Research Report

1. Background

Pre-implantation genetic diagnosis (PGD) is clinically defined as an extension of prenatal testing undertaken by means of assisted conception technology (IVF and ICSI), single-cell embryo biopsy, genetic marking, and molecular amplification (Chromosome FISH and PCR). It is described by the Human Fertilisation and Embryology Authority (HFEA) and the Human Genetics Commission (HGC) in their joint consultation paper on this innovative health technology as 'a technique that combines genetic testing and IVF in order to offer those who are at significant risk of passing on a serious genetic condition the choice of selecting embryos that are unaffected before pregnancy is begun' (HFEA/HGC 2001). As they point out, 'the wider implications of the technique are of concern to a great many people' (ibid. and see Franklin 2001b and d).

Public consultation into PGD was jointly initiated by the HFEA and the HGC in November 1999, as a result of which 16 recommendations were published two years later, as interim guidelines (www.hfea.gov.uk/pgd/pgdpaper.pdf). In June of 2002 a workshop was convened by the Department of Health of all UK units licensed to provide PGD services and commissioners of NHS services. On the basis of the discussions at this workshop, the Genetics Commissioning Advisory Group (GenSAG) endorsed guidelines to facilitate further NHS funding of PGD, described in a Department of Health report published in September 2002 as a technique for which 'clinical indications will widen' (DoH 2002).

The rationale for PGD was more simply described by Anne McLaren in 1987 in the opening sentence of her *New Scientist* article 'Can we diagnose genetic disease in pre-embryos?' (10, December). As she noted: 'Every pregnant woman wants to produce a normal healthy baby' (McLaren 1987:42 and see 1985; Penketh and McLaren 1987). PGD offers the possibility of improving the chances of achieving this outcome by taking steps to ensure a healthy pregnancy before it is even initiated (Bickerstaff et al 2001). For couples at risk of passing on a serious genetic disorder to their offspring -- and who may already have witnessed one or more children's unsuccessful struggles to survive a condition such as Spinal Muscular Atrophy or Tay Sachs -- the option to pursue PGD offers the reassurance that every possible effort has been made to conceive a child who will not suffer a similar fate (Braude et al 2002). Especially for couples for whom pre-natal diagnosis such as amniocentesis -- which involves a lengthy period of 'tentative' pregnancy and the possibility of third trimester termination -- is not a viable or acceptable option, PGD is an increasingly widely-used technique that offers a preferable, if more difficult, route to genetic family planning. It is also used for couples where a history of repeated miscarriages is diagnosed as the result of chromosomal translocations (Scriven et al 1998, 2001), and to sex embryos where a sex-linked disorder, such as Duchenne muscular dystrophy, is a risk factor.

PGD was first successfully practiced in Britain in 1990 (Handyside et al 1990), but has not developed as quickly in Britain as in the United States, where the technique is much more widely practiced, and is unregulated. By the year 2001 when we began our ethnographic study of this innovative and controversial health technology, only four clinics were licensed by the HFEA to offer PGD. Two of these, the Guy's and St Thomas' PGD unit and the PGD unit at the Leeds General Infirmary, agreed to assist us in our study by allowing us to participate in and observe clinical activities, and help us arrange interviews with PGD patients. During the period of our ethnography, numerous changes and developments affected the PGD field in terms of policy, public debate, and parliamentary activities. In February 2002, following a widely publicised case in the US, the HFEA issued the first license to use PGD not only to prevent the implantation of an embryo affected by a specific genetic disorder, but to test (HLA type) embryos for compatibility with an existing sibling suffering from the disease, in order that the resulting child might be a donor of tissue which could potentially cure a chronically-ill brother or sister (Verlinsky et al 2001). In the same month, one of the first of two licenses by the HFEA to construct human embryonic cell lines using PGD embryos was issued to the Guy's and St Thomas' clinic, again raising new ethical issues and social concerns. Throughout our study debate has surrounded the question of using PGD for aneuploidy screening (for chromosomal abnormalities), and the question of whether it should become a routine part of IVF, a more significant part of infertility treatment, or as part of the work-up for repeated miscarriage (DoH 2002, p. 2; Munne et al 1999). Both the decision to allow PGD to be used to select for HLA compatibility, and to provide a source of embryos to manufacture human embryonic cell lines, were accompanied by extensive public and parliamentary debate, and were the subject of considerable media coverage in 2001-2 (Franklin and Roberts 2002a, 2002e; Franklin in press a & b) .

