

European Parliament Interest Group on Mental Health, Well-being and Brain Disorders

Tuesday 20 January 13.00 - 15.00

Sound mental health policy development – the need for focused research

Report

Marian Harkin MEP welcomed colleagues, speakers and participants to this first meeting of the Interest Group in the new year and reminded the audience of the aims of the Interest Group, i.e. to support the development of sound policies that can contribute to mental health and good care for and empowerment of those affected by mental illness.

Marian then introduced the first speaker, **Barbara Kerstiens (Head of Sector Public health, DG Research & Innovation, European Commission)** who provided an overview of the Commission's current and planned activities in the field of neurological and mental disorders. Barbara underlined that these disorders constitute almost 11% of the global burden of disease¹; some 20% of the world's children and adolescents have mental health problems. EU research therefore has focused on this area: the EU's 7th Framework Programme on Research and Development (FP7) dedicated € 2 billion to brain related research including mental health, funding international multidisciplinary research to:

- ✓ Study brain diseases and identify new diagnostics, therapies and regenerative or restorative therapeutic approaches
- ✓ Improve the management of brain diseases i.e. provide better healthcare at lower cost
- ✓ Promote mental health, prevent mental disorders & strengthen the capacity of health care service

Examples of EU-funded projects are DEVELAGE - Pathways common to brain development and ageing: defining strategies for preventive therapy and diagnostics (2012-2014)² and EUROSPIN³, which aims to help understanding the basis of aberrant synaptic transmission with a view to developing novel therapies. In the field of public mental health FP7 funded projects took a life-course perspective and covered areas such as mental health promotion, increasing resilience and reducing abuse, prevention of suicide and depression, strengthening the capacity of health systems to meet population mental health needs, mental health and ICT, and establishing a roadmap for mental health research (ROAMER) (see below).

A new EU R&D programme - Horizon2020 - is now in place and this is composed of three main pillars, i.e. Excellent science, Industrial leadership and Societal challenges. The work stream entitled 'Health, Demographic Change and Well-being (part of the Societal Challenges pillar) aims to translate science to benefit citizens, test and demonstrate new healthcare models, approaches and tools, promote healthy and active ageing, improve health outcomes, reduce inequalities and support a competitive health sector. Calls under this pillar are based on two year work programmes, with topics challenge driven, broader and less prescriptive and with a stronger focus on end users

Horizon2020's 2014 Call for proposals included a number of topics relevant for brain and mental health research, such as understanding health, ageing and disease and active ageing and developing and comparing new models for safe and efficient, prevention oriented health and care systems. The 2015 Call "Personalising health and care" also addresses a number of relevant topics, such as understanding common mechanisms of diseases and their relevance in co-morbidities, health promotion and disease prevention (environment and health based interventions) and promoting mental wellbeing in the ageing population. The work programme for 2016 is currently being developed.

Marian Harkin then introduced **Juergen Schefflein (Policy Officer, DG SANTE, European Commission)** who informed the audience of the role of research in DG SANTE's mental health initiatives. He underlined that mental health and capital is a key resource, which is under strain. Mental health problems and disorders are leading contributors to Europe's burden of disease. Mental disorders are the most costly disorder group and/because they often affect people during their productive age.

¹ data from 2010

² <http://www.develage.eu/>

³ <http://eurospin.mpg.de/>

There is a need to act on mental health and to improve our understanding. The European Pact for Mental health and Well-being approached mental health as an issue which provides challenges and opportunities, which is a priority and which requires investment – in mental health promotion, disease prevention and improving treatment and care.

The Joint Action (JA) which is currently being implemented (led by Portugal) will run until early 2016, and is now finalising first draft reports and recommendations. The JA's objectives are to review of literature and EU-projects, analyse the situation in participating Member States, identify good practices, develop policy recommendations and agree on a common framework for action. The focus is on five themes, i.e. depression and to prevent suicides (eHealth), transition to community care, mental health in the workplace, mental health and schools and mental health in all policies.

In terms of research, the Joint Action builds on the existing knowledge base, including from EU-research, which it maps and summarises. The JA itself also includes a research dimension as it maps and analyses the situations in countries, and it may also issue recommendations for future research.

Juergen Scheftlein congratulated the ROAMER Consortium for the work undertaken, both in terms of the highly complex process as well as in terms of the resulting recommendations on research priorities and research advances. His personal view is that mental health should be seen as a priority across the whole lifespan, from childhood and youth via adulthood into old age. Mental health and physical health are intrinsically linked, and there is a need for research into the interaction between these too, including co-morbidity aspects. Furthermore, mental health is a key resource for the employability and productivity of people at work, while work is itself a factor supporting mental health. Lastly, the application of research knowledge will be promoted if academic researchers and practitioners, including those outside of the health field, have a dialogue. The ROAMER recommendations should be visible and the EU's Mental Health Compass could be a useful tool to support this. It will be further developed and implemented, with the objective of disseminating the Joint Action's Action Framework (once agreed) and inspiring investment in mental health.

