

# Influence of clinical history and demographic factors on infertility patients' willingness to participate in clinical research

Megan L. McCain, Valerie A. Flores, Carol A. Wheeler,  
Vrishali Lopes, Kristen A. Matteson

## ABSTRACT

**Aims:** To identify factors associated with patient willingness to participate in clinical research within a population of infertility patients. **Methods:** We performed a cross sectional survey of women undergoing evaluation or treatment of infertility at The Center for Reproduction and Infertility at Women and Infants Hospital between August 2010 and April 2011. The survey questions included information on demographic factors, infertility history and treatments, knowledge about clinical research and willingness to participate in research. **Results:** Questionnaires were distributed to 272 women and 213 (78%) participated. Thirty three percent of participants (n=72) indicated that they would

be willing to participate in clinical research, 38% (n=81) were uncertain and 28% (n=60) indicated that they would not consider participation in clinical research. Compared to patients with less than six months of infertility treatments, patients with a history of more than six months of infertility treatment were at increased odds for reporting willingness to participate in research [OR 3.86 95% CI (1.3-11)]. Similarly, patients with previous participation in clinical research were more likely to report willingness to participate in clinical research [OR 8.29 95% CI (2.1 - 31.9)]. These associations were still present when controlled for other factors and potential confounders.

**Conclusion:** Factors associated with willingness to participate in clinical research included a history of more than six months of infertility treatment and previous participation in clinical research. Understanding factors associated with patient willingness to enter infertility research may help assist clinical trial recruitment strategies.

**Keywords:** Clinical research, Infertility patients, Participation

## How to cite this article

McCain ML, Flores VA, Wheeler CA, Lopes V, Matteson KA. Influence of clinical history and demographic factors on infertility patients' willingness to participate in clinical research. *Edorium J Clin Res* 2015;1:1-7.

Article ID: 100001Co8MM2015

\*\*\*\*\*

doi:10.5348/Co8-2015-1-OA-1

Megan L. McCain<sup>1</sup>, Valerie A. Flores<sup>1</sup>, Carol A. Wheeler<sup>2</sup>, Vrishali Lopes<sup>3</sup>, Kristen A. Matteson<sup>4</sup>

**Affiliations:** <sup>1</sup>MD, Resident, Department of Obstetrics & Gynecology, Women & Infants Hospital of Rhode Island, Providence, RI, USA; <sup>2</sup>MD, Associate Professor, Department of Obstetrics & Gynecology, Women & Infants Hospital of Rhode Island, Providence, RI, USA; <sup>3</sup>MS, Database Administrator, Division of Research, Women & Infants Hospital of Rhode Island, Providence, RI, USA.; <sup>4</sup>MD, MPH, Interim Director, Division of Research, Associate Professor of Obstetrics and Gynecology, Department of Obstetrics and Gynecology, Women & Infants Hospital 101 Dudley Street, Providence, Rhode Island, USA.

**Corresponding Author:** Kristen A. Matteson, MD, MPH, Interim Director, Division of Research, Associate Professor of Obstetrics and Gynecology, Department of Obstetrics and Gynecology, Women & Infants Hospital, 101 Dudley Street, Providence, Rhode Island 02905, USA; Ph: +1 401-274-1100 x 48562, +1 401-276-7871; Email: kmatteson@wihri.org

Received: 13 February 2015

Accepted: 20 April 2015

Published: 02 July 2015

## INTRODUCTION

The evaluation and medical treatment of infertile couples has changed rapidly over the last 30 years. Delivery of evidence-based infertility care is essential for optimizing outcomes for this population of patients. However, engagement and recruitment of patients seeking infertility treatment for clinical research studies is challenging. This poses a problem for generating an evidence base for infertility care that keeps pace with the expectations for evidence based treatment, new technologies, new protocols, and new medications. Although studies have shown that most patients, including patients seeking evaluation for infertility, express overwhelming positive attitudes towards clinical research [1-4], enrollment of patients in clinical research is generally suboptimal. This commonly causes studies to close before enrollment is full, leading to inadequate sample sizes to answer relevant clinical questions and increased potential for bias [5].

