Sama is a Delhi based resource group working on issues of women’s rights and health. Sama seeks to locate the concerns of women’s health in the context of socio-historical, economic and political realities, and find linkages between women’s well being and livelihoods, food, violence and other larger issues that affect their lives. Sama has been working closely with community based organisations, health networks, people’s movements, women’s groups and health care providers across the country, primarily through building capacities, action research and advocacy.

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Constructing Conceptions

The Mapping of Assisted Reproductive Technologies in India

Sama–Resource Group for Women and Health
The information provided in this report is for wider dissemination, and may be used with due acknowledgement to Sama.

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Email: sama.womenshealth@gmail.com
www.samawomenshealth.org

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The Research Team

N Sarojini: overall coordination of the project
Preeti Nayak, Anjali Shenoi, Deepa Venkatachalam and Aastha Sharma: state-level coordination
Susheela Singh, N. Srilakshmi and Saalai Selvam, and Triptimayee Rout: research assistance in Uttar Pradesh, Tamil Nadu, and Orissa respectively
Vrinda Marwah: review and revision
Manjeer Mukherjee (consultant): content organization and inputs for chapters
Beenu Rawat: data entry

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Preface

The research report, ‘Constructing Conceptions: Mapping of Assisted Reproductive Technologies in India’, consists of six chapters, which are based on the research findings and their subsequent analysis.

‘Introduction: Laying the Context’, gives a brief overview of the history of ARTs and discusses some related feminist discourses. It examines infertility in India, as well as the larger frameworks of globalisation and private medical care, medical tourism, and the fertility industry. Kinship and social citizenship vis-à-vis ARTs are also explored.

Chapter One, ‘Methodology: Mapping the Process’, lays down the objectives of the research study, the methodology adopted, the areas of study, the process of gathering and analysing data, and the ethical considerations and methodological challenges faced during the research and fieldwork.

Chapter Two, ‘Profile: Users and Providers in the ART Landscape’, gives a detailed account of the profile of users of ARTs and ART clinics from the research sample. It examines the socio-economic characteristics of users, such as caste, religion, income, occupation, family type, marital status, as well as the location, accessibility, infrastructure, facilities, and registration mechanisms of clinics.

Chapter Three, ‘Infertility and Trajectory: Many Roads, One (Elusive) Destination’, looks at the medico-social understandings of infertility and their gendered associations. The chapter also examines the multiple facets of the journeys that users undertake in pursuit of a biological child.

Chapter Four, ‘Implications: What ART Use Entails’ details the various implications of accessing these technologies. These include not only health risks and adverse outcomes, but also other social and economic consequences. The processes of informed consent and counselling are also examined.

Chapter Five, ‘Cost: The Economics of Baby-Making’, investigates the financial accessibility to ARTs in both intra and inter-state terms, and explores how users are able to ‘afford’ these technologies.

Chapter Six, ‘Industry: Mapping ART Provision in India’, examines the increasing commercialisation of India’s ART industry through the following: proliferation, including fertility tourism; actors, agencies, and collaborations; features of the industry; and ethical concerns related to the lack of standardisation and regulation.

The concluding section, ‘Challenges and Strategies: Issues at Stake’, reflects on Sama’s advocacy initiatives around ARTs, the significant findings of this research study, and the possible areas of future inquiry.
Introduction: Laying the Context

Although it is generally perceived that assisted reproductive technologies (ARTs) are a recent development, the practice of artificial (non-coital) insemination became common in the mid-twentieth century. The first known example of artificial insemination dates as far back as 1785 and was conducted by a Scottish surgeon, John Hunter (Wilder, 2002). In 1866, the Italian physician, Montegazza speculated whether it would be possible for soldiers going into battle to have their sperm frozen beforehand, in the event that they were killed in battle, so that their wives might use the sperm to posthumously beget heirs. The first known birth through donor insemination (DI) took place in 1884 with the aid of Dr William Pancoast in Philadelphia. The technique of cryopreservation of human sperm was perfected in the early 1950s. (Wilder, 2002) The world’s first test-tube (IVF) baby, Louise Brown, was born in Oldham, Lancashire, UK, in 1978 under the ‘care’ of Dr Robert G. Edwards and Dr Patrick Steptoe. In 2010, Dr Edwards won the Nobel Prize in Physiology or Medicine for this achievement (Wade, 2010).

In 1978, just a few months after the birth of Louise Brown, Durga was born in Kolkata under the ‘care’ of a Kolkata-based fertility specialist, Dr Subhash Mukherjee. It was claimed that Durga was the second IVF baby in the world, but due to the lack of peer review and scientific documentation, Dr Mukherjee could not be credited with the achievement. (Sama, 2006)

Six years after the birth of Louise Brown, the Indian government established an IVF project at the Institute for Research in Reproduction (now the National Institute for Research in Reproduction [NIRRI]) in Mumbai. On 6 August 1986, the first documented IVF baby in India, Harsha, was born through the collaborative efforts of NIRR and the King Edwards Memorial Hospital (KEM), Mumbai (ICMR, 2005).

The era that began with the birth of the world’s first test-tube baby in 1978, and reached its zenith with the cloning of a higher vertebrate from an adult cell in 1997, continues apace today, marking a dynamic but contentious phase in the development of reproductive and genetic technologies.

Part I

The Oxford English Dictionary defines reproduction as ‘the action or process of forming, or creating or bringing into existence again’. Reproduction as a site of investigation and inquiry is a latecomer in the social sciences. This is because reproduction has been conceptualized as a biological process per se, relegated strictly to the private domain, functioning within the framework of family and kinship.

The credit for making reproduction the core of social theory (Rapp, 2001) can be attributed to feminist studies and medical anthropology followed by feminist science.
This scholarship has decentred Euro-American notions not only of the body but also of science in general and of biomedical science in particular. Women’s movements have also contributed to the visibilization of the politics of reproduction, the body, and science in public discourse. Processes of reproduction can no longer be seen as unalterable ‘facts’ of life, but rather as constituted in, and through, a range of institutions along the public–private continuum. It can thus be said that in today’s society ‘in no other area of human life, is the personal as political as in the sphere of human reproduction’ (Gupta, 2000: 55).

Much concern has been voiced from diverse quarters, ranging from feminist organisations to religious bodies, about the ethical, social, and medical implications of ARTs. These include questions on the health and gender implications of the use of these technologies on female bodies, their effects on women’s lives, and their implications for marriage, parenthood, and childhood. As anthropologist Shore (1992: 295) argues:

\[\ldots \textit{not only do they crystallise issues at the heart of contemporary social and political struggles over sexuality, reproduction, gender relations and the family} \ldots \textit{but they challenge our most established ideas about motherhood, paternity, biological inheritance, the integrity of the family, and the ‘naturalness’ of birth itself.}\]  

Mapping feminist debates on ARTs

This section examines feminist debates on ARTs through issues and concerns that have been centre stage rather than categories or ‘camps’ in feminist thought, such as liberal, radical, socialist, and poststructuralist. Feminist critiques of ARTs often understand technology as an inherently political phenomenon that reproduces existing power relations within a broader framework of capitalism and patriarchy. Technology and infertility are seen as socio-political constructs in a market economy that labels the users of technology as either ‘patients’ or ‘clients’, thus revealing, in the first instance, the medicalisation of infertility, and, in the second instance, its commodification.

Feminist analysis of the ART discourse responds also to the binarised axis of the ‘nature–culture divide’ (Ortner, 1972), around which ARTs are constructed. This binary opposition was first proposed by positivism, and implies a series of other oppositions, such as those between the mind and the body; between rationalism and mysticism; and even between male and female. Through this ‘Cartesian dualism’, the mind—the subjective—is seen as standing outside of the body, which, in turn, is seen as an objective reality. This purportedly makes the body available for observation, understanding, intervention, and control. Similarly, ‘nature’ comes to represent a sphere from which autonomy must be won in the interest of human freedom (Curtis, 1995: 164). This makes ‘nature’ available to observation and intervention. In this dualism, ‘male’ is seen to be the source of culture and rational thought, whereas ‘female’ is seen as being closer to ‘nature’, and therefore something to be ‘tamed’. The language used in relation to ARTs also points towards the positivist treatment of the female body, that is, emotional distancing from the physical body and a depersonalisation of women.
In the words of the sociologist Susan Ryan-Sheridan (1994: 15):

... technologies for ‘managing’ pregnancy and child birth are often embedded in a medical frame of reference that defines pregnant women as ‘patients’, pregnancy as an illness and successful child-bearing in terms that de-emphasise the social and emotional dimensions—many women are left with a sense of being mere onlookers in the important process of giving birth.17

Further, the patriarchal ideology of motherhood can be seen as inextricably linked to a woman’s desire for a child, thus creating and shaping the felt need for biological motherhood and compliance with these technologies. The development of ARTs is often attributed to the supposedly universal and fundamental ‘maternal instinct’ in women. As Dr Steptoe announced, ‘It is a fact that there is a biological drive to reproduce. Women who deny this drive, or in whom it is frustrated, show disturbances in other ways’ (cited in Stanworth, 1987: 15)18. Such proclamations not only legitimise the proliferation of these technologies for the ‘greater good’ (particularly of women) but also stigmatise those who are childless by choice.

Highlighting the significant risks associated with ART procedures, feminists have pointed out that ARTs are more a hit-and-trial technology still in need of important research inputs than a ‘treatment’ for infertility. There are substantial drug-related and procedural health risks associated with ARTs that must be monitored for the development of a standard protocol21 for ART use. Further, the process of informed consent must be fair and just, so that women have access to information on success rates and health risks.

The Feminist International Network of Resistance to Reproductive and Genetic Engineering (FINRRAGE) oppose these technologies on the ground that they exacerbate existing social inequalities. According to them, patriarchal and capitalist value is embedded in the design, development, and use of these technologies. The FINRRAGE group has raised concerns about the potentially damaging consequences of these technologies for women. They argue that with the standardization and routinization of ARTs, a majority of women will use this technology not only as recourse to solve the problem of their infertility but also to have children with desirable traits, including the preferred sex. These new ‘choices’ have the coercive potential to become the preferred mode of reproduction to satisfy parameters of social desirability. They raise critical questions about who controls these technologies, thus making the point that so-called new choices do not necessarily spell progress (Mies, 199022; Overall, 198723). Moreover, these technologies have a negative impact on women already disadvantaged by race and class (Holmes, 1992)24. Renate Klein, founder member of FINRRAGE, writes, ‘these technologies then, at their core, are not only sexist, but racist, classist and deeply eugenic and serve as old and new instruments of population control’ (Klein, 2008:158)25.

The portrayal, justification, and standardisation of infertility as a disease in need of treatment, the use of expensive technologies on otherwise healthy bodies has become routine (Raymond, 1993)19. None of the procedures developed under the gamut of ARTs cure infertility; rather they simply bypass it. ARTs are emotionally, physically, and economically exhausting and risky without any guarantee of success. In the wordplay around infertility and ‘treatment’, ‘more is at stake (here) than the correction of linguistic imprecision; the error in language is not innocuous’ (Kass, 1971:1177)20.
Feminist activist Gene Correa, questions technological intervention in what she considers, the otherwise natural process of reproduction. She believes that women derive special attributes, power, and meaning from their procreative role, and argue that these will lose their value if reproduction is technologised and controlled by male medical practitioners. Thus, technology is seen as having the potential to erode true female consciousness and female affinity with nature. (Correa, 1985)

Feminist proponents of ARTs regard these technologies as bearing the potential to conquer reproduction, thus liberating women from their subordinate position. They view women’s biological role as child bearers as the fundamental source of their oppression and relegation to the private, domestic sphere. Hence emancipation can be achieved through technologisation of reproduction. Feminists of this persuasion favour state-supported research on new genetics and have immense faith in the power of technology. Feminist author Shulamith Firestone (1971) feels that these technologies have the potential to liberate women from the burden of motherhood and hence act as an instrument through which women’s emancipation can be achieved. For supporters of this view, ARTs provide solutions for individual women in a context where infertility and childlessness result in social ridicule. Moreover, they empower women by giving them ‘choice’ and ‘control’ over their own reproduction.

Others argue against technological determinism, stating that reproductive technologies are only one facet of reproduction and as such should not be over-emphasized in their potential for either benefit or harm (Stanworth, 1987). Andrews and Stanworth, view technology in itself as neutral, and focus instead on the mode through which it is used. They point out that it is possible to achieve progress and liberation through rationalised management of technology. Hence, they stress the importance of regulation, the minimisation of harm, and equitable access to technology and information. According to them, the right to have a child should be given an equivalent status with the right to not have a child, and the state has an obligation to provide these technologies in the public health set-up (Andrews, 1989). Thus, it is the social context in which these technologies are deployed that must be scrutinised and suitably altered, and not the technologies themselves.

Many feminists point out the probability of upper-class women benefiting from these technologies at the cost of women from lower socio-economic backgrounds. This is fast becoming an everyday reality as women from poor socio-economic backgrounds are disproportionately offering to be egg donors or surrogates for payment. In the prevailing context of commercialised medical services, ARTs are often critiqued as commodifying the process of reproduction and motherhood, and the bodies of both the woman and the child, who now becomes the end ‘product’ of a service. In the words of US-based feminist scholar Marsha Darling (2006: 19):

. . . the concept of women’s bodily integrity is threatened by the extent to which women’s biological and reproductive organs, tissues, cells, including ovum and genes, are quickly becoming ‘spare parts’ in a medical industrial complex. At the very same time that reproduction is imagined as an industrial process by the biotech industry, women are sought after as consumers of the very technologies that will weaken women’s right to bodily integrity.
With the commercialisation of ARTs, surrogacy has become a significant area of contest and debate. On the surface, surrogacy appears to challenge the domestication of women’s sexual and reproductive labour and to enhance their autonomy, both financial and otherwise. However, commercial surrogacy is operationalised under the political economy of globalisation, which has jeopardized traditional livelihoods and opened new markets for informal labour that exploit and commodify the body. Feminists critical of surrogacy refer to it as ‘commercial breeding’ and ‘reproductive trafficking’ (Raymond, 1998). While surrogacy has been thus debated in terms of ban versus regulation, commercial versus altruistic, and agent versus victim, Pande, a sociologist, (2009), proposes that rather than taking moral positions on the issue, surrogacy should be seen as a new kind of sexualised care work, as ‘a structural reality, with real actors and real consequences’. Shah, a women’s rights and queer activist, (2009), similarly argues that surrogacy can be seen as ‘a possible choice, restricted but made with dignity, knowledge and consent’, and warns against the glorification of motherhood. Shah points out that the conflict over surrogacy surrounds the ‘disconcerting use of the language of ‘rights’ and ‘choice’ by the promoters of these businesses on behalf of the women going in for these technologies’, on the one hand, and ‘the assertion of rights over the body as a resource’, on the other hand. What remains unaddressed, particularly because of the absence of state regulation in the Indian scenario, are questions pertaining to the inefficiency and health risks of invasive procedures, the disruption of women’s lives, the insecurity of surrogacy dealings, the possible legal tangles regarding the citizenship of the child, the inadequate compensation paid to and lack of bargaining power of surrogates.

While there are broad differences between these perspectives on ARTs, there is also agreement that for a more comprehensive understanding of the implications of ARTs for the lives of women, an examination of the social, political, and economic influences that surround the development and use of these technologies is required. Indian scholarship on ARTs, particularly the operationalization and implications of these technologies, is limited, and this research study is an attempt to contribute to this field of inquiry.

Infertility in the Indian context

ARTs can be understood as encompassing political, economic, ethical, cultural, and social processes, thus raising questions of gender, family, bioethics, law, and feminism. While these technologies originated in the global North, their spread to the global South was rapid, accelerated in more recent years by globalisation and the neoliberal doctrine of trade without borders (Gupta and Richters, 2008). In a milieu like India’s, ARTs come with concerns, both old and new.

Varying definitions of infertility are found in studies on this subject. While these include the use of different reference periods (ranging from one to five years) for childlessness (women with no live birth), the World Health Organization (WHO) uses a one-year reference period to define infertility. It further classifies the condition into the two categories; of primary infertility—the lack of conception despite cohabitation and exposure to pregnancy, and secondary infertility—the failure to conceive following a previous pregnancy despite cohabitation and exposure to pregnancy (in the absence of contraception, breastfeeding, or postpartum amenorrhea) (ICMART and WHO, 2009). This understanding of infertility
has also been adopted by the Indian Council of Medical Research (ICMR) in its National Guidelines for the Accreditation, Supervision and Regulation of ART Clinics in India (2005) where infertility is defined as ‘the failure to conceive after at least one year of unprotected coitus’.  

According to an ongoing study by the International Institute for Population Sciences (IIPS), Mumbai (2010), childlessness among Indian couples has risen by 50 per cent in the 20-year period from 1981 to 2001. IIPS researchers analysed data from the census for 1981, 1991, and 2001 as well as from the National Family Health Surveys to assess the levels of childlessness, and found that while 4 per cent of married/ separated women in the age group 35 to 49 years in 1981 had never had a child, the figure rose to 6 per cent in 2001. More non-literate women (6.2 per cent) were childless compared to educated women (5.62 per cent), with similar levels of childlessness in both rural and urban areas. (Bhayana, 2010) Data taken from WHO suggest that approximately 13 to 19 million couples are likely to be infertile in India at any given time. According to figures provided by the ART industry, 15 per cent of all couples who wish to have children have problems conceiving (Srinivasan, 2010).

The aetiology of infertility varies from region to region, and even from one locality to another within the same population. WHO’s estimates of primary and secondary infertility in India are 3 per cent and 8 per cent, respectively (Cates et al., as cited in Widge and Cleland, 2009). According to WHO’s multi-centric studies of infertility in India, 40 per cent of women and 73 per cent of men show no demonstrable causes of infertility. The tubal factor was the most common cause of infertility among women (nearly 30 per cent), followed by anovulation (22 per cent). Among men, accessory gland infection was the most common cause of infertility (Cates et al., as cited in Widge and Cleland, 2009). Infertility due to female genital tract tuberculosis is considered almost absolute; all related medical therapies are associated with relatively poor fertility outcomes (Bapna et al., 2005).

Among men with a demonstrable cause, about one in three may have become infertile as a result of a sexually transmitted infection (STI). In India, the prevalence of STIs was found to be high among women reporting infertility and pelvic inflammatory disease. Untreated reproductive tract infections (RTIs), including pelvic inflammatory disease (PID), and STIs, and particularly chlamydia trachomatis and gonorrhea, unsafe or repeated abortions are also known correlates of infertility among women (Kushtagi et al; Chhabra et al. as cited in Widge and Cleland, 2009).

Maternal health factors such as unhygienic delivery, postpartum infection, and unsafe obstetric procedures are observed to be linked to sepsis and pelvic infections. Severe malnutrition and anaemia are also observed to affect fertility. Other preventable causes of infertility include ‘lifestyle factors’, such as obesity, weight gain and loss, eating disorders, and malnutrition. Dietary deficiencies of iodine and selenium have been linked to infertility in the developing world (Stewart, 1991), as has exposure to dietary aflatoxins —fungal metabolites that commonly contaminate staple foods in tropical countries (Ibeh, Uraih, and Ogonar, 1994). Consumption of tobacco, alcohol, and caffeine has been linked to decreased fertility in either males or females or both (Curtis, Savitz, and Arbuckle, 1997). In addition, female obesity, an increasing problem among some poor urban populations in the developing world, may be linked to ovulatory infertility (Inhorn, 1994). Environmental and occupational hazards constitute another cause of infertility.
Several studies have revealed that exposure to pesticides like DDT and to industrial chemicals like organic solvents and PCB leads to reduced sperm count in men (CSE, 2002). Men living in industrial and polluted towns have six times more abnormal sperm than men living in clean areas (CSE, 2002). The link between these hazards and decreased fertility is difficult to measure and is not always clear. Nonetheless, more than 50 chemicals found in the workplace and in the environment are known to be associated with adverse reproductive outcomes in men and women (Evens 2004).

Infertility care in India’s public health system: A conspicuous absence

As in many developing countries, in India too, as a public health priority infertility care and management are low on the epidemiological scale (Qadeer, 2009). Although infertility treatment is said to be available at government facilities, effective treatment is often difficult to access as there is little coordination between gynaecologists, infertility specialists, surgeons, and laboratory technicians. The public health system does not offer adequate preventive, curative, and counselling services. The National Population Policy (2000) mentions infertility treatment in the context of providing information, counselling, and a regular supply of medication only for communities like the tribals and for displaced and migrant populations who ‘may not need infertility regulation’ (MoHFW, 2000). Although the Tenth Five Year Plan (2002-07) discussed access to essential clinical examination, investigation, management, and counselling services for infertility, such services are, in effect, rarely available in the public sector. The Eleventh Five Year Plan (2007-11) states that nearly 5–8 per cent of couples in India report infertility, which implies that the prevalence may be higher. However, there is limited focus on services for the infertile in the Reproductive and Child Health (RCH) Programme and in the National Rural Health Mission (NRHM) Document.

There are multiple reasons why infertility is overlooked in the public health sector. The primary reason is that infertility is viewed as an individual medical condition as opposed to a social problem deserving systematic attention. When the issue of infertility is raised, it is often in the context of miraculous new reproductive technologies or its irrelevance in a resource-poor setting like India. To equate infertility with ARTs not only excludes individuals who do not need to resort to these technologies, but also, quite successfully, diverts attention away from the important question of preventive care for infertility.

Part II

Globalisation and private medical care

One can understand emergent biotechnologies such as genomics only by simultaneously analysing the market frameworks within which they emerge.

Kaushik Sunder Rajan (2006:33)

The advent of new reproductive and genetic technologies and the policies of liberalisation, privatisation, and globalisation are not independent of one another. Biotechnology is at once
promoted by the state as the high-technology answer to, amongst others, the hollowing-out effects of globalisation, and is celebrated as a ‘cutting-edge contribution’ to health care. Yet a case is made that these technologies, although beneficial, cannot be provided in the public health set-up, which further compounds their ‘need’ for, and proliferation in, the private sector, thus chipping away at the already withering welfare state. Some states, desperate to increase their population, do, however, provide these technologies in their public health systems. This differential access can be understood as ‘stratified reproduction’ (Ginsburg and Rapp, 1995)\textsuperscript{54}, an unequal power equation by which some categories of people are encouraged or empowered to reproduce, while others are devalued. In a climate of state restructuring and privatisation, the priorities of the state in relation to health care have shifted from protecting the public good to promoting the interests of industry, thus creating the conditions for health care to be ‘a site of corporate profit’ (Myktiuk, 2000)\textsuperscript{55}. Within this framework, as Kean Birch (2005), points out, ‘the biosciences rely on a future-oriented market that enables the generation of short-term value (i.e., in shares or venture capital returns) on the back of expectations that there is then no necessity to fulfil.’\textsuperscript{56}

Such developments have led to the suggestion that ‘governments are effectively acting as the midwives of globalisation, transforming the state apparatus, development strategies and regulations to respond to the ‘perceived exigencies’ of a global economy’ (Brodie, 1995: 6)\textsuperscript{57}. Since the mid-1990s, the expenditure of the central and state governments in India on health care has declined sharply. At the same time, the share that comes from private expenditure has increased, and today around 80 per cent of total spending on health care in India comes from the private sector. According to Government of India estimates, the Indian health care industry is worth $17 billion a year and could grow at the rate of 13 per cent in each of the next six years. Hence, India’s health care sector has emerged as the largest in the service sectors, contributing 6.2 per cent to the country’s gross domestic product (GDP). By 2012, this figure is expected to rise to 8 per cent, employing a staggering 9 million people (JSA, 2007)\textsuperscript{58}.

The privatisation of health care in India is taking all kinds of forms—from divestiture to lease contracts, to contracting out of services, to the introduction of user fees, and, through plain default, the neglect of public provision (JSA, 2007)\textsuperscript{59}. The pharmaceutical industry is a major driver of such growth. Indian pharmaceutical companies are global players and are multinational companies (MNCs) in their own right, with India being the fourth largest drug producer in the world (by volume) and with Indian pharmaceutical companies exporting 45 per cent of their total production (Duggal, 2004)\textsuperscript{60}.

This increased private control and marketisation of health care, in the complete absence of any regulation, has raised concerns that not only is access to health care for the poor going to get more difficult, but also that health care itself will be transformed into a commercial commodity like any other.

**Medical tourism**

The global medical tourism market accounted for more than 19 million trips in 2005 with a total value of $20 billion. Many countries are experiencing double-digit growth in medical tourism, which is forecast to grow to 40 million trips, 4 per cent of the volume of all global
tourism, by 2010 (TRAM, 2006)\textsuperscript{64}. According to one estimate by Professor Rupa Chanda, ‘medical tourism is slated to fetch an impressive $4 trillion on a world-wide scale’ (cited in Chhabria, 2005:3)\textsuperscript{62}. A World Trade Organization (WTO) study - conducted in Thailand, Malaysia, Jordan, Singapore and India–concluded that the number of medical travellers to these 5 countries alone was almost 1.3 million in the year 2003, collectively earning almost $1 billion in treatment cost (Chhabria, 2005)\textsuperscript{63}. Medical travel expenditure in these five countries are growing at the rate of above 20 per cent every year (Chhabria, 2005)\textsuperscript{64}. According to Giuseppe Tattara (2010:3), a professor of economic policy, ‘India is the second Asian provider for medical tourism with an inflow of 4,50,000 tourists in 2007’.\textsuperscript{65} A joint report by the Confederation of Indian Industry (CII) and McKinsey Consultants projects that, there is a 30 per cent growth annually in medical tourism in India, and this could become a $1–2 billion business by 2012. In 2004 alone, around 150,000 foreigners visited India for treatment, and these numbers have been rising by 15 per cent each year (Netscribes, 2008)\textsuperscript{66}. According to a quote on the Government of India’s website, ‘India is in the process of becoming the ‘Global Health Destination’ owing to these advantages.’\textsuperscript{67}

The Indian government endorses and promotes medical tourism, by offering easy access and financial incentives like low interest rates for loans provided to establish a hospital, special ‘medical visas’, subsidised rates for buying drugs, import of equipments, subsidised rates for land for these clinics etc. (JSA, 2007)\textsuperscript{68}. According to the Union Minister for Tourism, the Indian government is issuing M (medical) visa to medical tourists and MX visas to accompanying spouses, which are valid for a year (TNN, 2006)\textsuperscript{69}. India’s National Health Policy 2002 states: ‘To capitalize on the comparative cost advantage enjoyed by domestic health facilities in the secondary and tertiary sectors, NHP 2002 strongly encourages the providing of such health services on a payment basis to service seekers from overseas.’\textsuperscript{70} The rendering of such services on payment in foreign exchange will be treated as ‘deemed exports’ and will be made eligible for all fiscal incentives extended to export earnings (JSA, 2007)\textsuperscript{71}. Further, the proposed National Health Bill (2009) replaces the provisioning obligations of the state with free access to health care. It thus not only legalises both public private partnerships (PPPs) and medical tourism but also promises additional state subsidies to the latter through third party payments (Reddy and Qadeer, 2010)\textsuperscript{72}. Moreover, the General Agreement in Trade in Services (GATS) includes trade in medical services under World Trade Organization (WTO) that has enabled private hospitals treating foreign patients to receive financial incentives. These incentives included the ability to raise capital at low interest rates and eligibility for a low import duty on medical equipment. (Mulay and Gibson, 2006)\textsuperscript{73}

The state governments of Kerala, Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra, and Gujarat have also ventured into the promotion of medical tourism, with the respective tourism departments of these states maintaining their own websites. The Karnataka government, for instance, is encouraging private entrepreneurs like the Manipal Group to offer medical tour packages for patients from West Asian countries. One such initiative

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\textbf{The status of regulation of ARTs in India}

The National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India were developed in 2005 by the Indian Council of Medical Research (ICMR) and the National Academy of Medical Sciences (NAMS), India. However, these guidelines are legally non-binding. The proposed legislation for regulation of ARTs in India is the Draft Assisted Reproductive Technologies (Regulation) Bill & Rules, 2008 (now updated to 2010). This has not yet been tabled in Parliament.
is Meditour, a private enterprise aimed at promoting medical tourism in Tamil Nadu in collaboration with the Indian Medical Association (IMA) and the Tamil Nadu Tourism Development Corporation (TTDC). The Federation of Indian Chambers of Commerce and Industry (FICCI) has set up a task force for the promotion of medical tourism in the state of Maharashtra, another indication of the interest and potential in medical tourism.

Similarly, the private health sector in India includes corporate hospitals such as Apollo, Escorts, institutes set up by non-profit trusts like LV Prasad Eye Institute and the alternative therapy industry. Indian corporate hospitals are ‘networking with international health insurance companies so that these hospitals are recognised and NRIs can combine their treatment in India with family visits or tour to the country’ (Kaur et. al, 2007: 419). Apollo hospital gets 10-11 foreign patients every month. According to statistics offered by Apollo, over 96,100 foreign patients have come to them for treatment between 1988 and 2002. Similarly, five to seven per cent of patients at the Escorts hospital are from outside India. (Sachdeva, 2002)

The reasons for India’s status as an attractive destination of medical tourism are many. The key selling points of the medical tourism industry are its ‘cost effectiveness’, that is providing technologically advanced superior health care services at much cheaper rates than the developed countries. The health care industry also uses the ploy of selling the ‘exotica’ of the countries involved as well as the packaging of health care with traditional therapies and treatment methods. There are no waiting lists or queues to stand in, the doctors are comparable to anyone in the world and finally, language does not pose a problem as most people speak English. The services in great demand include kidney transplant, cardiac surgery, cancer treatment, paediatric care, eye treatment, knee/joint replacement, ayurveda, cosmetic surgery, and liposuction. Now ARTs are the latest services on this list, and already a major addition, attracting medical tourists from Asia, Africa, as well as from developed countries like the UK, the USA, Canada, and Australia. Further, what is unique about ARTs, as compared to other medical treatments, is that the major push and pull factors for travel also include restrictive laws enacted in response to emerging ethical, religious, and health concerns relating to access to these technologies in the home countries and to little or non-existent legislation in others (Smith-Cavros, 2009).

In the context of India’s collapsing public health system, which is unable to meet even the most basic health care needs of a vast majority, the aggressive promotion of medical tourism by the state raises many concerns. Heavy subsidies are being offered to promote medical tourism, to the corporate sector. While it is claimed that this will earn high revenues and contribute to overall economic growth, it is clear that steps towards the privatisation of health care will benefit the corporate sector, at the cost of public health.

**The burgeoning ART industry in India**

As an integral part of the growing medical tourism industry, the fertility industry is slated to bring in additional revenue of $1-2 billion by 2012. Although there are no accurate figures for the number of individuals who travel to India for ARTs, including surrogacy, it is estimated that the surrogacy business alone is worth $445 million (IANS, 2008). ART clinics are no longer concentrated in metropolitan and big cities, but are also appearing...
in smaller towns and cities that otherwise lack even basic civic amenities and necessary health care facilities. The ‘phenomenal growth’ of this sector is also demonstrated by the fact that the international umbrella organization for infertility consumers, the International Consumer Support for Infertility, lists Indian groups alongside African and South American groups, as well as with the aggressive advertisements of Indian ART providers in a bid to attract foreign clients (Mulay and Gibson, 2006). A market research report notes:

With infertility treatment stabilising in the major markets, pharmaceutical companies are exploring other markets where assisted reproduction techniques (ART) are in growing clinical supply and demand. India is an attractive market because of its highly pronatalist culture, ART-seeking South Asians living abroad and preference for branded products.

The ART industry is pegged on the movement of babies, reproductive body parts and women’s caring and reproductive labour; both as egg donors and surrogates from one country to another, resulting in the ‘globalisation of motherhood’ (Browner and Sargent, 2007), which impacts both women who mother and those who enable others to do so. This has led Professor Storrow (2009) to claim that fertility tourism acts to transform public oppression in one country into private oppression in another. The gendered experience of infertility and/or childlessness can be oppressive, and as such, must be examined in connection with the claims of ART providers that ARTs have the potential to ‘liberate’ women from this oppression, and indeed, to redefine dominant modes of kinship and gender relations.

**Part III**

**ARTs and kinship: Redefining or restoring?**

In the Indian context, childbirth is perceived as a unilinear progression from marriage. A marriage without children is more conspicuous and aberrant than one with children, and thus ‘infertility – like fertility – is socially visible and hence an object of social control and management’ (Bharadwaj, 2003: 1870). ARTs are pursued in order to achieve two interrelated goals, that is, to restore the normalcy of marriage and to have a child of one’s own (Mukherjee, 2008). Technologically assisted reproduction is generally regarded as a more desirable and feasible option than adoption, as in the latter case ‘the links between an adopted child and the social parent become a public, vocal, and visible admission of infertility that cannot be subsumed, like gamete conception, under a conspiracy of silence’ (Bharadwaj, 2003: 1867). With ARTs, the disruption of the fundamental biological triad of mother (womb), father (semen), and child (foetus) can be glossed over. For both men and women, this may demonstrate IVF’s validity over adoption in making them ‘real’ and ‘proper’ parents (Paxson, 2003).

The notion of the family as private, in traditional opposition to the market (public), is challenged by ART use, as it creates families embedded in the commercial exchange of reproductive goods and services. Indeed, the understanding of the term family itself may
be fundamentally transformed (Strathern, 1992). Through the usage of ART, reproduction, which has been the ground for kinship, is set amidst a ‘major set of cultural redefinitions and (literal) reconstructions’ (Franklin, 1995:326). ARTs thus have the potential to expand notions of relatedness by destabilising the ‘purity’ of the biological component in parenthood through the assistance of technologies and third parties. ARTs have pluralised notions of relatedness and kinship by introducing quasi-, semi-, or pseudo-biological forms of parenting. With the use of donor sperm, kinship is not only disconnected from biology, but the strong cultural symbolism and transfer of lineage that is associated with semen is also interrupted. Egg donation, on the other hand, creates kin-like female alliances, including those among actual kin (for example, sisters) who donate their ova, as well as those among unrelated women who ‘share’ their ova with other women in infertility clinics or who ‘donate’ them for a fee (Inhorn and Carmeli, 2008). These technologies also have the potential to unsettle traditional notions of heterosexual parenthood by creating previously inconceivable offspring for same-sex couples.

However, with ARTs, the revisiting of notions of ‘normal as natural’ and traditional parenthood is more apparent than real. In practice, much of ART use is to simply assist and ‘make normal again’ the deviation from the ‘natural’ progression to childbirth after marriage, thus restoring gender roles to their ‘rightful’ place. The power of ARTs to rectify the discrepancy of a childless marriage and to confer genetic or biological parenthood is precisely the reason for their popularity. While ARTs have the potential to destabilise traditional models of family and kinship, in actuality they perform exactly the opposite role, that is, they re-stabilise the traditional family structure of father–mother–child that may have been under threat from infertility.

The social imperative: Womanhood as motherhood

Infertility remains highly stigmatised in India, forming the basis for multiple exclusions from social and political life, particularly for women. Several studies have examined the implications of childlessness for women, and a common observation emerging from almost all of these is that it is women who carry the burden of responsibility for childlessness (Mukhopadhyay and Carmella, 1998; Mulgaonkar, 2001; Jejeebhoy, 1998; Unisa, 1999). While Jindal and Gupta (1989) point out that the pressure to reproduce is related to the structure of the Indian joint family system, Patel’s (1994) ethnographic study of a village in Rajasthan suggests that childlessness is considered a dreaded condition because motherhood enhances status and confers prestige. Thus, in the absence of other avenues, bearing a child, especially a male heir, represents access, respectability (Patel, 1994) and the affirmation of womanhood (Prakasamma, 1999). The disproportionately higher value accorded to a male child reflects patriarchal structuring in family lineage and property inheritance. Inability to conceive gives rise to feelings of low self-esteem in women and increases their susceptibility to physical and verbal abuse, even abandonment (Gupta, 2000). Women become the targets of covert and overt pressures both from the family and the community. This induces them to access various types of ‘treatments’ for infertility, albeit risky.

Any holistic understanding of the operationalisation of ARTs must thus consider socio-cultural norms that link the identity of women fundamentally to their reproductive capacity and role as mothers (Widge, 2002). These studies also reveal childlessness to be
in greater part a crisis of a social nature, given that biological parenthood is considered far superior to voluntary childlessness and to alternative forms of parenting, like adoption.

Given this high premium on motherhood and biological progeny, it is not surprising that a range of procedures and approaches are used by infertile men and women in their quest to be ‘delivered’ from childlessness. Although this includes superstitious practices, religious worship, and alternative systems of medicine like siddha, ayurveda, etc. the proliferation of ART services demonstrates that the private medical establishment, in particular, is capitalising on social norms to promote technological interventions as infertility ‘treatment’. The private medical market is deploying a patriarchal (and eugenic) value system to sell its services. In the case of ARTs, high-tech and state-of-the-art facilities are marketed by providers with the rationale that they are responding to the demand of women ‘desperate’ to be mothers. This is supposed to impart an almost noble veneer to ART provision: the ‘gift’ of a baby is a good deed, helping women lead more meaningful and joyous lives as mothers.

Thus, numerous ART clinics in the country represent themselves as the destination for couples requiring technological assistance for conception and/or birth. This ‘assistance’ is not treatment, and does not address any biological causes of infertility. This has prompted Shah (2009), to describe ARTs as a technological solution to the social problem of not having a child of ‘one’s own’. Hence, the priority of ART clinics may be said to be to produce a baby, rather than to prevent or ‘cure’ infertility.

Social citizenship and ARTs

The term ‘social citizenship’ implies access to those social rights and material conditions that ensure effective participation in society. This analytical construct was developed by T. H. Marshall (1964) in his early work on the welfare state by expanding the meaning of citizenship rights beyond formal legal and political equality to encompass social equality. This included the right to a minimum level of economic security and social welfare assured by the state. However, this version of social citizenship has mostly concentrated on wage labour in the public domain as a means to citizenship, ignoring the enormous contribution of women as unpaid domestic labour in the private realm. Further, the social and economic conditions that enabled the emergence of a post-war British welfare consensus, which was the context for Marshall’s writing, have undergone a political and material change. Nonetheless, feminist perspectives on citizenship also evolved as a critique of the Marshallian understanding.

Social citizenship has thus come to refer to two overlapping but analytically distinct sets of rights and guarantees. The first set, ‘conventional’ or ‘old’ social citizenship rights, refers to rights and entitlements to the state provision of social welfare services and benefits, such as pension and health care, and to state guarantees of economic security. The second set, ‘new’ social citizenship rights, refers to guarantees of equal opportunity for socially disadvantaged groups, such as women, dalits, tribes, and other minorities, to participate fully in public life and to live with human dignity (Erickson and Mathews, 2003). Contemporary feminist discourse no doubt highlights the necessity of economic security and opportunity towards social citizenship. But unlike Marshall, it carries
the debate further in advocating for governmental responsibility to support reproductive work, social in nature, wherein families, particularly women, care for children, the elderly, and other dependents. It thus proposes a more ethical framework of citizenship that is not limited to economic and political participation. As such, it advocates for a situation where women not only have avenues to earn a decent standard of living in healthy and gender-just conditions, but at the same time to receive recognition and support from the government for their domestic and care work.

With the introduction and proliferation of ARTs, reproduction has gained a new momentum in the public sphere. It is clear that reproduction within heterosexual marriage confers access and status, thus enabling fuller participation in social life. ARTs are used to restore normalcy within the socially regulated institution of marriage. To expand the notion of social citizenship, then, is to include, but not limit its understanding to, formal politico-legal and/or economic participation, but to examine also real, lived, and gendered participation in social processes. The latter is hampered by the stigma and exclusion that infertility generates, and is sought to be expunged through ARTs and through the reproduction of a biological child. Further, a nuanced approach would view multiple aspects of citizenship (and exclusion)-social, political, economic—not as watertight and mutually exclusive, but rather as interacting and interrelated. As scholar Naila Kabeer (2006: 3) puts it, ‘Social exclusion reflects the multiple and overlapping nature of the disadvantages experienced by certain groups and categories of the population, with social identity as the central axis of their exclusion’.

The process of exclusion and inclusion is mediated through the coordinated action of various institutions—the family, the state, law, medicine, religion, caste, class, ethnicity, gender, and the like. While exploring the implications of ARTs, it is important to move beyond categories of ‘women’ or ‘men’ used as monoliths, and to examine the manner in which issues such as access and affordability, caste, religion, and sexuality intermingle to create such categories. This inter-sectionality is made evident by ethnographer Lawrence Cohen (2007: 82) in his studies on organ donation and caste in south India.

(while) few families . . . expressed or demonstrated much concern with the biomorality . . . of a lower-caste kidney being inserted into a higher-caste body, practical concerns over which caste bodies would be able to perform the state of exception necessary for committee approval were more common. Conversely, with brokers’ growing experience in a given region and their ability to create sustainably exceptional narratives for clearly discordant donor bodies, caste and other performances could again diminish somewhat in relevance.

Caste-related negotiations in ARTs are demonstrated by the anxiety around donor matching. That the donor of a gamete, or the third party involved in ARTs in general, needs to be of an ‘appropriate’ caste, religion, class and the like are reflected in the ICMR guidelines. The guidelines emphasise the right of the couple to have the fullest possible information from the semen bank on the donor such as height, weight, skin colour, educational qualification, profession, family background . . . ethnic origin . . . before accepting the donor semen.
These attributes can be seen to stand in for appropriate caste, religion, class, and other hierarchies around which society is organised. Thus, the ART industry holds the promise of not just delivering babies, but also of enabling the reproduction of the desired caste, religion, class, etc. Therefore, it becomes imperative to examine the intersections between caste, gender, religion, class, region, and profession to understand the complexity of ARTs.

The related issue of access to health care also highlights the two-way connection between social citizenship and social exclusion. Denial of basic health care, especially reproductive health care for a majority of women, is the structural reality of the modern-day post-welfare society. In doing so, the state violates a central tenet of the old and conventional ideal of social citizenship. In the context of an unregulated private health care sector and an inadequate public health care sector, class becomes a critical qualifier for fuller participation in social life, thus directly impacting social citizenship status.

Another traditional understanding of citizenship that is destabilised by ARTs is political citizenship. This has been demonstrated in the many contestations around the legal status of children born to foreign couples in India through commercial surrogacy arrangements. In the absence of any legal mechanisms that can provide direction, the citizenship status of the child becomes the subject of debate and legal tussle. Countries may deny citizenship if surrogacy is illegal or unrecognised within their constitutional framework or parentage, and citizenship may be claimed by different quarters: gestational (surrogate), genetic (in case donor gametes were used) or even social (in case of a fallout between the commissioning couple). Further, these contestations point to the fact that the withdrawal of the state from areas in need of intervention or regulation is in effect a withdrawal from the state’s role as the custodian and guarantor of rights, thus jeopardising citizenship itself. ARTs bring back old and conventional notions and debates around social citizenship, while also raising newer questions and concerns. In doing so, they expand and transform the very construct of social citizenship itself.

**Conclusion**

It is within this wider context that the present research study situates itself. It is located within the framework of developing a critical and self-reflexive feminist discourse on health and wellbeing. This study is a continuation of Sama’s research on both contraceptive and conceptive technologies, and seeks to explore the multifaceted dimensions of reproductive technologies. As such, it documents the lived experiences of women of different class and caste backgrounds who access reproductive technologies to have a biological child. It addresses the impact of ARTs on women, concerning itself not only with commercialisation of the ‘baby business’; but also examining a wider set of issues in which ideas about market, science, culture, nature and kinship are intertwined in complex ways.
Notes

1 Assisted reproductive technologies (ARTs) encompass various procedures ranging from the relatively simple intrauterine insemination (IUI) to variants of in-vitro fertilisation (IVF) and embryo transfer (ET), more commonly known as ‘test-tube baby technology’.


3 In 1884, the first donor insemination (DI) took place in Philadelphia. A patient of Dr. William Pancoast, was inseminated by the doctor with the semen from the ‘best looking’ medical student in the class that he taught, without her knowledge or consent. It was later apparent that neither the woman nor her husband was aware of the insemination or the fact that the child that she finally gave birth to was not that of her husband. In 1945, four cases of artificial insemination by donor (DI) were reported in the British Medical Journal. Shortly after that, in 1948, the Archbishop of Canterbury, following a commission of inquiry, called for the criminalisation of DI. (Wilder, B. (2002). Assisted Reproductive Technology: Trends and Suggestions for the Developing Law. *Journal of the American Academy of Matrimonial Lawyers*, 18, 177-209)


7 NIRR is an institution of the Indian Council of Medical Research (ICMR).

8 Indian Council of Medical Research. (2005). *National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India*. New Delhi: Author


13 This approach enables a broad understanding of key ‘problem areas’ and their evolution, rather than overstating positions and their rigidity.


16 See Ortner, (1972) for a critique of this understanding.


21 For an extensive review of the health risks of ARTs, see Sama – Resource Group for Women and Health. (2006). *ARTs and Women – Assistance in Reproduction or Subjugation?* New Delhi: Author


36 Indian Council of Medical Research. (2010). National Guidelines for the Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author


40 Ibid.


Ibid


Ibid


Indian Council of Medical Research. (2005) *National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India*. New Delhi: Author
CHAPTER 1

Methodology: Mapping the Process

Assisted Reproductive Technologies (ARTs) became the theme of our research first in 2004 when we explored the social, medical, and ethical implications of these technologies. This previous study on ARTs was essentially undertaken to gain a holistic and realistic understanding of the way in which the concepts of choice, empowerment, and autonomy operate for women in today’s technology-dominated age (Sama, 2006). The questions we asked were: Do ARTs deliver the promised rights for women over their own bodies? Or is someone else’s choice being imposed on them through these invasive technologies? The sites chosen for this research were three metropolitan cities—Delhi, Mumbai, and Hyderabad. These cities, which have some of the most prominent providers in the field of ARTs, cater to a population of users not only from within the city and the country, but also from overseas.

The findings of this study hinted at developments (which took clearer shape in the following years) that merited further investigation into certain aspects of ARTs. For instance, these technologies did not appear to be isolated medical ‘treatments’; they were part of a larger business, which has now grown into a veritable ‘fertility industry’. The operationalisation of ARTs in India appeared to be shifting, moving from the metropolitan to smaller cities, with chains of referrals emerging as a notable feature. An initial visit to the ART clinics of Bhubaneswar and Cuttack in Orissa also revealed that IVF was being carried out in batches for cost-effectiveness, subject to the availability of the embryologist and the andrologist, both of whom were flown in from Mumbai and Hyderabad respectively. While medical tourism, specifically for ARTs for people from other countries coming to India continued to attract media and industry attention, local migration of couples from one city to another within India for ARTs was also growing gradually, albeit unnoticed.

Further, the absence of any state regulation raised significant ethical concerns. Thus, the proposed large-scale study in the three states sought to explore

a. access (with reference to class, caste, and gender);

b. industry dimensions of ARTs (with reference to the process of ‘local globalisation’);

and

c. advocacy (with regard to proposed regulatory mechanisms).

Thus, Sama’s field-based research, undertaken from February 2008 to December 2010, also formed the evidence base for our campaign initiatives, including the critique of the ART (Regulation) Bill and Rules, 2008 and 2010. These three objectives did not change over the course of the research project, although the outcomes and findings for each varied.
I. Objectives

The specific objectives of the study were:

a. to document the experiences of women undergoing ART procedures (IVF and IUI) and to focus rigorously on the class and caste dimensions vis-à-vis access to ARTs.

b. to explore the growth of the ‘ART industry’ in India by examining the inter-linkages between ART clinics in metropolitan cities and those in smaller cities and towns, and to understand the process of ‘local globalisation’.

c. to initiate a public debate on this issue both within the women’s movement and the health movement, and also to undertake policy advocacy for the regulation of the ART industry in India.

The review of secondary material or sources for the research study was done to develop a theoretical understanding on the issue, and to gather information on the status of the research work undertaken on the subject until now. This helped identify the gaps in the existing literature, sharpened our understanding of the subject under study, and aided in tailoring the objectives of the current research project to enrich, rather than duplicate, the existing body of literature.

This research project also forms a significant part of Sama’s ongoing work on technologies that target women’s bodies, and feeds into and facilitates our campaign work and policy advocacy regarding the regulation of the ART industry, with the aim of bringing this industry within the framework of ethical regulation.

II. Research design

The design of this research project is essentially exploratory and qualitative. The study seeks to establish the situation on the ground, to document the growth of the fertility industry, and to draw general conclusions based on a qualitative analysis.

III. Research process

The research began in February 2008. It involved collecting both primary and secondary data. A critical analysis of secondary data, such as relevant bills and guidelines, was also undertaken to gain an understanding of the status of laws, regulations, and policies that affect the ART industry, and to identify the issues that need or deserve public debate and discussion. The study also examined the websites and brochures of ART clinics, tourism departments, and medical tour operators and travel agencies, as well as advertisements in magazines relating to egg donation and surrogacy. This was done to analyse the content of these promotional materials and to understand the ways in which ART providers promote their services.
III.1. Developing the research questions

Some of the specific questions addressed in this study were:

a. How do the identities of class, caste, and sex determine access to, and control over, ART treatment?

b. How do we understand the economic and commercial aspects of ARTs and their provision, proliferation, access, and implications?

c. What are the features of India’s emerging ART industry?

III.2. Formation and training of the research team

Three members, including the research coordinator, had been part of the earlier phase of Sama’s research on ARTs and hence were familiar with both conceptual issues as well as the research methodology. Two of them had also been involved in critiquing the ART guidelines of the Indian Council of Medical Research (ICMR) in 2005. The other members of the research team were recruited through interviews. The research responsibilities were then divided within the team on the basis of each member’s individual skill, experience, interest, and expertise.

The local investigators were recruited on the basis of their familiarity with the geographical area, fluency in the local language, understanding of local socio-cultural practices, and communication and documentation skills. The research team members were well versed with the local languages of the states, namely Tamil, Oriya, and Hindi.

III.3. Training and capacity building of the research team

Since the initiation of the research process, the research team has been thoroughly trained by the research coordinator as well as by external resource persons through orientations and capacity-building sessions and through regular mentoring. The local investigators were also invited to Delhi for regular trainings and orientations.

The initial orientations were held with the following objectives:

- To develop a conceptual understanding of the research problem, and the rationale and objectives of the research project, along with an understanding of the timeframe of the activities.

- To frame questions for the research schedules; and maintain an ethical and objective perspective while conducting interviews.

The subsequent orientations focused on more advanced stages of research, such as interviewing skills, documentation, and advocacy of ARTs.
On interviewing skills

- To amend the interview schedules for both providers and users after testing these in the field.
- To strengthen the interviewing skills of the team while interacting with respondents from different regions and socio-economic backgrounds; and while conducting focus group discussions (FGDs) and interacting with women’s groups.

On documentation

- To provide guidelines and strengthen skills for the documentation of interactions in the field; and maintaining daily diaries.
- To clarify the importance of revisiting interviews soon after to identify and address lacunae in the transcripts; and conducting peer reviews.

On data analysis

- To use SPSS software for data entry and analysis, to prepare frequency tables, to categorise data.
- To engage in collective brainstorming regarding the structure and form of the research report.

Regular meetings were held to take stock of the progress of the research project, to share the experiences of the research team, to discuss problems faced in the field while interviewing, mapping, or documenting the narratives, and to find solutions collectively for the challenges faced. A mechanism for the peer reviewing of documented interviews was adopted, wherein the researchers provided feedback on each other’s documentation and highlighted the gaps in the interviews. Documenting interviews in as much detail as possible was encouraged, and a separate section on observations was included in the report.

An in-house workshop with a specific focus on the Draft ART (Regulation) Bill & Rules 2008 was conducted during which the research team collectively discussed and analysed various sections and clauses of the bill. The team also developed a detailed and comprehensive critique of the draft bill, which was sent to the Ministry of Health and Family Welfare (MoHFW) and the Indian Council of Medical Research (ICMR). The team was also oriented on reproductive physiology and human anatomy, and on concepts like gender, reproduction, citizenship, sexuality, and other concerns with respect to ARTs.

III.4. Formation of the advisory team

An advisory team was formed to look into the ethical and methodological issues concerning the process of the study and to act as the review board for the research project. This team included eminent social scientists, researchers, medical professionals, legal activists, feminist scholars, and activists, with both national- and international-level experience.
Regular meetings were held with the advisory team members over the course of the project period. In the first phase of the study (prior to the commencement of data collection), a meeting was held to sharpen the focus of the research agenda, to frame the research objectives, and to develop the scope, the study areas, and the methodology of the study. Subsequent meetings with the advisory team focused on ethical considerations of the research tools being used, dilemmas and practical limitations at the time of data collection, guidelines for data analysis, and the structuring of the research report.

Informal meetings with available advisory members were also held as and when required and as mutually convenient. The advisory members were kept up to date about the research study process and progress through regular correspondence. One advisory member was involved in the review of the research report in the final stages of data analysis.

III.5. Study area: Selection of research sites

Given the fact that hardly any credible data exist on the number, spread, and functioning of the ART industry in general, and of ART clinics in particular, the possibility of choosing a sample from an unclear ‘universe’ did not arise. Instead, based on the findings of our earlier study conducted in 2006, and also based on extensive discussions on the issue with a range of experts across the country, we decided to locate our present study in three diverse geographical areas, namely the three states of Orissa, Tamil Nadu, and Uttar Pradesh, with diverse human development indicators. A deliberate effort was made to capture the implications of ARTs on different population groups and also to be attentive to regional and geographical variations in India. It was decided that one state each from the north, east, and south would be studied so as to incorporate the different socio-cultural and economic backgrounds of the people.2

The three states chosen represent different stages of the development and advancement of the ART industry in India. While the industry in Orissa is quite nascent, in Uttar Pradesh it is growing rapidly, and in Tamil Nadu it is quite advanced, with the emergence of newer forms of partnerships. The study was undertaken in the rural, peri-urban, and urban areas of the three states.

III.6. Mapping and selection of districts, clinics, providers3 and users4

The mapping of ART clinics was perhaps the most important aspect of the study with respect to maintaining the validity and reliability of the research findings.

The mapping tools used for the selection included:

- The list of clinics registered with the National ART Registry of India (NARI) 2006, an initiative of the Indian Society for Assisted Reproduction (ISAR) was examined.

- Internet search: The clinics were initially identified through the Google search engine. Lists of ART clinics available on websites (such as pregnancymd.org; justdial.com, ask.com, hotfrog.in, indiaparenting.com, and whereincty.com)
and other online listing resources were accessed to gain a preliminary idea of the number of IVF clinics and the areas where they were most concentrated. An article in Outlook magazine listing the best IVF clinics in India was also used (Puri et. al., 2006). The keywords used for Web searches for each of the three states were ART clinic, IVF clinic, infertility clinic, and infertility treatment.

- Advertisements: Clinics in these states were also mapped through advertisements by ART providers in popular magazines and newspapers. A number of magazines were scanned for advertisements promoting services related to ART procedures. The magazines and newspapers examined included: India Today, Indian Express, Times of India, Hindustan Times (English); Navbharat Times, Dainik Jagran, Hindustan, Grihashobha (Hindi); Aval Vikatan, Kumudam Snegidhi, Thenmani, Mangayar Malar (Tamil).

- Telephone directory services: The team members used local telephone directories, the Tata Yellow Pages, and other telephone services (such as Just Dial Service) wherever available to get information about ART clinics.

- Members of known organisations working in these states and personal contacts were also pursued to gain first-hand knowledge of ART clinics.

Unlisted clinics were identified mainly through key informants and local organizations. The key informants played an important role at this stage, because most of the clinics that were operating were known about only through word of mouth. The key informants included public health care providers, local chemists, staff of tourism departments, auto rickshaw drivers, medical representatives of pharmaceutical companies, staff of clinics or hospitals, staff of gynaecology clinics, local shop owners, especially chemists and pharmacists, staff of law firms specializing in drafting surrogacy contracts, and hotel owners near IVF clinics, all of whom provided information about local infertility centres.

The selection of the districts in the states depended on the willingness of the ART providers of that district to participate in the research study. The existence of ART clinics in a district was the main selection criterion. However, special attention was also focussed to districts with features important to the objectives of the study, such as a skewed sex ratio, concentration of a particular caste group or a religious minority group, predominance of Dalit or Adivasi populations, and existence of popular tourist destinations. While the districts with striking caste-class diversity or features were considered to fulfil the first research objective, the districts with tourist attractions were important for understanding the linkage of the ART industry with the tourism industry, that is, the extent of ‘reproductive tourism’ occurring within these districts.

<table>
<thead>
<tr>
<th>Table 1: Sample districts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S. No./ State</strong></td>
</tr>
<tr>
<td>1. Cuttack</td>
</tr>
<tr>
<td>2. Ganjam</td>
</tr>
<tr>
<td>3. Sundargarh</td>
</tr>
<tr>
<td>4. Khorda</td>
</tr>
<tr>
<td>5. Allahabad</td>
</tr>
<tr>
<td>6. Kanpur</td>
</tr>
</tbody>
</table>
As a result of the exhaustive mapping and selection process:

a. 43 providers of ARTs–IUI, IVF, and ICSI–were interviewed. Of the total 43 providers, 18 were from Tamil Nadu, four from Orissa, and 21 from Uttar Pradesh.

b. 86 women who have in the last two years
   - undergone the IUI and IVF procedures
   - undergone the IVF procedure
   - undergone the IVF and ICSI procedures
   - been advised to undergo any of these procedures
were interviewed across the three states. Of the total number of women, 43 were from Tamil Nadu, 30 from Orissa, and 13 from Uttar Pradesh.

**III.7. Tools of data collection**

Research tools such as the interview schedule, consent form, and permission letter were prepared in consultation with the advisory team and were pre-tested as well as modified in line with successive field experiences to address emerging issues.

**Schedules**

Schedules or lists of open-ended questions were prepared to assist the team in conducting interviews with both providers and users accessing these procedures. The schedules were prepared in English, Hindi, Tamil, and Oriya, to be used according to the convenience of the participants.

**Field diary**

A field diary was maintained for recording the dates of visits and interviews with all respondents.

**III.8. Process of data collection**

**III.8.a. Process of informed consent**

As a research study that explores the personal journeys of women, strict adherence to ethical principles of data gathering was observed.

Securing written informed consent was an important component of the study. The researchers provided information about the study, the future use of the data being collected, and an estimated timeframe of the interview, so as to enable respondents to decide whether they would be able to participate. Participation in the study was completely voluntary, and the participants were duly informed about their right to withdraw from participating at any point during the interview. Confidentiality of both women and providers was maintained throughout the study. Anonymity was ensured by maintaining codes in data entry.

**Informed consent form**

The informed consent form in addition to English, was developed in the local languages of the respondents–like Hindi, Oriya, Bengali (some of the respondents at one hospital in Tamil Nadu were from West Bengal), and Tamil–to provide participants with information
regarding the purpose and intent of the study, and to assure them that the data being collected would remain confidential.7

The form was signed both by the respondent and the researcher, and a copy of the form was given to the respondent. This procedure and its importance were also explained to the respondent verbally. The researcher also sought prior consent for audio documentation of the interview.

Permission letter for provider
A formal letter stating the research objectives was prepared for public and private providers prior to the interviews.

III.8.b. Interviews
ART providers identified through the mapping exercise were approached for interviews. The research team explained the objectives of the study and presented the providers with the permission letter. Thereafter, depending on the willingness of the providers to participate in the study, in-depth interviews were conducted using the interview schedule. Apart from the providers, other staff members of the clinic, such as embryologists, junior doctors, counsellors, and hospital managers, were also interviewed. This was done to gain additional information on certain aspects, like marketing and promotion strategies.

One of the main sources of contact of women users for this study were ART providers. A few clinics provided the researchers with a list of the women registered at the clinic for these procedures. In some instances, the research team was asked by the provider to come at a time when the IVF–ICSI batches8 were held, when a number of women undergoing the IVF cycles would be available together. Thus, the women who participated in this study were those who were available for interviews during the field visits and who consented to be a part of this research. However, some women were also selected through the personal contacts of the local investigators.

Although the providers in Uttar Pradesh seemed fairly open to speaking to the team, in most cases they were reluctant to give permission to speak to users. One clinic in Meerut and a few in Lucknow were more forthcoming in this respect. However, they, too, withdrew permission after a few interviews were completed. As a result, only 13 interviews with users in Uttar Pradesh were possible.

<table>
<thead>
<tr>
<th>Table 2 : Total number of women interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>UP</td>
</tr>
<tr>
<td>UP</td>
</tr>
<tr>
<td>UP</td>
</tr>
<tr>
<td>UP</td>
</tr>
<tr>
<td>Subtotal</td>
</tr>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Subtotal</td>
</tr>
<tr>
<td>TN</td>
</tr>
<tr>
<td>TN</td>
</tr>
<tr>
<td>TN</td>
</tr>
<tr>
<td>Subtotal</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
The women were presented with the informed consent form, which was also orally explained to them. They were encouraged to read the form and were given sufficient time to decide if they wanted to participate in the study. Both written as well as oral consent was then obtained from them. In some clinics, the interviews were conducted in a separate room within the clinic to maintain the privacy of the respondents and to encourage them to talk freely. In some instances, when the women did not want to talk within the clinic premises or had to leave for home, interviews were conducted outside the clinics.

Thus, with their prior consent, the team conducted follow-up interviews with the women, held at a location of their choice, such as their homes, fields, temples, and lodges. Home-based interviews tended to be more in-depth and longer in duration, as women talked freely in the comfort and privacy of their own homes, and were not anxious about being away from home and their domestic responsibilities for a long time.

Some women were given the contact numbers of the researchers so that they could call them whenever it was convenient for them. Some interviews were conducted in two sittings. These interviews, held mostly with women users of ART procedures, and sometimes with both women users and their partners/ husbands, were conducted with the help of the interview schedule. The interviews addressed gender roles with respect to infertility, violence, economic implications, and access to health services by women. Views about the support that women expected and received from their partners/ husbands and families were also sought.

