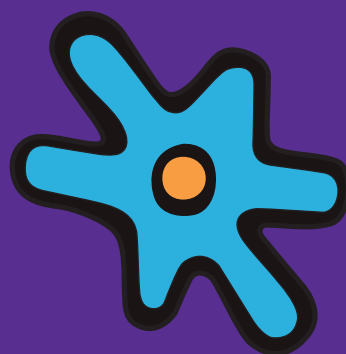# Service users' experiences of recovery under the 2008 Care Programme Approach

A research study – Dorothy Gould 2012

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Acknowledgements

Contents

Foreword

Introduced in 1991, the Care Programme Approach (CPA) was intended to create greater degrees of coordination between different practitioners and agencies involved with the support of an individual, but in its earliest incarnations it became associated with one of the landmark tragedies of community mental health care – the case of Christopher Clunis in 1992.

Christopher's story will be familiar to many who read this piece of research, and while I was reading it I was thinking of him. Christopher, a young black man, had reached such degrees of mental distress that he fatally stabbed Jonathan Zito at Finsbury Park tube station in London. The subsequent inquiry into his mental health care concluded that Christopher had not got the support he needed and that there was a lack of consistency between different episodes of care, rather than support to live with and manage a continuing mental health problem. Issues of race and racism were also highlighted in discussions. Twenty years on, I wonder if things would be different for Christopher under the Care Programme Approach; how would he define and experience his recovery?

There have been ongoing questions over whether the Care Programme Approach is an administrative process or a therapeutic approach. Perhaps it is both, but given the imperative of focusing on the person, it is crucial for service users to keep asking questions about its effectiveness. Does the CPA genuinely provide 'continuity of care' for the individual? To what extent does it allow the individual to influence and direct their own life while managing their mental health? How can the CPA work with newer, person-centred recovery models to better support people to lead fulfilling lives?

This report gives a vital insight into how people are experiencing the Care Programme Approach and recovery, including those who, like Christopher Clunis, are from black and minority ethnic backgrounds. It asks and seeks answers to searching questions about two core approaches in the current mainstream mental health system. The research is grounded in lived experience – it is a rare piece of robust, user-led research which can be used to challenge and inform knowledge on the subject. (It is rare because user-led research is seldom funded). The findings are authoritative and concerning. The challenges for the CPA today are the same as they were for the CPA twenty years ago – the approach needs to focus on and accommodate the whole person, particularly if it is to support them to define and lead their recovery.

This research clearly shows that a system which too often defines people by their diagnosis and medication finds it difficult to recognise the whole person and the unique individual. Participants said that they rarely had space to discuss non-psychiatric understandings of mental distress. Feedback from participants also indicated that they had limited opportunities to influence services: individually, or strategically. But in a context where choice and control for people who use services is a policy imperative, the room for such discussions on both individual and collective levels needs to be made. The voices of experience captured in this report should be sounding in this space and leading the discussion.

Dr Sarah Carr FRSA, Senior Research Analyst, Social Care Institute for Excellence and Trustee of the National Survivor User Network.

Executive Summary

Executive Summary

Part One: Introduction

1. Aim of the research study

This study was set up to explore how effective service users find the 2008 Care Programme Approach in promoting recovery as they understand it, to put forward their views and recommendations about the recovery role of the Approach and to produce a checklist of good practice for mental health professionals involved in this Approach.

2. Background to the study and reasons for it

2.1 The Care Programme Approach

At the time of the closure of long stay psychiatric hospitals and moves towards community services, the government thought it important to produce an updated framework for people receiving secondary mental health care. In 1990, therefore, the government introduced the Care Programme Approach. The Approach required that professionals from health authorities and local authorities worked closely with each other and with service users and carers to provide effective support. The Approach was implemented from April 1991 onwards. It was reviewed and refined in 1999 and then amended further in 2008. Since then, although everyone using secondary mental health services remains entitled to a high level of care, the Care Programme Approach has been designated for use only with people who have wide-ranging service needs, or are particularly at risk. In making this change, the Department of Health's intention was to reduce bureaucracy for service users with less complex needs.

2.2 Recent recovery concepts

In the 1980s and 1990s, service users in the United States defined recovery as having a meaningful life for oneself, whether or not one could be cured, and spoke of the importance of factors such as hope, personal choice, self-determination, links with social networks and flexible resources rather than purely medical approaches. This concept of recovery was a challenge to the idea of mental illness as a life sentence and to the 'maintenance' system on which medical models had often been built.

Related ideas of recovery have gained momentum in a number of other countries, in particular in the UK, Australia and New Zealand. The North American recovery literature has, however, been criticised for taking an individualistic approach that does not allow for ethnic differences. In addition, UK and international recovery writings as a whole have tended to focus on the perceptions and outlooks of dominant groups in society and not to address social and structural injustice which may be experienced by, for instance, women, members of black and minority ethnic groups, people who are younger, older, or disabled and people who identify as gay, lesbian or transgender.

2.3 Issues for service users

Service users in the UK have welcomed the fact that both professional bodies and the government in this country have endorsed recovery approaches. As recovery approaches have developed, however, quite a few service users have voiced the following concern: that mental health professionals and service users may both be talking of 'recovery' but may mean different things by it. A number of service users think, for example, that service user concepts of recovery have been re-interpreted in an essentially medical sense. In addition, service users from marginalised communities have raised the fact that descriptions of recovery may not fit their ideas of it.

An issue for various service users who

access services under the 2008 Care Programme Approach is the link between this Approach and coercive elements of the Mental Health Act 2007; as people who are considered to be particularly at risk, or sometimes a risk to others, they are more likely to be subject to the coercive parts of this Act. They find this link contradictory to the rights-based ethos which is central to most service user concepts of recovery. In addition, quite a few service users think that the growing focus on risk-assessment and risk-management within the Care Programme Approach is at odds with the holistic approaches that they view as important for recovery. The above concerns have been particularly high for a number of service users from black and minority ethnic communities who are over-represented within compulsory services.

3. Methodology

The research study was a user-led project which took place between September 2011 and February 2012. The project lead, Dorothy Gould, put the research proposal together and then carried out all stages of the research, in partnership with the manager (now managing director) of the National Survivor User Network (NSUN) and with the support of the Mental Health Foundation.

Participants needed to be mental health service users who had personal experience of the 2008 Care Programme Approach, were aged 18 and above and lived in a London borough. To obtain as wide a range of opinions as possible, the researchers forwarded information about the study to an outer London NHS Trust and to a variety of voluntary and user-led organisations within the London area. Contact details for the research team were supplied, so that interested service users could then get in touch with one of the researchers to enquire further. Because of criticisms that recovery approaches are not taking sufficient account of service users who may face additional disadvantages (see sections 2.2 and 2.3 above), the researchers also put a particular

emphasis on participation by service users who were as diverse as possible demographically.

Participants were invited to give their views through a combination of questionnaires, completed by 81 participants, and four focus groups, attended by a total of 22 participants. Quantitative data from the questionnaires was set out and analysed via Excel spreadsheets. Framework analysis was employed for analysing qualitative data from the questionnaire and from the focus groups.

The study was a small one and, whilst there was considerable demographic diversity amongst participants, there were some gaps; for example, there was little participation by people belonging to White Other and Chinese communities and none by Gypsy/Traveller communities. The study has, however, resulted in some significant findings that merit further scrutiny. (See Parts Two to Four below.)

Part Two: Findings and discussion

Approach taken

Data from the questionnaires and the focus groups were each analysed separately in relation to the research aims: how effective service users find the 2008 Care Programme Approach in promoting recovery as they understand it. Themes from each type of data were then collated and are set out in the ten sections that follow below. The themes relate to the sorts of concerns from services users that underlay the research, i.e. to those put forward in section 2.3 of Part One above, and to any further issues that participants raised about how well the 2008 Care Programme Approach supports their recovery. Each section starts with the findings and then moves on to a discussion of the findings in that section.

1. Descriptions of recovery

As has been indicated in Part One above,

concepts of recovery can vary. It seemed important therefore to start by finding out from participants what recovery meant to them.

Key findings

● In both the questionnaires and the focus groups, participants' definitions of recovery were varied and might, or might not be bound up with a medical model.

● Focus group members mostly thought that there were marked differences between their ideas of recovery and professionals' ideas. They found this unhelpful.

It appeared, therefore, that mental health professionals need to take more account of the diversity of service user views about recovery and to draw on service users' own ideas about it if service users overall are to find the Care Programme Approach helpful for their recovery.

2. Experiences of participants from marginalised communities

For the reasons given in Part One above, the researchers put a particular focus on also hearing from service users who may face particular disadvantages.

Key findings relating to gender

● Female respondents to the questionnaire were markedly less satisfied than male participants about the extent to which professionals acknowledged non-medical explanations of mental distress and about their experiences of recovery services supplied under the 2008 Care Programme Approach.

● In the focus groups, female participants gave more negative than positive comments. Their concerns related to sexism and to a failure to address issues such as childbearing and physical change such as the menopause.

Key findings relating to ethnicity

● In their answers to the questionnaire, African and African Caribbean men and women were particularly dissatisfied with mental health professionals' lack of openness to non-diagnostic explanations of mental distress. Their ratings for recovery services provided under the 2008 Care Programme Approach were also mostly lower than those given by participants as a whole.

● In the focus groups, participants from these communities all spoke at various points of being hindered by factors such as racial stereotypes, racist treatment and/or a failure to make use of alternative models and approaches in Africa and the Caribbean.

● Responses from Asian and Asian British participants were not markedly different from those of participants in general. Replies from participants belonging to other ethnic communities were not numerous enough, nor consistent enough for an analysis of their replies to result in clear findings.

Key findings related to physical disabilities and to age

● In the focus groups, participants indicated that the account taken of physical disabilities and of age issues was somewhat patchy.

Numbers of female participants and participants from African and Caribbean communities were comparatively small and so undue weight cannot be built on the above findings in isolation. If their responses are combined with other, similar literature, however, the picture that emerges is somewhat concerning. Similarly participants appeared to want more consistent account taken of physical disabilities and of age. Overall, therefore, the findings seem to support the concerns outlined in Part One above, that recovery approaches provided under the 2008 Care Programme Approach

should give more weight to demographic differences.

3. Qualities of mental health professionals

Many service users have underlined the importance to their recovery of the qualities which professionals bring to interactions with them. Research participants were, therefore, invited to say what part they find qualities from mental health professionals play in their recovery under the 2008 Care Programme Approach.

Key findings

● In both the questionnaires and the focus groups, participants stressed that professionals' qualities were at least as important to their recovery as any treatments. They mentioned hope, listening, respect, compassion, a supportive attitude, fairness, honesty and humility, for instance.

● Their feedback indicated that there is some good practice, but that there is also a considerable way to go before such practice becomes the norm.

These findings were, therefore, in line with the link made by other service users between professionals' qualities and effective recovery services and appeared to show a need for professionals involved in the 2008 Care Programme Approach to put a further focus on such qualities.

4. Explanations of mental distress

The research was partly undertaken because various service users have said that professionals put too much emphasis on medical models in their recovery work. Participants were, therefore, asked to give their views about psychiatric diagnoses and the impact of these on their recovery under the 2008 Care Programme Approach.

[1]Not all participants replied to each question

Key findings

● In the questionnaire, 89% of 79[1] respondents thought that it was important for professionals to acknowledge that there were more ways of explaining their difficulties than just psychiatric diagnoses.

● Only 36% of the 64 who gave ratings thought that this happened 'a lot', however, and 23% thought that it 'never' did. These ratings were the least favourable ones from participants.

● The use of psychiatric diagnoses alone satisfied some focus group members. Some had mixed experiences and the rest were left dissatisfied. The latter might prefer explanations linked to life experiences and to spiritual, or sociological phenomena.

● Whether they agreed with having a diagnosis, or not, most focus group members thought that their diagnosis had a negative effect on their recovery.

The findings seemed therefore to underline strongly the importance of professionals' supporting recovery under the 2008 Care Programme Approach by working more fully with the explanations of mental distress which best suit any one service user.

5. What support was helpful

Participants were also invited to say what part they thought psychiatric medication should have in recovery services offered under the 2008 Care Programme Approach and what part other options should have. This was again because of service user criticisms that recovery services can be too medically based.

Key findings

● In the questionnaire, 96% of the 78 respondents wanted medication to support their recovery if it was prescribed. 59%

(n=40) of respondents who gave ratings described medication as supporting their recovery 'a lot'.

● Most focus group members made negative comments about medication, however. One main reason was that they were concerned about unpleasant, or even dangerous side effects of medication.

● All respondents wanted a focus on whole-person (holistic) approaches, not on medication alone. They mentioned support with everyday life issues, access to a wide range of therapies and remedies, befriending schemes, support from other service users and self-management approaches, for example.

● Respondents cited some good examples of holistic practice, but many thought that there were considerable shortfalls, too.

Because quite a few service users have criticised medical models, it is interesting that as many as 59% of respondents regarded medication as helping 'a lot'; this was one of the highest ratings in this category. Participants' responses indicate a need to address service users' concerns about negative aspects of medication, however. It also seems that that an increasingly strong focus on whole-person approaches is required if service users are to find the 2008 Care Programme Approach effective in promoting their recovery.

6. Recovery tools

Because formal recovery tools are very much part of the current recovery scene, focus group members were asked to say how useful they found such tools in supporting their recovery under the 2008 Care Programme Approach. They commented particularly on the Wellness Recovery Action Plan (WRAP) and the Recovery Star.

Key findings

● Some focus group members found one or both of these useful. Others were not in favour of them; they thought, for example, that the tools were too set to suit everyone.

Participants' feedback may have implications for further efforts to develop recovery tools that, despite some flexibility within them, nonetheless draw on a particular framework and are intended to be applied consistently across organisations. This may be an issue, for instance, for recent initiatives such as the ImROC Project (Implementing Recovery through Organisational Change) and the REFOCUS study to consider further. There is seemingly a difficult balance to achieve between something that feels manageable organisationally and yet stays true to the fact that recovery means different things to different service users and that different service users have different ideas about the best ways to plan recovery.

7. Attitudes to risk

One reason for the research was that some service users have criticised the Care Programme Approach for putting too much focus on risk. Respondents to the questionnaire and focus group members had the opportunity, therefore, to say how helpful they found the focus on risk in promoting their recovery through the 2008 Approach.

Key findings

● 87% (n=69) of questionnaire respondents wanted the focus on risk in their care plan to be balanced and in proportion.

● 56% (n=34) of those who gave ratings said that this happened 'a lot', though 29% of those subject to compulsory treatment thought that it 'never' did.

Given the rationale for the research, it is interesting that as many as 56% of participants were satisfied with professionals' focus on risk a lot of the time; this rating was one of the highest ones. The figure still represents the view of only just over half the respondents, however. Because risk-assessments are part of the 2008 Care Programme Approach and should be carried out jointly with service users, it was concerning that focus group participants did not necessarily know whether they had had a risk assessment. It seemed that there was also a considerable way to go before participants find that risk-assessment and risk-management processes support their recovery under the 2008 Care Programme Approach.

8. Attitudes to compulsory treatment

As has been indicated in section 2.3 of Part One above, quite a few service users see a conflict between their ideas of recovery and the compulsory powers of the Mental Health Act 2007. Participants were, therefore, invited to say what impact compulsory treatment since October 2008 had had on their recovery under the 2008 Care Programme Approach.

Because of the comparatively small size of the research study, an undue weight cannot be placed on the quantitative data in isolation. The lower ratings nonetheless appear worth noting, however, especially when combined with the qualitative data and with other research findings. Overall, it seemed, too, that participants wanted more progress made with resolving conflicts between their human rights and the compulsory powers of the Mental Health Act 2007, particularly if they had experienced compulsion themselves. Some, but only limited progress appears to have been made in this respect.

9. Involvement, influence and control

Involvement, influence, and self-determination for service users have tended to be central to service users' definitions of recovery. In the questionnaire and the focus groups, therefore, participants had the opportunity to say how important these factors were to their recovery under the 2008 Care Programme Approach.

in control of their lives. The majority emphasised the value of support from other service users (peer support). Over 70% were also interested in service users' influencing strategic planning about the Care Programme Approach.

● Fewer than half thought that the points above happened 'a lot', however.

● In the qualitative sections of the questionnaire and in the focus groups, there was also an emphasis on personal power, on peer support and on involvement.

● These respondents drew attention to some good practice, but again thought that this was patchy; discriminatory professional attitudes towards mental health service users might be a problem, for instance.

Given the existence of anti-discriminatory initiatives such as the Time to Change Programme and the commitment which the government has made to such programmes, it is concerning that quite a few participants spoke of prejudiced professional stances. Participants' feedback would seem to imply, too, that some, but only partial progress has been made with recovery services which take into account government directives related to person-centred approaches, peer support schemes and a strategic role, too, for service users. Further attention to these elements seems needed, therefore.

10. Staffing and budgetary resources

In addition to the above themes, participants emphasised the importance of adequate resource allocation if they were to recover effectively under the 2008 Care Programme Approach.

Key findings

● In both the questionnaires and the focus groups, respondents stressed their need for professional time and for consistent,

reliable and flexible services. They expressed mixed views about the extent to which they received such services, however.

● Focus group members were concerned that it was already difficult to obtain adequate support because of budget cuts, were worried about the impact of further cuts and, in some cases, thought that budgets were used wastefully.

By definition, both staffing and budgetary resources are finite. What seems to be key, therefore, is that professionals who are involved in the 2008 Care Programme Approach put their focus on ways of working which service users say support their recovery. It seems that considerable further progress needs to be made with this, however, despite the emphasis in recent government documentation that listening to service users can help to reduce costs.

Part Three: Conclusions

Overall, data from participants indicates that, whilst there is some evidence of good practice, services provided under the 2008 Care Programme Approach are patchy in the extent to which they promote recovery as service users understand it. There also appeared to be some particular issues for service users from marginalised communities. Participants' feedback suggests, therefore, that considerable change is still needed in organisational cultures, approaches and practice if the 2008 Care Programme Approach is to be effective in promoting service user recovery. Participants' responses would seem to imply, too, that further consideration should be given to the tensions which service users often experience between the coercive parts of the Mental Health Act 2007 and service users' concepts of recovery. For service users, government recovery initiatives appear to have had only partial success therefore.

It remains to be seen, too, what effect the recently introduced Implementation Framework for the mental health strategy and the Health

and Social Care Act 2012 will have on recovery approaches. In its newly produced mandate for the NHS Commissioning Board, the government emphasises the need for the NHS to become 'radically better' at involving service users. Again, it is not yet clear, however, what impact this will have. How far the changes wanted by participants can and will be achieved is, in short, a huge challenge for politicians and mental health professionals alike.

Part Four: Checklist of good practice

As has been indicated in Part One above, participants were invited not only to share their experiences of recovery under the 2008 Care Programme Approach, but also to contribute points towards a checklist of good practice for professionals involved in this Approach. Feedback from participants resulted in the following list:

The Checklist

Are you:

1. Drawing on service users' personal descriptions of recovery?

2. Taking special account, too, of recovery concepts that service users from particularly disadvantaged groups and communities find meaningful and valid?

3. Helping service users to find the ways of understanding mental distress that make most sense to them, rather than offering medical explanations alone?

4. Putting as much emphasis on the warm, human qualities that service users want from professionals as on skills and knowledge that service users find support their recovery?

5. Recognising in practice that medical treatment is useful only insofar as it assists service users with leading lives that they find meaningful and offering treatment accordingly?

6. Employing the full range of holistic approaches that are important to a particular service user?

7. Allowing for drawbacks that set recovery tools can have and varying tools to meet differing service user wishes?

8. Having adequate discussion with service users when medication is prescribed, acknowledging service users' concerns about distressing side effects and working actively with service users to keep these to a level that service users find acceptable?

9. Tackling any staff discrimination towards people with mental health problems, including the additional discrimination which may be experienced by service users from marginalised groups and communities?

10. Helping service users to feel safe, whilst avoiding a focus on risk that service users say is counterproductive to recovery?

11. Making active use of positive risk-taking?

12. Addressing the tension highlighted by a number of service users: between the use of compulsion under the Mental Health Act 2007 and the exercise of choice, control and citizen rights that is fundamental to most service users' concepts of recovery?

