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Infertility provision in England



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RCN position

1. The RCN supports full implementation of the National Institute for Clinical Excellence (NICE) guidelines including the recommendation that at least three full treatment cycles are available to couples undergoing IVF treatment.
2. National non-clinical access criteria should be implemented to ensure equity.
3. Nurses should contribute to the commissioning process on a local level to ensure that commissioners understand the psychological impact of infertility and the pressures experienced by patients and their families in addition to the practical issues outlined earlier.

Introduction

Since the birth of Louise Brown in 1978, more than three million babies have been born worldwide through in vitro fertilisation (IVF).

Despite one in six couples in the UK having problems conceiving and the devastating social and psychological effect this can have, the provision of infertility services has varied in the extreme throughout the National Health Service (NHS) and has always been inequitable. As a result, many people have little option other than to explore treatment in the private sector, which at present accounts for about 75 per cent of IVF treatments in the UK.

Depending on individual Primary Care Trust (PCT) policy, entitlement to NHS funded treatment has ranged from no funded treatment to a full three cycles. It was against this background that the National Institute for Clinical Excellence (NICE) released guidelines in 2004 and the recommendation that all PCTs fund a full three cycles of IVF; this includes the transfer of any frozen embryos (resulting from the fresh cycle) before the commencement of the next cycle.¹ While some PCTs have attempted to implement these guidelines, many continue to fall short of the recommendations. Those unable to conceive naturally, are not afforded the opportunity of accessing NHS funded IVF or face the added financial burden of funding their own treatment.

At RCN Congress in 2008, an agenda item was passed calling for the RCN council to lobby for widespread implementation of the 2004 NICE guidelines. As a result, the RCN is committed to developing a strategy to undertake this work. The RCN Midwifery and Fertility Nursing Forum has strong links with Infertility Network UK (INUK), the patient led organisation whose key objective is to improve access to IVF treatment on the NHS. However, despite lengthy and vigorous campaigning the goal has not yet been achieved.

Another group closely affiliated with INUK UK is the National Infertility Awareness Campaign (NIAC) which is an umbrella body, created as part of National Fertility Week in 1993. NIAC continues to campaign for equal access to fertility treatment for those with an established clinical need. NIAC's current focus is on the implementation of NICE guidelines on fertility provision¹ and on the promotion of single embryo transfer where it is clinically appropriate.

¹ National Institute for Clinical Excellence (2004) *Fertility: assessment and treatment for people with fertility problems*, London: National Institute for Clinical Excellence (NICE)

It is now internationally recognised that multiple births are the greatest complication arising from IVF because of the increased risk to the health and welfare of mothers and babies. A multiple birth stakeholders' group, of which the RCN is a stakeholder, along with other professional bodies and patient groups, is supporting and advocating the implementation of changes in practice to elective single embryo transfer to significantly reduce the high number of twins.

Regulation of IVF in the UK

The number of women undergoing IVF treatment in the UK has increased steadily since the birth of Louise Brown in 1978 in Oldham and District Hospital in Manchester. The International Committee for Monitoring Assisted Reproductive Technology has estimated that over three million babies have been born in the UK as a result of IVF from 1978 to 2006.

Year	Women undergoing IVF treatment	Babies born
1985	3717	513
1995	22647	5791
2005	32626	12000

2

The first step towards the regulation of IVF treatment in the UK came about through the recommendations of the Committee of Inquiry into Human Fertilisation and Embryology (HFEA) which was established in 1982.³ This committee was created 'to consider recent and potential developments in medicine and science related to human fertilisation and embryology; to consider what policies and safeguards should be applied, including consideration of the social ethical and legal implications of these developments; and to make recommendations.'

In 1984 the committee published the Warnock Report which included a number of recommendations on the principles for regulation of IVF and embryology. In 1986, the Voluntary Licensing Authority was established to oversee the regulation of IVF treatment based on many of the recommendations in the Warnock Report albeit on a voluntary basis. This became the Interim Licensing Authority in 1989 and voluntary regulation continued until the Human Fertilisation and Embryology Authority commenced its statutory role as a regulator of IVF in 1991.

As new drugs have been developed and the treatment refined, in the UK the live birth rate per cycle has risen from 8.5 per cent in 1985 to 15 per cent in 1995 and to 21.6 per cent in 2005. About one in four IVF pregnancies results in the birth of twins. However, the incidence of triplets has dropped from 136 in 1995 to 34 in 2005.⁴ This was the result of published guidance from the British Fertility Society (BFS) and Royal College of Obstetricians and Gynaecologists (RCOG) which, in 2004, led to the HFEA making it a requirement of IVF clinics to transfer no more than two embryos in women under 40 years of age.

