



2020-2022 Work Programme

GAMIAN-Europe



GAMIAN-Europe

The voice of patients in mental health

www.gamian.eu

ABOUT US

'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

Our GAMIAN-Europe will address the following topics:

- **Depression**
- **Comorbidity**
- **Patient empowerment and self-management of treatment and care**
- **Effectively addressing schizophrenia**
- **Suicide prevention**
- **Digitalisation and e-health in mental health**
- **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?

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.



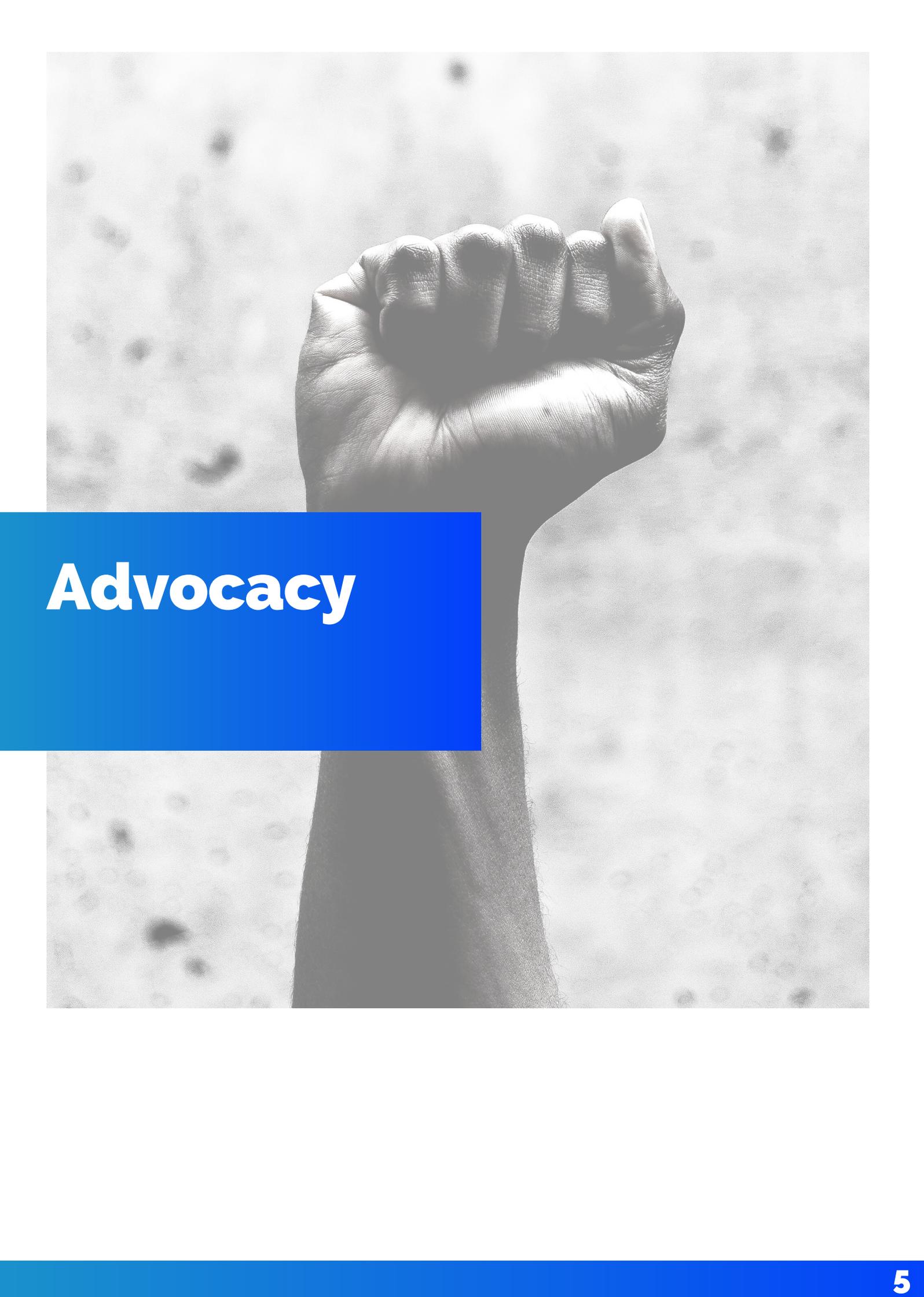
Advocacy



Information, Education, & Awareness



Capacity Building, Cooperation, and Partnerships



Advocacy

ADVOCACY

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.

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

It also lists the 6 areas of action that should be part of it, i.e.

- Inclusion of mental health as a priority in all relevant policy development: mainstreaming
- Awareness-raising and good practice exchange to facilitate mutual learning
- Stimulate the development of national action plans on mental health and well-being (as in EU cancer and rare disorder programmes)
- Financial support for innovative projects and advocacy efforts
- Meaningful data collection and research
- Inclusion of mental health stakeholders and experts by experience in policy development

One of GAMIAN-Europe's main policy priorities this year will be to step up our advocacy activities in relation to the development of such a Strategy, as there are some clear and current 'hooks' for this focus: the Finnish Presidency and EPSCO Council have invited the Commission to come forward with a Strategy on Mental Health. Health Commissioner Kyriakides has committed to being the champion for mental health within the new Commission.

GAMIAN-Europe will leverage this policy opportunity now, and will work in close alignment with other mental health stakeholders to secure this Strategy. The blueprint referred to above will be our main policy document.

MEP Alliance for Mental Health

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).



ADVOCACY

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.

The first meeting of this year took place in February and was organised in cooperation with Mental Health Europe. This meeting aimed to:

- Raise awareness of the need for a comprehensive EU Mental Health Strategy
- Raise awareness of the current policy opportunity to develop and implement such a Strategy and widen the MEP support base;
- Bring together all relevant stakeholders involved to explore and discuss the potential content of an EU Mental Health Strategy;
- Identify and agree on the most effective advocacy activities moving forward.

