

Millennium Cohort Study

**Women's Experiences of Successful
Infertility Treatment:
Results from the MCS Fertility Survey**

Edited by

Leslie Davidson and Maria Quigley

January 2006



Centre for Longitudinal Studies

Bedford Group for Lifecourse & Statistical Studies
Institute of Education, University of London

In collaboration with



NPEU, University of Oxford

Old Road Campus, Oxford OX3 7LF

First published in 2006 by the Centre for Longitudinal Studies
Bedford Group for Lifecourse and Statistical Studies
Institute of Education, University of London
20 Bedford Way
London WC1H 0AL

website: www.cls.ioe.ac.uk

© Centre for Longitudinal Studies

ISBN 1 898453 52 7

The Centre for Longitudinal Studies (CLS) is one of four centres that comprise the Bedford Group for Lifecourse and Statistical Studies (www.ioe.ac.uk/bedfordgroup).

CLS is devoted to the collection, management and analysis of large-scale longitudinal data. It has responsibility for Britain's internationally renowned birth cohort studies, the National Child Development Study (1958 cohort) and the 1970 British Cohort Study, and leads the consortium conducting the ESRC's Millennium Cohort Study.

**Women's experiences of successful infertility treatment:
Results from a survey linked to the Millennium Cohort Study**

Contributors

Maria A Quigley Chris Hockley Jennifer J Kurinczuk Jane Henderson Maggie Redshaw	National Perinatal Epidemiology Unit Oxford University
Leslie L Davidson	Mailman School of Public Health Columbia University, New York City
Heather Joshi, Denise Hawkes	Centre for Longitudinal Studies Institute of Education
Enda McVeigh, David Barlow	John Radcliffe Hospital, Oxford
Jane Denton	Multiple Births Foundation
Judy Shakespeare	Summertown Health Centre, Oxford

Source of funding

This report forms part of the Department of Health Contribution to the ONS consortium of government funders to the Millennium Cohort Study. The National Perinatal Epidemiology Unit, Oxford University has conducted this study on a sub-contract to the Centre for Longitudinal Studies, Institute of Education, London University.

Acknowledgements

CLS would like to thank all the mothers of MCS children who participated in this survey for their kind co-operation in producing the data set whose results are reported in this document.

Address for correspondence

Maria Quigley
National Perinatal Epidemiology Unit
Oxford University
Old Road Campus
Headington
Oxford
OX3 7LF.
Email: maria.quigley@npeu.ox.ac.uk

Contents

Purpose of this document

Executive Summary

1. Background
2. Study objectives
3. Methods
4. Results – Response rate
5. Results – Choice of groupings for infertility treatment
6. Papers in progress
7. Study limitations

References

Purpose of this report

This document describes the background and methods of the MCS fertility study, and is primarily aimed at those who want to analyse the data.

Executive Summary

Background

It is estimated that infertility affects one in seven couples in the UK. A large and growing number of babies are conceived through infertility treatment. Despite this, data on the characteristics and outcomes of such pregnancies are relatively scarce. The aims of this study are to describe the characteristics of women who delivered successfully following infertility treatment, their experiences in seeking treatment, and the outcomes for the child and the mother in a nationally representative sample of children born at the start of the 21st century.

Methods

The study participants were drawn from the Millennium Cohort Study (MCS), a nationally representative study of 18,819 infants born in the UK in 2000-1. Infants who were alive and living in the UK at age 9 months were drawn from child benefit registers. Disproportionately stratified sampling at electoral ward level ensured adequate representation of disadvantaged and ethnic minority areas. Parents were interviewed for the first time (sweep 1) when the infant was aged about 9-10 months, and detailed information was collected on a wide range of socio-economic and health factors. Consenting parents who reported having had any medical infertility treatment for this pregnancy were sent a postal questionnaire which asked more detail about their experiences of infertility treatment. Much of the statistical analysis involved comparing the women who had received different types of infertility treatment, either with each other or with women who had received no such treatment. All analyses allowed for the clustered, stratified sample design, with re-weighting where necessary to allow for the different sampling proportions.

Results

Of the 18,482 MCS mothers included in the analysis, 460 (2.5%) reported that infertility treatment had led to the conception of the MCS baby. 230 women (50%) responded to the postal questionnaire. Among the 460 MCS mothers who reported having had infertility treatment, 203 (44%) had clomid only, 207 (45%) had ART and 50 (11%) had surgery. Further results will be made available once they are accepted for publication.

Conclusions

This is the first nationally representative UK survey to describe the characteristics and experiences of women who delivered successfully following infertility treatment. Papers describing the key findings are currently in progress. The fertility survey dataset will be available for analysis early in 2006.

