DARING TO CHOOSE

10 ways to deliver Choice for people with depression and anxiety

DepressionAlliance

CONTENTS

Foreword	4
Executive Summary	5
Introduction	7
The Burden of Depression and Anxiety	8
Choice	9
Choice and Mental Health	10
Choice for People with Depression and Anxiety	12
Experiences of People with Depression and Anxiety	15
Barriers to Choice	17
The Way Forward	19
Recommendations	20
Conclusion	23
Appendix 1 Contributors to the report	24
Appendix 2 Experiences of people with depression and anxiety: detailed survey findings	25
Appendix 3 Definitions	31
References	33

FOREWORD

Welcome and thank you for taking the time to read 'Daring to Choose'. I would also like to thank the 500 members from Depression Alliance and the Patients Association who completed the questionnaire that formed the basis of this important report.

Depression Alliance is the leading national charity that works specifically with people who experience depression and anxiety in England. We decided to focus our 2009 report on Choice because for over 20 years Depression Alliance has been aware of the enormous impact that meaningful Choice in treatment can have on people, their families, employment, social lives, and friends.

People who experience depression and anxiety will know only too well that recovery is a journey not a destination. Having information in order to make choices on the full range of medical and non-medical interventions such as lifestyle, diet and exercise is essential in being able to maintain recovery.

The Government is currently planning to introduce personal budgets for people with conditions such as depression and anxiety. Furthermore the recently published NHS Constitution sets out 25 legally binding rights for patients, including the "right to make choices about your NHS care and to information to support these choices". However, the successful implementation of personal budgets and the NHS Constitution is reliant on Choice being available.

Through the survey results, we were able to identify a number of barriers that urgently need to be addressed in order to implement the Choice agenda at the national level, in the commissioning process and in front line services. The centrepiece of Daring to Choose is 10 clear recommendations to address these barriers.

We call upon the Government to take note of these 10 recommendations for inclusion in the New Horizons strategy framework. This would improve the range and quality of services for depression and anxiety, fulfil obligations according to the NHS Constitution and bring depression and anxiety services up to speed with NHS reform. By making Choice a reality we can look forward to a personalised health service for people with this debilitating condition.

Emer O'Neill
Chief Executive, Depression Alliance

EXECUTIVE SUMMARY

If you could change one thing about the care you received for depression, what would it be?

“That all doctors take depression seriously.”

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The global burden of depression and anxiety, measured in terms of disability-adjusted life-years, will rank second only to coronary heart disease by the year 2020. In the United Kingdom, nearly 10% of adults suffer from mixed depression and anxiety and a further 4.4% from generalised anxiety disorder. The total cost to the UK economy in the year 2000 was over £9 billion, including NHS costs. As a result of depression 110 million working days were lost and there were 2615 deaths. Depression and anxiety should be an urgent public health priority.

For people with depression and anxiety, Choice is critical to achieving a user-led personalised health service which offers options that are aligned with the complexity of their lives and helps them to become equal partners in their care, leading ultimately to self-care and recovery.

Depression Alliance believes that people have the right to make choices about their lives, including medical treatment and care, and that Choice will also help to prevent stigma and discrimination, and aid social inclusion.

This report identifies key barriers to achieving Choice for people with depression and anxiety: at a national level, in the commissioning process, and in front line services. A survey of over 500 people with depression and anxiety confirms the reality of these barriers and the effects they have, including a lack of information about their condition and the treatments available and inadequate involvement in decisions about their care.

Depression Alliance supports the Improving Access to Psychological Therapies (IAPT) programme but stresses that IAPT should be offered to people with depression and anxiety alongside, not instead of, a wide range of services to enable real Choice for service-users.

Choice will continue to be limited unless the conditions in which Choice can flourish are created. Critical developments include the capacity of services to offer Choice, clear information to enable users to choose between different options and support from professionals and user empowerment.

This report contains 10 recommendations to help overcome these barriers and realise the ambition of equitable Choice for all people with depression and anxiety.

National policy

1 **A specific national public health priority.** Within the spectrum of mental ill-health, depression and anxiety impose the greatest burden and must therefore become a specific national public health priority which is reflected in commissioning at local level. One way to facilitate this would be for the National Institute for Health and Clinical Excellence (NICE) to issue public health guidance for depression and anxiety.

2 **Combat stigma and discrimination.** Current initiatives to combat stigma and discrimination should be extended and strengthened including health promotion activities to encourage people with depression and anxiety to seek help.

3 **Make available a full range of treatment options.** Implementation of NICE guidelines should make available the full range of treatment options for people with depression and anxiety and not be unduly influenced by a single factor (e.g. cost). The recommendations relating to the provision of information should be acted upon as an urgent priority.

Commissioning

4 **Access to a diverse range of services.** Commissioners must ensure that a diverse range of high quality services, including culturally sensitive social treatments and self care, is commissioned at local level. It is worth noting that few primary care trusts choose to have a Locally Enhanced Service for depression and anxiety.

5 **Listening to service users.** Services and care must reflect the needs and preferences of people with depression and anxiety with service users involved directly in the commissioning and quality assurance of services.

6 **High-quality information.** Commissioners should work with Depression Alliance and other stakeholders to develop and provide easily accessible and understandable information.

7 **Empower service users and carers.** Commissioners should work with Depression Alliance to find ways to empower service users and carers through educational programmes for service users.

Front line services

8 **Training in depression and anxiety.** Training in Choice and its place in the management of depression and anxiety, including input from service users, should be a core component of training for all health professionals.

9 **Personalised care.** Services and professionals must develop personalised care for people with depression and anxiety, becoming familiar with and offering the diverse range of commissioned treatment options including alternatives to the medical model of care.

10 **Informing service users.** Individual health and social care professionals should be proactive in offering accessible information about depression and anxiety, services, providers and a wide range of treatment options including social treatments and self care.

INTRODUCTION

What was the worst thing about your experience of treatment for depression?

“Lack of understanding about depression.”

The National Service Framework for mental health (NSF) is coming to the end of its ten year life and is due to be superseded by the 'New Horizons for Mental Health Commissioning' document. The main focus of the NSF was on improving services for people with severe mental illness, with little mention of depression and anxiety.

In this report, Depression Alliance focuses on Choice for people with depression and anxiety. Key barriers to Choice are identified and recommendations made on how the barriers may be removed with the intention of informing the direction and content of the 'New Horizons for Mental Health Commissioning' document.

