

# « Patient driven research and medicine »

10-11 November 2011, Hotel Mövenpick, Lausanne

Organisation and chair:

**Olivier Dessibourg**, head Science&Environment section, Le TEMPS

**Christophe Ungar**, science journalist, for « 36.9°C » (TSR) and « Impatience » (RSR)

## Thursday 10 November

17:30 Welcome

17 :45 Introduction by Swiss Association for Science Journalism board and Interpharma

18:00-19:00 **Patient-driven research and medicine: an overview (50' talk+ 10' discussion)**

*Melanie Swan, MS Future (USA)*

**ABSTRACT:** Three recent trends have been starting to transform health care and are importantly providing a foundation for the contemplated shift to preventive medicine. The first trend is the growth in health social networks, groups of individuals joining online communities in health conditions of interest. These communities have become some of the largest aggregate patient registries and offer cost and efficiency benefits for study recruiting and operation. Health studies in crowdsourced cohorts may be run by traditional researchers, and also organized directly by community members (citizen scientists). Second: the low-cost availability of personalized genomic data, the applications of which include assessing family ancestry, carrier status, health condition risk, and drug response. There is debate about the validity and utility of health condition risk assessment, but the other three applications have a higher level of acceptance as neonatal carrier status screening is routine in many countries and the U.S. Food and Drug Administration has validated genomic biomarkers for approximately 75 drugs as of July 2011. Third: ability to integrate varied health data streams such as personal genomics and phenotypic data (e.g.; personal medical records, family history, self-tracking data, health social networking data, and blood test results) towards the goal of improved medicine. Genetic polymorphisms (e.g.; mutations) may lead to out-of-bounds phenotypic conditions that can be measured and ameliorated through personalized intervention. A third data stream may become more prevalent too, the microbiome, examining personalized bacterial profiles for linkage to disease development and drug response. This talk addresses how these trends are influencing the broader health ecosystem, and how the traditional physician-patient relationship is shifting as individuals are increasingly health literate and taking responsibility for their own health self-management.

19:00 Apéro, then dinner

## Friday 11 November

9:00-9:45 **Medicine by the masses: crowd-sourcing and patient-driven research (35' talk +10' discussion)**

*Paul Wicks, R&D director, Patientslikeme.com*

**ABSTRACT:** Patients are increasingly taking a central role in their own management by improving their understanding of their condition and sharing information between peers. Online tools such as PatientsLikeMe offer the opportunity to let patients share their personal health data including medical history, comorbidities, treatments, symptoms, and side effects, as well as personal narrative such as journals and annotations. Paul Wicks will share his company's experience on harnessing the power of collective patient wisdom to conduct high-quality peer-reviewed literature including studies of unmet needs, off-label medication use, and detail a novel observational study on the effects of lithium carbonate on the progression of amyotrophic lateral sclerosis (ALS) / motor neurone disease (MND).

9:45-10:30 **Direct-to-consumer (DTC) genetic testing: are they useful for the patients, for the doctors, for clinical research? (35' talk+ 10' discussion)**

*Muriel Bochud, assistant professor, CHUV, Lausanne*

**ABSTRACT:** Some genetic tests can be obtained directly by consumers on the internet. Among them, some are related to health issues, while others are not (so-called "recreational genetics", e.g., DNA ancestry). Some companies offer to test your DNA to predict your risk of developing selected diseases, such as type 2 diabetes, heart disease or Parkinson's disease. While the tests usually are of good quality (analytic validity), the clinical validity (i.e. do these tests appropriately predict risk of disease in an individual patient?) is often not demonstrated and the clinical utility (i.e. does the test results change the way the disease is treated and prevented?) is of ten extremely limited. Data collected online by some of these companies is being used for research and this led to some new research findings. DTC genetic testing raise important legal and ethical issues. Genomic research findings during the past 6-8 years undoubtedly provided important new insight into disease biology and open novel perspectives for treatment and prevention, but their use in clinical practice is too premature.

10:30-11:00 Coffee break

- 11:00-11:45 **Ethical consideration in « patient-driven research » (35' talk+ 10' discussion)**  
*Effy Vayena, Institute of Biomedical Ethics, University of Zurich*  
**ABSTRACT:** Health research has traditionally been done in the top-bottom approach with studies (i.e. clinical trials, epidemiology and other research) initiated by research teams either at the private sector or academic institutions and research subject been sought and recruited. Research with humans has raised numerous ethical concerns especially because history has not been sort of abuses of human subjects even within the pursuit of legitimate scientific questions. Numerous international guidelines and national laws are in place today to protect the individuals who participate in research. The emergence of patient-initiated or patient-driven research is signaling the development of a new trend in health research. This new and dynamic engagement of patients (and healthy individuals donate their genetic and phenotypic data for research) has raised some additional concerns about the ethics of such research while at the same time has challenged the conventional standards of research ethics review. Some of the specific questions that need to be addressed are: whether the ethical oversight of such studies is adequate, and appropriate; whether protection of the participants is a true priority and how can it be ensured; whether informed consent can be truly achieved in this context; whether our conventional ethics review of research needs to be revised to meet the new needs. These considerations are very timely and need to be explored while this type of research is still shaping up in order to maximize the potential contributions it can make and to avoid ethical mishaps.
- 11:45-12:30 **Online Communities & Patient-Driven Research in the Age of Exponential Medicine (35' talk+ 10' discussion)**  
*Gilles Frydman, founder of online patients' association ACOR.org*  
**ABSTRACT:** With the exponential rise in genomic data and the constant growth in the number and complexity of pathways, keeping up with current knowledge is an enormous challenge for all oncologists. Online patient communities have a long history in sharing that burden with clinicians, and have in many cases become centers of patient-driven research. Patient data collection, aggregation & analysis is just one aspect of patient-driven research. A more complex, less structured but no less important aspect is the optimization, in real time, of knowledge and information surfacing via expert patients. ACOR cancer communities, started 17 years ago, are a new form of peer-reviewed publication. These communities of e-patients conduct research on many levels: they generate scientific hypotheses, create centralized tissue banks to accelerate discoveries, maintain online specialized libraries of full text articles pertinent to their disease, study clinical trials as they are conducted and provide valuable post marketing surveillance, sometimes resulting in significant prescription labeling changes. Gilles Frydman will share some of the stories that have made ACOR an integral part of the developing rapid learning system for care of certain rare cancers.
- 12:30-14:15 Lunch
- 14:15-15:00 **The pharma perspective: looking at drivers for change in clinical trials (35' talk+ 10' discussion)**  
*Geoffrey Henning, formerly at Roche*  
**ABSTRACT:** Clinical trials are changing, embracing new approaches. What pressures are bringing these about? This session will look at the traditional trial and some of these new directions, assess the pressure points and suggest possible rationale for these changes and the patient's relationship to these developments.
- 15:00-15:45 **Co-production in health care: Towards patient-oriented medicine (35' talk +10' discussion)**  
*Michael Heberer, Institut für Chirurgische Forschung und Spitalmanagement, University Basel*  
**ABSTRACT:** Traditional concepts of health care may require revision: The status of the patient may develop via a customer/client status to the health care co-producer status. This new status will not only result in empowerment and shared responsibility but also lead to patient-oriented medicine. The novel concept will evaluate medicine not only on the basis of objective outcome criteria but introduce patient perception as a novel criterion. Implications on medicine will be discussed on the basis of results obtained by the research program co-production in health care that has been initiated at the University of Basel
- 15:45-16 :00 Final discussion and end