

Application Form Kortlopend onderzoek 2004-2005

Onderzoeksprogramma Netwerk van Netwerken

Dossiernummer:

1. Applicant(s)

main applicant/contact person

name, title(s): Prof. dr. N.E.J. Oudshoorn
university: University of Twente female
research school: Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC)
postal address: Faculty BBT, Department FWT, PO Box 217
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telephone: 053-4893344 fax: 053-4894734
e-mail: n.e.j.oudshoorn@utwente.nl

discipline: Science and Technology Studies
other applicants

names, titles, university and research school: Dr. L. Dubbeld, University of Twente, Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC) female
telephone: 053-4893301
e-mail: l.dubbeld@utwente.nl

discipline: Philosophy/Science and Technology Studies

names, titles, university and research school: Mr. dr. J. Nouwt, University of Tilburg, Tilburg Institute for Law, Technology and Society (TILT) male
telephone: 013-4662792
e-mail: J.Nouwt@uvt.nl

discipline: Law

names, titles, university and research school: Prof. dr. R.J.Wieringa, University of Twente, Dutch Research School for Information and Knowledge Systems (SIKS) male
telephone: 053-4894189
email: roelw@cs.utwente.nl

discipline: Computer Science

See appendix 1 for a Curriculum Vitae of the main applicant.

2a. Title of the research project

NL: Privacy en de dynamiek van netwerktechnologieën in de zorgsector.

UK: Privacy and the dynamics of network technologies in the healthcare sector.

2b. Short summary of the problem definition and objectives

Privacy has often been viewed as a constraint to the effective implementation and widespread use of Information and Communication Technologies (ICTs) in the healthcare sector, especially in the emerging field of telemedicine.

At the moment, little is known about workable ways to protect privacy in the context of telemedicine.

This project aims to provide a discussion of approaches to data protection that are currently available and in use, and to offer an in-depth study of socio-technical complexities regarding privacy in telemedicine. The analysis will result in an assessment of different mechanisms for protecting privacy with a view to healthcare organisations' data processing needs.

The project's main research questions are:

Which approaches to data protection are currently available and in use with respect to the use of ICT networks, in particular telemedicine, in the healthcare sector in the Netherlands?

Which of these approaches can be considered most adequate and satisfactory with respect to enabling organisations to use telemedicine applications as they wish while also protecting individuals' personal data?

In answering these questions, the project will contribute to knowledge about the dynamics of socio-technical networks in the health care sector. Also, insights will be gained in successful implementation and use of privacy policies for telemedicine applications.

2c. MaGW disciplines and keywords

40 (social sciences)

41 (sociology)

54002 (issues in science and technology)

privacy, data protection, healthcare sector, telemedicine, users

2d. NVN-theme:

Beleid en instituties

3. Proposed publications

- Three scientific publications in refereed international journals (i.e., interdisciplinary papers aimed at audiences in the fields of Science and Technology Studies, law, and computer science)

- Two professional publications that will be of interest to policy makers in the field of data protection and telemedicine in the Netherlands and Europe (one of which is the result of the dissemination workshop, see below)

4. Research team

Name, titles	discipline/university	fte
Prof. dr. N.E.J. Oudshoorn	Science and Technology Studies / University of Twente	0, 2
Dr. L. Dubbeld	Philosophy/Science and Technology Studies / University of Twente	0, 8
Mr. dr. J. Nouwt	Law / University of Tilburg	0, 4
Prof. dr. R. Wieringa	Computer Science/ University of Twente	0, 4

5. Duration of requested subsidy

duration (years): 2,5 years

to commence on (date): October 1, 2005

6a. Requested Personnel in duration of appointment and hours per week in €

	Personnel: in duration of appointment, in hours per week and €		
	Duration of appointment in months	Hours per week	Euro
Senior researcher, supervisor (Oudshoorn)	24	0,2 fte / 8 hours	31.270, 80
Postdoc (Dubbeld)	30	0,8 fte / 32 hours	114.760,00
Senior researcher (Nouwt)	12	0,4 fte / 16 hours	30.961,20
Senior researcher (Wieringa)	6	0,4 fte / 16 hours	15.480, 60
		TOTAL	192.472, 60

6b. Requested material goods €7000

6c. Total requested amount (6a and 6b) € 199.472, 60.

