

**Patient outcomes: what are the best methods for measuring recovery from mental illness and capturing feedback from patients in order to inform service improvement?**

**A report commissioned by the Bamford Implementation Rapid Review Scheme**

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## Ministerial Foreword

I am pleased to commend to you this Research Review that is one of a series focussing on priorities identified through the Action Plan that supports the Executive's response to the Bamford Review Recommendations. The Bamford Action Plan (2009-2011) is driving much-needed change in how we care for people affected by mental health or intellectual disabilities. One in six of our population has a mental health need at any one time, and it is estimated that between 1-2% of our population, that is around 24,000 people, have an intellectual disability. In addition, there are many others who have or will develop dementia in the future.

Our highly committed staff who deliver health and social care services have expertise and skills that must be supported by the best up-to-date knowledge. Through research, new knowledge is created. But it is now recognised that, for a variety of reasons, essential knowledge does not always reach the people who most need to use it. The knowledge can vary from better understanding of the causes of poor mental health or intellectual disabilities through to evidence on which services bring about the greatest improvements to the lives of people or their carers. To bring together this knowledge we have commissioned five Research Reviews.

Each Review was written by a team of experts in academia, clinical services and care who have collected the most up-to-date evidence from research done locally or globally. All of the review teams were based in Northern Ireland so we know that the Reviews are relevant to our local situation. The quality of each Review has also been assured through input from experts who are based in other parts of the UK or internationally.

The priority areas addressed by the Reviews are:

- Children & Young People including early interventions, the needs of looked-after children and the development of resilience;
- Patient Outcomes including the measurement of recovery and the capture of patient feedback;
- Intellectual Disability including the management of challenging behaviours;
- Psychological Therapies including how to embed these in services for children and adults across the lifespan and including those with intellectual disability and severe mental health problems;
- Primary Care including aspects important to the prevention, recognition and management of mental health in the community.

As well as providing accessible knowledge and information, each Review has highlighted gaps in our knowledge. We will commission new research projects aiming to fill those gaps.

My final acknowledgement is of contributions made by local people, patients and their carers who assisted in the selection of the priority areas covered by the Reviews and provided extremely helpful feedback to the review teams. Some of those people also serve through their membership of our Bamford Monitoring Group.

I dedicate these Reviews to the people who are affected by mental health or intellectual disabilities. I urge our health and social care staff, education professionals, members of voluntary organisations and others to use these Reviews so that all members of our community may receive the best possible support to live their lives with dignity.

**Edwin Poots MLA**

**Minister for Health, Social Services and Public Safety**

## **Executive summary**

The aim of this rapid review was to identify and assess the best methods for measuring recovery from mental illness and of capturing feedback from patients in order to inform service improvement. The review comprised two components: (1) measures of recovery 'outcome' and (2) methods of using measures to improve outcomes for service users. Systematic review methodologies were used throughout in an attempt to address the central question on which the review was based.

### **Key findings of the review**

#### *Measures of recovery outcome*

1. Measures of personal recovery were reviewed and three measures were recommended for consideration for use in Northern Ireland. These included: the Questionnaire on the Process of Recovery (QPR); the Warwick-Edinburgh Mental Well-being Scale (WEMWBS); and the Mental Health Recovery Star (MHRS)
2. Service-user rated measures of recovery orientation were reviewed and two measures - INSPIRE and Recovery Context Inventory (RCI) - were recommended for consideration for use in Northern Ireland.
3. Family member-rated measures of recovery orientation were reviewed, but none could be recommended for use.
4. Mental health professional-rated measures of recovery orientation were reviewed, but none could be recommended for use.

### *Methods of using measures to improve outcomes for service users*

A detailed review was undertaken of current available evidence on capturing process and outcome data from service users, and feeding this information back to inform treatment planning. Although a wide range of gaps in scientific knowledge were identified, the overall weight of evidence tended to be favourable and further research using measures to improve service user outcomes in the context of the recovery-oriented approach, was recommended.

### **Emergent principles**

Four principles emerged from the analysis of the reviewed literature:

1. Recovery involves more than the absence of mental illness
2. Recovery is a personal experience - it cannot be 'done to' a person
3. The routine assessment of recovery outcome data is necessary to support recovery
4. A recovery orientation needs to be a permeating organisational value.

### **Policy implications**

The review has four key policy implications:

1. Each person who uses mental health services should assess routinely the experience of personal recovery in order to identify how much they are experiencing recovery and associated outcomes, such as social inclusion and well-being.
2. The recovery orientation of the mental health service, as judged by the service user, should be assessed routinely and this information should be used to inform action

planning with the individual, as well as local, regional and national service developments.

3. Routine collection of recovery outcome data will not happen unless politically prioritised and adequately resourced, and implementation needs to be informed by approaches used in other countries.
4. Developing a recovery orientation involves organisational transformation. Any introduction of routine use of recovery measures should follow from that transformation, rather than being an end in itself.

### **Knowledge gaps**

The reviews presented here identified five principal gaps in scientific knowledge:

1. Most recovery measures have been developed outside the UK, and none have been developed in NI.
2. There are no measures of recovery orientation from either a family member or a mental health professional perspective which can be recommended (without reservation) for routine use in NI services.
3. Limited attention has been paid to using information from recovery outcome measures to increase service support for recovery
4. The current state of knowledge has focussed on the development of recovery measures, and scientific enquiry regarding the use of recovery measures is early-stage. Very little research <sup>1</sup> has been undertaken to examine the relationship between recovery outcomes (*e.g.* the CHIME Framework <sup>2</sup>) and traditional clinical outcomes (*e.g.* symptomatology, social functioning, risk). This is a key knowledge

gap, since empirical data are needed to inform the otherwise ideologically-driven debate about the benefits and challenges of a recovery orientation. Robust empirical enquiry into this question is of both national and international importance.

5. To date, feedback and monitoring systems remain under-utilised and under-researched. There is a need to examine how effective feedback delivery systems might be implemented usefully (and cost-effectively) into routine practice in ways that are consistent with a recovery-oriented model. Computerised systems, in particular, appear to offer potentially strong infrastructural benefits.

### **Priority research questions**

Four research questions are a priority for future research commissioning:

- 1. Which measures are most applicable for use in NI? The rapid reviews indicated that particular consideration should be given to the QPR, WEMWBS and Recovery Star for measuring personal recovery, and to INSPIRE and RCI for measuring recovery orientation.**

This question could be addressed by commissioning research to investigate:

- the nature and extent to which modifications are needed to adapt the measures for use in NI, whilst still retaining conceptual equivalence
- the views of key stakeholder groups (service users, family members, front-line workers, service managers) regarding each measure
- the feasibility of measures - this would involve the use of an established framework for assessing feasibility <sup>3</sup>. The feasibility of a measure is defined as *the extent to*

*which it is suitable for use on a routine, sustainable and meaningful basis in typical clinical settings, when used in a specified manner and for a specified purpose. An assessment of feasibility: (a) identifies the manner and purpose for which a measure is used; and (b) considers the degree to which a measure is brief, simple, acceptable, available, relevant and valuable when used in the designated manner and for the intended purpose.*

- the suitability of measures for use over time in NI - this inquiry would involve both careful appraisal of the existing evidence relating to test-retest reliability and sensitivity to change, and evaluation of the measures when used in NI services.

## **2. What are the costs and benefits of using these measures?**

This question could be addressed by commissioning research to establish:

- The resource implications of developing an approach to the routine collection and use of recovery outcomes based on best evidence from implementation science <sup>4</sup> and using the Ontario approach identified in Section 1.9 <sup>5 6</sup>. It is recommended that this approach should form the ‘backbone’ of any efforts to implement recovery measures in NI. Key questions might include:
  - Which features of organisational transformation are prerequisites for the use of recovery measures? (Please see Policy Implication 4 in Section 7.3).
  - What are the steps needed to maximise service ‘buy-in’ to, and ownership of, the process of introducing and using recovery measures?

- What are the enablers of change? How could recovery outcome measures be beneficial for service users and front-line clinical workers (who are the stakeholder groups who will need to provide the data)?
- What are the barriers to change? Particular consideration should be given to both logistical issues (electronic data collection, IT support, feedback report content and format) and workforce issues (attitudes, previous experiences, change fatigue)
- Which are the best methods or ways of aggregating data from individual service users? How much does sparseness or non-representativeness limit the use of aggregated data?
- Resource implications - what funding, political leadership and stakeholder ownership would be needed to implement the Ontario approach?
- Concurrent experimental investigation may be used to identify the benefits and costs of using recovery outcome measures as part of an overall organisational transformation process in NI services. Research designs currently being used in the REFOCUS Study in England may be relevant (NIHR Programme Grant, RP-PG-0707-10040, further information: [researchintorecovery.com/refocus](http://researchintorecovery.com/refocus)):
  - A country-wide cross-sectional qualitative investigation using focus groups and semi-structured interviews with service users to understand experiences of (a) recovery and (b) recovery support from mental health services
  - A qualitative investigation of the experiences of a specific sub-group who may not be well-served by mental health services

- A country-wide epidemiologically representative survey of service users and teams using standardised quantitative recovery measures to understand experiences of (a) recovery and (b) recovery support from mental health services
- Development and publication of the first NHS-based manualised intervention to promote recovery <sup>7</sup>
- Evaluation of the manual in a multi-site cluster randomised controlled trial (ISRCTN02507940) in England, both in relation to effectiveness and cost-effectiveness
- Development and use of an innovative approach to individualising clinical end-point assessment.

### **3. What is the relationship between outcomes related to personal recovery and clinical recovery?**

The distinction between personal recovery and clinical recovery is described in Section 1.6. This question could be addressed by commissioning research to:

- Identify a suite of personal recovery outcome measures suitable for use in NI. Potential outcome domains (with recommended measures and literature to consider) include connectedness <sup>8 9</sup>, hope <sup>10 11</sup>, identity <sup>12 13</sup>, meaning <sup>14</sup>, empowerment <sup>15 16</sup>, health-related quality of life <sup>17</sup>, strengths <sup>18-20</sup> and well-being <sup>21</sup>
- Identify a suite of clinical recovery outcome measures, including symptomatology, need, social functioning, risk, and therapeutic alliance

- Undertake longitudinal collection of both sets of data from a representative cohort of people using mental health services, with a multivariate repeated measures design and random effects regression modelling<sup>22 23</sup> to investigate the causal relationship between recovery outcomes and clinical outcomes.

#### **4. Does collecting and using patient feedback specifically support recovery?**

This final question may be addressed in the following way.

- Test the feasibility, transferability and effectiveness of existing or adapted/newly developed feedback delivery systems in NI across different contexts and with different patient populations using large-scale research studies that include longer-term follow-up.
- In particular, there may be merit in exploring the application of routine assessment and feedback mechanisms within existing IT systems in NI and opportunities for linking anonymised data for research purposes.
- Identify and assess the potential benefits of these systems and how they might best be translated into recovery-based practice in a cost-effective way
- Explore the attitudes, beliefs, ethos, work practices and training needs of mental health services staff in NI both in relation to: (a) working in a recovery-oriented way and (b) the routine use of outcome management systems that also incorporate user feedback
- More specifically, conduct qualitative research, process-oriented and economic evaluations related to all of the above that focus on assessing contextual factors,

sub-group variations, resource implications and the views of all key stakeholders including service users, family members, clinicians and managers.

In conclusion, this rapid review has identified and summarised current research evidence regarding the meaning and measurement of recovery and associated policy and practice implications for NI. In addition, it has identified important unanswered research questions that need to be addressed in order to progress the vision of Bamford and transform mental health care into a genuine recovery-oriented system.

## 1. Introduction

### 1.1 The review brief

This rapid review was undertaken in response to a ‘call’ from the Health & Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) in Northern Ireland. The research brief called for a rapid review of relevant literature and the identification of policy implications and key research questions regarding the topic of patient outcomes in terms of methods for the measurement of recovery and of capturing feedback from patients to inform service improvement (as one of five priority topic areas).

The central question that is addressed by the review, as indicated in the title, is: *what are the best methods for measuring recovery from mental illness and capturing feedback from patients in order to inform service improvement?* (We argue later that a comprehensive response to the research brief and the particular topic of patient outcomes requires a series of rapid reviews of specific sub-themes or questions). The review structure includes the following elements: a review of both the available published and grey literatures; building upon the Bamford Review, a brief analysis of the current context in Northern Ireland; the policy implications for the DHSSPS NI and other HSC organisations; and a clear identification of the priority research questions that need to be addressed within Northern Ireland.

It is planned that the rapid review will be used to refine the scope of a targeted research call by the HSC R&D Division and to support the implementation of the Bamford recommendations<sup>24-26</sup>.

## **1.2 How the work was carried out**

Our team was commissioned on 1 December 2010 to begin a rapid review in late January 2011 with a review deadline of 30 April 2011. The core review team comprised Michael Donnelly, David Scott and Tony O'Neill (Queen's University Belfast) and Sinead McGilloway (National University of Ireland, Maynooth). The review was informed by the expert knowledge and international experience of Mike Slade and the work of one of his PhD researchers, Julie Williams, at the Institute of Psychiatry, King's College London. A reference group of ten service users and mental health professionals was co-ordinated by Tony O'Neill.

Michael Donnelly and Mike Slade led the writing of the review and its compilation. Chapters are based where possible on existing work that is reported or updated in order to maximise the comprehensiveness of the review. Chapter 2 synthesises information from a review led by Philip Burgess (University of Queensland)<sup>27 28</sup> and two compendia of measures published in England<sup>29 30</sup>. Chapter 3 is based on a PhD chapter written by Julie Williams, supervised by Mike Slade and Mary Leamy (Institute of Psychiatry, King's College London), which was updated for purposes of this rapid review by David Scott. Chapter 4 reports new work undertaken for this rapid review by David Scott. Chapter 5 presents findings from the Burgess review<sup>27 28</sup> which was updated for this

rapid review by David Scott. Chapter 6 presents findings from a recent systematic review <sup>31</sup>, along with an updated rapid review undertaken by Sinead McGilloway.

### **1.3 What is a rapid review?**

A 'rapid review' approach was adopted in order to complete the study. What does this term mean? This review has been informed by two empirical studies of review methodology. First, a typology of review types identifies 14 varieties of literature review <sup>32</sup>. In this typology, rapid reviews are defined as "*assessment of what is already known about a policy or practice issue, by using systematic review methods to search and critically appraise existing research*" (p. 95). The completeness of searching is defined by time constraints. There is time-limited formal quality assessment. Synthesis is typically narrative and tabular. Finally, analysis addresses the quantity of literature and the overall quality and direction of effect shown in the literature.

Second, a comprehensive review of the term 'rapid review' suggested that, internationally, there is not a consensus about its meaning yet, or how it differs from a systematic review <sup>33</sup>. Key features appear to be restricted research questions and truncated search strategies. The authors concluded that the transparency of the methods used for each review is more important than the development of a formalised methodology by which to conduct rapid reviews.

Based on this previous research into rapid reviews, we have:

- focused on methodological transparency to allow replication and extension in future reviews

- emphasised sensitivity rather than specificity in search strategies in order to identify all of the most relevant research
- not robustly undertaken quality assessment approaches such as scoping searches, double rating to establish concordance on eligibility, or piloting of data extraction tables (although some of these approaches have been used where possible)
- undertaken modest validity assessment through a reference group comprising a convenience sample of mental health service users and professionals
- focused on achieving comprehensive coverage rather than on a detailed discussion of the strengths and limitations of each rapid review
- focused on narrative and tabular reporting of results, rather than aggregated or meta-analytic synthesis
- focused on appraisal of the overall strength of findings, in order to identify key scientific knowledge gaps and policy and research implications.

#### **1.4 Beyond the review brief - added value**

We have added value by extending beyond the brief in three ways. First, we have identified, based on current empirical evidence, the meaning of personal recovery in order to provide conceptual coherence for the review work. This is described in Section 1.6.

Second, the review brief related to “measuring recovery”. As will be discussed in Section 1.7, we suggest that measurement of recovery can be understood in two ways - assessing the experience of recovery and assessing the support for recovery offered by

services. Since the review brief related to service improvement, the latter aspect may have been the intended priority, and it is addressed in Chapters 3 to 5. However, we consider that improving recovery is the real goal of society, and therefore we have included in Chapter 2 a review of measures of personal recovery.

Finally, we consider that recovery is an experience, and therefore the ultimate arbiter of this experience is the service user. Measures of recovery orientation from a service user perspective are reviewed in Chapter 3. However, other stakeholder perspectives on recovery are also important including, in particular, the perspectives of family members and mental health professionals. Therefore, measures of recovery orientation from these two perspectives have also been reviewed, as reported in Chapters 4 and 5 respectively.

## **1.5 Structure of the report**

The main findings are presented in an Executive Summary. In Chapter 1, the conceptual foundations for the reviews are provided, and the policy context is described. Chapters 2 to 6 report the results of the rapid reviews. Chapter 7 identifies the key policy implications, knowledge gaps and research priorities.

## **1.6 What does recovery mean?**

People personally affected by mental illness have become increasingly vocal in communicating both what their life is like with a mental illness and what helps in moving beyond the role of a patient with mental illness. Early accounts were written by

individual pioneers<sup>34-39</sup>. These accounts provide ecologically valid pointers to what recovery looks and feels like from the inside. Once individual stories were more visible, compilations and syntheses of these accounts began to emerge from around the (especially Anglophone) world, e.g. from Australia<sup>40</sup>, New Zealand<sup>41-43</sup>, Scotland<sup>44 45</sup>, the USA<sup>46 47</sup> and England<sup>48 49</sup>. The understanding of recovery that has emerged from these accounts emphasises the centrality of hope, identity, meaning and personal responsibility<sup>40 50 51</sup>. We will refer to this consumer-based understanding of recovery as **personal recovery**, to reflect its individually defined and experienced nature<sup>52</sup>.

Opinions in the consumer literature about recovery are wide-ranging, and cannot be uniformly characterised. This multiplicity of perspectives in itself has a lesson for mental health services – no one approach works for, or ‘fits’, everyone. There is no right way for a person to recover. Hence, there is a need for caution about the universal applicability of any measure of recovery, especially where it does not incorporate personal values and goals, or when it has been developed in other cultures.

Despite this variation, some themes emerge. Recovery is seen as a journey into life, not an outcome to be arrived at: *“Recovery is not about ‘getting rid’ of problems. It is about seeing people beyond their problems – their abilities, possibilities, interests and dreams – and recovering the social roles and relationships that give life value and meaning”*<sup>53</sup>. Many definitions of recovery have been proposed by those who are experiencing it<sup>35 45</sup>. We will use the most widely cited definition that *“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 new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* <sup>54</sup>. It is consistent with the less widely cited but more succinct definition that recovery involves "*the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self determination*" <sup>40</sup>.

Personal recovery contrasts with traditional clinical imperatives – which we will refer to as **clinical recovery** – which emphasise the invariant importance of symptomatology, social functioning, relapse prevention and risk management. It is worth noting that this distinction has been referred to by other writers as recovery "from" versus recovery "in" <sup>55</sup>; clinical recovery versus social recovery <sup>56</sup>; scientific versus consumer models of recovery <sup>57</sup>; and service-based recovery versus user-based recovery <sup>58</sup>. Personal recovery and not clinical recovery is the focus of this report. The terms 'personal recovery' and 'recovery' are used as synonyms in the remainder of this report.

A recent systematic review and narrative synthesis has identified a conceptual framework for personal recovery <sup>2</sup>. The framework comprises three inter-linked, super-ordinate categories: Characteristics of the Recovery Journey; Recovery Processes; and Recovery Stages.

The thirteen characteristics of the Recovery Journey are shown in Box 1.1 (on next page)

Recovery is an active process

Individual and unique process

Non-linear process

Recovery as a journey

Recovery as stages or phases

Recovery as a struggle

Multi-dimensional process

Recovery is a gradual process

Recovery as a life-changing experience

Recovery without cure

Recovery is aided by supportive and healing environment

Recovery can occur without professional intervention

Trial and error process

### **Box 1.1: Characteristics of the Recovery Journey**

Five Recovery Processes were identified comprising (1) Connectedness, (2) Hope and optimism about the future, (3) Identity, (4) Meaning in life and (5) Empowerment. These processes can be summarised using the acronym CHIME. Finally, the thirteen identified Recovery Stages frameworks can be mapped onto the five-stage Transtheoretical Model of Change: Precontemplation, Contemplation, Preparation, Action and Maintenance & growth<sup>59</sup>, as shown in Table 1.1.

<b>Stage</b>	<b>Precontemplation</b>	<b>Contemplation</b>	<b>Preparation</b>	<b>Action</b>	<b>Maintenance &amp; growth</b>
1		Novitiate recovery: Struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
2	Stuck	Accepting help	Believing	Learning	Self-reliant
3	Descent into hell	Igniting a spark of hope	Developing insight/ Activating instinct to fight back	Discovering keys to well-being	Maintaining equilibrium between internal and external forces
4	Demoralisation		Developing & establishing independence		Efforts towards community integration
5	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
6	Dependent/unaware	Dependent/aware		Independent/aware	Interdependent/aware
7	Moratorium	Awareness	Preparation	Rebuilding	Growth
8		Glimpses of recovery	Turning points	Road to recovery	
9		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
10	Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability

11	Initiating recovery			Regaining what was lost/moving forward	Improving quality of life
12	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
13		Turning point	Determination		Self-esteem

**Table 1.1: Recovery stages mapped on to Transtheoretical Model of Change**

Supporting progress towards the identified CHIME Recovery Processes might be conceptualised as the targets for recovery-oriented mental health services. We consider now how recovery orientation might be measured.

### **1.7 Measuring the recovery orientation of services**

The recovery orientation of services refers to the extent to which services attempt to facilitate or promote recovery, and encompasses the different aspects of service delivery and practices which are believed to facilitate this goal <sup>60</sup>. Attempts have been made to outline what this means in practice and to provide guidelines for services on how to promote recovery, both in an Irish context <sup>61</sup> and internationally <sup>62 63</sup>.

The first standards for recovery-oriented systems were published in the USA<sup>64</sup>. Systems were defined as '*...a combination of services organised to meet the needs of a particular population*'. Recovery standards were identified for systems and for each system level dimension. Standards were developed as a first step in the process of transforming mental health services to become recovery-oriented. More recently, Davidson and colleagues developed a comprehensive and coherent set of standards or guidelines for recovery-oriented practice <sup>60</sup> as well as a measure of recovery orientation, the Recovery Self-Assessment <sup>65</sup>.

A goal of informing service improvement leads to a consideration of the operation of mental health services and systems. It is easy, therefore, to assume that measuring

recovery orientation *is* measuring personal recovery. However, the distinction between personal recovery and clinical recovery challenges this assumption <sup>66</sup>.

The traditional priority of mental health services has been to use evidence-based treatments for mental illness to maximise clinical recovery. Supporting personal - rather than clinical - recovery will still require these evidence-based treatment skills. However, ameliorating symptomatology and supporting recovery are not the same activity, since many people experience personal recovery in the presence of ongoing mental health problems. This is not of course an original observation: the World Health Organisation (WHO) declares that health is “*A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*” <sup>67</sup>. This is an empirically justified distinction, since epidemiological research indicates that mental illness and mental health may co-exist <sup>68 69</sup>.

What this means in practice is that recovery is influenced by far more than treatments provided by mental health workers. The CHIME Recovery Processes (Section 1.6) may be used to illustrate this point: connectedness arises from the experience of community, and is reduced when public attitudes towards mental illness are highly stigmatising <sup>70</sup>. Hope increases when role models of recovery are visible in society through celebrity disclosure in national anti-stigma campaigns <sup>71</sup> and when peer workers are employed in the mental health workforce <sup>72</sup>. The term ‘peer’ means someone working in a role for which a requirement is lived experience of mental illness, and with a role expectation that they will use this experience to inform their work. The only randomised controlled

trial using empowerment as the primary outcome, showed that peer-run programmes are better at promoting empowerment than traditional mental health services <sup>73</sup>.

Overall, available evidence reviewed elsewhere <sup>52</sup> shows that personal recovery is influenced by:

- (a) evidence-based treatments;
- (b) other aspects of the mental health system, including how treatments are provided and the organisational culture of the system
- (c) aspects which have nothing to do with mental health services, such as societal stigma, disability rights legislation, non-health related life events, cultural connection and spirituality.

This has implications for how workers can support recovery <sup>60 74</sup>, points to the need to incorporate new research into working practices <sup>75</sup>, and highlights evaluation challenges <sup>66</sup>. The implication for this rapid review is that we consider separately measures of personal recovery in Chapter 2 and measures of recovery orientation in Chapters 3 to 5.

The views of the service user about the recovery orientation of services should be given primacy – this is consistent with the central importance of personal experience that underpins recovery. However, other stakeholder perspectives on recovery are important to consider in order to gain a comprehensive understanding about the effectiveness of services in terms of supporting recovery. We highlight, in particular, the perspectives of family members and mental health professionals. Thus, measures of recovery

orientation from these two perspectives have been reviewed and are reported in Chapters 4 and 5 respectively.

### **1.8 Routine outcome assessment - historical perspective**

Turning now to the second aspect of the review - using patient feedback - we start with a historical overview of developments relating to routine collection and use of outcome data. Since the inception of the National Health Service (NHS) in 1948, a key policy driver has been establishing the value-for-money offered from this centrally-funded service. This has happened in stages <sup>76</sup>, mapping onto a focus on inputs, processes and outcomes <sup>77</sup>. For the first forty years of the NHS, including the NHS in NI known as HSS previously and as HSC now, effort was focussed on establishing the inputs. Inputs involved considering actual expenditure, with the goal of allocating resources to match supply with demand through the use of deprivation indices, initially based on GP consensus about patient characteristics predictive of psychiatric admission <sup>78</sup>, and more recently on statistical models quantifying the relationship between social variables measured in censuses and service use <sup>79</sup>. However, the organisation of the NHS in England and the HSS (NI) until around 1990 was oriented towards a strategic rather than managerial remit <sup>80</sup>. This changed in the early 1990s, with the imposition of the market structure onto the NHS and HSS (NI), involving the devolution to more local authorities in England and to 4 HSS Commissioning Boards and 18 hospital or community (provider) Trusts in NI <sup>81</sup> of administrative and financial responsibility, and the forcible introduction of general management. The result of this upheaval was a new focus on productivity.

