

NAS  
NATIONAL AUDIT OF  
SCHIZOPHRENIA



# Report of the National Audit of Schizophrenia (NAS) 2012



Commissioned by





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# Foreword

The National Audit of Schizophrenia is the first attempt to develop a comprehensive picture of the quality of care that people with this condition receive throughout England and Wales. The audit shows that there are some areas where quality of care is currently good and others where improvements need to be made. While many service users and carers have a positive experience of the care they receive, an important minority of people are not receiving optimal treatment. The assessment of physical health of people with schizophrenia is often well below recommended standards of care.

Over the last 30 years the development of community services and new psychological treatments and medications for people with schizophrenia has helped to improve the quality of care that they receive. However, concerns have rightly been expressed about the poor physical health of people with psychosis which leads to a reduction in life expectancy of almost 20 years. Findings from this audit, showing that many people with schizophrenia are not getting the assessments they need to detect and treat physical health problems, are therefore of deep concern.

Improving the assessment and treatment of physical health problems among people with schizophrenia requires high quality multidisciplinary working and clear communications between different services. Key amongst these are the relationships between primary and secondary care services. While there are many examples of good practice in this area, results from this audit suggest that more work needs to be done to improve communication between clinical teams if these basic requirements for keeping people well are to be delivered.

The audit also shows that some patients are receiving more than one antipsychotic drug at a time, something for which there is no clear evidence of benefit except in the minority of situations. Others, whose health does not improve when they are offered standard treatment, do not appear to have been offered psychological and pharmacological treatments that could help them.

Further attention needs to be paid to the needs of people who do not respond to the treatment they are initially offered, if the health and quality of life of all people with schizophrenia is to be improved.

The findings of this report would not have been possible without the commitment of clinicians and support staff throughout the 60 NHS Trusts and Health Boards that participated and the service users and carers who took time to respond to the survey.

We believe that the audit has helped to highlight areas of concern in the treatment of people with schizophrenia, and has encouraged healthcare providers to work together to reflect on their local audit reports and plan steps to improve findings of the audit when this is repeated in 2013.



**Professor Sue Bailey**

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Royal College of Psychiatrists



**Dr Clare Gerada**

Chair

Royal College of General Practitioners

# Acknowledgements

## **Development of standards and recommendations**

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We would like to thank the members of our Advisory Group and the staff at Mental Health Trusts/Health Boards, including medical directors and governance and audit personnel, for their support and advice and their contribution to the development of the audit standards and recommendations.

A list of members of the Advisory Group, together with the organisations they represent, can be found in Appendix B.

## **The NAS pilot**

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Thank you to the six Trusts who participated in the National Audit of Schizophrenia (NAS) pilot that preceded the main audit. Their feedback was of considerable help to us in refining the audit methods. A list of pilot Trusts can be found in Appendix A.

## **Service user and carer questionnaires**

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Thanks to the contributors to the service user focus and reference groups for their ideas and views on how to engage service users with this audit and for helping us develop the service user and carer questionnaires.

Many thanks to Rethink Mental Illness for their work to help us engage service users by contributing to the presentation of the service user and carer questionnaires, for providing supporting materials for service users, carers and local audit staff and for their telephone helpline during the active phase of the audit. We would also like to thank them for their work on the 'What you need to know' report.

## Data cleaning and analysis

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Many thanks to Roman Adroer and Sumera Bhatti from the POMH-UK project team for lending their assistance and expertise in the data cleaning and analysis of the NAS data set. Thanks also to Paul Bassett for his help and expertise in relation to the power analysis.

## Support and input

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We would like to express our special thanks to Dr Paul Lelliott, former Lead Auditor of NAS, and Rachel Marsh, Amber Shingleton-Smith and Izaba Younis, former members of the NAS team, for their contributions. Thanks also to the Healthcare Quality Improvement Partnership (HQIP) for their support and encouragement throughout.

A special thanks goes to Professor Thomas Barnes and Carol Paton of POMH-UK for their considerable contribution to the audit, particularly with the original audit bid.

NAS would like to thank all participating Trusts and Health Boards for their hard work and engagement in submitting data for this important baseline audit.

## Guidance on reading this document

- The term 'Trust' has been used to refer to both English NHS Trusts and Welsh Health Boards throughout this report.
- Many figures in the text and in data tables are rounded to the nearest integer, without decimal places, for clarity of presentation. Thus, the total percentages for some tables or graphs may add up to 99% or 101%.
- A glossary of terms is available from page 150.

# Executive summary

## Background

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This report presents the findings of the first National Audit of Schizophrenia (NAS), one of only three audits in the National Programme on Mental Health (<http://www.hqip.org.uk/national-clinical-audit-and-patient-outcomes-programme>). Approximately 220,000 people in England and Wales have a diagnosis of schizophrenia. It is an illness which commonly severely restricts an individual's life, varies considerably in outcome between individuals and is associated with premature mortality. In 2007 it accounted for approximately 30% of the total expenditure on adult mental health and social care services.

A national guideline exists for the treatment and management of those suffering from schizophrenia: the 'NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults' (NICE CG82, 2009) – throughout the remainder of this report this guideline will be referred to simply as the NICE Guideline (2009). The aim of this audit was to examine how far this guideline is being implemented and to stimulate improvements in the care and treatment of adults in the community with a diagnosis of schizophrenia.

The following quotation from one of the members of the independent Schizophrenia Commission in their report 'The Abandoned Illness' (Schizophrenia Commission, 2012) perhaps provides the strongest reason for initiating a process of national audit and quality improvement:

*"More is known in how to care and treat schizophrenia but it is not always applied. I want better from the mental health system for everyone."*

Yvonne Stewart-Williams



## Aims

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The key aims of the audit were to measure:

- Service users' experience of care and treatment and outcomes.
- Carers' satisfaction with the support and information they have received.
- Practice in the prescribing of antipsychotic medications.
- The use of psychological therapies.
- The quality of physical health monitoring and interventions offered.

## Standards and outcome indicators

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The standards set for this audit are based on the NICE Guideline (2009). Thus, the audit particularly focuses on the satisfaction of service users and carers with the services offered to them, prescribing practice, psychological interventions offered and the quality of monitoring of physical health for these service users.

## Method

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Of the 64 NHS Mental Health Trusts in England and Wales identified by the NAS team as eligible to participate at the time of data collection, 60 (94%) submitted data. Each Trust was asked to submit data on a representative sample of 100 adults under their care with diagnoses of either schizophrenia or schizoaffective disorder and who had been under the care of specialist mental health teams in the community for at least twelve months. A more detailed description of the methods and the development of the audit tools can be found in the methodology section (page 31).

It was clearly challenging for Trusts to establish a reasonably comprehensive list of those people under their care with a diagnosis of schizophrenia. However, Trust clinicians and audit departments worked hard to collect the relevant information from their own organisations and often also from primary care. This means that the audit of practice forms were completed in a comprehensive manner. Trusts also distributed the relevant service user survey forms to service users who, in turn, distributed the relevant surveys to the individual they considered to be their closest carer.

## **Key national findings**

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Many aspects of the treatment and care provided were positive. The survey of the views of service users indicated a good level of satisfaction with services, but it was clear that there are differences between the information that Trust staff think they have given to service users and the service users' perception of the understandability of that information. Although response rates from carers were rather low in number, their views generally mirrored those of service users.

Prescribing practice was very good in many Trusts. However, for some aspects of prescribing, for example polypharmacy, there continues to be a significant degree of variation between Trusts, beyond that which might be related to differences in the geographical distribution of people with a diagnosis of schizophrenia, such as between urban and rural populations. Clozapine is being widely used for those whose illness is most resistant to treatment. However, evidence emerged that a significant number of service users with treatment resistant illness remain for whom a trial of clozapine has not yet been considered. The availability of psychological therapies for those with schizophrenia is very variable.

The most serious deficits to emerge were in the monitoring and management of physical health problems. Those with schizophrenia have increased risks of premature death from coronary heart disease. Monitoring of cardiometabolic risk factors for this, particularly weight gain, is extremely poor. It is clear that a major initiative is required to address this issue. Improved protocols between primary and secondary care with regard to *'who does what and when'* are urgently needed, as well as an agreed set of parameters for the basic physical health measures to be assessed.

The following numbered points outline specific key findings by each major aspect of the audit:

### **1. Service user and carer views**

The audit showed that service users were generally satisfied with the experience and outcomes of their care. The average rating of satisfaction across Trusts was

76%, using a variety of measures in the service user survey. Overall 49% of carers reported being very satisfied with the support and information they received.

## **2. Involvement in choice of medication**

Many service users felt they were not provided with information about their medication in an adequately understandable form. Only 62% reported that the information was in a form they could properly understand. Further, they did not always feel sufficiently involved in the final decision about which medication they should take. While clinical staff reported that they thought they had involved service users in the choice of medication in 62% of cases, only 41% of service users felt their views were taken into account.

## **3. Prescribing**

Appropriate treatment guidelines are being followed for the majority of service users. An appropriate percentage of the most severely ill patients are receiving clozapine. However, 20% of the total population surveyed in the audit had not demonstrated an adequate response to treatment received, and would be regarded as treatment resistant. For some of these service users there were appropriate reasons for not being offered a trial of clozapine. However, 43% of the treatment resistant group had not been offered clozapine and had no documented reason for this.

The use of more than one antipsychotic drug at a time for treatment is not recommended, except in exceptional situations. While practice in this respect is good in many Trusts, overall 16% of service users were receiving more than one antipsychotic drug at a time. There were some Trusts where this was occurring in up to 30% of service users. This issue will need to be addressed. Some service users (5%) were also being prescribed medication in higher doses than is recommended in the British National Formulary (BNF), without clear documentation of the reasons.

#### 4. Psychological treatments

There was wide variation in the availability of psychological treatments between different Trusts. Across England and Wales 34% of service users who were not in remission had not been offered any form of psychological therapy.

#### 5. Physical health

People with schizophrenia have increased risks for development of physical health problems, particularly heart disease and diabetes. However, only 29% of this population received a fully comprehensive assessment of important cardiometabolic risk factors. In particular, only 56% of service users were reported to have been weighed during the previous 12 months.

For those service users with evidence of physical health problems, for example high blood pressure and high cholesterol levels, there is frequently no evidence that they have had further appropriate investigation or treatment for these problems. At even a simple level, for those with elevated BMI there was only evidence of advice being given about diet and exercise in 76% of cases.

This report makes a series of recommendations to help address the problems identified. A summary of these is below. **The full set of NAS recommendations are listed individually for key individuals and organisations and can be found on page 115.** Everyone should read this list to view the recommendations that apply specifically to their area of responsibility.

## Summary of Recommendations

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### **Experiences of people using services and experiences of carers**

- Mental Health Trusts should involve local people who use services and carers in developing a local action plan for improving care and support offered.

- For the next audit the minimum requirements for experiences and outcomes should be raised so that services continue improving.

### **Shared decision making**

- Health professionals should review the written information they provide to people affected by schizophrenia, and their carers, about medication and check that it is clear and easy to understand.
- Professionals who prescribe medication should have the appropriate skills to involve service users in decisions about medication. This should include the ability to talk about the benefits and risks associated with treatment.

### **Prescribing standards**

- Psychiatrists must recognise that antipsychotic polypharmacy is only rarely appropriate and if used requires clear documentation of the reasons.
- Psychiatrists should be aware of the upper dose limits for prescribing antipsychotic medication. If they prescribe above this level they should have a clear and documented reason for doing so.
- Trusts should make sure that health professionals understand the guidelines for the prescribing of antipsychotic medications and guidelines for prescribing outside the usual licensed indications.
- Trained clinical pharmacists should be available to offer advice on prescribing to other professionals.

### **Psychological therapies**

- Providers and commissioners of mental health services must ensure that there is good access to psychological therapies for people with schizophrenia, particularly cognitive behavioural therapy, family therapy and other evidence-based treatments.

- Trusts should identify and address the barriers they face in offering and delivering these therapies.

### **Management of physical health issues**

- All health professionals working with people affected by schizophrenia should have training on common physical health problems experienced by this group. This includes how to assess physical health and identify any problems, and knowledge of interventions for treating these problems.
- Mental health services should have access to the correct equipment to monitor a person's physical health. If treatment is needed for physical health problems, staff in mental health services should help to ensure that people receive this.
- Mental health services and primary care services need to work together to agree who will monitor and treat physical health problems among people with schizophrenia.

### **Conclusions**

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The results of this audit highlight good practice but they also point to a need for greater improvement. The audit results provide a benchmark against which services can compare themselves. In April 2012 each participating Trust received a report describing their own individual data in the context of the national findings. This was for the purpose of benchmarking and to provide an opportunity to begin a process of improvement. The full list of recommendations is provided on page 115. We hope that this will help clinical staff, managers and commissioners to plan and instigate improvements in the care of people with a diagnosis of schizophrenia. There are also important messages for the relevant professional bodies in relation to education. In particular, it is clear that the government and commissioners need to set a clear framework for the monitoring of physical health in service users with a diagnosis of schizophrenia.

# Table of contents

<b>This report has been compiled by</b> .....	3
<b>Foreword</b> .....	4
<b>Acknowledgements</b> .....	6
Development of standards and recommendations .....	6
The NAS pilot .....	6
Service user and carer questionnaires .....	6
Data cleaning and analysis .....	7
Support and input .....	7
Guideline on reading this document.....	7
<b>Executive summary</b> .....	8
Background.....	8
Aims .....	9
Standards and outcome indicators .....	9
Method .....	9
Key national findings .....	10
Summary of Recommendations .....	12
Conclusions .....	14
<b>Table of contents</b> .....	15
<b>List of figures</b> .....	18
<b>List of Tables</b> .....	21
<b>Introduction</b> .....	23
Clinical background .....	23
Primary care perspective .....	27
Service user perspective .....	28
Carer perspective.....	30
<b>Methodology</b> .....	31
Audit development .....	31
Standards and outcome indicators .....	31
Development of the audit tools .....	32
Identification of the case sample .....	35
Participating Trusts.....	36
Pilot audit .....	37
Main audit.....	37
Limitations of the methodology and data .....	40

<b>Demography of the audit population</b> .....	45
Demography of the case note audit sample (n=5,091) .....	45
Clinical parameters for the case note audit sample.....	49
Demography of the sample of carers.....	50
Layout of the audit data sections.....	52
<b>Experience of service users and carers</b> .....	53
Service user experiences .....	53
Standard 1 .....	53
Standard 2 .....	55
Carer experiences .....	57
Standard 3 .....	57
<b>Shared decision making about medication</b> .....	64
Standard 6 .....	64
Standard 7 .....	65
<b>Prescribing</b> .....	69
Adequacy of the current treatment regimen the service user is receiving.....	69
Standard 8 .....	70
Standard 9 .....	72
Standard 10 .....	75
Identification of treatment resistant service users and prescription of clozapine .....	76
Standard 12 .....	77
Management of service users who have treatment resistance .....	79
Standard 11 .....	80
Standard 13 .....	82
<b>Psychological therapies</b> .....	84
Standard 14 .....	84
<b>Physical health: monitoring and intervention</b> .....	87
Monitoring of physical health .....	87
Standard 4 .....	87
Intervention to address physical health issues .....	102
Standard 5 .....	102
<b>Discussion</b> .....	105
<b>Conclusions</b> .....	112
<b>Recommendations</b> .....	115
Resources .....	123
<b>Feedback and dissemination</b> .....	124
Feedback from participating Trusts .....	124



Dissemination of preliminary findings .....	124
Learning points .....	126
<b>Future of NAS</b> .....	127
Key dates in 2013 - 2014 .....	127
<b>References</b> .....	128
<b>Appendix A: Participating Trusts/ Health Boards</b> .....	133
<b>Appendix B: NAS Advisory Group</b> .....	138
<b>Appendix C: Footnotes to NAS standards</b> .....	139
<b>Appendix D: Audit lead packs and sampling options</b> .....	140
<b>Appendix E: NAS process flowchart</b> .....	142
<b>Appendix F: Service user responses from service user survey</b> .....	143
<b>Appendix G: The Positive Cardiometabolic Health resource</b> .....	148
<b>Glossary</b> .....	150

## List of figures

Figure 1: Timetable of development and management .....	31
Figure 2: Service users' experience of care over the past 12 months.....	54
Figure 3: Service users report positive outcomes from the care they have received over the past 12 months .....	56
Figure 4: Carers' satisfaction with the support and information they have been provided within in the past 12 months .....	57
Figure 5: Carers' satisfaction with information and support received over the past 12 months.....	58
Figure 6: Information and advice: In general how satisfied were you in the past 12 months.....	58
Figure 7: Involvement in treatment and care planning: In general how satisfied were you in the past 12 months with .....	59
Figure 8: Support from medical and/or care staff: In general how satisfied were you in the past 12 month with .....	60
Figure 9: Number of years the carer has cared for the service user .....	61
Figure 10: Employment status of the carer .....	61
Figure 11: Number of hours the carer spent caring for the service user in the last week.....	62
Figure 12: Carers' employment status and the number of hours they cared for the service user in the previous week .....	63
Figure 13: Provision of information about the most recently prescribed antipsychotic and understandability of this information .....	64
Figure 14: Service users' involvement in the decision about their antipsychotic medication, including discussions of the benefits and potential side-effects .....	66
Figure 15: Case note recording of involvement of the service user in the decision about which antipsychotic medication was prescribed .....	67
Figure 16: Service users' report on whether their view was taken into account when deciding on medication.....	68
Figure 17: Percentage of service users prescribed no antipsychotic medications, one antipsychotic medication or more than one antipsychotic medication.....	70

Figure 18: Percentage of service users whose total daily dose of antipsychotic medication exceeds the BNF recommended maximum .....	72
Figure 19: Treatment prior to clozapine for service users (not in remission and currently prescribed clozapine) who have had an inadequate response to a trial of antipsychotics for at least 4 weeks at optimal dose, prior to clozapine .....	80
Figure 20: Percentage of service users (not in remission and prescribed clozapine) currently prescribed a second antipsychotic medication with clozapine and who have had a trial on this combination for 8 weeks at optimum dose ....	82
Figure 21: The percentage of service users by Trust in full or partial remission (with minimal symptoms offered psychological therapy) .....	85
Figure 22: Percentage of service users by Trust regarded as treatment resistant offered psychological therapy .....	86
Figure 23: Monitoring of cardiometabolic health parameters, including family history and weight, once in the past 12 months .....	89
Figure 24: Monitoring of the cardiometabolic health parameters, excluding family history, once in the past 12 months .....	90
Figure 25: Monitoring of each of the important cardiometabolic risk parameters individually once in the past 12 months (Weight is also included here) .....	91
Figure 26: The percentages of patients versus proportion of cardiometabolic parameters monitored once in the past 12 months .....	91
Figure 27: Monitoring of weight and BMI in the past 12 months .....	93
Figure 28: Comparison of BMI between the NAS population and a national population sample .....	94
Figure 29: The relationship between BMI and time since diagnosis.....	94
Figure 30: Monitoring of blood glucose at least once in the past 12 months.....	95
Figure 31: Monitoring of blood pressure at least once in the past 12 months ...	96
Figure 32: The relationship between time since diagnosis and case note recording of smoking status and percentage who smoke .....	97
Figure 33: Monitoring of alcohol intake across Trusts in the past 12 months....	98
Figure 34: Monitoring of substance misuse across Trusts in the past 12 months.....	99
Figure 35: Monitoring of cardiometabolic parameters in the last 12 months in patients with a diagnosis of cardiovascular disease .....	100

Figure 36: Monitoring of cardiometabolic parameters in the last 12 months in patients with a diagnosis of diabetes ..... 100

Figure 37: Monitoring of cardiometabolic indicators in the past 12 months in patients with a BMI > 25 ..... 101

## List of Tables

Table 1: NAS Standards.....	33
Table 2: Number of returns obtained from each Trust .....	46
Table 3a: Numbers of service users by gender showing age and diagnostic groups (ICD-10).....	47
Table 3b: Numbers by broad age bands.....	47
Table 3c: Numbers by duration of illness.....	47
Table 4a: Number of service users and mean ages by ethnic group.....	48
Table 4b: Ethnic mix of NAS population compared to overall population of England and Wales.....	48
Table 5: Clinical teams caring for the service users in the case note audit sample.....	49
Table 6a: Numbers of carers by broad age bands .....	50
Table 6b: Ethnicity of the sample of carers.....	50
Table 7: Means and ranges of doses of medication prescribed by broad groups of medications and combinations of medications .....	74
Table 8: Service users who are not in remission and whether they were investigated for poor treatment adherence or alcohol/substance misuse. Includes patients both receiving and not receiving clozapine.....	75
Table 9a: Service users who are regarded as treatment resistant but who are not currently receiving clozapine .....	78
Table 9b: Prescription of clozapine for treatment resistant service users by various demographic parameters.....	79
Table 10: Numbers of service users on clozapine alone and on clozapine plus an additional antipsychotic medication versus whether clinically remitted or not...	83
Table 11: Percentages of service users with evidence of monitoring, once in the last year, of BMI, blood glucose, blood lipids and blood pressure by time since diagnosis.....	92
Table 12: Percentage of service users where a need for intervention was identified and percentage where there was evidence that such was offered ...	103



# Introduction

The National Audit of Schizophrenia (NAS) is managed by the Royal College of Psychiatrists' (RCPsych) College Centre for Quality Improvement (CCQI). It is funded by, and part of, the National Clinical Audit and Patient Outcomes Programme (NCAPOP), managed by the Healthcare Quality Improvement Partnership (HQIP). As part of NCAPOP all Mental Health Trusts in England and Wales were expected to take part in NAS. A list of NHS Trusts who submitted data for NAS is available in this report (please see Appendix A).

NAS is a Trust level audit consisting of an audit of practice enhanced by service user experience and carer satisfaction surveys. More details about how NAS was developed, the methodology used to identify the samples and collect the data and how the data were analysed can be found in the methods section of this report (see page 31).

The following sets out the clinical, primary care, service user and carer perspectives on the need for a national audit of schizophrenia.

## **Clinical background**

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The care of people with a diagnosis of schizophrenia is an important priority for the National Health Service (NHS). Approximately 220,000 people in England and Wales have a diagnosis of schizophrenia. It is an illness which commonly severely restricts an individual's life and has a variable course. Following a first episode, perhaps only 20-30% are relapse free after 5 years (an der Heiden and Hafner, 2011). Outcome is, however, difficult to quantify as there are many dimensions along which it can be examined (acute psychotic symptoms; 'negative' symptoms; social functioning; cognitive functioning). These dimensions do not necessarily progress or respond to treatment in parallel. Different individuals with the diagnosis may have different personal views of the impact of each. One analysis of longer term outcomes suggests that around 45%

of individuals experience recovery but 20% experience continuous symptoms and increasing disability (Barbato, 1998).

Life expectancy is 20% shorter in schizophrenia than for the general population (Thornicroft, 2011). The causes of this vary according to whether the person lives in a 'developed' or a 'developing' country. While suicide is a factor, a considerable amount of this reduction in life expectancy in Western societies is due to premature mortality from cardiovascular disease. Underlying this is an excess of modifiable risk factors such as obesity, hyperglycaemia, dyslipidaemia and smoking.

In 2011 the overall cost of schizophrenia to society in England was estimated at £11.8 billion (Andrews et al., 2012). In 2007 it accounted for approximately 30% of the £7.6 billion total expenditure on adult mental health and social care services (McCrone et al., 2008).

Clear national guidelines exist for the treatment of schizophrenia, such as the NICE Guideline (2009), and these have been added to by guidelines specific to the use of medications (Barnes, 2011). Yet there are considerable variations in how care is provided. Data from audits carried out by the Prescribing Observatory for Mental Health (POMH-UK) have previously indicated an overuse of polypharmacy and the use of unnecessarily high doses of medication in many inpatient units. An Audit Commission briefing (Audit Commission, 2010) showed that there is a 12-fold variation in occupied inpatient bed days for individuals with psychosis between Primary Care Trusts in England and Wales. In reviewing the availability of 'talking therapies' the recent report from the independent Schizophrenia Commission came to the conclusion that:

*"Our work suggests that despite the existence of NICE guidelines for schizophrenia, and user feedback on the importance of a range of treatments, access to interventions beyond medication remains limited. We view this position as totally unacceptable and argue that services should be commissioned in line with the evidenced-based treatment*



*recommendations in the NICE guidelines for people with schizophrenia and their families, including access to evidence-based talking therapies”*

Schizophrenia Commission, 2012.

Therefore, auditing how well services are meeting the NICE guideline for the care of people with schizophrenia is an appropriate and necessary exercise. The following paragraphs examine some of the important areas in more detail.

It has become clear over the last 15 years that antipsychotic medications can contribute significantly to weight gain in service users (EUFEST, Kahn et al., 2007; Alvarez et al., 2008). The effects of these medications can become evident within 8 weeks of commencing treatment (Foley and Morley, 2011). Perhaps the most telling statistic is the finding that 30% of service users in one arm of the CATIE study gained 7% or more of their baseline body weight (Lieberman et al., 2005). Weight gain, and consequent increase in BMI, is an important factor in the development of cardiometabolic problems. It is thus essential that attention is paid to these physical health issues.

Guidelines differ in their recommendations regarding the nature and frequency of monitoring for evidence of cardiometabolic problems, but a consensus is emerging that this should be at initiation of treatment, then after three months and then annually (American Diabetes Association and American Psychiatric Association, 2004; De Hert et al., 2009). It is clear that the execution of such monitoring is poor in clinical practice (Barnes et al., 2007; Prescribing Observatory for Mental Health, 2010). Even the measurement of something as simple as weight can be highly variable across individual mental health teams and Trusts.

Antipsychotic medications used appropriately are clearly effective for the psychotic symptoms experienced by many service users, improve engagement with rehabilitative psychosocial programmes and reduce the risk of relapse of acute symptoms. Poorly managed prescribing is likely to be less effective and result in unnecessary medication related adverse effects. Literature reviews and treatment guidelines emphasise the lack of evidence, for the majority of service

users, of any benefit from using more than one antipsychotic medication (antipsychotic polypharmacy) or the use of high doses, above BNF recommended maxima (e.g. Barnes, 2011). While polypharmacy may be an appropriate strategy for some treatment resistant service users it carries increased risks of medication related adverse effects. Thus, these are areas where it is important to audit, create national benchmarks and encourage clinicians to review their prescribing at the level of individual service users.

The management of people with so-called '*treatment resistant schizophrenia*' is a further important issue (Pantelis and Lambert, 2003). It is clear that there is considerable variation in the period of treatment until clozapine is introduced, the only treatment with consistent evidence for additional benefit in this group of patients. Some years ago, proportions of those with schizophrenia who received clozapine varied considerably across the UK. Yet treatment guidelines give clear advice about when clozapine should be considered. Thus, it is important to audit the management of those with treatment resistant illness. NAS will give a picture of the use of clozapine across England and Wales.

Non-adherence with medication is a further problem and rates seem to vary widely. However, it is the most common cause of relapse (Weiden, 2007). Patient attitudes towards medication are an important factor, and an important component of interventions to improve adherence includes discussion of appropriate information between the service user and the clinical team. This is emphasised in the NICE Guideline (2009) which recommends that the decision regarding which antipsychotic to use should be made in partnership with the service user, and carer if appropriate. Such a discussion will include likely effectiveness, common adverse effects and risks of not taking the medication. Thus, audit of this aspect of provision of care is also included.

The current NICE Guideline (2009) also places an increased emphasis on availability of psychological therapies. In particular, psychological therapies should be available for treatment resistant individuals where antipsychotic medication has been of limited benefit. Audit of this is therefore included.

## Primary care perspective

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Although an average general practitioner (GP) provides care for about 5-10 people with schizophrenia at any one time, many GPs feel that, in contrast with similarly complex patients with physical health problems, such as diabetes or heart failure, care of such people is beyond their remit. A study that included discussions between service users with severe mental illness, GPs and practice nurses provides some insights (Lester et al., 2005):

*"I know that I cannot look after people with severe and enduring mental health problems. I do not have the skills or the knowledge. I couldn't do it well."*

In contrast, most of the service users interviewed described primary care as the 'cornerstone' of their physical and mental health care, for example:

*"I mean, the GP has to have some understanding of mental health but I don't expect my GP to know all of the issues to do with my illness. I would though expect him or her to refer me to a specialist person. The important thing is that somebody is looking after you so it's not just you on your own."*

Most service users and GPs/practice nurses in the Lester et al. (2005) study agreed that primary care had a responsibility to continue prescribing drugs initiated in secondary care, monitor side effects and address physical health issues. All participants also felt that interpersonal and longitudinal continuity was vital for good-quality care and could be provided by primary care.

However, that culture of continuity may be changing, highlighted by a recent retrospective primary care records survey of 1,150 people with severe mental illness (schizophrenia - 56%; bipolar disorder - 37%) from 64 practices in England (Reilly et al., 2012). Over the previous 12 months, approximately two thirds of patients were seen by a combination of primary and specialist services and one third were seen only in primary care. Although superficially similar to the largest previous survey (Kendrick et al., 1994), this new study also revealed

a marked reduction in annual GP consultation rates for this population, averaging only 3 (range 2–6). This is much lower than the annual rates of 13 to 14 reported in the mid-1990s (Nazareth and King, 1992) and only slightly higher than the annual consultation rate for the general population of 2.8 (range 2.5–3.2) in 2008 (Hippisley-Cox and Vinograova, 2009). Thus, it seems that access to, and continuity with, a GP have become more problematic. Moreover practice nurses, who are key providers of cardiovascular risk screening and health education, saw this population on average only once a year compared with the general practice population rate of 1.8 times per year. The authors concluded that practice nurses appear to be an under-utilised resource (Reilly et al., 2012).

Another major change in the way primary care organises itself for people with schizophrenia is in the application, since 2004, of the Quality and Outcomes Framework (QOF; NHS Employers and British Medical Association 2011/12), which provides incentives for health promotion and disease management programmes for conditions like heart disease and diabetes. For those with serious mental disorders the focus of QOF is currently on four physical health indicators: Body Mass Index (*MH12*); blood pressure (*MH13*); total to HDL cholesterol ratio (*MH14*); and blood glucose (*MH15*). Moreover the NICE Guideline (2009) highlights the role of primary care in the provision of physical healthcare for those with schizophrenia.

In summary, primary care continues to have a substantial role in the care of people with schizophrenia and receives considerable funding through the QOF to support their physical healthcare. We can expect continuing change in how primary care interacts with mental health services as we move to a new era of clinical commissioning with new opportunities and risks.

## **Service user perspective**

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The need for a national audit of schizophrenia to help improve care and treatments for people with a diagnosis of schizophrenia was reinforced by two focus groups, attended by people with a diagnosis of schizophrenia. These were facilitated by the service user advisor for NAS. Common themes identified as the most important concerns for this group of service users included:

- *The need for information to be available in an accessible format that would enable service users to make informed choices about their care.* This should recognise the importance of both physical and mental health and how both need to be considered when making treatment decisions. For example, the information required to consider a risk benefit assessment about medication should be shared by doctors working in partnership with the service user.
- *Being listened to and actively involved in their care and being respected by professionals who are honest and non-patronising.*
- *Monitoring of physical health.* Service users had major concerns that basic health checks were not being carried out routinely and that there is a lack of clarity as to whose responsibility it is to conduct these; is it the community mental health team or the patient's general practitioner? Service users wanted more information and support so that they could take more responsibility to improve this.
- *Practical support for a 'normal life'.* Service users felt that there is a need for more opportunities for activities such as socialising and employment, for example.

Shared experiences from this group identified some excellent mental health practice, but this was patchy and not felt to be reflected widely within services. There were particular concerns about the lack of coordinated attention to physical health needs. The most prominent message was that the audit needed to provide a basis for translation of recommendations into action at a Trust level, by improving the quality of services and therefore improving the service users' experience of care. The importance of a second round of audit was also strongly endorsed by this group to assess the evidence of positive change taking place.

## Carer perspective

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The impact of care-giving is considerable as illustrated by a survey by Rethink Mental Illness (2003):

- 90% of carers are adversely affected by the caring role in terms of leisure activities, career progress, financial circumstances and family relationships.
- 41% have significant or moderately reduced mental and physical health.
- 29% provide support and care for more than 50 hours per week.

Moreover the *Partners in Care* campaign (Royal College of Psychiatrists and Princess Royal Trust, 2004), led by Dr Mike Shooter, highlighted the need to improve how psychiatrists worked with carers:

*"Carers are an integral part of the patient's support system... They are the ones with the day-to-day experience of the patient's condition, and they carry the most intimate responsibility for the patient's welfare... The carer's voice in decision making about admission and discharge is ignored at everyone's peril - and yet so often is."*

Dr. Shooter, President, Royal College of Psychiatrists (2004)

The NICE Guideline (2009) also emphasised the need to support carers and the benefits that this produced for the service user:

*"Families and carers should receive information about schizophrenia and its management to enable them to better help the user throughout treatment."*

Given this background, the effectiveness of the support provided to families and close friends involved in caring should be recognised as a critical marker of clinical quality and should be a priority in service delivery. NAS sets out to help clinicians reflect on how well they engage and support those family members or close friends who are providing substantial care.

# Methodology

## Audit development

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The key activities leading up the audit are outlined in Figure 1 below.

**Figure 1: Timetable of development and management**

January 2010	<ul style="list-style-type: none"><li>• Funding acquired from the Healthcare Quality Improvement Partnership</li></ul>
January 2010 - March 2010	<ul style="list-style-type: none"><li>• Project team and Advisory Group established</li></ul>
June 2010 - August 2010	<ul style="list-style-type: none"><li>• Development of standards and outcome indicators</li></ul>
August 2010	<ul style="list-style-type: none"><li>• Service user focus group</li><li>• Development of data collection tools</li></ul>
October 2010 - March 2011	<ul style="list-style-type: none"><li>• Pilot phase</li></ul>
February 2011 - June 2011	<ul style="list-style-type: none"><li>• Recruitment of eligible organisations</li></ul>
June 2011	<ul style="list-style-type: none"><li>• Standards and outcome indicators, tools and methodology finalised</li></ul>

## Standards and outcome indicators

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The NAS standards and outcome indicators were developed by the NAS team in collaboration with the Advisory Group members. They are based around the main recommendations in the NICE Guideline (2009).

This guideline, information from POMH-UK audits and a further literature search suggested that issues existed regarding the care and treatment of adults in the community with a diagnosis of schizophrenia. These particularly related to service user experience and outcomes; carer satisfaction; management of

antipsychotic medication; provision of psychological therapies; and monitoring of physical health, with intervention where appropriate. The NAS standards and outcome indicators therefore focused specifically on these areas.

A national consultation on the standards and outcome indicators identified areas for improvement in terms of measurement, focus and terminology. The standards were amended and taken to a service user focus group, where it was agreed that they covered the areas that were most important from a service user perspective. The standards for the audit are described in detail in Table 1.

## **Development of the audit tools**

Three tools were developed to collect data for NAS from participating Trusts. An audit of practice tool, a service user survey form and a carer survey form were agreed to include all the items necessary to measure adherence to the audit standards and outcome indicators. All NAS audit tools can be viewed and downloaded from the NAS website at: [www.rcpsych.ac.uk/quality/NAS](http://www.rcpsych.ac.uk/quality/NAS).

### **Audit of practice tool**

The NAS audit of practice tool was developed to collect demographic information, and information on antipsychotic prescribing practice, physical health monitoring, physical health interventions and psychological therapies offered. This information was to be gleaned largely from a service user's case notes but additionally, if appropriate, from consultants and general practitioners.

The audit of practice tool was developed from audit tools designed by the Prescribing Observatory for Mental Health (POMH-UK). It includes the twelve scales from the Health of the Nation Outcomes Scale (HoNOS) for working age adults, and also includes bespoke questions developed specifically to measure some NAS standards and outcome measures.

The tool was developed in conjunction with the NAS Advisory Group, tested and refined through the NAS Pilot and further tested and refined with consultant psychiatrists and GPs.



