



**Remaking  
Fertility**



fertilitynetworkuk



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## **Supplement to “Fertility Treatment Add-On Use, Costs and Information Transparency: Patient Survey Findings”**

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Remaking Fertility in collaboration with The Fertility Network UK

The brief is available at [www.qmul.ac.uk/remaking-fertility/survey-results](http://www.qmul.ac.uk/remaking-fertility/survey-results)

### **Purpose of this supplement**

The purpose of this supplement is to provide a detailed breakdown of the data presented in the accompanying brief. It aims to enhance the understanding of the findings by offering comprehensive explanations, context, and insights into the data collected. This document serves as a resource for stakeholders, researchers, and the public, ensuring clarity and transparency regarding the survey results. Further information can be found in the associated research article (Perrotta et al., 2024).

### **Overview of data collection**

An online survey was conducted targeting current or prospective IVF patients in the UK to gather their experiences with IVF and related add-ons. The questionnaire took approximately 15 minutes to complete and was pilot tested for clarity. Recruitment occurred via social media, aided by Fertility Network UK, to capture diverse perspectives. Data collection ran from January 17 to June 17, 2024, with eligibility criteria ensuring participants were 18 or older and resided in the UK. The survey included sociodemographic questions and assessed experiences with fertility add-ons, information sources, and associated costs, maintaining anonymity to encourage honest responses.

A total of 306 responses were collected for the study, with 304 qualifying for inclusion. Although not specifically targeting women, the majority of respondents (300) were female. Most participants identified as White (272) and were in heterosexual relationships (262). The respondents represented various age groups and geographic locations across the UK. Among them, the majority (177) had undergone treatment within the last two years, while 63 were prospective patients. Funding sources varied, with 48 relying solely on NHS support, 109 self-funding, and 82 utilizing a combination of both. The majority were highly educated, with 131 holding undergraduate degrees and 113 holding postgraduate degrees, while 222 reported a gross annual income exceeding £50,000.

## Add-on use, information sources and how reliable patients find them

This section offers a detailed breakdown of the data regarding add-on use, information sources, and patients' perceptions of their reliability.

<b>Question 13: Have you used any additional fertility tests and/or treatments (add-ons) other than IVF?</b>	<b>Yes (N)</b>	<b>Yes (%)</b>	<b>No (N)</b>	<b>No (%)</b>
Time-lapse imaging and incubation	82	41.4	116	58.6
Hyaluronate enriched pre-transfer culture medium (e.g. EmbryoGlue)	71	36.6	123	63.4
Elective freeze	46	24.6	141	75.4
Other treatments (please specify in the question below)	38	22.8	129	77.2
Endometrial scratching	42	22.3	146	77.7
I don't know	11	21.6	40	78.4
Immunological tests and treatments for fertility – Steroids (glucocorticoids)	32	17.4	152	82.6
Immunological tests and treatments for fertility – Intralipids	30	16.0	158	84.0
Pre-implantation genetic testing for aneuploidy (PGT-A)	27	15.1	152	84.9
Endometrial receptivity testing	23	12.6	159	87.4
Physiological intracytoplasmic sperm injection (PICSI)	20	11.1	160	88.9
Assisted Hatching	14	7.7	167	92.3
Intracytoplasmic morphologic sperm injection (IMSI)	11	6.2	165	93.8
Immunological tests and treatments for fertility – Intravenous immunoglobulin (IVIG)	11	6.1	168	93.9
Intrauterine culture	8	4.7	163	95.3
Prefer not to say	1	3.2	30	96.8

<b>Where patients received fertility treatment add-ons</b>	<b>N</b>	<b>%</b>
Both NHS and private	29	13.7
I don't know	18	8.5
NHS	28	13.3
Prefer not to say	8	3.8
Private	128	60.7

