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SESSION REPORT

548

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



Salzburg Global Seminar is grateful to our program partners:
The Dartmouth Center for Health Care Delivery Science,
the **Mayo Clinic** and **Arizona State University**
for their generous support of Session 548
and to the **Karolinska Institutet** for their programmatic co-operation.

Salzburg Global Seminar would like to thank all the Speakers, Discussion Group Facilitators and Resource Specialists for donating their time and expertise to this session and to all the participants that contributed their intellectual capital and superior ideas.

Session 548

Salzburg, March 22 to 27, 2015

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

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Introduction

When Florence Nightingale arrived at the Scutari Hospitals in Turkey during the Crimean War with a cadre of nurses to respond to the crisis of British soldiers dying without medical attention, fleas and rats infested the open wards and corridors. Laundry was done in cold water and there was minimal surgical and medical equipment. Nearly two thirds of soldiers were dying from disease alone. It was 1854. Social statistics were rarely collected—let alone analyzed and used. Men controlled the military and health care, very few women were educated and held jobs, and nurses were largely viewed as ignorant and uncouth. Yet Florence Nightingale was determined to address the problems she observed. She originated a hypothesis: lives could be saved by improving sanitary conditions. By studying available data, diligently recording sickness and mortality, and presenting her analysis with meaning she convinced even the skeptics that many deaths were preventable. Her use of statistics not only saved lives immediately, but also resulted in enduring medical reforms.

Today, the health care field faces similarly transformative opportunities through the use of data and analytics. In this spirit of leveraging data for health and health care reform, health care policymakers, providers and patients joined with data and information technology experts, ethicists, legal experts and representatives from business and media for the Salzburg Global Seminar session, *The Promise of Data: Will it Bring A Revolution in Health Care?*, held at the Schloss Leopoldskron in Salzburg, Austria from March 22 to 27, 2015.

“ Is data bringing a revolution in health care? There should be no question mark because it is yes. ”

Salzburg Global Program Director John Lotherington addresses the Fellows gathered in Parker Hall





1. Deven McGraw
2. Elliott Fisher and Darren Toh
3. Albert G. Mulley, Jr
4. Veronique Roger

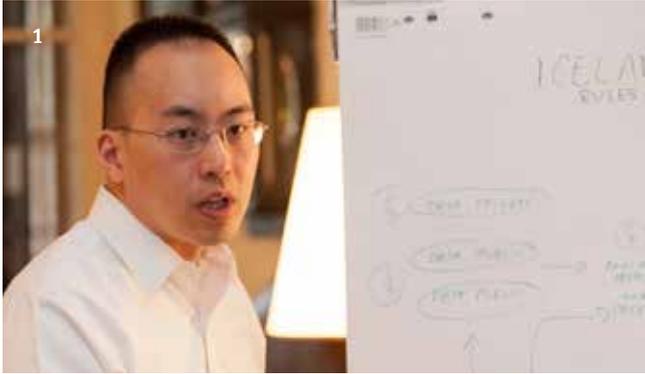
Participants were motivated by a common understanding of the untapped potential of new technologies, computing power, and data resources. They shared concerns about the unsustainable levels of cost and demand in health care, the changing burden of disease, fundamental shortcomings in current health care delivery models, and increasing societal needs and expectations. They held a common vision for high-value health care driven by the needs and wants of those to be served as an instrumental good for health, broadly defined. With this foundation, they set out to craft principles and concepts to realize the potential of data in health care in the 21st century.

Session partners and leaders from the Mayo Clinic, Dartmouth College, Arizona State University, the Karolinska Institutet, and Salzburg Global Seminar encouraged interdisciplinary collaboration and set a tone of rigorous inquiry. The session was framed by questions ranging from “how can we

ensure benefits from advances be distributed across the social gradient and globally?” to “what are the risks on the horizon and how can they be mitigated?” Global challenges from “identifying the conditions under which data should yield the greatest benefits to patients and populations” to “mapping links between social and physical environments, and consequent health determinants, where data on its new scale could also help us understand and manage the complexity underlying sustainability” generated debate and inspired creative group work. A process of discovery began with participants sharing hopes and fears for health data in the 21st century many of which are captured in **Table 1**.

Table 1: Participants’ Hopes and Fears for Health Data in the 21st Century

<i>We hope that health data...</i>	<i>We fear that health data...</i>
<ul style="list-style-type: none"> • Is universally accessible • Is analyzed and shared in ways that are meaningful to people and populations • Empowers patients with knowledge and capabilities to improve their own health and care • Fosters meaningful conversations between patients and health care professionals • Improves individual and system-level decision making • Is used by health care organizations and systems to lower costs, improve patient experiences, and achieve outcomes that matter to patients • Contributes to a global transformation from sick care to health care, and health care to health • Is used in secondary and tertiary care to prevent overuse and underuse of care • Contributes to the disruption of incumbent, low-value care models • Enables more evidence-based, adaptive health strategies and policies • Helps health systems and the organizations within them to become the learning systems and organizations they aspire to be 	<ul style="list-style-type: none"> • Succumbs to political, administrative, and financial forces that have contributed to waste and harm in health care • Results in increased inequities between high-income countries and low- and middle-income countries and among vulnerable groups within countries if benefits accrue disproportionately to those with greater power, capacity, and interconnectedness • Results in expanding and scaling up of “one-size fits all” models of care that further paternalistic health care practices and undermine equity and affordability goals • Is used to drive incremental improvements in current delivery models rather than to drive innovation that addresses fundamental shortcomings in current models of care • Leads to overinvestment in sharing information that has negative value which creates unnecessary anxiety and wastes scarce resources • Increases overuse of health care • Is flawed and biased for its lack of representativeness across populations and factors contributing to health



1. Felix Wong

2. Jens Deerberg-Wittram and Sara Riggare

Using data to improve, expand, and replicate the prevailing health care delivery models will be insufficient for the improvement of individual and population health. New models, driven by new data about patients' and populations' needs and wants with information fed back to clinicians, managers, policymakers, and patients, families, and communities, can better align the health care services that are delivered with what is valued by those they serve. A critical mass of data on needs and wants, and the analytical infrastructure and tools required to help make meaningful use of it, is a fundamental component of a sustainable health care system.

Sustainability rests on centering care delivery on what matters to those being served. In 1905, recognizing that helping his patients improve their health required reaching beyond the field of medicine, Richard Cabot integrated social services into clinical practice at Massachusetts General Hospital (MGH) in Boston, MA, USA. Social workers established friendly relationships with patients; they educated and re-educated patients on health issues and addressed common concerns including hunger, housing, and employment; and they conducted home visits and coordinated care with other divisions within the hospital. At the time, tuberculosis was a primary cause of death and a social and economic stressor for the MGH social workers' service population. In response, they conducted the first national study of tuberculosis in the US and recommended approaches that became fundamental to subsequent successful prevention and treatment approaches. Data strategies in the 21st Century can be led towards what will create health by integrating Cabot's understanding that factors other than medicine such as behavior, social and economic circumstances, and education, contribute disproportionately to individual and population health.

Health data strategies that contribute to the public good, as outlined in participants' hopes, involve a common goal of health for individuals and populations, new data on what matters most to patients, their families, and communities, and connections across disciplines to advance what is valued and contributes most to health.

