UNIVERSITY OF COPENHAGEN

'I want to die now. What will prevent me from taking action?' – exploring social media communities for individuals living with suicidal thoughts. Preliminary findings of a qualitative study.

Sørensen, Jane Brandt; Meyrowitsch, Dan Wolf; Kingod, Natasja; Konradsen, Flemming; Thomassen, Jacob Lauge

International Conference @ Department of Anthropology, Faculty of Social Sciences, University of Copenhagen

11-12 June 2019

THE DIGITALLY ENGAGED PATIENT
#digitalpatient

Conference Guide

Table of Contents

Welcome!

We are delighted to welcome you to Copenhagen for the international conference "The Digitally Engaged Patient", a part of the European Research Council-funded VITAL project. Our ambition has been to invigorate the momentum that has been gathering around social studies of digital technologies surrounding patients in the 21st century. Judging from the superb programme we have, there is certainly a solid momentum.

In recent decades, there has been a shift from preventing morbid death to the everyday challenges of living with disease, where quality of life indicators, as well as the wellbeing and life satisfaction of individuals and nations, are increasingly mapped out and tabulated. At the same time, while improving the lives of those living with illness is reflected in the objectives of global and national health policies, health care provision throughout the world is suffering from austerity and economic strain. Not least as a consequence, new ICT (information and communication technologies) initiatives are on the global health agenda with an aim to improve productivity and effectiveness, enhance services, and reduce costs on governments. The assumption is that ICTs in healthcare will reduce costs by enabling patients to care for themselves to larger degrees. Yet at the same time, we know that as technologies move from the clinic into the homes and daily lives of people with various health conditions, new obstacles and dilemmas arise due to shifts in tasks and responsibilities, which in turn raise questions about good care and the quality of life of patients.

Within this broader move towards ICT-based solutions, we have seen a rapid increase in the number of eHealth and mHealth projects globally. Health-related issues have always been an important part of internet studies, the first of which emerged in the mid-1990s. From these studies we have learned how the first-generation Web 1.0 allowed patients to seek health information through search engines, just as Web 2.0 created new opportunities for seeking and sharing information in interactive ways. New concepts such as health 2.0, eHealth and mHealth were coined as a result. Whereas eHealth covers

the use of and enrolment in online forums and communities, blogs, podcasts, YouTube, Twitter, Snapchat and Wikis, mHealth defines portable, device-based and mobile access to connect around a common illness diagnosis as well as opportunities for self-tracking, monitoring and even treating disease. With "smart-care" and smart-technologies based on downloaded apps on mobile devices, self-care and monitoring of disease has become available by reaching into the pocket – just one click away for those who have access to smartphones and ICT infrastructures. At the same time, researchers have pointed to the fact that new technologies and digital services not only change the way we communicate, but also offer innovative and creative ways of monitoring health and well-being, albeit for those who choose to engage with them.

This 2-day conference on The Digitally Engaged Patient addresses and challenges the recent transition from eHealth to mHealth and welcomes researchers within the fields of social science and humanities (anthropology, sociology, science and technology studies, cultural studies and the like). We hope the conference can be a venue for critical discussions around good care and quality of life for patients in the 21st century with digitalized technologies for (self-)caring.

Many of you know each other already, but surely you will also meet many new scholars and we hope very much that this conference can serve as a starting point for new collaborations. Do use the various coffee breaks, lunches and evening arrangements to share ideas, think up new projects and/or prepare grounds for collaboration. Please use #digitalpatient when engaging with the conference online.

We have a fantastic conference team who are here to ensure that we all have a productive conference. If you have any queries do ask any one of us from the conference team.

On behalf of the scientific and organizing committees,

Natasja Kingod, Nete Schwennesen & Ayo Wahlberg

Scientific and organizing committees

Scientific Committee

- Natasja Kingod, Department of Anthropology, University of Copenhagen & Steno Diabetes Center Copenhagen
- Ayo Wahlberg, Department of Anthropology, University of Copenhagen
- Nete Schwennesen, Department of Anthropology, University of Copenhagen
- Laura Louise Heinsen, Department of Anthropology, University of Copenhagen

Conference Team

- Natasja Kingod, Department of Anthropology, University of Copenhagen & Steno Diabetes Center Copenhagen
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- Nete Schwennesen, Department of Anthropology, University of Copenhagen
- Laura Louise Heinsen, Department of Anthropology, University of Copenhagen
- Vicki Antosz, Department of Anthropology, University of Copenhagen
- Camille Olsen Halling, Department of Anthropology, University of Copenhagen
- Jieun Lee, Department of Anthropology, University of Copenhagen
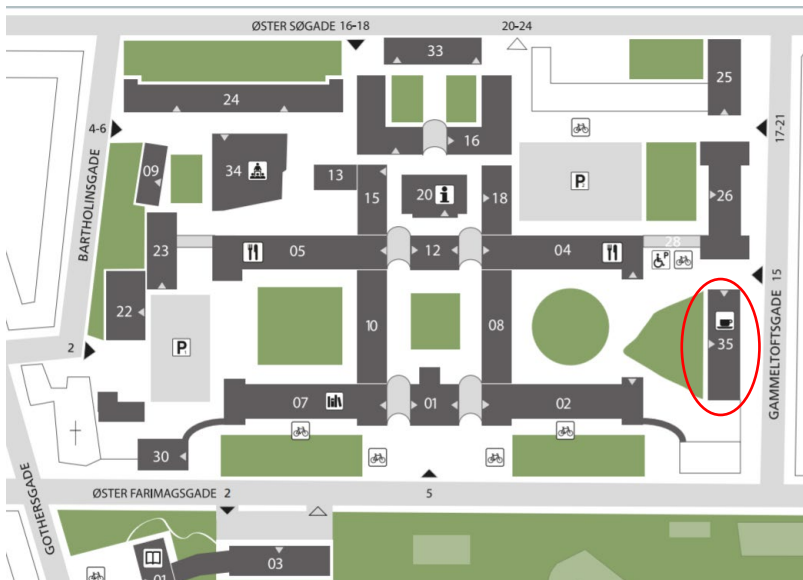- Anna Mann, Department of Anthropology, University of Copenhagen

Practical Information

The conference will take place at the University of Copenhagen, Faculty of Social Sciences at Øster Farimagsgade 5, 1353 Copenhagen K. Entrance to Campus via Gammeltoftgade 15..

Conference venue, Building 35, 3rd floor.
Conference Reception, Winter Garden, Building 28

Map

Reception and Conference Dinner

On the 11th of June there will be a reception at the University of Copenhagen from 16.30-17.30, at the winter garden, building 28. There will be vine and snacks at the reception.

After the reception, we are delighted to invite you to a conference dinner at Restaurant VÆKST, from 18.00.

At VÆKST, Nordic ingredients are in focus. The menu consists of lots of vegetables and local meat, fish and poultry. You will find VÆKST on Sankt Peders Stræde between Rådhuspladsen, Vesterport and Nørreport. The walk from campus takes around 15-20 minutes. Let us know if you need any assistance getting there.

Restaurant VÆKST
Sankt Peders Stræde 34
1453 Copenhagen K
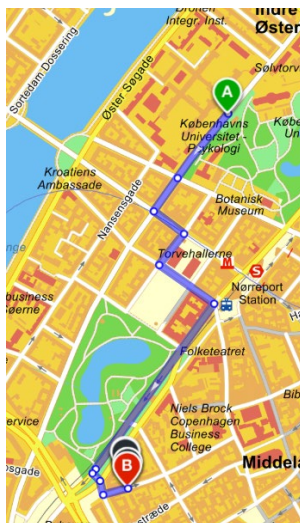
Keynote Abstracts

Deborah Lupton, SHARP Professor, Leader,
Vitalities Lab, Centre for Social Research in
Health and Social Policy Research Centre,
University of New South Wales, Sydney, Australia

Tuesday, 11 June 2019 at 9.45-10.45
Room: CSS 35.3.12, *Chair: Ayo Wahlberg*

A More-than-Human Perspective on Digital Health
In this presentation, I will bring together vital materialism theory with
my recent empirical studies into how people enact digital health. I will
refer to the more-than-human perspectives offered in the scholarship
of Haraway, Bennett, Barad and Bennett as well as in indigenous and
First Nations cosmologies. These perspectives emphasise the
distributed nature of agencies and vitalities in and through human-
nonhuman encounters. Using a range of methods, including design-
and arts-based approaches as well as interviews and focus groups, I
have sought to surface the affective forces and relational connections
that are generated when digital technologies and humans come
together. I will discuss how agential capacities are opened up or closed
off when the affordances of human bodies intra-act with those of
digital health technologies.

