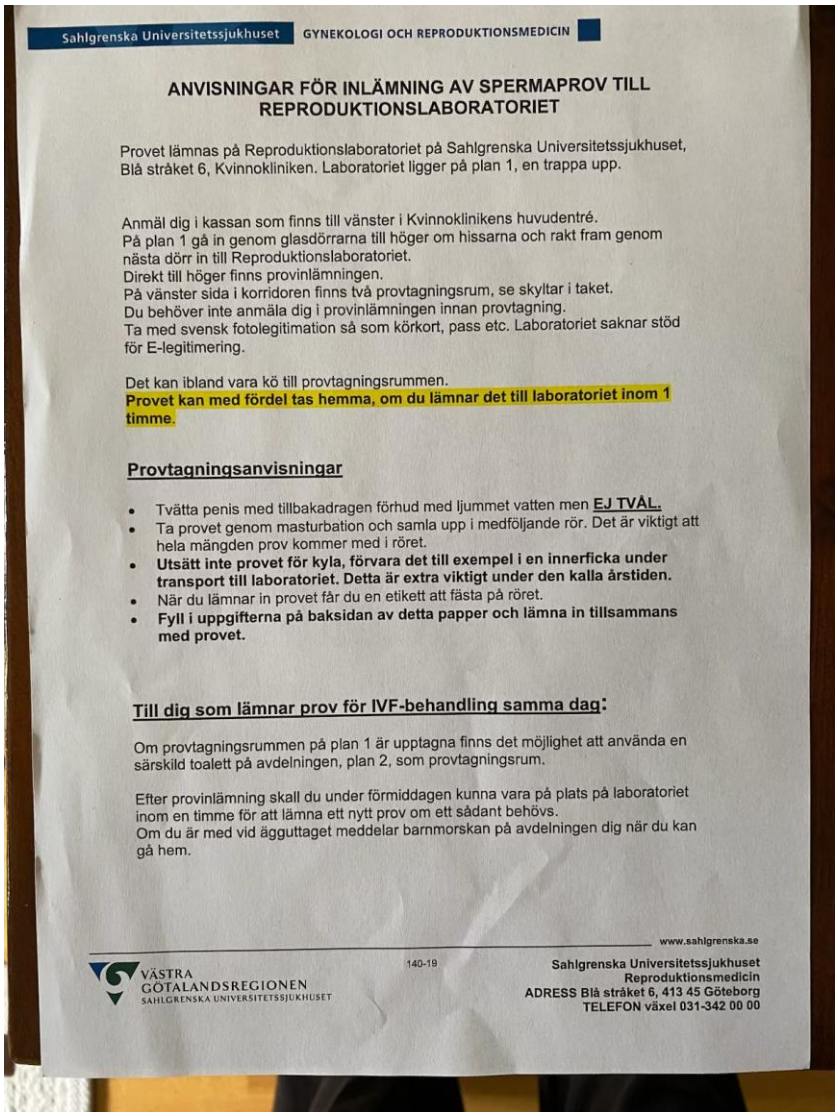
GONAL-f® (follitropin alfa), Rx, ATC-kod: G03GA05
Injektionsvätska, lösning i förfylld injektionspenna 150 IE/0,25 ml, 300 IE/ 0,5 ml, 450 IE/0,75 ml och 900 IE/1,5 ml. Follitropin alfa är ett rekombinant humant follikelstimulerande hormon (FSH). Indikation: Stimulering av anovulatoriska kvinnor (inklusive polycystiskt ovariesyndrom, PCOS) som ej svarat på behandling med klomifencitrat. Stimulering av multipel follikelutveckling hos kvinnor som genomgår superovulation för assisterad reproduktionsteknologi (ART), som in vitro-fertilisering (IVF), gametöverföring till äggledare och zygotöverföring till äggledare. GONAL-f tillsammans med ett preparat innehållande luteiniserande hormon (LH) rekommenderas för stimulering av follikelutvecklingen hos kvinnor med uttalad LH och FSH-brist. I kliniska studier definieras dessa patienter som de vars endogena serumnivåer av LH var <1,2 IE/l. GONAL-f är indicerat för stimulering av spermatogenesen hos män med kongenital eller förvärvad hypogonadotrop hypogonadism under samtidig behandling med humant koriongonadotropin (hCG). För övrig information var god se www.fass.se. Omfattas av läkemedelsförmånen förutom vid äggfrysning av sociala skäl. **Datum för översyn av produktresumén 12/2019.**

Ovitrelle® (koriongonadotropin alfa), Rx, ATC-kod: G03GA08.
Injektionsvätska, lösning i förfylld injektionspenna 250 mikrogram. Indikationer: behandling av vuxna kvinnor som genomgår superovulation för assisterad reproduktionsteknologi (ART) som in vitro fertilisering (IVF): Ovitrelle administreras för att inducera slutgiltig follikelmognad och luteinisering efter stimulering av follikeltillväxt. Behandling av anovulatoriska eller oligo-ovulatoriska vuxna kvinnor: Ovitrelle administreras för att inducera ovulation och luteinisering hos anovulatoriska eller oligo-ovulatoriska kvinnor efter stimulering av follikeltillväxt. Ingår i läkemedelsförmånen. För övrig information var god se www.fass.se. **Datum för översyn av produktresumén 10/2020**

MERCK

Merck AB, Box 3033, 169 03 Solna. Tel: 08-562 445 00.

