Introduction
As new information and communication technologies (ICTs) are being applied in healthcare, the most obvious and seemingly the only questions to ask would be if they are clinically effective and if they deliver positive outcomes for patients. In the medical tradition, outcomes are usually assessed in randomized controlled trials (RCTs) through clear and well-understood criteria of safety and clinical effectiveness. These seem to be suitable and fully adequate for evaluating drugs. (Although, of course, drug prescribing is more complex and includes, among others, economic considerations.) But are these criteria useful or sufficient when applied to the evaluation of ICTs in healthcare? In this paper we argue that they are not. ICT-related applications are complex and diverse and require a different and more encompassing approach to evaluation.

To illustrate this point we briefly introduce an example of a telecare system, utilizing a video link between patients’ homes and a central nursing station, allowing “video visits” to monitor the health status of frail patients. According to the authors, the main aims of such service—improved access to care and the reduction in healthcare costs—were achieved during the trial. They consider time saving (for physicians) resulting from the introduction of this system as a major benefit. They state that no time was spent on traveling to patients’ homes and “Video visits were of much shorter duration than home-care visits; less time was spent on conventional greetings and farewells.” Although, it seems the patients and healthcare professionals were satisfied with the service, a number of questions remain unanswered. For example, what would be the service’s long-term effects on patients’ well-being, including their mental health (can an impersonal service lead to increased feeling of alienation?), and in more general terms what are the implications for the structure of healthcare provision, professional roles, and the meaning of healthcare (substitution of care with treatment?). We also question the ability of a trial, involving a very limited number of patients (12) to adequately represent all human and organizational issues that may arise in a full-scale service even if the technical issues are addressed.

We believe that telehealth trials and operational services need to be more extensively evaluated. It is not easy, however, to agree on evaluation criteria.

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Furthermore, before such criteria are established, their ethical underpinnings must be explored and formulated. In this paper we do so by drawing on ethical traditions of disciplines from which telehealth stems. First of all, however, we define telehealth and describe its roots. The term “telehealth” is often used alongside or interchangeably with telemedicine and telecare. Telemedicine as traditionally conceived facilitates remote patient care in an institutional setting; for example, linking hospitals with remote surgeries and enabling remote diagnosis. Telecare refers to services that provide care for people away from institutions, typically in their own homes; for example, monitoring elderly people as they lead their normal lives. Telehealth is intended as a more encompassing term, to include opportunities for health promotion among a wide range of people including the young and healthy. We use the term “telehealth” here, rather than telemedicine, to draw attention to the wide scope of such services, beyond clinical settings and reaching out to communities and homes. Telehealth applications encompass a number of heterogeneous technologies and services, including databases, Internet and Intranet resources, as well as communications and imaging technologies. Telehealth systems also cut across professional and institutional boundaries, including aspects of medicine, health promotion, and health administration, education, and social services. Telehealth is not only rooted in the medical tradition but also draws on other disciplines including public administration and information systems (IS). Telehealth systems are (and ought to be) incorporated within other systems and institutions, not just in clinical settings or as part of hospital information systems, but also in social services, schools, and local government. Thus, we need to address telehealth in a variety of ways: as a “drug” or a therapeutic agent in a narrow medical or clinical context; as an information system embedded in an institutional or organizational context; but also as an information service in a societal or community context. In the first category is a telemedicine service such as remote diagnosis through fetal ultrasound, whereas a similar system also combining transmission and storage of patient data, X rays, sound and video conferencing, and appointment booking, all within a distributed clinical setting, could be placed in the second category. A complementary service providing pregnancy-related health and welfare information for single mothers through the Internet would belong more to the third category.

Whatever the type or focus of telehealth innovation being considered, both formative and summative evaluation is a practical problem that raises questions of what should be evaluated, based on what data, the perspective from which both technologies and services are to be assessed, in what way, and against what criteria? These questions can be addressed by referring to different models of technology in use drawn from different disciplines. Given that evaluation approaches are driven by different concepts of telehealth and draw on different reference disciplines, so too they draw on distinct ethical traditions. Consideration of these ethical resources for evaluation is important and interesting, both to understand the challenge of telehealth and to explore wider issues of the ethical basis of information society.

