

Continuity of care for carers of people with severe mental illness: results of a longitudinal study

Article

Accepted Version

Burns, T., Catty, J., Harvey, K. ORCID: https://orcid.org/0000-0002-6819-0934, White, S., Rees Jones, I., McLaren, S. and Wykes, T. (2013) Continuity of care for carers of people with severe mental illness: results of a longitudinal study. International Journal of Social Psychiatry, 59 (7). pp. 663-670. ISSN 1741-2854 doi:

https://doi.org/10.1177/0020764012450996 Available at https://centaur.reading.ac.uk/31109/

It is advisable to refer to the publisher's version if you intend to cite from the work. See <u>Guidance on citing</u>.

To link to this article DOI: http://dx.doi.org/10.1177/0020764012450996

Publisher: Sage

All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other copyright holders. Terms and conditions for use of this material are defined in the <u>End User Agreement</u>.

www.reading.ac.uk/centaur



CentAUR

Central Archive at the University of Reading Reading's research outputs online

Continuity of care in mental health: understanding and measuring a complex phenomenon

Short title: measuring continuity of care

Tom Burns¹, Jocelyn Catty, Sarah White, Sarah Clement, Gemma Ellis, Ian Rees Jones, Pascale Lissouba, Susan McLaren, Diana Rose, Til Wykes for the ECHO Group

The ECHO Group:

Main Phase: Tom Burns^{1,2}, Jocelyn Catty^{1,2}, Sarah Clement³, Kate Harvey⁴, Sarah White¹, Tamara Anderson¹, Naomi Cowan¹, Gemma Ellis¹, Helen Eracleous¹, Connie Geyer¹, Pascale Lissouba¹, Zoe Poole¹;

Qualitative Strand: Ian Rees Jones⁵, Nilufar Ahmed¹;

Developmental Phase: Diana Rose⁶, Til Wykes⁶, Angela Sweeney⁶;

Organisational Strand: Susan McLaren³, Ruth Belling³, Jonathon Davies³, Ferew Lemma³, Margaret Whittock³.

- 1. For correspondence: Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford OX3 7JX. Tel: + 44 (0)1865 226474. < tom.burns@psych.ox.ac.uk>
- 2. St. George's, University of London.
- 3. London South Bank University.
- 4. University of Reading.
- 5. University of Wales, Bangor
- 6. Institute of Psychiatry, London.

Word count: 2,973

Abstract

Background

Continuity of care is considered by patients and clinicians an essential feature of good quality

care in long-term disorders, yet there is general agreement that it is a complex concept. Most

policies emphasise it and encourage systems to promote it. Despite this there is no accepted

definition or measure against which to test policies or interventions designed to improve

continuity. We aimed to operationalise a multi-axial model of continuity of care and to use

factor analysis to determine its validity for severe mental illness.

Methods

A multi-axial model of continuity of care comprising eight facets was operationalised for

quantitative data collection from mental health service users using 32 variables. Of these

variables, 22 were subsequently entered into a factor analysis as independent components, using

data from a clinical population considered to require long-term consistent care.

Results

Factor analysis produced seven independent continuity factors accounting for 62.5% of the total

variance. These factors, Experience & Relationship, Regularity, Meeting Needs, Consolidation,

Managed Transitions, Care Coordination and Supported Living, were close though not identical

to the original theoretical model.

Conclusions

We confirmed that continuity of care is multi-factorial. Our seven factors are intuitively

meaningful and appear to work in mental health. These factors should be used as a starting-point

in research into the determinants and outcomes of continuity of care in long-term disorders.

Conflict of interest: none

2

Continuity of care is considered a corner-stone in the effective management of long-term disorders by service users, clinicians and healthcare policy-makers. It is fundamental in several policy documents (Department of Health 1990; Department of Health 1995; Department of Health 2001) and has been proposed as a useful criterion for mental health service evaluation (Johnson *et al.* 1997). The weight given it is reflected in the widespread use of case management (Mueser *et al.* 1998) and national policies such as the Care Programme Approach (CPA) in the United Kingdom (Department of Health 1990). Indeed, Tessler (1987) argues that it has replaced dependency and deinstitutionalisation as the central issue in service provision.

Yet while the importance of continuity of care has long been recognised, including for those with severe mental illness, it is generally agreed that there have been few attempts until recently to define it systematically, continuity being 'often lauded but seldom defined' (Freeman *et al.* 2000; see also Crawford *et al.* 2004). Definitions are frequently inadequate, often with only one or two elements included (Freeman *et al.* 2000). Freeman and colleagues (2000) identified 32 continuity of care studies in mental health and 14 in primary care but found more than ten definitions and few attempts to explicate and analyse the idea substantively. Crawford and colleagues (Crawford *et al.* 2004) reviewed 435 relevant papers, most of which did not define continuity of care. Haggerty and colleagues (2003), however, emphasise that without clear definitions of continuity of care it is possible neither to investigate nor to solve discontinuities.

