



## Improving patient empowerment and self-management of care in mental health<sup>1</sup>

### A Call to Action

*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.*

"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*

### 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<sup>2</sup>. 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<sup>3,4</sup>. 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 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

<sup>1</sup> <http://psychopathology.imedpub.com/empowering-people-with-mental-illness-within-health-services.php?aid=17223>,  
<http://psychopathology.imedpub.com/empowering-people-with-mental-illness-within-health-services.php?aid=17223>,  
[https://www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/\\$File/servpri.pdf](https://www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/$File/servpri.pdf),  
<http://www.ccomssantementalelillefrance.org/sites/ccoms.org/files/pdf/Empowerment%20and%20Mental%20Health%20in%20Community.pdf>

<sup>2</sup> <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources>

<sup>3</sup> [https://www.mentalhealthandwellbeing.eu/assets/docs/publications/Framework%20for%20action\\_19jan%20\(1\)-20160119192639.pdf](https://www.mentalhealthandwellbeing.eu/assets/docs/publications/Framework%20for%20action_19jan%20(1)-20160119192639.pdf)

<sup>4</sup> The ROAMER report states that this is up to 37% [https://cordis.europa.eu/result/rcn/171328\\_en.html](https://cordis.europa.eu/result/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 problems in any given year.

depression) often exacerbate unhealthy life styles including smoking, substance abuse, physical inactivity and insufficient sleep<sup>1,2</sup>.

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.

### ***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'<sup>3</sup>. This concept comprises many elements, such as health literacy, confidence, coping skills and self-management of treatment and care. It is opposed to 'disempowerment' which refers to taking away power from an individual thus leaving them feeling helpless, without control over their lives and less likely to succeed<sup>4</sup>.

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.

Disempowerment 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<sup>5</sup>. 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<sup>6</sup>. 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

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<sup>1</sup> [www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources](http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources)

<sup>2</sup> <http://www.ox.ac.uk/news/2014-05-23-many-mental-illnesses-reduce-life-expectancy-more-heavy-smoking>

<sup>3</sup> [http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing\\_paperpatient-empowerment\\_final\\_external.pdf](http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing_paperpatient-empowerment_final_external.pdf)

<sup>4</sup> <https://psychopathology.imedpub.com/empowering-people-with-mental-illness-within-health-services.pdf>

<sup>5</sup> <http://psychopathology.imedpub.com/empowering-people-with-mental-illness-within-health-services.php?aid=17223>

<sup>6</sup> <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>,

[http://www.euro.who.int/\\_data/assets/pdf\\_file/0018/124560/E94377.pdf.pdf](http://www.euro.who.int/_data/assets/pdf_file/0018/124560/E94377.pdf.pdf), <https://www.rethink.org/living-with-mental-illness/recovery/tools-for-recovery/self-management>, <http://mentalhealthrecovery.com/info-center/mental-illness-self-management-through-wellness-recovery-action-planning/>,

than someone who simply follows recommendations and complies with the treatment plan developed by a health professional'.<sup>1</sup> 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<sup>2</sup>. 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<sup>3,4</sup>.

***This Call to Action highlights what can be done to empower persons affected by mental ill-health and to engage them as partners in care***

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.

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<sup>1</sup> <http://www.heretohelp.bc.ca/visions/self-management-vol1/self-management-in-the-mental-health-field>

<sup>2</sup> <http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/pe-conference-report.pdf>

<sup>3</sup> <https://www.rethink.org/living-with-mental-illness/recovery/tools-for-recovery/self-management>

<sup>4</sup> <http://www.heretohelp.bc.ca/visions/self-management-vol1/self-management-in-the-mental-health-field>

## ***A Call to Action***

### ***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<sup>1</sup>, 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...***

- ...which are patient-centred, personalised, recovery-oriented, appropriately resourced and geared towards patient empowerment. They should be easy to access (e.g. affordable, limited waiting times, limited distances, provide reliable information on what is available and what persons affected by mental ill-health and carers are entitled to) and take account of the expertise of persons affected by mental ill-health in relation to their condition.
- ...which are less fragmented; there should be better coordination and communication between health and social services as well as between the various medical specialists.
- ...which aim to keep persons affected by mental ill-health in the community to the largest possible extent; community-based services need to be strengthened and developed.
- ... which effectively support the human rights as well as the capacity and competence of people affected by mental ill-health to manage their condition.
- ...which cater for a more holistic, proactive and preventative approach. Early detection and diagnosis is key; secondary and tertiary prevention are also crucial.
- ...which officially recognise peer support as beneficial to persons affected by mental ill-health.
- ...which are geared towards supporting persons affected by mental ill-health in the decision-making processes and aim for the least restrictive treatment and care alternative, safeguarding their freedom as much as possible<sup>2</sup>.
- ...which grant persons affected by mental ill-health the right of appeal of against decisions that are taken for him/her.
- ...which help organisations to build capacity and support their efforts to amplify the voice of persons affected by mental ill-health as well as the practical services these organisations offer to persons affected by mental ill-health and their carers (e.g. psycho-education, peer support, dissemination of good practice).
- ...which offer people using mental health services (persons affected by mental ill-health and carers) around the clock access to a crisis team.

