

**NIHR Dissemination Centre**

**THEMED REVIEW**

# FORWARD THINKING

NIHR research on support for people  
with severe mental illness



# FOREWORD

**T**his report reminds us of the significant disadvantages faced by many people with severe mental illnesses (SMI) – with difficulties in gaining and keeping employment, in maintaining stable relationships and receiving a decent income. They also face distinct inequalities when it comes to their mental and physical health, both in terms of having timely access to evidence-based mental health treatment and a experiencing a greater likelihood of poor nutrition, obesity and smoking-related diseases – all of which can and do contribute to premature mortality. Our intention is to change this as we implement the Five Year Forward View for Mental Health. With significantly increased investment in both the mental and physical health of people with SMI, we aim to not only help people with SMI quickly access evidence-based, NICE-concordant mental health care; we also want them to access NICE-concordant physical health care, to secure gainful and meaningful employment and for services across a range of sectors to work together to help improve their clinical and social outcomes in such a way that they have the same opportunities to live healthy, full and fulfilling lives like anyone else. In our view, we can no longer accept women and men with SMI struggling to access the high-quality care and support they ought to receive during their lifetime and dying 15 to 20 years before they should.

The findings set out in this useful research review will support this drive to improve care – and, indeed, lives – and we commend the report to you.

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# CONTENTS

- Evidence highlights and questions about your service.....4
- About this review.....7
- Introduction .....8
- Supporting early detection and intervention .....13
- Crisis care: location, settings and practices .....16
- Stabilising and managing physical and mental health.....21
- Supporting recovery, self-management and engagement.....24
- Looking ahead .....32
- Acknowledgements .....34
- Study summaries – published .....36
- Study summaries – ongoing .....42
- Study references.....46
- General references.....47

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# EVIDENCE HIGHLIGHTS AND QUESTIONS TO ASK ABOUT YOUR SERVICES

**P**eople with severe mental illness (SMI), like schizophrenia, often experience poorer health and die sooner than others. Access to services may be patchy and care is not always well coordinated. But with the right care and treatment, and knowing what kind of support is needed, people can live well with these conditions. Mental health is now a recognised priority for policy and service, with research playing an important part in delivering best care. This review features 30 published studies funded by the National Institute of Health Research (NIHR) and additional examples of ongoing research. These should be read alongside published clinical guidelines for services and treatments.

## SUPPORTING EARLY DETECTION AND INTERVENTION

### *Finding who to treat*

Identifying people with psychosis and starting the right treatment without delay leads to better outcomes. A large trial of over 50 GP practices showed the impact of an educational intervention for GPs in improving identification and referral rates for young people at risk of developing psychosis. However another trial of a community awareness programme showed no effect in improving early referral rates.

### *Avoiding delay*

A small trial comparing a public health campaign to raise awareness of psychosis in the local community and improve knowledge of early warning signs showed a significant reduction in delay in untreated psychosis compared to areas without this intervention. A study in Birmingham found that a third of individuals waited more than six months to start treatment despite long standing availability of early intervention services; the major delay identified was within the mental health service itself, suggesting the current configuration is a barrier to early intervention.

## QUESTIONS

- » Do we know how many people here might benefit from early intervention services?
- » Can we use a research- informed prediction tool like Psymaptic ([www.psymaptic.org](http://www.psymaptic.org)) to help us understand the burden of mental illness in our community?
- » Do we know how many people with early signs of psychosis are waiting more than 6 months for treatment in our community?
- » What are we doing to improve awareness and detection of psychosis in young people in our community? Any tailored approaches for particular populations or groups?
- » What early intervention services are available for our community?

## CRISIS CARE: LOCATION, SETTINGS AND PRACTICES

### *Developing alternatives to hospitals*

People experiencing mental health crises need expert and prompt support. A recent review found a lack of high quality evidence overall for models of mental health crisis care. What research there is suggests that crisis resolution teams in the community are more effective than inpatient care for many outcomes. Alternatives to hospital stays for mental health crises include crisis houses and acute day hospitals which appear as clinically effective as inpatient treatment and are largely preferred by those using crisis services. Research has explored the nature of therapeutic relations in crisis houses and why users tend to be more satisfied with these services.

### *Improving care on inpatient wards*

For people needing hospital care, research has looked at different approaches to managing disturbed behaviour, from seclusion to transfer to specialist units. One study found variation in practice, and supported prioritising therapeutic over coercive interventions. To test this further, a large-scale trial

in nine hospitals evaluated a package of evidence-based interventions (Safewards) to help staff manage flashpoints and improve safety in acute psychiatric wards. This was shown to be effective in reducing conflict and containment, such as the need to sedate patients. A study looking at the acceptability of locked ward doors to staff and service users found that the evidence was inconclusive in terms of locked doors reducing absconding and self-harm.

### *Caring for young people*

Other studies have looked at services for children and young people, important given that most severe mental illnesses start before adulthood, although SMI is very rare in children and young people. Should children and young people be admitted, one review stressed the importance of young people being allowed to lead as normal a life as possible, to make it easier to adjust to leaving hospital.

### **QUESTIONS**

- » What crisis houses and other alternatives to inpatient crisis care are available in our area?
- » Are we evaluating any new approaches we are testing, such as placing adults with SMI within foster families?
- » Do our hospital wards use Safewards interventions?

## **STABILISING, MANAGING PHYSICAL & MENTAL HEALTH**

### *Staying well*

We know that preventing relapse and recurring psychotic episodes is important to long-term health. A programme of research explored different approaches to keeping well in the first few years of illness, from therapeutic efforts to lifestyle change, but none of the interventions showed any significant effect. Another important aspect of keeping well is having regular medication, including injectable antipsychotics, but adherence can be poor. A trial showed that financial incentives improved attendance and outcomes, although the effect did not last after the payment stopped.

### *Planning future care*

Family involvement in care planning can lead to better outcomes for people with mental illness such as fewer inpatient admissions but this is often not implemented in mental health organisations. One study concluded that involving families in care plans may require a cultural and organisational shift towards working with families.

### **QUESTIONS**

- » What training do we give new patients in spotting early warning signs of relapse?
- » What is the rate of non-attendance at outpatients for injections? Could we consider financial incentives or other approaches to improve adherence?
- » Are patients and families given opportunities to be involved in care planning?

## **SUPPORTING RECOVERY, SELF-MANAGEMENT AND ENGAGEMENT**

### *Recovering better health*

New approaches to mental health care focus on recovery, with individuals taking control and setting goals for themselves that are meaningful to them. A study of NHS rehabilitation services showed that quality of care was positively associated with service users' autonomy, experiences and perceptions of therapeutic care. Vocational rehabilitation has been shown to be effective but has been poorly implemented; one study found that employment outcomes were improved by addressing staff ambivalence about service users returning to work. A study of recovery focused care planning found evidence of widespread commitment to safe, respectful, compassionate care, but the majority of service users and carers did not feel that they had been genuinely involved in the recovery process. A large trial showed clinical benefits of using social recovery therapy as part of early intervention services after first episodes of psychosis. One study to understand and promote recovery from psychosis was done in collaboration with service users and the

research team included two service user researchers. The research provided significant advances in the understanding and facilitation of recovery in both psychosis and bipolar disorder.

#### ***Using technology***

Digital technology is changing the way people with SMI seek information about their illness. One trial found that web-based interventions may prove an important, inexpensive, feasible, and acceptable step forward in creating a choice of evidence-based interventions at different stages of recovery. An evaluation of interventions to train people with schizophrenia to recognise early warning signs of psychosis showed some positive benefits.

#### ***Getting support from peers***

The use of peer workers is an interesting new development, with benefits and some challenges for organisations. Research highlights the importance

of keeping this as a distinct role and contribution. Another study suggested that more effort should be directed to support people with severe mental illness to build and maintain their personal networks.

#### **QUESTIONS**

- » What approaches do we have to support recovery in our area, from recovery colleges to therapies adopted by early intervention services and others?
- » How many service users in our patch have personalised care plans with recovery goals?
- » Do we use validated measures of recovery here?
- » Do we use peer workers at our organisations? How are they recruited and supported?
- » What kind of input do our provider organisations have from service users? How are they supported?
- » How are strategic decisions about services shared with patient groups?



# ABOUT THIS REVIEW

**T**he National Institute of Health Research (NIHR) was set up in 2006 as a health and care research system that focuses on the needs of patients and the public. It aims to produce an evidence base that is translatable into policy and practice.

This themed review provides an overview of recent research funded by the NIHR on the support for people living with severe mental illness. Unless otherwise stated, most of the research projects featured in this report are funded entirely or substantively by the NIHR through its project, programme or infrastructure support.

This report is not a systematic review of all the research conducted on the topic of severe mental illness. It highlights a selection of NIHR-funded research on aspects of severe mental illness that has been undertaken in health and social services since 2005. These studies were commissioned to address particular uncertainties and evidence gaps identified by those working in and using these services. We have included reference to some non-NIHR studies which we believe are important to demonstrate the overall context in which the NIHR research was undertaken.

We identified the 30 studies included in this review by searching online databases and websites where NIHR research is registered or published. We have chosen to particularly highlight research studies that are relevant to commissioners, provider organisations

(in the NHS and voluntary sector), specialist mental health and general health and care professionals, people living with severe mental illness and their family and carers, educators and others inducting and training staff in this area. Not all research in this review have findings for immediate action. Some will add insights and weight to a growing evidence base. We hope that this report will help those delivering and using services to be aware of and consider the implications of some relevant published and emerging research in this field.

We have not included a range of clinical trials and other studies on treatment effectiveness funded by NIHR. Many of these have supported clinical guidelines for the management of schizophrenia and other conditions. Treatment decisions are best made through the careful deliberations of guideline committees, so we have not featured NIHR-funded trials which could give a partial or misleading view on best practice. These can be found at [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk). For the same reason, we have not featured all relevant systematic reviews. Important resources are available from the NIHR-supported Cochrane review group (<http://schizophrenia.cochrane.org>). We have also not included relevant research in prison settings. This review focuses on general evidence to inform the support, care and services for people with severe mental illness.

# INTRODUCTION

## UNDERSTANDING SEVERE MENTAL ILLNESS

### WHAT IS SEVERE MENTAL ILLNESS?

Psychotic illnesses – such as schizophrenia and affective psychosis – affect somewhere between one in one hundred and one in two hundred adults.<sup>1</sup> Psychotic illnesses can have a profound effect on people and their families, and appropriate and effective interventions are needed. Schizophrenia is the most common psychotic illness. In England alone, it is estimated to cost over £7 billion a year, which is equivalent to about £36,000 a year for each affected person.<sup>2</sup>

Severe mental illness (SMI) is not always a long-term condition. A significant number of people with SMI can experience a reduction of both symptoms and associated impairments over time and make a full recovery. Research suggests that remission and recovery rates in first episode psychosis may be more favourable than previously thought, suggesting that a progressive deteriorating course of illness is not typical<sup>3,4</sup>. Indeed, for those who continue to live with the symptoms of psychosis, recovery in terms of personal, social and occupational aspirations is a realistic goal and sets the context for the recovery approach.

Severe mental illness is generally accepted to have the following attributes:

1. Mental illness with a diagnosis of schizophrenia, bipolar disorder or other psychotic disorder. During a psychotic disorder, people may experience hallucinations such as hearing voices or seeing, tasting, smelling or feeling things that other people do not. People with psychosis may hold strong beliefs that others do not, for example, someone is controlling their thoughts, or someone wants to do them harm (paranoid or persecutory delusions). Other experiences can include difficulties in thinking and concentrating, thought disorder, lacking emotional expression, and being withdrawn and unmotivated.<sup>5</sup>



2. Mental illness that results in significant disability in terms of day-to-day functioning.
3. Mental illness that has lasted for a significant duration, usually at least 2 years.<sup>6</sup>

In this review, we use the term 'mental illness' to denote the group of conditions also called 'mental health problems', 'disorders', 'ill health' and 'conditions'. In line with the definition of SMI above which we have adopted for this review, we have not included NIHR research on personality disorders and other conditions. The terms 'serious' and 'severe' are both used interchangeably in the literature in the context of SMI; for consistency, we will use severe mental illness (SMI) throughout this review. Similarly 'early intervention services' and 'early intervention services for psychosis' are terms used to describe the same services, the latter being used in the more recent literature. We have left the terms as they were used by the researchers in their papers rather than using one term in preference to the other.

## WHY IS SEVERE MENTAL ILLNESS IMPORTANT?

Currently the life-expectancy of people with severe mental illness is 15-20 years shorter than that of the general population, mostly due to preventable causes<sup>7</sup>. This excess mortality is one of the worst health inequalities in England and Wales.<sup>8</sup>

Physical health problems are exacerbated by uneven access to health care for people with SMI, and a lack of coordination between mental health and medical care providers.<sup>9</sup> Because of this, people with SMI use emergency services more, and preventative services less, than the general population; are three times more likely to attend A&E; and almost five times more likely to be admitted to hospital as an emergency.

People with SMI are also more vulnerable to higher rates of homelessness, victimisation, domestic violence, trauma, poverty, incarceration and social isolation.<sup>10, 11</sup> The unemployment rate for people with severe mental illness is 6 to 7 times that of the general population.<sup>12</sup> Most would like to work but only a few actually do, and this can be due to issues of stigma and discrimination as well as health. Employment rates for people with schizophrenia in the UK are about 8%, compared with a national employment average of 71%.<sup>13</sup> This low rate of employment just for people with schizophrenia is estimated to cost the economy around £3.4 billion.<sup>14</sup>

The causes of shortened life expectancy are many; suicide and injury account for about 40% of excess mortality; people with severe mental illness tend

to have high rates of alcohol consumption, poor nutrition, obesity (anti-psychotic medications can lead to weight gain) and are twice as likely to smoke than the general population. About 60% of excess mortality can be attributed to preventable medical conditions such as diabetes, heart, lung and infectious diseases. Premature mortality due to schizophrenia alone is estimated to cost the UK economy about £1.4 billion a year.<sup>15</sup>

Further inequalities can be found in ethnic differences in prevalence of psychosis. The 2014 Psychiatric Morbidity Survey found that the estimated prevalence of psychotic disorder was higher among black men (3.2%) than men from other ethnic groups (0.3% of white men, 1.3% in the Asian group), with no significant variation by ethnic group among women.<sup>16</sup> A study part-funded by NIHR, the SEPEA Study, investigated if the incidence of psychosis varied by ethnicity, generation status, and age-at-immigration in a diverse, mixed rural, and urban setting. The study found that people of black African, black Caribbean and Pakistani origins were at the greatest risk of first episode psychosis compared with the white British population. These patterns were observed across rural and urban areas.<sup>17</sup>

## TREATMENT AND INTERVENTIONS FOR SEVERE MENTAL ILLNESS

We now know much more about what can be done to improve health and wellbeing for people with severe mental illness. This includes early detection and intervention, and promoting choice and

## SECURITY AND THE RIGHT MEDICATION – KEYS TO A BETTER FUTURE

“I have experienced paranoid schizophrenia since 1994. From 1994-2004 I failed to find an antipsychotic I was happy with because of severe side effects and so kept relapsing on a yearly cycle of forced hospitalisation, treatment, release, stopping treatment and relapse. In the autumn of 1997, I became fearful that the police would come and get me again so I took flight to Newquay where I was able to rent a holiday flat that was part of the landlord’s house. Newquay is lovely in the winter and being near a family, even though not being ‘looked after’ by them, I felt peaceful and secure there. In fact, I felt better from the moment I arrived. I stayed happily there until the spring without the police or psychiatric team finding me and without getting into

any kind of trouble. But in the spring, seaside rental costs shoot up for the summer season and my calm and peaceful life there was disrupted. I was forced to move back to cities I had known before, firstly living on the street and then back into hospital with all the problems of medication and its side effects.

