

## **FOSTERING COMMON GOALS & SHARING VALUES: REVISITING FERCAP'S REGIONAL ALLIANCES\***

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Why might an anthropologist find the work of the *Forum for Ethical Review Committees in the Asian & Western Pacific Region* (FERCAP) interesting? Anthropologists study all aspects of human life, paying close attention to what people do and say. In my doctoral research, I focus on notions of capacity building and governance and have attempted to understand what gives FERCAP its distinctive organizational culture. As part of a *United Kingdom (UK) Economic and Social Council (ESRC)* project on *International Science and Bioethics Collaborations*, the work is a contribution to studies of biomedical science in action and the consideration of the place of ethics in practice (UK ESRC, 2007-2010). The methods employed for this research were primarily qualitative, involving semi-structured interviews and participant observation, as well as the analysis of documents and photographs. In interviews, I asked members of FERCAP why they were involved in ethical review, I talked to them about some of the challenges and difficulties but also about rewards and positive experiences. I was able to meet and talk with trainers and surveyors in five countries. As I have got to know members of the international medical community, I am certain that many of you who I have interviewed have been to twice as many countries in the same period, for conferences, events, teaching lectures, and trainings. FERCAP both represents and is a community distributed across the region. Findings presented here will be a familiar commentary to those

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\* Revised version of the paper presented during the 10<sup>th</sup> FERCAP International Conference: *Networking and Alliance Building for Ethical Health Research*, Equatorial Shanghai Hotel, Shanghai, China, November 24, 2010.

who are a part of FERCAP, as they reflect experiences shared with one another and with me as I attended surveys, trainings, conferences, and meetings. In this paper, I reflect on to the kinds of exchanges that go on in the events that are organized. I then turn to some of your comments and metaphors to look at how common goals and values are generated and sustained, and finally, consider how these contribute to growing the network you run.

Exchange is a well established theme in anthropological literature. One of the classic texts in Anthropology is *Argonauts of the Western Pacific* (1922), in which Bronislaw Malinowski writes about his experiences in the Trobriand Islands. These are a small group of islands off the eastern coast of Papua New Guinea, where Malinowski lived for many years during the Second World War. Today anthropologists continue to study the social relations of the people with whom they live. When Malinowski studied the Trobriand Islanders, he became fascinated by a network of exchange of valuable items that stretched across the islands. Through observations and by joining them on their canoe voyages, he found a pattern to the journeys, the gifts, and the ceremonies. The beautiful and valuable amshells they passed on were part of a rotating system of exchange that flowed anticlockwise, and necklaces were part of a rotating system of exchange that flowed clockwise. This system was called Kula.

As members of FERCAP will know, people are nowadays incredibly mobile, and their social networks are massively dispersed. Members of FERCAP clearly don't exchange shells, but they do exchange a different sort of "valuable." One is as physical, as tangible as the shells and necklaces -- files and paperwork. The other is far more intangible: experiences of ethical review practices. In focusing on what passes between members, I have noticed that in doing this work, another sort of valuable is created: the relationships between members which support and run a network of volunteer surveyors and trainers. Trainings and surveys are sometimes described in the language of exchange -- the exchange of information. We all experience exchanges in daily life; we are familiar with the market. Where there are things that can be passed between parties, they are commensurable. But this is quite impersonal language. Usually in economic or market exchanges we do not see the person we transacted with again. There isn't much point in earning their respect or their friendship, sharing

useful advice. That is why I am suggesting that what is going on in the FERCAP network is not *just* an exchange of information and experience, but it incorporates a dimension of reciprocity unusual in contemporary organizations.

### **Trainings, Paperwork, and Information**

Let us first reflect on why members of FERCAP exchange files, experiences, paperwork, and processes. As each of FERCAP's annual conferences show, the massive growth of the clinical trials industry is the cause of much of FERCAP's activities and concerns. FERCAP wants to develop regional capacity in ethical review and contribute to good research practices. Many members with whom I spoke stated that the primary goal is to contribute to human subject protection globally through better ethical review practices. However, with many different research environments, institutional and legislative contexts, it might be difficult to coordinate the effort. FERCAP hopes to ensure that the challenges faced across the region can be made into something that can be tackled through a common approach. This common approach involves the regular exchange of stories, advice, processes, and experiences.

Observations during the research have found that FERCAP trainers regularly incorporate the knowledge and stories they gain from surveys and meetings around the region into training sessions. Thus FERCAP trainings serve multiple purposes. As well as the primary activity of imparting information to participants, they provide the opportunity for people to ask questions, and aim to generate an environment that is conducive to learning. Trainings are also an opportunity for making a sense of community, as is evident in one statement I heard: "we form a group of ethics committees and act together to ensure we act ethically and ensure ethics is being carried out in each institution." In this description, the members of ethics committees form under common goals. But trainees don't necessarily start out having common goals. One trainer commented that

At the beginning they don't care. Then they start to listen. It's... transformative. At the beginning they don't care, then they hear... You see them change, from

the baseline to the end; they see different things; this one is not about the knowledge, more about motivating them.

