



Greater Manchester

Appendix 1



Greater Manchester

GM IVF cycles review engagement report

Executive Summary

During the engagement period, which ran from 21 May to 16 June 2024, NHS Greater Manchester (NHS GM) interacted with 440 people. Details as below:

Method	Engagement numbers
Online survey	433
Emails	4
Phone calls	3
Social media (21st to 24th May 2024 only – due to pre-election period limitations)	Reach: 12,265 Engagement: 128

The majority of respondents supported the principle of a standardised number of cycles being offered across Greater Manchester. Many felt the current arrangements were unfair or discriminatory, with the phrase “postcode lottery” often used to describe the current arrangements. Many respondents told us they would rather level up to a higher number of cycles available in another locality or adopt the NICE recommendation of 3 cycles. Quite a few respondents told us that 2 cycles would be more feasible, as they perceived the first cycle to be effectively a trial run and that success rates would always be low.

The impact that the currently differing numbers of cycles across localities had on people, and the potential impact if the number of cycles was reduced for some or all localities following the review was highlighted by many people. The main points raised concerned impact on mental health, relationships and work pressures, people relocating, inability to afford to pay for IVF, getting into debt to afford more cycles, reduced success rates, and reduction in chances of getting pregnant.

Over half of respondents said they would be impacted by any change in the number of cycles. There is the potential that people living in certain localities could be negatively impacted more than others if the number of cycles was reduced. Alternatively, if the number of cycles offered was raised for some localities, this would have a positive impact.

Textual analysis highlighted the following demographics would be impacted: current IVF patients/those on waiting list; single women; gay/same sex couples; certain faiths; age; disability, low socio-economic backgrounds or others with limited capacity to self-fund fertility treatment.

It was suggested by some that there should be IVF standardisation between same sex couples and heterosexual couples. Some patients felt discriminated against due to their sexuality or being single, affecting their access to treatment. It was also suggested that Intrauterine Insemination funding should be re-evaluated. This has been noted for future reference although it is outside the scope of the review.

People have had varied experiences with IVF treatment. Some found success with multiple cycles, while others faced challenges like administrative delays, poor communication, and unexpected funding limitations.

Some people suggested that, as the NHS is facing financial challenges, it should be honest with the people and advise that things need to change or be cut.

This engagement insight will be used by the NHS GM IVF Cycles Project Group to help inform the draft Equality Impact Assessment and any further engagement requirements should the project progress to formal consultation. The Group will also use the insight gained to help inform the criteria by which potential options are evaluated.

Introduction and background

In vitro fertilisation (IVF) is one of several ways available to help people with fertility problems. People with fertility problems may find it harder to get pregnant.

NHS GM is reviewing the number of times people can try NHS IVF treatment across Greater Manchester. This is because depending on where a person lives, it might not be the same as other people. Each IVF try is known as an IVF cycle.

NHS GM would like to look at how they can make accessing IVF treatment the same across Greater Manchester.

Things are different across Greater Manchester because the number of cycles were agreed when there were ten different NHS organisations, known as Clinical Commissioning Groups, making the decisions about healthcare. In July 2022, these were replaced by one organisation known as NHS Greater Manchester. NHS Greater Manchester is one of 42 Integrated Care Boards (ICBs) in England. ICBs are NHS organisations responsible for planning health services for the local population.

Eligibility across GM: For eligible people aged 39 and under, with a GP in these areas, the NHS will pay for:

- Bolton, Bury, Rochdale, Manchester, Oldham and Trafford patients can get 1 cycle of IVF (and receive a second try for a cancelled or abandoned cycles)
- Salford, Stockport and Wigan patients can get 2 IVF cycles (this includes cancelled or abandoned cycles)
- Tameside patients can get 3 IVF cycles (this includes cancelled or abandoned cycles)

To find out more about IVF in Greater Manchester and the criteria for eligibility view the NHS GM assisted conception policy.

The national picture: Access to NHS paid for IVF cycles also varies nationally:

- 24 ICBs provide 1 IVF cycle
- 7 ICBs provide 2 IVF cycles
- 4 ICBs provide 3 IVF cycles
- 7 ICBs have this under review

We have looked at our neighbouring ICBs:

- Cheshire and Merseyside are currently reviewing theirs
- Lancashire and South Cumbria offer 1 IVF cycle
- West Yorkshire offer 1 IVF cycle
- Staffordshire and Stoke-on-Trent offer 1 IVF cycle.

Approach

Considerable engagement had already been undertaken throughout Greater Manchester regarding IVF and cycles, so we started off by gathering and reviewing previous work.

We then developed a programme of proportional engagement that aimed to:

- test those previous findings still held true
- particularly seek views from localities where previous engagement had not taken place for whatever reason and, based on our Equality Analysis, targeting the south asian and LGBTQ+ communities whose views we understood least.

The engagement programme to support this project was broken into two phases.

Phase	Engagement activity	Aims and objectives
Phase 1 4 Feb-14 March 2024	Desktop exercise & draft Equality Impact Assessment developed	<ul style="list-style-type: none"> • Ascertain the type and level of engagement undertaken previously by GM CCGs • enable the IVF cycles project group to learn from and understand the issues/feedback raised during engagement activities and use the feedback to help

	Findings can be found at Appendix G	<p>inform an options appraisal and any further engagement activity</p> <ul style="list-style-type: none"> • make recommendations on the need to undertake further engagement prior to identifying options should consultation be required. • Consider gaps in insight and those who might be disproportionately affected by any changes.
<p>Phase 2</p> <p>21 May-16 June (Initially 2 weeks but extended to 3 weeks 6 days)</p>	<p>Engagement activities to address gaps in insight as highlighted in Phase 1 (pre-consultation engagement)</p> <p>Survey</p>	<p>To test that previous findings still hold and particularly seek views from localities where previous engagement has not taken place for whatever reason, and the south Asian and LGBTQ+ communities who we understand least</p>

It should be noted that a General Election was announced by the Prime Minister on 22 May and resulting in a pre-election period from 25 May affected what public bodies can do bodies to adhere to. This impacted on NHS GM’s ability to promote engagement activities during the majority of the Phase 2 engagement period. Therefore the engagement period was extended as mitigation.

Phase 2 – NHS GM engagement team ran an online survey between the 21 May and the 16 June. The survey received 433 responses over a period of 3 weeks and 6 days.

Social media posts were issued from 21st May up to and including 24th May 2024. This included paid for social media. Activity then ceased due to pre-election period limitations. To address this we: extended the phase 2 engagement activity to run for an additional week, with an online survey closing on Sunday 16 June instead of Sunday 9 June; liaised with Voluntary Action Oldham and LGBT Foundation to help us widen the reach to these South Asian and LGBTQ populations further. We contacted key voluntary, community, faith and social enterprise organisations across Greater Manchester to advise of the review and asked that they share details of how to get involved with their networks.

People were able to have their say by:

- completing the online survey;
- sharing their thoughts via Whatsapp,
- inviting NHS GM engagement team to attend their group (no invitations received).
- People were also able to request a printed version of the survey (one request received) and large print versions.

Whilst there were responses from a wide range of people and ages, the most common participant was a British woman aged between 26 and 45. 58.2% of participants to the survey described themselves as either having received IVF or may wish to in the future.

There were responses from across Greater Manchester, but the highest number was from participants living in Manchester, which correlates with that of the highest population. The demographic gaps during this pre-consultation included Black or Black British Caribbean and Gypsy/Traveller communities.

It should be remembered that the sample self-selected and was completed by far more people with experience of IVF than we would expect from the general population. Therefore we can say that the sample is representative of the public.

Findings

Findings from the phase 2 engagement are as follows:

Standardising the number of IVF cycles across GM

An overwhelming majority of respondents supported the principle of a standardised number of cycles being offered across Greater Manchester in place of the divergent numbers currently funded, as inherited from the 10 Clinical Commissioning Groups. Over 95% of respondents felt this standardisation was very or somewhat important. Many felt the current arrangements were unfair or discriminatory, with the phrase “postcode lottery” often used to describe the current arrangements.

However, the open text responses suggested that many respondents would rather level up to a higher number of cycles available in another locality or adopt the NICE recommendation of 3 cycles. Many respondents felt that 2 cycles were reasonable to provide, as several comments were made about health professionals having stating that the first cycle of IVF was considered to be a trial run and that success rates would always be low.

Consequences of current inequity or should number of cycles be reduced/increased.

Many respondents mentioned the impact that the current inequity of cycles across localities had on them, or would if the number of cycles were reduced for some or all localities following the review.

The main points raised were regarding mental health issues, relationships and work pressure, people relocating, inability to afford to pay for IVF, getting into debt to afford more cycles, reduced success rates, and reduction in chances of getting pregnant. It was suggested that waiting lists may become longer and therefore fertility may decrease for those on the waiting lists, if the number of IVF cycles were increased. Many respondents suggested that fertility treatment met a crucial health need and not just an emotional issue.

Those the changes could impact the most

Over half of respondents said they would be impacted by any change in the number of cycles. There is the potential that people living in certain localities could be negatively impacted more than others if the number of cycles was reduced. Alternatively, if the number of cycles offered was raised for some localities, this would have a positive impact.