In 2008, the Department of Health (DH) consulted on the regulations for the implementation of the new HFEA Act. It is likely that this will increase the overall time limit for storing embryos and gametes to 55 years for people who have become significantly and prematurely infertile. The RCN and RCN Fertility Nurses Group made a considerable contribution to the debates during the passage of the new HFE Act and its regulations.

² Human Fertilisation and Embryology Authority (2009) IVF in the UK: statistics 1985, 1995 and 2005, London : HFEA www.hfea.gov.uk/1316.html (accessed December 2009)

³Department of Health and Social Security (1984) Report of the committee inquiry into human fertilisation and embryology , London: DHSS (Chairman: M Warnock DBE)

⁴ Human Fertilisation and Embryology Authority (2009) IVF in the UK: statistics 1985, 1995 and 2005, London : HFEA www.hfea.gov.uk/1316.html (accessed December 2009)

Why IVF is needed?

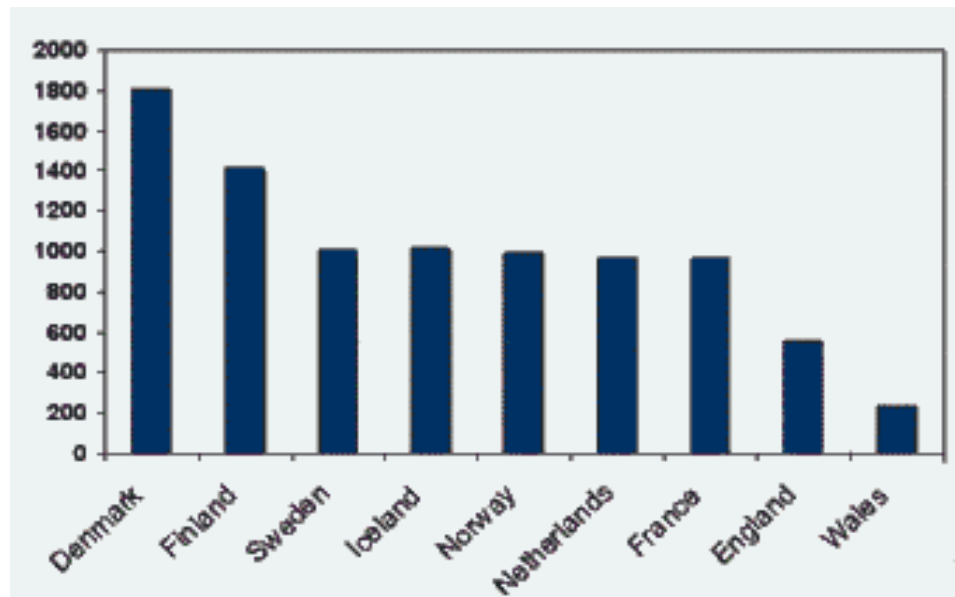
When the pioneering work was undertaken to create embryos 'in vitro' it was with the intention of enabling women with damaged fallopian tubes to have a chance of having a child. Since IVF has become established, the technique is used for a wider range of factors, including male infertility and 'unexplained infertility'.

Currently in the UK, women are choosing to defer pregnancy until later in life. The number of first time mothers under the age of 25 has halved in the last two decades and postponement of pregnancy and other lifestyle factors have led to an increase in unexplained fertility and reliance on IVF.

In 2006, the average conception rate for women under 35 undergoing IVF was 31 per cent. For women aged 40-42 the rate drops to 11.1 per cent.⁵

It is estimated that infertility affects one in seven couples in the UK.⁶ IVF accounts for over 1 per cent births in the UK, which is lower than other European countries.

Number of IVF cycles per million people (2004)



CG 11 Fertility: assessment and treatment for people with fertility problems, London: NICE. Available from www.nice.org.uk/CG011 Reproduced with permission.