1. Background

It is estimated that infertility affects one in seven couples in the UK [1]. Therefore, a typical primary care trust, health board or strategic health authority may expect to see around 230 new couples per 250,000 people in the population per year who seek evaluation and treatment for infertility problems [1]. There are a number of factors leading to infertility, including aging, lifestyle factors, genetic causes, a history of infection, structural and hormonal issues, and these potentially affect both the woman and her partner. Frequently more than one factor will play a role. While there has been no major change in the prevalence of fertility problems in recent years, more people seek medical help for such problems than previously, despite the often considerable personal costs incurred.

There are three main types of infertility treatment:

- pharmacological treatment (such as drugs for ovarian stimulation)
- surgical treatment which is unrelated to egg retrieval and embryo transfer (such as laparoscopy for ablation of endometriosis)
- assisted reproductive technologies (ART) i.e. treatment in which the gametes are manipulated in the laboratory such as *in vitro* fertilization (IVF), gamete intra fallopian transfer (GIFT), intra cytoplasmic sperm injection (ICSI) and related procedures.

In February 2004, the National Institute for Clinical Excellence (NICE) published a clinical guideline on the treatment and management of people with fertility problems [1]. One of the key recommendations of the NICE guideline was the provision of up to three free cycles of IVF for couples who have been unable to conceive for three years because of an identifiable reason, provided that the woman is aged under 40 [2]. In response to this, the UK Department of Health announced in April 2004 that all primary care trusts should offer at least one full cycle of IVF by April 2005. Since the substantial cost of IVF has deterred some couples from seeking IVF in the past, it is expected that, as a result of the change in policy, use of infertility services will continue to increase and will include a broader group of couples with different economic resources.

Despite the large number of babies conceived through infertility treatment, data on the characteristics and outcomes of such pregnancies are relatively scarce. In the UK, information about the number and characteristics of pregnancies following ART are collected by the UK Human Fertilization and Embryology Authority (HFEA), but since they do not distinguish between UK women seeking care and women from abroad who receive care in the UK, it is impossible to obtain national data. In addition, there is no information available on the outcome of the pregnancy other than whether or not there was a live birth.

In addition, there are no formal arrangements or legal requirements to register conceptions arising in association with other methods of infertility treatment, such as ovarian stimulation alone followed by natural conception, or surgery unrelated to egg retrieval and embryo transfer. The drugs used for ovarian stimulation, even when used as the sole therapeutic agent, have the capacity to lead to multiple conceptions. Furthermore, they can be prescribed in many clinical settings and are not restricted to use by specialist or licensed practitioners, nor to only those with access to facilities for monitoring the pregnancy (for instance through ultrasound). Despite this, there is relatively little information available which quantifies the impact these drugs have on the rising multiple birth rate. Moreover, recent review articles have given cause for an increasing level of concern regarding the effect of infertility treatment on perinatal outcomes [3] and birth defects [4],

and little is known about the long-term consequences of all types of infertility treatments on either the mother or the child [5].

There is also little information available on the amount, nature and costs of care regarding infertility treatment, whether it is the costs to the NHS, to insurers or to the patient, and no data are published on the out-of-pocket expenses, the time lost from work or from leisure time of the women and partners seeking treatment [6]. Another gap in our knowledge is on the appropriate timing of referral for specialist interventions. These issues may affect the efficiency of interventions, since a long wait for an intervention may be associated with a lower success rate. The RCOG guidelines which were in effect at the time of the MCS study recommended that a GP wait 18 months to refer a patient to specialist care whereas the new NICE guideline suggests 12 months. While the NICE guideline and the UK government have recommended that all primary care trusts should offer at least one full cycle of IVF, a survey of primary care trusts published by the All Party Parliamentary Group on Infertility in March 2005 suggested that this is not yet happening in practice [7]. Even if and when this is fully implemented, not all infertility treatment services will be available to all couples, for example, where the couple do not meet the eligibility criteria. Since one treatment may not be successful, it is likely, therefore, that many couples will continue to pay for infertility treatment themselves at least in the short term. In addition, successful couples who seek a second child will have to pay for ART themselves.

The aims of this study, therefore, are to describe the characteristics of women who delivered successfully following infertility treatment, their experiences in seeking treatment, and the outcomes for the child and the mother in a nationally representative sample of women delivering babies in 2000/2001. The study was conducted before the publication of the NICE guideline, but has been analysed and interpreted to provide information relevant to the current clinical context, where appropriate. When reading this report, it is important to remember that the findings apply only to women who delivered successfully following therapeutic interventions for infertility. It does not apply to those women who have tried infertility treatment without success, or indeed, to those who may have sub-fertility but have not attempted to treat it.

