

## **EUMIDON - Report of the Workshop**

### Executive summary

A selection of clinical, biological and social science professionals, and community-based representatives with a specific interest in the question of sharing organs and substances (tissues, blood etc) of human origin across populations differentiated by 'ethnic' or migratory origin, were brought together for a pan-European workshop sponsored by the ESF. A great many factors were found in common between the different national communities represented, and some solutions or problems shared.

The discussions held between the participants, based on a selection of papers which were presented and a discussion paper circulated by the organisers, led to an emergent consensus that this was an issue of considerable scientific and policy relevance, with the potential (if ignored) to create increasing future problems in practice, which may not be alleviated (but may be affected) by technological changes. Newer techniques are increasingly viewing the exchange of substances of human origin between dead (and increasingly, live) donors and non-related human recipients - and these are now exchanged over considerable distances, sometimes under regulated programmes and in an altruistic manner, but always with the possibility of less benign mechanisms. Given differing religious and cultural attitudes as well as genetic or biological differences between population groups, there remain some difficulties in ensuring that there is both equity and efficiency in the process.

Papers presented documented national situations and biological as well as socio-cultural patterns in differing groups, and projected some implications as well as demonstrating how solutions to under-supply have been tackled in various ways.

It was agreed during the progress of the workshop that there were many confusing and value-laden terms, some of which lead to confusion or conflict, and may carry messages which distort the discussion! One of these was 'ethnic minority' - although 'migrants' is also problematic since we also need to look at the situation of national 'autochthonous' societies: many groups no longer relate to notions of 'not belonging'. It was agreed that we were using the terms 'migrant/minority' to encompass a variety and diversity of marginalised and socially excluded or disadvantaged groups. We also adopted the term 'Diversity' but rejected the term 'Race' while recognising that there are processes of 'racialisation' and also members of specific genetic pools, and people who are grouped together on the basis of apparent similarity of appearance.

Organs, Tissues, Gametes, Blood, and other body parts all have slightly different processes, values and legislation or registers and bureaucratic rules attached. The workshop suggested working around a common interest in 'Substances of Human Origin' - SoHO. Models of successful intervention in respect of one type of material are likely to be transferable to other substances.

A fundamental need is the set up or collate and exchange processes of monitoring or audit of what is going on in respect of transfer of SoHO between individuals and groups (majorities/minorities) as it is not possible to regulate without this information: while some data (e.g. language, religion, ethnic group) may not be legally obtained or

recorded in current official registers in many countries, it is likely that research may be able to ask these questions 'for purpose'.

We agree that any future actions MUST be Multi-Disciplinary, based on Multiple Methods (Qualitative and Quantitative) and Bottom-up based.

It was felt that it would be helpful if all participants / 'national representatives' (maybe together) could begin to assist with a process of bringing together a basic collection of information to underpin the construction of a collaborative, comparative research programme, in order to determine immediate possible actions, and needs. We should in this be working within a wider agenda or brief, conscious of the aspirations of the World Health Organisation, Universal Declaration of Human Rights etc, for equity and justice and reduction of inequalities ("Health For All"). It was agreed that the "DMU Team" will assist in the collation of this and its circulation as we go along.

Key data which were urgently required included the following:

What baseline data are locally available, on donor registration and uptake rates - what indicators or categories of data can be used (if any) to identify or detect marginalisation or exclusion and differential situation of migrant/minorities

Are there are local 'grey' or unpublished studies, perhaps Qualitative, on processes or public health aspects that cast light on differential need and supply of SoHO?

Document / collect evidence or descriptions of Interventions (and if any, evaluations) to increase supply from 'marginalised' groups, Minorities etc

Relate to, and seek, "Community Consent" and support from minority representative bodies etc - i.e. ask them what might be their agendas, to obtain legitimacy & support.

It was noted that this process may itself be empowering, effective, and relate to wider questions of health, social participation & cohesion, and indeed also, have wider generic and general spin-off for improvement of health services overall.

### **Some Research Questions:**

- What are the basic conditions for eligibility for basic health care entitlement and organ transplantation in particular (insurance and residence conditions?)
- Models of procurement - i.e. what is the social interaction at the time that decisions are to be made, in the various societies / jurisdictions involved
- How is the non-donor population constituted and what factors underpin these views (i.e. what do we know about refusers?)
- How do different allocation rules and criteria impact upon different minority groups
- Does use of living organ donation have any differential role and impact on minority groups (NB this could be positive OR negative in effect).

## **Report of the EUMIDON Workshop.**

### Scientific content of the event

The workshop was organised around twelve main scientific papers and a presentation describing the work and programmes of the Council of Europe, which provides a regulatory or recommended framework of 'best practice' and is the basis of most national programmes for organising the sharing of 'substances of human origin' (SoHO), including blood, kidneys and other major organs and various forms of human tissues as well as gametes and bone marrow. Throughout the programme, opportunity was given for question and answer and comment, and periodic formation of small groups for discussion of issues arising, intending to lead towards some common understanding and agreed agendas between the representatives.