A comprehensive meeting report is available [here](#).

The agenda of the upcoming Alliance is not yet fixed, but the focus will be on GAMIAN-Europe's priority themes as well as on the interests of the MEPs. We are open to cooperation in organising meetings as well as to suggestions of specific meeting themes.





Information, Education, & Awareness



INFORMATION, EDUCATION, AND AWARENESS

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.

Actions

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 **suicide prevention in young adults**.

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 proposes the production and launch of a complement to the Schizophrenia Companion Guide. The present guide is an excellent tool to inform and educate patients, carers, and practitioners about the signs and treatment opportunities of schizophrenia. We now plan to develop a second guide that will inform on best evidence of:

- Health promotion and prevention addressing risk factors relevant to the lifestyles of people with schizophrenia
- Early detection and treatment of physical diseases associated with people with schizophrenia.

The guides will aim to:

- Provide accessible information - Evidence-based information to patients and families regarding schizophrenia and the promotion of healthy lifestyles that can reduce the risk of poor physical health and reduce early preventable death. The Guidewill seek to provide guidelines on how patients can improve and maintain their health and how families and friends can support them.



INFORMATION, EDUCATION, AND AWARENESS

- Work in partnership with practitioners – Patient-centred care and empowerment require an equal partnership between patients and practitioners. The Guide will be developed together with professional stakeholders, aiming to provide information and recommendations about good inclusive mental health and physical care.
- Connect patients across Europe - Learning from other patients' experience will be beneficial as it will help increase the understanding of the large number of people around Europe facing the same challenges. It will support families and carers in their efforts to exchange experience regarding health promotion activities and gaining the benefits from improved access to good quality health care.
- Empower patients - Patients should be able to recognise the challenges of their recovery process and learn the early signs of mental or physical health problems, being active and assertive partners in their care. They need to keep updated on the best practice related to their health challenges. GAMIAN-Europe's project will seek to encourage people living with schizophrenia and their families to be actively involved in the design of care plans, taking a holistic perspective of their health.