THE BURDEN OF DEPRESSION AND ANXIETY

For most people who are diagnosed with depression, the spectrum of symptoms they experience is not limited to depression, but much more frequently includes anxiety. In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE) has reported the prevalence of unipolar major depression among 16- to 65-year olds to be 2.1%; the prevalence of mixed depression and anxiety is nearly five times higher at 9.8%; and that of generalised anxiety disorder between these two at 4.4%.[2, 3] Of these, one in five will not recover fully from their first episode, and 70-80% of those achieving remission will suffer at least one recurrence of the illness. In addition to its effect on worsening health, depression is also too frequently a fatal illness, with an estimated 15% of sufferers eventually committing suicide.[4]

Over a decade ago, the World Health Organisation (WHO) projected that the global burden of depression, including depression and anxiety, measured in terms of disability-adjusted life-years, would rank second only to coronary heart disease by the year 2020.[5] In 2007, a major WHO-led epidemiological study of nearly a quarter of a million patients in 60 countries, suggested that depression, with or without anxiety, might have the greatest burden compared with other chronic illnesses including angina, arthritis, asthma and diabetes.[6] The study also showed that depression had the largest effect on worsening health, and people with depression in addition to another chronic illness had the worst health scores of all disease states. Depression and anxiety should be an urgent public health priority.

Depression has rightly been characterised as an illness that "is chronic and recurrent in nature, impairs family life, reduces social adjustment, and is a burden on the community".[7] It blights the relationships and quality of life not only of the individual affected, but also of the people they live with. Depressed people find it difficult to engage in social activities, including family life and work.

Disability and ill-health associated with depression and anxiety limits the activities and productivity of the affected individual, and the long-term recurring nature of the illness magnifies both its societal impact and economic burden. An economic review in 2000 put the total annual cost to the UK economy at over £9 billion, including £370 million for direct NHS costs, 109.7 million working days lost and 2615 deaths.[8] More recently the total loss of output due to depression and chronic anxiety was estimated to be £12 billion a year - 1% of national income, with a cost to the taxpayer of £7 billion.[9]

CHOICE

Choice is the right or ability to choose. Choice is a value. It permeates society, and we make choices about our lives so frequently that often we are not conscious of the value we place on Choice until something occurs to deprive us of it.

In the context of healthcare, it has been proposed that if people have increased choice over the care they receive they will be empowered by this, which in turn will lead to diversification both in the range and providers of services and improve standards through competition. Equitable choice - where everyone is able to select from a wide range of services designed to meet local needs and preferences - will reduce health inequalities and discrimination in health care. In this report, 'Choice' refers to the principle of choice, and 'choice' refers to the action.

Depression Alliance believes that people have the right to make choices about their lives, including medical treatment and care, and that Choice will improve and diversify services, support self-care and recovery and help to prevent discrimination against people with depression and anxiety.

CHOICE AND MENTAL HEALTH

What is the best thing about your treatment for depression?

“That my GP and my psychiatric consultant both listen and show respect for my views and experiences.”

Early policy developments in mental health made no recommendations about Choice. Although the 1999 National Service Framework for mental health stated that one of its guiding principles was that services would “offer choices which promote independence”, after making this statement of principle, the document made no further reference to Choice.[1] It was not until 2004 that Choice became a priority for mental health when *Choosing Health: making healthy choices easier* included mental health as one of six priorities and was informed by a number of principles including informed choice, personalised care to meet individual needs, and effective partnerships.[10]

In 2006, *Our Choices in Mental Health* described a national framework for choice in mental health which was intended to deliver the power for service users to choose their own path through services and keep control over their lives based on their preferences regarding the type, timing and location of the treatments they might receive including a range of care options to choose from, with information about each option and support to make their own decisions.[11] In 2008, the National Institute for Mental Health in England published *Medicines Management: Everybody's Business*.[12] Although this document was concerned only with medicines, it raised expectations that patients would be active partners in decision-making, and that any information that might affect or help them to understand their situation would be shared openly.

Most recently, in his final report of the review of the NHS, Lord Darzi stated that improving mental health care is one of six key goals for the future of the NHS.[13] Meaningful choice is essential if personalised care is to become a reality, and the new NHS Constitution introduces a number of rights related to Choice including:

- The right to be involved in discussions and decisions about healthcare and to be given information about proposed treatments in advance, including any significant risks and any alternative treatments which may be available and the risks involved in doing nothing.
- The right to make choices about NHS care, including the right to accept or refuse the treatment that is offered, and not to be given any treatment unless valid consent has been obtained.[14]

One of seven key principles informing the Constitution is that services must reflect the needs and preferences of people who use the NHS, their families and their carers and that they should be involved in and consulted on all decisions about their care and treatment. Depression Alliance is keen to see these rights put into practice as quickly as possible, as they

are likely to make an important contribution to enhancing care for people with depression and anxiety.

Two extensive reviews relating to Choice in mental health have identified a range of barriers to Choice for people with mental health needs.[15,16] Those that are particularly relevant to Choice relating to depression and anxiety are:

- Inadequate capacity of services to offer Choice including an apparent lack of a range of treatment options and restrictions on local service provision that make choices meaningless;
- Lack of support from health professionals including:
  - reluctance to support service users to make choices that might differ from their own;
  - reluctance to involve carers in decisions about treatment or care and;
  - lack of alternatives to the medical model of care;
- Insufficient information to enable people to make choices;
- Absence of service user empowerment without which Choice cannot become a reality.

Among other recommendations, it has been proposed that because the NHS has not responded well to the demands of users for Choice and services that are more responsive to their needs. Personal Recovery Budgets, adapted from the system of direct payments in social care, should be made available so that people could choose and fund their own programme of treatment and care.

Depression Alliance notes that direct payments may provide the ultimate answer to the lack of Choice, but is of the opinion that such an approach cannot work effectively in the absence of well-informed consumers and professionals. The introduction of Choice advocates may be a more effective means of delivering Choice in the short- to medium-term.

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What was the best thing about your treatment?

“Feeling that someone was paying attention to my comments and taking them on board.”

Over 90% of people with depression and anxiety who seek help from a health professional are seen in primary care. However, the GP may not be able, or even be best placed, to respond to all the needs of people with depression and anxiety. A limited number of them have a special interest in mental health: one study found that three quarters of GPs who took part had more or much more interest in general medicine than in psychiatry.[17] This is reflected in the finding that many patients feel that doctors do not spend enough time with them and that their training in mental health care is inadequate,[16] though short consultation times, which are a consequence of some appointments systems in primary care settings, do limit the time that can be spent with the patient.

