Maximizing Patient Value

Effective Involvement of Patients in Health Technology Decisions: What Does Best Look Like?

Workshop Summary

IHE INSTITUTE OF HEALTH ECONOMICS
ALBERTA CANADA

February 5, 2010
Matrix Hotel, Edmonton

EXECUTIVE SUMMARY

On February 5, 2010, the Institute of Health Economics hosted an invitational workshop on patient involvement in health technology decisions. Both in Canada and around the world, health systems are increasingly recognizing the importance of involving patients in the assessment of new technologies (drugs, devices and practices), as well as in decisions about which technologies are covered, who gets access, and how technologies are used.

The workshop brought together national and international experts, provincial stakeholders and patient groups, providing a forum to discuss patient involvement across local, national, and global contexts.

The workshop featured two keynotes: Dr. Karen Facey, chair of the **Health Technology Assessment International (HTAi)** Interest Sub-Group on Patient and Citizen Involvement and a leading international expert; and Dr. Marie-Pierre Gagnon of **the CHUQ Research Centre** at Hôpital St-Françoise d'Assise in Quebec, a leader in exploring patient involvement in health technology decisions at the local level.

Other speakers included Elaine MacPhail, who spoke to the development by the Canadian Agency for Drugs and Technologies in Health (CADTH) of a framework for patient involvement in drug reviews, George Tolomiczenko, who addressed the value of individual experience, and Cheryl Arratoon, who spoke about the role of patients and consumers in research through the Cochrane Network.

Through presentations and open discussion, several major themes emerged:

- **Patient perspectives are unique** – The experiential knowledge possessed by patients and their carers has an important role to play in decision-making, since only patients know what it is like to live with an illness. Patients are uniquely equipped to judge priorities and outcomes.
- **Patient involvement should have clear objectives** – Involving patients in good faith requires openness about how their input will be used, and all parties should be transparent about the goals of patient involvement processes.
- **The process for patient involvement should be suited to its goals** – There are many models for involving patients, either as individuals or through patient organizations. To maximize the value of patient input, the process for patient involvement should match the needs of both decision-makers and patients, who may require training or support to participate effectively.
- **Patient input can be a robust form of evidence** – To maximize its value to policy-makers, patient experience can be developed into rigorous and systematic qualitative evidence, which can be incorporated into technology assessments and health care decision-making.
- **Patients can be involved at multiple decision points** – If patients are acknowledged as partners in the health care system, then they should be involved at multiple points, from technology assessment to decisions about coverage, access and utilization.
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Next Steps

Patients are the end users of most health technologies, and it seems clear that their involvement in decision-making will be increasingly important. Patient involvement is a process of open dialogue, and there is great value in creating spaces for ongoing discussion among policymakers, care providers, researchers and patients.

For more information on Patient Involvement check out the **Patient and Citizen Involvement Interest Group of Health Technology Assessment International (HTAi)** http://www.htai.org/index.php?id=85.

Also for **full presentations** from the **IHE Patient Involvement workshop** go to: Institute of Health Economics (IHE): http://www.ihe.ca/research/patient-involvement/

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"Conversations are good – let's keep having them."

– Dr. Karen Facey, Chair, **HTAi ISG** on Patient and Citizen Involvement

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AGENDA:

Opening Remarks
John Sproule, Senior Policy Director, Institute of Health Economics

International Approaches to Engaging Patients in Technology Decisions
Dr. Karen Facey, Chair, HTAi Interest Sub-group: Patient and Citizen Involvement in HTA

Introducing patient perspective in health technology assessment at the local level
Dr. Marie-Pierre Gagnon, CHUQ Research center, Hôpital St-François d'Assise:.

