

Stakeholder response, Wboevink/Trimbos-institute, EU hearing, Brussels, 16 May 2018

Throughout my life, struggling with psychotic vulnerability and going in and out psychiatric hospitals, I have learned about the enormous potential of persons dealing with mental ill health, in particular those with ongoing serious psychiatric complaints. In my personal life I found support among peers to outgrow my identity as a passive psychiatric object, to grow beyond myself as being a psychiatric disorder. Within the user movement I learned to question the medical model as the only truth about human distress. I grew strong enough to reject the idea of me being a schizophrenic with a devastating brain disorder and a prescribed poor outcome. I found, with help from my peers, the courage to start on my road of recovery which to me means becoming who you really are: a person with talents and possibilities next to vulnerabilities and other challenges.

Recovery, empowerment, peer support are very important and hopeful concepts in the lives of persons being patients in psychiatry. So I would like to thank the Interest Group on Mental Health and Gamian for their work on this Call to Action. Thank you!! Nevertheless I think that on the list of stakeholders to address and to sign this important Call we should include pharmaceutical companies. They play a powerful and crucial role in the debate on how we should frame mental ill health. Are psychopharmaca the ‘first and only intervention to cure’ as we are often being told? Or are they just another supportive instrument in our recovery toolkit from which we ourselves choose what helps us most? That is why I would like to suggest to skip “personalised medicine” altogether and replace it by “personalised interventions”. Imagine a future European mental health care system in which pharmaceuticals practice modesty!

In the past twenty years of my career as a social scientist at Trimbos-Institute I saw how users of mental health care services took the lead in giving content to the concepts of recovery, empowerment and experiential expertise and in disseminating them. More and more persons with lived experience take the lead and become influential stakeholders in co-creating recovery oriented practices. User involvement refocuses the relevance of care on the person’s daily life – there where people want to succeed. Purposeful activities, meaningful relations, being able to participate and enjoy are the primary objective of most individuals. Traditional psychiatry has an exclusive focus on what goes wrong, disregarding personal strengths. What does relevance mean, when what really counts is disregarded in care? User involvement revalorizes what matters for users of mental health care. And a science that is inspired by this input brings a new focus on mental health and improves the content of care.

At Trimbos-institute we know that a User Research Center is the primary instrument to accumulate the evidence that will help develop and implement altered recovery-oriented care into mainstream in psychiatry. We are convinced of the surplus value of experiential expertise and thus of user research. In the past twenty years we invested in the development of experiential knowledge next to professional knowledge and scientific knowledge. We know that the development of experiential knowledge is challenging and demands new ways of conducting research. Yet, we prefer these challenges instead of trying to influence mainstream research or trying to get an advisory vote in mainstream research. At Trimbos we prefer a User Research Center.

I come to the end of my response.

The European Commission, Parliament and Council now have a unique opportunity to make a huge difference for people with mental ill health. Will you make mental health a key part in the new Framework Programme Horizon Europe? Will you use the results of the ROAMER project (more than 1,000 stakeholders supported the report!) to execute this comprehensive and well-balanced mental health research agenda? And will you guarantee that for every mental health research project people with lived experience are actively involved in the design of the themes and the topics and the call and the projects?

Thank you.