Barriers to study enrollment in clinical trials have been evaluated in subspecialty fields such as oncology or cardiology [4] and suggested that patient concerns regarding loss of dignity, concerns about receiving a placebo treatment, and lower quality of life as a research participant [6] are the main patient-level barriers for research participation. However, barriers to study enrollment may be different for different study populations. In the field of reproductive medicine, studies that focused on the donation of oocytes and embryos for research have suggested that research knowledge, stage of treatment, and attitudes towards oocytes/embryos may influence research participation. However, studies are limited and more research is needed specifically for women undergoing treatments for infertility [7-11].

Evidence-based infertility treatment can only be developed if patients are willing to participate in clinical research. Understanding infertility patient attitudes about clinical research and barriers to participation may assist in the development of strategies to improve patient recruitment into research studies. The purpose of this study was to investigate the overall willingness of infertility patients to participate in clinical research and identify the factors that affect reported willingness to participate. We also investigated potential barriers of participation and potential recruitment strategies to overcome those barriers.

## MATERIALS AND METHODS

We performed a cross sectional survey of women undergoing evaluation or treatment of infertility at The Center for Reproduction and Infertility at Women and Infants Hospital between August 2010 and April 2011. The Women and Infants institutional review board approved the study.

The anonymous survey was distributed to patients

when they registered for a new or revisit office appointment for evaluation or treatment for infertility. Patients were excluded (not given the survey) if they stated they were unable to read English, unable to complete the questionnaire, or unwilling to complete the questionnaire. The 24 survey questions included information on demographic factors, infertility history and treatments, knowledge about clinical research and willingness to participate in research. Questions on willingness to participate in clinical research were developed utilizing a previously published study conducted with oncology patients at our institution [6]. The survey took approximately 10 minutes for participants to complete. After completion of the survey, patients placed the survey in a locked box in the office. Survey data were collected and entered into an electronic study database.

Our independent variable, self-reported length of infertility, was determined by the initial survey question, "How long have you been trying to become pregnant?" Participants were asked to check the box indicating the length of time they had been attempting pregnancy, which included six months to one year intervals. Our outcome variable, willingness to participate, was determined by the survey question, "Would you be willing to participate in infertility research in the future?" Survey participants were asked to check a box indicating yes, no or unsure. A series of questions about clinical research were also asked to determine participant familiarity and knowledge with clinical research [6].

We hypothesized that length of self-reported infertility was associated with willingness to participate in clinical research. To determine the sample size needed for our study, we set our alpha at 0.05 and our power at 80%. Our primary independent variable was duration of infertility. In order to determine an absolute difference of 20% in willingness to participate between patients with different durations of infertility, we determined we needed to obtain data from 186 participants. To account for the possibility that 10% of patients would have missing data on the primary outcome, we needed completed surveys from at least 205 participants.

Groups were compared using chi-square or Fisher's exact test for categorical variables. Continuous variables were compared using *t*-test or ANOVA. The  $p < 0.5$  was considered statistically significant. To evaluate factors associated with willingness to participate in clinical research while controlling for potential confounders, multivariable logistic regression was used to calculate odds ratios with 95% confidence intervals. All statistical analyses were performed by SAS version 9.2 software.

## RESULTS

Two hundred seventy-two surveys were distributed and 213 were returned with responses (response rate=78%). The median age of participants was 35 years old

(range 21–45 years). The majority of participants were married/in a domestic partnership/engaged (97.1%), White non-Hispanic (84.4%), had private insurance (98.1%) and received some level of college education or higher (95.8%) (Table 1). Seventeen percent of respondents had previously participated in clinical research (n=35).

