Chapter 10

Communicating research

If you have an apple and I have an apple and if we exchange these apples then you and I will still each have one apple. But if you have an idea and I have an idea and we exchange these ideas, then each of us will have two ideas.

George Bernard Shaw

10.1 Introduction

Research is not complete until it is written up and its results shared, not only with other scientists who may build upon it to further advance the science, but also with those who may benefit from it, who may use it, and who have a stake in it. Etymologically, the Latin “communio” relates to participation and sharing. Communication and sharing are two words sharing the same concept.

It is an ethical duty to communicate research results. Editors of scientific journals should consider seriously for publication any carefully done study of an important question relevant to their readers, whether the results are negative or positive. Failure to submit or publish studies with negative findings contributes to publication bias. Pharmaceutical companies have occasionally been held guilty of suppressing research results that show that their products may not be as safe as they claim.

Researchers normally communicate their results to other scientists, by publishing in peer-reviewed journals and presentation in scientific meetings. The internet is revolutionizing the dissemination of scientific information in ways never thought possible before. If the research was funded, researchers have an obligation to submit periodic reports to the funding agency.

The primary aim of health research is to improve health. To achieve this aim, results of research should not be communicated to other scientists only. The information has to reach the health professionals. Research with practical implications should be scrutinized, synthesized and presented in the form of evidence-based reviews and guidelines about best practices. There is a growing awareness of a gap between clinical practice and the findings of research.

If research is to inform public policy, it should be properly communicated to policy makers. Sending a report is not enough. The research should be presented and discussed.
There is a need to communicate scientific information to patients. Patients need to participate in making informed decisions and choices about their treatment options. Health professionals should always keep in mind that they do not treat diseases; they treat patients who have their preferences, values and rights. An informed patient is also more likely to follow prescribed treatment, which is often ambulatory and self-administered. Packages of prescription drugs normally include an insert for patient information. The material in this insert is closely scrutinized for accuracy by the drug regulatory agency. Health lifestyle behaviour is a powerful determinant of health. For certain health conditions, it can be more important than the provision of health care. Empowering people with valid scientific information is more likely to induce a healthy lifestyle. Educating patients about the effectiveness of interventions is sometimes advocated as a way of changing the behaviour of health professionals who may be reluctant to change their traditional ways of treatment and to adopt more novel approaches. Pharmaceutical companies are now exploiting this patient-centred approach by targeting patients for their messages in public media.

Communities that have participated in research are entitled to know about the outcome of the research and its implications for them. Health researchers need to engage the public in what they are doing and what they hope to achieve. For one thing, science needs a favourable public environment. For another thing, there is a growing need to ensure and maintain public trust in science. Research can only thrive in a favourable scientific environment. Chairman Mao once said, when talking of revolutionaries, “the fish need a sea to swim in”. Science also needs a sea to swim in. It can only thrive if a culture for research is present in the society. Without a strong appreciation of science in society, the introduction of technology-driven solutions to everyday problems will be more difficult than it should be. Science should become more comfortably enmeshed in society’s collective consciousness. In this favourable environment, people volunteer as research subjects when they know that the scientific benefit will accrue to others, not to themselves. A distinction should be drawn between the public understanding of science and the public appreciation of science. It does not actually matter whether the public can distinguish a proton from a protein, in order to appreciate science.

This chapter provides general guidance to researchers on communicating their results to other scientists, to the funding agencies, to health professionals, to policymakers, to patients and to the public at large.

10.2 Communicating to scientists

10.2.1 Publication in scientific journals

Scientists always aim to publish their research findings in scientific journals that are peer-reviewed, that are indexed and that have a high impact factor. Peer-reviewed
journals are journals in which the articles are vetted by independent referees for quality and interest, and are therefore more highly regarded by researchers. Articles published in journals that are indexed by indexing services, such as the Index Medicus, are retrievable and accessible to other researchers, ensuring wider dissemination to the scientific community. Journals are ranked by their impact factor, a term used to indicate how many times, on average, journals papers are cited. This concept and its shortcomings are discussed in more detail in Chapter 14 on assessment and evaluation of research.

