Dear colleagues and friends,

Welcome to Berlin and to our symposium: DELSI – Digital Epidemiology and its ethical, legal and social implications!

Public health is in crisis – with the backdrop of the recent Ebola outbreak it has become apparent that the mechanisms we have historically relied upon for epidemiological identification, assessment, and response may no longer be sufficient. More than ever, this is a time in which public health practitioners are also being offered a wide range of innovative tools and methods enabled by newest developments in digital and mobile technology. These new tools and methods promise to offer new chances for our work, but in addition they carry with them new challenges.

The Robert Koch Institute, and public health practice in general — including epidemiologic surveillance — can benefit greatly from an intensified discussion around the interoperability of these tools within larger systems, both nationally and globally. Now is the time to investigate the scientific and social implications of digital epidemiology.

The symposium provides an interdisciplinary platform which brings together both academic and public health perspectives so that we can consider the advantages and disadvantages, expectations and concerns, opportunities and risks of adopting digital epidemiology as an instrument to perform epidemiological identification, assessment, and response.

We are pleased at the overwhelming interest and the willingness of this diverse, interdisciplinary community to share your experiences in and around this field.

Our team, comprising colleagues from the RKI, TU Berlin and King’s College London, has put together a full program that we hope will lead to lively dialogue and productive exchange – formal and informal — throughout the week.

We hope that you enjoy your time on Schwanenwerder!

Tim Eckmanns
About this event

DELSI 'Digital Epidemiology and its ethical, legal and social implications' (DELSI) is an interdisciplinary, binational symposium from September 14 - 18, 2015 in Berlin that welcomes participants from Germany and the United Kingdom. The event is organized by the Department for Infectious Disease Epidemiology at Germany’s Robert Koch Institute, and is in cooperation with the Center for Technology and Society, Technical University Berlin. The event is by invitation-only.

For public health and epidemiology, the Internet is increasingly recognized as a rich and expedient platform for capturing and sharing health information. Digital developments like Big Data analytics and data mining have created ground-breaking opportunities in knowledge generation in these fields. They promise faster disease assessment and response, easier exchange of data, lower costs and reduced administrative burden; however, new tools may also introduce critical epistemic questions public health science, and challenge the way established health systems perceive, prioritize and manage health events. They may also confront traditional decision making processes in public health research and practice. Opportunities for rights infringements, such as privacy violations and social discrimination, might also arise.

We welcome the participants to answer the following questions:

• Does the use of emerging technologies and digital tools, especially Big Data, present an epistemic shift in epidemiology?

• Might the use of new digital tools change prioritization in agenda-setting, resource allocation and decision-making for infectious diseases in public health practice, which has traditionally aimed to improve health states and address determinants of health?

• There are implications for privacy and discrimination in digital epidemiology. Is it possible to mitigate, or even prevent, any potential consequent rights infringements?

• How should we assess the ethical and social impact of digital epidemiology, particularly given an increasing linking of health and security concerns within contemporary infectious disease management?

• What particular nuances of digital epidemiology emerge given contemporary health events of global concern, such as Ebola in West Africa or increasing worldwide antimicrobial resistance?
About this event (cont.)

The DELSI symposium provides a forum to explore the ethical, legal, practical and social dimensions of new digital tools in public health practice and disease monitoring in Germany and the United Kingdom. Participants will discuss the opportunities and risks of emerging technologies that inform new methods of capturing, recording and analyzing epidemiologically relevant data from the Internet, social media, sensor data and other digital sources. In this context, they will discuss the possible tensions within, and between, the imperatives of public health, security, social justice and civil rights. By tackling the following complex interdisciplinary questions, we invite attendees to inform contemporary methods of practice and directions in future policy.

For your convenience, this program includes the abstracts and biographies of each participants according to the day s/he is presenting, and photos of each participant and the organizing team are located in the back. A copy of the event schedule for the week has been distributed separately.

The organizing team

Tim Eckmanns, MSc, MD, Robert Koch Institute
Edward Velasco, SM, PhD, Robert Koch Institute
Katherine Polin, MPH, Robert Koch Institute
Christiane Petasch, Robert Koch Institute
Tülin Yilmaz, Robert Koch Institute
Leon Hempel, PhD, Technical University Berlin
Klaus Scheuermann, Dipl.-Soz., Berlin
Prof. Barbara Prainsack, Dr phil, FRSA, (advisor),
King’s College London

Information on DELSI

On the web: www.rki.de/delsi
Email: Delsi2015@rki.de
Monday, 14 September 2015

Welcome and Introduction
An overview of digital epidemiology and its implications

Marcel Salathé is Associate Professor at the Schools of Life Sciences, and Computer and Communication Sciences, of EPFL, Switzerland. Before heading the Digital Epidemiology group in Geneva, he was Assistant Professor at the Center for Infectious Disease Dynamics (CIDD) at Penn State University, USA. His group uses mobile phones, wireless sensors, and social media data for epidemiological purposes in projects ranging from plant to human health.

New approaches to public health surveillance: algorithms for social justice?

As Porter (1994) argues, seminal histories of public health have emphasized either a utopic march of progress, which liberated societies from the perils of infectious disease (e.g., Rosen 1993), or a dystopic diffusion of discipline capable of propagating control and even confinement: “Everyone locked up in his [sic] cage […]” (e.g., Foucault 1995: 196).

The history of public health surveillance is bound up with these opposing representations. Sometimes surveillance has been described as a mechanism of control; sometimes it has been depicted as a pre-requisite for progress. However, the picture is more complex than simplistic, either-or representations admit. In North America, for example, the establishment of disease surveillance systems was characterized by the increasing displacement of social reformers by professionals trained in bacteriology, turf wars between public health officials and clinicians, and changing conceptions of privacy (Fairchild et al. 2007).

Reflecting on this complex history, this paper connects new approaches to public health surveillance to broader dynamics related to professionalization, institutionalization, and privacy. It considers published literature on select, computationally-driven public health surveillance and biosurveillance projects. The focus is not only upon their technical accomplishments but also upon their ramifications with respect to the health professions, public health institutions, and privacy. Key areas of exploration concern 1) the specialized knowledge they require and produce; 2) their potential to become disruptive innovations, unsettling the established institutional order; and 3) their potential implications with respect to privacy. A concluding question considers the complex, social justice implications of these projects in an effort to complicate utopic and dystopic discourses about the algorithms governing new approaches to public health surveillance.

Martin French is Assistant Professor of Sociology and Anthropology at Concordia University in Montreal, Canada. As a sociologist, he studies the social dimensions of technology with an empirical focus on communications & information technology (CIT). His research emphasizes the broader social and political contexts of CIT, focusing especially on risk, surveillance, privacy, and social justice. This involves the use of mixed methods to empirically specify and assess the information-processing practices of professionals, organizations and networks. The aim of this research program is to create an evidentiary foundation for understanding the relationship between information flows, the practices that nurture or impede them, and the resulting configurations of governance that they enable or disrupt. At a pragmatic, everyday level, this involves forging partnerships that span government, academic and community-based organizations, and using these partnerships to mobilize innovative best practices through the creation of evidence-informed policy.
Tuesday, 15 September 2015

Digital Epidemiology and/as Big Data – Epistemological, methodological and technical challenges
Dirk Brockmann
Robert Koch Institute

*Physics, networks, complexity and smart data in epidemiology*

Dirk Brockmann is a physicist and Professor at the Institute for Biology at Humboldt University of Berlin and the Robert Koch Institute, Berlin. Brockmann is known for his work in complex systems, complex networks, computational epidemiology, human mobility and anomalous diffusion.

