UK Cochrane Centre

THE POWER OF SHARING KNOWLEDGE

Consumer participation in the Cochrane Collaboration

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Acknowledgments

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The power of sharing knowledge

Knowledge is power, according to Francis Bacon. Its force is clear in health care - in people's experiences with professionals, and in the science that aims to helps them. It permeates decision making processes at all levels.

Developing knowledge is the focus of the Cochrane Collaboration, and "ensuring access" is one of its guiding principles. That this includes public access has been explicit from the Collaboration's beginning. It is a principle that should be applied more broadly through the enterprise than simply to its products. Because the value of results is determined by the quality of the processes used to achieve them, "ensuring access" needs to refer to the means, as well as the ends.

When particular forms of health care are determined to be "ineffective", there is likely to be increasing pressure to abandon them. This could lead to a better use of health care resources. But it is also a value judgment, and it should not be made by professionals and service providers alone. Another of the Collaboration's guiding principles is "avoiding bias". That concern needs to be directed towards reducing the bias that comes from research professionals' determination of almost everything that counts in research - and most of what is counted as well.

Making research and information relevant to consumers cannot be done unless their needs become more central than they have been in the past. For the Collaboration to be oriented towards people's needs involves a shift in focus, and for researchers to develop new relationships with consumers. It is something which may well be as radical and far-reaching as the shift to more evidence-based decision making in health care. It seems to me that neither will succeed without the other.

The notion of collaboration between professionals and consumers is a complex one. My dictionary reminds me that one of the meanings of collaborating is "cooperating treacherously with the enemy". More positively though, it means working in combination to produce something. What is being produced in this collaboration is knowledge. If consumers and professionals share their knowledge, there is great potential for re-aligning health care relationships and improving the quality of care. This report suggests ways these aims might be carried forward in the Cochrane Collaboration.

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Focusing on People's Needs

What does it mean?

"Would you tell me, please, which way I ought to go from here?" said Alice.
"That depends a good deal on where you want to get to," said the Cat.
Alice's Adventures in Wonderland

There is widespread acknowledgment that a more deliberate focus on the people who are meant to be served by health care is needed, but often less clarity about how to go about it. Sometimes people jump directly to "how?" without first sorting out exactly what they are trying to achieve. While different concepts and diffuse motivations remain tangled together, solutions can remain elusive.

The aim of this report is to identify issues related to people's participation in the Cochrane Collaboration's complex web of activities. One of the mechanisms already being developed is the Consumer Network, which will provide a focus for consumers in the Collaboration (Appendix). This should not, however, be regarded as "the" way this endeavour approaches the broad spectrum of people's concerns.

Keeping consumers' needs central is a shared responsibility throughout the Collaboration, and individuals at all levels of the enterprise need to consider ways of achieving this overall goal. Different opportunities are likely to be seen from inside and outside the group. The primary task is to encourage and develop relationships between professionals and the communities they serve.

If this is to be more than window-dressing, public processes need to go beyond one-off exercises taking information from communities, or using community resources to promote and broadcast professionals' opinions. Communities' perspectives need to be integrated throughout the Collaboration's work, and the organisation's processes need to be open and accessible to public scrutiny and response.

Effective dialogue takes time and effort to build. Yet, an understanding of the perspectives of the people relying on health care services is vital to balance the judgments of those sharing the research and provider cultures. Specialists' views of the world are by definition unbalanced and incomplete. Professionalism creates distances from the rest of the population, and vests professionals with a variety of interests which may or may not be consistent with public interests. Processes which acknowledge this bias, and seek to redress it through public participation are necessary to help build a relevant body of work that is guided by the realities of people's lives.

Differing concepts of the public's roles

Just as services would no longer be a matter of one group determining things for another, so research would move beyond being the reconstruction of one group's views and experience into another's data[1].

People's participation has for some time been seen by many as a goal in and of itself. One of the first elements of the World Health Organization's (WHO) vision in primary health is that, "The people have the right and duty to participate individually and collectively in the planning and implementation of their health care"[2]. Community participation is one of the principles of the WHO's "Health for All" strategy. Participation is also one of the mechanisms used to achieve other specific goals, for example public accountability[3].

Acceptance and practice of an active partnership with consumers varies greatly through health care, policy, and research. It seems to be increasing at many levels, with developing areas such as consumerism and community development approaches in primary health. By the late 1980s, international health agencies were analysing hundreds of case studies of community participation in primary health care programs, and developing ways of evaluating its status[4]. Participatory consumer movements in health, often accompanied by legislative support, are now features of the health scene internationally. A study of health care systems in France, Italy, Spain, and the United Kingdom identified this as a growing trend in each of these countries[5].

The rationales for seeking community participation have been described as falling into three categories: to improve services and decisions, to gain legitimation and/or community compliance, or as a means of bringing about social change with the redistribution of power or resources[6].

Some of these aims, and the mechanisms used to try and achieve them, can be quite narrow. Others are more broadly inclusive. Consumer and community groups prefer the latter. They call for mechanisms and systems which are open, participatory, and indeed enabling and empowering for the participants. The contest to broaden processes and research in these ways sees different compromises achieved in various settings, usually with at least incremental movements over time.

