What does involving consumers in research mean?

Consumers’ concerns and priorities for research are different from those of clinical researchers.\(^1\)\(^{-3}\) That is not surprising, since consumers’ and health professionals’ concerns and priorities for treatment and care are also different.\(^4\)\(^{-6}\) So creating the means for trying to reach agreement between consumers and doctors is important.\(^7\)\(^,\)\(^8\) For research, this is just beginning.

Academic institutions and large medical charities have generally left the choice of topics and methodologies to their professional and scientific committees rather than including non-professionals in making those decisions.\(^9\) Some consumer groups have long been concerned by what they see as the lack of investigation of certain topics, poorly designed or unsafe research, and a disregard of research evidence from other countries.\(^10\)\(^,\)\(^11\) However, their lobbying of governments and professional bodies made little progress until the development of new flamboyant techniques by AIDS consumers.\(^12\) Their methods, ranging from wearing red ribbons to civil disobedience, led to the routine consultation of consumers in the design of AIDS research. This success influenced the approach of consumer groups for other diseases, including breast cancer, Parkinson’s disease, Alzheimer’s disease and juvenile diabetes.\(^12\) Members of such consumer groups have pressed research organizations to include their members or other consumers on their research committees, or they have initiated research themselves, formulating their research questions and hypotheses and inviting clinicians and researchers to join them.\(^13\) Now consumers’ active involvement in research is being promoted by some clinicians and researchers.\(^14\) Moreover, the government endorses it.\(^15\) So it is time to look at the meanings for research of consumers and their involvement.

The term consumer here means patients, past patients, prospective patients, long-term users of health services, relatives caring for patients or users, and people who speak for these primary consumers through local and national support and activist groups, community organizations such as community health councils, local and national coalitions of such groups, and international networks. Health-care consumerism, also called the patient movement, is the active extension of patienthood. It is a voice speaking for the perspectives, ideas, interests and values of patients, users and carers as they define them. The perceptions, reflections and judgements of patients, users and carers inform the work of active consumers, called consumer representatives or consumer advocates.\(^16\) Active consumers work to secure changes to professional and institutional systems, policies and practices that will meet other consumers’ interests and values.\(^17\) Often, though not always, active consumers are or have been patients or carers or users of health care like those for whom they are now active.\(^18\) The changes they secure, accepted into practice, gradually change the experiences of patients and the expectations of the public. Members of the public, indeed everyone who is not a health-care provider, are also sometimes called consumers.\(^19\)\(^,\)\(^20\) But what matters for most medical research is that those counted as consumers are either patients, users or carers with experiential knowledge of the disease, condition or situation to be investigated, or are active consumers familiar with their perspectives and aligned with them.\(^18\)

Involvement in research means active involvement, not simply a role as participants or subjects. The ethical rationale for consumers’ involvement in research is their interest or stake in how well it creates new knowledge that could help patients or future patients like themselves. Consumers’ voices should be heard equally with those of clinicians and research scientists.\(^21\) The pragmatic and instrumental rationale is that consumers’ experiential knowledge and challenges to professional perspectives are valuable for bringing about improvements to the prevention of disease, to treatments and to the quality of care.\(^21\) Consumers will argue for research that looks at questions that matter to patients.\(^22\) Research that is relevant to patients’ needs as they experience them will make a more effective contribution to health care than other research.\(^23\)
Drawing consumers into the design of research will make it more sensitive to prospective participants’ or subjects’ concerns and so encourage them to take part.\textsuperscript{24} Using consumers to disseminate findings will prompt patients to request evidence-based new treatments or procedures and so speed up their acceptance into clinical practice.\textsuperscript{25} So hopes for involvement run high.

Involvement can take place in two main ways. The first is consultation. Examples are: asking consumers for their views on some specific topic through questionnaires or meetings; inviting consumers to explore issues in focus groups;\textsuperscript{26} sending consumers research proposals to comment on\textsuperscript{27} or published papers to review.\textsuperscript{28} What the consumers say can be influential. But they usually have no direct part in decisions about what action to take as a consequence of their views. Consultation is important, however, because it can be used at any stage of the research process, in any combination of methods and on any scale to draw on wider views than any research group has on its own.