13. Making sure that service users have involvement, influence and control in relation to their individual care plans?

14. Acknowledging peer support in practice when service users find that this helps to promote their recovery?

15. Providing opportunities for service users to influence the Care Programme Approach at a strategic level?

16. Employing resources as effectively as possible by listening to service users' expertise about useful recovery services, not to professionals alone, and by providing consistent and reliable support?

Part One
Introduction
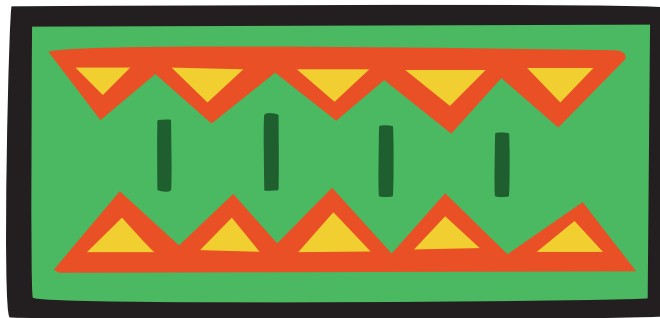
Part One: Introduction

1. Aim of the research study

This study was set up to explore how effective service users find the 2008 Care Programme Approach in promoting recovery as they understand it, to put forward their views and recommendations about the recovery role of the Approach and to produce a checklist of good practice for mental health professionals involved in this Approach.

2. Background to the study and reasons for it

2.1 The Care Programme Approach

The Care Programme Approach (CPA) was a measure brought in by the government (Department of Health, 1990) and implemented from April 1991 onwards. The context was the closure of long stay psychiatric hospitals and a strong move towards care in the community for mental health service users as well as other service users. Because of the service changes involved, it was thought important to provide an updated framework that would facilitate effective mental health support for people receiving secondary health care. The Care Programme Approach was seen as a way to ensure that different community services were co-ordinated and that, between them, they resulted in a good standard of care for individuals. The Care Programme Approach required that professionals from health authorities and local authorities worked together to arrange care and did so in partnership with service users and carers. There was an emphasis, too, on assessing risks for service users, or for others.

Its four main elements were:

1. Systematic arrangements for assessing the health and social needs of people accepted into specialist mental health services

2. The formation of a care plan that identified the health and social care required from a variety of providers

3. The appointment of a key worker (care co-ordinator) to keep in close touch with the service user and to monitor and co-ordinate care

4. Regular reviews and, where necessary, agreed changes to the care plan.

The model was reviewed and refined in 1999 and then, in March 2008, there was a change in eligibility for the Care Programme Approach (Department of Health, 2008a). Although people who access secondary mental health services remain entitled to a high level of care, the Care Programme Approach is now designated for use only with people who have wide-ranging service needs, or are particularly at risk. In making this change, the Department of Health's intention was to reduce bureaucracy for service users with less complex needs. Whether or not such changes have proved to be the most useful ones in general is a subject for other studies. In this study the focus has been on one particular aspect of the Approach: its effectiveness in promoting the recovery of service users from their points of view.

2.2 Recovery

Historically, people diagnosed with a severe mental illness have tended to be seen as incurable. This idea has not gone unchallenged, however. As far back as the late 18th century, a humanistic approach, *traitment morale*, was developed by Philippe Pinel and then put into practice through collaborative work between him and Jean-Baptiste Pussin; Pussin had been a patient in a Parisian asylum and then became its governor. Staff at institutions where this approach was used admitted people with serious mental illnesses for recuperation and approximately 90% of them were estimated to recover (Davidson *et al*, 2010).

As Davidson *et al*. indicate, quite a few people see the roots of recovery approaches

as stemming from Pinel's and Pussin's work and certainly their work had some influence on mental health practice in England and the United States. Then, in the 1980s and 1990s, service users brought in a particular idea of recovery one that was wider than approaches based on the more usual medical models. At this time, service users in the United States defined recovery as having a meaningful life for oneself, whether or not one could be cured, and spoke of the importance of factors such as hope, personal choice, self-determination, links with social networks and flexible resources rather than purely medical approaches, if one was to recover. They were influenced in this by the American civil liberties movement of the 1960s and 1970s. As Deegan (1993) put it:

'What matters is not whether we're using services or not using services; using medications, or not using medications. What matters in terms of a recovery orientation is, are we living the life we want to be living? Are we achieving the life we want to be living? Are we achieving personal goals? Do we have friends? Do we have connections with the community? Are we contributing or giving back in some way?'

This concept of recovery was a challenge to the idea of mental illness as a life sentence and to the 'maintenance' system on which medical models had often been built. Related ideas of recovery have also gained momentum in a number of other countries, in particular in the UK, Australia and New Zealand.

In the UK, for instance, there is now some quite extensive recovery literature both from people with experience of mental distress and from people without that experience. *Voices of Experience* (Basset and Stickley, 2010) is just one of many recent examples from people who have used mental health services. There has been formal professional recognition in this country of the importance of working in a recovery-based way; see, for instance, the Joint Position Paper from the Care Services Improvement Partnership, The Royal College of Psychiatrists and the Social Care Institute for Excellence (2007). The Department of Health has also given credit to recovery approaches;

relevant documents include the government's guide to the refocused Care Programme Approach (DH, 2008a) and its recent mental health strategy (DH, 2011a).

The North American recovery literature has, however, been criticised for taking an individualistic approach that does not allow for ethnic differences. Thus Lapsley *et al*. (2002) have pointed out that a tendency for Maori people is to put a value on someone's cultural origins and personal meanings as reference points for citizenship. They have explained that a more relevant way of describing recovery in a Maori context has therefore proved to be 'knowing who you are and where you come from and re-integrating yourself with your own people in your own way'.

Both UK and international recovery writings generally have, however, tended to be based mainly on the perceptions and outlooks of majority cultures and dominant groups: in relation both to ethnicity and to other demographic differences. This has been illustrated by Weisser *et al*. (2011). In their review of recovery literature, they draw attention to the fact that mental health recovery literature in Canada, the US, the UK, Australia and New Zealand rarely addresses social and structural injustice and that, where it does, it is uneven in its coverage. Thus they discovered that there are few recovery models related to culture and ethnicity and that even less account is taken of social inequities related to gender, sexual orientation and gender identity. Similarly, there seems to be a shortfall in recovery approaches that are related to age issues.

2.3 Issues for service users

As recovery approaches have developed, a difficulty for quite a few service users has been that mental health professionals and service users may both be talking of 'recovery' but may mean different things by it. There have, therefore, been expressions of concern amongst service users; they think that concepts of recovery which service users have tried to introduce have become somewhat lost, or have been re-interpreted in an essentially medical sense. Coleman

(1999), for instance, has argued that recovery involves every part of the human condition, but that the mental health system can destroy the fragile self-identity that service users may have: by being closed to holistic stances and explaining difficulties as biological. Service user writers such as Coleman have therefore asserted that there still need to be far-reaching changes to the approaches and attitudes of mental health professionals, to mental health service structures and to assessment and care plan systems, if service users' concepts of recovery are to work well. Service users have also stressed that measurements of success and evidence of recovery need to come from the person who has a mental health problem, not, as may happen at the moment, from professionals; this has been underlined by Perkins (2001), for example.

Various service users have, too, expressed concerns that descriptions of recovery are based on ideas prevalent in dominant sections of society and may not fit concepts held by service users who belong to marginalised communities. (See also the findings from Weisser *et al*. in section 2.3 above.) In, for example, a recent, fundamental study about the recovery experiences of African, African Caribbean and South Asian women, Kalathil (2011a) has drawn attention to the fact that most interviewees did not find that mental health service delivery resonated with their definitions of recovery and the meanings they gave to it. She then goes on to argue that recovery approaches being developed today within mental health services demonstrate little engagement with cultural perspectives of minority ethnic communities.

In addition, quite a few service users who access services under the 2008 Care Programme Approach are unhappy about links between this Approach and the Mental Health Act 2007 (HM Government, 2007). That is because the Act contains potentially coercive elements such as involuntary admissions to hospital and community treatment orders for service users who are thought to be particularly at risk, or to be a risk to others; service users considered especially likely to harm themselves, or others are amongst the key groups whom

the government has said should be supported by the 2008 Care Programme Approach (Department of Health, 2008a). For a number of service users, these elements come across as contradictory to the civil rights approach which underlies their definitions of recovery.

Similarly, they may experience a tension between the compulsory powers of the Mental Health Act 2007 and the emphasis on hearing the voice of service users that has been prominent in government documentation about the refocused Care Programme Approach (Department of Health, 2008a) and in the government's recent mental health strategy (Department of Health 2011a). Perkins (2012) argues, therefore, that there cannot be an adequate recovery approach in mental health services whilst professionals can treat patients against their will and that recovery-based mental health policy requires a rethink of current mental health legislation.

Furthermore, there has been a growing focus on risk-assessment and risk- management within the Care Programme Approach. Quite a few service users find this to be at odds with the holistic approaches that they view as important for recovery, however. This increasing emphasis has been underlined by Langan and Lindow (2004). They point out that there was no mention of risk in the circular that the Department of Health used in 1990 to introduce the Care Programme Approach, but that subsequently mental health service users have become increasingly defined in terms of the risk that they are thought to present, rather than in terms of their needs and rights.

Service users such as Trivedi (2010) have therefore questioned how a mental health system said to be based on service user control and empowerment can respond to pressures represented by a focus on public safety, risk and the Mental Health Act; Trivedi has raised this in general and particularly in relation to the over-representation of a number of black and minority ethnic communities within compulsory services.

Because of the various factors outlined above, the aim of this research study has been to explore how effectively service users think the

2008 Care Programme Approach supports them with recovery as they understand it.

3. Methodology

3.1 The research team

The research study was a user-led project which took place between September 2011 and the end of February 2012; researchers with personal experience of using mental health services put together the research proposal, implemented the research, analysed the data and collated the research report. The project lead, Dorothy Gould, is an independent service user consultant. She worked in partnership with the manager (now managing director) of the National Survivor User Network (NSUN), a national resource for user-led mental health organisations and for individuals with lived experience of mental distress. Support and guidance for the study was provided by the Mental Health Foundation, a national charity which carries out research in mental health and learning disability fields.

This user-led approach was employed because of increasing evidence of the value of user involvement in research and user-led research studies. Glasby and Beresford (2006), for example, have challenged the assumption that 'distance' from 'subjects' should automatically be considered an essential criterion for valid research evidence. They argue that, when service user experiences are the focus of a research study, researchers without such experiences may misunderstand, or distort research findings precisely because of their distance.

Barber *et al.* (2012) acknowledge that there are few evaluations of the impact that members of the public, such as service users, have on the quality of research. In these authors' view, however, there is emerging evidence of a number of positive effects. They mention, for example, an increase in the range of research topics, improved research designs, more open and in-depth responses from interviewees and improved analysis, resulting, for instance, from challenges to interpretations made by other researchers and the highlighting of new themes.

3.2 Terminology

The researchers were aware that some service users regard the word 'recovery' as unsatisfactory for describing the journey that they take to deal with their mental distress and for portraying the results of their journey. This has been highlighted by Turner-Crowson and Wallcraft (2002) amongst others; Turner-Crowson and Wallcraft explain that, for some service users in Britain, the word 'recovery' implies acceptance of an illness model with which they do not agree. Because the term 'recovery' is the one in common usage, however, and because there is no generally agreed alternative at present, the researchers thought it best, on balance, to use this term for the study.

3.3 Project design

3.3.1 Approach taken

In designing the research study, the researchers took into account national and international writings from service users, as well as research from mental health professionals. They drew on literature reviews related to recovery, in particular those by Ralph and Muskie (2000), Allott and Loganathan (2002), Bonney and Stickley (2008) and Ramon (2009), and documentation from the Department of Health. (See also sections 2.2 and 2.3 above.) They also consulted service users from a diversity of communities about the research. This was done to add to the range of service user views which helped to shape the research. This approach was also used to cover gaps in existing research material about the Care Programme Approach and about recovery; as indicated in section 2.2 above, the research team identified shortfalls related, for example, to age, ethnicity, gender and sexual orientation.

Since the purpose of the research was to find out more about participants' experiences, the approach taken had a strong focus on qualitative methodology. This type of research is particularly well suited to drawing out people's experiences and to providing insights into these and explanations of them, as has been indicated by Ritchie and Lewis (2003), for instance. It was decided, however, to seek participants' views through a combination of

questionnaires and focus groups rather than through interview methods alone.

The use of questionnaires was to ensure that there was an adequate sample size for the research project, despite the fact that there was a limited budget for it, and, importantly, to provide a snapshot of service users' views that could be employed for the development of purposeful group questions. In addition, whilst it was not feasible to offer individual interviews, within the budget available, the questionnaires were a source of individualised data. Drawing on focus groups as well then enabled an in-depth exploration of participants' experiences: individual perceptions and those that emerged as a result of group discussions.

3.3.2 The questionnaires

A new recovery questionnaire was devised for the research study, because existing questionnaires do not deal with the compatibility between service users' ideas of recovery and the 2008 Care Programme Approach, useful though some current material may be. In formulating questions the researchers made use of elements that, despite individual variations, have emerged frequently in service user literature about recovery: in, for instance, the literature reviews that are mentioned in 3.3.1 above. The researchers also gave scope for participants to express personal views. The researchers employed an essentially quantitative approach; the questions are mainly closed, or multiple choice. There was allowance for some free text responses as well, however.

Participants were invited to:

- Describe what recovery means to them

- State which out of a list of points they thought were important for their recovery under the 2008 Care Programme Approach. The list of points centred on elements such as hope, holistic thinking and practice, help with building a meaningful life, access to social networks, influence and control. If participants said that a point was

important to them, they were also asked to indicate how often they received such support from mental health staff involved in their care: 'a lot', 'sometimes', or 'never'.

- Mention other points that they found important for their recovery and again say how often these happened.

- Outline what impact sectioning or a community treatment order had had on their recovery, if they had experienced one, or both of these since October 2008.

- Make recommendations for a checklist of good practice for mental health staff: about the best ways to help service users to recover through the 2008 Care Programme Approach.

(A copy of the questionnaire may be viewed in Appendix A.)

3.3.3 The focus groups

The content of the focus group topic guide took into account the findings from the questionnaires, as well as the overall research aims, and so was particularly designed to explore participants' experiences of recovery under the 2008 Care Programme Approach in relation to:

- Their own and professionals' definitions of recovery

- The impact of psychiatric diagnoses

- The part played by medication/other resources

- The focus given to risk

- The exercise of compulsory powers

- The use of an anti-discriminatory approach

- The employment of set recovery tools such as the Recovery Star

(A copy of the focus group topic guide is available in Appendix B.)

3.4 Recruitment

3.4.1 Research participants

Participants were mental health service users who had had personal experience of the 2008 Care Programme Approach, were aged 18 and above and lived within a London borough; the funder had asked for recruitment to be London-based.

3.4.2 Recruitment methods used

To obtain service user opinions that allowed as fully as possible for varying perspectives, research team members recruited participants both through an outer London NHS Trust and through a variety of voluntary and user-led organisations based within London boroughs in general. Because of criticisms that recovery approaches are not taking sufficient account of marginalised groups (see sections 2.2 and 2.3 above), the researchers also put a particular emphasis on participation from service users who were as diverse as possible in terms of age, ethnic origins, gender, sexual orientation and physical abilities. The researchers invited involvement, too, from participants in both hospital-based and community-based services, including participants who were under a section, or on a community treatment order at the time of the research.

In the case of voluntary and user-led organisations, material about the questionnaires was circulated through staff who had a service user involvement role. (Copies of the recruitment leaflet and information sheet are available to view in Appendix A.) Service users who were interested in the questionnaires then had the opportunity to speak with a research team member and were provided with detailed information, so that they were in a position to make an informed choice about participation; the researchers spoke to them by phone, or during face-to-face meetings.

The original intention was to adopt a similar recruitment approach at the Trust which was involved in the research. Because the circulation of material there ran into some initial hurdles, however, the bulk of recruitment occurred through direct service managers and service staff whom the researchers supplied with detailed information. Recruitment also took place through meetings between the researchers and service users whom Trust staff had identified as interested in the questionnaires.

Participants who completed the questionnaires were invited to let the researchers know if they would be interested in coming to one of the four focus groups that would follow; this was to promote continuity between data from the questionnaires and data from the focus groups. Focus group places were then offered to participants who expressed an interest in a group and were available to attend. (Copies of the focus group recruitment leaflet and information sheet may be found in Appendix B.) The focus groups ran in facilities provided by community centres and voluntary organisations: one each in north, south, east and west London to make attendance as easy as possible, given the wide geographical spread of London boroughs.

Throughout the process, particular care was taken to ensure that potential participants fully understood the research process, so that, although people who draw on the 2008 Care Programme Approach are thought to be people with wide-ranging needs/ particularly at risk, there were no safety issues for them. The researchers made sure that there was careful dialogue with potential participants, for example, and let them know that they could withdraw from the research at any point, if they wished, without their services being affected.

To facilitate involvement by service users who belonged to marginalised communities, participants from such communities were also offered particular assistance, as helpful, with understanding the research documentation and the questions that they were asked. Support provided included interpretation, as happened for participants from South Asian communities. There was an option, too, for participants to bring a supporter with them to focus groups if they had particular needs. In the event, this did not prove necessary, however.

3.4.3 Demographic representation achieved

There were 81 replies to the questionnaire from people who fitted the research criteria. 42% (n=34) came from people recruited through the Trust involved in the research, 27% (n=22) from people who used voluntary organisation services, 28% (n=23) from people who were members of service user-led agencies and 3% (n=2) from people who were not sure where they had heard about the research. There was therefore successful recruitment in terms of research participants' coming from a range of agencies within London boroughs - and a particularly high proportion of participants from the Trust.

In Part A of the questionnaire, participants supplied the following demographic information about themselves:

42% (n=34) were women, 48% (n=39) were men and 10% did not give their gender. No-one identified as transgender. 84% (n=68) described themselves as heterosexual, 1% (n=1) as gay, 1% (n=1) as lesbian, 4% (n=3) as bisexual and 10% did not indicate their sexual orientation. 68% (n=55) classed themselves as disabled, 26% (n=21) did not and 6% (n=5) did not reply.

The proportions of participants from varied ethnic communities were as follows:
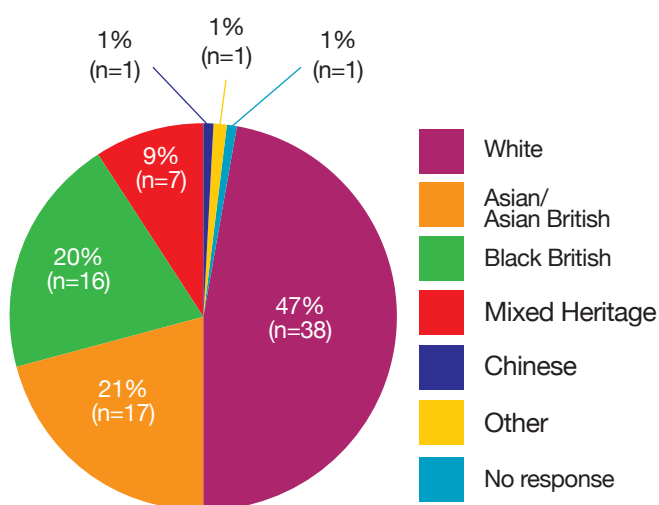
Figure 1: Ethnicity of participants

The age groupings of participants are indicated in Figure 2 in the next column:
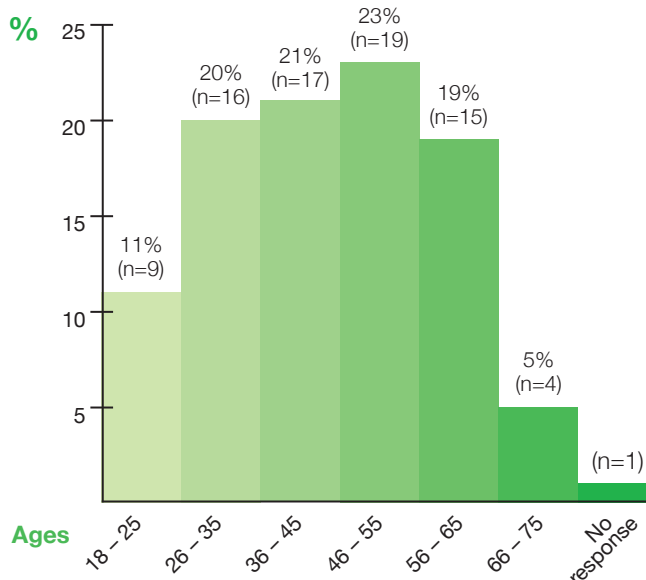
Figure 2: Age ranges of participants

Of the 89% of participants who replied, 35% (n=28) had been sectioned at some point since October 2008. 12% (n=10) said that they had been subject to a community treatment order after October 2008 and 9% (n=7) that they had both been sectioned and put on a Community Treatment Order since then. 11% (n=9) of participants were in hospital at the time of the research, the rest were using community services.