The floor was then given to **Josep Maria Haro (Project coordinator, Parc Sanitari Sant Joan de Déu, CIBERSAM, Universitat de Barcelona)** and **Til Wykes (Institute of Psychiatry, Psychology & Neuroscience, Kings College London)**, who jointly presented the work and findings of the ROAMER project.

ROAMER focuses on developing mental health and well-being research priorities for Europe⁴. In order to do so, the project looked at a wide ranging variety of mental health⁵ related topics, with the aim to analyse gaps and progress in these areas. Priority criteria included efficacy/effectiveness, impact/deliverability/economic benefits, answerability/feasibility and European research strength. about 1000 individuals (including more than 600 researchers, 108 national associations, policy makers, representatives of funding agencies and the industry, as well as a Stakeholder Advisory Board and a Scientific Advisory Board) who participated in meetings, scientific workshops and/or surveys."

One of the first findings was that the percentage of the health research budget allocated to mental health is very low (5.6% in Spain, 4.1% in France) compared to the burden mental disorders represent (12% of all diseases). The amounts spent on mental health budget vary enormously between countries.

A first inventory of potential research priorities led to a list of 140 topics. These have been integrated and narrowed down to six high-level priority topics, with special attention given to the views of service users:

- Research into mental disorder prevention, mental health promotion and other interventions in children, adolescents and young people
- Focus on the development and causal mechanisms of mental health symptoms, syndromes and well-being across the lifespan (including older populations)
- Developing and maintaining international and interdisciplinary research networks and shared databases

⁴ with a focus on mental and behavioural disorders, excluding organic brain disorders such as dementia, due to their being covered by other initiatives.

⁵ biomedical research and neuroscience, psychological therapies and treatments, social and economic issues, public mental health, well-being, clinical research and integration, infrastructure, funding and capacity building

- Developing and implementing effective and safe interventions using new scientific and technological advances
- Reducing stigma and empowering service users and carers in decisions about mental health research
- Health and social systems research that addresses quality of care and takes account of socio-cultural and socio-economic contexts and approaches

It was not an easy task to reconcile the views of hundreds of participants but the outcome is highly relevant for future research and more importantly, the development of sound policies and practices to support those affected by mental ill-health.

Josep Maria Haro and Til Wykes underlined that there is an expectation that this sort of research will have an impact and a follow-up, and that it will actively support individuals and improve their quality of life and well-being. This is why longer term research funding is required rather than the current practice, which consists of ad hoc and 'chunky' type funding. They called on the European Parliament to support this type research in debates and decisions on EU research priorities. Lastly, service users should be more directly involved in the research that concerns them.

Nessa Childers MEP took over the chair and briefly introduced the panel.

The first speaker was **Paul Arteel (Executive Director, GAMIAN-Europe)**, who addressed the needs of patients and the challenges for researchers in research on mental health. It is important for GAMIAN-Europe to involve patients' views and patients' expertise in academic research projects. The main aim is to be considered as **partners** (subjects) and no longer as objects of the research. Patients want to be involved both in the concept of the research (is the research relevant?) as well as the dissemination of the results (can we benefit from the results?).

As a result of GAMIAN-Europe's invitations to researchers to attend their annual conventions over recent years, a solid network of contacts was built and GAMIAN-Europe was invited to participate as a partner in ROAMER's Stakeholder Advisory Board. Three other FP7 funded projects – e-Compared, Mood Food and Mastermind – also invited GAMIAN-Europe as a full partner.

GAMIAN-Europe's role in these projects is to participate in the project from the very beginning, to play an advisory role in all work packages, to organise patient advisory boards related to the progress of the projects and to inform GAMIAN-Europe members. There is now a dedicated research page on the GAMIAN-Europe website, a quarterly newsletter is produced for each project and the activities are reported on the GAMIAN-Europe Facebook page.

The experience after one year is very positive: there is a real dialogue and mutual respect and trust. However, the limited financing is a major threshold for organisations such as GAMIAN-Europe: it is difficult to find the matching funding (50% for Mastermind, 25% for e-Compared). Also, the bureaucracy and administration represents a real barrier. GAMIAN-Europe does not have a large administrative department to deal with this type work (unlike most research institutes) and while researchers may see the value of the involvement of patients, the EU agencies involved in approving the grants do not. While GAMIAN-Europe would like to stay and become further involved with research, these are concrete obstacles to the organisation's involvement.

The next speaker was **David McDaid (London School of Economics)** who focused on four main issues:

Firstly, he underlined the multiple consequences of mental health problems for a number of different areas, such as the workplace, the situation of children, financial issues (the impact of debts and the need of fair credit), migration, education and many others. There are key transversal issues that go beyond mental health and the European Parliament and Commission would do well to bear this in mind when these areas and issues are debated. The impact of mental health goes way beyond the area of health. The second point related to mental health and co-morbidities. Whereas mental ill health has substantial personal and economic consequences, the situation gets much worse when there are physical health problems as well. Co-morbidities leads to additional costs, as, for instance, mental health problems can lead to bad management of a person's physical condition. The challenge is to avoid this from happening; prevention and early intervention are key in this respect. This requires better organisation and different models of organisation. The economic case can easily be made: there needs to be more investment in

mental health because of the potential (very costly) physical consequences. Work is being done in this area but a more consistent and robust approach is a matter of urgency.

