

Report to Health Scrutiny Sub-Committee

Outcome of Public Consultation on proposed IVF changes

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Purpose of the Report

This report informs the Health Scrutiny Sub-Committee on the methodology and outcome of Oldham CCG's recent consultation on the funding of In Vitro Fertilisation (IVF) and the subsequent decision of the CCG Governing Body on IVF Funding.

Executive Summary

The CCG proposed in the consultation to reduce funding from 3 to 1 cycles.

An eight week consultation period in relation to IVF provision in Oldham ran from 12th October to 8th December 2018 inclusive. 250 consultation surveys were completed.

95% of correspondents had read the supporting information and proposal prior to answering the survey.

Almost three quarters of all 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%).

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.

When the CCG Governing Body weighed the views expressed in the consultation against the balancing arguments, it unanimously supported reducing cycles funded from 3 to 1 for all new patients.

Recommendations

The Health Scrutiny Sub-Committee is asked to note the methodology of the consultation and the subsequent decision of the CCG Governing Body on IVF funding; and make any recommendations for undertaking future consultations and allocating scarce resources.

Funding of IVF

1 Background

- 1.1 The consultation set out four options for the number of cycles of IVF funded: 3 (the status quo), 2, 1 (the CCG's preferred option prior to consultation) and 0. It also included supporting information which set out the case for change and implications of each option.

The consultation survey asked consultees to choose an option and also provided an opportunity to give feedback on the proposals, and highlight any impacts the CCG had failed to identify and/or address.

IVF (in vitro fertilization) is one of several methods available to help a woman to have a baby. In IVF, an egg is removed from a woman's ovaries and fertilized with sperm in a laboratory. The fertilized egg (embryo) is then replaced into the womb to grow and develop. In IVF, the couple's own eggs and sperm can be used, or eggs or sperm from donors.

A full cycle of IVF includes one episode of ovarian stimulation, egg recovery, insemination, and embryo replacement into the womb. The cycle ends with the final transfer of all resultant fresh and frozen embryos or a successful live birth occurring during the cycle.

The Human Fertility and Embryology Authority (HFEA) reports on the activity and success rates of IVF clinics nationally. It's most recent analysis reports that around one in three treatment cycles results in a live birth for patients under the age of 35. Success rates reduce with rising female age, as the number of unsuccessful cycles increases.

2 Current Position

- 2.1 NHS Oldham CCG has previously commissioned assisted conception services in line with guidance by the National Institute for Health and Care Excellence (NICE). This guidance recommends the provision of three full IVF cycles for eligible couples where the woman is aged less than 40 years. The guidance is not mandatory to CCGs, and a number of CCGs have recently implemented changes to their policies following local consultation.

There is a wide variation in availability of funding for IVF across the English NHS (a so-called postcode lottery). Some CCGs do not fund IVF treatment for their residents at all. In contrast, Oldham has offered up to 3 cycles (the maximum funded by any CCG) to eligible couples where at least one partner has no children.

However, the CCG took the view that it was becoming financially unsustainable to continue to offer 3 cycles of IVF to Oldham residents at a time when other vital services were being inundated with an expanding population who arguably have

greater health needs. Oldham CCG therefore wanted to provide a number of cycles which was more consistent with other boroughs.

The main purpose of the consultation was to understand the views of the people of Oldham in regards to the review of the IVF service provision, and to highlight any outcomes that the CCG Governing Body, in their deliberations of this review had failed to consider relevant to the proposal.

3 **Proposal**

To make sure it is spending its budget as effectively as possible, the CCG continually reviews the services it commissions and pays for – and this includes IVF.

Oldham CCG recognises the pain of infertility and the effects it can have on individuals/couples, and is immensely proud that IVF was developed in Oldham. The NHS as a whole is facing significant financial pressure to maintain high quality services while experiencing ever increasing demand, which looks set to continue for the foreseeable future. An aging and growing population plus rising costs are all placing pressure on an already stretched system.

In January 2018, Oldham CCG reviewed a number of ways it could maintain its fiscal responsibility by avoiding non-essential expenditure. It was agreed to develop proposals for a number of these, including potentially reducing the number of IVF cycles offered from 3 to 1.

4 **Methodology**

An eight week consultation period in relation to IVF provision in Oldham ran from 12 October to 8 December 2018.

