

# The availability and quality across Europe of outpatient care for difficult-to-engage patients with severe mental illness: A survey among experts

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## Abstract

**Background:** As many patients with severe mental illness (SMI) who have complex needs are difficult to engage, outreach mental health services are needed to engage them into treatment. The extent to which these services exist in large European cities is unknown.

**Methods:** Experts in 29 European countries were sent a structured questionnaire containing two case vignettes of difficult-to-engage patients (a first-episode psychosis patient and a homeless chronic schizophrenia patient). The type and quality of outpatient care was assessed and related to several national indices.

**Results:** The questionnaire was returned by experts from 22 countries (76%) representing 92% of the EU population. Six countries (21%) had a systematic method for detecting difficult-to-engage patients. The most important route whereby such patients entered the mental health system was through informal care; the most important reasons for entering it were the level of psychiatric symptoms, nuisance and violence. Assertive outreach was available in nine countries (41%), with coverage ranging from a few teams (sometimes for a specific target group) to most of the country. The case vignettes showed that outpatient care for these difficult-to-engage patients varied widely. In seven (30%) of the 22 countries, a hospital would take no action if such patients who had been admitted voluntarily discharged themselves prematurely. On a scale of 0–10, the experts' mean scores regarding the quality of outpatient care for patients with SMI in general were 5.2 (SD = 1.9) and 3.2 (SD = 2.2) in difficult-to-engage ones. Explorative analyses showed that the quality of outpatient care for difficult-to-engage patients was associated with gross national income and the number of psychiatrists per capita.

**Conclusions:** Outpatient mental health services for difficult-to-engage SMI patients varied widely among European countries; experts judged their overall quality to be poor. It is now important to achieve consensus on a minimum European standard for the quality of care for such patients.

## Keywords

Outpatient care, difficult-to-engage patients, Europe

## Introduction

Patients with severe mental illness (SMI) have complex needs, and many do not use mental health care services (Torrey & Zdanowicz, 2001). As a group, patients with SMI have severe mental disorders (with or without comorbid addiction), have complex social needs in addition to their psychiatric problems, have problems in daily functioning, and need long-term mental health services (more than two years; (Parabiaghi, Bonetto, Ruggeri, Lasalvia & Leese, 2006; Ruggeri, Leese, Thornicroft, Bisoffi & Tansella, 2000). Overall, mental health services for SMI patients are organized either as office-based care provided by a psychiatric hospital, general hospital or private practice; or as community-based care provided by community mental health teams, early psychosis teams, assertive

outreach teams and/or crisis resolution home treatment teams (Becker & Kilian, 2006; Ruggeri et al., 2006). It is unknown how and to what degree SMI patients in Europe,

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including those who are difficult to engage, receive home-based care, including assertive outreach.

**Difficult-to-engage SMI patients.** Many SMI patients (20–40%) do not seek mental health care (Torrey & Zdanowicz, 2001) or they actively avoid care (Schout, de Jong & Zeelen, 2011). There are various reasons why they may be difficult to engage: patient-related factors such as lack of illness insight, motivational deficits or services-related reasons; service related factors include problems with continuity of care and lack of outreach services; or negative experiences with treatment (voluntary or involuntary), or with stigma (Schout et al., 2011) (Brunette & Mueser, 2006). The pathways to care of these patients may involve families, the police, general practitioners and emergency services. Clinicians who wish to establish contact need to use assertive outreach, motivational interviewing techniques and personal qualities (Schout, de Jong & Zeelen, 2010).

**Assertive outreach.** Assertive outreach (AO) is one model for engaging patients with mental health care (Priebe, Watts, Chase & Matanov, 2005). For the present study, AO was defined as care that involves caseloads of less than 15 service users per staff member, with contact usually taking place at service users' homes or in community settings, and with a frequency of contact that is substantially greater than in usual local care (adapted from the European Service Mapping Schedule 2; Johnson & Kuhlmann, 2000). Studies using AO have shown that engagement was better than in control conditions that did not provide AO than in those that did (Killaspy et al., 2009; Sytema, Wunderink, Bloemers, Roorda & Wiersma, 2007). It is unknown which European countries provide AO or which other interventions are used to detect and engage patients.

**Aims of the study.** To assess the availability of AO, and to assess the quality of outpatient care, we collected information on outpatient mental health services for SMI patients (difficult-to-engage and otherwise) in large cities in European countries. We also explored associations between the experts' scores on the quality of outpatient care for SMI patients – including those who were difficult to engage – and national indices, such as gross national income, and the number of psychiatric beds and psychiatrists per capita.