**Table 1: NAS Standards**

<b>S1</b>	Service users report that their experience of care over the past 12 months has been positive.	<b>S6</b>	The service user has been provided with evidence-based, written information (or an appropriate alternative), in an accessible format, about the antipsychotic drug that they are currently prescribed.
<b>S2</b>	Service users report positive outcomes from the care they have received over the past 12 months.	<b>S7</b>	The service user was involved in deciding which antipsychotic was to be prescribed, after discussion of the benefits and potential side-effects.
<b>S3</b>	Carers report satisfaction with the support and information they have been provided with to assist them in their role as a carer over the past 12 months.	<b>S8</b>	The service user is currently only prescribed a single antipsychotic drug (unless they are in a short period* of overlap while changing medication or because clozapine is co-prescribed with a second antipsychotic).
<b>S4</b>	The following physical health indicators have been monitored within the past 12 months: <ul style="list-style-type: none"> <li>i. Body mass index, waist hip ratio or waist circumference.</li> <li>ii. Blood pressure.</li> <li>iii. Use of tobacco.</li> <li>iv. Excessive use of alcohol.</li> <li>v. Substance misuse.</li> <li>vi. Blood levels of glucose, lipids (total cholesterol and HDL) and prolactin (if indicated).</li> <li>vii. History of cardiovascular disease, diabetes, hypertension or hyperlipidaemia in members of the service user's family.</li> </ul>	<b>S9</b>	The current total daily dose of antipsychotic drug does not exceed the upper limit of the dose range recommended by the BNF. If it does, the rationale for this has been documented.
<b>S5</b>	When monitoring within the past 12 months has indicated a need for intervention, the following have been offered to the service user or the treating clinician has made a referral for the service user to receive: <ul style="list-style-type: none"> <li>i. Advice about diet and exercise, aimed at helping the person to maintain a healthy weight.</li> <li>ii. Treatment for hypertension.</li> <li>iii. Treatment for diabetes.</li> <li>iv. Treatment for hyperlipidaemia.</li> <li>v. An intervention to reduce levels of prolactin.</li> <li>vi. Help with smoking cessation.</li> <li>vii. Help with reducing alcohol consumption.</li> <li>viii. Help with reducing substance misuse.</li> </ul>	<b>S10</b>	If there was no or inadequate response* to the first antipsychotic drug prescribed after a minimum of four weeks at optimum dose*: <ul style="list-style-type: none"> <li>i. Medication adherence was investigated and documented.</li> <li>ii. The potential impact of alcohol or substance misuse on response was investigated and documented.</li> </ul>
		<b>S11</b>	If there was no or inadequate response* to the first antipsychotic drug after a minimum of four weeks at optimum dose*, the first antipsychotic drug was stopped and a second antipsychotic drug given. At least one of the first two drugs prescribed was a second-generation antipsychotic.
		<b>S12</b>	If there was no or inadequate response* to the second antipsychotic drug after a minimum of four weeks at optimum dose*, clozapine was offered.
		<b>S13</b>	If there was no or inadequate response* to treatment despite an adequate trial of clozapine*, a second antipsychotic was given in addition to clozapine for a trial period of at least eight weeks at optimum dose*.
		<b>S14</b>	CBT or family therapy have been offered to service users whose illness is resistant to treatment with antipsychotic drugs*.

\*See Appendix C for full definitions.

### **Service user survey form**

The service user survey form was developed to capture service users' experiences of treatment plus satisfaction with information about physical health monitoring, with the way antipsychotic medication was prescribed and with the outcomes of their care.

It was developed around the Carers' and Users' Expectations of Services (CUES) questionnaire developed by the National Schizophrenia Fellowship, the Royal College of Psychiatrists' (RCPsych) Research Unit, the Royal College of Nursing Institute and the School of Social Work at the University of East Anglia (Lelliott et al., 2001). Additional items were added to measure specific standards about the way antipsychotic medication had been prescribed.

CUES had previously been validated and found reliable for use with this service user population (Lelliott et al., 2001). No other reliable, validated tool which might be better suited for use in NAS could be identified through a national consultation. The service user focus group also agreed that this tool adequately covered the key areas of importance to them.

The questionnaire was shortened and refined through the NAS pilot and in consultation with the charitable organisation Rethink Mental Illness and a service user focus group held on 6 August 2010. Ambiguities in the instructions were reduced and redundant qualitative sections of CUES were removed, as the analysis would be purely quantitative.

### **Carer survey form**

The carer survey form was developed to capture carers' satisfaction with the information and support they received.

The NAS carer survey form was based around the Carer Well-Being and Support (CWS) questionnaire developed by the RCPsych in collaboration with Rethink Mental Illness, the Alzheimer's Society and the London School of Hygiene and Tropical Medicine (Quirk et al., 2008).

The CWS had previously been validated and found reliable for use with this carer population (Quirk et al., 2008). No other reliable, validated tool that might be more suitable for use in NAS could be identified through a national consultation.

## **Identification of the case sample**

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There were two main, competing drivers in relation to identification of the sample of cases to be included in the audit. The ideal would have been to have had an entirely random sample from all of the appropriate cases currently under the care of each Trust with matched data from those service users and their carers. However, the lack of comprehensive information technology systems in many Trusts, lack of case registers and expected low response rates for the user and carer questionnaires made this ideal relatively unlikely to be achieved (this situation became clear during the audit pilot). We therefore laid out a clear set of rules for the process of case selection:

### **Sampling at Trust level**

As a result of the power analysis (see below), organisations taking part were asked to identify a random sample of:

- 200 service users to be sent service user survey forms **and**
- 100 service users (from the above 200) whose records would be included in an audit of practice (the same service user could therefore receive a survey form and be included in the audit of practice).

Organisations selected one of two sampling options (or a combination of both where sampling proved more difficult): **either** identification of service users' centrally **or** identification through the community mental health teams. For full details see Appendix D.

Participating organisations were asked to inform us which sampling method they used through the feedback questionnaire that followed receipt of their local Trust reports after analysis of the audit data. Of the Trusts who provided this information, 65% (n=28) reported that they used sampling option one, 23% (n=10) reported that they used sampling option two and 9% (n=4) used other

sampling options, which included a combination of the two sampling options. One Trust did not provide an answer to this question.

### **Power analysis**

A power analysis was conducted to determine the minimum number of returns required for meaningful statistical analysis on a national basis and per organisation. Details of this analysis can be requested by email at [NAS@cru.rcpsych.ac.uk](mailto:NAS@cru.rcpsych.ac.uk).

### **Inclusion and exclusion criteria**

Service users would be eligible for inclusion in NAS if they met the following criteria:

- Adults (18 years and older - no upper limit).
- Being treated in the community (not inpatients).
- Current ICD-10 diagnosis of F20.0-F20.9 (schizophrenia) or F25.0-F25.9 (schizoaffective disorder).
- ICD-10 diagnosis of F20.0-F20.9 (schizophrenia) or F25.0-F25.9 (schizoaffective disorder) for at least 12 months and diagnosis made before the age of 60 years.
- Been under the care of the Trust for at least 12 months.

Service users and carers were excluded from the sample if the service user was known to live in a nursing home, residential home or continuing care, or they had requested that they must be contacted via another person. To increase the generalisability of the sample, those on community treatment orders were not excluded from the audit.

## **Participating Trusts**

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### **Eligibility**

NAS is a Trust level audit. All NHS Mental Health Trusts/Health Boards in England and Wales were expected to participate if they provided care or treatment in the community to adults with a diagnosis of schizophrenia.

## **Services submitting data**

Sixty of the 64 organisations that were identified by the NAS team as eligible to participate at the time of data collection submitted data for NAS (see Appendix A).

## **Pilot audit**

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Six Mental Health Trusts in England volunteered to take part in the pilot phase of NAS (see Appendix A). A pilot initiation workshop was held in October 2010 and data collection followed during the months of January and February 2011. Data cleaning and analysis ran until May 2011 when a closing workshop took place.

In the pilot each Trust was asked to collect data from a case record review of 50 service users, and distribute 50 service user survey forms and 50 carer survey forms. The main purpose of the pilot was to test all aspects of the audit before the main audit was launched.

## **Main audit**

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It was clear from the pilot that good communication between the central NAS team and the Trusts would be important for the smooth running of the project. Thus, each participating Trust identified a NAS audit lead to co-ordinate their data collection. Four staff in the NAS/CCQI office were each then assigned 15 Trust audit leads with whom they would have regular liaison and who would provide a rapid conduit for dealing with any queries. Prior to the start of the audit the Trust audit leads were given clear timelines for identification of their individual case sample and preparation of their clinical teams for data collection.

## **Data collection:**

### **NAS audit lead packs**

Each NAS audit lead was sent a comprehensive pack of materials to support them, along with full details of documents to forward to service users, and a flow diagram of the process (see Appendices D and E for full details).

### **Service user and carer survey forms**

Using the sampling methods outlined on page 35, participating Trusts sent 200 service users a pack including information about the audit (see Appendix D). This included a service user survey form plus a carer survey form for the service user to pass on to the person they felt was most appropriate to complete this. Service users and carers were provided with a contact number at Rethink Mental Illness in case they had any questions about the audit or required assistance to complete the questionnaire. Rethink Mental Illness also ran a prize draw as an incentive for service users to return questionnaires. Each prize draw card included a tick box for service users to check if they wished to have a copy of the report.

Carers and service users returned completed survey forms to the NAS team using pre-paid envelopes provided; there was also the option to complete the survey forms online. Carers' and service users' responses were confidential and anonymous; a number on the front of the questionnaires identified the NHS Trust only. All forms will be destroyed in December 2012.

### **Case note audit of practice**

Psychiatrists were asked to complete one audit of practice tool for each of their service users included in the Trust's randomly selected sample of 100. These 100 cases then made up each Trust's case note audit of practice sample. In several services, some of the physical health data had to be collected from the service users' general practitioners. A template letter co-signed by representatives from the Royal College of General Practitioners was provided to assist this. Audit of practice data were submitted through an online version of the audit of practice tool directly to the NAS team.

### **Response rates**

- We received valid returns from the audit of practice tool for **5,091** service users (85% of those expected).
- In total, **2,323** service users returned service user survey forms, and **1,163** carers returned carer survey forms.

## Data handling and analysis:

### **Data entry and analysis**

All data were entered using SNAP 9 Professional Surveys via secure webpages. Data were extracted to PASW Statistics 18 (SPSS) and analysed using PASW Statistics 18 or Microsoft Excel 2007. The statistical techniques used in PASW Statistics 18 to analyse data were descriptive statistics, frequencies and cross tabulations.

### **Service user reference group**

A service user reference group took place on 31 October 2011. The meeting was led by the NAS service user advisor, and the group looked at the initial data collected at this stage to see if these reflected their experience of care. Discussions focused on: physical health monitoring, including the lack of clarity on what a physical health check should consist of; the lack of involvement in decision making; and the lack of information provided on medication. The reference group's comments on this were recorded and their suggestions for how things can be improved were integrated into the discussion (see page 105) and recommendations (see page 115).

### **Data cleaning**

Data cleaning was carried out between December 2011 and February 2012. A detailed process was outlined for NAS staff to follow to check that the sampling criteria were followed correctly and to check for any duplication of data, missing data, and unexpected values. Any suspected data errors were emailed back to Trusts on 16 January 2012 along with their datasets for clarification by the end of that month. Amendments were then made as necessary.

Trusts received a NAS Trust level report in April 2012. They were given one month after receiving this to alert the NAS team to any errors in their data. Further opportunities for highlighting errors were provided at a learning event for participating Trusts, held in London on 30 April 2012, and through an online feedback questionnaire, made available from 18 May to 3 July 2012. Out of the 60 participating Trusts, 43 (72%) provided feedback through the online questionnaire. A summary of this feedback can be found on page 126.

## **Outliers**

Trusts were identified as potential outliers if their performance against the NAS standards was more than three Standard Deviations (SD) outside the overall mean performance reported for all Trusts. The range of expected performance was derived from the audit findings and was determined by the average performance of the total national sample compared with the performance of each individual participating Trust.

The detection and management of outliers was based on guidance supplied by HQIP and the Department of Health (DH). The guidance document can be downloaded from the HQIP website: <http://www.hqip.org.uk/outlier-guidance-for-audit-providers-issued-by-hqip-and-the-department-of-health>.

## **Limitations of the methodology and data**

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### **Limitations**

The main limitations of the methodology were:

- Data returns were not evenly spread across Trusts. In the feedback from Trusts, reasons for this included: difficulties identifying and generating a random sample; difficulties getting consultants involved; and difficulties when mandatory information was requested in the audit of practice tool but was missing from the case notes, preventing the form from being returned.
- Data analysis is only adequately meaningful for those Trusts who have a case note audit of practice sample size of at least 73 after data cleaning (50 out of 60 Trusts; 83%).
- Variations in the amount and quality of physical health monitoring data was sometimes as a result of some Trusts not being able to access clinical records and information held by primary care.
- The results are a 'snapshot' reflecting the time that data were collected. Therefore comparisons over time cannot be measured.



## Caveats

General caveats that apply to the report are:

- The sample for this study focused on service users being treated in the community only. Therefore the results may not hold for the population as a whole.
- The sample only included service users who had been under the care of the Trust for 12 months or more.
- Physical health records were collected for current or most recent recordings. Therefore, because of the lack of longitudinal data, caution must be used when drawing inferences between cause and effect.
- Some cases were deleted because the Trust included inpatients or because a service user's date of birth was not included. Trusts were informed about these cases and gave permission for their deletion from the dataset.
- Service users and carers were asked to try to complete as many questions as they could in their respective survey forms. It was accepted that sometimes there might be questions with which an individual service user or carer felt uncomfortable and might not wish to answer.
- As described in the section 'Identification of the case sample', it was not possible to obtain populations of service users for the audit of practice tool completely matched to the samples returning service user and carer survey forms. Had we only sought survey forms from those cases included in the case note audit then returns would have been too low to be meaningful. Thus, direct comparisons between data from the audit of practice tool and data from the service user and carer survey forms must be interpreted carefully.
- In some cases data were only provided for systolic *or* diastolic blood pressure, and/or glycated haemoglobin *or* fasting plasma glucose. These cases were still included in the analysis.
- For question 8 in the audit of practice tool ('How long ago was this diagnosis first made?') there is a potential for overlap between the bands (1-2 years, 2-4 years etc.).

Throughout the report several comments and caveats regarding the data for specific tables and figures are stated in bulleted points below each relevant table or figure.

**NAS**  
NATIONAL AUDIT OF  
SCHIZOPHRENIA



# Findings of the National Audit of Schizophrenia

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Commissioned by



**HQIP**

Healthcare Quality  
Improvement Partnership



## Demography of the audit population

The audit set out to collect data on a randomly selected population of 100 people with a diagnosis of either schizophrenia or schizoaffective disorder from each of the identified 64 eligible organisations, i.e. ideally data on over 6,000 service users. Following data collection, entry and data cleaning there were 5,091 records from 60 Trusts that were suitable for further analysis. The mean number of returns for the audit of practice tool was 85 (SD 20); 83% of Trusts returning data achieved at least 73 forms; 27% of Trusts returned 100 or more forms.

Each Trust was asked to distribute service user surveys to 200 service users. We estimated from the audit pilot that the response rate was likely to be in the region of 20%. In total 2,323 service user survey forms were received, a mean of 39 (SD 12) per Trust.

Service users were given the carer survey form to pass to whomever they regarded as their closest carer. In total 1,163 of these forms were returned, a mean of 19 (SD 7) per Trust.

Table 2 shows how many of each type of return was obtained for each Trust.

### **Demography of the case note audit sample (n=5,091)**

Tables 3 to 6 show the demographic characteristics of the population of patients for whom the audit of practice tool was completed from the service users' case notes. Table 3a shows that 64.9% of the population was male and 85% of the service users had a diagnosis of schizophrenia. The proportion of females with a diagnosis of schizoaffective disorder was higher than for males. Such findings would fit into the range found in many surveys of patients in the community.

**Table 2: Number of returns obtained from each Trust**

Trust ID	Audit tool	User survey	Carer survey	Trust ID	Audit tool	User survey	Carer survey
NAS 001	85	16	6	NAS 036	20	49	22
NAS 002	59	17	17	NAS 037	79	46	23
NAS 003	72	39	21	NAS 038	86	40	22
NAS 004	74	53	24	NAS 039	83	24	13
NAS 005	100	44	16	NAS 041	102	30	16
NAS 006	101	36	20	NAS 042	54	37	9
NAS 007	100	44	26	NAS 043	17	40	24
NAS 008	89	37	22	NAS 044	92	50	25
NAS 009	80	30	22	NAS 045	93	54	31
NAS 010	98	25	15	NAS 046	77	40	26
NAS 011	100	47	27	NAS 047	95	31	15
NAS 012	102	54	25	NAS 048	73	35	19
NAS 013	101	45	15	NAS 049	100	56	32
NAS 014	83	20	10	NAS 050	88	52	17
NAS 015	79	29	24	NAS 051	76	31	17
NAS 016	100	36	18	NAS 052	59	63	34
NAS 017	83	43	17	NAS 053	97	44	18
NAS 019	101	43	22	NAS 054	85	25	10
NAS 020	60	39	17	NAS 056	93	57	32
NAS 021	86	43	14	NAS 059	93	52	21
NAS 024	86	58	35	NAS 060	69	34	9
NAS 025	105	32	19	NAS 061	99	35	19
NAS 026	96	29	16	NAS 063	83	50	33
NAS 028	86	43	24	NAS 064	56	7	4
NAS 029	54	44	16	NAS 065	86	21	0
NAS 030	87	31	22	NAS 066	101	38	23
NAS 031	95	31	14	NAS 067	92	69	34
NAS 033	100	49	20	NAS 068	57	22	10
NAS 034	100	30	8	NAS 069	134	38	18
NAS 035	88	36	16	NAS 070	102	30	19

**Table 3a: Numbers of service users by gender showing age and diagnostic groups (ICD-10)**

	Number	Mean age (SD)	Age range	Schizophrenia (n)	Schizo affective disorder (n)
<b>Total sample</b>	<b>5,091</b>	<b>45 (14)</b>	<b>18-93</b>	<b>4,327</b>	<b>764</b>
<b>Male</b>	<b>3,305</b>	<b>43 (12)</b>	<b>18-90</b>	<b>2,949</b>	<b>356</b>
<b>Female</b>	<b>1,782</b>	<b>49 (15)</b>	<b>18-93</b>	<b>1,376</b>	<b>406</b>
<b>Not stated</b>	<b>4</b>	<b>46 (5)</b>	<b>41-52</b>	<b>2</b>	<b>2</b>

**Table 3b: Numbers by broad age bands**

Age bands	Number (%) of cases in each band
<b>18-24 years</b>	<b>163 (3.2%)</b>
<b>25-34 years</b>	<b>919 (18.1%)</b>
<b>35-44 years</b>	<b>1,376 (27%)</b>
<b>45-54 years</b>	<b>1,308 (25.7%)</b>
<b>55-64 years</b>	<b>829 (16.3%)</b>
<b>65 years and over</b>	<b>496 (9.7%)</b>

**Table 3c: Duration of illness**

Time since diagnosis (years)	Number
<b>1-2</b>	<b>253</b>
<b>2-4</b>	<b>489</b>
<b>4-10</b>	<b>1,303</b>
<b>&gt;10</b>	<b>3,046</b>
<b>Total (n)</b>	<b>5,091</b>

The mean age of the population was 45 years (SD 14) with a range of 18–93 years. Table 3b shows that this was predominantly a middle-aged group. Table 3c shows that the majority of the service users had been ill for more than 10 years.

Tables 4a and 4b examine the proportions of the main ethnic groups within the population recruited for NAS. Table 4a shows that the gender split remains similar across ethnic groups and that the mean ages within each group are

similar, except for the Mixed Race group who are a little younger. Table 4b compares the NAS population with the mid-2009 estimated update of the census population figures for England and Wales (the census data does not allow an exact comparison for the age groups used in NAS). This suggests that the NAS population has a modest over-representation of patients of Asian/Asian British background and a considerable over-representation of patients with a Black/Black British background. The latter observation is to be expected given findings in many epidemiological studies of over-representation of this group among people with a diagnosis of schizophrenia (Fearon et al., 2006).

**Table 4a: Number of service users and mean ages by ethnic group**

<b>Ethnic Group</b>	<b>Male</b>	<b>Female</b>	<b>Not stated</b>	<b>Mean Age (years)</b>
<b>White</b>	<b>2,596</b>	<b>1,374</b>	<b>3</b>	<b>46</b>
<b>Asian/Asian British</b>	<b>258</b>	<b>157</b>	<b>-</b>	<b>41</b>
<b>Black/Black British</b>	<b>279</b>	<b>152</b>	<b>-</b>	<b>42</b>
<b>Chinese or other</b>	<b>45</b>	<b>30</b>	<b>1</b>	<b>44</b>
<b>Mixed</b>	<b>64</b>	<b>29</b>	<b>-</b>	<b>38</b>
<b>Not stated</b>	<b>63</b>	<b>40</b>	<b>-</b>	<b>46</b>
<b>Total</b>	<b>3,305</b>	<b>1,782</b>	<b>4</b>	<b>-</b>

**Table 4b: Ethnic mix of NAS population compared to the overall population of England and Wales**

<b>Ethnic group</b>	<b>Percentage in NAS population (age &gt;18)</b>	<b>Percentage in England and Wales population (age &gt;16)</b>
<b>White</b>	<b>78.0</b>	<b>88.8</b>
<b>Asian/Asian British</b>	<b>8.2</b>	<b>5.6</b>
<b>Black/Black British</b>	<b>8.5</b>	<b>2.7</b>
<b>Chinese or other</b>	<b>1.5</b>	<b>1.7</b>
<b>Mixed</b>	<b>1.8</b>	<b>1.2</b>
<b>Not stated</b>	<b>2.0</b>	<b>-</b>



## Clinical parameters for the case note audit sample

Service users were under the care of a variety of different clinical teams. In the Trust audit of practice tool a number of broad categories were provided, and while precise usage of these terms may differ from Trust to Trust, the majority of teams currently caring for these service users seemed to fit the categories provided (Table 5).

**Table 5: Clinical teams caring for the service users in the case note audit sample**

Type of clinical team	Number
Assertive Outreach Team	615
Community Mental Health Team	3,545
Crisis Resolution Team	9
Early Intervention	286
Psychosis Team	-
Other	636
<b>Total</b>	<b>5,091</b>

Scores on the HoNOS (Royal College of Psychiatrists, 1996) were available in 4,778 sets of case notes. The mean HoNOS score was 10.06 (SD 7.17). Comparison of those service users with a diagnosis of schizophrenia and those with a diagnosis of schizoaffective disorder did not reveal any significant differences. Question 10 of the audit of practice tool asked whether the patient was regarded as being in remission, partial remission (with minimal symptoms and disability), partial remission (with substantial symptoms and disability) or not in remission. In order to test the validity of the responses to this question, the total available HoNOS scores for all of the patients in each category were compared. For those in remission the mean HoNOS was 7.89 (SD 6.03) and for those not in remission it was 15.59 (SD 6.86). The responses to Question 10 were then used for determining which patients were regarded as being in remission when examining the issue of 'treatment resistance'.

## Demography of the sample of carers

The service users identified by each Trust were each sent a copy of the carer survey form to pass on to whoever they regarded as their carer. It is not possible for us to know how many of these were passed on by service users to their carers. As stated above, 1,163 were returned to the NAS team.

The mean age of the carer sample was 51 years with a range of 12–94 years. For those who supplied information on gender, 729 (65%) were female and 398 (35%) were male (no gender information was given for n=36). Other demographic characteristics of this sample are described in Tables 6a and 6b below.

**Table 6a: Numbers of carers by broad age bands**

Age bands (years)	Number (%)
Under 18	2 (0.2)
18-24	27 (2.3)
25-34	80 (6.9)
35-44	147 (12.6)
45-54	234 (20.1)
55-64	302 (26.0)
65 years and over	283 (24.3)
Not stated	88 (7.6)

**Table 6b: Ethnicity of the sample of carers**

Ethnic group	Number (%) in NAS carer population	Percentage in user population (from Table 4b)
White	947 (81)	78.0
Asian/Asian British	84 (7.2)	8.2
Black/Black British	63 (5.4)	8.5
Chinese or other	33 (2.8)	1.5
Mixed	-	1.8
Not stated	36 (3.1)	2.0

The data in these tables indicate that, like the service user sample, the carers were largely in middle age and older age groups. As explained in the Methodology section, it is not possible to directly compare the carer and service user populations. However, there is a relative similarity in percentages between these in terms of White and Asian/Asian British ethnic groupings with some trend to differences for the Black/Black British and Chinese groups, but these differences cannot be tested statistically.

## **Layout of the audit data sections:**

The following five sections of the report will present the data relating to measurement of the various audit standards. For some standards there is a clear benchmark by which to assess the results. For others there is no absolute benchmark but the results for individual Trusts can be seen against the averaged data, over the total population, for each particular measure. This is referred to in many of the figures as the Total National Sample (TNS) and has to be judged against what may be considered to be reasonable practice. In many respects, NAS may be considered to be developing a national benchmark and the real value of the audit findings will be their power to stimulate improvements in practice and improvements in a future second round of audit.

The results are presented according to the section headings below rather than in numerical order of the standards. This order makes more logical sense in terms of a service user's journey through the mental healthcare system.

1. Experience of service users and carers (standards 1-3).
2. Shared decision making about medication (standards 6 and 7).
3. Prescribing (standards 8-13).
4. Psychological therapies (standard 14).
5. Physical health care (standards 4 and 5).

Each table and figure has a number and title at the top and in some cases a set of bulleted points at the bottom indicating the number of cases used for the particular analysis and any significant caveats. Much of the information is presented as figures made up of bar charts with each bar representing the results for an individual Trust. In most of these figures the best performing Trusts are on the left and worse performing on the right. Where appropriate there will be a bar somewhere in the middle representing the national average for the total population and called 'TNS' (Total National Sample). Details of how to read these figures is provided on pages 53 and 54 in relation to Figure 2.

## Experience of service users and carers

Health and social care services have recognised for some years that the views of service users and their carers must play an important part in any review of services or development of new services. This applies across all aspects of the health service whether relating to physical or mental health issues. It is thus also important that we audit aspects of the interaction between mental health services, service users and carers as part of NAS.

A complete breakdown of service user responses by each item of the service user survey can be found in Appendix F.

### Service user experiences

Each Trust was asked to send out 200 service user survey forms. The NAS team received 2,323 responses to these. These forms were returned anonymously to the audit team. Service users were not asked to provide any information in relation to age, gender or ethnicity on these forms. Thus we cannot describe how well the population returning these forms matches the case note audit of practice sample.

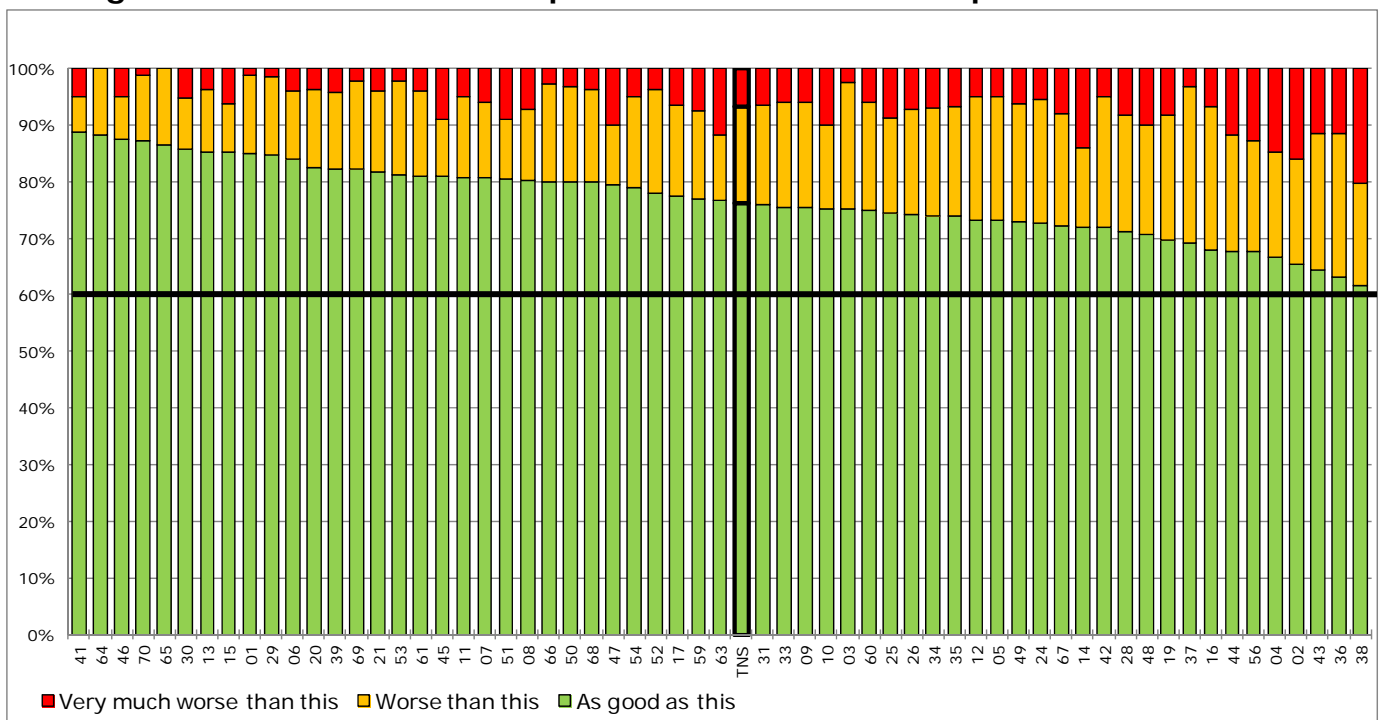
The need for good engagement with service users is an important theme in the NICE Guideline (2009). Standard 1 of the audit relates to this.

**Standard 1: Service users report that their experience of care over the past 12 months has been positive.**

Figure 2 shows a measure of service user experience using the service user survey form, based around the CUES questionnaire (see Methodology). The data in this figure are presented in a format that will be found in many of the figures throughout this report. Each Trust is represented by a vertical bar and these bars are identified by an anonymous NAS Trust identification code. The bars are divided into coloured sections, with a key for interpretation of these on each

figure. In most cases, as for Figure 2, the green section of the bar represents the percentage of cases in that Trust where the particular measure or standard was adequately measured or met. The bars are arranged with the best performing Trusts on the left and the worst performing on the right. In the middle there is a bar with a heavier black border around it labeled TNS. This bar represents the averaged data over the total population, i.e. the Total National Sample result. Beneath the figure are a number of bulleted points which provide additional information regarding the data represented.

**Figure 2: Service users' experience of care over the past 12 months**



- The number of responses included in this analysis is 2,323.
- There were 458 instances where an individual service user had not provided a response to a particular question.
- The questions from the service user survey that are relevant to the analysis for this figure relate to the following CUES items:
  - i. Information and advice about treatment and services available.
  - ii. Access to mental health services.
  - iii. Choice of mental health services.
  - iv. Relationships with mental health workers.
  - v. Consultation and control with regards to mental health workers.

The CUES questionnaire has previously been validated and a particular level of response set for it as representing a good standard of performance. This standard is met if over 60% in total of the CUES items included are rated as '1' (as good as this). For example, if 20 patients complete the five questions, 100 ratings have been made. If 62 of the 100 items are rated 1 (as good as this) the standard is met. With this rule in mind, the data show that the criterion to meet this standard, marked in a heavy black horizontal line on Figure 2, was met by all Trusts. The average response (TNS) was that 76% of responders gave a rating of 'as good as this'.

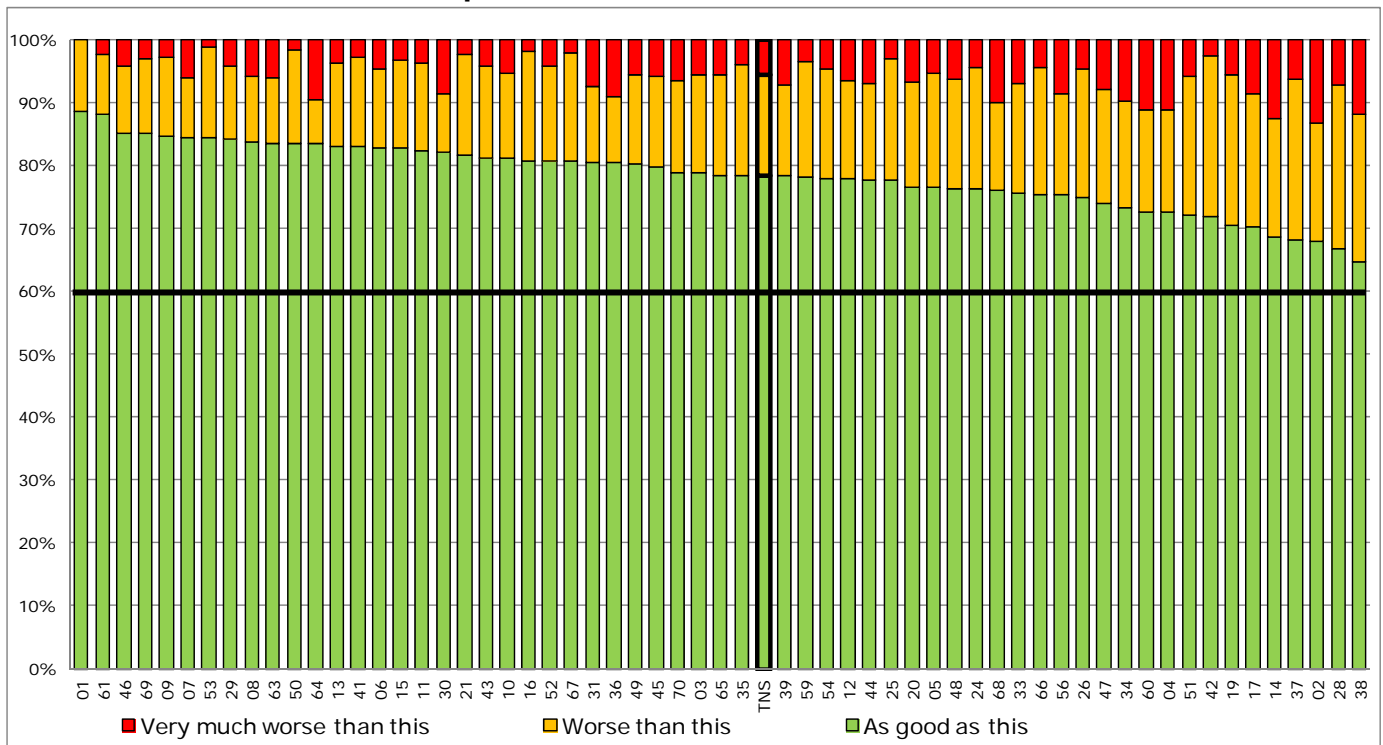
It is also important that a service should provide good outcomes. Measurement of outcome in mental health services is notoriously difficult because there are many dimensions to consider. It is not feasible to devise a single questionnaire with a single outcome score. Nevertheless it is relevant to have some impression of how service users perceive their outcome. Standard 2 reflects this.

**Standard 2: Service users report positive outcomes from the care they have received over the past 12 months.**

The data presented in Figure 3 address this standard. As for the CUES items used for Figure 2, Standard 2 is also met if over 60% of the relevant CUES items are rated 'as good as this' (the relevant items are listed below Figure 3). The data show that a standard of 60% was met by all Trusts with an average of 78% of responders in the total sample giving a response of 'as good as this'.

The CUES outcome items that were scored most negatively were those relating to the practical aspects of everyday life about which the service user focus groups expressed particular concern (see page 28): meaningful daily activity and socialisation (represented in questions 10, 11 and 12 of the service user survey). The scores for these questions indicated that 28%, 22% and 26%, respectively, felt their lives were worse or very much worse than the situation posed in the stem question.

**Figure 3: Service users report positive outcomes from the care they have received over the past 12 months**



- The number of service users included in this analysis is 2,323.
- There were 464 instances where an individual service user had not provided a response to a particular question.
- The questions from the service user survey that are relevant to the analysis for this figure relate to the following CUES items:
  - i. Where the service user lives.
  - ii. Money.
  - iii. Help with finances.
  - iv. How the service user spends their day.
  - v. Family and friends.
  - vi. Social life.

In relation to care of their physical health, over 80% of service users responding appeared to have a positive regard for the availability of acute medical care and the approach of those providing it (questions 21 and 22 of the service user survey). In addition, 78% thought they had had a general physical health check in the previous 12 months (question 6).



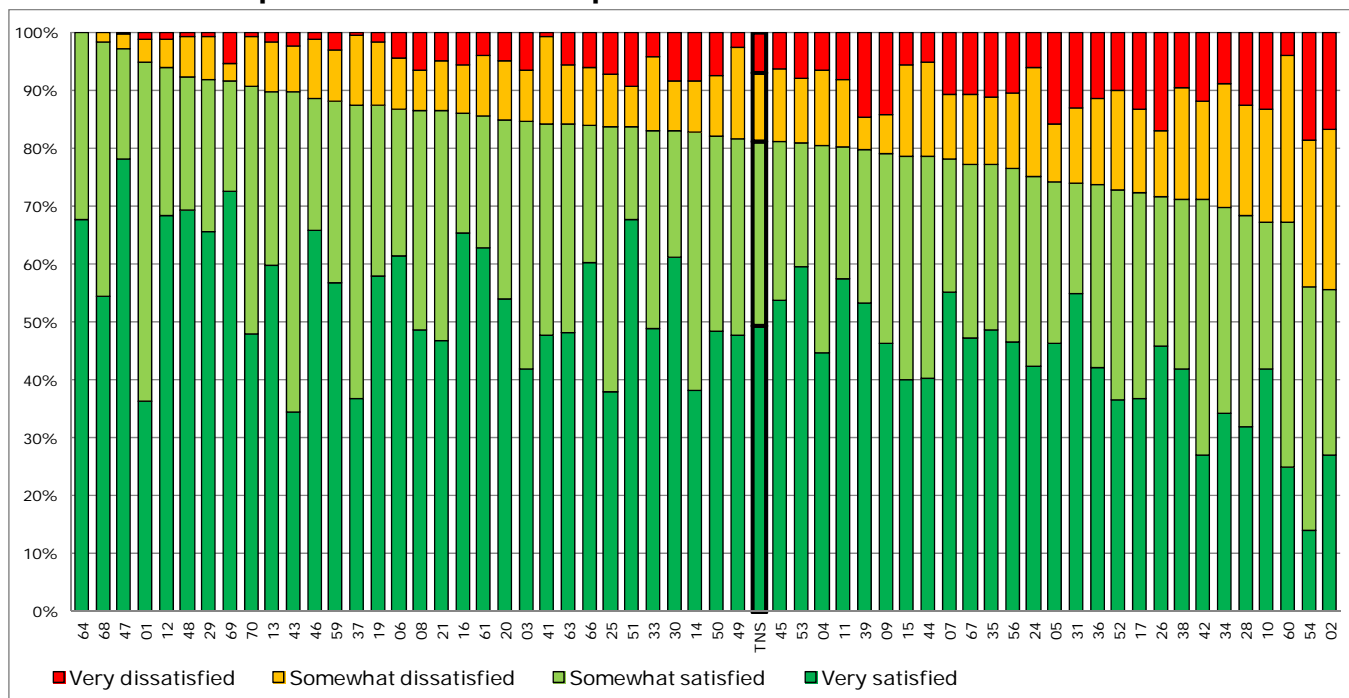
## Carer experiences

The need for good engagement and communication with carers is a further important theme in the NICE Guideline (2009). Standard 3 of the audit relates to this.

