Patient-focused Internet interventions in reproductive medicine: a scoping review

J.W.M. Aarts, P. van den Haak, W.L.D.M. Nelen, W.S. Tuil, M.J. Faber, and J.A.M. Kremer

1Department of Obstetrics and Gynaecology, Route 791, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands 2MijnZorgnet, Mercator II, Toernooiveld 300/C, 6525 EC Nijmegen, The Netherlands 3Scientific Institute for Quality of Healthcare, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands

Correspondence address. Tel: +31-243-61-73-51; E-mail: j.kremer@obgyn.umcn.nl

Submitted on November 1, 2010; resubmitted on October 11, 2011; accepted on October 14, 2011

Table of contents

Introduction
Methods
Results
Discussion
Conclusions

Background: The Internet has revolutionized fertility care since it became a popular source of information and support for infertile patients in the last decade. The aim of this scoping review is to map (i) the main categories of patient-focused Internet interventions within fertility care, (ii) the detailed composition of the interventions and (iii) how these interventions were evaluated.

Methods: A literature search used various ‘Internet’ and ‘Infertility’ search terms to identify relevant studies published up to 1 September 2011. The selected studies had to include patients facing infertility and using an infertility-related Internet intervention. We charted data regarding categories of interventions, components of interventions and evaluation methodology. We categorized the stages of research using the UK’s Medical Research Council framework for evaluating complex interventions.

Results: We included 20 studies and identified 3 educational interventions, 2 self-help interventions, 1 human-supported therapeutic intervention, 9 online support groups and 2 counselling services. Information provision, support and mental health promotion were common aims. Few interactive online components were present in the online programmes. Three studies were in the pilot phase and 17 were in the evaluation phase.

Conclusions: Several categories of patient-focused Internet-based interventions in fertility care are primarily applied to provide support and education and promote mental health. The interventions could be improved by using more interactive and dynamic elements as their key components. Finally, more emphasis on methodological standards for complex interventions is needed to produce more rigorous evaluations. This review shows where further development or research into patient-focused Internet interventions in fertility-care practice may be warranted.

Key words: Internet / eHealth / Health 2.0 / infertility / scoping review

Introduction

The Internet is revolutionizing healthcare (Hartzband and Groopman, 2010). According to Brown (2009), the Internet is ‘as vital as water and gas’, so it is not surprising that around 60% of the western world uses the Worldwide Web for health-related issues (Eysenbach and Köhler, 2004; Atkinson et al., 2009b). The Internet can help patients become active and well-informed instead of being passive...
healthcare consumers (Powell et al., 2003; Dedding et al., 2011). It offers a platform for virtual communication and shared participation to both patients and their healthcare professionals (Eysenbach et al., 2004; Demiris, 2006). Exchanging experiences in online communities can provide support and advice for peers 24 h a day, 7 days a week (Eysenbach et al., 2004; Malik and Coulson, 2008a).

The Internet has also become an increasingly popular source of support and information within the field of reproductive medicine (Weissman et al., 2000; Haagen et al., 2003; Wischmann, 2008), particularly because of the high emotional and psychological impact of being infertile (Schmidt, 2006; Cousseau and Domar, 2007; Verhaak et al., 2007). The degree of anonymity that the Internet provides may also contribute to its popularity, as those who feel stigmatized as a result of their fertility problems can openly discuss their experiences without feeling embarrassed (Berger et al., 2005; Malik and Coulson, 2008a). Furthermore, infertile patients are eager to learn more about their fertility disorder and wish to be actively involved in their own care process, a process which the Internet can facilitate (Haagen et al., 2003; Dancer et al., 2010; van Empel et al., 2010a). Internet-based interventions, such as web-based decision aids or psychological treatments, are thus promising within a fertility-care setting.

However, in general, Internet-based interventions have suffered from a lack of clarity and consistency (Gustafson and Wyatt, 2004; Nguyen et al., 2004; Barak et al., 2009). Knowledge of how these interventions should be composed, what they offer or to whom they might bring the most benefit is limited (Nguyen et al., 2004; Barak et al., 2009). There is an ongoing debate about the best way to evaluate these complex interventions because of their heterogeneity, multiple interacting components and dynamic and uncontrollable characteristics (Potts, 2006; O’Grady et al., 2009; Baker et al., 2010; Gentles et al., 2010). For instance, Internet interventions typically allow more individualization of the user experience and intensity of use. Participants themselves can determine use patterns without a therapist present to guide use (Baker et al., 2010).

This heterogeneity of interventions and the accompanying methodological challenges also apply to the research field of Internet interventions in fertility care. A scoping review serves best to gain insight into these matters (Arksey and O’Malley, 2005; Levac et al., 2010). Scoping reviews involve the synthesis and analysis of a wide range of research aiming at summarizing findings and identifying research gaps rather than aiming at estimating effectiveness (Arksey and O’Malley, 2005; Levac et al., 2010). Therefore, the aim of our scoping review was to map the research field of patient-focused Internet-based interventions within the field of reproductive medicine to get more insight into (Research Question (RQ) 1) categorization of Internet interventions that have been studied, (RQ 2) the detailed composition of these interventions and (RQ 3) how they were evaluated. This enables us to disseminate the current knowledge on this topic and drawing learning lessons for future research.

### Methods

The methods for this scoping review employed the methodological framework for Arksey and O’Malley’s (2005) scoping studies. Supplementary data, Appendix S1 presents a summary of this framework, divided into five stages.

#### Stage 1. Defining the research question

We focused the scoping exercise in this review by defining three research questions: ‘what main categories of patient-focused Internet interventions currently exist within fertility care?’; ‘what are the key components of these interventions?’; and ‘how are these interventions evaluated?’.

With respect to these questions, two particular parameters needed some further explanation: ‘patient-focused, Internet-based interventions’ and ‘the field of reproductive medicine’. We defined an Internet-based intervention as ‘healthcare delivered by the Internet’ (Oh et al., 2005). Such an intervention had to be designed and developed for patients (i.e. it was patient-focused). We interpreted reproductive medicine as the discipline in which patients who had either self-reported or diagnosed infertility according to the terminology of the International Committee for Monitoring Assisted Reproductive Technology (Zegers-Hochschild et al., 2009), or who might become infertile because of the harmful side effects of cancer treatment, for example. We chose this broad definition of the study population after we attained a first sense of the volume and general scope of the field.

#### Stage 2. Identifying relevant studies

We systematically searched the literature to identify original studies of the use of Internet-based interventions in fertility care published from the 1 January 1990 to 1 September 2011. We searched various electronic literature databases (PubMed, EMBASE, Cochrane CENTRAL, Psycinfo and Cinahl) using a syntax composed of ‘Internet’ and ‘eHealth’ and their synonyms combined with ‘infertility’, ‘IVF’ and ‘Reproductive techniques, assisted’ and their synonyms. Figure 1 provides the full syntax. We also checked the references of the included studies (in Stage 3) and searched related articles to avoid missing relevant citations.

#### Stage 3. Study selection

We manually checked all retrieved titles and abstracts for duplicates, and three of the co-authors (J.W.M.A., P.H. and M.J.F.) independently reviewed them for relevance. Then we screened the full texts of the selected studies using the same inclusion criteria. These inclusion criteria were: (i) the study had to be written in English; (ii) the study had to evaluate a patient-focused Internet intervention, (iii) which was applied within fertility care and (iv) the study population had to consist of patients with (self-reported or diagnosed) infertility or imminent infertility. We excluded papers studying Internet-based interventions focusing on healthcare professionals. We did not restrict study methodology in any way in order to avoid missing important or significant data in a rapidly expanding field, which meets the scoping review criteria (Arksey and O’Malley, 2005; Levac et al., 2010).