Michael Höhle
Stockholm University

*Statistical perspectives in digital epidemiology*

Michael Höhle works as an associate professor in mathematical statistics at the Department of Mathematics, Stockholm University, Sweden. Previous work places have been the Department of Infectious Disease Epidemiology, Robert Koch Institute, Berlin, and the Department of Statistics, University of Munich. His research interests are biostatistical methods, spatio-temporal modelling and statistical surveillance. Furthermore, he actively supports the implementation of such methods using open-source tools. Particularly, he maintains the R package ‘surveillance’, which contains functionality for the visualization, modelling and monitoring of routinely collected public health surveillance data.
Johannes Schnitzler
World Health Organization

Identify, assess, inform. Who needs to know what and when

The world requires a global system that can rapidly identify, assess and contain public health threats and emergencies to reduce morbidity and mortality and avoid disruption of travel, trade and society in general.

The revised International Health Regulations IHR (2005) provides a global legal framework for collective responsibility of States Parties to the IHR for the prevention, detection, and timely response to any public health emergency of potential international concern. WHO obligations under the Regulations include the rapid and consistent identification, assessment, verification and response to public health risks including information sharing through different channels. Since 1997, WHO has implemented epidemic intelligence activities to enhance the Organization’s capacity to detect, verify and rapidly assess global threats to public health.

The monitoring, analysis and rapid assessment of open source information available in the world wide web is a crucial part in the epidemic intelligence activities complementing reporting through official channels.

The ever increasing number of information sources and types of data available offers great opportunities for the early detection of new and the monitoring of ongoing public health risks. The amount of information and type of information available to a large audience is at the same time posing serious challenges to public health institutions including WHO and society in general.

These challenges include: Information overload resulting in a high workload, need for appropriate IT solutions supporting monitoring and analysis, pressure on public health institutions to monitor the available information and publish information rapidly, risk of breach of confidentiality for individuals/specific groups, possible negative impact on national authorities including the economy and public health services.

Public health institutions need to set examples/standards on information collation and dissemination including the use and further dissemination of information available in the world wide web. Further discussions need to inform one of the main questions related to information dissemination around public health risks: Who needs to know what at which point in time.

Johannes Schnitzler, MD, is working as medical officer at the World Health Organization in Geneva, Switzerland in the Global Surveillance and Risk Assessment unit on the identification, assessment and management of acute public health events. He has carried out his Field Epidemiology Training Program (FETP) at the Robert Koch Institute in Berlin. Working at the World Health Organization he has worked on the assessment of surveillance systems, outbreak response and event management. Combining epidemiology with IT skills he has designed and developed IT systems supporting indicator and event based surveillance.
Patty Kostkova
University College London

**Digital epidemiology: The new frontiers**
Web 2.0 technologies and real-time Big data streamed and shared from social media, mobile phones and wearable/tracking devices have dramatically reshaped the traditional surveillance landscape and created an epistemic shift. However, it is a double edge sword as governance and regulation frameworks for data privacy are lagging behind technological achievements.

**Surveillance Data Integration: Not Early Warning – Risk Assessment and Response saves lives**
Real-time location-aware non-medical data sources (social media, personal traces, shopping lists, mobile data) could be mined for improving early warning systems, analyzed for threats detection to assist public health experts with rapid risk assessment and response. While there is potential in early-warning systems using Big data (Google Flu Trends), an integrated solution for risk assessment and rapid response underpinned by frontline healthcare professionals training is urgently required, as the recent Ebola outbreak demonstrated.

**Sharing Data: Blessing for Public Health or Google: the Big Brother**
Population level surveillance data sharing could enable faster and better coordinated response during emergencies while opening new frontiers for data-driven research in public health. However, enabling access remains a challenge.

Perhaps the most alarming ethical and social concern is that never has so much data about so many citizens been held by so few with little police and legal oversight, such as the case of IT, MedTech and mobile industries. We need a radical shift in the direction of regulation of data usage by industry giving control back to users generating the data, however, this would bring dramatic business implications.

Patty Kostkova is Principal Research Associate for eHealth at the Department of Computer Science, University College London. She is also a Special Lecturer at the School of Arts and Social Sciences, City University, London delivering an interdisciplinary module on Social Media for postgraduate social science and informatics students. From 2012-13, she held a Research Scientist post at the ISI Foundation in Italy and in June 2014 was appointed ISI Fellow for her research into digital epidemiology. Until 2012, she was Reader and the Head of City eHealth Research Centre (CeRC) at City University, London, UK. Patty has MSc and PhD degrees in computer science and an extensive international experience at public health agencies such as WHO and ECDC. She built up CeRC into a thriving multidisciplinary research centre collaborating with international partners and funding bodies including ECDC, WHO, HPA, EC and the DH.

Patty’s research into Big Data in healthcare includes one of the first studies exploring the potential of Twitter for early-warning of pandemics indicating the social media interwork “predicted” swineflu 2009 two weeks before the official national surveillance authorities, and the importance of Twitter for risk communication. Medi-board, the public health dashboard project, explores integration of multiple Big Data sources for verification and effective response. Patty’s team was awarded the EHI (Ehealth Insider) 2012 Prize – finalist in Category “Best Use of social media in healthcare”. In the recent years, she was appointed a consultant at WHO, ECDC and Foundation Merieux.
Göran Kirchner
Robert Koch Institute

**Big data – little literacy**

The Robert Koch Institute is collecting, generating and analysing various kinds of data in diverse health related fields, ranging from microbiology to epidemiology. These data help to increase the understanding of the course, spread, and causes of diseases and help in preventing them. Based on these data many decisions are made to improve public health and reduce the burdens of diseases. Yet, before these decisions can be made, a good portion of statistics, mathematics and data science is used to transform the raw sets of data into useful information.

Instead of restricting the availability and access to data, we argue, that better tools for its understanding are needed, which make these data accessible, not only to experts but to citizens as well. To better judge its use or potential misuse, all these data should be readily analysable on every one’s personal interests, since data means little, if it can’t be understood. This immediately leads to the question of how to make these expertise and interpretations publicly available, how to move advanced analytics from the domain of specialists to everyday users. What needs to be done in order to help people getting answers relevant for them and how allowing people to make informed decisions? We will give examples of how the long path for this distant goal can be started, what our contributions and visions are, and how we try to meet our responsibilities as a governmental institution.

At first, there is a need for better visual tools that help novices and the mathematically innocent to explore, analyze and interpret data through interactive maps, charts, and other kinds of infographics. We will present some data-driven graphics and business-information tools to illustrate this topic.

A second need is the formalization of knowledge, to make the users aware of ambiguities and misinterpretations and guide them to their wanted answers. We give some examples in controlled natural language, showing how “table-thinking” can be avoided, and lay out future plans for semantic interoperability.

Both approaches will turn big data into attractive intelligible smart data and will finally improve the society’s literacy in a field of great personal interest and socio-cultural importance.

