

CASE STUDIES

CASE STUDY 1: Chiapas

Background:

Case description: the Maya ICBG

"Communities, whatever their scale, continue in heterogeneous ways to reconstitute themselves as they make the world their own, inevitably in the face of tremendous economic and political constraints on their actions. As a result, anthropology has increasingly become the study of instability and fragmentation, of systems caught in contradictory currents of change."

Introduction. In 1996, a project was initiated to collect ethno-botanical information in Chiapas, Mexico, set up as a joint project with four partners: a US university research team, a Mexican teaching and research center, a biotech company, and a non-profit organization set up by the project to represent the interests of the Mayan communities. The multiple aims of the project included preservation of local medicinal plant knowledge and its use to discover new therapies for a range of local and internationally important diseases, as well as the development of local economic and scientific capacity. Controversy erupted as some local and external groups charged that the project was exploitative, while the project partners defended it as mutually beneficial and socially responsible. Collection of plant materials for bioprospecting was never initiated, and the disputes led to withdrawal of the local public research center partner, cessation of funding, and termination of the project.

Background on Chiapas. The Chiapas region in southern Mexico is a region of extreme poverty, well below national averages for Mexico in important indicators such as child survival, per capita GDP, and educational levels. Approximately one third of the population is Maya speaking, belonging to one of eight language groups. While rich in natural resources, there are few economic opportunities for Chiapas residents, many of whom farm small plots of land. The economic situation for small farmers in the Chiapas region during the 1990's was bad, and it was getting worse, due to changes in prices and trade policies, as well as accelerated degradation of natural resources. Struggles for land reform in the region had been ongoing for many decades, and had led to the formation of many local peasant resistance groups, including, in 1983, the Zapatista Army of National Liberation (EZLN).² In 1994, the indigenous peoples of Chiapas gained world attention in an armed uprising of the EZLN, and became international symbol of ethnic resistance to globalization and the struggle for social equality and indigenous rights.

In Chiapas, governance was structured at the municipal level; indigenous land ownership had traditionally, and under Mexican law known as the ejido system, been communal. In the early 1990s, government policies protecting communal land ownership in the ejido system was eroding, but in response to the Zapatista uprising, the San Andres accords of 1996 established local indigenous communities as legitimate land owners. The accords were supposed to support indigenous peoples' rights in several areas: control of their traditional natural resources; participation in decision-making regarding public expenditures; control of their own judicial and administrative affairs. Subsequently there was disagreement and controversy regarding the implementation of the accords, which were not translated into legislative action or implementation by the Mexican government,³ creating further bitterness and disillusionment among indigenous communities.

Mayan traditions of healing. The highland Maya had a long tradition of use of medicinal plants for healing. These herbal traditions were not seen as a distinct class of medicine, but were part of a systemic view of health and healing that involves spiritual healers, prayer, rituals, and herbal preparations,⁴ although healers have become aware of the attractiveness of the use of medicinal plants to outside groups. Herbal preparations continue to be an important source of primary health care for the vast majority of Maya residents of Chiapas. The researchers in the ICBG project had studied the degree to which knowledge of herbal remedies was held by community members generally, and planned to study only those herbal preparations used by the community at large. Also, a large proportion of the herbal preparations are based on plants and knowledge that are shared with other communities outside of the region. However, the local healers group was concerned that specialised knowledge was being appropriated by outsiders.

Background on bioprospecting.

Most bioprospecting agreements do not result in economic gain for industrial partners in the short and medium term⁵ due to the low chances of developing a successful, marketable drug from plant or microbial sources; long-term benefits may vary, depending on whether products become commercially successful. Some bioprospecting efforts involve use of traditional knowledge in indigenous communities to focus on plants with known medicinal value, while some do not. Companies frequently view other strategies, such as combinatorial chemistry, as more efficient means of screening compounds with potential activity. However, there is a fairly widespread public perception that multinational drug companies can easily make millions from appropriation of natural resources of countries with rich biodiversity.⁶

The Convention on Biological Diversity (CBD) 1992 arose in part, out of concerns about appropriation or exploitation of biological resources in countries without adequate policies or regulations to protect natural resources or their local users. In the Bonn guidelines, which emerged from the CBD, it is recognized that indigenous groups should be able to share in benefits from their traditional knowledge (2002),⁷ and Prior Informed Consent (PIC) should be sought in communities where biological resources or traditional knowledge is utilized in research.