“ There’s not one drug that will be as beneficial as the data that’s currently available. ”

Sara Riggare: “At the Quantified Self I forget I have Parkinson’s Disease... It’s so liberating to really just be Sara”

Patient empowerment advocate on the importance of self-care, keeping track of your own health data and the liberating aspects of the Quantified Self movement

Sara Riggare is a major advocate for patient empowerment, and for years has been collecting her own data to help her and her neurologist manage her Parkinson’s Disease.

While participating in *The Promise of Data: Will this Bring a Revolution in Health Care?*, Riggare spoke to Salzburg Global about how patients can take responsibility for their own health data to make shared decisions about their treatment.

“I wanted to know more about the exact effects I had from my six different kinds of medication that I take six times a day with five different combinations and six different time intervals,” Riggare explains.

“A diabetic has the ability to measure quite easily, although that’s a very simplified picture. They can measure their glucose levels, so they know how active their disease is. In Parkinson’s it’s more complicated – there is no one simple measure – so I had to look around for what was out there, and found a finger-tapping test.”

As chief patient officer with Nerve, a small Stockholm-based digital health startup, Riggare has worked to develop an app that uses finger-tapping to help patients easily track their medication intake and other interventions like exercise and diet. The idea is to make doctor’s visits more beneficial and efficient for both parties by enabling the patient to bring in large volumes of data they have collected themselves.



Sara Riggare

“I see my neurologist once or twice a year for about half an hour every time,” she said. “That’s one hour per year. The rest of the year is 8,765 hours spent in self-care. The end goal is to have less time in health care.

“To me ‘self-care’ is every decision, every action I take relating to my health that’s outside of health care. If I decide to take my medication a quarter of an hour later, that’s self-care. If I travel across the Atlantic and need to shift my timings, the decision I make in that context is self-care.

“With a very complex chronic disease like Parkinson’s it takes a lot of conscious decisions to manage it in the best way. I very strongly believe that the more conscious decisions I can make, the less I need to care about Parkinson’s Disease.”

Riggare says she is very fortunate to have an excellent relationship with a neurologist she has partnered with for over 20 years. He has even told her that she now knows more about Parkinson’s research than he does.

She said: “It’s not about him knowing more than me because he has so many more diseases to keep track of, whereas I’m focused on one in particular. We have a very good collaboration with true shared decision-making.

“When I come to him he doesn’t say, ‘Are you taking your medication as prescribed?’ Instead he says, ‘Can you tell me how you are taking your medication now?’ Then he puts that in the medical record.

“I think shared decision-making is not happening more because a lot of health care people think it is the end goal, whereas for me it is merely a tool and a means to reach the goal.”

Riggare is heavily involved in the Quantified Self (QS), a movement founded by Kevin Kelly and Gary Wolf of *WIRED* magazine dedicated to using technology to self-monitor aspects of a person’s daily life.

She wears a tracking device that monitors activity and sleep patterns, but doesn’t feel compelled to monitor her data every day.

“If things seem to be working fine, I just want to get on with life,” she said. “That’s the big difference between the normal geeky QS tracker and the people with chronic diseases. They would probably rather commit suicide than admit they had missed a day of data, but for me the purpose is different. It’s a needs-based approach.”

The Quantified Self has a special place in Riggare’s heart that sets it apart from the other conferences and meetings she regularly attends as a participant and speaker.

“At the Quantified Self I forget I have Parkinson’s Disease,” she said.

“Everybody at QS tracks everything – they’re crazy. There’s no QS-er that isn’t a bit crazy, and I’m definitely one of them. Everybody tracks something, or often several things, but no one puts a judgement on anyone else’s tracking. Everyone is interested in what they do, not what they have.

“It’s so liberating to really be just Sara.”



Sara Riggare with Marco Monti

The Urgency and Opportunity of Data for Value

Progress in health care in the 20th century was largely driven by medical science. Today, it is driven by a different kind of innovation. Surgical robots and digital stethoscopes are dramatically altering health care workforce requirements. Smartphones are becoming personal health data repositories. User-generated data combined with patient-facing technologies are empowering patients to manage their own health and care. The digitization of medical records is improving understanding of patients' needs and helping health care professionals communicate more effectively.

As a whole, however, the health care sector lags behind other industries in the productive use of its data resources and technological capabilities. For instance, Amazon predicts its customers' preferences, while studies have shown that health care too often delivers services that patients would refuse had they been well informed. Google responds to user search patterns to predict and locate epidemics, ahead of national and international health data agencies.

On one hand, health care faces the dangers of inertia and resistance to change. Currently, many patients and their families struggle to find reliable health information. Many population segments who have the most to gain from health care innovations remain priced out of the market. Privacy concerns limit the pace of digitizing and sharing data. On the other hand, data collection and aggregation inside and outside of the health system is outstripping health systems' ability to analyze and use data. Advances in data

Illustrations from Fellows' group discussions on how both patients and physicians can use data



“ Data isn’t information and information is not evidence. ”



George Runger



Navjoyt Ladher



Fong Ho-ching

science and information communication technology (ICT) in health care, largely driven by the private sector, are also outpacing sound policy.

Harnessing the data revolution underway to reduce health inequities, maximize improvements in individual and population health, and reduce the impact of poor health is now incumbent on the field of health care. As Florence Nightingale taught us, information is a foundation for, and precursor to, improvement. More knowledge about health and health care can help individuals and societies attain the highest possible levels of health. Data, and its related infrastructure for effective use, is a fundamental component of this aspiration.

The commonly referred to “**4 V’s of Big Data**” are **volume** (amount of data), **variety** (different data sources and forms of data), **veracity** (levels of uncertainty and unreliability of data) and **velocity** (pace of data flow, change, processing, and analysis). Participants in Salzburg focused on a fifth V: **value**. The real breakthroughs in health and health care will come when data on health choices people make when well informed and supported in decision making are used to deliver services that are needed and wanted. This understanding of true demand can continuously guide health systems towards value as defined by those it serves and towards sustainability through the productive use of scarce common resources.

The value of data increases with their meaningful use. The same data can be used by multiple people for multiple purposes. Institutions collecting data relevant to health can contribute to the public good by sharing data and participating in a global effort to make data available and useful for the attainment of better health. Data are infinite, common resources. The potential benefits of a data revolution exists at all levels within the health care system as shown in **Table 2**.

Creating connections across contexts, industries, and fields of study is also essential to realizing the value of data for health. Integrating health with other sources of data, including on the social, environmental, cultural, and economic factors that determine health, will drive innovation and value. Cross-border and cross-sector integration and learning will require new global standards and common languages. Approaches for ensuring that vulnerable and disadvantaged groups also benefit from the knowledge gained from data will be needed because if health knowledge remains unevenly distributed, the power imbalances that continue to inhibit health attainment will persist. Innovative institutional and governance structures will be needed to capture and manage opportunities, mitigate risks, and support transparency.

