CHAPTER 2

FERTILITY PRESERVATION:
A CHALLENGE FOR IVF-CLINICS

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CHAPTER 2

Abstract

Objective

Acute fertility preservation for women is an interdisciplinary treatment that requires adequate information provision and early referral. This quality management project aimed to improve fertility preservation care by using a practical tool: Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis.

Study design

This quality management project was executed between May 2011 and July 2013. This project has been executed in a university affiliated IVF-clinic in cooperation with two oncological sites and used a four-step strategy: (1) monitoring baseline referral process, (2) exploring baseline fertility preservation program by Strengths, Weaknesses, Opportunities and Threats’ SWOT analysis, (3) setting up a new fertility preservation program and (4) evaluating the new fertility preservation program by means of SWOT analysis.

Results

During the three-months monitoring period, fertility preservation was requested for a total of 126 women. The mean age of the women was 33.8 years old (range 1–42 years old). Most requests came from women who wanted to cryopreserve oocytes because of age-related decline of fertility (n = 90; 71%). Most requests for acute fertility preservation concerned women with breast cancer (n = 16; 57%). Information leaflets and pre-consultation questionnaires for women and referring health care professionals improved the quality of first fertility preservation consultation as evaluated by final SWOT analysis. Collaboration with oncological centres and information about fertility preservation for health care professionals improved the referral process.

Conclusions

SWOT analysis proved useful for setting up a new fertility preservation-program and can be recommended as a tool to improve the management and organisation of new types of reproductive care.
FERTILITY PRESERVATION: A CHALLENGE FOR IVF-CLINICS

Introduction

Fertility preservation (FP) has emerged as a new discipline within reproductive medicine and aims to increase chances for future parenthood in case of fertility threatening circumstances. These circumstances may be planned gonadotoxic therapy or ovarian surgery, genetic disease that may lead to premature ovarian insufficiency, or age-related decline of fertility [1, 2]. Although major developments have taken place in cryopreserving and transplanting ovarian tissue [3, 4], ovarian stimulation followed by cryopreservation of oocytes or embryos is currently the only non-experimental FP technique for women [5]. The dominant clinical pathway in IVF clinics is elective IVF/ICSI, consisting of controlled ovarian stimulation (COS), follicle aspiration and fresh embryo-transfer after in vitro fertilisation, which may take 2–6 weeks, depending on the type of stimulation protocol [6, 7]. In contrast, COS followed by follicle aspiration and cryopreservation of oocytes or embryos is an acute treatment modality if women have cancer. IVF-clinics have therefore been challenged to organise reproductive care within a short period of time, as women often have to start cancer treatment soon after diagnosis.

Patient surveys have reported that only half of the cancer survivors recalled having discussed possible infertility as a consequence of their cancer treatment with their oncology team [8-10]. Also, a recent study estimated that only half of young women diagnosed with cancer receive information about fertility preservation before their cancer treatment [11]. This poses another challenge for IVF clinics, because the time-consuming process of informing patients about FP needs to be organised within the already restricted time available before women start their cancer treatment. It has been shown that adequate information provision about fertility preservation prior to cancer treatment increases quality of life on the long run [12]. It is also known that knowledge about FP and adequate time to ask questions results in less decisional conflict about whether or not to pursue with FP [12-15]. Therefore, a basic requirement for a FP-program is time for information provision. Early referral can help to increase time for information provision and decision-making [16]. Barriers for early referral have been identified such as lack of knowledge about risks of inducing premature ovarian insufficiency by specific treatments, lack of knowledge about available FP options, and lack of time [15-19]. Informing oncologists about FP can also be seen as a basic requirement for a FP-program so that the knowledge gap that is responsible for no or late FP referral can be overcome. In addition, it could be helpful to increase awareness among the general public about FP, so that women
themselves can address FP when their oncologists fail to do so [20]. Other require-
ments for a FP-program are guidance and support of women by doctors and nursing
staff [21] and [22]. Although literature suggests these basic requirements for a well-
functioning FP-program, no studies thus far have described how IVF-clinics have
set up an FP-program. In view of this, the aim of this study was to provide insight
in how an IVF-clinic has organised itself to manage FP-care. To do so, we used a
practical tool: Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis.
SWOT analysis has been used extensively in business settings to uncover new out-
looks and identify problems that would impede progress.

