

'REDEN SIE MIT! [TELL US!] - IN YOUR OPINION, WHAT QUESTIONS ABOUT MENTAL ILLNESS SHOULD SCIENCE TAKE UP?'

WWW.REDENSIEMIT.ORG

Process documentation on the crowdsourcing project by the Ludwig
Boltzmann Gesellschaft
(Last revised: April 2016)

A project in cooperation with

winnovation
winning by innovation

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INTRODUCTION TO THE ‘REDEN SIE MIT!’ PROJECT

The Ludwig Boltzmann Gesellschaft (LBG) is Austria's independent research incubator with a focus on the health sciences. With its 18 research institutes and clusters and approximately 600 employees, it conducts world-class research with the aim of generating innovations for society. The LBG is convinced that innovation is also the result of openness, interdisciplinarity, internationality, and a clear focus on quality. With its multi-year ‘Open Innovation in Science’ initiative,¹ the LBG has set about systematically opening up processes of innovation in science in an effort to enrich research through new knowledge drawn from beyond traditional disciplinary boundaries.

The ‘Open Innovation in Science’ initiative consists of two parts: the ‘Reden Sie mit!’ crowdsourcing project and LOIS (Lab for Open Innovation in Science), the training programme. As part of ‘Reden Sie mit!’, for the first time, people outside the science system were involved in the generation of research questions. LOIS is a training programme that begins on 16 April 2016 and conveys theoretical and practical knowledge on the use of Open Innovation methods and principles and Open Science principles in science.

LBG is a pioneer in Europe in the establishment of Open Innovation methods and principles in science and research. ‘Reden Sie mit!’ was Europe’s first crowdsourcing project for research questions. The model for the initiative came when Harvard Medical School conducted a project on the topic of Type 1 diabetes in 2010. The difference to the Harvard project is, inter alia, that LBG is taking on a highly taboo subject: mental illness.

The purpose of this process documentation is to provide a detailed description of the ‘Reden Sie mit!’ project in the period from 01/2015 through 03/2016.

¹ For more information about the overall project, and about the definition of the term ‘Open innovation in science’, go to: <http://www.openinnovationinscience.at> at LBG.

THE ‘REDEN SIE MIT!’ PROJECT AT A GLANCE

The crowdsourcing² project was implemented with the aid of an online platform – www.redensiemit.org. This platform (available in German and English) encouraged international participation in the project.

Figure 1: The ‘Reden Sie mit!’ project at a glance

OVERVIEW OF THE ‘REDEN SIE MIT!’ PROJECT



CONTRIBUTE

Contributions were submitted from 16 April through 6 July 2015. After that, the content was analysed and categorised.

RESEARCH AREAS

Following this, the main topics identified were summarised to create seven research areas. These form the basis for the identification of new research topics and questions.



VOTING AND JURY

The research areas identified were announced on the platform – ‘Reden Sie mit!’ – and all registered participants were invited to join in the participants’ voting. On 22 October 2015, an international jury of experts evaluated the research areas.

RESULTS

Our goal: Generation of new research questions in the field of mental illness as a basis for future research projects.



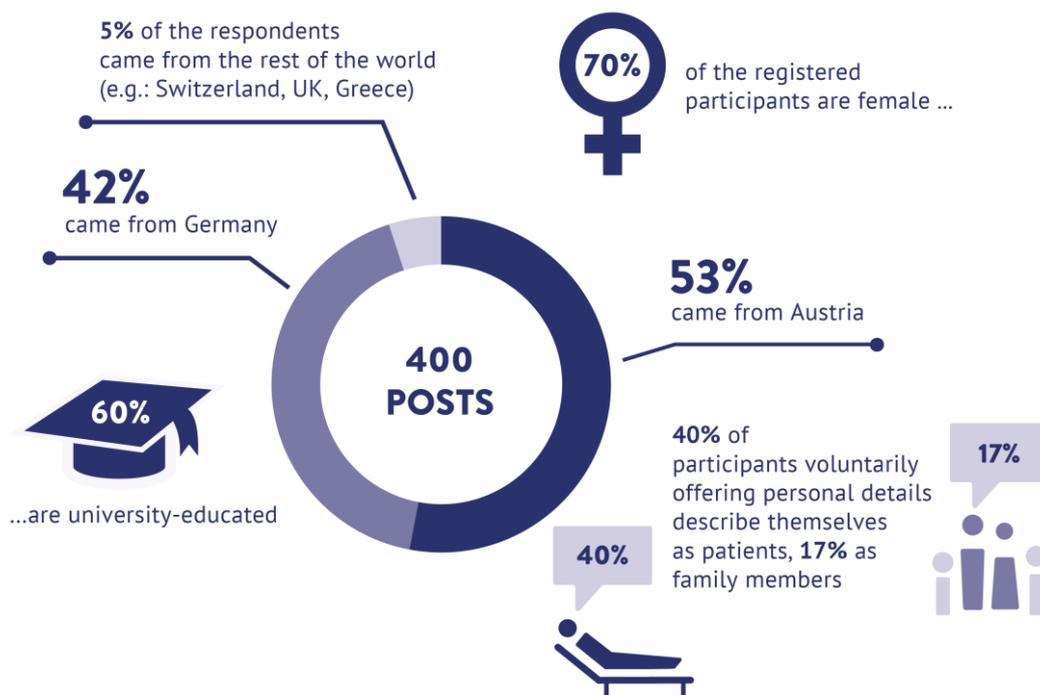
‘REDEN SIE MIT! IN YOUR OPINION, WHAT QUESTIONS ABOUT MENTAL ILLNESS SHOULD SCIENCE TAKE UP?’

For 11 weeks, patients, family members, nurses, doctors and therapists were invited to use the online platform to share their experiences, observations and open questions in the field of mental illness.

² *Crowdsourcing* denotes the harnessing of knowledge by the general public/a defined group through Internet-based communication. In the crowdsourcing process that LBG has initiated, a website (www.redensiemit.org) was set up to serve as a communication platform. Crowdsourcing is an interactive, community-based innovation strategy and takes place online (cf. Grassmann 2013, p. 6).

Web statistics show that ‘Reden Sie mit!’ has reached several thousand people in 83 countries.

Figure 2: Participant statistics at a glance



400 high-quality contributions for the future investigation of mental illness were submitted. The submissions were examined and evaluated by a trained team of analysts. More than 700 relevant passages were identified that could be divided into 446 sub-topics. As part of the pattern recognition and the so-called ‘clustering’, 17 main fields were identified and combined to create seven research areas: mental resilience, more precise diagnostics, psychosomatics, psychotropic drugs, alternative forms of therapy, health care structures and destigmatisation.

From 29 September until 18 October 2015, registered participants were welcome to visit the platform, at www.redensiemit.org, where in community voting they determined which of the seven research areas seemed to be of highest priority. Each registered participant had an opportunity to vote for two of the seven research areas.

Following the community voting, in which 217 persons participated, the research areas were evaluated by an international jury of experts. The jury’s mission was to assess the degree of novelty of the questions and topics as well as their relevance for research and society (details about the jury can be found beginning on page 49). In the course of the jury session, it turns out that all of the seven research areas mentioned contain elements and questions from the field of children and

adolescents. In the course of the jury session, then, and on the advice of professional experts, the research area of ‘Mental health of children and adolescents’ was added.

Taking into account the results of analysis and pattern recognition, community voting and the considerations of the jury, three research areas were identified as high-priority: 1. Child and adolescent mental health, 2. destigmatisation of mental illness and 3. healthcare research in regard to mental illness.

Now, the next step is a rapid transfer of the results into concrete research activities designed to build a bridge between science and society, and to address questions in an interdisciplinary way, applying Open Innovation methods and principles and Open Science principles.

Figure 3: Three priority research areas



THE 3 LEADING TOPICS:



1. Mental health among children and adolescents
How can mental health in children and adolescents be maintained, and how can children and adolescents recover quickly?



2. Destigmatising mental illness
What does it mean to be stigmatised to a person with a mental illness? How does the stigma affect the course of the disease?



3. Healthcare research
What structures does society need to create to ensure that the mentally ill receive the best support possible throughout their recovery process?

BACKGROUND OF THE ‘REDEN SIE MIT!’ PROJECT

Open Innovation in Science

Traditionally, research topics are determined by the scientific community within the framework of academic freedom; but questions of policy and economics also factor into determination of the research agenda. What has been missing to date is direct influence by society on research topics and questions. With the ‘Open Innovation in Science’ project and the sub-project ‘*Reden Sie mit!*’ LBG sees itself in a pioneering role destined to establish Open Innovation methods and principles in science as well.

The Open Innovation concept originally stems from operational innovation research; businesses have applied it with success for many years. ‘Open Innovation’ describes the systematic opening of an organisation’s innovation processes in the interest of knowledge-sharing with a variety of external actors: relevant knowledge is brought into the organisation/company from outside, or internal knowledge is systematically communicated outward (e.g. with regard to licensing). The aim is to strengthen problem-solving skills in such a way as to permit development of new ideas and concepts and overall application and exploitation of new knowledge. The LBG views Open Innovation in Science as part of a holistic consideration of openness. Open Innovation in Science surpasses the boundaries of traditional knowledge extraction and supports the linkage of different areas of a culture of opening. Open Innovation in Science is based on the principles of sharing, cooperation, transparency and participation, quality improvement and the enhancement of positive social impacts through values created as part of a joint effort.

The LBG is committed to the systematic enhancement of research processes through methods that stem from the fields of Open Innovation and Open Science. This means:

- solving issues through application of new approaches
- providing researchers with access to new sources of knowledge
- using new ways to make findings known
- strengthening the culture of cooperation and sharing (participation) and
- making research processes more open as a result

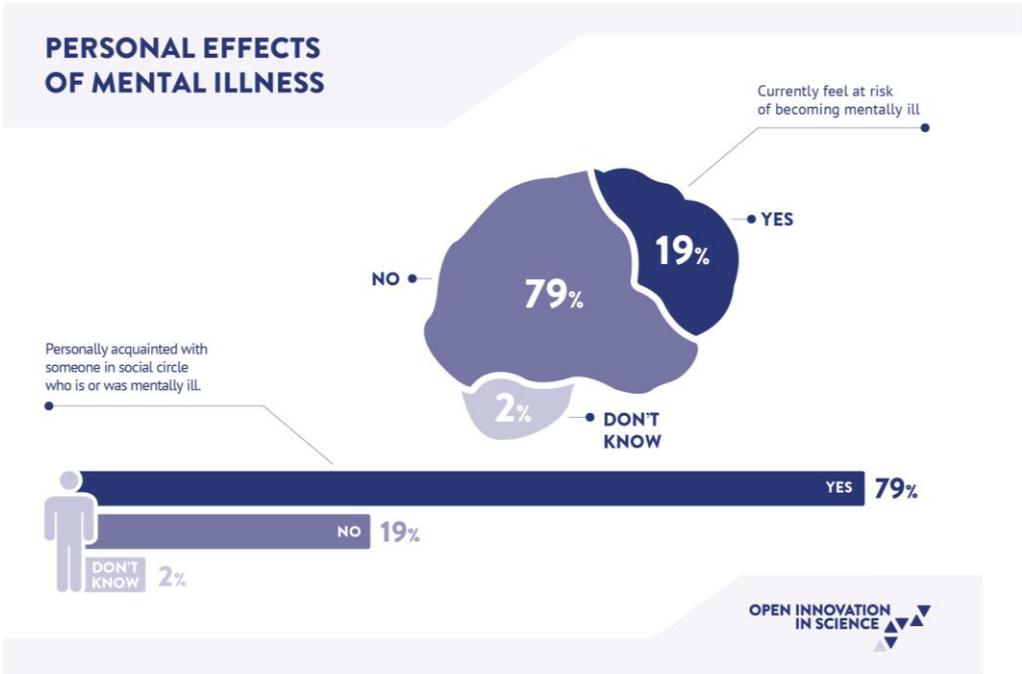
SELECTION OF THE TOPIC FOR THE CROWDSOURCING PROCESS

As an independent research organisation, in an extensive evaluation process using international experts (qualitative in-depth interviews) and analysis of secondary data, the LBG selected mental illnesses as the topic for the crowdsourcing project. The considerations governing the decision were that:

- Mental illnesses are less thoroughly investigated than other illnesses (e.g. cancer)
- There is a high prevalence, and thus a high level of individuals affected, among the population – both directly and indirectly, for instance in the case of family members (according to statistics, one person in five suffers from mental illness at some point during the course of his or her life)
- All ages and all segments of the population are affected by mental illness
- There is a high level of relevance for healthcare policy: Mental illness has drastic effects on society, e.g. due to early retirement or long-term illness rates

The topics of ‘Ageing society’, ‘Chronic illness’ and ‘Holistic patient care’ were evaluated as well.