It should be realized that much important research is conducted that does not make it into major international journals. Journals can only publish a fraction of all papers submitted to them. There may also be a bias towards publications from institutions in industrialized countries. The tools of the information age hold considerable promise for developing country researchers, enabling them to disseminate the results of their research more widely.

There is growing understanding of intellectual property rights by academics and their institutions, and an increasing knowledge of how to do licensing deals. A distinction is drawn between what is patentable and what is not. Publication of scientific findings puts the findings in the public domain, and jeopardizes any patent application. If there is no patent protection, industry will not be interested in the discovery. Publications from major university centres are now screened for patentable discoveries before proceeding with publication. Many universities now employ patent lawyers.

Chapter 11 provides detailed guidelines on how to write a scientific paper, and Chapter 12 on how to get it published.

10.2.2 Presentations in scientific meetings

Presentation of papers in scientific meetings is another important venue for scientific communication. For many years, it was the major venue of communication among scientists. Researchers should train themselves in the art of scientific presentation. There are both advantages and disadvantage to presenting papers in scientific meetings compared with publishing. Among the advantages are that the information presented is up to date (there is usually a long time lag before a paper is published in a reputable journal), and that presentations allow discussion and questions to the authors, provide an opportunity for meeting other researchers interested in the same topic and promote networking in research. Among the disadvantages are that scientific presentations are not subjected to the same level of peer review and are not retrievable in the literature. A paper presented at a scientific meeting can be submitted subsequently for publication provided that the conference papers as a whole have not already been published in a journal. However, papers presented at scientific meetings usually need substantial reworking before full publication.
10.2.3 The age of paperless papers

The dream that the results of the world’s biomedical research can be disseminated freely and widely to all may not be far away. The World Wide Web allows the distribution of information at only a fraction of the cost of distribution on paper. The internet was originally created as a place for scientists to do science. Until just a few years ago, researchers were the main inhabitants of cyberspace. The internet is now changing the process of research publication, ushering in a new age of paperless papers.

The time between the day an article is submitted to a traditional journal to the day it reaches a subscriber’s hands can amount to months of peer-review, editing, proof approval and simple queuing for space. To bypass paper altogether, some journals have already adopted the online system for manuscript submission, tracking and peer review. Other journals will soon follow. Researchers submit their articles by e-mail (instantly verifying that it has been received), and editors send them by e-mail for peer review without the delays involved in mailing. Reviewer’s comments are sent by e-mail to the authors, and requested revisions are sent back by e-mail. Through a tracking system, using the internet, authors can check on the paper’s status. Turnaround times can be much shorter as a result (weeks rather than months).

Some journals post early online papers on their websites ahead of print publication. The version of an article published early online is the definitive version, which will be identical in content to that published in the print journal. When the final article is assigned to an issue of the journal, the early online version is removed.

Electronic journals are supplementing and, in some cases, replacing paper journals. Subscription prices for electronic journals are a fraction of those for paper publications, and are sometimes free. As of the end of 1996, there were 306 electronic journals, 70% more than in the year before, and including the fields of maths, physics, chemistry, biology, medicine and the social sciences. The number has since been increasing.

It is too early to predict the death of the biomedical journal as we know it. But we are certainly experiencing a dramatic metamorphosis of the tools of scientific communication. The World Wide Web makes it inevitable that new systems for disseminating research will partly replace or supplement traditional journals.

