



EUROPEAN PSYCHIATRIC ASSOCIATION

Interest Group on Mental Health, Wellbeing and Brain Disorders



3 December 2018, European Parliament, Brussels

Event Report



Part 1 – a focus on policy



Tomas Zdechovsky MEP opened the meeting, reminding the audience of the aims of the Interest Group, i.e.: to advocate the development of sound EU policies which contribute to prevention of mental health problems and ensure good services, care and empowerment for those affected by mental health problems.

He welcomed the fact that this meeting was jointly organised with the European Psychiatric Association and underline that, while GAMIAN-Europe is responsible for the coordination of the Interest Group, the Group is open to other organisations; today's meeting is a positive example of this openness.

He also underlined the timeliness of the meeting and its topic, as the EU is on the verge of

embarking on a new and ambitious R&D effort; this needs to take mental health into account in a concrete way for a variety of reasons, such as the increasing recognition of the burden and prevalence of mental health conditions and the large proportion of the European population experiencing mental disorders every year. This goes hand in hand with a large proportion of the national health budget devoted to mental health, ranging between 4% to 18 across the EU.

Tomas Zdechovsky underlined that people affected by mental ill health should be at the centre of their treatment and care and be viewed as a partner in the care process. The aims of the meeting therefore were to "People affected by mental ill health should be at the centre of their treatment and care and be viewed as a partner in the care process."

- underline the importance of person-centred mental health research and care and increase the visibility of this topic;
- exchange views on how a person-centred perspective can be ensured in EU funded and other research addressing mental health;
- inform about ongoing research focusing on mental health in a person-centred way;
- stimulate discussion amongst stakeholders and forge links for future cooperation;
- underline the importance for Horizon Europe to take person-centredness as a guiding principle for future EU-funded mental health research.



"Efforts need to be made to ensure that mental health and person-centred research and care are an explicit part of this agenda."

Co-chairing the meeting, **Prof Silvana Galderisi** (President, EPA) also emphasised the timeliness of the meeting. She noted that disempowering attitudes and behaviours and stigma towards people with mental illness still exist in society. Clearly, there is an obvious need to address mental health conditions in the most effective way.

Issues related to mental health care and services have increasingly been part of EU and national research agendas. In parallel, the notion and importance of person-centred mental health services has gained ground. There is general consensus on the crucial importance of this concept: all mental health stakeholders - e.g. patients, healthcare professionals, policymakers, care and service providers - agree that person-centredness is essential if appropriate and high-quality care services are to be developed and delivered, based on this crucial principle.

A number of recent and current EU-funded research projects have already explicitly taken and are taking this perspective into account. As the EU is currently developing Horizon Europe efforts need to be made to ensure that mental health and person-centred research and care are an explicit part of this agenda.

Silvana Galderisi underlined that the European Psychiatric Society is devoting much attention to this topic; it is one of its priorities and basic principles.

She then gave the floor to the first speaker, Wolfgang Burtscher (European Commission, Deputy Director-General, DG Research and Innovation), who agreed that the disease burden associated with mental health disorders is indeed huge. Prevalence is high, and related (direct and indirect) productivity losses are estimated at 600 billion euro per year.

There are a number of specific challenges related to mental health disorders: they are severely underdiagnosed, e.g.80% of depressions remain undetected. Disease classifications, and hence diagnosis, depend largely on outdated clinical symptoms codes, with few measurable biological variables linked to causative mechanisms. Co-morbidities are frequent. Pharmaceutical investments in new drug development are decreasing. This is why mental health disorders are a priority for the Commission and it is encouraging to see that this concern is shared by the European Parliament and other relevant stakeholders. Mr Burtscher recalled the various initiatives at EU level in the area of mental health since 2004, and emphasised the recent bi-annual report entitled 'Health at a Glance: Europe', which specifically makes the case for the need to improve mental health across the EU.