Patient Involvement in Cochrane Network:
Cheryl Arratoon, Canadian Cochrane Network and Centre, Ottawa, Canada,

Patient Involvement in CADTH:
Elaine McPhail, Canadian Agency for Drugs and Technologies on Health

Tapping patient's expertise
Dr. George Tolomiczenko, Executive Director of Research & Scientific Liaison, Crohn's & Colitis Foundation of Canada

Facilitated discussion:
- - Why should we involve patients in health technology decisions?
- - How can we maximize the participation of patients in health technology assessment?
- - Where and when should we not involve patients?
- - What are the barriers to effective engagement of patients?
- - What should governments, public agencies and professional societies do to enhance effective patient engagement?

Panel remarks:
- Jennifer Ellis, Director Patient Engagement, Alberta Health Services
- Dr. Karen Facey, Health Technology Assessment International
- Durhane Wong- Reiger, Consumer Advocare
- Dr. Doug Perry, Senior Provincial Clinical Advisor, Alberta Health and Wellness

Involving Patients in Health Technology Decisions

An invitational workshop sponsored by the Institute of Health Economics
Feb. 5, 2010 at the Matrix Hotel in downtown Edmonton

SUMMARY

Introduction

John Sproule, workshop moderator and senior policy director of IHE, began the day by saying that what is viewed as valuable health technology, and what health consumers want, changes over time. We need to accommodate the dynamic changes in health technologies in assessment processes. He also highlighted that there is a ongoing conflict between 'individualized' experience and 'generalizable evidence' that can be applied to whole populations. Work is needed to develop valid and methodologically sound ways to capture individualized experiences in 'evidence-informed' policy and practice.

Keynote Speaker: Dr. Karen Facey

Dr. Facey is chair of the Health Technology Assessment International (HTAi) Patient and Citizen Involvement Interest Group. She is also chair of the HTAi Policy Forum and chair of the NHS Resource Allocation Board for Scotland.

International Approaches to Engaging Patients in Technology Decisions

Dr. Facey said her interest group has been looking at how to robustly include patients in the decision-making process. Rather than seeking patient involvement, she said, the health sector should be encouraging patient participation, making the inclusion of patients a two-way process.

There is never a single patient, Dr. Facey said. For every disease or illness, patients have different beliefs and values, experiences of medical treatment, and hopes and dreams. All those factors affect the decision a patient makes about a treatment. The community the patient is part of , such as a religious group, can also be a factor.

Most health systems, said Dr. Facey, are based on a value of equity of access for all according to need. In the United States, access by the ability to pay is a core value. Even in the United Kingdom, however, other issues affect how care is provided, such as the principle of statutory financial accountability. Her health board in Scotland cannot spend more than its set budget. That's a challenge, because health systems face inflating costs from new treatments, better diagnoses and an aging population. Finally, public and patient expectations must be considered. All those factors must be balanced to try to attain best value for the most health gained, Dr. Facey said. That's not easy.

Health technology assessment is one way to try to meet those goals, she said. HTAi defines HTA as the research-based, practice-orientated assessment of relevant available evidence and knowledge on the direct and intended effects of health technology as well as the indirect and unintended consequences.

In Denmark, said Dr. Facey, HTA is done using four different categories: clinical effectiveness; cost effectiveness; patient aspects; and organizational issues. Around the world, the focus varies. In the U.S. the focus is on clinical effectiveness. Countries like the U.K. and Canada look at both clinical and cost effectiveness. However a health system does the assessment, it's trying to inform policy decisions and trying to make the decision-making more transparent, Dr. Facey said.

For patients, the process can seem quite complicated, said Dr. Facey. To help patients, Health Equality Europe has produced a guide called Understanding Health Quality Assessment. Patients have something important to contribute to the process, because only patients know what it's like to live with an illness. They can tell you about the intended and unintended effects of a technology better than anybody. Patients can explain what the burden of illness is. They can tell what outcomes are important and what they mean to their daily lives.

Dr. Facey said that when evidence on patient perspectives is included in decision-making, value judgments can be diminished and recommendations are much stronger. Some key concepts, she said, are that decision-making should have robust evidence about patient perspectives of the illness and the use of the technology, and patients should participate fully in the decision-making process.

