Pathways to recovery:
A case for adoption of systematic pathways in psychosis

Jointly produced by Imperial College Health Partners and Wessex Academic Health Science Network

Supported by the Royal College of Psychiatrists and Rethink Mental Illness
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Foreword</td>
</tr>
<tr>
<td>3</td>
<td>Authors</td>
</tr>
<tr>
<td>4</td>
<td>Acknowledgments</td>
</tr>
<tr>
<td>5</td>
<td>Executive summary</td>
</tr>
<tr>
<td>6</td>
<td>Background</td>
</tr>
<tr>
<td>8</td>
<td>Developing a new pathway of care for psychosis</td>
</tr>
<tr>
<td>9</td>
<td>a. Co-production</td>
</tr>
<tr>
<td>11</td>
<td>b. Research and data</td>
</tr>
<tr>
<td>13</td>
<td>c. Stakeholder engagement</td>
</tr>
<tr>
<td>14</td>
<td>Evaluation</td>
</tr>
<tr>
<td>16</td>
<td>Contacts</td>
</tr>
</tbody>
</table>
In 2012, the Schizophrenia Commission report ‘The Abandoned Illness’ and in 2013, the National audit of Schizophrenia highlighted major problems with the state of care for people with psychosis across the country.

Today, people with psychosis die 15-20 years earlier than the rest of the population and it is unacceptable that people with psychosis can wait up to two years for care while evidence based treatments are available. It is also clear that while some areas commission and provide outstanding best practice care, the variation across England is large.

Therefore, I am delighted to introduce new pathways that have the potential to revolutionise care for people who suffer with psychosis in terms of helping people recover, and giving the NHS the best value for money. I applaud the efforts and drive of Imperial College Health Partners and Wessex Academic Health Science Network in the total partnership commitment, use of information and clinical engagement in developing these pathways.

I would like to call all providers, commissioners and other decision-makers to join this revolution so that we start our journey to recovery for psychosis.

Dr Geraldine Strathdee,
National Clinical Director, Mental Health
NHS England
Authors

Dr Shanaya Rathod, Consultant Psychiatrist and Director of Research, Southern Health NHS Foundation Trust

Alison Griffiths, Project Manager (Mental Health), Wessex AHSN

David Kingdon, Professor of Mental Health Care Delivery Honorary Consultant Psychiatrist University of Southampton

Bill Tiplady, Consultant Clinical Psychologist, Central and North West London NHS Foundation Trust (CNWL)

Tessa Jones, Mental Health Clinical Fellow, Imperial College Health Partners
We thank Rethink Mental Illness for financial support in writing this report. We acknowledge the support of all patients, carers, clinicians, commissioners, Healthwatch and partners from other agencies who have supported and contributed to this work through co-production workshops and engagement events.

Southern Health NHS Foundation trust received grants from NHS England (Regional Innovation Fund) and The Royal College of Psychiatrists General Adult Faculty for this work. Imperial College Health Partners also received funding from NHS England. A number of people helped us with advice, data, editing assistance and other important inputs. We are very grateful to at least the following people for this help, and apologise if we have missed anyone:

Central and North West London NHS Foundation Trust - Steven Reid, Bill Tiplady

Chair of NHS West London CCG - Fiona Butler

Hammersmith and Fulham CCGs - Claire Lyons-Collins, Beverley Mcdonald

Healthwatch Southampton - Rob Kurn

Hounslow CCG - Annabel Crowe

Imperial College Health Partners - Beverley Chipp (Patient representative), Axel Heitmueller, Natalie Hudson

Imperial College, West London Mental Health NHS Trust - Thomas Barnes

Janssen Healthcare Innovation - Tony Thomas

NHS England (Formerly Imperial College Health Partners) - Phoebe Robinson

NHS North West London CCGs - Michael Doyle

NHS North West Surrey CCG - Pardeep Dhillon

Southern Health NHS Foundation Trust - Nicola Abba, Carolyn Asher (Patient Rep), David Butler, Christie Garner, Lars Hansen, Michael James, Claire Morrish, Katherine Newman-Taylor, Pippa North, Jeremy Rowland, Paul Tabraham, Deborah Tee, Chris Woodfine

Stripe Partners - Tom Hoy and Simon Roberts

Tri-borough Social Services (Kensington and Chelsea, Westminster, Hammersmith and Fulham) - Stella Baillie

West Hampshire CCG - Jason Hope

West London CCGs - Glen Monks, Louise Proctor

West London Mental Health NHS Trust - Pradip Ghosh, Amrit Sachar

The views expressed in this report are those of the authors and not necessarily those of the Department of Health, NHS England, Royal College of Psychiatrists or Rethink Mental Illness.
Executive summary

The Schizophrenia Commission report, "The Abandoned Illness" (2012) highlighted major problems in the state of care for people with psychosis across the country. Evidence based and cost effective interventions are available, but spending continues to be skewed to the most expensive parts of services (Knapp, 2014).