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**Göran Kirchner** studied mathematics at Humboldt University Berlin and obtained his diploma in 1998 during a year stay at Université VII Paris his Maîtrise in pure mathematics in 1995. From 1999 to 2000 he worked as a software developer at SAP. From 2001 to 2006 he was a member of the international research training group “Arithmetic and Geometry” at Humboldt University Berlin and Université Paris-Sud 11 receiving his doctoral degree (rerum naturalium) in 2006. Since 2006 he is a scientist in the department of infectious disease epidemiology at Robert Koch institute.
Sven Opitz  
University of Hamburg  

**Simulating the transnational: The digital enactment of pandemics as a mode of global self-observation**

If the 20th century was the “age of the world picture” taken as a photograph from outer space, today’s observations of the planet are produced by means of computer simulation. Pandemic models are of peculiar sociological interest in this respect, since modeling contagion is closely intertwined with modeling the material connectivities of social life. By envisioning the global dynamics of disease transmission, pandemic simulations enact the relationscapes of the transnational world. This article seeks to analyze this enactment: It asks how the method of simulation establishes a peculiar political relation towards the social from within the social. In order to provide an answer to this question, and adopting Niklas Luhmann’s theory of world society, pandemic simulations are described as modes of global self-observation that can be specified factually, socially, spatially and temporally. They instantiate a “doubling of reality” (Esposito) for apprehending the potential future threat of disease transmission along the pathways marked by global infrastructures. In this sense, they constitute scopic regimes that virtually synthesize a global situation of universal communicability in such a manner as to turn it into the object of actual political intervention.

Sven Opitz will be appointed as Professor of Political Sociology at the University of Marburg by the end of this year. His work addresses the temporal, spatial and material aspects of security and law. In his most current research, he focuses on modes of global contagion and technologies of control. Conceptually, he draws on approaches that foreground a “politics of operation”: He investigates how infrastructural assemblages, media devices and territorial techniques are designed to govern connectivities that matter. Most recent publications include: “Future Emergencies: Temporal Politics in Law and Economy” (Theory, Culture & Society, 2015, with Ute Tellmann) and “Regulating Epidemic Space: The Nomos of Global Circulation” (Journal for International Relations and Development, 2015). A special issue for *Soziale Welt* entitled “The Politics of Nature in Times of Global Crisis: On Bruno Latour’s Social Theory” is under preparation and to appear in spring 2016 (co-edited with Ute Tellmann and Lars Gertenbach). Sven Opitz is Editor of the journals *Foucault Studies* and *Soziopolis* (the latter to be launched by the Hamburger Institute for Social Research this year).
Sarah Deeny  
Health Foundation/Public Health England

Describing shadow populations: the need to understand the drivers of antibiotic usage and AMR transmission

Plato’s allegory of the cave is an apt description of many of the challenges inherent in analysing routinely collected data. Routine data provide only vague shadows of the people they represent. The nature of routine data is that they were generated for the purposes of delivering health care rather than research, a motivation that influenced decisions about what data to collect and when. This means that analysts of routine data cannot assume that they provide the full or accurate clinical picture, let alone a full description of the health of the population.

As will be outlined in this paper, this problem is particularly acute when considering antimicrobial resistance; where both the primary driver of resistance (consumption of antibiotics) and transmission in the community are unlikely to be fully captured by routine health datasets. For example, the usage of antibiotics not necessarily directly linked to bacterial infection (due to inappropriate prescribing) and prescribing varies in response to social, economic and other factors. The surveillance of antimicrobial resistance faced with a similar problem, where reporting is primarily based on disease isolates from patients admitted to the health system. However, all healthy humans are colonized with bacteria; in comparison a small minority at any time will have an infection (urinary tract, wound, blood stream or other infection). Therefore surveillance produces a ‘shadow’ of the true bacterial population and interpreting the outcome of surveillance requires knowledge of the data generating system (who gets samples, how they are samples and why they are sampled) underpinned with additional knowledge of bacterial biology and transmission.

In our paper we outline the main methodological challenges in using routinely collected surveillance and prescribing data which stem from, in our opinion, the difficulty of understanding the data generating process and correctly model it these include surveillance bias and selection bias. We propose practical initiatives and outline imperatives for data collection that should be undertaken in order to improve our understanding of antimicrobial resistance and utilise digital tools to understand it.

Sarah R. Deeny joined the Health Foundation in January 2015 as Senior Data Analyst and Modeller. Prior to joining the Health Foundation, she was a mathematical modeller at Public Health England, where her work research focused on antimicrobial resistance and healthcare associated infections. She originally undertook an undergraduate degree in microbiology from Trinity College Dublin, and continued her studies with a MSc. in Epidemiology and a PhD in mathematical modelling from Imperial College London. In her current role (from January 2015) she leads work at the Health Foundation linking routine datasets to understand drivers of health; such as social structure, employment and environment. This work is at an early stage, however they will be linking large routinely collected datasets from healthcare, other governmental sources and individually generated data and investigating a number of epidemiological questions. She also retains a position in the Modelling and Economics Unit (MEU), Public Health England where she collaborates on a number of projects modelling antimicrobial resistance (AMR) with particular interest in modelling community determinants of resistance in gram negative bacteria. This position is funded from the NIHR HPRUs in Modelling Methodology and AMR and the RGNOSIS FP7 project on AMR in gram negative bacteria. She also supervises a PhD student, using routinely collected linked data to model AMR in long term care facilities for the elderly. Prior to January 2015 she spent four years working on a number of projects; modelling MRSA and C. difficile transmission and control, using statistical models and routine data to investigate E. coli BSI dynamics, and estimating the burden of paediatric HCAI from linked routinely collected datasets.
Lukas Engelmann  
University of Cambridge

**Digital epidemiology and the reinvention of abstract disease tableaus**

Epidemiology has always had an intricate relationship to clinical practice. To be established, understood and acknowledged, epidemiological knowledge requires specific and unambiguous disease entities to be clinically diagnosed and – if possible – proven in and through a laboratory. But diagnostics, the clinical space with its daily doctoring (Mol 2008) and elevated levels of improvisation (Livingstone 2012) actually delivers a highly ambiguous backdrop for the data used in most epidemiological studies.

While epidemiology inhabited throughout history a position of quantification, of rational surveillance to ‘tame the chances’ (Hacking 1990), the practices of diagnostics seem prone to ambiguous forms of knowledge, often bound to the arbitrary individuality of patients and cases, where the notion, and classification of a disease is achieved only through the gatekeeping authority of members of medical institutions.

I like to argue that the prospect of digital epidemiology is based on a specific understanding of disease as ontological entities, confined through their discoverable nature in unambiguous tests established through evidence based biomedical procedures. But a disease remains an elusive entity (Rosenberg 2008) and its specificity - especially if there is no infectious agent to be identified – is bound to complex procedures, deeply embedded in cultural and social practices. Engaging with the (natural) history of epidemics like TB, syphilis, AIDS or plague reveals foremost the contingency of these disease entities as epistemic things.

Instead of following the epistemic shifts promised by digital epidemiology, I like to point to its limited capability of incorporating the broad variety of disease models circulating throughout society and history. How can digital epidemiology possibly engage with the ongoing transformations of existing diseases, their changing natural history as much as their changing perception? In what way do newly emerging epidemics challenge the very epistemology digital epidemiology will stand for and how can complicated and messy phenomena like TB/HIV co-infection be accounted for? Finally, how is a disease ecology incorporated, how can the milieu of a disease (Canguilhem) be acknowledged and is the epistemic shift actually an epistemic shortcut back to a very abstract notion of disease tableaus?

