Development of a European Measure Of Best practice in Institutional Care for people with long term mental health problems

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- Specific Targeted Research Project
- Funded by European Commission's FP6
- Started 1st March 2007 – 36 months
- **Topic:** human rights and mental well being of people living in psychiatric and social care institutions in Member States.
- **Strategic objectives:** to improve the understanding of health determinants

Research objective

To develop a methodology for the assessment and review of the living situations, care and treatment practices in psychiatric and social care institutions for mentally ill and disabled persons in the European Union, with a particular focus on human rights, the protection of the dignity of residents, the use of restraint and the scope for health promoting measures.

DEMoBinc aims

- To build a “toolkit” to assess quality of institutional care for people with longer term mental health problems in countries at different stages of deinstitutionalisation
- Use “recovery model” as framework for assessment of dignity and human rights
- Include hospital and community based “institutions”

Consortium

1. Dr Helen Killaspy (co-ordinator), Professor Michael King, Tatiana Taylor, University College London and Dr Paul McCrone (IoP, health economist) - **UK**
2. Dr Christine Wright, Sarah White (statistician), Penny Turton, Saint George's University London - **UK**
3. Professor Dr Thomas Kallert, Dr Matthias Schuetzwohl, Mirjam Schuster, Technische Universitaet Dresden - **Germany**
4. Professor Jorge Cervilla, Dr Blanca Gutiérrez, Paulette Brangier, Danilo Manilos, Universidad de Granada - **Spain**
5. Professor Jiri Raboch, Dr Lucie Kalisova, Dr Martin Cerny, Alexander Nawka, Charles University Prague – **Czech Republic**
6. Dr Georgi Onchev, Dr Hristo Dimitrov, Alexiev Spiridon, Medical University Sofia - **Bulgaria**
7. Ass. Professor Giuseppe Dell'Acqua, Dr Roberto Mezzina, Dr Pina Ridente, Dr Kinou Wolf, Department of Mental Health, Trieste - **Italy**
8. Professor Durk Wiersma, Annemarie Caro, Ellen Visser, University Medical Centre, Groningen - **Netherlands**
9. Professor Andrzej Kiejna, Dr Joanna Rymaszewska, Patryk Piotrowski, Wroclaw Medical University - **Poland**
10. Professor Dimitris Ploumpidis, Dr Theodore Megaloeconomou, Frangiskos Gonidakis, George Konstantanopoulos, University Mental Health Research Institute, Athens - **Greece**
11. Professor Jose Miguel Caldas de Almeida, Ass Professor Graca Cardoso, Carla Coelho, University Nova Lisbon - **Portugal**

UCL

Recovery based practice

- Collaborative
- Empowering
- Getting away from paternalism
- Sharing of knowledge: patients as experts
- Trying things out
- Therapeutic risk taking
- Service user involvement
- Hope

Markers of Recovery

- Symptom resolution
- Working, studying and participating in leisure activities in mainstream settings
- Having good family relationships
- Having control of self-care, medication and finances
- Having a rewarding social life
- Taking part in the local community (e.g. voting)
- Being satisfied with life

(Liberman and Kopelowicz, 2002)

Phase 1. Identification of “critical success factors” for recovery in institutional care (Month 1-14)

1. Review care standards in each country
2. Systematic literature review (Centre 01)
3. Delphi exercise in each country (Centre 02)
4. Identify “domains” of care for inclusion in toolkit

   agreed by research partners and panel of international experts
5. Identify and translate measures to assess each domain = DEMoBinc toolkit

International expert panel

- Recovery - Jerry Tew (Birmingham)
- Social care - Tony Ryan, Michael Clark (CSIP)
- Rehabilitation – Prof. Tom Craig, Dr Frank Holloway, Dr Jaap van Weeghel (Trimbos Institute, Utrecht), Dr Joanna Meder (Warsaw), Prof Geoff Shepherd (UK)
- Service Users (Rethink) - Maurice Arbuthnott, Vanessa Pinfold
- Human rights law - Ass. Prof. Luis Fernando Barrios-Flores (Granada)
- International mental health law – Prof. Peter Bartlett (Nottingham)
- International mental health policy – Prof. Jose Miguel Caldas de Almeida (Lisbon)
- Disability Rights Commission – Liz Sayce (London)
- Healthcare Commission – Dr Geraldine Strathdee (London)