For the first time in the history of UK mental health, integrated care pathways that prescribe time frames around clinical interventions and service delivery have been developed. This work has been led by two Academic Health Science Networks (AHSNs) - Imperial College Health Partners (ICHP) and Wessex AHSN - and has used a similar approach to that taken to improve stroke care, where there has been a demonstrable improvement in outcomes for patients and carers. These new psychosis pathways aim to reduce the impact of disease and promote recovery by ensuring that every individual gets the best evidence based care at the right time and in the right place.

In developing these pathways, a multi-pronged approach has been used, using i) research and data, ii) co-production with individuals and carers, and iii) engagement with clinicians and other stakeholders including commissioners, primary care and third sector organisations. The approach has used a robust methodology which can be adopted for use across the wider NHS.

This document describes the approach used in developing the pathways and provides a guide for patients, carers, provider organisations and commissioners on adoption and implementation.
Background

Introduction

Psychosis frequently causes distress and major disruption to life. It usually comes on early in life and is associated with a 15-20 year reduction in lifespan (Saha et al. 2007). According to the National Institute of Health and Care Excellence (NICE, 2014), treatments are available which make a substantial difference in reducing relapse and promoting recovery, but there remain gaps in how people receive services (Knapp, 2014). Now, integrated care pathways have been developed that provide a route map which can make recovery a reality in an organised and timely way.

What is psychosis?

‘Psychosis and the specific diagnosis of schizophrenia represent a major psychiatric disorder (or cluster of disorders) in which a person's perception, thoughts, mood and behaviour are significantly altered. The symptoms of psychosis and schizophrenia are usually divided into 'positive symptoms', including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and 'negative symptoms' (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect). Each person will have a unique combination of symptoms and experiences’ (NICE, 2014).

What causes psychosis? How common is it?

Psychosis is a complex set of experiences with multiple causal factors. Genetic variation contributes to the risk of developing psychosis, and there is strong evidence for a causal role of environmental factors including traumatic experiences and substance misuse. In England, at least 32 in 100,000 people develop psychosis each year depending on factors such as age, sex, ethnicity, population density and social deprivation (Kirkbride et al., 2012). First episode psychosis occurs more often in young people, especially in men from their teens to twenties. New episodes are more common in some black and minority ethnic (BME) groups and in urban populations, particularly in deprived areas (Kirkbride et al, 2008). Unfortunately whilst 80% of people recover from a first episode, they are prone to recurrence, with only 20% not getting further episodes (Robinson, et, al. 1999).

Mild psychotic symptoms are common and, in a minority, these persist and cause distress. Up to 15% of the general population can experience hearing voices at some point in their life and 15-20% have regular paranoid thoughts (Tien, 1991; Freeman and Garety, 2006).

What effects does it have?

Schizophrenia causes a high degree of disability, which accounts for 1.1% of the total DALYs (disability-adjusted life years) and 2.8% of YLDs (years lived with disability). In the World Health Report (2001), schizophrenia is listed as the 8th leading cause of DALYs worldwide in the age group 15-44 years. The effects on relatives are highly significant. Health service use and other costs, e.g. lost employment, are high.

What can be done about it?

Treatment goals in psychosis are to identify people experiencing psychosis as early as possible, offer effective treatments and interventions, provide skills to individuals and their families, maintain the improvement over a period of time, prevent relapses and promote recovery (Rossler et, al. 2005). The longer the time between the onset of psychosis and the start of treatment (known as the Duration of Untreated Psychosis – DUP), the worse the outlook can be (McGorry et al., 1996). Delayed treatment can lead to significant impairments in function and social outcomes which become increasingly difficult to repair. Recovery can certainly occur but delayed access to services and evidence based treatments, especially early in the illness, is associated with less complete recovery with prolonged and increased distress and disability.
Currently there is considerable unmet need in the way individuals with psychosis access services and receive evidence-based treatments as prescribed by NICE (2014). The Schizophrenia Commission report (2012) and National Audit of Schizophrenia (2013) have highlighted deficiencies in psychopharmacological and psychological care and recommended changes to the way care is provided to people with schizophrenia. Spending is currently skewed towards the more expensive parts of the system, at £350 average cost per day for inpatient care compared with £13 average cost per day in community settings (Knapp et al. 2014). People from some minority communities are overrepresented in the more intense and coercive forms of care and this can be attributed to their non-engagement with services until a point of crisis (Mental Health Bulletin, 2009) making a case for cultural adaptation of services and interventions (Rathod et al. 2015). There is a strong cost-effectiveness argument supporting early intervention (Knapp et al. 2014). If early intervention was available to every person with psychosis, it would lead to reduction in hospital stays and the NHS would be able to redistribute an estimated £44 million each year (Kings Fund, 2008). The Access and Waiting Time Standard (NHS England, 2015) for first episode psychosis has been established to begin to address these issues.

Why are new pathways of care needed?

