

Preface to the special issue on personalization for e-health

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E-Health is defined by the World Health Organisation as ‘the combined use of electronic communication and information technology in the health sector’ (WHO <http://www.who.int/topics/ehealth/en/>). The Australian National e-Health strategy document builds on this definition by adding: “In more practical terms, E-Health is the means of ensuring that the right health information is provided to the right person at the right place and time in a secure, electronic form for the purpose of optimising the quality and efficiency of health care delivery” (National e-Health Strategy Summary 2008).

In the past few years, e-Health has been increasingly in the limelight, becoming an integral part of both national and international policies, attracting unprecedented levels of investment, and seeing research efforts and funding multiply consistently. In EU, for example, support for the implementation and the interoperability of e-Health solutions was one of the actions included in a white paper (EU 2008) laying out the Health Strategy for 2008–2013; it was recognised that e-Health “can help to provide better citizen-centred care as well as lowering costs and supporting interoperability across national boundaries, facilitating patient mobility and safety” (p. 9). This came after the Community, as early as 2004, adopted an e-Health action plan (EU 2004), which defined a set of targets in terms of the widespread use of ICT for health among the member States. In the US, in 2007, the eHealth Initiative (<http://www.ehealthinitiative.org>), after a six-month consultation, produced a Blueprint: “Building Consensus for Common Action” (eHealth Initiative 2007) representing an agreement among various

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stakeholders on a vision for health through IT, recognising the crucial role of IT in addressing the nation's challenges with respect to health care. The Blueprint was more recently reassessed in a report ([eHealth Initiative 2010](#)) which suggests that significant progress has been made in the uptake of that vision, perceived as still relevant. In Australasia, the Royal Australasian College of Physicians (RACP) states on its website that “[e-Health] should be viewed as the essential infrastructure underpinning information exchange between all participants in the Australia and New Zealand health care systems, and a key enabler and driver of improved health outcomes for all” ([RACP 2011](#)). In Australia, the National E-Health Transition Authority (NETHA) established a strategic Plan for 2009–2012, which states that “the National Health and Hospital Reform Commission (NHHRC) has identified that e-health has a major role to play in fostering genuine participation by consumers by allowing them to better manage their own care and be more informed in decision making about their healthcare and people they care for; supporting providers in the delivery of safer, more effective and more efficient healthcare; enabling a more agile, self-improving and sustainable health sector” [[NEHTA Blueprint \(2010\)](#): Executive summary, p 8]. It further states that “e-Health is viewed as a key enabler for change in the national Primary Healthcare Strategy and for health surveillance and monitoring in the National Preventive Health Strategy.”

E-Health is therefore here to stay. To differentiate it from the more general “health informatics”, e-Health is often characterised by a focus across many aspects of the health care delivery and the drive on being patient/consumer-centric (see, for example, the presentation by New Zealand's Associate Minister of Health in 2008: “New Zealand's New Vision for e-Health: Putting the Patient First: Enabling the Carer—Using information to support New Zealanders to be healthy, well & independent” ([O'Connor 2008](#))). This characterisation has been present in the public and academic scenes for many years. Besides the definition from the WHO mentioned above, many definitions of e-Health have been identified; all agree on the main principle that Information and Communications Technologies need to be utilised to improve not only the access, efficiency, effectiveness and quality of any processes related to health care, clinical and business alike, but also to facilitate citizens' engagement in their own healthcare, providing them with information to enable decision and control. To this ultimate aim, IT needs of course to support all stakeholders in the healthcare management, facilitating the data sharing among all health providers, supporting their decision making, and eventually shaping the healthcare landscape of the whole community.

This political and social vision is of course accompanied, and often preceded, by the growth of an interest in e-Health research. This is evidenced in the number of conferences and workshops (in both the scientific and industrial arena) dedicated to this theme, which has had a steady growth in the past number of years (see, for example, the conference series on e-Health (www.electronic-health.org), the IEEE Computer Based Medical Systems (CBMS) conference, now in its 24th year, the various conferences held in specific countries—e.g., in Australia: <http://www.ehealthconference.gov.au>, or the eHealth week in the EU, <http://www.worldofhealthit.org/>), newsletters (e.g., Med-e-Tel - Telemedicine and eHealth Newsletter) or the newly formed ACM Special Interest Group on Health Informatics <http://www.sight.org>).