Materials and methods

This quality management project was assessed by the Institutional Review Board
(IRB) of the Academic Medical Centre Amsterdam (project no W13_130). The IRB
stated by letter that the study was not subject to the Dutch “Medical Research In-
volving Human Subjects Act”, meaning that no further approval was needed be-
cause the project would not subject patients to investigations or treatment.
The initiation of the quality management project named ‘Optimising FP-care’
took place in February 2011. The Centre for Gyneacological Oncology Amsterdam
(CGGOA), which provides care at the Academic Medical Centre (AMC) and the An-
toni van Leeuwenhoek hospital (AvL), became project partner. The project used a
four-step strategy: 1. Monitoring baseline referral process, 2. Exploring the baseline
FP-program, 3. Setting up a new FP-program, 4. Evaluating the new FP-program.

Step 1: Monitoring baseline referral process

From May 2011 until July 2011 all health care providers from the centre for repro-
ductive medicine of the AMC were asked to fill out a notification form once they
received a request for fertility preservation from either a patient or a health care
professional. Disregarding whether women requesting FP did eventually pursue
with FP or not, the form recorded the origin (i.e. who referred the patient), the in-
dication of the request and suggestions to improve organisational handling of that
specific incoming request. Data were collected using SPSS version 20.
Step 2. Exploring the baseline FP-program

With regard to the monitoring period of incoming acute requests, a ‘Strengths, Weaknesses, Opportunities and Threats’ (SWOT)-analysis was chosen as a tool for exploring the then existing FP care (“baseline FP-program”) and ways to improve that FP care. SWOT analysis is a frequently used marketing and business tool for assessing factors that may influence business performance [23]. Attributes of the organisation that were helpful to achieve the objective – improving FP care– were defined as strengths; attributes considered detrimental for our purpose were defined as weaknesses. Additionally, external conditions considered as helpful to achieve the objective were defined as opportunities. External conditions that could be detrimental to the objective were defined as threats.

The analysis was performed by an expert-team: two gynaecologists (MG and FM), the head of the centre for reproductive medicine (FV), a fertility doctor/PhD student (TD).

Step 3: Setting up a new FP-program

Based on the data from the baseline referral process and the results of the SWOT analysis a FP-program was set up for women referred for acute cryopreservation of oocytes or embryos within the centre for reproductive medicine.

Step 4: Evaluating the new FP-program

To evaluate the progress and remaining challenges of the acute FP clinical pathway two years after its set-up, a final evaluative SWOT analysis was conducted in July 2013. This SWOT analysis was performed during a structured brainstorm session. Participants were selected from the various professional reproductive specialists involved in acute FP, including: one gynaecologist specialised in reproductive endocrinology and infertility, one IVF doctor, one fertility nurse, one physician’s assistant, one embryologist and one laboratory technician. The session was moderated by an experienced qualitative researcher (BD) and observed by a second researcher (TD). The moderator ensured that during the brain-storm session participants kept focus on mentioning strengths, weaknesses, opportunities and threats of acute FP only. This way it was ensured that the SWOT analysis would eventually only reveal issues relevant for FP in the acute setting. The session took place at a neutral location.
outside the fertility clinic to minimise the effect of collegial hierarchy on group dynamics. Aspects brought up by the participants during the structured brainstorm session were written in a quadrant standardised SWOT-template on a white board. The position of aspects that were brought up by the group was based on group agreement. At the end of the session, the moderator compared the findings with those of the baseline SWOT analysis and asked to discuss aspects that had changed quadrant or that had not been brought up in the final SWOT analysis. This led to the addition of new aspects based on group agreement. The session was audio-recorded and transcribed verbatim to allow in-depth analysis by checking whether all aspects brought up during the brainstorm session had been recorded on the white board by the moderator.