Table 2: Data Sharing Beneficiaries and their Benefits

Beneficiary	Benefits
Patients	<ul style="list-style-type: none"> • Better health, including longevity and higher levels of function • Better decisions through more accessible, meaningful information about themselves, scientific evidence, the experiences of others, costs of care, and opportunities for achieving health goals • Better health care experiences through improved relationships with health care providers and other social service providers based on shared knowledge • Greater transparency and accountability among health care professionals and organizations where services are rendered
Providers	<ul style="list-style-type: none"> • Better health outcomes for patients at lower cost • Improved professional experience through empowerment with knowledge and continuous learning and improvement • Improved communication and coordination among provider teams and between provider teams and other stakeholders, most notably patients • More meaningful information about what is valued by patients, families, and communities to support decision making • New knowledge to inform resource allocation
Policymakers	<ul style="list-style-type: none"> • Better outcomes for populations at lower cost • More effective mechanisms for transparency and accountability at national and local levels • More informed public debate • More rapid dissemination of information and innovation across borders and among sectors within an economy • New knowledge to inform resource allocation
Researchers	<ul style="list-style-type: none"> • Comprehensive, representative, high-quality data to accelerate the creation of new knowledge for better health • Faster, more accessible health information systems to reduce the time between discovery and impact of new knowledge
Industry	<ul style="list-style-type: none"> • Better employee health at lower cost • New business opportunities through new knowledge paired with information and communication technologies

Jörgen Nordenström: The purpose of Big Data in health care is to improve value for the patient

Swedish surgeon and author explains the five “V”s of Big Data in health care

As professor of surgery at the Karolinska Institutet in Stockholm, Sweden, Jörgen Nordenström has written extensively about value-based health care. He believes Big Data can play a huge part in making life easier and better for health researchers, practitioners and, above all, patients.

While participating in *The Promise of Data: Will this Bring a Revolution in Health Care?*, Nordenström spoke to Salzburg Global to explain what he calls the five “V”s of Big Data in health care, starting with the most important – **value**.

“We have many problems in health care, including siloed thinking and the problem of patients going from one provider to another – these transitions are always a risk factor for developing complications,” he explains.

“Value-based health care is the concept of creating value for the patient, to look at health care from the patient’s perspective rather than the health care provider’s perspective.

“There are many aspects, including quality improvement, use of best practice, motivating health care personnel, providing patient-centered care, and so forth. I think the name *value-creating* would be better than *value-based* health care.”

According to Nordenström, Big Data has a role in putting this philosophy into practice, summarized by five “V”s.

“The first “V”, **volume**, is the massive amount of data. The second one is **velocity** – we will be

creating data very rapidly, and we will be able to retrieve it at high speed.

“The third is **variety**. Big Data entails that we have data from many different sources – research data, electronic medical record data, patient experience data and public health data.

“The last one is **veracity**. We need to be able to trust the data that is coming out.

“These four “V”s should add up to a fifth “V”, namely **value**. That’s really the purpose of introducing more Big Data in health care – to improve value.”

Medical literature is also strongly characterized by the first “V”, volume, with researchers and practitioners confronted with an enormous and ever-expanding array of published articles to consult. Nordenström feels this is a conundrum that needs addressing.

“Health care workers are sometimes not keeping up-to-date with the current literature,” he said. “This is quite surprising –



Jörgen Nordenström

I think most patients would take for granted that at high-profile academic medical centers the doctors and nurses should be up-to-date.

“When you measure this, there are observations that perhaps 30-40% of patients do not get care which is in line with best practice. We need to promote this aspect – there perhaps needs to be a culture change, and there needs to be education on where to find the evidence and how to make use of it.”

Furthermore, Nordenström says Big Data has the power to radically transform how researchers go about their work.

“Randomized control studies are the gold standard for medical research, but the problem is that they are very expensive to undertake and sometimes involve many years of observations,” he said.

“It’s not unusual that a proper randomized control study can take up to ten years before it’s published.

“Another problem is there is a specific question that each study tries to address, and other questions are difficult to answer.

“The promise of Big Data is that you can reuse the data. You can have a question, you go into this bank of Big Data and you can get an answer. When you have another question you can go back to this data bank.

“I think this will add great value to future research, but one needs to be cautious about the accuracy of the Big Data pool, and I’m sure there will be ways of looking into this and getting the methodology correct.”

Nordenström also has clear ideas about the value of attending Salzburg Global’s session on Big Data.

“I think the most important part is the social networking part,” he said. “We spend five days here and we get to know other delegates, including very important and experienced researchers.

“It also gives you a broader perspective and gives you new ideas that need to be explored or discussed.

“It’s a wonderful update on the promise and problems of Big Data.”



Nordenström speaks on a panel alongside Amar Das, Lucy Savitz and Geraint Lewis

“ I don’t care one bit about patient-centered care because I don’t want care. I want health. ”

Fellows further examine issues raised by the panelists in small table discussions

The Revolution is Underway: Use Cases

Tangible benefits from the enhanced availability and management of data in both customized, personalized health care and population health are already materializing. Countless innovations and programs, and the approximately 2,000 articles published per day across 25,000 medical journals, illustrate the ever-expanding evidence base contributing to the wealth of health information resources globally.

Participants shared examples of data innovations from the private and public sectors in very different local contexts to facilitate cross-border learning and collaboration.





In **Rwanda**, the Ministry of Health collects and uses data at all levels of the national health care system to understand trends and inform decisions. The country has over 45,000 Community Health Workers (CHWs) who are equipped with cell phones and communicate real-time data via SMS text messages to the Ministry. This allows for community level identification of needs and problems and targeted, timely responses. For instance, when cholera presented at a refugee camp, CHWs’ data feeds triggered the Ministry’s rapid containment the epidemic. All public and private health facilities report directly to a central health information system facilitating data sharing across the health sector and giving the Ministry comprehensive data for planning and resource allocation. Data on individual and group performance of the health care workforce enabled Rwanda to introduce performance-based financing programs that reward health workers, clinics, and facilities for high quality care, thereby driving provider motivation and accountability. Data on patient needs and preferences are also driving a range of interventions, from the design of new community-based programs for the beginning and end of life to the distribution of health resources in order to ensure greater equity and access to care.

In **Sweden**, arthritis patients and clinicians use ICT to prepare for clinical encounters, compare levels of pain over time, and manage medications. Work is underway to enable patients with Parkinson’s disease to collect and analyze data about themselves with patient-created smartphone tools that enhance dose regimen discipline. Processes such as these, which are enhanced and supported by data and technology, are driving a fundamental shift towards more patient-centered care, self-motivated self-care, and shared decision making.

In the **UK**, many organizations are working to bring the National Health Service’s (NHS) extensive data sets to life with, for example, predictive risk models and patient-level technology tools. Its predictive risk models

1. Darren Toh, Andrew Bate and Mark Leenay

2. Geraint Lewis

“ No data, no problem, no action. ”

help address the rising rate of unplanned and costly hospital admissions that are potentially indicative of suboptimal care elsewhere in the system. Software tools combine clinical and patient history information with patient preferences to support decisions at the point of care. The NHS is also expanding its capabilities to incorporate patient preferences into their evidence base and to identify and manage instances of overdiagnosis and overtreatment. Guiding principles across all of these initiatives include transparency and flexibility to bring data to patients and providers, as well as confidentiality and data security.

In the **USA**, the Food & Drug Administration’s Mini-Sentinel distributed data system for monitoring the safety of medical products currently manages data on 178 million individuals. Combined with other public sector initiatives such as the Patient Centered Outcomes Research Institute’s PCORnet and the National Institute for Health’s Health Care Systems Research Collaboratory, Mini-Sentinel is a part of an emerging national distributed data infrastructure for evidence generation covering health plans, hospitals, clinics, and patient groups.