The second form of involvement is partnership. Partnership is face-to-face interaction in shared decision-making, with agreement that decisions will not be changed unilaterally, and with attempts to ensure that concerned parties are not excluded through lack of information or inadequate representation.\textsuperscript{29} This is an exacting standard. It can be applied to the doctor-patient clinical relationship, the paradigm of partnerships in health care. In research it can be applied to groups: prioritizing, advisory, steering, design, data monitoring, evaluation and dissemination groups. Whether and how it is applied varies. In 16 out of 60 randomized trials in UK, for example, consumers were members of the steering committee, but none was involved in monitoring data.\textsuperscript{30} In the USA, consumers take part at all levels in clinical trials, although not yet in all clinical trials.\textsuperscript{31}

Taking the first steps into partnership is difficult. Consumers who invite members of the medical and scientific research communities to join a research group know whom to approach, because those communities’ members are easy to identify and categorize, e.g. consultant cardiologist, medical statistician. But health professionals often feel uncertain about which consumers to approach. The answer is that much depends on the level and scope of the group and its work, as it does for other working groups of professionals and consumers.\textsuperscript{32} Consumers who are current or recent patients, users or carers can offer their knowledge and concerns from their immediate experience of the index disease, condition or situation, and from their treatment and care as it affected them. Those insights are indispensable. But each can usually speak only for himself or herself. The units of collective knowledge and action are consumer groups: their members can speak for the perspectives of consumers like themselves. Much of that will be of wide application, but it may not cover all the particular experiences and concerns of consumers in general. Consumer group members who have developed more extensive knowledge and can apply broad perspectives to policy and strategy are called consumer advocates.\textsuperscript{7,33} Though these categories overlap, a research group at national level prioritizing topics or overseeing a large clinical trial requires more consumer advocates than a group managing a local research project where consumer group members’ local knowledge is pertinent. It should become easier to find the right mix of consumers as the number of disease-, condition- or situation-specific consumer groups continues to rise\textsuperscript{12} and engenders more consumer advocates. To provide a mix, to prevent tokenism and to create partnership, several consumers should be appointed to each research group.

As for all appointments, inviting consumers to take part in consultations and appointing them to research groups should be done through open advertisements and transparent procedures. Invitations to apply can be issued through all relevant local and national consumer groups, mention in local and national media and notices in hospitals and general practitioners’ surgeries. Prospective patients who take a precautionary interest in a specific disease or condition they fear may afflict them can have useful perspectives. So can prospective participants or subjects.\textsuperscript{15} Special efforts will be needed to reach consumers who do not come forward readily, for whatever reason,\textsuperscript{34} and for conditions, situations or diseases for which there are no consumer groups or consumer advocates.\textsuperscript{31} But consumer advocates specializing in one disease, condition or situation should be able to apply general principles to another,\textsuperscript{16} provided they brief themselves on matters and issues particular to the new field. The consumers consulted or appointed to research groups should be as similar as possible to those who will be participants or subjects in ethnicity, social background, etc.\textsuperscript{35} For appointments, the selection panel should include two or three consumer members,\textsuperscript{18} helping professionals to avoid the temptation to cherry-pick consumers they think will always agree with them.\textsuperscript{36}

Partnership means including consumers in the group from the first so that they share in setting the agenda. It also means that they, like the professional members, will be expected to contribute as much as they can to every aspect of the group’s work. Professionals naturally read professional journals.
Consumer advocates read professional journals and consumer publications. They read the first for information, to pick up shades of professional opinion, and to identify conflicts and convergences with consumer perspectives. But finding parallel material in consumer publications can be difficult, because much consumer writing and debate is in the grey literature, not published in peer-reviewed medical or scientific journals, and so not listed on MEDLINE or other databases. Examples are the important consumer charters for research, statements of standards for the ethical conduct of research that supplement the guidelines drawn up by doctors and medical ethicists. So the consumers’ tasks can be onerous. They also have many commitments, may be housebound themselves or caring for others; their convenience and comfort should be considered.

Housebound themselves or caring for others; their convenience and comfort should be considered. Involving consumers in research is not the only way to work towards reaching consensus between consumers and clinical researchers about what research should be done and how it should be done. But it is a promising way.

Whatever the immediate effects of involving consumers in research, with thought and care, the benefits predicted, including that of encouraging patients to take part in research that seems to them worthwhile and sensitive to their fears and hopes, are probably achievable. Much will also depend on the wider environment, on the move from representative to participative democracy, on research ethics committees, on doctors with new and radical ideas and on the Department of Health. Involving consumers in research is not the only way to work towards reaching consensus between consumers and clinical researchers about what research should be done and how it should be done. But it is a promising way.

Charlotte Williamson
Chair, Consumers for Ethics in Research (CERES)
London

References