The third point addressed the obvious need to build capacity to research and address mental health in the Eastern part of the EU. There are huge knowledge gaps as to what is happening on the ground in the Eastern countries; research often focuses on the west of the EU, and this needs to be changed.

David's last issue related to the need to make better use of and share existing datasets and work with the Commission to try to improve data collection. Longitudinal datasets are in existence but more of these are urgently needed. Moreover, research questions need to be improved so that data found in different countries can be collected.

An important area for research and implementation is how health systems function across the EU and how health care is being delivered, also to see whether existing good practice in this area can be compared and transferred to other countries.

ROAMER has succeeded in creating broad consensus on research priorities and its recommendations should be acted upon.

The final speaker was **Patrice Boyer (Vice President, European Brain Council)**, who emphasized that EBC's research priorities are in line with the ROAMER findings and listed his organisation's most important issues:

- ✓ Research and intervention in specific mental disorders, with depression as the main example because the condition is linked to high indirect costs (it triples health costs in combination with any other medical condition) and is the leading cause of death for mental disorders among those under 45 years of age. EBC can coordinate studies and data collection for depressive disorders linked to mental, neurological and vascular diseases as well as raise awareness amongst policymakers.
- ✓ Development of shared databases and of European research networks, in order to avoid fragmentation. EBC can support the dissemination via its national Brain Councils.
- ✓ Revision of the clinical trials regulation and of the list of outcome measures: EBC can stimulate the organization of conferences and summits (e.g. with the EMA) to re-design clinical trials as well as bring together patients' and agencies' representatives.

Mr Boyer also listed some of the main barriers to mental health research, such as lack of recognition of the fact that mental disorders are just as 'valid' as physical conditions. In addition, the indirect costs associated with mental disorders are often underestimated, as well as the potential benefits of investment. Lastly, in terms of clinical trials, pessimism and negativity prevails in many cases.

In relation to the role of patients in research, Mr. Boyer stated that the priorities of patients for any specific condition needs to be known as the priorities of patients can differ from researchers priorities.

For EBC one of the most striking aspects of ROAMER is its approach to mental disorders as *developmental* disorders. Moreover, the ROAMER recommendation of assessing and comparing the efficiency of health care systems on well-being for orienting the funding of new research and services and the plea for more international and interdisciplinary networks and databases are very welcome. The EU should clearly recognize that not investing enough in mental health research will have severe consequences, work in close collaboration with stakeholders and support positive awareness campaigns. Horizon2020's objectives and scope should be better defined and the programme should support prospective population studies and bring together existing datasets.

Discussion

The following issues were raised in the discussion:

Mental health of the whole population:

It is important not to only focus on those affected by mental illness but to take a broader perspective as well and take measures that promote mental health for everyone. Investments in early life pay off and the return on investment in the areas of school and education is very high. Simple measures can make significant contributions to mental health and this is often forgotten.

Potential cuts to the 'societal challenges' pillar of Horizon2020:

There may be general budget cuts to the Horizon2020 programme, but at this point it is not yet known how and where these cuts will be made.

Room for ROAMER recommendations in Horizon2020 work programme:

When asked whether there will be room for the ROAMER priorities in the current and future research work programmes of Horizon2020, bearing in mind that mental health research remains underfunded across the board, the Commission replied that many of the recommendations fit under Horizon2020's broader areas. Specific research about mental health in older persons is already part of the priority setting, so the Commission is in favour of both specific as well as broader research.

Specific or broader approach in research?

The importance of sound mental health for society is clear and more should be done in terms of research. While there is a potential to address mental health issues as part of broader research topics, experience learns that specific calls for mental health research are needed to spark off the interest and boost this type research. The problem is that results are needed to boost more funding; and since there are no specific large charitable funders in the area of mental health, national or EU funding is required.

The pervasive nature of stigma:

While the stigma experiences by persons affected by mental health problems are clear, psychiatrists are often stigmatised as well. Status of mental health and psychiatry is low in medical circles, and the level of prejudice is very high.

Focus on co-morbidities:

It seems that a focus on physical co-morbidities can help move mental health into the public domain. There is some research on this in the US (in the field of diabetes), where the level of investment in tackling co-morbidities is high and it has been found that in many cases, very simple interventions are effective. However, longer term studies are needed to prove the impact of interventions. Breaking down barriers is important in this respect as there should be no 'competition' between mental health and physical condition. Rather, the links between the two should be found and alliances built to most effectively address both.

Conclusions

Marian Harkin MEP underlined the need for the co-chairs of the Interest Group on Mental health to meet and to see what steps can be taken to ensure that the ROAMER recommendations are taken on board by the Commission.

Christine Marking, 22 January 2015