The challenge is to make the patient evidence more robust, she said. It needs to be well planned, systematic, and reported in a clear way that shows any of the assumptions and the possible conflicts. Good qualitative research is needed that isn't just anecdotal.

While a systematic review can be done to look for studies that are already done, the main emphasis should be primary research, Dr. Facey said. Questionnaires can be used, but there are concerns whether they're robust enough. Individual interviews are an alternative, and focus groups can be incredibly valuable.

She gave an example from the Scottish Medicines Consortium (SMC), a body that advises the health system in Scotland about new prescription drugs. The consortium may do a rapid review of a drug, making a decision within eight or 12 weeks. That leaves no time to set up focus groups, so you have to do what you can in the available time, she said. In this case, a questionnaire was sent to patient groups, asking about their experience of current technologies and where they felt the unmet need is. That's been very helpful, Dr. Facey said.

When you're asking a patient organization to fill in a questionnaire, she said, give some guidance. Often you're asking them to do this for no money within a short period of time. That's where the new Health Equality Europe guide could be helpful to patient organizations, said Dr. Facey. It gives an idea of what groups might want to describe about a technology – benefits, side effects, difficulties of use.

Dr. Facey described an HTA involving diabetic retinopathy. The HTA looked at an annual screening process for diabetic retinopathy, and evidence emerged about what works, and doesn't work, to get people to return for screening. Sending more than two reminders didn't work, for instance.

In focus groups, researchers heard that patients didn't really see the importance of the screening and needed more information. Also, they didn't want to have their screening test one day and their feet looked at the next week, and asked for better coordination of such tests at the clinics.

As well, there were very strong opinions that people didn't like getting eye drops when they got their eyes tested. "That remark actually changed our whole assessment," Dr. Facey said. In fact, one island clinic had 97 per cent of patients returning for their annual check, because that clinic didn't give eye drops. Her group ended up setting up a testing service where eye drops were not needed except for particular cases.

Dr. Facey said it's important to think why you want to involve a patient, and what you want to get back. Are you merely informing them about something, or are you consulting them? If you consult, you must give them feedback on what they've said. You must also consider their concerns thoughtfully. Eventually, she said, she'd like to see a collaboration in which patients aren't merely offered a possible solution, but are partners in looking for solutions.

Dr. Facey cited research that rheumatology researcher Prof. Sarah Hewlett of Bristol University has done with a man with very severe rheumatoid arthritis. The man said that the outcomes that have been measured in rheumatoid arthritis that have led to drug authorization are not the right ones. He said he can live with the joint immobility but not with the fatigue, which means he cannot go to work.

This man has been frank about in saying that participating in such HTA discussions was quite daunting at the start, because often you're put in a room with professionals like doctors and senior managers. We need to treat such patients with respect, Dr. Facey said, and to support them.

Dr. Facey cited five principles for patient involvement:

1. If you're involving a patient in a deliberative process, you need to facilitate their involvement. Think about how they can be involved and what their contribution can be.
2. Identify appropriate projects for them to be involved in, and potential partners.
3. Foster an ethos of respect for what the patient is saying. The chair of the process needs to be trained in how to involve the patient appropriately in the discussion.
4. Support the patient, perhaps with a mentor or buddy. There is talk in the United Kingdom of requiring at least two patient members on a committee, so they can support each other.
5. Patients need the competencies to be able to contribute.

She said HTAi has produced a consumer and patient glossary to help demystify the language around health technology. Researchers should connect with patient organizations, tell them what they're doing and how they can be involved, said Dr. Facey. They can help select questions, help define outcomes, and help define the mathematical and economic modelling. They can get involved in qualitative research, and can even commission research – for example, searching their own data bases to get information about their population profile, or handing out a questionnaire to patients to ask their experience of a drug.

Patients can also help assess evidence, and assist in consultation. They can help develop patient communication and disseminate HTA results. And they can certainly help us to understand how better to interact with patients, said Dr. Facey.

