

# NAVIGATING knowledge LANDSCAPES



International Conference on  
Health and Person-Centered Care in the Digital Society

At Thon Hotel, Langbrygga 1, 1767 Halden, Norway

**Navigating Knowledge Landscapes** is an international trans-disciplinary research network with focus on health in the digital society. An aim of the network is to develop international and trans-disciplinary collaborations which will explore the area of on-line and off-line communication and distribution of health and biomedical information and knowledge. This includes the development of analytical tools and theoretical perspectives so that we can better understand, analyse and govern health in present society.

8:30–9:00 **Registration** 9:00–9:30 **Welcome** 9:30–9:50 **Health and knowledge in digital society**, on navigating Knowledge Landscapes 9:50–10:10 Knowledge Landscapes **Geography** 10:10–10:30 The Exploration of **Visual Analytics** in Navigating Knowledge Landscapes 10:50–11:10 The **human reproduction** in the digital communication: Promises and traps at the intersection of **science, rights and social needs** 11:10–11:30 **Negative effects of social support** - the case of inflammatory bowel disease 11:30–11:50 Dubbing national **eHealth** project: the case of Slovenia 13:00–13:40 **Panel Session Health narratives** and knowledge landscapes; DIPEX International; • **Contextualising patients' knowledge claims: Health Talk Norway** 13:40–14:00 Towards understanding **the digital mental health knowledge landscape**: Two studies of self-care apps and Twitter advocacy 14:00–14:20 **Integrative bioethics**, knowledge, and digital society 14:40–15:20 **Panel Session Patient Autonomy** and Knowledge Landscapes; Digital Society – the tension between **child protection** and **children's agency**; The **filter bubble** and its effect on online **personal health information** 15:20–15:40 **Successful Companies understand** the value of content 15:40–16:00 **Technological requirements** for health related navigation in knowledge landscapes 16:00–16:20 **Tracing** the 'doing' of **risk online** 16:20–16:40 Spiritual needs and **compassionate care** of patients

Østfold University College [Norway](#); University of Zagreb [Croatia](#); University of Oxford [UK](#); MUSE Science Museum Trento [Italy](#); University of Göttingen [Germany](#); La Laguna University Tenerife [Spain](#); VU University Amsterdam [The Netherlands](#); University of Tromsø [Norway](#); Wueen Mary University of London [UK](#); Lancaster University [UK](#); Uppsala University [Sweden](#), eZ-company Skien [Norway](#); Mid Sweden University Östersund [Sweden](#), University Ss Cyri and Methodius Skopje [Macedonia](#), University of York [UK](#), Palacky University Olomouc [Czech Republic](#).

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# **Navigating Knowledge Landscapes'**

## **1<sup>st</sup> International Conference on Health and Person-Centered Care in Digital Society**

Proceedings of the Conference

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Østfold University College

Halden, Norway

# Navigating Knowledge Landscapes' 1<sup>st</sup> International Conference on Health and Person-Centered Care in Digital Society

## Conference Program April 27<sup>th</sup>

8:30 – 9:00 Registration

9:00 – 9:30 Welcome – **Stein Haugom Olsen**, Østfold University College, Norway

9:30 – 9:50 *Health and knowledge in digital society, on navigating Knowledge Landscapes*  
**Anna Lydia Svalastog**, Østfold University College, Norway - [Abstract](#)

9:50 – 10:10 *Knowledge Landscapes Geography*,  
**Srecko Gajovic**, University of Zagreb, Croatia - [Abstract](#)

10:10 – 10:30 *The Exploration of Visual Analytics in Navigating Knowledge Landscapes*  
**Margareta Varga**, University of Oxford, UK - [Abstract](#)

10:30 – 10:50 Coffee

10:50 – 11:10 *The human reproduction in the digital communication: Promises and traps at the intersection of science, rights and social needs*  
**Lucia Martinelli**, MUSE Science Museum Trento, Italy - [Abstract](#)

11:10 – 11:30 *Negative effects of social support - the case of inflammatory bowel disease.*  
**Alexandar Palant** and **Wolfgang Himmel**, University of Göttingen, Germany - [Abstract](#)

11:30 – 11:50 *Dubbing national eHealth project: the case of Slovenia*  
**Jana Simenc**, Slovenian Academy of Sciences and Arts, Slovenia - [Abstract](#)

12:00 – 13:00 Lunch

13:00 – 13:40 Panel Session - Chair: **Emilio Sanz**, La Laguna University, Tenerife, Spain