Results

Monitoring baseline referral process

Information about fertility preservation was requested for a total of 126 women and girls during the three months monitoring period. All indications for requesting FP are shown in Table 1. The mean age of the women was 33.8 years old (range 1–42 years old). Most requests came from women who wanted to cryopreserve oocytes because of age-related decline of fertility (n = 90; 71%). Most requests for acute FP concerned women with breast cancer (n = 16; 57%). Three mothers requested cryopreservation of their oocytes for donation to their young daughters with Mosaic Turner syndrome.
Table 1: Incoming requests for fertility preservation between May 2011 and July 2011.

Reason for requesting cryopreservation oocytes

<table>
<thead>
<tr>
<th>Acute reasons</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy for breast cancer</td>
<td>16 (57%)</td>
</tr>
<tr>
<td>IOF after chemotherapy in the past</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Radiotherapy for brain tumour with risk of impairing pituitary gland function</td>
<td>2</td>
</tr>
<tr>
<td>Future ovarian surgery</td>
<td>2</td>
</tr>
<tr>
<td>IOF (not otherwise specified)</td>
<td>2</td>
</tr>
<tr>
<td>Chemotherapy for chronic lymphoid leukaemia</td>
<td>1</td>
</tr>
<tr>
<td>Radiotherapy for gynaecological cancer</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-acute reasons</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-related decline of fertility</td>
<td>90</td>
</tr>
<tr>
<td>Request for oocyte donation mother to daughter with Mosaic Turner syndrome</td>
<td>3</td>
</tr>
<tr>
<td>Mosaic Turner syndrome</td>
<td>2</td>
</tr>
<tr>
<td>MRK-syndrome (single) and wish to preserve oocytes for future surrogate pregnancy</td>
<td>2</td>
</tr>
<tr>
<td>PCOS</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>126</td>
</tr>
</tbody>
</table>

IOF, imminent ovarian failure; MRK, Mayer-Rokitansky-Küster; PCOS, polycystic ovarian syndrome.

Exploring baseline FP-program

The first SWOT analysis of 2011 indicated the need to set-up an FP-program as acute cryopreservation of oocytes or embryos was not regarded common reproductive practice in 2011 (see Table 2). More specifically, logistics of acute care were not yet incorporated into daily practice and delays in planning a first consult were common. The delays were not due to lack of motivation of staff but rather due to the absence of digital or paper information about FP.
Table 2: SWOT analyses for improving management fertility preservation in 2011 and 2013.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths in 2011 as well as 2013</strong></td>
<td><strong>Weaknesses 2011 but resolved in 2013</strong></td>
</tr>
<tr>
<td>Good laboratory capacity for urgent gamete freezing</td>
<td>Patients were informed insufficiently at time of the first consultation</td>
</tr>
<tr>
<td>Good access because of acceptance of self-referrals</td>
<td>Medical information of FP patient was not complete at the time of the first FP consultation and contact details of referring doctors were often not at hand</td>
</tr>
<tr>
<td>Acute FP requests are dealt with swiftly</td>
<td>Unstructured first FP consultation</td>
</tr>
<tr>
<td>Motivated personnel</td>
<td></td>
</tr>
<tr>
<td><strong>New strengths in 2013</strong></td>
<td><strong>Weaknesses from 2011 remaining in 2013</strong></td>
</tr>
<tr>
<td>FP-questionnaires and information leaflets available</td>
<td>No adequate follow-up of patients</td>
</tr>
<tr>
<td>Checklist during first FP consultation FP has become more common care</td>
<td></td>
</tr>
<tr>
<td>Oncologic centers are ‘team players’ in FP</td>
<td><strong>New weaknesses in 2013</strong></td>
</tr>
<tr>
<td></td>
<td>Insufficient time for adequate patient support</td>
</tr>
<tr>
<td></td>
<td>FP patients are discussed several times with different doctors in our clinic.</td>
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<tr>
<td></td>
<td>FP-care unavailable in the evenings/weekends.</td>
</tr>
</tbody>
</table>
### Opportunities vs. Threats