Under Mexican law, permits for collecting biological specimens need to be obtained from a national ministry, and in addition, permission from the owner of the land is needed for any collection destined for commercial purposes.⁸ However, the law does not address intellectual property or bioprospecting *per se*.

The International Cooperative Biodiversity Program (ICBG), started in 1993 and sponsored by 3 US government agencies⁹ aims to promote research programs that incorporate a commitment to conservation and biodiversity, as well as local economic development, in bioprospecting research.¹⁰ The intent of ICBG projects is that they be contracted as fair partnerships among organizations including research organizations, industrial partners, and community organizations, and to develop outcomes that benefit not only the partners, but also larger social goods locally and internationally.

Story of the Maya ICBG.

The Maya ICBG project involved collecting and cataloguing botanical species of the Chiapas highlands, including development of ethnobotanical gardens for conserving plants, evaluating traditional remedies, compiling monographs in several languages (including local languages) which would describe botanical and medicinal findings. The project's principal investigators had been investigating ethnobotany in the region for almost 30 years. Through the ICBG and other efforts they had begun to publish handbooks on traditional remedies for diarrhea, respiratory conditions, infectious diseases, and contraception in native languages with translations to Spanish and English.

The ICBG project involved four partners: a US university; a local Mexican public research center with a long history of multidisciplinary, sustainable development-oriented research activities in the region; a small biotech company based in Wales, whose mission was to identify promising new plant-based compounds that could then potentially be developed by larger pharmaceutical companies for clinical applications; and the Mayan communities themselves. The more than 250,000 Maya people potentially involved were not grouped in a single overarching organization, but had formed complex, diverse and dispersed political, religious and production-oriented organizations. Given that there was no overarching organization representing Mayan communities, the ICBG project leaders proposed instead PROMAYA: a trust fund initially promoted and governed by regional and national political figures sympathetic with the concerns of indigenous people; this governance was selected by the non-indigenous partners in the project.¹¹

The project never reached the stage of collections for research with commercial development potential. However, the participating organizations had begun drafting agreements regarding intellectual property. The draft ICBG-Maya Joint Ownership agreement stipulated that Maya communities would receive ¼ of any royalties and co-ownership of any licenses that emerged from the research—the other shares were divided in equal fourths among the US university, the biotech company, and the Mexican research institution. The Maya share was to be paid to the NGO/Trust fund PROMAYA. Decisions taken regarding use of PROMAYA funds were to be made by representatives from each of the participating communities; however funds could also be used for projects that benefited other local communities that declined to participate in the research.

Prior informed consent was sought in local villages using Tzeltal and Tzotzil language theatre, in order to meet the current legal requirements established by the Mexican government to provide collecting permits. The informed consent process emphasized that the chances of substantial financial benefits from the project were slim, and that other non-monetary benefits were more significant, such as conservation of traditional knowledge, creation of ethnobotanical gardens, and use of plant-based pest control agents. A consent form was signed, usually by elected community leaders, in each of the 46 villages that decided to participate (out of the 47 villages approached).

Twelve percent of the project budget was allocated to salaries for 24 Maya field assistants, who received training in transcription in their own languages, field botanical survey techniques, computer literacy, lab techniques, plant propagation, marketing and IP issues.

From the beginning of negotiations regarding the project, the local indigenous healers group, was not involved; they had been informed of the project informally by the Mexican research partner during the grant-writing stage. They did not join in the planning or grant-writing stages of the project, although they did attend a public workshop about the project after the grant was obtained.

In challenges to the informed consent process, a consortium of healers' groups, which included the local healers' group, and an NGO advocating widely against bioprospecting activities alleged that the consent of the participating villages was insufficient, and that national level policies regarding protection of indigenous right and resources would be necessary before any collection could begin. In 1999 the healers' consortium directed a letter to local and federal authorities called for a halt to the project. Denunciations of the ICBG project were published on numerous websites, and gathered increasing media attention, and support from observers unconnected to the case or to the region.

