

National Audit of Schizophrenia

What you need to know



Key facts

- Schizophrenia affects 220,000 people in England and Wales.
- The National Audit checked how much different Trusts were following national guidelines on care and treatment.
- The Audit looked specifically at:
 - The experiences of people affected by schizophrenia.
 - How involved people felt in their care.
 - Antipsychotic prescribing.
 - Physical health support.
 - Access to psychological therapies.

What is the National Audit of Schizophrenia?

Schizophrenia affects approximately 220,000 people in England and Wales. It can massively affect those people's lives. The care of people with schizophrenia is a national priority and there are many guidelines explaining how to provide this care.¹

But there are large differences in people's experiences of care and treatment across the country. There are also clear problems with key aspects of care. For example people affected by severe mental illness can die up to 20 years younger than everyone else because of poor physical health.

So it is very important to understand what services people with schizophrenia are receiving and where improvements should be made. This is what the National Audit of Schizophrenia (NAS) was set up to do. By looking at different pieces of guidance around schizophrenia and working out key priority areas, the audit measured how much different Trusts were following these guidelines.

What does the audit focus on?

The audit team had to choose some key parts of national guidance to focus on. The audit asked people affected by schizophrenia and schizoaffective disorder to give their views about what was important. Charities and health professionals also explained what they thought was important.

From this feedback, the project team decided on five key areas for the audit:

- The experiences of people using mental health services and their carers.
- How involved people feel in their care.
- Prescribing antipsychotic medication.
- Access to psychological therapies.
- The physical health support available for people affected by schizophrenia.

From these priority areas, the project team then developed a set of 14 standards. These standards helped to measure how Trusts are doing in these priority areas and show where Trusts need to improve services. You can find a full list of standards at the end of this report (see Appendix 1).

1. For examples, please see National Institute for Health and Clinical Excellence (2009) Schizophrenia (CG82) and Department of Health (2011).

How was the information collected?

The audit covered people aged 18 years and older with a diagnosis of schizophrenia or schizoaffective disorder who were using community mental health services. All Mental Health Trusts and Health Boards in England and Wales that cover this population were asked if they wanted to be part of the audit (when we talk about Trusts in this report we also mean Health Boards). In the end 60 out of 64 Trusts took part.

Once a Trust agreed to take part in the audit, they had to randomly identify 200 people with a diagnosis of schizophrenia or schizoaffective disorder who were using their community mental health services. These people then received a questionnaire about their experience of local services. They also received a carer questionnaire to pass on to their carer if they had one. The carer version of the questionnaire asked questions about the information and support for carers. Both questionnaires were anonymous. In total, 2,323 people with schizophrenia and 1,163 carers returned their questionnaires.

The Trust also had to randomly select 100 patient records and then send anonymous information from the records to the audit. This included information on the medication they were prescribed and whether there was a note of a physical health check on the person's record. For some people there will be results from their personal questionnaire as well as results from their Trust record. However we do not know for whom there is both as the information is all anonymous.

The National Audit team then combined information from the questionnaires and the patient records. They compared this information against the standards they had set on people's experiences of services, involvement, physical health, antipsychotic prescribing and psychological therapies.

What did the audit find out?

1. Experiences of people using services and experiences of carers

The audit looked at people’s experiences of care, outcomes for those people and the experiences of carers (standards 1-3).

