ROLE network
Relating Outcomes to Lived Experience

Outcomes in Mental Health

Discussion Paper

November 2010

ROLE Network CIC
Relating Outcomes to Lived Experience
North West

Evelyn Bitcon
Anne Broadhurst
Terry Broadhurst
Alwyn Cooper
Karen Machin
David Ralph
Pat Ralph
Eileen Riley
William Tompkins
Roland Urey
Robert Walker

ACKNOWLEDGEMENTS

ROLE Network would like to thank the following organisations for their support:

- Open Up
- Mental Health Improvement Programme
- St Helens Chamber
- The Center to Study Recovery in Social Contexts, New York

First published: November 2010
© ROLE Network CIC.
Registered Company No. 7429695.

The text in this document may be reproduced providing it is reproduced accurately and not in a misleading context. The copyright of the ROLE Network must be acknowledged and the address www.role.org.uk should be included. The work must not be resold.

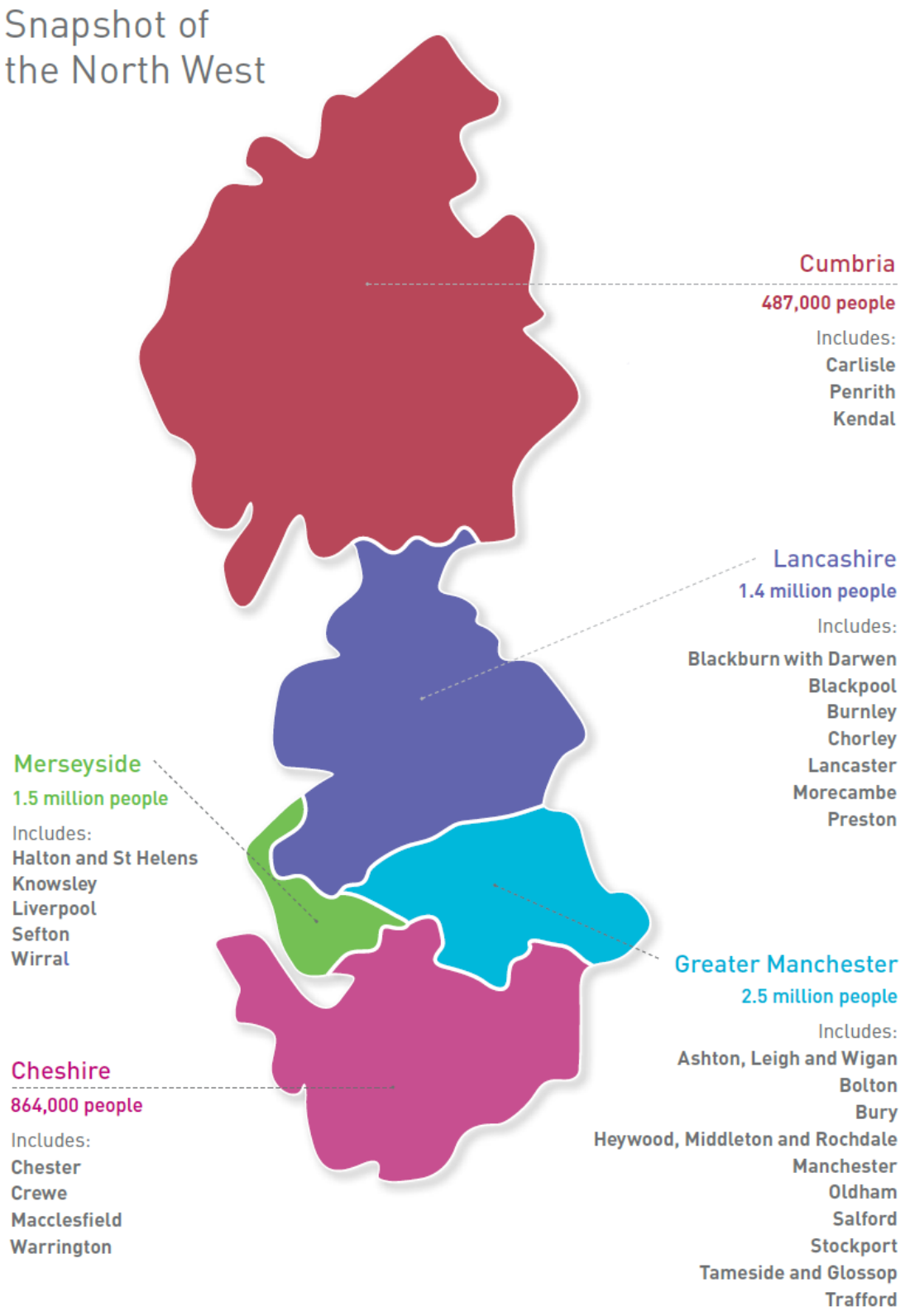
Further information: Please email us at: outcomes@role.org.uk

Our project was funded by Open Up, which is a part of *time to change*, England's most ambitious programme to tackle the stigma and discrimination faced by people experiencing mental health problems.

Contents

1. Executive summary 1
2. Introduction 2
3. Context 3
3. Evidence Base 5
5. Discussion 8
    1. Developing Recovery Enhancing Environments Measure (DREEM) 8
    2. User Controlled Evaluation (UCE) 8
    3. Recovery Outcomes Measure (ROM) (5 Boroughs Partnership Trust) 8
    4. Recovery Star 8
    5. Mental Health Centre of Denver (MHCD) – 4 Measures of Recovery 8
    6. Health of the Nation Outcomes Scale (HoNOS) 8
    7. NSIP Outcomes Framework 8
    8. Talking Points 8
    9. Mental Wellbeing Impact Assessment (MWIA) toolkit 8
6. In conclusion 12
Appendix A: Bibliography 13
Appendix B: The ROLE Network 15
Appendix C: Existing outcome measures 16
DREEM 16
UCE 16
ROM 16
Table C-1: Comparison of DREEM, UCE and Recovery Outcomes Measure 17
4. Recovery Star 18
5. Mental Health Centre of Denver – 4 Measures of Recovery 18
6. HoNOS 19
7. NSIP Outcomes Framework 19
8. Talking Points 19
Table C-2: Outcomes from Talking Points: Personal Outcomes Approach 20
9. Mental Wellbeing Impact Assessment 20
Appendix D: Recommendations from *A better future in mind* 21
Appendix E: Glossary of acronyms 22
Sources of support 23
National Mental Health Organisations: 23
National Carers Organisations: 23
NHS services across the region: 23

© ROLE Network CIC: November 2010



Map reproduced from the report "*A better future in mind – Mental health services in the North West, October 2008*" published by NHS North West.