2. Study objectives

The original study objectives were refined so as to fully exploit the available data from both the Millennium Cohort Study (MCS) and the postal questionnaire, and to reflect the current context for infertility treatment in the UK. The refined objectives are:

- i. To compare the socio-economic and career profiles and ages of those receiving various types of infertility treatment with other mothers in the context of a national child cohort study.
- ii. To determine the proportion of singleton and multiple infants which were associated with ovulation induction in the context of a national child cohort study..
- iii. To compare the perinatal characteristics of those receiving various types of infertility treatment with other mothers in the context of a national child cohort study.
- iv. To compare the health and development outcomes in infants born from different types of infertility treatment with other infants in the context of a national child cohort study.
- v. To gather information on women's experiences of health service utilisation in the treatment of infertile couples. In particular, to assess GP management with regard to appropriate and timely referral to a fertility specialist at an appropriate time and prescribing clomid without referral to a specialist clinic.
- vi. To gather information on the use and costs of infertility treatment from the women themselves and to measure the ease of gaining access to secondary, retrospective data in the context of a national child cohort study.

3. Methods

3.1 Millennium Cohort Study (MCS)

The Millennium Cohort Study is a nationally representative UK longitudinal observational study of 18,819 infants born in the UK between September 2000 and November 2001 [8]. A random two-stage sample of all infants born in England and Wales between September 2000 and August 2001, and in Scotland and Northern Ireland between November 2000 and January 2002 who were alive and living in the UK at age 9 months was drawn from child benefit registers [8]. Electoral wards were stratified into the following groups:

- *ethnic minority* i.e. those where at least 30% of the population was “Black” or “Asian” in the 1991 census
- *disadvantaged* i.e. the “non-ethnic minority” wards representing the poorest 25% of wards in England based on the child poverty index; the poorest 38% in Scotland, Wales and Northern Ireland
- “*advantaged*” i.e. the remaining wards, which were not disadvantaged.

Stratified sampling at electoral ward level ensured adequate representation of ethnic minority and other disadvantaged areas. Parents were interviewed for the first time (sweep 1) when the infant was aged about 9-10 months, and detailed information was collected on a wide range of socio-economic and health factors. The MCS does not cover births where the infant died within the first 9-10 months of age, but these constituted only about 0.6% of all births.

3.2 Fertility Postal Survey

The MCS Fertility Survey was funded by the Department of Health and subcontracted to the National Centre for Social Research (NatCen) and the National Perinatal Epidemiology Unit (NPEU). The work began with a pilot study of 100 women conducted in the Oxfordshire region in 2001. Both women using fertility services and specialist providers collaborated with the NPEU in designing a postal survey of 100 women, which had a 75% response rate. This pilot study led to refining and re-ordering the questionnaire for the MCS study. The questionnaire underwent further review by women who had received ART and experts in the field. The questionnaire was designed to supplement the information available in the MCS and so the only questions which overlapped were those about the type of treatment received.

Clearance was received from the Multi-centre Research Ethics Committee (MREC) to proceed with the survey. Permission was only granted for a single reminder notice to be sent to the women, who had all previously consented to be surveyed at the time of the initial MCS interview. A second reminder was deemed by the MREC to be too intrusive. A short self-completion postal questionnaire was sent to those mothers who indicated in MCS sweep 1 that the MCS baby had been conceived following infertility treatment and who consented to follow-up. The questionnaires were posted in May 2003 to mothers in England, Scotland and Wales, and in June 2003 to those in Northern Ireland. Though planned to be sent a month after the interview, many months of delay were introduced as a result of waiting for the MREC clearance and through establishing final agreement on the questionnaire with NatCen. In order to encourage participation in those women whose primary language was not English, the women were given the option of asking for a telephone interview in their own language, instead of completing the questionnaire by hand. Ten of the 481 women who received a posted questionnaire (see Figure 1, Section 4) requested a telephone

interview. Each questionnaire was reviewed for clarity by one of the investigators (LLD) and data entry commenced early in October 2003.

3.3 Data collected

The MCS questionnaire included one question on whether the respondent had “any medical fertility treatment for this pregnancy”. If the woman answered yes then a second question asked about the type of treatment. Data were also available on all MCS women on a wide range of variables including socio-demographic factors (age at delivery, marital status, ethnicity, social class, education, household income, number of children), perinatal factors (mode of delivery, multiple birth/conception, gestational age, and birth weight), infant health in the first 9-10 months after birth (hospital admissions and other health problems requiring a health professional, as reported by the parent) and infant development at age 9-10 months (parental response to selected statements from the Denver Developmental Screening test and the MacArthur Communicative Development Inventories, as described in [9]).