It has been reported that having mental health problems may result in a person being deregistered by their GP and then having difficulties in finding a new one.[15] Since GPs are the first point of access to services and care for people with depression and anxiety, it is essential that they are adequately resourced and trained to fulfil this role. As a minimum, they should be able to recognise when people are distressed and make a diagnosis of depression or anxiety and then provide their patients with simple clear information that includes:

- An explanation of depression and anxiety, including the available treatment options, the likelihood of success of treatment, and the likely consequences of failing to treat;

- The psychological therapies that are available;
- The self-help or non-statutory services that are available;
- The antidepressant medicines that are available, with information about common side effects and how likely they are to occur;
- Other treatment options that are available and how they can be accessed;
- How local voluntary organisations can help, and where they can be contacted.

Options for treatment

NICE has recommended a stepped approach for people with depression and anxiety, including psychological therapies for mild to moderate depression and anxiety, anti-depressants for moderate to severe depression and psychological treatment in combination with antidepressant medicines for severe depression.[2] However, access to psychological therapies is often very limited and people are rarely informed that it may be an option or even the recommended treatment.

Depression Alliance strongly supports the Improving Access to Psychological Therapies (IAPT) programme and hopes that this will go a long way to redressing this gap. IAPT is likely to offer a range of opportunities to further develop and improve the services and care available for people with depression and anxiety, particularly in the education of health professionals, fostering a holistic approach that responds to the complexities of individual needs. However, there is a real anxiety that these opportunities will be lost if psychological therapies are offered in place of, rather than in addition to, a wider range of services. Depression Alliance wants to ensure that the IAPT programme integrates psychological therapies with other services and does not replace them.

Depression Alliance does not take a position regarding whether a psychological treatment or antidepressant medication is preferable; the issue is Choice. Service users should be supported to make the treatment choice that best suits them. Many people find antidepressant medication helpful, the problem is that some GPs offer a prescription for an antidepressant without suggesting to or even informing their patients that other alternatives might be available.[15]

Although the NICE Depression Guideline promotes Choice, its recommendations about selection of antidepressants are Choice limiting.

"When an antidepressant is to be prescribed in routine care, it should be a selective serotonin reuptake inhibitor (SSRI)..."

"When prescribing an SSRI, consideration should be given to using a product in a generic form. Fluoxetine and citalopram, for example, would be reasonable choices..."

Although for many patients there may be good reasons why an SSRI should be prescribed, presenting recommendations in this way is likely to have the effect of limiting the choices that GPs may offer or that commissioners would be prepared to fund.

Choice must be based on a flexible mix of treatment and care options that leads to an individually tailored package of care, including non-medical support from local voluntary agencies. Individual care plans will help professionals and service users to achieve this. Treatment options should be offered together with the evidence that supports their use and should include as a minimum the stepped-care approach recommended by NICE. Adequate funding must be available to support this range of care options for every service user. Options for personalised care should include social treatments and self-care.

Social treatments are complementary to formal therapies like antidepressants or psychological therapies. Many people would like to have the option of a social treatment, such as access to help with diet or exercise;

advice about financial problems; relationship counselling; relaxation therapy; mindfulness-related therapies such as meditation, tai-chi and yoga; or local support groups or community services. People with depression and anxiety want their GPs to take a holistic approach to their needs and treatment that avoids the default position of a prescription for an antidepressant medicine. With the deepening financial crisis affecting the UK, the provision of social treatments is likely to become particularly relevant.

Depression Alliance believes that self-care could, and should, be the aim for many, if not most people with depression and anxiety. Cognitive-behavioural therapy teaches people skills that they can continue to put to use long after the formal programme of therapy has been completed, to keep control of their depression and to prevent recurrence. Self-help groups can be supported by mental health workers and educational packages that help service users to develop the knowledge and skills that are needed for successful self-care.

Information

It is impossible to make an informed choice from a range of treatment options without clear information regarding the implications of the choices that might be made.

"(Information)...is fundamental to choice and making informed decisions. Without information there is no choice. Information helps knowledge and understanding. It gives patients the power and confidence to engage as partners with their health service."[19]

However, too often only superficial, if any, information is offered about the alternatives that might be available and what impact the side effects of medication might have.[15]

In order to make choices, all service users need information on the range of options available to them in terms of treatment, services, support from voluntary agencies and other aspects of their lives. This information needs to be clear, appropriate and accessible.

The NICE clinical guideline for depression makes recommendations regarding the information about treatment that should be available.[2] Enough information should be given to enable properly informed consent to treatment and should include:

- Information about the nature and course of depression and anxiety;
- Enough information about a range of treatment options for the user to make an informed decision about which one they would prefer;
- Information about antidepressant medicines, patients and carers should receive information about:
  - The delay in onset of effect; the need for extended periods of treatment; the risk of discontinuation symptoms on stopping or missing doses; common side effects; problems that may occur including anxiety / agitation / restlessness / thoughts of suicide with antidepressants; how antidepressants react with other medicines, food, or alcohol.

There is abundant evidence to support a range of psychological, pharmacological and social treatments for depression and anxiety. However, in the midst of this abundance, the range of services available to most people is limited, and information about services and treatments is difficult to find. This severely constrains the opportunities to achieve good treatment outcomes and recovery.

These issues - the involvement of service users, the extent to which there is a wide enough range of services to tailor personalised care, and the accessibility of information that would enable Choice - could, and should, be taken up by strategic health authorities and local commissioners as quality indicators for service specifications, service development and audit. In addition, user experience should become a routine measure for audit of the services available for people with depression and anxiety. Adopting these measures would act as drivers to achieving the core competencies for World Class Commissioning.

EXPERIENCES OF PEOPLE WITH DEPRESSION AND ANXIETY

If you could change one thing about your treatment, what would it be?

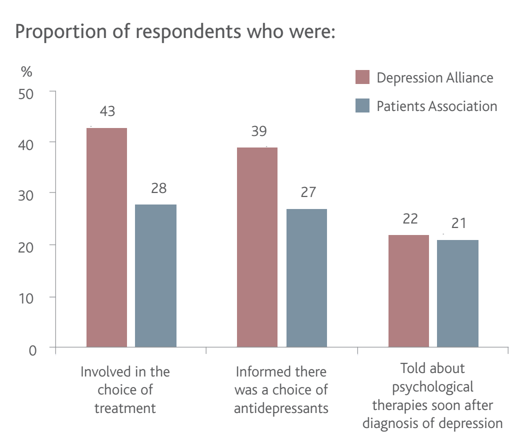
“More information/inclusion in my treatment and explanation of depression; mostly I feel like I’m not even included in any discussions.”

In order to understand the experiences of people with depression and anxiety in respect of Choice, a survey was conducted of members of both Depression Alliance (DA) and the Patients Association (PA) in December 2008. Over 500 people who had been diagnosed with depression or depression and anxiety by their GP responded. This survey confirmed that the more general findings of the Institute for Public Policy Research[15] and Sainsbury Centre[16] reviews concerning barriers to Choice were applicable to people with depression and anxiety.

