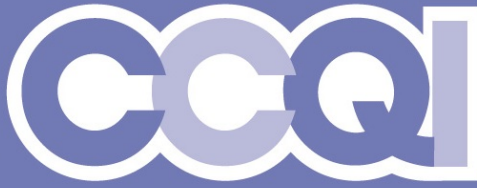
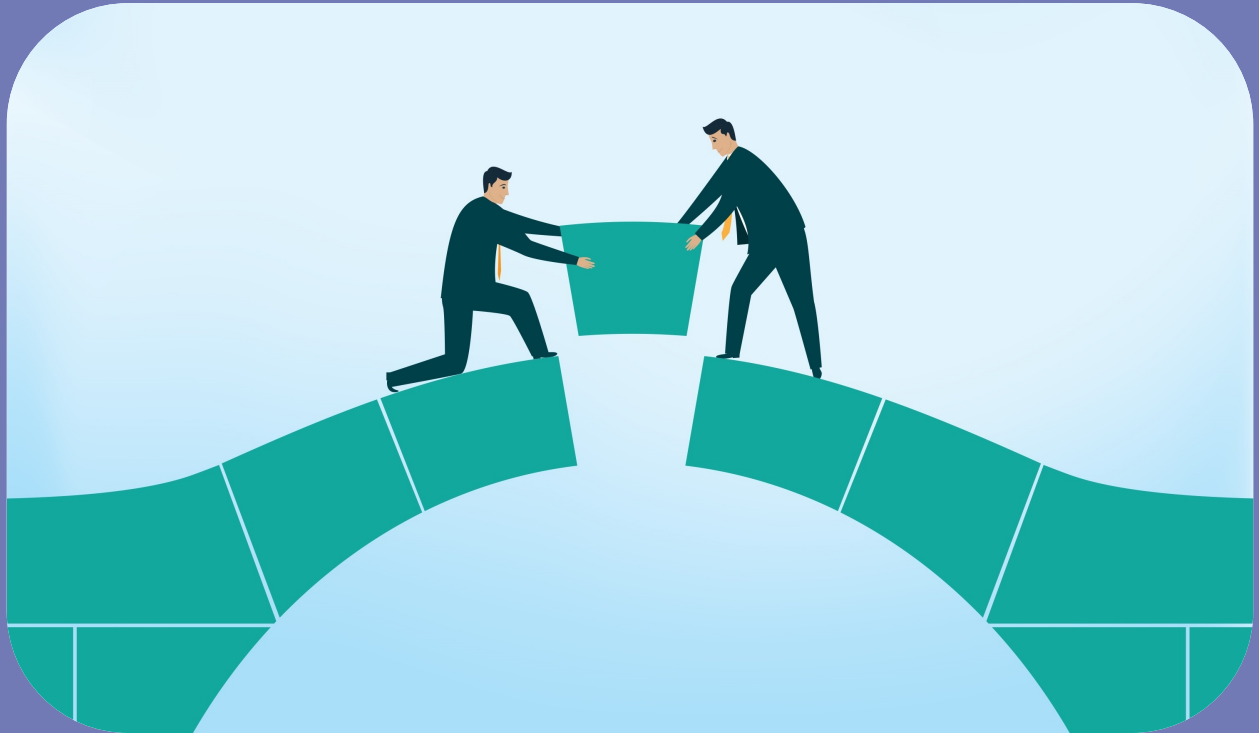


NAS  
NATIONAL AUDIT OF  
SCHIZOPHRENIA



# Report of the second round of the National Audit of Schizophrenia (NAS2) 2014



Commissioned by





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Healthcare Quality Improvement Partnership (HQIP)

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Prescribing Observatory for Mental Health (POMH-UK)

Rethink Mental Illness

Royal College of General Practitioners (RCGP)

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**October 2014**

**Publication number:** CCQI183

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**If citing this report, please reference it as:** Royal College of Psychiatrists (2014). *Report of the Second Round of the National Audit of Schizophrenia (NAS) 2014*. London: Healthcare Quality Improvement Partnership.

## Foreword

Schizophrenia is a severe mental illness that affects almost 300,000 people in the UK. Some people who develop the condition make a complete recovery and never experience another episode, but most people experience a recurrence at some point and for many it is a long term condition that they must learn to live with. A range of drug treatments can improve the health of people with this condition and psychological treatment can reduce the severity and impact of a person's symptoms. While most people with schizophrenia are receiving help to improve their health, concerns have been raised about the quality of care that some people receive.

Two years ago the first round of the National Audit of Schizophrenia reported shortfalls in the quality of care that some people were receiving for their physical and mental health. The results of the second round of this national audit are presented in this new report. This new round of the audit re-examined the quality of prescribing, access to psychological treatments and the assessment and treatment of physical health conditions for people with schizophrenia. It also included new questions on access to support at times of crisis and help with finding work and other activities.

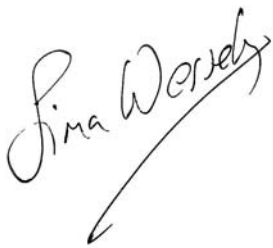
A major finding from both rounds of the audit is the lack of monitoring and intervention for key physical health indicators for this patient group. This finding prompted the College to work with NHS England, Public Health England, and other professional bodies to develop a quality improvement tool to promote better physical health care for people with psychosis. The Lester Cardiometabolic Resource is included on page 165 of this report.

While most people in contact with mental health services are satisfied with the quality of care they receive, a substantial proportion of carers feel that they do not receive the information and support they need. The audit also found that a substantial minority of people are being prescribed medication in excess of recommended doses.

There is considerable variation in access to psychological treatment and support for employment with half of those who would like to work reporting that they are not getting help to do this.

The information in this report is the result of a considerable effort of staff working in NHS Trusts and Health Boards across England and Wales, and the audit would not have been possible without the effort made by NHS staff to collect data and patients and carers who took part in the survey.

The results of the audit show how much more work still needs to be done to raise the standard of care that people with schizophrenia receive and ensure that people with this condition get the help they need in a timely manner.

A handwritten signature in black ink that reads "Sir Simon Wessely". The signature is written in a cursive style and is positioned diagonally across the page.

Professor Sir Simon Wessely  
President of the Royal College of Psychiatrists

# Acknowledgements

## **Development of standards and recommendations**

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We would like to thank the members of our Advisory Group for their contributions to the revised NAS standards and recommendations for this second round of audit.

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

## **Service user questionnaire**

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Thanks to the contributors to the service user focus group for their ideas and views on how to engage service users with this audit and for helping us develop the service user questionnaire. Thanks also to the service user reference group for their feedback on the findings.

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, 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 lay report.

## **Support and input**

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We would like to express our thanks to the Healthcare Quality Improvement Partnership (HQIP) for their support and encouragement throughout, and to the staff in participating Trusts and Health Boards for their hard work and engagement in submitting data for this second round of audit.

We would like to thank Dr Maxine Patel for her support and input into several sections of this report. We would also like to thank Professor Richard Holt for his advice regarding the data cleaning process for the data relating to physical health.

## Executive summary

### Background

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This report presents the findings of the second National Audit of Schizophrenia (NAS2). The audit set out to collect case record data on 100 service users, living in the community, from each of the Mental Health Trusts/Health Boards in England and Wales (hereafter referred to as 'Trusts'), and obtained a final database of 5,608 records (an 88% response rate). Data were also collected from service users and carers.

The first National Audit of Schizophrenia (NAS1; Royal College of Psychiatrists, 2012), provided an in-depth examination of the care of a similarly selected population of 5,091 service users. Among other important findings, it found very significant deficiencies in the monitoring and management of physical health problems in people with schizophrenia, deficiencies in some aspects of medication prescribing practice and deficiencies in some aspects of how clinicians communicate with service users and carers. The report of the independent Schizophrenia Commission, established by the mental health charity Rethink Mental Illness (Schizophrenia Commission, 2012), reported some similar deficiencies but also highlighted lack of access to appropriate psychological interventions and lack of opportunities for employment and training.

NAS2 set out to repeat the exercise conducted in NAS1, to see if improvements had occurred, and to examine service user experience in more depth.

### Audit standards

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The 16 standards agreed for this audit are based on the NICE guideline for schizophrenia (NICE CG82, 2009). (The more recent guideline [NICE CG178, 2014] was published after the end of data collection for this audit.) Two of the original NAS1 standards were amended and two new ones added in order to simplify the standards and incorporate care planning into these.



The broad aspects of care included in the standards are as below:

- a) Service users' experience of care, treatment and outcomes.
- b) Carers' satisfaction with the support and information they had received.
- c) Information and decision making about medication.
- d) Practice in the prescribing of antipsychotic medications.
- e) Availability and use of psychological therapies.
- f) The extent of monitoring and intervention for physical health problems.
- g) Care planning and crisis planning.

## Method

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All 64 Mental Health Trusts/Health Boards in England and Wales submitted data for NAS2. Each Trust was asked to submit data on a random sample of 100 adults under their care, with diagnoses of either schizophrenia or schizoaffective disorder, who had been under the care of mental health teams in the community for at least 12 months. Trust clinicians and audit departments collected retrospective information from their case records, supplemented where appropriate with information from primary care services. Trusts distributed the service user survey forms to service users who, in turn, distributed a carer survey form to the individual they considered to be their closest carer. Data collection was from August to November 2013.

## Conclusions

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Overall, the findings were largely unchanged between NAS1 and NAS2. There are none of the broad areas of care, below, in which Trusts may be regarded as providing an excellent level of service. The major areas of concern are:

- Poor monitoring of, and intervention for, risk factors for diabetes and cardiovascular disease.
- Service users whose illness is poorly responsive to standard antipsychotic medications are waiting too long to be commenced on clozapine.
- Significant gaps in the availability of cognitive behavioural therapy and family interventions.
- Inadequate provision of information and support for carers.
- Inadequacies in information systems (see discussion section).

## National findings

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A summary of comparisons between NAS2 and NAS1, for some of the indicators for each standard, are shown in Tables 1 and 2 at the end of this section.

The main findings are summarised below:

### (a) Service users' experience

The service user reference group set a criterion that for a Trust to meet the standards relating to user and carer experience, a threshold of 90% of responses (to key questions in the service user survey) should be 'very satisfied' plus 'fairly satisfied' combined (or their equivalent for different questions).

- With regard to services users' overall experience of care, 44% of Trusts met the required threshold. Individually, 88% of all service users responding stated that they were 'very' or 'fairly' satisfied with their care and 4% were reportedly 'not satisfied at all'.
- In relation to the proportion of service users reporting whether services had helped them to achieve good mental health in the previous year, 28% of Trusts met the 90% threshold. Individually, 86% of service users responding felt that services had helped 'a lot' or 'a little' with this.
- Regarding employment, 90% of service users were reportedly not working and 64% of responders said they were not looking for work. However, of those who were interested in looking for work, less than half reported receiving some help towards this.
- Thirty-four percent of service users were involved in some form of daytime activities but 43% said they were not involved in such and were 'OK with that'.

These findings represent a situation that has changed little since NAS1 two years previously. While service users' views might be stated as moderately satisfied overall, in terms of both experience of care and effect on their outcomes, only 57% actually described themselves as 'very satisfied' with their experience of care and only 61% reported that services have helped them 'a lot'. It is also clear that there are other areas where services can improve, such as in relation to employment.

### **(b) Carers' satisfaction**

The experience of carers also remains much as before. Only 9% of Trusts met the 90% threshold for carers feeling either 'very' or 'somewhat' satisfied with the information and support they were receiving. Individually, 20% of carers responding were 'dissatisfied' on this measure. The fact that only 9% of Trusts met the threshold is disappointing.

In particular, carers said they were dissatisfied with information about the service user's prognosis, about their involvement in decisions made about care, and ease of access for support for themselves. These are aspects of care in which most Trusts need to improve.

### **(c) Information and decision making about medication**

There has been some deterioration in communication of information about medication. This is another aspect of care where Trusts need to improve.

- Between NAS1 and NAS2, service users reporting receiving any information about medication reduced from 52% to 48%, with only 39% receiving this in a format they could easily understand. Trusts reported a reduction in giving information about medication from 42% to 37% of service users. The proportion of service users who 'definitely' felt involved in decisions about medication is unchanged (41%) but the extent to which Trusts say they involved service users has reduced from 62% to 54%.

### **(d) Prescribing of antipsychotic medications**

Appropriate guidelines are being followed for the majority of prescribing for the majority of service users. However, some deficiencies remain. For these particular areas there are quite wide variations between Trusts in their level of performance against guidelines.

- For service users not on clozapine, the prescribing of more than one antipsychotic medication at a time (polypharmacy), which is only appropriate in a few circumstances, remains at an average of 11%, with a

range from 1% of service users in two Trusts to 24% at the other extreme.

- The prescribing of doses of medication above those recommended in the British National Formulary (BNF; BMJ Group and RPS Publishing, 2013) was occurring for 10% of service users overall, with a range of 1% in one Trust to 22% at the other extreme. However, the frequency of recording of a rationale for this has improved from 25% of instances in NAS1 to 37% in NAS2.
- A trial of clozapine is recommended for service users who have had a poor response to trials of two other antipsychotics. We found that 28% of service users whose illness was not in remission, and who were probably appropriate for a trial of clozapine, had not yet been commenced on clozapine – an improvement from 40% in NAS1. However, 57% of service users currently receiving clozapine had been prescribed three or more antipsychotic medications prior to commencing clozapine, which means that their progress, to a medication more likely to be effective for them, was slower than it should have been. This problem is further highlighted by the finding that 93% of service users who were on their very first antipsychotic medication, and who were not in remission, had been on this first medication for at least six months. (If a medication is not effective it is usually not continued for more than 8 weeks.)

Thus, there are areas where prescribing practice can be further improved. This should be prioritised by psychiatrists, mental health pharmacists and their respective professional bodies.

### **(e) Psychological therapies**

In this audit, where reference is made to cognitive behavioural therapy (CBT) and family interventions, these are applied in a rather more generic sense than would be envisaged in some other reports.

- The percentage of service users whom Trusts reported had been offered CBT was 39%, though not all took up such offers. Trusts reported that 19% of service users had been offered and had taken up CBT and 18% of

service users reported that they had received CBT. These proportions remain low. The only data from NAS2 that can be directly compared with NAS1 relate to the percentage of service users whose illness was not in remission. For service users whose illness was not in remission, 29% had been offered CBT in NAS1, which increased to 45% in NAS2.

- Twelve percent of service users said they had received a family intervention, compared with 8% that Trusts said had taken up an offer of this treatment. For service users whose illness was not in remission, 10% had been offered a family intervention in NAS1 but 23% in NAS2.

It is clear that the numbers of service users having access to, and actually receiving, these types of intervention remain very low. This needs to be addressed and has significant funding implications.

#### **(f) Monitoring and intervention for physical health problems**

Diabetes and cardiovascular disease are more prevalent in people with schizophrenia and are significant contributors to the premature mortality suffered by this population. It is important that service users are monitored for six important risk factors for these disorders. Clinicians should enquire about family history of diabetes and cardiovascular disease as well as assessing five other factors: smoking, elevated body mass index (BMI), blood glucose control, blood lipids and blood pressure. This monitoring should be carried out on at least an annual basis. Yet reports such as NAS1 have demonstrated that such monitoring frequently does not occur.

- In NAS2, 33% had five of these factors (excluding family history) monitored, compared to 29% in NAS1, demonstrating some improvement but also the considerable ground that secondary care and primary care services need to make up to reach an acceptable provision of care.
- Only 9% of service users in NAS2 had all six of the above risk factors, including family history, assessed in the previous year. For 6% there was no evidence that any of these had been monitored. This is not adequate.
- Even monitoring of something as basic as a service user's BMI was only recorded for 52% in NAS2, and 51% in NAS1.

- The provision of interventions when evidence of health risks is found is also poor. For example, in NAS2 only 36% of service users with evidence of impaired control of blood glucose (suggesting diabetes or a pre-diabetic state) had evidence of intervention. This was 53% in NAS1.

Clearly the provision of such monitoring and appropriate intervention needs to be improved. Three barriers in this area are: (i) availability of staff time, appropriate facilities and equipment; (ii) the need for formal systems to review physical health data and interventions required on at least an annual basis; and (iii) the need for more formal arrangements regarding collaboration between primary and secondary care in relation to physical health. The new NICE guideline (NICE CG178, 2014) gives clear guidance regarding this last issue.

### **(g) Care planning and crisis planning**

This relates to a new standard so comparisons with NAS1 are not possible. Ninety-five percent of case records included details of a care plan, though this varied from 68% to 100% across the Trusts. Seventy-five percent of service users who responded said they had a care plan and 74% reported that they had a telephone number for use in a crisis.

## **Comparisons between NAS2 and NAS1**

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Tables 1 and 2, on the next two pages, provide a summary of some key comparisons between the findings in NAS2 and the findings in NAS1. In these Tables the standards are listed in order by standard number. A full list of NAS standards is provided on page 39 of the National Report. The list below indicates which Table relates to each of the broad aspects of care (a-g) described above:

- |          |  |
|----------|--|
| Table 1: | (a) Service user's experience                                |
|          | (b) Carers' satisfaction                                     |
|          | (f) Monitoring and intervention for physical health problems |
|          | (c) Information and decision making about medication         |
| Table 2: | (d) Prescribing of antipsychotic medications                 |
|          | (e) Psychological therapies                                  |
|          | (g) Care planning and crisis planning                        |

**Table 1: Key comparisons between NAS2 and NAS1 for each of the standards set for this audit (standards 1 to 7)**

<b>Standard / Indicator</b>	<b>NAS2 (%)</b>	<b>NAS1 (%)</b>
<b>Standards 1 &amp; 2 – service users' experience &amp; report of positive outcomes</b>		
Direct comparison not possible as the service user survey was modified		
<b>Standard 3 – carers' satisfaction</b>		
Carers report being 'somewhat' or 'very' satisfied with the information and support received	80%	81%
Range across Trusts	56– 100%	55 – 100%
<b>Standard 4 – monitoring of physical health risk factors</b>		
Monitoring of five risk factors (family history excluded)	33%	29%
Monitoring of smoking	89%	88%
Monitoring of BMI	52%	51%
Range across Trusts for monitoring of BMI	5 – 92%	27 – 87%
Monitoring of glucose control	57%	50%
Range across Trusts for monitoring of glucose control	16 – 99%	25 – 83%
Monitoring of lipids	57%	47%
Monitoring of blood pressure	61%	56%
Monitoring of five risk factors in those with established cardiovascular disease	37%	37%
Monitoring of alcohol consumption	70%	69%
<b>Standard 5 – intervention offered for identified physical health risks</b>		
Intervention for smoking	59%	57%
Intervention for BMI > or = 25kg/m <sup>2</sup>	71%	76%
Intervention for abnormal glucose control	36%	53%
Intervention for elevated blood pressure	25%	25%
Intervention for alcohol misuse	74%	72%
<b>Standard 6 – provision of information about medication</b>		
Service users said they received information	48%	52%
Trusts said they provided information	37%	42%
<b>Standard 7 – involvement in prescribing decision</b>		
Service users felt involved	71%	74%
Trusts said they involved the service user	54%	62%

**Table 2: Key comparisons between NAS2 and NAS1 for each of the standards set for this audit (standards 8 to 16)**

<b>Standard / Indicator</b>	<b>NAS2 (%)</b>	<b>NAS1 (%)</b>
<b>Standard 8 – antipsychotic monotherapy</b>		
Frequency of polypharmacy	11%	11%
Range across Trusts	1-24%	3-30%
<b>Standard 9 – dose within BNF maximum</b>		
Frequency of high dose (>100% BNF)	10%	10%
Range across Trusts	1-22%	1-24%
Rationale documented for high dose	37%	25%
<b>Standard 10 – investigation of alcohol and substance misuse in those with poor symptom response</b>		
Frequency in cases not on clozapine	62%	78%
Frequency in cases on clozapine	56%	81%
<b>Standard 11 – medication changed if poor response</b>		
Direct comparison not possible as standard was amended		
<b>Standard 12 – pathway to clozapine</b>		
Service users not in remission and not on clozapine <u>without</u> a reason normally considered as appropriate	28%	40%
<b>Standard 13 – augmentation of clozapine</b>		
Frequency of use of augmentation strategy in service users on clozapine	26%	22%
<b>Standard 14a – CBT offered</b>		
Those not in remission offered CBT	45%	29%
<b>Standard 14b – Family intervention offered</b>		
Those not in remission offered family intervention	23%	10%
<b>Standards 15 &amp; 16 – care planning and crisis planning</b>		
Comparison not possible as these are new standards		



## Recommendations

There are a number of areas in which the care of service users with schizophrenia falls significantly below the standards expected. Our recommendations relate to these aspects of care and the issue of poor information systems.

Since this audit commenced, NICE published a new clinical guideline: "Psychosis and schizophrenia in adults: treatment and management" (NICE CG178, 2014). Where appropriate we refer to the relevant recommendation by paragraph number in CG178, e.g. (*NICE 1.3.6.5*).

### **1. Recommendations for the Department of Health**

- 1.1 Develop information systems that can properly support a modern mental health service. These should be developed in partnership with CCGs, Trusts, Chief Clinical Informatics Officers and the Royal College of Psychiatrists. These systems need to enable estimations of local prevalence and incidence of different diagnoses, support sharing of information with primary care (*NICE 1.5.3.2*) and include decision support menus for clinicians.
- 1.2 Improve the minimum Mental Health and Learning Disability Data Set (formerly MHMDS) to enable the collection of data regarding all NICE-recommended effective interventions, including physical health assessments and interventions, within a timescale of six months. This would help to inform the development of national outcomes frameworks.
- 1.3 Develop a new primary care framework for supporting the physical and mental health of people with schizophrenia in light of the reduction in Quality Outcomes Framework (QOF) indicators for schizophrenia.
- 1.4 Ensure the Increasing Access to Psychological Therapies (IAPT) for severe mental illness programme has the same level of support as the existing IAPT for anxiety and depression. This should include a national data set, indicators in national frameworks and plans for how this could develop.

## **2. Recommendations for NHS England**

- 2.1 Given the slow pace of change indicated by NAS2, NHS England should commission future audits looking at the care of people with psychosis and schizophrenia. These should complement national CQUIN data collection.

## **3. Recommendations for Professional Bodies**

- 3.1 The Royal College of Psychiatrists, in collaboration with the British Association for Psychopharmacology, should ensure that postgraduate education and continuing professional development for psychiatrists includes modern competency based teaching on psychopharmacology and the physical health risks faced by people with schizophrenia.
- 3.2 The General Medical Council should ensure that medical schools include in curricula the necessary teaching about psychopharmacology and the physical health risks faced by people with schizophrenia.
- 3.3 The Royal College of General Practitioners should highlight and promote awareness among general practitioners of the new NICE Guideline and the requirement for primary care to carry out monitoring of physical health risk factors for service users with schizophrenia (*NICE 1.3.6.5*).
- 3.4 The Royal Colleges of Psychiatrists and General Practitioners should work together to improve the education of general practitioners in respect of mental illness.
- 3.5 The Royal College of Nursing should ensure that undergraduate and postgraduate education, and continuing professional development for nurses in mental health settings and primary care, include adequate teaching on psychopharmacology and the physical health risks faced by people with schizophrenia.
- 3.6 Health Education England should review the emphasis placed on mental health in their various programmes and, in particular, knowledge about psychopharmacology and the physical health issues facing people with schizophrenia.

#### **4. Recommendations for Commissioners (Clinical Commissioning Groups [CCGs] and Health Boards)**

- 4.1 Must work with the Department of Health and NHS England to improve the information systems available to mental health services.
- 4.2 Be aware of the important recommendation in the new NICE Guideline regarding lead accountability for the monitoring of service users' physical health (*NICE 1.3.6.5*):
- a) Specialist mental health teams to assume lead responsibility for the first 12 months or until the service user's condition has stabilised.
  - b) Thereafter primary care to assume lead responsibility, unless there are well developed local agreements.

Commissioners must also ensure that information systems are in place which support rapid sharing of the results of routine monitoring of physical health of service users between primary and secondary care practitioners (*NICE 1.5.3.2*).

Commissioners and senior clinical provider leaders must ensure that local agreements are in place between primary and secondary care to achieve the necessary collaboration.

- 4.3 Ensure that services are able to provide cognitive behavioural therapy (*NICE 1.4.4.1*) and family interventions for all those wanting to receive them (*NICE 1.4.4.2*). CCGs and mental health clinical leaders should map the prevalence and incidence of schizophrenia and review how spending can support this in order to reduce repeat admissions to hospital.
- 4.4 Commission services that support service users to stay in work or access new employment (*NICE 1.5.8.1*).

#### **5. Recommendations for Mental Health Trusts (Trust Boards and Chief Executive Officers)**

- 5.1 Mental Health Trusts and Chief Executive Officers, in collaboration with their medical director, director of nursing and lead psychologist, need to put in place robust governance processes which provide clear accountability for the implementation of NICE guidelines.

Trusts should have a named member of the Trust Board who:

- a) Ensures regular audit of, and compliance with, quality standards on the monitoring and treatment of cardiovascular and metabolic disease in people with schizophrenia through board-level performance indicators (*NICE 1.1.3.7*).
- b) Ensures that regular audit of, and compliance with, standards for the prescribing of antipsychotic medications occurs.

- 5.2 Be aware of, and support, implementation of the NICE Guideline regarding lead accountability for monitoring service users' physical health (*NICE 1.3.6.5*). This will require clear agreements to be reached with local primary care services.

This requires supporting the rapid sharing of the results of routine physical health monitoring between primary and secondary care (*NICE 1.5.3.2*).

- 5.3 Work with CCGs to ensure services are able to provide cognitive behavioural therapy (*NICE 1.4.4.1*) and family interventions for all those wanting to receive them (*NICE 1.4.4.2*).
- 5.4 Enable mental health services to support service users to stay in work or access new employment (*NICE 1.5.8.2*).
- 5.5 Be aware of, and ensure implementation of, NICE guidelines to provide support for carers (*NICE 1.1.5*). Develop protocols to support proper carer involvement and support.
- 5.6 Ensure that this report of the second National Audit of Schizophrenia, and the related individual local Trust Report, are disseminated to the appropriate managers, members of their mental health teams and others as appropriate, and that action is taken regarding the recommendations.
- 5.7 Ensure that where mental health team members require additional training to meet the requirements, above, that this is made available.

## **6. Recommendations for Medical Directors and Directors of Nursing**

- 6.1 Ensure that staff in Mental Health Teams have the resources, equipment and facilities to follow the recommendations that they are expected to meet, as described in the section "Mental Health Teams".
- 6.2 Work to change a culture which often regards physical health care and mental health care as separate. This can often be related to staff fears about areas they feel unfamiliar with. The Lester Resource provides a focus around which to base local education programmes.
- 6.3 Recognise the importance of regular activities for service users and enable specialist mental health services to support service users to stay in work or access new employment (*NICE 1.5.8.2*).
- 6.4 Be aware of, and ensure implementation of, NICE guidelines to provide support for carers (*NICE 1.1.5*) and assist Trusts in developing protocols.

## **7. Recommendations for Mental Health Teams and their Managers**

- 7.1 Be aware of, and implement, the recommendation in the new NICE Guideline regarding lead accountability for the monitoring of service users' physical health (*NICE 1.3.6.5*):
  - a) Specialist mental health teams to assume lead responsibility for the first 12 months or until the service user's condition has stabilised.
  - b) Thereafter primary care to assume lead responsibility, unless there are particular reasons for this remaining with secondary care.

This also requires supporting the rapid sharing of the results of routine physical health monitoring between primary and secondary care (*NICE 1.5.3.2*).

They should ensure that Chief Executive Officers, and other managers, are aware of the need for the Trust to develop agreements with primary care to enable this.

- 7.2 Ensure that service users' physical health is managed actively, as described in the Lester Resource. This includes the following:

- a) Monitor physical health risk factors and offer intervention when necessary (*NICE 1.1.3.2 and 1.1.3.6*).
  - b) Offer support for healthier eating and increased physical activity (*NICE 1.3.1.1*) and, if the service user smokes, help to stop smoking (*NICE 1.3.1.3*).
  - c) At the earliest opportunity, identify those at high risk of cardiovascular and metabolic disorders (*NICE 1.5.3.3*).
  - d) Offer appropriate interventions to prevent the development of obesity, type 2 diabetes and cardiovascular disease (*NICE 1.5.3.3*).
- 7.3 Institute a regular review process, at least annually, to ensure service users' physical health status and medication are updated and that interventions take place - "*Don't just screen, intervene*".
- 7.4 Support people with schizophrenia to stay in work, or access new employment, education or volunteering opportunities. (*NICE 1.5.8.2*).
- 7.5 Be aware of, and implement, NICE guidelines to provide support for carers (*NICE 1.1.5*).
- 7.6 Ensure that the care plan is an active document, which is regularly reviewed, with a copy given to the service user.

## **8. Recommendations for General Practitioners (and where relevant their primary care teams)**

- 8.1 Be aware of, and implement, the recommendation in the new NICE Guideline regarding lead accountability for the monitoring of service users' physical health (*NICE 1.3.6.5*):
- a) Specialist mental health teams to assume lead responsibility for the first 12 months or until the service user's condition has stabilised.
  - b) Thereafter primary care to assume lead responsibility, unless there are particular reasons for this remaining with secondary care.

This also requires supporting the rapid sharing of the results of routine physical health monitoring between primary and secondary care (*NICE 1.5.3.2*).

- 8.2 Ensure that service users' physical health is managed actively, as described in the Lester Resource, to cover the following:
- a) Monitor physical health risk factors and offer intervention when necessary.
  - b) Offer support for healthier eating and increased physical activity (*NICE 1.3.1.1*) and, if the service user smokes, help to stop smoking (*NICE 1.3.1.3*).
  - c) At the earliest opportunity identify those at high risk of cardiovascular and metabolic disorders (*NICE 1.5.3.3*).
  - d) Offer appropriate interventions to prevent the development of obesity, type 2 diabetes and cardiovascular disease (*NICE 1.5.3.3*).
- 8.3 Review the care of people with schizophrenia who have established diabetes or cardiovascular disease and who wish to have a review (*NICE 1.5.3.4*).

## **9. Recommendations for Psychiatrists**

- 9.1 Ensure that they adhere to the prescribing standards set out in the NICE guideline (*NICE 1.3.6*).
- 9.2 In situations where antipsychotic drugs are prescribed outside the recommendations of the BNF (British National Formulary), which is only rarely appropriate, a clear rationale must be provided to the service user and documented in the case record by the prescribing psychiatrist. This rationale should be reviewed and updated at least annually. This will most commonly be when:
- a) Use of more than one antipsychotic drug at the same time is being considered; or
  - b) The dose of medication may exceed BNF dose recommendations.
- 9.3 Service users whose symptoms do not respond well to adequate trials of two standard antipsychotic medications (i.e. are regarded as 'treatment unresponsive') should have a treatment trial of clozapine, unless contra-indicated. This should not be delayed by inappropriately long trials of the first two antipsychotic medications (*NICE 1.5.7.2*).

- 9.4 In collaboration with a Mental Health Pharmacist and service users, psychiatrists should review the written and/or online information about medication they provide to people affected by schizophrenia and their carers, and check that it is clear and easy to understand.
- 9.5 Ensure that prescribers are trained to work in a collaborative way with service users regarding decisions about medication (*NICE 1.3.5.1*).

## **10. Recommendations for Mental Health Pharmacists**

- 10.1 Review prescribing practices for antipsychotic medications in their Trusts and, where appropriate, develop educational programmes for members of Mental Health Teams.
- 10.2 Collaborate with psychiatrists and service users to review the written and/or online information they provide about medication to service users and their carers. Check that it is clear and easy to understand.

In these recommendations, reference is made to the Lester Resource<sup>1</sup> (see Appendix F of the National Report), which provides advice regarding the monitoring of risks for cardiometabolic disease in service users taking antipsychotic medication. This resource is endorsed by many professional bodies and NHS England. It is included in the list of resources that NICE consider appropriate to support the new guideline (<http://www.nice.org.uk/Guidance/CG178/Resources>).

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<sup>1</sup>Lester UK Adaptation: Positive Cardiometabolic Health Resource: an intervention framework for patients with psychosis and schizophrenia. 2014 update (Shiers et al, 2014)



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## Introduction

The National Audit of Schizophrenia (NAS) is managed by the Royal College of Psychiatrists' (RCPsych) College Centre for Quality Improvement (CCQI). This is the second national report from the National Audit of Schizophrenia (referred to throughout as NAS2). The first report was published in December 2012 (referred to as NAS1).

NAS is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). The programme is funded by NHS England and the Welsh Government. As part of NCA all Mental Health Trusts in England and Wales were expected to take part in NAS. For simplicity, both Trusts and Health Boards are referred to as 'Trusts' in this report. Appendix A provides a list of the NHS Trusts that submitted data for NAS2, along with the unique code which identifies each in the Tables and Figures within the report.

NAS is a Trust level audit consisting of an audit of practice accompanied by service user experience and carer satisfaction surveys. More detail 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 38).

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

### **Clinical background**

---

The care of people with a diagnosis of schizophrenia is an important priority for the National Health Service (NHS). Approximately 300,000 people in England and Wales have a diagnosis of schizophrenia. Studies suggest that 0.7-2.0 per 100 of the population may have an episode of schizophrenia at some stage of their life. Both genetic and, in a broad sense, environmental factors are

important in the causation of schizophrenia. Following a first episode, only 20%-30% are relapse-free after five years (an der Heiden and Häfner, 2011).

Life expectancy is 20% shorter in schizophrenia than for the general population (Thorncroft, 2011). The causes of this vary according to whether the person lives in a 'developed' or a 'developing' country. While suicide is a factor, premature mortality from cardiovascular disease (CVD) is probably the most important factor (Brown et al., 2010). Underlying this is an excess of modifiable risk factors such as smoking, obesity, diabetes and dyslipidemia.

A clear national guideline exists for the treatment of schizophrenia, '*Psychosis and schizophrenia in adults: treatment and management*' (NICE CG178, 2014) which is a revision of the previous NICE Guideline (NICE CG82, 2009), which was the focus of this audit. There is also a nationally respected guideline specific to the use of medications (Barnes, 2011). Two reports in 2012 described major deficiencies in the treatment and care provided for people with schizophrenia.

The independent Schizophrenia Commission, established by the mental health charity Rethink Mental Illness, reported many deficiencies (Schizophrenia Commission, 2012), including:

- Death 15-20 years earlier than the general population.
- Only 1 in 10 who might benefit from cognitive behavioural therapy have access to it.
- Lack of employment opportunities; only 8% in employment.
- Inadequate support and recognition of the role of carers.
- Problems in the services for those with African-Caribbean or African backgrounds.
- A need to extend Early Intervention for Psychosis services.
- A need for improved prescribing.

The first National Audit of Schizophrenia (NAS1) reported:

- Deficiencies in how well service users were involved in prescribing decisions.
- Continuing use of antipsychotic medications outside usual guidelines in too large a proportion of service users.

- Too many service users whose illness is poorly responsive to medication failing to be commenced on clozapine.
- Limited availability of psychological therapies and a wide variation between different Trusts.
- Failure to provide service users comprehensive monitoring of risk factors for the development of diabetes and cardiovascular disease.

The 'Introduction' to the NAS1 report described some of the important issues related to the monitoring and intervention for physical health risk factors and the prescribing of antipsychotic medications and these will not be repeated here (link: [www.rcpsych.ac.uk/quality/nas/reports](http://www.rcpsych.ac.uk/quality/nas/reports)). As the two reports above describe, there are deficiencies in both of these areas of practice. In its revised clinical guideline (NICE CG178, 2014), NICE has increased its emphasis on the need for adequate attention to physical health risk factors and problems.

Similarly, both reports note problems in the availability of psychological therapies. The new NICE clinical guideline (above) has also increased its emphasis on the need to offer cognitive behavioural therapy and family interventions from the very first episode of illness.

Thus, from a clinical perspective, audit of the treatment and care of people with a diagnosis of schizophrenia continues to be a necessary exercise.

## **Primary care perspective**

---

People experiencing schizophrenia generally regard primary care as having an important role in coordinating their mental and physical healthcare (Lester et al., 2005). In contrast, some primary care professionals hold negative attitudes to providing care for this group, seeing their role confined to treating physical illness (Bindman et al., 1997).

The Quality and Outcomes Framework (QOF) from 2006 provided an incentive to conduct an annual physical health review for people with severe mental illness. However, the last ten years have seen GP consultation rates fall sharply while practice nurses were not centrally involved in care and health education (Reilly

et al., 2012; Nazareth and King, 1992). Moreover NAS1 showed that recognition and treatment of both CVD and risk of CVD was poor, suggesting a lack of effective collaboration and agreement of responsibilities between primary and secondary care (Crawford et al., in press). Notwithstanding these concerns the QOF requirement to systematically monitor weight, blood glucose and cholesterol was removed from the annual review in April 2014.

However, the new NICE guideline (NICE CG178, 2014) continues to recognise the importance of primary care in long term monitoring of these aspects of care. The guideline emphasises the critical role of primary care in reducing the risk of obesity, diabetes and CVD (paragraph 1.5.3.3) and in treating effectively those with established CVD and diabetes (paragraph 1.5.3.4). NICE also clarifies clinical accountabilities with a new recommendation allocating specific responsibility for physical health monitoring to secondary care during the first 12 months, with transfer of that responsibility to primary care thereafter (paragraph 1.5.3.2).

Encouragingly, in April 2014 the Royal College of General Practitioners (RCGP) made mental health an enduring priority with the appointment of a clinical champion to lead this initiative over the next five years. However, it remains clear that audit is needed to monitor the primary care/secondary care interface in relation to physical health risk factors.

## **Service user perspective**

---

Service users attending the service user reference and focus groups welcomed NAS2 as an opportunity for service users' views to be heard. There was a strong view from these, and previous groups, that inclusion in the service user survey of questions around help with employment and structured activities was important. The previous NICE Guideline (NICE CG82, 2009), made some mention of the need for supported employment programmes and other occupational or educational activities. However, this is now further emphasised in the new guideline, paragraph 1.5.8 (NICE CG178, 2014), so the additional questions are timely.

In NAS1 it was found that monitoring of physical health care was poor and service users often felt that information about their medication was not provided in an adequately understandable form. These issues continued to be concerns and there was support for including more questions about these issues in the service user survey form.

At a recent service user reference group the Lester Resource (Shiers et al., 2014) was embraced by people as providing some clarity over the roles of primary and secondary care in the monitoring of physical health and risk factors for CVD and diabetes. The resource was viewed as an empowering tool for patients to share with mental health professionals.

