Living with schizophrenia
People’s experience of the condition

Lundbeck Ltd and Otsuka Pharmaceuticals UK Ltd provided funding to support the preparation of the survey which informed this study, and the writing and publishing of this report.

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Schizophrenia is a severe mental illness that causes a range of different symptoms and changes in behaviour\(^1\). It is a relatively common condition with around one in 100 people developing it in their lifetime\(^2\). The cause is unknown but it is thought to result from a combination of genetic and environmental factors\(^3\).

Schizophrenia can occur at any age, although the condition typically starts in early adulthood\(^4\) and is most often diagnosed between the ages of 15 and 35\(^5\). The symptoms are usually described as either positive or negative:

- **Positive symptoms** represent a change in behaviour or thoughts (for instance hallucinations or delusions)
- **Negative symptoms** represent a withdrawal or lack of function that you would expect to see in a healthy person (for example a lack of emotion or appearing apathetic)\(^6\)

The course of the condition can vary considerably from person to person, with some people experiencing positive symptoms very briefly while others may have them for many years\(^7\).

During acute episodes, the person’s experience and thought processes become distorted, which can lead to them feeling intense panic, anger or depression. Following resolution of the acute episode, usually after treatment, symptoms diminish and often disappear for many people, although sometimes a number of negative symptoms may remain.

The Government’s mental health strategy, *No health without mental health*, highlighted that people with serious mental illness have significantly worse health outcomes than the rest of the population, and called for this to be addressed as a priority\(^8\). People with schizophrenia and psychosis have an average life expectancy of around 15 to 20 years less than the general population\(^9\).

Schizophrenia can have an economic impact both on those affected by the condition and on the national economy. A UK study estimated that the annual cost to UK society attributable to schizophrenia is £11.8 billion a year (£60,000 per individual with schizophrenia)\(^10\). Of this, the cost to the public sector is estimated to be £7.2 billion (£36,000 per individual with schizophrenia) a year\(^11\).

Furthermore, many relatives and other unpaid carers of people with schizophrenia will give up employment or take time off work in order to provide care and support. It is estimated that 4.8% of carers of people with schizophrenia had terminated employment and 15.5% took an average of 12.5 days off work per year specifically as a result of being a carer\(^12\).

The condition also has a significant economic impact on NHS services. Relapse is a major driver of costs, mainly due to hospitalisation. A study in the UK found costs for relapsed patients were, over a six month period, four times higher than for non-relapsed patients (£8,218 compared with £1,899)\(^13\). Each day a person with a mental illness spends in an acute hospital is estimated to cost the NHS £295, with this figure rising to £585 per day in an intensive care unit\(^14\). For those that are admitted through A&E there is an additional cost of £131\(^15\). Given that nearly a third (32.2%) of NHS psychiatric bed days in England in 2010/11 were for people diagnosed with schizophrenia and related disorders, the costs to the NHS are significant\(^16\).
Overview

Schizophrenia is a serious mental illness that has a significant impact on people affected by it. The condition is also still associated with considerable stigma, fear and limited public understanding. It can have a major impact on family members and carers. As well as the human cost, substantial financial costs can result from a diagnosis of schizophrenia, for the NHS and wider society.

In order to inform what the priorities should be for schizophrenia care in the UK, SANE, in partnership with Lundbeck and Otsuka, asked patients and carers for their views on the care and support they have received.

Responses to our survey indicate that people with schizophrenia, their family and carers are still experiencing problems with the care and support they receive. For example:

- People are not being given enough information about their condition, with over half of respondents (58%, n=30) diagnosed with schizophrenia stating that they received no information at all at diagnosis

- The large majority of people with schizophrenia reported that they felt only partly involved or completely uninvolved (86%, n=41) in their choice of treatment. Furthermore, only one in four family members/carers (25%, n=12) stated that they were always involved in the treatment choice of the person they cared for

- We have also identified problems with access to treatment and with the support given. Nearly two-thirds (63%, n=29) of patients stated that there were delays in receiving psychological therapies and just over half (51%, n=49) of the people with schizophrenia, their family members and carers stated that they were dissatisfied with the support provided by doctors in monitoring physical health

Tackling these problems, as well as the other issues identified in this report, should enable people with schizophrenia to say:

