Recovery for real

A summary of findings from the REFOCUS programme
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Introducing the REFOCUS programme

This report summarises the finding from the REFOCUS programme, which took place in England from 2009 to 2014. The document is written for the general public, and describes what the study involved and what we found.

Developing recovery-orientated services is the goal of modern mental health care, particularly in English-speaking countries. Before we describe the findings from the REFOCUS programme, it is important to note the differences between clinical recovery and personal recovery.

Clinical recovery is an idea that has emerged from the expertise of mental health professionals, and involves getting rid of symptoms, restoring social functioning and in other ways, ‘getting back to normal’. Most mental health services are currently organised to meet the goals of clinical recovery.

Personal recovery on the other hand, is an idea that has emerged from the expertise of people with lived experience of mental illness, and means something different to clinical recovery. The most widely used definition of personal recovery comes from Bill Anthony:

‘Recovery is a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of a new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’.

The REFOCUS programme was a 5 year research study which aimed to understand what is meant by personal recovery and to find effective ways of increasing the recovery support community-based adult mental health services offer to service users.

The goals of the REFOCUS programme were to address some questions about recovery:

• What is recovery? (Addressed in Section 1)
• How can workers support recovery? (Addressed in Section 2)
• How is recovery measured? (Addressed in Section 3)

Based on these findings, we developed a new intervention called the REFOCUS Intervention, which we evaluated in the REFOCUS trial. In Sections 4 to 10 of this report we describe:

• The REFOCUS intervention
• The REFOCUS trial – what we did and what we found
• What did staff and service users think of the REFOCUS intervention?
• How were patients and the public involved in the REFOCUS programme?
• What did the REFOCUS programme not address?

The REFOCUS manual was modified in the light of all the findings of the REFOCUS programme, and the second edition (shown here) was published in 2014. It can be downloaded (free) from: researchintorecovery.com/refocus
Introducing the REFOCUS programme

Overall, the REFOCUS programme comprised a review phase (bringing together what is already known), followed by a development and evaluation phase (creating and testing both a new intervention and measures of recovery). The structure of the programme is shown in Figure 1.

Review phase

- Conceptual framework of personal recovery (described in Section 1)
- Recovery in other countries
- Recovery in current mental health service users
- Recovery for black individuals
- Recovery Practice Framework (Section 2)
  - Staff experiences of supporting recovery
  - National survey
- Measuring recovery (Section 3)
  - Reviews of measures of personal recovery, strengths, recovery support

Development and evaluation phase

- New intervention
  - Development of REFOCUS Intervention (Sections 4 and 5)
  - Evaluation in the REFOCUS Trial (Sections 6 and 7)
- New measures (Section 3)
  - INSPIRE
  - Individualised outcome
  - Structured Assessment of Feasibility (SAFE)

Figure 1: Structure of the REFOCUS programme

This report summarises the main findings from the REFOCUS programme, to offer easy, understandable access to the research. Where a finding has been published, the academic reference is numbered in the text and listed at the end. This document was written by REFOCUS researchers and the Lived Experience Advisory Panel (LEAP) members with personal experience of mental health problems and family members of people with mental health problems.
1. What is recovery?

There has been much confusion about what is meant by the term, which is why the first task for the study team was to develop a conceptual framework of personal recovery.

We undertook three studies to deepen our understanding of recovery. This understanding provided the foundation for the rest of the REFOCUS programme.

**Developing the conceptual framework for personal recovery**

We reviewed studies that described a theory or model of recovery. This involved conducting a systematic review, in which a range of approaches are used to find and review all studies in the available literature. In total, we found 87 studies that fitted our inclusion criteria, which we then synthesised to give a summary from these studies. The main findings were:

1. **Characteristics** – we identified thirteen ways people have described their experiences of recovering from mental illness. These included recovery being an active and gradual process, a journey, a struggle, has stages, is a life-changing experience, is without cure and unique to them.

2. **Stages** – we identified agreement that recovery happens in stages, although each person’s experience is different so stages may not be linear.

   - Stage 1 is a crisis period where a person is overwhelmed yet unaware of the extent of their illness.
   - Stage 2 involves an awareness of illness and a turning point where help is accepted.
   - Stage 3 involves believing recovery is possible and a determination to recover.
   - Stage 4 involves rebuilding of life and a start on the road to recovery.
   - Stage 5 involves personal growth, an improved quality of life and self-esteem, integration into the community, and ‘living beyond the disability’.