- Peer reviewed, international literature
- Published 1980-2007
- 11 electronic databases
- Quantitative
- Qualitative

Titles screened (n=12,182)

→ Studies excluded due to irrelevant population (e.g. cardiac patients) irrelevant setting, duplicates, editorials, books, book chapters (n=11,633)

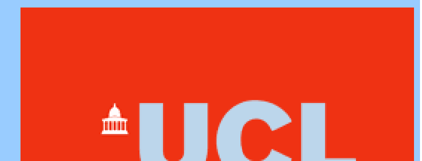
Abstracts retrieved (n=550)

→ Studies excluded due to non-generalisable intervention, irrelevant outcome, population or setting (n=327)

Papers read (n=223)

→ Studies excluded from the review due to insufficient data, single study included in a review, irrelevant outcomes, irrelevant patient group or setting (n=113)

Papers included (n=110)



Delphi exercise

- 4 stakeholder groups in each country (service users, practitioners, carers, advocates)
- 10-15 participants per group
- Delphi question:

  "In your view what most helps recovery for people with long term mental health problems in institutional care?"
- 3 rounds:

i) generate 10 items of care;

ii) rate on scale of 1-5 for importance;

iii) re-rate in light of group response

Domains identified from care standards review

- Living environment (community, small, homely, clean, privacy, laundry, diet, meals, cooking facilities)
- Mental and physical health supported, with medication appropriately administered, individualised care planning and review, and range of activities
- Therapeutic relationship (dignity, respect)
- Service users' autonomy and rights
- Service user involvement (unit and community)
- Staff training and support
- Clinical governance (safety, records, confidentiality, complaints, audit)

Domains identified from literature review

- Interventions for the treatment of schizophrenia
- Living conditions
- Physical health
- Restraint and seclusion
- Staff training and support
- Therapeutic relationships
- Autonomy and service user involvement
- Clinical governance

Domains identified from Delphi exercise

- Therapeutic interventions*
- Staff attitudes*
- Social policy and human rights*
- Social inclusion
- Self management and autonomy
- Governance
- Staffing
- Institutional environment
- Carers
- Physical health care

*=100% within group consensus of rating of 5 ("essential")

Domains agreed by PSC

Domains

- Living environment
- Therapeutic environment
- Treatments & interventions
- Self-management & autonomy
- Social policy, citizenship & advocacy
- Clinical governance

Cross-cutting themes

- Social inclusion
- Human rights
- Recovery-based practice

CROSS COUNTRY CARE STANDARDS

National/state care standards from all participating countries

International Expert Panel & PI Comments

Criteria for including comments
1. Evidenced in literature
2. Consensus in Delphi
3. Face validity
4. Included in care standards

EU CALL

"To develop a methodology for the assessment & review of the LIVING SITUATIONS, CARE and TREATMENT practices in psychiatric & social care institutions for mentally ill & disabled persons in the European Union, with a particular focus on HUMAN RIGHTS, the PROCTECTION OF DIGNITY of residents, the use of RESTRAINT & SECLUSION and scope for HEALTH PROMOTING MEASURES"

DELPHI

Question: In your view, what most helps recovery for people with long-term mental health problems in institutional care?

Participants: mental health & social care professionals, service users, carers and advocates

Items with scores 4 or higher across all countries helped in identification of domains

DOMAINS
1. Living environment
2. Therapeutic environment
3. Treatments & interventions
4. Self-management & autonomy
5. Social policy, citizenship & advocacy
6. Clinical governance

CROSS-CUTTING THEMES
1. Social inclusion
2. Human rights
3. Recovery-based practice

PROTOTYPE TOOLKIT

Developed by UK group

DRAFT TOOLKIT

DEMoBinc TOOLKIT

SYSTEMATIC LITERATURE REVIEW

Aims
1. Identify components of care
2. Examine the efficacy of these components

Included studies assessed for quality

PSC Meeting

Decisions regarding toolkit
1. Create our own toolkit ; not use existing measures as not relevant to domains, difficult format and not fit for purpose
2. Maximum time to administer - 45-60 mins.