In the following three sections we consider the ethical traditions of medicine, of information systems, and emerging work on information society. In this we examine the basis that these fields provide for evaluation of telehealth innovations. The paper then explores the practical challenges of evaluating telehealth and the guidelines proposed in the literature. The paper aims to uncover under-
lying ethical dimensions or, as may be the case, conflicting ethical principles. In
the conclusion both strands—the ethical dimensions of different domains and
the practice of telehealth evaluation—are brought together to consider how the
practice of evaluation might be enriched by these different approaches.

Ethics and Evaluation in the Medical Tradition

Ethics have a particularly strong formal position within the medical tradition,
reflecting deontological principles of seeing an action as right or wrong in itself
depending on its conformity with a moral rule, and not on consequences. This
is then overlaid with a utilitarian ethic of maximizing good and bringing about
the greatest happiness to the greatest number. Thus the medical tradition is
based on patients’ rights, doctors’ duties, and attempts to balance different
interests (of varied patients or patients/citizens groups). It also reflects to a
degree an Aristotelian account of virtues and the values of a profession. The
Hippocratic Oath and the World Medical Association’s International Code of
Medical Ethics are two widely known statements of the medical commitment to
serve humanity. Ethics in medicine, although based on such seemingly stable
systems, is influenced by wider trends in science, society, and politics and in
the past half century health provision in the Western world has undergone a
continuous process of managerialist rationalization. This can be seen, for exam-
ple, in the long history of reorganization of the United Kingdom’s National
Health Service (NHS) and in the recent trend toward evidence-based medi-
cine.3 Critics see this process as going further, as a medicalization of peoples’
problems, people themselves, and the services that they are offered.4 For exam-
ple, Cribb and Barber, discussing drug-prescribing practices, suggest that “The
biomedical paradigm does not only dominate in research, but is also employed
to frame policies and guidelines. Thus a guideline may define a patient in
biomedical terms (e.g., “elderly moderate hypertensive”) and then state the
drug and dose regime to be used.”5 The trend toward medicalization and
rationalization also finds opponents in the nursing profession. Simpson, fol-
lowing Benner and Wrubel, seeks to draw a clear distinction between illness
and disease.6 “Illness is understood as the human experience of loss or of dys-
function, while disease is understood as the manifestation of aberration at the
tissue or organ levels.”7 Nursing practice, it is suggested, should be concerned
with addressing problems of illness, seen from patients’ perspectives, in the
context of their experience and lives; “the integrity of nursing practice requires
an ethics of care and responsiveness. Or, put in a more Aristotelian vocabulary,
being guided by such an ethics is a virtue of a nurse.”8 An exclusively medical
or technical response to a patient’s illness is seen as inadequate or even unethical.

Notwithstanding these debates, evaluation schemas in medicine are guided
by dominant ethical systems within a rationalistic, scientific framework. The
goal of not causing harm and doing good is translated into evaluation based on
a scientific concept of rigor; a gold standard of proof realized in double-blind
RCTs. However, a changing understanding of health and illness in social terms
has influenced evaluation criteria, leading to some calls for a more qualitative
approach to evaluation and a broader representation of patients’ interests.9
Partly owing to growing pressures on funding, the evaluation of medical treat-
ments and health projects increasingly incorporates an economic dimension.
Such efficiency criteria are often considered under an ethical umbrella; for
example, when cuts in individual service provided are justified as freeing necessary resources for the population.

**Ethics and Evaluation in the Information Systems Tradition**

The field of information systems is broad but is primarily concerned with analyzing and modeling information needs of organizations and individuals, and designing and implementing different types of information systems. These may vary from small and fairly simple systems—for example, a stand-alone database for a clinic to large interorganizational systems utilizing networks and integrating or transforming many different organizational processes. Within the information systems discipline other areas, including the relationship between ICTs and society, public policy issues, and computer ethics, are increasingly considered. Nevertheless, compared to medicine, the field of information systems has a far weaker and less sophisticated ethical tradition. Discussion of computer ethics has been to a large extent concerned with professional codes of conduct and not wider societal issues. These codes can be interpreted as either a tool to sustain self-regulation, as enabling and expressing felt ethical need and opening of a dialogue, or as bolstering professional status and reassuring others. Berleur suggests two broader principles that should guide IT practices: reducing vulnerability of individuals and society, and promoting a socially sustainable development.