In the field of research and innovation, the EU's Horizon 2020 framework programme has spent some 3.2 billion euro on mental health/brain research in general. A good number of EU-funded projects focus on



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developing eHealth tools to prevent, monitor and treat mental ill health, ensuring that patients are able and willing to use these devices in their everyday life.

The large-scale public-private partnership between the EU and the pharmaceutical industry, the Innovative Medicines Initiative, has also undertaken targeted efforts to boost the development of new drugs for mental health disorders and of new monitoring devices.

Mental health disorders occur throughout the life span, from developmental disorders afflicting children and adolescents to adults during their work life and older people (dementias, mood disorders); Horizon 2020 caters well for this lifespan approach, which is proposed to be continued under Horizon Europe, the next EU research and innovation framework programme. A new Coordination and Support Action, i.e. the European Brain Research Area (EBRA), will help coordinate EU brain research. Organisations present today are involved in this work.

Turning to Horizon Europe and its focus on mental health, Mr Burtscher stated that the Commission has proposed a health cluster with a substantial budget of 7.7 billion euro, health research also being supported through other important funding instruments such as the European Research Council. The proposal deliberately does not single out individual diseases but it is clear that Horizon Europe will continue to focus strongly on mental health disorders, in particular through the first intervention area proposed for this cluster, which is 'Health throughout the Lifespan'. The focus on personalised medicine and intervention areas on digital solutions and healthcare systems will enable more patient-centred approaches.

The Commission has a track-record in addressing and promoting personalised medicine; Horizon Europe will now take this one step closer to citizens and patients, bringing personalised medicine into every day practice, also building on the unprecedented opportunities that digitalisation can provide.

In conclusion, Mr Burtscher reminded the audience of a conference forming part of the European Public Health Conference in Ljubljana at the end of November, entitled 'Public Mental Health throughout the lifespan'. He underlined that the prospects for mental health research and patient-centred health solutions are bright in general. And even more so for patient-centred approaches to detect, prevent, monitor, treat and care specifically for mental health disorders.

Silvana Galderisi then invited **Tomas Zdechovsky MEP** to inform the audience of the view of the European Parliament in relation to Horizon Europe. He informed the audience of the European Parliaments deliberations relating to next year's budget and the efforts to secure the highest possible budget for Horizon Europe; he personally advocates a sizable budget for mental health as the prevalence, burden and consequences of mental ill health call for more attention. Stigma is another issue, impacting patients but also relatives and social systems. There needs to be an open dialogue with relevant organisations, stakeholders and the Commission to ensure that mental illness can become a 'normal' part of society.

Panel response



Silvana Galderisi (EPA) stated that, in order to ensure a meaningful place for person-centred mental health research and care at EU and national level, more EU funding will be needed. Today, in Europe, funding for mental health research is much lower than justified by the impact of these disorders at the individual, family and social level. Horizon Europe could be a useful opportunity to shape person-centred policies and programmes. However, the allocated budget of 7.7 billion euro to the health cluster does raise concern within EPA and its partners, as this amount will be insufficient to address the societal challenges associated with mental health issues. In addition, it confirms a steady decrease of funding compared to earlier R&D Framework Programmes.

Research has shown that patient-centred care and research is associated with more favourable outcomes, increased collaboration in diagnostic and treatment plans, lower number of errors, reduction of stigma, reduction of substance abuse and improved quality of life. It therefore stands to reason that this should be the consistent approach to mental health, in research as well as in policy and care and services development.

There are a number of key topics for research on patient-centred mental health research and

care, as already identified by the ROAMER project, outlining a mental health research agenda for the future. However, different stakeholders have different priorities. For psychiatrists, key topics relate to early detection and management of

mental disorders, new medications for mental disorders, increasing access to available treatments and prevention. For patients, key topics are new psychological interventions, stigma and discrimination, rehabilitation and social inclusion, health and well-being of carers. And there are others, such as the users' perspective and unmet needs, self-management and e-mental health, mental health/mental disorders across the life span, person-related

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outcome measures (PROMs) and person-reported experience measures (PREMs) and barriers to implementation of person-centred research and care. We should speak with one voice and identify common ground; in any case, research should take place at clinical level (identifying clinical profiles predicting specific outcomes), at biological level (identifying endophenotypes enabling more precise diagnostics and treatment interventions) and at public health level (making the individual central in all decisions relevant to research and care implementation).