Adair and colleagues (2003), charting the definitions of continuity of care over thirty years, found that continuity was rarely distinguished from the interventions themselves until the 1980s, when the idea that it might be a multidimensional concept began to emerge (Bachrach 1981), while in the 1990s continuity became seen as a potential measure of system-level reform. Where continuity had previously been seen as indicating care by the same caregiver or group of caregivers, the idea of continuity as involving the coordination of the patient's progress through the system gained hold.

Operationalising the concept of continuity of care, however, has been notoriously difficult. Many of the earlier studies focused on discharge after an acute care episode rather than on longitudinal changes in continuity (Adair *et al.* 2003) and this has been the case even in some recent studies which have successfully distinguished between the continuity after discharge achieved by different mental health systems (Sytema *et al.* 1997; Sytema & Burgess, 1999). Sytema and colleagues (1997), however, also focused on flexibility of care, operationalised as the combinations of in-, day- and out-patient care used during follow-up, while other studies

have focused on cross-boundary continuity between primary and secondary care (Bindman *et al.* 1997), psychiatric and emergency services (Heslop *et al.* 2000), or inpatient and community settings (Kopelowicz *et al.* 1998).

Several groups have proposed a range of conceptualisations which emphasise differing features: 'a sustained patient-physician partnership' (Nutting *et al.* 2003); maintenance of contact, consistency in the member of staff seen and success of transfer between services (Johnson *et al.* 1997); and 'adequate access to care... good interpersonal skills, good information flow and uptake between providers and organizations, and good care coordination' (Reid *et al.* 2002), while discontinuity has been defined as gaps in care (Cook *et al.* 2000). Others have again emphasised that continuity of care be understood as multidimensional. Crawford and colleagues (2004) propose five factors based on sustained contact with services, breaks in service delivery, the same member of staff being seen, coordination of health and social professionals and the experience of care; Johnson and colleagues (1997) include maintenance of contact, consistency in the member of staff seen, transition and integration between services, adherence to service plans, and management of service users' needs; and Ware and colleagues (2003) utilise five domains: knowledge, flexibility, availability, coordination and transitions. Joyce and colleagues' (2004) systematic literature review found that continuity of care has been defined in terms of service delivery, accessibility, relationship base and individualized care.

The impact of continuity of care as a multidimensional concept on health and social outcomes has been less often studied, as studies have tended to either to examine outcomes with implications for continuity (such as loss of contact) or to examine interventions assumed to promote continuity (Freeman *et al.* 2000). Adair and colleagues (2005), however, found that better overall continuity, as a combined rating of a range of dimensions, was associated with better quality of life, better community functioning, lower symptom severity and greater service satisfaction, as well as with lower hospital costs and higher community costs (Mitton et al. 2005), although the direction of effects could not be determined.

Freeman and colleagues (2000) rated continuity of care studies from the service users' viewpoint according to relevance, method and concept and highlighted the necessity not only for clarity in the conceptualisation of continuity of care in order to be able to gauge its impact, but also for the inclusion of the service user's perspective. They summarise the principal characteristics of continuity of care in a 'multi-axial definition' comprising: experienced, cross-boundary, flexible, information, relational and longitudinal. In a subsequent study of continuity

in mental health settings (Freeman *et al.* 2002), they added two further definitions, *contextual* and *long-term*. This extended model was the starting-point for the present study. (See Box 1.)

- Box 1 about here-

Aims

We aimed to test whether a multi-factorial model of continuity of care could be operationalised for users of mental health services and whether systematically collected service user-level data would confirm the model's validity for this group.

Methods

Sample and procedure

People with long-term psychotic disorders were sampled from the caseloads of seven Community Mental Health Teams (CMHTs) covered by two mental health Trusts. The inclusion criteria were: clinical diagnosis of any psychotic disorder received at least two years previously, on the caseload of the CMHT for at least six months and aged 18 to 65. Diagnosis was confirmed by use of OPCRIT (McGuffin *et al.* 1991).

Freeman and colleagues' (2002; 2002) multi-axial model of continuity of care was taken as the starting-point. Each of its eight facets or definitions was operationalised by identifying data and/or measures which approximated to it. The variables used to operationalise each definition were agreed by expert consensus within the multidisciplinary research group. They were chosen for their closeness to the definition being considered, the likelihood and regularity of their being recorded in the case notes or the availability of established, validated instruments for obtaining them during a single interview.

Interviews collected basic data on: patterns of contact with services in the preceding 12 months; breaks in care; and referrals to other services including hospital admission. Demographic and illness data were also collected. Three questionnaire measures were also completed. The Camberwell Assessment of Need (CAN) (Phelan *et al.* 1995) was used in the operationalisation of *flexible continuity* and the Scale to Assess Therapeutic Relationships in Community Mental Health Care – service user version (STAR) (McGuire-Snieckus *et al.* 2006) was used in the operationalisation of *relational continuity*. *CONTINU-UM* (Rose *et al.* submitted), a usergenerated measure of continuity developed for the study, was utilised as a proxy for *experienced continuity*. Data on contact with services, number of professionals seen and information flow

were also collected from CMHT records by study researchers using a standard schedule developed for the study. This recorded every face-to-face and telephone contact made between team and the user; the discipline of the professional involved; for every transition in care (referral to an alternative or additional service, including admission to inpatient care), its date and whether appropriate documentation was recorded as having been sent or received; whether the annual CPA documentation was recorded as having been sent to the user, their carer and their GP; and contact between the CMHT and the GP.