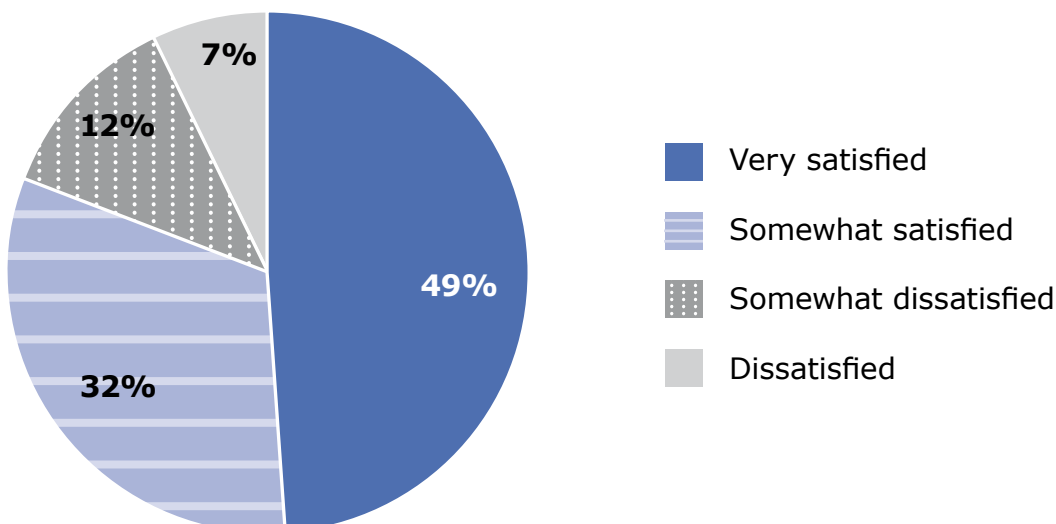
Experience of care

On average, 76% of people had positive experiences of care. While this is much higher than the 60% target set for this first audit, this still leaves nearly a quarter of people not having a positive experience of care. In some Trusts, more than 35% of people had bad experiences of care. The audit team believes that the target should be set higher for future audits. This would motivate Trusts to make improvements so that people have a better experience of care. There are other aspects of people’s experience that it might be useful to ask about in future audits to get a fuller picture. These include questions about housing, activity or social isolation.

Outcomes of care

78% of people said they had had positive outcomes. While this is encouraging, in some Trusts many fewer people said they had positive outcomes. Again, the audit team believes that the target should be set higher for future audits.

Figure 1: Carers’ satisfaction with information and support received over the past 12 months



Experience of carers

Between 14% and 78% of carers from different Trusts said they were very satisfied with the information and support they receive. This is a huge range. On average though 19% were dissatisfied with the information and support they received (see Figure 1).

It is crucial that carers are able to access high quality information and appropriate support when they need it. The involvement of carers in decisions about care and treatment can offer valuable information and insight when appropriate. It is therefore vital they can access information to help them be involved in decisions about the person they care for, if consent has been given.

What recommendations did the audit make for improvements in this area?

- Mental Health Trusts should involve both local people who use services and carers in developing an action plan for improving the care and support they offer.
- For the next audit the minimum requirements for experiences and outcomes should be raised so services continue improving.

2. Shared decision-making

The audit looked at how involved people felt in their care and the information they received (standards 6-7).