While the purpose of much research ethics training around the world is based on the imparting of information, we can see that the goal of FERCAP trainers is also to produce a competent subject, someone who is not just aware of ethics but also capable of performing ethics related tasks and reflecting on them. As one trainee said: "I think the idea is that we police ourselves not that the regulators tell us what's wrong with us." Bringing people together in training sessions, then, is not done solely to educate them, but also to inspire and offer encouragement. An important part of what has been called the "FERCAP model," is that the goals and values are intertwined, made, and reinforced through these interactions. In achieving a goal of training committee members, the training sessions also communicate values including cooperation and friendship. While the effectiveness of training is tested by measuring individuals, an aim that is impossible to quantify -- and one which is therefore not captured -- is the friendships and relationships that develop during these sessions. These relationships also have effects that are difficult to capture.

### **Surveys, Friendships, and Metaphors**

Bob Layton (1997, 101), a social anthropologist has noted that "reciprocal exchanges differ from market exchanges because they are used to create or maintain ongoing social relationships between the participants." One of the events that I both participated in and observed in detail was the process of conducting a survey. A survey *could* operate like this: the date is arranged, the surveyors come. They do their work, they deliver their verdict, and they leave. But as one of the surveyors put it, simply coming to do a survey *is not exchange for getting recognition*. The end of the survey is not the end of the relations. The parties -- both surveyed and surveyors -- part with obligations and responsibilities. The surveyors will prepare a report, the surveyed committee will act on it, and their response will be assessed. This is still not the end. It leads to another event, one that takes place at the conference, where delegates of recognized committees receive their plaques of recognition in the company of

colleagues. This could also be the end, but it is not. As part of a commitment to ongoing improvement and quality control, the committee will be resurveyed in three years. Trainees at the survey may go on to survey other committees, the surveyed become the surveyors, and so the connections continue.

Metaphors used by members of FERCAP offer a distinctive imagery through which to consider what the organization is trying to achieve. Linked with the ongoing connections of the survey, one of the most striking metaphors links the network to the idea of a family. The FERCAP conference is one of the best opportunities to see this metaphor in action, as people travel from across the region to meet up with one another. At the conference in 2009, one attendee commented that at the conference, “you have a lot of family members, everyone can see you, everyone can do something for you.” It is a place to go for support and also for friendship. Many conferences in ethics are about “updating one’s knowledge,” and of course this is important. But the FERCAP conference is also about seeing people and consolidating relationships. As one member commented last year, “If you are just here to talk about yourself, that is not the way, that is not the attitude, we are family in the region.”

Another way in which members of FERCAP have tried to explain their feelings and motivations about the network is through the images of houses. “We may have a really nice house,” commented a conference attendee “but the house might not be in a nice environment. We have to think about that, have to have some shared values.” I asked her to elaborate:

If you have your house and it is nice, you cannot just be happy with that. You need to think about what is around it. That is our values. You cannot just care about your house; you need to care about it all!

This comment shows how members of FERCAP think across borders, and think regionally when they consider the work of their network. Of course, the region covered by FERCAP includes nations with very different experiences of and priorities in hosting and conducting research. Ethics review committees are differently institutionalized, supported, and tested. Despite this, FERCAP

members regularly demonstrate both sensitivity to and accommodation for the differences. Another metaphor shows that this accommodation isn't always easy:

FERCAP lives in a big house, but sometimes they don't know the other culture is in the house. Even though the house is big and has everything, in other culture you need to change and change your regulations, depending on people's culture. Can't just say everything you're right and other is wrong.

In this quote, at the same time as acknowledging the necessity for attention to flexibility, by the house as a metaphor, the speaker illustrates how his thought returns to imagining the challenges as a common problem by situating everyone in the same house.

### **Models, Measurement, and Networks**

Conventional thinking dictates that when we design a model, we take it and implement it across a variety of settings. To a large extent, this is what *International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use* (ICH, 1997) and the *World Health Organization* (WHO/TDR, 2000) guidelines on ethics review committees are. Or as many of you have put it to me, they are a recipe. But, as with cooking, it matters when we put ingredients in. One of the ways in which FERCAP excels is that it appraises and tailors its recommendations to the committee in question, commenting on its resources, the kind of institutional support it has, the experience of its staff and its members. Surveys include an interview with members of the committee to take their views into account, and during the final report meeting, members are encouraged to be present so that they can ask questions, query particular recommendations. This has also been described in terms of cooking! As one member said to me,

FERCAP is a bottom up organization. We don't want people to have a meal, we say let's cook together. It's not "you will eat now and this is what you will eat and this is what you will cook."

This doctoral research has not been designed to produce statistics upon which recommendations for improving capacity building can be based. It has been about listening to the narratives, metaphors, and stories FERCAP tells about itself. In feeding back analyses of findings to you, it is in the hope that you will find them interesting, and perhaps even useful in some way, whether that is in arranging further activities, implementing them, or simply reflecting on what it is you are engaged in at this 10 year juncture. I would offer only one comment of caution on the proliferation of measurements. Measurements are extremely useful: we can use them to tell how well we are doing, where we can do better, and to some extent, how we can improve actions and processes. However, when everyone is focused on striving for improvement and committed to quality work, there is a tendency towards the measurement of all things. But as I think the metaphors I have highlighted here illustrate, there are qualities in your network and actions that cannot be quantified. Not all the qualities of people, or their relationships, are measurable. As the people of your network and the relationships they form between one another are one of your strongest resources, there may be ways other than measurement -- such as personal profiles, commentaries, peer-to-peer networking, life experience reflections, and newsletter articles -- that could celebrate this.

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