ERA-NET NEURON – Public involvement in research: when, where and how?

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How do you reinforce interaction between scientists, clinicians and society in the field of brain research? That was the question on everyone's lips when they met at the recent January ERA-NET NEURON meeting in Berlin, Germany. Leading neurologists, psychiatrists and neuroscientists discussed how to improve research collaboration between clinicians and basic scientists and how to involve patients in research activities.

In NEURON 27 ministries and funding organisations across Europe, Israel, Turkey and Canada have joined forces to support basic, clinical and translational research in the diverse fields of disease-related neuroscience.

The latest challenge to face European research funding organisations and the European Commission itself is the issue of public involvement. A number of scientific and societal challenges can be more efficiently addressed by public engagement and participation. The topic is hot because not only the complexities of brain diseases require new paradigms of interactions to tackle the most pressing research questions. Families, carers, clinicians and researchers – neurologists and psychiatrists – already face the challenges of the demographic change (e.g. aging population, chronic diseases) in the area of brain diseases: 'fewer to care for more' as Mary Baker (European Brain Council, EBC) pointed out.

The question is however, when, where and how to best involve the public. For research funders the term 'public' should be defined, as to include patients, potential patients, care givers and people who use health and social care services as well as people from umbrella organisations that represent service-users. Such precise definitions are necessary for funding measures because there is an important distinction to be made between the perspectives of the public, the perspectives of people with a professional role in health and social care services, and not least, research. Basic research approaches are different from those of translational or health care research. 'Public' involvement thus can address several different levels and roles. The most common and direct way is when people participate in a research study. 'People' in this case refers to patients or healthy volunteers, who are being recruited to take part in a clinical trial or other research study. There is no doubt that patient organisations can and do play a valuable role in advising on the recruitment of patients as participants and on ways of engaging with the public. The latter can be cooperation with researchers by helping to disseminate information to members of the public and explaining the findings of a study.

Taking this as a basis, the Berlin symposium went a step further, looking for new areas of public involvement in the field of brain disease. Can members of the public be actively involved - besides direct participation in research projects and in research organisations? As an example of joint funding Janine Blom (Netherlands Organisation for Health Research and Development, ZonMW) and Martin Boer (Epilepsy Foundation) provided an answer by outlining a successful collaboration between funding agencies, researchers, clinicians and patient organisations by installment of a 'user' panel within the grant assessment process.

Benefits in the field of neurology were pointed out by Donna Walsh (European Federation of Neurological Associations, EFNA) who has been working on identifying and prioritizing the most patient-relevant topics. Collaboration with basic scientists and clinicians as e.g. members of a project advisory or steering group could help to design better methods of obtaining informed consent from patients and/or carers, ensure that information sheets, questionnaires and interview schedules are patient-friendly, speed recruitment by providing researchers with better access to the patient community, and, not least help to disseminate results through patient-led advocacy, relating research findings to patients' own experience and presenting them in a user-friendly manner.

Ethical issues were brought up by Hervé Chneiweiss (INSERM Ethical board) who has been studying the ethical aspects of the relationship between patients and scientific and clinical professionals. The brain plays a fundamental role in our psycho-social make up and so it is natural that although ethical questions are not unique to neuro-technologies, they take on greater significance when we come to debate them. Because of the role of the brain in our lives, questions over whether or not to intervene when function is damaged and how much caution to exercise if and when proceeding become of the utmost importance, making public involvement all the more fundamental. Therefore, ensuring public confidence in novel neuro-technologies is crucial and that requires collaborative public engagement activities involving both researchers and clinicians, coupled with strong governance procedures and effective regulation. Scientific and technological developments are crucial for brain research and treatment of brain disorders, so it is not surprising that exactly these gains in knowledge play a central role in ethical issues, most notably over the issue of informed consent in the actual research context and associated consequences from that research. Ways that researchers and patient or umbrella organisations can engage with the public would be through science festivals where debates and discussions about research are open to the public; research centers could hold open days where members of the public are invited to find out about research; and research can be published in newspapers, on social media and be broadcast on television and radio; all of these methods encourage the sharing of knowledge and a deeper dialogue with the broader public.