6d. Specification and motivation of the requested personnel and material costs

Personnel

A post doc is required because, in view of the limited duration of the project, the researcher needs to have considerable knowledge of privacy law and policy, and have some oversight of the current literature on privacy in the context of ICTs in the healthcare sector. Also, the researcher needs to have sufficient experience with doing empirical fieldwork, especially interviewing. Moreover, with a view to the case studies that will be conducted in the course of the project, it is highly desirable that the researcher already has contacts with stakeholders in the healthcare sector.

Three senior researchers are requested in order to facilitate the project's interdisciplinary research approach and to contribute to the multidisciplinary publications that the proposed study of network dynamics aims to realise. Two of these researchers will also be indispensable as experts in specific themes covered by the postdoc's research (i.e., law and computer science).

For these reasons, different durations of appointments are proposed:

Oudshoorn will be responsible for overall project management, and integration of results produced by each individual researcher. Therefore, the requested subsidy is for nearly the entire project duration (24 months).

Because of his experiences with studying privacy protection in medical practices, Nouwt will participate in the project's second year (for 12 months), in order to assist in the legal analysis of the empirical study, and contribute to publication of final research results.

Wieringa will serve as an advisor regarding technical approaches for data protection, and his expertise is therefore needed in particular during the literature study and with respect to the analysis of study results. Wieringa will therefore need to be involved at the start of the project and in the final phase (for 3 months each).

See appendix 2 for a Curriculum Vitae of postdoc and senior researchers.

Material costs

Funding for material costs is requested for the postdoc researcher to cover conference attendance (i.e., one international conference per year) and payment of transcription services.

In addition, funding is requested for the organisation of two workshops. First, a project workshop half-way through the project to enable presentation of project members' research results to a limited number of scientific colleagues who will be able to give feedback and comments. Secondly, a dissemination workshop in the final phase of the project which is intended to provide an interested audience (policy makers and organisations in particular) with information about some of the research results.

Conference attendance by postdoc: 2000 euros.

Transcription services: 1000 euros.

Workshop organisation: 4000 euros.

Total: 7000 euros.

7. Has this application been submitted elsewhere?

no

8. Other funding for the project?

no

9. Description of the research project

See appendix 3 for the description of the research project

10. Past Performance

10a. Publications list(s) of Applicant(s) and Researcher(s)

N.E.J. Oudshoorn

Oudshoorn, N. and Somers, A. (te verschijnen) 'Constructing the Digital Patient: Patient Organizations and the Development of Health Web Sites' *Information, Communication and Society*.
Oudshoorn, N., Brouns, M. and van Oost, E.C.J. (te verschijnen) 'Diversity and Distributed Agency in the Design and Use of Medical Video-Communication Technologies'. In: Harbers, H. (ed) *Inside the Politics of Technology*. Amsterdam: Amsterdam University Press.

- Oudshoorn, N. (2004) 'Europese initiatieven voor de maatschappelijke inbedding van ICT'. In: Haan, J. de en O. Klumper (red) *ICT en Samenleving: Jaarboek 2004*. Amsterdam: Boom, 103-120.
- Oudshoorn, N.E.J. and Pinch, T.J. (2003) 'How Users and Non-users Matter'. In: Oudshoorn, N.E.J. and Pinch, T.J. (eds) *How Users Matter: the Co-construction of Technologies and Users*. Cambridge, Mass.: MIT Press, 4-22.
- Oudshoorn, N., Rommes, E. and Stienstra, M. (2003) 'Configuring the User as Everybody: Gender and Design Cultures in Information and Communication Technologies' *Science, Technology and Human Values*, 28 (4), 22-42.
- Brouns, M.L.M., van Oost, E.C.J. and Oudshoorn, N.E.J. (2000) 'Vorstudie ICT en maatschappij in verandering'. In: Raad voor Maatschappelijke Ontwikkeling *Ver weg en dichtbij: over hoe ICT de samenleving kan verbeteren*. Den Haag: Raad voor Maatschappelijke Ontwikkeling, 35 - 101.
- Rommes, E., van Oost, E.C.J. and Oudshoorn, N. (1999) 'Gender and the Design of a Digital City' *Information, Communication and Society*, 2 (4), 476-495.
- Oudshoorn, N.E.J. and Brouns, M. (1998) *Welzijn en cultuur: programmeringsstudie stimuleringsprogramma Maatschappij en Electronische Snelweg*. Den Haag: NWO.
- Oudshoorn, N.E.J. (1998) 'Shifting Boundaries between Industry and Science: the Role of the WHO in Contraceptive R&D'. In: Gaudilliere, J-P and Lowy, I. (eds) *The Invisible Industrialist: Manufactures and the Production of Scientific Knowledge*. Houndsmill, Basingstoke, Hampshire and London: MacMillan Press, 345-369.

