

STILL FORGOTTEN
STILL FORGOTTEN
STILL FORGOTTEN
STILL FORGOTTEN
STILL FORGOTTEN
STILL FORGOTTEN



Insights into schizophrenia and psychosis



This survey was co-created by Otsuka Pharmaceuticals, Lundbeck and SANE, and sponsored by Otsuka Pharmaceuticals and Lundbeck. The content of the report was prepared by SANE.

Contents

Foreword	3
Introduction	4
Summary of findings	5
Recommendations	6
Services following diagnosis	8
Support and information	9
Choice of treatment	11
Quality of life	14
Families and carers	16
Healthcare professionals.....	19
References	21
Appendix	22

About SANE

SANE is a leading UK mental health charity set up in 1986 to improve the quality of life for anyone affected by mental illness.

Our three main aims are:

1 To raise awareness and combat stigma about mental illness, educating and campaigning to improve mental health services.

2 To promote and host research into the causes and more effective treatments for mental illness at our flagship Prince of Wales International Centre for SANE Research.

3 To provide guidance and emotional support for people with mental health problems, their families and carers through our helpline, SANEline, Textcare and other services.

Foreword

SANE was founded in 1986 following the outcry generated by a series of articles in *The Times* called *The Forgotten Illness*. These articles I wrote highlighted the poverty of services available to people with schizophrenia, and the neglect they faced from nearly every section of society.

Over the last three decades, a lot has happened in mental health policy and awareness, but the conclusions of this report, appropriately named *Still Forgotten*, tragically continue to show just how little has changed.

People with schizophrenia continue to be let down by services, which all too often are simply unable to respond to their needs, or provide consistency of care. Our report shows that one in nine people receive no support service following diagnosis. This is a huge failing. In addition, half of people with schizophrenia or experience of psychosis do not feel supported by health-care professionals, and three-quarters want to be more involved in the decisions that affect their lives.

Family members and carers not feeling supported is also sadly a consistent finding, and our report highlights why they need clear and concise information for their needs as well.

For this report we spoke to our advisers in the field of mental health, as well as people affected by schizophrenia and psychosis, to come up with ways mental health provision can be improved. This report sets out their analysis as well as 10 recommendations for policymakers and NHS providers. Some of these recommendations, although not all, can only happen if more funding reaches the frontline.

As has widely been acknowledged, there is a crisis in mental health staffing and money pledged so far by the government is not reaching the people who need it most.

A report by NHS Providers found that almost three in five chairs and chief executives of mental health providers are worried or very worried about their ability to maintain the right numbers of staff to deliver high-quality care. This, they say, is “putting huge pressure on core frontline services”.¹

Despite previous pledges to boost mental health fund-

ing and the workforce, SANE continues to encounter the daily suffering of individuals and families who are being failed by underfunded and overstretched services. Demand for our helpline, SANEline, continues to grow, and we hear far too often of tragic cases of lives lost or ruined by this severe illness.

The aim of this report is to give a voice to the people who are so often forgotten in the mental health system. Our findings confirm there is a long way to go until we even come close to reaching equity between physical and mental health services.



A handwritten signature in blue ink that reads "Marjorie Wallace". The signature is written in a cursive, flowing style.

Marjorie Wallace
Chief Executive, SANE

Introduction

SANE conducted a survey to focus on the level of support that people living with schizophrenia and those who have experienced an episode of psychosis, as well as their families and carers, currently receive in the UK. The views of healthcare professionals were also surveyed.

The purpose of the survey was to determine the factors considered most important to individuals' wellbeing and assess how they were being met.

This survey was co-created by Otsuka Pharmaceuticals, Lundbeck and SANE, and sponsored by Otsuka Pharmaceuticals and Lundbeck. The content of this report was prepared by SANE, and has also been used to inform Head Start, a practical, educational and motivational support programme for people with schizophrenia for implementation through NHS services.

SANE hosted an online survey between June and October 2017. A total of 423 people took part in the survey, 231 of whom had a diagnosis of schizophrenia or experience of psychosis. Nine participants identified themselves as answering the survey on behalf of a person with schizophrenia or someone who had experienced psychosis. A total of 161 respondents were family members or carers, and 56 respondents identified themselves as a mental health or healthcare professional who cared for a person with schizophrenia or a person who had experienced psychosis.

People were able to identify themselves as a member of more than one of these groups as we are aware that many people with schizophrenia or experience of psychosis are also related to, care for or know someone else affected.

The survey featured 14 questions covering topics such as information received at diagnosis, awareness of risk factors and relapse indicators, and the availability of support services. Participants were able to rank statements on satisfaction scales, select options relevant to them from a multiple-choice list, and provide comment in open questions.

The aim of this report is to better understand what people living with schizophrenia and those who have experienced psychosis consider to be priorities for their

care, treatment and wellbeing, and to provide guidance to clinicians, NHS providers and policymakers on ways to ensure support is tailored to meet the needs of individuals, including family members and carers.

Key information

Schizophrenia is a severe mental disorder that will affect about one in every 100 people during their lifetime. Symptoms of the condition include hallucinations, delusions, and feeling controlled.²

The World Health Organization states that people with schizophrenia are around two times more likely to die early than the general population.³

Psychosis is an umbrella term meaning when a person's thoughts become so disturbed and distorted that they lose touch with reality. It can be the result of a severe mental illness such as schizophrenia or bipolar disorder.⁴

People who have a parent affected by psychosis are more likely to develop it themselves.⁵

Please note that the percentages used throughout this report have been calculated based on the total number of people who responded to the given question.

For an electronic version of this report, please visit www.sane.org.uk.

Summary of findings

People with schizophrenia or experience of psychosis:



1 in 9 have not received any support service since diagnosis.



Half feel unsupported by healthcare professionals.



54% do not know enough about what services are available locally.



47% do not understand what options they have for treatment, including medication.



73% want more involvement and to be given a choice in their care plan.



3 in 4 want more involvement in decisions affecting their everyday life.



2 in 3 have very low or quite low satisfaction with their social life.



3 in 5 do not feel hopeful about the future.

Family members and carers:



3 in 5 feel unsupported by healthcare professionals.



86% are not provided with sufficient information at diagnosis.

Healthcare professionals:



1 in 4 do not feel sufficiently informed about local service options for their patients.



10% do not understand schizophrenia risk factors, relapse indicators and symptoms.

Recommendations

1 Consideration should be given to reintegrating inpatient and community teams, where they have become separated, so that the patient receives care from the same team, or at least the same consultant, in both settings. Where this is not possible, either close or effective communication between teams is essential.

Our survey shows that one in nine of those with schizophrenia or experience of psychosis have not received any support service since they were diagnosed.

We recommend that, in order to ensure follow-up, a review should be carried out six months after diagnosis, to assess what services and psychological therapies are being received or planned, and identify any potential obstacles in doing so.

In many cases, lack of continuity of care between inpatient and community teams is a result of the division between the two teams. This can impair the consistency of care and risk hospitals and community teams working in isolation.

Trust between patients and those who provide services to them is fundamental for therapeutic relationships and disconnected working can make it very difficult for this to develop.

2 Better information that clearly outlines available service options should be provided at all stages of a person's treatment, especially following diagnosis.

Our report found that the majority of those with schizophrenia or experience of psychosis do not feel satisfied in understanding what support services are available to them and how to access them.

Accurate information tailored to the needs of the person being treated, as well as their families and carers, should cover all areas of care, including what to do in a crisis.

It should detail topics such as treatment options and the side-effects of any medications in a language that is easy to understand and jargonistic. It should also be regularly updated to take into account any changes in local service provision and care teams.

3 As far as practically possible, consistency of support

should be provided though individuals being seen by the same doctor, nurse or mental health professional.