### III.8.c. Focus group discussion (FGD)

FGDs were conducted to understand gender relations in the context of infertility, the social stigma of childlessness and the decision to use ART procedures, and perceptions of fertility and infertility prevalent at the community level. Guiding questions were formulated to facilitate these FGDs. The discussions were held in anganwadi centres, school courtyards, temples, homes of auxiliary nurse midwives (ANMs), and in the training spaces of organisations that facilitated the interactions. The FGDs, on an average consisted of 10–16 men and women. In a few places where FGDs were conducted, women with infertility were also part of the group. A deliberate attempt was made to conduct FGDs separately with people from different communities, like Dalits, Adivasis, and religious minorities.
III.9. Data analysis

III.9.a. Translation, documentation, and codification
Interviews conducted in the local language were translated into English by the researchers. Gaps were filled by referring to the field diary, or by transcribing the interview tapes, wherever relevant, before the interviews were codified according to the state in which they were held. The interviews were translated as closely and accurately as possible into English, although certain phrases and/or words did not have an appropriate equivalent in English. Codification was done in the following pattern: Initials of the state (such as UP for Uttar Pradesh), followed by ‘P’ for Provider or ‘U’ for User, and the relevant number. For instance, UPP-6 or UPU-3.

III.9.b. Review
Once fully documented and codified, the interviews were reviewed. During this process, the research coordinator and other members of the research team went through every interview in detail and gave comments on the content. These observations were used to fill in missing information, as well as to substantiate information that needed elaboration. The incorporation of feedback was done by referring once again to field notes, tapes, transcripts, etc. In some cases, the researchers made subsequent visits to the field to conduct follow-up interviews and to obtain the required information.

III.9.c. Categorisation
For the purpose of analysis, the fully documented interviews were then categorised using Microsoft Excel sheets. The process of categorisation was considered important from the perspective of analysis, as it would enable the organising of the interview data into categories that could be referred to easily and quickly. The data were divided into different sections. Within each section, information was further divided or grouped under various sub-headings. For example, under the category ‘Experience of Treatment’, the following sub-categories were added: reason for infertility (male factor/female factor/both/unknown); woman’s/man’s response to medical diagnosis and advice; woman’s experience of going through ARTs; distance from the clinic and commuting experience; change of doctors (frequency and reasons); and side effects experienced.

IV. Chapterisation of the report
After successive discussions, the research findings were divided into chapters that would reflect the emerging themes of the study. A working chapterisation framework was developed after much discussion, and each chapter was assigned to the researcher best equipped or most inclined to analyse that particular theme, for instance, commercialisation of ARTs. The drafts of the chapters were peer-reviewed by members of the research team who gave each other feedback. Regular meetings were held to map the progress of the chapters, as well as to discuss the conclusions and questions that emerged from the study. This also enabled the researchers to draw from each other’s observations and experiences, to forge connections, avoid overlaps, and to pull the findings together into a cohesive and comprehensive research study.
V. Methodological challenges

Given the fact that neither the medical establishment nor the government has credible information to share on crucial parameters such as: who are the infertile, what numbers constitute the infertile, how many clinics have been officially authorised to ‘treat’ infertility, etc., this study can be considered an attempt to bring together a range of interconnected issues, each of which still requires further and more in-depth engagement. What is important, nevertheless to point out, is the nature of challenges, methodological and otherwise, that this exercise has posed.

It must be established at the outset that no definite generalisations can be made from the research results. While qualified inferences can be drawn from the primary data, it must be borne in mind that the small size of the sample, which was purposively selected rather than chosen at random, was a limiting factor. While the selection of regions/states for the study was based on certain standard development indicators, the choice of clinics or personnel for interviews was not just purposive but also based on the knowledge of key informants about the existence of ART or ART-like facilities; the willingness of providers to provide access to ART users accessing these procedures, and their willingness to be interviewed.

The significance of stating this upfront lies in the fact that the study cannot arrive at definitive conclusions, on, for example, the magnitude of infertile couples in the country, the numbers of clinics providing ART services, the numbers of ‘successful’ cases and/or numbers of cases where ARTS have not resulted in a child being born, etc. What, however, the study does reveal in no uncertain terms is, at one level, the absence of any standards or ethics in what goes into the ‘treatment’ of infertility through ARTs; and, at another level, the complex set of issues that push couples to seek ‘treatment’ for not being able to bear a child, the financial implications of such a decision, the differential social implications that arise when infertility is attributed to either the male or female; the trauma of the treatment itself which gets compounded when it is not successful, to highlight just a few of the several rich insights that the study has documented.

Since the research focused primarily on users undergoing ART procedures, the findings may not be generalisable to those who did not, or who do not, seek infertility treatment (reasons why treatment is or was not sought could not be concluded on the basis of the research findings). Census data reveal that childlessness among married couples is increasing in the country and more so in the more developed states such as Tamil Nadu. We have no way of finding out whether or not all childless couple are seeking ART services, and if not, the reasons. Hence to that extent, the findings of this research are limited to those who have actively sought ARTs. In other words, there is no non-clinic-based comparison group, although an attempt was made to capture the nature and trajectory of the ‘treatments’ sought, including non-ART options.

Without studies of non-ART treatment seekers and in the absence of a non-clinic comparison group, it is impossible to completely untangle the effects of infertility from the effects of ART procedures for an understanding of all implications and outcomes.
V.1. Access to data, clinics and users

As already mentioned above, the absence of a credible, accessible and officially approved or certified database and registry of functional ART clinics, forced the research team to rely on a network of informal sources for information. Access to clinics and users was also not easy for several reasons. One, over the years, Sama has acquired visibility as an organization advocating for regulation of the medical sector. Two, given the pervasive absence of standards in medical practice compounded with no authorised body responsible for monitoring, reporting or taking action for any kind of lapse, clinics and providers were extremely vary of sharing information or providing access to any form of information, including published, even for research purposes.

In such a context, qualitative information provided by those willing to be a part of the research could not be be backed by quantitative information such as quantum of investments made in different facilities, sources for finances for such investments, numbers treated for infertility since inception of clinic, measures of ‘success’ parameters for evaluation of performance of clinics, nature, levels and numbers of personnel employed, etc. Nevertheless, wherever possible and however sketchy, some quantitative information has been provided along with qualitative data.

Access to users was initially through their respective providers (which itself was a challenge since the latter, very often, were keen to refer to the research team only their successful ‘cases’); some of the women interviewed subsequently put the research team in touch with other women known to them who had also undergone ART procedures. Therefore, much as the research team would have liked to include diverse categories of women-class, caste, religion- there was no way in which this could have been systematically (read scientifically) pursued in the absence of data either with the medical establishment or the state or central government. Hence, the predominance of Hindus among the users interviewed and/or the absence or the relatively small numbers of Muslims and Christians interviewed, should in no way be interpreted to mean, for example, lower incidence of infertility among these communities, or poor access to treatment, etc.

V.2. Conducting interviews

V.2.a. Gender norms made it difficult to interview women in certain spaces (such as the waiting rooms of hospitals, which were usually crowded) or to ask certain questions openly, particularly when more intimate details were being sought, in the company of husbands or mothers-in-law. Further, it may be especially difficult for women to narrate their experiences of childlessness and the associated stigma and despair, as a lot of these are traumatic to recount and relive.

V.2.b. It was difficult to conduct certain interviews because of logistical problems. For instance, some providers conduct IVF in batches or through camps, which were held only on certain days of certain months, thus providing only a small window of opportunity to gain access to a large number of users.

V.2.c. Some of the providers refused to answer questions pertaining to the costs of procedures, availability of surrogacy services, amounts paid to commercial donors, etc.
V.3. Accessing public health facilities

V.3.a. Obtaining permission from public health officials to interview providers was quite a challenge. The research team had to deal with bureaucratic delay, submit written applications in some places, absentee officials, etc., before the actual interview could take place. Obtaining permission from heads of departments was very time consuming.

V.3.b. Very often in public health set-ups, the staff was either very busy or not available for interviews. Often public health centres (PHCs) were without any medical officers. Moreover, government doctors were often burdened with a large patient load, and hence could not give the researchers their undivided attention or adequate time.

V.4. Generalisability issues

By tracking the rising use of ARTs and the demographic details of those who seek out these procedures, potential barriers to access become clearly visible. These include wealth, income, cost, marital status, age, location, sexual orientation, religion, and caste.

V.4.a. While no conscious attempt was made to include Hindu respondents, they nevertheless formed the majority of users in this purposive sample. This may also be a consequence of their higher proportion in the general population.

V.4.b. Although our sample has users from across the caste spectrum, this should not be taken to indicate that the market is blind to caste, thus bearing the potential to liberate from ascriptive identities. In India, given that caste is 'classed', access to ARTs must be understood as being mediated most significantly by class, and therefore by caste, because of this overlap.

V.4.c. Standard measures of economic class generally use income of the household and/or expenditure data. However, in the course of the research, we realised that the manner in which couples, across classes, sought and financed 'treatment' did not allow for data to be neatly classified into lower, middle or upper classes.

The research has recorded a range of contexts; one where, whatever be the level of income of the couple seeking treatment, the extended family members of the couple were willing to financially support them; two, the couples were willing to go to any length including selling their assets and/or means of livelihoods in their bid to finance their treatment; three, prolonged but unsuccessful treatment not only led to lowering of class status but also alienated those users who were part of joint families, since the latter had to bear the brunt of the financial that the treatment involved. Moreover, information about income and assets (considered standard indicators of class) was not shared by all users (particularly women), and could not be corroborated.

The economics of the ‘treatment’ was so deeply enmeshed with socio-cultural factors that the class factor had to be qualified by the context in which the couple seeking treatment was situated. Therefore, economic class data qualified with
socio-cultural information provided a more nuanced understanding of class. In other words, while economic class of those seeking treatment was necessary, it was not sufficient to comprehend why the distribution of data by class did not provide clear-cut answers.

V.4.d. Several providers did not want to share information about the costs of their services with us. Of the ones who did give information on costs, the figures quoted were sometimes vague. Providers did not detail what these costs did or did not include, such as hospital stay and cost of drugs. Moreover, in the absence of a registry or database, these figures could not be verified or cross-checked. To some extent, this was possible by asking users at the respective clinics; however users could be equally unclear about the exact amount spent and its break-up, given the long-drawn-out nature of ‘treatment’.

V.5. The definition

The definition of infertility has long been contested. How should infertility be conceptualized? Who should be considered infertile? How should straightforward definitions (such as that of ICMR) be expanded to include the experiences of women, especially those who may be classified as ‘infertile’ but who do not view themselves as such (cases of medical and/or voluntary childlessness)? These were some of the questions and challenges that emerged during the course of the research project.

V.6. Problems encountered during FGDs

V.6.a. In some places, it was difficult to conduct FGDs as per the convenience of the women. In many groups level, women were not aware of ARTs. Women were also not willing to stay for a long time because of household commitments. Hence, FGDs often had to be completed within a short span of time.

V.6.b. In most of the villages, particularly in Orissa, certain communities were clearly ghettoised. For instance, Dalits were unable to participate in FGDs involving members of upper castes. Similarly, Muslims were often found to be segregated from the rest of the community. As such, FGDs were conducted separately and exclusively for these communities so as to enable the research team to gain a more thorough understanding of the issue.

Conclusion

The Methodology provided the framework within which this research study was carried out. The research findings are discussed in the following chapters.
Notes


2 For more details on the states, see Annexure-1 on state profiles.

3 The term ART provider includes embryologists, clinicians, doctors, counsellors, and other paramedical staff, that is, all categories of personnel involved in the provision of these technologies. However, in this sample, all except one provider (42) were doctors, while one was an embryologist. Similarly, the term user(s) is employed interchangeably with women or couples undergoing ART procedures.

4 This research study employs the word ‘user’ rather than ‘patient’ because infertility is a condition (rather than a disease) for which ARTs may be sought for assistance in conception, but are not a cure. Similarly, ARTs are referred to as ‘procedures’ rather than treatments as they do not treat infertility, but instead bypass possible causes and assist directly in conception/ birth (where used, the word treatment is enclosed in single quotation marks to signify this).


6 Refer Annexure-2(a) for more details on research schedules used.

7 See Annexure-2(b) for detailed Informed Consent forms used.

8 An IVF batch is a group of women who are scheduled to undergo the embryo transfer procedure over a couple of days. Their cycles are regulated to coincide with each other so that efforts do not have to be duplicated for each user. This is usually done to save on expenses of culture media and on visiting embryologists and IVF experts.
CHAPTER 2

Profile: Users and Providers in the ART Landscape

This chapter presents the profiles of users as well as of clinics providing ARTs in the three states of Orissa (OR), Tamil Nadu (TN), and Uttar Pradesh (UP). It is organized in two parts.

- Section A discusses the socio-economic profiles of 86 users.
- Section B presents a detailed profile of 43 ART clinics based on interviews with providers.

Information on the profiles of users and clinics is necessary for understanding the variables that determine or influence access to ARTs. The socio-economic profile of users lays the foundation for a more nuanced analysis of the research data, particularly for highlighting complex issues and inter-linkages that inform the research objectives and for identifying areas that require further study. Similarly, information on the profiles of clinics also establishes the diverse nature of ARTs and facilitates a comparative analysis of the existing infrastructure, facilities, and practices vis-à-vis the recommended guidelines and protocols, wherever possible.

Section A

Profile of users

This section examines the socio-economic variables of age, religion, caste, education, occupation, income, family type, marital status, residence location, time span for undergoing ART procedures, etc. to determine how the profile of users influences access to ARTs, to explore the nature and extent of access, and to document different experiences and their implications.

I. Age

Information about the age of users was necessary to understand the influence of age on decisions by users and providers regarding the provision of ARTs, choice of procedure and number of cycles. Age-related data was necessary also to document the differential risks and consequences of ARTs for diverse age groups of users, given the significant correlation between age and women’s bodily processes, including fertility.

A significant majority of the women in the sample, that is about 58 per cent, were in the age group of 30-39 years, followed by nearly 27 per cent who were 20-29 years. Almost 13 per cent of the women were in the age group of 40-49 years, with one woman
above 50 years. The youngest woman in the sample was 20 years old from Tamil Nadu, while the oldest women (three) from the state were 40 years. In Orissa, the youngest and oldest women were 22 and 45 years respectively. In Uttar Pradesh the youngest woman was 28, and the oldest were 48 and 55 (also two of the oldest across the three states). The 55 year old woman at the time of the interview had a one year old son conceived 15 years after menopause. Similarly, among the men, nearly 57 per cent were in the age group of 30-39 years, followed by about 30 per cent who were in the 20-29 year group. The youngest male was 26 years old from Tamil Nadu, husband of the youngest woman in the sample and the oldest was 58 years from Orissa. Approximately 13 per cent of the women and 29 per cent of the men were between 40 and 49 years old. One woman and four men from the sample were over 50 years.

### Table 3: Age profile

<table>
<thead>
<tr>
<th>Current age of women</th>
<th>TN women</th>
<th>TN men</th>
<th>UP women</th>
<th>UP men</th>
<th>OR women</th>
<th>OR men</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29 years</td>
<td>16 (18.6%)</td>
<td>5 (5.81%)</td>
<td>1 (1.16%)</td>
<td>1 (1.16%)</td>
<td>6 (6.9%)</td>
<td>—</td>
<td>women - 23 (26.74%) men - 6 (6.97%)</td>
</tr>
<tr>
<td>30-39 years</td>
<td>24 (27.9%)</td>
<td>26 (30.23%)</td>
<td>6 (6.97%)</td>
<td>5 (5.81%)</td>
<td>20 (23.25%)</td>
<td>18 (20.93%)</td>
<td>women - 50 (58.13%) men - 49 (56.97%)</td>
</tr>
<tr>
<td>40-49 years</td>
<td>3 (3.48%)</td>
<td>11 (12.79%)</td>
<td>4 (4.65%)</td>
<td>3 (3.48%)</td>
<td>4 (4.65%)</td>
<td>11 (12.79%)</td>
<td>women - 11 (12.79%) men - 25 (29.06%)</td>
</tr>
<tr>
<td>over 50 years</td>
<td>—</td>
<td>—</td>
<td>1</td>
<td>3</td>
<td>—</td>
<td>1</td>
<td>women (1); men (4)</td>
</tr>
</tbody>
</table>

* Information not available for one man in Tamil Nadu and one man and one woman in Uttar Pradesh.

In the sample, women and men in the ‘typically’ higher age group accessing ARTs were in a significantly lower proportion, while the majority of women and men users were in the reproductive age category and in the comparatively younger age group. Hence, the general perception of the growing use of ARTs with the increasing age of users was not reflected in the research. The findings also raise doubts about the oft-cited belief that women delay marriage and pregnancy because of other priorities.

### II. Marital status

All users at the time of the interviews were married. All providers stated that they had provided ARTs only to married users. While some providers simply claimed that this was clinic policy, others elaborated that the non-provision of ARTs to single women and men...
was justified given larger social ramifications and lack of acceptability. Three providers claimed they would provide ARTs to single women if approached, after appropriate counselling.

III. Religion

An overwhelming majority, that is, 75 users identified as Hindu, five as Christian, four as Muslim, one as Sikh, and one as Jain. Of the 75 users who identified as Hindu, 29 were from Orissa, 34 from Tamil Nadu, and 12 from Uttar Pradesh. All five users who identified as Christian were from Tamil Nadu. Three users from Tamil Nadu and one from Orissa identified as Muslim. One couple from Tamil Nadu identified as Jain and another from Uttar Pradesh as Sikh. Although the four users in the sample who identified as Muslim were undergoing ART procedures, including IUI and IVF, they were open to considering the donor programme and did not raise any concerns vis-à-vis religion. There is insufficient literature on the nature, source, and negotiation of the opposition to ARTs with regard to religion in India. In addition, people negotiate with their religious beliefs in everyday life, including with regard to reproductive technologies like those for abortion. Like caste, religion is a deep-rooted force in people’s lives and may be a factor in determining access to, and use of, reproductive technologies. The relationship between religion and ARTs is complex and dynamic, and needs further exploration, especially in the Indian context.

IV. Caste

Data on caste were collected to explore the impact of caste on access to ARTs. The research also sought to study linkages, if any, between caste-based occupations and the causes of infertility. Information about caste was also important for exploring eugenic trends in the context of selection criteria of gamete donors.

Table 4 shows that the maximum number of users in the sample, that is, 51 per cent, identified as Other Backward Castes (OBC) and Backward Castes (BC), with nearly 9 per cent from the Scheduled Castes (SC), Most Backward Castes (MBC), and Scheduled Tribes (ST) across the three states. About 27 per cent of users identified as Forward Castes (FC). For approximately 13 per cent of the users information was not available. The large percentage of BC, OBC, SC, and ST suggests that those who undergo ARTs are from lower caste groups in the Indian context.

Table 4: Caste

<table>
<thead>
<tr>
<th>Caste category</th>
<th>Orissa</th>
<th>UP</th>
<th>TN</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduled Caste</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Scheduled Tribe</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other Backward Caste</td>
<td>18</td>
<td>1</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Backward Caste</td>
<td>–</td>
<td>21</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>Most Backward Caste</td>
<td>–</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Forward Caste</td>
<td>9</td>
<td>7</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>No information</td>
<td>2</td>
<td>3</td>
<td>6</td>
<td>11</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010). In case of different caste identities between a couple, the caste identity of the primary respondent was considered.
and ST users in the sample indicates that ARTs are accessed by users from castes that are recognized as socially and economically vulnerable, although a category like OBC could also include those who are relatively better off. It appears from the data that all castes are accessing ARTs.

V. Type of family

The families of users were categorised into joint and nuclear. Here, the nuclear family includes the couple and any children that they may have. The joint family comprises the couple, the in-laws, the natal family, and other relatives living together permanently or for substantial periods of time.

Forty seven users in the sample lived in a joint family, of which 16 were from Orissa, 22 from Tamil Nadu, and nine from Uttar Pradesh. In Orissa, one user stayed with her husband’s family, while the husband lived elsewhere due to his work; another user stayed alone in a rural area because of a work-related posting. Among the nuclear families in Orissa, three said that although their families were nuclear, their extended families—father-in-law and brothers-in-law—lived nearby.

Information about the type of family was collected to understand the family dynamics in the context of infertility in the case of a nuclear or joint family. Families play a critical role in determining the extent of stigma and exclusion faced by the couple, deciding the couple’s access to health care, and in providing much-needed financial and psychosocial support. The information was sought to determine the influence, both positive and negative, that the type of family had on a couple’s access to ARTs. The interviews with users drew attention to the implications for users, particularly women in a joint family environment.

Hence, the family type or structure played an important role in the entire process. However, it is difficult to arrive at any general conclusion with regard to users living in a joint family having the family’s support, financial and otherwise. Users living in joint families also stated that they faced problems because of their inability to have a child.

VI. Education

Information about the educational levels of couples was collected to see if there were any inter-linkages between levels of education and decisions about marriage, childbearing, and ‘treatment’. Levels of education were also considered important in the context of
information transaction regarding ART procedures and access to information about these technologies.

Nearly 28 per cent of women users were postgraduates and above, followed by 26 per cent who were graduates, and 16 per cent who had completed the higher secondary and secondary levels in school. No information was available about the educational levels of 10 respondents across the three states. However, the educational levels of women users from Orissa were most varied; four women were not literate (the lowest in the whole sample) and six women had completed their post-graduation. The inter-state variation at the level of graduation between women in Orissa and women in Tamil Nadu was apparent, with about 13 per cent women who were graduates in Orissa as compared to 35 per cent approximately in Tamil Nadu.

Hence, the majority of the women accessing ARTs in the sample were graduates, post-graduates or above. The research establishes that looking at education as a variable presents a diverse picture as far as access to ARTs is concerned. ARTs are accessed by users from diverse educational backgrounds.

### VII. Location of residence

Information about the location of residence was collected to explore access to infertility services and to ARTs, variations in the cost of living, and levels of affordability. While the majority of users lived in urban areas (50 per cent), the sample interestingly had more users from rural (31.39 per cent) than from semi-urban areas. Of the 27 users residing in rural areas, 19 were from Orissa, one from Uttar Pradesh, and seven from Tamil Nadu. Five users from Orissa, four from Uttar Pradesh, and seven from Tamil Nadu lived in semi-urban areas. Six users from Orissa, eight from Uttar Pradesh, and 29 from Tamil Nadu resided in urban areas.

Information about the residence or location of users enabled the mapping of the journeys undertaken by them to access treatment for infertility, including ARTs. This was useful to analyse the nature and extent of movement by users who may have left their places of residence to access ‘recommended’ clinics. Some users cited ‘anonymity’, ‘distance from family’, and ‘cost’ as reasons for their choice of clinics in other districts, states, and countries, just as some accessed treatment in cities where they had family/friends. The reasons for the journeys undertaken are discussed in more detail in Chapter 3.

<table>
<thead>
<tr>
<th>Table 6: Educational profile of users (women and men)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>State/ Category</strong></td>
</tr>
<tr>
<td>Women</td>
</tr>
<tr>
<td>Non-literate</td>
</tr>
<tr>
<td>Primary (below 10th grade)</td>
</tr>
<tr>
<td>Secondary (10th grade)</td>
</tr>
<tr>
<td>Higher secondary (12th grade)</td>
</tr>
<tr>
<td>Graduate</td>
</tr>
<tr>
<td>Post-graduate and above</td>
</tr>
<tr>
<td>No information</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)
While most users (70), were from the selected states, a few of those who accessed ARTs in these states were from other states, and even from overseas. This was particularly evident in the context of Tamil Nadu, where 30 per cent of the users interviewed were from other states–from West Bengal, Karnataka, Andhra Pradesh, and Jharkhand–and from the United Kingdom. In Orissa, nearly seven per cent of the users were from Jharkhand and Chhattisgarh. In Uttar Pradesh, one user was from Haryana. Clearly, Tamil Nadu attracted the most out-of-state users, which could be the result of the advanced ART industry in the state compared to Orissa and Uttar Pradesh, where it is comparatively less developed. The 70 users, although from within the sample states, belonged to different districts of the state.

Location or residence of users was an important factor in the analysis of various aspects of the research. For example, rural, semi-urban, or urban locations often determined the distances travelled to access ARTs, influenced the related costs incurred in terms of time and finances, and affected professional and personal lives.

### VIII. Work and occupation

The work or occupation of users has been categorised into primary work, secondary work, and services and others. Primary work includes agriculture and other related work. Secondary work includes manufacturing and production work. The third category ‘services and others’ include other miscellaneous kinds of work. None of the women users were involved in agricultural work.

Data on work and occupation were collected to explore linkages between infertility, ARTs, and work or occupation. Work or occupation detailed here includes paid and non-paid work. This information was sought to strengthen understanding about the possible linkages between occupational ill-health and infertility, that is, if the cause of infertility was in any way a consequence of the work engaged in by users. Finally, the data on work also presented the potential earning capacity of users and indicated the loss of income when they had to give up their work temporarily or permanently.

<table>
<thead>
<tr>
<th>Category / State</th>
<th>Primary (agriculture and related work)</th>
<th>Secondary (production/manufacturing)</th>
<th>Services and others</th>
<th>Currently not working outside the home</th>
<th>No information</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orissa Women</td>
<td>–</td>
<td>–</td>
<td>3</td>
<td>27</td>
<td>–</td>
<td>30</td>
</tr>
<tr>
<td>Orissa Men</td>
<td>3</td>
<td>1</td>
<td>25</td>
<td>–</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>TN Women</td>
<td>–</td>
<td>–</td>
<td>17</td>
<td>26</td>
<td>–</td>
<td>43</td>
</tr>
<tr>
<td>TN Men</td>
<td>2</td>
<td>1</td>
<td>40</td>
<td>–</td>
<td>–</td>
<td>43</td>
</tr>
<tr>
<td>UP Women</td>
<td>–</td>
<td>–</td>
<td>5</td>
<td>8</td>
<td>–</td>
<td>13</td>
</tr>
<tr>
<td>UP Men</td>
<td>1</td>
<td>–</td>
<td>12</td>
<td>–</td>
<td>–</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total Women</strong></td>
<td>–</td>
<td>–</td>
<td><strong>25</strong></td>
<td><strong>61</strong></td>
<td>–</td>
<td><strong>86</strong></td>
</tr>
<tr>
<td><strong>Total Men</strong></td>
<td><strong>6</strong></td>
<td><strong>2</strong></td>
<td><strong>77</strong></td>
<td>–</td>
<td><strong>1</strong></td>
<td><strong>86</strong></td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)
In case the user was involved in a family business, it provided more flexibility and allowed the user to continue dealing with a very demanding ART regimen in terms of time and money in a relatively less stressful manner. On the other hand, a family business also implied joint and collective decision making about whether or not to continue, or to undergo a certain procedure, which was also dependent on a ‘family’ decision.

Seven women were unable to continue working because of the health consequences of ARTs, or because they were forced to take short and long breaks from work because of the time-consuming ART procedures.

The sample reveals that nearly 63 per cent of the women accessing ARTs across the three states were homemakers, that is, they were not working outside the home and were not earning any income. Twenty-five women were working at the time of the interviews, a majority in the ‘services and others’ category. They worked as teachers, software development professionals, entrepreneurs in the hospitality industry, etc. The men worked in varied occupations, including agriculture, daily wage work, and business, both independent and family run.

IX. Income

Details about income and assets were collected wherever possible. The information was sought to strengthen understanding about the class dimensions of users accessing ARTs. Determining class is a complex task, and may not be established by income alone. It is also influenced by ownership of property and varied assets. Hence, information regarding assets owned by users was also sought through interviews.

<table>
<thead>
<tr>
<th>Income range (INR) per month</th>
<th>Rural</th>
<th>Semi-urban</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>UP</td>
<td>TN</td>
</tr>
<tr>
<td>2,000-4,000</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>4,001-10,000</td>
<td>6</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>10,001-20,000</td>
<td>6</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>20,001-50,000</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>50,001-1,00,000</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1,00,001-5,00,000</td>
<td></td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Did not give/ not available</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>19</strong></td>
<td><strong>1</strong></td>
<td><strong>7</strong></td>
</tr>
</tbody>
</table>

*(3 of these were family incomes and hence respondents were unable to give an amount)*

Source: Compiled form data collected during fieldwork (2008-2010)
However, this section presents data about income alone as it was one of the most significant indicators in understanding the nature and extent of access to ARTs and therefore their affordability. Income details given in Table-8 are also categorised by location of users and provide total monthly income as articulated by users. This was done to minimise the difference between income and routine expenses, based on the assumption that day-to-day living expenses vary between rural, semi urban and urban areas, and between states.

Twelve users did not provide any information about their monthly income, nine of the 12 respondents claimed that they did not know the size of their income, or they were not willing to divulge such information, mainly because it was ‘family income’, from which couples can take the amount that is required by them for expenses. However, no specific amount of income is divided between members of the joint family.

Information about sources of income and assets provided significant clarity about the economic implications of ARTs, which has been discussed in detail in later chapters. The analysis of this information shed light on the varied sources that users turned to for covering the expenditure of the procedures that they were undergoing or had completed. For almost all users, whether urban or rural, mere reliance on monthly income would not have sufficed for the treatment. In a few instances, income and ownership of assets also influenced the choice of the procedures undergone by users. Users either opted for a procedure like IUI that costs less, although IVF was recommended, or the provider suggested that the user undergo IUI for reasons of non-affordability, although IVF was the recommended procedure. Thus, trajectory of treatment differed based on the economic background of users.

Considering the high cost of ARTs, it is evident that income is a significant indicator reflecting the affordability of these technologies. As mentioned earlier, and as Table-8 shows, only monthly, or sometimes even annual, income was not always sufficient to access these technologies. Users often resorted to other means to gather financial resources to continue with the ‘treatment’ process.

### X. Years of undergoing ART procedures

Table-9 shows the state-wise variations with regard to the number of years that users have been undergoing ART procedures as well as other treatment for infertility. The majority of the users in the sample, that is, nearly 49 per cent, had been accessing ‘treatment’, including ARTs, for five years or less, followed by nearly 40 per cent who had been trying to address their infertility for five to fifteen years, about six percent who had been trying for 15-25 years, and about one per cent who had been trying for more than 25 years.

<table>
<thead>
<tr>
<th>State/Range</th>
<th>Orissa</th>
<th>UP</th>
<th>TN</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 years</td>
<td>11</td>
<td>4</td>
<td>27</td>
<td>42</td>
</tr>
<tr>
<td>5.1-15 years</td>
<td>16</td>
<td>6</td>
<td>12</td>
<td>34</td>
</tr>
<tr>
<td>15.1-25 years</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>25 years and above</td>
<td>–</td>
<td>1 (28 years)</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>No information</td>
<td>1</td>
<td>–</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
<td><strong>13</strong></td>
<td><strong>43</strong></td>
<td><strong>86</strong></td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-10)
Thus, opting for ARTs was a long and costly process for most users, demanding a time investment of anywhere between zero to 25 years.

The maximum duration of ‘treatment’, 28 years undergone by a couple from Uttar Pradesh who have two children through IVF, the second child was born a year prior to the interview, following a 15-year break after menopause. While the treatment trajectories of most users did not reflect major time gaps between procedures, a few users said that they had taken breaks ranging from a few months to several years, in most instances because of their difficult economic conditions.

As is evident from the socio-demographic profile of users, the research findings reinforce the fact that there is a strong desire for a biological child, and that access to ARTs to achieve this desire transcends the divides or variables of caste, class, religion, age, income, education, etc. Further, this presents a varied picture of users and providers, encompassing diverse and complex causes, motivations, factors, and results.

Section B

Profile of clinics

This section focuses on the size and spread of the ART clinics; their location; their infrastructure; the procedures provided; and the staff and the composition of the team. It also explores interstate and intra-state variations in terms of provision and access. It also discusses the registration and non-registration of clinics, especially with regard to sperm banks, surrogacy, and donor programmes affiliated with these clinics.

Although the term ART clinic(s) gives the impression of these clinics being homogeneous, this is not correct. ART clinics are extremely varied in terms of appearance, outreach, and composition of the team providing the procedures and services, as was highlighted by the study. Thus, given that the understanding of ART as an industry is closely linked to the kinds of facilities and the infrastructure that the clinics are able to provide to the users, this section provides an overview of the clinics in the research sample, which are then further analyzed in the following chapters.

I. Location and access

The research sample of clinics (four in Orissa, 18 in Tamil Nadu, and 21 in Uttar Pradesh), shows the clear spread of these technologies from the metropolitan cities to relatively smaller but burgeoning urban areas. Of the 18 clinics in Tamil Nadu, eight were located in different suburbs of the capital city, Chennai. Four clinics were located in Madurai, two in Coimbatore, three in Salem, and one in Vellore. Out of the four ART clinics in Orissa, one was located in the state capital of Bhubaneswar, one in Cuttack, and two in Rourkela. Out of the 21 clinics in Uttar Pradesh, six were located in Lucknow, three in Meerut, four each in Agra and Allahabad, and two each in Kanpur and Benaras. (Refer Table-10).
The research has tracked the expansion of the ART industry from the larger metropolitan cities and from state capitals like Chennai, Lucknow and Bhubaneswar to the smaller cities of Meerut, Madurai, and Rourkela.

Providers also mentioned a steady rise in the number of users from neighboring rural and semi-urban townships increasingly accessing ART procedures at their clinics. As TNP-13 mentioned:

*A lot of patients come here even from the nearby rural areas and villages. The clinic is located at the periphery of the city. So we get people from the adjoining villages and from other districts. They come from the districts of Theni, Dindigul, Sivaganga, and, of course, Madurai to our clinic.*

As UPP-6, an Agra-based provider, said:

*We get patients from all nearby places and from all over north India – Agra, Jabalpur, Jhansi, Bulandshahar, Delhi, Kanpur, Ajmer, Jammu & Kashmir, Palwal, Meerut, Surat, Noida, Bhopal, and Punjab. Actually, only twenty per cent of our patients are from Agra. The rest are all from outside.*

Similarly, interviews with providers in the ART clinics in Rourkela and Cuttack, also indicated that couples from the rural and tribal belts of Orissa, and also from the neighboring state of Jharkhand, accessed these clinics for ART procedures. (Detailed further in Chapter 6).

II. Clinic location

The ART clinics in the sample were spread across varied locations, including posh areas, middle-class neighbourhoods, and market areas. Many of them were situated in maternity nursing homes, obstetrics and gynaecology clinics and hospitals, large corporate super-specialty hospitals, or were stand-alone clinics.

**Orissa**

The clinic in Bhubaneswar was housed in a large multi-specialty hospital. Of the remaining clinics, two (one in Cuttack and one in Rourkela) were part of hospitals providing gynaecological and obstetric facilities. The clinic in Cuttack was a medium-sized hospital, well established for gynaecological services and ARTs, which it had been providing for almost a decade. Of the two clinics in Rourkela, one was a smaller hospital that had been functioning for about three years and the other was an independent infertility clinic.

**Tamil Nadu**

In Tamil Nadu, 12 of the 18 clinics (seven in Chennai, two in Madurai, two in Coimbatore, and one in Vellore) were housed in multi-specialty hospitals, which had state-of-the-art facilities. Apart from these, there were clinics that were either stand-alone fertility centres (one in Chennai, Madurai and Salem) or were part of smaller hospitals (one in Madurai and two in Salem) that provided obstetric and gynaecology services. It is also interesting to note that one provider in Chennai ran two hospitals, both of which provided ARTs. These were located in two different suburbs of the city, one in an extremely central and commercial part of the city and the other in a distant suburb.
Uttar Pradesh

In Uttar Pradesh, 15 of the 21 clinics were housed in multi-specialty hospitals. Some of these hospitals, located in the smaller cities of Meerut, Allahabad and Kanpur, were comparable with highly sophisticated clinics located in metropolitan cities. Of the remaining six clinics, five were situated in nursing homes (two in Lucknow, two in Meerut, and one in Benaras) that provided gynaecological and obstetric facilities, while one clinic (in Meerut) was an independent establishment that provided services only for infertility. As in Tamil Nadu, one provider in Allahabad owned two clinics, each located in different areas of the same city. Similarly, a provider in Meerut offered ARTs at one clinic and gynaecological services at the other clinic.

Many clinics situated in relatively small cities, such as Meerut, Vellore, Kanpur, Madurai, and Cuttack, could be considered to be on par with those in the metropolitan city of Chennai or in the state capitals of Lucknow and Bhubaneswar. In some cases, they catered to a much larger clientele and operated on a larger scale than some of their counterparts in the bigger cities, in a way negating the need for non-urban residents to access big cities for this purpose alone. Once again, this is evidence that ART clinics in smaller cities act as fulcrum sites in the horizontal expansion of the industry. In this context, there is an absolute lack of data on the number of ART clinics in India.

III. Registration of Clinics

Registration of the clinic and allied facilities, such as sperm banks, nursing homes, and obstetric units, appeared to be a grey area. Information regarding registration or its absence was available for only 21 of the clinics across the three states. Information provided by these clinics also varied widely, from statements that their clinics were registered under different gynaecological societies or with local authorities, or that only certain aspects or facilities of the set-up required registration, to a lack of knowledge regarding the appropriate authorities and registration facilities. While the waiting rooms of several clinics had boards proclaiming that they were registered under the Pre-Conception and Pre-Natal Diagnostic Techniques (PC and PNDT Act), 1994, this point was rarely brought up by the providers when asked about registration.
Registered as part of a hospital

In Tamil Nadu and Uttar Pradesh, given the higher numbers of ART centres located within multi-specialty hospitals or nursing homes and in obstetrics and gynaecology facilities, amongst those providers who responded, five (three in Tamil Nadu and two in Uttar Pradesh) said that the ART centre was registered as part of the hospital and did not require separate registration. As TNP-18 stated:

*There is no need for separate registration. Separate registration is required only if the clinic is carrying out some related research or, I think, if there are some chromosomal or genetic tests that are being carried out.*

Two clinics in Tamil Nadu (in Chennai and Salem) said that the IVF laboratory and ultrasound machines were also registered separately, without giving any further details. The provider of a clinic in Rourkela specifically stated that the clinic was registered with the state-level authorities under the Hospital Registration Act, Orissa. A clinic in Chennai said that the embryologist at the clinic was registered with the Tamil Nadu Directorate of Medical Services.

Registered with other autonomous bodies and societies

Four clinics (two in Orissa and two in Uttar Pradesh) said that they were registered with the Indian Society of Assisted Reproduction (ISAR). The clinics in Uttar Pradesh (one in Meerut and one in Agra) also made special mention of being part of the National ART Registry of India (NARI), a voluntary initiative started by ISAR. In this regard, provider UPP-2 particularly stressed the importance of being registered with these societies:

*It is registered under ISAR, [which] is also accredited by NARI. So the society itself regulates the clinics and makes sure that they are up to the mark.*

Similarly, another provider in Madurai said that the clinic was registered with the Medical Council of India (MCI).

ICMR guidelines

Five providers in Tamil Nadu (two in Chennai, two in Coimbatore, and one in Vellore) and one in Uttar Pradesh (Allahabad) simply stated the importance of the ICMR guidelines without any further elaboration on the requirement for registration. TNP-3 expressed disdain for the unethical practices prevailing amongst ART clinics:

*I looked into the ICMR guidelines before setting up the centre in this hospital. We try to follow the ICMR guidelines in our treatment. I feel that if clinics practise against regulation, they need to shut down their clinics. I think there are unethical practices by people as they are greedy and want to earn more money.*

Similarly, TNP-16 pointed out:

*There is no separate law as such. ICMR has to hold up certain things and take steps to cancel the licence if they practise in an unethical manner. The private practitioners have a different style of operating systems. The ART society [ISAR] requests to send statistics [sic], but it is voluntary in nature. However, there is no position or stand on this.*
Two providers from Kanpur who had only recently started ART centres expressed frustration at the lack of information on registration available in the public domain and emphasized the need for clarity. UPP-22 narrated the difficulty in obtaining information in this regard:

*We made a lot of efforts to find out how and where we should get registered, but could not get any information. We made several enquiries, [and] also wrote to the Chief Medical Officer, but there was no response.*

Two other providers (in Allahabad and Lucknow) expressed their irritation with the need for separate registration for everything, including ARTs. One of them insinuated that this was a money-making exercise on the part of the government. As UPP-8 emphatically stated:

*Yes. Registration is also a problem. Nowadays, clinics and hospitals need to be registered in several different ways. Each process has its own registration. Now even IVF needs a different registration. What is the need?*

Interestingly, one clinic in Rourkela said that it followed the guidelines or code of practice for ART clinics under the Human Fertilization and Embryology Act (HFEA)\(^4\), UK, given the inadequacy of Indian guidelines.

*The HFEA guidelines are followed in our clinic. We do appreciate the efforts of ICMR in bringing out the guidelines, but it has [sic] many shortcomings. Our own conscience is our guideline.* ORP-2

On being asked about registration for affiliated semen banks, two providers said that separate registration was required for semen banks; one clinic had registered under Federation of Obstetric and Gynaecological Societies of India (FOGSI).

The responses of the providers mostly reflected the nature and purpose of registration as perceived by them, that is, as merely a routine legal requirement for the clinic. However, registration could be an important step towards the creation of a system for regulation in the current situation where absolutely no information is available even about the number of ART clinics in the country.

As per the National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India (2005), based on their infrastructure and the facilities that they provide, all the clinics in the sample were required to be registered with, and regulated by, the State Accreditation Authority/State Appropriate Authorities.\(^5\)

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**According to the ICMR Guidelines (2005):**

Clinics involved in any one of the following activities should be regulated, registered, and supervised by the State Accreditation Authority/State Appropriate Authorities:

1. Any treatment involving the use of gametes, which have been donated or collected or processed in vitro, except for AIH, and for IUI by level 1A clinics who will not process the gametes themselves.
2. Any infertility treatment that involves the use and creation of embryos outside the body.
3. The processing or/and storage of gametes or embryos.
5. The term ART clinic used in this document refers to a clinic involved in any one of the first three of the above activities.
However, the lack of clarity among providers regarding the registration of ART clinics was apparent. The ICMR guidelines are currently the only available information regarding registration of ART clinics. Although Section 3.1 of the ICMR guidelines details the requirements of clinics for registration, the non-binding nature of the guidelines and lack of information and ambiguity about the relevant authorities mentioned in the guidelines complicate the matter further. In addition, registration with societies such as FOGSI and ISAR, while important for peer review processes, is not sufficient because these societies may not be able to play an objective role in auditing and regulation. These bodies are formed and mostly run by ART providers, and hence the possible conflict of interest must be recognised.

IV. The World of the ART clinic: Clinic infrastructure, facilities and procedures

IV.1. Infrastructure and facilities

Information about the infrastructure of clinics was gathered through interactions with providers and supplemented by observations by the researchers. In many clinics, the research team was not given permission to visit the facilities. Hence, it was not possible to corroborate the veracity of the information provided by the clinics through the interviews as well as the details given in their publicity material, including brochures, websites, and fliers.

While it was apparent that the infrastructure and facilities of clinics in Tamil Nadu and Uttar Pradesh were more developed and sophisticated compared with those in Orissa, there existed huge variations within each of the states.

The clinics offered a wide range of facilities, pointing to the heterogeneous nature of these entities. The range of facilities provided by some clinics, for example, in places like Meerut, Allahabad, and Coimbatore, were comparable with the facilities offered by sophisticated and advanced clinics located in larger cities. The facilities provided by a clinic in Allahabad (see box) showing that these are almost comparative with the facilities offered by a clinic located in a multi-specialty hospital in a metropolitan city.

IV.1.a. Semen banks

Semen banks within clinics were uncommon, with only 10 of the sample clinics (four in Uttar Pradesh, one in Orissa, and five in Tamil Nadu) from the three states reporting these facilities. Of these, two clinics in Tamil Nadu (one each in Chennai and Salem) and one in Orissa (Bhubaneswar) emphasized that access to the semen bank was only for those users who were undergoing ART procedures in their respective clinics. A large majority of the clinics in the three states sourced sperm from private semen banks.
A wide network of semen banks exists in the country, making it easy for ART clinics to access these banks (see box) rather than having their own banks. This was apparent from interactions with providers in Allahabad and Lucknow, who sourced sperm from Delhi, Secundrabad, Ahmedabad, and Mumbai. A clinic in Chennai sourced from Mumbai and Delhi; a clinic in Varanasi sourced from Aurangabad; and a clinic in Rourkela sourced from Raipur.

In Orissa, only one clinic, in Bhubaneswar, provided sperm-banking facility. However, it did not have a commercial sperm donation programme. Only sperm from users accessing ART procedures in the clinic, as well as from their relatives who were willing to donate, was stored in the semen bank. As the provider ORP-6 noted:

*We also don’t have commercial sperm donors. Males who come to the centre donate sperm. There is a sperm bank associated with the centre. No outside person is allowed to donate sperm.*

Another clinic in Rourkela maintained that it did not have a semen bank, but had college students donating sperm at the clinic.

In Tamil Nadu, five clinics had semen banks, of which three were in clinics in Chennai, Salem, and Coimbatore. One of the clinics in Chennai and the clinic in Salem permitted the semen bank to be used only for the storage of sperm that was through voluntary donation and primarily for the storage of gametes of users who had accessed the facility for ARTs. TNP-4 said:

*We do have our own sperm bank, but we only have voluntary donations, mostly from the couples who come in for treatment. If their gametes are in good condition, we ask them if they would like to donate. I feel doing it any other way is like doing business.*

In Uttar Pradesh, four clinics stated that they had a semen-banking facility. Unlike the other states, the presence of semen banks were spread out, with one each in Lucknow, Agra, Allahabad, and Kanpur.

The presence of a semen bank did not always correspond with the availability of other necessary facilities for ART clinics nor was it indicative of the advanced infrastructure of the facilities. For instance, some of the bigger, longer established clinics in Tamil Nadu and Uttar Pradesh said that they sourced sperm from external private banks.

### IV.1.b. Cryopreservation facilities

Cryopreservation facilities were provided by nearly 56 per cent of the sample clinics in the three states. However, the kind of infrastructure available for cryopreservation varied widely between clinics. While certain clinics in Orissa and Uttar Pradesh had rudimentary freezing facilities, such as ‘cryo-freezers’ for storing semen and embryos,
others, for example, situated in the multi-specialty hospitals, especially in Tamil Nadu (Chennai), had extremely high-tech facilities. Four clinics also reported preservation of oocytes; three of these clinics were situated in Tamil Nadu and one in Uttar Pradesh. One clinic in Tamil Nadu (Vellore) and another in Uttar Pradesh (Meerut), for example, said that they were using a more advanced rapid cooling technique called vitrification. In Orissa, two clinics, one each in Rourkela and Bhubaneswar, had cryopreservation facilities.

In Tamil Nadu, 12 clinics had cryopreservation facilities. Only one clinic in the sample (in Chennai) did not have a cryopreservation facility; two clinics in Salem and one each in Vellore, Madurai, and Coimbatore provided cryopreservation. In Uttar Pradesh, cryopreservation was available in 10 clinics; all the four clinics in Allahabad stated that they had the facility; two clinics each in Lucknow and Agra, as well as one each in Meerut and Benaras, offered cryopreservation. Three providers in the state (two in Lucknow and one in Kanpur) preferred using fresh gametes, which according to them had higher chances of success. UPP-23 said:

_Earlier, we used to cryopreserve but observed that the quality was considerably reduced when they were thawed to use them again. Also, most of the cryopreserved embryos or gametes never got used and it costs a lot to maintain them. So we decided to discontinue freezing and now always use fresh gametes and embryos._

UPP-2, who used the more advanced technique of vitrification, was not positive about the success rates using cryopreserved embryos and did not use them, but was storing them nevertheless:

_The vitrified embryos can be used by the patients in the next cycle instead of making fresh ones. The success rates, however, are much lower with frozen embryos, and I generally don’t recommend it to any of my patients. So far none of them have been reused. They are only stored._

The popularity and wide availability of cryopreservation facilities for embryos and eggs within clinics may stem from the difficulty in sourcing egg donors as compared with sperm donors. Hence the cryopreservation facility was perceived almost as a necessity for preserving embryos for subsequent cycles or in case of egg-sharing programmes (discussed in Chapter 5). However, there were extremely diverse opinions about the quality of stored

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<table>
<thead>
<tr>
<th>Table 11: Semen bank and cryopreservation facilities in the clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>State</strong></td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Cuttack</td>
</tr>
<tr>
<td>Bhubaneswar</td>
</tr>
<tr>
<td>Rourkela</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
</tr>
<tr>
<td>Tamil Nadu</td>
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<td></td>
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<td></td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
</tr>
<tr>
<td>Uttar Pradesh</td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008–10)
gametes and embryos, and their effective use in the future, which has serious implications for additional costs incurred by users as well as for the outcomes of the procedures.

The charges for cryopreservation were in addition to the costs of the ART procedure. The maximum duration for which gametes were cryopreserved was two years for most clinics. Some providers stated that in exceptional cases, gametes could be stored for longer periods. For example, TNP-3 said that the duration of the storage depended on the age of the user, and was flexible. She cited the instance of a woman who had developed cancer when she was 18 years old and whose eggs were stored for more than two to three years.

**IV.1.c. Pharmacies**

In-house pharmacies were also a common feature both within and across the different levels of clinics, with 37 of the 43 clinics having in-house pharmacies. The provision of medicines within the premises of the clinics was explained as a beneficial and convenient facility for users. It was claimed that provision of substantial discounts in the cost of medicines encouraged users to purchase these drugs from in-house pharmacies. This comes as no surprise given that the costs of drugs in ART procedures contributed the most to the overall costs of the procedure. The central role played by drugs in these procedures was apparent and was reinforced by the overwhelming presence of medical representatives in ART clinics. In fact, informal interactions with them by the research team were important sources of information regarding other ART clinics in that given area.

**IV.2. Procedures and programmes on offer**

**IV.2.a. IUI, IVF and ICSI**

While all the 43 clinics profiled in the three states had the facility to provide IUI and IVF techniques, they also reported offering a range of other diagnostic procedures, including laparoscopy, hysteroscopy, endoscopic surgery, and ovarian drilling, along with variations of IVF. Two clinics in Uttar Pradesh (one in Lucknow and one in Kanpur) had only just set up their centres and were in the process of registering users for IVF, although they had been carrying out IUI procedures for many years.

Further, various combinations of procedures were also observed. For instance, a provider in Rourkela stated that they were trying an experimental method where a combination of IVF and ICSI were both carried out. As ORP-2 stated:

*Now we are also trying a different method. We use half of the eggs retrieved for the IVF procedure and the other half for ICSI. For example, if we retrieve 10 eggs, then we carry out IVF for five eggs and ICSI for the other five. This also increases the chances of success, so that if one procedure fails, there is a chance of the other being successful.*

Similarly, although other providers did not particularly describe instances of trials and variations in methods, the narratives of users often highlighted a complete lack of standardization in ‘treatment’ protocols, which were often left to the discretion of providers. These combinations included IVF–ICSI, conversion IUI (where the user starts on an IUI protocol but at a later stage of follicular development, it is decided to carry out IVF
instead); several IVF cycles followed by IUI, and newer techniques such as Intracytoplasmic Morphologically-selected Sperm Injection (IMSI) and In Vitro Maturation (IVM).

ICSI was also becoming a standard facility provided at many clinics. For instance, even in the small sample size, only nine providers out of the 43 across the three states said that they did not offer ICSI. One clinic in Meerut said that although ICSI was offered to women and couples, the actual procedure was carried out at a different hospital in Delhi. But the clinic also said that it took complete responsibility, both before and after the procedure.

The reasons for not offering ICSI by two clinics in Madurai and one in Rourkela were attributed to the high costs that the clinic would have to accrue, on the one hand, and to the low probability of returns, on the other. As provider ORP-1 said:

Providing the technique of ICSI would mean spending an additional Rs 14–15 lakh on infrastructure and set-up, which I do not want to do. To me, not that many patients come with infertility problems, and even those who come do not want to spend a large amount of money.

Moreover, although the other three clinics in Orissa reported offering ICSI, no one amongst the sample of users who had accessed ARTs at these centres, reported having undergone ICSI, even in cases of male infertility. This can also be attributed to the lack of information on the part of the users regarding the exact procedure they have undergone.

The growing use of ICSI, however, does not take into consideration the potential adverse outcomes or health risks that are associated with the procedure. The ICMR guidelines address the concerns associated with ICSI:

This technique has never undergone critical evaluation in animal models before introducing it to treat human infertility. There are, therefore, some genuine concerns in regard to the use of ICSI . . . Although ICSI has revolutionized the treatment for male infertility; its widespread use has raised medical concerns about the transfer of genetic defects to future generations. . Because ICSI bypasses a part of the process of natural selection and certain early developmental mechanisms, concerns are expressed on the possible reproductive health risk(s) to the offspring. (ICMR, 2005: Section 1.6.11.2)7

IV.2.b. Preimplantation Genetic Diagnosis (PGD)

The technique of PGD was offered by three clinics—two in Tamil Nadu and one in Uttar Pradesh—for prenatal screening of the embryo prior to implantation. None of the four clinics in Orissa offered this facility. A majority of the providers perceived the procedure to be highly specialised and sophisticated due to the requirement of extensive investment, infrastructure, and expertise. As UPP-8 said:

PGD is a very sophisticated procedure. Most clinics cannot do it, and even if they say they do it, they are lying. It is done in AIIMS, Delhi and in Bombay.

A provider in a multi-specialty hospital in Tamil Nadu said that the cost of setting up of PGD facilities was close to Rs 4 crore, which made it a nearly unaffordable investment
for most centres. Although one clinic in Lucknow had listed PGD in its publicity material, during the interview, the provider said that it was not available due to inadequate funds.

The clinics that offered PGD projected it as a remarkable achievement in all their publicity material. For instance, TNP-18 claimed to be the first in the state to have PGD facilities. UPP-6 claimed higher success rates with PGD and also offered discounts on the costs. The clinic claimed that use of PGD in women of advanced reproductive age increases success rates.

Whether or not PGD improves success rates is a highly contested question. Studies\(^8\) carried out in the West have raised concerns about PGD causing significant damage to embryos, resulting in poor outcomes and in lower chances of a live birth. Further, there are concerns regarding the reliability of PGD and its high costs. Claiming higher success rates with PGD, and providing concessions, is a clear promotional strategy. In the context of existing scientific skepticism and the absence of regulation, this raises ethical concerns.

Given the growing variations even within ARTs, it is important to look at techniques like PGD and the profile of the clinics offering them. PGD has the potential to be misused for pre-selecting the sex of the embryo and the desired traits, before implantation, and hence raises concerns about sex-selection and eugenics. With the advent of PGD, disability selection has also acquired different connotations.

### IV.2.c. Other procedures

Procedures for sperm aspiration such as Percutaneous Epididymal Sperm Aspiration (PESA), Testicular Sperm Aspiration (TESA), and Microsurgical Epididymal Sperm Aspiration (MESA), Assisted Hatching, Blastocyst Transfer, Gamete Intra-fallopian Transfer (GIFT), and Zygote Intra-fallopian Transfer (ZIFT), were provided by at least 11 clinics in the sample—four in Tamil Nadu (all four in Chennai), six in Uttar Pradesh (two in Meerut, two in Agra, one in Lucknow, and one in Allahabad), and one in Orissa (Bhubaneswar). However, it was not possible to ascertain the total number of clinics from the sample that provided these procedures, as it was not possible during the interactions to cover an exhaustive list of every procedure available at each clinic. Further, not all the procedures were offered by each of the 11 clinics.

### IV.2.d. Surrogacy and donor programmes

#### Surrogacy arrangements

Twenty of the 43 clinics—one in Orissa, ten in Tamil Nadu, and nine in Uttar Pradesh—arranged surrogacy. Half the clinics said that they arranged the surrogacy entirely, while the other half stated that they provided procedures for surrogates and users only when the surrogates were arranged by the users themselves. They claimed that they did not get involved in any transaction between the intended parents and the surrogates.

<table>
<thead>
<tr>
<th>Implantation Rate (%)</th>
<th>Pregnancy Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-PGD</td>
<td>40</td>
</tr>
<tr>
<td>PGD</td>
<td>66</td>
</tr>
</tbody>
</table>

Source: Field notes: Observations at UPP-6’s clinic.
In Orissa, the lone clinic that provided ART procedures for surrogacy did so only if the users arranged for the surrogates themselves. The provider said that the numbers of surrogacy cases were few and far between and that the clinic had seen only three or four such cases. ORP-2 further asserted that this was not a commercial programme:

Surrogates are mostly relatives (sisters or sisters-in-law). At present, we have two cases of surrogacy. In both, the sisters-in-law are acting as surrogates. The clinic is not involved in the payment for surrogacy. It is between the couples and the surrogates. Since the surrogates are generally relatives of the couples, it is best that we do not get involved. We do not provide for commercial surrogates.

In Tamil Nadu, seven clinics (five of which were located in the state capital) arranged surrogates, the highest number among the three states. Three clinics provided services if surrogates were arranged by users. TNP-4 said:

We do not arrange for surrogates for the patients, but if the patients require a surrogate, they themselves have to arrange for one. Whether they do it commercially or altruistically, it’s up to them. Once they get the surrogate, however, we do have a certain protocol on the basis of which we might accept or reject her. This applies for donor eggs as well as surrogates.

A majority of these clinics were accessed by non-resident Indians (NRIs) and also by some non-Indians for surrogacy arrangements. One clinic had plans of starting services for surrogacy soon. A clinic in Tamil Nadu seemed ‘surrogacy savvy’ and promoted itself as ‘the largest and most successful ‘All in One’ medical, non-agency provider of surrogate services in India, and one of the leading surrogate services in the world.’ The clinics also claimed (on their websites):

For those that would also like to meet with potential surrogates at the same time, a prior notice will be required in advance of your visit so that the surrogates may be present. . . .

Couples living nationally and internationally have successfully become parents by working with XXX. Our surrogate database is certainly the most comprehensive because we verify our surrogates’ credentials and availability each month. This high-quality, highly successful service is provided to obtain the finest result and [to] make surrogate pregnancy an affordable option for those who need it.

In Uttar Pradesh, three clinics (one each in Lucknow, Agra, and Meerut) arranged surrogates themselves, while six said they offered surrogacy programmes only in those cases where users were able to arrange for their own surrogates. Amongst those who were engaged in surrogacy arrangement programmes, not all were of a commercial nature. For instance, although the clinic in Meerut arranges for surrogates, it is not involved in the actual financial transaction between the surrogate and the intended parents. As UPP-2 stated:

We also arrange for surrogates. In fact, we had three surrogates in our last batch. However, we don’t look into the payment of the surrogate at all. We simply source the surrogate and then the money matters are discussed between the patient and the surrogate. We have nothing to do with it. Sometimes, the patients also bring their relatives as surrogates.
Among the 23 clinics that were not involved in any kind of surrogacy arrangements, one was contemplating starting services for surrogacy soon and two more clinics stated that they were open to the idea, but had not provided surrogacy services thus far. The remaining stated moral, legal, and health reasons for non-provision. One of the providers in Kanpur did not provide services for surrogacy, but referred users to a well-established clinic in Ahmedabad where the provider had undergone training for ARTs. As UPP-21 said:

*I feel there is a genuine requirement for surrogacy. There are women who have had hysterectomies, have agenesis, that is, they cannot conceive even with IVF. So surrogates are sometimes really needed. But with so many unethical practices, it is difficult to get authentic surrogacy services. As of now, [we are] not going to start with surrogacy. Instead, we refer them [users, clients] to Dr XY in Ahmedabad. I was trained at that centre.*

Few providers across the three states were aware of the fact that surrogacy was linked to poverty and the potential exploitation of the surrogate. They shared their opinion on this question:

*We aren’t doing much of surrogacy now. There are controversies surrounding it, regarding the guidelines/bill on surrogacy. We decided to therefore wait and watch. As far as I am concerned, surrogacy must be used in the rarest of rare situations. The guidelines should be followed strictly, as it raises many ethical issues. In a way, commercial surrogacy is easier. The woman surrogate is in it for the money and she is keen on collecting the money after giving up the child. In such a case, there is a clear understanding and there are usually fewer complications.* TNP-6

*The health of the surrogate can be jeopardised and there is no provision of insurance, etc. for her. It is sad that the surrogate due to financial pressures, decides or may even be pushed (by her family), into becoming a surrogate; and they would keep doing it because of the money. Poverty and illiteracy are the main reasons why surrogacy is flourishing in India. I also believe that no woman would get into surrogacy if she was aware of the emotional, physical, and medical risks that she is taking.* TNP-4

*It’s far too complicated. Anyway, who would agree to carry someone else’s child for nine months? For a simple blood donation, people think so much; surrogacy has so many other complications. She gets emotionally attached. What happens if the child is born abnormal? What will she do if the parents abandon the child? The poor surrogate can’t even leave the child, since she gets so attached.* UPP-12

There is no doubt that the services are expanding as is evident from the clinics already providing surrogacy in the sample as well as those that are planning to start offering this service. ‘Market’ and ‘demand’ were the main concerns of the clinics that had not yet started the service, in addition to the legal and health issues that providers seemed wary of handling. It was also surprising that in spite of the ICMR guidelines explicit prohibition against the involvement of ART clinics in sourcing the surrogates or playing any role in arranging the surrogacy contracts, clinics were very much involved in sourcing the surrogates, pointing once again to the lack of regulation in the ART industry. Clinics had also found a way of minimising legal complications, at least for the present, by permitting users to bring their own surrogates.
Table 12: Arrangement for surrogacy and donor gametes

<table>
<thead>
<tr>
<th>Location</th>
<th>Surrogacy programmes</th>
<th>Donor programmes</th>
<th>Both arranged by clinic, which allows users to bring their donors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Arranged by clinics</td>
<td>Arranged by users</td>
<td>Arranged by clinics</td>
</tr>
<tr>
<td>Bhubaneswar</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Cuttack</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Rourkela</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Orissa Subtotal</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Chennai</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Madurai</td>
<td>1</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Vellore</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Salem</td>
<td>1</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Coimbatore</td>
<td>–</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Tamil Nadu Subtotal</td>
<td>7</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Lucknow</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Agra</td>
<td>1</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>Meerut</td>
<td>–</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Allahabad</td>
<td>–</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Benaras</td>
<td>–</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td>Kanpur</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>Uttar Pradesh Subtotal</td>
<td>3</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>10</td>
<td>24</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008–2010)

Donor programme

The donor programme caters primarily to the need for sperm, eggs, and embryos through donation, in situations where the user’s gametes cannot be used. The research findings showed that 34 of the 43 clinics arranged for donor gametes. Clinics that had donor programmes arranged the sperm, eggs or embryos for users; sperm was usually obtained from external semen banks where the donors were anonymous.

