



# Implementing the Early Intervention in Psychosis Access and Waiting Time Standard: Guidance



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### Foreword

Achieving parity of esteem for people with mental health needs is one of the NHS's core priorities and is written into the Health and Social Care Act. For too long, mental health has languished behind physical health in terms of priority and investment, and people have not received the high-quality support they need. Currently, one in four people will experience a mental health problem in their lifetime and the cost of mental ill health to the economy, NHS and society is estimated to be £105 billion a year. Both the human cost and the cost to the public purse have been seen, rightly, to be unacceptable.

The independent Mental Health Taskforce, which published its report in February 2016, highlighted the need to improve access to high-quality care for all. The introduction of the access and waiting time standard for early intervention in psychosis (EIP) services and improving access to psychological therapy (IAPT) services heralded the start of a new approach to deliver this improved access and embed standards akin to those for physical health.

The EIP standard is not just a new approach for mental health but is a clear national priority for the NHS. Delivering the standard is one of the national commitments for 2016/17 in both the Mandate and the NHS Shared Planning Guidance. This document is intended to provide support to local commissioners and providers in implementing the standard. It has been coproduced by a wide range of experts, including people with lived experience of services, to set out what works and provide a blueprint for localities to follow. It is not intended to direct but to support, by demonstrating the evidence and setting out clearly how progress will be measured.

Implementing this standard will make a major difference to the quality of care received by those with first episode psychosis, and greatly improve their ability to recover. But this is only a start – we must not stop with the initial standard but continue to push for further improvement. Responding to a recommendation made by the Mental Health Taskforce, we will expand provision further to increase access, ensuring that at least 60% of people referred begin treatment with highquality care by 2020/21.

The journey towards improving mental health services will build on the EIP approach, supported by a range of new pathways to be developed over the coming years to further embed change within local systems. This document represents a first step on that journey.

Professor Tim Kendall National Clinical Director for Mental Health

### Key messages

- 1. Psychosis is characterised by hallucinations, delusions and a disturbed relationship with reality, and can cause considerable distress and disability for the person and their family or carers. A diagnosis of schizophrenia, bipolar disorder, psychotic depression or other less common psychotic disorder will usually be made, although it can take months or even years for a final diagnosis.
- 2. Treatment can begin as soon as a provisional diagnosis of first episode psychosis is made it does not have to wait for a final diagnosis. Treatment should be provided by an early intervention in psychosis (EIP) service. These services are evidence-based, cost-saving and preferred by service users and carers over generic services.
- 3. People who experience psychosis can and do recover. The time from onset of psychosis to the provision of evidence-based treatment has a significant influence on long-term outcomes. The sooner treatment is started the better the outcome and the lower the overall cost of care.
- 4. To improve access to EIP services, NHS England is introducing an access and waiting time standard. It is for all people experiencing first episode psychosis (including that associated with trauma or substance misuse). The standard is also relevant for people at high risk of psychosis (an 'at risk mental state').
- 5. The standard requires that, from 1 April 2016, more than 50% of people experiencing first episode psychosis commence a National Institute for Health and Care Excellence (NICE)-recommended package of care within two weeks of referral. Treatment will be deemed to have commenced when the person:
  - a. has had an initial assessment; AND
  - b. has been accepted on to the caseload of an EIP service capable of providing a full package of NICE-recommended care; AND
  - c. has been allocated to and engaged with by an EIP care coordinator.
- 6. All NHS-commissioned EIP services will be expected routinely to record data regarding EIP waiting times, NICE-recommended interventions and outcome measures via the Mental Health Services Data Set. They will also be expected to take part in a national quality assessment and improvement programme.
- 7. EIP services should provide the full range of psychological, psychosocial, pharmacological and other interventions shown to be effective in NICE guidelines and quality standards, including support for families and carers. Effective and integrated approaches are needed to address the social and wider needs of people with psychosis to help them live full, hopeful and productive lives. EIP services also need the capacity to triage, assess and treat people with an at risk mental state, as well as to help those not triaged to access appropriate treatment and support.
- 8. Commissioning EIP services should be underpinned by estimated local incidence of psychosis, derived to incorporate a range of demographic features such as ethnicity, age, population density and deprivation to ensure services are designed to serve fully the needs of a particular locality.
- 9. Commissioners and providers shouldensure that children and young people (aged under 18) also benefit fully from the standard and that there are robust local arrangements in place between children and young people's mental health services and EIP services so that specialist expertise in working with children and young people with psychosis is available.
- 10. Health Education England will shortly make available a workforce planning tool to support commissioners and providers to plan the EIP capacity and skill mix required locally to ensure sustainable delivery of high-quality, NICE-recommended care.

### 1 Introduction

I was so wary of help and advice from others, that when I was referred into EIP, I felt I could relax in a way that I hadn't been able to in so long. Upon referral, I initially met with my designated Care Coordinator (CC). She became my 'guide' to the service as she led me through recovery. Having a CC worked so well for me as an individual – I think being so scared and unsure initially meant I was well suited having just one person of contact whom I could build trust, familiarity and security with.

My CC helped me evaluate the things I was doing in life that were more unhelpful than helpful and I started making small changes for the better. Looking at my symptoms closely helped me to identify when things were getting worse – or better; important for being able to ask for help. For me, I felt medication was a good route to try in tandem with talking therapies, but everybody finds different things useful.

Slowly the fog started lifting and I began to feel more like me again. I was able to make good use of CBT (cognitive behavioural therapy) sessions with my CC and sessions with the team psychologist. This helped me understand the way I was feeling when I developed psychosis and look at new ways of coping in future situations.

With the continued support of EIP across three years I feel like 'me' again; I have recently been discharged from the service and am no longer on any medication. I am very ambitious in my career, working full time for the last 2.5 years and am enjoying being a first time mum to my 10-month old baby

Source: Taken from the Early Youth Engagement (EYE) in First Episode Psychosis project.<sup>12</sup>

#### 1.1 Background

In October 2014, NHS England and the Department of Health jointly published Achieving better access to mental health services by 2020. This document outlined a first set of mental health access and waiting time standards for introduction during 2015/16. These commitments were reaffirmed in the Government's mandate to NHS England for 2016-17 and included as one of nine 'must dos' for the NHS in the NHS Shared Planning Guidance for 2016/17-2020/21.

#### 1.2 The early intervention in psychosis access and waiting time standard

The access and waiting time standard for early intervention in psychosis (EIP) services requires that, from 1 April 2016 more than 50% of people experiencing first episode psychosis will be treated with a NICE-approved care package<sup>a</sup> within two weeks of referral. The standard is targeted at people aged 14-65.<sup>b</sup>

In response to the recommendation of the <u>Mental Health Taskforce</u>, NHS England has committed to ensuring that, by 2020/21, the standard will be extended to reach at least 60% of people experiencing first episode psychosis.

<sup>a</sup> Throughout the rest of this document the term 'NICErecommended' package of care/intervention has been used at the request of NICE.

<sup>b</sup> EIP services may also be clinically appropriate for people outside the 14-65 age group. Professionals should use their clinical judgement when considering whether people outside the 14-65 age group should be referred to / accepted by EIP services with commissioners and providers ensuring that people are not inappropriately restricted from accessing care. The standard is 'two-pronged' and both conditions must be met for the standard to be deemed to have been achieved:

- 1. a maximum wait of two weeks from referral to start of treatment; and
- treatment delivered in accordance with NICE guidelines and quality standards for psychosis and schizophrenia – either in children and young people <u>CG155 (2013) and</u> <u>QS102</u> or in adults <u>CG178 (2014)</u> and <u>QS180</u>.

The approach to measurement of performance against the standard has been designed to ensure that both elements can be assessed and outcomes (clinician and service user reported) routinely collected and reviewed (see section 4).

#### 1.3 Why set a standard?

In 2011, <u>No Health Without Mental Health</u> highlighted the effectiveness of EIP services for people experiencing first episode psychosis. There is good evidence that these services help people to recover and to gain a good quality of life. EIP services have demonstrated that they can significantly reduce the rate of relapse, risk of suicide and number of hospital admissions. They are cost-effective and improve employment, education and wellbeing outcomes.<sup>3456</sup>

There are significant personal, social and health impacts of psychosis when treatment and support is not effective. The cost of not intervening early can often be poor health outcomes and lengthy, costly use of mental health services. The current cost of psychosis to society is estimated to be £11.8 billion per year resulting from direct healthcare costs, lost productivity due to unemployment or death and informal costs to families and carers.<sup>7</sup>

Despite this, in recent years, there has been evidence of disinvestment in EIP services including the absorption of some EIP services into generic community mental health services,<sup>8</sup> with consequent impact on the timeliness, quality and effectiveness of treatment. We know that currently far too few individuals experiencing or at high risk of first episode psychosis are receiving the 'right care' at the 'right time' and there can be very long delays in accessing some of the key effective interventions recommended by NICE. For example, only 10% of those with schizophrenia who could benefit from services receive appropriate psychological treatment<sup>7</sup> and only 33% receive recommended physical health checks.<sup>9</sup> These poor levels of access and long waits are unacceptable both in terms of quality of care and effective use of NHS resources.

The high level aims of the new standard are therefore to ensure that:

- Anyone with an emerging psychosis and their families and key supporters can have timely access to specialist early intervention services, which provide interventions suited to age and phase of illness.
- Individuals experiencing first episode psychosis have consistent access to a range of evidence-based biological, psychological and social interventions as recommended by the NICE guidelines and quality standards for psychosis and schizophrenia – either in children and young people <u>CG155 (2013)</u> and <u>QS102</u> or in adults <u>CG178 (2014)</u> and <u>QS180</u>.
- 3. Care is provided equitably taking into account higher rates of psychosis in certain groups who may experience difficulties in accessing traditional services.

#### 1.4 Expectations of commissioners and providers

Commissioners and providers should already be taking action to ensure delivery of EIP service development and improvement plans, as required in the 2015/16 planning guidance <u>The Forward View into Action: Planning for</u> <u>2015/16</u>. It is expected that in all areas work is underway to address identified gaps in capacity, skill mix and staff competencies (to deliver the full range of interventions recommended by NICE) through service investment, redesign and staff development. From 2015/16 an additional £40m was made available to CCG commissioners via the tariff specifically to support implementation of the new standard.<sup>cd</sup>

<sup>c</sup><u>https://www.england.nhs.uk/wp-content/uploads/2014/11/</u> payment-systs-mh-note.pdf

<sup>d</sup> https://www.england.nhs.uk/wp-content/uploads/2015/04/ tariff-arrangements-1516-qa-v9.pdf The <u>NHS Shared Planning Guidance for</u> <u>2016/17-2020/21</u> includes the EIP standard as a system 'must do' and local health and care systems are expected to include EIP developments in both their one-year operational plans and longer-term <u>Sustainability</u> and <u>Transformation Plans</u>. Progress against plans will be measured through the new <u>clinical</u> <u>commissioning group (CCG) improvement and</u> <u>assessment framework</u>.

Commissioners are responsible for ensuring that local plans are developed and implemented in collaboration with service users and their families or carers, as well as the local mental health provider and partner organisations, including voluntary and third sector organisations, drug and alcohol commissioners and providers and local authorities (social care, housing, debt, benefit advice, employment and education) to provide a framework for collaborative action. Local plans should be aligned with the overarching principles and ambitions to improve children and young people's mental health and wellbeing as set out in <u>Future in Mind</u>.

The reduction of inequalities in access and outcomes should be central to the development of EIP services. Local commissioners must make explicit in their plans how they have taken into account the duties placed on them under the <u>Equality Act 2010</u> and their duties with regard to reducing health inequalities as set out in the <u>Health and Social Care Act 2012</u>. Service design and communications should be appropriate and accessible to meet the needs of diverse communities (see <u>Guidance for Commissioners</u> on the Equality and Health Inequalities Duties).

#### **1.5 Purpose of this document**

This guide is intended to support local implementation of the EIP access and waiting time standard by CCG commissioners and mental health providers, working collaboratively with service users and their families or carers and partner organisations.

The guide has been organised into four further chapters as described <u>page 10</u>.

Additional resources have been brought together in the accompanying <u>Helpful</u> <u>Resources pack</u>. This pack includes:

- EIP positive practice examples (with a particular focus on delivery of one or more of the key statements from the <u>Psychosis</u> <u>and Schizophrenia in Adults NICE quality</u> <u>standard</u>)
- contact details for regional EIP leads
- · links to other helpful web-based resources.