Consistency of doctor, nurse or mental health professional is valued as most important, not only by those with schizophrenia or experience of psychosis, but also by families and carers, in order for those affected to achieve improvements in their wellbeing. This reflects SANE's own evidence from running our helpline for more than 25 years and other contact with patients, families and carers.

4 Choice of medication and treatments should be made by the patient and healthcare professional together, taking into account the views of families and carers, if this is agreed.

Four years on from the publication of SANE's *Living with Schizophrenia* report, many of its recommendations are still not being met.⁶ SANE called then for the choice of medication to be made by the patient and healthcare professional together, taking into account the views of families and carers, if the patient agrees.

Our report findings show this is still not the norm, as 62% of people with schizophrenia or experience of psychosis are dissatisfied in the choice they receive in treatment options, including medication.

It is important that confidentiality does not stand unnecessarily in the way of family members and carers being informed in choice of medication and treatments, if the person agrees.

5 Proper consultation must be a priority in care plans, with a section for a patient's own comments. The care programme approach meeting is an opportunity to jointly devise this plan.

Our survey shows evidence of insufficient consultation in care plans. Almost three in four respondents with schizophrenia or experience of an episode of psychosis want to be given more choice.

The Care Quality Commission (CQC) identified this as an area for improvement in *The State of Care in Mental Health Services 2014 to 2017* report, concluding: "In too many services, care plans do not truly reflect the patient's voice".⁷

Recommendations

The views of patients and carers can often be very different, with issues such as medication and community treatment orders typically being challenging areas.

SANE knows involvement in care plans to be a perennial problem for all concerned. Notwithstanding the pressures on healthcare professionals, it is important that adequate time is allowed to formulate the care plan in consultation with patients and carers, and keep it under review.

6 Clear objectives should be set from the outset for appointments with professionals, and evaluated continually.

Our survey shows almost half of patient respondents do not feel they are currently getting the most out of their appointments.

Appointments should be flexible and comprehensive, and look at a person's functioning and broader quality of life in areas such as physical health, relationships, budgeting, education, developing skills, and achieving personal goals.

Those with schizophrenia or experience of an episode of psychosis would welcome the aims of appointments being clearly defined at the beginning, and then assessed at the end.

7 If agreed with the patient, family members and carers should be consulted about plans for support services so that provision reflects the individual needs of the patient.

A very large majority (84%) of family members and carers want to be more involved in the decisions affecting support services for the person they care for.

Families and carers remain in the dark in an overwhelming number of cases, with many feeling marginalised and shut out as a result.

Families and carers should receive clear, written information about the support services available to them. This should spell out key topics such as confidentiality.

8 'Tube maps' should be devised to clearly inform mental health teams and patients so they are able to nav-

igate the system and know clearly where to go when they need something specific.

Our survey found almost one in four healthcare professionals do not feel informed regarding service options. This is a major problem, not only for them, but also in enabling patients to traverse the healthcare system.

Information on how and when different local teams connect in the course of a patient's treatment, displayed almost like a London Tube map, should be a standard part of good working practice to make sure all staff know and agree about care responsibilities.

9 Training of healthcare professionals should focus on joint-working, shared decision-making and communication skills.

Our report shows that one in five healthcare professionals do not feel supported by colleagues. As part of their training, professionals should be given information about the services available for their patients, and this information should be kept up-to-date.

Training of healthcare professionals should equip them to work together effectively on a continual basis, and ensure they are skilled at identifying and responding to the needs of people with schizophrenia or experience of psychosis.

Training of healthcare professionals should focus on ensuring services reflect the needs of the person involved, and this is best achieved by regular reviews and strong relationships. Professionals may well require additional training to communicate clearly and effectively with families and carers, especially on confidentiality.

10 Services need to be adequately funded to ensure that the fundamental needs of patients and carers are met.

Patients and carers report services being stretched and under resourced, meaning that healthcare professionals cannot respond to their needs.

Services should be funded so that staff working across hospital and community teams are adequately resourced.

Services following diagnosis

Our survey asked the participants who identified themselves as having schizophrenia or experience of psychosis, or as answering on their behalf, to tell us what services they had received following diagnosis. Participants were able to select from a list of 15 options.

The most common service patients had received following diagnosis was regular support from community mental health teams (CMHT) (59%). More than half of the participants (54%) had experience of hospital care.

Half of the participants had received some form of talking therapy (for the purposes of this survey this referred to counselling, psychological therapy, psychotherapy or other therapies); two in five had received cognitive behavioural therapy (CBT); and one in five had received a form of arts therapy.

Figure 1 shows that 14% of participants had received a service from an advocacy support organisation or charity, and 11% had received help from support groups.

One in nine participants (11%) had received no service

support at all following diagnosis. A further 4% were not sure if they had. Losing so many people to follow-up and contact with services is a worrisome finding.

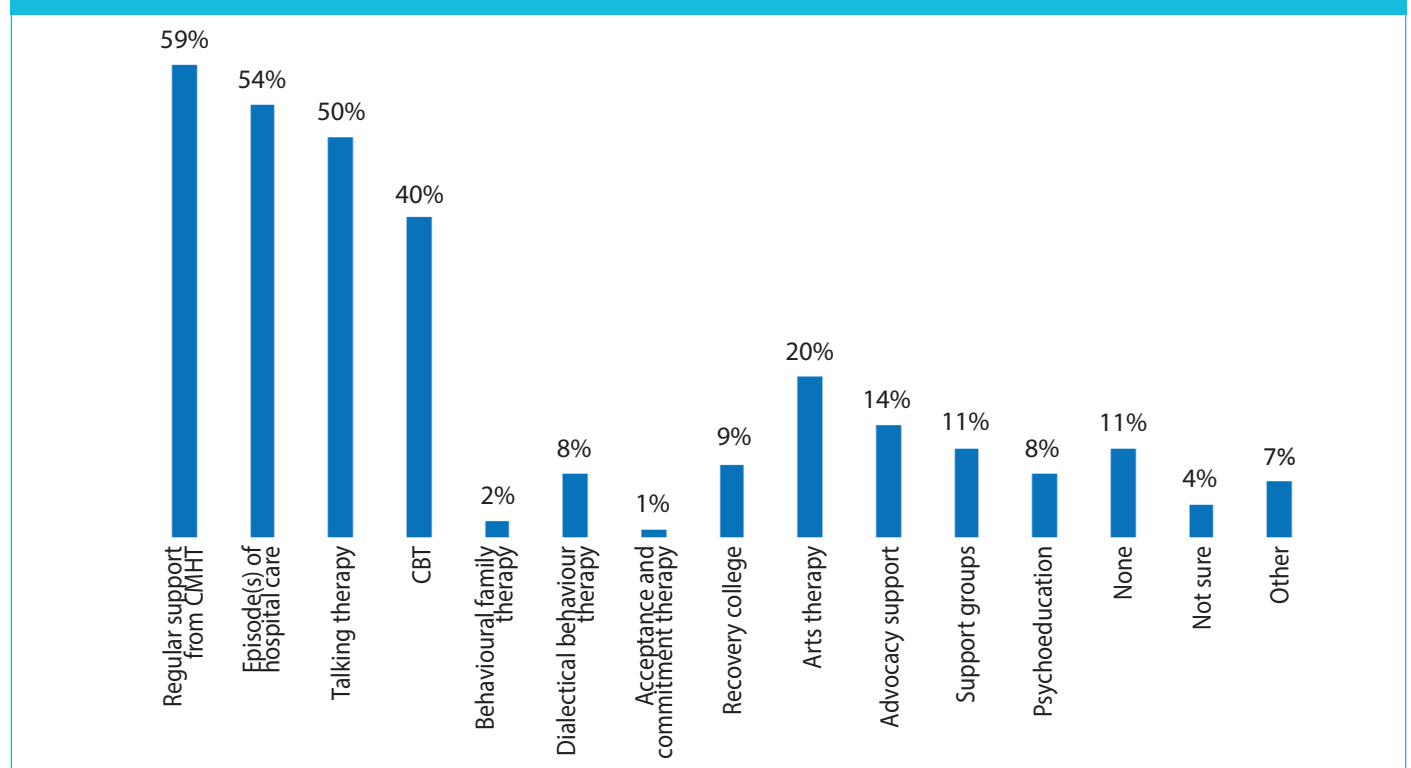
Breaking the answers in this particular question down further showed that participants aged 45 or under were more than twice as likely to have experience of CBT compared with those aged 46 and over (47% vs 21%).