The results across health care and research internationally, then, are highly variable. Take the example of consumer representation within committee structures. In the area of occupational health and safety, strong advocacy for workers in many communities has seen guidelines ensuring that management representatives do not outnumber employee representatives. In many countries, the chairperson of the occupational health and safety committee must be one of the workers' representatives as well[7].

In the area of health research ethics, at least some lay representation is required in most of the countries where guidelines formalise the area. In some countries (such as New Zealand), half the membership of research ethics committees must be lay people, including the chairperson. In the United Kingdom, either the chairperson or vice chairperson is required to be a lay person[7]. Legislation establishing regulatory

systems for health care professionals often mandates community representation, with the proportion of such representation increasing over time. In the United States, the Federation of State Medical Boards has now proposed that at least a quarter of all board members be representatives of the public[8]. Community health services and projects are often governed by boards made up largely (if not solely) of community representatives. However in other types of decision making bodies in health care, consumer representation, if achieved at all, is limited to a token single position - and that one is most certainly not in the chair!

Responsiveness to public involvement often faces evolutionary stages, with the translation of ideals into practice influenced by practicalities and the balances of power in the groups which get to make the decisions. One of the results is that the tentative and modest methods put in place are often inconsistent with the more ambitious ideals claimed. The "add one consumer and stir" recipe may achieve some measure of the legitimation described above, but it has less guarantee of success in improving results or shifting directions. It may largely maintain the comfort of the group (although not necessarily that of the lone consumer). However, limited measures are likely to have limited effectiveness. A more concerted effort is needed if initial consumer involvement is to become the thin edge of a wedge, rather than just the thin edge of a razor blade.

The role of consumer participation

> *The term "participation" usually implies more sharing, not only of information and opinion, but also of decision making power. Real participation means joint problem solving, joint decision making, joint responsibility*[9].

It has been argued that there is a ladder of participation, which reaches to citizen control at the top, with the manipulation of public opinion at the bottom. Informing and consultation activities are at the lower end of this scale, with delegating power and creating partnerships at the higher level[10].

In this framework, the example of occupational health and safety above demonstrates aiming for a degree of community control. Community boards governing individual health projects involves a delegation of power, while some of the systems described in research ethics committees and professional regulation are examples of partnership. Mostly, though, the place assigned for the public is at much lower levels, and often could not justifiably be referred to as actual participation at all.

The characteristics which define where something is placed along this spectrum are essentially the level of activity (as opposed to passivity) and influence of the consumers' role. Approaches which limit the scope of consumer involvement at the powerless receiving end of this continuum do not demonstrate strong regard for people's perspectives. They are unlikely to be rated highly by consumers either.

In research, these dimensions are also clearly evident. Consumers are calling for research that is participatory, that addresses issues of relevance to them, and that does not diminish what they have to say[1,11]. Others echo these concerns, and support approaches which provide for partnerships in research, moving people from the role of "subjects" to participants[12]. It is an approach which is gaining more ground in some areas than others, with successful examples in women's health, indigenous people's health, disabilities, and HIV.

At the other end of this spectrum are approaches which, rather than striving to achieve and communicate understanding of the diversity of people's lives and views, instead reshape social research into the kind of data that is more reassuringly familiar to the researchers. It has been pointed out that there is a "rather glaring inconsistency in exploring involvement in an excluding and unparticipatory way...Increased interest in canvassing service users for their opinions offers researchers a new subject to study, without perhaps the need for a more radical rethinking"[1].

Reducing people's values, and even the value placed on their lives, into monolithic numbers such as "utilities" and "QALYs" with the aura of precision and objectivity, provides researchers with a way to literally incorporate consumers without ruffling the surface. However, such techniques submerge people's varied experiences, and are widely criticised by consumers as devaluing and disempowering[1,11,13,14]. They should be regarded as being on the low rungs of the participation ladder.

People's views in pluralistic communities cannot, and should not, be squeezed into unidimensional frameworks to meet demands for mathematical order. Values cannot be measured with a ruler, and the pain of people's struggles with ill-health should not be homogenised till it is no longer recognisable. That something is useful, does not necessarily make it right. It should not be forgotten that utility does not equate with value, and that utilitarian decisions - "the greatest good for the greatest number", by definition discriminate against minorities.

The principle of evidence-based practice requires the impact of care on people's lives to become the centre of the health care endeavour. People should not remain at or near the bottom of the participation ladder in the process which aims to weigh the evidence. It is difficult to ensure that any product is relevant to a group if it is conceived and developed in isolation from those who are expected to use it, or to benefit from its use.

This is certainly true of information. Evidence-based decisions cannot be made unless the evidence critical to the decision maker exists. If the information considered important by consumers is not produced, then individuals' needs have not been supported. Consumers will not have the information they need to make decisions, and practitioners will only be able to frame their advice on treatment impact in terms of the priorities of their professions. The situation seems unlikely to improve spontaneously if recommendations about future research are limited to the groups responsible for the original agenda.

In the research reviewed in the Cochrane Pregnancy and Childbirth Database[15], issues of obvious significance to women are often conspicuous by their absence. An example is pain and discomfort. Often, procedures done to women's bodies report neonatal outcomes, but tell us nothing about women's comfort. There is almost no

research on relieving pain (such as backache) in pregnancy, little on pain after childbirth, and none on longterm consequences for women of pain relief in labour. There is nothing at all on pain after caesarean section, despite the operation's frequency, and the complexity of pain relief for breastfeeding women. The extent to which such gaps are pointed out by the Cochrane reviewers is inconsistent. Consumer participation should help to reduce such variability, and keep consumers firmly on the agenda by making it harder to overlook them.