## 1.6 How was this document developed?

NHS England has commissioned NICE to oversee delivery of an enabling programme of work to support the development and implementation of evidence-based treatment pathways in mental health, including the introduction of access and waiting time standards. NICE commissioned the National Collaborating Centre for Mental Health (NCCMH) to develop this guide. The NCCMH is a partnership between the Royal College of Psychiatrists and the British Psychological Society's Centre for Outcomes Research and Effectiveness at University College London. It was established in 2001 and was one of the first national collaborating centres set up by NICE to develop clinical guidelines.

An expert reference group (ERG), facilitated by NCCMH, was established to provide expertise and comment on iterations of this document. This informed the work of a supporting technical team responsible for drafting the document and developing an accompanying workforce planning tool. The ERG included commissioning, clinical, academic, operational and service leaders, people with lived experience and carer representation. The ERG was informed by the latest research findings and best practice consensus relevant to adults, children and young people with first episode psychosis, including perspectives from service users and their families. A range of other experts have provided invaluable input to the development of this guidance document. See Appendix 1 for details of ERG and technical team membership and expert input.

Chaj	oter	Purpose of the chapter
2	What is first episode psychosis and why is rapid access to effective treatment so important?	<ul> <li>To provide service user, carer and clinical perspectives in describing first episode psychosis and 'at risk mental states'.</li> <li>To provide key facts regarding psychosis incidence and why incidence levels may vary from area to area.</li> <li>To explain the critical importance of ensuring timely access to effective treatment.</li> </ul>
3	What are EIP services?	<ul> <li>To provide a service user account of the support offered by an EIP team and how this enabled recovery.</li> <li>To provide a description of EIP services and their benefits.</li> <li>To describe the essential interventions recommended by NICE that are relevant for EIP services and other key service functions.</li> <li>To describe the EIP skill mix necessary to deliver care in line with NICE recommendations.</li> <li>To describe optimal service models for urban, suburban and sparsely populated rural areas.</li> <li>To describe best practice in joint working with children and young people's mental health services.</li> </ul>
4	The new access and waiting time standard	<ul> <li>To describe, from a service user perspective, why timely access to the full range of interventions recommended by NICE is essential to enabling recovery.</li> <li>To clarify the approach to measurement for both elements of the standard (the waiting time and the delivery of care in line with NICE recommendations).</li> <li>To describe the recommended approach to routine measurement of outcomes (clinician and service user reported).</li> <li>To clarify data collection and reporting requirements.</li> </ul>
5	Key commissioning and service development considerations	<ul> <li>To provide a step-by-step process that local commissioners and providers can follow, working collaboratively with stakeholders, to ensure sustainable delivery of the EIP access and waiting time standard.</li> </ul>

## 2 What is first episode psychosis and why is rapid access to effective treatment so important?

2.1 Experiences of first episode psychosis

My first experience of psychosis occurred when I left home to go to university. This was a sudden change and there was a heavy party culture there involving late nights and increased alcohol consumption. This on top of the stress of a heavy work load all contributed to triggering my first episode of mania which led to psychosis.

Although I had previously suffered from depression since my early teenage years this episode led to my current diagnosis of bipolar affective disorder. In this manic state I started behaving erratically, spending large amounts of money and having endless energy, racing thoughts and elated mood. This led to me staying up all night, feeling no need for sleep. I had new found confidence and would talk excessively at a face pace about unusual and irrelevant things.

This obvious change in behaviour concerned my friends who tried to talk to me but at that point I was in denial anything was wrong. However soon this developed into psychosis where I had paranoid and delusional thoughts that someone was out to harm me. I became increasingly scared and whenever I heard sirens outside I thought they were relating to me.

The whole experience was incredibly scary and distressing as even though the thoughts and feelings had no basis they felt very real to me at the time.

Source: Taken from the Early Youth Engagement (EYE) in First Episode Psychosis project.<sup>12</sup>

<u>When my daughter f</u>irst became ill, she was unreachable. She was in a place that I didn't recognise. At first, she wasn't able to communicate at all; she was completely mute. Little by little she found the ability to start talking and spoke about events that had apparently happened to her. I recognised some of the real-life events that had been incorporated into her own version, but when she related an incident where she was in a police station being beaten up and she could hear me outside saying 'Stop, stop, they're really hurting her', I knew that hadn't happened. But to her it was as real as any other event. I felt that she was very lost and I wasn't able to help her.

I remember feeling that I was completely out of my depth. It was as if my daughter had been taken over and I no longer knew her, I no longer knew what was happening to her. But it was very obvious that she was in extreme psychic pain. Her stories didn't make sense to me, although they did seem to link, in her mind, to what she had been through. To me, she displayed every sign of somebody who had been traumatised and that this was post-traumatic stress.

At that stage I think we both needed help.

Source: Taken from the Early Youth Engagement (EYE) in First Episode Psychosis project.<sup>12</sup>

#### 2.2 Clinical definitions

#### 2.2.1 First episode psychosis

First episode psychosis is the term used to describe the first time a person experiences a combination of symptoms known as psychosis.<sup>e</sup> During an episode of psychosis, 'a person's perception, thoughts, mood and behaviour are significantly altered'.<sup>10</sup> Each person will have a unique experience and combination of symptoms. Core clinical symptoms are usually divided into 'positive symptoms', so called because they are added experiences, including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and 'negative symptoms', so called because something is reduced (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect).<sup>10</sup> A range of common mental health problems (including anxiety and depression) and coexisting substance misuse may also be present.

#### 2.2.2 At risk mental states

Typically, before an episode of psychosis, many people will experience a relatively long period of symptoms, which is described as having an 'at risk mental state',<sup>11</sup> often shortened to ARMS. This may include:

- a more extended period of attenuated (less severe) psychotic symptoms; or
- an episode of psychosis lasting less than seven days; or
- an extended period of very poor social and cognitive functioning (perhaps accompanied by unusual behaviour including withdrawal from school or friends and family) in the context of a family history of psychosis.

When treating a person presenting with an at risk mental state, it is important both to support them with their current needs as well as to try to prevent transition to psychosis.

# 2.3 How common is first episode psychosis?

Incidence rates refer to the number of new cases during a given period. The weighted average incidence of psychosis in England is 31.7 per 100,000.<sup>12</sup> However, it is important to note that incidence levels can vary significantly from one area to another according to age, sex, ethnicity, population density and social deprivation.<sup>12</sup>

First episode psychosis occurs most commonly between late teens and late twenties, with more than three quarters of men and two thirds of women experiencing their first episode before the age of 35.<sup>13</sup> This means that areas serving younger populations (e.g. areas with higher education colleges and universities) may have higher rates of psychosis.<sup>12</sup> A small proportion of people will also experience an onset of psychosis before the age of 16 years, with an additional peak in incidence in women in their mid-to-late 40s.<sup>12</sup>

Higher rates have also been found across a number of ethnic minority groups, notably migrants and descendants of black Caribbean and black African origins.<sup>12</sup> Geographically, the incidence rates of psychosis are also higher in more urban, more deprived and more densely populated settings.<sup>14</sup>

<sup>&</sup>lt;sup>e</sup> In the context of the access and waiting time standard, the term 'first episode psychosis' is used to describe the first time a person presents to services with a combination of symptoms know as psychosis. People who have experienced psychosis for the first time prior to presentation but who previously did not access EIP services are also eligible.

#### 2.4 What is the impact of not having timely access to effective treatment?

Psychosis and psychotic disorders can be extremely debilitating. A long duration of untreated psychosis is associated with poorer personal recovery, increased service use and poorer economic outcomes in both the shortand long-term.<sup>15</sup> People who do not access effective treatment quickly are far more likely to experience poor physical health, lower levels of social functioning and poorer occupational and educational outcomes.

- In the UK, only 8% of people with schizophrenia are in work, despite many more being willing and able to work.<sup>16</sup>
- People with severe and prolonged mental illness (diagnoses that usually involve psychosis, such as schizophrenia and bipolar disorder) are at risk of dying on average 15 to 20 years earlier than other people.<sup>17</sup> Two thirds of these premature deaths are from avoidable physical illnesses, including heart disease and cancer, many caused by smoking. This is one of the greatest health inequalities in England. People with psychosis are three times more likely to attend A&E with an urgent physical health need and almost five times more likely to be admitted as an emergency.<sup>f</sup>
- If untreated or poorly treated, psychosis can become a long-term condition with high levels of relapse, high rates of inpatient admission, increased detentions under the <u>Mental Health Act 1983</u> and high rates of comorbid physical health conditions.

For society, the current cost of psychosis is estimated to be £11.8bn per year.<sup>7</sup> This results from direct healthcare costs, lost productivity due to unemployment or death and informal costs to families and carers. It is clear that there are significant gains to be made by ensuring that people experiencing psychosis for the first time have rapid access to effective, evidencebased treatment.

<sup>&</sup>lt;sup>f</sup>http://www.qualitywatch.org.uk/sites/files/qualitywatch/ field/field\_document/QualityWatch\_Mental\_ill\_health\_and\_ hospital\_use\_full\_report.pdf

# 3 What are early intervention in psychosis services?

#### 3.1 A service user perspective

I first came into contact with the Pier team in 2011 whilst I was taking a year out of university. After deciding to travel the world I went to Thailand for a month. In the third week there I started getting symptoms of paranoia which led to a psychotic episode where I saw, heard and smelled things that weren't really there, due to various reasons such as stress, lack of sleep, stopping my medication and not eating properly. I was travelling alone so I was very scared about the ideas and thoughts I was having which all seemed very real at the time. I was very worried and anxious about the things I thought were happening and because of this I did not understand how I could carry on in the world if these things were actually real.

When I was back in England and met my family I thought that they were imposters and actually Thai people in the bodies of my family. I did not trust my family as a result. I didn't want them to cook for me, or drink anything they gave me and didn't want to leave the house. It was my family who contacted the GP as they were so worried and concerned about me because they had not seen me like this before and they didn't understand why I was behaving and thinking the way I was and ultimately they just wanted me to get better. It was a really stressful time for me but also for my family as well. The GPs assessed me and then sent round the crisis team who decided that I needed to go to hospital on a section.

After four weeks of being an inpatient I was very lucky to have met the PIER team who are a community early intervention psychosis team who were placed in charge of my care after I left the hospital and who have been integral to my recovery. Under the guidance of community psychiatric nurses, occupational therapists, psychologists and psychiatrists I have made a successful recovery from my diagnosis of paranoid schizophrenia and am in complete remission at the minute. They looked after me through my hardest times and also my best and really saw my potential and empowered me to: understand my illness; look after myself; and pursue my goal of becoming a mental health nurse. They really inspired me to do for others what they did for me.

I have had loads of side effects with various different medications such as weight gain, eye problems and hair loss so the psychiatrist in the PIER team really helped me through giving me advice to find the right medication for me to limit my side effects and also maintain my health. All the while allowing me to be in control of what medication I wanted to be on and making recommendations based on my wishes. I have also had a few relapses but I have always recovered from them due to the right care and realise the importance of taking my medication every day. At present I do not have any symptoms of my condition.

I have been helped to explore my issues through CBT with the psychologist there and this has really helped me to challenge my thoughts and understand my condition. I have learned through identifying early warning signs or possible triggers you can successfully manage your condition and this is really important.

I went back to university after my first psychotic episode and finished my degree and actually did surprisingly well and gained a 2:1 classification in Psychology BSc Hons in 2012 and now I am studying a PGdip mental health nursing course, as I was directly inspired by

the team to do this, and will hopefully qualify in two years by 2016 so maybe one day I can also work in a community mental health team!

The PIER team really showed so much compassion and care and empowered me to be where I am at today. I am forever indebted to them and I have had such a positive experience being one of their service users! Even during my transition from this team to a team in London they have kept me on the records until I settle in and they have been proactive in referring me to a team where I am studying. They have been great and really care about the welfare of their service users. I would highly recommend the PIER team and I will be calling up their 'complaint phone line' in order to leave them a massive compliment and positive feedback!

Source: Taken from: V Gupta My Story: From Psychosis to Psychology.

### 3.2 What are the benefits of EIP services?

Recovery from a first episode of psychosis is possible; people who receive the right treatment at the right time from an EIP service can go on to lead full, hopeful and productive lives.

