Part I

Development of scales to measure mental health outcomes

1 The EPSILON Study: aims, outcome measures, study sites and patient sample

Thomas Becker, Martin Knapp, Helle Charlotte Knudsen, Aart H. Schene, Michele Tansella, Graham Thornicroft, José Luis Vázquez-Barquero and the EPSILON Study Group

The development and translation of assessment instruments in mental health is a complex process, which becomes increasingly important in a uniting Europe. The major aim of the European Commission BIOMED-funded multi-site study, the European Psychiatric Services: Inputs Linked to Outcome Domains and Needs (EPSILON) Study, was to produce standardised versions in several European languages of instruments measuring five key concepts in mental health service research (Becker *et al*, 1999): (a) the Camberwell Assessment of Need (CAN), measuring needs for care; (b) the Involvement Evaluation Questionnaire (IEQ), assessing family or care-giving impact; (c) the Verona Service Satisfaction Scale (VSSS), measuring satisfaction with services; (d) the Lancashire Quality of Life Profile (LQoLP), assessing the quality of life of service users; and (e) the Client Socio-demographic and Service Receipt Inventory (CSSRI), assessing service utilisation and costs.

Aims

The outcomes translation, adaptation and reliability assessments presented in this book were part of a wider research project. This is a comparative cross-sectional study of the care of people with schizophrenia in five European countries. Six research teams in five centres were involved, located in Amsterdam, Copenhagen, London (Centre for the Economics of Mental Health and Section of Community Psychiatry, Institute of Psychiatry), Santander and Verona. The centres had experience in health services research and instrument development, and all had access to mental health services providing care for local catchment areas.

The instruments used assess a variety of dimensions of the care process, such as needs for care, service utilisation and costs, informal carer involvement, quality of life and service satisfaction. These research scales were used to study care for people with schizophrenia in five centres cross-sectionally in a sample of patients in contact with secondary mental health services. The EPSILON Study aimed: (a) to produce standardised versions of five key research instruments in five languages; (b) to compare data about social and clinical variables, mental health care and costs; and (c) to test instrument-specific and cross-instrument hypotheses. Facilitating future cross-national research into care for the severely mentally ill is a central objective of the EPSILON Study.

Study instruments

Five study instruments were adapted for use in the five languages and different service settings:

(a) Camberwell Assessment of Need (CAN);
(b) Client Service Receipt Inventory (CSRI);
(c) Involvement Evaluation Questionnaire (IEQ);
(d) Lancashire Quality of Life Profile (LQoLP);
(e) Verona Service Satisfaction Scale (VSSS).

These instruments are designed to assess a variety of dimensions of the care process; some of their characteristics are outlined in Table 1.1.

Patients' needs

The European version of the CAN (CAN–EU), an interviewer-administered instrument, was used to assess patients' needs. It is described fully in Chapter 4. It comprises 22 individual domains of need (accommodation, food, household skills, self-care, occupation, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company of others, intimate relationships, sexual expression, child care, transport, money, welfare benefits, basic education and telephone).

Service use and cost

The Client Socio-demographic and Service Receipt Inventory – European Version (CSSRI–EU) is an adaptation of the CSRI (Beecham & Knapp, 1992) which, on the basis of an interview, records socio-demographic data, accommodation, employment, income, and all health, social, education and criminal justice services received by a patient during the preceding 6 months (Chapter 8). It allows costing of services received on the basis of unit cost data.

Caregiving consequences

The IEQ measures the consequences of psychiatric disorders for relatives of patients (Schene & van Wijngaarden, 1992). The European version (IEQ–EU) contains five sections: general information on the patient, caregiver and household (15 items); caregiving consequences (31 items); costs (8 items); the General Health Questionnaire (GHQ–12); and the consequences for patients' children (11 items). The time frame is the past 4 weeks. Caregiving consequences are summarised using four scales (tension, worrying, urging, supervision) and a summary score (Chapter 10).

Quality of life

The European version of the LQoLP (LQoLP–EU) elicits objective quality of life indicators and subjective quality of life appraisal through patients' answers to interviewer-administered questions relating to nine fields: work/education, leisure/participation, religion, finances, living situation, legal and safety, family relations, social relations and health (Chapter 13).