The consultation methodology was designed to try and ensure as broad a response as possible, activities included:

- 12 Drop in sessions held for people to discuss the consultation in person, and have opportunity to complete the survey. The sessions were held in the following locations:
 - Town Centre Oldham Cares ‘Pop up shop’
 - Oldham Central Library (x 3 sessions)
 - Chadderton Health & Wellbeing Centre
 - Royton Health and Wellbeing Centre
 - Oldham Health and Wellbeing Centre
 - Honeywell Centre
 - St Chads Community Centre
 - Wernerth & Freehold Community Development Centre
 - Alexandra Children’s Centre
 - Springhead Community Centre
- An online survey, which was also available in paper format on request.

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- Promotion through all existing networks including through Voluntary, Community and Faith Sector organisations, Healthwatch Oldham, and seeking views from groups
 - Face to Face engagement with Oldham residents
 - 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.
 - Requests for presentations to specific groups or meetings were welcomed.
 - Views were invited to be sent to the CCG by letter or by e-mail.
 - Press release at the start of the survey
 - Communication to Health Huddle members at the start/ mid point and a week before consultation close.
 - Promotion on the CCG website with content including on the home page, NHS Oldham CCG Facebook page and Oldham Cares Twitter account

5 Consultation feedback

5.1 Key themes from the feedback are summarised below:

- Civic Pride: a number of comments were made around Oldham being the birthplace of IVF and as such, should continue to offer the full number of cycles.
- Concern was raised relating to the cost of private IVF cycles, and affordability for the people of Oldham and as such denying the opportunities for families in Oldham to have a family.
- The impact on the mental health of people who would be affected by a reduction in IVF services.
- Many comments pointed to the current NICE Guidance around IVF provision, and asked the CCG to continue to adhere to these guidelines
- There was a feeling that reducing variation in service provision should come in the form of keeping the number of cycles at 3 rather than reducing to 1
- There was concern that families are being penalised for being infertile.
- Feedback around personal experience of IVF with successful outcomes after cycle 1
- Comments were received relating to the comparatively low savings the proposed reduction would bring compared to the overall CCG budget.

Verbatim /other feedback received via the survey and wider consultation included:

During drop in sessions:

- Suggestions that savings could be made elsewhere in the health system, or through reducing running costs.
- A feeling that it 'didn't really affect men' so there was no need for men to complete a survey.

By Email:

- The consultation triggered an enquiry from a couple in Oldham who were concerned about current service provision and how any decisions made by the Governing Body would affect their current treatment. The couple were reassured through email correspondence that any changes would not apply retrospectively.

The couple were encouraged to complete the consultation survey and provided with the link.

- *'I am emailing in regards to news of the IVF consultation in Oldham and want to share my views on the subject.*

Please do not change the options or reduce the cycles of IVF. I believe every couple should have the right to be given a fair chance of becoming parents and it is so wrong and unfair to take that away.

IVF can sometimes be the only option for some people to ever have chance of being a parent for example operations from birth I.E. Undescended Testes, Cancer can also cause people to be infertile and IVF is the only option for ever having the chance of your own family.

I was told that due to low sperm count/motility there was no operations to improve it, no tablets, nothing that would change/improve it so IVF would be my only chance of having my own child/children that I desperately want.

If you want to cut services try cutting the quit smoking service, stop treating alcoholics, druggies. stop doing operations for transgender people and boob jobs that's millions the NHS can save from all of that.'

5.2 Breakdown of consultation survey results

Overall there were 250 consultation surveys completed, these were a mixture of face to face surveying and surveys completed online.

At the drop in sessions, all supporting information was available in printed form for people to read and discuss.

- 67% of respondents told us they were registered with an Oldham GP
- 95% of respondents told us they had read the supporting information provided by the CCG
- 74% gave 3 cycles as their preferred choice
- 13% gave 2 cycles as their preferred choice
- 9% gave 1 cycle as their preferred choice, and
- 2% 0 cycles as their preferred choice

10% of respondents had received IVF in Oldham in the last 5 years. Of these respondents:

- 100% told us that they had read the supporting information provided by NHS Oldham CCG
- 92% gave 3 cycles as their preferred choice
- 3.7% gave 2 cycles as their preferred choice
- 3.7% gave 1 cycle as their preferred choice, and
- 0% 0 cycles as their preferred choice