In 2001 the Mexican research institution withdrew from the project, citing the difficulties arising from the challenges of the healer's consortium and the NGO, the need for a self-organized indigenous partner, and for national level regulation to provide some resolution of the impasse. Without a local research partner, the project was no longer eligible for US government grant support, and in November 2001 the project folded.

Views of participants and observers in the ICBG-Maya story.

Two of the US researchers who had set up the Maya ICBG felt that NGOs had disrupted the research project in a setting where national level regulation was lacking:

"We argue these [local, national, and international] NGOs, as part of their unjustified equation of legitimate access to biological resources with what they call biopiracy, have usurped the rightful authority of local communities to act on their own behalf concerning the use of their own resources—resources that increasingly represent their best entry point into the world economy." ¹²

The researchers argue that after the local group opposing the project, COMPITCH, contacted RAFI, the latter provided a consultant who

"Attempted to sabotage all possible negotiations between the project and the healers group when the Mexican government took extraordinary measure to arbitrate the dispute in the early 2000. As a result, both the Mexican government representatives and we were forced to conclude that COMPTICH was not negotiating in good faith."

The position of the US researchers was that universal consensus among communities with shared knowledge is impossible and could not be a requirement for conducting research, and that knowledge that is widespread among many diverse groups is, by definition, publicly held.

"Does one person who opposes a project that offers an opportunity for sustainable development, social and economic benefits prevent all others from taking advantage of the opportunity? Does control of intellectual property only apply to veto power of a single individual? Our answer is that it does not."

One of the scientists at the company that partnered in the ICBG similarly felt that the NGOs' role was out of place:

"Clear winners in the biopiracy war are the 'biopiracy' lawyers who often have large salaries and a vested interest in making the process of reaching legal agreement of bioprospecting long and complex....clear losers are the indigenous peoples who often have no direct say in the campaigns on their behalf and who might benefit more from patents than 'protection' by action groups of well-heeled activists in cities."¹³

The program director at one the US sponsoring agencies, described ways that political tensions can derail projects and make negotiations difficult.

"Emotionally charged issues related to human rights, land tenure, the ability of poor communities to exploit the patent system and the morality of patenting inventions derived from study of living organisms ("patenting life") frequently inject themselves into the debate....The tensions are frequently at play even where culturally well-defined community governance systems exist, and may be overwhelming to a partnership that depends on participation of communities where such governance systems are lacking or poorly integrated with western legal systems. In such situations, global or national politics that might be considered external to local questions of stewardship and collaboration easily inflame the discussion." ¹⁴

Another commentator echoed the concern that local governance can be a critical factor in establishing agreements:

"In many cases, the diversity of political organization among local groups or the lack of strong regional or national Indigenous institutions will make the application of the concepts [of prior informed consent/prior informed approval] very problematic.

Communities will likely have conflicts within and between themselves over strategies for disseminating their knowledge and the compensation they desire, and there may be no indigenously controlled mechanisms for sorting out the conflicts.”¹⁵

Some local observers expressed reservations about the project. A Mexican physician working in the area and a longstanding member of the local healers group,¹⁶ felt that the project had isolated the use of plant medicines from the whole context of the Mayan approach to medicine, and that this was doing a disservice to the traditions of healing as part of an entire belief system—a view shared by some anthropologists working in the Chiapas region.¹⁷ This physician, as well as members of the local Mexican institution, felt that the huge amounts of time and energy spent trying to get the ICBG project moving forward were disproportionate, given the poverty of the region and the needs of the population, such as treatment for local endemic diseases of poverty. “Although he insisted that he had nothing against [a US researcher] or his research prior to the ICBG Maya project, [the physician] added that he sometimes thought the whole thing ironic. How could researchers come to Chiapas and listen to people for years, and then try to re-package what they learned to those very same people?”¹⁸

The issue of the adequacy of local representation was one of areas that led to objections by the local and external groups. The Mexican research partner, after engaging in government-mediated negotiations with the healers’ group in an effort to resolve the controversy,¹⁹ published a commentary in a major national newspaper, analyzing the pitfalls of ICBG experience, and reaffirming its commitment to developing fair agreements with indigenous communities.²⁰ While describing the Maya ICBG as a project in evolution, the statement reflected frustration about the impasse between the project’s supporters and detractors:

“Aside from the fact that the non-indigenous advisers of [the healers’ consortium] have systematically sought, in a variety of forms of mass media, to denigrate [the Mexican research institution] and its objectives of participating in this project, our desire has been to promote dialogue and information exchange, thus avoiding the addition of a new conflict to the already deteriorated social fabric of Chiapas.”