Henriette Langstrup, Associate Professor,
Section of Health Services Research,
University of Copenhagen

Wednesday, 12 June 2019 at 9.30-10.30
Room: CSS 35.3.12 *Chair: Nete Schwennesen*

Care in the cloud? – Considering the "respons-ability" of digital care infrastructures

The digitally engaged patient has co-emerged with increasingly sophisticated and widespread digital care infrastructures spanning public, personal and commercial domains. The protagonists of the digitalization of healthcare – whether policy makers, patient advocacy groups or commercial innovators – often draw a picture of the inevitability and potentiality of moving healthcare from the ground and up into 'the cloud'. Here in the cloud – it is promised – personal health data from apps, wearables and other sources can be uploaded and 'seamlessly shared' with 'relevant providers' positioning the patient at the center of a datafied and ubiquitous healthcare system. But clouds evoke pictures of thinness and immateriality; they can drift and dissolve – does digitalization then put healthcare "up in the air" leaving the patients and their data adrift?

In this talk, I draw on studies of patients' digital participation in health and chronic care infrastructures, to explore the notions of care and responsibility in relation to expectations and practices of "health care in the cloud". The suggested immateriality and seamlessness of the cloud stands in stark contrast to the materialities, entanglements and frictions of everyday practices of managing disease or designing digital devices and platforms. Who is responsible and what constitutes care is being negotiated with very material consequences in these digital infrastructures in which we are increasingly finding ourselves as patients and citizens. I will suggest that one helpful way to get us back on the ground in these discussions, is to conceptualize *care as the ability to respond* and thus ask: What is seen as worth responding to, when, how and by whom when trying to manage the unruliness of chronic living in digital care infrastructures?

Conference Program

Tuesday, 11 June 2019

09.00 - 09.30	**REGISTRATION**
09.30 - 09.45	<u>Welcome</u>: Natasja Kingod
09.45 - 10.45	<u>Keynote</u>: Professor Deborah Lupton, University of New South Wales, Sydney, Australia. Room: CSS 35.3.12, Chair: Ayo Wahlberg
10.45 – 11.30	**LUNCH**
SESSION 1	
11.30 - 13.30	<table><tr><td><u>1A: Accessing and negotiating healthcare online</u> Room: CSS 35.3.13 Chair: Nete Schwennesen • **Mikka Nielsen** • **Benjamin Hunter** • **Anjali Raj** • **Rachel Kent**</td><td><u>1B: Boundaries to online-offline interactions</u> Room: CSS 35.3.12 Chair: Ayo Wahlberg • **Simone Anna Felding** • **Anna Schneider** • **Benjamin Marent** • **Patricia Perrenaoud** • **Stine Lomborg, Camilla Moring & Cecilie Laursen**</td></tr></table>
COFEE & TEA 13.30 – 14.00	
SESSION 2	
14.00 - 16.00	<u>2A: Ethics and morality to mHealth</u> Room: CSS 35.3.12 Chair: Natasja Kingod • **Nedine Kachornnamsong** • **Dan Meyrowitsch** • **Victoria Neuman** • **Tina Sikka** • **Rikke Torenholt**
RECEPTION 16.15 - 17.30 University of Copenhagen, the winter garden, building 28.	
CONFERENCE DINNER 18.00 at Restaurant VÆKST	

Wednesday, 12 June 2019

9.00-9.30	**COFFEE & TEA**	
9.30-10.30	<u>Keynote</u>: Associate Professor Henriette Langstrup Room: CSS 35.3.12 Chair: Nete Schwennesen	
SESSION 3		
10.30-12.30	<u>3A: Digital health practices and patient experiences</u> Room: CSS 35.3.12 Chair: Laura Louise Heinesen • **Annette Wickström & Layal Wiltgren** • **Julia Bailey** • **Fadhila Mazandarani** • **Jane Sørensen** • **Raiana De Carvalho**	<u>3B: mHealth and engaged mPatients</u> Room: CSS 35.3.13 Chair: Jieun Lee • **Johan Salo & Martin Berg** • **Pater Fuzesi** • **Annemarie Levy** • **Samantha Gottlieb** • **Bianca Jansky**
LUNCH 12.30 - 13.30		
SESSION 4		
13.30-15.30	<u>4A: Apps and tracking</u> Room: CSS 35.3.12 Chair: Nete Schwennesen • **Laila Øksnebjerg** • **Claudia Bagge Petersen** • **Valerie Handunge** • **Antoinette Fage-Butler & Loni Ledderer** • **Natalia Orego Tapia** • **Sébastian Libert**	
COFFEE & CAKE 15.30 - 16.00		
16.00-16.30	<u>Conference Wrap-Up:</u> Professor, MSO, Ayo Wahlberg & Associate Professor Nete Schwennesen Room: CSS 35.3.12	

Paper Abstracts

Tuesday, 11 June 2019

SESSION 1

1A - *Accessing and negotiating healthcare online*

TIME: 11.30-13.30
ROOM: CSS 35.3.13
CHAIR: Nete Schwennesen

Interpreting, negotiating, and engaging in health data on sundhed.dk

- **Mikka Nielsen & Martina Skrubbeltrang Mahnke**
  Postdoc, Saxo Institute, University of Copenhagen. mikka.nielsen@hum.ku.dk

Sundhed.dk is the Danish eHealth portal providing access to healthcare services as well as patients' own health care records. The purpose of the portal is to create full transparency, so citizens can become well-informed and qualified partners in the public health care system. Based on an on-going interview study, this paper examines patients' use of and engagement with data available on the platform. It asks how access to data affects the patient's understanding of his or her disorder and discusses further the implications for the patient's involvement in treatment and therapeutic processes. The preliminary analysis suggests that access to numeric measurements increases patients' experiences of control over treatment plans. However, when it comes to qualitative descriptions made by the doctor about the patient, the opposite is the case.

These tend to foster insecurity on the patients' side. Another crucial point is the time and space of data access. As the platform is always available, the space and time when the patient meetshis or her data is re-negotiated. Therefore, understanding and having a sense of ownership of one's data is not only a matter of the data itself but also a question of where it is accessed and if the patient engages in (and is able to engage in) the opportunity of discussing the data with health professionals. Thus, the paper argues that access to health data on sundhed.dk produces new practices as well as new spaces of interpreting, negotiating, and engaging in health.

Digitally engaged patients in virtual healthcare marketplaces

- **Benjamin Hunter**, Department of International Development, King's College, London. benjamin.hunter@kcl.ac.uk

The process of accessing healthcare entails navigating a complex and opaque landscape of service provision and social institutions. This paper examines the growing role of online booking platforms in mediating access to healthcare. These platforms offer listings of providers, biographical information, user ratings and feedback, and booking systems; they are virtual marketplaces offering to simplify health system complexity for the digitally engaged patient.

Drawing on sociological theories of brokerage, this paper presents preliminary findings from research on the emergence and evolution of the global healthcare booking platform sector. The approach pays close attention to trajectories of the platform companies in order to better understand their practices and the implications for how people access healthcare. It is illustrated using findings from ongoing analysis of websites and promotional materials produced by healthcare booking platforms globally.

Findings show companies emerging in the aftermath of the 2007/8 financial crisis, fuelled by venture capital investments and focused on the most heavily marketised segments of healthcare sectors. Their marketing materials appeal to the digitally engaged middle-class, emphasizing ease of use and transparency, but with limited information on the generation and commercialization of user data. Some platforms are expanding internationally and acquiring rival companies, but not all expansion proceeded smoothly: search engine Baidu (China) terminated its venture after two years, and WeDoctor (China) and Doutor Ja (Brazil) faced city-wide bans in Beijing and Sao Paulo respectively, following medical professional opposition. The paper considers implications of booking platforms for user-provider relations and professions' territorial control in healthcare.