Involvement in choice

Only a minority of respondents considered that they had been involved in the choice of treatment, including a lack of involvement in choice of antidepressant medication (Figure 1).

FIGURE 1



Information

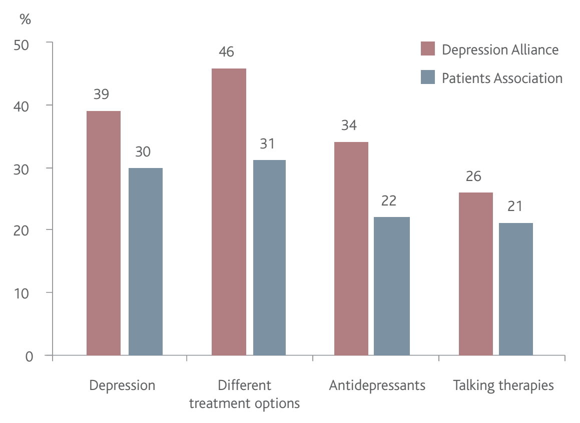
Only a minority of respondents considered that they had been given enough information about depression, the range of treatment options available, antidepressants, including information about common side effects, and psychological therapies (Figure 2). The most common sources of information about depression and anxiety were newspapers, magazines and websites.

Key positive themes that emerged from the verbatim comments of respondents include the beneficial effects of self-help, having a doctor who is sympathetic, who listens and respects the views of their patient, and finding the right treatment - whether an antidepressant medicine or a psychological therapy. In addition, the majority of respondents considered that having someone to help with isolation, being able to talk with a mental health worker and having someone to explain about medication would all be helpful or very helpful.

The full results of the survey can be found in Appendix 2.

FIGURE 2

Proportion of respondents who agreed that they had been given enough information about:



BARRIERS TO CHOICE

If you could change one thing about your treatment, what would it be?

“That the medics look at you as a whole person and not treat depression as an isolated problem.”

This report has focused on Choice for people with depression and anxiety. Many barriers to the realisation of Choice have been identified. This is an important aspect of moving towards Choice: removing barriers, or creating conditions where they can be removed will help the ambition for Choice to be delivered.

Barriers to Choice have been categorised depending on whether action to dismantle them is best taken from a national or public health perspective, by commissioners or at the user/practitioner interface by individual health and social care professionals.

National / Public health

- Depression is not a specific NHS or public health priority. This results in few incentives to improve the quality of care or individual practice.
- Presence of stigma and discrimination. This perpetuates negative attitudes and prevents inclusion.
- NICE Guideline recommendations. Some aspects of the NICE clinical guideline for depression run counter to Choice. Others that would foster Choice have been poorly implemented, if at all.
- The lack of information that would enable Choice for service users and carers.

Commissioning

- Gaps in the capacity of services to enable Choice including restrictions on local service provision that make choices meaningless, including the time available to GPs to give support to people with depression and anxiety, and a lack of diversity of services that would make Choice meaningful.

- Cost often has higher perceived importance than other considerations such as user experience and individual needs and preferences.

- The lack of user involvement in the commissioning process results in the perpetuation of the medical model of care with few, if any, alternatives such as social treatments and self-care.

- The lack of information that would enable Choice for service users and carers. This issue is of crucial importance at both national and local level.

- The lack of a range of treatment options, with the default position of offering treatment with an antidepressant regardless of user needs and preferences.

Frontline Services

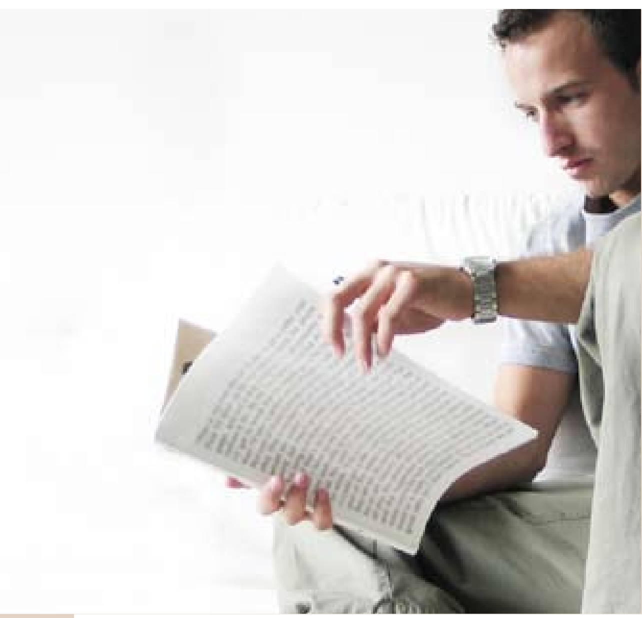
- The reluctance on the part of healthcare professionals to involve users and carers in individual decisions about treatment or care.

- The perception of service users that their concerns and preferences are often not taken seriously and their scepticism that they have genuine choices. Both of these points run counter to the proposition that care is best delivered within a therapeutic partnership.

- Reluctance by many health professionals to support service users to make choices that might differ from their own - thus perpetuating the medical model of care as the only option and preventing the development of a range of other options.

- The lack of information that would enable Choice for and empower service users and carers. This issue is of crucial importance at both national and local level.

- The apparent lack of a range of treatment options including alternatives to the medical model of care.



THE WAY FORWARD

If you could change one thing about your treatment, what would it be?

“To be respected as part of a partnership in my own recovery, that takes time both to listen properly and to supply sufficient information to be part of a team. As service users we develop so much expertise it should not be squandered.”

In trying to find a way forward, Depression Alliance takes a pragmatic approach and makes 10 specific recommendations which are all aligned with current thinking and policy and could be implemented within current financial resources. Our aim is to help health services and professionals to move more surely and quickly towards implementing and delivering Choice for people with depression and anxiety.

If you could change one thing about your treatment, what would it be?

“I would like the stigma of depression to be reduced.”

To move towards person-centred, user-led, individualised care for people with depression and anxiety, following the same categorisation as was used in identifying the barriers to Choice, Depression Alliance makes the following recommendations:

National policy

1 Prioritisation

Mental health is one of six ‘Darzi’ (NHS Next Stage Review Final Report) priorities.[13] Within this spectrum of ill-health, depression and anxiety have the greatest impact and must therefore become a specific national public health priority which is reflected in commissioning at local level. One way to facilitate this process would be for NICE to issue public health guidance for depression and anxiety.

2 Stigma and discrimination

It is essential that current initiatives to combat stigma and discrimination are extended and strengthened. This work should be supported at local level by health promotion activities to combat the stigma that is associated with mental ill health and to inform people with depression and anxiety that it can be treated, and to encourage them to seek help.