L. Dubbeld

- Dubbeld, L. (te verschijnen) 'Bescherming van persoonsgegevens bij telemonitoring van hartpatiënten' *Privacy & Informatie*.
- Dubbeld, L. (te verschijnen) 'Protecting Personal Data in Camera Surveillance Practices' *Surveillance & Society*.
- Dubbeld, L. (te verschijnen) 'The Role of Technology in Shaping Camera Surveillance Practices' *Information, Communication and Society*.
- Dubbeld, L. (2004) *The Regulation of the Observing Gaze: Privacy Implications of Camera Surveillance*. Enschede: PrintPartners Ipskamp.
- Dubbeld, L. (2004) 'Limits on Surveillance: Frictions, Fragilities and Failures in the Operation of Camera Surveillance' *Information, Communication and Ethics in Society*, 2 (1), 9-19.
- Dubbeld, L. (2003) 'Observing Bodies: Camera Surveillance and the Significance of the Body' *Ethics & Information Technology*, 5 (3), 151-162.
- Dubbeld, L. (2002) 'Cameratoezicht'. In: Prins, J.E.J. et al. (red) *Handboek Recht en Informatietechnologie: handboek voor rechtspraktijk en beleid*. Den Haag: SDU, hoofdstuk 6^E, 1-30.
- Dubbeld, L. (2001) 'Het einde van privacy zoals we haar kennen?' *Krisis: tijdschrift voor empirische filosofie*, 2 (3), 105-111.

J. Nouwt

- Nouwt, J. (2004) *Toegang tot patiëntengegevens: van wet naar praktijk: implementatie van de WGBO*. Utrecht: KNMG.
- Nouwt, J. (2003) 'Het recht op privacy in de gezondheidszorg'. In: Legemaate, J. (red) *Regelgeving beroepsuitoefening gezondheidszorg*. Houten: Bohn Stafleu Van Loghum, A7360.1-A7360.35.
- Nouwt, J., Prins, J.E.J., Meulen, B.M.J. van der and Lugt, M. (2003) *Transparency in Network Chains - Legal Dimensions*. Tilburg: UvT.
- Nouwt, J. (2002) 'Het recht op privacy van de bewoner, patiënt, cliënt of verpleegde'. In: *Handboek Huisvesting en verzorging ouderen*. Maarssen: Elsevier Bedrijfsinformatie, II 4.1-1-52.
- Nouwt, J. (2002) *Beveiliging van het EPD: rapportage van het juridisch laboratorium, binnen het kader van het programma Informatie- en Communicatietechnologie in de Zorg (ICZ) van ZonMw*. Den Haag: ZonMw.
- Dorn, N. and Nouwt, J. (2002) *Final Report on EMCDDA Study CT.00.EP.12 on the Implications of Data Protection Legislation for Epidemiological Information Systems in EU Member States*. London: Drugscope.
- Nouwt, J. (2002) 'Privacy en medische informatie'. In: Prins, J.E.J. en Berkvens, J.M.A. (red) *Privacyregulering in theorie en praktijk*. Deventer: Kluwer, 255-280.
- Nouwt, J. (2000) 'Digital Signatures and Encryption as Key Elements of Security in Health Telematics: Overview of National Legislative Approaches in the EU Member States: The Netherlands'. In: Rienhoff, O., Laske, C., van Eecke, P., Wenzlaff, P. and Piccolo, U. (eds), *A Legal Framework for Security in European Health Care Telematics*. Amsterdam etc.: IOS Press, 74-75; 138-140.
- Nouwt, J. (2000) *Handboek privacy Zorggroep Almere*. Almere: Zorggroep Almere.
- Nouwt, J. (1997) *Zorg voor privacy: informatietechnologie en informatieprivacy in de gezondheidszorg*. Den Haag: SDU.

R. J. Wieringa

- Hartel, P., Eck, P. van, Etalle, S. and Wieringa, R.J. (te verschijnen) 'Modelling Mobility Aspects of Security Policies'. In: *Construction and Analysis of Safe, Secure and Interoperable Smart cards (CASSIS)*. Berlin: Springer-Verlag.