There was therefore considerable demographic diversity amongst participants. They were also varied in terms of the types of services that they had received under the 2008 Care Programme Approach. There were some gaps as well, however, despite approaches to the groups concerned. In particular, there was little participation by people belonging to White Other and Chinese communities, none by Gypsy/Traveller communities and limited participation by people over 65 and by people who identified as gay, lesbian, or bisexual.

Four focus groups ran with a total membership of 22. All participants had put themselves forward for a focus group after completing a questionnaire. 64% (n=14) had been recruited originally through voluntary organisations, 27(n=6) through user-led groups and this time only 9% (n=2) through health. The low attendance of participants who came through the NHS was because the latter proved far less interested in coming to a focus group than

those recruited through voluntary agencies and user-led organisations.

The demographic breakdown of focus group members was as follows:

36% (n=8) were female, 59% (n=13) male and 5% had chosen not to give their gender on their demographic form. 86% (n=19) identified themselves as heterosexual, 5% (n=1) as lesbian and 9% (n=2) did not name their sexual orientation. 82% (n=18) classed themselves as disabled, and 18% (n=4) did not.

The proportions of focus group members from varied ethnic communities are set out in Figure 3 below:
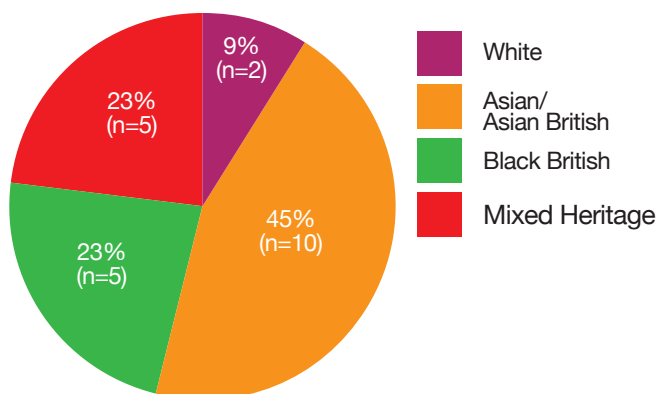
Figure 3: Ethnicity of focus group members

The age groupings of focus group members are indicated in Figure 4 below:
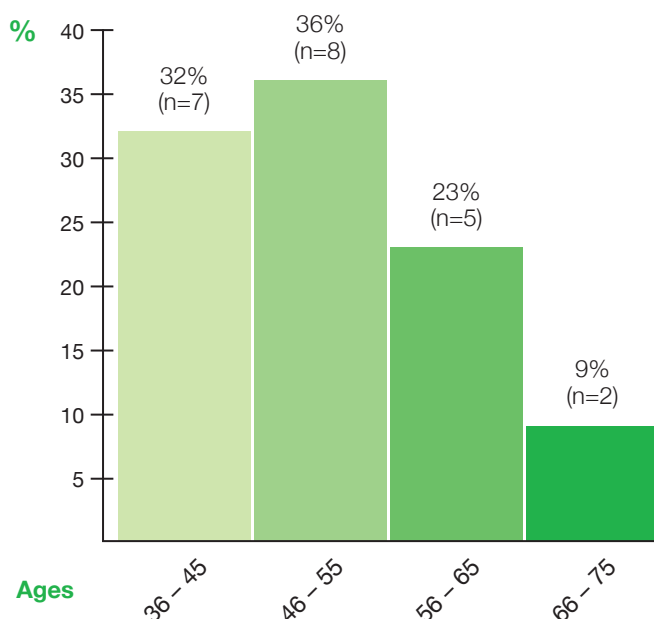
Figure 4: Age ranges of focus group members

Of the 96% of focus group members who stated whether they had been subject to compulsory treatment since October 2008, 23% (n=5) had been sectioned. It also became clear in the focus groups that there were other participants who had been sectioned prior to that. 14% (n=3) mentioned being on a community treatment order after October 2008 and 9% (n=2) indicated being both sectioned and on a community treatment order since then. No focus group members were in hospital when the focus groups occurred.

There was again a quite high degree of demographic diversity therefore, though the gaps were similar to those identified amongst the 81 participants as a whole and there were no focus group members aged under 36.

3.5 Analytic approach employed

Quantitative data gathered through the questionnaires was set out and analysed via Excel spreadsheets; given the comparatively small amount of data, this proved adequate for the purpose. Framework analysis (Ritchie and Spencer, 1994) was used for analysing the qualitative data gathered through Part B of the questionnaire and the focus groups. Spreadsheets were also employed for charting the qualitative data obtained through this methodology; formal tools such as NVivo were not deemed necessary for the amount of data concerned. Findings from the focus groups were then used to augment the critical findings from the questionnaires.

The research team chose framework analysis for the qualitative data because this has been established as a particularly effective tool for applied policy research, such as an evaluation of the Care Programme Approach. In addition, framework analysis provides responses quickly enough for public bodies to be able to take findings into account in their decision-making (Srivastava and Thomson, 2009).

3.6 Limitations of the study

The study is a comparatively small one. In addition, whilst participants were diverse in many ways, there were also some gaps; see

section 3.4.3 above. The project has, however, resulted in some significant findings that merit further scrutiny. (See Parts Two and Three below.)

Part Two
Findings and Discussion
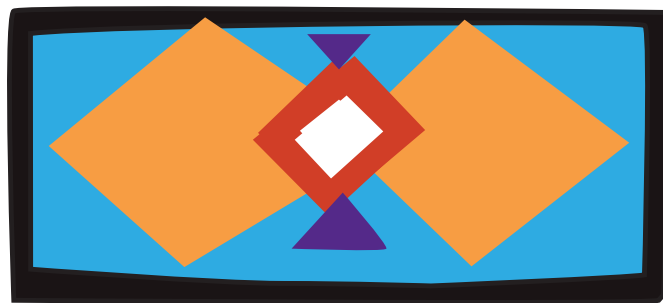
Part Two: Findings and Discussion

Approach taken

Data from the questionnaires and the focus groups were each analysed separately in relation to the research aims: how effective service users with experience of the 2008 Care Programme Approach find the Approach in promoting recovery as they understand it. Themes from each type of data were then collated and are set out in the ten sections that follow below. The themes relate to the sorts of concerns from service users that underlay the research, that is to those put forward in section 2.3 of Part One above and to any further issues that participants raised about how well the 2008 Care Programme Approach supports their recovery. Each section starts with the findings and then moves on to a discussion of the findings in that section. In addition, complete data tables for the quantitative responses can be found in Appendix C.

1. Descriptions of recovery

As has been indicated in Part One above, concepts of recovery vary and so it seemed important not to start with any assumption that there is one agreed definition of 'recovery'. In both the questionnaire and the focus groups, therefore, participants were invited to say what recovery means to them. Almost all participants responded and their definitions of recovery fell into the following broad themes. Recovery is:

- Having a good quality of life, one that is full and meaningful

- Experiencing positive emotions such as confidence, self-esteem, enjoyment of life, peace, contentment and a sense of security

- Being able to take part in everyday life, both in general and in relation to everyday activities such as self-care, household skills, recreation, travel, relationships, worship, further education, voluntary and paid work and community involvement. Whilst different participants picked out different aspects of everyday living, taken overall this theme was a particularly prominent one

- Getting better/feeling well, mentally and physically

- Being able to cope, though this may mean living with difficulties rather than being 'cured'

- Receiving necessary professional support, but also having independence and control.

The responses were therefore quite varied and different, too, from descriptions of recovery found in any one source elsewhere. This seems to underline thinking that service users' ideas about recovery are personal and so that any failure to take this into account under the 2008 Care Programme Approach may well result in service users' feeling dissatisfied with services provided.

Within the broad categories above, it is noticeable, too, that participants' concepts of recovery may be bound up with/include a medical model, or may be more wide-ranging. This appears to reflect the fact that service users may or may not find a medical model helpful and that using this model alone leaves a number of service users dissatisfied; see section 2.3 of Part One above. As Repper and Perkins (2003) have argued, ideas about recovery are not limited to any one model and do not have to be. Repper and Perkins indicate their agreement with Anthony (1993): that belief in recovery does not commit one to a particular social, psychological, spiritual, or organic understanding of it, nor to a use, or non-use of medical interventions.

Similarly, participants had varying opinions as to whether 'recovery' and becoming 'normal' were one and the same or not. In the questionnaires, a certain number of participants equated 'recovery' and 'normality', but many participants made no specific link between the two. In the focus groups, a few participants commented further about the issue. One participant saw 'recovery' and 'normality' as identical. For him, this was just logical

I thought they were both the same. Once you recovered, you do everything as normal even though you could have the odd check-up now and again...

Other participants had contrasting views, because, for instance, they thought that equating 'recovery' and 'normality' implies that mental distress is outside ordinary human experience, or that such a link is too connected with the medication-based approach that they regarded as prevalent in England

I reject the whole idea that there are two

types of people, 'normal and abnormal'. There are only human beings and their understandable responses to trauma and distress

... Recovery is you're off meds, or you may be taking medication, but also you have an income coming in ... For me, I find that, a lot of the time, when one would look at African countries, that is where recovery actually takes place, where someone does come off their medication, continues or furthers their career and so on, whereas here in the western model it's about medication ... There are social indicators that are also important around recovery, which is not taken into account with the western model. To them it's about normal being you're no longer hyper, or manic, or depressed, you're just there ...

The variation in views seemed to be linked with ways in which participants were looking at mental distress. Understandably, when they were looking at mental distress from a more illness-based model, they saw the presence or absence of mental health problems in terms of 'normal' and 'abnormal'. When they were viewing mental distress from non-medical/more holistic models, they did not find that it made sense to see mental distress, however major, as an indication of abnormality. Their thinking had some overlaps with Deegan's (1996):

'The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human. The goal is not normalisation. The goal is to become the unique, awesome, never to be repeated human being that we are called to be'.

In the focus groups, participants also discussed whether there was a match between their ideas of recovery and the ideas of professionals involved in their care plan. For a few participants, there was and they found this helpful in promoting an approach to recovery that was useful to them

She (the occupational therapist) is very clued into me. From the day I met her,

she was very much in touch with me and, without me actually saying very much, she could see by my face how I was feeling. She could pick it up and her sense of recovery is more about empowering me to do as much as I can for myself, in my own capabilities ...

For the majority of participants, however, there were marked differences between their ideas of recovery and the ideas of professionals involved in their care plans. These differences were on a scale that strongly backs one of the original reasons for the research: concerns from a number of service users that mental health professionals are using concepts of recovery with which they disagree and which they therefore do not find helpful in recovery terms. Differences of view arose because, for instance, participants did not feel heard, or thought that professionals mistakenly regarded recovery as having an end point. Participants might also be unhappy with recovery approaches' being set within a diagnostic and medical framework

When I had a CPA ... they called me, you know, and a staff key worker gives a report about me to the psychiatrist. She doesn't ask me, the psychiatrist. She depends on the report of staff. But they get a different report and I was saying different. But they don't believe me, they more believe your staff

I don't like the word 'recovery' because I think it sets the wrong tone from the professional that's dealing with your point of view. The word 'recovery', if you look it up in the dictionary, means recovering from ... and a lot of professionals see that, whether you have a mental health illness, or a physical disability, you do recover, so there is a start point and an end point for you accessing services and for you receiving treatment. ... And so the word recovery is always something I've battled with, because it doesn't really explain from a service user perspective, you know, that you're healing and that most people who have a mental illness are learning to live with it and maintain a good lifestyle and not many people do recover fully

I especially reject psychiatric diagnosis. Labelling people with pseudo-scientific categories is stigmatising, harms their recovery and often leads to people's human and civil rights as citizens being denied. I think 'recovery' can mean a whole creative process of self-transformation and professional growth where you become stronger and more whole than you were before. It can also mean transforming your personal circumstances – home, meaningful activity ..., relationships, society.

The above would seem to imply that, although there is some good practice, there also need to be further changes in professional views of recovery and further acceptance of the personal nature of service user concepts of recovery, if service users in general are to find the 2008 Care Programme Approach helpful for their recovery. This seems likely to pose a continuing challenge to mental health professionals. As Campbell *et al*. (2008) helpfully set out, the issue for practitioners is to find what recovery means for any one service user and not to turn recovery into another general model based on practitioner constructs.

As indicated in sections 2.2 and 2.3 of Part One above, recovery concepts have tended to be based on the thinking of people who belong to dominant communities in this country, rather than to take into account perceptions and outlooks of marginalised groups as well. The researchers put a particular emphasis, therefore, on also hearing from the latter. In the questionnaires, relevant data from participants who might experience more than one form of discrimination related mainly to gender and ethnicity. Comments from focus group members covered physical disabilities and, to an extent, age as well as gender and ethnicity.

2.1 Gender

Information related to gender issues emerged from both the quantitative parts of the questionnaire and the focus groups.

An analysis of the quantitative responses from participants indicated that female respondents tended to be less satisfied than male respondents about the extent to which non-medical explanations were acknowledged and the 2008 Care Programme Approach was helping them to recover. (See Table 3 in Appendix C.) Whilst the mean (average) number of women who said how often they received the support that they wanted was not large (i.e.26) and so no real weight can be built on this finding in isolation, the variation nonetheless appears worth a mention.

Women's ratings for support happening 'a lot' were lower than men's in 17 out of 21 questions (81%). In seven of these questions, women more often also thought that desired support 'never' happened and for three questions they had significantly worse ratings overall than men did. The questions concerned related to the influence of service user groups on the implementation of the Care Programme Approach (Q.14b), how balanced professionals' focus on risk was (Q.17) and how much control participants had over their lives (Q.18). Men had overall worse ratings

than women, however, for the extent to which professionals showed an interest in all the parts of their lives that mattered to them (Q.7) and a somewhat less favourable view about the extent to which medication was supporting their recovery (Q.10)

Focus group participants gave some positive responses about their experiences in gender terms, but, on the whole, had more negative than positive comments about the effectiveness of the Care Programme Approach in promoting gender-sensitive recovery approaches. For instance, African and African Caribbean men mentioned feeling stereotyped within the psychiatric system. (See further section 2.2. below.) Female participants raised a particular number of concerns, for example attitudes from mental health professionals that they found sexist and shortfalls in addressing issues that were important to them as women; the latter included childbearing and physical change issues such as the menopause

Things came to a head with one psychiatrist who I didn't get on with and, to be fair, he did not like his female patients. In the end, there was a bit of a bust-up with him because I flatly refused to see him ... I guess I was lucky in one way that they let me see another doctor

They (doctors) *brought up the fact that I was suffering from a genetic condition ... and they frequently said again about the effects of medication on a developing foetus ... I did become pregnant, so I had that terminated ... I tried to find some solid advice ... but there was a lot of contradiction. I'm not in the age group any more where I'm going to be thinking about starting a family, but I'd like to think that, in future, the information would be there for women to make a proper choice*

The CPA doesn't look at the menopause. I have a report from the lithium pharmacist for CPA. I have a report from the

dermatologist (side effects from lithium) for CPA. I have a report from the cardiologist (heart defect from meds) for CPA. But no report from my GP about the HRT for CPA: on how the terrible symptoms affect my day-to-day health.

There seems little evidence in general that concerns for women are receiving enough focus in services provided under the 2008 Care Programme Approach. In the National Mental Health Development Unit's report on working towards the wellbeing of women (Department of Health, 2010), there was recognition that inclusion of women's issues in assessment and care planning had not been at all routine. The government's mental health strategy (Department of Health 2011a) acknowledges that there needs to be an improved staff awareness about differences in rates and presentation of mental health problems between men and women. It may be, therefore, that there would be some mileage in now setting up research that specifically addresses women's experiences of recovery under the 2008 Care Programme Approach.

2.2. Ethnicity

In both the quantitative parts of the questionnaire and the focus groups, there was some somewhat negative information from African and African Caribbean participants about their experiences of recovery services provided through the 2008 Care Programme Approach.

An analysis of the quantitative responses from participants indicated that African and African Caribbean men and women were less satisfied than participants in general about professionals' openness to their ideas of recovery and about the extent to which the 2008 Care Programme Approach was supporting them with recovery. (See Table 4 in Appendix C.) The mean (average) number of African and African Caribbean participants who said how often they received the support important to them was again small (i.e.13) and so weight cannot be built on these responses in isolation. The less positive replies from African and African Caribbean participants

seem important to mention, however, given their similarity to findings in major reports such as *Breaking the Circles of Fear* (The Sainsbury Centre for Mental Health, 2002), *Inside Outside* (NIMHE, 2003), the Sainsbury Centre's further report (2006) about racial inequality and the costs of this and recent writings, such as *Mental Health, Race and Culture* (Fernando, 2010). These have provided evidence of continuing issues.

African and African Caribbean participants' ratings for support happening 'a lot' were lower than those from other participants in 18 out of 21 questions (86%). In 15 questions, they more often thought that desired support 'never' occurred. In addition they had worse ratings overall than other participants in four of the 21 questions. The questions concerned related to mental health professionals' openness to non-diagnostic explanations of mental distress (Q.4), support for participants with developing a new sense of themselves (Q.5), and the account that professionals took of the importance of friends who stood by participants (Q.12b) and of support from other service users (Q.13). The one question to which African and African Caribbean participants gave more positive ratings than participants in general was question 9b (professionals' carrying out their parts in care plans).

In the focus groups, African and African Caribbean participants all indicated at various points that they thought that their recovery under the 2008 Care Programme Approach had been hindered because of racial stereotypes in services, racist treatment and/or a failure to make use of alternative approaches used in Africa and the Caribbean

Well, you know, I am not illiterate, I'm not a criminal and a lot of the time I feel that I have been stereotyped in the context of being a black criminal who's high on something instead of a human being. Forget colour, just have a conversation with me and let's work together in coming up with a plan

I personally would like them to do more looking at other avenues and, also,

especially when it comes to black mental health, look at the Caribbean, look at Africa, find out how they are treating their own and see what you can take and apply to people of those origins within this country.

Responses from Asian and Asian British participants were not markedly different from those of participants as a whole. The former had lower ratings for support's happening 'a lot' in 11 out of 21 questions (52%) in the quantitative data, however. They also had the lowest overall ratings for professionals' listening to them (Q.2) and showing an interest in all the parts of their lives (Q.7), but the highest overall ratings for an appropriate focus on risk (Q.17). Participants from other minority ethnic communities and participants of more than one heritage were not numerous enough, nor their answers consistent enough for an analysis of their replies to result in clear findings.

2.3 Physical Disabilities

Focus group participants had mixed opinions about whether support related to their physical disabilities was helpful or not in promoting their recovery under the 2008 Care Programme Approach. Where positive views were expressed, these were because practical assistance was given with disability issues. Negative perceptions related to the absence of this and to experiences that might feel directly humiliating

I have a carer twice a day that comes in to help me with washing and dressing and stuff like that and cooking. ... I'm living in a disabled property and I've had it adapted to my needs as well

The disabled bathroom (on the ward) has no handles on it. The shower doesn't work. If I can get into the bath, because I'm waiting for an operation on my right shoulder, I'm unable to lift a jug of water to wash my hair. The staff are very unhelpful ... The last time I was in, I was almost forced to sit naked on a chair while they tipped jugs of water over me.

In its Guidance for the 2008 Care Programme Approach (Department of Health, 2008a), the government has emphasised public services' responsibilities under legislation which relates to people with disabilities, as well as to people from other marginalised groups. Further legal measures such as the Equality Act 2010 (HM Government, 2010) have underlined such duties. Feedback from a number of participants suggests that they regard their workers' progress with addressing physical disability issues as patchy, however. These participants stressed that further improvements are needed in this sphere if the Care Programme Approach is to support their recovery effectively.