In the pharmaceutical industry, Pfizer routinely licenses, structures, and analyzes “real world data” – anonymized data outside of randomized control trials – to further understand product risk profiles, drive innovation, and improve patient safety. It also partners with other organizations to innovate in data access, collection, or linking to increase that data’s value. For instance, it recently partnered with video game maker Akili to test a video game platform to detect cognitive differences in healthy elderly individuals at risk of developing Alzheimer’s disease.

Optum is a health services and innovation company and part of the UnitedHealth Group. Optum One, its population health and clinical analytic platform, processes data covering almost 70 million patients with over 8 billion lab results, 4 billion diagnoses, over 1 million medication prescriptions, and almost 5 billion clinician notes. By integrating claims, clinical, socio-demographic and care management data, Optum One provides both a retrospective and prospective view of patients and patient populations. Real-time processing power, combined with two decades of longitudinal data, predictive and clinical analytics, and technology and visualization solutions enables identification of at-risk patients earlier to preserve patient health, reduce costs and prevent complications.

The productive use of existing and future data resources across contexts has infinite potential to improve the health of individuals and populations. Yet, several barriers inhibit the full realization of this value. Risks will have to be mitigated and managed. Ethical concerns will require further analysis and addressing.



Ruth Bell



Nilay Shah

Andrew Muhire: “Cholera and other diseases don’t last long in Rwanda”

Health Ministry official on how Rwanda became the first country to contain a cholera outbreak at fewer than 15 cases

Since 2011 Agnes Binagwaho, Minister of Health of Rwanda, has regularly joined Salzburg Global Seminar’s *Health and Health Care Innovation* sessions by Skype to share how health care is being improved in her country.

During *The Promise of Data: Will this Bring a Revolution in Health Care?*, the Rwandan Health Ministry was also represented in person by Andrew Muhire, sector monitoring and evaluation and report lead specialist. He spoke to Salzburg Global about the innovative ways Rwanda is improving its health outcomes with limited resources.

Muhire says the Rwandan government’s investment in switching to electronic health information systems is paying dividends.

“Everything is being tracked using electronic information, from health center level to central level,” he said. “Everything is centralized, and it helps us to take decisions based on fact and be more focused, which really makes health care delivery more efficient and also reduces costs.

“It is a big change, because now we are really aggregated electronically. If there was an outbreak before, you had to know by someone telling you about it. Now because of this threshold that is set in the system, it is automatic.

“If there is any case of cholera reported, for example, the system automatically sends messages to people concerned, including the health facility in that catchment area. Not only that, it even helps us to track information



Andrew Muhire

that has been recorded by community health workers about the services that they offer. They either send it by SMS or they aggregate it back to internet reporting.

“Mobile phone technology is really interesting and attractive to monitor, because if there is any complication, the community health worker just sends the message through the server, then the server automatically informs the ambulance site, or even people at the central level to make sure they follow up if the ambulance was really sent.

“So the change is really significant, because now everything is electronic, data sharing is really good at all levels.”

The Health Ministry has embraced Rwanda’s high rate of mobile phone ownership and extensive mobile data coverage, common to much of sub-Saharan Africa. Using the central database of phone numbers and a server that sends messages to all contacts automatically, an outbreak alert can reach the country’s

45,000 community health workers in under 30 minutes.

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

Muhire said: “The good thing about these electronic systems is they really inform us at the early stages, so it helps us to send people to go and investigate and make sure that those people cannot contaminate the whole geographic area.

“Then we make sure that case is treated as soon as possible to make sure even the patient with cholera is not affected. It makes some real improvements when it comes to patient level, and also population level at risk.

“When you have a very strong surveillance system, it’s always easy to make sure that nothing is moving far away. In Rwanda our integrated surveillance system tracks if there is an outbreak – not only cholera, but any outbreak that can occur.

“The good thing about this system is it alerts you in seconds, if there’s anything it reported.

From that perspective, cholera and other diseases don’t last long in Rwanda.”

Muhire says he has found exchanging knowledge with other participants in Salzburg to be very valuable, with a number of Fellows expressing interest in Rwanda’s efficient and effective use of technology to improve health outcomes.

“All of us are learning from each other,” he said. “Participants are saying, ‘How do you manage to do that in that limited resources area?’ They don’t understand how Rwanda managed to do it, but it’s all about commitment, leadership, prioritizing what you want, having a vision, and also having an accountability approach. Rwanda is really good in all those components.

“I have gained exposure to very experienced people. This is a very big community that will keep working together. We have already created a forum where we will keep discussing and bring in some more new ideas to make sure not only Rwanda, but even the world, will really improve health delivery to our people.”



Rwandan Health Minister Agnes Binagwaho speaks to the session via Skype

Birgir Jakobsson: “We have a unique situation with our system to get health care that is really state of the art”

Surgeon General of Iceland on how his country is specially suited to using Big Data to improve population health

Is Iceland the perfect country for using Big Data in health care? With a population of only 325,000, concentrated largely in urban areas, an entirely public health care system, and genealogical records a millennium old, surgeon general and head of the Icelandic Directorate of Health Birgir Jakobsson says his country is in a unique position to use Big Data to improve the health of its people.

While participating in *The Promise of Data: Will this Bring a Revolution in Health Care?*, Jakobsson told Salzburg Global about the health care situation in Iceland and the Icelandic Digital Health Initiative created with help from his fellow participants.

“Iceland has a long tradition of keeping records of its health care system,” he explained.

“The cancer register in Iceland is very comprehensive, dating back to the early 1950s. The population has genealogical data from the beginning of civilization in Iceland 1,000 years ago. You can track the family trees back to the ancestors of the Icelandic population.

“More importantly, you recently have access to the genetic data of the population. About 150,000 people, half the population, has been genetically mapped. So you have immense possibilities of tracking diseases and risks, and using this data for creating health in the future.

“This has not been done as yet, so this is a challenge. That’s why I was very interested in coming here to Salzburg. How can we use this data to benefit the health of the population?”



Jakobsson offers advice during a peer coaching session

I think we have a unique situation with our system to get health care that is really state of the art in the future. We have had some economic difficulties for the last eight years or so, but the country is slowly coming back. I think if we do this wisely, learn from others and use our data, we have a marvelous possibility to create a health care system that is really one of the best.”

Jakobsson has been working with the Mayo Clinic in the USA and visiting countries across Europe to learn from their health systems.

“I think it’s very important to keep contact with as broad a network as possible, and this is a very good opportunity for that at Salzburg Global Seminar.

“We have our databases in Iceland, and we are discussing how they are made accessible for researchers and transparent so the population understands the benefits of these databases.

“What I have also learned here is the importance of collaboration with people keeping databases and quality records in other countries. In that respect we are very much looking to the other Scandinavian countries.”

As well as an enlarged network of contacts, Jakobsson was also able to take home an Icelandic Digital Health Initiative designed by the participants of his working group.

“It is an initiative to use the available data in the interests of public health in Iceland,” he said. “The databases there have been used a lot for research, but as I see it, they are not giving back what the Icelandic population should have out of it. That has been my concern now since I entered office – how can I do that in the interest of public health?”



Birgir Jakobsson

The initiative calls for a personalized medicine approach, beginning with the selection of patient needs, and aims for the highest intervention impact possible by health providers. With the data already available thanks to Iceland’s thorough record keeping, it would be relatively easy to identify a list of patients and diseases that deserved priority attention, with the public continually informed of progress and able to give feedback to the steering committees overseeing data use in Iceland.