- When I first had problems I was seen quickly and by the right people
- I am supported to learn about schizophrenia and I how it might affect me
- I am supported to choose the right treatment and care for myself
- I am supported to understand the importance of taking my medication properly
- My family and carers are helped to support me and feel supported themselves
- My treatment is reviewed regularly in a meaningful way
- My physical health needs are given equal importance to my mental health
- I feel that every contact with healthcare professionals is meaningful
Recommendations

Diagnosis

- Healthcare professionals should make every contact count to ensure that the early signs of schizophrenia are identified and people receive a timely and accurate diagnosis. This is particularly important for young people who first experience psychosis.

- Services that are likely to come into contact with people experiencing early signs of schizophrenia should have policies in place to ensure that people are referred to appropriate mental health services to reduce the number of people whose diagnosis is arrived at in in-patient settings.

Information and support

- People affected by schizophrenia should be provided with timely, accurate, and high quality information about the condition, the different treatment options available and potential side-effects of medications.

- Healthcare professionals should support people with schizophrenia to adopt the most effective treatment regime for them and ensure they can make informed decisions about their treatment.

- Choice of medication should be made by the patient and healthcare professional together, taking into account the views of family and carers if the person with schizophrenia agrees. This should be a meaningful ongoing discussion amongst all involved in the care planning process based on trust, familiarity and continuity of care.

- Healthcare professionals should routinely inform people affected by schizophrenia about patient organisations, and other relevant support organisations.

Care and treatment

- Avoiding relapse should be seen as an important outcome of effective treatment and the person’s family and carers should be supported to help prevent avoidable readmissions to hospital.

- Healthcare professionals should offer more frequent reviews of treatment and support, and involve the patient, their family and carers in reviewing care plans.

- NHS decision-makers should ensure that there is sufficient provision of a range of psychological therapies for people with schizophrenia so that people do not experience delays in accessing these treatments.

- People with schizophrenia and their families and carers should be involved in informing service design so that provision reflects their needs.

- NHS decision-makers and providers of services need to focus on ensuring people have an ongoing positive experience of care.

- People with schizophrenia should have their physical health monitored regularly and treated effectively.

Impact of schizophrenia

- Schizophrenia impacts on the quality of life of the individual, their family and carers, therefore policymakers and NHS providers should focus on reducing the economic and social consequences of the condition.
**Introduction**

To help improve the support for those affected by schizophrenia SANE partnered with Lundbeck and Otsuka to carry out a survey to explore how people are affected by the condition and what their experiences are of care and treatment.

The findings point to a number of measures that we believe need to be taken to ensure that people with schizophrenia, as well as those caring for them, are able to access high quality services that will help to improve their quality of life.

The aim of the report is to help clinicians, NHS managers and policymakers to be more aware of the impact of the condition on people’s lives and the steps they can take to make the experience of care and treatment a positive one.

**Methodology**

Between September and November 2013, an online survey was conducted to find out more about the impact of schizophrenia on people with the condition and their family and carers.

Respondents were filtered into two categories, one for people with a schizophrenia diagnosis, and the other for carers and/or family members of people with schizophrenia. The two groups of respondents were directed to two targeted sets of questions. Each respondent was subsequently asked to answer a number of questions unique to the category in which they had been placed.

People with schizophrenia were asked 31 questions on different aspects of their condition and experience. Carers and family members were asked 20 questions on their experiences and how the condition had affected both themselves and their family member/the individual they cared for.

People were asked to provide answers to a number of open, closed and multiple choice questions based on the following themes, around their experience of care and treatment:

- Diagnosis
- Choice
- Information
- Quality of life
- Treatment
- Concordance with medication
- Relapse

A total of 121 people completed the survey and all completed responses were included in the analysis in this report. Among the total number of respondents, 56 specified that they had a diagnosis of schizophrenia, while 62 indicated that they were family members/carers of people with schizophrenia. Statistics are presented both as percentages and numbers. Please note that the percentages used throughout the report have been calculated based on the total number of people that responded to the given question.

More information about respondents can be seen in Annex A.
Diagnosis

Our survey sought to gain a deeper understanding of people’s experience of the process of diagnosis, assessing their earliest experiences of symptoms, whether they had experienced delays in receiving a diagnosis, and the impact diagnosis had on their life.

