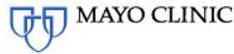




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# The Promise of Data: Will this Bring a Revolution in Health Care?

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## Case study: Rwanda

Agnes Binagwaho, Minister of Health for Rwanda, took time out of her busy travel schedule to join the session via Skype on Wednesday.

Several participants expressed how valuable it was to be able to ask the minister about points raised in her pre-recorded video message shown on Tuesday.

The Rwandan Ministry of Health is also represented in person by Andrew Muhire, who has also been providing examples of Rwanda's approach to health care data throughout the session.

Many participants were especially struck by Rwanda's use of rapid SMS messaging, widespread in much of Africa, to power efficient health care on a limited budget. SMS technology allows the ministry to pass vital messages to 45,000 community health care workers across the country in less than an hour.

When an ambulance is requested, an SMS is sent to the relevant district and also to the ministry, where officials can check if the ambulance attended the incident.

This enabled Rwanda to become the first country to contain a cholera outbreak at fewer than 15 cases.

A participant from an EU member state remarked that their country had a lot to learn from Rwanda's integrated approach to data, where electronic systems keep data management to a minimum, thus allowing health workers to spend more time with patients.

In the concluding remarks from another participant: "When you don't have data, you don't manage, and when you don't manage, you just hope you do the right thing."

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



Leo Ryan speaks from the podium as Rwandan Health Minister Agnes Binagwaho joins via video Skype

## Whose data is it anyway? Challenges of ownership & possession

Throughout the week in Salzburg, the issue of data privacy and ownership has been brought up repeatedly. On Wednesday, Fellows finally tackled this topic head on.

With expert legal input, Fellows compared different attitudes and policies in place in their respective countries and whether a globalized approach to data ownership and sharing should be pursued.

Data ownership is a complex legal issue because data exists in so many places. Data on a patient's drug prescription for example resides with the patient, the doctor, the pharmacy, the health insurers, and possibly others. Who owns this data? Anyone? Everyone? No one?

Possession of data, rather than ownership, could be more important, one Fellow pointed.

Patients in possession, even in copy, of their own health records and data (self-recorded or otherwise) are in a position to make more informed decisions about their care. Better self-care could ultimately reduce the burden on health systems and

improve public health at large.

Given the positive impact big data can have on public health, should health data be considered a public good? If so, how can we enable easier sharing of this data? In many countries, patients currently have to give consent for each different usage of their data, and countries like Italy do not allow doctors and researchers to use the same data for multiple studies. Could Sweden's "personal health accounts" through which patients can "donate" their data be a model to follow?

How can we encourage or even force private companies to share their data? Many companies use the "excuse" that they refuse to share data because of patients' privacy concerns when the "real reason" is fear of losing commercial advantages.

How can we ensure that all this data will only be used for the public good? As one Fellow pointed out: "There are probably good uses we can all agree on and bad uses we all want to avoid, but there's an awful lot in the mushy middle."



## Sharing ideas at the “Knowledge Café”

Stuart Milne

Thursday began with a “knowledge café” in Parker Hall, where participants rotated between five discussion groups led by an expert in a designated field.

Rebecca Emeny of the Munich Cancer Registry led a group discussion asking how big data in cancer registries can improve global health care.

Another group led by Leo Ryan, director of ICF International’s International Health and Development (IHD) Division, focused on the possibilities and limits of utilizing population-based data to inform decision-making in lower and middle income countries. Points raised included the importance of having strong national health management information systems to complement periodic national surveys; the challenges of fragmented health systems; the benefits and potential

pitfalls of aggregating multiple data sets into a single index and making it openly accessible.

Shahid Hanif of the Association of the British Pharmaceutical Industry discussed the putting patients at the heart of managing their health care data, particularly as patients, physicians and researchers are beginning to see the value of data/information provided by patients to augment their electronic health record data. Participants agreed that patient platforms do have the power to transform health care and research, but they need to be accessible, validated and of value to transform patient engagement in the provision of health care and patient participation in research.

Felix Chang, chief strategy officer of predictive analytics company DecisionQ, examined Big Data’s “So What”, and how to deploy it faster to create actionable predictive analytics in health care. One participant

suggested that DecisionQ could focus its analytic efforts on identifying data elements that could lead to even more predictive models, but are currently missing. That would help medical researchers and practitioners accelerate their work.

Harri Honko of the Digital Health Revolution Program presented MyData, a strategic Digital Health initiative and research program aimed to change Finnish health care around moving, citizen-managed data. Some participants raised devil’s advocate questions about having patients manage their own data. Would driving personal data control into the hands of individuals be doable without having large regulatory changes? Are we assuming individuals would really be actively managing use of their data, and what would the incentive be to take so much control (and work) onto their own shoulders?