The way in which care is delivered can have a considerable impact on outcomes and how well service users take up the services offered. In 2011, NICE published a clinical guideline titled 'Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services' (NICE CG136, 2011). In this and other relevant guidelines, NICE recommends offering help, treatment and care in an atmosphere of hope and optimism as well as promoting taking time to build supportive and empathic relationships as an essential part of care. The reference group strongly supported these factors and felt that, in some form, they should be part of the audit process.

## **Carer perspective**

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The impact of care-giving is considerable as illustrated in the results from a survey conducted 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.

In NAS1, the considerable commitment made by carers was confirmed, with over 50% of those carers who responded saying they had provided support for

over ten years. Of those who returned details of hours spent providing support, about 50% had spent more than 30 hours in the previous week.

The new NICE guideline (NICE CG178, 2014) has strengthened the requirements to support carers with several new recommendations (Section 1.1.5) which, in outline, include the responsibility of health professionals to:

- Give carers written and verbal information in an accessible format (paragraph 1.1.5.3).
- Negotiate with service users and carers about how information about the service user will be shared, fostering a collaborative approach (paragraph 1.1.5.4).
- Review regularly how information is shared (paragraph 1.1.5.5).
- Include carers in decision-making if the service user agrees (paragraph 1.1.5.6).

The effectiveness of the support provided to families and close friends involved in caring constitutes a critical marker of clinical quality and, as reinforced by the latest NICE guidelines, continues to be a priority in the standards and their assessment in NAS2.

# Methodology

## Audit development

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

**Figure 1: Timetable of development and management of the National Audit of Schizophrenia (NAS)**

<b>Initiation and first round of NAS (NAS1)</b>	
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>
August 2011 - November 2011	<ul style="list-style-type: none"> <li>Data collection and submission</li> </ul>
December 2012	<ul style="list-style-type: none"> <li>Report for the first round of audit published</li> </ul>
<b>Second round of NAS (NAS2)</b>	
January 2013	<ul style="list-style-type: none"> <li>Recruitment of eligible organisations</li> </ul>
March 2013	<ul style="list-style-type: none"> <li>Standards and methodology revised for the second round of audit</li> </ul>
April 2013	<ul style="list-style-type: none"> <li>Service user focus group</li> </ul>
May 2013	<ul style="list-style-type: none"> <li>Data collection tools and methodology finalised</li> </ul>

## Standards and outcome indicators

The NAS standards and outcome indicators were developed by the NAS team in collaboration with members of the Advisory Group. They are based around the main recommendations in the NICE guideline (NICE CG82, 2009).



**Table 3: NAS standards**

<b>S1</b>	Service users report that their experience of care over the past 12 months has been positive.	<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>S2</b>	Service users report positive outcomes from the care they have received over the past 12 months.	<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 were investigated and documented.</li> </ul>
<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>S11</b>	If there was no or inadequate response to the first antipsychotic drug within 8 weeks, part of which was at optimum dose, the first antipsychotic drug was stopped and a second antipsychotic drug given.
<b>S4</b>	The following physical health indicators have been monitored within the past 12 months: <ul style="list-style-type: none"> <li>i. History of cardiovascular disease, diabetes, hypertension or dyslipidaemia in members of the service user's family.</li> <li>ii. Use of tobacco.</li> <li>iii. Body mass index (BMI), or waist circumference.</li> <li>iv. Blood glucose control (blood glucose and/or HBA<sub>1c</sub>).</li> <li>v. Blood lipids (total cholesterol and HDL)</li> <li>vi. Blood pressure.</li> <li>vii. Use of alcohol.</li> <li>viii. Substance misuse.</li> </ul>	<b>S12</b>	If there was no or inadequate response to two antipsychotic drugs, one of which should be a second-generation antipsychotic at optimum dose, clozapine was offered.
<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. Help with smoking cessation.</li> <li>ii. Advice about diet and exercise, aimed at helping the person to maintain a healthy weight.</li> <li>iii. Treatment for diabetes.</li> <li>iv. Treatment for dyslipidaemia.</li> <li>v. Treatment for hypertension.</li> <li>vi. Help with reducing alcohol consumption.</li> <li>vii. Help with reducing substance misuse.</li> </ul>	<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 8 weeks at optimum dose.
<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>S14</b>	<ul style="list-style-type: none"> <li>a. CBT has been offered to all service users.</li> <li>b. Family intervention has been offered to all service users who are in close contact with their families.</li> </ul>
<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>S15</b>	Each service user has a current care plan
<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) and a rationale for this has been documented.	<b>S16</b>	Each service user knows how to contact services if in crisis

This guideline, information from the first National Audit of Schizophrenia (NAS1), the report of the Schizophrenia Commission (2012), POMH-UK audits (see [www.rcpsych.ac.uk/pomh](http://www.rcpsych.ac.uk/pomh)) and a further literature search suggested that problems continue to exist 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 and interventions for physical health risk factors.

The standards used in NAS1 were reviewed by the NAS team and Advisory Group and minor revisions made for NAS2. These included amendments to standards 11 and 12 and the inclusion of two new standards on provision of care plans and crisis planning. An outline of these changes, are described in detail in Appendix C.

## **Development of the audit tools**

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Three tools were developed to collect data for NAS2 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 NAS2 audit of practice tool was developed to collect demographic information, information on antipsychotic prescribing practice, physical health monitoring and interventions (where monitoring identified a need) and psychological therapies offered. This information was to be gleaned largely from a service user's case records but additionally, if appropriate, from consultants and general practitioners.

The audit of practice tool from NAS1 was developed specifically to measure NAS standards and outcome measures. This was refined for NAS2 with the aim of simplifying data collection, collecting information on care planning and more detailed information on psychological therapies.

### **Service user survey form**

A bespoke survey user survey form was developed for NAS2 in order to ask service users more targeted questions about their experience and outcomes of care. The service user focus and reference groups agreed that this tool adequately covered key areas of importance to them. The items in this survey form relating to service user satisfaction were taken from a patient satisfaction questionnaire used to measure newly referred psychiatric patients (Shipley et al., 2000). To allow for direct comparison with NAS1, the questions on medication from the Carers' and Users' Expectations of Services (CUES) questionnaire (Lelliott et al., 2001) remained the same.

### **Carer survey form**

The same survey form was used in both NAS1 and NAS2 to capture carers' satisfaction with the information and support they received. This was based on the Carer Well-Being and Support Questionnaire (CWS; Quirk et al., 2012) and was identified as the most suitable way to assess the views of carers about the information and support they received.

### **Organisational questionnaire**

In addition to the main audit tools associated with this audit, each participating organisation was asked to complete an organisational questionnaire, the purpose of which was to gather contextual information about participating organisations on the following themes:

- Dissemination and action planning.
- Actions taken on key recommendations in the NAS1 report (if they participated).
- Changes made within the organisation since NAS1.

## **Identification of the case sample**

Organisations selected one of two sampling options; **either** identification of service users' centrally **or** identification through the community mental health teams.

### **Sampling at Trust level**

In order to gather as representative a sample of service users as possible from each Trust, the sampling methodology was revised for NAS2 in favour of a more robust sampling framework in which the NAS team generated the random numbers from the number of eligible patients provided by the Trusts. The sampling method can be found in Appendix D. This sampling method produced:

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

Feedback from the organisational questionnaire was that only 70% of Trusts were able to identify patients with a diagnosis of schizophrenia via an electronic record system.

### **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).
- Were being treated in the community, including those in nursing homes and residential care, but were not hospital 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.
- Had been under the care of the Trust for at least 12 months.

*\* Although they were excluded from NAS1, patients who live in a nursing home or residential home were included in NAS2.*

## **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 or schizoaffective disorder.

### **Services submitting data**

All 64 organisations that were identified by the NAS team as eligible to participate at the time of data collection submitted data for NAS. A list of participating organisations can be found in Appendix A, along with the unique code which identifies each organisation in the Tables and Figures within this report.

An individualised Trust report, with further breakdown of some of these analyses, will be prepared for each organisation and sent to them ahead of the NAS learning event for their region (see section on dissemination page 146).

## **Process of the audit**

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### **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 pages 41-2, participating Trusts sent the 200 service users identified a pack of information about the audit (Appendix D). This included a service user survey form and 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 but wanted an independent person from whom to seek this assistance. 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.

Additionally for this second round of the audit, Trusts were sent a service user reminder pack, which comprised a covering letter from Rethink Mental Illness and a copy of the service user questionnaire.

Carers and service users returned completed survey forms to the NAS team using the 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.

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

Psychiatrists were asked to complete one audit of practice tool for each of their service users included in their Trust's randomly selected sample of 100. These 100 cases then made up each Trust's case record audit of practice sample. In several services, some of the physical health data had to be collected from the service users' general practitioner. A template letter co-signed by representatives from the Royal College of General Practitioners and Royal College of Psychiatrists 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 5,733 returns from the audit of practice, of which **5,608** were used in the analysis (88% of those expected) after data cleaning.
- In total, **3,379** service users returned service user survey forms, and **1,119** carers returned carer survey forms.
- Organisational questionnaires were received from all 64 participating Trusts.

## **Data handling and analysis:**

### **Data entry and analysis**

All data were entered using SNAP 10 Professional Surveys via secure webpages. Data were extracted to IBM SPSS Statistics 21 and analysed using IBM SPSS Statistics 21 or Microsoft Excel 2007. The statistical techniques used in IBM SPSS Statistics 21 to analyse data were descriptive statistics, frequencies and cross tabulations.

### **Service user reference group**

A service user reference group took place on 3 July 2014. The meeting was led by the NAS service user advisor. The group looked at the initial analyses of the data to see if these reflected their experience of care. Discussions focused on: suitable thresholds for some of the items in the service user survey; 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 139) and recommendations (see page 15).

### **Data cleaning**

Data cleaning was carried out between December 2013 and May 2014. 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. Data cleaning was carried out in three phases; a more detailed account of the data cleaning process can be found in Appendix G.

### **Outliers**

Trusts were identified as potential outliers for a particular standard if their performance 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. In concert with guidance from HQIP, analyses

to identify outlier Trusts will only be conducted in relation to standards where poor performance may be a fairly immediate threat to a service user's well-being.

The detection and management of outliers was based on guidance supplied by HQIP and the Department of Health. 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**

### **Limitations**

The main limitations of the methodology were:

- Data returns were not evenly spread across Trusts. Reasons given in feedback from the Trusts for this included: difficulties identifying a sample; difficulties getting consultants involved; and difficulties when mandatory information was requested in the audit of practice tool but was missing from the case records.
- Data analysis is only adequately meaningful for those Trusts which have a case note audit of practice sample size of at least 73 after data cleaning.
- Variations in the amount and quality of physical health monitoring data was sometimes as a result of 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 described.

### **Caveats**

General caveats that apply to the report are:

- The sample for this study focused on service users being treated by secondary care services in the community only. Therefore the results may not hold for the population as a whole.
- The sample does not include those receiving care whilst in hospital. The sample only included service users who had been under the care of the Trust for 12 months or more.



- The sample does not include service users with a diagnosis of schizophrenia or schizoaffective disorder in the community who are solely under the care of primary care services.
- Physical health data was collected for current or most recent measures. 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', whilst it was possible for the same service user to complete a service user survey and have an audit of practice form completed about them, it was not possible to match populations of service users for the audit of practice tool completely to the samples returning service user 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 survey forms must be interpreted carefully.

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 from the second round of the National Audit of Schizophrenia (NAS2)

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Commissioned by





## Guidance on reading this document

The guidance below may be helpful when reading this report:

- The term 'Trust' has been used to refer to both English NHS Trusts and Welsh Health Boards throughout this report.
- Many percentages in the text and in data tables and figures 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%. However, in some sections it was felt that decimal places were required due to the small percentages being reported.
- The first round of audit, published in 2012, is referred to in this report as NAS1. This second round of audit is referred to as NAS2.
- Where graphs contain analysis from the service user survey, the number of service users who responded to the given question or questions is given as a percentage out of the total 3,379 below each graph. For example, if 3,210 service users responded this is described as, "95% of service users answered this question".
- Where graphs contain analysis from the carer survey, the number of carers who responded to the given question or questions is given as a percentage out of the total 1,119 below each graph.
- A glossary of terms is available from page 173.

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

The following sections of the report will present data relating to the demography of the audit population and 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), i.e. the whole population included in the audit, and has to be judged against what may be considered as reasonable practice.

The results are presented according to the following section headings:

- Experience of service users and carers (standards 1-3 and 15-16).
- Shared decision making about medication (standards 6 and 7).
- Prescribing (standards 8-13).
- Psychological therapies (standard 14).
- Physical health care (standards 4 and 5).

Whilst this is not the numerical order of the standards, this order makes more logical sense in terms of a service user's journey through the mental healthcare system.

Each Table and Figure has a number and title at the top and, in most cases, a set of bulleted points at the bottom indicating the number of cases used for the particular analysis, along with any significant caveats. Much of the information is presented as Figures made up of bar charts, where each Trust is represented by a vertical bar. These bars are identified by a Trust code (see Appendix A for the corresponding Trust names) and are divided into coloured sections according to the 'key' underneath the Figure. In most of these Figures the best performing Trusts are on the left and worse performing on the right. A bar labelled 'TNS', highlighted with an arrow, denotes the findings for the total national sample.

At the end of each section there is a table comparing the results from NAS2 and NAS1, where it is feasible to do so.

## 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 64 Trusts identified as eligible. All eligible organisations submitted data. Initially n=5,733 returns were received but following data cleaning 5,608 records, from 64 Trusts, were regarded as suitable for further analysis. The reasons for exclusion of some cases are detailed in Appendix G. The mean number of returns for the audit of practice tool was 88 (SD 17) per Trust after data cleaning, slightly improved on the 85 per Trust achieved in NAS1. Fifty-four (84%) Trusts returned data for at least 73 cases, 12 Trusts returned exactly 100 cases and four Trusts returned more than 100.

Each Trust was asked to distribute service user survey forms to 200 service users. In NAS1 the response rate was 19%. On this occasion, 3,379 service user survey forms were received, a mean of 53 (SD 19) per Trust, a response rate of 26%. Service users were each sent a carer survey form to pass to whomever they regarded as their closest carer. In total 1,119 of these forms were returned, a mean of 17 (SD 6) per Trust, which is similar to the 19 per Trust rate in NAS1.

Table 4 shows how many of each type of return was obtained for each Trust.

### **Case note audit sample (n=5,608)**

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Tables 5 to 10 show the demographic characteristics of the population of eligible patients for whom the audit of practice tool was completed from the service users' case records. Table 5 shows that 65% of the population was male and 84% had a diagnosis of schizophrenia (NAS1: 65% and 85% respectively). The proportion of females with a diagnosis of schizoaffective disorder was higher than for males. Such findings are consistent with the range found in many surveys of patients in the community.

**Table 4: Number of returns obtained from each Trust**

Trust ID	Audit tool	User survey	Carer survey
NAS 001	99	68	30
NAS 002	51	77	16
NAS 003	100	58	16
NAS 004	44	27	12
NAS 005	98	61	21
NAS 006	96	42	15
NAS 007	100	40	19
NAS 008	84	14	12
NAS 009	110	64	12
NAS 010	99	66	21
NAS 011	95	48	20
NAS 012	101	73	28
NAS 013	100	47	18
NAS 015	85	35	17
NAS 016	87	56	21
NAS 017	90	42	13
NAS 019	101	65	23
NAS 020	89	70	22
NAS 021	92	8	0
NAS 024	75	54	33
NAS 025	100	56	19
NAS 026	100	47	18
NAS 027	100	68	19
NAS 028	95	74	14
NAS 029	65	27	14
NAS 030	96	65	26
NAS 031	79	35	20
NAS 033	26	60	18
NAS 034	94	40	17
NAS 035	82	68	10
NAS 036	71	68	19
NAS 037	100	83	23

Trust ID	Audit tool	User survey	Carer survey
NAS 038	96	40	11
NAS 039	96	52	20
NAS 041	96	54	13
NAS 042	81	34	9
NAS 043	37	65	12
NAS 044	89	64	18
NAS 045	95	100	27
NAS 046	86	30	16
NAS 047	90	35	19
NAS 048	85	30	8
NAS 049	99	75	28
NAS 050	97	42	15
NAS 051	99	46	18
NAS 052	48	70	24
NAS 053	100	76	15
NAS 054	96	55	18
NAS 056	92	72	15
NAS 059	105	30	15
NAS 060	89	56	16
NAS 061	97	76	12
NAS 063	71	78	22
NAS 064	100	9	1
NAS 065	90	24	11
NAS 066	100	70	24
NAS 067	100	79	32
NAS 068	63	37	17
NAS 069	68	52	15
NAS 070	100	55	12
NAS 071	74	31	11
NAS 072	95	45	20
NAS 073	86	51	19
NAS 074	84	40	20



**Table 5: Numbers of service users by gender showing age and diagnostic groups (ICD-10)**

	Number (%)	Mean age in yrs (SD)	Age range	Schizophrenia n (%)	Schizoaffective disorder n (%)
<b>Total sample</b>	5,608	46 (13)	18-96	4,686 (84%)	922 (16%)
<b>Male</b>	3,655 (65%)	45 (12)	18-94	3,201 (88%)	454 (12%)
<b>Female</b>	1,949 (35%)	50 (14)	19-96	1,482 (76%)	467 (24%)
<b>Not stated</b>	4 (<1%)	53 (15)	38-74	3 (<1%)	1 (<1%)

**Table 6: Numbers by broad age bands**

Age bands (in years)	Number (%) of cases in each age band
<b>18-24 years</b>	148 (3%)
<b>25-34 years</b>	1,011 (18%)
<b>35-44 years</b>	1,427 (25%)
<b>45-54 years</b>	1,552 (28%)
<b>55-64 years</b>	967 (17%)
<b>65 years and over</b>	503 (9%)

**Table 7: Duration of illness**

Diagnosis first made (years)	Number
<b>Between 1 and 2</b>	226
<b>From 2 to 4</b>	495
<b>From 4 to 10</b>	1,353
<b>More than 10</b>	3,534
<b>Total (n)</b>	5,608

The mean age of the population was 46 years (SD 13) with a range of 18–96 years (NAS1: mean age was 45 years and range 18-93 years). Table 6 shows that this was predominantly a middle-aged group. Table 7 shows that the majority of the service users had been ill for more than 10 years, as was the situation in NAS1.

Tables 8 and 9 show the ethnic profile of the population. Table 8 shows that the gender split remains similar across ethnic groups and that the mean ages within each group are similar, except for the Mixed group who are a little younger.

Table 9 compares the NAS population with the 2011 population census figures

for England and Wales (the format of the census data at the time of this report does not allow for an exact comparison with the age ranges used in NAS). This suggests that the NAS population has a modest over-representation of patients of Asian/Asian British and Chinese background and a considerable over-representation of patients with a Black/Black British background.

**Table 8: 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>	2,867	1,531	2	47
<b>Asian/Asian British</b>	280	166	-	43
<b>Black/Black British</b>	291	161	2	44
<b>Chinese or other</b>	72	36	-	47
<b>Mixed</b>	82	34	-	40
<b>Not stated</b>	63	21	-	47
<b>Total</b>	3,655	1,949	4	-

**Table 9: Ethnic mix of NAS population compared to the overall population of England and Wales (2011 census)**

<b>Ethnic group</b>	<b>Percentage in NAS population (age &gt;18)</b>	<b>Percentage in England and Wales population</b>	
		<b>All ages</b>	<b>(age &gt;24)</b>
<b>White</b>	78.5	86	89
<b>Asian/Asian British</b>	8.0	6.8	5.9
<b>Black/Black British</b>	8.1	3.3	2.8
<b>Chinese or other</b>	1.9	1.7	1.5
<b>Mixed</b>	2.1	2.2	1.2
<b>Not stated</b>	1.5	-	-

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 10).

**Table 10: Clinical teams caring for the service users in the case note audit sample**

Type of clinical team	Number
Assertive Outreach	689
Community Mental Health	4,035
Crisis Resolution	13
Early Intervention	239
Other	632
<b>Total</b>	<b>5,608</b>

## **Carer sample (n=1,119)**

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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 earlier, 1,119 were returned to the NAS team.

The mean age of the carer sample was 55 years with a range of 16–91 years (NAS1: 51 years and 12-94 years respectively). Regarding gender, 662 (59%) were female and 410 (37%) were male (NAS1: 63% and 34% respectively). Other demographic characteristics of this sample are shown in Table 11 below.

Table 11 shows that the carers were mostly in the middle and older age groups. The age distribution is almost identical to that in NAS1. The large majority of carers described themselves as White.

**Table 11: Key demographic characteristics of carers**

Key demographic characteristics		N	%	
Gender	Female	662	59%	
	Male	410	37%	
	Not stated	47	4%	
	<b>Total</b>	1,119		
Ethnicity	White	859	77%	
	Asian / Asian British	90	8%	
	Black / Black British	69	6%	
	Chinese or other ethnic group	7	<1%	
	Mixed	23	2%	
	I'd rather not say	22	2%	
	Not stated	49	4%	
	<b>Total</b>	1,119	-	
Age	Mean age in years (±SD)	55 (15)	-	
	Range in years	16 - 91	-	
	Age bands (years):	Under 18	1	<1%
		18-24	24	2%
		25-34	70	6%
		35-44	125	11%
		45-54	200	18%
		55-64	268	24%
		65 and over	267	24%
	Not stated	164	15%	
<b>Total</b>	1,119	-		

Table 12 (below) describes respondents' caring responsibilities. The majority cared for a son/daughter (34%) or a partner/spouse (20%). A quarter (25%) cared for more than one person with a mental health problem.

Table 13 shows that carers spent an average of 59 hours (SD 55) looking after someone with a mental health problem. Just over 20% of carers were in full-time employment (NAS1: 21%) and 28% were retired (NAS1: 30%).

Approximately half of carers have cared for the service user for more than 10 years (data not shown below), reflecting the long-term nature of this commitment.

**Table 12: Caring responsibilities**

Caring responsibilities		N	%
What is the relationship between you and the person you care for?	My son/daughter	379	34%
	My partner/spouse	223	20%
	My brother/sister	68	6%
	My parent	59	5%
	My friend	40	4%
	I'm a paid carer	171	15%
	Other family member	19	2%
	Other	36	3%
	Not stated	124	11%
	<b>Total</b>	<b>1,119</b>	<b>-</b>
Do you live with each other at the moment?	Yes	529	47%
	Some of the time	57	5%
	No	444	40%
	Not stated	89	8%
	<b>Total</b>	<b>1,119</b>	<b>-</b>
How many people with a mental health problem do you currently care for?	1 person	740	66%
	2 persons	91	8%
	3 + persons	188	17%
	Not stated	100	9%
	<b>Total</b>	<b>1,119</b>	<b>-</b>

**Table 13: Time spent on caring responsibilities and employment status**

	Number of hours spent	Number of carers	%
<b>How many hours you spent in the last week looking after someone with a mental health problem?</b>	0 hours	11	1%
	1-5 hours	42	4%
	6-10 hours	64	6%
	11-20 hours	79	7%
	21-30 hours	68	6%
	More than 30 hours	397	36%
	Not stated	458	41%
	<b>Total</b>	<b>1,119</b>	<b>-</b>
<b>Employment status</b>			
	Employment	Number of carers	%
<b>Employment status</b>	Employed full-time	230	21%
	Employed part-time	105	9%
	Self-employed	31	3%
	Unemployed	104	9%
	Retired	308	28%
	Student	14	1%
	Unable to work due to caring responsibilities	99	9%
	Unable to work due to ill-health /disability	124	11%
	Other	20	2%
	Not stated	84	8%
	<b>Total</b>	<b>1,119</b>	<b>-</b>

## Experience of service users and carers

The experience of service users and carers is a key component of the quality of health care. As in the first round of the National Audit of Schizophrenia we asked service users and carers to complete survey forms designed to assess whether they had a positive experience of the services they received. We asked service users if they had been given the information and support they needed, and about access to treatment, care planning and continuity of care. We asked carers if they were satisfied with the information and support they were offered.

The service user survey form was changed from NAS1 to NAS2 in order to improve the format and add new questions about a wider range of treatment and support. This makes a direct comparison of these data between the two rounds of the audit impossible. However, in the carer survey form all of the questions about satisfaction with support received remained the same. Thus, for carer experience the results from NAS1 and NAS2 are presented alongside each other.

Responses to the service user survey regarding decisions about medication, psychological treatments and physical health care can be found on pages 76, 107 and 113 respectively.

### **Service user experience**

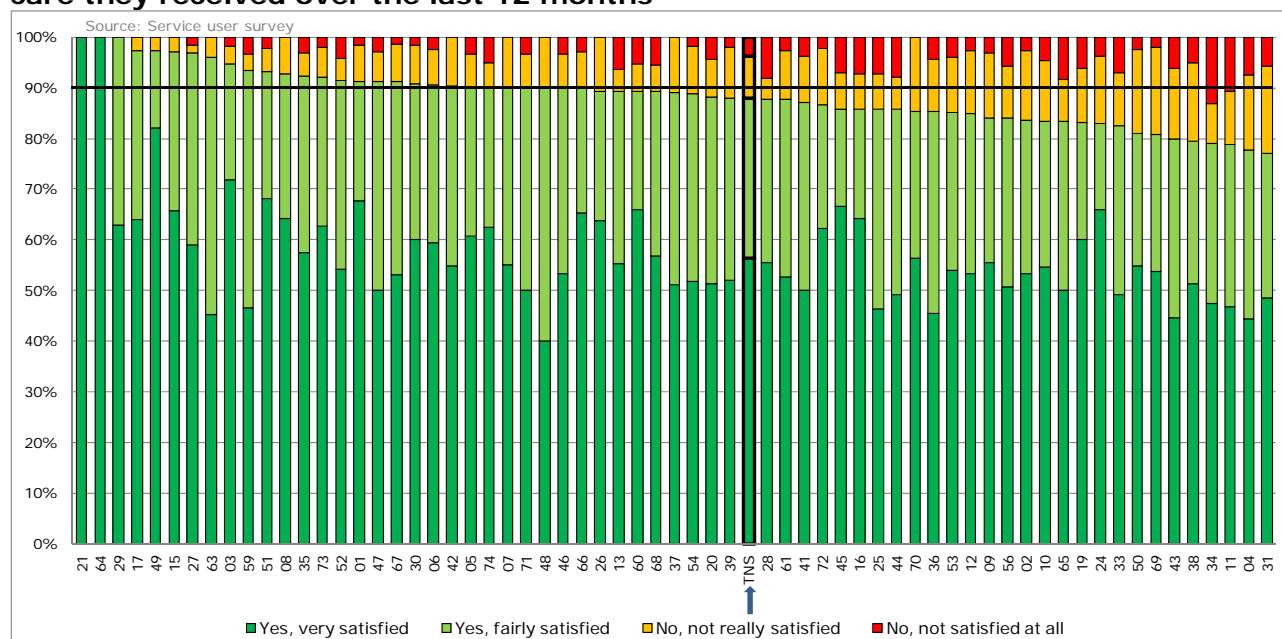
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Each Trust was asked to send out service user survey forms to 200 service users (for further information on sampling, see the Methodology section, page 38). The NAS team received 3,379 responses to these, a mean of 53 (SD 19) responses from each of the 64 Trusts that took part in the audit. Not all service users who took part in the survey answered all questions and the numbers responding are indicated in the bullet point below each Figure and Table.

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

Figure 2 shows the proportion of service users who reported that they were satisfied with the care they received during the previous 12 months. 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 a Trust code (see Appendix A for the corresponding Trust names). These bars are divided into coloured sections according to the key underneath the figure. A bar labelled 'TNS' denotes the findings for the total national sample, i.e. the whole population included in the audit.

**Figure 2: Proportion of service users reporting that they were satisfied with the care they received over the last 12 months**



- The data for Figure 2 are taken from Q4 of the service user survey.
- 99% of service users answered this question.
- The horizontal black line at the 90% level represents the threshold that each Trust is expected to achieve for 'very' plus 'fairly' satisfied combined to meet standard 1. This threshold was discussed and agreed by the service user reference group.

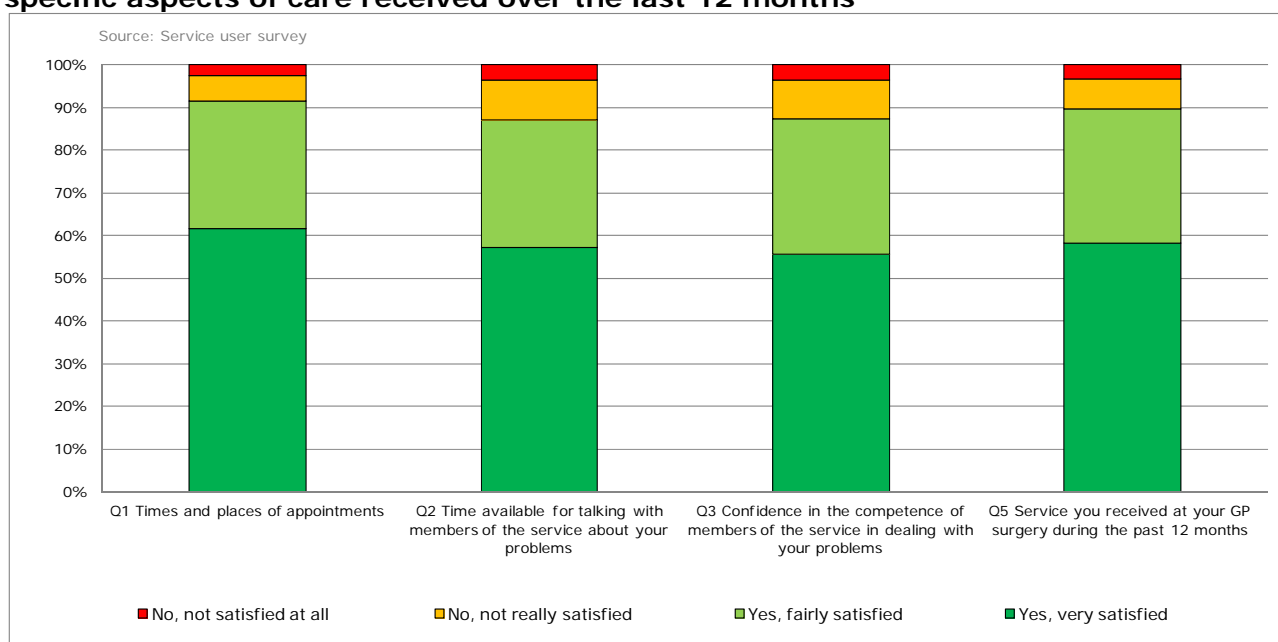
For the total national sample (TNS bar) 57% of service users stated that, taking everything into consideration, they were very satisfied with the care they had received from the service so far. There were 4% who reported that they were not satisfied at all with the care they had received, with a range across the 64 Trusts from 0% to 13% for this particular response to question 4.



The NAS service user reference group set a criterion that, to meet standard 1, a threshold of 90% of responses should be 'very satisfied' plus 'fairly satisfied' combined. Figure 2 shows that this is reached by 44% of Trusts.

Responses to four specific questions on satisfaction with appointments, amount of time given, confidence in staff at local mental health services and satisfaction with service received in primary care are presented in Figure 3 below for the whole audit population (TNS).

**Figure 3: Proportion of service users reporting that they were satisfied with specific aspects of care received over the last 12 months**



- The data for Figure 3 are taken from Qs 1, 2, 3 and 5 of the service user survey.
- This analysis is based on responses from 3,379 service users. There were 250 instances where an individual service user had not provided a response to a particular question.

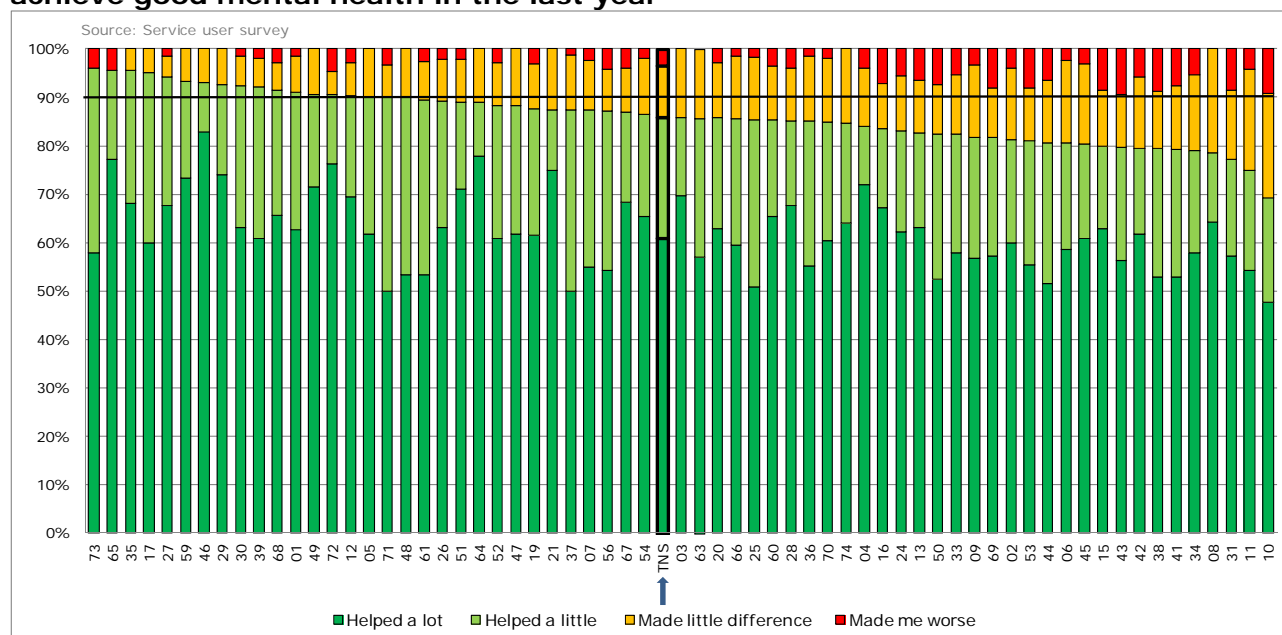
Levels of satisfaction with each component of care were similar. The percentages of service users reporting they were very satisfied on each component were: 62% with the times and places of appointments offered; 57% with the time available for talking to staff; 56% with the competence of mental health staff; and 58% with the treatment they received in primary care.

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

Service users were asked the extent to which services had helped them to achieve good mental health in the last year. In Figure 4, for the total national sample (TNS), 61% of service users felt that services had helped them a lot, 25% that they had helped a little, 11% that they had made little difference and 3% that services had made their health worse during the previous 12 months.

The service user reference group set a criterion that, to meet standard 2, a threshold of 90% of responses should be 'helped a lot' plus 'helped a little' combined. It can be seen from Figure 4 that this is reached by 28% of Trusts.

**Figure 4: Proportion of service users reporting that services had helped them achieve good mental health in the last year**



- The data for Figure 4 are taken from Q26 of the service user survey.
- 98% of service users answered this question.
- The horizontal black line at the 90% level represents the threshold that each Trust is expected to achieve for 'helped a lot' plus 'helped a little' combined to meet standard 2. This threshold was discussed and agreed by the service user reference group.

Involvement in regular daytime activity is important for people with chronic mental health problems of all types, whether this is work or other forms of activity. All patients were asked whether they received help to obtain work or get involved in other structured activities (e.g. education/volunteering/drop-in

groups). Responses to these questions are presented in Tables 14 and 15 plus Figures 5 and 6.

**Table 14: Whether service users had a job or wanted one, and were receiving help to find work**

Response	Number (%)	Percentage range
<b>I have a job</b>	331 (10%)	0 - 33%
<b>I do not have a job but I am getting help to find one</b>	330 (10%)	2 - 29%
<b>I do not have a job and I am not getting help to find one</b>	355 (11%)	0 - 29%
<b>I do not have a job and I am not looking for one at this time</b>	2,158 (64%)	43 - 89%

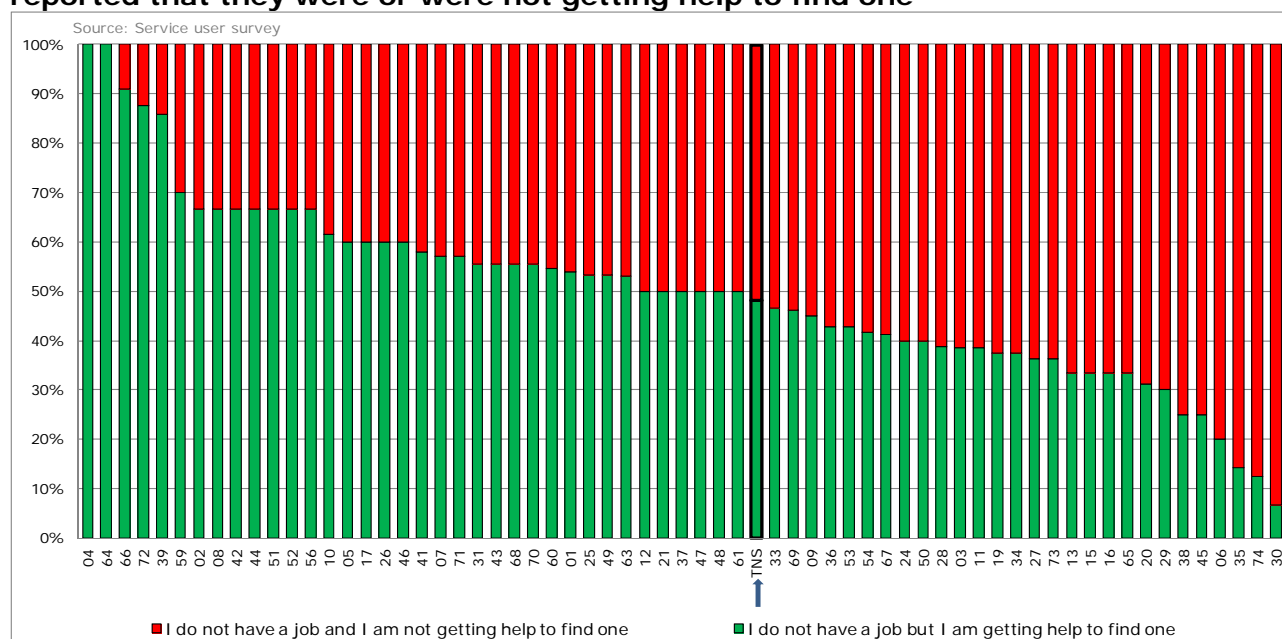
- The data for Table 14 are taken from Q22 of the service user survey.
- 94% of service users answered this question.

