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The Promise of Data: Will this Bring a Revolution in Health Care?

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Data collaboration

In today's data-driven world the challenge no longer is from where can we get data, but which data should we use and how can they be used together?

Addressing these questions and the issues surrounding how population health and health care can benefit from the enhanced availability and management of data were representatives from large corporate- and publicly-funded data collection projects.

Big data collection and analysis can enable better prediction of and thus response to epidemics, measurement of the efficacy and safety of new drug treatments, reduction of wasteful and harmful interventions, and cost-savings in resource-strapped health services.

In the US, this data is being derived not only from the extensive claims records (collected from over 148 million Americans from a total population of 315 million), but also clinical records, government records, consumer behavior data, employment data, demographic data and genomic data.

For both the corporate-funded and the public-backed/academic-led data analysis projects, collaboration between multiple data collectors and analysts is vital to ensuring accurate and valuable applications of the data. However, this can be difficult given not only the differences in methodologies and purposes – harmonization of these multiple data sources is needed for big data to be useful – but also regarding data ownership and patients' privacy concerns. Acquisition of this data can require monetary or credit-sharing incentives, and can raise ethical questions.

One main takeaway for many of the participants in Salzburg is that patient-centeredness, not corporate goals, should remain key.



(l-r) Darren Toh, Andrew Bate and Mark Leenay discuss the value of big data for populations at large

Customizable health care

The amount of data available to 21st century clinicians is vast, but how best can this be analyzed and how can this analysis be best applied to both the individual patient and populations at large?

Tackling issues surrounding the collection, use and application of data for individual patients were panelists Jens Deerberg-Wittram from the Executive Board of ICHOM (the International Consortium for Health Outcomes Measurement) and Sofia Ernestam from the Karolinska Institutet.

The advent of big data means now that doctors have more than just their own knowledge and patient data sample to draw upon; data is being collected and shared not only within countries but also across borders, too.

It also means that patients can become more aware of their condition and treatment options, but also leads to the possibility of self-misdiagnosis and resulting anxiety.

Generating more precise big data requires the collection of "small data" directly from patients. In Sweden, for example, where there are over 100 information registries, patient trust of this data collections has been gained through clear consent for collection

and ethical guidelines for usage.

Ensuring that this data can be used globally means harmonization and standardization of data collection and analysis is needed. Even when this data is standardized, what is useful and important to a doctor may not be what concerns their patient most.

ICHOM has a mission to "define a global standard of outcome measures that really matter to patients"; this means measuring more than just the ultimate outcome – did a patient survive after an intervention? – but also all the other outcomes, including side effects, a patient must live with.

Using the example of prostate cancer treatment, a patient is likely to not only be concerned with whether he survives the cancer treatment (be that surgery, chemo- or radiotherapy) but also whether or not he will experience urinary or erectile dysfunction as a result of a chosen course of treatment.

Just as patients and doctors value different outcomes differently, different patients have diverse values, too. Data does not account for the different risk assessments of patients – this can only be ascertained through shared decision making with the (human) doctor and patient.

The rise of the wearables

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From the Floor Quotes from Fellows

“There is no drug which can have as big an impact on healthcare as using all this data in the most effective way would have.”

“Wherever you go, geography can determine your destiny.”

“We need to not assume that just because the data came out of a computer it must be correct.”

“We need to make a renewed commitment to patient-centeredness.”

“‘Health’ does not equal ‘health care.’”

“Convenience is the easiest way to convince patients to adapt new behaviors and technology.”

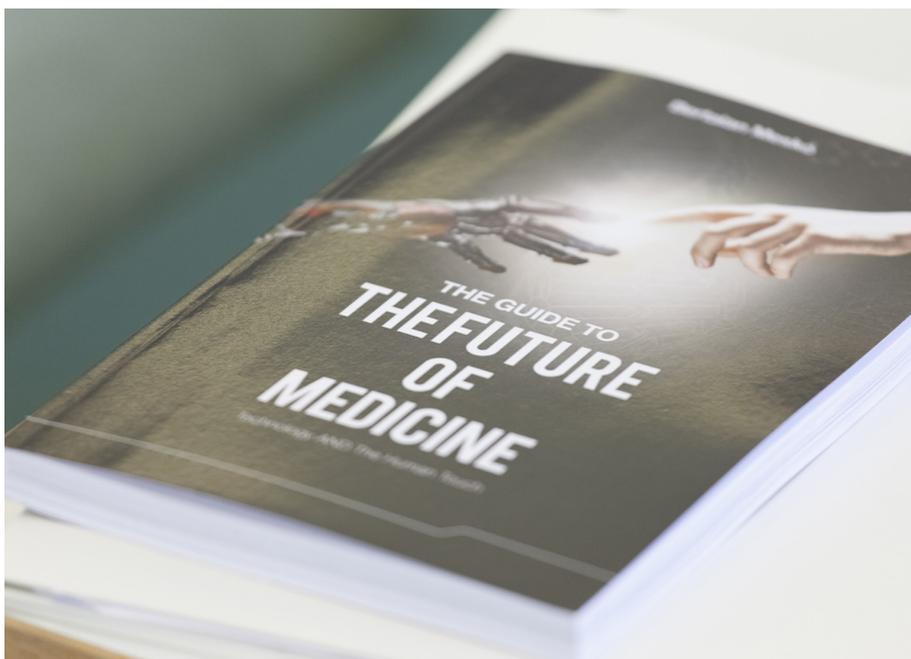
“70-80% of the stuff we worry about today, we’ll laugh at 15 years from now.”