PGD is thus a technique at the centre of a number of significant debates about the future directions of reproductive and genetic medicine. Issues connected to PGD include the current debate over sex selection for social reasons (ASRM 2001), rising concerns about the safety of IVF and ICSI (Intra-cytoplasmic sperm injection), the use of embryo selection for HLA typing (Meek 2002), aneuploidy screening, cloning (Franklin 2001d, 2002a, in press b), and stem cell research (for which PGD embryos are particularly useful, see Franklin 2001c, 2003). These debates raise questions not only for the patients and professionals involved in PGD, or the policy-makers and regulators responsible for its governance: as the extensive media coverage and public debate surrounding increased technological assistance to human origins demonstrates, the broad social questions often referred to as the 'designer baby' debate position the technique of PGD at the centre of numerous controversies, all of which are likely to intensify in the future.

Given its pivotal importance, in particular to the convergence of reproductive and genetic technology, it was anticipated this ethnography of PGD would be a means to create a particular window, through a specific innovative health technology, onto wider questions concerning social attitudes toward what are often vaguely referred to as 'the new genetics'. This proved very much to be the case. It remains unclear, however, how a multi-sited ethnography of a technique such as PGD is best conducted methodologically, what its main contributions are theoretically, or how its primary findings are best defined and identified. Our study was thus both very specific, and very open-ended and preliminary. While we have made numerous empirical findings that have helped us to arrive at our analytical themes, and to refine several avenues of ongoing research, it should be emphasised that the anthropology of biomedicine is at a very early stage, and only a handful of ethnographies of the new genetics exist (Rabinow 1996a, 1999; Rapp 1999; Finkler 2000), none of which are based in the UK. This project was thus, in a sense, an experimental ethnography, and its outcomes will continue to emerge in the future as more comparative material is produced by other researchers producing ethnographic studies of the new genetics.

Our study may be of particular value at this early, formative period in the anthropology of the new genetics by demonstrating links between this field and more established areas of anthropological enquiry, such as kinship studies (Carsten 2000; Franklin and McKinnon 2001a & b; Franklin 2001a), and the anthropology of biomedicine (Franklin and Lock in press a & b). Its main contribution is to the ethnographic analysis of new reproductive and genetic technologies in Britain (Edwards et al 1993, 1999; Edwards 2000; Franklin 1997; Konrad 1997; Strathern 1992a and b), and elsewhere (cited above, and see also Palsson and Rabinow 1999; Palsonn 2001 and in press; Hoyer 2002 and under review; Stefansson 2002; Ragone 1994). More broadly it contributes to the anthropology of science (Rabinow 1996b) and to the attempt to develop innovative ethnographic approaches to new forms of contemporary technology (Riles 2000). At the same time, it extends a longstanding anthropological tradition of participant-observation, conducted through open-ended enquiry that eschews any pre-determined assumptions about its outcomes (Marcus 1995).

2. Objectives

Our primary objective was to collect data within an 18 month period from several different sites, and to analyse these as a means of documenting and comparing a range of perspectives on the specific decisions and choices involved in PGD treatment. By so doing we aimed both to produce an ethnographic portrait of an innovative technique in a specific national context at a key point in its development, and to derive through analysis of our datasets theoretical and methodological insights and findings that would allow us better to describe and understand the social character of genetic choice and the changing uses of genetic information. Specifically our aim was to collect data through interviews with PGD patients about their experiences of the technique, to conduct participant observation in two PGD clinics, to interview policy makers and members of regulatory bodies involved in the governance of PGD, to produce an archive of media representations and policy documents related to PGD, and to participate in public consultation events concerning this technique.

By so doing we produced a collection of multiple and conflicting perceptions of what PGD is, who it is for, how it should be undertaken, how it might be developed in the future, and why it is controversial. In our analysis of our data, we have found that these various perspectives do not resolve into a coherent picture, and remain only partially connected and overlapping. Hence, the theme of the various *gaps* between different perspectives on PGD quickly emerged as a core analytical focus ('mind the gaps'). We

are able to show in our initial publications based on our material, and we will develop in the ethnographic monograph that is our main research output, some of the ways in which divergent and conflicting understandings of PGD are rooted in specific contexts of social life, and particular forms of social practice. Using an over-arching model of the ways in which obligations to care, obligations to improve treatment, and obligations to limit reproductive and genetic intervention conflict along specific axes, we have identified a formulaic pattern we aim to characterise more fully in our ongoing process of writing up.

