

# Implementing the NICE Guideline Recommendations on Rehabilitation for Adults With Complex Psychosis in the Australian Context

Helen Killaspy

Professor and Honorary Consultant in Rehabilitation Psychiatry

University College London and

Camden & Islington NHS Foundation Trust, London

[h.killaspy@ucl.ac.uk](mailto:h.killaspy@ucl.ac.uk)

# Rehabilitation for Adults With Complex Psychosis; NICE Guideline 181 [www.nice.org.uk/guidance/ng181](http://www.nice.org.uk/guidance/ng181)

## Aims

- To ensure people have access to mental health rehabilitation when they need it
- To promote a positive approach to long term recovery

## Covers

- Organisation of rehabilitation services
- Assessment, delivery of interventions, culture of services, care planning
- Physical health

## Who is it for?

- Health and social care professionals
- Commissioners of services
- Service users and their families/carers

# Development of the NICE guideline on mental health rehabilitation

- Lobbying: 2016-17
- Respond to NICE call for commissioning new guidelines: 2017
- NICE appoint Guideline Committee Chair and Topic Guide through open advertisement: Jan 2018
- Scope drafted: Feb-March 2018
- Public stakeholder consultation on scope: April 2018
- Scope agreed: May 2018
- Guideline Committee appointed through open advertisement: May-June 2018
- 10-12 committee meetings (1-2 days) to agree specification of each evidence review, review evidence, draft recommendations: July 2018-October 2019
- Draft guideline submitted to NICE: December 2019
- Public stakeholder consultation on draft guideline: January to February 2020
- Guideline published: 19<sup>th</sup> August 2020

## Why NICE Guidelines matter

- The NICE Charter – independent and authoritative guidance and quality standards, based on the best available evidence, set out the best ways to prevent, diagnose and treat disease and ill health, promote healthy living, and care for vulnerable people
- Legal status of NICE guidelines is reinforced in the NHS Constitution - patients have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if the doctor responsible for the patient's care says they are clinically appropriate
- Commissioners are accountable for commissioning services that can deliver the treatments and interventions recommended by NICE
- Service providers are responsible for delivering them

# Rehabilitation for Adults With Complex Psychosis; NG 181

## In scope

- Primary diagnosis of psychosis (schizophrenia, schizoaffective disorder, bipolar affective disorder, psychotic depression, delusional disorder) **plus**
- Severe, treatment refractory symptoms (positive or negative) **plus 1 or more of**
  - Cognitive impairment associated with psychosis
  - Co-existing mental health conditions (including substance misuse)
  - Pre-existing neurodevelopmental disorder (e.g. ASD, ADHD)
  - Physical health conditions (e.g. diabetes, cardiovascular disease, pulmonary disease) **and**
- Impaired social and everyday function (ADLs, interpersonal and occupational)

## Out of scope

- Primary diagnosis of common mental disorder (depression without psychosis, anxiety), personality disorder, obsessive compulsive disorder, eating disorder, substance misuse problem, or moderate to severe intellectual disability

# Content of the Guideline

- 1.1 Who should be offered mental health rehabilitation?**
- 1.2 Overarching principles of mental health rehabilitation**
- 1.3 Organisation of rehabilitation services**
- 1.4 Improving access to rehabilitation services**
- 1.5 Delivering services within the rehabilitation pathway**
- 1.6 Recovery-orientated rehabilitation services**
- 1.7 Person-centred care planning through assessment and formulation**
- 1.8 Rehabilitation programmes and interventions**
  - activities of daily living (self-care, cooking, cleaning, shopping, budgeting, maintaining a tenancy)
  - interpersonal functioning and social skills
  - vocational rehabilitation (leisure, education and work)
  - healthy living (diet, weight, exercise, sleep, oral health, health monitoring, accessing health services, self-medication programmes, cessation programmes for smoking and substance misuse)
- 1.9 Adjustments to mental health treatments in rehabilitation**
- 1.10 Physical healthcare**

## 1.1 Who should be offered rehabilitation?

Offer rehabilitation to people with complex psychosis:

- as soon as it is identified that they have treatment resistant symptoms of psychosis and impairments affecting their social and everyday functioning
- wherever they are living, including in inpatient or community settings

In particular, this should include people who:

- have experienced recurrent admissions or extended stays in acute inpatient or other psychiatric units, either locally or out of area
- live in 24-hour staffed accommodation whose placement is breaking down

## 1.2 Overarching principles of mental health rehabilitation

Rehabilitation services for people with complex psychosis should:

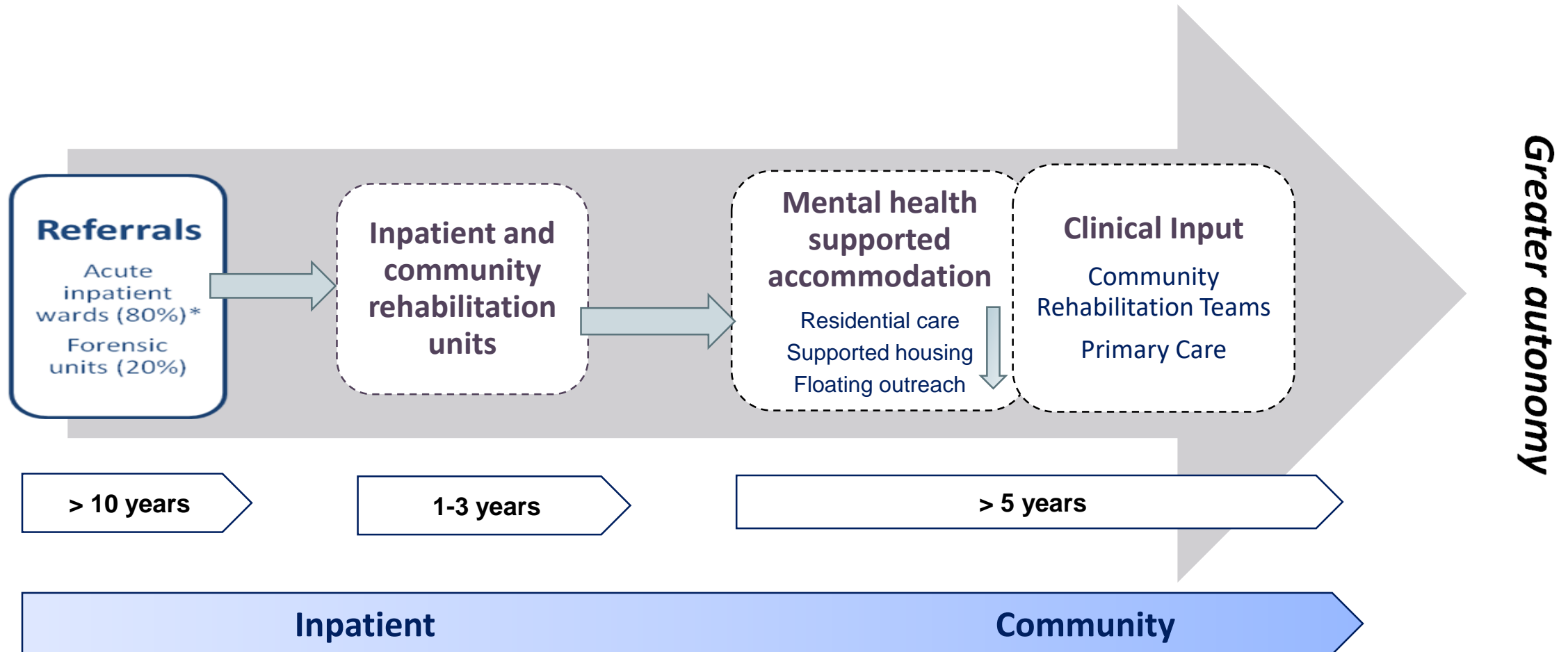
- be embedded in a **local** comprehensive mental healthcare service
- provide a **recovery-orientated** approach that has a shared ethos and agreed goals, a sense of hope and optimism, and aims to reduce stigma
- deliver individualised, **person-centred** care through **collaboration** and shared decision making with service users and their carers
- be offered in the least restrictive environment and aim to help people **progress** from more intensive support **to greater independence** through the rehabilitation pathway
- recognise that not everyone returns to the same level of independence they had before their illness and **may require supported accommodation** (such as residential care, supported housing or floating outreach) in the **long term**.



