*Psychiatria Danubina, 2016; Vol. 28, No. 2, pp 104-110* *Original paper*


# SCHIZOPHRENIA CAUSES SIGNIFICANT BURDEN TO PATIENTS' AND CAREGIVERS' LIVES

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received: 17.8.2015; revised: 2.2.2016; accepted: 1.3.2016

## *SUMMARY*

***Background:*** *Schizophrenia is a serious public health problem and is ranked among the most disabling diseases in the world. The sub-study presented here was part of a larger project to characterize the burden of schizophrenia on healthcare systems and on individuals living with the disease in Central and Eastern Europe (CEE).*

***Aims:*** *This sub-study aimed to assess and analyze the impact of schizophrenia on many aspects of the lives of patients and caregivers.*

***Methods:*** *Psychiatrists from selected centers in seven Central and Eastern European countries were asked to complete a questionnaire in order to collect information about the disease history, characteristics, treatment protocols and resources used for each randomly selected patient. All data were statistically analyzed and compared between countries.*

***Results:*** *Data from 961 patients with schizophrenia (mean age 40.7 years, 45.1% female) were included in the analysis. The mean number of days spent in hospital per patient per year across all seven countries was 25.3 days. Hospitalization occurred on average once per year, with psychiatrist visits 9.4 times per year. Of the patients in the study, 61% were single, 12% divorced and 22% married or cohabiting. Almost 84% were living with relatives or a partner; only 17% lived alone and, on average, 25% of patients received support from social workers. Relatives provided care for approximately 60% of patients and 4% of them had to stop working in order to do so. Twenty-nine percent of the patients were unemployed, and 56% received a disability pension or were retired, with only 19% in full-time employment or education.*

***Conclusion:*** *Schizophrenia has a significant effect on the lives of patients and caregivers and impacts their social integration.*

***Key words:*** *schizophrenia - burden of disease - retrospective data collection – patients - caregivers*

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## INTRODUCTION

The burden of schizophrenia affects many areas, including cost and health aspects. Burden of costs consists of costs of patients' treatment and care as well as loss of productivity caused by impairments, disability, caregivers' help or patients violent behavior. Health burden is associated with incidence, prevalence or mortality of schizophrenia. In addition to the direct burden, the affected persons must face prejudice and discrimination. The stigma related to schizophrenia leads to social isolation, unemployment, drug abuse, criminalization which further reduces the chances for recovery and reintegration into normal life (Rössler 2005).

This study is part of a larger project to characterize the burden of schizophrenia in Central and Eastern Europe (Szkultecka-Dębek et al. 2013). The project consisted of two parts: systematic review and a retrospective data collection based on patients medical records and independent opinion of medical experts. The aim of this sub-study is to assess the impact of the disease on the lives of patients and caregivers. A literature review carried out prior to the beginning of the study showed that the lives of both patients with schizophrenia and their caregivers are affected by this chronic disease (Walczak et al. 2013), e.g. by significant reduction of their quality of life (Szkultecka-Dębek et al. 2015). This sub-study aimed to explore the potentially considerable impact of

schizophrenia on an individual's social functioning. Accordingly, data relating to the impact of schizophrenia on the marital, employment and residential status of individuals were collected.

## METHODS

Seven Central and Eastern European countries (CEE) were included in the study: Croatia, Estonia, Hungary, Poland, Slovakia, Serbia and Slovenia (Figure 1) (Szkultecka–Dębek et al. 2013). These countries from the same geographic region exhibit some similarities in terms of health care systems and have similar levels of economic growth. In five of the countries, the gross domestic product (GDP) per capita ranged between 8,500 and 9,500 EUR. In Serbia, the GDP is lower at 3,100 EUR per capita while Slovenia has the highest GDP among the analyzed countries at 15,000 EUR (GDP per capita from 2012) (European Commission 2012).