3. Methods

Our methods of data collection combined approaches from several disciplines, including anthropology, science studies, and feminist theory. Participant observation at two PGD clinics was conducted by both investigators working as a team. We attended PGD team meetings, consultation sessions with patients, patient introduction workshops, clinical workshops, and we observed clinical procedures over the first fifteen months of our study. Both investigators interviewed 24 PGD patients, as well as clinical staff, scientific staff, policy makers, and parliamentarians, using a semi-structured personal interview format (6c). We attended scientific conferences, public consultation sessions, parliamentary select committee meetings, and patient support groups (6d). We kept field notes and made 26 presentations of our work in progress over the course of the study (6a). In addition to transcribing and analysing our interviews, we also recorded and transcribed the discussion sessions following our presentations in a number of settings, including academic departments, the HFEA, and the St Thomas' clinic, and a midwifery research day. We developed a new method we have denominated 'ethnopoint' by using powerpoint literally to 'frame' a wide range of perspectives on PGD collected over the course of our study (which included extracts of transcribed responses to previous presentations that became part of later ones) as a means both to present and to collect data (6b).

This method of presentation also enabled us to make interactive use of visual material including media coverage of PGD, such as the public debate over 'made to order' or 'designer' babies, and the powerful emergent visual imagery of micro-manipulation of cells. In addition to considerable policy literature, we have produced an extensive archive of media depictions of PGD during 2001-2. These have been analysed both visually and textually, as a means of characterising public debate, and identifying emergent forms of reproductive testimony, narrative, and imagery.

The intensive nature of our ethnographic work has also led us to consider in more depth what we have called 'ethnographic affect'. The considerable emotional work involved in both undergoing and providing PGD was a major empirical finding of the study, and was reflected in our own reactions to the material in a manner we seek to examine in further depth as part of an ongoing reconsideration of ethnographic methods. (This feature of our work was the subject of a separately-funded workshop held shortly after we completed our data collection, 6e). Franklin has also addressed the question of the ethnographic acquisition of scientific literacy as a means of revisiting the longstanding social scientific debate about 'natural facts' (Franklin, 2003)

4. Results

Several key themes have emerged out of our preliminary analysis of our findings. An early theme was the considerable discrepancy between public perceptions of PGD as the 'designer baby' method, and understandings of the technique among clinicians, scientists, and patients directly involved with it, almost all of whom expressed considerable resentment of this term(Franklin and Roberts 2002a, b, c, e; Roberts 2002b). The iconic figure of the 'made to order' baby was accompanied by two frequently repeated idioms, of the 'blonde-haired blue-eyed baby' and the 'off-the shelf' baby, which also came up frequently in our interviews, while being used in quite divergent ways in both contexts. Ethnographically, such images can thus be read as forms of partial connection between divergent perceptions of PGD, and help us to track the cultural landscape of literal and symbolic, personal and professional, meanings that attach to this technique. These divergences also co-exist simultaneously in other accounts of PGD, such as the year long column in the *Guardian* by PGD patient and journalist Leah Wild, whose account we have analysed as an emergent form of reproductive testimony, in which what might be described as the defining ambivalences, or conflicting obligations, of the PGD experience are made explicit as a form of public appeal (Franklin, McNeil and Roberts, forthcoming, and see Franklin and McNeil 1993).

A very different set of gaps became apparent in our initial analysis of PGD patients' accounts of their experience of treatment. A significant finding from these interviews was the very high level of patient appreciation of their treatment and the clinicians who treated them, despite the considerable difficulties and demands of the treatment protocol, the high likelihood of failure, and the often traumatic personal circumstances that led many couples to PGD to begin with. Our initial analysis of these interviews revealed a defining ambivalence of treatment focussed around its uncertainty. For example the choice of which embryos to re-implant is not always straightforward, and may involve balancing a number of factors. In the context of uncertainty in the midst of treatment, we found that while many patients clearly articulated the difficulty of decision-making, they also expressed a clear appreciation of the extent to which the clinicians refrained from making decisions on their behalf. If a high level of trust in clinical expertise is correlated to patients' appreciation of clinicians' restraint in guiding patients' decision-making, this could be described as a way in which patients value the opportunity *to manage their own uncertainty, rather than having it managed by others*. If we describe this value as 'uncertainty value', it suggests that although patients routinely describe clinical decision-making in the context of ambiguous or partial information as one of the most emotionally difficult and exhausting parts of treatment, it is also the source of one of the aspects of treatment they value most, as it increases their confidence they are receiving the very best care as well as treatment. If in an area of medicine as emotive as PGD, where obligations on behalf of unborn offspring are as much a component of treatment as the feelings of the patients themselves, the management of uncertainty becomes a highly valued component of clinical care, then such a finding can contribute to a more complex picture of social responsibility and parental obligation in the context of genetic choice (Franklin and Roberts 2002d & e).