Hilkka Kärkkäinen (GAMIAN-Europe) briefly presented GAMIAN-Europe as a representative coalition of patient organisations that seeks to put patients at the centre of all issues of the EU healthcare debate. The organisation brings together and supports the development and policy influencing capacity of local, regional and national organisations active in the field of mental health. GAMIAN-Europe has members in 25 European countries and a strong partnership with recognised European-level organisations such as EPA, EUFAMI and EBC.

Hilkka Kärkkäinen underlined that patient-centredness strongly features on her organisation's agenda. It is not just a word; it is

the principle upon which all its advocacy, information and education work is built.

One example: earlier this year, GAMIAN-Europe developed a Call to Action aiming to highlight the need to improve patient empowerment and self-management of care in mental health. This work was done in cooperation with some 15 relevant stakeholders (including the European Brain Council, EPA and EUFAMI); many others endorsed the Call before its formal launch in September. The Call contains specific recommendations for all stakeholders involved with mental health management, care and cure: policymakers, health professionals, payers, patients themselves, carers....as well as researchers. More specifically, it states that dedicated research on mental health is needed. Use should be made of the ROAMER roadmap, listing research priorities for the future and based on extensive stakeholder consultation (e.g. the specific needs of persons affected by mental ill health, the impact of interventions and treatment).

Research should also include those that provide informal care; and parity of esteem of physical and mental health should be ensured. We also need to pay attention to the translation of research findings into good practice. And last but not least: persons affected by mental ill-health should be included where possible in a meaningful way to ensure the relevance of research for those affected.

Patient-centredness should be the guiding principle for Horizon Europe-funded health research and Hilkka Kärkkäinen expressed her hope for this meeting to provide a strong impetus for the Commission to not only have a stronger focus on mental health – but rather, to have the <u>right</u> focus. A strong and united voice of the mental health sector will help achieve this aim.

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The final panellist, **Frédéric Destrébecq (European Brain Council)** briefly introduced his organisation as a non-Profit organisation gathering patient associations, major brain-related societies as well as industries. Established in March 2002, its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe.

He welcomed the Commission's ambitious proposal and <u>budget</u> for Horizon Europe, and its efforts to support and promote research as a whole. However, the EBC regrets to note that, despite the overall budget increase as compared to Horizon 2020, the budget for the next programme's health cluster has not increased. This means that the budget for health research has actually decreased in relative



terms. EBC and other organisations have elaborated and released a joint policy statement to flag this relative decrease.

In relation to the <u>structure</u> of the programme, more particularly the structure of the health cluster, it is not clear how brain and mental health research is being incorporated in a prominent and meaningful way. The leading role of the EU in setting the research agenda of third parties should not be underestimated; if the Commission is seen to prioritise the brain and mental health as important areas of intervention, it will lead to greater interest and support from others.

With respect to the concept of <u>missions</u> - a novelty in Horizon Europe, i.e. areas where the EU can truly add value, indicate clear directions and targets with measurable and realistic objectives – Frédéric Destrébecq stated that brain and mental health research should be one of those, and be addressed in a holistic and integrated way.

He underlined that, if private actors and third parties are pulling out of mental health and brain research and if the public sector does the same, then there will be no progress and change. It is the role of EBC and its members to advocate this topic and to make concrete suggestions to improve the proposal, with research on the brain and mental health clearly earmarked. The efforts of EPA and GAMIAN-Europe, working with EBC have been very welcome in this respect.

Lastly, Frédéric Destrébecq informed the meeting of EBC's involvement in the European Brain Research Area (EBRA) project, launched some 10 days ago, which will set out a proactive strategic agenda for the European

Commission and research funders in relation to brain and mental health research. It will provide EBC and other stakeholders with a platform for sharing priorities in a vocal manner and influence future priority setting.



