

# THE IMPACT OF WITHDRAWING NHS FUNDING FOR IVF

*Response to the Cambridgeshire and Peterborough Clinical Commissioning Group about the impact of its decision on people in Cambridgeshire to remove funding for specialist fertility services.*

*Analysis of 300 responses to an in-depth survey and of information received through Freedom of Information requests.*

**Prepared by Holdsworth Associates April 2019**



## OVERVIEW

In August 2017 Cambridgeshire and Peterborough Clinical Commissioning Group (C&PCCG) made the decision to remove funding for its Specialist Fertility Services, which includes IVF, Intra Uterine Insemination (IUI) and donor insemination.

It agreed to review the decision in April 2019 and to consider feedback on the impact this decision has made.

### **Impact of removal of funding**

Holdsworth Associates was commissioned by Bourn Hall, provider of NHS funded IVF treatment across the East of England, to conduct an in-depth survey during February and March 2019 to assess the impact of withdrawal of funding for Specialist Fertility Services.

The survey was promoted through the media, social media and sent to the 4,000 people who had responded to a petition organised during the consultation process ahead of the withdrawal of funding two years ago.

Of the 300 survey responses, approximately one third had received some type of fertility treatment, one third needed treatment and the remaining third did not require treatment themselves but had seen the impact on a close friend or relative.

### **Key findings**

The survey shows that the biggest impacts of withdrawing funding were:

- Severe impact on mental health – resulting in medication, depression, low self-worth, suicidal thoughts, hospital admissions, inability to work
- Stress on relationships – isolation, withdrawal from friends and family, destroyed marriages
- Devastating impact on lives – loss of meaning, all consuming, financial stresses

Through Freedom of Information requests (FOIs) to C&PCCG and Cambridge University Hospital Trust (CUH), it has also been possible to clarify numbers of patient referrals and waiting times, suggesting that cost savings were significantly less than that anticipated.

This information, combined with the survey feedback, has revealed that by removing the option of a referral for NHS funded treatment the entire fertility journey has suffered.

Currently over 50% of patients diagnosed with some form of infertility are left without resolution.

This, however, includes a cohort of patients that were able to access NHS funded treatment, suggesting that the situation will get worse.

A summary of the survey results is shown on page 7.

## RATIONALE FOR CUTS

In August 2017, Cambridgeshire and Peterborough CCG removed any NHS funding for IVF in what is understood to be a cost-saving measure.

In 2017 the CCG had a patient population of approximately 950,000 and a budget of £1,400,000,000. 142 women accessed NHS-funded IVF in the year up to October 2016 (CCG data).

### **Proposed cost saving**

In its consultation document the CCG suggested that removing IVF entitlement would save the NHS £700,000 a year. This saving was based on 200 women accessing one cycle of IVF treatment each year at the cost of £3,500 per cycle.

$$200 \text{ women} \times \text{£}3,500 = \text{£}700,000$$

### **Actual cost for year to October 2016**

However, it was later confirmed by C&PCCG in its response to the consultation that the price paid was £3,000 and in the period up to October 2016 only 142 women per year had accessed NHS-funded IVF. This means the potential saving using C&PCCG data is closer to £426,000.

$$142 \text{ women} \times \text{£}3,000 = \text{£}426,000$$

This is 0.03% of the total CCG budget.

## IMPACT OF CUTS ON PEOPLE OF CAMBRIDGESHIRE

The survey offers a snapshot of the impact that cutting IVF funding has had on the lives of people living in the Cambridgeshire and Peterborough CCG area.

Over 300 people responded to the survey, demonstrating the strength of feeling and the considerable support for reinstating NHS funding for IVF treatment.

One third of the responses were from people who felt strongly that the postcode lottery was unfair and should be removed, but were not directly affected by infertility. The majority of these people responded as they had a friend or relative that could not access treatment and they had witnessed the impact it had on their lives.

The most often cited impact is on mental health and wellbeing, loss of self-esteem and negative impact on relationships with partners, friends and family. The emotional and financial stress feeds into feelings of isolation, worthlessness and serious mental health issues.

Patients that require IVF treatment and are unable to afford it describe infertility as having a “devastating” impact on their lives.

### Summary of responses: ‘How has infertility affected you, your relationships and your health (or those of someone you care about)?’



## CAMBRIDGESHIRE PATIENTS

Fertility significantly declines after the age of 35 for women and every month is a waiting game. Good advice, prompt treatment and a resolution to enable people to move on with their lives are vital to promote mental health and wellbeing.