## 1.3 Organising the rehabilitation pathway

- All local mental healthcare systems should include a defined rehabilitation pathway
- Use the local joint strategic needs assessment to inform the commissioning of specific service components that make up the rehabilitation pathway, to match the needs of the local population.
- Conduct a local rehabilitation service needs assessment to identify the number of people with complex psychosis who:
  - are currently receiving inpatient rehabilitation ‘out of area’
  - have recurrent admissions or extended stays (e.g. > 60 days) in acute inpatient units and psychiatric intensive care units, either locally or out of area
  - are currently receiving care from forensic services or early intervention for psychosis services and already have or are developing problems that are likely to need mental health rehabilitation
  - are young adults moving from children and young people’s mental health services to adult mental health services
  - live in highly supported (24-hour staffed) accommodation
  - are physically frail and may need specialist supported accommodation

# The mental health rehabilitation care pathway components



## The mental health rehabilitation care pathway

- The exact complement of **components** required will vary between areas as the pathway **should be tailored according to the local** rehabilitation service **needs** assessment
- Services should be provided **as locally as possible** but more specialist components (e.g. highly specialist inpatient rehabilitation) **may need** to be provided at a **regional** level for people with particularly complex needs
- The rehabilitation pathway should be designed to provide **flexibility, smooth transitions and support over the longer term**, that enables people to:
  - join and leave the rehabilitation pathway at different points
  - move between parts of the pathway that provide higher or lower levels of support according to their changing needs
  - spend different periods of time at different stages of the pathway according to need
  - have access to more than one period of rehabilitation and be swiftly referred back to the pathway if their needs increase and they would benefit from further rehabilitation.

## 1.4 Improving access to mental health rehabilitation

- Commissioners and service providers should provide information about the local rehabilitation pathway and how it is accessed to health and social care practitioners, people who may benefit from rehabilitation and their families and carers.
- The lead commissioner should work together with service providers to ensure that everyone with complex psychosis has access to rehabilitation services regardless of age, gender, ethnicity and other protected characteristics and monitor and report on access at least every 6 months
- If any differences are found in rates of access for specific groups of people (for example, women or ethnic groups) compared with anticipated rates, these should be addressed, for example through:
  - providing bespoke services for specific groups, such as women-only services
  - providing outreach into other services that work with under-served groups, or home visiting
  - providing tailored information and advocacy

## 1.5 Delivering services within the rehabilitation pathway

- Inpatient and community rehabilitation services should be staffed by multidisciplinary teams with relevant skills and competence in mental health rehabilitation:
  - rehabilitation psychiatrists
  - clinical psychologists
  - nurses
  - occupational therapists
  - social workers
  - approved mental health professionals
  - support workers (including peer support workers)
  - specialist mental health pharmacists
- The multidisciplinary team should have access to physical exercise coaches, vocational trainers, welfare rights specialists, dietitians or nutritionists, podiatrists, speech and language therapists and physiotherapists

## Inpatient rehabilitation

- There are different **types of inpatient rehabilitation** unit (see RCPsych typology – high dependency, community, highly specialist) [https://www.rcpsych.ac.uk/docs/default-source/members/faculties/rehabilitation-and-social-psychiatry/mental-health-inpatient-rehabilitation-services-typology-table-20-3-19.pdf?sfvrsn=8fc19480\\_4](https://www.rcpsych.ac.uk/docs/default-source/members/faculties/rehabilitation-and-social-psychiatry/mental-health-inpatient-rehabilitation-services-typology-table-20-3-19.pdf?sfvrsn=8fc19480_4)
- Inpatient rehabilitation services should have an **expected maximum length of stay** (which should be used as a guide rather than an absolute) to reduce the chance of people becoming ‘institutionalised’
- Consider using a standardised tool to assess, monitor and drive up quality

	High Dependency Rehabilitation Unit	Community Rehabilitation Unit	Longer Term High Dependency Rehabilitation Unit	Highly Specialist Inpatient Rehabilitation Unit
Client group	Severe symptoms, (multiple) co-morbidities, significant risk histories, ongoing challenging behaviours. Most patients detained under MHA. Most referrals (80%) come from acute inpatient units, and 20% from forensic units.	Ongoing complex needs so cannot be discharged directly from high dependency rehab unit to supported accommodation. Most referrals from high dependency rehab unit or acute inpatient unit. Can take detained patients if registered as a ward (may have CTO/S41 patients if not registered as ward).	High levels of disability from treatment refractory symptoms and/or complex co-morbid conditions that require longer period of inpatient rehabilitation to stabilise. Significant associated risks to own health/safety and/or others. Most patients detained under MHA. Most referrals from high dependency rehab unit.	Specific co-morbidities that require very specialist approach e.g. psychosis plus traumatic brain injury, degenerative neurological disorder or autism. Challenging behaviour is often a significant issue.
Focus	Thorough assessment, engagement, maximising benefits from medication, reducing challenging behaviours, psychosocial interventions, re-engaging with families and communities. Step down for forensic services and repatriation of people from out-of-area placements.	Facilitating further recovery, managing medication (self-medication), psychosocial interventions (CBT, family work), gaining skills for more independent living including ADL skills and community activities (leisure, vocational).	To stabilise symptoms adequately such that function improves and move on to a less supported component of the rehabilitation pathway becomes feasible. Interventions as for high dependency and community rehab units in a highly supported setting.	To stabilise symptoms and challenging behaviours adequately. Managing challenging behaviours and physical aspects of co-morbidities is key.
Recovery goal	Move on to community rehabilitation unit or supported accommodation.	Move on to supported accommodation	Move on to community rehabilitation unit or supported accommodation.	Move on to a specialist, long term supported accommodation facility.
Location	Usually hospital based	Community based	Usually hospital based	Hospital based
Length of stay	Up to 1 year	1-2 years	3+ years	2+ years
Functioning	Domestic services provided, but ADL skills encouraged through OT	Self-catering, cleaning, laundry, budgeting etc with staff support	Domestic services provided, but ADL skills encouraged through OT	Domestic services provided. Physiotherapy, speech and language therapy and OT provided to improve all aspects of functioning
Risk management	Controlled access ('locked'). Higher staffed, full MDT	"Open" units. Staffed 24 hours by nurses and support workers with regular input from MDT.	Controlled access. Higher staffed, full MDT. May have air lock and higher staffing than standard HDRU if target client group require this.	Usually controlled access. Higher staffed, full MDT plus physiotherapy and SALT. Unlikely to need airlock.

## Community rehabilitation teams

For people with complex psychosis living in supported accommodation, specialist clinical care should be provided by a multidisciplinary community rehabilitation team that should:

- hold overall clinical responsibility for their mental health while they are living in the community
- provide a designated care co-ordinator for each person but operate with a shared team caseload approach
- make the majority of contacts with the person in their home rather than at the team base
- work closely with staff at the person's supported accommodation to tailor people's care plans to their needs and clarify which staff are responsible for providing specific treatments and support
- support and oversee the person's progression through the rehabilitation pathway by:
  - increasing the intensity of treatment and support during periods of relapse
  - providing ongoing contact and support during periods of inpatient care and enabling discharge as soon as possible
  - adjusting care plans to enable the person to gain the skills and confidence to manage in more independent accommodation
- liaise with the person's GP about their physical healthcare
- liaise with the relevant service when the person is ready to be discharged from the team to ensure a smooth transition



## 1.6 Recovery orientated rehabilitation services

- Staff in rehabilitation services should aim to foster people's autonomy, help them take an active part in treatment decisions and support self-management.
- Staff should build on people's strengths and encourage hope and optimism by:
  - helping people choose and work towards personal goals, based on their skills, aspirations and motivations
  - developing and maintaining continuity of individual therapeutic relationships wherever possible
  - helping them find meaningful occupations (including work, leisure or education) and build support networks using voluntary, health, social care and mainstream resources
  - helping people to gain skills to manage both their everyday activities and their mental health, including moving towards self-management of medication
  - providing opportunities for sharing experiences with peers
  - encouraging positive risk-taking
  - developing people's self-esteem and confidence through validating people's achievements and celebrating progress
  - recognising that people vary in their experiences and progress at different rates
  - improving people's understanding of their experiences and the treatment and support that may help them – for example, through accessible written information, face-to-face discussions and group work

# Universal staff competencies

- Ensure that staff training emphasises **recovery principles** so that all rehabilitation staff work with a recovery-orientated approach.
- Staff should **establish and maintain non-judgemental, collaborative relationships** with people with complex psychosis
- Provide support for staff to acknowledge and **manage any feelings of pessimism** about people's potential for recovery. Support could include helping staff to share experiences and frustrations with each other, for example through **supervision, reflective practice** and **peer support groups**
- Ensure staff attend appropriate **diversity training** and have the skills and competence to deliver non-discriminatory practice and understand that people may experience stigma resulting from their mental health condition, alongside stigma related to being in a minority group
- Ensure that **all** staff are trained and skilled in supporting **structured group activities and promoting daily living skills**.
- Ensure that staff have skills and competence in **risk assessment and management** to an appropriate level for the service they work in
- Ensure that staff are competent to recognise and care for people with psychosis and **coexisting substance misuse**.