The Mexican research institution’s document announced that bioprospecting permits would not be further pursued by the ICBG project until socially accepted legal requirements were put in place by the government, and until a self-organized, representative indigenous organization joined the ICBG Maya project as full partner.

The charge of inadequate Mayan representation was also made by outside NGOs. The NGO that challenged the project protested the design of the Maya ICBG on the grounds that many in the Maya community opposed the project, and that outsiders, they alleged, were making decisions for the indigenous people:

“Neither well-meaning anthropologists nor civil society organizations can make decisions for indigenous peoples; nor can outsiders appoint organizations to determine who will legitimately represent the interests of indigenous communities.”

The document from this NGO also makes reference to the lack of formal legal protections for indigenous communities: “Equity-based bioprospecting is a myth in the absence of regulatory mechanisms that safeguard the rights and interests of farmers, indigenous peoples and local communities.”²¹

There seems to be some difficulty in coming to agreement about the best ways to protect the rights and interests of indigenous groups. On the one hand, including indigenous groups in intellectual property benefits is meant to be a fair way to compensate these groups for their contribution to useful knowledge. On the other hand, the involvement of commercial entities and the logic of intellectual property law may arouse suspicions of exploitation or disrespect. Is this due to a fundamental philosophical difference regarding uses of knowledge, or is it a

misunderstanding? Mashelkar, while recommending that continued efforts are needed to reach appropriate benefit-sharing models, comments on the challenges of divergent cultural views:

"The existing IPR systems are oriented around the concept of private ownership and individual innovation. They are at odds with indigenous cultures, which emphasize collective creation and ownership of knowledge. There is a concern that IPR systems encourage the appropriation of traditional knowledge for commercial use, and that too without the fair sharing of benefits of the holders of this knowledge. They violate the indigenous cultural precepts by encouraging the commodification of such knowledge."²²

There is disagreement even about what particular ethical issues are most critical in this case. Is it primarily about the need to define informed consent at the community level? About the potential for exploitation of indigenous knowledge for the benefit of others?

About the capacity of these endeavours to actually make a difference in community development? About the need to respect cultural norms in disadvantaged communities? About the interference of external private organizations in agreements between researchers and community members? About the degree of protection provided under current Mexican National law or under international contract law? Discussion points for these questions are included in a separate document.

Discussion Group Questions

The lack of consensus about the Maya-ICBG project extended to a lack of agreement even about what ethical concerns were really at stake. Was the major ethical problem about consent, about intellectual property rights, about governance and decision-making, about the negotiation and planning process for research, about the objectives of the research, the design of the project itself, or a combination of some or all of these issues?

One way to think about these issues is to consider them as "nested" in the following way: if one starts with the supposition that a research project must have valid aims in order to be ethical, defining the aims of a project may be the first step in examining its moral worthiness—if it fails this test, specifying procedures relating to the ethical conduct of research will fail to address the gap. One of the aims, for example, which might be necessary, although not solely sufficient, is the advancement of the interests of local indigenous groups in a research project. If stakeholders agree that a project has morally acceptable aims, they may address the question of what project design will fulfill those aims, and the conditions under which the project can be ethically carried out. Among those conditions are the arrangements for partnership, consent, and benefit sharing.

There are nations where minority populations may be economically and politically disadvantaged relative to other national and foreign groups. Their knowledge, resources and other capacities can sometimes be critical for benefit-oriented, multi-partner research. In such research, each partner needs to have a voice in the research process, and to be accountable to the other partners, but the influence of various partners, and the degree to which each can hold the others accountable, may be quite asymmetrical. What kinds of measures are needed to allow indigenous groups to effectively promote and advance their best interests within bioprospecting projects? What kind of measures are needed to make these interests a significant factor in defining the project's goals, pace and procedures, while allowing for all stakeholder interests? In attempting to answer these general questions, it may be useful to consider the following issues.

