

GRANT SHAPPS MP

THE MESSY BUSINESS OF CONCEPTION

HOW THE POSTCODE LOTTERY IN NHS IVF
TREATMENT IS CREATING 'BABY BOUNDARIES'
FOR CHILDLESS COUPLES

MARCH 2007

INTRODUCTION

THE NICE GUIDELINES AND THE NEED FOR FAIRNESS OF PROVISION

BACKGROUND

It is estimated that at some time in their lives at least a quarter of couples experience a period of infertility lasting over 1 year.¹ Infertility is a cause of much distress for couples wishing to have a baby.

Fertility treatment is far from what might be considered a marginal healthcare issue. The most recent research by the Human Fertilisation and Embryology Authority (HFEA) estimates that in 2004 there were 1,750,000 couples living with the stresses of failing to conceive.² Most recent figures show that around 10,000 babies are born each year as a result of IVF.³

Prior to 2004 the supply of fertility treatment on the NHS was an entirely local decision: some Trusts offered it, some didn't.

Following reports of inequality in the provision of in vitro fertilization (IVF) treatment, in 2004 the National Institute for Clinical Excellence (NICE) published a new national guideline about the way in which the NHS should provide IVF and other forms of fertility treatment. One of the key recommendations was:

*'You should be offered up to three cycles of IVF if the woman is between 23 and 39 years old at the time of treatment.'*⁴

Essentially, by stating this clearly in their guideline NICE are recommending that it is appropriate to fund IVF treatment where the chances of success are 10% or greater.

The then Health Secretary, John Reid hailed the document, saying 'this will mean that thousands more couples should be able to have fertility treatment on the NHS'.⁵

The Department of Health used the announcement to confirm that in implementing the guidance it would ask all Primary Care Trusts to:

- Offer all women aged 23-39 who meet the NICE clinical criteria a minimum of one full cycle of IVF from April 2005
- Give priority to couples who do not already have a child living with them

THE PRESENT DAY

Two years after the date by which the Secretary of State for Health promised that the guidelines would be implemented throughout the NHS, there has been a worrying failure to implement the NICE recommendations, as well as a refusal to abide by the Department of Health's standardised nationwide rules.

In fact this research has found that it is still as complicated as ever to obtain NHS funded fertility treatment. In some parts of the country there continue to be a never-ending series of hoops to jump through for couples trying to prove themselves eligible.

Elsewhere, even when couples are technically eligible, meeting all the necessary criteria, funding still prevents the treatment from actually taking place.

This report represents the most comprehensive survey of its kind published to date and proves that despite the best intentions of NICE and the warm words of John Reid MP, the current rules mean that your chances of conceiving depend more on the county you live in than your need. Inconsistencies in the implementation of the guideline have created 'baby boundaries' where couples are effectively being told that they cannot have a baby while their friends on the other side of the street, who might have a similar set of circumstances are able to obtain three cycles of IVF provided for them by the NHS.

METHODOLOGY AND FINDINGS

This research is based on a Freedom of Information request to every Primary Care Trust (PCT) in the country. The response has been unusually high with up to 90% of Trusts providing the raw data.

However, the results show glaring inconsistencies in the services on offer to couples who are having difficulty conceiving.

CASH-STRAPPED LOCAL NHS TRUSTS

With NHS finances under sever pressure, there are some PCTs refusing to fund IVF, IUI or ICSI at all.⁶ These 'marginal' services are being squeezed out of Trust budgets and so in some areas there are generations of men and women losing their chance at starting a family because of the dire financial state of their local health economy.

The situation in Staffordshire seems to be most alarming. Of the three local PCTs, two have cancelled all referrals of couples looking for help conceiving:

- Stoke on Trent PCT insisted there would be no money available for IVF or ICSI during the whole of the 2006/07 budgetary period because it has been classified as a 'low priority treatment'.
- On 14th December 2006 North Staffordshire PCT decided to stop all fertility treatment, thereby extending the limitations placed on the service by its predecessor, the Newcastle PCT.