Preliminary findings from the PGD study, such as that described above, both confirm and extend the analysis presented in closely related ethnographic studies of the clinical management of genetic information, in particular those of Kaja Finkler (2000) and Rayna Rapp (1999). Both of these pioneering ethnographic studies of the new genetics identify the management of uncertainty as a key area, and describe somewhat paradoxical relationships to it. Rapp, for example, demonstrates the ways in which genetic information may become less and less 'obvious' or commonsensical *as it becomes more and more objectified*. The larger the gap, in other words, between a 'strictly clinical' account of genetic diagnosis and prognosis and a patient's inevitably much more intimate and emotive relationship to such information (which may suggest, for example, termination of pregnancy), the more likely genetic information in the form of a clinical diagnosis may become meaningless to some patients. Such a finding inverts the central premise of genetic counselling, that counsellors should present as strictly factual an account as possible an account of genetic testing to clients in order to remain as neutral as possible.

Finkler, in contrast, argues that it is precisely the objective quality of genetic facts, or DNA itself, which can create emotional bonds *because of its neutrality*. For Finkler, genetic information confirms the biological bond of genetic relatedness in a way that is more powerful because it is strictly factual and 'objective'.

Our study adds additional dimensions to the question of the 'genetic gap' and how it is negotiated, for example by exploring whether clinicians' adherence to a non-directive stance in the context of difficult decision-making may create a stronger bond between patients and clinicians.

An unexpectedly prominent theme to emerge out of all of the data sets concerns perceptions not of genetic information or choice, but of embryos. The extent, for example, to which highly contradictory impulses toward embryos can be seamlessly and unproblematically articulated is a notable feature of the patient interview set. Again, care proves to be a unifying theme: it is care for the embryo which can unify attachments to it as a visual image (we were shown dozens of embryo photos), a potential offspring, a sibling to an existing child, a valuable research object, or a 'gift of life' that may be used to benefit other couples. Patients also frequently described the opportunity to donate their embryos for scientific research as means by which they could repay a sense of indebtedness for the opportunity to have highly technologically advanced and complex treatment such as PGD. The question of the nature of the tie to embryos, which have, relatively recently, become much more prominent public, civic, visual, and scientific entities, is likely to remain a prominent theme (Morgan in press).

The broad themes of obligation, reciprocity, and limits which have emerged from a preliminary analysis of our findings both link our study to those of other researchers, and also add new dimensions to them. For example, this study builds directly on the ESRC funded study (R000 23 2537), 'The Representation of

Kinship in the Context of the New Reproductive Technologies', undertaken exactly a decade previously by Edwards, Franklin, Hirsch, Price and Strathern, which found that: 'Concern about the appropriate limits to human intervention...was a feature common across all of the [contexts], lay and professional' and that 'their cultural dimension is not to be underestimated' (Strathern 1991:8-9). The extent to which this concern appeared to be embedded in ideas about relationships, kinship, and future procreative ties was a major focus of the ensuing publication, *Technologies of procreation: kinship in the age of assisted conception* (1993, 1999).

Our study both builds on these conclusions, and extends them, by providing additional empirical data about the ways in which ideas about limits are both set against and enacted through obligations to care, to provide treatment, and to innovate. We link this broad finding about the reciprocal obligations that define reproductive assistance to specific instances and experiences, among both patients and professionals, and for us as ethnographic participants in PGD as well.

