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Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship

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If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post while you're here this week, please let Salzburg Global Editor Louise Hallman know or email your submission directly to lhallman@salzburgglobal.org.

If you do intend to write for your own organization either while you're here 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, do not hesitate to contact Louise.

We'll be updating our website with summaries of the panels and interviews with our Fellows, all of which you can find on the session page:

www.SalzburgGlobal.org/go/553

You can also join in the conversation on Twitter with the hashtag #SGSHealth and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-553

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. If you require non-watermarked images for your own publication, please let Louise know.

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag #SGSHealth, and we might feature your photos in the newsletter!



@MariaHagglund Lunch dessert on the schloss balcony. #academiclife



Participants break off into smaller groups for further discussion about the issues at hand

Transparency and medical records

Oscar Tollast

In 1998 at Salzburg Global Seminar, the fictional land of "PeoplePower" was founded. Its creators designed a health system built "through the patients' eyes." Central to the patient-clinician relationship proposed was an Internet-based patient record, one which was more accessible, easier to edit, track and correct.

Building on this work, a new cross-sectoral mix of health professionals, patient advocates, and clinicians have arrived at Schloss Leopoldskron for the session *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship*.

The session, supported by OpenNotes, is inviting participants to create new approaches to developing and recording a patient's journey through health and illness.

On the opening day of the session, co-chair Dr. Tom Delbanco, called for ideas which could be implemented quickly, likening it to an "avalanche." His co-chair, Professor Tobias Esch, said he was keen for participants to focus on the patients' perspective, and the relationships they have with health professionals.

Later that afternoon, Dr. Delbanco was interviewed by Salzburg Global Program Director John Lotherington about health care in a land called PeoplePower. During

this segment, Dr. Delbanco suggested patients were afraid of retribution if they challenged what their doctors told them. He also said shared decision-making, and patient power was a concept more talked about than put into action.

The following morning, participants learned about the origins of OpenNotes. This talk featured as part of a broader discussion on transparency and what difference it might make in health care systems.

Jan Walker, co-founder of OpenNotes, revealed the organization was established following a successful study. Despite doctors' concerns of having an increased workload, the 12-month experiment which followed proved to be an overwhelming success.

After 12 months, doctors barely noticed the notes had become accessible. Those who took part then completed a survey. Of those who responded, 99 percent said they would like the experiment to continue. At the end of the study, not one doctor signed off.

Patients felt they understood how to take better care of themselves. The study also found those people with the lowest literacy levels appreciated having accessible notes the most.

The initial study took place in three institutions. All three voted to keep the OpenNotes system in place.

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Dr. Tom Delbanco: The benefits of sharing medical details with a patient will outweigh the risks

Session co-chair discusses electronic medical records and his hopes for the session

Andrea Abellan

After hearing the enthusiasm with which Tom Delbanco talks about his life in medicine, nobody would say he could have done anything else other than work in that field. Surprisingly, at college, he was studying to be a political scientist, before eventually changing his career plan. Dr. Delbanco has led three previous sessions at Salzburg Global Seminar. He says this is the perfect place for someone like him, with “the generalist disease,” as it always helps to have his curiosity piqued here. *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship* is his fourth session and, in contrast to what happened on previous occasions, this time he hopes to act more as an observer rather than as a leader of the discussions.

OpenNotes is one of his most acknowledged achievements. He has led the organization together with Jan Walker since its creation in 2010. Dr. Delbanco recognizes the impact that his participation at the Salzburg Global Session, *Through the Patient’s Eyes: Collaboration between Patients and Health Care Professionals*, has had on him: serving as an inspiration to develop the digital platform. Discussions about the mythic nation of PeoplePower gave him the basics of what a patient-centered system should look like. He shared the outcomes of that meeting on a paper which has been circulated among the current group of participants at Schloss Leopoldskron. This paper is entitled *Healthcare in a land called PeoplePower: nothing about me without me*. Looking at the improvements in health technology 19 years later it seems that PeoplePower was more than a utopian proposal.

The book *Asylums: Essays on the Condition of the Social Situation of Mental Patients and Other Inmates*, written by sociologist Erving Goffman, has also played a key role in the development of Dr. Delbanco’s ideas. The book describes mental hospitals, concentration camps, and prisons, as “total institutions,” places where two groups of people are forced to live together. One of the groups is in charge of taking care of the other that certainly does not want to be there. Unhappily, the two groups tend to



Dr. Tom Delbanco (left) takes part in a discussion with Salzburg Global Program Director John Lotherington (right) on the origins of PeoplePower, prior to a Q&A

form separate societies, with an invisible wall between them. In reading this book, Dr. Delbanco started to reflect on “the invisible walls that also divides patients and health care workers,” a phenomenon he has experienced from both angles. Dr. Delbanco served as the founding Chief of the Division of General Medicine and Primary Care at Beth Israel Deaconess Medical Center in Boston for 30 years, and during this time he could see “how the medical staff interacted with each other while ignoring patients.” When he was a patient himself he could understand the situation better and realize the urgency of “breaking the walls down,” he says.