Dr. Facey said more work is needed on the methods for qualitative studies, because they are quite challenging. She and her colleagues hope to create a toolkit to support any agency that wants to involve patients in their deliberative process, whether it's HTA or clinical guidelines.

She said every HTA report should have a separate section on patient issues. As well, greater transparency in decision-making is needed, to show how all forms of evidence have been judged. Finally, said Dr. Facey, there's a need to spend money on qualitative research of patient issues. If we did, she said, we would get quite different decisions coming through.

Keynote Speaker: Dr. Marie-Pierre Gagnon
Dr. Gagnon is a researcher at the CHUQ Research Centre at the Hopital St-Francois d'Assise in Quebec City, and assistant professor of nursing at Laval University.

Introducing Patient Perspective in Health Technology Assessment at the Local Level

Dr. Gagnon is involved in a research project at Laval University that involves a systematic review of introducing patient perspectives in HTA. The province of Quebec has created HTA units – known as HTAUs – at the four university hospitals in the province, at Sainte-Justine pediatric hospital, and at the institute for physical rehabilitation. Most of the HTAUs are also responsible for covering their region – for instance, the one at Laval University in Quebec City is responsible for eastern Quebec. Dr. Gagnon said the research will focus on patient participation and perspectives, but will look as well at citizen involvement.

There's a general consensus on the importance and the need for more patient involvement in HTA, she said. But decision-makers want to know what the impact of such involvement will be, and how to involve patients and public in an efficient manner that will really make a difference. Dr. Gagnon's research team began its work in November 2008. Their goal is to explore how patient perspectives can be introduced into the work of the HTAU units at the local level. The research proposal was built in collaboration with the decision-makers, which took time, she said.
So far, Dr. Gagnon said, researchers have just finished the systematic review of literature, gathering the international experience of patient participation in HTA activities. The study will look at strategies to involve patients in HTA activities, especially at local levels. Finally, a consensual framework for Quebec will be created on how to engage patient participation in local HTA activities.

For the systematic review, the team looked at published experiences and grey literature published between 1980 and 2009. They looked for empirical research involving the participation of patients or members of the public in HTA. If the research had looked only at patient participation, she said, there would have been little research to include. The team found no research on experiences of patients with HTA at the local level.

Starting with 1,400 studies, the team finally included 24 studies, 22 of them published in scientific journals and two from reports in grey literature. Of the 24 studies, 13 were from the UK, three from the United States, three from the Netherlands, and one each from Canada, Australia, New Zealand, Denmark and Germany. Most were published since 2000, showing how new the topic is in the scientific literature.

The studies they found primarily looked at assessing patient preferences and perspectives regarding two alternative technologies or different modalities for dispensing or organizing health services. Also common was an assessment of a specific technology. Some studies looked at the process itself, on how to involve patients.

Most of the studies used qualitative methods. Dr. Gagnon said she agreed with Dr. Facey that we need to develop those methods, so we know which work best. Next steps in the Quebec study, said Dr. Gagnon, will be doing interviews with HTA producers, hospital managers, health care professionals involved in HTA, and patient representatives. The team plans to conduct about 30 interviews across Quebec. Then it will propose a set of strategies for considering the patient perspective in HTA. That proposed set of strategies will be discussed in the fall with a group including hospital decision-makers, HTA producers and patient representatives. She said the team hopes to implement the strategies at the HTAU at Laval University and assess the effects. How can involving patients benefit the health of patients and the public?

Question and Answer Session

In a question-and-answer session, Dr. Facey talked about the use of new media like websites and blogs to hear about patient experiences. She said she was involved in a paper in Australia where weblogs were reviewed to learn about aboriginals' views of diabetes. The blogs were used as a sort of community forum, and they contained the views of teenagers who are often hard to get involved in focus groups. There's an ethical question around whether it's appropriate for researchers to use material that was put on a website for a patient group, she said. However, new information technologies give all sorts of opportunities that researchers must be aware of.
Dr. Facey was asked how one reaches the point where patient input is accepted as a vital part of the health technology process. She said that in Scotland, she has seen health professionals who started off dubious and now want to involve patients in everything – even the design of hospitals. Collaboration requires trust, she said. She said if a new technology is being assessed, it's better to ask patients about their experience of living with the illness rather than their view of the new technology, which they may not have seen.