3 NICE Guideline recommendations

Implementation of NICE guidelines should make available the full range of treatment options (psychological, pharmacological, social and others) for people with depression and anxiety and not be unduly influenced by a single factor (e.g. cost). The recommendations relating to the provision of information should be implemented as an urgent priority.

If you could change one thing about your treatment, what would it be?

“More information about choices available with regards to medication and therapies and self-help groups etc.”

Commissioning:

Commissioners must invest in the infrastructure to support Choice.

4 A diverse range of services

Commissioners must ensure that a diverse range of high quality services, including culturally sensitive social treatments and self care, are commissioned at a local level in order for Choice to become meaningful. Services must involve working partnerships integrated across a range of agencies and enable sharing of both experiences and resources. Consideration should be given to commissioning voluntary and other agencies to provide support for health professionals in delivering Choice and for service users as part of their tailored package of care. It is worth noting that currently, few primary care trusts choose to have a Locally Enhanced Service for depression and anxiety. Additionally, depression and anxiety should be added to 'choose and book' so that people with these conditions have a right to choose from a range of five accredited providers when referred to specialist treatments in the community. People with chronic depression should be entitled to hold personal health and social care budgets alongside those with less disabling chronic illnesses.

5 Needs and preferences of people with depression and anxiety

Services and care must reflect the needs and preferences of people with depression and anxiety taking into account the complexity of their lives and experiences. Commissioning should be based on evidence of person-centred outcomes that are defined by patients and carers. This requires commissioners to be adequately trained about health, illness and its causes, and commissioning for healthy communities not just for those with poor health. Service users and other stakeholders must be involved directly in the commissioning of services, and their expertise and experience used to help develop personalised and responsive services and to inform quality assurance measures and continuing education for health professionals.

6 Accessible high-quality information

Commissioners should work with Depression Alliance and other stakeholders to develop and provide easily accessible and understandable evidence-based information whenever and wherever it is needed. Information should be available about depression and anxiety and the different treatment options that are available, services that are offered locally, and providers including specialists. This goes beyond mere leaflets: it should include developing the capacity to deliver peer-support interventions, particularly education and information about depression and its treatment for patients and carers. In addition, Choice advocates, who have the training to enable them to provide information on the choices available and help people to navigate their way through services, should be integrated across health and social care services.

What was the worst thing about your experience of treatment for depression?

“Many months of poor information which aggravated the anxiety.”

7 Empowerment of service users and carers

Commissioners should work with Depression Alliance to find ways to empower service users and carers. This could include educational programmes for service users, delivered at local level by other service users who have experienced depression and anxiety but who have recovered.

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If you could change one thing about your treatment, what would it be?

“Much much more support from the G.P. Relating to me as a patient and my needs and being helpful and giving advice and guidance.”

Frontline Services

Services and professionals must deliver personalised care for people with depression.

8 Culture change - training and education

A culture change is needed among health professionals if Choice in mental health is to succeed. Better mental health care depends on the development of collaborative therapeutic partnerships between professionals and service users. For Choice to become a reality, leadership is required in effecting culture change where services and professionals embrace the values of rights and Choice. Health professionals need training in how Choice is a core value in mental health services and how to offer and support Choice including how to provide information on the range of treatment options available. Training should take an integrated approach, be multidisciplinary and be structured to share the knowledge and experiences of both professionals and people with depression and anxiety. Depression Alliance notes the success of the 'Trailblazers' training and leadership programme developed by Professor Tylee at the Institute of Psychiatry and commends this approach.

9 Personalised care

Services and professionals must develop personalised care for people with depression and anxiety, becoming familiar with and offering the diverse range of commissioned treatment options including alternatives to the medical model of care.

10 Proactive provision of information

Individual health professionals should be proactive in offering easily accessible and understandable evidence-based information about depression and anxiety and its management whenever and wherever it is needed. Information should be available about services, providers, specialists, and a wide range of treatment options including social treatments and self care. In addition there is also a role for independent advocates to support Choice. Choice advocates would be based in a number of different settings and would provide information on the choices available and help people to navigate their way through services.

CONCLUSION

What was the best thing about your treatment?

“Becoming involved in a service user group. Everything I have found out has either been from them or through my own research.”

Depression Alliance believes that improving Choice is essential if user-led personalised care for people with depression and anxiety is to become a reality. We have been careful to make sure that our recommendations are practical, achievable, and in line with current health policy. If they are acted upon, they will make an important contribution to improving the care of a condition that has the largest effect on worsening health, and, if combined with chronic physical illness, leads to the worst health scores of all disease states. This is surely important enough to make delivering Choice for people with depression and anxiety a key health priority for the UK.

APPENDIX 1: CONTRIBUTORS TO THE REPORT

Membership of steering group

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Dr Chris Manning	Director UPstream Healthcare Ltd www.upstreamhealthcare.org
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Paul Corry	Director of Public Affairs, Rethink

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APPENDIX 2:
EXPERIENCES OF PEOPLE WITH DEPRESSION AND ANXIETY

In order to understand the experiences of people with depression and anxiety in respect of Choice, in December 2008 a survey was conducted of members of both Depression Alliance (DA) and the Patients Association (PA). A total of 3000 survey questionnaires was sent out: 1000 to DA members, and 2000 (1700 by email, 300 hard copies) to PA members. Of the 249 returned by DA members, 2 had not been seen by a doctor for depression or anxiety, giving a denominator of 247; of the 312 returned by PA members, 46 had not been seen by a doctor for depression or anxiety, giving a denominator of 266, a total of 513.

There were differences between DA and PA members in the responses they gave. The reasons for this are unknown and could be due to random chance or genuine differences between the groups. It is likely that DA members have access to a wider range of resources and information concerning depression and its treatment than PA members, and it may be that this is the main cause of the differences in the responses.

Survey findings

The majority of respondents said they had seen their doctor or been diagnosed with mixed depression and anxiety.