### Waiting times (CUH data)

*72 patients are currently waiting for infertility investigation. Over half have been waiting for more than 13 weeks and six have been waiting for more than four months.*

The survey of Cambridgeshire patients investigated the patient outcomes and reveals that over 50% of patients diagnosed with some form of infertility at Level 2 between 2015 and 2019 were left without resolution.

Deeper analysis has been made of responses from patients living within the C&PCCG area that sought help for infertility from 2015 – 2019. This showed the following:

- The majority of people waited more than two years for referral for fertility advice and testing after they realised they were struggling to conceive. Many of these were already 30 years of age or older
- 25% waited 18 weeks or more between referral and their first appointment
- 43% had four or more appointments for testing and diagnosis; 20% had nine or more
- Two thirds of the respondents referred to Level 2 after June 2016 (when C&PCCG reduced the entitlement to one cycle of treatment) did not receive any NHS-funded treatment for their infertility
- 70% of those that need IVF say they are unable to afford it
- Some patients who are not able to afford IVF in the UK are considering going abroad for treatment
- 15% of patients are still waiting for their first NHS appointment, several have had self-funded testing to speed up referral

A number of participants reported that the fertility service felt disjointed, with tests performed sequentially by different departments with delays between each.

Frustration with the lack of information and time delay is illustrated by this response to the question “What advice would you give to your younger self?”

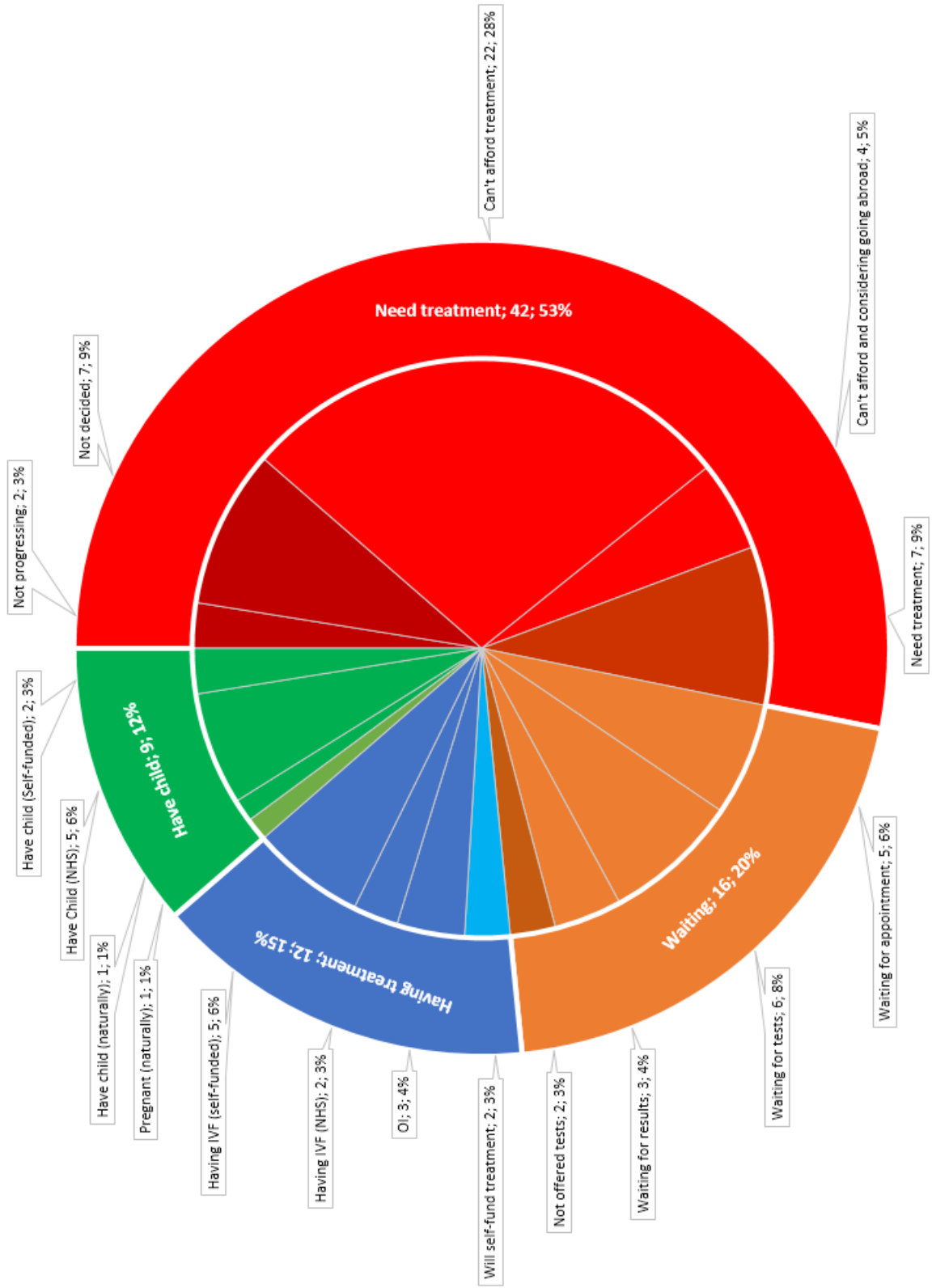
“*Ask more questions. Specifically: ask about the whole process of referral and your options at each stage.*