## Methods

In the period from September 2010 to June 2011, a questionnaire was sent by email to national experts in 29 European countries. These experts had been selected on the basis of their familiarity with the actual care for difficult-to-engage SMI patients, and of their being nationally acknowledged experts in the field of mental health care for patients with SMI in their country (e.g. through their publications).

The 29 European countries were the 27 EU member states (Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden and the UK), plus Norway and Switzerland.

### Structured questionnaire

The questionnaire contained structured questions on outpatient care for SMI patients, with a focus on difficult-to-engage patients in large cities; it had been developed by all co-authors, piloted in their countries, and amended. Due to the possibility of variations in the type of outpatient care within a country – between rural and urban areas, for example – and because most difficult-to-engage SMI patients live in large cities and not in rural areas, we focused on outpatient care in large cities (Ruggeri et al., 2006).

Questions on some general aspects of outpatient services for SMI patients were followed by questions on specific outpatient care for difficult-to-engage SMI patients and the degree to which AO was implemented in large cities in each country. We then used two case vignettes to assess patterns of care.

*Case vignette 1:* Peter was a young man aged 23 who lived with his parents and studied at a university in a large city in the Netherlands. He had stopped attending classes one year earlier. His friends noticed strange behaviour, but since he was not aggressive and did not bother anyone, they let it be. He stayed in his room and told his parents that he wanted to be independent. His room became a mess; he gave strange answers; and he talked to himself. He was not aware of his strange behaviour and did not want any help. He did not take drugs.

*Case vignette 2:* George was a homeless man of 45 who had been living on the streets in a large city in [insert a country] for many years. He actively heard voices and had paranoid delusions, and slept under bridges and in parks. He ate leftovers from restaurants. Somatically, he was apparently well. He was not dangerous towards others and not suicidal. He wore dirty clothes, smelled bad, and had long hair and a beard. He had no regular income, and it is not known whether he had any form of health insurance. He did not want any help. People living nearby thought he was psychiatrically ill and needed help. Drug use was likely but unknown.

Specifically, we asked the experts in each country whether the vignettes represented typical case histories in their country, and what would happen if the parents (in vignette 1), neighbours (in vignette 2) or general practitioner (GP) tried to get these patients into care. Finally, we asked what a psychiatric hospital would do if Peter or George discharged themselves from the psychiatric hospital prematurely, and whether this depended on the judicial status (involuntary or voluntary admission).

### Quality of outpatient care

The quality of outpatient care was assessed by asking the experts the following two questions: (1) On a scale of 0–10, how satisfied are you with the quality of outpatient care in large cities in your country for SMI patients overall? (2) On a scale of 0–10, how satisfied are you in general with the quality of outpatient care in large cities in your country for *difficult-to-engage* SMI patients who do not themselves seek treatment?

### Quantitative indices

Associations were assessed between the experts' score on the quality of outpatient care for patients (including those who are difficult to engage) and the gross national income per capita; the number of psychiatric beds per 100,000 citizens; and the number of psychiatrists per 100,000 citizens (Eurostat, 2010).

### Ethics approval

As no patient data were collected, ethics approval was not required for the study.

### Data analysis

Descriptive statistics and non-parametric correlations were used.

## Results

The questionnaire was returned by 22 experts (16 psychiatrists/researchers, five psychiatrists and one senior public servant from the Department of Health of Luxembourg) in 22 countries (76%), representing 92% of the EU population. No information could be obtained from Cyprus, Estonia, Hungary, Ireland, Malta, Romania and Slovenia.

### Outpatient care for SMI patients

In 10 countries (45% of 22 countries), most outpatient care for SMI patients in large cities was provided by outpatient units in a psychiatric hospital. In one country (5%), it was provided by a general hospital; in nine (40%), it was provided by community mental health teams and/or AO teams. In two countries (10%) outpatient care was provided by outpatient units in a psychiatric hospital as well as by community mental health teams.

### Systematic detection of difficult-to-engage patients

Six countries (28%) had a systematic way of detecting difficult-to-engage patients in large cities. For example, if

primary-care physicians in Finland were informed about a potential patient in need of care, they were obliged to arrange a meeting. Large cities in the Netherlands had local care networks in which the police, housing associations and mental health care workers collaborated and exchanged information on difficult-to-engage patients. A housing association might thus alert the network to a patient on the basis of his or her behaviour.