Publishing peer-reviewed original research has additional costs, even on the internet. Currently, subscribers meet the costs. A new model is now being experimented with whereby authors (or their institutions or funders) pay the costs of peer-review and electronic dissemination of their articles. Experiments with the “author pay” model are already under way. BioMed Central (http://biomedcentral.com/) is an independent commercial publisher, committed to providing free and immediate online access to the full text of peer-reviewed biomedical research. Authors retain copyright. BioMed Central has more than 90 peer-reviewed journals spanning the fields of biology and medicine,
Communicating research

and provides free technical support and hosting for groups of researchers wanting to run online, open access, peer-reviewed journals under their own editorial control. The company receives no support from governments or from scientific societies. Instead of charging users, BioMed Central covers the costs of peer review and publication by charging authors for processing manuscripts. The charge, US$ 500 per published article in 2003, can be paid directly by authors, usually from their research funds, or via their institutes through BioMed Central’s membership scheme. In 2003, BioMed Central had 291 institutional members from 29 countries. The charge is waived for authors from developing countries and others who are unable to pay. Widespread adoption of a US$ 500 charge per published article would represent a ten-fold saving for science and society. It has been estimated that the scientific community currently pays about US$ 5000 per published article (based on publishers’ gross revenues from journal subscriptions). It has been estimated that between 1999 and 2002, the global medical publishing sector grew by an estimated 20%, taking its revenue to US$ 2.69 billion.

The Public Library of Science PLoS (http:\www.plos.org/), a non-profit organization of scientists and physicians, is another initiative committed to making the world’s scientific and medical literature a freely available public resource. It is being funded during its first four years by a US$ 9 million grant from the Gordon and Betty Moore Foundation. The Internet and electronic publishing enable the creation of public libraries of science containing the full text and data of any published research article, available free of charge to anyone, anywhere in the world. To realize this potential, a new business model for scientific publishing is required that treats the costs of publication as the final integral step of the funding of a research project. To demonstrate that this publishing model will be successful for the publication of the very best research, PLoS plans to publish its own peer-reviewed journals. PLoS Biology launched its first issue on October 13, 2003, in print and online. PLoS Medicine will follow in 2004. PLoS Biology plans to meet its costs by charging authors $1500 for each published paper. If accepted for publication, the article will be made immediately and freely available online.

10.3 Communicating to funding agencies

Researchers need to report regularly to the funding agency on the progress of their research. Most agencies require a yearly progress report. A few require six-monthly reports. Normally in multi-year funding of a project, funding for the next period is contingent on the receipt of a satisfactory progress report, as well as a financial report on the expenditure during the period covered by the report.

The progress report should provide information to satisfy the agency about the progress of the project. Any problems encountered should be presented. The plan for the next period should be clearly outlined. Any papers submitted, accepted or published
should be mentioned. The financial report should be itemized. If the research did not go on schedule, the investigators may request a no-cost extension of the grant. At the end of the grant, a more detailed final report is expected. A final financial report is needed to close the books on the grant.

10.4 Communicating to health professionals

Researchers have a collective responsibility to ensure that health care providers have access to scientific evidence tailored to their needs. Reliance on passive diffusion of information to keep the knowledge of health professionals up to date is not enough. Although the skills for searching for evidence and critically appraising it need to be mastered, most health professionals cannot keep up with the strides of scientific knowledge. About two million articles on medical issues are published every year. An editorial in the British Medical Journal calculated in 1995 that, for doctors to keep up to date with the explosion of scientific information in their specialty, they need to read about 17 articles a day every day of the year. Most results from research appear first in peer reviewed journals. The small number of studies with practical implications for health professionals is spread thinly through a vast number of publications. The evidence from these studies needs to be synthesized.

Researchers can and should help in communicating new information to health professionals in a manner that is tailored to their needs. The development and publication of evidence-based reviews and clinical practice guidelines are examples of how this communication can be achieved.

Evidence-based reviews

There are now an increasing number of journals and abstracting services that review important papers rigorously and present the results in a way that busy health professionals can easily grasp. An example is Evidence-based medicine, published through a collaboration between the American College of Physicians and the BMJ (British Medical Journal) Publishing Group. It includes abstracts and commentaries from most specialties, with preference given to studies that cover conditions that are commonly encountered in practice. It also publishes systematic reviews and editorials of general interest. As the editors put it, the journal will publish the gold that intellectually intense processes will mine from the ore of about 100 of the world’s top journals. The journal is available online (http://ebm.bmjournals.com/), with free access for professionals from low-income and low-middle-income countries.