<table>
<thead>
<tr>
<th>Opportunities</th>
<th>Threats</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Opportunities from 2011 that had been taken up by 2013</em></td>
<td></td>
</tr>
<tr>
<td>To structure a multidisciplinary approach</td>
<td></td>
</tr>
<tr>
<td>To inform women with acute FP indication prior to their first visit to the centre for reproductive medicine</td>
<td></td>
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<tr>
<td>To inform doctors prescribing fertility threatening treatment about FP</td>
<td></td>
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<tr>
<td>To organize meetings to exchange information among involved specialisms in FP</td>
<td></td>
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<tr>
<td>To incorporate oncological centres as team members for FP</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td><em>New opportunities in 2013</em></td>
<td></td>
</tr>
<tr>
<td>Increasing FP knowledge amongst general public</td>
<td></td>
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<tr>
<td>Developing FP guidelines</td>
<td></td>
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<tr>
<td>Developing referral flow-chart for oncologists</td>
<td></td>
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<tr>
<td>Availability of more FP techniques in more centres nationwide</td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Threats from 2011 that had been taken up by 2013</em></td>
<td></td>
</tr>
<tr>
<td>More consensus about which medical doctor is in charge of the patient during FP (referring doctor or reproductive specialist) due to increased cooperation between IVF clinic and oncology site</td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Threats from 2011 remaining in 2013</em></td>
<td></td>
</tr>
<tr>
<td>Time shortage for FP because of overlap of oncological treatment trajectory; especially in case of neo-adjuvant treatment</td>
<td></td>
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<tr>
<td>Low number of referrals considering the amount of patients with cancer</td>
<td></td>
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<tr>
<td></td>
<td></td>
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<tr>
<td><em>New threats in 2013</em></td>
<td></td>
</tr>
<tr>
<td>Political climate of limiting health care costs</td>
<td></td>
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</tbody>
</table>

FP = fertility preservation  
AvL = Antoni van Leeuwenhoek hospital
Setting up a new FP-program

The new FP-program was set up after the baseline SWOT of 2011. Four general measures were taken to overcome weaknesses and threats of the baseline SWOT of 2011, and to use the opportunities mentioned.

Firstly, information about FP for patients was developed. Detailed information about FP became available on the website of the centre for reproductive medicine and via a link on the website of the oncological centre (AvL). An FP information leaflet was sent routinely to women who contacted the physician’s assistant of the centre for reproductive medicine by telephone with a FP request.

Secondly, several measures were taken to inform potential referring physicians. A letter was sent to all general practitioners working within the region of the Academic Medical Centre to ask specific attention for patients with an indication for FP. Detailed information about FP became available on the internal website for professionals working in the AMC. Information sessions about FP were organised for surgeons, radiotherapists, oncologists and nurses who work in the field of breast cancer, since breast cancer is the most prevalent malignancy among women of reproductive age. Alongside this quality management project, just after the baseline SWOT analysis in 2011, the Dutch national guideline for breast cancer was revised and information about the need to discuss FP option was added (http://www.oncoline.nl/breastcancer).

Thirdly, several organisational tools were developed to reduce time of first consultation. Women were asked to fill out a pre-consultation FP-questionnaire and bring it along at first visit to the centre so that all required information (e.g. from referring physicians) would be available at the time of first consultation.

Lastly, a checklist for the first consultation was developed, to make sure that all physicians at the centre for reproductive medicine could perform the first consultation and would cover all relevant FP items (see Appendix 1). The new FP-program is illustrated in Fig. 1.
**Figure 1:** New FP-program in detail.

1. **Incoming request for FP by email, telephone or fax**

2. **Doctors’ assistant**
   - Collects information from patient on:
     - (Cancer) diagnosis
     - Planned fertility-threatening treatment
     - Contact details referring doctor
     - Menstrual cycle day
     - Use of oral contraceptive

3. **Sends information to patient:**
   - Questionnaire on general reproductive health
   - Information leaflet about FP
   - Information leaflet about IVF/ICSI

4. **Plans FP intake with fertility doctor within 2 days**

5. **FP consultation by fertility doctor**
   - Fertility doctor collects information from patient:
     - Goes through filled questionnaire and agreements with patient
     - Works with FP information checklist
   - Fertility doctor collects information for referring doctor:
     - Changes of treatment-induced infertility
     - Time available for FP