#### Stages 4 and 5. Charting data and collating, summarizing and reporting the results

A descriptive analytical approach was used to chart and summarize the data. Three of the co-authors (J.W.M.A., P.H. and M.J.F.) independently extracted the data from each study included in this review with the aid of a standardized data-charting sheet. They discussed differences in data extraction until they reached consensus.

To answer our main research questions: ‘What categories of interventions have been studied in the field of reproductive medicine, what were their key components and how were they evaluated’, we extracted the following information.

First, to get more insight into the studies, we collected study characteristic data, such as design, setting, characteristics of study populations, recruitment setting and name of the intervention. Furthermore, we extracted the goals for development of the several Internet interventions.
Additionally, we allocated each intervention to one of Barak et al.’s (2009) categorization of web-based interventions. They distinguished six types of interventions: web-based education intervention, self-help therapeutic intervention, human-supported Internet intervention, online counselling, Internet-operated therapeutic software and other online activities (e.g. online support groups).

Secondly, we were interested in the detailed composition of each intervention and extracted the key components according to Barak et al.’s (2009) categorization model. According to this model, content of these interventions can be structured into four components: (i) programme content, indicating the nature of the information within the programme (e.g. educational or behaviour change content), (ii) multimedia use, indicating the use of different formats other than plain text, such as pictures, audio etc., (iii) interactive online activities, that is, features enabling patients to participate within the intervention, such as self-assessment tools or online bulletin boards and (iv) provision of tailored or generic support and/or feedback to help patients obtain information about themselves from others, whether it is human-supported or automatically generated by the online programme. We identified the various components of each Internet-based intervention included in this review, and applied Barak et al.’s (2009) categorization.

Thirdly, we extracted data about the evaluation of interventions such as exposure dosage to the intervention and attrition rates (the phenomenon of participants quitting usage and/or being lost to follow-up; Eysenbach, 2005). We specifically made a division between measures that describe the usage characteristics of the Internet-based intervention (process measure) and the actual intended outcome measure. We defined the process measure as an intermediate measure that preceded the outcome and could contribute to it, for example, the time that participants spent on the site. The actual intended outcome measure was marked as the main outcome of the intervention, such as degree of depression.

Furthermore, to summarize the heterogeneity in the research types, we used the framework of the UK’s Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Campbell et al., 2007). The MRC guidance defines complex interventions as those with several interacting components and several features that possibly make them complex. The MRC framework consists of a continuum of four research phases: development (identifying evidence base, modelling process and outcomes), feasibility and piloting (testing feasibility, piloting possible outcomes), evaluation (assessing effectiveness) and implementation (dissemination, long-term follow-up). The guidance stresses the importance of reporting all stages of research and cautions against focusing too much on the evaluation phase while neglecting the other phases. We categorized each study into one of the four phases.

Finally, we critically appraised the quality of all studies. Although quality assessment is not required in scoping reviews (Arksey and O’Malley, 2005), it enabled us to gain insight into the strengths and weaknesses of studies and to compare one to another. We did not exclude any study on the basis of this assessment. We evaluated the quality of the studies using three different types of quality assessment checklists: the Cochrane Risk of Bias for randomized controlled trials (RCTs) (Higgins and Altman, 2008); the Newcastle–Ottawa Scale (NOS) for observational studies (cohort, cross-sectional and case–control; Wells et al., 2011) and, for qualitative designs, the checklist from the National CASP Collaboration for Qualitative Methodologies (National CASP collaboration, 2006).

Each of three authors (J.W.M.A., P.H. and M.J.F.) assessed two-third of the 213

Figure 1 Syntax infertility and Internet interventions.
all studies so that all studies were independently assessed by two authors. The first author (J.W.M.A.) compared the assessments for each study, and any discrepancies were resolved by discussion. For the RCTs, we assessed possible risk of bias within studies and summarized them as low risk, unclear risk or high risk of bias. For the NOS and checklist for qualitative studies, low, moderate and high quality labels were assigned when a study met none to one-third, one-third to two-thirds or two-thirds to all of the quality items on these checklists, respectively.

Results

Stages 1, 2 and 3. Literature search and study selection

The literature search yielded 1910 citations, after duplicates were removed. Screening the titles and abstracts for inclusion criteria identified 78 studies, of which 60 were excluded after reading the full text. We decided to exclude papers that described the quality of infertility-related information on the Internet because infertile patients were not the subject of these studies (n = 5; Okamura et al., 2002; Epstein and Rosenberg, 2005; Huang et al., 2005; Zahalsky et al., 2005; Marriot et al., 2008). Furthermore, we excluded studies that evaluated infertility-related use of the Internet in general rather than use of specific infertility interventions (n = 6; Weissman et al., 2000; Haagen et al., 2003; Huang et al., 2003; Rawal and Haddad, 2006; Kahlor and Mackert, 2009; Hinton et al., 2010). We identified two more relevant papers from study reference lists. In total, we included 20 studies in this scoping review; the earliest study was published in 2000. Figure 2 shows the study selection procedure.

Stages 4 and 5. Charting data and collating, summarizing and reporting the results

Tables I–III present the data extracted from the studies in this review.

Study populations

Populations varied among the studies. Most studies questioned infertile couples or men and women separately, five questioned solely women and only two studies involved solely infertile men. The participants faced all relevant phases within fertility care: they experienced self-reported infertility, initial diagnostic assessments, different types of treatment and successful pregnancy after IVF. The mean sample size per study was 274 participants (i.e. women, men or couples) with a range of 20–1150 participants. The mean age of the participants varied from 32.0 to 35.6 years. These participants were of various nationalities, but were residing mainly in the USA and western Europe. Table I presents more characteristics.

Categorization of interventions (RQ 1)

Common goals addressed by interventions

The interventions addressed several aims: the provision of information and support (nine interventions; primarily online support groups), education about fertility preservation (two interventions), mental health promotion (three interventions) and patient empowerment or self-efficacy (three interventions in six studies). The aims of two interventions were not reported (Table I). Two interventions were specifically aimed at men (Malik and Coulson, 2008a; Huyghe et al., 2009), five only were aimed at women (Cousineau et al., 2008; Toscano and Montgomery, 2009; Meneses et al., 2010; Sexton et al., 2010; Isupova, 2011) and the remaining interventions were aimed at both partners of the couple, yet mainly used by women (Epstein et al., 2002; Himmel et al., 2005; Tuil et al., 2006, 2007, 2008, 2009; Steuber and Solomon, 2008; Van Selm et al., 2008; Malik and Coulson, 2008b, 2010a, 2010b, 2011; Hämmerli et al., 2010).

Main categories of interventions

Table II provides an overview of the main categories of interventions on the basis of Barak et al.’s (2009) categorization. There were three web-based educational interventions; two self-help, web-based, therapeutic interventions; one human-supported, web-based, therapeutic intervention; nine online support groups; and two online counselling interventions.

Six studies examined three different web-based educational interventions. Four studies investigated one intervention, a web-based personal health record (PHR) for patients undergoing an assisted reproductive technique (ART) treatment (Tuil et al., 2006, 2007, 2008, 2009). This PHR consisted of 15 functions, divided into three functional groups: ‘general information’, ‘personalized information’ (including the PHR itself) and a number of ‘communication’ options, in which professionals also participated. The other two web-based educational interventions were educational tools focused on delivering online education and support services to young breast-cancer survivors (Meneses et al., 2010; Fertility and Cancer Project) and young male cancer survivors (Huyghe et al., 2009; Banking on Fatherhood) with fertility concerns. The first web-based educational intervention consisted of educational modules, bulletin boards and the opportunity to communicate with researchers (Meneses et al., 2010); the second involved a decision aid and a knowledge test (Huyghe et al., 2009). The second educational tool, also offered to oncologists, consisted of a knowledge test and a section about communication skills with a checklist of topics to discuss with patients (Huyghe et al., 2009).