Most service users stated that they did not have a job and the majority of these stated that they were not looking for work. As reiterated by the service user reference group, this may well represent some of the consequences of long-term illness and the loss of motivation that often accompanies schizophrenia.

However, an important group are the n=355 (11% of the total national sample) who do not have a job but are not getting help to find one. Across Trusts the percentage in this group ranges from 0% to 29% of those who responded to the question about employment (question 22).

In Figure 5 we present the proportions of service users in each Trust, who were looking for a job, grouped by those who stated that they were or were not receiving help to find one. Only 48% of those who reported that they were looking for a job stated that they were receiving help to find one, with a range across Trusts from 7% to 100%.

**Figure 5: The proportion of services users who were looking for work who reported that they were or were not getting help to find one**



- The data for Figure 5 are taken from Q22 of the service user survey.
- This analysis is based on responses from the 685 service users who did not have a job but wanted help to find one (Table 14). The overall response rate to Q22 was 94%.

Information about whether or not service users were involved in daytime activities are presented in Table 15. Figure 6 then further examines the situation for those who are not involved in regular activities but appear to want help with this.

**Table 15: Whether service users were involved in daytime activities and, if not, if they wanted help to become involved**

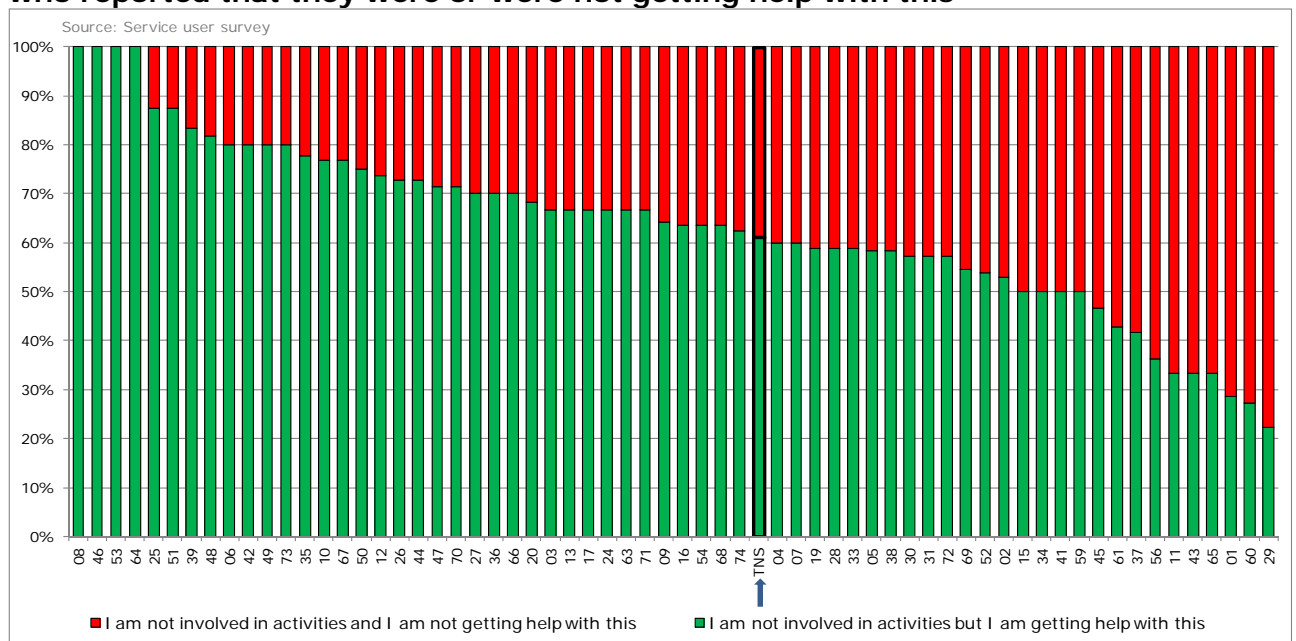
Response	Number (%)	Percentage range
<b>I am involved in activities during my day</b>	1,158 (34%)	19 – 63%
<b>I am not involved in activities but I am getting help with this</b>	380 (11%)	0 – 30%
<b>I am not involved in activities and I am not getting help with this</b>	241 (7%)	0 – 26%
<b>I am not involved in activities but I'm ok with that for the moment</b>	1,440 (43%)	20 - 62%

- The data for Table 15 are taken from Q23 of the service user survey.
- 95% of service users answered this question.

It is of some concern that many service users (43%) reported themselves to be in the category of not being involved in daytime activities but being happy with that. However, 34% of service users were involved in regular activities. In the total national sample, n=621 (19%) appeared to want other activities but not currently be involved with them, with a range across Trusts from 0% to 39%.

In Figure 6 we present the proportions of service users in each Trust who were not involved in other activities, but appeared to want such, grouped by those who stated that they were or were not receiving help to become involved. The TNS shows that 61% of service users who were not involved in daily activities were receiving help to find such, with a range across Trusts from 22% to 100%.

**Figure 6: The proportion of services users who were looking for other activities who reported that they were or were not getting help with this**



- The data for Figure 6 are taken from Q23 of the service user survey.
- This analysis is based on responses from the 621 service users who were not involved in activities but wanted help to be involved (Table 15).
- 95% of service users answered this question.

## Carer experience

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**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.**

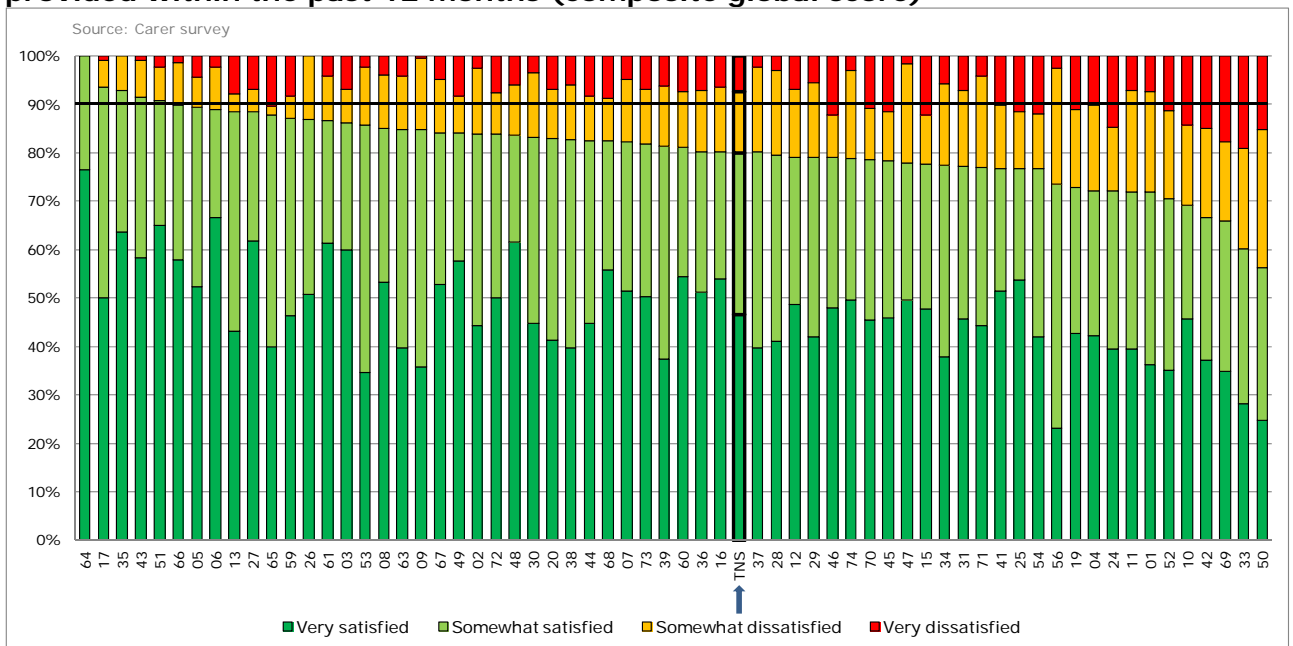
Trusts were asked to give the 200 service users, selected for the service user survey, a carer survey form to give to whoever they regarded as their carer. The NAS team received 1,119 responses to these, with a range from n=0 returns for one Trust to n=33 for the Trust with the greatest number of returns.

In the carer survey form, carers were asked 17 questions across three main domains relating to their satisfaction with the support they receive to help them in their role as a carer: information and advice; involvement in treatment and care planning; and support from staff. The responses to each individual question are shown in Figures 8, 9 and 10. In addition, a composite score was calculated from the total scores for each of the 17 questions. This composite score is shown in Figure 7 and provides a global picture of carer views of the services provided by Trusts.

Following the service user reference group it was decided that the same criterion for meeting standards 1 and 2 should be applied to standard 3 - a threshold of 90% of responses should be 'very satisfied' plus 'somewhat satisfied' combined. This criterion was met by 9% of the 64 Trusts. The TNS shows that 80% of carers reported feeling very satisfied or somewhat satisfied, with a range across Trusts of 56% to 100%.

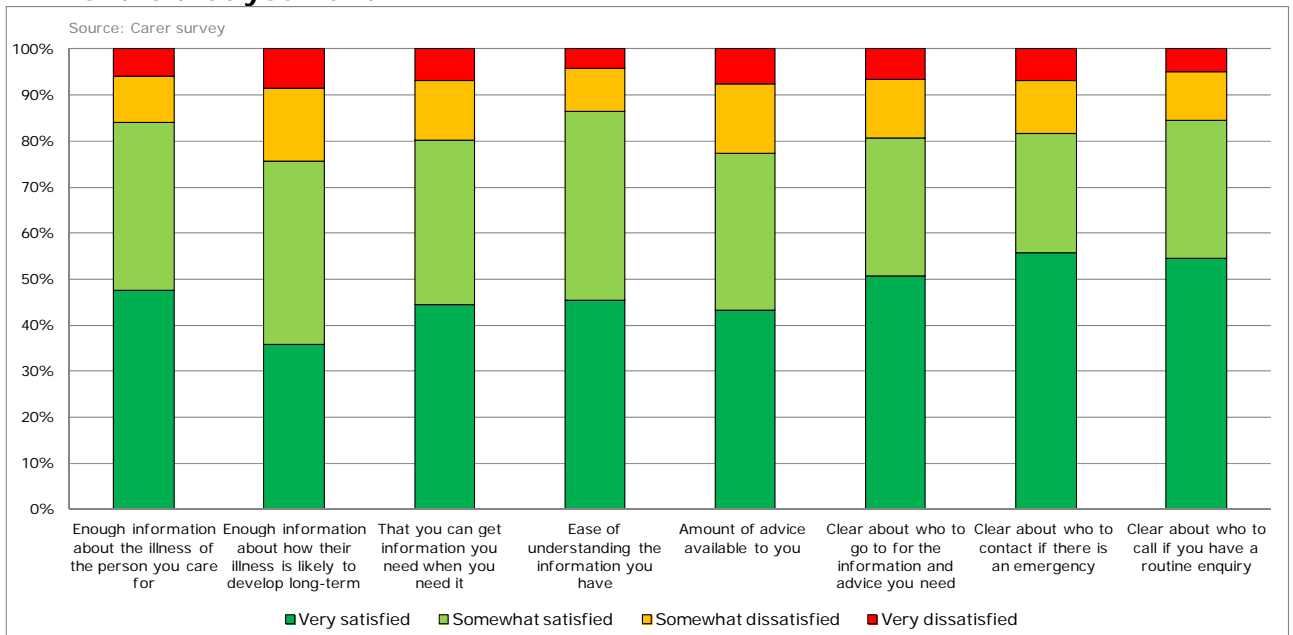
In the total national sample 47% of carers reported being very satisfied with the information and support they received, 33% somewhat satisfied and 20% dissatisfied, of whom 7% reported that they were very dissatisfied with the service they received.

**Figure 7: Carers' satisfaction with the support and information they have been provided within the past 12 months (composite global score)**



- The data for Figure 7 are taken from Qs 1, 2 and 3 of the carer survey.
- The analysis for Figure 7 is based on responses from 1,119 carers. There were 698 instances where an individual carer had not provided a response to a particular question.
- The horizontal black line at the 90% level represents the threshold that each Trust is expected to achieve for 'very' plus 'somewhat' satisfied combined to meet standard 3.

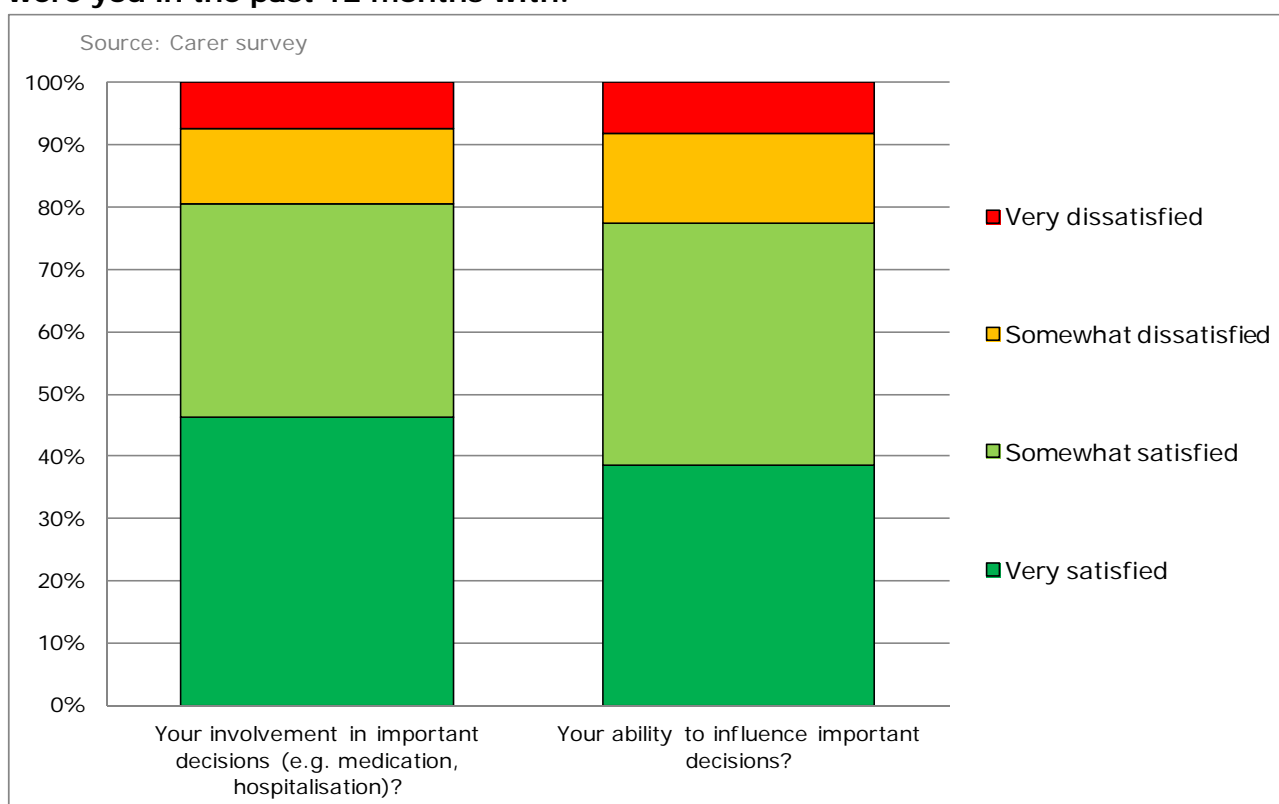
**Figure 8: Information and advice: In general how satisfied were you in the past 12 months that you have:**



- The data for Figure 8 are taken from Q1 of the carer survey.
- This analysis is based on responses from 1,119 carers. There were 323 instances where an individual carer had not provided a response to a particular question.

The results shown in Figure 8 suggest that there are significant improvements to be made in the information and support provided to carers and these improvements are needed across all of the specific aspects of care represented in the Figure. The one requiring most attention, however, is the degree to which carers feel informed about how the service user's illness is likely to develop in the longer term, i.e. the service user's prognosis, where 24% of carers stated that they were dissatisfied with the amount of advice they received (1,067 [95%] of carers responded to this question).

**Figure 9: Involvement in treatment and care planning: In general how satisfied were you in the past 12 months with:**

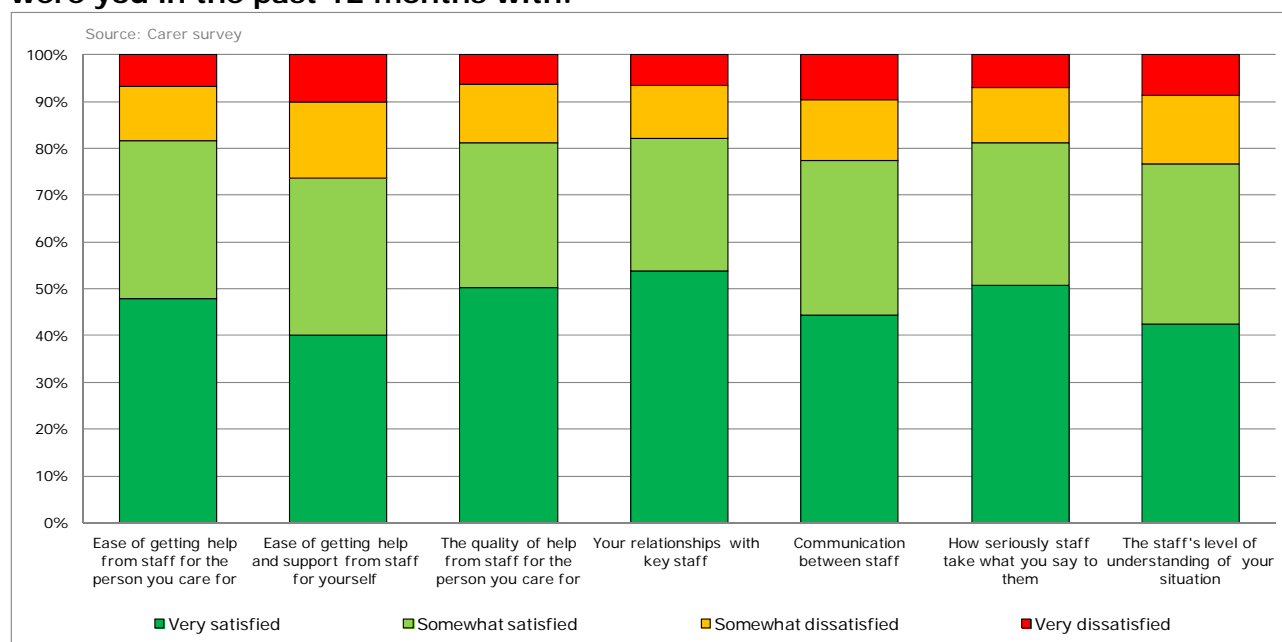


- The data for Figure 9 are taken from Q2 of the carer survey.
- 97% (left-hand column) and 95% (right-hand column) of carers answered these questions.

Figure 9 indicates that a relatively low percentage of carers feel very satisfied with their involvement in decisions made regarding the service user. Clearly there are issues of confidentiality and the requirements for service user autonomy in any decisions that can influence this. Thus, it is difficult to set a precise threshold that may always be appropriate here.



**Figure 10: Support from medical and/or care staff: In general how satisfied were you in the past 12 months with:**



- The data for Figure 10 are taken from Q3 of the carer survey.
- This analysis is based on responses from 1,119 carers. There were 290 instances where an individual carer had not provided a response to a particular question.

Figure 10 shows that most carers felt fairly or very satisfied with their contact with medical and care staff. However, 26% reported being dissatisfied in their attempts to get support from staff for themselves and 23% reported dissatisfaction with how well the staff they were in contact with appeared to communicate with each other, particularly about important information. The latter issue is one which causes carers intense frustration and results in uncertainty about the service user's care.

**Table 16: Key comparisons between NAS2 and NAS1 for carer satisfaction**

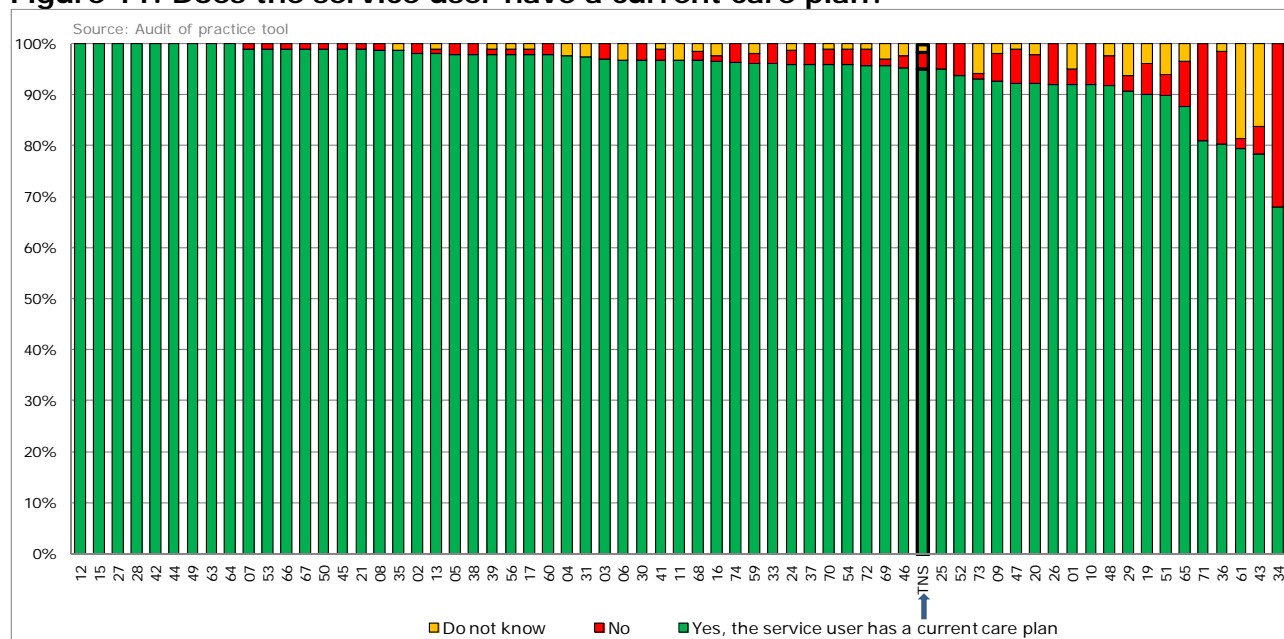
Standard / Indicator	NAS2 (%)	NAS1 (%)
<b>Standard 3 – carer satisfaction</b>		
Carers report being 'somewhat' or 'very' satisfied with the information and support received	80%	81%
Range across Trusts for the above parameter	56 – 100%	55 – 100%

## Care planning, continuity of care and access to services

**Standard 15: Each service user has a current care plan.**

Current NICE guidelines (NICE CG136, 2011) emphasise the importance of all people who are treated by secondary care mental health services having a jointly developed care plan, which includes information about the person’s current needs and what has been put in place to help meet these needs. We collected information about care plans from the audit of practice tool and asked services users if they had a care plan. In an attempt to find out if people who had a care plan were using it, we asked respondents who had a care plan whether they knew where it was.

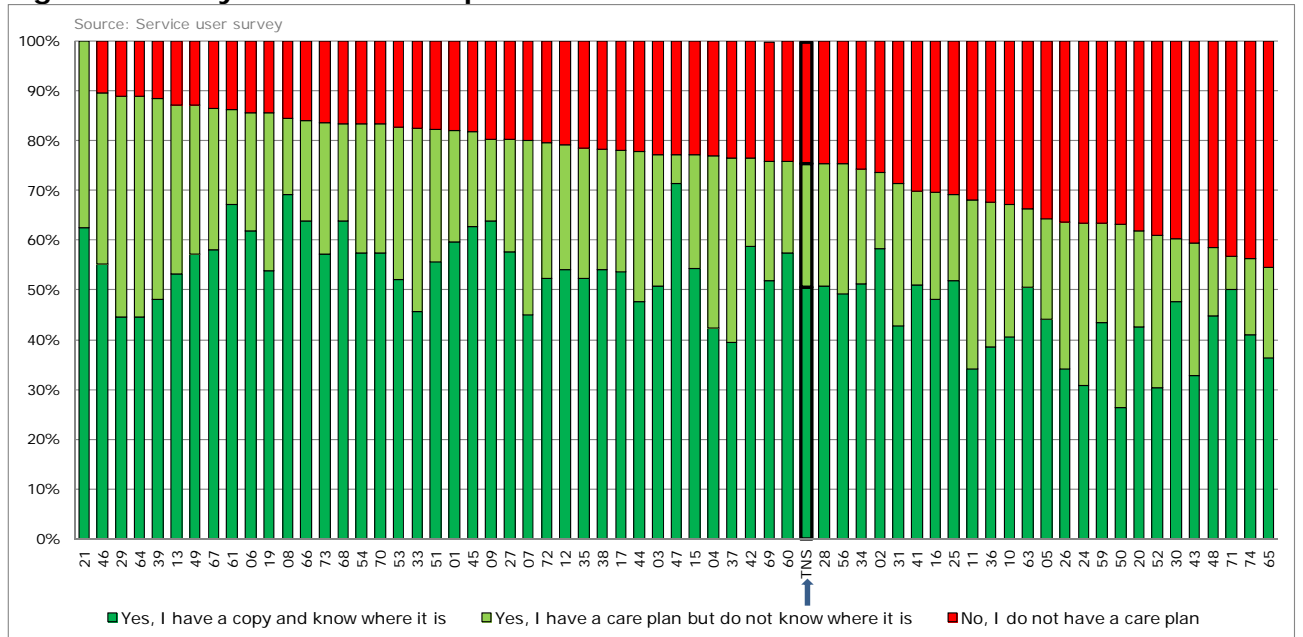
**Figure 11: Does the service user have a current care plan?**



- The data for Figure 11 are taken from Q45 of the audit of practice tool.
- This analysis is based on 5,608 case records.

In the total national sample 95% of case records included details of a care plan, a percentage which ranged from 68% to 100% across the 64 Trusts. Results from the service user survey are presented in Figure 12. While 75% of service users who responded reported that they had a care plan, one third of these did not know where it was.

**Figure 12: Do you have a care plan?**

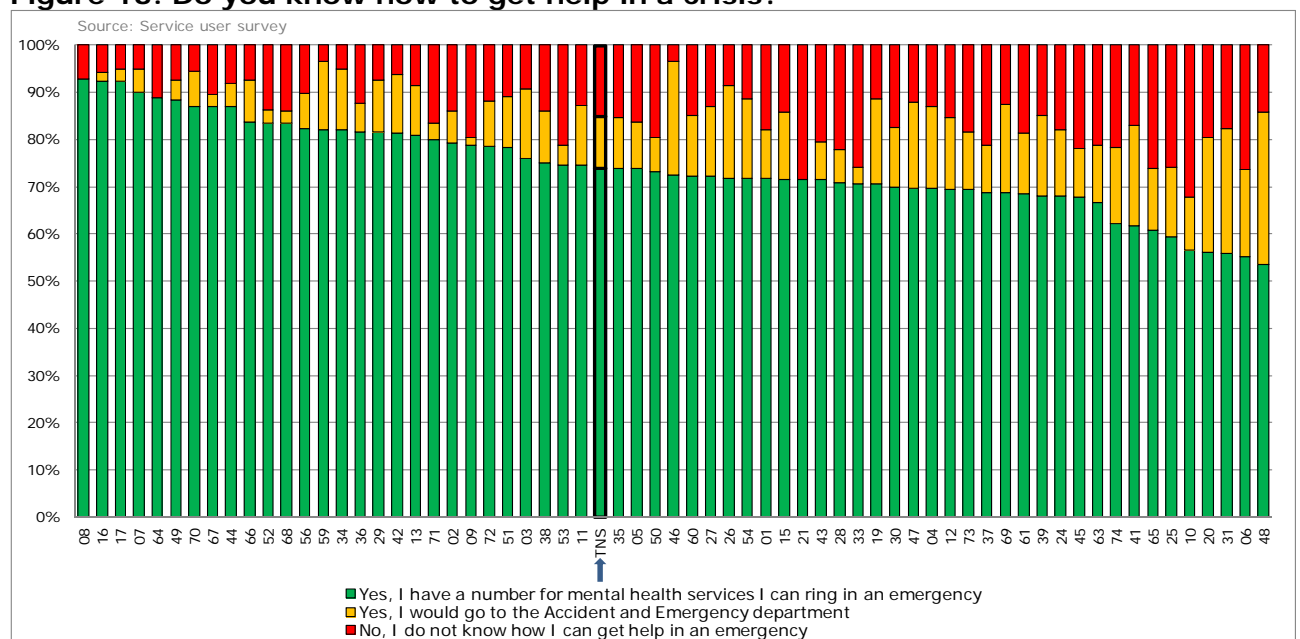


- The data for Figure 12 are taken from Q12 of the service user survey.
- 97% of service users answered this question.

**Standard 16: Each service user knows how to contact services in a crisis.**

NICE guidelines recommend that people in contact with mental health services are offered a crisis plan which includes information about how they can contact services if they need them urgently. We asked all service users who took part in the survey if they knew how to get help right away for their mental health if there was a crisis or emergency. Responses to this question are presented in Figure 13.

**Figure 13: Do you know how to get help in a crisis?**



- The data for Figure 13 are taken from Q11 of the service user survey.
- 95% of service users answered this question.

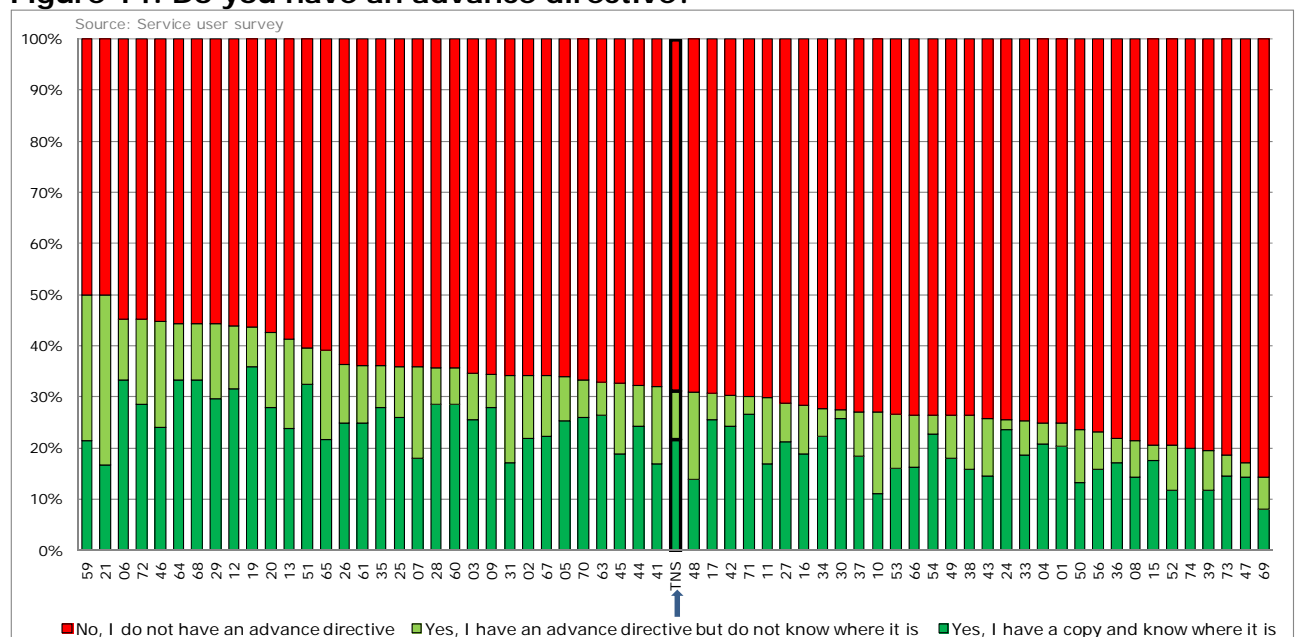
Overall, 74% of service users reported that they had a telephone number they could ring to access urgent help, but there was marked variation across Trusts in the percentage who reported this (from 54% to 93%). N=354 (11%) of service users who responded reported that they would go to a General Hospital Emergency department if they were in crisis, a figure which ranged from 0% to 32% across Trusts. Whilst going to an Emergency department is not recommended, for some situations it may be appropriate.

**Advance directives**

(This is not part of a specific standard but has relevance to standards 15 and 16.)

Advance directives allow people who have mental capacity to provide information about treatment they would want to receive in the event that they lose capacity at a later time. Mental Health Act legislation in England and Wales requires people who provide mental health services to follow information provided in an advance directive. We asked service users who took part in the survey whether or not they had an advance directive.

**Figure 14: Do you have an advance directive?**



- The data for Figure 14 are taken from Q13 of the service user survey.
- 96% of service users answered this question.

In total 31% of service users stated that they had an advance directive, ranging from 14% to 50% across the 64 Trusts.

## Shared decision making about medication

There is evidence in other areas of medicine that shared decision making can improve adherence to treatment (Hamann et al., 2003). While less is known about the impact of shared decision making in mental health (Duncan et al., 2010), people with severe mental illness want to be involved in treatment decisions (Adams et al., 2007), and this approach is recommended in NICE guidelines on schizophrenia (NICE CG82, 2009).

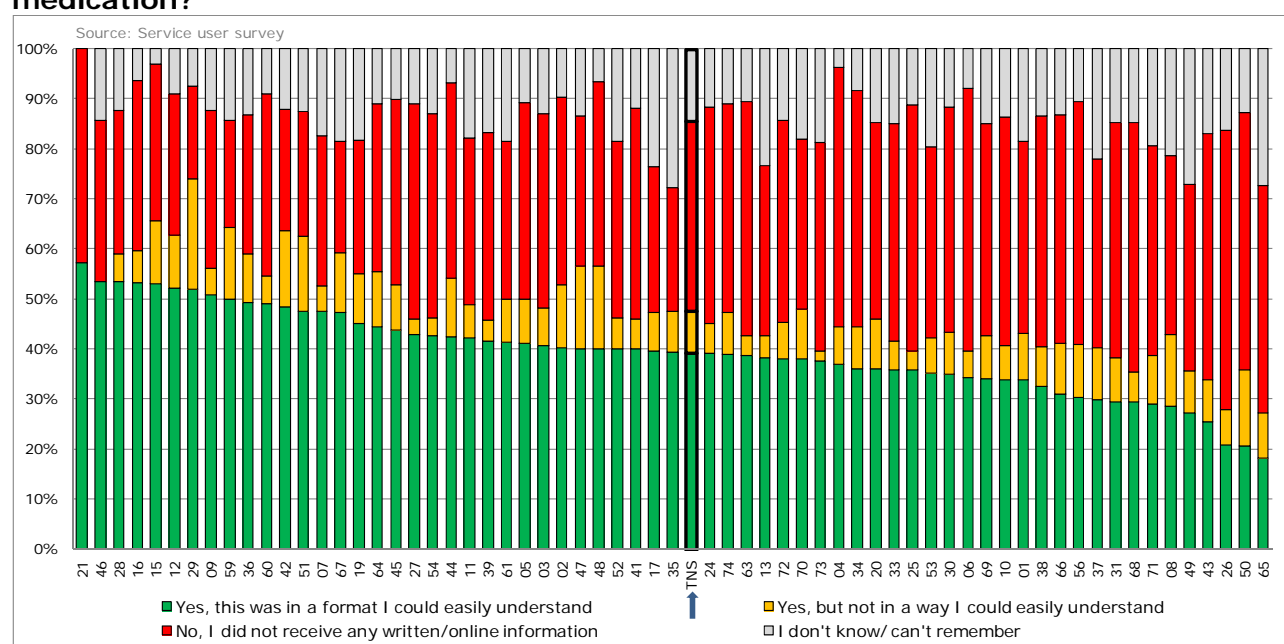
The main aspects of the findings from the audit that are presented in detail here are from the service user survey. Where appropriate some comparisons are made with information collected from case records using the audit of practice tool.

Standards 6 and 7 relate to interactions between service users and medical staff.

**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 15 presents the perceptions of service users across each individual Trust regarding whether or not they were provided with information and whether this was easily understandable. Figure 16 then compares the perceptions of Trust staff with the perceptions of service users for the whole population audited. When viewing Figures 16 and 18 it is important to remember that the service users returning survey forms are not matched to the case records from which the Trust data are collected. Thus any comparisons are not exact, but these are provided to gain some sense of how the performance of Trusts matches service user perception.

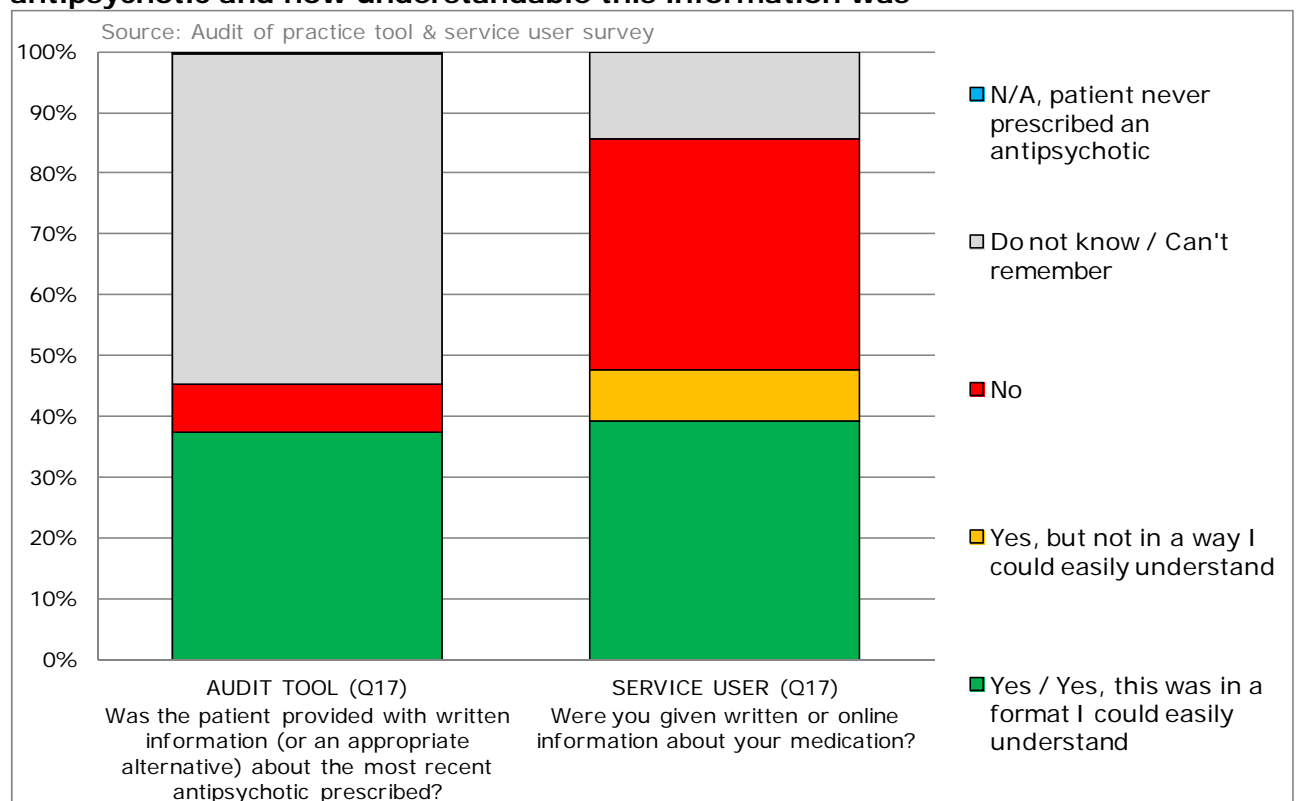
**Figure 15: Were you given written or online information about your medication?**



- The data for Figure 15 are taken from Q17 of the service user survey.
- 93% of service users answered this question.