### Gurchan Randhawa - University of Luton & UK Transplant:

#### Ethnicity & Kidney Transplantation in the UK

This KeyNote presentation described the well-documented increased rate of renal failure (ESRF) secondary to diabetes among minority ethnic groups in the UK, and its impact on the Government's Health inequalities programme and UK transplant services. Since the prevalence of ESRF rises with age, and the minority population has a relatively young demographic profile still, there are significant future demands implicit in the current pattern. Allocation of donor kidneys to recipients is largely determined by blood and tissue (HLA) matching, but monitoring data show that there are relatively few cadaveric donors from minority groups, and that minority patients tend to wait longer for a replacement kidney. In particular, while between one in five and two in five of South Asian and African-Caribbean people on the waiting list are of Blood Group type B, this blood group makes up only 7% of the donor list. It is however important to note that most donated kidneys are not given exclusively to people from the same ethnic group: nearly two thirds of kidneys donated by minority-ethnic (dead) donors went to 'White' users; 93% of minority-ethnic recipients had kidneys from a 'White' donor. South Asian and African-Caribbean people are very much under-represented on the donor register, but may be unaware of the need for them to register or to offer the organs of deceased family members. Alternative solutions may be found through attention to preventive strategies including reducing the rate of progression of diabetic (Type 2) disease. Care pathways need to be reviewed to ensure equity of access and care provision for all groups, but in the short term, attention must be paid to increasing donation rates from minority groups. Underlying all these is a need to recognise, record and reflect the ethnic heterogeneity of the UK population across the health services. These points all can be located within the current UK Government priorities and programmes to 'tackle inequality' in health.

### Dr Bernard Loty - Medical Director of the French Transplantation Agency

The French NTA maintains registers relating to a variety of organs and other substances of human origin which can be donated and shared. They have however problems of statistical analysis since while there are data on residency status, these only relate to citizenship and not to 'ethnicity'. There are major problems in recording such data in accordance with data protection law. Such data as they do have show that a significant number of people on the waiting list are 'foreign' or originate in the overseas French territories: these groups tend to wait longer for a transplant operation.

'Other European' people are also older than French nationals. There are issues associated with blood-group types, but a large number of people of Maghrebian origin may attend with a live related donor. As in the UK, 'matching' appears to be a main constraint on transplant successes, and the tradition of welcoming 'foreign' patients onto French waiting lists may be under some threat. Data problems are also an issue, and it is also unacceptable in France to ask about religion. Nevertheless, some data would be useful to combat expressions of possibly prejudicial concern and to explore ways of boosting areas where supply is weakest.

Following these two presentations, participants divided into small groups to explore areas of common interest. Several themes emerged, including:

- Questions of factors underlying Refusal to Donate, which may be cultural or psychological, or refer to a relationship with or perception of, the health service
- The information access patterns and ability of minority groups, including their social networks and knowledge of health services in general
- The effects of European enlargement and new nationalities
- Issues of social cohesion and exclusion affecting civil society
- Questions about differences and the use of terms such as 'ethnicity', "race", social class and other societal groups and actors, including the role of Institutions.

#### Alina Tatarenko (Council of Europe Directorate General III - Social Cohesion)

##### Perspectives of the work of the Council of Europe

The Council of Europe unites 45 national states within a framework founded on an understanding of Human Rights. There has been a longstanding agreement and understanding relating to the exchange of blood and blood products, and increasingly there is work within the Council relating to other "Substances of Human Origin" (A term adopted by the EUMIDON workshop, as 'SoHO', for the remainder of the workshop). Several committees oversee and produce reports relating to blood transfusion, cellular immune therapies, organ transplant organisation and quality assurance in relation to these substances. The Biomedicine Convention and an Additional Protocol have effectively outlawed payment for organs and regulate quality and ethical processes across all member states. Field action has been undertaken to ensure international maintenance of standards and provide training and guidance, and a number of consensus documents are produced, as well as co-ordinating the sharing of data between states. It was noted that the annual European Organ Donation and Transplant Day tends to open with an ecumenical service and a raising of the issue in the host nation's media (at least). While local policies are clearly culturally embedded, the Council's work is founded on consensus and there was some scope to raise the deliberations of this workshop at that level.