Defining pieces of legislation were the NHS and Community Care Act<sup>82</sup> in England and People First<sup>81</sup> in NI, which came into force in 1993/1994. An internal market was introduced into the supply of healthcare, positioning the state as an enabler rather than a supplier of health and social care provision. Furthermore, Local Authorities and HSS Boards were required to assess people for care and support, thus ensuring that people with mental health problems could access a full range of community care for both health and social needs. In England this approach was reinforced in the Mental Health National Service Framework (1999)<sup>83</sup>, which set standards for seven areas of mental health services for adults of working age (*i.e.* aged 16-65). Service Frameworks were not developed in NI until recently. Other legislation mandated that specific types of teams be introduced nationally, such as the 335 crisis response teams required by the NHS Plan (2000)<sup>84</sup>. The consequent focus since the 1990s has been on the structures and processes which allow an internal market to operate, integrated health and social care to be provided, and specific types of mandated teams to be available. Arguably, NI's care system has had a similar focus including improving collaborative joint-working though it has been integrated, at least administratively, since 1972. Overall, even in the context of the most recent restructuring and merging of organisations in NI's health and social care system (with one HSC Board and 5 HSC Trusts), it does not appear to have given the same kind of attention to outcomes *per se* as has been the case in England. It is likely that there are lessons to be gained from experiences in England and elsewhere particularly given the time lag in similar policy implementation in NI.

Only in the past decade has outcome – *the effect on patients' health status that is attributable to an intervention*<sup>85</sup> – become a major focus of effort in England. Initiatives include the development of a mandatory outcomes framework for routine evaluation in Child and Adolescent Mental Health Services (CAMHS)<sup>86</sup> and a growing focus on central collection of minimum outcome data for adults (Mental Health Minimum Data Set – MHMDS)<sup>87</sup>, underpinned by an information strategy specific to mental health<sup>88</sup>. The aim was explicit “*The prime purpose of the data set is to provide local clinicians and managers with better quality information for clinical audit, and service planning and management*” ([www.ic.nhs.uk/services/datasets/dataset-list/mental-health](http://www.ic.nhs.uk/services/datasets/dataset-list/mental-health)). Most recently, the policy imperative for routine collection and use of outcome data has been reinforced<sup>89</sup>. Objective (ii) of the six outcome objectives is “More people with mental health problems will recover”.

In retrospect, there are a number of problems with this approach<sup>76</sup>. No funding was allocated – implementation was to be undertaken within existing service provider resources. The MHMDS was in addition to, rather than replacing, other national reporting requirements. There was no national training strategy for the outcome measures. There was no central Information Technology (IT) strategy. Mental health providers use a wide variety of information systems, so resources were needed from each service to develop and evaluate IT systems which supported rather than hindered outcome measurement. Decisions about which outcome measure to use were made centrally using an undisclosed process which did not involve widespread consultation. This meant that the people who had to do the work – mental health professionals who

were asked to complete the measure – had no sense of ownership of the initiative. Perhaps most compellingly, the aim of the MHMDS (as stated earlier) did not mesh with the basic orientation of most clinicians. Whereas managers, service planners and policy-makers are highly interested in aggregated population-level information, most clinicians are highly interested in individual patient care.

In the light of these emerging challenges in England, the Care Services Improvement Partnership (CSIP) – an arms-length Government body which provides guidance to the field – established an outcomes initiative. Following the pilot studies, an Outcomes Reference Group was established, which published the results of the pilot study in 2005<sup>90</sup>. The results were not encouraging: “*The main barrier to successful implementation identified by the Reference Group was the need to gain the positive engagement of the service users, carers and clinicians. These key groups are most likely to engage with the initiative where they have a clear understanding of the benefits of outcome measurement to themselves and services as a whole*”. In response, the Reference Group proposed a Benefits Pyramid<sup>90</sup>, shown in Figure 1.1.

Figure 1. The Benefits Pyramid

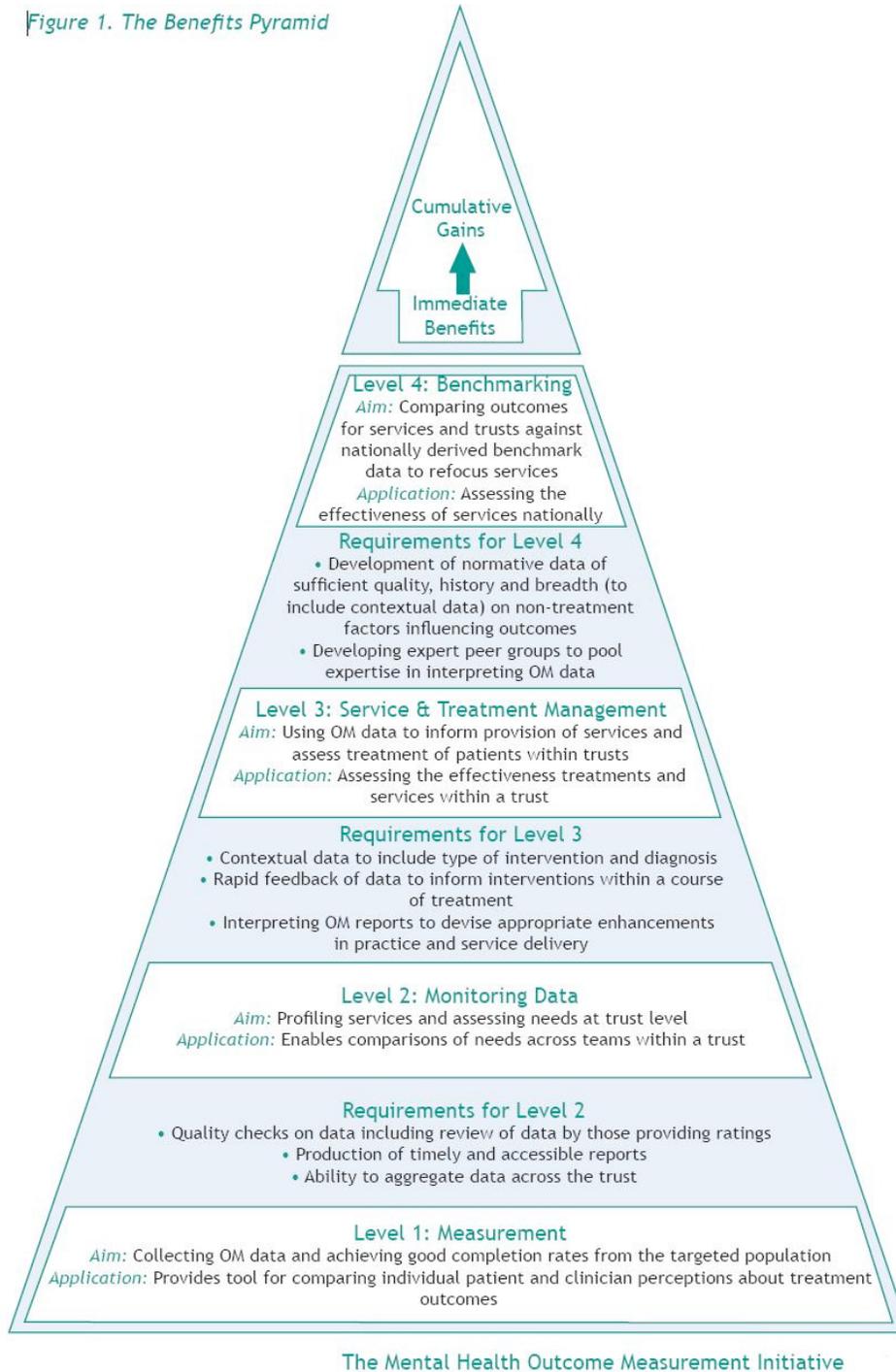


Figure 1.1: The benefits pyramid

However, this pyramid has had little impact on routine clinical practice, and outcome measurement remains an uncoordinated and fragmented activity. The situation is complicated further by commissioning developments. Two specific types of outcome commissioning have been proposed in England in the past five years. The Commission for Social Care Inspection has developed an outcomes framework for performance assessment of adult social care services <sup>91</sup>. This proposes that performance should be assessed in terms of nine key standards: Improving Health and Emotional Well-being; Improving Quality of Life; Making a Positive Contribution; Increasing Choice and Control; Freedom from Discrimination; Economic Well-being; Maintaining Personal Dignity and Respect; Leadership; and Commissioning and use of Resources. The National Social Inclusion Programme has also developed an outcome framework for mental health services <sup>29</sup>. It identifies key domains for outcome assessment as Community Participation, Social Networks, Employment, Education and Training, Physical Health, Mental Wellbeing, Independent living, and Personalisation & Choice. Service user satisfaction, service user involvement and diversity are key service outcome indicators. The Recovery Star ([www.mhpf.org.uk/recoveryStarApproach.asp](http://www.mhpf.org.uk/recoveryStarApproach.asp)), the Outcomes Star ([www.homelessoutcomes.org.uk](http://www.homelessoutcomes.org.uk)) and the Inclusion Web ([www.ndt.org.uk](http://www.ndt.org.uk)) are the outcome measures. These commissioning arrangements has not been implemented fully yet, and the move from Primary Care Trust to GP Commissioning (in consultation at the time of writing) will add further uncertainty. Nonetheless, it is likely that these experiences will afford learning opportunities for commissioning and service implementation in NI.

## 1.9 Capturing patient feedback

Having outlined in Section 1.8 the challenges of routine outcome assessment, we now turn more explicitly to the purpose of capturing feedback from people who use mental health services. Broadly, benefits may be derived at three levels (Figure 1.1). First, at the patient level, the capture and use of feedback may improve outcome. Second, at the team or service level, aggregation of patient-level feedback to provide benchmarking and performance data can lead to increased effectiveness and efficiency gains. Finally, at the regional or national level, aggregated outcome data can inform resource allocation decisions and policy priorities.

Evidence from the UK (reviewed in Section 1.8) and internationally (reviewed elsewhere<sup>92</sup>) clearly indicates a pattern. First, front-line workers (clinicians and other mental health professionals) do not express a high demand to use standardised measures of outcome<sup>93</sup>. Indeed, when frontline providers are asked how their work should be monitored, outcome is last – not first – on the list, after (in ascending order of rated importance) service use, access, process and satisfaction indicators<sup>94</sup>. Service users or carers do not prioritise formal outcome assessment.

Second, those funding the service - policy-makers in a tax-payer funded system and healthcare insurance companies in insurance-funded systems - express a reasonable wish to see outcome data, so as to ensure accountability, demonstrate value-for-money, maximise efficiency, limit financial risk, *etc.* Clinicians, on whom this demand falls in the

first instance, do not embrace this opportunity, since they do not need standardised measure data to do their jobs.

This creates what can be called a clash of cultures <sup>6</sup>. Despite the development of coherent conceptual frameworks <sup>90</sup> and clarity about the intended benefits <sup>95</sup>, this cultural gap has been found when introducing routine outcome assessment into both in-patient <sup>96</sup> and community settings <sup>97</sup>. The response from service funders to this lack of enthusiasm from the clinical ‘side’ to embrace routine use of standardised measures falls into one of three types:

- (a) An outcome measure is imposed on the system, using a mandated approach. The experience from England was outlined in Section 1.8. The largest financial investment in routine outcome assessment has been in Australia, and the implementation challenges that have arisen suggests that money is not the main limiting factor <sup>92</sup>.
- (b) There is general encouragement for the use of outcome assessment, but this is not centrally mandated. The result is a patchwork of local outcomes ‘initiatives’, which neither achieve economies of scale nor produce comparable data at the regional or national level. For example, in Italy “*Disappointingly few outcomes studies have been carried out...Most of these studies have been promoted in a few centres, such as Verona, Naples, L’Aquila and Milan*” (p. 63) <sup>98</sup> (interestingly, the internationally influential South Verona Outcome Project <sup>99</sup> <sup>100</sup> is one of the sites). The second

problem with this approach is that individual centres - more focussed on utility than psychometric robustness - often modify measures for local use, thus inadvertently making aggregation impossible.

- (c) The requirement to have a common assessment approach is mandated and resources are provided to support the system to choose and implement the best measure. We call this the Ontario approach since that is where it is most fully implemented, and it is more successful than (a) or (b). It is described fully by Smith <sup>5</sup>, and a summary (taken from elsewhere <sup>6</sup>) is shown in Box 1.2.

In 2006, Ontario (population 12 million) began the Community Mental Health Common Assessment Project (CMHCAP), with the aim of choosing and implementing a common tool for use in all 300 Ontario community mental health services <sup>5</sup>. CMHCAP staff were recruited for relevant subject matter expertise: change management; clinical and business analysis; procurement; project management expertise; communications; consumers; technical expertise; and adult education. A central aim was to ensure that implementation was owned by, and of benefit to, community mental health services.

Phase 1 (2006-2007) involved choosing a measure, and was led by a partnership of consumer, sector and planning leadership. Over eight months, 70 criteria were identified and 80 measures evaluated, followed by a full evaluation and presentations by advocates for 26 long-listed measures. A final short-list of 8 measures was produced,

from which the CAN <sup>101</sup> was chosen to underpin the Ontario Common Assessment of Need (OCAN).

In Phase 2 (2008-2009), sector-led working groups oversaw the development of additional data elements and training requirements. This service-level ownership led to 50 of the 300 services volunteering to take part in the pilot, from which 16 were chosen to test OCAN and associated processes. Findings informed modifications, and all 16 pilot sites continued to use OCAN post-pilot. In Phase 3 (2009 onwards), the OCAN is being rolled out across Ontario.

The implementation approach can be understood within the four-stage Replicating Effective Programs (REP) framework <sup>102</sup>. The four REP **pre-conditions** were met. *Need* was identified in Phase 1, an *evidence-based* measure was chosen, *barriers* were identified and addressed, and a *draft package* was developed for piloting. The three REP **pre-implementation activities** were undertaken. A community *working group of relevant stakeholders* led the pilot, the *pilot* led to OCAN modifications, and *logistical barriers* were reduced by the CMHCAP technical expertise. The **implementation** activities comprised *training* from professional adult educators with tele-conference support and on-line training, *technical assistance* from a help-line (1,600 contacts) and online information portal (100 hits per week), *evaluation* input from an external consultant, focus groups and online surveys, and *ongoing support* through presentations, newsletters, community consultations, conferences, regional meetings,

and sector champions. The final REP stage of **maintenance and evolution** is now the focus of CMH CAP activity in Phase 3.

Evaluation indicates that 84% of consumers felt the assessment helps their worker understand them better, and 74% that it was useful for assessing their needs <sup>5</sup>. Additionally 81% of staff stated OCAN provided an accurate assessment, and 56% that it identified a fuller range of needs than clinical judgement. A recent evaluation involving over 100 consumers identified 91% as satisfied or very satisfied with OCAN ([www.ccim.on.ca/CMHA/OCAN](http://www.ccim.on.ca/CMHA/OCAN)). Routine outcome assessment can produce benefits for people using, and working in, services.

### **Box 1.2: The Ontario approach to routine outcome assessment**

A key assumption made in the Ontario approach is that the primary goal needs to be patient-level benefit, with local and regional/national benefits from aggregated data an important but secondary aim. This is consistent with research from elsewhere <sup>103 104</sup>. In the review presented in Chapter 6, the focus has therefore been on the relatively large evidence base relating to routine collection and feedback of outcome data for patient-level benefit.

## **1.10 Policy context in Northern Ireland**

The Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland (NI) established an independent review of mental health and learning disability in 2002 – known as the Bamford Review <sup>26</sup>. The review was underpinned by the philosophy and approach of recovery:

*“Patient recovery should be at the very top of the mental health agenda and accepted as an integral and central part of any proposed model of mental health care”*

A number of recovery-related principles guide the Bamford vision including partnership working with service users in the individual assessment process and in therapeutic interventions of care and support. The NI Executive accepted the recommendations of the Bamford Review in a consultation document <sup>25</sup>, and recognised among other points the need to provide person-centred, service user-informed and partnership-delivered care. The consultation was followed by the final action plan for 2009-2011 <sup>24</sup>. The key actions have an end delivery deadline of December 2011 followed by a review of progress and the generation of a further action plan. One of the challenges noted in the action plan is the need for a ‘culture shift’ in the way in which we think about mental health and relate to service users in order to ensure the promotion of dignity, social inclusion and human rights. Furthermore, health and social services in NI should strive to support people to live as full a life as possible through, among other things, promoting

their independence, personal fulfilment and recovery. In December 2010, the DHSSPS (NI) produced for consultation a *Service Framework for Mental Health and Wellbeing* (with performance indicators and performance levels) which builds upon the Bamford Review and subsequent Action Plan and in which recovery is an important element <sup>105</sup>. In recent years, as noted above, recovery has emerged as a patient-centred approach to mental health care based on ideas of self-determination and self-management. It has been noted that this approach emphasises hope, meaning and the importance of maintaining a sense of self on a patient's journey to recovery <sup>106</sup>. However, defining and measuring patient recovery is a challenging task that has been the source of considerable debate and requires rigorous empirical investigation <sup>66 107</sup>.

This rapid review will provide relevant, up-to-date and important evidence that will inform the policy and practice of planning, providing and delivering recovery oriented mental health services in NI and elsewhere. In particular, the review will help to address gaps in our understanding about how local mental health services might measure recovery, capture patient feedback and improve services for service users and their families

## 2. Measures of personal recovery

The aim of this Chapter is to identify a candidate pool of measures of personal recovery, which can be the subject of further evaluative research. Although, the research brief did not require us to address this aim, we consider improving recovery to be the real goal of society, and therefore we undertook a review of measures of personal recovery.

### 2.1 Method: Personal recovery measures review

The chapter synthesises the findings from four sources.

Source A is a comprehensive review of recovery measures published by Prof Philip Burgess (University of Queensland) and colleagues. This work has been published both as an academic paper <sup>27</sup> and a research report <sup>28</sup>. The is based on the *Measuring the Promise* compendium published as a report in 2005 by the Human Services Research Institute <sup>108</sup>; and it is a comprehensive review of recovery measures that updates an earlier report <sup>109</sup>. All three reports provide a valuable resource and include several measures as Appendices. Source A is the only source to use explicit quality criteria for judging whether or not a measure should be included. These criteria comprised (in order):

- Explicitly measures domains related to personal recovery. Measures that did not meet this criterion are reported in other chapters.

- Is brief and easy to use - this was defined as met when the measure comprised no more than 50 items.
- Takes a consumer perspective, defined as consumer-rated.
- Yields quantitative data.
- Has been scientifically scrutinised, defined as published in a peer-reviewed journal article.
- Demonstrates sound psychometric properties (e.g. of internal consistency, validity, reliability and sensitivity to change).
- Is applicable to the Australian context - omitted in the context of this rapid review.
- Is acceptable to consumers, defined as being developed in consultation with consumers.
- Promotes dialogue between consumers and providers, defined as being completed through discussion between a provider and a consumer, rather than being completed by the consumer only.

A hierarchical criterion-based approach was used to analyse the measures, such that not meeting a criterion meant subsequent criteria were not evaluated for that measure.

Source B is the Outcomes Compendium published by the National Institute for Mental Health - England <sup>30</sup>. This compendium identifies recovery measures, as part of a list of 69 measures identified for routine clinical use. Measures were chosen for inclusion in the compendium based on:

- the results of an independent rating of their quality, covering evidence base (3 characteristics), psychometric properties (7 characteristics), availability of measure

(4 characteristics), practical issues (3 characteristics) and feasibility assessment (7 characteristics)

- recommendation by the practice group
- proposals by the Royal College of Psychiatry, the Royal College of Nursing and the British Psychological Society.

Source C is the Outcomes Framework for Mental Health published by the National Social Inclusion Programme <sup>29</sup>. This framework includes recommendations for measures to use for evaluating recovery. The means of identifying measures was not stated in the framework.

Source D is based on expert knowledge from Mike Slade and his REFOCUS Programme team at the Institute of Psychiatry regarding recently published UK-developed recovery measures; and on updating work by the rapid review team.

These key sources were used to generate a pool of candidate measures.

## **2.2 Results: Personal recovery measures review**

A total of 20 measures were identified from source A, 3 from source B, 2 from source C and 2 from source D. The resulting pool of 24 measures are shown in Table 2.1.

Measure	Source	Brief	Consumer-rated	Quantitative	Published	Psychometrics	Acceptable	Promotes dialogue
Illness Management and Recovery (IMR) Scales	A	Y	Y	Y	Y	Y	Y	Y
Recovery Assessment Scale (RAS)	A	Y	Y	Y	Y	Y	Y	Y
Recovery Process Inventory (RPI)	A	Y	Y	Y	Y	Y	Y	Y
Stages of Recovery Instrument (STORI)	A	Y	Y	Y	Y	Y	Y	Y
Recovery Orientation (RO)	A	Y	Y	Y	Y	N	-	-
Crisis Hostel Healing Scale (CHHS)	A	Y	Y	Y	N	-	-	-
Personal Vision of Recovery Questionnaire (PVRQ)	A	Y	Y	Y	N	-	-	-
Agreement with Recovery Attitudes Scale (ARAS)	A	Y	Y	Y	N	-	-	-
Mental Health Recovery Measure (MHRM)	A	Y	Y	Y	N	-	-	-
Consumer Recovery Outcomes System (CROS)	A	Y	Y	Y	N	-	-	-
Relationships and Activities that Facilitate Recovery Survey (RAFRS)	A	Y	Y	Y	N	-	-	-
Multi-Phase Recovery Measure (MPRM)	A	Y	Y	Y	N	-	-	-
Mental Health Recovery Star (MHRS)	AB	Y	Y	Y	N	-	-	-

Rochester Recovery Inquiry (RRI)	A	Y	Y	N	-	-	-	-
Recovery Interview (RI)	A	Y	Y	N	-	-	-	-
Milestones of Recovery Scale (MORS)	A	Y	N	N	-	-	-	-
Self-Identified Stage of Recovery (SISR)	A	Y	Y	N	-	-	-	-
Ohio Mental Health Consumer Outcomes System (OMHCOS)	ABC	N	-	-	-	-	-	-
Peer Outcomes Protocol (POP)	A	N	-	-	-	-	-	-
Recovery Measurement Tool (RMT)	A	N	-	-	-	-	-	-
Developing Recovery-Enhancing Environments Measure	B	N	Y	Y	Y	N	-	-
Outcomes Star	C	Y	N	N	Y	N	-	Y
Questionnaire on the Processes of Recovery (QPR)	D	Y	Y	Y	Y	Y	Y	Y
Warwick-Edinburgh Mental Well-being Scale (WEMWBS)	D	Y	Y	Y	Y	Y	Y	Y

**Table 2.1: Measures of personal recovery**

The first 20 measures listed in Table 2.1 were evaluated by Burgess <sup>27</sup> against a range of criteria. This evaluation identified IMR <sup>110</sup>, RAS <sup>111</sup>, RPI <sup>112</sup> and STORI <sup>113</sup> as meriting further consideration for use in an Australian context. These measures were developed in Australia (STORI) and the USA (IMR, RAS, RPI). It is worth noting that the Mental Health Recovery Star (the same measure as the 'Recovery Star' referred to in Sections 1.8 and 1.9) is the subject of a current (2010-2011) psychometric evaluation in England, led by Dr Helen Killaspy (University College London).

In addition, four further measures were identified. The DREEM is a self-rated assessment which spans personal recovery and recovery orientation. It is a modification of the Recovery Enhancing Environments <sup>114</sup> for use in England. Although it has been used in England <sup>115</sup>, it has no published psychometric evaluation.

The Outcomes Star (on which the Mental Health Recovery Star was based) was developed in England and is described in source C: *"[It] was developed for use in services for homeless people, and has a broader remit than just measuring social inclusion outcomes, although this forms an important element of the tool. It is a visual tool which looks to measure change on a 10 point scale in each of 10 areas of life: Motivation and Taking Responsibility; Self Care and Living Skills; Managing Money and Personal Administration; Social Networks and Relationships; Drug and Alcohol Misuse; Physical Health; Emotional and Mental Health; Meaningful Use of Time; Managing Tenancy and Accommodation; and Offending...[It] is primarily a tool to promote individual planning, but data can be aggregated as a means of monitoring changes in a*

*population over time. The Outcomes Star and associated materials and guidance are available to download through a Creative Commons Licence from [www.homelessoutcomes.org.uk](http://www.homelessoutcomes.org.uk).”*

The QPR is a new measure of personal recovery with published psychometric information (from one study) <sup>116</sup>, comprising 22 self-report items and developed from service users' accounts of recovery from psychosis. Its psychometric properties have been assessed <sup>116</sup> and the measure has good internal consistency, construct validity and reliability. The QPR is considered to be a useful tool and appears promising in terms of helping clients set and assess their treatment goals; and potentially it may be used in routine service evaluations and research trials. Currently, it is being used in a country-wide survey of mental health services in England and as the primary outcome for a multi-site cluster-randomised controlled trial in England to evaluate a pro-recovery team-level intervention <sup>7</sup> (further information is available at [researchintorecovery.com/refocus](http://researchintorecovery.com/refocus)).

Finally, the WEMWBS is presented for consideration because of the growing international interest in well-being, and the close relationship between recovery and well-being <sup>75 117</sup>. The WEMWBS was developed in the UK and is available in a 7-item or 14-item version. The measure originated from the work of an expert panel drawing on published literature, focus groups with 'users by experience' and psychometric testing of an existing scale <sup>21 1186</sup>. Although further psychometric testing is required, the WEMWBS has potential as a measure for monitoring mental well-being at the

population level and is a key consideration in the latest mental health policy in England

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### **2.3 Discussion: Personal recovery measures review**

The results presented here are based on a rapid review approach that identified a candidate pool of measures of personal recovery which may be the subject of further evaluative research. Other outcome compendia<sup>119-121</sup> and relevant textbooks<sup>92 122</sup> have been published, but were not reviewed due to time constraints and availability (these may contain further measures). Overall, the measures were subjected to critical appraisal as described earlier and detailed in the various sources (a separate additional evaluation of each measure was not undertaken by the rapid review team due to time constraints). It is recommended that these issues should be the subject of further research including the construction of an empirically-based conceptual framework, an assessment of the aspects of recovery covered by the domains in the measures and the relevance of each measure for use in Northern Ireland.

### **2.4 Conclusions: Personal recovery measures review**

This review found that there is no international consensus about the optimal measure of personal recovery. Caution is required regarding the use of personal recovery measures that have been developed in other countries. Three measures of personal recovery may be recommended as meriting further investigation and consideration for use in Northern Ireland: QPR, WEMWBS and (depending on the findings from the evaluation mentioned earlier) Mental Health Recovery Star. However, it should be recognised that all currently

available instruments require further research into their psychometric characteristics. Currently, even the best available measures are at an early stage in their development and require empirical investigation in terms of their reliability and validity before they might be considered for use with the NI population.