Open text analysis highlighted the following demographics may be impacted the most: current IVF patients/those on waiting list; single women; gay/same sex couples; certain faiths; age; disability, low socio-economic backgrounds or others with limited capacity to self-fund fertility treatment.

Criteria/eligibility

It was suggested by some respondents that there should be IVF standardisation between same sex couples and heterosexual couples. Some patients felt discriminated against due to their sexuality or being single, affecting their access to treatment. It was also suggested that

Intrauterine Insemination funding should be re-evaluated. Although these issues are not in scope of this work, they have been recorded for future reference.

Experiences

We asked those respondents who were currently undergoing IVF or had done so previously, to tell us about their experience of undergoing IVF. The key themes from the experiences shared:

- **Mixed experiences:** People have had varied experiences with IVF treatment in Greater Manchester. Some found success with multiple cycles, while others faced challenges like administrative delays, poor communication, and unexpected funding limitations.
- **Positive outcomes:** Many individuals were able to conceive and have children through IVF, whether on the first try or after multiple attempts.
- **NHS funding issues:** There was dissatisfaction expressed with the NHS funding for IVF, particularly where this is limited to one cycle. This has caused financial strain and emotional hardship for those needing additional attempts.
- **Support for policy change:** Several participants believe the NHS should fund at least two cycles to better align with NICE guidelines. They argue that fertility treatment meets a crucial health need and is not just an emotional issue.
- **Discrimination concerns:** Some patients told us they faced discrimination or insensitive treatment based on their circumstances, including age-related policy changes and misunderstandings about eligibility.
- **Private care satisfaction:** Private clinics received positive feedback for their supportive and effective services, contrasting with some negative experiences in NHS settings.

Impact on mental health: The journey through IVF treatment has had significant emotional impacts for some, including stress and disappointment, particularly when treatments are ultimately unsuccessful.

- **Calls for better communication:** Many patients highlighted the importance of clear communication and support throughout the IVF process, emphasizing the need for improved patient care and information provision.

These findings underscore the complex and emotional nature of IVF treatment, and the lasting impact this often has on individuals.

NHS Finances

Some people suggested that, as the NHS is facing financial challenges, we should be honest with the people and advise that things need to change or be cut.

The full analysis of the engagement is included in the appendices.

Conclusions and Recommendations

This insight should be used by NHS GM [GM IVF Cycles Project Group] to help inform:

- the draft Equality Impact Assessment update and any further engagement requirements should the project progress to formal consultation
- the criteria we should use to assess options for standardisation
- any future wider Assisted Conception service review – especially regarding criteria and discrimination concerns relating to single people and same sex couples

The engagement activity met the objectives to a) test that previous insight regarding IVF still held and b) particularly seek views from localities where previous engagement had not taken place for whatever reason, and c) the south Asian and LGBTQ+ communities who we understand least.

When considering the standardisation of IVF cycles across Greater Manchester, we should be particularly mindful of:

- considerable support for the principle of standardising the number of cycles across Greater Manchester
- the consequences of any change on individuals undergoing or seeking treatment
- any mitigations which could be put in place for those who may be particularly impacted by any proposed change
- the consequences of current inequity across Greater Manchester

During any future period of engagement, we should involve the **voice of lived experience and/or special interest groups** and target participants who have been underrepresented in the survey: **Black or Black British Caribbean and Gypsy/Traveller**. If affected, we should undertake **targeted engagement in any specific localities (should we reduced number of cycles in certain localities)**.

Appendix A

Telephone call/Teams calls - Notes

Public

We received no telephone calls from members of the public

Specialist advice

We had telephone conversations with representatives from following groups to seek support on widening reach of publication of the survey and ask if there were any specific established groups we could liaise with further to help address any gaps in our engagement.

Date	Organisation	Channel
23 May	Action Together Oldham (South Asian population)	Telephone
4 June	LGBT Foundation (Same sex couples)	MS Teams
11 June	NHS GM Equality & Diversity Team	MS Teams

Appendix B

Email submissions

We received 4 email submissions which have been included as follows:

Email 1:

From: Name removed

Sent: Wednesday, May 22, 2024 12:28 PM

To: ENGAGEMENT (NHS GREATER MANCHESTER INTEGRATED CARE BOARD)

[<gmhscp.engagement@nhs.net>](mailto:gmhscp.engagement@nhs.net)

Subject: vitro fertilisation (IVF)

Hi

We are planning to share your IVF survey on our Bolton Public Health social media channels.

Do you have a comms toolkit or any other promotional materials that we could use to help support.

Thanks

Email 2:

From: Name removed

Sent: Friday, May 24, 2024 11:04 PM

To: ENGAGEMENT (NHS GREATER MANCHESTER INTEGRATED CARE BOARD)

[<gmhscp.engagement@nhs.net>](mailto:gmhscp.engagement@nhs.net)

Subject: Ivf

Hi,

I am from rochdale i need printed version of survey

Email 3:**From:** Name removed**Sent:** Thursday, May 30, 2024 4:27 PM**To:** ENGAGEMENT (NHS GREATER MANCHESTER INTEGRATED CARE BOARD)[<gmhscp.engagement@nhs.net>](mailto:gmhscp.engagement@nhs.net)**Subject:** IVF survey feedback

Hello,

I have recently completed your IVF survey and have some concerns about the survey design. I feel that due to poor question and overall survey design the data you collect will not be robust enough to be used to inform policy decisions. There is a high risk of findings being misinterpreted or being used in a way which isn't transparent. My particular concerns are around lack of questions about the number of cycles, whilst asking whether participants favour the number of cycles being equal across GM.

I would like to query how you have analytically assured this survey?

Kind regards

Email 4:**From:** Fertility Network UK**Sent:** Friday, May 31, 2024 10:32 AM**To:** ENGAGEMENT (NHS GREATER MANCHESTER INTEGRATED CARE BOARD)[<gmhscp.engagement@nhs.net>](mailto:gmhscp.engagement@nhs.net)**Subject:** Review of IVF Cycles-Greater Manchester**Importance:** High

Hi,

Having found your social media post about reviewing the number of IVF cycles across the Greater Manchester ICB and as the leading fertility patient support charity, please could we be included on any expert panels and/or consultations that are involved in this decision-making process as well. It would have been great to have been contacted about this directly but I am sure we can work together with this review, please.

We have worked in the past with other ICB's consultation teams when reviewing IVF policies and we have shared your social media post on our social media channels and with any of our relevant fertility groups on Facebook, including our ethnic minority fertility groups too.

I look forward to hearing from you soon.

Kind regards

Appendix C

Social Media Analysis

NHS GM Digital Communications team coordinated the promotion of the survey via NHS GM social media accounts.

Social media posts were issued from 21st May up to and including 24th May 2024. Due to pre-election limitations, NHS GM was unable to actively promote the survey and how to get involved on social media past this point.

Date	Time	Channel	Organic or paid	Media/asset	Notes	Impressions or reach	Engagements	Engagement rate
21 st May 2024	11.55 am	GM ICP X	Organic	GIF		763	19	0.11%
21 st May 2024	11.35 am	GM ICP Facebook	Organic	GIF		368	16	2.97%
21 st May 2024		GM ICP Instagram	Organic	Static, split image on the grid (x3)		24 15 15 Total – 54	4 2 Total - 6	7.23%
24 th May 2024		GM ICP Facebook	Booste d (paid)	Static	£42 spe nt.	8973	77	14.13%
24 th May 2024		GM ICP Instagram	Booste d (paid)	Static	£14 spe nt.	2107	10	12.05%

It was highlighted by the team that the NHS GM IVF cycles website page was well visited in the short period of time social media activity was running. Content was well

engaged on Facebook and Instagram.

When thinking about the next phase of engagement, the digital team have suggested creating some different assets, such as clinician or commissioner talking, to help with engagement. They also suggested undertaking additional stakeholder mapping to understand if there are local organisations and community groups to reach out to from a digital point of view.

Appendix D

Online survey

Question 1

1. Are you responding mainly as:			Response Percent	Response Total
1	A member of the public/patient		80.60%	349
2	A carer		0.00%	0
3	A health/care professional		17.09%	74
4	Local Government		0.00%	0
5	An interested party responding on behalf of an organisation		0.46%	2
6	Community/faith group		0.00%	0
7	Other (please specify):		1.85%	8
			answered	433
			skipped	2

433 people answered this question. Most respondents (80%) were members of the public, with a further 17% being health or care professionals. There were two people who responded on behalf of an organisation.

Of the 8 people who ticked the “other” option, 7 people provided further details in the free text who identified themselves as:

- Health care professional and member of the public
- Previously refused NHS fertility treatment due to criteria.
- Concerned Individual
- Disability Equality Rights Expert & with a life-long disability experiencing inequalities

- Someone who works in healthcare and someone affected by IVF
- Patient
- Healthcare professional and previous IVF patient.