Although ethical concerns have been seldom given a central role in information systems, there is a sustained body of work that is concerned with ethical issues in practical contexts. For example, Mumford’s work on the ETHICS methodology, drawing on sociotechnical principles, continues to have influence. Similarly, the “Scandinavian approach” emphasizes the protection of workers’ skills and rights and the promotion of democratization in workplaces. Recently, Critical Theory, particularly as developed by Habermas, focusing on issues of emancipation, coercion, power, and distortion, has been applied within the information systems field to open a discussion on ethical dimensions of information systems.

In contrast to the lack of explicit ethical concerns, the evaluation of information systems has become a prominent, diversified, and contested field. Much of the discussion has evolved around the appropriateness of “scientific” methods (e.g., cost-benefits analysis), return on management, or return on investment. Many attempts have been made to produce comprehensive conceptual frameworks for evaluation. Symons, for example, applied Pettigrew’s framework of content, context, and process to evaluation of information systems. A similar framework, based on Donabedian’s work, was developed by Cornford et al. to produced a matrix of structure, process and outcome on one side and system functions, human perspectives (customer, actor, owner), and organizational context on the other. Such a framework allows for incorporating technical, professional, organizational, and societal aspects into an evaluation schema including user satisfaction. Agerou goes further and suggests that the evaluation process should include a community-wide discussion that can help to identify different interests and to resolve (or at least acknowledge) conflicts, treating evaluation as a continuing learning process rather than a search for judgment.
Information Society: Ethical Tradition and Evaluation Practice

The emergence of an information society is often heralded. This is usually taken to be a consequence of technological innovations (computers and communication technologies), combined with changing structures in the global economy and a new reliance on information and information products leading to occupational, institutional, and social changes. The ethical resources of this society are only now being explored as the concept comes to be debated. Indeed there is no agreement on the exact criteria to be met for society to become an “information society.” Webster, for example, identifies five major and contrasting aspects: technological, economic, occupational, spatial, and cultural, and each of these will bring distinct ethical debates and traditions. Yet, despite the lack of clear criteria, it is commonly assumed that many of the developed countries have become or are about to become information societies. Certainly this term is often used by the U.K. government and E.U. organizations as a rhetoric of (post)-modernity.

Some of the theorists of information society identify it in terms of discontinuities, implying a break from prior ethical traditions. They ask questions about the fundamental nature of information society, the dominant values and principles, and in what terms citizenship will be defined, pointing out tensions between different interests; for example, between citizens’ right to (free) information and the protection of intellectual and institutional property rights. The concept of information society has also found its way into political discourse with ethical dimensions reflected in arguments about the potential to improve quality of life and the efficiency and cohesion of our social and economic structures including in areas of health provision. New innovations such as telehealth certainly seem to pose new ethical challenges. Johnson argues that, although ethical issues that arise online are not radically different from ethical issues encountered offline, they do require careful consideration because of special features of communication in networks; scope (the reach of information), anonymity (of the source), and reproducibility (of information). Concepts of reality and identity also become problematic. Such ethical problems are addressed in postmodernist literature, although postmodernism is often seen as advocating ethical relativism. Lyon, for example, argues that even within postmodern discourse there is a place for ethics. Thus postmodern populism may be seen as democratizing as cultural hegemony becomes redundant, hierarchy and elites are destroyed, and mega-narratives serving interests of dominant/established groups are fragmented, giving a voice to minorities with citizenship defined in terms of social participation. Notwithstanding these distinctive approaches, when (if at all) ethical considerations are applied to information society projects, they are usually taken under separate discrete and fragmented headings; for example, access to information (information poor/information rich), confidentiality, security, or employment.

Miles tries to provide a more integrated model of alternative scenarios for information society. He points to two dimensions underlying the debate on the societal implications of ICTs: depth and width. The depth perspective depicts different views on speed and extent of change. At one extreme, “continuisim” stresses the continuity of trends, the limited extent of ICT-related change, and social and economic innovation in society (even to deny the notion of information society). At the other end, “transformism,” regards information society
as a fundamentally different society, where ICTs have an all-pervasive revolu-
tionary potential. Miles’s other dimension refers to contradicting views about
the nature of the information society—a place of greater democracy, decentral-
ization, self-expression, and personal choice; or a centralized society character-
ized by surveillance, control, alienation, and deskilling.

