Public Meeting – Bernard Wetherill House

6pm to 8pm on Tuesday 24 January 2017

Community Rooms, 8 Mint Walk, Croydon

Introduction to the event

An open public meeting was held on 24th January, 2017 to discuss the NHS Croydon CCG proposal to stop the routine provision of IVF. The meeting was attended by key members of Croydon CCG's commissioning and clinical team and Croydon University Hospital staff who are the main local provider of IVF:

- Paula Swann, Chief Officer, Croydon CCG
- Dr Tony Brzezicki, Clinical Chair, Croydon CCG
- Elaine Clancy, Director of Quality and Governance, Croydon CCG
- Agnelo Fernandes, Assistant Clinical Chair, Croydon CCG
- Jimmy Burke, Senior Commissioning Programme Lead, Croydon CCG
- David Garrett, Director of Integrated Women's, Children's and Sexual Health, Croydon University Hospital
- Mike Booker, Consultant, Croydon University Hospital

Lauretta Kavanagh acted as an independent facilitator for the event. The aim of the event was for the local NHS to explain the proposed service change and to listen to public and patients' views on the changes.

Presentations were given: Tony Brzezicki introduced the consultation exercise; Paula Swann explained the purpose and process of Croydon CCG's review of IVF provision; Agnelo Fernandes, detailed the proposal to stop the provision of IVF. The meeting ended with table discussions between members of the public and NHS staff focused on concerns about the proposal, how Croydon CCG should address these concerns and any exemptions to the proposal.

Summary of the Q&A session

A complete list of all the questions and answers can be found at Appendix A. This section provides a brief summary of the key points.

Questionners raised issues about whether the proposal to stop providing IVF is in line with NICE guidelines and the policies of other CCGs. Commissioners explained that Croydon was one of a number of CCGs that are currently consulting on proposals to decommission IVF. Although it is a national health service, services are commissioned locally in line with local needs. The down side to this policy is it means occasionally some areas cannot provide services other parts of the country are providing.

A question was asked about what would be an exceptional circumstance for IFR that would enable a person to continue to receive funding if routine provision of IVF is stopped. It was explained that it is difficult to define exceptional circumstances since there are too many possibilities to cover. However, the CCG is consulting about whether there should be specific exemptions made for particular groups in addition to IFR.

The panel were asked to give an indication of other budget areas which had been looked at in the review, and to give an indication of some services where decisions had been made to continue funding as normal. Examples were given of Children and Adolescent Mental Health Services and whether there was a potential for a reduction in the number of GP hubs for the urgent care model for the borough.

Summary of the table discussions

Several of the participants in the table discussions were reluctant to suggest groups who could be exempt from the proposal to cease the routine provision of IVF. The reluctance was due to a sense that everyone who needed IVF should be able to have it, rather than making decisions about what conditions deserved treatment and which did not. At the same time, there were concerns that not offering exemptions would mean the service would be cut for everyone.

Key concerns raised by participants included the sense the proposal could create an even greater postcode lottery in terms of where someone could have a family, with CCGs playing god. As Croydon already has a lower provision than the NICE guidelines, to remove the service completely would be to targeted the same area for cuts twice. It would be more fair to change other services. Everyone was paying into the national health system and some people suggested this was the only time they had needed to use a health services and they were being denied it. The high costs of IVF treatment for individuals to bear meant some people would be able to afford to have IVF and others would not.

Many of the tables discussed whether there were other options rather than a binary choice to keep or decommission IVF, especially as many people felt the savings were small overall. The possibility of shared funding arrangements was raised by several people, although it was noted that there are problems with the legality of part funding services which should be free at the point of use. Other potential solutions included longer waiting lists, the CCG paying for the drugs and patients paying for their treatment and greater collaboration between CCGs to provide economies of scale.

Issues around mental health services were raised at some tables, with concerns about whether these had been budgeted for. Similarly, the issue of people receiving IVF treatment abroad which could raise the number of multiple births locally was mentioned.

One of the tables had several members of staff from the IVF clinic.They raised some specific points about the service and consultation including concerns about where IFR patients would be treated, as other local hospitals have long waiting lists, the focus on cancer patients by the IRF panel and the difficulties of proving exceptionality. There was a suggestion that criteria could be tightened to increase the efficacy of the treatment and that patients should

not be given freedom of choice over where they have their IVF treatment, to increase cost effectiveness locally.

Evaluation

Those attending the public meeting were asked to fill in the standard evaluation form for events. 19 participants completed the form.

Of those responding:

11 people agreed or strongly agreed that the event was useful; four people either disagreed or strongly disagreed.

11 people agreed or strongly agreed that they were satisfied with the content; four people either disagreed or strongly disagreed. Two people suggested they would have liked a longer Q&A session, two people wanted more information about exceptional circumstances for exemption, one person felt the presentation suggested the consultation would not make a difference to the final decision as it had already been made.

14 people agreed or strongly agreed they would attend a similar event again in the future; 1 person disagreed.

Appendix A – Minutes of the Q&A

Q: I found it offensive that you suggested that IVF is a social need not a medical need. It has medical implications – for example infertility is very stressful. Your consultation is not transparent about what exceptional circumstances would be.

A: PS We are asking about what exceptions we should make. TB We have not stated what is exceptional as we do not know what those circumstances would be. E.g. an exception could be a woman with cancer. There are many reasons why people are truly exceptional. It is not possible to give a comprehensive list as there are so many circumstances that could be taken into account.