Question 2

2. Where do you live? (Greater Manchester covers the areas of Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Tameside, Trafford and Wigan) Please tick one:					
				Response Percent	Response Total
1	Bolton			2.99%	13
2	Bury			5.98%	26
3	Manchester			21.61%	94
4	Oldham			4.14%	18
5	Rochdale (incl Heywood & Middleton)			3.91%	17
6	Salford			6.67%	29
7	Stockport			17.47%	76
8	Tameside			6.67%	29
9	Trafford (incl Altrincham, Old Trafford, Sale and Urmston)			13.56%	59
10	Wigan (incl Ashton-in-Makerfield and Leigh)			11.95%	52
11	I do not live in Greater Manchester (tell us where you live below)			5.06%	22
				answered	435
				skipped	0

435 people responded to this question, with over 95% of respondents living in Greater Manchester. The largest number of responses were from those living in the City of Manchester. This is not surprising due to the higher population in this city.

Of the 22 people who told us they did not live in Greater Manchester, the majority (17 in total) lived in the North West region. They told us they lived in: Cheshire, Darwin, Lancashire, Lancaster, Macclesfield, Merseyside, Prescott, Preston, Rossendale and Wirral. These areas are based within neighbouring Integrated Care Board locations.

5 people told us they lived in the following areas: Buxton, Glossop, London, Solihul, Wolverhampton.

Question 3

3. Are you receiving or have you or your partner received IVF cycle treatment to help you try to have a baby?				
			Response Percent	Response Total
1	Yes NHS funded IVF		21.71%	94
2	Yes IVF paid by myself		7.39%	32
3	Yes both NHS funded IVF and paid myself too		9.24%	40
4	No but I may consider using NHS funded IVF in the future		18.48%	80
5	No but I may consider using IVF which I will pay for myself in the future		1.39%	6
6	No		36.26%	157
7	Prefer not to say		1.85%	8
8	Other (please specify):		3.70%	16
			answered	433
			skipped	2
Other (please specify): (16)				
1	Was due to receive NHS funded IVF but fell pregnant naturally just before we commenced the treatment			
2	Also due to start Private IVF			
3	Both N H S and self funded			
4	Waiting for fertility testing			
5	We were going through the process to receive IVF on the NHS but conceived naturally			
6	No because we are a gay couple we are not entitled until we have paid for IVF ourselves			

3. Are you receiving or have you or your partner received IVF cycle treatment to help you try to have a baby?			Response Percent	Response Total
7	I have a same sex partner and we are privately funding IUI treatment			
8	Same sex relationship should be equal opportunities with funding for ivf being provided.			
9	still starting process			
10	I am aware this survey is about IVF however, my partner had self funded IUI in a Manchester NHS hospital. Its unfair that we had to pay for IUI to 'prove' infertility because she was in a same sex relationship yet heterosexuals receive NHS funded IUI. Clearly discriminatory based on sexuality.			
11	IUI moving onto IVF			
12	Self funded IUI			
13	Had to have fertility treatments, just avoided IVF			
14	I am currently on the waiting list for this service			
15	In progress - on the waiting list			
16	Self funded iui and NHS funded ivf			

The reason for this question was to understand what proportion of respondents had experience of using IVF services. 38% of respondents had used IVF before (either NHS or self-funded). A further 19% said they may consider using IVF in the future.

In the "Other" free text, some people highlighted: they were due to start IVF but conceived naturally; on a waiting list for IVF; funding IUI treatment; same sex couple not yet started nhs funded until self funded IVF first.

Question 4

4. Which of the following applies to you in relation to IVF? Tick one				
			Response Percent	Response Total
1	A woman receiving treatment with a male partner		89.71%	122
2	A man supporting a female partner		2.94%	4

4. Which of the following applies to you in relation to IVF? Tick one				
			Response Percent	Response Total
3	A woman without a partner		0.74%	1
4	A woman receiving treatment with a female partner		3.68%	5
5	A woman supporting a female partner		0.74%	1
6	Other (receiving treatment)		0.74%	1
7	Other (supporting someone receiving treatment)		0.00%	0
8	Prefer not to say		0.00%	0
9	Other (tell us below):		2.94%	4
			answered	136
			skipped	299
Other (tell us below): (4)				
1	Had baby via ivf			
2	Female couple who have had successful nhs ivf previously			
3	I'm a former patient, I had successful IVF treatment			
4	Egg donor recipient			

Of those with experience of IVF, women receiving treatment with a male partner represented the vast majority of respondents.

Question 5

5. How many cycles have been completed?				
			Response Percent	Response Total
1	0		12.59%	17
2	1		50.37%	68
3	2		17.78%	24

5. How many cycles have been completed?				
			Response Percent	Response Total
4	3		7.41%	10
5	More than 3		11.85%	16
			answered	135
			skipped	300

Of those who had been through IVF, more than half had completed one cycle. The average number of cycles completed (assuming more than 3 = 4) was 1.56 cycles.

Question 6

6. When you first thought about seeking NHS funded IVF treatment, which, if any, of the following did you use to find out more? Please tick all that apply.				
			Response Percent	Response Total
1	GP		85.29%	116
2	Search engines (e.g. Google)		55.88%	76
3	Online forums		30.15%	41
4	Friends or family		19.85%	27
5	HFEA (Human Fertilisation & Embryology Authority) website		29.41%	40
6	Books or magazines		4.41%	6
7	Clinic websites		25.00%	34
8	Social network sites (e.g. Facebook or Twitter)		17.65%	24
9	Video blog (e.g. YouTube or TikTok)		5.15%	7
10	None of these		2.21%	3
11	Other (please specify):		5.88%	8

6. When you first thought about seeking NHS funded IVF treatment, which, if any, of the following did you use to find out more? Please tick all that apply.			Response Percent	Response Total
			answered	136
			skipped	299
Other (please specify): (8)				
1	Hospital consultant			
2	Discussed with gynaecology team			
3	Fertility Network			
4	Found we weren't eligible as we were a same set couple.			
5	Fertility clinic following IUI treatment			
6	Sought private treatment, then referred back to NHS			
7	Hospital			
8	Journal articles on reimplantation failure			

The answer showed that clinicians, including GPs and specialists were very important as trusted sources of advice and guidance on IVF. However, online sources including websites, forums and social media were also influential. Family and friends were also a source of information. This will be useful in planning any future communications around IVF in Greater Manchester,

Question 7

7. Which of the following best describes the current situation?			Response Percent	Response Total
1	In the first treatment cycle		12.50%	17
2	Successful, led to birth and no longer pursuing IVF		36.76%	50
3	Successful and undecided whether to start another cycle		5.15%	7
4	Successful, led to birth and planning to start another cycle		10.29%	14

7. Which of the following best describes the current situation?

			Response Percent	Response Total
5	Unsuccessful and undecided whether to continue IVF		2.21%	3
6	Unsuccessful and planning to start another cycle		14.71%	20
7	Unsuccessful and no longer pursuing IVF		5.88%	8
8	Don't know		0.00%	0
9	Prefer not to say		0.00%	0
10	Other		12.50%	17

	answered	136
	skipped	299

Other (17)

1	Currently 6 weeks 5 days pregnant with 1st cycle
2	Currently on the waiting list.
3	Currently 6 weeks pregnant following 3rd ivf cycle
4	Awaiting treatment cycle
5	Waiting to start first treatment cycle
6	Had a miscarriage following IVF, got pregnant naturally just as about to start 2nd cycle privately
7	Currently pregnant on 5th cycle, after two miscarriages
8	Successful and currently pregnant
9	Unsuccessful first round. Completed 2nd egg collection and waiting to be able to have an embryo transfer in coming months
10	Unsuccessful twice then conceived naturally
11	I had three IVF cycles before moving to Greater Manchester, 2 of which were NHS and one private. The final one was successful. Since moving to Greater Manchester we have completed one more private cycle, which has resulted in a pregnancy that I am still carrying.
12	on the third round which was privately funded
13	Treatment has been paused
14	Unsuccessful but attained pregnancy naturally
15	had to pay for 6 cycles of self funded IUI, received 6 on the NHS, now we are about to start NHS funded by the NHS

7. Which of the following best describes the current situation?			Response Percent	Response Total
16	1 unsuccessful cycle. 1 cycle private and successful			
17	Unsuccessful 3 transfers from one cycle, currently pregnant (spontaneous). 5 years trying to conceive total, one previous miscarriage			

A little over a third of respondents who had access IVF services described a positive outcome and no longer pursuing IVF. The remainder were at a wide range of stages, meaning we have hopefully captured a wide range of experiences and perspectives.

Question 8

8. Overall, how would you rate your experience?			Response Percent	Response Total
1	Very good		31.34%	42
2	Good		42.54%	57
3	Neither good nor poor		11.19%	15
4	Poor		11.94%	16
5	Very poor		2.99%	4
			answered	134
			skipped	301

Nearly three quarters of respondents described their IVF experience as being good or very good. This is much higher than those who had a successful outcome suggesting that many women still felt seeking IVF had been positive despite their unsuccessful outcome.

Question 9

“Please tell us more about your experience (and tell us which clinic/service, if you wish us to know”

We received 102 responses to this open text question. We have summarised these, outlining key themes which cover the key experiences and concerns of patients undergoing IVF treatment, highlighting both the positives and the areas that respondents cited needed improvement.