The fertility study postal questionnaire included questions on the woman’s experience of infertility treatment at different time points:

- when she first sought medical help for infertility and her experiences of GP management and referral (Section 1 of the questionnaire)
- the infertility treatment/drugs which led to the birth of the MCS baby (Sections 2 and 3)
- her previous infertility treatment/drugs and the number of pregnancies and live births which arose from this (Sections 4 and 5)
- the cost of infertility treatment (Section 6)
- her experiences in obtaining and undergoing infertility treatment (Section 7) including what she would tell policy makers.

3.4 Data analysis

Much of the statistical analysis involved comparing the women who had received different types of infertility treatment, either with each other or with women who had received no such treatment. The women in these groups were compared with respect to their socio-economic profile (objective i)), the proportion of multiple births (objective ii)), the proportion of births with particular perinatal characteristics (objective iii), and the proportion of infants with health or development problems (objective iv)). These proportions were compared using chi-square tests and when appropriate, adjustment for confounding factors was done using logistic regression. The analysis of health service utilisation and costs (objective v) was more descriptive than analytical, with results focussing on the proportion of women having a particular treatment or being referred, and the mean and median cost of treatment. The analysis of her experiences included both quantitative analysis and qualitative analysis of her comments.

Unless stated otherwise, all analyses allowed for the clustered, stratified sample using the “survey commands” in Stata version 8 (Stata Corporation, College Station, USA). This means that estimates of proportions, means, odds ratios, etc, were weighted to allow for the disproportionate stratified sampling design, and that p-values and 95% confidence intervals (CIs) were estimated allowing for the clustered design. For example, there were 18,482 natural mothers from MCS included in the present analysis and of these, 460 (2.5%) reported that the MCS baby was

conceived following infertility treatment. These numbers are unweighted and do not allow for the fact that women from ethnic minority or disadvantaged wards are over-represented. The weighted numbers, allowing for disproportionate sampling, result in 18,325 MCS mothers, of whom 542 (3.0%) reported that the MCS baby was conceived following infertility treatment. For simplicity and brevity, we have presented the unweighted totals (showing the actual number of individuals in each comparison group e.g. N=18,482), the weighted totals (showing the number of individuals “analysed” in each comparison group e.g. N*=18,325) and the weighted percentages (3.0% reported infertility treatment).

