



scottishdevelopmentcentre  
for mental health

## **Developing the Mental Health Research Agenda in Partnership with Users and Carers**

**Seminar 1: Asking the Right Questions  
29<sup>th</sup> October 2002**

**Seminar 2: Making Good Use of the Answers  
27<sup>th</sup> November 2002**

### **Report**

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## Executive Summary

### Seminar 1: Asking the Right Questions

#### **To what extent are/should service users and carers be involved in setting mental health research agendas?**

Although there has been progress in terms of involving service users and carers in the mental health research process, there is a strong perception that this is more rhetoric than reality. There is concern that achieving influence in the mental health field comes down not to what kind of evidence you produce to back up your argument but whether you have the power to push your argument.

Service users are generally dis-empowered in the mental health research field and rarely have the opportunity to shape agendas in partnership with other interest groups. Involving service users throughout the process can provide a 'reality check' through reflection of the major issues in mental health from first hand experience and there is a need for better processes to enable this.

#### **Including multiple narratives**

Real partnership with service users can mean that questions and answers are generated that challenge the status quo in mental health practice and policy and in turn challenge the realities of those in positions of dominance in the mental health field.

There are a huge variety of perspectives in mental health, each with their own context. In setting a research agenda in mental health, a fair balance should be sought between views of the public, service users and carers, practitioners, policy makers and others when developing the mental health research agenda. There is work to be done in terms of achieving an acceptance of the value of multiple narratives rather than a dominant medical / pharmaceutical model that holds up 'gold standard' quantitative research as the most valid form of evidence.

#### **Challenges for mental health research commissioners**

In the mental health field there tends to be support for research questions and messages that fit with dominant contexts rather than those which challenge our status quo. There is a challenge for commissioners to be more transparent and accountable about mental health research agendas and to address the present bias to clinical and medical types of research.

#### **Building capacity**

Champions with credibility are needed to promote and build capacity to carry out research that is:

- Diverse, taking into account differing narratives that challenge our understanding.

- About change, improvement and outcomes that promote positive health for the wider population.
- Value- based, collaborative and participative.
- More about people and less about services.
- Less de-personalised and more about relationships.
- Immersed in the context of those experiencing mental health problems.

### **What are the important mental health research questions?**

In addressing the important questions for mental health research there is an emerging idea shift towards the positive aspects of mental health including recovery from mental ill health. This raises the question of how the research process can be redesigned to make this happen. The key areas for research in mental health delegates suggested were as follows:

- Recovery – what are the factors behind peoples' recovery from mental ill health?
- Diagnosis – how does a diagnosis affect individual's health and lives?
- Medication – why is the use of medication increasing?
- Stigma – how does stigma affect people from within and from their environment?
- Balancing the needs of patients with the provision of different types of health – what are the alternatives to acute care and formal care?
- Mental health in the workplace.

### **Seminar 2: Making Good Use of the Answers**

#### **What makes good quality mental health research evidence?**

The quality of mental health research at the commissioning and publishing ends of the research process is decided by peer review, that is a panel of experts. Users and carers are rarely involved in this process. This leaves a gap in terms of the crucial expertise that people gain through experience. Commissioners need to go out and listen to practitioners, users and carers to find out what is wanted from research on the ground.

A key criteria for judging good quality research is the quality of the questions being asked, which determines how helpful research will be in contributing to change. However what equates to the 'right' questions and answers is subjective, and evidence may be used selectively to back up the desired changes in practice and policy.

The traditional hierarchy of evidence that currently dominates decision-making, places randomised controlled trials as the gold standard. This hierarchy was challenged by seminar delegates through discussion about the value of the human experience and benefits of qualitative research evidence which can be equally as robust, relevant and influential as 'sanitised' randomised controlled trials.

## **Demystifying the research process**

There is a feeling that there are barriers to involvement in the research process which detract from the quality of evidence produced such as:

- Lack of plain language.
- Lack of openness about research amongst professionals.
- Asking questions that do not relate to the concerns of those who have experienced mental ill health.
- Lack of easily accessible research findings.

## **New shared positive perspective**

Improving the quality of research evidence will mean establishing a shared vision that focuses on good mental health and keeping people well as well as mental illness. Traditional mental health research tends to focus on responding to problems, but this doesn't seem to impact on recovery rates, we need to find out what makes people well.

## **How can we get better at applying mental health research evidence to policy and practice?**

Targeted dissemination of research findings is essential if they are to influence those who make policy and practice decisions. Identifying the potential implications for change in research reports and publications would be helpful.

Mental health should be seen as a societal responsibility and therefore it should be open to anyone to become engaged as partners in an integrated policy process. To achieve better partnership between policy makers, practitioners, researchers and users we need:

- Better co-ordination of the mental health policy process within the Scottish Executive.
- Openness within and between policy and research institutional cultures to enable more transparency and partnerships within the policy process.
- Good information sharing about current policy agendas and the research informing them.

Raising mental health awareness amongst the general public may address stigma, which can be a barrier to policy development. More research that focuses on the positive side of mental health may help to change public perceptions and reduce stigma.

## Introduction

Two seminars on the theme of 'Developing the Mental Health Research Agenda in Partnership with Users and Carers' were organised by the Scottish Development Centre for Mental Health in autumn 2002 with support from the PPP foundation. An event planning group of service users and professional staff was set up to oversee the planning and implementation of the events (see appendix 1 for details).

The purpose of these research seminars was to advance the mental health research agenda in Scotland using a participative approach. Each seminar promoted user and carer involvement in mental health research by facilitating dialogue between professional researchers and commissioners, service users and carers interested in research.

The seminars were intended to be welcoming stimulating, challenging and productive experience for delegates. Speakers were selected to provide contrasting perspectives with the intention of providing food for thought and discussion. The validity of current national and local mental health research agendas in Scotland was questioned and debate and table discussions were used to identify the key issues and ways forward from a range of different perspectives.