Consistent evidence-based treatments can be provided through clearly defined clinical pathways prescribing key stages at which care should be delivered. They should be adapted to match the diversity of presentations that occur with psychosis, e.g. co-morbidity with substance misuse and trauma, which will improve access to evidence-based interventions and support recovery. The key outcome is to reduce the impact of disease and promote recovery through ensuring that every individual gets the best evidence-based care at the right time and in the right place, thereby reducing crisis, improving physical health and achieving independence.

New pathways of care are fundamental to improving both the physical health and reducing premature mortality in people with psychosis, as currently their average lifespan is shortened by 15-20 years compared with the general population. Pathways can ensure delivery of appropriate health promotion at key stages. For example, weight gain from antipsychotic medication is especially pronounced in the first eight weeks of administration but it is rare that specific support is offered at this stage. Similarly, smoking cessation support is key to improving physical health of individuals with psychosis.

Evidenced-based integrated pathways, such as those used very successfully for stroke, provide a standardised framework for good clinical practice and reduce variation in care. They improve quality by improving multidisciplinary communication and care planning, including with primary care and improve patient satisfaction (Campbell et al. 1998).

The psychosis pathways developed by ICHP and Wessex AHSN aim to address the unmet health needs of patients with psychosis. The aim of implementing the pathways is to improve individual outcomes and promote economic gains through more efficient delivery of healthcare. Ultimately, the psychosis pathway objectives are:

- Improved early detection and potential recovery for individuals;
- Early uptake of evidence-based treatments (based on NICE guidelines);
- Appropriate admission rates, lengths of stay and compulsory admissions;
- Outcome measurement and quality standards guiding service delivery and clinical research;
- Improved physical health reflected in appropriate monitoring systems.
Developing a new pathway of care for psychosis

How were the integrated care pathways for psychosis developed?

This guide for commissioners and providers describes the development, implementation and evaluation of integrated psychosis care pathways that could improve the Duration of Untreated Psychosis (DUP) and long term physical and mental health outcomes for patients. It uses case studies from Imperial College Health Partners (ICHP) and Wessex AHSN and describes how they set out to transform psychosis care within their two geographies, Wessex and North West London. Both AHSNs have led on the development and implementation of a psychosis pathway based on the stroke pathway template, which has been successful in prescribing care at certain points in the patient journey – helping to improve access and waiting times for treatment and improving patient outcomes (Rathod, et al. 2015). The template uses a staged and branched approach across the following areas:

- Time and course of illness (e.g. time frames for access to services, interventions, expectations for access to therapies);
- Different levels of severity and presentations of the illness (e.g. early presentation, acute crisis or chronic presentation);
- Different presentations such as co-morbidities (e.g. drug and alcohol misuse, trauma responses, later onset delusional disorder).

The pathways describe evidence-based approaches based on NICE Clinical Guidelines for Psychosis and Schizophrenia (2014); NICE Quality Standards for Psychosis (2015) (as set out in Appendix 1) and NICE Service User Experience 2014 (as set out in Appendix 2) to enable good practice in service delivery. They incorporate outcome and quality measures to evaluate how far an individual’s outcomes and experience has been improved.

What approach was used?

Wessex AHSN and ICHP have developed integrated care pathways and supported local partners in implementation to improve psychosis care in their respective areas at scale and pace. The approach to pathway development has used existing resources (National Leadership and Innovation Agency for Healthcare, 2005; Middleton et. al. 2008) and triangulated evidence from three sources – co-production with individuals and carers, research and data and wider stakeholder engagement, including clinical expertise. This approach has ensured that information from different sources has been validated and used intelligently, for clinical benefit. The approach also allows the work to be adapted and adopted in the wider NHS.
The importance of designing services with patients is now recognised in national policy (Department of Health, 2012). Co-production goes beyond personal consultation and leads towards developing a model of service delivery intended to impact on wider social systems and is described as “the contribution of service users to the provision of services” (Health Foundation, 2010). Co-produced interventions have been shown to have enormous potential benefits in terms of both improving outcomes and reducing costs (Needham, 2009).

In developing an understanding of the key issues and local need, both AHSNs gathered individual, carer, and wider stakeholder feedback through a series of co-production workshops, which allowed individuals to describe and document important experiences, both positive and negative, in relation to care they had previously received. The aim was to understand current service provision and seek how "experts by lived experience" would like to see improvements. The workshops were very well attended.

Rather than start with any assumptions, the facilitators let participants define what was important to them by asking them to write postcards about a chosen experience and address it to a person who they felt should hear their story. Overall hundreds of postcards were written, yielding many first hand experiences of current care in the two respective areas. All feedback was then collated into themes. The themes were then rated by individual participants in terms of importance. This enabled the development of a “shortlist” of key service improvement areas:

- Increased awareness amongst the general public;
- More available resources for early intervention;
- More resources for peer support;
- More intensive care available at home – home is at the heart of the care;
- Compassionate care and more contact time;
- Better access for places of safety in a crisis;
- More holistic and person-centred approach to care;
- Better signposting to services;
- Family centered approach to care;
- Empowering the patient to lead their own recovery.