Table 1.1 Core study instruments

Instrument	No. of domains	No. of facets/ sub-scales explored	No. of items	Mode of administration	Average completion time (mins)	Time frame	Sub-scale score	Summary score
CAN–EU	22	–	22 x 6	INT	20–30	Past month	Yes (met needs, unmet needs, total needs)	Yes
CSSRI–EU	5	–	110	INT	20–30	Past 6 months	Yes, 5 service use domains	Various
IEQ–EU	5	4 sub-scales and one total score	31 IEQ: 81 all modules	SA QU	10 min IEQ; 20–30 min for whole set	Past 4 weeks	Yes, 4 + GHQ	Yes
LQoLP–EU	9	Positive and negative affect, affect balance	105	INT	30	Past week, month or year (varies)	Yes	Yes
VSSS–EU	7	7	63	SA[1]	20–30	Past year	Yes, one for each domain	Yes

1. Assisted in some places:

EU, European Version; CAN, Camberwell Assessment of Need; CSSRI, Client Socio-demographic and Service Receipt Inventory; IEQ, Involvement Eval
Life Profile; VSSS, Verona Service Satisfaction Scale; GHQ, General Health Questionnaire; INT, interview-administered; SA, self-administered; QU, qu

Service satisfaction

Satisfaction with services was assessed using an adapted version of the VSSS (VSSS–EU), a self-administered instrument comprising seven domains (global satisfaction, skill and behaviour, information, access, efficacy, intervention and relatives' support) (Chapter 16).

Other instruments

Other instruments used included the Brief Psychiatric Rating Scale (BPRS 24-item version; Ventura *et al*, 1993) and Global Assessment of Functioning (GAF; American Psychiatric Association, 1987). These were used in English. Instruments documenting the sampling process (Prevalence Cohort Data Sheet), area socio-demographic descriptors (Area Socio-Demographic Data Sheet) and patients' psychiatric history (Psychiatric History Data Sheet) were developed for the EPSILON Study. Descriptions of site-level characteristics included socio-demographic area descriptors, availability of in-patient beds and other service components, and staff availability. The European Service Mapping Schedule was also used (Johnson *et al*, 1998; Becker *et al*, 2002). Data were collected for the EPSILON Study during the period September 1997 to August 1998.

Study sites

Amsterdam

General area characteristics

Data were collected in Amsterdam South-East, which is a 30-year-old borough in the south of the city. It is mainly a residential area, with a mixed lower- and middle-class population of 110 000. Unemployment is high. Fifty per cent of the inhabitants are from one of the 60 minority ethnic groups. Data were collected for 1 January 1998.

Mental health services in the local area

The mental health services in the Amsterdam South-East catchment area are in a process of change and integration, and this paragraph describes the services in January 1998 (during the period of the study). The large Santpoort mental hospital, located 25 km to the west of Amsterdam, during the 1990s started to provide services (out-patient, in-patient and residential) across the city. Having moved to Amsterdam, these services, formerly hospital-based, are now in the process of integrating with mental health services which have been available in the city for many years, such as the Regional Institute for Ambulatory Mental Health Care (Regionale Instelling voor Ambulante Gestelijke Gezordheilzorg, RIAGG) and the Department of Psychiatry at the Academic Medical Centre (AMC).

Since 1998 these three organisations (Santpoort, RIAGG and AMC) have been merged into one organisation called De Meren, with three separate services, for people aged over 65, 18–64, and below 18 years. For the adult population this new organisation offers out-patient services in three locations: the former RIAGG, the out-patient department formerly at Santpoort, and the AMC out-patient department. These three services have been merged into the Social Psychiatric Service Centre (SPSC). This SPSC has its in-patient units (eight beds on a closed ward, six beds on an open intermediate care ward, 20 beds on an open ward) in the AMC, where a 24-hour emergency room is also available. For long-term patients, non-acute 24-hour staffed residential services and sheltered accommodation

are available within the SPSC. Services for the catchment area population also include intensive home care, two shelters for homeless people with mental illness, a day care centre and a vocational rehabilitation centre. The wider context of mental health services in Amsterdam is described in more detail elsewhere (Schene *et al*, 1998; Becker *et al*, 1999).

