Citizen-centred health information technologies:
Communicative opportunities and challenges
(PAHI 2014)

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1   Introduction

The second European workshop on Practical Aspects of Health Informatics (PAHI 2014) took place at Kunnskapssenteret NTNU/ St.Olavs University Hospital in Trondheim May 19th and 20th, 2014, with participants from Norway, Scotland, Canada, and Belgium. The Norwegian University of Science and Technology (NTNU) and the Norwegian Research Network for Women in Health Informatics organized this year's workshop in collaboration with the Digital Health Institute, Scotland. The workshop was followed by a one-day post-workshop seminar where the aim was to discuss future cooperation between NTNU and the Digital Health Institute.

This year's workshop focused on citizen-centred health informatics, a term that is frequently used in relation to future health care systems. It describes a new era where citizens, patients or even consumers should take an active part in their own wellbeing or health decision-making. Definitions of citizen-, patient- or consumer-centred health informatics vary, and can be dependent on country or context. We have placed our workshop in a context of shared decision making for active and engaged citizens, where citizens provide health information by monitoring or using sensors for more accurate data. Within this context both communication and health literacy are central issues. In some countries citizen centeredness in healthcare services is increasingly emphasised, e.g., as can be observed in the current calls for research proposals in the European Horizon 2020 programme. There are expectations that health information technologies should be designed and implemented for maintaining citizen centeredness, but on the other hand healthcare institutions may not be ready to embrace such a change. For many years there has been an exponential development of software and tools which has not been successfully implemented. The future Health 2.0 mantra requires collaboration of stakeholders (e.g., patients, healthcare professionals, governance and technologist). Today, interdisciplinary collaboration represents a great challenge to many, due to e.g. lack of common language and goals. The Scottish government has taken an active role in facilitating collaboration with

stakeholders by publishing the health literacy action plan[1]. The action plan deems health literacy to be the responsibility of the health service and its practitioners. Our challenge is also to develop systems and workflows which can enable us to collaborate in improving citizens' health. However, due to the interdisciplinary complexity of the development and implementation of health information technologies, medical, technological, relational and communicative aspects must be examined before a successful implementation can take place. Furthermore, following the paradigms of co-design and co-creation, these aspects must also be covered as part of an iterative development process. The PAHI workshop aimed at highlighting interdisciplinary research questions concerning communication and citizen centred health information technologies. Hopefully, the workshop contributed to generating knowledge about theoretical, methodological and empirical approaches to interdisciplinary research in this field. We also see gender equality as an important issue, and for this reason we had a clear aim to challenge our fellow researchers from both genders to present their work and facilitate networking for future collaboration. In this respect we were particularly successful, as a perfect gender balance of paper authors and presenters was obtained.

1.1 The objective and aims of PAHI 2014

The objective of PAHI 2014 was to address communicative opportunities and challenges concerning citizen-centred health information technologies. The specific aims were: 1) to facilitate international networking and exchange of interdisciplinary perspectives on communicative opportunities and challenges in health information technologies, 2) to encourage researchers to produce scientific papers about communicative opportunities and challenges in health information technologies 3) to facilitate presentations of work relevant to communication and eHealth, 4) to explore possibilities for common research projects.

1.2 The review process

The call for papers to the workshop included, but was not limited to, the following topics: eHealth communication, eHealth literacy, professional and lay communication in citizen-centred records, quality and risk management in eHealth, eHealth ethics, the increasing mobility and communication in citizen-centred records, lessons learned in relation to failure projects, patient-centred ICT, the impact of ICT for professional healthcare practice, translating HI research into clinical practice, methodological development of healthcare ICT relevant for practice, usability of health informatics, policies and strategies for ICT in healthcare, bridging the gap between health informatics research and clinical practice, health informatics on new computing platforms, health informatics for home use, coordination aspects in use of health informatics, design aspects of health informatics.

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[1] http://www.scotland.gov.uk/Resource/0045/00451263.pdf

The international program committee consisted of 34 scientists, representing a wide range of professions: medical doctors, nurses, information scientists, engineers, sociologists, psychologists, pharmacists, radiographers, and health communication researchers. The program committee represented the following countries: Norway, Sweden, Denmark, Scotland, Austria, Ireland, USA and Canada.

We received a number of papers from researchers from many fields of health informatics. Each of the papers underwent minimum three reviews (some had five reviews) from anonymous reviewers, and was rated according to predefined criteria[2]. The accepted papers were categorised thematically, and we derived the following main topics for the paper presentations during the workshop: eHealth in context, Security and safety, eHealth Literacy and communication and Methodology.

2   Workshop summary

The workshop brought together scientists from medicine, technology studies and social science. The Dean of the medical faculty Stig Slørdahl opened the workshop and provided an introduction to NTNU.