I did eventually find an antipsychotic medication that suits me and have lived on it since 2004, enjoying my life without further hospitalisation. But I look back on that winter in Newquay and wonder how much of the anguish and expense of treating people like me could be avoided by providing comfortable accommodation that makes people feel calm and secure.”

**Clive Travis, service user**

autonomy. Important interventions aimed at tackling inequalities, especially physical health inequalities, are now recommended, such as health screening, health education, and steps taken to improve access to physical and mental health treatment in primary and secondary care.

Most people with severe mental illness who experience recurring episodes of psychosis receive their care from both primary and specialist mental health care (other settings not included in this review are education and the criminal justice system). About 30% of adults with severe mental illness are able to be cared for in primary care alone, but the majority of people with severe mental illness are supported by community services.<sup>18</sup> Anti-psychotic drugs are the primary treatment for psychosis and schizophrenia in the acute and maintenance phases, in both hospital and community settings. Many people with SMI are able to find an antipsychotic drug that suits them, enabling a return to a productive life.<sup>19</sup>

Other modes of treatment that have been shown to be effective in improving symptoms, include psychological and psychosocial interventions. These focus on a person's functioning in society and wellbeing and include cognitive therapy and behavioural therapy.<sup>20</sup>

With the growth of the internet and smartphone apps, healthcare services are beginning to use e-technologies as a way to monitor health.<sup>21</sup> Digital support for mental health is increasingly being developed including the use of online resources, social media and smartphone applications and is associated with improving access to services, online self-help and reducing stigma.<sup>22</sup>

## POLICY CONTEXT

### ENGLAND

#### *Improving access to mental health services by 2020*

In October 2014, NHS England and the Department of Health jointly published *Improving Access to Mental Health Services by 2020*, which was aimed at ensuring "parity of esteem", where mental and physical health services are given equal priority in terms of access time, service quality and allocation of resources.<sup>23</sup>

#### *The Five Year Forward View for Mental Health*

*The Five Year Forward View for Mental Health*<sup>24</sup> was published by an Independent Mental Health Taskforce in February 2016 and set out a series of recommendations for the NHS to prioritise services

for people living with SMI by 2020/21. In July 2016 NHS England published *Implementing the Five Year Forward View for Mental Health*.<sup>25</sup> This recommended that primary care services focus on the physical healthcare of people with SMI by increasing access to physical health assessments and appropriate interventions. The aim was for Primary Care to develop new models of care where GPs and practice nurses would deliver screening, outreach, and carer training, in order to meet the physical health needs of people with SMI. Another aim was for community-based services to be developed, so that people living with SMI are not held in restrictive settings for longer than needed; are supported by community-based services in residential rehabilitation; or supported by assertive outreach teams as close to home as possible. Another important aim was to help people with SMI achieve employment through the introduction of the Individual Placement and Support (IPS) programme. A new standard for waiting time was introduced requiring at least 50% of people with a suspected first episode of psychosis to start treatment with a NICE-recommended package of care within two weeks of referral.

In 2017, the *Five Year Forward View for Mental Health One Year On*<sup>26</sup> reported that since its inception, the waiting time element had been exceeded every month; with data at December 2016 showing 74% of people starting treatment within two weeks. Looking to the future, *Five Year Forward View for Mental Health One Year On* notes that the Sustainability and Transformation Plans (STPs) are tasked with facilitating collaboration across the health and care systems at the local level and are expected to be a powerful medium to deliver the Five Year Forward View for Mental Health.

#### *Stigma and discrimination*

The reduction of stigma and discrimination was one of the core objectives in the 2011 mental health strategy. Following this, the Department of Health provided funding for the Time to Change initiative, a national programme to reduce mental health stigma and discrimination, led by Mind and Rethink Mental Illness.<sup>27</sup> Currently the national *Time to Change* anti-stigma campaign is funded up to 2020/21.<sup>28</sup> Anti-stigma programmes have also been implemented in Scotland (See Me), Wales (Time to Change) and Northern Ireland (Change Your Mind).

#### *Thriving at Work*

*Thriving at Work: a review of mental health and employers*,<sup>29</sup> published in October 2017, sets out what employers can do to better support their workforce,



including those with mental health problems, to do well at work. The authors started from the position that the correct way to view mental health is that “we all have it and we fluctuate between thriving, struggling and being ill and possibly off work”. People with poor mental health including common mental health problems and severe mental illness can be at any of these stages, and a person with SMI can, with the right support, still be thriving at work.

### ***Children and young people’s mental health***

*Future in Mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing*, was published in 2015 by NHS England. The report made a number of proposals to improve mental health services for young people by 2020 and set out how to achieve this through better partnership working between the NHS, local authorities, voluntary and community services, schools and other local services.<sup>30</sup> In December 2017, the government published a green paper, *Transforming children and young people’s mental health provision*, which set out ways the government can support local areas to adopt a new collaborative approach to tackle the early signs of mental health issues and improve mental health support for children and young people in England.<sup>31</sup>

### ***Women’s mental health***

The Women’s Mental Health Taskforce was set up in early 2017 in response to the findings of the Adult Psychiatric Morbidity Survey (APMS) 2014. This had shown a significant rise in mental ill health among women, particularly between 16-24 years old. The Taskforce is due to report in 2018.

## **WALES**

In 2012, the Welsh Government published the *Together for Mental Health Strategy*,<sup>32</sup> and in 2016 the *Together for Mental Health Delivery Plan*.<sup>33</sup> This strategy echoes many of the aims in *Five Year Forward View for Mental Health*, particularly around physical health and early intervention. It is a 10-year strategy for improving the lives of people using mental health services, their carers and their families.

Primary legislation essential for the organisation of mental health services was passed by the Welsh Government in 2010, called the *Mental Health (Wales) Measure 2010*. This places legal duties on health boards and local authorities to improve support for people with mental ill-health and is aimed at helping people with mental health problems in four different ways:

1. Local Primary Mental Health Support Services

2. Care Coordination and Care and Treatment Planning
3. Assessment of people who have previously used specialist mental health services
4. Independent Mental Health Advocacy<sup>34</sup>

## SCOTLAND

The *Mental Health Strategy 2017-2027*<sup>35</sup> was published by Scottish Government in March 2017. It describes a 10-year vision “of a Scotland where people can get the right help at the right time, expect recovery, and fully enjoy their rights, free from discrimination and stigma”. It emphasises the challenge of achieving parity of esteem and tackling inequalities for people with mental ill-health and recognises the need for work to improve mental health across policy areas affecting poverty, education, justice, social security and employment. The strategy also reflects the critical role of new Integrated Health and Social Care Partnerships in delivering community mental health services with local authorities and geographical Health Boards providing more specialist aspects of care and treatment. The guiding ambition of this strategy is “to prevent and treat mental health problems with the same commitment, passion and drive as we do with physical health problems”.

The Strategy defines 40 actions and 20 ambitions which sit under 5 themes:

- » Prevention and early intervention
- » Access to treatment and joined-up, accessible services
- » The physical wellbeing of people with mental health problems
- » Rights, information use, and planning
- » Data and measurement

Suicide prevention will be published under a separate action plan in Spring 2018. Separate strategies exist for dementia, substance misuse, learning disability and autism. The Scottish Government published “What Research Matters for Mental Health Policy in Scotland 2015” to better align National Mental Health strategy and policy with research to improve both the impact of research and the evidence base for strategy.<sup>36</sup>

## NORTHERN IRELAND

In October 2011, the Health Minister of Northern Ireland published *the Service Framework for Mental Health and Wellbeing* which sets standards for the prevention, assessment, diagnosis, treatment, care and rehabilitation of people who have a mental illness. *The Regional Mental Health Care Pathway: You in Mind*, launched in October 2014, commits health and social care services to deliver care which is more personalised and improves the experience of people with mental health problems. There have been calls for a new ten-year mental health strategy for Northern Ireland and a mental health champion to promote, lead and co-ordinate work across government departments, by adopting a more evidence based/recovery-oriented approach to care across the system.<sup>37</sup>

## ACADEMY OF MEDICAL ROYAL COLLEGES

The Academy of Medical Royal Colleges and other professional bodies published an important policy document in October 2016: *Improving the Physical Health of Adults with Severe Mental Illness: Essential Actions*.<sup>6</sup> This report recommends that a new national steering group should be formed to lead and link key stakeholders with experts from the healthcare professions to enable key areas of physical health to be addressed and monitored at a national level. Amongst its many recommendations is that national organisations regulating healthcare professionals should review training requirements to ensure training standards and curricula prepare their trainees to recognise poor physical health in people with severe mental illness, to utilise health promotion and screening in disease prevention, and to manage long term conditions.

## FRAMEWORK FOR MENTAL HEALTH RESEARCH

In December 2017, a national *Framework for Mental Health Research*<sup>38</sup> was published by the Department of Health, stating a commitment to support high quality research in mental health across the main funding agencies.<sup>39</sup> The NIHR in December 2017 issued a call with opportunities for new research on mental health across its programmes.<sup>40</sup> At a national and local level, investment in mental health services and research is now recognised as a top priority.

# SUPPORTING EARLY DETECTION AND INTERVENTION



**T**he *Five Year Forward View for Mental Health* set out a series of recommendations for the NHS in England, one of which is to increase early detection of psychosis so that early intervention can take place.

## EARLY INTERVENTION SERVICES

Early intervention services (EIS) are specialised services for people who have an episode of psychosis that has not previously been treated (first episode psychosis). The early intervention service is targeted



at people aged 14-65 years (although professionals can use their clinical judgement when considering referral of people outside this age group).<sup>41</sup> People can be referred to early intervention services from primary care, from a Community Mental Health Team (CMHT), or Child & Adolescent Mental Health Services (CAMHS). Early intervention services offer a multidisciplinary, multi-agency approach to assessment, treatment and care. There is strong evidence that early intervention services lead to reductions in the number of admissions and overall inpatient bed days, contact with services at the end of the intervention, risk of relapse and risk of suicide. Early intervention services are associated with improved employment and education outcomes, better service engagement and higher levels of patient satisfaction.<sup>42</sup>

The time period between the onset of psychosis and starting anti-psychotic medication is called the 'duration of untreated psychosis' (DUP). The DUP is a treatment delay that has been the focus of much research because of its importance as a predictor of outcome.<sup>43</sup> If the DUP is long, then this appears to predict a poorer outcome for first episode psychosis. Reducing the DUP has become an important part of the detection and early intervention of severe mental illness. A national waiting time standard has been introduced in England<sup>44</sup> and Wales.<sup>45</sup> It is important to understand the barriers that people face when seeking, or failing to seek, help for psychosis.

An NIHR funded research programme (Study 1) produced a number of studies focused on first episode psychotic disorders and at-risk mental states. One of the studies in the programme (LEGS)<sup>46</sup> was a cluster randomised controlled trial (RCT), educating GPs to identify and refer young people at high risk of developing psychosis. The study explored the beliefs that influence GPs when they see young people with psychosis in primary care. The researchers used those beliefs to develop an educational intervention for GPs. After attending the educational workshop, GPs were found to have doubled the identification and referral of young people with high-risk mental states, first episode psychosis and other mental health problems.<sup>47</sup> This educational approach was found to be cost-effective largely by reducing the costs of unrecognised mental illness in primary care.

Study (2) was part of a wider research programme called the National EDEN Project<sup>48</sup>, which was an evaluation of differently configured early intervention services sites across England. Study (2) was conducted in the lead site in Birmingham and documented the care-pathway components of the DUP of patients and their link to delays in accessing specialised early intervention services in Birmingham. The duration of the various components making up the care pathway of people with first episode psychosis period was measured over 47 months. The study found that, in spite of the long-standing availability of early intervention services in Birmingham, a third of the 343 people in the study had a DUP greater than 6 months. The biggest contribution to the length of the DUP was found to come from delays within mental health services, followed by delays in people seeking help. The study showed that the impact of early intervention services on reducing DUP appeared to be failing due to structural barriers specifically by non-crisis generic mental health teams. The findings suggest that mental health services as currently configured are a barrier to early intervention and that a 'psychosis pathway' is needed to improve recognition, engagement and treatment delivery.

Study (3) examined the feasibility and impact of an intervention to reduce DUP involving two components of the care pathway. The first was the introduction of a youth mental health care pathway for young people aged 16-25 providing a seamless transfer to specialist care without the need for further assessment. The second component was a public health campaign to raise awareness of psychosis in the local community and improve

knowledge of early warning signs, and when and where to seek help. The results showed a reduction in median DUP in the intervention area of the study. However, there were limitations to the study; it was a small, pragmatic, quasi-experimental trial targeting only two components of the care pathway, and of limited duration, so a full evaluation could not be done. The researchers suggest that the proof of principle study, with an experimental intervention that focused on the community and use of youth friendly digital media, provides a generalisable methodology that could be used in further research into DUP.

Study (4) evaluated a one-year community awareness programme that targeted staff working in early intervention services in non-health service community organisations. The programme comprised 41 psycho-educational workshops delivered by 36 organisations to community staff working with young people vulnerable to experiencing early psychosis, and offering direct referral routes to

early intervention services. The impact on DUP was evaluated. The researchers found that the workshops with community organisations were well received and engaged large numbers of community staff working with young people vulnerable to experiencing early psychosis. However, the intervention led to very few new referrals through non-health pathways and there was no significant difference in mean or median duration of untreated psychosis for new referrals to the service in the year of the intervention, compared to the year before.

### ONGOING RESEARCH

Researchers are also using routine data to see if there are associations between markers of quality in primary care for people with severe mental illness, and health outcomes and hospital admissions (Study A). Other ongoing research in primary care is testing a collaborative care model with experienced mental health workers in GP surgeries (Study B).



# CRISIS CARE: LOCATION, SETTINGS AND PRACTICES

In 2014, the *Mental Health Crisis Care Concordat*, an England-wide national agreement between services and agencies involved in the care and support of people in crisis, was signed by 27 national bodies in health, policing, social care, housing, local government and the third sector. The Concordat sets out how organisations should work together to make sure that people get the help they need when they are having a mental health crisis. These standards were reinforced in recent Five Year Forward View guidance<sup>24</sup> outlining plans for seven day care. The Concordat set out four stages of the crisis care pathway: (1) access to support before crisis point; (2) urgent and emergency access to crisis care; (3) quality treatment and care in crisis; (4) promoting recovery.

Study (5) reviewed the existing evidence on the clinical effectiveness and cost-effectiveness of models of care at each of the four stages identified by the Crisis Concordat. The review highlighted a number of important principles: people at risk of mental health crisis should receive care with minimum delay and quick referral onwards; crisis resolution teams are more effective than inpatient care for a range of outcomes; crisis houses and acute day hospitals appear as clinically effective as inpatient treatment and are associated with greater service user satisfaction; individual-level based interventions found to be effective include self-management and supported employment. The researchers found the evidence for peer support largely inconclusive; further high-quality research is needed. Overall, the study found a lack of high quality evidence in the evaluation of models of mental health crisis care such as randomised control trials.



A photograph of a person lying on a paved path covered with autumn leaves. The person is wearing dark clothing and shoes. There is some trash, including a white plastic bag and a crumpled can, near the person's feet. The background shows more leaves and some greenery.