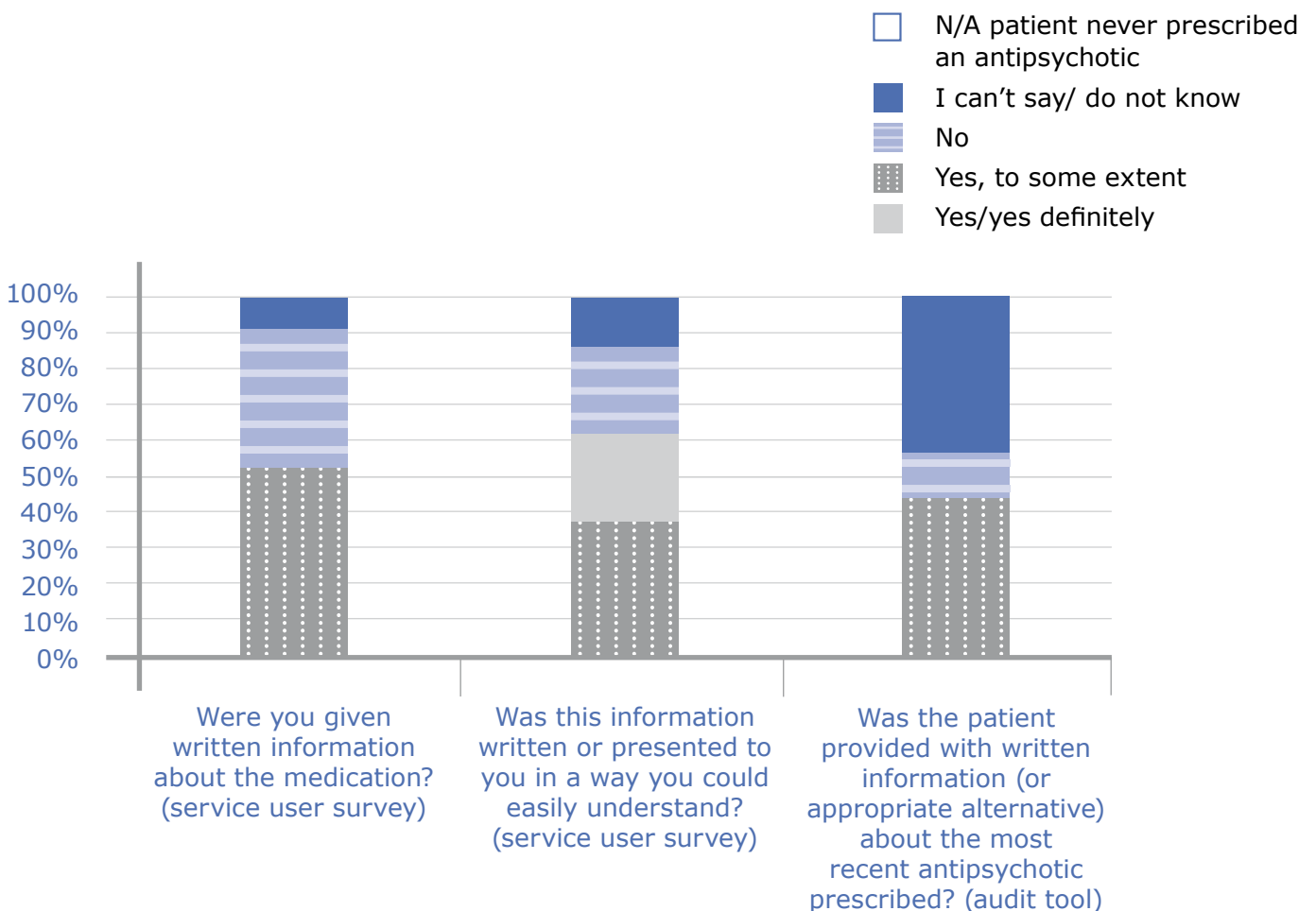
Accessible information

There was a big difference between what the Trusts reported and what people said in questionnaires. Data from Trusts said they provided information about medication in 43% of cases. However, in 44% of cases it was unclear from the records whether information had been offered or not. This is worrying as providing information is key to involving people in their care and empowering them to make informed decisions. There should be systems in place to ensure this is happening and is being recorded.

The questionnaires showed that 52% of people had been offered information. However, only 38% of people who had received information said it was definitely easy for them to understand (see Figure 2).

The left hand and middle columns of Figure 2 show data from the service user survey. The right hand column shows results from the patient records.

Figure 2: Whether people were given understandable written information



This highlights the need to improve how Trusts provide information so people can make informed choices around treatment and care. This is particularly important around medication as side effects can have a significant physical health impact and people need to be informed about risks as well as benefits.

Involvement in decisions about care

Only 41% of people answering questionnaires said that their views had definitely been taken into account in decisions around antipsychotic medication. The Trust data however said that just over 60% of people were involved in decisions. This reveals that professionals and people using services may hold different views on what involvement in decisions means. In almost a third of cases, the patient records were unclear about whether people were involved in decisions or not. The emphasis the NHS now places on patient-centred care and shared decision-making must also apply to people using mental health services. This audit suggests that this aspect of care needs improvement.

