A Study of the Provision of Infertility Services to South Asian Communities

Executive Summary of the Final Report

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Prepared for NHS Executive Trent, Policy and Practice Research and Development Programme

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Executive summary

INTRODUCTION:

This research project is the first major study of ethnicity and infertility services in the UK and was carried out between January 2002 and December 2003 with Gujarati Hindu, Punjabi Sikh, Bangladeshi Muslim and Pakistani Muslim communities in three English cities. It was funded by the NHS Executive Trent Region.

AIMS:

- To examine the social meanings of involuntary childlessness amongst South Asian communities and to explore the ethnic, cultural and religious context of access to infertility services.
- To examine the experiences of South Asian couples who have been medically diagnosed as sub-fertile or infertile.
- To make recommendations for the development of policy and practice to service commissioners and providers.

METHODS:

The research was carried out in two phases. Phase One consisted of 14 focus groups with South Asian participants (n=93) and individual interviews with key informants (n=21). Phase Two included interviews with South Asian individuals experiencing fertility problems (n=50) and interviews with health professionals providing infertility services (n=23).

KEY FINDINGS:

- In South Asian communities, children are highly desired; parenthood is culturally mandatory and childlessness socially unacceptable. Infertility is a highly stigmatised condition with significant social consequences, especially for women.

- There is little knowledge of causes of infertility and of ways in which people can be assisted to have a child, although infertility is regarded as a problem amenable to medical help.

- Most infertility treatments including IVF are socially and culturally acceptable. However, the use of donated gametes was widely regarded as socially unacceptable across all communities.

- The needs and concerns of ‘infertile’ people of South Asian origin are not dramatically different from those of ‘white’ service users. However, differences of language, culture and religion are often important. NHS funding for IVF is limited. The socio-economic profile of the Bangladeshi and Pakistani communities in particular, places them at a disadvantage in accessing non-NHS funded treatment.

- Some dissatisfaction with primary care was evident. People experiencing problems with fertility were generally satisfied with secondary care services, but some needs were less than fully met. These included: information needs, language and communication needs and emotional support needs.

RECOMMENDATIONS:

Infertility service provision

- The Department of Health should ensure the full implementation of the NICE Clinical Guideline on infertility treatment at the earliest opportunity to ensure fair and equal access to NHS infertility treatment for all couples regardless of where they live.
- Further research is needed to explore the issue of access to ‘inter-ethnic’ gamete donation and the guidance of the HFEA on this issue should be clarified.

Data availability and monitoring

- All relevant authorities should ensure that suitable and sensitive ethnic monitoring is in place and that regular analysis of data occurs. This would provide information on ethnic patterns of infertility incidence and prevalence, treatment outcomes and uptake of services.
- The HFEA should ensure that ethnicity data is available for all monitored treatments.

‘Social marketing’ of infertility treatment

- The HFEA and other interested agencies should consider engaging with key opinion formers and other partners in minority ethnic communities to increase understanding of infertility and infertility treatment and to reassure people about confidentiality in the NHS. Approaches could be made through religious centres (Mosques, Gurdwaras, Mandirs) and community centres and should utilise bilingual community workers.
- Information about infertility should also be made available via local Asian radio and Asian television networks

Provision of information

- Clinics should ensure that all patients receive appropriate written information about infertility and treatment at various stages of the treatment process.
- Clinics could conduct or commission their own research to investigate what information patients would find useful and in what form they would prefer to receive this.
- Clinics should consider providing patients with written individualised treatment plans.
- GPs and clinics should consider the use of patient-held record cards with dates and results of all tests as a means of avoiding unnecessary delays and costs of duplication of tests.
- Information about infertility and treatment should be made available in languages other than English. To avoid unnecessary expense, much of this could be provided by a central resource. The HFEA Guide to Infertility, for example, could be available in booklet form and on their Internet website in the main South Asian languages. This could be accessed by patients directly, and/or by clinics for distribution to non English speaking patients.
- Clinics should collaborate with each other and possibly with pharmaceutical companies to provide information on treatment protocols in minority languages.

- The needs of patients who do not read in their preferred language should also be addressed and material should be available in audio and video format.
- Service users and others from minority ethnic communities should be closely involved in the production of translated materials.
- The planned development of the NHS Online central depository of health promotion material could include the provision of translated material relevant to infertility. The planned extension of NHS Direct could also facilitate the provision of translated information and interpretation.

Interpreting services

- There is a clear need for improved interpretation services in most NHS trusts. However, this needs to happen alongside measures to increase the confidence of users in the effectiveness, cultural sensitivity and confidentiality of this service.
- It may be more practical for clinics and preferable for patients to use telephone-based interpretation (such as Language Line) on some occasions.
- Clinics should consider making the use an official interpretation service a mandatory component of at least some consultations where one partner does not speak English, to enable share decision-making, implement patient-centred care and ensure informed consent.
- Clinics should ensure that all staff receive training in the use of interpretation provision, including remote access services.

Emotional support

- Steps need to be taken to increase awareness of support counselling and the confidential nature of this service. Efforts should be made to ensure that counselling is culturally sensitive.
- Further research to investigate the reasons for the low up-take of counselling generally should be considered.
- Clinics should consider other ways in which the emotional needs of patients might be met outside of formal counselling.
- Clinics should provide patients with the contact details of infertility support groups and helplines.
- Infertility support groups should consider ways in which they might appeal more directly to users from minority ethnic communities, including producing publicity with material and imagery that is ‘inclusive’.

Professional Education

- Health professionals should be provided with educational opportunities to explore ethnic diversity and the influence of ethnicity on health and healthcare. This may be through specific training programmes in PCTs and Acute Trusts (which should involve individuals from minority ethnic communities) and/or by accessing web-based material via e.g. the National electronic Library for Health (NeLH).

OUTPUTS:

- *Trying for a Baby*: a basic information resource for childless couples published in Punjabi, Gujarati, Bengali, Urdu and English. This is available in booklet and audio format on CD.
- *South Asian Communities and Infertility*: a resource for professionals working in the field of infertility.