Miia Männikkö (EUFAMI) provided her view on patient-centred mental health and care from the perspective of families - the main carers for people affected by mental ill health.

Research carried out by the OECD has revealed that mental health problems affect more than 1 in 6 people across the EU each year (83,5 million citizens). Therefore, the number of families affected by mental ill health is enormous, amounting to 167 million of people in Europe. This represents a real burden in terms of cost - research is imperative to help bring change for all those concerned.

EU-funded research can develop innovative and interdisciplinary approaches to improve the lives, not only of the person affected but also of the whole family.

However, the crucial role of families in the provision of care to people affected by mental ill health is not reflected in research interests. In many cases, family members feel that their experiences are not fully listened to or heard, not least by researchers. Very little research has been done in relation to the impact of mental illness on the family. The EU would therefore need some mechanism – funding? - to make family-centred mental health research more interesting for researchers.

The EU has to develop a better understanding of the key role played by families and carers, saving billions of Euros to governments' health and social care budgets. Research could address the support methods developed by families in their organisations – e.g. psycho-educational training, peer support groups) as there is a need for an evidence base on 'what works'. This training is lacking in many Eastern European countries as there is no translation, evaluation and no research into the needs of families. The -sometimes complex- relationship between patients, families and health professionals needs more research as well.

The economic value of family care could be investigated and documented better. Carers spend on average 22 hours a week for caring, and this represents enormous savings. There are gender issues as well as 80% of family carers are female. Combining work and family responsibilities can be very challenging for these carers.

EUFAMI itself has been involved in research projects, mainly as an advisor or as playing a role in the dissemination and communication. A more active role would be desirable. Positive examples of involvement are the IMI PRISM project, which started in 2016. The EBC's Value of treatment project is another positive example. Inclusion of patients and patient-representative organisations is key to ensuring that research projects are aligned with the real needs and priorities of patients and their families. Clearly, all those involved in research and benefiting from research would stand to gain from involving patients and patient representatives from the earliest stages of planning and not just once the key components of a project have already been agreed.

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Audience debate



In the audience debate, chaired by **Tomas Zdechovsky MEP**, the following issues were raised:

- More support and more resources are needed for mental health research, also in relation to biomarkers. However, the industry will not invest unless they see an opportunity for success.
- The concept of person-centredness has many meanings and is used in different ways. Before taking on this concept as a core priority, consensus on what it actually means would be required. It encapsulates personalised, holistic, targeted treatment; it relates to including patients in the framework of research and to improving care. The medical as well as the psychosocial model come into play.
- ROAMER is indeed a good basis to identify key issues. However, we have to avoid overlap
 between national and EU research agendas. The Commission is keen to receive input from
 stakeholders regarding setting the research agenda and determining what should be done at
 which level.
- The Commission is proud with respect to the budget allocated to health research. Of course,
 it could be more, but there are other priorities as well. In any case, apart from the specific
 health cluster, there are possibilities to address health in other parts if the programme (e.g.
 environment, social research).
- Research on biomarkers is crucial and making headway in a number of practical areas such as tests predicting responses to antidepressants.
- It was again pointed out that all research areas addressed by Horizon Europe have increased

 apart from health. In absolute terms, the budget has remained the same. However, if there
 are ways to compensate and address health under other clusters of the programme, that
 would be positive.

Part 2 – A focus on practice



Prof Philip Gorwood (President-elect, EPA), chairing the second part of the meeting underlined the importance of implementation of personcentred care and research. He sees this global concept as parallel to the recent approach used in everyday practice of "shared decision making", where patients are systematically involved in medical decisions concerning their health care. The fundamental principle of personcentred care and research is guiding the work of the EPA, as can be seen from the various projects EPA is involved with. The organisation participates in research projects such as the 'Value of Treatment',

'Developing trust and effective care' (together with GAMIAN-Europe), a joint Call to Action to invest in mental health research and a European Implementation

Partnership on Mental Health and Well-being, the Commission's public consultation on future research and in the EBC Brain Missions. EPA also works closely with GAMIAN-Europe and EUFAMI; both organisations are now represented in the EPA Board.



