Client Sociodemographic and Service Receipt Inventory (CSSRI - EU)

MANUAL

Introduction

This manual has been developed for use by participants in the EU BIOMED study of schizophrenia in 5 European countries. The Client Sociodemographic and Service Receipt Inventory (CSSRI - EU) is one of five instruments that are being used to measure the needs, quality of life and cost of schizophrenia in each participating centre. The manual provides explanatory notes for particular questions or items in the schedule that require some additional information, definition or guidance.

Instrument overview

The CSSRI - EU brings together questions which allow the comprehensive costing of care packages for individual patients or clients with schizophrenia. It does this by collecting information on the current living arrangements and expenses of the client (including income, employment and accommodation), followed by questions about any use the client may have made of a range of health care, social care and other services over a defined retrospective period. A profile of each client's medication is collated in a similar way. Unit costs for each of these services and drugs are calculated (as a separate exercise) and subsequently applied to the resource use data from the CSSRI - EU, to give the total costs associated with each client's use of services and medication. The instrument is also used to collect key sociodemographic data. There are also costs associated with the informal care inputs by family members and friends, which we are obtaining from one of the other instruments in the study.

Contact point

If you have any queries regarding the meaning of any items, or are unclear about how to complete any aspect of the instrument, please contact Daniel Chisholm or Martin Knapp at the Centre for the Economics of Mental Health, Institute of Psychiatry, 7 Windsor Walk, London SE5 8BB, UK. Tel: + 44 171 919 3503; Fax: + 44 171 701 7600; e-mail: cemh@iop.bpmf.ac.uk

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Section by section explanatory notes

Frontpage: Patient's confidential details

This frontpage is to be completed at the beginning of the patient face-to-face interview. It should be stored securely in a separate location to the completed interviews. This is in order to preserve the confidentiality of the subjects surveyed in this study.

Centre number: Each participating centre has a numbered code: 1 = Amsterdam; 2 = Copenhagen; 3 = London; 4 = Santander; 5 = Verona

Patient number: Please ensure that this is recorded before the interview starts.

Date of birth: Complete both here on front page and on the main instrument (Q 1.1) so that subjects can be traced if the study number is illegible.

Section 1: Sociodemographic information

Q. 1.4 Ethnic group: It has not been possible to generate a coded shortlist of possible ethnic groups into which subjects will fall, since the study covers five countries, each with its own historical, political and cultural heritage.

Definition of ethnicity = 'shared origins, social background, traditions or culture that lead to a sense of identity and group' The ethnic group of most patients will be best described as 'White European'. Other possibilities include 'African-Caribbean', 'Sikh', 'Chinese', etc. Ethnicity is NOT to be confused with race (race = division of humankind by physical characteristics).

- Q. 1.5 Country of birth: is an objective (but potentially crude) index of ethnicity. A coding sheet for countries is attached to the back of this manual. Please include the number code for the country.
- Q. 1.7 Years of schooling: start point = beginning of compulsory (free) schooling.

Section 2: Living situation

- O. 2.1 Usual living situation: Please identify with the patient his/her usual or <u>normal</u> place of residence. *Definition of children* = under the age of 18.
- Q. 2.2 Type of accommodation: This item attempts to provide a simple classification of possible types of accommodation in which patients are residing. Some of the categories are (necessarily) broad in order to allow comparisons between centres to be made.

CSSRI- EU Manual 2 The following definitions should be employed for specialist community and hospital accommodation:

Community (non-hospital residential facilties):

Overnight facility, 24 hour staffed: Facility where a member of staff is present on site 24 hours a day, with responsibilities related to the monitoring and clinical and social care of patients (i.e. domestic or security staff are not included).

Overnight facility, staffed (not 24 hour): Facility where a member of staff is regularly on site at least three days a week for some part of the day, with responsibilities related to the monitoring and clinical and social care of patients.

Overnight facility, unstaffed: Facility where there is no regular staff presence (less than three days per week), i.e. staff are present only occasionally in the week, either as visits or in reponse to particular care needs.

Hospital:

Acute psychiatric ward: Acute facility to which patients are routinely admitted because of a deterioration in mental state, behaviour or social functioning which is related to psychiatric disorder.

Rehabilitation ward: Non-acute facility to which patients are referred, usually for a fixed maximum period of residence.

Long-stay ward: Non-acute facility to which patients are referred, usually for an indefinite period.

General medical ward: Facility whose core function is the care of inpatients outside the speciality of psychiatry.

Note: If hospital or (specialist) community accommodation: It is necessary to complete the supplementary page of the schedule (after the interview with patient), which asks for facility staffing and financial details. See p. 5 below.