Analysis

The continuity components were manipulated in order to give them comparable weight. Continuous variables were z-scored if normally distributed or otherwise converted into categorical variables. Variables were coded so that a positive score indicated an assumed positive scenario. The direction of relationships as determined by the factor analysis, however, would indicate the final direction of the variables. Variables were omitted from further analysis if there was insufficient spread of response (less than 5% in any category) or if two variables had a Spearman Rank correlation coefficient of 0.8 or more, in which case one was omitted.

Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy (Kaiser 1974) were used to evaluate the strength of the linear association between the items in the inter-item correlation matrix. Variables were omitted if their individual measure of sampling adequacy was unacceptably low, until the overall KMO measure of sampling adequacy reached an acceptable level.

Exploratory factor analysis was carried out on variables retained after preliminary screening. A Principal Component Analysis was used to extract factors with an eigenvalue greater than one. A Varimax rotation was then used to produce interpretable independent factors. Extracted factors were interpreted by identifying the items which loaded onto each with a rotated factor loading of over 0.5. Analyses were conducted in SPSS v.14 for Windows.

Results

Sample

Initially, 609 service users were identified as being potentially eligible for the study. Of these, 111 did not meet the inclusion criteria and 318 declined to participate, leaving 180 service users

to be interviewed. Characteristics of the sample are given in Table 1. The diagnosis of psychosis was confirmed by OPCRIT (McGuffin *et al.* 1991) for 171.

- Tables 1 about here
 - Box 2 about here -

Operationalising continuity of care

Freeman's eight definitions of continuity were operationalised using a total of 32 components for consideration for entry into the factor analysis (Box 2).

Experienced continuity: our over-arching concept for the purposes of this study (and therefore not necessarily interpreted as either 'coordinated' or 'smooth'), this was to capture the service user perspective and operationalised using CONTINU-UM.

Flexible continuity: conceptualised as the range of needs at any single time-point being met, this was operationalised using CAN and as response to change in clinical needs over time as increased rate of contacts in the three months prior to any hospital admission or service user-reported deterioration.

Cross-boundary continuity: conceptualised as transitions and fragmentations, this was operationalised as referrals to other services, admissions to hospital, discharges from hospital, number of agencies involved and any user-reported contact with primary care.

Continuity of information: determined by the number of transitions collected for cross-boundary continuity, this was operationalised as a) documents sent as a proportion of the identified transitions b) proportion of letters copied or sent directly to the user; c) number of people to whom CPA documentation was copied (an established good-practice requirement for long-term care in this group).

Longitudinal continuity: this was operationalised as a) any change in who acts as the user's care coordinator and the number of staff in that role; b) any change in who acts as the user's psychiatrist and the number of psychiatrists in that role; c) 'spread of non-medical CMHT input' (number of different non-medical team members seen out of the total number of contacts with non-medical team members) and d) 'spread of medical CMHT input' (number of different medical team members seen out of the total number of contacts with medical team members).

Relational or personal continuity: this was operationalised as the user-rated STAR.

Long-term continuity: interpreted as breaks in care and user-initiated discontinuity, this was operationalised as: user-reported level of attendance of appointments with CMHT; number of user-initiated breaks from mental health care reported by user; user-reported medication adherence; total number of CMHT contacts in year; longest gap between contacts with secondary care team; number of gaps of more than two months; number of more than average gaps (quantified as user's individual mean gap*2 + 2 weeks); number of days between hospital discharge and face-to-face contact with a member of the CMHT.

Contextual continuity: interpreted as social context, this was operationalised as living situation (supported accommodation or independent) and daily activities (day care).

When the inter-item correlation matrix was constructed, ten components were omitted from further analysis. 'Total number of phone calls' was omitted due to inconsistent case note recording. The variables 'Saw known CMHT member when hospitalised', 'Increased contacts in three months prior to user deterioration', 'Increased contacts in three months prior to admission' and 'Number of user-rated breaks in care' were omitted due to insufficient spread of response. 'Total number of face-to-face contacts' was found to be correlated with 'average gap between face-to-face contacts' (r=0.88) and was therefore omitted from further analysis. 'Longest gap between face-to-face contacts' was highly correlated with 'average gap between face-to-face contacts' (r=0.86) and 'gap of two months or more' (r=0.86), so was omitted. 'Referred to other agency' was highly correlated with 'had a transition' (r=0.81) and so was omitted. 'Number of unmet needs' was highly correlated with 'proportion of needs met' (r=0.94) so it was omitted, while 'CAN total number of needs' was highly correlated with 'CAN total level of need' (r=0.93) and was thus omitted. Thus 22 components were appropriate for entry into the exploratory factor analysis.