The first seminar concentrated on how we identify the issues in mental health that should be researched and the second seminar focussed on what makes good evidence and how that evidence can make a difference to policy, practice and ultimately people's lives.

This report gives a flavour of the main ideas and discussion points raised during the seminars and their relevance in terms of moving the mental health research agenda forward in Scotland.

## **Seminar 1: Asking the Right Questions**

Five speakers were selected to represent particular perspectives; professional researcher, policy maker, service user, research commissioner and mental health professional. Each speaker was asked to make a five-minute presentation answering two questions and each of these presentations was followed by time for debate and table discussions.

Chair: Dr Allyson McCollam, Director, Scottish Development Centre for Mental Health

### **Debate 1: To what extent are / should users and carers be involved in setting mental health research agendas nationally and locally?**

#### **Summary of Speakers' Presentations**

##### **a. Susanne Forrest: a professional researcher's perspective**

Although there have been positive developments in mental health research in terms of involving users and carers, there is a sense that there is 'more rhetoric than reality' ... the professionals still control the funding. There is a present hierarchy of power, power decreases as you go down the following list:

1. Setting and investing in the research priorities.
2. Commissioning research.
3. Doing research.
4. Reviewing research.
5. Supervising research.
6. Lobbying for research.
7. Identifying the problems, issues, questions that need answered.

In mental health research, the principles of empowerment are in conflict with the lack of service user and carer involvement. Key question: can we turn this hierarchy around so that the power flows the other way?

##### **b. Graham Morgan: a service user's perspective**

- The Highland Users Group's reports and papers express the views of many service-users, they start from people's experiences, not theoretical models.
- Mental health systems are built up from and reflect societal values and structures.
- Users need to be at the centre of the system, they should have a say to reflect the major issues from first hand experience and to campaign for change.
- Service-users should be involved in research as a 'reality' check and a 'safeguard'.
- Service-users have the right to be involved and to direct the research process.
- There can be difficulties for service users carers in terms of criticising professionals 'face to face' through the research process.
- There are many types of user involvement including representative groups; national organisations; those with research experience; those not yet connected to networks.
- We need to be creative about involving people.

### c. Colin McCormack: a mental health manager's perspective

"To ask the hard question is simple... but the answer is hard and hard to remember"

W.H. Auden (c. 1930)

- Answers are hard to take in the sense that it is hard to work out what research answers mean for different people, answers can be hard to hear.
- It is important to go beyond 'this matters' to 'this must change'. The research agenda should create action that really changes services for the better.
- It is not so much a question of whether we involve service users but **how** to involve service users.
- The NHS says it uses 'an evidence – based' approach, however this must be questioned. There can be a tension between the 'evidence' valued by the NHS and user's views. For example some users support counselling services over anti-depressants or cognitive behavioural therapy despite there being a strong evidence base for the latter, and equivocal evidence for the former. How do we balance these contradictions?

### d. Gregor Henderson: a policy maker's perspective

Users and carers are involved, but as recipients, not in setting the agenda or asking the questions. Some excellent examples exist of user-run, user-involved research but users are not setting the agenda. The questions being asked need to focus on service users with the notion of recovery, not on mental illness as a disabling disease. Recovery is currently a positive challenge to the status quo in mental health and the research agenda.

There are questions policy-makers need answered to provide the detail they need:

- Need more than two vested interests – questions need to challenge the status quo. What are all of the vested interests in mental health and where are they represented in mental health?
- What social movements and campaigns exist and may move things on?
- What works to improve people's lives? Not researching just what makes people worse mentally but what makes them better.

We are now beginning to accept multiple narratives rather than one dominant or psychiatric / medical narrative. Everyone has a bit of the truth but we need to be clear about current paradigms, does one narrative dominate or are there multiple influences?

Policy makers could:

- Be clearer on mental health policy objectives; make them coherent.
- Commission research for policy objectives and strategic action so that policies are not reactive but reflective and are grounded in real life experience and reality.
- Promote research to challenge the status quo.

In using multiple narratives we need to:

- Respect different perspectives.
- Collaborate more to produce better research.

#### **e. Emma Hogg: a research commissioner's perspective**

There is question over whether national and local research agendas for mental health exist. At best, individual national organisations have agendas but they are not internally co-ordinated or explicit. Mental health is not the only field where this happens – there's a lot of inconsistency and a lack of coherence in research agendas.

There is not a process for users and carers to be involved, so first we need to address the process of developing an appropriate agenda. From a research commissioner's perspective users and carers should be involved in setting the research agenda. This perspective is governed by various issues – ideological, political and practical.

- Ideological aspects include participation and empowerment.
- Political aspects include policy directives and emphasis on engagement with communities of interest.
- The practical aspects are that perspectives are lost if users and carers do not engage – they have valuable knowledge and so consulting them is ethical, imperative and effective.

So definitely yes, users and carers should be involved but to what extent? Being involved in setting the research agendas may bring better answers. However users and carers are not the sole voice and others have equal contributions to make. These others should not be excluded. Service users and carers bring knowledge and experience, researchers bring knowledge and skills around methodological issues and practitioners and policy makers bring yet more perspectives and skills – there is a role for everyone and every party brings a valuable contribution to the table in setting the research agenda.

If we look at mental health from a public health perspective – to include promoting good mental health, preventing mental illness and supporting those experiencing illness then users and carers are only one sub-section of the potential stakeholders. Promoting mental health is relevant to the whole population. This means that in addition to users and carers the whole population has a potential role to play in setting the research agenda.

The real question is how do we involve users and carers? Many professionals are not sure how to involve them in a representative way; there is concern about involving them in a token way. It's important to look at what is lost by not involving service users and carers and need to seek a balance between the public and service users interests. In conclusion, we need new ways to involve users and carers and the general population in the agenda once we get the process underway.