Dr. Delbanco shows his positivity regarding the future of electronic medical records. But he recognizes a backlash towards them coming from some health professionals. “Doctors may say they hate them, but at the same time they panic if you ask what would happen if we would stop using them.” Dr. Delbanco trains his students on the use of digital platforms, even if for him the best teachers are still patients: “It’s equally important to have patients able to correct the notes a doctor has written about them.” He is an advocate of transparency, but he still recognizes the negative impact that sharing all the details with a patient can have. Overall, he thinks “the benefits will outweigh the risks.”

When asked about where the US medical system is going now, with everyone now

focused on the political situation in the country, Dr. Delbanco answers from a very medical perspective. “It’s very easy to make a diagnosis, but hard to come up with the treatment.” For him, the main concern is still how to subsidize the health system and assist the 20 million citizens who are still not covered. Overall, he expects that the government will have a difficult time undoing past achievements.

Dr. Delbanco talks about himself as a person who finds it very difficult to slow down and as someone who likes “solving problems fixing things that do not work.” In fact, now that OpenNotes is working efficiently, with more than 12 million patients registered in its database, Dr. Delbanco has decided to get involved in a new project. OurNotes is his next plan, in partnership again with Jan Walker, who describes the project as “going from passive reading patients to active writing ones.” The idea is to have patients co-produce the records by writing their own medical history and stating their own priorities.

Dr. Delbanco expects to leave Salzburg feeling surprised as has happened in every past occasion. He wants to go home thinking “Why hadn’t I thought about these ideas before?!” He also wants to keep this session alive after it ends on Wednesday.

“I believe that new media and social media platforms are changing a lot and can help us with this purpose,” Dr. Delbanco concludes.



Continued from page one

Participants learned OpenNotes has grown exponentially. Its mission is to get adopted across the US and become the standard of care. The study, which concerned 20,000 patients, started in 2010. The paper was published in 2012, and OpenNotes' patient database passed 12 million people a month ago.

The question whether a patient could potentially erase or edit medical notes was described as a "central issue" which would be discussed during the week.

Transparency: the final blow to medical professionalism

On Saturday afternoon, participants were asked to consider in greater detail the pros and cons of full transparency in health care systems.

To spark debate among the crowd, a participant representing each side of the argument took to the stage to offer talking points from their side's perspective.

The participant arguing for full transparency in health care said there were several ethical, logical and evidence-based arguments to show transparency is essential to professionalism in medicine.

She argued to make a health care decision, a patient must be well-informed, and information which is deemed essential must be disclosed.

The participant put forward the point that physicians must be honest with their patients to empower them to make decisions about their treatment. She added health care was most effective when patients were active and engaged.

The participant arguing against full transparency in health care played the role of a doctor who said, "I have a body of knowledge [patients] don't have.... I have

to be efficient. I must not frighten them. I must not put them at risk."

The participant against full transparency also put forward the case that a transparent, open notes system could put patients at risk of having their data being hacked.

After each participant had offered their opening arguments, both were given a chance to provide supplementary points.

The participant arguing for full transparency said there were ways to implement transparency which would give clinicians more time.

In response, the participant against full transparency said the arguments of investing now and receiving a pay-off later had all proven to be in vain.

Participants were split into two groups and were asked to consider more arguments for either side. One-half of the room would argue for full transparency, the other half would argue against.

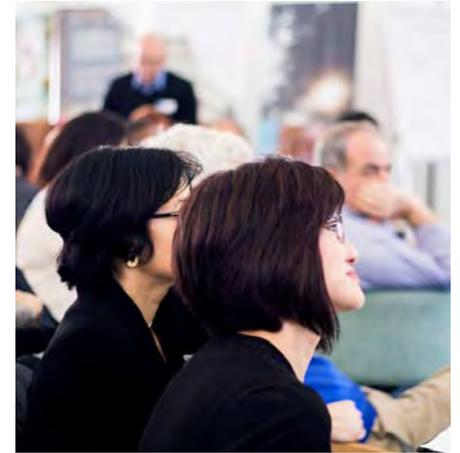
There were contrasting views as to whether transparency could move health care workers toward professionalism. While someone arguing for full transparency suggested it could, another participant said professionalism was earned in a different manner.

There was also a difference of opinion when it came to the matter of accountability. The participant playing the role of the doctor against full transparency said he would be protecting his patients more so than anyone else, as they wouldn't be held accountable for the medical notes.

This argument was countered with the claim that patients had to be accountable for their health, absolving them off that was not good for them or their clinician.

Saturday Highlights

A selection of photos from Saturday's activities, taken by Denise Macalino. These and more will be made available on Facebook and Flickr.



Hot Topic:

“How is transparency exercised between patients and clinicians in your country?”

Denise Macalino

“The basic notion is that transparency is a good thing - but nothing is all good. Some transparency is bad. There are always unforeseen consequences for changes, for culture changes and practice, and we should discuss that... [but] I think the notion of the greater good for the greater number of people is an important one and our experience is that increasing transparency will benefit far more people than it will hurt. And one of the things we feel strongly is it will benefit both patients and their families, and also, those who care for those patients so that it can be a win-win for both.”