AGE RANGE

Despite the NICE guideline indicating that the greatest chances of successful conception are seen in women aged 23-39 and the Department of Health requesting that PCTs offer treatment to women aged 23-39 who satisfy the rest of NICE's clinical criteria the situation remains unclear in many regions.

Indeed the astonishing situation exists where a female may be too old to qualify for NHS funding in one locality while the same woman would be considered ineligible for free treatment in another part of the country on the grounds that she is too young.

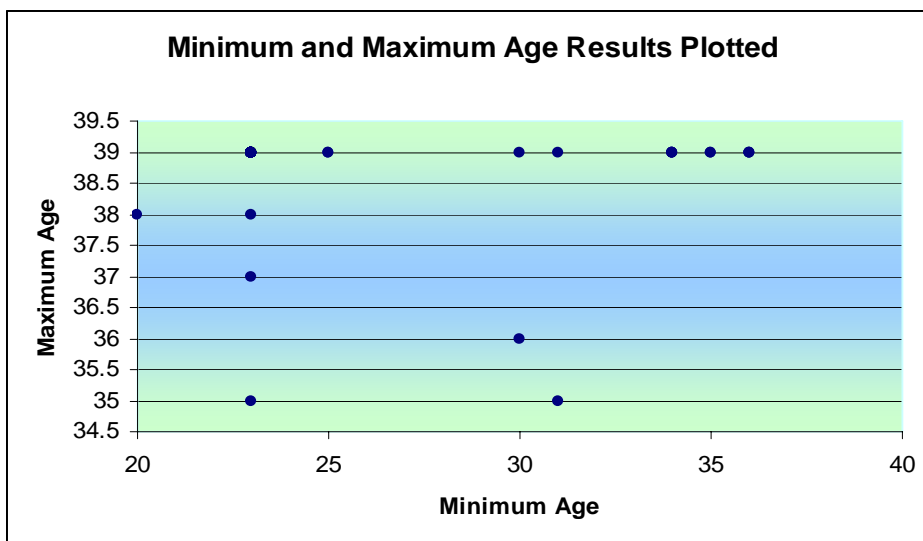
Examples:

- The local NHS Trust in Swindon offers treatment only to women meeting the clinical criteria between the ages of 30 and 36.
- Gloucestershire PCT will only offer fertility treatment to women in their thirties.

- Whilst in the Wiltshire PCT a particularly narrow age range is evident in the criteria. IVF is only available for women aged 31-35.
- Lincolnshire PCT and Luton PCT will only pay for couples in which the woman is under the age of 35 to have IVF.
- In Somerset PCT and Bath and North East Somerset PCT the female partner must be 35 or over before being referred to a specialist.
- Northampton PCT specifies that the female partner must be at least 31.
- In Isle of Wight PCT and Hampshire PCT women must be aged between 36 and 39. Estimates suggest that the number of women affected in Hampshire alone could be more than 20,000.⁷

The examples above demonstrate how a women living in one area could be too old to be provided IVF on the NHS, whereas in another area she would be considered too young.

In short, the system is a messy and insensitive to couples already experiencing the stressful experience of infertility. Furthermore it appears that financially unstable local NHS organisations are being forced to invent their own eligibility criteria in order to ration their increasingly scarce resources. The NICE recommendations are, in large part being ignored.



(two or more identical results appear just once)

The bizarre situation exists in Somerset where a woman in her early thirties must wait until she is over 35 before gaining access to services that could provide her with a family. This is despite medical opinion stating that the success rates of IVF diminish after the female partner passes 35. Paula Rowell (a senior embryologist at Guy's and St Thomas's, London), in an article published in the British Medical

Journal (BMJ) wrote that ‘the number and quality of oocytes retrieved continues to decline from age 35’.⁸

NICE’s own guideline suggests that ‘for every 100 women who are 36 to 38, around 15 will get pregnant. This represents a 5 per cent lower success rate than would be expected for a woman aged 35 and under.