- People experience improved outcomes when receiving care from an EIP service compared with standard care.<sup>18</sup>
- Evidence suggests that early treatment with CBT may prevent at risk mental states from developing into first episode psychosis.<sup>19 20</sup>
- Family intervention has been shown to improve outcomes significantly, predominantly through supporting the family to understand the experience of psychosis and to respond appropriately,<sup>21</sup> resulting in relapse rates reducing by 40%.
- CBT for psychosis has been shown to be effective in reducing the number of hospitalisations, bed days and crisis contacts. There is also a strong indication that it reduces symptomatology and has a positive effect on social functioning.<sup>22 23</sup>
- In the long-term, a 10-year follow-up study reported higher rates of symptomatic

<sup>9</sup> The Improving Access to Psychological Therapies for Severe Mental Illness (IAPT for SMI) project aims to increase access to a range of NICE approved psychological therapies for psychosis, bipolar disorder and personality disorders. The longterm ambition is to ensure that evidence-based psychological therapies are routinely available as a frontline treatment for all people with psychosis, bipolar disorder and personality disorders who could benefit from them. recovery (50%) and a 90% reduction in risk of unnatural-cause mortality when full family involvement was present at the first contact.<sup>24</sup>

 In the short and long-term, supported employment appears to improve employment outcomes, functioning and quality of life.<sup>10</sup>

The short- and longer-term economic benefits of EIP services are significant, with estimated net cost savings of £7,972 per person after the first four years, and £6,780 per person in the next four to 10 years if full EIP provisions are provided. Over a 10-year period this would result in £15 of costs saved for every £1 invested in EIP services.<sup>21</sup> The majority of these cost savings can be attributed to:

- the reduction in use of crisis and inpatient services
- improved employment outcomes
- the reduction in risk of future hospitalisation as a result of improved management and reduced risk of relapse.

Economic data from the South London and Maudsley NHS Foundation Trust EIP demonstration sites for the Improving Access to Psychological Therapies – Severe Mental Illness (IAPT-SMI) programme<sup>g</sup> suggest that, despite the increased cost of therapy, the provision of NICE-recommended psychological therapy within EIP services is cost-effective. This comes from reduced inpatient costs during the course of therapy and improvements in quality of life and employment status post-therapy. A recent randomised trial in the NHS showed that intensive liaison between primary care and EIP services to identify and refer people with first episode psychosis or an at risk mental state doubled referrals but saved money overall by avoiding the high costs of unrecognised illness.<sup>25</sup> The incremental cost per qualityadjusted life year (QALY) of providing CBT for psychosis is £12,731, and therefore is costeffective according to NICE.<sup>21</sup>

#### 3.3 EIP service description

An EIP service is a multidisciplinary community mental health service that provides treatment and support to people experiencing or at high risk of developing psychosis. This support typically continues for three years. The defining characteristic of an EIP service is its strong ethos of hope and whole-team commitment to enabling recovery through the provision of individually tailored, evidence-based interventions and support to service users and their families / carers.

Below is a summary, based on NICE guidelines, of the key components of a high-quality EIP service from the perspective of service users and carers / families<sup>h</sup>:

- swift assessment through a readily accessed point of contact by a practitioner competent in recognising first episode psychosis
- staff who build up trust and confidence
- provision of good information to help them to understand psychosis and treatment options
- a care coordinator who will support them throughout their time in the service, including helping them with selfmanagement skills, social care issues such as housing or debt management, and relapse prevention work
- a choice of psychological and pharmacological interventions
- support, information and advice for families and carers, including carers' assessments where required

- support with employment, training and / or education
- regular physical health checks, monitoring and appropriate treatment, with support and / or education
- regular monitoring of risk
- routine monitoring of other coexisting conditions, including depression, anxiety and substance misuse, particularly in the early phases of treatment
- a crisis plan and prompt service response to help them to manage when in crisis.

These key service components are considered in further detail later on in this chapter.

The core aims of EIP services are to:

- reduce the duration of untreated psychosis, including support for people with an at risk mental state, and for some, prevent transition to psychosis
- produce effective outcomes in terms of recovery and relapse rates.

#### 3.4 Relevant NICE guidelines and quality standards

The following NICE guidelines and their accompanying quality standards are directly relevant to the provision of EIP services:

- <u>Psychosis and Schizophrenia in Children and</u> <u>Young People NICE guideline</u>
- <u>Bipolar Disorder, Psychosis and Schizophrenia</u> <u>in Children and Young People NICE quality</u> <u>standard</u>
- <u>Psychosis and Schizophrenia in Adults NICE</u> <u>guideline</u>
- <u>Psychosis and Schizophrenia in Adults NICE</u> <u>quality standard.</u>

The key requirements of the quality standards (the individual statements) are summarised in the table on page 17. Tables providing further detail regarding the interventions recommended by NICE can be found in Appendix 2.

EIP services are also expected to continue to offer care and treatment to people with psychosis who may go on to receive a diagnosis of bipolar disorder or unipolar psychotic depression. Therefore, depending on the emerging diagnosis, other guidelines and

<sup>&</sup>lt;sup>h</sup> Further information can also be found in the <u>Initiative to</u> <u>Reduce the Impact of Schizophrenia (IRIS) guidelines</u> and in information from NICE developed for service users, families and carers both for <u>children and young people</u> and <u>adults</u>.

Headline	Quality statements		
	Children and young people QS	Adults QS	
Maximum waiting time from referral to treatment	Children and young people who are referred to a specialist mental health service with a first episode of psychosis start assessment <sup>i</sup> within two weeks.	Adults with a first episode of psychosis start treatment in early intervention in psychosis services within two weeks of referral.	
Psychological therapy	Children and young people with a first episode of psychosis and their family members are offered family intervention.	Family members of adults with psychosis or schizophrenia are offered family intervention.	
	Children and young people newly diagnosed with bipolar depression or a first episode of psychosis are offered a psychological intervention.	Adults with psychosis or schizophrenia are offered cognitive behavioural therapy for psychosis (CBTp).	
Support for carers and families	Parents and carers of children and young people newly diagnosed with bipolar disorder, psychosis or schizophrenia are given information about carer-focused education and support.	Carers of adults with psychosis or schizophrenia are offered carer-focused education and support programmes.	
Physical health and healthy lifestyles	Children and young people with bipolar disorder, psychosis or schizophrenia are given healthy lifestyle advice at diagnosis and at annual review.	Adults with psychosis or schizophrenia are offered combined healthy eating and physical activity programmes, and help to stop smoking.	
		Adults with psychosis or schizophrenia have specific comprehensive physical health assessments.	
Medicines management	Children and young people with bipolar disorder, psychosis or schizophrenia prescribed antipsychotic medication have their treatment monitored for side effects.	Adults with schizophrenia that has not responded adequately to treatment with at least two antipsychotic drugs are offered clozapine.	
Education, employment and training	Children and young people with bipolar disorder, psychosis and schizophrenia have arrangements for accessing education or employment-related training included in their care plan.	Adults with psychosis or schizophrenia who wish to find or return to work are offered supported employment programmes.	
Crisis care	Children and young people with bipolar disorder, psychosis or schizophrenia who are in crisis are offered home treatment if it is suitable.		

<sup>i</sup>The QS102 Committee reasoned that it was not appropriate to say 'start treatment' within two weeks of being waiting time referred because many children and young people will need to undergo a period of assessment before a from referral to diagnosis can be made and treatment can be started. Please note, however, that the 'Early Intervention Psychosis Access and Waiting Time Standard' is targeted primarily at people 14-65 and treatment will be deemed to have commenced when the person:

• has had an initial assessment, AND

• has been accepted on to the caseload of an EIP service capable of providing a full package of NICE recommended care, AND

• has been allocated to an engaged with an EIP care coordinator

See <u>chapter 4</u> for further details.

quality standards might also be relevant to the continuing treatment of people accessing EIP services, including:

- <u>Bipolar Disorder in Adults NICE quality</u> <u>standard</u>
- Bipolar Disorder NICE guideline
- Depression in Children and Young People NICE quality standard
- Depression in Children and Young People NICE guideline
- <u>Psychosis and Coexisting Substance Misuse</u> <u>NICE guideline</u>
- Depression in Adults NICE quality standard
- Depression in Adults NICE guideline
- <u>Service User Experience in Adult Mental</u> <u>Health Services NICE quality standard</u>
- Service User Experience in Adult Mental Health NICE guideline
- Anxiety disorder NICE quality standard
- Post-traumatic stress disorder.

#### 3.5 Other key functions of EIP services

#### 3.5.1 Supporting identification of psychosis and rapid referral

Failure to identify first episode psychosis and refer appropriately to EIP services can have a significant detrimental impact on service user experience and outcomes. There are still too many instances of people with first episode psychosis accessing mental health services for the first time only when they reach crisis point. Another common scenario is that the person is initially referred to generic community mental health services (adult or children and young people's), resulting in an increase in the duration of untreated psychosis as the person will not commence the right expert treatment and is more likely to disengage with mental health services.<sup>26</sup>

There are a number of reasons why identification of psychosis may be impaired or delayed:

 the clinical signs, which may not be easily identifiable, are often missed; a <u>guide</u> is available to aid referrers if they suspect psychosis to enable prompt access to services<sup>27</sup>

- those with identified psychotic symptoms attributed to a disorder such as posttraumatic stress disorder or emotionally unstable personality disorder may not be seen as appropriate for EIP services
- there may be other comorbid health problems that disguise or compound symptoms
- people may not seek help from mental health services, or fully disclose their experiences, because of stigma, lack of insight or distrust of services that are not attuned to youth culture or the cultural characteristics of the communities they serve
- due to transitions (such as moving to university) there may be difficulties in communication between services and concerned families and friends.

Supporting referrers and colleagues to identify first episode psychosis and refer appropriately and rapidly is an important function of any EIP service.

#### 3.5.2 **Recognising and addressing** coexisting health problems

A person may experience first episode psychosis with a number of comorbidities, including other mental health problems. This can impact directly on health outcomes and indirectly by introducing potential barriers to care. It is vital, therefore, that any coexisting problem is recognised and addressed.

#### Mental health problems

Coexisting mental health problems are common for people with psychosis; many will share a common cause with the psychosis, for example anxiety and / or depression.

Around 40% of people with first episode psychosis misuse substances at some point in their lifetime. As a result, people may present under the influence of a range of substances, including cannabis, cocaine or amphetamines.<sup>28</sup>

People with psychosis may also present with history of trauma. This may include emotional, physical and / or sexual trauma and a range of other adverse life experiences.<sup>29 30</sup>

Neurodevelopmental disorders are common in children and young people presenting with psychosis. It has been estimated that in childhood-onset psychosis, premorbid autism is present in 28–55%<sup>31 32</sup> and extremely low premorbid IQ (lower than 70) has been found in 30%.<sup>33 32</sup>

An EIP service should comprise staff who have experience and skills in working with people who have co-occurring problems with substance misuse, a history of trauma and neurodevelopmental disorders. This should include access to clinicians with expertise in working with children and young people.

#### **Physical health problems**

People with psychosis often have poor physical health.<sup>34</sup> This is the primary cause of premature mortality and higher rates of death in this population. Being exposed to antipsychotic medication for the first time can make people particularly vulnerable to side effects, such as rapid weight gain<sup>35 36</sup> and adverse cardiometabolic disturbance.<sup>37</sup> A combination of weight gain, poor diet and nutrition and lack of physical activity can also lead to high rates of illnesses such as diabetes and cardiovascular diseases.<sup>38</sup>

Other key physical health issues for people with first episode psychosis include:

- an increased risk of smoking and substance misuse<sup>39 40</sup>
- poor access to physical healthcare in both primary and secondary care<sup>9 41</sup> and
- low rates of recognition of physical health problems; symptoms are often ignored because of a co-occurring psychiatric diagnosis.<sup>42</sup>

This highlights the importance of EIP services meeting the requirements of NICE quality standards in relation to physical health and healthy lifestyles. Services that do not meet these quality standards are not delivering care in line with NICE recommendations.

#### 3.5.3 Support with social issues

After an acute episode of psychosis, there is an increased likelihood of social adversity, poverty, loneliness and social isolation, unemployment and homelessness, which can impair and slow recovery.<sup>10</sup> Social issues such as housing, debt, benefit advice, employment or education as well as the strength of cultural and community

support are often central to the lives of people experiencing psychosis. EIP services should work closely with local government and other agencies to address any key social care needs to ensure people with psychosis, their families and carers can access additional support, as outlined in the <u>Care Act 2014</u>.