6. Activities

a) *Conference and seminar presentations*

S. Franklin (2001) 'The loss of biological limits: Social aspects of the new genetics' Human Genome Organisation Annual Conference, Edinburgh, April

S Franklin (2001) 'Biopolitics and the New Genetics', Invited Lecture, Social Science Faculty, University of Coimbra, Portugal, 6 April

S. Franklin (2001) CRICT/ESRC Seminar Series: Social Dynamics of Controversy & Control in the Biosciences, Brunel University, 2 April

S. Franklin (2001) 'Visions of life, molecular politics and normalisation: making connections between genetics and the neurosciences', Hinxton Hall, Wellcome Trust Conference Centre, Cambridge, 17 – 18 July

S. Franklin (2001) Plenary Address, 'New Bio-Technical Bodies', Affective Encounters, University of Turku, Finland 15-16 September

S. Franklin (2001) 'Mapping the New Genetics', Department of Information Studies, Åbo Akademi, Turku, Finland 17-18 September

S. Franklin (2001) 'Scientific Method and Genetic Knowledge' Anthropology and Archaeology Section of the British Association, Glasgow, September

S. Franklin and C. Roberts (2001) 'The Social Life of Genetic Information', Ethnographies of the Centre. Lancaster, 10-11 October

S. Franklin (2001) Inaugural Lecture 'Anthropology and the New Genetics' Sussex Lectures in Anthropological Theory, 18 October

C. Roberts (2001) 'Seeing embryos: The politics of vision in pre-implantation genetic diagnosis', British Sociological Association: The 2nd Annual Conference of the Human Reproduction Study Group, Northampton, 15 November. Revised version presented at the Department of Gender Studies, University of Sydney, 9 April 2002.

S Franklin (2001) 'Biological propriety, Biological Form' session on Forms of Intellectual Creativity, Property, Transactions, Creations Conference, Department of Social Anthropology, Cambridge, 13-15 December

S. Franklin (2002) 'Respatialising genealogy, recalibrating life', Invited Lecture, Royal Society of Geographers Annual conference, Belfast, January

S. Franklin and C. Roberts (2002) 'Designer Babies: Consumer reproduction or parental obligation?' Things that Don't Quite Fit, Lancaster University, 1 March. Also presented at the Department of Sociology, University of Edinburgh, 6 March.

S. Franklin and C. Roberts (2002) 'Designer Babies: Reproductive choice, genetic selection and parental obligation', South East London Midwifery Research Symposium, King's College London, 25 March. Also presented at Department of Health and Policy Studies, University of Central England, Birmingham, 1 May.

C. Roberts (2002) 'Designing Babies: Demanding Citizens', Reimagining Communities, Lancaster University, 23 - 25 May.

S. Franklin and C. Roberts (2002) 'Babies by Design: Ethnographic Perspectives on Pre-implantation Genetic Diagnosis', Centre for Family Research Genetics Group Seminar Series, Cambridge University, 10 June

C. Roberts (2002) 'Reproducing Identity in The Context of Pre-Implantation Genetic Diagnosis', European Association for the Study of Science and Technology Conference, 31 July - 4 August

C. Roberts (2002) 'Embryo Tracings: Towards an Ethnography of the New Genetics', Keynote address, Wellcome Trust Postgraduate Forum on the New Genetics, Cambridge, 9-11 September

S. Franklin and C. Roberts (2002) 'New Reproductive Choices', Institute for Women's Studies seminar series, Lancaster University, 16 October

C. Roberts (2002) 'Definitions of Genetic Knowledge and Pre-Implantation Genetic Diagnosis: An ethnographic study', Reprogenetics Workshop, Lancaster University, 25 October.

S. Franklin and C. Roberts (2002) 'Definitions of Genetic Knowledge and Pre-Implantation Genetic Diagnosis: An Ethnography', GlaxoSmithKline Innovative Health Technologies Programme Workshop, Stevenage, 30 October

S. Franklin and C. Roberts (2002) 'Making Designer Babies', American Anthropological Association Annual Conference, New Orleans, 20-24 November

S. Franklin and C. Roberts (2002) 'Patient experiences of pre-implantation genetic diagnosis', CESAGen Meeting No. 1, Lancaster University, 16-17 December

b) *Technical Training*

In collaboration with the Information Support Services (ISS) at Lancaster University, we designed the first Advanced Powerpoint course, which was held in September 2001. This course, taught by the ISS, was designed specifically to meet the needs of this project ('Ethnopoint'). Celia Roberts has also attended courses in web design.