##### Marie-Paule Emonds:

##### Ethnic background, HLA and graft outcome in renal transplant patients of the Leuven Collaborative Group for Transplantation -

This paper presented a re-analysis on HLA match (HLA split level) and graft outcome in cadaveric renal transplantation added to a multi-variate analysis of tissue type and transplant success. It was noted that allochthones (mostly non-speakers of Belgian

national languages) had risen as a proportion of the national waiting list. Within this group, two 'ethnic' groups could be identified: the first was 'Caucasoid' ("White European") mainly of Turkish or Maghrebian origin who achieved a good HLA match comparable to autochthones. The second was mainly of African or Asian or Asiatic origin and were much harder to supply with a 'good match'. Although managing equal HLA match "Caucasian" allochthones had worse outcomes than autochthones, with higher rates of acute rejection, although equal graft survival rates (in those not rejected). Gendered results were very important, women who had delivered at least one child having raised levels of antibodies, but multiple parity did not worsen the outcomes. There were however problems which appear to arise from communication difficulties for allochthones which may be related to poor compliance and possibly also higher rates of smoking. The analysis was based on very small numbers, but had been able to record additional 'ethnicity' data for this purpose (not regularly recorded in Belgium).

Dr Lorraine Culley

Social Constructions of Infertility & Gamete Donation among South Asians

This paper described a major study conducted in the East Midlands of the UK. An extensive collection of studies from around the world show that involuntary childlessness can be a devastating experience for many; with significant consequences for social and psychological well-being. However, within the United Kingdom research on involuntary childlessness has mostly been carried out with middle class, white, treatment-seekers and consistently ignored non-treatment seekers, those accessing treatments other than *in vitro* fertilisation (IVF), those in lower socio-economic groups and those from 'non-white' ethnic groups. Studies of user satisfaction with infertility services have largely ignored ethnicity. More generally, inequalities in health between and within ethnic groups have become an increasing focus of research in Britain. However, studies of ethnicity and reproduction have tended to concentrate on childbirth and contraception rather than infertility. There is therefore, a dearth of literature on the way in which infertility might be experienced by people from minority ethnic communities and little is known about the impact of ethnicity on access to infertility services or the experience of assisted conception.

The needs and concerns articulated by infertile participants in this study arise for many who experience infertility, irrespective of ethnicity. A consideration of ethnic difference should not obscure commonalities between groups. The issues which are of concern to British South Asians are not dramatically different to those which the literature identifies as concerning many white infertility service users. Nevertheless, differences of culture, language and religion are also often important though not always in a unitary way. Specific cultural norms and values, language and communication needs, and the structural location of some minority ethnic communities in British society, give rise to specific areas of need which, this research suggests, are not always adequately met by existing service provision. A number of policy recommendations arise from this project.

Suitable and sensitive ethnic monitoring is required, to include the regular analysis of data. This would provide more robust information on ethnic patterns of infertility incidence and prevalence, treatment outcomes and uptake of services. There is also a clear need for improved interpretation services in most NHS Trusts. However,

improving interpretation services needs to happen alongside measures to increase the confidence of users in the effectiveness, cultural sensitivity and confidentiality of this service. It may be more practical for clinics and preferable for patients to use telephone-based interpretation services, at least on some occasions. In order to ensure effective communication, professionals should consider making use of an official interpretation service a mandatory component of at least some consultations where one partner does not speak English, to enable shared decision-making, implement patient-centred care and ensure informed consent. Health professionals should receive training in the use of interpretation provision and be provided with educational opportunities to explore ethnic diversity and the influence of ethnicity of health and health care.

Steps need to be taken to increase awareness of support counselling and the confidential nature of this service. Efforts should be made to ensure that counselling is culturally sensitive. Further research to investigate the reasons for the low up-take of counselling generally should be considered. Clinics should consider other ways in which the emotional needs of patients might be met outside of formal counselling. Infertility campaigning and support groups should consider ways in which they might appeal more directly to users from minority ethnic communities, including producing publicity with material and imagery that is 'inclusive'. The project included the development of two sets of resources. *South Asian Communities and Infertility*, a resource for use by professionals working in the field of infertility, and *Trying for a Baby*, a basic information resource in Punjabi, Gujarati, Bengali, Urdu and English.

### ***Two 'National Case Studies'***

#### **Italy - The View from a Country 'New' to Immigration**

Dr. Giovanna Campani - (University of Florence) Migration and Health  
Fiorella Marcellini - Italian National Institute on Aging & Dr Daniele Minardi -  
Polytechnic University of the Marche Region, Ancona - Italy -

"Policy of transplants and immigration in Italy".

*(This paper will be available on the MSRC web-site)*

It was noted that there were absolutely no data or research at present in Italy to inform this matter. Migration (in the sense of settlement of migrants into Italy) is a relatively recent phenomenon, and there is a growing base of research into migration, exclusion and poverty. Many migrants are single men or women, and there have been phases of controversy, and adverse conclusions drawn regarding the adequacy of socialisation of migrants as well as the training and attitudes of service providing agency workers. A major effort has been placed on developing cultural mediators and structures to facilitate access: most migrants however do not regard health as their main problem or priority, preferring rather to concentrate on housing and employment. In 1998 a right to health was recognised, and visas can also be issued for those visiting to obtain health care which give them the same rights and duties as Italian citizens. Poverty and social exclusion leads many migrants to rely on specialised, often voluntary sector, services.