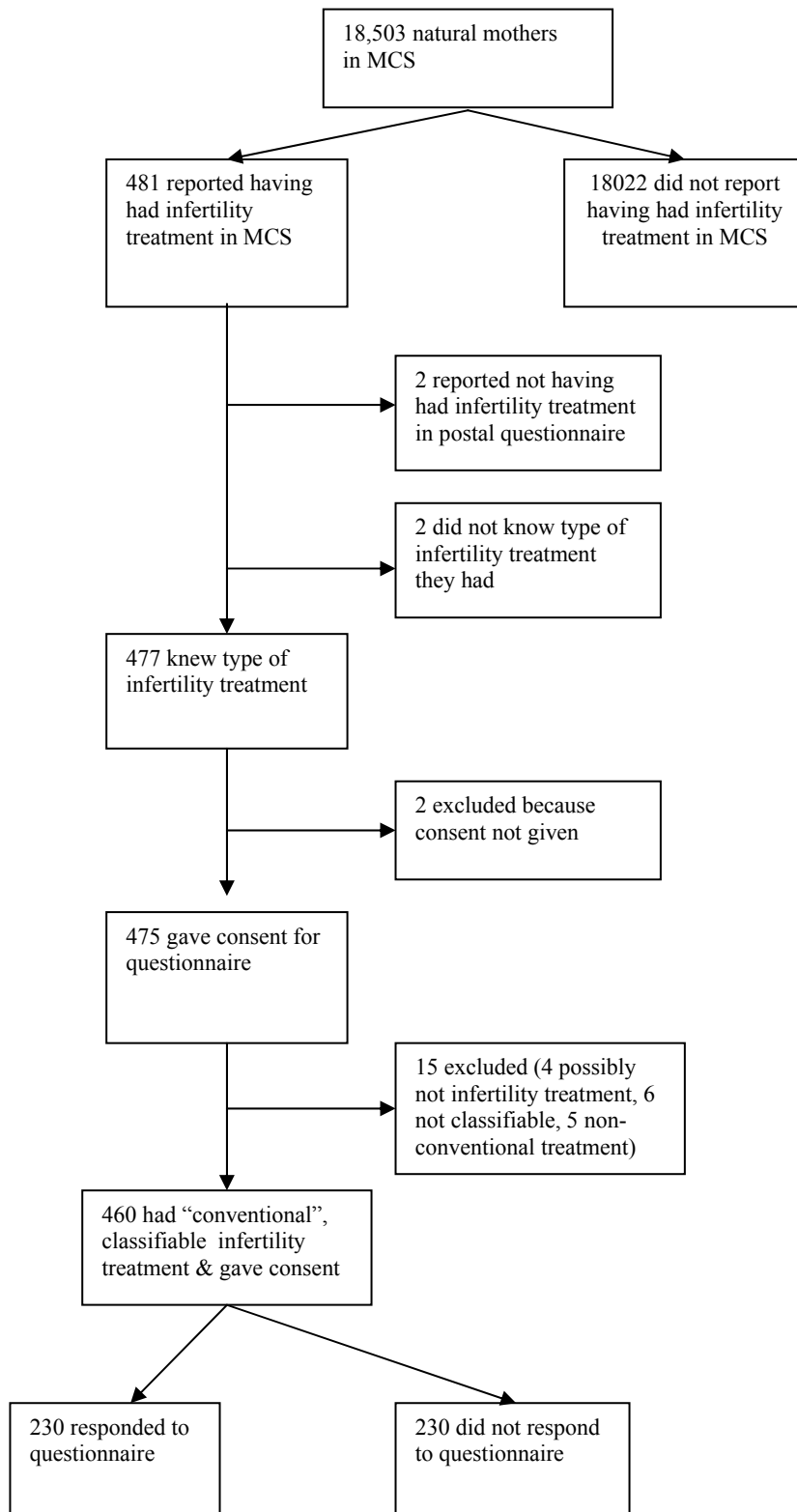
4. Results – Response rate

4.1 Overall response rate

Data were collected on 18,503 natural mothers in the MCS (sweep 1) and the overall response rate in the MCS was 72%. Figure 1 shows the response rate for the MCS question on infertility treatment and the fertility survey questionnaire. Overall, 481 (2.6%) of the 18,503 mothers reported at the MCS interview that they had had infertility treatment which led to the conception of the MCS baby. Two of the 481 were later found on the fertility questionnaire not to have had fertility treatment for the MCS baby and two did not know the type of infertility treatment they had had. 475 of the remaining 477 gave consent to receive the fertility survey questionnaire. A further 15 women were excluded from further analysis due to the treatment data not being classifiable (n=6), or the treatment being “non-conventional” such as homeopathy, herbal medicine or Chinese medicine (n=5) or the treatment possibly being for recurrent miscarriage rather than infertility treatment (n=4). Of the remaining 460 women, 230 responded to the fertility questionnaire and 230 did not respond, giving a response rate of 50%.

The final number included in the analysis was 18,482 women: 18,022 who had not had infertility treatment and 460 who had had infertility treatment (230 who responded to the questionnaire and 230 who did not).

Figure 1 Response rate for the MCS infertility treatment question and the fertility questionnaire.



The final number included in the analysis was 18,482 (460 with infertility treatment & 18,022 without).

4.2 Questionnaire item response rate

Most “unfiltered” items in the questionnaire were well completed (i.e. no more than 5% were missing) by the 230 responders. The only exception to this was the question which asked when medical help for fertility was first sought, with 97% completing the year but only 85% completing the month. There were some inconsistent responses within women, for example, answering “no” to a particular question but then giving details consistent with a response of “yes”.

4.3. Comparison of responders and non-responders in the Fertility Postal Survey

Responders to the Fertility Postal Survey were more likely to be married, white, of a higher social class, better educated, currently employed/on maternity leave and not live in ethnic wards compared with non-responders (Table 1). However, responders and non-responders were remarkably similar with respect to maternal age at delivery, previous living children, time taken to get pregnant and type of infertility treatment (Table 1) (for classification of infertility treatment, see Section 5). None of the health-related factors were associated with response (breastfeeding, currently pregnant, longstanding illness, current smoking, current alcohol; data not shown). When all the factors that were significantly associated with response were fitted in a logistic model, the only factors which remained statistically significant were ethnic group (Asian mothers were less likely to respond than white mothers) and education (mothers with a degree were more likely to respond than those without a degree) (Table 2). Ethnic group remained significantly associated with response even after adjustment for whether or not English was the main language spoken at home [10].