Table 1: Participant Characteristics (n=213)

| Characteristic                                 | n ( column %) <sup>a</sup> |
|--|----------------------------|
| Age (in years)                                 |                            |
| Mean (SD)                                      | 34.7 (4.8)                 |
| Median (range)                                 | 35 (21-45)                 |
| Marital status                                 |                            |
| Single/separated/divorced                      | 6 (2.9)                    |
| Married/domestic partner/engaged               | 207 (97.1)                 |
| Race/ethnicity                                 |                            |
| Hispanic or Latino                             | 11 (5.2)                   |
| White, Non Hispanic                            | 179 (84.4)                 |
| Black or African American, Non Hispanic        | 8 (3.8)                    |
| Asian  | 7 (3.3)                    |
| Other  | 7 (3.3)                    |
| Medical insurance                              |                            |
| Private  | 207 (98.1)                 |
| No insurance/self pay                          | 1 (0.5)                    |
| Other  | 3 (1.4)                    |
| Education level                                |                            |
| High school                                    | 9 (4.3)                    |
| Some college                                   | 50 (23.6)                  |
| Completed 4 years of college                   | 74 (34.9)                  |
| Graduate of professional school                | 79 (37.3)                  |
| Patient report of duration of infertility      |                            |
| Less than 6 months                             | 15 (7.0)                   |
| 6 months or more <1 year                       | 20 (9.4)                   |
| 1 year or more but less than 18 months         | 50 (23.5)                  |
| 18 months or more but less than 2 yrs          | 32 (15.0)                  |
| 2 or more years but less than 3 yrs            | 34 (16.0)                  |
| 3 or more years but less than 4 yrs            | 25 (11.7)                  |
| 4 years or greater                             | 37 (17.4)                  |
| Duration of Infertility Treatment <sup>b</sup> |                            |
| < 6 months                                     | 63 (41.5)                  |
| ≥ 6 months                                     | 89 (58.5)                  |
| Prior Fertility Treatments <sup>b</sup>        |                            |
| Clomiphene citrate                             | 118 (76.1)                 |
| Donor Eggs                                     | 2 (1.3)                    |
| Donor Sperm                                    | 7 (4.5)                    |
| Gonadotropins                                  | 58 (37.4)                  |
| IUI  | 83 (53.6)                  |
| IVF  | 70 (45.2)                  |
| Letrozole                                      | 13 (8.4)                   |

Abbreviations:

<sup>a</sup>Unless otherwise noted

<sup>b</sup>Duration of infertility and prior infertility treatments are among the 154 participants who endorsed already receiving treatment for infertility

The majority of participants had a self-reported duration of infertility of one year or more (83.6%, n=178). Only 45% of participants (n=96) identified a known cause of their infertility. Among women who identified a known cause of their infertility, irregular periods or anovulation was most commonly cited (42.1%, n=40). The majority of patients had already been treated for infertility (73%, n=154) and clomiphene citrate was the most common form of treatment (76.1%, n=118). Of women who had already been treated for infertility, 58% (n=89) had undergone treatment for six months or longer.

When surveyed about willingness to participate in clinical research, 34% of participants (n=72) indicated that they would be willing to consider participating in clinical research, 28% (n=60) were unwilling to consider participating and 38% (n=81) were uncertain about whether or not they would consider participation in clinical research. Age, education, insurance, duration of infertility, prior deliveries, and research knowledge were not associated with willingness to participate (Table 2). Factors that were associated with willingness to participate in clinical research included length of infertility treatment and previous participation in clinical research. Compared to women with shorter durations of infertility treatment, women with reported treatment for six months or longer were at increased odds of being willing to participate in research [OR 3.86 CI (1.3–11)]. Similarly, compared to women who had not previously participated in research, women who had previously participated in research were also more likely to be willing to consider participating in clinical research [OR 8.29 CI (2.1–31.9)] (Table 3).