⁵ Human Fertilisation and Embryology Authority, 2006 www.hfea.gov.uk

⁶ Royal College of Obstetricians and Gynaecologists (2007) *Scientific Advisory Committee Opinion Paper 8*, London: RCOG

NICE guidelines: Fertility assessment and treatment for people with fertility problems

In 2004, the NICE guidelines were issued to offer best practice advice on the care of people in the reproductive age group who have problems in conceiving.⁷ These recommended that three full cycles of IVF should be available for women aged 23 to 39. A full cycle of IVF is considered to be one which includes the transfer of any viable embryos which have been frozen and stored after the fresh cycle.⁸ This was accompanied by an announcement by the Department of Health that PCTs should offer at least one cycle of IVF by April 2005 and move towards implementing the guidelines in full in the longer term. Although the date for implementation was set, no extra funding was provided to support this.

A DH survey published in March 2009⁹ found that 30 per cent of PCTs were adhering fully to NICE guidelines by offering three full cycles of treatment, 23 per cent were offering two cycles, 25 per cent one full cycle and 22 per cent one fresh cycle. Only 2 per cent were not funding IVF. This was an improvement on a 2007 survey that found only eight PCTs offered three full cycles.

PCTs have applied non-clinical access criteria that are used to limit entitlement to IVF.¹⁰ Examples include:

- no children from current or previous relationship (very common)
- one partner has no children
- no previous sterilisation (in either partner)
- non-smoking
- priority to those with no children
- no children from current or previous relationship excluding foster or adopted children
- stable relationship
- age restrictions on female
- age restrictions on male
- BMI 20-25
- registration with local GP for a minimum of three years
- no children living with couple.

It is also worth noting that some trusts will not provide treatment for women over 35 whilst others will not provide treatment for women under 35.

Following the findings of the 2007 survey, an expert group on commissioning NHS infertility provision was established in 2008 by the DH.¹¹ This group, which includes a number of senior PCT commissioners, is charged with examining barriers to the implementation of the NICE guidance and devising solutions. An interim report was released in August 2008¹² and its findings include:

- infertility not being viewed as a priority by PCTs
- lack of expert knowledge by commissioners
- lack of clarity around what constitutes a cycle
- uncertainty about whether NICE guidelines are to be reviewed in the near future.

7 National Collaborating Centre for Women's and Children's Health (2004), *Fertility assessment and treatment for people with fertility problems*, London: NCCWCH

8 Department of Health, *Letter to PCT Chairs*, August 2008

www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_087134

9 Department of Health, 2008, *PCT Survey – Provision of IVF in England*

10 Primary Care Trust Survey, 2007, *Provision of IVF in England*,

11 Expert Group on Commissioning NHS Infertility Provision, 2008 *Interim Report*,

www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_087134

12 Expert Group on Commissioning NHS Infertility Provision, 2008 *Interim Report*,

www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_087134

This group is also working on the identification and development of tools to assist PCT commissioners in making decisions on fertility provision. They are also encouraging progress towards the full implementation of the NICE fertility guidelines.

The interim report recognises that fertility provision has not been prioritised by the NHS and is viewed as less important than more visible conditions. Hence the expert group is examining the unseen consequences of infertility now widely reported such as long term mental health issues and general wellbeing and the impact this has on NHS services.

In 2008 and on the recommendation of this interim report, the previous Minister of State for Public Health, Dawn Primarolo, wrote to all PCTs clarifying what they interpreted as 'one full cycle' as stipulated in the NICE guidelines. NICE clearly recommended where there were two or more remaining viable embryos, a full cycle should include the subsequent transfer of these embryos prior to commencement of the next treatment cycle.

Infertility Network UK, has been commissioned by the DH to undertake a project which involves liaising with PCTs in England to encourage the sharing of best practice and the implementation of the NICE (2004) guidelines:

- work with PCTs to enable the patient's voice to be heard at local level
- assist PCTs who have taken positive steps in the provision of fertility services to share good practice with others
- assist PCTs with less developed provision to learn from the practices of others, for example by combining with other PCTs in the area.

On 18 June 2009, Gillian Merron, the current Public Health Minister launched a commissioning aid for fertility services. This aid was developed by the Expert Working Group and serves as a good practice guide for commissioners. A representative from NICE also announced that the guideline on fertility provision would be updated and that the new version will be published in December 2011.

Financial implications of IVF for those seeking treatment

The average cost for a cycle of IVF in the NHS is £849.¹³ Currently, the NHS funds only 25 per cent of all IVF treatments; however, for those who do not meet the strict NHS criteria, private treatment can vary between £4,000-£8,000 per cycle. Thus the high cost of IVF in the UK is encouraging many couples to seek treatment abroad. Furthermore private treatment may not be an option for those on low incomes and this further creates inequities.