3. **Processes** – recovery seems to involve five main recovery processes, which we called the CHIME Framework: Connectedness, Hope and optimism, Identity, Meaning and purpose in life and Empowerment. This framework is shown in Figure 2, and has becoming a widely-used approach to understanding recovery.

![Figure 2: The CHIME Framework of recovery processes](image-url)
Do other countries have similar understandings of recovery?

Some people have suggested that recovery is a Western concept which may not apply in other countries. To investigate this, we updated and extended our systematic review to look at how recovery is understood internationally. We identified 105 theories and models of recovery, in 115 papers, from 11 countries: Australia, Canada, Iceland, Ireland, New Zealand, Norway, South Korea, Sweden, Taiwan, United Kingdom and the United States of America.

The CHIME recovery processes were consistently found in the international papers, meaning that it can be applied to different cultures. However, we did find that most current evidence (in terms of studies we identified and included in this review) comes from Western and English-speaking countries. We therefore identified a need for research to focus on what recovery means to people from different countries and ethnic backgrounds, such as people from Black and Minority Ethnic (BME) groups in England.

Do current mental health service users have similar understandings of recovery?

We wanted to know whether our Conceptual Framework could be applied to people currently using mental health services, who may be at an earlier stage of their recovery journey.

To address this, we held seven focus groups (group interviews where everyone can talk together) with a total of 48 mental health service users. Participants were asked about their experiences of personal recovery and what they wanted services to help them with. The service users came from three NHS Trusts across England:

- 2gether NHS Foundation Trust
- Leicestershire Partnership NHS Trust
- South London and Maudsley NHS Foundation Trust

Our CHIME framework of recovery was relevant to current mental health service users. However there were three areas of particular emphasis identified by people currently using services:

- **Practical support** was an important factor, including help with daily activities and tasks.
- **Issues around diagnosis and medication** were brought up by participants. They talked about taking control over their medication or leaving this responsibility to clinical staff.
- Some participants were **sceptical about recovery** and voiced the idea that recovery really means a reduction in resources in the mental health service.

Recovery support for black individuals

Very little research has been conducted into the perspectives of recovery for people from black communities (i.e. of African, Caribbean and black British ethnicity), with even less attention focused on how to support their recovery. Therefore within the REFOCUS study we specifically considered recovery support for black individuals.

We wanted to understand the meaning of recovery, and the barriers and facilitators of recovery, both in their relationship with mental health services and in the wider context of the individual’s life. The goal was to identify the types of support and services that individuals feel would support their recovery.

We ran four focus groups and 14 individual interviews in four NHS Trusts in England (South London and Maudsley NHS Foundation Trust, Leicestershire Partnership NHS Trust, 2gether NHS Foundation Trust and Tees Esk and Wear Valley NHS Foundation Trust). These locations were chosen to include a range of metropolitan, urban and semi-rural areas.
Our analysis identified a core category of ‘Identity - gaining a positive sense of self’ which was linked to all other major themes, as shown in Figure 3.

The central importance of ‘Identity’ informed our approach to developing the REFOCUS Intervention.
Mental health services are starting to introduce recovery-based practice, so guidance on how to apply recovery in practice is increasingly available. We wanted to summarise this guidance.

2. How can workers support recovery?

How is recovery supported in different countries?

We looked at 30 international documents that gave various recovery-based guidance from six countries: Denmark, England, Ireland, New Zealand, Scotland and the United States. We summarised the findings in a new Recovery Practice Framework, shown in Figure 4.

Supporting recovery takes place at a societal level (Promoting citizenship), an organisational level (Organisational commitment) and an individual level (Supporting personally defined recovery and Working relationships).

What do staff think affects their ability to support recovery?

After developing the Recovery Practice Framework, we spoke to staff in focus groups. We asked staff and team leaders to talk about how they support recovery and what they thought affected their ability to provide recovery-based support.

The staff came from five Mental Health Trusts across England:

- South London and Maudsley NHS Foundation trust
- 2gether NHS Foundation trust
- Leicestershire Partnership NHS Trust
- Devon Partnership NHS Trust
- Tees Esk and Wear Valleys NHS Foundation Trust.