Survey participants who reported that they were

Table 2: Demographic Characteristics and Willingness to Consider Participating in Clinical Trials<sup>a</sup>

|                     | Willing to consider (n=72) | Unwilling to consider (n=60) | Uncertain (n=81) | p- value          |
|---------------------|----------------------------|------------------------------|------------------|-------------------|
| Age in years        |                            |                              |                  |                   |
| Median (range)      | 36 (21-44)                 | 34 (22-44)                   | 35 (25-45)       | 0.11 <sup>e</sup> |
| Education           |                            |                              |                  |                   |
| High School         | 3 (4.2)                    | 3 (5.0)                      | 3 (3.7)          | 0.91 <sup>c</sup> |
| Some College        | 17 (23.9)                  | 11 (18.3)                    | 22 (27.2)        |                   |
| Graduated College   | 23 (32.4)                  | 24 (40.0)                    | 27 (33.3)        |                   |
| Professional School | 28 (39.4)                  | 22 (36.7)                    | 29 (35.8)        |                   |
| Race/ethnicity      |                            |                              |                  |                   |
| Hispanic or Latino  | 3 (4.2)                    | 3 (5.0)                      | 5 (6.3)          | 0.89 <sup>c</sup> |
| White, Non-Hispanic | 59 (81.9)                  | 54 (90.0)                    | 66 (82.5)        |                   |
| Black, Non-Hispanic | 4 (5.6)                    | 2 (3.3)                      | 2 (2.5)          |                   |
| Asian               | 2 (2.8)                    | 1 (1.7)                      | 4 (5.0)          |                   |
| Other               | 4 (5.6)                    | 0 (--)                       | 3 (3.8)          |                   |

Table 2: (Continued)

|  | Willing to consider (n=72) | Unwilling to consider (n=60) | Uncertain (n=81) | p-value              |
|--|----------------------------|------------------------------|------------------|----------------------|
| <b>Insurance</b>                         |                            |                              |                  |                      |
| Private                                  | 69 (97.2)                  | 60 (100)                     | 78 (97.5)        | 0.72 <sup>c</sup>    |
| Self-pay                                 | 1 (1.4)                    | 0 (--)                       | 0 (--)           |                      |
| Other                                    | 1 (1.4)                    | 0 (--)                       | 2 (2.5)          |                      |
| <b>Previous research participation</b>   |                            |                              |                  |                      |
| Yes                                      | 23 (32.4)                  | 4 (6.7)                      | 8 (9.9)          | <0.0001 <sup>b</sup> |
| No                                       | 48 (67.6)                  | 56 (93.3)                    | 73 (90.1)        |                      |
| <b>Duration of infertility</b>           |                            |                              |                  |                      |
| < 2 years                                | 33 (45.8)                  | 35 (58.3)                    | 49 (60.5)        | 0.15 <sup>b</sup>    |
| ≥ 2 years                                | 39 (54.2)                  | 25 (41.7)                    | 32 (39.5)        |                      |
| <b>Duration of infertility treatment</b> |                            |                              |                  |                      |
| < 6 months                               | 14 (23.3)                  | 22 (53.7)                    | 27 (52.9)        | 0.001 <sup>b</sup>   |
| ≥ 6 months                               | 46 (76.7)                  | 19 (46.3)                    | 24 (47.1)        |                      |
| <b>Already on infertility treatment</b>  |                            |                              |                  |                      |
| Yes                                      | 61 (84.7)                  | 42 (71.2)                    | 51 (63.8)        | 0.01 <sup>b</sup>    |
| No                                       | 11 (15.3)                  | 17 (28.8)                    | 29 (36.3)        |                      |
| <b>Types of Infertility Treatment</b>    |                            |                              |                  |                      |
| Clomiphene citrate                       | 43 (70.5)                  | 32 (76.2)                    | 43 (82.7)        | 0.31 <sup>b</sup>    |
| Donor Eggs                               | 2 (3.3)                    | 0 (--)                       | 0 (--)           | 0.33 <sup>c</sup>    |
| Donor Sperm                              | 2 (3.3)                    | 2 (4.8)                      | 3 (5.8)          | 0.88 <sup>c</sup>    |
| Gonadotropins                            | 27 (44.3)                  | 11 (26.2)                    | 20 (38.5)        | 0.17 <sup>b</sup>    |
| IUI                                      | 33 (54.1)                  | 21 (50.0)                    | 29 (55.8)        | 0.85 <sup>b</sup>    |
| IVF                                      | 35 (57.4)                  | 15 (35.7)                    | 20 (38.5)        | 0.05 <sup>b</sup>    |
| Letrozole                                | 4 (6.6)                    | 6 (14.3)                     | 3 (5.8)          | 0.33 <sup>c</sup>    |
| More than 1 form of treatment            | 47 (77.1)                  | 22 (52.4)                    | 34 (65.4)        | 0.03 <sup>b</sup>    |