A national law of 1999 regulates the free organ transplant system and a system of universal presumed consent (to cadaveric donation). On this basis a new organisation of transplantation has been instituted at national and regional level, which has led to a dramatic rise in the number of transplant operations being conducted, and in the number of donors. This was 5.8 per million population in 1992, and nowadays (2004) is 19.6 pmp. In this period, Italy has attained important results at a European level in respect of survival after organ transplantation and the quality of the transplant system. Nevertheless there is appreciable mortality on the waiting list and differences between regions in the rates of supply, particularly in relation to the southern area of the country which is less developed. It was hard to locate data on the donation rates of immigrants but birthplace data do suggest quite good levels among this relatively younger population, to the extent that there appear to be slightly more migrant donors than recipients.

### **Australia - the View from a Country of Immigration**

Prof. Maurice Eisenbruch, University of New South Wales, Sydney

Australian society has transformed itself since the mid-20<sup>th</sup> century, adding to a small (and previously almost hidden indigenous minority) a migrant population, so that now over 40% are of 'Non-English-Speaking background'. The proportion born overseas is still rising, with significant numbers of South-East Asian and also Mediterranean origins. Many migrants (especially those of Pacific island descent) have high rates of diabetes. There has however been a strong impact on the propensity of certain groups to donate following the example (or death) of high-profile sports stars. Nevertheless, states notable for high levels of diversity have low donation rates, and certain groups (also differentiated by socio-economic status) may show low willingness to donate: notable were Vietnamese, low-status Chinese people, and those of Arabic, Greek and Italian background, although some Muftis and Greek Orthodox religious leaders had been effective in persuading their followers to register. It was however noted that transplant teams and those charged with approaching potential donor families, held strong stereotypes and this may affect likelihood of asking. A programme of cultural competence development has been embarked on to tackle this. It was shown how folk beliefs and spirituality were important, and examples drawn from interviews with Aboriginal people. These also affect willingness to be a recipient of organs.

### Additional Case Study: Portugal (Ligia Ferreira)

Ligia Ferreira made a short presentation on the situation in Portugal, where there are no data available, but a law of presumed consent and universal approach (for cadaveric donation) which produced a rise in the number of transplants but has been very restrictive in relation to 'related live donors. The low rate of transplantation of 'live donor' organs (the lowest in Europe) is explained by this law, which only permits transplantation between relatives up to the third degree. It appears that there may be a gap between theory and practice: this is compounded by that very restrictive regulation and an attempt to avoid provoking stimulation of trafficking. Good practice in interviewing potential donors (such as psychiatric examination) may lead to a fall-off in achievement of donation.

Small-Group Discussion presented a number of additional themes: these included education at school-student level, the training and establishment of the role of organ donation promotion (procurement) workers, the role of media stereotypes, in-accuracy of registers, questions about 'living wills' and questions of poverty. It was noted that medical opinion is moving towards a preference for live donation which seems to produce better outcomes even in unrelated and poorly matched donors, but raises complex ethical issues and a number of 'urban myths'. There is a need to 'demystify' transplantation as well as educating about diversity and professionalising transplants.

### ***Ethical And Legal Issues***

Prof. David Price (DMU)

This paper also discussed the differential impact on South Asian communities of the shortage of cadaveric donors, especially aggravated by the UK policy of 'local use' where possible since South Asian populations are highly spatially concentrated. There have been advances in registration, so that now while 4% of the population they represent 3.5% of the registered donors (which is nearer the target), but this still fails to meet their representation on the list of those needing an organ. The refusal rate of relatives has in fact risen from 30% to 49%, despite faith leaders having expressed high levels of support for donation. It is suspected that a belief among transplant coordinators that they are 'reluctant donors' may depress the rate at which they are approached. The paper discussed the impact of EU principles and legislation such as those relating to free movement and competition, and harmonisation across states. It was felt that health service 'tourism' was growing as result of recent judgements, seeking perhaps areas where regulation was less severe (as in the case of fertility services, illustrated by the case of Diane Blood). This might also cause discussion about the willingness of national health insurance to pay for the costs incurred.

It was argued that many of these problems arose from, and demonstrated, unmet need. However, these and other aspects of the relationship between allocation and procurement may affect willingness to donate. It was shown that the criteria used are not ethnically neutral (e.g. reciprocity between centres) and principles such as Utility, Justice and Medical Needs might be in conflict: this was a hindrance to the development of a EU-wide database, although it was recognised that there are continual improvements in techniques affecting safety and the balance between these factors. However, at present EuroTransplant is a legal foundation that is only active (and recognised as the primary provider) in six countries, all of which outlaw 'non-resident' transplants. These issues are likely to require further resolution!