# Maintaining and supporting social networks

- Discuss with the person whether, and how, they want their **family or carers** to be **involved in their care**. Discuss this at regular intervals to take account of any changes in circumstances.
- Ensure that staff receive training in the **skills needed to negotiate and work with families and carers**, and in managing issues related to information sharing and confidentiality.
- **Respect the rights and needs of carers** alongside the person's right to confidentiality. Review the person's consent to share information with families and carers and other services regularly
- Give families and carers **information about support services** in their area that can address their emotional, practical and other needs
- Enable the person to **maintain links** with their home community by:
  - supporting them to maintain relationships with family and friends, e.g. by finding ways to help with transport
  - helping them to stay in touch with social and recreational contacts
  - helping them to keep links with employment, education and their local community activities. This is particularly important if people are in an out-of-area placement.

## 1.7 Person centred care planning

- Offer people a **comprehensive biopsychosocial needs assessment** by a multidisciplinary team within 4 weeks of entering the rehabilitation service.
  - **developmental history**: milestones; relationships with family and peers; problems at school (problems with social or cognitive functioning, motor development and skills or coexisting neurodevelopmental conditions); occupational and educational history
  - **psychological history**: relationships, abuse and trauma, coping strategies, strengths, previous psychological or psychosocial interventions
  - **social history**: accommodation history; culture; ethnicity; and spirituality; leisure activities; finances; current social network including any caring responsibilities; use of substances
  - **psychiatric history**: past admissions and treatments; response to treatments; side effects; adherence
  - **medicines reconciliation** by a specialist mental health pharmacist
  - **vulnerabilities and risks**: self-neglect, exploitation and abuse, risk of harm to self and others
  - **current skills in activities of daily living**
  - **cognitive impairment and capacity**

Be aware that people with complex psychosis often have comorbid mental health problems

(e.g. anxiety, OCD, ASD, ADHD, BPD, acquired brain injury, cognitive impairment, substance misuse)

# Physical health assessment

- Offer a physical health check as part of the comprehensive assessment including:
  - BMI; waist circumference; pulse and blood pressure; bloods (FBC, U&E, LFTs, HbA1c, lipids, TFTs, prolactin levels, calcium); medication levels (clozapine, mood stabilisers); ECG
  - smoking, alcohol and illicit substance use
  - nutritional status, diet and level of physical activity
  - continence and constipation (particularly if the person is on clozapine)
  - movement disorders
  - sexual health
  - vision, hearing and podiatry
  - oral inspection of general dental health
  - any difficulties with swallowing
- Be aware that people with complex psychosis often have comorbid physical health problems (e.g. obesity, diabetes, cardiovascular disease, COPD, )

## Care planning

- Use the results of the comprehensive assessment to make a team formulation to inform treatment and care planning. The care plan should:
  - be developed **collaboratively** with the person
  - include the person's **personal recovery goals**
  - **clarify actions and responsibilities** for staff, the person themselves and their family or carers
  - **Review** people's progress and **care plans** with them at multidisciplinary care review meetings at least:
    - every month in the inpatient rehabilitation service
    - every 6 months in the community.
- Incorporate both **staff-rated and service user-rated measurements** of the person's progress into their care plan reviews, so that their support can be adjusted if needed.
- **Update care plans** according to changes in the person's needs after these meetings and between meetings as needed. At every meeting or review, **consider and plan** with the person their **transition to the next step in the rehabilitation pathway**.
- **Ensure that care plans are shared** with the person and everyone involved in the person's care (clinicians, supported accommodation staff, family and carers, if the person agrees) at each review, each transition point in the rehabilitation pathway and at discharge from the service.

## 1.8 Rehabilitation programmes and interventions

- Promote activities to improve **daily living skills** (self-care, housework, laundry, shopping, cooking) as highly as other interventions
- Provide activities to help people develop and maintain **daily living skills** – individually tailored, goal focused, real-life settings (kitchens, laundry facilities)
- Offer structured **group activities** (social, leisure or occupational) aimed at improving **interpersonal skills**. These could be peer-led or peer-supported and should be offered: **daily in inpatient rehabilitation services; at least weekly in community settings**.
- Offer regular opportunities (e.g. ‘community meeting’) to discuss the choice of group activities
- Offer regular **one-to-one sessions** with a named member of staff (primary nurse, keyworker, care co-ordinator) to help the person plan and review their activity programme
- Programmes to engage people in **community activities** should
  - be **flexible** and make reasonable adjustments to accommodate the person's illness and fluctuating needs
  - be **individualised**
  - **develop structure and purpose** in the person's day
  - aim to increase their sense of identity, belonging and **social inclusion** in the community
  - involve **peer support**
  - recognise people's skills and strengths

## Leisure, education and employment

- Offer people the chance to be involved in a range of activities that they enjoy, tailored to their level of ability and wellness
- Offer people a range of educational and skill development opportunities, for example, recovery colleges and mainstream adult education settings, which build confidence and lead to qualifications if the person wishes
- For people who would like to work towards mainstream employment, consider referring them to supported employment that uses the Individual Placement and Support approach
- Take into account and advise people about the impact of supported employment on their welfare benefits.
- For people who are not ready to return to paid employment, consider alternatives such as transitional employment schemes and volunteering
- Consider providing a cognitive remediation intervention alongside vocational rehabilitation services.
- Develop partnerships, for example with voluntary organisations and local employment advice schemes, to increase opportunities for support to prepare people for work or education



## 1.9 Adjustments to mental health treatments in rehabilitation

- First - follow relevant NICE guideline (schizophrenia, bipolar affective disorder etc)
- Consider additional psychological interventions, especially for people who are not ready to engage in CBT e.g. mindfulness, therapeutically informed environments. Consider training all rehabilitation staff in motivational interviewing, positive behaviour support, behavioural activation, trauma-informed care.
- For people with complex psychosis whose symptoms have not responded adequately to an optimised dose of clozapine alone, consider augmenting clozapine with the following, depending on target symptoms:
  - an antipsychotic, for example aripiprazole for schizophrenia and related psychoses and/or
  - a mood stabiliser for psychosis with significant affective symptoms and/or
  - an antidepressant if there are significant depressive symptoms in addition to the psychotic condition

Be aware of potential drug interactions and note that not all combinations of treatments may be in accordance with UK marketing authorisations. Any off-licence prescribing should be communicated in writing with the person's GP. Seek specialist advice if needed, for example from another psychiatrist specialising in treatment-resistant symptoms or a specialist mental health pharmacist. Do not offer valproate to women of childbearing potential, unless other options are unsuitable and the pregnancy prevention programme is in place. Follow the MHRA safety advice on valproate use by women and girls.

