Draft Terms of Reference

EPF Thematic Working Group on Digital Health

Overall remit

The working group will inform, guide and support EPF’s work on digital health from both a strategic and content perspective, in order to support EPF’s broader membership, Board and the Secretariat in this work. The working group will contribute to developing EPF’s overall strategy in digital health, including work towards the gathering of patients’ views on various topics related to digital health, including the protection and sharing of data from patients’ electronic health records.

In its work it will take into account EPF’s ongoing work on health data, including the work within the IMI project, the European Health Data Network (EHDEN); issues emerging from the IMI ADAPT SMART project on real-world evidence; and the implementation of the EU Data protection Regulation (GDPR) from the health governance perspective. The group will also inform EPF membership on technical topics through briefings.

The group will take a lead on specific activities as defined by its members in an annual work plan or as requested by the EPF Board or Secretariat. Position documents developed by the group will be subject to a consultation of the full membership before their formal adoption.

Mandate

There is no definite timeframe set for the working group. The work of the group will be evaluated after for example two years and a decision regarding continuation will be made.

Objectives

* Guide EPF’s strategy on digital health;
* Identify and map digital health priorities from a patient perspective;
* Inform the patient community on technical aspects of digital health;
* Significantly contribute to specific policy and project work and activities relating to digital health;
* Develop coordinated patient group effort and action on digital health;
* Exchange between patient organisations and experts working on digital health;
* Strengthen the network of patient organisations and experts active in this field;
* To contribute to full membership engagement and constructive cooperation between EPF members in developing policy positions, projects work, and effective advocacy.

Membership

Membership of the working group is open to (1) all member organisations of EPF. Individual members should be nominated by their organisations to participate in the group. Membership is also open to (2) individual experts in the field of digital health based on an open call for interest. *“Members” below refers to both groups, unless otherwise specified.*

The term for both individual EPF members and individual experts is initially for two years.

In the event that a member is no longer able to fulfil their responsibilities as referred to below, they are to inform the EPF Secretariat. Similarly, in the event a member is not fulfilling its commitment to the working group, EPF can refuse to support travel and accommodation costs and will relieve the member from her/his duties. In this case, a call will be circulated to the EPF membership in order to identify a new member.

Substitute members will only be accepted on an exceptional basis, provided that the substitute is adequately briefed by the member and commits to reporting back to the member following the meeting.

To encourage diversity of participation, an EPF member organisation participating in the EPF Working Group on Digital Health cannot also participate in the Universal Access to Healthcare working group – and vice versa.

Membership will be reviewed should there be a change in the EPF membership rules or criteria.

Members’ Responsibilities:

* Members commit the necessary time to actively contributing to the work of this working group and commit to attending all face-to-face meetings and ad hoc web meetings;
* Members commit to reporting back to their organisations following working group meetings;
* Members will provide proactive suggestions for meeting agenda items to the EPF secretariat. To this end a request for suggestions will be circulated to members in advance of the meeting;
* Topical or reporting responsibilities (national level reporting for example) will be allocated at or after the first meeting.

Meetings and communication

The working group will meet either physically (in Brussels) or virtually twice a year. In 2018, the working group will have one face-to-face meeting and one virtual meeting. In addition, webinars and/or teleconferences may be organised on an ad-hoc basis. The group will communicate mainly by email.

Transparency

A list of the members of the working group and their affiliated organisations will be made publicly available on EPF’s website.

Minutes of the working group and draft documents pending formal adoption will be made available only to EPF’s membership via internal communications.

Logistical arrangements

Administrative support for the group meetings (travels, accommodation, organisation of teleconferences) will be provided by the EPF Secretariat as appropriate and according to [EPF travel and reimbursement policy](http://www.eu-patient.eu/globalassets/events/2018/epf_travel_and_reimbursement_policy.pdf). Travel and accommodation expenses for physical meetings are covered by EPF and will be booked directly by EPF’s Event Officer.