

SUMMARY

Informatics research and its results have a huge influence on society. It goes without saying that both the public and research funding bodies increasingly expect an exhaustive review of the ethical and legal dilemmas associated with this research. For example, is it permissible to hack a public transport smartcard or a keycard allowing access to all government buildings when investigating the security of such systems? And if so, subject to which conditions? At the moment, it is up to the researchers themselves to make the ethical and legal judgement call, explicitly or not. And although a number of institutions are experimenting with ethical review boards, such initiatives are still in their infancy. In the years ahead, we must develop a transparent review mechanism and an efficient infrastructure for assessing the ethical and legal aspects of informatics research. The Academy believes that this advisory report will support continuing professional development in the field of informatics research.

The Academy has installed a committee whose task is:
to identify ways to assess the ethical and legal aspects of informatics research.

The committee focused mainly on the dilemmas involved in research such as that conducted by informatics departments at Dutch universities and research institutes. Typical examples include research on network and computer system security, human-machine interaction, software reliability, and artificial intelligence. The ethical and legal aspects associated with collecting and using large (privacy-sensitive) datasets fall outside the scope of this report. The Academy has established a separate 'Big Data' advisory committee to address that subject.

The committee collected and analysed information in various ways. First of all, it interviewed key figures in the field. This has allowed it to form a picture of how institutions view this subject, and whether – and if so, how – they review their research and which dilemmas they encounter along the way. As background for developing a review mechanism, the committee analysed the protocols utilised by Dutch and foreign institutions. Medical science has already gained considerable experience in reviewing the ethics of research proposals. The committee therefore looked in detail at how the medical world is organised in that regard and what lessons we can learn from it. The committee presented the main outlines of its report to the research community during a liaison group meeting. The participants' comments at that meeting have been incorporated into this final report.

CONCLUSION 2.1

Society in general, but also – and in particular – research funding bodies are increasingly asking scientists to conduct an exhaustive review of the ethical aspects of their research. That is the case in many disciplines, but certainly in informatics, given its enormous societal impact and importance. We must develop an ethical infrastructure for informatics. This means that a transparent and distinguishable review mechanism must evolve about which the field has reached consensus. In addition, we must seek out an assessment method that is scrupulous and robust but also efficient and functional without being too bureaucratic.

CONCLUSION 2.2

The medical sciences have already gained considerable experience in the ethical scrutiny of research. Because it places heavy emphasis on the consequences for human test subjects, however, the system used in medical research cannot simply be transferred across the board to informatics research. The ethical issues involved in informatics research are highly specific to the field. Moreover, the law does not prescribe any form of ethical assessment for informatics research. That is why informatics can draw on the experiences of the medical disciplines but must develop its own review mechanism and assessment method.

The collection and processing of personal data is very common in informatics research, as are investigations into software or computer systems that are the property of others. That is why this type of research soon raises legal questions, for example concerning privacy or intellectual property rights. It is beyond the committee's remit to conduct an exhaustive study of what the law does and does not permit and the conditions and circumstances that apply in either case. The committee has therefore outlined recurring dilemmas in various phases of research and described potential measures for dealing with them. In specific cases, however, a legal expert should always be consulted. In every phase of research, researchers must be aware of the potential legal implications of their actions. How will my research affect the privacy of

others? Do the activities that I am undertaking within the context of my research comply with statutory rules and contractual agreements governing intellectual property rights? Scrupulousness and proper documentation are advised. What many researchers do not realise is that ‘doing nothing’ can also lead to liability issues. Researchers have a duty of care, which may mean that they run the risk of legal sanctions if they ignore unusual patterns.

CONCLUSION 3.1

When selecting a research subject, researchers should give top priority to the interests of science and offer solid arguments for why their research will serve the interests of society. They should clarify how and to what extent their findings could affect the interests of third parties, including their privacy and intellectual property rights. Researchers and other relevant stakeholders should explicitly weigh the scientific and societal interests of their research against the interests of any third parties whose rights may be infringed. In short, the end does not always justify the means.

CONCLUSION 3.2

Informatics researchers have a duty of care. This means that remaining passive in certain situations could lead to their being held liable. Researchers and research groups should therefore remain vigilant and report any perceived risks to persons and society to compliance officers within their own organisations and, where necessary, to the enforcement authorities.

The ethical issues associated with IT have been the subject of worldwide interest in the field of ethics since the 1980s. The literature addressing this subject, however, can largely be found in the social and behavioural sciences and mainly concerns social media and the internet. There is no well-defined set of international guidelines for review boards in informatics research, nor is there a tried-and-tested model for organising reviews efficiently. Both for society and the research field itself, it is important to develop such a model in the years ahead. The committee therefore favours the installation of local Ethical Review Boards for Informatics (ERBIs). In the committee’s view, the ERBIs would have three important tasks:

1. to assess the ethical aspects of informatics research, so that research that clearly raises ethical questions would ideally commence only after the relevant research proposal was given the greenlight by the ERBI.
2. to promote continuing professional development, so that researchers and institutions can account for their informatics research in ethical terms, based on informed judgement;
3. to embody the core and promote the continuity of a community of expertise in which knowledge concerning this subject is documented and continues to advance. The ERBI would thus serve as the linchpin of an organisation’s ethical learning process.

