In the current, Europe-wide efforts aiming to develop sustainable, patient-centred and cost-effective health systems, empowered patients are an essential part of the solution. Therefore, investing in patient empowerment should be seen as a priority.

Marco Greco, President, European Patients' Forum

This Call to Action aims to highlight the urgent need to stimulate the empowerment of those affected by mental ill-health and to recognise the vital role persons affected by mental ill-health can play in the management of their treatment and care, in partnership with health professionals and other care providers.

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Why a Call to Action?

The burden of mental ill-health is huge across the EU

It is increasingly recognised that the burden and prevalence of mental health conditions is huge: at least 27% of the European (EU, Switzerland, Iceland and Norway) adult population experience mental disorders every year. The proportion of the national health budget devoted to mental health ranges between 4% to 13% across the EU. Mental health conditions account for 22%-25% of the EU burden of disability, with neurologic and psychiatric disorders being among the third leading causes of disability-adjusted life-years in the WHO-Europe. Social and economic inequality and exclusion are both a cause and a consequence of mental ill-health.

Mental ill-health can affect persons at any age in a variety of forms (e.g. depression, bipolar disorder, schizophrenia, ADHD...). These conditions go hand in hand with substantial stigma, costs and consequences that impact individuals, families and informal carers, health and social systems, society and the economy.

Evidence shows that life expectancy can be reduced by mental disorders, sometimes with a greater impact than smoking or obesity. In particular, mental disorders can be the precursors to chronic diseases, consequences of them, or the result of interactive effects. In addition to a higher risk of physical illness such as coronary heart disease, Type 2 diabetes or respiratory disease, mental disorders (such as depression) often exacerbate unhealthy life styles including smoking, substance abuse, physical inactivity and insufficient sleep.

On the other hand, poor physical health increases the risk of mental ill-health: the risk of depression is doubled for people with diabetes, hypertension, coronary artery disease and heart failure, and tripled in those with stroke, end-stage renal failure and chronic obstructive pulmonary disease. Children experiencing a serious or chronic illness are also twice as likely to develop emotional disorders.

2 http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources
4 The ROAMER report states that this is up to 37% http://cordis.europa.eu/fas/projects/rcn/171328_en.html; also see Wittchen et al 2011, European Neuropsychopharmacology reporting that over 38% of the European population will experience a mental health problem in any given year.
5 ‘Informal carers’ refers to: family members, friends and neighbours and friends taking care of a person affected by mental ill-health.
6 www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources
There is an obvious need to address mental ill-health in the most effective way

Fortunately, good mental health is increasingly recognised as important for economic growth and social development; poor mental health is consistently associated with unemployment, less education, low income or standard of living, poor physical health, adverse life events and poor quality of life. However, across the EU, there is a lack of adequate mental health services and support available. Resources should be specifically ringfenced to enable the development of appropriate and accessible mental health treatment and care services and stimulate empowerment.

Empowered persons affected by mental ill-health should be seen as a resource in this respect

Patient empowerment is defined as a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important. This concept comprises many elements, such as health literacy, confidence, coping skills and self-management of treatment and care. It is opposed to ‘dism empowerment’ which refers to taking away power from an individual thus leaving them feeling helpless, without control over their live and less likely to succeed.

While the notion and need for patient empowerment has been increasingly accepted when it comes to persons affected by physical health conditions, this is not the case for those affected by mental ill-health; many individuals and organisations have highlighted the disempowering attitudes and behaviours towards people affected by mental ill-health which exist in society.

Dismempowerment occurs within health care, education, the workplace and society at large. While anti-discrimination legislation, promoting patient empowerment has been put in place in some countries, and while several organisations/ campaigns have contributed to positive change in this respect, discrimination and disempowerment towards persons with mental ill-health remain widespread. The stigma attached to having a mental health issue – as opposed to having a physical health issue - is pervasive and widespread; this stigma occurs at individual, organisational as well as at societal levels and is regarded as one of the main barriers to patient empowerment.