The Guide will be developed by GAMIAN-Europe in cooperation with EUFAMI. A Steering Group will supervise the content of the guide.

Patient-Clinician Experience Schizophrenia: In collaboration with the European Psychiatric Association (EPA), GAMIAN-Europe is planning to launch a project entitled 'Developing trust and effective care for people with schizophrenia: Patients and Psychiatrists working in partnership'. This project will identify the care experience of patients with schizophrenia, complemented by the narrative of mental health service providers. The two experiences will be brought together in a dialogue, leading to conclusions about desirable actions. The questions this process will address include:

- What does the interaction between patients with schizophrenia and mental health workers look like? What have been good and what have been negative experiences?
- What type of interventions facilitate a positive process[CM1] and ensure optimal benefit from treatment and care?
- What does system support for the psychiatric workforce from sectors such as social care, housing, and employment, limiting the scope of interventions to medical care, enabling holistic care look like?
- How can training and education of the mental health workforce be assessed, evaluated and, where necessary, optimised?

When both narratives have been produced, a meeting of all participants will be organised to discuss mutual experiences, facilitated by GAMIAN-Europe and EPA. The meeting will identify shared challenges and opportunities, and steps that would facilitate better care. A report will be produced jointly by GAMIAN-Europe and the EPA, describing some of the main patient and clinician experiences, and offering recommendations to policymakers, clinicians, training institutes, and patient groups.



INFORMATION, EDUCATION, AND AWARENESS

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 Depression: GAMIAN-Europe, in partnership with the European Psychiatric Association (EPA) will be working on a project called 'Developing trust and effective care: Patients and Psychiatrists working in partnership'. This will explore 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.

Major Depressive Disorder: This project unites multiple stakeholders working together on Major Depressive Disorder (MDD) with a focus on policy. To truly overcome stigma, it needs to be addressed more openly. For this reason, GAMIAN-Europe is part of the #BreakingDepression project, together with EUFAMI.



INFORMATION, EDUCATION, AND AWARENESS

'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 cancer, diabetes, and cardiovascular disease: A Patient Perspective:

This project aims to identify the experiences of patients and clinicians as well as the obstacles to care. Moreover, it intends 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

'GAMIAN-Europe's member organisations clearly possess the resources (users, professionals, experts, etc.) to help the design, development, and coordination of such evaluation systems.

If successful, GAMIAN-Europe will play a cross-Europe leading role in this emerging new field, which is also a new and challenging responsibility: people affected by mental ill-health would have better access to reliable online therapy and, in some EU countries, short term psychotherapy could be done through apps or websites.

Becoming part of an online community on Slack or similar platforms can also be a powerful tool for preventing loneliness and improving the mood of people affected by mental ill-health.

Some EU countries have platforms that allow connections with new people and discuss common interests while having facilitators on this platform to guide and inspire the conversation.

By means of this project we aim to look at one or more of several aspects regarding the interaction between digitalization and mental health. These aspects are:

- digital tools offered by healthcare providers to patients for self-diagnose
- social media apps and youth mental health
- the right to disconnect
- work-life balance (mental health and wellbeing in the digital era).

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: unravelling 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.
- **The European Brain Research Area project (EBRA)** was created as a catalysing platform for brain research stakeholders to streamline and better co-ordinate brain research across Europe while fostering global initiatives.
- **European Network of Active Living for Mental Health (ENALMH)** aims to enrich the therapeutic procedures of mental health services through the effective use of sport and physical exercise for the users.



ImpleMentAll



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. Survey topics will include stigma, e-health in mental health, capacity building of mental health patients and their organisations, COVID19 and mental health.

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

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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