Lukas Engelmann is a historian of medicine. He received his PhD in History at the Humboldt University of Berlin in 2013, titled “AIDS as a clinical picture of disease. The normalization of an epidemic in the AIDS atlas.” His dissertation engages with the visual history of AIDS/HIV, contributing to a broader perspective on visualizations in medical history and to an interdisciplinary research design for the emerging field of the historiography of AIDS. For his doctoral research he received a fellowship from the DFG Graduate School ‘Gender as a category of knowledge’, spent a term as a PhD-visiting student at the Department of the History of Science at Harvard University and was a Research Fellow at the Brocher Foundation in Geneva, Switzerland. He has published various articles in the history of science and medicine, gender and visual studies and organized a series of workshops on knowledge-politics and AIDS/HIV. In April 2013, he became a postdoctoral Research Fellow at the Institute for the History of Medicine at the University of Zurich. In May 2014, Lukas Engelmann was appointed post-doctoral research associate at CRASSH, working on the visual history of the Third Plague Pandemic in North and South America.
Wednesday, 16 September 2015

Privacy, Social Justice and Beyond – Ethical and Legal Aspects of Digital Epidemiology and Public Health
Barbara Prainsack  
King’s College London

**Bioethics and big data**

Barbara Prainsack is a Professor at the Department of Social Science, Health & Medicine, and Honorary Senior Research Fellow at the Department of Twin Research & Genetic Epidemiology at King’s College London. Her work explores the social, regulatory and ethical dimensions of biomedicine and bioscience. Her current research projects focus on personalized and “precision” medicine, on citizen participation in science and medicine, and the role of solidarity in medicine and healthcare. Her next book is devoted to “Solidarity in Biomedicine and Beyond” (with Alena Buyx, forthcoming with Cambridge University Press).

Effy Vayena  
University of Zurich

**Digital epidemiology: The question of legitimacy**

In previous work (1) I have argued that digital epidemiology (or digital disease detection) is a new field in need of an ethical framework. Such a framework ought to take into account at least three broad categories of issues a) context sensitivity, b) the nexus of ethics and methodology and c) the issue of legitimacy. By legitimacy I mean the extent to which digital epidemiology is actually ethically justified in imposing the compliance burdens that it does, and also the extent to which it is perceived to be ethically justified. This paper will focus on the challenging question of why and how DE ought to bootstrap its legitimacy. The paper will first address the ethical justification for conducting DE and for integrating it into standard surveillance programs. In the second part it will discuss specific activities that can help bootstrap the legitimacy of DE. The latter includes specific proposals about methods of monitoring DE activities, as well as the establishments of thresholds for compensating those affected by harm resulting from DE activities.

Effy Vayena, Ph.D., studied Medical History and Bioethics at the University of Minnesota (USA) and completed her habilitation in Bioethics and Health Policy at the University of Zurich. From 2000-2007 she worked at the World Health Organization (WHO), focusing on ethical and policy issues relating to reproductive health, and assisted reproduction as well as on health research ethics. In 2007, she joined the Institute of Biomedical Ethics and History of Medicine at the University of Zurich, with which she remains affiliated. She is a consultant to WHO on several projects, and visiting faculty at the Harvard Center for Bioethics, Harvard Medical School. In 2015–2016, she is a Fellow at the Berkman Center for Internet and Society at Harvard Law School. In 2015 she was named a Swiss National Science Foundation (SNSF) Professor of Health Policy and leads the newly-established Health Ethics and Policy Lab in the Department of Public Health at the EBPI, University of Zurich.

Her current research focus is on ethical and policy questions in personalized medicine and digital health. At the intersection of multiple fields, she relies on normative analyses and empirical methods to explore how values such as freedom of choice, participation and privacy are affected by recent developments in personalized medicine and in digital health. She is particularly interested in the issues of ethical oversight of research uses of big data, ethical uses of big data for global health, as well as the ethics of citizen science. Using the ethics lens in innovative ways, her work aims to provide concrete policy recommendations and frameworks that facilitate the use of new technologies for a better and more just health. She has published widely in major journals in medicine, public health, health policy and ethics (Lancet, Science Translational Medicine, PLoSMedicine, Journal of Medical Ethics). Her research has been featured in several media outlets including the Wall Street Journal, Neue Zürcher Zeitung, The Scientist.
Brent Mittelstadt
University of Oxford

**Group privacy rights in epidemiological big data**

Data is increasingly recorded about the health and behaviours of patients through clinical encounters, monitoring devices, internet surveillance and various other communications and interactions with health services (King 2013; Milinovich et al. 2014; Mittelstadt et al. 2014). Disease progression and prevalence can increasingly be modelled and tracked through mining of personalised health monitoring data and clinical records (Mittelstadt et al. 2014). However, new opportunities for violations of patient privacy and discrimination arise through such digital epidemiology. Algorithmic profiling of patients based upon shared characteristics (Rubinstein 2012) may constitute a violation of privacy by causing a loss of control over identity (Floridi 2011, 2013). Discrimination and benefits may become localised around groups that present easy or interesting opportunities for epidemiological data mining (Crawford et al. 2014, p. 1667). Existing privacy protection mechanisms (e.g. anonymisation, processing controls on personal data) fail to prevent such group-level ethical harms. Individuals will tend to lack the agency, knowledge, skills and understanding among required for informed and effective decisions concerning restriction of informational flows within complex and large-scale Big Data practices (Boyd 2012), establishing imbalanced power relationships with Big Data analysts and health authorities (Andrejevic 2014, p. 1678). Furthermore, profiles facilitate individualisation of anonymous data subjects by identifying characteristics, actions and predicted behaviours while ignoring identifiers (Sloot 2014), meaning individuals are interesting only insofar as they are members of a groups or profiles (Floridi 2014; Vedder 1999). Under these conditions it may be necessary to reconceive of privacy as a collective phenomenon (e.g. Vedder 1999) enforcing ‘technological due process’ (King 2013) which grants a right to oversight of profiling practices, and empowers groups to define contexts in which actions taken upon algorithmically assembled profiles are ethically unacceptable. Such an approach can protect the right to identify as one chooses or to maintain an “inviolate personality” by controlling information which constitutes identity (Floridi 2013, p. 244), as opposed to the broader (traditional) right to be left alone. The proposed paper describes a theoretical framework for group privacy rights, focusing on practical restrictions in the context of digital epidemiology and related forms of anonymised biomedical research.

Dr. Brent Mittelstadt is a Postdoctoral Research Fellow with the Oxford Internet Institute, University of Oxford. His research centres on the crossroads of computer ethics and bioethics, including a thesis on the ethical implications of personal health monitoring devices, in particular how they may undermine ‘internal goods’ of medicine understood as a virtuous moral practice. His immediate research interests lie in the ethics of emerging data sciences, in particular biomedical data mining and the possibility of an ‘ethics of algorithms’. His current work with the Prof. Luciano Floridi focuses on the ethics of biomedical big data.
Epidemiological communication and analysis – highlighting the law’s overreliance on the protection of individual rights (and not groups)

This content presentation has been selected both from relevant areas of my recent research and also because it relates to the issues that will be discussed on the Wednesday. This relate to issues including data protection, problems concerning stigmatization and discrimination that may be likely in response to epidemiological issues including communication program and epidemiological analysis. Much of this concerns the ability of legal approaches to apply to instances where activates to not involve or relate to identifiable individuals. The focus will therefore be on effects that occur at the group level and the weakness of the law in general in being able to regulate them. Accordingly this presentation will cover areas such as:

The individual as the focus of much of western law Examples include;
• Data protection focuses – on data related to specific identifiable individuals;
• Administrative law – little power exists to challenge practices of public bodies that do not have binding effects on individual rights;
• Anti-discrimination approaches – focused on the idea of ‘treatment’ (also highly individual centric).

Epidemiological strategies often impact at the group level.
• Can produce issues that affect groups including, stigma, discrimination, marginalization
• Such issues are unlikely to be regulated or controlled by prominent legal approaches. This can create problems in terms of feeling of non-restraint.