This approach helped understand what was intrinsically important to patients and carers, rather than relying on the assumptions of health and social care professionals. Although it has not been possible to address all of the issues prioritised, development of the new pathways has attempted to address as many as possible of the identified themes. For example, the pathways emphasise and facilitate early intervention through prescribing time frames for access to services. They also focus on the provision of holistic care, for example, by improving and standardising the initial assessment, which is now inclusive of both mental and physical health needs.
1. Attendees were invited to share personal experiences of psychosis which highlight areas for improvement and development.

2. We clustered these postcards to identify some key themes and opportunity areas.

3. The teams then identify specific opportunities they wanted to work on during the afternoon – each team chose two opportunities.

4. Each team worked on a template to ensure they captured all relevant aspects of their proposed solution.

**Fig 1:** Co-production process for understanding patient and carer perspectives

**Fig 2:** Example themes from a co-production workshop

**Feedback from service users who took part in the workshops**

“The workshops were refreshing, immersive and fertile, with ICHP understanding the value of true co-production.”

“We worked together not with our labels on but as human beings; all different but all equally valid nodes in a holistic process, and with a desire to make a real change.”
What research and data was used?

High quality data and its clinical interpretation underpins the development of integrated care pathways (NHS England, 2014). However, there are challenges in building clinically relevant baseline datasets from locally available information. These include:

- Difficulty in tracking complex, non-linear patient pathways, which often include interactions with various sectors and service providers within the health service;
- Problems with inconsistencies in the data being captured, which is stored across disparate systems;

In developing the psychosis pathways, ICHP commissioned work from Janssen Healthcare Innovation to build a comprehensive picture of service use from national data sets. This work was later extended in collaboration with Wessex AHSN. Pseudonymised, non-sensitive patient-level data from the following data sets was licensed from the Health and Social Care Information Centre:

- **Mental Health Minimum Data Set (MHMDS)** – This data captures Mental Health Trust (MHT) inpatient and community care service user activity;
- **Hospital Episode Statistics (HES)** – This dataset captures secondary care including emergency department attendances, inpatient and outpatient episodes.

Through these data sources, individuals with psychosis were identified across three measurement areas, although limitations with the data and method used were acknowledged.

1. **Diagnosis codes**

Individuals identified using the relevant ICD-10 clinical codes. While this data reliably captures patients admitted as inpatients, it could miss a large segment of community based people due to data entry and current problems with data transmission.

2. **Mental health (Payment by Results) PbR clusters**

This was used where diagnostic and Health of the Nation Outcome Scale (HoNOS) data was unavailable to identify those who were included in the ‘Psychosis supercluster’.

Care was taken to exclude “false positives” such as those who were solely diagnosed with bipolar disorder (F31), or solely with depression (cluster 15).

Using the above sources of data, individual demographics, incidence locality, and health service interaction were analysed to develop a comprehensive picture of the overall impact on the health service in the AHSN areas. The datasets were analysed at Clinical Commissioning Group (CCG) level and shared with individual CCGs so that the clinical commissioners were fully informed of local health needs and the quality and equity of the care that their population were receiving. This analysis was also made available to appropriate provider organisations.

3. **Lived Experience**

HoNOS data was used to identify individual profiles and needs based on clinical assessment and lived experience where clinical diagnosis was not available. This data varied in completeness and reliability but did provide valuable individual information.
What did the data show?

This approach confirmed that prevalence rates for psychosis in North West London ran at nearly twice the national average in the inner London boroughs, and nearly a third of the two main North West London (NWL) providers’ caseload were people identified as individuals with a diagnosis of psychosis (24,000 individuals with psychosis in the area, accounting for 29% of mental health work). In Wessex, pockets of higher than national prevalence were identified in city areas like Southampton and Portsmouth, and a rising incidence was noted in Hampshire (15,951 individuals with psychosis in the area, accounting for 26% of mental health work in Wessex). In both AHSN areas people with a diagnosis of psychosis:

- Had higher psychiatric hospital admissions with longer stays (on average over 50% longer than other mental health conditions);
- Accounted for the majority of community health professional contacts (around three times more in both areas);
- Had more attendances and admissions to local accident and emergency departments (over 60% of psychosis patients visited A&E during the time period analysed, and over 30% of these resulted in emergency admissions to acute trusts);
- Are keen to work but could not find employment.

**Feedback from commissioners involved with analysing data**

“Understanding the data for psychosis has been invaluable for commissioners. The work undertaken to examine psychosis prevalence, the identification of existing resources and gathering data about current waiting times has helped commissioners and providers begin scoping what future services need to look like.”
c. Stakeholder engagement

How were clinicians and other stakeholders involved?

Both AHSNs set up steering groups involving clinicians, commissioners, patient and carer representatives, general practitioners and other stakeholders who were essential to the development of the pathways. Information from the acquired data and coproduction workshops were triangulated with clinical expertise and national evidence to chart process maps (Middleton, et al. 1998). The process map aimed to identify:

- The scope of the pathway and key outcomes desired;
- The sequence of activities performed during delivery of comprehensive care;
- Gaps and delays in services;
- Specific timeframes for these activities;
- The areas where collaboration would be needed to provide integrated care;
- Potential challenges and opportunities.