Table 1 Comparison of maternal characteristics of responders and non-responders to the Fertility Postal Survey.

	Responders N=230 %	Non-responders N=230 %
Maternal age at delivery (mean) (range)	32.7 (20-51)	31.9 (17-48)
Marital status		
Married	85.2	78.7
Cohabiting	10.4	16.1
Lone parent	4.4	5.2
Ethnicity		
White	96.1	84.8
Non-white	3.9	15.2
Social class (NS-SEC)		
Manag/professional	48.3	35.6
Intermediate	5.2	4.4
Sm-emp/s-emp	11.7	9.6
Lo sup/tech	11.3	13.5
(Semi-)routine	10.0	16.5
None of these	13.5	20.4
Education (NVQ level)		
Higher (NVQ 4&5)	49.1	36.1
Medium (NVQ 3)	13.5	15.6
Lower (NVQ 1&2)	31.7	31.7
Overseas/other	0.9	2.6
None of these	4.8	13.9
Ward type		
Not disadvantaged	61.7	50.0
Disadvantaged	36.5	37.8
Ethnic	1.7	12.2
Currently employed/on leave		
Yes	72.6	56.1
No	27.4	43.9
Previous living children		
None	59.0	59.9
One	29.1	29.7
Two or more	11.9	10.4
Time taken to get pregnant**		
Median (range) (yrs)	3 (0-15)	3 (0-14)
% who took \geq 5 yrs	22.6	23.4
Infertility treatment		
Clomid only	42.2	46.1
Non-ART surgery	10.9	10.9
ART	47.0	43.0

** In those women planning to get pregnant only.

Table 2 Factors significantly associated with response to the Fertility Survey Questionnaire.

	OR	95% CI	P-value
Ethnicity			
White	1		
Other	0.33	0.05-2.07	0.237
Asian	0.13	0.02-1.08	0.059
Black	0.52	0.13-2.00	0.338
Education (NVQ level)			
None of these	1		
NVQ1-NVQ3	2.79	1.10-7.05	0.031
NVQ4-NVQ6	4.24	1.64-10.94	0.003

5. Results – Choice of groupings for infertility treatment

All of the numbers and percentages given in Section 5 are unweighted, since the objective was to classify each woman in the study into an infertility treatment group rather than obtain a valid estimate of the proportion of women in each group.

5.1 Distribution of infertility treatment as reported in the MCS interview

Data on the type of infertility treatment were ascertained from both the MCS interview and the fertility survey questionnaire, and in both sources, women could report more than one treatment. Both sources sought information on several types of infertility treatment (Table 3).

Table 3 Types of treatments asked about in the two questionnaires.

MCS questionnaire	Fertility Survey Questionnaire
<ul style="list-style-type: none"> • Clomiphene citrate • GIFT/Intrauterine insemination of your partner's sperm • IVF: In Vitro Fertilisation • ICSI: IVF with intra-cytoplasmic sperm injection • Frozen embryo transfer • Surgery involving the womb, tubes or ovaries • Other 	<ul style="list-style-type: none"> • Clomid/Seraphane (tablets) • Ovulation Induction (injections) • Gamete intra-fallopian tube transfer (GIFT) • Intrauterine insemination of your partner's sperm • Intrauterine insemination of donor sperm • In-vitro fertilisation (IVF) • IVF with intra-cytoplasmic sperm injection (ICSI) • Frozen embryo transfer • Diathermy to your ovaries • Specific treatment for your partner • Other

Treatments described using the wording in the questionnaires.

Data from the MCS interview were used to categorise the women according to type of infertility treatment because these were complete, whereas the fertility survey data were available only for the 50% of responders. The latter were used for verification of treatments where appropriate.

In the MCS interview, the maximum number of different infertility treatments reported for any individual was four. Among the 475 women who knew what infertility treatment they had received and gave consent for the questionnaire (Figure 1, Section 4), 412 (87%) reported one treatment, 45 (9%) reported 2, 12 (3%) reported 3, and 6 (1%) reported 4. The distribution of these 562 treatments (as worded in the questionnaire) reported by 475 women is shown in Table 4.

Table 4 Distribution of 562 infertility treatments reported by 475 MCS mothers.

Infertility treatment	No	%
Clomiphene citrate	242	43%
Gift	35	6%
IVF	118	21%
ICSI	62	11%
Frozen embryo transfer	14	2%
Surgery ¹	59	10%
Donor/other insemination	5	1%
Other answer	27	5%
Total	562	

¹ Surgery involving the womb, tubes or ovaries

Note that total is 562 rather than 475 because some women had more than one treatment.

