



# 2020-2022 Work Programme

GAMIAN-Europe



**GAMIAN-Europe**

The voice of patients in mental health

[www.gamian.eu](http://www.gamian.eu)

# ABOUT US

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'The Global Alliance of Mental Illness Advocacy Networks-Europe (**GAMIAN-Europe**) is a patient-driven pan-European organisation, representing and advocating the interests and rights of persons affected by mental ill health. Its main activities relate to:

- advocacy,
- information, awareness-raising, and education
- partnership and capacity building.

Overarching themes in our work relate to anti-stigma and discrimination and patients' rights. GAMIAN-Europe was established in 1998 as a representative coalition of patient organisations as it was felt that patients can and should play an effective and complementary role in developing positive and proactive policies and other initiatives with an impact on mental health issues and services.

**GAMIAN-Europe** has ambitious plans over the next three years, focusing on mental health and patients' needs and priorities.

This document sets out these main activities planned for 2020, 2021, and 2022. We remain open to suggestions for other activities that are in line with GAMIAN-Europe's vision, mission, and priorities.





# PLANNED ACTIVITIES DURING 2020-2022

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GAMIAN-Europe will focus on the following areas:

- **Depression**
- **Schizophrenia**
- **Patient-clinician relationship**
- **Patient empowerment and self-management of treatment and care**
- **Suicide prevention**
- **The impact of COVID-19 on patients and mental health services**
- **Digitalisation of mental health services**
- **Peer support**
- **The quality of life of people living with mental ill-health**
- **Capacity building for people living with mental ill health and their organisations**





# HOW DO WE ACHIEVE OUR OBJECTIVES?

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In line with our mission, we have developed a work programme based on our 3 pillars of activity as listed above, i.e.:

- advocacy,
- information, education, and awareness
- cooperation, partnerships, and capacity building.



**Advocacy**



**Information, Education,  
& Awareness**



**Capacity Building,  
Cooperation, and  
Partnerships**



A black and white photograph of a raised fist, symbolizing solidarity and protest. The fist is clenched and held high, with the arm extending upwards. The background is a blurred, light-colored surface. A solid blue rectangular box is overlaid on the left side of the image, containing the word "Advocacy" in white text.

# Advocacy

# ADVOCACY

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GAMIAN-Europe is strongly focused on providing European and national level policymakers with the expertise, experience, and expectations gathered from individuals living with a mental health condition in order to develop sound policies that take account of mental health in the broadest sense, i.e. prevention of mental ill health, promotion of mental health and appropriate and accessible treatment and care.

During 2020 – 2022, we will continue to keep decisionmakers well informed with regards to the latest trends and developments in the field, e.g. through our MEP Alliance for Mental Health events but also via contacts with Council and European Commission.

GAMIAN-Europe will continue to provide the coordination of the MEP Alliance for Mental Health (established in 2009 as the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders).

The Alliance aims to **bring together MEPs and relevant stakeholders to advocate for the development of sound EU policies which contribute to the prevention of mental ill-health and ensure appropriate and high-quality services and person-centred care, empowering individuals living with mental ill health.**

The Alliance will continue to meet 2-3 times a year; these meetings provide an opportunity to bring stakeholders together to underline the need for EU-level activities to take mental health into account in a variety of areas; they also serve to identify and plan advocacy activities.

## Actions

### EU Mental Health Strategy

**Since 2016, GAMIAN-Europe has been actively advocating for a comprehensive EU-level Strategy on Mental Health.** At that time, we produced a blueprint for such a Strategy, as it was felt that specific EU action in the field of mental health needed to be continued.

The blueprint outlines the urgency and the need for such a Strategy, which should be based on the notion of 'parity of esteem': mental health should be considered as important as physical health – there is no health without mental health. It should also address all relevant spheres of life at all ages (e.g. work, schools...), be adapted to new developments (e.g. cyberbullying), and comprise the entire spectrum of mental health, from prevention, early diagnose, appropriate treatment and services as well as long term care.



# ADVOCACY

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In 2020-2022, the MEP Alliance for Mental Health with the support of GAMIAN-Europe is launching a campaign to ensure that **one of the future European Years will be dedicated to Mental Health.**

European Years are EU-wide awareness campaigns to inform and educate European citizens and attract the attention of national governments of Member States to a particular issue, in order to change attitudes and behaviours at both the national and European level. Since 1983, there have been such European Years, each with a difference theme, e.g. Citizens, People with Disabilities, Active Ageing and many more.