Research on IT and e-Health has been moving in different directions, all contributing to the general vision whereby intelligent systems would, for example, enable:

- citizens to take more control of their well-being, by accessing relevant and qualified health information (both medical and pedagogical), accessing appropriate medical care and monitoring their health from their homes, or supporting each other in social networks;
- people who live in rural or isolated regions to get the health care they need, without the need to travel to a major city, thus saving patients the time and expense of travelling long distances to see medical specialists, while still providing them with appropriate care and enabling them to see the right specialist sooner;
- elderly patients to remain in their home while being able to be monitored as required and still receiving appropriate and necessary care;
- health professionals to manage their activity more efficiently, by receiving relevant and timely information and updates, obtain intelligent assistance at point-of-care, as well as discuss cases with each other and share experiences, also through (specialised) social networks and online communities;
- teams of health professionals to work together more effectively, coordinating their activities, sharing their knowledge about the patients they are collectively taking care of, and ensuring the best coordinated care is provided; and
- a range of support to be provided for many processes related to health care.

This special issue of the *UMUAI* journal focuses on a crucial tile in the e-Health mosaic, which relates to *personalization*. The patient-centric approach naturally implies that personalization plays an important role to achieve the e-Health vision—indeed, to provide relevant, timely and appropriate information or sophisticated intelligent support, a system ought to use personalization techniques.

Personalization in e-Health has been a focus of research for a number of years, both from a User Modelling perspective and from a medical perspective. Research in personalization for e-Health was originally mostly focused on the provision of information to consumers of health care (Lewis et al. 2005). This was largely in response to a significant change in how people looked for information about their health and their involvement in their own health care. While, in the past, the almost exclusive source of information was the medical staff directly concerned with the provision of care, the Internet and the World Wide Web provided new opportunities for a new generation of users, the “health information consumers”. These are people who seek information on various aspects related to health and well being, like health promotion, disease prevention, management of long term conditions, and so on. But as the amount of information available on the Web continues to grow, it is recognised that there is a need to design and develop intelligent systems capable of tailoring information for health care consumers (Hawkins et al. 2008), whereby only providing appropriate, timely and relevant information and exploiting this great potential to enhance health information and education through web (or mobile) delivery (Cawsey et al. 2007).

In recent years, however, personalization in e-Health has greatly expanded its scope, as reflected in the variety of contributions presented to a series of events dedicated to this topic, the “Personalization for e-Health workshops”. The series has been held annually since 2005, hosted by different venues, reflecting the multidisciplinary nature of the approach, starting with the User Modeling conference for the first two editions, the IEEE Conference on Computer Based Medical Systems for the third edition in 2008, the AI in Medicine conference for the fourth edition in 2009, and the ICST Conference on Electronic Healthcare for the twenty first century (eHealth) for the fifth edition in 2010. In recognition of the maturity of the research, this special issue of the *UMUAI* journal intends to build on the workshops’ success, although the papers presented here were solicited through an open call, not limited to the authors presenting at the workshops.

The papers selected for inclusion in this special issue provide a broad overview of the main e-Health research themes. They range from “classic” patient support and empowerment (Camerini et al. 2011) to support to the larger patient social community (family and friends) (Colineau and Paris 2011), and, from the medical perspective, from aid for just-in-time decision (Chittaro et al. 2011; Lindgren 2011) to a more efficient use of the resources (human time in this case) (Cohen 2011).

More specifically, from the e-Health consumer perspective, Camerini and colleagues (2011) and Colineau and Paris (2011) present work in line with the e-Health stated goal of enabling people to take more control of their healthcare and wellbeing. Camerini et al’s contribution further advances work on patient information and support, as they describe a system that presents personalised exercise videos for people with Fibromyalgia. The main aim is to enable these patients to self-manage their condition, following the by-now established principle that personalised material results in more compliance and gratification. Colineau and Paris (2011) investigate how to motivate members of a family to reflect upon their lifestyle and think of ways to improve it. They use the framework of an online portal. In particular, they look at whether providing explicit goals and tailored feedback can have an impact—namely, whether motivation, achievement and reflection can be enhanced when explicit goals and tailoring are provided. They explore these issues in a two week trial with families. Their goal is to motivate reflection and induce an intrinsic motivation, hopefully followed by action.