- Health narratives and knowledge landscapes, DIPEX International, **Emilio Sanz**, La Laguna University, Tenerife, Spain - [Abstract](#)
- Contextualising patients' knowledge claims, **Joyce Lamerichs**, VU University, Amsterdam, The Netherlands - [Abstract](#)

- Health Talk Norway, **Hege Kristin Andreassen**, University of Tromsø, Norway - [Abstract](#)
- 13:40 – 14:00 *Towards understanding the digital mental health knowledge landscape: Two studies of self-care apps and Twitter advocacy*  
**Nelya Koteyko**, Queen Mary, University of London, UK & **Dimitrinka Atanasova**, Lancaster University, UK - [Abstract](#)
- 14:00 – 14:20 *Integrative bioethics, knowledge, and digital society*  
**Hrvoje Jurić**, University of Zagreb, Croatia - [Abstract](#)
- 14:20 – 14:40 Coffee
- 14:40 – 15:20 Panel Session - Chair: **Anna Lydia Svalastog**, Østfold University College, Norway
  - *Patient autonomy and Knowledge Landscapes*, **Øystein Ringstad**, Østfold University College, Norway - [Abstract](#)
  - *Digital Society – the tension between child protection and children’s agency*, **Siv-Britt Björktomta**, Uppsala University, Sweden, and **Heidi Aarum Hansen**, Østfold University College, Norway - [Abstract](#)
  - *The filter bubble and its effect on online personal health information*, **Harald Holone**, Østfold University College, Norway - [Abstract](#)
- 15:20 – 15:40 *Successful Companies understand the value of content*,  
**Bård Farstad**, EZ-company, Skien, Norway - [Abstract](#)
- 15:40 – 16:00 *Technological requirements for health related navigation in knowledge landscapes*  
**Predrag Pale**, University of Zagreb, Croatia - [Abstract](#)
- 16:00 – 16:20 *Tracing the ‘doing’ of risk online*  
**Elin Montelius**, Mid Sweden University, Östersund, Sweden - [Abstract](#)
- 16:20 – 16:40 *Spiritual needs and compassionate care of patients*  
**Doncho Donev**, University "Ss Cyril and Methodius" - Skopje, R. Macedonia - [Abstract](#)
- 16:40 – 17:00 Wrap Up  
**Andrew Webster**, University of York, UK  
**Lenka Slepíková**, Palacky University Olomouc, Czech Republic  
**Hrvoje Jurić**, University of Zagreb, Croatia
- 18:00 Walking to dinner at the Fredriksten Castle

Navigating Knowledge Landscapes network information:

<http://knowledge-landscapes.hiim.hr/>

### 9:30 – 9:50 Health and knowledge in digital society, on navigating Knowledge Landscapes

Anna Lydia Svalastog, Østfold University College, Norway

#### Abstract

A short presentation of the Navigating Knowledge Landscapes (NKL)-network. The landscapes of communication in present digital society are complex, interacting, and overlapping. A person searching for, or being exposed to, medical advice online regarding an outbreak (epidemic or pandemic), a common complex disease (e.g. Alzheimer, diabetes, cancer, cardiovascular diseases), social or mental health issues, addiction, or substance abuse is targeted by a variety of senders with various intentions. Information is accessible from different sources, including contact information, institutional domains, research news, personal stories, but also rumors, conspiracy theories or information biased for commercial reasons. The aim of the Navigating Knowledge Landscapes network is to develop international and inter- and transdisciplinary collaborations, which will explore the area of online and offline communication and distribution of health and biomedical information and knowledge.

LINK: <http://knowledge-landscapes.hiim.hr/index.php/publications/>

### 9:50 – 10:10 Knowledge Landscapes Geography,

Srecko Gajovic, University of Zagreb, Croatia

#### Abstract

Besides being the places of the efficient presentation of academic and research based knowledge, the knowledge landscapes are also the places where knowledge is distorted and where incorrect and misleading information is distributed. The freedom to post diverse contents on the internet, and the egalitarian nature of the internet, where experts are in the same positions as all other content providers, does not allow users to discriminate not relevant from relevant and unreliable from reliable information. Though misconception and distortion might start out as a counter discourse, they may end up as a self-confirmatory process that create a self-perpetuating context, which serves as a new center of gravity, distorting the knowledge landscapes. If the isolation deepens, and the gravity center relying on the isolation gets stronger, the extreme form of knowledge landscapes is forming, which we refer to as a black hole.