**Standard 3: Carers report satisfaction with the support and information they have been provided with to assist them in their role as a carer over the past 12 months.**

Trusts gave 200 service users a carer survey form to give to whoever they regarded as their carer. Of these, 1,163 were returned to the NAS team. Figure 4 provides data from these forms that addresses this standard. The criterion set for this standard was 60%, to mirror that set for the CUES items in the service user survey. This criterion was met by all Trusts with an average of 81% of respondents giving a response of either 'very satisfied' or 'somewhat satisfied'.

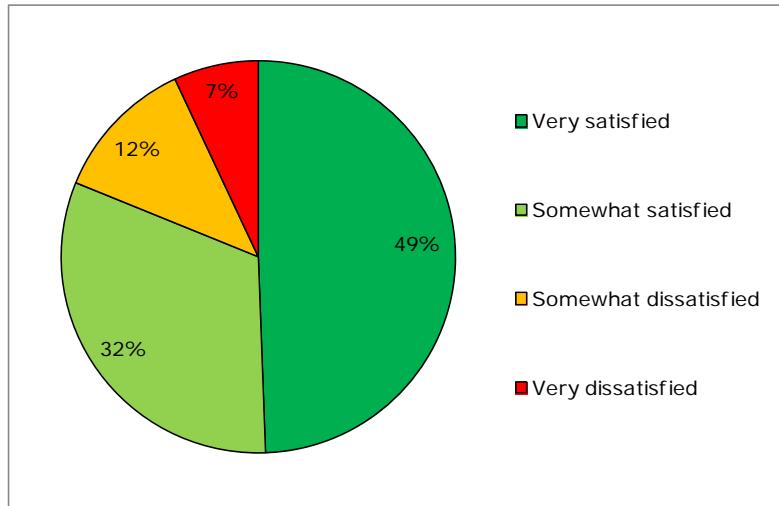
**Figure 4: Carers' satisfaction with the support and information they have been provided within the past 12 months**



- The data for Figure 4 is from Qs 1, 2 and 3 of the carer survey.
- The number of carers included in this analysis is 1,163.

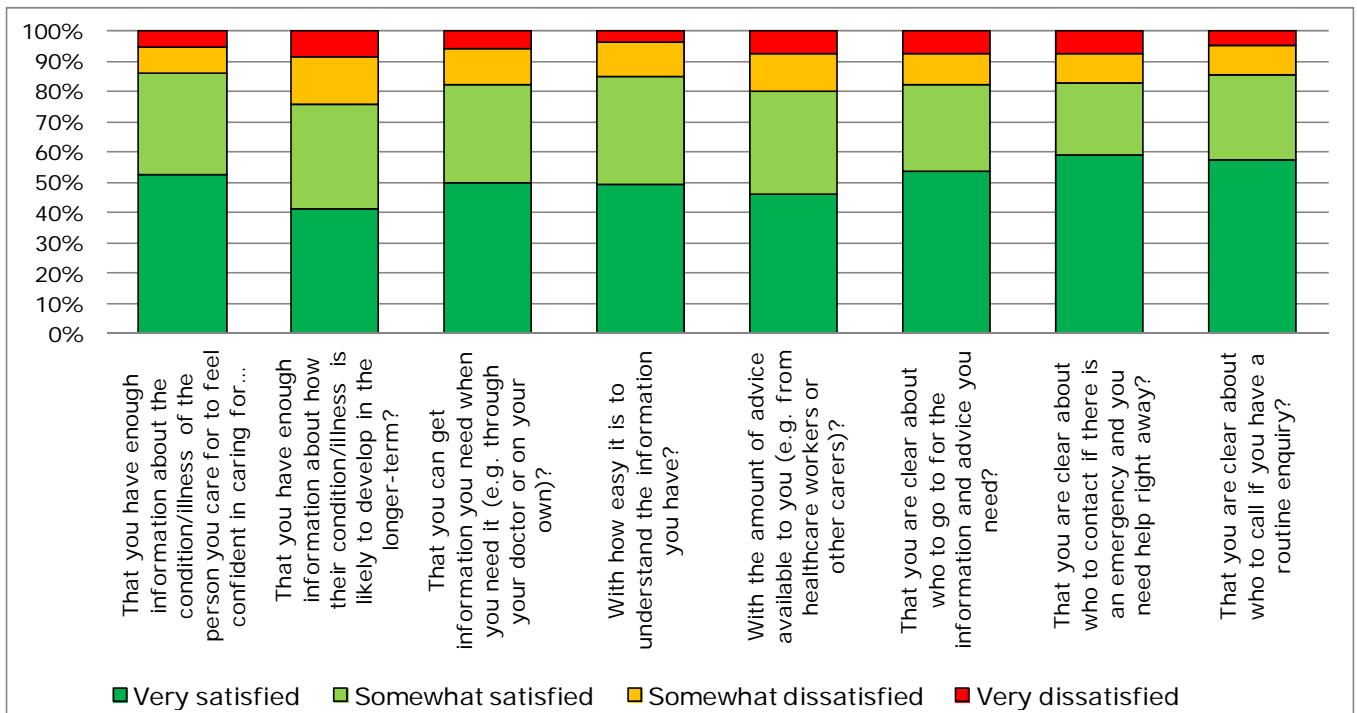
Figure 5 shows the overall responses for all of the 1,163 carers and gives an impression of the level of carer satisfaction at national level.

**Figure 5: Carers' satisfaction with information and support received over the past 12 months**



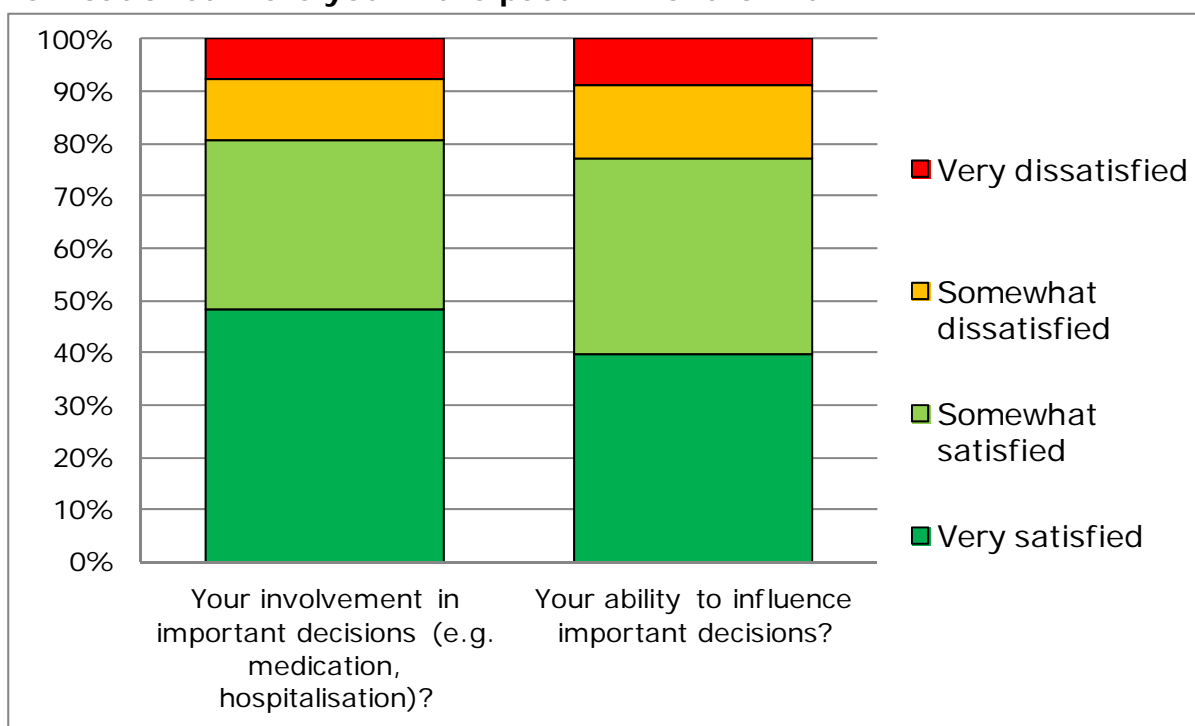
Figures 6-8 provide a more detailed breakdown of the carers' responses. The title for each figure includes the stem for each question asked.

**Figure 6: Information and advice: In general how satisfied were you in the past 12 months:**



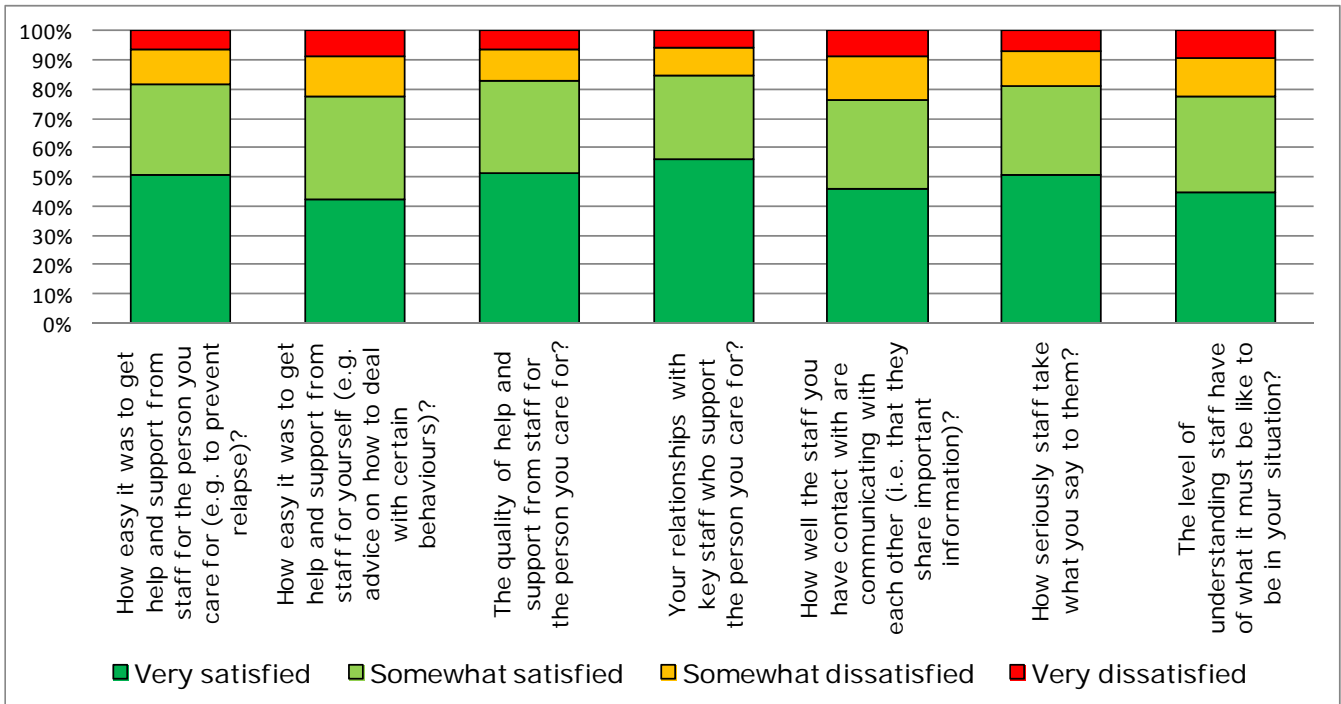
- The data for Figure 6 is from Q1 of the carer survey.
- The number of carers included in this analysis is 1,163. There were 402 instances where an individual carer had not provided a response to a particular question.

**Figure 7: Involvement in treatment and care planning: In general how satisfied were you in the past 12 months with:**



- The data for Figure 7 is from Q2 of the carer survey.
- The number of carers included in this analysis is 1,163. There were 114 instances where a response was not provided.

**Figure 8: Support from medical and/or care staff: In general how satisfied were you in the past 12 months with:**



- The data for Figure 8 is from Q3 of the carer survey.
- The number of carers included in this analysis is 1,163. There were 320 instances where an individual carer had not provided a response to a particular question.

Overall these results provide a reasonably positive picture from 81% of responders. However, a striking finding was the wide variation in the level of responders reporting that they were 'very satisfied', which varied from 78% in one Trust to only 13% in another. In addition, 19% of carers were 'somewhat dissatisfied' or 'very dissatisfied' overall.

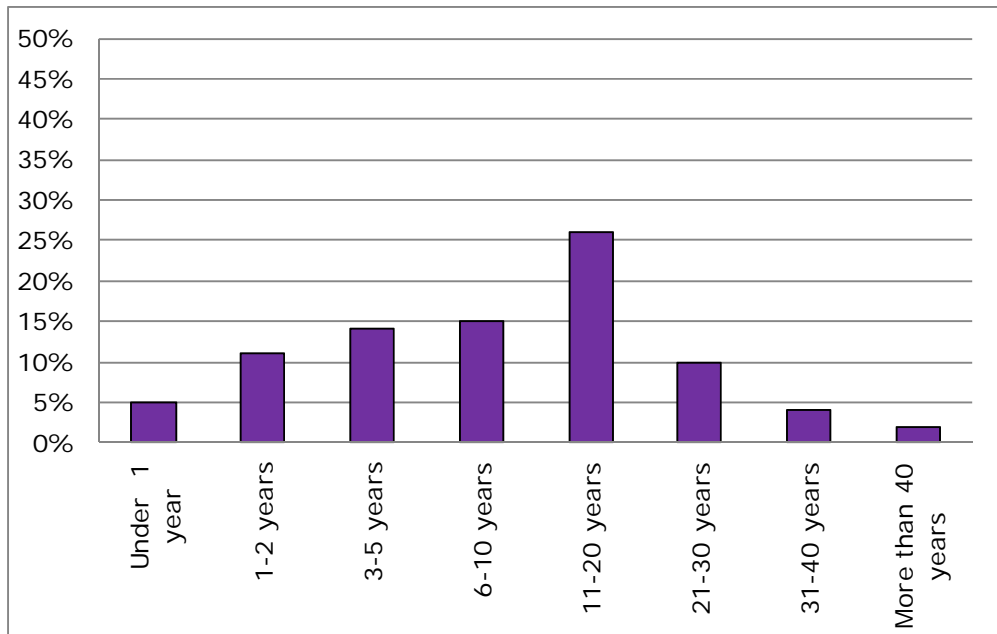
Carers' ratings of the individual sections of the survey (Figures 6-8) showed a fairly consistent pattern of rating suggesting that there is no particular area that is done better or worse than another.

### **Additional characteristics of the carer sample**

Figures 9, 10 and 11 provide some additional information regarding the carers. While this does not relate specifically to the audit standards it would seem

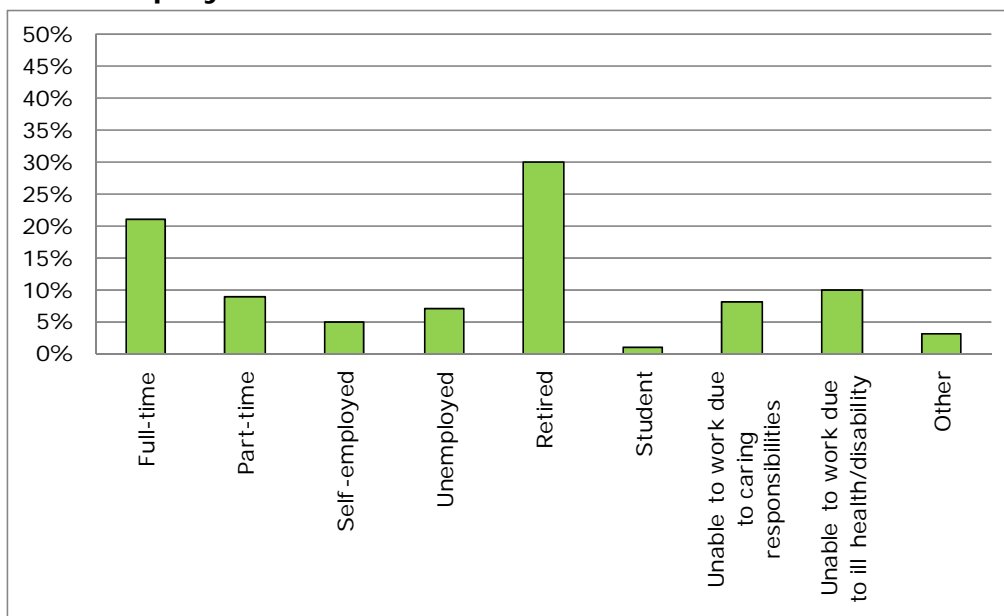
valuable to record it, given that the carer sample is collected from across a large proportion of the total number of Trusts.

**Figure 9: Number of years the carer has cared for the service user**



- The data for Figure 9 is from Q9 of the carer survey.
- The number of carers included in this analysis is 1,163. There were 151 instances where an individual carer had not provided a response.

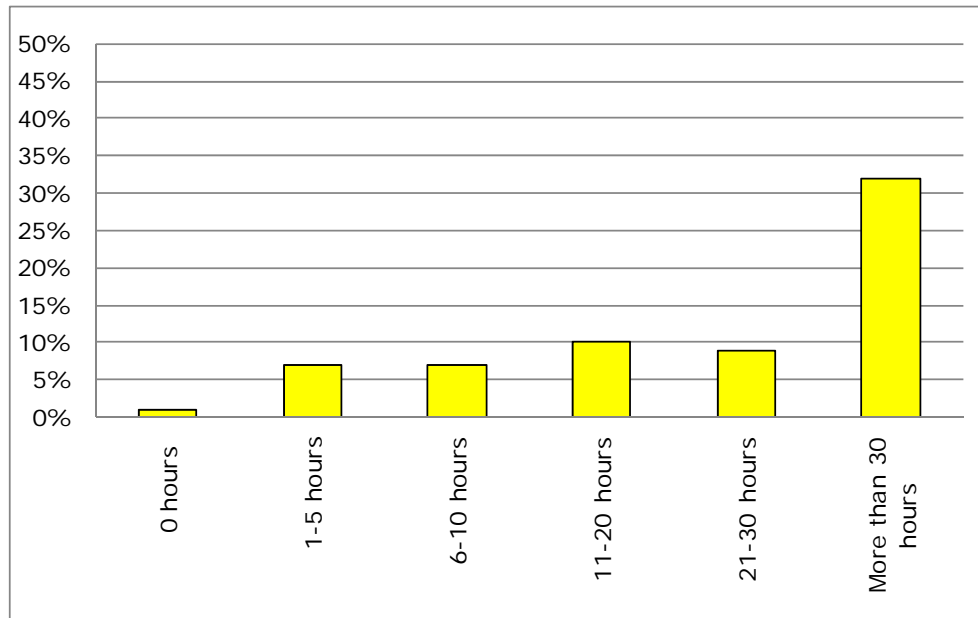
**Figure 10: Employment status of the carer**



- The data for Figure 10 are from Q8 of the carer survey.

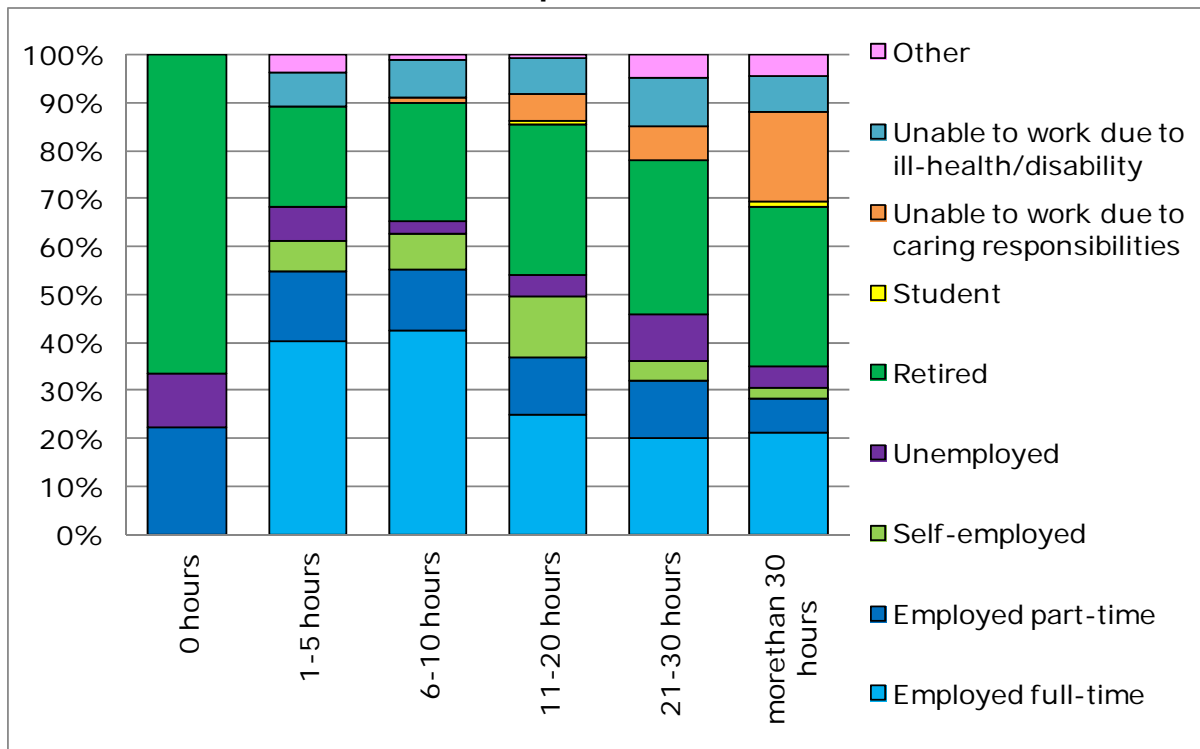
- The number of carers included in this analysis is 1,163. There were 65 instances where a response was not provided.

**Figure 11: Number of hours the carer spent caring for the service user in the last week**



- The data for Figure 11 is from Q10 of the carer survey.
- The number of cases included in this analysis is 1,163. There were 407 instances where the hours spent caring for the service user were not specified.

**Figure 12: Carers' employment status and the number of hours they cared for the service user in the previous week**



- The data for Figure 12 are from Q8 and 10 of the carer survey.
- The number of carers included in this analysis is 756.

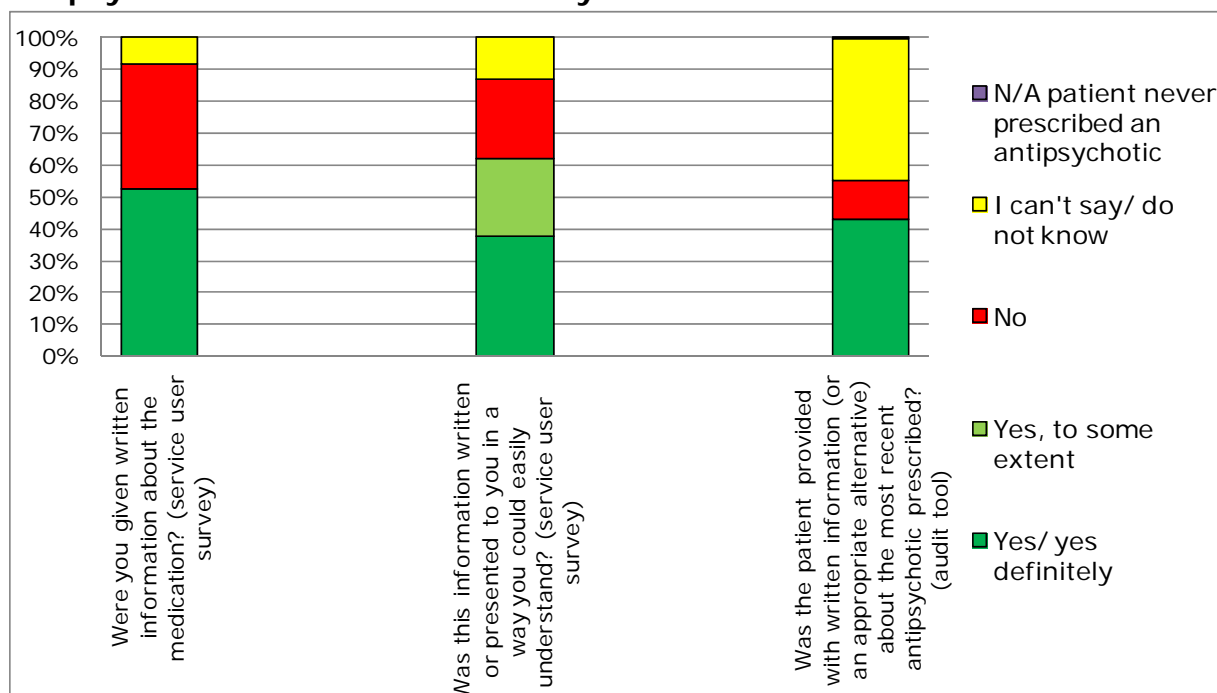
The fact that over 50% of carers had cared for the service user for more than 10 years is a reflection of the long-term nature of this commitment as well as the age structure of the population of service users included in the audit. Again, because of these factors, it is perhaps not surprising that the majority of carers surveyed are retired. Remarkably few responders indicated that they were unable to work due to caring responsibilities. However, over 20% of carers were employed full-time whilst caring for the service user for more than 30 hours a week.

# Shared decision making about medication

There is evidence in other areas of medicine that shared decision making regarding treatment can improve adherence with treatment (Hamann et al., 2003). This requires that service users are given information about the benefits and potential adverse effects of any medication and are given this in a form that they can understand. These issues are reflected in Standards 6 and 7 and are both recommended in the NICE Guideline (2009).

**Standard 6: The service user has been provided with evidence-based, written information (or an appropriate alternative), in an accessible format, about the antipsychotic drug that they are currently prescribed.**

**Figure 13: Provision of information about the most recently prescribed antipsychotic and understandability of this information**



- The left hand and middle columns of Figure 13 represent data from the service user survey and the right hand column data from the case note audit of practice tool.



- The data for Figure 13 are taken from Q4 and 5 of the service user survey and Q14 of the audit of practice tool.
- The number of cases included in the analysis for Figure 13 is 2,323 for the service user survey and 5,091 for the audit of practice tool.
- Missing cases (n=266 service user survey) have been combined with 'I can't say/I do not know', for the service user survey.
- Note that the cohort of cases from the audit of practice tool does not necessarily encompass all of the responders to the service user survey. Therefore we can only use the comparison made in the figure between service user views and what the clinicians report they have done in a broad qualitative way and cannot draw an absolute comparison.

To summarise, the Trust clinicians have recorded that they definitely provided 42% of service users with written information (or an appropriate alternative), whereas 52% of service users said that they were given such information. The discrepancy here is likely to be a result of poor recording in the case notes regarding the provision of such information.

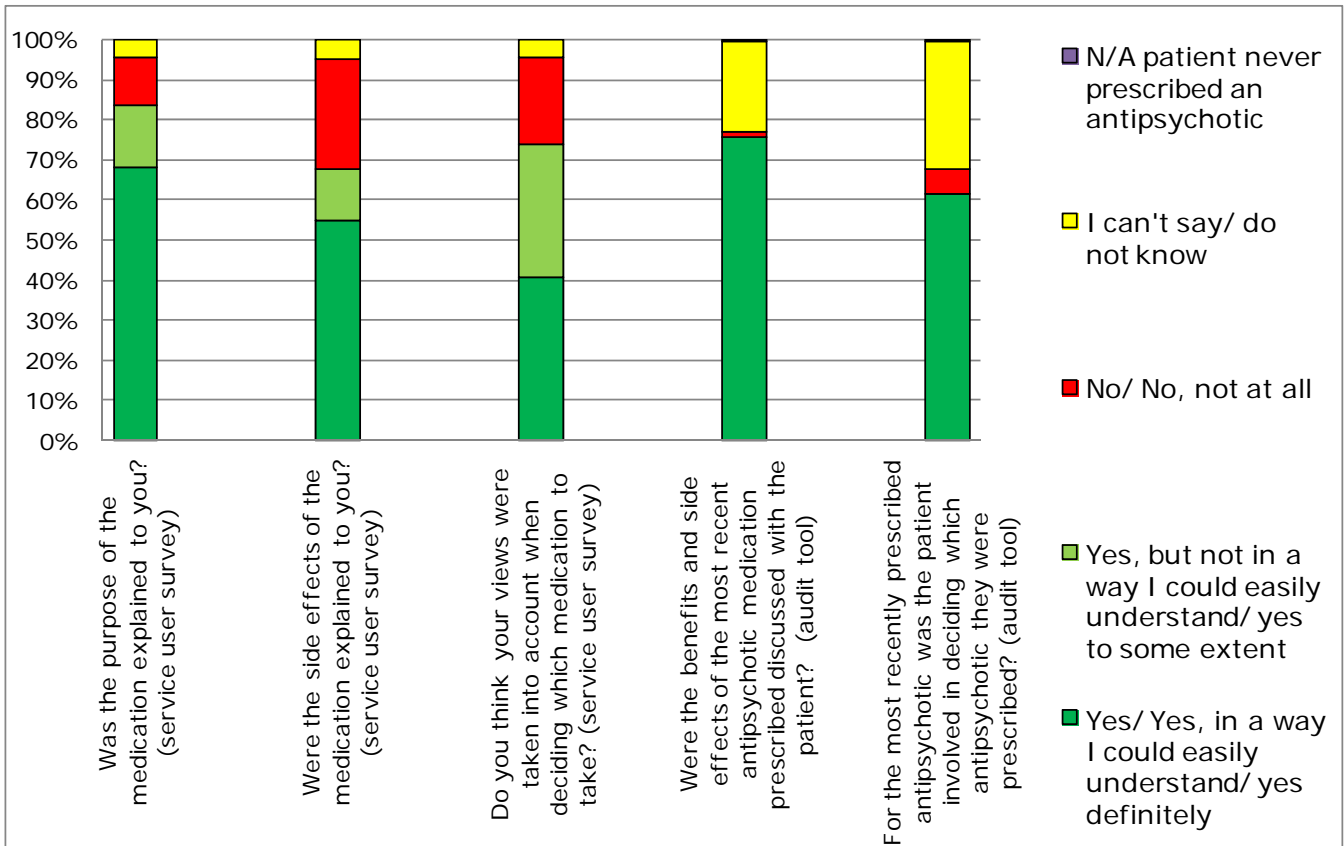
Only 62% of service users reported that this information was given in a way they could understand, either definitely or at least to some extent. Though a larger percentage of service users have responded to this than to the first question, this is likely to be because many have been given the information verbally.

The next step is consideration of whether the service user felt that the purpose and potential adverse effects of the proposed medication were explained and also whether or not the service user felt involved in the final decision regarding the prescription. These issues are reflected in Standard 7.

**Standard 7: The service user was involved in deciding which antipsychotic was to be prescribed, after discussion of the benefits and potential side-effects.**

Figure 14 contrasts the responses from the service user survey with the data from the audit of practice tool.

**Figure 14: Service users' involvement in the decision about their antipsychotic medication, including discussions of the benefits and potential side-effects**

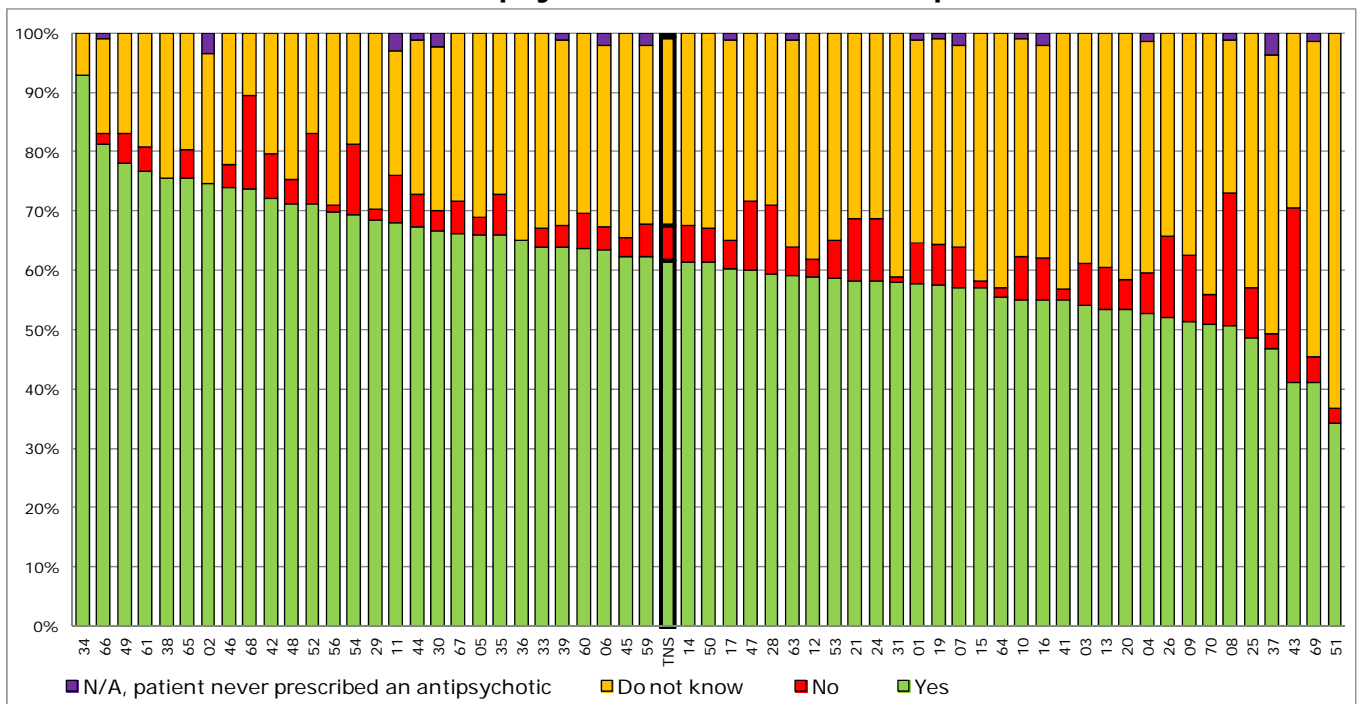


- The three left hand columns of Figure 14 represent data from the service user survey and the two right hand columns data from the audit of practice tool.
- The data for Figure 14 are taken from Qs 1, 2 and 3 of the service user survey and Qs 15 and 16 of the audit of practice tool.
- The number of cases included in the analysis for Figure 14 is 2,323 for the service user survey and 5,091 for the audit of practice tool.
- Missing cases (n=239 service user survey) have been combined with 'I can't say/I do not know', for the service user survey.
- Note that the cohort of cases from the audit of practice tool does not necessarily encompass all of the responders to the service user survey. Therefore we can only use the comparison made in the figure between service user views and what the clinicians report they have done in a broad qualitative way and cannot draw an absolute comparison.

The Trust case notes indicated that clinicians thought they had involved an average of 62% of service users in the choice of medication. However, in the service user survey only 41% of service users felt adequately involved in this choice, with 33% saying they were partly involved and 22% saying that their views were not taken into account.