Copenhagen

General area characteristics

Copenhagen is the capital of Denmark, with a total population of about 480 000. Copenhagen is divided into 14 social districts (boroughs). The two neighbouring social districts of Vesterbro and Kongens Enghave were the catchment areas for the project, with a population of about 50 000.

Mental health services in the local area

The mental health services in Vesterbro and Kongens Enghave are provided by Hvidovre Hospital. The psychiatric department of this hospital has an emergency unit with 4 beds, and 130 in-patient beds distributed across three locked wards, three open wards, one ward for young people with first-episode psychosis, one ward open Monday to Friday (each with 15 beds), and an old age psychiatry ward with 10 beds. They provide an extensive liaison psychiatric service to the general hospital. Further, Hvidovre Hospital has three community mental health centres (CMHCs): Vesterbro, Valby and Vanløse. Vesterbro Community Mental Health Centre provides services for inhabitants in the catchment areas Vesterbro and Kongens Enghave (population about 50 000) with chronic mental illness, mostly schizophrenia. Hvidovre Hospital's total catchment area is 130 000. The CMHC has a multidisciplinary team: psychiatrist, psychologist, social workers, nurses, occupational therapist and physiotherapist. The total number of staff is 22. Every patient has a case manager and a psychiatrist in the CMHC. At any one time, approximately 300 patients are on the CMHC case-load. The CMHC provides out-patient care, structured day activities (mostly workshops as social training: arts, cooking, gymnastics and psycho-education) and home visits to patients. The CMHC and the psychiatric department at the general hospital collaborate in setting up different types of conferences, educational programmes, etc. There is close collaboration between the CMHC and other services in the catchment area, such as general practitioners, social services, sheltered accommodation and voluntary organisations (Kastrup, 1998; Becker *et al*, 1999).

London (Croydon)

General area characteristics

Croydon is a predominantly suburban borough in south London, with a total population of 330 000. The population ranges from the somewhat deprived inhabitants of the north of the borough to the more affluent, middle-class residents of the semi-rural southern area. Patients in this study were recruited from a sector population of about 80 000 in the borough.

Mental health services in the local area

Specialist mental health services in Croydon are purchased by Croydon Health Authority and provided by the Bethlem & Maudsley NHS Trust. These specialist mental health services for the general adult

population include 70 acute adult psychiatric beds for the 330 000 population; 10 low-security in-patient places in a locked ward; and four medium-security forensic beds. Residential provision includes 25 places staffed around the clock by nurses, 166 places staffed around the clock by other care workers and 22 less well supported places. For the provision of community mental health services, the borough is divided into three localities, and sampling in this study was from the central locality, with a population of about 80 000. Each of these three localities contains two or three general adult community mental health teams, which typically include community psychiatric nurses, an attached social worker, attached occupational therapist, consultant psychiatrist and junior psychiatrist. There are four CMHCs for the whole borough of Croydon. These function as community multidisciplinary team bases, settings for out-patient and depot medication clinics, and as day centres, providing occupational therapy and psychotherapeutic groups. Social services and the private and voluntary sectors also provide day care places, work opportunities and 'drop-in' services (Johnson *et al*, 1997; Thornicroft & Goldberg, 1998; Becker *et al*, 1999).

Santander

General area characteristics

The study was conducted in Cantabria, an autonomous community with a population of about 560 000 in northern Spain. Patients were recruited from Cantabria as a whole. The city of Santander, a university town with a total population of about 194 000 inhabitants, is predominantly middle-class, with the majority of those employed working in services and light industry.