In Orissa, three clinics (one each in Rourkela, Bhubaneswar, and Cuttack) said that they arranged for gametes as well as permitted users to arrange their own donors. ORP-6 from Bhubaneswar where an incentivised egg donor programme was on offer stated:

_We don’t have any commercial donor programme. Many women who feel that they would not like to have any more children in future, come for donating eggs and we provide them with [a] family planning operation._ ORP-6

In Tamil Nadu, 12 clinics arranged for donor gametes and four other clinics allowed users to bring their donors and also arranged for gametes when required. In Uttar Pradesh, 12 clinics did not permit users to bring their donors and arranged for the gametes. Five
clinics followed both procedures—arrangement by users for donors as well as by the clinics. One clinic in Allahabad said that it permitted donors only if they were arranged by users.

Three providers from Uttar Pradesh (two from Lucknow and one from Kanpur) stated their preference for ‘fresh’ sperm as the success rate with this was higher. One of these providers did not have successful experiences with cryopreserved gametes and had hence discontinued the facility at her clinic. All three clinics said that they arranged for donors locally. One clinic had even advertised for egg donors in a local magazine but the response had been dismal.

Approximately 10 providers said that users preferred anonymity of sperm donors. Providers also stated that users preferred their relatives, friends, and other known persons for egg donation. Sourcing of sperm was perceived as relatively easier than sourcing of eggs. Hence, a substantial number of clinics conceded to making arrangements for donors, particularly of eggs. As shown in Table-12, twelve clinics allowed both clinic-organised donors and user-arranged donors. These clinics mostly sourced sperm from external semen banks, while users were encouraged to arrange egg donors on their own.

While many clinics have deliberately refrained from providing these facilities because of legal and other complexities, doctors, especially in smaller cities, cited the non-preparedness or unwillingness of people to come forward as commercial donors and surrogates. UPP-22 described the challenges in sourcing sperm donors:

We tried to approach different groups of potential donors. We met with groups of doctors, students, and other professionals to orient them about sperm donation. We found students were more open to and understanding about this than others. It was difficult to convince many people as there are many myths that make them apprehensive about sperm donation, like they may face ‘weakness’ later in life or that it might harm their health. We had to rope in andrologists and psychiatrists to explain things to them. We have to fight these myths. We are still very backward and far behind developed societies in this regard.

IV.3. Clinic staff

The composition of the team, too, varied depending on the size and scale of the clinic. While larger clinics that were part of multi-speciality or corporate hospitals and well-established clinics reported having complete in-house teams. Comparatively, newer and smaller clinics recorded a higher number of consultant doctors, with the presence of only one or more in-house ‘specialists’. The ICMR guidelines (Section 1.5) describe the importance of a well-qualified team:

The practice of ART requires a well-orchestrated teamwork between the gynecologist, the andrologist and the clinical embryologist supported by a counsellor and a program coordinator/director. This staff requirement would be mandatory for Level 2 and Level 3 clinics. In the case of small Level 2 and Level 3 clinics, the services of the andrologist, the clinical embryologist and the counselor could be shared.\(^9\)
On being asked about the requisite staff composition for the running of an ART clinic, almost all providers highlighted the importance of a well-trained and experienced ‘infertility specialist’ or gynaecologist and embryologist, while some also included counsellors, andrologists, pathologists, lab technicians, nurses, and administrative staff. Although the teams of the clinics profiled in the research consisted of varied personnel, in this section particular emphasis has been placed on only those staff who were directly engaged in the provision of ARTs. Further, despite the specific mention of the importance of an andrologist by some providers, details regarding them and other personnel were not always available.

IV.3.a. The infertility specialist: the gynaecologist
All 43 ART centres across the three states reported having in-house gynaecologists who also had additional specialisations in obstetrics, micro-surgery, laparoscopic surgery, embryology, etc. One clinic in Orissa (Rourkela) and two clinics in Uttar Pradesh (Allahabad and Benaras) also had visiting gynaecologists in addition to those available in-house. The senior-most gynaecologist was also either the founder of the clinic or the director/manager of the centre (particularly in the case of those clinics located in multi-specialty hospitals). Interestingly, in most cases, the same member was also referred to as an ‘infertility specialist’. The term ‘specialist’ in this regard is laden with ambiguity.

On being asked about the training or ‘specialisation’ required for an individual to set up an ART practice, the responses received were extremely varied. Some providers believed that specialised training was required for IVF and ICSI, while others felt that participation in workshops and seminars was sufficient training. Some providers were able to give information on the training courses available, while most stressed the need for praxis and experience to be gained by training under senior and experienced infertility specialists in the country. Other providers valued the training received at foreign clinics and institutes much more than the training provided by similar Indian programmes. A number of providers in the sample had undergone training abroad where they had worked closely with experts—in Germany, Australia, the UK, Singapore, Korea, Denmark, etc. Some of the providers at the newer clinics said that they had undergone training in well-established ART centres in different states. Providers talked of their participation in seminars and workshops on ARTs, organised by ISAR and other institutions, which was useful in enhancing their knowledge and skills on this topic.

Providers in Tamil Nadu and Uttar Pradesh mentioned existing courses in reproductive medicine that had been initiated by teaching hospitals and clinics. There was talk of potential tie-ups between medical universities and ART clinics. One clinic in Tamil Nadu even provided training in counselling specific to ARTs in the local languages. In contrast, this was completely absent in Orissa. Providers also talked of short courses offered by FOGSI on this subject.

IV.3.b. The embryologist
Many clinics did not have an in-house embryologist; 33 per cent of the clinics that responded had consultant embryologists. Clinics that had consultants or visiting embryologists, in most cases, only stated the place (a foreign country or the city) from which the embryologist visited and the number of years of experience, without providing any further details. Clinics claimed that their embryologists were often from larger clinics in the same city, or the same
In Orissa, three of the four clinics had their own embryologists. One clinic had an embryologist visiting them for the procedures, in addition to their in-house staff. No information was available for one clinic in the state.

In Tamil Nadu, ten clinics, of which six were located in Chennai, had in-house embryologists. Two clinics in Salem and three in Madurai had visiting embryologists. No information was available about the remaining three clinics.

In Uttar Pradesh, ten clinics had their own embryologists, seven had visiting embryologists, and no information was available for four clinics. Of the seven, two clinics each in Lucknow and Benaras, and one each in Meerut, Allahabad and Agra, had visiting embryologists.

In the course of the study, it was found that veterinary and agricultural universities offer courses in human embryology and oocyte handling, claiming the provision of extensive hands-on training on animal models. One such university was located in Maharashtra and claimed to have produced the first IVF calf! The general perception among some providers was that since animal embryology was so close to that in humans, it was a reasonable way to attain maximum training before actually moving on to working with humans, specifically women.

Many veterinarians and zoologists go in for embryology after a point. This is because there is very little scope in veterinary science. Further, they have a lot of practice by trying out IVF techniques on animals. The 'make-up' of animals and the technique to be used are the same. They cannot practice on people but they can on animals. Those animals are not going to protest nor talk back. Hence most embryologists have a veterinary or zoology background. TNP- 37

Though there are many zoologists trained in animal embryology, there are very few people trained in human embryology. So since I was already a pathologist, I was comfortable with the technology part. I could well operate microscopes and other lab equipment, while my fellow trainees were still struggling with them. Then I kept updating my knowledge and skills through trainings and conferences. My PhD is also in embryology. UPP-22

The above trends highlighted by the research study indicated increased interest in reproductive medicine, including embryology, thereby pointing to the expanding
ART industry and to its growing needs, particularly in the area of qualified and technically efficient human resources. The ICMR Guidelines have laid down the pre-requisites for qualifying as an ART provider and described the qualifications, skills, and roles of gynaecologists, embryologists, etc. The guidelines even recommend the testing of the knowledge and skills of embryologists by the relevant authority.

However, in the absence of binding norms and regulated practice, it was evident that providers decide upon their individual choice of training in India or overseas for varied durations of time as per their convenience.

IV.3.c. The counsellor

‘Medical treatment and counseling are not separate but interlinked and equally important.’ (Kemeter, 1998: 1099)\textsuperscript{10}

There are different opinions about who should counsel. Ahuja (2009) in his paper ‘Counseling in Infertility’ asserts that although there is no agreed set of professional criteria for counsellors associated with infertility or ART clinics, counsellors should at least have professional training in mental health and in the medical and psychosocial aspects of infertility.\textsuperscript{11} Not only do the ICMR guidelines (2005) state the importance of the ART team for different levels of clinics (discussed earlier in this chapter), but also specify the requisite qualifications:

\begin{quote}
A person who has at least a degree (preferably a postgraduate degree) in [the] Social Sciences, Psychology, Life Sciences or Medicine, and a good knowledge of the various causes of infertility and its social and gender implications, and the possibilities offered by the various treatment modalities, should be considered as qualified to occupy this position. The person should have a working knowledge of the psychological stress that would be experienced by potential patients, and should be able to counsel them to assuage their fears and anxiety and not to have unreasonable expectations from ART. A member of the staff of an ART clinic who is not engaged in any other full-time activity in the clinic can act as a counselor.\textsuperscript{12}
\end{quote}

However, on being asked about the qualifications of counsellors, many providers maintained that qualifications were not important and what was, in fact, more important was that the counsellor should understand the ‘psychological trauma and stigma’ of individuals and couples experiencing infertility and should be able to give information to the users of these technologies in a simple manner. While no generalised conclusion could be drawn regarding this aspect, the qualifications of counsellors across the clinics ranged from professional counselling degrees, to hands-on training, to the providers themselves taking on the role, which was most often the case.
Amongst the clinics profiled as a part of the research sample, in Orissa (Rourkela), only one had a professional counsellor who was also the embryologist. Here, too, the counsellor had no formal training in counselling, albeit he/she had received hands-on training under the provider. It was also the only clinic where a separate room for counselling was available. In all the other clinics, providers or support staff provided information to couples.

Similarly, in Uttar Pradesh, only two clinics reported having full-time professional counsellors; one of the two clinics (Kanpur) also had a qualified psychiatrist. At the other clinic (in Allahabad), the provider asserted that the counsellors had hands-on experience and, although not qualified counsellors, were well equipped to take on the responsibility.

No, not in counselling, but they know the field very well. They have been working with patients for so long and are able to counsel the patient very well. They are obviously very aware of the nitty-gritty of the process. They counsel the patient about their problem. UPP-8

While it was difficult to get information regarding counsellors from four clinics in Uttar Pradesh, at all the other 15 clinics, the ART providers themselves provided the information to users. In one clinic (Agra), counselling and the provision of information were carried out by the provider along with other staff members, including what the provider described as a ‘trained’ receptionist and other junior doctors.

Tamil Nadu presented a slightly different picture in this regard. Five clinics in Tamil Nadu (one each in Chennai, Salem, Vellore, and two in Coimbatore) reported having full-time professional counsellors. Of these five clinics, three mentioned having counsellors qualified in psychiatry and psychology to attend to the psychosocial needs of users accessing ARTs at their clinics.

In all the other 13 clinics, the providers along with other staff members reported providing information to users. In one such clinic (Chennai), the provider mentioned that the clinic had a counsellor, who was on leave at the time and had been replaced by another gynaecologist for the interim. At another clinic (Salem), the provider mentioned the presence of a male ‘biologist’ who attended to male users and counselled them about the ART process. Similarly, other clinic staff members, particularly nurses and junior doctors, were often given the responsibility of ‘providing information or talking’ to users after the initial consultation with the provider.

A clinic in Tamil Nadu, laid great emphasis on the process of counselling. It was amongst the only three clinics in the entire research sample to have a qualified counsellor on board to deal with the psychosocial needs of users accessing ARTs at the centre. In addition to the one-on-one counselling provided to users, the centre also had facilities for group counselling and video counselling sessions, where important information was made available. Increased attention was also paid to the psychological needs of users. Information and counselling were provided in several languages, including Bengali, Hindi, Telugu, Tamil, and English. An interpreters where possible were also available for these counselling sessions.

As TNP-2’s brochure proclaimed:

The moment the couple steps into XY Clinic, our nurse coordinators are their primary contact to provide personal support and guide them through the cycle treatment. They are available to answer any questions and will be there to take the patient step-by-step through the treatment programme.
Except for three clinics in Tamil Nadu, where there was strict adherence to the standard protocols, in all three states counselling was provided by a range of people with different educational qualifications. This points to the lack of mandatory or standardized training required to be a counsellor, as also to the lackadaisical approach adopted by ART clinics towards the all-important aspect of counselling and to the provision of information to users, evidence of a more perfunctory approach with a view to minimising the time spent with individual users.

**IV.3.d. ‘Flying’ doctors and specialists**

Interestingly, with the expansion and penetration of ART clinics into smaller towns very often lacking the necessary physical infrastructure and the requisite human resources, the demand for consultant specialists is consistently high. An immediate result of this ever-growing demand is the creation of a subset of ‘flying’ doctors and specialists, who mainly consist of so-called infertility specialists, embryologists, and other staff, who in most cases are either the heads of more established ART clinics, or regular staff at these clinics, or simply consultants. The term ‘flying’ doctors is used here to depict the nature of their movement from bigger cities and towns to more remote areas; or within the same city or town. While some may act as regular visiting staff, others are only called based on the requirements of the clinics.

Moreover, it was also found that this trend was not always unidirectional (from big city to small town) but that there was also considerable movement of providers between small towns as well. This trend was well established in Uttar Pradesh. Certain providers in Uttar Pradesh said that they collaborated with other ART clinics, which they referred to as collaborative partners, in smaller towns to expand their outreach. For instance, providers from an ART clinic in Agra provide ‘technical’ assistance for IVF and ICSI batches to other clinics, which they call ‘collaborative centres’, across Uttar Pradesh (Bareilly and Gorakhpur) and Punjab (Ludhiana and Ambala). Similarly, the brochure of another clinic boasts of ‘having taken these technologies from Agra to other towns like Bareilly, Meerut, Allahabad (Uttar Pradesh) and Jalandhar (Punjab), where the provider consults at local clinics’. A provider in Allahabad reported going as a consultant to clinics in Delhi and Noida, whereas a provider in Agra said that she was working as a consultant at a government hospital in Delhi that had recently started providing ARTs. Interviews with providers in Allahabad and Benaras further corroborated this trend, revealing that providers, particularly senior doctors were often shared amongst clinics, thus also affecting the referral patterns within the state.

**Conclusion**

The sample of 86 users and 43 clinics that provide ART services in the three states that are profiled here emphatically points to the expansion of the ART industry. The sample reveals the nature of the clinics, and the diversity in their infrastructure, facilities, and human resources across the states, and also within the states. This heterogeneity, along with the lack of any form of enforceable regulation or recordkeeping, raises many concerns and challenges with regard to the need for standard protocols for ART clinics in India.
1 Family income refers to the joint or collective income that is earned by members of a family either through a joint business, or through joint ownership of assets, or when the income earned by members of a family is pooled together and may be accessed as and when the need arises.

2 The Indian Society for Assisted Reproduction (ISAR) is an autonomous body of gynaecologists, scientists, obstetricians etc. interested in the field of assisted reproduction and related research with a mandate to make assisted reproduction easily available to needy infertile couples irrespective of caste, colour, creed and social status and to promote, sponsor, assist and organise easy access to assisted reproduction and carry out research in any aspect related to assisted reproduction and family welfare.

3 The National ART Registry of India (NARI) is a voluntary registration initiative for clinics offering assisted reproduction started by ISAR.

4 The Human Fertilisation and Embryology Authority (HFEA) as per the Human Fertilisation and Embryology Act is the UK’s independent regulator overseeing the use of gametes and embryos in fertility treatment and research. The HFEA licenses fertility clinics and centres carrying out in vitro fertilisation (IVF), other assisted conception procedures and human embryo research. Retrieved on October 20, 2010 from http://www.hfea.gov.uk/2070.html

5 Indian Council of Medical Research (ICMR). (2005). Chapter 3, Section 3.2.5. National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author

6 The facilities in a clinic’s reception and waiting area, the services offered, and the overall infrastructure were considered in determining the level of sophistication of the facilities.

7 Indian Council of Medical Research (ICMR). (2005). Indiscriminate use of ICSI. National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author


CHAPTER 3

Infertility and Trajectory: Many Roads, One (Elusive) Destination

Although fertility is directly influenced by a set of biomedical and environmental factors, there are perceptions of infertility that stem equally from social structures and communities, or from ‘personal, interpersonal and social and religious expectations’ (WHO, 2004)\(^1\). As Ganguly and Unisa (2010:131), point out, ‘The ease with which women can be labelled infertile or resist the label, the experiences of childless women and the process of seeking solutions for infertility all go beyond the biological fact of reproductive impairment.’\(^2\)

This chapter examines the diagnosis and perceptions around infertility, as well as the treatment choices made by couples seeking fertility, and is divided into two sections.

Section A of the chapter looks at the biological and social construction of infertility: beliefs, perceptions and the associated stigma around infertility, as well as the coping mechanisms adopted by users. It also explores trends and attitudes around infertility based on the views of the medical fraternity, users, as well as the community\(^3\).

Section B of the chapter analyses the trajectory of infertility treatment(s), including the ART procedures sought by users. It examines the complex and multidirectional journeys of users during the ‘treatment’ process, which include but are not limited to ARTs, and the factors influencing the twists and turns in these journeys.

**Section A**

This section presents the marital and obstetric intentions and histories of users, and highlights what they perceive as ‘infertility’, and whether and how it deviates from standard medical definitions of the same. Further, it investigates their conceptions and misconceptions regarding causes of infertility, particularly any gender-specific causes, and how this understanding guides their decisions to seek treatment. We also describe how couples’ experiences fit into, and are coloured by existing social and cultural norms around fertility, expectations and the resultant taboos surrounding the failure to conceive. The diagnosis of infertility is both highly debilitating and gendered; this is evident in users’ narratives of stigma and violence, as well as, in providers’ ‘prescriptions’—both medical and social, and community practices and their symbolism. This also marks the beginning of users’ journeys in pursuit of a biological child, the of which trajectory is explored in the next section.
I. Infertility: Definitional dilemmas and their implications

I.1. Perceptions of the medical fraternity

The study revealed variations in the understanding of infertility amongst the medical community. Amongst gynaecologists who are generally the first point of contact for infertile couples, there seemed to be no particular consensus regarding the reference period for infertility. The reference period used by gynaecologists to identify infertility ranged from one to five years. Some of them explained this understanding as based on variables such as age at marriage, past obstetric history, ‘genetic disposition’ towards other medical problems that may lead to infertility, frequency of cohabitation etc. A change in the reference period, from an earlier understanding of three to five years, was also pointed out. As gynaecologist UPP-26 categorically pointed out:

_Earlier, a two year time period was alright, but nowadays with all the problems and the increasing rates of infertility, one year is right. The sooner people find out that there is a problem and the sooner they get help, the better it is._

Gynaecologist TNP-33 explained:

_I feel that it should be at least two years of trying before you see a doctor, and even then it depends on a lot of factors. The most important factor is that the husband and wife live together, because very often the husband stays away on work and comes to visit the wife occasionally._

While no particular consensus was observed amongst ART providers either, the WHO/ICMR definition of infertility, with a reference period of one year, was largely subscribed to across the three states. Here too, an understanding that the definition had now ‘shrunk’ was expressed, accompanied by a range of arguments reiterating the importance of early medical intervention and diagnosis, ‘ideally’ after a year of marriage. Providers also mentioned catering to ‘young’ couples who came to the clinics within a few months of marriage, with a need for counselling about fertility cycles, low dosage ovulatory medication, and dietary counselling. Providers considered this a positive step; early access by users was perceived to be an indicator of increased awareness about ARTs among them.

I.2. Perceptions of users and FGD participants: Lived realities

Despite some variations both within and between the three states, infertility was perceived by ART users and FGD participants simply as the failure to conceive. Community understandings were useful towards examining the actual experiences of users, the relevance of medical definitions for communities, as well as the deviation between medical and cultural understandings of infertility. The reference period during which infertility or childlessness was identified as a ‘problem’ by the community also varied from that adopted by the medical fraternity. In the three sample states, FGDs revealed that societal pressure, name-calling, taunting, etc. starts about a year, and in some cases only months,
after marriage, while the need to seek medical intervention was usually felt about two to three years after marriage. In many cases, non-medical interventions like faith healing, prayer, fasts, etc., were pursued earlier than medical interventions. It was also stated that in the past, this reference period had been longer, but nowadays people believed in seeking medical intervention much sooner.

At an FGD in Tamil Nadu, a participant said:

> After marriage, within ten months, women are expected to have a child. After two months of marriage itself, people start asking if there is any ‘news’. If not, they taunt the woman by saying ‘No news. She is just ‘hanging’ around – without doing anything.’

At an FGD in Uttar Pradesh, a woman said:

> Nowadays, if a woman doesn’t conceive within one year [of marriage], she is told to go to the hospital and get checked. Even men have started demanding that the wife should conceive within three or four months of the wedding. Earlier, couples were happy to wait for a few years.

In Orissa, on the other hand, communities that participated in the FGDs perceived non conception to be a problem only after three to five years of marriage:

> Here, if there is no child birth within three to four years of marriage, people call her infertile. We think it is better if there is child birth within three years, otherwise problems come up.

Interestingly, participants in an FGD in Uttar Pradesh sought to highlight the differential perceptions of infertility in rural areas from those of more developed, urban areas:

> People say that if they have a child soon [within a year of marriage], then it’s good otherwise they may find it difficult. But in villages people still don’t worry too much about it until three to five years after marriage.

Similarly, amongst the users interviewed too, the period between marriage and the realisation of the ‘problem’ of infertility, though varied, was roughly two years. About 41 users said they had accessed some sort of intervention (whether medical or otherwise) within two years of actively trying for conception.

Thus, it is evident that the understandings of the term infertility are multiple, some of which converge, while others differ. The visibilisation of childlessness is clear, both through the stigma associated with it and within an expanding fertility market that pushes-through-providing medical intervention. ART providers emphasise the need for early medical ‘treatment’, capitalizing on the WHO and ICMR definitions of infertility. At the same time, community perceptions that could possibly resist these growing pro-market thrusts are also changing.
II. Rising numbers – growing markets?

Interactions with ART providers and gynaecologists echoed the trends reflected in demographic literature and infertility research, with almost all of them articulating the rise of infertility in their areas of work.

The incidence of infertility was generally estimated at 15-30 per cent, an over-estimation when compared to existing literature. A few gynaecologists were, however, a bit skeptical and felt that it was the increased awareness of the availability of medical interventions for infertility that had resulted in a greater recording of, and treatment for, infertility.

As gynaecologist ORP-13 stated:

*I don’t think there has been an increase in infertility over the years. Now a days more cases are being documented because of the rise in awareness about these treatments.*

However, others pointed out that this was just one probable factor responsible for increased instances of infertility reporting, while infertility as a demographic trend has been increasing due to a range of other factors. These factors included changes in lifestyle, environmental pollution, iatrogenic factors, and lack of sex education (this is explored further in the subsection on Perceived causes of infertility). As ART provider UPP-2 pointed out:

*Earlier, we used to think that the prevalence of infertility is only 15 per cent. But now, considering the number of patients we see every day, I can easily say that it is 30 per cent. There are definitely other environmental reasons. Change in lifestyle, increased stress about their jobs, etc. also play an important role, in the causes of infertility.*

Reiterating this perspective, ORP-2 added:

*Sources of information like the Internet, reach of the people, and affordability have improved with regard to accessibility to the treatment. Although sex and reproductive matters are still taboo issues, in the past few years our society has become a little more open with regard to discussing these things.*

Interestingly, one gynaecologist in Orissa disputed this trend of increasing infertility, ORP-16 stated:

*I have not really seen an increase in infertility. I don’t think lifestyles have changed that much in this part of the world for these factors to be linked directly to the causes of infertility.*

The rise in the demographic indicators of infertility certainly cannot be ignored. However, the over-emphasis on the rise in infertility by the ART industry is based clearly on vested interest and promotes a narrow, technological response to infertility.

According to a study by the International Institute for Population Sciences [IIPS], Mumbai, while Uttar Pradesh and Tamil Nadu have shown a substantial rise in childlessness [from 2.76 per cent to 6.11 per cent and 6.42 per cent to 11.20 per cent respectively] the rise in childlessness in Orissa has been marginal [from 5.80 per cent to 5.81 per cent]. (Ram, 2005)
III. Perceived causes of infertility

III.1. Biomedical causes

Table-13, compiled from user interviews, shows the levels of primary and secondary infertility within the given sample size of 86 users from the three research states. Almost 85 per cent (73) of the users profiled here were cases of primary infertility, while the remaining 13 users reported having achieved pregnancy at least once at the time of the interview, and who can thus be classified as persons with secondary infertility. Amongst the latter, 11 users had miscarried at different points during their earlier pregnancies, due to reasons ranging from heavy workload, reproductive tract and uterine infections, hormonal imbalances to unexplained factors. One of the users had given birth to two children, one of whom died soon after, while the second child was still born. Another user had one child, but was having difficulty in conceiving for the second time.

Providers estimated the incidence of male factor, female factor, and unexplained infertility to be equal, citing 15-30 per cent for each. In exceptional cases, providers claimed not to believe in the concept of unexplained infertility at all and said that a contributing factor to the diagnosis could be arrived at in every case. As ART provider UPP-3 categorically stated:

*It all depends on the provider’s diagnostic skills.*

_Earlier, there were no means to detect or diagnose the causes. Now we have all the techniques. Now we can diagnose the cause better and treat it effectively._ UPP-8

In the research sample, as shown in Table-14, 53 per cent of the users were diagnosed with female factor infertility, around 17 per cent were attributed to male factor, and about 12 per cent displayed both male and female factors.

<table>
<thead>
<tr>
<th>Table 13: Primary and secondary infertility</th>
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</thead>
<tbody>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Primary infertility</td>
</tr>
<tr>
<td>Secondary infertility</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)

<table>
<thead>
<tr>
<th>Table 14: Factors affecting infertility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orissa</td>
</tr>
<tr>
<td>Female factor</td>
</tr>
<tr>
<td>15</td>
</tr>
<tr>
<td>21</td>
</tr>
<tr>
<td>10</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)

Gynaecologists from the sample across the three states claimed that they tend to see more cases of female factor infertility, which they believed accounted for up to 50-70 per cent of all cases of infertility. They said that in case of non-conception, the problem was mostly seen to lie with the woman (who would then approach a gynaecologist), and men came forward to be tested much later in the couple’s treatment trajectory.
As depicted in Table-15, a whole host of bio-medical causes were cited by providers for both male and female factor infertility. However, interestingly, while many of the users were able to articulate some of the symptoms and some of the probable causative factors, very few were able to recall what their actual diagnosis had been. For instance, many of the women were able to report irregular menstruation as a probable causative factor, but were unable to further elaborate on what this meant in terms of their infertility diagnosis. In cases of male factor infertility, the men were able to articulate what the diagnosis had been, but at the same time, were unable to draw linkages with what the probable causative factors may have been. For instance, ORU-2’s husband reported undergoing a test for Filariasis but could not say why this test was conducted. This clearly brings out the inadequacy, if not the total lack of information given to couples undergoing ARTs.

<table>
<thead>
<tr>
<th>Table 15: Biomedical causes of infertility</th>
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<tbody>
<tr>
<td><strong>Causes cited by providers</strong></td>
</tr>
<tr>
<td>Male Factor Infertility</td>
</tr>
<tr>
<td>Lifestyle factors</td>
</tr>
<tr>
<td>Diseases such as filariasis</td>
</tr>
<tr>
<td>Occupational factors (such as exposure to chemicals, fertilizers, overheated work places - brick kilns and mines, sedentary lifestyle etc.)</td>
</tr>
<tr>
<td>Congenital abnormalities</td>
</tr>
<tr>
<td>Female Factor Infertility</td>
</tr>
<tr>
<td>- PCOD</td>
</tr>
<tr>
<td>- Ovulatory disorders</td>
</tr>
<tr>
<td>- Cysts (typically identified through irregular menstruation or amenorrhea)</td>
</tr>
<tr>
<td>Uterine factors</td>
</tr>
<tr>
<td>- Endometriosis</td>
</tr>
<tr>
<td>- Shape and size abnormalities</td>
</tr>
<tr>
<td>- Cysts</td>
</tr>
<tr>
<td>Tubal factors</td>
</tr>
<tr>
<td>- Blocked tubes</td>
</tr>
<tr>
<td>- Infections (PID/s/STIs/RTIs)</td>
</tr>
<tr>
<td>Gynaecology and obstetric history</td>
</tr>
<tr>
<td>- Abortions</td>
</tr>
<tr>
<td>- Miscarriages</td>
</tr>
<tr>
<td>Sexual dysfunction</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)
III.2. (Mis) Diagnosis – No diagnosis

It was not uncommon for users to report a complete change in diagnosis from one clinic to another. For instance, TNU-30 described her experience of mis-diagnosis at a clinic:

We were really disappointed with the kind of experience we had there. In XXX Centre, suddenly the sperm count came out to be really high, and we were happy that at least there was some improvement, and there was a new hope in us. But, later on we came to know that the test results were incorrect.

In such situations, users reported losing trust in the provider. They also said that their means of coping with their infertility through medical ‘treatment’, both in financial and emotional terms, was affected. Across the three states, users who had been in such situations reported being angry with the concerned providers and also suspected a commercial motive. Despite feeling cheated, some expressed their lack of ‘choice’, thus submitting to whatever the doctors said. Frustration was also expressed when the diagnosis was inconclusive, or was not disclosed at all. As was articulated by TNU-16:

When we went there, they did all the tests mechanically and did not even bother to take a look at our earlier test reports. After taking a look at my report, the doctor did not even say a single word about our problem or what the test result was. She just said, fix up dates and come for treatment. We really felt bad. Without even knowing about our problem, how can we proceed with the treatment?

We also went to some of the so-called best doctors but nobody could give the right diagnosis. I think these big doctors just cheat all the needy patients. UPU-6

We were not informed about any of the details by the provider during IVF. We just kept doing whatever he advised. Sometimes when I would ask him for any kind of details, then he would say, ‘You don’t need to understand anything. I will do whatever is needed.’ ORU-21

Some ART providers also blamed users for having sought or pursued improper ‘treatments’ previously, thus leading to mis-diagnosis and loss of ‘time’. Providers made frequent references to instances wherein an earlier incorrect diagnosis had led to further complications. Providers also expressed their distrust in alternative forms of treatment. UPP-2, a gynaecologist, summed it up:

Then there are also people in the villages who do not go to the right doctors and delay their treatment. We have seen cases where simple tests can tell that the husband’s sperm count is low or that there is a problem with the oocyte formation, but these conditions have been completely ignored. They go to bad doctors who prescribe wrong medicines, and their condition only gets worse.

Embryologist ORP-3 concurs:

Sometimes, unnecessary or repeated D&C [takes place]. In rural areas, people going to quacks if women do not conceive within six months to one year of marriage, etc. can also create complications for future conceptions.
III.3. ‘Cursed’, married ‘late’, pregnancy ‘delayed’ and ‘immoral’ behaviour

It was not uncommon for users to perceive their childlessness as a ‘curse’ or an ‘act of god’. Many credited childbirth as being a matter of faith and destiny. As TNU-18 said:

If god has written in our fate that we will have a child, we will have a child.

A similar belief emerged during the FGDs where women revealed community perceptions of infertility as not necessarily a ‘disease’, but rather, as being attributable to other non-medical and non-scientific causes:

Barrenness is not a disease. She does not get a child because of her bad luck. FGD–OR

Consanguinous marriages, irregular periods, insufficient sperms, uterine fibroids, uterine cysts, ‘loose’ cervix, ‘shrunk’ uterus, anaemia, pey puddichirunthal [if a spirit overtakes you]. FGD–TN

No, it is not considered to be a disease, but in fact it is written off as destiny. To have a child has to be in one’s destiny. Everything happens by god’s grace. If he so wishes, a child will be born. If it is against his wishes, then however much one tries, nothing will happen. FGD–UP

Women are also blamed because they are seen to ‘deserve’ their infertility. For instance, users were often rebuked by their relatives and neighbours for not having the qualities of a mother. Women also internalised this blame, and thought of themselves as having ‘brought on’ their infertility. For instance, TNU-12 narrated:

Everyone in the family said I am unfit to beget a child. This statement shattered me. I have cried for many nights and even now, I cannot sleep soundly.

When I went for repeated abortions at that time, the doctor had warned me about facing problems conceiving in future. But I didn’t take it seriously. I was in love with a person from another caste ‘lower’ than ours, hence couldn’t marry him. I also got pregnant while in a relationship with him. Now when I think of all this, I feel guilty that I must have done something wrong for which god is punishing me in this manner. ORU–8

Users’ narratives also revealed that women were regarded as being ‘cursed’, and bringing bad luck to the entire family. Interestingly, women reported being taunted in their marital homes because of ‘too much’ and ‘too little’ dowry, both of which compounded the stigma they had to face because of infertility. For instance, ORU-27 said that her mother-in-law did not like her because hers was a love marriage with no dowry and now, no child, while ORU-30’s mother-in-law insisted that she had brought a large dowry because she was infertile and ‘cursed’.

Clearly, blame was fixed on women in many ways. Providers too blamed women for their infertility, at least in part. This reveals the larger picture of the embeddedness of providers in the same socio-economic and cultural milieu that produces gendered
prejudices. Providers are not ‘above’ the society in which they operate. Rather, as products of their societal positioning, they more often than not reinforce and reproduce dominant notions and beliefs. With providers, an oft-cited perceived reason for female factor infertility was delayed pregnancy. As UPP-23 said:

In the educated class, among the career-minded people, there is a trend of delaying marriages. They want to keep building their career. And now even in villages, they are saying, ‘Please let me finish my studies first’. So people keep studying and working, and don’t want to get married. They give preference to their careers and as a result, marriage and pregnancy keeps getting delayed.

UPP-12 agreed that the rising age of marriage is the main factor for increasing infertility:

Today, people are getting married in their old age. Earlier people would marry around the age of 19-20 years, but nowadays people marry around the age of 25-30, even 35. So definitely infertility is increasing.

ORP-3 stated:

Marriage and starting a family are not the priorities now. The average age for women getting married has also gone up. Many of them are marrying in their late twenties or even after 30 years.

Other providers questioned the ‘immoral’ behaviour of women, indicating it to be the main cause of their childlessness:

Left and right use of contraceptives, premarital sex, early sex, and then unsafe abortions are all leading to infertility. In our school time, we used to have a subject called moral science. Nowadays, that subject is no more. Instead, TV, CDs, bad company have taken over. UPP-15

TNP-8 opined:

We are also becoming very westernised. Women are realising that they enjoy being single, not being answerable to anyone. So all said and done, women are definitely delaying their marriages. They are also enjoying their sex lives before marriage.

Many providers supported this viewpoint by citing biological and medical reasons linking delayed pregnancy with infertility. Gynaecologist TNP-34 asserted:

Couples use contraceptives to avoid unplanned pregnancies. More abortions and MTPs [Medical Termination of Pregnancy] are taking place up to 50 days, which can have an impact on the fertility of the woman. It is almost impossible to avoid sub-clinical infection in MTP procedures. This leads to complications like bilateral tubal block, which is a major reason for infertility.

If a girl marries at 18-21 years, then she can give birth to a child during her most fertile years. Before 25 years is the ideal age for marriage. With growing age, not only do the number of eggs reduce, but the quality of eggs also deteriorates. ORP-3
The above comments suggest that the 'modern', woman who prioritises her education and career over marriage and children, is only further reducing her chances of a 'successful' pregnancy. Such a conclusion assumes women, to be a homogeneous category involved in a linear movement away from a 'desirable' way of life, including family, marriage and childbearing to an 'undesirable' one, driven by education and career.

Interestingly, a look at the profiles of the couples compiled in Table-16 dispels these totalising assumptions. Amongst the women profiled, 73.2 per cent (63) were in the age group of 20-29 years at the time of marriage, with the majority being in their early twenties (20-25 years). Only six women were above the age of 30 years at the time of marriage, of which two cases were of male factor infertility.

While a majority of the women (64) did not mention any intentional delay in their pregnancies, even amongst those who did, conception was attempted within one to three years of their marriage. Only two women reported delaying their pregnancies for up to six years. Amongst those who had consciously delayed their pregnancies, only three stated career responsibilities as a reason. The other reasons ranged from financial problems to health and other family-related emergencies. In four cases, the delay was because the partners were living apart in the early years of their marriage. Only one woman perceived a pre marital relationship and a resultant abortion to be the cause of her infertility.

Further, the medical community itself seems to be divided on the issue of age and infertility. While the age group of 15-44 years in demographic terms generally represents 'reproductive age', it is important to note that all women cannot be looked at as a homogeneous group. Instances of pregnancy and childbirth vary greatly from one individual to another, with factors such as biology, social and cultural influences, exposure to environmental toxins and delay in treatment for STIs and RTIs acting as major determinants. As can be seen in Table-16, at the time of interview, 50 women were within the age group of 30-39 years, and were undergoing ART procedures despite belonging to an age bracket that most providers themselves categorised as ‘late’, with decreased chances of success.

### Table 16: The age factor

<table>
<thead>
<tr>
<th></th>
<th>Tamil Nadu</th>
<th>Uttar Pradesh</th>
<th>Orissa</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at marriage</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 20 years</td>
<td>6</td>
<td>2</td>
<td>8</td>
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<tr>
<td>20-29 years</td>
<td>32</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>30-39 years</td>
<td>5</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td><strong>Current age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29 years</td>
<td>16</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>20-29 years</td>
<td>16</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>30-39 years</td>
<td>24</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>40-49 years</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Over 50 years</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td><strong>Years of marriage at the time of interview</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-6 years</td>
<td>19</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>7-12 years</td>
<td>14</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>13-18 years</td>
<td>8</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>19-24 years</td>
<td>2</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>25 or more years</td>
<td>–</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td><strong>Delay in conception</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No intentional delay</td>
<td>30</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>1-3 years</td>
<td>9</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>4-6 years</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)
Providers’ perceptions betray anxiety about the stability of societal structures, institutions like marriage and childbearing, perceived to be under threat from women’s increased professional and personal mobility, individual agency, and the ‘new-age’ re-prioritization of their values and goals, whether real or imagined. Thus, providers prescribe the ‘ideal’ age for marriage, so as to capitalize on women’s ‘optimum’ eggs and their ‘appropriate’ fertility period. However, one cannot but suspect the role of the markets and the commercial interests of the ART industry in the propagation of these ideas, given that despite claims of failing fertility and increased difficulty in conception past the age of 30 years, the same providers continue to boast about the ‘marvel’ of technology in assisting even ‘post-menopausal’ women with achieving conception.

III.4. No sex talk, no sex

Comments by providers revealed a great deal of anxiety about premarital sex and sexuality, particularly with regard to women. This showed a deep disapproval of, and an underlying sense of losing necessary and adequate control over, women’s sexual/ising bodies:

Nowadays, infertility is increasing because there is more sexual freedom. And later in life, a heavy price has to be paid for it. TNP-3

A lot of women have multiple sex partners before marriage, and also after marriage, in the form of extra marital affairs. This often leads to STDs and RTIs, which again may lead to infertility. TNP-8

During our time in school, we were taught that our body is a temple and that we should keep it as pure as possible. Sex should not be as common as food. There is a difference between animal and man, and this is it. Even our Vedas say the same thing. Earlier in the gurukul system, there used to be brahmacharya, grihasth-ashram, vanaprastha, and sanyasa. It was taught that before marriage sex is wrong, and after marriage it becomes godly; producing children becomes an act of god. The same act which is wrong before marriage becomes right after it. And now you have pill 72, i-pill, etc., which actually harm women’s health. There is an increase in STDs, unwanted pregnancies, incomplete abortions, heavy bleeding, and anaemia. UPP-15

These comments are particularly revealing. Claims of the supposed freedom and irreverence surrounding sex today draw on references to an earlier, purer time—undoubtedly a romanticised, essentialised, and reductive portrayal of a sexually conservative ‘golden age’—from which there has been an apparent departure to arrive at today’s sexually explosive ‘dark ages’. Further, the notion of the body as a temple propounds the need for the preservation of its purity. A strong moral-religious discourse surrounds the body, which locates female sexuality as valid and acceptable only within marriage, and forecloses any possibility of sexual pleasure or variance outside marriage by labelling it corrupt and dangerous.

The absence of any institutionalised sex education curriculum compounds the silence around sexuality, creating and recreating an utter lack of awareness about the fertility cycle. This contributes to infertility, real and perceived, and consequently to many unnecessary treatments for preventable conditions. This systemic exclusion and repression of ‘sex talk’ is also responsible for misconceptions, stigma, abuse, and trauma.
For instance, TNP-4 reflected:

*Some women are unable to conceive as they have not been exposed to any form of sexual education. Most of the times these patients are very young and not quite sure what to do, or when to do it.*

Gynaecologist TNP-30 echoed this opinion:

*Even among educated people, information about infertility is lacking. They need lots of information, right from sexual intercourse to conception, and thorough counselling. For a few of them, simple counselling helps them to conceive.*

The lack of sex education was particularly significant in the case of users where one spouse lived away because of career and familial responsibilities.

**IV. Living trauma: Gendered experiences of infertility**

**Male factor/ female factor: Who is to blame?**

Providers asserted that despite the rise in male factor infertility, and its awareness, it remained highly stigmatised and shrouded in secrecy. They confirmed that people found a diagnosis of male factor infertility difficult to accept, given the strong association of masculinity with virility. For instance ART provider ORP-3 pointed out:

*The male ego is also such that they [men] don’t want to accept that anything can question their masculinity and their capacity to father a child. Some mention that they have done these tests recently and do not need to undergo the tests again.*

ART provider UPP-22 concurred:

*Men don’t generally accept that the fault lies in their body. Society feels that only the female is responsible if there is anything wrong in reproduction. The males are not even tested. We get a number of requests from husbands who have defective sperm to not divulge the details to their family members or to their wives. They don’t even want to let the wife know! The wife gets abused every day because of this! There was a case where the husband’s sperm was not up to the mark. The mother-in-law came up to me and said that first of all I should not tell the wife, because the daughter-in-law will not respect her son! Then she said that we should use the father-in-law’s sperm in place of the husband’s. It was so unbelievable.*

Similar instances of users denying the possibility of, and resisting the treatment for, male factor infertility were also found. In some cases where the wife’s medical reports were ‘normal’ and the husband was asked to get tested, the providers narrated being faced with point-blank refusal.
Andrologist TNP-37 said:

Men experience problems related to sex because of their lifestyle and unrealistic picture about life, which is often compared with movies and leads to high expectations and disappointment. They think movies are the real world and are unable to live up to that kind of a situation... I have men coming to me with a problem. When I confirm that the problem is with him, then he goes to another doctor. If that doctor also says that the problem is with him, then he will move to another. The male ego is still very much there. He will try as much as possible till he can accept it or till he finds a clinic where he is sure that his problem will not be revealed.

TNP-19 concurred:

Men are reluctant to even go in for semen analysis. And when I sometimes recommend testicular biopsy, they feel that it will ruin their life. Here they refer to the vas deferens as ‘ooyar nulli’ (life tube).

ORP-2 confirmed this unease:

Our society is still a male chauvinistic society. Men are not ready to come to terms with any kind of problem that they might have, and do not even want to talk about their reproductive problems.

However, on the other hand, some providers also felt that in rare instances, the desire for a child would override such concerns, thus softening an otherwise rigid attitude.

Gynaecologist ORP-15 said:

Now there is a change in the attitude of the couples towards visiting doctors with infertility problems. Both husband and wife come together. And it is not like earlier times when only women used to go to the doctor in cases of problem in conception. One of the reasons for this is that there is more awareness among people.

Andrologist TNP-37 further elaborated on the issue:

Earlier, men did not accept their problems or come for treatment. Now this has changed dramatically and they do come forward for treatment. However, the male ego does not permit him [the man] to admit [the problem]. However, women are not being thrown out of their homes. Men don’t marry again anymore. Women have also become shrewd. They are more informed and know that the causes of infertility do not lie only with them. Earlier, they used to accept it as their fate, and even men with azoospermia would have one or two or three wives. Now this has changed.
However, in many cases, women internalise the blame for infertility, including before, and sometimes even despite, the diagnosis. A provider at a district hospital in Uttar Pradesh said:

*Women mostly think, even before any tests are done, that they are the ones with the problem. We have to really insist on the husband getting tested as well.*

An FGD participant from Tamil Nadu narrated her personal experience in this regard:

*When we got married, he was working in Vellore district and he would come home only on two Sundays per month. My mother-in-law and my sister-in-law were very irritated as I did not conceive soon. They did not understand the basics. They scolded and abused me a lot. They even called me ‘maladu madu’ [infertile cow]. I cried a lot as my husband comes home once or twice a month. I was unable to tell him anything as I was new to their house.*

This assertion was repeated in several user interviews. Although ORU-2’s husband was diagnosed with low sperm count, she insisted that he should leave her and marry again to have a child. Her husband seemed to understand, but refused, saying:

*My wife has also told me many times to remarry, as she is not able to have a child. But I think it will not be proper on my part to remarry. After all, she is my wife and I cannot hurt her like this. She might be saying this out of desperation. Otherwise whatever the reason, no wife would like her husband to remarry.*

Some women also made it clear that they would rather bear the burden of infertility, than disclose a diagnosis of male factor infertility. This revealed how closely women’s honour was tied to that of their families, and how their sense of self-respect flowed from the status that their husband or family enjoyed in society. As TNU-3 said:

*The standard question is ‘Have you got a child? Why the delay?’ I cannot tell anyone that the problem is with my husband because people will say all kinds of things. He will lose respect in society. They call men ‘potta’ [effeminate]. I cannot tolerate all this and I remain silent when people ask me about a child.*

In a particularly telling instance, TNU-29’s in-laws could not come to terms with their son’s diagnosis of azoospermia, and were being hostile to the couple:

*Though we stay in the same house, we do not talk much. They [the in-laws] cook separately and I cook for my husband and myself. They do not even talk to my husband. After they found out about his problem, they started behaving strangely with us. Have you ever seen parents not interacting with their son just because of infertility?*

Nonetheless, they did not give their relatives the real picture of the couple’s infertility, and the relatives continued to think the ‘problem’ was with the daughter-in-law. In cases of male factor infertility, the man’s reputation is sought to be protected to prevent him from being called effeminate or lacking, ‘losing respect’, or from suffering ‘psychological’ harm. The double standards at play here are plain: motherhood is the expectation from the woman, and her inability to fulfill this role is not deemed worthy of defense.
V. The anatomy of violence

When asked about violence faced due to infertility, women referred to physical violence, while acts of emotional and mental violence, although clear from the narratives, were not reported explicitly as violence. A narrow definition of violence invisibilizes broader and more comprehensive understandings psychological, cultural, structural, etc. This limited definition of violence allows the violation of rights of the majority of women to continue. Physical violence was reported by a few women.

UPU-1’s account was particularly stark:

The first 14 years of our marriage were pure hell for me. My husband had a drinking habit and was often violent. When after the first year of marriage I did not conceive, his colleagues started taunting [him about] his masculinity. This got even worse in the subsequent years. He would spend all his money on alcohol and then come home in the nights and beat me. He would also abuse me and call me all sorts of names and throw things at me. I couldn’t do anything about this or even talk to anybody. After all, it was a matter of family honour. How could I let other people gossip about our family because of me? My mother-in-law knew this and was very supportive of me. She treated me very kindly, almost like a mother. One day, things got so bad that after beating me up, he locked me out of the house and left me in the rain all night long. The next day I packed some clothes and left the house to go live with my parents. It was eventually my mother-in-law who convinced my husband to apologise and get me back to the house.

It is not surprising to encounter the notion of family honour that keeps UPU-1 from ‘telling’ on her husband and his mistreatment of her. Women’s bodies are considered repositories of group honour, and as such, are strictly controlled to preserve the honour of family or community, or inversely, are defiled in order to dishonour another family or community.

Another interview highlighted the emotional and mental abuse directed at a user (TNU-16) by her mother-in-law and sister-in-law, despite her caring and supportive husband trying to defend her:

I have had to listen to all kinds of things from my mother-in-law and sister-in-law. I have had enough of them. My husband is very supportive and cares for me. Once he told his mother, ‘Don’t say harsh things to or about her’. My mother-in-law got really angry and gave it back to him, ‘Your wife, who has come into your life only recently, has become more important to you than your mother, who gave birth to you!’ She said she says these things to me only because she wishes to see her grandchild soon…Once when my sister-in-law came from the US, we were watching a television serial where the actress attempts suicide because she has infertility problems. My mother-in-law immediately said, ‘She is a good woman. She does not wish to create unnecessary problems. That is why she tried to end her life.’ These words really hurt me and I cried a lot. When my husband found out, he scolded his mother, but it backfired and she said that I have tied my husband to my saree. She is always murmuring something or the other. My sister-in-law would often say to me, ‘You have no potential to have a child, so why is your mouth so big?’ These two women were the problem in our lives.
Here it is clear that though the trauma that results from psychological and emotional violence manifests differently, it is not less devastating than physical violence. Indeed, they can be equally fatal. ORU-21 stated:

There is definitely pressure from everywhere when you are not able to conceive after so many years of marriage. People do say harsh things like you are a banjh [barren] and one should not see your face… When the doctor said that there is a problem with me, even my own family members started to blame me. Sometimes I used to feel so desperate that I even thought of committing suicide… The problem was with me, so what could I do? I had to listen to what everyone was saying.

ORU-21’s narrative reveals a sense of desperation and entrapment as she blames herself, and her lack of choice (‘what could I do?’). Juxtaposed against the discourse of ‘choice’ that is employed by providers to promote ‘treatments’, it is interesting to note that what appears to be pushing the infertility business is an utter ‘lack of choice’ that women feel they have in the event of infertility.

Within the framework of hetero-patriarchy, the non-fulfillment of motherhood after marriage leads to eruptions of physical and psychological violence against women. These acts draw legitimacy from a cultural violence that normalises and naturalises fertility, while marking and punishing infertility, through rituals, language and religion. Thus, physical and psychological violence against infertile women is rendered possible, even acceptable.

FGDs highlighted community perceptions of infertile women that considered them inauspicious as a rule, and not only on auspicious occasions like marriages and prayer ceremonies, or events involving fertility like child birth and baby showers. In daily life, it is considered unlucky, even sinful, to see an infertile woman’s face early in the morning, or when generally leaving for, or proceeding with, work. Many regard the act of drinking water served or touched by an infertile woman as sinful. Infertile women are not allowed into fields lest they ‘pass on’ their infertility to the land or to the crop, making it ‘barren’ and ‘unproductive’ like themselves. It is apparent that the infertile female body is subjected to a stringent and permanent quarantine that does not even end with the infertile woman’s death. When an infertile woman dies, an earthen pot is broken to symbolically invoke the end of her lineage. Further, turmeric powder (considered auspicious) is stuffed into her vagina before the final rites of cremation, to ensure that she will not be born infertile in her next life. Here, not only is a woman’s worth, mobility, and participation in community life wholly contingent on her reproductive capacity, but infertility marks her body as ‘dirty’ even in death, and thus, justifies the violation of her bodily integrity to supposedly expunge the ‘curse’ that afflicted her during her lifetime. Idioms used in ordinary speech by the community can contain stinging references to infertile women. Some idioms reported by FGD participants were: What does an infertile woman know of the pain of childbirth?; No seed can be sown on land that is barren; and Why feed a buffalo when it can produce no milk? Such derogatory references to women who do not or cannot reproduce are manifestations not just of devaluation, but also of commodification, as they reveal the dehumanised likening of women to property, land, cattle, etc. over which only men are seen to have rightful ownership.
In the Bundelkhand region of Uttar Pradesh, village women wear the tilri (a piece of jewellery) when a child is born and sing the following song, which describes a childless woman asking her husband for a tilri. The husband responds:

*How can you wear a tilri?*
*You are neither good, nor pretty.*
*Nor are you with child.*
*How then can you wear a tilri?*
[The woman conceives soon after. After nine months, she gives birth to a boy.]
*Husband: Here is your tilri, my sweet.*
*Let me put your tilri on you, my sweet.*
*Wife: Why, I am neither good, nor pretty.*
*Surely I cannot wear that tilri, my lord.*
*Husband: You are lovelier than gold.*
*For you have given me a boy.*
*You will wear this tilri, my sweet.*
*Came, let me put your tilri on you.*

Infertility treatment is not sought in a vacuum; the pressure and desire for a biological child are clearly compelling factors. This section explored factors that influence the onset of users’ treatment trajectories - shrinking, ‘modern-day’ definitions of infertility, as well as the gendered burden of fertility, potentially violent and deeply rooted in everyday culture. The next section will examine the outcome of these, that is, the treatment journeys of users who seek fertility.

**Section B**

Infertility may be sought to be treated through interventions, including but not limited to ARTs. The nature of the journey undertaken in pursuit of a biological child is complex, subjective, and multifaceted. These negotiations form a significant axis around which the access to infertility ‘treatments’, particularly ARTs – must be understood. This section explores the process and range of ‘treatments’ undergone by users, as well as their actual experiences of seeking formal and real access to infertility ‘treatment’. An attempt has been made to capture the variations and commonalities that emerged within and across the states. While quantified data has been presented wherever possible, greater emphasis has been laid on users’ narratives.

‘Treatments’ pursued by users are crucially influenced by the economic development and the locale-specific characteristics—particularly the provision and quality of health services—of the states (and districts) of which they are residents. A cursory look at the profile of the states and districts under analysis makes it apparent that there are clear economic and demographic variations both within and across them. It is well established that the availability of infrastructure, and the location of people (urban, rural, hilly areas, etc.) are directly connected with health-seeking behaviour and with access to health services. Further, users often choose multiple forms of ‘treatment’. More often than not, this makes it difficult, if not impossible, to arrive at a clear-cut compartmentalization of users’ journeys. Because users also access various ‘treatment’ options over a period of time, a linear or unidirectional
trajectory is not seen. On the one hand, the perspectives and experiences of users determine their choices along their ‘treatment’ journeys, at the same time providers also direct users and influence their choices, thus steering the course of their ‘treatments’.

I. Allopathy

This section examines users’ experiences with the allopathic mode of infertility treatment (including ARTs), through factors influencing the initiation and progression of the ‘treatment’ journey, the transition of couples from one level of treatment to the next, and the operationalisation of the referral mechanism. While this section ends with an examination of users undergoing advanced ART procedures like IVF, ICSI, ARTs are not the ‘final frontier’ of infertility treatment, or the definite and linear culmination or end. Since the success rate for ARTs is low, in many instances users revert back to or persist with other modes of treatment.

I.1. Starting treatment

The desire for a biological child transcended geographical boundaries, and certain common factors influenced the commencement of infertility treatment both within and across states.

- Advice by relatives and friends to consult a particular provider
- Reputation of the doctor consulted by the couples
- Proximity of the doctor to the residence of the users.

Users often decided to consult a provider voluntarily, impelled by their own concern or anxiety. In other instances, it was the pressure exerted by the immediate family, relatives, friends and others that made them go to the doctor.

The experience of accessing medical intervention was also closely connected to the role of the provider. The ‘treatment’ journey pursued depended on the providers’ advice, and also on the facilities available at the clinic. In the case of infertility ‘treatment’, providers were vested with a special power and seen as benevolent figures, helping couples achieve their dream of a biological child. Hence, it is important to understand the ‘treatment’ trajectory as shaped by the provider-user relationship (as with other medical interventions).

I.2. Reference and reputation of the provider

Whether a provider is known to many other people and what his/her attitude is towards the users, were important considerations for couples. Often individuals who had had

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<table>
<thead>
<tr>
<th>State</th>
<th>Average number of years</th>
<th>Time range</th>
<th>Total number of users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orissa</td>
<td>2.1 years</td>
<td>1 month after marriage to 8 years after marriage</td>
<td>30</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>2.7 years</td>
<td>4 months after marriage to over 12 years after marriage</td>
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</tr>
<tr>
<td>Uttar Pradesh</td>
<td>3.5 years</td>
<td>1 year to 9 years after marriage</td>
<td>13</td>
</tr>
</tbody>
</table>
successful ‘treatments’ with particular providers recommended them to other users. In smaller towns and rural areas, the same provider may have been the first point of contact for a large number of couples. This was seen especially in some rural and interior areas of Orissa, where many users with infertility problems consulted the same set of doctors at the beginning of their ‘treatment’.

Two years after marriage we tried for a child. Even on trying for some time, we did not have a child. On the advice of friends and family members we went to Dr. XXX. He is known to many people and prescribed us some medicines. ORU-2

For the first 3-4 years of marriage we didn’t think anything was wrong, we were sure that sooner or later I will get pregnant and have a child. However, even after 4 years when I had failed to get pregnant, we felt something may be wrong and went to a doctor who was recommended to us by some relatives. UPU-6

1.3. The gynaecologist: Often the first point of contact

As a general trend, the gynaecologist was the initial point of contact for users who sought infertility treatment. Users who wanted to have a child (on an average) soon after marriage went to the gynaecologist after one or two years of trying to conceive. In a few instances where couples delayed childbirth after marriage (for various reasons like pursuing higher education or living separately due to work, etc.) the gynaecologist was consulted after a longer period of trying to conceive, when it became evident that there may be a ‘problem’.

We got married six years ago [2003]. We started to consult doctors after six months of marriage. And within a year of marriage, we must have consulted all [the] famous doctors in Madurai. TNU -18

We got married 12 years ago and did not plan for a child immediately after that. During the initial five or six years, we also wanted to be free. We did not want any children then. Then she did get pregnant once. But there was a spontaneous abortion. After that, a lot of problems started, and she was not able to conceive. UPU-9

When my younger sister got pregnant two years ago, many of our relatives started asking us why we had not had a child yet. We were upset with such comments and decided that we should go for a checkup. Till then we did not really think very seriously about the fact that we had not had a child. TNU-38

1.4. Gynaecologists also give direction to this trajectory

Gynaecologists usually begin treatment with preliminary investigations and detailed history taking regarding prior conception, miscarriages, menstrual cycle, any kind of infection (in both partners), etc. Physical examination and hormonal assays of women, along with the simultaneous semen analysis of the men, are generally advised. These are
the basic diagnostic procedures. The establishment of male factor infertility, female factor infertility, and combined or unexplained infertility is also done at this stage.

The diagnosis determines the treatment process that is followed thereafter, often immediately. This may include regularising the menstrual cycle through drugs, treating ovarian factors, tubal factors like opening the blockage in the fallopian tube(s) through laparoscopy procedures, increasing the sperm count in men through medication and treating infections like PID, RTIs, STIs, etc. The diagnosis of male factor infertility might also mean that the users are referred to a Urologist or an Andrologist. In other cases, users who require advanced procedures like IVF or ICSI, are referred to ART clinics by the gynaecologist for future ‘treatment’, thus taking the trajectory of the users to another level. This distinction is depicted in the diagram below.

Across the three states, non-IUI gynaecologists gave details about the facilities they provide, and the stage at which they refer users for either IUI or IVF/ICSI:

*In this hospital, we provide diagnostic laparoscopy, diagnostic laboratory tests. We also do the HSG test, but the hormone tests need to be done outside.* ORP -19

*We have facilities for testing. For men, we would do the semen analysis. And for women, we screen for infections like PID, syphilis, RTIs, STIs. Once the problem is identified we prescribe medicines, or if we cannot help the patient, if the problem is beyond the scope of our services, we refer them to other places. We are quite limited here with our investigation. A lot of women come in complaining of irregular menses. We first try to regularise their cycles and counselling them about fertility cycles and also induce ovulation if necessary, but counselling regarding the fertile periods and ovulation is more important.* TNP-31

*I only do basic investigation for women and semen analysis for men. I look at other kinds of problems like PCOD, menstrual irregularities. I prescribe them medicines and refer them for further treatment.* UPP-33
These narratives also highlight some state specific details with regard to the facilities on offer. While some Tamil Nadu clinics were able to provide basic investigative facilities under one roof, in other cases (particularly in Orissa), procedures like hormonal assay had to be done outside the clinic. Similarly, a gynaecological clinic in Uttar Pradesh said that it provided only basic infertility investigations and counselling, but not even follicular monitoring. This makes it clear that even at the preliminary stages of the treatment trajectory, the range of available facilities was varied and users had to change providers. The study also reveals the differential levels of health care infrastructure in the three states.

I.5. What providers say about moving from IUI to advanced ART procedures

IUI providers across the three states said that they advised and conducted three to six cycles of IUI on an average. After this, the users were referred for IVF, or if needed, ICSI.