### Entrance into the mental health system

Difficult-to-engage SMI patients in large cities entered the mental health system through informal care (family, neighbours) in 11 countries (50%), through the police in three (14%), through crisis services in two (9%), and through various other pathways – such as the GP or municipal health services – in the remaining countries (27%).

The reasons that difficult-to-engage SMI patients entered the mental health system varied between countries, including the level of psychiatric symptoms in nine (31%) countries, nuisance in five (17%), and violence in three (10%). For example, if a difficult-to-engage SMI patient caused a nuisance, he or she was brought to the attention of the police, who would then call the crisis services.

### Availability of assertive outreach

Under the definition specified above, AO was available in large cities in nine (41%) countries. Its level of provision varied, underlain in some cases by a few teams (sometimes for a specific target group), and in other cases by many teams covering most of the country. In two other countries, plans were being made to implement AO in the near future.

### Case vignettes

**Typical case.** All experts considered Peter (vignette 1, the first-episode psychosis patient) to be a 'typical' patient. George (vignette 2, the homeless chronic schizophrenia patient) was considered to be a 'typical' case in 16 (73%) of the countries.

**Entrance into the mental health system.** The ways in which Peter and George would enter the mental health system (Table 1) varied between countries. In most countries, Peter would be taken to the GP by his parents, who would refer him to an outpatient psychiatric clinic. In only a few countries would the GP ask a community mental health team (18%), first-episode team (18%) or AO team (0%) to visit him at home. Overall, assuming that home visits were made only by community mental health teams, first-episode teams or AO teams, Peter would have been paid a home visit in only seven countries (32%). George would have been visited on the streets by a clinician from either a community mental health team or an AO team in only five

**Table 1.** Patterns of outpatient care in large cities in European countries based on two case vignettes of difficult-to-engage patients: (1) young man with early psychosis; (2) homeless man with chronic schizophrenia.

	Percentage of countries in which the actions in question would be likely*							
	Parents (vignette 1) or citizens (vignette 2) who tried to get the patient into care would take him to:		What would a GP do with this patient? Treat the patient himself (= GP) or refer him to:		Imagine that the patient is admitted <i>voluntarily</i> , but discharges himself prematurely. The hospital would call:		Imagine that the patient is admitted <i>involuntarily</i> , but escapes from the hospital. The hospital would call:	
	Vignette 1	Vignette 2	Vignette 1	Vignette 2	Vignette 1	Vignette 2	Vignette 1	Vignette 2
Nobody	N/A	N/A	N/A	5%	32%	46%	14%	9%
GP	59%	10%	0%	5%	23%	5%	9%	0%
General hospital	9%	10%	18%	24%	N/A	N/A	N/A	N/A
Psychiatric Hosp.	23%	24%	50%	62%	N/A	N/A	N/A	N/A
Outpatient PC	41%	14%	55%	38%	46%	23%	9%	5%
CMHT	9%	14%	18%	19%	23%	23%	14%	9%
FEP	18%	N/A	18%	N/A	23%	N/A	0%	N/A
AO	0%	5%	0%	14%	5%	14%	5%	9%
Police	0%	71%	0%	0%	0%	9%	77%	77%
Other	27%	19%	9%	10%	27%	23%	14%	14%

Note: See Methods section for case vignettes.

\*Since experts could indicate one to three possible answers, the total percentage is > 100%.

N/A = not assessed; GP = general practitioner; Outpatient PC = outpatient psychiatric clinic; CMHT = community mental health team; FEP = first-episode psychosis team; AO = assertive outreach team.

(23%) countries. While, in most countries, citizens would call the police (71%) if they saw George, it is not known whether the police would present him to the mental health system.

**Care after leaving the psychiatric hospital prematurely.** In 32% of the countries (vignette 1) and 46% of the countries (vignette 2), the hospital would take no action after Peter or George had discharged himself from the hospital prematurely during a voluntary stay (Table 1). If either of them escaped from a psychiatric hospital during an involuntary stay, the hospital in 77% of the countries would call the police and ask them to return him.

### Overall quality of outpatient care

The mean score of the *general* quality of outpatient mental health care for SMI patients was 5.2 (SD = 1.9); for difficult-to-engage patients with SMI it was 3.2 (SD = 2.2) (paired sample *t*-test;  $t = 5.6$ ,  $df = 21$ ,  $p < .001$ ). The specific scores per country can be obtained from the authors.