Mental health services in the local area

The Spanish Psychiatric Reform, which was formally initiated in 1985, had as its main objective the replacement of the old mental hospitals with alternative services in the community and in-patient psychiatric units in general hospitals (Vázquez-Barquero & García, 1999). These services are integrated in the Spanish National Institute of Health (INSALUD), providing free health care for the whole of the Spanish population. In this context, psychiatric services in Santander are mainly provided as follows:

(a) There is an acute psychiatric in-patient unit of 42 beds (there are also 12 beds in a long-term psychiatric hospital, used mainly by patients from the private sector, insurance companies and health consortia). This unit, which also meets the needs of the whole region of Cantabria, is located within the Marqués de Valdecilla University Hospital, which is both a teaching general hospital with 1199 beds, providing in-patient services for the region of Cantabria, and a referral hospital for the rest of Spain for tertiary, specialised forms of medical care.

(b) A 24-hour acute emergency unit is located in the university hospital.

(c) For the provision of community mental health services, Cantabria is divided into four areas, each with a community mental health service. Santander is one of these mental health service areas: the Santander mental health centre is divided into two multidisciplinary adult mental health teams, each including two psychiatrists, a community nurse, a psychologist and a social worker.

(d) For long-term psychiatric care, patients can be referred to a long-stay psychiatric hospital belonging to the Cantabria local authorities (114 beds) or to a long-stay psychiatric hospital belonging to a non-profit-making religious organisation (89 beds). Further information is given in Becker *et al* (1999).

Verona

General area characteristics

Data were collected in the South Verona community-based mental health service (CMHS). South Verona is a predominantly urban area with a population of about 70 000, on the southern outskirts of Verona, a city in northern Italy. Verona is predominantly middle-class, with services and industry constituting more than 90% of the economic sector.

Mental health services in the local area

The South Verona CMHS has developed gradually over the past 20 years, and it is the main psychiatric service providing care to South Verona residents (Tansella *et al*, 1998). It includes a comprehensive and well-integrated number of programmes, and provides in-patient care, day care, rehabilitation, out-patient care and home visits, as well as a 24-hour emergency service and residential facilities (three apartments and one hostel) for long-term patients. Staff of the CMHS are divided into three multidisciplinary teams, each responsible for a subsector of the catchment area. With the exception of hospital nurses, all staff (psychiatrists, psychologists, social workers and community nurses) work both inside and outside hospital. The 'single staff' module ensures continuity of care through the different phases of treatment and the different components of the service. A Psychiatric Case Register (PCR), which covers the same geographical area, has been operating since 31 December 1978. Private hospitals and other agencies in the larger province of Verona also provide information to the PCR. However, 1990–1993 data indicate that 82% of patients living in the area are receiving care from the South Verona CMHS, either solely or together with other services. The vast majority of patients with a diagnosis of schizophrenia are on the case-loads of public mental health services. It can be assumed that the sample assessed in this study is representative of all patients with a diagnosis of schizophrenia under 'active treatment' in the South Verona catchment area (Tansella *et al*, 1998; Becker *et al*, 1999). Data were collected from patients with schizophrenia attending the CMHS in the two 3-month periods October–December 1997 and April–June 1998; this timing was chosen to coincide with routine assessments taking place as part of the South Verona Outcome Project (Tansella *et al*, 1998; Becker *et al*, 1999).

Case ascertainment

In this study, adults aged 18–65 inclusive with any ICD–10 diagnosis from F20 to F25 were included at the screening stage. These administrative prevalence samples of patients with psychotic disorders were identified either from psychiatric case registers (in Copenhagen and Verona) or from the case-loads of local specialist mental health services (in-patient, out-patient and community). Patients needed to have been in contact with mental health services during the 3-month period preceding the start of the study. Thus, an administrative prevalence sample of people with schizophrenia in contact with mental health services was used in each site as the sampling frame. Cases identified were diagnosed using the item group checklist (IGC) of the Schedule for Clinical Assessment in Neuropsychiatry (SCAN; World Health Organization, 1992). On this basis, only patients with an ICD–10 F20 research diagnosis were included in the study.

