



IMIA Participatory Health and Social Media WG16 2020 Report

presented as part of the IMIA VP WG & SIGs report:

- **IMIA Board Meeting, November 22, 2020,**
- **IMIA General Assembly Meeting, December 6, 2020**

Kerstin Denecke, Chair (2020-2023)

Elia Gabarron, Co-Chair (2020-2023)

Carolyn Petersen, Co-Chair (2020-2023)

Website: <https://imia-medinfo.org/wp/5089-2/>

For the 2020 report please provide details on the following:

(Due to the COVID -19 pandemic, IMIA acknowledges that many functions were cancelled, delayed and disrupted from January 2020 to the end of June 2020)

1. Brief Background- current mandate, historical background, etc.

- **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.

- Objectives: 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 participatory health informatics.

2. Achievements - Events and projects conducted and publications completed

- In this year, we completed a scoping review targeting at identifying definitions for participatory health informatics. A paper with the results, a drafted definition and the facets of participatory health informatics has been submitted to IMIA's official journal "Informatics for Health and Social Care". This scoping review is part of a project of the group aiming to define 'Participatory Health Informatics'. As second step, it is planned to undertake 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 2019 and 2020 yearbook). Selected recent publications over the last 12 months include:
 - **Rivera-Romero O, Konstantinidis S T, Denecke K, Gabarrón E, Petersen C, Househ M, Merolli M, Mayer M A:** Ethical Considerations for Participatory Health through Social Media: Patient, Healthcare Workforce and Policy Maker Perspectives. IMIA Yearbook 2020, Aug;29(1):71-76.
 - **Gabarron E,** Larbi D, **Denecke K,** Årsand E: What do we know about the use of chatbots for public health?, Studies in Health Technology and Informatics, Ebook, Volume 270: Digital Personalized Health and Medicine, 796-800, 10.3233/SHTI200270
 - Abd-Alrazaq A, Safi Z, Alajlani M, Warren J, **Househ M, Denecke K.** Technical Metrics Used to Evaluate Health Care Chatbots: Scoping Review. J Med Internet Res. 2020;22(6):e18301.
 - Patients' perceptions and opinions about mental health chatbots: A scoping review. Alaa A Abd-alrazaq; Mohannad Alajlani; Nashva Ali; **Kerstin Denecke,** Bridgette M Bewick; **Mowafa Househ.** JMIR. 2020
 - **Gabarron E,** Larbi D, Dorrnzoro E, Hasvold PE, **Wynn R,** Årsand E. Factors engaging users of diabetes social media channels on Facebook, Twitter and Instagram: Observational study. J Med Internet Res 2020;22(9):e21204.
 - **Giunti G,** Claes M, Dorrnzoro Zubieta E, **Rivera-Romero O,** **Gabarron E.** Analysing sentiment and topics related to multiple sclerosis on Twitter. Stud Health Technol Infor 2020;270:911-915.
 - **Wynn R, Gabarron E,** Johnsen JAK, Traver V. Special issue on e-health services. Int J Environ Res Public Health 2020;17(8):2885.

3. Describe WG/SIG Participation - Engagement and participation in IMIA and health informatics events and activities in the past year

- As above, we continue to be a regular contributor to the IMIA yearbook publication
- Co-Chairs Denecke and Gabarron continue to contribute to review IMIA yearbook papers, and selection of best papers
- A joint panel on “Does Ethics matters for participatory health” (K. Denecke, C. Bond, L. F. Luque, E. Gabarron, G. Lopez-Campos) was accepted for MIE 2020, which was unfortunately canceled due to the pandemic situation.
- The group joined a common effort of multiple IMIA WG to react to the COVID-19 outbreak with a viewpoint paper on “Evidence-based health informatics as the foundation for the COVID-19 response: a joint call for action to transform hopes and hypes into realities”. This viewpoint paper aims at providing an overview of how the health informatics scientific community is helping to support the COVID-19 crisis.

4. Provide details of the WG/SIG’s Outreach - Recruitment and engagement of new members and target communities, publicity, and representation at major events and/or on social media.

Mark Merolli, chair since 2017, left the IMIA PHSMWG in 2020. The work was redistributed among the remaining executive team.

4.a Current number of members: 63

4.b. List of WG/SIG members:

1. Aboozar Eghdam
2. Anis Fuad
3. Annie YS Lau
4. Bart Brandenburg
5. C. Prajesh
6. Carlos Luis Sanchez-Bocanegra
7. Carol Bond
8. Carolyn Petersen
9. Charles Nobles
10. Chris Paton
11. Clara Bermudez
12. Colleen Young
13. Diane Skiba
14. Elia Gabarron
15. Erazo Camilo
16. Fernando Martin-Sanchez
17. Francisco Grajales
18. Francisco Lupiañez
19. Guido Giunti
20. Guillermo Lopez-Campos
21. Gunther Eysenbach
22. H.J. Tange
23. Humberto Mandirola
24. Iris Thiele Isip-Tan
25. James G. Kim
26. Jelle Visser
27. Jesus Daniel Trigo
28. Jonas Lauritzen

29. Juliana Brixey
30. Kerstin Denecke
31. Kevin Clauson
32. Kim Ruggiero
33. Leonie Ellis
34. Licoln A. Moura
35. Luis Fernandez-Luque
36. M.C. Murray
37. M.M. Clough
38. Margaret Hansen
39. Mark Merolli
40. Miguel Angel Mayer
41. Miguel Cabrer
42. Monica Murero
43. Mowafa Househ
44. Octavio Rivera
45. Osman Ahmed
46. Panagiotis D. Bamidis
47. Peter Murray
48. Rebecca Grainger
49. Renato Sabbatini
50. Rolf Wynn
51. Samantha Adams
52. Santiago Hors
53. Scott Erdeley
54. Shabbir Syed-Abdul
55. Sophie Bhebe
56. Stathis Th. Konstantinidis
57. Steven Bedrick
58. Suleman Atique
59. Talya Miron-Shatz
60. Taridzo Chomutare
61. Tobias Hartz
62. W. Ed Hammond
63. W. Ittak