What did the survey tell us?

As highlighted earlier, the survey was split into two sections, one for people with a schizophrenia diagnosis, and the other for carers or family members of people with schizophrenia. As shown in Figure 1 below, nearly two-thirds of respondents (65%, n=34) first experienced signs of schizophrenia between the ages of 15 and 19.

Figure 1: Age at which signs of schizophrenia were first seen – people with schizophrenia

A similar finding was reported when looking at the responses from carers and family members, with just under half (49%, n=28) estimating that they first saw signs of the condition in the person they care for/family member between the ages of 15 and 19 (Figure 2). This suggests that for many people their first experience of schizophrenia is also apparent to those close to them.

Figure 2: Age at which signs of schizophrenia were first seen – carers and/or family members of people with schizophrenia

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As Figure 3 above highlights, despite many people responding that they experienced symptoms associated with schizophrenia at a relatively young age, nearly two-thirds (63%, n=32) had to see a healthcare professional five or more times before receiving a diagnosis. These statistics broadly align with those answers from carers/family members, with Figure 4 below showing that 46% (n=26) of respondents stated that the person they care for/family member saw a healthcare professional at least five times before receiving their diagnosis.

Furthermore, our research shows that of those who stated that they had seen a healthcare professional five or more times before receiving a diagnosis (n=32), nearly all (88%, n=28) stated that schizophrenia has a very strong or strong impact on their overall quality of life.
Further analysis shows that, in regards to the setting in which patients first received their diagnosis, only 4% (n=2) of respondents received their diagnosis through a GP appointment, with over a third of people with schizophrenia who responded (37%, n=19) saying that they had received their diagnosis within an inpatient hospital care setting (Figure 5).

However, this percentage almost doubled when looking at the answers from carers/family members, with 61% (n=35) of respondents stating that the person they care for/family member received their diagnosis within an inpatient hospital care setting (Figure 6).

**What does this mean?**

Schizophrenia has a broad range of symptoms, and some of these can be similar to those of bipolar disorder and depression. This overlap and array of symptoms is the reason why people can be given different diagnoses by different clinicians\(^1\).
Schizophrenia is often only diagnosed when a person experiences psychosis, for example, hallucinations and delusions\(^\text{18}\). However, during the early stages of the condition, a person may experience disturbances in their sleep, emotions, communication and ability to think clearly\(^\text{19}\). The first acute episode can be a devastating experience because the person affected, and those close to them, are likely to be unprepared\(^\text{20}\). The next few years after onset can also be particularly upsetting and chaotic, and people may be at a higher risk of suicide during this period\(^\text{21}\).

Misdiagnosis of schizophrenia is a serious concern, as inappropriate treatment has the potential to destabilise a person’s condition further. However, GPs and psychiatrists also have to be cautious when making a diagnosis of schizophrenia. Such a diagnosis can often be a very traumatic experience for many, and has the potential to generate stigma as well as unwarranted pessimism\(^\text{22}\).

Our research suggests that more needs to be done to ensure appropriate services are available and people are being referred to these services as early as possible, as a significant number of people have to live with the symptoms of schizophrenia for some time before they receive a diagnosis. These problems with referral also mean that a high number of people receive their diagnosis after being admitted to hospital because of an acute episode.

Further to this, although it is difficult to make a definitive conclusion based on the sample size, our research suggests that those who experienced an earlier diagnosis demonstrated a better overall quality of life than those who had to wait longer for a diagnosis, although a majority still reported a strong or very strong impact on their quality of life.

### Recommendations

- Healthcare professionals should make every contact count to ensure that the early signs of schizophrenia are identified and people receive a timely and accurate diagnosis. This is particularly important for young people who first experience psychosis

- Services that are likely to come into contact with people experiencing psychosis should have policies in place to ensure that people are referred to appropriate mental health services to reduce the number of people whose diagnosis is arrived at in inpatient settings

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Information and support

Our survey included questions about the sort of information people were provided with when they were diagnosed and, following diagnosis, what sources of information they relied on most to find out about their condition. Similar questions around information were also asked of carers and/or family members, with respondents asked how satisfied they were with the level of information they received after a diagnosis was made.