An outcome led mhealth solution to improve optimum healthcare utilization during pregnancy and postpartum- A Case Study from India

- **Anjali Raj.** PhD student and Entrepreneur. Warwick Medical School, United Kingdom. a.raj@warwick.ac.uk

There is an exponentially large gap in awareness levels of couples with respect to pregnancy and childbirth. Myths, mis-information and peer pressure overloads couples with information that can at times be detrimental to the mother or baby's health. Increasing popularity of community-based apps also add on this issue of peer-to-peer anecdotal support which is not based on scientific evidence. There is a need for evidence-based mhealth, which can engage pregnant couples into monitoring their health, red flag when things are wrong and most importantly scientific advice on what needs to be done next. The statistics of India when it comes to breastfeeding, lifestyle disorders, postpartum depression, immunization, infant development etc. are deteriorating and there needs to be accessible and affordable solutions created to educate, engage and empower couples to take the right decisions. Health of the mother and baby during pregnancy and in the 1st 2 years of life have long lasting societal repercussions that are rarely focused on. For this paper, the author is taking a mobile app built by a company called ilove9months as a case study. Their beta version was launched in 2017, which won many awards including the prestigious India-Israel Innovation Challenge in Digital Healthcare. They are currently in the process of launching their AI based final version which is designed on the principle of being evidence based, outcome and solution led and regional language friendly for mass adaption. For this paper, the new app and user trends will be the case study.

(In)Visible Illness: Performing the Patient and Optimising Health on Social Media

- **Dr. Rachel Kent**, Teaching Fellow in Digital Media and Culture, Department of Digital Humanities, King's College, London. rachael.c.kent@kcl.ac.uk

Paper abstracts

Social media and self-tracking platforms can be understood as social venues to represent and perform illness and health identities. Conceptualizations of poor health or being 'a patient' is framed and interpreted by these users to demonstrate and encompass many aspects of their lifestyles and relationship with their bodies, behaviors and sense of personal identity. Through a textual and thematic analysis of ethnographic empirical data with 14 participants (from semi-structured interviews, reflexive diaries, and shared online content), this paper explores how patients suffering from temporary illness or chronic disease can perform specific identities for the communities' surveilling gaze on Facebook and Instagram. This enables the representation of being a positive and health optimizing role-model, as well as the legitimation of invisible illnesses for others dealing with poor health and disease, as well as healthy lay people viewing this content.

Participants perceived health often in terms of polarizing frames, such as 'success' (being 'healthier') or failure (being 'unhealthy' or ill), which were attributed to a personal belief in their own success or failure to manage and optimize their health. Inability to perform or reach specific self-proclaimed optimal health goals was considered to reverse health improvement and cause health deterioration, as well as increase the aging process. For these patients then, performing 'healthy' decisions on social media in the present, brings the potentially pathological future into the current day, by taking visible 'action' to reduce the likelihood of ill health in the future. Most interestingly, for these participants, if their social media community deemed these patients as visibly committed to practicing health-optimizing behaviors, they internalize the communities gaze and feel genuinely physically and mentally healthier in their everyday lives.

SESSION 1
1B - *Boundaries to online-offline interactions*

TIME: 11.30-13.30
ROOM: CSS 35.3.12
CHAIR: Ayo Wahlberg

Digital Meeting Places: Creating Intimate and Safe Connections with Digital Means

- **Simone Anna Felding**, & Nete Schwennesen,
- Research Assistant, Department of Public Health, University of Copenhagen. saf@anthro.ku.dk

Boblberg.dk is a digital platform offered to Danish municipalities, and is used as an element in municipal initiatives aimed at strengthening mental health and preventing loneliness among the municipality's citizens. The company behind has been successful in marketing Boblberg.dk as a "social" platform positioned in contrast to other commercial digital platforms.

In the paper, we consider Boblberg.dk as a socio-technical infrastructure (Star 1999) and we look more closely at the invisible 'articulation work' (Suchman 1996) that is necessary to configure Boblberg.dk as a platform that mediates intimate connections between people. This allows us to articulate the distributed, practical, and moral work done by municipalities, businesses and elderly people, which shapes Boblberg.dk as a safe and intimate meeting place.

Based on an ethnographic study among older users in two municipalities, we explore how Boblberg.dk is articulated in practice, from three different 'sites': 1) The socio-technical expectations (Mc Neal et al. 2016) and moral visions of 'good old-age life' 2) The concrete screening and exclusion of content and users 3) The expectations, digital production and experiences of use in practice.

Across the three sites we show how both human and nonhuman actors form connections digitally and physically. We argue that the different actors aim at different connections and have different expectations, that can work against each other. Finally, we discuss the challenges and opportunities that arise when municipalities try to mediate social contact with digital means.

References
McNeil, Maureen, et al. 2016. Conceptualizing Imaginaries of Science, Technology, and Society. In: *The Handbook of Science and Technology Studies*. Ulrike Felt et al., eds. p. 435-464. Cambridge: MIT Press
Suchman, Lucy. 1996. Supporting articulation work. In: *Computerization and controversy: Value conflicts and social choices* 2nd edition. Rob Kling, ed. p. 407-423. San Diego: Academic Press.

Star, Susan Leigh. 1999. The ethnography of infrastructure. *American behavioral scientist* 43(3):377-391.

Digitally Engaging Vulnerable Patients: Patient Involvement in Social Psychiatry

- **Anna Schneider,** Postdoc, Department of Marketing & Management, University of Southern Denmark, anna@sam.sdu.dk

The proliferation of mHealth technologies provides opportunities for increasing patient involvement in health management, in particular by creating a patient participatory culture (Appelboom et al., 2014). While these digital opportunities are naturally taken up by the more educated and resourceful patients (Goldstein and Bowers, 2015), they also hold great promise for more vulnerable patient groups. Already Joyce and Loe (2010) found that even senior citizens "creatively utilize technological artifacts" to "negotiate health and illness in daily life".

Social psychiatry cares for some of society's most vulnerable patients, with often severely reduced social and cognitive functions. This research investigates the implications of integrating an app-based mHealth platform into the everyday practices of patients of social psychiatry in a medium-sized Danish municipality. Data was collected through home visits and in-depth interviews with patients accompanied by social workers and through individual and group interviews with psychiatric nurses and social workers. Preliminary results indicate that patients' trust in mHealth is mediated by patients' relationship with their assigned social workers. The communication with other patients and health professionals enabled by the platform is found to foster feelings of inclusion and mitigate problems around feelings of loneliness (Mann et al., 2017). Both patients and health professionals insisted, though, that the platform was to be viewed as a supplement to rather than as a replacement of personal interactions. Based on these findings, it seems recommendable to view technologies not as objects with their own logics, but as actors supporting or extending existing logics of care (Mol, 2008).

Affordances of technologically-mediated doctor-patient interactions in HIV care

- **Benjamin Marent**, Flis Henwood and Mary Darking
- Research Fellow, School of Applied Social Science, United Kingdom, b.marent@brighton.ac.uk

Healthcare services are increasingly utilising digital technologies to facilitate mediated forms of doctor-patient interactions that fully or partially replace face-to-face consultations. Because theories of the 'interaction order' (Goffman) have been largely focused on the physical co-presence of interlocutors, less conceptual repertoire has been developed to analyse technologically-mediated interactions and to understand their different affordances that frame the possibilities of agentic action.

This paper compares the affordances of face-to-face and technologically-mediated forms of doctor-patient consultations that have been introduced to follow-up stable HIV patients in five clinical sites (Antwerp, Barcelona, Brighton, Lisbon and Zagreb). As part of a comprehensive sociotechnical evaluation of a newly introduced mHealth platform we conducted 8 co-design workshops and 66 interviews with a total of 72 HIV patients and 32 clinicians to understand how the new technology reconfigured practices of care. Particularly, patients and

clinicians were prompted to consider the differences of routine consultations being performed face-to-face (all five sites), by audio-video interfaces (Barcelona), by telephone (Zagreb), by email (Brighton), and through the newly introduced mHealth platform (all five sites).

Our data offers concrete examples of how different modes of interaction gradually dislocate, dissynchronize and standardise the clinical encounter and how these functional aspects enable and constrain medical examination, dialogue, patients' reassurance and the 'normalisation of HIV'. Understanding these functional affordances, we will outline what different forms of doctor-patient interaction mean for people in different situations. Our empirical evidence of technologically-mediated interactions challenges classic theoretical assumptions of co-presence through physical proximity and offers new avenues to reconceptualise the interaction order.