Looking at the medical staff perspective, Chittaro and colleagues (2011) present a system that also personalises instructions, but this time for medical practitioners in Emergency Medical Services (EMS), when they have to assist disabled patients. EMS have well-established general procedures to respond to various situations, but these are less able to deal with special cases, by necessity given the range of possibilities. In particular, the handling of patients with disabilities can be problematic. The system designed by Chittaro and colleagues aims at providing EMS nurses and volunteers the information and instructions appropriate for specific patients. The paper addresses the important e-Health issue of collaboration among different staff, and how efficient exchange of information is crucial to the quality of care. Moving towards decision support as opposed to information provision, Lindgren (2011), in her paper, describes a clinical decision support system to assist medical personnel in the diagnosis

of dementia. The system supports a medical practitioner by providing support for reasoning, decision-making and learning. The e-Health perspective addressed here is again the one of sharing data, by way of fusing different guidelines, so that the system could function as a common ground for collaboration and distributed teamwork, and as a way to collect high-quality data about patients that may later contribute to evidence-based medicine. Finally, the work by Cohen and colleagues (2011) presents yet another type of support for medical practitioners, in an emergency care unit scenario. In such hospital settings, it is of course crucial to employ the right person at the right time. A triage typically happens as a new patient comes in. Cohen and colleagues' thesis is that, while it is important to employ the best person for the job, it is also crucial to not interrupt—or bother—someone who is already critically engaged. They thus introduce a model for reasoning about the bother that might be occurred when agents decide to interact with each other. This could help emergency clinical assistants to make the best decision as to whom to call upon when a patient arrives, a result that dovetails nicely with the work by Chittaro and colleagues (2011).

All the papers of this special issue thus address different aspects of e-Health, all with personalization as a basis for support, whether to patients or medical practitioners. They contribute to the e-Health vision which “can benefit the entire community by improving access to care and quality of care and by making the health sector more efficient” by facilitating “information and data sharing between patients and health service providers, hospitals, health professionals and health information networks” (EU eHealth Policy, http://ec.europa.eu/health/ehealth/policy/index_en.htm). In all the papers, we find a number of themes emerging from designing systems that provide personalised support in e-Health. In particular, it is clear that issues of design and evaluation are paramount, but very difficult to address. To ensure a system will achieve its purpose and fit into a set of existing procedures, practices and habits, it is crucial to perform a thorough user requirement analysis. Once a system is designed and implemented, an evaluation must of course follow. Randomised trials remain the gold standard to evaluate interventions, but are particularly hard to carry out in e-Health settings (Jones and Goldsmith 2009), not only because of the intrinsic difficulty in forming the control groups, but also because parameters like “empowering the patient”, one of the main aims of e-Health, are hard to quantify and are often confused with others, like “patient satisfaction”, in the evaluation. Nevertheless, with the population of Internet users growing at fast speed, it is expected that more formal evaluations will come.

To achieve its stated aims, e-Health must include personalization, and it must do so in a variety of ways, addressing a number of issues and intended users, from patients to medical practitioners and carers. While we do not claim that this special issue provides an extensive coverage of work done in the field, we hope it will provide readers with a good overview of the research themes in this domain, a range of the possibilities personalization affords as well as the challenges that are being faced.

In memoriam

This special issue is in memory of, and dedicated to, Fiorella de Rosis and Alison Cawsey.