Weaknesses in the law do not mean there are less ethical obligations upon epidemiologists but often more.
• The fact that identifiable individuals are not severely harmed does not mean that serious issues are not brought about at the societal level.
• The lack of legal restraint available means that there is a duty upon those involved in epidemiological communication and the use of data to thoroughly consider the impact of their actions.
• Raises the role for impact assessments considering not only aspects related to privacy but also more ‘group orientated’ themes such as stigmatization and discrimination.

Paul Quinn, PhD is a post-doctoral researcher. His thesis concerned the Justiciability of Stigmatizing Public Statements Made by the State. Paul Quinn started as a researcher at LSTS in 2010. Since then he has worked on a number of European FP7 Research Projects including REACTION (involving the development of remote monitoring systems for diabetes), Moving Life (the creation of Roadmaps for the deployment of mHealth in Europe) and TELL ME (the development of strategies for vaccination communication). Paul has actively published in the last few years in the areas of cross border healthcare, privacy and safety in eHealth/mHealth and also on issues of stigmatisation. Paul is a (non practicing) Barrister in England and Wales and in addition to his legal degrees (LLM, MA) also has a bachelor degree in biochemistry (BsC).
Silja Samerski
University of Oldenburg

Datafication of health and the patient as risk profile

Since the ascendancy of medical statistics and risk medicine in the late 20th century, “calculating and recalculating risk profiles” has become “part of the core task of medicine” (Armstrong 2011). The classical triad of “diagnosis prognosis–therapy” has widely been substituted by the triad “data collection –risk assessment–risk management”. This transition from clinical medicine to risk medicine presents a fundamental epistemic shift:

The techniques and concepts of epidemiology have entered and reshaped clinical medicine. As soon as the concept of statistical risk joins clinical practice, it fundamentally transforms medical knowledge and the doctor-patient relationship. When epidemiology becomes clinical, patients are not treated as single bodies anymore, but as calculable data assets. A calculated risk profile, however, demands mindsets and practices, which are fundamentally different from those ones corresponding to the presence and disease of an incarnate patient: A risk profile cannot be diagnosed or cured. It demands risk management.

In this presentation, I will analyze the epistemology as well as social implications of risk medicine, which has paved the way for Big Data in the health system. It argues that Big Data does not trigger, but exacerbates the existing trend to treat patients as faceless risk profiles.

Based on this historical and epistemological analysis, I will outline levels of analysis for the assessment of ethical and social impact of digital epidemiology. I will especially focus on the generation of suspicion by risk calculations, the eclipse of the embodied patient and the inversion of the legal precept of innocent until proven guilty.

Silja Samerski is a biologist and sociologist. In 1996, she earned her diploma in the department of human genetics with a thesis in population biology. While working on the genetic makeup of Madagascar monkeys, she became aware of the ambiguity of technical terminology once it migrates from the laboratory. Terms such as "mutation", "genotype" or "risk" have a precise denotation for geneticists, but as part of ordinary conversations are loaded with everyday meaning and become powerless to denote anything. She earned her PhD at the University of Bremen focusing on genetic counseling as a paradigm for the popularization of genetic and statistical concepts. Afterwards, she collaborated with the historian Barbara Duden on the research project Das Alltags-Gen (The "pop-gene"), studying the meanings and connotations given to the word "gene" when it is used in everyday conversations.

In her ongoing research, Samerski explores the genealogy of the patient as a decision maker as well as the social and cultural dimensions of the demand to base personal decisions on statistical information. Since January 2013, she has been as a research fellow at the DFG Research Training Group “Self-making. Practices of Subjectivation” at the University of Oldenburg.

Her latest book “The Decision trap. Genetic education and its social consequences” (Exeter: Imprint Academic), Samerski explores the managerial rationality that is conveyed in medical counseling sessions which aim to increase patient’s autonomy.
Kerstin Denecke  
University of Leipzig

**Weighting model for assessing the ethical impact of digital epidemiology**

Internet-based research and social media usage in epidemiology and healthcare provides new technical, functional and formal challenges. Formal problems include quality and reliability of content, payment models as well as ethical and legal issues. The latter are related to the usage of data posted through social-media tools for research or epidemiological purposes. In this context, it is important to clarify responsibilities. Imagine a health status monitoring tool exploited by a health organization identifies a group of sick persons based on their social-media chatter. In which manner should the health organization react? Are they allowed to react? These and similar questions need to be answered before such applications go online.

To support this assessment of the ethical impact of digital epidemiology, we suggest a novel model. It comprises three aspects: application area, user and dimension. For a concrete social media application in epidemiology or medical social media research question, it first needs to be clarified which users are involved, which application area is concerned and on which dimension it is operated. Questions include:

- Who is affected by the analysis and application of medical social media data and how should they be affected by it?
- Who is compelled to act on the new knowledge?
- What action is appropriate based on the information learned as a results of the analysis?
- Who is responsible when a predictive analysis is incorrect?
- From the answers, ethical issues concerning confidence, privacy, data and patient security or justice may be judged and weighted.

Kerstin Denecke is scientific director of the Digital Patient Modelling group at ICCAS at the Medical Faculty of the University of Leipzig. Dr. Denecke holds a Diploma in Computer Science and was awarded a doctoral degree in Computer Science by the Technical University of Braunschweig. Before she joined the University of Leipzig, she worked as a researcher at L3S research center and as a software architect at an IT company providing software for hospitals. She coordinated several research projects, among others the EU funded project M-Eco: Medical Ecosystem on event driven surveillance of infectious diseases and was involved in the EU Projects Terence and LivingKnowledge. Beyond, she was involved in the SORMAS-project on surveillance and outbreak management of infectious diseases. Her main research interests are natural language processing, text and data mining. The specific areas she has been working on include medical language processing, information extraction, sentiment analysis and text classification and ethical issues related to the use of social media in healthcare settings. She has published a number of research papers in several international conferences and journals.
How to organize secondary data analyses of health-related data and what to consider?

The Robert Koch Institute is at the same time producer of data sets of public health interest and user of health-related datasets produced by others. Thus it experiences the potentials, limitations and challenges of secondary data analyses from both sides, the provider’s and the applicant’s perspective. Here we want to explore and discuss the logistical, technical, legal and ethical aspects of making available and using datasets collected for a particular purpose within a particular context for other purposes in other contexts, in two related case studies. One is a case study of obtaining anonymized social security health data (so-called Morbi-RSA data) from DIMDI (the data custodian) for secondary data analysis at RKI (re comparison with infectious disease notification data for underreporting estimates). The other is a case study of developing a framework for responding to data requests directed to RKI (re. infectious disease notification data for research or non-scientific publication). Using these examples I would especially like to discuss ethical and legal considerations of data protection, privacy and ownership associated with the re-use in public interest of health-related datasets originally produced for other purposes, often in public interest as well.

Justus Benzler is a medical epidemiologist, who works in the area of infectious disease surveillance. He discovered his interest in health information systems and database architecture, when he organized vaccination campaigns in Burkina Faso in the late 1980s. Thereafter he specialized in Medical Informatics and helped setting up and running Demographic Surveillance Sites in different African countries. In 2002, he joined RKI in Berlin in the wake of the introduction of the German Infektionsschutzgesetz (IfSG; Infectious disease control act), when the institute became responsible for implementing an electronic national surveillance system for notifiable diseases. Since then, he has spent his days trying hard to improve the quality and usefulness of the data collected, with small progress here and there. He also spent 4 years away from RKI, during which he lived on the Pacific island of New Caledonia and worked with two dozen Pacific island countries to strengthen regional infectious disease surveillance in that part of the world.
Thursday, 17 September 2015

Health and/or Security - The (Global) Politics of Pandemics
Stefan Elbe
University of Sussex

*Health and/or security. The (global) politics of pandemics*

**Stefan Elbe** is Director of the interdisciplinary Centre for Global Health Policy and Professor of International Relations at the University of Sussex, which he joined after holding positions at the University of Essex, the University of Warwick, the International Institute for Strategic Studies, and the London School of Economics, where he obtained his doctorate in the Department of International Relations. He is also Chair of the Global Health Section of the International Studies Association (ISA) and Co-Convener of the Global Health Working Group of the British International Studies Association (BISA). Previously he has served as the Head of the International Relations Department and as Director of Research for the School of Global Studies at the University of Sussex.