Egg retrieval and post-retrieval (4.1.4)



Sahlgrenska Universitetssjukhuset GYNEKOLOGI OCH REPRODUKTIONSMEDICIN

ANVISNINGAR FÖR INLÄMNING AV SPERMAPROV TILL REPRODUKTIONSLABORATORIET

Provet lämnas på Reproduktionslaboratoriet på Sahlgrenska Universitetssjukhuset, Blå stråket 6, Kvinnokliniken. Laboratoriet ligger på plan 1, en trappa upp.

Anmäl dig i kassan som finns till vänster i Kvinnoklinikens huvudentré.
På plan 1 gå in genom glasdörrarna till höger om hissarna och rakt fram genom nästa dörr in till Reproduktionslaboratoriet.
Direkt till höger finns provinlämningen.
På vänster sida i korridoren finns två provtagningsrum, se skyltar i taket.
Du behöver inte anmäla dig i provinlämningen innan provtagning.
Ta med svensk fotolegitimation så som körkort, pass etc. Laboratoriet saknar stöd för E-legitimering.

Det kan ibland vara kö till provtagningsrummen.
Provet kan med fördel tas hemma, om du lämnar det till laboratoriet inom 1 timme.

Provtagningsanvisningar

- Tvätta penis med tillbakadragen förhud med ljummet vatten men **EJ TVÅL.**
- Ta provet genom masturbation och samla upp i medföljande rör. Det är viktigt att hela mängden prov kommer med i röret.
- **Utsätt inte provet för kyla, förvara det till exempel i en innerficka under transport till laboratoriet. Detta är extra viktigt under den kalla årstiden.**
- När du lämnar in provet får du en etikett att fästa på röret.
- **Fyll i uppgifterna på baksidan av detta papper och lämna in tillsammans med provet.**

Till dig som lämnar prov för IVF-behandling samma dag:

Om provtagningsrummen på plan 1 är upptagna finns det möjlighet att använda en särskild toalett på avdelningen, plan 2, som provtagningsrum.

Efter provinlämning skall du under förmiddagen kunna vara på plats på laboratoriet inom en timme för att lämna ett nytt prov om ett sådant behövs.
Om du är med vid ägguttaget meddelar barnmorskan på avdelningen dig när du kan gå hem.

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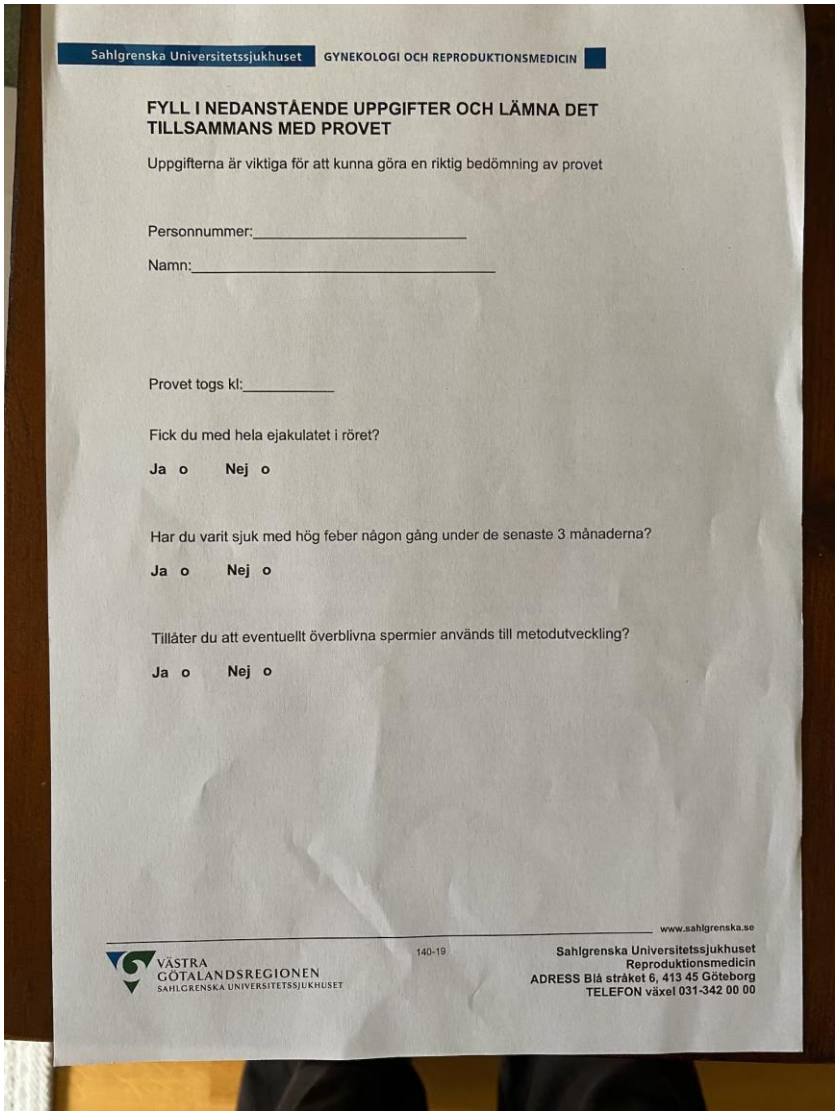

Sahlgrenska Universitetssjukhuset GYNEKOLOGI OCH REPRODUKTIONSMEDICIN

FYLL I NEDANSTÅENDE UPPGIFTER OCH LÄMNA DET TILLSAMMANS MED PROVET

Uppgifterna är viktiga för att kunna göra en riktig bedömning av provet

Personnummer:_____

Namn:_____

Provet togs kl:_____

Fick du med hela ejakulatet i röret?