1. Partnership. To what extent does the notion of "partnership" in research imply joint decisions about goals of research, minimal conditions for initiating research, research design, or determination of the nature of benefits to be sought, as well as a share in whatever benefits emerge? How can each partner be held accountable to the others, especially given that organizations and communities are composed of individuals representing a diversity of perspectives?

2. Governance and consent. What kind of conditions of governance or community representation need to be present in order to negotiate agreements, if any? When asking communities to participate in research, how can one determine the enumeration of relevant communities and their boundaries in the process of seeking consent and formalizing agreements?
3. Ownership of knowledge. How can it be determined what kind of knowledge exists in the public versus private domain, in communities where knowledge and property are held and transmitted via traditional cultural practices, rather than Western-defined intellectual property practices? How can competing accounts and views on ownership of natural resources and communally held knowledge be harmonized in the context of research? Are patents and formal intellectual property protections helpful, or a hindrance?

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- ² Harvey N. The Chiapas Rebellion: the Struggle for Land and Democracy. P. 164. Duke University Press, Durhan, 1998.
- ³ <http://www.globalexchange.org/countries/mexico/SanAndres.html>; page last updated Jan 20, 2004.
- ⁴ Ronald Nigh describes some aspects of Maya healing: "The Maya do not sharply dichotomize between 'organic' and 'supernatural' causes of disease—all sickness has both aspects, though in varying degrees, and both aspects must be treated if the patient is to be cured. Anyone can apply herbs or drugs, but if the nonorganic aspect is too strong only a j'ilol [shaman] can heal." Nigh R. Maya medicine in the biological gaze: bioprospecting research as hearbal fetishism. *Curr Anthropol.* 2002, Jun 3;43(3):459.
- ⁵ Garrity GM, Hunter-Cevera J. Bioprospecting in the developing world. *Curr Opin Microbiol.* 1999 Jun; 2(3):236-40.
- ⁶ Pollack A. Biological products raise genetic ownership issues. *The New York Times.* 1999 Nov 26; Sect. A:1 (col. 1).
- ⁷ <http://www.biodiv.org/programmes/socio-eco/benefit/bonn.asp>
- ⁸ Article 87 and 87 bis of General Law of Ecological Equilibrium and Protection.
- ⁹ The National Institutes of Health, the National Science Foundation, and the Department of Agriculture
- ¹⁰ The goals of the ICBG program are described at <http://www.fic.nih.gov/programs/oecdub.html>. The three main objectives are: "1) improve human health through discovery of natural products with medicinal properties; 2) conserve biodiversity through valuation of natural resources, training and infrastructure building to aid in management; 3) promote sustainable economic activity of communities, primarily in less developed countries in which much of the world's biodiversity is found."
- ¹¹ There were plans to elect representatives from each of the participating Maya communities to serve on the PROMAYA board; however, this stage was never reached.
- ¹² Berlin B, Berlin EA. NGOs and the process of prior informed consent in bioprospecting research: the Maya ICBG project in Chiapas, Mexico. *Int Soc Sci J.* 2003 Dec; 178:629-38.
- ¹³ Nash R. Who benefits from biopiracy? *Phytochemistry.* 2001 Mar;56(5):403-5.
- ¹⁴ Rosenthal JP. Politics, culture and governance in the development of prior informed consent and negotiated agreements with indigenous communities. In press 2004.
- ¹⁵ Hardison P. PIC/PIA Part II: ICBG-Maya: a case study in prior informed consent. *The Monthly Bulletin of the Canadian Indigenous Caucus on the Convention on Biological Diversity.* 2000 Nov; No. 16. From website: http://trade-info.cec.eu.int/civil_soc/documents/meeting/me-4-trips_c07.pdf.
- ¹⁶ Belejack B. The professor and the plants: prospecting for problems in Chiapas. *The Texas Observer.* 2001 Jun 22. Feature section.

¹⁷ Nigh R. Maya medicine in the biological gaze: bioprospecting research as herbal fetishism. *Curr Anthropol.* 2002, Jun 3;43(3):451-77.

¹⁸ Belejack B. The professor and the plants: prospecting for problems in Chiapas. *The Texas Observer.* 2001 Jun 22. Feature section.