Figure 4: Large numbers of persons directly and indirectly affected by mental illness



‘REDEN SIE MIT!’ – PARTNER NETWORK

National Foundation for Research, Technology and Development

The ambitious aim of conducting Europe's first crowdsourcing project for research questions required the support of strong partners. Thanks to a budget of EUR 2 million (approved in August 2013) of the Austrian National Foundation for Research, Technology and Development, it was possible to tackle Open Innovation in Science beginning in early 2014.

Cooperation: winnovation and LBG

The international innovation consultancy, winnovation research and consulting GmbH, emphasising Open Innovation under the leadership of Dr. Gertraud Leimüller, played a decisive role in the ‘Open Innovation in Science’ initiative of the LBG. The collaborative effort was based on the common goal of systematically opening up the research process in favour of generating fundamentally new methods, products and applications, ultimately promoting the potential for new results and radical innovations.

Advisory Board

In addition to this, the LBG built upon a prestigious, international Advisory Board that provided advisory support to the ‘Open Innovation in Science’ initiative, and hence to the ‘*Reden Sie mit!*’ sub-project.

- Pascale Ehrenfreund – until 2015 President of the Austrian Science Fund (FWF), (AT); since September 2015, CEO of the German Aerospace Center.
- Eva C. Guinan – Director of Reactor Program on Accelerating Clinical and Translational Research, Harvard Catalyst, Harvard Medical School, (US)
- Edwin Ladinser – Head of the Advisory Centre and Managing Director of HPE Österreich – Hilfe für Angehörige und Freunde psychisch Erkrankter, (AT)
- Keld Laursen – Professor in Economics and Management of Innovation, Copenhagen Business School, (DK)
- Matt Muijen – Programme Manager Mental Health and Neuro-Degenerative Disorders, WHO European Regional Office, (BG)
- Rebecca Müller – Treasurer GAMIAN – Global Alliance of Mental Illness Advocacy-Networks, (BG)
- Gabriele Sachs – Associate Professor for Psychiatry, Medical University of Vienna, University Clinic for Psychiatry and psychotherapy, (AT)

- Ulrike Schmidt – Senior Physician in the Protective Ward – Head of the Outpatient Clinic for Posttraumatic Stress Disorder – Head of the Molecular Psychotraumatology Research Group, Max Planck Institute of Psychiatry, (DE)
- Philipp Türtscher – Assistant Professor of Technology and Innovation, VU University Amsterdam, (NL)
- Alfred Pritz – Psychoanalyst, Secretary-General of the European Association for Psychotherapy and President of the World Council for Psychotherapy; co-founder of the world's first university for sciences in psychotherapy, Sigmund Freud University Vienna, (AT)

In addition, two renowned international organisations supported the project of the LBG:

- Wissenschaft im Dialog (an initiative of Germany's scientific community) and
- Science et Cité, (CH).

PROJECT TEAM

- Dr. Lucia Malfent
Project Manager OIS,
Ludwig Boltzmann Gesellschaft
- Mag. Claudia Lingner
Initiator of OIS and General Manager of the Ludwig Boltzmann Gesellschaft
- Dr. Gertraud Leimüller
Co-initiator of OIS and Open Innovation expert, winnovation
- Johanna Stieblehner, MA
Open Innovation expert, winnovation
- Asst. Prof. Dr. Marion Poetz
Academic Advisor for OIS, Copenhagen Business School
- Priv.-Doz. Dr. phil. Claudia Wild
Communications expert and Director of the Ludwig Boltzmann Institute of Health Technology Assessment
- Magdalena Theurl, BSc
Project collaborator OIS
Ludwig Boltzmann Gesellschaft

THE CROWDSOURCING PROCESS

Crowdsourcing process design

Even before the crowdsourcing process begins, the question presents itself as to whether people who are affected by a mental illness are interested in sharing their experiences, problems, etc., in a crowdsourcing context.

For this reason, the process design was heavily modified compared to other crowdsourcing processes and tailored to topic-related challenges. Even at this phase of the project, experienced international professionals were involved, bringing expertise in the areas of crowdsourcing (technical implementation and design) as well as patient involvement and surveying. Another important issue was the question of adequate protection (privacy protection) of the registered participants.

The main amendments to a conventional crowdsourcing process were:

- Complete anonymity of registered participants
- Minimum mandatory requirements for registration (cf. page 12)
- No publication of the contributions submitted
- No interaction among registered participants
- No presentation of awards to submissions – no ‘award-winning entries’

All of the submissions were visible and accessible exclusively to the analysis team, but at no time to any other participants. All posts are subject to privacy protection.

Provision of the following data was mandatory for those registering:

Figure 5: Registration information

NEW REGISTRATION

User name*

E-mail address*

Confirm e-mail*

Password*

I am participating in my capacity as a*

- Patient
- Family member
- General practitioner
- Psychologist
- Psychotherapist
- Psychiatrist
- Neurologist
- Other
- Healthcare and nursing professional

The following information was optionally surveyed:

Figure 6: Optional registration information

Country

Highest educational level achieved

Birth year

Gender male female

Crowdsourcing questions

On the crowdsourcing platform, registered participants were asked about ideas, experiences and observations. Regardless of the point of view from which the participant is confronted with mental illness. The main question was this:

WHAT UNRESOLVED QUESTIONS ABOUT MENTAL ILLNESS SHOULD SCIENCE TAKE UP?

The above question was modularized into three sub-questions. It was not necessary, however, for respondents to respond specifically to a sub-question.

- What problems and unresolved questions do you observe when it comes to early detection and diagnosis of mental illness?
- What problems and unresolved questions do you observe when it comes to the treatment, care and support of persons suffering from mental illness?
- What problems and unresolved questions do you observe when it comes to preventing mental illness?

The question was articulated in close consultation with the Advisory Board and the process experts mentioned above.

FROM CROWD TO COMMUNITY

If the crowd – in theory, everyone in the world with an Internet connection – was to come up with research questions, it would first need to become a community. The main question was how one goes about mobilising people to abstract from their own experiences, and to make their conclusions usable for and understandable to others. How does one create an atmosphere of security and confidence, especially as regards the handling of data? From this point of view, it can be seen that it was strategic communication more than anything else that presents a key element in tackling the task.

COMMUNICATION MEASURES AT A GLANCE

Throughout all of its phases, the *‘Reden Sie mit!’* initiative enjoyed the valuable support of strong partners; this includes an active communication in all parts of the project:

- BMWFW, the Federal Ministry of Science, Research and Economy
- BÖP, der Berufsverband Österreichischer PsychologInnen
- ÖBVP, Österreichischer Berufsverband für Psychotherapie

- Pro mente OÖ, Pro mente Austria
- HPE, Hilfe für Angehörige psychisch Erkrankter
- Science et Cité, Switzerland
- Wissenschaft im Dialog, Germany

Online measures at a glance:

- Website with interview videos (note: these videos were frequently called up through the '*Reden Sie mit!*' Facebook page. Proven YouTube click-through rates are thus irrelevant!)
- e-mails linking to the platform (the announcement of '*Reden Sie mit!*' reached around 10,000 people via e-mail)
- 10 newsletters were published in the period from April through October 2015
- Regular social media activities (Facebook, Twitter, YouTube)
- Expert interviews – published through Facebook and YouTube and in the newsletter

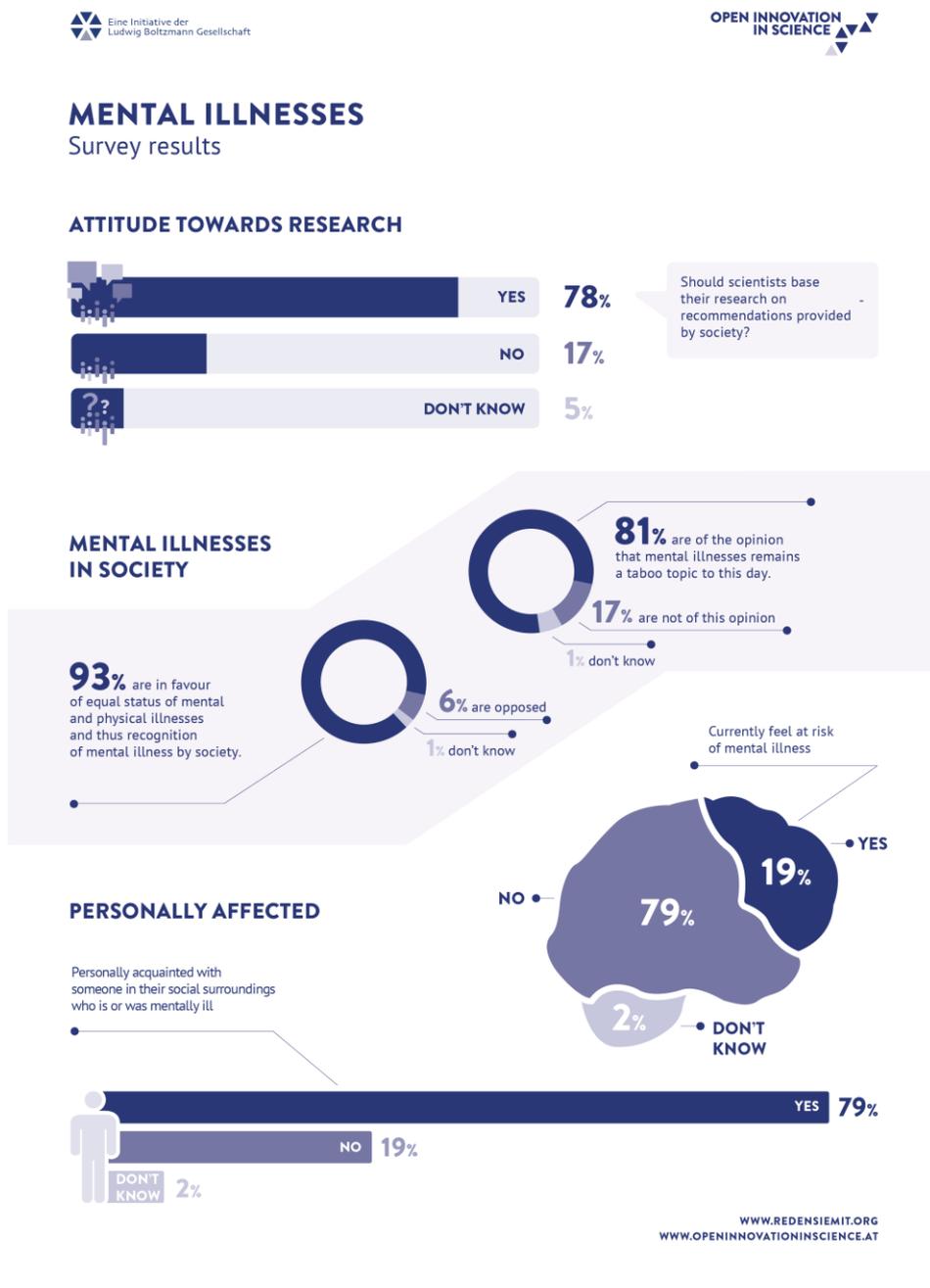
Offline measures at a glance:

- Gallup poll
- Press relations
- *KURIER* supplement
- Posters with tear-off tabs for www.redensiemit.org
- Folding cards
- Kick-off event
- Fact sheet
- Ads and advertorials in selected media
- Banner advertising

DISCUSSION: GALLUP POLL

Within the scope of ‘Open Innovation in Science’, the LBG commissioned a representative study devoted to the topic of mental illness; the study involved surveys of 1,000 respondents by the Austrian Gallup Institute. The survey found that nearly one-fifth of the population feels currently at risk of becoming mentally ill. Nearly 80 percent know someone in their own personal surroundings who either is or has been mentally ill. Four respondents in five are convinced that mental illness is still a taboo subject. At the same time, nine out of ten respondents favour placing mental and physical illnesses on an equal footing.