Ja o Nej o

Har du varit sjuk med hög feber någon gång under de senaste 3 månaderna?

Ja o Nej o

Tillåter du att eventuellt överblivna spermier används till metodutveckling?

Ja o Nej o

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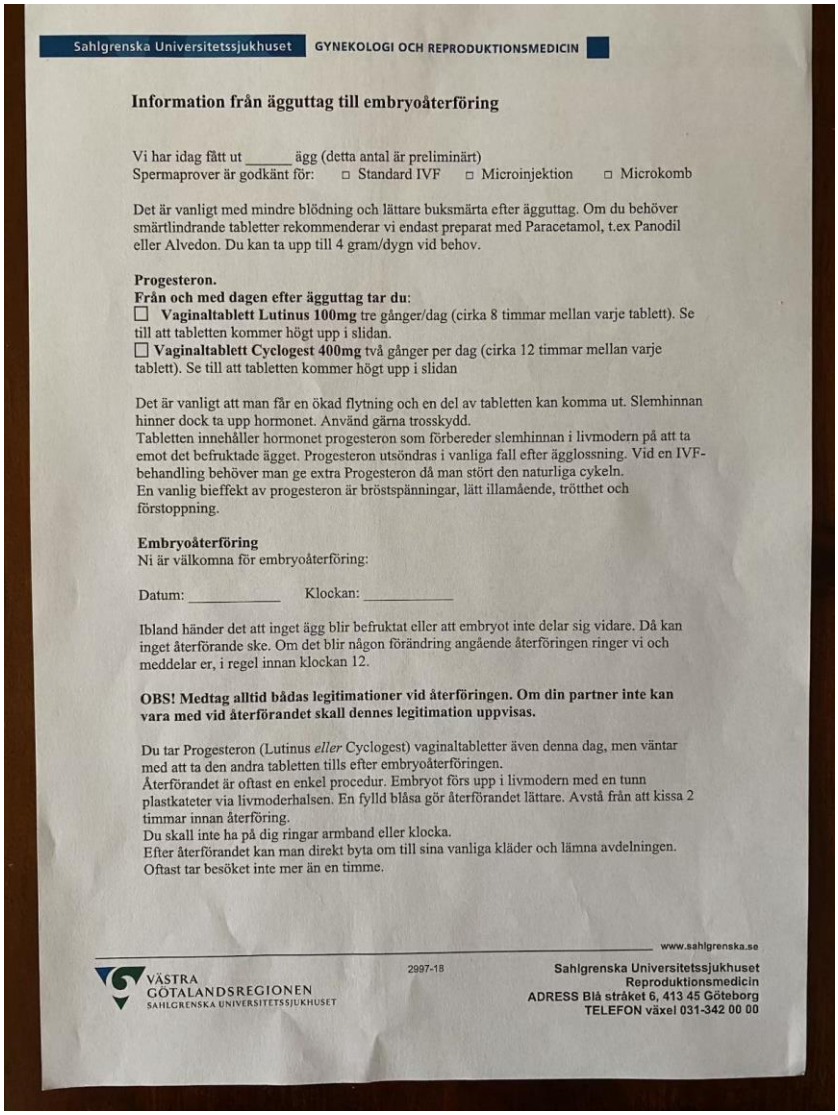

Sahlgrenska Universitetssjukhuset GYNEKOLOGI OCH REPRODUKTIONSMEDICIN

Information från ägguttag till embryoåterföring

Vi har idag fått ut _____ ägg (detta antal är preliminärt)
Spermaprover är godkänt för: ☐ Standard IVF ☐ Microinjektion ☐ Microkomb

Det är vanligt med mindre blödning och lättare buksmärta efter ägguttag. Om du behöver smärtlindrande tabletter rekommenderar vi endast preparat med Paracetamol, t.ex Panodil eller Alvedon. Du kan ta upp till 4 gram/dygn vid behov.

Progesteron.
Från och med dagen efter ägguttag tar du:
☐ **Vaginaltablett Lutinus 100mg** tre gånger/dag (cirka 8 timmar mellan varje tablett). Se till att tabletten kommer högt upp i slidan.
☐ **Vaginaltablett Cyclogest 400mg** två gånger per dag (cirka 12 timmar mellan varje tablett). Se till att tabletten kommer högt upp i slidan

Det är vanligt att man får en ökad flytning och en del av tabletten kan komma ut. Slemhinnan hinner dock ta upp hormonet. Använd gärna trosskydd.
Tabletten innehåller hormonet progesteron som förbereder slemhinnan i livmodern på att ta emot det befruktade ägget. Progesteron utsöndras i vanliga fall efter ägglossning. Vid en IVF-behandling behöver man ge extra Progesteron då man stört den naturliga cykeln.
En vanlig bieffekt av progesteron är bröstspänningar, lätt illamående, trötthet och förstoppning.

Embryoåterföring
Ni är välkomna för embryoåterföring:

Datum: _____ Klockan: _____

Ibland händer det att inget ägg blir befruktat eller att embryot inte delar sig vidare. Då kan inget återförande ske. Om det blir någon förändring angående återföringen ringer vi och meddelar er, i regel innan klockan 12.

OBS! Medtag alltid bådas legitimationer vid återföringen. Om din partner inte kan vara med vid återförandet skall dennes legitimation uppvisas.