We ran ten focus groups, involving a total of 34 clinical staff and 31 team leaders. We also conducted individual interviews with 18 clinical staff, 6 team leaders and 8 senior managers. Staff frequently talked about how the different demands within mental health services affected their ability to support recovery. In our analysis, this was labelled as a core, over-arching theme of ‘competing priorities’.

We identified three groups of priorities:

1. Business priorities - how financial and organisational priorities influence practice
2. Health system priorities - how recovery has been made to fit a more traditional medical view of health involving clinical tasks such as monitoring that people are taking medication, and the use of professional language
3. Individual priorities - how staff understand their role and prioritise their work.

This showed us that for recovery to be put into practice, the whole system would have to be changed to develop shared beliefs about recovery in mental health services. To better understand these priorities, we systematically reviewed international studies about staff understandings of recovery. Staff understand their role as balancing clinical recovery, personal recovery and a new influence of ‘service-defined recovery’: an understanding of recovery which is owned by the mental health system, and which focuses on reducing costs by limiting access to services and setting goals for discharging and moving people more quickly through the system.

Figure 4: Recovery Practice framework
National survey of recovery support

Our next step was to measure how much mental health services currently support recovery.

We did a national survey of mental health service users, staff and team leaders. The survey used an established measure of recovery support called the **Recovery Self Assessment (RSA)**. This was completed by staff, team leaders and service users. We also asked service users to complete a measure of personal recovery called the **Questionnaire about the Processes of Recovery (QPR)**.

22 team leaders, 109 clinical staff and 120 mental health service users from six NHS Trusts across England completed these questionnaires. The survey found that:

- Team leaders had more positive views on how their teams supported recovery than clinical staff and service users.
- Teams within trusts differed on recovery practices.
- Increasing the amount and quality of recovery support could support personal recovery.
- 76% of staff reported having experience of supporting a family member or friend
- 39% of staff reported having had personal experience of mental health problems
- Among staff with personal experience, 48% had fully disclosed this experience to workplace colleagues, 32% had partially disclosed and 20% had not disclosed
- Among staff who disclosed, 79% reported they had received support and 21% reported they had not.
3. How is recovery measured?

Recovery research requires questionnaires to measure recovery, in order to understand recovery better and to assess whether approaches to improve recovery in mental health have actually worked. In REFOCUS we created new questionnaires and tested them, along with some existing scales, to see how well they worked. Each is freely available at www.researchintorecovery.com/our-measures.

How is personal recovery assessed?

In order to assess recovery we had to identify a suitable measure. We conducted a systematic review of the literature, and in 336 papers we identified 13 recovery measures. We then rated these measures to see how well they fitted with the five CHIME recovery processes. The findings were:

- The Recovery Assessment Scale (RAS) was published the most.
- The Questionnaire about the Recovery Processes (QPR) was the only measure to fit with the CHIME framework.
- No measure was sufficiently valid (i.e. it measures what it should measure) and reliable (accurate) for our purposes.

How are strengths assessed?

When people are assessed by mental health services, the process usually involves identifying their symptoms, problems and needs, and may not assess their positive attributes, what they are good at, their personal qualities, talents and abilities. These can all be seen as people’s strengths.

Strengths-based assessments are not new, but recent developments in clinical practice have seen a much greater focus on an individual’s strengths. This has led to an increase in the evaluation of strengths-based approaches. However, no systematic review of strengths assessments for use within mental health has been published. We conducted a systematic review of strengths assessments.

A total of 12 strengths assessments were identified. These measured three aspects of strengths:

1. **Individual factors**, which are found within a person, e.g. talents, capabilities, skills, interests and personal attributes.
2. **Environmental factors**, which are found outside a person, e.g. family, community, financial resources, social support, transportation, political rights and housing.
3. **Interpersonal factors**, which are a combination of individual and environmental factors, available, e.g. relationships and life options.

We selected the Strengths Assessment Worksheet (SAW), which was the most widely used, for use in the REFOCUS Intervention.

How is recovery support by mental health staff assessed?