This was tested with clinical teams and patient groups. Both AHSNs collaborated on the final pathway development in order to share best practice. Both pathways are very similar in care delivery aspects and only vary where local needs are different. Appendix 4 sets out the Wessex pathway - TRIumPH (Treatment and Recovery In Psychosis), and Appendix 5 sets out ICHP’s pathway.

How are the pathways being implemented?

Successful implementation and the desired benefits of the pathways can only be achieved when they are a priority for both providers and commissioners. Information from data analysis and co-production workshops make a compelling case to prioritise this work. Effective implementation requires a clear implementation plan, project facilitators and a robust evaluation methodology in order to ensure continuous quality improvement and a change in culture. Another critical factor for success is clinical engagement and strong clinical leadership.

In both AHSN areas, plans for implementation have focussed initially on the first episode of psychosis, as this is now a priority for the NHS England Access and Treatment Standard (2015). Commissioning guidance is being drawn up by National Institute for Health and Care Excellence (NICE) for early intervention and pathway implementation is expected to be consistent with the work described here. Workforce planning will be specified to achieve accreditation for the standard and use of outcome measures e.g. HoNOS, DIALOG and the Process for Recovery Questionnaire, will be required, which will enhance the quality of interactions with individuals and improve the availability of data to evaluate services.

Education and engagement events have been conducted with primary care in order to gain their support in early identification and referral. This approach has enabled collaborative working between primary and secondary care. The pathways emphasise the importance of robust communication and integrated working between clinicians, social care and third sector groups, and their support has been essential in this work.
Evaluation

How is the work being evaluated?

Real time evaluation of the implementation of the pathways enables continuous quality improvement in the delivery of care. It helps to understand what works and where changes are needed to improve quality. It also provides the opportunity for teams to share their learning. Evaluation also helps to identify whether the pathways can be replicated across the health services to bring about improvement on a large scale. Evaluation methodology will include triangulation of findings from quantitative and qualitative analysis so that patient experience is an integral part of the evaluation. Evaluation measures that can be used by providers and commissioners are included in Appendix 3.

What are the implications for individuals, carers, providers and commissioners?

Individuals and carers

The psychosis pathways developed describe the care and services an individual and carer should expect to receive and when. They also provide a guide for how individuals and their carers can be more involved with the care process, giving them a better understanding of their journey, leading to improved collaboration and self-management. Having an organised, well communicated process is likely to see both individuals and their carers receiving the best care possible. Where progress isn’t being made, the pathways support individuals, carers and clinicians to develop a revised strategy.

Provider organisations

The psychosis pathways set a benchmark against which organisations can organise and audit their practice, which can also be used to evaluate the effectiveness of service changes. For practitioners, they provide practical guidance about what to do and when to do it, making best use of their professional skills. The pathways can also assist in establishing workforce and training need, such as professional, therapy and support worker time and training. Organisational leaders will also need to consider effective strategies for both pathway implementation and data collection. Engagement at board level is key to ensuring a culture change at clinical level.
Commissioners

Use of these pathways will help to support the implementation of NICE concordant evidence-based care, as described by the NICE Quality Standards for Psychosis. To assist commissioners, guidance for the national Access and Waiting time Standards for early intervention in psychosis is now being developed by NICE, and similar guidance for co-existing mental illness and substance use is also being prepared by Public Health England.

Commissioners should also look at a range of local data to help both assess local services and identify areas for improvement, working in partnership with their stakeholders. For example, the Joint Strategic Needs Assessment provides a platform to assess incidence, prevalence, service usage and outcomes from nationally available data for CCGs, local authorities and provider units. This is readily available as a ‘pathway of data’ through the National Mental Health Intelligence Network ‘Fingertips’ site. NHS England Commissioning for Value packs also include ‘pathways on a page’ for psychosis and for an integrated pathway for ‘substance use and mental illness’.

Cost effectiveness studies have shown that investment early in the pathway pays dividends but for commitment to be made to such incremental investment, data sources - especially outcome measurement - need to be robustly developed and routinely collected. Such data collection need not be onerous—measures proposed for early psychosis draw directly from clinical assessment or individually rated scales, and from data which is currently routinely collected though inadequately used.
Contacts

Imperial College Health Partners

10 Greycoat Place
Victoria
London
SW1P 1SB

Email
EA@imperialcollegehealthpartners.com

Telephone
+44(0)20 7960 6241

Website
http://imperialcollegehealthpartners.com/

Twitter
@ldn_ichp

LinkedIn
http://www.linkedin.com/company/imperial-college-health-partners

Wessex AHSN

Innovation Centre
Southampton Science Park
2 Venture Road
Chilworth
Hampshire
SO16 7NP

Email
enquiries@wessexahsn.net

Telephone
+44(0)23 8202 0840

Website
http://wessexahsn.org.uk/

Twitter
@WessexAHSN

LinkedIn
https://uk.linkedin.com/pub/wessex-ahsn/56/92a/ba4
References

doi: http://dx.doi.org/10.1136/bmj.316.7125.133 (Published 10 January 1998).


