



WG16 – Participatory Health & Social Media

2019 Report - June 2018 to June 2019

presented in Lyon, France for:

- **IMIA Board Meeting, August 25, 2019,**
- **IMIA General Assembly Meeting, August 26, 2019**

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Brief Background

- **Mission:** The WG's mission still echoes its earliest iteration, first conceived by Dr Peter Murray (prev IMIA CEO) – “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”. Having re-badged the WG's name to “Participatory Health and Social Media” (previously just “Social Media”), this mission holds true today more than ever, whilst acknowledging that we have moved well beyond the narrative of Web 2.0, as participatory health technologies become more engaging and intelligent than before. Recognising the increasing omnipresence of various participatory health enabling technologies, the scope and mission of the group is to not only bring together interested individuals, but to also help define and shape participatory health informatics.
- **Vision:** To be IMIA's vehicle for stakeholder engagement in participatory health,

including the study of the drivers of change, barriers, facilitators, and policies necessary for the application of the various participatory health technology 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.

- **Objective:** Our objective is to create an environment of intellectual human capital within IMIA to ensure patient-centered, empowering and shared- decision making continue to shape healthcare and healthcare research in informatics.

Achievement(s)

- Our first milestone for the last 12 months was to consolidate the newly branded participatory health and social media WG. We have done this by communicating the change to stakeholders and members on our Google group mailing list. Furthermore, efforts have centered on creating greater structure within the WG executive by inviting select active members of the WG to nominate for executive positions within our leadership. This has resulted in greater role structure and the reinstatement of scheduled meetings between the leadership group.
- Our current major focus, which is now underway is a project aiming to define 'Participatory Health Informatics'. This will be a two-stage project, commencing with a scoping literature review, before undertaking a Delphi study with stakeholders to elicit views and feedback, before culminating in our offering of a clear academic definition for participatory health informatics. We plan to disseminate our project through various formal and informal channels; including IMIA conferences, journal publication, and social media.
- The WG continues to actively publish in leading journals on participatory health and social media, commenting on a variety of areas relevant to patients, clinicians, and researchers (this includes publication in the IMIA 2018 and 2019 yearbook). Select recent publications over the last 12 months include:
 - **Merolli, M.**, Green, A., Busuttill, ML., Wåhlin, C. Global communication practices of physiotherapists on Twitter. *Eur J Physiotherapy*. 2018. <https://doi.org/10.1080/21679169.2018.1464061>
 - **Househ, M., Grainger, R., Petersen, C., Bamidis, P., Merolli, M.** Balancing Between Privacy and Patient Needs for Health Information in the Age of Participatory Health and Social Media: A Scoping Review. *Yearb Med Inform*. 2018. DOI: 10.1055/s-0038-1641197
 - **Petersen, C.** Through patients' eyes: regulation, technology, privacy, and the future. *Yearb Med Inform*. 2018 Aug;27(1):10-15.
 - Kuziemy, C. E., Gogia, S. B, **Househ, M., Petersen, C.**, Basu, A. Balancing health information exchange and privacy governance from a patient-centred connected health and telehealth perspective. *Yearb Med Inform*. 2018 Aug;27(1):48-54.
 - **Petersen, C.**, Lehmann, C. U. Social media in health care: time for transparent privacy policies and consent for data use and disclosure. *Appl Clin Inform*. 2018 Oct;9(4):856-859.
 - Dimaguila G, Gray K, **Merolli M.** 2018. Person-generated health data in simulated rehabilitation using kinect for stroke: Literature review, *Journal of Medical Internet Research*, 5(1). e11
 - **Merolli, M.**, K. Gray, **Martin-Sanchez, F.** TASoMe: Validating a Framework to Generate Evidence About Health Outcomes from Social Media Use. *Stud Health Tech Inform*. 2018. 247: 606-610.
 - **Gabarron, E.**, Dorrnzoro, E., **Rivera-Romero, O.**, Wynn, R. Diabetes on Twitter: A sentiment analysis. *Journal of Diabetes Science and Technology* 2019;13(3):439-444.
 - **Gabarron, E.**, Dorrnzoro, E., Bradway, M., **Rivera-Romero, O.**, Wynn, R.,