What recommendations did the audit make for improvements in this area?

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

3. Prescribing

The audit looked at how antipsychotic medications are prescribed (standards 8-13).

Multiple medications

The audit looked at how many people took two or more antipsychotic medications. Current guidelines on schizophrenia recommend that people should take just one antipsychotic medication at a time. Sometimes, psychiatrists might prescribe clozapine alongside another antipsychotic if people are not responding to the medication, but usually the recommendation is one antipsychotic medicine.

Prescribing more than one antipsychotic can increase the chance of negative side effects. The audit showed that, on average, just over 16% of people were taking two or more antipsychotic medications, and in some Trusts this reached 30%. The wide range of different results suggests that practice is inconsistent and this aspect of care needs to improve significantly.

Dosages

For most people, it will not help to exceed the maximum recommended dose of a medication. Again, Trusts showed great variation in rates of prescribing above recommended maximum levels. In some Trusts this was as low as 1%, but in others it was up to 15%. Such wide variation indicates this important aspect of practice could be improved and that existing guidance should be better put into practice.

Lack of response to medication

If people do not respond to treatment, it is very important that people, professionals and carers, explore the possible reasons for this. The audit looked at two key reasons why people might not be responding to medication, and what professionals were doing to investigate these:

1. People might not be taking their medication as advised, which could make it less effective. The audit shows that professionals discussed this in over 90% of cases in most Trusts, although in some Trusts this dropped to 60% - 80% of cases.
2. Or it could be that people are using alcohol or other substances which are reducing the effectiveness of medications. The audit suggests that professionals considered this in over 80% of cases on average, though this dropped as low as 47% in one Trust.

It is encouraging that most professionals are exploring the reasons for poor responses to medication, but there is scope for improving practice.

Clozapine

The audit also looked at the process that health professionals should follow before prescribing clozapine. Clozapine is often reserved for people who are receiving little benefit from standard antipsychotic treatment. In these cases a person's illness might be described as 'treatment resistant'. In general, around 30% of people affected by schizophrenia have a treatment resistant illness.

Before prescribing clozapine, guidelines recommend that people should try two different antipsychotic medications for at least four weeks to see if they are effective. In 86% of cases, professionals had followed this procedure. But some people may have had only one antipsychotic medication before starting clozapine. In other cases, different parts of the process have not been followed. It is unclear whether this difference is due to a person being severely unwell, poor recording of medication in the medical notes, or professionals not following the recommended process.

More people seemed to be taking clozapine than previous research suggested. This is probably because the audit focused on people being treated by secondary care services, which would include more people whose illness was treatment resistant. Even so, the audit showed that there were many people who were treatment resistant but had not been offered clozapine, without any recorded explanation why it had not been considered. This suggests that some people are not being offered recommended treatments and Trusts should look closely at this issue.

However, for many people whose illness is treatment resistant, clozapine will not be effective, even if the correct prescribing process is followed. In these cases it can be worthwhile adding a second antipsychotic medication to clozapine. The audit found that this had been done in only 28% of cases where it might have been helpful to add a second medication. This is an area of prescribing that needs further research and this low number could reflect the lack of evidence for this approach.

What recommendations did the audit make for improvements in this area?

- Psychiatrists should be aware of the upper limits for prescribing antipsychotic medication. If they prescribe above this level they should always note the reason why and discuss and agree this with the person taking the medication.
- Trusts should make sure health professionals put into practice guidelines for prescribing antipsychotic medications and guidelines for prescribing above the recommended dose.
- Trained clinical pharmacists should be available to offer advice to other professionals on dosage and on prescribing more than one antipsychotic medication.

4. Psychological therapies

The audit looked at how many people could get access to psychological therapies, such as cognitive behavioural therapy or family therapy, for people whose illness is treatment resistant (standard 14).

Cognitive behavioural therapy and family therapy are both recommended in the guidelines on schizophrenia from the National Institute of Health and Clinical Excellence (NICE).