In the United Kingdom, Stefan has provided advice and expertise to a number of research councils, including the Economic and Social Research Council (ESRC), the Medical Research Council (MRC), the Natural Environment Research Council (NERC), the Biotechnology and Biological Sciences Research Council (BBSRC) and the European Science Foundation. His research has been supported through the British Academy and the Economic and Social Research Council. He is currently the Principal Investigator on a four-year research grant from the European Research Council on the role of public-private partnerships in global health security.
Henning Füller  
Humboldt University, Berlin

*Biosecuring public health - The example of ESSENCE*

In the U.S., several several systems for syndromic surveillance, i.e. the collection and analysis of unspecified health data, have been installed recently in order to improve early detection of public health threats.

Closely following the implementation of one such system in the US National Capital Region (*ESSENCE - Electronic Surveillance System for the Early Notification of Community-based Epidemics*), the paper points out effects and impacts for the practice of epidemic control and public health more broadly.

The paper aims to further clarify the ongoing re-ordering of politics and reshaping of society in the name of security. The aim is not to evaluate ESSENCE as such, e.g. measuring its efficiency or appropriateness. Rather, the case study allows us to better understand the related shifts in modes of reasoning and power relations in the practice of epidemic control. The intention is to read current developments in public health as a refined form of biopolitics.

Drawing on empirical data collected during a six month field research (interviews with public health experts and epidemiologist on a state and county level, participant observation) the paper complements the often programmatic findings of a biopolitics of biosecurity with a case study ‘on the ground’.

The paper shows how the promise of data-driven detection and early warning is reworking the field of public health. The installation and use of ESSENCE advances a preemptive rationality. The moment of outbreak becomes the central concern while the non-outbreak is rendered normal and unproblematic. This implies a shift away of more structural health problems. Furthermore, the system evokes an expectation to proof the absence of anything unnormal. The assurance of absence in itself binds resources otherwise used to actively confront health problems. Finally, the introduction of algorithmic regulation and the inclusion of epidemiologist into the security architecture at the local and state level make way for a dequalification of knowledge production in public health and epidemic control.

Henning Füller is currently working as a postdoctoral staff member at the Department of Geography, Humboldt University Berlin. His research interests are on the conceptual relations of power, space and security. In his dissertation he applied the framework of governmentality to understand the changing mode of governing uncertainty in the context of inner-city redevelopment in Los Angeles.

His ongoing book project “Geographies of Biosecurity” aims to understand the impacts of an emerging diseases world view on the governing of cities and bodies. The book integrates separate case studies. Research has been done on epidemic control in Hong Kong after the SARS-epidemic and on a system of syndromic surveillance in the U.S. national capital region.

He studied Political Science at the Freie University of Berlin and did his Phd at the Department of Human Geography at Goethe-University in Frankfurt am Main. He worked as an Akademischer Rat at the University of Erlangen-Nuremberg before being employed at the Humboldt University Berlin.
Stephen Roberts  
University of Sussex  

Catching the flu: The role of syndromic surveillance systems in transforming global health security, 1994-present  

How can emergent or novel infectious disease outbreaks be more rapidly detected around the world? Policy-makers within pandemic preparedness have a keen interest in rapid detection and outbreak notification of emergent disease outbreaks - both in order to gain more time to prepare states and populations against a new pandemic, and in order to contain any new outbreak at source. Within this context, a number of new internet-based early warning systems have been developed and have proliferated over the past two decades, using a new method of surveillance - syndromic surveillance - which functions through (near) real-time monitoring, collection and reporting of a range of non-health specific open data sources that might indirectly indicate a new outbreak through revealing unusual cluster patterns of more general symptoms related to infectious diseases found online. While the early online health surveillance prototypes such as the Program for Monitoring Emerging Diseases (ProMed-mail) and the Global Public Health Intelligence Network (GPHIN), relied upon, and utilised combined human and automated analytics to support the operating processes of the respective online health surveillance technologies, the proliferation of a participatory and open World Wide Web as well as the ascendancy of the Big Data era and the social media revolution have resulted in the mass and indefinite production of unofficial online data sources and internet 'white' noise, further complicating surveillance initiatives by first-generation syndromic surveillance systems to predict and report outbreaks of infectious diseases as they occur. In seeking to harness the potential predictive content contained within infinite online mass data sets, emergent syndromic surveillance systems of the Web 2.0 era including HealthMap and Google Flu Trends have increasingly piloted and integrated the use of the algorithm into online health surveillance platforms to bolster capacities to filter, sort, translate and report upon global health outbreaks as they occur. This research thesis will investigate further how the algorithm is conceptualised and applied as a strategic instrument of power within global health surveillance systems and will seek to additionally present and comprehend the significance of the algorithm as a transformative agent within contemporary international relations.

Stephen L. Roberts is Doctoral Research Associate and Associate Tutor at the Centre for  
Global Health Policy, Department of International Relations, University of Sussex. He is a  
Chancellor's International Scholar at the University of Sussex and holds previous degrees from  
the Université d’Ottawa, Université de Fribourg and University of Sussex.

His present doctoral research focuses on the transformative role of online syndromic  
surveillance systems within frameworks of global health security. He holds further insight and  
research interest within the areas of Critical security studies, Global Health Security HIV/AIDS,  
Post-structuralist thought and Surveillance Studies.
Niamh Stephenson
Trinity College Dublin/ University of New South Wales

Speed, surveillance and ‘what the GPs are telling us about H1N1’: How ‘securitised’ modes of public health unfold in practice

Recent sociological analyses of ‘securitised’ public health foreground a potential break between preparedness plans animated by the spectre of future catastrophe and classical public health efforts that are anchored in epidemiological knowledge of populations. It has been argued that securitised public health is focused on ‘vital systems’ (e.g. on ensuring systems such as transport, electricity and government communication function) – as opposed to the focus of classical public health on minimising levels of disease in a population. Whilst analyses of these distinct rationales of public health governance suggests that they are likely to be entwined and to work in productive tension with each other, less attention has been paid to how this tension unfolds in practice.

Drawing on 27 semi-structured interviews with public health experts involved in the Australia’s pandemic influenza planning and response, this paper examines how preparedness efforts initially took the form of a command-control national led response, in accordance with the IHR (2005) (unusual for Australia where there is no national CDC equivalent). However command-control governance was quickly ruptured. One State – a State with advanced influenza surveillance systems and a concentration of international epidemiological expertise in influenza - used ‘informal intelligence’ from GPs to gauge severity as mild for most and abandoned the labour intensive contact-tracing phase of the national plan. Notably, the potential threat to command-control governance was rapidly neutralised, with the national command centre incorporating the insights from local expertise by quickly reworking its own pandemic response phases to align with the trajectory of the ‘noncompliant’ State. Our analysis indicates that classical population health efforts interrupted the vision of catastrophe embedded within securitised health, and interrupted the implementation of pandemic plans focused on ‘vital systems’, forcing the public health response in a new direction.