- Årsand, E. Preferences and interests of diabetes social media users regarding a health-promotion intervention. *Patient Prefer Adherence* 2018;12:2499-2506.
- **Gabarron, E.**, Bradway, M., **Fernandez-Luque, L.**, **Chomutare, T.**, Hansen, A.H., Wynn, R., Årsand, E. Social media for health promotion in diabetes: study protocol for a participatory public health intervention design. *BMC Health Serv Res.* 2018;18:414.
 - **Denecke, K.**, **Gabarron, E.**, **Grainger, R.**, **Konstantinidis, S.**, **Lau, A.**, **Rivera, O.**, **Miron-Shatz, T.**, **Merolli, M.** Artificial Intelligence for Participatory Health: Applications, Impact and Future Implications. *Yearb Med Inform.* 2019: doi: 10.1055/s-0039-1677902.

Participation - Engagement and participation in IMIA and health informatics events and activities by members of your WG/SIG

Our members continue to be active in IMIA related events and activities

- As above, we continue to be a regular contributor to the IMIA yearbook publication
- Co-Chairs Merolli and Gabarron continue to contribute to review of both IMIA yearbook papers, and selection of best papers
- At MIE 2018, in Göteborg:
 - The WG executive, (Merolli, Gabarron, Denecke, Petersen) + Bamidis and Martin-Sanchez presented a panel “Participatory health and the future of co-created eHealth”
 - Co-chair Merolli delivered a full paper – “TASoMe: Validating a Framework to Generate Evidence about Health Outcomes from Social Media Use”
 - Co-chair (Merolli) + Martin-Sanchez facilitated the IMIA Education Taskforce Workshop “IMIA recommendations on education in biomedical and health informatics – Perspectives from teachers, students and tentative employers”
- In June 2018 it was celebrated in Seville (Spain) the 1st International Workshop on Participatory Health Informatics supported by the WG (organized by Fernandez-Luque, Rivera-Romero, Co-Chair Gabarron)
 - Co-Chair (Gabarron) + Fernandez-Luque presented the session “Social media as enabler of health research”
 - Co-Chair (Gabarron) presented the session “Participatory Health and Social Media in the age of fake news”

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

Recruitment: As eluded to, a key initiative of the last 12 months since becoming the PHSM WG, has been to recruit key active members into the WG executive. We cordially acknowledge Prof Kerstin Denecke (Bern University of Applied Sciences) and Carolyn Petersen (Mayo Clinic). Prof Denecke has been a key contributor and driver of our yearbook contributions and research initiatives, and Ms. Petersen has been an active collaborator in several of our formal engagements, and a strong advocate for person-centered healthcare.

Our WG also recently has been proud to support Prof Luis Luque (former WG Chair) in nomination for the role as IMIA VP for WGs and SIGs

Current numbers of members: The IMIA PHSMWG continues to have a member forum and mailing list using Google groups with over 80 members engaging in the organizations of activities. Our core activity and business are largely driven by the members named in #1 above (+ select others, approx. 10-12). We have also a LinkedIn

Group with 206 members. We are still in the process of considering our outreach and communication strategy, which involves revisiting our social media approach and channels

Collaboration - Working with other IMIA WG/SIGs or external organizations or institutions (Please state the types of the collaborations and achievements of each collaboration attempted)

- Co-chair (Merolli) is an active member and contributor to the IMIA education group and taskforce – in 2019 Medinfo he will facilitate the IMIA Education Taskforce Workforce with Sabine Koch
- Co-Chair (Merolli) is a regular collaborator with members of the newly formed Exposome Informatics WG led by Prof Fernando Martin-Sanchez
 - In the past 12 months this has culminated in x1 refereed publication,

Merolli, M., K. Gray, Martin-Sanchez, F. TASoMe: Validating a Framework to Generate Evidence About Health Outcomes from Social Media Use. Stud Health Tech Inform. 2018. 247: 606-610.

- And, x1 major global research grant submission (currently under embargo and examination)