

# Contemporary Developments in Digital Health: An On-Going Conversation with Professor Jana Zvárová

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## Abstract

In the context of the 4 May 2018 Jana Zvárová Memorial Conference, this short article introduces my association with Professor Zvárová, the dialogues that brought us together and the content of our last conversation. It explores some imagined topics that we might still have been discussing

together today and contemporary digital health-related matters that might have been of interest to Jana.

## Keywords

Bio-informatics; Current directions; Developments; Digital health; Policy

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EJBI 2018; 14(2):49-52

Received: March 23, 2018

Accepted: March 29, 2018

Published: April 30, 2018

## 1 Introduction

Careers can be like woven fabrics. My own career has been like a journey through an organic landscape [1].<sup>1</sup> I have moved in sequence through several disciplinary areas. Originally grounded in the social sciences, my work has involved that discipline's methodological contributions to a number of fields – including health and the implementation of health-related services. For four decades now, my focus has been on the protection of people's rights in a good information and communication technology (ICT) society [2, 3]. Increasingly, my concentration has been on societies that are sound and full of well-being [4], and in which people continue to age actively and healthily.

Careers can also be much more sequential. Professor Jana Zvárová's academic career was clearly firmly in biomedical informatics. Yet her intellectual and personal concerns were much broader. She seemed particularly interested in placing biomedicine in its wider societal context. She set her own professional and career developments in a context that would offer a positive work-life balance. She always wanted to provide intellectual stimulus to young people, and she was especially encouraging of women younger than herself as well as of her own age.

Our careers were in many ways very different. Yet, our professional conversations were immediately interesting, engaging, and – above all – warm, ever since some first

discussions when Jana had visited the European Commission in Brussels as an external expert evaluating health informatics' proposals and reviewing project outcomes.

As summer approaches in the beautiful city of Prague, it is with considerable pleasure that I recall my last personal meeting five years ago with Jana.

## 2 Last Conversations

Conversations can take place in many settings in many locations. Physically, in the context of the June 2013 ICT, Society and Human Beings conference, Jana and I met and shared supper in an outdoor garden café near the city centre, close to the university buildings in the Czech capital.

My last evening meeting with Professor Zvárová took place shortly prior to Jana's founding of the EUROMISE Mentor Association. She was full of her plans for the future, the association and publications.

We discussed at length some of the upcoming societal and social trends in digital health. Jana expressed considerable interest in my presentation at the 2013 ICT, Society and Human Beings conference that encapsulated some first thoughts around the parallels between Slow Food and Slow Tech [5]: the emphasis was on good, clean, and fair technologies. These ideas, especially those on environmentalism and sustainability, were inspired in part by the writings of challenges to the future of humankind by former American Vice-President, Al Gore [6]. I was at

<sup>1</sup> Section 3 of this article is in particular an adaptation and re-working of part of this earlier publication.

an early stage of making preparations with my Italian co-author, Norberto Patrignani, to write a book on responsible, sustainable, and ethical technology [4], and initiatives to support Swedish colleague, Gunilla Bradley, on her own volume on the Good Information and Communication Society [3].

Of course, we continued to have many electronic mail exchanges following that. In the winter, spring, and summer before her death, Jana, Pirkko Nykänen and I had many email interactions, planning the publication of our co-edited special issue on women in health informatics [7].

### 3 Digital Health Directions

People always matter; they should be at the forefront. Chiefly, the 'person' or 'patient' is now being placed 'at the centre' of the (health or care) system or service. Of course, there can be many interpretations of this centeredness including, on the one hand, versions that are benign in their orientation and, on the other hand, ones that imply greater demands on the individual's own time, resources, and efforts – with fewer services provided by others.

Data as an issue is becoming more important. This change in orientation probably implies that much more support work will be needed by all individuals, with regard to the meaning, and maintenance, of their own data and their own systems. It will be particularly fascinating, and challenging, to see and understand how the General Data Protection Regulation [8] will be applied in the European Member States from May 2018 onwards, and what will be its particular implications for the health and care sectors. Those who work especially with older adults are concerned with regard to the competences needed by mature generations of citizens – who may or may not have the forms of 'literacy' needed to cope with changes in data-handling and data-sharing in a range of fields that are converging.

Similar questions can also be asked about employees in the health and care fields. Exciting research continues in the fields of organisational theory and behaviour. Labour is becoming more and more commoditised, as much in health and care services as in other professions and occupations.