We identified two self-help therapeutic interventions (Cousineau et al., 2008; Sexton et al., 2010). They were both built on evidence-based psychosocial theories and interventions for infertile patients. The user took behavioural skills training online in several steps, and then received automated feedback to learn to cope with infertility (Cousineau et al., 2008; Sexton et al., 2010).

The ‘Child Wish Online’ coaching programme was a human-supported therapeutic intervention aimed at improving mental health (in cases of depression, anxiety and distress) and increasing the pregnancy rate (Hämmerli et al., 2010). The intervention involved an 8-week programme with a self-help guide plus online contact with therapists.

Two interventions offered online counselling to patients by means of (i) a German expert forum in which infertile experts from all around Germany answered infertile patients’ questions (Himmel et al., 2005) and (ii) a chat module in which patients receiving ART treatment from one clinic could chat with their own healthcare providers or other patients (van Selm et al., 2008).

Nine studies evaluated online support groups (Epstein et al., 2002; Steuber and Solomon, 2008; Malik and Coulson 2008b, 2010a, b, 2011; Toscano and Montgomery, 2009; Isupova, 2011). These open online support groups were solely for peers; the groups were
asynchronous and could be accessed in the open and public domain of the Internet.

**Key components of interventions (RQ 2)**

Table II shows the various key components of each intervention. Not every study gave a detailed description of the intervention that was studied.

With respect to the first key component, programme content, several interventions provided material for cognitive behavioural change that was active, educational and structured (Cousineau et al., 2008; Hämmerli et al., 2009; Sexton et al., 2010). For instance, the content of the self-help, therapeutic, web-based intervention evaluated by Sexton et al. (2010) was based on cognitive behavioural therapy for ART patients, which had proved effective in a conventional, ‘offline’ intervention. This therapy included psychoeducation and skill-based approaches. In contrast, the content of online support groups was minimal and consisted primarily of free-flowing communications (Epstein et al., 2002; Steuber and Solomon, 2008; Malik and Coulson, 2008b, 2010a, b, 2011; Toscano and Montgomery, 2009; Isupova, 2011). The content relied on the contributions of participants within the online support group.

The second key component concerned the use of various multimedia forms other than plain text. Most of the interventions used primarily one format. The formats most commonly used were pictures and videos. Four interventions used at least three multimedia formats, including day planners, video vignettes, checklists and prognosis calculators (Tuil et al., 2006, 2007, 2008, 2009; Cousineau et al., 2008; Huyghe et al., 2009; Sexton et al., 2010).

---

**Figure 2** Literature search and study selection.
### Table 1 Characteristics of studies and interventions: alphabetical order.

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Study setting</th>
<th>Description study population</th>
<th>Mean age (years)</th>
<th>n</th>
<th>Name of intervention</th>
<th>Aim of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cousineau et al. (2008)</td>
<td>RCT</td>
<td>USA/multi-centric</td>
<td>Diagnosis of infertility and/or history of unsuccessfully trying to conceive for at least 1 year</td>
<td>34.2</td>
<td>188</td>
<td>Infertility Source: Interactive Support Tools When Trying to Conceive</td>
<td>Promotion mental health and self-efficacy</td>
</tr>
<tr>
<td>Epstein et al. (2002)</td>
<td>Cross-sect</td>
<td>USA, 14 countries/multi-centric</td>
<td>Visitors of website about infertility (<a href="http://www.inciid.org">www.inciid.org</a>)</td>
<td>32</td>
<td>589</td>
<td>Online support groups in general</td>
<td>Provision of information and support</td>
</tr>
<tr>
<td>Hammerli (2010)</td>
<td>RCT</td>
<td>CH/multi-centric</td>
<td>Women and men suffering from primary or secondary infertility for at least 1 year</td>
<td>33.5</td>
<td>144</td>
<td>Child wish Online Coaching program</td>
<td>Promotion mental health</td>
</tr>
<tr>
<td>Huyghe et al. (2009)</td>
<td>RCT</td>
<td>n.r./n.r.</td>
<td>Male patients, diagnosed with cancer and having had cancer treatment</td>
<td>32.4</td>
<td>20</td>
<td>Banking on fatherhood</td>
<td>Education on fertility preservation</td>
</tr>
<tr>
<td>Isupova (2011)</td>
<td>Qual</td>
<td>RU, UA, CZ/multi-centric</td>
<td>Infertile women, visiting the forum</td>
<td>n.r.</td>
<td>50</td>
<td>Interactive forum (<a href="http://www.probirka.ru">www.probirka.ru</a>)</td>
<td>Provision of social and psychological support</td>
</tr>
<tr>
<td>Malik and Coulson (2008a)</td>
<td>Qual</td>
<td>GB/multi-centric</td>
<td>Men visiting online bulletin board ‘men’s room’</td>
<td>n.r.</td>
<td>166</td>
<td>Men’s Room bulletin board of an online fertility support group</td>
<td>Provision of social support to men</td>
</tr>
<tr>
<td>Malik and Coulson (2008b)</td>
<td>Qual</td>
<td>GB/multi-centric</td>
<td>Visitors of online support groups</td>
<td>34.2</td>
<td>95</td>
<td>Several online infertility support groups</td>
<td>Provision of social support</td>
</tr>
<tr>
<td>Malik and Coulson (2010a)</td>
<td>Qual</td>
<td>GB/multi-centric</td>
<td>Visitors of online support group with seven sub-boards</td>
<td>35.6</td>
<td>778</td>
<td>Seven sub-boards of a UK peer-moderated online infertility support group</td>
<td>Promotion self-efficacy</td>
</tr>
<tr>
<td>Malik and Coulson (2010b)</td>
<td>Mixed-method</td>
<td>GB/multi-centric</td>
<td>Infertile individuals who had used an online infertility support community</td>
<td>34</td>
<td>295</td>
<td>Online support groups</td>
<td>Provision of information and support</td>
</tr>
<tr>
<td>Malik and Coulson (2011)</td>
<td>Mixed-method</td>
<td>GB, USA/multi-centric</td>
<td>People visiting online infertility support groups</td>
<td>34</td>
<td>295</td>
<td>Online support groups</td>
<td>Provision of social support</td>
</tr>
<tr>
<td>Meneses et al. (2010)</td>
<td>Cohort</td>
<td>USA, AU, IN, CA, ZA, TW, NL, GB/n.r.</td>
<td>Young breast cancer survivors accessing the FCP website</td>
<td>34.3</td>
<td>106</td>
<td>Fertility and Cancer project</td>
<td>Education and support on fertility preservation</td>
</tr>
<tr>
<td>Sexton et al. (2010)</td>
<td>RCT</td>
<td>USA/multi-centric</td>
<td>Receiving infertility-related medical assessments and/or treatments</td>
<td>32.6</td>
<td>43</td>
<td>Web-based ‘Coping with Infertility’ intervention</td>
<td>Promotion mental health</td>
</tr>
<tr>
<td>Steuber and Solomon (2008)</td>
<td>Qual</td>
<td>USA/multi-centric</td>
<td>Visitors of online venues for people coping with infertility</td>
<td>n.r.</td>
<td>438</td>
<td>Online support groups in general</td>
<td>n.r.</td>
</tr>
<tr>
<td>Toscano and Montgomery, 2009</td>
<td>Qual</td>
<td>USA, GB, AU, IE, CA, CO/multi-centric</td>
<td>Previously infertile women, pregnant via successful IVF</td>
<td>n.r.</td>
<td>n.r.</td>
<td>Online support groups</td>
<td>Provision of information and support</td>
</tr>
<tr>
<td>Tul et al. (2006)</td>
<td>Cross-sect</td>
<td>NL/mono-centric</td>
<td>Patients receiving ART treatment</td>
<td>34.4</td>
<td>51</td>
<td>PHR</td>
<td>Promotion patient empowerment</td>
</tr>
<tr>
<td>Tul et al. (2007)</td>
<td>RCT</td>
<td>NL/mono-centric</td>
<td>Men and women receiving ART treatment</td>
<td>34.6</td>
<td>89 &amp; 91</td>
<td>PHR</td>
<td>Promotion patient empowerment</td>
</tr>
<tr>
<td>Tul et al. (2008)</td>
<td>Cross-sect</td>
<td>NL/mono-centric</td>
<td>Patients receiving ART treatment</td>
<td>n.r.</td>
<td>115</td>
<td>PHR</td>
<td>Promotion patient empowerment</td>
</tr>
</tbody>
</table>