Factor analysis

A factor analysis was conducted to explore how the different components of continuity relate to each other. Entering the 22 components produced a KMO statistic of 0.49, just below the 0.5 threshold of an acceptable measure of sampling adequacy (Kaiser, 1974). The individual measures of sampling adequacy were then examined and two were found to be very low so removed from the factor analysis: 'gaps of (average gap*2 +2 weeks)' (0.28) and 'medical input spread' (0.22). In the repeated factor analysis, Bartlett's test of sphericity indicated that the

correlation matrix was not an identity matrix (χ^2 =540.5, p<0.001). The KMO measure of sampling adequacy was 0.54, which while still low was acceptable. (The correlation matrix is not presented but is available from the first author on request.) Seven factors were extracted with an eigen value of one or more, explaining 62.5% of the total variance in the data (Table 2). Where the factor was predominately characterised by a component or components used to operationalise the original multi-axial model, the name of that definition is added in parentheses in Table 2. Factor 5, *Managed Transitions*, was recoded into a straightforward trichotomous variable.

The majority of components loaded significantly onto one factor only, with rotated loadings of 0.5 and above. There were four exceptions to this. 'Any user-rated breaks in care?', 'CPA copied to GP and user?', 'number of care coordinators in the past year' and 'attended a day centre' all had absolute loadings between 0.4 and 0.5 onto only one factor so were allocated to that respective factor.

Summary statistics for the 20 components of continuity of care in the seven-factor model are presented in Table 3.

- Tables 2 and 3 about here-

Discussion

This study was based on the premise that continuity of care is 'often lauded but seldom defined' (Freeman *et al.* 2000). Anecdotal evidence would suggest that professionals tend to recognise the idea of continuity of care and intuitively accept it as a worthy goal, despite the paucity of evidence about what it means in practice.

We operationalised the original model to enable its systematic measurement and exploration using quantitative service user-level data. We used the global score of the new measure, CONTINU-UM, as a proxy for *experienced continuity* (as an overarching concept), treating it as a single measure that would reflect participants' own experiences and perspectives on the continuity of care they received. We operationalised the remaining elements utilising multiple components (collected both through interview and from clinical records) that, between them, would reflect the full range of concepts covered by the multi-axial model from which we started. By exploring the relationships between these components through a factor analysis, we found them to be grouped differently in practice, providing a new seven-factor model

comprising Experience & Relationship, Regularity, Meeting Needs, Consolidation, Managed Transitions, Care Coordination and Supported Living. These have clear relationships with the different elements of Freeman and colleagues' model, although they are not synonymous.

Our methodology was comparable to that of Adair and colleagues (2003), whose measure developed for the Canadian context includes both patient- and observer-rated scales. Our factors *Experience & Relationship* and *Meeting Needs* partially matched their patient-rated sub-scales 'relationship base' and 'responsive treatment' respectively, while their other sub-scale 'system fragmentation' seems to have been reflected in our analysis by three distinct factors, *Consolidation, Managed Transitions* and *Care Coordination*.

Our analysis thus confirms Freeman and colleagues' argument and Adair and colleagues' finding that continuity of care comprises more than one single entity. The overarching concept of continuity of care can be broken down into a number of independent concepts and the factors that emerged from our analysis seem intuitively meaningful and practical.

Methodological issues

The conclusions of this paper are inevitably derived from a sample who agreed to take part. How this group may have contrasted with the larger group who refused is unknown. It is possible, though not proven, that those who refused may have been less well engaged with or favourably disposed towards services. If this were the case, this would be likely to affect the levels of several of the continuity factors of the sample (such as *Experience & Relationship* or *Regularity*), rather than affecting the overall factor structure.

We took an inclusive approach to operationalising and measuring the original model. Consistently with this, we did not remove items from the Exploratory Factor Analysis which were weakly correlated with each other (<0.3 as is sometimes advised), as it was quite possible that different components of continuity would be unrelated to each other.

Given the nature of some of the components included, it was likely that some of them would not be related to each other, affecting the KMO-statistic (measuring sampling adequacy). Overall measures of good fit may, therefore, not be applicable to our aims.

Data from records were limited by the availability of the information on file. This may have varied between CMHTs. In assessing *information continuity* and its related components,

whether the requisite information was on file was highly relevant. We therefore worked on the assumption that information not on file had not been sent, a conservative estimation of information flow. It is possible that the accuracy of service contact or transitions data may have been compromised by the quality of case-notes in a way that could not be quantified and which may have varied between CMHTs.

While the factors are intuitively meaningful, their scoring is not and this complicates interpretation, which needs to be based on the components loading onto each factor.