Tom Delbanco

Co-chair, Co-founder of OpenNotes, Richard and Florence Koplow - James Tullis Professor of General Medicine and Primary Care at Harvard Medical School, USA

“So all throughout Sweden, there’s a national patient portal, which is virtual... One of the e-services that has been introduced in this national patient portal is that you also have access to your electronic medical records... As a patient, it makes a huge difference to be able to prepare for visits. To be able to see the names of the people you’ve spoken to. If you don’t have a chronic condition, usually you meet different healthcare professionals every time, new physicians, new nurses, etc.”

Maria Hägglund,

Senior Researcher at the Health Informatics Centre at the Karolinska Institutet, Sweden

“In Japan, I think a paternalist [method] is very popular. Most patients don’t want to decide by themselves which is the best way for them, but they want the doctor to decide the best way. The situation is now changing... The younger generation wants to decide for themselves. I think that, in Japan, the health care system has matured, in that, we can get the same level of treatment in every hospital. In this situation, the patients’ need is now changing from how to cure to how to be treated.”

Mark Ichi

Program Director at NHK, Japan

“In India, basically, we have a lot of access to the information pertaining to patients’ lab reports. We don’t have any culture of clinician notes, so we only have lab reports and the prescriptions. Even if we make access to those reports and prescriptions, the issues arise from the understanding of the patient regarding those reports. Though they might have access to those reports, their literacy level is not so high, that everybody will be able to understand what is written in them. There needs to be an accurate level of gaging what’s the level of understanding of a patient. So it might be more relevant to say that patients should also be educated about what are the conditions, rather than just giving access to information... Transparency is just another tool to actually ensure the information reaches the other body. But the understanding of it will really affect the behavior and how we perceive things.”

Shivangini Kar Dave

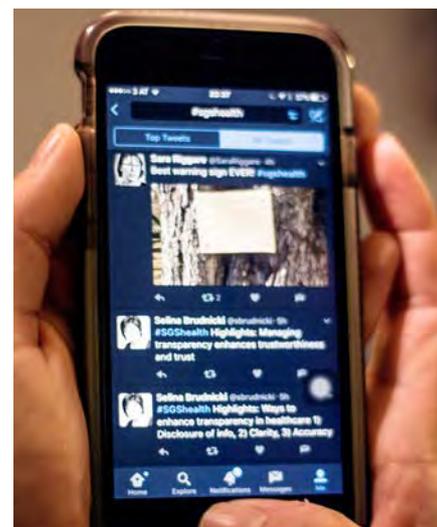
Senior Consultant with the Ministry of Health and Family Welfare, India

“I think we have a pretty conservative system in Switzerland. Transparency really depends on your doctor or on your clinic... A lot of the information that is written down is just stored on the computer of the doctor, or even hand written. The only thing, in Switzerland you really get from your doctor is what he tells you. So I wouldn’t consider it to be transparent... Right now there is the ongoing process of what’s called the Electronic Patient Dossier, which is just the electronic health record, which should be implemented over the next few years in Switzerland. So I guess this is an important step towards transparency... I think what’s needed is initiatives that not only to allow patients to get a copy of their personal data but really help to convey this information in a way that can be understood.”

Manuel Schneider

MIDATA.coop team, Switzerland

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#SGSHealth

Hearing at #sgshealth, in Germany average primary care visit is 6 minutes. [how much trust, let alone info, can be engendered in 6 min]

Harlan Krumholz
@hmkyale



#SGSHealth Clinicians measure what matters to them, patients have their own “metrics” of quality care. Jointly agreed measures make sense.

Tessa Richards
@tessajrichards



Inspired by @myopennotes I wonder how the UK can do the same with so few digital health records... #sgshealth

Jemma Batte
@dr_batte



Tom Delbanco implores us to create an avalanche, we need to create change and do it in a hurry #SGSHealth

Louise Schaper
@louise_schaper



Participant: “Once you recognize people are irrational you are in a better position to help them make decisions.” #sgshealth

Liz Salmi
@TheLizArmy



To view a list of participants at this session with Twitter accounts, please visit: twitter.com/SalzburgGlobal/lists/sgs-553



Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship

Monday, March 13, 2017

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@SaraRiggare Best warning sign EVER!
#sgshealth



Participants and faculty members involved in Session 553 | Toward a Shared Culture of Health

Care in communities and families

Oscar Tollast

*During the session **Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship**, participants have learned knowledge is not enough when it comes to tackling issues and creating pathways forward. A successful patient-clinician relationship is not only built on facts and figures. It should also be based on trust, understanding, and taking into consideration the patient's motivation. These factors take on a further degree of importance when it comes to providing care in the communities and supporting family members.*

In between plenary sessions held on Saturday, participants learned about motivation in health care, and what changes for families, friends, and communities.

Session co-chair Professor Tobias Esch discussed the neuroscience of motivation and self-care.

The word motivation comes from the Latin word "movere" - to move. Building on this, Esch said there were three types of motivation. Type A concerns moving toward something or wanting something. Type B is about avoiding or escaping something. Type C, meanwhile, is about staying and attaching yourself to something.

Type A is associated with pleasure, which you can obtain after passing through stages of creativity and learning. Type B, on the other hand, is linked to a state of relief, which can stem from protection and survival. Type C, simply put, is associated with happiness.