Eck, P. van, Gordijn, J. and Wieringa, R.J. (2004) *Value-Based Design of Collaboration Processes for E-commerce*. Enschede: University of Twente.

Wieringa, R.J. (2003) *Design Methods for Reactive systems: Yourdon, StateMate, and the UML*. San Francisco: Morgan Kaufmann.

Meyer, J.-J.Ch., Wieringa, R.J. and Dignum, F.P.M. (1998) 'The Role of Deontic Logic in the Specification of Information Systems'. In: Chomicki, J. and Saake, G. (eds), *Logics for Databases and Information Systems*. Denter: Kluwer, 71-115.

Wieringa, R.J. (1997) *Specification and Design of a Meeting Scheduler System*. Amsterdam: Vrije Universiteit Amsterdam.

Wieringa, R.J. (1996) *Requirements Engineering: Frameworks for Understanding*. Chichester: Wiley.

Dignum, F., Meyer J.-J.Ch., Wieringa, R.J. and Kuiper, R. (1996) 'A Modal Approach to Intentions, Commitments and Obligations: Intention Plus Commitment Yields Obligation'. In: Brown, M.A. and Carmo, J. (eds) *Deontic Logic, Agency and Normative Systems*. Berlin: Springer Verlag, 80-97.

Wieringa, R.J. and Meyer, J.-J.Ch. (1993) 'Actors, Actions, and Initiative in Normative System Specification' *Annals of Mathematics and Artificial Intelligence*, 7, 289–346.

d'Altan, P., Meyer, J.-J.Ch. and Wieringa, R.J. (1993) 'An Integrated System for Ought-to-be and Ought-to-do'. In: Horty, J., Shoham, Y., Doyle, J., Levesque, H. and Pollack, M. (eds) *Working Notes, AAAI Spring Symposium Series*. Stanford: Stanford University, 48-57.

Wieringa, R.J. and Meyer, J.-J.Ch. (1993) 'Applications of Deontic Logic in Computer Science: A Concise Overview'. In: Meyer, J.-J.Ch. and Wieringa, R.J. (eds) *Deontic Logic in Computer Science: Normative System Specification*. Chichester: Wiley, 17-40.

10b. Previous and current applications to NWO

Oudshoorn

file number: 458-03-111 (2004)

title: The dynamics of user-initiated innovation in ICT networks

Nouwt

file number: ITeR 014-38-521 (2004)

title: Dienen vormen van gebruik van ongeautoriseerd ter beschikking gestelde bedrijfs- en persoonsgegevens strafbaar te worden gesteld?

file number: ITeR 014-37-331 (1999)

title: De toepassing van privacyregels op elektronische berichten

Wieringa

file number: STW-Jacquard 638.000.000.04.N05 (2004)

title: Value-based IT alignment

file: Hefboomprogramma 641.000.410 (2004)

title : Process support in e-health

file: TIT 6679 (2004)

title: Integrated policy-based intrusion detection

file number: 612.023.419 (2002)

title: Deontic integrity rules, deadlines and real time databases

file number: 612-317-408 (1992)

title: Animation of formal database specifications

file number: 612-62-002 (1998)

title: Deontic activity and enterprise modeling with an object-oriented notation

Currently under review with NWO:

Coordination process correctness and trust assumptions (open competitie exacte wetenschappen)

Modeling control aspects of embedded systems (open competitie exacte wetenschappen)

I hereby declare that I have completed this form truthfully

Name: N.E.J. Oudshoorn

Place: Enschede

Date: 12 - 01 - 2005

Appendix 1: ad 1.

CV of main applicant, Prof. dr. N.E.J. Oudshoorn

Nelly Oudshoorn is professor of Science and Technology Studies at the Centre of Science, Technology and Society in the Faculty of Business, Public Administration and Technology at the University of Twente (0,4 fte 1995-1999; 0,8 fte 1999-now). In addition, she is a Visiting professor at the Department of Interdisciplinary Studies of Culture at the Norwegian University of Science and Technology (2000 – 2005), and has been visiting professor at the Department of Technology and Social Change in Linköping, Sweden (April-June 1998) and the Department of Science and Technology Studies at Cornell University in Ithaca, USA (August – December 1998). Before her appointment as full professor at the University of Twente, she has been an associate professor at the Department of Science Dynamics at the University of Amsterdam (1989-1999).