It is increasingly recognised that there is an urgent need for better and wider understanding of mental health and for effective action. The COVID19 pandemic has highlighted this crucial need. A dedicated European Year of Mental Health could be a tangible and coordinated initiative to raise awareness, provide a platform for exchanges and sharing, promote and facilitate discussion and contribute towards improving mental health across the board.





# Information, Education, & Awareness





# INFORMATION, EDUCATION, AND AWARENESS

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GAMIAN-Europe aims to raise awareness about a wide range of mental health aspects, with the objective of changing the societal and social perception of mental health.

A large number of our activities are focused on improving understanding and awareness of mental ill health in order to ensure and improve the availability, accessibility, and relevance of information. Quality information, in turn, supports the empowerment of patients and facilitates the fight against prejudice and ignorance.

Our activities are aimed at patients, carers, health professionals as well as the general public.

## **Workshops and Webinars**

GAMIAN-Europe plans to organise workshops and webinars to raise awareness by presenting studies, holding discussions, and offering the opportunity for knowledge exchange. In 2020 – 2022, we would like to start online and face to face discussions on the **quality of life of mental health patients** and **managing depression and anxiety**.

## **Projects**

We have previously developed educational guides –prepared 'by patients for patients' - containing practical advice on how to manage common situations that individuals living with mental ill health might encounter as well as a number of practical tools to support daily living. We aim to continue to produce these 'by patients for patients' educational guides in the future.

**Schizophrenia Companion Guide II: Continuity of Care:** With the aim of building on our work in the area of schizophrenia, GAMIAN-Europe produced the Schizophrenia Companion Guide II. This guide has been designed to provide practical advice to people with schizophrenia, and their caregivers, friends and family. It includes tips at the end of each section on how to manage a variety of situations that commonly arise. Some additional resources are listed in the appendix at the end of the guide. This guide is a follow-on from the first Schizophrenia Companion Guide produced by GAMIAN-Europe in 2016 which provides a comprehensive overview of schizophrenia, including symptoms and treatment. Even though there is some overlap with the first guide, the current guide includes more personal experiences of people diagnosed with schizophrenia, carers, friends and family; their discoveries and the strategies they used as part of their journey.

# INFORMATION, EDUCATION, AND AWARENESS

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**Quality of life: Living with a mental health condition:** The primary aim of this project is to identify what individuals do to improve their quality of life and what quality of life means to them. This project will focus on the health aspects of quality of life with a focus on mental health and well-being. The main objectives of the project are:

- To understand the perspectives of patients and significant others (e.g. carers, friends, family) and their experience of what impacts on and improves their quality of life, including areas such as their physical health and well-being, family, education, employment, wealth, and the environment where they live/work.
- To develop insights into the approaches people use with regards to self-learning, self-care, self-management, and self-healing. This includes what a person finds helpful through his/her own discoveries, which can be shared with other patients and healthcare professionals.

With regards to the methods used for this project, video and infographics will be used as the beginning of a larger discussion on quality of life and mental health both online and offline. Offline examples of output for this project include: a workshop on quality of life and mental health, poster and leaflet printing of the infographic for dissemination at congresses, and projecting the video at our booth in congresses. Online examples of output for this project include running social media campaigns to reach a wider audience on Twitter, Facebook, Instagram, and LinkedIn.

**Patient-Clinician Experience in Depression:** GAMIAN-Europe, in partnership with the European Psychiatric Association (EPA) worked on a project called 'Developing trust and effective care: Patients and Psychiatrists working in partnership'. This project explored the relationship and care experience of patients, complemented by the perspective of their psychiatrist and other health care professionals. The two experiences will be brought together in a dialogue, leading to conclusions about desirable actions for optimising this relationship. Twenty patient and psychiatrist pairs will be recruited from around Europe. Patients included will be asked to complete a semi-structured questionnaire to describe their outpatient meetings, relationship with their psychiatrist/patient, experiences of their care, their expectations, how the treatment was decided, what went right and what went wrong, and what they believe could have been improved. With the support of the European Psychiatric Association (EPA), clinicians will be requested to participate. They will independently write about their experiences of the relationship with the patient, treatment and care process, their intent, hopes, and frustrations, and why they think these succeeded or failed. A report will be produced jointly by GAMIAN-Europe and the European Psychiatric Association (EPA), containing the main patient and clinician experiences and offering recommendations to policymakers, clinicians, training institutes, and patient organisations.

**Patient-Clinician Experience in Schizophrenia:** Given the success of our Patient-Clinician Experience in Depression project, a similar project will be conducted on the patient-psychiatrist interactions in Schizophrenia, in partnership with the European Psychiatric Association. The project will aim to explore the care experience of patients with schizophrenia, complemented by the narrative of the mental health service providers. The two experiences will be brought together in analysis, leading to conclusions and recommendations for change. A focus on the carer and its interaction with the clinician and the patient will also be introduced in the analysis.