Financial implications for health and social services

There are also hidden costs associated with IVF and wider implications for health and social services. For example, in cases of women who conceive twins, the incidence of hospital antenatal care, complicated vaginal deliveries, and caesarean sections is higher and is associated with more frequent and longer maternal and neonatal hospital admissions.¹⁴ This can result in higher costs to the NHS with the 'care' cost of a twin pregnancy estimated at £9,122 being significantly higher than the cost of a singleton pregnancy - currently estimated at £3,313. Babies from multiple births are also more likely to need neonatal care and have ongoing health problems. The average costs of caring for a baby in a neonatal intensive care unit in the UK ranges from £671- £938 per day.¹⁵ To put this in context of equity of service provision, if both twin and triplet pregnancies resulting from IVF were eliminated, an additional 10,124 cycles of IVF could be funded by the NHS every year.

¹³ Department of Health (2009), *Reference costs 2006-2007*, London: DH

¹⁴ Fertility & Sterility, Cost analysis of singleton v twin pregnancy after IVF, *Fertility and Sterility*, 81 (5) pp240-1246

¹⁵ Department of Health (2009), *Reference costs 2006-2007*, London: DH

Health concerns

A multiple pregnancy is the single greatest health risk associated with IVF treatment to both mother and child. In the UK, approximately one in four of all IVF pregnancies results in a multiple birth.¹⁶ In comparison, only one in eighty women who conceive naturally has a multiple birth. Forty per cent of IVF babies are twins, and 25 per cent of all twins in the UK are born to mothers who have undergone IVF treatment.¹⁷

In 2006, the HFEA set up an independent expert group to review iatrogenic multiple births. The report '*One child at a time - Reducing multiple births after IVF*' resulted in a policy change announced in December 2007 advising all clinics that they must adopt a strategy to reduce their multiple pregnancy rates from 24 per cent to 10 per cent over three years. The HFEA predicted that this would result in clinics reducing the number of embryos transferred from two – which is current practice – to one embryo for women with a good chance of conception. The sole aim of this strategy was to advocate a singleton pregnancy as being the desired outcome of IVF treatment. In some European countries - notably Belgium and Sweden - this practice has been in place for some time for women under 40. However, this conflicts with some patients' wishes. Despite documented evidence that there are more complications associated with multiple births, couples who fund IVF treatment privately may feel that it is more cost effective (for them) to transfer more than one embryo at a time. But, the reality is that the NHS absorbs the cost of care for both mothers and babies, and for multiple pregnancies, this is increased. However, if three full cycles of IVF were available on the NHS, then it may well be that couples who met the criteria for elective single embryo transfer would find this acceptable, and costs to the NHS would subsequently be reduced.

Reproductive tourism

There has been a rise in the popularity of women choosing to go abroad for IVF treatment and this has been fuelled by both the high cost of private fertility treatment and the lack of donor egg availability in the UK. Whilst the policy of single embryo transfer has been implemented in Northern Europe, the same cannot be said for Southern and Eastern Europe and other parts of the world such as India and South Africa. If women seek treatment abroad and conceive, on their return to the UK the NHS bears the brunt of costs of treatment for both mothers and babies as a consequence.

The role of nurses

Nurses are at the front line of fertility treatment, supporting patients undergoing IVF and using their full range of skills when caring for patients. The nurse's role in this area is varied and includes both psychological support for prospective parents and the utilisation of extended clinical skills previously performed by medical staff - such as egg retrieval and the transfer of embryos - which ensures continuity of care for women.

When prospective parents are exploring the possibility of IVF, it is crucial that they are fully informed regarding the options and implications of treatment and supported psychologically throughout the process. This is of particular importance when fertility treatment does not result in a successful pregnancy.

An interim report by the expert group on Commissioning NHS Infertility Provision identified that 'a lack of knowledge and expertise in commissioning fertility services was a barrier to compliance with NICE guidelines'. There is no doubt that fertility nurses can contribute to this understanding by ensuring that concise, yet accurate and evidence-based information is disseminated and readily understandable by commissioners.

¹⁶ Human Fertilisation and Embryology Authority (2005) *The HFEA Guide to Infertility and Directory of Clinics 2005/2006* London: HFEA: 2005

¹⁷ RCN FNG Journal (2008) *Multiple pregnancy article*, RCN FNG Journal, April 2008