

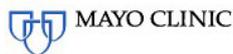


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The Promise of Data: Will this Bring a Revolution in Health Care?

Wednesday, March 25, 2015

In collaboration with:



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You can download the group photo from the Yammer group. Speak to Salzburg Global Editor Louise Hallman if you still need an email invitation.

Generational differences and patient expertise

Stuart Milne

Data collection and analysis is not a new phenomenon; as was pointed out on the very first day of the Salzburg Global program – Florence Nightingale used data to support her work in 1800s. But “big data” is considered by many as something “new”. If so, is there a generational difference in how we approach this new, big data?

The third day of the Salzburg Global program *The Promise of Data: Will this Bring a Revolution in Health Care?* began with an exercise exploring these potentially differing generational approaches to big data.

Participants were divided into groups of those under the age of 40 and those over 40, each tasked with deciding on their top three priorities for big data in health care.

The over-40s emphasized global standards for data access to ensure a level playing field, and getting patients the information they need – no more, no less. It was predicted that 10 years from now it will be

possible to say, “Siri – tell me, what day will I die?”

The under-40s presented a “Triple-A Action Plan for Big Data.” This prioritized Access (which must be fair regardless of socio/economic circumstances), Analysis (user-friendly to distil complex information into useful parts) and Action (data must have a purpose and should make future policy evidence-based).

It was noted that while the groups’ priorities were broadly similar, each generation collated their ideas differently: the over-40s delegated leaders of the sub-groups to finalize the ideas, while the under-40s crowdsourced.

When the plenary sessions began, Fellows heard the remarkable story of a participant with Parkinson’s disease who collects huge volumes of personal health data. The information is then shared with their doctor as they make treatment decisions together. The participant calculates that they spend 8,765 hours a year in self health care, compared to just one hour a year in neurological care.

One participant was moved to comment that if anyone present had had a friend with a similar condition, they would rather have had the friend speak to this Fellow than to any doctor. By collecting so much data, this Fellow had become an expert in their own condition, and this data and experience could prove valuable to others.

It was observed in the discussion that the attempts of health care providers to push patient-centeredness in a similar way can backfire if the approach is treated homogeneously. Instead, the preferences and particularities of the individual must be prioritized – health care cannot be patient-centered if providers try to do the same thing with every patient.

Another participant pointed out that the doctor/patient relationship should ideally follow this pattern: the patient has enough information to understand what treatment is possible, while the doctor respects the patient enough to know what matters to them, in order for both parties to make decisions together.



Ruth Bell explains how the UK is collecting data and tackling health equity

Using data to drive health equity

“Health is more than just health care,” remarked one Fellow. This is especially true when considering health equity.

Working to improve health equity means measuring more than just health outcomes; as well as measuring the distribution of health outcomes, we also need to measure the social determinants of these health outcomes, and thus the measuring and monitoring of indicators of not only health, but also social, economic and environmental factors is vital.

In addition to *measuring* these social determinants, to improve health equity we also need to *improve* the conditions in which people are born, live, grow, work and age. We also need to tackle the unequal distribution of power, money and resources.

In the UK, the *Marmot Review*, first published in 2010 and most recently updated in 2014, collects data across a set of indicators of the social determinants of health, health outcomes and social inequality including: life expectancy, life satisfaction, level of education achievement, rate of employment, income, and even outdoor exercise, amongst others.

However, despite collecting all this data, questions still remain around the *wholeness* of this data: are we sure

we are actually collecting data from those most vulnerable, disengaged and marginalized in society?

Studies show that those living in the most deprived communities are the least likely to opt-in to data collection programs. Data collected from clinical trials disproportionately represents the geography and demography of the area around the test center. Even convenient mobile apps such as Street Bump, the iPhone app that identifies the location of potholes on Boston streets, requires that all data collectors have an iPhone, thus the streets on which wealthier Bostonians live and drive are disproportionately represented, leaving poorer districts undocumented and ultimately with worse roads.

Mobile penetration rates are actually higher in much of Africa than the US and one country to capitalize on this is Rwanda. The Ministry of Health’s rapid SMS system enables the tracking of patients, the distribution of drugs and doctors, and even ambulance attendance, enabling not only data monitoring but also enhancing accountability.

As one Fellow put it: Without data, we don’t know what our problem is and we therefore cannot ascertain the right course of action. Or as another said: “In God I trust, for all else, I have the data!”

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