### Associations with national indices

**Associations with availability of assertive outreach.** Exploratory analyses did not show the availability of AO in a country to be associated with national income (Spearman

correlation coefficient  $r = 0.28$ ,  $p < .20$ ); number of beds ( $r = -0.33$ ,  $p < .14$ ) or number of psychiatrists per capita ( $r = 0.06$ ,  $p < .8$ ).

**Associations with quality of care.** There were no associations between the experts' scores regarding the *general* quality of outpatient mental health care for SMI patients and gross national income ( $r = 0.30$ ,  $p < .18$ ) or number of beds per capita ( $r = -0.04$ ,  $p < .86$ ); neither was there an association between the quality of outpatient mental health care for *difficult-to-engage* SMI patients and number of beds per country ( $r = -0.09$ ,  $p < .69$ ).

However, there were significant associations between the number of psychiatrists per country and quality of outpatient care for SMI patients in general ( $r = 0.44$ ,  $p < .05$ ) and for difficult-to-engage patients ( $r = 0.48$ ,  $p < .05$ ). Finally, there was also a significant association between gross national income per capita and the quality of outpatient care for difficult-to-engage patients ( $r = 0.53$ ,  $p < .05$ ).

## Discussion

Experts from 22 EU countries showed that there were considerable variations in outpatient care for SMI and difficult-to-engage SMI patients in large cities. Outpatient care was provided on a hospital basis in 50% of the countries; in the remaining countries, it was provided by community mental

health teams and/or AO teams. In only six countries was there a systematic method for detecting difficult-to-engage SMI patients.

The most important route for difficult-to-engage SMI patients to enter the mental health system in large cities was through informal care. AO was available in nine countries, and active attempts to enter difficult-to-engage first-episode psychosis patients or homeless schizophrenia patients into mental health care were made in only five (23%) countries.

The experts judged the quality of outpatient mental health care for difficult-to-engage SMI patients to be very poor. Explorative analyses showed that the experts' scores for quality of outpatient care for difficult-to-engage patients were associated with gross national income and the number of psychiatrists per capita, but not with the number of psychiatric beds.

### *Lack of outreach services*

These results indicate that outreach services are lacking in many European cities and that their quality may be poor. Due to a common trend towards de-institutionalization and less inpatient treatment, the problem may be increasing (Becker & Kilian, 2006). If more patients need to be treated in the community, strategies for successful engagement and intensive outpatient treatment need to be implemented. These strategies can be used not only by clinicians working in an AO team, but also by those in other teams that provide outreach services, such as community mental health teams or crisis teams. However, due to their larger and varied caseloads, these teams may be less capable of doing so than AO teams (Killaspy et al., 2009). Engaging care-avoiding patients into mental health care takes specific skills, time and effort, which may not always be available in non-assertive outreach teams (Priebe et al., 2005; Schout et al., 2011).

Only in four countries did the GP ask a community mental health team or a first-episode team to pay a home visit to the first-episode patient described in case vignette 1. This is surprising, since 40% of the countries have community mental health teams or AO teams that could make home visits. It may be that the GP was not always aware of this option, or that there were policies that prevented direct referral to such services.

Surprisingly, hospitals in over one third of the countries would take no action if patients who had been hospitalized voluntarily discharged themselves prematurely. The likely consequence of this would be such that patients would then have no formal mental health care, and would be left to the care of others.

We can only speculate about the reasons for the lack of outpatient care for difficult-to-engage SMI patients in European cities. It may be that some countries traditionally respect patients' autonomy (the 'right to rot'), whereas the attitude in others is more paternalistic (Schout et al., 2011);

this may be a consequence of attitudes/opinions of clinicians, including psychiatrists, and of the lay public. Alternatively, this group of patients does not by definition lobby the authorities or health insurance companies to improve their mental health services – although their family and informal care providers may do so. Finally, although we found no association between gross national income and the availability of AO per se, it may also be that richer countries have more financial means to invest in outreach services.

### *Association with national indices*

Explorative analyses revealed a correlation between the experts' scores of the quality of outpatient mental health care for difficult-to-engage SMI patients and the per capita gross national income, and the number of psychiatrists. However, the availability of AO was not associated with gross national income. It may be that a government or health insurance company's decision to organize AO services is not a matter of money, but of opinion about the necessity of having special AO services.

