

**Communicating the message of recovery:
an independent evaluation of SRN
communications**

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Notes and acknowledgements

Terminology

Throughout this report, while we recognise the complexities around language (including the use of the word diagnosis), we use the term **service users** to refer to people who have been previously diagnosed with mental health problems. We use the term **carer** to refer to people who have a personal relationship with service users and offer informal support. These include service users' families and friends.

When presenting an individual's view we do not disclose gender hence our use of he/she and his/her. This convention is used to further protect the **anonymity** of those involved in the research.

We use the term SRN **resources** to refer to its printed and electronic outputs.

Disclaimer

The opinions expressed in this publication are those of the researchers and are not necessarily those of the Scottish Recovery Network

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Executive Summary

Background

The Scottish Recovery Network (SRN) is funded by the Scottish Government's Mental Health Division to provide a national platform for promoting and supporting the message of recovery for people with mental health problems including those that are long term or serious.

A number of tenets or themes about recovery underpin much of SRN's activity and also are explicitly formulated as key messages. These include:

- people can and do recover from even the most severe mental health problems;
- recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms;
- no two people's recovery journey or experience will be the same; and
- the critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery.

A cornerstone of SRN's approach is to collect, distil and share narrative accounts or personal stories from service users on what has helped them recover. These accounts and messages are communicated in a number of ways including through:

- *Recovering Mental Health in Scotland* which is a detailed research report targeted at professions that distils the findings of interviews with over sixty service users on what has helped them recover
- *Journeys of Recovery* which is a compendium of twelve stories selected from the original pool of narratives to provide a spread of experiences;
- *Routes to Recovery* which is derived from the narrative research findings and distils some of the key factors that contribute to individuals' recovery;
- five postcards which provide one or two word recovery messages on one side, and more detail about SRN and recovery on the other; and
- its website, electronic communications and events.

Evaluation aims

In April 2008, SRN commissioned an independent evaluation to:

- assess the appropriateness and effectiveness of current SRN printed and electronic outputs to communicate the message of recovery in Scotland;
- explore whether, and how, the messages being communicated are understood and acted on by all its intended audiences, and identify levers and barriers; and
- develop recommendations for how the message of recovery might be communicated most effectively.

As a consequence, this evaluation focused on the key messages and resources outlined above.

Methods

The evaluation comprised:

- a web-based survey, primarily aimed at those with a professional interest in SRN which was completed by 388 professionals;
- one-to-one interviews with ten professionals;
- six one-to-one interviews and four focus groups with mental health service users; and
- six one-to-one interviews with carers.

Attempts were made to obtain views from a diverse range of individuals. However, as the web based survey was sent to those already on SRN's email list, and as professional interviewees were, in the main drawn from survey respondents, the sample of professionals may have provided a skewed (positive) perspective. Similarly, the sample is not representative of all service users and carers in Scotland.

Key findings

There was a high level of consistency in the views expressed by the professionals, service users and carers in this evaluation.

Messages of recovery

In general, SRN's messages of recovery, and the associated resources, were valued for being positive, optimistic and affirming. However, those service users who did not consider themselves to be in recovery tended to be less receptive to messages of recovery, and to the resources.

Some participants felt that the concept of recovery could be interpreted to mean either a state of full recovery or a journey or process and there is a need for SRN to clarify that both meanings are intended. Such 'either or' thinking was associated with some people disengaging with recovery messages.

Feeling in control of one's life and the support of others were seen as important features of recovery that were not explicitly formulated in SRN's current recovery messages.

The communications and resources

Overwhelmingly, the narratives that form the basis of the communications were valued for conveying real life experiences, and were seen as a useful way to communicate messages of recovery.

Individuals expressed an interest in more stories being published of the sort contained in Journeys of Recovery: in order that people could find a story to which they could personally relate, many felt the selection should cover a wider spectrum of experiences than currently contained in this publication.

The ability to dip into a booklet and read the bits that are of interest was valued. Many professionals and carers identified this as a strength of Routes to Recovery.

Service users, carers and professionals found it more difficult to find their way round Journeys of Recovery.

In general service users liked the short positive messages on the front of the postcards.

Many professionals found Recovering Mental Health in Scotland to be a useful resource for referencing and for endorsing the need for recovery-focused planning.

Some participants felt that booklets targeting service users needed to be adapted to take greater account of the concentration difficulties that they can experience because of their mental health problems. Service users and carers could disengage from messages or resources that were seen to use jargon or quite medical language.

The evaluation raised issues about when (early or later in terms of diagnoses and treatment) and with whom (those with mild and more severe illness) the resources should ideally be used. SRN do not currently provide supporting information to guide the use of the materials.

Awareness

It would seem that SRN's large scale distribution of resources has not translated into high levels of awareness among those who participated in this evaluation. The exception to this was awareness among those accessed via SRN's electronic mailing list, however, even in this group for some resources awareness was only around 50%.

Impact of knowledge and practice

Many service users found the resources generally were optimistic and hopeful, and felt that they validated their own experiences. Carers found the resources informative and reassuring.

The resources were used in varied ways by the professionals: some used them as part of a therapeutic encounter while others made them generally available for their client group to pick up.

Many of the professionals involved in the evaluation reported that SRN had influenced and reinforced their knowledge and practice and that of the organisations/structures within which they worked.

Selected recommendations

We recommend that SRN:

- continues to use personal narratives to communicate recovery messages;
- refines its key messages and creates new ones highlighting that recovery can refer both to a state and a process, and emphasising both the importance of supportive professionals, carers and families; and self- efficacy;
- publishes a wider range of stories including ones on people from BME communities;

- offers information to professionals to assist them on how and when they might best use available booklets; and
- further considers the information requirements of each of its 'audience types' and develops future communications that are more targeted and tailored to their respective needs in substance and style;
- pre test any new materials directly with the target groups at which they are aimed; and
- redevelops their existing database to enhance their knowledge of their client group, and the reach and uptake of their resources.

Conclusion

SRN is still relatively young: it was established at the end of 2004 to act as a catalyst of change, aiming to promote and embed recovery-oriented values and actions. This role reflects the fact that as a nation 'we are not yet there' in our recovery thinking and our practices, that more needs to happen. As such, the work of SRN has to be understood as part of, indeed a beacon within, a recovery movement that involves a paradigm shift in the way professionals, service users and others conceptualise mental health problems. Given this SRN have achieved much in terms of raising awareness about recovery and reinforcing or influencing the recovery orientated thinking and practice and capacity of some of Scotland's professionals, service users and carers. There remains, however, much to be done in terms of increasing reach and impact of SRNs key messages and learning if recovery orientated thinking, practice and support are to become the 'normal' experience for service users, carers and professionals in Scotland.

Chapter One: Introduction

This is a report on an independent evaluation of the messages and resources disseminated by the Scottish Recovery Network (SRN). This chapter briefly outlines the role of SRN and details the objectives of the evaluation.

About SRN

*"We believe that recovery is an issue for everyone. ... What we are doing is trying learn more about what helps and to share that information as widely as possible."*¹

SRN is funded by the Scottish Government's Mental Health Division to provide a national platform for promoting and supporting the message of recovery for people with mental health problems including those that are long term or serious.

SRN's vision is for improved outcomes for this target group. Its role in contributing to these is through promoting and embedding recovery oriented values, attitudes, behaviours, policies and practices. Accordingly, the target group for SRN is not only mental health service users but those who can play a part in supporting them viz. service providers, families, carers and indeed the general public.

SRN's activities include awareness raising, building understanding of what helps people recover, and identifying and supporting good practice. Through these approaches, SRN seeks to act as a catalyst for change.

A number of tenets or themes about recovery underpin much of SRN's activity and also are explicitly formulated as key messages. These include:

- people can and do recover from even the most severe mental health problems;
- recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms;
- no two people's recovery journey or experience will be the same; and
- the critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery.

While these key messages are presented on SRN's website, it should be acknowledged that SRN recognises that the last of these is a rather complex one.

A cornerstone of SRN action is its narrative investigation of mental health recovery through the collection and analysis of sixty four accounts from mental health service users which describe what has helped them recover and stay well. This work has spawned a number of key outputs, most notably: *Journeys of Recovery*² which is a compendium of twelve stories selected from the original sixty four; *Routes to Recovery* which distils some of the key factors that were felt to contribute to individuals' recovery; and *Recovering Mental Health in Scotland* which is a detailed research report aimed at professionals, particularly those with an academic interest in recovery. In addition, selected messages of recovery are presented on five postcards. On the reverse side of each of these an explanation is given of the message itself, the concept of recovery, and the role of SRN. All, in particular the

¹ <http://www.scottishrecovery.net/content/default.asp?page=s4>

² The narrative accounts presented in Journeys of Recovery are also available on CD and podcast.

more detailed booklets, are intended to contribute to positive change in knowledge and beliefs regarding the possibility of recovery, and in recovery-oriented activities.

These resources outlined above are complemented by a range of other communications. These include: SRN's website intended for use by professionals and non-professionals; its email update service to over 4,000 individuals and organisations; meetings and dissemination events. The website provides an opportunity for service users to add their own stories of recovery, and as a consequence about a hundred accounts can be accessed in this way.

A small team is responsible for leading SRN activity, particularly through developing, expanding, informing and mobilising a network of individuals and diverse organisations that all have an interest in the development of recovery.

As part of its research programme and to inform future activities, in March 2008 SRN commissioned this independent assessment of the impact and effectiveness of its core communications, particularly its electronic and printed resources.

The commissioned evaluation

SRN commissioned this evaluation to:

- assess the appropriateness and effectiveness of current SRN printed and electronic outputs to communicate the message of recovery in Scotland;
- explore whether, and how, the messages being communicated are understood and acted on by all its intended audiences, and identify levers and barriers; and
- develop recommendations for how the message of recovery might be communicated most effectively.

In response, this evaluation was developed to:

- explicate the knowledge, attitudinal or behaviour change that SRN anticipates among key target groups (professionals, those with mental health problems, carers and the general public) and to which SRN resources are expected to contribute;
- assess whether SRN's anticipated core target audiences are receiving the resources and what could be done to improve their distribution and uptake (reach);
- consider the extent to which the intended target audiences understand the SRN messages (comprehension);
- explore how the core messages are perceived and interpreted by different groups (perceptions);
- reflect on the appropriateness of the range of SRN resources for identified target groups and whether there is a need to adapt messages for different audiences (relevance);
- uncover whether/how the messages change the perceptions (e.g. their attitudes, values, outlook) of different target audiences and what they say they may *do* differently (behaviours and actions) as a result; and
- identify the settings and circumstances in which the resources are distributed and used, and the extent to which these contextual factors influence the intended use or impact of the resource (contextual influences).

The evaluation was conducted over the period April – September 2008.

Structure of this report

We have structured this report to enable the reader to dip in and read sections. Thus Chapter 2 provides a brief overview of the methods, with more detailed descriptions of these and associated findings given in subsequent chapters (3 – 6). Chapter 7 draws together the themes emerging from this whole evaluation, and we present our conclusions and recommendations in the final chapter.

Chapter Two: Overview of design and methods

This chapter briefly summarises the methods used to meet the evaluation objectives. There were two key stages to the data collection. The first focused on clarifying SRN's vision and its intended target audiences, and examining the extent to which its current systems enable it to track whether it is reaching these. This was achieved through a facilitated workshop with SRN staff and key stakeholders, and via a desk-based review of the information that SRN currently holds. The second stage involved collecting primary data from a sample of SRN's key target groups: professionals, service users and carers. The collection of these primary data, predominantly through interviews and focus groups, constituted the most significant dimension to the evaluation.

Formal ethical approval was not required for this work³, however our evaluation followed the ethical guidelines of the UK Evaluation Society⁴. Thus, informed consent was obtained from all those who participated in interviews or focus groups: all participants were given written information detailing the purpose of the evaluation, how their views would be used and reported, and written (signed) consent was obtained prior to any participation in the evaluation's interviews/focus groups.

In the remainder of this chapter, we summarise each of the dimensions to this evaluation.

Situation analysis workshop

A workshop was convened with SRN staff, members of its Management Board, and others with a role in its strategic planning. Using tools such as logic modelling and a SWOT analysis, this half-day session sought to identify: SRN's (internal) collective perspective on its intended outcomes; whether and how its suite of communication materials should or could contribute to these outcomes being achieved; and factors supporting or impeding the effectiveness of these resources. This workshop not only helped characterise the range of SRN's communication activities it also informed the rest of the research e.g. by clarifying the purpose and intended audiences of its booklets, website, electronic bulletins and events. In addition, a short report for internal use was produced.

Desk-based review of statistics held by SRN

The data that SRN hold on distribution of its communications were considered. The purpose of this desk-based review was two fold: first, (where possible) to distil information on the reach of SRN's assorted communications; and second, to appraise the usefulness of this routinely collected information with a view to subsequently formulating recommendations on how SRN might improve the quality (and meaningfulness) of the data it gathers. Accordingly, information was extracted

³ We liaised with the Scottish NHS Research Ethics Committee and were advised that our proposal represented a service evaluation, and as such, application for NHS ethics approval would not be required.

⁴ http://www.evaluation.org.uk/Pub_library/Good_Practice.htm

from SRN's records regarding its distribution of resources, email network, website activity and attendance at events. The findings from this have been fed back to SRN in a separate report.

Web-based survey

A web-based survey was developed, primarily but not exclusively targeted at people with a professional interest in SRN activities. This survey sought views on the full range of SRN's communications. Most questions required a response using a series of closed-set responses, although some provided an option for free text responses.

Unless respondents elected to provide their contact details, the survey was completed on an anonymous basis. A copy of the questions is available from SRN on request.

An electronic link to the web-based survey was sent to everyone on SRN's electronic distribution list and was live for 5 weeks.

Interviews with professionals

We conducted one-to-one interviews with ten professionals. Eight of these were recruited via the web-based survey which provided an option for respondents to provide their name and contact details if they were willing to be contacted for a follow up interview. These eight professionals were selected to provide a spread by profession and by geography. In addition, two professionals more "removed" from SRN were identified through appropriate national bodies relevant to their professional group.

Two topic guides were used: one for those more familiar with SRN (and recruited through the survey), the other for the two who were more removed from SRN activities. The topic guides principally focused on views of SRN and its activities and key messages, in particular views and use of SRN's written resources.

Interviews and focus groups with mental health service users

We conducted six one-to-one interviews and four focus groups with service users. Both interviewees and focus groups were selected with the intention of achieving diverse views. Thus, we purposively selected a wide range of individuals for our sample, attending to characteristics such as age, gender, socio-economic status, ethnicity, nature of mental health problem/illness, and (likely) familiarity/unfamiliarity with the concept of recovery. The six interviewees (three males, three females) were recruited through two general practices located in deprived areas of Glasgow and Renfrewshire, and through an NHS counselling service, also in Glasgow. Existing service user groups from across Scotland were used to recruit participants for the focus groups, each involving 5-6 individuals. With the exception of one all-women BME group, the focus groups had a roughly equal balance of men and women.

Interviews and focus groups focused on awareness and views of SRN and its activities, views on selected resources (Journeys of Recovery, Routes to Recovery and SRN's five postcards), and understanding and attitudes of SRN's key messages.