Du tar Progesteron (Lutinus *eller* Cyclogest) vaginaltabletter även denna dag, men väntar med att ta den andra tabletten tills efter embryoåterföringen.
Återförandet är oftast en enkel procedur. Embryot förs upp i livmodern med en tunn plastkateter via livmoderhalsen. En fylld blåsa gör återförandet lättare. Avstå från att kissa 2 timmar innan återföring.
Du skall inte ha på dig ringar armband eller klocka.
Efter återförandet kan man direkt byta om till sina vanliga kläder och lämna avdelningen.
Oftast tar besöket inte mer än en timme.

www.sahlgrenska.se

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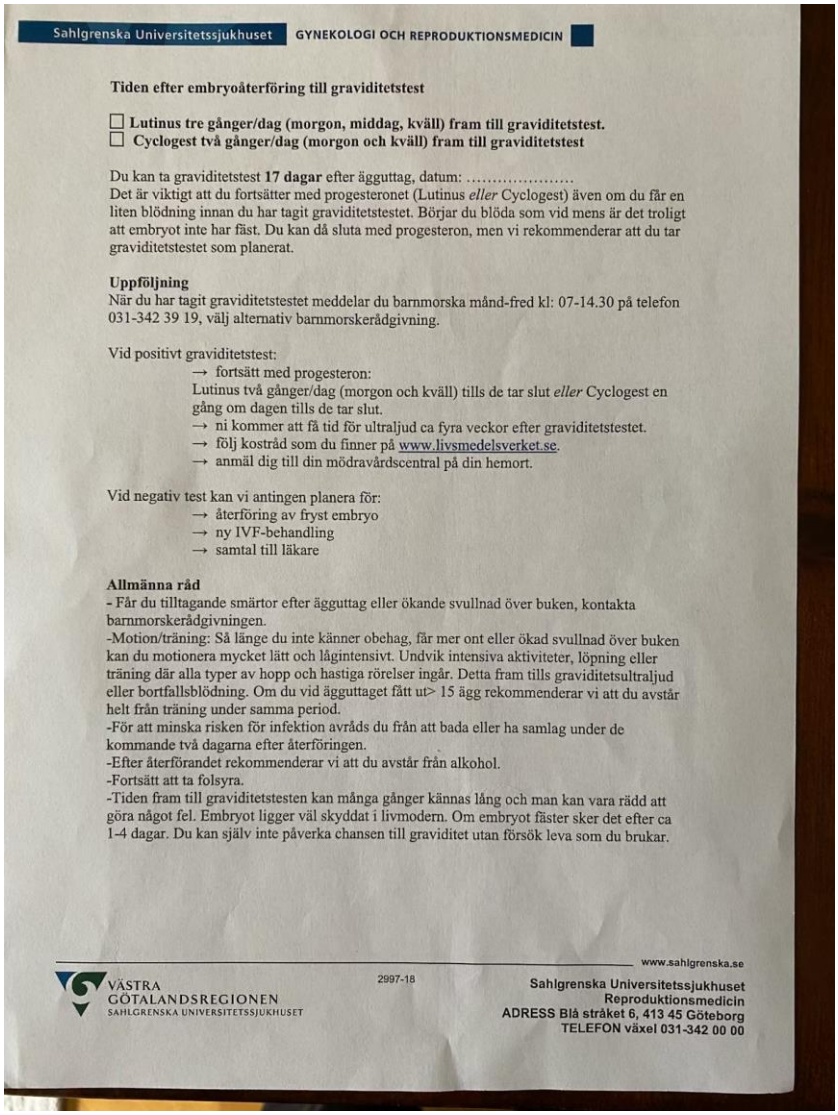

Sahlgrenska Universitetssjukhuset GYNEKOLOGI OCH REPRODUKTIONSMEDICIN

Tiden efter embryoåterföring till graviditetstest

☐ **Lutinus tre gånger/dag (morgon, middag, kväll) fram till graviditetstest.**
☐ **Cyclogest två gånger/dag (morgon och kväll) fram till graviditetstest**

Du kan ta graviditetstest **17 dagar** efter ägguttag, datum: .....
Det är viktigt att du fortsätter med progesteronet (Lutinus *eller* Cyclogest) även om du får en liten blödning innan du har tagit graviditetstestet. Börjar du blöda som vid mens är det troligt att embryot inte har fäst. Du kan då sluta med progesteron, men vi rekommenderar att du tar graviditetstestet som planerat.

Uppföljning
När du har tagit graviditetstestet meddelar du barnmorska månd-fred kl: 07-14.30 på telefon 031-342 39 19, välj alternativ barnmorskerådgivning.

Vid positivt graviditetstest:
→ fortsätt med progesteron:
Lutinus två gånger/dag (morgon och kväll) tills de tar slut *eller* Cyclogest en gång om dagen tills de tar slut.
→ ni kommer att få tid för ultraljud ca fyra veckor efter graviditetstestet.
→ följ kostråd som du finner på www.livsmedelsverket.se.
→ anmäl dig till din mödravårdscentral på din hemort.