Prof Gorwood then gave the floor to **Dr Michela Tinelli (Personal Social Services Research Unit, The London School of Economics)**, who addressed whether research in mental health actually addresses personcentred outcomes. Health care costs continue to rise and mental disorders become more prevalent internationally. Unfortunately, the quality of care for mental disorders remains suboptimal; gaps in access to mental health services remain across Europe. Health care providers and decision makers need valid information on quality of care in order to identify population needs and make decisions on how to provide the best services as well as to apply effective strategies to improve quality and reduce disparities.



Dr Tinelli, addressing the question of where person-centred outcomes can

be used, underlined the various domains that could be looked at in this respect such as the effectiveness and safety of care – does it reduce symptoms, improve function, improve quality of life? Does it cause harm e.g. complications? And what do patients think of the process of care provision - dignity, information, trust in staff, timeliness?

Referring to current practice Dr Tinelli informed the audience that the use of person-related outcome measures (PROMs) does not feature very visibly in academic literature. The data seems

"There should be more research of better quality, in terms of setting and interventions." to be insufficient; PROMs are reported in very few studies and the findings are subject to considerable uncertainty. There should be more research of better quality, in terms of setting and interventions. Research should also focus on symptoms and length of treatment; studies should measure potential harm, quality of life, social functioning, personal experiences and the costs of treatments (for the healthcare provider and for public funding provider perspectives).

A good example of such a study is the ESSENCE (EconomicS of Social carE CompEndium) Project. This looks at adult social care interventions (beyond pharmacological treatments) applied to mental health (together with other diseases/ user groups/settings etc.).

Apart from research, new measures should be developed and implemented to ensure a balanced portfolio of measures, addressing effectiveness of care (symptoms, functioning in daily life, quality of life), safety and the experience of care, reflecting the views of patients and care management choices.

Moreover, person-centred outcomes should to be embedded within existing electronic health records and other information technology tools and become part of routine data assessment and measurement. There should be a better use of person centred outcome measures, in terms of effectiveness research, comparison of performance and shared decision making, such as the LSE-based project entitled 'Care Quality Evaluation for chronic diseases. And finally, collaboration between international stakeholders should be stepped up to address the current issues that still prevent successful person centred research and care practices.

Panel discussion

The first panellist, Tamas Kurimay (Chair of EPA's Council of National Psychiatric Associations) informed the audience of a survey carried out amongst EPA's National Psychiatric Associations (NPA's) in 2017 with the objective to collect their input in and expectations of current and future EPA activities. The response rate was high (81%) and the survey yielded some interesting feedback with respect to research. NPAs feel that there should be more joint research, based on clear ethical guidelines and better communication of important research findings. One suggestion would be to pilot a collaborative multinational study/survey addressing critical areas, such as unmet needs. There are barriers to such collaborative research projects, related to funding and support.

Transcultural issues and the translation of research findings into clinical practice can be challenging as well. But the patient-centred subjective experience on mental disorders - including schizophrenia, mood disorders and depression – as well as the family experience is crucial if clinical practice is to be improved.



Prof Kurimay also presented the results of a recent small Hungarian survey to illustrate the type research he was referring to. The survey involved 155 patients living with schizophrenia and focused on diagnose, treatment and living with schizophrenia (hurdles, needs, feelings) taking demographic/personal data into account (e.g. age, sex, education, economic status, physical

activity, weight, smoking, alcohol, digital technology usage). The survey found a number of unmet patient needs, such as the need for more accessible information and the need for emotional and psychological support. Families are clearly the main source of care and support and should not be forgotten. The findings of the study have been published in Psychiatria Hungarica¹.