**Debate 1: To what extent are / should users and carers be involved in setting mental health research agendas nationally and locally?  
Key ideas and points raised in discussion.**

### **Issues of Power and Context**

- Giving weight to different views and achieving influence in terms of mental health research often comes down to issues of power. Research can produce evidence to back up most arguments, achieving influence however, comes down to who has the power to push the argument. The power balance in setting the mental health research agenda is currently perceived to be more top down than bottom up.
- There is a perception that there is medical domination of the mental health agenda including research. Psychiatrists do have a perspective but it is limited and the high share of power they have is disproportionate to their relatively low share of the wealth of valid perspectives. This kind of power imbalance can make it difficult to avoid user involvement tokenism.
- It is difficult for service-users to challenge what's there in the mental health system already. Many service-users don't know about the alternatives in mental health, they are disempowered and struggle to find the right questions to ask. However some service users and carers are empowered as a result of the process of being involved in research.
- Those who fund research in mental health also set the agenda and people who want to access funding are often frightened of upsetting them and challenging their realities. Private drug companies control much of the money for mental health research. The Scottish Executive should work in a more open and fair way in terms of resource allocation for mental health research. Money for research in mental health should be allocated more into communities and not so much into large powerful institutions.
- How do we shift the current power balances that disempower service users and others?
- How do we direct funds towards capacity building for research in the wider community?

### **Multiple Narratives**

- We are quite far from achieving an acceptance of multiple narratives in the mental health research field.
- Presently those who dominate professionally shape much of the research agenda, this will not change by demonising one group within the many interest groups who have narratives to offer.

"Research is driven by interests, for instance, Cognitive Behavioural Therapy research is driven by psychologists' interests – but what about service-user interests driving research?"

- There will always be different perspectives between different interest groups in mental health, each with a different of opinion of the important questions based on their own contexts and realities. Including and interpreting these different perspectives in the research agenda can be a difficult process.
- It is important to consider asking lots of people the same questions to gain a broad understanding of an issue for research. It can be difficult to weigh up different perspectives, as having both views might not offer a richer perspective but result in the differing perspectives cancelling each other out if they are contradictory. We need to expect these contradictions and to manage these complications by asking the kind of questions that will allow understanding of the answers from a range of contexts.
- There is the issue of how much weight to give to each different perspective. Seeking a majority view or consensus should not be an aim of listening to multiple narratives. In current practice this approach would not help, as it would tend to be the professionals' view that won over due to numbers involved.
- Research can lead to action but who shapes that action – which of the multiple narratives?
- How can we move to multiple narratives?

### **Building Coalitions**

- Awareness of mental health should become an everyday issue and this might be achieved by wider collaboration in mental health research. The general public need to be involved to address issues of stigma and discrimination. There should be education and research on health and not just ill health.
- It is important to recognise the fundamental importance of relationships in mental health research. There is an assumption that research should be de-personalised and this can result in relationships between those involved in the research process suffering. However, to a large extent the success of research does depend on the relationships between the people involved. There is a need to build coalitions between different interest groups in research and policy setting.

## Legitimacy of research, what is valid?

- Does service user research have to conform to the status quo?
- The influence that a piece of research has is directly linked to what is counted as valid evidence by those who can make changes to practice and policy.
- Frustration about the effort involved and little impact that much research has, what might make a difference?
- Mental health research should take into account the context of those who are being researched.
- The research agenda should not be judgemental, setting agendas should involve accommodation for different types of evidence.
- A tension already exists between the ideas of 'academic credibility' and 'multiple narratives'. Narratives require a qualitative methodology but this is not an approach many providers of mental health services value. The myth of RCT's as the gold standard needs to be dismantled, psychiatry, the medical model, is not an exact science, there is huge variation of approach amongst practitioners. Cognitive Behavioural Therapy has gained credibility through a double-blind research methodology however the multiple narratives model does same 'proof' but in the longer term how do people fare who use CBT or counselling? Could it be a different story?
- As part of the process need to think of what can change beforehand – if the resources to change things aren't there, should we be asking the questions?
- Many users and carers response to research is – 'you keep asking questions and nothing ever happens'. Users and carers want to know the chance of the research actually changing practice, researchers and commissioners need to be honest about this and the timescales for it. Research needs to inform operational change, but it can't necessarily give one clear answer as it gathers many different views – research does not help you weigh these up - it's more messy than that.

## Building Capacity for User Involvement

- There is a general feeling that users and carers are not involved at all in the setting of research agendas at almost all levels. In a real sense when service users are being employed as user/researchers, it's very often at a stage when the research questions have been already decided. Users and carers need to be involved at the very first, most important stage of research i.e. the setting up of questions and the areas of research.
- If service users are not happy with the agenda, they need to be in a position to challenge that and to get them at the heart of the research. However as long as the conventional wisdom states that users ought to be the recipients of research, rather than the instigators, then nothing changes.
- Users need to feel involved; that they have a voice and that it's been listened to. It's about feeling that you are making a little bit of a difference.

- Users are experts by experience and should be involved in judging proposals for funding.
- We need to look at barriers to involving service users in mental health research and build personal capacities.
  - The benefits system can hinder payment of service users who become involved in research.
  - Need for relevant training programmes for users and carers to become involved in research. Users may be being excluded because they have no academic background – creating barriers before we've even begun.
  - We need to start talking a plainer language about what we mean by phrases like competing narratives! Reporting of research findings should be user friendly, change the language to be more accessible.
  - Users need to become involved at whatever level they feel comfortable, with all aspects of mental health research.
  - Accessible training for those who have questions they would like to ask through research and are willing to learn how to do this. Service users need to acknowledge they have skills to learn and they have allies to help.
  - Feedback to service users involved – communication is essential to ensure an equal power balance and a focus on actions.
- Raising status of user-led research needs champions with credibility we need to demonstrate change through research to promote user-led research; this is difficult to do without reinforcing the status quo. Taking the idea of user involved and user led research into the policy agenda could boost its status and make it happen.