<b>Question 26. Which, if any, of the following sources have you or your partner used to find information about additional fertility tests and/or treatments (add-ons)?</b>	<b>Yes (N)</b>	<b>Yes (%)</b>	<b>No (N)</b>	<b>No (%)</b>
Search engines (e.g. Google)	194	87.8	27	12.2
Clinic websites	153	75.4	50	24.6
HFEA website	125	59.5	85	40.5
Medical/scientific articles	105	54.4	88	45.6
Social network sites (e.g. Facebook, Instagram, Twitter)	103	53.1	91	46.9
Charities (e.g. Fertility Network UK)	105	50.7	100	49.3
Online forums (e.g. Mumsnet, Netmums, FertilityFriends)	77	40.1	115	59.9
Friends or family	69	35	128	65
Podcasts	58	31.2	128	68.8
Books or magazines	49	26.1	139	73.9
I don't remember/None of these	13	23.6	42	76.4
Online written blog(s)	42	22.8	142	77.2

Events, such as open evenings	39	21.4	143	78.6
Video blog(s) (e.g. on YouTube)	30	16.8	149	83.2
I don't know	6	15.4	33	84.6
Cochrane reviews	27	14.8	156	85.2
Manufacturer websites	19	10.8	157	89.2
Other (please specify in the question below)	3	8.1	34	91.9
Prefer not to say	0	0	32	100

**Question 27. Please rate the reliability of the following online sources of information about additional fertility tests and/or treatments (add-ons) on a scale of 1 to 5, with 1 being extremely unreliable and 5 being extremely reliable.**

<b>Charity websites (e.g., Fertility Network UK)</b>	<b>N</b>	<b>%</b>
1. Extremely unreliable	0	0
2. Rather unreliable	7	3.6
3. Neither unreliable nor reliable	41	21.4
4. Rather reliable	85	44.3
5. Extremely reliable	59	30.7
<b>HFEA website</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	8	4.3
3. Neither unreliable nor reliable	44	23.5
4. Rather reliable	64	34.2
5. Extremely reliable	71	38
<b>NHS website</b>		

1. Extremely unreliable	6	3.4
2. Rather unreliable	22	12.3
3. Neither unreliable nor reliable	65	36.3
4. Rather reliable	58	32.4
5. Extremely reliable	28	15.6
<b>NHS fertility clinic websites</b>		
1. Extremely unreliable	4	2.3
2. Rather unreliable	19	10.9
3. Neither unreliable nor reliable	64	36.6
4. Rather reliable	68	38.9
5. Extremely reliable	20	11.4
<b>Private fertility clinic websites</b>		
1. Extremely unreliable	1	0.5
2. Rather unreliable	19	9.9
3. Neither unreliable nor reliable	56	29.3
4. Rather reliable	91	47.6
5. Extremely reliable	24	12.6
<b>Social network sites (e.g., Facebook, Instagram, Twitter)</b>		
1. Extremely unreliable	13	7.1
2. Rather unreliable	32	17.6
3. Neither unreliable nor reliable	89	48.9
4. Rather reliable	43	23.6
5. Extremely reliable	5	2.7

<b>Online blogs</b>		
1. Extremely unreliable	11	6.7
2. Rather unreliable	37	22.4
3. Neither unreliable nor reliable	85	51.5
4. Rather reliable	29	17.6
5. Extremely reliable	3	1.8
<b>Video blog(s) (e.g., on YouTube)</b>		
1. Extremely unreliable	12	7.4
2. Rather unreliable	33	20.4
3. Neither unreliable nor reliable	91	56.2
4. Rather reliable	25	15.4
5. Extremely reliable	1	0.6
<b>Forums (e.g., Mumsnet, Netmums, FertilityFriends)</b>		
1. Extremely unreliable	12	6.9
2. Rather unreliable	39	22.5
3. Neither unreliable nor reliable	90	52
4. Rather reliable	28	16.2
5. Extremely reliable	4	2.3
<b>Medical/scientific articles</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	7	4.3
3. Neither unreliable nor reliable	49	30.2
4. Rather reliable	54	33.3

5. Extremely reliable	52	32.1
<b>Cochrane reviews</b>		
1. Extremely unreliable	2	1.4
2. Rather unreliable	6	4.2
3. Neither unreliable nor reliable	86	60.1
4. Rather reliable	26	18.2
5. Extremely reliable	23	16.1
<b>Manufacturer websites</b>		
1. Extremely unreliable	4	2.8
2. Rather unreliable	14	9.7
3. Neither unreliable nor reliable	102	70.3
4. Rather reliable	20	13.8
5. Extremely reliable	5	3.4

### Cost of treatment and transparency

This section offers a detailed breakdown of the data regarding the cost of treatment and transparency.