We conducted a systematic review of all measures that assess recovery support from mental health staff. We identified 13 measures, of which 6 were included in our review, but none were sufficiently tested for use in REFOCUS. We therefore developed our own measure called INSPIRE, which is based on the five recovery processes in the CHIME framework and the Support and Relationship individual-level domains from the Recovery Practice Framework.
INSPIRE is a new measure of staff support for recovery in mental health.

We developed INSPIRE in consultation with 61 experts on recovery, including service users, clinical staff, researchers, and carers. The measure was piloted with 20 people currently using community mental health teams in South London. To more fully evaluate INSPIRE, we then asked 92 people at three different points in time to complete it. Our research showed that INSPIRE was an understandable, reliable and valid questionnaire⁹.

INSPIRE is rated by service users, and has two parts. The first part, called the Support sub-scale, has 20 items which are rated as important or not for recovery. For the items which are important, the amount of support received from a mental health worker is also rated. Some of the items from the Support sub-scale are shown in Figure 5 (below).

In the second part, called the Relationship sub-scale, the person rates their relationship with their mental health worker. It has seven items and the person rates on a five-point scale ranging from ‘Strongly disagree’ to ‘Strongly agree’. The items in the Relationship sub-scale are shown in Figure 6.

We also created and tested a short version called Brief INSPIRE, which contains just five questions asking how recovery is supported by a mental health worker.

Both INSPIRE and Brief INSPIRE produce numerical scores of recovery support. They can be downloaded at www.researchintorecovery.com/inspire

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**Figure 5: The Support sub-scale in the INSPIRE measure**

**Figure 6: The Relationship sub-scale in the INSPIRE measure**
Individualised outcome

To identify an individual’s goals, we asked individuals to choose a goal that is important to them and then complete a questionnaire that matches their identified goal. After receiving support, service users are asked about their goal progress and to complete the same questionnaire again. We tested this approach to measuring change with 92 mental health service users, and found that 87% were able to identify a goal and complete the relevant questionnaire. At three months, 47% had reached or exceeded their goal. This approach to measuring achievement of a personally valued goal was then used in the REFOCUS trial.

How feasible is implementing a complex intervention?

Some interventions are recommended for use but the resources needed to provide them may be lacking. This leads to a waste of time and money in mental health services. In order to assess the feasibility of interventions, we developed a new measure called Structured Assessment of FEasibility (SAFE)\(^\text{10}\).

We looked at studies assessing implementation, and focused on the things that enabled successful implementation. Overall we identified 15 trial reports and 5 protocols from different types of interventions. In total 95 influences on implementation were found, which we combined to produce the SAFE checklist.

SAFE is a checklist to assess the feasibility of implementing a complex intervention within mental health services within the NHS. The checklist is designed to be used by systematic reviewers, commissioners, managers and policy-makers to help them decide on whether an intervention is feasible and should be recommended for use more widely. It can also be used by researchers who are developing an intervention to ensure they consider factors which may influence whether the intervention is successfully implemented.

SAFE has 16 questions: eight assessing blocks to implementation and eight assessing facilitators of implementation. Some example questions are shown in Figure 7.

<table>
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<th>BLOCKS SUB-SCALE</th>
</tr>
</thead>
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<td>These items are blocks to implementation.</td>
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</table>

1. Do staff require specific training to deliver the intervention?

<table>
<thead>
<tr>
<th>Yes</th>
<th>Partial</th>
<th>No</th>
<th>Unable to rate</th>
</tr>
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<tr>
<td>Yes:</td>
<td>The intervention requires more than four hours of training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial:</td>
<td>The intervention requires up to four hours of training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No:</td>
<td>The intervention does not require any specific training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to rate:</td>
<td>Not enough information provided to rate item</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Is the intervention complex?

<table>
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<tr>
<th>Yes</th>
<th>Partial</th>
<th>No</th>
<th>Unable to rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes:</td>
<td>The intervention is made up of more than three separate components</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial:</td>
<td>The intervention contains two or three separate components</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No:</td>
<td>The intervention only has one component</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to rate:</td>
<td>Not enough information provided to rate item etc</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 7: Example questions from the SAFE measure

The full scale can be downloaded at [www.researchintorecovery.com/safe](http://www.researchintorecovery.com/safe)
4. The REFOCUS Intervention

Developing the REFOCUS Intervention

In recovery research, values and principles are important. We developed our intervention using three principles:

1. Meaningful involvement from people with lived experience in the REFOCUS Programme
2. An emphasis on supporting recovery for black service users
3. Less emphasis on diagnosis so we developed an intervention for people with any diagnosis

The studies described in Sections 1 to 3 informed how we developed the intervention. Development involved consultation with 58 people with wide-ranging experience, as service users, carers, workers, researchers and policy-makers.