*We were living from appointment to appointment and not understanding what the outcomes of each test would mean and what our options were at each stage.*

*Insist on having a named contact at each place you're dealing with, with a direct dial phone number - we were passed from pillar to post all the time, I spent far too long phoning down a list of numbers trying to find the right person to speak to get questions answered or to chase up appointments that we were waiting for.*

”

**The current situation of the 79 respondents to the survey from Cambridge and Peterborough who have had tests since 2017 or are still waiting for tests**



*Note: this pie chart shows the current status of patients that have been referred since the decision to cut all NHS funding for IVF in 2017. The larger sample of patients referred since 2015 shows that 70% currently need IVF and cannot afford it.*

## Analysis of 20 patients currently waiting

When did you realise you were struggling to conceive?	Have you discussed your infertility with your GP?	When were you referred for fertility tests?	Wait in months since referral	Current situation
01/10/2011	Advised to lose weight or other lifestyle change	Not referred		Waiting for referral
01/01/2016	Referred for NHS fertility tests			Waiting for tests
01/06/2016	Yes - referred for NHS fertility tests	01/02/2019	2	Waiting for tests
01/06/2016	Prescribed medication or other treatment (not IVF)	01/02/2017	26	Waiting for results
01/10/2016	Advised to wait	Not referred		Waiting for referral
16/11/2016	Referred for NHS fertility tests			Waiting for tests
01/12/2016	Yes - referred for NHS fertility tests	01/10/2018	6	Need treatment
01/01/2017	Referred for NHS fertility tests			Need treatment
01/01/2017	Referred for self funded tests	05/08/2018	8	Waiting for referral
01/01/2017	Referred for NHS fertility tests	07/03/2019	1	Waiting for appointment
01/01/2017	Yes - referred for NHS fertility tests	13/08/2018	8	Need treatment
10/03/2017	Advised to wait	08/03/2019	1	Waiting for appointment
02/09/2017	Advised to wait	Not referred		Waiting for referral
01/11/2017	Referred for NHS fertility tests	01/11/2018	5	Waiting for tests
12/12/2017	Referred for NHS fertility tests	03/10/2018	6	Waiting for tests
30/12/2017	Referred for NHS fertility tests	26/02/2019	1	Waiting for appointment
31/12/2017	Referred for NHS fertility tests	28/02/2019	1	Need treatment
01/01/2018	Referred for NHS fertility tests	01/02/2019	2	Waiting for appointment
03/07/2018	Yes - referred for NHS fertility tests	25/02/2019	1	Waiting for tests
01/01/2019	Advised to wait	Not referred		Waiting for tests

## IMPACT ON HEALTH AND WELLBEING

Patients that require IVF treatment and are unable to afford it describe infertility as having a “devastating” impact on their lives.

### Summary of responses: ‘How has infertility affected you, your relationships and your health (or those of someone you care about)?’

*“Profoundly. We now have a wonderful daughter and I am incredibly happy. However the process of answering these questions has reduced me to tears just reliving what we went through.”*