#### 3.5.4 Families and carers

Faced with the turmoil of a loved one's emerging psychosis, their very first experience of specialist mental health services is pivotal for carers. Repeated failed attempts to get help from a service which seems indifferent to the needs of their family member or close friend will never be forgotten... but get that initial encounter right and the way is paved for a positive collaborative relationship with the carer(s) which may prove crucial to the ongoing care and recovery of an individual.

Source: A carer, 2015.

Families and carers play an invaluable role in helping people to recover from psychosis. As set out in the <u>Care Programme Approach</u>, it is vital that this is acknowledged, valued and supported, both in terms of recognising families and carers as expert partners in care and in ensuring that they able to access support both as individuals and in their caring role.

Where a carer is identified who appears to have a need for support, it is likely that the carer will be entitled to an assessment of their needs by the local authority under the Care Act 2014 (or the Children and Families Act 2014 in the case of a child carer or parent carer of a child experiencing psychosis), and may receive support in their own right. This assessment is not reliant on whether the person they care for has any care and support needs. Arrangements should be put in place to support signposting to relevant local authority services so that assessments may be carried out.

#### 3.6 The EIP workforce

Having the right EIP workforce with the right skills is essential to ensuring that care can be delivered in line with NICE recommendations. EIP services are multidisciplinary and the key staff roles, functions and necessary competencies are described on <u>page 21</u>. All staff should have specialist knowledge and training in working with people with psychosis.<sup>j</sup>

#### 3.6.1 Other staffing

Teams will require sufficient management and administrative support. Support workers and peer support workers should also form part of the workforce and EIP service users should have access to specialist mental health pharmacists and occupational therapists.

Teams working with children and young people will also need access to clinicians (particularly clinical psychologists and child and adolescent psychiatrists) with specialist neurodevelopmental assessment and management skills and an understanding of the role of trauma including that experienced by 'looked after' children.

#### 3.6.2 Workforce planning tool

A <u>workforce planning tool</u> has been developed, with input from the EIP ERG, to support commissioners and providers to plan the capacity and skill mix required in local EIP services. The tool employs a range of assumptions, using estimates developed from published literature and clinical input, which can be varied according to local circumstances. Health Education England (HEE) has made the tool available for use via the HEE website.

<sup>&</sup>lt;sup>i</sup>https://www.nice.org.uk/guidance/CG178/ifp/chapter/Yourcare-team

Role	Functions and necessary competencies
Care coordinator	Care coordinators should be skilled in engagement and working with a biopsychosocial formulation (i.e. supporting people across the spectrum of their biological, psychological and social needs), and be able to function as part of a multidisciplinary team. They should be skilled in working with recovery-based approaches to care planning. They should be able to work flexibly and creatively with people in order to achieve their individual goals, supporting them across a range of health and social care needs, including housing, benefits and debt advice. Care coordinators can come from a range of professions but typically will be nurses, occupational therapists or social workers. Care coordinators may also deliver family intervention if they are trained and supervised in delivery.
Psychiatrist	Dedicated consultant psychiatrist input is essential <sup>43</sup> both in terms of direct service user contact and contribution and support to the multidisciplinary team. The consultant needs to be involved whenever there are doubts or conflicting opinions about diagnosis, safety or prescribing. Medical team members need to involve themselves actively in the assessment process, particularly if others carry out the face-to-face assessment. They also need to be involved in decisions about acceptance on to caseload and discharge especially where this is unplanned.
Psychological therapist/ clinical psychologist	Psychological therapists and clinical psychologists should have had formal training in CBT for psychosis and / or family intervention and be assessed as having the competencies to deliver these interventions. <u>Competencies</u> have been developed by the IAPT-SMI programme. All staff delivering psychological therapies must have regular <u>clinical supervision from a suitably qualified supervisor</u> .
Education and employment specialists	Education and employment specialists are skilled in supporting people in work, training or education, with an emphasis on employment or education as a primary goal. These workers should be an integral part of the clinical team, not an external resource. Competencies and attitudes should include high levels of initiative, empathy and persistence with specific knowledge of the local job market. There is some evidence that workers should be trained in motivational interviewing to help people achieve better long-term outcomes. <sup>44</sup> Those working with young people should have training in working with those who have additional learning needs as a result of atypical neurodevelopment.

#### 3.7 EIP service models

There are currently three main models for delivery of EIP services; the 'stand-alone', 'hub and spoke' and integrated models. These are described below and examples of different service models from across the country can be found in the <u>Helpful Resources pack</u>.

EIP support can also be provided within services for children and young people's mental health.

#### 3.7.1 'Stand-alone' model

A 'stand-alone' service works independently from other more generic community mental health teams (CMHTs). This model has a clear evidence base for effective delivery of EIP services. Research has found that 'stand-alone' teams are more clinically and cost-effective<sup>45</sup> and better enabled to implement NICErecommended interventions.<sup>18</sup>

#### 3.7.2 'Hub and spoke' model

'Stand-alone' models may not be viable in sparsely populated rural areas where service design must consider other factors including:

- delayed and lower referral rates
- lower capacity of services
- travel issues
- staff recruitment issues.

In the 'hub and spoke' model,<sup>46</sup> dedicated EIP team workers ('spokes') are based within more generic CMHTs and link to an EIP 'hub' for access to specialist EIP skills, support and supervision.

While perhaps necessary to ensure service viability in sparsely populated rural areas, there are some key risks associated with this model,<sup>47</sup> including:

- isolation of EIP workers
- · limitations in clinical supervision
- lack of availability of competent therapists
- abrupt or gradual increase in caseload numbers.

If this model is used inappropriately (for example in urban or suburban areas) as a means of reducing short-term costs, this can have negative impacts on clinical effectiveness, service user and carer experience and longerterm cost-effectiveness.

Where 'hub and spoke' models are in place, commissioners will need ensure that arrangements to mitigate the above risks are in place and reviewed regularly.

#### 3.7.3 Integrated model

With an integrated model, the EIP service is completely integrated into the CMHT, with individual staff having only a nominal role in focusing on first episode psychosis.

It was the consensus of the ERG that this model is less effective because the specialist focus on early intervention is lost. ERG members advised that integrated models have tended to lead to reduced adherence to NICE recommendations and higher caseloads, resulting in care coordinators being unable to engage with people assertively when they are experiencing a first episode of psychosis. A lack of assertive engagement can lead to a higher rate of people dropping out of treatment, never receiving treatment, or having a longer period of untreated psychosis.

### 3.7.4 Considerations for children and young people

The access and waiting time standard applies equally to children and young people, and commissioning and service development plans should reflect this.

There are a range of different arrangements around the relationship of EIP services and delivery of care for children and young people with mental health needs. For example:

- some children and young people's mental health services have specialist EIP services embedded within them
- some adult EIP services include staff with expertise in working with children and young people
- some adult services and children and young people's mental health services work together using joint protocols.

For young people whose first episode psychosis occurs when they are of transitional age, clarity about what is offered and when is important. This is to ensure they receive a timely and effective service. Where transition to adult services has to happen during the duration of treatment (usually three years), this should be supported by a transition protocol and reflect a shared decision between the children and young people's mental health service, the young person and the adult EIP team to best address the maturing needs of the young person.

Whichever model is used, to deliver the standard across all ages, it is important that there is a strong interface and relationship between children and young people's mental health services and EIP teams, and that expertise in working with young people and their families or carers is an integral part of an EIP service. This extends to training initiatives, supervision and / or consultation and joint protocols. EIP services should also have access to practitioners with expertise in identifying neurodevelopmental disorders in children and young people in the presence of psychosis<sup>48</sup> <sup>28</sup> to facilitate vocational and educational recovery and social functioning.

All services providing EIP care for children and young people should ensure that the staff are competent and have the capacity to work with families and carers and related evidence-based interventions are offered routinely. Services should include competencies around working with families and carers and addressing social care needs, including safeguarding, in their staffing and training and also in their relationship with children's social care.

Access to and participation in education and training is a crucial aspect of recovery and fulfilling children and young people's potential as adults. Services should ensure they have a strong interface with education to provide a personalised educational support plan, including re-integration after periods of non-attendance which may include an inpatient stay. Dedicated educational, training and employment specialists with a primary expertise in this area should be an integral aspect of service provision.

The IRIS document <u>Joint Working at the Interface</u> provides more information and examples of positive practice.

# 4 The access and waiting time standard

*I waited for seven years before I finally got access to the EIP team, but I cannot say enough good things about the support I got from it – the staff have been amazing.* 

With their support, I have gone from being sectioned to finishing my masters in Public Health. Now I'm engaged to be married, and have a job as a researcher on antibiotic resistance for the NHS. I believe the key to my recovery has been my EIP team, as well as peer support groups and my psychologist.

I feel like I lost out in my 20s, for a lot of the time I just hid. A lot of people are waiting to get access to early intervention, these services change lives. It was about seven years between my problems starting and when I got useful help. It shouldn't have to be like that. It totally transformed my life.

*Source: Kerry – <u>https://www.rethink.org/news-</u> <u>views/2016/4/waiting-time-standards-for-eip</u>* 

### 4.1 Requirements of the standard

The access and waiting time standard requires that from 1 April 2016 more than 50% of people experiencing first episode psychosis will be treated with a NICE-approved care package<sup>k</sup> within two weeks of referral. The standard is targeted at people aged 14-65 in line with NICE recommendations.<sup>1</sup>

The standard is 'two-pronged' and both conditions must be met for the standard to be deemed to have been achieved:

- 1. a maximum wait of two weeks from referral to start of treatment; and
- 2. treatment delivered in accordance with NICE guidelines and quality standards for psychosis and schizophrenia either in children and young people <u>CG155 (2013)</u> and <u>QS102</u> or in adults <u>CG178 (2014)</u> and <u>QS80</u>.

The approach to measurement of performance against the standard has been designed to ensure that both elements can be assessed and outcomes (clinician- and service user-reported) routinely reviewed.

<sup>k</sup> Throughout the rest of this document the term 'NICE recommended' package of care/intervention has been used at the request of NICE.

<sup>1</sup> EIP services may also be clinically appropriate for people outside the 14–65 age group. Professionals should use their clinical judgement when considering whether people outside the 14–65 age group should be referred to / accepted by EIP services with commissioners and providers ensuring that people are not inappropriately restricted from accessing care.

## 4.2 Measuring and reporting performance against the referral to treatment (RTT) waiting time requirement

#### 4.2.1 Measuring the clock start: referral, recognition and initial assessment

#### **Referral and recognition**

#### Fig 1: Referral to clock start



\* If assessed by the central triage point as suspected FEP this referral should be flagged and moved on to the first episode pathway, and the clock will start on the day the central triage received the referral.

Key: FEP = first episode psychosis; RTT = referral to treatment

The clock for the two-week pathway starts when a referral has been flagged as 'suspected first episode psychosis' or is recognised as such upon receipt. Referrals would usually be made either to a central triage point ('single point of access') or direct to an EIP service. Referrals may come from any source and may be internal (for example from a children and young people's mental health service, a CMHT, an inpatient ward, prison or forensic mental health services) or external (for example from a GP, carer, school or self-referral).

The key 'rules' for this part of the pathway are as follows:

- if a single point of access or triage service receives a referral flagged as 'suspected first episode psychosis' this will start the clock
- if a single point of access or triage service receives a referral not flagged as 'suspected first episode psychosis', but the person is assessed or triaged as such, this should be flagged and moved on to the first episode psychosis pathway, and the clock will start

on the date that the single point of access or triage service received the referral

- if a single point of access or triage service receives a referral flagged as 'suspected first episode psychosis', but following consultation with the EIP service it is triaged as clearly not psychosis, the referral should not enter the pathway or be counted against the access and waiting time standard
- if an EIP service accepts direct referrals, the clock will start from the date the referral is received by the EIP service.

The clock starts regardless of referral source, the age of the person being referred or comorbidities such as learning disabilities, substance misuse, personality disorder or autism. The only exemptions from these arrangements will be referrals of people who are experiencing psychotic symptoms with a confirmed organic cause, for example, brain diseases such as Huntington's and Parkinson's disease, HIV or syphilis, dementia, or brain tumours or cysts.

#### **Initial assessment**

Fig 2: Initial assessment



Key: DNA = did not attend

Assessment for first episode psychosis should be completed by a competent and qualified professional (see <u>section 3.5.1</u>). It is vital for services to work proactively to engage people experiencing first episode psychosis because it is often those who do not engage with services immediately who are most in need of support. Services must ensure that they engage equally effectively with people from all cultural backgrounds. **Non-attendance or cancellations will not stop or pause the clock for the access and waiting time standard**.