Where time permitted, interviewees were also asked questions about the extent to which their experiences of services have been recovery-oriented.

Interviews with family members and carers of service users

A purposive sample was recruited of six individuals who were closely related to and/or who cared for a person with a mental health problem. This sample was chosen to provide a spread of relationships such that it included a parent, sibling, partner, friend, and adult offspring/'child' of individuals with a variety of mental health problems. As with service users, the sample included individuals believed (on the basis of their address) to come from diverse socio-economic backgrounds. All were recruited from within Greater Glasgow and Clyde.

The topic guide largely mirrored that used with service users. In addition, it also asked questions on what does or might help and hinder them in communicating the message of recovery to the people they know with mental health problems.

Analysis of interviews and focus group data

Our analytic approach was informed by Framework⁵ (an approach devised for qualitative policy evaluation and used by the National Centre for Social Research). Thus emerging themes were identified within the accounts provided by service users, carers and professionals. In addition 'deviant cases were noted' i.e. those perspectives that differed from the 'common view'.

Triangulation of data

The data from each of the methods used were compared and contrasted. In this way we identified both cross-cutting themes and also areas where differences emerged between different types of respondent (i.e. professionals, service users and carers) and across data collection approaches (i.e. interviews and focus groups vs. survey data).

Summary

A number of data methods were used for this evaluation. These were:

- workshop with SRN staff, members of its Management Board, and others with a role in its strategic planning;
- a desk-based review of statistics held by SRN on the reach of its communications;
- a web-based survey, primarily aimed at those with a professional interest in SRN;
- one-to-one interviews with professionals;
- one-to-one interviews and focus groups with mental health service users;
- one-to-one interviews with family members/carers of mental health service users; and
- triangulation of data from the sources above.

⁵ Ritchie, J. Spencer, L. (1994) 'Qualitative data analysis for applied policy research' in Bryman, A. & Burgess RG. (eds). *Analysing Qualitative Data*. Taylor & Francis.

Chapter Three: Survey of professionals

This chapter summarises the findings from the web-based survey. The purpose of this survey was to obtain the views of many of the individuals signed up to receive SRN's electronic updates. Thus, through the survey we hoped to collect a breadth of data to complement the in-depth views that would be provided by the qualitative methods (interviews and focus groups).

At the time of the survey (June 2008), SRN held 4238 email addresses on its electronic mailing list. From these SRN received approximately 500 'bounce backs' making the adjusted total 3738, the majority of whom had a professional interest in SRN: SRN's records indicated that 2685 described themselves as directly involved in service provision.

These figures indicate that the majority of those receiving SRN's monthly electronic updates were professional stakeholders⁶. To reflect the composition of the distribution list, the survey was therefore developed primarily for completion by those with a professional interest in SRN. Our previous experience as researchers indicates that an electronic survey is a useful and appropriate method for collecting the views of this target group.

Survey design and administration

Although the survey was primarily intended to obtain views of professionals – by which we mean here anyone with a job that involves addressing the needs of people with mental health problems - it was designed with a view to providing opportunities for anyone on the email distribution list to complete it. The survey used a 'routing' system to ensure that respondents were posed questions that were appropriate and/or relevant to the answers they had previously given. In this way, it was possible to develop core questions for all, and an expanded set that would be relevant for professionals, the key target group for this survey.

Survey questions spanned a wide range of issues including: nature of interest in recovery (e.g. as a professional, service user or carer); awareness of the various SRN resources (written and electronic) and perceptions of their usefulness; and views on the appropriateness of SRN's key recovery messages. Also, those who described their interest as professional, were asked whether they would be willing to be contacted for interview, and if so, to provide their name and contact details.

A link to the survey was sent out via SRN's monthly email bulletin in June 2008 together with explanatory text highlighting that: SRN had commissioned independent consultants to carry out research on its communications; the survey was part of this; it would take a maximum of eight minutes to complete and that responses would be anonymous unless respondents opted to provide their contact details. A three week deadline was set for the survey's completion and this was subsequently extended by a further two weeks.

⁶ As the bounce backs may include professionals and non-professionals, it is not possible to determine the precise proportion of the adjusted total that are professionals. On the basis of available figures we can deduce that 63-72% of those on the distribution list are professionals.

Response rates

The survey was filled out by 388 individuals⁷. This represents just over 10% of those who were invited to complete the survey. Of the 388 respondents, 321 (83%) indicated that they had 'a job that involves addressing the needs of people with mental health problems'. Thus most respondents were from our intended target group.

As previously highlighted, although we know that 2685 of those on the SRN's email distribution lists describe themselves as professionals, SRN's records do not allow us to ascertain how many of these feature among its 500 'bounce backs'. As a consequence, it is not possible to determine the denominator precisely i.e. the exact number of professionals who were sent the survey in the first place. In turn, we cannot calculate the response rate for professionals (or for that matter, those who define themselves in other ways). On the basis of available figures, we can say that between 12 and 15% of professionals on the distribution list completed the survey. In the remainder of this chapter we summarise the responses of these professionals. A summary report of the results of the full survey however is available from SRN.

In considering the findings below, it is important to bear in mind that these should not be considered to be representative of the views of all professionals on the email distribution list (nor of course professionals more widely). In particular, it may be that those who are more attuned to, or supportive of, SRN will have been sufficiently motivated to respond. This potential bias should therefore be acknowledged.

Profile of professional respondents

The most common settings in which respondents worked were NHS Boards (43%) and the voluntary sector (32%). Over half (58%) indicated that they spent most of their professional time providing support/ treatment with far fewer describing their principal activities as strategic planning (15%), training (8%), research (2%) and advocacy (2%). Others described their activities as supervising/managing other staff, monitoring and evaluation, or administrative.

The professional roles of respondents were wide ranging and were characterised by their diversity: while the most commonly identified was that of mental health nurse (26%) respondents included occupational therapists, psychologists, pharmacists service managers, trainers, students, a bibliotherapist and a chaplain. Notably perhaps, there were only four psychiatrists and no general practitioners.

In addition to respondents with a Scotland-wide remit, there were respondents from each of the mainland Scottish NHS Boards. There were also two from Shetland and one from the Western Isles. Twenty one were from the wider UK with a further six from outwith the UK (e.g. the Netherlands, Canada, Australia and New Zealand).

Professionals' views on SRN's key messages

Extremely high levels of awareness were evident for three of SRN's key messages. 97%. 95% and 94% respectively indicated their awareness of the messages: 'People

⁷ As respondents could elect to 'skip' questions, not all 388 completed the full complement of questions that were posed

can and do recover from even the most severe mental health problems'; 'Recovery means the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms'; and 'No two people's recovery journey or experience will be the same'. 61% were aware of the message: 'The critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery'.

Respondents were asked to indicate the extent to which they agreed or disagreed with each of these messages, and the distribution of responses is shown in table 1.

High levels of agreement were evident across all with the most strongly endorsed being 'Recovery means the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms' and 'No two people's recovery journey or experience will be the same'. A significant minority (15%) indicated that they did not fully understand the message 'The critical assessment of attitudes and values can have a powerful impact on the an individual's prospect of recovery'.

Table 1: Agreement with key messages

	Strongly disagree	Disagree in part	Neither agree or disagree	Agree in part	Strongly agree	Don't fully understand message
People can and do recover from even the most severe mental health problems	2.6% [n= 8]	6.7% [n= 21]	2.6% [n = 8]	19.8% [n=62]	67.7% [n= 212]	0.6% [n = 2]
Recovery means the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms	2.9% [n= 9]	1.0% [n= 3]	1.3% [n= 4]	11.3% [n= 35]	82.0% [n= 255]	1.6% [n= 5]
No two people's recovery journey or experience will be the same	2.3% [n= 7]	1.6% [n= 5]	0.3% [n= 1]	9.0% [n= 28]	86.2% [n= 268]	0.6% [n= 2]
The critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery	1.9% [n= 6]	1.0% [n= 3]	2.6% [n= 8]	14.4% [n= 45]	65.1% [n= 203]	15.1% [n= 47]

Respondents were given the opportunity to add their comments on each of the messages, and high numbers did so: each of the four messages attracted between 67 – 105 comments. Below, we summarise the themes that emerged for each message. It is important to set these within the context of the strong agreement that was expressed across the key messages.

'People can and do recover from even the most severe mental health problems'

Many commented that the message is positive and that it gives hope: *It's a very strong and positive message* said one.

In particular, a number endorsed the message for conveying the possibility of recovery:

One has to have hope and be positive that recovery is possible

There is no reason that every person no matter what health issues they have cannot fulfil their unique potential

Others remarked on the veracity of the message. Thus some mentioned that their professional experiences testified to the truth of the message:

I know from experience in my own organisation and the amazing things people are capable of that this is true. They may have to live with some symptoms for their entire life, but that does not mean that they cannot be in recovery.

The more I practise in a recovery oriented way, the more convinced I am of the truth of this statement

Others reflected that the message is consistent with their personal⁸ experiences:

I am living proof that someone with long-term and classed as severe and enduring mental health problems can and do recover.

I meet people all over Scotland who are the evidence. Me too.

While these points explain and reinforce the respondents' agreement with the message, the remaining (and majority) of comments centred on respondents' reservations or caveats. Four key themes emerged. First, it was felt that it was important to acknowledge that people can and do recover *when the right supports are in place* i.e. when individuals have good personal support and appropriate treatment. Second, some expressed ambivalence about the notion of recovery as being relevant across all mental health problems:

Using the term "recovery" is reminiscent of the Santa Claus myth in that we use it to convince others that something is real when it is notRecovery in the true sense of the word is not possible for all who suffer from mental health issues, although it is without doubt possible for some. However, recovery in the sense that an individually tailored support system can help a sufferer to have an improved quality of life despite their illness is possible for most.

Dementia, Korsakoff's or sociopathy were highlighted as examples of problems that were unlikely to be amenable to recovery.

Such exceptions underpinned the third set of concerns that some held – that promoting recovery may give some people false hope. The possibility of the message creating unintended negative consequences was raised:

I still wonder about what "recovery" means to different people and about the possible negative message being sent to those who feel they have not "attained recovery".

This comment leads us to the next theme – that as a stand alone message, there is no acknowledgement that recovery can describe a process:

⁸ Some respondents described themselves as both having a professional role in mental health and as being service users or carers

This message requires background knowledge to understand fully what is meant by 'recover' and has a feeling of permanence about it which doesn't reflect the fluctuating journey that most people experience with their recovery.

'Recovery means the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms'

Comments concerning this message were overwhelmingly supportive: a great many felt that the message was positive, with some adding that that it was also realistic in its explicit reference to symptoms:

I think this is an essential part of the recovery message - that it doesn't have to mean that you have no symptoms or problems ever again, but that it IS possible to lead a 'real life' even with these.

This is a good statement as it concentrates on opportunity and fulfilment.... I do believe that if individuals look outward to the possibilities, the inward struggles or negative feelings can fade into the background or at the very least become less influential in the quest for happiness

However, although respondents liked the idea of promoting a full and satisfying life, some continued to express confusion over the concept of recovery, and specifically about whether recovery was possible in the presence of symptoms. As such, these reservations seemed to arise from difficulties with the word recovery:

Still believe that "Recovery" is the wrong word. Being able to cope and live with mental health problems to me is not being recovered

To recover, to me, means to be free of symptoms. I don't think it is possible to live as described in the presence of ongoing symptoms.

The final theme to emerge was around the language itself: *too long and wordy* said one, *I dislike the Americanisation of simple terminology. Why not just say 'getting better'* offered another.

'No two people's recovery journey or experience will be the same'

The comments that were made were largely further affirmations of the message: the uniqueness of individuals' experiences of recovery was restated by many (e.g. *It is like everything in life, everyone's experience is unique*). Furthermore, this message was seen to validate individuals' experiences:

I like it as it personalises recovery and alludes to the fact that there is no right or wrong way to recover.

Where respondents differed however was in relation to just how unique they felt that the actual steps to recovery are. So while some stressed that there are no definitive steps that people can take (e.g. *Nobody has a cookie cutter path to recovery*), others highlighted the possibility that individuals may share similar experiences:

Although each persons journey IS unique, people often share parallel / similar experiences and can learn from each other experiences. Shared experiences can lead to shared learning, building resilience, persistence and hope.

Here, (and in comments made by others), there is a sense that the message could be strengthened by introducing the idea that people could learn from others' experiences. One respondent suggested that this is important *so that patients don't feel that they are the only ones suffering in that way.*

‘The critical assessment of attitudes and values can have a powerful impact on an individual’s prospect of recovery’

In general terms, people agreed with the proposition that attitudes and values are important in shaping recovery. However, a common criticism of the message was that it was too complex, ‘too wordy’. *If I don’t fully understand this language others won’t either* commented one, *I agree, but it is too complex for most people to fully grasp. It needs to be simplified* said another. These sentiments are consistent with the fact (reported above) that quite a few (47, 15%) indicated that they did not fully understand the message.

In large part, people were confused about the reference to ‘critical assessment of attitudes and values’. Many said that they were unclear whose critical assessment was being referred to here and similarly whose values. Finally, some felt the term ‘critical assessment’, had negative and pejorative connotations. One suggested:

I think a softer way of putting the question would be to use the word "evaluation" rather than "critical assessment".

Awareness and views on written resources

SRN’s key booklets use stories (personal narratives) to communicate messages of recovery. Therefore, respondents were first asked how useful they felt such narratives were for service users, carers and professionals. As the distribution of responses in Table 2 indicates, overwhelmingly these were viewed as highly useful for all groups, particularly service users and carers.

Table 2: Views on usefulness of personal narratives

	Highly useful	Quite useful	Not useful	Not sure	Response Count
People with mental health problems	81.1% [n=253]	16.0% [n=50]	0.6% [n=2]	2.2% [n=7]	312
Families/friends /carers	80.4% [n=250]	17.0% [n=53]	0.6% [n=2]	1.9% [n=6]	311
Professionals	72.8% [n=225]	22.7% [n=70]	1.0% [n=3]	3.6% [n=11]	309

We asked respondents whether they were aware of SRN publications *Journeys of Recovery*, *Routes to Recovery* and *Recovering Mental Health in Scotland*. The percentages indicating their awareness of these were 81%, 53% and 58% respectively. The low levels of awareness for *Routes to Recovery* and *Recovering Mental Health in Scotland* are perhaps surprising given the fact that respondents are on SRN’s email distribution lists and therefore receive regular updates.

We then asked how useful respondents considered *Journeys of Recovery* and *Routes to Recovery* to be for professionals and for service users⁹. A breakdown of

⁹ Later in the survey we posed a series of separate questions that are relevant to the research report *Recovering Mental Health in Scotland*

responses is presented in table 3 with these indicating that the majority regarded both booklets as very useful for professionals and for service users.

