Demystifying schizophrenia

Treating schizophrenia presents huge challenges and those involved see first-hand how this diverse medical condition causes huge suffering and requires complex and costly care, often over a lifetime. In the Netherlands, Prof. Jim van Os is heading up an exciting and ambitious international research project that brings together professionals, patients and their families who depend on each other to unlock new answers and approaches to treatment. There is so much that we don’t yet understand about it and current treatments are inadequate, so there is a real motivation to work together and solve more bits of a complicated puzzle.

Young people at risk

Schizophrenia and related psychotic disorders disproportionately affect young people and particularly those living with other risk factors, such as previous trauma. Professionals working to treat them know many of the factors that contribute to the condition. But they urgently need to understand more about the complex relationships between them to help patients better.

All this is too big to resolve within any one country, but the EU-GEI project is facing these challenges with 28 different project partners from the EU and beyond, together

THE FRIGHTENING FACTS:

- **UP TO 3% OF YOUNG PEOPLE** in Western Europe suffer with schizophrenia and related psychotic disorders.
- Sufferers are poorly understood and often stigmatised, leaving them and their families isolated.
- Many drugs have been trialled, but a cure does not exist.

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Research and Innovation
with 7,500 individual patients and their families. No other study of this magnitude and with this amount of funding has been attempted, so now there is a way to consider a complex interplay of genetic, clinical and environmental factors and involve many partners with the different scientific disciplines required.

**WHO YOU ARE + WHERE YOU ARE**

Prof. van Os and his colleagues already know that over half of the vulnerability to schizophrenia is genetic, but it is extremely difficult to pin this down to specific genes because of the interaction between genetics and environmental factors.

Where you live, how you live and whether you are part of a minority population all have a bearing on your risk of developing schizophrenia. Urban environments are now shown to be a significant factor, as is the use of drugs such as cannabis and/or previous trauma in childhood. In other words, you may be genetically susceptible but never go on to become psychotic, whereas in someone else who is genetically similar the condition might manifest itself if the person is exposed to these additional environmental risks.

**PATIENTS AS EXPERTS**

Patients are now collecting their own data using special IT equipment, ‘Psymate’, which processes their information and provides them with feedback. They can record mood changes, stress factors, the effect of medication and their own activities. Their direct involvement is vital to this new insight into the disease and it increases their motivation to make positive changes in their lives. Instead of being on the receiving end of instructions, they can contribute unique data and get results that affect them personally.

**HARNESSING THE BEST EXPERTISE AND PERSEVERING THROUGH PROBLEMS**

A big key to the success is working with the national mental health networks in all the partner countries. Most of them are clinicians; they understand how people suffer and how difficult it is to grasp the entire complex interaction of factors in order to offer better treatments.

They have faced a number of big challenges though in getting the project off the ground. For example, getting the healthy siblings of patients involved in the research across the different countries has proved to be a difficult task.

Everyone is also very aware that science moves on and new areas of knowledge need to be brought into the study as it progresses. Crucially this involves genetics and epigenetics (the epigenome instructs molecules in how to create different specific cells from the common masterplan, which is the DNA).

**EARLY ENCOURAGEMENT**

At this relatively early stage, all the clinical studies have been approved. After a year of intense preparatory work, patients are being recruited to create a unique and evolving database to show how those at risk can face triggers in their lives that push them from genetic vulnerability to the onset of psychosis.

With the database complete, researchers aim to move on to building new genotype, environmental and mental state data that could ultimately enable reliable diagnosis and better monitoring of individual cases.