



TOWARDS ACTIVE PATIENT INVOLVEMENT IN HEALTHCARE

the mental health perspective

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GAMIAN–Europe (Global Alliance of Mental Illness Advocacy Networks-Europe)

A patient-driven pan-European organisation, which represents the interests of persons affected by mental illness and provides:



IMPORTANCE OF GAMIAN INVOLVEMENT ON EPF



GAMIAN-Europe has been involved since the beginning – is a co-founder of EPF

Prevalence of mental illness

1 out of 4 people is confronted with a mental health problem (life time prevalence);

Burden of mental illness

is higher than the burden of cancer + cardiovascular diseases;

IMPORTANCE OF GAMIAN INVOLVEMENT ON EPF



Comorbidity

- Majority (85%) of people with mental illness have physical problems;
- Majority of people with physical illness have mental problems (neglected situation).

→ All patients associations are confronted with mental health problems

Patients involvement at Policy level



- ❖ GE is involved in strategic projects aimed at influencing policies at the national/European level :
 - WHO,
 - WFMH,
 - EMA,
 - European Parliament (Interest group),
 - EC,...

- ❖ GE is represented, or is collaborating with most NGO's (EPF, EBC, EPPOSI, EUCOMED, EPFIA...)

MEP Interest Group on Mental Health, Well being and Brain Disorders



- ✓ initiate “working relations” with the European Commission and European Parliament;
- ✓ enable to support interactive dialogues on key policy issues with other European stakeholders in healthcare;
- ✓ ensures that policies are communicated effectively for the benefit of patients;
- ✓ it became imperative to work at this level in developing healthcare delivery systems that benefit patients.

MEP Interest Group on Mental Health, Well being and Brain Disorders



Some key factors of success:

👍 representativity

👍 transparency

👍 visibility

👍 following and responding to EU developments

MEP Interest Group on Mental Health, Well being and Brain Disorders



Some difficult points to overcome:

- ✖ high cost of the consultancy fees
- ✖ incertitude of the outcome
- ✖ potential effects on the finances

Listening to the voice of patients



- ❖ Strategic projects to listen to the patients voice:
 - Annual convention (information, education and exchange);
 - Annual regional Seminar (education and discussion);
 - Social Media (exchange and getting closer);
 - **Surveys (listen to the expert by experience).**

GAMIAN-Europe Surveys



GAMIAN-Europe endeavors to capture patient views through surveys sent out through the network member associations

Translated survey packs posted online on the GAMIAN website, Facebook, Twitter and LinkedIn pages



Stigma (2006 and 2010)

Physical and mental health (2011)

Adherence to treatment (2012)

Mental Health and workplace (2013)

GAMIAN-Europe Surveys



Some key factors of success:

- 👍 translation of the questionnaires;
- 👍 relevance of the chosen subjects;
- 👍 commitment of our members (associations);
- 👍 feeling of inclusion (patients).

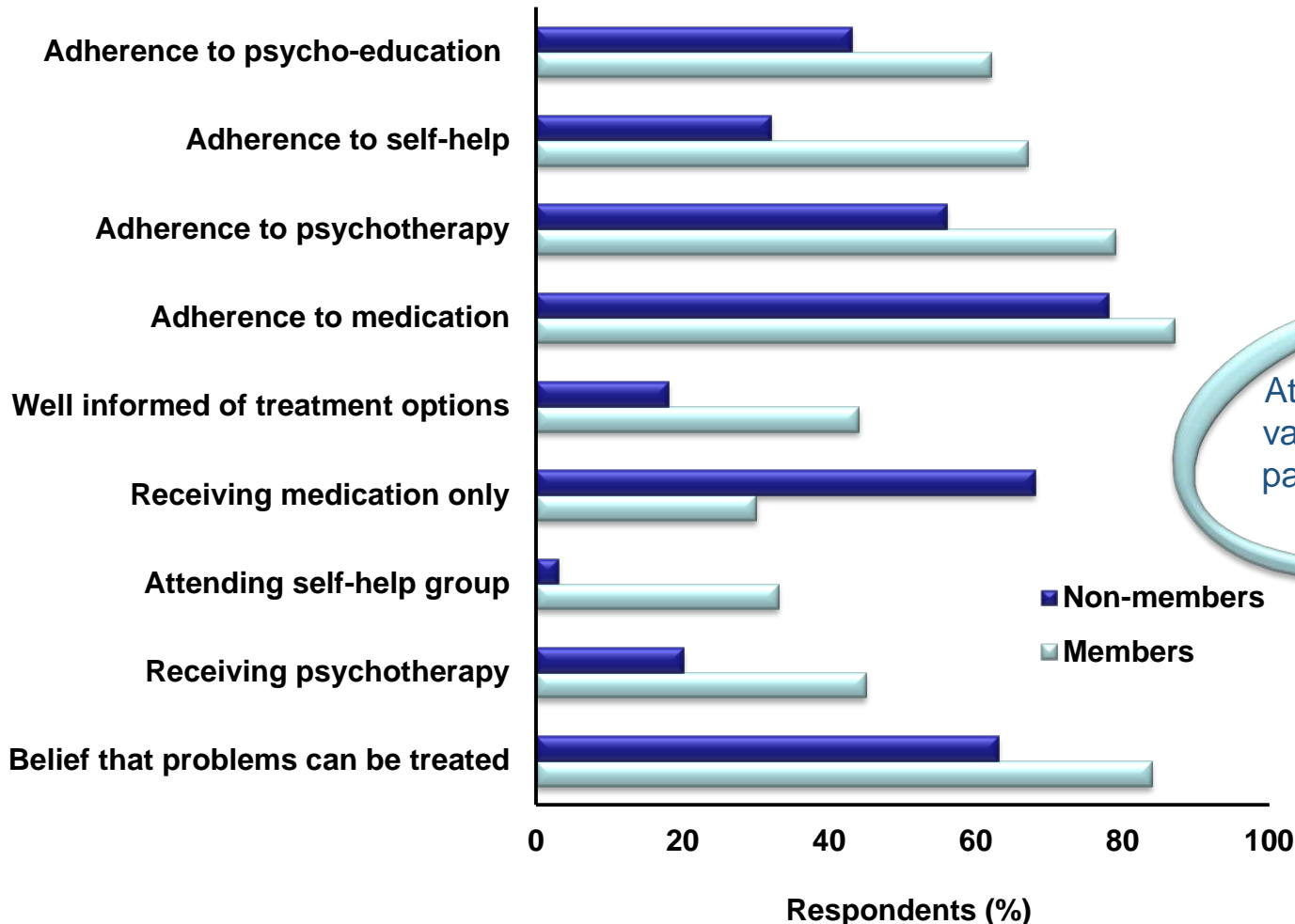
GAMIAN-Europe Surveys



Some difficult points to overcome:

- ✖ funding;
- ✖ get the answers on time;
- ✖ get enough answers from all countries.

Members of patient associations tend to have more positive attitudes towards treatment



Attitudes towards treatment varied according to whether patients were members of a patients' association

CONCLUSIONS



1. Mental Health issues are important for all patients associations;

2. Patients associations can represent the patient view, based on regular consultation of the members;

3. It is imperative that patients associations work at policy making level in developing healthcare delivery systems that benefit patients.



THANK YOU

<http://www.gamian.eu>