© ROLE Network CIC: November 2010

1. Executive summary

This document was produced by the ROLE Network CIC, a social enterprise formed by a group of service users/survivors and carers in the North West.

The aim of this report is to ensure that people have the information they need to build the case for local services that are helpful for people with lived experience. It is written for mental health service users and survivors, their carers and supporters to use to inform discussions with commissioners.

Reference is made on page 6 to the 2010 consultation on an Outcomes Framework for the NHS.

We looked at nine commonly available tools for outcomes in mental health. We could not recommend any one specific existing outcome measure. We suggest that an approach based on capabilities may encourage a holistic view and be less excluding.

Acknowledging that choice is empowering, and control itself is a determinant of wellbeing, the report clearly states:

- Outcomes must be selected by service users and carers.

And concludes:

All we ask is that services always ask of each individual:

> '*What is most important to you and how might we achieve that with you?'*
> (Findlater, 2008)

As it says in *Equity and Excellence: Liberating the NHS*:

> *"Nothing about me without me"*
>
> (Department of Health, 2010b, p13)

2. Introduction

Service user and carer representatives had told ROLE Network members that they are often isolated in their discussions with commissioners about service provision. They highlighted that it could be difficult to provide the evidence to back their requests, other than to offer the opinions of their local colleagues. They said this felt discriminatory, as if their views didn't count or were less valid than other views around the table. This was repeated in the recent video booth project (NHS North West, July 2010, p7).

Service users and carers told us that evidence from other service users across the region would help them when faced with conflict including different views on service provision. They also identified that it can help to speak in the language of commissioners, in terms of national performance indicators and targets. One useful measure is that of outcomes. However, when they start to read about it, they find many tools written in confusing jargon, so that they are unsure where to start.

The ROLE Network proposed that it would be helpful to produce and share a report on outcomes based on lived experience.

> *"To focus on outcomes also means that staff need to talk to users and carers about what they want to achieve, and how services can support their goals"*
>
> (Joint Improvement Team, August 2009)

© ROLE Network CIC: November 2010

3. Context

National

The government has indicated a move away from targets and towards outcomes,

> *"We need to recalibrate the whole of the NHS system so it focuses on what really matters to patients and carers and what we know motivates healthcare professionals – the delivery of better health outcomes."*
>
> (Department of Health, 2010a, p3)

There is a commitment to involving patients in their own care – "*no decision about me without me"* (Department of Health, 2010b, p13). Or as Lord Darzi pledged: "*You will be involved*" (Department of Health 2008, p4)

No mention has been made of any changes to the duty to consult given in Section 242 of the NHS Act 2006, although it is not clear who will have this responsibility after the closure of PCTs.

Section 242(1B) of the Act states that users should be involved in:

a. *the planning of the provision of those services*
b. *the development and consideration of proposals for changes in the way services are provided, and*
c. *decisions to be made by that body affecting the operation of those services*

Regional

The report '*A better future in mind'* (NHS North West, 2008) has been a main driver of work in the North West for the period April 2009 to October 2010. This report made a set of 12 recommendations that informed the Mental Health Improvement Programme (MHIP) and aimed to leave a legacy of improvements across the region.

A key area for improvement, highlighted in the report, was around the involvement and engagement of service users, carers and the public. The ROLE Network has been involved across this work stream. The other 2 work streams, workforce and commissioning, also include work on involvement: for example, members of the ROLE Network are on the steering group to develop best practice guidelines for involvement in commissioning (NMHDU, 2010).

One recommendation about outcomes, from '*A better future in mind'* was a

> *"programme of work in conjunction with service users and carers to develop and implement more service user and carer-defined measures of outcome and experience as part of the Advancing Quality Initiative."*
>
> (NHS North West, October 2008)

"*Commissioning for Mental Health Outcomes in the North West"* (Ryan & Oates, July 2010) states that it details "*outcomes that have been developed by providers and commissioners*" (*ibid*, p4) which leads us to suspect a disappointing lack of involvement of service users and carers.

So, while we can say that outcomes are being used for discussions on improving mental health services, and there is agreement that it is essential to have service users' and carers' views on service change, we suspect that, in practice, the definition of outcomes goes on without us.

Liberating the NHS – outcomes framework

The public consultation for an outcomes framework for the NHS covered effectiveness, patient experience and safety (Dept of Health, 2010a, p14). Their five suggested domains are:

1. Preventing people from dying prematurely.
2. Enhancing quality of life for people with long term conditions.
3. Helping people to recover from episodes of ill health or following injury.
4. Ensuring people have a positive experience of care.
5. Treating and caring for people in a safe environment and protecting them from avoidable harm.

These domains relate to a service perspective on outcomes. Service users and carers may well agree on the over-arching domains suggested in the document, but the indicators revert back to a systems language, which does not relate to their needs.

For example, the improvement indicators for domain 2, "*enhancing quality of life for people with long term conditions"*, are about emergency and unplanned hospital admissions for people with schizophrenia and bipolar disorder, HoNOS scores and mortality from suicide. Service users and carers would use more recovery-oriented language to describe how to measure the personal outcomes that would enhance their quality of life in the long term.

'*Enhancing quality of life'* could be reframed in positive recovery language including reference to increasing social capital, building hope and, where appropriate, return to employment. But these are not necessarily the sole responsibility of health care providers, and it would be more complex to untangle whose effort had delivered the outcome. To develop outcomes which sit purely within healthcare, we might need to look at, for example, a reduction in medication, control over appointment times and choice of service provider.

In addition the domains do not attempt to describe alternatives, decisions or efforts, which may be made by the person using those services. For mental health, it is particularly difficult to separate the outcome made by a change controlled by the service rather than by the individual. For example, for any individual, an improvement in HONOS scores may be because of the efforts of that individual. It can also be difficult to measure a positive outcome when distress is described as a roller coaster with no obvious reason or trigger behind it. A positive outcome may need to be a longer period between episodes of distress, but it may not obviously relate to a specific intervention or input.