Vid negativ test kan vi antingen planera för:
→ återföring av fryst embryo
→ ny IVF-behandling
→ samtal till läkare

Allmänna råd
- Får du tilltagande smärtor efter ägguttag eller ökande svullnad över buken, kontakta barnmorskerådgivningen.
-Motion/träning: Så länge du inte känner obehag, får mer ont eller ökad svullnad över buken kan du motionera mycket lätt och lågintensivt. Undvik intensiva aktiviteter, löpning eller träning där alla typer av hopp och hastiga rörelser ingår. Detta fram tills graviditetsultraljud eller bortfallsblödning. Om du vid ägguttaget fått ut> 15 ägg rekommenderar vi att du avstår helt från träning under samma period.
-För att minska risken för infektion avråds du från att bada eller ha samlag under de kommande två dagarna efter återföringen.
-Efter återförandet rekommenderar vi att du avstår från alkohol.
-Fortsätt att ta folsyra.
-Tiden fram till graviditetstesten kan många gånger kännas lång och man kan vara rädd att göra något fel. Embryot ligger väl skyddat i livmodern. Om embryot fäster sker det efter ca 1-4 dagar. Du kan själv inte påverka chansen till graviditet utan försök leva som du brukar.

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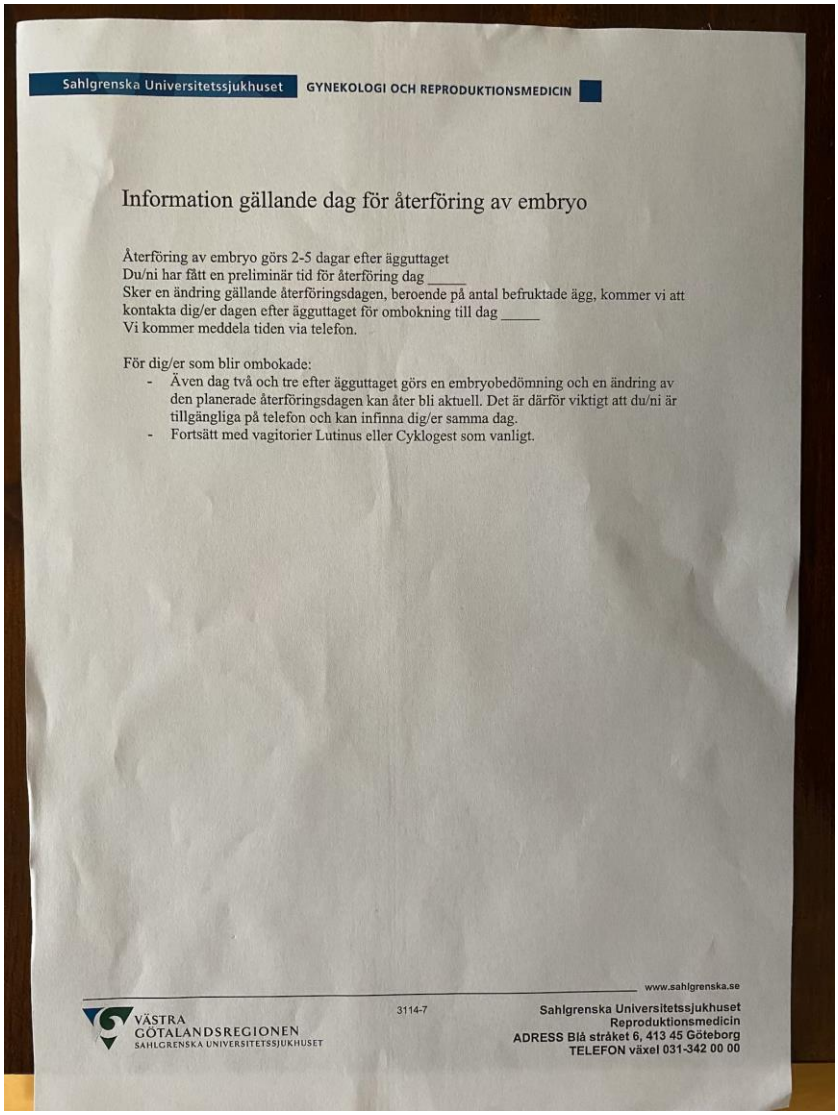

Sahlgrenska Universitetssjukhuset GYNEKOLOGI OCH REPRODUKTIONSMEDICIN

Information gällande dag för återföring av embryo

Återföring av embryo görs 2-5 dagar efter ägguttaget
Du/ni har fått en preliminär tid för återföring dag _____
Sker en ändring gällande återföringsdagen, beroende på antal befruktade ägg, kommer vi att kontakta dig/er dagen efter ägguttaget för ombokning till dag _____
Vi kommer meddela tiden via telefon.

För dig/er som blir ombokade:

- Även dag två och tre efter ägguttaget görs en embryobedömning och en ändring av den planerade återföringsdagen kan åter bli aktuell. Det är därför viktigt att du/ni är tillgängliga på telefon och kan infinna dig/er samma dag.
- Fortsätt med vagitorier Lutinus eller Cyklogest som vanligt.

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Appendix B: Mentimeter answers from staff perspectives

Patient Information in IVF Care: Staff Perspectives

Survey responses from clinical staff at the Reproductive Medicine Unit, Sahlgrenska University Hospital.
Responses are presented verbatim and translated from Swedish.

QUESTION 1 OF 3

"When do you experience that a patient is most receptive to information?"

17 of 18 respondents · 17 comments

- When they are prepared and know what we are going to go through.
- When they are worried about the prognosis.
- When they have a long appointment at the first IVF visit!
- When they are in a good mood.
- After the doctor's appointment.
- When the patient has first received written information that they have read. Then you can build the conversation further from that.
- When they themselves are interested and have a positive attitude towards the conversation.
- In calm and quiet, at home on the sofa.
- When they are calm, in a good mood, and you talk with them at "their" level of knowledge.
- When they have come a bit further into the process — when they have had time to settle and have already received answers to some of the questions they had.
- The first 20 minutes of the appointment. After a break in the meeting (after sample collection).
- The first visit — when they themselves contact us.
- When they have received information sent home before the visit.
- When they have received written information first and can then ask questions "live".
- When they are in a good mood and seem rested and not stressed. If they are nervous or stressed, they have a low level of comprehension and take in the information poorly.
- Primarily in situations where there is no time pressure.
- In calm and quiet. Without stress. If I am stressed, the patient becomes stressed too.