Figure 7: Discussion: Survey results of the Gallup survey



Evaluation of the crowdsourcing process

All in all, in the eleven weeks (16 April through 6 July 2015) in which the platform was open for submissions by registered participants at www.redensiemit.org, more than 400 posts of high quality were submitted.

According to the internal evaluation, around 40 percent of the participants who voluntarily provided personal details described themselves as patients, 17 percent as family members. Approx. one posting participant in four reported working in the healthcare and nursing field; 13 percent of the individuals participating are psychiatrists, psychologists and/or psychotherapists.

Nearly 70 percent of the participants are female, and six out of ten have a university degree.

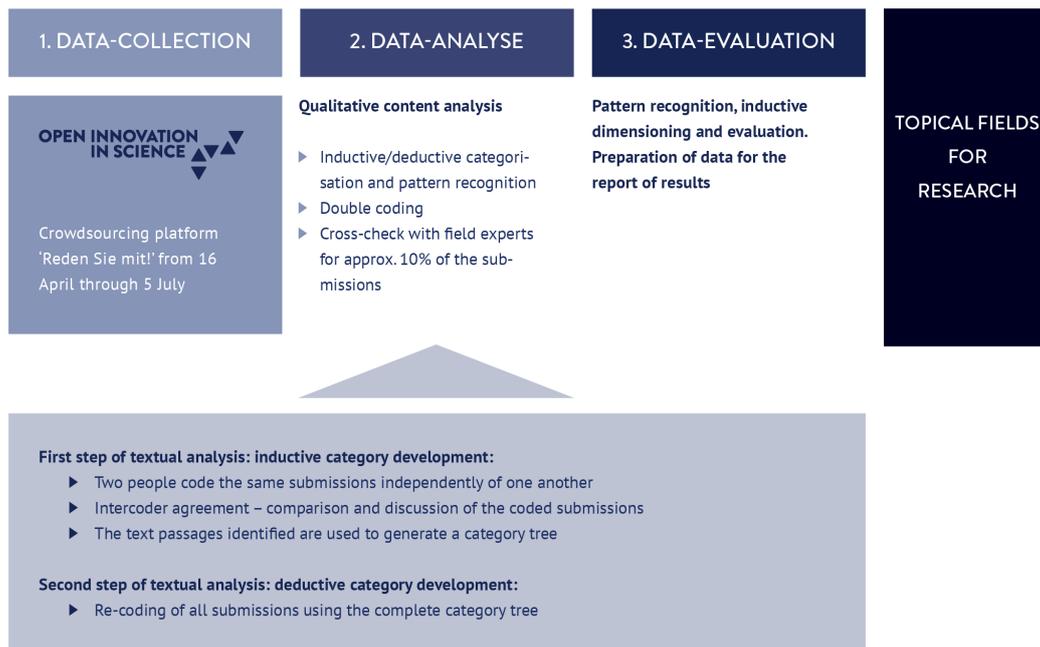
Particularly encouraging was the international participation in ‘Reden Sie mit!’. A little more than one-third of the participants each come from Germany or Austria. Another nearly one in three participate in ‘Reden Sie mit!’ from the rest of the world. One participant in ten, for instance, comes from the USA and nearly one in twenty from Russia.

PROCESS OF ANALYSING THE CONTRIBUTIONS SUBMITTED

The approximately 400 contributions were of high quality and suitable for a content analysis. Posts were 1,376 characters long on average (spaces included).

Each post was analysed by two trained content and text analysts, working independently of one another, using qualitative, inductive/deductive content analysis and a subsequent pattern-recognition process (pattern recognition). Following this, an intercoder agreement was reached in which the analysts compared and discussed the coded submissions.

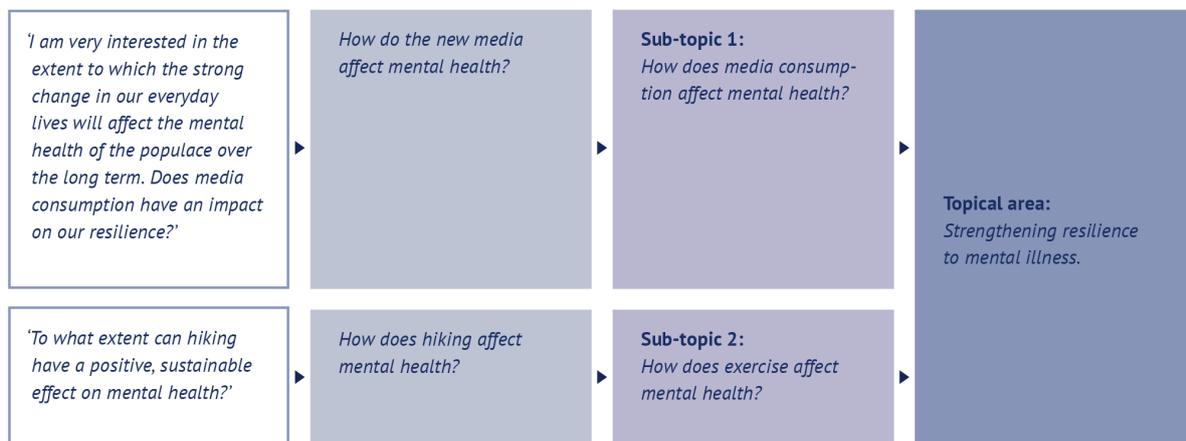
Figure 8: Schematic presentation of the analytical process



The analytics team consisted of a total of three trained and experienced content and text analysts from winnovation research and consulting GmbH and three experts from the field of psychiatry, psychology and the social sciences. To minimise any potential technical bias, the experts were consulted selectively for specific questions. The trained and experienced analytics team compiled the texts/posts without bias.

A total of more than 700 passages of text were distilled from around 400 submissions. 446 sub-topics could be identified; these were condensed into 17 main topic areas, which in turn were combined into seven research areas.

Figure 9: Sample analysis based on two text passages



THEMATIC AREA IDENTIFIED FOR RESEARCH

As indicated above, all submissions were condensed into seven research areas and, below these, 17 main topic areas using the cluster principle. Once the community's analysis was complete, the seven research areas were put to a vote, with each registered participant entitled to vote for two research areas.

Figure 10: Overview of the research areas identified

RESEARCH AREAS AT A GLANCE



1. MENTAL RESILIENCE



2. MORE PRECISE DIAGNOSES



3. PSYCHOSOMATICS



4. PSYCHOTROPIC DRUGS



5. NEW AND ALTERNATIVE THERAPIES



6. CARE STRUCTURES



7. DESTIGMATISATION

CLUSTER I: MENTAL RESILIENCE

Consists of three main subject areas:

- Strengthening resilience vis-à-vis mental illness
- Maintaining mental health among children and adolescents
- Effects on healthy individuals living with mentally ill persons

STRENGTHENING RESILIENCE VIS-À-VIS MENTAL ILLNESS

Contributors recommend increased exploration of the factors that promote resistance to mental illness. Patients particularly want to know why, when and under what conditions some people become mentally ill while others stay healthy under similar conditions. In the posts, the suspicion is expressed that certain lifestyles encourage mental health while others do not. The question is asked:

Through what factors (e.g. behaviours) can resilience to mental illness be explained and, in particular, strengthened in a systematic way?

Possible research questions in this connection are:

- What makes some people more resilient to mental illness than others?
- What effect do consumption behaviour and media consumption have on mental health?
- How does exercise affect mental health?

'To what degree can hiking have a positive, lasting effect on mental health?'

Family member

'I am very interested in the extent to which the strong change in our everyday lives will affect the mental health of the populace over the long term.'

Healthcare and nursing professional

Summary of the analysis:

Healthcare providers and nurses in particular delve into the topic of resilience in their submissions, but patients and family members also exhibit a certain degree of interest in the subject.

The submissions describe that resilient persons either contract no mental illness at all, or, if so, that they completely recover more quickly than others. With this in mind, the contributors recommend research into the factors that affect people's resilience.

Healthcare providers and nurses in particular are interested in learning how personal lifestyle affects the emergence and progression of mental illness; patients and family members are interested in these developments as well.

Healthcare providers and nurses in particular fear that the strong changes brought on by new media might adversely affect people's psyches. In light of this, they would like to see research focus on whether the constant flood of information and increasing media consumption contribute to a more frequent occurrence of mental illness.

Submissions also deal with the question of whether exercise and relaxation techniques (yoga, meditation, walking, etc.) would have a positive impact on maintaining mental health or recovering from existing mental illnesses. Research findings in this area ought to help generate new therapies and alternatives to conventional medicine.

MAINTAINING MENTAL HEALTH AMONG CHILDREN AND ADOLESCENTS

In numerous submissions, it becomes clear that adults attach great importance to improved and enhanced prevention or early detection of mental illness among children and adolescents. The contributions also raise the point that children of mentally ill parents suffer massive added strain. With this in mind, contributors ask themselves:

What can be done to maintain the mental health of children and adolescents?

Possible research questions in this connection are:

- What influencing factors affect the mental health of children and adolescents?
- What role can the family play in the early detection of mental illness?
- What role can the school play in the prevention and early detection of mental illness?
- What effective prevention and support measures are there to protect children of mentally ill parents from damage consequential to the parents' illness?

'Children and adolescents with mental health problems need to be identified, diagnosed and treated earlier than they previously were. Parents and teachers have a central role to play in this.'

No information provided

'How many people with mental illness had parents with mental illness, and, as a result, constant stress that then triggered the disease? In my experience, the risk of disease is not passed on through the genes but rather through major stress triggered by the behaviour of mentally ill parents (verbal abuse, withdrawal, ...).'

Patient

'At the outset, I described how I gradually slipped into this process during adolescence, and there was no one at all who was able to cope with it... Until it also became a psychosis and I turned "strange". My father finally took me to see a doctor – much too late. This is an area in which teachers and educators – I believe – have a huge responsibility to recognise things like this early on among adolescents.'