- **Administration:** There are frequent issues with paperwork, delays, and poor communication from clinics.
- **Financial stress:** Limited NHS-funded cycles and the high cost of private treatment cause financial worries.
- **Communication:** Many patients experience unclear instructions and unresponsive clinics. Clear, accurate, and timely information about treatment options and processes is essential.
- **Emotional support:** Patients often feel unsupported emotionally, especially after unsuccessful treatments.
- **Discrimination:** Some patients feel discriminated against due to their sexuality or being single, affecting their access to treatment.
- **Quality of care:** Some praise the medical care, while others criticize it for unprofessional behaviour and lack of empathy.
- **Access to treatment:** Long waiting lists and delays in treatment are common concerns.
- **Funding inequality:** Inconsistencies in the number of funded cycles based on where people live, causing frustration.
- **Success rates:** Patients talk about the importance of identifying and treating underlying issues to improve success rates.
- **Embryo storage:** Concerns about the cost and handling of embryo storage are mentioned.
- **Patient experience:** Experiences vary greatly between clinics, with some patients switching due to poor experiences.

- **Policy problems:** Issues like age restrictions and eligibility criteria for NHS funding are discussed.
- **COVID-19 impact:** The pandemic has caused delays and affected treatment availability, adding stress.
- **Healthcare workers' views:** Insights from healthcare workers show their dedication but also the challenges they face.
- **Personal circumstances:** Age, health conditions, and relationship status significantly impact experiences and outcomes.
- **Emotional toll:** The emotional stress of infertility and IVF treatment, including anxiety and disappointment, is a recurring theme.
- **Thorough diagnosis needed:** The importance of thorough investigation and diagnosis to tailor treatments effectively is emphasized.
- **Success despite challenges:** Many patients experience success and are grateful for the chance to undergo treatment despite various challenges.

Question 10

The purpose of this question was to test support for the principle of having a single, consistent number of cycles offered across Greater Manchester. We did not ask how many cycles this should be at this stage.

Overall the responses were:

10. Do you think all eligible patients should be offered the same number of NHS funded IVF cycles, regardless of where they live in Greater Manchester? (please tick one box)			Response Percent	Response Total
1	Yes		96.54%	419
2	No		2.07%	9
3	Don't know		1.38%	6
			answered	434
			skipped	1

We can see that an overwhelming majority supported the principle of a standardised number of cycles being offered across Greater Manchester in place of the divergent numbers currently funded, as inherited from the 10 Clinical Commissioning Groups

290 respondents also left additional comments to explain their answers. The most frequently occurring themes, in order, were:

- 224 said they felt the current arrangements were unfair or discriminatory. 80 of these used the phrase “postcode lottery” to describe the current arrangements, eg “*The postcode lottery is demonstrably unfair. There is no reason why people living over the road from others can get twice as many cycles*”.
- 37 said they supported the principle but felt that, in practice, this should mean levelling up or at least not reducing cycles offered, eg “*this should not be a race to the bottom whereby that means people in areas currently receiving 2 or 3 cycles are now offered only 1*”.
- 29 also said they supported the principle but felt this should be applied nationally. 11 of these cited the current NICE guidelines (i.e. 3 cycles), eg “*The NICE guidelines recommend 3 cycles and I believe if you offered this across Greater Manchester that would be the fairest*”.
- 16 took the opportunity to express their incredulity at what they saw as the anomalous and illogical current situation, eg “*...seems ridiculous that on one side of an area they can get more than someone living somewhere else*”.
- 5 explained why they did not support the principle. Of these, three suggested some form of means testing to favour those who could least to pay for IVF privately, one felt 1 cycle would save funds and reduce waits and the other suggested increasing the number of IVF cycles funded would result in the number of couples able to access IVF decreasing.

In summary, this question suggests almost universal support for a consistent number of cycles being offered across Greater Manchester, largely driven by a feeling that the present situation is unfair. However, the text answers suggest that, to many respondents, this means levelling up to

a higher number of cycles available in another locality or adopting the NICE recommendation of 3 cycles.

Question 11

11. How important do you feel it is for all eligible patients to be offered the same number of NHS funded IVF cycles, regardless of where they live in Greater Manchester? (Please tick one box)			Response Percent	Response Total
1	Very important		88.25%	383
2	Somewhat important		8.76%	38
3	Neither important or unimportant		1.15%	5
4	Somewhat unimportant		0.69%	3
5	Very unimportant		1.15%	5
			answered	434
			skipped	1

We can see that majority of the respondents felt it was very important that the same number of funded IVF cycles should be offered to all eligible patients regardless of where they live in Greater Manchester.

A significant number of respondents also left additional comments to explain their answers. The most frequently occurring themes, in order, were:

- 74 respondents said that it would be equal and fair for there to be the same number of cycles offered across localities in Greater Manchester, eg *“The NHS must provide equal and adequate support to all, ensuring that everyone has a fair opportunity to make their dream of having a family come true.”*
- 59 respondents stated that the fact there are currently different offers available in each locality is a postcode lottery. IVF cycles of treatment should not be offered more or less depending on where you live, eg *“I am from Rochdale where you are only eligible for one cycle of IVF, however my partner is from Tameside where you are eligible for three*

rounds of IVF. Because I went to my GP to begin my investigations into my fertility issues, we are only eligible for one round. It is extremely unfair that if my partner would have gone to the GP first, we would have been able to receive more help with falling pregnant”.

- 8 respondents mentioned finance being a factor for inequity as some people are able to afford more cycles of treatment, or potentially afford to move house to an area which would offer more cycles, eg *“Parenthood should not be a financial luxury”.*
- 8 respondents suggested there needs to be flexibility in criteria for number of cycles and that more work needs to be done to support couples to investigate why they may not be getting pregnant, eg *“It is a very fragile process and allowance needs to be made for this with some level of flexibility”.*
- There were 15 comments which mentioned consequences of the inequity of cycles across localities. The main points were around contributing to mental health issues and people needing to move house or get in debt to afford more cycles, eg *“Knowing other regions get more cycles than you can really affect your mental status, when that one and only one fails. It feels like you are being punished in some way and the unfairness eats you away.*
- A further 12 comments categorically stated that one cycle was not enough, mixed responses between those that thought 2 cycles or three were the right way to go.
- 2 respondents thought that the current variation of offer was discriminatory.
- 2 Respondents quoted NICE guidance in that there is a recommendation of three cycles to be offered to patients.

Other comments included:

- *“Whilst in principle I value fairness, its not that big a deal to me”.*
- *“Because there are good outcomes and women prepared to go through this intensive process must be really committed (and partners)!”*
- *“I think the ideal number would be maximum 1, so I am not keen for us to match the highest number across GM”.*

Question 12

The purpose of this question was to gain further understanding of any characteristics of people or certain demographics who might be particularly affected.

There were 434 respondents to this question. Overall, 286 respondents out of 434 respondents (65.90%) said that people like them would be impacted. The table below outlines this further:

12. If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact people like you?			Response Percent	Response Total
1	Yes		65.90%	286
2	No		14.75%	64
3	Don't know		11.75%	51
4	Not applicable		7.60%	33
			answered	434
			skipped	1

A breakdown of how people from certain protected characteristics responded to this question can be found in appendix F.

When asked to give reasons why they would be affected' 211 respondents provided a response in the free text area of the question. After analysing the responses, we found 8 key cohorts of people outlined who may be particularly affected and these are detailed below:

- a) Those living in certain localities

The table below shows how respondents living in each GM locality answered this question.

Where do you live? (Greater Manchester covers the areas of Bolton, Bury, Manchester, Oldham, Rochdale, Sa...													
If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact ...		Bolton	Bury	Manchester	Oldham	Rochdale (incl Heywood & Middleton)	Salford	Stockport	Tameside	Trafford (incl Altrincham, Old Trafford, Sale and Urmston)	Wigan (incl Ashton-in-Makerfield and Leigh)	I do not live in Greater Manchester (tell us where you live below)	Row Totals
	Yes	10 76.9%	15 57.7%	74 78.7%	12 66.7%	14 82.4%	21 72.4%	38 50.0%	17 58.6%	39 67.2%	33 63.5%	13 59.1%	286 65.9%
	No	2 15.4%	6 23.1%	7 7.4%	3 16.7%	0 0.0%	2 6.9%	20 26.3%	5 17.2%	9 15.5%	8 15.4%	2 9.1%	64 14.7%
	Don't know	1 7.7%	4 15.4%	6 6.4%	1 5.6%	2 11.8%	4 13.8%	14 18.4%	3 10.3%	6 10.3%	4 7.7%	6 27.3%	51 11.8%
	Not applicable	0 0.0%	1 3.8%	7 7.4%	2 11.1%	1 5.9%	2 6.9%	4 5.3%	4 13.8%	4 6.9%	7 13.5%	1 4.5%	33 7.6%
Column Total	13 3.0%	26 6.0%	94 21.7%	18 4.1%	17 3.9%	29 6.7%	76 17.5%	29 6.7%	58 13.4%	52 12.0%	22 5.1%	434 100%	

A total of 1 responses were not included in the above report as they skipped one of the questions.

One respondent chose to live in a certain locality as it provided more IVF cycles “*It affected my consideration on where to buy a home, knowing that moving 5 minutes away could double the chances of having a child if IVF was needed*”. They could be affected if cycle numbers in their area are reduced.

b) Current IVF patients or those on waiting list for IVF

8 respondents advised they were already in the IVF process (about to be referred onto waiting list/having tests/on an IVF treatment plan) and said they would be impacted. “*I am on the waiting list for treatment in Tameside where you currently get 3 cycles. I may end up having less chance*”.