Durhane Wong-Rieger, the head of the Consumer Advocate Network and a member of the audience, said that patient groups welcome the chance to participate more in HTA. HTA agencies are the gatekeepers to new treatments, she said, so patients need to become owners of that process. Dr. Facey said that she's interested in new work on developing patient decision aids. Spain is doing research on providing a decision aid to patients, in which patients can work through their own values and, with their physician, come to a good choice. That's the next step, she said, to empower individuals.

Dr. Facey was asked when one should involve patients, and when to involve the general public. If you want perspectives about the illness, she said, you talk to patients. If you want to talk about how the health service is managed or organized, or how we set priorities, that's for the public or the citizens.

Speaker: Cheryl Arratoon
Ms. Arratoon is the knowledge broker at the Canadian Cochrane Network and Centre located at the University of Ottawa.

Patient Involvement in the Cochrane Network

The international Cochrane Network has had consumers – patients who are linked with a patient organization – involved since 1995, Ms. Arratoon said. It's a natural fit, because Cochrane is a very bottom-up organization that tries to help people make well-informed decisions about health care.

At least half the 10 working principles of Cochrane are relevant to including consumers in the work, she said. Most people involved in Cochrane are volunteers. They are passionate about their systematic reviews, which is why they're spending their time being involved. Cochrane likes to minimize bias by having multi-disciplinary teams, so the systematic reviews include a variety of perspectives.

The Cochrane Consumer Network (CCNet) is a virtual network composed of patients and a variety of consumers. It acts as a forum for connecting consumers among themselves, and for sharing reviews. Review groups can also use it to ask for input from consumers. Consumers are usually part of patient groups or individuals with a specific disease condition. There are about 132 consumers involved in Cochrane in Canada in different ways, and 427 internationally on the list serve.

Their main role has been to provide a patient perspective and give comments on Cochrane review protocols. They can comment when the review question is decided on and how the review will be done. They can give their perspective when they've experienced an illness under review – talking about the need to reduce pain levels or increase mobility, for instance.

Cochrane reviews also have plain language summaries attached, and consumers often write them or help write them. Consumers are linked directly linked to review groups, where they might be asked for feedback on questions – identifying relevant outcomes, or giving feedback on the plain language summary. Patients may be asked if the summary makes sense to them. Patient groups use the plain language summaries to inform their own members about results of the reviews.

Cochrane consumers help recruit other patients, Ms. Arratoon said. And experienced consumers may expand their role. In Canada two patients have become review authors, she said, working with a review team to produce a systematic review.

When they start out, most consumers are concerned that their math and science skills won't be up to the job of participating in reviews. Ms. Arratoon said they need training and support to give them confidence. Cochrane provides on-line training and tutorials, plus a variety of workshops for consumers. Such training is not yet a requirement, she said, so that's an area that needs to be worked on.

Ms. Arratoon said an external review is currently being done to look for ways to increase the value of consumer participation.

She said some review groups are reluctant to include consumers. If a consumer isn't prepared, there's a lot of handholding and mentoring that the group has to do, and that holds up their process.

Another issue is the language barrier, given that many patients around the world don't speak English as their first language. Finally there's the lack of a formalized process to give feedback to consumer about their input.

Speaker: Elaine MacPhail
Ms. MacPhail is a program advisor with the Common Drug Review in the Canadian Agency for Drugs and Technologies on Health.

Patient Involvement in the Common Drug Review
and the Canadian Expert Drug Advisory Process

CADTH has three core programs, said Ms. MacPhail. The HTA program provides advice on drugs, surgical procedures and other procedures through full HTA reports or rapid responses.