### **3. Measuring recovery orientation from a service user perspective**

#### **3.1 Introduction: Service user-rated recovery orientation measures review**

The review presented in this chapter addresses the main question posed in the research brief: how to measure recovery to inform service improvement. In Section 1.7, it was noted that recovery is influenced by experiences both within and outside the mental health system. Recovery is not something the mental health services can ‘do to’ an individual. Therefore, measures of recovery orientation need to be informed by this understanding. Five principles were embedded in this review:

1. The measure should be rated by the service user (other perspectives are considered in chapters 4 and 5)
2. Measures should span a range of aspects specifically related to recovery, rather than being general good practice points
3. Personal recovery is unique to each person, so a means of identifying the importance (utility) of an item to an individual is desirable
4. The measure should be psychometrically robust and have a coherent conceptual basis
5. The measure should be applicable to a UK context.

## **3.2 Method: Service user-rated recovery orientation measures review**

### **Review question**

What are the optimal measures of the recovery orientation of services in Northern Ireland, from the perspective of people using mental health services?

### **Design**

This chapter uses the methodology of systematic reviewing together with psychometric criteria in order to produce an up-to-date, comprehensive search and critical appraisal of best available instruments for the measurement of the recovery orientation of services from the perspective of an individual user of mental health services. The systematic review was designed to identify all published standardised, service user-rated measures of the recovery orientation of services. Each identified measure was appraised in terms of its conceptual basis, psychometric properties, the extent to which items mapped onto the CHIME Recovery Processes, and the applicability of the measure to a UK context.

### **Data sources and search strategy**

A systematic search was conducted using seven data sources. Each data source and associated search strategy is described below.

Source 1: MEDLINE, PsycINFO, EMBASE, CINAHL, CSA Illumina, TRIP and ASSIA were searched from inception to March 2011 using the search terms that were identified

from the title, abstract, key words or Medical Subject Headings (MeSH). This is shown in Table 3.1.

1	'Recovery' OR 'personal recovery' OR 'wellness' OR 'mental adj wellbeing' OR 'recovery orientation' OR 'recovery promotion'	<i>Personal recovery</i>
2	'mental disease' OR 'mental illness\$' OR 'mental disorders' OR 'psychiatric diseases\$' OR 'psychiatric disorder\$' OR 'psychiatric illness\$' OR 'chronic mental illness' OR 'mood disorder\$' OR 'psychosi\$' OR 'schizophr\$'	<i>Mental illness</i>
3	'outcome assessment' OR 'outcomes research' OR 'measurement' OR 'outcome and process assessment' OR 'treatment effectiveness' OR 'evaluat\$' OR 'treatment outcomes' OR 'questionnaire' OR 'rating adj scale\$' OR 'standardised adj test\$' OR 'survey\$' OR 'scale\$' OR 'instrument\$' OR 'inventory' OR 'index' OR 'assessment' OR 'profile' OR 'measure\$' OR 'rating' OR 'tool\$' OR 'service user adj rate\$' OR 'self adj report\$' OR 'self adj assessm\$' OR 'self adj administer\$' OR 'client adj rat\$' OR 'user adj defined' OR 'process adj measur\$' OR 'outcome adj measure\$'	<i>Measure or instrument</i>
4	'reliability' OR 'validity' 'reproducibility of results' OR 'test adj validity' OR 'test adj reliability' OR 'test adj construction' OR 'test adj developm\$' OR 'scale adj develop\$' OR ' internal consistency' OR ' alpha' OR 'beta' OR 'cronbachs' OR 'design\$' OR 'generat\$' OR 'validat\$' OR 'validation adj study' OR 'stability' OR 'validation process' OR 'shorten' OR 'modify' OR 'change' OR 'compar\$' OR 'adapt' OR 'revis\$' OR 'alter' OR 'increase' OR 'improve' OR 'design\$' OR 'generat\$' OR 'construct\$' OR 'correlat\$' OR 'creat\$' OR 'pilot' OR 'test\$' OR 'assess\$' OR 'evaluat\$' OR 'soundness'	<i>Psychometric properties</i>
5	1 AND 2 AND 3 AND 4	

**Table 3.1: Search terms**

Search terms were modified for each database. For example, the MeSH terms used for mental illness were 'mental disease' in EMBASE, and 'mental disorders' in MEDLINE

and PsycINFO. Psychometric terms reflected the properties that denoted the quality of a measure or instrument. Thus, 'validity' and 'reliability' were used as MeSH terms in EMBASE; 'reproducibility of results', 'validity' and 'reliability' were used in MEDLINE; and 'test reliability' and 'test validity' in PsycINFO. Terms such as 'psychometrics' and 'psychometry' were not used as MeSH terms because they have specific and non-relevant meanings in EMBASE, MEDLINE and PsycINFO. The search terms used in CINAHL, CSA Illumina, TRIP and ASSIA were 'mental health', 'recovery' and 'measure' (because of their less sophisticated search engines).

Source 2: Google Scholar was searched using the terms 'recovery' AND 'mental health' AND 'measure'.

Source 3: Online repositories were searched using the terms 'recovery' and 'measure'. Repositories were chosen from countries that have developed recovery-related mental health policy (Mental Health Commission of Ireland [www.mhcirl.ie](http://www.mhcirl.ie); Department of Health [www.dh.gov.uk](http://www.dh.gov.uk); Scottish Recovery Network [www.scottishrecovery.net](http://www.scottishrecovery.net); Mental Health Commission of New Zealand [www.mhc.govt.nz](http://www.mhc.govt.nz); Mental Health Commission of Canada [www.mentalcommission.ca](http://www.mentalcommission.ca); US Health Department [www.samhsa.gov](http://www.samhsa.gov)), prominent UK mental health organisations (Sainsbury's Centre for Mental Health [www.scmh.org.uk](http://www.scmh.org.uk), now [www.centreformentalhealth.org.uk](http://www.centreformentalhealth.org.uk); Mind [www.mind.org.uk](http://www.mind.org.uk), Rethink [www.rethink.org](http://www.rethink.org), National Mental Health Development Unit [www.nmhdu.org.uk](http://www.nmhdu.org.uk)), and international leaders in recovery (Recovery Devon [www.recoverydevon.co.uk](http://www.recoverydevon.co.uk); Boston University Repository of Recovery Resources

[www.bu.edu/cpr/repository](http://www.bu.edu/cpr/repository)). The Department of Health, Social Services and Public Health (NI) was also searched for documents relating to recovery and mental illness in order to help contextualise the findings.

Source 4: Conference abstracts from two conference series were searched. The *European Network for Mental Health Service Evaluation (ENMESH)* conference is a leading mental health conference with a particular focus on measurement issues. The *American Psychiatric Association (APA)* conference is the largest USA psychiatric conference. Conference abstracts were searched from 1994 for ENMESH and from 1999 for APA.

Source 5: The table of contents of three journals that publish recovery-related research regularly were searched from 1990 to January 2010: *International Journal of Methods in Psychiatric Research*, *Psychiatric Services* and the *Psychiatric Rehabilitation Journal*. The search uncovered a number of existing reviews of measures<sup>28-30 108 121</sup>, which were hand searched.

Source 6: The International Advisory Board of the REFOCUS Project comprises academics, clinical researchers, user-researchers and clinicians<sup>123</sup>. They were consulted about measures of the recovery orientation of services. More information on this study is available at [researchintorecovery.com/refocus](http://researchintorecovery.com/refocus)

Source 7: The reference lists of all retrieved papers were hand-searched.

## **Eligibility criteria**

A measure was included if it:

- assessed the contribution of mental health services to personal recovery
- was rated by service users
- produced quantitative data
- was in English
- had at least one available psychometric paper
- did not require payment for use

A measure was excluded if it assessed:

- clinical recovery, *i.e.* improvement on predefined and invariant variables such as symptoms
- personal recovery, *i.e.* the experience of recovery (rather than the contribution of services to recovery)
- beliefs or attitudes towards recovery
- staff knowledge of recovery

## **Data extraction**

The majority of data were extracted by JW, and the review was updated by DS. Papers were entered into Reference Manager. Titles were reviewed, followed by the abstract of each relevant title. Two raters independently screened 50% of the abstracts and achieved 90% agreement. The full text of the paper of each relevant abstract along with the associated measure was obtained and a decision was made about eligibility following an examination of the paper. A search for psychometric data relating to each

included measure was then undertaken by (i) asking the lead author of the measure for any relevant unpublished data on psychometric properties; and (ii) a MEDLINE search using the name of the measure.

## **Quality assessment**

Measures which met eligibility criteria for inclusion in the review were evaluated in relation to psychometric properties, coverage of personal recovery, and applicability for use in the UK.

### *Psychometric properties*

Psychometric criteria were evaluated using the framework developed by the Scientific Advisory Committee (SAC) of the Medical Outcomes Trust <sup>124</sup>. Eight aspects were considered:

1. Conceptual underpinning and measurement model - this refers to the conceptual underpinning upon which a measure was based and the model of measurement that was used. Evaluation criteria includes a clear definition of the concept or concepts that are being assessed and a justification for the measurement model.
2. Reliability - this is evaluated by assessing the internal consistency and reproducibility of the measure. Internal consistency refers to the internal structure of the measure and the association of the items to each other and to the total score. The acceptable range of internal consistency considered adequate is debated. Norman and Streiner (2008) give a range of 0.70 to 0.90 as acceptable. If the

measure has sub-scales, internal consistency will be calculated for the items in each sub-scale. Reproducibility refers to the stability of the measure over time (test-retest), or when used by different people (inter-rater).

3. Validity - The SAC guidelines consider three forms of validity: content-related, construct-related, and criterion-related. Content-related validity refers to evidence that the content of the measure - the concept(s) being assessed - are considered appropriate by experts in the area. These experts could be researchers or clinicians with expertise in the area or the target population for whom the measure is intended. Construct validity concerns the relationships between the concept(s) being assessed and other, related, concepts. This is assessed by generating and testing hypotheses about the expected associations between the scores of the candidate measure and measures of other related concepts. Finally, criterion-related validity refers to the correlation of a measure to a criterion 'gold standard' measure. This can be assessed only if an agreed criterion measure exists.
4. Responsiveness - this refers to the ability of a measure to accurately measure change. The calculation of this involves the use of effect size statistics to translate scores from administration of the measure at different time periods into a standard unit of measurement.
5. Interpretability - this refers to how the scores from a measure can be interpreted to give a qualitative meaning to differences in scores over time. This interpretation may be informed by the performance of a measure in terms of similarities and differences between-groups and settings, or in terms of different aspects of people's lives - for example, a person's sense of 'where they are at' in their recovery.

6. Burden - this is broken down into respondent burden and administrative burden and refers to aspects of administering or completing a measure that could influence its use such as length of time to complete, and any resources needed to complete it.
7. Alternative forms - this includes self-report, interviewer-administered, computer-assisted interviewer, and trained observer rating and performance-based measures
8. Cultural and language adaptations (translations) - including an assessment of conceptual and linguistic equivalence

#### *Coverage of personal recovery*

Every measure was evaluated against the CHIME Recovery Processes, described in Section 1.6. The evaluation considered the breadth and depth of coverage of the five CHIME Recovery Processes. The goal was to establish that a measure was assessing what services can do specifically to support recovery, rather than other important but different aims (such as providing rehabilitation interventions or being accessible).

A rating system to assess the measure of fit was developed for this review. Each item in each measure was assigned to the most closely matching CHIME Recovery Process. If an item covered more than one theme, it was assigned to the most closely related theme. All ratings were made by four raters. Only items which had at least 75% concordance between raters (*i.e.* 3 out of 4) were retained as 'mappable items' in the analysis. This provided two metrics:

Recovery Relevance of the measure = (number of mappable items / total number of items ) x 100

Recovery Process coverage = (number of mappable items for each Recovery Process / total number of items) x 100.

### *Suitability for use in the NHS*

Each measure was rated in terms of the nature and degree to which needed to be adapted for use in a NHS context. For a measure to be used in a different country from where it is developed, the assumptions that the measure makes about societal and service contexts need to be applicable for that country. The criteria used for evaluation of measures in this review were that the language used would be understood in the UK, including both individual words and phrases, and the assumptions made about services and the wider context were consistent for the NHS context. Each included measure was read by two reviewers and rated in terms of whether any changes would need to be made to the measure for it to be used in the UK. Disagreement was resolved by discussion to produce a consensus rating. Measures were classified into three categories:

**No changes** meant the language and assumptions about service configuration were suitable for use in the NHS

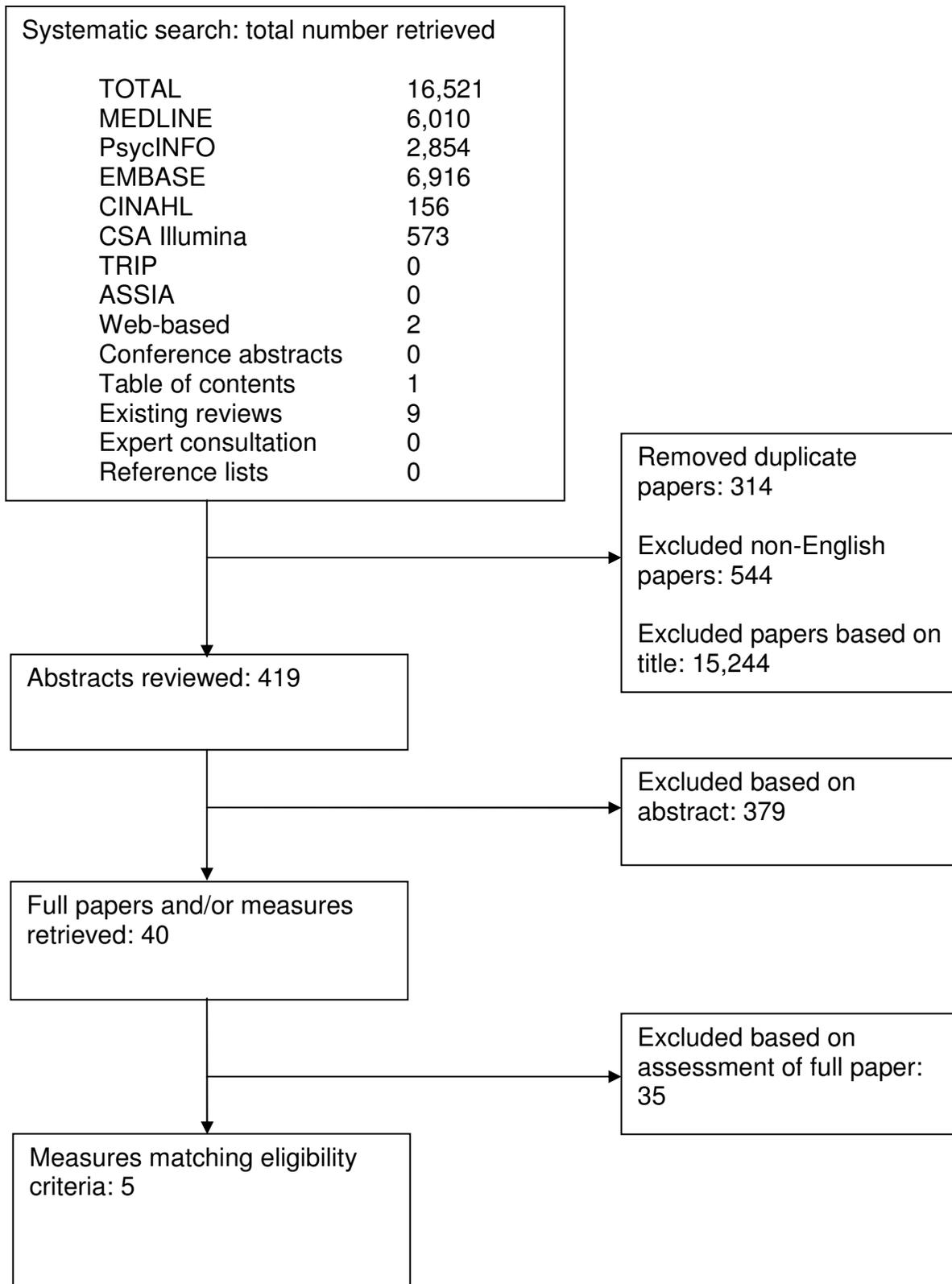
**Minor changes** meant that some changes would be needed to ensure that the measure was suitable for use in the NHS, but these changes were judged unlikely to compromise the psychometric properties of the measure

**Major changes** meant that the language and assumptions in the measure could not be modified for use in the NHS without a risk of compromising the psychometric properties of the measure.

In addition, the identified measures were reviewed by a reference group comprising ten service users and professionals.

### **3.3 Results: Service user-rated recovery orientation measures review**

The flow diagram for study selection is shown in Figure 3.1.



**Figure 3.1: Flow diagram - service user-rated measures**

Eleven measures were identified which assessed aspects of the recovery orientation of services. Six of these eleven measures were excluded because they did not meet other eligibility criteria, shown in Table 3.2.

<b>Measure</b>	<b>Reason for exclusion</b>
Recovery Promoting Relationships Scale <sup>125</sup>	Assesses staff competencies only
Recovery Promotion Fidelity Scale <sup>126</sup>	Completed by trained assessors
Recovery Based Program Inventory <sup>27</sup>	Does not provide quantitative data
PORSAT <sup>61</sup>	No published psychometric data
AACP ROSE <sup>108</sup>	No published psychometric data
Magellan Recovery Culture Report <sup>27</sup>	Not available

**Table 3.2: Excluded measures of recovery orientation (n=6)**

Five measures met the eligibility criteria, and are shown in Table 3.3.

<b>Measure</b>	<b>Description</b>
Recovery Self-Assessment (RSA) <sup>65</sup>	36-item measure of recovery supporting practices (versions also exist for completion by 'significant other', service provider and service director)
Recovery Enhancing Environment Measure (REE) <sup>114</sup>	166-item measure of contribution of services to recovery and of other aspects of recovery including organisational climate; designed for completion by service users only.
Recovery Oriented Systems Indicators (ROSI) <sup>108</sup>	42-item measure of the recovery orientation of systems for completion by service users only.
Recovery Interventions Questionnaire (RIQ) <sup>127</sup>	50-item measure of the aspects of support and treatment which facilitate recovery. Version also exists for completion by case manager.
Recovery Oriented Practices Index (ROPI) <sup>128</sup>	20-item measure of recovery oriented practices. Completion involves service users, especially in version called Scottish Recovery Indicator <sup>129</sup>

**Table 3.3: Included measures of recovery orientation (n=5)**

### **3.3.1 Psychometric properties**

The evaluation of psychometric properties against the SAC review criteria is shown in Table 3.4.

<b>Criteria</b>	<b>RSA</b>	<b>REE</b>	<b>RIQ</b>	<b>ROPI</b>	<b>ROSI</b>
<b>Conceptual basis (or target construct)</b>	Implementation of recovery oriented practices	Mental health recovery and performance of services during recovery	Aspects of recovery and of support which facilitates recovery	'Fidelity' to recovery at organizational level	Performance (indicators) of recovery at system level
<b>Basis for generating item content</b>	Phenomenological (qualitative) research	Literature review	Literature review	Review of existing measures and self determination theory	Large-scale mixed-methods research project
<b>Dimensionality (or composition of measure)</b>	<i>9 domains</i> Encourage individuality, Promote positive portrayal of illness, Strengths focus, Use language of hope, Offer treatment options, Support risk-taking, Involve stakeholders, Encourage users to participate in advocacy, Develop community connections	<i>8 domains</i> Demographics, Stage of recovery, Importance of each recovery element, Programme performance indicators, Special needs, Organisational culture, Recovery markers, Consumer feedback.	<i>8 domains / subscales</i> Medication use, Spirituality, Knowledge/acceptance of illness, Collaborative treatment planning, Relationships with case manager and services, Strengths-based interventions, Role of self will and self monitoring, Community and personal support.	<i>8 domains / principles</i> Meeting basic needs, Comprehensive services, Customization and choice, Consumer involvement and participation, Network supports and community integration, Strengths-based approach, Self-determination, Recovery focus.	<i>8 domains / factors</i> Person-centred decision making and choice, Invalidated personhood, Self-care and wellness, Basic life resources, Meaningful activities and roles, Peer advocacy, Staff treatment and knowledge, Access.
<b>Internal consistency (or agreement/correlation)</b>	<i>5 factors</i> Life goals .90 Involvement .87 Treatment options .83 Choice .76 Individually tailored services .76	Performance indicators .94 Organisational climate .97	Reported for 5 sub-scales: Medication use .72 Spirituality .71 Relationship with case manager.76 Strengths-based interventions .64 Self-will .69	Not reported	r = 0.95 for full measure
<b>Reproducibility (test-retest)</b>	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
<b>Content-related validity</b>	Reviewed by service users, providers, family members and researchers	Pre-tested with service users	Piloted or tried with 4 service managers and 3 case managers	Working group comprised service users	Workshop with 45 service users, Think-aloud with 10 service users
<b>Construct-related validity</b>	No hypothesis testing	No hypothesis testing	No hypothesis testing	Correlation with RSA r = 0.74, p<0.01	No hypothesis testing
<b>Criterion related</b>	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed

<b>validity</b>					
<b>Responsiveness</b>	Not assessed	Not assessed	Not assessed	Not assessed	Not assessed
<b>Interpretability</b>	Mean and SD reported for summary score and each factor score	Not reported	Mean scores for some sub-scales	Mean scores and SDs reported	Mean scores reported from pilot phase
<b>Number of items</b>	36 items	166 items	50 items	17 items	42 items
<b>Approx time to complete (mins)</b>	10 minutes	25 mins. (self-complete); 40 mins. (interview)	Not reported	Not reported	30 minutes
<b>Reading level</b>	Not reported	Flesh-Kincaid grade 7.8	Not reported	Not reported	Flesh-Kincaid grade 5.7
<b>Alternative forms</b>	None	None	None	None	None
<b>Cultural and language adaptations</b>	None	None	None	None	None

**Table 3.4: Psychometric properties for included measures (n=5)**

There was variation in the way recovery was conceptualised or the aspects of recovery that were targeted for assessment. Every measure involved service users in its development and the RSA also involved families, providers and researchers whilst the RIQ was tested with case managers. Overall, the correlations for internal consistency (regarding item content) were high though this was not evaluated for ROPI. The validity of the construct measured by each instrument was only tested between ROSI and RSA. Test-retest reliability was not assessed or reported for any measure and so the stability of each measure is unknown. Most importantly, no measure had evidence for responsiveness, so the suitability of the measures to detect change over time is unknown.

### **3.3.2 Coverage of personal recovery**

Each item in each measure was assigned independently by four raters to the most closely matching theme in the CHIME Recovery Processes. Only REE (82%) and ROPI (100%) had inter-rater agreement levels above 75% (*i.e.* agreement between 3 out of 4 raters) in terms of judgements about the 'fit' between individual items and the five CHIME Recovery Processes though there was an agreement level of 74% for the assignment of the item content of the ROSI to the CHIME Recovery Processes. There was a lower but still fairly good agreement between raters about the match between CHIME Recovery Processes and items in RIQ (66%) and RSA (69%) respectively. Only items with a concordance level of 75% and above were used to estimate degree of coverage. Table 3.5 shows the extent to which each CHIME Recovery Processes was covered by these items.

Measure	RSA	REE	RIQ	ROPI	ROSI
<b>Total items</b>	36	43	50	8	42
<b>Mapped items</b>	25	37	33	8	31
<b>Recovery Relevance<sup>1</sup></b>	<b>69%</b>	<b>86%</b>	<b>66%</b>	<b>100%</b>	<b>74%</b>

CHIME Recovery Process coverage

*n(%) of items mapped to each CHIME Recovery Process*

	RSA	REE	RIQ	ROPI	ROSI
Connectedness	5 (20)	8 (22)	10 (31)	1 (12)	6 (20)
Hope and optimism	2 (8)	3 (8)	0 (0)	0 (0)	2 (6)
Identity	3 (12)	4 (11)	0 (0)	0 (0)	1 (3)
Meaning and purpose	5 (20)	10 (27)	6 (18)	2 (25)	8 (26)
Empowerment	10 (40)	12 (32)	17 (51)	5 (63)	14 (45)

<sup>1</sup> Mapped items / Total items.

**Table 3.5: Coverage of personal recovery (n=5)**

The RSA and RIQ had lowest clear relevance to recovery. The REE and the RSA provided the broadest coverage across the five key recovery themes. ROPI and the RIQ covered only three themes. Hope and optimism and Identity received least coverage across the measures. The most comprehensively covered themes were Connectedness, Meaning and Purpose, and Empowerment.

### 3.3.3 Suitability for use in the NHS

A version of the REE - the DREEM <sup>115</sup> - is available for use in the UK, indicating No changes are needed. The RSA, RIQ and ROSI were judged to need Minor changes

to be suitable for use in the NHS. Finally, the ROPI was judged to require Major changes to be suitable for use in the NHS.

The reference group commented on the five measures. There was a consensus that the REE was the most user-friendly and useful. There was a feeling that the information from the RSA was useful for commissioners but would be difficult to administer and was not user friendly. The ROSI and ROPI instruments were not favoured.

### **3.4 Discussion: Service user-rated recovery orientation measures review**

This systematic, comprehensive review identified eleven measures that assessed the recovery orientation of services from the perspective of individual users of mental health services. Other measures were considered but did not meet the eligibility criteria. These measures included the Service Attachment Questionnaire (SAQ) <sup>130</sup>. The SAQ is a self-report measure, which examines the quality of service users' relationships with mental health services and provides a measure of the extent to which users are experiencing a listening, consistent, safe, comforting and enabling service. Although the SAQ is not a measure of recovery orientation, an examination of its content suggests that there is considerable overlap between this measure and validated recovery measures. Consequently, an examination of the applicability and psychometric qualities of the SAQ in a recovery setting merits further consideration.

Only five measures met full eligibility criteria. Currently, these measures are the best available measures of service user-rated recovery orientation though no single measure adequately captures recovery orientation. It is important to emphasise that

further research is required in order to address the gaps in our understanding regarding the best way in which to achieve agreement about the meaning of the concept of recovery including how to operationalise the construct in a routine service context. It is important to note that the measures described are at an early stage of their development and robust and rigorous research is required in order to subject measures of recovery orientation to full psychometric testing.