Who can represent consumers' perspectives?

It's important they know what it's like at our end[16].

Many of the aims of public participation cannot be achieved without the direct involvement of people's voices and influence. Just how effective that involvement can be will be affected by the characteristics of both the representatives themselves and the environment in which they are working. It also depends on the goals. There needs to be some kind of balance of these elements to enable the process to function productively.

Take as an example a situation of a token consumer in a large group of professionals who are including the representative to satisfy a ritual expected of them. Their only concern is to proceed as usual, with as little disruption as possible. Some are hostile and contemptuous of consumer representatives, and some are vaguely curious about this unusual life form. If the consumer's only goal is to get information, a successful experience all round is reasonably certain.

Suppose though, the consumer was there on a mission to shift the attitudes and focus of the group, and with a brief to ensure public accountability. The goals are ambitious, but the environment is not only unsupportive, it is like a fortress designed to repel incursions. The consumer representative is obviously hopelessly outnumbered, and occupying the least influential position in terms of that group's power structures. With such an infelicitous environment and high expectations, the consumer would need extraordinary skills to get anywhere at all - and a lot of outside support to help counter the effects of constantly banging your head on a brick wall!

Anyone seeking to involve consumers needs to address these various elements, and not just who to add to the mix. Any evaluation of consumer involvement certainly needs to take these dimensions into account, from the point of view of both the consumers and the other participants. There is information from consumer representatives about the skills they need, and what aspects of their situation are helpful or counterproductive[9,16-18]. Some of the most common pleas are for a supportive environment, skills development, and not being a lone consumer in a large group.

The authors of a recent Australian study cite a number of others from the United States, the Netherlands, and Australia which found that the influence of lay

members on research ethics committees is limited[19]. Their own study found that both administrators and medical graduates were rated as significantly more active and more important than the other members, with lay members significantly less so. There was not much difference between self-assessment and the assessments by others. The authors concluded that these findings question "whether lay members can effectively balance any bias which medical, scientific and other institutional members may bring to the committee"[19]. They make a number of suggestions, such as appointing experienced consumer representatives instead of just "lay people", and increasing the proportion and influence of their membership.

In Australia, a series of interviews with National Health & Medical Research Council (NHMRC) consumer representatives, committee chairs, and others found that the consumers felt marginalised, but the interviewees from the NHMRC "perceived consumer representatives to be powerful and astute members of the committees"[18]. Part of the difference in perception related to the difficulties and isolation the consumers felt as sole representatives, as well as their concern about not achieving more demonstrable change. The authors concluded that the consumers' feeling of powerlessness, "while considered groundless by fellow Committee members, remains reflected in a silence about many of their views and concerns at the top decision making level of council". One of the key issues was that those in the NHMRC saw consumers as one of many interests in committees, while the consumers' experience was of the rest of the group being from one interest bloc (that is, the medical/scientific community).

The question of the expertise of those charged with providing consumers' perspectives is a common theme through these studies. Together with the issue of representativeness, it forms one of the principal dimensions of the overall debate about who should undertake this role. In practice, consideration of "who" cannot be separated from an understanding of the goals participation is meant to achieve.

For example, if a goal is balancing perspectives, choosing a fellow professional is the wrong mechanism. Yet, to confuse the nature of the expertise required in this way is common. What is needed is expertise in consumers' experiences and representation, while a practitioner background is a distinct drawback, and often a disqualification[9]. There is evidence from a variety of areas that there is a significant difference in perspective between health care professionals and both the general public and patients[20-24]. There are differences among health care disciplines[20,24], but their perspectives set them, as a group, well apart from the people whom they serve.

Sometimes, individuals with professional backgrounds in health care are proposed as consumer representatives in an attempt to address the dimension of influence - particularly where the person will be in a token position. This is understandable, and can become a vital pioneering or evolutionary stage, but it is not ideal. In evaluating levels of community participation, that kind of situation has been categorised as the narrowest form possible[4].

Another variation of this is to appoint an "eminent" individual, with or without experience of the particular issues under consideration. Often in such situations the goal of those involving the person cannot in fact be called public participation: it is not a bridge to the community they are seeking, but rather one to power and/or prestige. For example, in the selection of hospital board members, "wealth" has been

spelled out as one of the criteria for the "perfect board member"[25]. Consumer groups, too, sometimes do the same thing in their committees and campaigns, particularly with celebrities. It can play a vital role, but that role is not community participation.

Nor is the inclusion of "eminent lay people" a guarantee that the difficulties of unequal influence will be overcome when the environment is inaccessible and allows only one position. Such individuals have "confessed to feeling intimidated by committees made up of internationally renowned scientists and clinicians"[26]. It would be better to ameliorate the powerlessness of representatives in other ways, such as ensuring strong outside support, and providing training and other backup. Most of all, it needs to be acknowledged that the problem largely lies with the environment, and that needs to be adapted if there is to be significant progress.