LINK: <http://knowledge-landscapes.hiim.hr/index.php/publications/>

### 10:10 – 10:30 The Exploration of Visual Analytics in Navigating Knowledge Landscapes

**Margareta Varga**, and **Helena Webb**, Seetru Ltd. and University of Oxford, UK

#### ABSTRACT

A simple click on any of the widely available search engines will, in less than a second, return an incredible amount of data from a simple query on any topic of interest. We benefit from these immense and readily available sources of data; but we are challenged by how to extract from this avalanche of data the relevant information and thence turn the information into relevant knowledge so as to be able to make informed decisions, for instance, in regard to health and person-centred care.

The DIKW (Data-Information-Knowledge-Wisdom) hierarchy is used to elucidate the progression from Data to Information to Knowledge and Wisdom. Simply put, raw Data becomes useful when it provides meaning, i.e. Information. Information in turn becomes Knowledge when it is cognitively processed and assimilated into human knowledge construction. Knowledge becomes Wisdom when it is used to make a decision.

Visualization enables the analysis for exploitation of massive and complex data, and supports users in understanding the inter-relationships within the data. In analysis, however, DIKW-like terms are often used inter-changeably though they represent different levels of, abstraction, understanding and exploitation.

Visual Analytics is the science of analytical reasoning facilitated by interactive visual interface. It is an iterative process, it integrates automated analysis techniques with interactive visualisation so as to provide users with an effective means to dynamically and visually interact with, explore and analyse big, complex, and at times, conflicting and uncertain data.

Visual Analytics enables users to utilise fully their cognitive and perceptual capabilities with the support of advanced computational capabilities to enhance the discovery process. It thus facilitates the understanding of the data, extraction of information and derivation of knowledge so as to support timely informed decision making.

This paper discusses the exploration of visual analytics in providing an effective means of navigating and exploiting knowledge landscapes for health and personcentred care. It demonstrates that applications of visual analytics can support users in the navigation of knowledge landscapes and also support analysts in work to understand knowledge landscapes. For instance, by providing a means for individual users to filter content in a way that is personally relevant to them, the techniques described in the paper reduce complexity of online content and increase its meaningfulness. This enhances user awareness and can be applied to support further decision making both online and offline. In addition visual analytics can form a vital component of interdisciplinary research on health in the digital society. Visual analytic techniques enable researchers – in particular those from non-technical backgrounds – to scope available content online and analyse it in order to gauge the volume of information available to users about particular health conditions, its provenance and the kinds of advice and

## **ABSTRACTS**

recommendations being offered. This kind of analysis can be combined with other approaches in order to make connections between online and offline health behaviours and create exciting opportunities to explore the dynamics of knowledge landscapes.



### **10:50 – 11:10 The human reproduction in the digital communication: Promises and traps at the intersection of science, rights and social needs**

**Lucia Martinelli**, MUSE Science Museum Trento, Italy

#### **ABSTRACT**

Assisted reproductive technologies (ARTs) offer favorable insights for analyzing women's and men's wishes, fears and contradictions through processes continuously negotiated in the intersection of science, politics and society. In the digital era, the media are taking on a new role, difficult to assess in absolutely positive or negative terms. The 'navigators of on-line medical knowledge', by participating in discussions on the web, act as both consumers and producers of contents (in)voluntarily shared and may affect people's attitudes and choices. In this framework, the digital agora acts as a dissemination tool for medical and scientific knowledge and collector of various desires, individual and social frustrations and contradictions.

Our essay explores critical issues in terms of science communication in the context of ARTs, and focuses the social and legal aspects underlying it. In our study, analysis of narratives of various actors involved in ARTs, in Internet-based social networking sites as well as during two focus groups with patients and stakeholders, pointed out the ambiguous interpretation of biological innovations as promoter of new opportunities or new facade of enduring contradictions. 'Timing' and 'aging' are particularly stressed in medical narrative, as well as in private clinics' web sites that aim at attracting patients. In distorted digital information, postponed parenthood (such in the case of social egg freezing) is proposed as a suitable alternative to conventional reproduction and poses new questions about timing related to fertility decline and motherhood. Moreover, they induce to reflect on "what is / who decides which is the 'right' time to be a mother".

When technology is proposed as a new opportunity to conciliate professional needs and pregnancy, we should question if a more inclusive society should instead find concrete structural solutions for supporting women to conciliate motherhood with social/professional lives. Thus, by shifting the awareness from a medical procedure to social relations, ARTs may result in a medicalization of social problems.