2.4 Age

Only a small amount was said about age issues. Such feedback as there was came from participants in the focus groups. One view was that younger service users are supported better with recovery under the 2008 Care Programme Approach. It was suggested, for instance, that younger service users are seen as easier to help and that professionals are less effective with older service users because they do not yet have lived experience of older age. Another participant said, however, that he found services better now that he was older. He thought that one reason might be that he had changed himself

Staff have education from the book. They have not practical experience of elders' lives

When I was younger with mental illness, I was getting worse treatment and less money and everything ... Maybe it's because I was more reckless then, when I was younger ...

To sum up, female participants, African and African Caribbean participants, physically disabled participants and participants of varied ages mentioned some examples of good practice. Their feedback also made it clear, however, that they experienced much professional input as inadequate in terms of promoting their recovery under the 2008 Care Programme Approach. The findings here seem,

therefore, to support the concerns outlined in Part One above, that insufficient account is being taken of demographic differences. As one participant put it:

> (My psychiatrist) *never sat down and said: 'Well, as a black female Briton, how do you think your illness is affected by those aspects of life. They* (psychiatrists and community psychiatric nurses) *never say: 'Well, how's life with you, taking those things into consideration, you know, or even just normal things like my age. ... I think that it* (the Care Programme Approach) *hasn't been applied properly. ... They haven't trained any of these people* (to take that approach).

These sorts of issues have been highlighted by Kalathil (2011b). She has drawn attention to the fact that various service users, communities and campaigners have experienced race equality as taking a back seat in recent mental health policy. For example, a main purpose of the government's mental health strategy (Department of Health, 2011a) is to improve recovery rates and service users' experiences of care and support. Kalathil is concerned, however, that, without a strategy to address specific issues affecting service users from black and minority ethnic communities, there is a risk that the latter will not benefit from the strategy. The same point might be made about mental health service users from other frequently disadvantaged communities.

3. Qualities of mental health professionals

Many service users have emphasised the importance to their recovery of the qualities which professionals bring to interactions with them. (See sections 2.2 and 2.3 in Part One above.) Research participants were therefore invited to say what part they find qualities from mental health professionals play in their recovery under the 2008 Care Programme Approach.

The responses received were very similar to those from other mental health service users. In both the questionnaires and the focus groups, participants in general gave considerable weight to the qualities which professionals bring to their practice. In the quantitative parts of the questionnaire, for instance, almost all participants indicated that they wanted to be given hope (Q.1), to be listened to (Q.2), to be helped to value themselves (Q.3) and to have their own knowledge about themselves respected (Q.6), The majority wanted support, too, with developing a new sense of themselves (Q.5). (See Table 1 in Appendix C.) In the part of the questionnaire where participants were invited to name other support that would help their recovery, a substantial number also emphasised the importance of qualities such as empathy, compassion, respect, a supportive attitude and encouragement.

A similar note ran through focus group responses to a number of questions. In addition to the qualities above, participants stressed the value to them of professional approaches that included reassurance, interest, courtesy, fairness, honesty, and humility. They emphasised that such qualities were at least as important to their recovery as any treatments

We go every week (to a day centre) because they treat us with sympathy. They look after us, they sell us food, drinks, they socialise with us. They ask our problems, try to help, you know. There's things you get help from far more than medicine

Those sessions were very important to me, because I was able to spend ... quality time with somebody, a health professional, who

I knew would preserve confidentiality, was understanding, and I was given enough sessions for them to understand, like we say, holistically, the whole picture on me.

This emphasis on qualities was reminiscent of Mind's Inquiry into acute and crisis mental health services (Mind, 2011); service users who contributed to this Inquiry saw being treated in a warm, caring and respectful way, or, in other words, with humanity, as a key part of services. It is also a note which has been picked up by the government; the Guidance about the 2008 Care Programme Approach links the success of professional approaches with the quality of relationships that professionals achieve with service users (Department of Health, 2008a).

Participants' feedback indicated that, whilst there is some good practice, there is a considerable way to go as well before such practice becomes the norm, however, a point that was again made in the Mind Inquiry. (See the table on the next page.) The figures in this come from particpants who said that a particular point was important to them and gave the point a rating.

How often points important to my recovery happen	A lot %	Some times %	Never %	Rate of reply %	Number of replies
1. Mental health staff giving me hope	44	49	7	92	72
2. Listening to me	53	41	6	91	70
3. Supporting me with valuing myself	45	47	8	93	72
5. Supporting me with developing a new sense of myself	42	45	13	93	55
6. Respecting my own knowledge about myself	46	43	11	93	72

Extract 1 from Table 2 in Appendix C

Comments from focus group members were similar. Some spoke of valuing a particular approach to them because the professional worker had the sorts of qualities outlined above; see the examples cited on the previous page. Others mentioned opposite experiences, however, and the negative impact that these had

I was not recovering ... and I was always complaining, but I used to go out in the town because I was smelling dirty things and so I would go to different places to eat ... But ward staff would say: 'You are going out, you are eating, so you are O.K ...'. They don't understand what we are suffering.

It seemed therefore that there is a need for professionals involved in the 2008 Care Programme Approach to put an increased focus on the qualities that they bring to their practice.

4. Explanations of mental distress

One reason for the research was that quite a few service users have said that mental health professionals put too much emphasis on medical models in recovery approaches. (See section 2.3 of Part One above.) Participants had the opportunity, therefore, to give their views about the place of psychiatric diagnoses in services that they received under the 2008 Care Programme Approach and to say what effect a psychiatric diagnosis had on their recovery under the Care Programme Approach.

4.1 The place of psychiatric diagnoses

In the quantitative part of the questionnaire, participants were asked whether they wanted mental health professionals to acknowledge that psychiatric diagnoses were not the only way of explaining their difficulties (Q.4). 89% of those who replied (n=79) thought that this was important. Of the 64 who then rated how often this happens, only 36% (n=23) thought that it happened 'a lot', however, and 23% (n=15) said that it never did. (See Table 2 in Appendix C.) These ratings are also the lowest ones that participants gave. They seem, therefore, to reflect considerable dissatisfaction with professionals' openness to non-medical explanations of mental distress.

In focus group discussions, some participants said that they were happy with the use of a psychiatric diagnosis to explain their difficulties, because their diagnosis made sense to them

> *I read a few books on my condition and I definitely have what they say.*

A psychiatric diagnosis might also be thought preferable to prejudiced lay language

> *I would rather be called bipolar than some names neighbours have called me, or some of the people that live around my estate, because, when I have been manic, it's been pretty obvious. So I've been known as the mad woman with the cats, the nutter, all that sort of thing, that we should all be locked away and burnt ...*

Quite a few focus group members had had mixed experiences. They did not necessarily disagree with their current diagnosis. They spoke, however, of difficulties arising from earlier misdiagnoses, a lack of information about diagnoses, a discontinuity of psychiatric staff which meant that they did not receive adequate explanations and the fact that they might have to take things into their own hands in order to establish a diagnosis that made sense to them

> *I had every diagnosis under the sun over some 20 years. Then I met this GP that I'm with now who actually said: 'But none of this fits, you know. You're bipolar, there's no question about it, but not just straightforward: mixed state, rapid cycling'. And once he gave me loads of information and I was reading through I thought: 'Why have I been in the system for well over 20 years and nobody actually picked it up?' It's blatantly obvious, when you it see on paper, that I fitted these criteria, even the old criteria for bipolar*

> *I used to only see my psychiatrist about every three or four months ... for about ten minutes, then ... they seem to come and go all the time, you know*

> *It took them quite a long while to diagnose me. ... I had a bad doctor as well and it took me a while to find a good one, but I'm so glad I persevered ... and that wasn't by accident. It was by researching and going on the Net and looking up GPs and seeing what their specialisms are.*

The remainder of views expressed were negative in a way that matched the concerns from a number of service users that underlay the current research; they found psychiatric diagnoses unhelpful, too narrow, or medically focused, for instance, and might, too, experience them as discriminatory.

I know what the symptoms are and I do suffer the symptoms, but all the definitions I've found, the official definitions are generally not useful

Most of us black men are just diagnosed with schizophrenia and violence ... and, to me, that is just something, mostly, I think, the media, you know, and society have put on black men over the years here in the UK.

To sum up, it would seem therefore that the use of psychiatric diagnoses alone satisfied some participants, but left a significant number dissatisfied as well. It may be, too, that the lack of focus on non-medical terminology and on diverse explanations in the government guidance about the 2008 Care Programme Approach (Department of Health 2008a) is compounding the situation.

4.2 The impact of psychiatric diagnoses on recovery

In the focus groups, participants also discussed the impact that a psychiatric diagnosis was having on their recovery under the 2008 Care Programme Approach.

For a few participants, their diagnosis had a positive effect; it gave them a baseline to use, for instance

Diagnosis is very important because it puts into focus what's going on in your system.

A few others indicated that the diagnosis helped with their recovery in general, but that they were unhappy with the side effects of medication that they were then prescribed. They viewed the latter as something of an obstacle to their recovery. (See further section 5.1 below in relation to medication side effects.) They might also experience other services as unhelpful, for example find that conditions on psychiatric wards held them back.

A couple of participants thought that their diagnosis had made no difference one way or the other to their recovery. The larger number of participants had negative views about the impact of their diagnosis on recovery,

however. They thought, for instance, that the diagnosis given was the wrong explanation of their difficulties and so led to unhelpful service approaches

My consultant and I have very different opinions about what's wrong with me and what the answer should be. She thinks that (because of her diagnosis) I should take medication. I disagree with that. I disagree very much

The effect (of my diagnosis) was negative ... I'm from a West African origin, from Gambia ... In Gambia, ethnically mental health there is different ... You have really just the spiritual and social traditional things applied to someone being mental.

Participants might also consider that a diagnosis impeded their recovery because of the link that they perceived between mental health diagnoses and stigma

We're not horrible people. We get ill and have to live with an illness for our life and another thing is to make clear, maybe to the media, that it's not our fault and we didn't choose it ... I think what needs to be made clear to the public is that we're not all murderers and killers

Having that diagnosis is having a devastating effect on my recovery... I'm not just a service user, I do work in mental health as well, so sometimes, to save the embarrassment, when people ask me what I do, I just say: 'Oh, I work in mental health, Many a time I've mentioned that I work with schizophrenia and depression and things like that and people always say: 'Oh, isn't it violent? Don't they get violent?'.

Overall, therefore, participants appeared to have a somewhat negative view of the role that psychiatric diagnoses played in helping them to recover, if for a variety of reasons. Thus it seems that the role given to such diagnoses needs further consideration if recovery services provided under the 2008 Care Programme Approach are to be effective.

4.3 Alternative descriptions of mental distress

Participants who thought that non-medical explanations of their difficulties were useful put forward some alternative concepts. They wanted their problems viewed in the context of the whole of their lives. They might, for instance, root mental distress in everyday human experiences, or link it with spiritual, or sociological phenomena

Someone who's had a setback, like who's suffering from bereavement. A problem that I couldn't see, understand, or cope with because I couldn't see it coming

Does anyone here know the work of Aidan Shingler who is diagnosed schizophrenic and who actually sees schizophrenia as a spiritual awakening? I like that

I don't know whether, from a spiritual point of view, people who have this diagnosis are in touch, or in tune with the conscience of society where they see suffering and it just hurts them inside.

Participants also seemed to struggle with finding words for alternative concepts, however. They spoke of mental health professionals not offering them anything other than psychiatric diagnoses, or being opposed to alternatives, and of a need to look elsewhere. Participants might, too, define different explanations of their problems as the recovery mechanisms that they would like used with them.

This sort of difficulty would seem to tie up with the dominance of a medical model in this country, a dominance that is apparent in government documentation and has been highlighted for some time by various mental health professionals as well. For example, members of the Critical Psychiatry Network[2], a group of British psychiatrists who first came together in 1999, have questioned the tendency of psychiatric practice to rest heavily on psychiatric diagnoses.

There have also been current challenges to diagnostic labels, such as the recently launched Inquiry into the 'Schizophrenia' label[3].

A point made by Beresford (2009) may be of relevance as well. Beresford points out that, although it has developed a range of key values, the mental health survivor movement has not been based on an explicit and ongoing social model equivalent to that put forward by the disabled people's movement. It may be, therefore, that, whilst there are advantages to holding back from one set model, the lack of such a model also makes it harder for people who use mental health services to conceptualise alternatives to psychiatric descriptions.

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[2]www.criticalpsychiatry.co.uk

[3]www.schizophreniainquiry.org

5. What support was helpful

Participants were invited to say what part they thought psychiatric medication and other options should have in recovery services offered under the 2008 Care Programme Approach. This was again because of criticisms from a number of service users that there is too much emphasis on medically-based services.

5.1 The role of medication

In the quantitative part of the questionnaire, 96% of the 78 participants who replied thought that medication, if prescribed, should be supporting their recovery (Q.10). Of the 68 who indicated whether this was occurring, 59% (n=40) thought that it was happening 'a lot', 32% (n=22) that it was happening 'sometimes' and 9% (n=6) that it was 'never' happening. Although the overall ratings here imply somewhat mixed views about the use of medication, the rating for 'happens a lot' was the highest one out of the 21 questions asked. (See Table 2 in Appendix C.) That is an interesting finding, given existing criticisms of medical models from a number of service users. Amongst participants who had been subject to compulsory powers since October 2008, however, 18% of respondents thought that their prescribed medication 'never' helped their recovery.

In the focus groups, although a few participants had a very positive view of the role of medication in their recovery, most had negative comments to make. It was not necessarily that they did not want to take medication, though compulsory treatment was not welcomed, but that they had strong concerns about some aspects of the medication process. One major reason was the fact that psychiatric medication frequently had unpleasant, or even dangerous side effects, such as the following:

Now he (the consultant) *has got me leaking ... and I can't control it and that's only the medication doing that*

I went up to a size 24 from a size 16

I've had medication almost kill me (lithium) *and it's taken three goes to get me on my current levels*

I've been through haloperidol, which was dreadful. I'd be stuttering and people thought I was drunk when I wasn't

Without medication, I couldn't manage my life. But the side effects, I can't manage with the side effects of the medicine: drowsiness and dizziness ... so in the morning I can't get up in time.

It is worrying that almost all focus group members voiced concerns about the side effects of medication. Participants' unease about these seems, too, to be very much in line with findings in a Mind report about coping with coming off medication (Reid, 2005). In that report, the side effects of medication represented one main reason for respondents' wanting to come off medication; they found the side effects unpleasant and sometimes harmful.

The policy and practice guidelines for the 2008 Care Programme Approach (Department of Health, 2008a) allude to side effects of medication that service users experience as 'intolerable', or find affect their quality of life. The guidelines also mention the need to assess and review medication in the light of this. They do so very briefly, however. In addition, there is no reference to side effects of medication in the government's mental health strategy (Department of Health 2011a) and outcomes documentation (HM Government, 2011b), nor in material published just after the completion of this research, for example the implementation framework for the strategy (HM Government, 2012). A further issue for quite a few participants was that they did not think mental health staff listened to them about difficulties with the medication

There's times you're taking two, three, four, five pills and they've got all these different side effects and you've got to live

with that. I think the nurses need to listen more to what we're saying.

Some participants also expressed concerns about being given a misdiagnosis and then receiving inappropriate medication. They might find medication ineffective, or experience difficulties when it was changed. They might be unhappy, too, because they thought that racist attitudes resulted in treatment approaches to them that focused on heavy doses of medication and were restrictive

For most of us ...the doses we were given in the beginning are always high ... We are less likely to be offered talking therapies, but more likely to be medicated (a black British participant).

5.2 Whole-person support

In both the questionnaires and the focus groups, participants put a strong emphasis on the importance that whole-person (holistic) support had in promoting their recovery under the 2008 Care Programme Approach. Where they thought that psychiatric medication had a place in their recovery, they nonetheless considered that such medication should not be prescribed in isolation, but as part of holistic practice.

In the quantitative parts of the questionnaire, most participants indicated that points which related to holistic interventions were important to them. Thus, over 80% of respondents thought that mental health professionals should:

- Show an interest in all the parts of participants' lives that mattered to them (Q.7)

- Take into account the importance to participants of family and friends who stood by them (Q.12a & 12b)

- Help participants with playing the part that they wanted in the community (Q.15)

- Support participants with rebuilding lives

that they found meaningful (Q.16).

73% of respondents (n=57) wanted professionals to take account, too, of the importance that spirituality had in their lives (Q.8) and 63% (n=47) thought that it was important for professionals to recognise that traditional remedies might also help them (Q.11).

(For the full figures, see Table 1 in Appendix C).

In addition, in the part of the questionnaire where participants were invited to name other support that they wanted from mental health professionals, one major theme was assistance with everyday life issues. Here participants mentioned aspects such as accommodation, self-care, household skills, relationships, recreation, finances, education and employment. Different respondents focused on different aspects of this. Overall, however, approximately half the comments from the 53 people who replied fitted into this theme. There were similar emphases in the focus groups. In addition, quite a few focus group members particularly stressed that effective physical health care mattered to them, because of general health problems that they had. Several mentioned the value of creative arts. In some cases, focus group members spoke again, too, of the important role which their faith had for them.

Focus group participants saw it as important to have a wide range of resources available to them under the 2008 Care Programme Approach, as part of their recovery. They mentioned talking therapies, therapeutic approaches based on art, writing, music and movement, alternative therapies, such as reflexology, aromatherapy, acupuncture and herbs, and access to sunshine. They again emphasised the qualities that they wanted from professionals. (See section 3 above.) They also spoke of the value of partnership working by professionals. (See further sections 8 and 9 below.)

A number of focus group members welcomed support from local voluntary groups. Participants from South Asian communities and from African and African Caribbean communities talked

about the importance to them of culturally-specific resources. The usefulness of groups related to gender and to age was mentioned. Focus group members put a value, too, on befriending schemes, support from other service users and self-management approaches. (For the latter, see also section 9 below.)

It was clear therefore that, for participants, effective help with recovery involved far more than just clinical treatments. In some cases, too, participants wanted to move away from clinical approaches and focus on other support. Reasons that participants gave were that they found purely clinical approaches too narrow to help adequately with their recovery, or might experience such approaches as unhelpful, or culturally inappropriate

They should look at you holistically, you know, on all aspects of your life, because what I see is that some of them they don't realise that, before we got unwell, we had a life. I had a home, I had a roof over my head, I had a partner, somebody to love ... I was in college ... When you're unwell ... they tend to just concentrate on ticking the boxes on the medical, clinical side of things

I think what all healthcare professionals should be looking at is to move away from the medical model and medical diagnosis and look more into the social which takes into account the person as a whole human being from childhood right up to adulthood, including all your accomplishments, including your creativity, because ... most service users that I've met have some creative talent

Here, the way western medicine is you want to cure the disease, or you nuke it, or you cut it out. Yet, if you looked at it from a holistic point of view, heal the body. It is healing that is needed. Heal the mind.

In the Statement of Values and Principles which the government has set out for the 2008 Care Programme Approach (Department of Health 2008a), care assessment and care planning are defined as follows:

'Care assessment and planning views a person "in the round" seeing and supporting them in their individual diverse roles and the needs they have, including: family; parenting; relationships; housing; employment; leisure; education; creativity; spirituality; self-management and self-nurture; with the aim of optimising mental and physical health and well-being'.

The government's mental health strategy (Department of Health 2011a) has a similar focus.

This holistic note from the government seems to fit quite closely with emphases from participants. In the quantitative part of the questionnaire, however, participants expressed somewhat mixed views about the extent to which they received holistic interventions. The ratings came from participants who had indicated that a particular point was important to them and then also said how often they found that the point happened. The results were as follows (See the table on the following page):

How often the following happen	A lot %	Some times %	Never %	Number of replies
7. Mental health staff showing an interest in all the parts of my life that matter to me	48	44	8	62
8. Mental health staff taking account of the importance that spirituality has in my life: in their work with me	38	37	25	52
11. Mental health staff recognising that traditional remedies (remedies from my own community) may also help me	36	43	21	44
12a. Mental health staff taking into account the importance to me of family who stand by me	51	43	6	65
12b. Mental health staff taking into account the importance to me of friends who stand by me	46	44	10	59
15. Mental health staff supporting me with playing the part that I want in the community	37	40	23	60
16. Mental health staff supporting me with rebuilding a life for myself that I find meaningful	45	39	16	67

Extract 2 from Table 2 in Appendix C

It was also clear from the qualitative elements of the questionnaires and the focus group data that, whilst there was some good practice, overall participants found their services somewhat patchy in terms of holistic practice. In the focus groups, in fact, participants identified a number of factors that they thought hindered the holistic services important to them. Participants mentioned issues such as an emphasis on medication, a 'command and control' ethos to the Care Programme Approach, the fact that GPs may not know very much about mental health, difficulties in relationships with mental health staff, family or friends, limited personal finances, obstacles with employment, limited service resources, cuts in services and the negative impact of racism and ageism in services. It seems, therefore, that there needs to be an increased focus on whole-person services if the 2008 Care Programme Approach is to become more effective in promoting recovery.