Exclusion criteria included current residence in prison, secure residential services or hostels for long-term patients; coexisting learning disability (mental retardation), primary dementia or other severe organic disorder; and extended in-patient treatment episodes longer than 1 year. This was done in

Table 1.2 Diagnostic distribution in initial sample at screening stage

ICD–10 diagnostic group	Amsterdam		Copenhagen		London		Santander		Verona	
	n	%	n	%	n	%	n	%	n	%
F20 schizophrenia	123	79	100	69	149	86	300	71	84	45
F21 schizotypal disorder	–	–	18	13	9	5	4	1	8	4
F22 persistent delusional disorder	9	6	6	4	–	–	44	10	29	15
F23 acute transient psychotic disorder	–	–	9	6	5	3	52	12	20	11
F24 induced delusional disorder	–	–	–	–	–	–	1	–	1	1
F25 schizoaffective disorder	2	1	5	4	6	4	22	5	17	9
Other	15	10	3	2	4	2	–	–	15	8
No diagnosis	5	4	3	2	–	–	–	–	14	7
Total	154	100	144	100	173	100	423	100	188	100

order to avoid any bias between sites due to variation in the population of patients in long-term institutional care, and to concentrate on those in current 'active' care by specialist mental health teams. The numbers of patients finally included in the study varied from 52 to 107 between the five sites, with a total of 404.

Patient sample

The distribution of diagnoses on the basis of the item group checklist (Table 1.2) shows that between 45% (in Verona) and 86% (in London) of the patients screened had an IGC diagnosis of schizophrenia. Schizotypal disorders were most likely to be diagnosed in Copenhagen (13%); both persistent delusional disorders and acute transient psychotic disorders were more likely to be diagnosed in Santander (10% and 12% respectively) and Verona (15% and 11% respectively) than in the other sites.

Table 1.3 shows the attrition of the samples and reasons why interviews could not be completed. Some differences require comment. The order of events was: (a) collection of administrative data, including all prevalent cases in contact with catchment area services; (b) random selection of patients who were diagnosed and/or interviewed (not in London and Verona, where all were eligible, in order to achieve a big enough sample); (c) diagnostic assessment on the basis of the IGC SCAN (World Health Organization, 1992); and (d) the study interview. In Copenhagen, the matching of prevalent cases and those interviewed was not possible, due to patient confidentiality regulations in the Danish legal and data protection systems. In Amsterdam, London and Verona all (or most) patients were contacted for interview, because large numbers of refusers and patients who could not be found, as

Table 1.3 Sample attrition

	Amsterdam	Copenhagen	London	Santander	Verona	Total
All prevalent cases	170	144[1]	173	423	188	1098
Selected for IGC rating/interview	154		173	125	184	–
Excluded (SCAN or ICG)	31		4	0	42	–
Lost/died/ill/refused/age excluded	62		85	25	35	–
Final data-set	61	52	84	100	107	404

ICG, item group checklist; SCAN, Schedule for Clinical Assessment in Neuropsychiatry.
1. Match between prevalent cases and subsequent screened individuals not possible owing to Danish patient confidentiality regulations (72 excluded altogether).

Table 1.4 Comparisons between those interviewed, and those selected at random and meeting inclusion criteria but not interviewed (excluding Copenhagen)

	Interviewed	Not interviewed[1]	*P*[2]
Number (maximum[1])	352	203	–
Age (years)	41.2	40.1	0.27
Years since first contact	11.7	11.7	0.95
Total number of contacts	1.96	1.98	0.37
Lifetime psychiatric admissions	4.0	6.3	0.14
Male	57%	59%	0.59
Married	18%	13%	0.21
White	93%	89%	0.26

1. Because lost, ill, died, refused.
2. Data missing for some individual variables.

well as substantial diagnostic heterogeneity, were expected. The proportion of patients excluded on the basis of the IGC diagnosis varied from none (Santander) to high rates of 18% and 22% (Amsterdam, Verona). This may reflect differences either in clinical diagnostic routine or in the case-load composition of the secondary mental health services in the various sites. Patients not located varied from 1% (Santander, Verona) to 16% (London), which may reflect more social integration in the former, and more deprivation and loss of social networks in the latter. The rate of interview refusals varied from 3% (Santander) to 32% (London). Again, Santander and Verona had low rates and contrasted with London, and this might reflect social context and degrees of deprivation or integration. Between 21% (Amsterdam) and 57% (Verona) of patients completed the interview at time 1, and this may reflect differences between recently established (Amsterdam) and long-standing (Verona) community mental health services. Table 1.4 shows comparisons between patients interviewed and those not interviewed; there was no significant difference.