Table 3: Views on usefulness of resources for professionals and for service users

		Very useful	Quite useful	Unsure	Not that useful	Useless	Can't remember
Journeys of Recovery	for professionals	61.9% n = 138	30.0% n = 67	5.8% n = 13	1.3% n = 3	0% n = 0	0.9% n = 2
	for service users	65.8% n = 146	25.7% n = 57	5.9% n = 13	1.8% n = 4	0% n = 0	0.9% n = 2
Routes to Recovery	for professionals	56.2% n = 68	28.1% n = 34	9.1% n = 11	1.7% n = 2	0.8% n = 1	4.1% n = 5
	for service users	61.8% n = 76	21.1% n = 26	9.8% n = 12	2.4% n = 3	0.8% n = 1	4.1% n = 5

In addition to rating the perceived usefulness of the resources, respondents had opportunities to provide (free text) comments in relation to each of the resources.

Comments regarding Journeys of Recovery

Consistent with the overall positive ratings that respondents provided, fifty one provided comments on perceived strengths of Journeys; less, twenty-nine, provided comments on weaknesses.

Many described this booklet as positive, inspirational, and engendering hope – strengths attributed to the fact that the content is drawn from service users' own perspectives. Others suggested that it should be mandatory reading for those working with people with mental health problems. However, a few were sceptical about whether many professionals would read it, and one suggested that it would be useful to have a partner volume that is 'more targeted at professionals'.

Some commented that they had received positive feedback from service users about Journeys, whereas many were concerned that a lot of service users may not relate to the stories. For example, it was felt that stories may not be personally relevant:

Some of the stories seemed to reflect high functioning people whilst a great many (service users) are not.

Next, some believed when someone is very ill, they may not be receptive to the messages of recovery that the stories convey.

Finally, reservations were expressed about the format of the book: there were concerns that it may be unappealing or even inaccessible to some because of its length and the density of the text. There were suggestions that more use should be made of colour and pictures especially as poor concentration can be a feature of mental health problems, and as medication can further exacerbate reading difficulties.

Comments regarding Routes to Recovery

Fifteen provided comments on perceived strengths of this booklet and two on perceived weaknesses.

Generally, then comments were very favourable. Echoing views on Journeys of Recovery, some commented that Routes too was positive and engendered hope. Furthermore, it was described as service user-friendly and accessible, for example:

Very useful to have themes drawn from the narratives to make it easier for people to understand the concept of recovery.

Other perceived strengths were that Routes lent itself to both being dipped into and being read cover-to-cover.

The criticisms about Routes were that it is too short (making it superficial), depressing, and that when service users are unwell they tend to be disinterested in others' experiences. This last comment raises the issue of timing i.e. when is the appropriate time to give service users this booklet (and arguably Journeys too)...

Views on Recovering Mental Health

Essentially a research report, Recovering Mental Health in Scotland is intended to distil and present the findings from the narratives research. In general, respondents' ratings indicated that they felt that the report's findings were consistent with what is already known about recovery, makes a valuable contribution to the evidence base, and provides a useful source of information for strategic planning, training, and writing articles.

As with other sections in the survey, respondents could opt to provide additional comments. Fifteen provided comments on strengths and eleven on weaknesses. By and large these simply reinforced their ratings rather than adding anything new:

Reinforces the need for a recovery driven service

I think this document pulls together much of the expected but in a new clearly evidenced way.

Electronic communications

96% of respondents indicated that they had visited the SRN website. Then, using a five point scale ranging from very good to very poor, they were asked to rate ease of navigation, appearance and content. Over 70% rated each of these features positively: as very good, or more commonly, as good. The main recommendations were regarding the website's appearance: to make it look less dense by either introducing more breaks, or by reducing the amount of text; to increase font size; to use more visuals; and to make it 'less technical' and 'friendlier' and more geared to service users e.g. by including a forum for people to talk about recovery and to ask for support to establish new networks.

70% said that they always read SRN's email bulletins and a further 29% said that they sometimes did. i.e. only 1% never read them. Similarly 99% described these as very useful or useful in parts. The open-ended comments indicated that people liked to dip in and read the bits that interested them.

Influence on knowledge, attitudes and practice

The final survey question asked respondents to indicate their level of agreement with three statements concerning the influence that SRN had had on their knowledge, attitudes and practice. The vast majority responded that they strongly agreed or agreed that their knowledge, attitudes and professional practice had been influenced by SRN's materials and/or activities: the percentages were 87%, 71% and 72% respectively. The breakdown of responses is provided in Table 4 (over).

Table 4: Level of agreement regarding SRN's influence on self

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree	Not applicable	Total
Knowledge influenced	40.3% [n=108]	46.3% [n=124]	7.1% [n=19]	4.1% [n=11]	0.4% [n=1]	1.9% [n=5]	268
Attitudes influenced	34.6% [n=92]	36.5% [n=97]	15.8% [n=42]	10.2% [n=27]	0.4% [n=1]	2.6% [n=7]	266
Professional practice influenced	30.6% [n=81]	41.9% [n=111]	14.3% [n=38]	6.4% [n=17]	0.4% [n=1]	6.4% [n=17]	265

The key issues that emerged from respondents' additional comments were that SRN is a useful central resource for information, and for communicating and promoting recovery more generally. Furthermore, many commented that although their knowledge of recovery was already quite developed, SRN reinforced and/or helped consolidate their understanding and views. For example:

I think I already had a high level of awareness and understanding of recovery but I have found this network an invaluable resource for communicating and promoting recovery to others.

Summary

A web-based survey targeting professionals was circulated via SRN's distribution list. 388 completed it, 321 of whom had a professional interest in SRN

The majority of professional respondents rated SRN's resources and messages very favourably, and valued these for communicating hopefulness

The key messages were generally supported but with certain caveats.

Some reservations were expressed about the format of Journeys of Recovery and whether the accounts would be relevant to all

The majority indicated that their knowledge, attitudes and professional practice had been influenced by SRN's materials and/or activities.

These views cannot be considered to be representative of all of those on the email network nor wider professionals

Chapter Four: Interviews with professionals

This chapter presents the analysis of the ten interviews conducted with professionals. The participants were sent copies of all the key SRN communications of interest to this evaluation in advance of their interview.

Profile of participants

Ten professionals were identified for interview. These were purposively selected to provide a breadth of professional roles, a gender balance, and representation from across Scotland. An attempt was made to select eight interviewees from the email survey responses who had a mix of positive and negative views on SRN communications. However the vast majority who agreed to be re-contacted (116 of the 321 professionals filling out the survey) had relatively positive views of SRN. We used professional networks to recruit a consultant adult psychiatrist and a general practitioner (GP) as no-one from these two professions had agreed to be re-contacted via the survey: of these, one had no previous knowledge of SRN while the other had heard of SRN but had had no direct contact with it. The professional roles of the remainder were: Choose Life co-ordinator; a housing support services manager; the chief executive of a mental health association; a lecturer; a community psychiatric nurse (CPN); an addictions worker; a consultant clinical psychologist; and a project manager for recovery within an acute mental health unit. Interviewees worked in settings across Scotland: in Renfrewshire, Inverclyde, Forth Valley, Glasgow, Aberdeen and Edinburgh. Geographical details have not been inserted as these might reveal individual identities. Four of the ten interviewees did not currently provide direct support to mental health service users but did manage or have direct contact with staff who provided that direct support.

It should be noted therefore that the sampling strategy has not been as successful at uncovering views of those who are less well disposed towards the recovery agenda or are sceptical of SRN's work, as we had intended. As such the findings may not be representative of the wider professional networks within mental health in Scotland, and may present a skewed (positive) perspective.

Awareness of, and involvement with SRN

All participants except the GP were aware of SRN and their work. The psychiatrist had heard of SRN but had had no direct contact with it. Five of the eight remaining participants had relatively strong associations with SRN having been involved for some time in the recovery agenda. The other three who knew of SRN were less closely involved with them and had become engaged more recently. These eight individuals were signed up to SRNs mailing list and four had attended at least one update event.

The nine participants who were aware of SRN perceived its role to be mainly that of raising awareness with regard to the recovery message. Most felt that this awareness raising was aimed at professionals, carers/families and service users.

Views on recovery

A significant portion of the interviews was spent discussing views on recovery generally. Throughout, interviewees demonstrated a sound understanding of the

concept, notably that recovery is a process or a journey, that recovery does not necessarily mean being free of symptoms, and that it is a highly individualised phenomenon:

Recovery for me is allowing somebody to develop to their best potential. In all likelihood for many patients is not going to be symptom free (P110).

SRN's messages of recovery

By and large, interviewees were in agreement with the four key messages. Below, we detail the issues, including the caveats, that they raised in relation to each of these. Before we do so, it is important to acknowledge that these individual messages were considered in turn, rather than collectively and that this raises the possibility that queries raised in connection with one message might be resolved in full or on part if all messages had been considered together. We return to this issue in our final chapter.

'People can and do recover from even the most severe mental health problems'

This was seen as a fundamental tenet of SRN. Furthermore, the message was welcomed as an optimistic one, and one that usefully serves to raise awareness of the possibility of recovery:

Yes, people do recover. Some might make an absolute recovery but that is reasonably rare ... so it needs some perspective. As a broad brush message to get people's interest it is appropriate (P11).

As this comment typifies, many felt that the message is more complex than the current wording suggests, particularly in relation to the extent to which it is universally relevant, and/or the extent to which service users are likely to be receptive to it:

It might depend on the individual and the illness that they have ... I think some people think there is a safety net around being unwell or having a diagnoses. Some people feel that the focus on recovery may remove this safety net (P13).

Additionally, concerns were expressed that service users may view recovery in the same way as recovery from a physical illness, or that those who relapse may feel they are failing in some way. These concerns might suggest that the message may be seen to communicate recovery as an end-state only, and by doing so, fail to communicate that recovery can mean living a good life with an illness.

'Recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms'

Interviewees were again generally positive about this message. As with the previous message however, this one also was seen as a complex one. On the one hand, some valued it as it helped to clarify the meaning of recovery as something qualitatively different to a full recovery or cure from a physical illness:

I think this is where the subtext comes in for the previous message. Some people might not see that they can recover and still have symptoms. Sometimes it's like a light bulb coming on. When they think- I am still going to see a doctor and still take medication but despite that there is a level of satisfaction I can have (P11).

Other interviewees on the other hand, highlighted complexities around some of the specifics of the message. So, while questions were raised about whether it was possible for all people to lead a positive and fulfilling life at the same time as experiencing symptoms, others expressed the view that a life free of symptoms may not be desirable to everyone anyway:

Some people don't mind their ongoing symptoms and are actually quite attached to them. Just because it might sound right to treat the symptoms it may not always be best. So, for some a satisfying and fulfilling life can be in a mildly psychotic state and that's OK (PI6).

These different perspectives suggest that recovery was viewed not so much as a immutable concept, but as something far more individualised: that the *definition* of recovery could vary from individual to individual depending on their circumstances.

'No two people's recovery journey or experience will be the same'

Again, this message was generally accepted as true and as a positive one to convey to service users. Two important dimensions to this message emerged. First some picked up on the term 'journey', associating this with a process – an individualised one at that:

I fully agree because no two people's life journey is the same. We don't come from the same background and have not had the same journey up to that point so recovery is not going to be the same (PI10).

Second, several highlighted the message's implications for those who have a role in supporting service users:

It's trying to say that recovery is a journey and if you treat individuals as unique you can see how best to support them through their journey (PI9).

However, while the majority generally lent their support to the message's emphasis on individuals, for some this was tempered by concerns that service users may be left feeling 'alone':

It's quite important to know that you are not alone. Emphasising the individuality could suggest that I am the exception to the rule...and if that is the case, maybe I'm the one who won't get better (PI7).

This brings us to the final theme that emerged: that the message fails to mention that there can be elements or features to recovery that are shared by many:

The more you see people the more you realise that they are similar but not identical (PI5).

It would seem reasonable to infer from these accounts the need for some kind of balance between respecting the uniqueness of the individual experience on the one hand, and letting people know that there is a body of evidence on common building blocks to recovery. One interviewee summed it up:

If we make sure that the messages are tailored to the individual but there are common features (PI4).

'The critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery'

This final message was viewed positively, at least in terms of its *meaning*: it was seen to raise an important issue both for professionals in their management of their clients, and for service users themselves in the attitudes that they themselves held.

However, the wording was described as cumbersome and complex. In turn, some questioned the value of the wording in its current format, especially for some patients:

Even for highly educated people, you'd need to read it over a couple of times to take it in. Not to sound awful, but for a lot of patients this would be absolutely meaningless, it's too complex (PI6).

Views on written resources

Interviewees were asked for their views on SRN's key outputs, with the major focus on the booklet Routes to Recovery, Journeys of Recovery, the postcards and the report Recovering Mental Health in Scotland.

Of the ten interviewees six had seen Journeys of Recovery and Routes to Recovery before agreeing to participate in the interview, with four having seen the postcards. Only two of the interviewees had seen the report Recovering Mental Health for Scotland before it was issued as part of this study. In the sections that follow, we summarise views on each of these.

Journeys of Recovery

First impressions of Journeys of Recovery were very positive. The majority of interviewees found it an excellent, high quality resource that was well written, and the use of personal testimonies was welcomed:

It's clear, it's not in any way condescending to service users or professionals. It's well set out, attractive and interesting and the language is fine (PI4).

I think it is excellent and I hand them out to people that I support. I think that what people have written about themselves is great (PI5).

However, when probed a bit further, it became evident that few had read the booklet in depth due to time constraints and the amount of detail that was contained within it:

I have dipped in and out of it...I don't have time so perhaps the layout isn't that attractive to us either, because we have to read it, regurgitate it and then decide if it's useful (PI8).

Some participants then went on to highlight a number of limitations that were seen to reduce the accessibility of this resource: the density of the text, the literacy levels that would be required, and the fact that some chapter titles did not convey the essence of the associated stories:

Sometimes it can be difficult to find the connection between the title and then the actual story. Some of the headlines are not highlighting what they were about (PI10).

Such considerations were seen to be particularly acute given the possibility of many service users experiencing difficulties concentrating:

People who have had a psychosis suffer from poor memory and concentration (PI8).

The problem is that people in the mist of mental illness have symptoms such as poor concentration and their memory is short. They are easily distracted so to get through Journeys of Recovery is actually really difficult (PI6).

To go some way to addressing these problems, one interviewee suggested that Journeys incorporate some of the many examples of art produced in psychiatric wards.

Interviewees were asked to consider when and how they would introduce a booklet of this nature. While some (a minority) said that they wouldn't use this resource with their patients as they felt it was targeted at professionals and at families, others explained that they would only give out Journeys when their patient was "ready" and open to hearing about the experiences of others. As such, this was described as depending upon where individuals are in their recovery process. One interviewee said that at the first appointment there is too much going on in an individual's head and it is unlikely that they would be receptive to the booklet at this time.

Another interviewee commented that s/he would introduce Journeys when the individual is able to participate in a partnership. In so doing, the utility of the booklet was seen to be dependent not just on timing but on context too. Two further interviewees specified how the resource might be used:

You are making an assessment of whether it is the right time. I would hope people don't say 'there you go, this will meet your needs. Come back in two weeks and read the books'. That would be a pointless exercise. You need to give them additional support, listen to them, help them apply the bits that are relevant (P11).

I think it could be used for patients in a group setting as a discussion group or as part of a one-to-one situation where a professional had identified a particular aspect or problem with a patient where they want to see some change (P110).