## LOCKED DOORS IN ACUTE INPATIENT PSYCHIATRY

Acute inpatient care involves the short-term care and treatment of people with severe psychiatric symptoms within accommodation that is secure and supervised 24 hours per day.<sup>49</sup> Acute inpatient care can be on a voluntary basis or a compulsory basis, for example when people are detained through the Mental Health Act for England and Wales. In 2015/16, a total of 25,577 people were subject to the Mental Health Act, of whom 20,151 were detained in hospitals.<sup>50, 51</sup> The treatment of people with psychosis costs the NHS around £2 billion a year, over half of which is associated with psychiatric inpatient care.<sup>52</sup>

A key issue facing acute psychiatric services is whether to have a system of permanent locking ward doors or a system of open wards. Increasing numbers of wards have a locked ward policy even though the policy contravenes legal guidance in the Mental Health Act. Patients who abscond are more likely to be associated with risk of self-harm and such an event is more likely to take place immediately following absconding. Clearly the safety of inpatients is paramount, but there is a lack of evidence that locking wards increases the safety of patients.

Study (6) was a literature review that investigated if rates of absconding from acute psychiatric wards were related to exit security, and also looked at the acceptability of locked doors to staff, patients and visitors. They found that the evidence was inconclusive regarding the effects of a locked door in that it can reduce absconding but does not eliminate it. Although staff believed that a locked door could prevent patients from leaving, the study showed that patients abscond even with a locked door. A locked door has no impact on inpatient suicide rates, and while it can make staff and patients feel protected, it can also make them feel confined. Patients can particularly feel under the control and power of staff, with feelings of being trapped like a prisoner rather than a patient. On the other hand, an open-door policy can lead to anxious vigilance by the staff. The study recommended that acute admission wards have a single main exit that is unlocked during the day but within the visibility of staff on duty. Patients judged to be at particular high risk of harming themselves should be managed through special observations or temporary transfer to a Psychiatric Intensive Care Unit (PICU). Further research on this topic was recommended by the researchers. A 15 year observational study in Germany reporting in 2016 found that locked doors might not be able to prevent suicide and absconding.<sup>53</sup>

## SECLUSION AND PSYCHIATRIC INTENSIVE CARE: 'COERCIVE PRACTICES'

Patients admitted to acute psychiatric wards may be at risk of harming themselves or the people around them, so staff may on occasion have to act to contain a person safely. Seclusion or transferring a patient to a PICU are two methods of containment or coercive interventions that are used in psychiatric wards. Previous research suggests that typical PICU patients in the UK are male, younger, single, unemployed, suffering from schizophrenia or mania, from a black Caribbean or African background, legally detained, and have a forensic history. The most common reason for seclusion or transfer to PICU is the management of aggressive behaviour. There is a need to reduce the use of coercive interventions which are supported by little or no evidence.

Study (7), the Safewards trial, was a large-scale cluster randomised controlled trial conducted in 31 acute psychiatric wards in 15 hospitals around London. The study aimed to evaluate a complex intervention targeted at nursing staff to reduce conflict and containment. Psychiatric wards that were in the experimental condition implemented a package of ten 'Safewards' interventions.<sup>54</sup> While there were limitations to the study, it had many strengths, and a demonstrable impact on conflict and containment rates. Decreased conflict means fewer injuries from violence, suicide and self-harm. In the absence of comparable quality of evidence, the researchers recommended that the Safewards interventions be implemented on adult acute mental health wards.<sup>55</sup>

Study (8), the SPICES trial, assessed the factors associated with the use of seclusion and PICU. The researchers used patient records in one NHS trust to compare patients who did and did not receive seclusion or PICU care. They found that it was not possible to state that seclusion or a PICU reduce aggression, and some evidence suggests that coercion may serve to increase aggression. In hospitals without access to seclusion, nurses were slower to manually restrain patients, but were more likely to use sedating drugs by injection. The researchers recommended that therapeutic rather than coercive interventions be prioritised in the management of disturbed behaviour, and the development of conflict and containment reduction strategies. Further research using randomised designs was recommended.

The rates of compulsory admissions to psychiatric inpatient beds have been rising in recent decades. If the number of Community Treatment Orders are included, then the numbers of people subject to the Mental Health Act has increased by about 5% per annum since 2007.<sup>56</sup> This is despite the development of a range of community-based psychiatric services. Study (9) investigated the increasing rates of compulsory admissions in England to see if this could be explained by variations in people and places. The anonymised records of over 1.2 million people for 2010/11 were analysed. The researchers demonstrated a statistically significant and largely unexplained variance in compulsory admission between local areas and mental health provider trusts. There is a need for in-depth qualitative research to explore factors that might explain the local variation in compulsory admission.

## CRISIS INTERVENTION

This Cochrane review<sup>57</sup> looked in 2015 at the effects of crisis intervention models in the home or community for anyone with severe mental illness experiencing an acute episode, compared to standard care. The reviewers included eight randomised controlled trials, involving 1144 individuals. Crisis care was found by this review to provide a package of support that avoided repeat admission to hospital and was worthwhile, acceptable and less expensive than standard care. Although this review drew on small trials subject to bias and some older studies which did not reflect current standards of care, this evidence has informed guidance, including endorsement of crisis resolution and home treatment teams.<sup>24</sup>

## ACUTE PSYCHIATRIC WARDS, THERAPEUTIC RELATIONSHIPS AND SERVICE USER SATISFACTION

Service user dissatisfaction with acute psychiatric wards is common and many find acute wards frightening places. The Alternatives Study (TAS) (Study 10) examined residential alternatives to standard acute psychiatric hospitals in England. One hundred and thirty-one residential alternative services in England were identified. These community-based services were mainly characterised by a less severely ill client group, fewer medical and nursing staff and fewer services that had on-duty on-site night staff. However, these less clinically oriented units still had significant collaboration with NHS mental health services, and accepted referrals from NHS mental health staff. The researchers estimated that there are just under 1300 beds in these alternative units compared to about 12,400 acute beds for adults in standard psychiatric hospitals in England, roughly 1 in 10 beds outside of standard acute beds. These alternatives “represent an important, but so far undocumented, uncoordinated and unevaluated component of the national mental health economy, mainly within the statutory sector.” Crisis houses are community-based service models that lie somewhere in between hospital services and other community services; residential crisis models vary considerably and include clinical crisis houses, specialist crisis houses, crisis team beds, recovery houses and non-clinical alternatives; and they tend to have 24-hour staffing by trained mental health staff and support workers. Only limited evidence is available on the effectiveness of crisis houses, and evaluating their impact is complicated further by the diversity of service models, making it difficult to compare studies and draw firm conclusions or make any recommendations for policy.<sup>58</sup>

Study (11) noted that the TAS study (Study 10) found that service users prefer crisis houses to hospital, but this preference was not explained by the care, the amount of staff–service user contact, or even differences in outcomes. Sweeney took the work of the TAS study further by seeking explanations for service users’ greater satisfaction with crisis houses. This was a mixed methods study. Researchers collected data from four crisis houses in two London mental health trusts and compared data with the same measures from 16 acute wards in the same trusts. For the qualitative component they interviewed 29 service users.

Three major themes emerged:

1. Basic human qualities lie at the heart of therapeutic alliances. Service users in both environments valued relationships with staff who were caring, honest, empathic and approachable.
2. Service users wanted staff to talk to them more, listen to them more, and demonstrate therapeutic counselling skills in structured and unstructured interactions.
3. A focus on recovery and hope were also important, though less so than the above factors.

This study confirmed the findings of the TAS study of greater satisfaction in crisis houses than acute wards, and better therapeutic relationships between staff and service users in crisis houses.

## CHILD AND ADOLESCENT MENTAL HEALTH SERVICE

Mental health problems that begin in childhood and adolescence can have a range of negative impacts on individuals and families that can continue into adult life. Mental illness in children is common and the majority of adult mental health problems are first manifest before the age of 15.<sup>59</sup> One in 10 children and young people between the ages of 5 and 16 years living in Britain has a diagnosable mental health problem but severe mental illness, as we have defined in the introduction to this review, is rare in children and young people. Child and adolescent mental health services are provided through a network of services: universal services (Tier 1), targeted services (Tier 2), Specialist Community services (Tier 3) and highly specialist services for severe and highly complex mental health needs (Tier 4).

## YOUNG PEOPLE RECEIVING TREATMENT WITHIN INPATIENT SETTINGS

Study (12) investigated the evidence in the area of risk for young people moving into, through, and out of inpatient mental health care. Young people who had been inpatients, together with carers, managers and professionals, helped to prioritise the types of risk that should be included in the study. Among the key recommendations was that young people receiving treatment within inpatient settings should be able to lead as normal a life as possible. Feeling separated from life outside and the subsequent

difficulties experienced on returning home were identified as some of the key issues. Service providers need to pay close attention to less obvious risks such as risks associated with friendship and peer relations, risk of stigma and discrimination, schooling, and family life. Young people often feel homesick, but often experience post discharge depression and suicidal ideation. Managing the risks of stigma and discrimination should be a high priority for policy makers, as should partnership with families during inpatient care.

## ONGOING RESEARCH

Ongoing research is mapping the use of acute day units as alternatives to inpatient care and comparing outcomes for those in crisis, including impact on admissions (Study C).



# STABILISING AND MANAGING PHYSICAL AND MENTAL HEALTH

## AVOIDING RELAPSE

Avoiding relapse after the first psychotic episode is important because with each successive relapse, the illness becomes more difficult to treat and the probability of a full recovery declines. Studies have shown that success in preventing relapse is poor. Although 85% of people who develop psychosis recover fully from the first episode, 50% may relapse within 18 months and as many as 80% may relapse within 5 years. Study (13), the HELPER programme, is an NIHR research programme aimed at developing three linked interventions to prevent relapse of psychosis and deterioration in the physical health of people after a first episode of psychosis: (i) an evaluation of cognitive remediation in combination with cognitive behavioural therapy (CBT), (ii) training staff to deliver a healthy living intervention, and (iii) integrated motivational interviewing plus CBT. This research was exploratory in nature and designed to make the case for larger definitive trials with relapse as a primary outcome measure. Across the three trials there was little evidence that any intervention reduced relapse.

## IMPROVING ADHERENCE TO ANTI-PSYCHOTIC MEDICATION

Non-adherence to medication is a normal phenomenon replicated in areas of physical and mental health. Poor adherence to long-term antipsychotic injectable medication in patients with psychotic disorders is associated with a range of negative outcomes, and ways to improve adherence are needed. Study (14) investigated whether offering financial incentives is effective and cost-effective in improving patient adherence. This was a cluster randomised controlled trial and participants in the intervention group received £15 for each long-term antipsychotic injectable medication. Patients in the control group received treatment as usual. The study found that patients who were offered money attended more often and reported a better quality of life. However, when the money was stopped, patients returned to missing appointments as before. So while financial incentives were shown to be effective in improving adherence to injectable medication, the effects were not sustained following the one year period during which the incentives were offered.

## INVOLVING FAMILY MEMBERS IN CARE PLANNING

Deinstitutionalisation of mental healthcare has moved a large part of the burden of care for people with SMI to their families. Family involvement can lead to better outcomes for people with mental illness such as fewer inpatient admissions, shorter inpatient stays and better quality of life, although some studies have found this not to be the case in some families of people with schizophrenia.<sup>60</sup> Study (15) was a systematic review that investigated the involvement of families in three-way communication between health professionals, families and adult patients with psychosis. Family involvement can include specialised interventions such as psychoeducation, family interventions and therapies to reduce expressed emotion and lessen the chances of relapse in SMI. The researchers found that despite a vast positive evidence base for family involvement, it is often not implemented in routine mental healthcare. Families generally feel isolated, uninformed, not listened to or taken seriously. The study concluded that involving families in care may require a cultural and organisational shift towards working with families. This can only be achieved if clinical teams are trained to have an open, non-judgemental approach towards a therapeutic alliance between staff, families and patients, an approach which is embraced by the whole organisation.

## MAINTAINING PHYSICAL HEALTH

In order to drive improvement in the physical healthcare of people with severe mental illness, primary care practices are incentivised under the quality and outcomes framework (QOF) to improve the access to physical health checks for their patients with SMI. This is reinforced by recent guidance for commissioners on improving physical health of people with SMI.<sup>61</sup> In England, secondary care is incentivised under Commissioning for Quality and Innovation (CQUINs) payments framework to do cardiometabolic assessments on inpatients with severe mental illness.

The NICE guideline on schizophrenia<sup>62</sup> puts an emphasis on maintaining physical health. Rethink's Integrated Physical Health Pathway<sup>63</sup> developed in collaboration with professional bodies, promotes joint working between the mental health and primary care sectors to support the physical health of people with SMI.

There is a high prevalence of smoking among people with SMI. Helping people with SMI to stop smoking would help improve their health, increase longevity and also reduce health inequalities. NICE has published guidance on a number of interventions, including mandatory recording of smoking status by mental health trusts; education for mental health workers on smoking cessation; smoke-free policies on NHS trust grounds; and rapid referral to enhanced smoking cessation services.<sup>64</sup> Study (16) is a pilot randomised control trial of a smoking cessation intervention for severe mental ill health (SCIMITAR) which was set in primary and secondary care mental health services in England; 97 people aged between 19 and 73 years who smoked between 5 to 60 cigarettes a day were recruited to the RCT. The smoking cessation intervention was behavioural support and medication, and was delivered by mental health professionals trained in delivering the intervention. This was compared with usual GP care in the control group. The study found that the odds of quitting at 12 months was higher in the intervention group but did not reach statistical significance. A definitive trial of a bespoke cessation intervention has been prioritised by the NIHR and the SCIMITAR pilot forms a template for a fully powered RCT.

Another important area of physical health in people with severe mental illness is sexual health. There is a high degree of variability in sexual activity among people with SMI,<sup>65</sup> for example people with schizophrenia are less likely than those with other major psychiatric disorders to be sexually active, possibly due to the known effect of antipsychotics on libido. People with SMI have the same right as the general population to have sexually intimate relationships, have families and be sexually healthy. Previous research has found that high-risk sexual behaviour is more common in people with SMI, as well as higher rates of blood borne viruses such as HIV and Hepatitis C.<sup>66</sup> Study (17) was a systematic review that evaluated the effectiveness of sexual health risk reduction interventions (such as educational and behavioural interventions, motivational exercises and counselling) for people with SMI. The study found that there was insufficient evidence to fully support or reject the identified sexual health interventions. The researchers noted the need for well-designed, UK-based trials of sexual health interventions for people with SMI, as well as training and support for staff implementing sexual health interventions.

## ONGOING RESEARCH

Ongoing research includes an early testing of an intervention, partly delivered by smartphone, to detect and prevent relapse in people with schizophrenia (Study D). Other digital health approaches include early work to assess a computerised resource to combat paranoid delusions, which could ultimately be delivered online via a smartphone app (Study E) and a study that is looking at a web-based monitoring service for people with bipolar disorder in primary care. (Study F).

Ongoing studies are also addressing the role of family and carers, including a trial of an online Relatives' Education and Coping Toolkit (REACT) as a resource to help relatives of those with recent-onset psychosis (Study G). REACT was preceded by a feasibility trial that showed that the toolkit was feasible and a potentially effective intervention to improve outcomes for relatives.<sup>67</sup> A further study will explore the barriers and facilitators to the implementation of REACT in the NHS to see how it can be best used and implemented (Study H).