QUESTION 2 OF 3

"When do you experience that a patient is least receptive to information?"

16 of 18 respondents · 17 comments

- After long appointments. After the examination.
- When they are in a bad mood and have already decided from the start to be negative.
- When they are stressed or nervous.
- When there is too much information at the same time.

When they are stressed or nervous.

When there is too much information at the same time.

During stress and worry.

When they are in a bad mood, sad, are stressed and dissatisfied.

When they are angry.

When they are sad/disappointed after a failed treatment.

When they are anxious, scared, or in pain.

When they are stressed, in a bad mood, tired, unprepared, and do not understand.

When they are upset.

When they have already received a lot of information.

When they are sad.

When the appointment is short and the couple is stressed!

When they have had a long appointment with a lot of information and are starting to get tired.

When they are receiving too much information.

When we call them unprepared.

QUESTION 3 OF 3

"Expectations and concerns about the project"

9 of 18 respondents · 9 comments

I expect an effective process that can lead to the goal!

Exciting to see what new things come. Perhaps an app or something completely unexpected.

That patients will receive and understand information tailored to their conditions and interests.

Hoping to get help giving information in a structured way that becomes more patient-friendly. Also good if we know more certainly that everyone has received the same information — that it does not depend on who they met.

That our patients will become better informed and that healthcare staff will have more time for other things (as fewer questions will be asked). No direct concerns as I think of right now.

Exciting to see what you come up with. Useful to see the operation with fresh eyes. There is much that can be improved and made more efficient. Thank you!!

The expectation that several patients will use an app and become more involved and understand the process.

That it would be very good if patients could receive more information via, for example, an app about the entire process in the lab.

That patients have different needs for how much information they want. That patients still do not have time to prepare themselves. That the project takes a long time and a lot of work but does not lead to anything.

Survey conducted as part of a master's thesis project examining digital patient information in IVF care at Sahlgrenska University Hospital, 2026. Responses translated from Swedish and presented in full.

Appendix C: Interview Guide

Questions for the secretary

Explain the purpose of the project, our role, ethics, and confidentiality.

1. Can you describe a typical working day for you?

Follow-up questions:
What usually happens first when you arrive?
What takes up most of your time?
At what point during the day is it most intense?
Are there any tasks that often interrupt your work?

Theme 1: Patient contact: What does it actually look like?

2. **Can you describe a specific patient case you handled recently, from start to finish**?

Follow-up questions:
In what situations do patients most often get in touch?
How did the case come in?
What did you need to do?
Did you need to collaborate with anyone?
What worked well?
Where did any difficulties arise?

Ask them to give an example, in order to get a deeper answer rather than a general one.

Recurring questions and needs

3. **What questions do you feel patients ask most often?**

Follow-up questions:
Why?
What do you think they actually need when they call?
Is there anything they often misunderstand?
Are there questions that keep coming up even though the information is already available?

4. How are patients' questions and concerns communicated internally?

5. When you think about the exchange of information with the patient, do any frictions or obstacles arise?

Follow-up questions:
What takes a lot of time but provides little value?
Is there anything that often creates stress?
Are there any steps that feel unnecessarily complicated?
How does this affect your work environment?
Theme 2: Responsibility and ownership in the IVF process
1. How do you view involving the patient in their own care?
Follow-up questions:
What is crucial?
If you think about the IVF process/treatment as a whole, who do you feel owns it?
Who has the overall responsibility?

Is this clear to the patient?
Do you feel that the responsibility is shared?
Are there any steps where it is unclear who is responsible?
Patient information: Reflection and understanding

Show the information sent to the patient.
2. When you look at this information/the handouts, what are your thoughts?
Follow-up questions:
Have you seen this before?
Does it match how the process actually works?
Is there anything you often need to clarify for patients?
Is there anything that usually creates questions or misunderstandings?
Is there anything you personally feel is missing from it?

Closing: Communication as a "hub"
If you look at IVF treatment as a communication flow, where do you feel it works best, and where does it work less well?

Questions for the midwives

Explain the purpose of the project, our role, ethics, and confidentiality.

Theme 1: Patient focus in your work
Focus: Work process and role in the information flow.
Meeting with the patient: Concrete description

1. Can you describe how a typical information or planning meeting with an IVF patient usually proceeds, from start to finish?
Follow-up questions:
How do you prepare for the meeting?
What usually happens first?
What usually takes the most time?
Are there any parts that often become more extensive than planned?
What questions do you feel patients most often ask?

2. Can you describe a specific patient case you handled recently, from start to finish?
Follow-up questions:
What type of information do you most often communicate?
In what situations do patients most often get in touch or ask questions?
How did the case come in?
What did you need to do?
Did you need to collaborate with anyone?
What worked well?
Where did any difficulties arise?

3. How do you view involving the patient in their own care?
Follow-up questions:
What is crucial?

If you think about the IVF process/treatment as a whole, who do you feel owns it?
Who has the overall responsibility?
Is this clear to the patient?
Do you feel that the responsibility is shared?
Are there any steps where it is unclear who is responsible?