However, although an isolated case, one interviewee highlighted that although s/he was a strong supporter of SRN, s/he did not use the materials:

Perhaps I could argue my head is so full of many things, it's just another thing to do...I think there's kind of we're all busy doing everything which is an awful excuse but it's true. But the reality is it's up to me and my staff to spread the word (P18).

These last points testify to the importance of the buy in and support of professionals in the distribution and use of these, and in all likelihood, other resources. It also raises an issue of whether, given time restrictions on such professionals, some guidance should be provided by SRN as to the contexts and ways in which the communications could best be used. Several professionals noted that passive distribution and unstructured or targeted use of communication materials was not ideal:

We have lots of booklets lying around the hospital. You see people taking them indiscriminately. I bet they don't read any of them. This passive way of accessing people with written materials is incredibly wasteful (P17).

Routes to Recovery

Prior to agreeing to participate in these interviews only four of the interviewees had seen Routes to Recovery. Reaction to this booklet was very positive and it was liked because of the length, the presentation style and the tips that are scattered throughout. While many were unsure at whom the resource was targeted, the majority of the interviewees felt that it would be a much better resource to give out to patients than Journeys of Recovery:

I liked this one better because of the way it is actually physically presented. The hand written pieces makes it clear that it is a person who is writing it – not an ‘official’ person...As a service user, I would find this more accessible. It’s about the right length and carries a very hopeful message (P17).

Against this background of overwhelmingly positive views, one interviewee suggested that the handwritten excerpts may be difficult to read.

Similar to the views expressed in relation to the use of Journeys, many suggested that Routes should be given out and/or used within a particular context or therapeutic encounters:

It should be used as part of a consultation or therapeutic intervention. My feeling is that a lot of these things are set up on a table or handed over to someone to go away and read. That way, the chances of them being used properly are slim (P110).

Asking relatives to get involved in the process is quite a useful way of encouraging the service user to have a look.. It’s also useful to say... ‘dip in and read this and see what you think’. I think there are some useful ideas in it but it takes a level of instruction (P17).

Thus, many felt that Routes was more likely to be useful to service users in those circumstances where others (professionals and families/carers) consider and discuss the content with them. That this is done within a supportive relationship was stressed by one:

I wouldn’t particularly want to censor what’s put out but on the other had I wouldn’t be handing these out to people that I am newly diagnosing. I don’t think I would inject hope and inspiration for people just by showing them how other people have coped. I think it’s much more complex than that and its all about building relationship and trust (P16).

Postcards

The majority of interviewees liked the postcards and felt they would be popular with patients who may have difficulty concentrating on large quantities of text. The messages on the front were particularly well-liked and were seen as *inspiring* and *positive*. They were considered as useful for pinning on notice boards and for leaving lying around for people to pick up.

Two made suggestions about how these materials could be improved: adding an image of a person, and including extracts from people’s stories.

Recovering Mental Health in Scotland

Only two of the interviewees had seen the report prior to being sent as part of the research. Recovering Mental Health in Scotland was praised for being a valuable reference resource for anyone with an interest in the recovery agenda. Moreover, the layout of the report was commended for being accessible and easy to navigate. As a consequence, the majority of the interviewees had not read it in depth however, instead having selected chapters or sections that were of particular interest. Two of the interviewees viewed the report as usefully distilling evidence on recovery that could (and should) underpin strategic developments:

This report should be used for strategic work – developing services. I wonder how many of the people in strategic positions have seen this report. It would be sad if they haven't (P18).

The material on reframing recovery was particularly helpful because it is really relevant to my field (P19).

Website

Most of the interviewees had accessed the website, often as a result of a link that had appeared in an email update as opposed to actively seeking it out. People who had been on the site felt it was useful, straight forward to navigate and was especially helpful as a mechanism to find out about events and new publications.

I navigate through the site with no problems. I've come across some brilliant links and got some great information about things coming up like a national awareness day on depression (P19)

It was generally believed that the site could be used by professionals, service users and their carers.

Email updates

Eight out of the ten interviewees were network members and regularly received email updates from SRN. These updates were described as a valued communication even if they were not read closely due to pressures of work. The frequency of the updates was considered appropriate.

Events

Four of the interviewees had attended an SRN event. Others expressed interest in attending but the main barrier quoted for non attendance was time.

Extent to which SRN has influenced practice

On the whole interviewees felt that SRN had played a major role in influencing their, and their organisations', knowledge and practice on recovery:

My own attitudes and opinions have been influenced greatly by SRN. It's been a really strong message for those organisations and institutions supporting those with mental illness (P13).

In many ways this influence seems to have been in terms of reinforcing professionals' or organisations' own early attempts at promoting recovery orientated thinking and practice or enhancing their existing conceptions of the notion and values associated with recovery:

Before I knew about SRN I didn't really fully associate what we were doing in terms of promoting independence and quality of life with recovery. It encourages us as well that we weren't barking up the wrong tree and that much more is possible than we imagined and that we can create hope (P14).

We have always agreed with the idea and the approach but without the depth of thinking they have put into it. It has greatly informed the ethos and value of our organisation (P11).

A minority, however, felt that the messages were well known by professionals and the principles of recovery had been used for a long time by staff working on the front line with patients and as such:

It's a bit like teaching your grand mother to suck eggs (P17).

Accessing SRN communications

Interviewees were predominantly happy with the way in which they could access SRN resources, suggesting that they could access them readily and had enough supplies. However, it is worth noting that six participants had never seen Routes to Recovery, four hadn't seen Journeys of Recovery and eight hadn't seen the Report Recovering Mental Health in Scotland before they were sent copies as part of this evaluation. This suggests that although significant numbers of the resources have been distributed, some key professionals who are in regular contact with service users had no idea they existed:

I don't know how they do communicate. I'm not aware of having received communication from them. I don't recognise any of these materials (P16).

Views on how else SRN could promote the message of recovery

SRN is seen by all professional interviewees as a credible organisation in terms of raising the profile of the recovery agenda. While it was recognised that raising the profile of the recovery agenda was a major challenge, a number of suggestions were made about opportunities for SRN to improve its communications with professionals and the public. These included: finding champions to promote recovery at a local level; achieving a higher profile with the Scottish Division of the Royal College of Psychiatrists (e.g. by presenting at a college meeting); liaise with the local medical councils and use their monthly newsletter to promote the work of SRN; create a high profile advertising campaign along the lines of See Me.

Summary

Interviews were conducted with ten professionals eight of whom were purposively selected from the email survey and two from professional networks. They were from a range of professions and geographical areas.

The majority of professionals were supportive of SRN's key messages however again some caveats were identified

Most interviewees found Journeys of Recovery an excellent, high quality resource, and liked the use of personal testimonies. However some had not read it in depth and several also highlighted concerns over its density and accessibility for both patients and professionals.

Routes to Recovery and the post cards were seen as more suitable for service users but the former had not been viewed by six of the participants prior to their involvement with this research. Again this highlights that despite associations with SRN many people are not familiar with all the communications.

Recovering Mental Health in Scotland was praised for being a valuable reference resource.

Most believed the resources should be used as part of a managed interaction with a service user, rather than simply distributed.

Most had used the website and were positive about this and the email updates.

Chapter Five: Focus groups and interviews with service users

This chapter presents the analysis of the four focus groups and six one-to-one interviews conducted with mental health service users.

Profile of participants

The participants were highly varied. In total 28 took part, 10 men and 18 women. Of these, six attended an all-women's black and minority ethnic service user support group and one was an asylum seeker. Three interviewees were purposively selected (by their GP) as being 'deprived'. Although participants were not asked about their socio-economic circumstances, the researchers had the impression that participants overall spanned a wide spectrum. Those who took part experienced a broad range of mental health problems. These spanned affective (e.g. depression), psychotic (e.g. schizophrenia) and eating disorders, and most had experienced their mental health problems for a several years, some since childhood. A smaller number talked of being 'recently diagnosed' but did not quantify this. We did not ask or select on the basis of age except that all participants were required to be over 18 years. Those who took part ranged from being in their twenties to being in their sixties or seventies with the majority being somewhere in between i.e. in the 30-55 age group. Participants lived in urban, suburban and rural areas, mostly within the central belt of Scotland, and six lived in the Highlands.

Awareness of SRN

As expected, none of those participating in the one-to-one interviews had heard of SRN prior to being contacted for interview. In the focus groups, all of which involved individuals attending recovery-oriented support groups, the picture was more mixed: in one group, all had heard of SRN and/or seen some of its resources, in two groups about half had, and in the remaining group, only one had heard of SRN.

Those who had some familiarity with SRN were asked to describe its purpose. Collectively, they described a range of activities including communicating the message of recovery, production of resources, hosting a website, running events, training and policy work with professionals. Several were of the view that SRN's primary focus lies with working with professionals:

It put forwards the belief that you can recover from a mental health problem and they are using the phrase IN recovery and they do it by communicating with professionals, mostly professionals I think. Yes (UFG2, 16).

Initially started out as an activist type organisation – service user based. Very quickly it moved into working with the authorities, likes of the Government etc. Apart from producing materials. And I think that is going away from what it started out as and that was for service users (UFG1, 11).

To reinforce the more general point that the key target audience for SRN seems to be professionals, one service user said that the SRN website was not service user-

friendly, while another said that its email updates included information on new jobs – news that was considered to be targeted at professionals¹⁰.

Views on recovery

A significant portion of the interviews and focus groups was spent discussing four of SRN's key recovery messages, and view that are specific to each are detailed below.

It is instructive to note at this stage however, that when discussing SRN's messages of recovery, participants could be broadly characterised as falling into one of four camps: first (and most commonly) those who considered themselves to be in recovery; second, those who felt that they were not in recovery but were open to the idea that recovery was possible; third, those who held ambivalent feelings about the concept; and fourth (a small minority) who did not believe in the possibility of recovery for themselves. Illustrative examples of the latter two perspectives are provided below:

The idea of recovery was built on the service user movement. If we are a community of people with a shared experience, it would be very strange to say that our community is an impaired community and needs to change in order to be better. But that is true too because we have all been through an experience which has usually been pretty unpleasant so there is a contradiction within it, isn't there? (UFG2, I3).

If you keep relapsing, how can you call it recovery? I've had been suffering from mental health for a good 30 years and every time I try and get into the recovery position I have a relapse so I find it very hard to even imagine a recovery situation (UFG2 ,I2).

Whether someone felt they were in recovery or not was a highly individualised thing based on how individuals defined their own experiences. This is illustrated in the extract (from UFG3) below in which two of the participants (I2 and I3) had the following exchange :

I've just got 100% belief in recovery. 100% and I totally identify with these two statements (of SRN's) and totally agree with them (I2)

I can't comprehend it. For me it doesn't make sense. For me it's more. I wouldn't like to think I'm in a situation where I've recovered because that would mean it's all gone, I don't have mental health problems. Because then I would be more disappointed if I had problems in the future. For me, I work more with the open door scenario that the door is always open or shut and at the moment it is wide open, and I might get it to the point that it is nearly completely shut, but I'll never get it to the point where it's shut totally. So I can't work with the recovery term. (I3)

Can you work with the term IN recovery that you are IN recovery? (I2)

No. It doesn't work for me (I3)

I think you live your life, I live my life with a mental health problem and at times, as you say the door is quite wide open and at other times it is closed but I have accepted that it's part of my life, and I think you are saying the same thing (I2)

Aye (I3)

¹⁰ It is important to acknowledge here that SRN proactively recruits people with lived experiences of mental health problems

*And I am trying to move on with that as part of my life but I see that as recovery whereas you just see it as living with it (I2)
I just see it as living with it, yeah and as I was reading all this stuff and I see the word recovery being mentioned all the time, it gets really aggravating (I3).*

This extract illustrates a more general issue that cut across many of the interviews and focus groups: that whether or not someone considered themselves to be in recovery influenced the attitudes they held to SRN's messages and resources.

SRN's messages of recovery

'People can and do recover from even the most severe mental health problems'

Many agreed with the accuracy of message. In addition, the message was considered to be a positive and a hopeful one:

It's giving people hope that you can and do recover. It's making people feel more positive isn't it? (UI1).

This is so official. This is the most powerful, this first message. I find it SO good it tells you yes, you do recover (UFG4, I5).

Furthermore, a number of key concerns were raised in relation to the precise wording used. First, the message was seen as inappropriately conveying recovery as an end point. Instead, recovery was seen to be a process:

I always feel you are IN recovery, not DO recover....Rather say it's an ongoing thing. You don't know when it's going to end (UFG1, I2).

Second, although some people liked the fact that the message is short and 'punchy', others felt that it was too general and that would be stronger and more accurate to add that recovery requires support from others such as families, friends and professionals.

Third, some – notably those who said that they had experienced mental health problems for many years and had no personal experience of recovery - questioned the veracity of the statement in relation to those with acute problems. In part their scepticism may be due to understanding recovery to (always) mean a cure:

It says people can and DO recover. Well you see I have difficulty with that just because I have seen a psychiatrist but he says I will probably have to live with my mental health problems for the rest of my life. The only thing is that he says that the medication may help slightly but I'll never get rid of it.... If it was me - I would think I was gonna be cured. That's the way I would look at it. I would think – there's a cure for me, that's great. (UI3).

I think it would be very difficult for someone to recover from a severe mental health problem, I think it'll always leave scars on the memory going through difficult times. (UFG2, I2).

Finally and interestingly, two individuals found the term mental health unclear and stigmatising, and as a consequence did not relate to it. For example, two individuals who had experienced depression for several years felt that for message to be relevant, the word depression would have to substitute mental health.

On balance then, this message was viewed as a positive and hopeful one but one that failed to adequately convey recovery as a process, and the importance of others' support.

'Recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms'

Views were mixed on this message. Many found it easy to understand and agreed with the sentiment of the message:

*If someone asked me how I was now- that's the quote I would say (UFG1,13)
It's very poignant cos it says that you can still have your symptoms but still be going through recovery which I think is very important (UFG1, 12).*

However, whereas some liked the wording, others found it overly complex:

It's a wee bit too much to take in, isn't it? It's awful crap. If you read it, I think you'd go humph and walk away.... It's all big words – absence, presence, satisfying, fulfilling (UI1).

Furthermore, some expressed reservations about both the language being divisive as it was seen to imply that service users ought to *change* – a sentiment that devalues the lived experience of service users:

It's sort of like we're being told that there was something wrong (with us) in the first place. That we need to mend ourselves. And in a way we do need to mend ourselves because a lot of what we have to go through is pretty horrible there's no denying that. It goes back to who your being is, who your spirit is, who your vision of yourself is and saying that your self is wrong is a rather strange thing to say. ..The way it phrased is a bit official-speak in a way. You know – 'ongoing symptoms' is not the most accessible way of saying something to people (UFG2, 13).

Others disengaged from the message because they felt reconciled with living with their illness, and this acceptance was a positive force:

Acceptance that I might never recover - I could actually use that as a positive thing: the acceptance of non recovery. Because I know my limits. ...I can accept that I will never recover because that sets me free. I am in jail again when somebody says to me you'll recover from this. It's like handing me a ladder without any rungs in it (UFG2, 11).