Representations and practices of immigrant (expectant) mothers regarding ICTs in Switzerland: a socio-anthropological study

- **Patricia Perrenaoud** & Caroline Chautems
- Associate Professor, School pf Health Studies (HESAV), HES-SO, University of Applied Sciences Western Switzerland, patricia.perrenoud@hesav.ch

As shown extensively by Deborah Lupton and other scholars, eHealth and mHealth form part of the contemporary experience of pregnancy. Many (expectant) mothers seek information on the Internet, use Apps to monitor themselves or their infant and communicate with peers on social media. ICTs provide information, social contact and comfort to (expectant) mothers, but these technologies also contribute to the stereotyping of (expectant) parents and to social pressure through their narratives. Our ongoing socio-anthropological study aims to unveil the representations, practices and needs of immigrant (expectant) mothers regarding ICTs in Switzerland. These (expectant) mothers and their infants have a lesser good health and access to information than their Swiss counterparts and therefore represent a priority public for an enquiry about the use of ICTs. Participant observation and ethnographic interviews as well as semi-structured interviews are the methods used to construct our data with (expectant) mothers, interpreters and health professionals. More precisely, we aim to identify if and how immigrant (expectant) mothers seek information through ICTs and in which languages. Our study also documents emerging practices that include ICTs to foster the access to services of non-native speakers. Finally, our study documents how immigrant (expectant) mothers use ICTs with their family and friends living abroad during the maternity period. The presentation will consist of preliminary results constructed with (expectant) mothers and interpreters.

Communication as ongoing care: a study of the use of the MyChart app among patients living with chronic bowel disease

- **Stine Lomborg,** Associate Professor, Media, Cognition and Communication, CCC, University of Copenhagen, slomborg@hum.ku.dk
- Camilla Moring CCC, University of Copenhagen

- Cecilie Laursen, Bispebjerg Hospital and Aalborg University

In 2016-17, the hospitals in the Capital and Zealand regions in Denmark implemented a new patient portal, MyChart, as part of a broader IT-infrastructure for healthcare, the Health Platform (Sundhedsplatformen). Drawing on the concept of *care infrastructures* (Danholt and Langstrup 2012) this article investigates how the patient portal is currently embedded in the collaborative care for people living with chronic bowel disease. Discussing findings from fieldwork among chronic patients and clinicians at a hospital unit for Gastroenterology in Copenhagen around the implementation and use of MyChart, we sensitize discussions about care infrastructures and the push for self-care to the role of mediated communication in care.

Specifically, MyChart introduces a new media choice in the patients' ongoing communication with the clinic. While they can still call the clinic during opening hours, MyChart enables patients to communicate in writing with their physician about their treatment at a time and place convenient to them, for instance on the bus on the way home from work or when they experience symptoms at night, through a smartphone app. Our fieldwork indicates that patients have clear – but very different – preferences for either oral or written communication with their physician, linking these modes to experiences of authority, authenticity and joint decision-making. We suggest that the introduction of more communicative flexibility for patients speaks to an important element in contemporary care infrastructures. This choice, while seemingly trivial, grants the patient communication agency, at a point where the patient can actually master the role of active partner in care.

SESSION 2
2A - *Ethics and morality to mHealth*

TIME: 14.00-16.00.
ROOM: CSS 35.3.12
CHAIR: Natasja Kingod

From telemedicine to mHealth: the development of telemedical abortion and its forthcoming challenges on women's privacy

- **Nedine Kachornnamsong,** Womens on Web International Foundation, nedine@womenonweb.org

In this paper, we examine the work of Women on Web International Foundation; a non-profit organization founded in 2005 to provide telemedical abortion to women in the countries where safe abortion is inaccessible. A thematic review aimed to explore the sentiments and challenges behind the organization's role as a telemedicine provider and women's rights advocate. Our findings revealed that the growing popularity of mobile technology, social media provides a unique

opportunity for women and girls to partake in the public discussions on abortion which are considered to be a stigma or taboo. This conversation between social media users has brought forward the topic of induced abortion to the mainstream media discussion. Many women and girls are openly discussing abortion and many vouched for the right to safe abortion. While this progress helps to increase access to safe Abortion by expanding the general public's knowledge on sexual & reproductive health, the preliminary analysis revealed an overall lack of awareness and understanding of data privacy and security among some groups marginalized women. Such issue remains highly underestimated and poses serious concerns to telemedicine providers, notably in light of the GDPR data privacy regulations. It thus appears crucial for the healthcare organizations who also carry out the advocacy   work, such as Women on Web to find a possible middle ground when it comes to corresponding and handling individual's data concerning health and abortion.

Ethical dilemmas in social media health research

- **Dan, W. Meyrowitsch,** Thomassen, J, Konradsen, F, Kingod, N, Sørensen, J.B
- Epidemiologist, Global health researcher, Department of Public Health, University of Copenhagen, dame@sund.ku.dk

An increasing number of individuals worldwide engage in online communication concerning human health and researchers have identified the need to gain further insights on how individuals and communities engage and respond to particular health topics discussed on social media. However, this type of research is not without ethical dilemmas. Though ethical guidelines on the conduct of online research do exist, there is a lack of practical tools and procedures for the initiation and implementation of research on social media platforms in a thoughtful and respectful manner.

When carrying out research involving human subjects, three ethical concepts are central: 1) confidentiality; 2) anonymity; and 3) informed consent. These dimensions need rethinking when conducting research on social media platforms. For instance, a researcher stepping into a social media community would initially present herself, the objective of the research, and implications for participants – as in any other research project. However, it is a challenge to maintain informed consent to a study in a rapidly changing online community with a changing composition of members.

Based on hands-on experiences from an ongoing research project in a Danish Facebook group of users and group administrators living with suicidal thoughts, we have encountered a range of challenges related to all three ethical concepts. These challenges have lead us to explore new paths and solutions. In this presentation, we will share our experiences and reflections.

The patient entrepreneur – how Distributed Ledger Technologies are reframing imaginaries of the patient

- **Victoria Neumann,** PhD fellow, School of Computing and Communication, United Kingdom. v.neumann@lancaster.ac.uk

Hype around Distributed Ledger Technologies (DLTs - commonly often referred to as blockchain) has entered the domain of health data management. In short, DLTs which are permanent, distributed and tamper-proof lists of records maintained in a network of independent and equal nodes without the need for a central authority (Neisse, Steri, & NaiFovino, 2017). Promises that decentralization will provide new means of confidential data management has led to a number of newly funded DLT projects. In my talk, I will highlight how the envisioned application of DLT in health is also reshaping imaginaries of the patient and pushes forward existing neoliberal agendas. Scholars analyzing these neoliberal developments in health tend to either belong to Marxist or Foucauldian traditions. Marxists focus on how changing health care regimes and advancing privatization are turning patients into consumers who are increasingly exploited not only financially, but also their health itself (Sunder Rajan, 2017). Taking another angle on neoliberal politics, Foucauldian scholars have identified how neoliberal approaches in health and technology are shifting responsibilities from the state on the patient as forms of technologies of the self and disciplinary power (Lupton, 2013). Drawing on interviews and document analysis of funding applications, I can show how the visions of DLT are merging these two concepts into a new form what I call the patient entrepreneur. Under the guise of control and transparency, DLT tools such as smart-contracts and digital currencies pave the way for data practices that increase the economically self-exploitation and self-governance of patients.

Personalized Nutritional Genomics: An Analysis of the Intersection of Racialisation, Nutritional Reductionism, and Nutritional Capital

- **Tina Sikka,** Newcastle University, Lancaster, United Kingdom.
Tina.sikka@newcastle.ac.uk

In this talk, I examine the rise of personalized nutritional genomics as a scientific and corporate initiative aimed at harnessing the power of digital technologies that draw on data collection strategies which are subsequently (either voluntarily or involuntarily) subject to algorithmic analysis. I contend that this process is used to produce dietary recommendations that are inaccurate in the best case (which is also undesirable), and, in the worst, results in the reification of biological conceptions of race and ethnicity, the further commodification of health in accordance with reductive nutritionism, and the production of a new locus of inequality rooted in the unequal distribution of nutritional capital between those who have access to and knowledge of these technologies and those who do not. I draw on feminist approaches to science, critical race theory and critical food studies as the theoretical basis of my critique as well as the primary means by which to offer solutions.