The first assessment is a critical step in an engagement process upon which therapeutic alliances and interventions are built. However, feelings of ambivalence towards the process are common and natural on the part of service users (and sometimes families and carers too). Where people referred do not attend or agree to an initial assessment, appropriate contact should be made with the referrer and with families or carers to gather further information and to provide support and advice to them where they have already become involved. Where families or carers have not been involved, a decision to contact them can be made if a safety assessment of the available information warrants it.

Guidelines on capacity and information sharing should always be followed. For children and young people, the <u>Working Together</u> to <u>Safeguard Children website</u> has detailed guidance and paragraphs 12 and 13 of the <u>Mental Capacity Act 2005 Code of Practice</u> pertain to young people aged 16 and 17. If someone aged 16 or over is assessed as lacking mental capacity, steps may be taken in their best interests in accordance with the Mental Capacity Act 2005 and its Code of Practice.

Attempts must continue to be made to engage the person and make an assessment, including visiting them at home or a mutually agreed location. Depending on the urgency of the situation, this should occur at least twice within the two-week period after referral and more frequently if there are safety issues, if necessary in collaboration with the crisis resolution home treatment team.

If contact has not been possible, a care coordinator should be allocated within the two-week period to continue attempts to complete an assessment and liaise with carers and the referrer. This will not stop the clock but represents good practice. In these circumstances, if there is enough suspicion about the presence of psychosis that the EIP service continues to work with the family and carers, this may include the allocated care coordinator undertaking therapeutic work with the family.

It is important in cases of poor engagement that services continue to make all efforts to engage the service user. This will help to prevent people from 'falling through gaps' and receiving inadequate care, and it can reduce the risk of long-term poorer outcomes and increased use of healthcare resources (and associated costs). Commissioners should review cases with providers on a six-monthly basis where the service has been unable to assess someone who was referred with a possible first episode psychosis.<sup>m</sup> Where contact is not made, discharge from the pathway should only occur with prior agreement of the carer and referrer, and the clock will then stop. In such cases, details should be recorded and information provided to enable rapid reassessment by the EIP service if necessary.

In scenarios where the individual moves areas (for example, to another country or to university), transfer of care to a local EIP service (or its equivalent) should occur unless it is more appropriate to maintain contact (for example, if the service user returns to the area periodically). In all circumstances, there should be effective communication with primary care.

<sup>m</sup> Commissioners and providers will need to work together to ensure that any review uses service user data appropriately and lawfully.

#### 4.2.2 Measuring the clock stop: start of treatment

Fig 3: Clock stop



Key: ARMS = at risk mental state; FEP = first episode psychosis; RTT = referral to treatment

#### Fig. 3 Notes

 A service will be judged 'capable of providing a full package of NICErecommended care' via the CCQI quality assessment and improvement programme (see <u>section 4.3.4</u>) and through the recording via the electronic care record of NICE-recommended interventions delivered (to be submitted as part of the Mental Health Services Dataset through use of SNOMED-CT codes – see <u>section 4.3.2</u>).

The quality assessment and improvement programme will be phased in during 2016/17. Until this has been established, the clock will be stopped when a person is: (1) accepted on to the caseload of an EIP service following an EIP service assessment, and (2) allocated to and engaged with an EIP care coordinator.

2. 'Engaged with an EIP care coordinator' means that the care coordinator actively attempts to form a therapeutic professional relationship with the person and offers treatment to them.

Assessment by the EIP service will ascertain whether the person:

- is experiencing first episode psychosis (see section 2.2.1)
- is not currently experiencing first episode psychosis but may have an at risk mental state (see section 2.2.2)
- does not have evidence of first episode psychosis or of an at risk mental state.

If there is any doubt about the presence of psychosis or an at risk mental state, the person should remain in the EIP service until the diagnosis is clear.

Following completion of the EIP assessment, if the person is experiencing first episode psychosis the clock will stop when:

 the person is accepted on to the caseload of an EIP service assessed as capable of providing a full package of NICErecommended care;<sup>n</sup> and  the person is allocated to and engaged with an EIP care coordinator<sup>o</sup> (engagement with the care coordinator should begin immediately upon allocation).

If the person is not experiencing first episode psychosis but may have an at risk mental state, the clock will stop when:

- the person is accepted on to the caseload of an EIP service; and
- the person is allocated to and engaged with an EIP care coordinator;<sup>p</sup> and
- an at risk mental state assessment has commenced by an appropriately trained and qualified clinician.

If the person is assessed as not experiencing first episode psychosis or an at risk mental state the clock will stop, but the service should still ensure that the person is supported to access any further help they need. This could involve:

- discharging the person back to primary care, with advice about next steps, for example, treatment of depression, anxiety or any other common mental health problem
- referring the person to an appropriate mental health service.

If a person's condition is very severe and the risk warrants it, they may first enter an acute care service, such as a crisis resolution and home treatment team, an acute inpatient service or a psychiatric intensive care unit. In such circumstances the person should be referred to EIP services as soon as acute care services suspect first episode psychosis, in order that (s)he has the same access to NICE-recommended care as those entering EIP services through any other route. The clock will start at the point of recognition and referral (which should take place simultaneously), and EIP services should assess and begin treatment within two weeks. This may involve EIP services working jointly with acute care services for as long as needed.

" See Figure 3, note 1.

<sup>°</sup> See Figure 3, note 2.

<sup>&</sup>lt;sup>p</sup> See Figure 3, note 2.

#### 4.2.3 Measuring Reporting performance against the referral to treatment (RTT) waiting time requirement

#### Submission of data via the Mental Health Services Dataset (MHSDS)

The MHSDS is a patient-level, output-based, secondary uses data set, which delivers robust, comprehensive, nationally consistent and comparable person-based information for children, young people and adults who are in contact with mental health and learning disability services. As a 'secondary uses' data set it re-uses clinical and operational data for purposes other than direct patient care.

An Information Standards Notice (SCCI0011) has been issued for the MHSDS Information Standard. More information on the MHSDS and the information standard notice can be found on the <u>HSCIC website</u>. The MHSDS will enable collection, measurement and reporting of the EIP referral to treatment waiting time. From 1 January 2016, mental health systems must be fully compliant with the new information standard and providers of mental health services, as defined in the information standard, must be able to collect the information defined in the technical output specification for local use.

Technical guidance to support data submission to the MHSDS for the EIP standard has been developed and is available alongside this document via the <u>NHS England website</u>.

### Submission of data via the interim UNIFY data collection

Data to support monitoring of the RTT waiting time element of the standard must also currently be submitted via the UNIFY system. This data collection monitors the waiting times both of people who have commenced treatment and those referred but still waiting to commence treatment. Data are submitted at an aggregate (rather than patient) level. The intention is for this data collection to run on an interim basis until EIP RTT waiting times can be monitored routinely and reliably through the MHSDS.

The first collection covered data for December 2015 and a full timetable for collection has been published via the Unify calendar. More information on compilation and submission of Unify returns is available via the <u>Unify website</u>.<sup>q</sup>

<sup>q</sup> Note that access to Unify 2 requires a Unify 2 account and password, which can be requested via the Unify 2 site.

# 4.3 Measuring and reporting performance against the requirement that the treatment accessed is in line with NICE recommendations

4.3.1 What is NICE-recommended treatment?



A NICE concordant EIP service is able to offer and deliver the below NICE recommended treatments. To meet the new standard, at least 50% of people must commence treatment with a NICE recommended care package within 14 days of referral.



The second 'prong' of the EIP access and waiting time standard requires that the treatment provided is in accordance with NICE recommendations. <u>Section 3.4</u> sets out the key components of the two NICE guidelines and accompanying quality standards that are directly relevant to the provision of EIP services:

- <u>Psychosis and Schizophrenia in Children and</u> <u>Young People NICE guideline</u>
- <u>Bipolar Disorder, Psychosis and Schizophrenia</u> in Children and Young People NICE quality standard
- <u>Psychosis and Schizophrenia in Adults NICE</u> <u>guideline</u>
- <u>Psychosis and Schizophrenia in Adults NICE</u> <u>quality standard.</u>

NICE recommends that specific therapeutic interventions should be delivered in the context of a holistic and recovery-focused service model as described in <u>section 3.3</u> and <u>section 3.5</u>. This will require an appropriate workforce with the requisite skills and competencies (see <u>section 3.6</u>) and an effective service model (see <u>section 3.7</u>).

Measurement of performance will focus upon delivery of the requirements of the above guidelines and quality standards. However, <u>section 3.4</u> also makes clear the expectation that EIP services should continue to offer care and treatment to people who go on to receive a diagnosis of bipolar disorder or unipolar psychotic depression. Therefore, depending on the emerging diagnosis, other NICE guidelines and quality standards (listed in <u>section 3.4</u>) might also be relevant to the continuing treatment of people accessing EIP services.

#### 4.3.2 Reporting NICE-recommended interventions using SNOMED-CT codes

The MHSDS includes a mechanism through which NICE-recommended interventions can be reported as part of routine dataset submissions: use of Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT) codes.

To submit interventions data in this way, providers firstly need to ensure that their electronic care record systems are developed to allow EIP clinicians to record the therapeutic interventions recommended by NICE that take place during a clinical contact, for example 'CBT for psychosis' (see section 3.4 and Appendix 3). My life with mental health struggles began as a young teen. I spoke to my GP about the challenges that were occurring in my mind and that I was convinced something was not 'right'. This is over 10 years ago now and the progression from ignorance to acknowledgment of an individual's struggle has improved greatly.

After my psychotic episode and hospitalisation, the knowledge of services such as the Early Intervention (EI) team were still alien to family/friends and myself. It took roughly two generous months and serious deterioration in my health to be referred on to EI from my local mental health support centre. Once I had managed to get the golden ticket to access EI, I immediately felt safer, less intimidated by the prospect of what I was going through and my recovery began.

I had an amazing care coordinator who I believe should be a benchmark for all. His experience and dedication was a major factor in my recovery and I believe a foundation for where I am today. However, I have since learnt that there were a plethora of services within EI that I was not aware of and in turn did not access. I did not see or work with our psychologist until just before my departure from the team, three years later, which I feel I would not have received if I were not a determined character.

I would like to see a progression from the current availability of EI to the health system reflecting on what could be progressed and worked on and taking these reflections seriously when it comes to implementing positive changes. Not only should there be a far clearer entry pathway for all, but a 'pillar' of services within EI that are offered without question, such as talk therapies for families as well as the individual.

*Source: Sarah, service user representative on the London EIP Preparedness Programme Clinical Reference Group* 

Providers will need to develop their electronic care record so that clinicians can record interventions using a set list of activity types (for example making these available via a dropdown menu). Where electronic care record systems are SNOMED-enabled, it should be possible for this information to flow directly to the HSCIC. However, few if any systems being used in mental health providers are currently SNOMED-enabled in this way. In most instances, provider information teams will need to map the relevant therapeutic interventions to SNOMED codes via a lookup or other mechanism before they can flow to the HSCIC. The relevant codes can be found in Appendix 3 and further information can be found in HSCIC user guidance.

#### 4.3.3 EIP national clinical audit

In preparation for implementation of the new EIP standard, the Health Quality Improvement Partnership has commissioned the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI) to undertake an <u>audit of EIP services</u>.

The audit will establish a baseline position regarding services' ability to provide timely access to the full range of interventions recommended by NICE (delivered by fully trained, qualified and supervised practitioners) in line with local demand. The audit has sampled patients accepted on to the caseload of EIP services between 30 June 2014 and 31 December 2014. Data have been gathered on interventions offered in the six-month period following their acceptance onto the caseload (or in the case of physical health interventions, until December 2015). Service-level information was also gathered for the provision of services as at December 2015.

The EIP audit report is expected to be published in early May 2016.

#### 4.3.4 **Quality assessment and** improvement programme

All EIP services will be expected to participate in a <u>quality assessment and improvement</u> <u>programme</u>. This will be organised and administered by CCQI. CCQI has been working with a subset of the EIP ERG to develop:

- an assessment framework for the 'second prong' of the EIP standard (care in accordance with NICE recommendations) and an accompanying four-point performance assessment scale
- an accompanying web-based self-assessment tool that local commissioners and providers can use to target areas for service development and quality improvement.

The framework, performance assessment scale and self-assessment tool will be published early in 2016/17. **All EIP services will be required to complete and submit the selfassessment tool.** 

CCQI will use the framework and selfassessment tool submissions to conduct an independent review of performance in all local EIP teams during 2016/17; this will be published. This programme will continue on an annual cycle to enable transparent tracking of progress.