#### Question 15a. How much in £ did you have to pay yourself to cover additional costs in your last NHS funded treatment?

(mean (SD))	Median	Minimum	Maximum	1 <sup>st</sup> Quartile	3 <sup>rd</sup> Quartile
325.49 (711.72)	0.00	0.00	2750.00	0.00	70.00

#### Question 15b. How much in £ did you have to pay in total to cover your last privately funded treatment?

(mean (SD))	Median	Minimum	Maximum	1 <sup>st</sup> Quartile	3 <sup>rd</sup> Quartile
11950.39 (24040.85)	8050.00	800.00	300000.00	5000.00	13000.00

**Question 16. How much in £ did you approximately pay for each of the categories below in your last treatment? Please state the price in £.**

	<b>Mean (SD)</b>	<b>Median</b>	<b>Minimum</b>	<b>Maximum</b>	<b>1<sup>st</sup> Quartile</b>	<b>3<sup>rd</sup> Quartile</b>
<b>Fertility treatment</b>	6778.31 (8755.30)	5000.00	0.00	75000.00	2700.00	8750.00
<b>Fertility testing (pre-treatment)</b>	870.70 (1388.60)	500.00	0.00	10000.00	190.00	1000.00
<b>Prescription charges for drugs</b>	1539.27 (2425.16)	1000.00	0.00	20000	200.00	2000.00
<b>Additional fertility tests and/or treatments (add-ons)</b>	1299.45 (2459.66)	495.00	0.00	15000.00	0.00	1425.00
<b>HFEA fee</b>	70.05 (79.87)	80.00	0.00	350.00	0.00	85.00
<b>Other costs</b>	1826.16 (4325.00)	500.00	0.00	21000.00	0.00	1000.00

**Question 15b. How much in £ did you have to pay in total to cover your last privately funded treatment?**

**Responses analysed by location of most recent privately funded treatment**

<b>NHS facilities (mean (SD))</b>	<b>Private facilities (mean (SD))</b>	<b>I do not know (mean (SD))</b>
6990.00 (4810.37)	12977.02 (27070.87)	16333.33 (8755.95)

**Question 15b. How much in £ did you have to pay in total to cover your last privately funded treatment?**

**Responses analysed by treatment cycle**

<b>Considering*</b>	<b>1 cycle</b>	<b>2-3 cycles</b>	<b>≥ 4 cycles</b>
20536.17 (30555.76)	13000.00	0.00	300000.00

\*Numbers were calculated on observed cases. This makes the mean values in the 'considering' category erroneous

**Question 19. What is the total amount in £ you have personally paid for all the fertility treatment cycles you have undergone so far?**

<b>(mean (SD))</b>	<b>Median</b>	<b>Minimum</b>	<b>Maximum</b>	<b>1<sup>st</sup> Quartile</b>	<b>3<sup>rd</sup> Quartile</b>
20536.17 (30555.76)	13000.00	0.00	300000.00	5000.00	25000.00



**Question 32. Overall, was the cost-related information you received from your clinic clear and reliable?**

	<b>N</b>	<b>%</b>
I don't know	30	11.5
No	53	20.2
Prefer not to say	4	1.5
Yes	175	66.8

**Question 31. Did you receive a bespoke costing for your treatment from your clinic?**

	<b>N</b>	<b>%</b>
I don't know	18	6.6
I haven't started treatment yet	47	17.3
I received complete information about the cost before I started my treatment (including fertility testing, drugs, and add-ons)	131	48.2
I received partial information about the cost before I started my treatment (including fertility testing, drugs, and add-ons), but additional costs I was not aware of were added later	74	27.2
Prefer not to say	2	0.7

**Question 17. In your last treatment, did you expect to pay for additional fertility tests and/or treatments (add-ons) other than IVF?**