Another study is looking at the feasibility of a new approach involving families of people at risk of psychosis (Study I). More research is also targeting certain communities such as the co-production and evaluation of an e-learning resource to improve knowledge about schizophrenia and engagement with services in African Caribbean families (Study J). Another tailored intervention for African Caribbean people with schizophrenia and their families will assess benefits when delivered by experienced community workers (Study K).

Ongoing research is also looking at interventions to improve physical health, including a large trial testing a structured lifestyle education programme, based on tested diabetes interventions, to help people with schizophrenia to lose weight (Study L). Another programme of work will develop and test an intervention to detect and manage cardiovascular risk better for people with severe mental illness in primary care (Study M). Looking at promoting sexual health, a study will test the acceptability of a new approach delivered by staff in mental health trusts (Study N).



# SUPPORTING RECOVERY, SELF-MANAGEMENT AND ENGAGEMENT



People with severe mental illness generally consider 'recovery' to be a journey of small steps, characterised by a growing sense of agency<sup>68</sup> starting with everyday activities and moving to participation in employment and education. The recovery approach says that a person with SMI should be allowed to set their own outcomes<sup>69</sup> and, in recent years, helping people to live the kind of life that they want, whether or not their experience of psychosis continues, is the main focus.



## INPATIENT MENTAL HEALTH REHABILITATION SERVICES SUPPORTING RECOVERY

Many people with SMI often have complex problems preventing their discharge home following an acute admission. Almost all NHS trusts across England have inpatient mental health rehabilitation units and most are community based. Study (18) is a programme of research comprising a number of studies aimed at providing a detailed understanding of NHS inpatient mental health rehabilitation services across England (the REAL (Rehabilitation Effectiveness for Activities for Life) research programme). The programme included (i) a national survey of NHS mental health rehabilitation services, (ii) development of a training intervention for staff to facilitate service user's activities, (iii) evaluation of the training intervention through a cluster RCT, and (iv) a longitudinal cohort study to identify components of care associated with better clinical outcomes. The main findings of the programme showed that quality of care was positively associated with service users' autonomy, experiences and perceptions of therapeutic care. The staff training intervention was found not to be clinically effective as staff reverted to previous practice once the intervention team left. Over half the service users in the cohort study were successfully discharged from hospital over 12 months.

## SUPPORT TO FIND WORK

This Cochrane review<sup>70</sup> looked at the effectiveness of supported employment, including individual placement and support (IPS), compared with other approaches to vocational rehabilitation or treatment as usual. The reviewers included 14 RCTs involving 2265 individuals. Supported employment (featuring intensive support and coaching to find work) was found to increase the length and time of people's employment. People on supported employment also found jobs quicker. Supported employment and IPS were shown to be better than other approaches for these outcomes. However, quality of evidence was not always high and there was little information of impact on mental health and wellbeing, days in hospital and costs.

The study provides evidence that NHS mental health rehabilitation services deliver high quality care that successfully supports service users with complex needs in their recovery.



## INDIVIDUAL PLACEMENT AND SUPPORT

Unemployment is common in young people recovering from a first episode psychosis. Individual placement and support (IPS) is a form of vocational rehabilitation which involves rapid job search combined with minimal pre-vocational preparation and ongoing support. Much research has been done on IPS, and the results suggest it is effective compared to alternative interventions.<sup>71</sup> Early intervention teams are among the few specialist mental health teams in England that have adopted the IPS approach and have vocational workers fully embedded within their teams. However, it has generally been poorly implemented because many clinicians discourage return to work through a fear that employment might be too stressful for their patients and may precipitate relapse. Study (19) investigated whether training early intervention staff in 'motivational interviewing' would improve the chances of young people with SMI getting employment. A pragmatic, cluster RCT was conducted in England with four early intervention teams. The ENDEAVOR study (Enhancing Delivery and Outcomes of Vocational Rehabilitation) included a trained vocational specialist who provided supported employment services to the service users. The study found that employment outcomes were improved by addressing the staff's ambivalence about service users returning to work, suggesting

that providing clinical staff with specific training in techniques to address service users (and their own) motivational conflicts may enhance their chances of competitive employment.<sup>72</sup>

## PERSONALISED AND RECOVERY FOCUSED CARE PLANNING

Care planning processes in mental health community services and on inpatient wards should be personalised and conducted in collaboration with the service user and should be focused on recovery. Two NIHR funded studies were conducted across six NHS mental health Trusts and Health Boards in England and Wales: first, recovery-focused mental health care planning and co-ordination in community health services: Collaborative Care Planning Project (COCAPP), Study (20) and second, recovery-focused mental health care planning and co-ordination in acute inpatient mental health settings (COCAPP-A), Study (21).

The COCAPP study found that good relationships are important for service users, carers and care coordinators in care planning and supporting recovery, but that people do not always feel involved in discussions about their own care or safety, indicating that there is a gap between national policy aspirations for recovery-focused, personalised care planning and co-ordination and the actual everyday

## SUPPORTING THROUGH WORK

Emily came to her local supported employment service after her stepfather heard about how they can help people find work. Emily has a serious mental health condition and has been under psychiatric care in the past. She was finding it difficult to find employment following a long period out of work and having limited job experience.

When she first approached the service, Emily's confidence was at an all-time low. A range of activities, have built up her confidence levels, including going out with staff to hand in her CV / speculative letters to employers and speak with managers about her skills. It took a few months, but she gradually regained her confidence.

Emily was supported to secure voluntary work at a charity shop. This developed her skills and she really

enjoyed the work. The shop also enabled Emily to complete a customer service qualification. At this point, Emily said she felt great in herself and started to go out on her own and approach employers to apply for positions. As she has anxiety, she asked for help to support her at interviews.

Following an interview, Emily was offered a position as a housekeeper. She is now working 16 hours per week in this role and she can retain her benefits for a year to see how she gets on. Staff at the employment service continue to work with Emily in order to sustain her confidence and skills and promote her recovery.

**Case study provided for this review by Rethink ([www.rethink.org](http://www.rethink.org))**

experiences of service users, carers and care co-ordinators. COCAPP-A found that there is positive practice taking place within acute inpatient wards with evidence of widespread commitment to safe, respectful, compassionate care, but the majority of service users and carers did not feel that they had been genuinely involved in the recovery process. Across both studies there was a lack of agreement in understanding of recovery and personalisation. The researchers recommended future research should focus on personalised, recovery-focused working and shared decision-making in risk assessment and management.

### ENHANCING SOCIAL RECOVERY

People who were treated by early intervention services can go on to develop chronic social functioning problems that can persist into adulthood. Study (22) assessed the efficacy of early intervention services plus social recovery therapy in patients with first episode psychosis. The researchers conducted an RCT (SUPEREDEN3) at four early intervention

services in the UK. The study found, after 9 months of intervention, those receiving social recovery therapy in combination with early intervention services showed clinically and statistically significant improvements compared to those receiving early intervention services alone. The findings suggest that social recovery therapy might be useful in improving functional outcomes in people with first episode psychosis. A larger more definitive trial is required to examine these effects over the longer term.

### PSYCHOLOGICAL APPROACHES TO PROMOTING RECOVERY

Service users see recovery as a process of establishing hope, restoring sense of self and rebuilding their lives. Although recovery-orientated services are recommended for adult mental health, there is little evidence to support this. The overall objective of Study (23) was to complete a series of linked projects to understand and promote recovery from psychosis and bipolar disorder (BD) in a way that is acceptable and empowering for

## SUPPORTING THROUGH WORK

Martin has a diagnosis of schizophrenia. Previously he was a poly-substance user and this caused him to become mentally unwell. In 2010 he had a relapse of his mental health and during that time he was detained by the police on two occasions, with incidents of challenging and violent behaviour, at times requiring rapid tranquilisation by staff.

Martyn stopped taking illegal substances in 2011 and completed three years with the early intervention team before residential care followed by supported independent living from a specialist team.

The very nature of Martyn's mental illness meant that, for him, without proper structure and input he would quickly become alienated and disengaged. Staff supported Martyn to continue to play football with the Early Intervention Team, pay his bills and set up support plans for him. This went well at first but slowly Martyn appeared to lose confidence, became anxious and refused to go. Other support plans fell by the wayside as Martyn went in on himself mentally. It became an effort for him to open his door and a short time later, even to see his family.

His medication was looked at and tweaked several times. Martyn would meet with staff but mostly on

his terms and when he was ready. His anxiety became so bad that he was unable to attend groups for more than five minutes and when he did he would be shaking with anxiety.

It was important that staff kept regular contact with him and to challenge him when his standards of personal care and flat tidiness slipped. Staff were not always successful in attempts to empower him through this period, but persisted in trying.

Eventually with the correct level of medication and staff support, Martyn's quality of life slowly began to improve. He regained contact with his family, eventually going to them for Sunday dinners, Christmas and having the occasional holiday abroad with them. He quit smoking, a remarkable achievement for someone whose anxiety was so great that he chain smoked.

It took a lot of work and gentle steps to get Martyn back to a place where his anxiety didn't overtake him so drastically and where he could function well from day to day.

Case study provided for this review by Rethink ([www.rethink.org](http://www.rethink.org))



service users. The programme consisted of 6 linked projects to (i) generate a concept of recovery from a service user's viewpoint, (ii) address the gap in the knowledge regarding subjective judgement of recovery; (iii) examine preferences for psychological treatment using a patient preference trial; (iv) explore the psychological mechanisms underlying the link between experience of psychosis and suicidal ideations; (v) understand the subjective recovery experiences of people with recent BD and (vi) develop a novel measure of recovery in BD and a new intervention for early BD.

All projects were conducted in collaboration with service users and the research team included two service user researchers. The research provided significant advances in the understanding and facilitation of recovery in both psychosis and BD, and a number of implications for clinical practice emerged from this research programme.

### SELF-MANAGING MENTAL HEALTH

Digital technology is changing the way people learn about and manage their illnesses, but little is known how people with SMI seek information about their mental health on the web. Study (24) investigated online mental health information-

seeking behaviour by people with psychosis and the acceptability of a mobile mental health digital application. Twenty-two people with psychosis were interviewed for this study. The researchers found that internet use was widespread among the interviewees, particularly seeking information about their psychosis, diagnosis, medication and side effects. Some people discussed the information with their clinicians, but some did not for fear of undermining their clinician's authority. The researchers concluded that a partnership approach to online health-information is needed where clinicians encourage patients to discuss information they have found online as part of a shared decision-making process. The findings also suggest that a mental health app would be well received.

Study (25) evaluated a Web-based Enhanced Relapse Prevention (ERP) intervention, which is a structured intervention for mental health staff to deliver face to face.<sup>73</sup> ERP is a psychological intervention specifically developed for adults with bipolar disorder (BD) and has been shown to improve symptoms and prevent relapses and hospitalisation.<sup>74</sup> A single-blind, parallel, primarily online RCT (n=96) over 48 weeks compared ERPonline plus usual treatment, with "waitlist control" plus

usual treatment for people with BD. The researchers found that web-based interventions may prove an important, inexpensive, feasible, and acceptable step forward in creating a choice of evidence-based interventions for people with BD at different stages of recovery. However, given high functioning and low relapse rates in this study, testing clinical effectiveness for this population would require very large sample sizes.

Five Year Forward View for Mental Health encourages the involvement of people with mental health problems in decisions about their long-term care, for example recommending that patients be more involved in medication reviews. The National Institute for Health and Care Excellence (NICE) guidelines on the treatment of schizophrenia emphasise the importance of doctors and patients making collaborative decisions about drug treatment, based on informed discussion. The Medication Review Tool consists of a form to help patients identify pros and cons of their current antipsychotic treatment and any desired changes that they may have. Study (26) investigated the use of the Medication Review Tool by people with severe mental illness. The RCT allocated patients to either the Medication Review Tool or usual care. This was a small study and not large enough to provide definitive data, but it showed that it was possible to introduce a Medication Review Tool to improve patients' ability to take part in discussions and decisions about their antipsychotic medication.

Many people with schizophrenia experience periods of active psychosis followed by periods of relative stability (although auditory hallucinations may remain in the background). Training techniques can teach people with schizophrenia how to detect and recognise the early warning signs of mental illness. Studies indicate that if a person with schizophrenia is able to notice even small changes in signs and symptoms, this can predict illness and relapse, and enable help-seeking to prevent or delay relapse. Study (27) evaluated prior research in interventions to train people with schizophrenia to recognise early warning signs of psychosis for its effectiveness. The study found that the evidence suggests there are positive benefits of early warning signs training, such as reducing rates of relapse and hospitalisation, however the overall quality of the evidence was judged to be very low, so it was not possible to conclude that early warning signs interventions would have the same beneficial effects in the population.

## ACTIVELY MANAGING PERSONAL NETWORKS

People's personal networks are important in shaping identity, and for people with SMI, are important for recovery, but the social aspects of living with SMI, such as friendship and wider connectedness, are not prioritised sufficiently by services. Study (28) investigated the personal networks of people with severe mental illness made up of connections to people, places and activities and their impact on wellbeing. The purpose was to describe personal wellbeing networks, looking for differences in network structure, people's ability to utilise and exchange resources, and to understand the role of practitioners in personal wellbeing network development. Data were collected from 150 network-mapping interviews and 41 in-depth follow-up interviews with people with SMI; in-depth interviews with 30 organisation stakeholders and 12 organisation leaders; and 44 telephone interviews with practitioners. While this exploratory study has limitations, the findings suggest that there is potential for people with severe mental illness and practitioners to use the personal wellbeing network mapping approach to support recovery.<sup>75</sup>

## PEER SUPPORT WORKERS

Peer support worker roles are increasingly being employed in the mental health workforce, mainly in the NHS and the voluntary sector, using their experience for the benefit of other people with mental health problems. However, the evidence demonstrating the benefit of peer worker-based interventions has largely been inconclusive and from outside the UK. Study (29) interviewed 89 peer workers, co-workers, managers and service users about their views and experiences of the peer worker role. The employment of service user researchers to carry out the research was fundamental to this project and especially relevant to peer support research. Two service user researchers conducted key aspects of data collection and analysis, and people with lived experience of using mental health services were core members of the research team, designing and leading the research. The most important issues found were around valuing and supporting peer workers to use their personal experiences of mental health problems. The researchers concluded that organisational cultures need to change to support the adoption of new peer worker roles.

## CO-PRODUCTION AND ENGAGING SERVICE USERS

Early literature suggests that NHS service users struggled to have a real impact on decision-making at either individual or strategic levels. Over the last decade, mental health services have been at the forefront of involving service users in decision-making about services. Study (30) investigated the impact of service user involvement in mental health in terms of service development, delivery, commissioning and personal benefit to users. The same question was asked of front line staff. Other research questions asked managers about their response to user-led organisations, investigated the role of users as governors on trust boards, and the implications of personalisation in health and social care. The researchers concluded that service users have become an integral part of the system, described as a new social movement that has changed in the last 30 years due to organisational change and complexity. However, the researchers raised concerns about personalisation (a way in which service users may control their own care) as the team could locate very few mental health service users who actually had personal budgets. In all the organisations studied, peer support was a critical factor.<sup>76</sup>

## ONGOING RESEARCH

There are a number of research programmes underway to explore aspects of recovery and self-management. These include development of an intervention to expand the social networks of patients with psychosis and test impact on patient outcomes and wellbeing (Study O). Another study is looking at the best way of delivering recovery-focused early intervention services (Study P). The role of volunteers in mental health services will be explored, including testing of a particular befriending scheme and its impact on outcomes (Study Q). Recognising that carers and families are not always involved in planning care, a study will combine observational work for insights on why this does not happen with interventions to train mental health staff and methodological work to provide better measures of family involvement (Study R). A research programme is also carrying out a large trial of peer workers to support discharge from hospital to the community for people with severe mental illness (Study S).