LK – I did not hear PS say that it was social circumstances.

Q: MM chair of HWB. Firstly, I have sympathy for the CCG as I know people do not want to cut the health services. This is about a government that has underfunded the services. In particular, Croydon has lost out on the funding differences between CCGs and that is something we will address politically. I want to ask about the 'strengthening' criteria issue in the presentation. That is CCG code for delaying things - treatment needs to be early. The work done in Oregon on local services asked the local population about what the priority services should be locally. What we have in this consultation is a case of open and closed – the priorities have already been decided. We don't know what else has been looked at to be cut and rejected.

A: TB Thresholds – we are looking at thresholds so people who need treatment get it. For example, when we treat people for osteoarthritis we treat people with lower pain thresholds than other CCGs but we have worse outcomes and so we are looking at why that is. We are looking at glare when people drive and don't think that is value for money to treat the condition. We are looking at the allocation that is made for a CCG our size and we have to live within this budget - there is no more money. So we have to think about what else we have to change.

PS: We looked at cuts to CAMHS and rejected it because we think without early treatment we get more mental health complications in later life. We were looking at extending referral to treatment time to 26 weeks and we rejected as we thought it would have too significant an impact.

We looked at reducing the number of GP hubs but rejected it because we did not think we had enough capacity.

We have looked at Better Care and changed local commissioning to reduce admissions for older people and length of stay.

Q: Is this not a 'national' health service that we all fund equally through national insurance? In that case why are there different criteria locally for IVF? A consultation like this is great, but these things do have impact on people and it is sad to see.

A: PS - Yes it is national but commissioning is by local CCG. The good side of that is that we can commission services that are good for the local population. The downside is that everywhere makes decisions differently and IVF is one of those areas where there is a difference. So with IVF we know there are other CCGs consulting on similar proposals to ours and there are other CCGs who have already passed proposals such as ours.

TB – all of us fully understand the impact on people if we stop fund IVF and I suspect it will be devastating. I have been a GP and my wife worked in an IVF clinic and this is not something we want to do. We don't know what else we can do instead – so if you know other areas to make the savings then suggest them but we still have a long way to go and we will be having this sort of conversation with people again and again over the coming year.

AF – this is not why I became a doctor. But we are tasked with the reality of the situation that we only have so much of a budget and if we don't prioritise then we cannot treat other people.

Q: I recently lost a couple of youngsters who died on a mental health ward and did so because there was not enough staff. So I can sympathise with the doctors here and the funding issues they have. I want to give a message of hope to people. When you conceive the feel good factor lasts for a lifetime of having a child. We have a pile of kids in Croydon who need adopting. Please do consider adopting because you can still be super dad with an adopted child.

Q: When I was preparing for this meeting I looked up what made IVF so expensive. Apparently what makes it expensive is the freezing process and I came across an article describing a form of treatment where the freezing process is different. Because they make the freezing agents differently the cost is £150.

A: MB – Cost aspect. Everything we do in this country is heavily regulated by HFEA and we have to abide by those rules. We run IVF as a very lean service and the amount of money the hospital makes just covers the costs and nothing more. The laboratory runs their service as cost neutral and they have not raised their prices for many years.

Infertility is a health need according to the WHO and that has always been the case. Around 1 in 50 babies in Croydon are born as a result of fertility treatment (all forms of fertility treatment not just IVF). The fertility services are valuable.

Q: I am attending the meeting on behalf of Fertility Fairness. We are very concerned about the blanket exclusion you are proposing. Nicola Blackwood says that decisions to stop IVF are unreasonable. The Under SoS for Health says it is deeply disappointing that some CCGs are stopping following the NICE guidelines and she is going to write to NHSE asking them to telling CCGs they should be following the guidelines – what would be your response be.

A: PS - We are looking at exceptionality so it is not a blanket removal of the service. TB – we are making no changes to the other aspects of the fertility treatment.

TB – How will you reply to SoS and NHSE – we have shared this plan with regulators and other areas across London. We are not the only CCG looking to make this change and we are working with South West London CCGs to look at this change.

Q: I have not been able to have children and I did not have the opportunity for IVF and it is very painful. I think the money should be for people who have cancer and life threatening illnesses because I accepted that it is just bad fortune to not be able to have children.

Q: The inability to have IVF will have an impact on mental health. What has been done around mental health? What has been done about agency costs?

A: JB – we have made plans, subject to the consultation, to make mental health services available to couples if the service is decommissioned.

PS – The CCG and Trust are in special measures and we have been working very hard to reduce vacancies and therefore agency staff. It would reduce the Trust's costs if they did not use agency staff but it would not reduce the costs to the CCG because we commission the service as a block.

AF – We have already made £40 million in efficiency savings and this new need for savings is on top of this.

Q: Endometriosis – pregnancy can allow surgical treatment to be avoided.

AF – Reasons for infertility are legion and often we cannot find a reason. Part of this consultation process is to identify areas we need to address. This could be one but I am not sure that having a child as a medical treatment is the main issue here.

Q: Can I go to another borough? What effect will what we say here today have?

TB – If this goes through then if you do not have a truly exceptional reason then you would not be able to have IVF on the NHS.

AF – There are 22 local clinics which provide IVF in a 10 mile area.

Initials:

PS – Paula Swann
AF – Agnelo Fernandes
TB – Tony Brzezicki
JB – Jimmy Burke