Fiorella de Rosis was an influential scholar in the field of user modeling and personalization. Her background in epidemiology allowed her to import many insights from the medical perspective to user modeling, and her work on public health informatics was well ahead of its time: hers were some of the early works on producing personalised patient information (Rosis and Grasso 1995). She was a leader in the field of intelligent interfaces, and her work on modelling affect and emotion in embodied agents was internationally recognised (de Rosis 2003). She died of cancer in July 2008.¹

Alison Cawsey was an internationally renowned scholar in the field of natural language processing and hypertext modeling. Her work on generating personalised natural language explanation was very influential, and its applications in the field of medical informatics were seminal, as well as robustly evaluated (Jones et al. 1999). Her book “Explanation and interaction: the computer generation of explanatory dialogues” (Cawsey 1992) remains one of the most comprehensive and clear on the subject, both for researchers and for students. She died of cancer in June 2009.²



Alison and Fiorella were at the very heart of the series of workshops on Personalization for e-Health, which gave origin to this special issue. Alison was part of the organising committee for the first two editions, held with the User Modeling conference, and Fiorella was a supportive and active member of the programme committee for all editions.

Alison and Fiorella were, however, most importantly, two exceptional human beings. We, Floriana and Cécile, had the privilege to work with them closely, and we feel honoured to guest edit this special issue in their memory. Floriana especially feels immensely fortunate to have had Fiorella as her MSc project supervisor, and Alison as her PhD thesis supervisor. In fact, Floriana can pinpoint precisely the moment she decided to be involved in research: when she attended, as an undergraduate student in informatics, a workshop on personalised interaction hosted by Fiorella at the University of Bari, where Alison was invited as a speaker. Working closely with them

¹ “Fiorella de Rosis, in memoriam”, *User Model User-Adap Inter* (2008) 18:539–540.

² Alison Cawsey Obituary, Heriot-Watt University, <http://www.macs.hw.ac.uk/cs/obituary.htm>.

was as much pleasant as it was stimulating. They were both unique mentors, each in her own way: Fiorella passionate and exhilarating, Alison profound and gentle, they both were able to transmit to their students the love for research as well as the rigour of scholarship. Cécile did her PhD at the same time as Alison, and they shared experiences while going through the sometimes difficult final stages of thesis writing and job seeking. Cécile met Fiorella over 20 years ago, during a workshop on the generation of explanations. She subsequently visited Fiorella at the University of Bari several times to give guest lectures, and traditionally shared a room with her at the International Conferences on User Modeling, something she always looked forward to, enjoyed tremendously and cherished. She was always impressed by Fiorella's energy, her creativity, and her enthusiasm for and support of younger researchers. Both Fiorella and Alison were kind, thoughtful, generous and good humoured, and most of all they were dear friends whom we will sorely miss, but whom we feel privileged to have known.

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Author Biographies

Floriana Grasso is a Lecturer in the Department of Computer Science at the University of Liverpool. She works in the recent research field of Argument and Computation, where she is interested in persuasiveness, and what it takes to achieve effective (and affective) communication. She approaches this from two points of view: high level discourse modelling and rhetoric (modelling the speaker's goals and strategies to generate persuasive discourse), where she draws on classical argumentation theory, and cognitive modelling, especially on modelling extra-rational characteristics such as opinions, values, emotions. She applied this research in public health informatics, where she especially looks at how to provide personalised and persuasive advice on healthier lifestyles. She has organised many workshops and events in the area of argumentation, persuasive technology and motivation. She is co-editor of the journal "Argument and Computation", published by Taylor and Francis.

Cécile Paris is a Science Leader at the CSIRO – Information and Communication Technology (ICT) Centre, in the Information Engineering Laboratory, Sydney, Australia. Dr. Paris leads the "Search, Language and Social Media" team and more generally supervises all the research in Human Computer Interaction in the ICT Centre. Dr. Paris received her B.A. degree in Computer Science from The University of California at Berkeley, USA, and her Masters and PhD degrees from Columbia University, New York, USA. Her main research interests lie in the areas of Language Technology, User Modeling and Human-Computer Interaction. Her PhD thesis was at the intersection of Natural Language Generation and User Modeling, and she has been in the User Modeling community since its inception. In recent years, her work has also included text summarisation and the exploration of Web 2.0 technologies, in particular online communities and social media. Dr. Paris has authored over a hundred technical papers. She was on the Editorial Board of UMUI for many years. She is currently the chair of CHISIG, the Computer Human Interaction Special Interest Group of the Human Factors and Ergonomics Society of Australia.