All three types of motivation can be linked with patients at different stages of their lives, according to Esch. He suggested Type A was often found in young people, while Type C involved those aged 65 and over. The majority of people in between these age groups are linked to Type B.

Esch cited research which suggested humans had three basic needs: existence, relatedness, and growth. Existence is a concern for those with a Type B form of motivation, while relatedness is closer to those experiencing Type C. Growth, meanwhile, has a closer match with Type A, as young people look to grow and move toward something.

Insights from behavioral economics
Following this talk from Esch, participants received new insights from behavioral economics and how this could affect decisions made by health care professionals.

To begin with, the speaker discussed the shaky foundations of health policy. These foundations included shared decision making, nutrition and calories labeling,

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Liz Salmi: “I hope to keep growing as a patient with the goal of doing something that will be respected by the whole profession”

Patient advocate discusses her experience blogging and the e-Patients movement

Andrea Abellan

Liz Salmi is attending *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship* as an advocate for patient access to complete medical records.

Salmi was diagnosed with a brain tumor eight years ago. Since then, she has overcome two surgeries and the consequent challenges of being affected by a serious disease.

Through her high participation in digital platforms, Ms. Salmi has become a voice of patients seeking greater access to their own health information. She spoke with Salzburg Global’s Andrea Abellan about her experiences.

AA: With more than 30,000 visits each year your blog, thelizarmy.com is a reference on patient-focused websites. What prompted you to start blogging about your illness?

LS: Before my cancer diagnosis, I was working in Marketing and Communications. When I first ended up in hospital, it came naturally to me to start writing about my situation. Eventually, I had to leave my job for a time to focus on my health, but I still felt that my ability to communicate was my strongest skill.

I started blogging about brain cancer and my health condition immediately became well-known by not only my closest friends and family, but also by people I didn’t know. In time I realized that the information I was sharing could be interesting because the number of comments kept growing. The decision to make my blog open was in hopes others could benefit from the information.

AA: How has your experience of blogging evolved over time?

LS: The topics I have chosen to blog about has changed a lot since I first started posting. In the beginning, as a newly diagnosed person, the blog was mostly focused on the uncertainties of my daily life. The content was very self-centered.

After the treatment, I started to get more interested in other things, such as disease-specific research and public policies. Over time, I became more informed on health technology and on the idea of patients



Patient advocate Liz Salmi speaking during a group session

engaging more with the information in their electronic medical records. I have grown as a patient blogger just as I could have grown in any other professional “career”.

AA: How are you involved in the e-Patients’ movement? What activities do you carry out as part of this group?

LS: There are 40,000 searches made in Google every second, 2,000 of which are related to health issues. The Internet gives people access to information that make it possible for our doctors to be better.

“e-Patient” is a person who is enabled, empowered, engaged in their health care. If you are engaged in your self-care and research about your health, then you might be an e-Patient. For now we need specific terms to describe this kind of active patient participation, but in the future, I hope this will become a standard attitude.

AA: You also co-founded Brain Tumor Social Media (#BTSM), a hashtag community helping to connect people diagnosed with brain tumors. How is this group working?

LS: Twitter has an amazing power to spread information. Health care professionals have realized the potential of

the platform to reach their specific target audience. The use of acronyms as hashtags is making it easier to aggregate patients, caregivers, and care providers in the same conversation.

Charlie Blotner and I were inspired by the online breast cancer social media (#BCSM) community to create something similar for people affected by brain tumors. We host a live tweet chat every first Sunday [of the month] at 6pm PT. These virtual gatherings have become a great opportunity to exchange support and learn about the latest developments in brain tumor research.

AA: What do you expect from your participation in this session?

LS: It is exciting to engage with Fellows who are facing the same challenges around the world. This [session] gives us the opportunity to learn how things are working in different parts of the world.

For years, a complete medical record has been hidden from patients. I think these discussions around transparency and “open access” to information will be a catalyst for increased engagement by patients and lead to satisfaction in healthcare decisions.



Continued from page one pay for performance incentives, informed consent, health care cost or quality transparency, and health insurance deductibles and copayments. These approaches are based on the view that given enough information, people will make decisions most likely to achieve self-interest.

By bypassing cognition, however, the speaker suggested health care professionals could obtain more positive results using behavioral reflexes. He claimed the science of motivation had evolved. Participants heard, “Once you recognize that people are irrational, you are in a better position to help them.” The speaker provided a list of examples of where this irrationality could be used for good. For example, a solution to regret aversion is alerting people to what might have happened.

Discussing life in the US, the speaker remarked upon health insurance choices, which can be presented in a fashion difficult to understand. He said an incentive you cannot understand could not work, and in designing complex incentives, you are giving up some value.

Participants were asked to consider what they heard through the lens of a patient and that of a clinician. One responded, “If you want to change a behavior, the new behavior has to feel as good as the one you change.”

What changes for families, friends, and communities?

On Saturday afternoon, participants were also asked to consider certain scenarios and how they might play out. They broke off into six groups and were given individual topics to develop a presentation around. These topics included chronic condition, elder care, the personal experience of using OpenNotes, the family caregiver, the problem patient and the

problem clinician, end of life care, and sexual health.