# 4.4 Routine collection of outcomes data

Clarity on expected service user outcomes is key to measuring and monitoring the effectiveness of services. The EIP ERG has recommended that three outcome tools should be used in EIP services. As a minimum, these should be used:

- during assessment
- at six and 12 months
- annually
- upon discharge.

However, services should be working towards routine use of these or other suitable measures (at every clinical session if possible). This will serve to support ongoing monitoring of service users to determine whether shared treatment goals are being achieved, to reinforce the therapeutic alliance and to ensure a full preand post-treatment outcome for 100% of all cases.

The three recommended tools together provide ratings of the clinician's assessment alongside service users' views of their needs, experience and stage of recovery. These have been chosen because they have been well-researched and cover a wide range of relevant outcomes while being brief and practical to use in routine clinical settings.

- Health of the Nation Outcome Scales

   (HoNOS) these clinician-rated scales cover safety, substance use, physical health, symptoms and social issues.<sup>49</sup> They have been used regularly in services and therefore are familiar to clinicians. The child and adolescent version (HoNOSCA) should be used for under 18s.
- DIALOG a service user-rated outcome measure, which focuses on quality of life, care needs and treatment satisfaction.<sup>50</sup>
- the Process of Recovery Questionnaire (QPR)

   developed in collaboration with service users,<sup>51</sup> the QPR asks about key aspects of personal recovery including connectedness, hope, identity, meaning to life and empowerment.

Both DIALOG and the QPR were developed for people aged over 18, although they may be suitable for some young people. The decision about which measure to use should be taken on a case-by-case basis in collaboration with the young person. If DIALOG and / or QPR are deemed inappropriate a general functioning tool should be used as a measure of outcome including the suite of outcome measures in routine use in children and young people's mental health services.

See <u>Appendix 4</u> for details of these three scales. HoNOS and HoNOSCA are already collected via the MHSDS and the MHSDS is to be developed to enable collection of DIALOG and QPR via SNOMED-CT codes (see <u>section 4.3.2</u>).

Improving access to psychological therapy (IAPT) services for common mental health disorders set a precedent and demonstrated the importance of routine outcome measurement for identifying services that are functioning well or improving, as well as those that are struggling. Similarly, routine outcome measurement has been a core element of the IAPT-SMI programme: this has demonstrated that it is possible to collect routine outcomes from people using secondary mental health care services as well as assess the impact of using these services. Further detail can be found in the <u>Helpful Resources pack</u>.

## Enablers for clinical outcome measures

### Make recording outcome measurement as easy as possible

 Ensure staff are trained to record outcomes data effectively and know how data analysis and outputs will benefit their work. Recording of measurement can be made easier by employing techniques which allow outcomes to be digitally recorded, either via SMS or an app, and / or embedded within the electronic patient record (EPR).

### Make outcome feedback as easy as possible

- Service users and clinicians need to be able to feed back outcomes continuously during the treatment process.
- Building a platform by which data and information can be inputted and accessed more flexibly by service users, clinicians and other front line staff, can strengthen self-management, continuous quality improvement and tailoring of care.
- Any lack of digital enablement does not mean that services should not provide routine clinical outcomes or data or feedback, alternative arrangements must be sought to support routine outcome measurement.

### Source: Mental Health Outcomes Clinical Reference Group<sup>r</sup>

Future payment models for mental health will be linked to outcomes. The proposed changes to the local payment rules for 2017/18 require that payment approaches are linked to the achievement of agreed quality and outcome measures.<sup>st</sup>

<sup>&</sup>lt;sup>r</sup> This is a group comprising a wide range of stakeholders, including representatives from professional bodies and experts by experience, that has been working collaboratively to develop guidance for the routine use of quality and outcome measures in mental health services. Publication is expected in May 2016.

<sup>&</sup>lt;sup>s</sup> https://www.gov.uk/government/collections/differentpayment-approaches-to-support-new-care-models#outcomesbased-payment-for-mental-healthcare

<sup>&</sup>lt;sup>t</sup> www.gov.uk/government/collections/different-paymentapproaches-to-support-new-care-models#multilateral-gainloss-sharing

# 5 Key commissioning and service development considerations

All areas will have a variant of an EIP service, but it is likely that services will require investment and significant development in order to meet the two key conditions of the new access and waiting time standard. This section provides a step-by-step process that local commissioners and providers can follow. Commissioning and service development plans should be coproduced with a range of stakeholders, including service users and their families or carers, partner organisations and relevant voluntary sector organisations.

There is a real buzz right now in developing and improving mental health services for all, which is so exciting. Waiting times and access to mental health treatment have and continue to be a serious problem for patients and services.

As a service user myself, I was delighted to be part of a move to tackle this issue and in working with a range of highly skilled and experienced professionals, I feel I have been given the opportunity to make a real and positive difference.

Unfortunately, service user involvement is too often omitted from these decisions. So, as a service user, I hope to demonstrate that people like me have something valuable to offer and bring to the decision table. It is great to be part of something so positive and influential.

Source: Adebola <u>https://www.rethink.org/</u> <u>news-views/2016/4/waiting-time-standards-</u> <u>for-eip</u>

#### Step 1: Understand local demand

Commissioners should develop a good understanding of local demand, drawing upon local provider intelligence. To achieve this, they should:

- Use the National Mental Health Intelligence Network's Fingertips tool to establish the estimated psychosis incidence rate per 100,000. While the access and waiting time standard is targeted primarily at people aged 14–65, it should be noted that the incidence rate defined by the Fingertips tool is for people aged 16-64 years. The incidence rate can be multiplied by the population of 16–64 year olds in the CCG catchment area to understand the expected number of new cases of first episode psychosis expected per year. Fingertips uses the predictions tool, **PsyMaptic**, which provides predicted incidence rates for local authority areas. Commissioners should familiarise themselves with the methodology used to produce these predictions, including the confidence levels and caveats that apply.
- · Work with providers to understand the current referral rate. This will be higher than the incidence rate because a number of people are referred who do not go on to develop first episode psychosis – this may mean additional referrals totalling up to double the incidence rate. As many EIP services have historically been commissioned only for people aged 14-35 years, it is important for commissioners to also consider referrals of people outside this age group, who are likely to be referred to generic community mental health services at present, and also the small number of referrals of people aged 65 and over. Commissioners should ensure that referrals of children and young people in the under 18 and under 14 age groups, especially to children and young people's mental health services, are

also captured. Referrals of children and young people will include some who were subsequently identified following assessment for a neurodevelopmental disorder or for trauma.

- Arrive at a local referral estimate. Combine the two factors above with any specific local factors that may impact on the referral rate.
- Understand the demographic profile. Beneath an overall incidence rate for an area, incidence rates vary across age, gender and ethnicity. PsyMaptic provides a breakdown of this for each local authority area, giving estimates split into two age groups (16–35 and 36–64 years), and then broken down again by gender and across different ethnicities. This will show commissioners the impact of any particular demographic considerations in their area on the incidence rate, which should be taken into account when designing services.

### Step 2: Develop an outline service model

Commissioners and providers should work together, using the staffing models, service examples and pathways provided in this tool to:

- Apply the understanding of local need to identify the staffing complement and competencies required. The workforce planning tool can be used to help with this. See <u>section 3.6</u>.
- Consider any reasons why the use of a 'stand-alone' team would not be the appropriate model, such as geography. If using a 'hub and spoke' model, consider how the service will overcome the inherent risks of this approach and deliver the same benefits as the evidence-based 'stand-alone' model. See <u>section 3.7</u>.
- Consider the age-appropriateness of the service offered. This should be informed by the age profile of the CCG area and the impact it has on incidence, and arrangements for those under 18.
- Outline the service model, including consideration of the number of teams, management, clinical leadership, and any specific characteristics the team will need in order to address demographic considerations identified in step 1.

 Identify and understand current referral pathways, including external and internal referral sources (for example, self-referrals, GPs, inpatient wards, assessment teams, crisis resolution and home treatment teams, drug and alcohol services, schools, colleges and universities, and the police), partners in service delivery or identification of referrals (for example, voluntary and community organisations and social services) and discharge pathways (for example, into CMHTs, primary care).

#### **Step 3: Obtain baseline current service provision and identify gaps**

Once an outline service model has been developed, a plan should be produced that sets out how to progress from current service provision to the new model. Commissioners should work with their providers to:

- Compare staffing numbers, skill mix and competencies in the new model with current provision. As well as current staffing of EIP services, this should take into account the resources currently being used for those aged over 35 (if not currently supported by an EIP service). Consideration also needs to be given to the qualifications, competencies and supervision arrangements of those providing CBT for psychosis and family intervention, prescribing, employment support and physical health interventions.
- Identify gaps in provision. This should enable development of recruitment and training plans.

This work should be informed by the findings of the EIP national clinical audit (see <u>section</u> 4.3.3) and the outcome of the local self-assessment exercise against the framework published by CCQI (see <u>section</u> 4.3.4).

#### Step 4: Baseline current performance against the new standard

Commissioners should work with their local provider to obtain a baseline of performance against the access and waiting time standard. There are sources of information available to support this, including existing performance reports, <u>NHS Benchmarking</u> data, NICE guidelines and quality standards and the <u>National Audit of Schizophrenia</u>. Commissioners should work with their local provider and stakeholders to:

- Assess current performance against the twoweek RTT waiting time standard, using the performance measurement criteria described in <u>section 4.2</u>.
- Assess current provision of CBT for psychosis and family intervention by looking at the percentage of caseload who have received one or both of these interventions.
- Assess the number of people who have received a physical health check and have been offered combined healthy eating and physical activity programmes. Information from the <u>National Audit for Schizophrenia</u> and <u>The Lester UK Adaption of the Positive</u> <u>Cardiometabolic Health Resource</u> will assist in understanding current performance.
- Assess current medication practice against the <u>Psychosis and Schizophrenia in Children</u> and Young People NICE guideline; Bipolar Disorder, Psychosis and Schizophrenia in Children and Young People NICE quality standard; <u>Psychosis and Schizophrenia</u> in Adults NICE guideline; <u>Psychosis and</u> Schizophrenia in Adults NICE quality standard and other relevant NICE guidelines.
- Assess level of provision of employment and educational support. This should incorporate both the number of service users who receive support and the type of support that is provided.
- Assess level of provision of carer-focused education and support programmes. This should incorporate both the number of carers who receive support and the type of support that is provided.

### **Step 5: Agree service redesign, recruitment and training plans**

Once assessment of workforce requirements has been made, the implications for service reconfiguration, recruitment and workforce development will need to be considered jointly with providers. This should include assurance that providers have a plan to collect and routinely use outcome measures as specified in <u>section 4.4</u>. A task and finish design and implementation group will need to be established to ensure the necessary changes are made. Commissioners should:

- Agree service redesign plans with providers. This may involve major or minor redesign, but should include arrangements to ensure:
  - the EIP service can routinely provide NICE-recommended interventions to people with or at high risk of developing first episode psychosis
  - interventions are provided by suitably qualified staff who are properly supervised
  - clinician and service-user reported outcomes are routinely collected and used effectively to improve care.
- Agree recruitment plans with providers, including how they will address any specific demographic issues. For example, in culturally and ethnically diverse areas, providers should actively try to ensure that the workforce reflects this same diversity.
- Agree training plans with providers, engaging local education and training boards as necessary, and ensuring that:
  - there are sufficient numbers of people trained in CBT for psychosis
  - staff delivering family intervention are suitably trained
  - staff delivering educational and employment support are suitably trained
  - all staff have a good knowledge of the importance of physical health interventions for people with psychosis, and how they will deliver these.
#### Step 6: Design local referral to treatment pathways and accompanying protocols and guidance

Having identified referral pathways in step 2, local services and commissioners will need to develop protocols and guidance consistent with their current referral practices, for example single point of access or referral directly to EIP services, and electronic care record systems.

They should:

- Compile a list of external and internal referral sources, consulting with stakeholders to ensure the list is comprehensive.
- Ensure that protocols and guidance are in place for the pathway. These should make it clear who should be referred and when in order to ensure that the access and waiting time standard can be met. There should also be protocols to ensure children and young people's mental health services and adult services work together as described in section 3.7.4.
- Provide education and training programme for referrers to ensure that people with suspected first episode psychosis or an at risk mental state are picked up in primary care, or in other non-specialist settings, including education, youth justice and third sector counselling, and promptly referred.
- Consider a public awareness campaign working with local authorities and other partners to raise the overall levels of awareness in the population about psychosis, in order to increase the likelihood of signs or symptoms of psychosis being recognised and reducing the stigma associated with it.