Currently, she is the leader of the research program Users of Science and Technology at the Centre for Studies of Science, Technology and Society, and member of the expert team of the Research Institute CTIT (Centre for Telematics and Information Technology), both at the University of Twente. She is contributing editor of the journal *Science, Technology & Human Values*, editorial adviser of the journal *Social Studies of Science*, member of the Advisory Council of the Society for the History of Technology, member of the *International Editorial Board of the European Journal of Women's Studies*, member of the Advisory Board of *Tijdschrift voor Genderstudies*, and member of the program committee of the Dutch Research Council's research program Society and the Electronic Highway (NWO Maatschappij en Electronische Snelweg).

Her research interests and publications include the mutual shaping of users and technologies, in particular medical technologies and information and communication technologies. She is chair of the board of the Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC).

Appendix 2: ad 6d.

CV of post-doc and senior researchers.

dr. L. Dubbeld.

Lynsey Dubbeld is postdoc at the Centre for Studies of Science, Technology and Society in the Faculty of Business, Public Administration and Technology at the University of Twente. She received her MA in Philosophy and MSc in Science and Technology Studies at the University of Amsterdam. In 2001, she published a book on prison architecture and social control ('In de geborgenheid van de gevangenis: de betekenis van de nieuwe Nederlandse gevangenisarchitectuur', Amsterdam University Press, 2001), which was based on her MA research. In 2004, she received a PhD in Philosophy at the University of Twente. Her dissertation, ('The regulation of the observing gaze: privacy implications of camera surveillance', Print Partners Ipskamp, 2004) is an empirical-conceptual exploration of the privacy aspects of public video surveillance systems.

Currently, she is working on a two-year project concerning issues of privacy and security in the context of telemonitoring systems in the health care sector. The project is funded by the Centre for Telematics and Information Technology at the University of Twente, and involves close cooperation with the Department of Computer Sciences.

She is a member of the Dutch Association for Gender and Technology, and a contributing editor of its newsletter. She also participates in the Dutch Privacy Colloquium, and the Netherlands Graduate Research School of Science, Technology, and Modern Culture (WTMC). She is peer referee for the international journal *Information, Communication and Ethics in Society*.

For CV of prof. dr. N.E.J. Oudshoorn, see above (appendix 1).

mr. dr. J. Nouwt.

Sjaak Nouwt is Assistant Professor at Tilburg University, Faculty of Law, where he is a member of the Tilburg Institute for Law, Technology, and Society (TILT). He studied Dutch Law at Tilburg University from 1978 to 1985. He was a University Lecturer in Computers and Law at the Faculty of Law at Tilburg University from 1985 to 1987. At present, he teaches courses in Computers and Law and, in particular on privacy and data protection, and government information law. These courses are given to both Dutch and foreign students.

In 1997, Sjaak Nouwt published his doctoral thesis on the use of information technology in the health care system and the protection of medical data. He has written several other articles on privacy and data protection issues. He is editor-in-chief of a Dutch journal on Data Protection in Health Care (*Journal Privacy Gezondheidszorg*) and also member of the editorial staff of other journals, text-books, and loose-leaf publications on privacy and data protection. Sjaak Nouwt is also editor-in-chief of the Dutch Internet Law Library.

prof. dr. R.J. Wieringa.

Roel Wieringa is Chair of Information Systems at the Faculty of Electrical Engineering, Mathematics & Computer Science of the University of Twente, the Netherlands.

Wieringa obtained his M.Sc. in Mathematics in 1978, an M.A. in Philosophy in 1987, and a Ph.D. in Computer Science in 1990. He taught mathematics at secondary schools from 1978 to 1983 and was a software instructor at Wageningen University. He was an assistant professor at the Free University, Amsterdam, from 1997 till 1998. Since 1998 he works at the University of Twente's Department of Information Systems. In 2002 he started his own company, which provides consultations on software requirements and ICT architecture in government organizations and financial businesses.

Wieringa is currently Chair of the Steering Committee of the IEEE Requirements Engineering Conference. He is also a member of the board of the Dutch ICT Architecture Forum, which organizes a yearly conference (the National ICT Architecture Congress) and aims to facilitate content-oriented working groups about topics of current interest.

In 2004, Wieringa edited amongst others a special issue of IEEE Software Magazine with Christof Ebert, and a special issue of the Requirements Engineering Journal. Wieringa is a member of the Dutch Research School for Information and Knowledge Systems (SIKS), and participates in projects funded by the Centre for Telematics and Information Technology at the University of Twente.