### **3.4.1 Psychometric evaluation**

Whilst the existing best available measures provide an assessment of the extent to which services support individual recovery, they vary in terms of their respective conceptualisations of recovery including the number and composition of domains. In addition, there is a lack of clarity about mental health service provision and delivery. This variation reflects the ongoing debate about the meaning and measurement of recovery<sup>131 132</sup>. Although there is a degree of commonality between the domains or in terms of the composition of the five measures, such as the centrality of empowerment, arguably, the measures differ much more than they agree regarding the domains or dimensions that they cover and the language that they use to describe these domains. For example, what is the nature and degree of commonality between ‘Encourage individuality’ in the RSA, ‘Collaborative treatment planning’ in the RIQ and ‘Self-determination’ in the ROPI? The lack of conceptual clarity and coherence makes it difficult to undertake a direct comparison between the measures. The RSA and the ROSI appear to have clearer and more coherent conceptualisations of recovery than the other three measures, indicated by the validity of their item content and related supporting studies. However, the absence of any statistical investigation of the dimensionality or factorial validity of any measure

is another indication of the need to conduct a robust evaluation of the measures of recovery orientation. Finally, the definition and assessment of *services* in the context of developing a measure of recovery orientation is a neglected issue that requires research attention alongside the operationalisation of recovery orientation. It is not clear from the assembled evidence why particular levels of measurement were used in the measures - each measure appears to target different aspect of service delivery and once again these differences in the levels of measurement makes meaningful comparison difficult.

There were no reports or studies to indicate that the measures had been subjected to a full and rigorous psychometric evaluation. There were attempts to assess the content validity of each measure by involving service users and eliciting their views regarding item content. The RSA also involved families, providers and researchers (as well as service users), and the RIQ elicited views from case managers. Arguably, the RSA is the most robust measure of the recovery orientation of services in the sense that the generation of item content was based on capturing the phenomenological experience or perspective of service users. The RSA, along with the lengthier REE, also mapped best in terms of coverage across the five CHIME Recovery Processes. Construct validity was assessed only for the ROPI – the measure had a strong positive relationship with the RSA indicating that there was a fairly good degree of commonality between measures about the construct of recovery orientation. A ‘gold standard’ measure of recovery orientation does not exist, and criterion validity was not assessed for any measure. Overall, the RSA appears to perform best in terms of validity.

Similarly, there were few studies of reliability. There was good to high internal reliability or consistency for four measures – an alpha correlation was not calculated or reported for the ROPI. Optimum internal consistency scores are considered to range of 0.70 to 0.90. Two measures (RSA and RIQ) each calculated alphas for their 5 sub-scales (range: .64 to .90) with mean average alphas of .82 and .70 for the RSA and RIQ respectively. The two scales of the REE achieved 0.94 and 0.97 respectively whilst an alpha correlation only (.95) was calculated for the full scale (or total number of items: 42) on the ROSI measure. Internal consistency scores over 0.90 may indicate item redundancy – some items may have identical or very similar meanings. Item redundancy is a concern for REE and ROSI.

Test-retest reliability and sensitivity to change were not assessed for any measure and so the stability of each instrument over time is unknown. This is an important weakness in all measures, since it limits the ability to recommend any measure for longitudinal use.

Respondent burden varied in terms of the number of items comprising each measure, the related time required to answer items, and reading difficulty. It is recommended that written material for health service users should be composed for an average reading age of 12<sup>133</sup>. The measure with the most items (166) was the REE (reading age: 12 – 13 years), though it had a number of ‘gates’ or filters that meant that a respondent was not required to answer every question. It takes approximately 25 to 40 minutes to complete, similar to the 42-item ROSI (reading age: 10 - 11 years). It is unlikely that it would be acceptable or feasible to implement the use of these measures routinely in local mental health services. In contrast, it

takes only 10 minutes to complete the 36-item RSA. Although the RSA appears to take the least amount of time to complete, Kidd and colleagues have developed a brief 12-item version due to concerns about respondent burden <sup>134</sup>. A report of the developmental process is being prepared (personal communication). Time-completion estimates were not reported for the 50-item RIQ or the 17-item ROPI. The reading age of other measures was not assessed or reported.

### **3.4.2 Coverage of personal recovery**

The consistency of the content of each measure with the REFOCUS conceptual framework was evaluated in terms of four researchers rating each item. Disagreement arose for two reasons. Firstly, some items posed questions about more than one concept or aspect, such as “*The service is safe and attractive*” (REE) and “*I am given the opportunity to discuss my spiritual and sexual needs*” (RSA). Secondly, some items were ambiguous, such as “*The service has enough resources to meet people’s needs*” (REE) and “*At this agency, participants who are doing well get as much attention as those who are having difficulties*” (RSA). Ambiguity in wording, or having two concepts to be assessed in any question, described as ‘double-barrelled’ <sup>135</sup>, impacts on the validity of a measure as respondents may be unclear about the meaning of the item, potentially leading to error in their responses. Thus, there is a need to improve clarity of item content and reduce ambiguity as these factors may lead to errors in responses and impact on the validity of a measure.

### 3.4.3 Suitability for use in the NHS

All five measures were developed outside the UK and NHS care system and therefore require adaptation and further psychometric testing in order to ensure their suitability for the NI context. Any changes to the language (eg 'agency') used in standardised measures may compromise content validity. The ROPI was judged to require major changes whilst the other three recovery measures were deemed to require only minor changes. A version of the REE has been used in the UK <sup>115</sup>, though it has no published psychometric evaluation.

This is an important issue, because it impacts on use. The experience of using recovery measures in the UK has had limited success. For example, a recovery training programme in England was evaluated using RSA (staff, service user and family member versions) <sup>65</sup>, ROSI (service user) <sup>108</sup> and Competency Assessment Inventory (CAI) (staff) <sup>136</sup>. One aim was to provide preliminary UK-based normative data for these measures, but this aim was only partially met. One stated reason was *"the measures used were not of high clinical relevance. Although tailored information was presented in person to each participating team, staff did not easily relate the information to their work."* (p. 13). It was also noted that "The cross-cultural validity of the measures has not been formally established. For example, some of the wording of the measures was not easily understood by respondents." (p. 14). Similarly, after an (unpublished) systematic review of all recovery orientation measures by a research team in London, it was concluded that no measure was suitable for use in England, so a new measure - INSPIRE (described in Section 3.4.4) - is being developed.

### 3.4.4 Horizon scanning

A recent submitted documentary analysis of international approaches to operationalising recovery presents the outcome of an attempt to develop a conceptual framework to guide efforts to assess recovery orientation<sup>137</sup>. It involved a qualitative analysis of 30 international documents offering recovery-oriented practice guidance. Inductive, semantic level thematic analysis was used to identify dominant themes. Interpretive analysis was then undertaken to group the themes into practice domains. The guidance documents were diverse; from six countries, and varying in document type, categories of guideline, and level of service user involvement. The emerging conceptual framework consisted of sixteen dominant themes, grouped into four practice domains: *Promoting citizenship*, *Organizational commitment*, *Supporting personally defined recovery*, and *Working relationship*. In future research, this framework may help to identify and clarify which aspects of recovery orientation are assessed by each measure.

A second relevant development is that a new measure of recovery orientation is being developed in London, based on qualitative research with people using mental health services throughout England. The measure is called INSPIRE, and the current version 3 comprises a 29-item user-rated assessment for people using UK adult mental health services. Further information is available at [researchintorecovery.com/inspire](http://researchintorecovery.com/inspire). INSPIRE addresses several issues raised in the review:

1. It has a strong empirical foundation insofar as it is based on the first systematic review and narrative synthesis of personal recovery<sup>2</sup>

2. Extensive piloting showed that it was not possible for individual service users to rate a team easily, so it focuses on the work with an individual mental health worker. Thus, it is located at the *Supporting personally defined recovery* and the *Working relationship* levels identified in the unpublished documentary analysis. INSPIRE comprises two sub-scales: *Support* (21 items) and *Relationships* (8 items)
3. Unlike any identified measure in the current review, it assesses utility - the extent to which a specific domain of support is important to an individual. This feature of the measure means that the overall score reflects the personal values of each respondent.
4. Formal psychometric evaluation is underway, and specifically investigates test-retest reliability and sensitivity to change.

A third relevant development is another measure called the Recovery Context Inventory (RCI). This has been developed as a web-based recovery profiling tool that enables respondents to identify personally important contextual factors that promote or hinder psychological and social wellbeing. The aim of the recovery research project - entitled *Understanding Recovery in Context* - is to provide mental health service users, family members/carers and mental health service providers with a practical, empowering and user-friendly profiling tool. The tool will facilitate a person in recovery/expert by experience to consider his/her life circumstances and comprehensively assess interpersonal, service and wider community recovery contextual factors that impact positively or negatively upon his/her individual recovery process. The resulting personal profile will enable the person to make decisions and take positive action to promote their wellbeing. The study is being

conducted by EVE Limited and supported by the Health Service Executive, the Irish Advocacy Network, the School of Psychology, University College Dublin, the National Disability Authority and Community Foundation Ireland. Further information is available by e-mail from Tom O'Brien, EVE Limited (ve.ie).

### **3.5 Conclusions: Service user-rated recovery orientation measures review**

In conclusion, once again the absence of evidence of test-retest reliability and adequate sensitivity to change mean it is not possible to recommend any of the identified measures of recovery orientation for widespread routine use in Northern Ireland. The fact that the five measures were developed outside the UK limits their suitability for use in the NHS and more locally. In the opinion of the review team, the new INSPIRE and RCI measures offer the greatest promise for implementing the routine use of recovery measures in Northern Ireland.

## **4. Measuring recovery orientation from a family member perspective**

### **4.1 Introduction: Family member-rated recovery orientation measures review**

Whilst the recovery orientation of a mental health service is primarily evaluated by the mental health service user, it is beneficial to consider measures from other perspectives, with a view to nurturing further a collaborative way of working towards developing and improving the recovery orientation of services. In this Chapter we consider the family member / carer perspective on recovery orientation.

An initial scoping search identified two recent reviews of measures for family members / carers: an unpublished research report <sup>138</sup> and a published literature review <sup>139</sup>. Neither review identified any family member-rated measure of recovery orientation. The review presented in this section therefore provides the results of a new systematic search for measures of the recovery orientation of services from the perspective of family members, with an appraisal of evidence for psychometric properties of identified measures.

### **4.2 Method: Family member-rated recovery orientation measures review**

#### **Key review question**

What are the optimal measures of the recovery orientation of services in Northern Ireland, from the perspective of family members of mental health service users?

## Data sources and search strategy

A systematic search was undertaken to identify relevant published or unpublished literature about family member-rated measures of the recovery orientation of services.

Medline, PsycINFO, EMBASE, CINAHL plus and ASSIA were searched from inception to March 2011 using relevant search terms from the review of service user-completed measures presented in Section 3.1 and supplemented with MeSH terms relating to family members and carers. The search strategy is shown in Table 4.1.

1	'Recovery' OR 'personal recovery' OR 'wellness' OR 'mental adj' wellbeing' OR 'recovery orientation' OR 'recovery promotion'	<i>Personal recovery</i>
2	'mental disease' OR 'mental illness\$' OR 'mental disorders' OR 'psychiatric diseases\$' OR 'psychiatric disorder\$' OR 'psychiatric illness\$' OR 'chronic mental illness' OR 'mood disorder\$' OR 'psychosi\$' OR 'schizophr\$'	<i>Mental illness</i>
3	'carer' OR 'caregiver' OR 'care giver\$' or carers or 'family caregivers' OR caregiver family OR spouse caregivers OR caregiver\$ spouse	<i>Carer</i>
4	1 AND 2 AND 3	

**Table 4.1: Terms used to search electronic databases**

Search terms were modified to suit each database. Google Scholar was also searched using the terms 'recovery' AND 'mental health' AND 'carer' AND 'measure'.

In addition, the online repositories listed in Section 3.1 were searched, and the reference lists of all retrieved papers were hand searched.

### **Eligibility criteria**

A measure was included if it:

- assessed the contribution of mental health services to recovery from the perspective of a family member or family carer
- was rated by a family member or carer
- produced quantitative data
- was in English
- had at least one available psychometric paper.
- did not require payment for use

A measure was excluded if it assessed:

- carer burden
- the service user's clinical recovery
- the service user's personal recovery
- carer beliefs or attitudes towards recovery

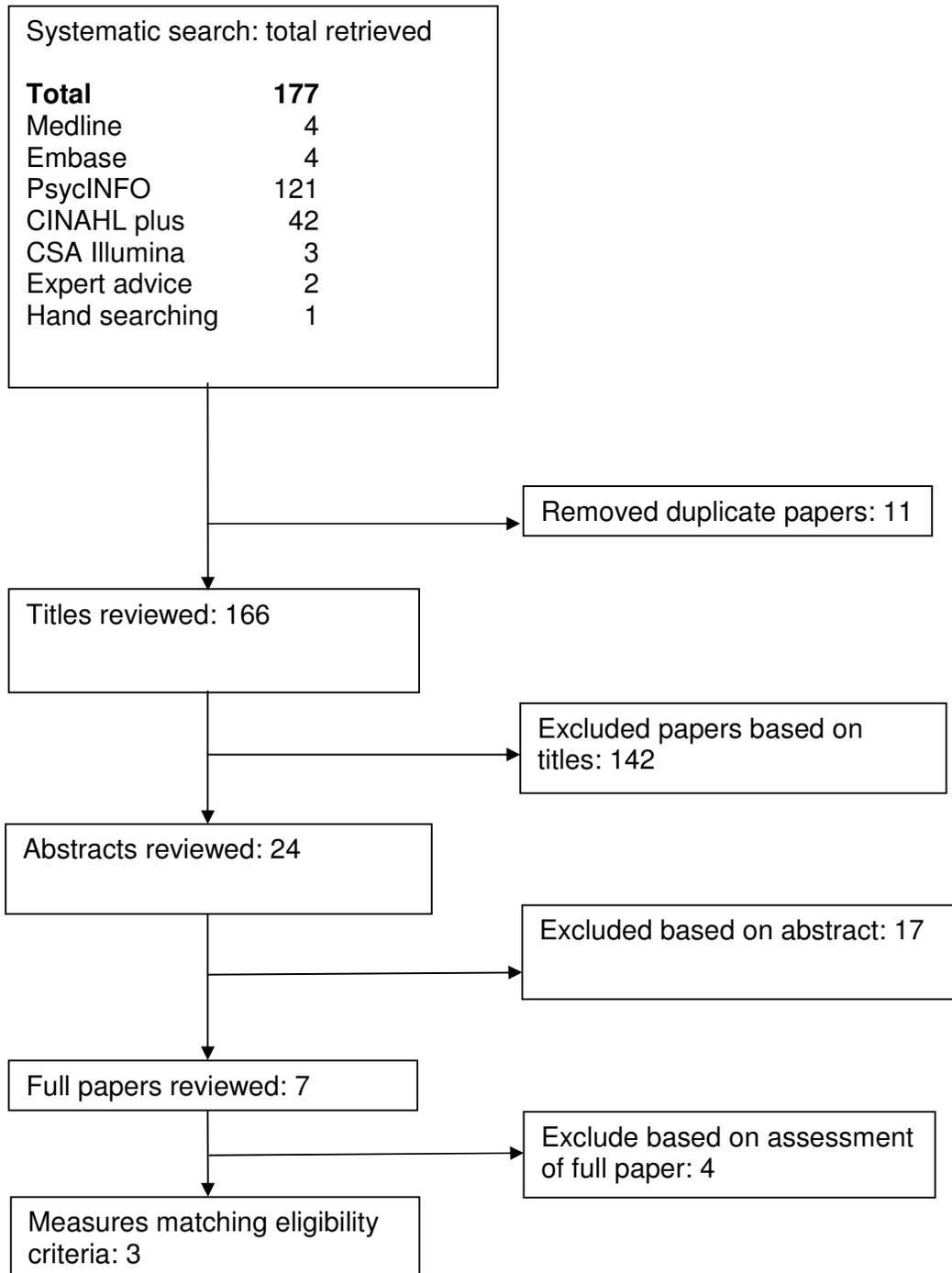
### **Data extraction**

Papers identified were entered into Reference Manager. Duplicate articles were discarded. Two reviewers, working independently, reviewed titles for relevance and discarded only titles that were clearly unrelated to the review question. Abstracts of the remaining papers were assessed (with 96% between-assessor agreement). The decision about whether or not to include a measure was based on an appraisal of

the full papers of the remaining articles. Finally, psychometric data for each included measure was identified using a MEDLINE search using the name of the measure.

### 4.3 Results: Family member-rated recovery orientation measures review

The flow diagram for study selection is shown in Figure 4.1.



**Figure 4.1: Flow diagram - family member-rated measures**

Three measures were identified which examined the recovery orientation of services from a family member or carer perspective: Recovery Self Assessment (Carers version) <sup>65</sup>; Recovery Assessment Scale (Carers version) <sup>140 141</sup>; and Recovery Oriented Service Evaluation (AACCP Rose) <sup>108</sup>. Searches were carried out using the titles of these three measures as key words. There were no reports of the psychometric performance for any of the measures.

#### **4.4 Discussion: Family member-rated recovery orientation measures review**

No measure of recovery orientation from a family member's perspective has published psychometric data. The only known use of a family member recovery orientation measure in the UK was a small study evaluating recovery training in London from, among others, the perspective of carers <sup>142</sup>. This used the RSA (Carer's version) but did not yield any publishable information due to low response rate.

#### **4.5 Conclusions: Family member-rated recovery orientation measures review**

No family member-rated measure of recovery orientation can be recommended.

## **5. Measuring recovery orientation from mental health professional perspectives**

### **5.1 Introduction: Professional-rated recovery orientation measures review**

The review presented in this section identifies and appraises measures of the recovery orientation of services from the perspective of mental health professionals. Whilst recognising the central importance of the perspective of the service user, an assessment by a mental health worker of the extent to which a service supports recovery contributes to the comprehensive evaluation of the recovery orientation of services. Similar to other rapid reviews reported here, the review attempts to follow as much as possible the methodology of systematic reviewing together with psychometric criteria in order to produce an up-to-date, comprehensive search and critical appraisal of best available instruments for the measurement of the recovery orientation of services from the perspective of mental health staff. The systematic review was designed to identify all published standardised, staff-rated measures of the recovery orientation of services, and then to appraise each identified measure in terms of its conceptual basis and psychometric properties.

### **5.2 Method: Professional-rated recovery orientation measures review**

#### **Key review question**

What are the optimal measures of the recovery orientation of services in Northern Ireland, from the perspective of mental health professionals?

### Data sources and search strategy

A recent review of recovery measures<sup>27 28</sup> employed systematic methods to identify measures completed by professionals that were designed to measure the recovery orientation of services. We updated this review.

A search was performed on the following electronic databases: MEDLINE, EMBASE, PsycINFO and CINAHL plus. The search terms used are set out in Table 5.1.

1	'Recovery' OR 'personal recovery' OR 'wellness' OR 'mental adj' wellbeing' OR 'recovery orientation' OR 'recovery promotion'	<i>Personal recovery</i>
2	'mental disease' OR 'mental illness\$' OR 'mental disorders' OR 'psychiatric diseases\$' OR 'psychiatric disorder\$' OR 'psychiatric illness\$' OR 'chronic mental illness' OR 'mood disorder\$' OR 'psychosi\$' OR 'schizophr\$'	<i>Mental illness</i>
3	'professional' OR 'health professional\$' OR 'profession\$ health' OR 'doctor\$' OR 'psychiatrist\$' or 'nurse' OR 'psychiatric nurse' OR 'clinician' OR 'staff'	<i>Professions</i>
4	1 AND 2 AND 3	

**Table 5.1: Search terms used to search electronic databases**

Search terms were modified to suit each database. Google Scholar was also searched using the terms 'recovery' AND 'mental health' AND 'professional' AND 'measure'. In addition, the online repositories listed in Section 3.1 were searched, and the reference lists of all retrieved papers were hand searched.

### **Eligibility criteria**

A measure was included if it:

- assessed the contribution of services to recovery from the perspective of a mental health professional
- was rated by a mental health professional
- produced quantitative data
- was available in English
- had at least one psychometric paper
- did not require payment for use.

Measures were excluded if they

- assessed the recovery oriented competencies of individual mental health professionals
- assessed clinical recovery
- assessed personal recovery (rather than the contribution of services to recovery)
- assessed mental health professionals' beliefs or attitudes towards recovery.

### **Data extraction**

Papers were entered into Reference Manager. Duplicate articles were identified and discarded. Two reviewers, working independently, reviewed titles for relevance and

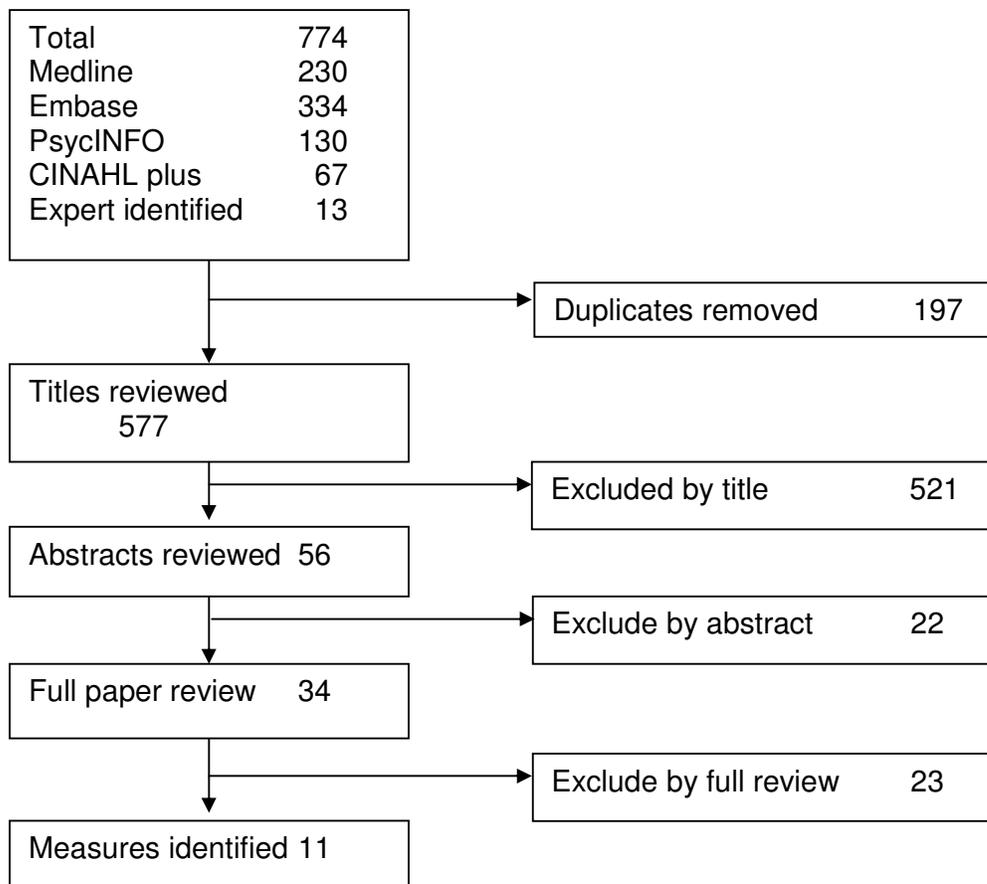
discarded only those titles which were clearly unrelated to the research question. Abstracts were obtained for the remaining papers and two reviewers assessed them independently and achieved 92% agreement. Full papers of remaining abstracts were obtained and a decision was made regarding eligibility after an examination of the entire text. Finally, psychometric data for each included measure was identified using a MEDLINE search using the name of the measure.

### **Quality assessment**

The approach described in Section 3.1 for evaluating psychometric properties was used with the identified measures.

### **5.3 Results: Professional-rated recovery orientation measures review**

The flow diagram for study selection is shown in Figure 5.1.



**Figure 5.1: Flow diagram - professional-rated measures**

Eleven potential measures were identified seven of which were excluded as they did not meet eligibility criteria. These are shown in Table 5.2.

Measure	Reason for exclusion
Competency Assessment Inventory (CAI) <sup>136</sup>	Not available
Magellan Recovery Culture Report Card (MRCRC) <sup>no ref</sup>	No published psychometric data
Recovery Based Program Inventory (RBPI) <sup>no ref</sup>	No published psychometric data
Recovery Enhancing Environments (REE) <sup>114</sup>	Completed by service users
Recovery Knowledge Inventory (RKI) <sup>143</sup>	Assessed staff knowledge / attitudes
Recovery Oriented Service Evaluation (AACP - ROSE) <sup>108</sup>	Limited psychometric data
Recovery Promoting Relationships Scale (RPRS) <sup>125</sup>	Assessed staff knowledge / attitudes
Staff Attitudes to Recovery Scale (STARS) <sup>144</sup>	Assessed staff knowledge / attitudes

**Table 5.2: Excluded professional-rated measures of recovery orientation**

The four measures meeting all inclusion criteria are shown in Table 5.3.

Instrument	Description
Recovery Oriented Practices Index (ROPI) <sup>128</sup>	ROPI is a 20 item measure which assesses practice in recovery-promoting values. It assesses the following domains: meeting basic needs; comprehensive services; customisation and choice; consumer involvement/participation; network supports/community integration; strengths-based approach; client source of control/self-determination; and recovery focus.
Recovery Oriented Systems Indicators Measure (ROSI) <sup>108</sup>	The ROSI measures the recovery orientation of a mental health system and factors which assist or hinder recovery. ROSI includes a 42 item consumer self report survey and a 23 item administrative data profile. The consumer report measures the following domains: person centred decision making and choice; invalidated personhood; self-care and wellness; basic life resources; meaningful activities and roles; peer advocacy; staff treatment and knowledge; and access. The administrative profile assesses: peer support; choice; staffing ratios; system culture and orientation; consumer inclusion in governance; and coercion. The ROSI uses a variety of response formats including closed-ended questions, Likert scales and open-ended questions.
Recovery Promotion Fidelity Scale (RPFS) <sup>126</sup>	The RFPS was designed to evaluate whether mental health services incorporate recovery principles into their practice. The measure comprises 12 items which examine the following domains: collaboration; participation and acceptance; self-determination and peer support; quality improvement;

and development. All items are rated on a 5-point Likert scale.

Recovery Self Assessment (RSA) <sup>65</sup> The RSA is a 36 item measure which assesses whether recovery-supporting practices exist in mental health services. The measure assesses five domains: life goals; involvement; diversity of treatment options; choice and individually tailored services. There are four versions of the scale for: service users; family members / carers; service providers; and managers. All items are rated on a 5-point Likert scale.