Hospital care was also the most common type of service received for people aged 46 and over (63%), ahead of regular support from community mental health teams (55%).

RECOMMENDATION

1 Consideration should be given to reintegrating inpatient and community teams, where they have become separated, so that the patient receives care from the same team, or at least the same consultant, in both settings. Where this is not possible, either close or effective communication between teams is essential.

Figure 1: Services received following diagnosis.

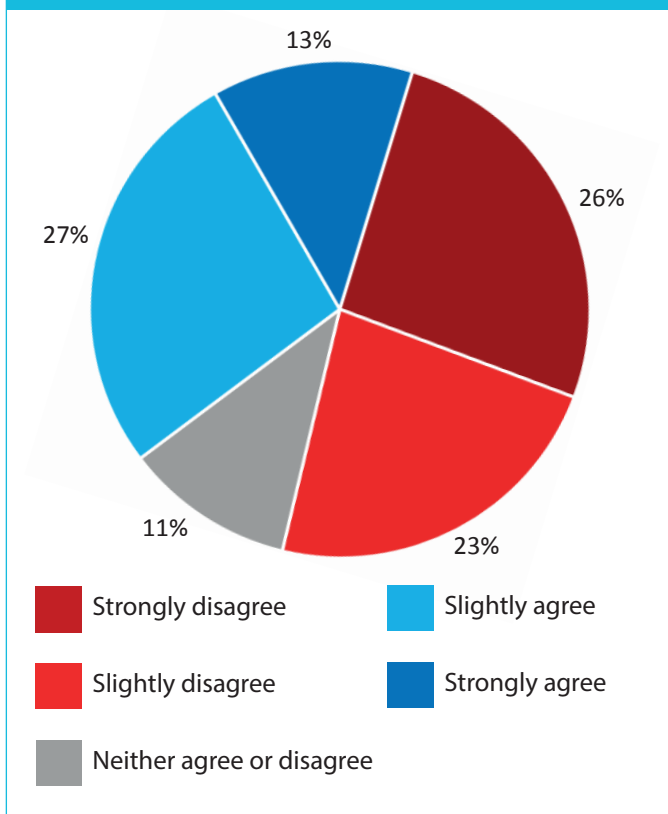


Support and information

Our survey included questions about the level of support and information received following a diagnosis of schizophrenia or episode of psychosis. These questions were to ascertain whether the person affected felt supported and informed.

The results show that 49% of people with schizophrenia or experience of psychosis do not feel supported by healthcare professionals. Individuals were much more likely to feel supported by family and friends, with 55% of respondents agreeing.

Figure 2: "I feel supported by professionals."



Similar findings were seen when looking at how informed people with schizophrenia or experience of psychosis felt regarding the service options available to them. More than half of respondents (54%) did not feel informed.

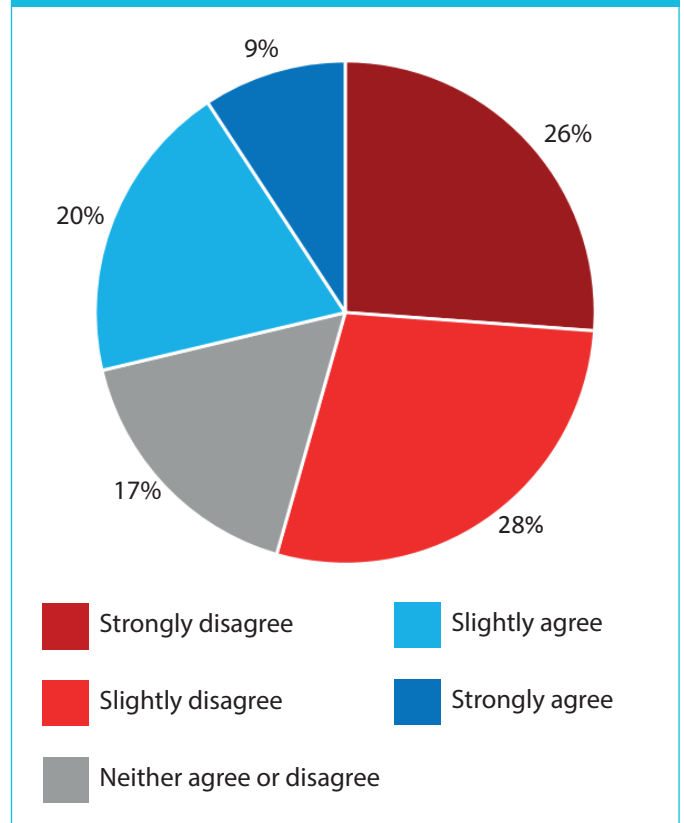
Further results show that 47% of respondents did not feel satisfied in understanding their treatment options, including medication. A total of 58% of respondents also did not feel satisfied in understanding what support services are available, including out-of-hours.

The survey showed that 43% of respondents felt unconfident in talking to a psychiatrist or other mental health professional about symptoms, treatment and management of their condition. This compares with 40% for a mental health or community support worker. In addition, 47% of respondents report low satisfaction with their appointments. See figure 4 for more.

SANE COMMENT

Our survey found that patients don't have trust or sufficient confidence in the people that can help them. How can patients get better if they feel unable to talk to their healthcare professional? What has gone wrong? The system appears to be set against having a consistent one-to-one relationship with a trusted professional. It's this relationship that we know to be the most significant factor in a person's stability and recovery. The healthcare professional has not been given the opportunity to be able to gain the trust of the patient.

Figure 3: "I feel informed regarding available service options."



Support and information

Figure 4: Agreement rankings.