### 11:10 – 11:30 Negative effects of social support - the case of inflammatory bowel disease.

Alexandar Palant and Wolfgang Himmel, University of Göttingen, Germany

#### ABSTRACT

**Background:** Social support is considered an important resource to cope with chronic conditions. Conducting a series of interviews with people who suffer from inflammatory bowel disease (IBD) we received the impression that contacts with family, friends or peers in face-to-face or online communication could also be a source of stress and strain. The aim of our study was to better understand and to describe possible negative aspects of social support and their impact on people with IBD.

**Methods:** This is a secondary analysis of narrative interviews, which are the basis of the IBD module of the German website project [www.krankheitserfahrungen.de](http://www.krankheitserfahrungen.de), a part of the DIPEX international network ([www.dipexinternational.org](http://www.dipexinternational.org)). The interviewees were selected using a maximum-variation sampling approach. Grounded theory and the 'OSOP' (one sheet of paper) method were applied to categorize those parts of the interviews that touched on negative effects of social support.

**Results:** A total of 42 interviews were analysed. Two interrelated categories emerged: (i) unwanted confrontation, e.g. with information about the disease, with possible negative disease outcome or with patients doing better than oneself and (ii) undesirable reaction, e.g. compassion and overreaction. For example, some patients preferred to avoid thinking about their disease, at least from time to time. During such times, they felt annoyed if family members, friends or other persons asked them about their condition. Some interview partners did not want to be pitied, especially in times when they did not really suffer. Consequently, some of our interview partners developed strategies to prevent getting into social contact with others or entirely stopped talking about their disease. Seeking support online or reading about health related information on the internet can also lead to more anxiety and uncertainty. Even if people can find endless information about a disease online, it is very hard for someone, who is not a medical expert, to know, which information you can trust.

**Discussion:** To the best of our knowledge, this is the first qualitative study to examine the negative effects of social support in IBD patients. Our participants experienced social support as negative, at least from time to time and therefore decided to be less open about their condition in the future. This may result in social isolation and even deteriorate their health. This process was intensified by the rapid growth of dubious online information sources. Before motivating ill people to seek, in their own best interest, contact with others, they should know about the negative effects of social support. The concept of knowledge landscapes may help to understand whether and how users may benefit, or suffer harm, from health-related information and support in the internet.

**Keywords:** *Inflammatory bowel disease, social support, negative effects, narration, qualitative research, knowledge landscapes.*

### 11:30 – 11:50 Dubbing national eHealth project: the case of Slovenia

Jana Šimenc, Slovenian Academy of Sciences and Arts, Slovenia

#### ABSTRACT

European countries, including Slovenia, have been following eHealth Action plan 2012-2020, the so called Innovative agenda for the healthcare in the 21st century. We can observe the development of national eHealth projects and the expansion of market-oriented providers of digital solutions in the field of health and healthcare. Policy makers and IT industry highlight the anticipated positive effects and benefits of digital medicine and digital health. There is a need for a more balanced critical evaluation of contemporary practices and recurrent transformations in healthcare happening due to unleashed digitization.

There is no doubt, that digitization and integration of new technological solutions in healthcare can improve and facilitate many of its aspects. Yet, despite the far reaching and rapid technological advances, the complex culture of eHealth is evidently in the phase of infancy. In several countries, together with Slovenia, national eHealth projects have been facing different financial manipulations, technical and human resources problems, various obstacles, with delays in project delivery.

*The proposed paper will be a contribution to a critical analysis of the socio-cultural dynamics generated by the uptake eHealth (e.g. e-prescriptions) development in Slovenia. Based on her medical anthropological research, the author will elaborate, how despite the growing trends of using “dr. google”, medical practitioners remain knowledge authorities in patient-doctor relationship. Furthermore, she will explain why medical doctors feel their practice is being reduced to administrative work, where the computer is becoming the central point of their work and interaction with patients. She will as well explore, how behind the ever rising trends in digital reporting, security and work evaluations, different interest of power and forces of control are performed.*

The presentation arises out of the postdoctoral research project. The author acknowledges the project »Health in the pocket and on the internet: critical re-examination of contemporary advanced tools and technological interventions in the healthcare arena« was financially supported by the Slovenian Research Agency.

About the author: Jana Šimenc, PhD, a research (postdoctoral) fellow at the Sociomedical Institut of the Research Centre of Slovenian Academy of Sciences and Arts. More on <http://dmi.zrc-sazu.si/en/sodelavci/jana-simenc-en#v>.