The Canadian Optimal Medication Prescribing and Utilization Service evaluates and promotes optimal use of drugs. It has just released a report on blood glucose test strips. The study found that in type two diabetics who are not on insulin, routine testing of blood glucose levels is not necessary. Periodic testing is adequate. They estimate that if the current practice changed to having periodic testing, there would be upwards of $150 million in savings to the publicly-funded drug plans.

The Common Drug Review is a national process to review clinical and economic information with regard to drugs. It also provides a formulary of existing information to all the participating drug plans. The drug plans make their own listing decisions.

The CDR reviews whatever the manufacturers submit to for review, said Ms. MacPhail. The review is of scientific and economic evidence of the drug, but there's always been recognition of the need for public input. There have been requests from patient groups and from industry to have patient involvement in our process. The House of Commons standing committee on health also recommended public or patient input.

In 2004 the CADTH board endorsed in principle that an examination be done of how to get patient or public involvement into the process, she said. A consultant prepared a report to provide some options, and the decision was made to take a staged approach. In 2006 two public members were appointed to the board of the Canadian Expert Drug Advisory Committee.

The next stage will be getting patient input into the drug review process. A working group was established, including CEDAC members, representatives from the drug plans and CDR staff. A review of literature was done, looking for an approach that could be adopted wholesale. "But we didn't quite find that," said Ms. MacPhail.

She said one objective is to have patient input coming early in the review process, not at the time of committee deliberation. Two provincial drug plans, those of B.C. and Ontario, are looking at having patient input in their process and were contacted to share ideas.

The agency has used several considerations in developing its approach:

- Patient input must be meaningful and must be incorporated into the drug review process in a meaningful way. It has to be meaningful to patients, who will want to see outcomes as a result of their time and effort. And it has to be meaningful and useful for the CDR.
- Patient information must be systematically included in the process, and incorporated early in the process – at the point of protocol development.
- Patient information must be considered in CEDAC deliberations and recommendations.
- Time frames must be respected. Stakeholders say it's important to stay on targets for time frames. Lengthening of time frames impacts patient access.
- The process should have limited impact on CADTH resources at this time, and should not duplicate patient involvement done by provincial drug plans.

A draft process for patient involvement has been prepared. It says:

- Patient information will be provided by organized Canadian patient groups. The agency doesn't the resources to review input by individuals, although it recognizes the value of individual patient input. Patients who would like to contribute their experiences to the CDR will be encouraged to get in touch with the patient group, and work through them.
- A template approach for getting patient input will be used, to facilitate submissions that are relevant to CDR and are quite consistent. The template resembles the Scottish Medicines Consortium template quite closely.
- A guidance document has been prepared for patient groups.

The template allows patient groups to describe their experience of the condition, their assessment of current drug therapy, and any adverse effects or problems accessing the medication. The template asks groups to comment on the drug being reviewed, since some patients may be in clinical trials. That last part may be changed, said Ms. MacPhail, since clinical trial experience is probably much different from a real-life situation.

Ms. MacPhail said there will be a page on the CADTH website for patient input. All drug submissions will be posted, along with the deadline date for patient groups to submit their comments. Patient groups as well as individuals will be encouraged to subscribe to agency bulletins so they will receive a blast email as soon as CDR has received a drug.

Patient groups will be asked to provide information about real-world experiences without giving personal or individual testimonials. The agency wants a representative description of the issues or views that people have about their condition or treatment. A collective picture of patient response is what's desired, at least for now.

Patient groups will have 15 days to provide input from the time the agency has received the drug. Information received from patient groups will be collated and summarized by CDR staff and then will be shared with CDR review team as well as CEDAC. All patient group submissions will also be attached. Information from patient groups will be shared with the provincial drug plans so they can use it in their decision-making.

The agency put this approach up on its website in December, and got a good response. The feedback contained kudos for making the move, but also concern about the short time frame, Ms. MacPhail said. "Everybody felt that 15 business days was too short," she said. There was also concern about the requirement that patient groups provide conflict of interest declarations. A lot of people are concerned that if they had got

funding from industry, it would preclude them from providing input to CDR. It won't, said Ms. MacPhail; it's just a matter of transparency.