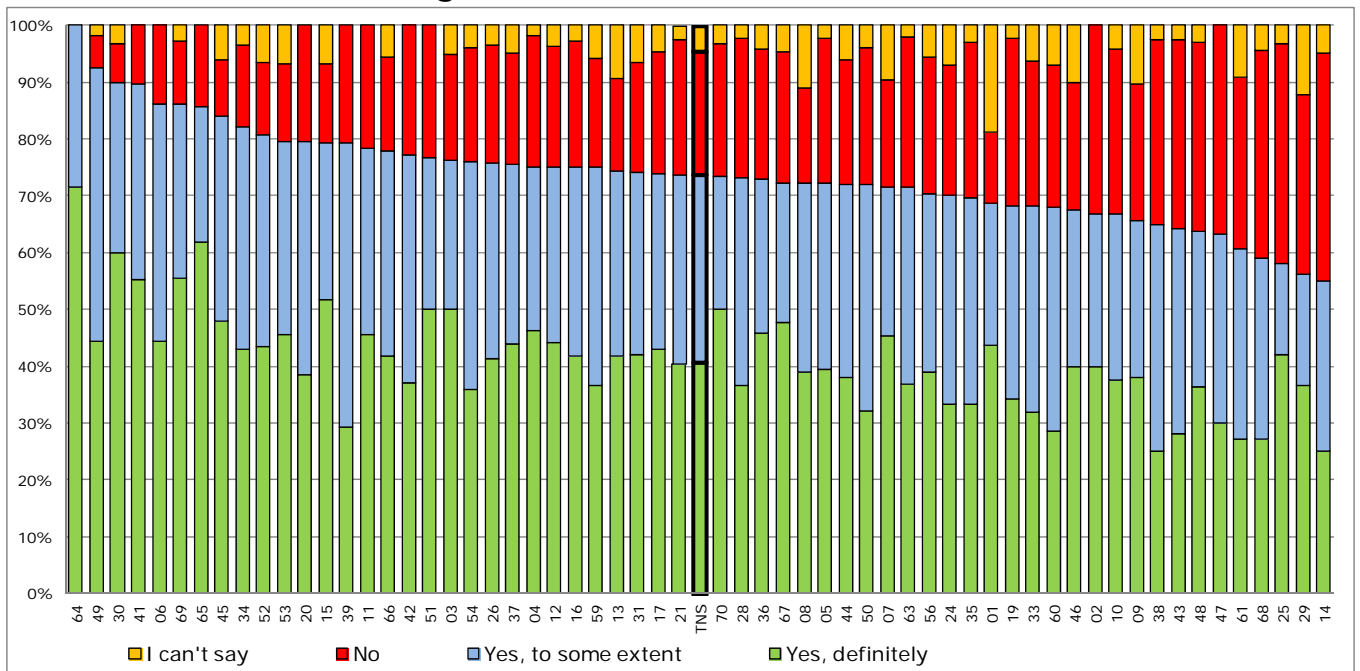
Figures 15 and 16 compare the responses by Trust to the key issue of service user involvement in making the final decision regarding which medication was prescribed. Figure 15 shows whether the clinicians had recorded involvement of the service user and Figure 16 the parallel view of the service users.

**Figure 15: Case note recording of involvement of the service user in the decision about which antipsychotic medication was prescribed**



- The data for Figure 15 is from Q16 of the audit tool.
- The number of cases included in this analysis is 5,091.

**Figure 16: Service users' report on whether their view was taken into account when deciding on medication**



- The data for Figure 16 is from Q3 of the service user survey.
- The number of service users included in this analysis is 2,323. There are 77 missing responses to this question.

Figure 15 indicates quite a degree of variation in whether or not Trust staff thought they had involved service users in the decision about medication. However, Figure 16 shows a fairly consistent view about this across Trusts by the service users themselves.

# Prescribing

The prescribing of antipsychotic medication is a key aspect in the management of someone with a diagnosis of schizophrenia. It is an important focus of the NICE Guideline (2009) and a number of standards in NAS mirror the NICE recommendations. Relevant sections of the audit of practice tool were constructed to try to capture information that would allow us to measure performance against these audit standards.

Across the sample of cases in the audit numbers may vary considerably between individual aspects of the data presentation. This is sometimes due to certain issues being partly dependent of the service user's stage of illness. It is also important to remember that all service users included in this audit have had their diagnosis for at least 12 months and have been in contact with the reporting Trust for at least 12 months. Thus, there should have been adequate time for clinicians to recognise whether there has or has not been an adequate response to the current treatment regime and adequate time to take appropriate action if there is evidence of poor response. Table 7 (page 74) shows the medications prescribed grouped into a number of broad categories with the numbers of service users in each category.

In the results that follow, the relevant standards will be considered under the following main headings:

- Adequacy of the current treatment regimen the service user is receiving.
- Identification of treatment resistant service users and prescription of clozapine.
- Management of service users who have treatment resistance.

## **Adequacy of the current treatment regimen the service user is receiving**

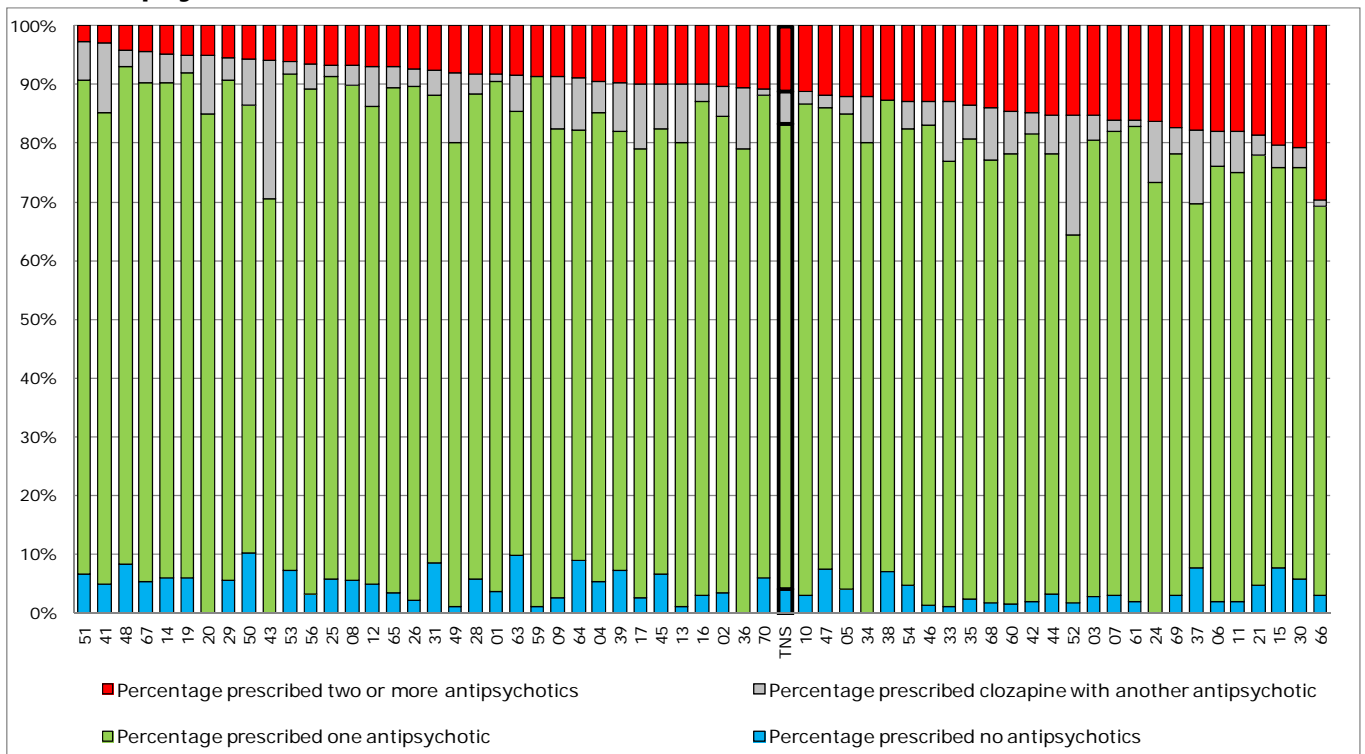
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Guidelines for the prescription of antipsychotic medications advise the use of only one medication at a time in the majority of situations. There is no evidence

for greater effectiveness, and the risk of adverse effects increases, as the number of medications used increases. Standard 8 relates to this and Figure 17 indicates the percentages of service users receiving more than one antipsychotic medication within each Trust as well as the national average (TNS column).

**Standard 8: The service user is currently only prescribed a single antipsychotic drug (unless they are in a short period of overlap while changing medication or because clozapine is co-prescribed with a second antipsychotic).**

**Figure 17: Percentage of service users prescribed no antipsychotic medications, one antipsychotic medication or more than one antipsychotic medication**



- The data for Figure 17 are taken from Q12 of the audit of practice tool.
- The number of cases included in this analysis is 5,078 (13 cases were excluded from the analysis of this standard due to data entry errors in antipsychotic medication doses).
- In some cases a second antipsychotic medication has been prescribed along with clozapine and this is shown in the figure.

Figure 17 indicates a wide variation across Trusts in relation to the occurrence of polypharmacy. The range across Trusts varied from 3% to 30% for non-clozapine antipsychotic medications. It seems unlikely that such a very wide range could be accounted for by differences in service user populations between Trusts.

There were 5,078 service users for whom adequate information about prescribing of antipsychotic medication had been provided (see Table 7; page 74). Of these, 312 (6%) were not receiving any antipsychotic medication, leaving 4,766 who were being prescribed antipsychotic medication, of whom 1,197 were being prescribed clozapine (two clozapine cases are excluded due to lack of sufficient information). Of the 4,766 service users on medication, 784 (16%) were receiving more than one antipsychotic medication. Of these 784, 352 (45%) were receiving a non-clozapine oral antipsychotic medication in addition to a depot antipsychotic. Of the 1,197 service users on clozapine, 265 (22%) were receiving an additional antipsychotic medication<sup>1</sup>. Of these 265 service users, 68 were receiving oral aripiprazole and 113 were receiving amisulpride. The numbers for each of the other antipsychotic medications prescribed with clozapine were relatively low.

The range of doses at which any individual antipsychotic medication may be effective varies widely between individuals and stages of illness. However, the BNF gives clear guidance on the maximum doses that should not be exceeded and evidence strongly suggests that in the majority of situations there is no advantage to exceeding these doses. Where a patient is receiving more than one antipsychotic medication it is convention to calculate the percentage of 'BNF maximum' at which each medication is being prescribed and then add these percentages to obtain an overall 'percentage of maximum' for that patient and allow a determination of whether they are receiving above the recommended upper limits. There are occasional situations where a person with treatment resistant illness may be given a trial of a higher than usual dose for a period of time. In such situations it is expected that the prescribing clinician will clearly

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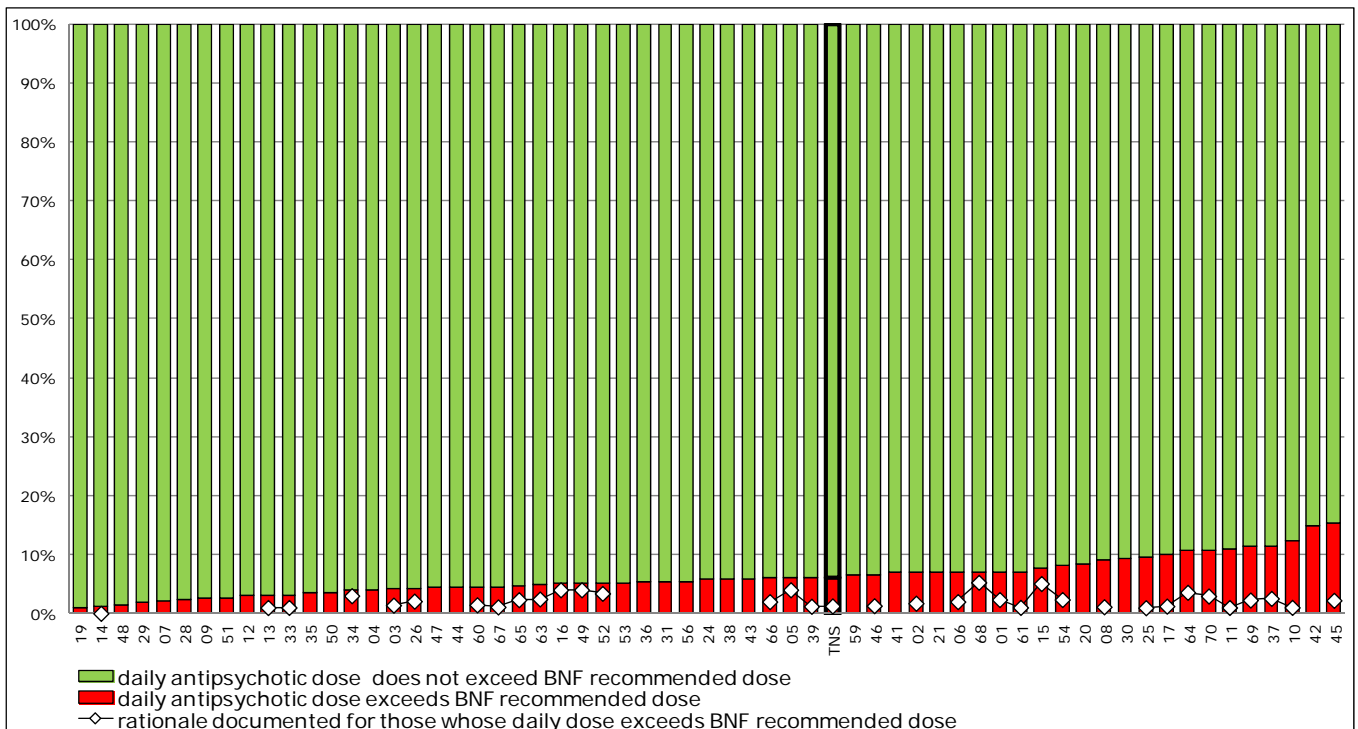
<sup>1</sup> This is often done in an attempt to augment the effect of clozapine for service users who remain treatment resistant. In some cases it is part of a strategy to try to minimize weight gain through the addition of aripiprazole.

document the reasons for this in the case notes and will have discussed this with the service user.

Standard 9 relates to these issues and Figure 18 shows how frequently high doses have been prescribed within each Trust and in what percentage of cases this has been accompanied by documentation of the reason.

**Standard 9: The current total daily dose of antipsychotic drug does not exceed the upper limit of the dose range recommended by the BNF. If it does, the rationale for this has been documented.**

**Figure 18: Percentage of service users whose total daily dose of antipsychotic medication exceeds the BNF recommended maximum**



- The data for Figure 18 are taken from Q12 and 13 of the audit of practice tool.
- The number of service users included in this analysis is 5,078.
- For some service users there has been documentation in the case notes of a reason for the high dose prescribed and the relevant Trust percentages are shown in the figure.



Figure 18 shows a range of prescribing behaviour across Trusts, with a range from 1% of service users receiving high doses at one end of the spectrum to 16% at the other end. The degree to which a reason has been recorded for this is quite variable between Trusts, as shown by the white diamonds in the figure.

In Table 7, where the medications prescribed are grouped into a number of broad categories, the mean of the BNF maximum dose prescribed can be seen for each category of prescribing as well as the range from minimum to maximum dose prescribed. The most striking finding is that when more than one drug is prescribed the mean dose is always higher than if only a single dose is prescribed. Though the mean doses for all categories (except the category depot plus two oral medications) are below 100%, the range of doses prescribed is high and it can be seen that the maxima exceed 100% for all categories except clozapine, though there is no trend for the range to relate to the numbers of medications prescribed.

For those service users (5%) whose total antipsychotic dose exceeded 100%, i.e. those who were receiving high doses above BNF maxima, the mean dose was 155% (SD 63).

It is clear that high dose prescribing is occurring across both oral and depot prescribing. We have not tried to break this down further by individual medications as many individual antipsychotic drugs were prescribed for small numbers of the total service user population. This would make any comparisons between different medications unlikely to be reliable.

**Table 7: Means and ranges of doses of medication prescribed by broad groups of medications and combinations of medications**

Type of prescribing regime	Number of cases	% of total sample (of 5,078)	% range across Trusts	Mean of BNF maximum dose prescribed (%)	Range of BNF maximum dose prescribed (%)
No antipsychotics	312	6	1-15	-	-
Single oral non-clozapine antipsychotic	1,869	37	61-100	47	0.2-400
Two or more non-clozapine oral antipsychotics	167	3	0-21	58	1-246
Clozapine only	932	18	6-31	43	1-100
Clozapine plus another oral antipsychotic	260	5	1-24	68	1-189
Clozapine plus a depot antipsychotic	5	-	0-1	61	23-133
Depot antipsychotic only	1,181	23	48-80	49	0.3-500
Depot plus one oral non-clozapine antipsychotic	337	7	0-21	74	3-406
Depot plus two oral non-clozapine antipsychotics	15	-	0-2	134	10-360

- Number of cases included in this analysis is 5,078. Some cases (n=13) were excluded because of errors in data entry on the audit of practice tool.
- In total 4,766 service users were being prescribed an antipsychotic medication.
- 'Depot' medication includes 'long-acting' injectable preparations.
- Acute, short-term intra-muscular medication is excluded.

Not all service users will demonstrate an adequate response to their treatment regime. Two common reasons for this can be poor adherence to the treatment regime and abuse of alcohol or drugs. It is particularly important that these issues are investigated in service users who are not in remission and that this is then documented in the case notes. Standard 10 relates to this and Table 8 shows the situation for the total sample of service users across all of the Trusts.

**Standard 10: If there was no or inadequate response to the first antipsychotic drug prescribed after a minimum of four weeks at optimum dose:**

- i Medication adherence was investigated and documented.**
- ii The potential impact of alcohol or substance misuse on response was investigated and documented.**

**Table 8: Service users who are not in remission and whether they were investigated for poor treatment adherence or alcohol/substance misuse (includes patients both receiving and not receiving clozapine)**

	<b>Service users not currently prescribed clozapine</b> n (%) (range) <b>No. of cases included</b>	<b>Service users currently prescribed clozapine</b> n (%) (range) <b>No. of cases included</b>
<b>Medication adherence has been investigated</b>	<b>923 (91%)</b> <b>(58-100%)</b> <b>1,010</b>	<b>318 (94%)</b> <b>(50-100%)</b> <b>337</b>
<b>Alcohol and substance misuse has been investigated</b>	<b>839 (83%)</b> <b>(47-100%)</b> <b>1,013</b>	<b>292 (86%)</b> <b>(33-100%)</b> <b>339</b>

- The data for this analysis are taken from Qs 10, 21, 22, 27 and 28 of the audit of practice tool.
- There were missing cases for each part of the analysis due to lack of fully completed audit of practice forms.
- The ranges given are from the worst performing to the best performing Trust.

While the data shown here indicate some degree of variation between Trusts, medication adherence has been investigated in over 91% of service users who are not in remission and not on clozapine. In 43 out of 60 Trusts this was carried out for 100% of treatment resistant service users on clozapine.

Of those service users who were not in remission, and had not yet had a trial of clozapine or for whom clozapine was not appropriate, but for whom there was no record of investigation of adherence (n=87), 24 had been prescribed a depot or long-acting injectable antipsychotic medication. This probably represents an attempt to overcome poor adherence. In some service users it may be the case that strategies such as supervised medication administration have been adopted but the audit was not structured to collect such information as it was felt this would not be reliably recorded. It is quite possible that in some cases adherence has been investigated but that this has not been clearly documented.

The investigation of alcohol or other substance misuse as a factor in poor clinical response appears to be less well carried out, being recorded in an average of only 83% of service users not in remission and not on clozapine. In 29 out of 60 Trusts this was carried out for 100% of treatment resistant service users on clozapine. Again, lack of adequate recording in the case notes may be a reason for these relatively poor figures.

## **Identification of treatment resistant service users and prescription of clozapine**

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There are a significant number of people whose illness does not show a reasonable response to standard antipsychotic medications, or who cannot tolerate these medications due to excessive adverse effects. Most studies suggest this is around 30% of those diagnosed with schizophrenia. Most studies also suggest that around 50% of these people will have a much better response to clozapine (the use of clozapine is restricted because of a particular adverse effect on white blood cell count). Thus it is important that service users who appear to be treatment resistant are identified and offered the opportunity to have a trial of clozapine.

Overall 1,199 service users included in the audit were receiving clozapine, of whom 363 were not in remission. This 1,199 represent 24% of the total case note sample and suggests that, across England and Wales as a whole, clozapine is being widely prescribed. However, it is important to remember that this particular sample of service users in the community does not capture those who are looked after solely by primary care services, up to 30% of those with schizophrenia (Reilly et al., 2012), and therefore very unlikely to be receiving clozapine because of the requirements for monitoring every four weeks. It also excludes current inpatients. Thus, it is probably reasonable to suggest that in the region of 15%-20% of all service users may be receiving clozapine.

All Trusts reporting to NAS had service users who were being prescribed clozapine. The mean percentage of the cases returned who were receiving clozapine was 23% per Trust, with a range across Trusts of 7% to 42%.

An important aspect of the NICE Guideline (2009) for the treatment of schizophrenia relates to the issue of identification of service users who are treatment resistant and who should be offered clozapine. It is advised that if a person fails to respond to the first antipsychotic medication prescribed, following a trial of that medication at optimum dosage for 4 to 6 weeks, that this should then be withdrawn and a second antipsychotic medication should be prescribed for a similar period. If there is then no adequate response, a trial of treatment with clozapine should be considered. Standard 12 of the audit was written to encapsulate this issue and Table 9a provides data showing those service users who were regarded as treatment resistant by their treating clinicians but who were not currently receiving clozapine. As all service users had been in contact with their reporting Trusts for at least one year, there was adequate time for proper management of those who were resistant to standard antipsychotic medications.

**Standard 12: If there was no or inadequate response to the second antipsychotic drug after a minimum of four weeks at optimum dose, clozapine was offered.**

**Table 9a: Service users who are regarded as treatment resistant but who are not currently receiving clozapine (total n=1,021)**

Reason for not currently receiving clozapine	Number of treatment resistant cases not receiving clozapine	Percentage of all reasons given (n=1,042)
Not yet had an adequate trial of two other antipsychotics	161	15%
Clozapine contraindicated	106	10%
Clozapine tried, patient did not respond adequately	63	6%
Clozapine offered but the patient refused	277	27%
None of the above	435	42%

- The data for this standard are taken from Q17 of the audit of practice tool.
- The number of treatment resistant service users not on clozapine was 1,021.
- For some service users more than one response may have been provided, as sometimes an individual may have more than one reason for not commencing clozapine. Thus the total does not add to 1,021.
- Adequate data were not available for 68 cases.

The data above show that of the total sample of 5,091 service users, 1,021 (20%) were treatment resistant (and not on clozapine) and that in 435 (43%) of these treatment resistant service users there was no clear reason for them not to have been given a trial of clozapine.

A further question that then arises is whether those treatment resistant service users not given a trial of clozapine seem to be from any specific population group. Table 9b shows a breakdown by age, gender, length of illness and ethnic origin of treatment resistant individuals who are currently receiving clozapine versus those not prescribed clozapine. There is perhaps a trend in this data for

female and Asian/Asian British treatment resistant service users to be less likely to be prescribed clozapine than male or White service users.

**Table 9b: Prescription of clozapine for treatment resistant service users by various demographic parameters**

Parameter	Treatment resistant and NOT prescribed clozapine but with no clear reason (n=435)	Treatment resistant and prescribed clozapine (n=363)
<b>Mean Age (Years)</b>	47	41
<b>Sex:</b> M	286 (66%)	264 (73%)
F	149 (34%)	98 (27%)
<b>Time since diagnosis:</b>		
1-2 yr	15 (3%)	6 (2%)
2-4 yr	36 (8%)	28 (8%)
4-10 yr	101 (23%)	90 (25%)
10+ yr	283 (65%)	239 (66%)
<b>Ethnicity:</b>		
White	346 (80%)	292 (80%)
Asian/Asian British	48 (11%)	22 (6%)
Black/Black British	31 (7%)	23 (6%)
Chinese or other	2 (0.5%)	7 (2%)
Mixed	4 (1%)	13 (4%)
Not stated	4 (1%)	6 (2%)

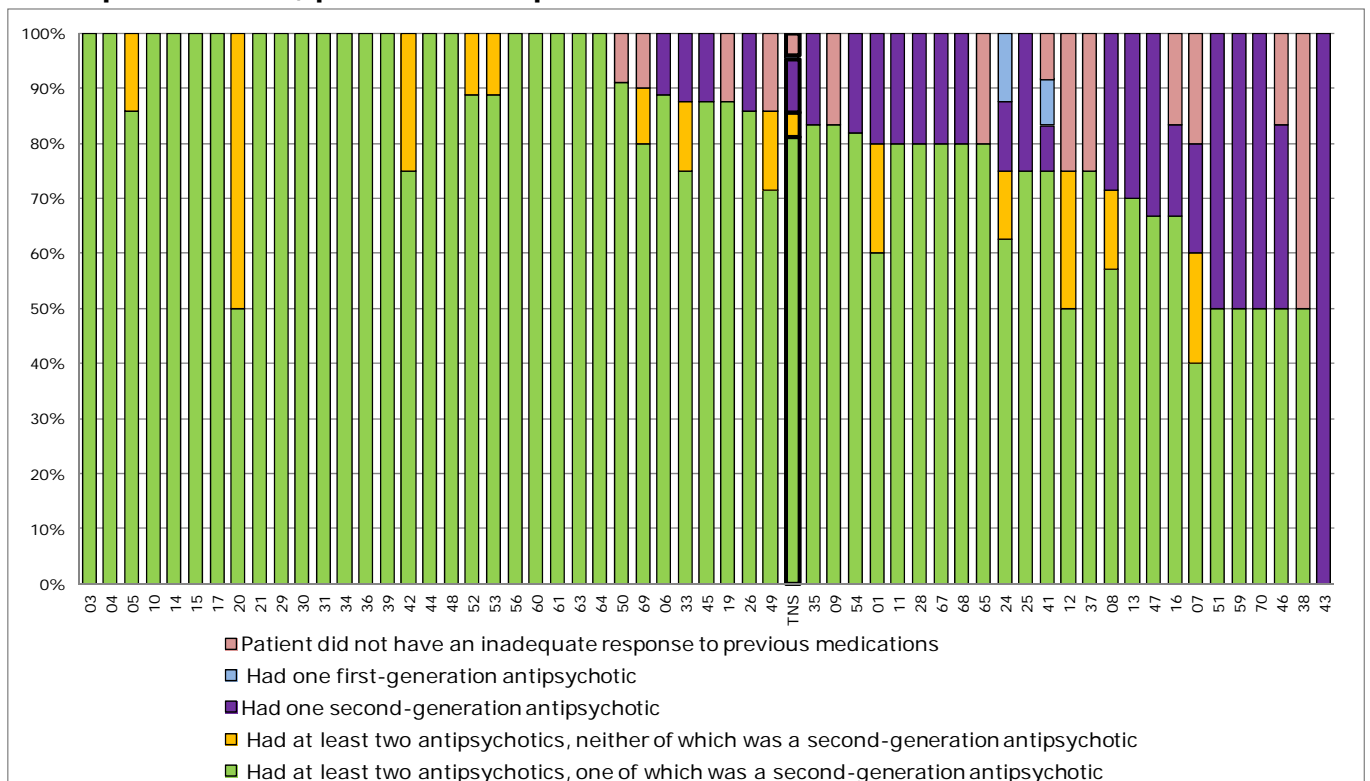
## Management of service users who have treatment resistance

As described above in relation to Standard 12, there is a preferred 'route' that should be followed before a service user is commenced on clozapine. The NICE Guideline (2009) also advises that one of the two antipsychotics tried should be a non-clozapine second-generation antipsychotic. Standard 11 relates to this guidance and Figure 19 shows the percentages of service users from each Trust

who have followed each of five different possible pathways prior to commencing clozapine.

**Standard 11: If there was no or inadequate response to the first antipsychotic drug after a minimum of four weeks at optimum dose the first antipsychotic drug was stopped and a second antipsychotic drug given. At least one of the first two drugs prescribed was a second-generation antipsychotic.**

**Figure 19: Treatment prior to clozapine for service users (not in remission and currently prescribed clozapine) who have had an inadequate response to a trial of antipsychotics for at least 4 weeks at optimal dose, prior to clozapine**



- The data for Figure 19 are taken from Q25 of the audit of practice tool.
- The bar for Trust 43 represents a single relevant case from that Trust.
- Trusts 02 and 66 did not have any cases fitting these criteria.
- The number of cases included in the analysis of this standard is 363. There were 16 missing cases.

It can be seen that the majority of service users have followed the preferred pathway and received at least two antipsychotic medications prior to clozapine,



one of which was a 'second-generation' antipsychotic. A significant number of service users appear to have received only one antipsychotic prior to commencing clozapine (one second-generation or one first-generation medication - purple and blue bars respectively). The reasons for this are not clear but it may represent a lack of adequate information in the person's case notes. Often at least one of the trials of treatment, especially for older individuals, may have been as an inpatient and these notes are not always readily available to a community team. Nevertheless, adequate recording of such information is vital for proper care. The cases recorded in the dark pink bars have not had a previous inadequate response to antipsychotic treatment and are presumed to be cases who commenced clozapine due to significant adverse effects of their previous treatment(s).

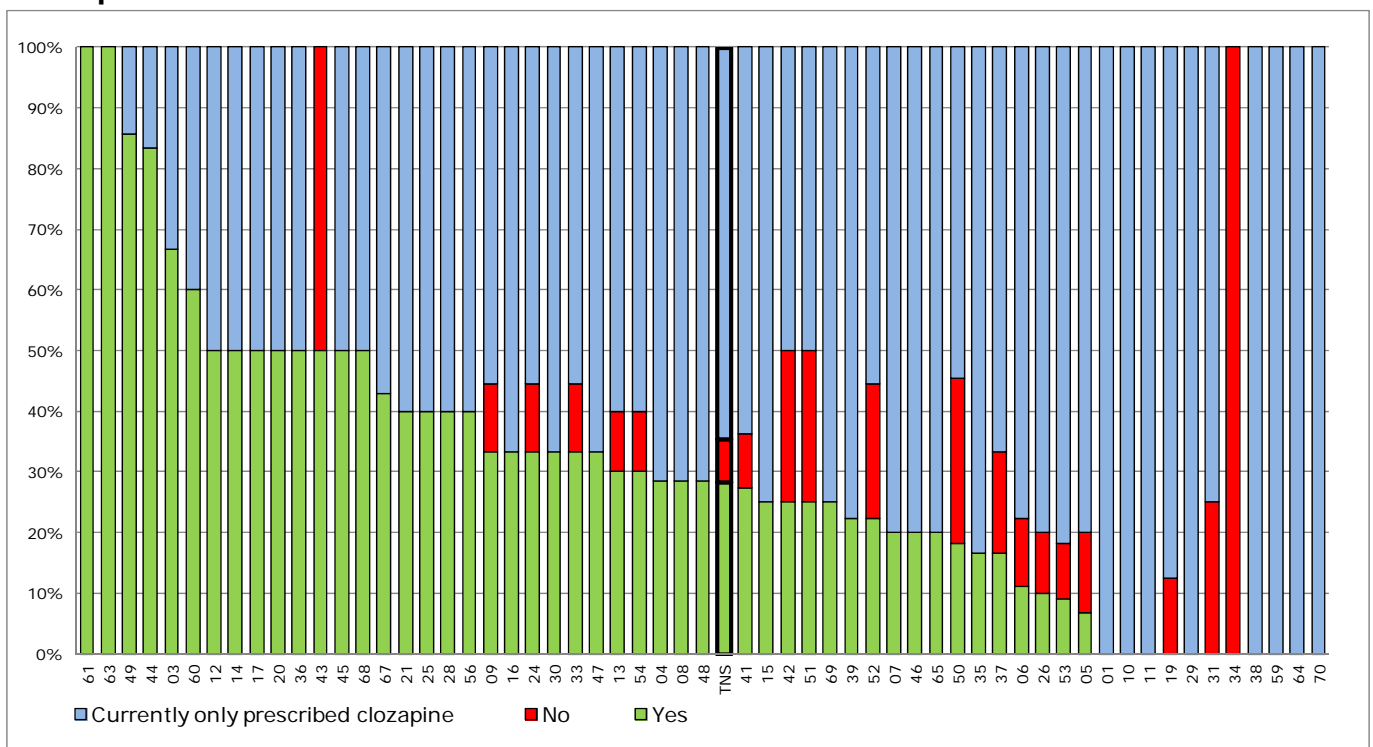
Other data collected from questions 18, 19 and 20 of the case note audit of practice tool examine whether service users not in remission and not currently on clozapine have been receiving their existing treatment for at least four weeks. The data from these questions show that for these service users, 72% have been receiving their current antipsychotic medication for at least four weeks and that prior to this 75% had received a different antipsychotic medication for at least four weeks. These data would appear to parallel some of the data from Figure 19, showing that service users not yet on clozapine are being given trials of other medications for at least four weeks. However, the data also suggest that though these service users have had such trials they have not yet graduated to a trial of clozapine despite being in contact with services for at least one year.

Not all treatment resistant service users will have an adequate response following an appropriate trial of treatment with clozapine. There is a lack of any clear guideline as to how best to manage this situation. The audit data show that many such service users have received a trial of clozapine alone, at optimal dose, for at least 8 weeks. One approach, suggested in the NICE Guideline (2009), is to consider adding a second antipsychotic drug in an attempt to augment the effect of clozapine (ideally this should only be considered following a period of psychological therapy). Standard 13 relates to this and Figure 20

shows the percentages of clozapine resistant service users who have followed this pathway across all of the Trusts.

**Standard 13: If there was no or inadequate response to treatment despite an adequate trial of clozapine, a second antipsychotic was given in addition to clozapine for a trial period of at least eight weeks at optimum dose.**

**Figure 20: Percentage of service users (not in remission and prescribed clozapine) currently prescribed a second antipsychotic medication with clozapine and who have had a trial on this combination for 8 weeks at optimum dose**



- The data for Figure 20 are taken from Qs 10, 12, 16a and 23 of the audit of practice tool.
- The bar for Trust 34 represents two relevant cases from that Trust.
- Trusts 02 and 66 did not have any cases fitting these criteria.
- The number of cases included in the analysis of this standard is 363. There were 16 missing cases.
- “Yes” = have had a trial of an additional antipsychotic for at least 8 weeks.  
“No” = have not had a trial of an additional antipsychotic for at least 8 weeks; interpreted as meaning patient currently undergoing such a trial.

The findings in Figure 20 demonstrate a wide variation in practice between Trusts, which probably reflects the lack of clear evidence for adoption of any particular approach or use of any particular medication for service users whose illness is resistant to clozapine. Table 10 shows the proportion of service users on clozapine, both in remission and not in remission, who have received augmentation with another antipsychotic medication.

**Table 10: Numbers of service users on clozapine alone and on clozapine plus an additional antipsychotic medication versus whether clinically remitted or not**

	<b>Augmentation status</b>	<b>Number</b>	<b>% of those on clozapine (n=1,199)</b>
<b>Service users in full/ partial remission with minimal symptoms and disability</b>	<b>Service users in remission and prescribed clozapine alone</b>	<b>681</b>	<b>57</b>
	<b>Service users in remission and clozapine has been augmented</b>	<b>155</b>	<b>13</b>
<b>Service users <u>not</u> in remission/ partial remission with substantial symptoms and disability</b>	<b>Service users <u>not</u> in remission and prescribed clozapine alone</b>	<b>251</b>	<b>21</b>
	<b>Service users <u>not</u> in remission and clozapine has been augmented</b>	<b>112</b>	<b>9</b>

- Data for this analysis are taken from Q10 and 12 of the audit of practice tool.

Of those service users on clozapine and in remission, 18% have received augmentation of clozapine. Of those on clozapine and not in remission, 31% have received augmentation but, at the time of data collection, with no evidence of benefit.

# Psychological therapies

The place of psychological therapies in the management of people with a diagnosis of schizophrenia has become much more established over the last ten years. In particular it has been recognized that cognitive approaches for positive psychotic symptoms (Wykes et al., 2008) and interventions with families (Pharoah et al., 2006) are effective. A number of categories of approach have a reasonably well established evidence base: individual cognitive and behavioural therapies for psychosis; family interventions for psychosis; neuropsychological and cognitive remediation approaches; social skills training and integrated approaches (NICE, 2009).

The NICE Guideline (2009) recommends that such therapies should be available in NHS Trusts for those with schizophrenia and should be used in combination with pharmacotherapy. In particular it says to:

- Offer Cognitive Behavioural Therapy (CBT) to all people with schizophrenia.
- Offer family intervention to families of people with schizophrenia living with or in close contact with the service user.
- Consider offering arts therapies, particularly to help negative symptoms of schizophrenia.
- Start CBT, family intervention or arts therapies either during the acute phase or later, including in inpatient settings.