“If all these monitoring apps do is make you exercise more, that’s already a positive.”

“Patients can become experts of their own health; the ‘ivory tower’ is over – doctors are no longer the sole gatekeepers of health information.”

“We need to forget about linear thinking, think outside the box and be brave.”

“I am excited and worried in equal measure.”



Copies of Bertalan Mesko's book are available for Fellows and online at Amazon.com

What will the future hold?

Bertalan Mesko started tracking his wellbeing as a teenager, and more than 6000 days later, the self-described geek is still doing it, and he believes more of us will be following his example.

As a doctor, researcher, geek and medical futurist, Mesko collects data on his mobility, sleep patterns, heart rate, brain activity, and even the speed of his eating through a number of a number of gadgets, including “wearable” tech and even a “smart fork”, enabling him to monitor and more importantly modify and optimize his behavior.

Wearable tech is a growing market with an estimated one in four Americans currently monitoring their health and general wellbeing either through dedicated devices or their mobile phones.

Such apps and devices enable not only the wearer to track their vitals on a daily and ongoing basis, but also share this data with their physician.

As this technology becomes more affordable and widespread, remote data transfers could enable patients to spend more time talking to their doctor about their condition during time-limited appointments, and for those living in remote areas, remove the need for them to travel large distances for simple procedures such as having their blood pressure

measured. Biosensors such as tattoos and digital stethoscopes could further ease this collection of data, which would not only enable the doctor and patient to be better informed of the individual's condition, but also help enhance large scale data sets.

In addition to the expansion of self-tracking and remote data collection other innovations that Mesko believes will have huge impacts on the future of health include 3D printing – enabling the speedier and more cost effective production of prosthetic limbs, bio-materials such as organs, and even drugs, creating the possibility for customized and immediate drug access; augmentation – enhancing prosthetic and natural limbs through the use of computerized exoskeletons; and nano-technology and nano-robotics – tiny programable devices that could exist inside the body to collect data.

These huge technological advances raise a multitude of concerns, not least of which is bio-terrorism. Mesko's advice to Fellows? Read more sci-fi; not for tech ideas, but to start considering now what might be the ethical challenges of the (possibly very near) future.

To listen to a full interview with Bertalan Mesko, visit www.soundcloud.com/SalzburgGlobal

Calling all bloggers!

Here in Salzburg this week, we're discussing a broad range of issues and if you would like to explore or reflect on some of these issues in more depth, the British Medical Journal is offering the opportunity to blog for them. Check out their blogs here: <http://blogs.bmj.com/bmj>

If you want to write for the BMJ, check out their guidance for authors: <http://www.bmj.com/about-bmj/resources-authors/article-types/blogs> If you have any questions, please speak to BMJ editor Navjoyt Ladher here in Salzburg.

Please remember that if you intend to write either for the BMJ or for your own organization's website or publication either whilst you're here in Salzburg or after the session, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, please do not hesitate to contact Salzburg Global Editor Louise Hallman or Program Director, John Lotherington.

Join in online

Salzburg Global Seminar is also interested in publishing your personal experience-led blogs on our website. Submit them to Louise via email: lhallman@salzburgglobal.org

You can also join in the conversation on Twitter and see photos on Instagram following the hashtag #SGShealth and find all your fellow Twittering Fellows via the list: www.twitter.com/salzburgglobal/lists/SGS-548.

Find us on Instagram at: www.instagram.com/salzburgglobal

We'll be posting all our official photos from our photographer Ela Grieshaber to our Flickr account: www.flickr.com/SalzburgGlobal and Facebook: www.facebook.com/SalzburgGlobal, where we'll also be posting all the interviews, recaps and features both during and after the session.

All the photos, interviews, recaps, features and session readings are available on the session webpage: www.SalzburgGlobal.org/go/548



Mining for gold: Data-driven health care solutions

The vast amount of data collected and analyzed in health care is like a gold mine: there are pieces of significant value, but it takes work to find them. How to find and apply this knowledge more quickly was the topic for the final panel of the day.

As one panelist pointed out, there is an average of 17 years between a medical discovery and its application as a best practice, and much of the health data that is generated has a research half-life of only five years.

“Yes we need to act upon data more quickly,” admitted the speaker, “but we have to do this smartly too.”

One way of being smarter about this action is to better engage the “end users” of the data: the doctors and the patients. However, four main barriers exist to transferring this knowledge into best practice: 1. clinicians and patients are unaware

that such knowledge exists; 2. a lack of resources, including time, hinders them from finding out more about such knowledge; 3. once the time is taken to read any of the 2000+ scholarly medical papers published everyday, the reader lacks understanding or information of the context necessary to put this knowledge into practice; 4. there is a lack of motivation to put new methods into practice, with many individuals assuming that these changes must be implemented first on a policy or institutional level rather than leading the change themselves.

Two of the main methods in which data is being put to use by clinicians is through predictive risk models and decision-making tools.

Predictive risk models can be used, for example, in anticipating return admissions of patients. While this can help allocate resources more

effectively, it is not foolproof and can generate false positives and false negatives that can lead to either unnecessary and potentially harmful interventions on one hand, or incorrect non-treatment on the other.

Decision making tools can combine an individual patient’s condition with larger data to enable a clinician to reach a decision about the best course of treatment. However, some of the preferences built into these tools are “hidden” rather than explicit and transparent, and therefore are not adjustable as they should be by the clinician together with the patients’ input. Thus these tools should enhance – not dictate – the human doctor’s decision.

An analogy can be found in a common decision-making tool: an in-car GPS/sat nav system – don’t follow its directions off a cliff!