Another area of difficulty to emerge was around the wording 'in the presence of symptoms'. The asylum seeker did not understand the word symptom at all, another interviewee misunderstood this to mean 'you'll always have symptoms', and in one of the focus groups several participants contested the notion that people would feel in recovery when experiencing symptoms.

Thus as the message stands, it resonates for some, but disengaged a sizable number because of the language used and, more fundamentally, because of its meaning. In part though, the extent to which people engage or disengage with the message may be associated with timing as suggested by this individual who felt moved on in his/her recovery after doing volunteering work four months previously:

If you had showed me that four months ago I probably would have said that's nonsense but because now I've done voluntary work, I know it's no' (UI3).

This raises the possibility that the messages chime more for those currently in recovery.

‘No two people’s recovery journey or experience will be the same’

The overwhelming majority of participants viewed this message as straightforward, apposite and positive:

It makes me feel good – I’m not different to anyone else. Just because it’s taking me a bit longer, it’s not a bad thing. It’s a positive message (UI1).

Features of the message such as being short, to the point, and in very service user-friendly language were also specifically highlighted and praised, and it was seen to be relevant to people across a wide range of mental health problems and at different stages in their recovery. Furthermore the message was liked as it was seen as validating individuals’ experiences:

I don’t feel at odds with everybody else. I feel this is my story and it doesn’t need to be the same as everybody else’s (UFG4, I5).

Encouragingly, some individuals who were highly sceptical of recovery in general and of the other specific messages, found something positive in this message, appreciating the fact that it acknowledged different experiences, and variations in the rate at which individuals progress. Also the message was seen as helpfully counterbalancing mental health information from other sources that might be daunting to someone who has recently received their diagnosis:

If it’s your first experience of mental health, then it would be really useful to know that because you’d probably be terrified. For example if this was my first episode and I read that book, I’d think –oh my God, I am going to have to get all this medication and that’s the way it’s gotta be, whereas if I had this message – no two people’s recovery... then it’s different. It balances it out (UFG3, I3).

However, although the vast majority liked the message, it did not receive unequivocal support. Participants in one focus group shared the view that ‘*It’s rather stating the obvious*’ and felt that it would be more helpful to offer ideas about what might help an individual on their recovery path:

To say that it is so individual – that you can’t say one is better than the other – is to say that you are lost because nothing’s good and nothing’s bad; nothing helps and nothing doesn’t help... I think that we know that there are some things that help each other and there’s nothing wrong with sharing that whilst acknowledging what is obvious – that everything is different for every single person (UFG2, I3).

‘The critical assessment of attitudes and values can have a powerful impact on an individual’s prospect of recovery’

Participants struggled to comprehend what this message was intended to convey. Many said that they did not understand it, and that they found the language off-putting: *It is something a psychologist would say* said one, *something only a person trained in mental health* said another.

As a consequence many talked of their difficulties in ‘getting their heads round’ the message. Specifically, some participants thought that the message related to the attitudes and values of professionals, others thought it referred to those held by service users themselves. Irrespective though of the difficulties that participants expressed in understanding the precise meaning of the message, many understood its gist, and agreed with it:

When you go through mental health problems you tend to be critical of yourself so when you hear positive things it’s like gold dust. There’s people in

the mental health system who are in positions of power to make or break it for you.... and if these people don't have attitudes and standards – if yours are higher than theirs – they have the power to make or break your pathway to wellbeing (UFG2 I1).

However, although there was agreement with the message, some homed in on the adjective “critical” which they found negative and “harsh”. One individual felt that the term might even unhelpfully remind an individual what is wrong with them, rather than giving any pointers to help:

I think if you've got severe depression, I think it's obvious that what you've got wrong with you is a negative attitude. I think that would just be rubbing it in – Yes I know that's wrong with me (laughs) (UFG2, I4).

Finally, in two focus groups the participants recommended changes to the message. In one, it was suggested and subsequently agreed by all in the focus group, that the term “realistic assessment” should replace “critical assessment”. In another, the participants shared the view that rather than having a message that emphasises the important influence that others can have on an individual's prospect of recovery, the crucial take home message should be for service users to be more empowered:

It's got to the stage that it's more about people taking control of their lives and living their life with their mental health problem. I think that's more important than this word recovery (UFG3,I2).

Views on written resources

Participants were asked for their views on SRN's key outputs, with the major focus lying on the booklets and Journeys of Recovery, Routes to Recovery and on the postcards. Their awareness and views on SRN's electronic communications (website and email) were also explored. In the sections that follow, we summarise their views on each of these.

Journeys of Recovery

Many liked Journeys of Recovery: the story format was very accessible and many described these as positive, inspiring and hopeful. In fact, despite being far longer and denser than Routes, participants on the whole found Journeys far easier to read than its slim companion. For example, this individual with dyslexia enthused:

A lot of it I could relate to, what's happened to me over the years. There was one I was reading there, I don't know if it was a bloke or woman, - and they were emphasising getting their own house, their own television and I can relate to that. ... I loved reading that one (UFG3,I4).

As this account illustrates, the ability to relate to a particular story was very important: those who ‘saw themselves’ in the stories tended to find the book very rewarding:

I liked reading other people's stories. I could relate to them so I did....It made me feel more positive because it made me think 'I done that'. (U11).

However not everyone felt that the stories were personally relevant. As a result, there was general agreement that there should be a wider range of stories including ones about people who received very little support from services or who came from different cultural backgrounds – a view reinforced by those from the BME focus group.

The narratives did not only provide reassurance. There was some suggestion that these impacted in a tangible way on some readers. For example, one interviewee

found the book helped challenge his/her habitual thinking around personal experiences:

It gave me new ideas for thinking about things....for example, the person who described thinking of her symptoms as allies....that really turned things on their head...I was then thinking well what are my symptoms trying to tell me....before my symptoms have always just been scary to me (UI6).

In the case of one individual (who described him/herself as not being in recovery), the stories had a very negative effect:

I read the first couple of stories and I was SO depressed. I was SO down after reading them because I thought these people have just done AMAZING things, they've just been so successful, and they've had all these support workers. They've had CPNs, they've had everything going for them. They've went and done voluntary work, paid jobs, great families, I couldn't read any more for about a week because I felt so depressed. Because they were so full of so much, and I thought, my God, I am such a failure – I can't manage to do that (UFG3, I3).

Similarly, another individual who had been diagnosed with depression fairly recently talked of being 'frightened' by the accounts contained in the book:

I thought they were valid and authentic, using people's voices, but they overwhelmed and frightened me a bit. There were a lot of people had been hospitalised, there were words like 'psychotic' and 'bipolar' and I don't see myself as fitting in with that. The more times that 'hospital' was mentioned and 'repeated episodes' – that all frightened me and made me think 'I am in this league?' But what made it more frightening was that there were some things in it that I did recognise (UI4).

These views highlight the potential for the resource to impact on individuals in ways opposite to that intended. In part, the issue might be one to do with targeting and timing: it may be that the resource is unhelpful, dispiriting even, for (some) people who are not in recovery:

I got it when it first came out and I wasn't well on the road to recovery then and I thought 'is that as good as it gets?' And I found it very negative. I know it's realistic now but then, I couldn't relate to it (UFG1, I4).

Before I read these (SRN booklets), recovery to me was something that finishes at some point. Recovery ends and you become well. To discover that for some people recovery just goes on, sometimes forever, I feel a bit down about that and it's a bit hard to accept that (UI4).

Despite the fact that the individual stories were described as very readable, some found the booklet as a whole too long and heavy going, and as a consequence were deterred from reading it. In fact, a couple of participants with advocacy roles mentioned that they had received copies of the booklet in the past but had not read them properly or even at all. Largely the problem seemed to be one of presentation with some service users saying that it was difficult to work their way round it and find the most relevant parts. For example:

They don't mean anything to you (the content headings) – they're not personal to me they're personal to the people who said it, so when you are depressed and you are looking for help ...well as a reference book it doesn't really work....the headings didn't mean anything to me...if you have a problem or looking for something to help you are looking for key words. You won't just start at page one and read right through. I didn't look at this as a piece of literature that I would read right through.... I wanted it to show me where to go (UI6).

Furthermore, the booklet's use of key words was not seen as helpful: some singled these out for mention and described these as irrelevant, and at worst, labelling and stigmatising.

Because of difficulties with the length, density and difficulties in navigating their ways round *Journeys*, some suggested that these stories (and others) should be published separately, and using colour rather than the current grey.

In one group, suggestions were made too about changing the title to *Journeys to a Possible Recovery* or *Journeys to Wellbeing*. As such, these reflect the difficulties that some participants had with the term recovery either because they felt they were not in recovery themselves or because they thought of recovery only in terms of being an absolute state and not as a process.

Routes to Recovery

Participants expressed very mixed views about this publication. Some were very positive about it, with different aspects being highlighted as valuable. Thus, several talked of the booklet communicating very positive messages:

It just shows how deep they were in their situation, their depression or psychosis or whatever, they were able to get out of it with help, using services, fighting for their own rights. There was a lot of that. .. it's quite powerful, and they were good stories (UFG4, I3).

Others valued the booklet for highlighting that there were others in the same boat – something that was seen to be reassuring or even affirming their own experiences:

I found I liked reading the snippets because I am quite isolated. Reading the snippets makes me feel there are hundreds of people out there. So I don't feel so alone (UFG3, I5).

It made me realise that I must be doing something right cos that's the sort of things I did. Some of them I could see like myself. They were real stories I could see myself in it a lot (U11).

On the other hand, many were critical of the booklet. A key issue in this respect was an inability to relate to it, a difficulty more commonly raised by those who did not consider themselves to be in recovery:

I didn't relate to it all. I think I was quite negative about it (UFG1, I2).

For such individuals, an inability to personally relate to the content was identified as an obstacle to reading *Routes* at all, or for those who did read it, was associated with more ambivalent or even negative feelings about its worth.

A specific concern raised by participants in the BME focus group, was the book's Westernised/white focus. This was seen to create difficulties not only in terms of participants relating to the content, but also by limiting its usefulness:

All the stories here are good but most of them will not be relevant to, say a lady who's in the house with children who's in an Asian community. It won't be relevant for their lifestyles. Not only language barrier. Also lifestyle. Where will go for help for example, what they will do for their recovery. It won't be the same as in this book (UFG4, I?)¹¹.

¹¹ It was not possible to discern from the recording which participant made this comment

Finally the usefulness of the booklet was seen to be a matter of timing:

I think that you've got to be at a certain stage before it relates to you (UFG1, 13).

While many agreed that it was important that people received the booklet at an appropriate time, views were divided about when the 'right time' would be. While a couple felt that this should be shortly after diagnosis, more commonly it was felt that it would be inappropriate to give the booklet out when people are very ill.

Views on the format of the booklet were also mixed. Some found it easy to read, attractive and engaging, liked the use of handwritten notes to authenticate the quotes, and liked the fact that it lent itself to being dipped into. Others valued the fact that it was easy to dip into:

The first time I read it, I read it foreign. From back. If someone is unwell, this is probably quite useful because it's not a continuous story.... It's easy to dip into (UFG3, 12).

On the other hand, others found the format unhelpful: *a bit like a yo-yo* said one, *a bit like them and us* said another. Others still said that the whole appearance was bland, and on this basis felt that it was not targeted or appropriate for service users. A couple viewed the text as being too small¹², and a few individuals, including one with dyslexia, said that they had found Routes hard to follow and therefore extremely frustrating because they experienced difficulties in concentrating – a problem associated with their illness. Finally, it was recognised that the booklet assumed a certain degree of previous knowledge: for example, in using but not explaining terms like cognitive behavioural therapy.

Many felt that Routes would benefit from being 'more visual' and suggested that it should incorporate more colour and graphics. Participants in one of the focus groups suggested that Routes may be a useful basis for facilitated discussion in service user groups.

Postcards

Participants liked the messages on the front of the postcards: they valued the fact that the messages were short, to the point, easy to understand, direct and very positive. Furthermore, they were seen to be well suited to service users' needs:

A lot of people with mental health problems have poor concentration and these cards are very useful for that. They're just short statements which is very good (UFG3, 15).

Notably, even the asylum seeker (whose ability to read English was very limited) found the postcards extremely accessible in contrast to the longer key messages described above. In the account that follows, it is evident that s/he understands the key messages that the postcards are meant to convey:

(Regarding The Journey) Journey – about these people, It means journey of the people. They are damaged because of their mentality. And this one (Recovery Happens) - Recovery – make recovery- you will become again and be happy again. A normal life. And this one (Inspire Hope) it means if you find hope you can make your confidence again and find yourself and get back to a normal life. If you are thinking about positive things (Value Positives), it is

¹² It should be noted that this booklet is available in large print on request

much better to come back to recovery, and the negative, if the negative come back to us it doesn't help. It doesn't benefit for us – we just have to think about the positive yes (UI2).

However, while views about the short messages on the front of the postcards were overwhelmingly positive, the majority did not find the text on the reverse side accessible or helpful: it was described as dense and in the main not very relevant to service users' needs. In fact, some felt that the text on the back was not aimed at service users at all but at professionals. Instead, participants suggested that the reverse side included positive sayings, poetry, pictures and photographs.

The bright colours used in some versions of the postcards and the ray of light in the graphic supporting the 'Inspire Hope' card were singled out for mention by some as these were seen to reinforce the optimism of the messages. However, while the postcards were valued for being eye-catching, most did not like the abstract graphics that were used, some saying that these *went for their eyes*.

The postcards were seen to be a potentially valuable resource that should be widely distributed targeting not only specialist services but also with a view to reaching people who may not realise they have mental health problems and those who can play an important part in supporting them. GP surgeries, pharmacies, libraries and supermarkets (*because that's the only place that everyone goes*) were all suggested:

And I don't feel so isolated when I see this. I think there are hundreds of people out there, because I felt very isolated. I don't see my GP much. So it makes me feel there are other people in the same boat (UFG3,15).

More specifically those in the BME focus group suggested that the materials should be distributed to mosques. Importantly, these would need to be translated:

They would be very useful to be translated. They would say this does not concern us. Maybe half of the people, they would not be reading it (UFG4,12).

Finally, across the groups and interviews, people were in agreement that the postcards were a useful resource for distribution at any point in an individual's life:

If someone is unwell, they will look at these and at first say – what a load of nonsense, I am ill and will never recover – that's the kind of the mentality people can get into, I know myself because I've been there - but sometimes during their time in hospital or during their time with their GP or with CPN – and these are up in the surgery, in the clinic, one day it will help, it'll click.... (UFG3, 11).

Perceived impact and use of resources

The most commonly articulated impact that service users talked of in relation to the resources was that these were reassuring and affirming of their own experiences: a number talked of feeling positive in the knowledge that they were doing something right in dealing with their own mental health problems. Others felt that the hopeful tone and content of the messages and materials had a positive impact on their attitudes, and acted as a useful reminder to think positively. However in the main this was not a new found optimism but rather a *reinforced* sense of hope. More specifically some felt that the materials and messages were reminding them to keep going:

It made me feel more positive cos it made me think 'I done that'.... Just to keep going, think positive, keep going, keep my life in order, keep going out with friends, keep doing things with the kids (UI1).