Nora Machado (Uppsala University)

### Ethical issues in Sharing Products of Human Origin -

When discussing ethics, at least two main stakeholders views must be considered: the patient's interest in living, and the physician's interest in developing medical science! The argument is posed that 'people are dying - we cannot wait', thus closing down a debate that actually cannot be avoided. It is for example assumed that donation and transplantation is an unconditional good, but decisions lead to identification of potential donors, who may be ventilated. Is the commodification of substances of human origin morally acceptable? There are issues of trust to set against the operation of a 'market'. Other moral dilemmas posed include matters of socio-economic status,



age and marital status (including attention to the cost of living after a transplant). Live donation also has the potential to harm the donor.

Three conceptual models could be envisaged: the logic of Bureaucracy, typified by a massive centralised and exchange-based system; the logic of the Market which may be personal and flexible but not always 'just'; and the ideal of a Community network founded on reciprocity. Human rights may be offset against community interests and challenges formed to concepts such as the sacredness of the body, by other values. When cultures meet, it may be that these become more complex. There is also a cognitive / analytic gap between willingness and action! There requires to be more research into differences between populations in these factors. Some of these were illustrated in discussion by reference to national differences in policies of 'presumed consent' and other regional traditions, as it was felt important not to regard only (migrant) minorities as 'presenting problems'. Attention is also required to the 'gatekeepers' of services, who also have their moral and ethical viewpoints.

Paper submitted by Tamar Ashkenazi, National Chief Coordinator of Israel Transplant (presented by local presenter)

Two papers presented a profile of the Israeli organ donor, and factors facilitating or inhibiting willingness to donate. Significantly, it was argued that organ sharing forms a 'bridge between Jews and Arabs' through a mutual need. Christian Arabs (50%) are slightly more likely to donate than Jews (49%) but African or Asian Jews were slightly less likely (27%) to donate than Muslim Arabs (29%). Education was a key variable, but the main reason for consenting was altruism in all groups. The percentage of Jews and Arabs waiting for a heart and those receiving one, were identical, but Arabs were somewhat more likely to receive a kidney as more were children, who got priority. Arabs and Jews overall, donate organs for transplant in the same proportion to their representation in the country at large.

Mustafa Ahmed - Kings College Hospital Renal Unit - 'Going Abroad'

Renal replacement therapy has been shown to be cost-effective, but the waiting list has continued to grow while the number of grafts and donors has remained fairly stable. There is some evidence that poor matches from live donors may have better outcomes than near matches from cadaveric donors: as a result, some South Asians in need have been travelling overseas to find willing live donors and a limited series of data were available to examine the outcomes. It does however appear to be reasonable effective, for those who survive - but as the procedure may be on the margins of legality in some cases, there are no tracking data to establish the full facts. Additional problems may arise in overseas operations, such as post-operative complications: it was also remarked that this way of obtaining grafts was not confined to people of South Asian origin.

Orin Lewis - The African Caribbean Leukemia Trust - 'Community Based' Recruitment of Bone Marrow Donors

This presentation was largely a descriptive one focusing on the work of the ACLT, and the ways in which a small community-based voluntary group, close to the culture of a specific community, had been able to raise registrations from that community on the basis of very carefully targeted social marketing and close identification between

community 'prominente' and the cause. This has required the energy and commitment of certain individuals but has been rewarding and effective. Within-group insights and close qualitative analysis enables them to attack myths and barriers, and provided a very inspiring model of good practice. Certain factors or lessons were certainly transferable - such as the need to identify local community events and locations, or the use of newsletters to those on the register to ensure that few are lost by attrition - and the difficulty of persuading religious organisations to take an active role.

*In addition, a number of 'poster' presentations were displayed and opportunities given for participants to discuss these with their authors: these were -*

Turkish Migrant Couples and Gamete Donation - Floor van Rooij, Frank van Balen, Jo Hermanns (Netherlands)

Religion in Organ Donation - Bert Elbertse (NL)

Recruitment and Reciprocity: Focus group method in researching infertility with minority ethnic communities - Lorraine Culley, Frances Rapport, Nichola Hudson (UK)

#### Assessment of the results, contribution to the future direction of the field, outcomes.

It was agreed during the progress of the workshop that there were many confusing and value-laden terms, some of which lead to confusion or conflict, and may carry messages which distort the discussion! One of these was 'ethnic minority' - although 'migrants' is also problematic since we also need to look at the situation of national 'autochthonous' societies: many groups no longer relate to notions of 'not belonging'.

We have been using the terms 'migrant/minority' to encompass a variety and diversity of marginalised and socially excluded or disadvantaged groups - the process of being identified and discriminated against, even if indirectly, may be termed 'minoritisation' and we shall continue to use this word, although in some specific locations numbers of members of such groups may be large! We also adopt the term 'Diversity'.

The word 'Race' should be avoided as far as possible - but recognising that there are processes of 'racialisation' and there are also members of specific genetic pools, and people who are grouped together on the basis of apparent similarity of appearance.