What did the survey tell us?

As shown in Figure 7, the most common type of information received by those diagnosed with schizophrenia was verbal advice from a healthcare professional, with 31% (n=16) of respondents receiving this type of advice. Just over a quarter (27%, n=14) of respondents stated that they had received some form of written information, and just 6% (n=3) were signposted to a website for further information. Worryingly, over half of respondents (58%, n=30) stated that they received no information at diagnosis.

Figure 7: Information provided at diagnosis – people with schizophrenia

Similar findings were seen when looking at responses from carers and family members of those with schizophrenia, as can be seen in Figure 8. Indeed, just over half (51%, n=28) stated that they had received no information at all at diagnosis of the person they cared for/their family member, with just under a third (33%, n=18) receiving verbal information.
As shown in Figure 9 below, when asked which source of information they relied upon most to find out about their condition since their diagnosis, over a third (37%, n=19) of those respondents with schizophrenia stated that they rely mostly on a mental health charity. Only 4% (n=2) relied upon a GP for information, and only 6% (n=3) relied on an NHS website or phone line.

**Figure 8: Information provided at diagnosis – carers and/or family members of people with schizophrenia**

**Figure 9: Source relied upon most to find out about schizophrenia condition – people with schizophrenia**

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In addition, carers and family members were asked if they had received any information specifically for family members and/or carers of people with schizophrenia. Despite the major role that these individuals play in caring for an individual with schizophrenia, it is worrying to see that nearly two-thirds of respondents (64%, n=34) reported that they had received no information specifically for family members and/or carers of people with schizophrenia. Just under a third (32%, n=17) stated that they received some information, and only 4% (n=2) stated that they received all the information they needed to care for an individual with schizophrenia.

**Figure 10: Information received specifically for carers and family members**

Respondents were also asked how satisfied they were with the level of information they received after diagnosis. As shown in Figure 11, results show a number of people with schizophrenia were dissatisfied with the information provided, with 37% (n=19) stating that they were dissatisfied or very dissatisfied with the level of information they received. Only 8% (n=4) answered that they were satisfied with the information provided, and no-one stated that they were very satisfied. Again, a significant number of respondents (42%, n=22) stated that they did not receive any information.

**Figure 11: Satisfaction with information provided – people with schizophrenia**

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Once again, carers and family members responded in a similar fashion, with Figure 12 below highlighting that 44% (n=24) answered that they were dissatisfied or very dissatisfied with the level of information they received. Only 9% (n=5) were satisfied with the information provided, and no-one stated that they were very satisfied. Furthermore, a significant number (27%, n=15) of carers and family members stated that they did not receive any information.

**Figure 12: Satisfaction with information provided – carers and/or family members of people with schizophrenia**

What does this mean?

People with schizophrenia should be central to decision-making and the phrase, ‘no decision about me without me’ should resonate with clinicians who need to strive to ensure that people are well-informed about their treatment and condition. A review by the Sainsbury Centre for Mental Health and The King’s Fund found that when medication is the preferred treatment option, people want full information on its effects and side effects. Providing timely and accurate information on treatment and care options helps people to feel in control and empowers them to make informed decisions. Indeed, this can be particularly valuable where people feel that their condition deprives them of empowerment and control.

When people with schizophrenia and clinicians make a joint decision, both are more likely to adhere to their treatment plan. This can only happen if people with schizophrenia are supported to make informed decisions about their care.

Our research findings suggest that more work needs to be done to ensure that people with schizophrenia, as well as family members and those who care for people with schizophrenia, are provided with high quality information about their condition and signposted to further sources of information by healthcare professionals.

Although the provision of verbal advice is extremely important, it can be easily forgotten after a face-to-face appointment. It is therefore important that people are provided with written information or
signposted to other sources of information in addition to their healthcare professional discussing matters with them directly at the point of diagnosis.

Finally, our findings also demonstrate the key role that patient groups play in the provision of information to people with the condition. GPs, psychiatrists and other healthcare professionals should therefore routinely provide information to people about patient organisations to ensure they can benefit from the information these groups make available.