Over the past decade of policy directions – and especially in later years, it has been the financial aspects of health systems and services that have been predominant, with a focus on what new business models of health need to be developed.

Technologies are coming ever closer to people physically, including the fact that they are being inserted inside human bodies. There is increasing convergence in the computational world, articulated in discussions on the brain, body, and being going back to 2010<sup>2</sup>, and before.

It remains critically important to explore the societal and ethical implications [9] and human needs in relation to <sup>2</sup>[https://www.itas.kit.edu/downloads/ta-kalender\\_20100518\\_cfp\\_converging\\_technologies\\_ifip\\_wg9.pdf](https://www.itas.kit.edu/downloads/ta-kalender_20100518_cfp_converging_technologies_ifip_wg9.pdf)

technologies in general and digital health specifically [10, 11]. As I first worded it a decade ago [12]:

*As we look towards the future, and particularly that peak in the West of baby-boom ageing around 2030, all citizens in our societies need to ask themselves certain basic questions. How [to find a balance] between those who need care and support and those few(er) who are economically active; between those regions and states which are blessed with abundant healthcare professionals and those which have insufficient; between those countries and institutions which extract the benefits of advanced telemedication and teleconsultation and those which remain as yet unconnected? How too can we move towards a more innovative and evolutionary view of thinking about and organising our healthcare systems and services?*

### 4 Contemporary Developments and Reflections on Professor Zvárová's Fields of Interest

Biomedicine remains a core topic of interest. As Reinhold Haux and colleagues concluded last year: "There is a high chance that [bio-medical and health informatics (BMHI)] will continue to flourish as an important discipline; its innovative interventions might then reach the original objectives of advancing science and improving health care outcomes" [10, 13].

Certain criticisms can be made, however, of the biomedical field [13]. Highlighting that advances in personalised medicine cannot be achieved in isolated situations or narrow settings, the panellists cited in this 2017 article pointed to the need for increased stakeholder engagement and involvement: today, one of these areas of increased involvement is predicted to be on the part of patients. Some panellists, who participated in the three (2015-2016) conferences at which experts for the Haux et al. article were interviewed, were especially critical of a contemporary trend (which suggests that health care and medical professionals accept vendor-supplied solutions and technologies in their routine work, without any particular questioning of them). In parallel, the interviewees observed that many informatics tools are developed and used without input from informatics professionals.

Professor Zvárová would surely currently be showing keen interest in the actions of Member States, and their research institutions to implement plans to link genomic data and biobanks to electronic health record systems that are being made accessible to citizens through patient / user portals.

Jana would today, no doubt, be intrigued by current developments in European and international policy in the field of digital health.

With her background in biomedicine and medical statistics, one can imagine that Jana might also

contemporarily be particularly interested in the second of the three bullets covering areas flagged up during the Digital Single Market mid-term review [14]. Its focus is on support for data infrastructure, with a view to ensuring progress being made in the field of research:

- Citizens' secure access to electronic health records and the possibility to share these across borders.
- Support data infrastructure to advance research, prevent disease and personalise health and care in key areas.
- Facilitate feedback and interaction between patients and healthcare providers enhance disease prevention and empower people to take responsibility for the management of their own health.

These are priorities that will be emphasised in a forthcoming Commission Communication on enabling the digital transformation of health and care in the Digital Single Market, due to be published around May 2018. It is anticipated that the Communication will identify actions by the European Commission, Member States and stakeholders: these will be intended to empower citizens and contribute to a healthier society. Here too, industry players – as in many other spheres – seem to be set to take on a higher involvement profile.

Jana would surely also be paying close attention to her own country's Health Ministry's endeavours to set up a National eHealth Centre during 2018-2019, undertaken with technical expertise and in close cooperation with similar ministries from both Austria and Denmark.<sup>3</sup>

Jana's focus on the future career directions of young people, especially researchers, would certainly find reflection in the educational and training directions taken by contemporary Horizon 2020 research Calls [15]. Areas include rare diseases, neuro-generative diseases, regulatory science, chronic conditions, digital health literacy, digital health and care, and cyber-security.

## 5 Conclusions

For all of these current, many and various reasons, it is good news to know that Professor Jana Zvárová's interests and concerns are being represented in today's 4 May 2018 Jana Zvárová Memorial Conference. It brings together in a vibrant, on-going community both her old and new colleagues, friends, and family.

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<sup>3</sup>The European Health Telematics Association (EHTEL) in Brussels, with which I work, is assisting in this initiative in providing individual expertise and communications support.

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