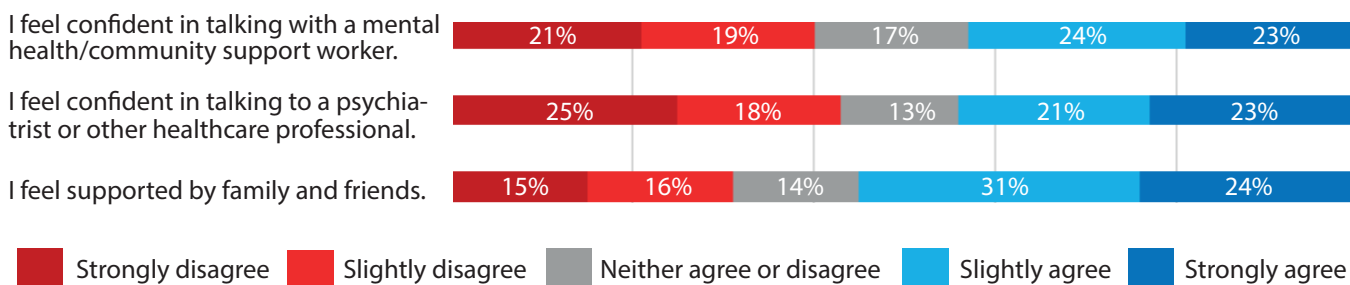
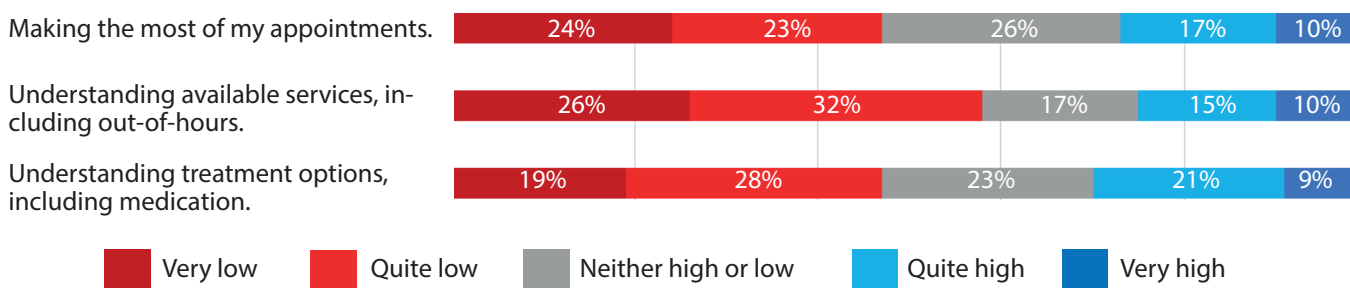


Figure 5: Satisfaction rankings.



"I'm fed up having to ring and chase, I am not being supported in any way. I have not been offered any additional help, talking therapies or groups. If it wasn't for my family I would have no support at all."

- Survey participant



"Health and social care professionals are overstretched and just firefighting emergencies as they happen."

- Survey participant

RECOMMENDATION

2 Better information that clearly outlines available service options should be provided at all stages of a person's treatment, especially following diagnosis.

"These findings show that not being given adequate support and information are typical experiences for many patients with schizophrenia, especially at the time of diagnosis. Nor do families and carers receive enough information, guidance and help to enable them to support the person for whom they are caring.

"A lack of consistent staffing is another factor hindering the support available for patients and families, where contact between the professionals and teams responsible for an individual's care becomes less regular and reliable."



Margaret Edwards,
Director of Strategy and
Communications, SANE

Choice of treatment

Our survey asked people with schizophrenia or experience of psychosis about how involved they felt in decisions affecting their daily life. The questions examined whether they would like to be more involved in decisions affecting available support services, care plans and treatment options, and the survey also asked people to highlight key areas they believed could improve their wellbeing.

Our survey findings strongly suggest there is a lack of consultation between patients and professionals in relation to care planning, as 73% of people with schizophrenia or experience psychosis wanted to be more involved in their care plan. Figure 6 shows that 46% of respondents believed this strongly.

As displayed in figure 7, just over three-quarters of individuals (76%) wanted to be more involved in decisions affecting support services and their daily life, 50% strongly and 26% slightly.

Figure 6: "I would like to be more involved/given a choice in my care plan."

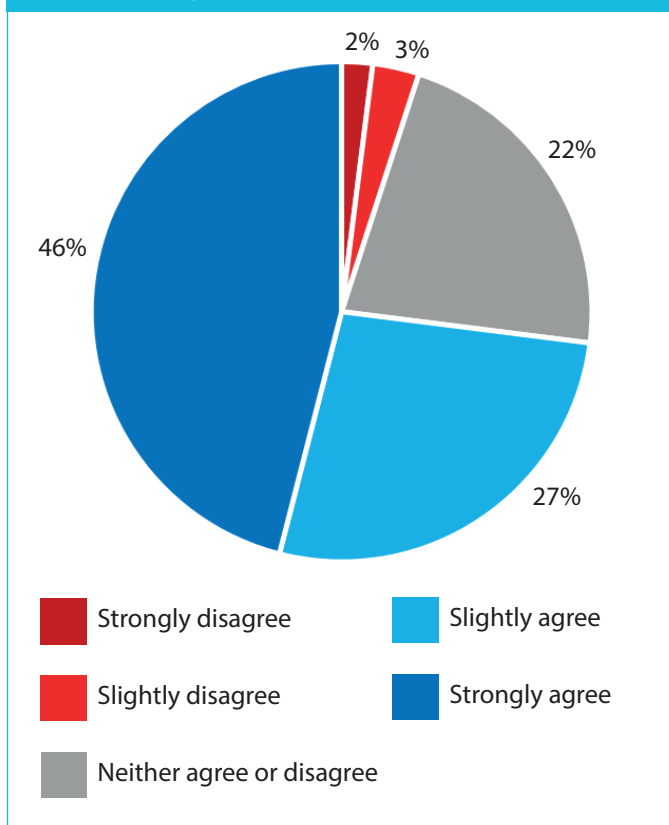
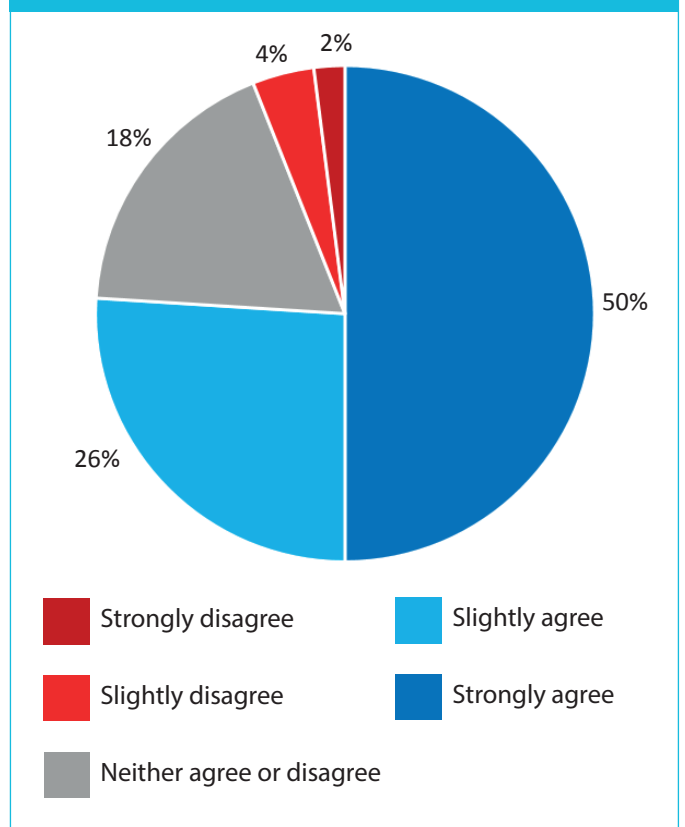


Figure 7: "I would like to be more involved in decisions affecting services and/or daily life."



SANE COMMENT

As with information, choice is important in mental healthcare as it gives people participation in, responsibility for, and influence over their treatment options. This is, however, only effective when people with mental health problems and healthcare professionals have strong working relationships based on trust, frequency of contact and understanding. This is the reason why in our *Living with Schizophrenia* report in 2014 we recommended people with schizophrenia, as well as their families and carers, "should be involved in informing service design so that provision reflects their needs".⁶ However, our survey shows this to be lacking. Without these strong working relationships, there's no way of fulfilling the government agenda that patients should be given choice, and National Institute for Health and Care Excellence (NICE) recommendations highlight the importance of choice.

Choice of treatment

Figure 8: Five most popular areas to improve wellbeing.