Appendix 3: ad 9.

Description of the research project.

9.1 Research topic and problem definition

Introduction

Privacy has often been viewed as a constraint to the effective implementation and widespread use of ICTs in the healthcare sector, especially in the emerging field of telemedicine (e.g., Moore, 1999; Rigby et al., 2000).

At the moment, little is known about workable ways to protect privacy in the context of telemedicine. That is, uncertainties exist with regard to the question which policies are suitable for addressing patients' privacy interests while also allowing organisations to make efficient use of electronic data processing systems and have easy access to medical information (e.g., Raad voor Volksgezondheid en Zorg, 2002; cf. DeCew, 1999; Cabrera, 2004).

So far, literature concerning data protection has been concerned with reviewing either how legislative requirements have been taken up in practice (e.g., Prins et al., 1995), or with assessing the adequacy of technical measures for data protection (e.g., Hes & Borking, 1998). In contrast, this project will adopt a multidisciplinary approach, discussing both policy and technical instruments for data protection. Hence, it will offer a thorough analysis of privacy protections for telemedicine systems, and an overview of data protection mechanisms that will not constrain the future growth of telemedicine.

Research aims

This project aims to provide a discussion of approaches to data protection that are currently available and in use, and to offer an in-depth study of socio-technical complexities regarding privacy in telemedicine. The analysis will result in an assessment of different mechanisms for protecting privacy with a view to healthcare organisations' data processing needs.

Research scope

The project will focus on *privacy* issues in the growing field of *telemedicine*.

Telemedicine provides a telling example of ICTs, as it has raised high expectations that (so far) do not appear to have been met in practice. Telemedicine, which can be defined as the delivery of healthcare services and the exchange of healthcare information across distances via ICTs (Moore, 1999: 245; Mair & Whitten, 2000: 1517; Wootton, 2001: 557), has been hailed as providing cost-effective or even cost-reductive healthcare services (Emery, 1998; Craig, 1999), and improving quality of care and access to healthcare services (Louis et al., 2003). Yet, similar to the implementation of other ICTs in healthcare organisations (Berg, 2001; Ministerie van Volksgezondheid Welzijn en Sport, 2000), the introduction of telemedicine systems in day-to-day healthcare practices in the Netherlands has tended to be problematic, uneven, and subject to negotiations between different actors involved (Seysener, 2001; Zwart, 2002; Hoeks & Nijhuis, 2004; cf. Wootton, 2000).

Privacy is one of the issues that is often held responsible for these difficulties: data protection tends to be viewed as a hindrance to adoption of data processing systems such as telemedical appliances (van Rijen et al., 2002; Skulimowski, 2004). Of course, issues concerning protection of personal data are not the only (potential) barriers to the use and growth of telemedicine. But privacy is unmistakably one of the most frequently invoked topics in public opinion (e.g., Hentenaar, 2003), policy debates (e.g., Raad voor Volksgezondheid en Zorg, 2002), and academic publications (e.g., Rigby et al., 2000a; Barber et al., 2004) regarding the use of ICTs in healthcare. Also, because of its networked character, telemedicine raises particular challenges to protecting personal information: telemedicine is essentially based on data flowing among a range of organisations and locations (including healthcare institutions as well as health insurers and patients' homes), which poses problems with respect to protection of medical data. Because of the limited duration of the project, the exploration and analysis of privacy will be limited to Dutch case studies and Dutch (and, where relevant, European) law (i.e., the Dutch data protection law, Wet bescherming persoonsgegevens, and European Directive 95/45/EC). For the same reason, the focus will be on data protection, even though in principle other aspects of privacy might bear relevance as well (cf. Nouwt, 1997: 2).

Research questions

1. Which approaches to data protection are currently available and in use with respect to the use of ICT networks, in particular telemedicine, in the healthcare sector in the Netherlands?
2. Which of these approaches can be considered most adequate and satisfactory with respect to enabling organisations to use telemedicine applications as they wish while also protecting individuals' personal data?

9.2 Approach

Theoretical framework

This project builds on theories regarding the roles of users in shaping socio-technical networks (e.g., Oudshoorn & Pinch, 2003). These user studies provide an important theoretical framework, because different users involved in the healthcare sector (such as doctors, patients, and health insurers) may have different, and indeed conflicting, privacy views (cf. Raab & Bennett, 1998). As this project will be concerned with exploring how apparently conflicting interests (such as organisations' intentions to use ICTs and have access to medical data on the one hand, and legal requirements of patient privacy on the other) can be balanced and reconciled, it will adopt a multi-user perspective on socio-technical practices (cf. Berg, 1999).