The table below shows responses to the question from those who have previously or are currently using IVF services:

If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact ...	Which of the following applies to you in relation to IVF? Tick one										Row Totals
		A woman receiving treatment with a male partner	A man supporting a female partner	A woman without a partner	A woman receiving treatment with a female partner	A woman supporting a female partner	Other (receiving treatment)	Other (supporting someone receiving treatment)	Prefer not to say	Other (tell us below):	
Yes	94 77.7%	3 75.0%	0 0.0%	5 100.0%	1 100.0%	1 100.0%	0 0.0%	0 0.0%	2 50.0%	106 77.4%	
No	13 10.7%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	13 9.5%	
Don't know	8 6.6%	0 0.0%	1 100.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	1 25.0%	10 7.3%	
Not applicable	6 5.0%	1 25.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0 0.0%	1 25.0%	8 5.8%	
Column Total	121 88.3%	4 2.9%	1 0.7%	5 3.6%	1 0.7%	1 0.7%	0 0.0%	0 0.0%	4 2.9%	137 100%	

A total of 298 responses were not included in the above report as they skipped one of the questions.

c) Those with certain medical conditions/disabilities

Seven respondents cited having medical problems/genetic conditions meant that IVF was their only option of having children and a higher number of cycles would offer them more chance of conceiving. *“I’m childless due to medical reasons. Had IVF in Salford been easier to access and had as many cycles as Tameside, people with my condition would have more hope of conceiving”* (patient with Ehlers Danlos Syndrome, POTs and scoliosis)

d) Single women

Two respondents said that they were currently single and might need to use IVF in the future. *“I am single in my thirties. I am not sure if I will be able to have kids without assistance”*

e) Low Socio-economic status / capacity to self-fund

25 respondents outlined the ability to self-fund IVF would be extremely difficult for them or others, with some outlining they would end up being in debt should they need to pay for further cycles. *“We are not in a position to pay privately, so this would mean our chances of starting a family could drastically drop”*.

Key themes included:

- Those from low socio-economic backgrounds would be less likely to afford to self-funded IVF.
- Those who considered themselves not to be on low incomes felt they may not be able to afford to pay for additional cycles
- Saving to be able to self-fund additional cycles may take time – resulting in fertility reducing
- Considering friend to be donor and use money on baby once born

“I don’t think it’s right for people... to be priced out of becoming parents”

Two respondents advised that they went abroad for IVF treatment as it was cheaper: *“we were quoted £20,000 for our 2nd round so we went abroad and paid £2,500”*.

f) Age

8 respondents cited age as reason for being impacted.

Key themes:

- **Impact of waiting lists on age and fertility:** *“With wait times of 3 years at the moment, no wonder women are getting older and older with fertility chances reducing significantly in this time period”*
- **Impact of having one chance of IVF on age:** *“I am a women in my thirties who has been trying to conceive for 5 years. I’m terrified of blowing my one chance and it has made me hesitate on when the right time is to seek help”*
- **Cost:** 1 respondent said that IVF “becomes more expensive as you get older”.
- 1 respondent queried why someone aged 40 should be treated differently to a 32 year-old person.

g) Gay/same sex couples

12 respondents cited they would be impacted due to their sexual orientation, as they would have to rely on fertility treatment and IVF to conceive.

Although this is out of scope for this project, two respondents felt that IVF eligibility should be standardised between same sex couples and heterosexual couples, and that same sex couples were at an “extreme disadvantage”.

h) Faith/belief

One person advised that they would be impacted due of their faith: *“As a practicing Muslim, some methods of overcoming fertility (such as surrogacy, donated sperm) are not accessible as they conflict with my faith beliefs. Therefore, IVF is one of my only options of becoming pregnant if I do struggle to conceive naturally”.*

Respondents to question 12 also outlined what they felt were consequences and impacts, should changes affect them. These are themed below:

- **Mental health/stress/anxiety** – 20 respondents highlighted the pressures fertility treatment places on patients and advised that reducing the number of cycles would impact their mental wellbeing negatively. Raising the number of cycles for those living in localities that offered one cycle or for all to move to 3 cycles was seen as a positive impact on patient mental wellbeing.
- **Chances of successful pregnancy vs number of IVF cycles** - 11 respondents outlined a negative impact if IVF funded rates were reduced “I strongly feel that offering one IVF cycle is not enough given the low chances of success”. Conversely, they felt that offering more cycles gave people a better chance of having a successful pregnancy. Five people cited that either 1 cycle was too low *“the first cycle is a waste of money”* and that 2 cycles would offer a better chance of pregnancy.
- **Impact on NHS** - If number of cycles was increased in some areas: waiting lists may get longer. If number of cycles were decreased in some areas: mental health services may be impacted

Other key themes from the open text responses relate to:

Inequity – many people felt it was unfair that those living close but not in the same locality had access to more IVF cycles *“I live in an area where only one round is available but if I lived five miles away I could get 2 or 3. It is likely all at the same place, St Mary’s. It is unfair”*

Presumptions relating to standardisation – 12 people presumed that standardisation would mean the number of cycles funded in their locality being increased, and felt this would have a positive impact. Five people presumed the rate would be decreased and would have a negative impact

Criteria/eligibility – it was suggested there should be standardisation between same sex couples and heterosexual couples and that the IVF criteria was discriminatory and should be reviewed. *“Rather than looking at the number of cycles for “eligible” patients, you need to focus on who you are excluding completely. I am in a same sex relationship and me and my wife have to date had to self fund almost £20,000 for 2 cycles of IVF treatment. It is really hard for me to read that you are putting your time and energy into trying to even out the playing field for those people who are “eligible” and still nothing is being done to help members of the LGBTQ+ community to have children unless they are able to pay thousands of pounds...How is this fair?”*

Intrauterine Insemination (IUI) funding – it was suggested this should be re-evaluated.

In summary, responses to this question suggest that:

- there is the potential that if the number of cycles offered was standardised, some people living in certain localities could be negatively impacted more than others if the number of cycles was reduced. For example if the number of cycles was changed to one, those living in the following localities would be affected (Salford, Stockport, Tameside and Wigan). Alternatively, if the number of cycles offered was raised for some localities, this would have a positive impact.
- the following demographics may be particularly impacted by any change: current IVF patients/those on waiting list; single women; gay/same sex couples; certain faiths; age; disability, low socio-economic backgrounds or those with limited capacity to self-fund fertility treatment
- the perceived consequential impacts should number of cycles be reduced include impact on mental health/wellbeing; reduction in chance to have a baby; impact on waiting lists; possibility of people going into debt.

Question 13

The purpose of this question was to test levels of overall support for funding IVF in the context of the wider financial and performance challenges of the NHS in Greater Manchester. It should be borne in mind that respondents were not asked to prioritise IVF against anything else.

13. Thinking about the wider NHS and all that it does, how high a priority do you think providing NHS IVF treatment should be?				
			Response Percent	Response Total
1	Very high priority		36.18%	157
2	High priority		38.48%	167
3	Medium priority		17.05%	74
4	Low priority		4.15%	18
5	Very low priority		3.46%	15
6	Don't know		0.69%	3
			answered	434
			skipped	1

We can see that nearly three quarters of respondents felt that IVF funding should be a high or very high priority for the NHS in Greater Manchester.

231 respondents also left additional comments to explain their answers. The most frequently occurring themes, in order, were:

- 54 said they felt IVF was not a priority compared to other things, eg “*There are far more serious issues within the NHS as a whole. Urgent Care and access to cancer diagnostics have fallen over, so the NHS cannot continue providing all services and treatment to all, without there being some restrictions*”.
- 44 cited the impact of untreated infertility on the wellbeing and mental health of women and couples, and potential costs for society in addressing these issues, eg “*The effect of struggling to conceive affects someone mentally. It has a wider effect on their mood, mental health and ability to work. Potentially on their overall health which will cost the NHS and the economy*”.
- 41 restated that IVF should be a high priority, often based on their own experience, eg “*it would be nice for something important that could have a great impact on a woman’s future to be considered as a very high priority*”.
- 32 felt that as infertility was an illness like any other, it should also be treated as a normal

medical problem, eg *“Infertility is a medical condition, patients wouldn’t only get a certain amount of care and [then] be cut off from accessing procedures/ medication for any other condition”*.

- 27 said they felt that having or being able to try for a baby was a right or entitlement, eg *“Everyone should have the opportunity to become parents if they want to”*.
- 24 cited the high cost of private treatment and the inequity that this was not affordable for many people, eg *“Without NHS funding it risks restricting fertility treatment to only wealthier people. This seems inequitable and against the principles of the NHS”*.
- 16 cited the need to increase the general population, eg *“We have an ageing population [and] declining birth rates. This will continue to get worse without fair and equal opportunities”*. And,
- 5 felt childlessness was not an illness and therefore not an NHS responsibility, eg *“the NHS shouldn’t be expected to be responsible for ensuring everyone get’s pregnant”*.

In summary, the responses suggests a large majority in support of IVF being a priority. That may in part reflect the self-selecting nature of the survey attracting people with lived experience of IVF.