6. **Team discussion with staff-members of IVF-clinic**
   - Consensus on indication for FP
   - Consensus on time-frame for FP
   - Consensus on type of FP (i.e. ovarian tissue freezing when no time for freezing oocytes or embryos)

7. **Fertility doctor discusses results of team-discussion on the same day**

8. **Patient receives time to decide whether or not to pursue with FP**

9. **FP ’start treatment’ consultation by fertility doctor is planned 24 hours later:**
   - Informed consent procedure on IVF including risks, complications and chances of success are discussed with patient
   - Starting date FP is set with patient
   - Patient receives medication to start FP treatment
Evaluating the new FP-program

The factors identified by the SWOT analyses of 2011 and 2013 are shown in Table 2. All four strengths identified in 2011 were still relevant in 2013, namely: good laboratory capacity for cryopreservation of oocytes or embryos, acceptance of self-referrals, swift dealing with acute requests, and motivated staff in the IVF-clinic. Compared to 2011, four new strengths had emerged that all resulted directly from the quality management project. For example, the neighbouring oncological centre (AvL) was now a ‘team player’ since communication during the referral process had much improved.

All weaknesses identified by the baseline SWOT analysis of 2011 had been taken up and developed into strengths by 2013 except for adequate follow-up after FP that was still lacking. The SWOT analysis showed that new weaknesses had emerged by 2013, such as insufficient time for adequate patient support and sometimes patients were discussed several times with different doctors in our clinic. Also, the fact that acute FP could not be organised in the evenings and weekends was mentioned as a weakness as weekend delay could impede starting FP on the ideal menstrual cycle day if women were to start cancer treatment soon. All opportunities identified by the baseline SWOT analysis of 2011 had been taken up and were no longer opportunities in 2013. Of all threats identified in 2011, two were still present in 2013 namely the short time span available for FP and the relatively small number of women referred for FP in relation to the number of women about to receive gonadotoxic treatment. All opportunities identified by the baseline SWOT analysis of 2011 had been taken up and were no longer opportunities in 2013. Of all threats identified in 2011, two were still present in 2013 namely the short time span available for FP and the relatively small number of women referred for FP in relation to the number of women receiving fertility-threatening therapy.

By 2013, the SWOT analysis showed that new opportunities had emerged. Generating more common knowledge about FP among the general public was seen as a future task, as well as developing FP guidelines to make FP-care more evidence based and uniform. Flow-charts for oncologists should be developed and to save travel time for patients, the availability of FP in more centres nationwide was considered required.

The political climate of limiting health care costs was identified as a new threat in 2013 because this could imply that the current reimbursement of FP costs in the Netherlands could be stopped.
Comments

This quality management project describes the logistic steps that have led to incorporation of acute FP into general reproductive care. We evaluated the handling and organising of acute FP requests in our centre in 2011 and found that the logistics for efficient FP care were not yet established after exploring the situation in 2011 by means of SWOT analysis. The starting point of this quality management project was exploring how incoming requests for FP were managed logistically, disregarding whether the request came from a woman eventually undergoing FP or from a woman declining FP after consultation. By means of SWOT analysis, we then explored the existing (baseline) FP-program in 2011 to eventually set up a new FP-program in 2013. The analysis showed that it was deemed important to develop information for patients and doctors who prescribe fertility threatening treatment to facilitate good time management at time of first FP consultation. A new FP-program was set up as a result of this evaluation, leading to several easy accessible sources of information about FP. When we evaluated the organisation of FP two years after the set-up of the FP-program by a final SWOT analysis, we found that new strengths emerged as a result of improved information provision for patients and surrounding oncology centres. Also, FP consultation was improved by introducing a FP-questionnaire for patients and a checklist for doctors to use during consultation. Our new FP-program can be used as an example for other IVF-clinics on how to manage acute FP care and can offer insight in how to use SWOT analysis as a practical tool to improve or start FP care.