Kirkbride, J.B., Errazuriz, A., Croudace, T.J., et al. (2012). Incidence of schizophrenia and other psychoses in


Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared
decision-making, Department of Heath, 2012.


Mental Health Bulletin (2009). Third report from Mental Health Minimum Dataset (MHMDS) annual returns, 2004-


in Adults.


National Institute for Health and Care Excellence (2014). Service user experience in adult mental health: improving
the experience of care for people using adult NHS mental health services (Clinical guideline 136).

practice (PDF 369.4KB). Llanharan: NLIAH.

Research briefing 31.


NHS England (2015). Guidance to support the introduction of access and waiting time standards for mental
health services.


Appendix 1

NICE Quality Standards for the care of people with psychosis and schizophrenia, derived from NICE clinical guideline 178

<table>
<thead>
<tr>
<th>Statement</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statement 1</td>
<td>Adults with first episode psychosis start treatment in services within 2 weeks of referral</td>
</tr>
<tr>
<td>Statement 2</td>
<td>Adults with psychosis or schizophrenia are offered cognitive behavioural therapy for psychosis</td>
</tr>
<tr>
<td>Statement 3</td>
<td>Family members of adults with psychosis or schizophrenia are offered family intervention</td>
</tr>
<tr>
<td>Statement 4</td>
<td>Adults with psychosis or schizophrenia that have not responded adequately to treatment with at least 2 antipsychotic drugs are offered clozapine</td>
</tr>
<tr>
<td>Statement 5</td>
<td>Adults with psychosis or schizophrenia who wish to find or return to work are offered supported employment programs</td>
</tr>
<tr>
<td>Statement 6</td>
<td>Adults with psychosis or schizophrenia have specific comprehensive physical health assessments</td>
</tr>
<tr>
<td>Statement 7</td>
<td>Adults with psychosis or schizophrenia are offered combined health eating and physical activity programs, and help to stop smoking</td>
</tr>
<tr>
<td>Statement 8</td>
<td>Carers of adults with psychosis or schizophrenia are offered carer-focused education and support programs</td>
</tr>
</tbody>
</table>
## Appendix 2

### NICE Quality Standards for service user experience in adult mental health services, derived from NICE clinical guideline 136

<table>
<thead>
<tr>
<th>Statement</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statement 1</td>
<td>People using mental health services, and their families or carers, feel optimistic that care will be effective</td>
</tr>
<tr>
<td>Statement 2</td>
<td>People using mental health services, and their families or carers, feel they are treated with empathy, dignity and respect</td>
</tr>
<tr>
<td>Statement 3</td>
<td>People using mental health services are actively involved in shared decision-making and supported in self-management</td>
</tr>
<tr>
<td>Statement 4</td>
<td>People using community mental health services are normally supported by staff from a single, multidisciplinary community team, familiar to them and with whom they have a continuous relationship</td>
</tr>
<tr>
<td>Statement 5</td>
<td>People using mental health services feel confident that the views of service users are used to monitor and improve the performance of services</td>
</tr>
<tr>
<td>Statement 6</td>
<td>People can access mental health services when they need them</td>
</tr>
<tr>
<td>Statement 7</td>
<td>People using mental health services understand the assessment process, their diagnosis and treatment options, and receive emotional support for any sensitive issues</td>
</tr>
<tr>
<td>Statement 8</td>
<td>People using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it</td>
</tr>
<tr>
<td>Statement 9</td>
<td>People using mental health services who may be at risk of crisis are offered a crisis plan</td>
</tr>
<tr>
<td>Statement 10</td>
<td>People accessing crisis support have a comprehensive assessment, undertaken by a professional competent in crisis working</td>
</tr>
</tbody>
</table>
### Appendix 2

**NICE Quality Standards for service user experience in adult mental health services, derived from NICE clinical guideline 136**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Statement 11</strong></td>
<td>People in hospital for mental health care, including service users formally detained under the Mental Health Act, are routinely involved in shared decision-making</td>
</tr>
<tr>
<td><strong>Statement 12</strong></td>
<td>People in hospital for mental health care have daily one-to-one contact with mental healthcare professionals known to the service user and regularly see other members of the multidisciplinary mental healthcare team</td>
</tr>
<tr>
<td><strong>Statement 13</strong></td>
<td>People in hospital for mental health care can access meaningful and culturally appropriate activities 7 days a week, not restricted to 9am to 5pm</td>
</tr>
<tr>
<td><strong>Statement 14</strong></td>
<td>People in hospital for mental health care are confident that control and restraint, and compulsory treatment including rapid tranquillisation, will be used competently, safely and only as a last resort with minimum force</td>
</tr>
<tr>
<td><strong>Statement 15</strong></td>
<td>People using mental health services feel less stigmatized in the community and NHS, including within mental health services</td>
</tr>
</tbody>
</table>
Appendix 3

Wessex AHSN - Measures used to assess the effectiveness of the pathway

Basic Data

- Incidence and prevalence of people with psychotic disorder;
- Number of people in services with diagnosis of psychosis with co-existing substance misuse &/or complex trauma (BPD) (from diagnostic coding & HONOS/MCHT);
- Demographic information.