6. Recovery tools

Because formal recovery tools are very much part of the current recovery scene, focus group participants were invited to say how useful they found such tools in supporting their recovery under the 2008 Care Programme Approach. There was particular discussion about the Wellness Recovery Action Plan (Copeland, 2006) and the Recovery Star (MacKeith and Burns, 2008); some, though not all participants were familiar with these.

There were mixed reactions to both tools. For example, some participants thought that the Wellness Recovery Action Plan could be helpful in helping them to plan and/or maintain recovery, particularly if they were given support with it and if there were regular reviews. Reservations were that filling in the Plan might be hard if one was unwell, that the Plan might not fit with particular cultures, or religions and that it is not useful for individuals who want to take control of their own recovery journey

I found it useful, I mean like sort of identifying bits and pieces, but I think, when you're unwell, it can be difficult

I used to use it, I used to call it my gentle reminder ... It did work for me ... For others it might not work, because their way of doing things might be different from a cultural point of view, or from a religious point of view, or from a traditional point of view ... Their recovery action plan must be incorporated with their traditional ways and their culture to suit them

Most of it seemed to be the same old stuff about what I would like to happen in the event of a 'relapse'. A true Wellness Recovery Action Plan for me would be to get off all 'medication', get the CTO (community treatment order), get the services out of my life and get back to doing my Art and my Yoga. And

work for Truth and Reconciliation in Psychiatry ...

They call it a recovery tool. I call it: 'Leave me alone!' I want to manage my own care.

Some participants liked the Recovery Star because, for instance, it enabled them to measure their progress. The importance of support with using it and of regular reviews was again emphasised, however. Others saw the Recovery Star as, for example, too complicated, as possibly putting too much pressure on service users with long term problems to find employment, or as unhelpful because it was a set tool

I like the fact that you could judge yourself. I remember the first time to the second time where there was a change

I haven't used any of them (recovery tools). My psychologist introduced me to concepts of recovery and we worked through one uniquely with myself. Otherwise it's not going to work; it's like trying to put a square peg in a round hole and we're not all the same.

These sorts of comments provided some interesting insights into participants' perceptions of the role of standardised tools in helping them to recover. The variety of views about particular tools and the note of caution from some service users about set tools seem to reflect the point that emerged from research participants in general: that recovery is a very personal matter.

This would appear to have implications for further attempts to develop recovery tools that, despite some flexibility within them, nonetheless draw on one particular framework and are intended to be applied consistently across organisations. This may be an issue, for instance, with initiatives such as the ImROC Project (Implementing

Recovery through Organisational Change)[4] and the REFOCUS[5] study to consider further. There is seemingly a difficult balance to achieve between something that feels manageable organisationally but also stays true to the fact that recovery means different things to different service users and that different service users have different ideas about the best ways to plan recovery.

In addition to commenting on the Wellness Recovery Action Plan and the Recovery Star, participants defined recovery tools more widely as well and in non-standardised ways. They suggested, for instance, that the following could be useful for recovery processes: a local day centre with a wide range of holistic activities, an Asian-specific day centre, local voluntary groups, befriending schemes, peer support and self-help. One participant suggested that recovery starts as a personal decision and that one then moves on through a stepping stone process to, for example, parts of the Care Programme Approach that are to do with recovery, to standardised tools and then to peer support and to self-management.

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[4]www.nhsconfed.org/imroc and www.centreformentalhealth.org.uk/recovery

[5]www.researchintorecovery.com/refocus

7. Attitudes to risk

Because one reason for the research was that some service users have criticised the Care Programme Approach for putting too much focus on risk, respondents to the questionnaire and focus group members had the opportunity to say how helpful they found the focus on risk in promoting their recovery through the 2008 Approach.

In the quantitative part of the questionnaire, 87% (n=69) of the 79 respondents said that it was important to them that the focus on risk in their care plan was balanced and in proportion (Q.17). Given the rationale for the research, it is interesting that 56% (n=34) of the 61 participants who then gave ratings were satisfied with the focus on risk 'a lot' of the time. Although this figure only represents the views of just over half of those who replied, the rating given here is one of the highest ones. At the same time, a somewhat different picture emerged from participants who had been subject to compulsory powers since October 2008; of the 21 who replied, 29% did not regard the focus on risk in their care plan as ever being balanced and in proportion.

In the focus groups, participants were not always sure whether they had had a risk-assessment, or not. This was concerning, given the fact that risk-assessments are part of the 2008 Care Programme Approach and that there is an emphasis in this Approach on collaborative work with service users (Department of Health, 2008a).

When focus group members discussed how much weight they thought should be given to risk in their care plans, they concentrated mainly on risk to themselves; they viewed this as the major issue. Quite a few participants stressed the need for safeguards against risk to themselves and, in some cases, they said that between 20% and 50% of their care plans should focus on risk; it was important to them that they were kept safe when they felt in a bad way.

In (my care plan) *there needs to be a high focus on risk, because I have a high suicidal ideation.*

In this sense, there was some similarity with service user views expressed in Mind's report about acute and crisis mental healthcare (Mind, 2011); contributors to this report also made some mention of wanting to be safe. For a number of other focus group members, however, the focus on risk in their care plan was out of proportion, or drew too much on past risk situations that no longer applied.

Quite a few focus group members, though not the majority, said that the actual focus on risk in their care plan was helping them to work towards recovery under the 2008 Care Programme Approach. This might be because they found a particular professional helpful, or were supported with positive risk-taking. One or two also thought that being asked about risk was or could be like an advance directive, enabling them to be in control

I've got my CPN (community psychiatric nurse) *like to look after me in case of any problems*

I always had the chance of taking positive risk

I found preparing the advance directive very helpful: feeling that you're in control and able to influence what is not necessarily a great period of your life, but how to manage it for the best.

Participants also named negative experiences, however. They might find that professionals did not involve them adequately in discussions about risk, an issue which has been highlighted by Sheldon (2011). They might consider that the content of risk-assessments and risk-management plans was too limited. Some professionals were thought to be influenced in their approach by racist assumptions that black men are particularly likely to be aggressive.

Another view was that mental health workers did not necessarily link risk-management and recovery. A criticism, too, was that professionals might not be proactive enough in their planning, or might not follow up agreed risk-management approaches quickly and adequately enough

They should, in my opinion, be trying to make you feel like you're a partner in compiling the care plan not somebody who's like an onlooker, as having something imposed on them (a point made in relation to the risk elements of the care plan)

The psychiatrist doesn't really relate risk management to recovery

I've got kind of a contingency plan, but how well they act on it, that is a whole different question.

For others, the focus on risk in their care plans was counter-productive in recovery terms, because it was overdone

My care plan focuses on risk of relapse and it really drives me mad because they go on about it all the time.

Several participants also talked about the value of managing risk for themselves. They gave mixed feedback as to whether this happened, or not, however.

The responses above suggest that a number of participants thought that the focus on risk in their care plan was in proportion and useful. The opinion of many participants, however, was that there is some way to go before risk-assessment and risk-management processes are used in a way which supports them with recovery under the 2008 Care Programme Approach.

8. Attitudes to compulsory treatment

As has been indicated in section 2.3 of Part One above, quite a few service users see a conflict between their ideas of recovery and the compulsory powers of the Mental Health Act 2007 (HM Government, 2007). Participants were, therefore, invited to give their views of compulsory treatment in relation to recovery under the 2008 Care Programme Approach. Relevant data from participants is set out below.

8.1 Views of participants who had experienced compulsory treatment

In the quantitative part of the questionnaire, participants who had been subject to compulsory treatment since October 2008 rated the support that they were receiving with recovery less positively than other participants did. (See Table 6 in Appendix C.) In their answers to 52% (n=11) of the questions, they did so in either two categories (support's happening 'a lot', or 'never' happening), or in all three categories; their replies to questions 2, 3, 8, 9b, 11 and 12a are examples of the former and their responses to questions 4, 6, 7, 9a and 15 illustrate the latter.

They gave more positive ratings in all three categories for question 12b (professionals' recognising the importance of friends) and in the two categories referred to above for question 14a (the opportunity to join a service user group about the Care Programme Approach) and question 16 (support with rebuilding a meaningful life).

It was particularly striking, however, that, in their replies to 86% (n=18) of the questions, these participants' ratings for desired support's 'never' happening were worse than those of other participants: as much as two, or three times so in twelve questions and between four and nine times so in a further four questions.

Because of the comparatively small size of the research study, an undue weight cannot be placed on these figures in isolation; the mean (average) number of respondents who had

experienced compulsion since October 2008 and gave ratings was 27. The more negative views of participants subject to compulsory treatment appear worthy of consideration, however, especially when combined with the qualitative findings below and other related literature.

It seems possible as well that the contrast between participants who had experienced compulsion and those who had not would have been still higher if the questionnaires had provided data covering participants who had been subject to compulsory powers before October 2008. In the focus groups, when the latter also expressed their opinions about the effect of this on their recovery, they, too, had mainly negative views about it. (See below.)

In the qualitative part of the questionnaires, participants made some direct comments about the impact that compulsory treatment since October 2008 had had on their recovery under the 2008 Care Programme Approach. They mostly discussed sectioning. The largest number of respondents described their experience of this as negative; being sectioned had been harmful emotionally, felt stigmatising and had hindered instead of helping their recovery

I was not happy the way they took me in the hospital like a thief without my consent

Being sectioned was a frightening, humiliating and isolating experience for me. ... I left hospital very traumatised and ashamed and lacking in confidence. This experience was a completely negative one and hindered my recovery.

Focus group members who had undergone compulsory treatment, whether before or after October 2008, gave still more negative feedback about its impact on their recovery. They spoke, for instance, of feeling punished, frightened, angry, hemmed in and held back by conditions on the ward and/or by rules and by

treatments used. They might also experience compulsory treatment as a breach of human rights, or as discrimination.

Compulsory treatment is discriminatory, punitive and just plain wrong. It is a violation of a person's human and civil rights under the UN Convention on the Rights of Disabled People ... I am currently on a community treatment order. This makes me feel depressed and angry. The drugs I am being coerced and threatened into taking make me tired all the time and have adversely affected my thought processes, particularly my capacity for creative work and deep concentration ... They have also robbed me of my libido and ... I (now) suffer from stress incontinence. Also, the procedure of attending the depot clinic for the injection is traumatic, humiliating and degrading

We are always more likely to be incarcerated, more likely to be sectioned, more likely to end up in a psychiatric hospital, more likely to be medicated and we're less likely to be offered alternative options, or alternative therapies (a black British male participant).

A minority of respondents to the questionnaire had positive views, or mixed perceptions about their experiences of compulsion. This was because they felt that sectioning had kept them safe, helped them to regain control and/or enabled them to take steps towards recovery

It was scary, but I think it was for the best as I would probably have killed myself if I hadn't been sectioned. I'd say therefore that it helped my recovery

(There was) more attention from mental health team members plus more referrals made, but restrictions held me back.

In one or two cases, focus group members also had mixed views about compulsion. They thought, for example, that compulsion might sometimes be justified, but that it had also been used unnecessarily and might then institutionalise them as well

The compulsory treatment that I have had, when they've taken me in, except for just recently has been appropriate... The last admission that I had actually harmed my recovery ... You get into some sort of hospital culture where you don't cook for yourself. It's a whole, it's not just the compulsory treatment ... When I came out this time, I didn't want to look after myself ... It's taken away my independence ... So I think they should use it wisely, you know, sparingly.

The somewhat negative views in the responses above are very similar to those in other literature. Sheldon (2011), for instance, describes a survey which she undertook with members of the Mental Health Act Commission's Service User Reference Panel (SURP); the SURP consists of approximately thirty people with current, or recent experience of detention under the Mental Health Act. Sheldon draws on the survey to underline how dehumanising such experiences could be. Service user participants in the University of Lancashire's review of independent mental health advocacy (Newbigging *et al*, 2012) expressed very similar views. This is particularly concerning given that the use of compulsory treatment continued to rise during 2011-2012 (The Health and Social Care Centre, 2012). Patients detained under the Mental Health Act increased by 5% to 48,600, the highest total since monitoring of the Mental Health Act began in 2007-2008. The number of people discharged from hospital under community treatment orders was up by 10% from the year before.

8.2 Views of participants who had not experienced compulsory treatment

The views of focus group members who had not been subject to compulsory powers were somewhat evenly balanced between more positive and more negative opinions. One view was that detention is important for safety or protection reasons, or to provide more effective support

I have had the experience of being in my flat for two weeks where I was completely

manic ... I would much rather have been taken off into hospital and sectioned, rather than being left in my own home and having to live with the consequences afterwards, because I was getting eggs thrown at my door. I had my windows broken.

Other views were that the restrictions involved ran the risk of hindering recovery and were stigmatising

I think it will slow down my recovery because of the restrictions put in place ... So I will be depressed, I will be anxious, I will be angry, so it will not help me

Obviously they need to know that you're safe, but it just feels like, for having an illness you haven't chosen, you're then on top treated kind of in a criminal way.

8.3 Voluntary admission to hospital

Whether focus group members had had personal experience of compulsory powers or not, quite a few of them had concerns about hospital staff's telling voluntary patients that they would be sectioned if they tried to leave. They spoke about their knowledge of such practice and about the unease that they felt about it; they saw it, for instance, as a breach of voluntary agreements and of service users' legal rights

If you're there and not on a section, they say: 'If you try to leave, we'll put you on a section ...'. As far as I can see, it infringes my human rights. It can't be legal.

One participant emphasised, however, that she had felt protected when she was not allowed to leave hospital despite the fact that she was a voluntary patient; she thought that she would have been at risk if she had gone out.

As part of its guide to *Independence, Choice and Risk* (Department of Health, 2007), the government speaks of trying to find a balance for mental health service users between positive approaches to risk-taking and the safety of service users and others.

This sort of balance is underlined in the government's documentation about the 2008 Care Programme Approach (Department of Health, 2008a). In the mental health strategy (Department of Health, 2011a) the government mentions its intention to keep the increased use of detentions and community treatment orders under review, so that the law can be changed, if necessary. In the strategy, the government also refers to the importance of patients treated under the Mental Health Act having a positive experience of care and support.

Feedback from participants, in combination with other service users' writings, would seem to indicate, however, that there is still considerable ground to cover in these respects. Their feedback also appears to demonstrate that some, but only limited progress has been made with resolving conflicts between human rights and the exercise of compulsory powers under the Mental Health Act 2007. It is noteworthy, too, that the recently published Mental Health (Discrimination) (No.2) Bill (The Stationery Office, 2012) does not address the latter. Further attention to the issues seems to be key, therefore.

9. Involvement, influence and control

Influence and self-determination for service users are themes which have tended to be central to their definitions of recovery. In the questionnaire and the focus groups, therefore, participants had the opportunity to say how important these factors were to their recovery under the 2008 Care Programme Approach. In response to this, participants emphasised the value of involvement, influence and control for themselves at personal recovery levels, their wish for input by their peers and, in many cases, stressed the importance of service user input at a strategic level also.

9.1 Involvement, influence and control at a personal level

In the quantitative parts of the questionnaire, 96% of the 79 participants who replied indicated that they wanted their care plan to focus on the things that they themselves said helped them to recover (Q.9a). 41% (n=29) of the 70 who rated how often this happened thought that it did so 'a lot'. This implies some good practice. It is also concerning, however, that the figure is not higher. 95% (n=75) of participants said that they wanted professionals to support them with being in control of their lives (Q.18). Amongst the 69 who went on to name how often this occurred, 45% (n=31) described it as being 'a lot', a slightly higher percentage than for question 9(a). 17% (n=12) thought that they 'never' received support of this sort, however.

Participants put a similar emphasis on personal power in the qualitative parts of the questionnaire. As has been mentioned in section 1 above, participants' descriptions of recovery included a mention of being independent and in control. When they mentioned other support that was important to them, involvement, independence and control were again emphasised by a number of participants. They gave mixed feedback as to whether they were supported with these, however.

As will be already be apparent in some of the sections above, focus group members voiced a strong wish for involvement and partnership in all aspects of the support that they received under the 2008 Care Programme Approach. They regarded this as important if they were to feel treated as equals and if interventions used were to be effective in promoting their recovery.

For focus groups participants the amount of involvement and partnership which they experienced was linked with professionals' attitudes to them as mental health service users. Some participants spoke positively about these

I've been lucky. I didn't have very many bad experiences.

Others experienced professionals as prejudiced towards them because of their mental health difficulties

Staff, their attitude. They just say: 'Ah, they're all nutters'. You have staff telling you that until today, you know.

It is clearly encouraging that there was some evidence from participants that they felt respected by professionals. It is worrying, however, that other participants were concerned about professionals' attitudes towards them despite ongoing anti-discriminatory initiatives such as the Time to Change programme[6] and despite government pledges to support and work actively with such programmes (Department of Health, 2011a).

Focus group participants also had divided views about how fully they were treated as partners. In some cases, participants were happy with services because of the active involvement that they had

My consultant is excellent (in this respect).

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[6]www.time-to-change.org.uk

In other cases, they saw approaches taken as too 'top down', for instance, or too rigid (sometimes particularly in the case of psychiatrists) and thought that it was difficult to complain without repercussions

Some service users I've spoken to, they don't want to go to CPA meetings and some of them even said to me: 'It's not for us, it's for the health professionals, because they're going to do what they want to anyway'

I would like psychiatrists to be open to the possibility they could be wrong

If you complain about staff, you are treated with prejudice.

In both the qualitative parts of the questionnaire and the focus groups, participants expressed an interest in taking direct control of their recovery when possible; they wanted, for instance, to help themselves and were aware, too, that they might have an expertise about themselves that professionals did not

It's taken me 15 years to get treatment that is actually correct for my wellbeing, for my lifestyle, to help me stay in recovery ... There were lots of times when I didn't have the energy to fight, but when I got stronger I did and I continued fighting and it's one of the reasons why I'm a service user rep today ... so that nobody goes through what I went through.

I have been low sometimes, but obviously I know my triggers. I can manage when I'm in that state.

9.2 An influence for other service users

Participants quite frequently indicated that it was important for their peers to have an influence on participants' recovery journeys under the 2008 Care Programme Approach. In the quantitative part of the questionnaire, for example, 82% (n=63) of the 77 respondents said that they wanted professionals to take into account the importance to their recovery of support from other service users (Q.13).

There was a similar note from quite a few focus group members. They thought that other service users might, for example, have a non-discriminatory attitude and personal qualities that participants valued. Their peers might also offer them approaches, or resources that they were not experiencing with professionals and might support self-directed care

... (I like service user) groups where you meet other people and you can converse. You don't just chat about your mental health, but people say: 'How are you?' And there's not that bias (about mental health)

I have found non-medical support myself (from other service users)

I think that user-led self-management courses and self-help groups are really important. They teach one to reduce risk.

Participants provided mixed feedback, however, as to whether professionals allowed for other service users' having an influence in the recovery interventions that were used. In question 13 of the quantitative part of the questionnaire, for instance, 42% (n=24) of the 57 respondents perceived professionals as giving a value to support from other service users 'a lot' and 21% (n=12) thought that they 'never' did so.

9.3 Involvement, influence and control at strategic levels

Participants' wish for involvement and influence was not limited to an individual level. In the quantitative part of the questionnaires, 73% (n=57) of the 78 participants who replied expressed an interest in joining a service user group that had an influence on the implementation of the Care Programme Approach (Q.14a). 74% (n=54) of the 73 respondents also wanted such a group to have an impact on how the Care Programme Approach was implemented with them (Q.14b). Of participants who gave ratings, 30% (n=15) said that they had 'never' had the chance to take part in this type of group, however, though 37% (n=19) thought that they had the opportunity 'a lot'. 40% (n=19)

believed that the group had 'a lot' of influence on professionals' work with them. 17% (n=8) thought that it 'never' had, however.