It is revealing that not one of the improvement areas for Domain 3, '*helping people to recover from episodes of ill health'* is concerned with mental health. The document seems to assume that mental ill health is long term.

We are told that mental health is essential:

> *"There is no health without good mental health and certainly no well-being."*
> Paul Burstow, quoted in J. Dunning, 2010

We would hope that any outcomes framework developed for health services in general would automatically emphasise positive mental health outcomes. And that these would be developed in partnership with people who use or have used mental health services.

 © ROLE Network CIC: November 2010

3. Evidence Base

What is the difference between outputs and outcomes?

Inputs and outputs are what we put in and get out of an activity or intervention. For example, inputs may be money, staff time and volunteer hours. Outputs might be the tasks that we do, the number of people taking part in an activity or the number of products created.

The outcome is the change produced by the intervention. These outcomes or impacts can be short, medium or long term. For example, project outcomes may be short term learning and awareness, medium term actions or policy changes, and long term economic or environmental impacts.

For a maintenance activity, outcomes need to be described in relation to what might have happened without that intervention. For example if a medication is used to keep someone stable, there would be no change over a period of time, so the outcome would need to be compared to any deterioration without the intervention.

For healthcare, particularly physical healthcare using a medical model, outcomes often relate to interventions of treatment. Where there is co-production of an intervention, as with many services delivered by social care and through direct payments, the outcome of the service may be harder to separate from the contribution of the person taking that service. For example, positive outcomes such as improved self confidence and access to learning opportunities will vary depending on the individual's input as well as the service's input.

Evaluation is the process of examining the outcomes of a service or activities. Any evaluation consequently needs to define the outcomes it seeks to assess, as well as the indicators it will measure or observe.

For example, a social enterprise may want to evaluate a service it provides. Service users suggest that the outcomes they want from the service are to feel more confident, and to gain skills in a creative activity. This will suggest indicators that record people's confidence in some way, as well as data on the skills or qualifications they obtain. But the organization captures data on attendance records and cost per trainee, and funders want information on the reduction in medication costs, and numbers of participants who return to work. None of these relate directly to the outcomes originally suggested by the service users.

This highlights that there are different types of outcomes which may be measured. Clinical outcomes, personal outcomes and service or process outcomes, may all be of interest to services, but service users and carers want the personal outcomes. There is always a risk that these service user defined outcomes are the ones that get sidelined and dropped.

What are we measuring?

What is measured is important. It reveals what is valued. If services measure, for example, '*increased number of people with mental health problems volunteering in mainstream settings'* (NSIP, 2009, p6), it is not indicative of positive personal outcomes unless they also ask other questions such as how long people stay in volunteering, whether this is what they wanted, and where they go to next.

As service users and carers we would hope that what is measured is what matters to us. We are not interested in specific processes or the details of how services are delivered at what costs. Essentially, we want to know that services deliver positive

personal outcomes for us. This becomes more important when we purchase those services and where we have choice.

We use a range of words to describe the outcomes we want. Some people talk of 'recovery', others talk about becoming 'stable', or 'better'. Some people might want to return to work, have a social life, enjoy relationships; others want to get out of hospital while others will want services which can provide a specific and limited period of stability such as during a crisis.

Recovery has become the key principle behind mental health services in New Zealand, the United States, Australia, Canada, Ireland and Scotland. In England, it has been taken up by many mental health Trusts, and has the support of organizations including the Royal College of Psychiatrists, and the Social Care Institute for Excellence, as well as many voluntary sector organisations. As such, much of the existing work on outcomes measures is focused on, and will continue to be focused on, measuring recovery. This could be acceptable to service users and carers, if recovery describes a continuing journey, including improvement in something of meaning to the individual, and not a specific end state, which implies the cut off of services.

One challenge in setting recovery within health services is that it can imply a medical model where '*People would be cured of the illness first and then return to a normal life afterwards*' (Davidson et al, 2009, p36). It also suggests that recovery is something that services provide for people, rather than something that individuals pursue for themselves. This then leads to indicators, as described above, which tend to be measures of activity or processes. It is helpful to distinguish 'clinical recovery' from 'personal recovery'. In mental health, it is the latter that is important.

Although its supporters say '*Recovery is an idea whose time has come*" (Geoff, Shepherd et al, March 2008), the concept of recovery is not without debate (Wallcraft, 2009), leading Mary O'Hagan, a recovery specialist from New Zealand to say,

> *"I still have the sense that recovery in England is largely led by professionals with a psychiatric rehabilitation slant."*
>
> *M. O'Hagan, 2009*

There is no one model of recovery. Locally, Marion Aslan, Mike Smith and colleagues developed THRIVE, an approach which goes *'beyond mere recovery and to a place of transformation'* (Aslan, 2008). They talk about the concepts of Time, Healing, Resilience, Interdependence, Vivacity and Emancipation. THRIVE looks to *facilitators* rather than *leads*, to emphasise that each individual is the expert in their own recovery. A common theme in their evaluations is that THRIVE is inspirational and puts the individual in charge of their destiny (Aslan, 2010).

Other researchers have looked for approaches from outside of mental health.

The capabilities approach was proposed by the Nobel prize winning economist, Amartya Sen. Sen's model involves capabilities, the full set of possibilities open to a person, and functionings, what that person actually does or achieves. An example to explain the difference would be that a person may have the capability to have a range of careers or jobs, but in reality has to choose one (functioning) at any point in time.

The model came from economics but has been used in anti-poverty work and disabilities. Recent research is looking to develop tools to measure capabilities, what people could do, as opposed to their functionings, what they actually do. There is interest from within mental health (Hopper, 2007, 2009; Davidson, 2009; Wallcraft, 2010).

 © ROLE Network CIC: November 2010

Recovery and THRIVE are approaches that relate specifically to mental illness or distress. There is an additional body of work around wellbeing, placing mental health within public health.

We are aware of people's anxieties when we talk of wellbeing rather than distress. Service users do have concerns that the more complex end of a spectrum may be ignored if resources are focused on the more media friendly wellbeing. But we all want to achieve a positive sense of wellbeing.

Frameworks describing social determinants and protective factors for mental wellbeing are available, as is evidence of the link between inequalities and poor mental wellbeing (Freidli, 2009; Marmot, 2010; Cooke, 2010). These may be of use when looking at personal outcomes for mental health.