Viewing health securitisation through the lens of practice foregrounds how pandemic planning and response can intensify public health experts’ diverse commitments to and modes of adopting responsibility - not only responsibility for effectively minimising disease in the population, but also responsibility for advancing the importance of ‘public health’ to government, and responsibility for influencing how epidemiological knowledge is translated into government action.

Niamh Stephenson is a Senior Lecturer in Social Science at the University of New South Wales. Her research examines the relationships between public health and social and political change. She has published in the fields of sociology of health and medicine, social research, cultural studies and qualitative research methods and books include: Escape Routes: Control and Subversion in the 21st Century, which interrogates how post-liberal regimes of control are impacting on the politics health, labour and migration (co-authored with Papadopoulos and Tsianos, Pluto Press), and; Analysing Everyday Experience: Social Research and Political Change, (co-authored with Papadopoulos, Palgrave). Her current projects examine the public health framing of pandemic influenza, the routinisation of obstetric ultrasound, and a forthcoming book on the politics of global HIV prevention.
Stefan Engert  
Free University, Berlin

**Look who is talking! The securitization of infectious diseases in democratic and authoritarian polities**

For quite a long time, “health” was identified merely as a personal issue and hence a non-politicized or private risk. Due to globalization, the thread perception of infectious diseases has considerably changed by entering the societal domain (public health) and by being upgraded to the high politics realm, that is: considered essential for national survival and security (cf. Price-Smith 2002; Davies 2008; Enemark 2009; Elbe 2010b: 31). Based on the theoretical assumptions of the Copenhagen School that views security as an inter-subjective thread constructed by authoritative speech acts, the paper analyzes the domestic conditions under which health – here: epidemic diseases – become securitized and ‘combatted’ with extraordinary measures such as police-or military methods (e.g. forced quarantine by internment, CCTV surveillance, wrist tagging of infected persons) rather than “ordinary” financial or medical means (hospitalization, medication, vaccines).

The research question of this analysis is: Is it the characteristics of the disease itself, i.e. the degree of contagiousness (IV 1: high – low) that determines the extent to which a health threat is securitized or is it the characteristics of the affected political community or state, i.e. the polity (IV2: democratic – authoritarian) that determines the securitization dynamics and hence the eventual negative impact on individual liberties as well as citizens & human rights. In order to elaborate on that issue, the paper empirically compares diverse political reactions (health policies) to infectious challenges (HIV/AIDS (low; sexual), SARS (high; respiratory)) in varying polities (democracy: Germany, Canada – authoritarian Cuba, Singapore). The paper will demonstrate that the political reaction to infectious challenges is primarily influenced by the polity of the affected community rather than the contagiousness of the pathogen:

Whilst HIV-infected persons received a rather harsh treatment in Cuba (internment into special camps; discrimination as homosexuals independent of their sexual orientation) in spite of not being a very contagious disease (sexually transmittable only with full protection available), the case comparison with Germany reveals that HIV-infected persons were significantly less discriminated within a democratic polity that emphasized public information and non-invasive measures (use of condoms). The second two case-comparison demonstrates that the highly transmissible SARS virus was contained with military methods that violated basic human rights (wrist tagging, permanent CCTV surveillance by a private security company, temperature scans at airports) in the authoritarian polity of Singapore, whilst the authorities in the democratic Canada (Toronto region) primarily resorted to public information campaigns and the judicial review of forced quarantine orders.

In sum, the analysis of the 2x2 case study comparison shows that democratic political systems based on the rule of law and with respect for individual liberties are indeed a sufficient condition that prevents the securitization of infectious diseases and henceforth the infringement of human rights.

**Stefan Engert** works at the Free University, Berlin. Recently, he was an associate professor at the University of Konstanz. After having studied Political Science, Economics and Law in Darmstadt, Mainz and at the University Aberystwyth in Wales, he earned his PhD from the University of Darmstadt in 2005. In his PhD thesis is entitled: "Explaining EU Enlargement and Socialisation. Turkey and Cyprus: A Double Puzzle." Afterwards he joined Ludwigs-Maximilian-University in Munich as a senior researcher. Stefan Engert has taught in Darmstadt, Munich, Frankfurt/M. as well as Berlin and was a visiting fellow at the University of Birmingham.
**Influenza surveillance in Germany and its problematizations**

Nearly 20 years ago David Armstrong (1995) observed “The rise of surveillance medicine”. With the outbreaks of highly pathogenic avian influenza H5N1, SARS, pandemic influenza H1N1, MERS-CoV and most recently the outbreaks of Ebola haemorrhagic fever in West Africa the development of surveillance medicine has gained considerable momentum. National systems of health surveillance increasingly experiment with various forms of syndromic surveillance and combine them with classic public health data to yield early warning systems for infectious disease outbreaks. In the process of visualising outbreaks these systems partake in the construction of a pandemic threat and claim the authority to represent the possible future threat of disease outbreaks.

Recent scholarship has emphasised the contemporary association of (global) public health with security issues (e.g. Elbe, King, Lakoff and Collier). An example for this association is the combination of pandemic preparedness planning with diverse forms of disease surveillance that link pandemic alert levels and the measures to be taken at each level to the detection of the infectious pandemic agent within the state territory. Consequently, the WHO is promoting the implementation of disease surveillance systems in all of its member states and beyond. However, the focus on security issues in scholarship on disease surveillance might have diverted attention away from the micro practices of disease surveillance and its effects on everyday life.

In drawing on the example of influenza surveillance in Germany this paper will outline two other problematizations (Rabinow) that lead to the development of this sophisticated syndromic surveillance system before the threat of a pandemic became the single most import reason for disease surveillance. The paper will argue that influenza surveillance sought to answer the question of the actual disease burden of seasonal flu and its impact on the national economy on the one hand, and tried to raise the vaccination rates in the German population on the other hand. By examining how influenza surveillance is conducted the paper draws attention to the processes by which practices of surveillance create, govern, and maintain social order by acting upon how we know and experience the space surrounding us (Zurawski, Lyon).

**Kevin Hall** is a research assistant at the Institute for Cultural Anthropology and European Ethnology at the Goethe University Frankfurt in Germany. He has a background in biochemistry, sociology and philosophy. His research draws on STS and Surveillance Studies to explore the social implications of scientific innovations in the areas of health and biomedicine. In his dissertation project he is investigating the multiple translations and transformations employed by the influenza surveillance system in Germany to aggregate data from disparate sources and to visualise influenza activity.

Linda Madsen  
Albert Ludwig University of Freiburg/University of Oslo

Digital re-configuration of disease, sites and technology

This paper examines British and German approaches to the use of Big Data related to disease surveillance and tracking and prediction of Ebola spread. It attends to how digital epidemiology and disease may influence each other mutually. How does digital technologies contribute to re-configure disease events? How may partial or biased information contribute to reproduce social- and medical iniquity? And, how to overcome such challenges?

Analyses of mobile phone data are used to track and predict Ebola spread. A recognized challenge to this epidemiological tool for surveillance is that only a minority of the population in the affected areas possess a mobile phone. As only the part of the population who own a mobile phone, only their movements and only the places they move within and between will be recognised within a mobile phone data tracking system, there is a risk that this tool for disease intelligence contributes to reproducing social and medical inequalities.

Another risk for reproduction of social inequity through digital epidemiology and a general challenge to Big Data are posed by weak or non-existent health infrastructures. This represent a general challenge in the affected regions of Africa where Ebola infections have occurred to date.