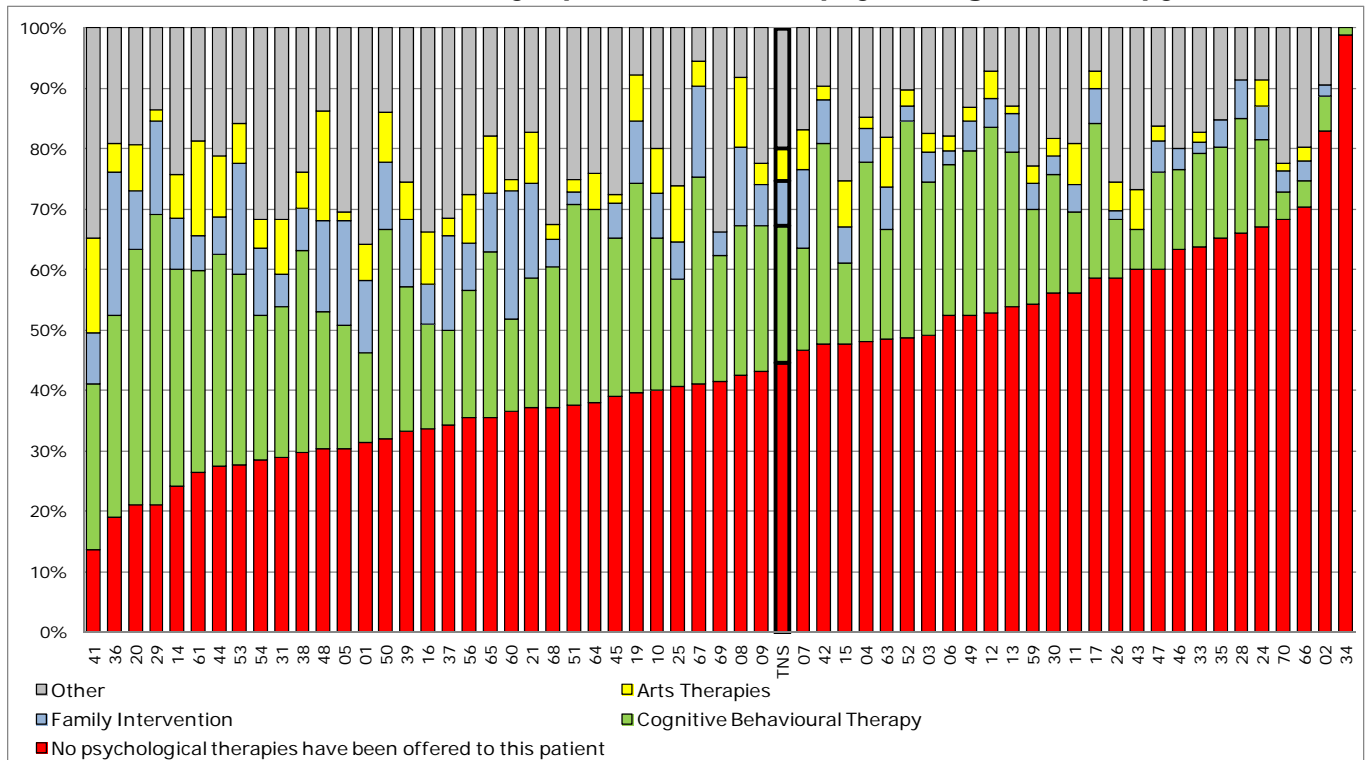
This guideline also recommends that engagement with psychological therapies should be reviewed for service users who have not responded adequately to treatment. Standard 14 of the audit relates to this issue.

**Standard 14: CBT and family therapy have been offered to service users whose illness is resistant to treatment with antipsychotic drugs.**

Data were collected regarding all service users in the case note audit of practice and whether or not they had been offered any form of psychological therapy.

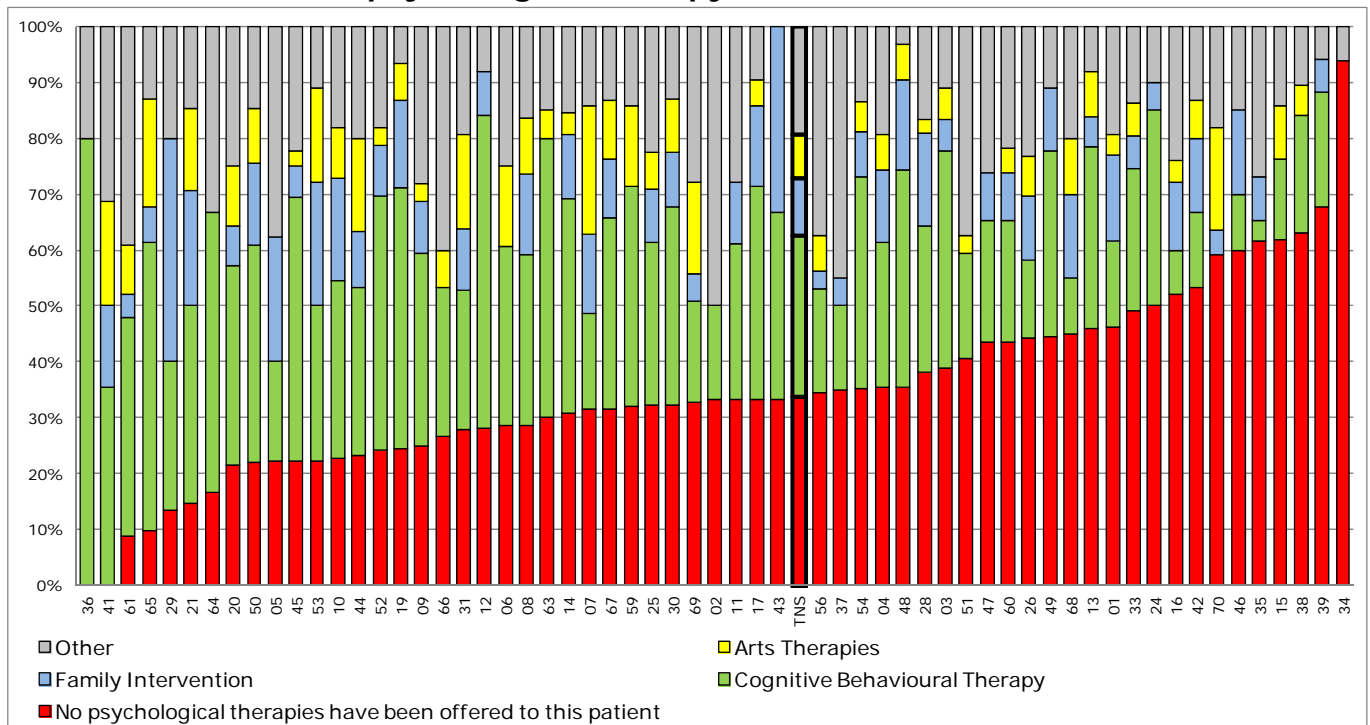
This is shown in Figure 21. The data for those service users regarded as treatment resistant, and which relates specifically to Standard 14, was then separately analysed and this is shown in Figure 22. There was little difference in the findings between availability of these therapies to treatment resistant service users and the whole population of service users.

**Figure 21: The percentage of service users by Trust in full or partial remission (with minimal symptoms) offered psychological therapy**



- The data for Figure 21 are taken from Q44 of the audit of practice tool.
- The decision regarding whether a service user was in full remission or partial remission (with minimal symptoms and disability) was made on the basis of the response to Q10 of the audit of practice tool.
- The number of cases included in this analysis is 3,647 (out of the total cases of 5,091).
- Some service users have been offered more than one type of psychological therapy.
- Although data are presented on service users being offered psychological therapies, we do not know whether or not psychological therapies were taken up by service users.

**Figure 22: Percentage of service users by Trust regarded as treatment resistant offered psychological therapy**



- The data for Figure 22 are taken from Q44 of the audit of practice tool.
- The decision regarding whether a service user was treatment resistant, i.e. not in remission or partial remission (with substantial symptoms and disability) was made on the basis of the response to Q10 of the audit of practice tool.
- The number of cases included in the analysis of this standard is 1,444 (out of the total sample of 5,091).
- Some service users have been offered more than one type of psychological therapy.
- Although data are presented on service users being offered psychological therapies, we do not know whether or not psychological therapies were taken up by service users.

The audit found that 34% of service users regarded as treatment resistant had not been offered at least one form of psychological therapy. The variation between Trusts was from 0% to 94%.

# Physical health: monitoring and intervention

As discussed in the Introduction (page 23), life expectancy is reduced in people with schizophrenia. While the relationship between schizophrenia and cardiovascular disease and diabetes is complex it is clear that weight gain secondary to antipsychotic drug treatment is an important factor. This can be very significant and can occur quite rapidly. Thus, it is vital to assess patients for cardiometabolic risk factors and monitor these once treatment is commenced. Further, it is important that when problems are identified appropriate action is taken.

## Monitoring of physical health

The NICE Guideline (2009) recommends that monitoring of various physical health parameters in service users with schizophrenia should be carried out regularly and at least once per year in primary care, with a focus on cardiovascular disease risk assessment. Standard 4 relates to this.

**Standard 4: The following physical health indicators have been monitored within the past 12 months:**

- i. **Body mass index, waist hip ratio or waist circumference.**
- ii. **Blood levels of glucose, lipids (total cholesterol and HDL).**
- iii. **Blood pressure.**
- iv. **Use of tobacco.**
- v. **Excessive use of alcohol.**
- vi. **Substance misuse.**
- vii. **Prolactin (if indicated).**
- viii. **History of cardiovascular disease, diabetes, hypertension or hyperlipidaemia in members of the service user's family.**

The NICE Guideline (2009) is not specific about the frequency of monitoring in secondary/specialist care nor about any division of responsibility between secondary and primary care. However, it does indicate the importance of

communication of the results between the two and an expectation that secondary care should ensure that the monitoring occurs.

The long-term studies of the Framingham Cohort have played a major role in establishing five important risk factors for the development of coronary heart disease in the general population (see Wilson et al., 1998). In particular these studies demonstrated the additive effects of these factors on the level of risk.

The five key factors identified are:

1. BMI.
2. Blood glucose (or HbA1c).
3. Blood lipids.
4. Blood pressure.
5. Smoking status.

For a comprehensive assessment of cardiometabolic risks these five should be assessed and in addition details of family history of cardiovascular disease, diabetes, hypertension and hyperlipidaemia should be collected.

The first sub-section of results relating to monitoring of physical health examines how comprehensively these five factors are being monitored in people with a diagnosis of schizophrenia.

Further sub-sections examine specific aspects of monitoring individual factors:

- Weight and BMI.
- Glucose, lipids and blood pressure.
- Smoking.

Two sub-sections then examine:

- Monitoring of prolactin.
- Monitoring of alcohol misuse and substance misuse.

A final sub-section examines monitoring of service users with co-existing cardiovascular disease, diabetes or a high BMI, i.e. those with particularly high risks.

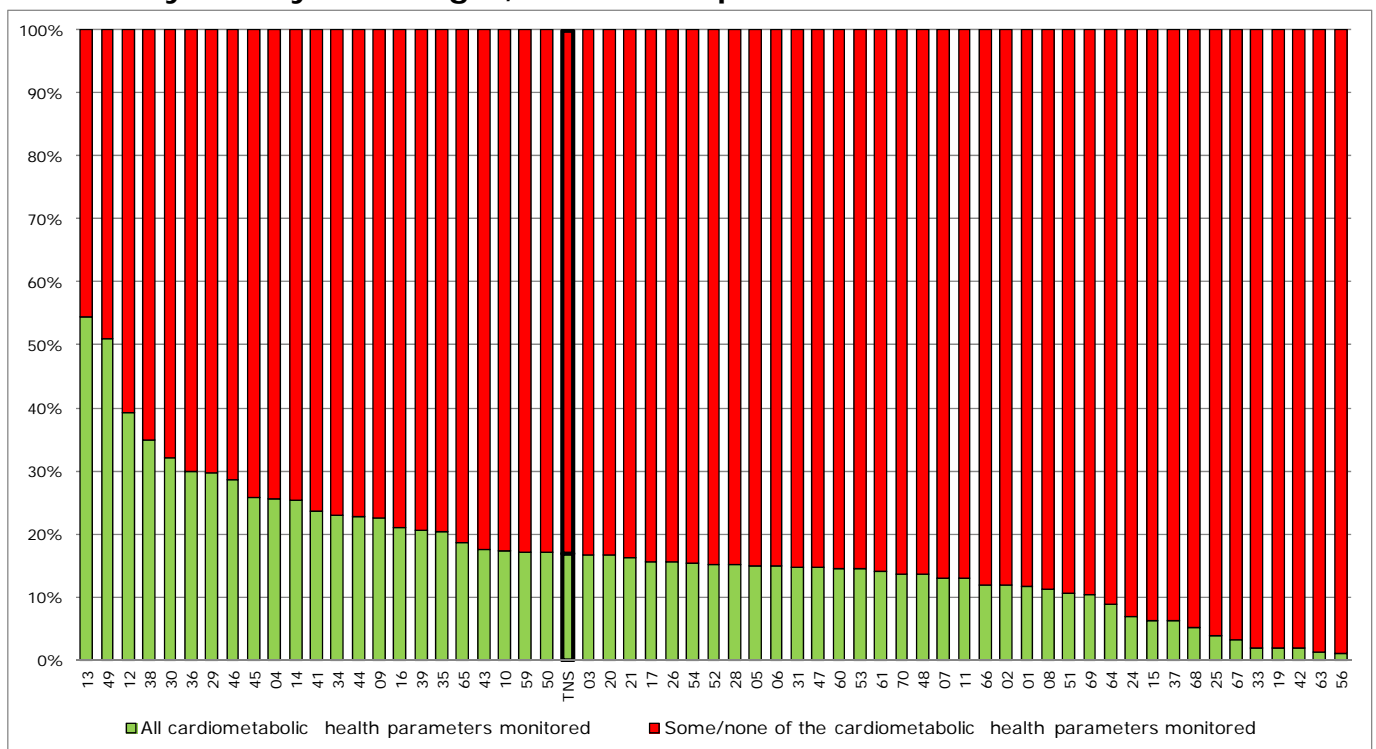


### How comprehensive is monitoring of cardiometabolic health?

The case note audit of practice tool collected information on whether or not information on these five parameters and family history and weight had been assessed in the previous 12 months for each service user and also collected a record of the most recent result for each of these measures, where it was available. In some case notes weight was recorded but BMI had not been calculated (more detail regarding weight is given in the next sub-section from page 92).

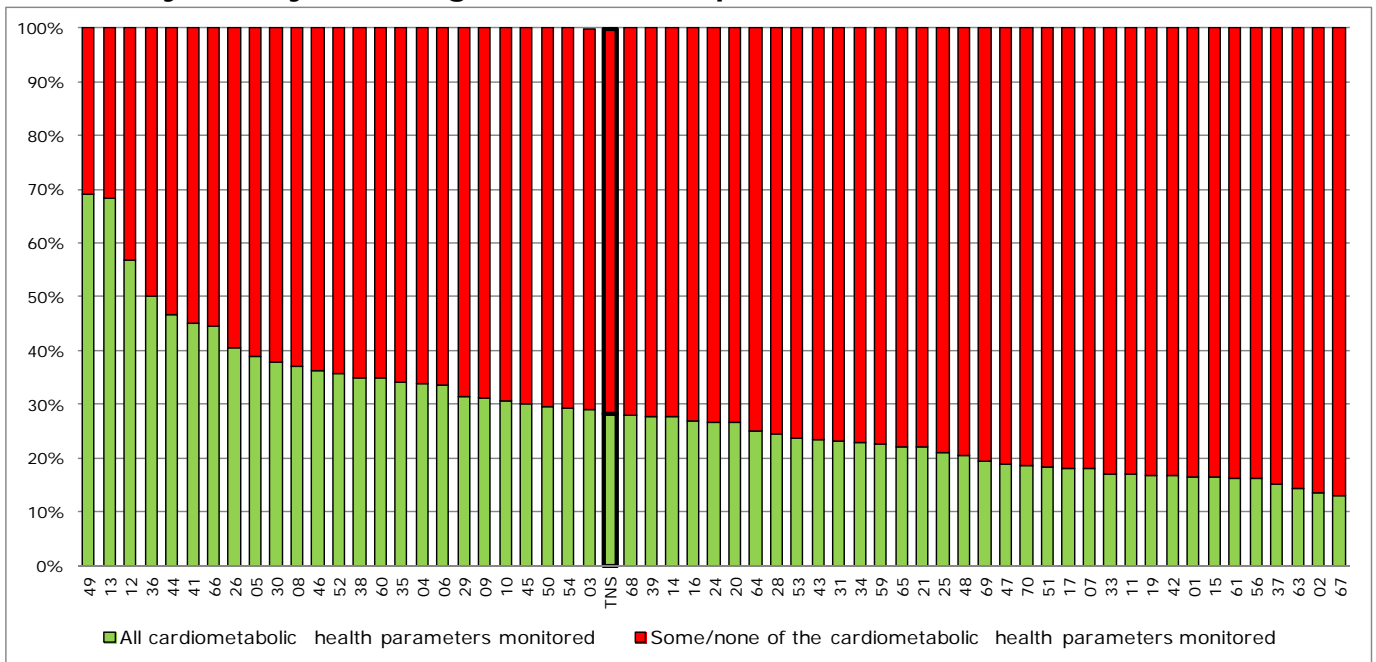
Figure 23 illustrates the percentage of service users in each Trust for whom information on the five main parameters and family history and weight was recorded. Figure 24 shows the same but with family history and weight excluded, i.e. just showing data for the factors numbered 1–5 above.

**Figure 23: Monitoring of cardiometabolic health parameters, including family history and weight, once in the past 12 months**



- The data for Figure 23 are taken from Q30 of the audit of practice tool.
- The number of service users included in this analysis is 5,091.
- BMI had not been calculated from the weight in all case notes.

**Figure 24: Monitoring of cardiometabolic health parameters, excluding family history and weight, once in the past 12 months**

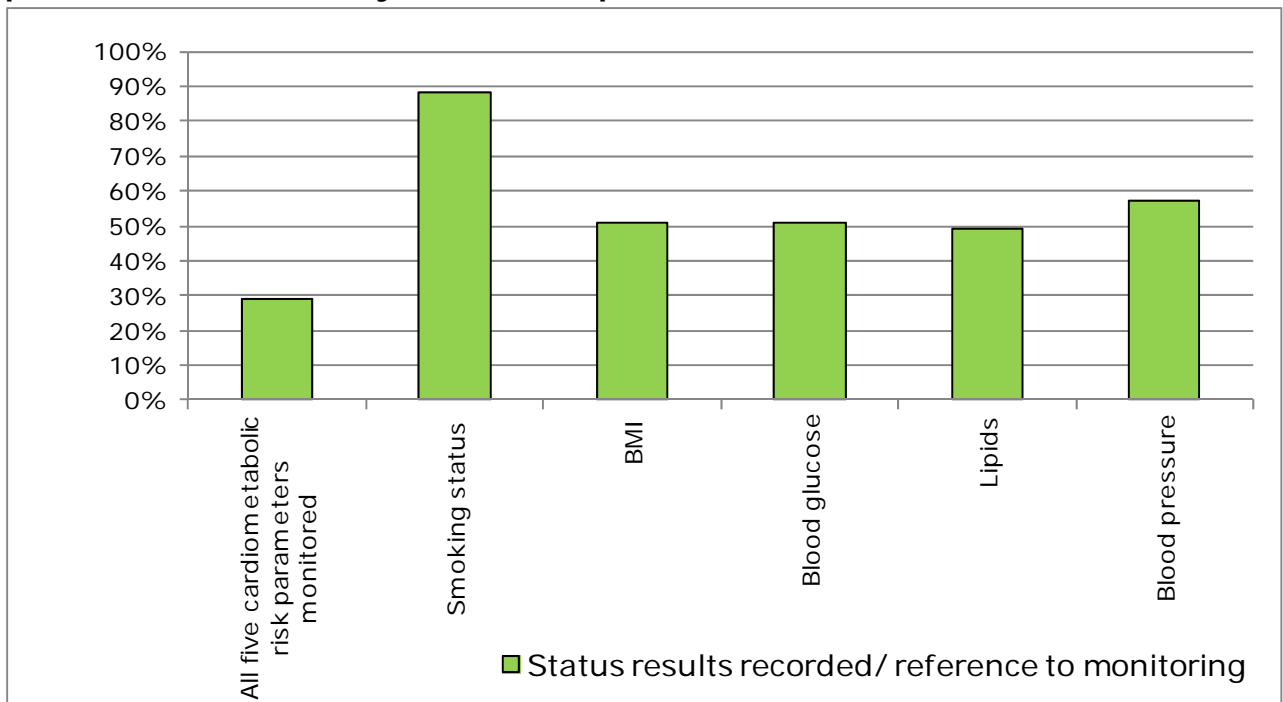


- The data for Figure 24 are taken from Q30 of the audit of practice tool.
- The number of service users included in this analysis is 5,091.

It is clear from Figures 23 and 24 that there is considerable variation between Trusts in how comprehensively these important parameters have been monitored. Even with family history and weight removed, the range is from only 13% to 69%. The average (TNS column) is only 29% for the five most important parameters.

Figure 25 shows the percentage of service users for whom each of these five important risk parameters have been individually monitored. This shows that, other than smoking status (recorded for 88%), routine monitoring of the other key, modifiable cardiometabolic risk parameters varied between 49% and 57%. In only 29% of patients was monitoring of all of these parameters recorded.

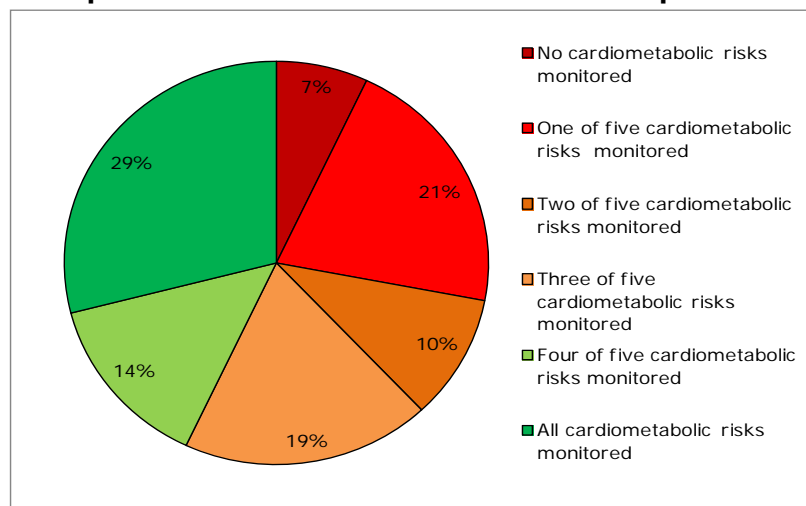
**Figure 25: Monitoring of each of the important cardiometabolic risk parameters individually once in the past 12 months.**



- The data for Figure 25 are taken from Q30 of the audit of practice tool.
- The number of service users included for each parameter is 5,091.

Figure 26 shows the percentages of service users for whom various proportions of these risk factors (BMI, glucose, lipids, blood pressure and smoking) were monitored, i.e. percentage with none monitored, one monitored, two monitored and so on.

**Figure 26: The percentages of service users versus proportion of cardiometabolic parameters monitored once in the past 12 months**



The data so far indicate a rather low level of monitoring of cardiometabolic risk factors. A further question then is whether this is at least better in younger service users whose illness onset has been in the period since clinicians became much more aware of these issues. Table 11 presents data for four of the parameters in relation to time since diagnosis. The parallel data for smoking is presented in Figure 32.

**Table 11: Percentages of service users with evidence of monitoring, once in the last year, of BMI, blood glucose, blood lipids and blood pressure by time since diagnosis**

Time since diagnosis	% of patients with BMI recorded	% of patients with blood glucose recorded	% of patients with blood lipids recorded	% of patients with blood pressure recorded
1-2 years from diagnosis	49	47	43	54
2-4 years from diagnosis	45	46	46	55
4-10 years from diagnosis	50	46	45	55
10+ years from diagnosis	53	54	52	59

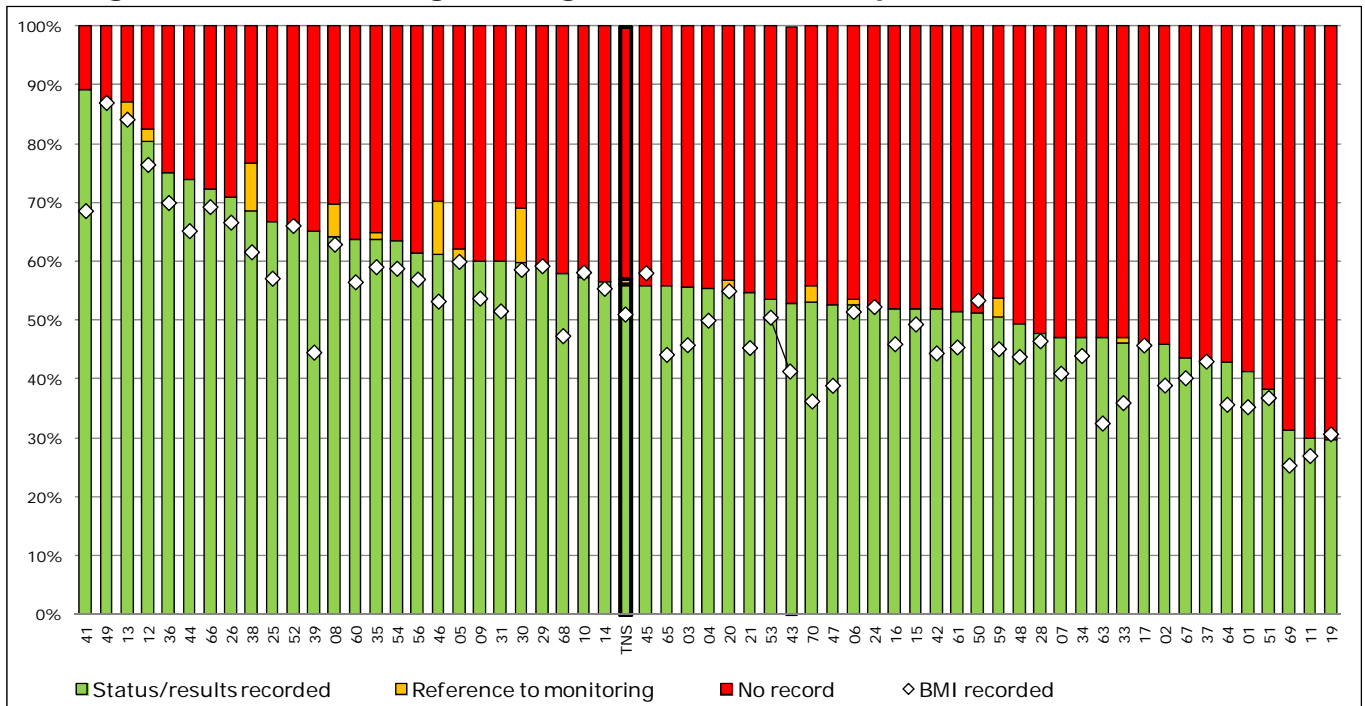
The results show that there is little variation across time since diagnosis for monitoring of cardiometabolic risk parameters. Indeed, this seems to be less likely to occur for those ill for shorter periods of time compared to those ill for more than ten years.

### **Monitoring of weight and BMI**

Weight is one of the most easily assessed risk parameters and is essential for the calculation of BMI. Given our knowledge of the effects of antipsychotic medications on weight monitoring of this is important.

Figure 27 shows the percentage of service users in each Trust who had their weight measured at least once in the preceding year and also indicates the percentage for whom BMI was calculated from this.

**Figure 27: Monitoring of weight and BMI in the past 12 months**

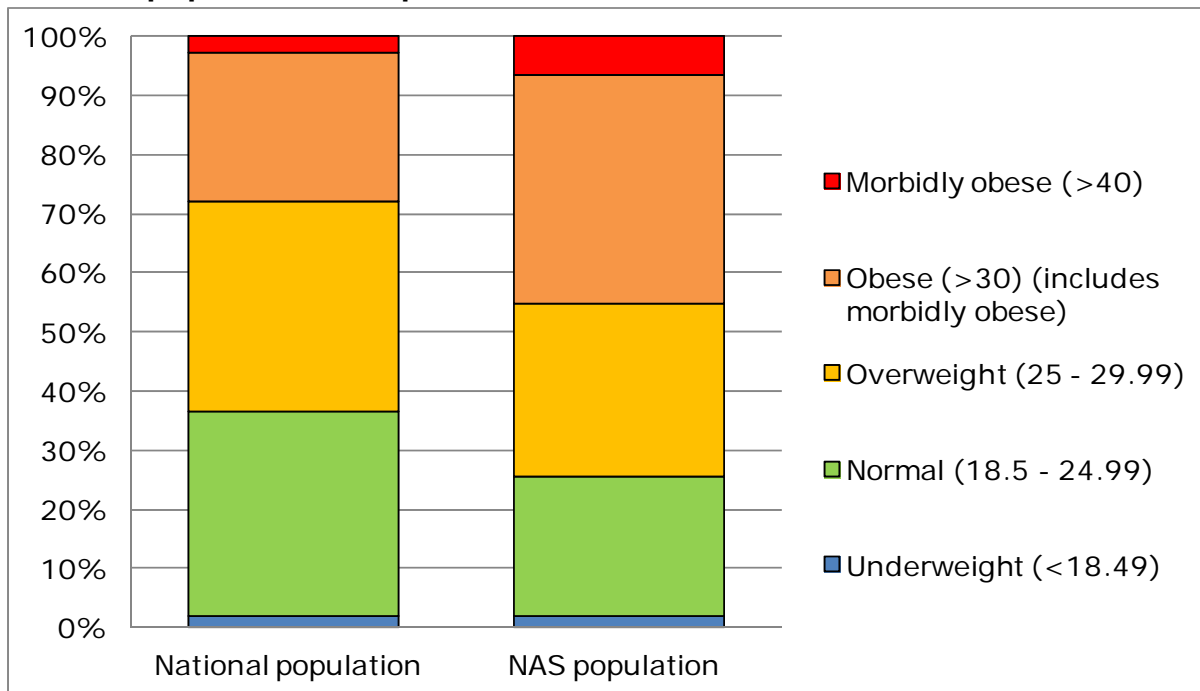


- The data for Figure 27 are taken from Q30 of the audit of practice tool.
- The number of cases included in this analysis is 5,091.

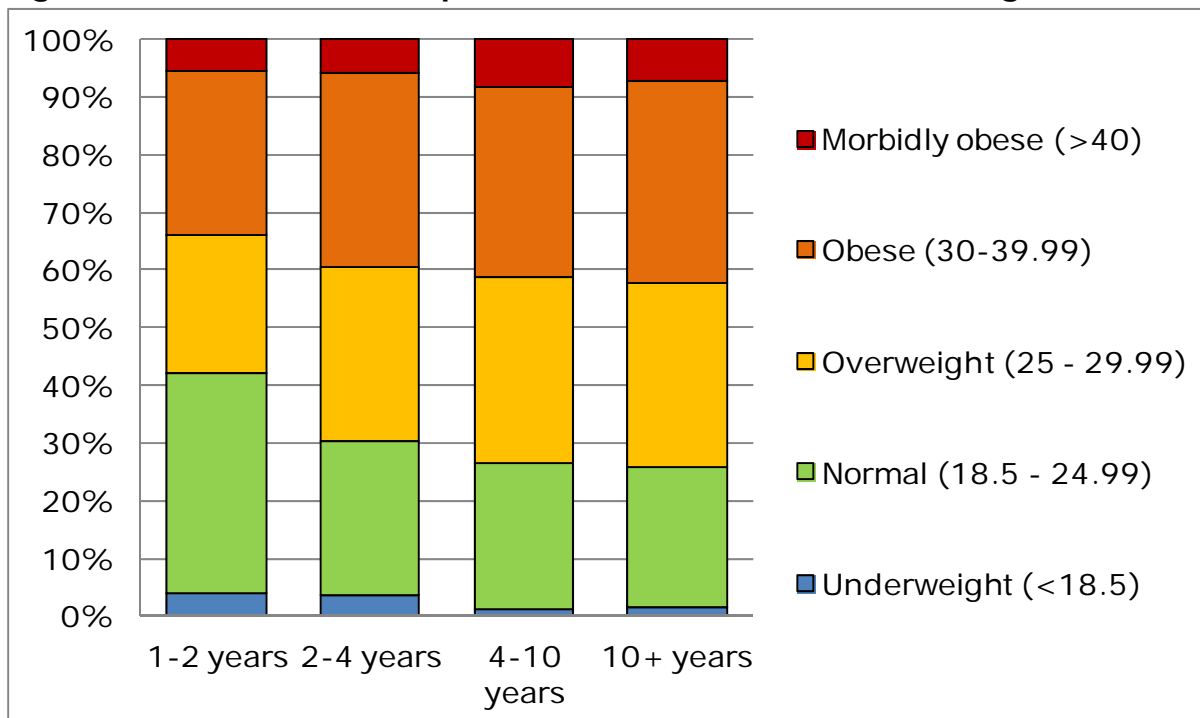
On average 56% of service users have had their weight measured and 51% their BMI calculated in the previous 12 months. There is clearly a very wide range from 88% of service users in some Trusts to 30% in others. This suggests a rather poor level of performance on this simple measure at a national level.

Obesity is a major determinant of future cardiovascular disease and type 2 diabetes. Of those service users who have had their BMI recorded (n=2,599), the comparison in Figure 28 indicates a high prevalence of obesity compared with data from a recent national survey of 7,086 adults aged 16 and over (2010 Health Survey for England; Trend tables – table 4; The NHS Information Centre for Health and Social Care). Moreover, a trend towards increasing rates of obesity with increased time from diagnosis is also evident (Figure 29).

**Figure 28: Comparison of BMI between the NAS population and a national population sample**



**Figure 29: The relationship between BMI and time since diagnosis**



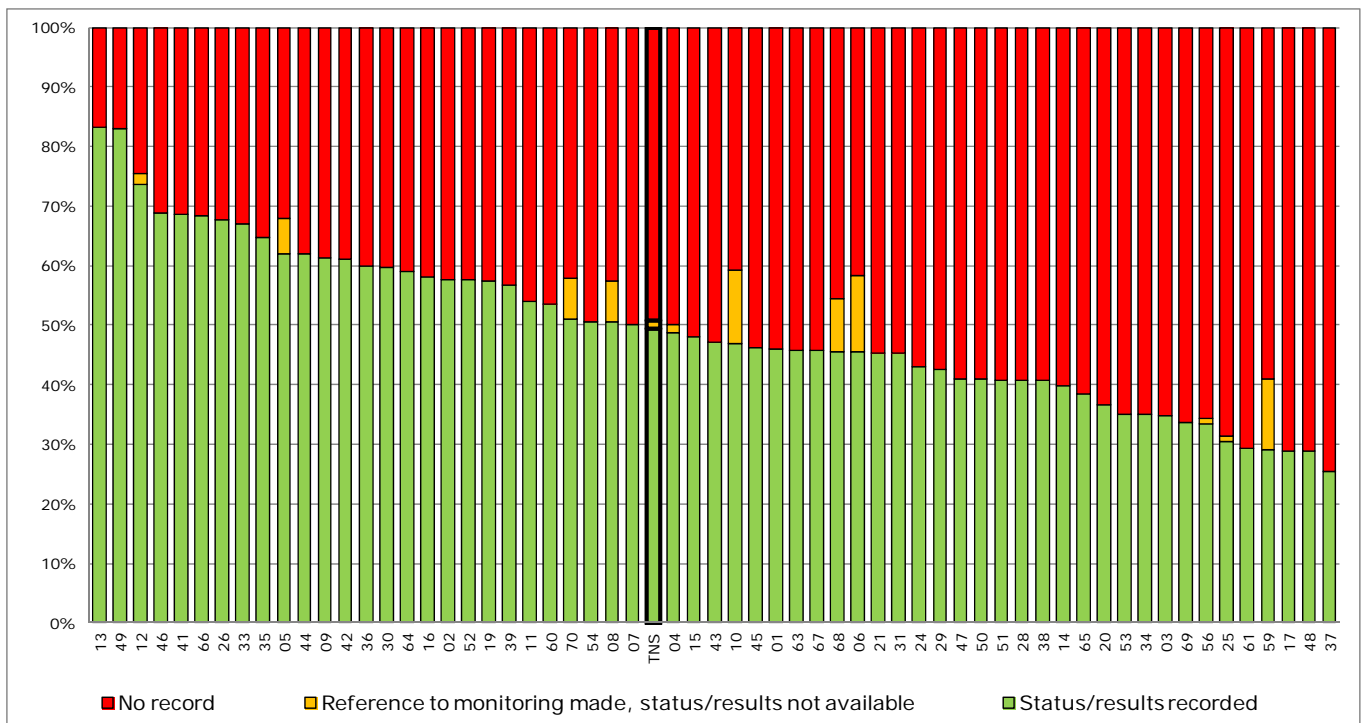
- For the NAS population there were 2,599 cases where BMI was recorded.
- The age bands of the NAS population and the national survey sample showed some differences with a greater proportion of the NAS sample being aged 25-64 (71%) than the national survey (52%).

- The BMI upper range of normal value for people of South Asian or Chinese descent is lower than for White Caucasian people (22.9 vs. 25 kg/m<sup>2</sup>). The NAS population has a similar proportion of Asian and Chinese people compared to the national census population for England and Wales (see Table 4b).