Thus overwhelmingly, positive impact was expressed in terms of reinforcing existing attitudes and validating personal experiences.

In one focus group (UFG4) however, the resources seemed to lead to a change in perspective with participants talking of feeling encouraged and more optimistic as a consequence of seeing the resources:

Your thinking does change. Very slowly. It makes you think that can happen to that person (15)

Yes it gives you strength (14)

I think it does make an impact on you because you think, oooh, there are so many people with different stages, different ways to cope with this illness.... It's not only one way, there are other ways you could envisage to go.... It's an eye opener... it's lots of hopes (12).

In contrast to this, a small minority felt that the resources had a negative impact: among those who considered that they were not in recovery, the resources were described as having an annoying or depressing effect on them.

Despite the references above to positive and negative impact identified by some, a significant number felt that the resources did not impact on them at all.

Prior to this evaluation, some (a minority) had seen the resources including two with roles in promoting recovery who had used the resources in talks they had given. Another, with a similar role, reflected how s/he had the resources but had never properly read them. About half said that they would retain the resources and/or show them to their relatives. A few talked of their intention to visit the SRN website.

Context of recovery messages within own experience of services

Experiences of services were extremely mixed. The majority talked of experiencing recovery-focused support from professionals, and this type of input was highly valued for being person-centred, optimistic and realistic. A significant minority however felt they had not experienced much in the way of recovery-oriented thinking or support.

Summary

Four focus groups and six one-to-one interviews conducted with mental health service users. BME individuals were included among these.

In the main, the service users were supportive of the general message that recovery is possible and that the recovery process is a very individual one.

It was felt that it is important to acknowledge that recovery requires an enabling context: that recovery is more likely where services and personal networks are supportive.

Personal testimonies were seen as a useful way to communicate messages of recovery. To ensure that these are personally relevant and useful, they need to be based on the experiences of people across a broad range of circumstances.

Many service users liked the short, sharp, direct messages conveyed on the postcards.

Some expressed negative views about the resources and the messages. In doing so they highlight differences in the ways people conceptualise their experiences which have implications for the content and distribution of recovery-oriented materials.

Chapter Six: Interviews with carers

This chapter presents the findings from six individual interviews with carers who had a relative or friend experiencing mental health problems.

Profile of interviewees

Five participants were female, one male. Five were selected by a professional recruiter and the sixth was accessed via a GP practice. Participants were not directly asked their age but were between 18 and 60 years. Five cared for a family member who was experiencing some mental health difficulty and one cared for a friend. The family relations were mother, daughter, partner, niece and sister, and for four of the participants they were the primary carer. The range of diagnoses included bipolar disorder, depression and panic attacks, eating disorder, anxiety and schizophrenia. For three of the service users, their mental health problems had spanned many years. The other three had experienced their mental health problems for two to three years.

Awareness of SRN

Five of the six carers had never previously heard of SRN. The one carer who had heard of the network worked within the mental health field and had heard of SRN within this context. She perceived the network as being:

to challenge the idea that you won't get better and the negativity around having a mental health problem (C4).

This individual thought she had also seen both Journeys of Recovery and Routes to Recovery before, possibly in a local hospital and at a conference.

All six interviewees felt sure that their family member/friend whom they cared for had never heard of SRN or seen any of the written resources.

Existing Views on Recovery

For four of the carers, the idea of 'recovery' as a concept and the language used to describe it was new for them. For example, one of these carers had a relative whose condition was diagnosed over thirty years ago and still experienced difficulties including periods of hospitalisation, and the idea of recovery as described in the resources was new to her:

I thought everyone was like my mum...had a wee episode, went into hospital and came back out again (C1).

Another, whose daughter had received a diagnosis two years before and was now *doing really well* (C5) had experienced many of the elements described within the resources as recovery but had never heard these articulated as a concept. The other three carers had received very little support from services and found this new notion of recovery – and of recovery-oriented support - very hopeful:

It was a new idea to me (the notion of recovery). When you think of severe mental health problems you think is it always going to be there? Also that you can get help, that there is more help available than you realise (C2).

SRN's Messages of Recovery

'People can and do recover from even the most severe mental health problems'

This was generally felt to be a positive message and one with which most of the carers agreed and felt to be well communicated within the written resources. One carer emphasised its use in challenging negative thinking, while another felt that the message didn't go far enough and needed to emphasise the importance of support in recovery:

It leaves you with the question 'How do they?' and without help you can't recover, you need help and support (C6).

The message's use of the word 'severe' evoked particular reactions in two of the interviewees. For one, who did not believe recovery was possible for people with severe mental health problems, the term had connotations of violence. For the other, the term was seen to be confusing and likely to undermine the recovery message itself:

I'm not sure about the use of the word severe - so what is that - what is the most severe mental health problem? Is it bipolar or schizophrenia? It would make me wonder. I don't know what that means, maybe the word 'complex' is better. If you are telling someone they have something 'severe' they would wonder how they could ever recover from that (C4).

'Recovery means having the opportunity to live a full and satisfying life in the presence or absence of ongoing symptoms'

This message was widely approved, described as hopeful yet realistic by some, and well illustrated by the narratives in the books which conveyed the ups and downs of living with mental health difficulties:

They seemed to manage to cope with how they were feeling. They might have a bad day but that they weren't going to give up. They were still living their lives and having fulfilling lives. That really came across in the books (C5).

Three of the carers however while agreeing with the essence of the message, were less sure about the language used:

It's too long winded in the wording...not so easy to take in. You need to read it a few times to understand it and take it in (C1).

When you are really depressed it would be hard to take this in – 'the presence or absence' and 'ongoing symptoms' that would all seem too jumbled...it needs to be really plain and simple...The use of the word 'ongoing' is also really negative (C6).

These comments illustrate a theme which was expressed by the majority of carers at some point throughout the interviews which was a strong feeling that any messages had to be short, clear and simple.

'No two people's recovery journey or experience will be the same'

All the carers interviewed agreed strongly with this statement, seeing it as realistic and affirmative to individuals' own experiences. It was described as being an

important message to impart to those experiencing mental health difficulties. Carers felt that this message was particularly well conveyed within both booklets through the relating of individual stories. It also seemed closely aligned to their own beliefs and experience of caring for individuals with mental health problems:

I really believe that. I believe that everyone is a unique individual and should be treated as such. It seems very relevant and important (C4).

I think this says you're not the only one, other people do suffer from depression or whatever. Other people have had help, why not you (C2).

One carer considered this message as particularly important for those experiencing mental health difficulties as it could affirm their experience of recovery whatever that experience might be.

'The critical assessment of attitudes and values can have a powerful impact on an individual's prospect of recovery'

This message caused confusion with all carers interviewed. Participants would read it several times but felt the statement to be ambiguous or unclear: they were unsure of what was being communicated and at whom this message is aimed:

What do you mean critical assessment - whose attitudes? Who is assessing? I don't know what it means. Is it people's attitudes towards those with mental health problems or is it the assessment process when they are being assessed and diagnosed? (C4).

I don't know who this would be meant for. I don't know whose attitudes they are talking about and whose critical assessment they are talking about. I don't really understand it (C1).

Another carer described this as being more medical because of the word 'assessment'. She interpreted the message as meaning *having a medical assessment to determine what stage you were at (C2)*.

It would seem then that the message was not just unclear to the carers interviewed, it could also be misconstrued.

Views on Written Resources

General

Participants expressed their views on both the content and style of the written resources, specifically Routes to Recovery, Journeys of Recovery and the series of Postcards. Views specific to each resource are detailed later, but participants started by describing their general impressions of the resources and the initial impact of reading them.

All six carers were generally positive about the Journeys and Routes books. Common areas of positive perceptions were that the booklets conveyed a positive message and a sense of hope. All six commented in particular on the use of a narrative style, feeling this method of writing communicated a sense of real people and their experiences with which they as the reader could identify. This narrative style was also felt to contribute strongly to the impact of the books in conveying the message of *not being alone*- a sentiment expressed by several. Furthermore, the

majority felt that the booklets were easy to understand and liked the fact they were not written from a medical perspective:

...showing you ways that you can recover without too many medical terms or jargon....that you can recover, it just takes time and healing but if you want to you can do it. That is the message they are putting out (C2).

This same carer described feeling helpless at times – about wanting to help and support his/her partner, but being unsure what to say or do. It was felt that such guidance would be useful but was not provided in Journeys and Routes:

more information for me as a carer of how to handle things. I don't know what to say to him for the best sometimes, how to deal with it better when he's really down. A bit more guidance for me (C2).

Although the writing style was viewed positively by all carers, two felt that both books had too much overall text in them. Both these carers described how their own relatives would need help and support to understand them and imagined they would be difficult to read for many people experiencing a mental health difficulty. One of these carers, whose relative had multiple needs, highlighted the resources as being largely inaccessible to those with learning difficulties or limited reading ability. This carer felt that to reach such individuals there would need to be less text overall, less text per page (in both books) and supporting visuals.

All participants liked the cover design of both books and two in particular liked the fact that the covers were discreet in communicating the content of the resources, acknowledging that they felt there was often a stigma associated with mental health difficulties.

Three interviewees specifically cited the listing of a variety of mental health organisations within the resources as particularly helpful, with two of them considering making contact with the most relevant for them.

Journeys of Recovery

The carers interviewed were expansive in expressing their views on Journeys. All six liked the narrative style of writing which they felt conveyed a sense of hearing people's real experiences and found they became interested in the characters and their individual stories.

Two of the carers had been or were currently in a situation where their relative was not realising or accepting they had a mental health illness which in turn was creating difficulties in them accepting help or support. From this perspective, they welcomed and felt encouraged by stories within Journeys:

Some of them seemed to have their illness for a long time. But they all seemed to recognise they had an illness which was quite good to see - I think often people don't really know that they're ill. But the people in this got help because they wanted it and they wanted to get better. It was good to see how they are all doing now and how they got on the road to recovery and had all these people to help and places they could turn to (C5).

What really leapt out at me was realising that to recover you need to have recognition of having a problem. If you recognise it then you can move onto the first step (C3).

Interviewees also talked of recognising or connecting with features or experiences in the narratives that they felt were shared by their family members:

Some of them thought this illness was their whole universe and that's how my daughter used to feel. I liked the message that their life was more than just their illness and that they realised well they had other things they had to cope with and get on with (C5).

Thus it would seem that many felt that they could relate to the stories and as consequence these could make them feel more hopeful. One carer felt the example of the occupational therapist telling her story provided a particularly important perspective as it portrayed an important message that *it can happen to anyone.... not just me working in a shop (C6).*

Whilst the overall feeling towards Journeys was very positive amongst the carers interviewed, there were a small number of specific comments about what was felt to be missing. One participant described having an overall sense of there being an imbalance in relation to the type of people telling their stories. Specifically the narratives were seen to be those of mainly articulate and educated people, and not representative of the full range of people experiencing mental health problems:

My only criticism of it would be that it seems to be mainly professional type people who the stories are from and who you would expect to pull out of it. I just think there is a slight imbalance. It's as if they have only listened to people who are coherent and intelligent - they're not like ordinary people (C3).

This same carer whose relative was currently unwell and not accepting help felt that it would be useful to have more insight into how the recovery process began:

... if they could go into a bit more detail of how bad they were at the outset of their illness and how they started on the road to recovery - how did they recognise it and how did others recognise it (C3).

From this we infer that the interviewee would have appreciated not just insight but some ideas on how to engender recovery.

While the points raised above relate to how useful Journeys was for carers, mixed views were expressed in relation to its suitability for their relatives. Two felt it would be unsuitable and not accessible to their relatives: for one this was because of learning difficulties and poor reading ability, and for both because of poor concentration. They felt there was so much text that their relatives would not be able to read and digest the material. Others however could imagine the resource being a real support to their relatives, particularly in relation to reducing their sense of isolation and offering hope and a positive message:

I think I would leave Journeys for XXX (partner) to pick up. It has a lot more personal stories and there are people in the book that have gone through similar things to him. So it maybe shows a little more understanding and would let him see that it's not just him that's dealing with this, it's other people as well...and that you can recover (C2).

Routes to Recovery

All the interviewees liked this resource, referring in particular to the style and layout. Only one carer found the style of using different handwriting difficult to read in parts. The others liked the use of individual's handwriting and the use of yellow 'post its':

The handwriting makes it feel individual to the writer, each writer is trying to get over their own personality and that works (C3).

Several interviewees remarked on how accessible they felt this particular resource was. One individual thought that because of this the Routes booklet might be easier

for their relative to read because it is shorter and *easier to dip into* (C5). Another described the book as one *you can refer to it without getting too involved* (C3). Another still remarked on the optimistic tone of Routes and viewed it as providing practical, positive steps to recovery.

Postcards

There were quite mixed views on the series of postcards, particularly on the visual style and graphics used.

Four interviewees commented that if they saw them sitting in a waiting room or anywhere else that they would not realise they were about mental health. Whereas some thought this was positive and would make it easier to pick them up, others thought they might easily be missed by those they were intended to target.

The messages on the reverse of the cards were generally considered acceptable, conveyed a sense of hope and were enough to let the reader know that sources of help were available. One carer however highlighted the discrepancy between this message and his/her own experience of receiving little help or support:

I like that it explains you are not alone and we can get you support. The other side of that though is that you can't promise someone that on a card and then there are no services there. The services have to be in place (C4).

There were very mixed views on the design of the postcard series. Four participants liked the graphics and colours used on the cards, describing them as colourful and positive. Two particularly highlighted the card '*Inspire Hope*' as conveying a strong feeling of optimism through the phrase and the design.

One carer of someone with epilepsy however highlighted the possibility of the graphics on the whole series of postcards being too stimulating and causing difficulty. The sixth carer strongly disliked the graphics, saying the lines *hurt my eyes* and describing the colours and general design being *dull and depressing* (C6).

Use and Distribution of Resources

There were mixed views on the best ways for the resources – and the messages contained within them - to be distributed and used.

One issue that emerged was that these were viewed as targeting those with long term mental health problems. This prompted one interviewee to muse over who should get the resources and when:

I felt the messages are aimed at people with 'enduring' or 'long term' mental health issues so I think of people who have had them for many years. So why would you not want to target the message to someone who had just received a diagnosis maybe a year ago. I don't think it should just be targeting people who are 'long term' - how long is long term? I'm not even sure what is meant by that (C4).

On a similar theme, another carer felt that the resources would have been most useful for her as a carer at the outset when she felt fear for her relative and doubted the prospect of her getting well. This was a time when as a carer she received little support and would have valued the perspective offered from the range of narratives in the booklets:

Something like these would have been really useful to me when XXX was first

diagnosed. I used to think how is XXX ever going to get through this, how is XXX ever going to fit into society. But when I read these I thought well there are a lot of people much worse than XXX and they get through it (C5).

There were mixed views however, around the timing of those with mental health problems receiving such resources. Some interviewees felt that the resources would be helpful for carers to receive at the early stage of diagnosis but not necessarily for those experiencing the mental health problem:

When my mum was first sectioned she wouldn't be able to take it in. But it would be good to speak to the families first and then to the person later - the CPN could bring it up and speak to them about it (C1).