19 respondees provided us with comments on the IVF Consultation – these have been thematically reviewed below

- Civic Pride: A number of comments were made around Oldham being the birthplace of IVF and as such, should continue to offer the full number of cycles.
- Concern was raised relating to the cost of private IVF cycles, and affordability for the people of Oldham and as such denying the opportunities for families in Oldham to have a family.
- The impact on the mental health of people who would be affected by a reduction in IVF services.
- Comments referencing the current NICE Guidance around IVF provision, and asked the CCG to continue to adhere to these guidelines

81 respondees told us that they were not registered with an Oldham GP, for this analysis we make the assumption that they live out of area:

86% gave 3 cycles as their preferred choice
7% gave 2 cycles as their preferred choice
3% gave 1 cycle as their preferred choice, and
2% gave 0 cycles as their preferred choice

51 of these respondees provided us with comments on the IVF Consultation, a thematic analysis of their comments are below:

- Many comments pointed to the current NICE Guidance around IVF provision, and asked the CCG to continue to adhere to these guidelines
- There was a feeling that reducing variation in service provision should come in the form of keeping the number of cycles at 3 rather than reducing to 1
- There was concern that patients are being penalised for being infertile and that infertility should be treated like other medical conditions.
- Concern that the people of Oldham would be financially impacted by the reduction in IVF cycles, therefore would be left without choice or children.
- Feedback around personal experience of IVF with successful outcomes after cycle 1.

Fertility Fairness Network UK tweeted about the consultation to their followers 5 times during the consultation period. We believe this may have encouraged non-Oldham residents interested in this subject to respond to the consultation.

Of those patients who told us they were registered with an Oldham GP, 68% 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 amongst Oldham patients was 16% and the reduction to 1 cycle (the preferred option of the CCG) was supported by 11%, with 2% supporting zero cycles.

Whilst the support for keeping the service provision at current standards remains clear in this comparison, we can see that patients registered with GP's in Oldham do show some support to the other options set out in the consultation.

6 Governing Body Decision

The CCG's Governing Body met to consider the outcome of the consultation at its meeting on the afternoon of 17 January 2018. At this meeting the outcomes were presented and weighed against other evidence including the overall financial position of the CCG and potential effect of this on other services, the positions taken by other (especially neighbouring) CCG's and the potential this created for so-called health tourism, as well as the relevant NICE Guidance.

The Governing Body was mindful of the need to ensure that in reaching a decision, the views expressed by the public were conscientiously taken into account and the Chair placed on record his thanks to all those who had taken the time to share their views.

The discussion was thorough and took into account the views of clinical, lay and executive voices around the table. The discussion reflected the tension between the needs of the individual and the population as a whole and also the very real pain and distress which infertility and childlessness can create.

Governing Body also revisited the Equality Impact Assessment which had identified potential differential impacts to ensure a thorough understanding of the effect of any decision on different groups.

Governing Body took particular note of the strength of view expressed – that nearly $\frac{3}{4}$ of all consultees (and just over $\frac{2}{3}$ of those registered with an Oldham GP) wanted the CCG to continue to commission 3 cycles of IVF for patients as per the NICE recommendations.

However, balancing arguments considered included:

- the potential effect on other services (and patients) of not reducing funding for IVF
- the risk of 'Health Tourism' attracting patients from other areas to seek funding for second or third cycles, particularly as only 12% of CCGs nationally now fund 3 cycles of IVF
- the position of the other CCGs in the north east sector of Greater Manchester. It was noted that Bury CCG recently reduced its funding from 3 to 1 cycle and a consultation on doing the same by Heywood, Middleton and Rochdale CCG closed the previous day.
- 1 full cycle of IVF can include the transfer of several embryos.
- maintaining 1 cycle maintains universal offer to all patients
- the EUR route for funding in exceptional cases will continue to apply
- any decision could be revisited at a future point as circumstances change

After discussion, the Governing Body unanimously supported reducing cycles funded from 3 to 1 for all new patients.

7 **Key Issues for Health Scrutiny to Discuss**

- 7.1 The Committee is asked to share any recommendations as to how the CCG might undertake future consultations in such a way as to ensure the public's voice continues to be effectively heard in commissioning decision making.
- 7.2 The Committee is asked to share any recommendations as to how future decisions should be made about making best use of limited NHS resources in an equitable and transparent manner.