1 Having a consistent doctor/nurse/healthcare professional.	60%
2 Being given tools and information on treatment choices, including medication.	48%
3 Being given tools and information on managing delusions/hallucinations or voices.	46%
4 Having shorter wait times to see a healthcare professional or access psychological therapy.	44%
5 Seeing a healthcare professional (doctor, nurse or social worker) more often.	36%

The CQC's report *Better Care In My Hands* found people with long-term health and care needs are "least likely to report feeling involved in their care and in making choices about their daily life". The report also reviewed the 3,836 care records of people detained under the Mental Health Act, finding one in four had no evidence of patients being involved in developing their care plans.⁸

When people with schizophrenia and healthcare professionals make joint decisions, both are more likely to adhere to their treatment plan.⁹ If opportunities to discuss medication, therapies and experiences are limited, then people may not be receiving the best treatment or outcomes for them.

The Schizophrenia Commission called for shared decision-making to be the "cornerstone of practice", so that

individuals can shape their own care and treatment plans through proper consultation.¹⁰

Our survey asked participants to pick any options from a list of 30 which they believed would best improve their own wellbeing. The findings in figure 8 show consistency, choice and shorter waiting times to be the most helpful choices. The most popular option, having a consistent professional, was picked by three in five people.

Practical tools to better understand treatment choices and manage delusions was a noticeable trend among this group, along with quicker and more frequent access to healthcare professionals and therapies.

Analysis on page 18 compares these findings with the results from the family members and carers group.

"The lack of continuity, which stems mainly from the splitting of services, particularly the division between community and inpatient services, and partly from the high turnover of staff, is one of the most pressing issues. It makes everything more stressful and disorientating than it need be for people who are already stressed and disoriented. It does not give time for trust to develop and trust, of course, is a fundamental starting point for any therapeutic relationship.

"One issue that is sometimes not appreciated is that this lack of continuity leads to inefficiency and errors as care is handed over from one team to the next. Another is that most mental health staff value long-term relationships with their clients so the fact that this no longer happens leads to high staff burnout and turnover - which then compounds the problem."

Dr James MacCabe,
Reader in psychiatry, King's College London



Choice of treatment

Sections of our survey where participants were able to write detailed responses identified several complaints about people not being able to access reliable support at points of great need such as during a relapse.



"I have had nine different psychiatrists in the last five years. They only stay a month or so. It's hopeless for any sort of patient-doctor relationship. No chance to build trust."

- Survey participant



"The people who deal with me at my hospital have all been lovely, and tried to help me [but] I just can't get any help when I relapse, I wait three to four months between appointments. They are so understaffed."

- Survey participant

"I suffered a psychotic breakdown, caused by the stress of running a demanding business. I could no longer work, hold a conversation, sleep, rest or relax.

"My brain was going haywire and I was eventually hospitalised for three months in a secure psychiatric unit following a suicide attempt.

"At the time I could see no other way out of the frightening nightmare I was trapped in. What I didn't know was that I had a treatable mental illness.

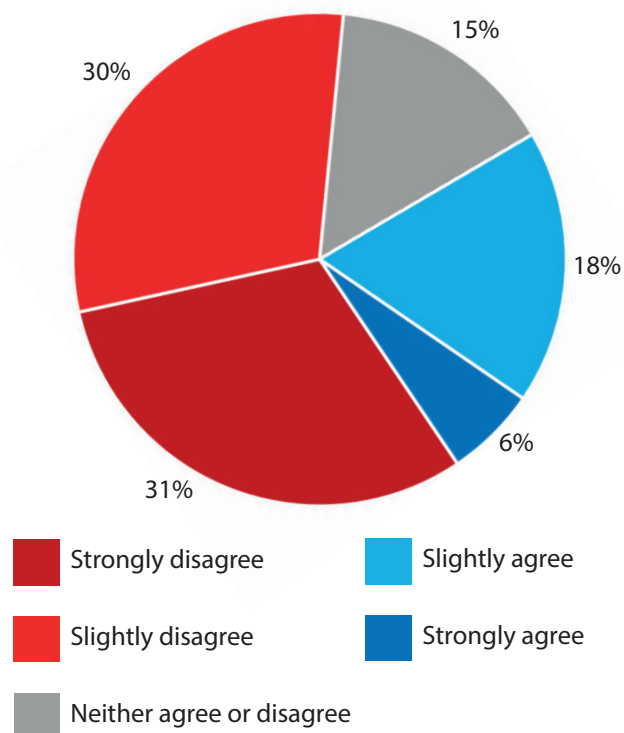
"Following an acute psychotic episode 10 days into my hospital stay, I was diagnosed with psychosis. That word scared me. I was afraid I would never get better and that I would be incarcerated forever.

"However, in time and with the right medication, treatment and support, the desire to die slowly melted away and my brain started functioning again."

Melanie Llewellyn,
Writer and designer



Figure 9: "I am given choice in my treatment options, including medication."



"I feel that healthcare professionals are just ticking boxes when I go to see them."

- Survey participant

RECOMMENDATIONS

3 As far as practically possible, consistency of support should be provided though individuals being seen by the same doctor, nurse or mental health professional.

4 Choice of medication and treatments should be made by the patient and healthcare professional together, taking into account the views of families and carers, if this is agreed.

5 Proper consultation must be a priority in care plans, with a section for a patient's own comments. The care programme approach meeting is an opportunity to jointly devise this plan.

Quality of life

Our research examined the impact a diagnosis of schizophrenia or an episode of psychosis can have on a person's quality of life. We asked people to rate the satisfaction they currently feel in a number of aspects, using a scale of one to five: one being very low satisfaction; two being quite low; three being neither high or low; four being quite high; and five being very high.

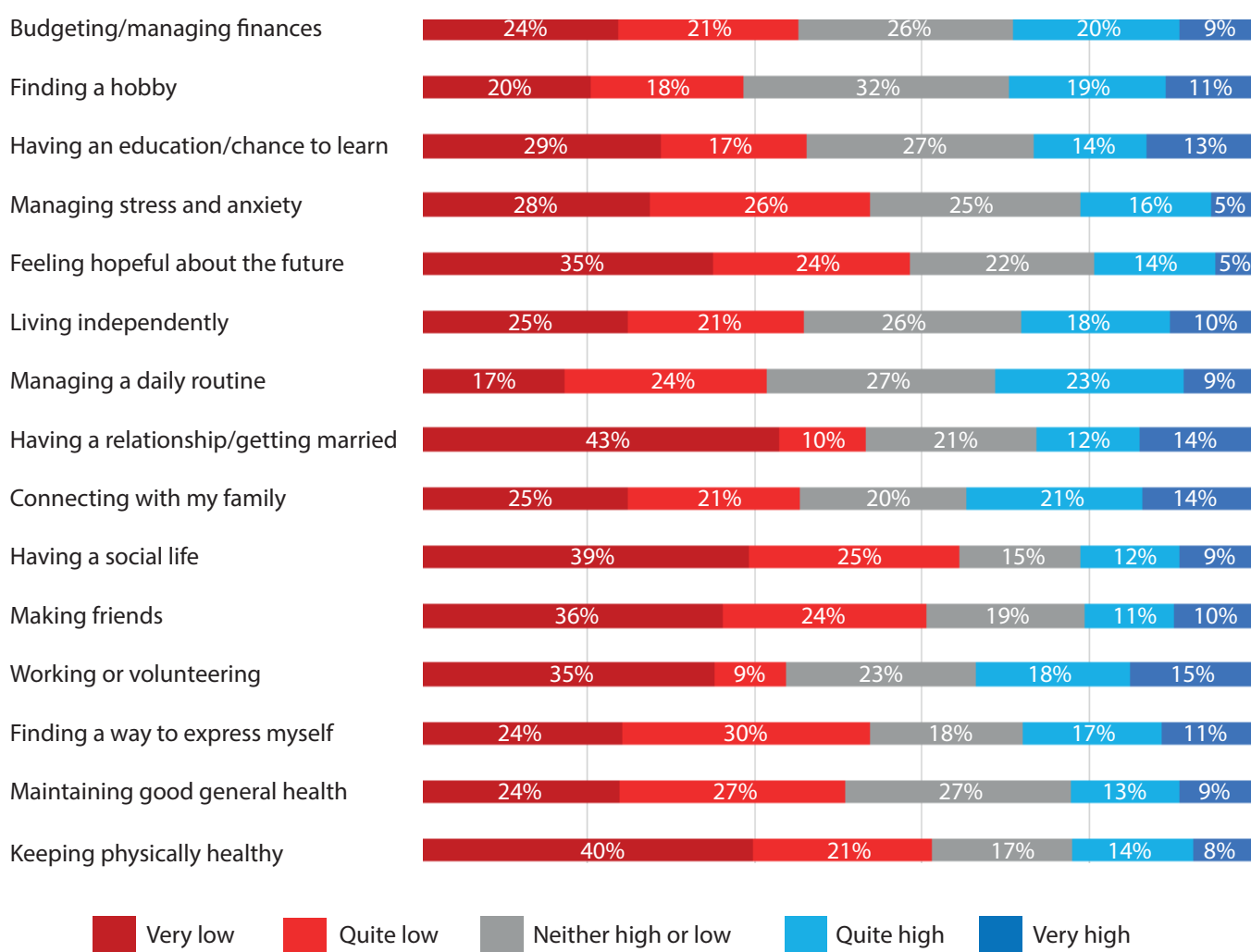
The findings in figure 10 show that schizophrenia or experience of psychosis can have a profound impact and leave many people feeling isolated. It is concerning that almost three in five people (59%) did not feel hopeful about the future when asked to rate this topic in the survey.