Patient data work: Former cancer patient's efforts producing Patient Reported Outcome data

- **Rikke Torenholt,** PhD fellow, University of Copenhagen, Denmark.
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With digital patient reported outcome (PRO) tools in clinical practice, patients are given new tasks of providing data that aim at supporting and individualizing care, and simultaneously reducing

unnecessary clinical visits. While the innovative potential of mobilizing PRO-data for care is increasingly explored, little attention is given to the efforts that the provision of PRO-data rests on – that is the data work that patients are expected to engage in. Based on ethnographic fieldwork carried out among former breast cancer patients receiving PRO-based follow-up care, we argue that with the increased clinical reliance on data produced through patient self-assessment, a nuanced understanding of patient data work is needed. Thus, to conceptualize how patients engage in PRO-data work we draw on the concept of valuation as a process of both assessment and production as suggested by François Vatin. Applying this framework, we demonstrate how the assessment involved in data work requires both embodied sensing and emotional coping. We further demonstrate that the production of PRO-data involves filtration work as patients filter out what they perceive as irrelevant symptoms in order to provide a true answer. Finally, we argue that work associated with assessment as well as production of PRO-data constitute work of hope.

Paper Abstracts

Wednesday, 12 June 2019

SESSION 3

3A - *Digital health practices and patient experiences*

TIME: 10.30-12.30
ROOM: CSS 35.3.12
CHAIR: Laura Louise Heinsen

Apps and downs: an ethnographic study of young patients' digital health practices

- **Anette Wickström & Layal Kasselius Wiltgren**
- Department of Thematic Studies, Linköping University, Sweden. Anette.wickstrom@liu.se

Young people increasingly manage their health and wellbeing digitally using self-tracking technology or mental health blogs, which become conversational agents and personal coaches. In school, pupils are encouraged to download apps for managing their psychological health through working on thoughts, emotions and behaviors. However, the technology do not only *treat* illness, but takes part in *creating* illness through representing young people's problems in terms of signs of, or risk for, illness. Our previous research demonstrates that the understanding of young people's health needs are constructed out of a biomedical-psychological reality that links poorly with young people's own perspectives of their problems. Thus, a critical perspective of what the technology offers in terms of expert discourses and of meaning-making is indispensable; how the technology transforms the subjective experience of the self and how young people in turn transform the intended meaning of the digital treatment.

In this paper, we outline a project where we investigate eHealth and mHealth from the perspective of young people. Doing interviews and participant observations in two schools from different socioeconomic catchment areas, we aim to explore how 14-year-olds collect and analyze their own data, and interact on blogs, in order to improve their health. Our interest is directed towards the practices as relational: the human/technology relationship, the sharing of digital health data and of mental health problems. How do young people construct their needs and their health selves? How does the technology present what counts as ill and healthy? What are young people's counter-narratives?

The *Contraception Choices* website: design and evaluation

- **Julia Bailey,** Associate Professor, Sexual Health Doctor, Research Department of Primary Care and Population Health, United Kingdom. Julia.baily@ucl.ac.u

An estimated 40% of pregnancies are unplanned globally, and this has a huge impact on health, wealth and the environment. Women may not be aware of the range of different contraception methods available, and frequently have questions and concerns which have not been addressed by health professionals.

Objective: To develop and evaluate a website offering tailored advice for contraception choice

Methods: We reviewed the literature, analysed Youtube videos and conducted focus groups and interviews with young women to explore barriers, benefits, worries, myths and misperceptions about contraception. Women's perspectives and concerns informed the design and content of the *Contraception Choices* website www.contraceptionchoices.org. We collected survey data in a randomised trial (n=927) and conducted a qualitative process evaluation (n=18 interviews).

Contraception Choices offers clear information via interactive infographics, text and video. A tailored decision tool helps to identify contraceptive method(s) that best suit individual preferences, suggesting three suitable options.

Findings: Women liked the website, trusted the information and appreciated honesty about potential benefits and drawbacks of contraception. They liked the convenience of online access, and said that the website gave them more confidence to discuss contraception with health professionals. The website helped to address women's doubts and concerns, and prompted reflection about contraception choice.

Conclusions: Contraception use is complicated, and is influenced by partners, friends, family and wider community, but digital interventions can play a part in informed choice.

A lamp on a hill: digital technologies and patient subjectivities, an (auto)biographical analysis of the sharing of health experiences online

- **Fadhila Mazanderani** & Cassidy, K.
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This paper is a longitudinal analysis of the transformation of one patient's subjectivity in relation to the use of digital technologies for health. It draws on a range of empirical materials – from public YouTube videos to private diary reflections, blogposts to patient forum discussions, Facebook postings to Parliamentary briefings – created, collected and catalogued by Kerri Cassidy, a patient activist living with Multiple Sclerosis (MS) in Australia, over an extended period (2008-2017). Rather than simply being its subject, Kerri is one of the paper's authors. Thus, it is simultaneously a sociological analysis of patient participation in healthcare and an experiment in participatory social science research. As such, it prompts ethical and epistemological questions about how social scientists research digital technologies in relation to chronic illness.

The paper traces how Kerri's use of social media to improve her health (e.g. cultivating support networks, searching for treatment) transformed into activities that changed the care landscape within which she is embedded (e.g. lobbying politicians, crowdfunding for clinical trials). It examines how the complex decisions Kerri faced in relation to her own care resulted in a technologically mediated shift in her subject position: from 'private' patient to impassioned 'public' activist. The paper explores how patients, such as Kerri, who choose to go 'public' with their

experiences, can come, often unintentionally, to represent, both as embodied subject and political figurehead, particular conditions and controversies. Furthermore, we unpack the dynamics, and at times tensions, between the public and private dimensions of online health information sharing over time.

'I want to die now. What will prevent me from taking action?' – exploring social media communities for individuals living with suicidal thoughts. Preliminary findings of a qualitative study.

- **Jane Brandt Sørensen**, Meyrowitsch, D.W., Kingod, N., Konradsen, F., & Thomassen, J.L.
- Mental Health Researcher, Psychologist, Department of Public Health, University of Copenhagen. janebs@sund.ku.dk

Background

Self-harm is a global public health problem. An increasing number of users engage in online communities designed to aid individuals living with suicidal thoughts. However, little is known about how individuals are affected by these social media groups.

Aim

To gain an understanding of the potential implications of a user controlled peer-to-peer social media community of individuals experiencing suicidal thoughts.

Methods

Content from a social media community for individuals experiencing suicidal thoughts was collected over a 4-month period. The content was imported into NVivo12 through NCapture. The analysis was data driven using Discursive Psychology.

Findings

The social media community was perceived as a safe space where it was socially acceptable to focus on the individual's own situation. Here they could share their frustration, suicidal thoughts, specific events of self-harm and provide emotional support. Furthermore, they shared experiences of treatment and shortcomings of the health system.

Although the forum clearly did not allow for sharing of information on means of suicide, it was a reoccurring phenomenon that individuals requested information on this topic. One event significantly violated the sense of a 'safe space' when an individual disclosed his suicidal thoughts in the group, which was subsequently shared with his family members by another user.

Conclusion

Preliminary findings suggest that the social media community had an important support function for individuals experiencing suicidal thoughts. However, the forum also entailed several potential risks. Findings from the study will help to better integrate social media communities in a cohesive health promotion approach for suicide prevention.

Cancer narratives among Brazilian Instagram users

- **Raiana De Carvalho,** School of Communication Studies, Kent State University. rdecarva@kent.edu

Paper abstracts

Cancer is the second leading cause of death globally. The illness is one of the disorders of our time that carries the most powerful symbolic loading in Western societies. Exploring personal illness accounts from cancer patients' perspectives has been a focus of research from scholars interested in exploring how illness storytelling can be shaped, constraint, and enabled by wider cultural ideologies, as well as how they are articulated by the ill-patient as a counterpart to a purely biomedical approach to the body. Recently, social media platforms have provided new sites from which to explore illness narratives created and shared for networked publics. This study adds to this body of literature by focusing on the cases of two Brazilian cancer patients who are in palliative care, have shared their cancer experiences on Instagram, and have been considered "digital influencers" in cancer-related topics in Brazil. Using illness narrative and personal identity theories as the theoretical lens from which to explore such cases, I analyze how those patients construct meanings about being seriously ill while engaging in narrative repair through their Instagram posts. After conducting thematic and semiotic analysis of social media archives posted by the subjects on their public Instagram profiles for a period of three months, I also discuss how cultural ideologies of health and illness are both reproduced and resisted through their stories. The potential social implications of those cancer narratives online – such as transforming current cultural understandings of palliative care in Brazilian society – are further discussed and problematized.
Key words: cancer, palliative care, illness narratives, social media, Brazil

SESSION 3
3B - *mHealth and engaged mPatients*

TIME: 10.30 - 12.30.
ROOM: CSS 35.3.13
CHAIR: Jiuen Lee

Compiling Bodies: Apple HealthKit and Google Fit as Computational Infrastructures

- **Johan Salo & Martin Berg**
- Doctoral Student, Department of Computer Science and Media Technology, Sweden

The number of mHealth devices and apps is growing continuously, and there is now a plethora of devices available to support health and wellbeing in health care as well as self-care settings. Devices and systems of this kind are increasingly interconnected through various forms of APIs (application programming interface), such as the Apple HealthKit and Google Fit, through which they become part of a larger ecosystem that allows for increased connectivity along with regulated and limited uses of data types. These backstage parts of mHealth and their behind-the scenes decisions are essential to take into account in order to understand what devices and systems of this kind could possibly do, and to what extent they allow for tinkering and everyday improvisation. It is uncommon that research in digital health engages with and question how these invisible backstage layers of control build on certain assumptions and how their design, marketing, and imagined functionality are underpinned by certain understandings of bodies, health, and wellbeing. Drawing on a literature review as well as critical readings of the Apple HealthKit and Google Fit API:s, this paper engages with how digital infrastructures of this kind could possibly be designed to address the complex nature of health and wellbeing.