What outcomes tools are available?

This review does not intend to provide a complete comparison of existing outcome measures. We wanted to look at some existing tools (described in Appendix C) to see how they fit with the language and needs of service users and carers.

5. Discussion

We considered (See Appendix C for references and descriptions):

1. **Developing Recovery Enhancing Environments Measure (DREEM)**
2. **User Controlled Evaluation (UCE)**
3. **Recovery Outcomes Measure (ROM) (5 Boroughs Partnership Trust)**
4. **Recovery Star**
5. **Mental Health Centre of Denver (MHCD) – 4 Measures of Recovery**
6. **Health of the Nation Outcomes Scale (HoNOS)**
7. **NSIP Outcomes Framework**
8. **Talking Points**
9. **Mental Wellbeing Impact Assessment (MWIA) toolkit**

UCE and ROM were each developed from the DREEM. The Recovery Star is a nationally used measure which comes from the voluntary sector and is being recommended for use by *rethink* (rethink, 2010, p18). The MHCD measures are used in Denver and recommended in *A better future in mind* (NHS NW, 2008). HoNOS and the NSIP framework are nationally used measures in health care. Talking Points comes from social care in Scotland. MWIA is used to measure the impact of projects on the mental wellbeing of individuals and the community.

Outcomes are often divided into those that measure quality of life for the individual and those that measure processes for a service, although this may not be stated explicitly. Recovery oriented outcomes should look at the outcomes that people want for themselves, and the relation to services is in ensuring those services can address those outcomes.

Recovery itself is unique to each individual, and '*tends to mean different things to different people'* (Repper & Perkins, 2008). Outcome measures should reflect this and work to a service user defined definition of recovery and required outcomes.

WRAP (Wellness Recovery Action Plan) developed by Mary Ellen Copeland (Copeland, 1997) is widely used in services to encourage people to think about their personal recovery. The materials are designed to be used by individuals (with support where needed) to develop their own personal action plan which is appropriate for their individual recovery.

We had hoped that recovery outcome measures aligned to WRAP would be available. Where services are using the WRAP model, we would expect them to have developed related measurement tools focused on the specific experience and needs of each individual. However, that was not the case. Many outcomes measures appear to measure processes rather than outcomes (Ryan & Oates, 2010). They measure details of outputs such as the number of interventions, rather than outcomes.

Table 1 compares three measures used in UK mental health services – Recovery Outcomes Measure, Recovery Star and Outcomes Framework with the five key concepts of recovery outlined in the WRAP framework and the ten Central Human Capabilities described by Nussbaum (2000).

This comparison highlights that the three measures do not reflect the 5 key concepts of WRAP. For example, education is mentioned in all three columns, but the measures do not relate to its use in WRAP. In the WRAP model, education refers to learning about experience of mental distress and a way forward: in the others it refers to work and a return to employment.

© ROLE Network CIC: November 2010

The Central Human Capabilities described by Nussbaum (2000) are included in the diagram to show this alternative perspective in comparison to familiar recovery and service evaluation tools.

Comparing it to the other models, the Capabilities appear to be more human. Words like *play* and *create* are included. They are appealing to a wider audience and appear to be less service-orientated and more person-focussed. They go beyond recovery and are universally applicable.

Using a capabilities approach, rather than a recovery-based model, may have some benefits in that it links measures around mental health to those of the general population. If capabilities are widely used for outcomes in other fields, it makes sense that mental health should relate directly to these for ease of comparison. The capabilities language may also be less stigmatizing and encourage a holistic view of the individual.

There is as yet no specific set of outcomes related to the Capabilities Approach. Many people are researching this in disabilities, including within mental health. Jan Wallcraft (2010) suggests that a Capabilities Approach could underpin mental health research and outcomes work:

> *"People can be asked – e.g. Focus groups – about essential capabilities they value, what they have available, what they would like, what helps and what prevents them from gaining access to those they don't have access to. Services and interventions could then be measured in terms of how well they enable people to develop their chosen capability set."*

HoNOS, the 4 measures of recovery from MHCD, and the NSIP outcomes framework are three frameworks used within existing services.

HoNOS measures clinical outcomes, and focuses on opinions of staff, rather than service users. It is a 'deficit' approach focusing on problems rather than an 'asset' approach valuing skills and potential. IDeA (2010) describe how a deficit approach

> *'… designs services to fill the gaps and the problems. As a result, a community can feel disempowered and dependent; people can become passive recipients of services rather than active agents in their own and their families' lives.'*
>
> *(J. Foot, 2010, p7)*

The MHCD framework is useful for services and has been recommended for use by MHIP (NW strategic health authority's Mental Health Improvement Programme) (NHS NW, 2008). Their framework is relatively complex with its triangulation approach and systems language. The ROLE Network have had discussions with Dr Roy Starks and Dr Antonio Olmos-Gallo, and would welcome a conversation with people who use the services at the Centre.

The NSIP framework measures process outcomes. The measures are related to aspects of personal recovery for service users, but measure the number of service users or interventions rather than details of outcomes for individuals.

Table 1: Comparison of outcomes measures with WRAP and Capabilities

WRAP	Recovery Outcomes Measure	Recovery star	Outcomes Framework	Central Human Capabilities
	• Mental health • Coping with stress	• Managing mental health	• Mental wellbeing	**Life** - not dying prematurely or before life is so reduced as to be not worth living
	• Physical health	• Physical health and self-care	• Physical health	**Bodily health** – good health including reproductive health, adequate nourishment, adequate shelter
	• Income • Accomodation	• Living skills	• Independent living	**Bodily Integrity** – move freely, secure against assault, with opportunities for sexual satisfaction and choice in reproduction
• Receiving support from and giving support to others	• Community involvement	• Social networks	• Social networks • Community participation	**Senses, imagination and thought** – able to use one's mind – imagine, think, reason, create – protected by guarantees of freedom of expression
	• Personal relationships • Supportive people	• Relationships	•	**Emotions** – to love and to grieve including experiencing justified anger. Not being blighted by fear and anxiety
• Education about what you are experiencing	• Education, employment or interests	• Work	• Employment • Education and training	**Practical reason** – to form a critical understanding of one's own life – including liberty of conscience and religion
	•	• Addictive behaviour	•	**Affiliation** – ability to live with others imagining their situation. Being treated as of equal worth.
• Personal responsibility • Self-advocacy	• Control	• Responsibilities	• Personalisation and choice	**Other species** – concern for animals, plants, nature
	• Faith and belief	• Identity and self-esteem	•	**Play** – laugh, enjoy recreational activities
• Hope	• Dreams, aspirations and ambitions • Hope	• Trust and hope		**Control over one's environment** – both political (including freedoms of speech) and material (including freedom to hold property, seek employment on equal basis with others)

© ROLE Network CIC: November 2010

The *Talking Personal Outcomes Approach* was produced in Scotland by the Joint Improvement Team. Service users and carers were involved in its development. (Cook and Miller, 2010). This approach is used across social care and is not specific to mental health. It therefore did not fit neatly into the comparison table showing outcomes used in mental health.