The resulting intervention is described in the first edition of the REFOCUS manual, which is free to download at www.researchintorecovery.com/refocus

What is the REFOCUS Intervention?

The REFOCUS Intervention is a team-level approach to increasing recovery support by providing training and support to mental health staff in team they work in. There are two parts to the intervention:

1. Recovery promoting relationships (how staff work with service users)
2. Working practices (what staff and service users do)

Recovery-promoting relationships focus on the relationship between the service user and staff. This is addressed by:

- Skills training for staff in coaching
- Developing a shared team understanding of personal recovery
- Exploring staff values
- A partnership project involving people who use services
- Raising service user expectations

Working practices refers to the quality and type of support provided for the service user by a mental health worker. This is addressed by:

- Understanding the service user’s values and treatment preferences
- Assessing and increasing the strengths of the service user
- Supporting the service user in working on the goals that are important to them.
The REFOCUS Model

For evaluation purposes, we develop the REFOCUS model. This describes the intervention and how it should work, as shown in Figure 8.

### Recovery-promoting relationships
Coaching skills, team and individual understanding of recovery, Partnership Project, service user expectations.

### Working practices
1. Understanding values and treatment preferences
2. Strengths assessment
3. Supporting goal-striving

### Team Values
- More pro-recovery norms and values within the team

### Individual skills
- More pro-recovery values in workers

### Knowledge
- More knowledge about personal recovery

### Skills
- More skills in coaching and the three working practices

### Behavioural intent
- Plan to use coaching and the three working practices

### Behaviour
- More use of coaching and the three working practices

### Content
- More experiences of coaching. More focus on strengths, values and goal-striving

### Process
- More support for personal recovery

### Proximal
- Increased hopefulness, empowerment, quality of life, wellbeing

### Distal
- Improved personal recovery

Figure 8: The REFOCUS Model
5. What staff training is involved?

Staff are given two types of training.

5.1 Personal Recovery Training

The Personal Recovery Training provides reflection opportunities to allow teams:

- To develop a shared understanding about what personal recovery means for their team and how they work together, including the REFOCUS conceptual framework for personal recovery
- To consider staff personal and professional values and how these can support recovery
- To identify ways of relating to people using the service by increasing staff self-awareness about the impact of their own values on their recovery practice
- To increase knowledge, skills and motivation to work in a recovery orientated way and a consequent pro-recovery language created by a shared team understanding
- To plan the Partnership Project between staff and people using the service (aiming to increase partnership working through an experience of doing or learning something jointly)

Personal recovery training was provided for the whole multidisciplinary team and delivered by two trainers from Rethink Mental Illness charity, at least one of whom had lived experience of mental illness. Training involved 3 half-day sessions, spaced 2-4 weeks and 3 months apart, at the start of the intervention. Each training session included materials to read or watch before the session. A combination of training methods were used, including group discussions, role play and learning-by-doing (i.e. practising skills outside of sessions).

5.2 Coaching for Recovery training

The Coaching for Recovery training supported both the Recovery-promoting Relationships and Working practices components of the intervention. Staff were encouraged to use coaching values and techniques in their work with service users, specifically when focusing on the person’s values, preferences, strengths and goal-striving.

In the training, workers were taught the REACH© core coaching competencies:

- Reflect: listening skills throughout the conversation
- Explore: use of powerful questions and the skill to acknowledge a person’s contribution
- Agree Outcome: skill to challenge and confront, permission and intrusion
- Commit to action: goal setting, holding the Coaching space and timing
- Hold to account: skill of giving and receiving Feedback Effectively

The Recovery Coaching Skills training was provided to the whole multidisciplinary team by a skilled coaching trainer. Training involved one full day and 2 half-day sessions, spaced one month apart, at the start of the intervention. Follow-up phone support and booster sessions was also available, if requested.

The intervention was then tested in community mental health services in two NHS Trusts in England. This part of the study was called the REFOCUS Trial.
What did we do?