# LOOKING AHEAD



**T**his review has highlighted a range of research funded by NIHR to support people living with severe mental illness. These include studies at different stages, from early intervention through to supporting longterm recovery and wellbeing. Evidence in this review show the strengths of different research methods to provide insights into the experience of care and evaluate services. The last ten years has seen more research into treatment and care for people living with SMI.

But there are still important gaps in what we know. During the course of this review, some areas have been identified where more research is needed. This is not a systematic analysis, but indicates just some of the areas of continuing uncertainty. This ranges from greater understanding of the social determinants of severe mental distress to research into the access and effectiveness of services for particular black and minority ethnic groups. We need more high quality evaluations of different organisational models and their cost-effectiveness, including approaches such as peer worker support. We do not know enough about the relationship between nurse staffing and outcomes, especially safe levels on acute inpatient wards. Important work has been done to understand the experience of those using services<sup>77</sup> and this could be enhanced to get new insights into quality of care. And new methods will be helpful, including participatory research involving communities and led by service user researchers.<sup>78</sup>

In a more systematic way, the James Lind Alliance (JLA) has identified particular priorities in relation to schizophrenia and bipolar disorder. These relate

to specific treatments, as well as broader service questions. The JLA Priority Setting Partnerships bring together clinicians, patients and carers to agree research priorities through a structured and careful process to identify the most important gaps in knowledge. The following priorities have informed and will influence future research supported by NIHR and other funders.

At the end of 2017, NIHR launched a themed call on mental health across its programmes<sup>40</sup>. Building on good work already completed, new research should strengthen our knowledge on what works to support people with severe mental illness to live their best lives.

### **James Lind Alliance top 10 research priorities for Schizophrenia (2011)**

1. What is the best way to treat people with schizophrenia that is unresponsive to treatment?
2. What training is needed to recognise the early signs of recurrence?
3. Should there be compulsory community outpatient treatment for people with severe mental disorders?
4. How can sexual dysfunction due to antipsychotic drug therapy be managed?
5. What are the benefits of supported employment for people with schizophrenia in terms of quality of life, self-esteem, long-term employment prospects and illness outcomes?
6. Do the adverse effects of antipsychotic drugs outweigh the benefits?
7. What are the benefits of hospital treatment compared with home care for psychotic episodes?
8. What are the clinical benefits and cost-effectiveness of monitoring the physical health of people with schizophrenia?
9. What are the clinical, social and economic outcomes - including quality of life and the methods and effects of risk monitoring - of treatment by acute day hospitals, assertive outreach teams, in-patient units, and crisis resolution and home treatment teams?
10. What interventions could reduce weight gain in schizophrenia?

### **James Lind Alliance top 10 research priorities for Bipolar Disorder (2016)**

1. What causes bipolar disorder?
2. How can treatments be tailored to individuals?
3. What is the most effective combination of self-management approaches, therapy and medication?
4. What are the best ways to manage suicide risk among people with bipolar disorder?
5. What could be done for people who do not get better with treatment?
6. What are the best ways to manage the side-effects of medication (including weight gain, problems with thinking and memory, and emotional numbness)?
7. Why does it take so long to get a diagnosis of bipolar disorder, and how could time to diagnosis be shortened?
8. Which are the best medications for treating episodes and for prevention of relapse in bipolar disorder?
9. How effective are talking therapies such as counselling, dynamic psychotherapy and cognitive behaviour therapy (CBT)?
10. Can medications with fewer side-effects be developed?

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# STUDY SUMMARIES AND REFERENCES

## STUDY SUMMARIES - PUBLISHED

### STUDY 1

#### Understanding Causes and Developing Effective Interventions for Schizophrenia and Other Psychoses.

*Published, 2016, Jones/Perez*

This randomised controlled trial evaluated an intervention to enable general practices to identify and refer young people at high risk of developing psychosis. The researchers developed the Liaison with Education and General PracticeS (LEGS) intervention and looked at whether this led to more people at high risk, being referred by GPs to an early intervention service. General practices in Cambridgeshire and Peterborough were randomly assigned to receive either low-intensity liaison (28 practices), which was a postal campaign to help with identification and referral, or high-intensity liaison (26 practices), which included a specialist mental health professional to liaise with each practice as well as the postal campaign. The intervention was run between 2010 and 2013. The primary outcome was the number of high risk referrals per practice. The researchers found that the high intensity intervention doubled GPs' identification and referral of young people with high risk mental states as well as those with first episode psychosis and other mental health problems. Cost analysis indicated this intervention had clinical and economic value. The researchers also followed 60 young people (aged 16-35 years) at high risk for 2 years in the Prospective Analysis of At-risk mental states and Transitions into psychosis (PAATH) study. Only three individuals transitioned to first episode psychosis. Most of the participants at high risk had significant depression and anxiety and many had suffered childhood trauma. Such early identification means services can offer appropriate and timely treatment. The researchers examined the incidence of new referrals for psychosis, finding considerable psychosis morbidity in diverse, rural communities. They also developed the population-level prediction tool, PsyMaptic, to estimate the numbers of young people who require early-intervention services across the country.

Programme Grants for Applied Research 2016.  
<https://doi.org/10.3310/pgfar04020>

### STUDY 2

#### Reducing duration of untreated psychosis: care pathways to early intervention in psychosis services.

*Published, 2013, Birchwood*

This study looked at the care pathway components to understand the duration of untreated psychosis (DUP) and their links with delays in accessing specialised Early Intervention Services (EIS) in Birmingham. The researchers collected data on 343 individuals aged 14-35 years with first episode psychosis (mean age of onset was 21.6 years). The researchers also conducted interviews with 14 families. The median DUP was 50 days. They found that a third of individuals had a DUP of more than 6 months. The main contribution to DUP was found to be from delays within mental health services, followed by help-seeking delays. A delay in reaching EIS was correlated with longer DUP. Delays were often caused by under-recognition of symptoms, poor disclosure and/or disengagement with services. These findings led to changes in local services, including a new clinical youth service in South Birmingham for young people (aged 16-25 years) who display signs of emotional or mental distress. In addition, a media-based public health campaign was implemented, aimed at reducing the stigma associated with mental illness and improving help seeking behaviour particularly in young people.

British Journal of Psychiatry 2013.  
<https://doi.org/10.1192/bjp.bp.112.125500>

### STUDY 3

#### Don't turn your back on the symptoms of psychosis: a proof-of-principle, quasi-experimental public health trial to reduce the duration of untreated psychosis.

*Published, 2016, Connor*

This study looked at the feasibility and impact of a new youth access pathway for first episode psychosis, enabling direct access to Early Intervention Services (EISs) to reduce duration of untreated psychosis (DUP) in Birmingham. The intervention 'Youth Space' consisted of a direct care pathway for 16-25 year olds to access EISs, and a community psychosis awareness campaign including raising community awareness in the community, a youth-friendly website, a psychosis information line, and youth advisors. The intervention targeted help-seeking behaviours and mental health services delays. It provided prompt clinical assessment in a youth appropriate setting, rapid access and expert assessment, provision of brief CBT (cognitive behaviour therapy) and home visits for repeat non-attendance. The researchers evaluated the intervention by comparing DUP in two areas of the city receiving early detection (n=77) vs detection as usual (n= 74). The researchers found that DUP in the intervention area was reduced from a median of 71 days (mean 285) to 39 days (mean 104). There was no change in the control area. Delays in help seeking behaviour was also reduced in the intervention area. The researchers concluded that their intervention is a feasible approach to address DUP. Further research is needed to evaluate its effectiveness.

BMC Psychiatry 2016. <https://doi.org/10.1186/s12888-016-0816-7>

### STUDY 4

#### Early detection of psychosis via community and educational organisations: a feasibility study.

*Published, 2015, Lloyd-Evans*

This study implemented a one-year community awareness programme in an inner London Early Intervention Service (EIS), which targeted staff in non-health service community organisations. The aim was to reduce treatment delay for people experiencing first episode psychosis. The programme included psycho-educational workshops and offered direct referral routes to EIS. It targeted staff working with young people in non-health organisations (for example housing and employment services and youth organisations). It ran for a year from 2009-2010. The researchers evaluated programme feasibility and impact on duration of untreated psychosis. Forty-one workshops at 36 community organisations were attended by 367 staff. A further 19 follow up workshops were run, and 16 services were allocated an EIS link worker. EIS link workers offered monthly meetings and point of contact for each organisation. Staff knowledge and attitudes to psychosis and mental health services improved significantly after the workshops, however, only 6 of 110 new service users reached EIS directly via community organisations a year after the intervention. As well as finding the intervention led to very few new referrals through non-health pathways, there was no significant difference in mean or median duration of untreated psychosis for new referrals to the service in the year of the intervention, compared to the year before. Discussions with stakeholders (including front-line staff, managers and services users) highlighted that barriers to referrals still remained, including uncertainty about the early signs of psychosis and disengagement by young people when they became unwell. The authors concluded that further research is needed to identify ways in which duration of untreated psychosis can be reduced.

BMC Psychiatry 2015. <https://doi.org/10.1186/s12888-015-0485-y>

### STUDY 5

#### Improving outcomes for people in mental health crisis: a rapid synthesis of the evidence for available models of care.

*Published, 2016 Paton*

This review looked at the clinical effectiveness of the models of care for improving outcomes at each stage of the Crisis Concordat pathway. The Crisis Concordat, a national agreement between services involved in the care of people in crisis, was established to improve outcomes for people experiencing a mental health crisis. The four stages of the crisis care pathway are: access to support before crisis point, emergency access to crisis care, quality treatment and care in crisis, and promoting recovery. The researchers searched the literature for evidence around the care pathway, and located one review of reviews, six systematic reviews, nine guidelines and 15 primary studies. The evidence for access for support before crisis point was very limited. There was evidence of benefits for liaison psychiatry teams in improving service-related outcomes in emergency departments, but the evidence was not of high quality. Similarly, there was limited evidence regarding models to improve emergency access to crisis care to guide police officers with reference to their Mental Health Act responsibilities. There was a large evidence-base promoting recovery with various interventions recommended by NICE. The researchers concluded that many of the studies were of low quality and many gaps were identified along the crisis care pathway. More UK research is needed on the clinical effectiveness of crisis care, especially interventions to prevent people reaching crisis point and recovery options for individuals attending specialist mental health hospital care.

Health Technology Assessment 2016. <https://doi.org/10.3310/hta20030>

#### STUDY 6

**The city 128 extension: locked doors in acute psychiatry, outcome and acceptability.**

*Published, 2008, Bowers*

This study looked at the issue of locked doors in adult psychiatric wards. The researchers examined routinely collected data as well as conducted interviews and surveys. From 2004 to 2005, a survey of 136 wards was undertaken, collecting information of patients, staff, service organisation, and containment events including door looking, absconding and drug/alcohol use. The researchers conducted interviews from three sample wards (35 individuals) with patients, staff and visitors. Absconding rates across all wards were very low (0.49 mean daily rate). Exit security was found to make significant use of technology, such as swipe cards, CCTV, key pads and intercoms. Most wards had exits that automatically unlock for fire alarms, and fire exits that could be released by patients. A third of wards had double exit doors. The study found that there was no relationship between absconding rates and exit security. Interviews indicated that patients did not feel informed about door locking policies and knowledge was gained through personal discovery. Both staff and patients had a clear view of the vulnerability of patients who absconded. Overall, the researchers concluded that locking the ward door reduced but does not eliminate absconding. Door locking increased feeling of social exclusion and depression, and associated with an increased risk of self-harm, but had no effect on alcohol or illicit drug use. The researchers recommend that acute admission wards should have a single main exit, unlocked during the day, with maximum visibility to the staff. Patients and families/friends should be informed about the door policy.

Report for the National Co-ordinating Centre for NHS Service and Organisation R&D. 2008. [www.journalslibrary.nihr.ac.uk/programmes/hsdr/081604163/#/](http://www.journalslibrary.nihr.ac.uk/programmes/hsdr/081604163/#/)

#### STUDY 7

**Reducing conflict and containment rates on acute psychiatric wards: The Safewards cluster randomised controlled trial.**

*Published, 2015, Bowers*

This study evaluated ten Safewards interventions that enable staff

to reduce the frequency of patient incidents in acute psychiatric wards that may threaten safety. The Safewards model highlights various staff actions that can impact on conflict or containment. The researchers recruited staff and patients in 31 psychiatric wards and 9 NHS trusts. Wards in the intervention arm implemented a package of ten Safewards interventions, which included mutually agreed standards of behaviour by and for patients and staff, how to manage flashpoints, regular patient meetings and a set of self-management tools for staff to offer patients who were distressed, such as hand oils, stress reducing items and light displays. The primary outcomes were the rates of conflict and containment. They found that these simple interventions aimed at improving staff and patients ward experience could significantly reduce the frequency of conflict and containment. For example, for shifts with conflict or containment incidents, the intervention condition reduced the rate of conflict events by 15% relative to the control intervention. The rate of containment events for the intervention condition was reduced by 23%. However, there was a large quantity of missing data in the intervention and control arms, and the intervention was only delivered for a short time period (3 months). Nonetheless, the researchers concluded that Safewards interventions can provide positive gains for staff and patients and recommended that a further trial is needed to determine replicability of the results.

International Journal of Nursing Studies, 2015. <https://doi.org/10.1016/j.ijnurstu.2015.05.001>.

#### STUDY 8

**Seclusion and psychiatric intensive care evaluation study (SPICES).**

*Published, 2017, Bowers*

The researchers examined the patient records of one NHS trust (2008-2013) to look at the outcomes of patients who were secluded (locked in a robust room alone) or transferred to a specialist high security ward with a high staff-to-patient ratio (PICU). These interventions are two methods for the management of disturbed behaviour of psychiatric patients in acute psychiatric hospitals. Compared to patients who were not subject to these interventions, the researchers found that these patients were more likely to be aggressive again afterwards, and their care needs also tended to be more expensive. However, the researchers noted that cause and effect cannot be conclusively determined. In a second study, the researchers interviewed 81 nurses at eight hospitals in England with and without seclusion rooms and on-site PICUs. The nurses also had a video test on restraint-use timing. When there was no seclusion available, the nurses used more rapid tranquillisation, nursing the patient in a side room and seclusion in an ordinary room. Hospitals without PICUs used more seclusion and de-escalation. Overall, this project found that the availability of seclusion and PICUs influences how disturbed behaviour is managed. However, the authors caution that it remains unclear as to whether these interventions reduce or worsen violence.

Health Service Delivery Research 2017. <https://doi.org/10.3310/hsdr05210>

#### STUDY 9

**Understanding the increasing rate of involuntary admissions in NHS Mental Health Care.**

*Published, 2014, Weich*

This study examined the rate of compulsory admission to inpatient mental services in England in 2010/11. The researchers accessed data from the Mental Health Minimum Data Set, and the analysis included 1,287,730 patients. Compulsory admission was defined as time spent in an inpatient mental illness bed subject to the Mental Health Act (2007). Patients were excluded if they were detained due to emergency assessment only, guardianship or supervision of community treatment. The researchers also consulted with users of mental health services, carers, and senior NHS mental health service managers and clinicians. The researchers

found that 3.5% of patients had at least one compulsory admission; 84.5% of the variance in this outcome were based on individual characteristics, whilst 6.7% variance was between local areas, 6.9% between provider trusts and 2.7% between GP practices. The data showed that patients of black ethnicity were almost three times more likely to have compulsory admission compared to white patients. Compulsory admission was greater in socioeconomically deprived areas. The authors recommend that future research should look at the causes of observed variance in compulsory admission rates and should take a mixed-methods approach.