## Debate 2: What are the important mental health research questions?

### Summary of Speakers' Presentations

#### a. Susanne Forrest: a professional researcher's perspective

Rather than raise specific questions, we should concentrate on the issues. It's not about gaps in knowledge but about making a difference. Research and development go together. What are the issues and the questions that are not acted on e.g. 'how can you make acute inpatient care more therapeutic and what are the alternatives to it?', for this area many issues have been raised but none have been acted on.

There is a mismatch between the priorities of professionals, who are concerned with efficacy, and consumers who are concerned with day-to-day life and distress. There is a mismatch between the views and priorities of different health professionals e.g. GPs and OT's

A diversity of views is useful but a pecking order exists that favours certain questions and approaches that value effectiveness, efficiency, and cost-effectiveness.

We need to challenge current values and the resulting evidence base. Dialogue in which commissioners are included is crucial to this.

#### b. Graham Morgan: a service user's perspective

A list of things I would like to know more about:

- The ideal user is described as someone who wants control, equality and empowerment – but what about the times people want sanctuary, reassurance and passivity? What do people want and when?
- The idea of us 'lacking in insight' which is often an excuse for bad treatment – is this really the case?
- Sanctions can work if imposed by people we love – should we use them if they work?
- The role of 'love, warmth and humanity' in keeping people going.
- How relationships are affected when people are ill?
- Spirituality and religion – a comfort or a cause of distress?
- Effectiveness of peer support.
- Is there a mental health service-users community with common values and culture?
- Mental health workers who are also service users – crossing these boundaries.
- Why do some people choose not to access services when they are in trouble?
- Motivation – why do people lose it and how do they regain it?
- The motivations of workers in joining and staying with mental health services.
- Professionals and stigma – some professionals choose not to recognise service-users outside of hospital so as not to make them a target for stigma – does this really protect people?

### **c. Colin McCormack: a mental health manager's perspective**

Forming questions is hard, good questions take time and effort, you need to start early at the beginning of your project. Often the answers to good questions are hard to take and hard to remember. Service providers and service-users are often saying different things. We need to distinguish between what is wanted and what is needed.

Implementation of change must be built in to the questions we ask, GPs and other staff are under pressure, they are looking for results 'now'. We're not investing enough in staff in the widest sense

Likewise commissioners of research make it hard to affect a broader 'well-being' agenda. Funders are reluctant to commit resources to alternative therapies for example.

How do we find a balance in the questions we ask? This is a massive issue – and it's about investing in health improvement ...

There is a distinction between primary care service-users, which takes in the whole population, and secondary care service-users who face greater difficulties and are a smaller group. It is hard to get primary care users to give mental health information.

Who knows best? It's not always the user. What does it mean to be a service user? How do we include everyone, especially those who experience mild to moderate problems such as depression or anxiety at primary care level?

We need a feedback process for questions routinely raised on a day to day basis.

Questions should be asked around abuse, poverty, racism which have a high impact on mental health. Young people are key but this has now dropped off the agenda

### **d. Gregor Henderson: a policy maker's perspective**

#### **Gregor Henderson**

- The whole population needs good mental health and well being.
- 70% recognise themselves as having had some form of mental health problem.
- 30 – 40% of the population visit their GP with a mental health problem.
- 7 – 10% of the population are diagnosed with severe and enduring mental health problems.

Some research questions are universal and some need to be targeted. The right research questions have to be asked:

- Of the whole population about mental health.
- Of those developing mental health problems.
- Of those diagnosed with mental health problems.

A modern mental health policy needs research questions to back it up and policy does not just apply to the 7 – 10% of the population with mental health problems.

Research needs to challenge the status quo by identifying what needs to change and demonstrate the value of the alternatives. It will be important to research people's experiences of mental health over the long-term and identify what made a difference. In Scotland mental health policy was made on research after 3 years of resettlement following 30 years of hospitalisation. In Vermont, research after 20 years found that the key aspects that made a difference to people were relationships, civic engagement, good housing and employment etc.

The focus of research on the severe and enduring end of mental ill health seems to benefit drug companies rather than the wider population. The pharmaceutical industry pathologises everything and we play into their hands. We need to look at why 20% of people with mental health problems don't recover and what helps those who do recover to achieve this? Supportive relationships and civic engagement matter – the business of mental health makes it something that we all have to engage with and not just those using services.

#### **e. Emma Hogg: a research commissioner's perspective**

There is a sense of being overwhelmed if we take a broad approach to the important questions in mental health research. The population needs good mental health and some have mental health problems so it's about promotion, prevention and treatment among diverse groups.

Under funding of research may mean that many questions are not answered. A lot of questions get asked and are not answered. We do not have a systematic way of arriving at priorities and we have not identified what we need to know in a participative way.

In answering the question set in a generalised way, we have to go back to basics:

- What priority areas (based on professional and lay views, political perspectives and epidemiology) have to be addressed?
- For each area - what do we know, what's already been done and what are the gaps?
- To address gaps, what research do we need?
- What makes things work in the short and long-term?
- How do we communicate gaps to the research community and people who will undertake it so that it is undertaken in a co-ordinated way?

The National Strategy set out 3 areas as a priority:

- Younger people.
- Older people.
- Workplace.

The evidence base for mental health is small – we do know some interventions are effective and some of the outcomes people. We need to identify the key aspects of these interventions and how effective they are in the long term and whether they can be generalised. It is important to match up effectiveness evidence with needs identified by those experiencing mental health problems.

So need to use basic questions to identify important research questions.

<b>What are the important research questions for mental health and why? Key ideas and points raised in discussion.</b>
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There was a call for mental health research to start concentrating more on the person and rather than services. Convincing professionals, providers and other decision makers of the value of qualitative research in addition to randomised controlled trials is a key challenge.