The audit showed that 66% of eligible people had been offered some form of psychological therapy. There was wide variation. Some Trusts offered psychological therapies in just 6% cases. But others offered it in 100% cases. Again this demonstrates that a large number of people are not being offered treatments that could have a real and positive impact on their condition.

What recommendations did the audit make for improvements in this area?

- Increase access to psychological therapies, particularly cognitive behavioural therapy, family therapy and other evidence-based treatments for people with schizophrenia.
- Trusts should identify and address the barriers they face in offering these therapies.

5. Physical health

The NHS has recently been prioritising the physical health of people with severe mental illness. This is because people in this group can die up to 20 years earlier than everyone else from preventable physical health conditions. People need comprehensive physical health monitoring at least once a year to help with risk factors, for example, the weight gain associated with antipsychotic medication.

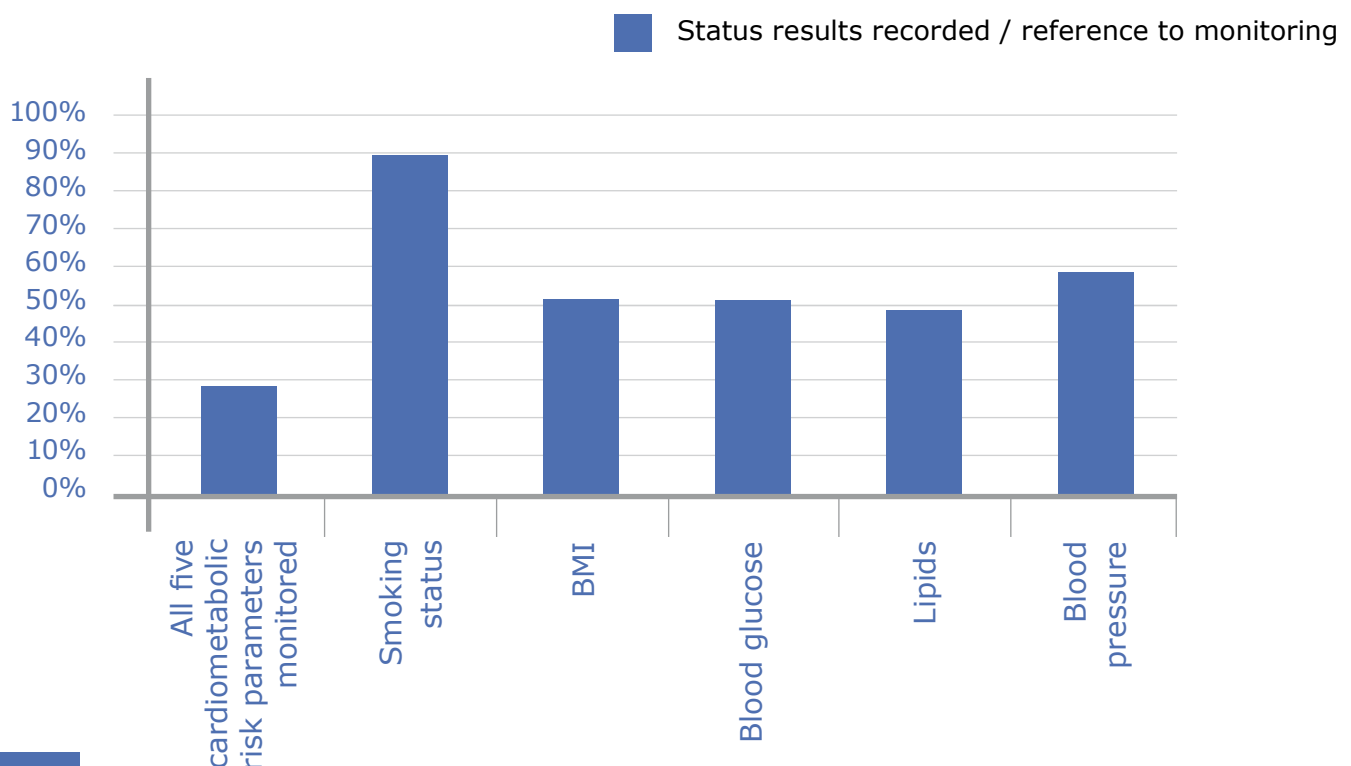
The audit looked at whether people had had a physical health check and what action Trusts took as a result of checks (standards 4 and 5).