This is the first time that the evolution of organising acute cryopreservation of oocytes has been followed over time within an IVF-clinic. Also, this is the first time an evaluation of organising FP for women has been described by means of SWOT analysis. Although this quality management project was undertaken to improve acute FP, the new FP-program also covers elective FP. The majority of women requesting FP during the three-month monitoring period in May 2011 were women with age-related decline of fertility. This could have been a temporary phenomenon as oocyte cryopreservation received a lot of media-attention in the Netherlands in April 2011 when women with age-related decline of fertility were allowed to cryopreserve oocytes. The lack of metric tools to evaluate the effectiveness of FP-programs that involve oncological centres has been pointed out by studies reviewing ongoing FP-programs such as Fertile Hope [22]. Because FP is a relatively new type of care within the field of reproductive medicine, SWOT analysis is a designated method to reveal factors that have an influence on management and organisation.
A primary limitation of the study is that benchmarking for quality was not possible since this quality management project was conducted in one IVF-clinic only. In addition, although we included professionals from different reproductive fields, quality was not assessed from the patient’s perspective, which can be regarded as a missing determinant in our SWOT analysis in terms of missing external conditions. Furthermore, the methods used in this project could not quantitatively examine the effectiveness of new FP-program in terms of referral rates, and patients’ and health care professionals satisfaction. In agreement with literature, most acute FP requests came from women with breast cancer [24-25]. Women with breast cancer may constitute the largest FP population because of their high risk on therapy-induced infertility and the increase in breast cancer incidence among young women [26]. Integration of information provision of FP and referral into patient care was lacking in high quality cancer centres [27]. Cooperation with oncological centres can stimulate timely referral and help to overcome difficulties in organising FP [28]. This is in is in accordance with our finding that the collaboration with two oncological sites has been evaluated as a factor that improved the referral process. Knowledge and information deficits at the level of patients and health-care professionals are barriers for effectively organising FP-care [29]. Implementing paper and digital information for patients and health-care professionals has been evaluated as important by SWOT analysis in this study and can be considered as a significant first step in overcoming gaps in knowledge. Despite efforts to ease access to information about FP for patients and oncologists by international networks such as ISFP and the ‘Oncofertility Consortium’, the importance of offering FP in an early stage to patients whose fertility is at threat is not yet resounded to its full potential [30]. Furthermore, with regard to follow-up of patients, registration of FP indications, treatments and outcomes is warranted so that the safety and efficacy of FP can be measured over time.

In conclusion, because the nature of acute FP is different from conventional elective reproductive assisted techniques, the set-up of a separate FP-program was required in our IVF-clinic to meet the needs for acute FP. SWOT analysis proved useful for setting up this program and can be recommended as a tool to gain insight in organizational process of new types of reproductive care. The scope of FP is rapidly broadening which will subsequently lead to subdivision in FP populations and FP options. Future studies will need to evaluate the specific challenges in organising optimal care for men, pre-pubertal boys and girls. Also, further studies are needed to quantitatively examine the effect of information strategies so that all patients with an indication for FP are adequately referred to IVF-clinics.
Conflict of interests

No conflict of interest.

Funding

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Acknowledgements

We would like to thank all participants of the structured brainstorm session.
Appendix 1

Checklist for oocyte cryopreservation

Date:
Fertility doctor:
Referring doctor:

Discussed with patient:
Oocyte cryopreservation in the Netherlands is regarded as “monitored introduction of new technique”
Follow-up children until the age of five years
IVF treatment precedes cryopreservation of oocytes (risks: bleeding, infection, ovarian hyper stimulation syndrome)
Treatment does not guarantee having a (future) child
Estimated number of oocytes needed for live birth is 20-30
Future use of cryopreserved oocytes for pregnancy will be preceded by medical and moral judgment of IVF-clinic staff
Costs of treatment: vitrification kit plus yearly storage costs
Ovum pick up is performed until the age of 40 years
Embryo transfer until the age of 45 years

Check whether patient received:
‘General patient information leaflet IVF/ICSI’
‘Patient information leaflet freezing oocytes’ or ‘Patient information leaflet freezing embryos’
References


CHAPTER 2