Participants decided they needed to find a business model for making this happen, with incentives for key stakeholders among the public, government and private industry.

“I’m very pleased with the working group I was working with,” Jakobsson said. “They were really helpful and engaged in the problem and understood it from the beginning. They had the knowledge to put it together into an initiative that I will be able to at least try to put into reality in Iceland. That is more than I expected when I came here.

“I will go back and present this document to my own office and collaborators, and then I will take it to the government level. Then we will see what happens.”

Barriers, Risks and Ethics

The Salzburg Global session surveyed ethical considerations, risks and barriers to realizing the promise of data. Profound ethical considerations and long-term risks for health care data strategies surfaced: the World Health Organization estimates that 20-40% of all health spending is wasted; studies across contexts have shown how *more* care does not necessarily mean *better* care, and can lead to harm; failures to engage patients, families, and communities in the creation and implementation of knowledge results in care that does not meet needs and exceeds wants.

Research shows that in the US, the majority of patients who say they want to die at home die in a hospital. It has also been shown that increased health knowledge among patients results in lower rates of costly surgical interventions. If investments in health data are not analyzed through the lens of creating value from the patient perspective and in terms of their contribution to health, advances in health data risk driving health systems towards more waste and harm with dramatic implications for national budgets for human and social services that also contribute to health.

The barriers to realizing the promise of data explored in Salzburg largely fell into five categories:

Ignorance

Until patients, families, and communities are routinely engaged in the design and delivery of health care, and accurate indicators of their needs

“ Data ownership is a red herring and a non-issue...does it matter who owns it? ”

1. Desiree Daniega and Harri Honko

2. Kate Niehaus, Andrew Muhire, Shahid Hanif and Gaetano Brianese





1. Ruth Bell and Ivan Ivanovic

2. Rebecca Emeny

and wants are integrated into health data sets, health knowledge will remain concentrated at the top. Care will remain distorted by supplier-induced demand and the use of clinical evidence alone to inform health decisions. Too often, information fails to reach the point of care, and when it does, it is not communicated in meaningful ways. There is too little data on outcomes that matter to patients: their ability to do things they love, their comfort and survival, and their dignity at death. In contrast, the data that clinicians have are primarily related to sickness and medical interventions. Information on individuals' social and economic contexts, beliefs, and values are not systematically captured. Existing data sets, by and large, do not include the social determinants of health such as income, education, living conditions and relevant circumstances such as whether a person is experiencing domestic violence or levels of crime in a community. Population data sets are also often incomplete, with minimal data on children, the elderly, and vulnerable groups. Without data on what matters to patients and populations, policymakers, and care providers will be solving the wrong problems.



Jean-Pierre Kocher



Milica Begovic Radojevic

Resources

Data collection, aggregation, analysis, presentation, dissemination, and use is expensive and time-intensive. It requires technical skills and capacity that are in short supply. Much of the data we have is not used, and the data we should have is not collected. Patients – and their families and communities – remain the largest untapped resource in health care. However, they are not systematically engaged in research or in the creation of data resources and technology tools, nor do they have many outlets through which to share data and knowledge. Innovations are often well advanced before patients' needs and wants are integrated, resulting in uninformed investments in new

practices that perpetuate, or even expand, waste and harm in health care with the associated opportunity cost.

Context

Randomized Control Trials (RCT), the gold standard for medical research, often focus on a relatively narrow segment of the population of interest. These populations that generate the evidence for a particular innovation are often more homogenous than many of those where the innovation is, if supported by the evidence, eventually used. Contextual differences make the more general application of innovations generated by RCTs problematic. Furthermore, because data systems and technologies vary across contexts, the successful replication of proven approaches often requires adaption. Needs and wants of individuals and populations vary across contexts due to historical, cultural, demographic, and environmental factors, among others.

Motivation

Data are being harvested without being fully translated into knowledge and action. Patients are not linked to data sets that could enable positive change from the bottom up. Many innovations have failed to achieve public health goals or translated into value for patients in terms of convenience, price, outcomes, or experience. The public and individual benefits of data sharing have not been clearly defined and communicated, resulting in a lack of collective purpose and of coordinated activity to support the achievement of agreed aims.

“ In a world of infinite demands and finite resources, we need to figure out how we move forward in a sustainable way. ”

Group discussions in the Max Reinhardt Library and Study



“In God I trust.
For everything else,
I need data.”



Mihajli Rabrenovic and Leo Ryan



Per Gunnar Batelson



Kristen Anton



Sander Klous

Trust

Patients and the public often distrust authority and have concerns about the misuse of data and loss of privacy related to data sharing. Health care professionals often worry that they will be held accountable for outcomes beyond their control. Businesses keep and use patient data. Intellectual property is owned by its creators, often for private benefit, and individual concerns over who gets credit for innovations may hinder their use for the public good. Predictive risk models are a form of population screening, the harms of which can exceed the benefits. Technology-based decision tools are often infused with industry and/or provider biases that promote a particular treatment or course of action. Clear policies, regulatory frameworks, and data quality standards are needed.

In general, overcoming these barriers will require coordinated action to balance public and private interests and voluntary divestment from private interests towards the public good. It will require providing alternatives that address the limitations of tax-funded and market-driven health care economies in inclusivity of vulnerable populations and co-production of value with patients, families, and communities. Silos will have to come down or be bridged. The production and consumption paradigm of sick care will have to shift to one based on the promotion of health. While these are lofty and seemingly distant goals, leadership like Florence Nightingale’s and Richard Cabot’s, increased public awareness of the value of health data, and global action for the public good can help get us reach the aspiration vision for health data in the 21st century constructed in Salzburg.

Keith Lindor: “People want health and we sell them health care”

Dean of College of Health Solutions at Arizona State University on why more money should be spent on *health* instead of health care

Keith Lindor firmly believes health care is a poor substitute for health, and by investing too heavily in the former, policymakers are missing the point.

While participating in *The Promise of Data. Will this Bring a Revolution in Health Care?*, the executive vice provost and dean of the College of Health Solutions at Arizona State University told Salzburg Global why the focus should instead be on what matters most: staying well.

“I think that most people want health – they don’t want to be patients, they want to be people,” Lindor said. “If we could do things to let them have health rather than require health care, they would be happier. What happens is people want health and we sell them health care.”

According to Lindor, the statistics show the country spending the most on health care has got its priorities the wrong way round.

“In the United States we spend a lot of money on health care, and yet we have very poor

health. Our health outcomes rank around 30th in the world, and yet our expenditures are 60% higher than the next most free-spending country, so we get very little for the money that we spend.

“We spend about 95% of the dollars on health care and about 5% on health. When we look at the determinants of health, about 10% are health care, so we’re spending a lot of effort on a very short arm of a lever.

“As we look into the future, I think greater investment in the *health* of a population will probably lead to better health of a population. Trying to continuously push on the *health care* end means that our ability to leverage mechanisms to improve the health of a population may continue to be fairly futile.

“I suspect that this would be a ripe topic for future Salzburg Global sessions because I think that other countries clearly do a much better job at investing in health, and hence have better health than we do in the United States.”

In addition to his roles at Arizona State, Lindor is also an international authority on cholestatic liver disease, which, like many chronic conditions, ties into the session topic of how best to use Big Data to improve health outcomes.