Patient

'I suffer from schizophrenia. My daughter is studying psychology and constantly grappling with the question of whether she will contract the disease as well. Interestingly, my foster son has schizophrenia, too. Maybe the decisive factor is not inheritance but the influence of child-rearing?'

No information provided

Summary of the analysis:

Healthcare and nursing staff, family members, patients and psychologists emphasised child and adolescent mental health in their submitted posts. They would all like to know what factors have a major role in influencing child and adolescent mental health. By recognising the factors at play, they hope to enable early preventive intervention. This is a particularly important topic for healthcare professionals and nurses, family members and patients.

Patients, healthcare providers, nursing staff and family members described prevention and early detection of mental disorders in children and adolescents as a very important issue in general. Because early detection can have a positive impact on the course of mental illness, the individuals submitting posts call for practical measures at schools. All contributors would like for teachers in schools to play an active role in the prevention of mental disorders, depression in particular. In this connection, it was specifically proposed to investigate whether mental illness can be countered even before it develops, through promotion of personality education in schools (development of inner stability, reflection, self-esteem and a constructive approach to conflicts).

It is suggested that teachers and educators be trained to identify suicide risk, harassment and a variety of mental disorders at an early stage. Depression and bipolar disorder were mentioned as examples. According to a patient, bullying and other forms of psychological violence had a serious impact on mental health, and yet teachers often fail to recognise the seriousness of the problem, and fail to respond appropriately as a result.

According to the submissions, early detection should be practised in families as well. Parents are often very slow to react even though the children's symptoms are clearly manifest. The complaint is voiced that children are brought to experts only very late as a result. The consequence of this, it is said, is that mental illnesses develop in children, manifesting themselves and worsening over the years.

Sufferers' family members in particular, as well as healthcare and nursing professionals and patients, insist on developing preventive measures through research that will protect children and adolescents from the development of mental health problems. In order to intervene at the earliest possible juncture, a special focus in this regard is on the patterning phase.

The contributors also point out the fact that children whose parents are mentally ill are often required to take on 'adult' tasks and responsibilities at an early age, often face a higher stress level and go to lengths to maintain a normal outward appearance. Consequently, these children, it was observed, have a greater risk of mental illness themselves. Another influencing factor mentioned in the posts is upbringing. The question exists of whether certain models of upbringing promote the emergence of mental illness. Besides, the contributors address the seemingly endless flood of information as well as the poor role models in the media where eating disorders are concerned. It is suspected that constant media consumption has a negative impact on the child psyche.

EFFECTS ON HEALTHY INDIVIDUALS LIVING WITH MENTALLY ILL PERSONS

Different groups of people express their concern over a possible negative influence of mentally ill people on individuals who are not mentally ill and living in their closer social environment.

How do mentally ill people affect their social environments?

'Could depression on the part of the grandmother with suicide be a precursor for the granddaughter?'

Family member

'How many mentally ill individuals actually live out their lives with their family? How does this affect the quality of life of all those concerned?'

Family member

'Could it be that people who are good at placing themselves in other people's shoes and are thus extremely empathetic (yet have a weak sense of self-worth) can well understand the experience of the mentally ill individual and can place themselves in the shoes of that individual, then to some extent consciously appropriating the same behaviours of the mentally ill person (in order to understand the family member even better, for instance), and subconsciously reflecting the mentally ill person through behaviour and appropriated experience, and based on this contracting this mental illness him- or herself?'

Healthcare and nursing professional

Summary of the analysis:

Family members in particular, but also healthcare and nursing professionals and patients as well, want to know to what extent sufferers of mental illness affect their social environment as a result of their illness.

A recurrent topic is the influence of mentally ill members of the immediate family, particularly on children and grandchildren. It is asked whether these children have greater problems than others, e.g. poorer school performance. The point is also raised that intensive dealings with the mentally ill family member may itself pose an increased risk of mental illness. Contributors call for more research in order to intervene to provide systematic assistance in a timely fashion.

CLUSTER II: MORE PRECISE DIAGNOSES

Consists of one main subject area:

- Avoiding misdiagnoses and wrong treatments through improved diagnostics of mental illness

AVOIDING MISDIAGNOSES AND WRONG TREATMENTS THROUGH IMPROVED DIAGNOSTICS OF MENTAL ILLNESS

Various groups identify the problem that diagnoses are made incorrectly or imprecisely; the question thus arises:

How can the diagnosis of mental illness be improved, in order to provide more accurate diagnoses while preventing the faulty treatment in which these can result?

Possible research questions in this connection are:

- What can be done to improve the bases for decision-making involved in the diagnosis of mental illness?
- How can mental illnesses be delineated more clearly from one another, facilitating proper diagnoses?
- When is a person said to have been healed from a mental illness? How is recovery defined, and what is the diagnosis of this?
- What can be done to prevent misdiagnoses due to withdrawal of psychotropic drugs?

'Psychiatric diagnoses vary greatly depending on the physician issuing the diagnosis. This sometimes even leads to entirely different treatments!'

Psychologist

'The parents' questionnaire presented as part of the medical history is very general in nature; there is little latitude for comments, and there is a lack of common conversation following evaluation of the questionnaire form.'

Family member

'As a psychosis patient, I found it very difficult to accept a diagnosis based solely on medical observations. This is common for many mental illnesses. A sound, quantitatively measurable, diagnostic methodology, e.g. involving the use of modern brain-research methods, would make it easier for all concerned to deal more effectively with psychosis and accept this diagnosis.'

Patient

Summary of the analysis:

The need for improved diagnostics for the avoidance of misdiagnoses is a topic of great relevance for nearly all groups of persons – especially for patients, healthcare and nursing professionals, family members and psychologists. In the contributions submitted, they describe dissatisfaction with current diagnostics: often, misdiagnoses are issued, making certain mental disorders difficult to

delineate. This leads to what is often years of wrong treatment approaches and enormous suffering for sufferers and their families.

Diagnoses are rarely reviewed or updated; as a result, an – often outdated – diagnosis attaches to the patients and impedes their further development. The lack of a ‘recovery diagnosis’ for mental illnesses is complained of by patients, healthcare and nursing professionals and family members alike: the posts note that there is no officially recognised recovery from mental illness, and that sufferers are seen as ‘the illness sufferer’ for the rest of their lives.

For one, the contributions submitted ask in greater depth how the bases for decision-making in diagnoses might be improved; there are two specific starting points in this connection:

1. The investigation of relevant biomarkers: there is a belief that inclusion of biomarkers such as blood levels, hormone levels, brain waves, etc., could improve or clarify diagnoses of mental illness. So there should be investigation of which biomarkers are linked with, and possibly mutual influencing factors of, mental illnesses.
2. A more comprehensive medical history: particularly proposed is an examination of the extent to which involvement of family members or a larger number of medical professionals even at the medical-history stage can lead to the soundest possible or more precise diagnoses. Because in the eyes of patients, family members, healthcare and nursing professionals and psychologists, the mere recording of symptoms in the patient consultation currently leads to an abbreviated/distorted picture. In this context, there is also discussion of the role and importance of knowledge about the patient by the general practitioner, who often has known the patient for a long time and could help to sharpen the image.

On the other hand, in the posts submitted, healthcare providers and nursing staff, patients, family members and psychologists note that the diagnosis of certain diseases (Asperger's autism, borderline personality disorder, dementia, Alzheimer's, etc.) is difficult because individual syndromes are not clearly distinguished from one another. In their view, symptoms do not apply to only one syndrome, and this makes arriving at a diagnosis more difficult. In the case of some mental disorders (e.g. depression), there is a lack of full differentiation among different forms.

According to patients as well as healthcare and nursing professionals, misdiagnoses often result during discontinuation of psychotropic drugs. Both groups point out that symptoms that emerge during weaning are misdiagnosed as recurrence of mental illness. As a result, there is confusion as to

which symptoms are in fact connected with the respective illness and which are attributable to discontinuation of the drug.

CLUSTER III: PSYCHOSOMATICS

Consists of one main subject area:

- Physical effects of mental illness

PHYSICAL EFFECTS OF MENTAL ILLNESS

Various groups of persons repeatedly describe the interactions between their mental and physical health; this raises the following question:

In what way can mental illness affect physical health?

Possible research questions in this connection are:

- How does the digestive system relate to mental illness?
- How do mental illnesses, particularly dissociative identity disorders, relate to perception of pain and exhaustion?
- To what degree do mental illnesses prompt earlier onset of age-related phenomena?

'Are there age-related limitations that develop earlier or develop in some other way as a result of mental illness?'
Healthcare and nursing professional

'I'd be interested to know why sufferers of mental illness are never examined for micronutrients and amino acids, even though it is known that these are essential for the formation of neurotransmitters. Especially if pre-existing conditions such as food intolerances are already known and the patients have essentially no way of getting a balanced diet.'

Patient

Summary of the analysis:

In addition to the sufferers themselves, it is mainly healthcare and nursing professionals who show an interest in the relationship between mental illness and the patients' physical condition. This question is less relevant for family members and psychotherapists. Still, all four groups of individuals express the desire for science to deal with the question of how digestive problems (abdominal discomfort, irritable bowel, etc.) and nutrition affect mental health. Food intolerance can mean that allowances of essential nutrients, such as amino acids and vitamins, are not met.

People posting contributions lack knowledge of whether it would be advantageous if, through holistic treatment, first a doctor were to investigate the body's requirements and deficiencies before continuing, in the light of these findings, and in cooperation with the therapist, to work on the patient's mental health. Mental illnesses identified in connection with this topic are: anxiety disorders, depression, ADHD, dissociative identity disorder, schizophrenia and ADD.

But the reverse approach is emphasised as well: In their posts, patients as well as healthcare providers and nursing staff write about physical changes as a result of mental illness. For the contributors, it cannot be that the phenomena described, such as e.g. the early onset of age-related limitations, exhaustion or distorted perception of pain, are brought on by drugs or by the physical health of the person affected. Dissociative identity disorder is referenced as a concrete example of a mental illness that entails side effects such as these.

CLUSTER IV: PSYCHOTROPIC DRUGS

Consists of three main subject areas:

- Better compatibility of psychotropic drugs and development of alternatives
- Effects of multiple medication and long-term administration of psychotropic drugs
- Avoiding negative impacts in the course of weaning from psychotropic drugs

BETTER COMPATIBILITY OF PSYCHOTROPIC DRUGS AND DEVELOPMENT OF ALTERNATIVES

Numerous submissions report that patients suffer from the massive side effects of psychotropic drugs in their everyday lives. This leads to the question:

What can be done to improve the compatibility of psychotropic drugs so that the patient is not forced to suffer from side effects?

Possible research questions in this connection are:

- How can side effects of psychotropic drugs be reduced or even eliminated?
- What effects does the administration of psychotropic drugs have in childhood and adolescence?
- What is the relationship between patients' individual factors and the effects of psychotropic drugs?
- What reasonable alternatives are there to treatment with psychotropic drugs?
- What can be done to render the approach taken to psychotropic drugs more responsible (through better information about side effects and long-term effects, for instance)?

'When it comes to psychotropic drugs, what I always experienced the most clearly were the side effects – they always affect my stomach and digestion.'

Patient

'As the mother of a schizophrenic child, I'd like to finally see an alternative to the far too highly dosed psychotropic drugs.'

Family member

'Are psychotropic drugs and mood boosters really the wisest solution?'

Healthcare and nursing professional

'The effect of psychotropic drugs can vary greatly. For instance, with neuroleptics I generally react to very low dosages; e.g. if I take 2.5 mg of Zyprexa in the evening (Zyprexa only available in Austrian pharmacies in dosages beginning with 5 mg), then I sleep until the next day and am very tired until lunch time... yet patients' individual reactions are not taken into account in the dosage of the drugs. They're simply swept under the rug, and the experts assume the condition is a companion sign of the disease.'