The approaches we see in the evaluation of self-declared information society
projects reveal strong utilitarian principles evident, for example, in the empha-
sis on social inclusion (regenerating poor areas, improving lives of deprived or
excluded groups) or improving competitiveness (and thus wealth) of individ-
ual industries or regions. Deontological principles are also seen, for example, in
projects that take as their evaluation criteria concern that new technologies may
lead to deskilling, loss of jobs, or concern with surveillance. The Aristotelian
approach is manifested too in attempts to make life and work more meaningful
and to provide means for people to contribute to and to participate in society.

Telehealth: Ethics and Evaluation

The availability of diverse, cheap, and reliable technologies, financial pressures
on the healthcare sector, and a growing demand from the public for universal
access to high-quality medical care, has led to a rapid growth in telehealth
projects in the United Kingdom and across Europe. Major telehealth projects
have been initiated by the European Union as a part of the Advanced Infor-
matics in Medicine (AIM) program (1989–1994) and the Telematics Application
Programme (1994–1998). Early projects focused on technologies and standards,
but a number of pilot projects in domains including pathology and transplants
have been established. The majority of these projects are in research, develop-
ment, or pilot stages, rather than being fully operational, and rely on research
funding. The United Kingdom is involved in many of these European projects
and its own Information for Health Strategy22 sets out a number of goals for
utilizing ICTs to deliver information to patients, healthcare professionals, man-
gers, planners, and the public. These include NHS Direct (a 24-hour telephone
medical advice line), NHS online (a Web-based service for citizens), as well as
tele-education resources, telecare, and various clinical telemedicine applica-
tions.

The decentralization of healthcare delivery and health budgets has also encour-
aged a number of independent telehealth projects. These projects are often
small scale, bottom up, and driven by small teams of health professionals from
diverse disciplines, such as radiology, dermatology, health promotion, or psy-
chiatry. One example would be a telepsychiatry project using a video link
between a local doctor’s surgery and a hospital consultant. Not surprisingly,
the medical tradition is dominant in most of these projects and the popularity
of the term “telemedicine” (rather than “telehealth”) in most publications reflects
the preoccupation with medical aspects of healthcare delivery.

We argue that this is too narrow a focus. Rather, as telehealth activity grows,
it needs to address questions that go well beyond the medical or clinical con-
text and develop from a concern with information society. Issues we identify
include: is telehealth the best option for patients; what is the impact of tele-
home-care on patients’ and carers’ well-being; how will it affect the doctor-
patient relationship and the “art of medicine”; could telehealth exaggerate
inappropriate adoption and utilization of medical technology; will it increase
equity and equality of access to services or exaggerate differences between the
better off and the poor, the educated and the less educated; will it contribute
toward social cohesion or amplify social isolation and exclusion; will telehealth
be used for empowerment of patients or will its main aims be cost cutting and
control (e.g., standardization of medical practices)?

Reviewing the literature suggests that, indeed, telehealth applications still
pose a number of practical ethical dilemmas for those involved. From the above
list the following concerns are most often voiced: telehealth’s effects on the
doctor-patient relationship, balance of benefits between doctor and patient, and
questions of accessibility. Other important concerns mentioned include: data
security and patients’ confidentiality, the use of innovative but unproved tech-
nologies, allocation of scarce resources and opportunity costs, and medical
practice, employment, and job satisfaction. Beyond these multiple themes we
see a more fundamental questioning of the degree to which telehealth drives on
the medicalization of essentially social phenomena.23

One could ask if these problems arise because different ethical and evalua-
tion traditions from a number of disciplines come together in telehealth appli-
cations. Are those different traditions necessarily leading to conflicting values
and unworkable or partial evaluation frameworks? Our argument would be
that they do cause some tensions, not only because of different ethical approaches
but also because of different practices and methods applied. Nevertheless,
conflicts between deontological and utilitarian perspectives occur even in “purely
medical” areas such as drug development and prescribing (proving that there
are no “pure and simple” projects). Focusing on issues of safety and narrowly
understood clinical outcomes only postpones the necessity to deal with “wider”
issues, including economic viability. Thus we must strive to create evaluation
frameworks that encompass these different traditions, with of course different
levels of priority assigned to varied criteria.