I generally refer the patient to go in for IVF after three cycles of IUI. However, many a times the patients insist that they want to keep trying for up to six cycles of IUI at my clinic. ORP -16

I generally wait till a maximum of six cycles before advising IVF. But most of the time, couples do not follow up after four cycles. UPP-32

IUI providers in Tamil Nadu seemed to follow a more systematic and detailed process:

The course of treatment depends on a lot of factors like the patient’s age and also their previous treatment. If they have previously undergone medical treatment, like taken drugs to improve their fertility and still have not been successful, we would suggest a laparoscopy. If they are still not able to conceive we would recommend ovulation induction, and after about four cycles, would recommend that they go in for IUI. Usually, we would complete three cycles of Ovulation Induction, give a gap of two months, then do laparoscopy. Three months after the laparoscopy, we would do IUI. We recommend IUI more when there is male factor infertility. I usually tell them to go in for three cycles, not more than that. TNP-20

Lack of resources does not appear to be the only reason why gynaecologists do not invest in advanced technologies. Many of them do not believe that these technologies are a solution or ‘treatment’ for infertility at all. For instance, the above narratives suggest that even at the level of IUI, gynaecologists spend substantial time and resources conducting in-depth and detailed investigations. They also mentioned that in many cases, counselling couples about their reproductive biology was more effective than medical intervention.

1.6. The shift and referral mechanism in play

In case IUI was not successful, users were referred to advanced procedures like IVF/ICSI. In many instances, the referral for more advanced procedures was also made to different town or cities. Users also chose to access these procedures in a different state for various reasons. Therefore, for users accessing IVF/ICSI, the procedural shift to a higher-order procedures was sometimes accompanied by a geographical shift to another city, town or state. Although from the perspective of the providers, this transition was a logical step forward, users had to consider other determining factors. Some users continued to
undergo IUI cycles although they had been advised IVF, because they lacked the requisite financial resources but desired to continue with ‘treatment’ in some form. Providers also quite readily provided whatever procedures the users were able to afford. For poorer users, even at the preliminary stages a considerable amount of money was spent on ART ‘treatment’ that resulted in unsuccessful IUI cycles, leaving them with no option but to discontinue treatment until they gather enough resources to resume again, if at all. Users also underwent procedures like IUI with multiple gynaecologists. This pushed the cumulative average of the number of IUI cycles undergone by users far above the range of three to six cycles of IUI that was stated by the providers.

This highlights the need for regulation, monitoring, and implementation of ethical standards, given the adverse impact of excessive IUI cycles on the health and finances of users, particularly women. These concerns were reinforced by the study; ORU-4 mentioned having undergone a total of 12 cycles of IUI with at least two different providers:

*We went to XXX clinic. He is a well-known gynaecologist. At this clinic, treatment was carried out for two years and I underwent four cycles of IUI. But none of the cycles was successful. Then we went to ORP-2. There also I underwent eight cycles of IUI.*

Even though gynaecologists were the first point of contact for majority of the users, in a few cases, users also began their ‘treatment’ at a tertiary level or multi-speciality hospital, or at an ART clinic, in the public or private sector. Users chose to begin treatment at a specialised ART clinic for the same reasons that they opted for a gynaecologist, including references by friends or family, well reputed, proximity to the clinic, and positive feedback from other couples with similar problems.

*My father works at the hospital, in the maintenance department. As his children / dependents we get subsidised treatment in the hospital. I have always come here for all my treatment, I know the place and hence preferred to come this time too. We also felt that this hospital is well known for its treatment. We did not go anywhere else nor did we try any other treatment. We came here directly.*

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I.7. Too long a ‘treatment’ process

When users shifted from one provider to another, the time spent on the ‘treatment’ also tended to get prolonged. These were reflected in statements such as–‘We have not kept an account of how many doctors we have visited or the amount of money spent’; ‘It has been so long’. For couples undergoing treatment for an extended period of time, this was a standard response when asked about the sequence or history of their treatment.

\[
\text{I took so many medicines at that time, that I have completely lost track of what I took when and which doctor gave me what. UPU-1}
\]

\[
\text{I have consulted so many doctors all these years that I do not remember their names clearly. TNU-7}
\]

\[
\text{It has been so many years since we have been going for treatment and we have spent so much of money that I do not even remember how much has been spent. ORU-20}
\]

It can be concluded that in a majority of the cases, opting for ART treatment is not only a significant financial, emotional and physical investment, but also a long-term one that could continue for years on end, perhaps without ever achieving the desired result.

I.8. The advanced ART procedures

The decision to avail infertility treatment in general was articulated by all couples as being a mutual one. However, upon deeper investigation, this did not appear to be the case. Other than a few stray instances, such as UPU-5’s emphatic claim, ‘It is me who takes the decisions, not him. He has supported me in whatever decisions I have taken, and has always agreed with me’, the study makes evident the male control over the decision to access ARTs. Wives were often largely unaware of their medical diagnosis, and were unable to exert much control over the course, length, and type of infertility treatment to which they were subjected. While often both the husband and the wife were unaware of their exact diagnosis and the details of their ‘treatment’, the wife was almost always much less informed than her husband, including in cases of female factor infertility. As ORU-17 stated:

\[
\text{Whatever the information, it was given to my husband [by the doctor]. Wherever he says to go [for treatment], I go, whether I want to or not.}
\]

While in some instances, users underwent procedures like IVF/ ICSI within a few years of beginning ‘treatment’, others underwent advanced ART procedures after long periods and after other ‘treatment’ experiences proved unsuccessful. The trajectories of the users in the different states revealed that the advanced ARTs had been accessed at different points in their overall ‘treatment’. Further, users regarded various ART procedures as part of their overall treatment (seen as necessary in the pursuit of a biological child), rather than viewing them as strictly compartmentalised from each other.

A very ‘simplistic’ understanding of how ‘complicated’ this trajectory can be may be guaged from the process of a single IVF cycle. (See box for a brief description of the phases that usually constitute one IVF cycle.)
Considering that one cycle of IVF typically lasts for a total of 20-25 days, it is evident that users need to repeatedly consult the doctor for follow ups and check ups, undergoing first the process of egg retrieval, followed by embryo transfer. Depending on the situation and the advice of the doctor, users may prefer to be with the same doctor for the delivery as well. Thus, they may have to come to the clinic much in advance and stay there. Every stage of the treatment has implications for users, which in turn determine the future course of their treatment. For instance, prolonged stay in a new place for treatment has, among other factors, considerable financial implications for them (Discussed further in Chapter 4).

<table>
<thead>
<tr>
<th>Ovarian Hyper Stimulation</th>
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<tr>
<td>The ovaries need to be stimulated to generate more eggs. To facilitate this, the woman undergoing IVF is required to take hormones like Clomiphene Citrate daily from the second or third day of menstruation. Around the ninth day, the woman is given a hormone injection of hMG (Human Menopausal Gonadotropin). This hormone helps the follicle to mature. Regular blood and urine tests along with vaginal ultrasounds, are carried out to check the level of hormones and the development of the follicle. The woman is then administered Human Chorionic Gonadotropin. This is a hormone that induces ovulation. The entire hormone treatment lasts for about 17 days.</td>
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<th>Egg Retrieval</th>
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<td>Within 24-38 hours, the egg cells which have developed are retrieved from the follicles. One of the techniques through which this is performed is Trans Vaginal Ultrasound Directed Oocyte Recovery (TUDOR). In this, the eggs are retrieved through the vagina, through laparoscopy, which is a surgical procedure. This procedure is done under local anaesthesia. During this phase, the sperm of the husband or the donor is obtained. About 48 hours after the retrieval of the eggs, the woman is administered the Progesterone hormone to prepare the uterus for embryo transfer.</td>
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<th>Fertilisation</th>
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<td>Within a few hours of the above-mentioned process of egg-retrieval, the egg is put together with the sperm in a petri dish in a culture medium, for fertilisation to take place. After 16-17 hours, it is checked for fertilisation.</td>
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<th>Embryo Transfer</th>
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<td>Five days after fertilisation, the embryos are checked for development. The most well-developed embryos, those with the highest chances for further development, are transferred to the uterus using a catheter. The number of embryos transferred is dependent on the age of the woman, her overall health condition and other factors, and the number and quality of embryos available to be transferred. The spare embryos (embryos that are not transferred) are cryopreserved for use in the future. Within 9-11 days of the embryo transfer, the uterus is checked for implantation and confirmation of pregnancy.</td>
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I.9. Information: Integral, if not fully available

Access to information about treatment is necessary for users to make an informed choice about any kind of medical intervention, but the degree of complexity inherent in ART procedures (combined with other factors like low success rates) makes access to information a particularly critical factor in decision making. Information facilitates users’ decisions about whether or not to undergo procedures like IVF or ICSI at all because of various factors (the high cost, requirement of donor gametes, or associated stigma), or their decision to shift to a different provider or to another city to access these procedures. However not only was the nature and level of information (discussed further in Chapter 4) dependent on the discretion of the providers to a large extent, but in the absence of any standardised protocol, this was also found to vary considerably across states and clinics.
Interesting variations were observed regarding the sources of, and access to, information pertaining to infertility and ARTs. Users said that they had learned about these technologies through television soaps, magazines, newspapers etc. The range of information available to the users in Tamil Nadu was much wider as compared to the other two states. Tamil Nadu users reported hearing about ARTs through TV shows, including soaps like Atipookal, Kolangal, Sondam, and Arasi and other shows with interactive and informative formats. Users from Tamil Nadu made frequent references to these shows; some women said that they watched these shows, which saddened them, while others seemed to derive a sense of community and solidarity from them because they portrayed the suffering of ‘others like them’. In addition, columns and articles in local newspapers and magazines also constituted an important source of information.

In Uttar Pradesh, one of the users (UPU-6 in Meerut) mentioned going to a particular clinic after reading about the provider in the local newspaper. Saat Phere, a popular TV soap in Hindi, contained a track on an IVF pregnancy. Many users in Orissa mentioned having some information about surrogacy through a daily TV soap, Gayatri. However, the nature of this information was very limited compared to Tamil Nadu, where even the number of television programmes was proportionally higher than in the other two states. As such, TV shows and films that explore childlessness and ‘treatments’ for childlessness (like IVF and surrogacy) have contributed to the public imagination, as well as to the local moral worlds and discourses of users of ARTs. Filhaal, a mainstream Hindi film starring two popular actresses, is about a surrogacy arrangement between two friends and the many emotional upheavals that they go through. This film came up in user interviews during discussions on surrogacy as a common frame of reference. Interviews and FGDs also revealed disparity; women from some tribal and remote rural communities in Orissa and Tamil Nadu had limited or no access to TV.

I.10. Determining ‘treatment’ decisions

Inevitably, by the time users accessed advanced ART procedures, it was in the private sector health set-ups. Further, even with a small number of ART clinics in a state like Orissa, users reported having approached multiple providers. Highlighted below are some users’ narratives about moving from one provider to another, as a result of various factors:

My brother is also a gynaecologist, and he suggested that we go to Cuttack and meet ORP-5. We were not satisfied with the treatment there. Then my brother introduced us to another gynaecologist. She suggested that we meet ORP-2 in Rourkela. I, too, had read about his first successful IVF procedure in Orissa when I was doing my graduation. ORU-3

My wife’s friend is a doctor and she is in the United States of America. She is very close to my wife. During her visit last year, we shared our experiences about the treatment with her. She saw the prescription and scolded us, saying why had we spent so much money on vitamin tablets. She asked us to consult another doctor who was a very close friend of her’s. Now we have been coming here for the past one and a half years. TNU-1

After some time, we went to a renowned gynaecologist in Benaras. She did two cycles of IUI and we spent around Rs 15,000-17,000 there. Both the cycles were unsuccessful. Then she referred us to UPP-4 for IVF. UPU-12
Once the procedure starts, the success of the cycle and the attitudes of the providers become additional factors influencing their ‘treatment’ experience, and hence, the course of future ‘treatment’. In many cases, these experiences were not pleasant. Users who had undergone ‘treatment’ with multiple providers were likely to compare the attitudes of providers at different clinics, and cite the nature of their interaction as an integral part of their treatment journey.

*It was a very terrifying and bitter experience in that hospital because of the atmosphere. I was not comfortable with the safety mechanisms the hospital used to deal with patients undergoing advanced techniques.* TNU-10

*The hospital was so dirty, the nurses were rude, and the toilets were so filthy. It was like torture going to that hospital. I would never want to step in there again. The process was difficult, and all the cycles were unsuccessful. We could not continue there anymore.* UPU-7

*That clinic is very unfriendly to patients. In one day, only 30 patients can meet the doctor. You have to take appointments in the morning. We were not satisfied with the treatment there. The doctor doesn’t give you any time. They are also very rude with you. We were very disheartened and gave up the treatment there.* ORU-3

The outcome of the treatment at a particular clinic is perhaps the key determinant of whether couples choose to continue or discontinue treatment there. In case of a failed cycle, the entire process of ‘treatment’ may well be deemed worthless. The experiences of users both within and across the states reveal that a majority had changed providers due to unsuccessful treatment.

*The counselling provided to us was good. We were given full information. The behaviour of doctors and the staff was also good, and adequate facilities were provided. However, these things are immaterial as the final result has been negative, so for us the experience has been bad. How can the experience be good if the treatment has been unsuccessful?* UPU-8

The same user said that the success rate as claimed by the providers did not matter to users, and what really mattered was the actual success of the cycle(s).

*All the things about the success rate actually don’t matter. If there is a pregnancy, then it is 100 per cent. Otherwise it is zero per cent. I only understand this.*

Along similar lines, TNU-28 stated:

*Doctor said the chance is only five per cent. We will stop trying when he says it is zero per cent. We have not thought about any other options. Only time will tell. We have heard negative news, but time is powerful.* TNU-28

The story of UPU-6, narrated on page 93, reveals that her ‘treatment’ trajectory did not stop with the birth of a daughter through ARTs. Rather the successful outcome through IVF encouraged her to seek ART procedures once again. This time around, she gave birth to a son. Her story also raises several concerns that have brought ARTs under scrutiny.
Journey of UPU-6

UPU-6 is 55 years old and has been married for the last 32 years. The couple live in a city in western Uttar Pradesh with their teenage daughter and son, who was born a year ago (in 2008), long after UPU-6 had reached menopause.

Despite having no major health problems, UPU-6 had been unable to conceive for several years after her marriage. During the first few years of marriage, the couple did not think about this too much, and never imagined that anything was wrong. However, after four years of trying to conceive, UPU-6 consulted a neighbourhood gynaecologist who was recommended by a relative. Following routine investigations at the clinic, the doctor reassured them that nothing was wrong and that UPU-6 would conceive naturally in due course. When UPU-6 remained childless despite repeated attempts, the couple decided to consult another doctor. In time, they had been to most of the gynaecologists in the city, but to no avail. The pursuit of ‘treatment’ for their childlessness also took the couple to other cities, both within Uttar Pradesh, like Agra and Mathura, as well as other cities, like Patiala, Ambala and Saharanpur in Punjab, and Delhi and Mumbai. In addition to allopathic treatment, the couple also tried Ayurvedic medicine and home remedies. Accessing ‘treatments’ in different places started taking a toll on the husband’s work, and it became increasingly difficult for him to get leave. As a result, UPU-6 started going to clinics by herself, with her husband joining her when needed.

UPU-6 found it difficult to recollect the exact details of her ‘treatment’ over many years. She recalled undergoing every procedure suggested by the providers, which included three to four operations (for what she understood to be an enlargement of the mouth of the uterus), other laparoscopic surgeries, and procedures like IUI (several cycles at different clinics). She first found out about IVF from an information booklet available in the waiting room of a renowned hospital in Mumbai. She decided to undergo her first IVF cycle there. Following the failure of this cycle, she underwent many more cycles in several clinics. Despite conceiving a few times, she would miscarry after three months. These repeated miscarriages frustrated her, but she was determined to persist. She had consistently been told that her tests were normal, as were those of her husband. At one of the clinics, UPU-6 saw her sperm under a microscope, which she described as being ‘strong and robust’. She had become familiar with the technical details of the procedures; she remembers that on an average about 18 eggs were formed (during each cycle), but she was not informed about the number of embryos transferred or the status of spare embryos and oocytes.

Finally, at a clinic in Mumbai, following yet another IVF cycle, UPU-6 conceived and finally was able to carry the pregnancy to term. Her daughter, was born through a natural delivery at the same clinic.

The couple was overjoyed at the birth of their daughter and decided to stop all treatments. They regarded their daughter as ‘both their son and daughter’. However, in 2007, almost 14 years after she was born, UPU-6 read a newspaper article about a post-menopausal woman who had conceived through IVF at a local fertility clinic. On enquiry, she found that the clinic had received very good reviews and decided to speak to the doctor there. The doctor went through her previous reports and conducted some rounds of investigative tests. It was concluded that her chances of conceiving with IVF were still quite high. Although happy with this news, UPU-6 was concerned about bearing the ‘burden’ and ‘responsibility’ of another girl child at her age and expressed this to the provider. However, the provider assured her that nothing was wrong, and that UPU-6 would conceive naturally in due course. When UPU-6 remained childless after a few more cycles, the couple decided to consult another doctor. In time, they had been to most of the gynaecologists in the city, but to no avail. The pursuit of ‘treatment’ for their childlessness also took the couple to other cities, both within Uttar Pradesh, like Agra and Mathura, as well as other cities, like Patiala, Ambala and Saharanpur in Punjab, and Delhi and Mumbai. In addition to allopathic treatment, the couple also tried Ayurvedic medicine and home remedies. Accessing ‘treatments’ in different places started taking a toll on the husband’s work, and it became increasingly difficult for him to get leave. As a result, UPU-6 started going to clinics by herself, with her husband joining her when needed.

Nonetheless, the long and arduous treatments have taken a toll on UPU-6’s body. She has put on a lot of weight, and often feels like her body is withering under the burden of all the medicines she has taken over the years. She suffered from severe insomnia, which led to mental instability. She expressed anxiety all the time and felt as though her body was ‘being hollowed out from the inside, like with cancer’. Yet, she has great regard for the provider and remembers that there were 15 other women in her batch who had undergone IVF, of which 13 had gone on to give birth to healthy babies. UPU-6 pointed out how ironic it was that she had spent her entire married life looking for a ‘good’ doctor in faraway places when the ‘best’ one was right next door.
I.11. Accessibility in the public health sector

Interviews with users reflected the different levels of robustness of the public health system in the three research states. The public health system in Tamil Nadu is more developed than the system not only in Uttar Pradesh, but also in most other states in India. In contrast, in Orissa, the availability of even basic facilities is extremely limited, especially in rural areas.

This differential extends also to the available facilities for infertility treatment. In all three states, facilities for infertility care and management were inadequate at public health set ups, even at the tertiary level. This was particularly evident in Orissa, where even basic screening for infertility is unavailable in the public health system. User narratives suggested that the lack of provision for basic infertility care and management in the public health system resulted in them accessing, in the first instance, or shifting, in the course of their treatment, to private services. A user from Uttar Pradesh (UPU-7), began her treatment with IUI in a tertiary level public health set-up in Lucknow, but shifted to private health care for further treatment. Another from Tamil Nadu said:

When we went to the Government Hospital, they said that there is no treatment there for our problem. TNU-14

While the non-availability of ARTs in the public health system has been a matter of debate, the non-availability of even basic screening facilities and/or treatments for infertility in the public health sector raises concerns regarding equity and accessibility. Infertility care and management, which includes not only technological intervention and curative care but preventive care as well, has never been an integral part of India’s health policies. Rather than focusing on preventive care, public health today is largely dominated by a ‘technocentric perspective’ (Qadeer, 2010)\(^\text{12}\) and concentrates on ‘single-focus’ programmes that are sponsored and supported by international agencies (Das Gupta et al, 2009)\(^\text{13}\). Though access to essential clinical examination, investigation, management and counselling services for infertility have been discussed in Five Year Plans, there is limited focus on services for the infertile in the Reproductive and Child Health Programme (Planning Commission, 2002 in Widge and Cleland, 2009)\(^\text{14}\). Widge and Cleland (2009) list some of the barriers to public sector infertility management in India as: ‘Lack of infrastructure and equipment; lack of information, skills, training and exposure; preoccupation with other public health issues; low priority at all levels; infertility patients are time intensive and high maintenance; private practice by public sector doctors; non-implementation of clear protocols at primary, secondary and tertiary levels; and inadequate regulatory mechanisms.’\(^\text{15}\)

Further, a disproportionate emphasis on population targets dominates the public health mindset and operational plans. A holistic perspective is required, one that gives greater credence to the ‘social context of health and health services’ and goes beyond narrowly determined paradigms of ‘technological and educational interventions’, thus serving developmental and welfare needs (Qadeer, 2010)\(^\text{16}\).

I.12. Stigma and secrecy around ART procedures

Despite the pressure to have a biological child, ‘treatment’ for infertility appears in several cases to be stigmatised and shrouded in secrecy. ARTs in particular are more stigmatized
as they involve the artificial handling of gametes outside the body, which goes against the
perception of ‘normal’ and ‘natural’ conception. With the possibility of using donor gametes
in ARTs, suspicions may be raised about the child’s genetic parentage. This may motivate
users to shift to another town/city in order to maintain privacy and confidentiality. Given
such a context, it is not unusual to find that users often do not even inform close family
members about the procedure, far less involve them in it. Further, some users chose not to use
donor gametes, and continued with other ‘treatment’ options or even opted for adoption.

Even if it is a success, we are not going to tell anyone that we had our child
through this method. It is going to be a secret between both of us. There is no point
telling anyone else.  ORU-14

People and family members only know that in trying for a baby, we were under
medical treatment for a long time. But, no one knows that any kind of artificial
procedure has been used for conception. ORU-21

Matters of reproduction and sexuality remain strictly regulated and contained within
the realm of the private and the personal. Users undergoing ARTs feared rumours,
stigma or ostracism, and were concerned that their children born through ARTs could
similarly encounter these exclusions in their lifetimes. As such, stress and anxiety that
the ‘truth’ about ART use for conception could be exposed remains even after the birth
of the child:

We haven’t thought about telling our children about the treatment yet. We are
very sure we won’t tell the others though. We don’t want our children to hear
wrong things about their birth from outsiders. UPU-4

We won’t even tell her [the daughter] about this. If she comes to know somehow,
then it is different, but we won’t tell her. After all, we have to look after the future
of the child and it might create problems. ORU-22

Very few users seemed open to admitting their use of these technologies, and stated
that they did not intend to hide this fact from others.

I personally feel that many of our citizens do not have a good opinion about ARTs,
and they feel that all ARTs use either donor eggs or donor sperms. They fail to
understand the concept thoroughly before passing comments. This should change
and people need complete information about ART services and how it is done in
various hospitals…Now we have two children and we concentrate on bringing
them up. Everybody knows that we have had a child only after ART treatment.
TNU-10

Yes, I will definitely tell her [child]. I have collected all the documents. I have
also taken pictures of the hospital and the doctor, which I will show her. She will
know everything. I’ll tell her about every step of the treatment. She should know
how precious she is and all that her mother went through to have her, how many
people helped in bringing her into this world, especially the good doctor. She will
understand how special she is. UPU-12
These days, you don’t need to tell children anything. They get to know on their own. Now look, I am conceiving after 22 years of marriage. I cannot hide this fact. She will also come to know, when she is old enough to understand. And there is nothing to hide in this. In fact, she must know. UPU-13

Every year on my son’s birthday or around that date, Dr. XXX organises a function at the clinic for all the children and he cuts a cake on that day. You must have noticed the big poster of the doctors with my son. He was the first IVF baby in the Centre. A lot of newspapers had written about him at that time. I have kept all the clippings in a scrap book and like to look at it every now and then. UPU-1

While ARTs are ‘irregular’ in that they comprise a technologically-facilitated deviation from natural/ised and normal/ised conception, this irregularity appears to be either stigmatised or embraced, depending on the associations and meanings attributed to it. Clearly, UPU-1’s was not a regular ART case. Rather, as the city’s first IVF baby, the story of her son’s birth through ARTs has achieved celebrity status. Media coverage of this ‘technological miracle’ has made his birth a signifier of modernity. Outpourings of congratulations from relatives and friends have followed, as the birth is seen as a ‘good’, even ‘great’, irregular (this is in marked opposition to the more general perception of ART births as not acceptable). With such a high degree of social validation, it is perhaps not surprising that UPU-1 is able to embrace, even showcase, the truth about his birth. In the case of one of the above narratives, that of UPU-12, the use of ARTs imbued the birth of their daughter with a sense of how ‘special’ and ‘precious’ she was.

I.13. Failure is not the end

Infertility treatment in general, and ARTs in particular, involved long and demanding procedures. In spite of that, in several cases, users did not stop their efforts at achieving fertility with the failure of ARTs; they continued their ‘treatment’ with practitioners of alternative medicine. For instance, after a failed IUI and IVF cycle, ORU-20 mentioned:

About one and a half years back, we went to a doctor in the village. He is a well-known Ayurvedic practitioner and many people with similar problems go to him.
Further, users who are unable to bear the financial burden of ARTs discontinued with them, while continuing other forms of infertility ‘treatment’, till they could accumulate sufficient finances to re-start ARTs. Thus, the pursuit of a child included but went beyond ARTs, and there was no definite, generalisable boundary for when each ‘treatment’ began or ended. Elaborated in the box (on page 99), is the journey of ORU-16, where the failure of the first IVF cycle resulted in the couple adopting a child rather than continuing with the treatment.

II. Together with and beyond allopathy: Alternatives, religious beliefs and emotional connotations

Accessing alternative forms of treatment in the case of different ailments is practised commonly in India, and a strong tradition and history of this use continues despite the developments in, and the increasing popularity of, allopathic medicine. In the sample, an overwhelming majority of the users (82 out of 86) began their trajectory with the allopathic mode of treatment, while only four started with alternative forms such as siddha\(^{17}\), ayurveda\(^{18}\) and unani\(^{19}\). In most cases, while alternatives might not be accessed at the start of infertility treatment, they were accessed at some stage, albeit later. Just as there were various factors determining access to allopathic treatment (including ARTs), similarly users underwent alternative ‘treatments’ because they were recommended as options that ‘worked’. Users resorted to other treatments when allopathic modes were unsuccessful.

The experience of gathering ‘assistance’ for reproduction appeared to be an interplay of what lay ‘inside’ the ART clinic (technology and treatment), as well as what lay ‘outside’ (faith healing and religious belief). Faith and science become, in this way, tropes that are not mutually exclusive, but rather, that work in conjunction with each other. Despite faith, science is required and for science to work, faith is required. In addition to ART procedures, couples also turned to homeopathy\(^{20}\), ayurveda, siddha, unani and even home remedies. In a few cases, couples had started their infertility treatment with other forms of medicines, highlighting that the ‘treatment’ path treaded was not always uniform or straight forward.

*The first doctor whom we consulted was a doctor who practices unani in Chennai.* TNU-9

*Two years after marriage, when we did not have a child, we decided to see a doctor. On the advice of my grandmother and mother, we went to an ayurvedic doctor in Chhotaip. ORU-7*

*We went to all kinds of doctors, vaids and pandits in Jalgaon, Dabra, Gwalior, Allahabad. Somebody would say eat this vegetable and somebody would say don’t eat this masala. Then someone would say fast on this day. We went to different places for poojas also. Along with these treatments, I also tried many home remedies that people would tell me about. I also took ayurvedic treatment for sometime. There was nothing I didn’t try.* UPU-6
The strong desire for a biological child often cuts across the kinds of treatment sought or undergone. In the treatment trajectory of users, non-allopathic treatment entailed, was not without significant investment. (For a more detailed analysis, see Chapter 5).

In around 2002, we had also tried ayurvedic treatment from a doctor in Bihar. We had heard from some other people that he is a good doctor and many people go to him with the problem of non conception. We must have spent about Rs. 15,000 in those five months. UPU -5

An ayurveda practitioner from a village in Khorda district stated:

A number of people come with infertility problems. In a week there must be around 15-20 patients coming for treatment. It is not only people from this village who come to me, but also people come from the other districts. My medicines also go to cities like Delhi and Bombay. Even educated people, whose relatives stay in these cities, and who have such problems, take medicines from me and send these to them.

For ORU-21, non-allopathic treatment was a significant part of the overall treatment journey:

We also tried ayurvedic, homeopathic and traditional medicines. Along with this, we also went to many babas, temples, kept fasts and offered endless prayers to have a child. Out of desperation for a child, we did whatever people suggested to us.

These narratives highlight the diversity in users’ ‘treatment’ choices and trajectories. As with ARTs, there is also a geographical movement of users in pursuit of non-allopathic treatment. Further, the hope or belief in the efficacy of treatment also cuts across the educational level of users. The treatment process was also fluid, with many medicine systems being accessed at once, many switches being made, and many providers being visited, all of which was motivated by the desire to leave no stone unturned in the quest for a biological child.

II.1 Alternative medicine seen as unscientific and unreliable

Some users who had not accessed alternative treatments claimed that they did not believe in them because of their non-scientific and unreliable nature. Some of the apprehensions were:

My individual perception is that medical science has advanced a lot and proper diagnosis is also very important. A proper treatment should follow the diagnosis. ORU -13

We also did not go to many temples and babas for a child. I don’t believe in all this. If there is a problem, there should be a treatment for it. UPU -8

My husband had got medicines from a local healer (vaid), but I did not take them. I don’t know, but I did not feel like it. You never know what these local healers give. May be they just feed you ashes. I think all of this is a farce, and I do not believe in any of this. UPU -10
II.2 Religious beliefs

Strong religious beliefs were found to underlie most ‘treatment’ journeys. Visiting temples, conducting rituals, keeping fasts, and ‘making a wish’ or ‘asking for a boon’ at particular places of worship were some of the practices undertaken by users. The co-existence of science, technology, and religion is not specific to infertility treatment, and is found in other medical interventions as well. Both–users and providers–seemed to subscribe to the legitimacy of the interplay between the provider and god, and situated treatment failure in the lack of one of the two elements of the interplay. While providers advised the users to have faith in god, users mentioned performing special rituals for the success of the ART procedures.

We offer prayers when others say to do so. When they looked at our horoscope, they said that we have ‘nagadosham’ [curse of the snake god]. So we went to Rameshwaram made a ‘nagar’ [snake god] idol in stone and offered prayers, had a holy dip in the sea and kept the idol in the temple. We were also asked to make a silver idol of nagar and I was asked to take a bath in the temple pond in Tiruparankundram and put the idol inside the pond. TNU-15

I used to have the medicines in the name of Lord Anant Gopal. The medicine was made from a mixture of milk, methi (fenugreek) and some kind of roots. ORU-9
We both have lots of faith in god and we both fast on ‘Sasthi’ [auspicious day for lord Muruga] and apart from that we also fast on the day of ‘Shravanam’ [auspicious day for lord Venkatachalapathi]. On Shravanam day we have food that does not have salt, there is a belief that ‘Perumal’ [God] will listen to our prayers and put an end to our sufferings. We do our regular prayers at home and have gone to all the famous temples in Tamil Nadu. All the gods should listen to our prayers and bless us with a child soon. TNU-12

From 2001 to 2004, when we were not taking any treatment, we went to two dhaams [Hindu pilgrimage sites]. I vowed that I would do all four [that is, visit all the four dhaams] with my child if god was kind to me and blessed me with one. UPU-1

Religious rituals have powerful symbolic and cultural value, and through them ideas of childlessness and ideas of begetting a child both acquire meaning. Therefore, even users who did not believe in religious ritualism, found themselves adopting these measures on the advice of others. Furthermore, family members who might not be involved in, or even aware of, the couples’ ART procedures, were active participants in performing religious rituals for the couple. For instance, mothers and/or mothers-in-law often made religious offerings (visited temples, etc) on behalf of couples. One such temple specifically for infertile couples was referred to by users in Tamil Nadu. This temple is known as Karparakshambigai, and is situated in the district of Tanjavur. Users who had visited this temple had done so alongside their medical ‘treatment’, allopathic, alternatives or otherwise. (see box)

III. An emotional journey

Not only is the experience of childlessness traumatic for users who opt for ARTs, but the ‘treatment’ process itself is a long-drawn-out, uncertain, and emotionally demanding one. This was expressed by users who had particularly unpleasant or unsuccessful experiences. They stated categorically that they did not want to recollect that period or phase of the treatment, as it was too traumatic to recall. Since having a biological child was a priority, an unsuccessful cycle evoked deep frustration and despair among users.

Somehow I was not feeling good about the Hospital. It will also make me think about my dead child, so I decided not to go there again. TNU-6

Maybe we look fine to you right now, but when the first cycle failed, we were very depressed. We didn’t know what to do. That was a very difficult period for us. UPU-8

‘This is an ancient Siva temple about 20 km east of Thanjavur dedicated to Sri Mullaiavananather and Sri Karparakshambigai. It is a huge temple spread over a wide expanse with imposing gopurams and a tank in front of it. It is believed that childless people who worship here with devotion and faith are blessed with pregnancy and pregnant women with safe deliveries. Unmarried women also pray here for their marriages.

Its origin speaks of the story of Sage Nidhruva and his wife Vedhika who conceived after many prayers. Once while the sage was away, the pregnant Vedhika was fast asleep when Sage Urdhvapada came to her door asking for alms. Therefore, she did not hear him and failed to respond. He cursed her and the foetus slipped out of her womb. She prayed to the Goddess who appeared and protected it, keeping it in a pot till it developed into a male child. Naidhruvan,[sic]21
Some users were unable to express the many and intense emotional upheavals they had undergone, and some others broke down while recounting their experiences of childlessness and infertility treatment. The disappointment of not being able to have a child even after undergoing complicated procedures for prolonged periods was also manifested in the form of psychological stress among users. (Discussed in detail in Chapter 4).

Conclusion

It is evident from the study that the causes, perceptions, and beliefs surrounding infertility are varied. While users tread on multiple and sometimes simultaneous treatment paths, women are doubly vulnerable. Women bear the burden of responsibility for infertility and are also the subjects of the treatment process, including in cases of male factor infertility. The desperation to have one’s own biological child results in a long and extended ‘treatment’ journey. This is influenced not only by family, relatives, friends, and providers, but also by various socio-cultural and religious norms. The ‘treatment’ trajectory of couples seeking fertility appears to almost always be multifaceted. In the desperate attempt to ‘solve the jigsaw puzzle’ of having a biological child, all permutations and combinations of ‘treatments’ are tried. Indeed, in many cases, it would not be an exaggeration to say that several years of the couples’ lives, especially women’s lives, are dedicated to pursuing the treatment process. Other studies on the treatment-seeking behaviour of childless or infertile couples also point to multiple treatment options being accessed by them. It is impossible to identify an objective cut-off point for ‘treatment’, as users push the limits of what and how much they can invest in such ‘treatment’, financially, emotionally, or physically. Users also stop different treatments at different points, only to continue some of them when they are ready again, financially or otherwise. Although ARTs are accessed as one ‘treatment’ option, they are not seen as the only option available. Typically, one finds multidirectional trajectories, with ‘treatments’ that can be understood as both vertical and horizontal, that is as occurring consecutively (IUI to IVF), or concurrently (allopathy and homeopathy). Progress is not linear, and ARTs are not the culmination of infertility ‘treatment’, with users reverting back to medical ‘treatments’ or choosing to adopt.

Notes


3 Community perceptions are drawn from the FGDs, the description and participation for which is given in Chapter 1

4 Refer to ‘Infertility in the Indian Context’ in ‘Introduction: Laying the Context’.

5 This number does not include those diagnosed with secondary infertility (13) and those narratives (10) that did not give a clear idea of the number of years before which intervention was sought.

6 Here, demographic literature pertains to the literature available on statistics of infertility – put out both by public demographic bodies as well as their analyses; for instance, data regarding infertility available from the National Family Health Surveys, and analyses of such data by demographers like Usha Ram, Indian Institute of Population Studies, etc.

The definition of infertility (primary and secondary) used here is as per the WHO. For more details, refer to ‘Infertility in the Indian Context’ in ‘Introduction: Laying the Context’.

Filaria is a parasitic infection, which when persistent is known to cause varicocele that is one of the major causes of male factor infertility.

As per the categories in the Census of India, the reproductive age group of the population is defined as all between the ages of 15 to 44 years.

Allopathic medicine is a system of medical practice which treats disease by the use of remedies which produce effects different from those produced by the disease under treatments. (Source: http://www.medterms.com).


Siddha Medicine is a form of South-Indian traditional medicine and part of the trio of Indian medicines- Ayurveda, Siddha and Unani. It is believed to be one of the oldest medical systems. (Source: http://en.wikipedia.org/wiki/siddha_medicine).

Ayurvedic medicine is a system of healing that originated in ancient India. In Sanskrit it is defined as ‘knowledge of living’, and utilizes diet, detoxification and purification techniques, herbal and mineral remedies, yoga, breathing exercises, medication and massage therapy as holistic healing methods. (Source: http://medical-dictionary . the freedictionary.com).

Unani Medicine means ‘Greek Medicine’ and is a form of traditional medicine widely practiced in South Asia. (Source: http://en.wikipedia.org/wiki/Unani).

Homeopathy is a system or therapy based on the concept that diseases can be treated with drugs (in minute doses) thought capable of producing the same symptoms in healthy people as the disease itself. (Source: http://www.medterms.com/script/main/art.asp).

CHAPTER 4

Implications: What ART Use Entails

ARTs are often perceived as technologies that have changed the lives of many experiencing infertility, and that empower women who otherwise have to bear the brunt of the stigma and violence associated with infertility. That these technologies are not without adverse outcomes and risks, and directly impact the health and lives of users, is largely overlooked or not highlighted sufficiently. If at all, the fact that ARTs end the trauma of childlessness is said to outweigh the adverse outcomes and health risks associated with these procedures. This chapter presents the health (physiological and psychological), economic and other social implications of ARTs for users that have emerged from the research.

I. Adverse effects on health of women and children

Recent studies on health risks for women and children born using ARTs have established quite clearly that there is an increased associated risk for peri-natal, obstetric, pediatric and other outcomes (Sama, 2006). According to the guidelines issued by the Society of Obstetricians and Gynecologists of Canada and the Canadian Fertility and Andrology Society, ‘….a higher proportion of ART pregnancies are associated with obstetrical and peri-natal complications and (that) children conceived through ART may have a higher risk of abnormalities than spontaneously conceived children’ (SOGC-CFAS, 2006). A study in France (European Society of Human Genetics, 2010), which followed up with 15,162 children born using ARTs between 2003 and 2007, found major congenital malformation—heart diseases and malformations of the uro-genital system—in 4.24 per cent of the children compared with the two to three per cent that had been established by previously published studies. Other malformations, according to the study, included angiomas, and an increase in rare genetic disorders. Yet another study (Temple University, 2010) has established that children born using ARTs are at greater risk of certain kinds of birth defects, of having low birth weight, and of obesity, hypertension and diabetes later in life.

I.1 Providers’ perceptions

I.1.a. Providers’ perceptions of health risks and adverse outcomes

Of the 43 providers in the sample, 41 commented on health risks and adverse outcomes resulting from ART procedures. No information was available from the remaining two providers. Health risks associated with ARTs were perceived as resulting from the intake of drugs as well as the procedures. Table-18 details various health risks that were articulated by the providers. It also includes procedure related risks and adverse effects such as anaesthetic complications and bruises caused by frequent injections. Some providers across the three states were able to quantify the incidence of risks and adverse outcomes either based on the outcomes, in their clinics or based on available medical literature.
While 60 per cent of the providers stated that Ovarian Hyperstimulation Syndrome (OHSS) was a risk and nearly 42 per cent said that there was an increased risk of miscarriages. Only about 21 per cent of the providers talked about multiple pregnancies, which was an extremely common outcome of ARTs. Just four per cent of the providers mentioned weight gain and hormonal disturbances as adverse outcomes. Most providers did not seem to have even perceived these as risks or adverse outcomes. There were also extreme variations in the providers’ understanding of their incidence. For example, a provider in Uttar Pradesh stated that the chances of having twins were five per cent, whereas a provider in Orissa opined that it was 50 per cent. With regard to delivery following ARTs, while one provider mentioned that the chance of caesarean delivery was almost 99 per cent, another said that it was 50 per cent. These extreme variations in providers’ responses reflected the very subjective information provided by clinics as well as the absence of systematic collation of data based on the experiences of clinics providing ARTs.

About nine providers (three in Orissa, two in Tamil Nadu and four in Uttar Pradesh) in the sample stated the adverse outcomes and risks of ARTs without any hesitation, prompts or caveats:

**ORP-2 mentioned:**

*Hyper stimulation syndrome: Chances are very high. In fact, the woman in Room X [in the clinic] suffered from OHSS. Spontaneous abortion or miscarriage: Chances are very high. Ectopic Pregnancy: very high proportion. In fact, there have been six cases of ectopic pregnancies in the last six years. For this we blame ourselves. Multiple births: Rate of multiple births is also very high. It is a bad thing, but as a doctor I would say one has little choice. ARTs as a medical procedure do have this disadvantage; the chances of premature births are many times higher. In fact it is three times higher than the deliveries through normal conception. Ovarian Cancer: this is still questionable, but it is a possibility. Early Menopause: it is an incidental problem with women accessing these technologies.*
TNP-1 opined:

 Definitely there are health risks. Hormonal injections are given to the woman and to support the baby. I don’t know how they [women] do it. They are constantly being pricked–injections, tests, etc. OHSS is life threatening.

About seven providers initially dismissed adverse outcomes and risks, and mentioned them only following probes by the research team, a reflection possibly of their reluctance to acknowledge the risks associated with ARTs, or their limited perception of risk itself:

Side effects? There are no side effects. [Upon probing] Till now, there have been no side effects. Only the risk of OHSS, if you have heard about it, is there. There may be some complications because of this. UPP-10

There are no health risks as such. [Upon probing] There may be some hormonal disturbances. But that gets okay after two or three menstrual cycles. TNP-5

‘In 20 to 33 per cent of the cases, mild OHSS is said to exist, while in one per cent of the cases, severe OHSS could lead to hospitalization, renal failure and death’ (Sama, 2010: 95). The absence of adequate safety data for many infertility drugs, especially the class of drugs that suppresses ovulation such as Lupron, has been pointed out by women’s health activists, even as anecdotal evidence of harm keeps growing. Twenty five providers acknowledged that some adverse outcomes and health risks maybe associated with ARTs, but were quick to dismiss, minimise and even rationalise these using various caveats. Risks were ‘normalised’ as age related complications that were more frequently observed among those accessing ARTs due to their advanced age and associated poor health profiles:

There are no health risks. Women say that they gain weight, which is due to the hormonal medicine. Other than that if there are any problems they are not because of the procedures. Usually women who come for these procedures are older and this may be the reason why some problems arise. TNP-1

TNP-3 opined that users who were accessing ARTs had pre-existing health problems and hence were not comparable with others who were not undergoing ARTs:

‘Lupron (leuprolide acetate) is the drug that is most often used to shut down a woman’s ovaries, before stimulating them with other drugs to produce multiple follicles. It has caused a range of problems reported to the (US) Food and Drug Administration, including rash, dizziness, chest pain, nausea, depression, amnesia (disturbance in memory), hypertension (high arterial blood pressure), muscular pain, bone pain, liver function abnormality, vision abnormality, anxiety, myasthenia (muscle weakness) and vertigo.’ (Norsigian in Sama, 2010: 95)

It would be wrong to compare these men and women with the healthy population because they have problems. If one was to measure the health risks in a woman having a late pregnancy in the healthy population with that of a woman having a child late through ARTs, it would not be a correct comparison as she [the latter] has a problem anyway. The patients who come to us have problems in the first place. For example, if a man can produce only ten sperms, then there is something wrong with him. The health problems exist with the profile of the patient. Normally with increasing age, health decreases, causing diabetes and many other problems.
UPP-2 believed that users’ carelessness also contributed to the outcomes:

*Miscarriages are a big problem. Almost 20 per cent of the pregnancies end up in spontaneous abortions. There is nothing a doctor can do about it. Sometimes it is also because the patients are careless.*

Some providers believed that the ART-related health risks were similar to complications that arise in any normal pregnancy and delivery. According to TNP-11:

*There are no health risks as such. [Upon probing] There are chances of ectopic pregnancies and miscarriages, but these are also there in case of normal pregnancies.*

One provider, ORP-3, even compared ova donation with blood or eye donation, thus dismissing any additional risks:

*There are no side-effects of a process like ova donation. It is the same as blood donation or eye donation. Have you heard of any complications with these?*

Though blood and eye donation processes are not without some risks, to compare ova donation with them is to be reductive, almost denying significant other risks involved with the latter. Providers also dismissed adverse outcomes of ARTs by stating that these were ‘statistically insignificant’, minimal or extremely rare:

*IVF and ICSI do raise concerns but there are no statistically significant health problems. It all depends on the health condition of the woman. If the woman had blocks in her tubes earlier, for example, the chances are higher. With a well-equipped lab, and a trained person, there should not be any major issue. TNP-3*

*Our patients do not face many side effects and other problems. They have minor problems, which vary from woman to woman, and some women don’t even have that. … Sometimes there may be premature births, and genetic disorders may be possible, but that is also very, very rare. UPP-5*

Some providers dismissed the health risks associated with ARTs by categorising them as ‘manageable’, thus validating and normalizing their occurrence as routine and resolvable:

*The side effects of the procedures are minimal. Most common is OHSS, which happens at the time of stimulating ovaries for producing eggs. But this is manageable. ORP-3*

Some providers mentioned health risks that they were ‘aware’ of, while clarifying that they had not experienced these in their own clinics as they were following standard protocols. UPP-11 said:

*My cases have not had any such thing as yet. I give as less hormones as possible. These drugs are very harmful. Our protocol is such that we do not give unnecessary hormones. If we can get four or six eggs, maximum six eggs, that is enough. If about two or three embryos are formed, then it is more than enough. We do not transfer more than three embryos.*
Some providers felt that users did not ‘mind’ multiple pregnancies. 

*Women have twins and they are happy with that. So that is not a problem.* ORP-1

The providers attempt to ‘justify’ potential risks, which are often portrayed as safe. They also place the burden of the risk on users who willingly undergo these procedures. Some providers did not give much credence to health risks because of insufficient literature or research about them. As TNP-9 opined:

*There is not enough literature on it. For that we need to keep a track of the patients after treatment. Someone should do a specific research on this, but it is difficult to carry out such a study as it needs involvement and it would also consume lots of time.*

Further, long term risks were not taken seriously by most providers as they were perceived as something that might happen ‘later on’, and as not having been conclusively established. A few providers denied any long term risks. UPP-10 said:

*I told you, there is only risk of OHSS, otherwise no other risk. That too is an immediate risk, not a long term one. There are no long-term risks because there is nothing artificial.*

### I.1.b. Adverse outcomes in children

Eight providers also spoke about genetic and other abnormalities in children born following ARTs, (two in Orissa, one in Tamil Nadu and five in Uttar Pradesh). Two providers, one each from Orissa and Tamil Nadu, said that there was a higher incidence of neonatal deaths with ARTs.

ORP-1 talked about the long-term adverse outcomes that their clinic had witnessed in children:

*In the last four years, 15 babies have been born through ARTs (in the clinic). There have also been two cases of children being born with genetic disorders like Turner’s syndrome*.8

*Now that you are asking about congenital abnormalities, yes, some of our babies have had some abnormalities. But these are very rare cases. So far, out of the 100 cases of IUI, IVF, ICSI, we have had only three such cases.* UPP-2

### I.1.c. Adverse psychological outcomes: Providers’ perceptions

While most providers talked about the physical health implications of ARTs, only three providers (one in Tamil Nadu and two in Uttar Pradesh) said that there were psychological outcomes. UPP-14 stated:

… I think the most common and most important side effects are the psychosomatic effects like stress. Couples and specially women are under a lot of stress throughout the process, and it can be very harmful- it can have adverse effects on their health, including their fertility! So I think more than the other risks, the psychosomatic effects are most serious.
According to UPP-12:

*In infertility treatment, there is a lot of tension and frustration. Patients feel anxious about whether it will be successful or not, from where they will mobilize resources for it. Many times people think that it is better to remarry than go through this.*

Although providers stated various health risks and adverse outcomes of ARTs, the largely casual attitude towards these is a cause for concern. Most providers glossed over the risks with a string of qualifiers, including lack of established data, and the profile of users seeking ARTs—their age, health problems, etc. Moreover, the psychological outcomes were not even acknowledged by a large majority of the providers. Those who did, talked about them only in the context of pressures and expectations of having a child. Providers also dismissed the risks by stating ‘women say…’ in a manner implying that this was not conclusive in itself, thus challenging the credibility of women’s experiences. This attitude is not unique to ARTs. Documented experiences of women’s interactions with the health system over several decades, particularly those of women from marginalised backgrounds, have reinforced the dismissive attitudes and inattention of the medical establishment to women’s experiences and health. Providers, while admitting that health risks and adverse outcomes exist, also distanced themselves and their practice from these, perceiving them not as inherent—related to the technology, procedures or drugs—but rather, as a crisis of management, something that could be easily resolved if the provider was competent. The absence of regulation and research further compounds the non-accountability of providers with regard to health risks.

**1.2. ‘Pain beyond words’: Women’s articulation of adverse outcomes**

Nine users said that they had not experienced any health consequences as a result of ARTs (three in Orissa, two in Tamil Nadu and four in Uttar Pradesh). Four women from Tamil Nadu were just starting their ART procedures and hence could not comment on adverse outcomes. Adverse physical outcomes articulated by the remaining 73 women have been listed in Table-19.

The adverse health outcomes reported by users did not necessarily result from ART procedures alone (IUI, IVF, ICSI), but included other diagnostic and therapeutic procedures such as laparoscopy, hysteroscopy, dilation & curettage, etc. Users also expressed undergoing emotional and psychological stress; this was a result of not just the trauma and stigma of childlessness, but also of the treatment process - repeated cycles, negative outcomes, financial pressures, etc. It was not always possible to clearly demarcate the adverse outcomes of ARTs from that of other treatments for infertility, as most of the women had undergone a range of procedures over several years.

*I had several side effects from the medicines. I was so thin, and then because of the medicines, I developed an allergy to some of the medicines and experienced a lot of nausea and weakness. I also developed a rash and itchiness all over the body. This stopped only when I stopped taking medicines after my son was born. Even today, I suffer from extreme weakness, restlessness, swelling, water retention, and severe back pain.  UPU-6*
There is a constant pain in my lower abdomen, which is sometimes very intense. There is a feeling of nausea and sleepiness. I also feel very weak, so much so that sometimes I am not in a position to even move a small and light vessel. If I get up from a sitting position, then I suddenly get black outs. ORU-10

I still feel the effect of all the medication even after so many years. Every doctor we went to prescribed us so many medicines. ORU-21

While most women stated that they had experienced adverse effects as a result of the ‘treatment’, a few of them either did not perceive these effects as linked to the procedures or did not perceive them as ‘major’ or ‘serious’ problems at all. TNU-34 reinforced this:

Many women are not aware of the mood swings. Many just think that they are feeling depressed, angry, teary, etc. and are not sure why they are experiencing this. It would be better for them if they knew that these mood swings could be caused by medication as it is easier then to blame the medication rather than oneself.

UPU-12 mentioned a range of side effects—excessive vomiting, constipation, severe pain in the joints, weakness, and dizziness. However, she felt that the adverse effects were not because of ARTs but were problems with her body and her own health.

I don’t know if all this is because of IVF or not. I used to experience these earlier also. This is a problem with my body; the doctor is not to be blamed.

TNU-7 had undergone 10 IUI cycles:

Throughout the treatment, I cannot say that any physical discomfort I felt was because of the treatment. I have put on a lot of weight—especially in the last two years. But this could also be because of age. Now I sometimes find it difficult to even get up. I feel heavy. Otherwise I haven’t experienced any side effects.
TNU-11 had had a miscarriage and wondered if it was because of anything she had done:

The reasons for the miscarriage are still not clear to me… it may be due to the daily travel for hormonal injection…I stayed in the hospital for a week after the embryo transfer, and only after everything was normal I went back to my uncle’s place. Even the counsellor was unable to explain to me the reasons for failure.

One user had given birth to a baby girl through IVF. She blamed herself for her infertility, because she had been unable to go through with a painful tubal blockage treatment in the past:

The process of tubal blockage opening was to go on for three months. But it was so painful that I could not bear it after one month. I think it was my fault, my laziness that I could not complete the treatment. It was so painful that I could not tolerate it. I could not gather the courage. UPU-12

A mother finally at 40, she was in awe of the doctor, as well as her husband and his aunt, all of whom were more educated than her. She underplayed her own trauma, and overplayed their goodness and accomplishments by saying several times, ‘I am nothing in front of them’. Instances where women attributed adverse outcomes to their own selves rather than to ARTs (much like some providers) reveal not only a lack of information, but also that the burden and blame for infertility has been internalized in some cases to such an extent as to trivialize side effects and devalue women’s own experiences. Further, ‘the social burden of infertility, and the desire for a biological child, are extremely compelling factors that persuade users to undergo ARTs in spite of the known risks and complications’ (Sama, 2006)⁹.

While a majority of the women stated that they experienced physical and psychological outcomes, eight of the users said that they had experienced only adverse psychological outcomes—stress, anxiety, depression, tension, etc. throughout their ‘treatment’. There was a strong tendency not to conceive of psychological problems as serious enough and/or as requiring medical attention.

Thirty-four women expressed that they were experiencing or had experienced tension, depression, sadness, guilt, etc., (see Table-20) resulting from the procedures and the process:

Of course, there was always tension and anxiety. Sometimes I would get so depressed and worried that I was just not able to sleep. I would stay awake for many nights because of this. This also led to general weakness and headaches and body-aches. UPU-4

<table>
<thead>
<tr>
<th>Table 20 : Adverse psychological outcomes experienced by users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological outcomes</td>
</tr>
<tr>
<td>Stress/Tension/Anger/Frustration/Fear</td>
</tr>
<tr>
<td>Depression/Mood swings/Sadness/Cry/Anxious</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010), as perceived and articulated by users.
I feel that ART techniques are good for couples as it gives a chance for them to try and have their own child. If you ask me personally, when I go through all these procedures, it pains a lot. Women need to undergo so much to have their own child. There are lots of psychological worries when a woman is undergoing ART treatment. I cannot express my pain in words. [Her voice trembled and she tried to control her tears.] TNU-18

I also suffered from anxiety. Every time I went through the cycle, I used to keep hoping, worrying and thinking that it should be successful. I was depressed. When I was alone, I used to think a lot about my fate. Personally the whole process was very traumatic. TNU-10

Due to the lack of information provided about procedures, drugs, adverse effects, risks, etc., users were rarely able to discern if what they were experiencing was an outcome of a certain procedure or drug. Often, users were not even fully aware of the drugs that they had consumed. It is, therefore, difficult to compartmentalise and be specific about the nature and extent of psychological risks of ARTs. However, the above narratives are indicative of the implications of ARTs for mental health.

1.3. Health risks and side effects

Table-21 presents standard drugs and dosages that are used in ARTs, the established risks and side-effects of these, and adverse outcomes and risks associated with ARTs, as articulated by users and providers who were part of the research sample.

A substantial number of health outcomes—physical and psychological—that were mentioned by users as well as providers in the course of the research study, coincided with the established adverse outcomes of the drugs. It is clear therefore that given the absence of standard protocols for practice and redressal, there exists no system to ensure the accountability of clinics to the users.

1.4. Increasing caesarean section deliveries

Many providers opined that the delivery of the child by caesarean section (c-section) was the preferred choice in the case of children conceived through ARTs. This preference for c-section was justified as necessary because of the high incidence of multiple births, the advanced age of women who access ARTs, and the low success rates of the ARTs:

Most of the times, we insist on the patients having a c-section delivery. After going through so much trouble to become pregnant, we think it’s just safer to go with caesarean rather than a normal delivery. UPP-2

All the children [in the hospital] were born by caesarean section. It is basically done so that there is no harm to the baby. Neither the parents nor the doctors want to take any risk. ORP-1

C-sections are more in number in ART deliveries because the pregnancy is precious and the doctors or the parents do not want to take any risks. UPP-23
A couple of doctors, however, said that deliveries by c-section were not the norm and instead, were determined by the age and health of the woman who was giving birth. TNP-24 said:

> Everyone considers this a precious pregnancy. Every attempt is made to ensure that there is no morbidity related to it. But this does not mean that a c-section is done every time. It is done often as both doctors as well as patients consider this a very precious pregnancy. Everyone has gone through so much to get here; no one wants to take a chance. We use c-section especially if the woman is older and when the incidence of diabetes and hypertension is more prevalent. Often patients themselves ask.

In IVF or ICSI, if the woman gets pregnant with a single child, we do all the tests and monitor the child for as long as possible. If the child and the mother look stable, we proceed with a normal delivery. But if the woman has a low threshold for normal or assisted delivery, even if the child is single we go in for a caesarean section. Our first priority is to save the child at all costs, and especially when it has been a difficult pregnancy and also a precious one. But it’s not a done deal that all children born with ARTs are c-sections. We are very cautious with our decisions. When the patients have twins or triplets, we usually do recommend c-section. TNP-4

One provider felt that the rate of c-sections in cases of children conceived through ARTs was not any higher than in the cases of those who were conceived without technological intervention. Rather, she perceived it as a reflection of the larger scenario in private facilities where c-sections were increasingly becoming the norm for all deliveries:

> In the private sector, 50 per cent of all deliveries that take place are through c-sections. ...Because the doctors don’t wait for the right time. They don’t have the time! They just want to get over with the case and move on. So if you compare with that, then the rate of c-sections in IVF is not any higher. Actually, the moment the embryo is implanted after IVF or ICSI, then it is like any other pregnancy. There is no difference between a normal and an ART pregnancy after implantation. UPP-21

TNP-18 said that providers had little choice because of the pressure on them from couples and their families:

> Even if we wanted to do normal deliveries, we are unable to do so. There is a lot of pressure on us from the patients. They literally threaten us .... The chances of failure are high and hence the patients don’t want to take any chances and prefer c-section deliveries. They have to wait for a normal delivery, but no one wants to do that; they are not ready to do that. The risk of money is high and no one wants to take that risk.

Clearly, providers and users do not want to ‘risk’ a baby conceived through ARTs, considered extremely ‘precious’ medically, socially and economically. C-section maybe medically indicated for multiple births, which are highly prevalent in the case of ARTs. However, this rationale may not be necessary for, and should not be stretched to, all cases.
<table>
<thead>
<tr>
<th>(1) Drugs + Injections</th>
<th>(2) What it does</th>
<th>(3) Known risks and adverse outcomes</th>
<th>(4) Side effects emerging from the study: articulated by users</th>
<th>(5) Side effects emerging from the study: articulated by providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bromocriptine</td>
<td>Bromocriptine lowers prolactin levels to normal and allows the ovary to get back to normal</td>
<td>Nausea, Dizziness</td>
<td>Abdominal pain, Anaemia, Anger, Back pain, Bed rest, Black out, Bloated feeling, Blood clots, Boils, Burning sensation, Constipation, Damaged uterus, Depression, Diabetes, Dizziness, Drowsiness, 'Eaten up body', Edema, Exhaustion, Feel 'Body used as experiment', Feel sick with medicines, Feeling Sad, Frustration, Gastric problems, Headache, High BP, Insomnia, Irregular menstruation, Itching in vaginal area, Joint pain, Miscarriage, Mood Swings, Nausea, No lifting heavy objects, Painful procedures, Piles, Relationship affected, Skin problems, Stomach pain, Stress, Tension, Tiredness Ulcers, Vomiting, Weakness, Weight gain</td>
<td>Anaesthetic complications, Cancers (breast and ovarian), Cervical incompetence, Congenital abnormalities, Deep vein thrombosis, Early menopause, Ectopic pregnancies, Edema, Genetic abnormalities, Hormonal disturbances, Hypertension, Miscarriages / Spontaneous abortions, Multiple pregnancies, Placental abnormalities, Pre-term births, Stress, Weight gain</td>
</tr>
<tr>
<td>Letrozole</td>
<td>Inducing ovulation</td>
<td>Osteoporosis, Birth defects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clomiphene citrate</td>
<td>Affects certain hormones in the body in order to stimulate ovulation. This is especially helpful for women who do not ovulate (or who do not ovulate very often).</td>
<td>Breast soreness, Enlarged ovaries, Hot flushes; Blurring of vision, Severe abdominal pain, Allergic reactions, Dermatitis, Depression, Vaginal dryness, Fatigue, Multiple births</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hMG (Human Menopausal Gonadotropins) injections</td>
<td>Inducing ovulation to produce multiple follicles</td>
<td>Enlargement of the ovary and an accumulation of fluid in the abdomen, OHSS, Abdominal distension, Abdominal pain, Fluid retention, Allergic sensitivity, Pain, Rash, Swelling at the injection site, Mood changes, Hot flushes, Nausea, Increased pelvic pressure, High risk of miscarriage, Weariness</td>
<td></td>
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</tr>
</tbody>
</table>

Columns 4 & 5: Compiled from data collected during fieldwork (2008-2010), as perceived and articulated by users and providers.
1.5. *Multiple embryo implantations*

The national ICMR guidelines as well as international guidelines currently limit the number of embryos that can, and should, be transferred, to three.

*No more than three oocytes or embryos may be placed in a woman in any one cycle, regardless of the procedure/s used, excepting under exceptional circumstances (such as elderly women, poor implantation or poor embryo quality), which should be recorded.* (ICMR, 2005: 4)

However, this was not seen to be the case, with some providers stating that they transferred more embryos to ‘improve’ the success rate. Provider UPP-5 explained that countries where only one embryo is permitted to be implanted were those where the government sponsors up to six IVF cycles per couple, ‘but here our aim is to optimise the possibility of pregnancy’. In most cases, the risk of multiple pregnancies and the option of multi-foetal reduction were mentioned by providers. However, one provider from Uttar Pradesh said that the final decision about how many embryos were to be transferred was left to users.

*We generally transfer two or three embryos, but it depends on the patients. What is their financial situation? Can they afford any more cycles? They generally want it to be successful at one go only, because they just cannot have another cycle. Sometimes patients also do not want foetal reduction. They want two or three children at the same time. Because they cannot afford [the treatment].* UPP-9

Often, couples who seek infertility treatment are ‘desperate’ to conceive and might not have the wherewithal to make an objective decision with regard to the risks of a multiple-embryo transfer. Hence, the provider is duty-bound and obliged to inform and guide users about the recommended protocol.