FIGURE 3

Proportion of respondents who agree with the statement
"I have been given enough information about depression":

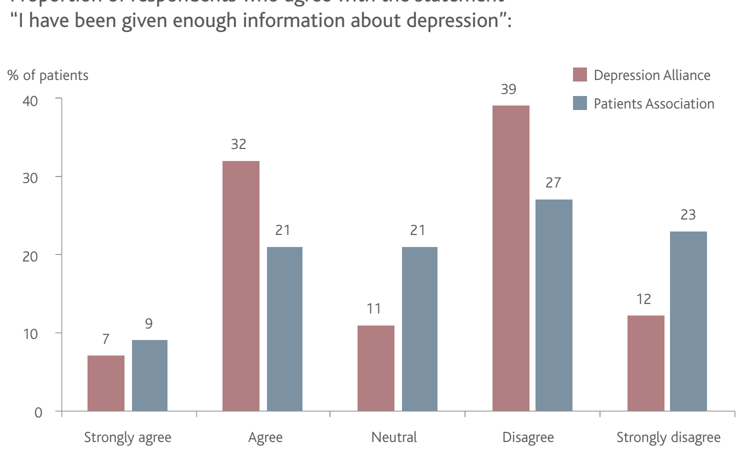
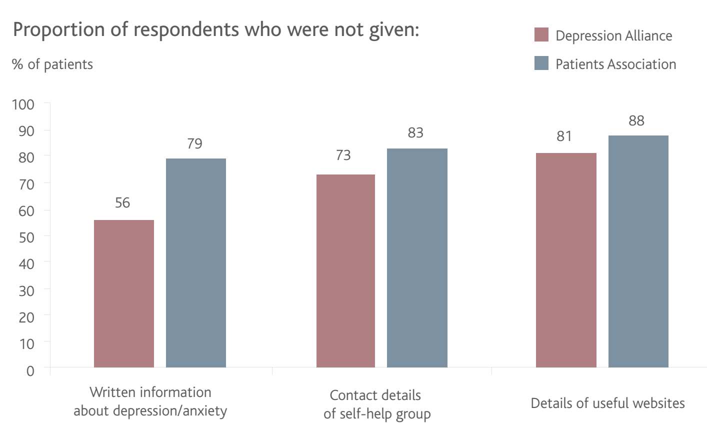


FIGURE 4

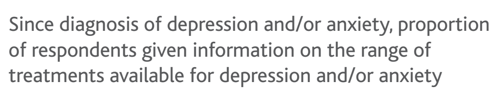


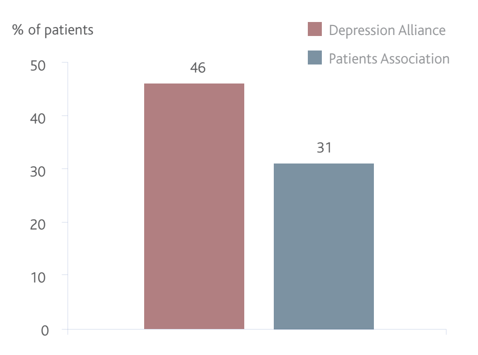
Information about depression and anxiety

Only a minority of respondents agreed that they had been given enough information about depression (Figure 3). The majority stated that they had received no written information about depression and anxiety, or been given details of self-help groups or useful websites (Figure 4).

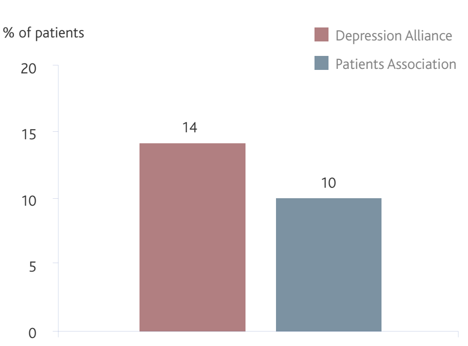
Information about treatments

Similarly, the majority of respondents were not given information about the range of treatment options for depression and anxiety (Figure 5) and only a small proportion had received a copy of a treatment plan (Figure 6).





Proportion of respondents who were given a copy of a treatment plan



Information about antidepressants

The majority of respondents considered they had not been given enough information about antidepressants (Figure 7). Although a majority agreed that they had been told it would take a while before antidepressants started to work and that there were risks involved if antidepressants were stopped too quickly, only a minority agreed that they had been told how long antidepressants needed to be taken for, or been given information about common side effects (Figure 8).

FIGURE 7

Proportion of respondents who agree with the statement
"I have been given enough information about antidepressants":

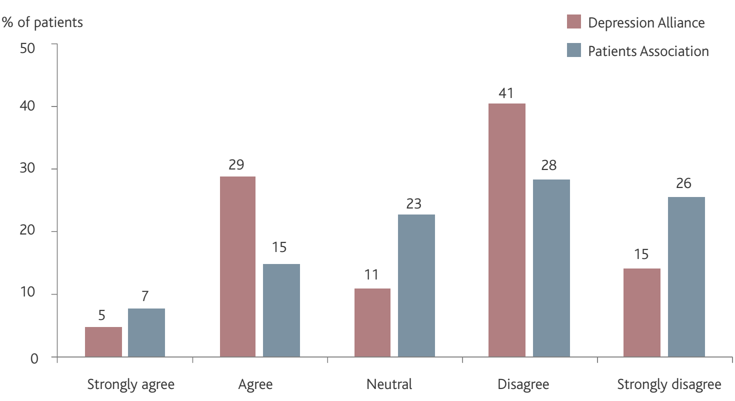
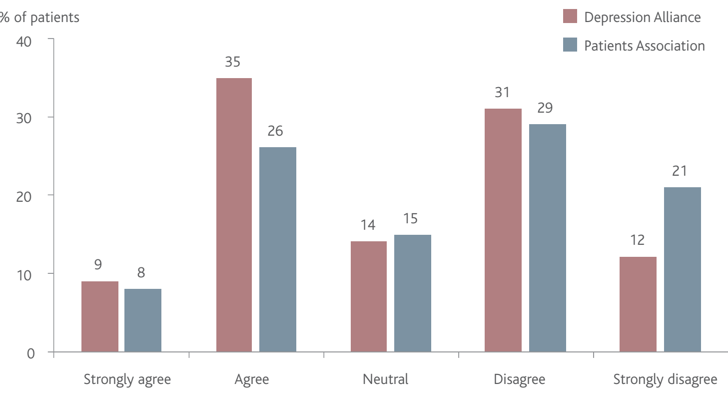


FIGURE 8

Proportion of respondents who agree with the statement
"I was given information about the common side effects of antidepressants":



Information about talking therapies

Nearly two-thirds of respondents considered they had not been given enough information about psychological therapies (Figure 9). Only one in five had been given information about psychological therapies as soon as they had received a diagnosis; most commonly, doctors did not offer such information, or gave it only when specifically asked (Figure 10).