¹⁹ Tripartite Negotiation Table, Agreement of June 30, 2000. COMPITCH: Juan Ignacio Dominguez, Esteban Ordiano, Ana Valadez; ICBG-Maya Ecosur: Luis Garcia, Eduardo Rubio; SEMARNAP-INE: Josefina Bravo, Arturo Argueta, Andres Ortiz. ACCORDS AGREED UPON BY ICBG-MAYA, ECOSUR, COMPITCH, SEMARNAP AND INE. San Cristobal de las Casas. Published in *La Jornada* July 18, 2000.

²⁰ Luis E. Garcia Barrios, Mario Gonzalez Espinosa. ECOSUR AND THE BIOPROSPECTION PROJECT ICBG-MAYA EN CHIAPAS. San Cristobal de las Casas, Chiapas, published as a paid editorial in *La Jornada*, October 28, 2000.

²¹ The ETC Group, formerly RAFI. US government's \$2.5 million Biopiracy Project in Mexico Cancelled. 2001 Nov 9. News release. From website:

http://www.etcgroup.org/documents/news_ICBGterm_Nov2001.pdf

²² Meshelkar RA. Intellectual property rights and the third world. From website: http://sustsci.harvard.edu/ists/TWAS_0202/mashelkar_undated.pdf. Mashelkar goes on to describe a successful benefit-sharing arrangement with the Kani tribe in Kerala state, India, in which 50% of the license fee and royalty were shared with the tribal community. "The prime concern of the tribals in the beginning was to evolve a viable mechanism for receiving such funds."

Discussion

Rapporteur:

We felt that this was a unique case and regretted that the project was cancelled when other projects, with a worse background, have succeeded. Although it would be ideal to discuss private-public ownership issues before a project is launched, this is very difficult in real life.

Our discussion of partnership focused on the Maya's motivation for being involved in this project. The project was initiated by researchers who then sought to convince the community of its value. However, although they were successful in explaining that regional knowledge would be conserved, they failed to convince the community that benefits would be relevant and fairly shared. The stratification of the community meant that the most politically involved were also those with the most knowledge of the project and resulted in a dislocation of the consent process.

A major dilemma centered on the ownership of knowledge, that is, whether the knowledge was owned by the healers or was owned by the whole community and simply held in trust by the healers. Given the key role played by the healers, it is clear that they were not sufficiently involved in project discussions.

The question of benefit rights arises even when partnerships have been developed. In this case, it was unclear whether the benefits would go to the people who would use the knowledge, the community, or the community stakeholders, that is, the healers. The presence of a profit-driven pharmaceutical company must also be considered. One practical answer would be to say that, as healing techniques are used throughout the community, the whole community should benefit from any products which are developed.

The role of the national government is also important. In Chiapas, the Ministry of the Environment was central to the project and the government also stepped in as a mediator when opposition developed. Unfortunately, by this stage, support had already been lost and the government's capacity to act had been severely reduced.

This case shows the importance of involving all key stakeholders and the difficulty of doing so. (Although a universal solution is practically impossible given the different dynamics of different

communities, it might be possible to develop a generalized process which can be adapted to individual circumstances.

On the subject of 'public' knowledge, it would seem that when nothing is formally in the public domain, the government should always play a mediating role in negotiations.

Comment:

I will retain several things from our exchanges. First, we talked about the conflict of trust problem, which is associated with plurality of interests and logics of exchange. This set of elements corresponds to an economic translation of the notion of exchange and sharing. Also, within this complex network is the definition of the concept of a community's heritage and universal heritage.

We also dealt with the plant property issue. We came up against the following question: can a human being really claim plant property for him/herself insofar as plants are living organisms? We then proposed a number of paths for reflection. The first of these paths deals with the issue of heritage. Heritage must be considered as a pension to be paid to know-how. In fact, it would seem preferable to attach rights to the production of know-how than to declare this or that plant the property of such and such laboratory.

The issues of heritage and therapy must, in other words, be centered on the subject (the taking charge of individuals), and not just on the object (the active substance).

It would furthermore be a good idea to avoid any prioritisation of medicine and, on the contrary, to develop a balance between conventional medicine and modern medicine.