Others however felt that it was important to communicate the possibility of recovery right from the outset.

Most felt that the resources could stand alone, yet a number highlighted how they might best be used in consultation with a professional. One example of this was their possible use being supported within a GP consultation:

It would be good to have them in a doctor's surgery then they can talk to the GP about it or the GP could have some and give them to the patient when they are in and talk to them about it (C2).

In contrast, one carer emphasised the importance of the resources being freely available to pick up:

A lot of people who are depressed won't even go to their GP...it's amazing how many people out there are suffering from depression and anxiety and won't talk about it.. so this really could be the first step for them if they pick this up (C6).

Participants listed a number of places where they felt such resources should be available including medical venues such as general and psychiatric hospitals and doctor surgeries. Most participants felt they should also be available in general community venues such as libraries, residential care establishments, homeless units and hostels. Television and local radio were also considered good mediums for communication recovery messages. One participant raised the concern that organised seminars and events might only reach a limited audience of carers, and possibly those who were in some way already accessing support mechanisms. She suggested the need to be creative in reaching target audiences:

My experience is that seminars and events tend to be attended by the same people over again like groups of carers who have organised themselves in some way. I think you need to look at how to get this out to a wider audience. It would be useful for SRN to go into a wider range of services and talk to people and carers who are using services and maybe even meeting with smaller groups of people (C4).

Context of recovery messages within own experience of services

Interviewees discussed the messages of recovery portrayed within the resources and how these fitted in relation to their own experience of services.

One carer talked about her relative receiving very mixed care: sometimes her relative was simply managed via prescription whereas other times she had received 'superb' person-centred support that was more recovery-oriented. For the five other carers however, the messages of recovery communicated within the books did not fit with their experience of services and the support given to their relatives. This was in

relation to both a lack of service provision and in the quality of contact with existing providers.

So while the majority of interviewees found the SRN messages of recovery positive and hopeful, in the main these messages did not seem aligned with their actual experience of how services had responded to their relatives.

Perceived impact

The majority of carers felt they had learned new things from reading the publications. This included specifics such as the range of support organisations listed, to more general descriptions around widening their perspective on recovery. Two carers felt it had influenced their beliefs around the possibility of recovery, having previously feared that this might not be possible. No one described any differences in behaviours at the time of interview, although half imagined they would use the resources as a support in talking to their relatives in the near future.

Summary

Six participants were interviewed who cared for a family member or friend experiencing mental health difficulties.

The majority had no previous awareness of SRN or their publications.

Overall, there was agreement with SRNs four key messages which were viewed as positive and hopeful. There was much difficulty in understanding the fourth message, and a general feeling that any messages needed to be short and simple.

The resources were well received by all. The main strength described was the narrative style and feeling of personal relevance found within the stories. There were some criticisms around the format, specifically there being too much text and Journeys being too dense in layout.

There was agreement that the resources should be widely available, although mixed views around the timing of their introduction to those experiencing mental health difficulties.

Many felt that their knowledge increased after reading the resources.

Chapter Seven: Triangulating the findings - what the full range of data indicate

In this chapter we consider the findings that have emerged and identify areas where professionals, service users and carers shared similar views, and where these differ.

Overall, there was remarkable agreement: strengths and weaknesses in messages and materials raised by one target group were commonly identified by another. However, differences also arose, not only within a target group (as already reported in previous four chapters) but between them too.

Views on key messages

The messages were viewed as positive. Several difficulties were identified with them when considered as stand alone messages.

‘People can and do recover from even the most severe mental health problems’

The fact that the message was short and punchy was valued. This brevity brought problems though with people taking different meanings out of the message: for some recovery was taken to mean an end-state free of symptoms, for others it meant living with an illness. As a consequence of this lack of clarity, the accuracy of this message was challenged: it was felt that there are some conditions from which a complete recovery in the traditional sense of the word (i.e. as an end state) is not possible. Professionals cited specific illnesses where this does not apply, and some service users talked of there being no cure for their particular condition, or felt that the message did not seem relevant to their experience of relapses. The message was seen by these individuals as failing to convey recovery as a journey or a process.

The message was seen as requiring some elaboration. Professionals, service users and carers all highlighted the importance of support – from families, friends, and professionals – and felt that this should be made explicit.

‘Recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms’

In general terms there was a lot of agreement with the essence of this message. All target groups appreciated that it stated that recovery was possible while living with mental health problems. Therefore it was seen as more realistic and truer than the previous message. However, some service users were resistant to the message feeling that it seemed to imply that their mental health problems made them deficient in some way, that they ‘ought’ to recover. Service users and carers said that they found the message too long and struggled with what they perceived as complex language.

‘No two people’s recovery journey or experience will be the same’

This message was accepted as true and as validating individuals’ experiences. Professionals valued it for conveying the importance of treating clients as individuals. Despite these favourable views, the message was seen by some as simply stating the obvious. Furthermore, some suggested that it would be important to also stress

some common experiences or factors underpinning recovery such as the support of services, families and friends.

Some professionals were concerned that by emphasising the uniqueness of individuals, the message may inadvertently make people feel alone in carving a new path rather than starting down a well trodden one. Given the fact that some service users and carers talked of feeling reassured by learning that others had comparable experiences, this would seem to be an important point.

‘The critical assessment of attitudes and values can have a powerful impact on an individual’s prospect of recovery’

While people grasped the general idea that attitudes are important, there was widespread difficulty and confusion with this message. People (across all groups) were unclear whose attitudes and values were being referred to. Service users and carers felt that it was something that a health professional would say, and again struggled with the complexity of the language and structure used.

Awareness of SRN

This evaluation purposively included people who were expected to be familiar with recovery issues and/or SRN (because they were on SRN’s distribution list and/or attended a service users’ support group) and those who were not so obviously linked to the recovery agenda. Amongst those service users attending support groups, there was some limited awareness of SRN with it being viewed as largely targeting professionals. Neither the remaining service users, nor five of the six carers were aware of SRN.

Awareness of SRN resources

Our desk-based assessment of the information that SRN holds indicated that since 2006, it has distributed significant numbers of resources with many people accessing the website and email updates. However, prior to taking part in this evaluation, there was only limited awareness of the resources among those involved. While some focus group participants (i.e. those attending service user support groups) had seen the resources before, not all had. No carers had seen the resources before.

Among the professionals, the web-based survey highlighted that only 53% of respondents were aware of Routes to Recovery, whilst 58% were aware of the report Recovering Mental Health in Scotland. Journeys of Recovery had a much greater awareness (81%) among survey respondents but in their interviews a number of professionals admitted that they had never read it in detail or used it in consultations with patients. These low levels of awareness are notable considering all the professionals who responded to the email survey (and eight of the ten professionals in the interviews) were on SRN’s email update system, and therefore likely to be engaged with SRN and the recovery movement.

Views on use of narratives

Overwhelmingly, the use of narratives was seen as a useful way to communicate messages of recovery. They were valued for being real people with real experiences – features to which many service users and carers could relate. Despite this, some commented on the need for a range of narratives that would be relevant to people

with different circumstances e.g. individuals from minority ethnic groups, and people who are less privileged, have not received further education, and experience less support.

Carers and service users were explicitly asked whether the key messages were communicated within the resources: in general, there was a feeling that the resources were consistent with, and communicated the first three messages.

Journeys of Recovery

The narratives accounts provided were seen as a useful way to convey stories of recovery. Whether or not service users found these personally useful largely rested on the extent to which they could relate to the stories contained within this booklet. Service users who could relate to them, found the stories hopeful, helpful or affirming of their own journeys. On the other hand, some of those who could not connect with the stories responded very negatively to them: they felt dispirited by their own personal lack of recovery or by the fact that they did not receive the helpful support of professionals, families and friends that the narrators of the accounts experienced. A need was identified to make available a wider range of narratives that would be relevant to more people e.g. from different socio-economic backgrounds, cultures and those whose recovery has been difficult.

Concerns were expressed across all target groups over the length of the booklet and the density of the text. As such, these features of the booklet's format were felt to make it not only difficult to digest, but may actually deter someone from reading it, or make it inaccessible to those who have trouble concentrating – a difficulty frequently experienced by people with mental health problems.¹³ Some service users remarked on the use of the individual key words (presented in orange text) as unhelpful, and in a couple of cases, use of terms such as 'psychotic' were felt to be stigmatising. Furthermore, all target groups felt that the booklet's layout did not lend itself to easily finding those stories that might be of most personal interest or relevance. To go some way to remedy this, it was suggested that the booklet might add summaries of the stories, and headings that clearly communicated key features of the stories. Professionals and service users also suggested that pictures are used to brighten it up. Many service users tended favour this booklet over Routes to Recovery.

Routes to Recovery

Professionals and carers liked this resource: the fact that it is short and made use of some imagery (post its and handwriting) was seen to make it highly accessible. It was also valued for being an easy booklet to dip into. Service users on the other hand held mixed views. Overall the content was liked for being positive and affirmative. However the format was described by some as confusing and bland, and that it would benefit from the use of more visuals. Many preferred the narrative style of Journeys of Recovery.

¹³ Journeys of Recovery is available on request from SRN in CD format

Postcards

The postcards were well-liked, particularly by the professionals and the service users. The one or two line messages on the front were viewed as direct and very positive. Only the service users talked at length about the reverse side and they felt that this text was not directed at them. As such, this reflected a wider issue: that most carers and some service users were unclear about the intended audience for the postcards.

The bright colours of the postcards were welcomed but service users and carers did not like the graphics that were used. Service users and professionals felt that the postcards should be widely available for people to pick up, possibly redesigned in a slightly different format bearing in mind the negative comments about them.

Relevance, context and timing

Service users and professionals raised issues to do with when resources should be made available. While some suggested they should be freely available for service users to pick up, both groups highlighted that the resources could bring unintended consequences if given too early on in an individual's diagnosis. It was suggested that if these were read soon after diagnosis, some individuals could feel daunted or overwhelmed by the prospect of recovery as a long process, and some service users and professionals felt that the booklets would be quite inaccessible when service users were quite ill.

Accounts from service users and carers suggested the need for additional resources that were directly relevant for people with mild and moderate mental health problems. Carers indicated that they would welcome more directly relevant guidance for them in their capacity of providing support to service users. The BME service users identified the need for culturally relevant narratives, for resources to be translated into minority languages, and for these to be distributed to places frequented by BME people e.g. mosques.

Recovering Mental Health in Scotland

As this is a research report, only the professionals were asked for their views on this publication. It was widely praised and seen as a useful reference and for endorsing the need for recovery-focused planning.

Recovery oriented practices

Professionals involved in this evaluation made references to their recovery oriented practice. In part, such (desirable) behaviours may reflect the bias in our sample. A very different picture emerged from the service users and carers: about half of the service users and none of the carers received support that was felt to be recovery-focused.

Perceived impact

Many professionals reported that their practice and the broader context for their work had been influenced by SRN's activity; many service users found the resources

optimistic and hopeful, and some felt that they validated their own experiences; and carers found the resources informative and reassuring.

Summary

There was remarkable consistency in the view of professionals, service users and carers.

In general, the messages were supported. They were valued for being hopeful.

Messages need to be concise yet sufficiently detailed to be meaningful and true.

The language used in some messages was confusing for several service users and carers.

The use of personal narratives was valued but a greater range of stories is required.

Professionals, service users and carers favoured different resources.

The context and timing of resource use requires some consideration.

Chapter Eight: Conclusions and recommendations

In this final chapter, we reflect on the key issues that emerged from across the evaluation and on the basis of these, offer recommendations on how to capitalise on SRN's current communications and resources, and on how these might be strengthened in the future.

Overview

In the round, the story from this evaluation is a positive one. Our survey with professionals, and interviews/focus groups with professionals, service users and carers indicate that there is a lot of interest and support for recovery as a concept. Furthermore, SRN's use of narrative accounts is seen as providing a highly accessible medium for communicating relevant, positive and hopeful messages.

This evaluation is generally a good news story. It is also a highly nuanced one, and it is in the detailed (including critical) comments that we find many of the pointers as to how things could be improved.

It is important to remember that the views identified in this evaluation are not intended to be generalisable in as much as we did not have representative samples from all service users, carers of professionals in Scotland. We purposively attempted to involve people who might be likely to hold a broad range of views. This is conventional and desirable in a qualitative study of this sort.

We acknowledge that we did however have a bias in our professional sample. Most were recruited through our survey and while we had intended to identify a mix of professionals who held positive views of SRN's work, and *some who did not*, respondents (and hence our sample) were overwhelmingly supportive of SRN and its work. Even those we recruited who were less aware or engaged with SRN were still relatively positive. On probing, these professionals did highlight some areas of difficulty, but it is important to bear in mind the likely (positive) bias in their views.

Finally, it is important to recognise that the communications and messages that were the focus of this evaluation were considered from the perspective of their relevance and use with *adults*. It is important that findings are not generalised to children and young people whose needs and recovery paths will be qualitatively different.

A note on context

SRN is still relatively young: it was established at the end of 2004 to act as a catalyst of change, aiming to promote and embed recovery-oriented values and actions. This role reflects the fact that as a nation 'we are not yet there' in our recovery thinking and our practices, that more needs to happen. As such, the work of SRN has to be understood as part of, indeed a beacon within, a recovery movement that involves a paradigm shift in the way professionals, service users and others conceptualise mental health problems. This movement is characterised by a belief that people can and do recover from mental health problems. The take home message for all, particularly for service users, needs to be one of hope and optimism. And for professionals, mental health problems have to be conceptualised – or in some cases perhaps, reconceptualised – so that recovery-oriented policies and practices follow.

This evaluation needs to be located within this context of continuous change. It is important to acknowledge that individuals – professionals, service users, carers – will be at different stages in their understanding and thinking about recovery. The challenge for SRN then is how to turn around the views of some, while deepening understanding in others on how to improve the chances of recovery.

The concept of recovery is not an easy one to promote and this evaluation attests to a number of obstacles to individuals understanding or accepting the concept. In fact, views on the messages and materials were difficult to disentangle from views on recovery more generally: if people did not agree with the notion of recovery and/or did not see it as personally relevant, they were unlikely to engage or agree with messages that promote it.

This is an important issue that we pick up throughout this chapter as we recommend that the materials and messages need – where possible - to be tailored so that they are relevant, accessible and acceptable to their target audience.

Key Messages

In very general terms, the essences of the key messages were supported. Therefore, there is very clearly value in SRN continuing to distil what recovery means.

In particular, it was evident that certain features of messages were valued: if they were felt to be concise and clear, positive and optimistic, affirmative, and above all – true. However, the extent to which these qualities were felt to apply to each individual message was highly variable. The concerns and caveats that were raised point to the need for some refinements.

First, people challenged the message that ‘people can and do recover’: despite the fact that this message does not state that all people can recover, it was often misinterpreted as such. Furthermore, some found the proposition of recovery as an end-state unhelpful, preferring to view recovery as a process or journey. In fact, the second message – ‘Recovery means having the opportunity to live a satisfying and fulfilling life in the presence or absence of ongoing symptoms’ does indeed convey a different meaning of recovery to the state of full recovery implied or perceived by the first.