Potential use of these factors

Our factor structure is helpful in challenging preconceptions about likely correlates of care practices. For instance, care components linked with *Care Coordination* and those linked with *Experience & Relationship* loaded onto separate factors, suggesting that focusing care on a single care coordinator is no guarantee in itself of better *relational* or *experienced continuity*. The loading of 'designated psychiatrist' onto *Care Coordination* suggested this was common and reflected a choice in provision of care: users were more likely to see no psychiatrist or more than two (that is, to have no particular psychiatrist relating to them) if they saw only one or two care coordinators. This suggests that teams were choosing between emphasising continuity achieved through the care co-ordinator *or* through the psychiatrist, without any evidence of this being based on an explicit policy. Any assumption that the one smoothly substitutes for the other is challenged by service users' reports in in-depth interviews conducted in a related study (Jones, personal communication), which found that they disliked having to see several psychiatrists, even if they had a single care coordinator.

Johnson and colleagues (1997) proposed that continuity be used as an important quality measure for services, but until recently there have been no metrics. Our operationalisation of Freeman and colleagues' original model draws on routinely collected data and well-known and validated measures. Our factors may in future be used to identify service user characteristics associated with different levels of continuity and therefore help target extra support to vulnerable groups. They may also be used as outcomes against which to test measures (in particular service configurations) deployed to improve continuity. It is unlikely that a model comprising seven factors would be used in routine services. As it presently stands, however, it may provide for clinicians a means of conceptualising continuity of care for mental health, along with a wideranging set of measures of continuity in its different facets, from which different aspects could be selected to reflect service priorities. The relative clinical importance of the seven factors

remains to be tested against relevant clinical and social outcome measures. Further research should then identify the optimal continuity of care factors as the minimum necessary components of care for service users with chronic mental health problems.

This study was funded by a grant (SDO/13(d)2001) from the
National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)
London School of Hygiene and Tropical Medicine
99 Gower Street,
London WC1E 6AA

Tables and Illustrations

Box 1: Multi-axial definition of continuity of care

Generic (Freeman et al. 2000)

Experienced (experience of a coordinated and smooth progression of care from the user's point of view)

Flexible (to be flexible and adjust to the needs of the individual over time)

Cross-boundary (effective communication between professionals and services and with service users)

Information (excellent information transfer following the service user)

Longitudinal (care from as few professionals as possible, consistent with other needs)

Relational (to provide one or more named individual professionals with whom the user can establish and maintain a therapeutic relationship)

Mental health-specific (Freeman et al. 2002)

Long-term (uninterrupted care for as long as the service user requires it)

Contextual (care which should sustain a person's preferred social and personal relationship in the community and enhance quality of life)

Box 2: Continuity of care components

Type of continuity

Component (later omitted)¹

Experienced Continuity

CONTINU-UM²

Flexible Continuity (Range of needs)

CAN Total number of needs^{2, 3}

CAN Number of met needs²

CAN Number of unmet needs²

CAN Total level of needs^{2, 3}

CAN Total level of needs met by informal

carers^{2, 3}

Proportion of needs met²

Flexible Continuity (Meeting changes in

clinical needs)

Increased contacts in 3 months prior to user

deterioration²

Increased contacts in 3 months prior to hospital

admission

Cross-boundary continuity

Had a transition?

Referred to other agency

Contacts with primary care professionals²

Number of agencies used in previous year²

Information continuity

Documented transition

Proportion of letters sent by CMHT copied to

user

CPA copied to GP and user

Longitudinal continuity

Designated care coordinators (CC)²

Designated psychiatrists (Psych)²

Non-medical input spread (number of different non-medical

team members seen out of the total number of contacts with

non-medical team members)

Medical input spread (number of different medical team

members seen out of the total number of contacts with medical

team members)

Relational continuity

STAR total score-any professional^{2, 4}

Long-term continuity

Average gap between face-to-face contacts ³

Gaps of 2 months or more

Longest gap between contacts ³

Gaps of (average gap*2 +2 weeks)

Number of user-rated breaks in care^{2, 3}

Total number of face-to-face contacts

Total number of phonecalls

Saw known CMHT member when hospitalised²

Any user-rated breaks in care?²

Contextual continuity

Attendance at day care²

Supported accommodation²

- 1. Items in italics were subsequently dropped from the analysis, for reasons given in the text.
- 2. Information from the service user.
- 3. Variable reversed so that a high score indicates an assumed positive scenario: e.g. a high score for 'average gap between face-to-face contacts' would indicate short average gaps.
- 4. For users with no identified care coordinator (STAR-c rating), the STAR concerning the relationship with the psychiatrist (STAR-p) was used; where no psychiatrist was identified or rated, the STAR concerning the relationship with a third identified professional (STAR-o) was used, to maximise data.