Abbreviations:

<sup>a</sup>N (%) unless otherwise noted

<sup>b</sup>Chi square

<sup>c</sup>Fisher's exact test

<sup>t</sup>t-test

<sup>a</sup>anova

uncertain or unwilling to participate in research were then asked to indicate reasons for their uncertainty or unwillingness (Table 4). The most common reason participants were unsure or would not participate in clinical research was lack of knowledge about research trials (46%, n=65). Other common reasons listed were lack of time, not wanting to undergo more interventions and concern about compromising pregnancy rate. When respondents who were unsure about participating in clinical research were questioned about what would make

Table 3: Reasons given for unwillingness/uncertainty to participate in research and factors that would influence future willingness participate.

| "Willingness to consider participation in clinical research"   |             |                       |                          |          |
|--|-------------|-----------------------|--------------------------|----------|
|  | Total N (%) | "Unsure" N (%) (n=81) | "Unwilling" N (%) (n=59) | p-Value  |
| <b>Reasons for unwillingness/uncertainty</b>                   |             |                       |                          |          |
| Don't want to be a guinea pig                                  | 35 (25)     | 17 (21.0)             | 18 (30.5)                | 0.19a    |
| Afraid of getting a placebo                                    | 25 (17.8)   | 19 (23.5)             | 6 (10.2)                 | 0.04a    |
| Don't know enough about research trials                        | 65 (46.4)   | 44 (54.3)             | 21 (35.6)                | 0.02a    |
| Don't have time to participate                                 | 46 (32.8)   | 23 (28.4)             | 23 (39.0)                | 0.18a    |
| Don't want to undergo more interventions                       | 46 (32.8)   | 26 (32.1)             | 20 (33.9)                | 0.82a    |
| Worried my provider would treat me differently                 | 5 (3.6)     | 3 (3.7)               | 2 (3.4)                  | 1.0b     |
| Worried that it would compromise my pregnancy rate             | 47 (33.6)   | 33 (40.7)             | 14 (23.7)                | 0.03a    |
| <b>Factors that would influence willingness to participate</b> |             |                       |                          |          |
| Discussion with provider                                       | 56 (43.7)   | 48 (61.5)             | 8 (16.0)                 | <0.0001a |
| Provided written literature                                    | 43 (33.6)   | 38 (48.7)             | 5 (10.0)                 | <0.0001a |
| Meeting with other participants                                | 16 (12.5)   | 13 (16.7)             | 3 (6.0)                  | 0.07a    |
| Provided financial compensation                                | 21 (16.4)   | 17 (21.8)             | 4 (8.0)                  | 0.04a    |
| Nothing  | 40 (31.2)   | 13 (16.7)             | 27 (54.0)                | <0.0001a |

Abbreviations:

N (%) unless otherwise noted

a Chi square

b Fisher's exact test

them more willing to participate in research, 61% (n=48) reported they would be more willing to participate after a discussion with their provider. The majority of participants (54%, n=27) who were not willing to

Table 4: Odds of reporting being willing to participate in clinical research.