Getting a check

The audit revealed that, on average, only 29% of people had received a full check of Body Mass Index (BMI), smoking, blood pressure, blood glucose and lipids in the previous 12 months. These are key risk factors for conditions such as heart disease and diabetes, so it is important they are checked. In some Trusts, this number was below 15%. There was also a large variation in the results. This suggests there is not a consistent approach across the country and that physical health is not being properly prioritised.

There also appear to be many differences in which risk factors professionals monitor. In 88% of cases, records included notes on smoking status. But notes on weight or BMI were only included in about half of cases (see Figure 3). This is particularly worrying as medication can cause significant weight gain and this can lead to heart disease and diabetes. If people’s physical health is not being monitored properly, then they will not receive the support or services they need to avoid serious health complications.

Figure 3: Whether key physical health checks have been carried out in the past 12 months



The column 'all five cardiometabolic risk indicators monitored' in Figure 3 includes smoking status, BMI, blood glucose, lipids and blood pressure.

When people using services were asked if they had received a physical health check in the last 12 months, the number was much higher, with 78% saying they had had a check, versus 29% of service users who Trusts said had had a full check. This large difference could indicate that people are unclear what a full health check involves.

For example, someone might think they have had a health check if they were weighed and asked about smoking. However, a full physical health check involves a whole range of different tests.

People need more information about physical health checks. There are also no clear guidelines or agreements among health professionals as to whose responsibility it is to monitor physical health. This means that checks can be missed and it also makes it difficult for people to know with whom they should raise their physical health concerns.

Taking action on physical health results

The results on this were varied. 76% of people with high BMI measurements were offered support or advice. However, only 25% of those with high blood pressure were offered appropriate treatment. This shows that a lot of people are not getting the right support, even when the checks are showing they need it. If these risk factors continue to be ignored, people's physical health could deteriorate and they could become seriously unwell. It is important that interventions are made early so that these risk factors can be addressed and treated.

What recommendations did the audit make for improvements in this area?

- Trusts should agree locally who is responsible for physical health monitoring at different stages of a person's care. Trusts could use the Integrated Physical Health Pathway, developed by Rethink Mental Illness, to help them do this.
- All health professionals working with people affected by mental illness should have training on common physical health problems experienced by this group. This includes being able to assess physical health and identify any problems.
- Health professionals should refer to the Positive Cardiometabolic Health Resource to be clear what to measure when and what action to take if concerns are raised.
- If someone needs treatment for physical health problems, staff in mental health services should support people to access this treatment.
- Mental health services should have access to the correct equipment to monitor a person's physical health.

What happens next?

This report highlights just some of the key recommendations made by the audit. A full list of the recommendations can be found in the national report and on the National Audit of Schizophrenia website (see below). We hope that Trusts and other bodies involved in the care of people with schizophrenia will consider these recommendations to improve their practice and take action where needs have been identified.

Where can I see how my Mental Health Trust did?

The results of this audit are anonymous. But the audit will happen again in 2013 to track what improvements Mental Health Trusts and other bodies have made.

Who ran the audit?

The audit is managed by the College Centre for Quality Improvement (CCQI) at the Royal College of Psychiatrists (RCPsych). There is also a project team and advisory committee made up of health professionals, charities, people with mental illness and carers.

Want more information?

If you want to read the whole list of recommendations, find out more or keep up to date on the progress of the project, go to www.rcpsych.ac.uk/quality/NAS



Glossary

Adherence: For this report, this means taking medication in a way that allows it to be effective; i.e. at the prescribed times and dosage.