Indeed North East Lincolnshire PCT state clearly in their criteria that the reason they *do not* fund treatment for over 35s is because:

‘clinical and scientific evidence indicates an age of 35 years as being the point at which a woman’s fertility begins to decline’

It therefore seems strange that many Trusts are restricting treatment to couples for whom it is less likely to succeed.

IVF Success Rates by Age

Age	Success Rate
23-35	20%
36-38	15%
39	10%
40+	6%

(NICE Guideline p.149)

Where one PCT has the same minimum age criterion as another PCT’s maximum age, this appears to defy medical logic and the system runs the risk of failing to serve everyone. Meanwhile PCTs are ignoring the advice of NICE and the direction of the Secretary of State for Health. To an extent PCTs are in a position of playing God; deciding who has the right to a child and who does not, based largely on the state of their annual budgets and deficit.

John and Jane are both 33. They live in Stoke on Trent and have been together for some time. They would like a baby but are having trouble conceiving. They get in touch with their GP who informs them that they are unlikely to receive NHS funding for fertility treatment because the local Primary Care Trust (PCT) has refused to fund IVF and other methods of assisted conception except for in ‘exceptional circumstances’.

Desperate to have a baby but unable to afford private treatment, John and Jane, who know that Hampshire PCT fund fertility treatment, take the drastic step of moving to Hampshire where Jane has family. After setting up their new home they go and visit their new GP and tell them that they are interested in investigating the possibility of assisted conception.

Unfortunately, Jane is too young to qualify for NHS funding in the area. Hampshire PCT specifies that the female partner must be at least 36 before qualifying for free treatment.

The couple hear that Wiltshire PCT do provide free IVF and desperate to have the baby that they believe will complete their family; they look into the possibility of moving there. By now Jane is 36 so is too old to qualify for free treatment there.

John and Jane once again approach Hampshire PCT and find that they are now eligible for free IVF treatment.

Upon being placed on the waiting list the GP informs them that because of Jane's age the chances of success have reduced by around a quarter compared to when they originally inquired.

PREVIOUS CHILDREN

While welcoming the NICE clinical guideline, John Reid announced in 2004 that he would be 'asking the NHS to give local priority to couples who do not have any children living with them.'⁹

In fact only two PCTs will even consider providing IVF for couples with a child from their current relationship. For example Bristol PCT's criteria for IVF provision states that 'the couple must not have more than one living child between them from this or from any previous relationship'.¹⁰ The implication therefore being that couples who have already parented a child together are able gain access to NHS funded treatment.

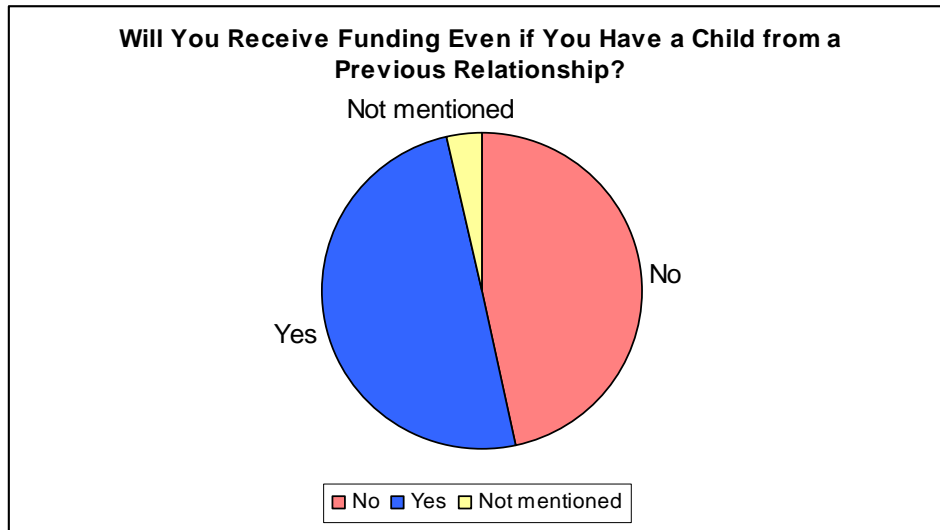
But once again the situation, even with regard to children from previous relationships, lacks clarity. Around half of the Trusts will offer IVF to couples where a partner has living children from an earlier relationship.

