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

Sunday, March 12, 2017

## Write! Tweet! Post!

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](mailto: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](http://www.SalzburgGlobal.org/go/553)

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](https://twitter.com/salzburgglobal/lists/SGS-553)

We're updating both our Facebook page [www.facebook.com/SalzburgGlobal](https://www.facebook.com/SalzburgGlobal) and our Flickr stream [www.flickr.com/SalzburgGlobal](https://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](https://www.instagram.com/SalzburgGlobal). Use the hashtag [#SGSHealth](https://twitter.com/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.





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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.

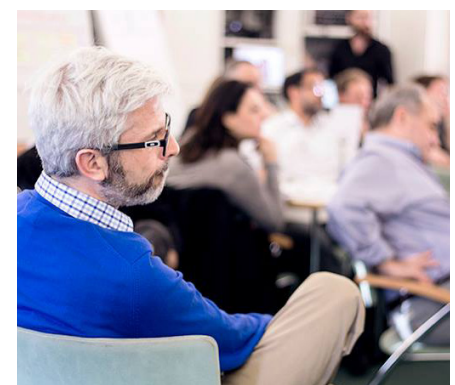
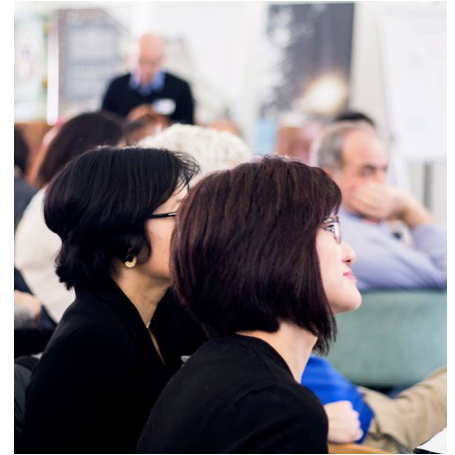
There were contrasting views as to whether transparency could move health care workers toward professionalism. While someone arguing for full transparency suggested it could, another participant said professionalism was earned in a different manner.

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

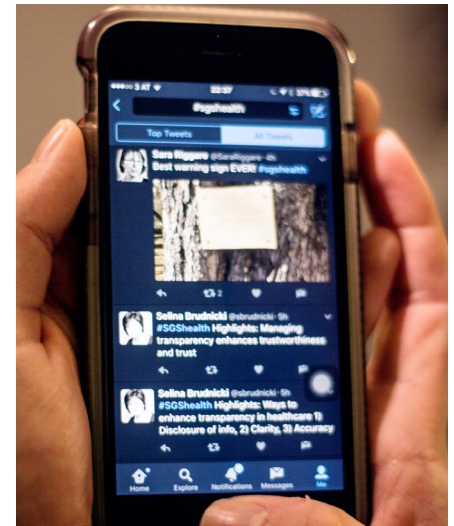
“I think we have a pretty conservative system in Switzerland. Transparency really depends on your doctor or on your clinic... A lot of the information that is written down is just stored on the computer of the doctor, or even hand written. The only thing, in Switzerland you really get from your doctor 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

Want to join the conversation?

Tweet @SalzburgGlobal using the hashtag #SGSHealth



## #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](https://twitter.com/SalzburgGlobal/lists/sgs-553)