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

Audit: A clinical audit is a quality improvement process. It reviews care against specific standards or criteria.

Blood glucose: Level of sugar in the blood. Measuring this can show if someone has diabetes.

Blood pressure: This gives a measure of how healthy a person's cardiovascular system is, i.e. the functioning of their heart and blood vessels.

Body Mass Index (BMI): This is an indicator of healthy body weight.

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

Cardiometabolic problems: Problems related to both heart disease and metabolic disorders such as diabetes.

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.

Cholesterol: An important component of blood lipids (fats), which helps to work out how healthy your cardiovascular system is. If this is high, it may lead to heart problems.

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

Diabetes: A long-term condition caused by having high sugar in the blood.

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

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

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

Hypertension: High blood pressure. This could lead to heart disease and stroke.

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.

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

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

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.

Optimum: Ideal; most favourable.

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

Physical health check: A medical examination, which ideally should include speaking to the patient about their family history, smoking, substance misuse and alcohol intake plus measures of weight, height, blood pressure and blood levels of glucose, lipids and prolactin (if indicated).

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

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

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

Psychosis: A term describing people having specific types of symptoms, usually delusions or hallucinations, and where they may lose touch with reality. Symptoms can include difficulty concentrating and confusion, conviction that something that is not true is so (false beliefs or delusions), sensing things that are not there (hallucinations) and changed feelings and behaviour. Psychosis is treatable. It can affect people of any age and may sometimes be caused by known physical illnesses.

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.

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

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

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

Substance misuse: The use of illegal drugs to the extent that it affects daily life. It can also refer to the use of legal drugs without a prescription.

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

Trusts: National Health Service Trusts are public service organisations that provide healthcare services.

Appendix 1: List of standards

	Standard	Priority area
1	Service users report that their experience of care over the past 12 months has been positive.	Experience of people using services and carers
2	Service users report positive outcomes from the care they have received over the past 12 months.	Experience of people using services and carers
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.	Experience of people using services and carers
4	Body mass index, waist hip ratio or waist circumference; blood pressure; use of tobacco; excessive use of alcohol; substance misuse; blood levels of glucose, lipids (total cholesterol and HDL) and prolactin (if indicated); history of cardiovascular disease, diabetes, hypertension or hyperlipidaemia in members of the service user's family have been monitored in the last 12 months.	Physical health
5	Advice about diet and exercise; treatment for hypertension; treatment for diabetes; treatment for hyperlipidaemia; an intervention to reduce levels of prolactin; help with smoking cessation; help with reducing alcohol consumption; help with reducing substance misuse have been offered when need was indicated.	Physical health
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.	Shared decision-making

7	The service user was involved in deciding which antipsychotic was to be prescribed, after discussion of the benefits and potential side-effects.	Shared decision-making
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 prescribed as well as a second antipsychotic).	Prescription of antipsychotic medication
9	The current total daily dose of antipsychotic drug does not exceed the upper British National Formulary limit. If it does, the reason for this has been documented.	Prescription of antipsychotic medication
10	Where there is no or inadequate response to the first antipsychotic drug prescribed after a minimum of 4 weeks at optimum dose medication adherence and alcohol or substance misuse was investigated and documented.	Prescription of antipsychotic medication
11	If no or inadequate response to the first antipsychotic drug after a minimum of 4 weeks at optimum dose the first antipsychotic drug was stopped and a second antipsychotic drug was trialled.	Prescription of antipsychotic medication
12	If no or inadequate response to the second antipsychotic drug after a minimum of 4 weeks, clozapine was offered.	Prescription of antipsychotic medication
13	If there was no or inadequate response to clozapine, a second antipsychotic was given in addition to clozapine for a trial period of at least 8 weeks.	Prescription of antipsychotic medication
14	CBT or family therapy have been offered to service users whose illness is resistant to treatment with antipsychotic drugs.	Psychological therapies



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