The text answers suggest a broader range of views, especially showing concerns about the affordability of IVF in the context of wider NHS demands and challenges. It also suggests key reasons for people supporting IVF are the wider impact of infertility on individuals and society, that infertility was like an other illness and shouldn’t be singled out, and the idea of women and couples having the *right* to try for a family.

Question 14

“Do you have any other comments about our plan to review NHS IVF cycles?”

The purpose of this question was to gather any wider views or thoughts on IVF which weren’t captured as part of the pre-determined questions. There were 208 responses to this question. Respondents often quoted they were supportive of standardising the number of cycles across

Greater Manchester (32 were supportive vs 2 who stated they should be different across localities).

“I think it’s a great idea to ‘even the playing field’ so to speak. Everybody should receive the same level of care.”

The key themes identified from this question are:

- 61 respondents pleaded for the number of cycles provided to be more than 1, or for the standardising across Greater Manchester not to mean reduce all areas to 1 cycle. Most respondents from this theme felt 2 cycles was reasonable to provide, as a number of comments were made about health professionals stating that the first cycle of IVF was considered the ‘trial run’ which indicates the success rate will always be low.
- In support of the first theme, 19 respondents quoted NICE, WHO or national guidelines around the number of IVF cycles which should be provided was 3. They felt Greater Manchester should follow suit, eg *“It should be in line with nice guidelines like cancer treatment is and shouldn’t be treated any other way.”*
- 40 respondents highlighted specifically that equity of offer is of high importance. The demographics or characteristics they specifically referred to included sexual orientation and same sex couples, marriage status, disability, previous children, and BMI
- *“Same sex male couples should be included. Being gay or bi is not a choice, so why is it treated like one for IVF?”*
- The final theme to highlight was concerns from respondents around NHS finances and disagreeing that this review into IVF cycles was not a cost saving exercise. 11 respondents made comments specifically about this, eg *“You say this is not about saving money, but it clearly is as you are running a deficit of many millions of pounds. When are you going to start being honest with the public that you have no money and that many things are going to have to change or be cut???”*

Other comments to note would be for NHS GM to consider the mental impact and strain that fertility treatment has on its patients, and for this to be taken into account throughout this review, eg *“To take into consideration that infertility already feels incredibly unfair. We have to watch everyone around us easily getting pregnant, some who want to and others who don’t, terminations etc.”* and *“To have a chance of being parents taken from us by reducing the number of rounds that are funded, would be another blow to a life that’s already pretty emotionally and mentally hard to live.”*

In summary, this question suggests a large majority specifically stated that they felt the number of cycles should not be reduced to 1 across Greater Manchester, for reasons such as success rates, NICE guidance or the impact on mental health of those with cycles which are unsuccessful.

Appendix E

Survey Monitoring Data

15. What is your age?				
			Response Percent	Response Total
1	Under 18		0.00%	0
2	18-25		3.46%	15
3	26-35		42.96%	186
4	36-45		40.88%	177
5	46-55		8.78%	38
6	56-65		2.54%	11
7	66-75		0.69%	3
8	76+		0.69%	3
			answered	433
			skipped	2

16. How do you identify your gender?				
			Response Percent	Response Total
1	Female		93.98%	406
2	Male		4.40%	19
3	Intersex		0.00%	0
4	Non-binary		0.23%	1
5	Prefer not to say		0.69%	3
6	Other (please specify):		0.69%	3
			answered	432

16. How do you identify your gender?			Response Percent	Response Total
			skipped	3
Other (please specify): (3)				
1	I am a woman. My gender is not defined by me but society.			
2	I am a woman			
3	My sex is female. I don't really understand the concept of "gender identity" as distinct from biological sex.			

17. Is your current gender the same as the sex you were described at birth?			Response Percent	Response Total
1	Yes		98.61%	426
2	No		0.23%	1
3	Don't know		0.46%	2
4	Prefer not to say		0.69%	3
			answered	432
			skipped	3

18. Are you a carer? (A carer is someone who provides support to family or friends who couldn't manage without this help).			Response Percent	Response Total
1	Yes		9.77%	42
2	No		90.23%	388
			answered	430
			skipped	5

19. How do you describe your ethnic background?				
			Response Percent	Response Total
1	Asian or Asian British Bangladeshi		0.23%	1
2	Asian or Asian British Indian		1.40%	6
3	Asian or Asian British Pakistani		1.63%	7
4	Asian - other background		0.47%	2
5	Black or Black British African		1.40%	6
6	Black or Black British Caribbean		0.00%	0
7	Black or Black British - Any other background		0.00%	0
8	Chinese		0.47%	2
9	Chinese - other background		0.23%	1
10	Mixed - white and black Caribbean		0.47%	2
11	Mixed - white and black African		0.70%	3
12	Mixed - white and Asian		1.86%	8
13	Mixed - other mixed background		1.17%	5
14	Other ethnic group - Arabic		0.47%	2
15	Other ethnic group - Latin American		0.23%	1
16	White - British		81.12%	348
17	White - Irish		1.63%	7
18	White - Polish		0.70%	3
19	White - Latvian		0.23%	1
20	White - Ukranian		0.00%	0
21	White - Gypsy/traveller		0.00%	0
22	White - other		3.73%	16
23	Other (please specify):		1.86%	8
			answered	429
			skipped	6

19. How do you describe your ethnic background?			Response Percent	Response Total
Other (please specify): (8)				
1	Prefer not to say			
2				
3				
4				
5	Manx			
6	European			
7	prefer not to say			
8	romanian			

20. Do you consider yourself to have a disability? (A disability is a condition that affects an individual's ability to carry out normal day-to day activities. It can be a mental health or physical condition, visible or hidden, it can last 12 months or longer and be recurring.)				
			Response Percent	Response Total
1	Yes (feel free to add further details below)		11.14%	48
2	No		88.86%	383
			answered	431
			skipped	4
Comment: (18)				
1	Ileostomy from IBD in 2023 (Had IVF 4 years ago pre IBD diagnosis)			
2	I have a lifelong condition called Triplegic Spasmodic Cerebral Palsy due to a prolapsed cord at birth as I was 10 days past the due date. I only have 10 minutes of lack of oxygen. I am well aware of the issues of giving birth and this meant to save my child from any birth issues I had a caesarean in August of 1996 at the age of 30. I have struggled to be accepted as an equal parent without there being any evidence of neglect or difficulty and this just born out of pure stereotype discrimination.			
3	I have endometriosis, and have been suffering with it for 13 years.			

20. Do you consider yourself to have a disability? (A disability is a condition that affects an individual's ability to carry out normal day-to day activities. It can be a mental health or physical condition, visible or hidden, it can last 12 months or longer and be recurring.)

		Response Percent	Response Total
4	Epilepsy/fits		
5	I suffer from Fibromyalgia and IBS. I also have anxiety and depression.		
6	Neurodiverse		
7	Ehlers Danlos Syndrome and POTs, scoliosis		
8	ADHD		
9	Ptsd		
10	Long Covid		
11	I have Lupus		
12	Mental Health condition		
13	Myopia, dyslexia		
14	ADHD		
15	I have anxiety and depression.		
16	dyslexia		
17	Mental health - bipolar		
18	fibromyalgia		

21. Are you or have you ever been a member of HM Armed Forces? (Regular or Reservist)

			Response Percent	Response Total
1	Yes, I am a current serving member of the Armed Forces		0.23%	1
2	Yes I am an Armed Forces Veteran (someone who has previously served in HM Armed Forces - regular or reservist)		0.70%	3
3	No		99.07%	424
			answered	428

21. Are you or have you ever been a member of HM Armed Forces? (Regular or Reservist)		
	Response Percent	Response Total
	skipped	7

22. Do you consider yourself to be:			Response Percent	Response Total
1	Asexual		1.87%	8
2	Bisexual		6.31%	27
3	Gay		2.10%	9
4	Heterosexual/straight		76.64%	328
5	Lesbian		7.94%	34
6	Pansexual		1.17%	5
7	Don't wish to say		3.97%	17
8	Other (please specify):		0.00%	0
			answered	428
			skipped	7

23. What is your religion or belief?

			Response Percent	Response Total
1	Atheist/non		44.39%	190
2	Buddhism		0.70%	3
3	Christianity		35.75%	153
4	Hinduism		0.23%	1
5	Islam		2.80%	12
6	Judaism		0.23%	1
7	Sikhism		0.47%	2
8	Prefer not to say		11.21%	48
9	Other (please specify):		4.21%	18
			answered	428
			skipped	7

Other (please specify): (18)

1	Agnostic
2	Catholic
3	
4	
5	Various blended belief of multiple religions including Pagan
6	Hethen (not atheist)
7	Agnostic
8	None
9	
10	None
11	agnostic
12	No set religion, different to atheism
13	Agnostic
14	Non denominational
15	Spiritual