## Medication (abridged)

- Optimise the dosage (as tolerated) of medicines used to manage complex psychosis according to the BNF and therapeutic plasma levels in the first instance
- Only use multiple medicines, or doses above BNF or summary of product characteristics limits, to treat complex psychosis:
  - if this is agreed and documented by the multidisciplinary team and the person (and their family, carer or advocate, as appropriate)
  - as a limited therapeutic trial, returning to conventional dosages or monotherapy after 3 months, unless the clinical benefits of higher doses or combined therapy clearly outweigh the risks
  - if the medicines are being used to treat specific symptoms that are disabling or distressing
  - after taking into account drug interactions and side effects
  - if systems and processes are in place for monitoring the person's response to treatment and side effects (monitoring may include physical examination, ECG and appropriate haematological tests)

## Medication (abridged)

- Regularly review medicines used to manage complex psychosis and monitor effectiveness, adverse effects (including constipation for those taking clozapine) and drug interactions
- If pharmacological treatment is not effective, **consider stopping** the medicine:
  - following a thorough review of treatment
  - after agreeing and documenting the decision at a meeting with a multidisciplinary team and the person (and their family, carer or advocate, as appropriate)
  - with caution, particularly if the person has been on the medicine for many years
  - by reducing the dose slowly and closely monitoring the person for symptoms of relapse.
- Monitor drug levels to check adherence and guide dosing
  - At least annually and as needed for clozapine and mood stabilising anti-epileptic medicines (be aware that changes in smoking affect clozapine levels)
  - Every 3 to 6 months for people established on lithium
- Consider annual ECGs

## 1.10 Physical healthcare (abridged)

- GPs should develop and use **practice case registers** to monitor the physical and mental health of people with complex psychosis in primary care
- For people having **community rehabilitation**, GPs should assume **lead responsibility** for the person's physical health needs, including health checks and treatment of physical health conditions, working collaboratively with the community mental health rehabilitation team and other services as relevant
- For people **having inpatient rehabilitation**, the **rehabilitation team should ensure** that health checks, treatment of physical health conditions and other healthcare needs are addressed
- **Nominate a professional from the rehabilitation service to provide continuity of physical healthcare** across settings, liaising between the rehabilitation service, primary care, secondary mental health and secondary physical healthcare
- The **nominated professional should work in collaboration with a healthcare professional to develop and oversee the physical healthcare plan** – this should address any **physical health care** problems, plus **routine monitoring and health promotion/screening** and clarify which practitioners are responsible

## Breakout

- How will you identify people who need mental health rehabilitation services in your area?
- How can you ensure your services operate with a recovery based approach?

# Metrics and measures for mental health rehabilitation

## **NICE Guideline:**

- 1.5.4 Consider using tools to support quality improvement such as the Quality Indicator for Rehabilitative Care (QuIRC) for inpatient rehabilitation units, and the QuIRC-Supported Accommodation (QuIRC-SA) for supported accommodation.
- 1.7.10 Incorporate both staff-rated and service user-rated measurements of the person's progress into their care plan reviews, so that their support can be adjusted if needed.

## Quick poll

How often do you use outcome measures and metrics to inform your clinical practice?

## Defining 'quality'

The effectiveness and safety of treatment and care alongside a positive experience for those who use services (Department of Health. *High Quality Care For All: NHS Next Stage Review final report*. London: The Stationery Office, 2008)

- **Effectiveness** - survival rates, measures of clinical improvement, patient-reported outcome measures
- **Safety** - doing no harm e.g. complication rates
- **Positive experience** - compassion, dignity and respect e.g. satisfaction



# Principles when choosing outcome measures and metrics

## Data need to be:

- Available
- Collectable (brief measures, ideally free of copyright restrictions and fees)
- Meaningful (measures should have good psychometric properties – valid, reliable, and sensitive to change)
- Collatable (by data management systems that work!)
- Interpretable (by clinicians as well as performance departments)
- Useful at group and individual level
- Formattable so that results can be fed back in accessible form to staff and service users

# RCPsych recommended routine quality and outcome measures for mental health rehabilitation services

## **Service Quality**

- QuIRC for inpatient units and QuIRC-SA for supported accommodation services

## **Clinical Improvement**

### ***Clinician Rated Outcome Measures***

- General clinical improvement - Health of the National Outcome Scale (HoNOS)
- Needs - Camberwell Assessment of Needs Short Appraisal Scale (CANSAS)
- Social function - Life Skills Profile (LSP)

### ***Patient Reported Outcome Measure***

- Quality of life - DIALOG (based on seven domains of Manchester Short Assessment of QoL)

## **Patient experience**

- Patient Reported Experience Measure – Family and Friends Test

# Quality Indicator for Rehabilitative Care (QuIRC)

- Standardised quality assessment tool for use in longer term mental health services
- Completed by manager / senior staff member on-line – takes about 45 minutes
- Psychometric properties: excellent inter-rater reliability, good internal consistency, good convergent validity

**BMC Psychiatry**

Study protocol

**Open Access**

**Study protocol for the development of a European measure of best practice for people with long term mental health problems in institutional care (DEMOBINC)**

Helen Killaspy<sup>1</sup>, Michael King<sup>1</sup>, Christine Wright<sup>1</sup>, Sarah White<sup>2</sup>, Paul McCrone<sup>3</sup>, Thomas Kallert<sup>4</sup>, Jorge Cervilla<sup>5</sup>, Jiri Raboch<sup>6</sup>, Georgi Onchev<sup>7</sup>, Roberto Mezzina<sup>8</sup>, Durs Wiersma<sup>9</sup>, Andrzej Kiejna<sup>10</sup>, Dimitris Ploumpidis<sup>11</sup> and Jose Miguel<sup>12</sup>

**BMC Psychiatry**

Research article

**Open Access**

**A systematic review of the international published literature relating to quality of institutional care for people with longer term mental health problems**

Tatiana L Taylor<sup>1</sup>, Helen Killaspy<sup>1</sup>, Christine Wright<sup>1</sup>, Penny Turtur<sup>1</sup>, Sarah White<sup>2</sup>, Thomas W Kallert<sup>3</sup>, Mirjam Schuster<sup>4</sup>, Jorge A Cervilla<sup>5</sup>, Paulette Branger<sup>6</sup>, Jiri Raboch<sup>7</sup>, Lucie Kalisova<sup>8</sup>, Georgi Onchev<sup>9</sup>, Hristo Dimitrov<sup>10</sup>, Roberto Mezzina<sup>11</sup>, Kinou Wolf<sup>12</sup>, Durs Wiersma<sup>13</sup>, Ellen Visser<sup>14</sup>, Andrzej Kiejna<sup>15</sup>, Patryk Piotrowski<sup>16</sup>, Dinitza Ploumpidis<sup>17</sup>, Fragkos Gontidakis<sup>18</sup>, Jose Caldas-de-Almeida<sup>19</sup>, Graça Cardoso<sup>20</sup> and Michael B King<sup>1</sup>

**Promoting Recovery in Long-Term Institutional Mental Health Care: An International Delphi Study**

Penelope Turton, Ph.D., Christine Wright, Ph.D., Helen Killaspy, M.R.C.Psych., Ph.D., and the DEMOBINC Group

**Abstract:** Service provision in psychiatric and social care is increasingly guided by recovery principles. However, little is known about the range of consensus among stakeholders in diverse contexts on the components of care that most promote recovery. This study aimed to identify specific items of care that key stakeholders regard as most important in promoting recovery for people with long-term mental health problems in institutional care, to measure consensus between and across stakeholder groups and countries, and to develop a conceptual framework of the most important domains of care. Methods: Ten European countries in various stages of deinstitutionalisation participated in a series of conventional three-round iterative Delphi exercises. In each country, individuals in four separate expert groups (service users, mental health professionals, caregivers, and advocates) identified components of care that they considered important to recovery and their role of their group's vignettes in terms of importance. Median and consensus ratings were assessed. High-ranking items were grouped into domains. Results: A total of 4,095 separate items of care were proposed by the 40 participating groups. Eleven broad domains of care important for recovery were identified: social policy and human rights, social inclusion, self-management and autonomy, therapeutic interventions, governance, staffing, staff attitudes, institutional environment, post-discharge care, caregivers, and physical health care. Consensus between service users and providers, as well as among researchers and policy makers, that key attributes of a recovery-oriented mental health treatment approach that are consistent between service users and providers and

**BMC Psychiatry**

Research article

**Open Access**

**The development of the Quality Indicator for Rehabilitative Care (QuIRC): a measure of best practice for facilities for people with longer term mental health problems**

Helen Killaspy<sup>1</sup>, Sarah White<sup>2</sup>, Christine Wright<sup>1</sup>, Tatiana L Taylor<sup>1</sup>, Penny Turtur<sup>1</sup>, Matthias Schützwohl<sup>3</sup>, Mirjam Schuster<sup>4</sup>, Jorge A Cervilla<sup>5</sup>, Paulette Branger<sup>6</sup>, Jiri Raboch<sup>7</sup>, Lucie Kalisova<sup>8</sup>, Georgi Onchev<sup>9</sup>, Spiridon Alexiev<sup>10</sup>, Roberto Mezzina<sup>11</sup>, Pina Rindone<sup>12</sup>, Durs Wiersma<sup>13</sup>, Ellen Visser<sup>14</sup>, Andrzej Kiejna<sup>15</sup>, Tomasz Adamowski<sup>16</sup>, Dimitri Ploumpidis<sup>17</sup>, Fragkos Gontidakis<sup>18</sup>, Jose Caldas-de-Almeida<sup>19</sup>, Graça Cardoso<sup>20</sup>, Michael B King<sup>1</sup>