|                                     | Adjusted Odds Ratios <sup>a</sup><br>(95% CI) |
|-------------------------------------|---|
| <b>Duration Infertility</b>         |   |
| < 2 years                           | 1.93 (0.7-5.2)                                |
| ≥ 2 yrs                             | Ref   |
| <b>Length Infertility Treatment</b> |   |
| < 6 months                          | Ref   |
| ≥ 6 months                          | 3.86 (1.3 -11)                                |
| <b>Prior Deliveries</b>             |   |
| Yes                                 | 5.34 (0.64 -44.2)                             |
| No                                  | Ref   |
| <b>Research Participation</b>       |   |
| Yes                                 | 8.29 (2.1 – 31.9)                             |
| No                                  | Ref   |
| <b>Research Knowledge</b>           |   |
| < 3/6 correct                       | 1.51 (0.56 – 4)                               |
| ≥ 3/6 correct                       | Ref   |

**Abbreviations:**

<sup>a</sup>Full Model: Adjusted for prior deliveries, length of infertility treatments, previous participation in research and knowledge of clinical research

consider participation in clinical research, when asked the same question reported nothing would make them more willing to participate.

**DISCUSSION**

In this study, we found that infertility treatment for at least six months and previous participation in clinical research were both associated with willingness to participate in clinical research. Among the 38% of patients who were uncertain about whether or not they would participate in clinical research, many would be more willing to participate in clinical research after a discussion with their healthcare provider and they commonly cited lack of knowledge about research as their reason for participation uncertainty. Focusing recruitment efforts on patients who would consider research participation and improving the comfort level of “uncertain” patients with clinical research may improve enrollment of infertility patients in clinical studies.

The discrepancy between patient attitudes regarding research participation and actual participation in research likely reflects patient-level, provider-level, and study-specific barriers to study participation. In social and health research, individuals participate in clinical trials for various reasons. One reason for participation in research is altruism, the idea that participating in research will allow for scientific contribution that will benefit future patients [7]. Studies have shown that positive attitudes regarding research and positive beliefs about the necessity of patient participation in clinical research are associated with clinical trial participation [12]. Another factor

contributing to patient participation in clinical research includes perception of having improved access to a novel treatment [8]. Not surprisingly, factors that negatively impact willingness to participate in research include the possibility of receiving a placebo treatment and potential additional burdens associated with participation [13].

Though positive attitudes regarding research in general and concerns about placebo treatment and additional time burden likely also influence research participation for women undergoing treatment for infertility, there may be factors that uniquely affect this population given the complex treatment and often very personal decision-making process. One study has shown that sense of closure may motivate patients who have undergone IVF treatment to participate when they have a longer duration of treatment. Among patients concluding their IVF treatments, reasons cited for participation in clinical research included the opportunity to express their gratitude for the care they received, the ability to further discuss the difficulties associated with their decision to discontinue further treatment, and the possibility of helping future couples undergoing IVF [9]. Though in our study, we did not ask participants questions specific to gratitude and sense of closure, these feelings may, in part, explain why patients in our study with six months or longer duration of infertility treatment were more likely to endorse willingness to consider participating in clinical research.

How research knowledge affects willingness to participate in research is unclear. Similar to our study findings, Jenkinson et al. found that research knowledge and study educational materials were not associated with research participation [12]. However, our study results suggest that “uncertain” patients viewed research knowledge as a barrier to research participation and that these patients may be more willing to consider participating in research after a discussion with their provider. It is possible that the healthcare provider is instrumental to this process of providing study information to patients. As such, strengthening patient-provider dialogues about research within their recruitment sites could potentially improve research recruiting. Given the complexity of infertility treatment, patient education about the risks, benefits, and potential burdens associated with specific studies may make a difference for this particular population of individuals who were “uncertain” about research participation. Based on these findings, we suggest future research comparing the effectiveness of strategies for optimizing research recruitment into studies on infertility treatments.