c) *Interviews*

PGD project interview and ethnopoint transcription list

Organisation/people	**Date**	**Interviewer(s)**
Progress (1 person)	03/03/01	SF and CR
HFEA (2 people)	04/04/01	SF and CR
HFEA (1 person)	24/04/01	SF and CR
St Thomas' (nurse co-ordinator)	04/04/01	SF and CR
Leeds GI (genetic counsellor)	10/07/01	SF and CR
PGD patients	14/07/01	SF and CR
PGD patients	24/07/01	SF
PGD patient	25/07/01	SF
St Thomas' (embryologist)	26/07/01	SF
PGD patient	27/07/01	SF

PGD patients	03/07/01	SF and CR
PGD patients	04/07/01	SF and CR
PGD patients	19/09/01	SF and CR
PGD patients	06/10/01	SF and CR
PGD patients	15/10/01	SF and CR
St T's PGD study day	17/10/01	N/A
PROGRESS conference	07/12/01	N/A
Leeds GI (embryologist)	05/02/01	SF and CR
Austin Smith	06/03/02	SF and CR
Lancaster science studies conference	01/03/02	SF and CR – ethnopoint discussion
Edinburgh Sociology Dept Seminar	06/03/01	SF and CR – ethnopoint discussion
KCL Midwifery conference	250/3/02	SF and CR – ethnopoint discussion
UCE (Birmingham) Health and Social Policy Genetics and Society seminar	01/05/02	SF and CR – ethnopoint discussion
Lisbon anthropology dept	07/05/02	SF – ethnopoint discussion
PGD patients	11/05/02	SF and CR – ethnopoint interview
PGD stem cell consultation	15/05/02	CR
Cambridge genetics group	10/06/02	SF and CR – ethnopoint discussion
Onora O'Neill	11/06/02	SF and CR
Anne McLaren	11/06/02	SF and CR
Guys & St Thomas' team meeting	17/06/02	SF and CR – ethnopoint discussion
PGD patients	20/06/02	SF and CR
PGD patients	24/06/02	SF and CR

d) *Scientific and medical events attended by both investigators as observers (does not include conferences at which we gave papers).*

Date	**Event title**	**Event type**	**Organisation**	**Location**
23/2/01	Innovation in assisted reproduction and related technologies	Study day	British Fertility Society	Royal College of Obstetricians and Gynaecologists, London
21-22/6/01	Stem Cells	Discussion Meeting	The Royal Society	The Royal Society, London
7/12/01	Controversy, control and creativity: Public policy making in assisted reproduction and genetics	Conference	PROGRESS	Institute of Child Health, London
9/7/01; 16/7/01; 23/701; 15/10/01	House of Lords Select Committee on Stem Cell Research	Select Committee Hearings	House of Lords	Parliament House, London
22/2/02	Designer Embryos and stem cell design: the final frontier in assisted conception	Study Day	British Fertility Society	Royal College of Obstetricians and Gynaecologists, London
16/5/02	Donor information	Conference	PROGAR	St Alban's Centre, London

	consultation			
7-10/7/02	Society for Reproduction and Fertility Annual Conference	Conference	Society for Reproduction and Fertility	University of Leeds
11/9/02	Stem cells: Prospects for Research and Therapy	Conference	Medical Research Council	Millennium Gloucester Hotel, London
18/11/02	Cloning: Separating fact and fiction	Public lecture and discussion	Café Scientifique	Sun Café, Lancaster

e) *Workshops*

We convened two methodologically-orientated workshops connected to the project:

'Ethnographies of the New Genetics' (2 Feb 2001) was attended by 30 people from Britain, Europe, and North America (see Franklin and Tutton 2001, Tutton 2002).

A 'Reprogenetics Workshop' (25 October 2002) was attended by 12 people from Britain, Europe and North America (see Franklin and Nahman 2003).

f) *Visits*

The project hosted three visitors during its completion. Professor Margaret Lock, a leading medical anthropologist, gave considerable assistance during a week-long stay in Lancaster in April of 2002. Two PhD students, Svea Hermann from Germany and Mette Svendahl from Copenhagen, contributed very helpfully to the project by bringing in comparative national perspectives on PGD and stem cell research. These visits are the basis for ongoing collaboration including a workshop on 'Genetic Relatedness' to be held in Copenhagen in May of 2003.

7. Publications

Franklin, Sarah (in press a) 'Ethical Biocapital: new strategies of cell culture' in S. Franklin and M. Lock, eds., *Remaking Life and Death: toward an anthropology of the biosciences,* Santa Fe, NM: School of American Research Press.