Multiple centers were selected from different regions within each country in order to obtain a representative sample of patients with schizophrenia. The study involved in total 29 (from three to six per country) medical centers of different types: university hospital, psychiatric hospital, psychiatric ward of a general hospital or outpatient clinic. Patients who were treated within the last five years, inpatients and outpatients were selected randomly. Newly diagnosed patients comprised less than 20% of the sample. Psychiatrists working in each center were asked to complete a pre-defined questionnaire to collect information about the disease history and characteristics of each patient with data on social status (e.g. marital status, employment), along with treatment protocols (such as first-, second-line treatment, medications prescribed for refractory patients) and resources utilized (e.g. number of treatment courses, additional non-antipsychotic prescriptions for co-administration and switching patterns with antipsychotic treatments). Information requested included also the number of days spent in hospital and the total number of hospitalizations, the number of outpatient visits to psychiatrists during the year. Local expert psychiatrists provided data from patient medical records. The retrospective data collected via questionnaire covered the whole course of the disease from the diagnosis, and in cases when this information was not available – data from the last five years were collected. A second specially-designed questionnaire (with some duplicated questions for validation purposes), was utilized to obtain additional data not recorded in the medical history, but within the scope of the experience of the treating psychiatrist.

Results presented are expressed as percentages calculated both from the total sample and country-specific samples. Where data represent sample characteristics, the main statistics are presented as the arithmetic mean and median and dispersion is assessed using minimum and maximum values. Number of hospitalizations/ outpatient visits and frequency of hospitalization gathered from the whole course of disease or for last five years had been converted to annual data.