For analysis, the different types of infertility treatment were grouped so as to form a small number of broad groups which allowed for multiple treatments per woman. The complete data for each woman from the MCS interview and the fertility survey were used to form these groups, where appropriate and available. For example, data from open-ended questions or the actual questionnaire items listed under “other” were used. The distribution of the different combinations of fertility treatment together with the final grouping is shown in Table 5.

Table 5 Distribution of (grouped) infertility treatments reported by 475 MCS mothers.

Combination of treatments	No	%	Final grouping	No	%
Clomid ¹ only	203	43	Clomid only	203	43
ART ² only	176	37	ART	207	43
ART ² & surgery	4	0.8			
ART ² & clomid	21	4			
ART ² & surgery & clomid	6	1			
Surgery only	33	7	Surgery ⁴ only <u>or</u> surgery ⁴ & clomid	50	10
Surgery & clomid	17	4			
Treatment for recurrent miscarriage	4	0.8	Excluded	15	3
Non-conventional treatment ³	5	1			
Not known	6	1.3			

¹ clomid refers to clomiphene citrate, clomid and seraphane given as the sole therapeutic agent.

² includes GIFT, IVF, ICSI, and frozen embryo transfer.

³ treatment such as homeopathic, herbalist, Chinese medicine.

⁴ surgery involving the womb, tubes or ovaries without ART

Overall, 203 women (43%) had clomid only (“clomiphene citrate” is hereafter referred to as “clomid”), 207 (43%) had ART (with or without other infertility treatment, hereafter referred to as “ART”) and 50 (10%) had surgery (with or without clomid, hereafter referred to as “surgery”). In

addition, 4 women (0.8%) had treatment for recurrent miscarriage rather than infertility treatment, 5 (1%) had non-conventional treatment (e.g. homeopathic tablets, Chinese herbal medicine, herbs from herbalist) and 6 (1.3%) were not known (i.e. not able to be classified); these latter 15 women have been excluded from the remaining analysis.

The final groupings in the 18,482 women included in the remaining analysis are:

- 203 had clomid only
- 207 had ART
- 50 had non-ART related surgery
- 18,022 had no infertility treatment

5.2 Results – Distribution of infertility treatment as reported in the Fertility Survey

Of the 230 women who responded to the fertility survey questionnaire who were classified as having had infertility treatment, 218 (95%) women gave details of the infertility treatment which led to the birth of their MCS baby. These 218 women reported 277 treatments, the distribution of which (as worded in the questionnaire) is shown in Table 6.

Table 6 Distribution of 277 infertility treatments reported by 218 Fertility Survey mothers.

Infertility treatment	No	%
Clomid/seraphane (tablets)	93	34%
Ovulation induction (injections)	29	10%
Diathermy to ovaries	3	1%
IUI of partner's sperm	14	5%
Donor insemination	7	3%
GIFT	0	0%
IVF	50	18%
ICSI	36	13%
Frozen embryo transfer	11	4%
Treatment for partner	3	1%
Other	31	11%
Total	277	

The most common treatments reported were clomid (34% of women), IVF (18%) and ICSI (13%).

When asked “what did the medical tests show as the likely cause of infertility”, 37 women reported that their partner had a problem with sperm, and 26 women (11%, 95% CI: 7.5-16.1%) reported this as the only problem. Of the 36 women who reported having had ICSI, 21 (58%) reported a problem with sperm and 18 of these (50%) reported this as the only problem.

5.3 Results – Agreement between data on infertility treatment in MCS and Fertility Survey

Of the 230 women who responded to the fertility survey questionnaire who were classified as having had infertility treatment, 218 women gave details of the infertility treatment in a form that could be compared with what was reported in the MCS. Infertility treatment ascertained from the MCS questionnaire was grouped as clomid only, non-ART-related surgery or ART (see Section 5). Infertility treatment ascertained from the Fertility Survey questionnaire was grouped as:

- *Clomid only* if the woman reported “clomid/seraphane (tablets)” or “ovulation induction (injections)” and nothing else
- *Non-ART-related surgery* if the woman indicated “diathermy to your ovaries”
- *ART* if the woman reported “intrauterine insemination of your partner’s/donor’s sperm” or “GIFT” or “IVF” or “ICSI” or “frozen embryo transfer”

Data on infertility treatment ascertained from the MCS questionnaire and the Fertility Survey questionnaire were compared (Table 7). For clomid only and ART, agreement was very high, with 85% of the 97 women who were classified as clomid only on the MCS questionnaire and 95% of the 108 women classified as ART having the same classification on the Fertility Survey questionnaire. Of the 25 women classified as surgery on the MCS questionnaire, 10 (40%) had the same classification on the Fertility Survey questionnaire, although 11 of the remaining 15 discrepancies were classified as “other” or “missing” on the Fertility Survey questionnaire.