	<b>N</b>	<b>%</b>
I don't know	21	9.4
No. I did not expect to pay for additional fertility treatments before starting. I was informed during treatment	27	12.1
No. I did not expect to pay for additional fertility treatments before starting. They were included in the initial cost	39	17.4
Yes, but I ended up paying more than advised before treatment	30	13.4
Yes. I paid the amount advised before starting treatment	90	40.2
Other	16	7.1
Prefer not to say	1	0.4

**Question 18. In your last treatment, was the total cost you were advised about before starting the treatment the same as the amount you paid at the end?**

	<b>N</b>	<b>%</b>
I don't know	22	10.1
No, I ended up paying less than what I was advised before starting the treatment	5	2.3
No, I ended up paying more than what I was advised before starting the treatment	59	27.2
Prefer not to say	1	0.5
Yes, I ended up paying what I was advised before starting the treatment	130	59.9

## Cost information sources

This section offers a detailed breakdown of the data regarding the cost information sources.

Question 28. Before starting your treatment, where did you look for information to verify your treatment costs?	Yes (n)	Yes (%)	No (n)	No (%)
Private fertility clinic website	239	96	10	4
Conversation with fertility clinic staff	166	75.8	53	24.2
NHS fertility clinic websites	126	58.3	90	41.7
Fertility clinic leaflets	105	51.7	98	48.3
Conversations with people who have undergone similar treatment	98	49.5	100	50.5
Social network sites (e.g. Facebook, Instagram, Twitter)	77	40.3	114	59.7
Human Fertilisation and Embryology Authority (HFEA) website	66	34.7	124	65.3
Conversations with friends or family members	59	31.4	129	68.6
Forums (e.g. Mumsnet, Netmums, FertilityFriends)	40	22.1	141	77.9
Prefer not to say	7	10.8	58	89.2
Other sources (please specify in the question below)	9	7.6	109	92.4

Video blog(s) (e.g. on YouTube)	12	6.9	161	93.1
Online blogs	11	6.4	161	93.6

**Question 29. Please rate the reliability of the following sources of information about the cost of fertility treatment on a scale of 1 to 5, with 1 being extremely unreliable and 5**

<b>NHS fertility clinic websites</b>	N	%
1. Extremely unreliable	0	0
2. Rather unreliable	34	17.7
3. Neither unreliable nor reliable	66	34.4
4. Rather reliable	53	27.6
5. Extremely reliable	26	13.5
<b>Private fertility clinic websites</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	21	9.8
3. Neither unreliable nor reliable	38	17.7
4. Rather reliable	102	47.4

5. Extremely reliable	47	21.9
<b>Fertility clinic leaflets</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	18	10.2
3. Neither unreliable nor reliable	63	35.8
4. Rather reliable	68	38.6
5. Extremely reliable	24	13.6
<b>Conversation with fertility clinic staff</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	16	8.6
3. Neither unreliable nor reliable	44	23.7
4. Rather reliable	74	39.8
5. Extremely reliable	49	26.3
<b>Human Fertilisation and Embryology Authority (HFEA) website</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	13	7.8

3. Neither unreliable nor reliable	76	45.8
4. Rather reliable	53	31.9
5. Extremely reliable	22	13.3
<b>Social network sites (e.g. Facebook, Instagram, Twitter)</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	30	18.9
3. Neither unreliable nor reliable	79	49.7
4. Rather reliable	33	20.8
5. Extremely reliable	6	3.8
<b>Online blogs</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	28	18.8
3. Neither unreliable nor reliable	92	61.7
4. Rather reliable	15	10.1
5. Extremely reliable	1	0.7
<b>Video blog(s) (e.g. on YouTube)</b>		

1. Extremely unreliable	0	0
2. Rather unreliable	29	19.7
3. Neither unreliable nor reliable	94	63.9
4. Rather reliable	11	7.5
5. Extremely reliable	1	0.7
<b>Forums (e.g. Mumsnet, Netmums, Fertility Friends)</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	33	21.6
3. Neither unreliable nor reliable	86	56.2
4. Rather reliable	19	12.4
5. Extremely reliable	2	1.3
<b>Conversations with friends or family members</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	25	16
3. Neither unreliable nor reliable	80	51.3
4. Rather reliable	34	21.8