Table 1: Clinical a	and Demographic characteristic	cs					
		n	Trust 1	n	Trust 2	n	Total
Age mean (sd)		85	42.5 (10.71)	95	43.7 (11.09)	180	43.1 (10.90)
Min – max			22-63		19-65		19-65
Gender	Female	85	36 (42.4%)	95	44 (46.3%)	180	80 (44.4%)
n (%)	Male		49 (57.6%)		51 (53.7%)		100 (55.6%)
Ethnic group	White	85	47 (55.3%)	95	73 (76.8%)	180	120 (66.7%)
n (%)	Black		24 (28.2%)		11 (11.6%)		35 (19.4%)
, ,	Other		14 (16.5%)		11 (11.6%)		25 (13.9%)
Duration of illness	s (months) mean (sd)	81	209.7	91	214.6 (141.5)	172	212.3 (137.69)
Min – max			(134.08)		24-588		18-588
Number of lifetim	e None	85	4 (4.7%)	95	8 (8.4%)	180	12 (6.7%)
hospital							
admissions	1-5		59 (69.4%)		62 (65.3%)		121 (67.2%)
n (%)	6 and over		22 (25.9%)		25 (26.3%)		47 (26.1%)
Diagnosis (by	Schizophrenia	84	55 (65.5%)	89	62 (69.7)	173	117 (67.6%)
OPCRIT)	Bipolar disorder		9 (10.7%)		10 (11.2%)		17 (11.0%)
	Depression with psychotic features		1 (1.2%)		1 (1.1%)		2 (1.2%)
	Other psychotic disorder		18 (21.4%)		15 (16.9%)		33 (19.1%)
	Depression without psychotic features		1 (1.2%)		1 (1.1%)		2 (1.2%)
Living situation	Living alone	85	39 (45.9%)	95	34 (35.8%)	180	73 (40.6%)
n (%)	(+/- children under 18) Living w/ others		46 (54.1%)		61 (64.2%)		107 (59.4%)
	(+/- children under 18)						
Accommodation	Unsupervised	85	74 (87.1%)	95	65 (68.4%)	180	139 (77.2%)
type n (%)	accommodation Supervised accommodation		11 (12.9%)		30 (31.6%)		41 (22.8%)
Education	School up to 16	85	26 (30.6%)	95	43 (45.3%)	180	69 (38.3%)
Laucanon		1 05	20 (30.070))5	TJ (TJ.J/U)	100	07 (30.370)

n (%)	School above 16	!	59 (69.4%)		52 (54.7%)		111 (61.7%)
Employment	Paid employment ¹	54	9 (16.7%)	83	9 (10.8%)	137	18 (13.1%)
Status n (%)	Unemployed or unpaid work ²		45 (83.3%)		74 (89.2%)		119 (86.9%)

- 1. Includes full-time, part-time and sheltered work and self-employment.
- 2. Includes seeking work, unable to work, studying, retired or other.

Factor	Items	Description	% of	
		(high score)	Variance	
1	CONTINU-UM	Experience & Relationship (experienced &	12.5%	
	STAR total score-any professional	relational continuity)		
	Proportion of needs met	high experienced continuity, good therapeutic		
	Any user-rated breaks in care? (negative ¹)	relationship, a greater proportion of needs met		
		and not having a user-rated break in care		
2	Average gap between face-to-face	Regularity (long-term / longitudinal continuity)	12.2%	
	contacts	being seen more frequently by staff from fewer		
	Gaps of 2 months or more	different non-medical disciplines		
	Non-medical input spread			
3	CAN Total level of needs	Meeting Needs (flexible continuity)	9.5%	
	CAN Number of met needs	high level of need, high number of met needs and		
	CPA copied to GP and user	CPA copied to GP and user		
4	Number of agencies used in previous year	Consolidation (cross-boundary continuity)	8.1%	
	Contacts with primary care professionals	having contact with fewer different agencies and		
		not seeing primary care professionals		
5	Had a transition?	Managed Transitions (cross-boundary	7.3%	
	Documented transition	continuity)		
		1=no transition, 0=documented transition,		
		-1=undocumented transition		
6	Designated care coordinators	Care Coordination (longitudinal continuity)	6.5%	
	Designated psychiatrists (negative ¹)	having a designated care coordinator, having no		
	CAN Total level of needs met by	psychiatrist or more than two and fewer needs		
	informal carers (reversed ¹)	met by informal carers		
7	Supported accommodation	Supported Living (contextual continuity)	6.4%	
	Attendance at day centres or hospitals	living in supported accommodation, attending		
	Proportion of letters sent by CMHT	day care and having more letters copied to the		
	which were sent or copied to user	user		
		Total	62.5%	

^{1. &#}x27;Negative' indicates that the component loads negatively onto the factor, indicating an inverse relationship, while 'reversed' indicates that the variable was reverse-scored from the outset so that a high score would indicate a positive scenario.

