



WG16 – Participatory Health & Social Media

**2018 Report - July 2017 to June 2018
presented in Colombo, Sri Lanka for:**

- **IMIA Board Meeting, October 8, 2018,**
- **IMIA General Assembly Meeting, October 9, 2018**

Chair (2013 - 2018 outgoing/finished)

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Co-Chair (2017 - 2018 (ongoing x1 more term))

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Brief Background (including recent changes since 2017)

Over the last decade, social media tools and services have transformed health and medicine. The need for a more coordinated work in the area of health social media ignited the creation of a Web

2.0 Exploratory Taskforce at IMIA under the leadership of Dr. Peter Murray (IMIA-CEO) in 2007. The aim of the task force was to “bring together interested individuals from within and outside IMIA to explore the nature and potential of Web 2.0 applications, aiming at developing background materials and proposing specific lines of action for the IMIA Board and General Assembly”. The task force rapidly attracted the attention due to the active networking at several conferences and finally in 2012 the IMIA Social Media Working Group was accepted by the General Assembly of IMIA under the leadership of Chris Paton. In 2013, the leadership of the working group was renovated with the approval of the General Assembly in Medinfo 2013.

The Social Media Working Group (SMWG) in its original inception has always aimed to be IMIA's vehicle for stakeholder engagement in Social Media, including the study of the drivers of change, barriers, facilitators, and policies necessary for the application of the various social media categories in the health domain, including 1) health care delivery, 2) health care professional education; 3) public health; 4) clinical and disaster medicine; and 5) research.

As described in this report the first term of the SMWG was to be consolidated as an active working group. During the last four-five years the SMWG have been actively involved producing research papers, workshops and panels in nearly all the leading conferences of medical informatics. Furthermore, it won the award of the best working group in IMIA in 2012 and 2013.

In 2016, the IMIA Social Media Working group organized a track on Social Media and Participatory Health during Nursing Informatics 2016 (Geneve, Switzerland). Further, that same year we published a book (high downloaded) in Social Media and Participatory Health. This focus on participation and social media has been since the inception of the working group as a natural extension of what is called Health 2.0 and Medicine 2.0.

Achievement- Events and projects conducted and publications completed

As the IMIA executive would be aware, a landmark decision for our WG was in 2017 for the group to change our name to “Participatory Health and Social Media” WG. We are pleased that this change was formally accepted by the IMIA General Assembly at Medinfo (2017) in Hangzhou, China. This WG amendment has been extremely well received by our membership, and members have been very appreciative of the expanded scope of practice to encompass the broader expertise and interests of WG membership (i.e. social media, mobile apps, games, etc)

Furthermore, Luis Luque and Elia Gabarron have been instrumental in coordinating a Summer School for summer (June) 2018 in Sevilla, Spain for 30+ research higher degree PhD students on “Participatory Health Informatics”, with partners Salumedia, CHESS, CATCH and ENJECT

Publication(s)

The WG cordially produced the below manuscript for publication in the IMIA Yearbook

- Publication of WG's contribution to the IMIA 2017 Yearbook: Balancing Between Privacy and Patient Needs for Health Information in the Age of Participatory Health and Social Media: A Scoping Review <https://www.thieme-connect.de/products/ejournals/pdf/10.1055/s-0038-1641197.pdf>

Participation - Engagement and participation in IMIA and health informatics events and activities

With regards to active participation within the group, the best metrics are the activities organized by the group:

- X2 Panels at MedInfo 2017 Hangzhou, China (ca. 20-30 participants):
 - Unintended Consequences of Social Media
 - Social media for knowledge management and translation
- Participatory health panel in MIE 2018 (ca. 20-30 participants)
- Chair of WG participating in Educator's WG workshops at MEDINFO 2017 & MIE 2018
 - Unintended consequences of social media use

Outreach - Recruitment and engagement of new members and target communities, publicity and representation at major events and/or on social media

The IMIA PHSMWG continues to have an active member forum and mailing list using Google groups with over **80 members** that actively engaging in the organizations of activities. We have also have a LinkedIn Group which continues to have 206 members <https://www.linkedin.com/groups/3508923/> . However, we have been revisiting our social media strategy and are considering our outreach mechanisms from 2019 onwards.

In May of 2018, we have also created a collaborative database for WG members (OPTI-IN) to attempt to drive greater collaboration between WG members. Members welcomed this exercise as a way to stimulate greater professional opportunities and collaboration from within the group.

Collaboration - Working with other IMIA WG/SIGs or external organisations or institutions

At present, our major collaborative efforts have centred around an ongoing re-working of key leadership within the WG leadership now that active engagement and growth has started to consolidate. Furthermore, as this will be the end of the terms of Chair, Luis Luques. Our ongoing priorities continue to be defined as follows:

- O1: Consolidate leadership - Luis Luque will be formally stepping down from position of co-chair, and Elia Gabarron will assume this position - leaving further room for other members to step into leadership positions – the WG has examined nominations, and we welcome Dr. Kerstin Denecke from Berne, Switzerland and Carolynne Petersen (Mayo Clinic, USA) to the executive. Along with Dr. Merolli and Dr. Gabarron, they will provide further support to drive collaboration and join initiatives with other WGs and organisations
- O2: Reinforcement of cooperation among other working groups since social media and participatory health are topics transversal to most working groups. We are planning logistics to submit a panel for Medinfo 2019.
- O3: Participate in the 2018 IMIA Yearbook (ongoing commitment) – paper being prepared
- O4: To create tutorials and materials for public health officials in the use of social media for participatory health (initiative with WHO - Luis Luque (outgoing chair) is contact point - work in progress)
- O5: Create whitepaper defining “participatory health informatics” – major landmark piece for the WG
- O6: Explore scoping a position statement for the inclusion of patients in health informatics conferences
- O7: Fernando Martin-Sanchez (WG member) has been and will continue to work with the Society for Participatory Medicine to shape a library of participatory health resources.
 - Prof Martin-Sanchez will visit Melbourne Australia in Oct 2018 to present a seminar on health informatics for Dr. Mark Merolli, at Swinburne University of

Technology, which is further evidence of the collaborative nature of the members of the WG