Organs, Tissues, Gametes, Blood, and other body parts all have slightly different processes, values and legislation or registers and bureaucratic rules attached: it was however felt that there was enough commonality of interest in the basic processes of unequal supply and need or demand, and of means of combating these inequalities, to suggest that we should try and work around a common interest in 'Substances of Human Origin' - SoHO. Models of successful intervention in respect of one type of material are likely to be transferable to other substances.

A fundamental need is the set up or collate and exchange processes of monitoring or audit of what is going on in respect of transfer of SoHO between individuals and groups (majorities/minorities) as it is not possible to regulate without this information:

while some data (e.g. language, religion, ethnic group) may not be legally obtained or recorded in current official registers in many countries, it is likely that research may be able to ask these questions 'for purpose'.

We agree that any future actions MUST be Multi-Disciplinary, based on Multiple Methods (Qualitative and Quantitative) and Bottom-up based.

### **Synthesis of Necessary Immediate Actions**

It was felt that it would be helpful if all participants / 'national representatives' (maybe together) could begin to assist with a process of bringing together a basic collection of information to underpin the construction of a collaborative, comparative research programme, in order to determine immediate possible actions, and needs. We should in this be working within a wider agenda or brief, conscious of the aspirations of the World Health Organisation, Universal Declaration of Human Rights etc, for equity and justice and reduction of inequalities ("Health For All"). It was agreed that the "DMU Team" will assist in the collation of this and its circulation as we go along.

Key data which were urgently required included the following:

What baseline data are locally available, on donor registration and uptake rates - what indicators or categories of data can be used (if any) to identify or detect marginalisation or exclusion and differential situation of migrant/minorities

(For this we may ask how we can make these 'comparable' and to what extent; and also seek to disentangle the effects of other competing explanatory variables, such as social class, geographical location, age, gender etc - if at all!)

Are there are local 'grey' or unpublished studies, perhaps Qualitative, on processes or public health aspects that cast light on differential need and supply of SoHO?

We should try to document or verify (while aware that there are 'Council of Europe' generic standards) what are local procurement policies and practices with explicit regard to Minorities (including as appropriate, 'national minorities')

Document / collect evidence or descriptions of Interventions (and if any, evaluations) to increase supply from 'marginalised' groups, Minorities etc

Relate to, and seek, "Community Consent" and support from minority representative bodies etc - i.e. ask them what might be their agendas, to obtain legitimacy & support.

It was noted that this process may itself be empowering, effective, and relate to wider questions of health, social participation & cohesion, and indeed also, have wider generic and general spin-off for improvement of health services overall.

Finally - having done any or all of these above actions - participants of the EUMIDON network were requested to 'Report Back and Feed Back' - i.e. discuss their experience at the workshop with their domestic networks and peers, and then feed back any responses and information to the whole network!

### **Some Research Questions:**

It would be useful to document and bring together in an accessible form the following information to be the basis of a wider comparative enquiry:

- What are the basic conditions for eligibility for basic health care entitlement and organ transplantation in particular (insurance and residence conditions?)
- Models of procurement - i.e. what is the social interaction at the time that decisions are to be made, in the various societies / jurisdictions involved
- How is the non-donor population constituted and what factors underpin these views (i.e. what do we know about refusers?)
- How do different allocation rules and criteria impact upon different minority groups
- Does use of living organ donation have any differential role and impact on minority groups (NB this could be positive OR negative in effect).

### Outcomes of the Workshop

The papers of the workshop, with some additional ones to be commissioned, will be edited to be published as a book (a publisher has agreed in principle to this).

There have already been several bilateral conversations regarding the development of research proposals, and members of the workshop are already feeding back their discussions to significant meetings of the Council of Europe and European Community (working groups on social exclusion, racism and human rights).

Members of the group, and others, will continue to collect data and exchange information and propose to formulate a research programme in the new year to seek funding to explore the issues raised in the workshop on a comparative, and scientifically grounded, basis.

It is also expected that local studies will be stimulated and seek funding in national settings, proposed by individual members of the group: these will be shared in the first instance through the group network, as the basis for emulation.

