



## **IMIA Participatory Health and Social Media WG 2023 Report (June 2022 – June 2023)**

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Bern, Switzerland

### **Elia Gabarron, Co-Chair (2020-2023)**

University Hospital of North Norway, Norwegian Centre for E-health Research  
Tromsø, Norway

### **Carolyn Petersen, Co-Chair (2020-2023)**

Mayo Clinic, Division of Biomedical Statistics and Informatics  
Rochester, Minnesota, USA

### [WG Website](#)

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#### **1. Achievements – IMIA WG Events and projects conducted, and publications completed**

- We came up with a new format to trigger exchange of ideas and collaboration, which is a virtual “Working group Tea Time”. One such event was held in March 2023; another one will be scheduled for October, given the two IMIA events taking place in between (Medinfo, MIE) where additional meetings are scheduled for the WG.
- We continued in shaping the definition around participatory health informatics by working towards a taxonomy. This was undermined by a workshop held at MIE conference on “Development of a taxonomy on participatory health informatics: Concepts and Categories Definition”
- Working group members held a panel on “Why does Ethics Matter in Participatory Health” at MIE conference 2023.
- Working group members held a workshop on “Requirements for a Digital therapeutics (Dtx) Design and Trial Service: An Expert Workshop” at MIE conference 2023.
- Working group members contributed to an IMIA Yearbook paper entitled “How Participatory Health Informatics Catalyzes One Digital Health”.
- An invited IMIA Yearbook paper entitled “Exploring the Evolution of Social Media in Mental

Health Interventions: A mapping review” was written by Elia Gabarron and Kerstin Denecke assessing the history of social media in mental health.

- A project proposal was submitted by Kerstin Denecke in collaboration with Guillermo Lopez Campos to the Swiss National Science Foundation on “Novel methods to identify adverse digital therapeutics` reactions/responses/risks
- 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 2022 yearbook). Selected recent publications over the last 12 months include:
  - **Lopez-Campos G, Gabarron E, Martin-Sanchez F, Merolli M, Petersen C, Denecke K:** Digital Interventions and their unexpected outcomes - Time for Digitalovigilance, Medinfo 2023
  - **Denecke K.** Towards Safe Conversational Agents in Healthcare. Stud Health Technol Inform. 2023 May 18;302:157-161. doi: 10.3233/SHTI230094. PMID: 37203638.
  - Larbi D, **Wynn R**, Årsand E, **Denecke K**, Zanaboni P, **Gabarron E**. Exploring Obese Adults' Preferences for a Physical Activity Chatbot: Qualitative Study. Stud Health Technol Inform. 2023 May 18;302:478-479. doi: 10.3233/SHTI230179. PMID: 37203723.
  - **Gabarron E**, Dorrnzoro E, **Reichenpfader D, Denecke K.** What Do Autistic People Discuss on Twitter? An Approach Using BERTopic Modelling. Stud Health Technol Inform. 2023 May 18;302:403-407. doi: 10.3233/SHTI230161. PMID: 37203705.
  - **Denecke K**, von Kaenel F, Miletic M, Fernández-Llatas C, Ibañez-Sánchez G, Valero-Ramón Z, Martínez-Millana A, Segura M, **Rivera Romero O.** How to Design Successful Participatory Design Workshops for Digital Health Solutions? Stud Health Technol Inform. 2023 May 18;302:641-645. doi: 10.3233/SHTI230227. PMID: 37203769.
  - **Denecke K, Rivera Romero O, Merolli M, Miron-Shatz T, Gabarron E, Petersen C:** How participatory health informatics catalyzes one digital health. Accepted for IMIA Yearbook 2022
  - **Gabarron E**, Skafle I, Nordahl-Hansen A, **Wynn R.** Social media interventions for autistic individuals: systematic review. Frontiers in Psychiatry 2023;14:1089452. doi: 10.3389/fpsy.2023.1089452.
  - **Denecke K, Rivera-Romero O, Petersen C**, Benahm-Hutchins M, **Cabrer M, Davies S, Grainger R**, Hussein R, **Campos G, Martin-Sanchez F**, McKillop M, **Merolli M, Miron-Shatz T, Trigo J**, Wright G, **Wynn R**, Hullin C, **Gabarron E.** Defining and Scoping Participatory Health Informatics – An eDelphi Study. Methods of Information in Medicine 2023. DOI: 10.1055/a-2035-3008
  - Patten C, Brockman T, Kelpin S, Sinicrope P, Boehmer K, St Sauver J, Lampman M, Sharma P, Reinicke N, Huang M, McCoy R, Allen S, Pritchett J, Esterov D, Kamath C, Decker P, **Petersen C**, Cheville A. Interventions for Increasing Digital Equity and Access (IDEA) among rural patients who smoke: Study protocol for a pragmatic randomized pilot trial. Contemp Clin Trials. 2022 Aug; 119:106838 Epub 2022 June 25 PMID: 35760340 DOI: 10.1016/j.cct.2022.106838
  - Diaz MI, Medford RJ, Lehmann CU, **Petersen C.** The lived experience of people with disabilities during the COVID-19 pandemic on Twitter: content analysis. Digital Health. 2023 May; In press.

**2. Describe WG/SIG Participation - Engagement and participation in IMIA, IMIA Region or member health informatics events and activities in the past year**

As described above, we continued to be a regular contributor to the IMIA yearbook publication. Additionally, Denecke and Gabarron continued to contribute to review IMIA yearbook papers, and selection of best papers. Members attended the MIE and MedInfo conference including a WG joint dinner of WG members.

**3. 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.**

New WG members have been recruited at MIE conference and from project collaborations. Three new members have joined the WG over the last 12 months.

**4. Current List of members:**

- Aboozar Eghdam
- Anis Fuad
- Annie YS Lau
- Bart Brandenburg
- C. Prajesh
- Camilo Erazo
- Carlos Luis Sanchez-Bocanegra
- Carol Bond
- Carolyn Petersen
- Charles Nobles
- Chris Paton
- Clara Bermudez
- Colleen Young
- Daniel Reichenpfader
- Dari Alhuwail
- Diane Skiba
- Elia Gabarron
- Fernando Martin-Sanchez
- Francisco Grajales
- Francisco Lupiañez
- Guido Giunti
- Guillermo Lopez-Campos
- Gunther Eysenbach
- H.J. Tange
- Humberto Mandirola
- Iris Thiele Isip-Tan
- James G. Kim
- Jelle Visser
- Jesus Daniel Trigo
- Jonas Lauritzen
- Juliana Brixey
- Kerstin Denecke

- Kevin Clauson
- Kim Ruggiero
- Leonie Ellis
- Licoln A. Moura
- Luis Fernandez-Luque
- Maja Nielsen
- M.C. Murray
- M.M. Clough
- Maja Nielsen
- Margaret Hansen
- Mark Merolli
- Miguel Angel Mayer
- Miguel Cabrer
- Monica Murero
- Mowafa Househ
- Octavio Rivera-Romero
- Osman Ahmed
- Panagiotis D. Bamidis
- Peter Murray
- Rebecca Grainger
- Renato Sabbatini
- Rolf Wynn
- Samantha Adams
- Santiago Hors
- Scott Erdeley
- Shabbir Syed-Abdul
- Shauna Davies
- Sophie Bhebe
- Stathis Th. Konstantinidis
- Steven Bedrick
- Suleman Atique
- Talya Miron-Shatz
- Taridzo Chomutare
- Tobias Hartz
- W. Ed Hammond
- W. Ittak
- Zhenni Ni