Assistive Technology Futures and the Limits of Market-Making

- **Dr. Peter Fuzesi,** Early Career Researcher, Sociology, Lancaster University, United Kingdom. P.fuzesi@lancaster.ac.uk

Since the advent of digital technologies, there have been increasingly loud calls for technologies to be used in health and social care. Yet, the provision of assistive technologies (AT) for veterans and disabled people by state agencies and within healthcare systems dates back at least to WW1. Juxtaposing 'old' and 'new' healthcare technologies highlight another salient feature of latter i.e. their alignment with markets. Even though designers and users are posited as its main drivers, at least in English-speaking countries, this change is almost always imagined as the creation of new products and markets. The movement from (medicalizing) assistive technologies towards commercially available services and products means not only leaving medical and care settings behind but also welfare state provision. The implicit assumption, underlying these imaginaries is

that future users correspond to consumers, health and social care needs are another 'problems' to be solved by markets. To discern some of the specificities and alternatives of these imagined futures, I draw on ethnographic fieldwork into healthcare professionals' design practices at a Regional AT Centre in England, a highly creative site, which provides access, choice and ongoing engagement. These hybrid access arrangements are indicative of how in order to accommodate a highly diverse population of users as co-designers, market relations of supply and demand are mediated and transformed in public healthcare systems. Moreover, studying healthcare professionals' design practices also demonstrate the extent seemingly technological figures, like user, design and device are rooted in market-imaginaries and their respective limits.

Making the invisible VISIBLE: BrainFx Screening and Risk Management Program

- **AnneMarie Levy,** PhD, Josephine McMurray[1] PhD, Azim Essaji[1] PhD, Moyosorelouwa Sogoalu[1] MSc, Elizabeth Kalles, BSc[2], Kai Yan Lui MSc[2], Paul Holyoke[2] PhD
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Early identification of mild cognitive impairment (MCI) is essential to delivering evidence-based interventions and helping patients and families living with declining cognition adopt coping strategies that slow disease progression and improve their quality of life (QOL). In practice, early detection is limited by labour intensive tests designed to detect moderate to severe decline using questions that lack ecological validity. The BrainFx Screen is a tablet-based digital tool designed to identify functional deficits that appear during early phases of cognitive decline. Results of the Screen are interpreted with respect to similar patient cohort populations tested and the report includes interventions tailored to address deficits in the seven cognitive domains assessed. The present study is a concurrent, mixed methods, prospective design to evaluate the sensitivity/specificity of the BrainFx against a validated MCI screen in people aged 55 and older not reporting cognitive decline and an economic evaluation of the Screen use in vulnerable populations. Results of ~8000 anticipated Screens will be used to develop an Early Identification Tool that electronically reviews medical records to identify those at risk for early cognitive decline whose QOL would benefit from early screening and intervention. Patient perceptions and attitudes towards the Screen, their willingness to participate in the study, the effectiveness of any interventions and their engagement in decision-making will also be explored qualitatively. In combination with similar healthcare provider data, we hope to explore socially constructed barriers to MCI screening and early invention.

The Fantastical Empowered Patient: Digital Health and Engaged Patients in the U.S.

- **Samantha D. Gottlieb,** PhD, MHS, anthropologist, United States. Samantha.gottlieb@gmail.com

This paper explores the Fantastical Empowered Patient through two concurrent phenomena in the U.S. health care space: the impact of collaborative communities of people living with type 1 diabetes (PWT1D) who reshape their tools to improve their lives with a chronic health condition; and the efforts across the Food and Drug Administration (FDA) to reimagine what constitutes

patient involvement in the regulatory process. Independently, these efforts are complex and potentially radical. Exploring them together, they indicate discordant shifts in how institutions, clinicians, and patients themselves imagine the agency of the patient and the mediation of patients' experiences. The variable register of patienthood highlights inadequacies in the institutional imaginary of the patient. The PWT1D DIY communities, are simultaneously "deliberately non-compliant" (Scibilia 2017) and exemplars of the Fantastical Empowered Patient, demanding knowledge and control for which the FDA struggle to account. PWT1D-developed algorithms and hybrid closed loop systems, built through bricolage of existing devices, can now provide semi-automated diabetes management, altering life with diabetes. The PWT1D communities invoke transparency, safety, trust, and control that commercial manufacturers and the FDA promise, but fail to understand fully from patients' perspectives. The frameworks the FDA uses for its institutional standards lack deep understanding of the embodied knowledge that the PWT1D community draws upon. This paper considers this reverse form of embodiment: PWT1D translate internal states into digitized traces to generate evidence and to live more fully, to do what the FDA fantasizes what patient-reported data should do –turning data into evidence.

From Do-it-Yourself to Do-it-Ourselves: Self-care in Type 1 Diabetes therapy as a collective endeavor

- **Bianca Jansky**, & Verina Wild,
- PhD Candidate, Institute of Ethics, History and Theory of Medicine, Ludwig-Maximillians-University Munich. Bianca.Jansky@med.uni-muenchen.de

Do-it-yourself (DIY) modifications of diabetes technologies have gained momentum in recent years. Patients ‚hack' their glucose-sensors in order to get real time access to glucose data, and even build artificial pancreas systems. Drawing on findings of a situational analysis of DIY approaches in Type 1 Diabetes (T1D) self-care, the objective of this paper is to explore the dynamics and complexities of those practices.

We argue that it is instructive to understand the emergence of the observed DIY practices as a collective endeavor. Despite the emphasis on yourself, a dependency on others seems characteristic: whether through sharing experiences and knowledge, collaborating on source-code and instructions, or in real-life meet-ups.

This leads to the conclusion that DIY practices in T1D self-care can be interpreted as do-it-ourselves approaches. New forms of expertise are arising in this collective. Legislative regulations as well as advice from medical-trained professionals seem to have little influence on patient's decision-making.

The global network of likeminded people working on solutions for their health problems together can enhance patients' solidarity and empowerment, but at the same time could reinforce inequality and new forms of risks could emerge.

Keywords: Self-care; Do-it-yourself; Type 1 Diabetes; Online Communities, Collectivity

SESSION 4
4A - *Apps and Tracking*

TIME: 13.30-15.30.
ROOM: CSS 35.3.12
CHAIR: Nete Schwennesen

How can we promote adoption of assistive technology for people with dementia? Perspectives from the ReACT1 study

- **Laila Øksnebjerg,** Neuropsychologist, PhD student, Danish Dementia Research Centre, Rigshospitalet, Denmark. Laila.oeksnebjerg.02@regioh.dk

Various forms of assistive technology (AT) are recognized to have potential to support cognition and self-management of people with dementia. There is, however, an increasing awareness a range of research issues that needs to be explored within this field, e.g. the need for user involvement in development and test of AT, and the need for evidence-based methods for deployment and adoption of AT to people with dementia.

The ReACT study aimed to investigate how an app-based AT solution can be designed to meet the special needs of people with dementia, and how this app can be successfully adopted by end-users. Perspectives on data-driven outcome measures were also explored.

As part of the study, the ReACT app was designed and tested through an iterative user-involving process. It is a multi-functionality app, supporting memory and structure in daily living. We also conducted two substudies (N=130), where two diverse methods for deployment and adoption were designed and explored. Data from these sub-studies gives insight into the applicability of these methods and the characteristics of people with dementia who adopted the technology, compared to those who did not adopt the technology or abandoned it.

