



Research in Mental Health Needs of patients & Challenges for Researchers

Recent Experiences of GAMIAN-Europe

Paul Arteel, executive director

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- GAMIAN-Europe, a patient-driven pan-European organisation, represents the interests of persons affected by mental illness and provides:



Background of GAMIAN-Europe

↑ ↑ ↑ GE is involved in strategic projects aimed at influencing policies at the national/European level : (WHO,WFMH, EMA, Euro Parliament, EC,...
GE is represented, or is collaborating with most NGO's

↓ ↓ ↓ Strategic projects to listen to the patients voice:

Annual convention (information, education and exchange)

Annual regional Seminar (education and discussion)

Social Media (exchange)

Surveys (listen to the expert by experience)



GAMIAN-Europe

For Gamian-Europe it is important **to involve patients views** and patients expertise in academic research projects

The main aim of is to be considered as **partners** (subjects) and no longer as objects of the research,

In particular the patients want to be involved in the concept of the research (**is the research relevant?**) and the dissemination of the results (**can we profit from the results?**)

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Since the start GAMIAN-Europe has invited researchers to the Annual Convention to present the results of their research projects to GAMIAN-Europe's members (patient associations).

This resulted in an ongoing dialogue, beyond the convention settings



GAMIAN-Europe

GAMIAN-Europe was accepted as a partner in ROAMER's Advisory Board

GAMIAN-Europe was accepted as a partner in 3 FP7 projects:



**MoodFood
2014-2018**

**E- Compared
2014-2016**

**Mastermind
2014-2017**



In the FP7 projects GAMIAN-Europe is a **full** partner ,

The role of Gamian in this projects is:

To participate in the project from the very beginning (the application form).

To be include a in an advisory role in all work packages.

To organise on a regular base meetings of a patient advisory board (Mastermind)

To inform GAMIAN-Europe members on the ongoing projects by

- creating a research page on the GAMIAN-Europe website
- editing a quarterly Newsletter (for each project)
- to report on the research activities on the GAMIAN-Europe Facebook page



Experience after one year:

Positive dialogue and mutual respect and trust:

- The patients are listened to (printed documents to inform patients are submitted to patients representatives for approval, Questionnaires are discussed)
- The research teams are happy to have a new method to inform patients and get their participation



Experience after one year:

False note:

The limited financing is a major threshold

- Only 50% reimbursement for mastermind
- Only 75% reimbursement for E-Compared
- MoodFood hgives an 100% reimbursement and

Mail form the Commission to the project leader:

Due to the recent financial verification of the partner 20- GAMIAN, with a result of co-financing capacity weak, we would like to request this partner some information on the financial resources to be used by this partner to cover his own financial contribution in the project.



Experience after one year:

False note:

- The Bureaucracy of the Commission is a difficult threshold to take:
- The website is not really user friendly
- The Research Activity Agency refused to accept Gamian-Europe as a partner:

Thank you for sending your request to validate the "GLOBAL ALLIANCE OF MENTAL ILLNESS ADVOCACY NETWORKS-EUROPE" in the participants' database for the Seventh Framework Programme.

However, the documents you have sent us do not provide us with sufficient evidence to qualify your Association as a research organisation under FP7.

Please consider that the mere financing of research activities carried out by other entities, the dissemination of knowledge and the promotion or coordination of research activities are not considered as "research activities" within the sense of the FP7 definition.

If you still believe that your Association should qualify as a research organisation, please send us any necessary supplementary evidence.