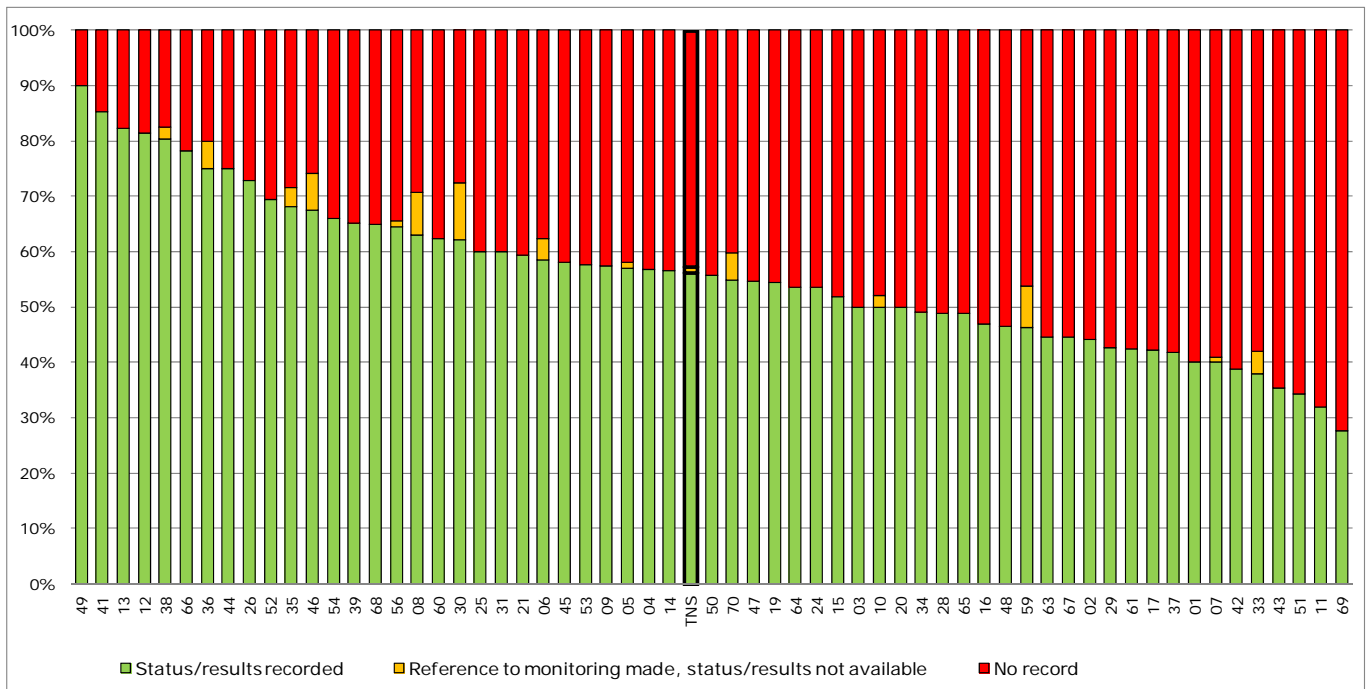
### Monitoring of glucose, lipids and blood pressure

The audit shows a similar pattern of widely varying performance between Trusts in relation to monitoring of blood glucose and blood pressure (Figures 30 and 31), with a range of between 25% and 83% for glucose and 28% and 90% for blood pressure. The results for lipids (not shown here) ranged from 27% to 80%.

**Figure 30: Monitoring of blood glucose at least once in the past 12 months**



**Figure 31: Monitoring of blood pressure at least once in the past 12 months**



- The data for Figures 30 and 31 are taken from Q30 of the audit of practice tool.
- The number of service users included in the analysis is 5,091.

### Monitoring of smoking

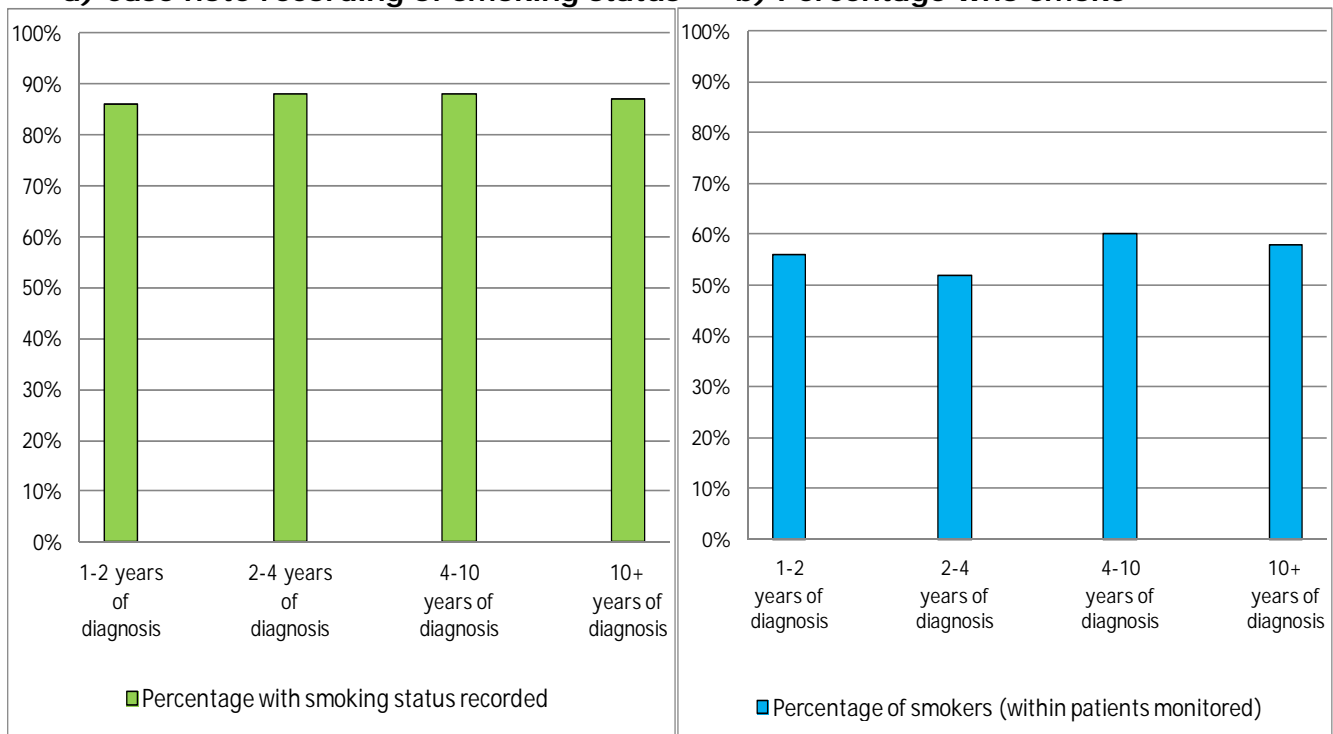
People with schizophrenia are more likely to smoke than the general population, making this an important contributor to their health inequality through its adverse impact on cardiovascular and respiratory health (Brown et al., 2010).

The audit shows that smoking status was recorded in 88% of cases with a range across Trusts of 55% to 100%.

Figure 32a shows that the percentage for whom smoking was recorded does not appear to vary with time since diagnosis. Further, for those service users for whom smoking was recorded, time since diagnosis does not seem to be a factor in their rate of smoking (Figure 32b), which varied from 52% to 60%. Thus, smoking remains a significant issue and it is clear that intervention to reduce rates of smoking are required for all age groups of those with schizophrenia.



**Figure 32: The relationship between time since diagnosis and:**  
**a) Case note recording of smoking status    b) Percentage who smoke**



### Monitoring of prolactin

Raised serum prolactin can be an important adverse effect of antipsychotic medication. The risk of occurrence varies from medication to medication, largely in relation to their potency in antagonism of D2 dopamine receptors. Not all patients on potent antagonists will necessarily develop elevated levels. Thus, monitoring of prolactin levels is generally only considered if: relevant symptoms occur; or where the prescriber has switched the antipsychotic medication to reduce established hyperprolactinaemia; or where there are concerns about bone density and perhaps other monitoring, such as annual dual energy X-ray absorptiometry (DEXA) scans, is being considered. Routine monitoring of prolactin is not generally recommended in most treatment guidelines.

With the above issues in mind, the audit shows that about 10% of people in the case note audit have had their prolactin levels monitored in the previous 12 months. Rates of prolactin monitoring were independent of time from diagnosis, were slightly more common in females, and were not linked to any particular medication prescribed.

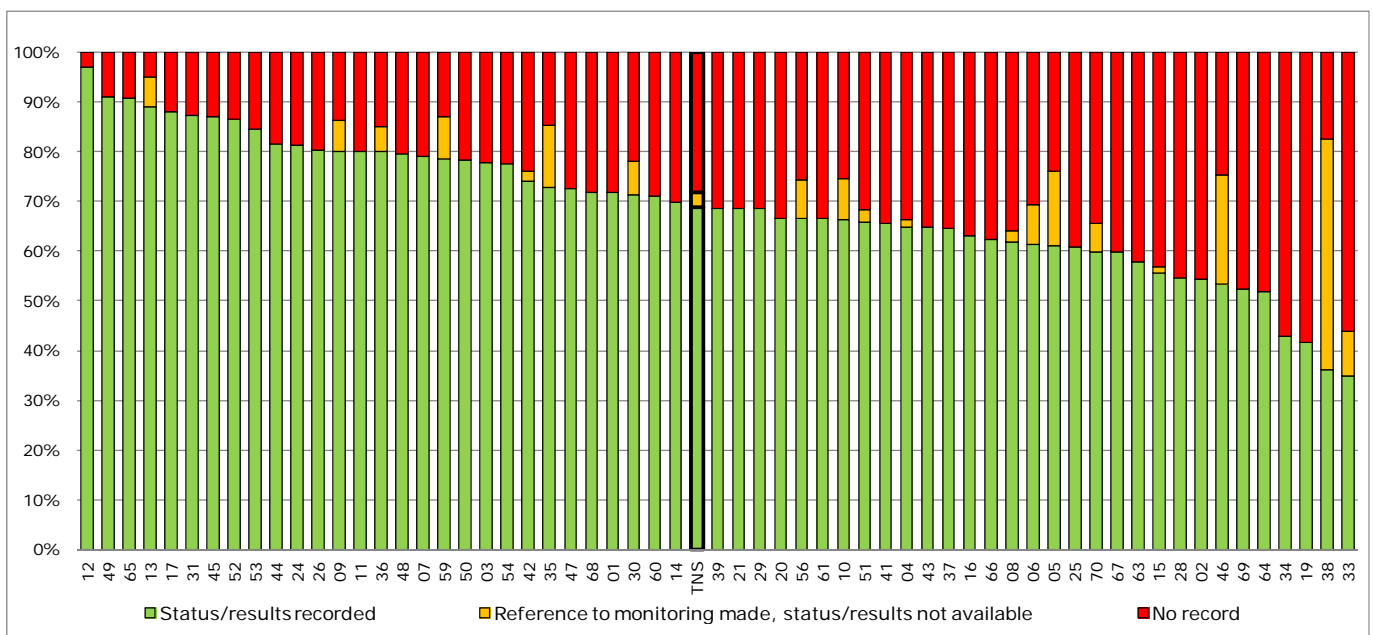
## Monitoring of alcohol intake and substance misuse

Excessive alcohol intake and substance misuse can adversely affect physical and mental health, may compromise the quality of healthcare received (Mitchell et al., 2009) and sometimes contributes to failures in treatment programmes.

Figures 33 and 34 show the percentage of service users for whom there was evidence of monitoring in the last year by each Trust.

In total 3,668 service users out of 5,091 (72%) had evidence of monitoring of alcohol use recorded. The range across Trusts varied from 42% to 97%. The data in Figure 33 illustrates how poorly some Trusts are performing on this rather basic expectation.

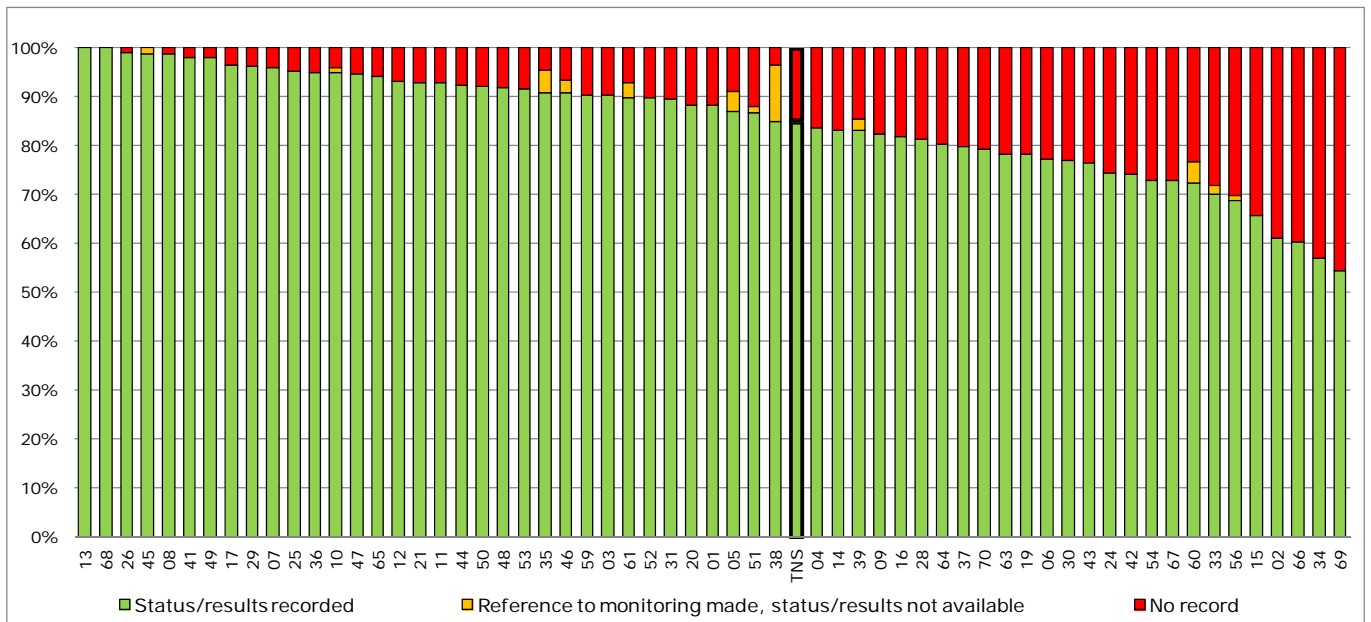
**Figure 33: Monitoring of alcohol intake across Trusts in the past 12 months**



- The data for Figure 33 are taken from Q30 of the audit of practice tool.
- The number of cases included in the analysis is 5,091.

Monitoring of substance misuse was carried out to a better level and in total 4,351 service users out of 5,091 (85%) had evidence of this being carried out during the previous year. The range across Trusts varied from 54% to 100%. The data in Figure 34 illustrate this narrower range of performance compared to that for alcohol.

**Figure 34: Monitoring of substance misuse across Trusts in the past 12 months**



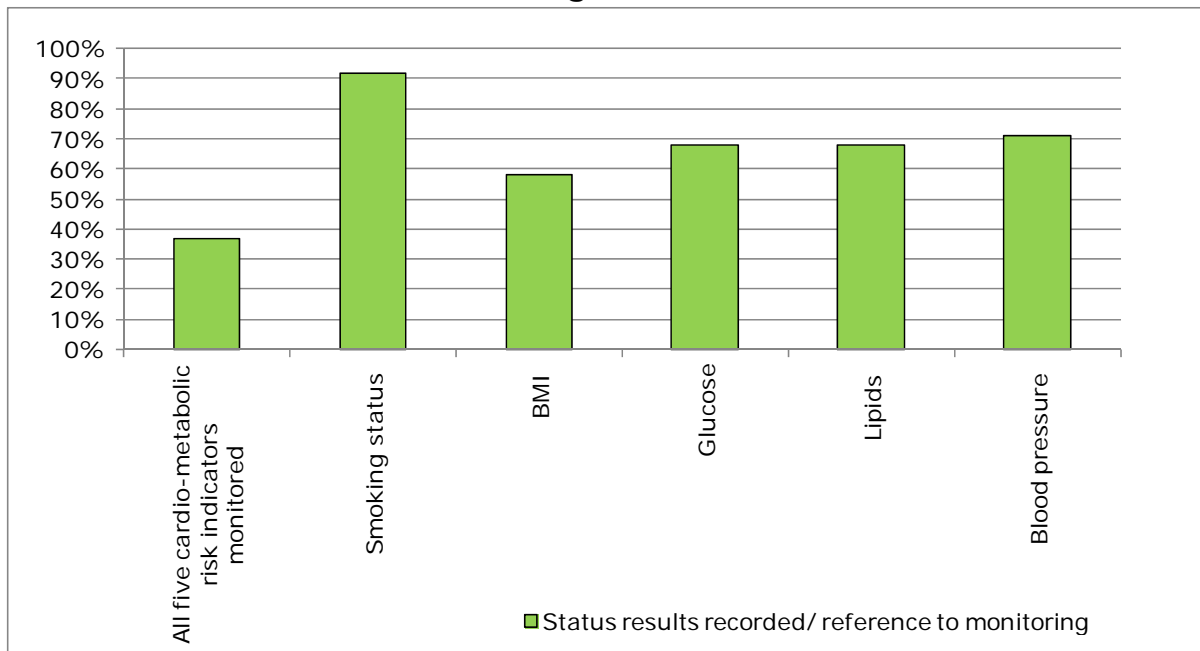
- The data for Figure 34 are taken from Q30 of the audit of practice tool.
- The number of cases included in the analysis is 5,091.

**Monitoring of those service users who have co-existing cardiovascular disease, diabetes or a high BMI**

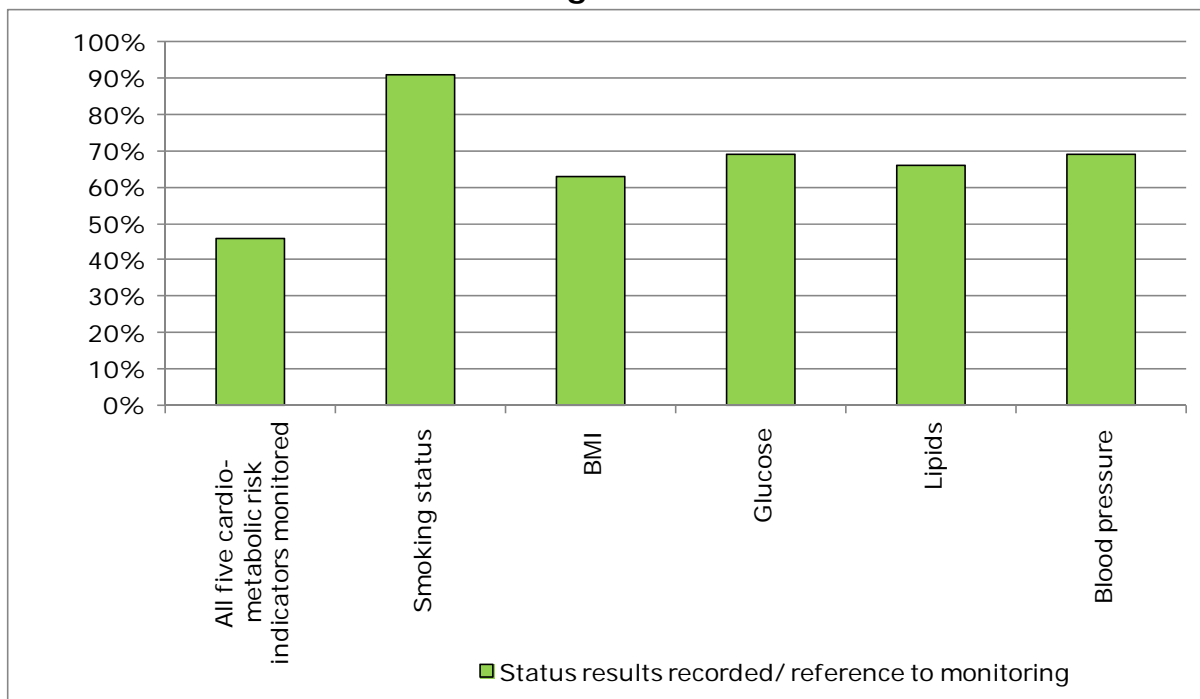
People with schizophrenia have two to three times higher rates of cardiovascular disease and diabetes than the general population. The quality of the healthcare they receive for these illnesses is poorer than their peers with the same physical conditions but without psychiatric illness (Mitchell et al., 2009; Manderbacka et al., 2012)

Figures 35 and 36 show the data for monitoring of cardiometabolic risk factors in service users with known diagnoses of cardiovascular disease and diabetes respectively. While the level of monitoring is a little higher than for the case note audit population as a whole (Figure 25), it is only slightly so and confirms that this group with known pathology are far from receiving ideal care.

**Figure 35: Monitoring of cardiometabolic parameters in the last 12 months in service users with a diagnosis of cardiovascular disease**

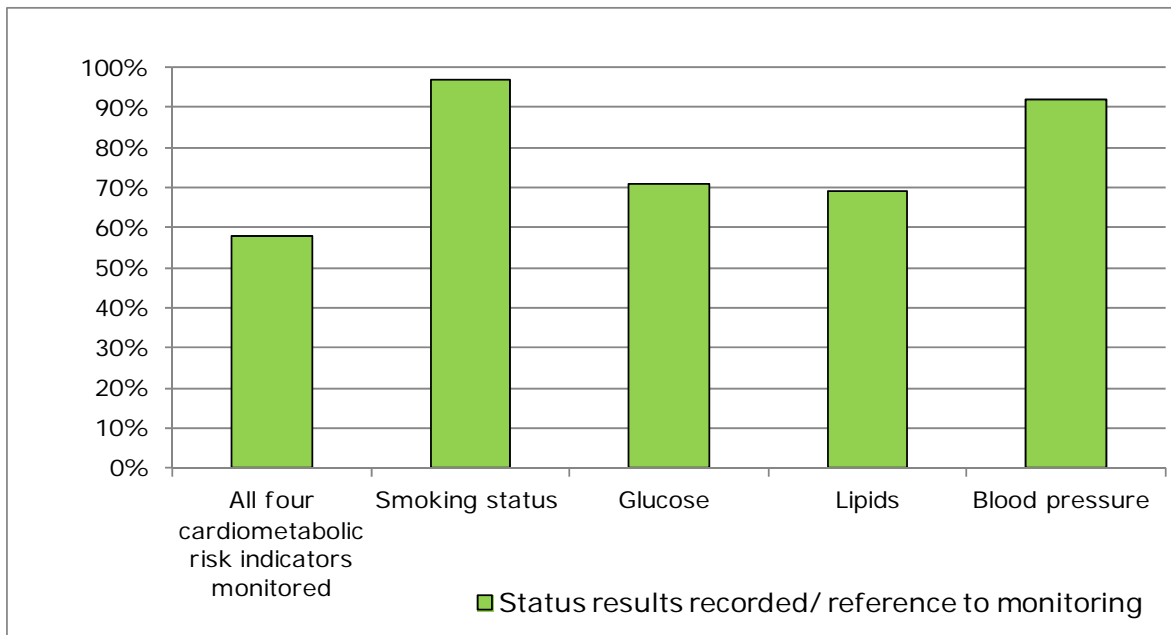


**Figure 36: Monitoring of cardiometabolic parameters in the last 12 months in service users with a diagnosis of diabetes**



- 353 cases with cardiovascular disease (Figure 35) and 640 cases with diabetes (Figure 36) are included in the analysis (7% and 13% respectively of the total case note audit population of 5,091).
- The column '*all five cardiometabolic health indicators*' includes monitoring of smoking status, BMI, glucose, lipids and blood pressure.

**Figure 37: Monitoring of cardiometabolic indicators in the past 12 months in service users with a BMI > 25**



- The analysis for Figure 37 includes 1,894 cases with BMI >25 (37% of the total case note audit population of 5,091).
- The column '*all four cardiometabolic risk indicators monitored*' includes monitoring of smoking status, glucose, lipids and blood pressure.

Another group at higher risk are those service users with a BMI above 25. We would expect that more attention would be paid to monitoring their cardiometabolic risk parameters and Figure 37 indicates that these do seem to be being paid closer attention in this group of service users. However, comprehensive monitoring still only occurs in 57% (column: *all four indicators*).

## **Intervention to address physical health issues**

Clearly, if as part of monitoring of cardiometabolic and other risk parameters, evidence is found that a person has test results outside the range of normal, then the expectation would be that some appropriate action is taken. Similarly, if there is evidence of excessive weight gain, smoking, alcohol misuse or misuse of other substances, then some form of action would be appropriate. The audit sought to examine this issue, which relates to Standard 5.

**Standard 5: When monitoring within the past 12 months has indicated a need for intervention, the following have been offered to the service user or the treating clinician has made a referral for the service user to receive:**

- i. Advice about diet and exercise, aimed at helping the person to maintain a healthy weight.**
- ii. Treatment for hypertension.**
- iii. Treatment for diabetes.**
- iv. Treatment for hyperlipidaemia.**
- v. An intervention to reduce levels of prolactin.**
- vi. Help with smoking cessation.**
- vii. Help with reducing alcohol consumption.**
- viii. Help with reducing substance misuse.**

The relevant data are provided in Table 12. Points to note about this table are as below:

- Questions 29 to 42 of the case note audit of practice tool address the measures required to assess this standard. In particular, the answers to questions 34 to 40 give data that can be assessed against expected normal values to determine whether or not a value (e.g. for blood glucose) is outside the expected range.
- The percentage of patients where monitoring indicated a need for some intervention is expressed as a percentage of the total case note audit sample (5,091). This is because the numbers monitored for each parameter are very variable. Using the percentage of total population provides an indication of the proportion that might be expected in any particular Trust.

- The percentages provided for the proportions offered an intervention, where this was indicated, are expressed as a percentage of the number for whom a need for intervention was indicated, not against the total population.

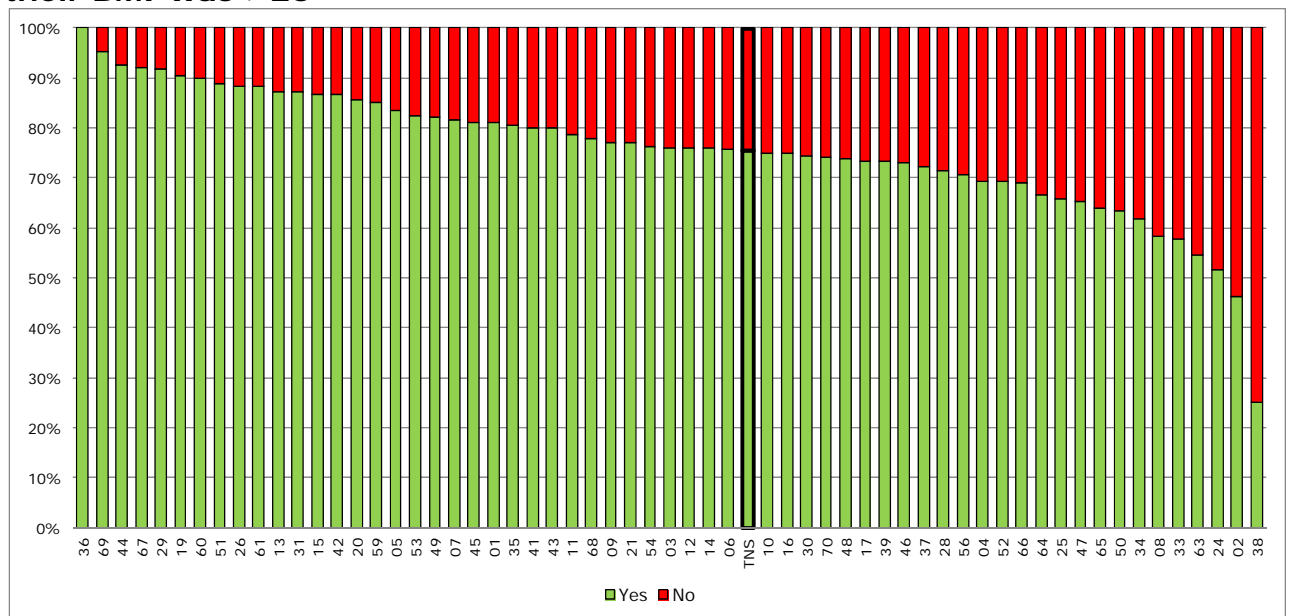
**Table 12: Percentage of service users where a need for intervention was identified and percentage where there was evidence that such was offered**

Physical health indicator	Service users monitored  n (% of total population)	Service users with an identified need for intervention  n (% of total population)	Service users offered an intervention where need was indicated  n (% of those with identified need)
BMI	2,599 (51)	1,894 (37)	1,368 (76)
Blood glucose levels	2,523 (50)	518 (10)	277 (53)
Lipid levels	2,394 (47)	1,185 (23)	236 (20)
Blood Pressure	2,863 (56)	556 (11)	140 (25)
Smoking status	4,445 (87)	2,575 (51)	1,473 (57)
Prolactin levels	502 (10)	190 (4)	49 (26)
Substance misuse	4,315 (85)	588 (12)	430 (73)
Alcohol consumption	3,518 (69)	386 (8)	278 (72)

The audit shows that for those where monitoring has identified a need, many do not receive appropriate interventions. Of particular concern are those where an important parameter for cardiometabolic risk has been found to be abnormal. For example, low rates of intervention were observed for those with abnormal blood pressure (25%), abnormal lipid levels (20%) and abnormal blood glucose or HbA<sub>1c</sub> (53%). Only 57% were recorded as having an intervention to stop smoking in the last 12 months.

Figure 38 illustrates the percentage of those with BMI >25 (i.e. those in the 'overweight' or 'obese' range) who were offered advice about diet and exercise, the most simple intervention possible, and shows considerable variation between Trusts. On average, 76% of those with BMI >25 were offered some form of advice about diet and exercise. This first audit did not enquire in detail about the nature of such interventions and this may be an appropriate issue for future audits.

**Figure 38: Service users offered advice about diet and exercise when their BMI was >25**



In contrast to the disappointing response observed for some of the cardiometabolic abnormalities, almost three-quarters of those where a problem with substance misuse or excessive intake of alcohol had been identified, were offered an intervention.



## Discussion

This first National Audit of Schizophrenia has been successful in recruiting almost all of the Trusts who provide care for large numbers of people with a diagnosis of schizophrenia and schizoaffective disorder in England and Wales. Those organisations have identified and collected information on an average of 85% of the numbers of cases we had as our initial aim (5,091/6,000). The response rate for the service user survey was within the expected range found by others carrying out such surveys. The overall response rate for the carers' survey was below that which the NAS team had hoped for (20%) but does provide information gleaned from those experiencing services across almost all of England and Wales. The low response rate means that generalized conclusions cannot be made.

While there are inevitably some missing items of information, for example service users and carers were told they did not have to answer all questions on their survey forms (see page 41), the size of the sample covered and the relative consistency of findings suggests that it is unlikely that this had any major effect on the utility of the data collected.

The demography of the population sample we have acquired seems to be reasonably similar to that which one might expect in terms of age distribution, gender split and distribution of those with diagnoses of schizophrenia and schizoaffective disorder. Ethnicity largely mirrors that of the general population of England and Wales, except for an excess of service users of Black or Black British origin, which mirrors other epidemiological findings for schizophrenia (Fearon et al., 2006).

We did not ask service users to provide demographic information with their survey forms. As a result we cannot say how well they mirror the case note survey sample. In the second round of audit we will attempt to link these two surveys so direct comparisons can be made, in so far as this is consistent with maintaining service user confidentiality.

The demography of the carer sample seems consistent with what we would expect given the demography of the sample for the main case note audit.

The sections that follow provide some further comment on the results and are organised according to the order of the data sections in this report.

## **Service user and carer issues**

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Service users' experience of care mirrored the outcomes of the focus groups outlined in the Introduction. Service users reported a level of satisfaction in nearly 80% of cases overall. This met the standard of 60% set for the CUES questionnaire used in the audit. In our report we have not produced summary figures for all of the data from the 22 questions of the service user survey. However, important themes where respondents were less satisfied about what was available included choice of services and social and occupational activity. Detail of the responses can be found in Appendix F.

In the focus groups service users reported concerns about how care of their physical health was managed. Inadequacies in the management of their physical health, especially in relation to cardiometabolic risks, are highlighted later in the discussion (page 110). Responses regarding physical health check-ups differed greatly between service user's responses and information provided by Trusts (78% vs. 29%). This could represent a failure to record information in case notes, which may explain some of the inconsistency. However, it is more likely that this may represent a lack of understanding on the part of service users as to what constitutes an appropriate 'check-up'.

The audit findings strongly suggested that there is a complete lack of agreement regarding who should take responsibility for physical health checks and who should take the lead role in this at different stages of a service user's care. This arose from information provided in the focus groups, feedback from the pilot Trusts, subsequent interactions with psychiatrists, feedback when presenting some of the results at meetings of College divisions, and from information received during the course of the NAS team's interactions with Trust staff in

relation to the data collection. There also appears to be a lack of clear agreement regarding what should be assessed and, among some groups of staff on mental health teams, a lack of adequate education about the issues involved. Service users reported in the focus groups that they have a sense of this confusion but feel frustrated by it and powerless to change it. These are clearly issues requiring attention.

Carers reported levels of satisfaction of around 40%-50% on average across most of the questions they were asked regarding support and provision of information. However, a significant percentage responded saying they were only 'somewhat satisfied' on these issues (32%), and the same applied to their view of their involvement in decision making (33%). This suggests a need for Trusts to examine aspects of communication with carers.

## **Shared decision making about medication**

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Clinicians working in mental health teams appear to be making reasonable attempts to discuss medication with service users and provide them with written or other appropriate forms of information. This is something that is not always recorded in the case notes, an issue that Trusts should address.

A large percentage of service users agree they have received some information about their medication. The main issue, however, is about how understandable this information is. It is clear that service users find the information provided does not always meet their needs. Similar percentages of service users and Trust case notes seem to agree that the potential benefits and adverse effects of medication were explained. However, they differ in relation to the proportion of service users who felt fully involved in their final treatment decision.

Thus, there are issues relating to different aspects of communication that need to be addressed.

## Prescribing

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The results suggest that, for the majority of service users, appropriate treatment guidelines were being followed in relation to pharmacotherapy.

The area of most concern relates to antipsychotic polypharmacy, i.e. where more than one antipsychotic medication is being prescribed at once. There is no good evidence to support this as a regular treatment strategy. A certain amount of case report literature and clinical consensus supports a time limited trial of a co-prescribed, second antipsychotic medication in some service users with marked treatment resistant illness. It is thus of concern that there is a very wide range (3%-30%) of prescribing practice in relation to this and that 16% of service users overall were receiving more than one antipsychotic medication at a time. It seems unlikely that this range can be accounted for by differences in patient populations between Trusts and thus suggests a need for more education of psychiatrists on this issue. In particular, 45% of those in receipt of polypharmacy were receiving a second antipsychotic medication in addition to either a depot or a long-acting antipsychotic medication and this is perhaps an area for more detailed investigation in a second round of audit.

Prescribing doses above those recommended in the BNF was lower than we might have expected from previous audit data examining this issue in samples of inpatients. The range of practice also did not vary too greatly. As for polypharmacy, there are situations where a trial of a medication at higher than usual doses is appropriate. Again, while no absolute standard can be set for this it is important that where it occurs a clear reason is documented by the psychiatrist in the service user's case notes. Yet it is clear in Figure 18 that reasons are frequently not recorded.

The other key area of prescribing practice examined was the use of clozapine. Overall, 24% of this population of service users was receiving clozapine. This is a relatively high figure but is probably because a large proportion of those service users less likely to be prescribed clozapine are managed solely in primary care and would therefore not be recruited into the audit. The overall level of prescribing of clozapine is probably in the region of 15%-20%, if all those with

schizophrenia were included. This is an appropriate figure given that approximately 30% of service users will not gain remission with standard antipsychotic medications, and around half of them would be expected to improve on clozapine.

The percentage of service users being prescribed clozapine varied from 7%-42% across Trusts. This is a wide variation and without knowing more about the precise case note sample each has collected, it is not possible to determine the reason for this. It would be a concern if some Trusts were not making this medication adequately available, and equally a concern if some were overprescribing it. This is another issue worthy of further examination in a second round of audit.

Out of those service users identified as treatment resistant but not receiving clozapine (1,021), 43% had no clearly documented reason as to why. This seems a fairly significant number and suggests that there is also a need for further education of mental health teams regarding the care of such individuals.

## **Psychological therapies**

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The wide variation between Trusts in the percentage of their service users who had been offered a psychological therapy is of considerable concern. This seems to be regardless of whether or not the service user was in remission. Worryingly 34% of service users who were treatment resistant were not offered a psychological therapy. The current NICE Guideline was published in 2009, but the first NICE guideline on the treatment of schizophrenia published in 2002 included guidance about the use of psychological therapies. We might therefore have expected an offer of psychological therapy to a higher proportion of service users, as well as a greater level of consistency between Trusts.

This is therefore an area where Trusts need to review their service provision and where commissioners need to develop clear specifications.

## Physical health

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It is a matter of serious concern that only approximately one quarter of people with schizophrenia have received a comprehensive assessment of their cardiometabolic health within the previous 12 months. In some Trusts this may be below 15% of patients. Just over half have had their weight recorded and this applies even if their diagnosis was relatively recent. This is an extremely simple measure to monitor and, as demonstrated in Figure 28, obesity is a significant problem among service users.

The low level of reporting of intervention being offered when a problem relating to physical health is identified is a further concern from this audit. At the most basic level, only 76% of those with elevated BMI were offered advice regarding diet and exercise.

The 20% reduction in life expectancy is largely explained by 2-3 fold higher rates of cardiovascular disease compared to the general population. Whilst approaches to prevent cardiovascular disease have successfully reduced deaths in the general population it appears that people with schizophrenia are missing out (Brown et al., 2010). Systematic monitoring of cardiometabolic risk is a prerequisite to preventing cardiovascular disease. Lifestyle factors also contribute to these problems. The audit confirms that adequate monitoring and, when necessary, intervention is not in place in many Trusts for the majority of patients with schizophrenia.

Weight gain contributes to future cardiovascular disease and type 2 diabetes and is often a distressing effect of treatment that serves to enhance stigma. It has a negative impact on self-esteem and physical fitness and can contribute to social isolation for people who are often already quite isolated. The CATIE study also recognised it as a factor to why up to 75% of patients discontinue medication within the first 18 months (Lieberman et al., 2005).