There was marked variation between Trusts in the proportion of service users who reported having been given written, or online, information about the medication they were prescribed in a format they could understand (green section of the bars in Figure 15). The range across Trusts was from 18% to 57% with an average of 39% of service users feeling the information was appropriate.

**Figure 16: Provision of information about the most recently prescribed antipsychotic and how understandable this information was**



- The audit of practice tool analysis is based on 5,608 case records
- 93% of service users answered this question

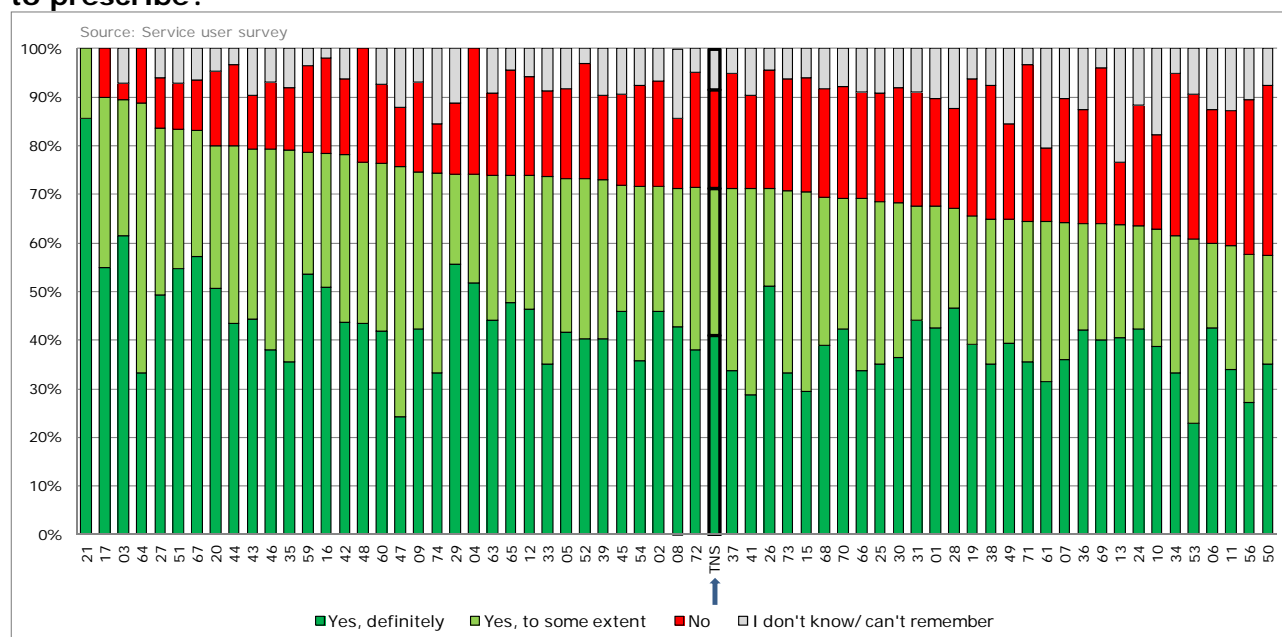
Figure 16 shows that there was documented evidence in the case notes that clinicians provided written information about the last antipsychotic the patient was prescribed in 37% of cases. In relation to all medication they were currently taking, 1,494 (48%) service users reported that they had been given such information, with 1,233 (39%) stating that it had been in an understandable format.



**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 17 presents the perceptions of service users across each individual Trust regarding whether or not their views were taken into account the last time they had a new medication prescribed for their mental health. Figure 18 then illustrates how well the perceptions of Trust staff match the perceptions of service users.

**Figure 17: Were your views taken into account when deciding which medication to prescribe?**



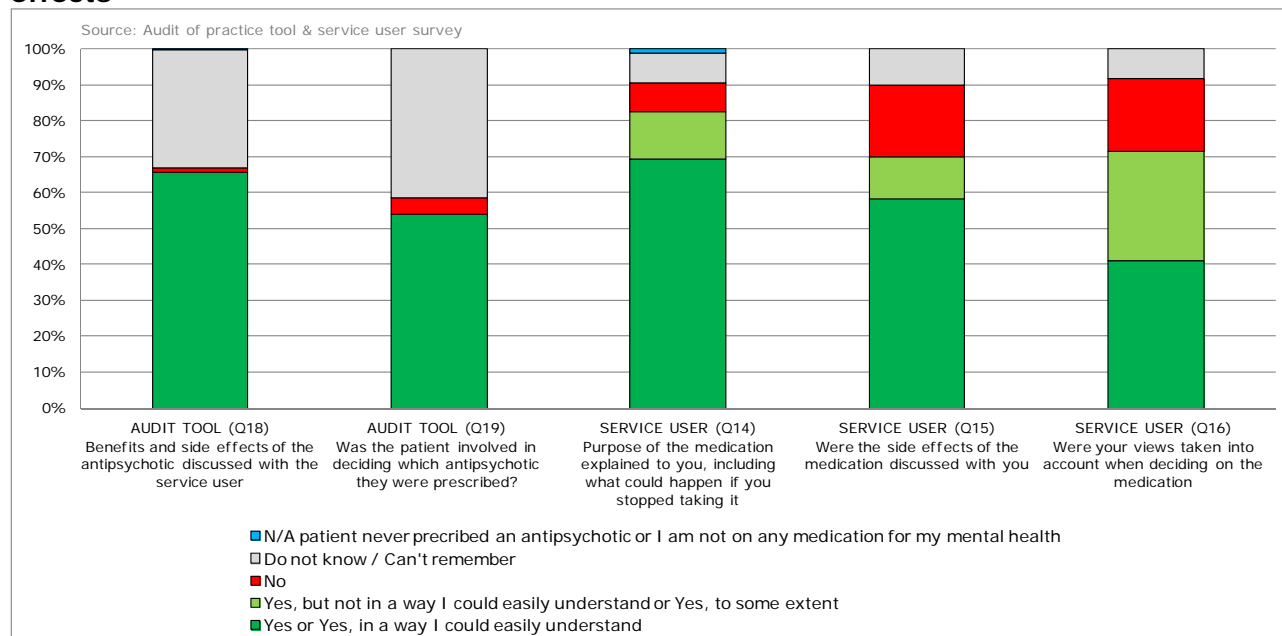
- The data for Figure 17 are taken from Q16 of the service user survey.
- 96% of service users answered this question.

If one takes a conservative view of these data then only 41% of service users felt that their views had 'definitely' been taken into account in the decision about which medication to prescribe. A more liberal interpretation is that 71% reported having their views taken into account at least 'to some extent'. Of more concern, perhaps, is the fact that in one-fifth of Trusts, 25-35% of service users reported that their views had not been taken into account at all in these decisions.

The service user survey also asked if service users felt that the purpose and potential adverse effects of the medication had been explained to them. Figure 18 presents the findings from these questions, and one about decision making,

alongside the results from the case record audit of practice for the whole population audited.

**Figure 18: Service users' involvement in the decision about the current/most recent medication, including discussions of the benefits and potential side-effects**



- The audit of practice tool analysis is based on 5,608 case records.
- The percentage of service users answering each question is: 98% for Q14, 96% for Q15, and 96% for Q16.
- No information was provided for Q19 of the audit of practice tool in 142 cases.

Service user involvement was documented in 54% of case records (see Figure 18). In contrast, 71% of service users reported that their views had been taken into account, at least 'to some extent', while 19% felt that their views had not been taken into account at all.

In 65% of case records there was evidence that benefits and adverse effects of medication had been discussed with service users. A similar proportion of service users (69%) reported that the purpose of the medication had been adequately discussed with them, while 58% stated that adverse effects had been adequately discussed.

Table 17 compares the findings in this second round of the audit (NAS2) with the findings from NAS1. The findings from NAS2 are all worse than in the previous round.

**Table 17: Key comparisons between NAS2 and NAS1 for shared decision making**

<b>Standard / Indicator</b>	<b>NAS2 (%)</b>	<b>NAS1 (%)</b>
<b>Standard 6 – provision of information about medication</b>		
Service users said they received information	48%	52%
Trusts said they provided information	37%	42%
<b>Standard 7 – involvement in prescribing decision</b>		
Service users felt involved	71%	74%
Trusts said they involved the service user	54%	62%

## Prescribing

The prescribing of antipsychotic medication is a key part of the management of someone with a diagnosis of schizophrenia. It is an important focus of the NICE guideline (NICE CG82, 2009). Standards 8 to 13 for this audit mirror the main NICE recommendations relating to the use of antipsychotic medications. Relevant sections of the audit of practice tool were constructed to try to capture information that would allow us to assess performance against these audit standards. A full appraisal of some of the NICE recommendations, and hence the audit standards, would require a prospective study or a more detailed retrospective analysis of case notes than is feasible in a cross-sectional audit process. However, it is possible to collect simple data that can be used to provide a reasonable assessment of how well the NICE guideline is being followed. The data are presented against each of the audit standards in turn.

It is 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 clinical response.

Much of the data described below relate to the total audit sample of n=5,608 cases. However, some of the audit standards relate to subgroups of this sample, particularly those individuals whose illness is not in remission. The derivation of these subgroups is either described in Tables 19 and 20 or in notes below the relevant Figure or Table.

The findings are presented for each audit standard in the order of the standards.

## Standard 8

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Regarding the prescription of antipsychotic medications, the NICE guideline advises that, in the majority of situations, only one antipsychotic medication at a time should be prescribed (monotherapy). There is no evidence for greater effectiveness, and the risk of adverse effects increases, with polypharmacy, i.e. the prescription of more than one antipsychotic drug at the same time. Standard 8 relates to this and Figures 19 and 20 indicate the percentages of service users receiving none, one, two or three antipsychotic drugs within each Trust as well as the average across all Trusts (TNS column). In total n=139 (2.5%) service users were not receiving any antipsychotic medication at the time of the audit.

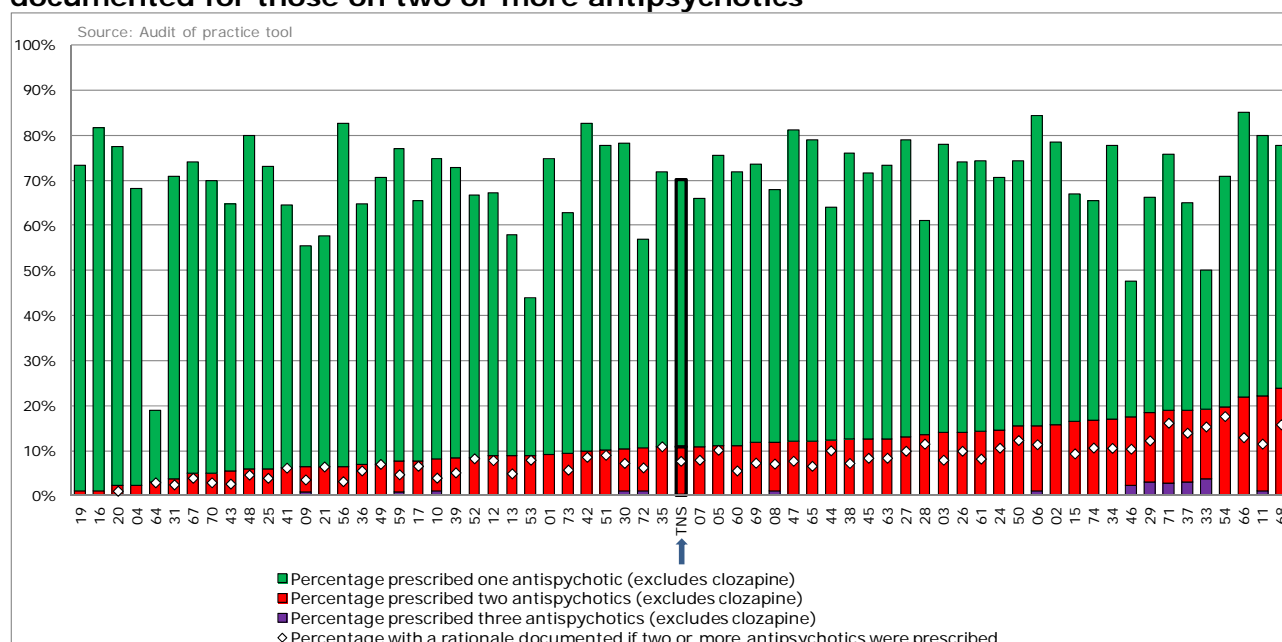
**Standard 8: The service user is currently only prescribed a single antipsychotic drug (unless they are in a short period of overlap while changing medication or because clozapine is co-prescribed with a second antipsychotic) and a rationale for this has been documented.**

Figure 19 shows the percentage of service users in each Trust, who are not currently prescribed clozapine, for whom there is polypharmacy in relation to the prescribing of antipsychotic medication. Where a service user has a particularly treatment unresponsive illness there can be an appropriate rationale for use of more than one antipsychotic medication for a short period of time to see if this will help. However, a clear rationale must be discussed with the service user and recorded in the case notes. Thus, also indicated (in white diamonds) is the percentage of cases for whom a rationale has been documented for such polypharmacy.

In total, n=616 (11%) service users were being prescribed more than one non-clozapine antipsychotic concurrently. (Please note that service users prescribed both an oral and a depot or long acting injectable [LAI] version of the same medication are regarded as being on a single antipsychotic medication. Thus, this number cannot be calculated directly from the data provided in Table 18.) It is clear that there is a wide variation across Trusts in the occurrence of polypharmacy for this group. The range across Trusts varies from 1% to 24% with a TNS average of 11%. In NAS1 the range was 3% to 30% with a TNS average of 11%. It seems unlikely that such a very wide range could be

accounted for by differences in service user populations between Trusts or differences in proportions who are treatment unresponsive. Documentation of a rationale was provided for n=435 (71%) of those cases who were receiving polypharmacy, but Figure 19 also seems to suggest that those Trusts with a higher percentage of cases receiving polypharmacy may be more likely to have a lower proportion of such cases with a documented rationale.

**Figure 19: Percentage of service users across Trusts prescribed one, two or three antipsychotics (excluding clozapine) and whether a rationale was documented for those on two or more antipsychotics**

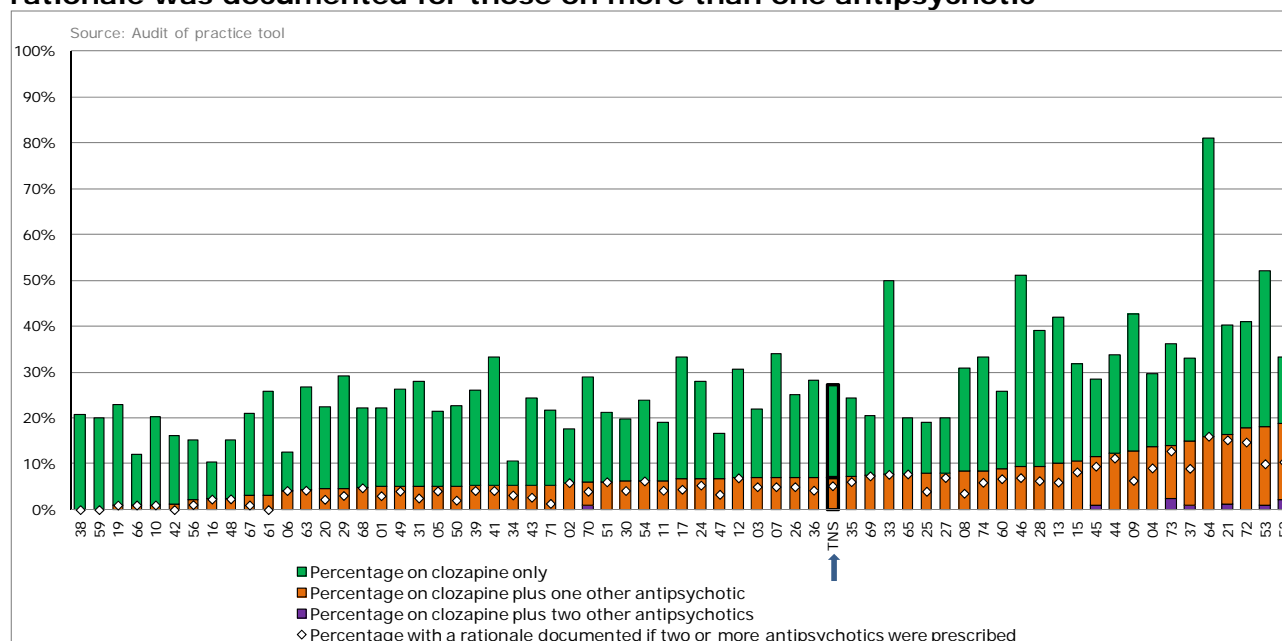


- The data for Figure 19 are taken from Qs 11 and 13 of the audit of practice tool.
- The number of cases included in this analysis is the 3,935 cases not on clozapine. Percentages are expressed as a percentage of the total number of cases for each Trust (which make up the 5,608 total cohort).
- Service users prescribed both an oral and a depot [or LAI] version of the same medication are regarded as being on a single antipsychotic medication.
- No service users were receiving >3 antipsychotic drugs at the same time.

For service users currently prescribed clozapine, whose symptoms are still not in remission, the addition of a second antipsychotic medication to try to augment the effect of clozapine is a recognised strategy and is supported in the NICE guideline. However, this must be accompanied by discussion with the patient, and recording in the case notes, of a rationale for such polypharmacy. There is also evidence that addition of aripiprazole can sometimes be useful in mitigation of weight gain, but again this rationale must be explained and documented.

Figure 20 shows the percentage of service users in each Trust, who are currently prescribed clozapine, for whom there is polypharmacy in relation to the prescribing of antipsychotic medication. Again, the white diamonds indicate where a rationale has been documented.

**Figure 20: Percentage of service users across Trusts prescribed clozapine alone or clozapine with one or two other antipsychotic medications and whether a rationale was documented for those on more than one antipsychotic**



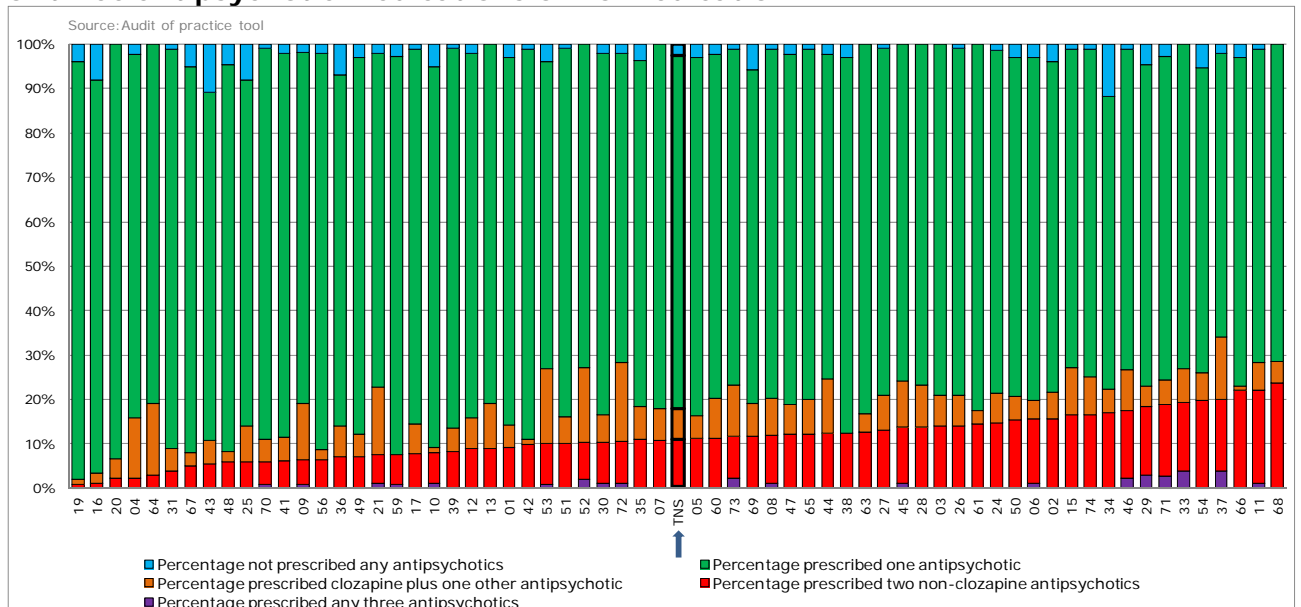
- The data for Figure 20 are taken from Qs 11 and 13 of the audit of practice tool.
- The number of cases included in this analysis is the 1,534 cases on clozapine. Percentages are expressed as a percentage of the total number of cases for each Trust (which make up the 5,608 total cohort) not the number of cases on clozapine.
- No service users were receiving >3 antipsychotic drugs at the same time.

In total, n=399 service users on clozapine were being prescribed one or more non-clozapine antipsychotics concurrently. There is a wide variation across Trusts from 0% to 19% with a TNS average of 7%. In NAS1 the TNS average was 5%. Documentation of a rationale in NAS2 was provided for n=292 (73%) of those cases who were receiving polypharmacy.

Trusts where the use of polypharmacy for service users not on clozapine is high are not necessarily those where it is high for service users on clozapine, and vice versa. The data in Figures 19 and 20 are combined to give Figure 21 which shows the overall level of polypharmacy across Trusts. The recording of a

rationale is not shown here as the situations in which polypharmacy is appropriate are different between those on and not on clozapine.

**Figure 21: Percentage of service users across Trusts prescribed either one, two or three antipsychotic medications or no medication**



- The data for Figure 21 are taken from Q11 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.
- Service users prescribed both an oral and a depot (or LAI) version of the same medication are regarded as being on a single antipsychotic medication.
- No service users were receiving >3 antipsychotic drugs at the same time.



**Table 18: Prescribing by broad groups of, and combinations of, antipsychotic medications: numbers of cases with means and ranges of doses for each group**

Type of prescribing regime	No. of cases	% of total sample	% range across Trusts	Mean of BNF maximum dose prescribed (%)	Range of BNF maximum dose prescribed (%)
<b>No antipsychotic</b>	139	2.5%	0.0 – 11.7%	-	-
<b>Antipsychotic monotherapy</b>					
one oral (not clozapine)	1,900	33.9%	7.0 – 59.8%	57.8%	2.0 – 266.7%
one LAI	1,336	23.8%	7.0 - 38.0%	44.6%	1.0 – 300.0%
clozapine	1,135	20.2%	5.3 – 65.0%	42.3%	2.8 – 100.0%
<b>Antipsychotic polypharmacy, excluding clozapine</b>					
two orals	241	4.3%	0.0 – 11.7%	103.9%	26.3 – 250.0%
one LAI + one oral	428	7.6%	1.1 – 17.7%	93.3%	7.5 – 250.0%
two LAIs	1	<0.1%	0.0 – 1.6%	66.7%	-
three orals	4	0.1%	0.0 – 2.0%	152.4%	82.1 –245.0%
one LAI + two orals	21	0.4%	0.0 – 3.8%	138.9%	36.7 – 283.3%
<b>Antipsychotic polypharmacy, including clozapine</b>					
clozapine + one oral	381	6.8%	0.0 – 17.9%	82.9%	18.3 – 177.8%
clozapine + one LAI	10	0.2%	0.0 – 2.1%	59.0%	16.7 – 117.3%
clozapine + two orals	7	0.1%	0.0 – 2.1%	118.8%	58.1 – 193.3%
clozapine+one LAI+one oral	1	<0.1%	0.0 – 1.2%	131.4%	-
<b>Excluded cases</b>	4	0.1%	-	-	-

- LAI = long-acting injectable or depot antipsychotic medication.
- BNF = British National Formulary.
- Oral = oral antipsychotic medication.
- The data for Table 18 are taken from Q11 of the audit of practice tool.
- The number of cases included in this analysis is 5,608. Percentages are expressed as either a percentage of the total number of cases (3rd column) or of the numbers for each Trust (4th column).
- The doses for the n=4 'excluded cases' (see below) have been excluded from the calculations of dose means and ranges because they were considered to be probable data entry errors. These doses were >400% of the usual BNF maximum dose and were considered to be impossible to have been dispensed. The respective Trusts had not responded to data queries regarding these cases (see Appendix G).
- The 'excluded cases' are: (a) one fluphenazine depot case where the dose was >400% BNF and (b) three cases where the dose of one (in italics) of the two drugs prescribed was >400% BNF – *paliperidone LAI* & aripiprazole oral; *pipotiazine depot* & quetiapine oral; *risperidone oral* & quetiapine XL oral.

Table 18 describes the broad types of combinations of medications employed and the numbers of service users within each group. The majority, n=4,371 (77.9%) were receiving a single antipsychotic drug (antipsychotic monotherapy) and 139 (2.5%) were not receiving any antipsychotic medication. No service user was receiving more than three antipsychotic medications at the same time. The most frequent combinations leading to polypharmacy were a combination of a non-clozapine oral antipsychotic with a long-acting or depot antipsychotic and a combination of an oral antipsychotic with clozapine.

A small number of service users were receiving medications not currently listed in the BNF (Table 37 in Appendix G). None were being prescribed at doses above their individual commonly recognised upper doses but three out of eleven instances were in combination with another antipsychotic medication. These instances of polypharmacy are included in the data provided in Table 18. Where Trusts responded to data queries regarding these unlicensed medications, it was clear that special arrangements had been made to continue individual service users on the medication. However, if it is necessary to continue a service user on a medication no longer licensed in the UK one would assume that it was because of a unique response and therefore that it might be unlikely to require addition of a second antipsychotic medication.

## Standard 9

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The range of doses at which any individual antipsychotic drug may be effective varies widely between individuals. This sometimes relates to individual sensitivity to a particular drug and sometimes to differences in plasma drug concentrations achieved. However, the British National Formulary (BNF) gives clear guidance on the maximum doses that should not be exceeded and evidence strongly suggests that for the majority of service users there is no advantage to exceeding these doses. Where a patient is receiving more than one antipsychotic drug it is convention to calculate the percentage of 'BNF maximum' at which each drug 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, i.e. above 100% BNF maximum. There are occasional situations where a service user with treatment unresponsive illness may be given a trial of a higher than 100% BNF maximum for a period of time. In such situations it is expected that the prescribing clinician will clearly document the reasons for this in the case notes and will have discussed this with the service user.

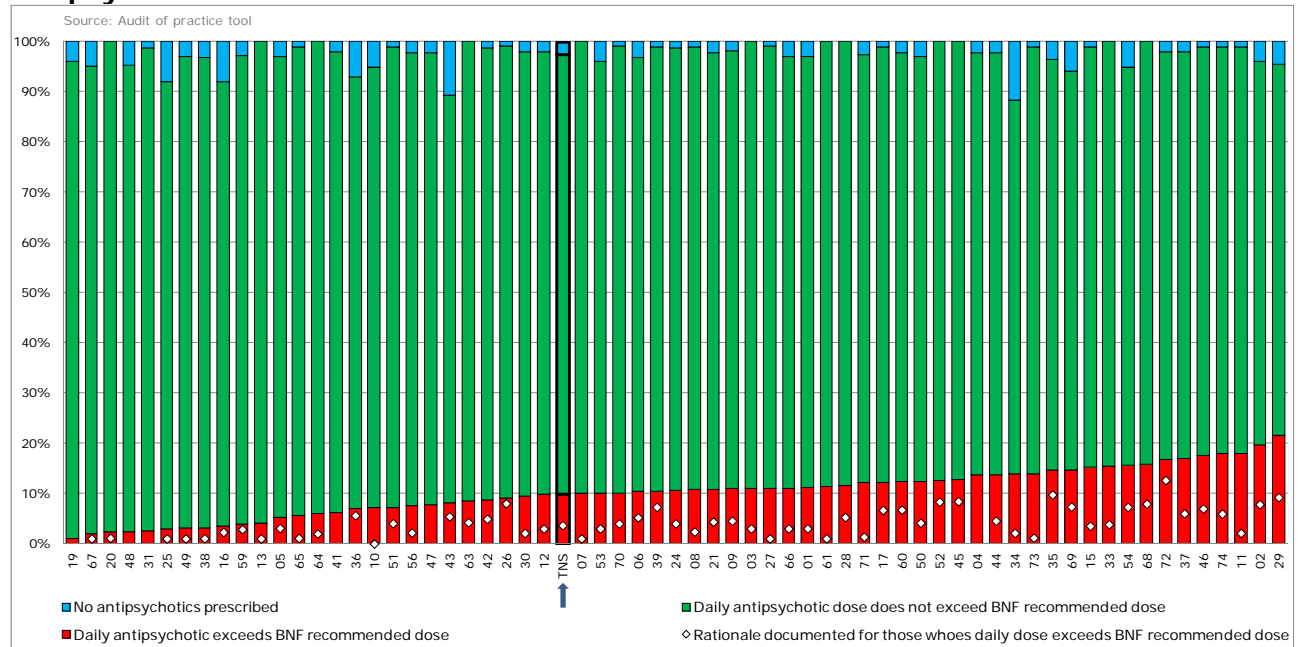
Standard 9 relates to these issues and Figure 22 describes how frequently doses greater than the 100% BNF recommended maximum have been prescribed within each Trust and in what percentage of cases this has been accompanied by documentation of a reason.

**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.**

In total n=555 service users were being prescribed doses of antipsychotic medication at doses above 100% BNF maximum. The range across Trusts is shown in Figure 22 and varies from 1% to 22% of service users with a TNS average of 10% receiving such doses. Documentation of a rationale for this (white diamonds in Figure 22) was provided in n=205 cases, 37% of those who were receiving doses above 100% BNF. In NAS1 the range was 1% to 24% with

a TNS average of 10% and documentation of a rationale in 129 (25%) of those receiving above 100% BNF doses.

**Figure 22: Percentage of service users across Trusts whose total daily dose of antipsychotic medication exceeds the BNF recommended maximum**



- The data for Figure 22 are taken from Qs 11 and 12 of the audit of practice tool.
- The number of cases included in this analysis is 5,604.
- The doses for n=4 cases have been excluded from the calculation because they were >400% BNF and considered to be data entry errors (see notes under Table 18).

From Table 18 (page 87) it can be seen that the use of polypharmacy would appear to be one explanatory factor whereby service users receive higher than usual doses. In those combinations of antipsychotics where three antipsychotics are prescribed, the mean total dose was always more than 100% BNF. All combinations of two antipsychotics resulted in a mean total dose higher than those reported for any groups involving prescription of a single antipsychotic, though only above 100% in one instance ('two non-clozapine oral antipsychotics').

## **Sub-categorisation of service users used in the analyses for standards 10 to 13**

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The next set of standards to be considered, standards 10, 11, 12 and 13, relate to issues concerning service users who have not demonstrated a good response to treatment, i.e. are not in remission. The grouping of individual audit records into those service users in remission or not in remission was done using the information supplied for question 9 in the audit of practice tool, which distinguished four categories of 'current mental health':

- full remission
  - partial remission with minimal symptoms
- } **regarded as in remission**
- 
- partial remission with substantial symptoms
  - not in remission
- } **regarded as not in remission**

(These categories were also used in NAS1 in which they were validated by HoNOS scores.)

Service users *in remission* and *not in remission* are first categorised by whether or not they were currently being prescribed clozapine (Table 19).

Those *not in remission* and *not on clozapine* (**Group a**) are then further categorised according to whether they were currently being prescribed their first antipsychotic medication or not (Table 20).

The group who are *in remission* and *not on clozapine* (n=3,063 in Table 19) are not considered further here as they have a reasonable response to standard, non-clozapine antipsychotic medications.

**Table 19: Service users in remission and not in remission categorised by whether or not they are currently prescribed clozapine**

	<b>Not on clozapine n (%)</b>	<b>On clozapine n (%)</b>
<b>In remission</b>	3,063 (54.6%)	1,166 (20.8%)
<b>Not in remission</b>	1,011 (18.0%) <b>(Group a)</b>	368 (6.6%) <b>(Group b)</b>

- These numbers are derived from Q9 of the audit of practice tool.
- The numbers in the table relate to 5,608 cases.

**Table 20: Service users who are not in remission and not on clozapine categorised by whether or not the current antipsychotic prescribed is their first antipsychotic medication**

<b>On first antipsychotic medication</b>	<b>Not in remission and not on clozapine n (% of 1,011 cases; Group a)</b>
<b>Yes (Group c)</b>	85 (8.4%)
<b>No (Group d)</b>	856 (84.7%)

- The data for Table 20 are taken from Q21 of the audit of practice tool.
- The total number of cases included are the n=1,011 (Group a) from Table 19. Percentages are expressed as a percentage of these 1,011 cases.
- Data was not entered by the Trust for Q21 in 70 cases (6.9% of the 1,011 in Group a).

## Standard 10

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The first issue to be considered is whether or not those service users *not in remission* had the issues of adherence to medication and misuse of alcohol or other substances considered in relation to their poor response to treatment. These factors are often important in poor response to treatment.

There are three main groups of cases for whom this is relevant:

**Group (c):** Those not in remission and still on their first antipsychotic medication (n=85).

**Group (d):** Those not in remission who have had more than one antipsychotic but are not on clozapine (n=856).

**Group (b):** Those on clozapine who are not in remission (n=368).

**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 were investigated and documented.**

Standard 10 applies specifically to Group (c). However, while not explicitly part of standard 10, it is also important to record whether service users in groups (d) and (b) have been assessed regarding treatment adherence and alcohol and substance abuse.

Table 21 shows that evidence of attention to these factors is well below 100%. While there are variations between each of the three categories of treatment group all are below what is expected.

Numbers are too small in the individual groups to derive meaningful bar charts comparing the 64 Trusts with each other. The individual Trust reports, to be made available by late October 2014, will provide each Trust with their own figures in comparison to the national figures for this standard.

**Table 21: Percentages of service users, not in remission, in whom poor treatment adherence or alcohol/substance misuse have been investigated as potential causes for poor response**

Treatment Group	Medication adherence has been investigated n (% of total cases in the relevant Group)	Alcohol and substance misuse have been investigated n (% of total cases in the relevant Group)
<b>Group (c):</b> Not in remission, on first antipsychotic (n=85)	52 (61.2%)	43 (50.6%) (i)
<b>Group (d):</b> Not in remission, not on first antipsychotic, not on clozapine (n=856)	580 (67.8%) (ii)	545 (63.7%) (iii)
<b>Group (b):</b> Not in remission, on clozapine (n=368)	267 (72.6%) (iv)	207 (56.3%) (v)

- For Group (c): Analysis in Table 21 is derived from Qs 9 and 21 of the audit of practice tool and then the responses to Qs 24 and 25.
- For Group (d): Analysis in Table 21 is derived from Qs 9 and 21 of the audit of practice tool and then the responses to Qs 24 and 25.
- For Group (b): Analysis in Table 21 is derived from Q9 of the audit of practice tool and then the responses to Qs 28 and 29.
  - i. There are 2 cases for whom a response was not provided to Q25.
  - ii. There are 21 cases for whom a response was not provided to Q24.
  - iii. There are 8 cases for whom a response was not provided to Q25.
  - iv. There are 22 cases for whom a response was not provided to Q28.
  - v. There are 27 cases for whom a response was not provided to Q29.

Within Group (d) there are service users for whom poor treatment adherence has apparently not been investigated. The number of these is n=255 (856 cases, *minus* 21 cases for whom there was no response to question 24, *minus* 580 for whom a positive response was provided). Of these 255 cases, n=145 (56.9%) were being prescribed a depot or LAI medication, quite probably in an attempt to overcome poor adherence. (If these were assumed to be equivalent to '*medication adherence has been investigated*', then for Group (d) in Table 21 the percentage with this investigated would become 84.7%.)

In NAS1, Groups (c) and (d) were combined for this analysis. Using comparable analyses, Table 22 shows the comparison between NAS2 and NAS1. In NAS2



there is a reduction in the percentages for whom these factors have been investigated.

**Table 22: Comparison of NAS2 and NAS1 percentages of service users in whom poor treatment adherence or alcohol/substance misuse have been investigated as potential causes for poor response**

Treatment Group	Medication adherence has been investigated		Alcohol and substance misuse have been investigated	
	NAS2	NAS1	NAS2	NAS1
Not in remission, <u>not</u> on clozapine	67%	86%	62%	78%
Not in remission, on clozapine	73%	88%	56%	81%

## Standard 11

If a service user does not have a reasonable clinical response to a particular antipsychotic medication after eight weeks the evidence is that that particular medication is unlikely to be effective for that person and that it should be changed to an alternative. This is particularly so in the early stages of illness but also relevant for later stages. Standard 11 relates to this issue.

**Standard 11: If there was no or inadequate response to the first antipsychotic drug within 8 weeks, part of which was at optimum dose, the first antipsychotic drug was stopped and a second antipsychotic drug given.**

Standard 11 relates specifically to Group (c) in Table 20 (page 92), i.e. those service users not in remission but still on their first antipsychotic medication. Though not explicitly part of standard 11, it is also important to record whether service users in Group (d), those not in remission but on at least their second antipsychotic (and not on clozapine), are remaining on this subsequent medication for longer than 8 weeks without adequate clinical response.