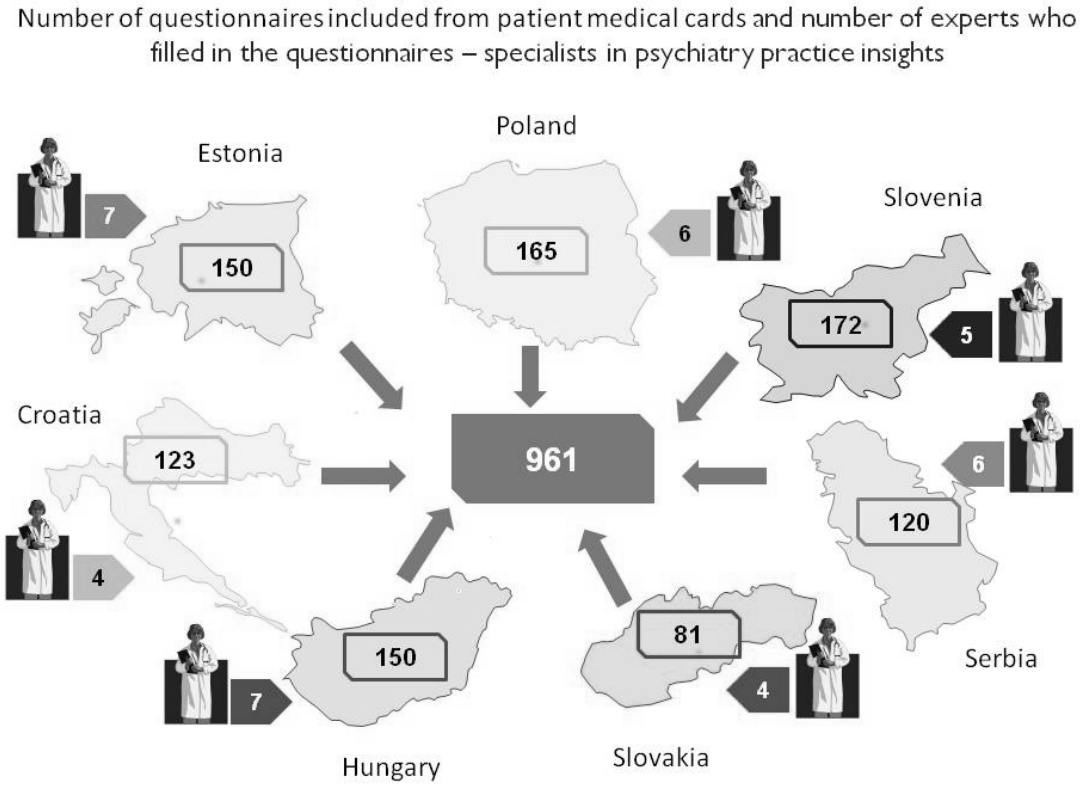


**Figure 1.** Study details (number of expert psychiatrists and questionnaires)

## RESULTS

Retrospective data were collected from 961 patients with schizophrenia acrosss even CEE countries. The mean age of the patient sample was 40.7 years, and 45.1% of patients were females. Little variation in mean patient age was seen between countries, with the youngest, 39.2 years (Croatia) and oldest, 42.1 years (Poland). The highest percentage of females with schizophrenia was observed in Estonia (54%) and the lowest in Slovenia (32.6%). Average body mass index (BMI) was 26.2 (the highest was 27.2 in Hungary and the lowest 25.2 in Poland and Slovenia). Patient characteristics by country are presented in Table 1.

The mean number of days spent in hospital per patient per year across all seven countries was 25.3 days, with a median of 15.3 days. There were differences in length of hospitalization between countries. The longest hospitalization observed was in Serbia (mean 33.9; median 24 days) and the shortest in Hungary (mean 15.5; median 9.2 days) (Table 2).

On average a patient with schizophrenia was hospitalized once per year, and visited a psychiatrist 9.4 times per year (Table 2). In Croatia, more frequent hospitalization was observed (mean 1.6/year, median 1/year) compared with the other countries which varied between a mean of 0.7 to 1.2, and the median for the total sample was 0.5 hospitalizations/year (i.e. one hospitalization every two years). Visits to specialists in psychiatric disease in an ambulatory setting were most frequent in Slovakia, Hungary, Serbia and Estonia (mean for those countries ranged between 10.7 and 11.6 visits/patient/year; median 8.3 to 12.0 visits/patient/ year). The lowest number of visits was reported in Poland (mean 6.2, median 6.0).

**Table 1.** Patient characteristics by country and total sample

| Parameter | Total sample (N=961) | CRO | EST | HUN | PL | SK | SLO | SRB |
|---|---|---|---|---|---|---|---|---|
| Age, mean (years; SD) | 40.7 (11.7) | 39.2 (10.9) | 41.9 (11.9) | 41.3 (10.8) | 42.1 (13.0) | 39.7 (11.7) | 40.1 (11.7) | 39.3 (11.2) |
| Sex – females | 45.1% | 40.7% | 54.0% | 52.7% | 44.5% | 51.9% | 32.6% | 43.2% |
| BMI, mean (SD) | 26.2 (4.8) | 26.3 (5.0) | 26.3 (5.6) | 27.2 (4.6) | 25.2 (4.3) | 25.8 (4.5) | 25.2 (4.2) | 27.5 (4.8) |

CRO = Croatia; EST = Estonia; HUN = Hungary; PL = Poland; SK = Slovakia; SLO = Slovenia; SRB = Serbia
SD = Standard deviation

**Table 2.** Length of hospitalization, hospitalization frequency and number of outpatient visits to a psychiatrist due to schizophrenia

| Parameter | Total sample (N=961) | CRO | EST | HUN | PL | SK | SLO | SRB |
|---|---|---|---|---|---|---|---|---|
| Length of hospitalization (days/patient/year) | | | | | | | | |
| Mean | 25.3 | 29.4 | 17.2 | 15.5 | 28.3 | 19.6 | 31.7 | 33.9 |
| Median | 15.8 | 20.0 | 11.3 | 9.2 | 21.0 | 10.0 | 21.6 | 24.0 |
| Hospitalization frequency (number/patient/year) | | | | | | | | |
| Mean | 1.0 | 1.6 | 0.7 | 0.8 | 1.2 | 0.7 | 0.7 | 1.0 |
| Median | 0.5 | 1.0 | 0.4 | 0.4 | 0.4 | 0.5 | 0.5 | 0.6 |
| Number of psychiatrist visit (per patient per year) | | | | | | | | |
| Mean | 9.4 | 7.4 | 11.0 | 11.5 | 6.2 | 11.6 | 8.0 | 10.7 |
| Median | 8.0 | 6.0 | 8.3 | 12.0 | 6.0 | 12.0 | 7.0 | 10.0 |

CRO = Croatia; EST = Estonia; HUN = Hungary; PL = Poland; SK = Slovakia; SLO = Slovenia; SRB = Serbia