Research design and methodology

The proposed research will involve a literature study, questionnaires, and empirical case studies. The literature study serves as a starting point for gaining an overview of current data protection issues, approaches, and instruments. Questionnaires will explore which data protection measures are proposed as desirable by organisations involved in telemedicine projects. The case studies will investigate in more detail data protection problems and solutions that play a role in actual telemedicine practices.

Combining the results of the literature study, questionnaires, and empirical case studies will enable a comparison between data protection perspectives that have been developed in theory and law, organisational policies, and everyday practice. This comparison will result in an evaluation of different approaches to data protection relevant to the case of telemedicine, and a recommendation as to the most successful and most promising perspectives with a view to future uses of telemedicine.

Literature study

Legal, policy, and technical literature on data protection, and some of the current literature on privacy issues in telemedicine (and, where relevant, other ICT applications in the healthcare sector), will be studied in order to identify perspectives and solutions with regard to balancing data protection requirements with organisations' interests in data processing. This review will yield an overview of instruments for data protection relevant to the case of telemedicine, and drawbacks and benefits of each (cf. Bennett & Raab, 2003).

Questionnaires

Questionnaires will be sent to ten to fifteen healthcare organisations that are involved in the use of telemedicine systems, in order to gain insight in professionals' views on data protection. Organisations will be selected through amongst others databases (www.nictiz.nl); <http://database.nitel.nl>), and project members' existing contacts in the healthcare sector (such as Roessingh, Enschede).

Case studies

Two case studies will explore day-to-day approaches to data protection and the dynamics of privacy protection in actual telemedicine practices.

The cases concern two types of telemedicine:

1. Asynchronous store-and-forward telemedicine, which involves teletransmission of medical data among healthcare practitioners.
2. Systems that enable interactions at a distance between healthcare professionals and patients.

Based on current insights in telemedicine projects, candidates for case studies include:

Ad 1: Teledermatology in Teledermatologisch Consultatie Centrum Nederland, an email-based communication network between hospital dermatologists and general practitioners in the northern region of the Netherlands (<http://www.teleconsultatie.nl>).

Ad 2: Telemonitoring of thrombosis patients through a Dutch telemedical service centre, Telemedicine TrainingsCentrum Antistolling (Kramer, 2004).

A comparison between these types of cases is informative, because each case can be expected to bring to the fore a specific aspect of network dynamics: type of data being processed (ECGs, images, patients' medical records), type of interactions (doctor-to-doctor, or doctor-patient), and aspects of privacy that come to the fore with particular force (data protection, or professionals' duty of confidentiality).

The case studies will draw upon methods used by Prins et al. in their evaluation of the former Dutch data protection law (Prins et al., 1995, chapter 1): interviews, site visits, observations, and document analysis. As a recent study made clear, these methods are well suited, if not indispensable, for studying everyday privacy practices in contemporary socio-technical networks (Dubveld, 2004; cf. Berg, 1999).

9.3 Scientific relevance

This project will contribute to knowledge about the dynamics of socio-technical networks in the healthcare sector. As privacy issues can be considered one of the factors shaping the adoption and use of network technologies, insights in policies for data protection will improve our understanding of the development of innovative network technologies.

9.4 Social and policy relevance

This project discusses the adequacy of different approaches to data protection with a view to enabling organisations to make use of telemedical networks while also taking into account data protection requirements. Hence, it contributes to knowledge about successful implementation and use of ICTs in healthcare practice.

In addition, the project contributes to policies for privacy regulation in the context of telemedicine. As a consequence of the growing use of ICTs in the healthcare sector, risks regarding protection of patient information are likely to augment (Inspectie voor de gezondheidszorg, 2004: 12).

Therefore, policy initiatives with respect to protecting privacy (while also taking into account organisations' interests in data processing) appear to be necessary and urgent. Also, privacy could become one of the themes in the development of standards for telemedicine systems, which are often considered a prerequisite for the realisation of successful telemedicine applications (cf. Toussaint & Berg, 2001). For these reasons, the project will distinguish a number of instruments for addressing data protection that are most promising from a practical and policy perspective, and discuss measures that might need (more) government stimulation.

9.5 Literature references

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