These various reflections led us to conclude the following: it is necessary to plan for international arbitration, in order to balance the discussions between the different partners. This arbitration should favour a knowledge-sharing ethic, of its source and the properties and patents that result from it.

Comment:

Our discussions focused on ethical issues which arise when groups with different goals, objectives, and knowledge systems interact.

It is vital to respect and acknowledge the history and cultural and traditional context in which a community operates. Most of the problems which arise are less to do with access to plants, and more to do with access to knowledge about plants. These communities are often resource-poor and tend to have suffered a history of exploitation and disenfranchisement; they recognise that their knowledge is of value to others. Transparency is required if trusting relationships are to be built with these stakeholders.

It was noted that indigenous people are rarely questioned about their own ethical and moral position in such situations. If the case arose that a plant in developing country A could be of medical benefit to developing country B, and A refused access to the plant, whose ethical system should take precedence? On this basis, we considered whether anyone has the right to walk into a pharmaceutical company and take, without asking, drugs which would be of use in developing countries or to tackle neglected diseases.

We feel that there is a need to work towards the goals of indigenous people as well as research goals. Community issues and processes must be understood, appreciated and respected.

Comment:

We greatly appreciated the clear, non-partisan presentation of this case as it enabled us to make an objective examination of the topics involved.

Our workshop began with a discussion of partnership. We felt that the central lesson is that a partnership must start with a shared vision of common goals, otherwise it will never be a partnership but will only be a collaboration or joint venture. Furthermore, it is unrealistic to seek a partnership in a non-functional community such as the Maya community, which had a high level of political instability and a recent history of war. Researchers should be pre-warned that such societies will not make good partners unless in very unusual circumstances. Political instability was a contributing factor to the breakdown of the project. The proposal was presented to a people who have been disempowered for years, if not generations, and whose only power is negative. They used their negative power to pull down what had already been set up.

Ethical protocols do not take sufficient account of the time required for communities to understand and give informed consent to proposals. Grant-making bodies operate on a six- or twelve-month schedule whereas communities operate far more slowly than this. It would be helpful if funding bodies recognised that not only that community consent is necessary, but also that it is a consuming process.

There are three important players in the sphere of governance. First we considered NGOs. Although there are diverse opinions on NGOs, they are recognised as increasingly important partners. This has led to the phenomenon of 'NGO shopping', whereby community involvement is obtained by approaching the NGO which is most easily accessible or most likely to give its approval. Such tactics can result in problems with accountability, as approval might not be legitimate, and could cause the failure of a project. Furthermore, NGOs often represent those local communities which have no legal status in their country.

Research funding bodies are important to governance. In the Maya case, the project was imposed on the community without a prior shared vision. It was felt that allowing the community to create a benefit sharing vehicle would help to make them participants in the research and would provide them with a positive role.

International law also has a significant impact. While the CBD gives rights to indigenous communities, it does not define them adequately. A formal structure or definition would simplify matters.

Our discussions of ownership centred on the definition of 'public'. Much of the Maya project related to compiling and consolidating information which was already in the public domain; However, it was questioned whether this information was truly public, or was actually 'collectively secret'. The concept of collective secrecy is used in intellectual property law to cover trade secrets which are known only by a selected number of people. It might be useful to make this distinction in similar cases, for example, when it is necessary to distinguish between the knowledge of traditional healers and that of the general public. We also considered the fact that concepts of 'public domain' differ among communities.

In addition to ownership of knowledge, the ownership of the project must also be defined. Interests accrue when millions of dollars are invested in a project: even in developed countries, researchers sometimes feel that there is more scope for co-ownership.

The good intentions of the principal investigators were recognised throughout our discussions as was the fact that, unfortunately, good intentions are not enough.

Chairperson:

Thank you for these summaries. Before we take questions, I would like to make two brief comments. First, it is incomprehensible to me that research should be conducted in areas of political instability, particularly when the research does not relate to an emergency health situation. I cannot see how political instability is in any way conducive to informed consent. The question of where research should and should not be conducted would be an interesting topic for

further discussion.