☞ We recommend that SRN develops a simple, clear but unifying message to the effect that some people can and do make a full recovery while others can go on to lead a full and satisfying life in the presence or absence of symptoms.

There were some concerns about the language or ‘jargon’ used in some messages, particularly where this was seen to be highly medicalised e.g. some were confused or put off by terms such as ‘presence or absence of ongoing symptoms’ and ‘severe mental health problems’. In turn, some service users and carers misconstrued and/or disengaged from some messages.

☞ We recommend that SRN develops a series of core messages that can then be articulated clearly and appropriately taking account of the needs of its different target groups including the role that each can play in engendering recovery. Such messages should use language appropriate to individual target groups.

☞ We recommend that SRN keeps its messages as short and simple as possible for all target groups.

More specifically, in message two, the precise wording 'presence or absence of ongoing symptoms' was not only confusing for some service users, but both service users and professionals raised the fact that not everyone wants to rid themselves of their symptoms. While we recognise that the message might be intended to acknowledge this very issue, it was sometimes misread as devaluing (some) service users' lived experiences.

☞ ***We recommend that SRN ensures that its message(s) better reflect the fact that for some people recovery means accepting their mental health problem as part of who they are.***

The message – no two people's journey is the same – was valued as it was seen to be true, short and to the point, and validating of individuals' experiences and of the need for person-centred care. However, it would seem that the message might be more reassuring if it stressed that others have taken this journey. Furthermore, consideration of service users' views indicated highly individualised notions and experiences of recovery. At the heart of these was the importance of feeling in control.

☞ ***We recommend that SRN considers the development of an additional message to reflect the importance of service users' self-efficacy.***

Given the fact that individuals often experience common facilitators to their recovery, it would be useful to provide pointers on what might assist the recovery process (although we recognise that this is also what Routes to Recovery seeks to do). The importance of supportive individuals and services was specifically highlighted as an important building block to recovery that was not made explicit in the messages.

☞ ***We recommend that SRN develops targeted messages for professionals and families/carers to the effect that recovery is more likely if those in contact with service users are optimistic, supportive and encouraging about their recovery prospects. This should replace the confusing fourth message regarding the critical assessment of attitudes.***

Finally, it is important to acknowledge that this evaluation explored views of existing messages. It did not seek to identify and reach agreement on new ones. Therefore:

☞ ***We recommend that following any refinements or new developments, SRN pre-tests messages on their intended target audiences to ensure that these are understood, acceptable, and above all - cause no harm.***

Awareness and targeting

It is important to acknowledge that SRN is still comparatively new, has a national remit and is a relatively small team. It also has a very ambitious agenda: in the situation analysis workshop that was run with a view to informing this evaluation, SRN and its key partners confirmed that they were hoping to reach professionals, service users, carers and the general public.

It is questionable how feasible this is. If SRN is seeking to maximise its impact, it needs to reach large numbers of individuals, and these need to be likely to benefit from the communications and materials SRN provides.

We know that SRN has circulated large quantities of its various resources, the distribution list for its email updates is over 4,000, it has many visitors to its website and its events are well attended. However, SRN's current systems do not allow one to easily extract information on the profile and spread of these recipients. In a

separate report to SRN, we detail how these technical issues can be addressed through redesign of its databases. In general terms, the need for SRN to collect and record information in a consistent manner across characteristics such as individuals' interest/professional role, organisation, city and postcode lie at the heart of this report.

It would seem that SRN's large scale distribution of resources has not translated into high levels of awareness however among those who participated in this evaluation. The exception to this was awareness among those accessed via SRN's electronic mailing list, however, even in this group for some resources awareness was only around 50%. Less than half of the service users recruited through support/recovery groups had heard of SRN, and none of those recruited through NHS services. Furthermore, five of the six carers had not heard of SRN and the GP who was recruited for interview had never heard of SRN despite having a very strong interest in mental health issues. We make no claims that these individuals were in any way representative but the point remains: to date has only limited *reach* within their intended target audiences.

☞ ***We recommend that SRN is clear about who are the intended audiences for its communications, proactively targets them to ensure that they are reached in large enough numbers to (plausibly) make a difference, and tailors its communications accordingly. As such these communications, resources and distribution channels should be based on a clear understanding of the outcomes that SRN hopes to achieve through the use of each, and use a variety of approaches appropriate to each target group.***

It may be worth exploring the possibility and likely attendance at accredited sessions for certain professional groups such as GPs and psychiatrists.

Our survey indicated high levels of satisfaction with the SRN's electronic updates among the professionals who responded. It would seem then that these updates meet their needs, and should be continued. However, the fact that about half the survey respondents were unaware of Routes of Recovery and Recovering Mental Health in Scotland would seem to indicate that those on the network may need to be regularly reminded or primed regarding the availability of key resources.

There was a commonly held perception among the (few) service users who knew about SRN, that it is for professionals. This was reinforced by a couple of comments about the updates and the website not being very relevant to them.

☞ ***We recommend that if SRN's intention is to target service users and carers that it develops (separate) tailored communications that are appropriate and relevant to them e.g. a carers' newsletter, a specific section on the website for service users with short narrative stories and tips how to cope etc.***

Resources

The resources that were considered in this evaluation were largely based on personal narratives. Overwhelmingly the use of real and personal stories was valued as a powerful and accessible technique to communicate the possibility of recovery, and through this to inspire hope. Without a doubt, SRN's use of these stories must be considered to be a key strength or success.

A number of issues emerged around the content, format and best use of the three more generic resources: Journeys of Recovery, Routes to Recovery and the postcards.

We deal first with the cross cutting issues and then move on to recommendations that are specific to each of these resources.

The importance of personally relevant stories

The narratives were viewed extremely positively when people could relate to them. Conversely, their value was limited when the stories were felt to be irrelevant to an individual's own circumstances. There were, however, some examples where the stories were described as having a detrimental effect e.g. references to severe symptoms evoked fear among some. While we acknowledge that it is unrealistic to expect there to be a story that 'matches' each and everyone's unique experiences, a broader range of narratives would be useful.

☞ We recommend that SRN complements its currently used narratives with ones that cover a wider range of experiences and circumstances than currently detailed in Journeys. Suggestions include accounts from BME individuals, more from people who have not gone to college or university, and people with challenging or 'bumpy' journeys of recovery. Furthermore, we recommend that the range of narratives is extended to include ones on mild and moderate mental health problems. SRN should capitalise on its large pool of collected stories for this, and if necessary, proactively identify other individuals to ensure that a broader spectrum of experiences is presented.

Conducive contexts for resource use

Journeys of Recovery, Routes to Recovery and the postcards were valued for being positive, uplifting and hopeful. Despite this, many considered that Journeys of Recovery and Routes to Recovery would be unsuitable for someone early in their diagnosis: it may not simply be a case of people being unreceptive to these when they are very ill, but also and more worryingly, that the resources may dispirit or even alarm someone by suggesting that problems may be long-standing before they have come to understand and accept their diagnosis. From this we conclude that timing may be an important consideration. Furthermore, and as outlined earlier, *in their current form* resources may not all be appropriate to many people with mild to moderate mental health problems.

☞ We recommend that SRN considers issuing supporting information about the content of the resources and when in a person's recovery these resources might best be read. Any information of this nature should be tailored to meet the respective needs of professionals, service users and carers.

This supporting information might usefully reiterate the key messages (following their refinement as recommended above), seek to encourage a sense of satisfaction in any steps to recovery no matter how small, and promote the fact that audio files of selected narratives are available on CD and via podcast on the SRN website.

Resource-specific issues

We now turn to some issues that were more resource-specific.

- It was felt that Journeys of Recovery would benefit from better headings and signposting (to help people find their way round the stories) or from dividing into a series of separate publications. In addition, it was felt that it would be

- improved by including a wider range of accounts, a less dense layout, and more use of colour and graphics.
- Routes to Recovery would benefit from the use of more creative visuals. This evaluation suggested that it may be more useful for carers/families than for service users.
 - The intended use and target group for the postcards was unclear. Service users liked the short punchy messages on the front of the postcards but the information on the reverse side however was generally considered to 'not work'. While the use of bright colours was welcomed, the graphics were not. Specific concerns were raised about the suitability of the postcards for people with special needs (reading difficulties and epilepsy).
 - Recovering Mental Health in Scotland was highly valued by professionals, in particular as a useful source of reference.

Based on the points above, we recommend that in the short term (until existing resources are 'used up'):

☞ **SRN continues to disseminate Journeys and Routes taking account of the recommendations made earlier;** and

☞ **the existing postcards are made available in a wide range of health and social care settings, and where feasible, in less 'conventional' areas e.g. libraries, places of worship etc.**

Furthermore:

☞ **Recovering Mental Health in Scotland should be distributed to departments and lecturers delivering professional and vocational training to professions allied to medicine.**

In the longer term, we recommend that in relation to **Journeys of Recovery** that SRN:

☞ **collects and packages a more extensive range of stories;** and

☞ **produces a single resource that is easy to navigate around, or produces a series of stand alone stories to replace Journeys. In either case, it will be important that these developments attend to features such as visual appeal and accessibility.**

In relation to **Routes to Recovery**, we recommend that SRN:

☞ **revamps the design of this booklet to make it more visually appealing;** and

☞ **considers expanding the content to provide some suggested steps to recovery.**

In relation to the **postcards**, we recommend that SRN:

☞ **creates a new resource for service users using the short messages currently featured on the front of the postcards. This might be partnered with a top tip or a poem and might take the form of a wallet sized aide memoir.**

Importantly,

☞ **We recommend that SRN carries out significant pre-testing of all new or refined materials on its intended target group.**

Impact on knowledge, attitudes and behaviour

The data gathered from the situational analysis and the interviews and focus groups illustrate that the range of SRN communications considered in this evaluation are not specifically targeted and are not accompanied by information or advice on the context, timing or nature of their use. As such SRN has also not specified the precise changes in knowledge, attitudes and behaviours/practice that they anticipate will occur amongst their specific target groups (service users, carers, professionals) from the dissemination of its messages and communications. However the findings from this evaluation are encouraging: many of the professionals involved reported that SRN had influenced their practice and that of the organisations/structures within which they worked; many service users found the resources were optimistic and hopeful, and felt that they validated their own experiences; and the carers found the resources informative and reassuring.

In a process allied to this evaluation we have worked with SRN to support them in the development of the logic model that was drafted as part of the situational analysis. This model and activity starts the process of further clarifying the outcomes (including changes in knowledge and behaviour) that SRN hopes to achieve in different settings and with different target groups. We would anticipate that this work, along with the findings from this evaluation, will help to identify ways in which the communications can be more appropriately targeted and linked to other aspects of SRN's work which are more orientated towards practice or organisational change such as the Scottish Recovery Indicator Tool.

Summary

The general story is a good one: professionals, service users and carers identified many positives in SRN's communications and materials.

SRN should continue to distribute and extend its use of narrative accounts.

The essence of SRN's core messages should be retained, but the precise wording should be refined.

To strengthen the impact of its communications and resources, SRN needs to become more sophisticated in targeting specific audiences with messages and materials tailored to meet their needs.

SRN's current resources should continue to be distributed in the short term. To minimise the risk of the resources bringing unintended negative consequences, guidance should be issued to professionals regarding the use of these.

In the longer term, SRN should refine its resources to make these more accessible and appealing.

All future developments in messages and/or materials should be pre-tested with their target groups.

Appendix One: Further details of recruitment approaches and methods

One to one interviews with service users

To recruit individuals in an ethical manner, mental health service users were identified through two channels: GPs and through a counsellor. Acting as a bridge between the researchers and the service users, these gatekeeper were asked to identify clients/patients in order that we could obtain a purposive sample with the following characteristics: two individuals with a diagnosis of a depressive condition; two with either an anxiety or mixed affective disorder; one with a diagnosis of schizophrenia; and one with an eating disorder. All were to be over 18 years of age and be considered sufficiently well to participate in a one-to-one interview about recovery.

These stakeholders sent out letters that we had written and which described the study, and explained that all those who participated would receive £25. If individuals were willing to participate, they were asked to return the consent form direct to the researcher. A stamped addressed envelope was provided for this purpose.

Once the researchers received the consent forms, they liaised directly with the individuals to arrange an interview time. In addition, they sent out a pack of SRN resources (Routes to Recovery, Journeys of Recovery and five postcards) to be read prior to the interview.

At the start of the interview, participants were given an envelope containing £25 for participating, and contact cards for Samaritans and Breathing Space (a telephone helpline for people with low mood and depression).

Interviews lasted between 50 minutes and one and a half hours, were recorded (with permission) and subsequently transcribed.

Focus groups with service users

Four focus groups were held. Each of these comprised service users attending an existing service users' group, and for this reason these participants were expected to be "closer" to the recovery agenda than those involved in the one-to-one interviews.

Researchers approached four service user groups from across (mainland) Scotland to request their participation. Three were mixed gender and one was an all women's ethnic minority group.

A key contact person within the host agency for each of these service user groups sent out information on the researchers' behalf requesting participation at a focus group on a specific date, and asking that those willing to be involved should send back the signed consent form to the researchers using the stamped addressed envelope provided. It was made clear that a maximum of six places would be available at each group.

As with the interviews described above, materials were sent out in advance of the focus group, and £25 was given to each participant immediately prior to the focus group.

Focus groups lasted one and a half hours, were recorded and subsequently transcribed.

One to one interviews with family members and carers of service users

The researchers enlisted the support of a professional recruiter with the intention of identifying six individuals who had a close family link with a mental health service user. The recruiter was provided with a specification regarding selection criteria. These included: all interviewees must be over 18 years old.

Similar to the procedures outlined above for recruiting service users, the researchers provided an information sheet and consent form which the recruiter gave to all those identified as meeting our selection criteria.

As the recruiter was unable to identify a family member of someone diagnosed with schizophrenia, an individual with this profile was identified through a GP.

One to one interviews were held in a room hired in a community venue and £25 was given to all those participating.

Interviews with professionals

Ten professionals were recruited for interview. Eight of these were recruited from those completing the email survey and who agreed to be contacted for interview. Two, who were not engaged with SRN, were recruited via the professional Royal Colleges. A purposive sample was taken such that it included individuals:

- from both the statutory and non statutory sectors;
- with responsibility for strategic/service planning and others with a delivery/care role;
- across a range of health and social care professional groups including mental health professionals (e.g. CPN, psychiatrist, psychologist) and non-specialists (GP, addictions worker)
- across Scotland (e.g. Aberdeen, Stirling, Inverclyde, Glasgow Edinburgh and Livingston)

One-to-one interviews were carried out with all following their signed consent to participate. Because of time constraints, most requested that their interviews were conducted by telephone.

SRN communications were sent out prior to these interviews. In addition to those sent to service users and carers (i.e. Routes to Recovery, Journeys of Recovery and five postcards), professionals were also sent a copy of the research report *Recovering Mental Health in Scotland*.

Two topic guides were used: one for those more familiar with SRN (and recruited through the survey), the other for the two who were more removed from SRN activities.

Seven interviews were carried out by phone and three were conducted face-to-face. These ranged in duration from 30 minutes to one hour. All were recorded and subsequently transcribed.