It is encouraging that there was some evidence of participants' having a personal and strategic involvement in recovery services provided under the 2008 Care Programme Approach, of their influencing these at personal and strategic levels and of professionals' giving a place to peer support. It is concerning that under half of participants experienced such practice as commonplace, however. At the heart of most recovery literature is an emphasis on service users' being at the centre of support processes and on self-direction. (See, for example, the references in Part One above.). The government has also promoted professional stances of this sort. The Department of Health's leaflet about the 2008 Care Programme Approach, for instance, is subtitled: *It is **not** about how you fit into services. It **is** about how services fit with you* (DH, 2008b).

The government has underlined the importance of person-centred practice, self-direction and peer support in subsequent documentation such as *Personalisation through Person-Centred Planning* (Department of Health, 2010a) and *Putting People First: Planning Together – Peer Support and Self-Directed Support* (Department of Health, 2010b). There has also been an emphasis in such documents on service users' having a strategic role as well. It seems, however, that, whilst there has been some progress, recovery services provided under the 2008 Care Programme Approach still need to move further in these directions.

As well as raising issues that were similar to concerns from service users mentioned in section 2.3 of Part One above, participants brought up one further matter; the importance of adequate resource allocation if they were to recover effectively under the 2008 Care Programme Approach. Their points related partly to staffing and partly to budget.

10.1 Deployment of staffing

In the questionnaires, where participants were invited to name other assistance that supported their recovery under the 2008 Care Programme Approach, quite a few respondents stressed the importance to them of professionals' achieving a good fit between the timing of their interventions and participants' support needs. Respondents alluded, for instance, to the need for regular services and reviews, reliability, punctuality, consistency and flexibility from staff, staff's spending adequate time with them and staff's being available at times of crisis. Respondents expressed somewhat mixed views about the extent to which they received this sort of support, however. The impression was, therefore, of services that participants were finding patchy in these respects as well.

In the quantitative part of the questionnaire, participants had also given mixed feedback about the reliability of professionals involved in their care. Of the 93% (n=71) who said how often professionals carried out their parts of a care plan (Q.9b), only 49% (n=35) of participants thought that professionals did so 'a lot'. 44% (n= 31) thought that professionals did so 'sometimes' and 7% (n=5) that they 'never' did.

In the focus groups, consistency was also a key issue for a number of participants. Participants found services too disruptive to support their recovery well when they had constantly changing professionals. Another problem might be a lack of communication between staff, arising, for instance, from shift work and from a lack of dialogue between different professionals. Participants also found it difficult when agreed action was not implemented or reviews were irregular.

... You don't always see your psychiatrist. You will see another under-doctor and they might be there for six months and then you see someone else and they don't really know you ... At the moment I've only seen my psychiatrist once ... and her understudies you can talk to ... but it seems like they're not knowing you personally. And then, they can give you a Care Co-ordinator, or a CPN (community psychiatric nurse) and you might be comfortable with them, just get sorted, six months let's say, then they change it all around again

When it comes to the ward, the ward consultant and the community consultant they don't talk to each other ... And, my last admission, they could have found out a lot of information from a ward that I had been on in the past by just phoning up, because, when you are in the hospital environment, sometimes you are agitated and you do not want to be given so many questions ... But that does not happen

There are lots of guidelines for the CPA and my own experience often now is they're not followed and I've had problems because of that.

10.2 Budget allocation

In the focus groups, participants emphasised that there needed to be adequate funding if the 2008 Care Programme Approach was to work well in promoting their recovery. One point made was that funding may not be ongoing enough because professionals do not have an adequate understanding of recovery from mental health problems

A lot of professionals see that, whether you

have a mental health illness, or a physical disability, you do recover, so there is a start point and an end point for you accessing services and for you receiving treatment ... (But) Most people who have a mental health illness are learning to live with it and maintain a good lifestyle living with an illness, so not many people do recover fully.

One or two African and African Caribbean participants also stressed that adequate funding is vital if there is to be a change in the disproportionate numbers of people from black and minority ethnic communities in the mental health system.

Some focus group members mentioned that it was already difficult to obtain sufficient support, because of budget constraints. They voiced fears, too, about further cuts; they thought that the latter would cause still more problems

They want people to recover and get better and yet they've shut all the services and, to make the books look good, they're discharging everybody and I just think it's so unfair, because you're screaming out for help. There isn't any help

We have an EKTA group monthly (a South Asian mental health support group).*They call us, so we feel joyful that we will get the socialising ... Otherwise, we feel isolated if there are no day centres, no such group as* (the local) *Mind ... When I was so ill, X introduced me to the befriender. I was scared to travel only two bus stops. He was taking me for haircuts, dropping me back ... If the government will cut down this help, you will be isolated and back in the hospital.*

There was also a feeling that budgets might be used wastefully. For example, one participant alluded to the fact that a supported housing project in his area had been refurbished as recently as a year ago and then closed this year.

In both its mental health strategy (Department of Health, 2011a) and its supporting document on the economic case for improving the quality and efficiency of mental health care

(Department of Health, 2011b), the government has underlined the growing cost of mental health services and the need to use money efficiently and well. By definition, resources are finite and, in turn, that will affect the numbers of mental health professionals who can be employed and the availability of particular resources. What seems to be key, therefore, is that mental health professionals who are involved in the 2008 Care Programme Approach put their focus on ways of working that service users find support their recovery.

The government has itself described an increased involvement of service users in decisions about their health and care as a way of reducing costs. This was set out in *Equity and Excellence: Liberating the NHS* (Department of Health, 2010c), now enshrined in the Health and Social Care Act 2012 (HM Government, 2012).

Research participants' feedback about their involvement in recovery services is somewhat mixed however, as has been highlighted in the sections above. Participants drew attention to examples of good practice, but also indicated that, in their experience, there is a considerable way to go as well. Further progress seems important, therefore.

Part Three
Conclusions
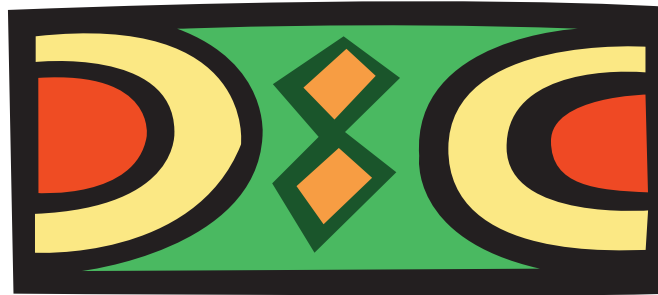
Part Three: Conclusions

Overall, feedback from participants indicates that services provided under the 2008 Care Programme Approach are patchy in the extent to which they promote recovery as participants understand it. In the quantitative sections of the questionnaire, for example, there is evidence of satisfaction with a number of services; ratings that indicate satisfaction 'a lot' of the time fall between 36% and 58%. (See Appendix C, Table 2.) Most such ratings are below 50%, however, and for eight of the points in Table 2, the ratings suggesting that a supportive approach happens 'sometimes' are higher than those indicating that it happens 'a lot'. In addition, in the case of seven points, over a fifth of participants thought that they 'never' happened. It is concerning, too, that ratings from women and from African and African Caribbean participants tended to be still lower.

The findings above are in some contrast to those in recent surveys about patients' views of mental health services collated by the Care Quality Commission (Care Quality Commission, 2011 and 2012). In the 2011 report, 29% of participants rated their overall care as excellent, 30% as very good, 20% as good, 13% as fair, 5% as poor and 4% as very poor. This survey implies a high level of service user satisfaction, therefore. In the 2012 survey, the ratings are very similar, though 1% more of respondents described their care as excellent and 1% fewer described it as fair. Participants in the current research indicated, however, that, although there is some good practice, they think that considerable improvements are still needed.

There are various possible reasons for the contrasting results. The surveys published by the Care Quality Commission are different from the current piece of research in a number of ways. They are England-wide surveys. They include care plan information from people who might, or might not be drawing on the Care Programme Approach, though significant variations between the two groups have been highlighted. There are demographic differences between respondents. Respondents to the 2011 survey were aged 16 and above and as many as 30% of them were aged 66 and above. In addition, 92% of respondents were white. The demography of respondents to the 2012 survey was similar, though this survey did not include anyone who was under 18.

In contrast to the current research, the survey programme carried out by the Care Quality Commission operates at NHS Trust level and so the survey is not also circulated through voluntary agencies and user-led groups. A further significant factor may be the fact that the survey is professionally-led, whereas the current research has been user-led; as was indicated in section three of Part One above, there is evidence that service user researchers may draw out findings that researchers without personal experience of using services do not.

Qualitative responses from participants are similar to those in the quantitative data; participants again drew attention to some good practice, but thought that considerable further progress was needed as well. (See sections one to ten in Part Two above.)

Overall, therefore, the study findings would seem to indicate that, whilst there are some undoubted strengths to the recovery services provided under the 2008 Care Programme Approach, participants had considerable concerns as well. The issues that they raised are in line with the sorts of misgivings from service users that underlay this research study: shortfalls in the extent to which mental health professionals draw on service users' ideas of recovery, take adequate account of service users from marginalised groups, put an emphasis on warm, human qualities, use holistic, rather than purely medical explanations and approaches, avoid an unduly risk-based focus and support a real voice for service users. The disquiet expressed by many participants about the coercive powers of the Mental Health Act 2007 also corresponds to the view of a number of other service users:

that there is a tension between these powers and the respect for service users' human rights and the focus on involvement, influence and control for service users which they think should be at the heart of recovery services. In addition participants mentioned inadequacies in staffing and budgetary resources which they saw as hindrances to their recovery.

Participants' feedback appears, therefore, to demonstrate a need for further change, both organisational and political. There seems further ground to break in terms of organisational cultures and practices. As Repper and Perkins (2003) have indicated, moving to a recovery approach represents a major change for mental health professionals. That is because, with this sort of approach, the focus is no longer on treatments as such, but on the extent to which these enable service users to lead lives that they find meaningful.

How far the recently introduced Implementation Framework for the mental health strategy (HM Government, 2012b) and new legislation such as the Health and Social Act 2012 (HM Government, 2012a) will now help to support such change remains to be seen. Both are very new. In addition, the All Parliamentary Group on Mental Health (2012), for example, has already raised some queries about the effectiveness of the Health and Social Care Act for mental health service users, not least for those from seldom heard groups. Despite the Act's emphasis on mental health and physical health being given equal importance, members of the All Parliamentary Group have, for instance, queried whether the Act will result in increased access to the personalisation agenda for mental health service users and adequate commissioning processes for them.

Similarly, it is very encouraging that the government's newly produced mandate for the NHS Commissioning Board (Department of Health, 2012) makes it a Board objective to ensure that the NHS becomes 'dramatically better' at involving patients as well as carers. What now needs testing, however, is the extent to which the NHS can succeed in making this major cultural shift.

It might also be questioned whether the 2008 Care Programme Approach is a suitable mechanism for recovery-based approaches if these are to be personal to individuals and to rest on service user choices. As Goodwin and Lawton-Smith (2010) have pointed out:

> 'There remains a political and cultural tension in delivering a traditional, government provided mental health service whilst simultaneously championing the role of the individual and their co-ordinator as brokers of how care is delivered and money spent'.

Links between the 2008 Care Programme Approach and the coercive powers of the Mental Health Act 2007 would appear to be adding to the tension highlighted by Goodwin and Lawton-Smith.

How far the changes wanted by participants can and will be achieved, therefore, is the huge challenge for politicians and mental health professionals alike.

Part Four
Recommendations

Part Four: Recommendations

To increase the effectiveness of the 2008 Care Programme Approach in supporting service users with recovery, the following measures are recommended:

4.1 Acknowledge the fact that service users' understandings of recovery are personal and varied and work with service users' personal concepts of recovery

4.2 Recognise that there are few recovery approaches which take account of additional disadvantages that some service users face and take action to address this

4.3 Work with individual service users to find the way(s) of understanding mental distress that prove most useful to them, rather than offering solely medical explanations

4.4 In service provision, allow for the fact that the personal qualities which mental health professionals bring with them are as important to service users as actual services

4.5 Use treatment options to help service users live lives that they find meaningful, rather than as an end in themselves, and make fuller use of holistic approaches that any one service user says assists recovery

4.6 Recognise drawbacks to the employment of standardised recovery tools and be open to using tools that are personal to the service user concerned and suit him/ her best

4.7 Make sure that, when medication is prescribed, there is adequate discussion with service users and that concerns from service users about side effects are fully and adequately acknowledged and addressed

4.8 Tackle any staff discrimination towards people with mental health problems, including the additional discrimination which may be experienced by service users from marginalised groups and communities

4.9 Whilst offering service users protection from risk when they feel in need of it, take on board the fact that quite a few service users find professionals' focus on risk disproportionate. Draw more fully, too, on positive risk-taking

4.10 Be aware that, for a number of service users, tensions between emphases in recovery approaches on choice, citizen rights and control and the use of compulsory powers under the Mental Health Act 2007 remain unresolved and give further consideration to how these might be addressed

4.11 Promote service users' involvement, influence and control through care planning processes, peer support and opportunities for them to be involved at strategic levels

4.12 Make optimum use of resources by:

Taking adequate account of service user views about the deployment of staff, ensuring consistency and reliability of staff also

Focusing in practice on the approaches and interventions that service users say best support them with recovery under the 2008 Care Programme Approach.

Part Five
Checklist of good practice
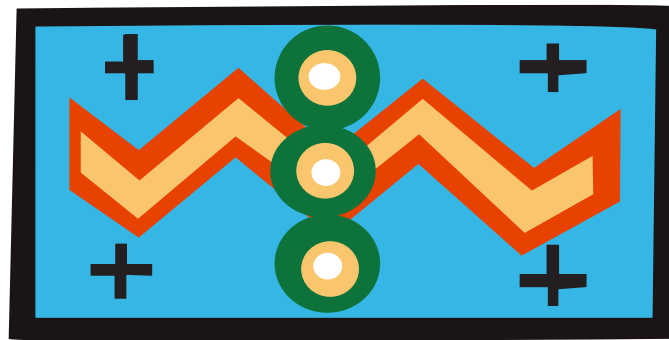
Part Five:
Checklist of good practice

As has been indicated in Part One above, participants were invited not only to share their experiences of recovery under the 2008 Care Programme Approach, but also to contribute points towards a checklist of good practice for mental health professionals, ones that would support services users' recovery under the 2008 Care Programme Approach. The majority of participants made suggestions for the checklist.

They gave especial weight to a sensitive and imaginative approach involving qualities such as empathy, good listening skills, encouragement respect, friendliness, caring, patience, an anti-discriminatory stance and a holistic outlook.

They also described the following as important:

● A good fit between the timing of professional interventions and participants' support needs; they mentioned, for example, the need for increased contact, regularity, punctuality and immediate availability at times of crisis

● Support with everyday life issues such as accommodation, self-care, relationships, activities, form-filling, voluntary work and community support

● Medication management: having the right type of medication, receiving information about side-effects, being helped with medication, having a choice about whether to take it or not and medication reviews

● Care plan processes: regular, focused plans with realistic goals, multi-disciplinary input and a high level of involvement and control by service users.

Data obtained from the quantitative parts of the questionnaire and from other qualitative responses contain points that overlap with the themes above and additional material that is relevant to the checklist. (See sections one to ten in Part Two above.) These responses have therefore been taken into account as well for the checklist of good practice that follows:

The Checklist

Are you:

1. Drawing on service users' personal descriptions of recovery?

2. Taking special account, too, of recovery concepts that service users from particularly disadvantaged groups and communities find meaningful and valid?

3. Helping service users to find the ways of understanding mental distress that make most sense to them, rather than offering medical explanations alone?

4. Putting as much emphasis on the warm, human qualities that service users want from professionals as on skills and knowledge that service users find support their recovery?

5. Recognising in practice that medical treatment is useful only insofar as it assists service users with leading lives that they find meaningful and offering treatment accordingly?

6. Employing the full range of holistic approaches that are important to a particular service user?

7. Allowing for drawbacks that set recovery tools can have and varying tools to meet differing service user wishes?

8. Having adequate discussion with service users when medication is prescribed, acknowledging service users' concerns about distressing side effects and working actively with service users to keep these to a level that service users find acceptable?

9. Tackling any staff discrimination towards people with mental health problems, including the additional discrimination which may be experienced by service users from marginalised groups and communities ?

10. Helping service users to feel safe, whilst avoiding a focus on risk that service users say is counterproductive to recovery?

11. Making active use of positive risk-taking?

12. Addressing the tension highlighted by a number of service users: between the use of compulsion under the Mental Health Act 2007 and the exercise of choice, control and citizen rights that is fundamental to most service users' concepts of recovery?

13. Making sure that service users have involvement, influence and control in relation to their individual care plans?

14. Acknowledging peer support in practice when service users find that this helps to promote their recovery?

15. Providing opportunities for service users to influence the Care Programme Approach at a strategic level?

16. Employing resources as effectively as possible by listening to service users' expertise about useful recovery services, not to professionals alone, and by providing consistent and reliable support?

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Appendix A
Questionnaire documentation
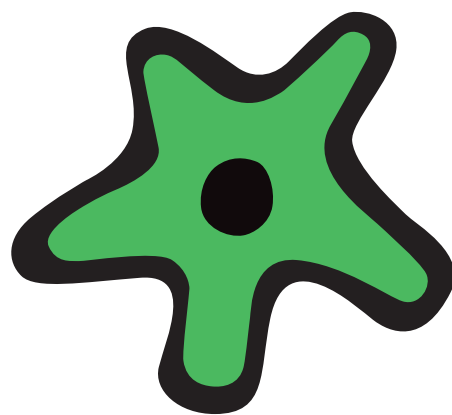
A Study about Service Users' Experiences of Recovery under the 2008 Care Programme Approach

Would you like to contribute your experiences to this?

Recruitment Leaflet for Questionnaires

Version 1.0 – 13/06/11

1

The Mental Health Foundation is carrying out a study about recovery: in partnership with The National Survivor User Network. The study is called: **What part service users find the 2008 Care Programme Approach can play in their recovery.** Would you like to help the research team with this study?

If you have had experience of the Care Programme Approach since October 2008, we would like to know:

- How you see recovery

- What support you want from mental health staff and how far you receive this

- If you have been sectioned, or put on a Community Treatment Order what effect this has had on your recovery

- What recommendations you have about recovering under the Care Programme Approach.

If you are interested, we will ask you to share your views by filling in a questionnaire. This has been put together by research team members with direct experience of using mental health services.

Contributing your views will give you the opportunity to influence future services. As a token of our appreciation, people who complete the questionnaire will also have the chance to enter a prize draw for one of the £10 vouchers that are available.

If you think you would like to give your views in a questionnaire, please read the information sheet with this leaflet. The information sheet provides more details about the study and lets you know how to get in touch with us about it.

We look forward to hearing from you.

The CPA and Recovery Study Team

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mental health foundation

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INFORMATION ABOUT A RESEARCH STUDY IN WHICH YOU ARE INVITED TO TAKE PART
Participant Information Sheet (questionnaires): Version 2.0 - 27/07/2011

Study title: Service users' experiences of recovery under the 2008 Care Programme Approach

We are inviting you to take part in this study, if you would like to do that. To help you decide, we are providing you with details about the study in this information sheet. Please take time to read the information carefully before you make up your mind. Please also feel free to talk with someone else before you make your decision.

What is the study about?
The study will explore what role service users think the 2008 Care Programme Approach can have in promoting recovery as they understand it.

Why is the study happening?
In the 1980s and 1990s, service users came up with their own ideas about recovery from mental health problems. They said that recovery need not mean that you are free from difficulties; what is important is whether you can recreate a sense of yourself and build a meaningful life, regardless of problems. They emphasised the importance of things such as hope, personal choice, control over what happens to you, social networks and the use of a wide range of resources, rather than purely medical ones. Since then, professionals have put an increasing emphasis on recovery-based approaches. A number of service users have expressed concerns about professional approaches to recovery, however; they think that professional definitions of recovery are different from their own definitions. Service users have also questioned whether the revised Care Programme Approach introduced in 2008 does promote recovery as they mean it. For example, they are unhappy that the Care Programme Approach is linked with sectioning and community treatment orders. It seems important therefore to explore further how well service users think the 2008 Care Programme Approach can support them with their own idea of recovery.