Patient

Summary of the analysis:

Different groups of persons discussed the effects and side effects of psychotropic drugs. Particularly patients – those people who feel the effects/side effects on their own bodies – weighed in on this subject in large numbers. But also professionals in healthcare and nursing, family members, psychologists, psychotherapists and general practitioners identified the effects of administration of psychotropic drugs revenue as an open question for research.

Patients, healthcare and nursing professionals, family members and general practitioners are the groups calling most often for side-effect-free drugs or side-effect-free treatment, as the side effects are often the root cause for a patient's refusal to take psychotropic drugs, or his or her decision to discontinue them without consulting an attending physician. The side effects described range from headache through exhaustion to diarrhoea and also include anxiety and despair. Patients describe increasingly withdrawing due to side effects (e.g. weight gain, exhaustion) and neglecting social contacts, which in turn has adverse effects on the healing process.

Contributors want research into the effects of psychotropic drugs – specifically antidepressants, benzodiazepines and neuroleptics – on children and adolescents. The question is whether the brain of the child or adolescent – still deeply involved in the process of developing – responds to medications in ways different to an already developed/adult brain.

Patients and family members in particular find it problematic that individual physical conditions of patients are not sufficiently taken into account in the administration of psychotropic drugs. According to the posts submitted, physicians only question dosages when serious problems arise. In their submissions, patients in particular describe how psychotropic drugs affect each individual differently: For instance, a particular active ingredient may induce very positive reactions in one patient while producing few results or only harmful side effects in another. According to the contributors, physicians are not sufficiently aware of the individual nature of a drug's effectiveness.

In light of the drastic side effects and the ambiguity as to how psychotropic drugs affect the sufferer of mental illness or the illness itself, patients in particular, as well as healthcare and nursing professionals, and to a lesser extent family members and psychologists, ask whether there are alternatives to treatment with psychotropic drugs.

EFFECTS OF MULTIPLE MEDICATION AND LONG-TERM ADMINISTRATION OF PSYCHOTROPIC DRUGS

Groups of individuals with a professional approach to the topic of mental illness, as well as people who are themselves mentally ill, observe negative or unclear effects when patients are treated with psychotropic drugs over the long term and/or must take multiple medications simultaneously, which is apparently a situation that arises very often in practice. This results in the question:

How does intensive treatment with psychotropic drugs [administration of various psychotropic drugs (e.g., neuroleptics and antidepressants), or combinations of psychotropic drugs and other medications, or long-term administration of psychotropic drugs] affect the sufferer and the course of the mental illness?

Possible research questions in this connection are:

- What is the impact of simultaneous administration of different psychotropic drugs or the combination of psychotropic drugs with other medications?
- What are the long-term effects of psychotropic drugs on children and adolescents?
- What are the impact and long-term consequences of sustained medication with psychotropic drugs?

'What I think is particularly important and not yet investigated is research into the effects of medication in cases of multiple diagnoses.'

Psychotherapist

'I'd be interested in studies that investigate the long-term effects of administration of psychotropic drugs among children, particularly antidepressants and psychostimulants.'

Psychologist

'Are modern antidepressants truly safe? – in my opinion, scientific research is still required in this area. Often modern antidepressants are prescribed for years at a time; how does this long-term administration affect the individual?'

Psychologist

'After the birth of my child 8 years ago, I contracted a severe depression with unpleasant thoughts and an anxiety disorder. The consultations with doctors and the experiments with medication in the years that followed seemed senseless to me and only aggravated the problem... In some cases, the interactions among the various medications rendered me suicidal and amplified my anxiety even more.'

Patient

'Why doesn't anyone ask how it can be that countless pharmacogenic mental illnesses are known today that are often caused by random sampling of a very wide variety of substances? Why is something that the drug culture considers 'highly risky, polytoxic consumption' brought on each and every day, as a matter of routine, through multiple prescriptions by psychiatrists and general practitioners?'

Patient

Summary of the analysis:

Particularly patients, healthcare and nursing professionals, psychologists, family members and psychotherapists attached a high level of relevance to the topic of the effects of sustained medication or use of multiple medications.

In their posts, patients as well as professionals in healthcare and nursing, write about the consequences that arise because the individual drugs in a combination of multiple drugs do not work as they should. They also point out that medical personnel tend to be far too careless in the way they deal with multiple medications. On the one hand, the submissions point out that in some cases multiple medication may be the result of a co-morbidity³. On the other hand, they also complain that the manner in which multiple medications are prescribed is seemingly indiscriminate. In their posts, psychologists and psychotherapists also point to a dearth of research into the ways in which different medications interact. Also of importance to healthcare and nursing professionals is the fact that there is very little experience with the side effects of combination therapies, e.g. simultaneous administration of several different neuroleptics.

The people posting contributions were also interested in the long-term effects of psychotropic drugs (antidepressants and psychostimulants) among children and adolescents. Research should incorporate the existing findings of personalised medicine, as these take the patient's individual circumstances into account. Given the fact that children change very quickly physically and mentally, contributors propose therapy that continuously adapts to these changes.

Healthcare and nursing professionals in particular are quite clear in articulating that there are too few scientific studies on chronic administration of psychotropic drugs that provide an indication of how this affects the patients and the disease. Patients, family members and psychologists also criticise the lack of knowledge in this area, albeit less forcefully.

AVOIDING NEGATIVE IMPACTS IN THE COURSE OF WEANING FROM PSYCHOTROPIC DRUGS

In the contributions submitted, a very wide range of groups noted that massive health problems occur during or following discontinuation of psychotropic drugs. It is not clear to any of these groups how psychotropic drugs can best be discontinued. This results in the question:

³ Co-morbidity = simultaneous presence of multiple diseases in the same individual, such as anxiety and depressive disorder, or Alzheimer's disease and diabetes mellitus.

How can psychotropic drugs be discontinued successfully and without any lasting effects?

Possible research questions in this connection are:

- What symptoms accompany weaning of or withdrawal from psychotropic drugs, and what weaning strategies can be applied to counteract these?
- What long-term effects might emerge following treatment with or discontinuation of psychotropic drugs, and how can these be prevented?

'Many treatment professionals are overwhelmed at the moment, as the conventional wisdom is that one can wean a patient from SSRI relatively quickly (over about 2-4 weeks) – as soon as problems surface, these are attributed to the underlying disease.'

Psychologist

'Am emotionally jaded, have lost my sex drive, have major problems with an erection, and my genital area feels completely numb, like the rest of my body. I didn't have any of these symptoms before discontinuing SSRI.'

Patient

The doctor said I could simply quit taking the drug, or I should wean myself off of it over 3 months – that would be on the safe side. After 3 weeks, I contracted a strange 'flu' that wouldn't go away, panic, nausea, vomiting, brain zaps, sleep disorders, panic, aggression... That was 3 years ago! I'm still going through withdrawals; I have symptoms that I NEVER had before... for doctors, though, this problem doesn't exist! Antidepressants are not habit-forming, according to the standard wisdom among doctors.'

Patient

Summary of the analysis:

Various groups of respondents raised the issue of discontinuation of drugs. Patients particularly frequently offered observations on the subject; for them, the discontinuation of psychotropic drugs obviously entails significant risk potential. But healthcare and nursing professionals, family members, psychologists and psychotherapists are also very pointed in addressing this problem.

The goal of any therapy should be to heal the person receiving it. From a long-term point of view, the patient should be in a position to lead a healthy life without medication, as one psychiatrist states in his/her post. Given the high risk of dependency on psychotropic drugs, and the mental and physical consequences experienced after discontinuing them, patients often refuse to take these medications. According to the medical personnel who participated in the survey, it hardly is a sustainable approach to cure a person of mental illness but then expect that individual to combat the problems associated with discontinuing medications.

Discontinuation of psychotropic drugs poses immense hurdles for the patient. The contributions ask whether there are medication-based therapies that do not result in dependency, or what opportunities there are to discontinue psychotropic drugs in ways that are free from side effects. Even the ‘gradual weaning’ from drugs as a discontinuation strategy often leads to physical and mental complaints on the part of the persons concerned. Contributions by patients identify the emergence of anxiety, fatigue, insomnia, depersonalisation, perceptual disorders, etc. Patients and psychologists make it clear that useful medical advice on discontinuing psychotropic drugs without inducing side effects is scarce. According to the submissions, it is often unclear which symptoms are attributable to the original mental disease (underlying disease) and which are after-effects of discontinuation of medication.

Patients, healthcare and nursing professionals, family members and psychotherapists also note that they are confronted with sexual limitations following discontinuation of SSRI⁴ (psychotropic drugs). Both men and women report not to have suffered from this type of sexual dysfunction during their illness and treatment with SSRI. Particularly those affected describe how, when asked, the supervising physicians attribute sexual aversion and erectile dysfunction to the underlying disease and dispute any links with discontinuation of SSRI.

⁴ SSRI = selective serotonin reuptake inhibitor – these are antidepressants that have an effect on the serotonin transporter and thereby increase the concentration of serotonin in the tissue fluid of the brain.

CLUSTER V: NEW AND ALTERNATIVE THERAPIES

Consists of four main subject areas:

- Individual suitability of psychotherapies for certain (groups of) persons
- Effective treatment and therapy options for personality disorders
- More effective treatment and therapy options for psychotic disorders
- Consideration of traumatic events in the explanation, treatment and therapy of mental disorders

INDIVIDUAL SUITABILITY OF PSYCHOTHERAPIES FOR CERTAIN (GROUPS OF) PERSONS

Many patients focused on the problem that it was not clear what psychotherapies and supportive therapies (e.g., ergotherapy, occupational therapy, etc.) were best-suited for which patient groups.

The question is asked:

Is there a connection between the type of therapy applied and the effectiveness for certain individuals or groups?

'Are there certain groups of people (men, women, teenagers, etc.) who respond more to one kind of therapy than to another?'

Patient

'For two years, I received depth-psychological therapy with two sessions per week, and although I learned some things there, learned about myself and discovered important things, I don't know if healing took place there. I am currently experiencing the contrast in a group therapy, which uses many elements of body work. Physically acting out, feeling closeness and distance in partner exercises, touching, cuddling, shouting in anger and hitting a pillow, small lineups. All of this seems to appeal to levels that would be off-limits to me sitting face-to-face with an interlocutor.'

Patient

Summary of the analysis:

The question of which form of therapy best suits which individuals or groups of persons is primarily a major concern for patients. The calls for more research in this area are less urgent among family members, general practitioners and psychotherapists

Patients ask which therapy suits each group of individuals – for example, women, men, children and adolescents – because in their experience the responses to different forms of therapy are quite individual – a particular treatment approach works better for one person and less well for another.

Research should thus aim to be in a position to offer recommendations as to which therapy suits which individuals or groups of persons.

EFFECTIVE TREATMENT AND THERAPY OPTIONS FOR PERSONALITY DISORDERS

Two groups of respondents expressed themselves in regard to personality disorders and the problem that therapies for these either do not exist or are insufficient: patients and healthcare and nursing professionals. For them, the following question is of great relevance:

Do narcissists and persons with intellectual deficits and personality disorders require new forms of therapy?

Possible research questions in this connection are:

- What effective treatment and therapeutic options exist for narcissists?
- What treatments and therapies could be used for sufferers of personality disorders with reduced intelligence?

'I'd be interested to know whether people with a disrupted, false self-image – narcissism – tend to suffer more from personality disorders? If narcissism is the basis for the disease, then presumably tailored treatment concepts are called for.'