II. Under-informed or uninformed

Lack of sufficient and appropriate information presents a barrier to users giving informed consent. The non-serious perception of risks and outcomes by providers directly impacted users’ access to information and in turn, their decisions regarding ARTs. The ‘counselling’ provided in most clinics was limited to minimal communication regarding the costs, procedures, etc., with the exception of a few clinics that had set up more comprehensive systems for counselling.

A correlation between access to information and the users’ socio-economic status, including levels of education, was observed across the three states. Although a ‘well-educated’ user did not always have access to comprehensive information or counselling, the level of education by itself as well as as an indicator of class, did appear to impact the nature and extent of information provided to users.

This was particularly evident in Orissa and Uttar Pradesh, where users with lower education levels (including non-educated users) were often completely ignorant of the
details of the procedures that they were undergoing. These users were generally not in a position to negotiate with providers, thus revealing the authoritative power of the providers, and compounding their dependency on the latter for information:

*We were not informed about any of the procedural details by the provider during IVF. We just kept doing whatever he advised. Sometimes when I would ask him for any kind of details, he would say, ‘You don’t need to understand anything. I will do whatever is needed’. No information regarding the success or failure rate, side effects, and multiple births was given to us.* ORU-21

*The doctor knew best and we did not question her. The doctor is very great. I am nobody in front of her. Just by hearing her say that things will be okay, half the problem and pain goes away. Whatever she does is right. I do whatever she tells me to because I am not more accomplished than her. I am not more intelligent than her.* UPU-12

*The doctors also never explained the procedure to us. He [the doctor] used to tell our brother-in-law everything and we knew only what he [the brother-in-law] told us. I do feel that this attitude of the doctor is also because of our level of education. If were more educated, we could have asked at least some things. No counselling was provided to us prior to the process. Doctors also never give the real picture of the situation. They always give hope so we can be optimistic about successfully having a child.* ORU-2

Moreover, users with higher education levels had access to other sources of information including popular media like magazines, brochures, internet, etc. They were also better able to articulate the details of their diagnosis and procedures, and generally reported a better understanding of the overall process from the provider. In some instances, information deemed relevant was provided to husbands or other members of the family who were seen as ‘managing’ everything (including resources), or otherwise considered ‘worthy’. As ORU-18 shared:

*When my husband used to speak to the doctor, I would sit outside. All the information was given to him only. All that the doctor ever said to me was not to worry and that I would definitely have a child. I also never felt the need to inquire about these things from the doctor as my husband was looking after everything.*

The nature and extent of information that women users were ultimately privy to was limited and depended entirely on the discretion of providers, partners and family members. As pointed out by ORU-22’s husband:

*The doctor asked me not to tell her about this as she might get tense and scared. Therefore, I did not tell her about all these things previously.*

Differential counselling on the basis of the individual users’ gender, class and education levels, points to the deeply entrenched patriarchal attitudes of ART providers, as much as to the need for binding regulation.
II.1. Consent and counselling

In most cases, users’ consent was perceived as important only to pre-empt any kind of legal and other complications, and to diminish the accountability of providers. The consent process did not appear to promote the agency of users to take informed decisions about their bodies and health. In such a scenario, users too perceived consent merely as a ‘form’ that required their signature prior to a procedure; a formality that did not warrant too much attention.

We were given a form but it was more like a risk undertaking. Nobody reads such forms. Anyway, they just mention that if you die during the procedure, then the clinic will not be responsible for it. ORU-4

Some providers held similar views; UPP-5 stated:

You know, many times patients also harass us. Everyone thinks that doctors take so much money, they harass patients, but I think the patients also harass the doctor. This case12, it was a nightmare! It went on for quite some time and then we showed their signed consent forms in the court and that really saved us. These consent forms are very important. Since then we take special care to get consent forms signed. We learnt a lesson.

Although 15 clinics (four in Orissa, eight in Tamil Nadu and three in Uttar Pradesh) said that both the husband and the wife were required to sign the consent forms, proxy consent was not uncommon. This was highlighted particularly by a few providers in Uttar Pradesh. As UPP-10 said:

Anybody can sign the form. It is generally the husband who signs it.

Several users’ narratives also confirmed this:

I am not aware of any such form. Even if any such form has been signed, it would have been done by my husband. Whatever information the doctors were giving was given only to my husband. ORU-8

The above quotes demonstrate a violation of what the ICMR guidelines have stated as mandatory in the context of any person(s) undergoing ARTs. Proxy consent taken from a relative or only one partner, especially the one who is not actively undergoing the procedures nor directly impacted by them, is an absolute travesty of free and informed consent. Further, as stated in the guidelines, it is important that information be provided and consent taken at every stage of the process. Counselling per se encompasses much more than information transaction regarding costs and basic procedural details; it requires discrete and trained human resources to address the emotional and psychological state of the users throughout the process of ‘treatment’. However, a far more restricted and narrow view of counselling and consent was regarded as adequate by most providers.

‘No treatment should be given without the written consent of the couple to all the possible stages of that treatment, including the possible freezing of super-numerary embryos….. Specific consent must be obtained from couples who have their gametes or embryos frozen, in regard to what should be done with them if he/she dies, or becomes incapable of varying or revoking his or her consent.’ (ICMR, 2005)
III. Implications for the sexual lives of users

‘The complex experience of childlessness is viewed as a condition of infertility, and various mechanisms of monitoring, control and intervention are justified on this basis. Medicalization thus, becomes a process through which a women’s relationship with her body is mediated through technology’ (Sama, 2007: 26).

Of the couples who commented on the impact of childlessness and ARTs on their sexual lives, several made it apparent that the treatment had negative implications. In an extension of the medicalization of their bodies, the couples undergoing fertility treatment found themselves submitting to sex according to a ‘plan’, with the singular aim of conception. This made sex more mechanized than spontaneous.

After marriage our sexual life was nice and good. But frankly speaking, now we both have lost interest. Now we have sex only to have a child and there is not much pleasure in it. I don’t want to talk about this. TNU-18

Our sexual life is definitely affected in a way, because we are told to abstain from sex for certain periods as part of the treatment. ORU-3

Now we have sex to conceive. I cannot say that there is pleasure in our sexual life; rather, there is pressure to perform better and have a child. Now our sexual life is to have a child. TNU-13

Earlier, when we were undergoing treatment in Delhi, the doctor would map out my fertile period and tell us to increase sexual activity at that time. However, we never really used to stick to those recommendations. You can’t do it by force. Sometimes it’s just not possible. UPU-3

Although her own sexual relationship with her husband was ‘not really affected’, UPU-5 commented more generally:

Your personal life is definitely affected by these technologies, in the sense that it is completely disturbed. One has to follow just what the doctor says. Everything needs to be done as per their advice. The relationship between a husband and a wife is something that is delicate and might get strained because of this. As it is, one is stressed, and then there is an additional pressure while undergoing these technologies. Some kind of confrontation is bound to happen.

On the other hand, some couples highlighted their closeness and compatibility and denied that their sexual lives had been affected by the ‘treatment’. TNU-14 said:

In our case, we talk with each other. This gives us moral support. Couples who opt for ART treatments should keep this in mind. Sharing your concerns with friends and colleagues eases your heart and relaxes your mind. But sharing your concerns with your life partner is truly fruitful. When there is mutual understanding, life becomes better and the bond between a husband and wife is strengthened.
TNU-16 from Villupuram district in Tamil Nadu was married in 2000. In 2001, after a year and a half of being married, she and her husband went for a check up to Hyderabad (Andhra Pradesh). They were advised HSG and laparoscopy for a hormonal problem. She was prescribed chlomiphene and folic acid for three months but there was no improvement. After six months, i.e., in 2003 she underwent two IUIs with a gap of six months in between the cycles. However, both were unsuccessful. In 2004, she came to Madurai (Tamil Nadu) and was asked to go in for continuous treatment. However, she was working at the time in Andhra Pradesh, and did not undergo treatment till 2006. In 2006, she went to a very reputed ART clinic in Chennai, but was not happy with the services and found it too expensive. In 2007, she visited a gynaecologist in Villupuram who suggested that she undergo IUI with donor sperm. However, she and her husband decided against the donor programme. She then quit her job and decided to stay with her grandmother and aunt in Madurai (2008) and continue treatment there. She was asked to try to conceive normally at first. After trying for three months she has been asked to undergo IUI. Her husband continues to work in Villupuram.

UPU-8 denied that her relationship with her husband had been affected in any way because they couldn’t have a child. She said:

*In fact, he has become more caring now. He gives me a lot of attention.*

That ARTs seek to direct the sexual lives of users is clear; however, different users negotiated the situation differently with their partners through the ‘treatment’ process. Given that women and men are not homogenous categories, their positioning and the diversity of their responses to a situation must be understood not just socio-structurally, but also individually.

**IV. Locating, relocating**

Undergoing ART procedures ‘is not restricted to the clinic alone, outside which one’s daily life can be reclaimed’ (Sama, 2006: 65). Instead, ARTs claim various aspects of the lives of users, especially women.

The research clearly highlights the movement and relocation of users and sometimes families (particularly women’s natal families) towards accessing ARTs. Such movement across towns and cities, districts and states is not uncommon to access medical services that are either unavailable, inaccessible, or of poor quality in the area where users reside. Similarly, users in the research sample spoke about the journeys that they had undertaken towards a successful outcome, that is, a child. Users, particularly those who had been undergoing ARTs for longer durations, had moved across several towns and cities seeking ‘better’ and comparatively cheaper clinics. For instance, ORU-6, from Jharkhand had been accessing infertility treatment for nearly 17 years from Ranchi (Jharkhand), Mumbai (Maharashtra), Bhagalpur (Bihar), Kolkata (West Bengal) and, at the time of the interview, Rourkela (Orissa).

The choice of destination for ART ‘treatment’ was often directed by the location of supportive family and friends, and the choice of providers, dissatisfaction with experiences in other clinics, referral by doctors, etc. (for more on treatment trajectory, referral mechanisms and movements, see Chapter 3 - Section B). The shifts undertaken by users were not limited to geographical relocation alone but also involved the reconfiguration of social and other relations that make up people’s lives. Invariably, the experience of moving was extremely gendered; ART procedures are primarily carried out on women’s bodies, necessitating their constant movement for visits to the clinics. Men’s role, comparatively, is limited.
Users also moved to places where they felt that they would be assured of anonymity throughout the procedures. A few users mentioned that they had not disclosed even to immediate family that they were undergoing ARTs and hence accessed them in ‘distant’ clinics.

TNU-34 had come from abroad to access ARTs:

XXX is also a good place to come to because it provides a great degree of anonymity.

According to TNP-18:

Patients keep changing their doctors. This is probably because they want to keep it a secret that they are going through such treatment. People migrate from place to place for treatment. They go from Erode to Coimbatore, Salem to Coimbatore, Erode to Salem and even to Chennai, and outside the State sometimes.

Driven by the desperation to have their own child, and given the low success rates of ARTs, users were willing to access these technologies from recommended providers who had a good track ‘record’ even if this meant being on the move, traveling considerable distances, or even relocating temporarily to another place. As ORP-13 shared:

When I hear from someone that a particular doctor is good, then I feel we should go [there].

V. Disruption in work and occupation

Seven users (two from Uttar Pradesh and five from Tamil Nadu) had discontinued working as a consequence of the ‘treatment’. The users said that their work suffered because they had to be absent for long periods of time. While some jobs allowed the users to be on leave, others had to quit because of their irregularity, as ARTs were time-consuming and exhausting. Those who did not have a fixed salary, or belonged to the unorganised sector, were more prone to loss of wages. Some women could not continue working due to adverse outcomes of the treatment. Daily routines often revolved around the procedures, an arrangement that was difficult and inconvenient for women, but one that was also perceived as being necessary and beyond their control:

I have exhausted all my leave in the course of the treatment. On the day that I am supposed to visit the doctor, I work in the morning, leave from there after work, and reach here [home] in the evening. Then immediately we have to come to the clinic, and it is not that the doctors will see you at the time they have given. One has to wait, sometimes even for two hours. Sitting there and waiting for the doctor is quite exhausting in itself. By the time one meets the doctor and goes back home, it is almost late night. The next day I have to leave early morning from here to reach my office on time. It is really stressful and time consuming. Sometimes, if I am late or not going, then I have to inform the General Manager. This is also awkward, because I am the only female staff in the branch, and these kinds of problems one is not comfortable sharing with male colleagues. ORU-13

Doctor had advised not to do heavy work and lift loads. But one cannot just stop doing household work and sit. ORU-2
In one instance, TNU-34 was able to secure part time employment that allowed her to accommodate her busy ‘treatment’ schedule and continue working:

> There has been tremendous support on the work front. XXX provides a system of part time work for those who have to care for family members with disability, illness, old age, etc. I applied for this as I was not able to manage otherwise. I was the first person to be given part time for this reason [treatment for infertility]. So I can continue to earn some income.

Users also reported feeling lonely; they felt that their work had provided much needed distraction, emotional support as well as financial resources, some of which had been now lost. TNU-10 said:

> When I was working, I had more outlet as I could spend time with my colleagues. I did not really think about my problems. In 2005, sitting at home alone during the day used to make me think of all kinds of nonsense.

Apart from women users, some of their husbands also mentioned disruptions in their lives as a result of ARTs.

> I was an agent with a company. I am unemployed since the past two months. I have to frequently be on long leave and am unable to do any work. Now I will go back and try again. UPU-9

> This [the treatment] is very inconvenient and we encounter a lot of difficulties. Now we are stuck here, while her medical leave is piling up in the school. I am also unable to hold on to my job. I had to leave my last job and am not able to go for the new one. My work is going hay-wire. Of course it is problematic. UPU-9

ART procedures appeared to take significant control over the lives of users (especially women), leaving some women with no choice but to be full time ‘prospective mothers’.

**VI. Affordability**

The costs of ‘treatment’, the low success rates and the resultant need for successive ART cycles, as well as the pressure and desperation for a biological child, were factors that severely impacted the economic status of users accessing ARTs. Users borrowed money, sold and mortgaged assets, etc., to raise resources to undergo these procedures:

> It has been a long and financially draining process without any successful result. It is actually very frustrating for us. Before the IVF procedure, I consulted my in-laws (wife’s parents) also and told them that lot of money would be spent on it. They told us to go ahead with it and not to think about the money. We have spent almost everything on it. To construct a pucca house, we had got iron rods, chips and other materials, but now we don’t have any money left for this (house). We also sold some of these things for money and are now left with only the bricks. Now I feel that perhaps we should have spent money more carefully on the treatment. Now we have neither money nor a child, and we are losers in both ways. We are completely in debt and don’t know how to repay the loan amount. ORU-2
Other users considered innovative ways of earning quick money, repaying loans or cutting back on expenditure. ORU-4 said that while she was cutting down on her household expenditure to save money for further ‘treatment’, she had also considered participating in a popular game show on television:

*I had also considered participating in Kaun Banega Crorepati to earn quick money and fame.*

The economic implications of ARTs for couples appeared to be quite severe. Users were found to be pushing their limits of affordability as much as they could. (This is discussed in detail in Chapter 5).

### VII. Gendered burden of payment

Although infertility affects both men and women – it is usually the woman who is blamed for childlessness. This reasoning emerges from a patriarchal belief system that treats reproduction as a woman’s responsibility (Sama, 2006:8).

The present research not only reinforced this, but also its extension to the women users’ natal families, which were blamed for ‘defective goods’ and expected to ‘set right’ or ‘fix’ the situation. As TNU-7 said:

*My parents initially supported us by paying for the treatment. Being the girl’s parents they felt that if we did not have a baby, if I did not conceive, it was their responsibility.*

Her husband added:

*When we went to the hospital for treatment, my mother said that only my mother-in-law should meet the medical expenses. At that time my mother-in-law was busy with her second daughter’s marriage preparations. She agreed that it was her duty and promised to give me the money later, and asked me to proceed with the treatment with the money I had. When my mother came to know about this, there was a big fight. It resulted in us dropping the treatment. Now we live separately without the support of either of the families because of this problem.*

In some cases, the woman’s parents paid, at least in part, for the ‘treatment’ regardless of the diagnosis. As pointed out by TNP-19:

*Usually parents of the girl bring her [for treatment], even in the first instance, as though they are responsible for some ‘defective’ goods.*

Parents or families of 11 women users had been approached by the couple for financial support and three more users said that they might approach their parents if necessary. Seven of the users said that the male partner’s families, also extended some financial support. However, financial support from the male partner’s family was available mostly in case of joint families wherein there was joint ownership of financial resources.
Women’s families also played a critical role in providing non-financial support during the entire ‘treatment’ process, as reinforced by thirty-two users. This included emotional support, and accompanying and staying with the users, especially women, during ‘treatment’. Mothers of women users were particularly involved throughout the process as care-givers. Such support was needed for varying stretches of time, ranging from a few days to several weeks, to many months and years, given the low success rates of procedures.

*After the fifth month of my pregnancy, I was advised complete rest. I was in bed most of the time and my mother took care of me. She stayed with me for months on end.* TNU-10

As mentioned previously, users’ choice of clinics were also dependent on the presence of their parents and families in that city. TNU-38, for example, decided on a hospital in the town where her natal family lived. She moved from Coimbatore to Vellore for this purpose, although ART clinics were available in Coimbatore as well, where her husband continued to work:

*My parents are aware of the treatment that I am undergoing but my in-laws are not aware. We did not want to tell them as they may not understand and may get upset. Since I started my treatment I have been staying with my parents. My mother accompanies me for scans and tests.*

Thus, it is clear that in several instances, women’s families provided support—financial, emotional, and logistical—quite unquestioningly, managing the woman’s (and therefore her family’s) ‘responsibility’ for infertility, as a given.

**VIII. Other gendered implications**

This research has reiterated certain deep-rooted gendered notions that are internalised and reinforced through the medical system, whether in the context of the invisibilization of male infertility or sex-selection practices. As TNP-19 said:

*If it is a male problem then unfortunately there is a lot of pressure on me. I have had three or four male patients with azoospermia who have begged me not to reveal this to their wives. They have pestered me to carry out Artificial Insemination with Donor sperm (AID) without their wives knowing. One man and his parents came to me. He had azoospermia and they pleaded with me not to reveal this to the wife. They wanted the father-in-law’s sperm to be used instead. They did not want the child to be outside their gene pool. I imagined the wife carrying the father-in-law’s child and wondered how she would face him, and that she was not supposed to know. I refused to do it. In another case, they wanted the man’s brother’s sperm to be used as the man had a problem. The wife knew and I did it, but luckily it was not successful.*

Given the potential for pre-selection of the sex of the child through preimplantation genetic diagnosis (PGD), ARTs raise grave concerns about exacerbating sexism, threatening the well-being of children, and setting the stage for consumer eugenics in which parents are sold techniques to select not just their child’s sex, but a range of other traits as well (Darnovsky, 2003)\(^7\). In the guise of free choice, eugenics may also be promoted through the screening and elimination of all ‘abnormalities’. As such, genetic reductionism challenges
the social mode of understanding and responding to disability, and centre-stages only biology and ‘abnormality’.

Of particular concern in India, also is sex-selection; India is already grappling with astonishingly skewed sex ratios, with an estimated 50 million girls ‘missing’ (Agnivesh et. al, 2005) from the Indian population because of sex-selective abortions, female infanticide and the neglect of the girl child. Almost all ART providers from the sample stated that they were against sex-selection. While asserting that an equal number of boys and girls had been born at the clinic, ORP-1 conceded in the same breath:

*It is difficult to the say about the exact number, but many a times parents do want a boy more than a girl.*

Despite the vehement opposition to sex-selection expressed by providers, it was evident from the narratives of some of the women users that it was being practised (See Chapter 3 and Chapter 6 for user narratives). PGD and ARTs present the potential means through which son preference can be furthered in a climate of untrammeled commercialisation. Recent media reports have also highlighted travel by couples to other countries to access PGD for sex-selection (Straus, 2010).

**Conclusion**

The implications of undergoing ARTs were not limited to the bodies and minds of users, but impacted many other aspects of their lives. Adverse outcomes (for women and children) were found to be under-researched, and inadequately represented, if at all, to users. A narrow perception of risks prevailed, with significant risks, especially long-term and psychological risks either denied, trivialised, or normalised as ‘routine’ and ‘manageable’. While in the case of women users, it was not uncommon to find that the burden of risks — like the burden of blame for infertility — had been internalised as a necessary price to pay, in the case of providers, the limited understanding of risks also restricted the nature and extent of information and counselling that the users were given. In such a situation, the process of informed consent, barring a few exceptions, was reduced to a mere formality.

In the Indian context, the absence of a national registry that collates information systematically is a serious concern that prevents follow up and study of health risks and outcomes. This chapter highlights the need for standard protocols, especially for counselling and consent, throughout the process of ‘treatment’. Detailed information about the procedures, their psychological, medical and other implications, realistic success rates, comprehensive costs, and enumeration of other alternatives, including adoption, should be mandatory and a pre-requisite for the ‘treatment’.

Undergoing ART procedures can be a long and arduous process, involving disruptions to work and daily routines, geographical relocation for varying periods of time and last but not the least, significant financial burden. Implications of ART procedures were found to be gendered, with women, and even their natal families in some cases, bearing the brunt. ARTs were often seen to medicalise couples’ sexual lives and child-birth, and in some instances, facilitate sex-selection practices and neo-eugenics. As such, processes and systems are needed that will ensure that the vulnerability of women in these situations is not further exploited.
Notes


6 Ibid

7 Ova donation involves stimulation of the ovaries using drugs for development of ova and their retrieval. This is an invasive procedure involving insertion of a small needle through the back of the vagina, guided via ultrasound into the ovarian follicles to collect the fluid that contains the eggs. Over stimulation may lead to early menopause, which has its own implications for health. A woman is born with the total number of eggs, while blood (in case of blood donation) is replenished by the body, and corneal transplant (eye donation) takes place following the death of the donor.


10 The list and description of drugs used in ART procedures in the table is sourced from the internet as users were unable to identify all drugs used. It was not possible to present the adverse outcomes as per the different procedures because the users were unable to recall and correlate the two.

11 Indian Council of Medical Research. (2005). National Guidelines Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author

12 Referring to a legal case, where users of IVF sued the provider for the lack of success of the cycle.

13 Indian Council of Medical Research. (2005). Chapter 3, Section 3.2.5. National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author


16 Ibid


CHAPTER 5

Cost: The Economics of Baby-Making

The economic aspect or cost factor is one of the most significant and direct factors influencing access to infertility treatment in general, and to ARTs in particular. Accessing or availing medical intervention for any medical condition or disease entails financial investment, and ARTs require couples to spend substantial sums of money, often over several years. It is an established fact that ARTs are expensive and have low success rates. Therefore, users’ capacities to access ARTs is directly contingent on their capacity to spend; this forms a necessary area of analysis for an understanding of access as determined by class.

This chapter will examine various aspects related to the costs of different ART procedures and related expenditure, the commercialisation of these technologies within the clinics, the trends in cost-cutting being employed by providers, and also some emerging commonalities and variations observed within and across the states with regard to these aspects. Further, the cost-related experiences of users, including the measures undertaken by users to arrange the required funds, as well as the perceptions of providers regarding the same, will be examined.

I. Cost of ART procedures

Unlike other medical procedures, undergoing ART procedures is a prolonged, step-by-step process. Although IUI and IVF are both clubbed under ARTs, they differ substantially in nature, process, risks involved, and cost. For example, IVF involves taking hormonal injections for a specific period of time to stimulate the ovaries, conducting the egg-retrieval procedure, carrying out the fertilization of gametes in the laboratory, and transferring the embryo formed into the uterus. The whole process takes about 20–25 days. The time period for IUI varies depending upon the number of days for which hormonal drugs need to be taken. IUI may also be conducted without hormonal drugs. ICSI, also an in vitro procedure, differs from IVF in terms of the initial process and the expense involved (ICSI is more complex and more expensive than IVF)¹.

Although providers proceeded with each user in a different way, the general course of action was to first perform diagnostic tests, then begin the medication, and finally conduct the required ART procedure. The user may have had to be admitted to the hospital or clinic during this process. Thus, based on this generalised course, the expenditure on ARTs can be divided into four main heads: the cost of diagnostic tests, the cost of drugs, the cost of the cycle, and the charges for the hospital stay.

I.1. How much do providers charge for ART cycles?

While 12 providers refused to reveal the fees or rates charged by them (seven in Uttar Pradesh and five in Tamil Nadu), those who did were not always very clear...
about the same. Many did not provide a clear breakup of the costs. They either quoted the range of the total amount or only the cost of the basic cycle. Many providers quoted a price range but did not specify whether it included or excluded the cost of drugs, tests, hospital stay, etc. The ambiguity in the cost was justified almost universally by the claim that actual costs varied from user to user.

The state-wise findings related to the costs of the IUI, IVF, and ICSI cycles, and the variations in the costs between and within the three states, are discussed below.

**Orissa**

The range in the cost of the IVF procedure in a particular state or city would typically mean the minimum and the maximum expenses as cited by providers for one IVF cycle. The range was often mentioned, including cost of drugs. In other instances, providers gave the costs of the drugs and the procedure separately. In both cases, however, the other expenses incurred by users during the process were not taken into consideration while mentioning the cost.

In Orissa, providers from the four clinics said that the costs of IVF (cycle only) ranged from Rs 30,000 to Rs 80,000. The ICSI procedure was provided at three clinics (one each in Bhubaneswar, Cuttack, and Rourkela). Only one provider, ORP-5, shared their ICSI charges as Rs 1 lakh (per cycle).

In general, the total cost of the IVF procedure, including cost of drugs, went up to Rs 1.5 lakh. This amount excluded the cost of other things like diagnostic tests, investigations and hospital stay. Two providers in Orissa (ORP-6 and ORP-2) did not give a clear indication of the cost. ORP-6 quoted a figure of Rs 30,000 to Rs 60,000; it was not clear whether this included or excluded the cost of drugs.

Intra-state variations in cost were also observed, even in the small sample of clinics in Orissa. While the cost of IVF was mentioned as Rs 80,000 per cycle in Cuttack, the provider in Bhubaneswar said the charges were Rs 60,000 per cycle. However, as mentioned earlier, there was no clarity on whether the costs in the latter were inclusive of drug charges. Intra-district differences were also noticed between two clinics in Rourkela (Sundargarh district). One clinic (ORP-1) charged Rs 60,000 for IVF (including cost of drugs), while the other clinic (ORP-2) in the same town charged Rs 1.5 lakh for a cycle. There was a marked difference in the charges of the two clinics for the IUI procedure also. While the former charged Rs 3,000–4,000, the latter conducted the procedure for only Rs 1,500.

The profile of users accessing the two clinics in Rourkela was also very different. ORP-1 attracted users from a lower socio-economic background, and these were also fewer in number compared to the other clinic. The number of IVF cycles conducted in the clinic was also lower, with only about 15 IVF cycles conducted in the last four years. The provider said that he was ‘doing IVF as a hobby, and not to earn money’. He also stated that he was able to substantially bring down the overall cost of the cycle by using gonadotropins, which were cheaper.

**Tamil Nadu**

In Tamil Nadu, the cost of the IVF cycle ranged from Rs 50,000 to Rs 3 lakh, the widest difference in the three states. A majority (8 out of 14) of the providers who gave information
about their charges cited the total overall cost of the IVF cycle as between Rs 1 lakh and Rs 2 lakh (two in Chennai; three in Madurai; one in Coimbatore; one in Vellore and one in Salem). A clinic in Salem charged Rs 1–3 lakh per cycle.

The overall cost of the IVF cycle went up to Rs 1.5 lakh if the cost of drugs was included, while the cost of the ICSI cycle went up to Rs 2 lakh. In Salem, IVF cycles were offered by two out of three clinics at Rs 1 lakh or below (Rs 70,000) per cycle. The clinic in Salem (TNP-18) that charged Rs 1–3 lakh per IVF cycle, included in its quoted price two extra cycles free if the first one failed. (This aspect has been discussed in detail in the section on packages.) TNP-37 in Salem said that the cost per IVF cycle had been reduced from Rs 1.5 to Rs 1 lakh, owing to increasing competition among ART providers in the area. In Vellore, the cost per IVF cycle was Rs 60,000; with drugs, it went up to Rs 1–1.25 lakh. In Coimbatore, the providers quoted Rs 1–1.5 lakh per IVF cycle. Most clinics in Madurai provided IVF cycles at a cost ranging from Rs 50,000 to Rs 80,000, revealing once again the intra-city variation in costs. Discussing the comparatively lower fee charged by the clinic for different procedures, TNP-13 said:

*I charge a very minimal amount for all the procedures. For example, I charge only Rs 2,500 for IUI. This includes charges for semen preparation, canola, and even for their [the users’] stay for the day here after the IUI is done. I charge only Rs 50,000 for the IVF cycle. This includes the cost of the media, drugs, ovum pick-up, etc.*

It is interesting to note that small towns and cities had a considerable diversity of services and costs. They catered to a range of users, from the urban rich to the rural populace. Clinics in these smaller towns and cities appeared to be the nerve centres of the proliferation and diversification of the ART industry.

While some clinics conducted IVF and ICSI cycles at the same cost, others charged as much as Rs 70,000 (TNP-12) or Rs 50,000 (TNP-4) extra for the ICSI cycle. At a clinic in Salem, the difference between the costs of the IVF and ICSI cycles was Rs 2 lakh. While a number of clinics provided IVF and ICSI at the same charge, the difference between the IVF and ICSI cycles at these clinics was quite surprising. Providing ICSI at no extra cost may also have served to promote the procedure, particularly because ICSI (as claimed by providers) increases the success rate of the individual cycle and hence the overall success rate of that particular clinic.

Regarding the IUI cycle, variations were found in both the upper and lower ranges of the cost in clinics in Chennai and those in smaller towns and cities. For example, most providers in Chennai quoted the cost of the IUI cycle in the range of Rs 5,000–8,000, while those in the smaller cities said it was generally Rs 2,500–Rs 3,500. While this trend was found in most clinics, it was not universal. A provider in Madurai (TNP-10) quoted the rate of the IUI cycle as Rs 10,000 with husband’s sperm and Rs 15,000 with donor’s sperm, which is quite expensive, and even exceeds the cost in Chennai. Substantial variations were observed in the cost in smaller towns and cities as compared to clinics in a metropolitan city like Chennai.
In Uttar Pradesh, the total cost of the IVF procedure as quoted by providers ranged from Rs 50,000 to Rs 1.5 lakh. Within this range, only one provider cited a cost as high as Rs 1.5 lakh, while most other providers placed the total cost at Rs 70,000–80,000. In Agra, half the providers did not wish to share the cost of procedures at their clinics.

Table 22: The district-wise lowest and highest cost quoted by providers in the three states

<table>
<thead>
<tr>
<th>State</th>
<th>District</th>
<th>IUI cost (Rs)</th>
<th>IVF cost (Rs)</th>
<th>ICSI cost (Rs)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Lowest</td>
<td>Highest</td>
<td>Lowest</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>Allahabad</td>
<td>2,000</td>
<td>2,000</td>
<td>65,000-70,000</td>
</tr>
<tr>
<td></td>
<td>Benaras</td>
<td>–</td>
<td>–</td>
<td>30,000</td>
</tr>
<tr>
<td></td>
<td>Agra</td>
<td>8,000</td>
<td>8,000</td>
<td>50,000-70,000</td>
</tr>
<tr>
<td></td>
<td>Lucknow</td>
<td>3,000</td>
<td>6,000-12,000</td>
<td>30,000-40,000</td>
</tr>
<tr>
<td></td>
<td>Kanpur</td>
<td>3,500</td>
<td>15,000</td>
<td>60,000-65,000</td>
</tr>
<tr>
<td></td>
<td>Meerut</td>
<td>–</td>
<td>–</td>
<td>85,000-1 lakh</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>Chennai</td>
<td>1,500</td>
<td>8,000</td>
<td>80,000</td>
</tr>
<tr>
<td></td>
<td>Vellore</td>
<td>–</td>
<td>–</td>
<td>1.1-1.25 lakh</td>
</tr>
<tr>
<td></td>
<td>Coimbatore</td>
<td>–</td>
<td>–</td>
<td>1-1.5 lakh</td>
</tr>
<tr>
<td></td>
<td>Madurai</td>
<td>2,500</td>
<td>10,000-15,000</td>
<td>50,000</td>
</tr>
<tr>
<td></td>
<td>Salem</td>
<td>3,000 (IUIH)-5,000 (IUID)</td>
<td>15,000</td>
<td>50,000-70,000</td>
</tr>
<tr>
<td>Orissa</td>
<td>Sundargarh (Rourkela)</td>
<td>1,500</td>
<td>4,000</td>
<td>40,000-60,000</td>
</tr>
<tr>
<td></td>
<td>Khorda (Bhubaneswar)</td>
<td>–</td>
<td>–</td>
<td>30,000-60,000</td>
</tr>
<tr>
<td></td>
<td>Cuttack</td>
<td>–</td>
<td>–</td>
<td>75,000-80,000</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)
Note: Table 22 is based on the information shared by providers on cost of procedures. Out of the 43 providers, 12 did not provide information on cost. In many cases, providers gave a combined figure without elaborating further, and so it was not possible to get segregated figures for cycles and drugs.

Uttar Pradesh
In Uttar Pradesh, the total cost of the IVF procedure as quoted by providers ranged from Rs 50,000 to Rs 1.5 lakh. Within this range, only one provider cited a cost as high as Rs 1.5 lakh, while most other providers placed the total cost at Rs 70,000-80,000. In Agra, half the providers did not wish to share the cost of procedures at their clinics.
Among those who shared information about this aspect, the cost of IVF (cycle only) in one clinic was Rs 27,500 and the cost of ICSI (cycle only) was an additional Rs 10,000, that is, approximately Rs 37,500. The users at this clinic paid the cost of drugs over this fixed basic cycle cost. The price of the IUI procedure at the same clinic was Rs 8,000. Another clinic in Agra provided IVF and ICSI at the same price, at Rs 50,000–70,000.

In Allahabad, the cost of the IVF cycle alone provided by UPP-11 was Rs 65,000–70,000, which was almost triple the amount of the cycle cost in the Agra clinics. The overall IVF cost was quoted as around Rs 80,000 to Rs 1 lakh. ICSI was again offered at an extra charge of Rs 10,000 at one clinic. UPP-8 said that they charged an additional Rs 10,000 for assisted hatching in case it was required. The IUI charges were quoted at around Rs 2,000. Hence, in the sample of clinics in Allahabad (among those who shared the cost), the cost was found to be significantly higher than in Agra (approximately three times as much).

Interestingly, both the providers interviewed in Kanpur provided IUI cycles in packages. While UPP-23 charged Rs 15,000 for three IUI cycles (drugs included), UPP-21 charged Rs 3,500 for three cycles (drugs excluded). The IVF cycle at the former was priced at Rs 60,000–65,000 and the ICSI cycle, at Rs 90,000.

In Lucknow, the cost of IUI (cycle alone) ranged from Rs 3,000 to Rs 4,000. The cost of the IUI cycle (drugs included) ranged from Rs 10,000 to Rs 12,000. One provider (UPP-19) said that the cost of IUI may even go up to Rs 20,000 because of the cost of drugs:

\[\text{Costs depend a lot on the amount of drugs used. If a lot of drugs are required, IUI may cost Rs 20,000.}\]

In Lucknow, regarding the cost of the IVF cycle, UPP-17 quoted perhaps the lowest cycle cost, Rs 25,000. However, with the cost of drugs included, the provider brought the cost to Rs 1 lakh, which was almost equivalent to the cost in other clinics. Other providers in Lucknow quoted the cycle cost as Rs 30,000–40,000 and the total cost of the IVF procedure as Rs 80,000 to Rs 1 lakh. This shows that drugs are a major component of the expenditure for procedures such as IVF. ICSI was offered at Rs 1 lakh in one clinic in Lucknow.

In Meerut, the costs of the cycles in the clinics were almost similar. IVF cycles were priced at Rs 80,000 to Rs 1 lakh. UPP-2 said that she charged Rs 35,000 extra for providing donor eggs in IVF.

In Benaras, the IVF cost (cycle only) was around Rs 30,000, which went up to Rs 70,000 with the cost of drugs. Thus, in Uttar Pradesh, Lucknow and Meerut turned out to be the most expensive cities with respect to IVF procedures. The high cost of the procedures in Lucknow may be attributed to the city being the state capital and the commercial centre of the state. However, the high cost of IVF procedures in Meerut as compared to Benaras, Agra, and Allahabad is revealing. Meerut had a significant number of gynaecological clinics offering IUI. Providers in Meerut mentioned that a large number of their users were from in and around Delhi, which could be attributed to Meerut’s proximity to the capital and comparatively lower costs of procedures than in Delhi. Thus, clinics in such locations act as a fulcrum, providing these facilities to users from both larger and smaller cities, thereby constituting an important component in the category of clinics offering ARTs.
A provider in Agra (UPP-5) said that about 80 per cent of the people coming to the
clinic for ARTs were from outside the city. Providers also said that they were approached
by Non Resident Indian (NRI) couples. The in-country or domestic movement of couples
seeking to access ARTs was well established. (The proliferation of ARTs is discussed in
more detail in Chapter 6). In the absence of a national registry, it is difficult to give the
exact number of clinics. Nevertheless, a rough compilation of data from various sources
points to more clinics (in addition to clinics profiled in the research) providing IVF in Agra,
more than even the state capital of Lucknow.

Of the three states, Uttar Pradesh seemed to present the most varied picture in terms
of the cost factor. In terms of the spread of the ART industry, it neither seemed to be like
Orissa, with its limited clinics and facilities, nor like Tamil Nadu, with its large spread of
clinics with advanced facilities. Uttar Pradesh seemed to be located at a ‘middle level’ with
regard to the development of the ART industry, which is also reflected in the cost of the
procedures on offer and the kinds of services available.

It is evident that the average cost of IVF procedures is the highest in Tamil Nadu and
the lowest in Orissa. While Tamil Nadu has a high number of clinics (18 in our sample),
the entire state of Orissa has only four. Further, as discussed in the section on the profile
of clinics, there is a clear distinction in both the states with regard to the level and kind of
facilities on offer, and also the profile of the users accessing these technologies.

That the cost of IVF cycles differed substantially in the two branches of the same
chain of corporate hospitals - in Uttar Pradesh (Benaras) and Tamil Nadu (Chennai) also
emerged from the research. In Benaras, the cost was Rs 60,000–70,000, including the cost of
drugs. In Chennai, the comparative cost was Rs 1.5 lakh. This clearly establishes the impact
of location of clinic or hospital on the price of treatment. While Benaras is well known as a
tourist destination, it is a smaller town compared to Chennai. One can speculate about the
various factors that might influence costs in two branches of the same corporate enterprise.
More couples are likely to access ART facilities in Chennai than in Benaras, and hence
the cost of treatment at the hospital in Chennai would also be based on the volume of
people coming there. Further, the facilities provided in Chennai are likely to be much more
commercialized, also reflected in the higher cost of IVF cycles as compared to Benaras.

In most clinics across the states, the cost of the IUI cycle was higher if donor semen
was used. For example, in a clinic in Tamil Nadu, the cost of an IUI cycle with husband’s
sperm was Rs 3,000, and with donor sperm was Rs 5,000 (as stated by TNP-19). Although
the extra payment was the cost of the semen sample, either obtained fresh from a donor or
was a frozen sample from a bank, some clinics also charged extra for arranging the sample.
In many instances, as the clinics have to source the sperm from even outside the state in
which they are located, this also adds to the total cost of the cycle, becoming an additional
charge that users have to pay.

A comparative study of the costs of IVF cycles in well-established clinics in the
metropolitan cities of Delhi and Mumbai with those in the smaller cities and towns highlights
interesting trends. In Mumbai, for instance, at the Malpani Infertility Clinic, the cost of the
IVF cycle is Rs 1.8 lakh (including Rs 45,000 for drugs). In Delhi, at the Delhi IVF & Fertility
Clinic, the cost of IVF is Rs 1.05 lakh (including drug charges of Rs 60,000). However,
clinics in Meerut, Vellore, Coimbatore, Madurai, and Sundargarh (Rourkela) were found to be charging similar amounts. Thus, although there continues to be a difference in costs in metropolitan cities and smaller cities and towns, the picture in these smaller cities and towns is also far from homogeneous, with expensive clinics coming up in these places as well. Similarly, it would be interesting to compare the costs of these private clinics with the cost of ART facilities at the All India Institute of Medical Sciences (AIIMS), Delhi, one of India’s premier public hospitals, where ART procedures are being provided. The charges at the AIIMS ART centre are given in Table-23.

### I.2. Cost of drugs and diagnostic tests

Many providers claimed that hormonal drugs were the single most expensive element of the procedures. Different drugs are used for effecting different changes in the woman’s reproductive system—first to suppress the body’s natural release of hormones, then to stimulate the ovaries to produce the oocyte containing follicles, and to facilitate the maturation of the oocytes. Some commonly used drugs are Decapeptyl, Clomiphene Citrate (brand name: Clomid, Serophene), Recagon, Letrozole (brand name: Femara), Menotropins (brand name: Pergonal, Humegon), and other gonadotropins.

> The only one injection that I was asked to take during IUI for getting good-quality eggs/follicles was expensive. I took this injection at xxx Hospital. I think it cost about Rs 12,000. TNU-7

As stated by the providers, the cost of the hormonal drugs used varied from Rs 30,000 to Rs 40,000. However, providers also said that the drug dosage depended on the age of the woman. In case the woman was above 35 years, she would be given higher doses.

Users had to also undergo various tests. For women, these tests included hormonal assays and analysis (checking the hormonal levels through a blood test), screening for infections, tubal assessment through hysterosalpingography (commonly known as the dye test) or sonosalpingography, ultrasound (to check for ovarian cysts, etc.), laparoscopy (as a diagnostic test or as a correctional procedure), and ovarian study. For men, the tests included semen analysis, advanced spermiogram, and semen culture.

The costs of the tests were not generally included in the total cost quoted by providers. Some providers said that drug charges lead to variation in the total cost. Owing to differential responses to the drugs by different women, the dosage also varied. In some cases, according to providers, a low dosage worked, while in other cases a high dosage of hormonal drugs was required. There was a difference in this perspective as well. Some providers claimed to have a fixed and established protocol of drug dosage that they followed, while others stated that it varied ‘from patient to patient’.

<table>
<thead>
<tr>
<th>Table 23</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedure</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>IUI</td>
</tr>
<tr>
<td>IVF package</td>
</tr>
<tr>
<td>ICSI package</td>
</tr>
<tr>
<td>Embryo freezing</td>
</tr>
<tr>
<td>Frozen embryo replacement</td>
</tr>
<tr>
<td>Donor Oocyte IVF</td>
</tr>
<tr>
<td>Assisted hatching</td>
</tr>
<tr>
<td>Extended blastocyst culture</td>
</tr>
</tbody>
</table>

*Source: Accessed from the AIIMS website.*
Users also gave diverse responses with regard to the duration of medication as part of the procedure. While some reported that they were on medication for as long as six months, others said that they were asked to take drugs for two to four months. The time period, for which IVF users were given hormonal injections for ovulation induction before the egg-retrieval process, was on an average around 15 days.

It was evident that those who had been accessing these procedures for longer periods of time had spent substantially more on the drugs and diagnostic tests. Some users also reported that they had to undergo the same tests repeatedly with each procedure even if these had been done before. If they shifted from one doctor to another, they were made to undergo the same tests again. The reasons cited for this by providers was that they preferred to conduct their own tests rather than trust the earlier reports. In addition, if the reports related to tests conducted at a certain period in the past, the results were likely to be unreliable because of changes that could have occurred since then, and hence the tests had to be done again. Users described their experiences of undergoing repeated diagnostic tests with multiple providers.

ORU-23 noted that going back to the same doctor meant not having to undergo the diagnostic tests again:

> If we go to some other doctor, then the new doctor will advise us to undergo all the tests again. Therefore, I feel that if we are able to manage the money again, we should go to ORP-5 only [the same provider who had conducted IVF for her].

Similarly, TNU-1 also expressed their frustration:

> As soon as we enter they give a time-table to undergo various tests. I feel they are ‘minting money’.

ORU-20 shared about the repeated tests that they had to undergo with various providers:

> Then we went to another doctor and there also we had to undergo all the tests like blood test, semen analysis, ultrasound, and urine and stool examination. We must have spent about Rs 20,000 on various tests and medicines. Then we went to ORP-2 and were tested again. We were prescribed medicines for three months.

The result was repeated expenditure on the same diagnostic tests, and hence the cost of tests and drugs increased with time. Significantly, it was not only the cost aspect about which users remained uninformed in many cases (as the narratives above reflect), but also important technical and procedural details were conspicuously absent in the information and counselling provided to them. (For a more detailed analysis of the counselling and information provided to users, see Chapter 4)

As ORU-21 said:

> We don’t know why the injections were given as the doctor did not tell us anything, and we just did everything the doctor said. One injection cost us about Rs 12,000. The doctor prescribed medicine for both of us, but again did not tell us about the diagnosis. All in all, we spent about Rs 30,000 on the treatment there.
It is evident that a huge sum of money is spent on diagnostic tests, drugs, and other investigations. A single injection costs up to Rs 12,000, showing clearly the high cost involved in accessing ARTs.

Only one provider said that the hospital realised the burden of the high cost borne by users on account of drugs, and hence were making efforts to lower this cost. Their strategy was to approach the drug companies directly to obtain them at a cheaper rate. TNP-5 described the efforts of the clinic:

_We are now trying to reduce the drug costs by going to the drug companies directly and by obtaining the drugs at a cheaper rate._

Considering the expensive nature of these procedures, efforts have been made in recent years to bring down the cost of ARTs and to make them more affordable. Although these efforts are being made at the global level, more concentrated initiatives for achieving this end are being discussed and attempted in the context of developing countries or resource-poor settings. However, questions have been raised about the appropriateness of applying a global standard of cost-cutting across countries. In the present context, the question of a real cost-benefit analysis of ARTs in developing countries is extremely challenging. For instance, considering only the diagnostic techniques, little is known about the minimal costs needed in different countries. The overall impact of all this on reduced cost and on the outcome of the success rate still needs to be established (Ombelet and Campo, 2007)\(^5\).

An initiative by AIIMS, Delhi, as part of an experiment called Affordable IVF for Minimal Stimulation Plan was in the news for having successfully conducted 12 IVF cycles, each at a cost of Rs 20,000, including cost of drugs. By using low-dosage drugs and by stimulating the ovaries minimally, the doctors at AIIMS were able to drastically reduce the cost of the IVF cycle to one-fourth or one-fifth the cost of what is usually charged by other clinics (Jha, 2010)\(^6\).

While these efforts have provided an option (though limited) to users accessing ARTs, or to those who are advised to do so, in a country like India, these endeavors are still quite rare, and IVF users continue to spend large amounts on drugs and diagnostic tests in private ART clinics.

**I.3. Staying in the hospital or clinic during the procedure**

Hospital charges also added to the total cost of the procedure, but were never included in the cost quoted by providers. Regarding the need for hospital stay for women users, widely different perspectives were found among providers. While some maintained that IVF did not require an overnight stay at the hospital, other providers felt it was necessary for women to be admitted:

_There are beds here, but we do not ask them to stay as they are people from the local area. They can go back home and come for the follow-up. Why ask them to pay bed charges when they all come from Chennai?_ TNP-9
The patients stay with us for six weeks, after which, based on the outcome, they go back or stay for two more weeks. If they are going back, then they are referred to their local doctors. This depends on where they are going to and the condition of the patient. If they wish to stay with us, we accept [them]. TNP-3

Thus, it seemed that, the necessity and duration of stay at the hospitals, was entirely up to the providers' discretion. If providers asked users to be admitted, they had to comply. The cost of hospital stay varied greatly across the clinics and hospitals and also between different kinds of accommodation facilities within a particular hospital. Some users said that they had to stay for long periods. ORU-11, however, felt that staying in the hospital was less expensive than having to return repeatedly for follow-ups:

In August, after the IVF procedure, I stayed here in the clinic for 15 days. After that, I went home. But in December, there was a little bit of bleeding. Wanting to take no chances, we again came here. ORP-2 advised me to stay here only. I have been here for almost two months now. The money being spent on staying here is still less than the cost of coming every month for a check-up.

The expenditure on hospital stay was also unforeseen at times. While overnight stay for a day or two could be expected at the time of oocyte retrieval and embryo transfer, some women said that they had to be rushed to the hospital (either the one where they had undergone the ART procedure or the nearest health facility) owing to emergency situations. As the chances of miscarriage and other complications during pregnancy are higher in the case of ARTs than in normal pregnancies, unanticipated hospital admission was observed as a common trend. This directly added to the overall cost for users. For instance UPU-4 elaborated on the added expenditure following the IVF cycle, in the event of her premature delivery:

After I got pregnant we have spent a lot of money. The one month the children had to stay in the nursery itself cost us Rs. 1.5 lakh. Over and above that there was also the cost of the caesarean, hospital fees, transport etc. I had to stay in the hospital for about ten days after the delivery as well.

Some hospitals had also provided special facilities for accommodating users of ARTs; TNP-18 said that a village near the clinic offered accommodation for those who came from other cities, states, and even countries, to the clinic.

In a clinic in Orissa (ORP-2), apart from the few beds in the clinic, a row of rooms had been constructed for couples undergoing ARTs who had to stay for longer periods. These rooms had very basic facilities there was only one bed and a stove for the couple to cook their own food.

Apart from the facilities provided by the clinics and hospitals, the emergence of different types of accommodation around ART clinics was an interesting phenomenon observed in smaller towns and cities. A lodge near a clinic in Orissa attracted many ART users till the clinic itself began providing facilities.
ORU-11 who had stayed at the lodge said:

At first, the doctor asked us to come on the second day of the menstrual cycle (every month). At that time, we used to stay in a lodge nearby. The room charge for the lodge was Rs 80 per day. There was no facility of food there, so we also had to spend extra money for food and other charges. During our regular visits for check-ups, we used to stay for one to two days. But when we used to come for IVF, we had to stay for 15–20 days. The doctor would advise us to stay here for some time.

Apart from the lodge, a shopkeeper had built a few rooms to accommodate the clinic’s ARTs-seeking users. The shop, located just outside the hospital, also offered the services of a telephone booth and items of daily need (including groceries). Many people staying at the hospital (for other procedures) or at the ART centre availed the facilities of the shop. The accommodation offered was extremely basic; couples either had to cook or arrange for food on their own. The rent for these rooms ranged from Rs 80 to Rs 170.

The growth and proliferation of ART clinics is also leading to the growth of affiliated businesses. In addition to highlighting the cost factor, this is also an indication of the growing links in the ART industry. (More details in Chapter 6).

I.4. Other related costs

Other related costs included the cost of donor gametes, when donor sperm or eggs were used, and the cost of cryopreservation of embryos.

I. 4. a. Donor gametes

Providers were less forthcoming when it came to discussing donors and the expenses related to donor gametes. As one provider said:

There are a number of brands emerging within the donor sperm market. The prices are, of course, higher as their samples are of high quality and are doubly/triply tested and guaranteed to be free from any infection. Donor sperm samples from semen banks are sent to the clinics with catalogues that have donor characteristics like height, skin colour, hair colour, education, marital status, etc. listed. UPP-22

According to a sperm bank owner in Kanpur, the payment for each donation ranged from Rs 100 to Rs 500. The clinic also charged users extra for arranging a commercial donor for them. In most cases, there was a substantial difference between the amount paid to the donor and the amount charged by the clinic from users for arranging donor semen. As provider, TNP-19 said, users had to pay the clinic for arranging the donor semen, in addition to paying the cost of the semen sample:

IUUI costs about Rs 3,000, including drugs. IUUI with donor sperm costs Rs 5,000. Rs 2,000 is shared by the biologist who works here and who arranges the donors and the samples.
Very few clinics had the provision of using donor eggs. These eggs were mostly donated by a family member (sister, sister-in-law) of the woman user. A provider in one clinic in Uttar Pradesh (UPP-2) said that they arranged for donor eggs at an additional charge of Rs 35,000. This is almost comparable with the amount of Rs 40,000 charged by the Malpani Infertility Clinic (a leading infertility clinic in Mumbai). One couple from Orissa said that they paid Rs 2,000 for donor eggs. Another couple at the same clinic said that they paid Rs 200 for donor sperm.

As the costs show and as has been established earlier, there is always a considerable difference in an ART cycle using donor eggs as compared to one using donor semen. This is directly related to the fact that egg donation, unlike semen donation, is a much more invasive and risky process requiring hormonal intervention in the body of the donor. Therefore, an egg donor is always paid more than a semen donor, which is reflected in the difference in the overall charges of the cycle requiring one (egg) vis-à-vis the other (semen).

I.4.b. Cryopreservation

While many clinics had provision for cryopreservation of embryos, very few offered egg cryopreservation or egg banking. (A detailed break-up of clinics offering cryopreservation is given in Chapter 2). Of the clinics profiled, only four clinics offered the facility of egg banking. Three of these clinics were in Tamil Nadu, and one in Uttar Pradesh.

Variation was also observed in the amount charged by the different clinics for the facility of cryopreservation. The cost of cryopreservation of embryos ranged from Rs 5,000 to Rs 60,000 per annum. One clinic in Uttar Pradesh had fixed the cost for each freezing and thawing cycle for embryos at Rs 30,000. One clinic in Tamil Nadu quoted the cost of sperm freezing at Rs 1,000 per annum.

It is widely recognised that if oocytes and embryos are cryopreserved, a woman will not have to undergo the hormonal drug regime and oocyte retrieval again. Nevertheless, doubts about the quality of the gametes or embryos after thawing remain. Providers across the states noted the difference in the success rates of the cycles using cryopreserved embryos:

Embryo freezing is useful and reduces the cost by half. If we get embryos and store them, then we need not repeat the injections for the second cycle if the first fails. TNP-19

When the patients are going in for another cycle of IVF, I feel the result from frozen embryos is not very good, so we advise our patients against it and prefer to retrieve the eggs again. The remaining embryos are either given for research or donated to other couples. UPP-1

We freeze only embryos but not oocytes. The oocytes lose their quality once they are frozen. Then they are of no use. The vitrified embryos can be used by the patients in the next cycle instead of fresh ones. The success rates, however, are much lower with frozen embryos, and I generally don’t recommend it to any of my patients. So far, none of the frozen embryos have been reused. They are only stored. UPP-2
While the facility of cryopreservation is being provided by many clinics, providers differ among themselves regarding the effectiveness and success of using cryopreserved embryos. Although cryopreservation offers users and providers the option of not having to go through all the phases of the procedure, there are also cost implications of this, as users have to pay an additional amount.

The majority of providers stated that the media for cryopreservation is very expensive. Indeed, it is one of the factors that make the overall cost of IVF very high. Hence, providers resort to different ways to reduce costs, one of them being conducting IVF for a batch of women together, which was a common practice among the researched hospitals and clinics.

I.5. Inconsistency in costs

Even for those providers who shared information about the cost, there was an element of ambiguity in the figures they quoted. While it was unclear whether the cost of cycles quoted included or excluded the cost of drugs, there was also a large difference between what the providers quoted and what the users ended up spending. For example, while a provider in Tamil Nadu said that each IUI cycle costs Rs 1,500, including medicines, a user from the same clinic said that she underwent three IUI cycles for Rs 10,000, implying that each cycle cost more than Rs 3,000. The difference could be accounted for by the ‘hidden’ nature of some of the expenses.

On many occasions, different staff members at the same clinic quoted different amounts as the cost of ART procedures. For example, TNP-5 and TNP-6 at the same clinic in Tamil Nadu quoted the cost for one cycle of IUI (all expenses included) as Rs 1,500 and Rs 6,000 respectively.

Similarly, in Orissa, ambiguity regarding the costs of procedures and the concession given to users was especially evident in one of the clinics where the provider and the embryologist claimed that they charged only for the costs incurred and operated on a no-profit basis.

"From people who are economically well-off and can pay more, we charge a little bit extra, so that those who cannot afford it get the benefit. This is the difference between hospitals and clinics in the metros and here. In metropolitan cities, a fixed amount is charged, and people who do not have that much money cannot access these treatments. But here we don’t function like that." ORP-3

This claim was contradicted by the administrative staff (ORP-4) of the clinic, who gave the actual range of the amount charged from users:

"The cost of the cycle varies from a minimum of Rs 50,000 to a maximum of Rs 1,00,000–1,50,000." ORP-4

ORP-4 also said that certain fees were waived for consecutive cycles, at the doctor’s discretion.
However, a user at this clinic also shared about the costs that they incurred at the same clinic, which also countered the claims of the provider (ORP-3):

After we visited the doctor for the first time, he asked us to bring Rs 1,30,000 the next time. In May, we went with the money and he said that we should stay there for 20 days... Out of the five eggs retrieved, two eggs were implanted and the other three were used for someone else. We were given a concession of Rs 10,000 for having donated these eggs. I conceived after this. . . . The doctor has demanded a gift of Rs 80,000 if it is a girl and Rs 1 lakh if it is a boy.  ORU-27

II. How much did they actually pay? Users describe the amount they spent

It is difficult to calculate and analyse the expenditure borne by users, as has been done in the case of providers in the above section, because the costs quoted by users were varied. Not all users were able to isolate the cost of one cycle from their overall expenditure on undergoing ARTs, or give a detailed breakup of the costs incurred on drugs and hospital charges, among other things. Many women were also genuinely not aware of the expenditure because they did not have access to information, nor were they part of the decision-making process. Further, many couples did not recollect the details of the money they had spent so far or did not want to reveal the costs incurred.

While providers look at the costs of IUI, IVF, and ICSI on the basis of a single cycle, for users, tests or investigations, repeated ultrasounds, drugs, and injections are the essential components of expenditure. Travel, food, and accommodation costs add to this expenditure. In addition to accessing allopathic forms of ‘treatment’ (including ARTs), users also go in for alternative forms of medicine like homeopathy, ayurveda, unani, siddha, and home remedies. All of this constitutes one long continuum of expenditure, and the cumulative effect of the expenditure over the years adversely affects the overall economic status of users as well as that of their families.

Many users found it difficult to recall the exact sum of money they had spent and were not able to provide details regarding the same. Most made rough calculations of the amount spent at each clinic and for specific procedures. Those, especially with a prolonged history of infertility ‘treatment’, found it more difficult to calculate the exact amount spent in total.

You are asking these questions [referring to the amount spent on the treatment], but it is difficult to say [anything] about the expenses. Do you yourself know how much is spent at your home? Whatever we had has been spent on her [daughter-in-law] treatment. Mother-in-law of ORU-9

Some users said that the expenditure had occurred a long time ago and that they did not keep a record. Other users said that they did not wish to keep track of the money being spent on infertility procedures and would do whatever was required in the quest for a biological child. The male partner of a woman undergoing IVF stated that he felt that it was unreasonable to calculate the money being spent for having a child.

We have never counted the amount of money that we have spent on this treatment. We don’t worry about it either. We give whatever amount the doctor asks us for. All we want is success, so that we can have our own child. UPU-2
It is evident that the end product—the baby—is considered above financial calculations of cost by some users. It is seen as a rightfully demanding investment, as something that is so precious and invaluable as to negate or invalidate all costs. These notions actually make users more susceptible and vulnerable to exploitation in the case of ARTs because they are predisposed to ‘do whatever it takes’; including bearing high costs and undergoing repeated cycles. Hence, while users cited various reasons for not keeping track of the money spent, the underlying factor seems to be that when compared with the satisfaction of having a biological child, any amount of money spent is deemed to be worth the effort.

UPU-6 felt that spending money on IVF was like a gamble. She did not keep track of the money spent, only to realise the extent of the expenditure later:

*My husband used to say to me, ‘So what if the treatment fails? We will just assume that we were gambling with the Rs 1 lakh and we have lost the gamble.’ In this way, we wasted almost Rs 15–20 lakh on treatment in the initial years.*

However, not so affluent users mentioned financial constraints even in undergoing less expensive IUI procedures. Although the costs of IUI were much lower than the advanced IVF/ICSI procedures, sometimes users from lower socio-economic backgrounds could not afford even this expense. The actual money spent on these procedures by users is discussed below.

**II.1. Expenditure on ART cycles**

**II.1.a. IUI cycles**

Although the per cycle cost for IUI is lower than the cost for IVF/ICSI, it was found that users had spent a substantial amount of money undergoing even IUI. The money spent on IUI varied considerably even within the same state. In Orissa, ORU-2 reported spending Rs 30,000 on one cycle of IUI, while ORU-7 spent Rs. 50,000 and ORU-13 spent Rs. 1,100. Users in Orissa spent an average of Rs. 2,000–4,000 on each cycle of IUI. In Tamil Nadu, TNU-16 said that the cost of the IUI cycle she was undergoing was Rs. 10,000. Whereas, TNU-19 said that it may cost her more than Rs. 15,000 for one IUI cycle at the same clinic. TNU-6 said that the clinic in Chennai where she was undergoing IUI, charges Rs. 6,000–7,000 per cycle including lab and drug costs. Although the users themselves did not claim this, the variation may have been due to the cost of the drugs prescribed before the IUI procedure. As the choice of drugs and their dosages may vary from individual to individual, this also has an impact on the overall cost of the cycle. Further, while some users had undergone IUI at gynaecological clinics, others had undergone or were undergoing the procedure at specialized ART clinics. The difference in the amount spent on the IUI cycles even within the same state emerged as an important factor. For example, ORU-2 who spent Rs 30,000 on each IUI cycle underwent a total of five cycles, spending Rs 1.5 lakh only on IUIs, while ORU-1 said that she underwent eight to nine cycles of IUI, incurring expenses to the tune of Rs 20,000 on these cycles.