23. What is your religion or belief?			Response Percent	Response Total
16	Spirituality			
17	None			
18	Agnostic			

Appendix F

Breakdown of respondents for question 10 regarding impact

Respondents living in each locality

If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact people like you?					
	Yes	No	Don't know	Not applicable	Row Totals
Bolton	10 3.50%	2 3.10%	1 2.00%	0 0.00%	13 3.00%
Bury	15 5.20%	6 9.40%	4 7.80%	1 3.00%	26 6.00%
Manchester	74 25.90%	7 10.90%	6 11.80%	7 21.20%	94 21.70%
Oldham	12 4.20%	3 4.70%	1 2.00%	2 6.10%	18 4.10%
Rochdale (incl Heywood & Middleton)	14 4.90%	0 0.00%	2 3.90%	1 3.00%	17 3.90%
Salford	21 7.30%	2 3.10%	4 7.80%	2 6.10%	29 6.70%
Stockport	38 13.30%	20 31.20%	14 27.50%	4 12.10%	76 17.50%
Tameside	17 5.90%	5 7.80%	3 5.90%	4 12.10%	29 6.70%
Trafford (incl Altrincham, Old Trafford, Sale and Urmston)	39 13.60%	9 14.10%	6 11.80%	4 12.10%	58 13.40%
Wigan (incl Ashton-in-Makerfield and Leigh)	33 11.50%	8 12.50%	4 7.80%	7 21.20%	52 12.00%
I do not live in Greater Manchester	13 4.50%	2 3.10%	6 11.80%	1 3.00%	22 5.10%
Column Total	286 65.90%	64 14.70%	51 11.80%	33 7.60%	434 100%

The table below shows responses to the question from those who have previously or are currently using IVF services

If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?					
I am:	Yes	No	Don't know	Not applicable	Row Totals
A woman receiving treatment with a male partner	94 88.70%	13 100.00%	8 80.00%	6 75.00%	121 88.30%
A man supporting a female partner	3 2.80%	0 0.00%	0 0.00%	1 12.50%	4 2.90%
A woman without a partner	0 0.00%	0 0.00%	1 10.00%	0 0.00%	1 0.70%
A woman receiving treatment with a female partner	5 4.70%	0 0.00%	0 0.00%	0 0.00%	5 3.60%
A woman supporting a female partner	1 0.90%	0 0.00%	0 0.00%	0 0.00%	1 0.70%
Other (receiving treatment)	1 0.90%	0 0.00%	0 0.00%	0 0.00%	1 0.70%
Other (supporting someone receiving treatment)	0 0.00%	0 0.00%	0 0.00%	0 0.00%	0 0.00%
Prefer not to say	0 0.00%	0 0.00%	0 0.00%	0 0.00%	0 0.00%
Other:	2 1.90%	0 0.00%	1 10.00%	1 12.50%	4 2.90%
	106 77.40%	13 9.50%	10 7.30%	8 5.80%	137 100%

Respondent IVF status

If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?						
Are you receiving or have you or your partner received IVF cycle treatment to help you try to have a baby?		Yes	No	Don't know	Not applicable	Row Totals
Yes NHS funded IVF		72 25.40%	8 12.50%	8 15.70%	5 15.20%	93 21.50%
Yes IVF paid by myself		21 7.40%	8 12.50%	1 2.00%	2 6.10%	32 7.40%
Yes both NHS funded IVF and paid myself too		30 10.60%	5 7.80%	2 3.90%	3 9.10%	40 9.30%
No but I may consider using NHS funded IVF in the		68 23.90%	1 1.60%	10 19.60%	1 3.00%	80 18.50%
No but I may consider using IVF which I will pay for myself in the future		6 2.10%	0 0.00%	0 0.00%	0 0.00%	6 1.40%
No		66 23.20%	42 65.60%	27 52.90%	22 66.70%	157 36.30%
Prefer not to say		6 2.10%	0 0.00%	2 3.90%	0 0.00%	8 1.90%
Other:		15 5.30%	0 0.00%	1 2.00%	0 0.00%	16 3.70%
Column Total		284 65.70%	64 14.80%	51 11.80%	33 7.60%	432 100%

Age

		If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?				
What is your age?		Yes	No	Don't know	Not applicable	Row Totals
Under 18		0 0.00%	0 0.00%	0 0.00%	0 0.00%	0 0.00%
18-25		9 3.20%	0 0.00%	3 5.90%	3 9.10%	15 3.50%
26-35		142 50.00%	13 20.30%	23 45.10%	8 24.20%	186 43.10%
36-45		117 41.20%	30 46.90%	21 41.20%	8 24.20%	176 40.70%
46-55		12 4.20%	14 21.90%	3 5.90%	9 27.30%	38 8.80%
56-65		3 1.10%	2 3.10%	1 2.00%	5 15.20%	11 2.50%
66-75		1 0.40%	2 3.10%	0 0.00%	0 0.00%	3 0.70%
76+		0 0.00%	3 4.70%	0 0.00%	0 0.00%	3 0.70%
Column		284	64	51	33	432
Total		65.70%	14.80%	11.80%	7.60%	100%

Sexual orientation

		If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?				
Do you consider yourself to be:		Yes	No	Don't know	Not applicable	Row Totals
	Asexual	5 1.80%	1 1.60%	2 4.00%	0 0.00%	8 1.90%
	Bisexual	17 6.00%	6 9.50%	2 4.00%	2 6.10%	27 6.30%
	Gay	4 1.40%	3 4.80%	1 2.00%	1 3.00%	9 2.10%
	Heterosexual/ straight	215 76.50%	48 76.20%	38 76.00%	26 78.80%	327 76.60%
	Lesbian	30 10.70%	2 3.20%	2 4.00%	0 0.00%	34 8.00%
	Pansexual	3 1.10%	1 1.60%	0 0.00%	1 3.00%	5 1.20%
	Don't wish to say	7 2.50%	2 3.20%	5 10.00%	3 9.10%	17 4.00%
	Other:	0 0.00%	0 0.00%	0 0.00%	0 0.00%	0 0.00%
	Column Total	281 65.80%	63 14.80%	50 11.70%	33 7.70%	427 100%

Disability

	If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?					
Do you consider yourself to have a disability?		Yes	No	Don't know	Not applicable	Row Totals
Yes		25	12	6	5	48
		8.80%	18.80%	12.00%	15.20%	11.20%
No		258	52	44	28	382
		91.20%	81.20%	88.00%	84.80%	88.80%
Column Total		283	64	50	33	430
		65.80%	14.90%	11.60%	7.70%	100%

Armed forces

		If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?					
Are you or have you ever been a member of HM Armed Forces? (Regular or Reservist)		Yes	No	Don't know	Not applicable	Row Totals	
	Yes, I am a current serving member of the Armed Forces	1 0.40%	0 0.00%	0 0.00%	0 0.00%	1 0.20%	
	Yes I am an Armed Forces Veteran	3 1.10%	0 0.00%	0 0.00%	0 0.00%	3 0.70%	
	No	277 98.60%	63 100.00%	50 100.00%	33 100.00%	423 99.10%	

Religion

		If the number of NHS funded IVF cycles changed in your area, do you think this would particularly impact do you think this would particularly impact people like you?					
What is your religion or belief?		Yes	No	Don't know	Not applicable	Row Totals	
	Atheist/non	131 46.30%	23 37.10%	26 52.00%	10 31.20%	190 44.50%	
	Buddhism	1 0.40%	2 3.20%	0 0.00%	0 0.00%	3 0.70%	
	Christianity	101 35.70%	27 43.50%	13 26.00%	12 37.50%	153 35.80%	
	Hinduism	0 0.00%	0 0.00%	1 2.00%	0 0.00%	1 0.20%	
	Islam	10	0	1	1	12	

		3.50%	0.00%	2.00%	3.10%	2.80%
	Judaism	1 0.40%	0 0.00%	0 0.00%	0 0.00%	1 0.20%
	Sikhism	2 0.70%	0 0.00%	0 0.00%	0 0.00%	2 0.50%
	Prefer not to say	23 8.10%	8 12.90%	8 16.00%	8 25.00%	47 11.00%
	Other:	14 4.90%	2 3.20%	1 2.00%	1 3.10%	18 4.20%
	Column	283	62	50	32	427
	Total	66.30%	14.50%	11.70%	7.50%	100%

Appendix G

Desk based exercise findings

Overview of public engagement/consultation activity by Greater Manchester localities relating to IFV cycles

Locality	Consultation Undertaken Yes/No/?	Previous engagement or consultation	Key Findings and outcomes
Bolton	No	Did not consult or engage. No records available.	One funded cycle @ 2018/19
Bury	Yes	A six-week consultation period in relation to IVF provision in Bury ran from 6th August to 16th September 2018 inclusive.	There were 437 consultation surveys completed. • The vast majority of respondents understood why the CCG explored all areas of spend to identify where savings could be achieved and the reasons why the CCG was reviewing the level of funding for IVF services. A smaller number (28%) agreed with the