**Table 3.** Marital and employment status of patients with schizophrenia

| Parameter | Total sample (N=961) | CRO | EST | HUN | PL | SK | SLO | SRB |
|---|---|---|---|---|---|---|---|---|
| Marital status | | | | | | | | |
| Single | | 70% | 58% | 62% | 60% | 56% | 70% | 72% |
| Married or cohabiting | | 18% | 20% | 26% | 25% | 23% | 19% | 23% |
| Divorced | | 12% | 20% | 10% | 7% | 21% | 9% | 8% |
| Employment status | | | | | | | | |
| Unemployed | | 53% | 14% | 16% | 18% | 14% | 37% | 58% |
| Employed or student | | 14% | 21% | 17% | 17% | 28% | 25% | 15% |
| Disability pension or retirement or employed on sick leave | | 36% | 82% | 69% | 70% | 63% | 38% | 28% |

CRO = Croatia; EST = Estonia; HUN = Hungary; PL = Poland; SK = Slovakia; SLO = Slovenia; SRB = Serbia

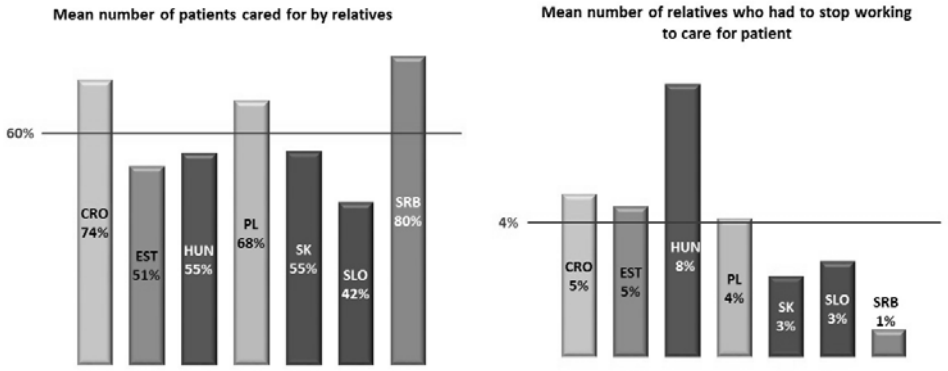


**Figure 2.** Disease impact on caregivers (shown as mean percentage for each country)

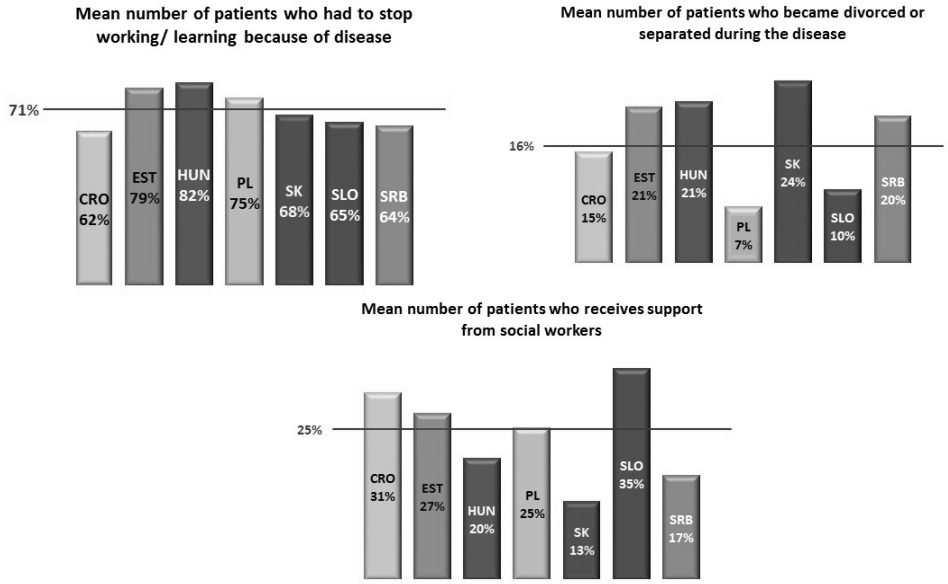


**Figure 3.** Social impact of schizophrenia on patients (shown as mean percentage for each country)

Analyses of social data included marital status, unemployment and education level. Marital status analyses showed that 61% of the patients in this sample were single, 12% divorced and 22% married or cohabiting (Table 3). This contrasts with the general population of these countries: percentage of single people is 39-48% and of married people 38-40% (Estonian Statistics 2012; European Commission 2012).