Continued
The interventions used several interactive online activities (the third key component). Most interventions were partially or moderately dynamic; they offered online bulletin boards for interacting with peers, researchers or healthcare professionals (e.g. Himmel et al., 2005; Tuil et al., 2006, 2007, 2008, 2009; Hämmerli et al., 2009; Meneses et al., 2010).

We noted whether the several interventions provided feedback to patients (the fourth key component). Human-supported feedback was mainly from peers (online support groups, e.g. Epstein et al., 2002; Isupova, 2011) or healthcare professionals/therapists (online counseling, e.g. Himmel et al., 2005) and was thus tailored to the patient. This feedback provision could be both synchronous (chat) and asynchronous (online forum). The self-help, web-based, therapeutic interventions included very tailored, automated feedback, which became available after the patient filled out a form or checklist on the website (Cousineau et al., 2008; Sexton et al., 2010). Two web-based, educational interventions did not provide any feedback (Huyghe et al., 2009; Meneses et al., 2010).

### Evaluation of the interventions (RQ 3)

#### Study designs

Of all studies (Table I), seven were qualitative (Malik and Coulson, 2008a, 2008b, 2010a; Steuber and Solomon, 2008; van Selm et al., 2008; Toscano and Montgomery, 2009; Isupova, 2011). Three studies used mixed methods, combining qualitative analysis of online posts and quantitative analysis of a questionnaire (Himmel et al., 2005; Malik and Coulson, 2010b, 2011). Four studies were cross-sectional (Epstein et al., 2002; Tuil et al., 2006, 2008, 2009), and one was a before–after study (Meneses et al., 2010). The remaining five studies were RCTs (Tuil et al., 2007; Cousineau et al., 2008; Hämmerli et al., 2010; Huyghe et al., 2009; Sexton et al., 2010).

#### MRC framework

According to the MRC framework, all the interventions were complex because they consisted of multiple interacting components. Using this framework, we identified, for instance, one study that evaluated the pilot phase (Tuil et al., 2006) and used patients’ experiences and views to improve the intervention before evaluating it with an RCT in the evaluation phase (Tuil et al., 2007). In total, three studies were categorized as being in the pilot phase, 17 were in the evaluation phase, and none were in the development or implementation phase. Some of the studies in the evaluation phase shared some information about the development and briefly mentioned pilot testing the intervention before the final evaluation (Cousineau et al., 2008; Hämmerli et al., 2010; Sexton et al., 2010). However, the development or pilot phase was never the scope of these studies.

#### Process measures: usage characteristics of Internet interventions

The measures evaluated in the studies related to the type of usage of the Internet interventions by means of type of communication (i.e. topics discussed online), dosage of exposure to the intervention and online behaviour based on the monitoring of the automated logging of requested pages.

Seven studies explored the communication that occurred within an online support group between peers (Steuber and Solomon, 2008; Malik and Coulson, 2008a, 2010a, 2010b; Toscano and Montgomery, 2009; Isupova, 2011), within a chat module (Van Selm et al., 2008) or on an expert forum (Himmel et al., 2005) between patients and professionals. Qualitative analysis (both inductive thematic analysis and content analysis) unravelled the topics of patients’ online messages or utterances. These studies had differing focuses. For instance, Malik and Coulson (2008a) concentrated solely on messages posted by men to obtain a better understanding of their specific experiences and needs when facing infertility. Another study found that 58% of the utterances in a private chat room, only accessible for patients under treatment in the same fertility clinic, were about the IVF treatment itself, not the emotional threat of childlessness (van Selm et al., 2008). Himmel et al. (2005) showed that the expert forum provided primarily basic information and explanation, but also independent medical advice (second opinions) as a check or help in decision-making.

One study (Malik and Coulson, 2011) stated patients’ self-reported use of online support groups, in terms of number of hours spent and the number of messages posted, both per week. Six studies looked into the website usage by logging all user-requested pages (Tuil et al., 2007; Cousineau et al., 2008; Tuil et al., 2008; Hämmerli et al., 2010; Tuil et al., 2009; Sexton et al., 2010). Four studies counted each

---

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Study setting</th>
<th>Description study population</th>
<th>Mean age (years)</th>
<th>n</th>
<th>Name of intervention</th>
<th>Aim of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuil et al. (2009)</td>
<td>Cross-sect</td>
<td>NL/mono-centric</td>
<td>Patients receiving ART treatment</td>
<td>n.r.</td>
<td>51</td>
<td>PHR</td>
<td>Promotion patient empowerment</td>
</tr>
<tr>
<td>Van Selm et al. (2008)</td>
<td>Qual</td>
<td>NL/mono-centric</td>
<td>Patients receiving ART treatment</td>
<td>n.r.</td>
<td>22</td>
<td>Chat-module</td>
<td>n.r.</td>
</tr>
</tbody>
</table>

USA, United States of America; RU, Russia; UA, Ukraine; CZ, Czech Republic; DE, Germany; CH, Switzerland; CA, Canada; GB, United Kingdom; NL, Netherlands; AU, Australia; IN, India; ZA, South Africa; IE, Ireland; CO, Columbia; TW, Taiwan; multi-centric, study was performed at more than one fertility clinic; mono-centric = study was performed at one fertility clinic; n.r., not reported; IVF, in vitro fertilization; ART, assisted reproductive techniques, including IVF and ICSI procedures; ART, assisted reproductive technique; Yrs, years; PhR, personal health record.

n = number of patients participating in the study.

*Study design: RCT, randomized controlled trial; Cross-sect, cross-sectional study; Mixed-method, combination of qualitative and quantitative research; Qual, qualitative study.