The ReACT study provides new results and perspectives that are important in the discussion of how AT can be designed and introduced to people with dementia in an individualized and sustainable manner.

Minor creations of self-care for life with chronic disease and technology

- **Claudia Bagge-Petersen,** PhD Fellow, Department of Public Health, University of Copenhagen, Denmark. clba@sund.dk

Through ethnographic research the project investigates everyday life for minors with chronic diseases to account for self-care as it is formed in daily living and contrast it with emerging mHealth scripted notions of self-care. Thereby the study relies on an emerging technology methodology to guide insights about what makes minors a special group of mHealth users.

The study demonstrates how the minors and families ritualize disease management and separate it from everyday life spaces by (non-) involvement of various everyday life technologies, which suggests a dichotomy between chronic living and minor living. Within the spaces of chronic disease, the condition is dealt with by coordinated performances of bodies and things, which this paper acknowledges as interembodied assemblages of disease management rather than dealings of a single person. The paper's contribution thus lies in identifying minor self-care as fluently ritualized practices that tame the disease and limits its space. For mHealth the findings imply designing for dynamic assemblages in restricted disease spaces which contrasts result oriented, user-focused, holistic mHealth approaches of tracking everyday life elements like mood.

Keywords: minors, self-care, disease space, interembodiment.

The performativity of value in digital service innovation: The case of psychiatric smart pills and changing practices of medication adherence

- **Valerie Handunge,** Warwick Business School, United Kingdom.
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The first ever smart pill was approved for the treatment of schizophrenia and bipolar disorder in 2017. The smart pill is a **drug**/device combination consisting of traditional active drug agents embedded with an ingestible biosensor and a wearable patch that tracks if a patient has ingested the medication. A mobile app allows patients to document mood and sleeping patterns and a web-based portal allows clinicians to monitor data. The resulting digital service ecosystem is shifting lived experiences of the clinically coined practice of medication adherence. To this end, we ask the question: How do concepts of temporality explain changing everyday practices of medication adherence with the emergence of smart pills?

To understand the emergence of smart pills in everyday practice, we bring together established theories of temporal agency from classical organizational studies and contemporary practice-based approaches in relational sociomateriality to make a unique contribution to the emerging literature on digital service innovation.

Drawing on our empirical research, we argue that the smart pill is leading to a present day "crisis of practice" (Reckwitz 2002 p.256) at the nexus of habitually performed routines with past inheritance and the anticipatory future of a new human experience – the interpenetration of the past, present, and future.

We find that the complex past, future, and present materializations of self-identity influences the value of innovations in use, which is consequential for firms as they organize for digital service innovations in healthcare.

Adolescents' decision-making using a diabetes app: Findings from a development project

- **Antoinette Fage-Butler** & Loni Ledderer
- Fage-butler@cc.au.dk

In line with the current biopolitical impetus towards greater patient participation, patients are increasingly encouraged to make informed decisions about their healthcare, and health apps have been touted as supporting this endeavor. Patients with diabetes have particular decision-making needs as they need to monitor constantly their blood sugar levels to avoid diabetes-related complications. The aim of this paper is to analyse the role of a diabetes app prototype in facilitating adolescents' health-related decisions.

Our data derive from a qualitative case study of the development of a diabetes app at two outpatient clinics in Denmark. Data comprise the transcripts of individual and group interviews with the adolescents from the test phase; the data were analysed using qualitative content analysis.

Our findings indicate the complex ecology of decision-making around the adolescents where the app emerged as one element. A number of the app's functions, e.g. the app's visualisation of blood glucose levels and the calendar function, supported decision-making, whereas the function that provided medical information about diabetes was rarely used. Some adolescents wanted a private space in the app to interact with other adolescents with diabetes about diabetes-related decisions.

Inspired by the theory of distributed decision-making, we argue for the methodological value of investigating the health-related decision-making supported by mHealth technologies contextually, as the decision-making supported by the app prototype implicated a plurality of times, situations, people and technologies that intersected with the app.

WhatsApp as a mobile health tool: alternative routes to the social experience of rare diseases in Chile

- **Natalia Orrego Tapia, Social Anthropologist, Sociology, Diego Portales University, Chile. Natalia.orregotapia@gmail.com**

Even though the use of mHealth apps and devices has had a dramatic growth in the last decade, Latin America and, particularly, Chile are markets where mobile health usage is marginal in front of social media and mobile games. In this context, the current presentation focuses in the use of the platform WhatsApp as a mobile health tool for lower and middle income patients with myasthenia gravis - a rare, chronic and neuromuscular disease with approximately 1.200 people diagnosed in Chile. Regarding the methodology, digital ethnography with participant observation, interviews and reenactments produced dense data that was analyzed with qualitative and quantitative approaches. The main results show how WhatsApp is heavily used in Chilean myasthenia informal and formal communities - more than other apps, platforms and websites - to access expert patient knowledge and new social networks that support the ill and their loved ones.

Additionally, the platform allows to express and perform illness, and monitor disease with others. These genres of use reinforce the way that rare diseases are, simultaneously, an individual experience of symptoms and a collective experience of misinformation, injustice and diverse struggles that are invisible to health professionals, the state and other external actors. With this presentation, it is expected to stimulate dialogue on the centrality of the use of social media for health and, above all, the importance of digital technologies that do not reduce the user experience to personal matters of the body but take into account the social experience of disease.

Brain training and active ageing: tracking success in social division

- **Sebastian Liebert,** PhD Student, Division of Psychiatry, University College London, United Kingdom. rejusli@ucl.ac.uk.

In the past few decades there has been a shift in dementia strategies towards prevention (e.g. The Lancet Commission on Dementia Prevention, Intervention and Care) as a continuation of the dominant active ageing ideal. Alongside this we also observe the success of brain training technologies for individuals reaching later life. As part of a multi-sited fieldwork including users and developers of computer-based 'brain training' technologies; a collaboration with The PROTECT Study; and the Intras Foundation, I have explored how brain training technologies and 'apps' have become part of the daily life of individuals. I have also investigated the rationales behind their use and development. Following this research, l argue that the increasing use of mhealth for self-tracking and therapy in later life finds its origin in already existing social divides between active and independent '3rd agers' on one side, and dependent elderly individuals caught up in the social imaginary of the 4th Age on the other. The term fourth age was originally introduced into English by the historian Peter Laslett (1989) and further theorized by Gilleard and Higgs (2010) and is used to describe current representations of the most unwanted sides of ageing. This presentation will discuss the increasing popularity of such technologies; their relation to previous health and fitness regimes associated with late capitalism; and how their design may help to reproduce practices of distinction performed by active, responsible consumer-citizens in order to dissociate themselves from dependent individuals living with dementia and frailty.

References:
Gilleard, C., & Higgs, P. (2010). Aging without agency: Theorizing the fourth age. *Aging & Mental Health, 14*(2), 121-128.
Laslett, P. (1989). A fresh map of life. London: Weidenfeld and Nicholson.

Where to go in Copenhagen

DRINK:
<u>Close to conference venue:</u>

Zaggi´s Coffee/ Frederiksborggade 43, 1371 København
Zaggi´s Coffee is very close to campus and serves nice and cheap coffee-to-go. With some pretty dedicated regulars, many of them students, Zaggi´s coffee is often full of people both inside and outside on the sidewalk benches. They only accept MobilePay or cool cash.

Espresso House/ Frederiksborggade 24, 1360 København
A Swedish spacious coffee chain that serves great coffee and a variety of bread, sandwish, cake and other desserts.

Torvehallerne/ Frederiksborggade 21, 1362 København
It is not a supermarket – it is a super market. At Torvehallerne in Copenhagen, you will find over 60 stands selling everything from fresh fish and meat to gourmet chocolate and exotic spices, as well as small places where you can have a quick bite to eat. Here, you can eat breakfast at Grød, drink a nice cup of coffee at Coffee Collective, eat tacos at Hija de Sanches and so much more. Torvehallerne were designed by architect Hans Hagens and opened in September 2011.

Paludan Bogcafe/ Fiolstræde 10-12 KBH K
Bring your own book or borrow one from the cafe, while you enjoy a wonderful cup of coffee at Paludan Bogcafe.