Key areas in which participants were more likely to report very or quite high satisfaction were connecting with family (a total of 35%), working or volunteering (33%), managing a daily routine (32%), finding a hobby (30%), and budgeting/managing finances (29%).

Key areas in which participants reported very or quite low satisfaction were having a social life (a total of 65%), keeping physically fit (61%), and making friends (61%).

These findings reaffirm SANE's view that physical health should be regularly assessed alongside mental health by healthcare professionals, due to this being of high importance for overall personal development and esteem.⁶

Figure 10: Current satisfaction in key wellbeing measures.



Quality of life



“The current priority is to decrease symptoms to the extent that the person can cope. This is not enough. The person should be helped to regain independence. The services (art therapy, support groups etc) that make life fun and worth living are always the first to get cut.”

- Survey participant

People with schizophrenia are more likely to smoke, be obese and develop obesity-related cancers.¹¹ In 2015, NICE published its treatment standard which specified that people with schizophrenia should have physical health assessments and be given help with healthy eating, exercise and quitting smoking.¹²

Our survey showed a recognition by participants that they were unhappy with their current level of physical health, with just 14% of respondents having quite high satisfaction in this area.

A key finding in both rounds of the *National Audit on Schizophrenia* by the Royal College of Psychiatrists was the lack of monitoring and intervention for physical health indicators.¹³ It prompted the development of a quality improvement tool to promote better physical health for people with psychosis.

The link between physical activity and improved well-being outcomes has been connected in many research studies, including a systematic review which found that 30 minutes of aerobic exercise, such as running on a treadmill or cycling, three times a week for 12 weeks, was effective at improving mental health outcomes for people with schizophrenia or schizoaffective disorder.¹⁴



“Psychiatry appointments are very focused on positive symptoms and medications, and very little on life impact.”

- Survey participant

RECOMMENDATION

6 Clear objectives should be set from the outset for appointments with professionals, and evaluated continually.

“I have lived with schizophrenia for most of my life. I have been cared for by many special consultants, nurses, social workers and therapists, both in the private sector and the NHS.

“There have been some very dark experiences, resulting in me being sectioned under the Mental Health Act.

“But all along the journey I have assimilated strategies that have evolved, providing me with a greater resilience.

“I have had the opportunity to acquire creative release. From this vantage-point, my quality of life has improved.

“I have been able to set up my own studio facilities. Over the years, I have built up a vast archive of material.

“When I am coping with my condition, I can get a myriad of different sounds in my head, and I try to translate these into music in my studio.

“For me creativity is, quite literally, a lifeline.”

Robert Bayley,
Musician and writer



SANE COMMENT

Despite the prime minister’s pledge for parity of esteem, our survey shows 40% of patients have very low satisfaction with their physical health and it suggests that they are not being encouraged, monitored and provided with means of achieving better physical health. This again points to the disconnect between the secondary services and the GP, and the lack of information or availability of initiatives on the ground.

Alongside the ambition to live normal lives with families and friends, with good physical health and independence, our survey highlights the importance for the majority of patients to find meaningful activities and hobbies, opportunities for volunteering and learning, and ways of expressing themselves.

Families and carers

Our survey polled family members and carers of people with schizophrenia or experience of psychosis on the level of information and support they received. They were also asked to provide their views on what could be done to improve the wellbeing of the person they know. A sample of 161 such people responded to the questionnaire.

Three in five (61%) family members and carers feel unsupported by healthcare professionals, despite the major role they play. This outstrips the patients themselves, with 49% saying so.

The NICE guidance on the prevention and management of psychosis and schizophrenia in adults states that carers should receive written and verbal information in an accessible format about diagnosis and management of psychosis and schizophrenia, positive outcomes and recovery, types of support for carers, role of teams and services, and getting help in a crisis.¹³

However, when the statement “I feel informed regarding the available service options” was put to family

members and carers in our survey, two-thirds (66%) disagreed.

Four in five (80%) family members and carers wanted to be more involved and given a choice in the care plan of the person they knew. This view is slightly higher than that of those affected directly as the combined figure for people with schizophrenia or experience of psychosis was 73%. See page 11 for further analysis of this topic.

A total of 84% of family members and carers wanted to be more involved in decisions affecting support services available to the person they know or care for.

Figure 10: “I feel supported by professionals.”

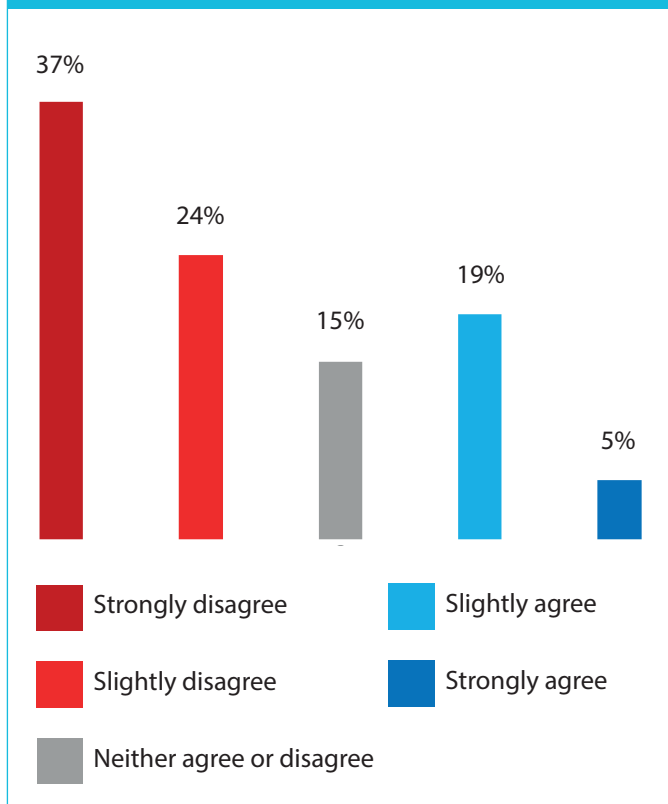
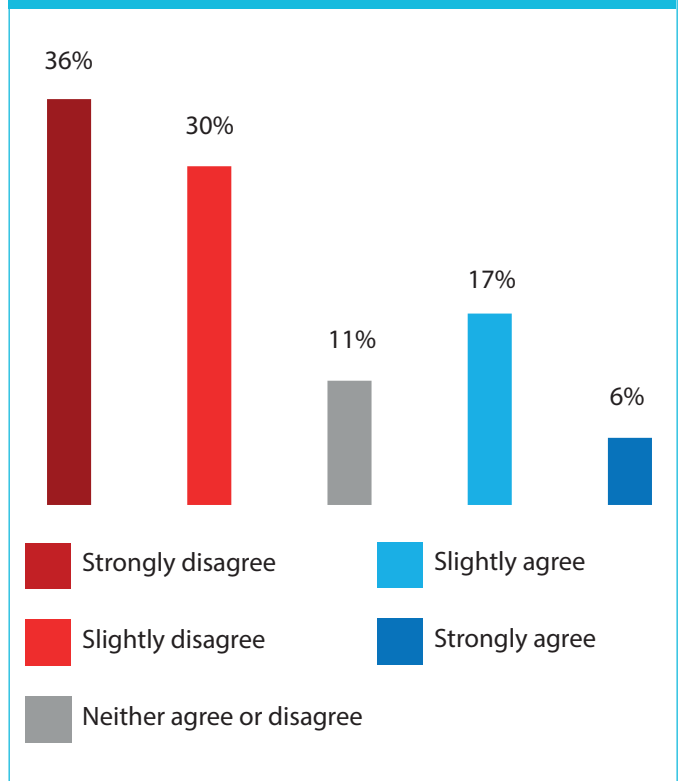