# INFORMATION, EDUCATION, AND AWARENESS

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'Breaking Depression' is a pan-European health awareness campaign aiming to raise awareness of the challenges of living with different types of depression, including major depressive disorder (MDD). The campaign aims to raise awareness of the challenges of living with depression, including MDD, one of the more severe forms. Taking the 'kintsugi process' as a powerful metaphor for the journey faced by people living with MDD, i.e. by acknowledging that any repair process is complex, taking each broken piece one at a time, the campaign reveals eight works of kintsugi art, inspired by stories from people living with MDD. Their stories reveal that with time, care, and patience, people with MDD can begin the healing process.

## **A Charter for the Rights to Treatment & Care for People with Schizophrenia:**

This project was launched in 2019; we will continue its dissemination via our social media channels by relaunching it on World Schizophrenia Day (May 24th) and World Mental Health Day 2020 (October 10th). We will also be translating it into various European languages for more visibility and further engagement of mental health patients.

## **Comorbidity of depression with physical health conditions: cancer and hearing loss:**

These projects aim to identify the experiences of patients and clinicians as well as the obstacles to care. Moreover, they intend to raise awareness of the impacts of comorbidity such as stigma and discrimination by providing a patient perspective on this issue. In addition, this project aims to raise awareness of the importance of early intervention in depression as this will increase the effectiveness of treatment. It will also identify challenges faced by health care systems to offering adequate access and treatment to people with co-morbidities.

As part of this project, GAMIAN-Europe will:

- Organise seminars to engage different stakeholders such as patients, clinicians, researchers, and EU and national policymakers in an exploration of challenges linked with comorbidity.
- Invite speakers who suffer from comorbidity or have suffered in the past to share their experiences - both positive and negative.
- Invite clinicians to share the challenges they face in treating depression comorbidity.
- Identify health system factors and their remedies.
- Provide policy recommendations for a future approach to managing comorbidity.
- Formulate future actions to raise awareness and change attitudes and behaviour.

**Digitalisation:** Since 2017, GAMIAN-Europe has been working on the impact of digitalisation on mental health. We believe that digital tools and technologies are powerful channels for treating mental health conditions. We consider the role of mobile applications in the future of mental health hugely important. Currently, there are great differences in the quality of the applications used by patients. Furthermore, there has been a dramatic growth in mental health mobile applications in recent years; there is a demand for a reliable evaluation system that assesses the qualities and rates the applications themselves.



# INFORMATION, EDUCATION, AND AWARENESS

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**Peer support project::** The proposed project sets out to create a virtual resource center of best practice peer support activities, methods and training programmes. A key purpose of this resource centre is to provide the opportunity and resources to develop and share experiences of peer support activities across EU countries.

A second aim of the project will be to bring together peer support workers and other relevant stakeholders to develop and share existing best practices through workshops and webinars.

**Suicide Prevention Project:** This project aims to raise awareness of the issue of suicide in youth with a focus on the COVID-19 pandemic and gathering in-person perspectives. The project will consist of running a social media campaign aimed at sharing information and spreading helpful messages surrounding the topic of suicidal ideation. The project will be carried out in collaboration with youth groups such as Euro Youth for Mental Health.

**Quality Control of Mental Health Services:** This project aims to perform quality assurance of mental health services by user-focused groups in different European countries through :

- Developping of user-led quality assessment tools for mental health services
- Producing user-led output pertaining the evaluation of different aspects of mental health services in different European countries
- Providing and disseminating user-developed recommendations to improve the mental health services

In order to achieve this, we will map existing user- and provider-led quality assessment systems (or tools) in some EU countries and share the needs, shortcomings, and good practices among the group of service user-experts in these different countries. GAMIAN-Europe will then develop a (European) QA tool/model based on a literature study and practical experiences and establish recommendations as to how to start with or improve available user-led QA systems.

**Mind@Work:** GAMIAN-Europe will be partnering with Mind@Work, a European-wide project aiming to spread information about mental health in the workplace through a series of podcasts with experts by experience.



# INFORMATION, EDUCATION, AND AWARENESS

## EU-funded Research Projects

GAMIAN-Europe is also committed to strengthening meaningful patient input and participation in EU-funded research projects. Our role usually relates to ensuring the patient perspective in these projects as well as support the widest possible dissemination of the research findings. Currently, we are taking part in five European projects: ImpleMentAll, CAPICE, SYNergies for Cohorts in Health: integrating the ROle of all Stakeholders (SYNCHROS), the European Brain Research Area (EBRA), and the European Network of Active Living for Mental Health (ENALMH). We have been invited to participate in several other projects, which are currently undergoing review.