This Approach looks at factors related to quality of life (maintenance), process, and change (see Appendix C). It provides different sets of measures for service users and for carers. Whilst this may be appropriate in other caring situations, for example those where the cared for person lacks capacity, this does not feel appropriate in mental health where a holistic approach would be preferable. For example 'freedom from financial hardship' is appropriate to all people, not just the carer.

Aside from such reservations, this approach may have value for carers because it describes some outcomes specifically related to the caring role, which may be overlooked with other measures. The project also provides valuable evidence of the effect an outcomes approach has in practice on staff. Organizations are using it in mental health and it will be a useful line of further enquiry.

The Mental Wellbeing Impact Assessment toolkit (Cooke et al, 2010) describes the protective factors for wellbeing. The process described in the toolkit may be useful for defining indicators for specific projects with individuals. The toolkit also refers to evidence about how to improve wellbeing, such as the New Economics Foundation's *five ways*:

- Connect: with the people around you
- Be active: exercising makes you feel good
- Take notice: be aware of the world around you and what you are feeling
- Keep learning: try something new
- Give: do something for others

These general suggestions on wellbeing could also provide some useful direction for personal outcomes, which can be linked in with the whole population and not limited to people experiencing distress:

There is a potential difference between outcomes selected for individuals and those applicable at a population level.

Service users are focused on outcomes, and consequently outcome measures, which reference them as individuals. They are interested in personal outcomes, which help them to measure their own personal progress. Such outcomes also help them to engage in a conversation with service providers on an individual level.

We would like to see commissioners and service providers acknowledging personal outcomes as of prime importance. Commissioners appear to be more interested in population level measures so that they can assess, define and plan their service provision across their population. If a service is successfully measuring personal outcomes, these could surely be translated into process and population level outcomes for commissioners.

6. In conclusion

We would like to see a set of outcomes focused on the needs of people as individuals and wider than mental health. Enabling people to select appropriate outcomes encourages them to take responsibility and control for their whole lives and recovery. Control over our lives is a determinant of well-being across cultures and a fundamental element of health promotion practice (Cooke et al, 2010) as also highlighted by Sen:

> *"the process through which outcomes are generated has a significance of its own. Indeed, 'choosing' itself can be seen as a valuable functioning"*
>
> (Sen, 1999 quoted in Davidson, 2009, p39)

Focussing on outcomes also has a positive impact on services:

> '*Some staff have reported that where the conversation is successfully focused on outcomes rather than services, individuals find it relatively easy to talk about continuing concerns at review, as well as areas of progress.*'
>
> (Cook and Miller, 2010, p6)

We believe a user-developed outcomes tool shows potential benefit to individuals as well as to the services which aim to support them. These were also recommended in the report "*A better future in mind"* (NHS North West, October 2008, *p27).* The Mental Health Improvement Programme, which produced the report, is nearing completion, but we would hope to see all recommendations of their work continued. Their recommendations are included as Appendix D.

We recommend further work looking at capabilities and how these can be applied for outcomes in mental health. We also suggest that reference to WRAP is always considered when developing outcomes.

We would prioritise a piece of work to involve service users and carers across the North West and seek their views on outcomes appropriate for mental health. The ROLE Network wants to develop further discussion documents based on a capabilities approach. The Network is looking for partners to take this forward.

Until such work is developed further, all we ask is that services always ask of each individual:

> '*What is most important to you and how might we achieve that with you?'*
>
> (Findlater, 2008)

As is stated in "*Equity and Excellence: Liberating the NHS"*, (Department of Health, 2010b, p13):

"Nothing about me without me"

 © ROLE Network CIC: November 2010

Appendix A: Bibliography

5 Boroughs Partnership NHS Trust, 2010, *Recovery Outcome Measure*

Andresen R, Caputi P and Oades L, 2010, *Do clinical measures assess consumer-defined recovery?* Psychiatry Research. www.uow.edu.au/health/iimh/stori/index.html

Aslan, M, 2008, *The Art of Thriving: Beyond recovery*

Aslan, M, 2010 *evaluations from a series of THRIVE courses including Oldham, Stockport, Sandwell,* America, personal correspondence to obtain information

Bryant L, Duhig L, March 2008, *Big Issues in Mental Health* (paper presented at the *Big Issues – Burning Embers* event in Preston)

Cook A, and Miller E, June 2010, *Talking Points: Personal Outcomes Approach Update report June 2010: Focus on making use of information on outcomes*

Cooke, A., Friedli, L., Coggins, T., Edmonds, N., O'Hara, K., Snowden, L., Stansfield, J., Steuer, N. and Scott-Samuel, A. (to be published, October 2010) (2nd Ed.) *The mental well-being impact assessment toolkit*. 2nd ed., London: National Mental Health Development Unit

Copeland, M.E., 1997, *Wellness Recovery Action Plan,* Peach

Davidson, L, Ridgway P, Wieland M, O'Connell M, Fall 2009, *A capabilities approach to mental health transformation: a conceptual framework for the recovery era,* Canadian Journal of Community Mental Health, Vol 28, No 2

Department of Health, May 2008, *Our NHS, Our future: NHS Next Stage Review, Leading Local Change*

Department of Health, 2010a, *Transparency in Outcomes – a framework for the NHS*

Department of Health, 2010b, *Equity and Excellence: Liberating the NHS*

Dunning J, September 2010, *Care services minister outlines revised mental health strategy*, Community Care accessed online (September 2010) at www.communitycare.co.uk/Articles/2010/09/02/115218/care-services-minister-outlines-revised-mental-health-strategy.htm

Glendinning C, March 2005, *Research to develop new approaches to measuring and understanding social services outputs and productivity: some conceptual issues*, York:SPRU

Findlater J, 2008 in film: '*Fit for the future, a digital story'* at www.digitalstorylibrary.scot.nhs.uk/FitForTheFuture.html (October 2010)

Friedli, L, 2009, *Mental health, resilience and inequalities*, Europe: WHO

Hopper K, September 2007, *Rethinking social recovery in schizophrenia: What a capabilities approach might offer*, Social Science & Medicine **65**: 868-879.

