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GAMIAN-Europe								



EPA Forum
3 March 2018, Nice

Measuring quality and outcome of person-centered mental health care - The point of view of users

**Hilkka Kärkkäinen,
President of GAMIAN-Europe**

About the organisation

GAMIAN-Europe is a representative coalition of patient organisations that seeks to put **patients at the centre of all issues** of the EU healthcare debate.

We bring together and support the development and policy influencing **capacity of local, regional and national organisations active in the field of mental health.**

Objectives



Represent the views of patients with mental disorders

Ensure that this voice is heard in the development of sound EU and national level policies

Ensure good services, care and empowerment for those affected by mental health problems

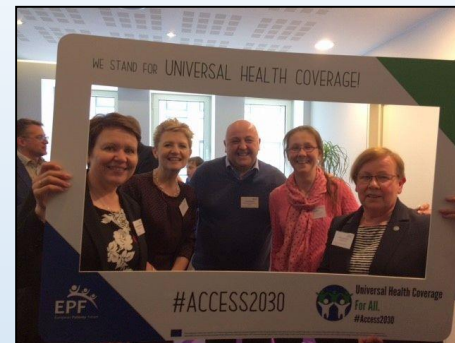
Activities



Advocacy



Interest Group Meeting



EPF Campaign Access 2030



Workshop, GAMIAN-Europe
Convention 2017



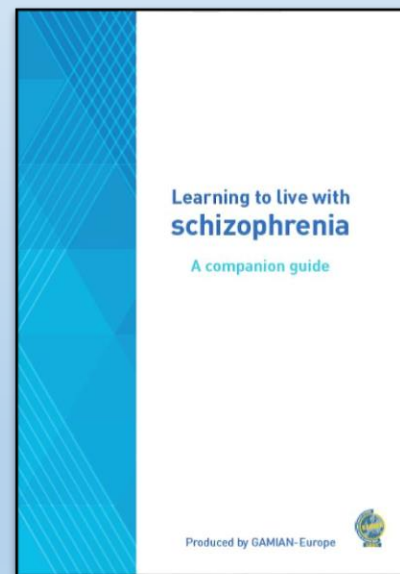
Education/information



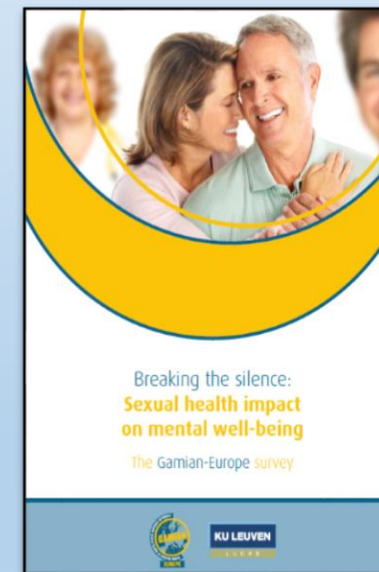
**Partnerships and
networking**



**Building/strengthening
the organisation
and information
exchange**



Schizophrenia Companion Guide



Gamian Questionnaire

Examples of concrete actions

- ✓ **Expert Policy Paper improving transition to adult mental healthcare services for mental health patients.**
- ✓ **We are advocating for a change in social perception about mental health.**
- ✓ **2016 GAMIAN-Europe has developed a schizophrenia companion guide, written by patients for patients in a lay language**
- ✓ **GAMIAN is advocating for patient rights.**

Partners and Members

GAMIAN-Europe has developed a networking of mental health organisations. We have members from **25 European countries** and a strong partnership with **recognised European-level organisations**.



What is quality? - Patient's expectations

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- **Easy access to care without complicated referral systems**
- **Information on his/her situation and the illness itself**
- **Patients need time to understand what is happening to them when they become ill**



What is quality? - Patient's expectations

- Information on what to expect with different treatment options
- Honest information on the side-effects of each antidepressant
- Information about mental health services, self-help groups and other services – all aspects of care
- Information on self-management tools:
 - Apps, mood calendars, “questions for my doctor” lists, care planning tools, patient education materials, etc.



What is quality? - Patient's expectations

- **Holistic care**
- **A “safe” place to go to when relapsing but not necessarily a psychiatric hospital**
- **Possibility of community care**
- **Social and occupational functioning**
- **Recovery and rehabilitation**



Relationship with a doctor

Relationship with a doctor

- **Patients want to be equal partners in care, to become heard**
- **Both parties being experts in their respective subject areas**



Relationship with a doctor

- **Personal care and discussions on the current situation**

- **Allowing time for patient to speak**

- Dept. of Health study in UK found that patients speak for 13 seconds only before interrupted by physician. If allowed to speak freely patient would only do so for two minutes.

- **Genuine interest in the patient's situation**



Relationship with a doctor

- **Assisting the patient in exploring preferences and making decisions**
- **Freedom of choice regarding life decisions including management and treatment of illness**
- **Skills which help cope with symptoms (reference to peer-support group)**
- **Trusting relationship without criticism**



Policy for quality improvement

Policy for quality improvement

Patients expect their country's policymakers to ensure that:

- consultation processes are in place and that patient groups form an integral part of the consultation processes
- partnerships are developed with patient advocacy groups
- legislation reflects emphasis on quality by supporting minimum standards for access and quality
- funding is available to ensure quality and resources for interventions, treatment and research

Policy for quality improvement

- Mental health outcome measures should not only focus on symptoms and functioning, but also on issues such as quality of life, life management and recovery.
- There is a need for development and implementation of performance measures that reflect patients' views and treatment choices.
- Mental health outcomes will need to be assessed more routinely, and measurement-based care should become part of the overall culture of the mental health care system.

Conclusions

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- Mental disorders are common worldwide, yet the quality of care for these disorders has not increased to the same extent as that for physical conditions.
- The level of mental health quality of care is poor and the rate of improvement is slow compared to general medical conditions.
- Patient reported outcomes should be an essential part of measuring the quality of care.
- The field of mental health quality improvement needs involvement of patient advocates.



Thank you!

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