Section 3: Employment and income

This section is aimed at getting information on patients' employment and It is an important source of information for income circumstances. establishing the knock-on effects (or indirect costs) of schizophrenia, such as lost ability to work, and also for estimating the living expenses of the patient.

- Q. 3.2 Occupational categories: The categories are based on the International Standard Classification of Occupations (ISCO), a copy of which is attached. (Please note that ISCO categories 6,9 and 0 have been dropped from the list at Q. 3.2 and should be identified at 'Other....' on the schedule if applicable.)
- Q. 3.4 State benefits: The approach taken here has been to identify a number of international categories of benefits/entitlements, and to have a list of national variants that fall under these broad international categories. This meets the dual requirement of making consistent comparisons between centres whilst building up a set of data that has most meaning and use in each individual site.

CSSRI- EU Manual 3 O. 3.6 Personal income: We have attempted to reduce the sensitivity of questions about personal income by offering a number of possible income bands. The income bands can be shown to patients on a separate card, who can than be asked to point to the number of the band which corresponds to their total personal income (per week, per month or per year - it does not matter which, each amounts to the same income level). If at all possible, this should be given as a gross income level, i.e. before tax and other deductions, but if this is not possible, the net income level can be inserted (i.e. after tax and other deductions). Please note that this question is asking for the income of the patient, NOT household income.

Section 4: Service receipt

Note: All service receipt is being collected over a retrospective period of 3 months.

- O. 4.1 Inpatient hospital services: Please see above for definitions of hospital services. Please record all days in these facilities, including if the patient was identified at Q. 2.2 as currently living in one of these settings.
- Q. 4.3 Community-based day services: These are services which are normally available to several patients at a time and which usually provide some combination of treatment for problems related to mental illness, structured activity, social contact and/or support. Facilities have regular opening hours.
- Q. 4.4 Primary and community care contacts: These are services which involve contact between health and social care professionals and patients for some purpose related to management of mental illness and its associated clinical and social difficulties. They are provided separately, i.e. do not form part of the delivery of residential or day services.
 - Please identify the sector from which the service contact is delivered (1 = Statutory/government; 2 = voluntary; 3 = private). If there is a mixture of sectors for any given contact type, indicate the main sector of provision.
- Q. 4.5 Criminal justice services: Please code 9 if number of police contacts, nights in custody, psychiatric assessments or court appearances not known.

Section 5: Medication profile

Q. 5.1 Medication: Please record all drugs taken, not just those related to mental illness. Please code 9 if dosage not known, otherwise give volume per unit of measurement (e.g. 5 mg).

Supplement: Hospital/community accommodation details

The final page of the schedule only needs to be completed for patients who are resident in hospital or specialist community settings (rather than domestic accommodation). Data should be collected after the face-to-face interview, in

CSSRI- EU Manual 4 consultation with a facility manager or senior key worker. We recommend that time is made available as soon after the patient interview as possible.

- Note: For study patients who reside in the same facility, the accommodation details will only need to be obtained once. However, please ensure that accommodation details are recorded on each patient's schedule.
- Q. 1 Number of places/beds: Please give the number of places in the residential facility or hospital ward that are <u>both</u> currently available <u>and</u> occupied.
- Q. 2 Staffing: Please include all staff involved in the direct care and management of patients. The number of full-time equivalent (FTE) staff is calculated by aggregating all full-time and part-time positions and expressing them in terms of full-time posts. For example, a facility with 4 full-time posts and 4 posts working half-time would have a FTE count of 6. The total annual cost of the various categories of staff should include actual salaries only (salary on-costs, such as national insurance, will be calculated separately by CEMH).
- Q. 3 Recurrent cost (excluding care staff): Apart from the salaries of care workers, there are other revenue or recurrent costs involved with operating the facility. Using annual accounts (if available), please identify the annual costs associated with catering and cleaning staff and consumables, heating and lighting, transport etc. For hospital wards, an apportionment of the overall hospital recurrent costs (excluding care staff) may be the best estimate possible.
- Note: There are also likely to be other costs, such as rent, capital or overheads. These are a relatively small proportion of the overall cost and will be calculated separately by CEMH. Please do NOT include these costs in this question.
 - (If you do have useful information about these costs that you can share with us, please contact Daniel Chisholm at CEMH.)
- Q. 4 Charge per week: Charge refers to the fee or price that is payable in the market for residential care. It is often different to the actual cost of resources involved in residential/hospital care (staffing, running costs etc.). For example, a private, for-profit company may charge a fee above what it actually costs to provide care. Fees or charges for a place at a facility are often available, and are useful where it is difficult to estimate the true cost.

THANK YOU FOR YOUR VALUABLE HELP IN THIS STUDY

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