Another option sometimes chosen is to use social scientists who study people's experiences of health care. It is a perspective which should often be included in its own right, but it broadens the base of professional expertise rather than involving the community. The appropriateness of researchers speaking outside the confines of their research on behalf of the people whom they study is highly questionable, unless the community has designated them as their advocates.

In moving, then, to consider involving consumers as their own representatives, there are essentially two choices. One is to involve consumer advocates, and the other is to involve a non-aligned individual. I would argue that this can be the beginning of real participation, but it has a kind of hierarchy of its own. Moving from non-aligned individuals, through to advocates employed by institutional services, it is advocates from consumer and community groups (employed or otherwise) who emerge as the best community proxies realistically possible.

Non-aligned individuals and institutionally-employed advocates may be unable to represent a broad range of views. Advocates employed by an institutional provider may focus more narrowly on the group who use particular services, and their ability to speak out may in some circumstances be limited by their employment.

Non-aligned individuals would generally have a more limited access to others' experiences than would those involved in groups. Nor would they have the other advantages of group support, including the assistance of colleagues in developing ideas and keeping up-to-date. They may or may not have personal experience of the issues under consideration. This can add a further difficulty in perspective. Sometimes, there may not be a great difference in view between those who have experienced something, and those who can only hypothesise about it[20]. The difference can, however, be great[21].

In the Cochrane Collaboration, a hierarchy of evidence is acknowledged, going from the randomized controlled trial down to the individual anecdote. Similar issues effectively arise in consumer representation. It is not that the "*n* of 1" is not important. Far from it. One person's experience can highlight problems dramatically, help identify solutions, and give life and meaning to ideas. However, while they can be balancing, they are not necessarily a good source of balance in themselves. The "*n* of 1" can be very compelling, but there are dangers in changing direction in response to only that.

Sometimes, there is no group, yet a start towards participation must be made. An individual in this position needs to seek a suitable existing network, or develop

one. Otherwise, they are unlikely to become a force for increased public involvement, or for community action. As they become immersed in professionals' interactions without a balancing involvement outside, there is a danger that they could come to share the perspective of those inside.

Consumer representatives' allegiance to their communities rather than to the cultural *mores* of the researchers' world is one of the reasons that they are more likely to "mention the white horse on the table, or the emperor's apparent lack of apparel"[27]. For some, this is welcomed as one of the reasons for involving consumer advocates in the Cochrane Collaboration: "Of course consumer groups, too, may have their own vested interests, agendas, and biases: but if you're trying to identify people who haven't got vested interests in distorting information about the effects of health care, then surely it must be sensible to turn to patients"[28].

The issue of accountability outside the group is often a controversial aspect of public participation - so much so that while for some it is a reason to support the concept of consumer involvement in research, for others it forms the basis of opposition[29]. Yet, the controversies over interpretation of data do not exist separately from the often political debates that feed them. For researchers, concern for maintaining group cohesion in these situations may ultimately prevail. How such controversies are dealt with and brought into the public domain needs, however, to be negotiated with the public interest paramount.

Another concern frequently expressed is that consumer advocates' accountability to possibly sectional and unrepresentative interests may limit the value of their contributions. While this is sure to occur at times, it does not outweigh the advantages of group support in general. Rather, it supports the argument that public participation should be as wide as possible, supplemented by research into the views and experiences of people living in a variety of situations. Having said that, there is at least some evidence to suggest that while consumer advocates' views may not be identical with those of the general public, they are similar[23]. The differences between consumer advocates and other consumers, it would seem, are much smaller than those between the community and professionals.

At its heart, this is an issue about equity in decision making. It is one that consumer advocates should be concerned to address themselves[9]. It should not, however, be their responsibility alone. A concern for equity should be at least as high a priority throughout the Cochrane Collaboration as the interest in effectiveness and efficiency.

Consumers, users, patients, sufferers...or people?

The traditional concept of a consumer was narrowly defined to someone who chose and purchased a product in the market place. The emerging notion of consumer is much broader[30].

There is no universal agreement about the words meant to specify the people who use, or are meant to be served by, health care. Each of the options has positive and negative attributes, and all attract controversy. The debate is fuelled by the fact that this is not just an argument about words, but about ways of seeing and portraying people and their relationships with the health care system. In short, each word has ideological baggage weighing it down.

At that point in an unwinnable contest over language, there are essentially two options: to invent a new term, or to settle on a changed meaning of an existing one. Some people have opted for coining a new word or term, but this seems unlikely to achieve much other than confusion and occasional disbelief. The latter was my personal response to a suggestion, for example, that pregnant women be called "maternents".

Other attempts to encapsulate preferred concepts in a name have resulted in phrases which are clumsy to use, such as "partners in health", "producers of health", and "co-producers of health". Even if there was no debate on the concepts, these seem unlikely to catch on, and would be meaningless jargon to most people. There are also terms which I wish had never caught on, but are widely used in some areas - like "clients" and "customers". These are not often put forward or seized on by the people themselves, although there are some who like "client". Some people like to use "citizen" or "tax-payer", but citizenship is not extended to all the residents of countries, and many people do not earn enough money to pay tax.