**Recommendations**

- People affected by schizophrenia should be provided with timely, accurate, and high quality information about the condition, the different treatment options available and potential side-effects of medications

- Healthcare professionals should support people with schizophrenia to adopt the most effective treatment regime for them and ensure they can make informed decisions about their treatment

- Choice of medication should be made by the patient and healthcare professional together, taking into account the views of family and carers if the person with schizophrenia agrees. This should be a meaningful ongoing discussion amongst all involved in the care planning process based on trust, familiarity and continuity of care

- Healthcare professionals should routinely inform people affected by schizophrenia about patient organisations, and other relevant support organisations
Care and treatment

Over the last 30 years there have been significant improvements in the development of community services and new psychological treatments and medications for people with schizophrenia, which has helped to improve the quality of care. This chapter explores some of the issues around care and treatment, including:

- Choice of treatment
- Concordance with treatment
- Involving family and carers
- Physical health monitoring

Choice of treatment

What did the survey tell us?

The large majority of respondents reported that they felt completely uninvolved, or only partly involved (86%, n=41) in their choice of treatment (Figure 13). Many respondents also reported that the full range of treatment options was not discussed with them at diagnosis. Pills or tablets were the treatment options most often discussed (87%, n=41), followed by psychological therapies (49%, n=23). Long-acting injections were only discussed in under a third (28%, n=13) of cases (Figure 14).

Figure 13: Patient involvement in choice of treatment for schizophrenia
Of those people who felt that they were not at all involved in decisions about their treatment (42%, n=20), only two stated that their doctor had discussed all three types of treatment with them when they were diagnosed. Overall, only one in ten (23%, n=11) stated that their doctor had discussed all three types of treatment with them.

In addition, all but one respondent stated that their doctor did not discuss the benefits and risks of the different treatment options. Only 15% (n=7) stated that their doctor had discussed the benefits and risks of different treatment options with them.

Furthermore, over a fifth of respondents (23%, n=11) stated that the last time they had a review of their treatment with a healthcare professional was more than twelve months ago. A third (33%, n=15) of people reported that they are dissatisfied or very dissatisfied with the overall effectiveness of their current medication.

Also, a large proportion of respondents (42%, n=20) noted that they had tried five or more types of medication before being placed on their current prescription (Figure 15). Clearly, it can take time to find medications or other forms of treatment that suit the individual, but as our survey results indicate, people do not feel involved in the decision-making process.

**Figure 15**: Number of treatments tried before current treatment

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Support for people with schizophrenia should include a range of interventions, including access to a full range of psychological support\textsuperscript{16}. The responses from people with schizophrenia, their family and/or carers, indicate however that only one in five (21\%, n=20) were being treated with psychological therapies.

In addition, our survey results indicate that delays in accessing recommended treatments may further exacerbate symptoms and may limit the effectiveness of other treatments. As shown in Figure 16, nearly two-thirds (63\%, n=29) of respondents stated that there were delays in receiving psychological therapies. It appears that this may be having very damaging consequences for some people, with a lack of access to psychological therapies reported as one of the two most common reasons for relapsing and being admitted to hospital (38\%, n=18). This is shown in Figure 17 below.

\textbf{Figure 16: Assessment of whether people experienced delays in accessing psychological therapies}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure16.png}
\caption{Assessment of whether people experienced delays in accessing psychological therapies}
\end{figure}

\textbf{Figure 17: Reasons identified for relapse and admission to hospital}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure17.png}
\caption{Reasons identified for relapse and admission to hospital}
\end{figure}
What does this mean?

Choice is particularly valuable in mental health care as it helps to give people a sense of empowerment and control. However this is only possible where there is a degree of trust, familiarity and continuity in the relationship between patients and professionals. Our survey indicates that people on the whole do not feel involved in decisions about their treatment, which would suggest that the degree of trust with their clinicians is not as good as it should be. This may also further support our impression, linked to our findings in the previous chapter, that people do not feel equipped enough to be involved in their choice of treatment.

In order to make parity of esteem a reality for people with schizophrenia, the person with the condition should be central to decision-making and should be provided with the tools and support to make this possible. This could include providing better information on different types of treatment, ensuring that there are more opportunities to have treatment reviewed, and preventing delays in accessing psychological therapies.

Our research indicates, however, that best-practice guidance\textsuperscript{27} which recommends, for example, that people with schizophrenia should be treated using a combination of medication and talking therapies, may not be being followed in every case.