The associations between the experts' score on the quality of outpatient mental health care for difficult-to-engage SMI patients and gross income and number of psychiatrists per capita may indicate that these services were altogether of better quality in rich countries than in poorer countries, even though all countries – even rich ones – lacked systematic methods for detecting these care-avoiding patients. Further studies should examine these associations in more detail.

### *Consequences of not receiving mental health services*

In most countries, bringing care-avoiding patients into mental health services depended on the level of informal care and the level of psychiatric symptoms, nuisance or violence – which is hardly surprising, since patients who show symptoms or cause nuisance are liable to attract attention. Conceivably, this also suggests that care-avoiding patients who lack informal care, whose symptoms are mainly negative (including self-neglect), may not attract attention and thus may not receive care. Such patients may attract the attention of the health services only when their self-neglect is very severe and causes problems in terms of domestic squalor (Day, 2010). However, the magnitude of this problem is unknown (Day, 2010).

The case vignettes showed wide varieties in the type and quality of outpatient care for difficult-to-engage first-episode psychosis patients and homeless chronic schizophrenia patients. By producing higher numbers of untreated first-episode patients, a lack of outreach services for first-episode psychosis patients may lead to worse long-term outcome (Emsley, Chiliza & Schoeman, 2008). Another

study also showed that one consequence of failure to follow up non-attenders even to a service for people at risk for psychosis was that patients who received no treatment developed a psychotic illness (Green, McGuire, Ashworth & Valmaggia, 2011). Longer periods of untreated psychosis may worsen prognosis (Owens, Johnstone, Miller, Macmillan & Crow, 2010). In contrast, AO for first-episode patients has been shown to improve short-term prognosis (Petersen et al., 2005), although the long-term effects are uncertain (Bertelsen et al., 2009).

A lack of outreach mental health services for patients with chronic schizophrenia living on the streets may result in various other problems. Since these patients live in unsafe and unhealthy circumstances, they are at risk of victimization and somatic problems (Kooyman, Dean, Harvey & Walsh, 2007). They may also be hospitalized involuntarily (Mulder et al., 2008), or untreated psychotic symptoms may lead them to be imprisoned for aggressive behaviour or causing nuisance (Calsyn, Yonker, Lemming, Morse & Klinkenberg, 2005). AO has been shown to reduce nuisance and may help difficult-to-engage SMI patients to stay out of the criminal justice system (Staring, Blaauw & Mulder, 2011).

Taken together, if this specific target group is to be engaged with mental health services and its needs are to be addressed, we believe that AO should be provided in one way or another. Importantly, the inadequate provision of outpatient care is a violation of the fundamental right of the EU, which states that everyone has the right to benefit from medical treatment under the conditions established by national laws and practices (Charter of Fundamental Rights of the European Union 2000/C 364/01). It is therefore important to achieve a consensus on a minimum European standard for AO and quality of care for difficult-to-engage SMI patients.

### Limitations

The questionnaire was completed by only one expert from each country. Although all experts were chosen on the basis of their knowledge of the mental health system, especially with respect to difficult-to-engage patients in large cities in their country, their answers are not necessarily representative of the judgement of all experts in the country concerned, and may thus have been biased. However, we selected well-qualified and experienced experts whom we trust and who we believe to be best placed to assess the given system.

Although we also used case vignettes, the definitions of 'difficult-to-engage SMI patients' and AO may both be unclear. With regard to the former, the reasons for avoiding care differ among patients, making difficult-to-engage SMI patients a varied group (Schout et al., 2011). With regard to the latter, the definition of AO was based on the European Service Mapping Schedule 2 (Johnson & Kuhlmann, 2000).

But there are different AO models (van Veldhuizen, 2007) and the prerequisites essential to engaging patients are unknown, although visiting patients in their own environment is likely to be a *conditio sine qua non*.

Our national indices represented only a few of the possible indicators. The use of other indicators, such as the per-capita health budget, might have yielded other results. Finally, if a correlation coefficient in the explorative analyses was not statistically significant, it may have been due to low power.

### Conclusions

This study shows that outpatient mental health services for difficult-to-engage SMI patients vary widely among large cities in European countries and that experts judge the overall quality of these services to be poor. Although our results were based on information provided by only one expert per country, it is likely that a substantial group of difficult-to-engage SMI patients lack adequate outpatient mental health care, and that this may violate the fundamental right to benefit from medical treatment provided under the Charter of Fundamental Rights of the EU. It is therefore important to develop a minimum European standard for AO and quality of care for difficult-to-engage SMI patients.

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### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

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