Figure 11: “I feel informed regarding available service options.”



“More information and support should be available to family members and carers. Continuity of care is also very important and often lacking in overstretched and underfunded community teams.”

- Family member

Families and carers

Figure 13: "I would like to be more involved/given a choice in the care plan of the person I know."

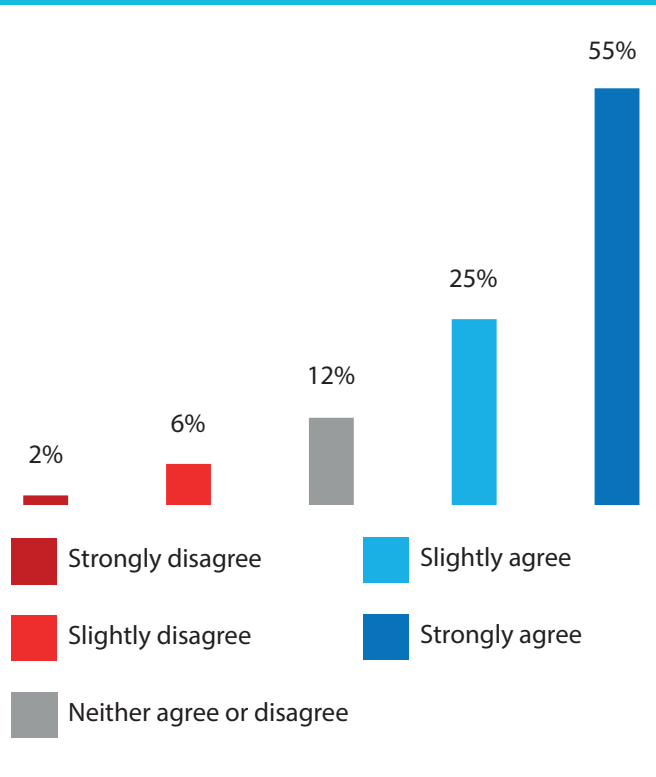


Figure 15 also shows that 86% of family members and carers would have liked to have received more information at the time the person they knew or cared for was diagnosed with schizophrenia or experienced psychosis. This particular result proved to be one of the most resoundingly clear conclusions in our survey, exemplifying just how important this group value being informed at this crucial stage, and the apparent failures in communication currently.

“After the initial excellent care and support my son had for the first few years of being unwell, the service and support became less and less.”
- Family member

“We have no support in our community. We have to travel 100 miles for any treatment or support.”
- Family member

“Around a fifth of the people who contact our services at SANE are concerned about the people they care for with a mental health problem.

“One of the major issues these people face is the feeling of helplessness.

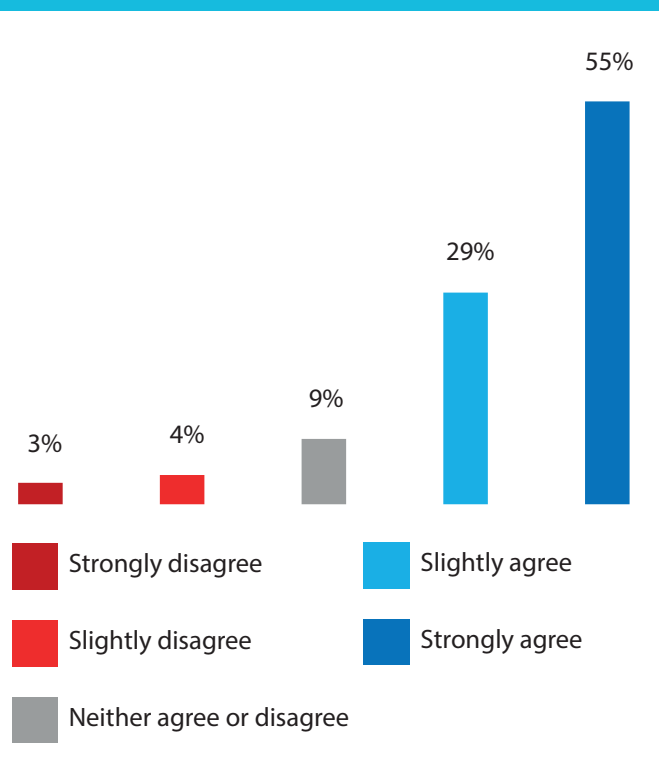
“Many family members can feel excluded from services and by professionals, and feel as though they are not involved in the care of the person they love.

“Our role at SANE is to provide emotional support, guidance and information to those who contact us, and understand how these pressures are also impacting their own wellbeing, as this can be overlooked or neglected.”

Leigh Wallbank,
Head of Services, SANE



Figure 14: "I would like to be more involved in decisions affecting services and/or daily life."

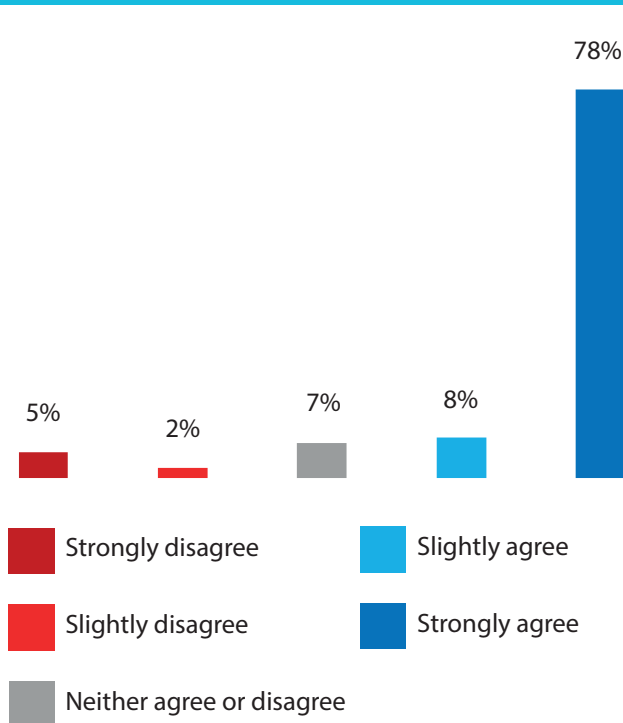


Families and carers

Figure 14: Five most popular areas to improve wellbeing.