As previous studies of avian influenza has shown, the effects of or problems arising from incomplete or biased reporting is not limited to the sites from where information depart, often referred to as infected area or site of outbreak. Rather contrary, while complexities may well be handled locally, partial information submitted into digital networks – and not least, information submitted in languages not picked up by monitoring systems – may contribute to a different image of disease events at a distance.

Drawing on resources from an area of science and technology studies (STS) preoccupied with translocal knowledge production, this paper offers analysis of processes through which outbreak places, disease, and tools for digital epidemiology mutually contribute to reconfigure each other.

Linda Madsen holds a PhD from TIK Centre for Technology, Innovation and Culture, Faculty of Social Sciences, University of Oslo. I recently defended my thesis, entitled Avian flu mobilities. Following bio(in)securities in Turkey and beyond. My work is based within Science and Technology Studies (STS) and I am interested in production and trans-local circulation of knowledge, issue formations and socio-technical ordering processes; that is relations, practices and performances that shape and re-shape social and material realities. A major concern is the inclusions and exclusions involved in issue formation, and the politics and effects thereof.
Friday, 18 September 2015

The Global Future of Digital Epidemiology
Mike Catchpole
European Centres for Disease Prevention and Control

The future of infectious disease surveillance and digital epidemiology

Mike Catchpole is a medical doctor who has worked in infectious disease epidemiology and response at the national and international level since 1991. He is Chief Scientist at the European Centre for Disease Prevention and Control (ECDC). Prior to that he was Director of Public Health England’s national Centre for Infectious Disease Surveillance and Control, and was the UK member of the ECDC Advisory Forum from 2007 until 2014. He has 20 years’ experience of management of communicable disease surveillance and response, including leadership of the national epidemiological response to the 2009 influenza A(H1N1) pandemic in England, developing and managing the surveillance systems for the 2012 London Olympics and the surveillance systems that have been instrumental in driving the dramatic reductions in MRSA and C.difficile in England.

His primary research interests have included HIV and other sexually transmitted infections, the wider health effects of major incidents, and public health information systems development. He has also been a member of the steering groups for a number of European projects, and chaired the Steering Committee of the European Programme for Intervention Epidemiology Training (EPIET) from 2001 to 2006.

He has academic appointments, as a visiting professor, at Imperial College London and City University London.

Dirk Schumacher
World Health Organization

From counting cases to tracking transmission changes – data challenges during the Ebola outbreak

I have worked on the Ebola response for 9 months mostly on data and information aspects in the epidemiology teams in Geneva, Switzerland, Freetown, Sierra Leone and Conakry, Guinea. In this talk I will present my experiences on some of the data challenges we faced during the response. Some of those problems can translate into potential future developments in the field of epidemiological data management and analysis such as robust data collection, surveillance and analysis systems that can be deployed and used faster. However with increasing amounts of data being gathered, analysed and moved into online systems, privacy, security and ownership of data become more and more important aspects. The concept of zero-knowledge privacy could help bringing tools for epidemiological analysis and data management into the cloud.

Dirk Schumacher is currently working as an independent consultant and data scientist. He has previously worked for the WHO during the Ebola outbreak doing data analysis and management, for the German Robert Koch Institute on infectious disease epidemiology, in particular on data management, software engineering and statistics, and for UNICEF in an inter-agency procurement project. Up until 2011 he studied business informatics in Paderborn, Germany and Seoul, Korea.

*Some abstracts have been modified from the original format: citations have been omitted to fit the program. An original copy is available upon request.*
Venue address

Protestant Guest House at Schwanenwerder
Inselstraße 27
14129 Berlin
Phone. 030 8035486
Schwanenwerder is an island in Berlin rife with history. Should you decide to walk around the estates you will see some information on this history, but few villas have been marked. The following was written in 2013 by Christine Fischer-Defoy, Chairperson of the Aktives Museum Faschismus und Widerstand in Berlin e.V.

“The idea to install on-site historical information on Schwanenwerder arose from the public debate sparked by plans to sell several government-owned properties on the island. About a third of the properties on the island had belonged to Jewish owners until the 1930s and were sold due to Nazi persecution. Some of the proceeds of their sale were then to go towards a “history trail” to remind visitors of these events. The Berlin House of Representatives resolved to “develop and install historical information on public highway land on Schwanenwerder on the history of the island as a whole and on individual properties with a Nazi background” on 9th December 2010. Following an initial delay in the sale of properties and consequent availability of funds, in summer 2012 the Senate Chancellery – Cultural Affairs commissioned the Aktive Museum in cooperation with Steglitz-Zehlendorf district council to realize the project on the condition that the panels were installed as part of the 2013 theme year 2013 “Deversity Destroyed” and with the participation of local residents. On 9th October 2012 and 7th February 2013, public meetings were held in the guest house of the Protestant Church at Insel Strasse 28. Residents were concerned to avoid attracting further “sensation-seeking tourism” on account of the island’s Nazi history. For this reason, it was decided not to install panels marking individual properties.

I would like to warmly thank all those involved in this project for their assistance and contributions. By remembering the Jewish residents who suffered persecution and were driven off the island between 1933 and 1945 we wish to take a stand against intolerance and support diversity.”

More information can be found online at: www.aktives-museum.de
Organizing Team

Tim Eckmanns is trained as a medical doctor and is board-certified in hygiene and environmental health. He also has a Master of Science from the London School of Hygiene and Tropical Medicine and has a Master of Medical Computer Science (MCS) from the Berlin University of Applied Science. Dr. Eckmanns is the head of the Division for healthcare-associated infections, surveillance of antimicrobial resistance and consumption at the Robert Koch Institute, the German national public health institute. He has wide-spread expertise in infectious disease epidemiology, particularly regarding surveillance and hospital-based infections as well as in evidence-based public health. In 2014 and 2015 he was seconded for 11 months to the World Health Organization working on Ebola from Geneva and in the field in Sierra Leone.

Leon Hempel, PhD, is Senior Researcher at the Centre for Technology and Society (CTS) at the Technical University Berlin where he is leading the research unit security – risk – privacy. For over ten years he has focused on empirical studies of diverse security and surveillance technologies to assess their effectiveness as well as their social, political and ethical implications. He investigates the security culture and vulnerabilities of different critical infrastructures regarding manipulation, sabotage and other interferences of ICTs. Furthermore, Hempel leads the interdisciplinary research network ‘human technology lab’ at the CTS, which focuses on the cooperation of social scientists and engineers in the context of human centered technology design.

Katherine Polin is a research associate at the Robert Koch Institute. Before joining the RKI, she was a 2014-2015 Transatlantic Fellow with the Robert Bosch Stiftung. Prior to this, she worked for 7 years in the field of global maternal, child and reproductive health and rights. A native of New York City, Katherine holds a Masters in Public Health from Columbia University with a major in population and family health and a minor in epidemiology and a BA in Humanities from Yale University.

Klaus Scheuermann is an independent researcher and writer in the fields of science and technology studies, science communications and visual media. His current work focuses on the societal implications of digital surveillance technologies in public health, among other things. He has studied sociology at the Free University of Berlin and media studies a the University of Tübingen.

Edward Velasco has worked in public health for 15 years and since 2008 in infectious disease epidemiology. A northern California native, he studied religious studies at Berkeley, has a master’s in social and behavioral sciences and social epidemiology from the Harvard School of Public Health, and completed a PhD in medical sciences at Charité-Humboldt-Free University Berlin. His current research interests in public health focus on: improving management of hospital outbreaks of resistant pathogens with social network analysis, general antibiotic resistance, and innovating in public health practice with new technologies.
Tim Eckmanns

Leon Hempel

Katherine Polin

Barbara Prainsack

Klaus Scheuermann

Edward Velasco
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