A Prerequisite for Patient Centred Care is Empowering and Engaging Patients in the Digital Health: Report from EFMI Special Topic Conference (STC) 2017

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doi: 10.5455/aim.2017.25.281-283
ACTA INFORM MED. 2017 DEC; 25(4): 281-283
Received: Oct 25, 2017 • Accepted: Nov 03, 2017

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ABSTRACT
The European Federation for Medical Informatics (EFMI) held its Special Topic Conference (STC) in October 2017 in Israel. EFMI holds STC’s to focus on a particular issue, whereas its major annual conference Medical Informatics Europe (MIE) has a much wider remit. This conference challenged the informatics community to engage patients in digital health. Examples of the gap in digital engagement from the conference contributions include: An app to connect parents to a paediatric emergency department was presented. We heard how comparisons between general practice and paediatrician-led health systems were being compromised through the lack of available databases and that Europe needs a fit-for-purpose paediatric electronic health records (EHR). The public should be involved in shared EHR platform development. We were informed patients preferred clinicians to use their mobile device and how the online community can be a source of research subjects. A visualisation tool is being developed to display data about attention deficit hyperactivity disorder (ADHD). On a more sombre note the conference remembered Assa Reichert, a long standing member of EFMI. Notwithstanding our reflections on Assa’s service to EFMI and informatics, this conference provide a real opportunity to explore how digital health might empower patients.

Keywords: EFMI STC, Publications Officer EFMI Board.

1. BACKGROUND AND ABOUT EFMI
The European Federation for Medical Informatics (EFMI) held its Special Topic Conference (STC) in the autumn of this year in Tel Aviv. EFMI holds STC’s to focus on a particular issue, by way of contrast with its major annual conference Medical Informatics Europe (MIE) which has a much wider remit.

This STC was held in parallel with the Israeli Association for Medical Informatics (ILAMI) annual meeting, ILAMI has a long association with EFMI and history, it was founded in 1983. The STC also provided an opportunity for the EFMI Board and Council to meet (Figure 1).

EFMI (www.efmi.org) is the leading organisation in Medical informatics in Europe representing 32 countries. EFMI is organized as a not-for-profit federation concerned with the theory and practice of information science and technology in the European context. EFMI was conceived at a meeting, assisted by the Regional Office for Europe of the World Health Organisation in September 1976.

Proceeding and informatics journals are also an important part of EFMI.
The Federation endorses a range of journals, an issue previously visited in depth by a journal task-force (1).

2. AIM OF THE EFMI STC 2017
The focus of the conference was to challenge the informatics community to empower patients through access to digital technology. Put another way: If patients are to be empowered in modern health systems, a prerequisite is that they should be engaged with digital health.

The conference also remembered Assa Reichert, a long standing member of EFMI as its Israeli representative as well as being a longstanding officer of the Federation (2).

EFMI conferences generate free-full-text proceedings that provide a long term reference as well as enhance the scientific gravitas of the occasion; the front piece of the proceedings of this SRC is reproduced below (Figure 2) (3).
3. THE EFMI PUBLICATION OFFICERS CHOICE

There was a great range of material at the conference and those selected are the personal choice of the EFMI Publications Officer. There were several examples from paediatrics: Firstly, there were excellent presentations on the development and use an app to connect parents to a paediatric emergency department. This app appeared to both manage parental expectations as well as workflow.

We also had described how comparisons between general practice and paediatrician led health systems were being compromised through the lack of available databases about paediatrician led services (5). There is also a need for fit-for-purpose paediatric electronic health records (EHR) across much of Europe (6).

We learned about the need for public involvement in the development of shared EHR platforms, where development has traditionally been professionally led. A public involvement process to achieve a health user consensus about where benefits might lie is being piloted across a large UK city with 30 health providers (7). Sticking with patient preferences, another study described how patients preferred clinicians to use their mobile device to look things up during hospital-based consultations (8). The conference also heard how a visualisation tool is being developed to display data about attention deficit hyperactivity disorder (ADHD). The visual display was compared to statistical analysis but to me the value of this approach was that data could be readily visualised and understood by patients and public. Finally, a further submission suggested that online communities and crowd-sourcing should be given greater consideration as places to recruit research subjects (9).

4. CONCLUSION

Notwithstanding very moving reflections on Assa’s service to EFMI and informatics, the EFMI STC provided an in depth opportunity to explore how digital health might empower patients (10). There is a real depth and breadth of interest here. Submitting to, and attending EFMI conferences should be part of the agenda of every European informatician - and of many friends from beyond. I look forward to meeting as many of you as possible at EFMI’s next Medical Informatics Europe.

REFERENCES

1. Masic I, Kern J, Zvarova J, de Lusignan S, Vidmar G. Task force of the European Federation of medical informatics journals: background, rationale and purpose. Acta Inform Med. 2009; 17(4): 180-2. doi: 10.5455/aim.2009.17.180-182
2. Masic I. In Memoriam on Assa Reichert (1943-2015). Acta Inform Med. 2015 Jun; 23(3): 185-6. doi: 10.5455/aim.2015.23.185-186.
3. Engelbrecht R, Balicer R, Hercigonja-Szekeres M. The Practice of Patient Centered Care: Empowering and Engaging Patients in the Digital Era. Studies in Health Technology and Informatics 2017. ISBN 978-1-61499-823-5 (print) | 978-1-61499-824-2 (online) URL: http://ebooks.iospress.nl/volume/the-practice-of-patient-centered-care-empowering-and-engaging-patients-in-the-digital-era
4. Ehrler F, Siebert JN, Rochat J, Schneider F, Galetto A, Gervaix A, Lovis C. Connecting Parents to a Pediatric Emergency De-
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5. Liyanage H, Hoang U, Ferreira F, Alexander D, Rigby M, Blair M, De Lusignan S. Availability of Computerised Medical Record System Data to Compare Models of Child Health Care in Primary Care Across Europe. Stud Health Technol Inform. 2017; 244: 8-12.

6. Rigby M, Kühne G, Greenfield R, Majeed A, Blair M. Enabling Good Healthcare for Children in Europe Through Fit-For-Purpose Electronic Records - Advantage Lost and Significant Work Needed. Stud Health Technol Inform. 2017; 244: 90.

7. Leeming G, Thew S. DataWell: Public Involvement in the Development of a Federated Platform for Shared Patient Records in Greater Manchester, U.K. Stud Health Technol Inform. 2017; 244: 48-52.

8. Assis-Hassid S, Grosz BJ, Ziemlichman E, Rozenblum R, Bates DW. EHR Use and Patient-Centred Care in the Inpatient Setting: Challenges and Opportunities. Stud Health Technol Inform. 2017; 244: 78-9.

9. Benis A, Hoshen M. DisEpi: Compact Visualization as a Tool for Applied Epidemiological Research. Stud Health Technol Inform. 2017; 244: 38-42.

10. Lamas E, Salinas R, Coquedano C, Simon MP, Bousquet C, Ferrer M, Zorrilla S. The Meaning of Patient Empowerment in the Digital Age: The Role of Online Patient-Communities. Stud Health Technol Inform. 2017; 244: 43-7.