The results show that 51 PCTs will exclude couples where one of the partners already has a child. 54 PCTs have criteria that do not reject those couples while 4 of them do not explicitly mention previous children as a factor in their policies.

The Effect of a living child from a previous relationship on eligibility for IVF

Ineligible	Eligible	Not mentioned in criteria
46.8%	49.5%	3.7%

Confirmation of this confusing lack of uniformity can be demonstrated by considering the case of two neighbouring Primary Care Trusts. Kensington and Chelsea PCT will subsidise artificial insemination while Hammersmith and Fulham PCT do not. Couples being refused by Hammersmith and Fulham on these grounds could conceivably have friends in the same situation, living on the other side of the street receiving free IVF, IUI or ICSI.



If you live in Essex then the state of affairs is particularly puzzling. The table below shows the five Primary Care Trusts covering the county and their rules for those who have a child from a previous relationship.

Essex PCTs and their Policies on Couples in which a Partner already has a child

Essex Primary Care Trusts	Eligible?
West Essex PCT	No
South East Essex PCT	No
Mid Essex PCT	Yes
North East Essex PCT	Yes
South West Essex PCT	Yes

Essex serves as a perfect snapshot of the problem across the country. Not only are two of the PCTs failing to offer provision as advised by NICE and requested by the Department of Health but the lack of any semblance of consistency is absurd. Couples in West and South East Essex are being locked outside the 'baby boundaries' of the county.

PREVIOUS FERTILITY TREATMENT

More than half of the Trusts that are currently providing specialist fertility treatment reject any couples who have previously attempted treatment on the NHS.

A minority of PCTs will allow couples to go for IVF, ICSI or IUI even if they have tried on an earlier occasion using public money.

Many Primary Care Trusts will bar couples from IVF if they have ever had fertility treatment in the past at all. 14.5% of PCTs will not consider for

referral couples who have had treatment in the past, whether NHS or self-funded.

Couples who decide to opt out of the NHS, perhaps because of waiting lists or, as discussed above the odd age limits in existence, are then being permanently excluded from the NHS.

A couple might spend all of their savings on a shot at a family they long for not realising that they are, in effect opting out of state-funded fertility treatment forever.¹¹ It's hard to escape the conclusion that the current system has a tendency to punish couples for trying to help themselves.

OTHER FACTORS

- Where couples are able to jump through all the correct hoops there then exists considerable variation in the number of cycles of treatment that the NHS will pay for.

Couples meeting the criteria in the Thames Valley region will likely receive one free treatment cycle. This compares rather unfavourably to the situation in most of Merseyside and Cheshire where the PCTs have agreed to fund two cycles. Central Lancashire PCT will commission three IVF cycles per couple.

- There are slight nuances in the Body Mass Index (BMI) parameters that Trusts insist must be met while some do not even give a passing mention to BMI.
- A similar level of non-conformity can be seen in the length of relationship of the couple. Many Trusts do not specify a period that the couple should have been together for. The most common request is a union of two years.

Gloucestershire PCT asks that couples are together for three years before seeking treatment while Kensington and Chelsea PCT identify a relationship length of just one year.

Hartlepool PCT's offering is that the relationship is 'stable' while Haringey PCT would like couples to be in a 'long term relationship'. Neither seek to explicitly define these terms.