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**Table 5.3: Included professional-rated measures of recovery orientation**

## Quality assessment

Table 5.4 shows the evaluation of the psychometric properties for the four included measures.

Criteria	ROPI	ROSI	RPFS	RSA
<b>Conceptual basis (or target construct)</b>	'Fidelity' to recovery at organisational level	Performance (indicators) of recovery at system level	'Fidelity' to recovery at organisational level	Implementation of recovery oriented practices
<b>Basis for generating item content</b>	Review of existing measures and self-determination theory	Large scale mixed-methods research project	Literature review, concept mapping, expert review	Phenomenological qualitative research
<b>Dimensionality (or composition of measure)</b>	<i>8-domains</i> Meeting basic needs, Comprehensive services, Customisation and choice, Consumer involvement / participation, Network supports and community integration, Strengths-based approach, Self-determination,	<i>8 domains/factors</i> Person-centred decision making and choice, Invalidated personhood, Self-care and wellness, Basic life resources, Meaningful activities and roles, Peer advocacy, Staff treatment and knowledge, Access	<i>5 domains</i> Collaboration, Participation and acceptance, Self-determination and peer support, Quality improvement, Development	<i>9 domains</i> Encourage individuality, Promote positive portrayal of illness, Strengths focus, Use language of hope, Offer treatment options, Support risk-taking, Involve stakeholders, Encourage advocacy, Develop roles and hobbies

	Recovery focus			
<b>Internal consistency (or agreement / correlation)</b>	Not reported	R = 0.95 for full measure	Not reported	5 factors: Life goals .90 Involvement .87 Treatment options.83 Choice .76 Individually tailored services .76
<b>Reproducibility (test – retest)</b>	Not assessed	Not assessed	Not assessed	Not assessed
<b>Content-related validity</b>	Working group comprised service users	Workshop with 45 service users, Think aloud with 10 service users	5 focus groups, brain-storming, stakeholder meetings	Reviewed by service users, providers, family members and researchers
<b>Construct-related validity</b>	Correlation with RSA r = 0.74, p,<0.01	No hypothesis testing	No hypothesis testing	No hypothesis testing
<b>Criterion related validity</b>	Not assessed	Not assessed	Not assessed	Not assessed
<b>Responsiveness</b>	Not assessed	Not assessed	Not assessed	Not assessed
<b>Interpretability</b>	Mean scores and SDs reported	Mean scores reported from pilot phase	Overall score & 4 categories: recovery model fully/moderately/ slightly/not - implemented	Mean and SD reported for summary score and each factor score
<b>Number of items</b>	20	42 self-report; 23	12	36

		admin data profile		
<b>Approx time to complete (mins)</b>	Not reported	30 minutes	Not reported	10 minutes
<b>Reading level</b>	Not reported	Flesh-Kincaid grade 5.7	Not reported	Not reported
<b>Alternative forms</b>	None	None	None	None
<b>Cultural and language adaptations</b>	None	None	None	None

**Table 5.4: Psychometric properties for included measures**

There was variation in the way in which recovery was conceptualised across the various measures. Each measure involved service users in their development. The RSA and RPFS involved stakeholders in the initial stages of their development and also employed further stages of testing such as conceptual mapping, principal components analysis and factor analysis. The development of the ROSI and ROPI measures also employed service users in the initial stages and undertook tests of factor structure. It should be noted that neither the ROSI nor ROPI measures have been published in peer-reviewed journals though they have been presented at conferences, and technical reports detailing their development and administration are available. Correlations for internal consistency are not reported for either the ROPI or RPFS. The internal consistency of the ROSA and the five factors identified in the RSA are high. Construct validity was reported on one occasion only - a strong, positive correlation between ROSI and RSA ( $r = 0.74, p < 0.01$ ). Test-retest reliability and sensitivity to change were not assessed for any measure.

#### **5.4 Discussion: Professional-rated recovery orientation measures review**

This rapid review identified eleven measures which appeared to assess the recovery orientation of services from a professional's perspective. Seven of these measures did not meet full inclusion criteria. Four measures met the eligibility criteria, indicating that some progress has been made towards measuring the recovery orientation of services from a professional's perspective. This review and other studies<sup>27 108</sup> indicate that the psychometric properties of measures need to be tested and investigated before they could be employed with confidence to measure the recovery orientation of services in NI.

No measure adequately captures all aspects of recovery support. Similar to the rapid review that examined measures of service orientation by users (Chapter 3), there was significant variation in the content of the four professional-rated measures. In particular they varied in terms of their conceptualisation of recovery, and the number and composition of domains assessed. Further development and testing of these instruments would be required to ensure that they are appropriate for use in local health and social services.

This review has highlighted that there is no 'gold standard' measure of the recovery orientation of services as assessed by mental health professionals. However, the instruments included here have some merit. For example, the eligible instruments were developed in conjunction with service users and, as a result, have high levels of face validity and acceptability. Measures vary in terms of their length, response format, domains covered and administration methods. Whilst this may reflect a lack

of conceptual clarity, it has led to the development of a range and potential choice of instruments. It may be the case that there are aspects of recovery orientation that are particular to specific groups of service users and settings, or that the relevance of key recovery domains assessed in particular measures will vary depending on the service being evaluated. In other words a particular measure may perform well in one setting whilst failing to achieve the same degree of sensitivity in a different setting – pointing to the need for recovery oriented service-specific measures similar to the condition-specific measures of quality of life that are used alongside generic measures of quality of life in health care evaluation. Service providers and researchers may wish to select a recovery measure that they deem to be suited best to their service users or setting. In addition, there may be the basis for developing a generic or core measure of recovery orientation among the various best available instruments that transcends user groups and settings. Of course, these ideas and research questions must be subjected to debate and empirical enquiry.

There may also be a need to evaluate measures of recovery orientation in a NI context. For example, the Scottish Recovery Network (SRN) was established in 2004 to increase awareness about the potential to recover from mental health problems. Specifically, this arose from the major Scottish government initiative “Rights, Relationships and Recovery” which was designed to inculcate a recovery culture into the Scottish NHS. (The SRN delivers training and acts as a policy advisory to the Scottish government whilst it is also closely involved in implementing the Wellness Recovery Action Planning (WRAP) programme.) One of the (significant) tasks undertaken by the SRN was to develop the Scottish Recovery Indicator (SRI) <sup>129</sup>. Although modelled on the ROPI measure, the SRI was developed to take into

account Scottish language and terminology as well as the development of mental health services in Scotland. The instrument is completed online and requires extensive data collection including reviews of documents, interviews with service providers and with current and previous service users followed by discussion and reflection as part of a SWOT-like analysis. The process of completing the SRI is designed to orient staff towards the recovery approach, and the assessment process is considered to be as important for staff development as the data that it generates. SRI-produced data indicates to staff the extent to which their service is recovery oriented. At a national level, it has been used to demonstrate progress and difficulties towards the implementation of the recovery approach. It is important to note that the rapid review did not uncover any papers that examined the psychometric properties of the SRI, though the description of its development provides an illustration of how an existing measure might be amended and used in a different context and setting.

As noted in Section 1.10, the Bamford Review <sup>26</sup> and subsequent NI policies subscribe to the recovery approach. There is a need to support local health and social care Trusts to meet the challenge of implementing recovery in practice. It would appear that any of the identified measures that might be employed to monitor and improve recovery oriented services would be consistent with existing policies and services in NI, though research and development activity? is required to examine some of the additional administrative complexities and burdens with outcome assessment. For example, Burgess and colleagues point out that it is not always clear which specific professional should complete measures, how the views of different stakeholders should be weighted, or how to respond on occasions when

a consensus may be lacking<sup>27</sup>. A further uncertainty relating to the validity of measures is the extent to which users in services that are rated highly on recovery orientation, experience greater levels of individual recovery than those in non- or low-recovery oriented services.

### **5.5 Conclusions: Professional-rated recovery orientation measures review**

It is not possible to recommend without further testing and development any of the professional-rated measures of recovery orientation for routine use in NI mental health services. Research is required to investigate the psychometric properties of the measures and their applicability and implementation to the NI context.

## 6. Capturing feedback from service users to inform service improvement

In this Chapter we review approaches that employ outcome information provided by mental health service users in feedback to inform and improve care.

### 6.1 Introduction: Capturing feedback review

Mental health services, particularly in the UK, have been relatively slow to embrace an approach to care that involves assessing outcomes routinely and capturing and using service user feedback in ways that might help to improve the process (and experience) of service delivery and promote a shift toward recovery-oriented care.

Gilbody and colleagues found that only 10% of psychiatrists in the UK used standardised outcome measures as part of their routine practice<sup>93</sup>. Whilst routine outcome data collection is “...becoming more widespread, these data are rarely fed back to practitioners – let alone to patients – in meaningful ways”<sup>96</sup>. This may be due to negative evidence that emerged from earlier work, including two systematic reviews<sup>145 146</sup> and two randomised controlled trials<sup>147 148</sup>. Other reasons were reviewed in Sections 1.8 and 1.9. There was a general lack of conviction amongst many clinicians about the merits of outcome monitoring and management systems in general<sup>149</sup>, despite the typically high rates of negative or unchanged outcomes in mental health care<sup>150</sup>. More recent work in this area has illustrated considerable variability in the attitudes of mental health practitioners toward routine outcome measurement, as well as some interesting differences across disciplines<sup>151</sup>.

The feedback of individual outcome information to clinicians and service users is considered to be a central tool of an outcome management system<sup>96</sup>. However, the conceptualisation of 'feedback' across studies is variable. The term 'feedback' may refer to different types of general and specific interventions that purport to effect changes in behaviour or to maintain aspects of positive behaviour. These can range from 'one-off' forms of generic advice or information (verbal and/or written) to more complex, intensive and repeated forms of personalised feedback. There is some evidence regarding the use and effectiveness of feedback to improve staff training and performance/professional practice in the mental health field and beyond<sup>152-154</sup>. Other research has focused on monitoring treatment outcome in mental health care and feeding back this information to clinicians and/or service users (usually across a number of points in time). It is this service user-centred feedback in mental health services that is the focus of this review.

Feedback in the context of this review refers to a two-stage process: eliciting information from service users or others (*e.g.* staff, family members) about their progress, treatment outcome or general functioning, and providing this feedback to relevant stakeholders. It therefore sits within the overall technology of outcomes management (OM)<sup>155</sup>, a healthcare technology proposed by Paul Ellwood in his 1988 Shattuck Memorial lecture, which has been influential across healthcare settings. OM involves the systematic and routine collection of relevant outcome data to produce a 'massive' database, followed by segmentation and distribution of this database to meet the needs of different stakeholders. For example, patient-level progress information would be used to inform care planning, caseload-level data to benchmark performance, and national-level data to inform resource allocation.

Our focus in this review is on evidence relating to use of patient-level data. The rationale for this decision is given in Sections 1.7 and 1.8. In terms of the Pyramid of Benefits shown in Figure 1.1, progress towards Levels 3 and 4 internationally has been very slow. The few regional settings that have reached Level 3, such as the South Verona Outcome Project<sup>99 100</sup>, tend to be atypical with inspirational leadership and workforce skills which may not be present in other settings. There is no good quality evaluative data about use of feedback data at Levels 3 and 4, because it has proved difficult in practice to reach those levels.

Outcome assessment refers to “*the ongoing measurement and use of outcome data to inform decisions about whether to continue, change or curtail treatment*”<sup>103</sup>. A central goal of an OM system is the continuous monitoring of treatment outcome using standardised measures and, ideally, the subsequent sharing of this information among stakeholders<sup>156</sup>. Information from service users may be provided to clinicians for discussion with the service user in a collaborative way. In addition, the feedback process might incorporate users’ views and satisfaction with different aspects of their treatment and care, or with the feedback intervention itself. There is general agreement about the key principles of outcome monitoring in general, such as the use of standardised measures and assessment of multiple perspectives, although there is less consensus on the specifics due to considerable variation in the goals of such assessment<sup>104</sup>. Furthermore, little systematic evidence exists on the nature and extent of patient feedback – as a central component of these types of monitoring systems.

## 6.2 Method: Capturing feedback review

### Key review question

What are the best methods of capturing feedback from patients in order to inform service improvement?

### Data sources and search strategy

The initial scoping search for this rapid review identified a recently completed relevant and high-quality systematic review <sup>31</sup> which we refer to as the '**original review**'. The original review collected data until March 2008, and for this rapid review, was updated by repeating the search for January 2008 to March 2011, which we refer to as the '**updated review**'.

The full methodology is provided in the original review. In summary, Medline, PsycINFO, the Cochrane Central Register of Controlled Trials, the Cochrane Database of Systematic Reviews, the Current Controlled Trials Register and Google Scholar were searched. A broad set of search terms was employed in order to ensure comprehensive coverage and the search terms were modified to suit the requirements of each database (see Box 6.1). In addition, the reference lists of all retrieved papers were hand searched.

1	Feedback.mp
2	Feed back.mp
3	Fed back.mp
4	Feeding back.mp
5	Outcome\$ management
6	Patient-focused research
7	1 OR 2 OR 3 OR 4 OR 5 OR 6
8	Psychotherapy or exp psychotherapy/
9	Psychiatry
10	exp psychiatric hospitals or psychiatric mp. or exp psychiatric patients/ or exp psychiatric clinics
11	Mental health.mp or exp mental health
12	Mental disorder\$.mp. or exp mental disorders
13	Mental disease\$ mp.
14	Mental illness.mp
15	8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14
16	Exp treatment outcomes/ or exp psychotherapeutic outcomes/ or outcome.mp
17	Patient-reported.mp
18	Assessment\$.mp or exp measurement/
19	17 AND 18
20	16 OR 19
21	7 AND 15 AND 20

**Box 6.1: Search terms for Capturing feedback review**

In addition, the reference lists of all retrieved papers were hand searched.

English and German language publications were included in the original review, and only English language papers in the updated review. Eligible studies included adults with mental health problems that were treated in a (community, inpatient or out-patient) psychiatric or psychotherapeutic setting. Feedback was defined as the provision of individual information on outcomes (based on standardised measures) to mental health professionals or service users. Only studies with a controlled design that evaluated the effects of feedback interventions on patient outcome were eligible. In the updated review, three reviewers decided independently whether or not studies should be included, and disagreements were resolved through discussion. Studies in which outcome assessment was used exclusively for routine screening or diagnosis were excluded from the study. All identified papers were entered into Reference Manager, and duplicate papers were removed. Titles were reviewed first and clearly irrelevant titles were discarded. The abstract of each potentially relevant article was obtained and two members of the review team independently screened all retrieved abstracts and achieved 97% agreement. The full text of each relevant paper was obtained and a final decision made about inclusion.

### **6.3 Results: Capturing feedback review**

#### **Original review**

The original review identified 21 studies fulfilling inclusion criteria <sup>31</sup>. Nine were excluded: three could not be located, one in another language, five ongoing. Therefore, 12 studies were included and available for meta-analysis (average

sample size 378, pooled sample size 4,540). Location varied across USA (n=6), UK (n=4) and Germany (n=2), 10 were randomised controlled trials, 10 included people with mixed diagnoses mental illness (primarily affective disorders), 9 were based in out-patient settings, and 10 involved feedback to staff only. Meta-analysis was undertaken to a high standard, with statistical estimation of heterogeneity, random-effects modelling to estimate aggregate effects, and separate modelling for short-term (end of therapy) and long-term (3-12 month follow-up) effects. No evidence for publication bias was found using funnel plots,

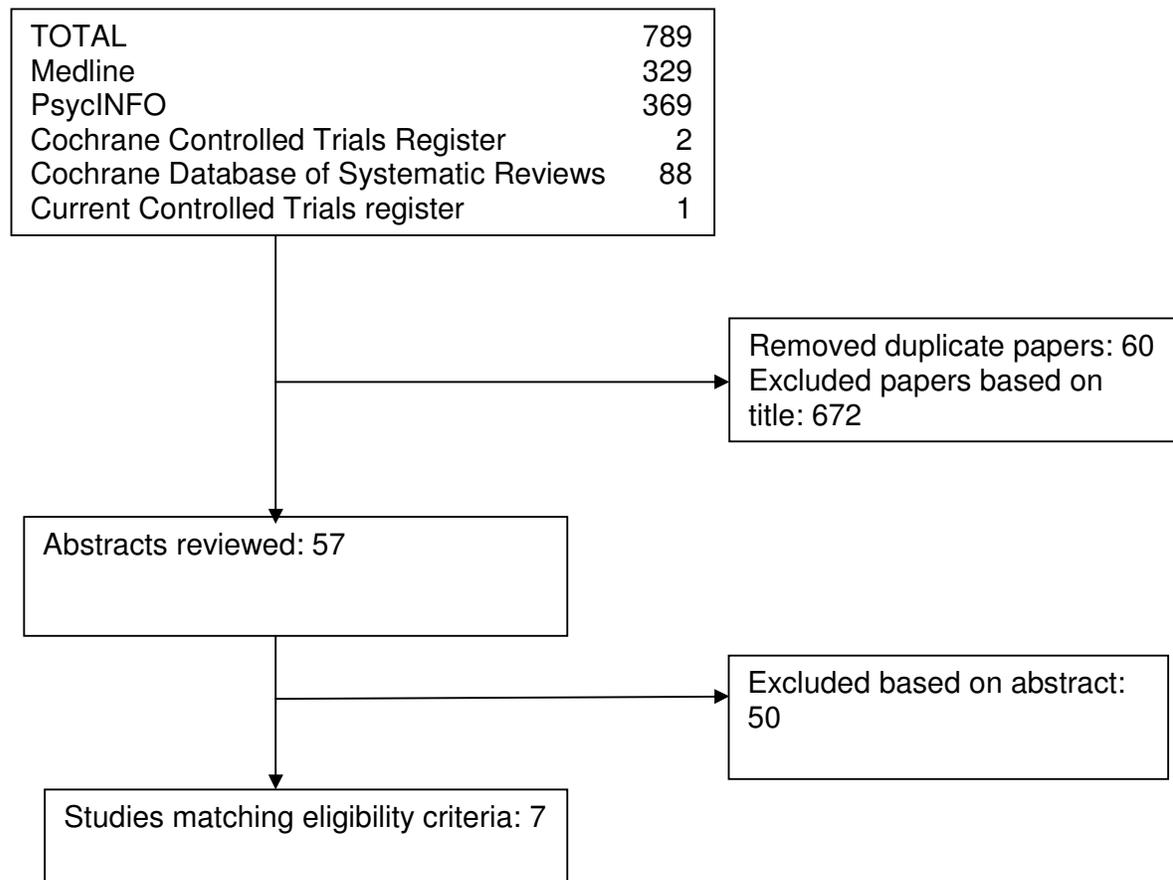
In relation to short-term outcome, feedback of outcome had a small, albeit statistically significant short-term effect on improving mental health outcomes ( $d = 0.10$ , 95% CI 0.01–0.19). This effect was found to be consistent across a variety of outcome measures, and sensitivity analyses revealed that the exclusion of any single study only marginally changed the overall effect sizes of all three analyses, implying relative stability of the results.

In relation to long-term outcome, this effect did not prevail. After termination of treatment and outcome feedback, symptomatic impairment in study participants allocated to control groups was no worse than in those who had received outcome management. On the one hand, this finding suggests that outcome management has no persistent effect on improving mental health. On the other, it could also be interpreted to suggest that it might be wise to continue using outcome feedback at least to some extent after the end of treatment in order to avoid wearing off of short-term benefits. A clear interpretation of this finding was difficult since long-term effects have only been studied in five trials.

Moderator analysis found evidence that feedback was more effective if it was given to both patients and staff (rather than only to staff), was reported at least twice (rather than only once) and comprised information on patient progress (rather than just on current status). Finally, no advantage of outcome management was found with respect to reduction of treatment costs or cost-offset.

### Updated review

The flow diagram for the updated review is presented in Figure 6.1. Seven new studies were identified, as shown in Table 6.2.



**Figure 6.1: Flow diagram - feedback studies**

Author, year (design)	Key elements	Population	Feedback (I)	Usual care (C)	Key results/outcomes
Van Os, 2004 <sup>157</sup> (Multi-national RCT – 7 European centres)	<b>2-COM</b>	Outpatients with schizophrenia (n= 134) Mean age: 41yrs 'Typical outpatient population'	2-COM completed at baseline and approx 6 weeks later	Standard care/ TAU  (but completed questions on quality of clinician-patient communication)	Tested using GAF  Two main outcomes (1) quality of pt report communication & (2) change in clinician behaviour ( <i>i.e.</i> reported changes in management)  Improved pt-clinician communication in intervention group (small to moderate effect size) and greater likelihood of change in clinician behaviour.  Some needs more likely to induce treatment change than others and change more likely in pts with higher need;  Weakness: unable to assess longer term effects on outcome; no masking.
Harmon 2007 <sup>158</sup> (RCT plus quasi-experimental, USA)	<b>OQ-45</b> plus CST measures (therapy relationship,	University counselling centre N=1374 multi-	Therapist feedback only (n=687) Therapist and pt feedback (n=687)	Archival comparison grp derived from random	Focused on 'on track' (at risk) and 'not on track' (not at risk) patients  Feedback to therapists reduced deterioration rates and improved outcomes across clients especially those considered

	motivation and social supports) Computerised	ethnic group. Mean age: 22.65yrs; range 17-58)		assignment in previous studies – no feedback	to be at risk. but no additional outcome-enhancing effects of providing feedback to BOTH clients and therapists.  Feedback works best for 'on track' clients (those not at risk)
Slade, 2008 <sup>159</sup> (RCT, US)	<b>OQ-45</b> and CST feedback to therapists and 'at-risk' clients only Computerised	University counselling service (n=1101 'current' plus 2818 archival) (n=3919) Range of informal diagnoses Age range:22-24	Therapist OQ-45 feedback  Therapist-client OQ-45 feedback	TAU  (No feedback archival group)	Neither progress nor CST feedback to clients improved outcomes. However the timing of the feedback proved to be important (week vs. 2-week delayed groups).
Priebe, 2007 <sup>160</sup> (Multi-national - 6 European countries including UK -	<b>DIALOG</b> manualised system (QoL questionnaire	Community- based – outpatients with long-term	DIALOG completed every 2mths for 1 year	TAU	Primary outcome at 12 months: subjective QoL Secondary outcomes: number of unmet needs and satisfaction with treatment (PANSS symptom assessment) Above outcomes significantly better in intervention group, but

cluster RCT)	covering 11 domains (MANSA) designed to promote patient-clinician dialogue  Computerised	schizophrenia or psychosis (n=507) (Mean age – early 40s); 134 clinicians			small effect sizes and no effect on symptom levels.  No. of consultations ( ) but high follow-up rate (90%) and high levels of satisfaction with (visual) system and without any additional time requirements; also easy to implement.
Puschner, 2009 <sup>96</sup> (Cluster RCT in Germany)	<b>OQ-45 German version</b> (EBS) Weekly computerised assessment - written summary incl. graph to intervention group; clinician received 9 feedback algorithms	Inpatients mainly with affective disorder or schizophrenia (n=294) Mean age: early 40s	Computer entry of EBS (OQ) (symptom distress, interpersonal & social role performance) at weekly intervals and & relayed back to patient & clinician (1-2 days later) and at discharge.	Full range of care options plus EBS system used for outcome monitoring purposes only (no feedback)	EBS/OQ (+ GAF symptom assessment) + evaluation questionnaire  Positive views of EBS - useful for patients who found it to be - motivating/helpful but mixed views re effect on treatment; used less than expected in conversations with professionals.  Computerised tools highly feasible but no effect of feedback on outcome.

Reese, 2009 <sup>161</sup> (RCT, USA)	<b>PCOMS</b> (Miller & Duncan) – 2 measures (ORS and SRS) to track outcomes and therapeutic relationship Computerised	Two client samples at university counselling centre: (n=74) or graduate training clinic (n=74) Age range :20-33yrs	PCOMS completed by client and then discussed with therapist	TAU (no feedback)	PCOMS clients showed statistically significant treatment gains when compared to TAU clients. Also more likely to experience reliable change and in fewer sessions.
Newnham, 2010 <sup>150</sup> (Matched cohort design, Australia)	<b>WHO-5</b> Feedback to clinicians and patients during 10-day group-based CBT	Inpatients (60%), day pts (40%) depression/anxiety (n=1308) Mean age: 39.8yrs	(1) Monitoring measures/feedback at end of therapy (2) Monitoring measures/feedback mid-midway	TAU All 3 cohorts also completed the DASS-12, SF-36 (self-report) and HONOS (clinic report)	Primary outcomes: well being and depressive symptoms  Feedback improved depressive symptoms in both feedback conditions but not anxiety or stress  No effect on well being No effect of feedback on HONOS  Only study to provide group-based feedback.

**Table 6.2: Studies included in the updated review**

In addition, a further five studies were identified which did not meet full inclusion criteria but are related to included studies and help inform understanding about the particular feedback interventions and systems. Two<sup>97 162</sup> were also included in the original review. These are shown in Table 6.3.