5. Extremely reliable	8	5.1
<b>Conversations with people who have undergone similar treatment</b>		
1. Extremely unreliable	0	0
2. Rather unreliable	18	11.3
3. Neither unreliable nor reliable	60	37.7
4. Rather reliable	60	37.7
5. Extremely reliable	18	11.3

<b>Question 30. Have you found the cost-related information you looked for on fertility clinic websites?</b>	<b>N</b>	<b>%</b>
I don't know	13	4.7
No, I didn't find the costs I looked for	27	9.8
No, I found the cost of additional fertility tests and/or treatments (add-ons), but not the cost of basic treatment	7	2.5
Other	9	3.3
Yes, but I found only the costs of basic IVF treatment	83	30.2
Yes, I found the costs of basic IVF treatment, as well as of each additional fertility test and/or treatment (add-on)	136	49.5



## Policy recommendations informed by patient perspectives

This section offers a detailed breakdown of the data regarding policy recommendations informed by patient perspectives.

<b>Question 34. In your opinion, what actions should be taken to ensure that fertility clinics provide accurate and updated information on their websites? (This was a multi-answer question)</b>	<b>Yes</b>	<b>%<sup>°</sup></b>
Implement regular audits or reviews of website information	233	82
Enhance transparency through patient feedback or rating systems	190	66.9
Establish an independent oversight body to monitor website accuracy	159	56
Invest profits from treatment add-ons in research to establish conclusive evidence about their effectiveness	139	48.9
Provide resources or tools for clinics to easily update their website data	125	44
Offer incentives or penalties for clinics based on information accuracy	99	34.9
Develop public website compliance reports or databases	90	31.7
I don't know	14	4.9
<sup>°</sup> The percentages presented in this table were calculated based on the total number of answers, which is 284.		

**Q35. On a scale of 1 to 5, with 1 being 'Not helpful at all' and 5 being 'Extremely helpful,' please indicate to what extent the following proposals would be helpful for you as a (prospective) patient:**

<b>Providing accurate and updated information about the total expected cost of treatment, on fertility clinic websites</b>	N	%
1. Not helpful at all	1	0.4
2. Rather unhelpful	0	0
3. Neither unhelpful nor helpful	10	4
4. Rather helpful	31	12.4
5. Extremely helpful	208	83.2
<b>Providing accurate information about the total expected cost of treatment, directly to patients after initial consultation in a fertility clinic</b>		
1. Not helpful at all	2	0.8
2. Rather unhelpful	2	0.8
3. Neither unhelpful nor helpful	8	3.3
4. Rather helpful	31	12.6
5. Extremely helpful	203	82.5

<b>Sharing information about the total amount charged by a clinic on average per treatment</b>		
1. Not helpful at all	2	0.8
2. Rather unhelpful	9	3.7
3. Neither unhelpful nor helpful	21	8.6
4. Rather helpful	67	27.5
5. Extremely helpful	145	59.4
<b>Sharing information about the number and cost of treatment add-ons offered by a clinic per year</b>		
1. Not helpful at all	3	1.2
2. Rather unhelpful	7	2.9
3. Neither unhelpful nor helpful	29	11.9
4. Rather helpful	64	26.2
5. Extremely helpful	141	57.8
<b>Providing information on the actual costs of treatment add-ons incurred by clinics, including the mark-up compared to the charges imposed on patients</b>		
1. Not helpful at all	5	2
2. Rather unhelpful	9	3.7

3. Neither unhelpful nor helpful	27	11.1
4. Rather helpful	54	22.1
5. Extremely helpful	149	61.1

### Additional Resources

**References:** Perrotta, M., Smietana, M., Adesina, M. and Wilkinson, J. (2024). 'Exploring fertility treatment add-on transparency in the UK: Patient survey results on information and costs'. Pre-print available at [www.qmul.ac.uk/remaking-fertility/survey-results](http://www.qmul.ac.uk/remaking-fertility/survey-results)

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