**Table 23: Service users not in remission and not prescribed clozapine, and the length of time they have been on their current antipsychotic medication**

<b>Length of time on current antipsychotic medication</b>	<b>Service users on their first antipsychotic. Group (c) n (% of the 85 cases)</b>	<b>Service users <u>not</u> on their first antipsychotic. Group (d) n (% of the 856 cases)</b>
<b>8 weeks or less</b>	4 (4.7%)	69 (8.1%)
<b>Between 8 weeks to 6 months</b>	1 (1.2%)	101 (11.8%)
<b>More than 6 months</b>	79 (92.9%)	674 (78.7%)

- The data for Table 23 are taken from Qs 21 and 23 of the audit of practice tool.
- The cases included here are the 1,011 not in remission and not on clozapine (Table 19). These are then further categorised into those on their first antipsychotic (Group c) and others who have had more than one antipsychotic medication (Group d) (Table 20).
- Data not entered by the Trust for Q23 in 13 cases (Group c: 1 case; Group d: 12 cases).

It can be seen from Table 23 that a significant proportion of service users who are not responding to their medication, and are not currently on clozapine, (n=79+674=753) are remaining on medication that appears to be ineffective for periods exceeding six months (13.4% of the total audit sample). This is one of the most clinically significant findings in this audit in relation to prescribing practice. It is worth reiterating here that all service users in the audit have been in contact with the relevant Trust for at least 12 months giving adequate time to institute treatment changes.

Comparisons with the findings in NAS1 are not possible as the details of this standard were amended for NAS2.

## Standard 12

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Standard 12 relates to the pathway followed for those service users who have not responded to standard antipsychotic medications and who then require to be considered for treatment with clozapine. The NICE guideline (NICE CG82, 2009) recommends that clozapine should be considered following two unsuccessful trials of other antipsychotic medications.

In total n=1,534 (27.4%) service users were receiving clozapine. Here 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). Service users being supported solely in primary care are unlikely to be receiving clozapine because of the requirements relating to initiation of treatment and subsequent monitoring, every four weeks. Thus, it is probably reasonable to suggest that in the region of 20% of all service users in the community (primary and secondary care) may be receiving clozapine.

**Standard 12: If there was no or inadequate response to two antipsychotic drugs, one of which should be a second generation antipsychotic at optimum dose, clozapine was offered.**

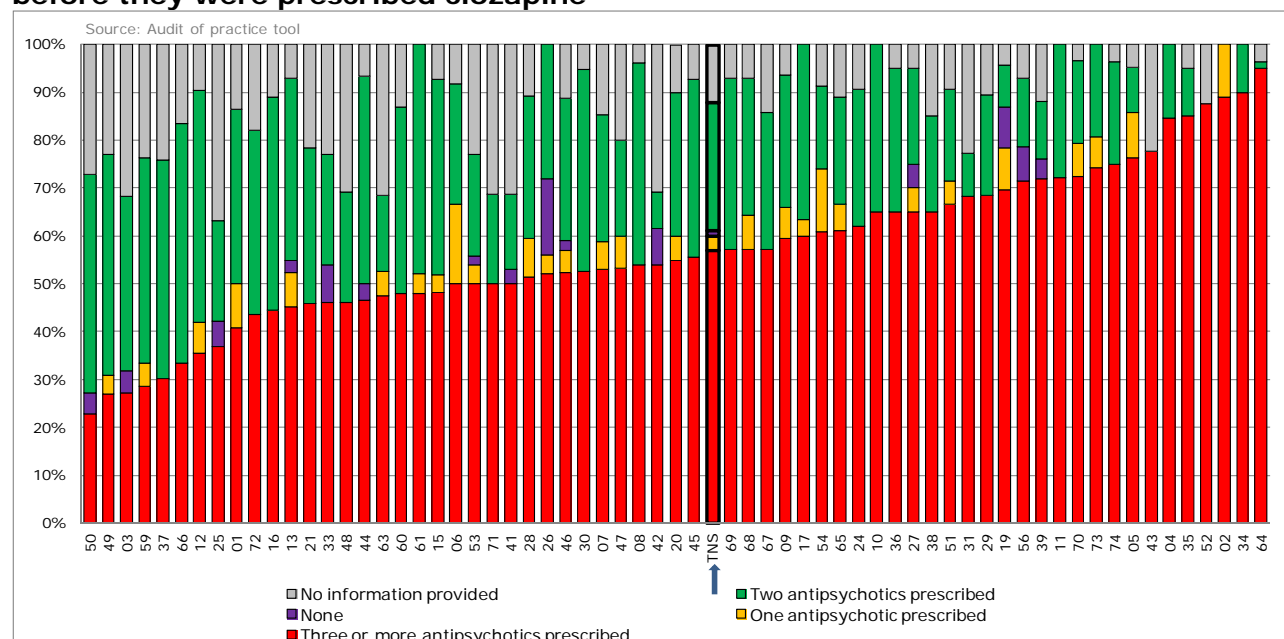
Figure 23 shows how many previous antipsychotics were received by those service users currently receiving clozapine. Figure 24 then shows the percentages of service users on clozapine who are not in remission (Group b, Table 19) who have not had a trial of a second generation antipsychotic before commencing clozapine.

Overall, n=874 (57%) of service users currently prescribed clozapine have received three or more antipsychotic medications prior to clozapine, with considerable variation across Trusts from 23% to 95% (Figure 23). Only n=410 (27%) appear to have followed the recommended pathway and received only two other antipsychotic medications before commencing clozapine.

A small number of service users (n=19) appear to have received no previous antipsychotics, or only one, prior to commencing clozapine. The reasons for this

are not clear but in 14 of these cases the service user had been ill for more than 10 years, so this may represent a lack of adequate, or adequately accessible, information in the person's current case records. (For example, inpatient and community records are not always combined.) Nevertheless, adequate and accessible recording of such information is vital for appropriate long-term planning of care. There are also a significant number of cases for whom question 16 was not answered.

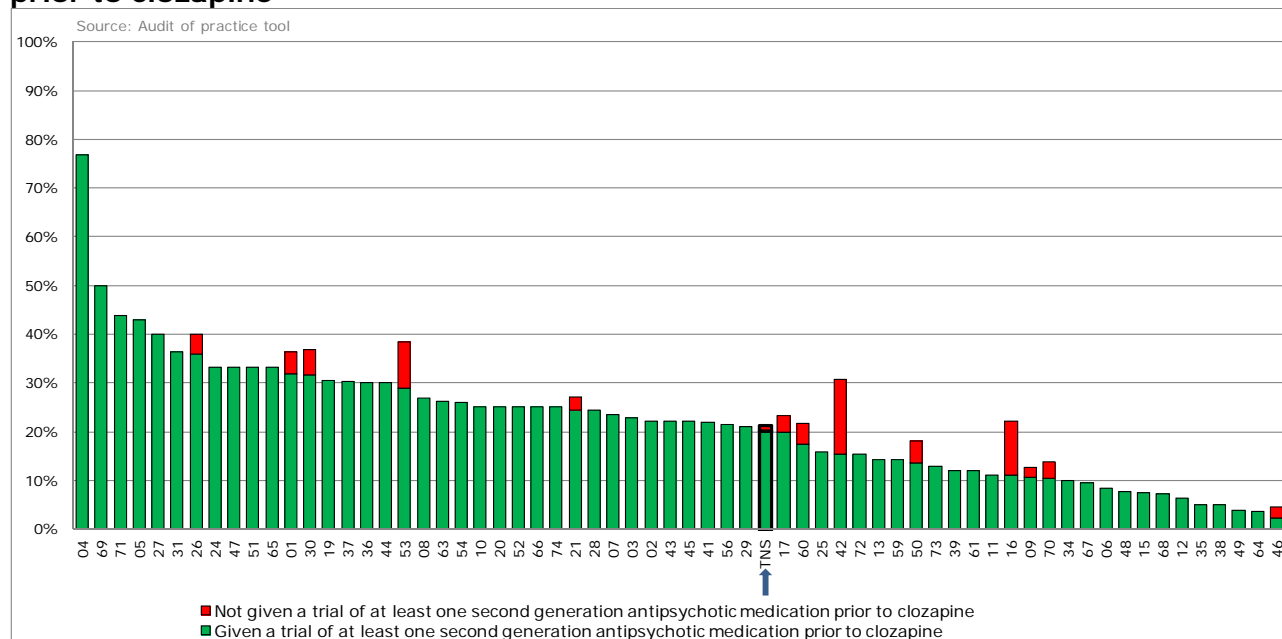
**Figure 23: Number of antipsychotic medications patients were prescribed before they were prescribed clozapine**



- The data for Figure 23 are taken from Qs 11 and 16 of the audit of practice tool.
- The number of cases included in this analysis is the 1,534 cases on clozapine (Table 19). Percentages are expressed as a percentage of the number of cases on clozapine.
- No information was provided for Q16 in 185 cases.

The NICE guideline advises that service users should have a trial of at least one second generation antipsychotic medication before commencing clozapine. It is of note that the pathway for n=18 (5%) of those who are receiving clozapine and are not in remission (Group b, n=368) has not included a second generation medication, but that this has only occurred in 14 Trusts (Figure 24).

**Figure 24: Percentage of service users, not in remission, showing proportion not given a trial of at least one second generation antipsychotic medication prior to clozapine**



- The data for Figure 24 are taken from Qs 9, 11 & 26 of the audit of practice tool.
- The number of cases included in this analysis is the 368 cases on clozapine who are not in remission (Group b, Table 19). Percentages are expressed as a percentage of the total 1,534 cases on clozapine. (Thus this can be seen as a sub-set of Figure 23.)
- No information was provided for Q26 in 39 cases.

(Data relating to use of a second generation medication prior to clozapine was not collected for those on clozapine and in remission.)

It is also relevant to standard 12 to examine the treatment history of those n=1,011 service users not in remission and not on clozapine – Group (a) from Table 19 (page 92). Table 24 describes aspects of the medication history for all 1,011 cases not in remission and not on clozapine. Some of these cases are either on their first or second antipsychotic and thus not yet eligible for consideration for clozapine and for some the relevant data has not been provided (see notes below Table). However, n=706 cases (69% of those not in remission) have had treatment with three or more antipsychotic medications and are not currently on clozapine.

**Table 24: Treatment history for those service users who are not in remission and not currently on clozapine**

Number of antipsychotics prescribed sequentially over the course of the service user's illness	n (% of 1,011 cases)
<b>Service users not yet eligible for clozapine</b>	
None*	2 (0.2%)
On 1 <sup>st</sup> antipsychotic	85 (8.4%)
On 2 <sup>nd</sup> antipsychotic	125 (12.4%)
<b>Service users who could be considered eligible for clozapine</b>	
On 3 <sup>rd</sup> antipsychotic	194 (19.2%)
On 4 <sup>th</sup> or greater antipsychotic	512 (50.6%)

- The data for Table 24 are taken from Qs 9, 21 & 22 of the audit of practice tool.
- This Table describes information for the 1,011 cases in Group (a), Table 19.
- Q21 was not answered for 70 (6.9%) cases and Q22 was not answered for 23 (2.3%) cases.
- Percentages in the Table are, however, calculated against the total 1,011 cases.
- \* Two cases were not currently on any medication and had no recent medication history.

Table 25 provides a more detailed examination of the reasons why those service users who are on standard, non-clozapine antipsychotic medications and are not in remission (i.e. have not responded or have an inadequate clinical response) are not receiving clozapine. The audit of practice tool provided a list of reasons (largely derived from experience in NAS1) that could be marked and a section for 'none of the above' where Trusts could note reasons we had not initially allowed for. During the data cleaning process, three new categories were created for some cases reported in the 'none of the above' category: 'short term relapse'; 'poor compliance expected'; and 'abuse of alcohol and/or other substances'. These now appear in Table 25 as well as all the original categories of reasons.

The percentage of cases for whom either a '*not usually appropriate*' reason is provided or '*none of the above*' is the response is 28%, which is less than the 40% in NAS1. While the number of cases who are not receiving clozapine due to Trust related issues is small, nevertheless it is important to recognise that provision of appropriate facilities and staff for the initiation of clozapine is essential.

**Table 25: Reasons provided for failure to prescribe clozapine for service users who are not in remission**

Reason	Number of cases	Percentage of cases (n=1,011)
<b>Reasons that may be considered as appropriate</b>		
Clozapine offered but the service user refused	339	34%
Clozapine contraindicated for the service user	145	14%
Not yet had an adequate trial of two other antipsychotics	126	13%
Clozapine tried, service user did not respond adequately or had undue adverse effects	86	9%
Ongoing depression and anxiety but not psychotic symptoms	42	4%
Short term relapse	12	1%
<b>Reasons that are <u>not</u> usually considered as appropriate</b>		
Poor compliance expected	117	12%
Lack of facility for community initiation	12	1%
Abuse of alcohol and/or other substances	9	1%
Waiting for an inpatient bed	4	0.4%
Trust restrictions on use of clozapine	2	0.2%
<b>"None of the above"</b>	132	13%

- The data for Table 25 are taken from Q20 of the audit of practice tool.
- The cases included here are the 1,011 not in remission and not on clozapine previously described in Table 19.
- More than one reason was allowed to be selected for Q20 so numbers may add up to more than 1,011. The percentages have been calculated using 1,011 cases as denominator to show what percentage of cases used each reason.
- No answer was provided for Q20 in 46 cases.

The most common, potentially inappropriate reason for not commencing clozapine was 'poor compliance expected'. While poor compliance can clearly be a problem in trying to establish someone on clozapine it can also be the case that if clozapine improves the individual's mental state this may then result in improved adherence with treatment. Clinicians must give careful consideration to the clinical situation of service users where compliance may be a problem. The data provided to the audit suggest it is being used too commonly as a reason to justify not commencing a trial of clozapine.



Abuse of alcohol and/or other substances is another clinical reason given for not commencing clozapine. While the numbers were small, again consideration needs to be given as to whether clozapine may help to reduce these problems and whether a trial of treatment should be attempted. The other reasons provided under 'none of the above' were quite heterogeneous and could not be re-coded into any meaningful categories.

## Standard 13

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Not all treatment unresponsive service users will have a good response to clozapine. There is no clear guideline regarding how best to manage this situation. One approach, suggested in the NICE guideline (NICE CG82, 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. Table 26 shows the percentages of service users on clozapine who have been commenced on a second antipsychotic medication and some of the types of combinations employed.

**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 8 weeks at optimum dose.**

The most commonly prescribed antipsychotic medications in augmentation strategies are aripiprazole and amisulpride. Aripiprazole is often prescribed together with clozapine as a strategy to reduce clozapine induced weight gain but is also considered by some clinicians for augmentation of treatment response. For those service users receiving additional antipsychotics other than aripiprazole the aim is almost invariably augmentation of treatment response.

Excluding those service users receiving augmentation with aripiprazole, n=100 (27.2%) of those individuals on clozapine and not in remission were receiving augmentation to attempt to improve response and n=186 (16.0%) of those on clozapine and in remission. Thus, this strategy is clearly being employed. Numbers are too small to derive a meaningful chart comparing the 64 Trusts with each other.

Overall, 26% of service users on clozapine in NAS2 were in receipt of some form of augmentation strategy (including aripiprazole) which is slightly greater than the 22% in NAS1.

**Table 26: Additional antipsychotic medications prescribed to service users together with clozapine**

Details of antipsychotic medications	Service users on clozapine <u>not</u> in remission n (% of 368)	Service users on clozapine and in remission n (% of 1,166)
<b>Clozapine monotherapy</b>	225 (61%)	910 (78%)
<b>Clozapine augmentation with other antipsychotic(s)</b>		
+ oral aripiprazole	43 (12%)	70 (6%)
+ oral amisulpride	51 (14%)	110 (9%)
+ one other oral	41 (11%)	66 (6%)
+ two other orals (i)	4 (1%)	3 (0.3%)
+ one LAI	3 (1%)	7 (1%)
+ one oral + one LAI (ii)	1 (0.3%)	-

- LAI = long-acting injectable or depot antipsychotic medication
- Oral = oral antipsychotic medication
- The data for Table 26 are taken from Qs 9, 11 and 27 of the audit of practice tool.
- The two groups of cases are as described in Table 19.
- (i) Prescribing for these 7 patients entailed: clozapine+amisulpride+aripiprazole (n=2); clozapine+amisulpride+haloperidol (n=2); clozapine+amisulpride+quetiapine; clozapine+haloperidol+sulpride; clozapine+chlorpromazine+sulpride
- (ii) This patient was prescribed: clozapine+aripiprazole+depot zuclopentixol

## Key comparisons between NAS2 and NAS1 for prescribing practice

Table 27 shows a summary of key comparisons between the findings in this second round of the audit (NAS2) versus the findings in the baseline audit (NAS1). These are shown as percentages, which relate to the appropriate groups and sub-groups of service users used for each section of the analysis. Thus, these percentages do not automatically apply to the whole population included within the audit. Some of the percentages shown for NAS1 may differ slightly from those in the original report as the method of calculation differs slightly for some indicators between the audits and some have been recalculated to allow for this.

**Table 27: Key comparisons between NAS2 and NAS1 for prescribing practice**

<b>Standard / Indicator</b>	<b>NAS2 (%)</b>	<b>NAS1 (%)</b>
<b>Standard 8 – antipsychotic monotherapy</b>		
Frequency of polypharmacy	11%	11%
Range across Trusts	1-24%	3-30%
<b>Standard 9 – dose within BNF maximum</b>		
Frequency of high dose (>100% BNF)	10%	10%
Range across Trusts	1-22%	1-24%
Rationale documented for high dose	37%	25%
<b>Standard 10 – investigation of alcohol and substance misuse in those with poor symptom response</b>		
Frequency in cases not on clozapine	62%	78%
Frequency in cases on clozapine	56%	81%
<b>Standard 11 – medication changed if poor response</b>		
Direct comparison not possible as standard was amended		
<b>Standard 12 – pathway to clozapine</b>		
Service users not in remission and not on clozapine <u>without</u> a reason normally considered as appropriate	28%	40%
<b>Standard 13 – augmentation of clozapine</b>		
Frequency of use of an augmentation strategy in service users on clozapine	26%	22%

## 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. The NICE Guideline (NICE CG82, 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. (Note: sometimes family intervention is referred to by certain staff as family therapy. Strictly speaking, family therapy is a specific type of family intervention, but not everyone uses these terms in a precise way.)

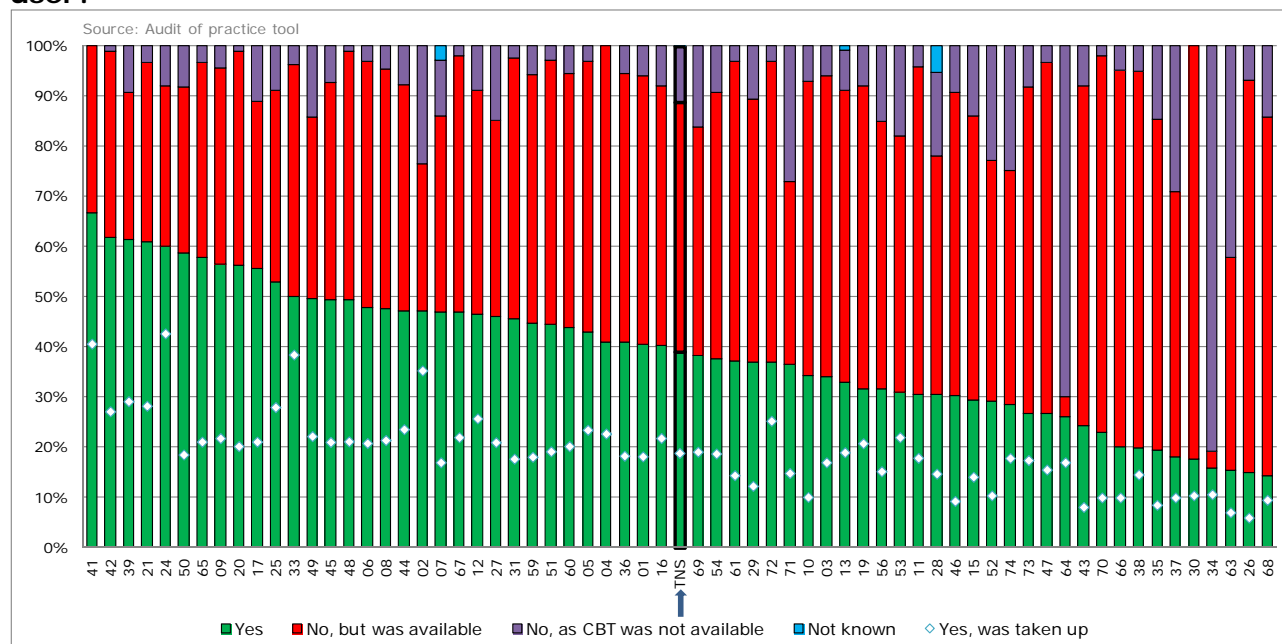
It is important to note that when referring to these therapies, and in particular CBT, the data collected for NAS relate to all forms of CBT and family interventions as recognised by staff in Trusts (see questions 42 and 43 in the audit of practice tool). This is in line with the recommendations made by NICE (2009; 2014). Thus, the standards of service provision reflected in NAS may not fully match what is envisaged by the Improving Access to Psychological Therapies (IAPT) programme (see [www.iapt.nhs.uk](http://www.iapt.nhs.uk) for details). The National Audit of Psychological Therapies (NAPT; Royal College of Psychiatrists, 2013) addresses therapies for people with anxiety and depression and does not address psychological therapies for psychosis.

**Standard 14:**

**a. CBT has been offered to all service users.**

Figure 25 shows data from the case record audit of practice tool, across all of the Trusts, regarding whether CBT had ever been offered to service users and whether it was taken up (indicated by white diamonds).

**Figure 25: Has cognitive behavioural therapy ever been offered to the service user?**

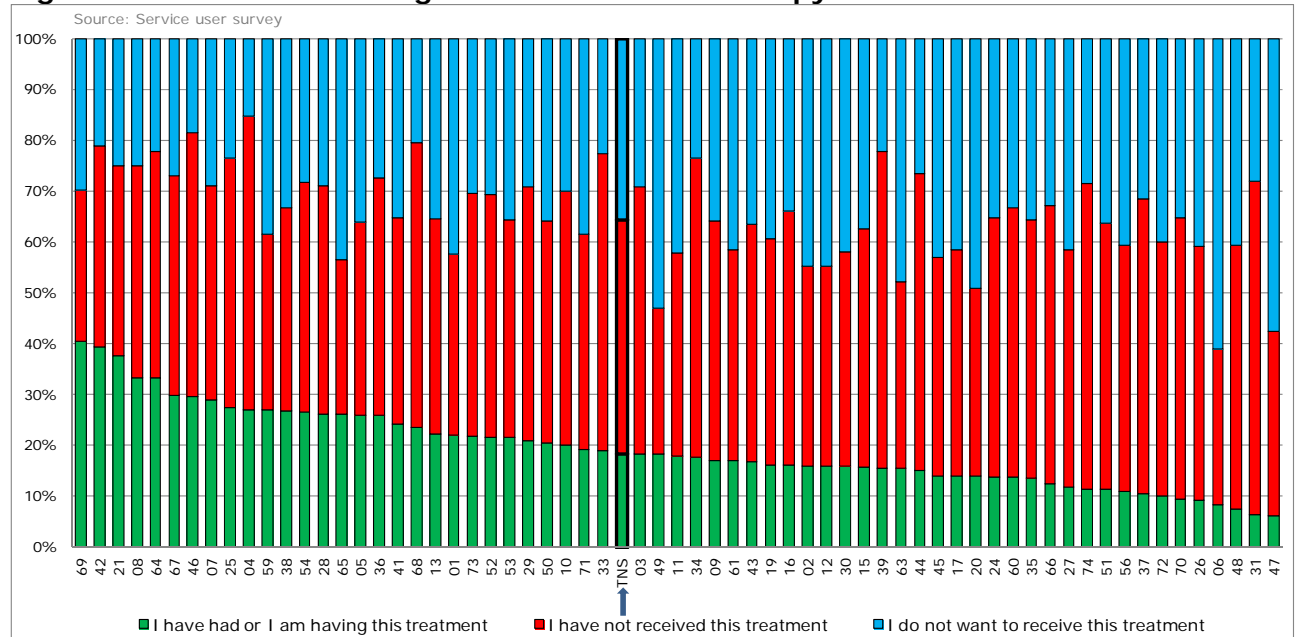


- The data for Figure 25 are taken from Q42 and Q44 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.
- There were no cases where Q42 was not answered and 102 cases where Q44 was not answered.

CBT was offered to 39% of service users, with a range of 14% to 67% across Trusts. Of those offered CBT (n=2,187), 48% had taken it up, i.e. 19% of all service users. However, 50% of service users did not have CBT offered to them, even though it was reported to have been available in the Trust.

In the new service user survey form devised for NAS2, service users were asked to indicate whether they had received or were having CBT, had not received such therapy or did not want to receive it. The responses are shown in Figure 26.

**Figure 26: In relation to cognitive behavioural therapy:**



- The data for Figure 26 are taken from Q24 of the service user survey.
- 91% of service users answered this question.

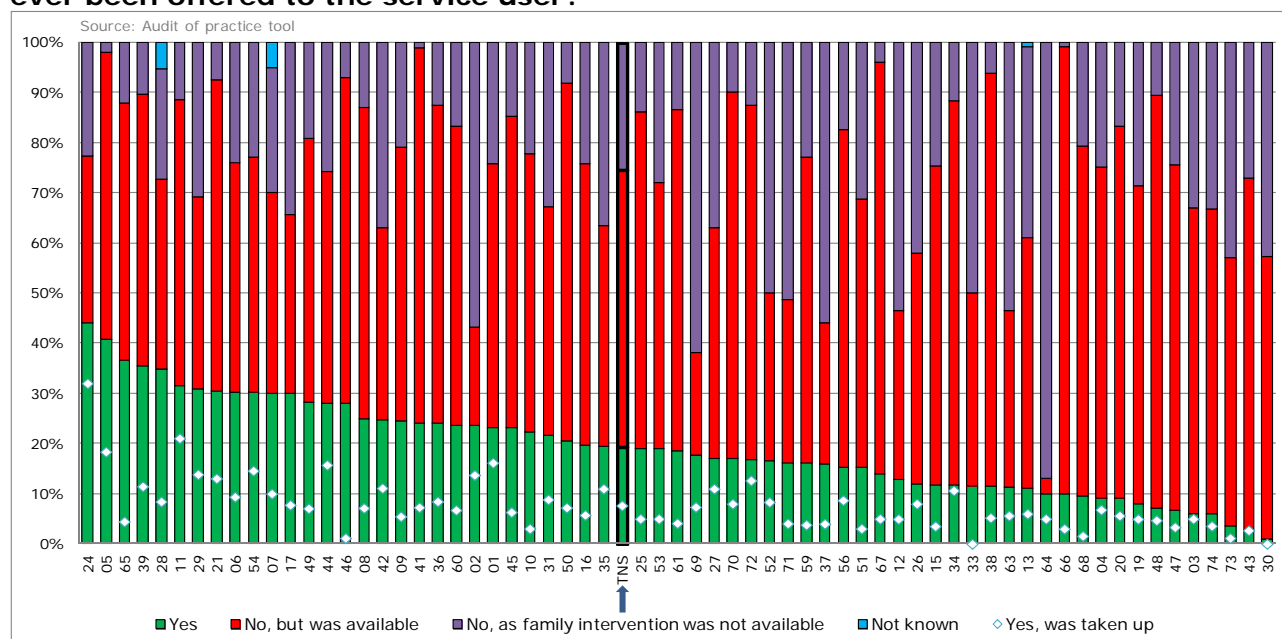
The percentage of service users reporting that they had received or were receiving CBT (18%) was very similar to the percentage reported by Trusts to have taken up CBT (19%). The percentage of service users reporting that they had not received CBT and had not indicated that they did not want to receive such was 46%, which is again similar to the 50% Trusts said had not been offered CBT.

**Standard 14:**

**b. Family intervention has been offered to all service users who are in close contact with their families.**

Figure 27 shows data from the case record audit of practice tool, across all of the Trusts, regarding whether any form of family intervention had been offered to service users and whether it was taken up (white diamonds).

**Figure 27: Has family intervention (where patient is in contact with the family) ever been offered to the service user?**



- The data for Figure 27 are taken from Q43 and Q44 of the audit of practice tool.
- The number of service users' responses included in this analysis is 5,608.
- There were no cases where Q43 was not answered and 121 cases where Q44 was not answered.

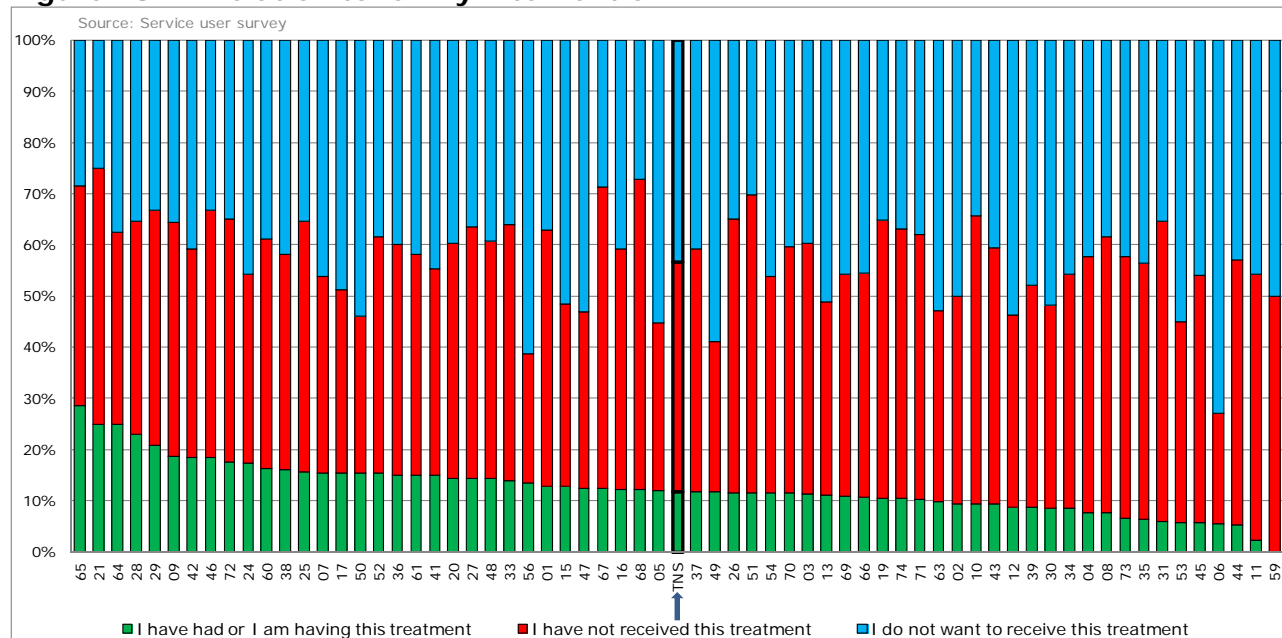
Family interventions were offered to 19% of service users, with a range of 1% to 44% across Trusts. Of those offered a family intervention (n=1,088), 39% had taken it up, i.e. 8% of all service users. However, 55% of service users did not have a family intervention offered to them, even though such support was reportedly available in the Trust.

In the NAS2 service user survey form, service users were asked to indicate whether they had received or were currently receiving a family intervention, had



not received such intervention or did not want it. The responses are shown in Figure 28.

**Figure 28: In relation to family intervention:**



- The data for Figure 28 are taken from Q25 of the service user survey.
- 91% of service users answered this question.

The percentage of service users reporting that they had received or were receiving a family intervention (12%) was rather more than the percentage reported by Trusts to have taken up family intervention (8%). The percentage of service users reporting that they had not received family intervention, where they had not indicated that they did not want to receive such, was 45%, again somewhat similar to the 55% Trusts said had not been offered family intervention.

Table 28 compares the findings from NAS2 with those from the baseline audit. Please note, in NAS1, standard 14 was written differently and asked whether CBT and/or family intervention had been offered to service users whose illness was resistant to treatment with antipsychotic drugs, i.e. those not in remission. In NAS2, standard 14 referred to all service users. (Thus, the data in Figures 25 to 28 refer to the NAS2 standard.) However, for Table 28 we have analysed the comparable subgroup data in the NAS2 database that allows comparison with the NAS1 findings.

**Table 28: Key comparisons between NAS2 and NAS1 for psychological therapies**

<b>Standard / Indicator</b>	<b>NAS2 (%)</b>	<b>NAS1 (%)</b>
<b>Standard 14a – CBT offered</b>		
Those not in remission offered CBT	45%	29%
<b>Standard 14b – Family intervention offered</b>		
Those not in remission offered family intervention	23%	10%

## Physical health: monitoring and intervention

Evidence shows that people with a diagnosis of schizophrenia have poor physical health, suffer from increased rates of cardiovascular disease and type 2 diabetes and, as a consequence, suffer from premature mortality (Phelan et al., 2001; Saha et al., 2007). A considerable proportion of the risk for these disorders is due to antipsychotic medication-induced weight gain. NAS1 revealed serious inadequacies in the identification and management of risk factors for these disorders. Alcohol and substance misuse present additional problems. Standards 4 and 5 for this audit reflect the main NICE recommendations regarding monitoring of risk factors and instigation of appropriate interventions to reduce these risks.

The results will be described in four main sections:

- ***Monitoring of physical health:***
  - a) How comprehensive is monitoring of cardiometabolic health? (What proportions of service users have had monitoring of some or all of **six important risk factors**: family history, smoking history, BMI, blood glucose control, blood lipids and blood pressure.)
  - b) Monitoring of the individual risk factors.
  - c) Monitoring of those with co-existing cardiovascular disease, diabetes or a high BMI (i.e. those who have already developed poor health).
- ***Intervention to address physical health problems.***
- ***Monitoring and intervention in relation to alcohol and substance misuse.***
- ***Key comparisons between NAS2 and NAS1.***

Where appropriate, comparison will be made with the results from NAS1. Please also note that in this second round of the audit the service user survey was modified. It now consists of more questions and thus provides more detailed feedback from service users regarding their experience of the monitoring of their physical health. Where appropriate, the results present comparisons between Trusts' recording of monitoring and service users' reporting of this.

## **Monitoring of physical health**

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The NICE guideline (NICE CG82, 2009) recommends that monitoring of various physical health parameters in service users with schizophrenia should be carried out regularly, with sharing of results between primary care and secondary care teams, and with a focus on cardiovascular disease risk assessment. Various aspects of standard 4 relate to this and are summarised in standard 4a below.

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

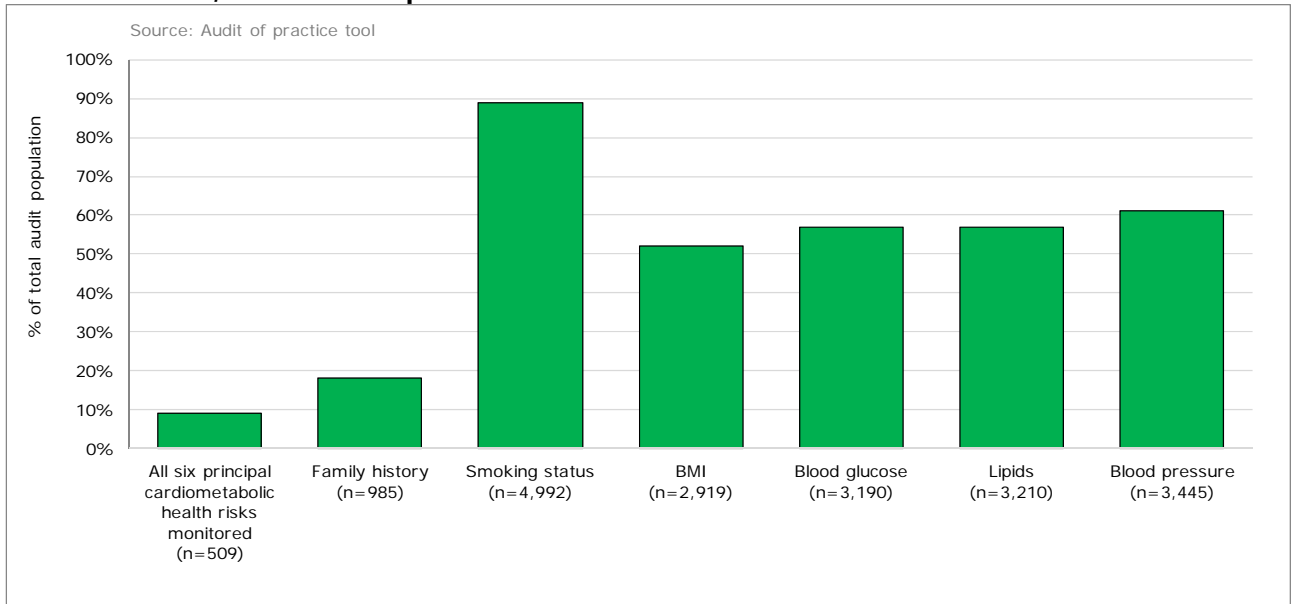
- i. History of cardiovascular disease, diabetes, hypertension or dyslipidaemia in members of the service user's family.**
- ii. Use of tobacco.**
- iii. Body mass index (BMI), or waist circumference (see Appendix G).**
- iv. Blood glucose control (blood glucose and/or HbA<sub>1c</sub>)**  
**(Please see Note on page 125 about measures used for glucose control).**
- v. Blood lipids (total cholesterol and HDL).**
- vi. Blood pressure.**

### **How comprehensive is monitoring of cardiometabolic health?**

This section provides an overall view, for the whole population audited, of how comprehensive an assessment of the main cardiometabolic risk factors service users received. This was judged on whether a comprehensive assessment of the six factors from standard 4 (above) had been carried out within the previous 12 months. The audit did not attempt to determine whether this assessment was made in primary or secondary care, simply that results of these assessments could be found in the Trust case records.

The bars in Figure 29 show the overall percentage of service users who have had each individual risk factor monitored alongside the bar for those who had combined monitoring of all six of these. Figure 30 then shows the percentages of service users who have had various possible combinations of risk factors monitored. The proportion having a full screening, i.e. of all six risk factors, is low (9%), due particularly to poor recording of details of family history of relevant risk factors.

**Figure 29: Percentage of service users who had monitoring of each of the six individual cardiometabolic health risk factors and the percentage who had all six monitored, once in the past 12 months**



- The data for Figures 29 and 30 are taken from Qs 31, 34, 36, 37, 38, 39 of the audit of practice tool.
- The number of cases included in the analyses in Figures 29 and 30 is 5,608. In Figure 29, the numbers who had been monitored for each factor are shown in brackets under each bar.
- The 'bar' for blood glucose includes measurement of blood glucose and/or HbA<sub>1c</sub>.