### **Recovery**

- Research which addresses potential factors that might form a broader programme in researching 'the fundamental' elements that we all need to sustain mental well-being.
- Impact of relationships and supporting relationships in prevention and recovery and to sustain well being.
- What might motivate people to recovery and to sustain it e.g. workplace, friendships, raising confidence and reducing stigma.
- What factors might contribute to maintaining or re-integrating people within their community, particularly the value of employment and the value of supporting relationships.
- Developing insight and control and influence over your mental health problem and therefore your own life – what is the role of self-help/responsibility?

### **Diagnosis**

- What are the effects of labelling with a diagnosis, particularly the effects of multiple and different diagnoses on the service user? The effects on the patient and their ability to recover and gain understanding of their illness as a result of this multiple labelling should also be a priority.
- How does life pan out for people following diagnosis with a mental illness?
- People with dementia not told diagnosis – why not?
- Does a diagnosis leave you labelled or are people left in limbo without a diagnosis and damaged by this?
- How are relationships with carers and family members affected if they get given a diagnosis and the person does not?
- How long do labels last?

### **Medication**

- Why the increasing use of medication – is there a culture change surrounding perceptions of mental health/mental illness and are problems being dealt with in other ways? Is this increase patient-led, media-driven or the medical professions response to the management of societal problems?
- Does 'treatment' provided the diagnosis – is the diagnosis was just a secondary factor to justify the chosen medication?

### **Stigma**

- What shapes public attitudes towards mental health and what changes these attitudes?
- What is the effect of 'stigma within' people with mental health problems?

- People with mental health problems have stigma themselves about their problems and can do more of a disservice to themselves than other people can.
- How to get people who have experienced MH problems to feel valued, to allow them to shed their own perceived stigma and to feel part of the community despite their illness?
- Forensic services and 'stigma' – ineffectual campaigns at present – campaigns need to be specific strategies for specific communities.
- Where supported accommodation has been set up in the face of a NIMBY reaction, what happens in the years afterwards? Did consultation help or hinder the process? What are relationships like between the neighbours? Has any of the issues feared by neighbours arisen?

### **Balancing the needs of patients with provision of different types of help**

- How do people learn to access services?
- When is one approach more appropriate than the other, for whom and in what circumstances? More specifically, if some form of sanctuary (hospital care) is required is there a point where this serves to make things more difficult?
- How can service providers become partners with service users in making decisions as to which type of care is appropriate and at different points in time?
- How can acute care be made more therapeutic? What are the alternatives to acute care and how to make acute services more therapeutic and effective?
- Research that addressed why there was often inconsistency with psychiatry in relation to diagnosis should be conducted.
- Why has sectioning increased recently? Has stigma and the media been involved in this?
- How can types of support be set within individual contexts that may change?
- Advocacy – what does it mean? Does it exist and if not why not?
- Being open to the value of new 'genetic' research to medical services and mental health – around human genome.

### **Locally based research**

- What is the use of regional research; does it always have to be national and applicable to all areas?

### **Mental health and the workplace**

- If people become ill in the workplace, managers and workmates don't know what to do and ignore it or don't deal with issues – if people are not 'experts' they feel they don't know what to do. This needs to be addressed.

### **Care in the community**

- Care in the community – what does it mean? Does it exist and if not why not?
- What does the system do about people who are totally alone in the community?

### **Young people**

- Need to highlight the importance of research into mental health of children and young people.

**And next** ... communicating all this with others.

## Seminar 2: Making Good Use of the Answers

A further five speakers were selected to represent particular perspectives; professional researcher, policy maker, service user, research commissioner and mental health professional. Each speaker was asked to make a five-minute presentation answering two questions and each of these presentations was followed by time for debate and table discussions.

Chair: Maddy Halliday, Director (Scotland & UK Development), The Mental Health Foundation

### Debate 1: What makes good quality mental health research evidence?

#### Summary of Speakers' Presentations

##### a. Sue Cowan: a professional researcher's perspective

A meaningful partnership between service users and professionals has to exist from the outset and be sustained throughout the process. Guidelines are needed about involving people including payment. These need to be respectful but also corrected as 'we' go.

Issues in assessing the quality of research:

- Justification is needed to carry out any research, there is no point in reinventing the wheel, there must be a clear need for it. Check to see if someone has already looked at this area and whether that research can be used 'off the peg'.
- Research questions should be clearly researchable.
- Methods should be relevant to what is being researched – different types of method from randomised controlled trials to qualitative interviews for different research questions.
- The right process should be in place, this involves: going to the right people for information, using the right tools, reaching the right conclusions from the analysis.
- The research should have 'fruitfulness' - a practical outcome is needed.
- Recommendations should be clearly linked lead logically from findings.
- Research should recognise its limitations.
- Ethics should ensure informed consent and full participation.
- Reports should be accessible to the target audience.

##### b. Denise Coia: a policy maker's perspective

Service users should drive research and this is where there should be investment leading to a partnership between professionals and users. What makes good quality mental health research evidence depends on how you define evidence. As a commissioner, I see three areas of evidence:

###### 1. Evidence-based medicine

This is a scientific principle that most doctors hate; there was a recent vote in The Royal College of Psychiatrists where 184 to 12 psychiatrists did not support it.

Evidence-based medicine is based on the following concepts:

- Utilitarianism – getting the most for the population.
- Positivism – it can be measured.
- Randomised Controlled Trials (RCT).

We know that evidence-based medicine will work and so we don't offer people the impossible. But it can stifle innovation. There are many types of mental health interventions that we simply cannot measure. It limits individual therapies such as for alcohol misuse / relationship difficulties etc. as they don't fit the boxes that RCT demands, real life experiences are excluded from many RCTS making them unrealistic.