Frameworks and guidelines
4. Are there any guidelines, templates, or treatment protocols that determine what you should inform patients about? If so, how do you feel they work in practice?
Follow-up questions:
Do you sometimes need to adapt the information?
What they themselves emphasize
5. Is there anything you personally always try to emphasize in particular during the meeting with the patient?
Follow-up questions:
Why that specifically?
Did you learn this through experience?
Is it something you have noticed that patients often miss?

Theme 2: Their view of problems in the IVF process
Consequences of insufficient information
1. What happens when a patient is not sufficiently prepared or well-informed before a meeting?
Follow-up questions:
How does this become noticeable during the meeting?
Does it affect the amount of time needed?
Does it affect the patient's sense of security?

Closing: Communication as a "hub"
If you view the IVF process as a communication flow, where do you feel it works best, and where does it work less well?

Questions for the Physician

Explain the purpose of the project, our role, ethics, and confidentiality.
Theme 1: Patient focus in your work
Focus: Work process and role in the information flow.
1. Can you describe how a typical information or planning meeting with an IVF patient usually proceeds, from your perspective?
Follow-up questions:
What do you usually focus on the most?
What usually takes the most time?
How do you notice how the patient processes or responds to the conversation?

2. Can you describe a specific patient case you handled recently, from start to finish?
Follow-up questions:
What type of information do you most often communicate?
In what situations do patients most often get in touch or ask questions?

How did the case come in?
What did you need to do?
Did you need to collaborate with anyone?
What worked well?
Where did any difficulties arise?

3. What type of information do you feel is important for you to communicate?
Follow-up questions:
Is there anything you always try to emphasize in particular when meeting IVF patients?
What do you feel is your main responsibility?
What clearly falls under your responsibility, and what falls under other professions?
Is the division of responsibility clear in practice?

4. How are your meetings affected by guidelines, laws and regulations, templates, or treatment protocols?
Follow-up questions:
Do they provide support?
Do they limit anything?
Is there room for individual adaptation?
5. How much do you think a patient needs to prepare before an IVF treatment/the first meeting?
6. How do you view the relationship between the information provided and any questions that arise later?
Follow-up questions:
Is it about the amount of information?
Timing?
Complexity?
Emotional burden?

Theme 2: Their view of problems in the IVF process
7**. How do you view involving the patient in their own care?**
Follow-up questions:
What is crucial?
If you think about the IVF process/treatment as a whole, who do you feel owns it?
Who has the overall responsibility?
Is this clear to the patient?
Do you feel that the responsibility is shared?
Are there any steps where it is unclear who is responsible?

8. How has the approach to patient information and meetings changed in recent years?
Follow-up questions:
What drove the change?
How did it affect the meetings?
How did it affect the patients?

Closing question
9. If you view the IVF process as a communication flow, where do you feel it works best, and where does it work less well?

Questions for the Process Owner

Focus 1: Ownership and decision-making authority

1. How would you describe your assignment?

Follow-up questions:
What does it involve in practice?
What mandate do you have to make changes?
What falls outside your mandate?
What does it mean to be a process owner?
How does someone become a process owner?
What do you feel is the purpose of your assignment?

Balancing the role of physician versus process owner.

2. What do the decision-making pathways look like when routines or information materials need to be changed?

Follow-up questions:
Who initiates changes?
How are decisions made?
Who needs to be involved?
How much room is there to experiment or test new ways of informing patients?
How are other staff groups involved in the work? For example, information intended for assistant nurses or midwives.
How is the process made visible?
Many people work on different areas.
Is she working on the process ownership alone?
Cross-functional work?

What is it like to be new as a physician in reproductive medicine?

Follow up questions:
Are there PMs/internal guidelines to follow?
Guidelines versus learning by doing?

Focus 2: Decisions about patient information

3. Can you describe how a typical information or planning meeting with an IVF patient usually proceeds, from your perspective?

Follow-up questions:
What do you usually focus on the most?
What usually takes the most time?
How do you notice how the patient processes or responds to the conversation?
Why are all patient conversations different?

4. Can you describe a specific patient case you handled recently, from start to finish?

Follow-up questions:
What type of information do you most often communicate?
In what situations do patients most often get in touch or ask questions?
How did the case come in?
What did you need to do?
Did you need to collaborate with anyone?

What worked well?
Where did any difficulties arise?

5. How do you reason about what is important for the patient to understand in relation to the medical content?
Follow-up questions:
Do you receive feedback from patients?
Do you use any form of follow-up?
How do you capture misunderstandings or recurring questions?

6. How do you work to include the patient perspective in the care, treatment, and information provided?

Closing question
7. If you view the IVF process as a communication flow, where do you feel it works best, and where does it work less well?

Questions for the Patient

Inform the participant about confidentiality and ethics. No names will be shared with SUH.

Warm up the patient and try to understand the person.
Theme 1: Patient focus
Focus: To get a picture of the patient's everyday life and their experience of the appointment letter and the information it contained.

- Tell us what a typical day in your life might look like.
- Can you describe your knowledge of IVF before you started the IVF process?
- How did you find reliable information?
- Can you tell us about when you received the appointment letter for your first visit?
- What was your spontaneous reaction when you read the appointment letter?
- How did this affect your expectations before the meeting?
- What types of healthcare professionals did you meet during your IVF journey?

Focus: To understand how the patient experienced the information during the day they were there, whether they were aware of what would happen, and whether any information was missing before the appointment.