A potentially very serious consequence of low rates of glucose monitoring (50% in the audit), is delayed detection of diabetes. This can develop rapidly as a consequence of commencing antipsychotic treatment (McIntyre et al., 2001).

People of South Asian and Black ethnic origin have higher risks for this than other populations which suggests that they should have higher rates of recording, but this was not the case.

Smoking is another concern. Eighty-seven percent of service users had their smoking status recorded. Of these 51% were smokers. This prevalence was similar whatever the length of illness and should be viewed against the backdrop of a prevalence in the general population estimated at 21% in 2009 (The NHS Information Centre, Lifestyles Statistics, 2011). Only 57% of service users who were smokers were offered smoking cessation advice. A significant proportion of service users therefore appear to be missing out on help to reduce an important risk factor for cardiovascular disease.

Finally, the audit shows that even when service users have a clear, known diagnosis of cardiovascular disease or diabetes or have a high BMI, and are at particular risk of developing these conditions, inadequate monitoring remains a problem.

As discussed in the section on users' and carers' issues, it would appear that a lack of co-ordination and agreement between specialist services and primary care plays a significant part in these deficiencies. The future audit must try to address this issue as well as the availability of resources for monitoring physical health factors.

Good prescribing practice relies on a balanced understanding of risks and potential benefits of treatment, which should be discussed between the mental health team, the service user and, if possible, the main care-givers. Such poor performance in monitoring the main physical health risk factors facing service users with schizophrenia inevitably means that users and their carers are unable to make properly informed treatment decisions.

## Conclusions

This audit provides the largest systematic picture available of important aspects of the delivery of treatment and care to people with a diagnosis of schizophrenia and schizoaffective disorder across England and Wales. Practice has been assessed against standards derived from the NICE 'Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults' (2009). The findings of the audit provide a benchmark against which Trusts can compare the performance of their local mental health teams.

It is clear that there are aspects of care where the standards set are being met to a reasonable level for the majority of service users, for example communication with service users and carers and the prescribing of clozapine for treatment resistant individuals. However, even for these standards there are some Trusts where performance could improve significantly and there are issues about whether it is easy to understand the information provided to service users and their carers.

There are areas where performance at a national level is less than ideal, where the performance of some Trusts is good, but many Trusts need to improve, for example in relation to polypharmacy and the provision of psychological therapies.

However, with regard to the monitoring and management of the physical health of service users, an issue of major importance, even the best performing Trusts are performing below what should be considered an adequate standard. Without action this will result in considerable costs to the health service as the result of inadequate treatment now will lead to a considerable burden of cardiovascular disease in this population in the future. The results of the audit suggest this is a seriously neglected aspect of care.



In general terms, dealing with the issues arising from the audit will require consideration of:

- How agreements between specialist and primary care are made regarding who manages certain aspects of physical health care at different stages of a person's illness, and how resources are distributed.
- Education of staff working in mental health teams in relation to aspects of prescribing and physical health care and education to improve awareness of these issues at Trust Board and Chief Executive level.
- Improved engagement with service users and voluntary agencies and work to empower them to care for their physical health needs.

The detailed recommendations (see page 115) are addressed to a variety of organisations involved in the planning, commissioning and delivery of care for people with schizophrenia and to individuals within those organisations. These recommendations can be reduced to a number of key requirements:

1. The physical health needs of people with a diagnosis of schizophrenia need to be recognised at all levels of the NHS - from the Department of Health (DH), to commissioners, Trust Boards and mental health teams on the ground. Voluntary organisations may be able to help empower service users to take greater interest in this. Resources should be made available so that mental health teams and general practitioners work together to ensure that adequate monitoring for cardiovascular risk factors occurs and that intervention occurs when indicated for individual service users. Achieving this will necessitate a proper agreement between staff in specialist services and staff in primary care as to 'who does what and when' and how results are shared between them. If necessary a formal policy directive from the DH may be required regarding this.
2. Education relating to a number of aspects of the care of people with schizophrenia needs to be improved. This includes education about pharmacotherapy and physical health issues. This is required by all professions within mental health teams, not just psychiatrists, and primary care staff, such as practice nurses.

3. The availability of professional staff with appropriate training and dedicated time to provide evidence based psychological therapies needs to be addressed.
4. Some aspects of communication between clinical staff and service users and carers need to be addressed. Principally, Trusts need to ensure that easy to understand information about medications is available and that the best efforts are made to involve service users in decisions about their treatment. It is appropriate in this context for Trusts to seek collaboration with voluntary agencies.
5. Mental health teams need to be encouraged to carry out regular, collaborative audit which involves medical, nursing, pharmacy and social work professionals. Audit too often is largely uni-professional because not all professional groups are supported to make the necessary time available. This will also help teams with the critical issue of identifying where important information is not being clearly recorded in case notes.

# Recommendations

- 1. Recommendations for the Secretary of State for Health and the Minister for Health and Social Services**
  - 1.1 To ensure that health services demonstrate parity of esteem so that physical healthcare received by people with schizophrenia is at least as good as that received by people who do not have this condition.
  - 1.2 To ensure the Department of Health demonstrates increased access to psychological therapies, particularly cognitive therapy, family therapy and other evidence based treatments for people with schizophrenia.
  - 1.3 To ask the National Institute for Health and Clinical Excellence (NICE) to review the age restrictions of the Quality Outcome Framework (QOF) for people with severe mental illness, as this currently excludes people under the age of 40 from being screened for blood glucose (MH14) and cholesterol/HDL ratio (MH15). All people with a diagnosis of schizophrenia should be included within the QOF for severe mental illness, irrespective of age.
  
- 2. Recommendations for Professional Bodies**
  - 2.1 The Royal College of General Practitioners (RCGP), the Royal College of Nursing (RCN) and the Royal College of Psychiatrists (RCPsych) should drive forward the recently agreed Integrated Physical Health Pathway<sup>2</sup>, developed by Rethink Mental Illness, for the physical health care of people with schizophrenia. Practitioners should collaborate to develop and implement this or similar local protocols for the monitoring of physical health, communication of results and responsibility for intervention.
  - 2.2 The RCGP, the RCN, the Royal College of Physicians and the RCPsych should promote the collaboratively developed Positive Cardiometabolic Health resource (CMH-resource; see Appendix G)<sup>3</sup> for the monitoring and management of cardiometabolic problems associated with the use of antipsychotic medications.

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<sup>2</sup> Available to download at <http://www.rcpsych.ac.uk/quality/NAS/resources>

<sup>3</sup> Positive Cardiometabolic Health resource, Lester et al 2012

- 2.3 The Chief Examiner of the RCPsych should review training for psychiatrists to ensure that this includes the knowledge and skills needed to assess and treat physical health problems that are prevalent in people with schizophrenia.
- 2.4 The RCPsych should ensure that the curriculum for both undergraduate and postgraduate training in psychiatry provides a sufficient focus on psychopharmacology to ensure that psychiatrists can properly monitor clinical response, recognise treatment resistance and the onset of adverse effects. The RCPsych should ensure that education in psychopharmacology extends to continuing professional development (CPD) and facilitate the availability of appropriate teaching programmes, such as those provided by the British Association for Psychopharmacology (BAP).
- 2.5 The RCGP should review the training and skills for general practitioners (both trainees and established GPs) to ensure that this includes awareness of the common physical health problems experienced by people with schizophrenia and the knowledge needed to assess and manage their treatment.
- 2.6 The RCN should encourage mental health nurses to ensure they have the necessary knowledge and skills to assess and manage the treatment of common physical health problems experienced by people with schizophrenia and appropriate knowledge to understand the principles behind prescribing for these service users, including the indications for and risks and benefits of medicines.
- 2.7 The RCGP, the RCN and the RCPsych should ensure that prescribers have appropriate skills and competencies to involve patients in prescribing decisions. This will include the ability to discuss the benefits and risks associated with treatment and provide information to enable patients to make informed choices.

### **3. Recommendations for the General Medical Council, Nursing & Midwifery Council and Universities**

- 3.1 The General Medical Council (GMC) and the Nursing & Midwifery Council (NMC) should ensure that the curricula for pre-registration training in medicine and nursing (particularly mental health nursing) provide an

- appropriate focus on both psychopharmacology and the recognition of important physical health problems in people with severe mental illnesses.
- 3.2 Universities should ensure that their Schools/Faculties of Medicine and Nursing provide teaching programmes at undergraduate level that address knowledge and skills in relation to psychopharmacology and an understanding of the important physical health issues encountered by people with schizophrenia and other severe mental illnesses. Early introduction to these issues is likely to play a vital role in preventing poor clinical practice in the future.
  - 3.3 The GMC and NMC should also ensure that practitioners, particularly those working in mental health, maintain and develop their knowledge and skills throughout their careers in relation to these issues. Universities should consider the development of appropriate courses to assist in this, where appropriate in collaboration with local training bodies and/or the Royal Colleges.
  - 3.4 The GMC and NMC should ensure that prescribers have appropriate skills and competencies to involve patients in prescribing decisions. This will include the ability to discuss the benefits and risks associated with treatment and provide information to enable patients to make informed choices.

#### **4. Recommendations for Public Health and Health and Wellbeing Boards**

- 4.1 Public Health England should develop a strategy to address the health inequalities faced by people with schizophrenia.
- 4.2 Directors of Public Health should ensure that the Joint Strategic Needs Assessment and Health and Wellbeing Strategy identify the unmet needs of people with schizophrenia, including physical health needs, and develop recommendations to address these.
- 4.3 Directors of Public Health should ensure parity of provision of health promotion to people with schizophrenia. These may need to be specifically targeted interventions, particularly smoking cessation, exercise and diet, provided by Local Authorities as well as the NHS.
- 4.4 Health and Wellbeing Boards should demonstrate in their annual reports how their commissioned interventions are targeted to meet the needs of

people with schizophrenia and how these are improving their health outcomes.

- 4.5 Health and Wellbeing Boards should demonstrate in their annual reports an assessment of the needs of carers for people with schizophrenia and how their commissioned interventions target appropriate provision to meet these needs.

## **5. Recommendations for Clinical Commissioning Groups (CCGs)**

- 5.1 Clinical commissioning strategies should address the needs identified in Joint Strategic Needs Assessments relating to people affected by schizophrenia. Particular attention should be paid to:

- Ensuring this population can access appropriate treatment programmes for diet, exercise and smoking cessation to counter problems related to obesity, smoking and cardiometabolic risks.
- The needs of patients with treatment resistant illness, for whom it is important to ensure good systems for their recognition and the provision of high quality prescribing that follows recognised treatment guidelines.
- The needs of patients solely under the care of primary care services (patients not engaged with secondary care).
- Provision of psychological therapies, particularly cognitive therapy and family interventions.
- Supporting the health and wellbeing of carers of people affected by schizophrenia.

- 5.2 Demonstrate in their annual reports that their commissioned interventions are being delivered.

## **6. Recommendations for Trust Boards**

- 6.1. Monitor implementation of the recommendations set out for Chief Executives, Medical Directors, Directors of Nursing, Chief Pharmacists and clinical teams in their Trust (sections 6 to 10 below).
- 6.2 A named member of the Board should report annually on the following issues related to the physical health care of patients with schizophrenia:
- Audit of the Trust's delivery of physical health monitoring.

- Availability and proper maintenance of equipment for the monitoring of physical health (see 6.3).
- Adequacy of training of nursing staff on the team to ensure they have the competencies required to use the equipment and to complete data recording.

6.3 Involve local service users and carers in developing action plans to improve the physical and mental health care of people with schizophrenia.

## **7. Recommendations for Chief Executives of Trusts**

7.1 Review their services for people with schizophrenia in relation to the proposed priorities for the CCGs, as below:

- Ensure this population can access appropriate treatment programmes for diet, exercise and smoking cessation to counter their needs relating to obesity, smoking and cardiometabolic risks as described in the CMH-resource (see Appendix G).
- Ensure their Trust has good systems for the recognition of patients who are treatment resistant to standard antipsychotic drugs. Ensure that the care of these patients includes high quality prescribing that follows recognised treatment guidelines.
- Ensure provision of psychological therapies, particularly cognitive therapy and family interventions.
- Support the health and wellbeing of their carers.

7.2 Review whether:

- All inpatient and community mental health services have the equipment required to monitor the physical health of people with schizophrenia<sup>4</sup>. They should ensure that this is properly maintained and replaced when faulty.
- Systems are in place to assist clinicians with monitoring the physical health care of patients. These should allow clinicians to access accurate up-to-date records; indicate when screening is due or has been overlooked; flag up abnormal results requiring clinical

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<sup>4</sup> Equipment to include weighing scales, stadiometer (or tape measure) for height, sphygmomanometer for blood pressure, and facilities for testing blood glucose and lipids.

consideration; facilitate sharing of results with primary care (in both directions); and facilitate audit of this aspect of care.

- Mental health services have effective working relationships with physicians in relation to patients whose physical health problems cannot be managed solely by their general practitioner, e.g. those on inpatient units; those with abnormal electrocardiograms (ECGs). This may be facilitated by reference to the Integrated Physical Health Pathway, recently developed by Rethink Mental Illness (see resources) or a similar resource.

7.3 Ensure that staff have the appropriate training in communication skills and have adequate time to provide users and carers with opportunities to discuss treatment plans.

## **8. Recommendations for Medical Directors of Trusts and Health Boards**

8.1 Medical Directors should ensure that clinicians are aware of guidelines for the prescribing of antipsychotic medications and guidelines for 'off label prescribing'. This includes ensuring that prescribers carefully document any off label use of a drug<sup>5</sup>.

8.2 Ensure that a system is in place to identify treatment resistant patients and review whether they should be offered clozapine. This may be through the use of case registers and regular review of these by each relevant clinical team. Ensure that funding and facilities are in place so that those who have not responded to full trials of antipsychotic medication are offered a trial of clozapine.

8.3 Ensure that all prescribing clinicians take responsibility for monitoring and intervening to prevent, identify or treat the metabolic side effects of antipsychotic medication. This may be facilitated by use of the CMH-resource (see Appendix G).

8.4 Consider strategies for support of patients discharged to their GP, who are no longer under the direct care of the Trust. It is important to ensure that GPs are supported to provide high quality prescribing and physical health care for these patients.

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<sup>5</sup> This requires documented informed consent, as described in the [GMC guidelines, Good Practice in Prescribing medicines 2009 paras 18 – 24](#)



## **9. Directors of Nursing**

- 9.1 Ensure that nursing staff have appropriate training in the assessment and management of the physical health problems that may arise secondary to antipsychotic drug treatment.
- 9.2 Ensure that all nurse prescribers take responsibility for monitoring and intervening to prevent, identify or treat the metabolic adverse effects of antipsychotic medication. This may be facilitated by use of the CMH-resource (see Appendix G).
- 9.3 Ensure that mental health nurses in their Trust understand the important principles behind modern prescribing, including the indications for and risks and benefits of medicines.

## **10. Recommendations for Chief Pharmacists**

- 10.1 Review written information that is provided to people with schizophrenia about the medication they receive to ensure that it is legible, clear and easy to understand.
- 10.2 In collaboration with the Medical Director, ensure that systems are in place so that those who have not responded adequately to initial trials of antipsychotic medications are recognised and offered a trial of clozapine.
- 10.3 Review the use of polypharmacy and high dose prescribing (including off label prescribing) with antipsychotics and offer advice to prescribers, in particular with regard to documentation of the justification for such decisions.
- 10.4 Ensure that all clinical pharmacists are aware of the metabolic adverse effects of antipsychotic medication and how to counter these. This may be facilitated by use of the CMH-resource (see Appendix G).
- 10.5 Ensure that appropriately trained clinical pharmacists are available to counsel service users about their medication.

## **11. Recommendations for clinical teams and clinical staff working in mental health services**

- 11.1 Multidisciplinary teams should meet and discuss NAS findings within their Trust. They should develop action plans and work towards meeting these.
- 11.2 Psychiatrists and nurse prescribers should be aware of the upper limits for prescribing antipsychotic medication and document reasons when these

limits are exceeded on every occasion this happens. They should also be aware that antipsychotic polypharmacy is only rarely appropriate and if used requires clear documentation of the reasons.

- 11.3 Team managers should ensure that appropriate monitoring and interventions for cardiometabolic problems are implemented. This may be facilitated by use of the CMH-resource (see Appendix G).
- 11.4 Staff should recognise that family history of physical health problems may change and take steps to ensure that information on risk factors is updated.

## **12. Recommendations for clinical teams in General Practices**

- 12.1 General Practitioners and practice nurses, working with their practice managers, should ensure that staff are aware that;
  - Patients with schizophrenia are a priority group for prevention and treatment of cardiovascular disease and diabetes as recommended in NICE schizophrenia guidelines.
  - The Quality Outcome Framework severe mental illness register (MH Indicators 12-15) and the NICE recommended checks (see NICE CG 82; updated 2009) should be carried out.
  - Vulnerable patients may lack motivation to take up physical health checks and may benefit from particular encouragement. This could include offering assessments at home or support to attend the surgery for their annual assessment.
- 12.2 Responsibilities for physical health checks should be clearly defined. This requires a collaborative arrangement between primary and specialist care, formalised in a local protocol defining roles and responsibilities, and systems for shared communication of findings:
  - All patients with schizophrenia should receive regular and systematic assessment of physical health and monitoring for adverse treatment effects as described in NICE guidance<sup>6</sup>.
  - This may be facilitated by reference to the Integrated Physical Health Pathway, recently developed by Rethink Mental Illness (see Resources) or a similar resource.

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<sup>6</sup> NICE 2009 CG 82 p370-371 sections 10.1.4.3, 10.4.1.1 and 10.4.1.2

- 12.3 Practices should ensure that all their GPs, practice nurses and other clinical staff are trained in the assessment and management of people with schizophrenia and the related physical health checks required (See 2.8).
- 12.4 GPs and nursing staff in primary care should ensure that appropriate interventions for cardiometabolic problems are implemented. This may be facilitated by use of the CMH-resource (see Appendix G).

### **13. Recommendations for voluntary organisations**

- 13.1 Voluntary organisations should assist health service organisations either to produce their own accessible information for service users or to advise them where this information is already available.
- 13.2 Voluntary organisations should consider approaching local Trusts to implement a 'Health passport' system for patients with schizophrenia.
- 13.3 Voluntary organisations should work with Public Health in producing accessible health programmes (see 3.3).

## **Resources**

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In addition to the recommendations listed above, a list of resources for clinicians, service users and carers is available on the NAS website at:

<http://www.rcpsych.ac.uk/quality/NAS/resources>.

# Feedback and dissemination

## **Feedback from participating Trusts**

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Feedback was sought from participating Trusts to collate their opinions on the baseline audit process and constructively appraise how the second round of audit, scheduled for 2013, should be carried out.

A learning event for baseline participating Trusts was held in London on 30 April 2012. This was a half day event, during which presentations on the baseline data were given. Trust representatives were given the opportunity to raise comments and issues about their individualised Trust level reports and the audit process, and a record was made of these (see page 126).

An online questionnaire was distributed to participating Trusts for them to comment on the audit process, contextual data about sampling and the way that the audit was managed in their Trust, and the presentation of individualised Trust reports. This questionnaire was available between from 18 May to 3 July 2012. We also asked Trusts to alert us to any inaccuracies in their reports during this period. Of the 60 participating baseline Trusts, 43 (72%) provided feedback using this questionnaire.

## **Dissemination of preliminary findings**

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In order to stimulate improvements in clinical practice at the earliest opportunity and to gather feedback on the audit process and methodology, with a view to improving this for a second round of audit, preliminary findings were presented at relevant meetings. All presentations included the caveat that, as these findings were preliminary and had not yet been ratified by the Department of Health and the Welsh Government, they should not be shared outside of these meetings. No handouts of these presentations were provided to attendees.

## **HQIP ESQH European National Clinical Registries and Audit Summit**

*London, 26-27 April 2012*

Poster presentation on the progress of the audit to date.

## **NAS learning event**

*London, 30 April 2012*

This event included presentations on the audit methods and results to representatives of participating Trusts. Attendees were given the opportunity to provide feedback on the audit process at the event on the day or via an online feedback form.

## **Royal College of Psychiatrists' divisional meetings**

Preliminary findings were presented at the meetings listed below by Professor Stephen Cooper and Dr David Shiers. These meetings were attended by psychiatrists who were members of the College.

RCPsych Eastern Division, *1 May 2012*

RCPsych South West Division, *11 May 2012*

RCPsych West Midlands Division, *11 May 2012*

RCPsych South Eastern Division, *30 May 2012*

RCPsych Trent Division, *10 October 2012*

RCPsych North West Division, *31<sup>st</sup> October 2012*

## **Other meetings of the Royal College of Psychiatrists**

RCPsych General and Community Faculty, *10 October 2012*

## **Rethink Mental Illness, Schizophrenia Commission**

*London 1 May 2012*

Closed session discussing the preliminary NAS findings.

NAS will continue to disseminate findings at meetings and events following the publication of this report. Dates of future meetings can be found on our website:

[www.rcpsych.ac.uk/quality/NAS](http://www.rcpsych.ac.uk/quality/NAS)

Feedback collected included:

- Suggestions for the methodology for the second round of audit, which included further investigation into reasons for prescribing more than one antipsychotic and further facilitating the engagement of CEOs and GPs in the second round of audit.
- That there may be issues around service user involvement, including capacity of patients under community treatment orders to become fully involved with their treatment. A lack of advocacy for service users was felt to be key to these issues.
- A key theme at many of these meetings was the issue of whose is the responsibility for physical health monitoring. This is addressed in our recommendations (page 115).
- The Positive Cardiometabolic Health resource, which was developed in parallel with the audit, was well received. The resource can be found in Appendix G and can be downloaded from our website ([www.rcpsych.ac.uk/quality/NAS/resources](http://www.rcpsych.ac.uk/quality/NAS/resources)) along with further information on the genesis of this resource.

## Learning points

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Following feedback from our Advisory Group and participating Trusts the NAS team also have some recommendations for the second round of audit:

1. Seek to identify more information regarding collaboration between mental health and primary care providers and examples where this may have improved the quality of monitoring and intervention to improve the physical health of people with schizophrenia.
2. Consult stakeholders on the benchmark for judging levels of service user and carer satisfaction with services and experience of care and consider increasing these in any future audit in order to raise the bar.
3. Clarify the Trust audit tool to ensure it is clear where we are asking for information from the records (i.e. whether it has been recorded that an intervention has been offered).

## Future of NAS

In March 2012 an extension to the NAS contract was agreed with HQIP for a further two years in order to run a second round of audit from January 2013. All eligible organisations in England and Wales are expected to participate.

The second round of NAS will run from January 2013 to December 2014. The process will remain largely the same as the first round: audit leads will be sent a pack containing the audit materials, including questionnaires to be sent to service users and carers, and the audit tool for data collection and online completion.

In accordance with the Government's transparency agenda, information about participation and performance of individual Trusts against the audit standards will be made available as data files on the NAS website at a Trust level only.

More information can be found via the HQIP website at:

<http://www.hqip.org.uk/transparency-agenda-and-the-national-clinical-audit-and-patient-outcomes-programme/>

or on our website: [www.rcpsych.ac.uk/quality/NAS](http://www.rcpsych.ac.uk/quality/NAS).

### Key dates in 2013 - 2014

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**January – February 2013:** Registration for the second round of NAS.

**June 2013:** Organisations to be provided with materials to raise awareness of the audit.

**June – August 2013:** Organisations to be provided with audit tools and will be required to select their sample.

**September – October 2013:** Data collection.

**November 2013:** Online data entry.

**2014:** Participating organisations receive their individual reports.

**2014:** Publication of the national report.

## References

- Alvarez-Jimenez, M., Gonzalez-Blanch, C., Crespo-Facorro, B., et al. (2008). Antipsychotic-induced weight gain in chronic and first episode psychotic disorders – a systematic critical reappraisal. *CNS Drugs*, 22: 547-62.
- American Diabetes Association & American Psychiatric Association (2004). Consensus development conference on antipsychotic drugs and obesity and diabetes. *Diabetes Care*, 27: 596–601.
- Andrews, A., Knapp, M., McCrone, P., Parsonage, M., & Trachtenberg, M. (2012). *Effective interventions in schizophrenia the economic case: A report prepared for the Schizophrenia Commission*. London: Rethink Mental Illness.
- Audit Commission (2010). *Maximising resources in adult mental health*. Audit Commission Briefing, June 2010. Available at: [http://www.audit-commission.gov.uk/nationalstudies/health/financialmanagement/Pages/100623\\_maximisingresources.aspx](http://www.audit-commission.gov.uk/nationalstudies/health/financialmanagement/Pages/100623_maximisingresources.aspx).
- Barbato, A. (1998). *Schizophrenia and Public Health*. Geneva: World Health Organisation.
- Barnes, T.R.E. (2011). Evidence-based guidelines for the pharmacological treatment of schizophrenia: recommendations from the British Association for Psychopharmacology. *British Journal of Psychopharmacology*, 25: 567-620.
- Barnes, T.R.E., Paton, C., Cavanagh, M-R., Hancock, E., & Taylor, D.M. on behalf of the UK Prescribing Observatory for Mental Health (2007). A UK audit of screening for the metabolic side effects of antipsychotics in community patients. *Schizophrenia Bulletin*, 33: 1397–1401.



Brown, S., Kim, M., Mitchell, C., et al. (2010). Twenty-five year mortality of a community cohort with schizophrenia. *British Journal of Psychiatry*, 196: 116-121.

De Hert, M., Dekker, J.M., Wood, D., Kahl, K.G., Holt, R.I. & Moller, H.J. (2009). Cardiovascular disease and diabetes in people with severe mental illness position statement from the European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC). *European Psychiatry*, 24: 412–424.

Fearon, P., Kirkbride, J.B., Morgan, V., et al. (2006). Incidence of schizophrenia and other psychoses in ethnic minority groups: Results from the MRC AESOP Study . *Psychological Medicine*, 36: 1541-1550.

Foley, D., & Morley, K.I. (2011). Systematic Review of Early Cardiometabolic Outcomes of the First Treated Episode of Psychosis. *Archives of General Psychiatry*, 68: 609-616.

Hamann, J., Leucht, S. & Kissling, W. (2003). Shared decision making in psychiatry. *Acta Psychiatrica Scandinavica*, 107: 403–409.

an der Heiden, W., & Häfner, H. (2011). Course and outcome. In *Schizophrenia 3<sup>rd</sup> Edition* (Eds. D.R. Weinberger & P.J. Harrison); Chapter 7, pp. 104-141. Chichester: Wiley-Blackwell.

Hippisley-Cox, J. & Vinogradova, Y. (2009). *Trends in consultation rates in general practice 1995-2008: Analysis of the QResearch® database*. UK: The NHS Information Centre for health and social care.

Kahn, R.S., Fleischhacker, W.W., Boter, H., et al. (2007). Effectiveness of antipsychotic drugs in first-episode schizophrenia and schizophreniform disorder: an open randomised clinical trial. *Lancet*, 371: 1085-1097.

Kendrick, T., Burns, T., Freeling, P., et al. (1994). Provision of care to general practice patients with disabling long-term mental illness: a survey in 16 practices. *British Journal of General Practice*, 44: 301–305.

Lelliott, P., Beevor, A., Hogman, G., Hyslop, J., Lathlean, J., & Ward, M. (2001). Carers' and Users' Expectations of Services – User version (CUES-U): a new instrument to measure the experience of users of mental health services. *The British Journal of Psychiatry*, 179: 67-72.

Lester, H., Tritter, J.Q., & Sorohan, H. (2005). Patients' and health professionals' views on primary care for people with serious mental illness: focus group study. *BMJ*, 330: 1122.

Lieberman, J.A., Stroup, T.S., McEvoy, J.P., et al. (2005). Effectiveness of antipsychotic drugs in patients with chronic schizophrenia. *The New England Journal of Medicine*, 353: 1209-1223.

Manderbacka, K., Arffman, M., Sund, R., et al. (2012). How does a history of psychiatric hospital care influence access to coronary care: a cohort study. *BMJ Open*, 2: e000831 doi:10.1136/bmjopen-2012-000831.

McCrone, P., Dhanasiri, S., Patel, A., Knapp, M., & Lawton, S. (2008). *Paying the price. The cost of mental health care in England to 2026*. London: King's Fund.

McIntyre, R.S., McCann, S.M., & Kennedy, S.H. (2001). Antipsychotic metabolic effects: weight gain, diabetes mellitus, and lipid abnormalities. *The Canadian Journal of Psychiatry*, 46: 273-81.

Mitchell, A.J., Malone, D., & Doebbeling, C.C. (2009). Quality of medical care for people with and without comorbid mental illness and substance misuse: systematic review of comparative studies. *British Journal of Psychiatry*, 194: 491-499.

Nazareth, I.D. & King, M.B. (1992). Controlled evaluation of management of schizophrenia in one general practice: a pilot study. *Family Practice*, 9: 171–172.

NHS Employers and British Medical Association (2011). *Quality and Outcomes Framework*. London: The NHS Confederation (Employers) Company Ltd.

NHS Employers and British Medical Association (2011). *Quality and Outcomes Framework guidance for GMS contract 2011/12*. Available at:

[http://www.nhsemployers.org/SiteCollectionDocuments/OOFguidanceGMScontract\\_2011\\_12\\_FL%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/OOFguidanceGMScontract_2011_12_FL%2013042011.pdf).

NHS Information Centre for Health and Social Care (2010). *Health Survey for England 2010: Trend tables*. Leeds: The NHS Information Centre for Health and Social Care.

NICE (2009). *Schizophrenia: Core Interventions in the Treatment and Management of Schizophrenia in Primary and Secondary Care*. Clinical Guideline 82. London: NICE.

Pantelis, C., & Lambert, T.J.R. (2003). Managing patients with “treatment-resistant” schizophrenia. *Lancet*, 178 (Suppl): S62-S66.

Pharoah, F.M., Mari, J., & Streiner, D. (2006). *Family interventions in schizophrenia*. Cochrane Database of Systematic Reviews Issue 4, CD000088.

Prescribing Observatory for Mental Health (2010). *Topic 6b report: re-audit. Assessment of the side effects of depot antipsychotics*. Prescribing Observatory for Mental Health, CRTU086 (data on file).

Quirk, A., Smith, S.C., Hamilton, S., et al. (2008). *Development and Validation of the Carer Well-Being and Support (CWS) Questionnaire. Report to the NCCSDO*. London: NCCSDO.

Reilly, S., Planner, C., Hann, M., Reeves, D., Nazareth, I., & Lester, H. (2012). The role of primary care in service provision for people with severe mental

illness in the United Kingdom. *PLoS ONE* 7(5): e36468.  
doi: 10.1371/journal.pone.0036468.

Rethink (2003). *Who cares? The experiences of mental health carer accessing service and information*. Kingston Upon Thames: Rethink.

Royal College of Psychiatrists & Princess Royal Trust (2004). *Partners in Care*. Available at: [www.rcpsych.ac.uk/campaigns/partnersincare.aspx](http://www.rcpsych.ac.uk/campaigns/partnersincare.aspx).

Royal College of Psychiatrists (1996). *Health of the Nation Outcome Scales (HoNOS)*. Available at: <http://www.rcpsych.ac.uk/training/honos.aspx>.

The NHS Information Centre, Lifestyles Statistics (2011). *Statistics on Smoking: England, 2011*. Available at: <http://www.ic.nhs.uk/pubs/smoking11>.

The Schizophrenia Commission (2012). *The abandoned illness: a report from the Schizophrenia Commission*. London: Rethink Mental Illness.

Thornicroft, G. (2011). Physical health disparities and mental illness: the scandal of premature mortality. *British Journal of Psychiatry*, 199: 441-442.

Weiden, P.J. (2007). Understanding and addressing adherence issues in schizophrenia: from theory to practice. *Journal of Clinical Psychiatry*, 68 (Suppl. 14): 14–19.

Wilson, P.W.F., D'Agostino, R.B., Levy, D., Belanger, A.M., Silbershatz, H., & Kannel, W.B. (1998). Prediction of coronary heart disease using risk factor categories. *Circulation*, 97: 1837-1847.

Wykes, T., Steel, C., Everitt, B., & Tarrier, N. (2008). Cognitive behaviour therapy for schizophrenia: Effect sizes, clinical models and methodological rigour. *Schizophrenia Bulletin*, 34: 523-537.

**NAS**  
NATIONAL AUDIT OF  
SCHIZOPHRENIA



# Appendices

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Commissioned by





## **Appendix A: Participating Trusts/ Health Boards**

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### **Pilot Sites**

**The Trusts that participated in the pilot phase are listed below:**

Derbyshire Mental Health Services NHS Trust  
Lincolnshire Partnership NHS Foundation Trust  
Mersey Care NHS Trust  
Pennine Care NHS Foundation Trust  
Somerset Partnership NHS Foundation Trust  
South Essex Partnership University NHS Foundation Trust

### **National Audit**

**The Trusts/ Health Boards that participated in the national audit are listed below in alphabetical order:**

2gether NHS Foundation Trust  
5 Boroughs Partnership NHS Foundation Trust  
Abertawe Bro Morgannwg University Health Board  
Aneurin Bevan Health Board  
Avon and Wiltshire Mental Health Partnership NHS Trust  
Barnet, Enfield and Haringey Mental Health NHS Trust  
Berkshire Healthcare NHS Foundation Trust  
Birmingham and Solihull Mental Health NHS Foundation Trust  
Black Country Partnership NHS Foundation Trust  
Bradford District Care Trust  
Cambridgeshire and Peterborough NHS Foundation Trust  
Camden and Islington NHS Foundation Trust  
Central and North West London NHS Foundation Trust  
Cheshire and Wirral Partnership NHS Foundation Trust  
Cornwall Partnership NHS Foundation Trust  
Coventry and Warwickshire Partnership NHS Trust  
Cumbria Partnership NHS Foundation Trust  
Derbyshire Mental Health Services NHS Trust  
Devon Partnership NHS Trust  
Dorset Healthcare NHS Foundation Trust  
Dudley and Walsall Mental Health Partnership NHS Trust

East London NHS Foundation Trust  
Hampshire Partnership NHS Foundation Trust  
Hertfordshire Partnership NHS Foundation Trust  
Humber NHS Foundation Trust  
Hywel Dda Health Board  
Isle of Wight NHS Primary Care Trust  
Kent and Medway NHS and Social Care Partnership Trust  
Lancashire Care NHS Foundation Trust  
Leeds Partnerships NHS Foundation Trust  
Leicestershire Partnership NHS Trust  
Lincolnshire Partnership NHS Foundation Trust  
Manchester Mental Health and Social Care Trust  
Mersey Care NHS Trust  
NAViGo Health and Social Care CIC  
Norfolk and Waveney Mental Health NHS Foundation Trust  
North East London NHS Foundation Trust  
North Essex Partnership NHS Foundation Trust  
Northamptonshire Healthcare NHS Foundation Trust  
Northumberland, Tyne and Wear NHS Foundation Trust  
Northumbria Healthcare NHS Foundation Trust  
Nottinghamshire Healthcare NHS Trust  
Oxfordshire and Buckinghamshire Mental Health NHS Foundation Trust  
Oxleas NHS Foundation Trust  
Pennine Care NHS Foundation Trust  
Plymouth Teaching PCT  
Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust  
Sheffield Health and Social Care NHS Foundation Trust  
Somerset Partnership NHS Foundation Trust  
South Essex Partnership University NHS Foundation Trust  
South London and Maudsley NHS Foundation Trust  
South Staffordshire and Shropshire Healthcare NHS Foundation Trust  
South West London and St George's Mental Health NHS Trust  
South West Yorkshire Partnership NHS Foundation Trust  
Suffolk Mental Health Partnership NHS Trust  
Surrey and Borders Partnership NHS Foundation Trust



Sussex Partnership NHS Foundation Trust  
Tees, Esk and Wear Valleys NHS Foundation Trust  
University Hospitals Coventry and Warwickshire NHS Trust  
West London Mental Health NHS Trust  
Worcestershire Mental Health Partnership NHS Trust

## **Appendix B: NAS Advisory Group**

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### **In alphabetical order:**

Professor Thomas Barnes - Prescribing Observatory for Mental Health UK (POMH-UK); British Association for Psychopharmacology

Victoria Bleazard– Rethink Mental Illness

Dr Katherine Darton – Mind

Dr Catherine Duggan - Royal Pharmaceutical Society of Great Britain (RPSGB)

Ellie Gordon – Royal College of Nursing (RCN)

Stephen Guy – College of Mental Health Pharmacy (CMHP)

Helen Laing – Healthcare Quality Improvement Partnership (HQIP)

Ian Maidment – College of Mental Health Pharmacy (CMHP)

Lucy Palmer – College Centre for Quality Improvement (CCQI, RCPsych)

Dr Maxine Patel - Psychiatry Special Interest Group (PSIG; RCPsych)

Carol Paton – Prescribing Observatory for Mental Health UK (POMH-UK)

Dr Imran Rafi – Royal College of General Practitioners (RCGP)

Yvonne Silove – Healthcare Quality Improvement Partnership (HQIP)

Dr Geraldine Strathdee – NHS London

## Appendix C: Footnotes to NAS standards

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Short period: Up to 6 weeks.

Inadequate response:

When the consultant caring for the patient has used their knowledge about the patient's current mental health and has rated them as being either:

- in partial remission with substantial symptoms and disability  
or
- not in remission.