			<p>proposal to review the level of funding for IVF services in Bury. A high proportion (40%) of respondents said that if the level of funding for IVF services in Bury was reduced, that they felt the decision would affect them.</p> <ul style="list-style-type: none">• Around two thirds of respondents had a preference for the CCG to continue to offer up to three funded cycles of IVF, with the remainder (32%) comfortable with a reduction. <p>Concerns around the impact on mental health of a reduction in provision of IVF was one of the strongest themes to emerge from the feedback.</p> <ul style="list-style-type: none">• Health, Overview and Scrutiny Committee members resolved not to specify a preference with regards to the number of IVF cycles stating only, that a service must still be provided i.e. not going down to zero cycles. Members of the Committee agreed unanimously that a reduction in the number of IVF cycles, would still allow safe, sustainable and accessible services for the local population. <p>27 September 2018: Decision was made at CCG Governing Body to reduce provision from up to three</p>
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			funded cycles to one from October 2018.
Heywood, Middleton, Rochdale	Yes	Consultation period ran from 3 December 2018 to 16 January 2019	<p>Policy as at 2018/19 – 3 funded IVF cycles</p> <p>The six-week consultation period consisted of a range of different approaches to ensure that there was a broad and inclusive response that involved a wide range of stakeholders.</p> <p>91.9% of all respondents were opposed to the preferred policy option of one funded cycle.</p> <p>The key issues raised in the comments were: • Everyone had the right to bear a child and reducing the number of cycles was counter to this. • Subfertility is not a lifestyle choice or self-inflicted and should be viewed as a medical condition • Three cycles provide a better chance of pregnancy than just one cycle • Given the relative deprivation of the borough of Rochdale many people would not be able to pay for fertility treatment if they could not access it through the NHS • Have the consequences of reducing IVF provision been properly considered, what about the deterioration in mental health that may be a result of</p>

			<p>not being able to bear a child • The proposal is about cost cutting and has not been made for justifiable medical reasons • Everyone should have the right to 3 cycle to achieve pregnancy • NICE guidelines recommend 3 cycles</p> <p>There were some anomalies in the survey returns: Certain IP addresses had been used a number of times (In one case the same IP address was used 38 times. There were an unusually large number of respondents from the M24 post code</p> <p>CCG preferred option after consultation – 1 funded cycle cost saving of £259,000</p> <p>The CCG were satisfied that after consultation and the decision to move to one funded cycle that all evidence from the consultation was considered as well as the need to respond to the significant financial pressure currently facing the NHS.</p> <p>HMR CCG adopted the new one funding cycle policy from 1 February 2019, this was supported by the</p>
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			Integrated Commissioning Board
Manchester	No records available	No records available	Currently one funded IVF cycle.
Oldham	Yes	<p>Eight-week consultation period in relation to IVF provision in Oldham ran from 12 October to 8 December 2018.</p>	<p>Engagement activities throughout this period included:</p> <ul style="list-style-type: none"> • 12 Community Drop-in sessions held for people to discuss the consultation in person and have opportunity to complete the survey. • An online survey, which was also available in paper format on request. • Healthwatch Oldham Women's Health Forum on November 28th at the Millennium Centre, Oldham, Engagement session in the Oldham Care pop up shop and Locality Devolution Difference Event in October. • Promotion through all existing networks including through Voluntary, Community and

			<p>Faith Sector organisations, Healthwatch Oldham, and seeking views from groups.</p> <ul style="list-style-type: none">• Face to Face engagement with Oldham residents <p>There were 250 consultation surveys completed.</p> <ul style="list-style-type: none">• 95% of correspondents had read the supporting information and proposal prior to answering the survey.• Around three quarters of respondents (74.30%) had a preference for the CCG to continue to offer up to three funded cycles of IVF.• Support for reducing the number of cycles to 2 was below 15% (13.65%) and the reduction to 1 cycle (the preferred option of the CCG) was less than 10% of the overall responses (9.24%).• There was little support for reducing the number of IVF cycles to zero (2%).
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			<ul style="list-style-type: none">• In terms of feedback, a strong theme from the people of Oldham was the feeling of ‘Civic Pride’ in the development of IVF in the town meaning we should continue to champion the procedure, especially when linked to the idea of reducing the postcode lottery by reducing the number of cycles on offer.• NICE guidelines which recommend three cycles were also a recurrent theme in the feedback received.• However, it should be noted that consultees were not presented with choices between cuts to different clinical services or affecting different groups of patients – they were asked about IVF in isolation. i.e. unlike the CCG Governing Body they were not presented with any particular consequence to not reducing the cycles of IVF offered
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			17 January 2019: Oldham CCG's Governing Body agreed it would reduce the number of IVF cycles offered to new patients from three cycles to one cycle.
Salford	No	Did not consult or engage. No records available.	
Stockport	Yes	<p>Consultation period ran from 9 September 2019 to 20 October 2019.</p> <p>Stockport CCG reviewed and reflected on engagement feedback and decided not to progress further with the consultation.</p>	<p>400+ people responded to the consultation. Access to full engagement records not available.</p> <p>As at 2018/19 2 funded cycles</p>
Tameside	No	Did not consult or engage. No records available.	As at 2018/19 3 funded cycles
Trafford	No	Did not consult but undertook a	Engagement activity included:

		<p>series of targeted focus groups and held conversations with national interest groups between 7 March 2018 to 19 March 2018.</p> <p>This was to seek views about four proposed schemes to reduce costs in order to begin financial recovery in Trafford. IVF by exception was one of the considered proposals.</p>	<p>4 x focus groups (Youth cabinet; Age UK Trafford; Low-income individuals; Patient group)</p> <p>2 x discussion groups (Foodbanks)</p> <p>2 x telephone discussions (Fertility Fairness; Fertility UK)</p> <p>Key themes from engagement feedback:</p> <ul style="list-style-type: none"> • People welcomed the opportunity to have open and honest conversations regarding how best to use NHS resources wisely • There was a mix of support for and against ending IVF funding – especially relating to financial position and whether IVF should be a • Regarded a ‘harsh’ change to make • IVF ‘postcode lottery’ a great concern • Many felt they should be given one chance of having a child • Acknowledged to be an expensive treatment particularly in the context of the 20-35% success rate • Being denied the chance to conceive may be a stressful event, and incur greater NHS costs in the
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			<p>longer term, but there's also anxiety attached to failed IVF treatment</p> <ul style="list-style-type: none">• Those on low incomes will be particularly disadvantaged• Childless parents may not have someone to help care for them in later life• Suggestions:<ul style="list-style-type: none">○ Save money by looking instead at ending other expensive treatments○ Perhaps tighten criteria instead○ Greater support should be offered if funding is ceased○ Offer funding based on income of individuals○ Partially fund treatments○ Better promote options to foster and adopt <p>Research organisation 'Fertility Fairness' feedback</p> <ul style="list-style-type: none">• were strongly against the ceasing of funding• suggested the CCG may be able to save money by changing providers (having analysed the data
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			<p>across CCGs) or renegotiate contracts with providers</p> <ul style="list-style-type: none"> feel it would penalise women who focus on their careers and wait until their 30s to have children <p>27 March 2018: Trafford CCG's Governing Body did not support the proposal to fund IVF by exception only and instead agreed to retain one cycle of IVF and renegotiate costs with the providers.</p>
Wigan	No	Did not consult or engage. No records available.	As at 2018/19 2 funded cycles
GM wide	No	<p>Greater Manchester Health and Social Care Partnership/NHS GM Assisted conception and fertility treatment service review</p> <p>28 May-27 July 2021</p> <p>commissioners undertook an 8-week listening exercise with patients, staff and the public.</p>	<p>Engagement activity:</p> <p>The listening activity was an integral part of the pathway review from referral to treatment. Due to Covid limitations, engagement took place virtually.</p> <ul style="list-style-type: none"> Online service provider survey Online patient and public survey (220 responses)

		<p>The number of NHS funded IVF cycles was not in scope of this review. However the review highlighted the inequity in this provision across GM and therefore is useful to consider as part of the IVF cycles project.</p> <p>One of the recommendations from this review is to harmonise the NHS GMICP policy.</p>	<ul style="list-style-type: none"> • Letters sent to patients who had received treatment in the past 12 months from their NHS funded providers. Letters encouraged participation in the online survey and/or focus groups. (7039 letters sent out) 3.5% response rate. • Focus Groups and/or telephone interviews were offered to directly engage LGBT populations, ethnic minority groups and people with learning disabilities (including long term conditions) and a general ‘catch all’ group was also offered. People who identified with several groups could join as many groups as they felt were relevant to them. • Presentations at meetings with Healthwatch, GMCA, Equality Alliance and Cancer Network. • Engagement report is available from NHS GM Engagement Team <p>NHS GM Greater Manchester Review of Assisted Conception and Fertility Preservation – final report (July 2023)</p>
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			<p>Includes how the engagement activities fed into the review and recommendations for further development of the Model of care including:</p> <ul style="list-style-type: none">- Further patient and public engagement on the proposed pathways required to test out the model and secure feedback on it, based on the earlier comprehensive engagement.- Further provider engagement required regarding changes to service delivery to ensure new pathways are fully implemented. <p>Also reviews whether aims of the review had been delivered – including seeking public views.</p> <p>Risk to implementation - although the varying IVF cycles and polices across GM were outside the scope of this review, the recommendation from the review is for the inequity currently in the number of cycles to be picked up by the GM ICB</p> <p>Key themes from the engagement:</p>
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			<ul style="list-style-type: none">Access to NHS funding aligned to NICE guidelines.Good communication and family supportRegular ongoing infoLocation to be considered as part of a referral.Having patient and group support availableHaving person centred careAccess to more clinics and resources to cut down on waiting time for appointments.
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To request specific engagement reports listed for any of the above localities, please contact NHS GM's engagement team via email: gmhscp.engagement@nhs.net