Category of impact	Responses	Example comment
Severely impacted mental health and/or that of partner	62	<i>“My husband suffers from depression, have drifted away from friends and families as can't cope with seeing their children, now avoid social situations.”</i>
Created stress on relationships, with partner, friends and family	52	<i>“My marriage has suffered and so has my mental health. I was diagnosed with circumstantial depression and anxiety shortly after my infertile diagnosis in 2016. This affects me daily. “</i>
Concerned about the impact on someone close to them	36	<i>“Both daughters - it is terrible to see the trauma this causes, surely IVF is cheaper for the NHS than a lifetime of depression prescriptions?”</i>
Unfairness of postcode lottery	20	<i>“Being one of the lucky ones meant I live in a postcode area that does fund IVF. If I wasn't in that position, I honestly don't know that I would still be here... I am forever grateful to the NHS for our miracle.”</i>
“Devastating” impact on their lives	17	<i>“Massively affected every friendship with people who have children, pressure on my marriage, affected work. Had to reduce working hours. It controls my whole life everyday.”</i>
Suffered from financial stress	6	<i>“Nearly lost my husband, and depression for me. Paying for a donor is very expensive, but if I got two rounds of IVF, this would relieve the stress of the money situation.”</i>
Having a genetic condition still did not result in help	3	Includes patients with known genetic conditions such as cystic fibrosis
Secondary infertility stress	1	
Went abroad for treatment	1	
Other	13	
<i>Total responses</i>	<i>210</i>	



## WHAT ADVICE WOULD YOU GIVE YOUR YOUNGER SELF REGARDING FERTILITY?

Common themes of the responses to the question about patients' learning experiences were: don't wait, don't be fobbed off and seek early advice.



## What advice would you give your younger self?

Category	Responses	Example advice
Ask more questions, push for answers and testing	35	<i>"Do your research first and know what to ask, typical response always seems to be the very least rather than what's best for patient."</i>
Don't wait	32	<i>"Push for answers sooner, you know your body, don't be fobbed off with the "it's because you are overthinking it" answer – you had to deal with this for 2 years before being taken seriously."</i>
Journey is disjointed	5	<i>"Ask more questions."</i>
Admit you have infertility and get support from others	7	<i>"Don't be afraid to admit when times are emotionally hard and seek professional help for mental health for this journey."</i>
Save for treatment	9	<i>"We saved up a lot of money, I went to work self employed at home ready to give a suitable home to a baby. However with 3 miscarriages and 2 ectopic (I'm pretty much infertile, my remaining tube is so badly damaged) my mentality is easily snapped. Some days I just spent an entire day crying because I'm desperate for my own family and for something to wake up for. My boyfriend brought me a puppy and without that "baby" I don't know where I would be now."</i>
Don't give up	4	<i>"Trust your instincts if something doesn't feel right. Don't wait to speak with your GP &amp; try not to blame each other as a couple. Have faith that there are others like you, and that good doctors will try their best to help you become a parent."</i>
Lose weight	2	<i>"To keep healthy, keep weight down, try not to stress about it."</i>
Stop pill earlier	1	<i>"If I wasn't on the pill I would have been diagnosed with endometriosis earlier and could have gone for tests earlier."</i>
Try not to let it dominate your life	3	<i>"Treatment decisions aren't fair, but they aren't a reflection of your self-worth. You are not on your own. You will get there, you don't need to worry. But it's ok to cry, there is no shame in where you are, it's hard but miracles do happen."</i>
Freeze your eggs	1	
Move	2	<i>"Move to Norfolk so that you can have treatment funded. Cambridgeshire do not care about you."</i>
Other	4	
<b>Total responses</b>	<b>99</b>	

## RECOMMENDATIONS

Fertility declines rapidly after the age of 35 but the majority of people seek advice in their twenties, so it is proposed that implementing a high quality integrated fertility pathway that provides tailored advice, rapid testing and a range of fertility treatment would improve patient experiences and outcomes.

Bourn Hall is one of the IVF clinics commissioned by the NHS to provide IVF for the East of England and the only NHS approved provider of IVF in Cambridgeshire. Bourn Hall also provides Level 2 services (diagnosis and treatment) for Norfolk CCGs.

30% of the patients it sees are helped to become parents naturally and others through alternative parenting options. It has a 40% live birth success rate for NHS funded IVF patients.

This knowledge of Level 2 and Specialist Fertility Services has enabled Bourn Hall to be able to predict future demand for fertility treatments.

It estimates that around 100 people each year would be eligible for NHS funded IVF treatment in the Cambridge area.

Bourn Hall has submitted a proposal to the C&PCCG to offer an integrated pathway from GP to resolution, which will provide a better patient experience and mitigate the costs of reinstating NHS funded IVF in the region.

This proposal included all of the anonymised feedback received from the survey.

### **In conclusion**

The number of people requiring IVF is very small but the impact of infertility on the quality of life of those directly affected and their wider family and friendship groups is heart-breaking.

Without proper support these patients are left without resolution and the ability to move on with their lives.

A fully integrated fertility service would enable more people to become pregnant with minimal intervention and the opportunity for IVF for those that need it.

The contribution that these IVF babies will make to the economy and to society will more than repay this investment.