**II.1.b. IVF/ICSI cycles**

Notwithstanding the invasive nature, high cost, and health implications of procedures like IVF and ICSI, it was observed that users were undergoing as many as four cycles of IVF as well as ICSI. In Orissa, the maximum number of IVF cycles undergone by users was three.
In Tamil Nadu, the corresponding number was four. In Uttar Pradesh, none of the users had undergone IVF for more than two cycles.

None of the users in Uttar Pradesh and Orissa had undergone an ICSI cycle. However, on many occasions, especially in Orissa, users were not able to articulate clearly whether they had undergone IVF or ICSI cycles. In Tamil Nadu, seven users had undergone the ICSI procedure, with one of them undergoing her fourth cycle.

As seen from the Table-24, most users accessing and undergoing ICSI did so at a cost that far exceeded their annual income. In addition, it is evident from their occupation and annual income that they belong to diverse economic levels and backgrounds. This substantiates the argument that even costly advanced procedures like ICSI are accessed not only by users who can afford these (with regard to their income or the economic resources available), but also by those who are not in a position to even remotely afford the expense. However, as is clearly evident, they still access these procedures by somehow arranging the necessary financial resources—by taking loans and/or by selling assets (discussed later). Hence, the correlation between affordability and income is not simple, linear, and direct. Sometimes users opt out of, or discontinue, the ‘treatment’ process when it becomes completely out of their reach financially and return for future courses of the ‘treatment’ after they put together sufficient savings. In a few instances, users supplement their income through various means.

The fact that some costs remained hidden, even after the expenditure has been calculated and accounted for, was evident in some cases. ORU-29 said that she underwent two cycles of IUI, each for Rs 3,000, but added that the total expenditure on IUI was Rs 40,000. Similarly a couple from Tamil Nadu who underwent two cycles of IVF costing Rs 1.25 lakh each said that they had spent a total of Rs 4 lakh. The total expenditure incurred over and above the actual cost of the cycles clearly indicates the ‘hidden’ costs that users have to bear.

### II.2. Hidden Costs

A substantial amount of money was also spent on various related aspects beyond the ART cycles. Often, even the couple was not aware of how and where the money had been spent.
This expenditure could be on travel, accommodation, and food, which is not usually explained or communicated by providers as being a necessary part of the ‘treatment’.

*If we had known that it would cost so much money, we would not have gone ahead with the treatment. ORU-15*

*So far, we have spent about Rs 2 lakh for treatment. This does not include medicines, travel, food, and stay. That is all extra. Now [for the current IVF cycle] the cost is Rs 80,000 only for the lab tests. Medicines and injections, stay, food, travel is all extra. Follicular scan has a one-time charge. TNU-2*

*We first came to this hospital in June 2007. . . . The cost of IVF was very high. We had to make arrangements especially for a huge sum of money. We also had to arrange for the treatment cost and also for other expenses like travel and stay. So we informed the doctor that we will make arrangements and come for treatment. TNU-5*

Various other expenses are incurred by couples undergoing infertility treatment. These include the money spent on transport and commuting, accommodation, and food. Commuting charges may be comparatively lower if the clinic is close to the users’ home, but may increase substantially when users access clinics in other states and cities. While accessing out-of-town services, the cost of accommodation and living expenses also increase substantially. These expenses do not feature, or are not reflected anywhere, when the cost of infertility procedures is calculated, and hence can be termed as hidden or additional costs.

*A lot of time was spent in commuting also. It used to take about three hours by bus or train. We also had to spend Rs 100 for our accommodation. Every time we have to spend. . . . Within a year, we spent about Rs 40,000–50,000. ORU-1*

*When we come here, we usually stay in a hotel or lodge close to the hospital. The rent for accommodation is about Rs 80 a day. It is a small space with a small bathroom and latrine. There are big rooms with a lift, but they are costly, about Rs 170–180 per day. We cook our food in the verandah and buy the vegetables locally. TNU-28*

*While going to one doctor, we used to commute by bus and spend Rs 40 per person travelling back and forth. Then, while going to Rourkela [referring to ORP-2], we had to spend Rs 500 on each trip. We rented a room for Rs 5,000 per month near the clinic and stayed there. Almost every day we used to go to him [the doctor] for check-ups. The amount for the room was in addition to the money that we had to spend on food. On an average, Rs 100–150 was spent on food every day. ORU-7*

**II.3. Money spent on other therapies**

Alternative practices and systems of medicine were observed as a common trend. When the fertility of either partner was in doubt, couples took refuge in pujas and visits to
temples, dargahs, babas, and faith healers, while continuing these practices alongside ART procedures. (Elaborated further in Chapter 3-Section B).

When no treatment was successful, I also went to some gunias (tantriks) and babajis, as some of the villagers suggested. On the remedies suggested, we spent about Rs 8,000–10,000. ORU-1

My mother-in-law did sudarshana and dhanvantri homam just before we started ICSI. We had to spend a lot of money for performing this homam. TNU-10.

Some of the users confessed that although they themselves did not believe in these, they followed them because of pressure from the elders in the family and from others in the community:

Sometimes when we visit our in-laws in the village, they force us to do many kinds of things because they think that will help. Then one has no option but to actually do what is suggested by them. For instance, there is one lady who is known to provide some kind of home remedy for such problems. My mother-in-law was very keen that I consult her. She gave some kind of seeds, and both I and my husband took them. It was not for a very long duration. At that time, my mother-in-law gave her Rs 500. Although we were not carrying money at that particular time, she just borrowed it from someone and gave the money to the lady. ORU-23

While users may have resorted to seemingly cheaper alternative forms of ‘treatment’ in the context of not being able to afford ART procedures, often alternative treatments were also found to be quite costly and long drawn.

We got married 15 years back. We have been taking various treatments for the past 10 years. All these years, I have spent around Rs 20 lakh. You may think that the amount is very high, but the cost of treatment in siddha, unani, and ayurveda is also very high. TNU-8 [with a daily income of Rs 100–200 earned from a telephone booth that they owned]

Accessing multiple forms of ‘treatment’, therefore, contributed to the overall high cost of managing infertility by users. As this study shows, some users also spent substantial sums of money on worship and visits to holy places, temples, and dargahs. Hence, in understanding the overall economic factor involved in infertility ‘treatment’, it is not only the money spent on ARTs but also the other aspects that become equally essential.

III. Affordability

To afford means to be able to do something without risk of adverse consequences (oxforddictionary.com). The draft National Health Bill, 2009 defines an affordable (health) service as that which can be secured by every person without reducing that person’s capacity to acquire other essential goods and services, including food, water, sanitation, housing, health services, education, etc.
The affordability of infertility ‘treatment’ depends on the economic situation of the individual or the couple who seeks to access these technologies. The understanding of affordability by users and providers also varied. The responses ranged from how much money they could spend from existing resources to how much money can be sourced for the purpose of undergoing the procedures. While the question of whether the woman could afford to undergo these procedures physically, owing to the potentially severe health risks and side effects involved, remained a valid concern; this did not come up at all as a consideration for either users or providers. Both providers and users considered affordability only in financial terms. Most couples said that they had to make efforts to accumulate the required funds. ORU-7, who had exhausted all their finances and as a result had to give up ART procedures, said:

*I think it is beyond us now and we are not in a position to do that [get more money]. It has now become difficult even to maintain a decent life for ourselves. We have to compromise on many aspects. We cannot eat the way we want. Even the kinds of clothes we wear are not what we would like. Look at the condition of my footwear. [Saying this, he pointed to the bathroom slippers he was wearing]. Now it is completely out of the question to go in for treatment again. Sometimes I feel that I will go mad thinking about all these things. Now we just want to spend the rest of our lives and don’t want anything else now. Thinking about or recollecting past experiences will only give us pain, so we don’t even want to think about anything now.*

We started to plan for meeting the cost.... If we had enough money or if we were very rich, money would not have been an issue. Hailing from a middle-class family, Rs 4 lakh was a big amount for us.... Till now we have saved some money, and with our total savings we have around Rs 1.5 lakh. He is likely to get a promotion. And we also plan to make use of his bonus and take a loan from the provident fund money. His eldest sister’s husband is very rich; he said that he will give us money and we can pay them back at leisure. But my husband prefers to take a loan from other sources and not from family members. TNU-12

Affordability was a major factor in the decision to go in for IVF and ICSI. However, a few users said that they did not know about IVF and the procedural details, and hence did not have an opportunity to make an informed decision. One user (ORU-22) said that they were asked to bring Rs 1 lakh by the provider if they wanted a child without any other details being explained to them:

*The doctor told us, ‘I will definitely help you to have a child and you will definitely have a child. But before I start anything, I need money. Without money, I will not even touch the case. You have to arrange for at least Rs 1,00,000 and come to me.’* After meeting him, we came back and arranged for money. It was a big sum of money and we were not sure of how we would arrange for it. We sold land and gold ornaments (whatever we had) and somehow arranged the money. ORU-22

Thus, a lot depended on the way providers projected the scenario to users. For instance, in the case of ORU-22, in the absence of information regarding the success rates, health risks, choice of procedures, etc., towards weighing the pros and cons of undergoing such a
procedure, the demand of Rs 1,00,000 by the provider as a pre-condition to ‘treatment’, left
the couple with no options. Although the woman conceived through IVF, the pregnancy
was not successful and she miscarried. This was quite frustrating for the couple as they
had invested considerable financial resources in the IVF cycle.

Providers also shared their views on how ‘affordable’ the ‘treatment’ was for users:

*IVF involves a lot of time and it is expensive. The couples need to spend a few
thousands every month. So IVF is tried for two or three cycles only. The ART
treatments are so expensive that ordinary people cannot afford them. People save
money and come for treatment. Nowadays, even people who are middle class, who
earn about Rs 15,000–20,000 a month, come for treatment.* TNP-1

*I have also done three cycles for a particular case. Couples generally cannot afford
more than two cycles. Even the one or two cycles that they get done, they face a
lot of financial problems. They have to sell land, take loans, and what not. So they
have to arrange money like that.* UPP-14

However, due to the expensive nature of ARTs, some providers believed that these
technologies were accessed only by the rich, that is, by those who could comfortably afford
them, and not by the poor. They believed that it was practically impossible for people
without the necessary financial capacity to avail ARTs.

*Upper-middle-class people and the rich come here for treatment. Poor people
rarely save money and come here for treatment.* TNP-14

*In my opinion, ARTs are definitely expensive procedures and there is no way that
poor people can afford [them]. There is no question that the poor would be able
to afford the cost of the techniques for assisted conception. It is only middle-class
and upper-middle-class people who are able to access and continue with the ART
procedures.* ORP-1

One provider (UPP-8) had a different opinion regarding affordability of ARTs, arguing
that the costs were not unreasonable at all and could be afforded by any person across the
class divide. For some providers, therefore, the cost incurred was a relative factor, which
everyone (even those from the lowest socio-economic background) could manage. Indeed,
UPP-8 said that IVF was one of the cheapest medical ‘treatments’, affordable for everyone.
She explained the cost factor:

*Last month, my maid got her daughter married. She spent one or one and a half
lakh rupees. These days, Rs 1 lakh is not expensive at all. It is quite ordinary.
Everybody spends around that much on one’s child’s marriage. Everyone can
afford this much. You can also ask your maid. Look at other procedures. One heart
surgery costs Rs 10 lakh! I think this [IVF] is the cheapest treatment in medical
science. What can be cheaper than one lakh rupees? And it is the cheapest in India.
People come here from all over the world. The doctor’s fee is minimal in this. It is
the drugs that take the cost up and make it so expensive.*
Some couples continued ‘treatment’, but switched to cheaper procedures like IUI or gynaecological care when they could no longer afford more IVF cycles. Users described their experience of financial constraints:

Doctors checked both of us and said that the best option for us would be IVF and that it would cost one lakh rupees. We could not afford that much money then. We said we will make arrangements for the money and come back. In 2008, we came to this hospital again as we had saved some money and my parents and younger brother said that they would help me financially. TNU-29

After the first cycle was not successful, ORP-5 told us to undergo another cycle of IVF. But as we had already spent so much money and did not have any further financial resources, we could not continue with it. If we can somehow manage the money again, we will try for IVF again with him. ORU-23

We have lost all count of the money we have spent so far on treatment. You can imagine that we have been trying this for almost 14 years now. Earlier, whatever money my husband earned would all go into the treatment. Sometimes we had to take a break because we had no money. UPU-4

After undergoing many procedures over many years, some users said they felt ‘frustrated’ because of the high expenditure incurred, the unsuccessful ‘treatment’ involving a number of cycles, with the added pressure to have a biological child at the earliest. However, users said that they would keep going because they ‘desperately wanted a child’:

We have spent so much money on this procedure. But we don’t mind spending money as we want a child desperately. ORU-11

We have spent so much money on this. In total, we must have spent about Rs 6,00,000. Definitely, it feels bad that so much money is spent and there is no positive result. Initially, when we started the treatment and so much was spent on this, I used to feel that it is like taking the money and throwing it into a river. We were not sure if the treatment would be successful. But now we understand that this treatment is like this only. TNU-13

Thus, affordability was a significant, though a stretchable and subjective, factor in accessing ARTs. All the 86 users in the sample were, in the end, able to ‘afford’ undergoing these technologies by arranging the necessary funds in some way or the other. However, the question is: at what cost? Those undergoing the ART cycles for prolonged periods of time experienced the depletion of their resources and their day-to-day living becoming increasingly difficult because most of their financial resources were sucked into paying for ART procedures. The following section looks at the way in which users arranged the necessary funds for undergoing the procedures.

**III.1. How couples arranged their financial resources**

For most couples, the IVF procedure was beyond their means, and hence they had to arrange the required amount from sources external to their regular income. Most users arranged
the funds through multiple sources, rather than relying on one source. These included taking loans from local moneylenders, banks, and even their offices, selling or mortgaging agricultural land, selling household assets (television sets, motorcycle and gold jewellery), and borrowing money from relatives and friends. In many cases, users were also helped financially by their families, particularly by the women’s families.

Some couples kept trying with IUI cycles because they could not afford IVF cycles, even if they were advised to do so. Providers also confirmed the fact that availability of finances guided the course of treatment.

**Orissa**

In Orissa, 19 of the 30 women interviewed underwent at least one IVF cycle. Of these, 15 users (about 80 per cent) had to source funds beyond their current earnings and savings. As many as nine of these users (60 per cent) borrowed money—from banks, moneylenders, and friends. The loan amount as mentioned by the users varied, ranging from Rs 10,000 to Rs 3 lakh. Those taking loans from moneylenders said that they had to pay rates of interest as high as 10–15 per cent.

Eleven users (about one-third of the sample) resorted to selling their assets and possessions in order to raise money for ART procedures. The assets sold included agricultural land, gold jewellery, household assets, and, in many cases, most or all of these. Eight users sold their land, seven sold their gold ornaments, and the others sold their tractors, television sets, motorcycles, etc. One user said they sold their cattle. Many users were also helped by their relatives. One woman’s mother-in-law sold her gold jewellery to give the couple money. Five users were helped financially by the woman’s family—by parents or brothers.

The narratives below also highlight the difficulties faced by users in raising the financial resources for undergoing the procedures:

For the treatment, we have taken [a] loan of Rs 50,000 from the bank and borrowed a sum of about Rs 40,000 from people outside the family. I have not taken any money from any of the family members. To arrange money for the treatment, we have also sold about 10 gunths\(^{11}\) of land. [The husband did not elaborate on the amount]. The in-laws have also helped in whatever way they could. We have also sold the gold ornaments we had. Now nothing is there. ORU-17

For money, we had to sell many of our assets. Like we have sold 18 gunths of land and are now left with only one acre of agricultural land from which we get about 60–70 sacks of rice in one year. We had a two-wheeler [scooter], which I sold for money when I was really desperate. At home, initially I told [the family] that I had mortgaged it for money, but later I had to tell the truth. Even my in-laws have helped me a lot. They have also given us money by selling cattle. My wife was not aware of this. For the band party we had eight trolleys, out of which five have been sold [a trolley costs about Rs 7,000–8,000], and two have been given on rent\(^{12}\). In addition to this, I have also borrowed money from moneylenders. We are completely in debt and I don’t know how to further repay the loan amount. ORU-2
In the case of IUI, only one user had to take financial help from external sources (the brother of the husband). The others undergoing IUI in Orissa (10 users) said that they did not face many problems related to the expenses incurred through IUI because it is not a very expensive procedure.

The ways in which couples gathered funds for ART procedures in the three states are summarized in Table-25.

<table>
<thead>
<tr>
<th>State</th>
<th>Savings/Earnings</th>
<th>Loan</th>
<th>Selling assets</th>
<th>Helped by family/friend</th>
<th>Other sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Friend/Relative</td>
<td>Bank/Office/Moneylender</td>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orissa</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10 (6 are from woman’s family)</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>28</td>
<td>5</td>
<td>10</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12 (5 are from woman’s family)</td>
</tr>
<tr>
<td>Uttar Pradesh</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td>–</td>
</tr>
</tbody>
</table>

Source: Compiled from data collected during fieldwork (2008-2010)

(The above figures for each state do not add up to the total number of users in the respective state because each user accessed multiple sources for the required funds. Moreover, in Tamil Nadu and Orissa, not all women were undergoing IVF and ICSI. Users who underwent more advanced ARTs bore an excessively heavy financial burden, while users who accessed procedures like IUI faced a lighter financial burden (13 users in Uttar Pradesh, 22 in Orissa, and 30 in Tamil Nadu accessed IVF and ICSI)).

Tamil Nadu
Of the 43 users in Tamil Nadu, 28 (66 per cent of the sample) said that they relied on their current earnings and savings to fund the infertility procedures. Fifteen users said that they had taken loans to raise money for ‘treatment’.

*I have taken a loan against my land, and I have also taken loan against the crop in the past. The value is usually about Rs 50,000 against two acres with 8 per cent interest. I just heard that the government is waiving farm loans. That will be really useful for me.* TNU-24

Six users were helped financially by the woman’s family. Two more said that if they faced financial difficulties, they would ask the woman’s parents for help.

*My mother, mother-in-law, and brothers said that they will give us money.* TNU-35

*My parents and brother are very supportive. They gave me Rs 1.5 lakh for treatment. We did not ask them for any money, but since they gave it, we made use of it in the last cycle.* TNU-3

Two users in Tamil Nadu had to sell their assets. The assets sold in both cases was jewellery, with one of the users having sold jewellery worth Rs 15,000.
**Uttar Pradesh**

In Uttar Pradesh, only one user (out of 13) said that she faced financial problems while accessing ART and hence were helped by a relative. Three users said that they did not face a problem paying for the IVF procedure (approximately 23 per cent); two women users were not aware how the procedure was paid for because the husband took care of the payment. One user said that they had used their savings for the procedure. Six users (almost half) did not share information about the financial aspects of the treatment.

UPU-1 said that her husband managed all the details of the financial arrangements:

> Although initially my husband had threatened not to pay for the treatment, later he came around and paid for the whole thing. I don’t know where he got the money from, but I think it must have been from his savings. As far as I know, he has not taken any loan or anything.

Although users across the states adopted similar means to raise financial resources, variation in the economic profile of users was observed across the states. Users from the sample in Uttar Pradesh were much more affluent than users from Orissa. In Uttar Pradesh, the minimum annual family income was Rs 1.2 lakh and the maximum was Rs 48 lakh. The average family income was Rs 8.93 lakh (calculated on the basis of those users who revealed their income). In comparison, in Orissa, many users said that they faced difficulty because of depleting financial resources as a result of undergoing infertility treatment in general, and ARTs in particular.

In a few instances, users expressed their frustration with the non-availability of loans specifically for infertility treatment. As TNU-38 said:

> Nobody gives loans for such treatments. Health insurance does not cover the cost of ARTs. Even though my father works in this hospital, he cannot help in this department. We cannot get any subsidies because the actual costs are high, mainly because of the lab procedures and medicines. The centre, therefore, does not give any subsidies or concessions. We have managed some savings over the years and that will be used for the treatment.

Just as there is an absence of loans for infertility treatment, there is hardly any kind of public or private insurance cover for infertility. Very few organizations and companies reimburse the medical expenditure on these procedures. Two of these are Bharat Petroleum Corporation Ltd. (BPCL) and Oil and Natural Gas Corporation (ONGC). Both these organizations clarify that the reimbursement will be given only in case of primary infertility (‘no conception by any other method’) and only for the first child; will be limited to three cycles, and will only extend to Rs 45,000 per cycle.13

TNU-30 mentioned:

> Government jobs or private company jobs do provide some kind of health insurance, but in business it is different. Although we have Mediclaim, it does not cover fertility treatment.
Similarly another user (TNU-32) an employee at a private insurance firm, further elaborated on the lack of insurance:

*There is no medical claim for ART procedures. I work with an insurance company; once a big company approached us and wanted us to include infertility, even TATA AIG does not cover infertility. We had series of discussions regarding this but finally it was concluded that infertility cannot be covered.*

Users who sold their assets to pay for treatment over prolonged periods of time found themselves deeply in debt. Some users said that as a result of paying for treatment, they did not have enough money for their daily living expenses. The impact was more severe on those who were already sustaining at a relatively lower economic level. Paying for these procedures had an impact towards impoverishing them further. Of the three states, the financial condition of users from Orissa seemed to be the most deeply affected as a result of spending on infertility ‘treatment’; Orissa is also the state with the lowest socio-economic profile of the three states. For example, a user with an annual income of Rs 20,000 who had sold most of their assets to pay for one cycle of IVF was rendered almost penniless. The husband summed up their financial situation as follows:

*You can imagine our financial condition that we don’t even have enough proper vessels at home for even our own use, leave alone for any outside guests. ORU-10*

*There is no fridge in the house, but we had a television, which we had to sell. Anyway, there is no electricity in our house because we have not paid the outstanding bill of about Rs 20,000–25,000. Our electricity connection has been cut. I also got a two-wheeler as dowry during our marriage, which we had to sell for about Rs 18,000–20,000 for our treatment. ORU-9*

One user said that they kept taking loans and trying for further cycles on the advice of the provider. In the end, although they successfully had a child through IVF, their economic condition had deteriorated considerably:

*The doctor always gave us hope about the success of the technique, and on getting an optimistic response from him we took loans for further treatment. Now, with interest included, the amount is about Rs 45,000. In total, I have taken a loan of Rs 1.5 lakh. We have also sold almost all the jewellery and now there is nothing left for the daughter [born through IVF]. Everything has gone into the treatment. Sometimes it has also happened that we had to stop her from going to school because we did not have money to pay her fees. Her exam results have been adversely affected by this. She also knows that we are under severe financial constraint. My utmost worry now is how we are going to repay all the loans we have taken for the treatment. ORU-21*

The deep desire for a biological child, the sheer desperation of this want, can be gauged from the way users accumulate the money needed for the procedures. It shows just what they are ready to lose in order to gain a child. It is not only the monetary value of the objects sold and mortgaged to pay for the ‘treatment’ that is important, but that these possessions hold deep social value that the couples trade for the possibility of a successful outcome.
However, only some users understood that what they gain is not the child itself, but only a chance to have a child. Not all users grasped the concept of the success rate, which could be a crucial factor in influencing their decision about the amount of money they could afford to spend. Most of the times, this is not conveyed to users in a way that they can understand.

III.2. ‘Till there is money in the pocket’ : How finances dictate the choice of procedure

Some providers explained that the couple’s financial capacity was an important factor based on which they decided the procedure that needed to be conducted. Thus, unlike other medical procedures that are generally guided by medical indications, what sets apart the procedures for infertility ‘treatment’ is that in addition to the medical indication, most decisions — whether to avail of, or even to discontinue, the process — also largely depend on the financial resources available to users. Whether one kind of procedure (less expensive) can be substituted by another (more expensive), and whether this would be successful (the diagnosis and indications might be different), are significant economic aspects of the treatment. While desperation or desire for a biological child compels users to continue with some form of ‘treatment’, the interest of providers in continuing to do such cycles cannot be overlooked. Thus, the perceptions of providers and the experiences of users both highlight the fact that the availability of finances guided decisions about:

- the number of cycles to be conducted on the user
- the procedure to be conducted
- whether eggs/sperms/embryos will be cryopreserved, and is so, for what duration.

When asked how the decision is taken about whether to go in for IUI, IVF or ICSI, TNP-18 candidly explained:

Do you want a diplomatic answer or do you want to know the reality? I can say that it will depend on each patient and their problem. Actually, it depends on the capacity of the patients to pay — how much they can afford to pay for their treatment. If they can afford only IUI, then we do an IUI. Otherwise, if they can afford IVF, then we do that or ICSI. It all depends on how small or large the pocket of the patient is. I am willing to do as many cycles as they want. I am willing and ready to do six cycles, or even seven to ten cycles. But there should be money in the patient’s pocket. And if the patient is willing, then we are too. There is no problem. TNP-18

Another provider in UP (detailed in Chapter 6) said that apart from dictating the number of cycles, the available finances also dictated the number of embryos that were transferred so as to increase the chances of a successful outcome.

It was also observed that if users could not afford further cycles, providers prepared many embryos and cryopreserved them. Thus, in addition to the medical indications, finances seem to dictate the ‘treatment’ pattern in a very significant way. The use of donor sperm, the number of cycles, the choice of ART procedure, and cryopreservation of embryos are also linked to the amount of money that users are able or willing to spend.
Whether infertility ‘treatment’ is a medical need (like undergoing other life-saving medical treatment) is a debatable matter, but for most users accessing ARTs, the need and desire for a ‘biological child’ becomes all encompassing and the most significant drive in their life. Hence, to keep trying until success has been achieved is a trait unique to users of ARTs.

As discussed above, the correlation between financial capacity and accessibility to ARTs is direct and clearly evident. The research has also highlighted that disruption of professional work and the resulting loss of wages are equally significant factors in understanding the economic aspects of ARTs. (Discussed in detail in Chapter 4).

**IV. Market features in play**

Clinics adopted different measures such as packages and schemes to reduce costs and to attract clientele. As per the Oxford English Dictionary, the word ‘package’ means to combine (various products) for sale as one unit. It is also defined as to present (someone or something) in an attractive or advantageous way. In ART parlance, this means offering a number of services together and putting a single price tag on them. These services may be quite diverse and may include the cost of the IVF/ICSI cycle, laboratory charges, the cost of a number of cycles being offered together, drug charges, cost of donor egg or sperm, charges of hospital stay, and cost of tests. In the present context of the burgeoning ART industry, the provision of varied packages by clinics is fast becoming a common feature.

The idea behind offering a ‘package deal’ is the same as in any other service, i.e., providing users an incentive to opt for more services or products, as the combined cost of these services or products is lower than their individual cost, making the deal seem economical. Moreover, the ways in which these deals are presented and promoted further encourage users to avail them, claiming huge benefits for users. While such deals are commonplace when buying consumer products, applying the same principles in the case of medical procedures primarily carried out on women’s bodies raise many ethical and medical concerns with regard to such practices. Along with packages, many clinics also offer certain ‘schemes’ like the ‘shared-risk scheme’, the ‘egg-sharing scheme’, and the ‘money-back guarantee scheme’ towards drawing more users and dealing with the market competition.

Some of the sample clinics offered package deals of ART and related services, although the nature and the rationale behind them varied to a great extent. In Tamil Nadu, three clinics were found to offer such packages. Two of them combined the costs of the various steps involved in the IVF procedure and offered them as an IVF package, collapsing all procedures and costs into one overall cost. A provider (TNP-3), said that they have a package for an IVF cycle that costs Rs 1 lakh, which includes everything. If all the items are billed separately, they would amount to around Rs 2 lakh, as charged by other clinics in that area. The third clinic had a more attractive offer: if one cycle failed, it offered the next two cycles for free. However, the cost of one IVF cycle in this clinic was substantially higher than the cost at other clinics—Rs 1–3 lakh for an IVF cycle and Rs 3–5 lakh for an ICSI cycle. Assuming that on an average each IVF cycle costs around Rs 1 lakh, as reported by other clinics, it is evident that users have already been charged for almost three cycles at the time of availing such facilities.
In Uttar Pradesh, similar packages for IUI cycles were observed in two clinics in Kanpur. One offered three IUI cycles for a total cost of Rs 15,000. The provider (UPP-23), said, ‘We charge Rs 15,000 for an IUI cycle. If the couple does not conceive, the next two cycles are free.’

In these cases, if the user conceives in two cycles or less, the clinics stand to make a large profit as they have been paid already for the cycles that they do not need to conduct. In case the user does not conceive, she cannot complain as she has already been offered the ‘free cycles’.

These kinds of schemes on offer resemble the ‘shared-risk scheme’ made popular by many clinics in bigger cities and in other countries. In this ‘scheme’, the couples undergoing IVF pay a fixed amount at the beginning of the cycle and get part of the money back if they do not have a successful pregnancy after a predetermined number of attempts. Concerns have been raised about the promotion of such schemes. For example, in the ‘shared-risk scheme’, there is both the possibility of clinics ‘pre-selecting’ users to whom these facilities would be extended (users with the maximum chances of conceiving will be selected through screening), and also users undergoing repeated cycles over a fixed span of time (as the money has already been paid). However, in the clinics under consideration, neither were these schemes referred to as ‘shared-risk schemes’, nor did users get their money back if they were unable to conceive as a result of the cycle.

**Conclusion**

Most of the expenditure is undertaken in pursuit of either tangibles like commodities and goods or intangibles like services and non-material goals. Expenditure on intangibles can be related to our physical lives (spending money on health and health care), intellectual life (spending money on education), or emotional life (spending money on status symbols, on maintaining relationships, on friends, or on hobbies). In the case of infertility treatment, the expected outcome is dual: a tangible object, the child as well as an intangible goal such as a better state of being a parent.

In general, expenditure on a particular good or service is incurred keeping in mind the expected outcome or object gained by the expenditure. For example, in education, the cost of pursuing a particular course or degree would be measured against the money that one would be able to earn after obtaining that degree. Only if the outcome is satisfactory — that is, if there is a high probability that the money spent would be recovered before long with a profitable margin — is the expenditure or cost considered a worthwhile investment. The principle applies to expenditure, even when the outcome is a tangible object (as in the purchase of any commodity), or to a state of being. In the case of intangibles, where quantifying gains is not possible, this is understood in terms of the emotional or psychological effect that the expenditure is able to create. In the case of health care, while spending money on a particular course of treatment, one is almost certain (barring certain exceptions) that the process would have a positive effect on the health of the person. However, money spent on ARTs does not guarantee a child. Further, information on health risks is either not available (related studies may not have been conducted at all) or is not provided (such as the success or failure rates of the treatment under consideration) for the
users to be able to undertake an accurate cost-benefit analysis, which can then determine their decision whether or not to access ARTs. The distinction, however, does not end here. Another downside is that in case the expected outcome is not achieved, the user may have to bear the consequences of a negative outcome, which goes beyond loss of money and includes deterioration of health, economic status and possible strain on relationships.

Some of these aspects distinguish the cost aspect of these procedures from other medical expenditures. This is compounded by the fact that this expenditure is linked to what has been constructed as an ‘inherent desire to procreate’ and to the partly natural, partly social ‘need’ for a biological offspring. This construction inspires users to ‘do whatever it takes’, including pushing the limits of what they can afford to pay. Users may compromise on their standard of living despite knowing that their efforts are but a ‘gamble’.

It is also significant that the money spent by couples to manage or overcome infertility is not confined to investment in ARTs alone. In many cases, ARTs are resorted to at a later stage and may be preceded by opting for medical management, surgical methods, and alternative systems of medicine, undertaking religious practices, and performing rituals. These ‘other’ ways may also be pursued simultaneously with ART treatment. Hence, the cost factor associated with infertility extends to these other areas as well.

Users do not realise the significant hidden costs until they enter the ‘treatment’ process, which is substantial for users in terms of the overall cost and expenditure.

The research shows that the costly nature of ARTs has deep implications for access, especially for users from the lower socio-economic strata. Given the limited provision of these procedures in the public sector, the economic aspect is often the determining factor for many users belonging to the poorer sections.

Notes

1 Details regarding the procedures are available in Glossary.


3 The charges for the IVF and ICSI packages at AIIMS are for a comprehensive package, including follicular monitoring by ultrasound for a whole month, consumables and media for culture used in one cycle, examination of husband’s semen, and sperm-wash procedure. (Retrieved June 11, 2010 from http://www.aiims.edu/aiims/hosp-serv/art-centre.htm)


7 The couple had been married for 12 years. At the time of the interview, the user was undergoing the second IVF cycle. Their monthly income was Rs 8,000-10,000.
Homam (in Tamil) or havan (in Hindi) is a ritual in which offerings (such as food items) are put into the sacred fire on a special occasion, or to drive away evil, or to ensure success and well-being. The estimated cost is upwards of Rs 8,000-10,000.

The couple had been married for 12 years and have been undergoing different ‘treatments’ for 10 years – ayurvedic, allopathic, and 1 cycle of IVF. The husband was a police constable and the wife a homemaker. Their monthly income was Rs 3,000–4,000 (including overtime) and had spent about Rs 6,00,000 on ‘treatment’.

The respondent was 38 years old and had been married for 10 years (at the time of the interview). The couple had begun trying to have a child after two years of marriage. The respondent was undergoing the third cycle of IVF.

Gunth is a unit of land measurement in Orissa. 25 Gunths is the equivalent of 1 acre.

The couple said that they owned music bands, that is, hired groups of people who performed music at weddings, festivals, poojas, etc. Trolleys are used for carrying the equipment used by the band. The couple sold some and rented out two of the trolleys to raise money for the ‘treatment’.

CHAPTER 6

Industry: Mapping ART Provision in India

India’s fertility market, engaged in infertility care and management, has achieved the proportions of an industry. Here, a high premium is placed on the product, that is, the baby. Not only has the ART industry transformed the character of fertility technology in India but it has also streamlined the commodification of body parts, reducing women to vendors of ova and renters of uteri, and to providers of tissue for stem cell research (Srinivasan, 2010). The last few years have seen the ‘local globalisation’ of ARTs, wherein there has been a rapid proliferation of ART clinics in smaller towns and cities. At the international level too, India is becoming the favoured site for reproductive tourism, with the ART industry, also receiving support from the Indian government. India also represents a market for the pharmaceutical industry selling drugs for ARTs. New commercial possibilities emerge as ART clinics are also a source of embryos for stem cell research (Sen Gupta, 2010). A combination of biological factors, social pressures, eugenics and commerce drives the ‘baby business’, raising several ethical concerns in the process.

This chapter, under different sections, explores the increasing spread of ARTs, including fertility tourism and the ‘rationale’ behind this spread. It looks at the actors and agencies that constitute the ART industry, including newer players and collaborations between players. The chapter also examines in detail the features of this industry, and related ethical concerns.

Section A

Proliferation and expansion of ARTs

Clinics providing ARTs have sprung up in most parts of the country. ARTs are becoming the routine ‘treatment’ for infertility, with people going in for innumerable cycles and variations of IUI, IVF, ICSI, including IUI followed by IVF, or IVF followed by IUI. According to estimates by the Indian Council of Medical Research (ICMR), there were roughly 3,000 ART clinics in India in 2002 (Krishnakumar, 2003). ‘According to Dr Thankam Varma, Medical Director, Reproductive Medicine and Women’s Health Unit at a well-known Chennai hospital, there are over 30,000 infertility clinics in India, with 17 of these in Chennai city alone’ (Krishnakumar, 2003). The National ART Registry of India (2006), lists 116 ART clinics in India. According to a provider in Agra:

All the clinics [providing ARTs] have not registered yet. There may be many more clinics. NARI is an initiative of FOGSI, not a governmental one. It is FOGSI’s own system. Registration is based on the number of cycles conducted in a year, the number of staff in the clinic, and many other such specifications. So many clinics are not able to qualify for the registration. UPP-5
The above statement indicates that there could be many more ART clinics that have not been included in NARI, because they failed to meet the requisite standards. Another indicator of the growth of the ART industry in India is the steep rise in the membership of the Indian Society for Assisted Reproduction (ISAR), which was set up in 1991. The number of ISAR members has shot up from 184 in 1997 to over 600 in 2005, which may yet be a conservative estimate. The spread of the industry is also evident from the locations chosen by ISAR for hosting their national conferences. While the earlier conferences of ISAR were held in metropolitan cities, the venues have shifted to smaller cities like Indore, Jodhpur, Cochin, Ahmedabad, Guwahati, and Bhubaneswar in recent years. Although the absence of a mandatory registration makes it difficult to estimate the number of ART clinics in the country, the perspectives of some providers, together with the steep rise in the membership of ISAR, are indicative of the growth of the ART industry.

According to provider ORP-2:

*In the beginning, these technologies were available in one or two centres, in Mumbai and Chennai. There were very few clinics providing ARTs. The late 1990s were marked by the spread of these technologies to other states in India. Since then there has been an increase in the number of ART clinics in our country.*

A medical representative in Madurai said:

*At present, [ART] clinics are as prevalent as pettikadais [small street shops]. There are clinics on every street. These were not there earlier.*

The research findings also reinforce the fact that ART clinics are no longer situated only in the metropolitan and big cities, but also in smaller cities and towns. The research sample included 43 clinics located across 13 districts in three states: Cuttack, Sundargarh, Khorda, Meerut, Lucknow, Agra, Benaras, Allahabad, Vellore, Madurai, Chennai, Coimbatore, and Salem. The proportion and scale of the ART industry, however, differed between the states. The ART industry in Orissa, with only four ART clinics at the time of the research study, was at a relatively nascent stage as compared with the other two states. However, by the end of the research period, that is, within two years, two more ART clinics were expected to start operating. Similarly, a substantial number of users in the research sample were accessing the clinics from rural and semi-urban areas that otherwise lacked even basic civic amenities and necessary health care facilities. TNP-19, located in Salem, described the spread of ART clinics to smaller towns:

*Most of our patients come from Salem town now. Earlier, we used to get patients from the peripheral areas too, but now there are specialists, gynaecologists, and scan centres everywhere.*

Similarly, UPP-10 stated:

*Patients at our centre come from all over the state and also from neighbouring states like Madhya Pradesh. We get enquiries from even far-off places. Many patients come from places like Pratapgarh, Lucknow, Jaunpur, Bina, Sagar, Mirzapur, and Kanpur.*
Not only has the industry proliferated, but the quality and standards of clinics in bigger cities are also being replicated in smaller cities and towns, thus reducing the need for non-urban residents to access big cities for this purpose alone. Providers in smaller cities and towns expressed their keenness to establish their practice in bigger cities, so as to expand their user base:

We have been working in this field for the last four years, since 2005. We actually have our centre in XXX. But we realised that XXX was a very small area to have this kind of hospital. We [decided we] should move to a bigger town. Now we feel that even Meerut is not big enough. UPP-2

The fact that there were several clinics providing ARTs across the state of Uttar Pradesh, for example, did not seem to deter the provider quoted above—an indication of the perception of the vast potential of the expanding fertility market. Providers located in metropolitan and larger cities also pointed to the potential markets in rural and semi-urban areas. Thus, the growth of the fertility industry is not unidirectional.

The ART market is not limited to only IVF procedures but also includes commercial surrogates and commercial egg donors. And as India’s ART industry grows, so do commercial surrogacy and commercial egg donation. In the absense of a national registry, recording and monitoring of ARTS, statistics on the number of surrogacies being arranged in India for foreigners are not available. However, anecdotal evidence suggests a sharp increase.

The reproductive segment of the Indian medical tourism market is valued at more than $450 million a year and was forecast by the ICMR to be a $ six billion a year market in 2008. Between 2004 and 2006, the number of websites advertising ART more than quadrupled with marketing heavily geared to foreigners. (Smerdon, 2008: 24)

According to another estimate, India’s rapidly growing commercial surrogacy industry is worth US $445 million per year (IANS, 2008). Clinics offering commercial surrogacy arrangements to international clients are not situated in the major metropolitan and big cities (like Kolkata, Mumbai, Delhi, and Chennai) alone, but have also sprung up in smaller cities like Pune, Indore, Bhopal, Ahmedabad, Lucknow, and Madurai. Anand (a town in the western state of Gujarat) has become the epicenter of India’s commercial surrogacy industry. In the sample states too, providers said that there is a significant demand for surrogacy arrangements.

Internationally, an estimated eight million viewers of the Oprah Winfrey Show were informed about the new phenomenon of ‘women helping women’, wherein Americans go to India to hire surrogates. This was represented not as potentially exploitative, but instead as a ‘confirmation of just how close our countries can be’. Winfrey referred to an American couple who had appeared on the show as ‘cultural ambassadors’ to India and as benefactors of the woman whose ‘womb they had rented’.

A recent article stated the growing demand for surrogacy in the town of Gorakhpur, in east Uttar Pradesh. A gynaecologist quoted in the article commented on this trend, ‘the demand for surrogacy is on the rise and there are many patients waiting for surrogate mothers; but since many people out here are ignorant about surrogacy we try other ways to give a baby to a childless couple. But we also tell the patients that if they can get a surrogate mother then it will be a blessing for them. Moreover in Purvanchal, there are more cases of Tuberculosis, which is one of the causes of infertility and that’s the reason why surrogacy is in demand.”
According to UPP-6:

Till three years ago, there were no surrogacy cases. There were four cases of surrogacy in 2007 done by Dr XXX. And now the surrogacy trend is on the rise.

Another provider (TNP-9) discussed the surrogacy programme that the clinic planned to start:

We are also planning a surrogacy programme. We have kept away from commercial sperm and egg donation, and surrogacy so far. But we will need to think through and follow strict guidelines and procedures.

A provider (TNP-18) spoke about catering to the needs of same-sex couples from outside India:

Many gay couples come here from abroad. About 250 foreign gay couples have come to our clinic so far. We carry out surrogacy arrangements for them.

The rapid growth of commercial surrogacy raises many social, ethical, and medical concerns. Cross border surrogacy may also have legal implications, particularly in the context of payments, custody of the child or children, and citizenship. Such aspects are contentious and need resolution.

Commercial egg donation also appears to have become a significant component of the ART industry. According to a newspaper report, 50 clinics are added every year to the current 500 IVF clinics in the country; egg donation is on the rise among women aged 18–35 (Kohli, 2010). Women are selling their eggs for Rs 20,000–50,000, depending on their qualifications and looks. A number of clinics also have information on egg-donation programmes on their websites.

For instance, TNP-1’s website, along with stating success rates of 67% for their ‘donor programmes’, also proclaims:

Our physicians and staff are dedicated in helping you to realize your dreams and offer exceptional success rates for patients participating in our egg donation programme. Our programme offers anonymous egg donation. At the centre, we make it obligatory for the donor to have at least one child. Our donors are between the ages of 20 and 25 and have completed a thorough medical and psychological screening. … We have a full service of surrogacy and egg donation, that includes an attorney assistant. We believe in a well structured professional environment that clearly states the responsibilities of each party.

Further referring to the same clinic’s donor programme, another provider (TNP-6) stated:

Some of the nurses from TNP-1’s clinic have a network of donors. One of our patients, whose ovaries had been removed, got an egg donor from Salem, through this network. The donor was unrelated [to the user] and the woman had paid the donor money, I don’t know how much.
Similarly, UPP-2 spoke about their donor programme:

*In case the patients need donor oocytes, then they have to pay an extra Rs 35,000. We arrange for professional egg donors at the clinic. We generally approach women who are married and between the age group of 25-35 years for this purpose. We don’t approach the lower classes at all. The patients may not accept women from this class. So we only consider women from the middle class. We maintain all the records of all the donors as sometime the patients want the same donor when they come back for another cycle.*

The adverse health impact associated with egg retrieval, particularly repeated retrievals, are not mentioned in the promotional material of any clinic. Further, the Draft ART (Regulation) Bill and Rules, 2010 says under ‘Sourcing of Donor Gametes’, ‘No woman shall donate oocytes more than six times in her life, with not less than a three month interval between the oocyte pick-ups.’ This provision reveals disregard for the health and well-being of the donor, and facilitates rather, commerce in oocytes.

**Section B**

**Rationale for the expansion of the ART market**

**I. Demand and supply**

Part of the rationale given by providers for the proliferation of the ART industry is that they are merely responding to the demand of women ‘desperate’ to become mothers. They argued that with the widespread and steady rise of infertility, ARTs had become the ‘need of the hour’. According to TNP-2:

*Now most of them [users] know about the ART techniques and they demand them. There are actually [other] less expensive methods too, but this is what people prefer.*

*These technologies are proliferating because there is a demand. Big demand! Why does anything work or sell in the market? Because people want it. And why do people want it? Because it gives them pleasure and relief. It is more effective than any other option available. UPP-21*

The field of infertility ‘treatments’ is characterised by market rhetoric and the language of demand and supply, and is a prime example of a capitalist enterprise being marketed based on patriarchal ideology. Another example of this is seen in the statement of a provider, ORP-3, interviewed in Orissa:

*Every woman wants to become a mother herself, that is, through her own womb. During pregnancy when a woman is able to feel the child kicking from inside, or after marriage when she breastfeeds her child, she is most happy. It is said that when a child cries out of hunger, then the milk automatically flows out of the mother’s breast.*
An indication of the ‘demand’ side of the ART market is the significant movement of users across districts, states, and countries. Apart from the 13 districts where the sample clinics were located, users also came from districts located in at least nine other states. This demand is clearly not limited to the domestic market. TNP-18 claimed:

We also get patients from abroad. There is this village not far from here where people who have come for treatment stay. A lot of the foreigners stay in the village. We have created a complete set-up, which provides them privacy.

Providers in Uttar Pradesh and Tamil Nadu said that users who accessed ART services (including egg donation and surrogacy) in their clinics comprise of couples from South Asia, Southeast Asia, the Middle East, Australia, Canada, Europe, the USA, and Africa. In Uttar Pradesh, providers in Allahabad, Meerut, and Agra said that their foreign patients were primarily of Indian origin, with family associations in these cities and towns. UPP-2 said:

Yes, I have had a few foreign patients. Of course, most of them are NRIs who have their roots in India, here in Meerut. Some of them still have relatives in Meerut and come here on their advice. I have had one couple from Pakistan as well. They went through IVF and had a beautiful baby boy. Very recently, I also had a couple from the USA, and also from Manchester in England. Both these couples went on to have twin boys.

TNP-3 reinforced this observation:

We have patients coming here [primarily NRIs], referred from all over the country and abroad. People come from Kolkata, Mumbai, USA and UK for all ART services. Patients come especially for gamete-embryo transfer from Australia, Europe, Singapore, Malaysia, US and UK.

However, none of the clinics in the sample from Orissa mentioned being accessed by users from abroad, while Tamil Nadu had a substantial number of clinics that catered to overseas users. The extent of commercial surrogacy in Orissa was also much more limited than in the other two states. The providers also did not seem very keen on expanding their facilities to provide such arrangements. They cited the social context and the associated legal issues as reasons for not having gone ahead with such a programme.

II. Fertility tourism

Situated within a globalising and corporatised medical market, fertility tourism has expanded beyond the domestic market, bolstered in good measure by support from the Indian state. The reasons for the growth of fertility tourism overlap with the reasons for the growth of medical tourism in general. Significantly lower costs, technologically advanced procedures, English-speaking providers, an ample supply of Indian women interested in serving as surrogates, a ‘business climate’ that encourages the outsourcing of Indian labour, world-famous tourist destinations, and the absence of binding industry regulation, act as contributive factors. According to the Government of India (GOI) website, India is in the process of becoming a ‘Global Health Destination’ owing to these advantages.
The key reason why people from other countries are attracted to the ‘baby business’ here is the cost advantage that India offers vis-à-vis developed countries. Data shows that an IVF cycle in the US costs around $20,000 (approximately Rs 90,000) as opposed to $2,000 (approximately Rs 9,000) in India. A surrogacy arrangement, including IVF, costs about $11,000 (approximately Rs 50,000) in India, while in the US, surrogacy alone, excluding ART charges, costs $15,000 (approximately Rs 67,500). In the UK, an IVF cycle costs about £7,000 (approximately Rs 50,000) and surrogacy costs about £10,000 (approximately Rs 70,000).

Further, in the US, not only is surrogacy many times more expensive than it is in India, but the surrogate is also in a better bargaining position (Oza, 2006). In addition to medical expenses related to the pregnancy, the surrogate is given health insurance for the period of involvement, as well as all other expenses, including maternity care and clothing. Further, the commissioning parents also pay for expenses pertaining to the independent lawyer who would have to be hired by the surrogate. While in the US, up to 50 per cent of the cost of ART with a surrogate arrangement goes to the surrogate, in India most of the money is appropriated by sperm banks, clinics, etc. (Qadeer, 2009).

Fertility tourism also effectively deploys and markets Indian ‘exotica’ and packages health care with other traditional therapies such as ayurveda and yoga. Some clinics provide special services like interpreters, offer special diets, facilitate travel arrangements, arrange for daytime excursions to tourist sites, etc.

India is already a medical hub for the SAARC countries and treats foreign patients from the Gulf countries and many developed countries. Holistic medicine in India has always attracted foreign patients, and this inflow has increased with better tourist packages. UPP-7

According to a representative of a law firm in Tamil Nadu that deals with surrogacy:

A large number of people come for surrogacy from other countries. Of course, every year the numbers of intended parents are increasing. Only the US and India allow commercial surrogacy. Now due to [the] recession, even the rich people who could afford surrogacy, for example, in the US, come to India.

Apart from the above-mentioned reasons for the expansion of the fertility industry and fertility tourism, the Indian government has also played a key role in pushing medical tourism, which has contributed substantially to the growth of the fertility industry. (Qadeer, 2009)

Section C

Actors, agencies, and collaborations in the ART industry

The expansion of the ART industry draws on a network of myriad actors at the national and international levels—clinics and hospitals, health care consultants, semen banks, cryobanks, donors and donor networks, pharmaceutical companies, the hospitality industry, state tourism departments, surrogacy agents, surrogacy law firms, and other agencies specialising in the promotion of medical tourism.
I. ART consultants

India’s fertility industry has witnessed the growth of agencies that specialise in providing consultancy services to both providers and users of ARTs, including commercial surrogacy.

- Indian Med Guru, which caters exclusively to international users, defines itself as ‘a consultancy for infertility treatment and artificial reproductive techniques in India’.¹⁵

- Forerunners Healthcare Consultants markets itself as a pioneer in medical tourism. ‘As the name suggests, the company is one of the first and the most respectable company in India today, giving consultancy to foreign patients about the cost effective treatment options available in India.’¹⁶

- Trivector Scientific International promotes itself as ‘the most trusted source for all Infertility Management Needs of IVF centres all over India and outside. Trivector is the first and foremost company which offers everything under one roof at reasonable cost(s) for setting up and successfully running an Infertility Centre.’¹⁷

- ART Associates, based in Mumbai, advertises itself as providing ‘various services to assisted conception clinics. Our products Reprosoft & Scopysoft are complete software solutions for IVF & Gynaecological endoscopy clinics. We also provide consultancy services to IVF clinics for setup & troubleshooting.’¹⁸

- Shivani Scientific Industries Pvt. Ltd. provides turnkey project services for the setting up of IVF labs: ‘We Shivani Scientific Industries (P) Ltd. are [a] highly focused company for manufacturing of Bio-Medical Equipments with [a] proven track record of over 26 years . . . ’¹⁹
• The home page of a surrogacy agency in India states, ‘IVF Surrogacy by We Care Health Services India is the only professional organization of its kind in India, providing comprehensive services related to Surrogacy and Egg Donation programmes. At We Care Health Services India, we are always with you, like a shadow, supporting you, guiding you through every step of your new journey, may it be parenthood, or becoming a surrogate mother or just donating life through your eggs / sperms.’

While some of these do not expressly promote ‘IVF tourism’, clinics can rely on their ‘expertise’ to upgrade their facilities and to enhance their technical capacity, so as to market their services more effectively to international ‘clients’. These new service providers either specialize in a particular service or follow the approach of providing ‘all services, under one roof’. (Sama, 2008)

II. Law firms

Against the backdrop of the growing demand for commercial surrogacy, as well as the absence of a relevant legal framework, specialised law firms and agencies that deal with legal issues and contractual agreements vis-à-vis surrogacy have come up.

A representative of one such law firm in Chennai detailed their role:

Some of the intended parents who go through our website or hear about our services approach us first. They usually have little idea about the legalities, and want to be sure that the surrogacy arrangement that they may enter into is sound. Some of them go through a round of hospitals and [after] understanding the processes there, identify the hospitals and come to us for legal advice. There are also those intended parents who come to us if something goes wrong or if there is a breach of contract by the hospital or surrogate mother. If they come to us [instead of the hospital], then we also try and identify [a surrogate] for them. We deal directly with parents and surrogate mothers.

These services were accessed mainly by intended parents from abroad. The law firm also offered services to clinics, aimed at ensuring compliance with ‘standards’, so as to prevent legal problems from arising. However, the firm had rarely been approached by clinics, as the latter were not open to being audited, etc.

The website of KayLegal, a Mumbai-based law firm, advertises its services as follows:

Our record of achievement in the area of surrogacy law has earned us [a] reputation for excellence and an ability to effectively resolve client matters. Our relationships, dedication to quality, unparalleled understanding of the law and devotion to client services at KayLegal provide us with an ability to achieve outstanding results for our clients. We are a professional firm with a dedicated team committed to provide high quality, personalized surrogacy, representation and related legal services to help couples and individuals create the family that they have always wanted. We have more than 100 successful cases to our credit over the last few years for various IVF Clinics in India. You will receive skilled, experienced, personal legal help at every step....
III. Hostels and hotels

Hospitality services formed yet another part of the fertility industry, providing a range of boarding and lodging facilities in all three states. The increased movement of users across cities, districts, states, and even countries, has created a demand for these services. Located around ART clinics were lodges and guesthouses catering to the needs of users accessing ARTs, particularly for accommodation over extended periods. Many clinics claimed to refer their clients to these facilities. Further, in the sample states, users preferred reasonably priced accommodation that was in close proximity to ART clinics and hospitals. Some users also stated their preference for facilities that provided the space and amenities for cooking, which they required following the recommendation of providers to avoid outside food. (Discussed in detail in Chapter 5).

Given the increasing demand for surrogates in India, hostels that house surrogate women for the duration of their pregnancy are also emerging. A Delhi-based surrogacy centre’s website displays pictures and provides details of the surrogacy home staff, including the ‘landlord’ of the surrogacy home. Describing the ‘role’ and ‘responsibilities’ of the landlord, the website states:

... XXX provides us with spacious Studio Apartments that are fully furnished; have cooling to cope with the Delhi heat as well as fridges and cable televisions in each apartment, the cost of which is met by intended parents. XXX is currently looking to expand the Surrogate home from 50 to 100 apartments to meet our growing needs.  

In surrogacy hostels like the one in Anand, surrogates for commercial arrangements are cared for with rich nutritional support and careful medical supervision. This is ironic given that most of these surrogates were probably deprived of basic nutritional support and medical facilities when they gave birth to their own children (proven fertility is a criterion for being a surrogate), as they often belong to poor socio-economic backgrounds.

IV. Collaborations

A new development in the ART industry today is the emergence of joint collaborations between Indian clinics, as well as between Indian and international clinics. Some ART clinics in India have tied up with global hospitals and agencies to solicit ‘clients’ globally. The latter may be headquartered in the US or in other countries from where couples seeking ART and surrogacy services are sourced. For example, Planet Hospital (PH), a medical tourism agency headquartered in California, has an exclusive surrogacy arrangement with Dr Gautam Allahbadia, the director of Mumbai-based Rotunda – The Centre for Human Reproduction. PH’s client base is primarily American, including those of Indian origin, and also includes Europeans. (Points, 2009) Rudy Rupak, co-founder and president of Planet Hospital, said he expected to send at least 100 couples to India in 2008 for surrogacy, up from 25 in 2007, the first year he started offering the service. ‘Every time there is a success story, hundreds of inquiries follow’, he said. (Gentleman, 2008) In 2009, their surrogacy volume was about five births per month. The company said it received 15 to 20 inquiries about surrogacy per day. PH describes their approach as ‘full service’, including assistance
with donor selection, updates about the outcome of IVF attempts, and the progress of the pregnancy, all via support staff in India. (Points, 2009)26

Often such agencies also employ on-the-ground support staff in countries where the surrogates reside. These agencies typically act as brokers between the ‘clients’ and the clinics, reassuring the former about the credibility and professional qualifications of foreign health care providers located in faraway India, and coordinating all aspects of the treatment, including specific requirements.

A US-based company, Proactive Family Solutions (PFS)27, with a branch in India, recruits egg donors and intended parents for surrogacy in the US, and also coordinates ART and surrogacy services in India. The company takes care of everything – travel, boarding, lodging, coordination with the hospital, as well as tourism. The website of the company highlights that surrogacy in the US is ‘not accessible to everyone’ due to costs of IVF, obstetrics and legal concerns. The website goes on to state:

*The sentiments about surrogacy in India are much different than in the United States. In India, women step forward to be surrogates because of the financial rewards. The financial remuneration that an Indian woman receives to be a gestational surrogate provides the opportunity for a quality of life that she and her family would not otherwise have. The surrogates that we work with are, generally, married women with children. To them, this is gainful employment.*28

In the case of Egg donation also, agencies have begun catering to more specific requirements for donors. For instance, the website of New York based ‘Indian Egg Donors’ states that it was started in 2006 when the founder, a physician, found it difficult to find an Indian egg donor for a couple that had approached him. The agency now provides the option of US and India based Indian egg donors, as well as India based ‘egg sharing professionals’. The website mentions:

*Indian Egg Donors is not an IVF Center. We are an Egg Donor Agency that facilitates the availability of egg donors and surrogates of Indian origin to potential parents seeking an egg donor of Indian origin. We are pleased to announce that we are licensed as an Egg Donor Agency by the State of New York and are providing services to clients worldwide from our New York location.*29

A kind of ‘reverse’ tourism was also seen in the case of egg donation, with some companies bringing in women from the Global North to donate their eggs, as well as travel, in India. A Delhi-based ART clinic recruits egg donors from various countries like USA and South Africa, through a California (USA)-based agency known as Global Egg Donors.30 Similarly, the website of another agency, New Life India, states:

*New Life India is an agency of an international network of infertility treatment centers, our patients have unique opportunity to choose egg donors not only of Indian origin, but also Caucasian egg donors from Georgia and Ukraine [sic]*31.
ART clinics within India also enter into collaborations among themselves in order to build in-house capacities for conducting ART procedures. For example, a clinician from Agra, Uttar Pradesh provided technical assistance to other IVF clinics (referred to as collaborative centres) in smaller towns in India, such as Bareilly and Gorakhpur in Uttar Pradesh, and Ludhiana and Ambala in Punjab, as well as to clinics in neighbouring Nepal (Kathmandu) and Bangladesh (Dhaka). Similarly, a provider from Meerut was also a consultant at ART clinics in other towns in Uttar Pradesh (Bareilly, Meerut, and Allahabad) and in Punjab (Jalandhar). One such collaboration, between a clinic in Allahabad and a well-established ART centre in Delhi, was a two-year contract during which time the latter would train the former in ART procedures. Another example of such collaboration was a Meerut-based clinic that offered ICSI, although the procedure was carried out at a collaborating hospital in Delhi.

The ART industry also draws on the nexus between the medical profession and the drug industry. For example, the annual conferences of bodies like FOGSI are sponsored by pharmaceutical companies, and by manufacturers of laparoscopes and other medical equipment related to ART procedures. These conferences are attended by a large number of gynaecologists in the country. Sponsors may determine conference programmes and the junkets offered therein. By offering free trips abroad for advanced training in ARTs, the company may increase its network of future equipment buyers. India is also seen as a big market for specialized ART drugs (Srinivasan, 2010). According to a market research report:

> With [infertility] treatment stabilizing in the major markets, pharmaceutical companies are exploring other markets where assisted reproduction techniques [ARTs] are in growing clinical supply and demand . . . India is an attractive market because of its highly pronatalist culture, ART-seeking South Asians living abroad and preference for branded products.

It is clear that the ART industry comprises of a range of stakeholders. With the globalisation of medical services, this range is also spread across space, and includes actors stationed in different countries. However, complete details regarding these collaborations were unavailable and hence it is not possible to estimate their full scope.

Section D

Features of the ART industry

Like any other market, the ART market also deploys common strategies for creating demand, such as offering packages, schemes, and concessions; inflating success rates; and undertaking aggressive advertising through the use of attractively designed websites, brochures, street hoardings, bus stop signs, and announcements on local television channels. Clinics claim to offer the best services, including discounts and tourism packages.
I. Aggressive advertising: Websites, brochures, and other promotional material

A significant number of ART clinics had websites promoting their services and facilities, with sections devoted to information on infertility, overseas users, the profile of the clinic, staff, etc. Some websites also included IVF success stories and testimonials from clients, success rates, cost of various procedures, packages, picture gallery, Frequently Asked Questions (FAQs), fertility ‘myths and facts’, and IVF videos. For overseas users, tourist attractions were highlighted in addition to these. The language used in the brochures and websites to describe services and procedures was marked by hyperbole. Most of the clinics claimed to be ‘the first’, ‘the most innovative’, ‘the best with high rates of success’ and the ‘most affordable’.

The homepages of many of these websites also carried slogans about the pleasures of motherhood and parenthood, usually accompanied by photographs of newborn babies with their mothers or families. References were also made to the new hope represented by technological intervention and to the ‘miraculous’ nature of ARTs.

They say women make the world go round. How true! It is because they are mothers: The creators and sustainers of every generation

A new baby is like the beginning of all things – wonder, a hope, and a dream of possibilities.

We respect every woman’s dream to mother a baby

Way to parenthood made easy

A baby for every couple

A bundle of joy to paraplegic husband: A dream come true

A brochure of a clinic in Uttar Pradesh begins with sentences on the ‘disappointment’, ‘conflict’, ‘bitterness’, and ‘struggle’ that is caused by infertility. It describes infertility as a ‘challenge’ that one does not expect, but states that new technologies bring ‘new hope’. The brochure also points out, rather simplistically, that while India, on the one hand, is facing population growth at an explosive rate, which is creating difficult circumstances, on the other hand, infertility and childlessness are also serious problems for today’s generation. The brochure title reads ‘Infertility is no longer a curse’.