*Study setting: Country/setting.
<table>
<thead>
<tr>
<th>Study</th>
<th>Type of intervention</th>
<th>Key components of intervention*</th>
<th>Programme content</th>
<th>Multimedia use</th>
<th>Interactive online activities</th>
<th>Feedback support provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cousineau et al. (2008)</td>
<td>Self-help therapeutic intervention</td>
<td>Structured content, based on cognitive behaviour theory</td>
<td>Audio, animations, pictures</td>
<td>Self-assessment checklist</td>
<td>Tailored automated feedback after filling out checklist</td>
<td></td>
</tr>
<tr>
<td>Epstein et al. (2002)</td>
<td>Online support groups</td>
<td>Minimal programme content, based on participants’ utterances</td>
<td>?</td>
<td>Peer support forum</td>
<td>Human support and feedback from peers (asynchronous, text-based)</td>
<td></td>
</tr>
<tr>
<td>Hämmerli et al. (2010)</td>
<td>Human-supported therapeutic intervention</td>
<td>Structured content, based on cognitive behaviour theory</td>
<td>?</td>
<td>Peer support forum and other collaborative elements</td>
<td>Tailored human support and feedback from therapist (text-based)</td>
<td></td>
</tr>
</tbody>
</table>
| Himmel et al. (2005)          | Online counselling          | - Non-active educational content  
- Content based on utterances participants                                                                                               | One format, not specified                                                          | Forum and E-mail                                  | Tailored feedback from infertility experts (asynchronous, text-based)                                |
| Huyghe et al. (2009)          | Education intervention      | Educative content: Generic, Decision aid                                                                                                     | Video vignettes, checklists, animated knowledge test                              | ?                                                | None                                               |                                                                                                          |
| Isupova (2011)                | Online support group        | ?                                                                                                                                             | ?                                                                               | Peer support forum                               | Human support and/or feedback from peers                                                           |
| Malik and Coulson (2008a)     | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | Peer support forum                               | Human support and/or feedback from peers                                                           |
| Malik and Coulson (2008b)     | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | ?                                                | Human support and/or feedback from peers                                                           |
| Malik and Coulson (2010a)     | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | Seven bulletin sub-boards                         | Human support and/or feedback from peers                                                           |
| Malik and Coulson (2010b)     | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | ?                                                | Human support and/or feedback from peers                                                           |
| Malik and Coulson (2011)      | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | ?                                                                               | Peer support forum                               | Human support and/or feedback from peers                                                           |
| Meneses et al. (2010)         | Education intervention      | Non-active, generic educational content                                                                                                       | ?                                                                               | Bulletin board for peers, interaction module with researchers | None                                               |                                                                                                          |
| Sexton et al. (2010)          | Self-help therapeutic intervention | Structured content, based on cognitive behaviour theory                                                                                       | Vignettes, video demonstrations of progressive muscle relaxation, PDFs             | No interactive activities offered                 | Tailored automated feedback                                                                       |
| Steuber and Solomon (2008)    | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | ?                                                | Human support and/or feedback from peers                                                           |
| Toscano (2009)                | Online support groups       | Minimal programme content, based on participants’ utterances                                                                                   | One format, not specified                                                          | ?                                                | ?                                                  |                                                                                                          |
- Personal information (PHR)                                                                                                                      | Prognosis calculator, day planner, PDFs, PHR, pictures, video                     | Peer forum, expert forum, chat-module             | Tailored human-supported feedback and support                                                     |
participant’s website visits (median of 4 times; Cousins et al., 2008) and page views, varying from an average number of 1–318 pageviews per content type per patient (Tuil et al., 2007, 2008, 2009). Two studies logged the number of sessions of the online programme completed per patient (Cousins et al. 2008; Sexton et al., 2010). In fact, in the Sexton et al.’s study (2010), all participants used the introduction section, 76% the behavioural section, 43% used the cognitive restructuring content, 48% accessed the ‘other coping skills’ page and 33% elected to use the personalized coping plan. Cousins et al. (2008) also reported the participant’s median time spent on the site, which was 63 min. However, these data were briefly mentioned in the several papers. Tuil et al. more extensively evaluated the type of PHR usage by participants in two papers which were part of the same research project. In the first paper (Tuil et al., 2009), the researchers attempted to extract usage differences during the various stages of IVF treatment by looking at the number of page views of the website’s functions for each treatment phase. The number of page views per couple ranged from 24 to 1951 over the 70-day study period. The intensity of use varied significantly. There was a peak in the number of page views during the laboratory stage in which oocyte retrieval and embryo transfer take place (Tuil et al., 2009).

The other paper about this research project aimed at evaluating the online behaviour of women undergoing their first IVF treatment cycle based on the number of page views per patient (Tuil et al., 2008). Three styles of online behaviour were discovered: ‘Individual information style’ including navigating primarily to personal information, ‘Generic information style’ involving navigating to areas with general information and ‘Communication style’ including navigating to the forum and chat module, or a combination of these styles (Tuil et al., 2008).

Outcome measures
As Table III shows, several patient outcome measures were investigated, such as knowledge, self-efficacy, mental health and pregnancy rate. Both self-made (n = 14) and established, validated (n = 22) measurement instruments were used for assessing the various outcomes, as well as infertility-specific (n = 17) and generic (n = 19) instruments. Social and emotional support was primarily qualitatively studied. A combination of several standardized and validated questionnaires, that is, self-efficacy, actual and perceived knowledge, and patient involvement in the decision process, was used to determine patient empowerment, which was considered a multidimensional concept. Five studies measured outcomes at the overall programme level, such as acceptability, usefulness and satisfaction with the programme (Himmel et al., 2005; Tuil et al., 2006; Cousins et al., 2008; Hämmerle et al., 2010; Malik and Coulson, 2011).

Control groups in RCTs
In four RCTs, the control group consisted of patients placed on a waiting list for their next treatment cycle (Tuil et al., 2007; Cousins et al., 2008; Hämmerle et al., 2010; Sexton et al., 2010). They were all granted access to the online programme after the study period. One study provided no information about the control group (Huysge et al., 2009).

Attrition rates
Attrition rates varied from 16 to 68% among the studies that reported the number of patients who completed the online intervention. Completion declined over time as patients continued in these programmes.

Study quality
The most right column of Table III presents the results of the quality assessment.

We used the Cochrane Risk of Bias tool (Higgins and Altman, 2008) to appraise the five RCTs in this review for study quality. Cousins et al.’s (2008) study showed high quality, meeting most of the criteria resulting in low risk of bias. Huysge et al.’s (2009) study lacked much information about how it was conducted. Overall, the studies addressed the scientific background and study objectives. However, the studies did not adequately describe the trial design and allocation procedure. Only Cousins et al. (2008) blinded the participants and described the randomization type. None of the studies determined sample sizes before commencement of the study. Moreover, attrition rates were generally high, and exposure rates to the intervention were rarely adequately described. These factors increase the likelihood of bias.

We used the NOS checklist (Wells et al., 2011) to critically appraise the five observational studies (four cross-sectional studies and one before–after study). Three studies (Himmel et al., 2005; Malik and Coulson, 2010b, 2011) used mixed methods (a combination of a survey and qualitative research); the NOS checklist was used to assess the quantitative part. The quality of most studies was moderate. However, eligibility criteria, potential bias and determination of sample sizes were not adequately addressed. Information about non-participants or participants with missing data was also lacking in most studies.
### Table III: Evaluation methodology per study.