Hopper, K, 2009, *Reframing First Breaks and Early Crisis: A Capabilities-Informed Approach*, INTAR.

IdeA, 2010, *A glass half full*

Joint Improvement Team, August 2009, *Talking Point: Personal Outcomes Approach. Information for people using community care services and their carers*

Lakeman, R, 2004, *Standardized routine outcome measurement: Pot holes in the road to recovery,* International Journal of Mental Health Nursing 13: 210-215

Mead S, Copeland ME, 2000, *What recovery means to us,* NY: Plenum Publishers

McKeith, J. and Burns, S, 2010, *Mental Health Recovery Star: User Guide* (2nd ed), Mental Health Providers Forum, London.

nef, 2008, *Five ways to wellbeing: a report presented to the Foresight Project*

NHS North West, October 2008, *A better future in mind*

NHS North West, July 2010, *Video Diary Room Project*

National Social Inclusion Programme, 2009, *Outcomes Framework for Mental Health Services*

NMHDU and MHIP, 2010 (to be published), *User, Carer and Public Engagement in the Commissioning Cycle: Best Practice Guideline*

Nussbaum, M, 2000. *Central Human Capabilities*. in Women and Human Development: The Capabilities Approach (pp 70-86). Cambridge University Press, Cambridge, UK and New York.

O'Hagan, M, 2009, Recovery article for Mental Health Today available online at www.maryohagan.com/resources/Text_Files/Recovery%20for%20Mental%20Health%20Today.pdf (accessed October 2010)

Repper J & Perkins R, 2008 *Recovery & Social Inclusion* in Brooker C & Repper J, 2008, *Mental Health: From Policy to Practice*, Edinburgh: Balliere Tindall

Rethink, 2010, *fair treatment now*

Ridgway P, Press A, December 2004, *Assessing the recovery-commitment of your mental health service: A user's guide for the Developing Recovery Enhancing Environments Measure (DREEM): UK version 1,* Piers Allott, Peter Higginson (eds)

ROLE Group, March 2008, *Big Issues – Burning Embers: report of a one day conference,* published and circulated by CSIP

Ryan T, Oates M, July 2010, *Commissioning for Mental Health outcomes in the North West – Working Paper 2*

Schmidt LJ, Garratt AM, Fitzpatrick,R. September 2000., *Instruments for Mental Health: a Review Report from the Patient-reported Health Instruments Group (formerly the Patient-assessed Health Outcomes Programme) to the Department of Health*

Self Help Alliance, 2007, *A Peer Support Guide to Mental Health Recovery for Individuals with Lived Experience - Skills Workbook,* Canada

Shepherd G, Boardman J, Slade M, March 2008, *Making recovery a reality*, London:Sainsbury Centre for Mental Health

Starks R and McGuckin S, Sept 2010, *Instruments to measure recovery from mental illness*, available at http://www.thenationalcouncil.org/cs/recordings_presentations

Wallcraft J, September 2009, *Recovery – a double edged sword?*

Urey R, Cropper I et al, 2006 *User Controlled Evaluation*

Urey R, 2010, *personal correspondence in answer to query about the future of UCE*

Wallcraft J, September 2009, *Recovery – a double edged sword*, Paper presented at Critical Psychiatry Network Conference 2009 and available at http://www.mentalhealth.freeuk.com/Doubleedged.htm

Wallcraft J, August 2010, *The capabilities approach in mental health: what are the implications for research and outcome measurement?* Available from www.recoveryinsight.com

This report is also informed by the discussions and conversations we each have with our colleagues and peers who are service users, survivors and carers across the North West of England and beyond. Much of this is informal conversation. Some of it is confidential. Hardly any of it is recorded for academic reference, although some groups (notably the Survivors History Group) are making more information available online.

Survivors history group: www.studymore.org.uk/mpu.htm
Links to groups in our region are available from www.role.org.uk

 © ROLE Network CIC: November 2010

Appendix B: The ROLE Network

The ROLE Network has a history of work on outcomes, originally with CSIP and the ROC-ROLE project. The CSIP Northwest Routine Outcomes Collaborative (ROC) programme used a proven collaborative method. It was designed to ensure the use of outcome measures during the routine practice of mental health service delivery. The primary objective of the collaborative was to ensure that outcome measure data was collected, analysed, studied and used to inform service improvements where necessary.

The collaborative was focused on three parallel streams of outcomes:

- service/system outcomes;
- clinical/care outcomes;
- service user and carer determined outcomes.

The ROLE Group (Relating Outcomes to Lived Experience) provided a lived experience perspective to all streams.

The ROC-ROLE project finished in March 2008. The ROLE Group held a final event to share experiences with service user and carer colleagues across the region. (ROLE Group, 2008)

The ROLE Network grew from the original, informal ROLE Group. The Network is now a social enterprise, based in the North West of England and informed by the regional situation. The North West covers a large area with very diverse conditions including the rural area of Cumbria as well as major urban conurbations of Manchester and Liverpool. Network members are based across the region.

The ROLE Network currently consists of the following active members:

- Evelyn Bitcon (North Cumbria)
- Anne Broadhurst (Greater Manchester)
- Terry Broadhurst (Greater Manchester)
- Alwyn Cooper (East Lancashire)
- Karen Machin (Merseyside)
- David Ralph (South Cumbria)
- Pat Ralph (South Cumbria)
- Eileen Riley (East Lancashire)
- Bill Tompkins (East Lancashire)
- Roland Urey (Greater Manchester)
- Rob Walker (Cheshire & Wirral)

More information about the ROLE Network is available at www.role.org.uk

The ROLE Network is actively seeking opportunities to work with service commissioners and providers, service users, survivors and carers, to improve outcomes for people with lived experience.