### 2. Satisfaction with services

How do you get the questions right? Should they be open-ended or should we use standardised ratings scales? One good scale is the Avon Scale which has been piloted in Scotland and gives a reasonable view of ratings of services.

### 3. Qualitative research

Stirling University is involved in research into personality disorders. All agencies involved are in disagreement but this research looked at what do people access and feel the benefit from? The methods used are individual interviews and this gives a richer tapestry. Psychiatrists are fond of case studies and people writing about their experiences. It is a much richer way of describing problems people face in their lives.

The difficulty remaining is which of the above three do you prioritise?

### **c. Ron Coleman: a service user's perspective**

I'm a research fellow with UCE but I hate research. Mental Health researchers always claim to be the 'principle author' when in fact they are just the 'writer'. The authors are the people who tell their stories. The writers should state name and 'et al'. An example of good practice would be a book of stories on recovery published in New Zealand.

Clinical evidence around medication is 'sad'. The problem is that medicine dominates research, that is, the drug companies. Haloperidol is often used as a comparison for new medication, but it is a very poor drug – making new medications look better than they really are. Drug companies do not fund research that looks at why some people don't relapse and actually recover.

This is not enough honesty in mental health research, honesty is needed but this is not enough in itself. For example research found that 57% of people relapsed when they stopped taking anti-psychotic medication. But this hides the results from the control group where 16% of people relapsed in any case. So there was a real difference of 41%! And if you change the perspective to looking from the angle of recovery, 10 months after stopping taking medication 43% of people had not relapsed but recovered!

So drug companies fund most of mental health research... who would fund research into recovery instead?

#### d. Peter Craig: a research commissioner's perspective

A hierarchy of evidence	
1+ +	High quality meta-analyses, systematic reviews of RCTs, RCTs with a very low risk of bias
1+	Well conducted meta-analyses, systematic reviews of RCTs, RCTs with a low risk of bias
1-	Meta analyses, systematic reviews of RCTs, RCTs with a high risk of bias
2+ +	High quality systematic reviews of case-control or cohort studies or high quality case-control or cohort studies with a very low risk of confounding, bias, chance, etc.
2+	High quality case-control or cohort studies with a low risk of confounding, bias, chance, etc.
2-	Case-control or cohort studies with a high risk of confounding, bias, chance, etc.
3	Non-analytic studies, e.g. case reports, case series
4	Expert opinion

There is the hierarchy of evidence used in compiling SIGN guidelines and to inform decisions about health research commissioning in Scotland. The strength of recommendations depends on the quality of evidence.

In the top group are randomised controlled trials and systematic reviews. Meta-analysis is a way of pooling and re-analysing the data from many studies on related questions (such as 'is CBT an effective treatment for depression in elderly people?') to get more precise and reliable results. In the 2nd group of the hierarchy are observational studies and reviews of these studies. Nearly all such studies are subject to problems of bias and confounding, so they are not as reliable as good trials. In the 3rd group are weaker forms of evidence from smaller scale studies; and bottom of the heap is expert opinion.

Some people argue that this hierarchy itself is biased against some kinds of research and against the kinds of treatment that do not attract the highest quality research designs.

There is some truth in this. For example, by designing trials to minimise bias, they may end up being nothing like everyday clinical practice. But there are many examples where results from weaker designs such as cohort studies have been shown to be misleading when put to the test in randomised trials. Clinical guidelines based on quality of evidence may overlook the organisation of care and the demands of effective changes in practice.

So, the answer is not to abandon the hierarchy but to make sure that good quality evidence is gathered across the whole range of clinical and non-clinical interventions, and that studies are designed in such a way that the results apply to everyday practice. We can still use the hierarchy but we need:

1. More realistic and pragmatic trials.
2. More trials around methods of service delivery and organisation of care.
3. Evidence of cost-utility, not just effectiveness.

### e. Chris Williams: a mental health professional's perspective

Good quality evidence means:

- Asking relevant questions and clarifying what we do and don't know by taking into account different perspectives and what works for whom?
- Recognising that proven 'efficacy' of treatment from well-controlled studies may not actually work in like real lives ... we need to know what is effective, and that will have to take into account issues like 'equitable access' to services.
- Being effective – for psychological therapies this means:
  - having a structure to our work.
  - built on therapeutic relationships – takes two to tango.
  - focus on what is relevant to the patient/client.

When an intervention is effective the therapist may describe success as 'depression reduces', the client as 'feeling better, doing well'. Mental health treatment is not like taking a pill, we need to listen and use everyday language as we do in Cognitive Behavioural Therapy.

Training is needed for staff and for users and carers, in evidence-based approaches that address the above questions.

<b>What makes good quality mental health research evidence? Key ideas and points raised in discussion</b>
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### **What makes an expert?**

- Deciding what good research is at the commissioning and publishing ends of the research process is undertaken by peer review by those considered to be experts. There is concern that the traditional peer review processes may be less legitimate due to a general lack of user and carer involvement. It is important that peer review includes people who represent the different contexts that are under investigation.
- We are all potential users and/or carers, putting people into different boxes can be unhelpful, our roles in life are always open to change. There are users who have PhDs, we should get better at using their expertise and knowledge. However when comes to funding, it is unlikely a researcher will get a grant if labelled as user.
- There was a gut fear that good quality evidence for commissioners and government departments is very different to the evidence wanted on the ground. Commissioners need to get out and listen to practitioners and service users.
- The crucial place of service user 'experiences' should not be underestimated. People's experiences are real; they are alive and felt, bringing a validity check to theoretical analysis and academic exercises.