As with the brochure detailed above, promotional material often includes a paragraph or two about the trauma of infertility and establishes that the providers ‘understand’ the distress of the infertile couple and ‘empathise’ with them. Infertility is first magnified as a serious, urgent, and traumatic impairment, and then ARTs are offered as the decidedly final solution for it.

Some home pages of the clinics researched in Tamil Nadu and Uttar Pradesh also have images of conventionally good looking Caucasian babies and mothers. Similar trends have been observed in the brochures as well. This kind of an air-brushed reality that is being marketed through the images serve to white-wash the messy, imperfect nature of the technologies and what is realistically attainable through their use. The images, language,
and slogans serve to reinforce the tragedy of childlessness and the sentimentality of childbearing, particularly motherhood, while deliberately ignoring, omitting, or playing down the concerns and complications that come with medical intervention (such as side-effects, efficacy, and costs). The immense social pressure on women to bear children has enabled the fertility industry to justify the existence of ARTs by portraying these technologies as beneficial to women. The assumption that motherhood is the ‘dream’ that can now be fulfilled through technology is premised on the reinforcement of parenthood as the naturally ordained destiny of every woman. This excludes alternative forms of parenthood like adoption or voluntary childlessness.

II. Schemes, packages and concessions

Clinics advertise schemes and packages that sound no different from the sale of any other consumer product, such as ‘double your chances offer’ and ‘two cycles with one free’ (including the statement ‘conditions apply, offer open for limited time’). Clinics also come up with schemes and concessions to expand their market and to maximize their profit. These include ‘money-back guarantee’, ‘egg-sharing scheme’, ‘shared-risk scheme’, ‘economy IVF package’, and ‘refundable IVF package’. Among the clinics in the sample, the egg-sharing scheme was popular, especially in smaller cities and towns. Under this scheme, if a woman undergoing IVF agrees to share her eggs with another woman, the former is able to secure a reduction in the cost of her IVF cycles. While only one clinic each in Tamil Nadu and Orissa offered the egg-sharing scheme, eight clinics in Uttar Pradesh offered it.

As part of the scheme, one clinic gave a flat 50 per cent discount on the total cost of the cycle, and another waived the cost of the drugs used in the cycle. Provider TNP-4 maintained that the concession was not standard for all the users who availed this scheme, but rather depended on the number and quality of the eggs retrieved. The motivation seemed to be to charge users based on their paying capacity, in order to continue being ‘affordable’, even in the case of repeated failed cycles. As another provider, TNP-18, stated:

\[
\text{We don’t have any packages. The only criteria are how much money the patient has and how much they can spend. Packages are, therefore, dependent on the patient.}
\]

Concessions were portrayed as expressions of the providers’ benevolence and generosity, and were expected to earn the goodwill and patronage of users, thus contributing to wider word-of-mouth publicity for clinics. Of the 43 clinics in the sample, six provided concessions in the total cost to select users, but entirely at the discretion of the provider. Two clinics (UPP-8 and UPP-23) offered concessions based on the number of IVF/ICSI cycles undergone by users, that is, they offered ‘discounts’ (Rs 10,000 to Rs 20,000) for each successive cycle if the previous one had failed. Another clinic (UPP-6) announced:

\[
\text{On the occasion of our first successful PGD (Pre-implantation Genetic Diagnosis) baby. The first 10 patients: Free; Next 10 patients: 50\% off.}
\]
One provider had an interesting opinion about concessions. UPP-15 stated that even though the clinic did not offer concessions, the fact that it had not increased its charges for a long time was a concession in itself:

*We haven’t raised our charges since we started in 1997. Everything has become expensive. Rates have become double and triple. So not increasing rates for a decade is also like a concession for the patients.*

A couple of providers said that they do a cycle free of cost after a number of failed cycles, and acknowledged the role of such concessions in contributing strategically to the clinic’s success in the long term. As UPP-2 said:

*Sometimes, in case patients cannot afford to go in for the third or fourth cycle, we just do it for them for free. We do not think about it so much. After all, if they have a successful cycle, then they will recommend our clinic to others and we will benefit in some way or the other. This also increases their trust in us.*

In Orissa, the providers offered concessions as and when the need arose. They claimed to be guided less by commercial interests and more by benevolence, which they believed set them apart from clinics in larger cities and towns. One of them (ORP-5) said that they gave concessions on drugs, disposables, laboratory and operation theatre charges, and total fees, if required.

Along with the schemes, some clinic websites even have an exclusive section devoted to packages for overseas couples. These generally combine boarding, lodging, and visits to local tourist attractions (such as the Taj Mahal, palaces in Jaipur, spas in Goa or Kerala) alongside the ART ‘treatment’ schedules. For instance, TNP-5’s clinic website states:

*… at the hospital you can make use of some of the finest comforts apart from medical care, to ensure a completely hassle-free experience . . . And if you would like to see the sights and take-in a few of the exotic destinations that surround the city, we can arrange that too. Remember your comfort and pleasure is one of our top priorities here [sic].*

The Chennai-based law firm also confirmed this:

*Today, surrogacy and ART clinics are very closely tied with tourism. They are trying to get people from abroad for tourism as well as to undergo procedures. This is now promoted as a package. For example, a free trip to the Taj Mahal is included when they come here. These are usually for the elite foreign travellers. These agencies and hospitals facilitate the whole process for intended parents.*

Schemes attempted to create a sense of urgency and competition among users, urging them to ‘not miss’ the available opportunity to reduce the overall cost of ART ‘treatment’. Although represented as empathetic and helpful gestures aimed at reducing the financial burden of treatment for couples, schemes, packages and concessions worked also to benefit and popularise the clinics themselves.
III. Camps and batches

Infertility camps and procedures in batches were other features of the ART industry that emerged from the research. While infertility camps were used for wider outreach and recruitment of users, procedures were carried out in batches to minimise costs and to accommodate visiting specialists in the absence of the requisite in-house experts. Four clinics (two in Tamil Nadu and two in Uttar Pradesh) organized infertility camps. The nature of the camps organised by the four clinics, however, was different and with varying time frames.

In Uttar Pradesh, one clinic held monthly camps, while the other clinic held ‘free infertility and IVF consultation camps’. These camps were advertised on clinic websites, in local newspapers, and through posters in public places. Diagnostic tests were also carried out in some camps. Questions such as ‘Trying to conceive, but cannot?’ ‘Want to be a mother soon?’ and ‘Do you think you are infertile?’ were used to attract not only couples diagnosed with fertility problems, but also those who were trying to conceive. Users who were found to require IVF were referred for ‘treatment’ to the clinic. A clinic in Tamil Nadu conducted camps to generate awareness about infertility, through which demand for ARTs was also sought to be generated.

According to TNP-5:

With a tie-up with Rotary and Lions Club, we conducted village camps and informed villagers about the causative factors of infertility. While visiting the villages, we found that people were not aware of infertility and the scientific knowledge was lacking. Camps were organised to create awareness and get their consent for treatment related to infertility. We observed that poor people and agricultural labourers majorly suffered from anaemia. It was due to their food intake. They had secondary infertility problems and guidance was essential. Infertility was higher. We organised camps in the villages for almost three years. We explained the reproductive system, body functions, and reasons and treatment for infertility. Now there is awareness in the villages. People wish to come for treatment but the costs are very high.

However, some of the providers in three states were quite critical of the camp approach. A provider in Tamil Nadu said:

They have these ridiculous schemes like ‘10,000 free tests’, which is a straight way of cheating people. Patients have come here with these test reports and my biologist says that the reports are false and contain nothing. They are not done properly. Sometimes the clinics say they are doing a laparoscopy and I think they just put some tube in. The reports do not reflect any diagnosis. TNP-19
Clinics also carried out procedures for users in batches, rather than individually. Instead of conducting IVF procedures for users as and when they approached the clinic, providers would ‘gather’ or ‘collect’ IVF users over a period of time and then conduct the procedure for all of them together over a period of two or three days. In this way, providers were able to make judicious use of the expensive ‘IVF medium’ used for fertilization and cellular division of the embryo. Conducting IVF in batches was also expedient for providers who had visiting specialists on their staff. Of the 43 clinics in the sample, 21 clinics conducted IVF in batches (two in Orissa, 12 in Uttar Pradesh, and seven in Tamil Nadu).

Such strategies raise concerns about the quality and standards of interventions, given that the rationale for holding camps and organizing batches of users is based on the ostensible advantages of volume and scale. These approaches minimize the probability of users receiving individual attention and care in a situation where many clinics already lack adequate infrastructure and human resources, and function without accountability.

IV. Claims

On a waiting room wall at an IVF centre in Uttar Pradesh is an enlarged photograph of the provider carrying a newborn baby, with a caption announcing the birth of the city’s first IVF baby. Similar captions proclaiming many ‘firsts’, and other breakthroughs and landmarks in ART births were found in clinics across the three states, including on websites, in brochures, and in advertisements in journals and newspapers. The following claims were made by clinics in the sample:

First set of triplets in Meerut
1st IVF and ICSI baby in Orissa
First Laser Hatching Baby of Allahabad
First frozen embryo transfer pregnancy in South India
First ART Center to be Certified with ISO 9001: 2000 in India
First Test Tube Baby of XXX in menopausal female by oocyte donation
Over 455 pregnancies in last Six Years by IVF

Like other commercial ventures, the ART industry operates in a competitive market environment, which fuels claims to significant milestones and successes ostensibly achieved by clinics. These serve to establish the credibility and competitiveness of the services provided, in a bid to attract users. For instance, by claiming to be the first or the oldest in the business, clinics demonstrate superior expertise and/or experience. In the absence of a national registry or an external audit of ART clinics, it is impossible to gauge the authenticity of these claims.
V. Inflated success rates

Inflating the success rate to attract users was another common marketing strategy adopted by ART providers. The success rates of ART procedures quoted were often exaggerated, or unclear and misleading. Some success rates cited by clinics were:

- Our pregnancy rate[s] at 65–70% is among the highest in the world
- Today we have a success rate of 40–50% per treatment cycle
- We are able to achieve an astounding success rate of 35–40%
- With the advent of ARTs our clinical pregnancy rates have shot up from 25 to 50% and our take home baby rates have risen from 20 to 44%
- We have now consistent pregnancy rates in IVF/ICSI of about 32% to 40%

It was found that clinics rarely quoted the take-home-baby rate (or live birth rate)\textsuperscript{35}, taking advantage of the lack of awareness among users regarding the difference between the take-home-baby rate (or live birth rate) and the implantation rate (or pregnancy rate)\textsuperscript{36}. The success rates can be very specific, referring only to the percentage of biochemical pregnancies (as determined by a blood test) out of those ovary-stimulation cycles that resulted in ovum retrieval, fertilisation, and embryo transfer. But women may find after taking a course of ovary-stimulating drugs that no ova could be retrieved. Even if ova are retrieved, they may not be fertilised. And even if they do get fertilized and are transferred into a woman’s uterus, the embryos may not get implanted. Finally, an implanted embryo does not necessarily develop into a healthy baby. Some clinics reported the implantation or pregnancy rate as the success rate. Moreover, the success rates claimed by clinics were nearly never substantiated on the basis of the number of users or the time period over which these rates were calculated. This made it difficult to discern the extent of the ‘success’ denoted by stand-alone figures and percentages. Providers also alluded to a greater number of cycles as improving the success rate of the procedure. While the cumulative success rate might well improve, this is not the norm for reporting the success rate.

The success rates claimed by providers who were part of the research sample varied between 25 per cent and 60 per cent in the case of IVF, and between 10 per cent and 30 per cent in the case of IUI. Success rates vary with the type of procedure used, like IUI, IVF, and ICSI, etc. Therefore, they are meaningful only if provided in conjunction with the specific parameter whose success they measure. Some clinics claimed to have the ‘best’ pregnancy rates in the world, without providing any data to authenticate such an assertion. Providers stated:

- Now if I say 100 per cent that is not possible. The success rate is 50 per cent. Generally, 15 days after embryo transfer, we do a pregnancy test. If that is positive, then we call it a successful case. After that, what complication ensues, whether the foetus is aborted, who knows? UPP-10
- The success rate of IVF is about 40-50%, for IUI it is higher and with ICSI about 60%. TNP-37
- For IVF the success rate is 70% and for IUI it is 30–40%. The take home baby rate is 60% for IVF. TNP-5
Although most of the existing literature establishes that IUI has a lower success rate than IVF, ORP-13, an IUI practitioner, claimed exactly the opposite.

_The success rates of IUI are quite high, almost 70–80 per cent, while those of IVF are very low at 20–30 per cent._ ORP-13

Success of IVF cycle depends on a number of factors like the quality of the eggs, use of donor gametes, and the type of procedure used. The chances of a successful pregnancy via IVF may vary based on the age of the woman (which determines the quality of the eggs). Success rate also depends upon how eggs are sourced at the time of conducting an IVF cycle. The procedure can be undertaken in diverse ways—with fresh eggs, frozen eggs saved from a previous cycle or with donor eggs. As has been amply illustrated in clinical practice as well as scientific documentation of the same, each of these options can give rise to different outcomes with regard to conception.

Another way of ‘improving’ success rates used by clinics is by transferring a large number of embryos. Although many of the clinics acknowledged the increased risk of multiple pregnancies, they also propagated an alternative solution of fetal reduction for the same. Many clinics offered this option of foetal reduction and advocated its use to avoid increased incidence of abortion and premature labour associated with multiple pregnancies.

An interesting finding was the promotion of the IVF-ICSI combination by the clinics as a means of improving their success rates. A Tamil Nadu provider (TNP-5) mentioned recommending ICSI to users above 38 years of age. ICSI is fast becoming a preferred method among clinics since it is more expensive and generates higher earnings. It is important to note that ICSI is currently being used in cases of severe male factor infertility. For users who have limited knowledge of these procedures and often rely on the provider to both diagnose the problem and suggest the appropriate course of ‘treatment’, this can be misleading. Since the time of the inception of this method, concerns have been expressed about the safety of ICSI in two aspects: genetics and child development. Men with abnormal sperm production have an increased rate of sex chromosome anomalies, presumably increasing the potential for transmission of sex chromosome anomalies to the offspring. Another concern is child development (see box) The indiscriminate use of ICSI appeared to be growing despite the potential side effects that are associated with the procedure.

_We directly start with IVF or ICSI. The success rates are higher in case of ICSI._
_We do more of ICSI here._ UPP-5

_The trend these days is to do ICSI as clinics want to increase their success rates._
_They prepare half embryos by IVF and half by ICSI._ TNP-19

_Generally ICSI gives good results as compared to IVF. ICSI is done when there is a male problem and also in case of previous failures with IVF treatment._ TNP-12

Though no difference has been noted between children born from IVF and the general population up to the age of 13 years, a small study from Australia suggests that the Bayley score at one year is statistically significantly lower in those conceived through ICSI compared to IVF and naturally conceived children. The rate of sex chromosome abnormalities are 1% compared to 0.2% in the general population.37 Similarly, in another study conducted on 301 infants in Western Australia, it was found that infants conceived with use of ICSI or IVF have twice as high a risk of a major birth defect as naturally conceived infants.38
Most clinics do not provide disaggregated data on success rate based on the above factors. Usually a generalised picture of success rates is presented, only emphasising the magnitude of the numbers and not their scientific basis. Success rates (or the publicity around them) serve as a major draw for users. Clinics are able to get away with misrepresentations through the use of ‘false’ claims because of the lack of monitoring and regulation. The examination of the information provided clearly brings forth the urgent need to not only better regulate the ART industry, but in particular, the need to introduce checks and balances with regard to the way individual clinics market their services using media such as websites and brochures.

Section E

I. No rules: Lack of standardisation and related ethical concerns

A lot of foreign nationals are coming here for treatment . . . because it is cheaper and because there are no rules. TNP-13

India’s ART industry operates in an environment characterised by a glaring lack of standardisation. While this may be a general characteristic of the private health care sector as a whole, the gaps in the industry—both within and across different procedures like IUI, IVF, and ICSI—are substantial and alarming. Further, the standard competitive market model, as well as free-market principles cannot be considered applicable to, or adequate for, the health care sector in general and ARTs in particular. The reasons for this include the health hazards involved, the unequal access to information and services, and the uncertainty of outcomes. In the case of the ART industry, the absence of any legally binding regulatory mechanism is exploited by providers.

The absence of a standardised ‘treatment’ protocol for ART procedures paves the way for the exploitation of users, both physically and economically:

IVF can be done ‘n’ number of times. Dr XXX from Singapore, who was in the National Hospital there and [who is] considered a pioneer in IVF, says that people can try IVF as many times as they want. It all depends on how much money they have and [they] can try accordingly. TNP-2

Not only do procedural costs for IUI and IVF vary widely, but the costs of drugs were also found to be disparate. The cost for IUI ranged between Rs 1,500 and Rs 10,000; the cost for IVF ranged between Rs 75,000 and Rs 1.5 lakh. These costs were much higher when hidden costs for repeated tests, drugs, travel, boarding, and lodging were included. (Discussed in further detail in Chapters 4 and 5)

II. Lack of information and informed consent

Despite some variations based on education, socio-economic background, and access to alternative sources of information (like the Internet), most users had scant, inadequate, and piecemeal information about the procedures that they had undergone or were undergoing.
Although most providers spoke of the importance of counselling (understood largely as a one-time transaction of information, rather than an ongoing process of providing support), the nature and level of information provided varied according to what they considered ‘appropriate’ for users:

> When the doctor is counselling the patient, she has to decide how much information to give out. Not everyone has the capacity to understand everything and I only give the user as much information as is needed. TNP-15

This was in marked contradiction to the notion of ‘informed’ choice that consumers are expected to make in a competitive market. The requirement of obtaining informed consent was treated by providers as a mere technicality. In the absence of a standard format for obtaining consent, clinics decided what and how much information should be included in their respective consent forms. The study revealed that in most cases, the form for informed consent had minimal information, and sought to absolve the clinic of any responsibility or liability. Further, providers sought informed consent at their own discretion, and only for some and not all procedures. In several instances, the form was signed only by the husband, often without a thorough reading of the contents.

**III. Sex-selection**

ARTs also raise various ethical dilemmas and eugenic concerns, especially with regard to pre-implantation genetic diagnosis (PGD) and sex-selection. The procedure of sex-selection has become a huge business in itself, especially in countries where a lot of premium is placed on sons. (For further details refer to Chapters 2 and 4). Some providers mentioned that they get requests from couples for the implantation of embryos of their choice and they do get demands for carrying out sex-selection.

> Once a 40 year old woman who had two boys came to me. She wanted to have a girl. It was quite surprising as usually people prefer to have a son. I decided not to do it as I would have had to do sex-selection. TNP-19

Similarly, one provider in Uttar Pradesh mentioned:

> You must have heard of the 70 year old woman who went through IVF here and delivered twins. She had one boy and one girl, and while she was very happy with the son, she was very upset about having had a daughter. UPP-2

In a stark narrative of the unethical practice of sex-selection at ART clinics, one of the users mentioned:

> As they planned to develop two or three embryos, which we were informed about, I requested the doctor to develop one daughter and [one] son. They developed and transferred one boy and one girl, and the third, also a female embryo, is in the freezer. TNU-10

Although The Pre-Conception and Pre-Natal Diagnostic Techniques (PC&PNDT) (Prohibition of Sex Selection) Act, 1994, prohibits sex-selection before and after conception. The Act has no mention of Assisted Reproductive Technologies and their use to detect
or select the sex of the embryo. There is a mention of bodies like IVF centers, etc. using equipments or techniques to conduct sex-selection before or after conception in only one of the annexures that talks about registration clinics. The Act defines the terms of sex-selection as:

‘Sex selection’ includes any procedure, technique, test or administration or prescription or provision of anything for the purpose of ensuring or increasing the probability that an embryo will be of a particular sex.\textsuperscript{39}

However, there is no mention of diagnostic techniques prior to implantation in procedures such as IVF. The problem lies in the mechanism of registration of the IVF clinics itself; there is no way to know the exact number of such clinics. In such a scenario, it becomes doubly difficult to keep track of the ART clinics involved in sex-selection. None of the providers in the sample agreed to give out sex-disaggregated data of live births that had taken place at their clinics.

The use of ARTs to ‘select’ and ‘design’ children cannot be ruled out in the present climate of son-preference and pro-natalist eugenics. High-tech sex-selection poses a range of policy dilemmas, especially the challenge of addressing sex-selection without weakening women’s access to safe abortion.

### IV. Ethical concerns with stem cell research and trade of embryos

The commercialisation of ARTs extends beyond just assisted reproduction. The fertility industry has opened new domains of research in the arena of stem cells, especially with embryonic stem cell as ART clinics are also a source of embryos for stem cell research. In this regard, one of the most striking features of contemporary biomedicine is that the reproductive biology of women is being used increasingly as a generative site, i.e. a medium for biological raw material. This is separate from a woman’s ability to produce children, and rather, provides a way to ‘harvest’ biological materials as well as information for scientific, medical and commercial purposes. A report in the ICMR Bulletin (2003) notes:

*IVF . . . has not only opened up novel ways of treating infertility involving third and sometimes fourth party parenting of a child in a tandem manner, but [has] also advanced our understanding of the basic biology and pathology of human reproduction. With new developments occurring in the potential use of embryonic stem cells in the development of bio therapeutics, IVF is the only way to obtain pluripotential embryonic stem cells.*\textsuperscript{41}
The use of spare and frozen embryos for research on stem cells is rapidly gaining ground. This practice has led to a thriving nexus between the fertility clinics and stem cell research institutes, which has raised many ethical concerns across the world. The ever-growing numbers of fertility clinics and people accessing these ‘treatments’ has only added to these concerns. There is also now an effort on the part of scientists and doctors to access fresh embryos in order to derive stem cells; it is claimed that it is easier and better to derive stem cells from fresh embryos rather than from frozen ones. Therefore, many of the providers themselves are demanding a re-look into the existing guidelines. (Mudur, 2005)

Of the important questions that are being raised about stem cell research, several are not of a scientific nature at all, but are instead related to ethical issues in the use of human embryonic cells, intellectual property rights and funding. State endorsement and private profiteering appear to be operating in close collaboration in an unregulated environment, raising concerns such as obtaining informed consent for the use of ‘spare’ IVF embryos for embryonic stem cell research.

Like with ARTs, the field of stem cell research too lacks binding legal regulation. The only document seeking to regulate stem cell research is ICMR’s non-binding, Guidelines for Stem Cell Research and Therapy by the ICMR and the Department of Biotechnology (DBT), 2007.

Conclusion

Overall, then, the fertility trade is a wide and disparate market, defined by clusters of providers specializing in distinctive competencies. All of them are selling into a market where ‘whatever it takes’ is often the going price. They are selling to clients joined by their desire to buy but divided sharply by their ability to pay. They are selling a product that is simultaneously hope and medicine. And they are selling in an environment constantly enveloped in ethical concerns and political oversights. To understand the modern fertility market, therefore, we need to probe deeper, going beyond an abstract notion of supply. We need to break the market into its component parts; looking at how each operates and how together they meet and shape the ever-present demand. (Spar 2006: 35)

Although often under-researched, the market perspective provides the framework within which ARTs and related biotechnologies are flourishing today. As corporatised health care pushes the growth of medical tourism, the Indian state is also extending its support to this burgeoning sector. On the one hand, the state favours medical tourism, taking pride in the rising numbers of foreigners visiting the country for ARTs, and the advances made in the field. On the other hand, it has yet to acknowledge infertility as a
public health issue and to take preventive steps to mitigate its worst effects through the provision of a stronger and more effective public health system.

The contours of the ART industry can be mapped by examining the features of the market, including the actors and agencies that are part of this industry. Linkages have emerged between providers within and across countries, and innovative selling strategies include holding ART camps and providing discounts when eggs are shared. As this industry proliferates beyond big cities into smaller ones, ARTs are being promoted through inflated success rates and unverified claims. The lack of standardisation is a disturbing feature that has potential for the exploitation of users, physically, emotionally, and financially.

Clearly, the interests of ART providers are in conflict with the interests of the people who seek their services. The consequences of the uncontrolled commercialisation of ARTs, and the urgency of regulating these technologies, must be recognised and appropriate action be taken. The regulation of the ART industry must take into account inequities and must protect the vulnerable. Regulation must be supported by public involvement, whether in the form of public debate or campaigns on issues related to ARTs, ranging from women’s rights to medical ethics and processes of public redressal.

Notes

4 Ibid
9 Kohli, N. (2010, March 28). Young Women Take to Selling Eggs, Hindustan Times

http://www.google.co.in/#hl=en&source=hp&biw=1024&bih=549&q=forerunners+healthcare+consultants+pvt, Retrieved October 6, 2009

http://www.trivectorindia.net, Retrieved October 6, 2009


http://www.kaylegalsurrogacy.com, Retrieved October 6, 2010

http://drshivanisachdevgourdelhi.blogspot.com/, Retrieved November 24, 2010


http://www.proactivefamilysolutions.com/ParentsFAQ Retrieved December 2, 2010

Ibid


A vial of the IVF medium once opened cannot be stored.

The take-home-baby rate or the live birth rate refers to the percentage of ART cycles started that actually result in live birth (delivery of one or more live born infant(s)).

The pregnancy rate refers to the percentage of ART cycles that produce a pregnancy. This rate is therefore higher than the live birth rate because a pregnancy may end in miscarriage, or in an induced abortion, or in stillbirth.


Mudur, G.S. (2005). Scientists Seek Access to Fresh Embryos - Flop Attempts to Grow Stem Cells With Frozen variety spark call to change ethical norms, The Telegraph


Challenges and Strategies: Issues at Stake

This concluding chapter is organised into three sections. The first section reflects on Sama’s advocacy initiatives around ARTs over the research period. Section B highlights the significant findings of this research study, while section C, points out the possible areas of future inquiry.

Section A

Sama has been addressing concerns around Assisted Reproductive Technologies (ARTs) through various strategies, including action research, advocacy, and information sharing. Advocacy around ARTs and related issues has been central not only to the research study, but also to Sama’s larger efforts as a resource group for women and health. Advocacy constituted one of the three key objectives of this study, and was also the logical extension of the other two objectives, translating the research findings into policy recommendations, and generating awareness and discussion through the dissemination of these findings. Although much of this was sought to be consolidated and concretised within the research period, advocacy is by nature an ongoing exercise. As such, the research findings will continue to inform Sama’s work around the medicalisation of women’s bodies, technology, bioethics, regulation, and so on. Although public health was not the focus of this research, Sama’s advocacy efforts have been — and continue to be — situated within a larger framework that recognises the inter-linkages of ill-health in general, and of infertility in particular, with social determinants (such as poverty, patriarchy, and hazardous occupations), and stresses the need for universal health coverage, thus mandating the strengthening of the public health system.

Advocacy was targeted at a range of actors simultaneously rather than in succession so as to maximise impact. Engaging at multiple levels together—the community, policy making, international, academia, the media, etc.—was useful for integrating varying perspectives into our work, as much as to involve multiple and diverse stakeholders in the ART discourse. Sama has been engaged in cross-sectoral movement building that has brought to the fore voices from organisations advancing women’s rights, public health rights, legal rights, disability rights, and LGBTQ+ rights, to initiate discussions and debates around ARTs, especially with regard to their regulation. Although different strategies were adopted for different audiences, they were united by their common focus—securing of women’s health and rights pertaining to the use of ARTs in India.

I. Policy-level engagement

The study provided much needed evidence from the ground to strengthen the demand for regulation, highlighting instances of unethical medical practices and the potential
for abuse of women’s health and users’ rights in the absence of standard protocols. For instance, mechanisms for providing information and counselling were found to be absent or limited in most cases. The need for an expanded regulatory framework that is not restricted to ART clinics alone emerged clearly from the study, given the multiple actors involved in the ART industry. Further, such a framework would need to consider newer aspects of technology, such as embryonic stem cell research, that uses ‘spare’ IVF embryos, thus raising ethical concerns such as obtaining informed consent from users. Given that there are no systematic and credible data on clinics (registration, infrastructure, services offered, etc.) or on health risks (of both procedures and drugs), the study reinforces the need for long-term information collection towards the monitoring and review of ARTs. Engagement with policy making was done by educating and sensitising policy makers, such as parliamentarians, officials of national bodies, and representatives of state agencies.

At present, there is no legislation for the regulation of ART clinics in India. At the onset of the study, the only document guiding the conduct of ART clinics in India was the National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India (2005), by the ICMR, which was not, however, legally binding. As part of its preliminary advocacy efforts, Sama had, in 2006, critiqued the guidelines from the perspective of women’s health and rights, and had highlighted the need for comprehensive legislation formulated through a wider, participatory and transparent process.

During the research period, in 2008, MoHFW and ICMR released the ART (Regulation) Bill and Rules, 2008. This was made public at Sama’s national consultation on ‘ARTs: Emerging Concerns and Future Strategies’ in September 2008, where nearly 70 participants provided feedback on the contents of the Draft Bill. Sama drafted and released a detailed critique of the Draft Bill at a press conference in November 2008. In February 2009, MoHFW directed ICMR to take into consideration some of the concerns raised by Sama while revising the Draft Bill (2008). In 2010, the Draft ART (Regulation) Bill and Rules, 2010, prepared by ICMR and incorporating revisions to the previous draft bill, was made available. This draft was also examined and a critique of its problematic provisions was developed by Sama. (For a critique of the Draft Bill, 2010, see Annexure 3).

The state bodies that Sama engaged with included:

- Ministry of Health and Family Welfare (MoHFW)
- Indian Council of Medical Research (ICMR)
- National Human Rights Commission (NHRC)
- Planning Commission
- National Commission for Women (NCW) and State Commissions for Women
- Ministry of Women and Child Development (MWCD) and Members of Parliament

The National Commission for Women (NCW) invited Sama to develop an approach paper for the consultation on the ‘Commercialisation of ARTs and Surrogacy’ in April 2008. The consultation was attended by activists, academics, legal experts, and members of NCW. The outcome of the consultation was a letter sent by NCW to MoHFW, highlighting issues and concerns around ARTs, and demanding that these be addressed and that the Draft Bill (2008) be made public.

Similarly, in February 2009, Sama was invited to make a presentation on surrogacy in India in the context of the Draft Bill (2008) at a national consultation on ‘The Medical, Legal and Social Aspects of Surrogate Motherhood: Towards a Gendered Perspective’, organized by the West Bengal State Women’s Commission, the Women’s Studies Cell at Kolkata University, and the West Bengal Ministry of Health and Family Welfare, Kolkata.
Sama also participated in consultations organised by state bodies such as the National Commission for Women (NCW), and has conducted meetings with the state chapters of NCW. From the outset, the state was regarded as an important agent of change and was sought to be engaged with proactively.

A policy brief on ARTs for newly elected parliamentarians, following the general elections of 2009, was developed by Sama as part of an initiative by the Centre for Legislative Research and Advocacy (CLRA) and the Parliamentarians’ Group on the Millennium Development Goals (PG-MDGs). The policy brief was aimed at sensitising parliamentarians to the shortcomings in the draft bill, so as to facilitate informed discussion in the Indian parliament. Sama was also involved in the analysis and critique of other policy documents. These included the Ninth, Tenth, and Eleventh Five Year Plans, as well as the second Reproductive and Child Health (RCH) Programme and the National Health Policy.

Some concerns regarding the Draft ART (Regulation) Bill and Rules, 2010

- The Draft Bill restricts itself to regulating only ART clinics and ART Banks, without taking cognisance of other players like travel agents, surrogacy agents, surrogacy law firms, or even public hospitals providing ARTs, that form the diverse components of this growing industry.
- While minimum age for undergoing ARTs is 21, no maximum age is prescribed.
- Though the Draft recommends that not more than three oocytes be transferred (for GIFT) and not more than three embryos (for IVF-ET), it also makes allowance for ‘exceptional circumstances’, thus leaving scope for exploitation.
- The Draft discriminates on the basis of sexual orientation and declares that ARTs can only be accessed by couples who have a sexual relationship that is legal in India.
- The health risks and adverse outcomes of ARTs, especially for children, are not adequately listed.
- The Draft allows a woman to donate oocytes up to 6 times in her lifetime with a minimum interval of 3 months between the cycles. Not only is the stipulated interval inadequate, the maximum number of cycles that a woman can undergo has not been specified. This is a significant omission, as every cycle may not result in oocytes viable for donation. Also, no system has been suggested to monitor and record the number of times a woman donates oocytes. Further, the maximum number of oocytes to be retrieved needs to be prescribed not only in case of donors, but also for women undergoing IVF or in egg-sharing programmes.
- The number of live births a surrogate is permitted has been raised from three to five, including her own children. Not only is this on the higher side, thus risking the surrogate’s health, but the maximum number of cycles that a surrogate can undergo has not been specified. This is significant because repeated cycles may be required for a live birth.
- Though the Draft outlines that commissioning parent/s should ensure that the surrogate mother and child are ‘appropriately’ insured, the nature and kind of insurance are not specified. Further, responsibilities of the commissioning parent/s with regard to post-delivery and follow-up care are not clarified.
- There is no provision for legal aid for the surrogate.
- The appointment of a local guardian to keep a close watch on the surrogate is an impingement on her autonomy, freedom and rights. In case the commissioning parent/s give up custody of the child, the local guardian is responsible for either bringing up the child or giving the child to an adoption agency. Herein, the welfare of the child has been left to the discretion of an individual.
- The proposed mode of payment to the surrogate is highly imbalanced and unfavourable to her. The Draft stipulates that the payment will be made in five installments, with 75% to be given in the fifth and last installment, after the delivery of the child. This entirely reduces the labour and risks (emotional, physical, social, ethical, etc) undergone by the surrogate to a measurable output, i.e. the baby.
II. Interactions with the community

Interactions at the level of the community—both through FGDs and orientations with community-based organisations—formed the axis around which Sama’s understanding of infertility, gender, and society evolved. These sessions involved much discussion on patriarchy, health, and access, which problematised both local cultures and larger structures. The gendered burden of childlessness and the associated stigma and violence were emphasised strongly, and participants also drew attention to related problems, such as malnutrition, anaemia, tuberculosis, violence, and inadequate public health care, that were often causative factors for infertility. These interactions were important opportunities for disseminating information on infertility, ART procedures, as well as the proposed ART legislation. The organisations and networks that participated were working on diverse issues and with diverse constituencies, including women from dalit, adivasi, and Muslim communities.

III. Consultations

Conversation around ARTs is still nascent, and an important focus of Sama’s work has been to encourage related debates within various social movements. This is significant considering that issues pertaining to ARTs occupy a complex intersection between technology, health, gender, commerce, and sexuality. Further, technology is developing too fast to be regulated by laws, guidelines, or even social norms. Discussions on ARTs must focus on the future course of action for the women’s and health movements. During the course of the study, it became clear that there is an urgent need for further discussion on these technologies, for debates on the different views expressed within various social movements, and for the development of strategies to deal with the many concerns posed by ARTs. In the last three years, Sama has organised two consultations—at the national and international levels—to initiate dialogue that will integrate diverse perspectives on ARTs and surrogacy into a collective articulation of non-negotiables with regard to women’s health and rights. That this industry is no longer restricted to state borders is a well-established fact—‘globalisation of reproductive process, labour and tissues by cross-border sourcing of reproductive labour through surrogacy and egg donation and medical tourism . . . has facilitated the commercialisation and commodification of women’s bodies and reproductive tissues’ (Sama, 2010:2).

Sama sought to link its advocacy efforts with the current global discourse through an international consultation, held in January 2010, that focussed on the commercial, economic, and ethical aspects of ARTs. This consultation, titled ‘Unravelling the Fertility Industry: Challenges and Strategies for Movement Building’, was attended by over 90 participants from more than ten countries. It was an attempt to build a network of scholars, policy makers, activists, and medical practitioners who are working on reproductive technologies, as well as to learn from the experiences of regions that are witnessing the implications of these technologies. The participants discussed possible strategies for responding more effectively as a campaign or a movement to ARTs, both locally and globally, including the possibility of establishing an international regulatory framework.

Similarly, consultations and workshops organised by coalitions and networks such as Jan Swasthya Abhiyan, National Bioethics Conference, World Bioethics Conference,
People’s Collective for Economic, Social and Cultural Rights, provided the fora where concerns and demands with regard to ARTs could be highlighted and linked with other agendas.

Universities and other institutions of higher education were tapped, both nationally and internationally. Lectures and seminars where ARTs could be discussed provided an opportunity not only for the dissemination of the research findings, but also for influencing future research on a range of issues. Sama was, in turn, approached by researchers, students, filmmakers, and journalists who were looking to consolidate their understanding of ARTs, including surrogacy, in India. Sama engaged the media as a significant tool to mobilise public opinion. This was done through contributions to newspapers and journals (including peer-reviewed journals), TV interviews, as well as press conferences and press releases.

The complex nature of the issues involved in infertility treatment and ARTs, as well as the range of individuals, organizations, and institutions that need to come together to work on this issue, emphasises the need for continued alertness, preparedness, information sharing, and strategising. Advocacy serves as a critical, although challenging, means with which to affect understandings and to effect interventions. As such, the findings of this research study will enable activism for women’s health and rights within India’s ART industry.

Some of the debates that have emerged from Sama’s advocacy efforts are:

- How can we protect women’s health and rights at a time when oocytes are an important research ‘raw material’ from female foetuses, and unregulated practices in ART clinics in some countries have led to unethical and uninformed sourcing of embryos and oocytes?
- Can surrogacy be considered a form of livelihood or is it becoming a temporary survival strategy for some economically vulnerable women in countries like India?
- New markets for women’s labour under globalisation deploy women’s bodies in highly gendered and sexualised roles. While surrogacy pushes the limits of women’s labour from the private to the public, and from care to work, the accompanying objectification and rampant exploitation of their bodies poses serious threats to their health and rights. While we question notions of chastity and naturalness that make reproduction acceptable only within marriage, we must also challenge the interlocking structure of capitalism and patriarchy that are normalising, almost glorifying with an altruistic veneer, the buying and selling of women’s body parts and bodily labour.
- Choices, while constrained and constructed, must also be recognised as contributing to the operation of hetero-patriarchy. Are women who choose to be surrogates victims, or agents, or do they occupy a position somewhere in the middle? Is the body a legitimate resource? Or is this line of argument a slippery slope of relativism for women? How do we balance our questioning of women’s choices with our respect for their right to self-determination, given that in surrogacy, ‘exploitation and opportunity are bound and wound up in one’ (Hartmann in Sama, 2010)?
- With varying laws across countries regarding citizenship and nationality, how do we decide on the nationality of the child born to a surrogate? For instance, twins born to a surrogate in India for a German couple had been refused citizenship by both the countries.
- Do ARTs reinforce hetero-normativity or do they de-link reproduction from hetero/sexuality and marriage and actually make biological parenthood an option for LGBTQs?
- How can we ensure that ARTs are not misused for sex-selection or for creating only ‘able’ babies with desirable gender and other traits?
Section B

This section examines some of the main findings of this research study.

I. Infertility and medicalisation of women’s bodies

- The definitions and understandings of infertility were found to be fluid across communities. However, there is an increased medicalisation and pathologisation of the condition and its causative factors, with the industry pushing for early medical intervention, including ARTs.

- Stigmatisation and ostracism continue to mark the experience of infertility, with misconceptions surrounding ARTs often forcing couples to keep their ‘treatments’ a secret, sometimes even from family members. Simultaneously, the growing ART industry deploys, and thus re-produces, the hetero-patriarchal institution of marriage followed by childbirth. Thus, more and more women users seek ARTs to be ‘delivered’ from the trauma of childlessness (overt or covert), and to avail a higher status within the family and the community.

- It is not surprising to find that women bear a disproportionate burden of the blame for infertility, including for male factor infertility. Further, women often internalize this burden, with many experiencing shame, guilt, and anger, both at oneself and at others.

- An increased awareness of the availability of assisted reproduction for couples experiencing infertility was observed even amongst communities in remote and rural villages. However, information regarding fertility cycles and the causative factors of infertility was lacking and often misconstrued. Community perceptions of infertility were influenced also by other beliefs (religious, cultural, etc.) that may consider infertility a predetermined or predestined condition rather than a disease.

- Providers tended to put forward populist perceptions of the causes of infertility such as lifestyle, age at marriage and delay in pregnancy, thus homogenising the experience of infertility for all couples (particularly women), and blaming them at least in part for their condition. Only in exceptional cases was attention paid to causes such as occupational hazards, environmental reasons, iatrogenic factors, and other preventable conditions, such as long-standing STIs, RTIs, and other persistent infections and diseases.

- With even basic preventive care for infertility and its causative factors largely absent in the public sector, the growth of the private ART industry is being promoted.

II. Access to ARTs

- The decision to avail infertility ‘treatment’ is not taken in a vacuum or in isolation. It is the result of a combination of socio-cultural and economic factors, and is also governed by institutions such as the family and ties of kinship. It was also clear—particularly in the absence of regulation (and possibly in the event of lax
monitoring and implementation of ART regulations in the future)—that ART clinics were run according to the whims, perceptions, compulsions, and positions of individual providers.

- It was evident from the sample that ARTs were being accessed largely by married couples. There were no LGBTQ, single, or HIV positive users in the sample, and many providers expressed their objections (including moral objections) to making ARTs available to these constituencies. However, at the same time, some providers were making their services available to gay couples of foreign origin.

- Although the sample has users from across the caste spectrum, this should not indicate that the market is blind to caste, thus bearing the potential to liberate us from ascriptive identities. In India, given that caste is classed, access to ARTs must be understood as being mediated most significantly by class, and therefore by caste, because of this overlap.

- While ARTs were accessed by users from across different religions (Hindu, Muslim, Christian, Jain, and Sikh in the sample), religion can be understood as often circumscribing the limits of technology use, as much as technology is deployed in ways that preserve and perpetuate religious affiliations.

- Caste and religion were also particularly relevant in the eugenic trends observed in the context of donor gametes and surrogacy arrangements, wherein donors or surrogates from particular castes or religions were preferred over others.

- Despite the high and many hidden costs of ART procedures, the sample consisted of users from different classes, with several were willing to push the limits of their affordability in the quest for a biological child.

- The impact of ART procedures on women’s lives, including the disruption to their work, was clearly brought out by the study. Some providers perceived women’s work and careers as the main cause of delay in marriage, and therefore of infertility. However, upon investigating the age profile of women users in the sample, including age at marriage, this does not appear to be the case.

III. Growth and proliferation of the ART industry

- The interaction of patriarchal ideology and market forces constitutes the larger framework within which the ART industry in India is growing, with an increasingly market-driven approach to infertility. This growth is linked to the proliferation of the larger biotechnology industry globally.

- Given the lack of any formal state-regulated registration of ART clinics and affiliated set-ups, it is difficult to arrive at any definite numbers regarding the extent of their growth; nonetheless this growth is clear from anecdotal evidence, including industry reports.

- The extent of the growth of the ART industry has not been uniform across cities, districts or states, with different areas displaying differential growth trends. Further, while clinics are situated in predominantly urban areas, they are reaching out also to users in rural areas and in different cities and states.
As a part of the growing ‘reproductive tourism’ market, ARTs and related arrangements like surrogacy are increasingly being offered along with other tourism packages to cater to foreign demand. The reasons for this growth include significantly lower costs, superior technology, medical expertise, lack of regulation, and English-speaking providers, coupled with the marketing of Indian ‘exotica’.

The fertility industry comprises of a range of stakeholders, including players from both private and public tourism agencies, private health care establishments, consultancy agencies, law firms, and state and central governments. With increased globalisation of medical services, this range cuts across geographical boundaries and now includes actors stationed in different countries.

Drawing on other profit-driven markets, the ART industry also deploys common strategies to bolster the demand for these technologies. These measures include inflating success rates and undertaking aggressive advertising, such as attractively designed websites, brochures, advertising on walls, and hoardings in streets, near adoption agencies, on local cable channels, bus stops, etc. Clinics also organise subsidised camps for infertility diagnosis, give discounts and money-back offers. These serve to promote the ‘product’—the precious biological child—while blurring into the background, concerns and complications that come with any medical intervention (like side effects, cost, and efficacy).

The ART industry enjoys the support of the Indian state. On the one hand, the state offers incentives for the setting up of ART clinics, such as the facilitation of medical tourism with lenient visa norms and subsidies on infrastructure costs. On the other hand, there are less tangible forms of state ‘incentives’ for industry, such as through inattention to public health and the absence of regulation for private health care, thus allowing the unhindered commercialisation, ethical violations, and non-accountability of ART clinics to persist.

This reluctance of the state to regulate the ART industry, in turn, jeopardises the concept and practice of political and social citizenship. ARTs thus reopen older debates around social citizenship, while also engendering new debates about economic participation and legal-political citizenship. In doing so, ARTs transform and expand the very notion of social citizenship.

IV. Practice

The absence of any legally binding regulatory mechanism is exploited by providers. Practices like sex-selection, multiple-embryo implantation, and even the inducement of pregnancy in post-menopausal women were observed in a few clinics.

Despite some variations based on education, socio-economic background, and access to alternative sources of information like the Internet, most users were found to have scant, inadequate, and piecemeal information about their ‘treatment’.

The process of obtaining informed consent was treated by providers and users alike as a mere technicality, with very little attention being paid to the content of the consent form. A lax attitude was observed in the taking of consent, with
several instances where no form had been signed or where forms were signed without being read. The form was in some instances signed by the husband alone or an educated relative instead of the couple themselves.

- Similarly, in many clinics, the important aspect of counselling was addressed superficially, with its scope being limited only to information giving. Support and therapeutic counselling were absent, with very little attention paid to the emotional well-being and mental health status of users.

- The ART industry employs no standardisation of costs for the various procedures available; a wide variation in costs was found not only across the three states but also between clinics in the same state. The costs quoted often left out other hidden costs, including money spent on travel, accommodation, medication, and loss of wages.

- At the same time, the end product—the desired child—is considered to be ‘above’ all financial calculations of cost and is seen as a justifiably demanding but rewarding investment. This attitude often leaves the user more vulnerable to unethical practices such as repeated cycles.

- There are no standard ‘treatment’ protocols for ART procedures, which paves the way for the exploitation of users, both physically and economically. While lack of standardisation may be a general characteristic of the private health sector as a whole, the differences in the ART industry—both within and across different procedures like IUI, IVF, and ICSI—are substantial and alarming.

- Surrogacy, as a practice and as an issue, continues to be viewed with a degree of novelty in smaller towns and cities, although its reach is expanding.

- Although the ICMR guidelines explicitly prohibit the involvement of ART clinics in sourcing surrogates or arranging surrogacy contracts, even within the small sample size of this research study, there were clinics that were directly involved in sourcing the surrogates. This trend was observed more in Tamil Nadu where the industry is in a relatively advanced stage. In Orissa, on the other hand, providers were still reluctant to engage in commercial surrogacy, fearing legal and moral complications.

V. Multidirectional and multifaceted infertility treatment

- While ARTs are accessed by users to have a biological child, they are not the only form of intervention or treatment sought. A range of interventions are pursued, sometimes in combination, including ARTs, allopathic medication, alternative systems of medicine (such as unani, siddha, ayurveda, homeopathy, and home remedies) and also religious and faith-based interventions. In most cases, while alternatives might not be accessed at the start of infertility treatment, they are usually accessed at some stage.

- Economic and demographic variations (both across and within states) feed into the ‘treatment’ trajectory of couples experiencing infertility. For instance, it is a well-established fact that the availability of infrastructure in the location where
people live (urban, rural, hilly area, etc.) has a direct impact on their health-seeking behaviour; this is also the case with ARTs.

- Gynaecologists were the first point of contact for most users who accessed infertility treatment. The reasons why users chose a particular provider included reference by friends or family, proximity to the clinic, and/or information that other couples with similar problems had benefited. The attitude of the providers, as well as the outcome of the ‘treatment’, also affected ‘treatment’-related decision-making.

- While in many cases, the couple was unaware of their exact diagnosis and the details of their treatment, women were almost always much less informed than their partners or husbands, including when the ‘treatment’ was for female factor infertility.

- It was not uncommon to find the use of ART ‘treatment’ shrouded in secrecy, with some users even accessing clinics in other cities to maintain anonymity.

- In a majority of the cases, opting for ARTs was not only a significant financial, emotional, and physical investment, but also a long-term one that could continue for years on end, perhaps without the desired result ever being achieved.

- ARTs are not considered the final stage of infertility treatment by users. ART users communicated their faith in both scientific technological medical interventions and in other belief systems like religion. This blurring of the line between science and faith, applicable to other kinds of medical interventions, is also evident in infertility ‘treatment’.

VI. ARTs and public health

- Services for infertility care, including basic screening facilities, are conspicuous by their absence in the public health system. This includes health infrastructure for addressing preventive and secondary causes of infertility, which can be dealt with at a preliminary stage. Many couples felt that they had no option but to access private-sector treatment for infertility, including ARTs. This raises larger questions of access, equity, and affordability.

- Even though public health set-ups were the initial point of contact for a few users in the sample, none continued their treatment there (because of non-availability and other factors).

- While in Tamil Nadu and Uttar Pradesh, the public health infrastructure is relatively well developed, Orissa offers a picture of complete contrast, with public health facilities for infertility being almost non-existent.

- At least one of the tertiary-level public hospitals in the state capital of Uttar Pradesh (Lucknow) was providing ART facilities till the level of IUI, and was in the process of being upgraded to the level of IVF/ICSI. In comparison, one of the main public hospitals in the state capital of Tamil Nadu offered tubal recanalisation and treatment for tuberculosis (a causative factor for infertility). In Orissa, it was
observed that some of the providers in public health set-ups were providing IUI in their privately run gynaecology clinics.

VII. Implications of ARTs

- Users’ narratives highlighted several implications of ART use. These include, but are not limited to, deterioration of health, with a direct impact on the physical and social functioning of individuals, increased health risks faced by children born through ARTs, psychological problems and increased stress level, geographical and social relocation, strained sexual relations, disruption of work and daily routines, and financial instability.
- While the movement of users from one health facility to another, across towns, cities, districts, states, and even countries, is known to occur, short and long-term geographical relocation was observed amongst ART users in this sample, resulting in many cases of complete reconfiguration of social worlds and realities.
- Users’ narratives raised concerns that ARTs enhance ‘choices’ with regard to the intended child through practices like sex-selection and genetic pre-screening, thus setting the stage for sexism and consumer eugenics.
- Women’s experiences reflected the coercive nature of their supposed ‘choices’, given that they were faced with the option of either using ARTs with their adverse consequences, or remaining childless with its own set of negative implications.
- The responsibility for childlessness and its ‘treatment’ rested disproportionately with the woman and her natal family. Often, the woman’s family was expected to provide financial as well as emotional support for undergoing ARTs.

VIII. Policy and monitoring

- Although ICMR and MOHFW have proposed legislation to regulate ARTs, the Draft Bill (2008 and 2010) tends to safeguard the interests of the private-sector ART providers and to promote the growth of the ART business. Rather, the legislation should focus on regulating the providers of these technologies and safeguarding the rights and interests of users, particularly women, by incorporating provisions to prevent misuse and malpractice, and by promoting accountability.

Section C

This concluding section puts forward certain recommendations and outlines future areas of inquiry thrown up by the study.

- ARTs in a globalised world are the end services and products of a chain of actors and organisations that dot the globe. This complex chain can be mapped ethnographically so as to highlight both the experiences of the actors (for instance, the meanings they attach to these processes and their negotiations of modern technology) as well as the operationalisation of the chain itself (for instance, how connections and recruitments are made, and how finances are arranged by clinics).
- Credible and accessible information on ARTs, such as success rates, side effects, and costs, is very important for couples. Without this, users cannot be considered
to have given ‘informed consent’ for ARTs in the true sense. Standards for the kinds of information that must be mandatory, should be put in place to ensure ethical care for those who seek ‘treatment’.

- A central database for registration, monitoring, and data collection should be in place to provide data on the number of ART clinics and their outcomes; number of cycles performed, number of live births, number of failed cycles, sex of the children born, number of surrogate cases, and so on.

- A code of good practice regarding the provision of counselling services and obtaining of informed consent should be developed to ensure transparency and the ethical administration of ARTs.

- The ramifications of pregnancies in older women and couples have also not been examined, although this has been the focus of media attention. There is a lack of long-term studies on the health risks for women and children, both procedural and drug related, in ARTs. This is of critical importance, especially in high-risk pregnancies (such as post-menopausal and/or multiple-embryo implantation pregnancies).

- Information should be provided on the preventive and curative aspects of infertility treatment, and appropriate and effective information campaigns should be designed to reduce stigmatisation and social exclusion of infertile women and men. Information on adoption should also be made available.

- The impact of pregnancy loss, both material and emotional, has not been studied, although its rate of occurrence in ARTs is high.

- Researchers in the future may want to address the themes of why childlessness is increasing, among whom, and where, as well as the contexts that compel some couples to access ARTs rather than other options, such as adoption or voluntary childlessness.

- The primary causes of infertility, particularly their linkages with larger determinants such as livelihoods, need more research and documentation.

- Religious perceptions of infertility and ARTs have not been studied in-depth. There is a need to understand local interpretations and accommodations of religion, rather than only doctrinal stands taken by different religions.

- The impact of ART procedures on women’s lives, including the disruption of their work, daily routines, and social relations, was clearly brought out in the research study. Some providers perceived women’s work and careers as the main cause of delay in marriage, and therefore as responsible for their infertility. This is an important area for future research.

- Services for infertility treatment should be integrated into larger reproductive and child health services. A policy on infertility care could be formulated as part of an integrated reproductive health care programme, based on an analysis and evaluation of the availability, functioning, and effectiveness of the actual health care infrastructure. Investigations for infertility could be conducted at various levels of the health care system. For instance, service provision at the level of the subcentre or urban health post could include couple counselling on fertility-related issues and appropriate treatment and referral for STIs. Basic diagnostic tests, treatment
of some STIs, and referral services should be available at the level of the primary health centres, while specialised tests and advanced treatment could be provided at the tertiary level.

- Health care providers at each level need to be trained to impart screening, examination, diagnosis, referral, and treatment services for infertility as appropriate.

- Questions of regulation need to be explored. Given that ART provision, including surrogacy, is crossing borders in today’s world, the possibility of creating an international regulatory framework or guideline should be considered. Further, proposals for ART regulation in India need to be revisited and read together. For instance, the report of the Law Commission (2009) recommends a complete ban on commercial surrogacy, while the ICMR guidelines (2005) and MoHFW’s Draft Bill (2008 and 2010) seek to regulate the same.

- The use of embryos—the by-products of IVF—for stem cell research is a practice that needs further and systematic investigation in the Indian context. The interlinkages of ARTs with sex-selection also need further examination and strict regulation.

- The boundaries of nationhood and citizenship are being redefined through ARTs. As such, nation states need to better respond to citizenship issues that arise in the case of international surrogacies.

- Several ethical issues in ARTs still need to be explored. For instance, in gamete donation, whose rights prevail: those of the child to know, or those of the parent(s) and donor(s) to privacy and autonomy?

- ARTs present a route through which to examine adoption more closely. Adoption may not be an initial option for some infertile couples, who would rather submit to new and complex kinship ties through technological intervention (with the gamete donor, surrogate, etc.) in order to have their own biological child. Further, the newer forms of kinship and family ties that are created with the use of ARTs are also areas for future research.

It is essential to recognise that ARTs are related to the political, economic, cultural, and social institutions within a given context. We hope to use this report to share our concerns about the ART industry in India and their implications, so that we have some information at hand, however insufficient, to initiate a discussion on strategies and to plan collaborative research and advocacy both at the national and international levels.

Notes

1 Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ)
3 Ibid.
4 Ibid.
Bibliography


Indian Council of Medical Research. (2005). National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India. New Delhi: Author


Jan Swasthya Abhiyan. (2007). Globalization and Health: Towards the National Health Assembly-II. New Delhi: Author


Khanna, S.K. (1997). Traditions and Reproductive Technology in an Urbanizing North Indian Village. Social Science and Medicine, 44 (2), 171-180


Kumar, T.C. (2003). Silver Jubilee of In Vitro Fertilization in India. *ICMR Bulletin, 33*(10)


Monthly Index of Medical Specialities. (2006, July). Tropic Hormones & Related Drugs, 26 (7), 157-159


Ortner, S. (1972). Is Female to Male as Nature is to Culture? Feminist Studies, 1(2)


Paxson, H. (2003). With or Against Nature? IVF, Gender and Reproductive Agency in Athens, Greece. Social Science and Medicine, 56, 1853-1866


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Sama-Resource Group for Women and Health. (2009, December 22). Assisted Reproductive Technologies–A Critique. *Indian Association for Women’s Studies (IAWS) - Special Issue Newsletter*


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<tr>
<th>Abbreviation</th>
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<tr>
<td>ANM</td>
<td>Auxiliary Nurse Midwife</td>
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<td>ARTs</td>
<td>Assisted Reproductive Technologies</td>
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<tr>
<td>D&amp;C</td>
<td>Dilation and Curettage</td>
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<td>DDT</td>
<td>Dichloro-diphenyl-trichloroethane</td>
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<td>ET</td>
<td>Embryo Transfer</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>FOGSI</td>
<td>Federation of Obstetric and Gynaecological Societies of India</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>GIFT</td>
<td>Gamete Intrafallopian Transfer</td>
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<td>HCG</td>
<td>Human Chorionic Gonadotropin</td>
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<td>HSG</td>
<td>Hysterosalpingography</td>
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<td>ICMR</td>
<td>Indian Council of Medical Research</td>
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<td>ICSI</td>
<td>Intra Cytoplasmic Sperm Injection</td>
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<td>IMSI</td>
<td>Intracytoplasmic Morphologically Selected Sperm Injection</td>
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<td>ISAR</td>
<td>Indian Society for Assisted Reproduction</td>
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<td>IUI</td>
<td>Intra Uterine Insemination</td>
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<td>IVF</td>
<td>In Vitro Fertilization</td>
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<td>IVM</td>
<td>In Vitro Maturation</td>
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<td>MCI</td>
<td>Medical Council of India</td>
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<td>MESA</td>
<td>Microsurgical Epididymal Sperm Aspiration</td>
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<td>MNC</td>
<td>Multinational Companies</td>
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<td>MoHFW</td>
<td>Ministry of Health and Family Welfare</td>
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<td>NAMS</td>
<td>National Academy of Medical Sciences</td>
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<td>NARI</td>
<td>National ART Registry of India</td>
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<td>NFHS</td>
<td>National Family Health Survey</td>
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<td>NIRRR</td>
<td>National Institute of Research in Reproduction</td>
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<tr>
<td>PC &amp; PNDT Act</td>
<td>Pre Conception and Pre Natal Diagnostic Techniques Act</td>
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<tr>
<td>PCB</td>
<td>Polychlorinated Biphenyl</td>
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<tr>
<td>PESA</td>
<td>Percutaneous Epididymal Sperm Aspiration</td>
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<td>PGD</td>
<td>Pre-implantation Genetic Diagnosis</td>
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<tr>
<td>PID</td>
<td>Pelvic Inflammatory Disease</td>
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<td>RCH</td>
<td>Reproductive and Child Health</td>
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<td>RTI</td>
<td>Reproductive Tract Infection</td>
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<td>TESA</td>
<td>Testicular Sperm Aspiration</td>
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<td>USFDA</td>
<td>United States Food and Drug Administration</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>ZIFT</td>
<td>Zygote Intrafallopian Transfer</td>
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Glossary

Angioma: A benign tumor composed chiefly of blood vessels or lymphatic vessels.

Anovulation: The failure, cessation or suppression of ovulation (to produce eggs; discharge of mature egg from the ovary).

Artificial Insemination: The introduction of semen into part of the female reproductive tract (at the cervical opening, uterus, or fallopian tube) by other than natural means.

Azoospermia: Absence of sperm from the seminal fluid.

Blastocyst Transfer: Embryos are grown to a more advanced, stronger stage, very similar to the stage when embryos implant in the uterus, and are transferred five days after the egg retrieval.

Caesarean Section: A surgical incision of the walls of the abdomen and uterus for delivery of offspring.

Chlamydia Trachomatis: A human pathogen (i.e. the bacterium lives within human cells) that causes or is associated with various diseases of genitourinary tract including trachoma, lymphogranuloma venereum, cervicitis, and some forms of nongonococcal urethritis. Chiefly transmitted by direct sexual contact.

Cryopreservation: A method of preserving tissues (including sperm and eggs) and organs in a viable state by freezing at extremely low temperatures.

Dilation and Curettage (D&C): A medical procedure in which the uterine cervix is dilated and a curette is inserted into the uterus to scrape away the endometrium (as for the diagnosis or treatment of abnormal bleeding or for surgical abortion during the early part of the second trimester of pregnancy).

Ectopic Pregnancy: In an ectopic pregnancy, the fertilized egg implants in a location outside the uterus and tries to develop there. The most common site is the fallopian tube, the tube that normally carries eggs from the ovary to the uterus. However, ectopic pregnancy can also occur in the ovary, the abdomen, and the cervical canal (the opening from the uterus to the vaginal canal).

Edema: An abnormal accumulation of fluid beneath the skin or in one or more cavities of the body.

Egg Retrieval: The procedure in which eggs (oocytes) are obtained by inserting a needle into the ovarian follicle and removing the fluid and the egg by suction. Also called oocyte aspiration or follicle aspiration.

Embryo: The fertilised ovum that has begun cellular division and continued development up to the blastocyst stage till the end of eight weeks.

Endometriosis: A condition in which bits of the tissue similar to the lining of the uterus (endometrium) grow in other parts of the body. Like the uterine lining, this tissue builds up and sheds in response to monthly hormonal cycles. However, there is no natural outlet, for the blood discarded from these implants. Instead, it falls onto surrounding organs, causing swelling and inflammation.