In this interactive plenary session, participants considered how private, and secure AI tools similar to Siri could tackle the taboo of discussing sexual health. An idea for an online platform called “Check-in Now” was also put forward, which would allow patients with a chronic condition, their family members, and doctors to have access to data in one place.

Participants heard family caregivers want to be able to communicate with health providers quickly, and should receive more tools and support. One participant said caregivers would like a seat at the table, one as important as the patient’s and the health care professional’s.

Transparency with socially at-risk and culturally diverse patient populations
Participants also looked at transparency with socially at-risk and culturally diverse patient populations. The speaker leading the event talked about the origins of mistrust in medical care found in socially at-risk groups. This mistrust can stem from a legacy of discrimination, disparities in access and quality of care, and disparities in interpersonal treatment.

She said those at risk included ethnic minorities, religious cultural minorities, low-income groups, people with low health literacy, people with disabilities, and people from the LGBTQ community.

The speaker said to enhance transparency there should be a focus on disclosure, clarity, and accuracy. To engage patients, health providers should consider one-on-one coaching, group-based classes, web-based interventions, patient portals, and mobile apps. What’s important to remember, she claimed, is that cultural, social, language and literacy adaptation remains critical in this process.

Sunday Highlights

A selection of photos from Sunday’s activities, taken by Denise Macalino. These and more will be made available on Facebook and Flickr.



Hot Topic: “How will greater patient agency affect health care in your country?”

Denise Macalino

“In many ways, I think nowadays, what I see in Chile, is kind of a division between the patient and the physician. There is a mistrust, I think, from both sides. The new and empowered patient is demanding more attention from the physician. The physicians today just don’t know how to relate to that, how to answer to that. I think that transparency and agency create paths to develop a new relationship, that will result in more efficiency and better care... Today we have a kind of crisis with the relationship between the doctor and the patient. So somehow there has to be a solution for this crisis. And I think that this solution comes from better agency, patient agency, better involvement. Institutions and doctors should change a lot to achieve that.”

Ricardo Zisis

CEO of AméricaEconomía Media Group, Chile

“[Australia Digital Health Agency]’s agreement is to make health information move seamlessly around the country, to support better health outcomes, and giving people a happier and healthier life, and a better deal out of the healthcare services. That is essentially what we’re there to do... I think that patient empowerment is one of the fundamental principles that should underpin an enlightened healthcare system in the modern age. My organization has a role to digitally enable health care services and technology, and make them accessible to people. And in that way, we are empowering people by providing them with access to their own health information. And we know that people who have an understanding of, and better access to their own health information in many different disease models have better health outcomes with those conditions. So it’s really vitally important.”

Meredith Makeham

Chief Medical Advisor for the Australian Digital Health Agency, Australia

“Both before I came here and during the course of our discussions, I think we’re trying to define how to share the roles and responsibilities of patient empowerment

with the clinicians and their teams, and with the patient. An informed patient, a patient who is actively a part of their care giving and a patient who asks active questions, I think, is more engaged in their care. And I think that’s critical. It’s not just the doctor’s and their team’s responsibility. The patient also has a role and responsibility, and the more you know, the more you can play a major role and a positive role in that care. And I think that the discussions we’ve been having really point that out. I mean, I think it’s good.”

Jacqueline Woods

Senior Consultant for Academic Search, Inc., USA

“Medicine has always consisted of three elements of doctors doing something with the patient, and then providing care for the patient. But the third part is what the patient himself or herself can actually add to really resource-oriented, patient-centered medicine. And this part is completely missing, I would, say in the German health care system. We expect from this seminar, and from the idea of patient empowerment and engagement, that this third leg, from the three-legged stool of patients: self-help, self-care, and patient activation is really becoming healthcare again.”

Tobias Esch

Dean for Organizational Development and Professor of Integrative Health Care at Witten/Herdecke University, School of Medicine, Faculty of Health, Germany

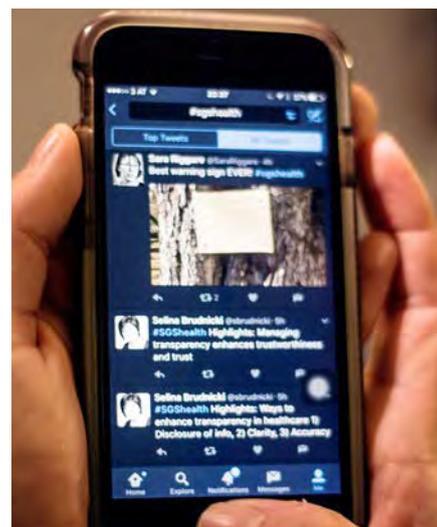
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Have an opinion on any of our hot topics this week?

Email Salzburg Global Seminar Editor
Louise Hallman

(lhallman@salzburgglobal.org)

with either a short 50-100 word response or a 500-750 word article and we will consider it for publication in the report to be published in mid-2017!



#SGShealth

#SGShealth Interesting to know doctor's notes are usually written in prescriptions in India. Wondering why they are not written in Japan.

Maho Isono
@mahoisono



Patients seek a revolution in healthcare. So do clinicians working in its #burnoutshops. Debating how to join forces at #SGSHealth.