Concordance with treatment

What did the survey tell us?

Our survey found that only a third (33\%, n=15) of people always remembered to take their medication. Forgetting (48\%, n=22) was the most common reason given by respondents to the survey on the occasions when medication was not taken as recommended.

However, over half of people (57\%, n=26) stated that lapses related to the fact that they either did not get on with their current medication, or wanted to avoid side-effects, implying that it was an intentional decision on their behalf. It appears that, in the majority of cases, this was also an informed decision, as nearly three quarters (74\%, n=35) stated that they understood the impact of not taking their medication.

As would be expected, of those who stated their current form of medication was a long-acting injection, all but one respondent stated that they always or mostly remembered to take their treatment. The remaining respondents stated that the question was less relevant as they were on a long-acting form of medication. The results were far more mixed for those taking pills or tablets, with responses split almost equally as follows:

- 35\% (n=12) stated that they always remembered to take their medication
- 32\% (n=11) stated that they remembered most of the time
- 32\% (n=11) stated that they occasionally, seldom or not always remembered to take their medication

In terms of the consequences of non-concordance, the survey found that nearly a third of people (31\%, n=14) had experienced relapses and had to go to hospital as a result of not taking their medication. With over a third of respondents (36\%, n=16) reporting a typical hospital stay following a

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relapse as lasting between one and three months, it is clear that non-concordance can place a significant burden both on people with schizophrenia and the NHS.

In order to understand the steps that are needed to support better concordance with treatment, we asked respondents to state what measures would help them to take their medication as it is prescribed to them. According to respondents, more involvement in decisions about the medication prescribed (49%, n=21) and better information on the potential side-effects (47%, n=20) were the two forms of support that would help the most (Figure 18).

**Figure 18: Types of support that people with schizophrenia stated would help them to take their medication as it is prescribed**

What does this mean?

Concordance with treatment is a major issue for people with schizophrenia. Over three quarters of people diagnosed with the condition who are prescribed medication are not concordant with their recommended treatment. Recent evidence suggests that the majority of these people are unintentionally non-concordant. Supporting those who wish to take their treatment to do so is crucial in making sure that they can manage their condition effectively and prevent relapses and hospitalisation, which often occur due to non-concordance.

Our research has indicated that people with schizophrenia would value being more involved in decisions with their medication and that more information may help with concordance. Therefore, if opportunities to discuss options, experiences and side-effects relating to treatment are limited, people may not be receiving the best treatment.
Involving family and carers

What did the survey tell us?

Our survey found that a significant proportion of carers/family members had to remind the person they care for to take their medication. 41% of respondents (n=20) stated that they had to remind the person on a regular basis, some every day (25%, n=12), some every week (10%, n=5) and some every month (6%, n=3). These results are shown in Figure 19 below.

Figure 19: Assessment of how often family members and/or carers have to remind the person with schizophrenia to take their medication

Our survey also asked carers and/or family members about their level of involvement in treatment decisions. Only one in four (25%, n=12) stated that they were always involved in the treatment choice of the person they cared for/their family member. Over a third (37%, n=18) noted that their level of involvement was through the choice of the person diagnosed with schizophrenia while a quarter (25%, n=12) stated that their involvement was due to the preference of the prescribing clinician.

What does this mean?

Carers and families have always played an important role in the management of schizophrenia and, with the increasing emphasis on supporting people to manage their condition in the community, this has assumed even greater significance. Although schizophrenia is primarily treated with medication, many people with the condition require regular support by family members and carers.

Families who are carers save the public purse £1.24 billion per year but are not receiving sufficient support. Evidence suggests that families are often not treated as partners in schizophrenia care, and regularly have to battle for basic services. This is contrary to guidance on the management of schizophrenia, which emphasises the need to support carers and the benefits this has for people with the condition. If health professionals and carers work in partnership, the care of people with schizophrenia is likely to be optimised, ensuring that people are supported within the community rather than relying on long-term hospital care, which ultimately has a long-term effect on resources.

Our survey has shown, however, that these problems persist and that too few carers are involved in the treatment choice of the person they cared for, despite their importance in day-to-day support.

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Physical health monitoring

What did the survey tell us?