Health Service Delivery Research 2014.  
<https://doi.org/10.3310/hsdr02490>

## STUDY 10

### Inpatient and residential alternatives to standard acute psychiatric wards in England.

*Published, 2009, Johnson*

The aim of this research was to identify and describe all inpatient and residential alternatives to standard acute psychiatric wards in England. The researchers carried out a national cross-sectional survey of alternatives to standard acute inpatient care. They found 131 such services, most of which were hospital-based and in deprived areas. Community-based service types included clinical crisis houses, specialist crisis houses, crisis team beds, and non-clinical alternatives managed by the voluntary sector. Hospital-based service types included general therapeutic wards, wards for specific groups and short-stay wards. Some types of care available within hospital services were less likely to be provided in community alternatives, such as psychological treatments, structured activity programmes and medication review. The researchers concluded that standard acute psychiatric wards represent an important, but unevaluated, sector of mental health services.

The British Journal of Psychiatry, 2009.  
<https://doi.org/10.1192/bjp.bp.108.051698>

## STUDY 11

### An investigation of therapeutic alliance and its relationship to service user satisfaction in acute psychiatric wards and crisis residential alternatives (TAS 2).

*Published, 2014, Sweeney*

This mixed-methods study interviewed service users who had attended crisis houses and acute psychiatric wards to better understand their experiences of staff-service user relationships. The researchers collected quantitative data from 108 individuals (regardless of diagnosis) who had been a resident in a crisis house for at least 1 week. Data was also collected from 247 participants who had been resident in acute wards for a minimum of 2 weeks. Qualitative interviews were conducted with 29 service users and 16 staff from acute wards and crisis houses. Hospital patients were more likely to be diagnosed with schizophrenia, and crisis house residents more likely to be diagnosed with personality disorder or depression. The researchers used a variety of quantitative measures such as the Client Satisfaction Questionnaire and Recovery Assessment Scale, and interviews covered respondents' views about the characteristics of good staff-service user relationships and factors that promoted or hindered good relationships. Overall, the researchers found that respondents experienced better therapeutic relationships between staff and service users and felt greater satisfaction with crisis houses than acute wards. The researchers found that diagnostic and demographic characteristics were not associated with satisfaction, suggesting that service user satisfaction was related to their surroundings. Good therapeutic relationships were characterised by kind, warm and empathic staff. These results reflect previous findings concerning greater satisfaction with crisis houses.

Health Service Delivery Research 2014.  
<https://doi.org/10.3310/hsdr02220>

## STUDY 12

### An evidence synthesis of risk identification, assessment and management for young people using tier 4 inpatient child and adolescent mental health services.

*Published, 2015, Hannigan*

This study was an evidence synthesis on what is known about the identification, assessment and management of risk in young people (11-18 years) with complex mental health needs entering, using and exiting tier 4 inpatient child and adolescent mental health services in the UK. First, the researchers scoped the literature from two databases, to identify the types of risks faced by this group of individuals. An analysis of this literature (124 articles) was supplemented by input from a range of stakeholders including young people who had been inpatients, carers, managers and professionals. This led to the identification of two risk areas: dislocation and contagion. The researchers defined dislocation as the risks of being removed from normal life, of experiencing challenges to identity and of being stigmatised, and risks to family, friendships and education. Contagion referred to the risks of learning unhelpful behaviour and making unhelpful relationships. The researchers then searched 17 databases and relevant websites for evidence around these two risks, including outcomes, costs, policies and service responses. Forty articles were identified along with 20 policy and guidance documents. From this data set, the researchers concluded that there is little evidence to support the identification, assessment and management of the dislocation and contagion risks. However, the studies were often of limited quality and none had a cost analysis. The documents did indicate that young people undergoing treatment within inpatient settings should be able to lead as normal a life as possible. More research is now required to better understand these less obvious risks.

Health Service Delivery Research 2015.  
<https://doi.org/10.3310/hsdr03220>

## STUDY 13

### Early phase treatment for the prevention of relapse in first episode schizophrenia.

*Published, 2013, Marshall*

This study evaluated three exploratory randomised controlled trials aimed at preventing relapse and/or deterioration in physical health in people with first episode psychosis. All trials took part in the north-west of England with participants aged 16-35 years who had recently experienced a first episode of psychosis. The three trials were: 1) cognitive remediation (CR) to improve metacognition and enhance engagement in subsequent cognitive behaviour therapy (CBT), with 61 participants drawn from a waiting list of people referred to routine CBT; 2) a healthy-living intervention to control weight in individuals taking antipsychotic medication, where participants (105) were required to have a body mass index (BMI) of  $\geq 25$  kg/m<sup>2</sup>; and 3) integrated motivational interviewing and CBT (MiCBT) to reduce cannabis use, where participants (110) were diagnosed with cannabis use/dependence. CR involved 13 sessions over 12 weeks, the healthy living intervention consisted of 8 face-to-face session plus group activities over 12 months, and MiCBT was delivered as brief (12 sessions over 4.5 months) or long (24 sessions over 9 months) formats. Overall, there was no effect of CR on psychotic symptoms, but the amount of CBT subsequently required was significantly less after CR. There was no significant BMI reduction in the healthy-living trial. Outcome data for the MiCBT trial was not yet reported. Although none of the trials had significant success, the researchers concluded that CR required more research.

Programme Grants for Applied Research 2015.  
<https://doi.org/10.3310/pgfar03020>

## STUDY 14

### Financial incentives to improve adherence to antipsychotic maintenance medication in non-adherent patients - a cluster randomised controlled trial: FIAT.

*Published, 2016, Priebe*

This randomised controlled trial looked at the use of incentives for attending appointments to receive antipsychotic medication (injections) by individuals with schizophrenia. The researchers recruited participants (aged 18-65 years) who had a diagnosis of schizophrenia, schizoaffective psychosis or bipolar illness, receiving  $\leq 75\%$  of their prescribed medication. Seventy-three mental health teams participated from 29 NHS trusts, and 141 patients consented to take part (78 intervention and 63 control). The intervention lasted for 12 months, with a 24 month follow-up. Participants in the intervention group received £15 for each medication appointment they attended, whilst the control group received treatment as usual. Outcome data was available for 131 patients. Baseline adherence (attending medication appointments) was 69% in the intervention group and 67% in the control group, and during the intervention adherence was significantly higher in the intervention group (85% versus 71%). Once the money was stopped, adherence was then similar across both groups with no significant difference 6 months and 24 months follow-ups. The average cost of the incentive was £303, but costs between the intervention and control group were not significantly different. The researchers interviewed 45 patients and 59 clinicians; both groups felt positive about the incentive, although a few patients felt guilty about accepting the money. The authors concluded that financial incentives can be an effective way of improving medical adherence and is also cost-effective.

Health Technology Assessment 2016.  
<https://doi.org/10.3310/hta20700>

## STUDY 15

### Family involvement in the treatment of patients with psychosis.

*Published, 2014, Eassom*

This systematic review looked at the barriers and facilitators to family involvement in the treatment of patients with psychosis. Forty-three studies were included, 23 based in the UK and 32 focused only on staff perspectives. The papers included data from 588 professionals, 321 patients and 276 family members. Most studies were cross-sectional and 13 were naturalistic observations. Many papers discussed the use of the behavioural family therapy approach, psychosocial interventions or family psychoeducation. The researchers found that facilitating the training and ongoing supervision needs of staff are necessary but not sufficient conditions for consistent family involvement. Lack of resources, poor support from managers and de-valuing or de-prioritising family work were all key barriers to family involvement. Strong leadership, whole team coordination, active collaboration with families and ongoing support are important facilitators for effective involvement. The researchers concluded that organisational cultures can hinder or facilitate involvement, and suggested that family involvement is only successful when there is a shared goal of all members of the clinical/services team and enabling working practices.

BMJ Open 2014. <https://doi.org/10.1136/bmjopen-2014-006108>

## STUDY 16

### Smoking Cessation Intervention for severe Mental Ill Health Trial (SCIMITAR): a pilot randomised control trial of the clinical effectiveness and cost-effectiveness of a bespoke smoking cessation service.

*Published, 2015, Peckham*

The aim of this pragmatic, two-arm, parallel-group, pilot RCT was to develop and test a bespoke smoking cessation (BSC) service

specifically tailored to individual patients with severe mental illness. The overarching objective was to establish the clinical effectiveness and cost-effectiveness of the BSC intervention compared with usual general practitioner (GP) care. The BSC service was delivered by a mental health professional trained to deliver smoking cessation behavioural support, who provided an individually tailored smoking cessation service based on current guidelines for smoking cessation services but with enhanced levels of contact and support. Participants randomised to usual GP care were advised to see their GP or to consult with usual NHS quit smoking services with no specific adaptation or enhancement in relation to SMI. The primary outcome was carbon monoxide (CO)-verified smoking cessation at 12 months. In the absence of a CO measurement, self-reported smoking cessation was used. Aspects of health economics and service utilisation were collected by questionnaire in order to measure cost-effectiveness. At 12 months, 36% of participants had stopped smoking in the BSC group, compared with 23% in the usual-care group. The adjusted odds ratio was 2.9 (95% confidence interval 0.8 to 10.5) indicating a greater likelihood of smoking cessation in the BSC group than the usual-care group, but this was not statistically significant. Estimates of effect based on an underpowered pilot trial show a direction of effect across a range of outcomes that are in favour of a BSC intervention. There was some evidence of lowered mood in the BSC intervention and this issue needs to be explored further in a fully powered trial.

Health Technology Assessment 2015.  
<https://www.journalslibrary.nihr.ac.uk/hta/hta19250/#/abstract>

## STUDY 17

### The effectiveness of sexual health interventions for people with severe mental illness: a systematic review.

*Published, 2014, Kaltenthaler*

This systematic review evaluated the effectiveness of sexual health risk reduction interventions for people with severe mental illness living in the community. The researchers included 13 randomised controlled trials, all based in the USA, that compared sexual health risk reduction interventions with usual care. The content of the interventions varied between studies, however, most included HIV intervention programmes (that focused on providing education to prevent or reduce the risk of HIV and strategies and skills development for safer sex). Interventions were generally delivered by trained facilitators, mental health counsellors or mental health professionals, and lasted from 4 to 15 sessions. Standard usual care included HIV educational sessions, health promotion, money management, waiting list or no treatment. The researchers used a narrative synthesis approach to combine the research findings. There was no clear and consistent evidence that the interventions reduced the total number of sex partners or improved behavioural intentions in sexual risk behaviour. However, the evidence indicated that the interventions had a positive effect on attitudes about and use of condoms, measures of HIV knowledge, sexual behaviours and practices. However, the researchers caution that the results are not robust given the large variability between studies, small sample sizes and low quality of studies. They recommend that high quality, well-designed UK based trials are needed in this important area.

Health Technology Assessment 2014.  
<https://www.journalslibrary.nihr.ac.uk/hta/hta18010/#/abstract>

## STUDY 18

### The Rehabilitation Effectiveness for Activities for Life (REAL) study: a national programme of research into NHS inpatient mental health rehabilitation services across England.

*Published, 2017, Killaspy*

This research programme investigated NHS inpatient mental health rehabilitation services across England. Scoping work

indicated that quality of care in NHS mental health rehabilitation services in England is higher than similar facilities across Europe. The researchers initially conducted a national survey of relevant NHS services, and 133 Trusts across England took part. Most inpatient mental health rehabilitation units were community based, providing on average 14 beds and had an average length of stay of 18 months. Most service users had a diagnosis of psychosis. The researchers also developed and evaluated a 'hands-on' staff training programme to help staff engage service users in activities on and off the unit. They recruited 40 units that scored below average on quality assessment measures from the survey. The main findings of the programme showed that quality of care was positively associated with service users' autonomy, experiences and perceptions of therapeutic care. The staff training intervention was found not to be clinically effective as staff reverted to previous practice once the intervention team left. However a realist evaluation identified feasible adjustments to strengthen it. Over half the service users in the cohort study were successfully discharged from hospital over 12 months. Factors associated with this were service users' activity levels, social skills and the recovery orientation of the unit (which includes collaborative care planning with service users and holding hope for their progress). The study provides evidence that NHS mental health rehabilitation services deliver high-quality care that successfully supports service users with complex needs in their recovery.

Programme Grants for Applied Research 2017.  
<https://www.ncbi.nlm.nih.gov/books/NBK425139/>

## STUDY 19

### Improving employment outcomes for young people with first episode psychosis.

*Published, 2014, Craig*

This study assessed whether a motivational interviewing intervention for clinical staff could enable them to provide better occupational choices for their patients. Four early intervention teams based in London and the Midlands, who already provided individual placement and support (IPS), were selected to take part. All teams had a vocational specialist who provided employment support based in the IPS model. Two teams were randomised to receive the intervention. The motivational interviewing technique focused on attitudinal barriers to employment, aimed at addressing staff concerns about the value and risks of return to open (competitive) employment. Staff receiving the intervention attended a 3 day course, with refresher sessions. The researchers recruited 159 participants, aged 18-35 years not currently in work or full-time education and expected to remain under the care of the early intervention service for at least the subsequent 12 months. Although not an inclusion criteria, all participants expressed a desire to return to work. Occupational outcomes were obtained from 134 patients (84%) at 12 month follow up. The researchers found that more patients in the intervention teams achieved employment by 12 months compared to the IPS-only teams (29/68 versus 12/66). The authors concluded that the motivational interviewing intervention successfully addressed clinicians' ambivalence about their patients returning to work suggesting that providing clinical staff with specific training in techniques to address service users (and their own) motivational conflicts may enhance their chances of competitive employment.

British Journal of Psychiatry 2014.  
<https://doi.org/10.1192/bjp.bp.113.136283>

## STUDY 20

### Cross-national comparative mixed-methods case study of recovery-focused mental health care planning and co-ordination: Collaborative Care Planning Project (COCAPP).

*Published, 2015, Simpson*

This study looked at care planning and coordination in

community mental health settings and whether it is organised to help people's recovery and whether this is carried out in a personalised way. The researchers identified six NHS trusts/health board sites in England and Wales. They reviewed relevant policies and literature and surveyed staff and service users to explore their views on recovery, empowerment and therapeutic relationships (n=649). They also interviewed managers, clinical staff care coordinators, service users and carers (n=117) and reviewed 33 care plans. The researchers found that good relationships were important for all groups in care planning and supporting recovery but that service users did not always feel involved in their care and risk assessments were often kept from service users. Understandings of recovery and personalisation varied among the service users and staff and staff reported too much paperwork. The researchers cautioned that the survey response rate was low (between 9-19%). However, they concluded that new ways of working should be investigated to increase staff contact time with service users and carers, with a focus on recovery.

Health Service Delivery Research 2016.  
<https://doi.org/10.3310/hsdr04050>

## STUDY 21

### Cross-national mixed methods comparative case study of recovery-focused mental health care planning in acute inpatient mental health settings (COCAPP-A).