<table>
<thead>
<tr>
<th>Study</th>
<th>Research aim</th>
<th>Recruitment patients</th>
<th>Design and Methods</th>
<th>Primary and secondary outcome measures</th>
<th>Exposure dosage&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Attrition rate&lt;sup&gt;c&lt;/sup&gt;</th>
<th>MRC framework&lt;sup&gt;d&lt;/sup&gt;</th>
<th>Study quality</th>
</tr>
</thead>
</table>
| Cousineau et al. (2008) | Effectiveness of online program on outcome measures | Offline | • RCT  
• Questionnaires at baseline and 1 month follow-up  
• Control group without access to program  
• Website usage tracking | - Infertility-related stress  
- Self-efficacy  
- Ways of coping  
- Marital cohesion  
- Perceived spousal support  
- Decisional conflict  
- Satisfaction with program  
- Website usage | 4 visits — median = 63 min per visit | 64% | Evaluation phase | High quality/low risk of bias<sup>e</sup> |
| Epstein et al. (2002) | Comparison between OOs and AOs on emotional wellbeing | Online | • Cross-sectional  
• Self-made online survey | - Internet activity  
- Perceived consequences  
- Self-assessment coping  
- Social and emotional wellbeing | n.r. | n.a. | Evaluation phase | Moderate<sup>f</sup> |
| Hämmerli et al. (2010) | Efficacy on mental health and pregnancy rate | Offline and Online | • RCT  
• Paper questionnaire at baseline, after 2 and 5 months follow-up  
• Waiting-list control group | - Depression  
- Anxiety  
- Infertility related distress  
- Pregnancy rate  
- Acceptance  
- Usage | n.r. | 54% | Evaluation phase | High quality/low risk of bias<sup>e</sup> |
| Himmel et al. (2005) | Needs, expectations, experience and satisfaction with expert forum | Online | • Mixed-method  
• Online survey  
• Content analysis of requests | - Expectations and needs  
- Experience and satisfaction  
- Content requests | n.r. | n.a. | Evaluation phase | Moderate<sup>f</sup>/moderate<sup>g</sup> |
| Huyghe et al. (2009) | Feasibility and efficacy of intervention | Offline | • RCT  
• Questionnaires before and after viewing program  
• Control group not specified | - Knowledge  
- Decisional conflict | n.r. | n.r. | Pilot phase | Moderate quality/unclear risk of bias<sup>e</sup> |
| Isupova (2011) | Communication within virtual community | Online | • Qualitative study  
• Forum messages analysed using Netnography method | - Experience of being infertile and using the forum | n.r. | n.a. | Evaluation phase | High<sup>f</sup> |
| Malik and Coulson (2008a) | Communication within online support group | Online | • Qualitative study  
• Messages analysed using inductive thematic analysis procedure | - Experiences and needs of infertile men | n.r. | n.a. | Evaluation phase | High<sup>f</sup> |
<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Title</th>
<th>Setting</th>
<th>Methods</th>
<th>Findings</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malik and Coulson (2008b)</td>
<td>Online experiences of individuals accessing infertility support groups</td>
<td>Offline</td>
<td>Qualitative study, Online questionnaire with open-ended questions, Inductive thematic analysis of answers</td>
<td>Perceived (dis)advantages, Impact on coping, Impact on marital relationship</td>
<td>Evaluation phase (Moderate)</td>
</tr>
<tr>
<td>Malik and Coulson (2010a)</td>
<td>Communication within online support group</td>
<td>Online</td>
<td>Qualitative study, Content analysis messages according theoretical framework self-help mechanisms</td>
<td>Self-help mechanisms</td>
<td>Evaluation phase (Low)</td>
</tr>
<tr>
<td>Malik and Coulson (2010b)</td>
<td>Perceived disadvantages of online infertility support communities</td>
<td>Online</td>
<td>Mixed-method, Online questionnaire, Responses to open-ended questions analysed with inductive thematic analysis</td>
<td>Perceived disadvantages</td>
<td>Evaluation phase (Moderate/Moderate)</td>
</tr>
<tr>
<td>Malik and Coulson (2011)</td>
<td>Characteristics, motives and experiences of lurkers of online infertility support group</td>
<td>Online</td>
<td>Mixed-method, Online survey, Content analysis of answers to open-ended questions</td>
<td>Use of support group, Satisfaction with group, Perceived (dis)advantages, Feelings of loneliness, Perceived social support, Marital satisfaction, Infertility-related stress</td>
<td>Evaluation phase (Moderate)</td>
</tr>
<tr>
<td>Meneses et al. (2010)</td>
<td>Changes in mood, functioning, knowledge</td>
<td>Offline</td>
<td>Before-after study, Questionnaires at baseline and 6 months follow-up</td>
<td>Health status, Knowledge of fertility, Mood states</td>
<td>Evaluation phase (Moderate)</td>
</tr>
<tr>
<td>Sexton et al. (2010)</td>
<td>Feasibility and efficacy of intervention on outcomes</td>
<td>Offline</td>
<td>RCT, Questionnaires at baseline and 2 weeks follow-up, Waiting-list control group, Computer logs</td>
<td>Depression, General stress, Fertility stress, Website usage</td>
<td>Pilot phase (Moderate quality/unclear risk of bias)</td>
</tr>
<tr>
<td>Steuber and Solomon (2008)</td>
<td>Communication in online venues</td>
<td>Online</td>
<td>Qualitative study, Discourse analysis of messages posted</td>
<td>Effect of infertility on marital relationships</td>
<td>Evaluation phase (High)</td>
</tr>
<tr>
<td>Toscano and Montgomery (2009)</td>
<td>Communication within online communities</td>
<td>Online</td>
<td>Qualitative study, Phenomenological analysis of online posts</td>
<td>Psychological, emotional, and physical health</td>
<td>Evaluation phase (High)</td>
</tr>
<tr>
<td>Tuil et al. (2006)</td>
<td>Development, implementation and patient-perceived usefulness</td>
<td>Offline</td>
<td>Cross-sectional study, Evaluation experts and pts, Pilot evaluation with 5 pts, Final questionnaire study</td>
<td>Evaluation content of PHR, Usefulness</td>
<td>Pilot phase (High)</td>
</tr>
</tbody>
</table>

Continued
<table>
<thead>
<tr>
<th>Study</th>
<th>Research aim</th>
<th>Recruitment patients</th>
<th>Design and Methods</th>
<th>Primary and secondary outcome measures</th>
<th>Exposure dosage</th>
<th>Attrition rate</th>
<th>MRC framework</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuil et al. (2007)</td>
<td>Effectiveness on patient empowerment</td>
<td>Offline</td>
<td>RCT, Questionnaire at start and end of first IVF cycle, Waiting-list control group, Counting page views</td>
<td>- Self-efficacy, Knowledge about IVF, Patient’s involvement decision process, Patient satisfaction, Illness cognition, Social Support, Anxiety, Website usage</td>
<td>n.r.</td>
<td>16%</td>
<td>Evaluation</td>
<td>Moderate quality/low risk of bias</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>phase</td>
<td></td>
</tr>
<tr>
<td>Tuil et al. (2008)</td>
<td>Online behaviour of patient couples</td>
<td>Offline</td>
<td>Cross-sectional study, Logging of all page views</td>
<td>- Behavioural styles</td>
<td>n.r.</td>
<td>n.a.</td>
<td>Evaluation</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>phase</td>
<td></td>
</tr>
<tr>
<td>Tuil et al. (2009)</td>
<td>Changing information and communication needs during stages of treatment</td>
<td>Offline</td>
<td>Cross-sectional study, Automated logging of all requested pages</td>
<td>- Usage (type and intensity) of the PHR, Experience IVF treatment</td>
<td>Median = 421 page views per couple</td>
<td>4%</td>
<td>Evaluation</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>phase</td>
<td></td>
</tr>
<tr>
<td>Van Selm (2008)</td>
<td>Communication between patients and professionals</td>
<td>Online</td>
<td>Qualitative study, Content analysis of utterances in chat sessions</td>
<td></td>
<td>n.r.</td>
<td>n.a.</td>
<td>Evaluation</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

n.r., not reported; n.a., not applicable; RCT, randomized controlled trial; PHR, personal health record; pts, patients; OOs = only outletters; persons for whom the Internet is the only outlet for talking about their fertility problems; AOs = additional outletters; persons for whom the Internet is an additional outlet for talking about their fertility problems.

