

## AVENUES FOR REFLECTION ON THE ETHICS OF KNOWLEDGE SHARING

AT WHAT POINT SHOULD RESEARCH-GENERATED KNOWLEDGE BE TRANSFERRED?

CAN PRELIMINARY RESULTS BE TRANSFERRED?

WHAT ARE THE RESPECTIVE RESPONSIBILITIES OF RESEARCHERS, KNOWLEDGE BROKERS, AND DECISION-MAKERS IN THE DECISION-MAKING PROCESS?

HOW CAN THESE PRACTICES BE BETTER SUPERVISED, AND SHOULD THEY, IN FACT, BE SUPERVISED?



The practice of knowledge sharing raises a number of ethical issues for which there are no ready answers. This is why the Québec Population Health Research Network (QPHRN) organized a colloquium during the May 2007 ACFAS convention, bringing together ethicists, population health researchers, decision-makers and interveners working in knowledge sharing, to discuss the ethical issues surrounding the ways in which decisional and interventional settings make use of research.

Three general conclusions resulted from the colloquium. This edition of the PopHealth Notes series presents these conclusions as approaches that could enrich current thinking on the topic.

## CONCLUSION

# 1

## Knowledge sharing involves numerous challenges

*Knowledge sharing is most often understood as a strategy for solving problems.*

Knowledge sharing aims at helping decision-makers arrive at informed research choices. It is meant to stimulate organizational innovation; give citizens greater access to research results; and enable community organizations to transform these results, over time, into strategies for action. Yet although knowledge sharing leads to remarkable knowledge exchanges, it also introduces sizeable difficulties for those involved. It requires researchers, stakeholders, decision-makers and journalists to step outside their comfort zones. The involvement of previously excluded non-university stakeholders in the research process tends to shake up current practices. This is why the colloquium's speakers stressed the importance of addressing the new demands that go along with knowledge-sharing practices.

The accounts below, given during the colloquium by a researcher, a knowledge broker and a decision-maker respectively, concretely illustrate the ethical issues faced by these three players.



JOANNE OTIS

### A RESEARCHER'S EXPERIENCE

Joanne Otis, a professor in UQAM's Department of Sexology and Chairholder of the Canada Research Chair in Health Education, explained that the main ethical issues facing researchers engaged in the knowledge sharing process involve negotiating and sharing responsibility with research users. She particularly referred to the matter of the rights and powers of both these sets of players with regard to research data; possible biases towards certain communities; and, above all, the risks run by each group of actors. In her view, compromise is a necessary element of the knowledge-sharing process, because it sparks synergy between the imperatives of science and urgent community needs.

Ms. Otis also spoke about the additional workload inherent in knowledge sharing as well as its impact on researchers' careers. Participation in community activities and in one-off media interventions takes time away from the production of scientific articles. Her own experience as a researcher in the OMEGA study, which was conducted in conjunction with Montreal's gay community and community organizations and clinical stakeholders, also made her aware of the fears engendered by knowledge sharing (for example, the fear of disappointing the target community); the high degree of investment required; and the moral obligation to continue the relationship with research users once a study is over. Ms. Otis expressed her conviction that, despite these difficulties, the OMEGA study could not have been carried out without formal community involvement and without the nurturing of links of trust and reciprocity with those participating in the research project.



GINETTE BOYER

### A KNOWLEDGE BROKER'S EXPERIENCE

The aim of knowledge brokering is to create links between researchers and decision-makers in such a way as to facilitate interactions between them. The knowledge broker's role, which is still a new one, is to buttress the development of clinical and organizational practices, and increase the use of research-generated knowledge by means of science-popularization activities, animation and networking. Ginette Boyer, of Sherbrooke's CSSS-IUG, has worked in the field of knowledge brokering for the last several years. In her talk, she mentioned four issues surrounding a broker's role:

- 1) his or her professional identity;
- 2) the process of knowledge appropriation;
- 3) network building;
- 4) the popularization of knowledge.

In essence, Ms. Boyer sketched the challenges knowledge brokers face in working without the help of a well-defined skills profile; intervening in work overload or crisis situations; becoming personally involved in a variety of settings while at the same time remaining honest and impartial; and faithfully rendering researchers viewpoints without simplifying them or taking credit for them. In short, she said that transparency is essential to fulfilling a broker's duties, obliging brokers to remain alert for any shifting terrain with respect to their personal biases and values.



DENIS A. ROY

### A DECISION-MAKER'S EXPERIENCE

Denis A. Roy, Director of Information and Knowledge Management for the *Agence de la santé et des services sociaux de la Montérégie*, places ethics at the heart of any decision to invest in knowledge application rather than in services. Addressing this matter from the standpoint of the responsibility of health system managers towards the population, Mr. Roy maintained that a decision-maker's ethical involvement requires him or her to narrow the gap between what is scientifically recognized and what organizations actually do. In his opinion, implementing knowledge sharing in the network is, therefore, necessary for enlightened decision-making using evidence-based data, and that this imperative goes above and beyond organizational cultures, administrative constraints, or interest-group preferences. Mr. Roy also stressed that there are challenges that go along with knowledge sharing per se. One example he gave is that it is hard to identify the people who should participate directly in knowledge-sharing activities, since this decision involves political considerations.