As evaluation is debated there is a particular tension seen between those who
advocate evaluating telehealth projects through the strongest medical approaches,
RCTs, and those who point out their limitations.24 The argument is made that
these methods do not allow for contextual, complex issues to be addressed, are
difficult to generalize, and have not yet provided any major indication of
improved patient outcomes or cost effectiveness, whereas the institutional set-
ting and societal dimensions are ignored. In some cases, RCTs seem more
motivated by a desire to achieve credibility in the medical community than
belief in the value of findings. Alternative suggestions include undertaking
evaluation of telehealth projects in their normal settings (rather than under
laboratory conditions) and focusing not only on the clinical or therapeutic
outcomes but also on changes to work processes and institutional structures.

Varied attempts have been made to construct such expanded evaluation
frameworks. For example, Taylor provides a survey of telehealth systems and
services’ evaluation and a set of guidelines.25 His approach suggests that assessment
should consider if telemedicine is first safe, second practical, and third
worthwhile. Thus the focus of evaluation develops from the (technical) system,
ono the services delivered and experienced, and finally to the health outcomes
achieved. Within each of these categories Taylor discusses a set of relevant
criteria and methods, and how they might be applied in practice. Field’s guide-
lines also reflect the IS literature, including the call for evaluation to be con-
sidered as an integral part of project design, implementation, and redesign, and
understood as a continuous learning process going beyond a single project.26
The suggested content of evaluation includes questions about the clinical process of care, on patient status, health outcome, accessibility, costs, and acceptability when compared to alternative healthcare strategies. Yet, despite the influence of IS ideas in both these guidelines, the dominant perception of telehealth that is revealed in published studies is still as a medical technology or treatment; this is reflected in the content and methods of evaluation and their ethical underpinnings. Not surprisingly, perhaps, as new technologies are explored, assessment is often limited to questions considering feasibility, safety, and clinical outcomes within traditional medical terms.

Conclusions

The application of ICTs in healthcare brings many new issues to consider as described in the previous section, and all carry ethical choices and concerns that need to be addressed in evaluation. Given that telehealth draws on different disciplines and crosses institutional boundaries, we have argued here that ethical resources from different fields need to be considered. These traditions each bring with them their own concerns: for example, from the IS perspective, conflicting information needs of different participants; and from an information-society perspective, the place of ICTs in our daily lives. Following this argument we believe that evaluation should, and inevitably will, draw on a variety of traditions. Certainly, treating telehealth as a drug or medical procedure and concentrating on RCTs is very limited and, in many cases, of doubtful benefits. Nor does it reflect significant ethical concerns; for example, long-term effects on doctor-patient relationships or institutional structures of health delivery. These tensions between different traditions of diverse disciplines highlight the complexity of evaluating telehealth. They could also be taken as an illustration of the wider struggle to define the ethical underpinning of ICTs in the information society.

As this field further develops—and it will, with or without evaluation—and becomes more central to healthcare delivery, the treatment of ethical issues in telehealth needs to be seen as going beyond individual projects or clinical situations and be considered in relation to society as a whole and varied interest groups within it. Thus telehealth could be increasingly evaluated in terms of empowering patients and communities, contributing to social cohesion, and democratizing healthcare structures and service delivery versus intensifying social exclusion (information rich and poor), alienation and depersonalization of health services (providing treatment, not care). This also suggests evaluation approaches that explore the implications of the standardization and enhanced levels of control (surveillance) it may imply.

We see telehealth as needing to be understood not only as a medical technology/treatment, or in terms of an information system supporting information needs within formal health institutions, but also as an information service. The overriding ethical concern behind the concept of information services is the idea of information as a right. From this perspective information is a tool of self-empowerment. And although many proponents of telehealth maintain that it offers a way to follow a deontological need to do best for an individual person and the utilitarian aim of allocating limited resources in the best way possible to the benefit of the whole population, we argue for a more
Aristotelian approach with an emphasis on the achievement of healthy people leading fulfilled lives.

Notes

7. See note 6, Simpson 1995:169.