Patient

'I was very disturbed when I was told by a psychologist that there are no established treatment approaches for people with an intellectual disability/reduced intelligence who suffer from a personality disorder due to childhood trauma. The situation of such people, who, with no prospects for therapy, are considered permanently emotionally disabled, is extremely stressful and challenging for those affected, as well as for their surroundings.'

Healthcare and nursing professional

Summary of the analysis:

In the posts submitted, patients note that they view narcissism as the origin of a personality disorder. They posit, furthermore, that new therapies must first be developed for patients suffering from illnesses rooted in narcissism.

In connection with personality disorders, one healthcare and nursing professional notes that there is no therapeutic outlook for individuals with intellectual deficits and a dissociative personality disorder. In his/her experience, there are no treatment concepts customised for people with diminished intelligence; consequently, new and suitable therapeutic concepts need to be developed for this case.

MORE EFFECTIVE TREATMENT AND THERAPY OPTIONS FOR PSYCHOTIC DISORDERS

Psychosis is one of a few specific mental illnesses often singled out for discussion by the various groups of people.

What can be done to treat psychotic illnesses more effectively?

Possible research questions in this connection are:

- What forms of therapy for psychotic disorders can be developed to treat psychoses?
- What can be done to intervene at an early stage in the course of an acute psychotic phase, thereby minimising the extent and duration of the acute phase or even eliminating acute phases altogether?
- How can the events that sufferers experience during an acute psychotic phase be taken into consideration more effectively during therapeutic treatment?

'Prior to an acute phase, I notice that I am no longer in my normal healthy state and am headed for the next psychotic episode. But there's nothing I can do to counteract or prevent that. At some point, then, any sense of suffering from a disease is missing. It would be so wonderful if I could react at that point, when I notice it's starting again.'

Patient

'Someone who is in an acute schizophrenic-psychotic phase undergoes an experience that, viewed objectively, could be described as a delusion, but to that person it is reality..'

'What if psychotic experiences are the means of forgetting painful, fearful and overstraining content? If these experiences were integrated into therapy, the sufferer could take new steps towards development.'

No information provided

Summary of the analysis:

Posts by medical professionals (psychologist and healthcare/nursing professional) note the possibility of a cure for psychotic disorders. It is unclear, however, to what factor(s) the recovery is due, and through which therapy patients are cured. Patients primarily ask what specific active ingredients can provide relief for psychosis. In the contributions, the effect of (high-dose) psychotropic drugs is called into question; possible alternatives are identified at the same time and include oestrogens, processed opium and marijuana. Contributors with professional access to mental illness (psychologist, psychotherapist, healthcare and nursing professionals) are more sweeping in their questioning of the effectiveness of the current forms of therapy as, in their view,

the medical effect of different therapeutic approaches has not been scientifically compared and validated.

A psychosis is marked by psychotic acute phases⁵; in an acute phase, the patient suffers relapses accompanied by the occurrence of delusions, hallucinations and the like. According to contributing patients and family members, the onset of an acute phase is discernible well in advance. They wonder just how they can intervene at this precise juncture – immediately prior to an acute phase – to have an impact on the psychosis without a need to turn immediately to psychotropic drugs. Early, successful management or control of an acute psychotic phase is thus highly relevant, in the view of patients and family members, as awareness of the illness is usually completely lacking during an acute phase. Professionals in the healthcare and nursing fields also ask whether therapy can succeed at all during an acute phase.

According to patients' statements, the mental events that psychosis sufferers experience during an acute phase are not sufficiently taken into account in the treatment of psychotic disorders. The contributors are quite clear in stating that these psychotic experiences may offer access to the relevant medical history and possibly be the key to healing. Patients consider it an obstacle that therapeutic approaches treat these experiences as unreal and hence non-existent or not 'proper'. The contributors wonder whether integrating psychotic experiences into therapeutic treatment might lead to healing.

⁵ THE PRODROMAL PHASE – the 'prodromal phase' (translated: the 'precursor' phase) is the phase that extends from the onset of first psychological changes and/or negative symptoms up to the continuous occurrence of positive symptoms of psychosis (e.g. hallucinations or delusions). THE PHASE OF UNTREATED PSYCHOSIS – this refers to the first phase extending from the continuous occurrence of psychotic symptoms (e.g. hallucinations or delusions) through to first treatment. THE ACUTE PHASE – this is the complete outbreak of the disease, with hallucinations, delusions and inconsistent thinking. Part of the disease involves the possibility that patients have difficulties grasping that they are ill. THE LONG-TERM PHASE – Once acute symptoms have vanished and the patient's condition has stabilised, negative symptoms may persist over a period of time that varies in length. This phase may be accompanied by relapses into the acute phase.

CONSIDERATION OF TRAUMATIC EVENTS IN THE EXPLANATION, TREATMENT AND THERAPY OF MENTAL DISORDERS

The contributors would like to know why they are mentally ill, and they suspect that trauma is the cause.

To what extent are traumatic experiences the cause of mental illness, and what can be done to counteract their effects?

Possible research questions in this connection are:

- To what extent do traumatic experiences cause mental illness?
- To what degree can an approach that takes traumatic childhood experiences into account promote the patient's healing process?
- What mental problems arise among migrants and asylum-seekers as a result of traumatic events, and what assistance do they need?

'Research into what migrants/asylum-seekers need if they are mentally ill, or to minimise disease (war trauma, flight, separation, loss, death, etc.). What science can do: help make audible/tangible to decision-makers and the population that this group of people in particular needs our support.'

Healthcare and nursing professional

'I myself specialise in the treatment of depressive and anxiety syndromes within the framework of psychotherapy. In roughly 15% of my patients, it turns out that the disorder is the result of trauma.'

Psychologist

'For this, we (also) need research that examines how many people with mental illness have traumatic childhood experiences in their biographies, particularly bonding traumas and emotional violence, trans-generational traumatisations and much more. "Simple disorders" such as eating disorders, borderline, chronic depression, anxiety disorders and the like should no longer be considered or taken in isolation, apart from all biographical background.'

Patient

Summary of the analysis:

Primarily among healthcare and nursing professionals, the need for more research into the origins of mental illness through trauma⁶ is very pronounced. But patients, psychologists, psychotherapists and family members are also interested in this topic. The above-mentioned groups of people consider it important to get to the bottom of the origins and causal relationships involved in mental illness.

⁶ Trauma [2] in psychology is the term that describes the emotional causes of mental disorders (birth trauma, for instance; consequences of early separation from the mother and all manner of emotional distress brought on by profound, shock-like experiences). Syn. Emotional trauma.

Contributors ask whether traumatic experiences – emotional or physical violence, for instance (emotional neglect, abuse, etc.) – trigger mental disorders. In several cases, dissociative identity disorder is seen as a sequel disease, but also occasionally depression, anxiety disorder, and autism. According to the statements submitted, to date, treatments of these diseases have not drawn a connection to traumatic experience; therapy is consequently not mindful of this experience and fails to take it into account.

Contributors suspect that traumatic events in childhood (including emotional and physical violence within the family) preceded the development of mental illness. They posit that it may be helpful to patients' recovery if their history were investigated for signs of violence, trauma in bonding and transgenerational traumatisation, with difficult childhood experiences focussed upon and dealt with during the healing process.

Migrants and asylum-seekers who have managed to make their way to Austria already have a host of awful experiences behind them. For the most part, they are not in a position to process the trauma of war, flight, separation and loss on their own; as a result, psychological/psychiatric help would be urgently needed. Many of the posts submitted suggest research into the types of psychological problems these people develop as a result of their pasts, and to define therapies with which people can best help the individuals affected. Contributors propose extensive involvement on the part of family members – if possible – in the healing process. Particularly those sufferers who had to flee their homes and were torn from their accustomed surroundings need to rely on their tight-knit social situation for some stability and security.

CLUSTER VI: THE STRUCTURE OF CARE

Consists of four main subject areas:

- Improving care of the mentally ill in the clinical setting
- Involving peers and lay assistants in the care and treatment of sufferers of mental illness
- Improved access to care and support services
- Improved inclusion of the mentally ill in the workplace

IMPROVING CARE OF THE MENTALLY ILL IN THE CLINICAL SETTING

Different groups of people raise the problem that psychiatric clinics in their current form do not optimally promote quick recovery, and in some cases even impede recovery to some extent. This results in the question:

In what way can the environment or approach to patients in psychiatric hospitals be improved to do more to promote recovery?

Possible research questions in this connection are:

- What is the optimal clinical recovery environment like?
- What can be done to create a respectful and empathetic relationship between patients and healthcare professionals?

'It is very conspicuous that staff shortages are increasing enormously in psychiatric facilities, of all places ... I'd like to know, first off, what minimum staffing would have to be on a ward, e.g. General Acute Psychiatry – with a maximum of 36 patients, in order to still be able to provide professional care.'

No information provided

'The development of concepts and guidelines for coping with overstimulus and understimulus should – based on the concept of the "optimal healing environment" – be advanced to provide caregivers and other healthcare experts with the knowledge they need to provide optimum, person-centred healthcare.'

Healthcare and nursing professional

Summary of the analysis:

The need for improved clinical surroundings was identified by a majority of patients as well as healthcare and nursing professionals, family members, psychologists, psychotherapists and psychiatrists. In the contributors' view, the way clinics currently operate does not go far enough towards promoting recovery beyond therapy.

The contributions submitted explore the clinical setting optimal for recovery. In this context, there is a demand for the best possible facilities, conducive fittings and furnishings and optimal duration of

in-patient/out-patient treatment for a rapid recovery. The contributions also emphasise research into the optimum number of professional care staff and improved coordination among them in order to offer the best possible conditions for patient recovery. Contributors also ask about the minimum qualifications of clinic staff and would like to know what influence this has on the recovery of mentally ill individuals.

A major topic in patients' view, but to a lesser extent in the view of healthcare and nursing professionals as well as family members, is the lack of human, empathetic treatment in the clinical setting. Particularly in the psychiatric field, the lack of trust between patients and therapists is singled out. There, patients feel as though their needs are simply quieted through drugs meant only to facilitate the work of the staff. Yet patients want to be taken seriously with their problems and needs; they want to speak with caregivers on an equal footing and experience more respect when interacting with them.

So they ask what kind of vocational preparation, supplemental training or other measures caregivers and the cared-for can pursue together as equal partners seeking recovery.

INVOLVING PEERS AND LAY ASSISTANTS IN THE CARE AND TREATMENT OF SUFFERERS OF MENTAL ILLNESS

In an everyday setting, mentally ill people receive extensive support from family members, self-help groups, peers and lay assistants. In many cases, however, non-professional caregivers' contributions towards treatment and therapy are unclear or not recognised. This leads to the question:

How can peers, self-help groups and other non-medical persons optimally participate in the care (including therapy) of mentally ill individuals?

Possible research questions in this connection are:

- What can family members do to actively support patients on their path to recovery?
- What can non-family support sources (e.g. lay assistants, peers and self-help groups) do to contribute?

'I would be interested in evidence-based studies that demonstrate that care provided by non-physicians, non-psychologists and laypeople is as effective as care provided by physicians, psychologists and psycho-therapists.'

Psychologist

'How does peer care measure up against work performed by caregiver staff/physicians? To what degree can peer work foster patient recovery? And what are the difficulties and disadvantages involved?'