2.1   Invited keynotes

The two keynote speakers were both medical trained with special interest in health information technology. Arild Faxvaag presented his views on health informatics and how technology has influenced the field of medicine. Arild Faxvaag is Professor at NTNU and head of the Norwegian Centre for Electronic health records research (NSEP). He got his M.D. in 1986 and dissertated in 1995. He became a specialist in rheumatology and associate professor in 1999. He began engaging in health informatics implementation activities and started doing health informatics evaluation research in 2000. He is a founding member of NTNUs multidisciplinary health informatics research community, an activity that he now leads. He has 31 full text papers of which most are indexed in PubMed (H-Index 13), in addition to 18 conference papers and 6 reviews, book chapters and reports.

The second day keynote was held by Grant Cumming BSc (Hons) MBChB MD FRCOG. He is Consultant Obstetrician & Gynaecologist at Dr Gray's Hospital, NHS Grampian and Honorary Senior Lecturer at University of Aberdeen. He is also an Honorary Professor at University of the Highlands and Islands.

Grant Cumming has a special interest in health informatics which stems from an enthusiasm to use technology to improve the delivery of health care. He has been involved in building the evidence base for using digital technologies to deliver healthcare which has been recognised with the development of a life science building in Elgin with a remit to develop digital health further. This work has also been recognised by the WHO who hosted a meeting in the locality and also by the

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[2] We used the standard EasyChair rating: Strong Accept – Accept – Weak Accept – Neutral – Weak Reject – Reject – Strong Reject.

University of Highlands and Islands who created a new chair in digital health based in the life science centre.

The Internet of things gives us the opportunity to predict behaviour and provide preventative, participatory and personalised medicine. The summary of his keynote on page 145 provides an overview of the challenges healthcare is facing,.

2.2   Mind the gap – Abilia

Abilia is a commercial actor involved in development of ICT in healthcare. The firm presented some of their product and development areas. They also called for collaboration and welcomed researchers who might take interest in their field. Commercial health ICT industry in Norway has in some areas had great impact on people's lives with tools that could deliver valuable information for future projects.

2.3   Panel discussion

The aim of the panel discussion at the conference was to investigate and discuss the different approaches being taken by different disciplines while investigating and researching possible new approaches to Health Informatics. The panel was made up of a diverse set of researchers active in both clinical, social science and computing fields. These research areas have tended in the past to concentrate on research methodologies using quantitative and qualitative methods. In some cases action research and mixed methods have also been used. It is acknowledged by the organisers of the panel and discussion that as we innovate in this field and work in a progressively more cross disciplinary way, we need also to forge and test appropriate and possibly new research methodologies.

Four invited speakers presented their field of research to the audience:

1.   Professor Dag Svanes presented a view on healthcare technology from a technology perspective.

2.   Professor Arild Faxvaag presented a view on healthcare technology from a medical perspective.

3.   Professor Aksel Tjora presented healthcare technology in a sociological perspective. Based on this presentation, he was invited to submit a full paper which was peer-reviewed, and can be found on page 135 of the proceedings.

4.   Professor Bård Kulseng and General Practitioner Morten Jensvoll presented a clinical project for better communication across disciplines in healthcare (page 155).

The panel started with short presentations from each of the participants followed by brief discussion. It was recognised that different approaches had been taken, as was appropriate to the different contexts. The group then split into smaller teams who were given a task of discussing which method could be used for one of two presented innovation scenarios. There was good discussion taking place within the groups, and

the exercise gave the participants the opportunity of better understanding the choices colleagues from different disciplines took when deciding which approach would be taken.

2.4   The post-workshop seminar "Future collaboration?"

On Wednesday 21th May, a post-workshop seminar on possible future collaboration was held at NSEP, Medisinsk teknisk forskningssenter.

  Digital Health Institute (DHI) was represented by Elizabeth Brooks, Design Director and Tara French, Innovation designer. They met local health informatics researchers and local innovation representatives. The researchers were composed from three different faculties of the University (Informatics, medicine and sociology) and represented different professions. From the faculty of medicine Professor Arild Faxvaag participated, Professor Dag Svanæs and Senior Engineer Terje Røsand represented the department of Computer and Information Science, and Professor Aksel Tjora represented the Department of Sociology and Political Science. From the administration of the faculty of medicine, Karin Tømmerås presented her special focus related to innovation in the faculty of medicine. Ketil Thorvik represented Hosptial innovation (Operation Theatre of the future). Each participant presented their focus of research, and possible areas for collaboration. Other participants included Kirsti Berntsen, Heidi Gilstad and Ellen Jaatun. The meeting was open for all interested parties.

3   Participants

The Norwegian University of Science and Technology, NTNU, and the Norwegian Research Network for Women in Health Informatics organized this year's workshop in collaboration with the Digital Health Institute, Scotland.