Internationally, the terms most commonly used by community groups to identify themselves are "consumers" or "people" (generally when qualified in some way such as "older", "with disabilities", or "living with AIDS"). The terms "user" and "patient" are less popular. "People" is by far my favourite, but the need for accompanying words to clarify exactly which people are meant makes it clumsy to use. Putting just "people" in phrases such as "people's representative" and "The People's Network" is going to sound nebulous and a touch grandiose to some.

While the term consumer has overtones of a type of commercial relationship which is problematic in health, the meaning has been broadened as it has been claimed by consumer movements worldwide to describe those who use, are affected by, or who are entitled or compelled to use services[30]. Even if, like all the other options, it is disliked by some, it is widely recognised, and easy to use.

In some areas, people have begun to favour the term "user", but that is not internationally recognised, and is unlikely to overturn the popularity and acceptance of "consumer". It implies, even more so than does consumer, that what is being discussed is people who actually use the service. Often, the largest consumer issues are around those who do not have access to a service, or whose "use" is involuntary,

for example. In many communities, "user" is also more narrowly applied to the use of drugs, particularly in mental health and addiction.

Some still use "lay people" and "patients", but their use is declining, and they are strongly opposed by many consumers. Other consumer groups in specific areas prefer particular terms, such as "user" and "ex-user" (in benzodiazepine-user support groups, for example), and "survivor" (of mental health services particularly). Some still use "victim" and "sufferer", but these are also quite widely rejected.

There is actually no need for a single uniform term for all purposes within the Cochrane Collaboration, although where workable, words such as "people", "men", "women", and "children" are preferable. Non-human terms such as "subjects" and "cases" should be avoided. To differentiate between people "using" health services and those using reviews or software, it would be helpful to reserve the term "consumer" for the first, and "user" for the latter.

Making the Cochrane Collaboration Accessible to Consumers

The thin edge of the wedge

> *I've always wanted to just stand up and say I think we could do it differently*[16].

The pioneering end of consumer representation is not an easy place to be. Some things make it harder, and having impenetrable information and decisions whiz past you is one of them. The areas of specialised activity involved in the Collaboration's review process present enough barriers to consumer involvement in themselves, without the complications added by descriptions only being available in an extremely technical English version. Consumers will not be the only ones to benefit if the Cochrane Collaboration makes its products and workings easier for a broad range of newcomers to understand.

One of the first priorities for the Consumer Network must be the preparation of materials describing the Collaboration, randomized controlled trials, and systematic reviews for consumers and community groups. These could be adapted by consumers in different areas, and made available through Cochrane centres and groups as well as consumer groups. All parts of the Collaboration, though, need to keep review users in mind, and not allow themselves to spin too far off into new forms of technical jargon.

"Ensuring access" means making information both comprehensible and available to others. These two elements need to be of equal concern. A rush to make reviews available without full concern for balanced content has inherent dangers. One of those is the extent to which such a process could exclude consumers, as "the efficient delivery of undigestible quantities of information leaves the public little room to be more than a spectator"[31].

Making sure reviews encompass people's needs and concerns will be more difficult if consumers are left only to tinker around the edges of others' essentially completed work. It will be especially difficult in the Cochrane Collaboration, where many researchers' claims of objectivity in their analyses suggest that they are unaware of the value-laden elements of what they do at so many steps along the way. Consumers and professionals may well see "threats to validity" in completely different places. As consumers point out, this raises "significant methodological issues for us, because we may be expected to justify ourselves by rules and ways of working, which we are actually calling into question"[1].

For consumers, particular problems also arise in structures where they are systematically placed in a minority position. That experience is a difficult one: "Being in an unequal position can leave you feeling demoralised"[9]. There is an obligation on those in the majority to be inclusive rather than exclusive, and to seek to appreciate consumers' expertise and experiences rather than to expect conformity. And while in some instances a sole consumer representative might be a reasonable option, in others where the group is larger, a greater proportion of consumer places may be essential.

If there is a disheartening load on one individual, effective participation is severely compromised. Maintaining balance becomes inordinately difficult, and the experience can feed apathy or paranoia. Neither is constructive. Support from consumers outside can help keep things on track, but sometimes real progress will only be achieved when a better balance is achieved. Better balance lies in forms of partnership rather than tokenism.

Clashes of culture

"I've been through the university you know!"
"Yeah! Pleasant stroll, isn't it?![32]"

Professionals and researchers have a culture of their own, and so does the consumer movement. Individual communities within those areas vary too. Cultural diversity adds richness and depth to decision making, but it means that people need to become accustomed to each other, and to other ways of acting. That kind of understanding comes from ongoing relationships. For researchers, it cannot come from sporadic forays seeking isolated responses, or from reading papers which enumerate "utilities".

Getting to understand their own and others' situations is what people in consumers' networks do. Making consumer advocacy and self-help groups work involves a lot of mutual contact and support, understanding and negotiating gulfs in viewpoints, and developing collective action. People who achieve it are spending a lot of time hearing what people want, and living and sharing in the consequences when people are hurt by illness and by others' efforts to help them.

The expertise acquired in this way can make a vital contribution to attempts to improve people's lives and health care. As consumer advocates represent the people at the sharp end of the scalpel, though, they often have to convey people's urgent needs for improvements in systems of care. People get hurt by health care practitioners, albeit unintentionally. It will not always be comfortable for those driving the system to be vividly confronted by that. Researchers need to learn how to cope with this rather than reject it, and find ways in partnership with advocates to translate ideas and concerns into constructive action.