Self-management of care and treatment is an important element within the context of patient empowerment. Self-management refers to an ‘active engagement of the health care consumer in dealing with his or her disorder, meaning that the person with the disorder is an active participant in care, rather than someone who simply follows recommendations and complies with the treatment plan developed by a health professional. Interestingly, self-management can have as positive an impact on mental health as medical treatment, enabling people to lead fuller, more active lives. Self-management of chronic conditions is increasingly seen as a tool that may help struggling healthcare systems reduce costs and at the same time empower persons affected by mental ill-health. Many people with physical health problems already self-manage their care and treatment and are seen as competent and capable to do so.

However, when it comes to mental ill-health, questions are raised as to whether individuals affected by mental ill-health are able to meaningfully and effectively self-manage their care and treatment. In fact, for many of those affected by mental ill-health, lack of legal capacity is still the reality. However, most people with mental ill-health, most of the time, do have the competence to self-manage their treatment and care; they are able to comprehend the required information and to apply this to making rational decisions. They are able to develop the skills needed to manage their conditions: the majority of individuals affected by mental ill-health have the full capacity to manage their care.

11 https://www.mentalhealth.org.uk/a-to-z/s/self-management-mental-ill-health,
http://www.heretohelp.bc.ca/visions/self-management-vol1/self-management-in-the-mental-health-field,
12 http://www.heretohelp.bc.ca/visions/self-management-vol1/self-management-in-the-mental-health-field,
The overarching principle:

The need for parity of esteem of mental and physical health:

Parity of esteem is the principle by which mental health must be given equal priority to physical health, also in terms of resources. In some countries, the government requires health services to work for parity of esteem to mental and physical health. However, there are many areas where parity of esteem has not yet been realised. For instance, in the UK, mental ill-health account for 28% of the burden of disease but only 13% of NHS spending.

This lack of parity is a key element in disempowering those affected by mental ill-health.

The undersigned call on the following stakeholders to take action as a matter of urgency in order to turn patient empowerment into a reality:

Policymakers/governments should put into place health systems...
Policy makers should also take action with respect to the identification and dissemination of good practice – between professionals, persons affected by mental ill-health, family carers and other stakeholders at local, regional, national and European levels – as this would help to share and develop evidence-based models and enable positive change. They should also provide incentives to employers to enable people affected by mental ill-health (and their carers) to enter, participate and stay in the labour market. Governments should launch awareness campaigns to educate society about mental ill-health and facilitate more informed views and opinions.
Health care professionals should...

- be aware of their crucial role in facilitating and stimulating the empowerment of those affected by mental ill-health. They should work in partnership and treat them with dignity and respect, working towards the highest level of shared decision making.
- legally and ethically maximise the autonomy of those affected by mental ill-health and make use of non-invasive, non-traumatic treatments.
- inform and involve family carers in treatment and care plans of their relatives as they play a pivotal role in the implementation and success of these plans.
- take the potential of peer support into account when developing and implementing treatment and care plans.
- have a positive outlook and address the strengths of persons affected by mental ill-health and not focus on their limitations. Persons affected by mental ill-health should be viewed in a holistic way; the focus should be broader than their condition only. Treatment should have a recovery focus and should be multi-modal (medication, psychotherapy, coaching, life-skills...)
- view the provision of information to persons affected by mental ill-health and their carers as a key professional task; they can contribute to health literacy – a crucial element in self-management of treatment and care. Information should be accessible (easy to obtain and easy to understand). Where and when needed, persons affected by mental ill-health and carers need to be informed of the specific condition and its warning signs, medication prescribed and possible side effects of pharmacological treatment.

Persons affected by mental ill-health should...