**Figure 30: Percentage of service users with different proportions of cardiometabolic health risk factors monitored once in the past 12 months**

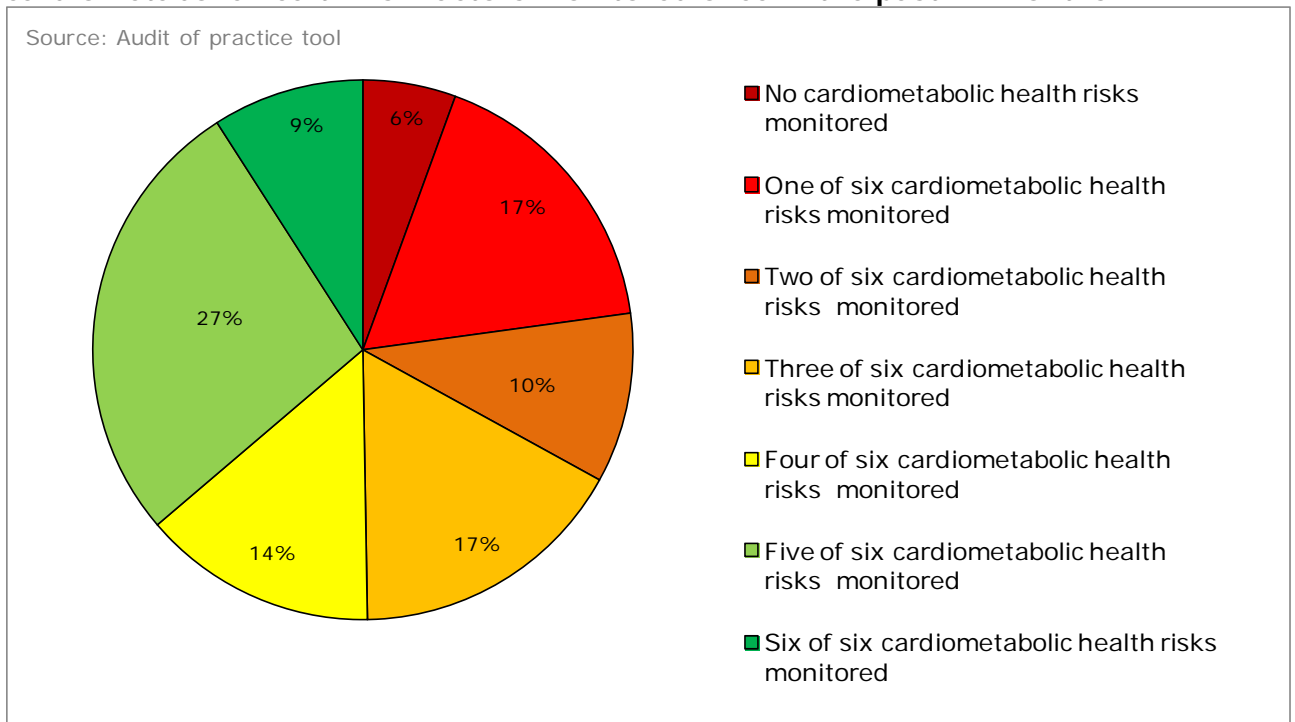


Table 29 provides a comparison between NAS2 and NAS1 showing the percentages of service users in each round of the audit who have had each factor monitored.

**Table 29: Percentages of service users who had monitoring of each of the six individual cardiometabolic health risk factors once in the past 12 months: comparison between NAS2 and NAS1**

Risk factor	% of service users in NAS2	% of service users in NAS1
Relevant family history	18%	44%
Smoking status	89%	88%
BMI	52%	51%
Blood glucose control (glucose and/or HbA <sub>1c</sub> )	57%	50%
Blood lipids	57%	47%
Blood pressure	61%	56%

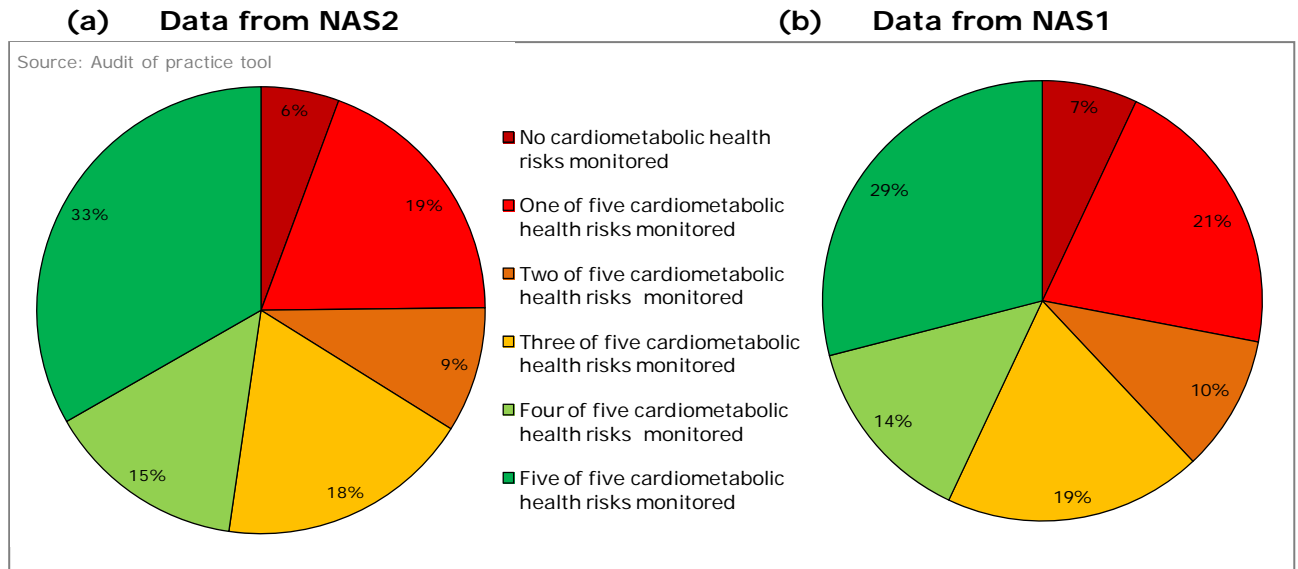
➤ The data for Table 29 is taken from Qs 31, 34, 36, 37, 38, 39 of the audit of practice tool and from the equivalent data in NAS1.

There is little change between the two audits, except for family history, the recording of which is low.

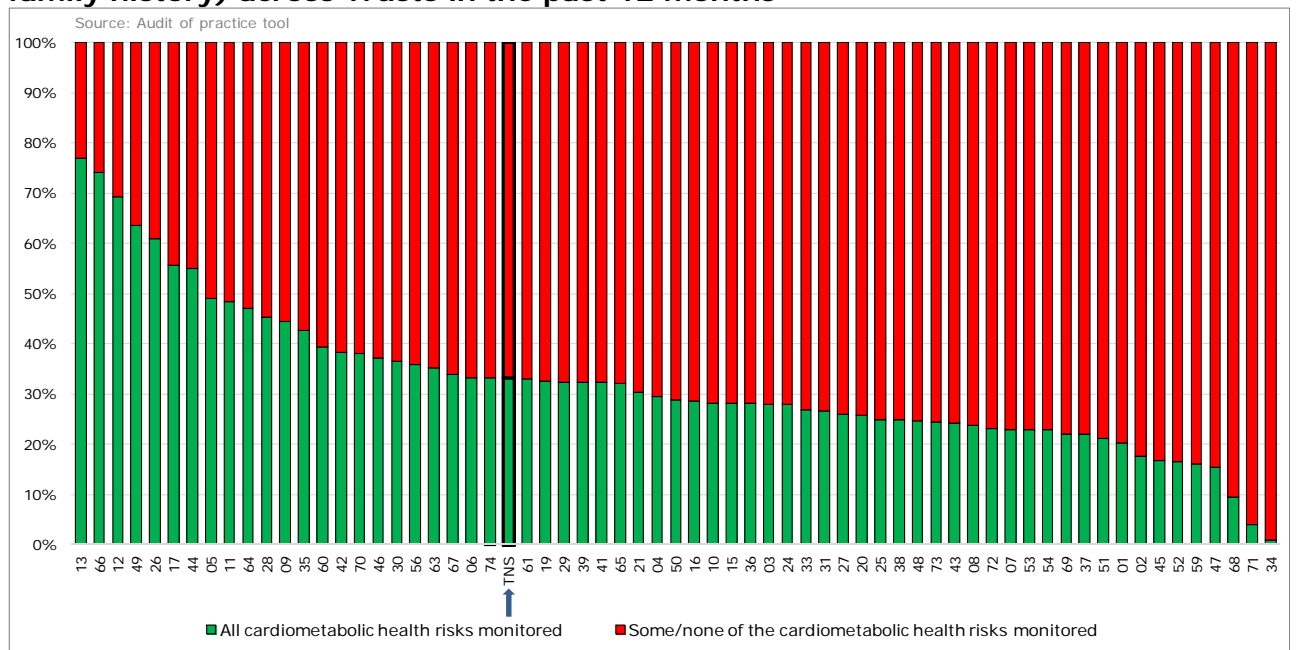
In NAS1 we focused particularly on only five of these six risk factors - the above six excluding family history. The proportion having five out of five of these factors monitored in NAS2 has slightly increased from NAS1. This comparison is shown in Figures 31a and 31b from the NAS2 and NAS1 audits respectively. (These two Figures are similar to Figure 30 but exclude family history).

Figure 32 presents the variation in performance across Trusts for monitoring of these five risk factors in NAS2. Family history is excluded from this Figure as the poor rate of recording of this (Table 29, above) obscures the results for the other factors.

**Figure 31: Percentages of service users with different proportions of cardiometabolic health risk factors monitored once in the past 12 months (excluding family history):**



**Figure 32: Monitoring of five cardiometabolic health risk factors (excluding family history) across Trusts in the past 12 months**



- The data for Figure 32 are taken from Qs 31, 34, 36, 37 and 38 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.
- The five risk factors are: smoking, BMI, blood glucose control, blood lipids and blood pressure.

While the average performance for the monitoring of five out of five of these risk factors in the total national sample (TNS average) is now 33% (NAS2),

compared with 29% (NAS1), the variation across Trusts in performance in NAS2, shown in Figure 32, ranges from 1% to 77%, compared to 13% to 69% in NAS1.

A further question is whether service users with a more recent diagnosis of schizophrenia were more likely to receive monitoring, given that clinicians should now be more aware of cardiometabolic health risk factors when initiating treatment. Table 30 shows the percentages of service users monitored in cohorts grouped by duration of illness. The data do not suggest that any increased attention is being paid to this by teams supporting service users in the earlier stages of illness, though this audit does not include service users in their very first year of illness. Only 52% of those in their second year since diagnosis had their BMI recorded despite weight gain being greatest in the early stages of illness.

**Table 30: Percentages of service users with evidence of monitoring of individual risk factors, once in the last year, by time since diagnosis**

<b>Time since diagnosis (years)</b>	<b>% of cases with BMI recorded</b>	<b>% of cases with glucose and/or HbA<sub>1c</sub> recorded</b>	<b>% of cases with blood lipids recorded</b>	<b>% of cases with blood pressure recorded</b>
<b>Between 1 and 2 years</b>	52%	55%	56%	58%
<b>From 2 to 4 years</b>	49%	54%	53%	57%
<b>From 4 to 10 years</b>	51%	57%	57%	61%
<b>More than 10 years</b>	53%	57%	58%	62%

- The data for Table 30 are taken from Qs 34, 36, 37 and 38 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.

The overall picture remains one of serious inadequacy of monitoring and this is one of the most significant findings from the audit.



## **Monitoring of individual risk factors**

### **• Screening for family history of cardiometabolic risk**

Asking about family history of cardiovascular disease, diabetes and lipid problems is important in determining well recognised familial risk factors for cardiometabolic disease. However, as can be seen from Table 31, these questions only had a definite positive or negative record in between 19% to 25% of cases ('yes' and 'no' columns combined). Most often the audit form returned stated that this was not recorded either one way or the other in case records, or the relevant question in the audit of practice tool was simply not answered. This represents a significant area of poor practice given that people with schizophrenia suffer from premature mortality primarily due to cardiovascular disorders.

**Table 31: Percentage of service users for whom family history of relevant physical illnesses was recorded over the last 12 months**

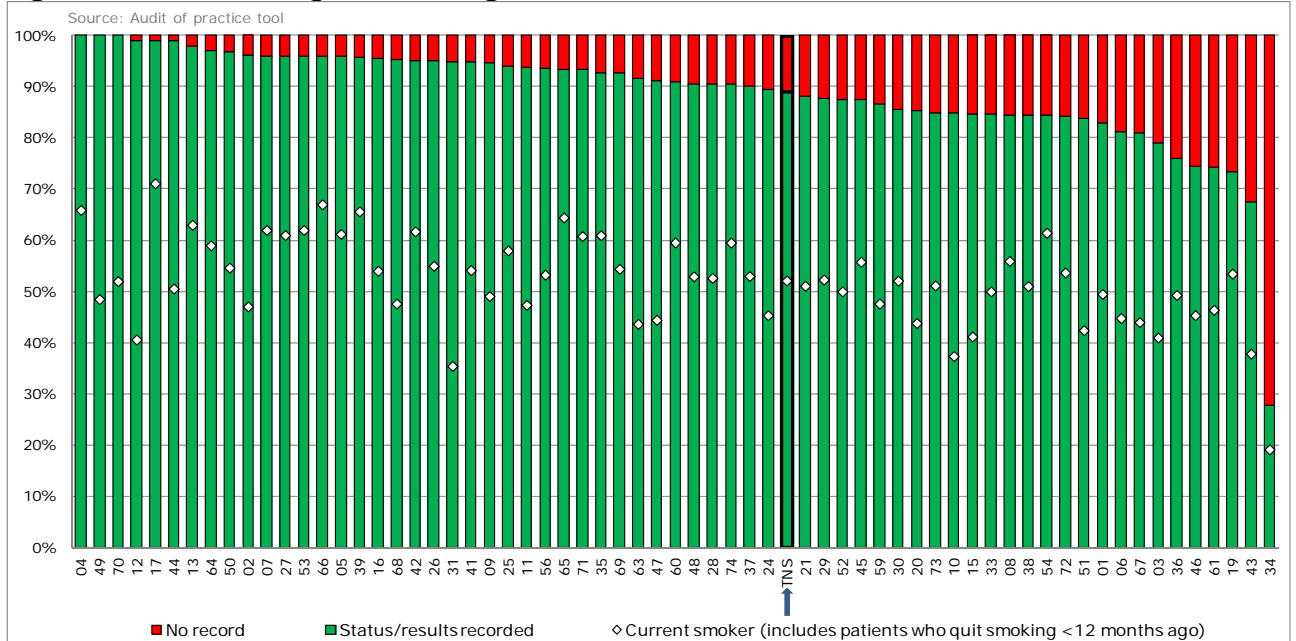
	<b>Yes, a positive family history recorded n (%)</b>	<b>No, a negative family history recorded n (%)</b>	<b>No record of being asked n (%)</b>	<b>Q39 not answered n (%)</b>
<b>Cardiovascular disease</b>	425 (8%)	973 (17%)	3,712 (66%)	498 (9%)
<b>Diabetes</b>	343 (6%)	1,005 (18%)	3,751 (67%)	509 (9%)
<b>Hypertension</b>	265 (5%)	937 (17%)	3,891 (69%)	515 (9%)
<b>Dyslipidaemia</b>	120 (2%)	923 (17%)	4,025 (72%)	540 (10%)

- The data for Table 31 are taken from Q39 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.
- Percentages are calculated as a percentage of 5,608.

### **• Monitoring of smoking**

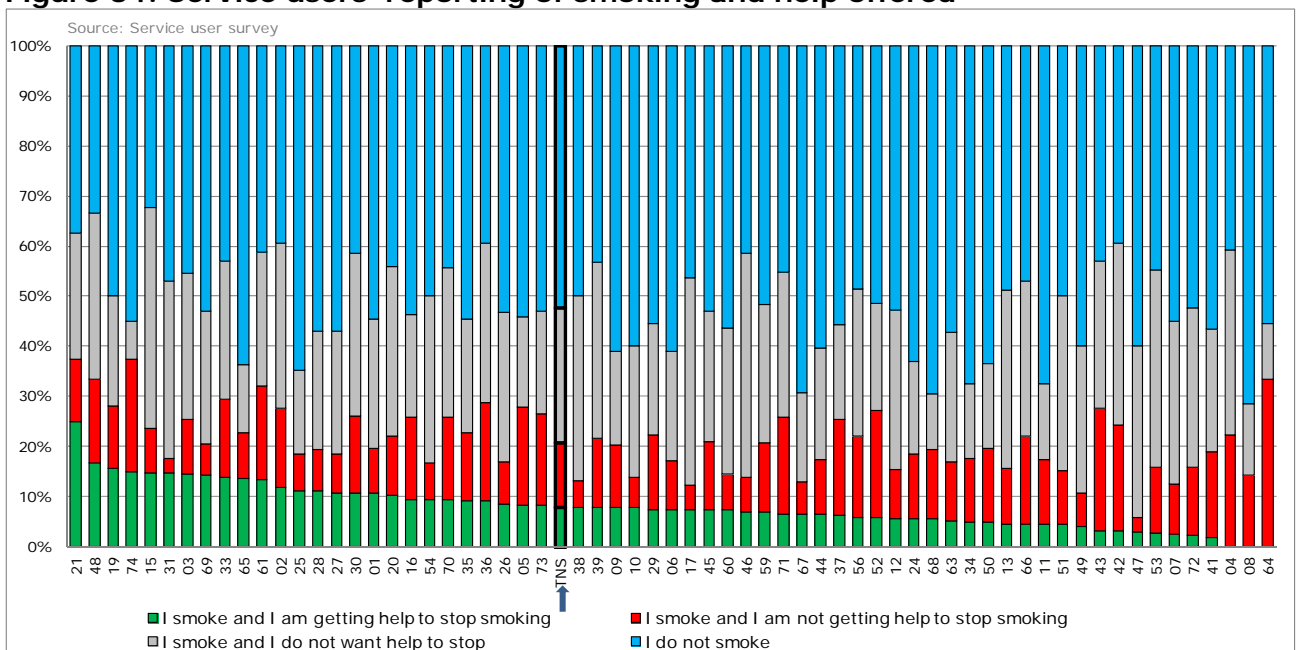
Figure 33 shows a TNS average recording of smoking status in NAS2 of 89% (range 27-100%), similar to the findings in NAS1 of 88% (range 55-100%). One Trust accounts for most of the variation in NAS2.

**Figure 33: Monitoring of smoking across Trusts in the last 12 months**



- The data for Figure 33 are taken from Q31 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.

**Figure 34: Service users' reporting of smoking and help offered**



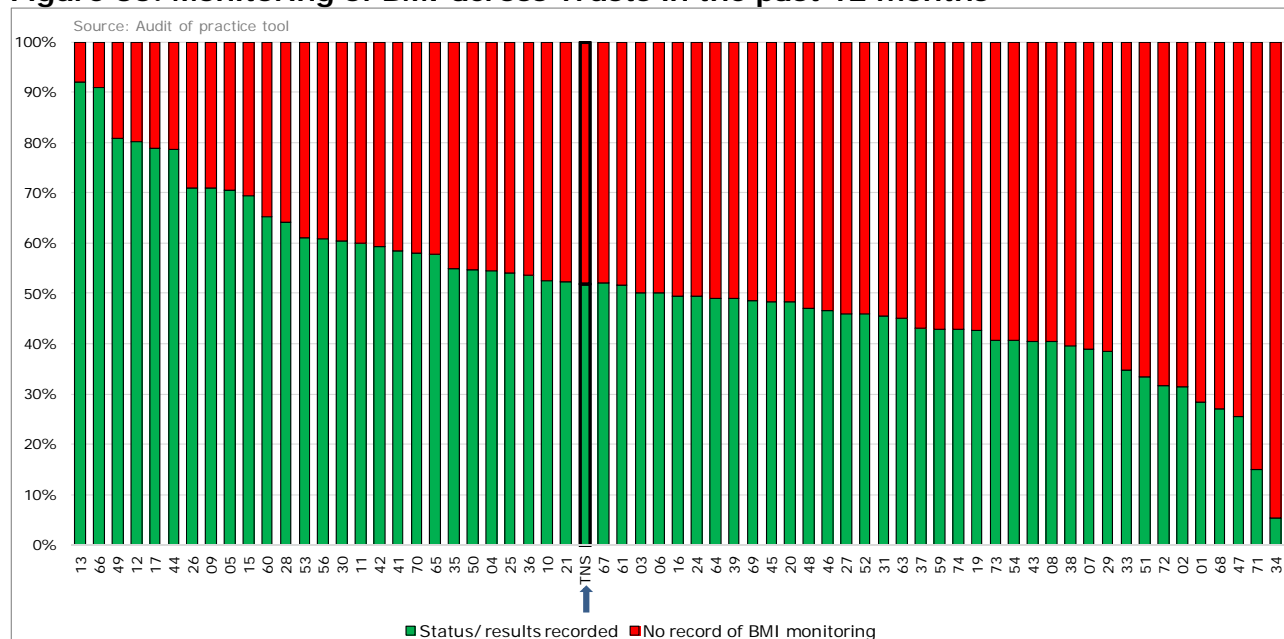
- The data for Figure 34 are taken from Q21 of the service user survey.
- 98% of service users answered this question.

Figure 34 shows that 48% of service users responding described themselves as smokers in the previous 12 months. This group is made up of 8% of total responders who had received help to stop, 13% who said they smoked and were not receiving help to stop and 27% who smoked and did not want help to stop.

• **Monitoring of BMI**

Figure 35 shows the percentage of service users in each Trust who had their BMI monitored and recorded at least once in the previous 12 months. There is a wide range across Trusts, from 5% to 92% being recorded as monitored in NAS2, with a TNS average of 52%. In NAS1 the range was 27% to 87% with a TNS of 51%.

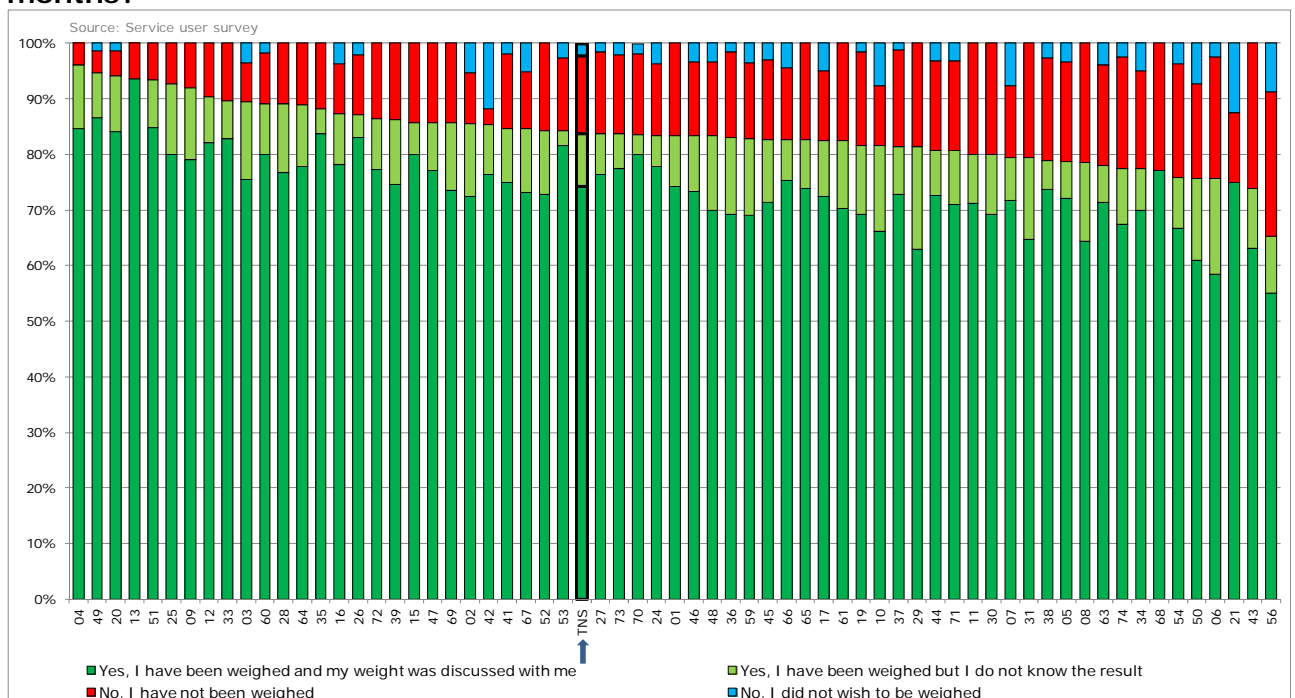
**Figure 35: Monitoring of BMI across Trusts in the past 12 months**



- The data for Figure 35 are taken from Q34 of the audit of practice tool.
- The number of cases included in this analysis is 5,608.

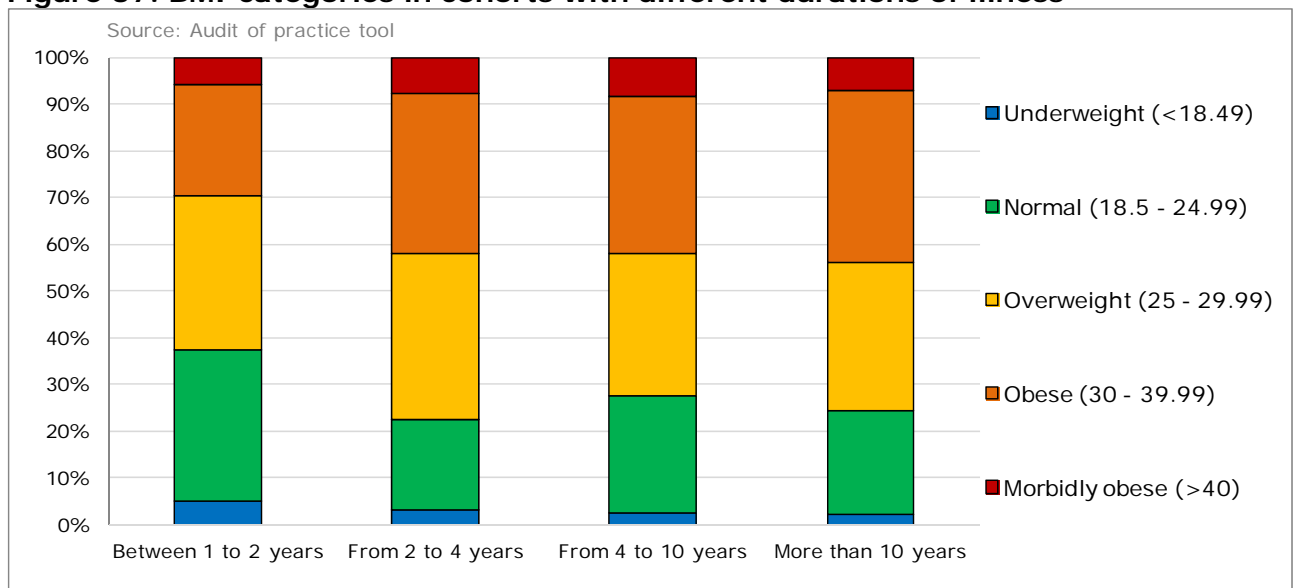
There is considerable variation across Trusts for the monitoring of BMI. This contrasts with the greater percentage of service users who report in the service user survey that their weight was measured (Figure 36): 84% service user report *versus* 52% Trust recorded. Service user report ranges from 65% to 96%, a much more narrow range than for the monitoring/recording of BMI by Trusts. This suggests either a substantial failure to record information on BMI in the case records or much closer monitoring in primary care.

**Figure 36: Has your weight been checked by a nurse or doctor in the last 12 months?**



- The data for Figure 36 are taken from Q18 of the service user survey.
- 98% of service users answered this question.

**Figure 37: BMI categories in cohorts with different durations of illness**



- The data for Figure 37 are taken from Qs 8 and 34 of the audit of practice tool.
- The number of cases included in this analysis is the 2,919 who had their BMI recorded.

Weight gain is a major determinant of future cardiovascular disease and type 2 diabetes. The data in Figure 37 suggest that after two years of illness most of the shift away from normal BMI in this population has happened, though this

must be seen against the usual trend for BMI to increase with age. Further, comparing the proportion of those in the 'normal' weight category, within the cohort who have been ill between one and two years, this has reduced from 38% in that cohort in NAS1 to 32% in the equivalent NAS2 cohort, suggesting an increasing problem in this population.

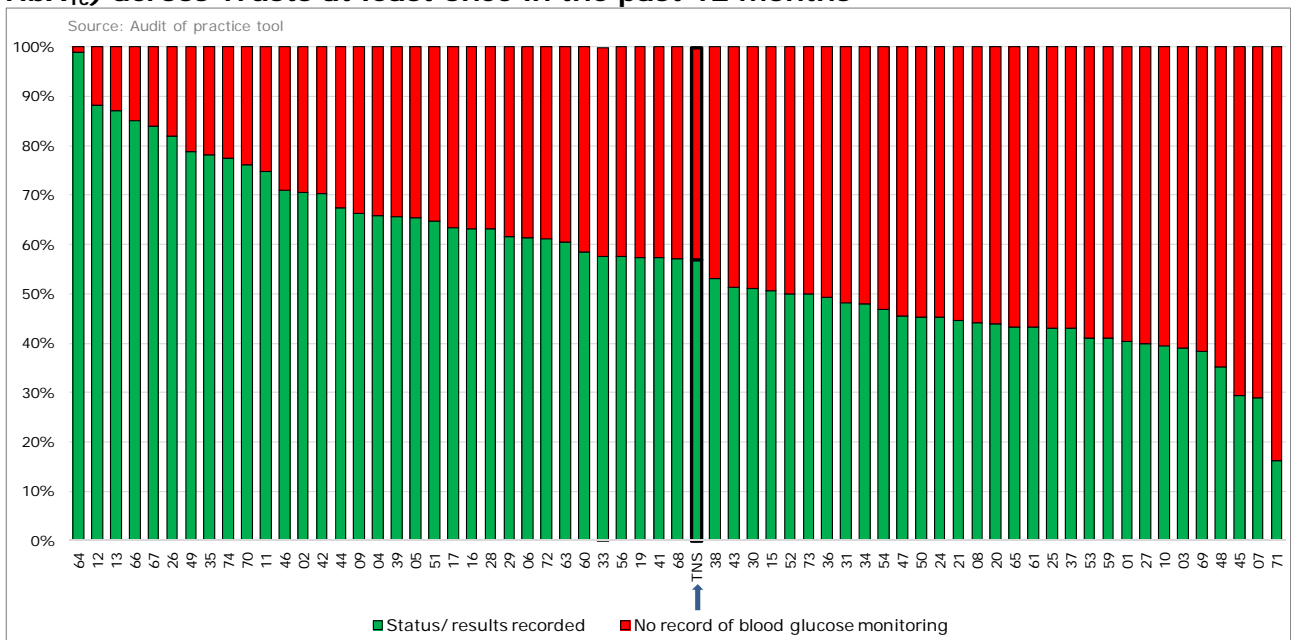
- **Monitoring of blood glucose control and lipids**

(**Note:** For many years the 'gold standard' for assessment of whether someone had developed diabetes, or might be in a pre-diabetic state, was a fasting plasma (blood) glucose level (FPG), supported where necessary by a glucose tolerance test. Recently a World Health Organisation Expert Consultation (WHO, 2011) and a NICE Public Health guideline (NICE PH38, 2012) advised that the use of glycated haemoglobin (HbA<sub>1c</sub>) was an adequate alternative to a plasma glucose sample. Hence, in this audit, Trusts were asked to provide either a fasting plasma/blood glucose result and/or a HbA<sub>1c</sub> result to allow us to assess whether a service user had an assessment of blood glucose control. Hence, in all Figures and Tables referring to 'glucose control' this refers to both plasma/blood glucose levels and HbA<sub>1c</sub> levels. However, if both were supplied, only one of these is counted in the analysis with respect to any individual service user.)

The audit shows widely varying performance between Trusts in relation to the monitoring of blood glucose control and blood lipids (Figures 38 and 39). The patterns are very similar for both parameters. Monitoring of glucose control in NAS2 was 57% (TNS average), increased from 50% of service users in NAS1. However, this apparent improvement is offset by increased variation between Trusts: NAS2 16% to 99%; NAS1 25% to 83%.

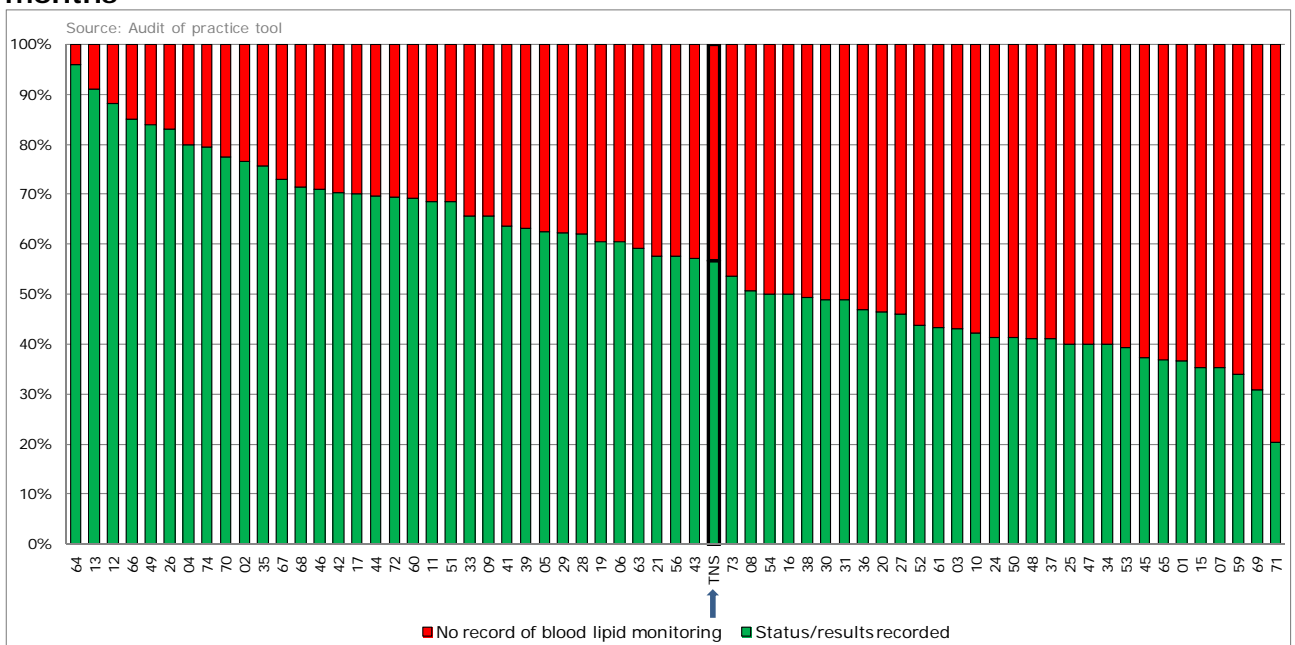
Monitoring of lipids was recorded for 57% (TNS average) of service users in NAS2 compared to 47% in NAS1, with a range between Trusts of 20% to 96% in NAS2 and 27% to 80% in NAS1.

**Figure 38: Monitoring of blood glucose control (fasting plasma glucose or HbA<sub>1c</sub>) across Trusts at least once in the past 12 months**



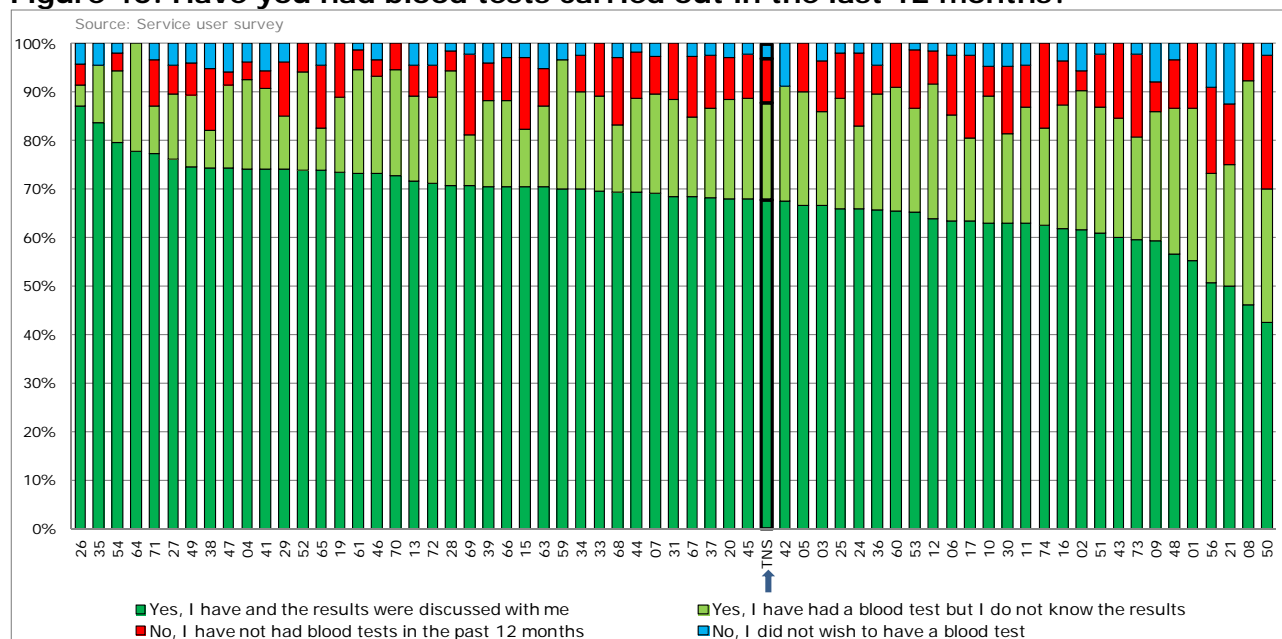
- The data for Figures 38 and 39 are taken from Qs 37 and 38, respectively, of the audit of practice tool.
- The number of cases included in the analyses is 5,608.

**Figure 39: Monitoring of blood lipids across Trusts at least once in the past 12 months**



Similar to the results seen for BMI, the service user survey showed that on average 87% of users recalled having had a blood test in the previous 12 months (Figure 40), while Trusts have only recorded blood test results for n=3,500 (62%) service users (one of: glucose/HbA<sub>1c</sub>/lipids). A caveat to interpreting this evidence is that the service user survey did not specify the precise reason for the blood test or where it was done. Of further note, 20% of service users recalled having blood tests done but without the results being conveyed back to them.