Our survey assessed whether people were satisfied with the support they, or the person they cared for/their family member, received from their doctor in monitoring their physical health. Looking at the combined responses across the two groups, just over half (51%, n=49) of people stated that they were dissatisfied with the support provided (see Figure 20).

Figure 20: Assessment of how satisfied people with schizophrenia and, family members and/or carers are with support with physical health monitoring

![Pie chart showing satisfaction levels]

What does this mean?

The 2012 National Audit of Schizophrenia reported major concerns about the poor physical health of people with schizophrenia. The audit illustrated that many people are not getting the assessments they need to detect and treat physical health problems. This contributes to the significantly worse physical health outcomes that people with schizophrenia experience compared to the rest of the population.

Our survey has found that physical health monitoring remains a problem and the majority of people are not satisfied with the support received. This is particularly concerning given recent changes to the Quality and Outcomes Framework (QOF) – an incentive scheme aiming to encourage GPs to undertake certain activities – which mean that a number of the incentives relating to monitoring the physical health of people with schizophrenia will no longer be used.
## Recommendations

- Avoiding relapse should be seen as an important outcome of effective treatment and the person’s family and carers should be supported to help prevent avoidable readmissions to hospital.

- Healthcare professionals should offer more frequent reviews of treatment and support, and involve the patient, their family and carers in reviewing care plans.

- NHS decision-makers should ensure that there is sufficient provision of a range of psychological therapies for people with schizophrenia so that people do not experience delays in accessing these treatments.

- People with schizophrenia and their families and carers should be involved in informing service design so that provision reflects their needs.

- NHS decision-makers and providers of services need to focus on ensuring people have an ongoing positive experience of care.

- People with schizophrenia should have their physical health monitored regularly and treated effectively.
Impact of schizophrenia

Our research built on the above and examined the impact that schizophrenia has on those affected, to further develop our understanding of the condition.

What did the survey tell us?

Our survey asked people to rate what impact schizophrenia has had across a number of aspects of life. A slightly different set of categories was looked at for people with schizophrenia and for family and/or carers.

In the responses from people with schizophrenia, the three areas where it was reported as having the greatest impact were in respondents’ ability to work (58%, n=29), their overall quality of life (52%, n=26), and their overall mood (50%, n=25). The top three areas which carers and/or family members felt had been most affected were overall quality of life (44%, n=23), their outlook for the future (37%, n=19), and their overall mood (25%, n=13). These results are illustrated in Figures 21 and 22, with the areas of greatest impact highlighted for ease of reference.

Figure 21: Impact of schizophrenia on quality of life of people with the condition
The survey also asked people to rate their quality of life at the time they were experiencing symptoms but before being diagnosed, and at the time they had received a diagnosis and had commenced treatment. A similar question was also asked of carers/family members. These results are shown in Figure 23.

Over half of respondents (54%, n=27) rated their quality of life as poor when they were experiencing symptoms before receiving their diagnosis. 32% (n=16) of respondents rated their quality of life as poor after receiving their diagnosis and receiving treatment. Over a quarter of respondents (28%, n=14) reported no change to their quality of life before and after diagnosis.

A significant proportion of carers/family members rated their quality of life as below average or poor (39%, n=20) before the person they care for/family member was diagnosed with schizophrenia and experiencing symptoms. Over half (55%, n=28) rated their quality of life as below average or poor after the person they care for/family member was diagnosed and receiving treatment. 37% (n=19) reported no change to their quality of life before and after diagnosis.
What does this mean?

Schizophrenia impacts upon both an individual’s quality and length of life. This can have a profound effect on the person with the condition, as well as those around them and wider society. Our survey has shown that quality of life for people with schizophrenia and their families and carers should be a key consideration when people are making decisions about services and support. Schizophrenia can affect people in a range of ways, impacting on their employment, their personal relationships and their outlook for the future.

The care and support offered should enhance the quality of life of people with schizophrenia, in line with the objectives of the NHS Outcomes Framework. Our research would indicate, however, that this is not always the case and, as such, a vital first step is for policymakers and NHS providers to focus on making schizophrenia care count for patients, family members and carers.