Franklin, Sarah (in press b) 'Stem Cells R Us: emergent life forms and the global biological'**,** in A. Ong and S. Collier, eds., *Global Anthropology: technology, governance, ethics,* New York: Blackwell.

Franklin, Sarah and Lock, Margaret (in press c) 'Animation and Cessation: the remaking of life and death', in S. Franklin and M. Lock, eds., *Remaking Life and Death: toward an anthropology of the biosciences,* Santa Fe, NM: School of American Research Press.

Franklin, Sarah (2003) 'Rethinking Nature-Culture: anthropology and the new genetics' *Anthropological Theory,* 3(1)65-85.

Franklin, Sarah and Nahman, Michal (2003) *Ethnographic Encounters with Reprogenetics: a Workshop Report*, Department of Sociology, Lancaster Univeristy

Franklin, Sarah (2002) 'Communicating Health and the New Genetics' *Finnish Information Studies* 20: 27-45.

Franklin, Sarah (2001a) ‘Gene answer spawns a lot of questions’, *The Times Higher Education Supplement*, June 15, p. 19.

Franklin, Sarah (2001b) 'Culturing Biology: cell lines for the second millennium' *Health* 5:3:335-354.

Franklin, Sarah (2001c) 'Sheepwatching' *Anthropology Today* 17:3:3-9.

Franklin, Sarah and Richard Tutton (2001) 'Revisiting Concepts of Gift in the New Genetics', *Workshop Report*, Department of Sociology, Lancaster University.

Roberts, Celia (2001) 'Listening to "gene talk"', *Science as Culture* 10(4):573-579.

8. Impacts

Preliminary project findings have been presented to the Human Fertilisation and Embryology Authority, where assessment of both PGD and stem cell research is ongoing. The PROGRESS Educational Trust, a registered charity promoting public awareness of developments in new reproductive and genetic science, has shown considerable interest in the project and its outcomes. The MRC and the Wellcome Trust have both expressed interest in funding ongoing research developing out of this study. The Guy's, King's and St Thomas' clinic has invited the investigators to become part of a major research application for stem cell research, which will include a social scientific dimension building directly on the research outcomes of this project.

Franklin authored a feature for the *Times Higher Educational Supplement* concerning the changing meaning of genetic information following the Human Genome Organization annual meeting in Edinburgh, April 2001 (Franklin 2001b), which was also the basis for a feature in the periodical *Anthropology Today* (Franklin 2001d).

Ongoing feedback from the project will continue to inform policy development in the areas of PGD and stem cell research through links established during the project with the Parliamentary Office of Science and Technology, the Human Genetics Commission, the Genetics Interest Group, and the British Fertility Society.

9. Future Research Priorities

The prominence of concern about embryos from all of the datasets collected for this project, combined with the unique ethical issues raised by the human embryonic stem cell research which began at Guy's, King's and St Thomas' in the midst of our study, has created a specific research priority which we are in the midst of pursuing as a direct outcome of this project. Since August, with funding from the Wellcome Trust, we have designed and piloted two questionnaires exploring PGD patients' attitudes to donation of embryos for stem cell research, with the aim of investigating factors that influence PGD patients understandings both of embryo donation and of stem cell research. We are in particular seeking to identify factors that influence patients' attitudes towards both topics in order to provide both empirical data which will improve the process of acquiring consent and a longitudinal profile of patients' understandings of the consent process.

This project, which is currently funded as a preliminary pilot study, is the basis for a larger bid in conjunction with clinical and scientific staff at Guy's, King's and St Thomas'. The current study of PGD patients' attitudes toward donation of embryos to stem cell research has been developed in tandem with a very similar study based in Newcastle, submitted to the Wellcome by Professor Erica Haimes and Dr Alison Murdoch. Together, the two studies will provide a longitudinal and comparative analysis concerned at one level with a specific question about embryo donation, but at another level with more general issues about consent, donation of reproductive tissue, public understandings of stem cell research, and attitudes toward embryos. Both studies will also contribute to the ongoing work of the Lancaster-Cardiff Centre for the Social and Economic Aspects of Genomics (CESAGen), which will commence its research programme in January 2003.

The opportunity for the Lancaster team to become part of a large clinical and scientific study at Guy's and St Thomas' represents a significant outcome in terms of realising the goal of facilitating more substantial cooperation between natural, medical, and social science in the area of genomics.

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