Patient

Summary of the analysis:

Family members in particular, as well as healthcare and nursing professionals, followed by patients, are interested in effective involvement by peers, self-help groups and non-medical persons in the treatment of the mentally ill. Patients in particular report that non-medical caregivers rank highly as they offer quick support, helping fill the time spent waiting for therapy. Contributors also ask whether the relevant vocational training automatically guarantees greater acceptance of care by sufferers of mental illness, or whether lay assistants, peer caregivers and self-help groups might aid sufferers just as well or even better.

Family members in particular want to assist their sick relatives wherever they can. According to their statements, it is very stressful for them to be helpless in the face of some of the situations they witness. So they call for research into the extent to which it is helpful to involve family members in the healing process of mentally ill persons, and into the options available to them to become actively involved in therapy themselves. Mental diseases mentioned in this context are: bipolar disorder, anorexia and social withdrawal.

IMPROVED ACCESS TO CARE AND SUPPORT SERVICES

Numerous contributions report that mentally ill individuals feel underserved in the everyday setting; if they are to cope with their illness, they report, certain support services are needed quickly, unbureaucratically and in an affordable form. Contributors ask:

What can be done to improve access by the mentally ill to care and support services?

Possible research questions in this connection are:

- How can sufferers find simpler, more affordable and attainable access to assistance (acute help, hotlines, in-patient and out-patient treatment, mobile care, etc.)?
- What legal conditions must be created to offer mentally ill people the best possible support in their everyday lives?

'I think easier access to psychotherapy (on insurance, as most cannot afford it otherwise) is necessary. It should be a source of long-term support for sufferers. Currently, there are so few patients' therapy slots paid by public insurance schemes that waits of 4-6 months are normal – that's far too long in the case of first-time onset of mental illness!'

Family member

'What criteria must legislation be based on to focus on the wellbeing of patients and their chances of recovery, and to permit treatment rather than hinder it?'

Psychologist

Summary of the analysis:

Optimizing care and support offerings is of high relevance, particularly for patients, healthcare and nursing professionals, psychologists and family members. They call for improved access to different forms of assistance and caregiving structures in the form of acute assistance, in-patient and semi-in-patient services, hotlines, counselling centres, early-detection centres, after-care centres and psychotherapy options. They are mainly interested in gaining access to, and in sufficient temporal and spatial availability of, services that can improve the quality of life for sufferers of disease while assisting them in their everyday lives. Contributors point out that assistance offers are sometimes very expensive and nearly non-existent in rural areas. It is also noted that patients can often afford only whatever therapy is covered under their health insurance scheme. The consequence of this is that they can not pay for adequate support later on.

The contributions have made it clear that, where their rights as patients and as human beings are concerned, mentally ill individuals feel abandoned, marginalised, discriminated against and not treated well enough. Psychiatrists and hospitals, it was pointed out, make decisions that affect patients' lives without regard for the patients' needs. Their sense of powerlessness and neglect also manifests itself in the fact that sufferers lack an umbrella advocacy group for mentally ill people, a group that would advocate on their behalf at a higher level. Also at stake is the legal framework for effective treatment and the right to adequate therapy. Patients want to know what legal conditions or political structures need to be created to provide mentally ill individuals with the best possible support, both in the clinical setting and in everyday life.

IMPROVED INCLUSION OF THE MENTALLY ILL IN THE WORKPLACE

Different groups addressed the problem that the everyday lives of mentally ill people, and their return to a normal working life, are fraught with many obstacles. This leads to the question:

How can mentally ill persons, taking the disease into account, be re-integrated into the process of work in keeping with their qualifications and skills?

Work gives meaning to life and gives people with a mental illness an opportunity to participate in social life. Unfortunately, many of those affected, whether in phases of the illness or over the long term, cannot work full-time. But they'd be willing to take on part-time work on a schedule compatible with their condition. They don't do so, however, because as a rule this means sacrificing subsidies, compensatory allowances, sick leave, early retirement, etc., which in turn threatens their livelihood.'

Patient

Summary of the analysis:

The need for improved assistance and opportunities for (re)integration in the labour market is highly relevant for patients as well as healthcare and nursing professionals. The contributions submitted criticise the poor support situation for mentally ill people and the lack of structures to afford them a regular working life.

As they are directly affected, patients rank this issue as very important: work lends meaning to their lives, and participation in the labour force would permit them to participate actively in social life once more. Currently, though, they have little chance of gaining a foothold in the labour market, because they are not taken seriously on account of their mental illness. As a result, the very specific question is raised concerning research into successful measures and adequate structures that would help sufferers of mental illness participate in the ordinary working world. At the moment, access is difficult for them for want of flexible working-time models and customizable subsidy systems, yet these are what people with mental disorders need if they are to have a chance in the labour market that is commensurate with their capabilities and qualifications.

CLUSTER VII: DESTIGMATISATION

Consists of one main subject area:

- Problems that arise due to social stigmatisation of the mentally ill

PROBLEMS THAT ARISE DUE TO SOCIAL STIGMATISATION OF THE MENTALLY ILL

Many sufferers experience the social stigma associated with their disease. They feel impeded in a variety of ways.

With this in mind, contributors ask themselves the following question:

How does social stigmatisation affect the course of mental illness, and how it can be systematically reduced?

Possible research questions in this connection are:

- What are the effects, on the mentally ill or on the course of the disease, of stigmatisation by society, by the public authorities (health insurance schemes, pension funds), but also by medical professionals involved in treatment?
- What stigmatising effects do specific diagnoses have for those affected?
- Where is the best point at which to apply systematic measures, including education, to combat stigmatisation?

'Once you have a psychiatric diagnosis, you're stuck with it. Today's psychiatric diagnostics are static, not dynamic. If they were dynamic, then there would be recovery diagnoses that would still need to be explicitly elaborated'

Patient

The knowledge of the populace about mental illness is practically non-existent; one cannot speak about it even if someone in the family is not doing well; people discuss it behind closed doors, or else the situation is dismissed with the sentence "she's not feeling so well, you know...'

Psychologist

Summary of the analysis:

Patients, healthcare and nursing professionals as well as family members have specifically addressed this topic. Especially the latter ascribe great importance to destigmatisation. For sufferers, stigmatisation not only means a lack of treatment on par with treatment of the physically ill; it also represents a considerable obstacle in everyday life, such as interactions with the public authorities. According to the contributors, sufferers of mental illness are discriminated against in ways that prevent them from being dealt with on an equal footing; people do not take them seriously and do not offer the same kind of acceptance they would in the case of the physically ill. Many reported finding that some mental illnesses are stigmatised to an even greater degree than

others; a specific example of this is the borderline personality disorder. Healthcare and nursing staff, as well as psychotherapists, would like to know to what extent stigmatisation affects the course of the disease.

Another type of stigmatisation is often found in the diagnosis itself: contributors report that diagnoses are rarely reviewed or updated. As a result, an – often outdated – diagnosis attaches to the patients and impedes their further development. The lack of a ‘recovery diagnosis’ for mental illness is complained of by patients, healthcare and nursing professionals and family members alike: the posts note that there is no officially recognised recovery from mental illness, and that sufferers are seen as ‘the illness sufferer’ for the rest of their lives.

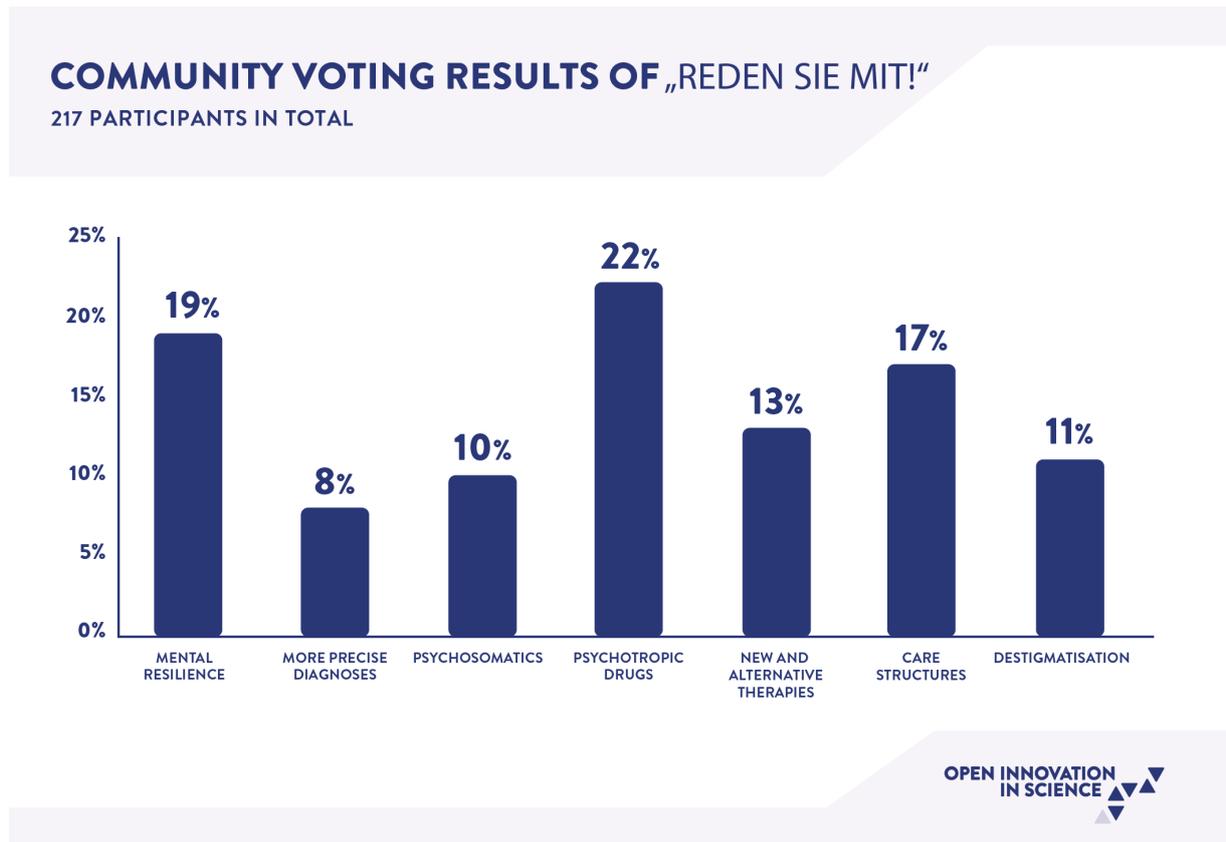
Particularly for patients, family members and healthcare and nursing professionals, one reason the problem as described is so virulent is that, as they report, it is very difficult to declare oneself mentally ill even within one’s own family. Direct discussion of the disease is typically avoided, and family members in particular go to lengths to keep up appearances. This also concerns the fact that parents do not want to be perceived as ‘guilty’ for the mental health of their children. As a result of this stigma, many sufferers would not dare to seek professional help. Beyond this, general practitioners often lack the expertise required to correctly identify the disease; consequently, sufferers often failed to receive adequate treatment.

With this in mind, the contributors call upon the science community to find out which countermeasures would be effective in mitigating these problems in a sustainable way. According to the contributors, support groups and schools could be important starting points. The aim is to promote awareness in society and create the kind of understanding required in order not to exclude the mentally ill. Beyond awareness outreach, there ought to be an ‘official’ certificate of recovery for sufferers, i.e. ‘proof’ that they have overcome the disease.

ONLINE COMMUNITY VOTING

Registered participants in community voting had from 29 September until 18 October 2015 in which to go to www.redensiemit.org and vote on which research areas, in their view, should be given priority. Anyone who was logged in was entitled to vote for 2 clusters within the seven research areas presented (regardless of whether or not he or she submitted a post of his or her own).