Systematic reviews of research, such as the work done by the Cochrane Collaboration have also become a useful resource, as described in Chapter 14.
Communicating research

Clinical practice guidelines

The medical literature can be biased towards innovations. But innovations need to be critically assessed. The challenge is to promote the adoption of those innovations that have been proven to be beneficial, to delay the spread of innovations not yet shown to be effective, and to prevent the uptake of ineffective or potentially harmful innovations. There are dangers in uncritical acceptance of medical innovations by health professionals.

Systematic reviews of evidence will not always lead to clear and unambiguous recommendations. Rigorously developed guidelines can translate complicated research findings into actionable recommendations for clinical practice. Evidence-based clinical practice guidelines can decrease the use of inappropriate health care and can promote the introduction of new knowledge about best practices. A growing number of guidelines are being developed after exhaustive reviews of evidence, by a multitude of professional organizations.

To be useful, guidelines should balance the strengths and limitations of all relevant research evidence with the practical realities of the health care and clinical settings. They should also acknowledge the uncertainty. Authoritative medicine is giving way to evidence-based medicine. Uncertainty makes it difficult to make definite recommendations, based on evidence, in all situations. Based on the available level of evidence, recommendations on management or interventions are now commonly graded according to the following categories (ACOG, 1998):

A. There is good evidence to support the recommendation.
B. There is fair evidence to support the recommendation.
C. There is insufficient evidence to support the recommendation; however, the recommendation may be made on other grounds.
D. There is fair evidence against the recommendation
E. There is good evidence against the recommendation.

10.5 Communicating to policy-makers

Health policy-makers need adequate and scientifically validated information to make evidence-based policy. Where the research has policy implications, researchers have the responsibility to communicate the results to the concerned policy-makers. Merely publishing the study or sending a copy of the report of the study is not enough. It is much better, where possible, to have a face-to-face presentation with ample time for discussion. Grant-making bodies usually approve an allocation in the budget for dissemination of the research results. This may include, where appropriate, a meeting with health managers and policy-makers to inform and discuss the results with them.
For research with policy implications, communication should not be left until the completion of the research. It should ideally start during the stage of planning the research to ensure that research questions are framed appropriately and tested in relevant contexts using interventions that can be replicated in practice. Where possible, those who are most likely to use the results of research should also be involved in the implementation of the research project.

The following are some guidelines for investigators when making a presentation of their results to policy-makers.

- Know your audience and tailor the presentation to the particular audience. The audience may be physicians only, or may include nurses, community leaders, and donor agencies. If necessary, more than one presentation should be made.

- Avoid technical jargon. It will not impress. It will simply confuse and distract.

- Do not overload the presentation with statistical data. Include only the data that justify and explain the conclusions and recommendations.

- Follow the same steps as in a scientific presentation, with emphasis on the conclusions and recommendations. Recommendations are more likely to be implemented if they are directed to those who should and can implement them and if attention is given to the feasibility of their implementation. Specific recommendations are better than general recommendations. A plan of action is even better. Policy-makers often prefer to be given options about what can be done, with an outline of the advantages and disadvantages of each option. They prefer not to be told what to do, but to be given the information upon which they can make appropriate decisions.

- Visual aids, properly selected and designed, are useful in highlighting the important points in the presentation, including the main conclusions and recommendations.

- Allow adequate time for discussion.

- Be prepared to accept comments, criticisms and suggestions. But be also prepared to defend your results.

- Have an informative executive summary of the study, and make it available for distribution in the meeting. A copy of the visual aids may be given at the end or at the beginning of the presentation. It is always better that participants in the meeting take something with them. The full report is less likely to be read than an executive summary.