Lead author, year (design)	Key elements	Population	Feedback (I)	Usual care (C)	Key results/outcomes
Van Os, 2002 <sup>163</sup> (8 European countries including UK, observational study)	<b>2-COM</b> (19-item self-report needs schedule that assesses areas of need most relevant to severe mental illness)  Computerised	Outpatients with non-affective psychosis (n=243)  Mean age: 41yrs  Subgroup of 95 pt-prof dyads - > profs also asked to rate the needs	N/A	N/A	Strong association between 2-COM and global outcomes  Useful in bridging gap in perception of needs between pts and profs  Extends consultation by 13 mins but viewed positively by over half of profs and 4/5 of pts. Pt satisfaction not related to longer consultation times.  May work best for those who need it most.  No data on whether 2-COM resulted in changes in outcome.
Hawkins, 2004 <sup>164</sup> (RCT, US)	<b>OQ-45</b> (graphical plus written 'progress' feedback (feedback messages	Hospital-based psychotherapy outpatient clinic (n=201); mood and anxiety disorders	OQ-45 feedback to therapists and to patients and therapists (3 psychologists and 2 social workers)	TAU	First study to provide feedback to BOTH patients and therapists  Both feedback conditions led to significantly greater improvement at termination.

	categorised into 13 options). Computerised	formal diagnosis? Mean age: 30.8 yrs			
Van Os, 2008 <sup>165</sup> (Observational study, Belgium, UK, Netherlands)	<b>2-COM</b> Pt and prof-completion of, and rated usefulness of the slightly adapted 2-COM completed at baseline, 2mths and 6mths later	460 outpatients and inpatients with schizophrenia Mean age: 38 yrs	N/A	N/A	Greater patient-clinician discordance predicted less reduction in pt-reported needs at follow-up, but not clinician-reported needs  No control group, 42% attrition, some degree of preparation required to use the 2-COM in routine clinical practice
Schmidt, 2006 <sup>162</sup> (RCT, UK)	<b>MEDS:</b> Intensive repeated personalised feedback add-on to CBT guided self-care: pre-	61 pts with bulimia nervosa/ EDNOS attending Eating	10 weekly CBT sessions – MEDS feedback (n=32)	TAU – no feedback (n=29). Complete d computerised assessments but no feedback	Outcomes assessed before and after treatment and 6months later (SEED – outcome measure)  Added feedback improved outcome with regard to two key symptoms, but no effect on uptake or drop-out from treatment.

	post treatment letters, symptom feedback form, computerised feedback on symptoms every 2 weeks;	Disorders Unit Mean age: 29yrs		provided.	
Slade, 2006 <sup>97</sup> (RCT, UK)	<b>Patient-clinician written feedback</b> Staff-pt pairs completed monthly postal questionnaire/ received postal feedback, 3-mthly intervals; follow-up at 7mths	Representative community patients, mainly schizophrenia, bipolar affective Paired with CMHT staff. Mean age: 41.2 yrs	TAU plus staff-pt pairs completed postal questionnaire (CANSAS-P, MANSA& HAS-P)	TAU (CMHT +GP)	Primary outcomes: needs & QoL – no change. Secondary outcomes: mental health problem severity, symptoms and social disability – no change.  Intervention group had fewer and shorter admissions  Cognitive behavioural impact of intervention at follow-up showed model to be highly valid.  Only study to include cost-effectiveness - intervention found to be cost-effective.

**Table 6.3: Additional relevant studies**

Some identified studies pre-date the end of the original review, but the full list of studies identified in the original review is not given, so it is not possible to identify whether they were identified then excluded or not identified in the original review.

A summary of the 12 (7 eligible, 5 additional) studies identified in the updated review is given in Table 6.4

<b>Properties</b>	<b>Number</b>
<b><i>Location</i></b>	
USA	4
Europe: Cross-national	4
UK	2
Germany	1
Australia	1
<b><i>Setting</i></b>	
Inpatient	1
Outpatient – psychotherapy	4
Outpatient – other	4
Mixed	3
<b><i>Mental health problems</i></b>	
Schizophrenia / psychosis	5
Bulimia Nervosa, eating disorders	1
Other (mixed)	6
<b><i>Design</i></b>	
Randomised controlled trial (RCT)	10
Observational study	2

**Table 6.4: Summary of studies in the updated review**

Follow-up periods for the RCTs ranged from 2 weeks to 12 months. Sample sizes varied from between 61 and 2475 participants. All took place in a range of naturalistic, mainly community-based service settings such as outpatient

clinics (n=6), university counselling centres (n=3) or a specialist mental health (Eating Disorders) unit (n=1). Studies focused mainly on outpatients (n=9), or on a combination of outpatients and inpatients (n=1), inpatients and day patients (n=1), or inpatients only (n=1). Thus, only two studies<sup>96 150</sup> did not include outpatients in their samples. Patients presented with a range of diagnoses including depression, anxiety, eating disorders, schizophrenia and psychosis, although in most studies, patients were at the less severe end of the severity spectrum. Typically, studies used two or more standardised outcome measures as a means of testing the effectiveness of their feedback interventions / tools. All studies used treatment as usual (TAU), or 'no feedback' for the control group comparison (where applicable).

A total of seven different feedback interventions and systems were identified overall, five of which involved the computerised / automated delivery of feedback to both clinicians and patients and three of which were the subject of an ongoing series of investigations. In all but one study<sup>150</sup>, the feedback system incorporated an assessment of need and / or quality of life, although others included additional information on the therapeutic relationship or mental health symptomatology. Information was also usually elicited on client and clinician views. All involved a requirement for, or the possibility of, some level of discussion of feedback with a mental health professional - studies were only considered eligible for inclusion if this element was incorporated into the system due to the focus of the current review. All but one<sup>150</sup> involved individualised rather than group-based feedback formats.

The studies identified in the updated review were organised around particular methods or ways of arranging or implementing feedback. Further relevant studies relating to each feedback arrangement (usually from the same research groups) were included to aid understanding and appraisal of each feedback tool. The review was also organised or grouped according to studies of automated / computerised delivery of feedback (that tended to be carried out as part of larger scale ongoing investigations) versus non-computerised feedback (typically undertaken as single studies).

### **6.3.1 Computerised feedback delivery systems**

#### **The 2-COM feedback system**

A number of continuous computerised feedback systems aimed at different groups of service users were identified and the work of two research groups featured particularly prominently in this regard. The first of these, led by Prof Jim van Os, involved three large multi-national studies in Europe, based mainly on outpatient samples<sup>157 163 165</sup>. Observational studies are included because they comprised a programme of linked studies that collectively addressed the same research topic of feedback. Also, unlike most other studies, they focused on patients with more severe forms of clinical diagnoses such as schizophrenia and psychoses. Their series of studies developed and extended the work of previous authors who showed that the use of simple checklists increased service user involvement in treatment<sup>166 167</sup>.

All three studies by the Dutch group were undertaken to examine the use of a system or tool called the *Two-Way Communication Checklist (2-COM)*; this was designed and developed with the explicit aim of fostering better patient-professional communication in everyday clinical practice. The instrument has been subjected to a fairly robust psychometric analysis<sup>163</sup> and, according to the authors, the use of this tool is necessary because: (1) staff and service user assessments of need often differ<sup>168</sup>; (2) there are strong associations between unmet need and QoL<sup>23 99</sup>; and (3) unmet needs are generally least responsive to service provision<sup>169</sup>. Therefore, it follows that any lack of assessment or miscommunication of unmet needs may have adverse effects and should be monitored and addressed sooner rather than later.

The 2-COM is a 20-item self-report schedule which was developed to identify areas of need most relevant to people with severe mental illness and, in so doing, to facilitate a discussion between service user and clinician around how best these needs may or may not be met. A range of different areas or domains are assessed, including housing, relationships, finances, psychological distress and sexuality. Service users are asked to identify their needs in each area and to rate the extent to which they would like to talk about them. The measure is completed by both patients and professionals prior to the consultation and the content discussed with the clinician during the consultation. Service users were also asked to complete several self-report standardised outcome measures (*e.g.* global well being) at one or more points thereafter, in order to monitor and track changes in need, symptomatology and general functioning over time.

In the first (uncontrolled) observational study (n=243) conducted in 8 countries (including the UK, Germany, Denmark and Spain), service user and clinician participants were asked to: (a) to rate the utility of the tool; (b) the extent to which they felt that the clinician knew more about their problems as a result; (c) whether the tool had identified any potentially problematic areas that had hitherto not been identified; (d) whether the tool had been important in facilitating discussion; and (e) whether or not the subsequent two-way discussion had led to any changes in the treatment plan <sup>163</sup>. There was a strong association between 2-COM (or needs) and global functioning outcomes. Notably, and as predicted, there was a low level of agreement between user and clinician ratings of need and especially among users with higher levels of need. The tool was found to have good face validity though it extended the consultation time by approximately 13 minutes on average. It was also viewed positively by over half of the professionals and 80% of the patients who had used it, though service users were more likely to find it useful and to think that it would impact upon their treatment. Clearly, this has implications for service user engagement in the treatment process and especially for those considered to be most in need.

A second RCT-based study (n=134) was conducted in seven European centres located in Germany, the Netherlands, Italy and France <sup>157</sup>. It was based on a representative sample of outpatients with schizophrenia, and extended the previous study by giving service users a greater opportunity to engage in the evaluation process, whilst also assessing changes in clinician

behaviour. Thus, both intervention (2-COM) (n=67) and control group patients (usual care) (n=67) were invited to provide feedback on: the perceived quality of patient-clinician communication, their views on their relationship with their clinician and attitudes to their illness and care. The results showed that there was a small to moderate improvement in the perceived quality of patient-clinician communication in the intervention group which was maintained six weeks later. Intervention-group clinicians were also statistically more likely to introduce self-reported changes in the treatment process during the period immediately following the 2-COM intervention and especially in patients with the highest levels of need. These findings provide the first evidence of tangible changes in clinician behaviour as a result of a service user-centred feedback intervention. It is also worth noting that some needs, such as the need for information on illness and treatment, were more likely to lead to changes in clinician management behaviour than others.

The third study, another uncontrolled observational study, took place in the Netherlands, UK and Belgium<sup>165</sup>. It is novel in that it is one of only two studies included in this review, that recruited and assessed *both* inpatient and outpatient groups (n=460), again with more serious mental illness (schizophrenia or schizoaffective disorder). This study, based on a slightly modified version of the 2-COM, included a longer follow-up period (6 months) and focused specifically on the impact of the intervention on patient-clinician discordance. The findings indicated, firstly, a negative impact of high patient-clinician discordance on six-month outcomes and, secondly, the role of 2-COM in contributing to a reduction over time on the same dimension. This is

an important finding in view of the typically low levels of concordance (with regard to diagnosis and treatment) in mental health compared to other areas of health and social care, and especially among people with more severe mental illness.

### **The OQ-45**

A second major US-based research group, involving Hawkins, Lambert and colleagues, conducted a series of studies that focused on providing feedback to therapists and more recently to patients attending outpatient psychotherapy clinics. Their earlier research, and a subsequent meta-analysis on feedback to clinicians only, produced convincing results in terms of outcome and cost-effectiveness <sup>170</sup>. Each of the three studies included in the current review, assessed the utility of a patient-focused feedback delivery system based on the use of a self-report *Outcome Questionnaire* (OQ-45) in routine service settings. This was devised specifically by the American team to measure and monitor patient progress (or global functioning) during the course of therapy, to subsequently share the results with *both* therapists and clients and to identify, in particular, any 'at risk' clients or non-responders. According to the authors, the development of this measure was informed by a meta-analysis of the effects of feedback interventions on performance <sup>152</sup> and, as in the case of the 2-COM, an analysis of its psychometric properties has shown good results <sup>171</sup>.

The OQ-45 comprises 45 items, rated on a 5-point Likert scale, which tap into three dimensions including subjective discomfort, interpersonal relationships

and social role performance. The items assess characteristics related to overall QoL as well as symptoms and difficulties commonly experienced in psychological disorders. Total scores are graphed, accompanied by written statements and monitored using a 'signal system' of coloured dots to identify the extent to which a client is progressing as expected and the type of client feedback that should be given; the results can be analysed and fed back quickly to both staff and clients (Immediate Electronic Feedback; IEF) using OQ-Analyst Software. A separate body of work has been conducted to identify relevant norms and cut-off scores for use with the software<sup>172 173</sup>. Interestingly the authors also devised a separate battery of measures and a decision tree called Clinical Support Tools (CSTs) to support therapists and these can be used in conjunction with the OQ-45 in order to enhance the feedback intervention<sup>174</sup>. These comprise four brief measures of therapeutic alliance, motivation and social support, as well as information on diagnostic re-formulation and referral. However, the studies reviewed here focus only on those which involved the sharing of patient progress information with patients as well as therapists.

The first of these was a pragmatic RCT involving a typical sample of outpatient mainly with mood and anxiety problems (n=201)<sup>164</sup>. It was the first study to assess the therapeutic effects of providing systematic feedback to service users in psychotherapy. A central hypothesis was that the greater involvement of service users in their treatment and the attendant development of the therapeutic alliance, would lead to better outcomes, both of which, would also be clearly relevant to the promotion of a recovery-oriented service.

Service users were randomly allocated (using therapists as the blocking variable) to one of three arms of the trial: two feedback intervention conditions (therapist only, n=70; and therapist and service user, n=67) and a control condition (no feedback - treatment as usual (TAU); n=64) and assessed before, during and after treatment. Feedback in the service user-therapist condition was supplemented, where possible, with a discussion with the service user (although this element was not monitored in the study). A total of five therapists were involved (two social workers and three psychologists). Potential non-responders were encouraged to discuss their concerns, progress and treatment goals with therapists in order “further facilitate the collaborative alliance”. Almost all service users (99%) rated the feedback highly and the results showed that the provision of feedback to both service users and therapists improved outcomes when compared to the therapist only and TAU conditions (moderate effect size,  $d=.33$ ). Importantly, they also found that service users expressed a strong interest in receiving this kind of progress information and despite their high levels of distress, were able to deal with, and were not negatively affected by, the objective feedback they had received on their progress. However, unlike their previous work, they found no benefits for treatment ‘non-responders’, a finding which they attributed to a lack of statistical power.

A subsequent study failed to replicate these findings using a similar design in a sample of clients who were attending a university counselling centre (n=1,374) when compared to a ‘no feedback’ archival control group (n=1,445)<sup>158</sup>. On this occasion, feedback to therapists (n=72) was enhanced by using

the CSTs, but the results suggested no additional benefits of providing weekly progress feedback to both clients and therapists as opposed to therapists alone. However, the authors acknowledge that most of their sample were less disturbed than in the first study described above and that this may have accounted for the difference. Again, therapists were encouraged, but not required to discuss the results with the client and this element was not monitored in the study.

The final study conducted by the OQ-45 group extended the work described above by exploring the effect of the timing (1- or 2-week delayed) of weekly computerised progress and enhanced CST feedback to three groups<sup>159</sup>. They looked at week-delayed (n=1,374) versus immediate electronic (1,101) feedback. Hence the first of these included 'therapist only' (n=687), 'therapist and patient' (n=687) and an archival 'no feedback' control group (TAU). The total sample, the largest in the current review, totalled 2,475 patients. The authors were particularly interested in those considered to be most at risk or 'not on track'. They found that progress feedback relayed directly to service users did not improve outcomes when compared to the other groups, a finding consistent with one previous study<sup>158</sup> and inconsistent with the other<sup>158</sup>.

The most recent study on the OQ and the only independent replication of the above work (outside a US context), was undertaken by Bernd Puschner and colleagues in Germany<sup>96</sup>. They designed and implemented a cluster RCT to assess the effectiveness of the adapted German version of the OQ, which they called the EB-45 (*Ergebnisfragebogen 45*). They administered this to 294

adult psychiatric inpatients as part of their EMM trial (Outcome monitoring and outcome management in inpatient psychiatric care). Most patients presented with affective disorder, although one third had a diagnosis of schizophrenia. A total of 48 clinicians were randomised to the intervention (n=22) or control group (n=26). All patients in the intervention group were asked to complete the (computerised) measure at admission and then very week until discharge. There were some subtle differences between this system and the OQ described earlier in that clinicians were regularly invited to take part in “quality circles” facilitated by researchers, in order to discuss the EMM feedback in a collaborative and co-operative format, whilst patients were also asked for their views. Treatment adherence was high (80%). At discharge, clients’ views of the EB-45 clients were overwhelmingly positive with the great majority indicating high levels of satisfaction with the quality, length, accessibility and personal relevance of the content, as well as the helpfulness of feedback received; views were more mixed, however, about any perceived treatment-related effects and there was no effect of the intervention on patient-reported outcomes during inpatient care. Furthermore, most patients reported that feedback was only rarely discussed with staff. The researchers acknowledged that they had no control over this and they also reported the aversion of clinicians to the use of the treatment recommendations.

### **The P-COMS**

A more recent extension of the above series of studies involved the development of a continuous feedback delivery system called the Partners for Change Outcome Management System (PCOMS) <sup>175</sup>. This is based on two

brief four-item measures – the Outcome Rating Scale (ORS) and the Session Rating Scale (SRS) – which were devised to track outcomes and the therapeutic relationship/alliance respectively. These are based loosely on the OQ-45 although there are a number of important differences between the two. Aside from its relative brevity, the PCOMS is designed to be an integral element of therapy and may be used to monitor and assess the therapeutic relationship on a session-by-session basis with a view to providing, if required, an immediate response. Importantly within the context of this review, the feedback that was generated - which took the form of detailed graphical outputs - was also used to form the basis of a collaborative, shared discussion between therapist and service user. General guidelines were also provided to assist therapists to relate to service users who were not responding appropriately to treatment (i.e. who did not show ‘reliable change’).

Similar to the OQ-45, feedback was automated using a system called SIGNAL (Statistical Indicators of Growth, Navigation, Alignment and Learning) which uses a traffic light signal to provide ‘real time’ alerts to staff, of ‘at risk’ clients. The initial research study <sup>176</sup> is not included in this review as it involved a telephone-based counselling service as part of an international Employee Assistance Programme in the US and did not, therefore, involve face-to-face contact in mental health service settings with ‘regular’ patient populations (n=6,424) <sup>176</sup>. Despite plausible arguments by the authors that the provision of such services - which are growing in popularity - is comparable in large part, to face-to-face assessments, the evidence is equivocal in this regard and much future work is required. Nonetheless, it is worth noting that initial

psychometric work on PCOMS has been positive and the use of the system with the above sample during a two-year period, led to significant improvements in client retention and outcome.

A subsequent and more relevant, albeit smaller, controlled study replicated the above research in two successive studies involving client samples who were receiving therapy from a university counselling centre (n=74) and a graduate training clinic (n=74) respectively <sup>161</sup>. Patients from the first study were randomly assigned to either a 'feedback' (PCOMS) or 'no feedback' (TAU) condition and assessed before and after treatment. In the second study, therapists were randomly assigned to the feedback and no feedback conditions. Therapists received a one-hour training session in advance. In both feedback conditions, progress was monitored, graphed and discussed immediately with the client during every session. The results showed that those clients who had used PCOMS showed statistically significant improvements in treatment outcome (at the end of treatment) when compared to those who had received no feedback. They were also statistically more likely to experience 'reliable change' by the end of treatment. In both studies, the improvement in the 'feedback group' was twice that of the 'no feedback' group with medium to large effect sizes reported (d=0.54 and 0.49). These findings suggest that the continuous outcome assessment facilitated by the PCOMS led to better outcomes in clients and not only those considered to be most at risk. Interestingly, this distinguishes the study from those described earlier and raises questions about the reasons underpinning this difference. For example, it has been suggested by the authors that the OQ-45 system

only incorporates an assessment of the therapeutic relationship in at-risk clients as opposed to all clients. However, the above study is limited by a small sample size whilst the authors indicate that data were also missing for a substantial number of clients. Neither was there any attempt to monitor treatment fidelity (*i.e.* the extent to which the system was being used in the way it was intended).

### **The DIALOG tool**

The largest study to be conducted in Europe involved the use of a cluster RCT to pilot test an automated, manualised system called DIALOG in a large community-based sample of people with chronic schizophrenia and related difficulties (n=517) <sup>160</sup>. This new system, developed over a two-year period, was designed to promote better structured communication between key workers or clinicians (n=134) and service users in routine practice by incorporating both visual and auditory feedback. Service users were invited to rate, on a two-monthly basis, their levels of satisfaction with 11 domains of perceived/subjective quality of life (*e.g.* mental and physical health, leisure activities, social support, medication) as well as their unmet needs for care and satisfaction with treatment at 12 months. The results were graphed and discussed between clinicians and service users with an explicit focus on users' views and options for treatment. The above outcomes were assessed using standardised measures including the Manchester Short Assessment of Quality of Life (MANSA) <sup>17</sup> and the Camberwell Assessment of Need Short Appraisal <sup>101 177 178</sup>. Clinicians were randomly allocated to either the intervention or TAU.

The findings showed that, at 12-month follow-up, the (feedback) intervention group when compared to their 'no feedback' control group counterparts, had significantly higher levels of subjective QoL, a lower level of unmet need and a higher degree of satisfaction with treatment, but with no changes in overall symptom levels. Whilst the effect sizes were small (0.20-0.27), further sub-group analysis with those patients deemed to be most 'at risk' (n=195), revealed moderate effect sizes with respect to both QoL (0.43) and unmet need (0.52), thereby supporting previous findings<sup>157</sup>. However, as in most other studies, no attention was paid to monitoring treatment fidelity. This study had a number of key strengths including: its large sample size; its implementation across a range of health care contexts; a high follow-up rate (90%); the requirement of little additional time required by clinicians to use the system; and the incorporation of a longer term follow-up. The authors also argue for the simplicity, brevity and non-intrusiveness of the DIALOG system, its inexpensiveness and practical utility.

A related small-scale RCT conducted in the UK assessed the extent to which a type of *multi-component feedback tool* or arrangement comprising intensive personalised individual feedback added to a 14-week guided cognitive behavioural (CBT) self-help programme made a difference to user outcome<sup>162</sup>. This study differed from other studies in several important ways: (a) it was based on an intervention that was tailored specifically to patients with a particular disorder – in this case, bulimia nervosa and other eating disorders; (b) it involved several forms of feedback/information exchange; and (c) regular

computerised feedback on a range of bulimia-specific and generic psychological symptoms was provided to patients throughout treatment.

This multidimensional feedback intervention comprised several elements including: two detailed and carefully worded personalised letters to the user before and at the end of treatment; the completion by patients and therapist together, of a specific symptom feedback form mid-way through treatment (focusing on several domains including behaviour, cognition, affect and interpersonal functioning); and the provision, on a fortnightly basis, of both normative and personalised computerised feedback on symptoms (bulimia and depression and anxiety) – based on three standardised questionnaires. The tone and content of the letters, the collaborative approach to discussing symptoms and the regular provision of symptom-related feedback, are all important elements which are markedly consistent with the ethos of a recovery-oriented intervention/service. For example, the first letter focused on current problems as perceived by the patient and the impact of these on their life, their hopes and fears of a positive/negative outcome, factors that might increase hope for recovery and treatment-related information. Importantly, according to the authors, “*special emphasis was put on identifying what clients could do for themselves*”. A summary of the patient’s life story (with a focus in strengths and difficulties) was also included and a range of treatment options and identified. Notably, the researchers also paid close attention to treatment fidelity by providing training in letter writing and delivering feedback whilst weekly supervision was available during treatment. The important issues of training/supervision fidelity have been relatively neglected in

feedback studies, to date, despite the fact that these, arguably, are key quality assurance mechanisms. Sixty-one patients in the study were randomly allocated to the 'feedback' or 'no added feedback' condition and three outcome measures (on eating disorders and anxiety/depression) were then completed before and after treatment and six months later.

The results showed no effect on service uptake or attrition, although an improvement in outcomes was observed with regard to self-induced vomiting and dietary restriction, both of which, as indicated by the authors, have been found to be predictive of positive longer term outcome in bulimia nervosa. The authors hypothesised that uptake was negatively influenced by a protracted delay (often several weeks) between assessment and contact with a therapist; the extent to which this was indeed the case, is an obvious direction for future research. This kind of multi-component feedback also merits further investigation, perhaps using the MRC Framework for Evaluation of Complex Health Interventions<sup>179-181</sup> as a scientific framework.

### **6.3.2 Non-computerised feedback delivery systems**

Two other types of feedback arrangements merit consideration. These focused on *non-computerised feedback* tools which were implemented and assessed on a 'one-off' basis only.

The first type of non-computerised feedback arrangement was the FOCUS Study, which comprised *written feedback* (via surface mail) to outpatient-clinician pairs on needs, quality of life, mental health severity and therapeutic

alliance<sup>97</sup>. The intervention was evaluated over a 7-month period using an RCT conducted in the UK. Participants tended to have typically more severe disorders such as schizophrenia, bipolar affective disorder and other psychoses. All intervention group outpatients (n=101) were invited to complete a monthly postal questionnaire comprising three standardised measures of quality of life (MANSA<sup>17</sup>), needs (CANSAS<sup>101</sup>) and therapeutic alliance (Helping Alliance Scale (HAS)<sup>182</sup>). Likewise, all participating clinicians were asked to complete three measures of severity (Threshold Assessment Grid<sup>183 184</sup>), needs (CANSAS<sup>101</sup>) and therapeutic alliance (HAS<sup>182</sup>). Identical feedback was then provided at three-monthly intervals to both groups to illustrate changes over time in the form of colour-coded graphics and text and highlighting areas of disagreement. The 'no feedback' control group (n=59) were provided with TAU. However, unlike the other 11 studies included in this review, the intervention did not include a formal requirement for a two-way discussion of the information between clinicians and users although this was a possible outcome of the model. All researchers received standardised training by means of, for example, role play, vignettes and assessment-based observation and a number of user assessments were also double-coded to check reliability. Importantly, this study was unique in the context of this review with regard to its additional inclusion of a cost-effectiveness analysis which yielded an average cost per user of £400.

The findings on outcomes showed no effects of the feedback intervention on either the primary outcomes (QoL and unmet need), or secondary outcomes (mental health severity, symptoms or social disability). However, the

intervention group patients had fewer hospital admissions with greater cost savings, indicating that the intervention was cost-effective. Data on the perceived cognitive and behavioural impact of the intervention/model revealed generally very positive views from both staff and users with regard to its content and accessibility and in raising awareness of the staff-user relationship, although only around one third of users felt that the receipt of feedback had led them to discuss the content with staff whilst fewer than one in five had changed their behaviour as a result. The authors surmised that the fall in admission rates may have been due to the greater availability of information for staff in the feedback condition, although a need for further research is indicated. Notably, the authors also highlighted a lack of continuity of care (as indicated by a high staff turnover rate at follow-up (26%)) and a progressive decline in staff return rates, as barriers to successful implementation of the intervention. They also identified the feedback 'gap' as perhaps too long to be optimally effective and the follow-up period of 7 months potentially too short to see meaningful changes in service utilisation.

The second type of non-computerised feedback arrangement was developed in Australia <sup>150</sup>. This approach involved the development and evaluation of a *WHO-5 feedback system* for use in a sizeable sample of both day (40%) and inpatients (60%) (n=1308), most of whom had either depression or anxiety. They adapted the World Health Organisation Wellbeing Index (WHO-5) <sup>185</sup> to monitor user progress in a two-week CBT programme and to feed back the information to clinicians and users. The WHO-5 is a measure of positive well being and mood which has performed well with mental health service users.

Three well known outcome measures (SF-36 <sup>186</sup>, HoNOS <sup>187</sup> and DASS-21 <sup>188</sup>) were already being used routinely by the clinicians who took part in the study. This study used an historical cohort design (non-randomised – cohorts matched on severity) recruited over a four-year period in order to recruit and assess the following three groups: (1) users completed the three outcome measures but not the WHO-5 (n=461); (2) users completed the outcome measures and the WHO-5 and feedback was provided to the user and clinician at the end of therapy (n=439); and (3) users who completed the WHO-5 routinely during therapy, but were provided with feedback on their progress at day 5 and day 10 (n=408). Feedback comprised a graph plus an explanation provided to both clinicians and users, followed by a group-based discussion around the interpretation of the graphical output and attendant scores and how the feedback might be helpful in assessing progress and treatment goals. This study is notable in that it was the only one of the 12 here that assessed the provision of feedback in a group scenario.