Raluca Nica (Global Alliance of Mental Illness Advocacy Networks, GAMIAN Europe) is doing just that in the area of psychiatric disorders. Besides advocacy on behalf of psychiatric patients, this patient-driven pan-European organisation provides information, education and training for patients with psychiatric illnesses and the general public; they work on anti-stigma and anti-discrimination campaigns, and cooperate and make partnerships with professional associations, pharmaceutical companies

and decision making bodies. Among the key conceptual and social issues that psychiatry is facing today experts and practitioners recognize the need to incorporate multiple dimensions (relating to severity, distress, impairment) into their assessment procedures to better accommodate advances in relevant basic brain and behavioral sciences and to enhance clinical relevance. The field of psychiatry is scientifically committed to both optimizing treatment outcomes and personalizing treatment for those living with psychiatric disorders. This commitment led to the creation of models of care (e.g. depression care management) that allow evidence-based practice to reach both specialized mental health and general medicine settings.

Views from researchers, their needs and responsibilities were highlighted by Monica Di Luca (Federation of European Neuroscience Societies, FENS). She spoke about the development of novel tools and approaches in order to better integrate and advance knowledge. A better understanding of the underlying pathogenic mechanisms of brain diseases offers opportunities to generate novel therapeutic approaches for the benefit of society.

Günther Deuschl and Wolfgang Gaebel have been looking in how to reinforce the links between the professional communities in approaches 'from bench to bedside'. Deuschl (European Academy of Neurology) explained the necessity to increase the availability of diagnostic and treatment standards through introducing more guidelines and making sure that there was more education on the subject. Reinforcement for the diagnosis and treatment of neurologic diseases could be achieved by the use of evidence based methodology, and collaborations with subspecialty societies, neighboring societies and patient organisations. Wolfgang Gaebel (European Psychiatric Association, EPA) shared the view that neurologic and psychiatric research are moving closer together in the tools they use, the questions they ask, and the theoretical frameworks they employ. Consequently, potential areas of fostering the interactions between scientists, clinicians and society comprise a) the participation of lay organisations in scientific congresses, b) the presence of brain/mental health research related publications in mass media and social networks, c) joint statements regarding ‚hot' topics like e.g. refugee mental health, d) joint positions against stigmatization and discrimination of people with brain/mental disorders, e) the participation of representatives of lay organisations and policy makers in guideline development committees like e.g. the European Guidance project of the EPA, and f), not least, the joint development of policy recommendations.

ERA NET NEURON members at the January 2016 meeting in Berlin hosted by the Federal Ministry of Education and Research (BMBF).

In conclusion, the multitude of these different activities – involvement, engagement and participation – is often linked and although they are distinct can complement each other. While participation of patient organisations in the assessment procedures of funding agencies will be – due to often tight time constraints of national funding regulations – limited to exceptional measures, other public involvement is appreciated and often sought. Collaboration with research funders to prioritize research could include participation in workshops and thematic strategic symposia. Feasible activities on the researcher's side include engagement of lay people in research projects where applicable by e.g. offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants. It was concluded that all sides – funders, researchers, clinicians, practitioners, carers and the actual and potential patients – would benefit from enhanced public involvement; so the next major step is to identify individually for each area and each measure at which stage, and in which role, public involvement would help benefit the research being carried out.

As Etienne Hirsch (INSERM), the organizer of the symposium summarized: 'The symposium stressed the needs and challenges because it must be individually decided – in line with the specific disease area researched and corresponding patient groups - what is the most appropriate type of participation? Patient organisations can be key partners in clinical trials. There is however a need to educate patients and scientists on why patient involvement in research is necessary and how it can be done. Such efforts should be directed towards the current lack of experience, education and awareness on both, patient organisation and scientists/clinicians sides'.