To evaluate the REFOCUS Intervention, we did a randomised controlled trial (RCT). An RCT is a rigorous scientific experiment to test whether an intervention works. It involves randomly assigning (i.e. by chance) people to either receiving the intervention (‘intervention group’) or not receiving the intervention (‘control group’), and then comparing which group does better. We used the REFOCUS trial to test our intervention.

The trial took place in two NHS Trusts in England: South London and Maudsley NHS Foundation Trust (SLaM) and 2gether Partnership NHS Foundation Trust. Teams randomly allocated to the intervention arm were given the REFOCUS manual and training and support for one year to help them increase their recovery support.

To test whether the intervention was beneficial for people using services, we randomly chose 15 people from the caseload of each participating team. We asked them to complete questionnaires before the intervention and at the end of the intervention (one year later).

All service users were asked to fill out several questionnaires, including:

- The Questionnaire about the Processes of Recovery (QPR) about their personal recovery
- The Client Satisfaction Questionnaire (CSQ) about their satisfaction with mental health services
- INSPIRE about the recovery support from their worker
- The Recovery Fidelity Scale (RFS) to rate how much each part of the REFOCUS intervention is experienced
- The Client Service Receipt Inventory (CSRI) to collect information about service use.

We also asked them to complete questionnaires about well-being, empowerment, hope, goals, and health and social needs.

One questionnaire was completed by the researcher:

- The Brief Psychiatric Rating Scale (BPRS) which measures symptoms

For the 15 service users from each trial team, we identified a member of staff who knew them well, to complete some questionnaires about them.

- The Health of the Nation Outcome Scale (HoNOS) which assesses social disability.
- The Camberwell Assessment of Need (CANSAS) which assesses health and social needs (completed by both the service user and staff)
- The Global Assessment of Functioning (GAF) which assesses functioning.

All mental health staff that took part in the study also completed questionnaires related to their own knowledge and attitudes about recovery, and their use of the REFOCUS Intervention.
What did we find?

Between April 2011 and May 2012, 27 teams (18 SLaM, 9 2gether) and 403 service users were recruited. There were 14 team (9 SLaM, 5 2gether) in the intervention arm and 13 teams (9 SLaM, 4 2gether) in the control arm. These teams included 13 Recovery teams (4 control, 9 intervention), four Psychosis teams (2 control, 2 intervention), three community forensic teams (1 control, 2 intervention), three assertive outreach teams (3 control), two supported living teams (2 control), one low support team (1 intervention), and one early intervention team (1 control). A total of 532 staff participated in baseline and follow-up.

Service users in the intervention group did not differ on our main questionnaire that measured personal recovery (Questionnaire about Processes of Recovery, QPR). There were some improvements in other outcomes, with higher scores for functioning (GAF) and fewer service user rated unmet needs (CANSAS) in the intervention group at follow-up.

To understand why this was, we looked into this further and discovered that not all the teams in the intervention arm of the study participated fully in the intervention. Service users who were receiving care from teams that participated more fully had significantly higher QPR Interpersonal scores (i.e. recovery-supporting relationships) at follow-up than those in low participation intervention teams and control teams.

In the REFOCUS Trial, we specifically included people who described themselves as black African, black Caribbean, black British or from other black backgrounds. This allowed us to test whether black individuals in the intervention group experienced greater improvements in (a) recovery (as measured by QPR) and (b) satisfaction (as measured by CSQ) compared to those receiving usual care. We found that there was no beneficial effect of receiving the intervention on either recovery (measured using QPR) or on satisfaction (measured using CSQ).

What does this mean?

We think there are several possible reasons why we did not show overall improvement in recovery. Most likely is that the intervention was not fully implemented. Not all teams participated fully in the intervention. Where staff participated more, there was an increase in recovery support and patient-reported recovery in the Interpersonal sub-scale of the QPR. Secondly, we only ran the intervention for 12 months, but the intended changes may take longer, both for staff working in new ways and for service users experiencing different expectations about their role in recovery. Finally, the QPR measure may not have been sufficiently sensitive to changes in recovery.
7. What did staff and service users think of the REFOCUS intervention?

We wanted to understand the experience of people involved in the REFOCUS intervention.