There was no effect on well being or general functioning at the end of treatment for those who received feedback when compared to those who did not. However those users at risk of poor outcome (*i.e.* who were deemed ‘not to be on track’) showed a significant improvement in depression, vitality and role emotion scores when compared to those who were on track for improvement. The tool was also viewed positively by the staff who took part in the study in the extent to which it was perceived to improve treatment planning and goals, promoted greater dialogue between clinicians and users

with regard to progress and expectations, whilst also facilitating better communication with the other members of the treatment team.

#### **6.4 Discussion: Capturing feedback review**

Increasingly, service user monitoring and feedback systems are regarded as an important addition to routine mental health provision and delivery. However, collectively, evidence suggests that they remain under-utilised and under-researched<sup>150 160</sup>. In particular, there is very little research evidence on how feedback systems might be developed and used to promote more effective communication between users and mental health professionals in a way that is consistent with the principles of a recovery-oriented approach.

The review identified seven new studies and five related studies in addition to the studies identified in the original review<sup>31</sup>, which were conducted by researchers in a wide range of European and non-European countries and across different routine service settings. Seven different user feedback delivery interventions, tools or systems were identified and evaluated in a variety of service user groups, although with a particular emphasis on outpatients with less severe affective problems. There were similarities across the seven systems in terms of the type of feedback provided (need, quality of life, general functioning, symptomatology, severity), the use of standardised outcome measures to test for effectiveness, and the sharing and discussion of feedback between staff and users. There was also considerable heterogeneity across identified studies and systems, making meaningful comparison difficult.

There are also a number of important limitations of the body of research reviewed here. For example, whilst the aggregated sample size across studies is very large, it is based on only a small number of studies conducted by several individual research groups. Furthermore, only one feedback intervention system was subject to independent replication (the OQ-45<sup>96</sup>). Neither is it possible to be conclusive about representativeness in terms of user characteristics, types of mental health problems, or severity, all of which might introduce a source of bias and which preclude any kind of meaningful sub-group analyses to examine differential effectiveness by, for example, service user group/setting. Furthermore, whilst the quality of the studies was generally high in the form of RCTs, the unit of randomisation was normally the service-user and, therefore the possibility exists that some element of cross-contamination might have reduced the 'real' effects of the intervention<sup>31</sup>. Blinding was also not possible in most RCTs.

Nonetheless, the collective findings reviewed here are informative and useful on a number of fronts. The groups of studies and systems might be assessed and compared with regard to their overall impact along the following key dimensions: (1) symptoms, general functioning, need/unmet need and QoL; (2) effect on other indicators of impact relating to, for example, admission rates, service uptake and levels of attrition; and (3) the attitudes and views of both users and clinicians with respect to general utility, ease of implementation/use, impact on treatment, improving two-way communication etc.

#### 6.4.1 Effectiveness of feedback

On balance, the evidence that is available suggests sufficient positive findings to merit further investigation. The original review used robust meta-analytic investigations to demonstrate short-term benefits. In the updated review, half of the studies - pertaining to 5 of the 7 interventions, (2-COM, OQ-45, PCOMS, DIALOG and MEDS) - reported positive outcomes for people who received the intervention. Improvements were reported in quality of life, unmet needs and specific groups of symptoms. Three of these studies (utilising the 2-COM, OQ-45 and DIALOG) were based on sizeable samples and all involved computerised feedback delivery. Effect sizes, when available, were small to moderate. It should also be noted that two of the three studies on the 2-COM<sup>157 163</sup> were undertaken specifically to assess user and clinician views and any concomitant changes in clinician behaviour, rather than user outcomes *per se*. The findings from the remaining six studies were more mixed with respect to outcomes, in that positive outcomes for those who received the intervention were either absent or limited to a specific group of symptoms only<sup>96 97 159 162</sup>, or in evidence for only an 'at risk' subgroup of people considered to be at risk of deteriorating over time<sup>150 158</sup>.

The last of these is interesting in that it suggests that users with the greatest scope for improvement might benefit most from these kinds of feedback interventions, perhaps because they are less able to communicate their needs, or may have more difficulty in identifying their needs<sup>158</sup>. This is challenged by a finding from one of the RCTs that *higher* pre-morbid IQ was associated with increased response to the intervention<sup>189</sup>.

There is a hint that the follow-up periods in this body of research may have been too short to allow real tangible changes in outcome to materialise. This suggests a need for research into medium and longer-term outcomes in a range of user populations in more diverse settings. Other benefits were also reported in relation, for example, to lower admission rates and greater cost savings in the intervention group patients<sup>97</sup>. Studies tended to be limited by a lack of longer term follow-up and a general neglect of issues related to fidelity and economic evaluation.

#### **6.4.2 Feasibility of feedback**

The evidence is convincing with regard to the feasibility and practical implementation of these systems and their benefits in relation to the cognitive and behavioural aspects of care. For instance, all the systems/interventions, though with differing points of emphasis and content, appeared relatively straightforward to incorporate into routine practice and were highly accessible to both users and staff. Thus, the evidence appears unequivocal with respect to the potential that exists to devise and apply brief, easy-to-use measures, typically with an element of computerised refinement, which would appear to present no difficulties for users or staff and which are generally viewed positively by those who use them. Users with a range of different mental health problems and with varying severity appeared to be able and willing to engage meaningfully with the systems. The staff who used the computerised systems received some form of training or instruction and, in general, they were positive about the utility of these systems or interventions, not only in

alerting them to their clients' (met and unmet) needs, but also in improving the flow, and enhancing the quality, of information between them and service users. The psychometric work on the computerised systems also appears to have yielded satisfactory results. The issue of how to ensure the regular recording of feedback information and the use of computer systems to record and audit this process on a large scale is worthy of further investigation.

It must also be remembered that half of the studies included in this review, were conducted in the US or Australia. Attitudes amongst mental health professionals toward outcome management systems, as noted in Section 1.8 and 1.9, are in general less positive in the UK. Indeed, the three studies by Lambert and colleagues are an example of successfully securing 'buy-in' from therapists on the importance of using progress feedback in routine clinical practice and in contributing toward the promotion of a 'culture' of supporting the use of these kinds of tools across a number of settings. There may be useful generalisable lessons from this work for other mental health services elsewhere and especially in Northern Ireland. However, this research focuses only on the field of psychotherapy and the American group also focused on student populations. It is likely, therefore, that some of the mental health problems presented may differ in type and severity from those experienced by people using NHS mental health services.

#### **6.4.3 Routine outcome assessment and recovery**

Does collecting and using patient feedback specifically support recovery? A recurring finding throughout all studies reviewed here relates to the role of

these systems or interventions in promoting better communication and dialogue between staff and users, involving users more in the process of treatment planning and delivery (giving them ‘a voice’) and in strengthening the therapeutic relationship. Feedback monitoring and delivery systems can “...improve safety issues, increase the reliability of outcome measurement and foster a more collaborative relationship between clinician and patient”<sup>150</sup>. Overall, the evidence indicates that service users were much more involved in their care, not only through the provision of more information or feedback to them, but also by means of active discussion of this information with their clinician or key worker in a collaborative format. Arguably, these aspects or elements are consistent with the recovery approach and reflect the practice of three of the four critical recovery values outlined by the Centre for Psychiatric Rehabilitation (<http://www.bu.edu/cpr/about/index.html>) which focus on person orientation, personal involvement/partnership in recovery and self-determination/choice in the recovery process. Therefore, in this respect alone, the incorporation into routine practice, of these kinds of feedback systems/interventions, would appear to play an important role in developing, providing and delivering recovery-oriented services and especially in the extent to which they contribute toward developing more empowering forms of services for service users, whilst also encouraging more reflective practice amongst mental health professionals.

Similarly, the 2-COM ‘structured communication’ system was developed to improve user-therapist communication and to promote subsequent changes in care. Thus, potentially, it may have a practical and intuitive appeal in the

context of promoting a recovery-based approach. It includes a detailed and wide ranging assessment of need which, despite extending the average consultation time by 13 minutes, was viewed positively by both therapists and users alike. This system appears to be particularly well suited to users with more severe and persistent mental health problems such as schizophrenia and affective psychosis. It also shares some similarities with DIALOG and OQ-45, both of which also focus on people with more severe diagnoses. Each of these systems – as well as the P-COMS and the MEDS - appear promising in the extent to which they provide a brief, accessible and sophisticated means of eliciting feedback from clients and enabling a subsequent shared discussion - between service users and staff - around tangible computerised written and graphed feedback.

The issue of the relationship between feedback and recovery has begun to be explored. A recent book chapter presented three international case studies of routine outcome assessment in support of recovery <sup>190</sup>. One relates to the FOCUS Study, which was described in Section 6.3.2. The other two case studies relate to work not identified in the original or updated review - the first because it brings together a programme of work not published in a single paper, and the second because it was published online in April 2011, after the end of the updated review period (March 2011). The two case studies in the book chapter <sup>190</sup> are reproduced here.

#### 6.4.4 Case Study 1: The Collaborative Recovery Model and AIMhi study

Notwithstanding the increasing interest in personal recovery and recovery oriented services, there are few practice models, particularly which seek to combine personal recovery principles and evidence based practices in mental health. Moreover, a recent review of research into case management<sup>191</sup> demonstrated that only one of 13 outcome studies investigated user perspectives at all. The Collaborative Recovery Model (CRM)<sup>144 192</sup>, developed in Australia by a combination of mental health researchers, practitioners and service users seeks to combine key skills that are supportive of personal recovery and clinical recovery. The development and implementation of the model included the requirement that all six parts of the model be operationalised and include the potential for quantitative measurement as part of routine clinical practice. A key aim of this approach is to bridge the previously assumed dichotomy between personal recovery and evidence based practice<sup>193</sup>. The components of the model and its operationalisation and measurement are illustrated in Table 6.5.

<b>Component of CRM</b>	<b>Protocol and outcome measurement</b>
1. Recovery as an individual process	Stages of Recovery Instrument (STORI)
2. Collaboration and autonomy support	Working Alliance Inventory (WAI)
3. Change Enhancement	Decisional balance worksheets
4. Needs Identification	Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)
5. Collaborative Goal Striving	Collaborative Goal Technology (CGT)
6. Collaborative Homework & monitoring	Homework Assignment

**Table 6.5: Components of the Collaborative Recovery Model (CRM) and its quantitative measurement possible as part of routine clinical practice**

As one part of the Australian Integrated Mental Health Initiative (AIMhi), the Collaborative Recovery Model (CRM) was trialled across four states of Australia in 12 different community-based adult service settings, from government and non-government organisations in metropolitan, regional and rural sites. Inclusion criteria for consumer participants were a diagnosis of schizophrenia, schizoaffective disorder or bipolar disorder of at least 6 months duration and high support needs, with six or more needs identified using the CANSAS. Individuals with dementia, severe mental retardation or brain injury were excluded. Co-morbid substance misuse or personality disorders were not excluded. Following baseline, data collection was at 3 monthly intervals, consistent with national routine data collection. Measures included the Health of the Nation Outcome Scales (HoNOS), Life Skills Profile (16-item) and Kessler-10, and the Recovery Assessment Scale.

AIMhi particularly focussed on the use of the Collaborative Goal Technology and Homework Assignment worksheets as part of routine clinical practice. The goal striving component is now described to demonstrate the role of routine outcome measurement to directly support personal recovery and to indirectly support clinical recovery. The personal recovery process involves personal choice and growth, in which goal striving is ubiquitous. Goals are linked to the aforementioned key aspects of recovery; hope, meaning, identity and personal responsibility <sup>40</sup>. That is, collaborative goals when set

appropriately are a key part of the personal recovery process. Hope and goals are closely linked. Personal meaning and identity are often expressed via personal goals. The act of setting and working towards a goal is indeed related to personal responsibility.

The Collaborative Goal Technology (CGT) <sup>194</sup> was used to operationalise the collaborative goal setting, striving and review process between staff and service user pairs. Derived in part from Goal Attainment Scaling, the CGT involved staff and service user collaboratively identifying up to three goals, which were reviewed after three months. Three-monthly periods of review were set to be consistent with other routine outcome measurement data collection. Based on a utility (value) model, service users were asked to rate the relative importance of each goal by assigning a total of ten points across the goals sets. Upon review each goal was rated for its level of attainment across three levels defined previously by staff member and service user. This is illustrated in Figure 6.2.

My personal recovery vision is: <i>To stand on my own two feet</i>				
<b>Stage 1</b> <b>Meaningful</b> <b>Vision and</b> <b>Goals</b>	<b>ATTAIN</b> Point allocation must total 10	<b>GOAL 1</b> <i>To do my own shopping</i> Perceived Importance points = <input type="text" value="5"/>	<b>GOAL 2</b> <i>To find a job</i> Perceived Importance points = <input type="text" value="3"/>	<b>GOAL 3</b> <i>Improve medication taking</i> Perceived Importance points = <input type="text" value="2"/>
	<b>Awesome</b>	<i>To do my shopping at least once by myself</i> <input checked="" type="checkbox"/>	<i>Go to the return to work program</i> <input type="checkbox"/>	<i>Complete a medication diary more than 3 times per week</i> <input type="checkbox"/>
	<b>Success</b> >70% confident	<i>To do my shopping at least once with a friend</i> <input type="checkbox"/>	<i>Go to first appointment with employment assistance service</i> <input checked="" type="checkbox"/>	<i>Complete a medication diary up to 3 times per week</i> <input type="checkbox"/>
<b>Stage 2</b> <b>Manageable</b> <b>Goals</b>	<b>Keep Going</b>	<i>To do my shopping with my case worker</i> <input type="checkbox"/>	<i>Continue discussing employment goal with case-manager</i> <input type="checkbox"/>	<i>Remember to take medication</i> <input checked="" type="checkbox"/>

Figure 6.2: Example of completed Collaborative Goal Technology

This enables an idiographic measurement of goal attainment to be calculated, which is weighted by service user defined value. This score is called the Collaborative Goal Index. Two points are awarded for attainment of a goal at the highest level, one point for the middle level, and no points for the lowest level. The Collaborative Goal Index is a percentage score, calculated as five times the sum of each attainment x importance score. Hence in Figure 6.2 the Collaborative Goal Index is  $5 \times ((2 \times 5) + (1 \times 3) + (0 \times 2)) = 65$ . The score is a function of level of goal attainment, anchored by perceived difficulty, then weighted by subjective importance.

In addition to calculating the index, staff members and service users were asked to discuss and identify issues that may have impacted on thwarting their goal attainment. Sixteen options were provided for example; *“I found a better goal”*, *“Goal was too difficult”*, *“People criticised me for having this goal”*. This qualitative component added to the clinical utility of the routine instrument, by informing the next goal setting cycle.

Whilst many staff and service users are familiar with goal setting, the routine use of the full cycle of goal striving, in which individual goals are set and then their attainment is systematically and quantitatively reviewed, is less common. Training in the use of Collaborative Goal Technology demonstrated a transfer effect for staff members in using evidence based goal setting principles in their general case notes and documentation. In a related study, an audit tool, the Goal Instrument for Quality (Goal-IQ) <sup>195</sup> was used to review 122 goal records in several eastern Australian mental health services as part of AIMhi.

Seventy-four percent of people in recovery had a documented goal record and these records had 54% of the evidence-based goal-setting principles measured by the Goal-IQ. It was demonstrated that staff trained in goal setting showed significant improvements in the frequency and quality of documenting goals.

Routine use of tools such as the Collaborative Goal Technology are likely to provide useful empirical linkages between nomothetic clinical definitions of recovery and idiographic aspects of personal recovery. Whilst goal setting is often conceptualised as an intervention or a process, goal attainment by definition is quintessentially an outcome. At the time of writing further research is investigating (a) the relationship between the level of goal attainment and symptom distress; and (b) the types of goals service users are setting with staff members and how they relate to stage of recovery.

Our second Case Study involves an intervention at the point of discharge from hospital.

#### **6.4.5 Case Study 2: The NODPAM Study**

There is broad consensus that relapse prevention is one of the major aims of aftercare. However, the success of attempts to reduce high re-hospitalisation rates in people with severe mental illness has been limited so far. Insufficient discharge planning and follow-up is considered one of the main reasons for limited community tenure and unfavourable clinical outcomes<sup>156 196</sup>. There is

a lack of specific interventions targeting the needs of high utilisers of mental health services<sup>197-199</sup>.

The study "Effectiveness of Needs-Oriented Discharge Planning and Monitoring for High Utilisers of Psychiatric Services" (NODPAM) tests such an intervention. NODPAM is a multicentre randomised controlled trial (ISRCTN59603527) carried out in five psychiatric hospitals in Germany<sup>200</sup>. Consecutive recruitment started in April 2006. Inclusion criteria comprised the following: informed consent, adult age, diagnosis of schizophrenia or affective disorder, and a defined high utilisation of mental health care. During a period of 18 months, comprehensive outcome data on 491 participants has been collected at baseline (*i.e.* discharge from psychiatric inpatient treatment) and at three follow-up measurement points.

Measures completed by the research worker during patient interview included the Camberwell Assessment of Need (CAN-EU), the Brief Psychiatric Rating Scale (BPRS), the Hamilton Depression Scale (HAM-D), and the Manchester Short Assessment of Quality of Life (MANSA). Patient-rated measures included the Symptom-Check-List (SCL-90-R), the patient version of the Scale to assess the therapeutic relationship in community mental health care (STAR-P), and the German version of the Client Satisfaction Questionnaire (ZUF-8). Staff-rated measures included the Global Assessment of Functioning Scale (GAF), and the clinician version of the STAR (STAR-C). Satisfaction with therapeutic work in the outpatient setting was measured with the ZUF-THERA consisting of six rephrased items of the ZUF-8.

Each site had a NODPAM research worker in charge of recruitment and data collection, and a NODPAM intervention worker responsible for carrying out the intervention. It was hypothesised that participants receiving the intervention would show fewer hospital days and readmissions to hospital (primary), and show better compliance with aftercare as well as better clinical outcome and quality of life (secondary).

The manualised intervention focuses on the inpatient-outpatient transition and is based upon principles of needs-led care <sup>201</sup> and critical time intervention <sup>202</sup> <sup>203</sup>. The manual describes the tasks of the intervention worker and delineates structure and content of the intervention sessions. A central part of the manual was to complement each of the 22 needs of the Camberwell Assessment of Need <sup>204</sup> by pragmatic, evidence-based recommendations on what to do in case of an unmet need. Intervention workers invited the 240 participants allocated to the intervention group to attend two sessions (45 minutes each). Core participants in these sessions were patient, clinician, and intervention worker. Furthermore, patients were asked to invite carers to take part. One week before discharge, patient and inpatient clinician talked about needs after discharge in a discussion moderated by the intervention worker. This session resulted in a *NODPAM discharge plan*, a copy of which went to the outpatient clinician named by the patient as being in charge of his or her treatment after discharge. Three months after discharge, goals as outlined in the discharge plan were discussed among patient and outpatient clinician. Result of this session was the *NODPAM outpatient needs plan* consisting of a

list of the remaining unmet needs and description of measures on how to contribute to reducing need in the near future.

As shown in Table 6.6, a NODPAM discharge plan had a predefined format, including detailed content of the need in plain language, objectives and measures for how to achieve them, when to act, responsible person(s), and who to contact for further implementation if applicable. The last category was completed when there was a disagreement between patient and clinician about how to proceed.

<b>Need</b>	<b>Problem</b>	<b>Objective</b>	<b>Time</b>	<b>Responsible</b>	<b>Contact</b>	<b>Compromise / dissent</b>
12 Alcohol	Peter tends to drink too much when in a crisis.	Concurrent treatment of mental illness and alcohol problem.	Immediately	Peter	Dr. Smith	-

**Table 6.6: Excerpt from a NODPAM discharge plan**

Recruitment ended in July 2007, and follow-up data collection was completed in February 2009. At discharge, highest ratings for needs by patients were in the domains of Psychological Distress, Company and Daytime Activities. The three needs with the lowest ratings were Drugs, Safety to others and Telephone. Patient behaviour during the first intervention session as rated by the intervention worker was cooperative for the most part, and rarely passive, hostile, or suspicious. These first results indicate that the intervention was well accepted and feasible. Acceptance by staff was also remarkable as indicated by high participation rates among inpatient and outpatient clinicians. Unfortunately, carers rarely attended the intervention sessions which may be considered a problem since carer burden after hospital discharge may be heavy. Anecdotal evidence based on researcher impressions from patient meetings suggested that a number of patients wished for additional effort including increased involvement of NODPAM staff in carrying out the discharge plan for the brief critical time intervention <sup>202</sup>. The approach has promise as a feasible manualised intervention, based on an established instrument to comprehensively assess the needs of people with mental illness. Formal results have just been published <sup>205</sup>.

#### **6.4.5 Future research**

The findings reported here provide some intriguing insights into the potential utility of user feedback systems or interventions in contributing toward the development and implementation of genuine recovery-oriented services. The systems or interventions provide some potentially promising tools for use in routine practice and indeed, most of the authors recommend future replication of these systems across different

contexts and with different populations. For example, Priebe and colleagues call for future studies to test the “*feasibility and effectiveness of similar procedures [the DIALOG system] with other patient groups and in other outpatient settings*”<sup>160</sup>. However, there are several key unanswered research questions. In particular, the findings reviewed here highlight an urgent need for more large-scale, well designed, research studies in order to:

- adapt and test existing interventions or tools and develop and evaluate one or more explicitly recovery-based feedback systems in order to promote and enhance user-professional communication in routine mental health care and to subsequently improve service delivery;
- identify and assess the potential benefits of these systems and how they might best be translated into routine practice, as well as delineating more clearly their role in recovery-based service provision.

More specific areas and questions for future research are outlined below.

Firstly, and especially within a UK context, there is a need to focus on assessing and, where necessary, attempting to modify, the attitudes, beliefs, ethos, philosophy of mental health services staff toward the routine use of outcome management systems that also incorporate user feedback. (There is a similar question regarding service provider and staff ‘buy-in’ to working in a recovery oriented way independent of the question about acceptance and implementation of feedback interventions). Generating positive clinician attitudes is the first step toward improving the processes and effectiveness of routine outcome assessment<sup>206</sup>. Arguably, these kinds of feedback systems should be more stringent and more prescriptive for

clinicians/clinical teams and more explicitly linked to the process of quality improvement/assurance in mental health services more generally<sup>96</sup>. Thus there is a need to investigate ways in which to support and train staff regarding feedback (as well as outcome measurement and recovery orientation) and to identify attitude and behaviour change strategies that will encourage and promote the active use of feedback systems perhaps especially among psychiatrists. The use of computer systems to routinely record and audit the collection and implementation of feedback systems has potential benefits and is worthy of further investigation. Puschner has concluded that: *“A major challenge in all efforts toward outcome orientation in mental health care seems to find an adequate balance between standardisation and often fuzzy and complex practice in order to avoid over-burdening of routine care with manualised procedural rules”*<sup>96</sup>.

Related to the above point is the need for further research to focus on assessing organisational and cultural factors and other workforce-related factors in the use of feedback systems that might affect outcomes and the overall success or otherwise of these systems. For example, supporting recovery requires culturally relevant services and “culturally competent” practitioners<sup>207</sup>. Organisational beliefs and working practices may need to change in order to ensure that the intervention is not “swimming against the tide” and that, in order to be taken seriously, this will require a systematic programme of research rather than isolated studies<sup>97</sup>. There is a further need for qualitative research and process-oriented evaluations that focus on assessing contextual factors and subgroup variations and illuminate the experiences and views of stakeholders including service users, family members, clinicians and managers. This research would be invaluable in terms of identifying the limiting and

facilitative factors in the successful implementation of user feedback systems and interventions, as well as illuminating the ways in which feedback might best be utilised and acted upon, by both staff and service users.

Equally, it is crucial to assess the resource implications of implementing these kinds of systems and interventions in routine practice and to ascertain their overall cost-effectiveness. This is a significant gap in our knowledge, to date, and was only addressed by one study reviewed here <sup>97</sup>. Some specific questions include: how much time is required to develop, adapt and implement these systems in routine practice and in a way that minimises staff burden whilst maximising overall impact? What is the nature and extent of the IT infrastructure/resources required to support the implementation of these tools? To what extent could existing interventions be adapted to other contexts? What would be the nature and extent of training required by the staff users of these systems? To what extent might these systems lead to cost savings in the form of reduced or shorter admissions?

There are many specific issues around the feedback delivery process itself, including: providing group-based versus individual feedback to service users; the optimal time period within which to provide feedback (*e.g.* immediate versus delayed, regular versus intermittent); the precise form and structure of feedback ‘messages’ and those aspects of feedback that are most effective; the use of the kinds of CSTs described by Harmon and colleagues <sup>158</sup> to support feedback delivery; the extent to which highly personalised forms of feedback might be more effective than other forms of feedback; whether or not it would be advisable to target entire mental health teams or individual clinicians; identification of the kinds of factors that might affect

admission, service uptake, attrition/engagement; the assessment of the longer term effects of providing feedback; the need to monitor staff use of progress feedback to ascertain the extent to which they are sharing and discussing information with clients and to determine whether any changes in behaviour occur and the extent to which these are maintained and reflected in practice.

Finally, there are scientific questions. What are the mediating mechanisms or processes between the provision of feedback/communication and more favourable outcomes (and including at risk patients); that is, how and why does progress information affect outcome? What are the limitations of user feedback (*e.g.* taking into account the potential influence of demand characteristics or social desirability on the users' part and especially when completing measures in the presence of a clinician/therapist and then discussing)? To what extent might expectancy effects arise from continuous assessment or does weekly feedback help to increase attention/motivation and promote better collaboration by focusing on the therapeutic relationship? What are the benefits of adding discussion to feedback systems? What might be the effects on clients of receiving 'negative' progress feedback? To what extent does feedback enhance motivation and promote better engagement and more effective use of consultation time? How do interactions differ after reviewing and discussing the feedback about treatment progress? Are users and clinicians able to collaborate more effectively or is it simply a way of allowing the clinician to focus more on understanding client concerns and therefore becoming more empathetic?