### 13:00 – 14:40 Panel Session - Chair: Emilio Sanz, La Laguna University, Tenerife, Spain

- Health narratives and knowledge landscapes, DIPEX International, **Emilio Sanz**, La Laguna University, Tenerife, Spain
- Contextualising patients' knowledge claims, **Joyce Lamerichs**, VU University, Amsterdam, The Netherlands
- Health Talk Norway, **Hege Kristin Andreassen**, University of Tromsø, Norway

#### **Health narratives and knowledge landscapes, DIPEX International**

##### **Abstract**

**Emilio Sanz**, La Laguna University, Tenerife, Spain

The health knowledge available on the media and the internet is wide, ample and mainly based on the scientific domain and the management of diseases, even when oriented towards general public. Most of the health information is, in fact health education, or increasing health literacy.

Both within the medical world and on the health information available on the internet, the perceptions, experiences and narratives of the patients have been generally neglected.

The project DIPEX International ([www.dipexinternational.org](http://www.dipexinternational.org)) is focused in eliciting the patient's experiences and perceptions and showing it to other patients in order to help them to incorporate personal narratives that might be at stake for them. The project is based a rigorous and scientific methods for the collection, analysis and presentation of the experiences, based in multiple open semi-structured interviews to a wide sample of patients of a given health issue. It is not a recollection of positive and inspiring anecdotes, nor the selection of opinions biased by commercial or ideological interests.

The international collaboration shares a common methodology, grounded on the social and medical anthropology and the methods of social sciences, and present the elaborated information based on the interviews, illustrated with 50-100 micro videos of the actual interviews.

The narratives of the patients have a great potential for the deep understanding of the disease, the changes that a new condition imposes in life and the way the people adapt and react to it. This personal, internal and individual domain is as relevant as the more scientific ones.

Navigating the knowledge landscapes entitles also the finding, use and enjoy of this relevant type of information.

### **Contextualising patients' knowledge claims**

#### **Abstract**

**Joyce Lamerichs**, VU University, Amsterdam, The Netherlands

In the last decade, Dutch health organisations have undergone an interesting transformation in their online presence. This transformation can be described as creating online knowledge communities. One of the drivers of this transformation has been to provide patients and their carers with trustworthy and relevant health information. In practice, this means that websites offer knowledge 'libraries' as an integrated part of the online platform, in which the latest scientific research on the illness is made available. Blogging has become an important functionality for members to share the stories of their illness.

In my talk I will offer an illustration of how these changes have taken place with two Dutch health organisations. I will present some preliminary findings of a small study in which we have explored how members of these communities present their knowledge claims as part of their illness trajectories. We are beginning to see that members' epistemic practices are part of larger interactional projects that are related to identity work.

It is my aim to show how these 'contextualising practices' matter for both the writer (e.g., often patients, sometimes caregivers) and the reader who visits these online platforms. I want to show how these findings can contribute to our understanding of how patients themselves construct epistemic claims and epistemic primacy as an integral part of identity work and decision making. Looking at epistemics as a member's category may pose a fruitful way of conceptualising what constitutes 'relevant' and 'trustworthy' health information and why.

### **Health Talk Norway**

#### **Abstract**

**Hege Kristin Andreassen**, University of Tromsø, Norway

Health Talk Norway is currently under development, and will build on the DIPEX research methodology and web-based dissemination procedures.

The Norwegian project is, in line with other national DIPEX initiatives, much focused on the benefits such a service will have for the patients themselves - for their learning and everyday life. In addition, an important discussion in Norwegian research on patient narratives are the use of such in the health services, i.e., their potential to be deployed as a basis for quality improvement.

User involvement is key to meet the growing pressure on the health and welfare services due to demographic changes, increasing options in treatment and care, and political demands of efficient service delivery and patient centeredness.

To succeed with real user involvement the perceptions, experiences and narratives of the patients have to be lifted forward both in the medical community and in policy discourse. Substantial work must be done to develop, gather and validate data about patient and user experiences. This knowledge must be made available for patients; health and social care workers and policy makers alike.

Further, knowledge on user experiences needs to be translated into clinical and care practices. To avoid undesirable variation in how user involvement is practiced in the health and care services, user involvement procedures anchored in a common knowledge base must be developed.

The primary goal of Health Talk Norway is quality improvement in clinical encounters and health service planning, research is a secondary aim. The establishment of a digital database and the presentation of data and analysis through an online platform will maximise accessibility to knowledge on user experiences and user involvement - and thus maximise the benefits of the project for all target groups: patients, professionals and policy makers.