*Published, 2017, Simpson*

This study looked at the care planning processes in acute mental health wards. The researchers focused on 19 mental health wards in six NHS sites in England and Wales. They conducted a survey of staff (n=290) and service users (n=301), case studies involving interviews with staff, service users and carers (n=76), and reviewed care plans (n=51) and care review meetings (n=12). Overall, the service users rated the quality of care and therapeutic relationships highly when the ward seemed to be more recovery-focused. Both service users and carers said that most care was good and individualised. Across all sites, staff rated the quality of therapeutic relationships as significantly higher than service users. Although staff highlighted the importance of involving service users in care planning, the interviews and care plan reviews indicated that this did not always happen. Staff were keen to help with recovery, but there were different understandings of recovery and a focus on recovery was considered more difficult when the service user was very distressed and/or had been detained under the law. A key priority for staff was keeping everyone safe, which was recognised by service users, although staff did not always discuss safety measures with the service users. The researchers concluded that this study highlighted the commitment to safe, respectful and compassionate care in mental health wards. They suggested that future research should look at ways in which staff can increase their contact time with service users to promote recovery-focused, personalised care.

Health Service Delivery Research 2017.  
<https://doi.org/10.3310/hsdr05260>

## STUDY 22

### Sustaining Positive Engagement and Recovery (SuperEDEN) – the next step after Early Intervention for Psychosis.

*Published, 2018, Fowler*

This was an RCT to evaluate the efficacy of enhancing social recovery from First Episode Psychosis (FEP) by supplementing Early Intervention Services (EIS) with Social Recovery Therapy (SRT). The intervention took place at four specialist EIS in the UK. Participants (aged 16-35 years) had non-affective psychosis, attended EIS for 12-30 months, and had severe social disability (defined as being engaged in less than 30 hours per week of structured activity). EIS was provided by specialist teams, consisting of intensive recovery-oriented case management, supported employment, peer support

and family work, alongside CBT for psychosis and medication management. The SRT intervention was developed by the researchers as an outreach and case management package. SRT was delivered by a therapist and consisted of engaging the individual, assessing motivations and goals, preparing for new activities, and activity engagement. Participants were assessed at baseline, 9 months post-intervention and at 15 months follow up. The primary outcome was time spent in structured activity at 9 months. 154 participants took part, 75 were assigned to SRT plus EIS, and 79 assigned to EIS only. 143 participants provided data at 9 months. The study found that receiving SRT plus EIS was significantly associated with an increase in structured activity of 8.1 hours, greater than EIS alone. The authors concluded a more definitive trial with long-term follow up is now needed.

The Lancet Psychiatry 2018.  
[https://doi.org/10.1016/S2215-0366\(17\)30476-5](https://doi.org/10.1016/S2215-0366(17)30476-5)

## STUDY 23

### Psychological approaches to understanding and promoting recovery from psychosis.

*Published, 2016, Morrison*

This programme of research aimed to understand and promote recovery in psychosis and bipolar disorder (BD), with service user involvement central to the programme. The researchers undertook six related projects to understand what is meant by recovery by individuals with psychosis and BD, how to measure recovery as defined by service users, what psychological factors promote recovery, how recovery, symptoms and psychological well-being are related, and the factors that may predict recovery. The researchers also conducted three interventions. The first intervention evaluated cognitive-behavioural (CB) approaches to guided self-help (89 participants). The second intervention evaluated CB therapy for understanding and preventing suicide in psychosis (49 participants), and the final intervention evaluated a CB approach to assist with recovery in recent onset BD (67 participants). Overall, the researchers developed feasible and valid measures of recovery. They found that factors such as reduced negative emotions, increased self-esteem and hope are predictive of recovery. The interventions they developed also showed beneficial effects for individuals with psychosis, suicidal thinking and BD. The researchers concluded that the interventions now required larger definitive trials to evaluate the effectiveness.

Programme Grants for Applied Research 2016.  
<https://doi.org/10.3310/pgfar04050>

## STUDY 24

### App to support Recovery in Early Intervention Services (the ARIES study): Usability testing and pilot randomised controlled trial of a supported self-management smartphone application for psychosis.

*Published, 2016, Aref-Adib*

This study explored the use of online mental health information seeking. The researchers recruited 22 people with psychosis based in London (aged ranged from 21 to 57 years). They asked them about their current and historical use of online mental health information and their use of technology. The researchers found that the use of the internet to obtain mental health related information was widespread amongst the participants. Eighteen individuals used the internet to help them make sense of their psychotic experiences and their diagnosis, and also to seek information about their medication and its side effects. Two individuals discontinued their medication use because of the information they found, without discussions with their clinician. However eight individuals actively discussed the information with their clinician and this gave them a sense of empowerment and independence. The researchers concluded that individuals with psychosis are seeking information from the internet, and this could be used collaboratively with their clinician to guide their

treatment. A partnership approach should be encouraged, as the gathering of such information could have impact in the patient's health care decisions. The researchers said there is scope for the development of a mental health app that could provide useful information.

BMC Psychiatry 2016. <https://doi.org/10.1186/s12888-016-0952-0>

## STUDY 25

### Assessing feasibility and acceptability of web-based enhanced relapse prevention for bipolar disorder (ERPonline): A randomised controlled trial.

*Published, 2017, Lobban*

This randomised controlled trial evaluated the feasibility and acceptability of a web-based enhanced relapse prevention intervention (ERPonline) for individuals with bipolar disorder. The researchers recruited 96 participants with bipolar disorder who were randomised to ERPonline or waitlist control (WL). ERPonline was developed with extensive input from individuals with bipolar disorder to adapt a manual-based format to a web platform and consisted of 12 modules. Participants interacted with the site so an individualised staying-well plan could be developed. The researchers found that access to ERPonline was associated with a significantly more positive model of bipolar disorder at 24 and 48 weeks, increased monitoring of early warning signs of depression at 48 weeks, and hypomania at 24 and 48 weeks. ERPonline did not impact on medication adherence or clinical outcomes, but relapse rates were low for both intervention and control groups. ERPonline cost £19,340 to create. The researchers concluded that the intervention provides an inexpensive and accessible option for people seeking ongoing support following successful treatment.

Journal of Medical Internet Research 2017.  
<https://doi.org/10.2196/jmir.7008>

## STUDY 26

### Development and preliminary evaluation of a Medication Review Tool for people taking antipsychotic medication.

*Published, 2014, Moncrieff*

The researchers conducted a pilot evaluation of a Medication Review Tool they developed to assist people to participate more effectively in discussion about antipsychotic drug treatment. The tool enabled patients to identify the benefits and disadvantages of their current antipsychotic treatment, and any changes they wanted to make. Participants also had access to a linked website containing information about medication. The researchers recruited participants diagnosed with psychotic disorders (18-35 years) from community mental health services. Sixty patients were randomised to receive either the Medication Review tool or usual care. When the patients attended their scheduled medical consultation, those in the intervention arm completed the tool with the assistance of a health professional and took the completed form to their consultation. The researchers used the Decision Self Efficacy scale (DSES) as the primary outcome measure. After 3 months, there was no difference on the scores of the DSES, symptoms, side effects, antipsychotic doses, or patient satisfaction. There was a small increase in positive attitudes to antipsychotic medication in patients who used the tool compared to the control group. Feedback from the patients indicated that they valued the tool as it enabled them to identify positive and negative aspects of their antipsychotic use. The researchers concluded a tool could be used by patients to discuss their medication and further research into this area is needed.

BMC Psychiatry 2016.  
<https://dx.doi.org/10.1186%2Fs12888-016-0921-7>

## STUDY 27

### Training to recognise the early signs of recurrence in schizophrenia.

*Published, 2013, Morriss*

This review looked at the literature on the effectiveness of early warning signs interventions on time to relapse, hospitalisation, functioning and symptomatology. Early warning signs interventions are designed to train people with a diagnosis of schizophrenia to recognise early warning signs of recurrence episodes. This can include education, self-monitoring, and early action strategies such as seeking help early. The review included 34 studies involving 3554 people with schizophrenia or other non-affective psychosis over 16 years of age. The main findings indicated that there are positive benefits of training in early warning signs. It significantly reduced relapse rates compared to usual care (23% versus 43%) and significantly reduced re-hospitalisation compared to usual care (19% versus 39%). There was a lack of evidence on patient satisfaction and cost estimates. The researchers caution that training in early warning signs was mainly used alongside other psychological therapies, so it is difficult to untangle the most beneficial component parts. Furthermore, the researchers assessed the quality of the included studies to be low, so recommend future high quality research assessing the effectiveness of early warning signs interventions.

Cochrane Database of Systematic Reviews 2013.  
<https://doi.org/10.1002/14651858.CD005147.pub2>

## STUDY 28

### Improving community health networks for people with severe mental illness: a case study investigation.

*Published, 2015, Pinfold*

This exploratory study looked at the personal wellbeing networks of individuals with severe mental illness (SMI) using an approach that explored a person's connections to all the places, activities and people that were important in their lives. The researchers collected network-mapping interview data from 150 individuals with SMI, and they subsequently interviewed 41 individuals from this cohort to explore how they managed and developed their connections over time. The researchers also interviewed 41 organisation stakeholder or leaders, and 44 practitioners. The researchers found three types of personal wellbeing networks in the data which they named diverse and active, family and stable, and formal and sparse. They found that wellbeing and social capital (access to resources) varied both within network types and between them. The researchers also found that whether a person lived alone or not, their housing status, formal education and long-term sickness or disability were significantly associated with a participant's network type. Whilst health-care practitioners recognised social factors as important for recovery, they highlighted system-level barriers that prevented them from addressing these fully. Such barriers included workload, administrative bureaucracy and limited time with clients. The researchers concluded that people with SMI could be better supported to develop their personal networks to benefit their well-being.

Health Service Delivery Research 2015.  
<https://doi.org/10.3310/hsdr03050>

## STUDY 29

### New Ways of Working in mental health services: assessing and informing the emergence of Peer Worker roles in mental health service delivery.

*Published, 2014, Gillard*

This qualitative study used a comparative case study approach to explore the role of peer workers in a variety of settings. The researchers chose 10 different case settings, comprising mental health NHS trusts, voluntary sector service providers and

partnerships between the NHS and voluntary sector or social care providers. Paid and unpaid peer workers were employed in a variety of roles in psychiatric inpatient settings, community mental health services and black and minority ethnic specific services. The researchers interviewed 89 participants including service users, peer workers, (non-peer) co-workers, line managers, strategic managers and commissioners. Interviews contained a range of questions to explore experiences and views about peer worker adoption and roles. The researchers used a framework approach to look at the data between different settings and groups. They found that whilst peer worker roles were more established in the voluntary sector, adopting such roles in the NHS posed a number of challenges to fit into existing cultures of practice. However, peer workers were able to bring their lived experiences into their roles, and could engage people in the services by building strong relationships. Overly formal role could result in a barrier to engagement. The researchers recommend more research is needed into the effectiveness of peer worker interventions and a cost analysis.

Health Service Delivery Research 2014.  
<https://doi.org/10.3310/hsdr02190>

## STUDY 30

### How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study.

*Published, 2014, Rose*

This study investigated the extent of service user involvement (SUI) in mental health on shaping policy agendas and key decisions. The study took place in three NHS Foundation Trusts (FTs) in rural and urban areas. The researchers initially conducted a set of surveys with service users and found that there was high SUI, and they perceived that this produced a positive impact on service development and delivery. Frontline staff also encouraged SUI. The researchers then explored user-led organisations (ULOs), which showed they need to be flexible and adapt to a complex organisational culture. Rather than traditional styles of confrontation and campaigning, service users adopt more corporate and professional roles. The researchers also looked at the role of service user governors in NHS FTs, finding that they were working within a system of cultural norms but were beginning to organise collectively. The researchers concluded that service users and managers are working in a climate of dynamic and complex organisational change, where user involvement is an integral part. They indicate that has led to SUI as a new social movement. They suggest the next step is exploring how service users may personalise their involvement and take control of their own care.

Health Service Delivery Research 2014.  
<https://doi.org/10.3310/hsdr02100>

## STUDY SUMMARIES - ONGOING

### STUDY A

#### Does better quality of primary care influence admissions and health outcomes for people with serious mental illness (SMI)? A linked patient-level analysis of the full patient care pathway.

*Due to publish 2019, Jacobs*

This study is looking at whether better management of serious mental illness (SMI) in general practice, improves outcomes for people with SMI. The researchers will make use of the Quality and Outcomes Framework (QOF) indicators, which were introduced in 2006 whereby general practices receive financial rewards for achieving specific quality targets for different conditions. The researchers will measure the quality of SMI by achievement on relevant SMI QOF indicators, such as having care plans in place, and doing a physical review. The study will also investigate non-QOF quality indicators derived from current literature, Patient

and Public Involvement and Steering Group input which could be used in primary care to manage patients with SMI. The quality indicators include inappropriate polypharmacy and continuity of care. Outcome measures will include hospital admissions for SMI, emergency admissions for Ambulatory Care Sensitive Conditions, accident and emergency (A&E) attendances, costs for SMI patients in primary and secondary care, and mortality. The researchers will develop a data set covering the full patient care pathway using routine data from different sources.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/135440/#/>

## STUDY B

### **PARTNERS2: development and pilot trial of primary care based collaborative care for people with serious mental illness.**

*Due to publish 2019, Birchwood*

This project aims to develop and evaluate a collaborative care model for people with schizophrenia and bipolar disorder. The researchers will help primary care and community based mental health services to work more closely with each other. This will be achieved through enhancing the role of experienced mental health workers in GP surgeries, who will act as both therapist and co-ordinator to support individuals to access other relevant services and activities. This professional would see the service user on a regular basis, enable them to help themselves to facilitate recovery and liaise with community/voluntary organisations and secondary mental health care when necessary. The researchers will be working with GPs, psychiatrists and service commissioners in Birmingham, Manchester and South Devon.

<https://www.clahrcprojects.co.uk/impact/projects/partners2-development-and-pilot-trial-primary-care-based-collaborative-care-people>

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Birchwood+M%22+gid:%22RP-PG-0611-20004%22+ga:%22DH/NIHR%22>

## STUDY C

### **Acute Day Units as Crisis Alternatives to Residential Care AD-CARE.**

*Due to publish 2020, Osborn*

This study will assess the use of Acute Day Units (ADUs), which are used during crisis care in some areas across England. The project includes three work streams, including collating data on all ADUs across England to explore aspects such as admission data staffing and user case mix. The researchers will then select 5 ADUs as case studies, and will look at routine data, user/family experience, clinician and patient-rated outcome measures. They will also recruit 400 individuals who have attended ADUs and compare to 400 individuals discharged from the crisis care team in the same Trust/ locality without ADU input. Main outcomes include readmission to acute pathway at 6 months, and satisfaction with services. The researchers will interview a smaller sample of service users, carers and stakeholders.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/152417/#/>

## STUDY D

### **EMPOWER: Early Signs Monitoring to Prevent Relapse and PrO mote Wellbeing, Engagement and Recovery.**

*Due to publish 2019, Gumley*

This is a pilot randomised controlled trial of an intervention to detect and prevent relapse in people with schizophrenia. The researchers aim to recruit individuals with schizophrenia (aged 16+) who have been admitted to a psychiatric inpatient service at least once in the previous 2 years for a relapse of psychosis. The intervention will be delivered on smartphones with online support, delivered within a Stepped Care Relapse Prevention Pathway. Participants will be recruited from mental health services based in the UK and Australia. The researchers will obtain a number of

measures, including symptoms, service engagement, adherence to early signs of monitoring, number of help-seeking attempts, and changes in relapse management. This results from the pilot will be used to inform a larger trial.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/1315404/#/>

## STUDY E

### **Cognitive Bias Modification for Paranoia: A novel attempt to treat paranoid delusions.**

*Due to publish 2019, Yiend*

This study is evaluating the feasibility of the Cognitive Bias Modification for paranoia (CBM-pa) intervention for patients with paranoia. CBM-pa is a computerised, self-administered psychological procedure that involves reading text inviting paranoid interpretations, but then generating responses reflecting an alternative, non-paranoid interpretation. CBM-pa aims to manipulate paranoid biases toward more adaptive processing. The researchers will evaluate whether CBM-pa could be a targeted therapy, looking at the acceptability of the intervention. They aim to recruit 60 stabilised outpatients, presenting with persistent distressing paranoia, to receive either CBM-pa or text-reading control (both in addition to treatment as usual). Each participant will receive one 40-minute session per week for 6 weeks, with 1 and 3 months follow-ups. Eight participants will be interviewed about their experiences of the intervention.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Yiend+J%22+gid:%22PB-PG-0214-33007%22+ga:%22DH/NIHR%22>

## STUDY F

### **Collaborative Care Model for Bipolar DisOrder (COMBO).**

*Due to publish 2018, Attenburrow*

This feasibility study is assessing True Colours (TC), a web-based symptom monitoring service for people with mood instability and bipolar disorder in primary care. The TC service encourages patients to answer questions about their symptoms (usually weekly), and the answers are plotted on a graph which can be personally annotated. The service allows the individual to monitor and manage their own symptoms and share their information with their health professionals, allowing for early identification of relapses. The research aims to assess the feasibility of using True Colours in Primary Care as a tool to develop a collaborative care model for the management of bipolar disorder. The study has currently recruited eight patients and six GPs. All individuals are trained to use TC and interviewed to understand their experiences.