He said: “On the one hand, we’re faced with using genomic information or personalized medicine. An example would be molecularly-targeted therapy for liver cell cancer, in which we will typically use genomic information to determine what our potential targets are



Keith Lindor



Lindor gives input during the peer mentoring session

for chemotherapy. So that's one end of the spectrum – very patient-specific and tumor-specific, even mutation-specific within a tumor.

“On the other hand, we're dealt with population health issues that we do an inadequate job of facing. We don't have vaccinations for hepatitis C, a big problem, but we do for hepatitis B.

“However, our application of vaccination programs for hepatitis B is poor, particularly if we look at infants born to mothers with hepatitis B. We don't really do a good job of applying broadly the hepatitis A or B vaccination for patients with chronic liver disease, or even people who are at risk of developing those infections.

“We have to deal with populations in which we can intervene in a much less expensive way, but more broadly, and hopefully save many lives by appropriate interventions in disease prevention.”

While Lindor says he had few clearly defined expectations before the session, he has found grounds for optimism that the work begun by participants at Schloss Leopoldskron will be taken forward.

“I think the biggest surprise is how valuable these sessions have been,” he said. “Part of it was the fluid nature of the program and how effective that was.

“The other part of this which has been so valuable is the diversity of the group. We see people from a variety of different countries, from different professions and vocational backgrounds.

“One of the biggest surprises has been the influence of the younger group that has been here. We have a lot of really bright younger people who think differently about data and the technology that uses it.

“I think that's a group that's going to really have to pave the way for what we do in the future.”

Getting from Here to There

Solutions proposed for realizing the promise of data for health clustered around (1) creating greater opportunities for patients to take care of themselves and manage their health and health care; (2) equalizing the distribution of power in current health care systems through more evenly distributed access to usable information; (3) making information more relevant, meaningful, and empowering to patients, their families, and communities; and (4) supporting learning and improvement in health systems.

The session culminated in presentations from eight working groups that:

1. Drafted a Salzburg Global Statement on data sharing for the public good;
2. Developed an app for connecting the “iPhone patient” with the “iPad doctor”;
3. Created a strategy for combing Iceland’s clinical, genomic, and genetic data to benefit the country’s population;
4. Developed England’s National Health Service (NHS) and National Information Board’s data strategy for high quality care for all, now and for future generations;
5. Scanned the horizon to conceptualize possible future states;
6. Formulated recommendations for medical education that support a dynamic health care work force;
7. Developed an app for data-driven self-care; and
8. Conceptualized a nonprofit organization to serve as a vehicle for action.

Benjamin Liu, Johan Thor and Tom Woodcock deliver their groups’ solutions for realizing the promise of data for health and health care



The efforts of these working groups each represent a pathway for creating greater understanding and action.

Participants at the Salzburg Global session encouraged policymakers to enact policies and create incentives for data sharing in the public's interests, remove obstructions, and invest in the infrastructure necessary to support data collection, aggregation, analysis, presentation, dissemination and use. Policymakers were also encouraged to protect people against misuse of data, build trust and generate action through articulating the data sharing value proposition to individuals and society, and create an environment conducive to learning and adaptation. Data holders, including industry and private individuals, both in health care and other sectors, were encouraged to contribute their data in the public interest. To then realize the public value, socially and financially sustainable business models for cleaning, structuring, validating, storing, analyzing, and visualizing data for the public good will need to be created. There was strong support for a multi-stakeholder initiative to create and implement new measures and information tools with and for users with feedback loops to policymakers and system leaders to enable informed capacity investment and disinvestment decisions. There was also great interest in forming a global standardization initiative to enable cross-border and cross-sector learning and action.

All participants committed to bringing the insights generated at the session back to work in their own contexts, sharing their knowledge with a wider audience, and working across contexts to realize the promise of data for individual and population health.

Fellows of the session
The Promise of Data: Will This Bring a Revolution in Health Care?





1. Fellows gather for working groups in the Max Reinhardt Library

2. Bertalan Mesko demonstrates one of the many gadgets he uses to monitor his health

3. Yael Harris demonstrates a mobile health data app to Christoph Hamelmann, Lucy Savitz, Rebecca Emeny and Veronique Roger

4. William Riley and Salzburg Global Intern Stuart Milne

5. John Lotherington, Sofia Ernestam and Jens Deerberg-Wittram

6. Rapporteur Merritt Patridge

7. Tom Woodcock

Hamish Tomlinson & Yan Yu: How can we teach students about the huge opportunity Big Data holds to improve the health care of patients?

Rhodes Scholars share their ambition to reform health care in their own countries and change the way future doctors study medicine

Hamish Tomlinson and Yan Yu come from different professional backgrounds, but both are passionate about health care reform. As two of the seven Rhodes Scholars who attended *The Promise of Data: Will this Bring a Revolution in Health Care?*, they spoke to Salzburg Global about their respective work and their vision for the future of health care and medical education.

Tomlinson earned his Bachelor's degree in mechanical engineering from the University of Canterbury in his native New Zealand, and is currently studying for his PhD at the Institute of Biomedical Engineering at Oxford University, where his research group measure biomedical signals from patients in the intensive care unit.

He said: "What we do when we create predictive analytics with those [biomedical signals] is try to answer questions such as, 'If we have this continuous stream of information about the human body and illness, can we use that to try and predict whether they will get a certain complication, where they might next go in the hospital or whether they might live or die?'

"We're collecting so much data at the moment, and with machine learning you can almost teach models to make decisions without implicitly telling them what decisions to do. Netflix will do that – they'll have a look at all your preferences, what you've done in the past, and then use some complex models based on what other people who have watched the same things as you have done to try and predict

what you might like, and use that as a basis for advertising."

Yan Yu, a Canadian medical doctor, is now pursuing a Master's degree in Public Policy at Oxford, and already has clear ideas about what health care policy reforms he would like to see in his own country.

"Canada is the only developed nation in the world that has a government-funded health care system but does not have government-funded universal pharma care," he said.

"Many experts in Canada agree that if we're able to have the government bulk-buy medications and fund the provision of medications, that will not only improve patient access to necessary medications but also reduce medication costs to the health care system as a whole."

While Yu harbors an ambition to teach medicine later in his career, he has already had a major impact on the way medical students learn.

In his first year of medical school at the University of Calgary, he was part of a group of students who worked with their faculty and the IT department to develop the Calgary Guide to Understanding Disease, a series of freely accessible flow charts that explain the signs and symptoms of diseases in a step-by-step manner.

The guide has been used in over 100 countries and downloaded more than 200,000 times.

“We’re quite astonished that it’s making such a large impact,” Yu said. “I think that speaks to the need in medical education right now. Students need timesaving tools to help them learn in a quick, accurate and effective way that relies on not just memorization but true understanding of the pathophysiology behind disease.”

During the session the pair collaborated in the working group dedicated to medical education, which Tomlinson says gave him an opportunity to spread the medical innovations discussed at Schloss Leopoldskron back to New Zealand.

He said: “My sister’s a medical student, my parents are doctors, and I can’t help but think: ‘They don’t know about this stuff.’ That is going to be a massive rate-limiting step in the uptake of many of these tools.