- make efforts to get better organised in order to strengthen their voice as well as allowing for the provision of peer-support (counselling, information, practical support, psycho-education...). Peer support networks are self-empowering as well as helpful to persons affected by mental ill-health.
- take an active stance and learn about their condition and its management, as experts of their condition and their needs and requirements.
- become and be more aware of the positive role they can play in managing their care and treatment, in so far as they are capable of doing so.
- regularly check the physical health of people affected by mental ill-health and the mental health of those affected by physical health problems. Being diagnosed with a specific (mental or physical) condition should not lead to a sole focus on that condition: in many cases, persons affected by mental ill-health are affected by multiple conditions and these should all be addressed in parallel.
- put in place better ways of communication and cooperation with the different medical disciplines involved (GPs, psychiatrists, other medical specialists or health care professionals) as well as with social services.
- pay special attention to children and their mental well-being. Early detection is key; the earlier the detection, the better chance of recovery and effective treatment.
- ensure a seamless transition when persons affected by mental ill-health move from childhood to adult mental health services.
- should strive for informed consent and avoid coercion to the largest extent possible.
- engage in meaningful dialogue with policymakers (regarding services development and implementation) health professionals and family carers (working in partnership towards shared decision making).
- participate in training and educational programmes, sharing the views and experiences of persons affected by mental ill-health. This will help bridge the gap between persons affected by mental ill-health and health professionals.
Years of under-investment in mental health means that persons affected by mental ill-health often experience poorer access to services and lower quality of care than those with physical health conditions. Clearly, mental ill-health needs to be better addressed as a matter of urgency and at a variety of different levels. Involving those affected by these conditions with the treatment and care decisions that affect them will ensure patient-centredness as well as treatment relevance. This in turn will translate into more effective treatment and care, which will contribute to sustainable health systems and budgets. This in turn will help increase the self-confidence and facilitate the integration on people affected by mental ill-health in the community.

Persons affected by mental ill-health should be seen as resource in this respect, and empowering persons affected by mental ill-health will ensure the best possible ‘use’ of that resource, while putting them at the heart of care provision.

Primary and secondary schools should...

- ...address mental health in their educational programmes and encourage children to speak about their emotional problems. This would help ‘normalise’ mental ill-health.
- ...change their policy and, rather than trying to get all children to do the same things, treat children as individuals and help them to find their individual strengths.

Informal carers should...

- ...ensure the involvement of persons affected by mental ill-health and their carers when deciding on what services are required (e.g. supported housing, contacts with social workers...) and how these should be provided.
- ...take a holistic approach and take the entire situation of the patient into account.
- ...work with the other health professionals involved in order to ensure coordination and integration of care.

Social services should...

- ...ensure equal priority to physical and mental health in relation to resources, reimbursement of the best and most appropriate treatment and care. Mental health remains under-resourced across the EU.
- ...recognise that prejudice plays a significant part in decisions that relate to reimbursement of mental health treatment and care. The coverage in this area is much less than the coverage for physical health conditions. This holds true for medical interventions and treatment as well as for psychotherapy, counselling, peer support and other forms of treatment.
- ...address the lack of parity of esteem between physical and mental health as a matter of urgency, also in view of the fact that there is increasing evidence that the return on investment is highest in the field of psychiatry.

Health insurances should...

- ...aim to ensure a holistic approach in health care training and education curricula, both those aimed at medical students as well as those targeting retraining and life-long learning curricula. Aim to stimulate an open mindset, in order for health professionals to take the views of persons affected by mental ill-health into account and be open to the concept of shared decision making and patient-centredness.
- Persons affected by mental ill-health can be involved in education with respect to shared decision making and patient-centred care, which is useful for medical students and health professionals on the one hand side as well helpful to empowering persons affected by mental ill-health on the other.
Research institutes should...

- engage in more dedicated research in the field of mental health. The EU-funded ROAMER project resulted in a roadmap for priority research, focusing on social, societal and medical aspects of mental ill-health and provides a useful guide towards useful research. Examples: persons affected by mental ill-health and their specific needs and requirements, the impact of interventions and treatment (medical, psychological, peer support...), decision making models.
- not forget about carers when undertaking research in the field of mental health.
- redress the balance and ensure that mental health receives the same amount of attention as physical health in health research.
- include persons affected by mental ill-health, and their family carer(s), where possible, in a meaningful way and advisory capacity to ensure the relevance of research to those directly affected.
- pay attention to the translation of research findings into (good) practice.

Employers/social partners should...