3.1   Chairs

General Chairs: Ellen Jaatun (NTNU) and Elizabeth Brooks (DHI)

Program Chairs: Kirsti E. Berntsen (NTNU) and Heidi Gilstad (NTNU)

Publication Chair: Martin Gilje Jaatun (SINTEF ICT)

3.2   International Program committee (reviewers)

Elke Beck, University of Saltzburg, Austria
Johan Gustav Bellika, University of Tromsø, Norway

Kirsti Berntsen, NTNU, Norway
Pernille Bertelsen, Aalborg University, Denmark
Berit Brattheim, Sør-Trøndelag University College, Norway
Brian Dixon, InDI, Glasgow School of Art, UK
Gunnar Ellingsen, University of Tromsø, Norway
Arild Faxvaag, NTNU, Norway
Florian Foerster, Georgia Institute of Technology, US
Tara French, InDI, Glasgow School of Art, UK
Heidi Gilstad, NTNU, Norway
Gunnar Hartvigsen, University of Tromsø, Norway
Anna Marie Balling Høstgaard, Aalborg University, Denmark
Erna Håland, NTNU, Norway
Ellen Jaatun, NTNU, Norway
Martin Gilje Jaatun, SINTEF ICT, Norway
Bridget Kane, Trinity College Dublin, Ireland
Gunnar Klein, Ørebro University, Sweden
Yngve Lamo, Bergen University College, Norway
Andreas Landmark, NTNU, Norway
Børge Lillebo, NTNU, Norway
Wendy MacCaull, St Francis Xavier University, Canada
Anne Lise Sagen Major, Central Norway Pharmaceutical Trust Ålesund, Norway
Line Melby, UiO, Norway
Marius Mikalsen, SINTEF ICT, Norway
Irene Olaussen, Norwegian Directorate of Health
Claudia Pagliari, University of Edinburgh, UK
Rune Pedersen, Norwegian Centre of Integrated Care and Telemedicine, Tromsø
Anders Kofod-Petersen, NTNU, Norway
Isabella Scandurra, Uppsala University, Sweden
Gry Seland, Vivit, Norway
Inger Sørby, Vivit, Norway
Gøril Thomassen, NTNU, Norway
Leendert Wienhofen, SINTEF ICT, Norway

3.3   Participants

Adrian Rutle, Ålesund University College, Norway
Aksel Tjora, NTNU, Norway
Andreas Landmark, SINTEF Technology & Society, Norway
Anita Das, NTNU, Norway
Arild Faxvaag, NSEP/NTNU, Norway
Berit Brattheim, NTNU, Norway
Bård Kulseng, NTNU / St. Olavs Hospital, Norway
Dag Svanæs, NSEP/NTNU, Norway
Davy Preuveneers, Department of Computer Science, K.U.Leuven, Belgium
Elizabeth Brooks, Digital Health Institute, United Kingdom

Ellen Jaatun, NTNU / St. Olavs Hospital, Norway
Erna Håland, NTNU/SVT, Norway
Fazle Rabbi, Bergen University College, Norway
Grant Cumming, Dr Gray's Hospital / University of Aberdeen / University of
    Highlands and Islands, United Kingdom
Gry Seland, Vivit AS, Norway
Gunnar Klein, NTNU/NSEP & Ørebro, Sweden
Hans Georg Schaathun, Høgskolen i Ålesund, Norway
Hans Moen, NTNU/IDI, Norway
Heidi Gilstad, NSEP/NTNU, Norway
Ingeborg Grønning, NTNU/SVT, Norway
Karin Kajber, Sweden
Kirsti Berntsen, NSEP/NTNU, Norway
Lene Larsen, Abilia, Norway
Line Melby, University of Oslo, Norway
Marianne Hestvik, Abilia, Norway
Martin Gilje Jaatun, SINTEF ICT, Norway
Morten Jensvoll, Fosen Helse IKS, Norway
Pieter Toussaint, NSEP/NTNU, Norway
Ragnhild Hellesø, University of Oslo, Norway
Tara French, Digital Health Institute, United Kingdom
Tobias Buschmann Iversen, Helse-Vest IKT, Norway
Wendy MacCaull, Dept of Math/Stats/Comp Sci, St. Francis Xavier University,
    Canada
Yngve Lamo, Bergen University College, Norway

4   Presentations of the organizations involved in the workshop

1. Norwegian University of Science and Technology (NTNU) is located in Trondheim and is the second largest university in Norway.
2. Research network for women in health informatics: Interdisciplinary network which started at NTNU in 2009. The network has contributed to several national and international research events.
3. NSEP/Health Informatics Research Group, NTNU Interdisciplinary group of researchers within NTNU.
4. Digital Health Institute, Scotland is an innovation institute collaborating with academia, stakeholders and Industry. The institute will co-create sustainable economic growth through new products, services and systems developed together with businesses, academics, healthcare specialists and citizens. The aim is to generate high-value health and social care solutions to the benefit of the people of Scotland and wider.