Almost 84% of patients with schizophrenia were reported to be living with relatives or a partner; with only 17% living alone. On average 25% of patients were receiving social work support. The highest number of patients living alone was in Slovenia (20%), Estonia (21%) and Hungary (25%). Conversely, in Croatia and Serbia, more than 90% of patients (95% and 92%, respectively) live with relatives, a partner or others.

In the study sample, 29% of patients with schizophrenia were unemployed, 56% were receiving disability pension or were retired and only 19% were in full-time employment or education (Table 3). The disability rate and unemployment distribution across countries is different, probably due to different social security structures, but the employment rate was found to be similar across all the countries in our sample and much lower than in the general population. In 2012, the employment rate in the general population ranged from 35 to 38% in Croatia and Hungary and 43 to 46% in Slovakia, Estonia and Slovenia (data for Serbia not available) (European Commission 2014). In the study sample, the employment rate among individuals with schizophrenia ranged from 8 to 13% in Croatia and Poland and from 20 to 27% in Estonia and Slovakia.

Approximately 60% of patients with schizophrenia were cared for by relatives and 4% of relatives had to stop work in order to provide care for their family member with schizophrenia (Figure 2).

Approximately 71% of patients in this study had to stop work or leave education due to schizophrenia and this rate was very similar across all seven countries. It was also found that 16% of patients divorced during the disease period, with the highest divorce rates being in Slovakia (24%) and Estonia and Hungary (both 21%), and the lowest in Poland (7%). Study data also showed that on average, 25% of patients required the support of a social worker. Figure 3 presents details of these findings by country.

## DISCUSSION

This project is the first of its kind to provide real-world data, allowing us to better characterize the impact and burden of schizophrenia on patients and caregivers in CEE countries. An analysis in Western Europe has been described in several previous studies, including the European Schizophrenia Cohort (EuroSC) study, with data from France, Germany and the UK (N=1208 patients) (Bebbington et al. 2005, Roicket al. 2007) and the European multinational EPSILON study which was conducted in The Netherlands, Denmark, the UK, Spain and Italy (N=404 patients) (Meijer et al. 2004, Thornicroft et al. 2004).

In this sub-study, data from patients with schizophrenia were compared with data from the general population in the seven countries identified. This was achieved using data gathered by the European statistical office (Eurostat), with additional data from Estonia, where Eurostat information was incomplete. The most recent Eurostat data on marital or employment status were from 2012 and, unfortunately, are not available for all seven countries in this study: the employment rate was missing for Serbia, while marital status data were available for only three countries: Estonia, Hungary and Slovenia.

Based on the Eurostat data from 2012 (European Commission 2012), the employment rate in the general population is much higher than in the population with schizophrenia: 35–46% of patients across six countries were employed (Serbia data not available). In our sample, only 8–27% of patients with schizophrenia were employed (see Figure 3). Lack of employment is linked to lack of social inclusion. Employment enables individuals to actively participate in society. The barriers to employment for people with mental illness are linked to stigma, prejudice and discrimination (Boardman et al. 2003). Furthermore, lack of employment equates to lack of earnings potential for an individual and has an impact on society in terms of productivity and on the national income in terms of tax.

Similarly, it was found that the majority of our sample were single (61%) in contrast to the percentage for the general population in the same geographical area, which is 39–48% (Estonian Statistics 2012; European Commission 2012). Also, in the study sample, 12% of schizophrenia patients were divorced and only 22% were married or cohabiting, compared with 38–40% who were married in the general population (Estonian Statistics 2012, European Commission 2012). A high percentage of unmarried individuals was also observed in a study of people in Western European countries by Kovess-Masféty et al. (2006). This study highlighted how central marriage is to quality of life for patients with schizophrenia.