Table 3: Levels of continuity cor	nponents						
Mean (sd) or n(%) Factor 1: Experience & Relationship CONTINUUM Mean score (1-5)			Trust 1	n	Trust 2	n	Total
			3.5 (.692)	89	3.4 (.818)	167	3.5 (.764)
							1.5-4.8
STAR Total score - Any profession	onal	83	37.6 (8.68)	81	35.4 (9.26)	164	36.5 (9.01)
(0-48)							6-48
CAN-Proportion of needs met	< 65%	84	27 (32.1%)	94	32 (34.0%)	178	59 (33.1%)
	65-91%		23 (27.4%)		26 (27.7%)		49 (27.5%)
	> 91%		34 (40.5%)		36 (38.3%)		70 (39.3%)
Any user-rated breaks in care	Yes	85	3 (3.5%)	93	9 (9.7%)	178	12 (6.7%)
	No		82 (96.5%)		84 (90.3%)		166 (93.3%)
Factor 2: Regularity							
Average gap between face-to-face contacts		83	22.2 (12.46)	83	67.6 (44.47)	166	44.9 (39.71)
(days)							4-206
Gaps of 2 months or more	Yes	84	27 (32.1%)	92	77 (83.7%)	176	104 (59.1%)
	No		57 (67.9%)		15 (16.3%)		72 (40.9%)
Non-medical input spread	=> 50%	82	5 (6.1%)	40	19 (47.5%)	122	24 (19.7%)
	21-49%		6 (7.3%)		8 (20.0%)		14 (11.5%)
	=< 20%		71 (86.6%)		13 (32.5%)		84 (68.9%)
Factor 3: Meeting Needs							
CAN- Total level of needs (0-66)		84	8.2 (4.56)	94	8.7 (5.15)	178	8.5 (4.87)
							1-23
CAN- Number of met needs (0-22	(.)	84	4.3 (2.11)	94	4.4 (2.51)	178	4.4 (2.33)
							0-12
CPA copied to GP and user	No	79	9 (11.4%)	68	26 (38.2%)	147	35 (23.8%)
	To one		35 (41.2%)		26 (38.2%)		61 (41.5%)
	To both		35 (44.3%)		15 (18.8%)		51 (34.7%)
Factor 4: Consolidation							
Number of agencies used in the		72	5.2 (2.71)	79	4.9 (3.05)	151	5.1 (2.89)
Previous year							1-16
Contact with primary care	Yes	72	52(72.2%)	79	35 (44.3%)	151	87 (57.6)

professionals		No		`20 (27.8%)		44 (55.7%)		64 (42.4)
Factor 5: Managed Trai	nsitions							
Had a transition?		Yes	82	33 (40.2%)	92	21 (22.8%)	174	54 (31.0%)
		No		49 (59.8%)		71 (77.2%)		120 (69.0%)
Documented transition?	Documen		82	7 (8.5%)	92	10 (10.9%)	174	17 (9.8%)
	No relevant transition			49 (59.8%)		71 (77.1%)		120 (69.0%)
	Undocumented transition			26 (31.7%)		11 (12.0%)		37 (21.3%)
Factor 6: Care Coordina	ation							
Number of designated care		0 or 3+	85	9 (10.6%)	90	24 (26.7%)	175	33 (18.9%)
coordinators		1 or 2		76 (89.4%)		66 (73.3%)		142 (81.1%)
Number of designated psychiatrists		0 or 3+	85	18 (21.2%)	95	20 (21.1%)	180	38 (21.1%)
		1 or 2		67 (78.8%)		75 (78.9%)		142 (78.9%)
CAN- Total level of needs met by informal carers (0-22)			84	3.6 (4.18)	94	3.2 (3.96)	178	3.4 (4.06) 0-21
Factor 7: Supported Liv	ring							
Supported accommodatio	n	Yes	72	4 (5.6%)	77	15 (19.5%)	149	19 (12.8%)
		No		68 (94.4%)		62 (80.5%)		130 (87.2%)
Attendance at day centres or		Yes	72	18 (25.0%)	77	12 (15.6%)	149	30 (20.1%)
hospitals		No		54 (75.0%)		65 (84.4%)		119 (79.9%)
Proportion of letters sent	by CMHT	None	79	38 (48.1%)	80	50 (62.5%)	159	88 (55.3%)
sent or copied to user		<= 50%		10 (12.7%)		15 (18.8%)		25 (15.7%)
		> 50%		31 (39.2%)		15 (18.8%)		46 (28.9%)