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Prof Kurimay also put forward his suggestions for mental health research priorities and the best possible implementation of research findings for Horizon Europe: research should involve all relevant stakeholders (including patients and carers); it should focus on all major public mental health problems (e.g. mood and anxiety disorders, addiction (including behaviour addictions) and dementia, the unmet need of patients and carers, quality of service provision in different settings (e.g. community services), effective and early interventions and risk-measurement approaches.



"E-COMPARED clearly found that, if face to face treatment is blended with smart technology-based digital interventions, we can indeed increase the effect."

The next speaker, **Dr Heleen Riper (Vrije Universiteit Amsterdam)** highlighted the fact that mental health is not a uniform area; there are huge differences between the various conditions and the way these impact on individuals; mental health does not have one single face. As the prevalence of mental ill health has not decreased, there is a still much room for improvement and preventative efforts.

There are huge differences between European countries in terms of health services delivery and resources, e.g. number of GPs, psychiatrists, psychologists, psychiatric beds and level of expenditure.

Heleen Riper welcomed the references made by previous speakers to the importance of smart use of technologies in mental health services delivery as this is the area where she herself if most active. Research efforts are ongoing to identify more effective ways of offering services to patients in the area of digital services. The growing interest in this domain is clearly demonstrated by EU-funded projects like MasterMind, E-COMPARED and others. In these projects, countries work together to make progress in this area and learn from each other. There are a number of 'frontrunner' countries, such as The Netherlands and Sweden, with Germany not far behind; these countries can be seen as worldwide examples of good practice in the area of smart digital interventions, showing how these can be implemented and reinforced. However, it needs to be borne in mind that much effort and resources will be needed to reinforce and develop these interventions in order to strengthen and keep this 'frontrunner' position.

Heleen Riper provided a concrete example of one such project, i.e. E-COMPARED. It has already been demonstrated that digital interventions

are acceptable to patients and that they yield similar clinical impact compared to face to face treatment. This is good; but it would be even better if we could demonstrate that they actually have more effect and do <u>better</u>. E-COMPARED clearly found that, if face to face treatment is

¹ Herold R, Kurimay T, Dobi E, Kun E, Fehér L: Subjective patient journey in schizophrenia –learnings from a national survey. Psychiat. Hun. 2018, 33 (3): 243-265

blended with smart technology-based digital interventions, we can indeed increase the effect. However, implementation and uptake in routine care of these interventions is low, even in advanced countries. One of the reasons for this low uptake may be that the needs of patients and health professionals should be better mapped and included in the process. Ultimately, patients and their organisations should become a proactive partner in all aspects of the research cycle.

Lastly, Dr Riper underlined the importance of a personalised medicines approach, where neurological, bio as well as behavioural markers should be included. The latter can play a role in improving diagnose and treatment and can be easily measured, making use of smart technology.

The next panellist, **Erik Van der Eycken (GAMIAN-Europe)** emphasised that there is no such person as THE patient; individual differences are huge. He is an expert by experience in mental health, representing GAMIAN-Europe in four EU-funded research projects - MasterMind, E-COMPARED, ImplementAll and MoodFood, speaking on behalf of patients.

One of the issues he noted in this work is the fact that researchers seem to speak another language. One of the requirements to effectively engage patients in research is an extra activity (e.g. working (sub)group), wherein patients can work together with researchers to translate the findings into accessible language so that actual outcomes from research can be better understood and disseminated. There should be more two-way communication channels to facilitate communication and dissemination as, until now, GAMIAN-Europe's role in the research projects has consisted mainly of communication and dissemination. GAMIAN-Europe produces bespoke newsletters related to the projects, which are then disseminated. Another priority for EU-funded research would be to engage patients from the start and involved them in the first discussions to develop a project rather than bring them in once all actions have been agreed.

In terms of the practical implementation of research results into the practice of care provision, it is important to bear in mind the environment in which the patient finds him or herself and involve carers and families. For instance, digital sessions with health professionals require a calm and quiet space for patients; families need to be made aware of the requirements and state of play.