LINK: <http://www.dipexinternational.org/>

### **13:40 – 14:00 Towards understanding the digital mental health knowledge landscape: Two studies of self-care apps and Twitter advocacy.**

**Nelya Koteyko**, Queen Mary, University of London & **Dimitrinka Atanasova**, Lancaster University

#### **ABSTRACT**

The recognised importance of social networks in mental health has led to increased use, and academic interest in, the social media platforms and digital apps which enable users not only to produce personal narratives, visualise and track different emotional states, but also share the resulting content with others. These processes are part of the Knowledge Landscapes which 'contain all the different communicators (...) the content communicated, and the pathways used for communication' (Svalastog et al, 2014: 54), but have been understudied by social science researchers. In this presentation, we examine how these new opportunities for self-presentation and relationship building may be shaping professional and lay experiences of support, self-care, and patient advocacy in mental health. Drawing on our work on two studies - 1) on semiotic choices and constraints in depression-related tweets (Koteyko & Atanasova, under review) and 2) on digital peer networking apps for depression management - we argue that the above mental health-related digital practices can be examined through language use and other meaning making resources. As shown by existing applied linguistics research (e.g. Demjén, 2014), such approaches can be particularly illuminating for revealing the lived experiences of depression and establishing supportive relationships. The results can bring insights into how both organisational actors and individuals with mental health conditions understand and use the digital platforms in the everyday and how they evaluate their experiences.

## References

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- Koteyko, N. & Atanasova, D. (under review) Semiotic choices and constraints in depression-related tweets: The case of #WhatYouDontSee. *Discourse, Context & Media*.
- Svalastog, A. L., Allgaier, J., Martinelli, L. & Gajovic, S. (2014) Distortion, confusion, and impasses: Could a public dialogue within Knowledge Landscapes contribute to better communication and understanding of innovative knowledge? *Croatian Medical Journal*, 55, 54-60, doi: 10.3325/cmj.2014.55.54.

## 14:00 – 14:20 Integrative bioethics, knowledge, and digital society

**Hrvoje Jurić**, University of Zagreb, Croatia

### Abstract

Integrative bioethics is an innovative concept and project in the field of bioethics, which gathers various scientific approaches (interdisciplinarity) and cultural approaches (pluriperspectivity) to the ethical issues of life and current life manipulations in the global technological society. It covers broad spectrum of topics – from clinical medical practice and biomedical research, over human-animal relationships, to global-ecological problems. By doing so, integrative bioethics opposes any scientific and cultural reductionism, and criticises the regimes of total power over knowledge and life (represented by ruling models of technoscience, economy, politics, and media), which is the point where integrative bioethics meets biopolitical theory (e.g. Michel Foucault and Giorgio Agamben). In this paper I will try to answer the question: How the conceptual framework of integrative bioethics and its methodology can be applied in the context of digital society, including the challenges of managing information and knowledge, health and life.

**Key words:** integrative bioethics, interdisciplinarity, pluriperspectivity, knowledge, life, technology, digital society

**14:40 – 15:20 Panel Session Chair: Anna Lydia Svalastog, Østfold University College, Norway**

*Patient autonomy and Knowledge Landscapes, Øystein Ringstad, Østfold University College, Norway*

### ABSTRACT

Making health-related information freely available in the digital society may contribute to enhanced patient autonomy. In my contribution, I will reflect on two preconditions of patient autonomy: understanding and freedom from controlling influences. Referring to these preconditions, I will discuss how health care practitioners may support patient autonomy in their conversations with patients about such information.

*Digital Society – the tension between child protection and children's agency, Siv-Britt Björktomta, Uppsala University, Sweden, and Heidi Aarum Hansen, Østfold University College, Norway*

### ABSTRACT

Digital Society and the increasing use of internet and social media generates new challenges on child welfare services (Aarum Hansen, Björktomta & Svalastog 2017). Today, internet is wholly integrated in the Scandinavians' daily lives and the border between on-line and off-line is virtually erased. Almost 46 % of nine years old Swedish children are the owner of a tablet. Moreover, five percent of children younger than one year are using internet every day (Statens media råd 2015). It is also the children and young people that are more active on social networks with updating and posting their's own content (e.g. text, photos or videos).

The 2.0 Web<sup>1</sup> has made communication available in new ways, all the time, and more or less everywhere. Instagram, Snapchat and Kik Messenger are examples of popular formats of informal social communication that fit children and young peoples' way of communicating, and therefore facilitates their agency. The content and the relations that children and young people establish and develop on-line are mostly available only for their friends. So, consequently this mean that they could be under the radar for people, e.g. parents and other adults, in their off-line contexts. More recent studies have shown that there are a group of parents who underestimate the risks children expose themselves to on the internet (von Feilitzen, Findahl & Dunkels 2011). A number of international studies suggests that children in a danger-zone on-line also are children with a risky life off-line. Furthermore, this is often linked to a hard and/or conflictual life at home, in school and/or with friends (e.g. von Feilitzen 2009, Shannon 2007, Svedin & Åkerman 2006, Ungdomsstyrelsen 2009).