References

- Adair CE, McDougall GM, Beckie A, Joyce A, Mitton C, Wild CT, Gordon A, Costigan N (2003). History and measurement of continuity of care in mental health services and evidence of its role in outcomes. *Psychiatric Services* **54**, 1351-1356.
- Adair CE, McDougall GM, Mitton CR, Joyce AS, Wild TC, Gordon A, Costigan N, Kowalsky L, Pasmeny G, Beckie A (2005). Continuity of care and health outcomes among persons with severe mental illness. *Psychiatric Services*, **56**, 1061-1069.
- **Bachrach** L (1981). Continuity of care for chronic mental users: a conceptual analysis. *American Journal of Psychiatry*, **138**, 1449-1455.
- Bindman J, Johnson S, Wright S, Szmukler G, Bebbington P, Kuipers E, Thornicroft G (1997). Integration between primary and secondary services in the care of the severely mentally ill: patients' and general practitioners' views. *British Journal of Psychiatry* 171, 169-174.
- **Cook RI, Render M, Woods DD** (2000). Gaps in the continuity of care and progress on patient safety. *British Medical Journal*, **320**, 791-794.
- **Crawford M, Jonge E, Freeman G, Weaver T** (2004). Providing continuity of care for people with severe mental illness. *Social Psychiatry and Psychiatric Epidemiology*, **39**, 265-272.
- **Department of Health** (1995). Building Bridges: A guide to arrangements for inter-agency working for the care and protection of severely mentally ill people. Department of Health: London.
- **Department of Health** (1990). The Care Programme Approach for people with a mental illness referred to the Special Psychiatric Services Joint Health/Social Services Circular HC (90) 23/LASS (90) 11. Department of Health: London.
- **Department of Health** (2001). *Mental Health Policy Implementation Guide*. Department of Health: London.
- Freeman G, Shepperd S, Robinson I, Ehrich K, Richards S (2000). Continuity of Care: Report of a Scoping Exercise for the SDO Programme of NHS R&D. National Coordinating Centre for Service Delivery and Organisation: London.
- Freeman G, Weaver T, Low J, de Jonge E, Crawford M (2002). Promoting Continuity of Care for People with Severe Mental Illness whose needs span primary, secondary and social care. National Coordinating Centre for Service Delivery and Organisation: London.

- Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R (2003).

 Continuity of care: a multidisciplinary review. *British Medical Journal*, **327**, 1219-1221
- **Heslop L, Elsom S, Parker N.** (2000). Improving continuity of care across psychiatric and emergency services: combining patient data within a participatory action research framework. *Journal of Advanced Nursing*, **31**, 135-143.
- **Johnson S, Prosser D, Bindman J, Szmukler G** (1997). Continuity of care for the severely mentally ill: concepts and measures. *Social Psychiatry and Psychiatric Epidemiology*, **32**, 137-142.
- Joyce A, Wild T, Adair C, McDougall G, Gordon A, Costigan N, Beckie A, Kowalsky L, Pasmeny G, Barnes F (2004) Continuity of care in mental health services: toward clarifying the construct. *Canadian Journal of Psychiatry*, **49**, 539-550.
- Kaiser HF (1974). Index of Factorial Simplicity. Psychometrika, 39, 31-36.
- **Kopelowicz A, Wallace C, Zarate R**. (1998). Teaching psychiatric inpatients to re-enter the community: a brief method of improving the continuity of care. *Psychiatric Services*, **49**, 1313-1316.
- **McGuffin P, Farmer A, Harvey I** (1991). A polydiagnostic application of operational criteria in studies of psychotic illness. Development and reliability of the OPCRIT system. *Archives of General Psychiatry*, **48**, 764-770.
- McGuire-Snieckus R, McCabe R, Catty J, Priebe S (2006). A new scale to assess the therapeutic relationship in community mental health care: STAR. *Psychological Medicine*, **37**, 85-95.
- **Mitton CR, Adair CE, McDougall GM, Marcouz G** (2005). Continuity of care and health care costs among persons with severe mental illness. *Psychiatric Services*, **56**, 1070-1076.
- **Mueser KT, Bond GR, Drake RE, Resnick SG** (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bulletin*, **24**, 37-74.
- **Nutting PA, Goodwin MA, Flocke SA, Zyzanski SJ, Stange KC** (2003). Continuity of primary care: to whom does it matter and when? *Annals of Family Medicine*, **1**, 149-155.
- Phelan M, Slade M, Thornicroft G, Dunn G, Holloway F, Wykes T, Strathdee G, Loftus L, McCrone P, Hayward P (1995). The Camberwell Assessment of Need: the validity and reliability of an instrument to assess the needs of people with severe mental illness. *British Journal of Psychiatry*, **167**, 589-595.

- **Reid R, Haggerty J, McKendry R** (2002). *Defusing the Confusion: Concepts and Measures of Continuity of Healthcare. Final Report.* Canadian Health Services Research Foundation (CHSRF): Ottawa, Canada.
- Rose D, Wykes T, Sweeney A, Leese M, Clement S, Jones IR, Catty J, Burns T (submitted).

 Developing a user-generated measure of continuity of care. *Acta Psychiatrica Scandinavica*.
- **Sytema S, Burgess P** (1999). Continuity of care and readmission in two service systems: a comparative Victorian and Groningen case-register study. *Acta Psychiatrica Scandinavica*, **100**, 212-219.
- **Sytema S, Micciolo R, Tansella M** (1997). Continuity of care for patients with schizophrenia and related disorders: a comparative South-Verona and Groningen case-register study. *Psychological Medicine*, **27**, 1355-1362.
- **Tessler RC** (1987). Continuity of care and client outcome. *Psychosocial Rehabilitation Journal*, **11**, 39-53.
- Ware NC, Dickey B, Tugenberg T, McHorney CA (2003) CONNECT: a measure of continuity of care in mental health services. *Mental Health Services Research*, **5**, 209-221.