FIGURE 9

Proportion of respondents who agree with the statement
"I have been given enough information about talking therapies":

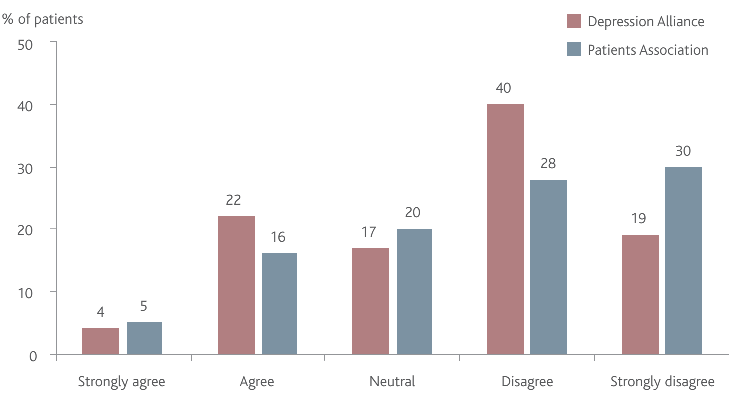
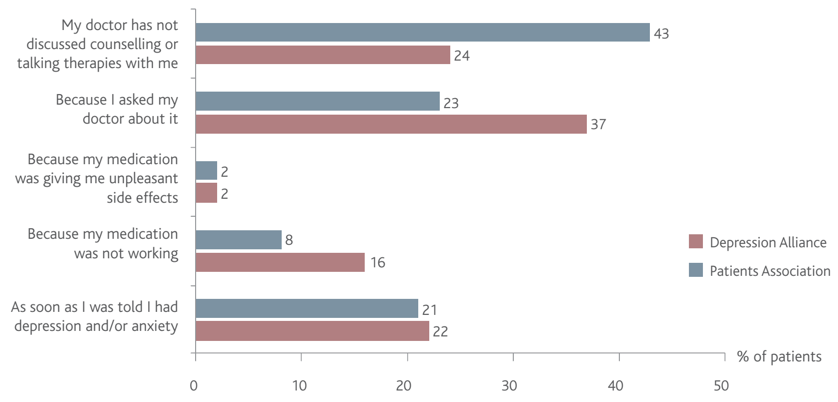


FIGURE 10

Provision of information about counselling or talking therapies



Choice of treatments

Overall, only a minority of respondents considered that their doctor had involved them in the choice of treatment (Figure 11). There are differences in the responses of DA and PA members with respect to information, choice, and referrals to psychological therapies. A higher proportion of PA members did not discuss psychological therapies with their doctors, while more DA members appear to have asked specifically for this information (Figure 10). More DA members than PA members were involved in the choice of their treatment (Figure 11) and a markedly higher proportion of DA than PA members were referred for psychological therapies (Figure 12).

FIGURE 11

Proportion of respondents who agree with the statement
"My doctor involved me in choosing the treatment of my depression and/or anxiety":

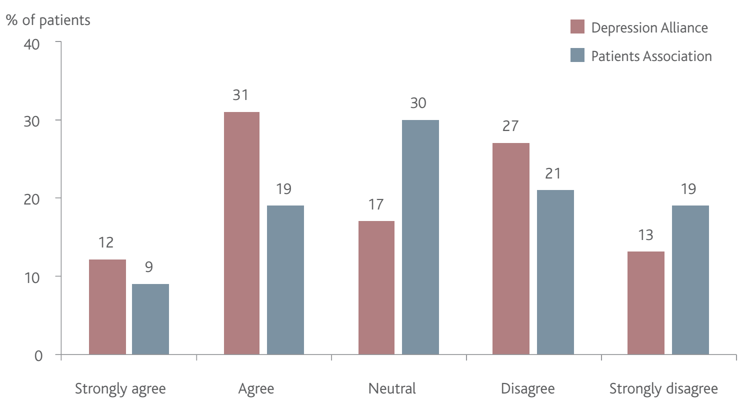
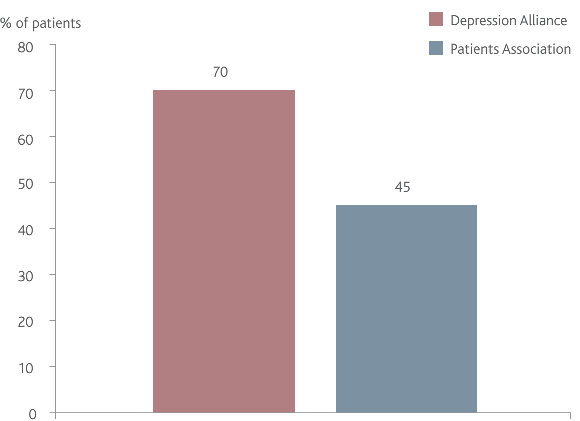


FIGURE 12

Proportion of respondents referred to counselling or talking therapy



Choice of antidepressants

Only a minority of respondents considered that they had been informed that there was a choice of antidepressants that they could have (Figure 13); the most common response concerning how medication was chosen was "my doctor told me which medication to take" (Figure 14).

FIGURE 13

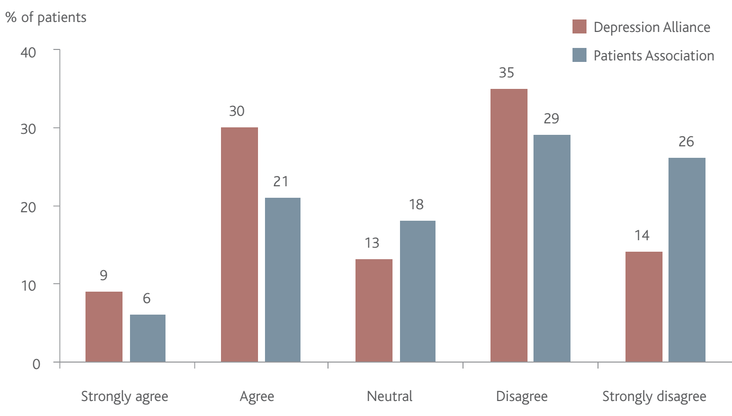
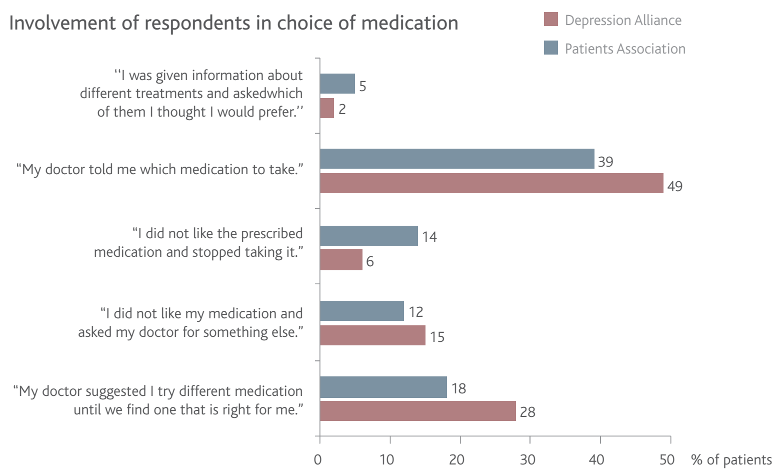


FIGURE 14



Potential social treatments

When asked how helpful a range of potential social treatments to help people with depression and anxiety might be, three were considered helpful by a majority of respondents. These were (in order of how helpful respondents thought they would be):

	Depression Alliance members	Patient Association members
	Helpful / very helpful	Helpful / very helpful
Having someone to help with isolation	78%	73%
Being able to talk with a mental health worker	77%	62%
Having someone to explain about medication	71%	66%

APPENDIX 3: DEFINITIONS

In the context of this report, some key terms are defined as follows:

Ability: Possession of the power, means or skill to do something. In this context it should not be confused with mental capacity.