- Have a record of the meeting, and a note of any agreements made. This should be prepared shortly after the meeting, before the meeting is forgotten. The record or minutes should be circulated to those who attended the meeting and also to those who were expected to attend but could not.
10.6 Communicating to patients

The health research community has an obligation to ensure that patients have access to appropriate scientific information. There has been an explosion of health information on the internet. More than 100 000 medical websites (of varying quality) exist, and their number is growing rapidly (Kiley and Graham, 2002). The internet revolution in health care is largely driven by a massive consumer demand for online health resources. There is a growing body of health information, directed at patients, which is both scientifically sound and intelligible. In 1998, the US National Library of Medicine (http://www.nlm.nih.gov) launched a consumer health page called MEDLINEplus, designed to direct consumers to resources containing information that will assist in researching their health questions. The pages are designed for educational use only and are not intended to replace advice from a health professional. The pages provide a carefully selected list of resources, not a comprehensive catalogue.

Care should be taken in communicating research findings to patients. People need to be empowered with scientifically valid and intelligible information. Information, particularly on health risks or benefits of different interventions can be confusing if not adequately presented and explained. Confusion can lead to patients making wrong decisions. For example, women aged over 50 years old may be told that mammography screening reduces their risk of dying from breast cancer by 25%. Few patients would understand that this impressive figure means an absolute risk reduction of only one in 1000: of 1000 women who do not undergo mammography, about four will die from breast cancer within ten years, whereas out of 1000 women who do three will die (Gigerenzer and Edwards, 2003).

10.7 Communicating to the community

If the research was a community-based study, the community has a right to know the outcome of the study. It is the duty and responsibility of the investigators to do this and to select the appropriate form and way of doing it. It is advisable to share the information with the community before putting it into the public domain. It would also be useful to check whether they agree with the findings and conclusions, and whether there are additional questions that needed to be addressed. The feasibility of any actionable recommendations can also be discussed.

10.8 Communicating to the public

The public is entitled to accurate scientific information on issues that can influence individual behaviour or public policy. Communicating scientific health information to
the public can be done by popular scientific publications targeted at a lay audience, by
using the channels of public media, and, increasingly now, by using the internet.

Scientists need to engage the public in what they are doing. This involves more than
just making scientific information freely available. The role of scientists is no longer
to preach enlightenment to the ignorant masses. On certain issues, the role of scientists
is to present the case objectively to an enlightened citizen jury to allow them to make
an informed judgement. Scientists must accept that they are no more qualified than the
general public to make value judgements as to the uses to which science shall be put. The
uncertainty, inherent in the scientific process, must be adequately exposed. The arrogance
of science must give way to a scientific culture of social responsibility.

Scientists, in arguing the case for academic freedom, state that scientific progress
should not be stopped because of the possibility of abuse. The public, however, has
a right to be concerned. One should never underestimate the ability of human beings
for irrational behaviour. The atomic bomb and other scientifically developed weapons
of mass destruction are still in the memory of the public. The objective of science is
to work for a better world. Science should not be used for purposes intended to harm
human beings or the environment. Scientist should consider the ethical implications of
their work.

The task of educating the public is achievable, as evidenced by a recent referendum in
Switzerland on genetic engineering. Voters were divided on the issue. After Switzerland’s
scientists opened their laboratories and communicated with the public, the result was a
two-third majority against a total ban on genetic modification of plants and animals, and
their release into the environment.

10.9 Communicating to the public media

Scientists should be careful in communicating scientific data to the public media.
The media, in its presentation of science, aims first to engage and entertain, and only
second to inform. Scientists should resist the temptation to communicate just for the
sake of publicity. Scientists should help the public media to prepare and present accurate
reports of scientific data of interest to the public.

There are ethical considerations in communicating the results of scientific research
to the public media. Media reports of scientific research before the work has been peer-
reviewed and fully published may lead to the dissemination of inaccurate or premature
conclusions. Very little medical research has such urgent implications for public health
that it should be released before full publication in a scientific journal. In such a situation,
the decision should be made, not by the researchers, but by the appropriate public health
authority. Improperly communicated scientific information can result in unjustified
public alarm. Researchers who present their work at a scientific meeting may discuss
their presentations with media reporters, but they should not go beyond what they have presented.

References and additional sources of information