#### Step 7: Ensure the necessary changes have been made to provider electronic care records and information systems to enable monitoring of performance against the standard

HSCIC has notified providers regarding the changes required for submission of the new MHSDS, which will support monitoring of the EIP access and waiting time standard (see section 4.2.3). Commissioners should assure themselves that their local provider has made

the necessary updates to their electronic care record system to ensure clinicians are able to enter the data required to monitor performance against the new standard as per the Information Standards Notice.

The electronic care record system should enable collection and submission of data in three key areas:

- Referral to treatment waiting time performance – see section 4.2.3
- Performance against the requirement that the treatment accessed is in line with NICE recommendations – see <u>section 4.3.2</u>
- Routine measurement of outcomes as specified in <u>section 4.4</u>.

#### **Step 8: Agree data quality improvement and performance monitoring plans**

Commissioners should:

- Agree a data quality improvement plan with their provider to ensure full reporting against the standards (as per step 7 above), including timescales and milestones.
- Agree a schedule for performance reporting – this may be worked into existing performance reporting and management arrangements.

## Step 9: Agree benefits realisation plan

This should identify key benefits and set out how they will be delivered, measured and reported, in the context of a multi-year development trajectory. Key benefits of providing an EIP service should include:

- reduced waiting times for people accessing services through meeting the two-week maximum RTT waiting time standard
- improved care for individuals, families and carers through routine access to the full range of NICE-recommended interventions delivered by suitably qualified and supervised staff
- improved mental health, physical health and social outcomes for service users
- improved experience of services for people in need of mental health care and their families

- potential for reduced costs, through reduced use of crisis and acute services, including use of the Mental Health Act 1983
- improved awareness and satisfaction among referrers.

## Engagement in regional preparedness programmes

Commissioners and providers should already be aware that four regional EIP preparedness programmes have been established with broad stakeholder input. The work of these programmes has included:

- raising awareness of the requirements of the new standard
- bringing together local experts and establishing quality improvement networks, ensuring effective linkage with strategic clinical networks
- analysing levels of demand in constituent CCGs and any inequities in access relative to the levels and patterns of psychosis incidence in the population
- analysing baseline performance and capacity and undertaking a gap analysis
- supporting work to optimise local referral to treatment pathways
- supporting preparation for the new data collection requirements
- supporting local workforce development programmes.

Contact details for regional leads can be found in the <u>Helpful Resources pack</u>.

### Appendix 1 – ERG membership

#### Matthew Patrick (Chair)

Chief Executive, South London and Maudsley NHS Foundation Trust

#### Tim Kendall (Facilitator)

Director, National Collaborating Centre for Mental Health; Medical Director and Consultant Psychiatrist Sheffield Health and Social Care NHS Foundation Trust; Visiting Professor, University College London

#### **Tom Ayers**

Service Director, Community Services, Sheffield Health and Social Care NHS Foundation Trust; National Service Advisor, National Collaborating Centre for Mental Health

#### **Alison Brabban**

National Clinical Advisor for SMI (IAPT), NHS England

#### Ceri Dare

Expert by experience

#### **Rhiannon England**

GP Clinical Lead for Mental Health City and Hackney CCG

#### **Paul French**

Associate Director, Greater Manchester West NHS Mental Health Trust; Clinical Lead for Mental Health, Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network; Honorary Professor, Institute of Psychology Health and Society, University of Liverpool

#### **Philippa Garety**

Professor of Clinical Psychology, Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London; Honorary Consultant Clinical Psychologist, Clinical Director and Joint Leader, Psychosis Clinical Academic Group, King's Health Partners and South London and Maudsley NHS Foundation Trust

#### Rebecca Gate

Research Assistant, National Collaborating Centre for Mental Health

#### **Becki Hemming**

Mental Health Access and Waiting Times Programme Manager, Mental Health Clinical Policy and Strategy Team, Medical Directorate, NHS England

#### Sonia Johnson

Professor of Social and Community Psychiatry, Division of Psychiatry, University College London

#### **Peter Jones**

Professor of Psychiatry, University of Cambridge

#### Sarah Khan

Deputy Head of Mental Health, Mental Health Clinical Policy and Strategy Team Medical Directorate, NHS England

#### **David Kingdon**

SMI Expert Reference Group Chair, Wessex Academic Health Science Network; National Clinical Advisor, National Collaborating Centre for Mental Health

#### James Kirkbride

Sir Henry Dale Fellow, Division of Psychiatry, University College London

#### Warren Larkin

Consultant Clinical Psychologist, Early Intervention in Psychosis Service; Clinical Director Children and Families Network, Lancashire Care NHS Foundation Trust

#### Suzanne Law

Research Assistant, National Collaborating Centre for Mental Health

#### **Belinda Lennox**

Clinical Senior Lecturer, Department of Psychiatry, University of Oxford

#### **Max Marshall**

Medical Director, Lancashire Care NHS Foundation Trust

#### Stephen McGowan

National Lead, IRIS Early Intervention in Psychosis Network

#### Jonathan Mitchell

Consultant Psychiatrist, Sheffield Health and Social Care NHS Foundation Trust

#### Maryla Moulin

Senior Project Manager, National Collaborating Centre for Mental Health

#### **Carol Paton**

Chief Pharmacist, Oxleas NHS Foundation Trust

#### Paula Reid

Senior Policy Officer, Rethink Mental Illness

#### **David Shiers**

Retired GP, Leek, North Staffordshire; carer representative

#### Jo Smith

Professor of Early Intervention and Psychosis, University of Worcester

#### **Geraldine Strathdee**

National Clinical Director for Mental Health, NHS England

#### **Clare Taylor**

Senior Editor, National Collaborating Centre for Mental Health

#### **Alison Yung**

Clinical Professor of Psychiatry, University of Manchester; Honorary Consultant Psychiatrist, Greater Manchester West NHS Mental Health Foundation Trust

#### Special acknowledgments

#### Susie Ackner

Clinical Psychologist, Worcestershire Early Intervention in Psychosis Service, Worcestershire Health and Care NHS Trust

#### Sarah Amani

Senior Program Manager, Oxford Academic Health Science Network

#### Rachel Ball

Service Manager, Leeds EIP service, 'aspire'

#### **Max Birchwood**

Professor of Youth Mental Health, Division of Health and Wellbeing, Warwick Medical School, University of Warwick

#### Anita Brewin

Consultant Clinical Psychologist and Clinical Lead, Bradford and Airedale EIP Service

#### **Frank Burbach**

Consultant Clinical Psychologist, Lead for Triangle of Care and Early Intervention in Psychosis and Head of Psychology and Psychological Therapies Somerset Partnership NHS Foundation Trust; Operational Manager for STEP, asperger's services and carers services

#### **Roger Davies**

Clinical Psychologist, Adolescent Mental Health Team, City and Hackney Specialist CAMHS, East London NHS Foundation Trust

#### Jane Dunning

Deputy Director of Clinical Strategy, NHS England North Mental Health Team

#### Guy Dodgson

Consultant Clinical Psychologist in EIP, Northumberland, Tyne and Wear NHS Foundation Trust

#### **Tony Gillam**

Clinical Manager, Worcestershire EIP Service, Worcestershire Health and Care NHS Trust

#### Lynne Howey

Consultant Clinical Psychologist, Tees, Esk and Wear Valleys NHS Foundation Trust

#### **Chris Jackson**

Clinical Lead, Birmingham and Solihull EIP Service

#### Louise Johns

Consultant Clinical Psychologist and Project Lead, IAPT-SMI Psychosis Demonstration Site, South London and Maudsley NHS Foundation Trust

#### **Paul Jones**

Team Manager, Southampton EIP Service

#### **Steve Jones**

Special Advisor, Child and Adolescent Mental Health Clinical Strategy and Policy, Medical Directorate, NHS England

#### **Claude Jousselin**

Clinical Service Lead, Early Intervention and OASIS, Lambeth Early Onset Service, South London and Maudsley NHS Foundation Trust

#### **Clare Lamb**

Consultant Child and Adolescent Psychiatrist, North Wales Adolescent Service and FACTS

#### Iain Macmillan

Consultant Psychiatrist, Northumberland, Tyne and Wear NHS Foundation Trust

#### **David Monk**

Partner and Co-founder, Symmetric

#### **Margaret Oates**

Outcomes and Informatics Project Manager, Mental Health Clinical Policy and Strategy Team, Medical Directorate, NHS England

#### **Mary Parfitt**

Regional Quality Assurance Manager, Midlands and East

#### Sacha Schofield

Headteacher, Becton School, Kenwood Centre and Hospital and Home Education Service, Sheffield

#### Judd Skelton

Interim Head of Integrated Commissioning, Adults and Older People, Salford CCG

#### Tom Tasker

Clinical Lead for Mental Health, Salford CCG

#### **Matthew Taylor**

Associate Clinical Director, Early Intervention Pathway, South London and Maudsley NHS Foundation Trust; Clinical Senior Lecturer, King's College London

#### **Kim Thompson**

Regional Medical Manager, NHS England North Mental Health Team

#### Miranda Wolpert

CYP IAPT National Informatics Advisor

#### Ann York

Child and Adolescent Psychiatrist, Clinical Lead, CYP IAPT South West Collaborative

# Appendix 2 – Essential components of a NICE-approved care package

This appendix provides a summary of NICE-recommended interventions from the <u>Psychosis and</u> <u>Schizophrenia in Children and Young People NICE guideline</u>, the <u>Psychosis and Schizophrenia in</u> <u>Adults NICE guideline</u> and the <u>Psychosis and Schizophrenia in Adults NICE quality standard</u>.

## Table 1: NICE-recommended interventions for children and young people with psychosis

Intervention	Delivery of the interventions	Provider	Outcome
Assessment	To address psychiatric, medical, physical health and wellbeing, psychological and psychosocial, developmental, social, occupational, and economic domains, and to routinely monitor coexisting conditions, for all children and young people with first episode psychosis.	Specialist EIP service, whether situated in a children and young people's mental health service or an adult EIP service with input from consultants from children and young people's mental health services.	Comprehensive coproduced biopsychosocial formulation inclusive of trauma and adversity.
CBT for psychosis	To be offered in conjunction with family intervention and antipsychotic medication. Advice that they are more effective in combination should be provided. If the child or young person has a psychological intervention without antipsychotics, a time limit of one month for reviewing treatment options should be agreed. Deliver on a one-to-one basis over at least 16 planned sessions.	Clinical psychologists or CBT therapists who have undertaken specific training in CBT for psychosis, on a course meeting competency standards for NICE- recommended therapy. <sup>52</sup>	Reduced hospitalisation, improved symptoms of psychosis and depression.

Intervention	Delivery of the interventions	Provider	Outcome
Family intervention	To be offered in conjunction with CBT for psychosis and antipsychotic medication. Advice that they are more effective in combination should be provided. If the child or young person has a psychological intervention without antipsychotics, a time limit of one month for reviewing treatment options should be agreed.	A therapist or care coordinator, who is trained in family intervention.	Reduced hospitalisation and relapse, and improved social functioning.
Antipsychotic medication	To be offered in conjunction with CBT for psychosis and family intervention. Advice that they are more effective in combination should be provided. A baseline investigation and regular and systematic monitoring of symptoms and side effects should be conducted.	Psychiatrist.	Reduced symptom severity and associated distress, improved rates of recovery, decreased relapse rates.
Monitoring of physical health	To be monitored at least once a year. Children and young people who smoke or who have high blood pressure, raised lipid levels or increased waist measurement should be identified and cardiovascular disease and diabetes monitored for.	Mental healthcare provider maintains responsibility for monitoring physical health and the effects of antipsychotic medication for at least the first 12 months or until the child or young person's condition has stabilised; thereafter, the responsibility for this monitoring may be transferred to primary care (the GP or practice nurse) under shared care arrangements.	To reduce the trajectory towards weight gain, minimise adverse change in glucose and lipid metabolism, improved quality of life and improved rate of smoking cessation.