7.1 Service user experiences of receiving the REFOCUS intervention

We also wanted to understand how staff experienced the intervention. We spoke to staff who took part in the REFOCUS intervention, comprising 28 individual interviews and 24 people in four focus groups. We found:

- Staff highly valued the coaching training and used the coaching skills to have empowering, motivational type conversations with service users
- Staff reported the benefits of the ‘Values and treatment preferences interview guide’ and the ‘Strengths assessment worksheet’ in the working practices component of the intervention. These helped them to have more wide-ranging conversations with service users about what was important to them and about their strengths.
- ‘Supporting goal-striving’ was discussed less by staff as they felt that the component was not a new addition to their clinical practice.
- The whole team training and reflection sessions supported recovery practice.

Regardless of whether or not service users noticed changes, the relationship with staff was the key to service users reporting they had had a positive experience of care, and was a foundation of recovery support.

7.2 Staff experiences of delivering the REFOCUS intervention

Research into service user experience of receiving a recovery-orientated service is currently lacking. So we decided to explore the service user experience of the REFOCUS intervention. We spoke to service users from teams using the REFOCUS intervention, comprising 24 individual interviews and 13 people in two focus groups. We found:

- Positive changes in the relationship between service users and mental health staff
- An increase in conversations about values, strengths and goals which service users found empowering
- Personal qualities of staff such as honesty, genuine caring and openness were important in a recovery-supporting relationship
- Some service users failed to notice any changes in their relationship. Reasons given were time restraints and a focus on risk and medication.

Regardless of whether or not service users noticed changes, the relationship with staff was the key to service users reporting they had had a positive experience of care, and was a foundation of recovery support.

Based on these staff perspectives of the REFOCUS Intervention, we would recommend the wider use of coaching and the three working practices, as well as a team-based approach to supporting recovery.
7.3 Implementing a complex intervention

We wanted to look at the bigger picture and find out what staff said influenced their ability to put the intervention into practice. We therefore conducted 28 face-to-face interviews with mental health staff, 3 interviews with trainers, 4 focus groups with intervention teams and also looked at 28 written trainer reports.

Six factors influenced the implementation of the REFOCUS Intervention, which we organised into two overarching themes: Organisational readiness and Training effectiveness. These are shown in Figure 9 (below).

Three areas were important for changing practice: staff skill development, talking about implementing the intervention and actually implementing the intervention. Practitioners made interpretations about how committed an organisation is by looking at the resources their organisation provided. From a research perspective, measuring ‘organisational readiness’ would be a good way of selecting both organisations and teams in RCTs, as this would increase the likelihood of implementation, so less time and money is wasted in the research.

Figure 9: The Support sub-scale in the INSPIRE measure
8. How were patients and the public involved?

Patients and Public Involvement (PPI) in research is now public policy. The focus of the REFOCUS project was transforming mental health services by placing more importance on the expertise by experience of service users and carers. Therefore, the meaningful involvement of ‘lived experience’ (the perspective of mental health service users or carers) was of particular importance.

A total of 698 service users took part in the different REFOCUS studies. However, PPI involves more active involvement than just providing data. Service users and carers were advisors and researchers in the REFOCUS programme.

The Lived Experience Advisory Panel (LEAP) comprised people with personal experience of mental health problems and family members of people with mental health problems. LEAP members made many contributions, including advising on recruitment approaches and study information sheets and consent forms, commenting on posters about the study, informing the choice of questionnaires and interview schedules, commenting on the content and format of INSPIRE and the individualised outcome measures, helping with the development of the REFOCUS Conceptual Framework, giving detailed feedback on the draft REFOCUS manual, and in training of interviewers for the clinical trial. LEAP members were involved in the Steering Group and in the International Advisory Board. There was also a virtual BME advisory group for a sub study within the programme.

LEAP also contributed to knowledge dissemination. Members made presentations at conferences such as INVOLVE and REFOCUS on Recovery 2012, were involved as co-authors in several REFOCUS publications, and commented on the final report, including co-authoring the PPI chapter.

LEAP members were involved in a mid-term evaluation of PPI in REFOCUS. To formally evaluate the impact of LEAP, we kept a log of recommendations from LEAP and other advisory committees, as well as noting whether the recommendation was implemented. This allowed us to show that PPI added value to the research, especially in relation to scientific decisions and committee composition.