The major briefing papers prepared for the workshop will be made available through the CEEHD/MSRC website – [www.dmu.ac.uk/msrc](http://www.dmu.ac.uk/msrc)

Final programme

## **Conference Programme**

Friday 10<sup>th</sup> September 2004

Arrival at Birmingham (International Airport/ International railway station, travel to Birmingham New Street main central railway station and transfer directly to Britannia Hotel which is a short walk down the ramp from the shopping mall above the station)

Registration & Orientation - Poster Displays - Sandwich & Fruit Buffet lunch

### **Posters:**

Turkish Migrant Couples and Gamete Donation (Floor van Rooij, Frank van Balen, Jo Hermans)

Religion in Organ Donation (Bert Elbertse)

Recruitment and reciprocity: Focus Group Method in researching infertility with Minority Ethnic Communities (Lorraine Culley, Frances Rapport, Nicola Hudson)

### ***2.00 Official Opening and Welcome***

Professor Mark R D Johnson - The purpose of the Workshop

(including ESF / EMRC presentation - 'a word from our sponsor')

### ***2.30 Keynote: Minorities, Migration, and Sharing of Human Tissue Resources***

Dr Gurchan Randhawa - University of Luton & UK Transplant

3.15 Dr Bernard Loty - Medical Director of the French Transplantation Agency

### ***4.00 TeaBreak***

4.30 - Small groups - Getting to know each other: purposes and themes aspired to

5.30 - Alina Tatarenko - Perspectives of the work of the Council of Europe (Directorate General III - Social Cohesion)

### ***7.00 Dinner***

### ***8.30 Evening Workshop - Some Clinical Issues***

Ethnic background, HLA and graft outcome in renal transplant patients of the Leuven Collaborative Group for Transplantation - Prof. Marie-Paule Emonds

Social Constructions of Infertility & Gamete Donation among South Asians - Dr Lorraine Culley

## ***Saturday 11<sup>th</sup> September***

Breakfast at the Hotel!

### ***9.00 National Case Studies***

Italy - The View from a Country 'New' to Immigration

Dr. Giovanna Campani - Migration and Health

Fiorella Marcellini - Italian National Institute on Aging & Dr Daniele Minardi -

Polytechnic University of the Marche Region, Ancona - Italy - "Policy of transplants and immigration in Italy".

10.30 Australia - the View from a Country of Immigration

Prof. Maurice Eisenbruch, University of New South Wales, Sydney

11.30 - Coffee and Small Groups discussion

12.45 - Feedback

13.00 Lunch Break

***14.00 Ethical And Legal Issues***

Prof. David Price (DMU)

Ethical issues in Sharing Products of Human Origin - Nora Machado

Paper submitted by Tamar Ashkenazi; National Chief Coordinator of Israel Transplant (presented by local presenter): The Profile of the Israeli Donor/Factors affecting willingness to donate.

**TeaBreak**

*Small groups to discuss Topics*

Blood Groups and Histo-Compatibility (MP Emons Facilitator)

Kidney and similar organs (Gurch Randhawa, facilitator)

Fertility (Sperm & Egg) Treatments (Lorraine Culley, facilitator)

***7.30 for 8.00 Conference Dinner***

Including short speeches from User/Community Representatives

There will be time for Networking and Informal Discussion

***Sunday 12<sup>th</sup> September 2004.***

***9.00 - Alternative solutions to the problem of supply and demand***

Mustafa Ahmed - Kings College Hospital Renal Unit - 'Going Abroad'

Orin Lewis - The African Caribbean Leukemia Trust - 'Community Based'

Coffee - Small groups - developing an agenda for Research

Feedback

1.00 Lunch

Conclusions and Future Directions (Prof. M Johnson)

3.00 - 3.30 Depart

Final list of participants (including full title, address, tel, fax, email)