“I would like to make sure the tools get used, and part of that is thinking about how we can educate the medical workforce, in terms of

doctors, nurses and all other people who are stakeholders in medicine and health care. Also the future of the workforce – medical students – how can we teach them about how Big Data is a huge opportunity to improve the health care of patients? So it’s been really interesting to discuss that and come up with some ideas as to how we might best achieve that with some great people who have some experience in education like Yan.”

Yu is convinced the group of seven Rhodes Scholars are well positioned to continue their work upon their return to Oxford.

He said; “I think we’re going to leave here with an enriched understanding of the role of Big Data in health care. Because we’re all coming from different backgrounds we’re going to be able to take our new found knowledge into our respective fields and then re-congregate for further in-depth conversations about these topics in the future. The ideas can only expand from there.”

To read more about the Salzburg Global Scholarship Program for Rhodes Scholars, please visit: www.SalzburgGlobal.org/go/Fellows/Rhodes



Tomlinson and Yu (left) with fellow Rhodes Scholars Alice Wang, Kate Niehaus, Kit Dobyngs, Benjamine Liu and Michael Mackley

Amel Farrag: “I thank Salzburg Global Seminar for giving me this chance to learn from these expert people”

Egyptian Health Ministry consultant shares how contacts made at Schloss Leopoldskron have influenced her work

Amel Farrag is very happy to be back at Schloss Leopoldskron, just over a year after attending her first session in the multi-year series *Health and Health Care Innovation*.

While participating in *The Promise of Data: Will this Bring a Revolution in Health Care?*, she spoke to Salzburg Global about how her time in Austria has shaped her work as a quality consultant for the Ministry of Health and Population in Egypt.

She has fond memories of her first visit to Salzburg in December 2013 for *The Drive for Universal Health Coverage: Health Care Delivery Science and the Right to High-Value Health Care*.

“It was a very interesting experience,” she told Salzburg Global. “I learned a lot from my colleagues about universal health coverage.

“I discovered the work the World Bank and Salzburg Global Seminar are doing to bring all countries together sharing information, knowledge and experience of how to develop universal health coverage, especially in lower- and middle-income countries.”

The contacts made at Schloss Leopoldskron laid the groundwork for the formation of Egypt’s first national task force for governance, on which Farrag serves alongside the three other Egyptian Salzburg Global Fellows who attended the session.

She said: “The idea started at Salzburg Global Seminar with the Egyptian team and the World Bank, and we talked to our minister who developed this task force. We have developed a patients’ bill of rights and discussed many other subjects.”



Farrag with fellow Egyptian participants and Marilou Bradley (center) at the December 2013 session on universal health care



Amel Farrag

While Farrag credits Salzburg Global faculty member, World Bank Senior Operations Officer Marilou Bradley for mentoring her work since she returned home from Salzburg in December 2013, she has continued to build a valuable network among the participants of Salzburg Global’s Big Data session.

“I work to develop quality in Egypt, and I have met many experts [in Salzburg] who can help me,” she explains. “I have a design in my mind, and they are helping me to improve my design to create a new quality department. I hope to carry it out when I go back to Egypt.

“We collect data and analyze it to develop new protocols for health care delivery in Egypt. We analyze the results after implementing these protocols, and we can use these results for continuous improvement.”

Farrag says this improvement is necessary given the challenges surrounding health care in her country. “In Egypt we are still some distance away from quality, from understanding how health care delivery science can be developed. We are facing many problems, like funding,” she says.

“We have many hospitals and primary care centers suffering from a shortage of doctors and nurses. We need to improve their skills and practices to improve health care outcomes in Egypt.”

“This session is very, very interesting,” she said. “I’m so fascinated by the knowledge and experience I can learn and share with all these experts in data management and quality, in health care delivery. I have learned a lot and I thank Salzburg Global Seminar for giving me this chance to learn from these expert people.”



Farrag with other participants during the March 2015 program

Appendix I

Chair

Veronique Roger
Medical Director, Center for the Science of Health, Mayo Clinic, Rochester, MN, USA

Faculty

Keith Lindor
Executive Vice Provost and Dean, College of Health Solutions, Arizona State University, Phoenix, AZ, USA

Albert G. Mulley, Jr.
Director, Dartmouth Center for Health Care Delivery Science, Hanover, NH, USA

Jörgen Nordenström
Professor of Surgery, Karolinska University Hospital, Solna, Stockholm, Sweden

Guest

Lecturers

Agnes Binagwaho
Minister of Health, Kigali, Rwanda

Bertalan Mesko
Medical Futurist, Budapest, Hungary

Rapporteur

Merritt Patridge
Director for Strategy and Operations, Dartmouth Center for Health Care Delivery Science, Hanover, NH, USA

Participants (positions correct at time of session – March 2015)

Megan Anderson Brooks
Global Health Living Foundation, Washington, DC, USA

Kristen Anton
Director, Geisel School of Medicine at Dartmouth College, Lebanon, NH, USA

Andrew Bate
Senior Director, Analytics Group Lead, Pfizer Ltd., Tadworth, UK

Per Bätelson,
Founder, Global Health Partners AB, Göteborg, Sweden

Milica Begovic Radojevic
Knowledge & Innovation Specialist, United Nations Development Programme, Istanbul, Turkey (Montenegro)

Ruth Bell
Senior Advisor, University College London, London, UK

Gaetano Brianese,
Psychiatric Nurse, San Carlo Borromeo Hospital, Milan, Italy

Felix Chang,
Chief Strategy Officer, DecisionQ, Arlington, VA, USA

Desiree Daniega,
Department Head of Health Service, Mapua Institute of Technology, Manila, Philippines

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Associate Professor of Biomedical Data Science, Dartmouth Institute for Health Policy and Clinical Practice, Hanover, NH, USA (India)

Jens Deerberg-Wittram
Executive Board Member, International Consortium for Health Outcomes Measurement (ICHOM), Cambridge, MA, USA (Germany)

Kit Dobyns
Rhodes Scholar, University of Oxford, Oxford, UK (USA)

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Sofia Ernestam
Senior Consultant and Researcher, Department of Rheumatology, Karolinska Hospital, Stockholm, Sweden

Amel Farrag Hammad
Quality Improvement Consultant, Ministry of Health and Population, Cairo, Egypt

Elliott Fisher
Director, Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH, USA

Fong Ho-ching
Senior Medical & Health Officer, Electronic Health Record Management Team, Department of Health, Hong Kong, Hong Kong SAR

Christoph Hamelmann
Regional Team Leader, United Nations Development Programme, Istanbul, Turkey (Germany)

Anna Hanchar
Senior Consultant, Narrate/Cognitive Edge Consulting, Bedford, UK (Belarus)

Shahid Hanif
eHealth Data Development Manager, Association of the British Pharmaceutical Industry, London, UK

Yael Harris
Senior Health Researcher, Mathematica Policy Research, Washington, DC, USA

Harri Honko
Researcher & Project Manager, Personal Health Informatics Group, Tampere University of Technology, Tampere, Finland

Ivan Ivanovic
Head of Department of Informatics & Biostatistics, Institute of Public Health of Serbia, Belgrade, Serbia

Birgir Jakobsson
Surgeon General and Chief, Icelandic Directorate of Health, Reykjavik, Iceland

Sander Klous
Head of Technology, KPMG Global Leadership Team on Data & Analytics, Amsterdam, The Netherlands