Choice: The right or ability to choose; the act of choosing; a range from which to choose; something chosen.

Equitable choice: Choice which is fair and impartial and offers a similar range of options across the NHS.

Equitable choice depends on a number of factors including:

- Nation-wide availability of treatments and interventions
- Choice available not only between different treatments and interventions, but within treatment types
- Having accessible information made available proactively
- Transparency and disclosure when equitable Choice is not available locally eg. Through local restrictions or variations in implementation of NICE guidelines.

GP with a special interest in mental health:

A GP who can provide assessment, advice, information and treatment on behalf of primary care colleagues for patients with common mental health problems. In addition, they may have leadership and educational roles disseminating good practice, training, and audit in the identification, prevention and management of common mental health problems, and supporting the development of care pathways across the primary-secondary care interface to improve the delivery of mental health services.

Generalised anxiety disorder

The defining feature of generalised anxiety disorder is excessive anxiety and worry about a number of events or activities which occurs more days than not for a period of at least 6 months. The anxiety and worry must be accompanied by at least three additional symptoms from a list that includes:

- restlessness
- being easily fatigued
- difficulty concentrating
- irritability
- muscle tension
- disturbed sleep

The person affected finds it difficult to control the anxiety and its intensity, duration or frequency is out of proportion to the actual likelihood or impact of the feared event and interferes with attention to tasks being undertaken.

Major Depression

The defining features of major depression are a loss of interest and enjoyment in ordinary things and experiences (anhedonia), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms. Low mood and anhedonia tend to be unreactive to circumstance, and remain low throughout the course of the day.

Behavioural and physical symptoms include:

- Agitation (common)
- Marked anxiety (common)
- Poor sleep (common)
- Tearfulness
- Social withdrawal
- Thoughts of suicide
- Attempts at self-harm or suicide
- Poor appetite (sometimes with marked weight loss)
- Low libido
- Fatigue
- Low activity
- Feelings of guilt, worthlessness and deserved punishment
- Recurrent pessimistic and negative thoughts about oneself, one's past and the future
- Low self-esteem
- Loss of confidence
- Irritability
- Pain
- Feelings of helplessness
- Concentration difficulties and reduced attention
- Mental slowing and rumination

Major depression is generally diagnosed when a persistent and unreactive low mood and anhedonia are accompanied by a range of symptoms taken from the above list.

Patient

The term patient denotes a relationship of care between a health professional and a person with depression and/or anxiety, where the professional has a clear duty of care.

Service user

Many people in mental health prefer this more neutral term to 'patient'. The two terms are not necessarily interchangeable. Service user is a helpful term to describe situations where people with depression and anxiety may be accessing services where a health professional is not involved, particularly in the case of social treatments or other types of service.

REFERENCES

1. **Department of Health**
   National Service Framework for Mental Health: Modern Standards & Service Models
   London: Department of Health, 1999.

2. **National Institute for Health and Clinical Excellence**
   Depression: managing depression in primary and secondary care. Clinical Guideline 23;
   Full Guideline.
   London: British Psychological Society & The Royal College of Psychiatrists, 2004.

3. **McIntosh A, Cohen A, Turnbull N, et al**
   Clinical Guidelines and Evidence Review for Panic Disorder and Generalised Anxiety Disorder
   Sheffield: University of Sheffield/London: National Collaborating Centre for Primary Care, 2004.

4. **Scott J**
   Depression should be managed like a chronic disease.
   British Medical Journal 2006;332:985-986

5. **Murray CJL, Lopez AD**
   Alternate projections of mortality and disability by cause 1990-2020: global burden of disease study. Lancet 1997;349:1498-1504

6. **Moussavi S, Chatterji S, Verdes E, et al**
   Depression, chronic diseases, and decrements in health: results from the World Health Surveys.
   Lancet 2007;370:851-858

7. **Klerman GL, Weissman MM**
   The course, morbidity, and costs of depression.
   Archives of General Psychiatry 1992;49:831-34

8. **Thomas C, Morris S**
   Cost of depression among adults in England in 2000.
   British Journal of Psychiatry 2003;183:514-519.

9. **London School of Economics Centre for Economic Performance's Mental Health Policy Group**
   The depression report: A new deal for depression and anxiety disorders
   London: The London School of Economics and Political Science, 2006

10. **Department of Health**
Choosing health: making healthy choices easier.
London: Department of Health, 2004.

11. **Care Services Improvement Partnership.**
Our choices in mental health: A framework for improving choice for people who use mental health services and their carers.
London: Care Services Improvement Partnership, 2006.

12. **NIMHE National Workforce Programme**
Medicines Management: Everybody's Business.
London: Department of Health, 2008.

13. **Department of Health**
High Quality Care For All: NHS Next Stage Review Final Report.
London: Department of Health, 2008.

14. **Department of Health**
The NHS Constitution for England.
London: Department of Health, January 2009

15. **Rankin, J**
A good choice for mental health: mental health in the mainstream; Working paper 3.
London: Institute for Public Policy Research, 2005.

16. **Warner, L., Mariathasan, J., Lawton-Smith, S. & Samele, C**
Choice Literature Review.
London: The Sainsbury Centre for Mental Health and King's Fund, 2006.
(Available from www.scmh.org.uk and www.kingsfund.org.uk)

17. **Boardman J, Henshaw C, Willmott S**
Needs for mental health treatment among GP attendees
British Journal of Psychiatry 2004; 185: 318-327

18. **National Institute for Health and Clinical Excellence.**
Depression: management of depression in primary and secondary care
Clinical Guideline 23 (Amended).
London. National Institute for Health and Clinical Excellence, 2007.

19. **Department of Health**
Better Information, Better Choices, Better Health: Putting information at the centre of health.
London: Department of Health, 2004.

SIGNATORIES

The following organisations support the recommendations in this report to deliver Choice for people with depression and anxiety:

DepressionAlliance