Tessa Richards
@tessajrichards



Thought provoking days @SalzburgGlobal #sgshealth so far - we have not designed systems with patients in mind & gaps in how trained as docs

Harpreet S Sood
@hssood



#SGShealth Highlights: We need to look to patients as teachers, co-designers, and innovators

Selina Brudnicki
@sbrudnicki



#SGSHealth Patients can be teachers for other patients, clinicians, and decision makers

Cecilia Rodriguez
@ceciliarod



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Wednesday, March 15, 2017

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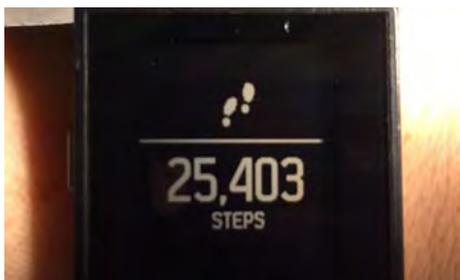
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You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-553

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. If you require non-watermarked images for your own publication, please let Louise know.

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag [#SGSHealth](https://twitter.com/SGSHealth), and we might feature your photos in the newsletter!



@louise_schaper I beat my daily step record at #SGSHealth 🙌👏👏👏



Participants contribute to a discussion during Session 553 | Toward a Shared Culture of Health

Technology in the patients' hands

Oscar Tollast

Developments in technology afford new methods of treatment, new methods of recording data, and new methods to share information with more people than ever before. With that in mind, participants at Salzburg Global's session on *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship*, have been asking themselves how this technology can be better used. Technology can be used to empower patients, physicians and other health professionals. The question is how to make this technology work for all invested parties in the patient-clinician relationship.

In the past few days at Schloss Leopoldskron, participants have considered how patients have recorded their medical data as a form of empowerment, and as a method of seeking positive change through better treatment. They've also heard from speakers who have looked at the relationship between technology and transparency. These talks have been designed to enable fruitful thinking as to how create and enable new ways of recording a patient's journey.

Make health care easy

On Monday morning, participants heard about what could occur if the right tools were placed in the right hands. The speaker

behind the talk outlined the future of health lies in the optimum use of technology for primary health. In his presentation, he promoted the view that a multidisciplinary expertise could enable a comprehensive understanding of the needs of the health care system.

After describing health care as "one of the most stress inducing topics," the speaker highlighted work taking place in India to make the patient treatment workflow better. He cited work taking place at Mohalla Clinics. In between April and December 2016, 110 clinics in Delhi treated 1.5 million people. The clinics are praised for treating minor ailments outside hospitals, which in turn free up doctors to focus on complicated diseases and surgeries. The speaker said these clinics provided a paperless clinic workflow, where the average time for patients end to end hovered around four minutes. Participants heard the clinics were easy to use, accessible, instant, and patients were co-designers of health.

The clinic is an example of a greater push in how the future of primary health care can be reimagined. The speaker suggested there was existing technology in place which could be used to a better advantage. He said, "It's time for us to reformulate the role of the local clinic." Ending his presentation, he outlined four points: make health care easy; share data but have mediators to help

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Anatole Menon-Johansson: “For me electronic records are like black boxes on airplanes, they allow you to manage information”

Fellow discusses empowering women and the use of digital health tools in his work

Andrea Abellan

Dr. Anatole Menon-Johansson’s testimony is clear proof of the successful integration of digital health tools in everyday clinical activities. Menon-Johansson’s professional experience is focused on sexual and reproductive health. He puts his energy in various activities; he is the clinical director for the charity Brook, the lead of the integrated service at Guy’s & St Thomas’ NHS Foundation Trust and the founder of two innovative social enterprises: SXT and SH:24.

Menon-Johansson is a passionate advocate of the possibilities technology offers to assist patients. He decided to start using digital tools a long time ago, starting a decade ago with the use of text messaging results. Through this system he sees patients getting back more promptly to reduce the spread of infections. Text messaging is now a standard practice in sexual health care, but Menon-Johansson was one of its early adopters.

The Sexual Health Clinic he leads in London became completely paper-free four years ago. “We have all data saved in one single platform, which helps us to monitor our activities. For me electronic records are like black boxes on airplanes, they allow you to manage information properly,” he explains. Patients can make online appointments through booking service Zesty. Their time spent in the waiting room is reduced with the digital queues that a software named Qudini enables. Patients can get registered in the reception and then leave if they want to do anything else. A text message will let them know when their time arrives. In the meantime, they can keep their position in the line. “We have digital tools involved in the whole process, since a patient books the service and waits to be seen until they get their results back by an SMS,” the doctor states.

The platform SXT.org.uk that Menon-Johansson designed, helps users to find the right service when they need to get tested for sexually transmitted infections, and if they need advice for abortion or sexual violence support. Another interesting adaptation of the platform is the partner notification through which users can anonymously inform their sexual partners about a diagnosis. The sexual partners are



advised on the best options to be tested. Another website he has helped to design, SH24.org.uk is focused on providing free testing for sexually transmitted infections (STIs). Its functionality is easy to navigate and oriented to preserve the confidentiality of users who receive the test and the results within 72 hours.