- **ImpleMentAll** is a European collaboration towards faster and more effective implementation of eHealth interventions.
- **CAPICE (Childhood and Adolescence Psychopathology: unraveling the complex etiology by a large Interdisciplinary Collaboration in Europe)** aims to unravel the complex etiology in child and adolescent mental health symptoms.
- **SYNergies for Cohorts in Health: integrating the ROle of all Stakeholders (SYNCHROS)** is a three-year European project funded under the Research Programme Horizon 2020. It sets out to establish a sustainable European strategy for the development of integrated population, patient and clinical trial cohorts.
- **The Inter-Active Living for Mental Health (InALMH)** project aims to create an Interactive Platform (IP) for the collection, the organisation and the dissemination of information concerning the PE Practices providing free access to all interested parties and individuals together with the enhancement for the development of new practices.
- **The European Brain Research Area project (EBRA)** was created as a catalysing platform for brain research stakeholders to streamline and better coordinate brain research across Europe while fostering global initiatives.
- **IT4Anxiety** aims to support the implementation of innovative solutions with the objective of reducing the anxiety of patients suffering from mental disorders.
- **PSY-PGx** is the first initiative to propose a large-scale non-industry sponsored clinical study that demonstrates the clinical benefits and potential of implementing pharmacogenetics for psychiatric patients in existing medical settings.



ImpleMentAll



SYNCHROS



**InALMH**  
InterACTIVE LIVING  
FOR MENTAL HEALTH



EUROPEAN BRAIN RESEARCH AREA



# INFORMATION, EDUCATION, AND AWARENESS

## Speaking at conferences

GAMIAN-Europe is increasingly invited to speak and showcase its activities at conferences. We intend to continue this activity; it helps us to raise awareness about issues that are important to patients in events such as the Congresses of the European Psychiatric Association (EPA), the European College of Neuropsychopharmacology (ECNP), the World Psychiatric Association (WPA) and events of scientific associations dedicated to the science and treatment of brain disorders (e.g. European Brain Council).

## Surveys and questionnaires

In order to monitor changes in the patients' views on society's attitudes of mental health problems, we are planning to invite GAMIAN-Europe members to fill in surveys and questionnaires on a regular basis.

## Communication

GAMIAN-Europe believes that external as much as internal communication is of the utmost importance to raise awareness of our activities and achievements. For that purpose, we will continue maintaining our (renewed) website and having an active presence on social media (FB, Twitter, Instagram, LinkedIn). Through these channels, we also have continuous discussions with our supporters.





# **Capacity Building, Cooperation, and Partnerships**



# CAPACITY BUILDING, COOPERATION AND PARTNERSHIPS

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## **Membership engagement**

While GAMIAN-Europe currently enjoys a representative membership base, which supports our credibility, we aim to expand this. Our objective is to reach a Europe-wide membership, covering at least all EU Member States and all mental health conditions. We aim to support our members in their activities as well as facilitate the exchange of good practices, experience, and knowledge.

We are keen to involve our members in our activities and to find out what they need and expect from GAMIAN-Europe. We want to know what their priorities are and find out how they can be aligned with GAMIAN-Europe activities. This is done through email exchanges, surveys, phone conversations, webinars, and the GAMIAN-Europe Slack platform. Our members are involved in GAMIAN-Europe projects.

## **Actions**

### **Annual Convention**

GAMIAN-Europe's Annual Convention, serving as a vital element and tool for the cohesion and representation of the organisation, gathers members to share their expertise and collect input on GAMIAN-Europe's strategy and activities. The next Annual Convention will be held in 2021.

### **Regional Seminars**

Our regional seminars, which are smaller-scale events aimed at advancing knowledge on specific topics, provide another occasion for members to meet, exchange, and share information, best practices, and experiences from our members' countries.

### **Partnerships**

We are already collaborating with many other relevant stakeholders in the field of mental health, such as the European Federation of Associations of Families of People with Mental Illness (EUFAMI), European Brain Council (EBC), the European Federation of Neurological Associations (EFNA), the European Psychiatric Association (EPA), the European Patients' Forum (EPF), the European Union Medical Specialists (UEMS), the International Alliance of Patients' Organizations (IAPO), the European College of Neuropsychopharmacology (ECNP), the European Medicines Agency (EMA), and the Expert Platform on Mental Health - Focus on Depression, European Federation of Pharmaceutical Industries (EFPIA).

**These collaborations will be continued and strengthened as this will help amplify the voice of patients.**



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