**BMC Psychiatry**

Research article

**Open Access**

**Quality of Longer Term Mental Health Facilities in Europe: Validation of the Quality Indicator for Rehabilitative Care against Service Users' Views**

Helen Killaspy<sup>1</sup>, Sarah White<sup>2</sup>, Christine Wright<sup>1</sup>, Tatiana L Taylor<sup>1</sup>, Penny Turtur<sup>1</sup>, Thomas Kallert<sup>3</sup>, Mirjam Schuster<sup>4</sup>, Jorge A Cervilla<sup>5</sup>, Paulette Branger<sup>6</sup>, Jiri Raboch<sup>7</sup>, Lucie Kalisova<sup>8</sup>, Georgi Onchev<sup>9</sup>, Spiridon Alexiev<sup>10</sup>, Roberto Mezzina<sup>11</sup>, Pina Rindone<sup>12</sup>, Durs Wiersma<sup>13</sup>, Ellen Visser<sup>14</sup>, Andrzej Kiejna<sup>15</sup>, Patryk Piotrowski<sup>16</sup>, Dimitris Ploumpidis<sup>17</sup>, Fragkos Gontidakis<sup>18</sup>, Jose Miguel Caldas-de-Almeida<sup>19</sup>, Graça Cardoso<sup>20</sup>, Michael King<sup>1</sup>

**BMC Psychiatry**

Research article

**Open Access**

**Adaptation of the Quality Indicator for Rehabilitative Care (QuIRC) for use in mental health supported accommodation services (QuIRC-SA)**

Helen Killaspy<sup>1</sup>, Sarah White<sup>2</sup>, Sarah Dowling<sup>3</sup>, James Kroll<sup>4</sup>, Peter McPheer<sup>5</sup>, Sina Sarich<sup>6</sup>, Maurice Abutouh<sup>7</sup>, Sarah Curtis<sup>8</sup>, Gerard Lawley<sup>9</sup>, Stefan Rebel<sup>10</sup>, Geoff Shephard<sup>11</sup> and Michael King<sup>1</sup>

**Abstract:** Background: No standardised tools for assessing the quality of specialist mental health supported accommodation services exist. To address this, we adapted the Quality Indicator for Rehabilitative Care (QuIRC) that was originally developed to assess the quality of longer term residential and community based mental health facilities. The QuIRC, which is completed by the service manager and gives ratings on nine domains of care, has good psychometric properties. Methods: Focus groups with staff of the three main types of supported accommodation in the UK (residential care, supported housing and housing with care) were carried out to identify potential amendments to the QuIRC. Additional advice was gained from consultation with three expert panels, two of which comprised service users with lived experience of mental health and supported accommodation services. The amended QuIRC (QuIRC-SA) was piloted with a range of each of the three service types. Item response validity, inter-rater reliability and internal consistency were assessed in a random sample of 23 services. Factorial structure and discriminant validity were assessed in a larger random sample of 67 services. Results: The QuIRC-SA comprised 143 items of which only 18 items showed a narrow range of response and five items had poor inter-rater reliability. The tool showed good discriminant validity, with supported housing services generally scoring higher than the other two types of supported accommodation on most domains. Exploratory factor analysis showed that the QuIRC-SA items loaded onto the domains to which they had been assigned. Conclusions: The QuIRC-SA is the first standardised tool for quality assessment of specialist mental health supported accommodation services. Its psychometric properties mean that it has potential for use in research as well as audit and

**BMC Psychiatry**

Research article

**Open Access**

**Quality of care and its determinants in longer term mental health facilities across Europe: a cross-sectional analysis**

Helen Killaspy<sup>1</sup>, Sara Carlotto<sup>2</sup>, Cesar White<sup>3</sup>, Christine Wright<sup>1</sup>, Jose Miguel Caldas de Almeida<sup>4</sup>, Penny Turtur<sup>1</sup>, Tatiana L Taylor<sup>1</sup>, Matthias Schützwohl<sup>5</sup>, Mirjam Schuster<sup>6</sup>, Jorge A Cervilla<sup>7</sup>, Paulette Branger<sup>8</sup>, Jiri Raboch<sup>9</sup>, Lucie Kalisova<sup>10</sup>, Georgi Onchev<sup>11</sup>, Spiridon Alexiev<sup>12</sup>, Roberto Mezzina<sup>13</sup>, Pina Rindone<sup>14</sup>, Durs Wiersma<sup>15</sup>, Ellen Visser<sup>16</sup>, Andrzej Kiejna<sup>17</sup>, Tomasz Adamowski<sup>18</sup>, Dimitris Ploumpidis<sup>19</sup>, Fragkos Gontidakis<sup>20</sup> and Michael King<sup>1</sup>

**The British Journal of Psychiatry**

Service quality and clinical outcomes: an example from mental health rehabilitation services in England

Helen Killaspy<sup>1</sup>, Linder Beets<sup>2</sup>, Samuel J Cole<sup>3</sup>, Nicholas Green<sup>4</sup>, et al.

**Abstract:** Background: Current mental health service quality measures focus on service users' views. Objectives: To investigate the relationship between quality of mental health rehabilitation services in England, staff behaviour, service user characteristics and clinical outcomes. Methods: Data were used to assess the quality of mental health rehabilitation services and service users' outcomes, quality of care, experience of care and ratings of the therapeutic relationship. Results: A significant relationship between service quality, service user characteristics and clinical outcomes was found. Conclusions: This study highlights the importance of service user characteristics in mental health rehabilitation services. It also suggests that service user characteristics may be used to predict clinical outcomes.

**BMC Psychiatry**

Research article

**Predictors of quality of care in mental health supported accommodation services in England: a multiple regression modelling study**

Christina Dobson-Kalish<sup>1</sup>, Helen Killaspy<sup>2</sup> and Michael King<sup>1</sup>

**Background:** Mental health supported accommodation services are a key component for the provision of mental health services. However, little is known about the predictors of quality of care in these services. This study aimed to identify predictors of quality of care in mental health supported accommodation services in England. Methods: Data were collected from 100 mental health supported accommodation services in England. Results: The predictors of quality of care were: service user characteristics, staff characteristics, and service characteristics. Conclusions: This study highlights the importance of service user characteristics in mental health supported accommodation services. It also suggests that service user characteristics may be used to predict quality of care.

**BSPych**

Relationship between national mental health expenditure and quality of care in longer-term psychiatric and social care facilities in Europe: cross-sectional study

Tatiana Taylor, Sarah White, Helen Killaspy and Michael King

**Background:** Mental health expenditure is a key determinant of the quality of care in mental health services. This study aimed to investigate the relationship between national mental health expenditure and quality of care in longer-term psychiatric and social care facilities in Europe. Methods: Data were collected from 100 mental health services in Europe. Results: There was a positive relationship between national mental health expenditure and quality of care. Conclusions: This study highlights the importance of national mental health expenditure in determining the quality of care in mental health services.

**BMC Psychiatry**

Research article

**Clinical outcomes and costs for people with complex psychosis: a naturalistic prospective cohort study of mental health rehabilitation services in England**

Helen Killaspy<sup>1</sup>, Sarah White<sup>2</sup>, Sarah Dowling<sup>3</sup>, James Kroll<sup>4</sup>, Peter McPheer<sup>5</sup>, Sina Sarich<sup>6</sup>, Maurice Abutouh<sup>7</sup>, Sarah Curtis<sup>8</sup>, Gerard Lawley<sup>9</sup>, Stefan Rebel<sup>10</sup>, Geoff Shephard<sup>11</sup> and Michael King<sup>1</sup>

**Background:** Mental health rehabilitation services in England focus on people with complex psychosis. This group has the highest need for mental health services. This study aimed to investigate the clinical outcomes and costs for people with complex psychosis in mental health rehabilitation services in England. Methods: Data were collected from 100 mental health rehabilitation services in England. Results: There was a positive relationship between clinical outcomes and costs. Conclusions: This study highlights the importance of clinical outcomes and costs in mental health rehabilitation services.