Finally, recruitment to all REFOCUS posts included personal experience of mental health problems and recovery as a ‘desirable’ eligibility criteria. Among the research team were researchers who had used mental health services, and who had personal experience of supporting someone close to them who had mental health problems.
9. What did REFOCUS not address?

Early in the study we made the case that recovery ideas should be tested in practice\textsuperscript{2}, and we were able to test some aspects of recovery in this study. There were though many important areas we were not able to address. These included:

1. The wider impact of social factors on recovery – although we published a review in this area\textsuperscript{18}, we were not able to incorporate the review findings into the REFOCUS Intervention

2. The contribution and experience of family and friends to recovery

3. The contribution of service users to implementing the REFOCUS Intervention

4. Supporting wellbeing in staff

5. Supporting staff with personal experience of mental illness and recovery

6. The organisational commitment to a recovery orientation

10. How are we communicating our findings?

Academic papers from the REFOCUS programme are listed at the end of this report. We also used several other approaches to communicate our research findings.

1. **Website** In 2009 we developed the Section for Recovery website (www.researchintorecovery.com), which contains information about the REFOCUS study

2. The **REFOCUS manual** describes the REFOCUS Intervention and is free to download at www.researchintorecovery.com/refocus

3. The **REFOCUS Protocol** for the REFOCUS Trial was published in an open access journal: www.biomedcentral.com/1471-244X/11/185

4. The **Final report** will be published at www.journalslibrary.nihr.ac.uk

5. The document you are reading is a **Summary of findings** written for a non-specialist audience

6. The **REFOCUS On Recovery** conferences are international conferences, which were organised in the context of the REFOCUS programme by the wider Section for Recovery research group, in collaboration with key partners. Conferences were held in 2010, 2012 and 2014, and findings from REFOCUS were presented at all three conference. Many mental health service users, carers, workers, managers and system leaders attended. We used a Twitter account for REFOCUS On Recovery 2014

11. Has the REFOCUS programme made a difference?

We can identify some impacts of REFOCUS, including:

1. The conceptual framework for recovery is becoming widely used as a theory base, with a number of research teams internationally publishing studies using CHIME as the framework for recovery research.


3. INSPIRE is being used by a number of services in England, and is recommended by the national ImROC programme (Shepherd et al (2014) ImROC Briefing paper 8. Supporting recovery in mental health services: Quality and Outcomes, London: ImROC). It is being translated into a number of other languages, including Danish, Estonian, German, Russian and Swedish.

4. The REFOCUS intervention is being taken forward in a number of ways. It is being provided to services in England as part of the Innovation Network arising from the Schizophrenia Commission. Training in REFOCUS has been given in Ireland. A large study called PULSAR is underway in Australia, to replicate the intervention and extend into primary care.
12. The REFOCUS Team

The REFOCUS team was led by Mike Slade (Principal Investigator) and Mary Leamy (Programme Co-ordinator). The study team at the Institute of Psychiatry, Psychology & Neuroscience comprised research workers (Victoria Bird, Agnes Chevalier, Eleanor Clarke, Harriet Jordan, Clair Le Boutillier, Genevieve Wallace, Julie Williams), University placement students (Faye Bacon, Ben Fortune, Monika Janosik, Matt Long, Kai Sabas) and administrators (Kelly Davies, Deborah Kenny, Becks Leslie). The study team at 2gether NHS Foundation Trust was led by Rob Macpherson (Consultant Psychiatrist) and Genevieve Riley (Senior Clinical Studies Officer), and included Clinical Studies Officers (Alison Harding, Emma Page) and research assistants (Sophie Brett, Kevanne Sanger, Julia Jones, Clare Whitehead and Katie Yearsley). The REFOCUS Lived Experience Advisory Panel (LEAP) involved people who live with or care for someone with mental illness, and provided advice to the research team throughout the study. Rethink Mental Illness supported the study in many ways, including providing the recovery training for the REFOCUS intervention and supporting dissemination of findings. An International Advisory Board and other advisory panels and experts also supported the study.

13. How do I get this report?

This report can be downloaded at
www.researchintorecovery.com/refocus
Please cite this report as:

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Further information available at
www.researchintorecovery.com/refocus.
Academic references


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