Who is responsible for the study?
A research team based at the Mental Health Foundation, a leading UK charity based in south London. As part of its role, the Mental Health Foundation carries out research into issues and helpful resources for people with mental health problems. Dr. Dan Robotham is in charge of the research team. The two research team members are Dorothy Gould, who will lead the day-to-day process, and Sarah Yiannoullou. Dorothy and Sarah are both people

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who have used mental health services themselves. Sarah is also the manager of the National Survivor User Network (NSUN), a national resource for user-led mental health organisations and for individuals with experience of mental distress; NSUN is a partner for the study. The study has has been funded by the London Development Centre/National Mental Health Development Unit.

Why have I been invited to take part in the study?
You have been approached because you have had experience of the Care Programme Approach since October 2008 and so are in a good position to comment on it. The Trust whose services you use is also London-based, which fits the requirements of the funders.

Do I have to take part?
No. It is entirely up to you. The care that you receive will not be affected in any way by your decision. If you do choose to join in the study, you can also withdraw at any point without giving a reason and again without your care being affected at all. We will then destroy any information which we have from you.

What will be involved if I decide to take part?
The first step will be for you to contact the research team, using the details at the end of this information sheet. A research team member will then talk more with you about the research, give you the chance to ask questions and check that the information about the research is clear to you. If you then make a definite decision to take part in the research study, the researcher will send you a consent form to complete and sign. You will also receive a questionnaire to fill in, together with a letter which explains the questionnaire.

The questionnaire will be about your experiences of recovery under the 2008 Care Programme Approach. The questionnaire has two parts. In Part A you will be asked for some brief information about yourself, e.g. your gender, your approximate age and your ethnic origin. That is because people can have different experiences of services, depending on their background, and it is helpful to know how diverse participants are. Part B of the questionnaire has questions about recovery: how you see it, what support you want from mental health staff and whether you receive this from staff involved in your care, what impact sectioning, or a community treatment order has had on your recovery (if you have experienced either of these) and what recommendations you have about recovering under the 2008 Care Programme Approach.

You can answer most of the questions by ticking a box and in a few places, you are asked to write in a response. Everyone is different, but on average we would not expect the questionnaire to take more than 20-30 minutes to complete. If there are any questions that would make you feel uncomfortable to answer, you can just go past these and move on to the next question. You are under no obligation to reply to all the questions if there are some that you would prefer not to answer.

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How long will I have to complete the questionnaire?
You will have up to a fortnight to do that.

Who will see my answers?
All the information that you provide will be treated in strict confidence. Only research team members and their administrative staff will have access to it, unless you mention anything which indicates that you, or someone else is at risk of serious harm, or make a criminal disclosure; in that case we would contact your care co-ordinator, letting you know that we need to do so. Information from you will be stored securely in locked cabinets and computer records that only research team members can access; Dr Dan Robotham, the research team leader, will have responsibility for that. If you take part in the research, we will ask you for contact details, but only so that we can communicate with you about the research. Your answers will also have your name and address removed and replaced with a numerical code, so that you cannot be identified. We will also shred any information from you within six months of the end of the research.

How will my answers be used?
The information that you provide will be included in a report and recommendations about the part that the 2008 Care Programme Approach can play in promoting recovery and in a check list of good practice. These will take about 6 months to produce. Your name and any details that might identify you, or your social networks will be omitted from these documents. We then plan to publish the documents on the Mental Health Foundation, National Survivor User Network and Department of Health websites, with links to other relevant websites, and to circulate them to mental health organisations and to study participants.

What are possible benefits of taking part?
The study will give you a chance to say how effective the 2008 Care Programme Approach has been in helping you to recover and what recommendations you have about it.

What will I receive in return?
You will have the opportunity to be entered into a prize draw. There are five £10 vouchers to be won and you will have a one in twelve chance of receiving one of these. You will be offered a summary of the research findings once the study is complete. The full report will also be available on request.

What are possible disadvantages of taking part?
There are no major disadvantages. The questions will, however, be about your experiences of mental distress and of drawing on mental health services. Because of this, it is possible that a question might bring up a difficult memory for you. We have therefore asked your organisation to name support that can be made available to study participants, if necessary,

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and we will pass this information on to you. If you should become upset, you are completely free, too, to stop answering the questionnaire.

What if I have a complaint about the study?
The researchers will do everything they can to make sure that things go well. If you are not happy, however, please let us know so that every effort can be made to put things right for you and to prevent such errors in the future. You will also be able to talk with Eva Cyhlarova, the Mental Health Foundation's Head of Research (tel: 020 7803 1113), if you want, and she will try to resolve the issue. If a problem is not sorted out within a reasonable amount of time, the issue will automatically be passed on to the Mental Health Foundation's Chief Executive, Dr. Andrew McCulloch, and he will take action about it. If you remain dissatisfied, you should write to the Mental Health Foundation's Trustees. Staff at the Mental Health Foundation will be available to advise and help you through this process.

Who has reviewed the study and made sure that it is of good quality?
The study has been reviewed and checked by Dr Jayasree Kalathil, an experienced service user researcher who holds a PhD, and by a NHS Research Ethics Committee, an independent group of people who are responsible for ensuring that research has been set up safely and well and that participants' interests are safeguarded.

How do I make contact with the researchers if I want to take part in the study?
Either Dorothy Gould, or Sarah Yiannoullou will be available to talk with you, if you are interested in the study. You can phone Dorothy to let her know (on 020 8340 3029) or email her at gould.dorothy@gmail.com. Alternatively, you can contact Sarah Yiannoullou at the National Survivor User Network. Her phone number is 020 7820 8982/ 07778 659390 and her email address is sarah.yiannoullou@nsun.org.uk. Please also feel free to use a supporter to help you make contact if you want.

And thank you for taking the time to consider taking part in this research study

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Study title: Service users' experiences of recovery under the 2008 Care Programme Approach
A questionnaire for service users Version 2.0 - 27/07/2011

Part A: Some information about you

Thank you very much for agreeing to fill in this questionnaire. Please reply to whichever of the following questions about yourself you are comfortable answering. If there are any questions which you would prefer not to answer, please leave them out.

Age (Please tick one box only)
18-25 ☐   26-35 ☐   36-45 ☐   46-55 ☐   56-65 ☐   66-75 ☐   Over 75 ☐

Gender (Please tick the appropriate box.)   Male ☐   Female ☐   Transgender ☐

Ethnicity (Please put a tick one box only. If you tick "other", please write your ethnic background on the line next to the tick box.)

White		Black British	
British	☐	African	☐
Irish	☐	African Caribbean	☐
Other………………………………	☐	Other………………………………	☐

Asian/Asian British		Mixed heritage	
Bangladeshi	☐	White and African	☐
Indian	☐	White and African Caribbean	☐
Pakistani	☐	White and Asian	☐
Other………………………………	☐	Other………………………………	☐

Chinese		Gypsy/Traveller	
Chinese British	☐	Irish traveller	☐
Other Chinese	☐	Gypsy	☐
		Romany	☐

Other ethnic background	
……………………………………………..	☐

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Sexual orientation (Please tick one box only.)

Heterosexual ☐　　　Gay ☐　　　Lesbian ☐　　　Bisexual ☐　　　Other............................☐

Do you consider yourself to have a disability?　　Yes ☐　　　　No ☐

Have you had experience of using the Care Programme Approach since October 2008?

　　　　　　　　　　　　　　　　　　　Yes ☐　　　　No ☐

Thank you very much for replying to this part of the questionnaire. Please now move on to Part B. As before, if there is any question which you would rather not answer, please leave it out.

Part B: Your experiences of the 2008 Care Programme Approach

Section One: What recovery means to you

When you think about recovering, what comes into your mind? (Please put your answer in the space below.)

Section Two: Support from mental health staff who are involved in your care plan

The questions in this section are to find out:
(i) What you like mental health staff to do to support your recovery
(ii) Whether you receive such support from mental health staff involved in your care

In the first column, please indicate whether a point is important to you by circling **"yes"** or **"no".**

When you have circled **"yes"** to a point, please say whether the point happens **"a lot"**, **"never",** or **"sometimes"** by ticking whichever box in the next three columns fits your experience best. When you have circled **"no",** please move on to the next point without ticking a box.

Action from staff	Important to me	Happens a lot	Sometimes happens	Never happens
1. Mental health staff give me hope	Yes / No			
2. They listen to me	Yes / No			
3. They support me with valuing myself	Yes / No			
4. They acknowledge that medical diagnoses are not the only way of explaining my difficulties	Yes / No			

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Action from staff	Important to me	Happens a lot	Sometimes happens	Never happens
5. They support me with developing a new sense of myself	Yes / No			
6. They respect my own knowledge about myself	Yes / No			
7. They show an interest in all the parts of my life that matter to me	Yes / No			
8. In their work with me, they take into account the important part that spirituality has in my life	Yes / No			
9(a). My care plan focuses on the things that I have said help me to recover	Yes / No			
9(b). Mental health staff carry out their parts in my care plan	Yes / No			
10. Medication that I have been prescribed is supporting my recovery	Yes / No			
11. Mental health staff recognise that traditional remedies (remedies from my own community) may also help me	Yes / No			
12 (a) Mental health staff take into account the importance to me of family who stand by me	Yes / No			
12 (b) They take into account the importance to me of friends who stand by me	Yes / No			
13. They take account of the importance to me of support from other service users	Yes / No			

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Action from staff	Important to me	Happens a lot	Sometimes happens	Never happens
14 (a). Mental health staff give me the chance to join a service user group that discusses the Care Programme Approach	Yes / No			
14 (b) This group influences how mental health staff implement the Care Programme Approach with me	Yes/No			
15. Mental health staff support me with playing the part that I want in my community	Yes / No			
16. They support me with rebuilding a life for myself that I find meaningful	Yes / No			
17. The focus on risk in my care plan is balanced and in proportion	Yes / No			
18. Mental health staff help me to be the person who is in control of my life	Yes / No			

19. If there is anything else which you think mental health staff should do to support your recovery, please put it below. Please also indicate whether it happens "a lot", "never", or "sometimes" by ticking the box which fits your experience best:

Support I want from mental health staff	Happens a lot	Sometimes happens	Never happens
(a)			
(b)			
(c)			
(d)			

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20. Have you been sectioned since October 2008?   Yes ☐   No ☐

If yes, please say below what effect this has had on your recovery? If no, please move on to the next question.

21. Have you been put on a community treatment order since October 2008?

Yes ☐   No ☐

If yes, please say below what impact this has had on your recovery? If no, please go on to the last section of the questionnaire.

Section Three: Ideas for a check list of good practice

The research team is planning to put together a check list of good practice for mental health service providers: a list of the best ways to support service users with recovery when the 2008 Care Programme Approach is used. What do you think will be three particularly important things to include in the check list?

1	
2	
3	

Thank you very much for your responses. Please now turn over to the last page.

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If you would also be interested in any of the following, please tick the relevant box:

Coming to a group to talk more about issues raised through this questionnaire: if
a place is available   ☐

Receiving a summary of the report which will be produced   ☐

Receiving the full report   ☐

If you have asked for a copy of the report, please say whether you would like us to send it
to you in the post/by email. (Please circle one.)

**Thank you for this final information. Please now send your completed questionnaire to
Dorothy Gould at PO Box 49677, London N8 8WQ, or electronically. Please send your
consent form at the same time as the questionnaire, because the research team will not
be able to look at your replies without this.**

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Appendix B
Focus group documentation

A Study about Service Users' Experiences of Recovery under the 2008 Care Programme Approach

Would you like to contribute your experiences to this?

Recruitment Leaflet for Focus Groups
Version 1.0 13/06/11

1

The Mental Health Foundation is carrying out a study about recovery: in partnership with the National Survivor User Network. The study is called: **What part service users find the 2008 Care Programme Approach can play in their recovery.** Would you like to help the research team with this study?

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- If you have been sectioned, or put on a Community Treatment Order what effect this has had on your recovery

- What recommendations you have about recovering under the 2008 Care Programme Approach.

If you are interested, we will ask you to share your views by coming to a one-off group to talk about your experiences.

The group leaders will be people with direct experience of using mental health services.

Contributing your views will give you the chance to influence future services. As a token of our appreciation, people who come to a group will also receive £30 worth of vouchers plus expenses.

If you would like to take part in a group, please read the information sheet with this leaflet. The information sheet provides more detail about the study and lets you know how to get in touch with us about it.

We look forward to hearing from you.

The CPA and Recovery Study Team

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INFORMATION ABOUT A RESEARCH STUDY IN WHICH YOU ARE INVITED TO TAKE PART
Participant Information Sheet (focus groups): Version 2.0 - 27/07/2011

Study title: Service users' experiences of recovery under the 2008 Care Programme Approach

We are inviting you to take part in this study, if you would like to do that. To help you decide, we are providing you with details about the study in this information sheet. Please take time to read the information carefully before you make up your mind. Please also feel free to talk with someone else before you make your decision.

What is the study about?
The study will explore what role service users think the 2008 Care Programme Approach can have in promoting recovery as they understand it.

Why is the study happening?
In the 1980s and 1990s, service users came up with their own ideas about recovery from mental health problems. They said that recovery need not mean that you are free from difficulties; what is important is whether you can recreate a sense of yourself and build a meaningful life, regardless of problems. They emphasised the importance of things such as hope, personal choice, control over what happens to you, social networks and the use of a wide range of resources, rather than purely medical ones. Since then, professionals have put an increasing emphasis on recovery-based approaches. A number of service users have expressed concerns about professional approaches to recovery, however; they think that professional definitions of recovery are different from their own definitions. Service users have also questioned whether the revised Care Programme Approach introduced in 2008 does promote recovery as they mean it. For example, they are unhappy that the Care Programme Approach is linked with sectioning and community treatment orders. It seems important therefore to explore further how well service users think the 2008 Care Programme Approach can support them with their own idea of recovery.

Who is responsible for the study?
A research team based at the Mental Health Foundation, a leading UK charity based in south London. As part of its role, the Mental Health Foundation carries out research into issues and helpful resources for people with mental health problems. Dr. Dan Robotham is in charge of the research team. The two research team members are Dorothy Gould, who will lead the day-to-day process, and Sarah Yiannoullou. Dorothy and Sarah are both people

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who have used mental health services themselves. Sarah is also the manager of the National Survivor User Network (NSUN), a national resource for user-led mental health organisations and for individuals with experience of mental distress; NSUN is a partner for the study. The study has been funded by the London Development Centre/National Mental Health Development Unit.

Why have I been invited to take part in the study?

You have been approached because you have had experience of the Care Programme Approach since October 2008 and so are in a good position to comment on it. The Trust whose services you use is also London-based, which fits the requirements of the funders.

Do I have to take part?

No. It is entirely up to you. The care that you receive will not be affected in any way by your decision. If you do choose to join in the study, you can also withdraw at any point without giving a reason and again without your care being affected at all. We will then destroy any information which we have from you.

What will be involved if I decide to take part?

The first step will be for you to contact the research team, using the details at the end of this information sheet. A research team member will then talk more with you about the research, give you the chance to ask questions and check that the information about the research is clear to you. If you then make a definite decision to take part in the research study, the researcher will send you a consent form to complete and sign, together with an invitation to join a discussion group about your experiences of recovery under the 2008 Care Programme Approach.

The group that you are invited to join will consist of approximately eight service users. The group will be led by Dorothy and Sarah, the two research team members mentioned above. We will aim to find a date, time and place that is convenient to you and will let you know what this is nearer the time.

We will start by welcoming you to the group. After that, we will ask you to fill in a brief form with some information about yourself, e.g. your gender, approximate age and ethnic background. That is because people can have different experiences of services, depending on their background, and it is helpful to know how diverse participants are. We will remind you what will happen in the group and then ask you and other group members some questions. The questions will be about: how you see recovery, what support you want from mental health staff and whether you receive this from mental health staff involved in your care, what impact sectioning or a community treatment order has had on your recovery (if you have experienced either of these) and what recommendations you have about recovering under the 2008 Care Programme Approach. The first part of the discussion will

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last for about 45 minutes. After this there will be a break for a meal and then a further 45 minutes' discussion. We will also provide other breaks if necessary.

To make sure that group members' views are remembered accurately, we would like to use a digital recorder backed up by handwritten notes to record what group members say. We will seek your agreement to this through the consent form that we send to you. If we ask any questions that make you feel uncomfortable, you will also be completely free not to answer them.

You are welcome to bring a supporter to the group; s/he will be there to assist you in any way you want, though not to contribute to the group. If any focus group member objects to a supporter being present, the research team will stop the group temporarily, speak to the people involved, assess the situation, and decide the course of action on a case-by-case basis.

Who will see what I say?
All the information that you provide will be treated in strict confidence. Only research team members and their administrative staff will have access to it, unless you mention anything which indicates that you, or someone else is at risk of serious harm, or make a criminal disclosure; in that case we would contact your care co-ordinator, letting you know that we need to do so. Information from you will be stored securely in locked cabinets and computer records that only research team members can access; Dr Dan Robotham, the research team leader, will have responsibility for that. If you take part in the research, we will ask you for contact details, but only so that we can communicate with you about the research. Your answers will also have your name and address removed and replaced with a numerical code, so that you cannot be identified. We will also destroy any recordings, notes and information from you within six months of the end of the research.

In addition, the research team will discuss confidentiality with the group before starting. The group will agree confidentiality rules about what people say. If supporters are present, they will be asked to keep to these rules as well.

How will what I say be used?
Information from you will be included in a report and recommendations about the part that the 2008 Care Programme Approach can play in promoting recovery and in a check list of good practice. Your name and any details that might identify you, or your social networks will be omitted from these documents. We then plan to publish the documents on the Mental Health Foundation, National Survivor User Network and Department of Health websites, with links to other relevant websites, and to circulate them to mental health organisations and to study participants.

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What are possible benefits of taking part?
The study will give you a chance to say how effective the 2008 Care Programme Approach has been in helping you to recover and what recommendations you have about it.

What will I receive in return?
You will receive a £30.00 voucher as a token of our appreciation for your contributions to the group. If you are receiving benefits, the voucher might affect your benefit payments, however. We would advise you therefore to speak to a benefits adviser if you are in any doubt about the effect that accepting this voucher might have. The refreshments and meal provided at the group will be free. We will also refund travel or other expenses which you may incur through attending the group. Receipts for travel and expenses should be produced where available. You will be offered a summary of the research findings once the study is complete. The full report will also be available on request.

What are possible disadvantages of taking part?
There are no major disadvantages. The questions will, however, be about your experiences of mental distress and of drawing on mental health services. Because of this, it is possible that a question might bring up a difficult memory for you. We have therefore asked your organisation to name support that can be made available to study participants, if necessary, and we will pass this information on to you. If you should become upset, you are completely free, too, to withdraw from the group.

What if I have a complaint about the study?
The researchers will do everything they can to make sure that things go well. If you are not happy, however, please let us know so that every effort can be made to put things right for you and to prevent such errors in the future. You will also be able to talk with Eva Cyhlarova, the Mental Health Foundation's Head of Research (tel: 020 7803 1113), if you want, and she will try to resolve the issue. If a problem is not sorted out within a reasonable amount of time, the issue will automatically be passed on to the Mental Health Foundation's Chief Executive, Dr. Andrew McCulloch, and he will take action about it. If you remain dissatisfied, you should write to the Mental Health Foundation's Trustees. Staff at the Mental Health Foundation will be available to advise and help you through this process.

Who has reviewed the study and made sure that it is of good quality?
It has been reviewed and checked by an experienced service user researcher, Dr Jayasree Kalathil, who holds a PhD, and by a NHS Research Ethics Committee, an independent group of people who are responsible for ensuring that research has been set up safely and well and that participants' interests are safeguarded.

How do I make contact with the researchers if I want to take part in the study?
Either Dorothy Gould, or Sarah Yiannoullou will be available to talk with you, if you are interested in the study. You can phone Dorothy to let her know (on 020 8340 3029) or

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email her at gould.dorothy@gmail.com. Alternatively, you can contact Sarah Yiannoullou at the National Survivor User Network. Her phone number is 020 7820 8982/ 07778 659390 and her email address is sarah.yiannoullou@nsun.org.uk. Please also feel free to use a supporter to help you make contact if you want.