Lastly, Erik Van der Eycken underlined the importance of evidence-based research results as it is not often clear to patients and the general public which information, reaching us via social media, is true and credible.



"It is important to bear in mind the environment in which the patient finds him or herself and involve carers and families."



The final panellist, **Milan Popovic (European Commission, DG CONNECT)** stated that his Unit is involved in funding research and development of digital tools for patient-centred mental healthcare. Examples of currently ongoing projects are NEVERMIND (NEurobehavioural predictive and personalised Modelling of depressive symptoms during primary somatic Diseases with ICT-enabled self-management procedures), STARS (Empowering Patients by Professional Stress



Avoidance and Recovery Services) and DynaMORE (Dynamic MOdelling of REsilience). Recently completed projects include NYMPHA-MD (Next Generation Mobile Platforms for HeAlth, in Mental Disorders), MASTERMIND (MAnagement of mental health disorders Through advanced technology and services – telehealth for the MIND) and m-RESIST (Mobile Therapeutic Attention for Patients with Treatment Resistant Schizophrenia).

Projects typically focus on the development of e-health and m-health devices, collecting and processing various types of data (physiological data, exercise, sleep patterns, speech, frequency of social interactions) from affected individuals, predicting onset of depressive or manic symptoms in real-time and allowing them to take pre-emptive preventive actions. Such decision support systems put patients at the centre of their

mental healthcare, encouraging active self-management and allowing them to follow individually tailored therapies and take measures to avoid relapse. They are further expected to decrease the burden on the mental health workforce, reduce waiting time and support mental health professionals make better and more personalised treatment decisions. These digital tools are not always limited to patients but can also be used by healthy or at-risk individuals for resilience building and the prevention of stress-related disorders.



Audience debate

Tomas Zdechovsky MEP invited participants to come forward with their questions and views. The following issues were raised:

- There seems to be a lot excitement related to research on digital mental health interventions and the efficiency that those can bring. However, the person-centred aspects of that type research need to be kept in mind. How can patients be more involved with this type research?
- How can patients play a role in the development of these digital tools? Digital tools pose
 problems for the older generations; there are privacy considerations as well. And how
 accurate are the mental health apps, checking on symptoms? How can real enthusiasm be

distinguished from manic behaviour? While e-mental health may be the way forward, we need to address these issues as well.

- An increased focus on research related to biomarkers to increase knowledge is a good development. However, a system that assesses and evaluates the capacity and values of patients is also required. This would be truly person-centred.
- In terms of research priorities, it would be useful for revisit the ROAMER roadmap and assess what has been done already. This may help identify the next steps.





Concluding remarks

Tomas Zdechovsky MEP thanked speakers and participants ed organisers and expressed his intention to keep working as a champion for mental health in the European Parliament. He then gave the floor to the co-organisers of the meeting, EPA and GAMIAN-Europe, for some concluding remarks.

Prof Galderisi welcomed the input received from the stakeholders and speakers present in the meeting, with the need to better involve patients in research as well as in their care being one of the highlights. She also recognised the need to define the concept of person-centredness, taking account of the clinical, neuroscientific, biological and public health levels. The concept must have clinical relevance and be translated into concrete measures at all these levels.

Hilkka Kärkkäinen noted that GAMIAN-Europe has strong links with the MEPs in the European Parliament and that they could be approached to table some Written Questions for the Commission to reply to, related to our discussions today. These could focus on the need for more mental health research in Horizon Europe, the need to include patients and relevant stakeholders in determining the priorities in order to ensure relevance and patient-centredness and the need to act on the recommendations put forward by ROAMER.

Philip Gorwood also underlined the need for a definition of the concept of person-centredness, which would ensure that patients are at the centre in every respect. Once that is the case, we will have reached our goal. There are many positive signals that we are on our way; this is a learning process in which we all need to learn to speak the same language. Meetings such as these can help develop that language.