### **Does good quality evidence equate to helpful evidence?**

- It may be useful to think about what research is 'helpful' rather than 'right'. There was scepticism that evidence can be manipulated to suit a political process where research may be viewed as good and be used if it gives the 'right' answers from the policy maker's perspective, or 'bad' and ignored if it gives the 'wrong' answers.
- For many users and carers, the question of whether research evidence is of good quality or otherwise can often become irrelevant when findings which might lead to change/improvement in the lives of users and carers are put on selves or conveniently buried depending on the outcomes of that research.
- Good quality evidence and research also needs to be above 'current politics' if it is independent, values the personal experience and is helpful then it is valuable and needs to be heard and acted upon.
- Good quality of research should underpin the ethos of partnership with users/carers, where there was a clearly justified need for the research and where there were clear research questions.

## Does the traditional hierarchy of evidence promote good quality evidence?

- The traditional hierarchy of evidence is not value-free and there was concern about power relationships exercising dominance e.g. CBT is the fad now. The hierarchy is a framework for commissioning and evidence-based decision making, currently the medical community has the ears of the Ministers. There's a top down approach to research, that is, professionalism of research and the hierarchy makes it difficult for newcomers to access funding.
- To gain a full picture and influence many people, evidence needs to be produced through many different methodologies. People are influenced by many different kinds of evidence, from RCTS to the arts e.g. poetry, theatre.
- Need an objective review about RCTs drugs and CBT – to find out where the gaps are.
- The quality of the evidence is very much dependent on the quality of the questions just as much as the quality of how you get the answers.
- People's stories are hugely important evidence but are described as 'anecdotes' in an attempt to discredit qualitative work by decision makers. However qualitative data is no less generalisable than 'sanitised' RCTs.

## Demystifying the research process

- The whole process of research could do with some demystification. We are all involved with evidence, we are all experts and good evidence can come from everywhere.
- The language used in research is a barrier at all stages.
- The quality of research evidence would be improved if questions being asked of service users were set in everyday language thus allowing people being asked, a far better opportunity of participating and contributing.
- Research quality would also be enhanced if people were questioned in a safe environment, given appropriate information about the research and if there was an 'openness' about the research which would somehow help to demystify research.
- Research questions should relate to the needs and interests of people with mental health problems such as better housing, employment, etc.
- Research could be made more of a helpful tool for people who experience mental health problems. This might mean asking how do people manage their own illness and what role does insight have into this? Hearing Voices are very good in terms of making sense of this and recognise people deal with this in different ways. People need to be able to try different things and feel that they are in control.
- Where does the evidence go? There is not some recognised outlet for sharing information although access to what counts as quality evidence is essential.
- Research should be reflected back to users to find out what it means to them.

- It was argued that using users as researchers was valuable, because quite often people were more open and honest with their answers, meaning that the evidence produced in such a situation was of good quality.

### **New perspectives in research - from mental ill health to mental well-being**

- It will be important for all stakeholders to interact more together and generate a shared vision that brings together mental illness and good mental health, keeps focus on keeping people well and values personal experience.
- We tend to focus on problems in research, we need to turn negatives into positives, it's not all about mental health problems but about well being and mental health. The usefulness of concept of recovery needs to be explored and alongside the characteristics of successes and aspirations.
- Drug company research can distort the evidence about medication; more research on medications should be done in partnership with users and carers.
- Funders and commissioners should take more risks.
- To be able to turn these experiences, both of well-being and of illness, into legitimate research evidence, there is a need to involve service users at all levels of research and indeed, at all stages of any research programme.

## Debate 2: How can we get better at applying mental health research evidence to policy and practice?

### Summary of Speakers' Presentations

#### a. Sue Cowan: a professional researcher's perspective

Different styles of reporting of research findings need to be tailored to the needs of different audiences we want to influence. The length of time between research findings and publications is too long.

Understanding the barriers to implementing research findings, lets us find ways to overcome them. Often management systems can thwart innovation and the use of new evidence based approaches.

Political lobbying is a key way to influence the use of evidence and service users and carers need to get involved in this.

#### b. Denise Coia: a policy maker's perspective

Do we want to apply the evidence? The discussions at today's seminar are not clear about this. Stakeholders need to be signed up and agreed on evidence – is this what is happening? We need to be clear about where evidence is coming from and how it relates to our own context. Opening up commissioning to the public might bring together our very different ideas.

How do we decide what to give up for new evidence-based interventions? Do we give up those interventions for which there is a poor evidence base? One example is non-directional counselling, despite a lack of research evidence of effectiveness, people who receive it value it.

Currently research money is funding small, distinct projects. We need to coalesce together and review of value of research undertaken and it's utilisation in terms of increasing positive outcomes. This learning could help to build a research funding strategy.

How do we get evidence into policy and practice? There are two key service issues here, management accountability and clinical effectiveness. These are difficult to join-up and implement because there is no one in health services with a role to direct this. Audit and evaluation of what we are doing now, at present, is important.

#### c. Ron Coleman: a service user's perspective

I've decided I'm not a service user anymore, score that out, I'm a person.

The question 'How can we get better at applying mental health research evidence to policy and practice?' should be 'When are we going to start applying the evidence?'

One thing we're great at is ignoring the evidence. Research has been ignored. In 1966 William Sergeant looked at recovery rates in schizophrenia:

- 1938 – 33%
- 1958 – 33% (with new medication)
- 1988 – 33% (with new medication)
- 1998 – 33% (with new medication)

We've done nothing with this evidence – the recovery rate remains constant. In India, the recovery rate is 87%. They get better, quicker – why? We don't know and there are no funds for research into this.

The recent Milan report was research, a gathering of information, analysis and application of consultation about the Mental Health Bill. It identified 10 principles for a mental health bill but the Bill threw them out, this demonstrates no reciprocity. Policy makers ignore the evidence when it's presented and refuse to implement it.

The impact on policy and practice is political; you cannot just go to MSPs and give them research results. They don't get out and about and are guided by others. The commissioners decide what to research based on the flavour of the month.

Recent research has shown that personal relationship is a big part of recovery. Research showed that 40% of a recovery outcome depends on relationships compared to 15% of outcome depending on the therapy received. What does this mean for the kind of research we do?