The committee has identified a number of key success factors that will ensure the robustness of these ERBIs, including local engagement, speed of action, and the status and legitimacy of their opinions. Local engagement is hugely important because an ERBI can only function if the distance between the board and the researchers is minimal, both physically and in terms of sentiment. The committee therefore supports the installation of local review boards. It is very important, however, for the boards to develop a shared conceptual framework (review/action mechanisms). A national peer-review model can assist them in this.

CONCLUSION 4.1

One way that the informatics research community can live up to its ethical and public responsibility and demonstrate its awareness that informatics plays an important role in shaping society is to install an Ethical Review Board for Informatics, monitor the performance of this board, and reflect on the lessons learned in this manner.

RECOMMENDATION 4.1

The committee advises all governing bodies of institutes or departments active in informatics research to install an Ethical Review Board for Informatics (ERBI), either on their own or in cooperation with sister institutions. The primary task of the ERBIs is to assess the ethical aspects of informatics research. They can also function as the core of a community in which knowledge concerning this subject continues to advance.

RECOMMENDATION 4.2

Ethical assessment of informatics research is still in its infancy. No blueprint or ideal description of an Ethical Review Board for Informatics can be provided, nor does any set of predetermined standards exist. In addition, informatics is an exceptionally dynamic field, making it impossible to predict which issues will arise next year. ERBIs are advised to develop their own methods and set of standards, and to do so in close consultation with other ERBIs.

It is difficult to pinpoint precisely which type of research will raise ethical or legal dilemmas and the attendant risks. Nevertheless, in the interests of scientific progress and efficiency, an ERBI must identify, as quickly as possible, proposals whose ethical or legal aspects require further examination. As a starting point for discussion within ERBIs, the committee therefore proposes a review procedure that distinguishes between a more lenient and a more stringent assessment. The lenient, and therefore faster, procedure is for research of a more standard nature. The more stringent procedure is for non-standard research. A critical factor in the entire review cycle is the report issued by the ERBI and how it documents and shares the cases it has reviewed. It should preferably do so in a way that allows researchers and all other ERBIs to consult the reports easily. Specifically, that will allow all ERBIs to work together on developing a uniform review mechanism.

CONCLUSION 5.1

Ethicists use ethical value types to articulate the arguments advanced in the process of ethical assessment. Examples of value types are ‘respect’, ‘privacy’ and ‘wellbeing’. There are many different and divergent values that cannot be reduced to a single type, however. Values do not, furthermore, fit into neat classifications, and they may even conflict with one another. This is equally true of the values common in informatics research. This ‘value pluralism’ means that it is impossible to provide an unambiguous, unchanging review mechanism. Assessments will have to be made on a case-by-case basis.

CONCLUSION 5.2

The protocols and guidelines for ethical assessment currently used by many Dutch and foreign organisations are relatively limited in scope. The questions they pose generally concern the ethical aspects of identifiable research subjects. They rarely address the effects of research on society or the environment in terms of their ethical dimensions.

RECOMMENDATION 5.1

ERBIs are advised to develop an efficient and transparent procedure that distinguishes between a lenient and a more stringent assessment. The lenient procedure is meant for proposals that concern more standard research. The present advisory report outlines a possible review procedure of this kind.

RECOMMENDATION 5.2

ERBIs are advised to document their opinions properly and to make them available to researchers and other ERBIs. In the longer term, the committee recommends working to build a well-organised, shared repository where all decisions are available for perusal. Having a central repository of ‘ethical case law’ makes it possible to check for consistency and convergence between reviews and will help to construct a more uniform review mechanism.

Installing ERBIs and developing a shared review mechanism are important steps forward, but they are not enough. It is very important that all researchers become and remain aware of the ethical and legal aspects of their actions. Review boards and the governing bodies of institutions must not take responsibility away from individual researchers. University faculties must nurture a culture in which it becomes ‘normal’ to think about and discuss these subjects. To do this, they could consider:

- talking about ethical and legal dilemmas during regular and bilateral meetings;
- drafting a code of conduct or making practical agreements in this respect;
- appointing an ethics adviser;
- making training in ethics and integrity a compulsory part of a researcher’s education.

CONCLUSION 6.1

Informatics research, and the context in which it is conducted, are in a continuous state of transition. As a result, new ethical and legal issues are constantly arising in relation to research projects. It is not enough to have a review board conduct a one-off review of these issues at the start of a project. Research institutes and individual researchers must work constantly on raising ethical awareness and conducting ethical reviews and make these an inherent part of the organisation.