Phenomenology = turning to a phenomenon, investigating an experience as it is lived, reflecting on the essential themes, describing the phenomenon through writing and rewriting, maintaining an oriented relation to the phenomenon, and balancing the research context by considering the parts and the whole.

Lurkers = Internet users who read messages posted by others on electronic spaces, without also posting their own messages or in any way signalling their observation.

*offline = patients were recruited in an offline setting; online = patients were recruited from the online public domain of the Internet.

1Exposure dosage.
2Attrition rate = moet voldaan hebben aan volledige programma zoals door researchers gesteld.
3MRC framework: development phase, pilot phase, evaluation phase, implementation phase.
4Methodological quality assessed using the Cochrane Risk of Bias checklist for RCTs.
5Methodological quality assessed using the New-Castle Ottawa Scale for observational studies.
6Methodological quality assessed using the checklist from the National CASP Collaboration for Qualitative Methodologies.
Seven studies performed qualitative research. We used the checklist for qualitative research to appraise their quality (National CASP collaboration for qualitative methodologies, 2006). We appraised the qualitative parts of the mixed-method studies of Himmel et al. (2005) and Malik and Coulson (2010b) using the same checklist. The qualitative approach was appropriate for all the studies, the findings were clearly stated, and the studies’ values were addressed. However, almost none of the studies adequately considered the relationship between the researcher and the participants, which is important in qualitative research. Further, most of these studies did not report ethical issues.

**Discussion**

This scoping review shows that several categories of patient-focused Internet-based interventions in fertility care are now being applied to provide support and education and promote mental health. With respect to the composition of these interventions, most interventions consist of a moderate number of different multimedia formats or interactive components. Furthermore, the majority of the interventions assessed effectiveness and were consequently identified as studies in the evaluation phase according the MRC Framework. Our scoping exercise enabled us to map the research field in the current state and identify gaps for future research and clinical practice, which we now discuss.

With respect to the categorization of Internet interventions within fertility care (RQ 1), five different main categories of Internet interventions could be identified addressing aims, such as information provision, emotional support (both from peers and healthcare professionals), patient empowerment and mental health promotion. This is in line with eHealth-related review studies in other fields of medicine (e.g. Gentles et al., 2010; Samoocha et al., 2010). However, when comparing to these other medical fields, for the application of eHealth within the field of reproductive medicine, topics related to prevention of infertility, ending infertility treatment, seeking timely medical advice or life after infertility could be particularly relevant. For instance, patients’ fertility awareness or personal risk perception about lifestyle habits that might jeopardize fertility has gained attention within the scientific infertility community in recent years (Homan et al., 2007; Bunting and Boivin, 2008, 2010). Education about issues associated with fertility self-care, such as the influence of age, smoking or obesity on one’s fertility potential (Homan et al., 2007; Bunting and Boivin, 2008, 2010) is needed. A web-based educational intervention could be promising in this context, just as the educational tool for breast-cancer survivors threatened with infertility (Meneses et al., 2010) filled the gap left by their oncologists’ lack of the provision of information about reproductive health. In this respect, we could also learn from diabetes care, for instance, that the development of a web-based lifestyle coach for treating obesity (Tate et al., 2001) or helping people to stop smoking could be effective in preventing infertility (Van den Berg et al., 2007; Norman et al., 2008; Simkin-Silverman et al., 2011). Interventions aimed at lifestyle changes that contribute to improved fecundity may thus be particularly promising and beneficial, especially when they are delivered via the Internet (Michie et al., 2009; Brouwer et al., 2011).

The Internet interventions in this scoping review were exploited primarily in the USA and western European countries, which is not surprising because these countries are known for their good Internet broadband penetration. However, in comparing these countries to others (e.g. those of eastern Europe), we must be aware of the possible threat of the ‘digital divide’. This expression refers to the gap between people with effective access to the Internet and those with limited access or no access at all (Wyatt et al., 2005; Gorini et al., 2008). In this context, we must bear in mind that Internet interventions are only applicable when the Internet is broadly and freely accessible to the citizens, and preferably government encouraged. This may be a task for European organizations such as the European Society for Human Reproduction and Embryology (ESHRE). Furthermore, it should be noted that development (or translation) costs of Internet interventions are significant barriers for the implementation of eHealth in non-Western and low resource countries.

It is remarkable that some interventions were specifically or also aimed at men, because the psychological impact of infertility on men has not always been included in infertility-care services (Malik and Coulson, 2008a). Although infertility is a couple condition male wellbeing only began to receive attention in recent years (Schanz et al., 2005; Chachamovich et al., 2010). In this perspective, Internet infertility interventions are positive in acknowledging the man as a ‘patient’ instead of as the ‘partner of a patient’.

Regarding RQ 2, we were interested in the detailed composition of the interventions that we encountered in the literature. Choosing the appropriate ‘ingredients’ for an Internet intervention aimed at a specific medical problem is indispensable. Barak et al.’s (2009) taxonomy appeared to be applicable for consistently describing the components of each intervention. The use of different multimedia formats and interactive elements in the web-based interventions in this review was modest. Only a few of the Internet-based interventions made use of a great variety of multimedia formats. However, most contained plain text and one or two additional formats, such as pictures. Although the benefit of incorporating a variety of multimedia formats within a web-based intervention has yet to be established, it is generally assumed that a greater variety of multimedia formats is advantageous and that patients prefer it (Ritterband et al., 2006). Such variety makes the intervention more dynamic and engaging (Kerr et al., 2006; Barak et al., 2009). This also accounts for the use of interactive elements within the intervention, such as online forums, to encourage patients to participate more actively. These dynamic elements give patients a chance to make care more personalized (Potts, 2006; Swan, 2009). This might facilitate a greater sense of connectedness to the online programme (Stevens et al., 2008; Barak et al., 2009). Interactivity, participation and engagement relate closely to the concept of Web 2.0, which has gained popularity worldwide and is characterized by participation, collaboration and social networking on the Internet. This phenomenon has also extended to healthcare in recent years, and is known as Health 2.0 (Eysenbach, 2008; Van de Belt et al., 2010). Especially the use of social networking applications, which involves modelling relationships between users (both patients and healthcare professionals), might be very interesting. Wikis, blogs and podcasts can add new collaborative dimensions to the types of interventions we have discussed (Boulos et al., 2006; Richardson et al., 2010). Patients become more socially engaged when the community feeling of the participants increases. Eventually, this may also improve adherence in Internet-based interventions (Richardson et al., 2010).
The last RQ 3 of our scoping review related to the methods that have been applied to evaluate these interventions. As already shown, Internet interventions are complex since they are composed of multiple interacting components (Gentles et al., 2010). This makes the interventions dynamic. Furthermore, Internet interventions can change over time, which provides evaluation difficulties, such as the difficulty of standardizing the design and delivery of Internet-based interventions and their sensitivity to cultural or organizational context (Campbell et al., 2007; Baker et al., 2010). This is why an evaluation of complex interventions often contains a recommendation for adopting a continuous evaluation design to take these changing processes into account (Campbell et al., 2007; Shiel et al., 2008). The MRC framework defined several phases in which complex interventions can be evaluated: the development phase, pilot and feasibility phase, evaluation phase and implementation phase (Campbell et al., 2007). This categorization facilitates collecting reasonable evidence for the effective application of an intervention. It was remarkable that most studies in this review were studies in the evaluation phase (assessing effects of interventions) according to the MRC framework. Consequently, knowledge about the underlying mechanisms of these interventions is lacking (development and/or pilot phase). Such mechanisms may influence outcomes or descriptions of the constant and variable components of the intervention. Thus, to test effectiveness, we suggest using phased approaches to the development and evaluation of Internet-based interventions, starting with a pilot study, moving on to an exploratory evaluation, and then a definitive evaluation (assessing effectiveness).