#### **d. Peter Craig: a research commissioner's perspective**

I don't think there is any coherent objection to the principle of evidence-based practice. The questions are to do with:

- The availability of good, relevant evidence.
- What counts as good evidence?
- How to get it into practice quicker.

Systematic reviews often reveal that what looks initially like a very large volume of research quickly boils down to a very small number of good quality studies. Information about cost-effectiveness is particularly scarce and some economists question whether standard methods of economic appraisal are a good basis for making decisions about whether to implement effective but costly new interventions.

Another important issue is how to use non-standard sources of evidence, for example qualitative or ethnographic studies, to improve estimates of the effectiveness of interventions without building in biases. Methods are being worked up but they are complicated and time-consuming and still very much at the development stage.

Evidence-based policy is a more debateable notion. Clinical practice is subject to many influences that may delay or block the implementation of evidence. Policy-making is subject to an even wider array of influences other than evidence about effectiveness, and measuring the impact of research is virtually impossible. Policies may have a number of explicit and implicit objectives to which research evidence

may not really be relevant. Researchers find this frustrating - and so do policy-makers and members of the public, who can't understand why research is often so indeterminate.

The way forward, according to one influential argument, is to develop more of a 'policy community' in which researchers, policy-makers, practitioners and users of services can exchange ideas, and also to develop more sophisticated ways of commissioning research, including 'iterative tendering' in which practitioners and users have a say in determining priorities.

Again there are experiments under way, many research funders including the MRC and the CSO are developing mechanisms for user involvement, for example, and it will be interesting to see how these turn out.

However successful these are at making research more relevant, the other influences on policy will remain important, so researchers who seek to influence policy will need to look to their own strategy, and look for the turning points when policies are open to change, and make sure that when these moments arrive they have something to say that is worth listening to.

#### **e. Chris Williams: a mental health professional's perspective**

There is a large literature showing that Cognitive Behavioural Therapy (CBT) and self-help can be very effective for people with depression and anxiety. There are 35 systematic reviews about self-help however these are ignored by services. SPIRIT is trying to bring together of commissioners, researchers and practitioners. SPIRIT is training practitioners in use of self-help in teams and aims to take evidence into practice. CBT has been proven effective for many problems but it s difficult to access because there are only 800 credited CBT practitioners.

SPIRIT offers training in use of CBT with a self-help workbook that is jargon-free and at low cost and it can be photocopied. SPIRIT produces jargon free workbooks that help self-input, however trained staff are needed to train people on how to use the workbooks.

Overview of training:

- Identify trainers and teach.
- Train the trainers course.
- Training delivery.

The training is multi-disciplinary, staff work in pairs to deliver training, there are 3 courses of 16 sessions and 20 staff attend each course.

There is evaluation of practitioner training and a researcher has been appointed to gather the views of clients and the impact of SPIRIT on clinical services asking questions like 'are staff learning about caring?' and 'how can we improve self-help and is it helping people?'

## Discussion: How can we get better at applying mental health research evidence to policy and practice?

### Is dissemination enough?

- Research is about gathering information and sharing it, if it's not published then the people who make decisions cannot access the information. Researchers should be disseminators as part of the research process.
- There is an ethical responsibility to feedback to users and carers the results of research and look at why it does or does not make a difference.
- It would be helpful to focus research reports on the potential implications for change as a result of findings.
- Dissemination needs time and should be targeted using various means such as publications and interacting with people in seminars.
- Monitoring and evaluation should be built into the research process from the start and evaluate the effects on practice and lessons for policy.

### Engaging as partners in the policy process

- People outside government have to take on the responsibility to engage with policy, because we are all potential users, it is a societal responsibility.
- We can all engage with the policy process, no one group should have ownership; it should be an integrated process.
- In order to achieve good partnership between policy makers, practitioners and researchers, we need to open up 'institutional' cultures to give more transparency to the process of using evidence in mental health policy.
- There is little mental health co-ordination in the Scottish Executive, how can we get better when we don't know what is happening? Better co-ordination would help to develop relationships and partnerships amongst stakeholders.
- When evidence is somehow clearly 'amended' or even worse completely ignored, for political reasons, we need to put ourselves in a position to challenge this. If there is a current political agenda in mental health then users and carers need to know a) that it exists, and b) how they can influence it. This is about good information sharing as well as good timing.

### Commitment to change

- If we are really going to get better at applying evidence to both policy and practice then we need to have a real commitment to change, whether that is in the context of political lobbying, in the creation of improved mutual respect or in the creation of a new research culture.
- Stigma is a barrier to getting things changed especially in terms of inpatient care, formal care and medication. Raising mental health awareness amongst the

general public by opening up research and debates to public to help things change. More research that focuses on the positive side of mental health might change public perceptions and reduce stigma.

- Mental health less effective as lobbyists in comparison to other groups of health and social interest, there are not many high profile champions for the cause, is this because of the stigma?
- We need to ensure that the language of research evidence is such that it is understood by those we wish to influence and other interested groups, this would allow more stakeholders to take part in the policy and practice end of this agenda.

## **Appendix 1**

### **Developing the Mental Health Research Agenda in Partnership with Users and Carers**

#### **Planning Group Members**

Chair: Joanne McLean, Researcher, SDC  
Monica Griesbaum, Research Support Worker, MHF Scotland  
Bob Hvidsten, SDC Consultant  
Maggie Keppie, SDC Consultant  
Charlotte Lee, SHS Trust  
Eileen McCallum, Research and Resource Worker, SDC  
James McGill, SDC Consultant  
Nicola Williamson, MHF Scotland  
Laurence Wilson, Development Worker, Mental Health Network Greater Glasgow

#### **Additional Facilitators**

Gail Cunningham, SDC Consultant  
James Henderson, Action Researcher, SHS Trust  
Margaret Maxwell, Senior Research Fellow, University of Edinburgh