**BSPych**

Predictors of moving on from mental health supported accommodation in England: national cohort study

Helen Killaspy, Sarah White, Peter McPheer, James Kroll, Linder Beets, Sarah Dowling, Sina Sarich, Maurice Abutouh, Sarah Curtis, Gerard Lawley, Stefan Rebel, Geoff Shephard, Sarah Edwards and Michael King

**Background:** Mental health supported accommodation services are a key component for the provision of mental health services. This study aimed to investigate the predictors of moving on from mental health supported accommodation services in England. Methods: Data were collected from 100 mental health supported accommodation services in England. Results: The predictors of moving on from mental health supported accommodation services were: service user characteristics, staff characteristics, and service characteristics. Conclusions: This study highlights the importance of service user characteristics in mental health supported accommodation services. It also suggests that service user characteristics may be used to predict moving on from mental health supported accommodation services.

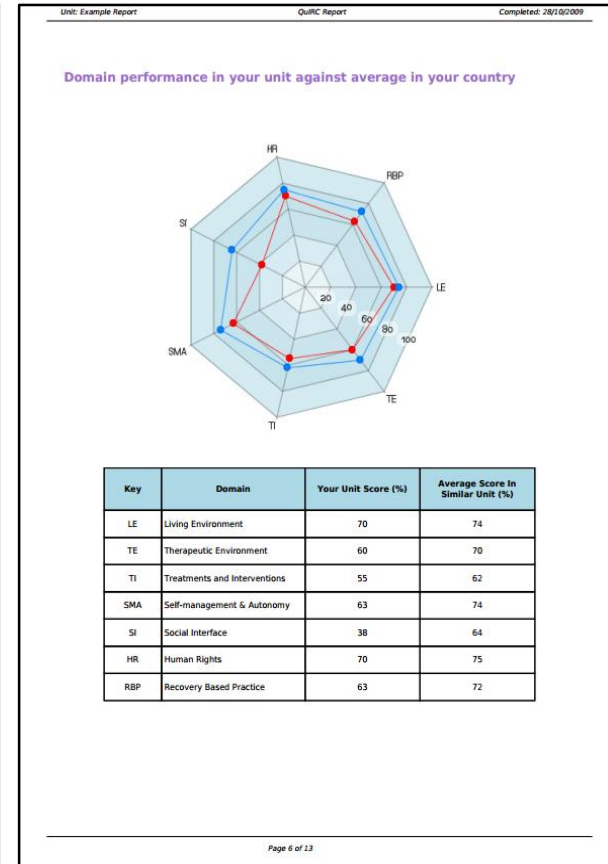
# Quality Indicator for Rehabilitative Care (QuIRC)

## 143 items:

- Staffing, training, supervision
- Built environment/facilities
- Evidence based interventions
- Activities (in and outside the service)
- Care planning processes
- Service user involvement
- Family support
- Promotion of autonomy and independent living skills
- Physical health promotion
- Management of challenging behaviours
- Complaints processes, confidentiality, access to advocacy and lawyer

## Assess 7 domains of care:

- Living (built) environment
- Therapeutic environment
- Treatments and interventions
- Self-management and autonomy
- Social interface
- Human rights
- Recovery based practice

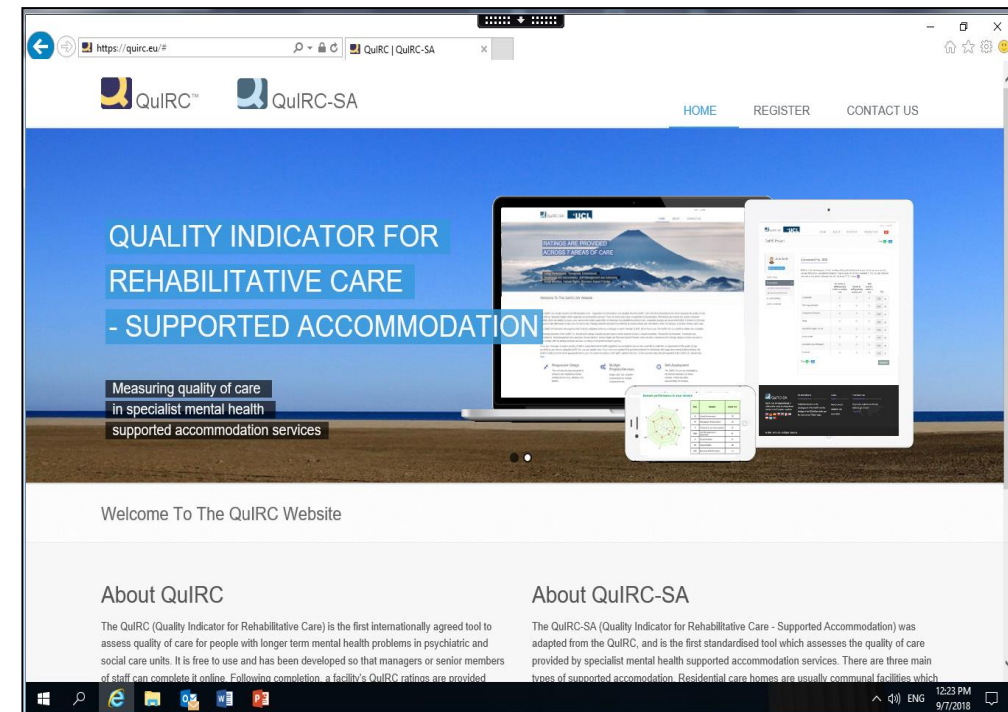
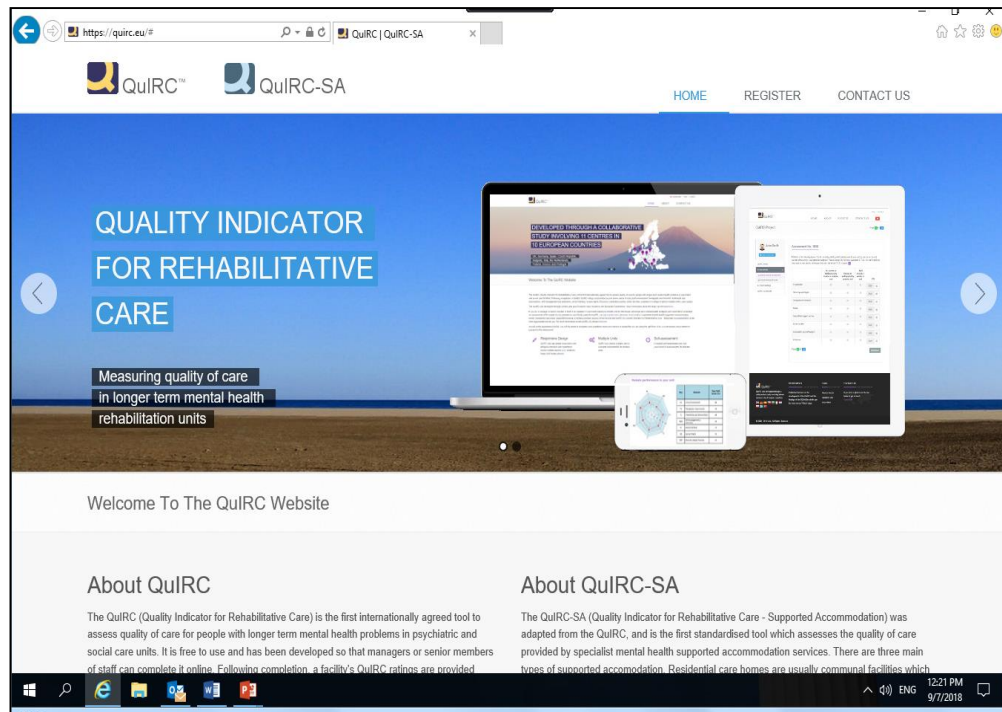




# The Quality Indicator for Rehabilitative Care (www.quirc.eu)

>1000 current users;

Australia, Bulgaria, Brazil, Canada, Czech Republic, Germany, Greece, Italy, Ireland, Netherlands, New Zealand, Poland, Portugal, Spain, UK, US



# Drivers of better outcomes in mental health rehabilitation

<b>Predictors of outcome</b>	<b>OR (95% CI)</b>	<b>Study</b>
<b>Successful discharge from hospital</b> associated with greater:		
• social skills	1.13 (1.04 to 1.24)	<b>REAL</b>
• engagement in activities	1.04 (1.01 to 1.08)	
• recovery orientation of service	1.03 (1.01 to 1.05)	
<b>Successful move on to more independent accommodation</b> associated with greater:		
• human rights promotion of service	1.09 (1.02 to 1.16)	<b>QuEST</b>
• recovery orientation of service	1.06 (1.00 to 1.11)	

**Recovery orientation domain**

- Therapeutic optimism
- Expected maximum length of stay
- Collaborative, individualised care planning
- Strengths based approach
- Supporting the person to gain/regain ADL skills
- Service user involvement in running the service
- Ex-service users employed in the service

**Human rights domain**

- Access to legal representative
- Access to advocate
- Assistance to vote in elections
- Privacy/dignity
- Confidential case notes
- Access to communication (phone, email)
- Complaints procedures



# Camberwell Assessment of Need Short Appraisal Scale

Phelan et al., (1995) *BJP*, 167: 589–595; Slade et al., (1998) *Psych Med*, 28: 543–550.