- Other social criteria have been muscled into the IVF eligibility rules of Trusts. Some random PCTs, for instance Birmingham East and North PCT ask that both partners are non-smokers.

Devon PCT only requests that the female partner is a non-smoker. Others extend this principle by specifying a period of six months as the length of time the female partner has been nicotine free. An example of this being Plymouth Teaching PCT.

CONCLUSION

A muddled approach by the Department of Health and a failure to follow the NICE guidelines, combined with growing PCT deficits in many parts of the country, have created entirely arbitrary borders that decide which couples can start a family and which couples cannot.

Those who miss out pay the worst possible price because three years on from the NICE guidelines and the Secretary of State's direction, starting a family is still regarded as a 'marginal' treatment in the NHS.

When the Secretary of State for Health claimed in 2004 that from then on it would be made simple for needy couples to access specialist fertility treatment, he was wrong. In reality cash strapped NHS Trusts are being forced to flout the clinical guidance on offer and, as a result, millions of couples are facing even more anxiety during what is often a hugely stressful period in their lives. Indeed, couples who are desperate for comprehensible, unambiguous guidance are being given precisely the opposite.

The evidence suggests that even where a couple meets the detailed criteria of the PCT that might potentially fund their treatment, they frequently discover that the budget simply doesn't exist to actually access IVF. The detailed work which has gone into producing criteria and guidelines is thereby entirely irrelevant to a couple in this position.

In short, two years after the date predicted by the Secretary of State for Health for the nationwide implementation of the Department of Health recommendations the situation is cryptic, confused and inconsistent; in 2007 the business of conception is nothing short of a mess.

ABOUT THE AUTHOR

Grant Shapps is married to Belinda and he was elected to Parliament in 2005.

In 1999/2000 Grant Shapps was treated for Hodgkin's Lymphoma. The chemotherapy meant that when it came to starting a family IVF presented the only chance.

Two out of three IVF cycles attempted were successful and all three of his children (a 6 year old boy and twins – Girl and Boy) are through IVF.

The research for this report was undertaken following complaints from constituents who were unable to access IVF treatment on the NHS, despite meeting all PCT criteria.

¹ D J Gunnell and P Ewings (1994) 'Infertility Prevalence: Needs, Assessment and Purchasing' *Journal of Public Health Medicine*; 16(1): pages 29-36

² *Regional Breakdown: Infertility* (www.hfea.gov.uk)

³ HFEA Facts and Figures, www.hfea.gov.uk

⁴ *Fertility: Assessment and Treatment for People with Fertility Problems: NICE Clinical Guidance* (February 2004): Appendix A, page 149

⁵ 'Health Secretary welcomes new fertility guidance' *Department of Health Press Release* (25 February 2004), PR Ref Number: 2004/0069

⁶ IUI stands for intrauterine insemination and ICSI is intracytoplasmic sperm injection. The latter accounts for 44% of all fertility treatment in the UK (HFEA Statistics, www.hfea.gov.uk)

⁷ Estimates based on population and co-habitation statistics from the 2001 Census as well as the estimate that 1 in 4 couples experience problems conceiving

⁸ P Braude (ed) and P Rowell (11 October 2003) 'Assisted Conception II – In Vitro Fertilisation and Intracytoplasmic Sperm Injection' *British Medical Journal*, vol. 327, pages 852-4

⁹ 'Health Secretary welcomes new fertility guidance' *Department of Health Press Release* (25 February 2004), PR Ref Number: 2004/0069

¹⁰ *Referral to the Specialist Fertility Service (Bristol)*, page 3

¹¹ "A typical cost of a cycle of IVF treatment alone is approximately £3000. On top of this, the couple will have to pay for the costs of consultation, drugs and tests. Other procedures, such as embryo freezing, will also be charged for separately." (HFEA Facts and Figures, www.hfea.gov.uk)