The broad impact of schizophrenia on the patient is evident from the guidelines for the management of the condition. These recommendations emphasize the need for pharmacotherapy to be accompanied by psychosocial interventions, such as psychoeducation and cognitive behavioral therapy to help reduce the severity of both positive and negative symptoms and risk of relapse (Barnes 2011, Lehman et al. 2004). Similarly the benefits of support and involvement of the family is also highlighted (Barnes 2011, Lehman et al. 2004). Cooperation between the patient and psychiatrist is recommended to identify the best therapy or therapy combination for the patient, and the engagement of family members and other caregivers in this process is key (Lehman et al. 2004). Lehman et al. (2004) drew particular attention to the role of family and engagement of other significant support persons. This study did not look at adherence to guidelines, but we did highlight how 42–80% of patients were able to rely on care from relatives.

The families of patients with schizophrenia have previously been reported to provide disproportionately large amounts of help to their relative in comparison to the amount of support provided by health care and social institutions (Kogovšek & Dolničar 2009). It is the relatives of patients with schizophrenia who have to manage the disturbances to family life and the repetitive crises associated with periods of deterioration in schizophrenia, which may persist for long periods of time (Kogovšek & Dolničar 2009). Burden of care for caregivers is defined broadly and covers emotional, psychological, physical and economic impact, including feelings of shame, embarrassment, guilt and self-blame (Awad & Voruganti 2008). The economic impact on family caregivers was highlighted in this study, with up to 8% (Hungary) of patients having a relative give up work to care for the patient.

The caregiver burden is greater in families who have close relationships with one another: the more time the caregivers devotes to their family member and the more the caregivers accept the family member's mental illness, the higher the subjective burden (Hadryś at al. 2011). The level of parental burden and patient stigma in schizophrenia has been noted to be similar to that in other mental illnesses, such as personality disorders or depression (Chrzastowski 2005, Świtaj et al. 2011).

This perceived level of burden differs between families of inpatients and families of patients treated in day-care units or community care groups. In the first group impaired family relationships, an atmosphere of tension and feelings of shame are among the most frequent problems, while in the second group low levels of participation in housework, inactivity and lack of self-care on the part of the patient with schizophrenia are among the factors which disrupt family life most (Konieczynska et al. 1996, Konieczynska et al. 1997). In this study, we did not investigate how the setting of care impairs family relationships; however, a comparison with previous studies of schizophrenia patients in different populations highlights differences in social culture.

The comparison between this study of CEE countries and the EuroSC and EPSILON studies from Western Europe regarding the impact of schizophrenia on patients' lives is of interest. There are differences between the studies in terms of living situation: in Epsilon and EuroSC 30–34.5% patients were found to live alone compared with only 17% of patients in this study. Conversely, in Western European countries, fewer patients were found to be living with their relatives – 39% in EPSILON and only 24.4% in EuroSC, while in CEE these patients represented the majority at 65% in this study, possibly reflecting a different social culture.

However, there are many similarities between the populations of patients analyzed in all three studies. The mean age of the study populations was approximately 41 years (40.7 in this study, 40.8 in EuroSC and 41.8 in Epsilon) and fewer females than males were included (ranging from 38.5% in EuroSC to 45.1% in this study). Furthermore, in all three studies the majority of patients were single (from 61–65%, in our study and EPSILON respectively), with only 17% married or cohabiting in EPSILON and 21–22% in other two studies. The employment rate (including student and/or supported employment) is also very similar: from 19% in this study to 21.4% in EuroSC. These figures may be indicative of the significant impact that schizophrenia has on the social functioning of the individual.

## CONCLUSION

Considering the significant impact on social functioning of patients with schizophrenia and the associated burden for their caregivers, this study provides real-world data on schizophrenia patients living in some Central and Eastern European (CEE) countries. Although similarities were observed with studies of patients from Western European countries, such as a mean age of ~40 years, a gender bias towards males and a high unemployment rate, some important differences have been found. In the present study, 61% of schizophrenia patients were unmarried but only 17% lived alone. The majority of patients reported living with their relatives, a significant departure from Western populations where as few as 24% of patients with schizophrenia live with family members. Among patients studied only 19% were employed whereas merely one forth of them received support from social workers. This indicates socio-economical and cultural differences in the support systems of CEE countries, which may influence the overall burden of disease for both patients with schizophrenia and their caregivers.