## Assesses 22 domains

- 0=no problem (no need)
- 1=no/moderate problem due to help given (met need)
- 2=serious problem regardless of whether help given (unmet need)
- Staff, service user and carer versions available
- Good inter-rater reliability
- Clinicians do not need specific training
- Takes about 10 minutes
- Change in proportion of met: unmet needs over time gives a measure of service's performance
- Useful for care planning

- Food/diet
- Psychotic symptoms
- Accommodation
- Psychological distress
- Looking after the home
- Self-care
- Daytime activities
- Finances/budgeting
- Physical health
- Understanding of mental health problems
- Safety to others
- Safety to self
- Social supports
- Welfare benefits
- Alcohol
- Substances
- Transport
- Relationships
- Sexual expression
- Literacy/numeracy/language
- Child care
- Telephone

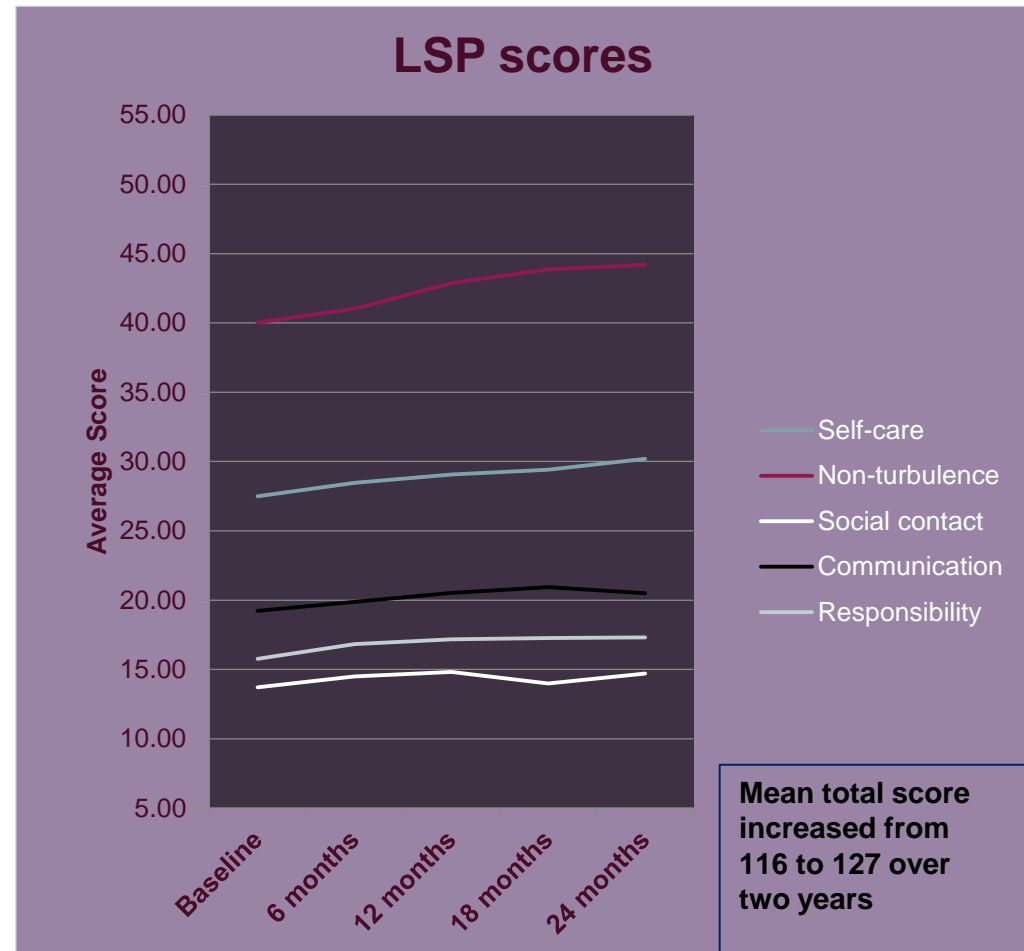
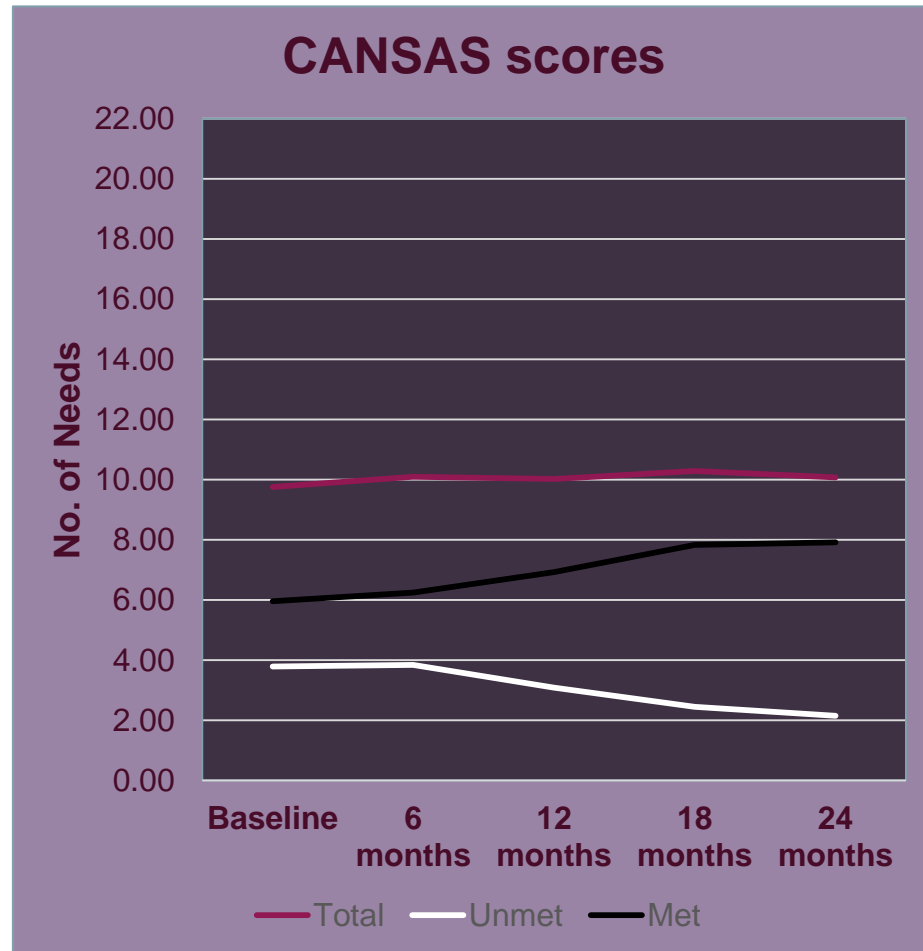
## Life Skills Profile

Parker G, Rosen A, Emdur N, Hadzi-Pavlov D. The Life Skills Profile: psychometric properties of a measure assessing function and disability in schizophrenia. *Acta Psychiatrica Scandinavica*, 1991;83:145–52.