		E-mail
Prof. Mark RD Johnson	Convenor; MSRC, 266 London Road, Leicester LE2 1RQ Tel: 0116 201 3906	<a href="mailto:mrдж@dmu.ac.uk">mrдж@dmu.ac.uk</a> <a href="mailto:johnsons@cv77dq.free-serve.co.uk">johnsons@cv77dq.free-serve.co.uk</a>
Prof. David Price	School of Law, De Montfort University, Leicester LE1 9BH,	<a href="mailto:dpp@dmu.ac.uk">dpp@dmu.ac.uk</a>
Dr Gurchan Randhawa,	Principal Research Fellow, Institute for Health Services Research, University of Luton; 15-17 George Street, Luton LU1 2AF Tel: 01582 743797 or 07718 517196	<a href="mailto:gurch.randhawa@luton.ac.uk">gurch.randhawa@luton.ac.uk</a>
Dr Lorraine Culley	Reader in Health Studies, De Montfort University, Leicester LE1 9BH Tel. 0116 257 7753	<a href="mailto:lac@dmu.ac.uk">lac@dmu.ac.uk</a>
Mustafa Ahmed	King's College Renal Unit/LSHTM, London Tel 0207 737 4000 ext 2256	<a href="mailto:mustafa.ahmed@lshtm.ac.uk">mustafa.ahmed@lshtm.ac.uk</a>
Orin Lewis	African Caribbean Leukemia Trust, PO Box 670 Croydon CR9 5DP Tel +44 208 667 1122 Fax 208 667 1626 www.aclt.org	<a href="mailto:orin@aclt.org">orin@aclt.org</a> ; <a href="mailto:aclt1@aol.com">aclt1@aol.com</a>
Prof. Jan Lerut	Clin. Univ. Saint-Luc, Univ. Cath. De Louvain, Ave. Hippocrate 10, Brussels 1200	<a href="mailto:Lerut@chir.ucl.ac.be">Lerut@chir.ucl.ac.be</a> or <a href="mailto:catherine.dochez@clin.ucl.ac.be">catherine.dochez@clin.ucl.ac.be</a>
Prof. Marie-Paule Emonds	As Yves Vanrenterghem (see below)	<a href="mailto:Marie-paule.emonds@uz.kuleuven.ac.be">Marie-paule.emonds@uz.kuleuven.ac.be</a>
Marta Soler	C/o Rosa Valls, CREA Barcelona University	<a href="mailto:Crea@pcb.ub.es">Crea@pcb.ub.es</a>
Mrs. Germania Tapia Gomez	Participant in FACEPA Multicultural Group C/o Rosa Valls	<a href="mailto:Crea@pcb.ub.es">Crea@pcb.ub.es</a>
Ligia Evora Ferreira	CEMRI – Open University R. Escola Politécnica, 147 1269-001 Lisboa Tels:+351 213916446; +35196 8849513	<a href="mailto:lief@univ-ab.pt">lief@univ-ab.pt</a>
Dr Nora Machado	Dept. Sociology, Uppsala University Box 624 SE-751 26 Tel +46 18 121 450 and GU / also visiting scholar, NIAS, NL	<a href="mailto:Nora.machado@soc.uu.se">Nora.machado@soc.uu.se</a>
Prof Tom Burns	Dept. Sociology, Uppsala University & EU Xenophob project	<a href="mailto:Tom.burns@soc.uu.se">Tom.burns@soc.uu.se</a>
Giovanna Campani	Italian Research into Migration, Univ. di Firenze, Via di Parione 11/B I-50123	<a href="mailto:Campani@unifi.it">Campani@unifi.it</a>
Fiorella Marcellini	Italian Nat. Inst on Aging - 0039 ( Italy) 071 ( city code)- 8004788	<a href="mailto:f.marcellini@inrca.it">f.marcellini@inrca.it</a>
Dr Daniele Minardi	Institute of Urology , Clinica Urologica Università Politecnica delle Marche Azienda Ospedaliero-Universitaria "Ospedali Riuniti" via Conca 71 , 60020 Ancona - Italy	<a href="mailto:d.minardi@univpm.it">d.minardi@univpm.it</a>

Floor van Rooij	PhD Student, U Amsterdam	<a href="mailto:F.B.vanRooij@uva.nl">F.B.vanRooij@uva.nl</a>
Drs. Bert Elbertse	Programmecoordinator NIGZ, P.O. 500, 3440 AM Woerden Netherlands	<a href="mailto:Belbertse@nigz.nl">Belbertse@nigz.nl</a>
Prof. Bernard Loty	French Transplant Agency	<a href="mailto:b.loty@free.fr">b.loty@free.fr</a>
Philippe Tuppin	Evaluation Dept, EFG (French Transplant Agency)	<a href="mailto:Ptuppin001@efg.atrium.rss.fr">Ptuppin001@efg.atrium.rss.fr</a>
Konstantine Podara	Clinical Psychology PhD student (Young Researcher)	<a href="mailto:geko@tellas.gr">geko@tellas.gr</a>
Alina Tatarenko	Council of Europe Health Division, Strasbourg	<a href="mailto:Alina.tatarenko@coe.int">Alina.tatarenko@coe.int</a>
Maurice Eisenbruch	Centre for Culture and Health - University of New South Wales, Sydney NSW 2052 Australia Tel: +61 (2) 9385-2324; Fax 61 (2) 9385 8739	<a href="mailto:m.eisenbruch@unsw.edu.au">m.eisenbruch@unsw.edu.au</a>

Additional Visitors who were able to attend the workshop (but did not incur costs to the programme) included Maulana AKM Kamruzzaman, official Muslim Chaplain to the Birmingham hospitals, Professor Ala Szczepura of the University of Warwick Medical School, and Nazir Ul Haq of the University of Birmingham Department of Social Studies. All of these were able to contribute to the discussion and speak with participants about local initiatives and interests. We believe that this provided some 'added value' and networking for the group. Apologies for non-attendance at the last minute for health or other professional reasons were also received from Cynthia Davies and Dr Langer (Hungary): their papers were tabled, along with papers by Tamar Ashkenazi (Israel).

Statistical information on participants (age bracket, countries of origin, etc.)

Under 30	2
30-40	7
40-50	9
Over 50	5
Total attending:	23

Countries of Origin:

UK	6
Belgium	2
Spain	2
Portugal	1
Sweden	2
Italy	3
Netherlands	2
France	3
Greece	1
Australia	1

Gender

Male	Female
12	11

Four members of the seminar considered themselves to be 'Young Researchers'. Two students also attended for part of the workshop.