Foetal Reduction: The practice of reducing the number of foetuses in a multiple pregnancy (those involving more than one foetus).

Filariasis: The name for a group of tropical diseases caused by various thread-like parasitic round worms (nematodes) and their larvae. The larvae transmit the disease to humans through a mosquito bite. Filariasis is characterised by fever, chills, headache, and skin lesions in the early stages and, if untreated, can progress to include gross enlargement of the limbs and genitalia in a condition called elephantiasis.
Follicle (Ovarian): A fluid–filled sac located just beneath the surface of the ovary, containing an egg (oocyte) and cells that produce hormones. The sac increases in size and volume during the first half of the menstrual cycle and at ovulation, the follicle matures and ruptures, releasing the egg. As the follicle matures, it can be visualised by ultrasound.

Gamete Intrafallopian Transfer (GIFT): Retrieval of oocytes from the ovary, followed by laparoscopic placement of the oocytes and sperm in the fallopian tubes.

Gonadotropin: The hormones synthesized and released by the pituitary gland that acts on testes or ovaries to promote production of sex hormones and sperm or ova.

Gonorrhea: Gonorrhea is a highly contagious sexually transmitted disease that is caused by the bacterium, Neisseria Gonorrhoeae. The mucous membranes of the genital region may become inflamed without the development of any other symptoms. When symptoms occur, they are different in men and women. In men, gonorrhea usually begins as an infection of the vessel that carries urine and sperm (urethra). In women, it will most likely infect the narrow part of the uterus (cervix).

Gross Domestic Product (GDP): The total market value of all final goods and services produced in a country in a given year, equal to total consumer, investment and government spending, plus the value of exports, minus the value of imports.

Human Chorionic Gonadotropin (HCG): A hormone similar to the pituitary gonadotropin, given by injection to treat delayed puberty, undescended testes, premenstrual tension and sterility due to lack of ovulation.

Hysterosalpingography (HSG): Examination of the uterus and fallopian tubes by radiography after injection of an opaque medium.

In Vitro Fertilisation (IVF): The fertilisation of an egg with sperm in a laboratory dish or test tube. If the egg fertilises and begins cell division, the resulting embryo is transferred into the woman’s uterus, where it is expected to implant in the uterine lining and further develop.

In Vitro Maturation (IVM): The technique of letting ovarian follicles mature in vitro. Oocytes can mature outside the body prior to IVF. However, there still isn’t enough evidence to prove the effectiveness and security of the technique.

Insomnia: Prolonged and usually abnormal inability to obtain adequate sleep.

Intra Cytoplasmic Sperm Injection (ICSI): Injection by a micro-needle of a single sperm into an egg; followed by transfer of the egg to an incubator where fertilisation takes place and then introduction of the fertilised egg into a female’s uterus. Used most commonly in cases of male infertility or where the eggs can not be easily penetrated by sperm.

Intra Uterine Insemination: Involves the introduction of sperm into the uterus of the woman.

Intracytoplasmic Morphologically Selected Sperm Injection (IMSI): The sperms are selected before the microinjection takes place. This is done using an inverted microscope that is able to provide a much greater magnifying power (around 6000 times) than those that are normally used in reproductive laboratories (200 times) to carry out the ICSI.

Laparoscopy: A visual examination or operation of the inside of the abdomen by means of a laparoscope.

Laser Assisted Hatching: Assisted hatching involves making a small hole in the pellucid zone (the layer that surrounds the embryo) to aid the embryo in the hatching process.

Micromanipulation: The technique or practice of manipulating cells or tissues (as by microdissection or microinjection).
**Microsurgical Epididymal Sperm Aspiration (MESA):** The retrieval of sperm from the epididymis by using microsurgical techniques, done in men with obstructive azoospermia.

**Miscarriage:** Spontaneous expulsion of a human foetus before it is viable, especially between the 12th and 28th week of gestation.

**Multiple Pregnancy:** A pregnancy where more than one foetus develops simultaneously in the uterus.

**Oligospermia:** Deficiency of sperm in the semen.

**Oocyte:** The female sex cell (ovum) produced by the ovary, which, when fertilised, produces an embryo.

**Ovarian Cyst:** A benign or malignant growth on an ovary.

**Ovarian Hyper Stimulation Syndrome (OHSS):** An iatrogenic complication of assisted reproductive technology. OHSS usually develops several days after assisted ovulation following gonadotropin therapy. This syndrome is characterised by ovarian enlargement due to multiple ovarian cysts and an acute fluid shift into the extravascular space. In mild cases, ovarian enlargement, abdominal distension and weight gain may occur. In severe cases, women may also suffer renal impairment, liver dysfunction, blood clots and in some cases may also be fatal.

**Pelvic Inflammatory Disease (PID):** Infection of the female reproductive tract (the fallopian tubes and ovaries) that results from micro-organisms transmitted especially during sexual intercourse but also by other means (as during surgery, abortion, or parturition), is marked especially by lower abdominal pain, an abnormal vaginal discharge, fever, and is a leading cause of infertility in women.

**Percutaneous Epididymal Sperm Aspiration (PESA):** The retrieval of sperm from the epididymis by using fine-needle aspiration, done in men with obstructive azoospermia.

**Polycystic Ovarian Disorder (PCOD):** Development of multiple cysts in the ovaries due to arrested follicular growth, and is perceived to be a common cause of infertility among women.

**Pre-implantation Genetic Diagnosis (PGD):** Technique for screening of embryos for determination of chromosomal abnormalities, before it is transferred to the uterus.

**Preterm Birth:** (Also known as premature birth). The birth of a baby before the standard period of pregnancy is completed. In most cases of human pregnancy, prematurity is considered to occur when the baby is born sooner than 37 weeks after the beginning of the last menstrual period (LMP).

**Prolactin:** A protein hormone released by the pituitary gland that induces and regulates, associated with lactation.

**Reproductive Tract Infection (RTI):** Infections that affect the reproductive tract. In women, reproductive tract infections can be in either the upper reproductive tract (fallopian tubes, ovary and uterus), or/ and the lower reproductive tract (vagina, cervix and vulva); in men, these infections are at the penis, testicles, urethra or the sperm tube.

**Sexual Dysfunction:** Sexual dysfunction is broadly defined as the inability to fully enjoy sexual intercourse. Specifically, sexual dysfunctions are disorders that interfere with a full sexual response cycle. These disorders make it difficult for a person to enjoy or to have sexual intercourse. While sexual dysfunction rarely threatens physical health, it can take a heavy psychological toll, bringing on depression, anxiety, and debilitating feelings of inadequacy.

**Sexually Transmitted Infections (STI):** Any of various infections that are transmitted by direct sexual contact including some (as syphilis, gonorrhea, chlamydia, and genital herpes) chiefly spread by sexual means and others (as Hepatitis B and HIV) also contracted by nonsexual means.
**Sonosalpingography:** Similar to HSG, but is done with the help of a saline solution (instead of a dye) and sonography (instead of x-ray, as is done in the case of hysterosalpingography).

**Sperm:** The male reproductive cell that fertilizes a woman’s egg. The sperm head carries genetic material (chromosomes), the mid-piece produces energy for movement, and the long, thin tail propels the sperm.

**Syphilis:** A chronic contagious usually sexually transmitted infection and often congenital disease that is caused by a spirochete of the genus Treponema (T. pallidum) and if left untreated produces chancre, rashes, and systemic lesions in a clinical course with three stages continued over many years.

**Testicular Sperm Aspiration (TESA):** The extraction of sperm directly from the testis through the skin, for men with obstructive azoosperma.

**Varicocele:** The abnormal enlargement of the veins of the spermatic cord, which produces a soft compressible tumor mass in the scrotum.

**Zygote Intra-fallopian Transfer (ZIFT):** Retrieval of oocytes from the ovary, fertilization and culture in vitro; laparoscopic placement of the resulting zygotes in the fallopian tubes, 24 hours after oocyte retrieval.

**Sources:**


ANNEXURE 1

State Profiles and Maps

I. Profiles of the three research states

Orissa

Orissa is located on the eastern coast of India with an area of 155,707 sq. km. and a population of 36.80 million. There are 30 districts, 314 blocks and 51349 villages. The State has population density of 236 per sq. km. (as against the national average of 312). Orissa remains one of the most under-researched states in the country, with poor socio-economic indicators.

About 87 per cent of Orissa’s population lives in villages. As per the 2001 Census, scheduled castes and tribes constitute 16.53 per cent (6.08 million) and 22.13 per cent (8.15 million) of the state’s population, constituting a significant 38.66 per cent of the state’s total population. This proportion is quite high compared to the national proportion of 16.20 per cent SC and 8.19 per cent ST (combined 24.39 per cent) of the total population. As such, Orissa presents a profile that contrasts starkly with that of Tamil Nadu and Uttar Pradesh, both in terms of economics and demographics. The state registers the lowest annual per-capita income. The proportion of people living below the poverty line in 1999-2000 was 47.15 per cent which is nearly double the all India average of 26.10 per cent. The percentage of households in the lowest wealth quintile is 48.5, while those in the highest wealth quintile is 9.1(DLHS 3).

Over the last two decades, Orissa has seen very slow development. Basic amenities like electricity, housing, and safe drinking water are found to be grossly lacking. The findings of the DLHS 3 (2007-08) reveal that, of the total number of households surveyed, only 38.8 per cent had electricity supply, 16.9 per cent had toilet facilities, 64.2 per cent lived in kuchha housing.

The life expectancy at birth for the state is 59.6 years, one of the lowest in country and the infant mortality rate is 73 per 1000 births. The Total Fertility Rate of Orissa is 2.4, close to the national average of 2.6. The Infant Mortality Rate is 69 and Maternal Mortality Ratio is 303 (SRS 2004-2006), which is higher than the national average. While the sex ratio in the State is 972 (as compared to 933 for the country), sex-selection is not uncommon. Orissa’s Nayagarh district gained notoriety recently (in 2007) when remains of around 40 aborted female foetuses were found dumped in a disused well. The female literacy rate is 50.5 per cent marginally lower than the national average of 53.7 per cent (Census 2001), while the female work participation rate (2001) is 24.62.

Orissa’s public health system and health status also present a dismal picture. Approximately fifty-one per cent women in Orissa (47.4 per cent in rural and 78.3 per cent in urban areas) were found to have had a safe delivery (DLHS 3). Sixty-one per cent of
women in Orissa have anaemia (NFHS-3). About 38 per cent of women aged 15-49 years experienced spousal violence and only 41.8 per cent participated in household decisions. More than eight per cent women were found to have symptoms of RTIs and STIs and 7.7 per cent women were found to be facing infertility (DLHS 3). With regard to health facilities, 80.7 per cent of the villages have sub-centres within 3 kilometres while 83.6 per cent of villages have Primary Health Centres within 10 kilometres (DLHS 3).

**Tamil Nadu**

Tamil Nadu lies in the southernmost part of India and ranks eleventh in terms of size by area and seventh in terms of population. As the fifth largest contributor to India’s GDP and the most urbanised state in India, Tamil Nadu is home to the highest number (10.56 per cent) of business enterprises in the country.

The state of Tamil Nadu covers an area of 130058 sq. km. and has a population of 62.41 million (Census 2001). There are 30 districts, 385 blocks and 16317 villages. The State has a population density of 479 per sq. km. (as against the national average of 312).

It is one of the foremost states in the country in terms of overall development, with the percentage of population below poverty line at 21.12 per cent (DLHS 3), which is lower than the national average. The population below the poverty line is considerably lower than the other two states, with 6.6 per cent households in the lowest wealth quintile and 23.8 per cent in the highest quintile (DLHS 3). The scheduled caste and scheduled tribe population of the state is 11.86 million and 0.65 million respectively.

Almost 91 per cent households have electricity, about 39.3 per cent have access to toilet facilities. Demographically, Tamil Nadu is characterised by below replacement level growth of population, low fertility rates that cuts across rural-urban and across all economic and social classes; the total fertility rate for the state is 1.7. The Infant Mortality Rate is 31 and Maternal Mortality Ratio is 111 (SRS 2004-2006), which are lower than the national average.

While the overall child sex ratio for the state (2001) is 942 (as compared to the national average of 927), the child sex-ratio for districts in the research sample are: Salem (851), Madurai (926), Vellore (943), Coimbatore (963), and Chennai (972), with evidence of sex-selection among specific communities in certain districts.

As per the DLHS 3, 59.9 per cent of currently married women in the age group of 15-49 years use some form of contraception, 53.9 per cent and 54.6 per cent of ever married and pregnant women are anemic. With regard to access to public health facilities in the state, villages with sub-centre within 3 kilometres is 83.7 per cent while villages with primary health centres within 10 kilometres is 78.5 percent (DLHS 3). Safe delivery is at 95.6 per cent.

The incidence of RTIs and STIs is 7.1 percent (NFHS 3) and the primary and secondary infertility (DLHS 3) is 6.7 per cent. Nearly 42 per cent of the women (NFHS 3) in the state face spousal violence. The percentage of ‘currently married women who usually participate in household decisions’ is 48.8 (NFHS 3).
Tamil Nadu has witnessed a phenomenal growth in medical tourism in recent years and is one of the leading destinations for medical tourism in India, of which ART services are a new and already major addition. Efforts are being undertaken proactively towards this. In Chennai, for example, 207 users from abroad accessed ART procedures in a private IVF clinic in 2006 alone, and advanced procedures for infertility are offered at many major hospitals.

**Uttar Pradesh**

Uttar Pradesh, located in northern India, has an area of 240,928 sq. km. and a population of 166.20 million making it India’s most populous state. The state comprises 71 districts, 813 blocks and 107452 villages. The State has population density of 689 per sq. km. (as against the national average of 312).

Uttar Pradesh occupies an important place in the religious and political landscape of the country. Hindus constitute 80 per cent and Islam is practised by about 18 per cent of the state’s population. The state’s numbers make it a heavyweight in electoral politics, and the numerous castes and sub-castes within the population add complexity and dynamism to the state’s political arena.

Uttar Pradesh is one of the BIMARU states, which are characterised by poor socio-economic indicators, especially for women. The population living below the poverty line is 31.15 per cent, with 31.8 per cent households in the lowest wealth quintile, and 11 per cent of households in the highest wealth quintile (DLHS 3). The state comprises of 35.15 million (21.1 per cent) of scheduled caste population and 0.11 (0.1 per cent) million scheduled tribe population.

Forty-three per cent of households (28 per cent of rural households and 85 per cent of urban households) have electricity. Sixty-seven per cent of households including more than four-fifths of rural households (84 per cent) have no toilet facilities.

The female literacy rate is 42.2 per cent, lower that the national average and the female work participation rate is 16.82 (census 2001), lower than the other two sample states. Among all the major Indian states, Uttar Pradesh has the highest fertility rate at 3.8, higher than the national average (2.6), as well as that of Orissa and Tamil Nadu. The Infant Mortality Rate (SRS 2008) is 67 and Maternal Mortality Ratio is 440 (SRS 2004-2006) which are higher than the national average of 53 and 254 respectively.

The sex ratio in the state is alarmingly low at 898 (as compared to 933 for the country), with the child sex ratio at 916. The prevalence of spousal violence among ever-married women between 15 and 49 years for the state is 42.4 per cent (NFHS 3). The number of women who reported symptoms of RTI/STI is a whopping 20.5 per cent, and the number of women with primary or secondary infertility at 10.1 per cent, substantially higher than in the other sample states. Nearly seventy-six per cent of the villages have sub-centres within 3 kilometres while 77.8 per cent of villages have primary health centres within 10 kilometres. Of the three states, at 30 per cent, Uttar Pradesh has the lowest percentage of women who have had safe deliveries.
The state also has relatively higher levels of permanent childlessness by place of residence of the woman and higher proportion of older childless women who have experienced violence. A study (Ram, 2008) of 14 major states in India, shows that Uttar Pradesh is one of the four states that have higher levels of permanent childlessness than the national average, with 7 per cent of the ever married women aged 35-39 years childless in 2001 in the state. Nearly 16 per cent of childless women aged 35-39 years as against less than one per cent among those with children in the central region (which includes the state of undivided Uttar Pradesh and Madhya Pradesh) were divorced/separated/deserted.

II. Maps

Location of the three research states
Research districts
Source:
The following were the main sources of information for the state profiles:

- District Level Household and Facility Survey III (DLHS 3), India, 2007-08
- National Family Health Survey (NFHS-3), India, 2005-06
Tools of Data Collection

A. Schedules

The interview schedules were designed in the form of a list of questions that would initiate discussion, rather than as a guiding format. Interviews extended beyond the issues addressed below.

I. Interview schedule for providers of ARTs

Name of the provider
Name of clinic/ hospital
Address
Telephone
Email

Section I

What are the different Assisted Reproductive Technologies used by you in this clinic?
• IUI
• IVF
• IVF-ICSI
• Commercial surrogacy
• Any other
Since when have you been using these technologies?
Any background information on the specialisation of the provider? Are you required to undergo any specific training; what are the required qualifications?
Do you think infertility is increasing or has the access to treatment facilities increased?
What are the different causes of male and female infertility? What is the percentage of male, female and unexplained infertility?
How many users do you see on an average in a day/month? How many of these are accessing your clinic for the first time?
How do users find out about your clinic/hospital? Do you have any brochures that we can have?
Do you have any links with surrogacy agencies, tourism companies, etc?
Section II

Profile of users

What is the average profile of users coming for treatment?
- Age
- Caste – general/SC/ST/OBC/any other
- Religion
- Income

Do post-menopausal women access these procedures?
Any differential perceptions amongst the different religious communities with regard to ARTs, donor insemination, surrogacy, etc?

Educational background

Marital Status
- a) Married
  - Temporarily not living with spouse/partner
  - Separated (married but not living with spouse)
  - Divorced
  - Widowed
- b) Single
- c) Lesbian couples
- d) Gay couples
- e) Any other

What do you feel about HIV +ve couples accessing ARTs?
Are there Non Resident Indian (NRI) couples accessing ARTs and Surrogacy at your clinic? Which region/country do they generally come from? Why?

Clinic set up / infrastructure

What is the composition of your team for ARTs at this clinic? Do you have an embryologist, gynecologist, andrologist, counsellor? How much does it cost to set up an ART clinic?
What are their qualifications and do they require any specific training for ARTs?
Are these personnel in-house or are they consultants? If consultants, where do they come from? Are they associated with other ART clinics?
Could you describe the physical infrastructure of the clinic and how it is maintained? [laboratories, cryopreservation units, operation theaters (OTs), consultation rooms, etc.]
Do you link up with other clinics/research institutes/semen banks, etc.?
Do you need to register separately for providing these procedures? If yes, where do you need to register?
Do you have a semen bank? If yes, is it registered separately?

Section III

Practice

According to you, what is the appropriate reference period (number of years) for couples before seeking medical intervention for infertility?
At what stage of treatment do you advise users to go for IUI, IVF or ICSI?
How are treatment related decisions made and by whom?
What is the maximum number of attempts/cycles that is carried out in case of IUI and IVF?
According to you, how many cycles do women generally need to go through to have a successful pregnancy? What do you prefer - fresh or preserved semen?
When do you decide to discontinue the procedure for a couple? Are there any standard protocols followed for this process? How are these decisions made?
Are the medicines for the procedures available/provided in/by the clinic/hospital?
What media is used for IVF? Where is this media sourced from?
Do you refer women/couple to other providers? How and at what stage? Who do you refer them to?

Egg retrieval and embryo transfer

Can you describe to us the processes of egg retrieval and embryo transfer? What drugs are used in this process?
How many eggs do you retrieve in a cycle?
How many embryos are developed and transferred in one cycle?
What happens to the spare eggs / embryos? Do you use cryopreserved eggs / embryos for IVF? Is there any difference in the success rate?
For how many years do you preserve the embryos? What is the additional charge involved?

Information and counselling

Is counselling optional or mandatory? Who provides counselling? What is the content of the counselling provided?
What kind of information is given to the user regarding
• Procedures
• Costs
• Side effects
Informed consent

Are there different informed consent forms for different procedures?
What is the content of the informed consent form?
In what language(s) is/are the consent form?
Who signs the informed consent form? What is the process followed in cases of neo-literate or non-literate persons?

Success rate

What is the success rate per cycle with IUI, IVF, ICSI?
- Pregnancy rate
- Implantation rate
- Take home baby rate

How many babies have been born at the clinic with IUI, IVF and ICSI? How many of these were:
- Through normal deliveries/C- sections
- Single children/twins/triplets/other multiple births?
- Boys/girls

Health risks

What are the health risks involved with IVF and ICSI?
What are the chances of women undergoing the following:
- Ovarian Hyperstimulation Syndrome  
- Spontaneous abortion or miscarriage  
- Ectopic pregnancy  
- Multiple births  
- Difficult labour and caesarean sections  
- Premature births  
- Ovarian cancer  
- Early menopause  
- Mental health related (depression, mood swings, etc.)  
- Any other

What are the chances of the following (with regard to the children’s health):
- Premature births  
- Low birth weight
• Pre-natal and neo-natal mortality
• Congenital abnormalities, genetic disorders
• Any other

Are the chances of these risks higher with any particular procedure?

**Costs**

What are the costs of these procedures?
• IUI (with husband/donor sperm)
• IVF
• IVF; using donated eggs, embryos
• ICSI
• Surrogacy

Do you have any specific packages?
• Egg sharing
• Shared Risk Programme
• Discount on medicines/tests
• Money back offers
• Any other

**Donor anonymity**

What is the source of donor sperms, oocytes, embryos?
What is the procedure to get donors? How are the donors selected?
What is the general profile (class, educational background, occupation, etc.) of donors?
Does the clinic maintain information about the donors? Is this mandatory? For how long are the records kept?
Does the recipient couple have a choice in selecting donor gametes? If yes, how is confidentiality ensured?

Do you perform donor matching and what characteristics do the users request for?
• Features: height, colour of hair, eyes, skin, etc.
• Religious, caste and ethnic backgrounds
• Class
• Educational background
• Age
• Any other

What are the screening criteria for the donors?
• Complete physical examination
• Blood group screening
• Screening for diseases like HIV/AIDS, Hepatitis, thalassemia, any other

Do the clinics pay the donors or is this done by the recipients? What is the average payment made?

What do you think of young college girls selling eggs?

**Surrogacy**

If a couple wants to go for a surrogacy arrangement, do you help them seek surrogates?

Do you get requests from women who want to act as surrogates (including single women)?

What is the general background (age, income, marital status, religion, etc.) of these women?

How do you select the surrogates?

Do you think there are any issues of legal parenthood in surrogacy arrangements?

Have you experienced any contractual complications in surrogacy arrangements? What happens if there is a complication with the surrogate’s pregnancy?

Are the identities of surrogates kept confidential? If not, do they keep in touch directly with the couple or through the clinic?

What do you think of commercial surrogacy? How much do you charge for arranging surrogates for the couples?

How much do the surrogates expect to be paid?

What do you think of relatives acting as surrogates?

What is your opinion about foreign (gay) couples accessing surrogacy in India?

**Adoption**

What information is given about other possible options available like adoption?

When do / would you suggest adoption as an option? What is the response of the users to adoption?

**Regulation**

Do you think that the ICMR guidelines (2005) are comprehensive? What do you think of the Draft Bill (2008)?
II. Interview schedule for users (women/men) of ARTs

Name of the Respondent(s)
Address
Telephone
Email

Section I

Socio economic profile
Religion
Caste/Tribe
Community: SC/ST/BC/OBC/others
Age
Age of your spouse/partner
Education
a) Literate (specify secondary school/undergraduate/graduate/postgraduate/any other)
b) Non literate
Education of spouse/partner
Marital status
a) Married
   • Living with spouse/partner
   • Temporarily not living with the spouse/partner
   • Separated (married but not living with the spouse)
b) Single
   • Divorced
   • Widowed
   • Unmarried
c) Lesbian/ Gay relationship
d) Any Other
Type of family
• Nuclear
• Joint family
• Any other
Details of family members including head of your family.
Occupation
   a) Self employed
   b) Employed
      • Government job
      • Corporate job/BPOs- specify
      • Any other
   c) Business
   d) Agricultural labourer
   e) Wage worker
   f) Not working [if ever employed]
   g) Any other (doctor/ other professional/film maker/architect/living abroad/ working in army, etc.)

Your spouse/partner’s occupation

Monthly income
   • Yours
   • Your spouse/partner’s
   • Other family members (wherever applicable)

Other indicators
   a) Land (how many acres, arid, barren or fertile, etc.)
   b) House
      • Own
      • Rented
   c) Borewell
   d) Vehicle
      • Four wheeler
      • Two wheeler
      • Tractor
      • Any other
   e) Fridge/TV
   f) Any other assets (e.g. plough-bullocks, etc.)

Section II

Treatment trajectory
How long have you been married or been in a relationship?
Were you using any form of contraception? Which method? How long was this method used for? Did you suffer from any side effects at that time?
Have you conceived previously? When did you feel there was a problem in conception? What was the problem and with whom?

What kind of treatment did you first try?
- Allopathic (including ART)
- Ayurvedic
- Homeopathic
- Home remedies
- Performing rituals
- Visiting shrines, dargahs, gurudwaras, temples, churches, etc.
- Any other

How did you decide to go for medical intervention/professional help? Did anyone advise you to go for check up? Where did you go?

Who went to the doctor first (woman/man)? Who accompanied you to the clinic for check up?

When did you first realise that you cannot conceive without medical intervention?

What was your reaction? What was your partner’s reaction?

What was your family’s (both natal and marital) reaction? What advice did they give you?

What kind of advice did you get from friends, neighbors, relatives?

Did you face any problem because of not conceiving – from partner, family, and community?

What are the options available for diagnosis and treatment in your area?

What are your general views on the availability and quality of health facilities in your area?

What was the diagnosis with regard to (details about the diagnosis):
- Male factor infertility
- Female factor infertility
- Unexplained infertility
- Any other

Is this your first attempt to have a child through treatment? If not, what was the result of the previous treatment? Were there any complications during and after the treatment?

Before going in for ART procedures, whom did you speak to about your plans to have a child using ART?

Did you at any point adopt multiple treatments? What was the result for all of these? How much money was spent?

Was there any kind of feeling of exploitation and/or a feeling of hope during these treatments?
How did you decide to go for this procedure? How did you come to know about this particular clinic/hospital? How did you feel when the doctor told you that you have to go for IUI/IVF/ICSI?

Are your family members aware that you are seeking treatment from an ART provider? What was your family members’ behavior like, towards you, during the ‘treatment’ phase? Who referred you to this clinic? Was he/she also going to this clinic for ART procedures?

On what basis did you make your decision about which clinic to go to?

- Word of mouth
- Cheaper clinic
- Good package deal
- Attractive advertisements
- Suggested by a doctor/friends/relatives
- Any other

Did you consult any other doctor before for ART? What was the reason for changing doctors?

When did the doctor advise you to go for IUI/IVF/ICSI and why? Did you ask for IVF/ICSI or was it suggested by the doctor?

How many cycles have you undergone - IUI/IVF/ICSI?

At what intervals were the cycles performed?

Were you in a position to negotiate with the doctor, regarding the procedures, information, costs, etc., in any way?

Have you conceived using ARTs previously?

In case of pregnancy how did you feel? Were there any anxieties? What did you feel then?

How did you feel while undergoing the procedures?

What was your experience with infertility?

How do you feel about this entire (ART) experience?

Have you thought about how long you would like to continue to access these procedures?

Has the diagnosis changed during the course of undergoing these procedures or/from an earlier ‘treatment’?

**Costs**

How much does one cycle (package) cost?

- IUI
- IVF
- IVF + ICSI
- Any other

Were any schemes/packages offered to you?

- Egg sharing
• Shared risk
• Money back scheme
• Any other

What is included in one package of IUI/IVF/any other?
What are the additional things that need to be paid for but are not included in the package?
How much have you spent till now on the ‘treatment’?
Where are you getting the money for the ‘treatment’ from?
  • Own savings
  • Loan from family members
  • Medical insurance
  • Loans from money lenders
  • Sale of assets/ property
Are you able to afford the cost?
Are these procedures covered in your insurance package?
Was the choice of ‘treatment’ in any way dependent on the cost factor?

Information and Counselling
Were you aware of the IUI/IVF procedures before coming to the clinic?
What prior information did you have? What was the source of this information?
Do you have any information on the number of eggs retrieved in each sitting, the number of embryos transferred, what happens to the spare oocytes or embryos?
Are you aware if any donor gametes were used?
What was the information provided before and during the course of treatment?
  • Success rate
  • Side-effects
  • Costs
  • Any other
Was this information provided to you, your partner or both together? Was this done before you began with the procedure or was it a continuous ongoing process?
Who provided the counseling: a specialist, the provider himself/herself or any other staff?
What was discussed? Did you feel that your queries were satisfactorily answered? Did the counselor give you adequate time?

Informed consent
Were you or your partner given informed consent form(s) to sign before the treatment? If yes, who signed the form(s)?
What was explained in the form(s)?
In what language was the form(s)? Was the language in which the information was provided, easily understandable?
In case of non-literate users: Did someone read out and explain the contents? Did you understand the contents completely?

**On donors**

Did you or your partner/spouse/family agree to use donor gametes (sperm/egg)? What was their reaction?

How was your donor selected? Were you given a choice in selecting the donor? If yes, who was your first choice? Known or unknown donor? Why?

Did you look for any special characteristic, age, etc.? Why?

Did the clinic offer to provide you with a donor? If yes, were you charged extra?

Was the monetary transaction between you and the donors channelised through clinic or independently?

**Health Risks**

Are you experiencing/have you experienced any of the following health risks or side effects:

- Ovarian Hyperstimulation Syndrome
- Spontaneous abortion or miscarriage
- Ectopic pregnancy
- Multiple births
- Difficult labour and caesarean sections
- Premature births
- Peri-natal and neo-natal mortality
- Genetic disorders/ defects
- Ovarian cancer
- Hepatitis B
- Weight gain
- Depression/Anxiety/Mood swings
- Severe abdominal pain
- Irregular periods
- Sleeplessness
- Any other

**Other implications**

Did the treatment affect your general routine? How?

- Daily course of work
- Ongoing education
- Occupation
- Has it had any effect on the relationship with your family, your partner (negative and positive)
- Sexual life
- Any other

Did you experience depression, stress, and trauma because of not conceiving? How did you cope with these problems?

Were you able to share your anxieties, concerns with anyone?
Would you recommend this ‘treatment’ (ART) to other women/couples?
What is your perception of motherhood/fatherhood?
Have you thought of any other options, such as adoption or being without a child? What is your opinion on adoption?
What is the importance of a biological/your own child for you and your partner?
What was your emotional response towards conceiving? Do you plan to tell the child about how (s)he was conceived? If yes, when and what would you share?
Could you share with us how you felt throughout this process?
What is your perception of private clinics and the providers?
Any other experience?
III. Discussion points for focus group discussions (FGD)

Composition of group

Number
Age
Caste
Community
Occupation

Venue of discussion
Date
Facilitated by

What are the general health problems/issues in the area?
What are the reproductive health problems faced by women in the area?
What is your source of information with regard to access to health care? Whom do you first go to address the problem?
What is the average age at which girls begin menstruation? Has the age for menarche increased or decreased? What are the reasons?
How has the notion of fertility and infertility been defined and perceived within your group or community? Is it felt that infertility is increasing or decreasing?
What are the reasons for female and male factor infertility (both medical and psycho-social factors) as perceived by you? Which contributory factors are perceived as higher?
After how many years of marriage is not being able to conceive or not being able to bear a child considered a problem?
What do the couples do first when faced with such a problem?

Medical treatment

When do women/couples go for medical treatment of infertility?
Reasons for accessing or not accessing public health services as the first point, (if it is so).

Reasons for not accessing public health:

- Less accessible
- Long waiting periods
- Unhygienic surroundings
- Low availability of staff and drugs
- Inadequate provisions for testing and diagnosis
- Unfriendly behaviour of staff
- Attitudes towards the poor and people from other marginalised communities
- No female medical officers
What is the involvement of other family members in the treatment or as support system?
What does Informed Consent mean to women? What is the perception of quality of care?

**Alternative options**

What are the alternatives accessed? For example, visiting temples, shrines, astrologers, tying sacred threads, doing any kinds of rituals?
Do you know of any deity, or places of worship (temple, dargah, etc.) in your area, particularly accessed for fertility? Do women or couples visit these?
Any other social or cultural norms associated with infertility?
Any the specific rituals conducted to have a child and specific rituals to have a boy?
Any proverbs or quotes regarding infertility?

**Perceptions about fertility and infertility**

What is the perception of motherhood within the community?
Is infertility attributed to destiny Or considered a disease Or as a social burden within the community?
Why are women more burdened because of infertility?
What is the attitude of the community towards infertile women and men? Is there any difference? In terms of
- Non-acceptance
- Blaming the woman
- Violence and abuse faced by women because of infertility
- Fear of questioning masculinity and social status of the man in cases of male infertility
- Low self esteem because of infertility

What are the options available to women when there is male factor infertility? Men often go in for remarriage if the woman is not able to conceive. Is remarriage an option for women in case of male factor infertility? If yes why? If no why?
What is the impact on social relationship because of infertility/not being able to conceive?

**Perceptions about ARTs and surrogacy**

Have you heard about the techniques of IUI/IVF/ICSI? What kind of information and what is the source of information?
Have you heard about surrogacy? What is the source of this information?
Perceptions about commercial surrogacy and altruistic surrogacy.

**Perceptions about Gamete donation**

Have you heard about egg-donation?
What is your opinion about egg-donation; about young girls donating eggs?
What is your opinion about having your ‘own child’ through egg-donation?
Who are preferred-family members or outsiders-as egg donors?
What is your opinion about having a child through sperm donation?
Is adoption perceived as a better option than having a child through sperm donation?

Other options

Is adoption considered as an option? If yes, why? If no, why? At what point of time?
What are the perceptions with regard to adopting a child vis-à-vis having own child through IVF/IUI? Reasons for adopting or not adopting?
Do couples prefer adopting a child from within the family or from outside? What are the reasons for both?
What about voluntary childlessness?
B. Informed consent form for women using Assisted Reproductive Technologies (ARTs)

Sama–Resource Group for Women & Health is a Delhi based women’s organisation. We are conducting a study on Infertility and Assisted Reproductive Technologies (ARTs). Towards this end, we are interviewing women who are undergoing these procedures to understand the implications of these technologies. In this context we seek your permission to interview you about your experiences and thoughts in relation to ARTs.

The interview will take from one to two hours. With your permission, we would like to audiotape this interview so we can record the details accurately. As per research ethics, your name and identity will be kept anonymous and any identifying characteristics will not be revealed. Personal information provided by you will be strictly used for research purposes.

You are free to withdraw from the interview at any point of time. You can also refrain from answering any question that you feel inappropriate. There are no direct benefits to the participant in this study, and the results of this study will add to the generalised knowledge of research on ARTs. Please feel free to ask us for any questions about this study.

Thank you for your participation in the study.

Name and Signature of interviewer/s

Date: Place:

I understand the objectives of the study being conducted by Sama–Resource Group for Women and Health and I agree to being interviewed for this study.

My participation in this study is voluntary. I may withdraw from the interview at any point of time. I understand that there will not be any risks for me and my name will not be published without my consent.

Name and Signature of the participant:

Date: Place:
संयोगतः सामा महिलाओं एवं स्तनपायकों (स.ए.आरटी) का प्रयोग करने वाली महिलाओं के लिए सहायता प्रदान

परिचयः सामा महिला और स्तनपायकों के लिए संयोगतः समूह बनाये गए हैं जिन्हें एक संस्था कहा जा सकता है। इन अनुसंधान एवं संयोजन प्लान में सहायता देने वाली महिलाओं (स.ए.आरटी) पर एक संस्था का रोच करता है। इसलिए इन तकनीकियों के साथ-साथ सहायता के क्षेत्र में अपनी कहानी का यह नियम उन महिलाओं से साक्षात करना रखा है जो इसका प्रयोग कर रही है। इस उद्देश्य के लिए इस संस्था में हम अपने समुदाय और लोकतांत्रिक को समाज के क्षेत्र में हम समेत उन महिलाओं से साक्षात करना रखा है जो इसका प्रयोग कर रही है।

इस संस्था का उद्देश्य हमें अपने समुदाय और समाज को सहायता प्रदान करने की अनुमति प्रदान करता है। इस संस्था का उद्देश्य इस संस्था का समय एवं उद्देश्यों को बढ़ाना है। हम यदि अपनी सहयोग या सहायता की होगी तो हम इस संस्था का उद्देश्य बढ़ाना है।

अपने इस संस्था में नारी लेने के लिए निकले (उद्देश्य) लोक/पति एवं हर्षवदन्त महिलाओं के लिए समय प्रदान नहीं होगा। इस लोक के लिए हम नारी लेने के लिए उद्देश्य होगा।

इस संस्था में हमें नारी लेने के लिए अपनी ध्यान देना जरूरी है।

इंद्रधनुष करने वाले/वाली का नाम एवं हस्ताक्षर –

निर्देशः रस्ता:

मैं सामा महिला और स्तनपायकों के लिए संयोगतः समूह द्वारा किए जा रहे इस संस्था के उद्देश्यों को समेत उन्हें इंद्रधनुष/सहायता के लिए अपनी सहयोग देने हैं। मैं अपनी सहयोगशाला इस संस्था में मिले हैं। मैं समय की सहयोगशाला के लिए ऐसा में हमें नारी लेने के लिए उद्देश्य होगा।

इंद्रधनुष में हमें नारी लेने के लिए अपनी ध्यान देने का नाम एवं हस्ताक्षर –

निर्देशः

8-45, 2nd Floor, Mahi Road 2nd Block, Marwadi Nagar, New Delhi-110067
Phone: 011-25035122, 99903900
Email: sama@womenhealth@gmail.com; sama_womenhealth@esp.net

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Critique of the Draft ART (Regulation) Bill and Rules, 2010

The Draft Assisted Reproductive Technology (Regulation) Bill and Rules, 2010, is the latest draft following the incorporation of additions and modifications to the Draft Bill (2008) (Sama’s critique of the Draft Bill, 2008 can be accessed at www.samawomenshealth.org). While the previous draft was an effort to include issues concerning ARTs, it had several limitations, and was expected that the new draft would address these gaps. We acknowledge and appreciate that the Indian Council of Medical Research and the Ministry of Health and Family Welfare have taken into consideration some of the concerns raised by Sama-Resource Group for Women and Health with regard to the Draft Bill (2008). Nonetheless, the present draft (2010) is not as yet comprehensive and falls short of addressing many concerns vis-à-vis women’s health and rights.

While changes have been made in different clauses, significant modifications have been introduced in clauses specific to surrogacy. This is a welcome step, considering the complexities of issues such as citizenship of the children born out of surrogacy arrangements. However, some earlier concerns regarding the nature of operationalisation of the provisions of the bill, the functional relationship between the ART Bank [referred to as Semen Bank in the Draft Bill (2008)] and the ART clinics, etc., still remain.

I. The preamble

The Draft Bill (2010) has incorporated a Preamble, which was expected to explain the significance and rationale of the proposed legislation. However, the Preamble in its present form represents infertility as one of the most highly prevalent medical problems, mandating technological intervention. In fact, ARTs and medical technologies have been made to sound like the miracle solution to every kind of infertility problem. The Draft states... ‘With the enormous advances in medicines and medical technologies, today 85 per cent of the cases of infertility can be taken care of through medicines, surgery and/or the new medical technologies…..’. The social stigma associated with infertility combined with the availability of these technologies in a way is justified for accessing ARTs. Further, this narrow perspective, to have a biological child seems imperative with the availability of technologies and is also reflected in statements in the Draft Bill suggesting that children are a kind of ‘old age insurance’ in India. Not only do such statements reinforce biological parenthood, but they are also based on simplistic and generalised assumptions (such as the assumption that every biological child will take care of his/her parents in their old age).

Although the preamble puts forth the ‘need for regulation, ethical practice and the rights of all concerned’, it must also include a more nuanced, comprehensive and inclusive understanding of infertility. Further, the inter-linkages with other relevant issues and policies such as health, population, etc., is completely lacking in the Draft Bill (2010).
II. The other actors and provision in the public health

As in the Draft Bill (2008), the present document, also restricts itself to regulating only ART clinics, without recognising the role that other actors like travel agents, surrogacy agents, surrogacy law firms, etc. play. A draft legislation must take cognisance of the diverse actors of the ART industry to effectively regulate it and must include concrete and necessary provisions for regulating these varied agencies.

Further, the Draft Bill (2010) does not adequately dwell on the regulation and monitoring mechanisms of public hospitals offering ARTs, although some public hospitals have started providing these technologies for the past few years.

III. Maximum age limit not stipulated

The Draft Bill (2010), like the previous draft, does not specify the maximum permissible age for women undergoing ART procedures. The minimum age is mentioned as 21 years (as in the previous draft). Given that the health implications of ARTs increase considerably with age, there is a need to stipulate the maximum age for women undergoing these procedures. Further, with regard to processes of oocyte retrieval and embryo transfer, the draft leaves room for practices that are detrimental to women’s health.

‘...not more than three oocytes should be transferred for GIFT and not more than three embryos for IVF-ET at one sitting, excepting under exceptional circumstances (such as elderly women, poor implantation, advanced endometriosis or poor embryo quality).’

Rules 6.13.1 of the Draft Bill (2010), quoted above allows for more oocytes to be retrieved and more embryos to be transferred in the case of older women, poor implantation, and other specific situations, considerably increasing the health risks.

IV. Eligibility

The Draft Bill (2010) states that ‘Assisted Reproductive Technology shall be available to all persons including single persons, married couples and unmarried couples.’ While seeming liberal, the present Draft is still restricted to a heterosexual framework.

While the words man and woman are not used in defining ‘married couple’ and ‘unmarried couple’, the Bill by its very definition of couple prohibits same sex couples from accessing ARTs in India. The Draft Bill (2010) defines couple as two persons living together and having a sexual relationship that is legal in India.

V. Health risks and side effects

The present Draft of the Bill has done away with the word ‘small’ in describing risks associated with ARTs. This is an acknowledgement of the adverse health implications of these technologies. The draft lists complications such as multiple gestation, ectopic pregnancy (5 per cent), spontaneous abortion and Ovarian Hyperstimulation Syndrome (0.2 to 8 per cent) same as in Draft Bill (2008). It does not, however, elaborate on other
complications arising from the use of these procedures, which have been established by recent studies. Further, though the Draft Bill (2010) does mention that ART procedures carry risks both to the mother and the child, there is no listing of the risks and adverse outcomes of these technologies for children which different studies have clearly highlighted.

VI. Adoption

The present Draft, as was previously the case, does not adequately emphasise adoption as an alternative to ARTs. Rule 2.4 mentions that, ‘The counsellor must invariably apprise the couple of the advantages of adoption as against resorting to ART involving a donor.’ Further Rule 5.4 states, ‘Further treatment for the unresponsive couple will then consist of counselling and an in-depth investigation, leading to the use of ART-failing which, adoption may be the only alternative’. The bill therefore regards adoption as an option only in case of requirement of donor gametes, or failure of ARTs. Considering the low success rates and health risks associated with ARTs, the legislation should present adoption as an equally, if not more, valid course of action.

VII. Oocyte retrieval

With regard to oocyte retrieval the Draft Bill (2010), Clause 26(8), mentions that a woman may donate oocytes up to 6 times in her lifetime with not less than 3 months interval between the cycles. However, there is no specification regarding the maximum number of cycles that a woman can undergo, which may be 6 or more, as not every cycle may result in viable oocytes for donation. Also, there is no system stipulated to monitor and record the number of times a woman donates oocytes.

Further, the three-month interval between the donations, as stipulated in the draft is extremely inadequate as oocyte retrieval requires the stimulation of ovaries using hormonal drugs, which adversely affect women’s health.

Further, the specification regarding number of oocytes to be retrieved is only in case of donors. It is also important for a legislation to specify the number of oocytes that can be retrieved from women undergoing IVF or from women in egg-sharing programmes, where there is a possibility of retrieval of a large number of eggs, with serious implications for health.

VIII. Pre-implantation genetic diagnosis (PGD) and sex-selection

The use of technologies like PGD has raised many social and ethical issues; concerns around eugenic implications including sex-selection.

The Draft Bill (2010), like the previous one, does not detail any separate Consent Form for the procedure of PGD. Further, the Consent Form for IVF and ICSI (Form D, Pg 41) does not mention the prohibition of sex-selection during these procedures. Given the growing use of PGD, it should be strictly monitored and made available only in cases where there is significant risk of a serious genetic condition in the embryo. Moreover, in the Agreement for Surrogacy (Form J) there is a mention that the surrogate will not be asked to undergo a sex determination test. However, this does not include PGD, which is conducted before the
embryo is transferred into the surrogate’s uterus. This form should clearly state the non-use of PGD for determining the sex of the embryo or any other characteristics.

IX. Role of the ART bank

The nomenclature of ‘Semen Bank’ used in the Draft Bill (2008), has been replaced with ‘ART Bank’ in the current draft. However, there is an absence of clarity about what or who comprises an ART Bank, as well as its role, registration, functions, etc. As a substantial part of the management of ART ‘treatment’ is expected to be carried out by the ART Bank, merely changing the nomenclature without detailing its various aspects is limiting and problematic.

Surrogacy

X. Age and number of cycles

As per the Draft Bill (2010) the maximum age at which a woman can become a surrogate has been reduced from forty five years [Draft Bill (2008)] to thirty five years. However, the draft has also increased the number of successful live births that a surrogate is permitted, from three [in the Draft Bill (2008)] to five. Although this number includes the surrogate’s earlier pregnancies, the reasons for this increase are not clear. The previous draft did not include earlier pregnancies that the surrogate may have undergone. The increase to five successful births for a surrogate seems to emerge from the need/pressure to retain the number of permitted live births to at least three, after factoring in the surrogate’s own children, assumed to be two. However, the Draft does not limit the maximum number of cycles that the surrogate is permitted to undergo. This is extremely important because the number of live births is not, in most instances, equivalent to the number of ART cycles. A major concern is that ARTs, given their low success rates, often imply multiple cycles for successful outcome, thus posing serious risks to the surrogate’s health.

XI. Eligibility

While it explicitly permits single women to access ARTs, the Draft Bill (2010) like the previous one, neither prohibits nor explicitly permits single women to be surrogates. It also states:

‘In the event that the woman intending to be a surrogate is married, the consent of her spouse shall be required before she may act as such surrogate’ Clause 34 (16)

Whether single women are permitted to be surrogates or not has been left open to interpretation. Such ambiguities should be avoided and the provisions of the bill should be clear.

The Draft Bill (2010) has also an added clause prohibiting the ART Bank or ART clinic from receiving or sending an Indian for surrogacy abroad. Clause 34 (22), states that Only Indian citizens shall have a right to act as surrogate, and no ART bank or ART clinic shall receive or send an Indian for surrogacy abroad.
XII. Insurance for the surrogate

The Draft Bill (2010) also states that the commissioning parent(s) shall ensure that the surrogate mother and the child she delivers are ‘appropriately’ insured till the child is handed over to the commissioning parent(s)…… till the surrogate mother is free of all health complications arising out of surrogacy - Clause 34 (24). Although a welcome addition, the Bill does not elaborate on the nature and the kind of insurance, nor does it state the factors which determine the ‘appropriateness’ of the insurance. Also, it does not clearly lay down the responsibilities of the commissioning parent(s) with regard to post-natal and follow up care of the surrogate mother. The surrogate might need assistance even after the child has been handed over to the commissioning parent(s). Further, there is no provision for legal aid or assistance to the surrogate. Given that a surrogacy arrangement entails considerable legal complexities, the Draft Bill should take steps to address the legal needs of the surrogate. Therefore, detailed information with regard to health insurance and legal aid for the surrogate is required in the Draft.

XIII. Guardianship

Clause 34 (19) of the Draft Bill, 2010 mentions that in case the intended parents are from outside India and refuse to take custody of the child born out of the surrogacy arrangement, following a period of one month, the ‘local guardian’ shall be legally responsible for either bringing up the child or handing over the child to an adoption agency. It has also been stated that in either instance, the child will be given Indian citizenship. Such additions to the earlier Draft appear to have been done keeping in mind recent legal tussles about the citizenship of the children born out of surrogacy. However, the welfare of the child or children cannot be the sole discretion of an individual–the local guardian–in such a situation. There is need for a system that can objectively discern the course of action to be taken, and follow-up and monitor the same, keeping the child or children’s best interests in mind. Such concerns should be addressed and the role of the local guardian should be clearly explained.

Further, the appointment of a local guardian to keep a close watch on the surrogate is an impingement on the autonomy, freedom and rights of the surrogate, and is completely unacceptable.

XIV. Payment to the surrogate

The present draft’s provisions with regard to payment to the surrogate raise serious concerns about the undermining of her rights. According to this draft, payment to the surrogate is to be made in five installments instead of three (previous Draft) with the majority, i.e. 75 per cent, to be paid as the fifth and final installment, following the delivery of the child. This is in complete contrast to the previous Draft, wherein the majority of the payment, i.e. 75 per cent, was to be paid as the first installment. This shift reflects that the priority accorded to the intended parent(s) is much higher than to the surrogate and can lead to further exploitation. The health risks that the surrogate might face (as a result of undergoing IVF) are not taken into account, and her ‘worth’ is wholly contingent on a measurable reproductive ‘outcome’, i.e. the baby.
XV. Requirement of legal documents from foreign couples

A positive addition in the Draft Bill (2010) is the requirement of legal documents from foreign couples declaring that their respective countries permit surrogacy and that the child born out of such an arrangement will be the legal citizen of their country. This provision will be useful in addressing legal complications that have been known to arise regarding the citizenship status of children born from surrogacy arrangements.

The Draft Bill (2010) with additions and modifications has tried to take into consideration some of the concerns with the previous draft. While some of these are welcome changes, the draft in its present form is far from being an inclusive document. If the proposed legislation is expected to effectively regulate the proliferating ART and surrogacy industry in India, these lacunae will have to be addressed.

* A detailed critique of the Draft ART (Regulation) Bill and Rules, 2008 can be accessed on Sama’s website (www.samawomenshealth.org)
ANNEXURE 4

Advocacy Initiatives

A. Memorandum to the Union Ministry of Health & Family Welfare

Dr. A Ramadoss
Union Minister for Health and Family Welfare,
Ministry of Health and Family Welfare,
Nirman Bhavan,
New Delhi 110 108.

Date: October 10, 2008

Subject: Extending the time frame for comments on the Assisted Reproductive Technology (Regulation) Bill and Rules-2008 (Draft) till March 2009 and holding Public Hearings for comments and suggestions on the Bill.

Sir,

We, women’s groups, health groups, academicians, medical professionals, researchers, sexual rights groups and legal experts working on women’s health and rights across the country would like to express our concern regarding the Draft Assisted Reproductive Technologies (Regulation) Bill & Rules-2008. The Draft Bill was presented by the Indian Council of Medical Research (ICMR) at a two-day National Consultation organized by Sama Resource Group of Women and Health on ‘Assisted Reproductive Technologies (ARTs): Emerging Concerns and Future Strategies’ held in New Delhi on 13th-14th September, 2008.

First of all, we would like to mention that we welcome the concern and interest demonstrated by the ICMR and the MOHFW in developing the draft legislation to regulate Assisted Reproductive Technologies, which we have been advocating for since a long time. We are happy that the legislation has been drafted and that it has been finally opened for public discussion.

Through a cursory perusal of the document, as was possible in this short while, we strongly feel that the Draft Assisted Reproductive Technologies (Regulation) Bill & Rules-2008 tends to promote the interest of the private sector providers of these technologies rather than regulate them. We are concerned about the Bill’s inadequacy in protecting and safeguarding the rights and health of women and children. The Bill promotes medical tourism, encourages commercial interests at the cost of women’s health, reiterates patriarchal values and is silent on people with different sexual orientations.

These are, however, only some of the issues with the Bill and we would need more time to concretize our suggestions towards strengthening the Bill. This is a very crucial stage in the process of regulating ARTs and we feel that the government must not act in a hasty manner and go ahead with the document without resolving the problem areas.
Last week, we had come across a statement by Dr. Pushpa Bhargava that the Bill will be introduced during this winter session of the Lok Sabha (Ref Livemint 24 Sept, 2008). The article also mentioned that the Ministry of Law will post it on its website for public feedback through a 30 day window period. TNN also reported that the Bill will be introduced in the winter session (Ref Times of India, Mumbai, Sept. 30, 2008).

We are concerned about the short duration of time for which the Bill is being opened for public comments. We feel that this duration is not adequate for the concerned groups and individuals to provide their feedback.

We urge the MOHFW and ICMR to not rush into finalizing the Bill till a wider debate across the country, at various levels and regions has been conducted and their responses incorporated. We demand the ICMR and MOHFW to organize public hearings in different parts of the country with active involvement of women’s and health movements and other sections of the civil society. We would like to express that one month’s time to gather suggestions regarding this Bill is not sufficient and we urge the ICMR and MOHFW that the Bill be kept open for public critique for at least a period of six months i.e. till March 2009, during which all concerned groups can adequately articulate their suggestions and give concrete feedback.

We urge you to consider these issues very seriously and act upon this matter in the larger interest of the health and well-being of the women of this country.

Sincerely,

1. Sarojini, Sama Resource Group for Women and Health, Delhi
2. Dr Amit Sen Gupta, Delhi Science Forum, Delhi
3. Dr Amar Jesani, Mumbai
4. Dr Padmini Swaminathan, Chennai
5. Dr Vineeta Bal, Saheli, Delhi
6. Aleyamma, Sakhi, Trivandrum
7. Dr Sunil Kaul, The Ant, Guwahati
8. Dr. Ajay Khare, Madhya Pradesh Vigyan Samiti, Bhopal
9. Dr Sanjib Mukherjee, Kolkata
10. Subhash Mendapurkar, SUTRA, Solan
11. Jashodhara Das Gupta, Sahayog, Lucknow
12. Amitava Guha, FMRAI, Kolkata
13. Dr Saraswati Swain, Cuttack
14. Asha, ANTHRA, Hyderabad
15. Manisha Gupte, MASUM, Pune
16. John Bosco, FIAN Ashraya, Belgaon
17. Trupti Shah, Sahilyar, Baroda
18. Dr. Sundari Ravindran, Trivandrum
19. Ammu Abraham, Women’s Centre, Mumbai
20. Dr Mohan Rao, Delhi
21. Pramada Menon, Delhi
22. All India People’s Science Network
23. Jennifer, Bongaigaon
24. Dr Anant Bhan, Pune
25. Dr Ravi Duggal, Nagpur
26. Dr Sunita Bandewar, Toronto
27. Chayanika, LABIA, Mumbai
28. Dr Lakshmi Lingam, Mumbai
29. Advocate Kamayani, Mumbai
30. Nandita Shah, Akshara, Mumbai
31. Sanjay, Human Rights Law Network, Delhi
32. Prabha, TARSHI, Delhi  
33. Kalamani, Centre for World Solidarity, Hyderabad  
34. Dr. Vandana Prasad, People’s Rural Health Network, Delhi  
35. Neha Madhiwalla, Centre for Studies in Ethics and Rights, Mumbai  
36. Nandini, Jagori, Delhi  
37. Jaya Sharma, Nirantar, Centre for Gender and Education, Delhi
38. Preeti Nayak, Delhi  
39. Anjali Sheni, Delhi  
40. Beenu Rawat, Delhi  
41. Aastha Sharma, Delhi  
42. Deepa Venkatachalam, Delhi  
43. Susheela Singh, Delhi

For further information, please contact:

Sarojini N.B. and Aastha Sharma  
Sama Resource Group for Women and Health  
B-45, 2nd Floor, Main Road Shivalik  
Malviya Nagar  
New Delhi- 110017  
sama.womenshealth@gmail.com  
Phone: 011-2669 2730, 011-6563 7632
We, activists, researchers, academicians, medical professionals and lawyers working on women’s health and rights across the country would like to issue a statement of concern regarding the Draft Assisted Reproductive Technologies (Regulation) Bill & Rules-2008. The Draft Bill was presented by the Indian Council of Medical Research (ICMR) at a two-day National Consultation on Assisted Reproductive Technologies (ARTs): Emerging Concerns and Future Strategies held in New Delhi on 13th-14th September, 2008.

We strongly feel that the focus of the Draft Assisted Reproductive Technologies (Regulation) Bill & Rules-2008 tends to promote the interest of the private sector providers of these technologies rather than regulate them. We are concerned about the Bill’s inadequacy in protecting and safeguarding the rights and health of women and children.

Our concerns that have emerged through deliberations on the Bill are as follows:

1) A clear preamble outlining the purpose/framework/fundamental approach to the Bill emerging from the government’s own perspective within the context of pre-existing policies on population and health is seriously lacking in the Bill.
2) There is an urgent need for REGULATION of present practice, NOT just regularisation and promotion.
3) The Bill promotes medical tourism and encourages commercial interests at the cost of women’s health.
4) The Bill compromises on women’s health and the rights of women and children in many ways.
5) The Bill attempts to promote invasive and expensive technologies, instead of encouraging adoption.
6) The Bill is retrograde in its intent because it reiterates patriarchal values, reinforces eugenic tendencies and is silent on people with different sexual orientations.

Keeping in mind the above mentioned concerns, we urge the ICMR to not rush into finalising the Bill till a wider debate across the country, at various levels and regions has been conducted and their responses incorporated. We demand the ICMR to organise public hearings in different parts of the country with active involvement of women’s and health movements and other sections of the civil society. We urge the ICMR that the Bill be kept open for public critique for at least a period of six months, during which all concerned groups can adequately articulate their suggestions.

Signed by
Sarojini N.B, Sama Resource Group for Women and Health, Delhi
Dr. Amar Jesani, Mumbai
Sandhya Srinivasan, Mumbai
Dr. Amit Sen Gupta, Delhi
Dr. Lakshmi Lingam, Mumbai
Dr Padmini Swaminathan, Chennai
Urvashi Butalia, Delhi
Rajashri Dasgupta, Kolkata
Renu Khanna, Baroda
Dr. Ravi Duggal, Nagpur
Dr. Vandana Prasad, Delhi
Jaya Sharma, Nirantar, Delhi
Dr. Sunil Kaul, Assam
Chayanika, Mumbai
Mary John, Centre for Women’s Development Studies, Delhi
Kalamani, Centre for World Solidarity, Hyderabad
Sabala, Mumbai
Philomena Vincent, Bangalore
Dr. Subhashree, Chennai
Neha Madhiwalla, Mumbai
Dr. Imrana Qadeer, Delhi
Anjali Shenoi, Sama Resource Group for Women and Health, Delhi
Aastha Sharma, Delhi
Preeti Nayak, Delhi
Kranti, Mumbai
Shalini, Mumbai
Dr. Nandini Prasad, Hyderabad
Saheli, Delhi
C. Response from the Union Ministry of Health & Family Welfare to the critique of the Draft ART (Regulation) Bill & Rules, 2008

No. M.110193/2008 - F.P.
Government of India
Ministry of Health & Family Welfare
Family Planning Section
Room N0.-413-D

Nirman Bhawan, New Delhi
Dated: 4th February, 2009

To
Shri R.S. Sharma
Dy. Director General
Scientist – F, Division of RHN
Indian Council of Medical Research
Ansari Nagar, P.B. No. 4911
New Delhi – 110 029.

Subject: Comments and suggestions on the Assisted Reproductive Technology (Regulation) Bill and Rules – 2008 (Draft) and request to discuss and examine comments by Expert Committees constituted in ICMR and further necessary action.

Sir,

The undersigned is directed to forward herewith the copy of the above mentioned subject received from various organizations/institution

1. Shri Suresh P. Prabhu M.P.(Lok Sabha) representation dt: 15.10.2008 from Dr. Sadhana Desai, President, Indian Society for Assisted Reproduction enclosed herewith a copy of the letter of acknowledgement of Union Minister for Health & F.W.
3. The letter dt: 15.10.2008 received from Dr. Sadhana Desai, President, Indian Society for Assisted Reproduction forwarded by Shri Mahabir Prasad Minister of Micro, Small and Medium Enterprises.

It is requested that the necessary comments/reply may be sent to:
1. Dr. Sadhana Desai, President, Indian Society for Assisted Reproduction;
2. Sama, Resource Group for Women and Health.

A copy of reply may also be endorsed to this Division.

It is also requested that the comments and suggestions received may kindly be considered for discussion and examination of the Expert Committees constituted in ICMR and inclusion in the ART (Regulation) Bill and Rules – 2008 (Draft).

Yours faithfully,

( DR. KIRAN AMBWANI )
Deputy Commissioner (FP)
Tel.Fax.:011-23062485

Encl.: As stated above
Copy for information to:
1. Dr. Sadhana Desai, President, Indian Society for Assisted Reproduction, Flat 23-A, 2nd Floor Elco Arcade, Hill Road Bandra(West), Mumbai- 400 050.
2. Sama, Resource Group for Women and Health, B-45, 2nd Floor, Main Road Shivdik, Malviya Nagar, New Delhi – 110017.
Constructing Conceptions

The International Development Research Centre (IDRC) is a Crown corporation created by the Parliament of Canada in 1970 to help developing countries use science and technology to find practical, long-term solutions to the social, economic, and environmental problems they face. IDRC support is directed towards creating a local research community whose work will build healthier, more equitable, and more prosperous societies.

Sama – Resource Group for Women and Health

Sama is a Delhi based resource group working on issues of women’s rights and health. Sama seeks to locate the concerns of women’s health in the context of socio-historical, economic and political realities, and find linkages between women’s well being and livelihoods, food, violence and other larger issues that affect their lives. Sama has been working closely with community based organisations, health networks, people’s movements, women’s groups and health care providers across the country, primarily through building capacities, action research and advocacy.