<https://www.clahrc-oxford.nihr.ac.uk/research/collaborative-care-model-for-bipolar-disorder-combo>

## STUDY G

### **An online randomised controlled trial to evaluate the clinical and cost effectiveness of a peer supported self-management intervention for relatives of people with psychosis or bipolar disorder: Relatives Education and Coping Toolkit (REACT).**

*Due to publish 2019, Lobban*

This randomised controlled trial is comparing REACT, and Resource Directory including treatment as usual, to Resource Directory and treatment as usual. The Relatives' Education and Coping Toolkit (REACT) is an online evidence-based toolkit of supported self-management for relatives of people with recent onset psychosis. The Resource Directory provides information about how to access available online support. The researchers aim to recruit 666 relatives over 18 living in the UK who support someone with psychosis or bipolar disorder. The primary outcome is relatives' distress (GHQ-28). Outcome measures will be taken at baseline, and 3 and 6 months later.

<http://bmjopen.bmj.com/content/7/7/e016965.full?ijkey=gjxltwISmLK8GQ4&keytype=ref>

## STUDY H ONGOING

### **IMpLeMentation of A Relatives Toolkit (IMPART study): Examining the critical success factors, barriers and facilitators to implementation of an online supported self-management intervention in the NHS.**

*Due to publish 2018/2019, Lobban*

This case study project will explore the barriers and facilitators to the implementation of The Relatives' Education and Coping Toolkit (REACT) in the NHS. The toolkit is an evidence-based online supported self-management intervention for relatives of people with recent onset psychosis. REACT is divided into manageable modules, has been co-produced with relatives, and has shown to significantly reduce distress and increase perceived ability to cope. The researchers will also develop a national implementation plan, as REACT fulfils NICE Guideline recommendations to provide an education and support programme to relatives. The researchers will assess REACT across 6 NHS Trusts.

<https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/140416/#/>

## STUDY I

### **Combined individual and family therapy in comparison to treatment as usual for people at risk of psychosis: A feasibility study.**

*Due to publish 2019, French*

This feasibility study is investigating whether a combined individual and family CBT (IFCBT) intervention is an acceptable, feasible and potentially effective treatment option for individuals at risk of psychosis. IFCBT aims to minimising transition to psychosis, reduce distress, increase quality of life and reduce disability. Seventy-six individuals will be randomised to one of two conditions. In the treatment as usual group, participants will be monitored for 1 year to assess levels of transition to full psychosis and in the intervention group they will be monitored for one year plus receive IFCBT. Assessments will be carried out at baseline, 6 month and 12 month follow up. The researchers will also conduct interviews with participants (n=15-20) and family members/carers (n=15-20) to understand experiences of therapy and trial participation.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22French+P%22+gid:%22PB-PG-1014-35075%22+ga:%22DH/NIHR%22>

## STUDY J

### **Co-production and evaluation of an e-learning resource to improve knowledge about schizophrenia and engagement with services in African Caribbean families.**

*Due to publish 2018, Edge*

This study aims to co-produce and pilot an educational e-learning resource with African Caribbean stakeholders to improve family attitudes and knowledge about schizophrenia to facilitate engagement with services. Collaborative working with key stakeholders will determine how best to construct and deliver a culturally-appropriate e-Learning intervention. This information will be used to design the intervention (including 'look' and 'feel'), as well as developing content to illustrate key topics about schizophrenia from carer, service user and healthcare professional perspectives. The topics will be determined by stakeholders but are likely to include: diagnosis, symptoms, and approaches to treatment, as these are topics raised by members of this community who were involved in developing the research. Factual information, for example, about schizophrenia and its management together with culturally-relevant content such as alternative conceptualisations of mental health and illness (illness models) will also be included. The intervention will be tested in a pilot RCT in which 20 individuals will be randomised to receive the intervention. The intervention will be accessible via computers, tablets, laptops and smartphones. A DVD version might be

produced if consultation determines that this is warranted. Trial participants can be from any ethnic background but must have a family member who is of African-Caribbean origin and who has been diagnosed with schizophrenia or related psychoses. The researchers will collect outcome data (knowledge about psychosis and attitudes to mental illness) and qualitative information about perceptions of the intervention and participants' experiences of using it. In addition to being able to test their knowledge, participants will also be able to reflect on their personal experiences (e.g. via a 'Things I wished I'd Known' page) and share these via the intervention to improve future iterations. Members of the control group, who will complete the same outcome measures as those in the intervention group, will receive the intervention after 3-months' follow-up.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Edge+D%22+gid:%22PB-PG-0212-27109%22+ga:%22DH/NIHR%22>

## STUDY K

### **Culturally-adapted Family Intervention (CaFI) for African Caribbeans with schizophrenia and their families: A feasibility study of implementation and acceptability.**

*Due to publish in full 2018, Edge*

This primary aim of this study is to assess the feasibility of culturally-adapting, implementing and evaluating a family intervention for service users of African-Caribbean backgrounds who have been diagnosed with schizophrenia, and also for their families. The secondary aim was to test the feasibility and acceptability of delivering CaFI (culturally-adapted family intervention) via Family Support Members (FSMs) or 'proxy families' where biological families were not available. CaFI was successfully co-produced using qualitative and consensus methods with current and former service users of African-Caribbean descent, their families/caregivers, advocates (including voluntary sector organisations) and healthcare professionals. The intervention was delivered in acute, rehabilitation and community settings in Manchester by therapists with experience of working with families who received cultural awareness training as part of the study. The feasibility trial recruited 31 family units and successfully delivered CaFI, comprising 10 one-hour sessions of therapy, within a 20-week therapy window. High retention rates were achieved with 24 of the 26 family units that commenced CaFI completing all 10 sessions. CaFI received high (above 80%) acceptability ratings from service users, their families and FSMs. It was also positively rated by therapists. Reported service user benefits included improved symptoms (better mood, less paranoia) and social functioning (engaging in volunteering and/or actively planning to return to work and full-time education). Therapeutic alliance was positively rated by all groups. Service users' quality of life (health utility index) improved; especially among those not in contact with their families who participated via FSMs. Staff, families, and service users reported improved communication and engagement. The intervention now needs to be tested in a fully-powered randomised controlled trial (RCT) to evaluate its clinical and cost-effectiveness compared with usual care. Further work is also required to determine whether culturally-adapted interventions like CaFI would have broad appeal across ethnic minorities groups as well as to service providers, commissioners and policy makers. In this context, working with FSMs where no biological families are available (such as with refugees and forensic populations where Black and other ethnic minorities are over-represented) would mark an important development in tackling ethnically-based disparities in accessing evidence-based care.

CaFI Study Report (full report available later in 2018, early findings published in first look summary):

Edge, D., A. Degnan, S. Cotterill, B. K., J. Baker, R. Drake and K. M. Abel (In Press). "Culturally-adapted Family Intervention (CaFI) for African Caribbeans with schizophrenia and their families:

A feasibility study of implementation and acceptability “ NIHR Journals.

First look summary: <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/12500162/#/>

## STUDY L

### STEPWISE: STructured lifestyle Education for People With Schizophrenia.

*Due to publish 2018, Holt*

This randomised controlled trial assessed the effectiveness of a group-based structured education programme for individuals with schizophrenia to help them lose weight. The researchers recruited 441 adults with schizophrenia, schizoaffective disorder or first episode psychosis, from 10 UK Mental Health Trusts. The intervention was based on the psychological theories and behaviour change techniques of the Diabetes Education and Self-Management for ON-going and Newly Diagnosed (DESMOND) programme. The 12-month intervention comprised four 2.5 hour weekly sessions, with further contact every two weeks and group sessions at 4, 7 and 10 months. 341 participants completed the trial. At 12 months, the weight reduction did not differ between groups and physical activity, dietary intake and biochemical measures were unchanged. Although intervention was neither clinically nor cost-effective, both participants and facilitators expressed high levels of interest in and acceptability for the intervention.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/122805/#/>

## STUDY M

### Prediction and management of cardiovascular risk for people with severe mental illnesses. A research programme and trial in primary care. (PRIMROSE).

*Due to publish 2018/9, Osborn*

This programme of research aims to evaluate the effectiveness and cost-effectiveness of an intervention for practice nurses who work with individuals who have SMI and cardiovascular disease (CVD). The researchers will develop a nurse-led intervention that aims to reduce the CVD risk in SMI in primary care. They will also develop a new web-based CVD risk score tool, specifically for individuals with SMI, which will be made available to NHS clinicians. The intervention will be developed with input from service users, practice nurses and GPs, and other relevant individuals. The researchers will evaluate the intervention in a cluster randomised controlled trial, where the intervention will be compared to treatment as usual in 40 general practices and involve 400 people with SMI. The primary outcome is cholesterol level after one year.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Osborn+D%22+gid:%22RP-PG-0609-10156%22+ga:%22DH/NIHR%22>

Publications from this study:

Primrose CVD risk score work:

<https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2043173>

<http://bmjopen.bmj.com/content/7/9/e018181>

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## STUDY N

### The RESPECT Study (Randomised Evaluation of Sexual Health Promotion Effectiveness informing Care and Treatment): a feasibility study of an intervention aimed at improving the Sexual Health of People with Severe Mental Illness.

*Due to publish 2018, Hughes*

This feasibility study is an RCT to promote sexual health for people with severe mental illness, and evaluate how this can be delivered within mental health services. The researchers will design a manualised behavioural intervention to promote sexual health by assessing and targeting specific needs. Service users, clinicians and academics will help design the intervention. The researchers will use a variety of quantitative measures, including sexual health knowledge, violence in relationships, and quality of life. They aim to recruit 100 participants and will also interview a subsample to assess the acceptability of the intervention. The results will be used to inform a larger trial.

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/1417201/#/>

## STUDY O

### SCENE: Improving quality of life and health outcomes of patients with psychosis through a new structured intervention for expanding social networks.

*Due to publish 2022, Priebe*

This programme of seven work packages will investigate an intervention for enhancing social networks of individuals with psychosis to improve their quality of life. The researchers will explore the social networks of 100 patients with psychosis across a range of rural and urban areas (Devon, East London, Luton/Bedfordshire and North East England). Using this information, alongside data collected from focus groups and interviews with patients and stakeholders, the researchers will design an intervention to expand the social networks of patients with psychosis, develop a training module for health professionals and develop an NHS implementation plan. The researchers aim to recruit 453 patients to a pilot randomised controlled trial to evaluate the 6 month intervention, with measures taken at baseline, 6, 12 and 18 months.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Priebe+S%22+gid:%22RP-PG-0615-20009%22+ga:%22DH/NIHR%22>

## STUDY P

### Building Resilience and Recovery through Enhancing Cognition and quality of Life in the early PSYCHOSIS (ECLIPSE).

*Due to publish 2022, Wykes*

This programme of research is investigating the optimal method of providing cognitive remediation therapy (CRT) in Early Intervention Services. CRT aims to improve cognitive and functional recovery. The researchers will assess cost-effectiveness and seek views from service users, staff and service providers. The research consists of four stages, including the development of a web-supported training programme for cognitive remediation therapists and the evaluation of three different methods of providing CRT across ten EIS teams. The findings will help guide UK-wide implementation of CRT.

<https://www.journalslibrary.nihr.ac.uk/programmes/pgfar/RP-PG-0612-20002/#/>

## STUDY Q

### Volunteering in Mental Health Care for People with Psychosis (VOLUME).

*Due to publish 2018, Priebe*

This programme of research is exploring the benefits of volunteers in mental health services for people with psychosis, where volunteers provide unpaid care and are often part of one-to-one befriending schemes. It consists of a synthesis of the

literature and mapping of current NHS volunteering programmes; the researchers have also explored the experiences with 20 volunteers and 20 patients with psychosis who have received one-to-one volunteer input over a period of at least six months. A volunteering scheme was designed, and an exploratory randomised controlled trial in East London to compare patient outcomes following a 12 month befriending intervention has been completed. The programme is now in the phase of analysis and will report this year.

<https://www.journalslibrary.nihr.ac.uk/programmes/pgfar/RP-PG-0611-20002/#/>

## STUDY R

### Enhancing the quality of user involved care planning in Mental Health Services (EQUIP).

*Due to publish 2018, Lovell*

This programme grant is looking at the effectiveness and cost effectiveness of user and carer involvement in care planning in mental health services. The researchers will develop, evaluate and implement a user/carer-led training package for mental health professionals to improve the ways in which users and carers are involved in planning. The researchers will also design and evaluate a patient reported outcome measure (called PROM) to assess this level of involvement. The study will take place in Manchester Mental Health and Social Care Trust and Nottingham Healthcare Trust. The researchers will develop tools such as a care planning audit tool, materials to empower users and carers to facilitate change, and training materials for mental health services.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Lovell+K%22+gid:%22RP-PG-1210-12007%22+ga:%22DH/NIHR%22>

## STUDY S

### Enhanced discharge from inpatient to community mental health care (ENRICH): a programme of applied research to manualise, pilot and trial a Peer Worker intervention.

*Due to publish 2020, Gillard*

The aim of the ENRICH programme is to improve the discharge experience from psychiatric inpatient care for mental health service users, prevent readmission, reduce costs and improve individual recovery. The researchers will investigate the effectiveness and cost-effectiveness of a peer worker intervention to enhance discharge. The researchers will develop a manual with input from expert panels, which will involve ways to train and support Peer Workers, and then run a pilot trial. This will be used to inform a large randomised controlled trial conducted across six Mental Health Trusts. The primary outcome is readmission to psychiatric inpatient care within one year of discharge. Other measures will include behavioural and service user outcomes.

<https://europepmc.org/grantfinder/grantdetails?query=pi:%22Gillard+S%22+gid:%22RP-PG-1212-20019%22+ga:%22DH/NIHR%22>

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