- offer adapted working conditions to enable people affected by mental ill-health to enter, participate, remain in and return to the labour market, as good work is empowering and beneficial for mental health and well-being. Work can support recovery.
- address the lack of understanding as well as the lack of knowledge about how to support people in the workplace. Some examples of support measures: flexible working hours or patterns, changes in the physical environment, support with work load and support with/ from colleagues.
- share examples of good practice of what works.

This Call to Action was developed with the kind support of Ferrer
Annex 1

Endorsing organisations
Annex 2

How this Call to Action was developed

On 7 March 2018, GAMIAN-Europe convened an expert workshop on the issue of empowerment and self-management of mental health care and treatment, as a first and crucial step towards the development of this Call.

This meeting brought together key stakeholders with an interest in empowerment of persons affected by mental ill-health and better management of their care (this includes patient organisations, health professionals organisations (psychiatrists, psychologists, GP’s, mental health nurses), carers and policy makers and had the following objectives:

1. explore the current situation in relation to the empowerment of people affected by mental ill-health and their ability to self-manage care and treatment;
2. identify the barriers to empowerment and self-management of care, both to persons affected by mental ill-health as well as their carers;
3. come forward with recommendations to improve the situation.

The outcome and content of the discussions was used as the basis of a Call to Action on patient empowerment and self-management of care, which was then further elaborated; participants had the possibility to take a critical look at a draft and provide input and comments. This second version was discussed in a meeting of the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders, taking place on 16 May 2018 and finalised on the basis of input received on that occasion.

Annex 3

7 March Workshop participants

1. ADHD-Europe
2. ADHD, ASC&LD Belgium
3. Anoiksis
4. ELIFAM
5. Eurocarers
6. European Brain Council
7. European Federation of Psychologists Associations
8. European Persons affected by mental ill-health’ Forum
9. European Psychiatric Association
10. European Psychiatric Association
11. Ferrer
12. GAMIAN-Europe
13. GAMIAN-Europe
14. GAMIAN-Europe
15. GAMIAN-Europe
16. GAMIAN-Europe
17. Mental Health Europe
18. Hospital Gregorio Maranon
19. Standing Committee of European Doctors
20. Union Européenne Médicaux Spécialistes
21. University of London
22. Ups and Downs
23. Ups and Downs

Joanne Norris  Board Member
Beverley Sinton  Vice-President
Leo Finn  Board Member
Margaret Walker  Executive Director
Stecy Vghemonos  Director
Fred Destrebecq  Executive Director
Ruta Sargautyte  Associate Professor Psychology, Vilnius University
Lyudmil Ninov  Policy and Scientific Officer
Mari Fresu  Trainee
Ulrike Kool  Corporate Director, Patient Advocacy & Public Affairs
Alfredo Gracia  Board Member
John Bowis  Board Member
Dolores Gauci  Secretariat
Lina Papartyte  EU Advisor and workshop organiser
Christine Marking  Executive Director
Nigel Olisa  Project Manager
Marcin Rodzinka  Professor of Psychiatry
Alfredo Calcedo  EU Policy Advisor
Markus Kujawa  President Psychiatry Section
Marc Hermans  Freelance researcher
Angela Coulter  Board Member
Erik Van der Eycken  Board Member
Anouk Drieskens  Board Member
OVERALL OBJECTIVES

ADVOCACY

Act as the voice for patients and demonstrate that this voice is useful as well as indispensable.

Ensure that patients are at the centre of all aspects of healthcare provision.

Work to improve the availability, and quality of treatment for all mental health problems.

INFORMATION & EDUCATION

Improve the provision, Reliability & quality of information on mental health problems for patients as well as the general public.

Assist in improving the training, education and understanding of mental illness of health and other professionals.

STIGMA & DISCRIMINATION

Increase awareness, knowledge and understanding of mental health problems.

Help reduce stigma, prejudice, and ignorance in relation to mental health problems and fight discrimination.

PATIENTS RIGHTS

Focus on the development and enforcement of rights for persons affected by mental health problems, e.g. access to appropriate treatment.