The strengths of our study include our excellent response rate (78%), which allowed us at least in our clinical population to characterize willingness of patients seeking evaluation or treatment for infertility to participate in clinical research. One weakness of this study is that the data are based solely on patient report, including data on duration of infertility and treatment. Patients also had to be willing to participate in this study,

which may have missed a population of patients that were not willing to even participate in the survey. This study was conducted at a single clinical site and there was lack of diversity in the study population. Therefore the results may or may not be applicable to all infertility populations. The study was also limited to English speaking patients.

## CONCLUSION

Our study aimed to identify patients' view on research in infertility, and attempted to provide insight into potential barriers to participation in clinical research. Understanding factors associated with patient willingness to enter infertility research may help assist clinical trial recruitment strategies. Providing patient education on clinical research and involving providers in recruitment may improve participation of infertility patients in clinical research but these potential interventions still require further studies to verify improvement in participation.

\*\*\*\*\*

## Author Contributions

Megan L. McCain – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Valerie A. Flores – Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Carol A. Wheeler – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Vrishali Lopes – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Kristen A. Matteson – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

## Guarantor

The corresponding author is the guarantor of submission.

## Conflict of Interest

Authors declare no conflict of interest.

## Copyright

© 2015 Megan L. McCain et al. This article is distributed under the terms of Creative Commons Attribution License which permits unrestricted use, distribution

and reproduction in any medium provided the original author(s) and original publisher are properly credited. Please see the copyright policy on the journal website for more information.

## REFERENCES

1. Cassileth BR, Lusk EJ, Miller DS, Hurwitz S. Attitudes toward clinical trials among patients and the public. *JAMA* 1982 Aug 27;248(8):968-70.
2. Johnstone E, Sandler JR, Addaun-Andersen C, Sohn SH, Fujimoto VY. Asian women are less likely to express interest in infertility research. *Fertil Steril* 2010 Sep;94(4):1249-53.
3. Madsen S, Holm S, Riis P. Ethical aspects of clinical trials: The attitudes of the public and out-patients. *J Intern Med* 1999 Jun;245(6):571-9.
4. Trauth JM, Musa D, Siminoff L, Jewell IK, Ricci E. Public attitudes regarding willingness to participate in medical research studies. *J Health Soc Policy* 2000;12(2):23-43.
5. Charlson ME, Horwitz RL. Applying results of randomized to clinical practice: impact of losses before randomization. *Br Med J (Clin Res Ed)* 1984 Nov 10;289(6454):1281-4.
6. Mathews C, Restivo A, Raker C, Weitzen S, Disilvestro P. Willingness of gynecologic cancer patients to participate in clinical trials. *Gynecol Oncol* 2009 Jan;112(1):161-5.
7. Jenkins V, Farewell V, Farewell D, et al. Drivers and barriers to patient participation in RCTs. *Br J Cancer* 2013 Apr 16;108(7):1402-7.
8. Ovretveit, J. *Health Service Quality*. Oxford: Blackwell Press 1992.
9. Peddie VL, Porter M, Van Teijlingen E, Bhattacharya S. Research as a therapeutic experience? An investigation of women's participation in research on ending IVF treatment. *Hum Fertil (Camb)* 2006 Dec;9(4):231-8.
10. Purewal S, van den Akker O. Attitudes and intention to donate oocytes for research. *Fertil Steril* 2010 Mar 1;93(4):1080-7.
11. Hug K. Motivation to donate or not donate surplus embryos for stem-cell research: literature review. *Fertil Steril* 2008 Feb;89(2):263-77.
12. Jenkinson C, Burton JS, Cartwright J, et al. Patient attitudes to clinical trials: development of a questionnaire and results from asthma and cancer patients. *HHealth Expect* 2005 Sep;8(3):244-52.
13. Jenkins V, Fallowfield L. Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *Br J Cancer* 2000 Jun;82(11):1783-8.

Access full text article on  
other devices



Access PDF of article on  
other devices