In an earlier article (Aarum Hansen, Björktomta & Svalastog 2017) we point to the need of developing new methodologies of social work with children and young people, i.e., to support as well as protect them against harm. Although there is many researches about digital society, how and when children and young people are on-line, few (neither) of

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<sup>1</sup> 2.0 Web is interaction contrary to 1.0 Web which is homepages etc. without interaction.



them focused on the digital society versus the tension between child protection and children's agency regarding social welfare services and child protection. So, this chapter attempts to fill this gap of knowledge and provide a more detailed exploration regarding new methodologies of social work with children and young people.

To further discuss the challenges on child welfare services in digital society in general and on child protection in particular, we will take inspiration from the sociology of childhood.<sup>2</sup> The point for the departure is an understanding of childhood as reflecting time and context with the key concepts *being* and *becoming*. Whilst the "being child" interprets as a social actor who actively is constructed "childhood". The "becoming child", however, interprets as an "adult in the making". Furthermore, a child that is lacking competenc

*The filter bubble and its effect on online personal health information, Harald Holone, Østfold University College, Norway*

### ABSTRACT

The filter bubble and its effect on online personal health information

One of the aims of the Knowledge Landscapes network is to better understand how the public uses online resources to make decisions about personal health. The rise of the internet as a common medium has led to well documented changes in how people in general get informed about their own health situation. From the perspective of the Filter Bubble (Eli Parisier, 2011), this talk concerns the algorithms in use by social media and search engines, and the effect they have on our search for health related information on-line.

The filter bubble influences the way the public find personal health information online. The algorithms that support us in finding relevant information quickly can also bring us closer to a gravitational black hole of information, which subsequently can lead us to make bad decisions about health issues. This problem will not go away by itself, and I suggest a few ways forward to help alleviate the problem. Hopefully, through the Knowledge Landscapes network, we will gain an even better understanding of the way the public use online resources for managing their own health, and be able to provide ideas that can improve the quality of health related information that reaches the public.

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<sup>2</sup> The childhood sociology has a critical view on former dominant developmental psychological perspective e.g. Freud and Erikson which interpret children as innocent object under (a natural) development.

### 15:20 – 15:40 Successful Companies understand the value of content

**Bård Farstad**, EZ-company [www.ez.no](http://www.ez.no), Skien, Norway

<https://www.youtube.com/watch?v=niMluh99tE>

#### ABSTRACT

In this session Bård talks about how content is driving successful businesses. That all companies need to be prepared to produce content in unique ways, to adapt and stay relevant. With the right content helps you engage with customers. In order to succeed in todays digital marketplace you need to ensure the right content, to the right user and the right time. Future proofing your content to stay relevant on and beyond the web is key.

### 15:40 – 16:00 Technological requirements for health related navigation in knowledge landscapes

**Predrag Pale**, University of Zagreb

#### ABSTRACT

“Googling” or browsing and searching Internet has become a major way of learning, or, at least, of gathering information. Despite the fact that the amount of freely available data on the Net is fascinating and ever growing, the process of searching for the right knowledge remains a primitive, cumbersome process. Therefore the hungry traveler frequently either disappointed and impatient gives up or reaches for the low hanging fruit of sensationalistic information, inaccurate but appealing explanations or simple, pure garbage. In order to change this, the traveler needs help, some tools.

First of all a navigation map is needed. GPS coordinates of required knowledge are not known to the seeker, but he rather has to chart the vast territory. Some help is needed. An updated map of the landscape would be very useful. It’s most important component should be the legend: clearly designating safe and unsafe areas, those for specialists and those for common public. It should also clearly identify territories by the major topic they cover.

The territories a traveler visits speak foreign, specialized languages. Thus a handy, universal translator to the layman’s native language is needed.

The traveler’s eyesight is often blurred by dust storms of irrelevant media hype, garbage filled winds of hoaxes or blinded by sparkling marketing or by thunders of anti-something activists. He needs eyeglasses capable of filtering out all those artifacts, preventing them to distract his attention from the real path in his quest for information.

Knowledge is often in the intricate patterns of coral reefs, but the traveler lacks competence to understand both the big picture and details. However, they do often contain pearls which he could use. However, they are often covered with seas of statistical or other data. The knowledge seeker lacks the skills and equipment to dive

through them and reach pearls. Therefore glass-bottom boats and tourist submarines are needed, specifically designed for tourists in order to help them enjoy the unobstructed view on the pearls.

