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Proposed changes to IVF consultation: Mid-point PPI review

3 February 2017





Introduction

On January 4 2017 NHS Croydon CCG launched an eight week (4/1/17 to 1/3/2017) consultation programme around the proposal to de-commission IVF, an assisted conception treatment currently commissioned through Croydon University Hospital.

The engagement has made specific efforts to include previous and current users of IVF services. An engagement plan was produced and shared with the provider ahead of the launch of the engagement. The focus of the engagement is to allow patients and Croydon residents who may have a particular interest in IVF services, local stakeholders and community and voluntary sector organisations, especially those that provide support services in the Borough.

Purpose of the report

The purpose of this report is to present a mid-point review of the engagement process. This includes:

- Who we have engaged with to date, including demographic details to ensure we are reaching populations who are likely to utilise IVF
- The types of engagement activity to date
- Key issues raised during the engagement
- Specific and general concerns expressed by participants
- Any gaps in the reach of the engagement and mitigating action to address any gaps

Engagement activity to date

Up to and including the date of this report the following activities have taken place as part of the engagement process:

Activity	Reach	Numbers attending	Date
Consultation materials released and uploaded to CCG website	All Croydon	n/a	4 Jan
Notice sent to PPI Contacts via Get Involved	CGG Network – patients and CVS	300+	4 Jan
Notice sent to Stakeholders and Members	Stakeholder and members list	60+	4 Jan
Consultation documents sent to CUH	Service users	n/k	20 Jan & 24 Jan



Consultation documents sent to all GP Practices	57 GP Practices	n/k	19 Jan
Letter sent to all current users of IVF services in Croydon and those on waiting list	Current users of IVF services in Croydon and those on waiting list (via CUH)	n/k	23 Jan & 1 Feb
BME Groups contact and meetings	Croydon BME Forum Broad Green Asian Women's Group	40+	30 Jan, 31 Jan and 2 Feb
Outreach sessions	Croydon wide	40+	various
Public Meeting CCG – 24/1/17	Croydon wide	56 signed up	24 Jan
Site visit to talk to IVF service users	IVF service users	Not yet undertaken	Not yet undertaken
On-line and paper survey	All	163 (to 3 Feb)	Launched 4 Jan
Drop-in sessions	Croydon wide	2	2 Feb

Participant features: survey and public meetings

Participants at the CCG meetings were encouraged to complete an evaluation form which asked for equalities monitoring details. Around half of the attendees completed these details at the public meeting on 24 January 2017.

The on-line and paper survey request demographic details from the respondent's. The respondent can skip these questions.

Analysis from all sources shows that in the domains of age the respondents are representative of the service user group (63% 25-44). The age bandings in the survey do not correspond with the Croydon cut off point for IVF treatment (39).

The ethnic profile of survey respondents compared to the equalities impact assessment data shows an over-representation of white respondents and an under representation of Asian/Asian British respondents.

While there is a reasonable geographic spread of responses, particular neighbourhoods are over represented by residents from the south of the Borough.

- 63% of respondents are aged 25-44
- 60% of the respondents identify themselves as white British or white other

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- 5% identify themselves as Asian or Asian British against 36% of service users in 2016-17

Response to survey questions

Below is a brief summary of the responses to the survey questions (163 responses):

Question	Strongly agree/agree	Strongly disagree/disagree
Having read the document, I understand the reasons the local NHS is proposing to stop funding IVF and ISCI.	53%	42%

Question	No change	Decommission
Which option do you think Croydon CCG should choose?	81.25%	18.75%

Key themes/issues

The key themes that have emerged through both the survey and the face to face discussions are:

Concerns about the 'fairness' of the proposal and the impact on low-income couple. Groups who are felt to be most vulnerable under the proposals are:

- Women in the upper age bracket for treatment (35+)
- Low income families
- People experiencing mental health issues due to infertility

The second concern focuses on the 'post-code' lottery aspect of IVF treatment. Neighbouring boroughs are seen as being more generous than Croydon and more willing to fund IVF treatment. Respondents believe that this proposals unfairly penalises Croydon residents for living in Croydon

The third main concern is that of the impact on couples which are seen to be multi-dimensional and focus on:

- The psychological impact on couples of infertility where the only option may be for private treatment
- The emotional and financial costs to couples if they had to pay privately for treatment
- The consequences of costs for the local health economy if couples were to go overseas for treatment which may result in multiple births which may led to premature birth and the costs associated with pre-term babies

Gaps and mitigations for the engagement process

The current data shows that the current engagement methods are reaching the service users age profile but are not yet reaching BAME groups, especially Asian and Asian British couples. There also needs to be a greater focus on deprived areas, where a requirement to pay for private treatment may lead to low income couples not being able to afford IVF or ICSI treatments.

To mitigate this and ensure that groups sharing protected characteristics are supported to engage the CCG Engagement team will be undertaking outreach across Croydon focusing on the Thornton Heath, Broad Green and New Addington wards initially. The engagement team has already made contact with the BME Forum lead who has agreed to disseminate message to hard to reach BME groups on the CCG's behalf.

Fertility Fairness have been involved in the engagement but other organisations supporting people who may be affected by the proposal in particular have not yet submitted comments. It would be helpful to contact these groups supporting couples with infertility or medical conditions that may affect their fertility such as endometriosis and fibroids, to encourage them to respond to the proposals.

Planned Activity to 1 March 2017

- Drop-in session at the Town Hall 6/2
- Public Meeting 1 March 2017
- Outreach sessions in Libraries (New Addington and Thornton Heath)
- Outreach in Leisure Centres (New Addington, Central Library, Thornton Heath)
- Outreach to faith groups, including mosques, synagogues, Sikh temple
- Follow up contacts with specialist fertility support groups

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