Contents and outlook

This book summarises the EPSILON Study in terms of instrument adaptation (Chapter 2) and psychometric methods applied in testing instrument reliability (Chapter 3). The individual instruments used and adapted in this study are described in detail in Chapters 4, 8, 10, 13 and 16. The output of this process is a set of 'EU' instrument versions available in five languages (Danish, Dutch, English, Italian and Spanish). Data obtained using these instruments provided a multidimensional picture of the needs of people with schizophrenia, their service use and their subjective appraisal of quality of life and services available. By making these instruments available to a wider audience of researchers and service managers involved in mental health services research and planning throughout Europe, it is hoped that they will make a lasting contribution to the field of mental health services research.

References and further reading

American Psychiatric Association (1987) *Diagnostic and Statistical Manual of Mental Disorders* (3rd edn, revised) (DSM–III–R). Washington, DC: APA.

Becker, T., Knapp, M., Knudsen, H. C., *et al* (1999) The EPSILON Study of schizophrenia in five European countries: design and methodology for standardising outcome measures and comparing patterns of care and service costs. *British Journal of Psychiatry*, **175**, 514–521.

Becker, T., Hülsmann, S., Knudsen, H. C., *et al* (2002) Provision of services for people with schizophrenia in five European regions. Social Psychiatry and Psychiatric Epidemiology, **37**, 465–474.

Beecham, J. & Knapp, M. (1992) Costing psychiatric interventions. In *Measuring Mental Health Needs* (eds G. Thornicroft, C. R. Brewin & J. Wing), pp. 163–183. London: Gaskell.

Johnson, S., Ramsay, R., Thornicroft, G., *et al* (eds) (1997) *London's Mental Health*. Report to the King's Fund London Commission. London: King's Fund.

Johnson, S., Salvador-Carulla, L. & the EPCAT group (1998) Description and classification of mental health services: a European perspective. *European Psychiatry*, **13**, 333–341.

Kastrup, M. (1998) Mental health in the city of Copenhagen, Denmark. In *Mental Health in Our Future Cities* (eds D. Goldberg & G. Thornicroft), pp. 101–123. Hove: Psychology Press.

Oliver, J., Huxley, P., Bridges, K., *et al* (1996) *Quality of Life and Mental Health Services*. London: Routledge.

Schene, A. H. & van Wijngaarden, B. (1992) *The Involvement Evaluation Questionnaire*. Amsterdam: Department of Psychiatry, Academic Medical Center, University of Amsterdam.

Schene, A. H., Hoffmann, E. & Goethals, A. L. J. (1998) Mental health in Amsterdam. In *Mental Health in Our Future Cities* (eds D. Goldberg & G. Thornicroft), pp. 33–55. Hove: Psychology Press.

Tansella, M., Amaddeo, F., Burti, L., *et al* (1998) Community-based mental health care in Verona, Italy. In *Mental Health in Our Future Cities* (eds D. Goldberg & G. Thornicroft), pp. 239–262. Hove: Psychology Press.

Thornicroft, G. & Goldberg, D. (1998) London's mental health services. In *Mental Health in Our Future Cities* (eds D. Goldberg & G. Thornicroft), pp. 15–31. Hove: Psychology Press.

Vázquez-Barquero, J. L. & García, J. (1999) Deinstitutionalization and psychiatric reform in Spain. *European Archives of Psychiatry and Clinical Neuroscience*, **249**, 128–135.

Ventura, J., Green, M. F., Shaner, A., *et al* (1993) Training and quality assurance with the Brief Psychiatric Rating Scale: 'the drift busters'. *International Journal of Methods in Psychiatric Research*, **3**, 221–244.

World Health Organization (1992) *Schedules for Clinical Assessment in Neuropsychiatry* (ed.-in-chief J. K. Wing). Geneva: WHO.