There are many study designs to choose from, and which design suits the research question most adequately should be carefully considered for each phase (Campbell et al., 2007). The studies included in this review applied different study designs and used qualitative, quantitative or mixed methods. The value of different types of study design should not be underestimated in research into Internet interventions (Shrier et al., 2007). RCTs are widely accepted as the most reliable method of determining effectiveness, especially when a single intervention, such as a drug treatment, is being evaluated. However, this becomes rather challenging in complex interventions because the different components may be difficult to specify or to control (Hawe et al., 2004; Campbell et al., 2007). Another specific need of RCTs is to test for intended outcomes. However, in the young research field of Internet interventions, we are not yet sure what the most appropriate outcome measures will be. Because the outcomes of complex interventions are generally not straightforward (Campbell et al., 2007), it might be interesting to explore and discover unexpected effects first. Rigorously performed observational studies can generally aid in clinical reasoning and detecting these unexpected outcomes (Shrier et al., 2007; Vandebroucke, 2008, 2009). In this respect, qualitative research is very valuable as well (Gustafson and Wyatt, 2004) because it can provide rich descriptions of complex phenomena, track unique or unexpected events, and shed light on patient experience and interpretation (Sofaer, 1999; Pope et al., 2002). Himmel et al.’s (2005) study provides an example of the value of studies with a mixed-method design, in which qualitative data merge with quantitative data to provide more depth in understanding the results. By supplementing quantitative evaluations with qualitative studies, we can explore what users of an Internet-based intervention feel when they use the technology and how it affects their lives (Gustafson and Wyatt, 2004).

These considerations also touch on the high value of a process evaluation of a complex Internet intervention. This involves mapping the processes that might be relevant for the eventual intervention outcome and involves (i) a detailed description of the intervention, (ii) a check of the actual exposure to the intervention and (iii) a description of the experience of those exposed. It can provide insight into the ‘mechanisms and processes responsible for the result and the variation in results in the target group’ (Hulscher et al., 2003; Campbell et al., 2007). In our scoping exercise, it was perplexing that usage behaviour (e.g. exposure dosage) or other intermediate measures that could influence the outcome were not consistently reported for all interventions. Investigating the exposure to Internet interventions is especially important because evidence from other research indicates that exposure rates are generally low, which limits the potential impact of these interventions (Evers et al., 2005; Stopponi et al., 2009; Chiu and Eysenbach, 2010; Van ’t Riet et al., 2010). In this review, Cousineau et al.’s (2008) study underpinned these facts. Their exploratory analysis showed that, among the intervention participants, the women who spent more time on the site had lower stress scores, for instance.

The threat of high attrition rates also requires some discussion, as these rates appeared to be high in the studies in this review. Attrition involves the phenomenon of participants quitting and/or being lost to follow-up; attrition is one of the fundamental characteristics and methodological challenges in the evaluation of Internet applications (Eysenbach, 2005; Nijland et al., 2009). Reports of only 1% of participants who completed a programme are not uncommon, and consequently, this has great influence on the interpretation of results (Eysenbach, 2005). Particularly in reproductive medicine, the attrition rate may already be substantial as patients become pregnant as time elapses or drop out of treatment, primarily because of the high emotional impacts of infertility and the accompanying treatment (Verhaak et al., 2007; Verberg et al., 2008; Brandes et al. 2009). Therefore, it is important, especially in fertility care, to minimize the attrition that results from intervention-related causes. One possible method to overcome this problem is to design the web-based interventions in a user-centred approach and evaluate this development phase as we have already recommended. Including patients as an integral part of the design and development process and team (Spool et al., 1999; Atkinson et al., 2009a; Murray et al., 2010) makes the intervention more amenable to adherence and might also guarantee its sustainability (Parasuraman, 2000). Another method would be to explore barriers to participation in a pilot study after which the intervention and its implementation can be optimized (i.e. Phase I study in MRC framework; Campbell et al., 2007).

We need to consider some limitations and strengths of this scoping review. First, the risk of publication bias should be taken into account, which could mean that only studies showing a beneficial effect of Internet-based interventions have been published.

Secondly, we included only studies of Internet interventions that focused on patients. However, the Internet could also offer many educational or collaborative opportunities for healthcare professionals or researchers. For instance, virtual communities enable healthcare providers to interact and work on cases as members of ‘virtual teams’ to improve collaboration (Boulos et al., 2006; Schleyer et al., 2008; Archambault et al., 2010; Varga-Atkins et al., 2010). The Internet can be used as a vehicle for educational purposes, which could be particularly
interesting in rapidly evolving fields such as reproductive medicine (Whittington et al., 2004). A web-based training programme for delivering reproductive medicine education has been valued positively because of the reduction of geographical restrictions and the multidisciplinary and international aspects (Jenkins et al., 2001; Whittington et al., 2004). In future research activities, it would be valuable to explore these educational and collaborative possibilities for professionals in fertility care.

Thirdly, we restricted ourselves to electronic health databases to identify relevant scientific literature, leaving out, for instance, the grey literature. However, ‘e-Health runs faster than e-Health research’ (Potts, 2006), and we may have missed scientifically unevaluated Internet interventions published in grey literature.

A strength of this study is the fact that we performed a scoping review. Scoping reviews are gaining ground and becoming more popular in complex research areas, such as e-Health (Gentes et al., 2010), particularly when the subject has not yet been comprehensively reviewed (Arksey and O’Malley, 2005). The use of a scoping review certainly applies for the broad purpose of the present study (to map the field of Internet interventions within reproductive medicine). A scoping review can be used as the first step in reviewing the literature of a novel subject within care. Furthermore, although we did not restrict ourselves by choosing a narrower focus and answering a more specific research question, this review identified gaps in research knowledge and provides directions for future systematic reviews in this field.

Conclusions
This scoping review study provides a map of the health literature about how Internet-based interventions are being used and studied to facilitate care for patients with infertility. First, five different categories of Internet interventions have been repeatedly applied to provide support and information, promote mental health, and empower patients. Secondly, with regard to the composition, these interventions could gain from adding more interactive elements. Thirdly, almost none of the interventions were evaluated following a phased approach to development, feasibility, evaluation and implementation. This puts greater emphasis on using methodological standards such as the MRC guidance for complex interventions to produce more rigorous evaluations of Internet interventions in the future. This review will be especially helpful to those deciding where further development or research into patient-focused Internet-based interventions in fertility-care practice may be warranted.

Supplementary data
Supplementary data are available at http://humupd.oxfordjournals.org/.

Authors’ roles
J.W.M.A.: designed the study, searched the literature, extracted and interpreted the data and drafted the paper. P.H. and M.J.F.: analysed and interpreted the data and drafted the paper. M.J.F. also contributed to designing the study. W.L.D.M.N. and W.S.T. contributed to the interpretation of data and critically revised important intellectual content. J.A.M.K. designed the study, interpreted the data, and critically revised important intellectual content. All authors gave their final approval of the version to be published.

Funding
This work was funded by the Department of Obstetrics and Gynaecology of the Radboud University Nijmegen Medical Centre, The Netherlands.

References
Brown G. The Internet is as vital as water and gas. The Times, June 16, 2009.
Chiu TML, Eysenbach G. Stages of use: consideration, initiation, utilization and approval of the version to be published.
Deddicating E, van Doorn R, Winkler L, Reis R. How will e-Health affect patient participation in the clinic? A review of e-Health studies and the current


Sullivan E, van der Poel S. The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary on ART terminology, 2009.