**Figure 40: Have you had blood tests carried out in the last 12 months?**



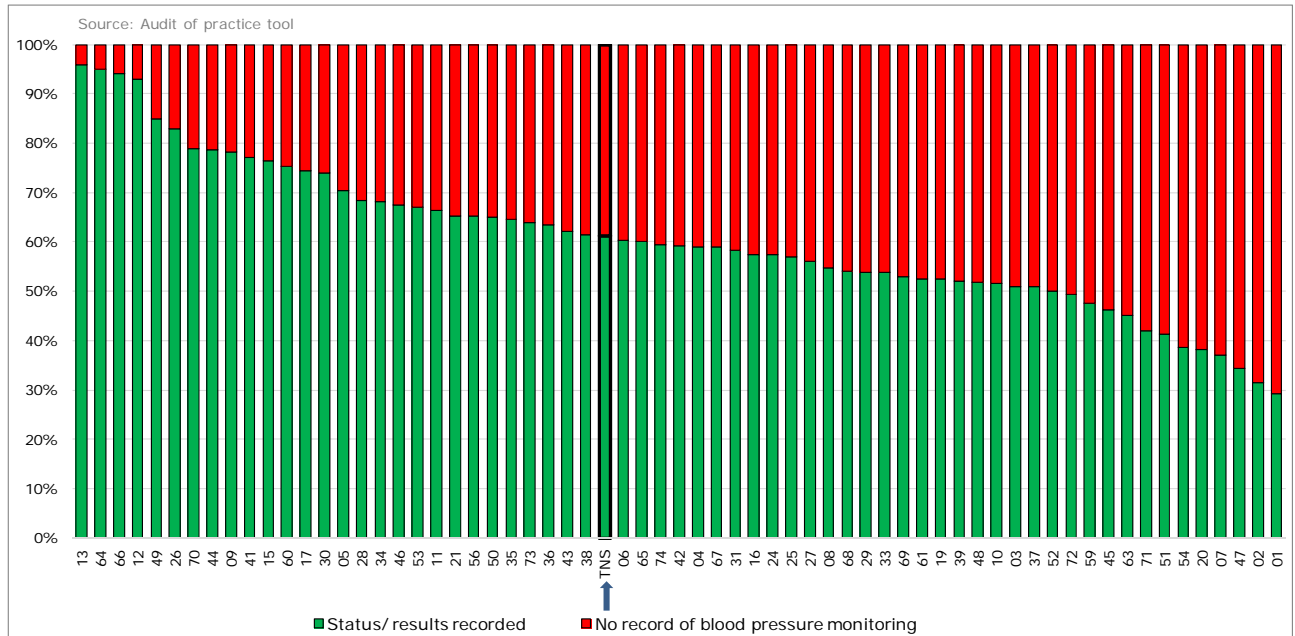
- The data for Figure 40 are taken from Q20 of the service user survey.
- 98% of service users answered this question.

However, again it is clear that Trusts' performance remains poor. Trusts need to ensure they have adequate means of recording all test results and a regular review process to ensure that service users' physical health status is updated. It may be that many of the tests have been carried out in primary care, but the NICE guideline places an onus on GPs and Trusts to share their results.

- **Monitoring of blood pressure**

The variation across Trusts for measurement of blood pressure (Figure 41) also shows considerable variation in practice.

**Figure 41: Monitoring of blood pressure across Trusts at least once in the past 12 months**



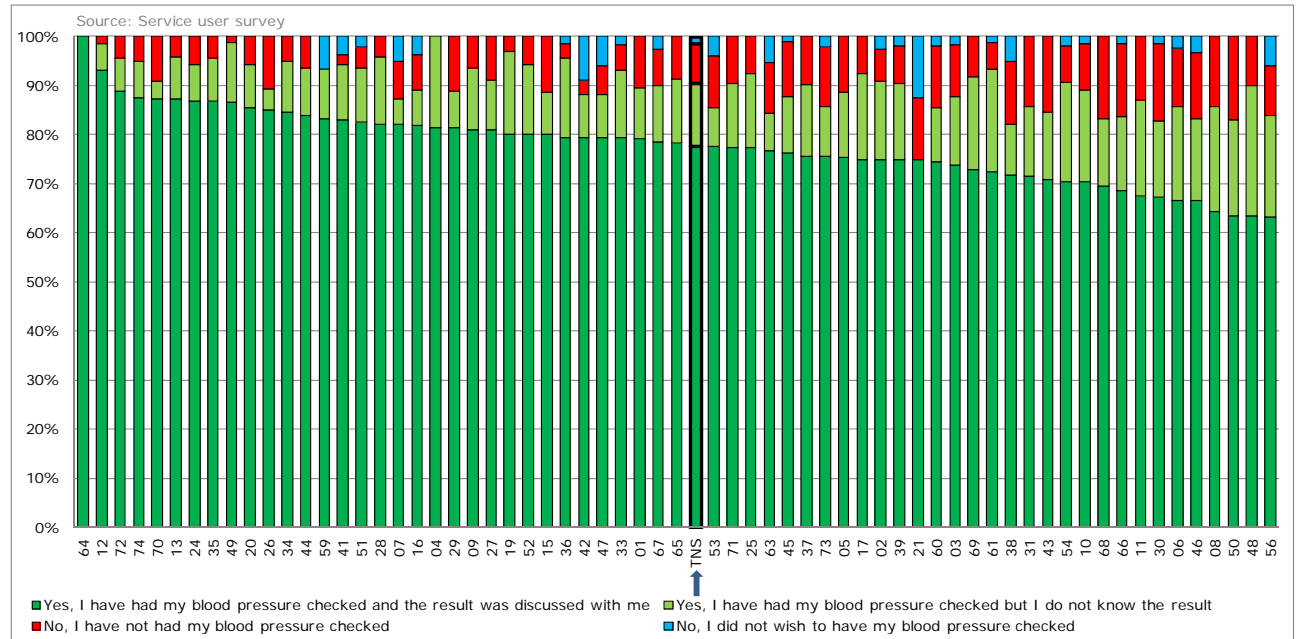
- The data for Figure 41 is taken from Q36 of the audit of practice tool.
- The number of service users included in the analysis is 5,608.

Measurement of blood pressure was 61% (TNS average) in NAS2, better than the 56% in NAS1. However, variation between Trusts in recording is similarly wide in NAS2 (29% to 96%) compared to NAS1 (28% to 90%).

The service user survey (Figure 42) indicates that 90% of service users recalled having their blood pressure measured, much higher than the evidence from the Trusts. Again this may be partly an issue of case note recording and/or that it may have been measured in primary care rather than by a hospital clinician.



**Figure 42: Has your blood pressure been checked by a nurse or doctor in the last 12 months?**



- The data for Figure 42 are taken from Q19 of the service user survey.
- 98% of service users answered this question.

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

Service users with schizophrenia have higher rates of cardiovascular disease, diabetes and obesity. Inevitably this means that a proportion of the population selected for the audit will already have these problems. We would perhaps expect these groups of service users to have better monitoring of their various risk factors than other service users.

The NICE guideline on obesity (NICE CG43, 2006; paragraph 1.2.2) regards those with a BMI of 30kg/m<sup>2</sup> or greater as being at increased risk of long-term health problems, with an increasing risk as waist circumference increases. Thus, it seems pertinent in this context to review the level of monitoring provided to those with BMI greater than or equal to 30kg/m<sup>2</sup>.

**Table 32: NAS2 findings for the monitoring of cardiometabolic health risks for service users with an established problem and comparison with NAS1**

Cardiometabolic health risks monitored	Percentage of service users monitored in each subgroup. (n=number in each group with known problem in NAS2)		
	Cardiovascular disease (n=384)  NAS2 / NAS1	Diabetes (n=803)  NAS2 / NAS1	BMI > or = 30 (n=1,245)  NAS2 / NAS1
Smoking status	95% / 92%	91% / 91%	97% / 96%
BMI	53% / 58%	59% / 63%	(By definition has been measured)
Blood glucose control (glucose and/or HBA <sub>1c</sub> )	64% / 68%	70% / 69%	76% / 72%
Lipids	64% / 68%	70% / 66%	75% / 71%
Blood pressure	66% / 71%	69% / 69%	93% / 92%
All of the above five risk factors monitored	37% / 37%	43% / 46%	65% / 60%

- The data for Table 32 are taken from Qs 30, 31, 34, 36, 37 and 38 of the audit of practice tool.

Table 32 shows the proportion of service users with an established problem who have had appropriate monitoring, as a percentage of those with the problem. The equivalent percentages from NAS1 are shown for comparison. It can be seen that there is little overall change from NAS1 to NAS2. This is particularly disappointing given that these groups have an identified problem linked to longer-term morbidity.

Comparing these figures with those in Table 29, which presents data for the whole NAS2 audit population, it can be seen that monitoring is a little better for these groups with established problems. However, it remains well below what should be expected.

## **Intervention to address physical health problems**

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Intervention is clearly vital if monitoring identifies a problem and this is encapsulated in the strap line of the Lester Resource '*Don't just screen, Intervene*'. Standard 5 reflects the main issues regarding intervention in the NICE guideline (NICE CG82, 2009).

**Standard 5a: 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. Help with smoking cessation.**
- ii. Advice about diet and exercise, aimed at helping the person to maintain a healthy weight.**
- iii. Treatment for diabetes.**
- iv. Treatment for dyslipidaemia**
- v. Treatment for hypertension.**

The relevant data are provided in Table 33. Points to note about this Table are:

- Questions 31 to 40 of the audit of practice tool address the measures required to assess this standard. In particular, the answers to questions 34, 36, 37 and 38 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. Evidence of an intervention comes from Q40.
- The percentage of service users who were monitored for a particular risk factor is expressed as a percentage of the total audit sample (n=5,608).
- The percentage of service users where monitoring indicated a need for some intervention is expressed as a percentage of the number for whom there was evidence of monitoring for that risk factor. This is because the numbers monitored vary between risk factors.
- 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 audit population.
- Two thresholds for intervention are used for BMI:

- (a) BMI greater than or equal to 25kg/m<sup>2</sup> is used as this equates to the 'overweight' category for which the NICE guideline on obesity (NICE CG43, 2006) recommends a variety of lifestyle and diet interventions.
- (b) BMI greater than or equal to 30kg/m<sup>2</sup> equates to the 'obesity I' category (NICE CG43, 2006) in which people are regarded as being at increased risk of long-term health problems.

**Table 33: Percentage of service users where a need for intervention for a physical health problem was identified and percentage where there was evidence that this was offered**

Physical health indicator	Service users monitored  n (% of total population)	Service users requiring an intervention  n (% of those who were monitored)	Service users offered an intervention  n (% of those requiring intervention)
Smoking status	4,992 (89%)	2,923 (59%)	1,724 (59%)
All those with BMI $\geq$ 25kg/m <sup>2</sup>	2,919 (52%)	2,171 (74%)	1,531 (71%)
All those with BMI $\geq$ 30kg/m <sup>2</sup>	2,919 (52%)	1,245 (43%)	923 (74%)
Blood glucose control (glucose and/or HbA <sub>1c</sub> ) <sup>(i)</sup>	3,190 (57%)	1,309 (41%)	468 (36%)
Lipid levels <sup>(ii)</sup>	3,210 (57%)	556 (17%)	165 (30%)
Blood pressure <sup>(iii)</sup>	3,445 (61%)	648 (19%)	160 (25%)

- (i) Two cases recorded as 'missing values' where there were data entry errors in recording one each of fasting glucose and HbA<sub>1c</sub>.
- (ii) Two data entry errors for total cholesterol recorded as 'missing values'.
- (iii) One case recorded as a 'missing value' where there was a data entry error in recording systolic BP.

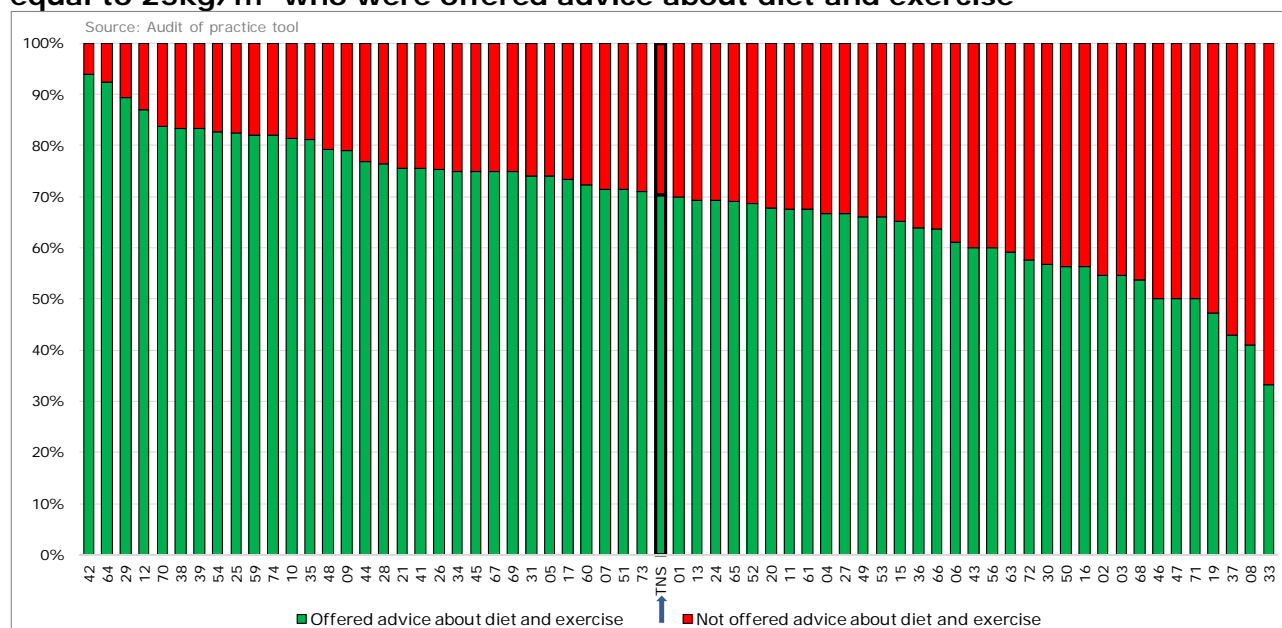
It is important to note that in Table 33 the calculation for the percentage of those who *require an intervention* is based on the actual numbers who were monitored, which are quite low for all risk factors except smoking. Thus, we

must be cautious in extrapolating to the whole population in the audit from the percentages of those requiring an intervention and the percentages offered an intervention. We cannot know if those for whom no data was supplied were more or less likely to require an intervention.

The levels of intervention, where evidence suggests it is required, are poor and of particular concern in relation to glucose control.

Figure 43 presents the data across individual Trusts showing whether or not service users with a BMI greater than or equal to 25kg/m<sup>2</sup> were offered advice about diet and exercise. This shows that in NAS2 the TNS average is that 71% were offered advice, which is little changed from NAS1 in which it was 76%.

**Figure 43: Percentage of service users across Trusts with BMI greater than or equal to 25kg/m<sup>2</sup> who were offered advice about diet and exercise**



- The data for Figure 43 is taken from Qs 34 and 40 of the audit of practice tool.
- The number of cases included in the analysis is the 2,171 who had BMI > or = 25kg/m<sup>2</sup>.

Similar comparisons across Trusts for intervention in relation to glucose, lipid and blood pressure tool results are not shown as they do not lend themselves to this type of analysis. (The numbers for each Trust are small and variations of only one case would be unduly magnified by a presentation showing percentage differences.) The individual Trust reports that will be provided to each Trust will provide each Trust with their own figures in comparison to the national figures.

Table 34 shows the comparison between NAS2 and NAS1 findings with regard to the percentages of service users monitored, those demonstrating a requirement for an intervention and those who were offered an intervention.

**Table 34: Comparison between NAS2 and NAS1 of the percentage of service users where need for intervention for a physical health problem was identified and percentage where there was evidence that this was offered**

<b>Physical health indicator</b>	<b>Service users monitored</b>  <b>% of total population</b> <b>NAS2/ NAS1</b>	<b>Service users requiring an intervention</b>  <b>% of those who were monitored</b> <b>NAS2 / NAS1</b>	<b>Service users offered an intervention</b>  <b>% of those requiring intervention</b> <b>NAS2 / NAS1</b>
<b>Smoking status</b>	89% / 87%	59% / 58%	59% / 57%
<b>All those with BMI &gt;/= 25kg/m<sup>2</sup></b>	52% / 51%	74% / 73%	71% / 76%
<b>Blood glucose control (glucose and/or HbA<sub>1c</sub>)</b>	57% / 50%	41% / 21%	36% / 53%
<b>Lipid levels</b>	57% / 47%	17% / 49%	30% / 20%
<b>Blood pressure</b>	61% / 56%	19% / 19%	25% / 25%

Table 34 shows that there was little overall change in the likelihood that an intervention would be offered where a need had been identified. There were some marginal differences as the Table shows, but in both positive and negative directions. The main message from this Table is that the rates of identification and intervention remain particularly low for these five cardiometabolic health risk factors.

## **Monitoring and intervention in relation to alcohol and substance abuse**

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Abuse of alcohol and various other illicit substances may exacerbate symptoms of schizophrenia, and sometimes increase risk of suicide in service users with schizophrenia. Alcohol, in particular, and other drugs of abuse may cause additional physical health problems. The relevant aspects of standards 4 and 5 are summarised below as standards 4b and 5b. Alcohol and substance abuse can affect symptom remission. The importance of this in relation to antipsychotic drug treatment has already been considered in the 'Prescribing' section (from page 82).

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

- vii. Use of alcohol.
- viii. Substance misuse.

**Standard 5b: 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:**

- vi. Help with reducing alcohol consumption.
- vii. Help with reducing substance misuse.

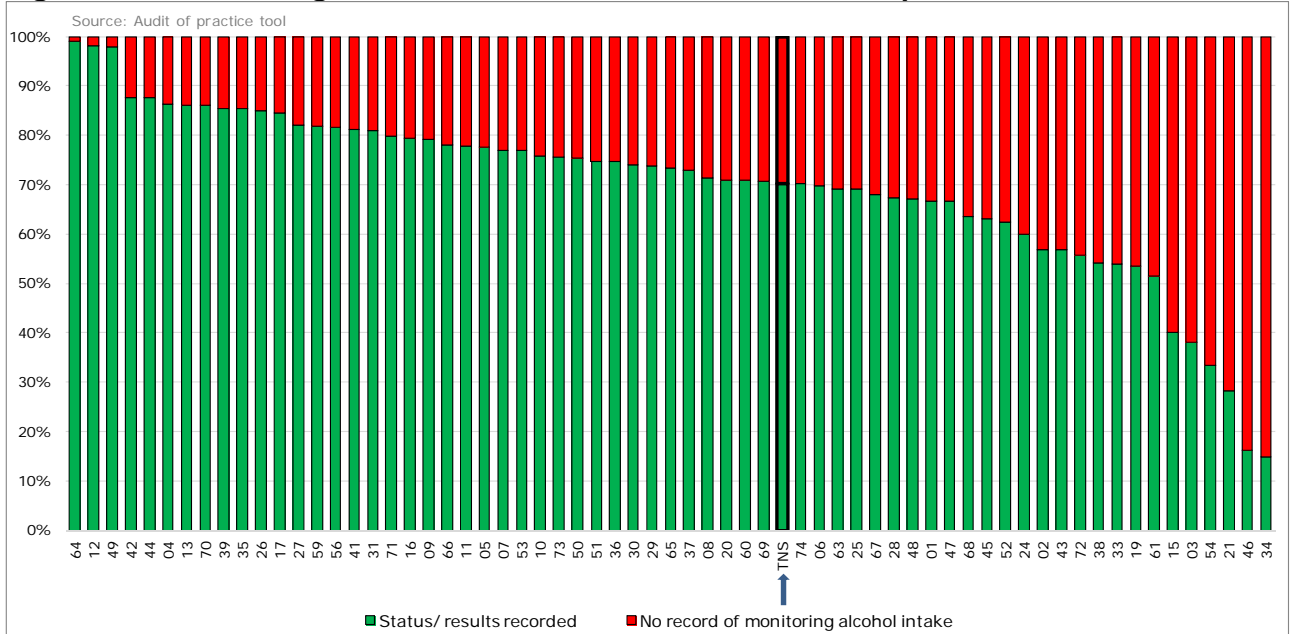
### **Monitoring of alcohol intake and substance misuse**

The TNS average proportion of service users monitored for alcohol intake per Trust was 70% in NAS2, similar to the 69% in NAS1. The variation in recording of monitoring across Trusts in NAS2 is shown in Figure 44. The range is 15% to 99%, but part of this variation was contributed to by only two Trusts with much lower performance than others. The range in NAS1 was 36% to 97%.

Monitoring of substance misuse in the previous 12 months (Figure 45) was 89% in NAS2 compared to 85% in NAS1. The range across Trusts is 22% to 100%, but one Trust in particular contributed to this variation. The range in NAS1 was 54% to 100%.

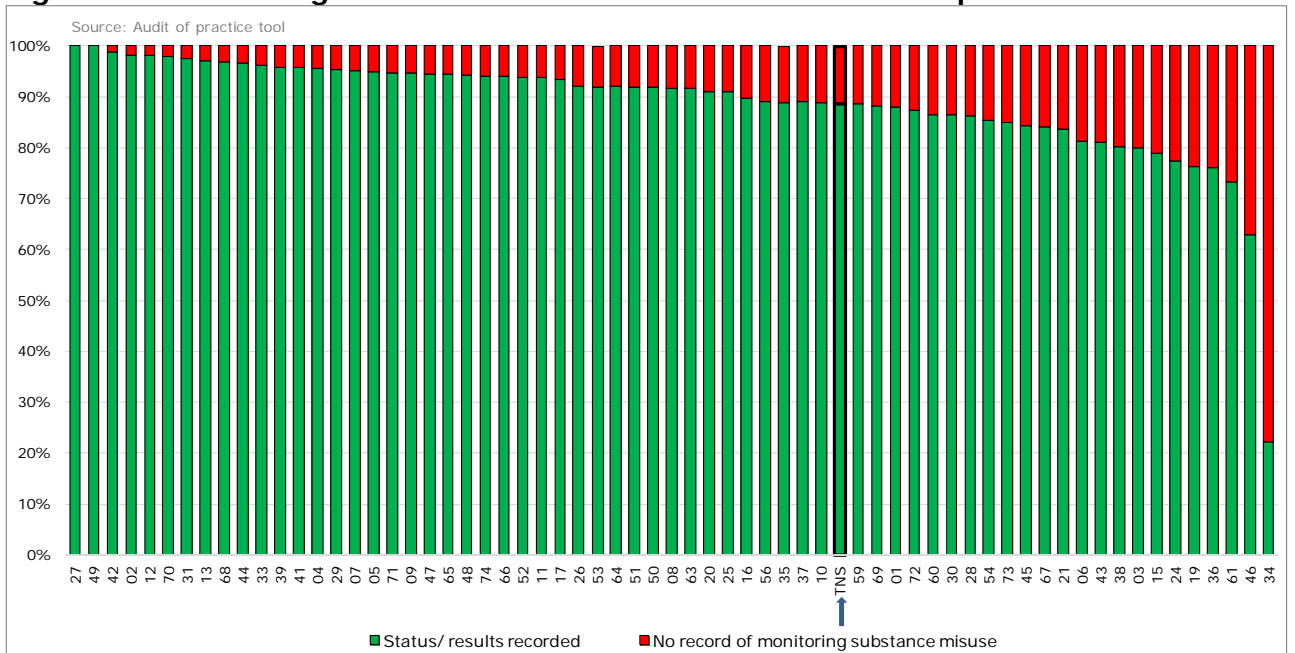


**Figure 44: Monitoring of alcohol intake across Trusts in the past 12 months**



- The data for Figure 44 are taken from Q32 of the audit of practice tool.
- The number of cases included in the analysis is 5,608.

**Figure 45: Monitoring of substance misuse across Trusts in the past 12 months**



- The data for Figure 45 are taken from Q33 of the audit of practice tool.
- The number of cases included in the analysis is 5,608.

**Intervention in relation to alcohol consumption and substance misuse**

The top half of Table 35 presents the numbers of service users in NAS2 for whom there was evidence of monitoring, the numbers for whom it was deemed that an intervention was required and the numbers for whom there was actual evidence that an intervention had been offered. For alcohol, the thresholds for expecting intervention were 21 units per week for males and 14 units per week for females.

The bottom half of Table 35 shows the comparisons between NAS2 and NAS1 with respect to monitoring and intervention. There has been no meaningful change.

**Table 35: Percentage of service users where a need for intervention for an alcohol/substance misuse problem was identified and percentage where there was evidence that this was offered (and comparison of NAS2 and NAS1 findings)**

Clinical group	Service users monitored	Service users requiring an intervention	Service users offered an intervention
	n (% of total population)	n (% of those who were monitored)	n (% of those requiring intervention)
Alcohol consumption (NAS2)	3,946 (70%)	383 (10%)	283 (74%)
Substance misuse (NAS2)	4,971 (89%)	646 (13%)	473 (73%)
	<b>NAS2 / NAS1 comparisons</b>		
	<b>Monitored</b>	<b>Require intervention</b>	<b>Offered intervention</b>
Alcohol consumption	70% / 69%	10% / 11%	74% / 72%
Substance misuse	89% / 85%	13% / 14%	73% / 73%

- The data for Table 35 are taken from Qs 32, 33 and 40 of the audit of practice tool.
- For NAS2, percentages in the first column are based on the total audit population of 5,608.

In Table 35, as for Table 33, the calculation for the percentage of those who *require an intervention* is based on the actual numbers who were monitored.

While the levels of recording of monitoring and intervention for alcohol and substance misuse could be improved upon, they are relatively high in comparison to those for other aspects of physical health. This may be an example of the tendency for mental health services to be comfortable with what may be seen as mental health issues, but less comfortable with what are seen as physical health issues.

## Key comparisons between NAS2 and NAS1 for physical health monitoring and intervention

Table 36 shows a summary of key comparisons between the findings in this second round of the audit (NAS2) versus the findings in the baseline audit (NAS1). These are shown as percentages. Most of these percentages relate to the whole audit population. However, those percentages relating to 'intervention offered', relate to the percentages of service users for whom there was evidence that intervention was required. Some of the percentages shown for NAS1 may differ slightly from those in the original report as the method of calculation differs slightly for some parameters between the audits. Some NAS1 percentages have therefore been recalculated.

**Table 36: Key comparisons between NAS2 and NAS1 for physical health monitoring and intervention**

Standard / Indicator	NAS2 (%)	NAS1 (%)
<b>Standard 4 – monitoring of physical health risk factors</b>		
Monitoring of five risk factors (family history excluded)	33%	29%
Monitoring of smoking	89%	88%
Monitoring of BMI	52%	51%
Range across Trusts for monitoring of BMI	5 – 92%	27 – 87%
Monitoring of glucose control	57%	50%
Range across Trusts for monitoring of glucose control	16 – 99%	25 – 83%
Monitoring of lipids	57%	47%
Monitoring of blood pressure	61%	56%
Monitoring of five risk factors in those with established cardiovascular disease	37%	37%
Monitoring of alcohol consumption	70%	69%
<b>Standard 5 – intervention offered for identified physical health risks</b>		
Intervention for smoking	59%	57%
Intervention for BMI > or = 25kg/m <sup>2</sup>	71%	76%
Intervention for abnormal glucose control	36%	53%
Intervention for elevated blood pressure	25%	25%
Intervention for alcohol misuse	74%	72%

## Discussion of findings and conclusions

The findings from the first National Audit of Schizophrenia (NAS1; Royal College of Psychiatrists, 2012) and from the independent Schizophrenia Commission (Schizophrenia Commission, 2012) were both published in late autumn 2012. These two reports used different methodologies but came to a similar conclusion: that the care and treatment provided for people with a diagnosis of schizophrenia had major inadequacies in virtually all aspects reviewed.

Conclusions common to both reports were that:

- Better engagement and communication with service users is needed.
- More attention needs to be paid to how staff communicate with carers.
- Some aspects of prescribing practice need to be improved.
- The availability of psychological therapies is poor.
- The extent of monitoring and intervention for service users' physical health problems is entirely inadequate.

Following NAS1 we disseminated the findings at different levels. This included presentations to the various regional Divisions of the Royal College of Psychiatrists and other professional bodies. Members of the NAS team were also invited to a Ministerial round table discussion at the Department of Health, in conjunction with members of the Schizophrenia Commission, to consider the inadequacies encountered. The main aim of this second National Audit of Schizophrenia was to repeat the previous audit and see what, if anything, had changed.

### **Discussion of key findings in NAS2**

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The second National Audit of Schizophrenia has been successful in recruiting all 64 Trusts/Health Boards in England and Wales who provide treatment and care for people with a diagnosis of schizophrenia or schizo-affective disorder. The final database of 5,608 case record audit of practice forms (an 88% response rate) means that the care of approximately 2% of the total population of people with schizophrenia in England and Wales has been assessed. As before, the focus of this audit is on those service users who are living in the community and

have been in contact with a Trust for at least 12 months. This means that the Trusts have had ample opportunity to implement the advice provided in the NICE guideline (NICE CG82, 2009) which was current at the time of data collection from August to November 2013.

When the findings are compared with the baseline audit (NAS1), there is little evidence of meaningful change. Comparisons with the data from NAS1 are provided in all of the sections of results and Tables 1 and 2 in the Executive Summary (pages 13 and 14). Some of the major areas of concern are discussed below.

### **Monitoring and intervention for physical health problems**

This is clearly poor for all risk factors assessed in the audit. The results of most concern are shown in Figure 30 (page 115). Only 9% of service users have evidence of assessment, during the previous 12 months, of all six of the important risk factors for cardiovascular disease and diabetes: family history of diabetes and cardiovascular disease, smoking, elevated BMI, blood glucose control, blood lipids and blood pressure. Six percent have not had monitoring of any of these in the previous 12 months. In NAS1 this statistic was only calculated for five of these measures (family history excluded). In comparison with NAS1 there has been a slight improvement in the percentage of assessment of these five risk factors, from 29% to 33%, but this is still a very low proportion.

Figures 33, 35, 38, 39 and 41 (page 120 to page 126) show the percentages of service users in each Trust who have been monitored for each individual risk factor. There are wide variations between Trusts for how effectively monitoring is being carried out. This is something of which those Trusts with poor performance and their commissioners of services need to be aware.

There can be a number of barriers to adequate monitoring: (i) restricted availability of staff time, appropriate facilities and equipment; (ii) lack of formal systems to review physical health data and interventions required on at least an annual basis; and (iii) lack of formal arrangements regarding collaboration

between primary and secondary care in relation to physical health. Trust Boards should take responsibility for monitoring their own arrangements.

The need for proper, agreed arrangements between secondary care services and primary care was addressed in the recent NICE guideline (NICE CG178, 2014). This clearly outlines what the position should be, unless other local agreements are in place. It places the responsibility on secondary care for the first 12 months or until the service user's condition is stable, and then expects primary care services to take over monitoring of physical health. This needs to be taken up by commissioners and agreed between Trusts and primary care services.

There is also need for further training of general practitioners, and their practice nurses, in this area. One of the Schizophrenia Commission's recommendations was that: "... the Academy of Medical Royal Colleges, the Royal College of Nursing and the Health and Care Professions Council should place greater emphasis on physical health in severe mental illness in the training of all doctors, nurses and mental health practitioners".

### **Prescribing practice**

Significant deficiencies remain in prescribing practice and again this is something which varies considerably between Trusts. A trial of clozapine is recommended for service users who have had a poor response to trials of two other antipsychotic medications. Yet, 57% of service users currently receiving clozapine had been prescribed three or more antipsychotic medications prior to commencing clozapine. This means that their progress, to a medication more likely to be effective for them, was slower than it should have been.

The issue of slow progression from a medication that is not proving effective is further exemplified by the fact that 93% of service users who were on their very first antipsychotic medication, and who were not in remission, had been on this first medication for at least six months. (If a medication is not effective it is not recommended that it is continued for more than 8 weeks.)

Two other issues relating to prescribing practice have continued at a similar prevalence to the situation in NAS1: polypharmacy and use of doses greater than 100% of BNF recommended dosing. The evidence is that neither of these

practices is routinely likely to improve clinical outcome and both are likely to increase adverse effects experienced by the service user. Accepted practice is that only a single antipsychotic medication should be prescribed (monotherapy). For service users not on clozapine, 11% were receiving more than one antipsychotic (polypharmacy), the same percentage as in NAS1. The variation across Trusts was from 1% to 24%. The use of higher than recommended doses was found in 10% of service users, with a range from 1% to 22% across Trusts. For both polypharmacy and high dose prescribing it is the range across Trusts that is of concern as there is no obvious reason for some Trust populations to require such a different approach to treatment.

Such prescribing can be permissible for certain clinical situations but then a rationale must be recorded in the case records. For instances of polypharmacy, 71% of service users had a rationale recorded. For high dose prescribing a rationale was recorded in 37% of instances, which was an improvement from 25% in NAS1.

There are clearly issues relating to prescribing where psychiatrists must implement improvements and Trusts and Medical Directors must monitor through regular local audit. Mental Health Pharmacists can provide valuable assistance in helping with this local monitoring and involvement in national POMH-UK (Prescribing Observatory for Mental Health) audits is also likely to improve prescribing practice in a Trust.

### **Psychological therapies**

The percentage of service users offered either CBT or a family intervention remains low and the proportion taking up such therapies is even lower (19% and 8% respectively). While there are different views on what constitutes cognitive therapy for psychosis (and we have taken a broad view here) it remains the case that such therapies are not reaching most service users.

Resolving this issue will require commissioners and Trusts to consider the funding implications of training and appointing more staff with the appropriate skills. However, this is probably the largest deficit that exists in the treatment services provided by Trusts.



### **Carers' satisfaction**

This was assessed using an established questionnaire which looks at a number of dimensions of satisfaction with information and support made available to a carer. As described in the results, a threshold was set that 90% of responses to the questions should be either 'very' or 'somewhat' satisfied for a Trust to be regarded as meeting the standard set for carer satisfaction. Only 9% of Trusts reached this threshold. In particular, carers said they were dissatisfied with information about the service user's prognosis, about their involvement in decisions made about care and ease of access for support for themselves.

This issue may relate to either or both of how staff approach carers and the time available for this. However, carers are a crucial part of the system of care for the majority of service users and it is vital to engage with them. In its report, the Schizophrenia Commission said: "Families who are carers save the public purse £1.24 billion per year but are not receiving support, and are not treated as partners". Clearly Trusts need to ensure that staff have the appropriate approach and time to work with carers.

### **Information systems and procedures**

An important general issue, evident from problems in data collection and from aspects of the analyses conducted, is the frequently poor quality of information and information systems within Trusts. It is clear that this has affected the ability of staff to collect much of the data requested by the NAS audit team and must have an impact on the ability of staff to deliver care.

For some items requested there was no information available from almost 50% of the case records. For example, where service users were asked if they had been weighed by a nurse or doctor, 84% said they had been, yet the Trusts could only report BMI for 52%. For measurement of blood pressure, 90% of service users said it had been done but Trusts could only report results for 61%. Trusts could only report blood glucose levels for 57% of service users. In the section of the audit of practice tool asking for information about current medication, question 12 asked: 'If the patient is currently being prescribed two or more antipsychotic drugs at the same time, has a rationale for this been documented in the patient's records?' In the responses to this there were 185

instances where a Trust 'did not know' and 49 instances where the Trust said 'yes' but the service user was in fact only on one medication.

A number of issues relating to information and information systems need to be considered. Firstly, measures of physical health have probably often been collected in primary care but the Trust has no record. Yet, the NICE guideline clearly states that Trusts and primary care must share their information. There is clearly a need for vastly improved arrangements for sharing information between primary care and secondary care.

Secondly, in many of the Trust information systems it appears to be difficult to access some of this information. In some Trusts certain data is only to be found on laboratory systems that are associated with a different acute Trust and not necessarily accessible to all staff.

Thirdly, information is not always clearly recorded in case notes and/or letters from Trusts to primary care. This applies particularly to information about diagnosis and current medication. In some Trusts this is routinely added to all letters about a service user. In others it is not. There can be variation in how treatment history information is stored, which has a knock-on effect for future decision making.

Fourthly, for much of the data requested in the audit the existence of an annual summary regarding the service user's care would have provided what was being sought. Such a summary might include information on major prescribing decisions (e.g. why clozapine was commenced or whether cognitive therapy was offered), results of monitoring of physical health risk factors and information on interventions offered for physical health problems. The point here is that such an annual summary would ensure that readily accessible information was available for future care planning and that an annual review occurred to ensure that the appropriate monitoring had been done and acted upon.

Hence, some of the recommendations from the audit relate to an urgent need for improvements to information systems and the need for a regular (annual) review of key information relating to each service user.

## Conclusions

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Deficiencies in the care of those with schizophrenia continues to leave many service users receiving treatment that is below standard, which may limit their recovery, and continues to leave many vulnerable to serious physical health issues. Many carers continue to feel inadequately supported.

The recommendations from this report address a number of areas but in particular:

- The need to implement the recent NICE guideline (NICE CG178, 2014) regarding responsibilities for the care of service users' physical health.
- The need to change a culture which often regards physical health care and mental health care as separate.
- The need for improvements in antipsychotic prescribing practice.
- The need to improve access to psychological therapies.
- The need for improved information and support for carers.
- The need for improvements in information systems.

## Feedback and dissemination

### Learning points

Following feedback from our Advisory Group and participating Trusts, the NAS team have some recommendations for any future rounds 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. Work with Trusts to further refine the random sampling method.
3. Split the audit into several parts, e.g. service user and carers; prescribing; psychological therapies. This will be especially relevant if the physical health CQUIN continues.
4. Consider how to increase feedback from carers.

### Dissemination of findings

NAS will be holding a series of multidisciplinary learning events across England and Wales at the end of 2014. The aim of these one-day workshops will be to:

- Discuss the findings from NAS2 in the local context.
- Discuss the methodology used and elicit suggestions for any future rounds of audit.
- Share good practice.
- Action plan.

A full list of dissemination events attended by NAS in 2013/14 can be found in Appendix H. 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)

### **Service user involvement**

A service user focus group, led by the NAS service user advisor, took place on 9 April 2013. The aims of this group were to revise the updated service user questionnaire and consider ways to improve response rates. Fifteen service users attended, all of whom requested to continue to be involved in the audit.