- Take us through the day when you were at the IVF clinic's production unit. How did it begin?
- How did the information you received before the appointment help you during your IVF journey?
- What types of questions came up in the different situations you experienced at SUH?
    - The meeting with the physician
    - The meeting with the midwife
    - At home with the injections
    - Returning for the ultrasound
    - Egg retrieval

- At what level would you have liked to receive the information? In other words, how involved or informed did you want to be?

Theme 2: Their view of problems in the IVF process
Focus: To create a deeper understanding of their experience.

- What information would have been important for you to receive before the meeting, now that you understand the process better?
- What would you have wanted to know, or what information would you have wanted to receive, during the different parts of your treatment?
- What did you go through during the first meeting with the physician?
- What questions or concerns came up after your meeting with the physician?
- What information did you receive during the meeting with the midwife?
- What questions or concerns came up after your meeting with the midwife?
- How do you view your involvement in your own care?
    - Follow-up questions:
    - What is crucial?
    - If you think about the IVF process/treatment as a whole, who do you feel owns it?
    - Who has the overall responsibility?
        - Is this clear to you?
    - Do you feel that the responsibility is shared?
    - Are there any steps where it is unclear who is responsible, or where you need to turn to other sources of information?
    - How well did the information you received match the knowledge you had already built up or received beforehand?

Focus: Closing and final insight.
- Looking at the overall experience, the appointment letter, the information, and the first meeting, how would you describe your experience?
- Were there any problems along the way? What types of problems?
- Did you use any digital tools during your journey?
- How do you view the information now?

Final question: Communication as a "hub"
- If you view the IVF process as a communication flow, where do you feel it works best, and where does it work less well?

Questions for Embryologists

Focus 1: Their role in IVF treatment
1. Can you describe your role in IVF treatment and where you enter the process?
Follow-up questions:
What needs to be in place before you can do your work?
What information is crucial for it to work?

Focus 2: The information flow to the laboratory
2. How do you receive information about patients and treatments that involve the laboratory?
Follow-up questions:

Where does the information come from?
Is it clear and structured?
Are there situations where information is missing or unclear?

3. How do you notice when something in the information flow to the patient is not working as it should?
Follow-up questions:
What happens then?
How does it affect your work?
How does it affect scheduling or safety?
How does the information flow between departments work?
How does the digital communication work?
How does the verbal communication work?
How does dialogue about patients and before patient meetings work?
What types of questions usually come up here?
How do you work with knowledge sharing between departments?
How do you view your role and your area of expertise?

Focus 4: Patient perspective
4. In what ways do you notice the patient's own IVF journey through your work?
Follow-up questions:
Is it noticeable if patients are uncertain or unprepared?
Is it noticeable if the planning changes late?
Are there any steps where you are especially dependent on the patient information having been clear?
How could you influence the journey and have a significant or greater impact regarding information?
Process: How can you notify or update other staff groups about status?

We want to understand what their collaboration looks like.
5. Are there situations where insufficient information to the patient has consequences?
6. How do you view involving the patient in their own care?
Follow-up questions:
What is crucial?
If you think about the IVF process/treatment as a whole, who do you feel owns it?
Who has the overall responsibility?
Is this clear to the patient?
Do you feel that the responsibility is shared?
Are there any steps where it is unclear who is responsible?

Closing question
7. If you view the IVF process as a communication flow, where do you feel it works best, and where does it work less well?

Questions for Copenhagen midwife

Concrete patient case
Purpose: Ask for a real example to move away from general answers.

Can you describe a specific patient case you recently handled, from beginning to end?

How do you prepare patients who want to start IVF treatment, in terms of information?
Follow-up questions:
What type of information does the patient receive before coming to a meeting with the physician/midwife, or before their first meeting in general?
How did the case come to you?
What did you need to do?
Did you need to collaborate with anyone?
What worked well?
Where did any difficulties arise?

Purpose: To understand what patients struggle with.
What recurring questions do you find that couples tend to have?
What kinds of questions do they usually ask?
What are patients most often worried or uncertain about?
Is there information that patients almost always need explained again?
At what point in the process do the most questions arise?
In which situations do patients most often get in touch or ask questions?
How do you usually handle these questions?

Follow-up questions:
What type of information do you most often communicate to patients?
How do patients usually contact you?
Patient preparedness

Purpose: Since our project focuses on this.
Do you experience that patients sometimes arrive unprepared for the initial consultation?
What do you think could help patients come better prepared?

Information channels
Purpose: To understand how information is distributed.
What different information channels do you use?
Follow-up questions:
Which channels do you use, for example meetings, brochures, website, app, webinars, etc.?
When do you use each channel?
What do you find works best for patients?
Is there anything you have tried that did not work?

Digital tools
Webinar
Can anyone participate in these?
What is the purpose of them?

App
How does this app work?

Who uses it?
Is it something midwives and doctors use together with patients, or something patients use independently?

Patient involvement
How do you view involving the patient in their own care?
How do you view the partner's role in IVF treatment?
F*ollow-up questions:*
What is crucial for this to work?
If you think about the IVF process/treatment as a whole, who do you feel "owns" the process?
Who has the overall responsibility?
Is this clear to the patient?
Do you feel that responsibility is shared?
Are there moments where it is unclear who is responsible?

Frameworks and guidelines
Are there guidelines, templates, or treatment protocols that determine what information you should provide?
If yes, how do you find they work in practice?
Follow-up questions:
Do you sometimes need to adapt the information?
How do these frameworks affect your work?

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