Menon-Johansson presented his web-based emergency contraception calculator during the Salzburg Global session *Toward a Shared Culture of Health: Enriching and Charting the Patient-Clinician Relationship*. He says, “In the UK we have 186,000 abortions every year. We expect about 400,000 births, but we end up with 700,000. These numbers show the real disconnection between what women want and what actually happens to them.”

Thus, Menon-Johansson explains, it is important to keep raising awareness of contraception methods. He supports the use of the Intrauterine Device (IUD) with copper as one of the methods offering better results. Menon-Johansson argues, “Research proves that it’s more reliable than any other emergency contraception method. I want to make sure that women understand that there are good alternative solutions they can benefit from.”

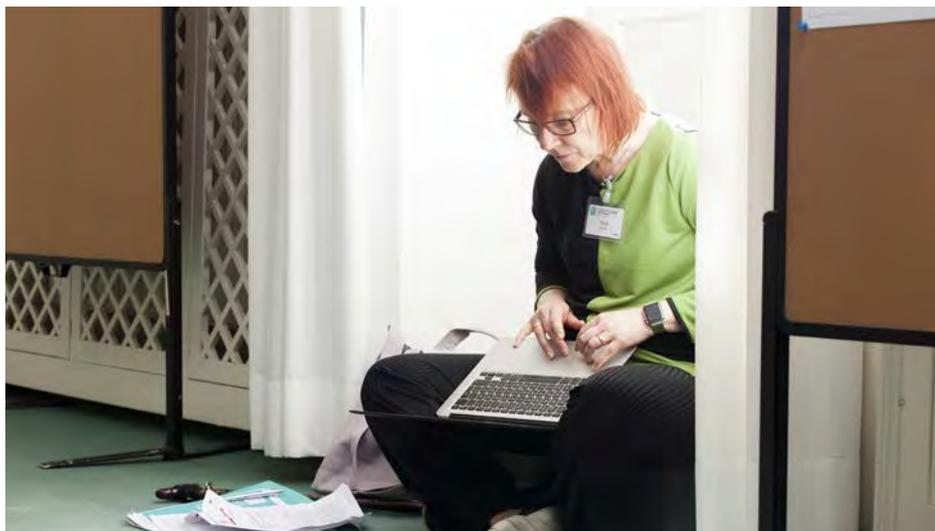
The calculator service has a positive effect on the doctor-patient relationship too. It helps women analyze the data they have stored on their phones so they can have an idea of their risk of pregnancy and of the options they have. Menon-Johansson says, “I have real troubles when this information is not given to a woman before she meets the specialist because then she can feel

under pressure to follow the doctor’s instructions and that goes against their autonomy.”

The calculator was well received by the Fellows, who provided Menon-Johansson with useful advice. Most of the suggestions were oriented toward a better promotion of the platform. Participants proposed to include advertisements in social media channels, games or dating apps seeking to reach young women who might be those facing a bigger risk. Menon-Johansson explains that one of the biggest challenges he finds when developing health care technology is convincing a still very conservative audience. He says, “I have already proved that the system I’m using works, now I want to show its potential to amplify the quality of the health care system and to support clinicians in their work.”

The calculator is currently only available in the UK, but Menon-Johansson expects this will change soon. In May, he is attending the Health 2.0 Europe conference which will take place in Barcelona and hopes this event will open the doors to the Spanish market.

Menon-Johansson says he is leaving Salzburg Global feeling richer in knowledge and is looking forward to implementing many of the suggestions fellow participants have given to him. He says, “I have enjoyed the way the seminar has evolved from exposing problems to looking for solutions. It’s always important to reflect about how to implement good ideas that can make real things happen.”



Continued from page 1

patients understand it; get data automatically; and address human needs through community contact, as well as personal contact.

In response to this presentation, one participant outlined activities which were already in practice in the US. In one area, something similar to DNA biobanking is taking place except the data being used is people's past and present social media posts. Around 5,000 patients have agreed to this, which allows them to "passively" contribute to their medical records just by going about their day-to-day lives. The participant said that because personal behaviors are digital and more accessible, patient engagement now means something entirely different.

Good over evil

This talk was followed by a presentation on learning from patients. Prior to starting, the speaker said the theme of the conference was "good over evil." He highlighted presentations participants had heard from on Sunday to highlight the role of the patient. The end game is improving the way people work together, respect and honor, and the use of technology. As much as people want a good relationship with their clinician, the speaker said they would also like effective treatment and to be in a better situation.

The speaker referred to the "kingdom of research," a land where "subjects" exist under the rule of a sovereign (researcher). In scenarios like this, the subject often doesn't receive results, doesn't feel part of the team, and doesn't receive thanks. The speaker said he didn't like using the word "patient." Rather than learning from patients, he said he prefers learning *with people*, suggesting each party brings something new to the table to be

considered. While citing related research, the speaker suggested patients should be seen as partners to achieve better results, not just participants. He later elaborated on this, suggesting nothing should be hidden behind people's backs. Participants heard legislation in the US allows people the right to information but there is a need for tools to make that information more accessible. He advocated for technology in medicine to be highly "permission-based."

This presentation drew several responses. Participants said most people were happy to give over their data, but the challenge was to inform people.

Let health care help patients help themselves

On Sunday, participants learned about one participant with Parkinson's disease. She explained how she increased "feel-well time" as a result of self-tracking.