And thank you for taking the time to consider taking part in this research study

FOCUS GROUP TOPIC GUIDE

1. Definitions of recovery

(a) To set the scene, can you each say in one word what recovery means to you

(b) How similar do you find your idea of recovery and the ideas that professionals involved in your care plan have about recovery?

Probes

Similarities/differences
The impact of these

2. Medical diagnoses

(a) How much does any psychiatric diagnosis that you have been given make sense to you? (Make it clear that we are not asking people to go into detail about their diagnoses.)

(b) What effect is your diagnosis having on your recovery under the 2008 Care Programme Approach?

Probe

Whether a helpful/unhelpful effect and examples of this

(c) What non-medical ways of explaining your difficulties do/might you like from professionals involved in your care plan

Probes

Reasons
Whether offered any
The extent to which professionals make use of these
How these help participants with recovery

3. Medication

(a) What role is medication having in helping you to recover under the 2008 Care Programme Approach?

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Probe

Whether it is helpful/unhelpful and why

(b) What, if anything, do you/might you find more helpful than medication from professionals involved in your care plan?

Probes

Whether participants are given information about other options
Whether they are offered other options
Whether these are to replace medication/be used alongside it

<div align="center">

Break

</div>

4. Risk

(a) To start the discussion about this, it would be helpful to know which of you is aware of having had had a risk assessment under the 2008 Care Programme Approach (Make it clear that we are just asking for a 'yes', or 'no' here. Explain further what a risk assessment is, if necessary.)

(b) How much focus on risk do you think there should be in your care plan?

Probe

Reasons

(c) How much does the actual focus on risk in your care plan help you to work towards recovery?

Probe

Reasons

5. Compulsion

(a) How aware are you of the compulsory powers of the Mental Health Act, for example, sectioning and community treatment orders? (Ask just for 'yes'/'no' answers. Explain the two powers further if necessary.)

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(b) What effect has compulsory treatment had on your recovery under the 2008 Care Programme Approach/do you think it might have? (Vary the question according to the makeup of the group. Explain that we are asking for further detail because there was varied feedback in answers to the questionnaire.)

Probes

What compulsory treatment participants have/have not experienced
Reasons for thinking it helpful/unhelpful

6. Anti-discrimination

(a) What helpful, or unhelpful experiences have you had from staff involved in your care plan: related to things such as your gender, ethnicity, age, sexual orientation, or to disabilities that you may have?

(b) What effect have these had on your recovery under the 2008 Care Programme Approach?

7. Recovery tools (optional question if time)

(a) What recovery tools, if any, have you used as part of your recovery under the 2008 Care Programme Approach? (Ask just for names of these. Explain recovery tools further if necessary.)

(b) How helpful, or unhelpful have you found a recovery tool in supporting you to recover under this Approach?

Probes

Impact of such tools on the weight given to participants' ideas of recovery, their preferences for the content of recovery plans and the provision of resources that they find helpful.

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Appendix C
Tables of results
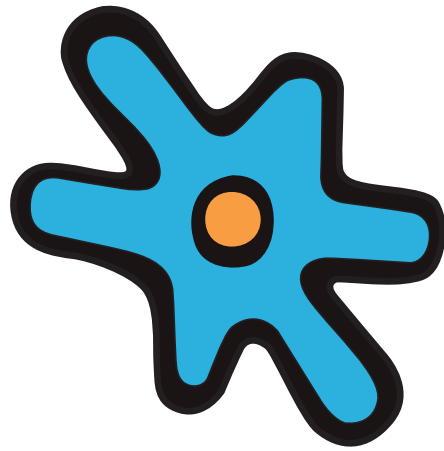
Table 1 What was important to participants

Important to me	Yes %	No %	Reply rate %	Number of replies
1. Mental health staff giving me hope	99	1	97	79
2. Listening to me	97	3	97	79
3. Supporting me with valuing myself	97	3	97	79
4. Acknowledging that mental health diagnoses are not the only way of explaining my difficulties	89	11	97	79
5. Supporting me with developing a new sense of myself	78	22	94	76
6. Respecting my own knowledge about myself	99	1	96	78
7. Showing an interest in all the parts of my life that matter to me	83	17	96	78
8. Taking account of the importance that spirituality has in my life: in their work with me	73	27	96	78
9(a). My care plan focusing on the things that I have said help me to recover	96	4	97	79
9(b). Mental health staff carrying out their parts in my care plan	96	4	97	79
10. Medication that I have been prescribed supporting my recovery	96	4	95	78
11. Mental health staff recognising that traditional remedies (remedies from my own community) may also help me	63	37	93	75
12(a). Mental health staff taking into account the importance to me of family who stand by me	89	11	94	76
12(b). Mental health staff taking into account the importance to me of friends who stand by me	85	15	90	73
13. Mental health staff taking account of the importance to me of support from other service users	82	18	95	77
14(a). Mental health staff giving me the chance to join a service user group that discusses the Care Programme Approach	73	27	96	78
14(b). This group influencing how mental health staff implement the Care Programme Approach with me	74	26	90	73
15. Mental health staff supporting me with playing the part that I want in my community	84	16	95	77

Table 1 What was important to participants

Important to me	Yes %	No %	Reply rate %	Number of replies
16. Supporting me with rebuilding a life for myself that I find meaningful	91	9	97	79
17. The focus on risk in my care plan being balanced and in proportion	87	13	97	79
18. Mental health staff helping me to be the person who is in control of my life	95	5	97	79

Table 2 Ratings from participants overall

These represent ratings from participants who both saw a point as important and said how often it happens.

How often points important to my recovery happen	A lot %	Some times %	Never %	Reply rate %	Number of replies
1. Mental health staff giving me hope	44	49	7	92	72
2. Listening to me	53	41	6	91	70
3. Supporting me with valuing myself	45	47	8	93	72
4. Acknowledging that mental health diagnoses are not the only way of explaining my difficulties	36	41	23	91	64
5. Supporting me with developing a new sense of myself	42	45	13	93	55
6. Respecting my own knowledge about myself	46	43	11	93	72
7. Showing an interest in all the parts of my life that matter to me	48	44	8	95	62
8. Taking account of the importance that spirituality has in my life: in their work with me	38	37	25	91	52
9(a). My care plan focusing on the things that I have said help me to recover	41	47	11	92	70
9(b). Mental health staff carrying out their parts in my care plan	49	44	7	93	71
10. Medication that I have been prescribed supporting my recovery	59	32	9	92	68
11. Mental health staff recognising that traditional remedies (remedies from my own community) may also help me	36	43	21	93	44
12(a). Mental health staff taking into account the importance to me of family who stand by me	51	43	6	96	65
12(b). Mental health staff taking into account the importance to me of friends who stand by me	46	44	10	95	59
13. Mental health staff taking account of the importance to me of support from other service users	42	37	21	90	57
14(a). Mental health staff giving me the chance to join a service user group that discusses the Care Programme Approach	37	33	30	89	51
14(b). This group influencing how mental health staff implement the Care Programme Approach with me	40	43	17	87	47
15. Mental health staff supporting me with playing the part that I want in my community	37	40	23	92	60

Table 2 Ratings from participants overall

These represent ratings from participants who both saw a point as important and said how often it happens.

How often points important to my recovery happen	A lot %	Some times %	Never %	Reply rate %	Number of replies
16. Supporting me with rebuilding a life for myself that I find meaningful	45	39	16	93	67
17. The focus on risk in my care plan being balanced and in proportion	56	29	15	88	61
18. Mental health staff helping me to be the person who is in control of my life	45	38	17	92	69

Notes:

1. The percentages in the fifth column show the proportions of participants who rated the frequency of a point that they had said was important to them

2. Numbers in the final column indicate the numerical equivalent of these. The numbers here also vary according to the numbers of participants who saw a point as important

3. The percentages in this and other tables have been rounded to the nearest whole number. They will, therefore, will not always add up to 100%.

Table 3 A comparison of ratings from female and male participants

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Women	Men	Women	Men	Women	Men	Women	Men
1. Mental health staff give me hope	42	48	48	46	10	6	94 (n=31)	92 (n=35)
2. They listen to me	40	62	53	32	7	6	94 (n=30)	92 (n=34)
3. They support me with valuing myself	34	50	59	38	6	12	97 (n=32)	92 (n=34)
4. They acknowledge that medical diagnoses are not the only way of explaining my difficulties	21	46	54	27	25	27	90 (n=28)	94 (n=30)
5. They support me with developing a new sense of myself	32	44	54	44	14	11	92 (n=22)	93 (n=27)
6.They respect my own knowledge about myself	37	50	47	41	16	9	94 (n=32)	92 (n=34)
7. They show an interest in all the parts of my life that matter to me	49	48	44	42	7	10	96 (n=27)	93 (n=29)
8. In their work with me, they take into account the important part that spirituality has in my life	24	48	43	28	33	24	91 (n=21)	89 (n=25)
9(a). My care plan focuses on the things that I have said help me to recover	28	49	61	37	11	14	93 (n=28)	92 (n=35)
9(b). Mental health staff carry out their parts in my care plan	43	44	53	44	3	12	94 (n=30)	94 (n=34)
10. Medication that I have been prescribed is supporting my recovery	64	55	32	33	4	12	93 (n=28)	89 (n=33)
11. Mental health staff recognise that traditional remedies (remedies from my own community) may also help me	22	44	61	30	17	26	90 (n=18)	88 (n=23)

Table 3 A comparison of ratings from female and male participants

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Women	Men	Women	Men	Women	Men	Women	Men
12 (a). Mental health staff take into account the importance to me of family who stand by me	50	50	46	40	4	10	96 (n=28)	91 (n=30)
12 (b). They take into account the importance to me of friends who stand by me	37	52	48	41	15	7	93 (n=27)	84 (n=27)
13. They take account of the importance to me of support from other service users	33	48	46	26	21	26	92 (n=24)	87 (n=27)
14 (a). Mental health staff give me the chance to join a service user group that discusses the Care Programme Approach	36	33	27	42	36	25	96 (n=22)	86 (n=24)
14 (b). This group influences how mental health staff implement the Care Programme Approach with me	30	45	40	45	30	9	83 (n=20)	76 (n=22)
15. Mental health staff support me with playing the part that I want in my community	25	41	46	38	29	21	89 (n=24)	88 (n=29)
16. They support me with rebuilding a life for myself that I find meaningful	38	45	45	36	17	19	93 (n=29)	89 (n=31)
17. The focus on risk in my care plan is balanced and in proportion	48	62	24	31	28	7	89 (n=25)	85 (n=29)
18. Mental health staff help me to be the person who is in control of my life	41	46	31	42	28	12	93 (n=29)	89 (n=33)

Notes:

1. In this table and in the tables that follow, the numbers in the final columns again vary according to the numbers of participants who said that a point was important to them and gave it a rating as well

2. The percentages in this table and tables 4 - 6 have been rounded to the nearest whole number. They will, therefore, not always add up to 100%.

Table 4 A comparison of ratings from African and African Caribbean participants and participants overall

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	African & African Caribbean	Overall	African & African Caribbean	Overall	African & African Caribbean	Overall	African & African Caribbean	Overall
1. Mental health staff give me hope	43	44	57	49	0	7	93 (n=14)	92 (n=72)
2. They listen to me	36	53	64	41	0	6	93 (n=14)	91 (n=70)
3. They support me with valuing myself	38	45	54	47	8	8	93 (n=13)	93 (n=72)
4. They acknowledge that medical diagnoses are not the only way of explaining my difficulties	31	36	31	41	38	23	93 (n=13)	91 (n=64)
5. They support me with developing a new sense of myself	36	42	43	45	21	13	93 (n=14)	93 (n=55)
6. They respect my own knowledge about myself	36	46	50	43	14	11	93 (n=14)	93 (n=72)
7. They show an interest in all the parts of my life that matter to me	36	48	55	44	9	8	100 (n=11)	95 (n=62)
8. In their work with me, they take into account the important part that spirituality has in my life	25	38	50	37	25	25	100 (n=12)	91 (n=52)
9(a). My care plan focuses on the things that I have said help me to recover	54	41	31	47	15	11	93 (n=13)	92 (n=70)
9(b). Mental health staff carry out their parts in my care plan	50	49	50	44	0	7	100 (n=14)	93 (n=71)
10. Medication that I have been prescribed is supporting my recovery	54	59	38	32	8	9	93 (n=13)	92 (n=68)
11. Mental health staff recognise that traditional remedies (remedies from my own community) may also help me	17	36	50	43	33	21	100 (n=12)	93 (n=44)

Table 4 A comparison of ratings from African and African Caribbean participants and participants overall

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	African & African Caribbean	Overall	African & African Caribbean	Overall	African & African Caribbean	Overall	African & African Caribbean	Overall
12 (a). Mental health staff take into account the importance to me of family who stand by me	27	51	67	43	7	6	100 (n=15)	96 (n=65)
12 (b). They take into account the importance to me of friends who stand by me	36	46	43	44	21	10	93 (n=14)	95 (n=59)
13. They take account of the importance to me of support from other service users	31	42	23	37	46	21	93 (n=13)	90 (n=57)
14 (a). Mental health staff give me the chance to join a service user group that discusses the Care Programme Approach	17	37	50	33	33	30	86 (n=12)	89 (n=51)
14 (b). This group influences how mental health staff implement the Care Programme Approach with me	15	40	54	43	31	17	93 (n=13)	87 (n=47)
15. Mental health staff support me with playing the part that I want in my community	7	37	57	40	36	23	93 (n=14)	92 (n=60)
16. They support me with rebuilding a life for myself that I find meaningful	40	45	40	39	20	16	94 (n=15)	93 (n=67)
17. The focus on risk in my care plan is balanced and in proportion	47	56	33	29	20	15	94 (n=15)	88 (n=61)
18. Mental health staff help me to be the person who is in control of my life	50	45	21	38	29	17	93 (n=14)	92 (n=69)

Table 5 A comparison of ratings from Asian and Asian British participants and participants overall

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Asian & Asian British	Overall	Asian & Asian British	Overall	Asian & Asian British	Overall	Asian & Asian British	Overall
1. Mental health staff give me hope	33	44	60	49	7	7	88 (n=15)	92 (n=72)
2. They listen to me	40	53	40	41	20	6	88 (n=15)	91 (n=70)
3. They support me with valuing myself	33	45	53	47	13	8	88 (n=15)	93 (n=72)
4. They acknowledge that medical diagnoses are not the only way of explaining my difficulties	55	36	27	41	18	23	85 (n=11)	91 (n=64)
5. They support me with developing a new sense of myself	45	42	45	45	9	13	85 (n=11)	93 (n=55)
6.They respect my own knowledge about myself	43	46	43	43	14	11	82 (n=14)	93 (n=72)
7. They show an interest in all the parts of my life that matter to me	42	48	42	44	17	8	86 (n=12)	95 (n=62)
8. In their work with me, they take into account the important part that spirituality has in my life	36	38	50	37	14	25	82 (n=14)	91 (n=52)
9(a). My care plan focuses on the things that I have said help me to recover	36	41	57	47	7	11	87 (n=14)	92 (n=70)
9(b). Mental health staff carry out their parts in my care plan	50	49	37	44	12	7	94 (n=16)	93 (n=71)
10. Medication that I have been prescribed is supporting my recovery	50	59	43	32	7	9	87 (n=14)	92 (n=68)
11. Mental health staff recognise that traditional remedies (remedies from my own community) may also help me	36	36	36	43	27	21	78 (n=11)	93 (n=44)

Table 5 A comparison of ratings from Asian and Asian British participants and participants overall

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Asian & Asian British	Overall	Asian & Asian British	Overall	Asian & Asian British	Overall	Asian & Asian British	Overall
12 (a). Mental health staff take into account the importance to me of family who stand by me	46	51	54	43	0	6	87 (n=13)	96 (n=65)
12 (b). They take into account the importance to me of friends who stand by me	45	46	45	44	9	10	78 (n=11)	95 (n=59)
13. They take account of the importance to me of support from other service users	55	42	36	37	9	21	78 (n=11)	90 (n=57)
14 (a). Mental health staff give me the chance to join a service user group that discusses the Care Programme Approach	50	37	20	33	30	30	77 (n=10)	89 (n=51)
14 (b). This group influences how mental health staff implement the Care Programme Approach with me	56	40	33	43	11	17	69 (n=9)	87 (n=47)
15. Mental health staff support me with playing the part that I want in my community	46	37	27	40	27	23	78 (n=11)	92 (n=60)
16. They support me with rebuilding a life for myself that I find meaningful	42	45	42	39	17	16	80 (n=12)	93 (n=67)
17. The focus on risk in my care plan is balanced and in proportion	60	56	30	29	10	15	77 (n=10)	88 (n=61)
18. Mental health staff help me to be the person who is in control of my life	45	45	45	38	9	17	78 (n=11)	92 (n=69)

Table 6 A comparison of ratings from participants subject and not subject to compulsory treatment since October 2008

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Subject to	Not subject to	Subject to	Not subject to	Subject to	Not subject to	Subject to	Not subject to
1. Mental health staff give me hope	46	44	42	52	12	4	93) (n=26	90 (n=46)
2. They listen to me	50	55	42	41	8	4	93 (n=26)	90 (n=44)
3. They support me with valuing myself	35	50	54	43	11	7	93 (n=26)	92 (n=46)
4. They acknowledge that medical diagnoses are not the only way of explaining my difficulties	32	38	36	44	32	18	86 (n=25)	93 (n=39)
5. They support me with developing a new sense of myself	44	38	39	51	17	11	90 (n=18)	92 (n=37)
6.They respect my own knowledge about myself	38	50	38	46	23	4	93 (n=26)	92 (n=46)
7. They show an interest in all the parts of my life that matter to me	45	50	41	45	14	5	92 (n=22)	95 (n=40)
8. In their work with me, they take into account the important part that spirituality has in my life	37	40	37	36	26	24	90 (n=19)	92 (n=33)
9(a). My care plan focuses on the things that I have said help me to recover	37	44	41	51	22	5	93 (n=27)	91 (n=43)
9(b). Mental health staff carry out their parts in my care plan	37	57	52	39	11	4	93 (n=27)	94 (n=44)
10. Medication that I have been prescribed is supporting my recovery	61	60	21	38	18	2	93 (n=28)	89 (n=42)
11. Mental health staff recognise that traditional remedies (remedies from my own community) may also help me	21	43	43	43	36	13	87 (n=14)	94 (n=30)

Table 6 A comparison of ratings from participants subject and not subject to compulsory treatment since October 2008

How often points important to my recovery happen	A lot %		Some times %		Never %		Reply Rate %	
	Subject to	Not subject to	Subject to	Not subject to	Subject to	Not subject to	Subject to	Not subject to
12 (a). Mental health staff take into account the importance to me of family who stand by me	46	54	46	41	8	5	93 (n=26)	95 (n=39)
12 (b). They take into account the importance to me of friends who stand by me	50	43	45	43	5	14	92 (n=22)	92 (n=37)
13. They take account of the importance to me of support from other service users	47	40	18	45	35	15	81 (n=17)	93 (n=40)
14 (a). Mental health staff give me the chance to join a service user group that discusses the Care Programme Approach	40	35	30	35	30	29	87 (n=20)	91 (n=31)
14 (b). This group influences how mental health staff implement the Care Programme Approach with me	47	36	21	57	32	7	86 (n=19)	87 (n=28)
15. Mental health staff support me with playing the part that I want in my community	33	38	33	44	33	18	87 (n=21)	93 (n=39)
16. They support me with rebuilding a life for myself that I find meaningful	50	42	37	39	12	19	89 (n=24)	91 (n=43)
17. The focus on risk in my care plan is balanced and in proportion	57	56	14	36	29	8	87 (n=21)	87 (n=39)
18. Mental health staff help me to be the person who is in control of my life	46	44	27	44	27	12	90 (n=26)	91 (n=43)

Mental Health Foundation

Colechurch House
1 London Bridge Walk
London SE1 2SX
United Kingdom

Telephone
020 7803 1101

Email
info@mentalhealth.org.uk
Website
www.mentalhealth.org.uk

changing
minds

together we
are stronger

National Survivor User Network

NSUN
27-29 Vauxhall Grove
London. SW8 1SY
United Kingdom

Telephone
020 7820 8982

Email
info@nsun.org.uk

Website
www.nsun.org.uk