The Cochrane Collaboration has also already developed its own distinct culture, which adds further layers of complexity. Some elements of the Collaboration's emergent ethos contrast sharply with aspects of consumer movement philosophies, and are likely to be ongoing sources of friction. For example, "ensuring access" is a principle for community groups which invokes notions of equity and inclusion. That should translate into always trying to envisage the response to the call "Hands up who's not here". It is an active concern for addressing what researchers would call "self-selection bias", with an acknowledgment that this does, indeed, affect judgments and the priorities of decision making groups.

In the consumer approach, removing barriers to participation therefore becomes a goal. This is in stark contrast with the Collaboration's statement in its *Handbook* that, "the disincentives that confront those who are wondering whether they should become involved are a useful screening test in themselves"[33]. This should certainly not characterise attitudes in the Consumer Network, and this difference in philosophy is sure to stimulate many arguments about the consequences of exclusion and elitism in the Cochrane Collaboration.

Barriers to participation are generally major issues among consumers, who can feel them quite acutely. A consumer group has pointed out that this gets stressed in times of worldwide financial stress, and is inevitably magnified for people who are "often on the fringe, or on the outer, of politically influential systems"[16]. Issues around feeling valued rather than disregarded, get tangled together with resentment over costs, and can easily contribute to people feeling exploited by professionals. It can also be humiliating to underscore differences in status by having to ask for access to things like information, phones, and reimbursement for out-of-pocket expenses which have not been offered.

There are also quite significant differences in access to resources for consumers as a group. While this is a curse for professionals as well, it seems to me that quite different orders of magnitude are operating. Many researchers will feel under-resourced in comparison with other professionals, but they will be perceived to be very well-resourced by non-professionals and people from communities that are less well off. For some consumers, such as those in reasonably well-funded groups who may even be employed as advocates, the situation is similar to that of professionals. In fact, sometimes it may even be easier for them to participate.

However, for individuals where health care is irrelevant to their livelihood and days of participation may mean losing pay, the situation is different. "Barrier to participation" means something else again for people who have other burdens with which to contend. Take for example this description of what one consumer group means when they speak of hurdles in getting to a meeting about research: "The least disabled one drives to the second most disabled one, and they drive together to the most disabled one - and even the least disabled had polio and has only one lung plus osteoarthritis![34]"

In Australia, Aboriginal communities have clearly identified the cost of participation as an issue of ethics for researchers. They argue that in considering the costs of projects, researchers need to count in the costs of all their co-investigators, not just the professional ones. They also point out that "compensation" should not necessarily be seen as an issue just about money, stressing the value placed by

communities on transfers of skills and knowledge[35]. People in the Cochrane Collaboration need to think through what contributions should be paid for, as well as what forms of assistance they could offer volunteers. While most of the work in the Collaboration is being done by professionals volunteering their time, for consumer advocates, this is likely to be yet another layer of volunteerism on top of their already unpaid community activities.

Identifying resources to support consumer participation in the Collaboration also needs to be a priority for the Consumer Network. Consumers need to make the most of suitable funding opportunities, and try to move past some of the worse aspects of the "poverty consciousness" which can inhibit many of us. This is not to say that there are not real barriers to funding consumer participation. I eventually had to give up trying to find funding to cover the full costs of my undertaking this Fellowship for the Cochrane Collaboration. As a consumer, I found myself ineligible for funding almost everywhere I turned. In one place it would be because I had dropped out of high school and had no degree. In another, I would be ineligible because I was not employed in the health field, and so it went. I wasted time and cash I could not afford on this fruitless search. Funders' attitudes need to be changed, and other types of funders need to be found.

One of the other great differences between the emerging culture of the Cochrane Collaboration and that of consumer advocates is time allowed for debates and decision making. Considering broader views and consulting with consumers takes more time than others may be used to allowing. There can, indeed, be a direct conflict between ideals of policy development and efficient administrative processes[6,31]. The goal of quick decision making can be achieved at the cost of proper consideration and consultation. Sometimes, people need to take time to consider whether they are "doing the right thing, doing it the right way, or ought in fact to be doing something else"[31]. Yet, speed is in danger of being endowed with some kind of inherent value in the workings of the Collaboration, as an academic culture seeks to race onto the information superhighway. It is important that people do not get lost in the rush.

Participation and electronic ghettos

The technology can be compared to a car. Some people are driving, some people are along for the ride, but a lot of people are running behind and as it speeds up they get left further and further behind[36].

Electronic communication and computer-based information are integral features of the Cochrane Collaboration. In fact, the organisation is in many ways being shaped and defined by its reliance on these technologies. We hear a lot about its undoubted advantages, and the promises it offers for the future. For some, indeed, the future has already arrived. The advantages, we are assured, will trickle down, and everyone else will catch up sooner or later. They just have to get a modem, and the world will be theirs as well.

There is still a lot of patience in the Collaboration for those of us who are a little more techno-challenged, but there needs to be more discussion of the negative implications of putting so many of the organisation's eggs into the Internet basket. (The Internet being an international computer network.) The positive potential of electronic communication is indeed great. For those who are actually on the Internet, sending messages and information barrelling down the information superhighway is cheaper than any other form of international communication (for now at least). There is no comparable way of getting access to such a vast amount of information. There are a lot of people who already have access: between 22 and 30 million, and booming[37].