A smaller service user reference group with seven people took place on 3 July 2014. The aim of this group was to review the data analysis and feedback on the design of the NAS1 lay report. The opinions of this group have been included in the discussion section and the recommendations for NAS2.

NAS were shortlisted for the 'Partnership working with patients and service users' National Clinical Audit and Patient Outcomes Programme (NCAPOP) award 2013.

### **Trust reports**

Trusts will receive their individualised reports ahead of the learning event for their region. They will be encouraged to disseminate findings from this report throughout their Trust, to both professionals and service users and carers. They will be provided with an action planning template. Trusts will be encouraged to complete the template and share it with the NAS team to promote learning across Trusts.

### **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>.

Subsequent to the publication of the NAS1 report in December 2012, the NAS team and Advisory Group have been instrumental in the publication of the following:

Crawford, M., Jayakumar, S., Lemmey, S.J., Zalewska, K., Patel, M.X., Cooper, S., & Shiers, D. Assessment and treatment of physical health problems among

people with schizophrenia: national cross-sectional study. *British Journal of Psychiatry* (accepted for publication).

Patel, M.X., Bishara, D., Jayakumar, S., et al. (2014). Quality of prescribing for schizophrenia: Evidence from a national audit in England and Wales. *European Neuropsychopharmacology*, 24: 499-509.

Shiers, D.E., Rafi, I., Cooper, S.J., & Holt, R.I.G. (2014). *Positive Cardiometabolic Health Resource: an intervention framework for patients with psychosis and schizophrenia. 2014 update (with acknowledgement to the late Helen Lester for her contribution to the original 2012 version)*. London: Royal College of Psychiatrists.

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**NAS**  
NATIONAL AUDIT OF  
SCHIZOPHRENIA



# Appendices

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Commissioned by





## **Appendix A: NAS2 Participating Trusts/Health Boards**

### **Trusts and Health Boards listed in alphabetical order next to their NAS ID code:**

07 2gether NHS Foundation Trust  
30 5 Boroughs Partnership NHS Foundation Trust  
64 Abertawe Bro Morgannwg University Health Board  
68 Aneurin Bevan Health Board  
08 Avon and Wiltshire Mental Health Partnership NHS Trust  
25 Barnet, Enfield and Haringey Mental Health NHS Trust  
09 Berkshire Healthcare NHS Foundation Trust  
73 Betsi Cadwaladr University Health Board  
10 Birmingham and Solihull Mental Health NHS Foundation Trust  
61 Black Country Partnership NHS Foundation Trust  
26 Bradford District Care Trust  
53 Cambridgeshire and Peterborough NHS Foundation Trust  
48 Camden and Islington NHS Foundation Trust  
74 Cardiff & Vale University Health Board  
59 Central and North West London NHS Foundation Trust  
42 Cheshire and Wirral Partnership NHS Foundation Trust  
56 Cornwall Partnership NHS Foundation Trust  
29 Coventry and Warwickshire Partnership NHS Trust  
36 Cumbria Partnership NHS Foundation Trust  
72 Cwm Taf Health Board  
01 Derbyshire Healthcare NHS Foundation Trust  
43 Devon Partnership NHS Trust  
67 Dorset Healthcare NHS Foundation Trust  
11 Dudley and Walsall Mental Health Partnership NHS Trust  
65 East London NHS Foundation Trust  
27 Greater Manchester West Mental Health Trust  
44 Hertfordshire Partnership NHS Foundation Trust  
38 Humber NHS Foundation Trust  
46 Hywel Dda Health Board  
34 Isle of Wight NHS Primary Care Trust

- 12 Kent and Medway NHS and Social Care Partnership Trust
- 13 Lancashire Care NHS Foundation Trust
- 39 Leeds and York Partnership NHS Foundation Trust
- 63 Leicestershire Partnership NHS Trust
- 02 Lincolnshire Partnership NHS Foundation Trust
- 69 Manchester Mental Health and Social Care Trust
- 03 Mersey Care NHS Trust
- 66 NAViGO Health and Social Care CIC
- 33 Norfolk and Suffolk NHS Foundation Trust
- 47 North East London Foundation Trust
- 15 North Essex Partnership NHS Foundation Trust
- 70 North Staffordshire Combined Healthcare NHS Trust
- 37 Northamptonshire Healthcare NHS Foundation Trust
- 60 Northumberland, Tyne and Wear NHS Foundation Trust
- 16 Nottinghamshire Healthcare NHS Trust
- 28 Oxford Health NHS Foundation Trust
- 41 Oxleas NHS Foundation Trust
- 04 Pennine Care NHS Foundation Trust
- 17 Plymouth Community Healthcare
- 51 Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust
- 19 Sheffield Health and Social Care NHS Foundation Trust
- 71 Solent NHS Trust
- 05 Somerset Partnership NHS Foundation Trust
- 06 South Essex Partnership University NHS Foundation Trust
- 20 South London and Maudsley NHS Foundation Trust
- 45 South Staffordshire and Shropshire Healthcare NHS Foundation Trust
- 21 South West London and St George's Mental Health NHS Trust
- 35 South West Yorkshire Partnership NHS Foundation Trust
- 52 Southern Health NHS Foundation Trust
- 50 Surrey and Borders Partnership NHS Foundation Trust
- 54 Sussex Partnership NHS Foundation Trust
- 49 Tees, Esk and Wear Valleys NHS Foundation Trust
- 31 West London Mental Health NHS Trust
- 24 Worcestershire Mental Health Partnership NHS Trust

**Trusts and Health Boards listed numerically by NAS ID code:**

- 01 Derbyshire Healthcare NHS Foundation Trust
- 02 Lincolnshire Partnership NHS Foundation Trust
- 03 Mersey Care NHS Trust
- 04 Pennine Care NHS Foundation Trust
- 05 Somerset Partnership NHS Foundation Trust
- 06 South Essex Partnership University NHS Foundation Trust
- 07 2gether NHS Foundation Trust
- 08 Avon and Wiltshire Mental Health Partnership NHS Trust
- 09 Berkshire Healthcare NHS Foundation Trust
- 10 Birmingham and Solihull Mental Health NHS Foundation Trust
- 11 Dudley and Walsall Mental Health Partnership NHS Trust
- 12 Kent and Medway NHS and Social Care Partnership Trust
- 13 Lancashire Care NHS Foundation Trust
- 15 North Essex Partnership NHS Foundation Trust
- 16 Nottinghamshire Healthcare NHS Trust
- 17 Plymouth Community Healthcare
- 19 Sheffield Health and Social Care NHS Foundation Trust
- 20 South London and Maudsley NHS Foundation Trust
- 21 South West London and St George's Mental Health NHS Trust
- 24 Worcestershire Mental Health Partnership NHS Trust
- 25 Barnet, Enfield and Haringey Mental Health NHS Trust
- 26 Bradford District Care Trust
- 27 Greater Manchester West Mental Health Trust
- 28 Oxford Health NHS Foundation Trust
- 29 Coventry and Warwickshire Partnership NHS Trust
- 30 5 Boroughs Partnership NHS Foundation Trust
- 31 West London Mental Health NHS Trust
- 33 Norfolk and Suffolk NHS Foundation Trust
- 34 Isle of Wight NHS Primary Care Trust
- 35 South West Yorkshire Partnership NHS Foundation Trust
- 36 Cumbria Partnership NHS Foundation Trust
- 37 Northamptonshire Healthcare NHS Foundation Trust
- 38 Humber NHS Foundation Trust

- 39 Leeds and York Partnership NHS Foundation Trust
- 41 Oxleas NHS Foundation Trust
- 42 Cheshire and Wirral Partnership NHS Foundation Trust
- 43 Devon Partnership NHS Trust
- 44 Hertfordshire Partnership NHS Foundation Trust
- 45 South Staffordshire and Shropshire Healthcare NHS Foundation Trust
- 46 Hywel Dda Health Board
- 47 North East London Foundation Trust
- 48 Camden and Islington NHS Foundation Trust
- 49 Tees, Esk and Wear Valleys NHS Foundation Trust
- 50 Surrey and Borders Partnership NHS Foundation Trust
- 51 Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust
- 52 Southern Health NHS Foundation Trust
- 53 Cambridgeshire and Peterborough NHS Foundation Trust
- 54 Sussex Partnership NHS Foundation Trust
- 56 Cornwall Partnership NHS Foundation Trust
- 59 Central and North West London NHS Foundation Trust
- 60 Northumberland, Tyne and Wear NHS Foundation Trust
- 61 Black Country Partnership NHS Foundation Trust
- 63 Leicestershire Partnership NHS Trust
- 64 Abertawe Bro Morgannwg University Health Board
- 65 East London NHS Foundation Trust
- 66 NAViGO Health and Social Care CIC
- 67 Dorset Healthcare NHS Foundation Trust
- 68 Aneurin Bevan Health Board
- 69 Manchester Mental Health and Social Care Trust
- 70 North Staffordshire Combined Healthcare NHS Trust
- 71 Solent NHS Trust
- 72 Cwm Taf Health Board
- 73 Betsi Cadwaladr University Health Board
- 74 Cardiff & Vale University Health Board



## **Appendix B: NAS Advisory Group for NAS2**

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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)

Dr Maxine Patel – Psychopharmacology Special Committee (PSC; RCPsych)

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

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

Paula Reid – Rethink Mental Illness

Yvonne Silove – Healthcare Quality Improvement Partnership (HQIP)

Dr Geraldine Strathdee – National Clinical Director for Mental Health, NHS England

## Appendix C: Modifications to NAS standards

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### **Standard 4** (physical health monitoring):

- Waist/hip ratio was removed (rarely recorded). Amended to BMI and waist circumference alone to simplify the standard and data collection.
- Prolactin removed in order to simplify the standard and focus on cardiometabolic factors. Also there is not a good consensus of views about monitoring of prolactin.

### **Standard 5** (physical health interventions):

- Prolactin removed in order to simplify the standard and focus on cardiometabolic factors.

### **Standard 11** (prescribing):

- Prescribing of a second generation drug prior to clozapine moved to standard 12 which is mainly about the pathway to commencement of clozapine.

### **Standard 12** (prescribing):

- See standard 11, above.

### **Standard 14** (psychological therapies):

- Modified to better match the NICE guideline.

### **Standard 15** (care planning):

- New standard on availability of a care plan.

### **Standard 16** (crisis planning):

- New standard on availability of a crisis plan.

## **Appendix D: Audit lead packs and sampling options**

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### **NAS audit lead packs**

1. Part 1 (preparation and sampling):
  - Covering introductory letter.
  - Guidance booklet for parts 1 and 2.
  - 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 3a (service user and carer survey questionnaires):
  - Guidance booklet for part 3.
  - Document to support staff in responding to queries.
  - 200 x service user survey forms with Trust ID pre-printed.
  - 200 x carer survey forms with Trust ID pre-printed.
  - Service user cover letter example.
  - Carer cover letter example.
  - 200 x Rethink Mental Illness leaflets: 'How is your service?'
  - 200 x service user FAQs.
  - 200 x carer FAQs.
  - 400 x pre-paid envelopes.

Part 3b (service user reminders)

  - Reminder letter from Rethink Mental Illness.
  - 200 x pre-paid envelopes.

### **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 Rethink Mental Illness leaflet 'How's your service?'
- 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.

### **Sampling**

The following sampling instructions were sent to Trusts and Health Boards. It was expected that, where Option 1 was employed, the identification of service users would usually be from an electronic database within the Trust.

'Using one of the options below, identify all patients receiving care from your Trust/Health Board who meet the eligibility criteria for this audit. The NAS team will then generate random numbers for patients for the service user survey and the audit of practice (200 patients in total).

The same service user can receive a questionnaire and be included in the audit of practice.

#### **Sampling option 1:**

- Identify all service users across the Trust/Health Board meeting the criteria on the census day. Assign each a number and add them on a list.
- Contact the NAS central team with the total number of patients meeting NAS criteria. The NAS team will randomly select a total of 200 numbers relating to patients on this list. Send the service user questionnaire to all these 200 patients.

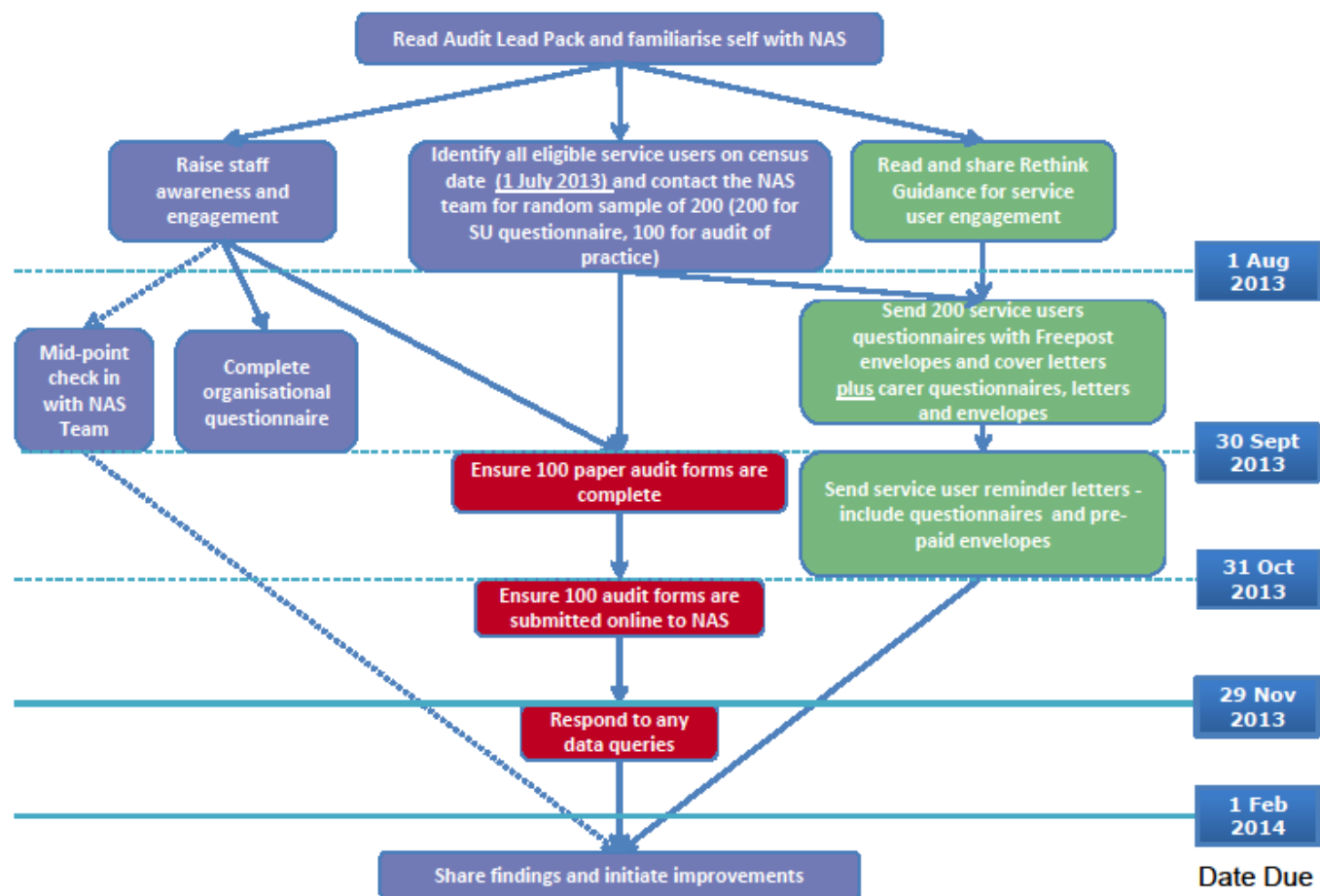
- NAS team will also randomly select a subsample of 100 of these 200 patients to complete the audit of practice.
- Assign each patient from the subsample selected for the audit of practice a NAS patient ID (number 1-100). **Please do not send any lists to the NAS team.**
- Contact the consultants responsible for the care of these 100 patients so they can collect the audit data.

**Sampling option 2:**

- Contact all consultants in the Trust 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 on the census day. Compile these patients on a central list and number them.
- Contact the NAS central team with the total number of patients meeting NAS criteria. The NAS team will randomly select a total of 200 numbers relating to patients on this list. Send the service user questionnaire to all these 200 patients.
- NAS team will also randomly select a subsample of 100 of these 200 patients to complete the audit of practice.
- Assign each patient from the subsample selected for the audit of practice a NAS patient ID (number 1-100). **Please do not send any lists to the NAS team.**
- Contact the consultants responsible for the care of these 100 patients so they can collect the audit data.

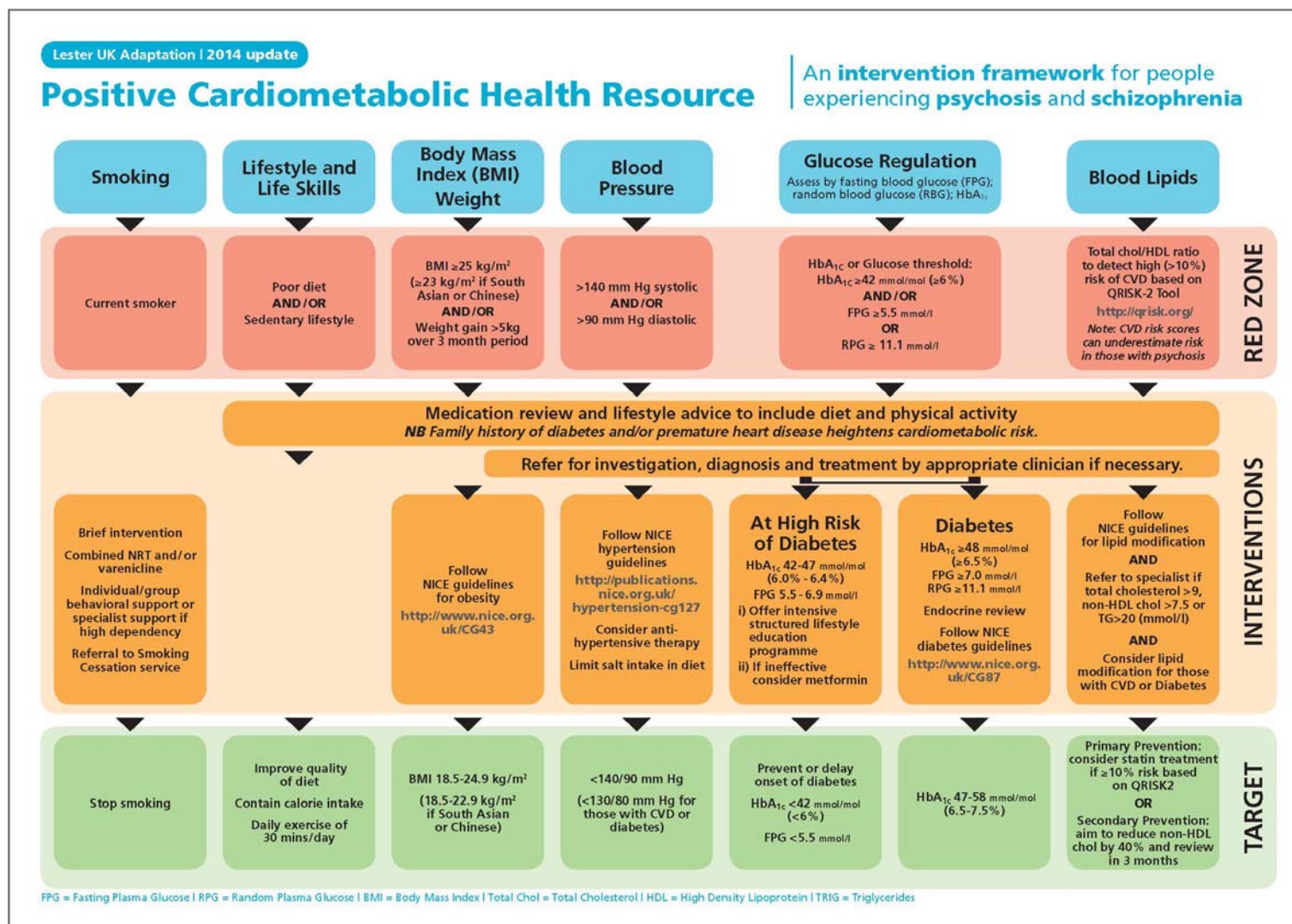
Your sample for collecting service user and carer feedback through the questionnaires should **not** include patients who have requested that they must be contacted via another person.'

## Appendix E: NAS process flowchart



NAS Local Process Flow Chart

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



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

**Frequency:** Normally supervised by the psychiatrist. As a minimum review those prescribed a new antipsychotic at baseline and at least once after 3 months.  
 Weight should be assessed weekly in the first six weeks of taking a new antipsychotic, as rapid early weight gain may predict severe weight gain in the longer term.  
 Subsequent reviews should take place annually unless an abnormality of physical health emerges. In these cases, appropriate action should be taken and/or the situation should be reviewed at least every 3 months.

#### At review

**History:** Seek history of substantial weight gain (e.g. 5kg), especially 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 <55 yrs male relatives and <65 yrs female relatives) and gestational diabetes. Note ethnicity.

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

**Investigations:** Fasting estimates of plasma glucose (FPG), HbA1c, and lipids (total cholesterol, non-HDL, HDL, triglycerides). If fasting samples are impractical then non-fasting samples are satisfactory for most measurements except for triglycerides.

**ECG:** Include if history of CVD, family history of CVD; where examination reveals irregular pulse (if ECG confirms atrial fibrillation, follow NICE recommendations <http://guidance.nice.org.uk/CG36>), or if patient taking certain antipsychotics (See SPC) or other drugs known to cause ECG abnormalities (eg erythromycin, tricyclic anti-depressants, anti-arrhythmics – see British National Formulary for further information).

**Chronic Kidney Disease\*\*:** Screen those with co-existing diabetes, hypertension, CVD, family history of chronic kidney disease, structural renal disease (e.g. renal stones) routinely:

1. Monitor renal function:
  - a) urea & electrolytes
  - b) estimated glomerular filtration rate (eGFR)
2. Test urine:
  - a) for proteinuria (dip-stick),
  - b) albumin creatinine ratio (laboratory analysis)

\*Presence of chronic kidney disease additionally increases risk of CVD.  
 Follow appropriate NICE guidelines on chronic kidney disease.

#### Monitoring: How often and what to do

Applies to patients prescribed antipsychotics and mood stabilizers.

	Baseline	Weekly first 6 weeks	12 weeks	Annually
Personal/FHx	■			■
Lifestyle Review <sup>1</sup>	■			■
Weight	■	■	■	■
Waist circumference	■			■
BP	■		■	■
FPG/HbA <sub>1c</sub>	■		■	■
Lipid Profile <sup>2</sup>	■		■	■

<sup>1</sup>Smoking, diet, and physical activity <sup>2</sup>If fasting lipid profile cannot be obtained, a non-fasting sample is satisfactory  
 Monitoring table derived from consensus guidelines 2004, *J Clin Psychol* 65:2. APA/ADA consensus conference of 2004 published jointly in *Diabetes Care* and *Journal of Clinical Psychiatry* with permission from the Ontario Metabolic Task Force.

### Specific lifestyle and pharmacological interventions

Specific lifestyle interventions should be discussed in a collaborative, supportive and encouraging way, taking into account the person's preferences:

- **Nutritional counselling:** reduce take-away and "junk" food, reduce energy intake to prevent weight gain, avoid soft and caffeinated drinks and juices, and increase fibre intake.
- **Physical activity:** structured education-lifestyle intervention. **Advise physical activity such as a minimum of 150 minutes of 'moderate-intensity' physical activity per week** (<http://bit.ly/Oe7De5>). For example suggest 30 minutes of physical activity on 5 days a week.

**If the patient has not successfully reached their targets after 3 months, consider 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. (If total cholesterol >9, non-HDL chol >7.5 or TG>20 (mmol/l), refer to metabolic specialist.) 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 a metformin trial** (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/guidance/ethical\\_guidance/14327.asp](http://www.gmc-uk.org/guidance/ethical_guidance/14327.asp). 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 500mg once daily and build up, as tolerated, to 1500-2000mg daily.

#### Review of antipsychotic and mood stabiliser medication:

Discussions about medication should involve the patient, the general practitioner and the psychiatrist. 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 effects:
- As a first step prescribed dosages should follow BNF recommendations; rationalise any polypharmacy.
  - Changing antipsychotic medication requires careful clinical judgment to weigh any benefits against the risk of relapse of the psychosis.
  - An effective trial of medication is considered to be the patient taking the medication, at an optimum dosage, for a period of 4-6 weeks.
  - If clinical judgment and patient preference support continuing with the same treatment, then ensure appropriate further monitoring and clinical considerations are carried out regularly.

It is advised that all side effects to antipsychotic medication are regularly monitored, especially when commencing a new antipsychotic medication (**GASS questionnaire** <http://mentalhealthpartnerships.com/resource/glasgow-antipsychotic-side-effect-scale/>), and that any side effects, as well as the rationale for continuing, changing or stopping medication is clearly recorded and communicated with the patient.

The Psychiatrist should maintain responsibility for monitoring the patient's physical health and the effects of antipsychotic medication for at least the first 12 months or until the person's condition has stabilised, whichever is longer. Thereafter, the responsibility for this monitoring may be transferred to primary care under shared care arrangements. Discuss any non-prescribed therapies the patient wishes to use (including complementary therapies) with the patient, and carer if appropriate. Discuss the safety and efficacy of the therapies, and possible interference with the therapeutic effects of prescribed medication and psychological treatments.

Available for download from [www.rcpsych.ac.uk/quality/nas/resources](http://www.rcpsych.ac.uk/quality/nas/resources)



## **Appendix G: Data cleaning**

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Data cleaning was carried out between December 2013 and May 2014. A detailed process was outlined for NAS staff to follow to check that the sampling criteria were followed correctly by Trusts and to check for duplication of data, missing data, and unexpected values. Data cleaning was carried out in three phases:

### **Phase 1:**

- Screen for duplicate cases and 'orphan' cases.
  - 78 duplicate cases were removed.
  - Orphan cases removed: 12 cases in the database had no Trust identified with the data submitted. Various approaches were used to try to identify them with a particular Trust but these were only successful for two cases. Both of these turned out to be duplicate entries for other cases and were deleted.
- Screen for cases outside age limits for inclusion.
- Ensure all details relating to demography and diagnosis have been entered.
- Screen for cases where incompatible data were entered (e.g. Q9 says 'on clozapine' but no dose entered for clozapine in Q11f).
- Detailed screen of doses of antipsychotic medications:
  - Doses above BNF 100%.
  - Combined doses above 100% BNF.
  - Drugs prescribed that are not currently in the BNF. Details of these are provided in Table 37. All of these drugs and doses were included for analysis in the 'Final' database.
  - Doses prescribed not possible from available posology.
  - Doses of depot or LAI formulations entered in the correct place.
- Detailed screening of data entries for cases regarded as not in remission. Review of entries in Sections E & F of the audit of practice tool in relation to entries in other related sections.
- Detailed screen of entries in Section G on physical health:
  - Values reported that are outside the usual normal ranges.

- Values that seem incompatible with each other (e.g. systolic and diastolic blood pressures entered in reverse).
- Compatibility of medical history data with data for individual test results.

Where potentially aberrant data were found a 'data query' was sent to the respective Trust. This process generated 2,202 data queries, the largest group of which related to doses of medication entered.

**Phase 2:**

- Thirty-five cases were removed as screening and responses to data queries indicated that they did not meet the selection criteria. Reasons included: diagnosis made after age 60 years; being an inpatient on the audit census date; had died before the census date; had moved elsewhere for treatment on the census date.
- The Trusts' responses to data queries were reviewed and revised information entered. Some of the more common issues encountered were:
  - Many data queries were about doses of drugs that had been entered under the wrong medication.
  - Problems entering daily or weekly doses of medication because on the Trust computer system the on-line database would not accept a decimal point. Amended doses were entered.
  - Queries on physical health parameters where the wrong units had been used or data were entered in the wrong place.
- At this point we also reviewed all of the responses placed in boxes labeled 'other' or 'none of the above, please state reason' supplied in the audit of practice tool. Many of these responses were actually compatible with existing categories supplied and were appropriately recoded. (The text boxes had included additional narrative.) There were some responses in these boxes that were sufficiently numerous or important to be grouped together and included for analysis as additional categories.
- Not all data queries received a response and where these were critical to the integrity of the database they were sent out again.
- After updating all of this information, a copy of the revised database for each Trust was sent to them for a final check on the data they had supplied.

Trusts were also asked to examine particular aspects of their data for issues that we had found to be more problematic than others.

### Phase 3:

- Following receipt of all amended data from the Trusts a 'pre-Final' database was created. This consisted of all the data provided by Trusts with any duplicate and 'orphan' cases removed.
- All of these data were then reviewed to examine the extreme ends of ranges for doses of medication and physical health parameters. A small amount of data were so far outside normal doses/ranges that a decision was made to recode these values to '9999' which would then, for most purposes, be regarded in the SPSS analyses as a missing value. This decision was made by a panel of the NAS team (SJC, DS, SL) and an Advisory Group member (MXP), with input where necessary from an academic Consultant diabetologist (Professor Richard Holt).  
(Please note that for any case where data were amended the other data for the case were retained as provided by the Trust. No cases were deleted because of these data uncertainties.)
- The database with these NAS team amendments included is the 'Final' database and the one used for the data analyses presented in this report.
- Instances where data were amended to '9999'/'missing value' are detailed below:
  - Doses of medications where the dose reported was >400% of the upper limit allowed in the BNF. Such a dose is extremely unlikely to be prescribed by a doctor and/or dispensed by a pharmacist. Also, service users' doses of medication are generally reviewed by their community nurse, if they have one, who would be likely to note such an aberrant dose.
    - (i) one fluphenazine depot case where the dose was >400% BNF.
    - (ii) three cases where the dose of one (in italics) of the two drugs prescribed was >400% BNF – *paliperidone LAI* & aripiprazole oral; *pipotiazine depot* & quetiapine oral; *risperidone oral* & quetiapine XL oral.

- One case with a systolic blood pressure submitted of 5.30mmHg with no record of a diastolic.
- One case with a glucose of 80mmol/l recorded but there was no other evidence of having diabetes (e.g. on medical history data). If glucose was 80mmol/l the individual would be extremely ill and it would be unlikely a diagnosis of diabetes had not been recorded.
- One case with HbA<sub>1c</sub> >140mmol/mol where the blood glucose was incompatible with this and there was no medical history of diabetes.
- Two cases with cholesterol of >40 mmol/l reported (usual normal range <5.2 mmol/l).
- Three cases with exceptionally high HDL of >10.0mmol/l reported. These were likely to be errors in placing of the decimal point but as the Trusts did not respond to data queries they were recoded as 'missing values'.
- Waist circumference data were only returned for 578 cases (i.e. <10% of the total audit population). The range was 17–184cm. These data were judged to be insufficient, and clearly partially unreliable. These data were not amended but it was decided not to use them in the analyses.
- There were other instances where data with extreme values was retained for the analysis:
  - One case had a BMI of 12.0. Though unusual, this was retained.
  - Six cases with unusually high blood glucose levels (between 30mmol/ and 50mmol/l), but evidence in three of a diagnosis of diabetes. These were all retained.
  - Six cases with unusually low blood glucose values were all retained.
  - 35 cases with unusual HbA<sub>1c</sub> values reported. A number of these were almost certainly being reported in the wrong units. Some of these cases had incompatible blood glucose results. It was decided to give glucose data primacy in the data analysis and retain the HbA<sub>1c</sub> data.

**Table 37: Details of non-licensed medications prescribed**

Medication	Upper dose limit	Doses prescribed	Other drug if being given in combination	Total dose as percentage of BNF maximum
Fluspirilene depot	10mg/week	8mg/week	-	80%
Melperone	400mg/day	100mg/day	-	25%
Sertindole	24mg/day	1mg	-	4%
		4mg	Risperidone LAI	32%
		4mg	-	17%
		6mg	-	25%
		13mg	-	54%
Thioridazine	600mg/day	300mg/day	-	50%
Zotepine	300mg/day	5mg	Clozapine	32%
		300mg	Haloperidol	167%
		300mg	-	100%

## Appendix H: Dissemination from NAS1 in 2013-14

Event	Date	Further information
<b>RCPsych London Division</b> Divisional learning event, London	17 January 2013	
<b>5 Boroughs Partnership</b> Joint Academic Forum, Warrington	21 January 2013	Presentation by Professor Stephen Cooper
<b>West Midlands region Mental Health Trusts audit meeting</b> Shared learning event for MH Trusts in West Midlands, Dudley	31 January 2013	Presentation by Dr David Shiers
<b>RCPsych Welsh Division</b> Divisional Spring meeting 'The Future of Psychiatry', Swansea	17 May 2013	Presentation by Dr David Shiers
<b>South Essex Partnership University NHS Foundation Trust</b> Service user focus group, London	28 May 2013	Presentation by Angela Etherington on the physical health findings from NAS1
<b>East of England clinical network</b> Managed clinical network meeting	18 June 2013	Presentations by Angela Etherington and Dr David Shiers on the findings from NAS1
<b>Royal College of Psychiatrists' International Congress</b> Annual psychiatry conference, Edinburgh	2 July 2013	Presentation by Professor Stephen Cooper
<b>Healthcare Quality Improvement Partnership (HQIP)</b> Annual conference, Nottingham	14-15 Oct 2013	Poster and oral presentation, by Angela Etherington and Suzie Lemmey, on service user involvement (NCAPOP awards shortlist)
<b>Govknow</b> Mental Health Conference, London	21 November 2013	Presentation by Professor Sue Bailey, former President of the Royal College of Psychiatrists
<b>Clinical Audit for Improvement 2014 supported by HQIP</b> Clinical audit conference, London	26-27 February 2014	Presentations by Angela Etherington and Suzie Lemmey
<b>Improving physical health for people with mental health conditions</b> Mental health conference, Birmingham	20 May 2014	Stand
<b>Healthcare events</b> 'Psychosis and Schizophrenia in Adults', London	3 June 2014	Presentation by Angela Etherington and Krysia Zalewska.

Please refer to the report from NAS1 (Royal College of Psychiatrists, 2012) for a list of dissemination activities prior to January 2013.

## 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*.

**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*. (The term blood glucose is used in this report as a more familiar terminology for non-medical readers than the more correct plasma glucose.)

**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.

**Carers' and Users' Expectations of Services (CUES):** Questionnaire from which the NAS service user survey was derived (for full details see page 41).

**Carer Well-Being and Support (CWS):** Questionnaire from which the NAS carer survey was derived (for full details see page 41).

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

**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.

**Chief Clinical Informatics Officer:** A *clinician* who provides leadership and management of ICT (information and communication technology) and information development activity to support the safe and efficient design, implementation and use of computing technologies and development (informatics) solutions to deliver improvements in the quality and outcomes of care.

**Chief Executive (CEO):** Appointed as the lead of a health organisation, e.g. a *Trust*, to manage how healthcare is delivered.

**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 Commissioning Groups (CCGs):** Groups of *clinicians* led by *GPs* who take on the role of purchasing local health services in England.



**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.

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

**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 (CMHP):** 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.

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

**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.

**CQUIN:** The Commissioning for Quality and Innovation (CQUIN) payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals.

**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.

**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 which increases the risk of having a heart attack or a stroke.

**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:** Whether a family member has suffered a common or relevant physical health condition, for example *diabetes*.

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

**General Medical Council:** The body that approves doctors to practice medicine in the UK and regulates their work.

**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 Boards:** The Welsh equivalent of NHS *Trusts*.

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

**Health Education England (HEE):** Established as a Special Health Authority in June 2012 to ensure that the workforce has the right skills, behaviours and training, and is available in the right numbers, to support the delivery of excellent healthcare and drive improvements (<http://hee.nhs.uk/>).

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

**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*.

**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.

**Increasing Access to Psychological Therapies (IAPT):** The IAPT for Severe Mental Illness (SMI) project aims to increase public access to a range of NICE approved psychological therapies for psychosis, bipolar disorder and personality disorders (<http://www.iapt.nhs.uk/smi-/>).

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

**Lester Resource:** See Appendix F.

**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.

**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.

**Mental Health and Learning Disability Data Set (MHLDDS):** An approved NHS Information Standard that delivers information on people in contact with specialist secondary mental health services. It covers not only services provided in hospitals, but also in outpatient clinics and in the community, where the majority of people in contact with these services are treated.

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

**mmHg:** Millimeters of mercury.

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

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

**National Clinical Audit Programme (NCA):** 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. The programme is funded by NHS England and the Welsh Government.

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

**NHS England:** The National Health Service (NHS) England exists to care for people. Their goal is to provide high quality care for everyone, now and in the future. At a more local level, NHS England works together with *Clinical Commissioning Groups* (CCGs) who deliver health services locally, and local authorities (Councils) to make shared plans for services that put patients at the centre (<http://www.england.nhs.uk/>).

**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.

**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.

**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 of illness, smoking, *substance misuse* and alcohol intake plus measures of weight, height, *blood pressure* and blood levels of *glucose*, *lipids* and *prolactin* (if indicated).

**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.

**POMH-UK:** The Prescribing Observatory for Mental Health-UK is a system of *audit*, managed through the *Royal College of Psychiatrists*, for assisting clinical staff in *Trusts* to monitor and improve their practice in relation to the use of medications in the treatment of *service users* with mental illnesses.

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

**Pre-diabetic state:** This describes a state in which some but not all of the diagnostic criteria for *diabetes* are met. It is where control of blood sugar levels is not normal but not yet definitely sufficiently abnormal to say that diabetes has developed.

**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.

**Prognosis:** The prognosis for a *service user* is an opinion, usually given by a senior doctor, of how a service user's illness is likely to respond to treatment and what the longer term outlook for that person may be.

**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.

**Psychopharmacology:** The name for the science surrounding our knowledge of the mechanisms of action of, and practice of, prescribing of medications that are used in the treatment of many mental disorders. For example *antipsychotic*, antidepressant and antianxiety medications.

**Psychosis:** A term describing people having specific types of symptoms, 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.

**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.

**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 a questionnaire 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.

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

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

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

**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*.

**Secondary care:** This refers to care provided by specialist teams in *Trusts* rather than care provided by *general practitioners* and *primary care* services. Mental Health Trusts provide secondary care services, most of which involve care provided in the community rather than in hospitals.

**Service user:** 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.

**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 unresponsive:** 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, this 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 unresponsive to treatment 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 (NHS) 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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The Royal College of Psychiatrists is a charity registered in England and Wales (228636)  
and in Scotland (SC038369)  
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