The ROLE Network is currently considering priorities including crisis services, personalisation, recovery, carers strategies, employment, police and housing.

Appendix C: Existing outcome measures

DREEM

Probably the best known outcome measures tool for recovery is DREEM (Ridgeway et al, 2004). It was designed to be used as a self-reporting tool to find out where people are on their recovery journey and to rate the services they have received. It has been criticized for being too long and complicated – it has over 150 questions.

UCE

DREEM was used as a basis for the User Controlled Evaluation (UCE) toolkit developed in the North West for CSIP (Urey et al, 2006). This was based on a balanced score card tool to identify areas of effective service delivery. It identified key areas or measures of high impact for service users. The group wanted to ensure that service users were involved in the whole process of evaluation from start to finish. The aim was to eventually develop user led standards. This tool sets out 101 questions including high level measures and subset questions. It was anticipated that these would be modified according to the area to be evaluated. The UCE is currently under revision (Urey, 2010).

ROM

The UCE has been used as a foundation for the Recovery Outcomes Measure developed by 5 Boroughs Partnership Trust (2010). The Recovery Outcomes Measure was developed as a simplified set of factors for use within one Trust. This has now been piloted. The Recovery Outcomes Measure is built into their current commissioning contract as one of the CQUIN measures.

Table C-1 illustrates the number of indicators for each of these tools, showing the areas they each focus on and how they have reduced the number of questions from over 150 in DREEM to 14 in the Recovery Outcomes Measure.

 © ROLE Network CIC: November 2010

Table C-1: Comparison of DREEM, UCE and Recovery Outcomes Measure

DREEM (2004)	96 questions on • Elements of recovery & recovery enhancing services 20 questions on specific needs: • Culture, race and ethnicity • Dual diagnosis • Abuse and trauma • Lesbian, gay or bi-sexual • Parenting 14 questions on Organisational climate 28 questions on Recovery markers 4 qualitative questions
UCE (2006)	A selection from 72 questions, 12 each on • treatment and interventions • dignity • empowerment • access & choice • CPA & care planning • Expectations & rights 15 questions for: • Race and culture • Dual diagnosis • Parenting • Abuse & trauma • Sexuality 14 questions on organizational climate
Recovery Outcomes Measure (2010)	14 questions ▪ mental health ▪ physical health ▪ income ▪ accommodation ▪ supportive people ▪ personal relationships ▪ faith or beliefs ▪ coping with stress ▪ education, employment or interests ▪ developing skills, strengths and talents ▪ community involvement ▪ dreams, aspirations and ambitions ▪ hope ▪ control

4. Recovery Star

The Recovery Star (MacKeith & Burns, 2010) is a tool for supporting and measuring change in adults of working age who access mental health support services. It was developed as a tool to be used by workers with people who use their services or projects. It can be used to measure change for individuals and for projects.

The Recovery Star was based on the Outcomes Star developed by St Mungo's, a London based charity providing services for people who are homeless. The Mental Health Providers Forum commissioned a version for the mental health sector in 2007. It is now in a second edition having been updated to include more consideration regarding cultural competencies.

The measure has been criticised as describing a linear ladder of recovery which sets up unrealistic expectations and demands, and standardized goals. It is however widely used in the voluntary sector and has been recommended for use by *rethink* (rethink, 2010).

The Recovery Star uses a 10 step ladder of change on each of the 10 domains:

- Managing mental health
- Physical health and self-care
- Living skills
- Social networks
- Work
- Relationships
- Addictive behaviour
- Responsibilities
- Identity and self-esteem
- Trust and hope

5. Mental Health Centre of Denver – 4 Measures of Recovery

The Mental Health Centre of Denver (www.mhcd.org) has developed recovery measures as part of their work on a system wide approach to recovery (Starks & McGuckin, 2010). They involve service users in this work. Their approach involves four separate measures:

- Recovery Marker Inventory - staff rating of consumer's progress
- Promoting recovery in organizations (PRO) – the consumer's evaluation of the mental health centre
- Consumer recovery measure – rating of their own recovery
- Recovery needs level – the best level of service for a specific stage of recovery

Using the combination of all these measures, they can identify which parts of their service work well and they can profile individual service users (consumers) to see who would benefit from a different approach.

Their consumer recovery measure looks at five dimensions:

- Active / growth orientation
- Hope
- Symptom's interference
- Perceived sense of safety
- Satisfaction with social network

 © ROLE Network CIC: November 2010

6. HoNOS

HoNOS (health of the nation outcomes scales) is the most widely used routine clinical outcome measure used in English mental health services. It offers 12 scales which are intended to be used before and after a treatment. They can show whether a given intervention has had a clinical outcome and can be used by managers to build up a picture of effectiveness of treatments for specific client groups.

The HoNOS scales cover:

- Overactive, aggressive, disruptive or agitated behaviour
- Non-accidental self-injury
- Problem drinking or drug-taking
- Cognitive problems
- Physical illness or disability problems
- Problems associated with hallucinations and delusions
- Problems with depressed mood
- Other mental and behavioural problems
- Problems with relationships
- Problems with activities of daily living
- Problems with living conditions
- Problems with occupation and activities

7. NSIP Outcomes Framework

The National Social Inclusion Programme (NSIP) created an '*Outcomes Framework for Mental Health Services'* in 2009. This was developed from a previous piece of work on day services. The framework describes 11 categories to reflect life domains and functions of mental health services, with two outcomes for each category. A variety of outcome indicators are listed.

The categories are, for individuals:

- Community participation
- Social networks
- Employment
- Education and training
- Physical health
- Mental wellbeing
- Independent living
- Personalization and choice

Service outcome indicators are:

- Service user satisfaction
- Service user involvement
- Diversity

8. Talking Points

In Scotland, the Talking Points Personal Outcomes Approach has been developed by the Joint Improvement Team to focus on outcomes for people who use community care services in Scotland. This has included people who use mental health services. Their work has identified the outcomes shown in Table 2 as being of use to service users and to carers. There is an emphasis on person-centred goal planning and reviews through semi-structured conversations.