There were some suggestions that the agency get input from other sources, like health care providers. Also, there were questions about how patient information will be weighted in any drug review. There's no answer yet to that question, she said. Finally, there was concern about how patient experience could be provided if testimonials weren't allowed.

Next steps, she said, will be to complete analysis of consultation feedback and adjust the process if it's required. The goal is to announce implementation in the spring of 2010, she said.

Speaker: Dr. George Tolomiczenko
Dr. George Tolomiczenko is executive director of research and scientific liaison for the Crohn's and Colitis Foundation of Canada.

Tapping Patients' Experience for Experiential Insight

Dr. Tolomiczenko cautioned against "banishing the outlier" in the new CADTH system of getting patient input. It would be a loss not to hear individual stories, he said. His foundation has a lot of patient involvement, with 65,000 supporters and 75 local chapters. It's incumbent on CCFC to participate in the CADTH call for input, he said.

One challenge for patients in CCFC is that there is too much information, on the Internet or circulating between patients, and it's hard for them to sort out. One patient group will have a theory about their disease and that's what explains it for them.
A new study in Alberta, now in the first year of five, is of environmental factors and inflammatory bowel disease, he said. It will include patient involvement.

Question and Answer Session
In the question session, Dr. Facey said a deadline for patient input of 15 business days will be a challenge. What the Scottish Medicines Consortium does to help is give an early indication of drugs that might be coming up for review. The question of whether to reimburse patient groups for their costs is also an issue, she said. In the UK, the government has said that patients should be reimbursed for their time and travel expenses to attend meetings.

Ms. MacPhail said CADTH doesn't plan to reimburse patient organizations for their participation. It's another thing to think about, she said. Dr. Tolomiczenko of CCFC said a large portion of a patient group's submission could be prepared ahead of time.

Cheryl Arratoon said 90 per cent of Cochrane collaborators are volunteers, but it's important to provide training and support.

Can individual patient experiences be generalized, as CADTH is suggesting? Dr. Tolomiczenko said it would be extremely hard to do so. Ms. MacPhail said it's necessary to be pragmatic; it would be hard to deal with hundreds of patient scenarios in a review of a drug for a large population. That's why CADTH is looking for trends in patient experience. Dr. Facey said the individual patient experience can be valuable as a sort of safety alert.

Reports from Discussion Groups (notes)

1. Why should we involve patients in health technology decisions?

    - It's the ethical thing to do.
    - Patients offer an alternative point of view, from those with experience of the disease.
    - Patients can better define outcome measures, why something works or doesn't work.
    - Decisions will be more consensus-driven.
    - Patients can help identify research gaps and priorize topics.
    - It will help close the gap between patients and the system.

2. How can we maximize the participation of patients in HTA?

    - Increase patient awareness of HTA as a process that matters to them.
    - Explore the use of social media.
    - Use plain language, encourage health literacy. Provide guides to help patients navigate the system.
    - Provide orientation and training.

3. Where and when should we not involve patients?

    - Include patients in all stages, but find the appropriate level of engagement.
    - Don't involve them if it's just tokenism.
    - Don't involve them if they are lobbyists for the pharmaceutical industry.
    - Don't involve them in situations where they don't have the capacities and skills to do the job.

4. What are the barriers to effective engagement of patients?

    - Language issues.

- Lack of awareness of how the system works, or the complexity of the system.
- Not all patients can speak for themselves.
- Lack of resources.
- Many patients do their own technology assessment and aren't interested in HTA.
- Patient experiences are not always valued or respected. Patient groups may be seen as having an agenda.
- Disrespect for common and traditional wisdom.
- Lack of belief that all participants are equal.

5. What should governments, public agencies and professional societies do to enhance effective patient engagement?
    - Ask patients how they can be involved.
    - Build expertise in including patients and provide resources.
    - Consider a broad sharing of information between patient groups.

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