<sup>1</sup> <https://www.centreformentalhealth.org.uk/parity-of-esteem>

<sup>2</sup> as also stipulated by the UN Convention on the Rights of Persons with Disabilities, Article 12

- ...which meaningfully engage in dialogue with persons affected by mental ill-health with respect to their needs and how the system is providing the care and treatment they need, giving persons affected by mental ill-health and their families a voice in the development of services.
- ...which recognise and take account of the pivotal role played by family carers in terms of care and support offered to relatives affected by mental ill-health. Research has indicated that the risk of developing a mental health condition is 20% higher for carers who do not receive any support. Systems need to ensure that there are support services in place, such as information, training and respite care. Assessment of carers' needs and situation, and support in cases where the burden is too heavy, is also vital.
- ...which allocate appropriate resources for mental health care and management, ensuring that people with mental ill-health are empowered to manage their condition is so far as they are capable to do, having access to the most appropriate and innovative treatment and care.
- ...which provide reassurance to individuals in the form of distance monitoring and the use of 'E' and 'M' Health.

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 either 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 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.
- ...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.

#### 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.
- ...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.

#### Informal carers should....

- ...advocate for recognition of their role, contribution in the care provision and knowledge of their relatives affected by mental ill-health. This contribution needs to be recognised by policymakers/governments and catered for by health systems and health professionals.
- ...call for better access to information regarding the condition of the patient they care for, of the basic rights and entitlements, and the treatment plan in place.
- ...advocate their needs for support, in practical as well as psychological terms.
- ...request access to training to help them with the daily care needs of their relatives.
- ...advocate the option NOT to provide care. Caring should not be seen as an obligation but rather as an informed choice.

#### Social services 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.

### Health insurances 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.

### 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.

### Health and care related higher education institutions 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<sup>1</sup> 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.

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<sup>1</sup> [https://cordis.europa.eu/result/rcn/171328\\_en.html](https://cordis.europa.eu/result/rcn/171328_en.html)

*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.

**LOGOs of endorsing organisations to be added**



## **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**

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|--|---------------------|---|
| 1. ADHD-Europe   | Joanne Norris       | Board Member  |
| 2. ADHD, ASC&LD Belgium                                  | Beverley Sinton     | Vice -President                                       |
| 3. Anoiksis  | Leo Finn            | Board Member  |
| 4. EUFAMI  | Margaret Walker     | Executive Director                                    |
| 5. Eurocarers  | Stecy Yghemonos     | Director  |
| 6. European Brain Council                                | Fred Destrébecq     | Executive Director                                    |
| 7. European Federation of Psychologists Associations     | Ruta Sargautyte     | Associate Professor Psychology, Vilnius University    |
| 8. European Persons affected by mental ill-health' Forum | Lyudmil Ninov       |   |
| 9. European Psychiatric Association                      | Mari Fresu          | Policy and Scientific Officer                         |
| 10. European Psychiatric Association                     | Ulrike Kool         | Trainee   |
| 11. Ferrer   | Alfredo Gracia      | Corporate Director, Patient Advocacy & Public Affairs |
| 12. GAMIAN-Europe  | John Bowis          | Board Member  |
| 13. GAMIAN-Europe  | Dolores Gauci       | Board Member  |
| 14. GAMIAN-Europe  | Nigel Olisa         | Executive Director                                    |
| 15. GAMIAN-Europe  | Lina Papartyte      | Secretariat   |
| 16. GAMIAN-Europe  | Christine Marking   | EU Advisor and workshop organiser                     |
| 17. Mental Health Europe                                 | Marcin Rodzinka     | Project Manager                                       |
| 18. Hospital Gregorio Maranon                            | Alfredo Calcedo     | Professor of Psychiatry                               |
| 19. Standing Committee of European Doctors               | Markus Kujawa       | EU Policy Advisor                                     |
| 20. Union Européenne Médicaux Spécialistes               | Marc Hermans        | President Psychiatry Section                          |
| 21. University of London                                 | Angela Coulter      | Freelance researcher                                  |
| 22. Ups and Downs  | Erik Van der Eycken | Board Member  |
| 23. Ups and Downs  | Anouk Drieskens     | Board Member  |