### CONCLUSION

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### Several ethical viewpoints are valid

*In light of these challenges, an ethical question arises:  
how can we succeed in "getting it right?"*

The ethicists present at the colloquium agreed that the answer to this question lies in how each person understands the concept of knowledge sharing. Each definition has its own particular ethical emphasis, and each is as valid as the other. To illustrate this point, Dr. Hubert Doucet, a professor at *Université de Montréal* in Bioethics and Director of GREB (*Groupe de recherche en bioéthique*), and Burleigh Trevor-Deutsch, Director of the Ethics Office at the Canadian Institutes of Health Research, reviewed the most common definitions of knowledge sharing, demonstrating how each relates to a specific view on ethics. Their comments are summarized below.

### KNOWLEDGE TRANSFER

The term “transfer,” widely used in the field of knowledge sharing, refers to the communication of research results by the scientific community to those working in the field, for the purpose of improving the quality of life of potential users of these results. Knowledge transfer involves the ethics of experts, with those who know reaching out to those who do not know.

### DEMOCRATIZING KNOWLEDGE

This interpretation of knowledge sharing makes links with the community a fundamental precept. The focus is on each citizen’s right to access research results. Here, however, communication is still basically unilateral.

### KNOWLEDGE EXCHANGE

Knowledge exchange aims at solving problems through cooperative efforts between researchers and decision-makers. It functions through mutual learning that is continuously fed by research results. This process is based on collaboration and interaction which have at heart the equality of all stakeholders. Partnership is necessary here, as a right and a responsibility. However, citizen involvement is still not a part of this definition.

### CITIZEN INVOLVEMENT

The European Commission’s “dialogue workshops” provide the best illustration of this form of knowledge sharing. These workshops bring together researchers, decision-makers, non-governmental organizations and concerned citizens so that they can share, debate and assess the implications of research in terms of actions that have political impact. The citizen’s viewpoint forms the core of this approach, which is based on the values of equality, cogeneration of knowledge and participatory democracy. Moving beyond mere access to research data, the concept also involves recourse to several sources of knowledge, including the experiential knowledge of citizens themselves.

**One basic value transcends these four concepts:** the opening-up of the research process to potential users. This aim, however, in and of itself, is not enough to guide stakeholders when conflicts of interest or complex situations arise. When this happens, the practice of knowledge sharing enters unknown territory, and organizations tend to revert to the “trial and error” method.

*At present, we are learning as we go, with no guidelines, and it is hard to know whether we are doing what must be done **correctly and fairly.***

*Joanne Otis*

In view of the demands faced by researchers, knowledge brokers and decision-makers when practicing knowledge sharing, it is becoming vital to draw up clear and effective standards for guiding the work of each stakeholder.

## CONCLUSION

### 3

## Guidelines are needed

*The involvement of stakeholders in the research process must be planned and orchestrated, because it requires negotiation among all players.*

The more the model favours citizen involvement, the greater the need for guidelines. All the colloquium's speakers agreed that the time has come to build a standards framework based on managing these deliberations in order to guide the practice of knowledge sharing. Participants expressed the view that the creation of venues and mechanisms for exchanging views on ethical matters is proving to be one of the most promising avenues for supporting knowledge sharing. Managing such proceedings can take various forms and can be kept current by means of:

- formal arrangements or agreements in principle, clearly setting out the concerns of all parties;
- an independent entity, mandated to help players manage the uncertainties that may arise along the way;
- mechanisms enabling citizens to come into contact with researchers;
- rules requiring each granting agency to explain its ethical models on knowledge sharing in clear terms, so as to guide the actions of researchers and scientific organizations.

## What role does ethics play in this process?

Ethics helps us: probe the myriad facets of any problem issue; develop a critical point of view; and facilitate choices so that all players can peacefully coexist. More specifically, applied to knowledge sharing, ethics can contribute to stimulating collective thinking about each player's responsibility, thus harmonizing relationships among players. The colloquium's participants stated that, among other things, ethics helps clarify the various parties' expectations and provide ongoing support for interaction between researchers and research users. In addition, if researchers do take practitioners' temporal and cultural constraints into account (and vice-versa), this will encourage researchers, decision-makers and those working in the field to better harmonize their pace of work. A gap has always existed between the logistics of knowledge advancement in the research community and the operational logistics guiding players in the field. In sum, players directly involved in knowledge sharing can only gain from including ethicists in their reflection processes. In this respect, the primary contribution this colloquium will have made is to give specialists in these two areas an opportunity to discuss these issues.



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QPHRN

Created in 2002, the Québec Population Health Research Network (QPHRN) is a network of approximately 600 researchers working in the fields of public health, population health, health care services, health policy and health and society. Its mission is to support research infrastructure, innovative, multidisciplinary scientific activities and publications, champion a new generation of young researchers by funding graduate studies, and foster knowledge sharing. Its ultimate goal is to identify, understand and act on the social determinants of health to improve the health of populations. The scientific director is Dr. Gilles Paradis.

Knowledge Sharing and Application Group

The *PopHealth Notes* series is an initiative of the QPHRN's Knowledge Sharing and Application Group (*Axe Partage et utilisation des connaissances*). The group's research mandate is to sensitize researchers, public policy decision-makers, central and regional managers, and local workers in the field to the findings of health and population research and the issues raised by them. The group's activities reflect a two-pronged role – supporting other research themes of the QPHRN and initiating new projects designed to increase the sharing and application of knowledge in population health. The group is composed of Pierre Bergeron (INSPQ [*Institut national de santé publique du Québec*]) and QPHRN), Marie-Claire Laurendeau (INSPQ and QPHRN), Pierre Joubert (INSPQ and QPHRN), Joseph Lévy (UQAM [*Université du Québec à Montréal*]) and QPHRN) and Karine Souffez (QPHRN).

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[http://www.santepop.qc.ca/acfas\\_e.asp](http://www.santepop.qc.ca/acfas_e.asp)

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