Most of the people I know are not in that group. That, of course, is not surprising. It may be cheap once you get there, but getting there is prohibitive. Internet use, while growing, is still restricted to particular parts of communities. Although there are few concrete data on Internet users, some things are clear: there is an over-representation of people from academic institutions, and they are mostly men[37]. It is estimated that only 10% of those on the Internet are women, and that those 10% use it less than the male users do[38].

Basically, when it comes to the electronic information "haves" and "havenots", there are three major biases: income (high), gender (male), and age (young). That profile does not reflect the largest demand for health care, or information about its effects. For example, monitoring of health information services in the UK and USA "indicates with remarkable consistency that callers are predominantly female by a factor of 3 to 1"[39]. That is partly shaped by the technology of those services: the plain old telephone is more widely used by women than men[38]. However, women are also disproportionately the health carers in most communities, and may remain for some time at least the people most commonly seeking independent sources of health information. They do not seem to be embracing databases and superhighways.

Predictions about patterns of adoption of new technologies are notoriously unreliable. In the early stages, over-enthusiasm from the converted is common. Consumer advocates are questioning, however, whether totally disembodied and de-personalised systems of communication will ever achieve the kind of popularity some

proponents of the technologies claim. While some people stress increasing demands for more and more information, others point to at least some "signs of overload of both content and technology"[38].

Leaving aside the issue of how many of the world's people will ever get onto the superhighway and start consulting databases for information, it is likely that at least some community groups will get there, and benefit greatly. It will not, however, be a way for them to communicate with their members generally. The Consumer Network will not be able to rely on electronic communication, as the costs of the consequent exclusion should be too great for a group of consumers to accept. Nor could it afford to neglect the opportunities provided by the technology. The dangers of increasing gaps between the information rich and poor suggest a dual role for consumer advocates: helping as many people as possible to get to the inside, and trying to ensure that the information needs of the people outside remain an equal priority. It is important that in the Cochrane Collaboration, the concept of "access" does not have the silent coda "for those on the Internet".

Consumers and the Collaboration's structures

> *Now for the discussion on human existence, popular culture, genetic engineering, current consumer price index analysis, and what's happening around the planet, it's over to our community rep!*[32]

Expectations of consumer participation can occasionally be excessive. The effort and expertise required to focus on consumers and engage the community are often underestimated. In some areas, this is going to be a long slow process, but without it, consumer contributions to developing, improving, and using the results of reviews will be hampered. It is not enough to just produce reviews, and wait for spontaneous consumer input which may or may not arrive. As in any area of consumers and health care, a lack of complaint does not necessarily signify satisfaction, or that an issue is not considered important. Sometimes, the message has not been directed to the people who would respond, there may not have been enough information, or people believe putting in the effort would be futile. Being invited to contribute, and knowing that someone will be receptive and responsive, are two entirely different things.

Lots of guidelines for community consultation have been developed, and there are also excellent resource materials for involving consumer representatives. It may be helpful if the Consumer Network and Cochrane centres could direct people to materials which could be useful locally.

The Collaboration's review groups needs a strategy for meeting people's needs through the various stages of developing and using reviews. They need to identify individuals who will be responsible for considering consumers' perspectives, but they should not shift too great a load onto one person's shoulders. The strategy should

ideally be developed with consumers, and consumer representatives themselves need in turn to be involved with, and accountable to consumers.

A review group's processes should incorporate consumers in representative and advisory roles, as well as mechanisms for reviewing literature on people's views and experiences. Consumer advocates and groups should also be identified for consultation and liaison, in conjunction with the Consumer Network. Review groups might also consider subscribing to some relevant consumer group publications, or entering some kind of publication exchange.

Similar strategies should be developed by the Collaboration's fields. In some cases, the fields will constitute a brief for a population group, such as older people. A significant level of consumer participation is then called for from the outset.

The Collaboration's methods groups seem more complicated. Some will be very important to consumers, and consumer involvement will be essential. In others, which are dealing with issues that often become more remote from consumers' areas of interest, involving consumers may pose more difficulties. There may also be issues around which the Consumer Network itself may initiate methods groups. Certainly, any area directly related to methodologies in assessing consumers' views would need to be developed in conjunction with the Consumer Network.

In many ways, Cochrane centres and the Collaboration's Steering Group are a little simpler. An early decision of the Steering Group was for Cochrane centres to have steering committees, with consumer representation. I have been acting as consumer representative for the international Steering Group. In future, the Steering Group's consumer representatives should be nominated by the Consumer Network. It will be important for there to be proportionately more such "seats" on that committee, as a lone position is difficult to sustain at that level in an international organisation. I would also hope that the Cochrane centre steering committees move towards additional consumer involvement.

The Consumer Network, with the Cochrane centres, will need to facilitate liaison between consumer representatives locally and internationally where possible. Individuals throughout the Collaboration need to notify the Network of consumer contacts and groups, to help develop an extensive directory of potentially interested consumers internationally.