### Recommendations

- Schizophrenia impacts on the quality of life of the individual, their family and carers, therefore policymakers and NHS providers should focus on reducing the economic and social consequences of the condition
Making schizophrenia care count

This report has highlighted a number of areas that we believe should improve to ensure that people with schizophrenia receive effective support and treatment. NHS decision-makers also have a vital role to play, including:

**Purchasers of NHS services across the UK should make sure people affected by schizophrenia:**

- Can access and are being referred to appropriate services when symptoms first present
- Can access a full range of psychological therapies and are not subjected to unnecessary delays
- Are being regularly assessed to ensure their treatment plan is working for them
- Are listened to when services are being designed, focusing service changes on achieving recovery goals, avoiding relapses and improving people’s experience of care

**Every provider of health services should make sure people affected by schizophrenia are:**

- Receiving care and support in line with best practice guidance and similar to those services achieving the best outcomes
- Involved in choosing treatment options and provided with the support they need to participate actively in making choices
- Given all the information they need to make informed choices about treatment options available, with the benefits and risks of different treatment types explained to promote concordance with their care plan
- Regularly asked about their experience of care and any problems are addressed
- Referred to organisations and sources of information that could offer further support and advice
- Having their physical health needs regularly assessed and managed appropriately
- Being offered tailored information about their physical and mental health, including specific information for family members and carers

**National bodies should develop guidance – such as the forthcoming NICE quality standard – highlighting the importance of treating people effectively and:**

- Providing accessible, high quality, information for people with schizophrenia, about all aspects of their treatment, especially about the benefits and side effects of different medications
- Offering tailored support and information for family members and carers of people with schizophrenia
- Assessing the support needs of the family members and carers of people with schizophrenia
- Regularly assessing the physical health as well as mental health of the person with schizophrenia
- Monitoring performance against best practice guidance and benchmarking against the best performing services
Annex A: Information about respondents

Of the 121 people that completed the survey, 115 respondents specified their gender. 54 of these were people with a diagnosis of schizophrenia, while 61 were carers/family members of people with schizophrenia.

Of those respondents who had been diagnosed with schizophrenia, Figure 24 below shows that the majority (74%, n=40) who completed the survey were female, with only 26% (n=14) male.

Figure 24: Responses by gender – people with schizophrenia

A similar response was found when assessing the gender of carers and family members of people with schizophrenia. Figure 25 shows that just under 10% (n=6) of respondents were male, while 90% (n=55) were female.

Figure 25: Responses by gender – carers and/or family members of people with schizophrenia

Of the 121 people that completed the survey, 113 respondents specified their age; 52 of whom were people with schizophrenia, while 61 were carers/family members.
The largest majority of respondents with schizophrenia (30%, n=16) were between the ages of 30 and 39 (Figure 26). While just over a fifth of carer/family member respondents (21%, n=13) were between the ages of 60 and 69 (Figure 27).

Figure 26: Responses by age – people with schizophrenia

![Figure 26: Responses by age – people with schizophrenia](image)

Figure 27: Responses by age – carers or family members of people with schizophrenia

![Figure 27: Responses by age – carers or family members of people with schizophrenia](image)

The aim of the survey was to look at the everyday experience of people affected by schizophrenia from across the UK, and respondents were asked to specify which region they lived in. The devolved nations of the UK were defined as regions for the purpose of this survey and the definition of English regions was based on that used to define the areas of responsibility for government regional offices.

As set out in Figure 28, the largest group of respondents among people with schizophrenia from a single region was from Greater London (18%, n=10), followed by those from South East England (15%, n=8). The region with the fewest responses from people with schizophrenia was North East England, with no responses.
Figure 28: Responses by region – people with schizophrenia

Figure 29 below shows that the largest group of carer and family member respondents from a single region was also from Greater London (29%, n=18), followed by those from North West England (15%, n=9). The regions that had the fewest responses from people with schizophrenia were North East England, Scotland, and Northern Ireland with 2% (n=1).

Figure 29: Responses by region – carers and/or family members of people with schizophrenia

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About us

SANE is a UK-wide charity established in 1986 to improve the quality of life for people affected by mental illness. It campaigns to raise awareness of all mental illness and to combat stigma, undertakes research to understand the causes of mental illness and provides emotional support and information through its telephone, email, Textcare and online support services.
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