Optimum dose: Up to three-quarters of BNF maximum or until side effects preclude further dose increase.

Adequate trial of clozapine: At least 8 weeks at optimum dose.

Resistant to treatment with antipsychotic drugs:

- A diagnosis of schizophrenia (F20) or schizoaffective disorder (F25);
- and the continuing (present for at least six months) experience of moderately severe or severe hallucinations and delusions (as indicated by a current score of 3 or 4 on HoNOS scale 6);
- and moderately severe or severe disturbance of behaviour (as indicated by a current score of 3 or 4 on either of HoNOS scale 1 or 2);
- or of moderately severe or severe social problems (as indicated by a current score of 3 or 4 on at least one of HoNOS scales 9, 10, 11 or 12);
- despite the sequential treatment with at least two different antipsychotic drugs (at least one of the drugs should be a non-clozapine second-generation antipsychotic) at an optimum dose (up to three-quarters of BNF maximum or until side effects preclude further dose increase) for an adequate time (up to 6 weeks after reaching optimum dose).

## Appendix D: Audit lead packs and sampling options

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### NAS audit lead packs

1. Part 1 (NAS overview and NAS audit lead guide):
  - Covering introductory letter.
  - CD with electronic copies of all documents.
  - Process flow diagram and key dates.
  - Audit lead checklist.
  - Sampling options and criteria.
  - Standards and indicators.
  
2. Part 2 (audit of practice):
  - Audit of practice forms (x100) with Trust ID pre-printed.
  - Template letter which could be sent to clinicians to inform them of audit and that their service user was included in the audit sample.
  - Example GP letter to inform them of audit and that their service user was included in the audit sample.
  
3. Part 3 (service user and carer survey questionnaires):
  - Trust guidance for sending questionnaires to service users.
  - Document to support staff in responding to queries.
  - 200 x service user survey forms with Trust ID pre-printed.
  - 200 x carer survey forms questionnaires with Trust ID pre-printed.
  - Service user cover letter example.
  - Carer cover letter example.
  - 200 x service user FAQs.
  - 200 x carer FAQs.
  - 400 x pre-paid envelopes.

### Sampling

Organisations selected one of two sampling options (or a combination of both where sampling proved more difficult). This involved identification of service users centrally or through the community mental health team.

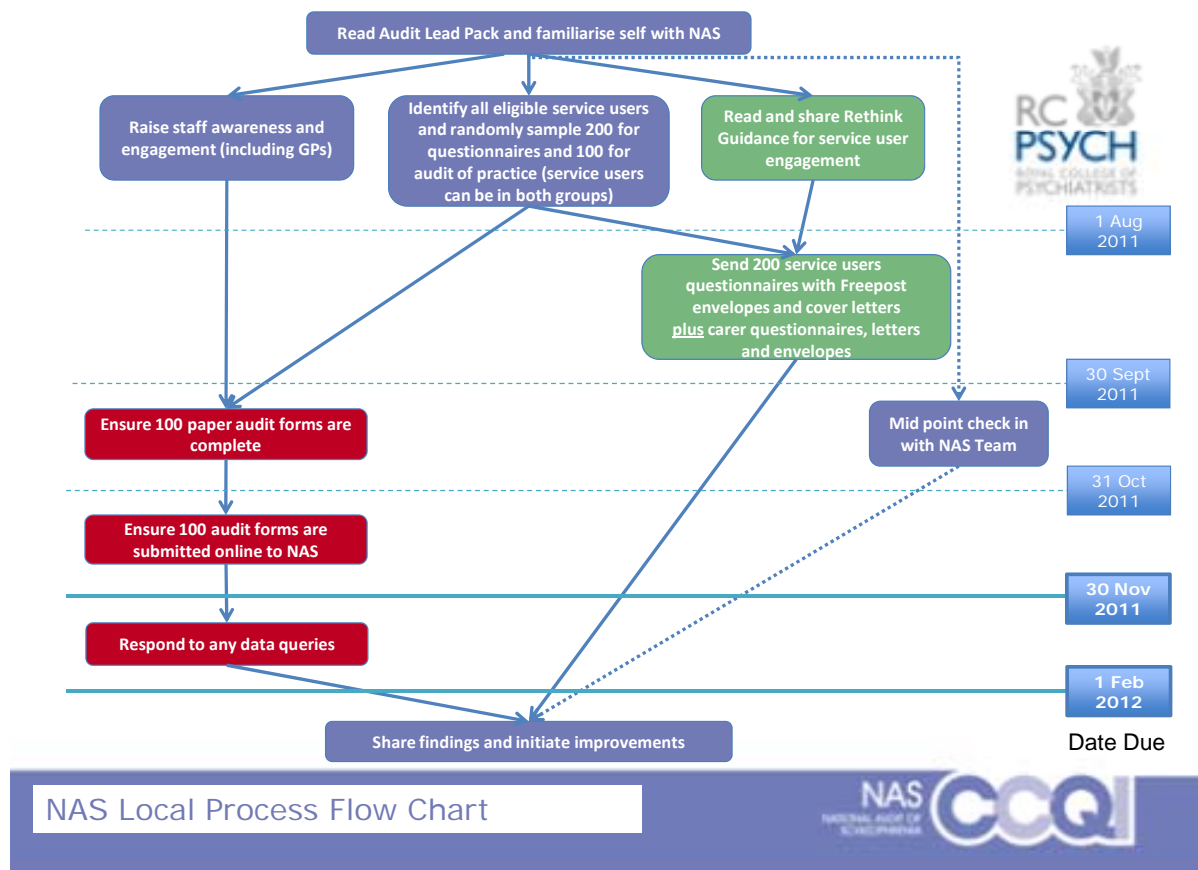
Sampling option 1	Sampling option 2
<ul style="list-style-type: none"> <li>• Identify all service users across the organisation meeting the criteria on a given census day.</li> <li>• Randomly select sample from this total list, using established randomisation techniques, the NAS online randomisation tool or randomly generated numbers from the NAS team.</li> <li>• Contact the consultant responsible for the care of that service user so they can collect the audit data.</li> </ul>	<ul style="list-style-type: none"> <li>• Contact all consultants in the organisation and ask them to send the details of all service users directly under their care, or whose care they are consulted about, that meet the criteria.</li> <li>• Randomly select sample from this total list, using established randomisation techniques, the NAS online randomisation tool or randomly generated numbers from the NAS team.</li> <li>• Contact the consultant responsible for the care of that patient so they can collect the audit data.</li> </ul>

**Service user and carer questionnaires:**

Each participating organisation sent 200 randomly sampled service users:

- A personalised cover letter from their psychiatrist.
- A service user survey form.
- A service user Frequently Asked Questions (FAQ).
- A pre-paid envelope.
- A prize draw postcard to be returned to Rethink Mental Illness.
- A pack to pass to a carer they have identified, including:
  - A carer cover letter.
  - A carer survey form.
  - A carer FAQ.
  - A pre-paid envelope.

## Appendix E: NAS process flowchart



## Appendix F: Service user responses from service user survey

This section contains the service users responses to each individual item about prescribing of medication (Questions 1-6) and each CUES item (items 7-22) included in the service user survey (n= 2,323).

<b>About your mental health medications</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
	<b>Yes, in a way I could easily understand</b>	<b>Yes, but not in a way I could easily understand</b>	<b>No, not at all</b>	<b>I can't say</b>	<b>Did not answer</b>
<b>Q1</b> Was the purpose of the medication explained to you?	1527 (66)	349 (15)	273 (12)	97 (4)	77 (3)
<b>Q2</b> Were the side effects of the medication discussed with you?	1230 (53)	282 (12)	618 (27)	108 (5)	85 (4)
	<b>Yes, definitely</b>	<b>Yes, to some extent</b>	<b>No</b>	<b>I can't say</b>	<b>Did not answer</b>
<b>Q3</b> Do you think your views were taken into account when deciding which medication to take?	914 (39)	742 (32)	489 (21)	101 (4)	77 (3)
	<b>Yes</b>		<b>No</b>	<b>I can't say</b>	<b>Did not answer</b>
<b>Q4</b> Were you given written information (or appropriate alternative)?	1167 (50)		877 (38)	180 (8)	99 (4)
	<b>Yes, definitely</b>	<b>Yes, to some extent</b>	<b>No</b>	<b>I can't say</b>	<b>Did not answer</b>
<b>Q5</b> Was the information written or presented to you in a way you could easily understand?	817 (35)	519 (22)	539 (23)	281 (12)	167 (7)
	<b>Yes</b>		<b>No</b>	<b>I can't say</b>	<b>Did not answer</b>
<b>Q6</b> In the past 12 months, have you had a general physical health check up with your MH team, psychiatrist, GP or practice nurse?	1807 (78)		406 (17)	45 (2)	65 (3)

<b>About what is happening in your life</b>		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>The place you live in should meet your individual needs. You shouldn't have to worry about having to move out, and it shouldn't be too out of the way. You should be able to come and go when you want, be alone when you want and not be harassed by the people you live with, by staff or by neighbours.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q7</b>	How does the place you live in compare with the above description?	1927 (83)	233 (10)	103 (4)	60 (3)
<b>You should have enough money to pay bills, stay out of debt and not miss meals. You should not have to feel isolated or cut off from society because of lack of money.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q8</b>	How does your money situation compare with this description?	1836 (79)	326 (14)	104 (4)	57 (2)
<b>Many people find they need help with claiming benefits, filling in forms, and working out how to manage their money. You should get as much help as you need in doing these things.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q9</b>	How does the help you get compare with this description?	1833 (81)	268 (12)	93 (4)	79 (3)
<b>You should have the opportunity of spending your day in some form of regular and meaningful activity. This could be working, studying, training, going to a day centre or to a day hospital.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q10</b>	How does the way you spend your day compare with this description?	1543 (66)	487(21)	195 (8)	98 (4)
<b>Mental illness can affect a person's relationships with the people he or she cares most about. You should be able to maintain good relationships with the people closest to you.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q11</b>	How do your relationships compare with this description?	1722 (74)	400 (17)	112 (5)	89 (4)

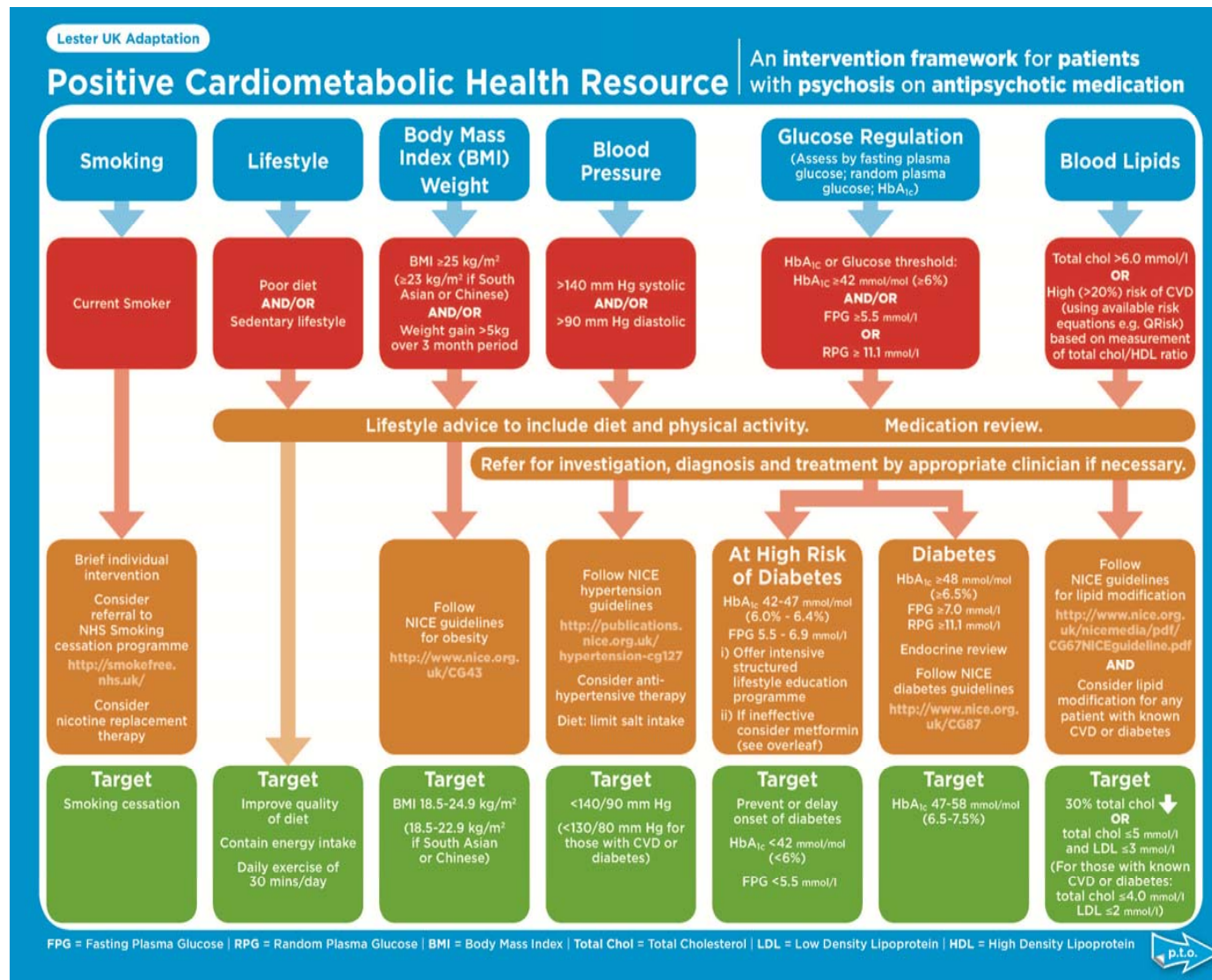


<b>About what is happening in your life</b>		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>You should have the opportunity to mix with people and form new friendships and relationships. To make this possible, you should have enough money, access to transport if you need it, and the use of a phone.</b>					
<b>Q12</b>	How does your social life compare with this description?	1645 (71)	442 (19)	155 (7)	81 (3)
<b>You should be given as much information as you want or need about the services and treatments available to you, about the Mental Health Act and how it works, and about the mental health system generally. Some people find it helpful for someone like them (such as another service user or a member of the same community) to explain things to them. The information you are given should be available when and where you need it.</b>					
<b>Q13</b>	How does the information and advice your get compare with this description?	1605 (69)	461 (20)	165 (7)	92 (4)
<b>You should be able to get help from your local mental health services when you need it, throughout the week, at any time of the day or night.</b>					
<b>Q14</b>	How does your ability to get help from mental health services compare with this description?	1720 (74)	381 (16)	133 (6)	89 (4)
<b>A range of services should be available to you, and you should be able to choose those which best meet your needs, including complementary/alternative therapies, counselling and psychotherapy. You should have a choice about the mental health workers you meet with regularly (for example being able to choose their sex or ethnic background), and be able to change workers if you don't get on.</b>					
<b>Q15</b>	How does the range of choice you have compare with this description?	1567 (67)	471 (20)	180 (8)	105 (5)

<b>About what is happening in your life</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>Doctors, nurses, social workers and other mental health workers should show you respect, be honest with you and discuss things with you in a way you can understand. They should be trustworthy and do what they say they will. They should offer regular appointments and not keep you waiting. They should keep information about you confidential or ask your permission before passing it onto others. If they pass on information, it should be accurate and save you from having to repeat yourself to new mental health workers.</b>	<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q16</b> How does your situation compare with this description?	1833 (79)	279 (12)	131 (6)	80 (3)
<b>Mental health workers should not pressure you into doing anything you don't want to, or take decisions on your behalf without getting your permission first. Even if you have been 'sectioned', people should listen to you and take your opinions seriously.</b>	<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q17</b> How does your situation compare with this description?	1778 (77)	308 (13)	145 (6)	92 (4)
<b>You should be able to put your views across to people in authority. This can be difficult for several reasons, such as the effects of medication, if English is not your first language, or if the situation is frightening or intimidating. If you want, you should have someone (an advocate) to help support you, or speak for you. You should feel this person really understands what you want and genuinely represents your views when he/she speaks on your behalf.</b>	<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q18</b> How do your circumstances compare with this description?	1777 (76)	317 (14)	119 (5)	110 (5)

<b>About what is happening in your life</b>		<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>	<b>n (%)</b>
<b>You should feel safe and other people should not harass, exploit, victimise or be violent towards you. You should not experience stigma or discrimination at home, at work, from mental health workers, police or any other section of the community.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q19</b>	How do people treat you compared with this description?	1634 (70)	423 (18)	178 (8)	88 (4)
<b>Medication should only be given to relieve the symptoms of ill-health and to reduce your distress. All medication can have unwanted side effects but these should not cause more disruption to your life than improvement.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q20</b>	How does your medication compare with this description?	1771 (76)	302 (13)	139 (6)	111 (5)
<b>You should be able to get the care and treatment you need for your physical health when you need it, whether you are in hospital or living at home. You should be registered with a GP and have regular check-ups from a dentist. You should have access to other types of care, such as opticians, chiropodists, physiotherapists and so on.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q21</b>	How does your physical health care compare with this description?	1906 (82)	249 (11)	82 (4)	86 (4)
<b>The people who give you physical health care should listen to you, show you respect and take your condition seriously.</b>		<b>As good as this</b>	<b>Worse than this</b>	<b>Very much worse than this</b>	<b>Did not answer</b>
<b>Q22</b>	How does your situation compare with this description?	1940 (84)	227 (10)	67 (3)	89 (4)

## Appendix G: The Positive Cardiometabolic Health resource (CMH-resource)



**Don't just  
SCREEN -  
INTERVENE**  
for all patients in  
the "red zone"

Although this clinical resource tool targets antipsychotic medication, many of the principles apply to other psychotropic medicines given to people with long term mental disorders.

The general practitioner and psychiatrist will work together to ensure appropriate monitoring and interventions are provided and communicated. The general practitioner will usually lead on supervising the provision of physical health interventions. The psychiatrist will usually lead on decisions to significantly change antipsychotic medicines.

Primary care's **Quality and Outcomes Framework (QOF)** includes four physical health indicators in the mental health domain: BMI (MH12); blood pressure (MH13); total to HDL cholesterol ratio (MH14); Blood glucose (MH15). Currently MH14 and MH15 are only for those aged over 40yrs.

### History and examination following initiation or change of antipsychotic medication

**Frequency:** as a minimum review those prescribed a new antipsychotic at baseline and at least once after 3 months.

Ideally weight should be assessed 1-2 weekly in the first 8 weeks of taking a new antipsychotic as rapid early weight gain may predict severe weight gain in the longer term.

Subsequent review should take place annually unless an abnormality of physical health emerges, which should then prompt appropriate action and/or continuing review at least every 3 months.

#### To review

**History:** Seek history of substantial weight gain (e.g. 5kg) and particularly where this has been rapid (e.g. within 3 months). Also review smoking, exercise and diet. Ask about family history (diabetes, obesity, CVD in first degree relatives <60 yrs) and gestational diabetes. Note ethnicity.

**Examination:** Weight, BMI, BP.

**Investigations:** Fasting estimates of plasma glucose (FPG), HbA<sub>1c</sub>, and lipids (total cholesterol, LDL, HDL, triglycerides). If fasting samples are impractical then non-fasting samples are satisfactory for most measurements except for LDL or triglycerides.

**ECG:** Include if history of CVD, family history of CVD, or if patient taking certain antipsychotics (see Summary of Product Characteristics) or other drugs known to cause ECG abnormalities (eg erythromycin, tricyclic anti-depressants, anti-arrhythmics - see British National Formulary for further information).

### Interventions

**Nutritional counselling:** reduce take away and "junk" food, reduce energy intake to prevent weight gain, stop soft drinks and juices, increase fibre intake.

**Physical activity:** structured education-lifestyle intervention. Advise physical activity: e.g. Advise a minimum of 150 minutes of 'moderate-intensity' physical activity per week (<http://bit.ly/Oe7DeS>).

If unsuccessful after 3 months in reaching targets, then consider specific pharmacological interventions (see below).

### Specific Pharmacological Interventions

**Anti-hypertensive therapy:** Normally GP supervised. Follow NICE recommendations <http://publications.nice.org.uk/hypertension-cg127>.

**Lipid lowering therapy:** Normally GP supervised. Follow NICE recommendations <http://www.nice.org.uk/nicemedia/pdf/CG67NICEguideline.pdf>.

**Treatment of Diabetes:** Normally GP supervised. Follow NICE recommendations <http://www.nice.org.uk/CG87>.

**Treatment of those at high risk of diabetes:** FPG 5.5-6.9 mmol/l; HbA<sub>1c</sub> 42-47 mmol/mol (6.0-6.4%) Follow NICE guideline PH 38 Preventing type 2 diabetes: risk identification and interventions for individuals at high risk (recommendation 19) - <http://guidance.nice.org.uk/PH38>.

- Where intensive lifestyle intervention has failed consider metformin trial (this would normally be GP supervised).
- Please be advised that off-label use requires documented informed consent as described in the GMC guidelines, [http://www.gmc-uk.org/static/documents/content/Good\\_Practice\\_in\\_Prescribing\\_Medicines\\_0911.pdf](http://www.gmc-uk.org/static/documents/content/Good_Practice_in_Prescribing_Medicines_0911.pdf). These GMC guidelines are recommended by the MPS and MDU, and the use of metformin in this context has been agreed as a relevant example by the Defence Unions.
- Adhere to British National Formulary guidance on safe use (in particular ensure renal function is adequate). Start with a low dose e.g 500 mg once daily and build up, as tolerated, to 1500-2000 mg daily.

**Review of antipsychotic medication:** Normally psychiatrist supervised. Should be a priority if there is:

- Rapid weight gain (e.g. 5kg <3 months) following antipsychotic initiation.
- Rapid development (<3 months) of abnormal lipids, BP, or glucose.

The psychiatrist should consider whether the antipsychotic drug regimen has played a causative role in these abnormalities and, if so, whether an alternative regimen could be expected to offer less adverse effect:

- As a first step prescribed dosages should follow BNF recommendations; rationalise any polypharmacy.
- Changing antipsychotic requires careful clinical judgment to weigh benefits against risk of relapse of the psychosis.
- Benefit from changing antipsychotic for those on the drug for a long time (>1 year) is likely to be minimal.
- If clinical judgment and patient preference support continuing with the same treatment then ensure appropriate further monitoring and clinical considerations.



Download Lester UK Adaptation:  
[www.rcpsych.ac.uk/quality/NAS/resources](http://www.rcpsych.ac.uk/quality/NAS/resources)

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## Glossary

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**Adherence:** In the context of this report, this refers to taking medication in a way that allows it to be effective; i.e. at the prescribed times and dosage. Non-adherence therefore refers to either not taking the medication or not following the prescription.

**Adverse effect:** An unpleasant or harmful consequence associated with taking a medication. (Sometimes called 'side-effects' but not absolutely equivalent.)

**Alcohol misuse:** The use of alcohol to the extent that it affects the person's daily life. It can lead to dependence on alcohol and can affect the person's mental health.

**Antipsychotics:** A group of medications that are prescribed to treat people with symptoms of **psychosis**.

**Arts therapies :** A form of **psychological therapy** that uses art media as its primary mode of communication.

**Audit:** Clinical audit is a quality improvement process. It seeks to improve patient care and outcomes through a systematic review of care against specific standards or criteria. The results should act as a stimulus to implement improvements in the delivery of treatment and care.

**Audit standard:** A standard is a specific criterion against which current practice in a service is measured. Standards are often developed from recognised, published guidelines for provision of treatment and care.

**Augment:** To change by adding something. In the context of the treatment of schizophrenia it is often adding another treatment to a treatment the person is already receiving. (It thus differs from **switching** from one treatment to another.)

**Benchmark:** A standard result that can be used as a basis for comparison.

**Blood glucose:** Level of sugar in the blood. Measuring this is done to see if someone has diabetes.

**Blood pressure:** This gives one measure of how healthy a person's cardiovascular system is, i.e. the functioning of their heart, blood vessels and aspects of their kidney function. It is measured using two levels: systolic and diastolic blood pressure.

**Body Mass Index (BMI):** This is an indicator of healthy body weight, calculated by dividing the weight in kilograms by the square of the height in metres.

**British Association for Psychopharmacology (BAP):** A scientific society that brings together doctors and scientists from clinical and scientific disciplines with an interest in how licensed therapeutic medications, potential new medications and other drugs may affect mental function and behaviour.

**British National Formulary (BNF):** A publication that provides guidance on prescribing for health professionals. It also publishes maximum recommended doses for different medications.

**Carer:** A person, often a spouse, family member or close friend, who provides unpaid emotional and day-to-day support to the service user. In this audit, service users identified their own carers.

**Cardiometabolic problems:** Problems which concern both heart disease and metabolic disorders such as diabetes. Cardiometabolic risk has a wider compass than **metabolic syndrome** because it includes smoking and genetic risks as well as poor glucose control in those with established diabetes (whereas metabolic syndrome is only concerned with pre-diabetes).

**Caveat:** A factor relating to some (often unavoidable) aspect of the design of a study or problem in the collection of data that should be noted as it may (or may not) have had an effect on the results.

**Cognitive Behavioural Therapy (CBT):** A form of **psychological therapy**, which is usually short-term and addresses thoughts and behaviour.

**Clinical Commissioning Groups (CCGs):** From April 2013, these groups of **clinicians** led by **GPs** will take on the role of purchasing local health services in England.

**College Centre for Quality Improvement (CCQI):** A section of the Royal College of Psychiatrists, which works with services and service users to raise standards in mental health care.

**College of Mental Health Pharmacy:** The College of Mental Health Pharmacy (CMHP) is a scientific society with the overall objective of advancing education and research in the practice of mental health pharmacy. It is mainly aimed at pharmacists and pharmacy technicians.

**Chief Executive (CEO):** Appointed as leads of health organisations to manage how healthcare is delivered.

**Chief Pharmacist:** Responsible for a team that looks after purchasing and provision of medicines in a Trust. They also take a major role in ensuring that good practice is adhered to, i.e. they have an important role in governance.

**Cholesterol:** An important component of blood **lipids** (fats) and a factor determining cardiovascular health. If this is high, it may lead to heart problems.

**Clinical Director:** A person with experience of clinical work in healthcare organisations but who assists in leading and managing a specialist service. They can cover both hospital and community care.

**Clinician:** A health professional, who sees and treats patients and is responsible for some or all aspects of their care.

**Positive Cardiometabolic Health resource (CMH-resource):** (see Appendix G).

**Community Mental Health Team (CMHT):** A group of health professionals who specialise in working with people with mental health problems outside of hospitals.

**Community Treatment Order (CTO):** An instruction under the Mental Health Act that someone should continue their care out of hospital.

**Consultant psychiatrist:** A doctor who is a medical expert in psychiatry and on the General Medical Council's Specialist Register.

**Contraindicated:** The available evidence suggests that something (e.g. medication) should not be used.

**The Carers' and Users' Expectations of Services (CUES):** Questionnaire from which the NAS service user survey was derived (for full details see page 34).

**The Carer Well-Being and Support (CWS):** Questionnaire from which the NAS carer survey was derived (for full details see page 34).

**Cardiovascular Disease:** Diseases of the heart, blood vessels and blood circulation.

**Depot:** A long lasting antipsychotic medication administered by injection.

**Diabetes:** A long-term condition caused by having high levels of sugar in the blood. There are two types; **type 1** diabetes which can be controlled with insulin injections, **and type 2** diabetes which can generally be controlled through diet.

**Director of Nursing:** A registered nurse who manages and supervises the care of patients within their health organisation as part of the senior management team.



**Dual energy X-ray absorptiometry (DEXA) scans:** A scan that checks bone density.

**Dyslipidaemia:** A condition where a person has an abnormal level of one or more types of lipids. Most commonly there is too high a level of lipids (see **hyperlipidaemia**).

**Electrocardiography (ECG):** A test that measures the electrical activity of the heart.

**Ethnicity:** The fact or state of belonging to a social group that has a common national or cultural tradition.

**Fasting plasma glucose:** A blood test to see if someone has **diabetes**.

**Family history (FH):** Whether a family member has suffered a common or relevant physical health condition, for example **diabetes**.

**Focus groups:** A meeting of a group of people with similar experience from whom feedback is gathered.

**General Practitioner (GP):** A doctor who works in practices in the community and who is generally the first point of contact for all physical and mental health problems.

**Glucose:** A type of sugar. The body uses this for energy.

**Glycated haemoglobin:** See below.

**HbA1c:** Glycated haemoglobin. A form of haemoglobin that is bound to the sugar glucose and can provide an indication of how well **diabetes** is being controlled.

**Health and Wellbeing Board:** Established in 2012 and becoming fully active in April 2013, these boards will consist of **Clinical Commissioning Groups** and councils. They will undertake the **Joint Strategic Needs Assessment** and together develop strategies for addressing these.

**Health Boards (Wales):** The Welsh equivalent of NHS **Trusts**.

**Health check:** See **physical health check**.

**Health of the Nation Outcomes Scales (HoNOS):** Developed to measure various aspects of the level of symptoms, social and other functioning and general health of people with severe mental illness.

**Health passport:** A document that the service user keeps to make their own record of their healthcare.

**High Density Lipoprotein (HDL):** One of a group of proteins that transport lipids in the blood.

**Healthcare Quality Improvement Partnership (HQIP):** An organisation which funds clinical audits and works to increase the impact of these to improve quality in healthcare in England and Wales.

**Hyperglycaemia:** A situation where a person is found to have high blood glucose (sugar) levels above those normally expected. If persistent it usually suggests the person is suffering from **diabetes**.

**Hyperlipidaemia:** A condition where the person has a high **lipid** level. This increases the risk of having a heart attack or stroke.

**Hypertension:** High blood pressure. This is a risk factor for heart disease and stroke.

**ICD-10:** The International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> Revision. A list of medical disorders, classified into sections according to areas of the body or functions principally affected, published by the World Health Organisation. It defines the full range of recognised clinical disorders and contains lists of symptoms for these. It is a useful diagnostic tool for clinicians.

**Informed choice:** Providing the service user with accessible information to allow them to make a decision based on this.

**Inpatient:** Someone under care in hospital.

**Joint Strategic Needs Assessment (JSNA):** Analyses of data on the health and wellbeing status of the local community to highlight inequalities and unmet needs. This also evaluates existing interventions and makes recommendations for future practice.

**Lipids:** Fats, such as **cholesterol**. They are stored in the body and provide us with energy. Levels too far outside of the normal range increase risk of certain diseases.

**Literature review:** Searching for academic and other articles on a given subject, reading the material and assessing its quality.

**Medical Director:** A doctor within a health organisation who works as part of the senior management team to provide clinical leadership and advice, and act as a bridge between medical staff and the organisation.

**Metabolic:** Relating to metabolism; this refers to all the chemical processes that happen in the body, in particular those associated with food.

**Metabolic syndrome:** A cluster of features (high **BMI** plus two of the following: high blood pressure; high blood glucose; high blood lipids) that increase risk of type-2 diabetes and **cardiovascular disease**.

**mmHg:** Millimeters of mercury.

**mmol/l:** Millimoles per litre.

**Multidisciplinary:** Usually refers to a team of health professionals from different professional backgrounds.

**National guidelines:** Nationally agreed documents which recommend the best way of doing something, for example treating a mental health problem.

**NCAPOP (National Clinical Audit and Patient Outcomes Programme):** A closely linked set of centrally-funded national clinical audit projects that collect data on compliance with evidence based standards, and provide local Trusts with benchmarked reports on the compliance and performance. They also measure and report patient outcomes.

**NICE (National Institute for Health and Clinical Excellence):** An independent organisation responsible for providing national guidance on promoting good health, and preventing and treating ill health.

**NICE guideline:** Guidelines on the treatment and care of people with a specific disease or condition in the NHS.

**ng/ml:** Nanograms per litre of volume.

**Obesity:** An abnormal accumulation of body fat, usually 20% or more over an individual's ideal body weight. Obesity is associated with increased risk of illness.

**Off label prescribing:** Sometimes it is appropriate to prescribe medication outside the usual terms of its licence. This is known as 'off label' prescribing. Most commonly this may occur in a situation where a patient is **treatment resistant** and a trial of a higher than usual dose is thought to be worthwhile, or where a drug has been demonstrated to have potential benefits for certain conditions but has never received a formal licence for such. The clinician must make clear record of why a drug is used 'off label' and ensure careful review of the outcome.

**Optimum:** Ideal; most favourable.

**Outcomes:** What happens as a result of treatment. For example, this could include recovery and improvement.

**Outcome indicators:** A measure that shows **outcomes**.

**Physical health check:** A medical examination, which ideally should include speaking to the patient about their family history, smoking, **substance misuse** and alcohol intake plus measures of weight, height, **blood pressure** and blood levels of **glucose**, **lipids** and **prolactin** (if indicated). (It is clear these are important for people with schizophrenia but doctors must always ensure the physical health of all patients is properly monitored and managed.)

**Pilot:** A trial run of a project such as audit or research which tests out methods and data collection materials.

**Polypharmacy:** The prescription of more than one medication at a time.

**Power analysis:** A means of determining the minimum number of returns (e.g. survey responses) required for meaningful statistical analysis of the collected data.

**Prescription:** The supply of medications under the instruction of a health professional.

**Primary care:** Healthcare services that are provided in the community. This includes services provided by GPs, nurses and other healthcare professionals, dentists, pharmacists and opticians.

**Professional bodies:** Usually not-for-profit organisations for members of a particular profession. Their aims include assuring training and continued development for professionals and highlighting issues that are important to their members and the general public.

**Prolactin:** A hormone produced in the pituitary gland. It has a number of functions in the body, including reproductive and **metabolic**.

**Psychological therapies:** Covers a range of interventions designed to improve mental wellbeing. They are delivered by psychologists or other health professionals with specialist training and can be one-to-one sessions or in a group.

**Psychosis:** A term describing people having specific types of symptoms, usually delusions or hallucinations, and where they may lose touch with reality.

Symptoms can include difficulty concentrating and confusion, conviction that something that is not true is so (false beliefs or delusions), sensing things that are not there (hallucinations) and changed feelings and behaviour. Psychosis is treatable. It can affect people of any age and may sometimes be caused by known physical illnesses.

**Public Health England:** From April 2013 the mission of this body will be to improve the health and wellbeing of the population and ensure that health inequalities are addressed.

**Quality and Outcomes Framework (QOF):** A voluntary incentive scheme for GP practices throughout the UK to help ensure good patient care. Contains a number of indicators against which the practice is measured. The practice is then financially rewarded for how well they perform.

**Quantitative:** Information which is numerical or categorical, and can be displayed as graphs.

**The Royal College of General Practitioners (RCGP):** The professional and educational body for GPs in the United Kingdom.

**The Royal College of Nursing (RCN):** The professional and educational body for nurses in the United Kingdom.

**The Royal College of Psychiatrists (RCPsych):** The professional and educational body for psychiatrists in the United Kingdom.

**Randomised Controlled Trial (RCT):** A design for research that is considered to be of high quality.

**Relapse:** Becoming ill again after a period of being better.

**Reliable:** Consistent over time, for example if different people completed it they would get the same answers. An indication of a good measure or tool.

**Remission:** When someone is not currently suffering from the symptoms of an illness that has affected them they are said to be in remission.

**Schizoaffective disorder:** A mental illness where the person suffers from both symptoms of **schizophrenia** and an affective disorder such as depression at the same time.

**Schizophrenia:** 'One of the terms used to describe a major psychiatric disorder (or cluster of disorders) that alters an individual's perception, thoughts, affect and behaviour.' (NICE CG82, 2009, p16). Symptoms can include **psychosis**.

**Secretary of State for Health:** The cabinet minister responsible for the Department of Health.

**Service user (SU):** Person who uses mental health services.

**Side effects:** A consequence of taking a medication that is in addition to its intended effect. Unlike **adverse effects**, side effects are not always negative.

**Sphygmomanometer:** An instrument used to measure blood pressure.

**Standard Deviation (SD):** Shows how spread out the data are.

**Substance misuse:** The use of illegal drugs to the extent that it affects daily life. Can also refer to the use of legal drugs without a prescription. Substance misuse can lead to dependence on the substance and can affect the person's mental health.

**Total National Sample (TNS):** The combined data set of the national sample.

**Treatment resistant schizophrenia:** Most commonly used to describe patients who have clinically significant, persistent and usually disabling symptoms despite trials of treatment, for an adequate period of time, with at least two different antipsychotic medications at adequate doses. In some situations, treatment resistance may occur because **adverse effects** limit the dose of a medication that a person can tolerate. There have been a number of different definitions but in general around 30% of patients may become treatment resistant and some may be poorly responsive to treatment even from their first episode.

**Trust Boards:** A group of executives, including the **Chief Executive, Medical Director** and **Director of Nursing**, and local non-executive members who meet to, amongst other purposes, plan and govern the Trust and monitor and set high standards for performance.

**Trusts:** National Health Service Trusts are public service organisations that provide healthcare services. They include: **Primary Care** Trusts; Acute Trusts, which manage hospitals; Care Trusts, which cover both health and social care; Foundation Trusts, which have a degree of financial and operational freedom; and Mental Health Trusts, which provide health and social care services for people affected by mental health problems.

**Valid:** When an instrument or tool measures what it sets out to it is said to be valid.



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