Translation

Translated & back-translated by each country

Piloting

Each country pilots toolkit with managers from 2 units

PSC Meeting

Toolkit amended post piloting

Draft toolkit

154 questions

- Some descriptive items
- Staffing, staff training, supervision
- Built environment
- Interventions, activities in and out of unit
- Care planning
- Service user involvement
- Choice/autonomy, promotion of independence
- Health promotion
- Dealing with challenging behaviour
- Social inclusion
- Complaints, access to advocacy

Living environment

	Very poor condition	Quite poor condition	Acceptable condition	Quite good condition	Very good condition
What do you think of the general condition of the building outside? **(please tick one box)**	☐	☐	☐	☐	☐
What do you think of the general décor indoors? **(please tick one box)**	☐	☐	☐	☐	☐

Do patients/residents have access to any of the following outside space **which is part of the unit?**

No outside space that is part of the unit	☐		
	No	Yes	
garden	☐	☐	
patio	☐	☐	
balcony	☐	☐	
Delivery/refuse collection area	☐	☐	

Living environment, autonomy, social inclusion, human rights

Is there a private room for patients/residents to meet with their visitors:			
	No	Yes	
There is a room patients/residents can use to meet visitors	☐	☐	
There is a specific visitors' room	☐	☐	

Are your patients/residents allowed to have visitors in their room: **(please tick <u>one</u> answer that applies)**		
Only during visiting hours	☐	
Anytime during the day or evening	☐	
Anytime night or day	☐	
Never	☐	

Therapeutic environment, recovery based practice

How hopeful are you that **the majority** of your current patients/residents will show improvement in their general functioning over the next **2** years? **(please tick one box)**	No hope	Very little hope	Neither hopeful nor hopeless	Hopeful	Very hopeful
	☐	☐	☐	☐	☐
Approximately how many of your patients/residents will move on to more independent accommodation in the next **2** years? **(please tick one box)**	Almost no one	Around one quarter	Around half	Around three quarters	Almost everyone
	☐	☐	☐	☐	☐
Please estimate the number of your patients/residents who have moved on from your unit to more independent accommodation in the last **2** years?					

Phase 2 – reliability (Month 15-20)

Inter-rater reliability testing: 20 institutions in each country (200 in all)

Definition of an institution

- specialisation in mental health care
- community residential or inpatient
- communal/group facilities
- >/= 6 service users
- on-site clinical staff, ideally 24 hours/day
- longer-term care (at least one year)

Excluded institutions

- Specific sub-groups (e.g. forensic, LD, MHCOP, substance misuse problems)

Selection of institutions

Range of size, geographic location (urban, rural), funding (private, public), demographics of service users (age, gender)

Phase 3. Refinement of toolkit (Month 21-22)

- Results of the reliability analysis
- Usability - feedback from managers of institutions (interviewees) and researchers
- Usefulness - ability to provide useful information to feed into local and regional/national systems for changes and improvements in care
- Consensus agreement of final toolkit contents between research partners and IEP

Feedback

Interviewees:

- 94% thought toolkit questions relevant or very relevant to their unit
- 88% thought toolkit would be useful or very useful in internal audit

Researchers:

- 93% took less than 2 hours
- 18% difficult to access info to complete

Phase 4. Association with service user experiences of care (Month 23-30)

- To test whether toolkit (manager interviews) can provide a “proxy” measure of SU experiences
- Reassess each institution using refined toolkit
- Interview 10 SUs per institution (N = 2000)
  - Specific questions about any abuses of care
  - QoL (MANSA, Priebe et al., 1999)
  - Autonomy (Resident Choice Scale, Hatton et al., 2004)
  - Markers of Recovery (Liberman and Kopelowicz, 2002)
  - Experience of care (Your Treatment and Care, Webb et al, 2000)

Analysis of Phase 4

- Multivariable multilevel regression of pooled toolkit domain scores/ranks and service user standardised measure data
- 170 units gives sufficient power to test for 20 predictors (toolkit domains and other descriptors) of service user measures

Phase 5: Health economic component (Months 30-32)

- Individual service user service use data and unit costs are being collected in Phase 4
- Health economic analysis will provide assessment of institution's "value for money" by comparing costs and toolkit domain ratings using multilevel modelling

Phase 6. Dissemination and further development (Month 33-36)

- Project website (http://www.ucl.ac.uk/mental-health-sciences/Current%20research/DEMoBinc.htm)
- Publication of results
- Workshops w. key stakeholders
- Presentations/discussions with WHO, DHs in each country and care standard agencies re. use of toolkit and incorporation into existing systems of review of institutional care
- Web based version – adjust "weighting" of domains according to intra-country care standards/expectations