As indicated earlier, the systems or interventions included in this review targeted specific user groups in particular settings - further research is required to examine

the extent to which these interventions are transferable to other user populations, settings and contexts. For example, the type of treatment provided in inpatient settings is more intensive and short-term than community settings, and users generally are more unwell than in outpatient care, so a system designed for one group may not necessarily generalise to other groups. Similarly, the kind of services offered to inpatients tends to be more time limited and intensive than provided to outpatients and community-based service users<sup>150</sup>. Differences between responders and non-responders across all groups are worthy of investigation. In addition, it would be useful to assess the characteristics of a diverse range of participating staff (*e.g.* discipline, experience etc) in order to identify any differences in their attitudes toward, and use of, user feedback systems. There may be merit in considering the application of models of behaviour change such as 'readiness to change'<sup>59</sup> to examine how the characteristics of service users impact on the effectiveness of feedback interventions. Lastly, any procedures need to capture accurate, timely and meaningful information using a brief instrument that is sensitive to change over time and which can be administered regularly and in a cost-effective way. Arguably however, and in an ideal world, the full impact of these kinds of systems may only be realised in the context of: a wider focus on the user perspective within services generally; a systematic identification of the full range of health and social care needs of service users; the subsequent development of innovative services to address those needs; and an evaluation of the impact of those services on overall quality of life. Methodologically and in order to avoid bias, it would be preferable to undertake multi-centre studies where entire services are randomly allocated to intervention or control groups<sup>147</sup>.

In conclusion, there is evidence to suggest that feedback is beneficial on a number of counts, including an accommodation of the user's view, the reinforcing effects for the user of positive change, and the provision of useful insights into the effectiveness, and need for re-evaluation, of treatment. The inclusion of a user component in feedback interventions has been shown to have the added benefit of promoting and enhancing the therapeutic relationship or alliance between the service user and clinician. These systems may be regarded as a form of quality improvement that attempt to bridge the 'science-practice' gap by using clinician- and service user-based outcome data in an attempt to continuously improve the effectiveness of service provision <sup>96</sup>. Clearly, there is a need to better understand ways in which to enhance user outcome, and feedback delivery systems would appear to offer a promising means of contributing toward this goal within the context of a recovery-oriented approach. Whilst a need for further research is indicated (particularly in a UK context), the studies and systems reviewed here offer some potentially very useful approaches and tools to capture user progress and outcome data and relay this information in meaningful ways, to both users and mental health staff and providers.

## 7. Implications and future research questions

### 7.1 Summary of main findings

The review brief was to address the question “*What are the best methods for measuring recovery from mental illness and capturing feedback from patients in order to inform service improvement?*” This has been approached by separating the question into two components: measures and methods.

In relation to measures, four aspects have been considered. Measures of personal recovery were reviewed in Chapter 2. Three measures of personal recovery - QPR, WEMWBS and Mental Health Recovery Star - were recommended for further psychometric testing and consideration for use in Northern Ireland. Service-user rated measures of recovery orientation were reviewed in Chapter 3. No existing measures could be recommended, due to limitations in their published psychometric evidence. Two new measures - INSPIRE and RCI - were recommended for consideration for use in Northern Ireland. Family member-rated measures of recovery orientation were reviewed in Chapter 4, and mental health professional-rated measures of recovery orientation in Chapter 5. Neither review identified a measure which could be recommended for use in Northern Ireland.

In relation to methods, a detailed review was undertaken of current available evidence on capturing process and outcome data from service users, and feeding this information back to inform treatment planning. The overall weight of evidence was somewhat favourable, and a wide range of scientific knowledge gaps were identified in Section 6.4.5.

## **7.2 Has the commissioning brief been met?**

As described in Section 7.1, the commissioning brief was separated into questions about measures and questions about methods. The primary focus of work has been on the production of rapid reviews on the central question about measures (Chapter 3) and the central question about methods (Chapter 6). Both reviews are relatively systematic, with the methodology clearly stated and including quality improvement approaches. The review of recovery orientation measures is contextualised by a synthesis of four data sources on personal recovery measures (Chapter 2), by a discussion about the meaning of recovery (Section 1.6), and an overview of learning from efforts to measure recovery orientation (Section 1.7). It is also amplified by further relatively systematic reviews of recovery orientation from the perspectives of family members (Chapter 4) and mental health professionals (Chapter 5). The review of approaches to capturing patient feedback is contextualised by a historical review of routine outcome assessment (Section 1.8) and an overview of international experience (Section 1.9).

In summary, our response to the elements of the commissioning brief comprised: a review of both the available published and grey literatures (theoretical and empirical) primarily based on health-related reviews and databases (Chapters 2-6); a brief analysis of the current NI context including the Bamford Review (Chapter 1 and 7); consideration of the policy implications for the DHSSPS NI and other HSC organisations (Chapter 7); and the clear identification of the priority research questions that we think need to be addressed within Northern Ireland, many of which have high relevance for mental health services elsewhere. We have not focussed on

mental health issues arising from the 'troubles' or on the epidemiology of mental health as these issues have been reported and debated in many other forums and since recovery is an approach relevant to all people with mental health problems and to all mental health systems. However, it is important to note that the mental health care system (and the wider NI HSC system) is undergoing organisational change or is experiencing readjustment following rationalisation and reorganisation.

In addition, three added value components have been included. First, the meaning of personal recovery was defined in Section 1.6. Second, measures of the experience of personal recovery were reviewed in Chapter 2. Finally, measures from the perspective of family members and mental health professionals were also reviewed, in Chapters 4 and 5 respectively.

### **7.3 Key policy implications**

Four policy implications were identified, based on explicit principles.

#### **Principle 1: Recovery involves more than the absence of mental illness**

*In terms of our capacity to deliver a recovery oriented service, a more pervasive difficulty, perhaps, exists in the overall culture of our mental health services, in the norm of distancing ourselves from service users rather than acknowledging a common humanity, in the tendency towards maintaining a stance of authority rather than putting our skills and knowledge at the disposal of the service user, in the culture of seeking compliance rather than concordance, of failing to promote self-management rather than dependence and often failing to promote optimism. (p. 39)<sup>208</sup>*

The recent Service Framework “*is underpinned by the ethos of ‘recovery’...The concept of recovery is at the heart of the mental health Service Framework.*”<sup>105</sup> (pp. 58-59). Making this aspiration a reality will involve change in the goals, values and practices, and therefore the evaluation, of mental health services. Ensuring that evidence-based treatments for mental illness are available when needed is an important contribution to the recovery journey of many people experiencing mental illness, but it is not the same as supporting recovery. Services that are fully supporting recovery do not assume responsibility for an individual’s recovery; instead, the focus should be on supporting each person to reach personal goals and helping them to choose and use methods for doing so. Since recovery can happen within and outside the mental health system, the goal of the service should be to support personal recovery, which may or may not be related to the provision of treatment. The success of the service should therefore be judged in terms of the recovery experienced by people using the service, not by the level of treatment provided.

**Principle 2: Recovery is a personal experience - it cannot be ‘done to’ a person**

*Improving the health and wellbeing of the population requires action right across society and it is acknowledged that health and wellbeing is influenced by many other factors such as poverty, housing, education and employment.*

(p. 54)<sup>105</sup>

Fully supporting recovery involves changing long-standing working practices, as recovery orientation has implications for language, values, attitudes and

role expectations. These are now being explored in the UK <sup>52 53</sup>, and free-to-download guides are available both at the organisational level <sup>209 210</sup>, the team level <sup>7</sup> and the individual worker level <sup>74 211</sup>. A consistent theme is that mental health services can support recovery, so evaluation by the service user of recovery support is a central means of quality improvement

**Principle 3: Routine assessment of recovery outcome data and the attendant use of effective feedback delivery systems are necessary to support recovery**

*Mental health treatment and care services extend beyond traditional health and social care boundaries and such services can play a major role in promoting the recovery of an individual who has a mental health need. (p. 25)<sup>24</sup>*

The challenges of routine collection and use of outcome data and the successful implementation of effective patient feedback systems have been outlined in Sections 1.8, 1.9 and Chapter 6. These are goals worth achieving - without these kinds of data and infrastructural developments, organisations will show a natural tendency towards retaining existing practices: “*our statutory mental health services continue to operate largely in a traditional hierarchical way with health professionals firmly in charge of the planning, organisation and dispensing of services*” (p. 38) <sup>208</sup>. Since supporting recovery involves changes in working practices, the routine collection and use of recovery outcome data coupled with the use of appropriate and effective feedback delivery systems, are necessary. Implementation approaches will need to be informed by experiences in other countries, as outlined in Section 1.9.

**Principle 4: A recovery orientation needs to be a permeating organisational value**

There are many demands on the mental health work-force, with continuing requirements to modernise, make efficiency savings, and deal with an uncertain political and commissioning environment. However, it would be misplaced to see 'recovery' as just another demand to add to this long list. Specifically, international experience, outlined in Section 1.9, suggests that it would be a mistake to interpret the challenge of moving to a recovery oriented service as only getting a particular type of recovery measure used. This view would lead to a focus on paperwork rather than on where it should be - obtaining and using new information and facilitating new conversations so as to improve recovery support. These principles are summarised in Box 7.1.

**Principle 1: Recovery involves more than the absence of mental illness**

**Principle 2: Recovery is a personal experience – it cannot be 'done to' a person**

**Principle 3: Routine assessment of recovery outcome data and the use of effective feedback delivery systems are necessary to support recovery**

**Principle 4: A recovery orientation needs to be a permeating organisational value**

**Box 7.1: Principles emerging from the rapid review**

Although the language and manner of expression may vary, the conceptualisation of recovery that is set out at the beginning of this report resonates with the Bamford Review and with stated health and social care policy (albeit perhaps with less salience in formal policy responses than in Bamford). For example, regarding the Bamford Review, Wilson and Daly noted that partnership with users and carers in

the planning, development and monitoring of services was one of the key principles, and commented that service users helped to shape the agenda and eventual recommendations such as the need to develop educational approaches and a person-centred service that improves choice and promotes recovery<sup>212</sup>.

According to service users, the Bamford review did not give sufficient attention or emphasis to recovery, empowerment and the need to shift professional attitudes about the positive value and role of the experience of a person with mental health problems<sup>213</sup>. Heenan too, in her critical review of NI mental health policy, questioned the nature and extent to which there was a genuine commitment and investment in user involvement<sup>214</sup>. For example, although service users' views in the context of the Bamford Review were recognised as 'Experts by experience', their formal written contribution to the main review report was 'relegated' to an appendix which, according to both Heenan<sup>214</sup> and Wilson and Daly,<sup>212</sup> indicated a power imbalance and uncertain status.

The results of this rapid review and international research demonstrate clearly that the transformation of a mental health and social care system to a genuinely recovery oriented system requires the full involvement of service users from the beginning through every stage of service delivery. Thus, there is a need to build and expand significantly on the good work and current plans regarding local service involvement.

Arguably, there is considerable uncertainty in local policy and mental health practice about the meaning of recovery, particularly in terms of its implications for policy and the organisation and delivery of services. Chapter 1 attempts to begin the process of

developing a clearer understanding of recovery. There may be a need to develop, deliver and evaluate an ongoing education and training programme to facilitate the transformation of NI mental health care system into a recovery oriented service. Similarly, the universities in partnership with professional training bodies should inculcate the recovery approach into the education of tomorrow's mental health professionals. The PHA has an important lead role to play regarding the promotion of the positive message of recovery to the public and to specific groupings such as employers. Service users should play a central role in these education, training and promotion activities.

The lack of clarity surrounding the meaning of recovery is also reflected in the various ways in which measures of recovery orientation have been conceptualised and operationalised. Clearly, there is a need for a programme of research in order to develop robust, valid and reliable measures of recovery in NI's mental health system. Overall, the rapid review has identified the best available measures and, ideally, HSC Trusts and care organisations should collaborate with recovery researchers to develop relevant measures further, and to evaluate their implementation into routine service delivery in terms of the extent to which they facilitate a recovery support focus.

It is important to note that recovery and recovery oriented care is in the early stages of its development internationally <sup>60</sup>, and so perhaps the uncertainty and lack of clarity is unsurprising. There appears to be a need to support HSC Trusts and other care providers, perhaps using a research and development approach (including implementation science) to develop and implement a formal plan for the

transformation of services and practices to become recovery oriented. The plan should draw upon best practice and evidence regarding recovery oriented systems and services. Davidson and colleagues have used a 'bottom-up' approach to service development beginning with the needs, preferences and goals of the person in recovery and aggregating up to the care system as a whole <sup>60</sup>. Each service user should have an individual 'recovery plan' and it's worth noting that one of the standards in the consultation version of the Service Framework for Mental Health and Wellbeing states that "*A person receiving treatment and care in primary care and/or mental health services (community and inpatient) should have a care plan prepared in partnership with them that is recovery focused, evidence based and fully recorded*" <sup>105</sup>. The document states very clearly that the concept of recovery is at the heart of the mental health Service Framework.

We presented a conceptual framework in Section 1.6 which identified the characteristics, processes and stages of the recovery journey. The rapid review indicated that there appeared to be a fair degree of consensus about the key principles of recovery oriented mental health care, despite the lack of clarity regarding the concept of recovery *per se*. This framework provides a basis for service transformation that could be used by HSC Trusts and other organisations to reorient their services and practices to become recovery focused. Davidson and colleagues transformed their mental health service using a similar framework comprising nine components that they used as a basis for identifying and developing recovery oriented practices and supports <sup>60</sup>. Local Trusts and organisations should consider developing (using a bottom-up approach) practices that mental health staff could use to support each component or aspect of recovery and that, in turn, could

be organised and managed into programmes and systems that would facilitate care organisations to provide recovery supports and practices. Ideally, this programme of work should be coordinated across Trusts and providers and supported unambiguously centrally by the regional HSC Board and the DHSSPS (NI).

Clearly, the issue of resources particularly at this time is an important consideration in the context of recommendations for the development of a recovery service development plan and the transformation of services to become recovery oriented. Arguably, considerable progress could be made by reallocating existing resources to recovery focused goals and community integration. Recovery oriented care draws upon natural supports in local communities and shares the challenge of responding appropriately across individual practitioners, teams and provider organisations: *“If existing services do not promote and support recovery, then what functions or purposes do they serve?”*<sup>60</sup>. HSC Trusts and other providers should consider reviewing existing services and practices in terms of the extent to which they support recovery. Employing a bottom-up approach alongside best evidence, existing services could be transformed by developing and orienting them to support recovery and in a gradual, planned way provide a recovery focused care system. Ideally, as mentioned previously, this review and planning activity should be undertaken in a coordinated way across Trusts and care providers.

In the context of HSC cuts and ‘savings efficiencies’, approaches might include: developing (and evaluating) online training and assessment material that is facilitated by existing training staff and accredited by professional bodies, local universities and/or the Open University; combining training in use of measures and

feedback arrangements to educate and train staff in recovery practices as part of a research and development programme; developing and training a network of dedicated 'recovery leads' or 'lead dyads' comprising a service user and professional working in partnership in each HSC Trust and care organisation (cluster) to provide advice and training as well as monitor implementation.

**Box 7.2: Key policy implications** (based on the principles of recovery that emerged from the review – Box 7.1) for the DHSSPS NI and other HSC organisations.

**Policy implication 1**

Each person who uses mental health services should assess routinely the experience of personal recovery in order to identify how much they are experiencing recovery and associated outcomes such as social inclusion and well-being.

**Policy implication 2**

The recovery orientation of the mental health service as judged by service users should be assessed routinely, and this information used to inform action planning with the individual, as well as local, regional and national service developments.

**Policy implication 3**

The routine collection of recovery outcome data and use of effective feedback delivery systems will not take place unless politically prioritised and adequately resourced, and implementation needs to be informed by approaches used elsewhere.

**Policy implication 4**

Developing a recovery orientation involves organisational transformation. Any introduction of routine use of recovery measures should follow from that transformation, rather than being an end in itself.

## 7.4 Identified knowledge gaps

The reviews presented here have identified five scientific knowledge gaps:

1. Most recovery measures have been developed outside the UK, and none have been developed in NI.
2. There are no measures of recovery orientation from either family member or mental health professional perspectives, which can be recommended (without reservation) for routine use in NI services.
3. Limited attention has been paid to using information from recovery outcome measures to increase service support for recovery
4. The current state of knowledge has focussed on the development of recovery measures, and scientific enquiry regarding the use of recovery measures is early-stage. Very little research <sup>1</sup> has been undertaken into the relationship between recovery outcomes (*e.g.* the CHIME Framework <sup>2</sup>) and traditional clinical outcomes (*e.g.* symptomatology, social functioning, risk). This is a key knowledge gap, since empirical data are needed to inform the otherwise ideologically-driven debate about the benefits and challenges of a recovery orientation. Robust empirical enquiry into this question will have both national and international importance.
5. To date, feedback and monitoring systems remain under-utilised and under-researched. There is a need to examine how effective feedback delivery systems might be implemented usefully (and cost-effectively) into routine practice in ways that are consistent with a recovery-oriented model. Computerised systems, in particular, appear to offer potentially strong infrastructural benefits.

## 7.5 Priority research questions

Four research questions are a priority for future research commissioning:

### **1. From the pool of QPR, WEMWBS and Recovery Star for measuring personal recovery, and INSPIRE and RCI for measuring recovery orientation, which are most applicable for use in NI?**

This can be addressed by commissioning research to address the following questions:

- Are any minor modifications needed to adapt the measures for use in NI, whilst still retaining conceptual equivalence?
- What are the views of key stakeholder groups (service users, family members, front-line workers, service managers) regarding each measure?
- Are the measures feasible for use? This will involve the use of an established framework for assessing feasibility<sup>3</sup>, which defines the feasibility of a measure as: *'the extent to which it is suitable for use on a routine, sustainable and meaningful basis in typical clinical settings, when used in a specified manner and for a specified purpose'*. Assessment of feasibility: (a) identifies the manner and purpose for which to use the measure; and (b) considers whether the measure is brief, simple, acceptable, available, relevant and valuable when used for that manner and purpose.
- Are the measures suitable for use over time in NI? This will involve both careful appraisal of the existing evidence relating to test-retest reliability and sensitivity to change, and evaluation of the measures when actually used in NI services.

## 2. What are the costs and benefits of using these measures?

This can be addressed by commissioning research to establish:

- The resource implications of developing an approach to routine collection and use of recovery outcome based on best evidence from implementation science<sup>4</sup> and using the Ontario approach identified in Section 1.9<sup>5,6</sup>. This approach should form the 'back-bone' of any efforts to implement recovery measures in NI. Key questions will be:
  - What other features of organisational transformation will be needed as a prerequisite for use of recovery measures? (See Policy Implication 4 in Section 7.3)
  - What are the steps needed to maximise service 'buy-in' to, and ownership of, the process of introducing and using recovery measures?
  - What are the enablers of change? How could recovery outcome measures be beneficial for service users and front-line clinical workers (who are the stake-holder groups who will need to provide the data)?
  - What are the barriers to change? Consider both logistical issues (electronic data collection, IT support, feedback report content and format) and work-force issues (attitudes, previous experiences, change fatigue)
  - Can the data from individual service users be aggregated? How much does sparseness or non-representativeness limit the use of aggregated data?
  - Resource implications - what funding, political leadership and stake-holder ownership would be needed to implement the Ontario approach?
- Concurrent experimental investigation may be used to identify the benefits and costs of using recovery outcome measures as part of an overall organisational

transformation process in NI services. Research designs currently being used in the REFOCUS Study in England may be relevant (NIHR Programme Grant, RP-PG-0707-10040, further information: [researchintorecovery.com/refocus](http://researchintorecovery.com/refocus)):

- A country-wide cross-sectional qualitative investigation using focus groups and semi-structured interviews with service users to understand experiences of (a) recovery and (b) recovery support from mental health services
- A qualitative investigation of the experiences of a specific sub-group who may not always have been well-served by mental health services
- A country-wide epidemiologically representative survey of service users and teams using standardised quantitative recovery measures to understand experiences of (a) recovery and (b) recovery support from mental health services
- Development and publication of the first NHS-based manualised intervention to promote recovery <sup>7</sup>
- Evaluation of the manual in a multi-site cluster randomised controlled trial (ISRCTN02507940) in England, both in relation to effectiveness and cost-effectiveness
- Development and use of an innovative approach to individualising clinical end-point assessment.

### **3. What is the relationship between outcomes related to personal recovery and clinical recovery?**

The distinction between personal recovery and clinical recovery is described in Section 1.6. This question can be addressed by commissioning research to:

- Identify a suite of personal recovery outcome measures suitable for use in NI. Potential outcome domains (with recommended measures and literature to consider) include connectedness <sup>8 9</sup>, hope <sup>10 11</sup>, identity <sup>12 13</sup>, meaning <sup>14</sup>, empowerment <sup>15 16</sup>, health-related quality of life <sup>17</sup>, strengths <sup>18-20</sup> and well-being <sup>21</sup>
- Identify a suite of clinical recovery outcome measures, including symptomatology, need, social functioning, risk, and therapeutic alliance.
- Undertake longitudinal collection of both sets of data from a representative cohort of people using mental health services, with a multivariate repeated measures design and random effects regression modelling <sup>22 23</sup> to investigate the causal relationship between recovery outcomes and clinical outcomes.

#### **4. Does collecting and using patient feedback specifically support recovery ?**

This final question may be addressed in the following way.

- Test the feasibility, transferability and effectiveness of existing or adapted/newly developed feedback delivery systems in NI across different contexts and with different patient populations using large-scale research studies that include longer-term follow-up.
- In particular, there may be merit in exploring the application of routine assessment and feedback mechanisms within existing IT systems in NI and opportunities for linking anonymised data for research purposes.
- Identify and assess the potential benefits of these systems and how they might best be translated into recovery-based practice in a cost-effective way
- Explore the attitudes, beliefs, ethos, work practices and training needs of mental health services staff in NI both in relation to: (a) working in a recovery-

oriented way and (b) the routine use of outcome management systems that also incorporate user feedback

- More specifically, conduct qualitative research, process-oriented and economic evaluations related to all of the above, that focus on assessing contextual factors, sub-group variations, resource implications and the views of all key stakeholders including service users, family members, clinicians and managers.

Finally, mindful that limited research funds are available, the most 'payback' from research investment in terms of scientific and service development benefits for mental health services in NI is likely to come from a cluster-RCT. This should be designed to investigate a pro-recovery intervention using a standardised recovery measure as the primary clinical end-point, and including fidelity assessment, a (preferably computerised) feedback component and process and economic evaluations.

In conclusion, this rapid review has identified and summarised current research evidence regarding the meaning and measurement of recovery and associated policy and practice implications for NI. More specifically, it has identified important unanswered research questions that need to be addressed in order to progress the vision of Bamford and transform mental health care in NI into a genuine recovery-oriented service.

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## Glossary

<b>Abbreviation</b>	<b>Meaning</b>
2-COM	Two-way Communication Checklist
APA	American Psychiatric Association
ARAS	Agreement with Recovery Attitudes Scale
BPRS	Brief Psychiatric Rating Scale
CAI	Competency Assessment Inventory
CAN	Camberwell Assessment of Need
CAN-EU	Camberwell Assessment of Need - European Union
CANSAS	Camberwell Assessment of Need Short Appraisal Schedule
CGT	Collaborative Goal Technology
CHHS	Crisis Hostel Healing Scale
CHIME	Connectedness, Hope and optimism, Identity, Meaning and purpose, Empowerment
CRM	Collaborative Recovery Model
CROS	Consumer Recovery Outcomes System
CSIP	Care Services Improvement Partnership
CST	Clinical Support Tool
DHSSPS	Department of Health, Social Services and Public Safety
DREEM	Developing Recovery-Enhancing Environments Measure
ENMESH	European Network for Mental Health Service Evaluation
GAF	Global Assessment of Functioning
GOAL-IQ	Goal Instrument for Quality
GP	General Practitioner

HAM-D	Hamilton Depression Scale
HAS	Helping Alliance Scale
HoNOS	Health of the National Outcome Scale
HSC	Health and Social Care
HSS	Health and Social Services
IEF	Immediate Electronic Feedback
IMR	Illness Management and Recovery
IT	Information Technology
MANSA	Manchester Short Assessment
MRCRC	Magellan Recovery Culture Report Card
MHMDS	Mental Health Minimum Dataset
MHRM	Mental Health Recovery Measure
MHRS	Mental Health Recovery Star (also known as Recovery Star)
MORS	Milestones of Recovery Scale
MPRM	Multi-Phase Recovery Measure
N/A	Not applicable
NHS	National Health Service
NI	Northern Ireland
NODPAM	Needs-Oriented Discharge Planning and Monitoring
OM	Outcomes Management
OMHCOS	Ohio Mental Health Consumer Outcomes System
OQ	Outcome Questionnaire
ORS	Outcome Rating Scale
PCOMS	Partners for Change Outcome Management System
PHA	Public Health Agency

POP	Peer Outcomes Protocol
PVRQ	Personal Vision of Recovery Questionnaire
QoL	Quality of Life
QPR	Questionnaire on the Processes of Recovery
R&D	Research and Development
RAFRS	Relationships and Activities that Facilitate Recovery Survey
RAS	Recovery Assessment Scale
RBPI	Recovery Based Program Inventory
RCI	Recovery Context Inventory
RCT	randomised controlled trial
REE	Recovery Enhancing Environment Measure
RI	Recovery Interview
RIQ	Recovery Interventions Questionnaire
RKI	Recovery Knowledge Inventory
RMT	Recovery Measurement Tool
RO	Recovery Orientation
ROPI	Recovery Oriented Practices Index
ROSE	Recovery Oriented Service Evaluation
ROSI	Recovery Oriented Systems Indicators
RPI	Recovery Process Inventory
RPFS	Recovery Promotion Fidelity Scale
RPRS	Recovery Promoting Relationships Scale
RRI	Rochester Recovery Inquiry
RSA	Recovery Self-Assessment
SAC	Scientific Advisory Committee

SCL-90-R	Symptom-Check-List - 90 Revised
SISR	Self-Identified Stage of Recovery
SRS	Session Rating Scale
STAR	Scale to assess the therapeutic relationship
STARS	Staff Attitudes to Recovery Scale
STORI	Stages of Recovery Instrument
SWOT	Strengths, Weaknesses, Opportunities, Threats
TAU	Treatment As Usual
UK	United Kingdom
WAI	Working Alliance Inventory
WEMWBS	Warwick-Edinburgh Mental Well-being Scale
WHO	World health Organisation
ZUF-8	German version of the Client Satisfaction Questionnaire

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