- Clinician rated measure
- Developed in Australia for assessment of social function of people with schizophrenia
- 39 items assess 5 sub-scales:
  - Self care
  - Non-Turbulence
  - Social Contact
  - Communication
  - Responsibility
- Each item rated between 1 and 4:  
total score range = 39-156
- Do not need specific training
- Takes about 10 minutes
- Good psychometric properties
- Used routinely in Australia
- Shorter versions available:
  - LSP-20**
  - LSP-16**



# Islington community mental health rehabilitation team – clinician rated routine outcome measures



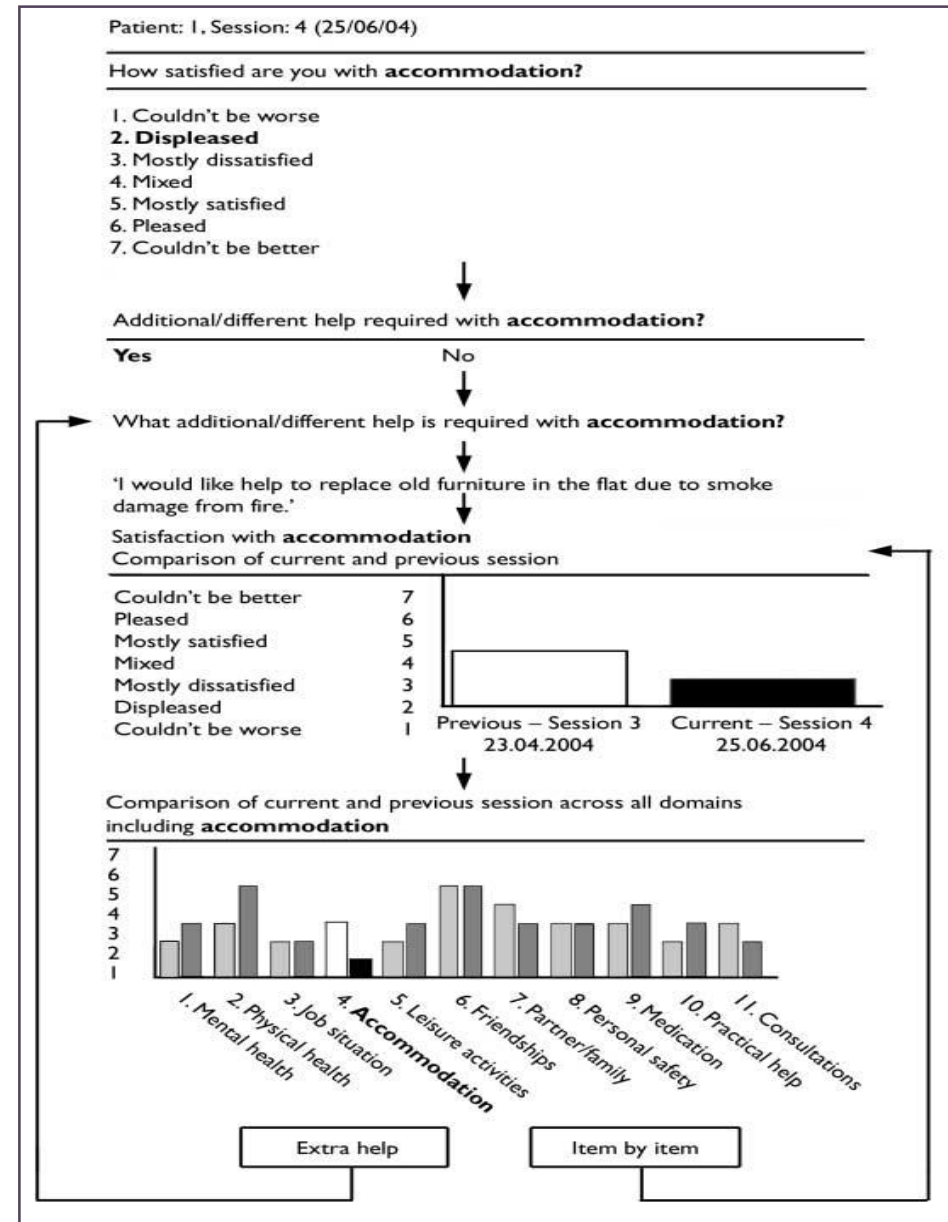
## DIALOG

Priebe, S., McCabe, R., et al (2007) Structured patient–clinician communication and 1-year outcome in community mental healthcare: Cluster randomised controlled trial. *British Journal of Psychiatry*, November 2007 191:420-426

- Patient Reported Outcome Measure
- Provides structure for communication between service user and clinician (can be an intervention in itself)
- Minimal training required
- Useful for care planning as well as monitoring change over time
- Electronic (handheld device/app) and paper versions

## 11 domains

- Mental health
- Physical health
- Job situation
- Accommodation
- Leisure activities
- Family relationships
- Friendships
- Personal safety
- Medication
- Practical help
- Meetings with MH professionals
- Score 1- 7 on each item



# Family and Friends Test

One item from Client Satisfaction Questionnaire; Reichheld, F. F. (2003). The one number you need to grow. Harvard Business Review, 81(12), 46-55.

**How likely are you to recommend our services to friends and family if they needed similar care or treatment?**

1. Extremely likely
2. Likely
3. Neither likely nor unlikely
4. Unlikely
5. Extremely unlikely
6. Don't know

# RCPsych recommended routine quality and outcome metrics for mental health rehabilitation services

## Patient Safety

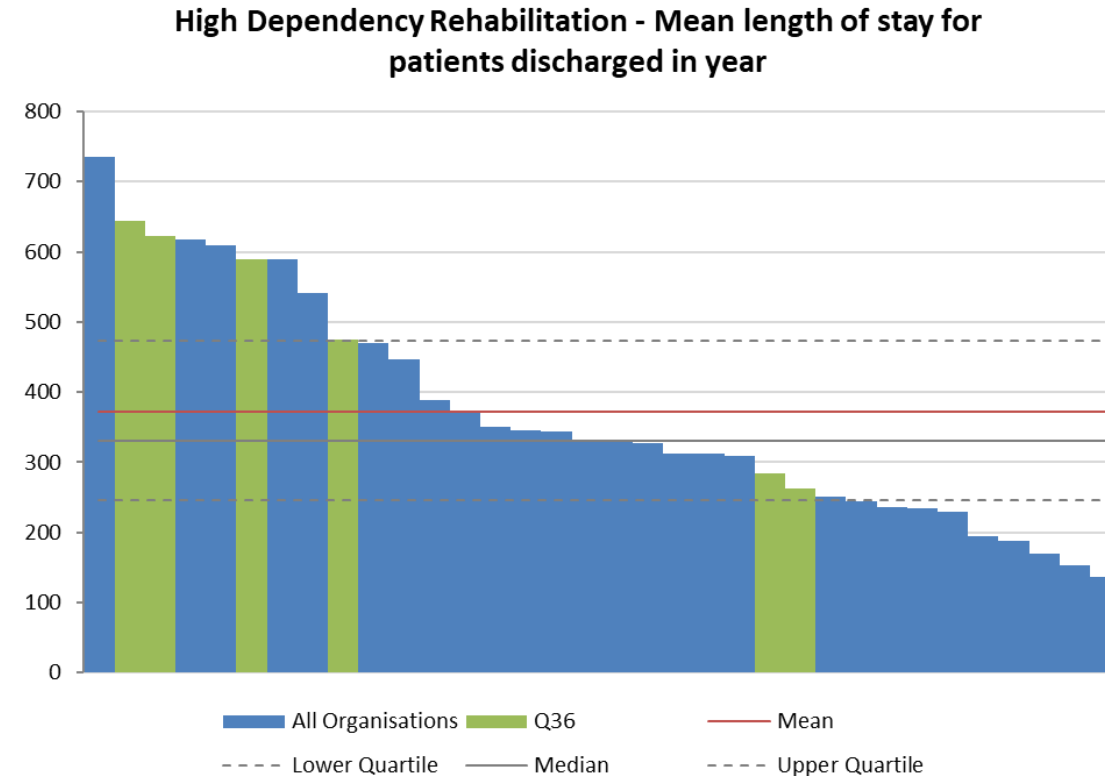
- Number of serious incidents/deaths
- Number (%) service users who receive annual physical health check
- Number (%) of service users with complex psychosis placed out of area

## Clinical Improvement

- Length of stay (expected LoS different for different components of rehabilitation pathway)
- Number (%) readmitted within certain timeframe
- Number (%) whose community placement breaks down within specific timeframe
- Number (%) service users discharged to community or move on to less supported accommodation within expected timeframe without readmission/placement breakdown
- Number (%) service users participating in work, education, leisure

# High Dependency Rehabilitation Units – length of stay (2016-17)

- Average 372 days for patients discharged in year
- London units highlighted in green



## Final thoughts

- No getting away from the need to collect and report routine data
- ✓ Make it useful
- ✓ Make it meaningful
- ✓ Make it as simple as possible



**Many thanks  
for your attention!**

**[h.killaspy@ucl.ac.uk](mailto:h.killaspy@ucl.ac.uk)**