Table 7 Agreement between infertility treatment reported on MCS and Fertility Survey questionnaires.

Reported in Fertility Survey	Reported in MCS			
	Clomid only	Non-ART surgery	ART	Total
Clomid only	82 (85%)	4 (16%)	1 (1%)	87
Non-ART surgery	1 (1%)	10 (40%)	0(0%)	11
ART	3 (3%)	0 (0%)	103 (95%)	106
Other	4 (4%)	6 (24%)	4 (4%)	14
Missing	7 (7%)	5 (20%)	0 (0%)	12
Total	97	25	108	230

6. Papers in progress

The following paper has been posted as a technical working paper on the CLS website:

- i) Hawkes, D. An analysis of the Millennium Cohort Study (MCS) Fertility Survey Response. Centre for Longitudinal Studies, Institute of Education, University of London.

This paper describes the response rate for the fertility survey and the factors associated with non-response.

The following papers are currently in progress and will be submitted to peer-reviewed journals:

- ii) The contribution of infertility treatment to births in the UK at the turn of the millennium. (Kurinczuk, JJ, *et al.*)

This paper describes the socio-economic profile and perinatal characteristics of women who have had infertility treatment, and measures the proportion of multiple births due to infertility treatment.

- iii) Health and development of infants conceived following infertility treatment compared with those conceived spontaneously. (Quigley, MA, *et al.*)

This paper compares infants conceived following infertility treatment and those conceived spontaneously in terms of infant health in the first 9-10 months of age, and infant developmental delay at 9-10 months of age..

- iv) A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. (Redshaw, M, *et al.*)

This paper describes the experience of women in the survey, focussing on perceptions of treatment and care as reported in the open-ended sections of the fertility survey questionnaire.

The questionnaire can be accessed from the CLS website at the following location:

<http://www.cls.ioe.ac.uk/studies.asp?section=00010002000100140002>

7. Study limitations

1. The MCS only includes ‘successful’ couples. Women who have had treatment which did not lead to a live birth with survival until age 9 months, are not represented.
2. The response rate in the fertility postal survey was 50% and there was evidence of under-representation of women from ethnic minorities and lower socio-economic groups. However, there was no evidence of response bias according to maternal age at delivery, previous living children, type of infertility treatment, time taken to get pregnant, current smoking, current alcohol, and long-standing illness.
3. Most data were ascertained using maternal reporting which may not always be accurate e.g. infertility treatment, time when started trying to get pregnant, etc.

References

1. National Collaborating Centre for Women's and Children's Health. Fertility: assessment and treatment for people with fertility problems. CG11. 2004. London, RCOG Press.
2. White C. Infertile couples to be given three shorts at IVF. *BMJ* 2004;328:482.
3. Helmerhorst FM, Perquin DAM, Donker D, Keirse MJNC. Perinatal outcome of singletons and twins after assisted conception: a systematic review of controlled studies. *BMJ* 2004; Jan 31:328(7434):261 (Epub).
4. Hansen M, Bower C, Milne E, de Klerk N, Kurinczuk JJ. Assisted reproductive technologies and the risk of birth defects – a systematic review. *Human Reproduction*, 2005; 20: 328-338.
5. Doyle P. The UK Human Fertilisation and Embryology Authority. How it has contributed to the evaluation of assisted reproduction technology. *Int J Technol Assess health Care* 1999; 15:3-10.
6. Garceau L, Henderson J, Davis L-J, Petrou S, McVeigh E, Barlow D, Davidson LL. Economic implications of assisted reproductive techniques: a systematic review. *Hum Reprod* 2002;17:3090-3109)
7. All Parliamentary Group on Infertility. Survey of Primary Care Trusts, March 2005.
8. Plewis I. Millennium Cohort Study First Survey: technical report on sampling, 3rd edition, June 2004.
9. Dex S and Joshi H (editors). Children of the 21st Century. Bristol: Policy Press 2005.
10. Hawkes, D. MCS Technical Document: An analysis of the Millennium Cohort Study (MCS) Fertility Survey Response. Centre for Longitudinal Studies, Institute of Education, University of London. (www.cls.ioe.ac.uk/mcs).
11. Thomson F, Shanbhag, S, Templeton, A, Bhattacharya, S. Obstetric outcome in women with subfertility. *BJOG* 2005;112:632-637.