Early access to services

- Timeliness;
- EIP referrals/predicted incidence;
- No and % who access Acute Care Team;
- Length of stay with ACT;
- MHA detention rates;
- A&E attendances;
- Section 136 assessments;
- Contact with Criminal Justice System;
- Emergency admissions to hospital.

Access to interventions

- Timeliness - to CBT (Cognitive Behaviour Therapy), FI (Family Intervention), IPS (Independent Placement Support);
- Duration of untreated psychosis;
- Delayed discharge;
- Medication.

Physical health

- % of individuals who have their physical health assessed and monitored regularly;
- Admissions to general hospital;
- Physical health checks (QOF) & intervention (CQC) (MHLDDS).

Outcomes

- Change in symptoms: HoNOS, DIALOG +/- DRAKE, PHQ9, GAD7, Mania scale;
- Changes in Hope Agency and Opportunity (PROM): Accomodation & Employment;
- Carer and family support.

Recovery & relapse rates at 6 months, 1 & 2 years

- Self-harm / suicide / premature mortality.
Appendix 4

Wessex AHSN - Treatment and recovery in psychosis pathway

Routine Referral

**Screen**
- Referral received
- Tel. triage using screening checklist to:
  - determine urgency
  - consider medication, social, psychological and physical health needs

**Holistic Assessment**
- 'At risk of psychosis' assessment:
  - engagement
  - medication, social, psychological and physical health needs
  - patient and carer views
  - outcome measures incl. PROM

**MDT Discussion**
- Involving medical, nursing and social care staff as minimum to agree:
  - provisional formulation/diagnosis
  - priorities for care planning

**Care Plan/CPA**
- Collaborative planning from first contact:
  - Safety and crisis plan
  - Medication, social, psychological and physical needs
  - Carers support
  - Substance misuse

**Delivery of Care**
- Engagement from first contact (incl. assertive)

**Review of Care Plan**
- If deterioration in mental health/crisis/relapse:
  - identify any deterioration early and fast track
  - consider acute care pathway

**Discharge**
- Plan with patient/carer, including GP if over 6-12 months:
  - stable and functioning well
  - no medication or stable medication
  - not detained
  - acute care pathway not needed

**Care Plan/CPA**
- Allocation of care coordinator and care plan within 14 days of referral
- Formulation by medic within 21 days of referral

**Delivery of Care**
- Commence within 14 days of referral

**Review as Required by Personal Plan**
- Weekly face to face: if first episode
  - if medication changes, changing mental state, current risks, carer concerns, specific interventions
  - weekly/biweekly: difficulties engaging in services
  - every 4 weeks: consider Clozapine if no response to antipsychotic medication

- if mental state is settled, consider increasing review to 3 monthly then 6 monthly
- Annual review: (if not indicated sooner) of Care Plan/CPA (incl. items listed in Care Plan/CPA box above). Completion of outcome measures

---

**Additional Notes**

- **Prevention and Early Detection**
  - Screen:
    - Referral received
    - Tel. triage using screening checklist to:
      - determine urgency
      - consider medication, social, psychological and physical health needs

- **Routine Referral**
  - **Screen**
    - Within 24 hours
  - **Assessment**
    - First face to face contact within 7 days
  - **MDT Discussion**
    - Within 7 days of assessment
    - Earlier medical review if /concerns
    - Discharge signpost if psychosis pathway not appropriate
  - **Care Plan/CPA**
    - Allocation of a care coordinator and care plan within 14 days of referral
    - Formulation by medic within 21 days of assessment
  - **Delivery of Care**
    - Commence within 14 days of referral
  - **Review of Care Plan**
    - If deterioration in mental health/crisis/relapse:
      - identify any deterioration early and fast track
      - consider acute care pathway
  - **Discharge**
    - Plan with patient/carer, including GP if over 6-12 months:
      - stable and functioning well
      - no medication or stable medication
      - not detained
      - acute care pathway not needed
    - Complete crisis and contingency plans
    - Comprehensive communication with primary care, patient and carer
  - **Care Plan/CPA**
    - Allocation of care coordinator and care plan within 14 days of referral
    - Formulation by medic within 21 days of assessment
  - **Delivery of Care**
    - Commence within 14 days of referral
  - **Review as Required by Personal Plan**
    - Weekly face to face: if first episode
      - if medication changes, changing mental state, current risks, carer concerns, specific interventions
      - weekly/biweekly: difficulties engaging in services
      - every 4 weeks: consider Clozapine if no response to antipsychotic medication
  - if mental state is settled, consider increasing review to 3 monthly then 6 monthly
  - Annual review: (if not indicated sooner) of Care Plan/CPA (incl. items listed in Care Plan/CPA box above). Completion of outcome measures