The Royal Smushi Café/ Amagertorv 6, 1160 KBH K
The Royal Café is located inside the flagship store of Royal Copenhagen. The café represents an unusual and adventurous combination of Danish food and Danish design. On the menu, you will find "smushi", which is a Danish open faced sandwich prepared like sushi.

The Living Room/Larsbjørnsstræde 17, 1454 KBH K
In the heart of downtown Copenhagen you will find the Copenhageners' shared living room with comfy couches and a nice fireplace. It is indeed a chilled hipster hangout with vintage looks on 2 floors serving organic brunch.

Where to go in Copenhagen

Bo-bi Bar/ Klareboderne 14, 1115 KBH K
Since 1917, this Copenhagen establishment has served thirsty customers drinks within a smoky red baroque-style wallpapered interior.

Elsewhere:

Harbo Bar/ Blågårdsgade 2d, 2200 KBH N
Harbo Bar is located in the hip area on Nørrebro and has become a popular hangout for many Copenhageners.

Mikkeller/ Victoriagade 8, 1655 KBH V
Danish Mikkel Borg Bjergsø has created one of the best beer bars in the world – a small, cool place for beer enthusiasts as well as novices to enjoy top quality micro brewed beer from Mikkeller and other innovative breweries from around the world.

Kassen/ Nørrebrogade 18, 2200 KBH N
Kassen at Nørrebrogade is always good for a cheap cocktail. Several days a week you will find some kind of happy hour at this bar.

EAT:
Close to conference venue:

Aamann's/Øster Farimagsgade 10, 2100 KBH
This smørrebrød deli sets new high standards for the Danish traditional, open-faced sandwich lunches. Adam Aaman's innovative interpretation of classical Danish smørrebrød dishes has made his eatery a success. Aamanns offers a constantly changing menu of seasonally inspired dishes and can now be ordered-to-go as well as home-delivered.

Scurry Hub/Fiolstræde 30, 1171 KBH K
A small Thai restaurant in the heart of central Copenhagen with low prices.

Bibi's Diner/ Rosengården 14, 1174 KBK K
The owner is mediterranean and so is the food.

Riz Raz/ St. Kannikestræde 19, 1169 KBH K
Mediterranean specialties at very reasonable prices. This restaurant is for those who are looking for a lot of food at a cheap price. Help yourself at the vegetarian buffet or combine the buffet with a dish from the menu.

Where to go in Copenhagen

SimpleRAW/ Gråbrødretorv 9, 1154 København
Serves vegan and vegetarian food, juices, smoothies, shakes, limonades and coffee. The place to go if you crave a ginger-shot.

Restaurant Ida Davidsen/ Store Kongensgade 70, 1264 KBH K
Restaurant Ida Davidsen is probably the most famous place in inner Copenhagen to taste Danish smørrebrød. If you think Danish Crown Prince Frederik, footballer Michael Laudrup, or entertainer Victor Borge are dishy, this may be the place for you. All have had smørrebrød sandwiches named after them. In all, there are more than 250 types to choose from.

Elsewhere:

Kebabistan/ Istedgade 105, 1650 KBH K.
Shawarna, falafel and hummus.

Ahaaa Arabisk madhus/ Blågårdsgade 21, 2200 KBH N
Possibly the best falafel in town is served at this Lebanese place.

Nose2Tail/Flæsketorvet 13a, 1711 KBH V
The sustainable Nose2Tail in the Meatpacking District makes food with respect for the animal and the nature surrounding it. All their meat comes from Danish, free range animals, and the food is as local and organic as possible.

BioMio/Halmtorvet 19, 1700 KBH V
Trendy restaurant BioMio at Halmtorvet in Copenhagen is focusing on 100 Percent ecology and sustainability.

Radio/Julius Thomsens Gade 12, 1632 KBH V
Restaurant Radio is located between Vesterbro and Frederiksberg and is serving organic and Nordic food.

MUSEUMS:
Close to conference venue:
Ny Carlsberg Glyptotek/ Dantes Plads 7, 1556 KBH V
The art museum is founded by the brewer Carl Jacobsen and contains two main departments of ancient and modern art in fabulous architectural surroundings. You can view collections of Egyptian, Greek, Etruscan and Roman art as well as Danish and French paintings and sculptures of the 19th and 20th century.

The Danish Jewish Museum/ Proviantpassagen 6, 1218 KBH K
A visit to the Danish Jewish Museum, designed by Daniel Liebeskind, will give you a good insight into the enthralling universe of Danish Jewish culture and its 400 year history.

Davids samling/Kronprinsessegade 30,1306 KBH K
The David Collection is housed in the building once occupied by the museum's founder, Christian Ludvig David, and in a neighboring property that was acquired later. Both date to the beginning of the 19th century. They underwent comprehensive renovation between 2005 and 2009 and today provide the setting for a fully modern museum that respects its historical heritage.

Medical Museion/Bredgade 62, 1260 KBH K
Medical Museion is a combined museum and research unit at the University of Copenhagen. The museum was founded on a private initiative in 1907 to mark the 50th anniversary of the Danish Medical Association with a public exhibition of historical medical artefacts. It remained a public museum until 1918, when it was taken over by the University.

Rosenborg Castle/ Øster Voldgade 4a, 1350 KBH K
Rosenborg Castle in Copenhagen is home to some of Denmark's greatest cultural treasures. The castle was built in 1606-1634 by Christian IV as a pleasure castle. In the basement you will find the Danish crown jewels and regalia. At Rosenborg Castle you can also see a portrait of Johan Friedrich Struensee, painted by Hans Hansen in 1824, and a portrait of Queen Caroline Mathilde painted in 1771 by Jens Juel.

The Danish Centre for Architecture/ Strandgade 27B, 1401 KBH K
The Danish Centre for Architecture (DAC), aims at displaying trends in Danish and international architecture to ensure continuous public exposure. It features exhibitions with models, sketches and photographs. Study tours and debate meetings can also be arranged, alongside lectures on subjects connected to the exhibitions.

Elsewhere:
Finn Juhl's House/ Vilvordevej 110, 2920 Gentofte
The Art museum Ordrupgaard celebrates the centenary of Finn Juhl. His private home built in 1942 - right next to Ordrupgaard - is open to the public.

OTHER SITES:

Close to conference venue:

The Little Mermaid/ Langelinie 0, 1263 KBH K

At Langelinje Pier you will find one of Copenhagen's most visited tourist attractions: The Little Mermaid.

The statue from 1913 was originally a gift to the city donated by brewer Carl Jacobsen.

Tivoli Gardens/ Vesterbrogade 3, 1630 KBH V

Tivoli is a must for all children and those who like to play. Tivoli is located just a few minutes walk from City Hall, and with the Copenhagen Central Station as its nearest neighbor it is very easy to get to.

Amalienborg/ Amalienborg Slotsplads 0, 1257 KBH K

Considered one of the greatest works of Danish Rococco architecture the Queen's residence is, made up of four identical buildings spread around the octagonal courtyard.

Get a glimpse into the Royal abode or watch the daily shift-change of the Royal Guard.

Nyhavn/ Nyhavn 0, 1051 KBH K

Nyhavn - packed with partying people, restaurants, and bars.

During December the street is frosted with a christmas bazaar.

Canal Tours Copenhagen/ Nyhavn 3, 1051 KBH K

Get the best views onboard the canal boats in Copenhagen. A guide will let you in on stories and fun facts about the sights along the way.

Christiansborg Palace/Prins Jørgens Gård 1, 1218 KBH K

Christiansborg Palace houses the Danish Parliament, Supreme Court, and Ministry of State. It is also used by the Royal Family for various functions and events.

Strøget/ Strøget 0, 1160 KBH K

Copenhagen's largest shopping area is centered around Strøget in the heart of the city. Strøget is one of Europe's longest pedestrian streets with a wealth of shops, from budget-friendly chains to some of the world's most expensive brands.

<u>Elsewhere:</u>

Christiania/ Bådmandsstræde 43, 1407 KBH K
Christiania, the freetown of Copenhagen, is without a doubt one of
Denmark's most popular tourist attractions.
This controversial area is loved by many, but has often been a turning point
for strong debate. During the month of December they have a famous
christmas fair.

Carlsberg/ Gamle Carlsbergvej 11, 2500 Valby
Carlsberg is among the largest tourist attractions in Copenhagen and now
you have the opportunity get closer to the roots of Carlsberg, the history
and the beer.

For more ideas: http://www.visitcopenhagen.com/