At other times the knowledge is in the form of a jungle where old, useless branches and trees are tightly intertwined with solid, stable trees and insecure, young, fresh branches. The traveler cannot traverse them. They need to be transformed into well groomed parks if not botanical gardens with smaller and larger sign-posts: info-texts providing required information to understand more complex concepts.

The purpose of the trip in the knowledge landscapes can be very practical: to quickly satisfy immediate hunger. However, often the traveler is burdened by worries, anxiety of fear. This cannot be solved by one trip, but can be only healed by longer and multiple trips. In order to achieve the healing effect, the traveler shouldn't only wander or walk the same, safe paths all the time. Instead, his trips should be exploratory and well planned. If this is not possible or convenient, they should at least be well documented.

There should be a wizard telling the traveler whether trips are necessary at all, and what to search for.

For this purpose the traveler needs a traveling journal as well as a marking tool to chart the places she has already visited and leave her marks, observations. Many times there are many side-paths one cannot explore immediately, but would like in the future. Those paths need to be marked for the future and current thoughts they inspired should be recorded. Today we use bookmarks, but they are even less effective than breadcrumbs would be.

In short, the technology should be used to draw knowledge maps on demand clearly marking areas the user might find useful for the particular need. There should be way to get warning about new, truly relevant information in relevant form. There should be a mechanism to interpret professional text from the layman's perspective. Filters should eliminate hoax, spam, flame wars and advertizing. Finally, the user should be able to record his browsing and searching in a way helping him to efficiently browse next time, to record his thoughts and open questions and to easily interpret and use them during the next search. Most importantly, there should be a simple, quick, objective and reliable way for the user to check his own knowledge.

### 16:00 – 16:20 Tracing the ‘doing’ of risk online,

**Elin Montelius**, Mid Sweden University, Östersund, Sweden

#### ABSTRACT

Given the importance of online social interaction between people it becomes ever more imperative to investigate how risk is constructed in these interactions. In this presentation I draw on the theoretical perspective of ‘doing risk’ and elaborate on how this perspective can be applied to analyze how food risk is done in the online discussion boards. This framework can be described as a combination of intersectional theory and risk theory. It develops a theoretical understanding of how risk is ‘done’ and ‘undone’ in relation to prevailing power structures. This framework opens up for an analysis of how for instance health risks intersects with for example gender, class or sexuality. Using a discourse analysis I investigate the performativity of risk as food risk is ‘done’ and ‘undone’ in the discussions on online discussion boards. Risk is ‘done’ in interaction with others and by focusing on the performativity of risk it is possible to analyze its’ moral dimensions and the normalizing functions.

### 16:20 – 16:40 Spiritual needs and compassionate care of patients

**Doncho Donev**, University "Ss Cyril and Methodius" - Skopje, R. Macedonia

#### ABSTRACT

**Aim:** To review the definitions and importance of spiritual health and needs of the patients, spirituality and psychological medicine with compassionate care as an essential part of the overall care for establishing functional relationships between doctor and patient, influencing the positive behavioral, emotional, and physical health outcomes of the treatment and decreasing sufferings of patients with severe diseases.

**Methods:** Review and critical analysis of relevant published literature, materials and documents, Internet sources and personal experience, thoughts and observations of the author.

**Results:** Spirituality as a factor contributes to health in many people. Introducing spirituality in health care might be a source of affirmation, inspiration and practical approaches for doctors and caregivers who are passionate about supporting patients’ journeys toward healing and wholeness. Spiritual or compassionate care involves helping the person as a whole, meeting all dimensions of health needs—the physical, mental, emotional and spiritual. Patients care may involve spending time with them, holding their hands, spiritual conversation and talking about what is important to them. There are mutual advantages for doctor and patient from understanding patients’ spiritual needs and practicing spiritual care to patients and their family members.

**Conclusion:** Spirituality is being increasingly accepted as integral to human psychology, vital for physical and mental health. Integration of spirituality in health care is paramount but still an essential question remains - how to bring it into the professional

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work of doctors, citing lack of time, training and skills. It is necessary to pay much more attention, involving national efforts, for improving medical education, research and practice related to spiritual needs and care in hospitals and other health care settings, strengthening the multidisciplinary teams and evaluation of outcomes, as well as development of shared ethical codes for systematic incorporating spirituality and compassionate care into an integrative medicine in Europe.

**Key words:** spiritual health, spirituality, spiritual needs, spiritual care, compassionate care