The patient used this data to see progress or changes, rather than relying on one hour a year with a doctor. The data collected led to a change in her prescribed medication. She called for health care to help patients help themselves, and proposed the idea of a "lead patient," who patients are encouraged to become.

In the presentation which followed, the speaker spoke about herself and her son dealing with separate illnesses. She shared how health care quantifies both her and her son, tracking changes over years, and medications needed.

She suggested many doctors tend to attribute symptoms to generalized demographics, rather than treat cases individually. As a carer of her son, she was treated as an enemy, not an ally.

She said patients can help other patients through peer support, and this form of support can actually give more help and strength than what doctors provide.

Monday Highlights

A selection of photos from Monday's activities, taken by Denise Macalino. These and more will be made available on Facebook and Flickr.



Hot Topic: “What are the advantages in integrating new technology into health care?”

Denise Macalino

“I think this is a very important issue, and I think there are many lines that can be developed. And those lines are not necessarily integrated. On the one hand, from a user or patient perspective, technologies allow users to develop stronger solidarity among them. And better forms of communication, to actually give advice, to actually do self-help, but also to move beyond that and develop forms of advocacy work, and to request better treatment. In the user world, technologies have a very specific meaning while, in the medical world, what we see is an imperative to be more efficient, to create more value out of interventions. I think those are kind of two different paths, and I think we need to think of them [as] one.”

Cristian Montenegro

Sociologist pursuing doctoral studies at the London School of Economics' Department of Methodology, UK/Chile

“As part of being here in Salzburg and actually seeing what other individuals, and other organizations, and countries have done, it's really opened my eyes in terms of what might be possible. People have advanced, and especially in health care, [with] tools that have been built from the other countries, in helping people manage their health and prevent certain diseases or conditions – or even speed up the process of patient's getting care. So that's how I see the technology helping patients, and the process, and speeding it up... I think when people think about technology, they're scared, and it's sometimes very complicated and it's trying to explain that in simple words. I think fear is sometimes our greatest enemy. It's the unknown that makes us not want to change or not want to move forward.”

Selina Brudnicki

Program Lead for myUHN Patient Portal at the University Health Network in Toronto, Canada

“I think that it's hard for me to imagine a future of health without technology integrated into it. We are being a lot less experimental, a lot less adventurous with

technology. I think that there's a lot of historical reasons for it. But I feel that technology that is actually driven by the health care system, can actually be really, really good. What's happened up until now is that the health care technologies have had a little bit of a step-brotherly treatment. The health care system doesn't really own them, it buys them. I'm a really big fan of [asking] what if the health care system reimaged and reinterpreted technology? [What] would it mean if they were doing it themselves? So I think that there's a lot of scope for doing that, and there are ways to encourage the DIY movement in health care – by that I mean the health care systems actually developing some of the [technology]. That would be, I think, a major revolution. That also applies to patients. Patient-driven technology, technology designed by patients and patient groups, would be fascinatingly applicable and revolutionary for the health care system. So I'm very excited about that.”

Kanav Kahol

Independent Consultant, India

“The advantages are that it allows patients to access their records and understand their health much better. And they can manage their health conditions much more effectively than in the five minutes they get with a doctor. The advantages for clinicians are that it makes our jobs easier, right? It makes it more efficient to do prescribing using digital technologies to write our letters to each other, to make referrals between health care professionals. It makes our lives easier, and it makes it easier for patients to manage their health conditions.”

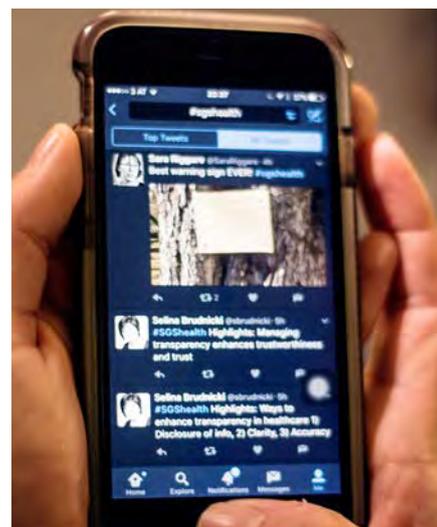
Jemma Batte

Clinical Fellow to Bupa's National Medical Director, UK

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this week?

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Louise Hallman
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#SGShealth In healthcare decisions clinicians are confronted by more ignorance than knowledge.

Tessa Richards
@tessajrichards



Should @myopennotes be a vital part of the nation's #patientsafety initiatives. Transparency = potent intervention. Why not? #SGShealth

Harlan Krumholz
@hmkyale



50 great thinkers and doers come up with over 130 ideas for action. Let's get started! #SGShealth

Louise Schaper
@louise_schaper



#SGShealth An immense amount of valuable information in 2 Knowledge cafes. Appreciation for all the coordinators.

Maho Isono
@mahoisono



Impressed w/ work in India at community clinics. Avg end to end care is 4 min 18 sec. Includes diagnostic tests & instant results #SGShealth

Selina Brudnicki
@sbrudnicki



To view a list of participants at this session with Twitter accounts, please visit: twitter.com/SalzburgGlobal/lists/sgs-553