---

**Wessex AHSN – NHS Creative – May 2015**

---

**Imperial College Health Partners and Wessex AHSN: Pathways to recovery**

---

**23**
Appendix 4

Wessex AHSN - Treatment and recovery in psychosis pathway

Crisis and Acute Care

Screen
Referral received
- determine urgency
- consider medication, social, psychological and physical health needs

Holistic Assessment
Centred around views of patient and carer (review assessment if one already present):
- engagement
- medication, social, psychological and physical health needs
- patient and carer views
- outcome measures incl. PROM

MDT Discussion
Involving medical, nursing and social care staff as minimum to agree:
- provisional formulation /diagnosis
- priorities for care planning

Care Plan/CPA
- Update care plan
- Risk management plan
- Physical health
- Safeguarding (adult/child)
- Social issues
- Family issues
- Medication Management plan
- Carers support
- Consider psychological interventions
- Commence discharge planning

Delivery of Care
- Assertively engage if needed
- Begin/adjust medication, (crisis management), social care unless contraindicated
- Initiate psychological interventions (see stepped pathway)

Review
- MDT discussion (CPA if criteria met) to review mental state, medication, social, psychological & physical health needs; update care plan
- Advanced statement
- WRAP, vocational needs
- Review outcome measures incl. PROM

Worsening mental state:
- monitor risk
- monitor changes
- monitor compliance
- monitor self care
- Review care plan
- Reviews psychological interventions (see stepped pathway)
- Review care plan
- Review psychological interventions (see stepped pathway)

Delivery of Care
Commence within 24-48 hours of assessment
Medication review within this time frame
Allocation of a care coordinator within 14 days

Review as per Personal Crisis Plan
In crisis: daily or twice daily if needed for medication compliance, interventions, review of risk and mental state and need for inpatient care, etc.
- Review of frequency via MDT
- Discuss response to treatment
- Discharge CPA (if inpatient) within 7 days of assessment
- 7 day follow up after discharge from acute pathway

Transfer to Community Team
- MDT discussion
- Review needs and plan care including crisis plan
- Comprehensive communication with community team, primary care, patient and carer

Screen
Within 4 hours

Assessment
Urgent – face to face within 24 hours
MHA assessment if needed
Medication review within 48 hours of referral

MDT Discussion
Within 24 hours of assessment
Consider medication Formulation with medic within 72 hours of assessment

Care Plan/CPA
Commence within 24-48 hours of assessment
Medication review within this time frame
Allocation of a care coordinator within 14 days

Review
- MDT discussion (CPA if criteria met) to review mental state, medication, social, psychological & physical health needs; update care plan
- Advanced statement
- WRAP, vocational needs
- Review outcome measures incl. PROM

Worsening mental state:
- monitor risk
- monitor changes
- monitor compliance
- monitor self care
- Review care plan
- Reviews psychological interventions (see stepped pathway)
- Review care plan
- Review psychological interventions (see stepped pathway)

Delivery of Care
Commence within 24-48 hours of assessment
Medication review within this time frame
Allocation of a care coordinator within 14 days

Review as per Personal Crisis Plan
In crisis: daily or twice daily if needed for medication compliance, interventions, review of risk and mental state and need for inpatient care, etc.
- Review of frequency via MDT
- Discuss response to treatment
- Discharge CPA (if inpatient) within 7 days of assessment
- 7 day follow up after discharge from acute pathway
Appendix 5

Imperial College Health Partners - Early intervention in psychosis pathway

- People who are seeking help with “prodromal” experiences which commonly precede psychosis, refer to EIS for assessment;
- Allocate a care co-ordinator;
- Have a multidisciplinary team (MDT) assessment;
- Offer a carer’s assessment.

- Offer CBT;
- Offer Medication;
- Offer Family Intervention;
- Offer physical health checks and review and act on results - using Lester tool as a guide. Where service user declines, renegotiate this regularly.

- Offer an individual formulation (a systematic individual explanation of the person’s difficulties) which may involve a diagnosis.
Appendix 5

Imperial College Health Partners - Early intervention in psychosis pathway

- Medicines reviewed with reference to initial agreement and expectations of risks and benefits and side effects;
- Non-compliance and substance misuse should be discussed, and other options including Clozapine;
- Review of MDT involvement.

- Offer structured, collaborative, recovery focused relapse planning including a flexible approach to engagement e.g. text, apps, email, phone, visits, family;
- Physical health check review;
- Offer Individual Placement Support (IPS);
- Offer support with self-management e.g. that provided in a recovery college.

- Transfer discussed and planned ahead of time;
- On day of transfer ensure a structured handover CPA and allocation to new care-coordinator or GP.

Illustrations by Charlotte Hollands.