## *Funding acknowledgement:*

The authors received editorial support from inVentiv Medical Communications, which was funded by F. Hoffmann-La Roche, Ltd.

## *Acknowledgements:*

This research project would not have been possible without the support of many people. We would like to acknowledge everyone involved in the Retrospective Data Collection:

**Croatia**
University Psychiatry Hospital "Vrapce" in Zagreb: V. Jukić, V. Barić, M. Sisek Šprem
Clinical Hospital Center Zagreb: M. Jakovljević, I. Filipcic, M. Rojnic-Kuzman
Clinical Hospital Center Rijeka: T. Frančišković
Clinical Hospital Center Split: G. Dodig
Clinical Hospital Center Osijek: O. Koic
Roche Ltd, Zagreb, Croatia: D. Maric, I. Hanzl Dujmović, S. Antolić

**Estonia**
North Estonian Medical Centre: K. Aadamsoo, E. Saluveer, E. Eding, K. Eino, A. Parksepp
Tartu University Hospital: S. Janno, D. Madissoon
Pärnu Hospital: A. Puusild, R. Pilli
Roche Eesti OÜ, Tallinn: A. Indrikson

**Hungary**
Semmelweis University in Budapest: J. Tolna, I. Bitter
Petz Aladár Regional Teaching Hospital in Győr (Outpatient Clinic): Z. Tislerics, R. Németh, G. Feller
Dr. Kenessey Albert Kórház and Outpatinet Clinic in Balassagyarmat: K. Karácsonyi
Psychiatry and Addictology Outpatient Clinic in Vác: M. Varga, Z. Tótváradi
Roche (Magyarország) Kft: M. Varga, K. Gyulay

**Poland**
Prof. Kaczynski Neuropsychiatric Hospital in Lublin: M. Domański
Medical University of Bialystok: B. Galińska-Skok
J. Babiński Specialist Hospital in Cracow: A. Markiewicz
Institute of Psychiatry and Neurology in Warsaw: M. Jarema, R. Reszczyński
L. Rydygier Specialist Hospital in Cracow: W. Wąsik
Regional Psychiatric Hospital in Gdansk: T. Wróblewski, J. Żebrowski
Roche Polska Sp. z o.o.: S. Małysiak , G. Dębowska

**Serbia**
Military Medical Academy (Clinic for psychiatry): R. Samardzic, G. Dedic
Clinical Center of Serbia (Clinic for psychiatry): S. Milovanovic, N. Maric, D. Duisin, Z. Pavlovic
Clinical Center of Nis (Clinic for psychiatry, Clinic for Mental Health): D. Lazarevic, J. Nikolic, S. Manojlovic, V. Tamburic, L. Mitic-Randjelovic, G. Grbesa, M. Simonovic
Clinical Center of Vojvodina (Clinic for psychiatry): S. Drezgic, G. Knezevic
Roche d.o.o., Beograd: M.Tadic Milosevic

**Slovakia**
University Hospital in Bratislava: J. Pecenak
Private Psychiatry office (Zaporozska Bratislava): L. Vavrusova
Private Psychiatry office (Mytna, Bratislava): E. Janiková
Faculty Hospital Trnava: D. Sedivá, B. Lopasovska
Roche Slovensko, s.r.o., Bratislava: I. Šulková

**Slovenia**
Psychiatric Hospital Begunje: M. Logar, P. Lapajne, J. Knific, A. Žmitek
Psychiatric Clinic Ljubljana: B. Kores Plesničar, V. Novak Grubič, D. Terzič, M. Derganc, A. Turčin, R. Tavčar, M. Zvezdana Dernovšek
University Medical Centre Maribor: J. Koprivnik, P. Koprivšek, A. Čelofiga, L. Lunder
Roche farmacevtska družba d.o.o., Ljubljana: P. Veržun

## *Conflict of interest:*

No authors had any direct conflicts of interest to declare. However, authors who are also employees of Roche could potentially have a conflict of interest in case Roche develops a product in the schizophrenia area in the future.

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