Secondly, there is a difficulty with decision-making when contradictory opinions exist within the same community. It appears that major public relations exercises may be required to avoid one group sabotaging a project for strategic reasons and that it is vital to involve all stakeholders, including those who are not directly involved, if it appears that they might be tempted to veto involvement. We should remember that, even in relatively unsophisticated, uneducated communities, there are great capacities for lobbying and negotiating.

I would just like to remind you of the position of a famous French anthropologist, Marc Ollier, who distinguished French anthropology from the Anglo-Saxon current by radically differentiating between phytotherapy and ceremonial medicine. According to this anthropologist, conventional medicine is a complex assembly that blends ceremonial medicine and pharmacopoeia. Despite the benefits often brought up by research, the inevitable outcome is the disappearance of conventional medicine and, predictably, the community, of which healthcare is one of the bonding elements.

Comment:

The notion of community, very present in the South but less present in the North, is tending to disappear. I would however like to draw your attention to a tendency brought up by an eminent researcher during a symposium recently held in Lyon. This colleague emphasized the increasing weight of patient associations in the decision-making process. Since the beginning of the AIDS pandemic, patients in the United States and Europe have become more and more associated with research policy assessment. In spite of the individualist reputation of the countries of the North, this "community" effort can constitute a meeting point between the North and the South.

Comment:

Allow me to go back over the difficulty of adopting an approach that combines conventional medicine and modern medicine. Let's not forget that modern medicine is a product of conventional medicine. This parentage does not allow us to talk about opposition or even reciprocity: it would be more appropriate to think about the most equitable arbitrage possible, one that would allow for the espousal of parallel approaches between conventional medicine and modern medicine. Actually, it would be a good idea to provide one and the other of these two forms of medicine with the means by which to develop.

The need to maintain these two forms of medicine leads us to the question of heritage. What is heritage and to whom does it belong? I say knowledge belongs to a heritage that must be shared. Heritage is specific to communities that possess centenary, even millenary, and traditional know-how. The implementation of some form of arbitrage should allow for knowledge-sharing and the parallel development of know-how in modern and conventional medicine, without which the latter would disappear.

Comment:

The fraternal community can be contradictory. I would actually like to react to Francois Hirsch's intervention, which mentioned the emergence of communities of the sick. This tendency has been confirmed since the entry into force of the Act of March 4, 2002 on the rights of the sick. This type of association does not constitute a community of shared interests but rather a community of personal interests, which often amounts to a lobby. Meanwhile the management of lobbies collides with the democratic management of access to healthcare: it is appalling to imagine that we would privilege healthcare access to the most influential communities. The politicisation of health issues, which dates back to the 1980's and the development of AIDS, is an essential part of our debate.

Furthermore, the debate on natural medicine (that is conventional medicine) leads us to question its intrinsic values, and thus to oppose this "anthropologic" value to the commercial values that biomedical science allows for the exploitation of its knowledge. This debate on values must, for example, lead us to ask the following question: what right does a universal and anonymous biomedical science, governed by commercial interests that go against the rules of community, have to contest the role of the conventional doctor?

I suggest we go back to the discussion on the concepts of ethics. Justice and equity are fundamental issues. A number of developing countries are going through a crisis of interests that threatens their future. In this context, what about virtual conventional knowledge compared to scientific knowledge, which is likely to help these populations survive? In present day France, science is more and more criticized and its integration in community life is challenged. The countries that do not question the sense behind their biomedical practices are in the process of challenging the democratic idea itself.

Comment:

It is important to recognise that communities can be defined on many different levels. In Malawi, many people would say that community is more a question of locality than a political or social construct. Often, an indigenous community may, in fact, be better represented by a long-standing artificial community which has developed over time.

Secondly, I would like to question the level of benefit and risk assessment which was undertaken in the Maya case. A case study in Malawi has shown that introducing modern medicine to traditional communities can have a destructive effect. The community's trust in traditional medical methods is eroded with the arrival of modern drugs and techniques, but there is insufficient access to modern medicine to meet all of the community's needs. Was this issue considered in the Maya case?

On the subject of governance, I believe that the Mexican government was not in a position to represent the Indians as the Indians were not represented within the government. Although the Mexican government is democratic, it may fail to achieve the standards necessary for accurate and honest representation of an indigenous minority group.