Jean-Pierre Kocher,
Director, Bioinformatics Program, Mayo Clinic, Rochester, MN, USA

Navjoyt Ladher
Clinical Editor, The British Medical Journal (BMJ), London, UK

Mark Leenay
Chief Medical Officer, Optum International, London, UK (USA)

Participants (continued)

Geraint Lewis

Chief Data Officer, NHS
England, London, UK

Benjamin Liu

Computational Biologist; CEO,
Trialspark; Rhodes Scholar,
Oxford University, Oxford, UK
(USA)

Michael Mackley

Rhodes Scholar, Oxford
University, Oxford, UK
(Canada)

Deven McGraw

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Applied Researcher &
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Andrew Muhire

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Kate Niehaus

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Officer, Nerve Lab; Ph.D.
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Alice Wang

Rhodes Scholar, Oxford
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Zealand)

Tom Woodcock

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Observer

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Seminar Coordinator,
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Development Intern

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Communications Intern

Appendix II

Daily Recaps and Audio Interviews

Day 1

Hopes and Fears

www.salzburgglobal.org/topics/article/the-promise-of-data-day-1-hopes-and-fears

Day 2

Customization, Collaboration and Solutions

www.salzburgglobal.org/topics/article/the-promise-of-data-day-2-customization-collaboration-and-solutions

Day 3

Generational Differences, Patient Expertise and Health Equity

www.salzburgglobal.org/topics/article/the-promise-of-data-day-3-generational-differences-patient-expertise-and-health-equity

Day 4

Ownership and Possession of Data

www.salzburgglobal.org/topics/article/the-promise-of-data-day-4-ownership-and-possession-of-data

Day 5

Salzburg Global Fellows Call for Big Data Revolutions in Health Care

www.salzburgglobal.org/topics/article/salzburg-global-fellows-call-for-big-data-revolutions-in-health-care

Elliott Fisher

“How can we use Big Data to improve the value of health care?”

Co-creator of Accountable Care Organizations speaks about the wasteful health care spending in the US and what to do about it
www.salzburgglobal.org/topics/article/elliott-fisher-how-can-we-use-big-data-to-improve-the-value-of-health-care

Bertalan Mesko

Is 3D printing the most disruptive trend for the future of medicine?

Doctor, researcher, medical futurist and self-described geek explains what the future holds for medicine
www.salzburgglobal.org/topics/article/bertalan-mesko-is-3d-printing-the-most-disruptive-trend-for-the-future-of-medicine

Albert G. Mulley, Jr.

“I have found Salzburg to be a wonderful place to cross contexts and borders”

Health program veteran discusses patient-centeredness and why he keeps coming back to Salzburg
www.salzburgglobal.org/topics/article/al-mulley-i-have-found-salzburg-to-be-a-wonderful-place-to-cross-contexts-and-borders

Veronique Roger

“The highlights are the desire, passion and commitment to action that came out of this week”

The Promise of Data session chair on how the week unfolded, the Fellows’ action plans and taking their work forward
www.salzburgglobal.org/topics/article/veronique-roger-the-highlights-are-the-desire-passion-and-commitment-to-action-that-came-out-of-t

Session Agenda

Day 1

15:30 – Welcome

Stephen Salyer

President and CEO, Salzburg Global Seminar, USA

Clare Shine

Vice President & Chief Program Officer, Salzburg Global Seminar, Austria

Véronique Roger, Session Chair

Director, the Mayo Clinic Center for the Science of Healthcare Delivery, USA

Albert G. Mulley Jr

Director, the Dartmouth Center for Health Care Delivery Science, USA

Jörgen Nordenström

Karolinska Institutet and University Hospital Solna, Sweden

15:50 – Introductions of Participants

17:30 – Opening Remarks

Véronique Roger, Session Chair

Director, the Mayo Clinic Center for the Science of Healthcare Delivery, USA in conversation with

John Lotherington

Program Director, Salzburg Global Seminar, UK

18:30 – Tour of the Schloss

19:30 – Dinner

Day 2

09:00 – Customized, Personalized Health Care

In what ways might health and health care benefit from the enhanced availability and management of data?

In particular, how well based are current claims for Big Data, and what tangible benefits are already on the horizon?

Jens Deerberg-Wittram

Executive Board, ICHOM (International Consortium for Health Outcomes Measurement)

Sofia Ernestam

Karolinska Institutet

11:00 – Guide to the Future of Medicine

Bertalan Mesko

Medical Futurist at medicalfuturist.com

12:30 – Lunch

14:00 – Population Health

Andrew Bate

Senior Director, Analytics Team Lead, Pfizer Inc.

Elliott Fisher

Director, the Dartmouth Institute

Mark Leenay MD

Chief Medical Officer, SVP; Optum International

Darren Toh

Department of Population Medicine at Harvard Medical School and Harvard Pilgrim Health Care Institute

16:30 – Session 4

How can we ensure that enhanced knowledge derived from the data we command is translated rapidly and effectively into practice?

Geraint Lewis

Chief Data Officer, NHS England

Jörgen Nordenström

Professor of Surgery, Karolinska Institutet, Stockholm

Lucy Savitz

Director of Research and Education for the Institute for Health Care Delivery Research, Intermountain Healthcare
Discussant:

Amar Das

Director, Division of Biomedical Informatics, Geisel School of Medicine at Dartmouth

19:00 – Dinner

Day 3

09:30 – Session 5

How will we ensure that translation into practice accords with the true needs and preferences of patients, and not just providers?

Sara Riggare

Founder, Chief Patient Officer at Nerve Lab

Nilay Shah

Scientific Director, Optum Labs collaboration, Mayo Clinic Center for the Science of Health Care Delivery

Discussant:

Albert G. Mulley Jr

Director, the Dartmouth Center for Health Care Delivery Science

11:30 – Using data to drive equity in health and health care

Ruth Bell

Institute of Health Equity, University College London

The Hon. Agnes Binagwaho

Minister of Health, Rwanda

13:00 – Lunch

Free Afternoon: Optional walk into Salzburg and Concert at Mozart’s Birth-house

19:00 – Dinner

20:30 – Open Space Knowledge Exchange / Case Clinics

Participants and Faculty post questions or discussions they want to have with others. People self organize into small groups around the topics they are most interested in.

Day 4

09:00 – Review

09:15 – Knowledge Café

Knowledge café with 6 stations offering specific expertise in enhancing behavioral and mental health care systems: Participants move every 30 minutes among stations. Each table has a facilitator, drawn from among the participants, who gives a brief introduction to the topic, leads the discussion, and records major points for posters.

11:15 – Session 7

Who owns data – and does it matter? How do we strike the balance between the public and private good? What are the implications for privacy and its protection?

Deven McGraw

Partner, healthcare practice, Manatt, Phelps & Phillips, LLP

Elliott Fisher

Director, the Dartmouth Institute

12:45 – Lunch

14:00 – Skype Call

with **The Hon. Agnes Binagwaho**

followed by Working Groups

To define core issues/questions they will need to address and their possible audiences: such as providers; clinicians; patients; corporations; researchers

19:00 – Dinner

Day 5

09:00 – Review

09:15 – Peer Coaching

14:00 – Plenary Presentations of Action Plans

17:00 – Taking the Work Forward

17:30 – Close

18:30 – Reception

19:00 – Concert

20:00 – Farewell Banquet Dinner

Day 6

Participant Departures

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