Figure 11: Result of community voting



All in all, 217 participants took part in the two-week community voting. 22 percent of all of the votes cast went to the area of psychotropic drugs, followed by psychological resilience with 19 percent and care structures with 17 percent. These were followed by the research areas of new and alternative forms of treatment (13 percent), destigmatisation (11 percent), psychosomatics (10 percent) and more precise diagnoses (8 percent).

EVALUATION BY AN INTERDISCIPLINARY JURY OF EXPERTS

Following the community voting, the seven research areas were also evaluated by a jury of nine specialists. The international jury, consisting of representatives of patients' organisations, representatives of the fields of psychiatry, psychotherapy, psychiatric nursing and clinical psychology, discussed and evaluated the results of the analysis of the 'Reden Sie mit!' crowdsourcing project "Have your say!" at a meeting of the jury held on 22 October 2015. The interdisciplinary composition of the jury permitted exciting, interdisciplinary discussion of a kind that is atypical in the field and, moreover, rarely encountered. The jury members were impressed by the strong response that the initiative managed to generate, and by the remarkable quality of the submissions and, hence, of the results as well.

The jury members were not aware beforehand of the outcome of the community voting. Jury members were asked to assess which of the submissions were relevant for research and society, and to indicate where they saw new questions for research.

The evaluation of the clusters was conducted by means of an evaluation sheet for each research area, with each area assessed on the basis of two criteria:

A) RELEVANCE FOR RESEARCH:

- Is this research field likely to generate new knowledge?
- How novel are the questions contained? (where there was already extensive work on the topic: little relevance)
- If the issues identified are not new – do you see a possibility for new connections or insights to develop within this research area, from which new knowledge could be generated? Are new partnerships (e.g. high interdisciplinarity) or other innovative forms of access to knowledge and methods needed to address these questions in a meaningful way?

B) RELEVANCE FOR SOCIETY:

- Is there a potential for newly generated knowledge (incl. new solution approaches or unconventional perspectives) in this research area that will significantly improve the situation for those affected (patients, family members, professionals in nursing, therapy and medicine, etc.)?
- Opportunities for knowledge transfer and implementation: Is it likely that the knowledge newly created will be relevant enough for applications that it can be applied or made

available to stakeholders (e.g. through existing intermediaries) and implemented in practice?

The jury could award 1 to 10 points, with 1 point denoting no novelty/relevance/potential and 10 points for very high novelty/relevance/potential.

Figure 12: Sample jury assessment form based on the research area of mental resilience

OPEN INNOVATION IN SCIENCE

An initiative of the Ludwig Boltzmann Gesellschaft

EVALUATION CLUSTER 1: MENTAL RESILIENCE

1. STRENGTHENING RESILIENCE TO MENTAL ILLNESSES
2. RETAINING THE MENTAL HEALTH OF CHILDREN AND ADOLESCENT
3. IMPACT ON HEALTHY INDIVIDUALS LIVING TOGETHER WITH SUFFERERS OF MENTAL ILLNESS

Now, please evaluate the cluster based on the following criteria:

A) RELEVANCE FOR RESEARCH (1-10 POINTS*) _____ POINTS

- ▶ Is this research field likely to generate new knowledge?
- ▶ How novel are the questions contained? (where there was already extensive work on the topic: little relevance)
- ▶ If the issues identified are not new – do you see a possibility for new connections or insights to develop within this research area, from which new knowledge could be generated? Are new partnerships (e.g. high interdisciplinarity) or other innovative forms of access to knowledge and methods needed to address these questions in a meaningful way?

NOTES:

B) RELEVANCE FOR SOCIETY (1 – 10 POINTS²) _____ POINTS

- ▶ Is there a potential for newly generated knowledge (incl. new solution approaches or unconventional perspectives) in this research area that will significantly improve the situation for those affected (patients, family members, professionals in nursing, therapy and medicine, etc.)?
- ▶ Opportunities for knowledge transfer and implementation: Is it likely that the knowledge newly created will be relevant enough for applications that it can be applied or made available to stakeholders (e.g. through existing intermediaries) and implemented in practice?

NOTES:

¹ 1 = The jury could award 1 to 10 points, with 1 point denoting no novelty/relevance/potential and 10 points for very high novelty/relevance/potential.

THE JURY MEMBERS



From left to right: Kurt Senekovic, Johannes Wancata, Peter Stipl, Sandra Lettner, Werner Schöny, Ulrike Schmidt, Edwin Ladinser, Jutta Fiegl, Dorothea Sauter

JUTTA FIEGL

Jutta Fiegl obtained her doctorate from the University of Vienna. She is a psychotherapist (systemic family therapy), clinical psychologist, health psychologist and trainer. Jutta Fiegl is co-founder and Vice-Rector of Sigmund Freud University Vienna and was involved in the substantive design of the Department of Psychotherapeutic Science; she is an instructor in the programmes and electives in systemic family therapy.

EDWIN LADINSER

Edwin Ladinser has a degree in sociology from the universities in Graz and Vienna. He worked as a research assistant at the Ludwig Boltzmann Institute for Social Psychiatry for many years. In 1998, initially in a volunteer capacity, he went to work with HPE – Hilfe für Angehörige und Freunde psychisch Erkrankter. An example of his dedication is the organisation of an anti-stigma project in schools. Today, Edwin Ladinser is Head of the Advisory Centre and Managing Director of HPE Österreich.

SANDRA LETTNER

Sandra Lettner is the President of the Berufsverband Österreichischer PsychologInnen [Federation of Austrian Psychologists' Association]. She has represented clinical psychologists in Upper Austrian hospitals since 2005; in 2012, she assumed leadership of the Department of Clinical Psychologists of Austrian Hospitals [Referat Klinischer PsychologInnen der Österreichischen Krankenanstalten]. In her primary professional capacity, Sandra Lettner is a Senior Clinical Neuropsychologist at Krankenhaus der Barmherzigen Schwestern Ried Betriebs GmbH, a hospital. She also has a private practice in clinical neuropsychology and is a sworn and judicially certified expert.

DOROTHEA SAUTER

Dorothea Sauter is Vice-President of the German Professional Psychiatric Care Association [Deutschen Fachgesellschaft Psychiatrische Pflege (DFPP e.V.)], a project officer for nursing documentation at the Westphalia-Lippe Regional Authority [Landesverband] (LWL) and the author of textbooks in her field. From 2010 to 2014, Dorothea Sauter was also a member of the Advisory Board at *Psych. Pflege Heute*, a professional journal. She studied psychiatric care at the Fachhochschule der Diakonie Bielefeld from 2011 to 2014, and since 2014 she is enrolled in a programme in health and care sciences at Martin Luther University in Halle (Saale).

ULRIKE SCHMIDT

Ulrike Schmidt is Senior Physician in the Protective Ward, Head of the Outpatient Clinic for Posttraumatic Stress Disorder and Head of the Molecular Psychotraumatology Research Group, Max Planck Institute of Psychiatry in Munich. She studied medicine before continuing to complete specialist training as a psychiatrist and psychotherapist. Thereafter, Ulrike Schmidt dealt intensively with the trauma psychology and completed the course of study in 'Special Psychotraumatology (DeGPT)'.

WERNER SCHÖNY

Werner Schöny studied medicine at the universities of Innsbruck and Vienna. He was medical director of the State Psychiatric Clinic Wagner-Jauregg in Linz, Austria. He retired from this post at the end of 2011. Werner Schöny was also Head of the Academy of Occupational Therapy in Upper Austria and scientific director of the Academy for Health Professions at the State Psychiatric Clinic Wagner-Jauregg in Linz. Werner Schöny is CEO of pro mente Upper Austria and President of pro mente Austria.

KURT SENEKOVIC

Following several psychological crises, in 2006 Kurt Senekovic founded the association Achterbahn [Roller Coaster], a platform by and for people with mental health difficulties. Since then, he has been Chairman and CEO of the association. In this capacity, he is actively involved in sociopsychiatric planning for the Austrian state of Styria. He has played a key role in the reform of the rules of guardianship and in the closure of the state's Schwanberg nursing home. He is also one of the initiators for academic peer training in Styria. He is a frequent lecturer and instructor for basic instruction in sociopsychiatry and at relevant symposiums. He also provides sensitivity training for the police security academy [SIAK] in Styria.

PETER STIPPL

Peter Stippl is President of ÖBVP (the Austrian Federal Association for Psychotherapy). He has been a psychotherapist in private practice since 1995. He is also technical director and co-founder of the Krisenintervention Burgenland, a crisis-intervention initiative. His work focuses on: the person in crisis and trauma therapy. Prior to his therapeutic work, Peter Stippl worked as a business consultant and authorised signatory for an international IT group. He serves as an instructor with the Red Cross, the fire brigade, universities of applied sciences and in PT training institutes.

JOHANNES WANCATA

John Wancata graduated from the University of Vienna with a degree in medicine. He is Head of the Clinical Division of Social Psychiatry at the Medical University of Vienna. There, he also serves as the coordinator for the doctoral programme in Mental Health & Behavioural Medicine. Since 2009, John Wancata has been in charge of the ombudsman's office of the Vienna Archdiocese for victims of sexual abuse in the Catholic Church.

Evaluation of the research areas by the jury

An additional research area was constituted on the basis of the deliberations at the jury meeting. From all of the areas hitherto existing, aspects that were seen in combination with children and adolescents were extracted, and an independent area of research, 'mental health of children and adolescents', was formed. The jury argued for this separation of aspects in light of the fact that the social relevance of this topic is extremely high. There was also agreement that there is far too little research of child and adolescent mental health.

The jury sees a considerable need for research into many of the research areas formulated in the course of the crowdsourcing process.

Two examples of this:

1. patients and the experts who care for them have a burning interest in research into the role that those concerned – family members and the patients themselves – can play in destigmatising mental illnesses. The scientific mechanisms of action are completely in the dark, however, as they have scarcely been a focus of research. This calls for cross-disciplinary, close interplay among the social sciences, neurology, psychology, communication and information sciences in order to address such novel and complex questions in ways that are scientifically meaningful. There is an enormous field of activity here, and an opportunity to develop highly new insights.
2. What steps can be taken to prevent children who live in a family with sufferers of mental illness, or who experience a trauma themselves, from becoming mentally ill later on? For many of the families affected, and for therapists and physicians, this is a question of great importance, but in science it means breaking new ground: the factors involved in early identification of children with risk potential are largely unexplored; here, too, a decidedly interdisciplinary approach is required for scientific investigation of this new question.

CONCLUSION AND OUTLOOK

Based on the findings of the analytical process, the community voting and the jury meeting, ultimately three priority fields of research were identified and presented to the public at a press conference held in December 2015:

- Mental health among children and adolescents,
- de-stigmatization of mental illness and
- achieving major advances in healthcare research.

The aim of LBG is to launch a new research programme on the basis of these findings. The objective is to enlist this research programme in order to address issues in an interdisciplinary way, and to apply the principles and methods of Open Innovation in Science (e.g. participation, Open Access publication, etc.).

In any event, the active participation and the great interest on the part of the population confirmed the relevance and urgency of the issue of mental illness. It also clearly emerged that the affected individuals, their families and the experts tasked with their care have extensive knowledge that researchers can tap in order, ideally, to reach better results, more quickly, that offer direct benefits to society.

But methods and principles of Open Innovation in Science can also be implemented throughout the entire research process. One step in this direction could be seen in the second part of the ‘Open Innovation in Science’ project. In the LOIS (Lab for Open Innovation in Science) training programme that is being carried out in 2016/17, researchers learn Open Innovation and Open Science methods and receive training in their application to everyday research.