Table C-2: Outcomes from Talking Points: Personal Outcomes Approach

Outcomes important to service users		
Quality of Life	**Process**	**Change**
Feeling safe	Listened to	Improved confidence / morale
Having things to do	Having a say	Improved skills
Seeing people	Treated with respect	Improved mobility
Staying as well as you can	Responded to	Reduced symptoms
Dealing with stigma and discrimination		

Outcomes important to carers			
Quality of life for the cared for person	**Quality of life for the carer**	**Managing the caring role**	**Process**
Quality of life for the cared for person	Maintaining health and wellbeing	Choices in caring including the limits of caring	Valued / respected and expertise recognized
	A life of their own	Feeling informed / skilled / equipped	Having a say in services
	Positive relationship wth the person cared for	Satisfaction in caring	Flexible relationship with practitioners
	Freedom from financial hardship	Partnership with services	Accessible, available and free at the point of need

9. Mental Wellbeing Impact Assessment

This toolkit (Cooke et al, 2010) focuses on positive mental health so that projects can maximize positive impacts and minimize negative impacts. It suggests protective factors for individuals within the framework of:

- Enhancing control
  - A sense of control including setting and pursuit of goals
  - Belief in own capabilities and self-determination
  - Knowledge, skills and resources to make healthy choices
  - Maintaining independence
- Increasing resilience and community assets
  - Emotional wellbeing including self esteem
  - Ability to understand, think clearly and function socially
  - Have beliefs and values
  - Learning and development
  - Healthy lifestyle – eating, physical activity
- Facilitating participation and promoting inclusion
  - Having a valued role
  - Sense of belonging
  - Feeling involved

The toolkit is intended for use before a project starts, to develop indicators which can then be used to measure outcomes.

 © ROLE Network CIC: November 2010

Appendix D: Recommendations from *A better future in mind*

These are the complete recommendations from the report (NHS North West, October 2008, *A better future in mind, p27).* They recommended:

1. the strategic health authority uses its leadership and influence to create a cross-agency programme to support and scrutinise significant performance improvements in service user, carer and public engagement in mental health. This should directly address the known organisational, managerial, professional and cultural barriers to effective engagement.
2. the strategic health authority uses its leadership and influence to support the North West NHS and other partners to establish a service user and carer engagement development initiative. This should enable service users, carers and communities to participate effectively as equal partners in the design, delivery and evaluation of services.
3. the creation of mental health commissioning teams operating across a city region or other wider footprint and contracted by individual PCT and LA partnerships to deliver significant elements of mental health commissioning on their behalf.
4. further investigation and implementation of models like 'Connected Care' as a means of developing more community-centred and integrated commissioning for health and well-being.
5. a programme of work in conjunction with service users and carers to develop and implement more service user and carer-defined measures of outcome and experience as part of the Advancing Quality Initiative.
6. the wider use by commissioners across the North West of the measures of recovery developed and in use in the Mental Health Centre of Denver, USA.
7. that commissioners, working with other agency partners, develop and implement more measures and targets that promote paid work, education, leisure and volunteering in support of well-being, illness prevention and recovery for those experiencing mental illness.
8. that financially-transparent, comparative information on levels of investment by PCTs on well-being, mental health prevention, and mental illness treatment (including recovery) be made publicly available to ensure greater accountability for investment choices.
9. that commissioners critically review their expenditure on well-being, illness prevention and recovery, to ensure that they are maximising the opportunity to lower the personal and societal costs of mental illness and poor mental health.
10. that paid roles which value the service user experience are developed and implemented more widely and that service users and carers are more involved in the appointment of staff and the on-going assessment of their competence and capability.
11. that the recently launched 'Time to Change' campaign is used by mental health service providers as an opportunity to work with staff to challenge attitudes and practices, and further promote new ways of thinking and working.
12. investing more in the development, training supervision and coaching of staff, to better enable them to deliver strengths-based approaches to recovery.

These recommendations are currently being refreshed by MHIP in relation to the end of the programme and the structural changes to the NHS proposed in *Liberating the NHS.*

Appendix E: Glossary of acronyms

CPA	Care Programme Approach
CQUIN	Commissioning for Quality and Innovation
CSIP	Care Services Improvement Partnership
DREEM	Developing Recovery Enhancing Environments Measure
HoNOS	Health of the Nation Outcomes Scale
LA	Local Authority Partnership
MHCD	Mental Health Centre of Denver
MHIP	Mental Health Improvement Programme
MWIA	Mental Wellbeing Impact Assessment
NHS	National Health Service
NMHDU	National Mental Health Development Unit
NSIP	National Social Inclusion Programme
PCT	Primary Care Trust
PRO	Promoting recovery in organizations
ROLE	Relating Outcomes to Lived Experience
ROM	Recovery Outcomes Measure
THRIVE	Time, Healing, Resilience, Interdependence, Vivacity and Emancipation
UCE	User Controlled Evaluation
WRAP	Wellness Recovery Action Plan

© ROLE Network CIC: November 2010

Sources of support

The following are some links to other organisations who offer support to people experiencing distress or mental health problems, and their families and friends.

National Mental Health Organisations:

Alzheimer's Society	www.alzheimers.org.uk
Anxiety UK	www.anxietyuk.org.uk
beat	www.b-eat.co.uk/Home
Depression Alliance	www.depressionalliance.org
Hearing Voices Network	www.hearing-voices.org
Making Space	www.makingspace.co.uk
Manic Depression Fellowship	www.mdf.org.uk
Mind	www.mind.org.uk
Rethink	www.rethink.org
Together	www.together-uk.org

Elsewhere on the ROLE Network website, we've referred to national and local groups on self harm at www.role.org.uk/2010/12/31/selfharm

and support around suicide at www.role.org.uk/links/suicide

National Carers Organisations:

(Many of the organisations listed above also provide support for carers)

Carers Direct	www.nhs.uk/carersdirect/
Carers UK	www.carersuk.org/Home
Princess Royal Trust for Carers	www.carers.org

NHS services across the region:

Cumbria Partnership	www.cumbriapartnership.nhs.uk
Lancashire Care	www.lancashirecare.nhs.uk/index.php
Pennine Care	www.penninecare.nhs.uk
Manchester Mental Health	ft.mhsc.nhs.uk
Greater Manchester West	www.gmw.nhs.uk/default.aspx
5 Boroughs Partnership	www.5boroughspartnership.nhs.uk
Mersey Care	www.merseycare.nhs.uk
Cheshire & Wirral Partnership	www.cwp.nhs.uk/Pages/welcome.aspx

ROLE network

Relating Outcomes to Lived Experience