The Consumer Network itself is envisaged as a broad coalition of individuals and groups concerned with public participation in the Cochrane Collaboration. (The proposal for the Network is an appendix to this report.) There is already sufficient interest and support to get it started, and its initial shape and focus will be determined through 1995. As its membership base grows, it should be able to provide a base of support and additional lines of accountability for consumers in the Cochrane Collaboration.

The evolution of consumer participation within the Collaboration's activities and structures will depend on widespread commitment. Progress will often be slow, although there could be areas and periods of very rapid growth. As strategies and various models of participation are initiated in the Cochrane Collaboration, it seems a good time and place to initiate documentation and evaluation of these activities. Consumer involvement in the development and use of research, after all, holds one of the keys to getting the most out of information about the effects of health care.

Consumer involvement in research

I should like to feel I could persuade researchers of the priority of the moral claim that people have to a say in research about them[1].

There is a kind of closed circuit that can keep the public at arm's length from the conduct of health care research. Much of the research community actively seeks distance from people in the name of objectivity, and does not try to make their work accessible until the point where they want action on results. Further, "obscurity has somehow set the tone for all levels of scientific work, thus making any sensible intervention by the citizenry virtually impossible"[31]. The fact that people are not informed enough about research then becomes another argument to justify more of the same. Both researchers and consumers who want this to change can find it hard to find a place where they can break the circuit.

The review of accumulated research is one good place to start. Seeing reviews can both inform people, and offer them a way to systematically address gaps in understanding and research. Working in partnership with consumers in one activity can provide a foundation for joint work in other areas as well. Similarly, encouraging consumer involvement in other areas will also benefit the Cochrane Collaboration.

Many consumer groups around the world undertake health research themselves[1,11,34]. It is a trend that researchers should welcome and support, both for the unique information that can result, and because of the potential this has for shifting balances in the research world.

However, the extent to which consumer groups place research as a priority in their activities varies. For example, a study of advocacy groups in the United States, the United Kingdom, and France found that research was a priority in cancer groups, while education and prevention were of greater concern to groups concerned with HIV[40]. Getting access to quality care, though, was the highest priority in the United States and United Kingdom for all the groups. In the face of urgent immediate needs, getting people whose resources are already stretched to take time out for research issues can be difficult. Encouraging other consumers to consider the important opportunities which the Cochrane Collaboration presents will be vital, particularly for the Consumer Network.

Some consumers, too, have become disillusioned to say the least with research. It is one of the consequences of being the subject of so many data raids that yielded little value for the public. As one consumer has put it, researchers "take, take, take and give nothing back"[34]. The concern that research has so often been disheartening is widely expressed by consumers[1,11,35]. It needs to be addressed by "research which gives people information as well as seeking it"[1], and a demonstration that relevant information and products for the community can emerge from the research enterprise.

Both researchers and consumers stand to gain from a new kind of partnership and the sharing of knowledge. This report began with Bacon's statement that this is an issue of power as well. It has been pointed out that Bacon suggested a world where senior scientists "would decide in secrecy what to do with the new knowledge and how much to tell the population at large...Bacon opted for secrecy and manipulation in the best interests of the public"[31]. That model has in practice characterised much of the health research field, but it is not in the public's interest.

In choosing instead a more participatory path to knowledge, researchers can benefit from wider expertise, and be reminded constantly to put people and their needs first. Partnership with consumers in research, as in health care, is essential. The priorities of the Cochrane Collaboration, after all, are ones which would be shared by many consumers. They have been for a long time. Fifty years ago, many people's hopes for health care and participation were summed up by a woman responding to one of the Australian National Health & Medical Research Council's first community consultations:

> *We desire to express our personalities in our own way, we desire obsolete customs eliminated, and certainly we desire a voice in our own destinies*[41].

APPENDIX: The Consumer Network

The Cochrane Collaboration's Consumer Network is envisaged as a coalition of consumers and their organisations. There is a commitment by consumers in Australia, and some resources for supporting the development of the Network through the Australasian Cochrane Centre.

The basic *aims* of the Consumer Network will be to:

- help foster an environment within the Collaboration which encourages and facilitates consumer input; and
- promote consumer groups' participation in, and use of, systematic reviews of the effects of health care.

Roles and activities of the emerging Network will be to:

- identify people with an existing interest in this area, primarily by canvassing the consumer organisations where they are likely to be involved;
- produce and distribute information to encourage greater awareness of, and participation in, the Cochrane Collaboration by consumer groups with an interest in health;
- in conjunction with Cochrane Centres, foster liaison between consumer representatives in the Collaboration;
- encourage the increasing development among consumers of skills in critical appraisal, in using the databases, and in research generally; and
- conduct, coordinate, and encourage reviews and research related to consumers' interactions with health care systems and their participation in research.

There should be no membership fee for the Network, although the capacity to seek contributions and financial support needs to be developed. Possible formalised structures need to be explored, for discussion and perhaps ratification at the 1995 Cochrane Colloquium. There should be a formal meeting of the Consumer Network at least annually, in conjunction with the Cochrane Colloquium initially.

Lines of accountability for consumer representatives within the Collaboration need to be built over time. Those involved in the developing Consumer Network should be able to provide a growing base of contact, support, and accountability internationally. The Consumer Network should elect the consumer representatives on the Collaboration's Steering Group.

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