Intervention	Delivery of the interventions	Provider	Outcome
Assessment	<ul> <li>To be carried out if a child or young person experiences:</li> <li>transient or attenuated psychotic symptoms OR</li> <li>other experiences or behaviours suggestive of possible psychosis.</li> <li>If no clear diagnosis can be made, monitor for changes in symptoms and functioning for up to three years.</li> </ul>	Children and young people's mental health services or an EIP service; assessments in children and young people's mental health services should include a consultant psychiatrist; assessments in EIP services should be multidisciplinary.	To identify whether or not a child or young person may be at risk of developing psychosis.
Individual CBT with or without family intervention	To be offered along with interventions recommended in NICE guidelines for coexisting mental health problems (see row below). CBT: Deliver on a one-to- one basis over at least 16 planned sessions. For the number of sessions of family intervention see Table 1.	Clinical psychologists or CBT therapists, who have undertaken training, on a course meeting competency standards for NICE-recommended therapy. <sup>52</sup> A therapist or care coordinator, who is trained in family intervention.	To prevent transition to psychosis.
Interventions for coexisting mental health problems	To be offered for depression, any of the anxiety disorders, emerging personality disorder or substance misuse, along with individual CBT (with or without family intervention).	Primary care, children and young people's mental health services, substance misuse services.	To treat coexisting mental health problems
Antipsychotic medication	NOT to be offered to children and young people for psychotic symptoms or mental state changes not sufficient for a diagnosis of psychosis or schizophrenia OR with the aim of decreasing the risk or preventing psychosis.	_	_

# Table 2: NICE-recommended interventions for children and young people with an at risk mental state

## Table 3: NICE-recommended interventions for adults with psychosis

Intervention	Delivery of the interventions	Provider	Outcome
Comprehensive multidisciplinary assessment	To address psychiatric, medical, physical health and wellbeing, psychological and psychosocial, developmental, social, occupational, and economic domains, and to routinely monitor coexisting conditions, for all people with first episode psychosis.	Psychiatrist, a psychologist or a professional with expertise in the psychological treatment of people with psychosis or schizophrenia.	Comprehensive coproduced biopsychosocial formulation inclusive of trauma and adversity.
Antipsychotic medication	To be offered in combination with family intervention and individual CBT for psychosis for first episode psychosis and subsequent episodes. The choice of drug should be made by the service user and healthcare professional together, after provision of information and discussion about the likely benefits and possible side effects of each drug. Adults with schizophrenia whose symptoms have not responded adequately to treatment with at least two antipsychotic drugs used sequentially should be offered clozapine. Antipsychotic medication should not be offered to people considered to be at increased risk of developing psychosis or with the aim of decreasing the risk of or preventing psychosis.	Psychiatrist.	Reduced symptom severity, and associated distress, improved rates of recovery.

Intervention	Delivery of the interventions	Provider	Outcome
CBT for psychosis	To be offered in combination with family intervention and antipsychotic medication for first episode psychosis and subsequent episodes. CBT for psychosis should be delivered on a one-to- one basis over at least 16 planned sessions.	Clinical psychologists or CBT therapists who have undertaken specific training in CBT for psychosis, on a course meeting competency standards for NICE- recommended therapy. <sup>52</sup>	Reduced distress and severity of symptoms, improved social functioning and reduced hospital rates.
Family intervention	To be offered in combination with individual CBT for psychosis and antipsychotic medication for first episode psychosis and subsequent episodes. Family intervention should be delivered for between three months and one year over at least 10 planned sessions; the person with psychosis should be included if practical; and the family's preference for single- or multi-family group intervention and the relationship between the main carer and the person with psychosis should be taken into account.	A therapist or care coordinator who is trained in family intervention.	Reduced hospitalisation and relapse, increased medication adherence and improvement in social functioning.
Supported employment programmes and vocational rehabilitation	To be offered to people with psychosis who wish to return to work. Other occupational or educational activities, including pre-vocational training, can be considered for people who are unable to work or are unsuccessful in finding employment.	Trained vocational workers or employment specialists, who are aware of the specific needs of people with psychosis.	Higher rates of competitive employment, longer duration of employment and number of hours worked.

Intervention	Delivery of the interventions	Provider	Outcome
Carer-focused education and support programmes	To be offered as early as possible to all carers. These programmes, which may be part of a family intervention, should be available as needed and provide a message about recovery.	Any EIP team member.	Reduced carer burden, reduced long-term distress and improved experience of caregiving.
Physical health interventions and monitoring	A combined healthy eating and physical activity programme should be offered to people with psychosis, especially those taking antipsychotics. Weight and cardiovascular and metabolic indicators of morbidity should be monitored. If a person has rapid or excessive weight gain, abnormal lipid levels or problems with blood glucose management, interventions in line with relevant NICE guidance should be offered. Help to stop smoking should be offered.	Mental healthcare provider maintains responsibility for monitoring physical health and the effects of antipsychotic medication for at least the first 12 months or until the person's condition has stabilised; thereafter, the responsibility for this monitoring may be transferred to primary care (the GP or practice nurse) under shared care arrangements.	To reduce the trajectory towards weight gain, minimise adverse change in glucose and lipid metabolism, improved quality of life and improved rate of smoking cessation.

Intervention	Delivery of the interventions	Provider	Outcome
Assessment	<ul> <li>To be carried out if a person is distressed, has a decline in social functioning and has:</li> <li>transient or attenuated psychotic symptoms OR</li> <li>other experiences or behaviours suggestive of possible psychosis OR</li> <li>a first degree relative with psychosis or schizophrenia.</li> </ul>	A consultant psychiatrist or mental health practitioner in an EIP service or specialist mental health service with training in identifying at risk mental states.	To identify whether or not a person may be at risk of developing psychosis.
Individual CBT with or without family intervention	To be offered along with interventions recommended in NICE guidelines for coexisting mental health problems (see row below). CBT: Deliver on a one-to- one basis over at least 16 planned sessions. For the number of sessions of family intervention see Table 3.	Clinical psychologists or CBT therapists, who have undertaken training on a course meeting competency standards for NICE-recommended therapy. <sup>52</sup> A therapist or care coordinator who is trained in family intervention.	To prevent transition to psychosis.
Interventions for coexisting mental health problems	To be offered for depression, any of the anxiety disorders, emerging personality disorder or substance misuse, along with individual CBT (with or without family intervention).	Primary care, secondary care mental health services, substance misuse services.	To treat coexisting mental health problems.
Antipsychotic medication	NOT to be offered for people considered to be at increased risk of developing psychosis OR with the aim of decreasing the risk or preventing psychosis.	-	_

### Table 4: NICE-recommended interventions for adults with an at risk mental state

### **Appendix 3 – SNOMED-CT codes**

Providers should ensure that the following list of NICE-recommended interventions can be entered by EIP clinicians on to the electronic care record and submitted as SNOMED-CT codes<sup>u</sup> as part of Mental Health Services Dataset (MHSDS) submissions.

NICE recommended intervention		SNOMED-CT concept description	SNOMED-CT concept
1	Cognitive behavioural therapy for psychosis	Cognitive behavioural therapy for psychosis	984091000000108
2	Family intervention	Family intervention for psychosis	985451000000105
3	Antipsychotic medication	Medication monitoring	395170001
4	Physical health interventions and monitoring	Assessment of physical health	705139001
	und monitoring	Weighing patient	39857003
		Diabetic care	385804009
		Weight management programme	990121000000104
		Cardiovascular therapy	309513005
		Combined healthy eating and physical education programme	967251000000101
		Referral to smoking cessation service	871661000000106
5	Supported employment programmes and vocational	Educational rehabilitation	183339004
	rehabilitation	Vocational rehabilitation	70082004
6	Carer-focused education and support programmes	Carer-focused education and support programme	985651000000108
7	Care planning	Mental health care and treatment planning	861361000000109
		Provision of information about psychosis	985681000000102
8	Substance misuse	Substance misuse assessment	77704100000105
		Substance use therapy	385989002

To access the latest version of the SNOMED-CT codes, click here.

<sup>*v*</sup> SNOMED-CT (Systematized Nomenclature of Medicine Clinical Terms) consists of comprehensive scientifically validated content. SNOMED-CT is available in more than 50 countries and is managed and maintained internationally by the <u>International Health</u> <u>Terminology Standards Development Organisation</u> and in the UK by the <u>UK Terminology Centre</u>.

SNOMED-CT supports recording of clinical information in a way that allows data management and analysis to support patient care, while enabling data extraction and data exchange. SNOMED-CT is specified as the single terminology to be used across the health system in <u>Personalised Health and Care 2020: A Framework for Action</u>.

## **Appendix 4 – Outcome measures for routine use in EIP services**

This appendix provides the outcome measures recommended for routine use in EIP services. Sources of further information are listed below each questionnaire.

#### **DIALOG: user-reported outcome measure**

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DIALOG	Totally dissatisfied	Very dissatisfied	Fairly dissatisfied	In the middle	Fairly satisfied	Very satisfied	Totally satisfied	Additional help wanted Y/N
How satisfied are you with your mental health?								
How satisfied are you with your physical health?								
How satisfied are you with your job situation?								
How satisfied are you with your accommodation?								
How satisfied are you with your leisure activities?								
How satisfied are you with your friendships?								
How satisfied are you with your partner/family?								
How satisfied are you with your personal safety?								
How satisfied are you with your medication?								
How satisfied are you with the practical help you receive?								
How satisfied are you with consultations with mental health professionals?								

Name ..... Date .....

DIALOG has been developed by <u>s.priebe@qmul.ac.uk</u> – it is free to use and no permissions are needed

#### Health of the Nation Outcome Scales (HoNOS) – clinician-rated outcome measure

HoNOS is the most widely employed routine clinical outcome measure used by English mental health services. The HoNOS is a 12-item scale covering a wide range of health and social domains – clinical symptoms, physical health, functioning, relationships and housing:

- 1. Overactive, aggressive, disruptive or agitated behaviour
- 2. Non-accidental self-injury
- 3. Problem drinking or drug-taking
- 4. Cognitive problems
- 5. Physical illness or disability problems
- 6. Problems associated with hallucinations and delusions
- 7. Problems with depressed mood
- 8. Other mental and behavioural problems
- 9. Problems with relationships
- 10. Problems with activities of daily living
- 11. Problems with living conditions
- 12. Problems with occupation and activities
- All scales are scored using the following format:
- 0 = no problem
- 1 = minor problem requiring no action
- 2 = mild problem but definitely present
- 3 = moderately severe problem
- 4 = severe to very severe problem

Each scale is rated in order from 1 to 12. Information rated in an earlier item is not included except for item 10 which is an overall rating. The rating is made on the basis of all information available to the rater (whatever the source) and is based on the most severe problem that occurred during the period rated (usually the two weeks leading up to the point of rating).

HoNOSCA (child and adolescent) was developed for children and adolescents (under the age of 18) in contact with mental health services.

HoNOS and HoNOSCA have been developed by the Royal College of Psychiatrists. They allow without express permission the free use, copy and reproduction of HoNOS score sheets for use in NHS-funded care. Use, copy or reproduction of HoNOS score sheets for any other purpose should be with the explicit permission of the Royal College of Psychiatrists. Information can be found <u>online</u> or by contacting Emma George <u>eqeorge@rcpsych.ac.uk</u>.

### The Process of Recovery Questionnaire (QPR) – user-reported outcome measure

		Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly
1	I feel better about myself					
2	I feel able to take chances in life					
3	I am able to develop positive relationships with other people					
4	I feel part of society rather than isolated					
5	I am able to assert myself					
6	I feel that my life has a purpose					
7	My experiences have changed me for the better					
8	I have been able to come to terms with things that have happened to me in the past and move on with my life					
9	I am basically strongly motivated to get better					
10	I can recognise the positive things I have done					
11	I am able to understand myself better					

The QPR has been developed by <u>Heather.Law@gmw.nhs.uk</u> and <u>Sandra.Neil@gmw.nhs.uk</u> – it is free to use and no permissions are needed.

#### Appendix 5 – The full referral to treatment pathway



#### Notes

- If assessed by the central triage point as suspected first episode psychosis this referral should be flagged and moved on to the first episode pathway, and the clock will start on the day the central triage received the referral.
- 2. A service will be judged 'capable of providing a full package of NICErecommended care' via the CCQI quality assessment and improvement programme (see section 4.34) and through the recording via the electronic care record of NICE-recommended interventions delivered (to be submitted as part of the Mental Health Services Dataset through use of SNOMED-CT codes – see section 4.32).

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- The quality assessment and improvement will be phased in during 2016/17. Until this has been established, the clock will be stopped when a person is: (1) Accepted on to the caseload of an EIP service following an EIP service assessment, and (2) allocated to and engaged with an EIP care coordinator.
- 'Engaged with an EIP care coordinator' means that the care coordinator actively attempts to form a therapeutic professional relationship with the person and offers treatment to them.

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