1 Having a consistent doctor/nurse/healthcare professional.	65%
2 Having greater support within the community.	58%
3 Being given information to help better understand schizophrenia.	52%
4 Being given tools and information on treatment choices, including medication.	50%
5 Having shorter wait times to see a healthcare professional or access psychological therapy.	49%

Figure 15: “I would have liked to have received more information from professionals at the time the person I know for was diagnosed.”



SANE COMMENT

The majority of patients said that they don't trust their healthcare professionals and rely on their families. Despite this, the families are given little or no support. Interpretations of confidentiality means they are often excluded from vital information which could prevent distress and crisis. Investment in involving families and carers cannot be overemphasised in preventing relapse.

Our survey asked family members and carers to pick as many options as they wished from a list of 30 which they believed would best improve the wellbeing of the person they knew or cared for. The results, as outlined in figure 14, show that consistency of care, greater support in the community, more information and shorter waiting times are key priorities for this group.

Almost two-thirds of family members and carers (65%) picked having a consistent person responsible for their care, matching the results of participants with schizophrenia or experience of psychosis as the most popular area to improve wellbeing.

Comparing these findings with those in figure 8 shows that family members and carers rank having greater support within the community slightly higher. The full breakdown of these 30 options from both groups can be found in the appendix of this report.

Mental health carers make up roughly one in every four carers in the UK, which equates to about 1.5 million people. This also means that roughly one in every 40 people is a mental health carer.¹⁵ The triangle of care approach is a method of good practice across the mental health care pathway, linking patients, professionals and carers.¹⁶ It is important that the model's principles are upheld so that teams work in partnership with carers.

RECOMMENDATION

7 If agreed with the patient, family members and carers should be consulted about plans for support services so that provision reflects the individual needs of the patient.

Healthcare professionals

Our survey asked mental health and healthcare professionals who care for someone with schizophrenia or someone who has experienced psychosis to give their views on various topics, including how well they understand symptoms and navigating the care system. A sample of 56 such people responded to the questionnaire.

Figure 16 charts the response to the statement “I understand schizophrenia risk factors, relapse indicators and symptoms,” with more than half (54%) of healthcare professionals agreeing strongly. However, one in ten participants disagreed with this statement.

Nearly a quarter of professionals (23%) surveyed did not feel informed regarding the available service options.

Analysis shows that 57% of professionals felt supported by other healthcare professionals, but a fifth did not. It’s vital, therefore, that teams are fully staffed and well-resourced as we know these to be the best conditions for strong collaboration, leadership and communication across agencies.

This point is outlined in the *Five Year Forward View for Mental Health*, which states “the right workforce with the right skills is the single most important component of good care.”¹⁷ Healthcare professionals value building trust and spending time with patients, but the shortages of staff and regular usage of locums undermine this.

Vacancy rates

11% - Nursing and midwifery posts in mental health trusts - 7,600 out of 67,800 posts vacant.¹⁸

12% - Medical posts in mental health services - 1,400 out of 11,400 posts vacant.¹⁹

13% - Consultant posts - 700 out of 5,400 posts vacant.¹⁹

As outlined in the *Five Year Progress Report* by the Schizophrenia Commission, the workforce “continues to struggle with high turnover, and the plans for development do not go far enough to ensure a strong, sustainable foundation upon which to deliver high-quality, evidence-based care.”²⁰

“It is difficult for patients to traverse the healthcare system. There is an urgent need for ‘tube maps’ for teams and patients to know where to go when they need something specific.

“Training of healthcare professionals needs to focus on shared decision making, confidentiality and communication skills.

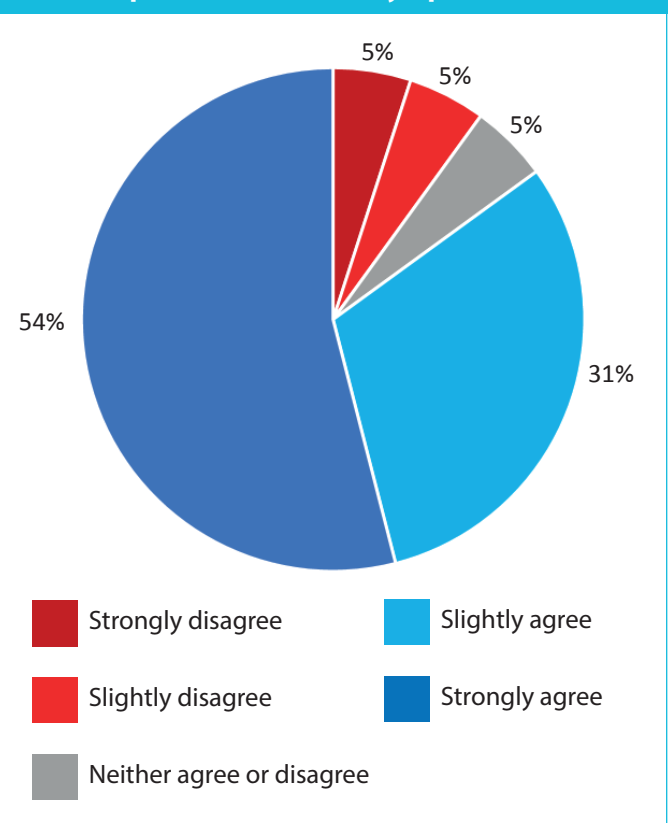
“Issues of informing and working with families and carers is critical, especially in line with confidentiality issues.

“There needs to be assertive outreach training for teams in the support and help they can give friends and families.”

Professor Dinesh Bhugra,
Former president, World
Psychiatric Association

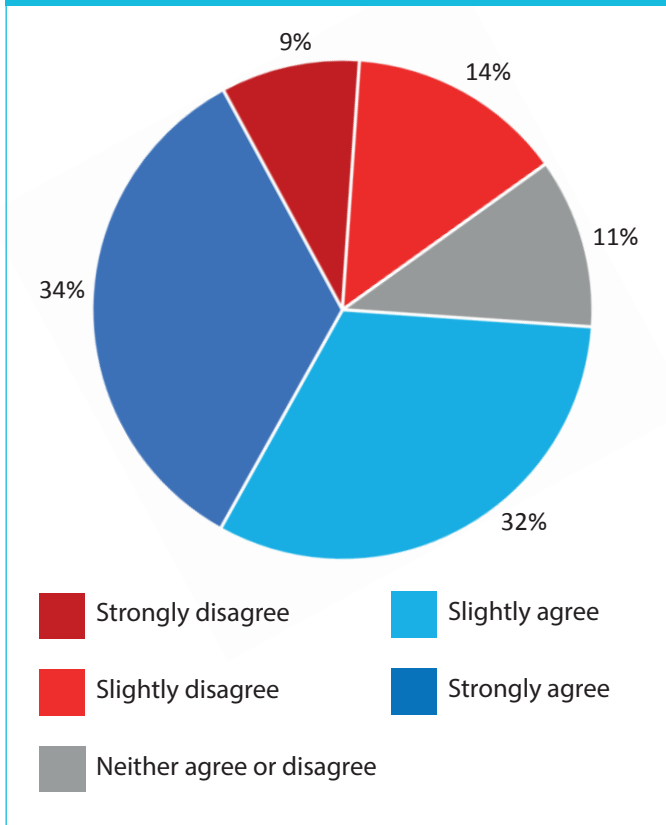


Figure 16: “I understand schizophrenia risk factors, relapse indicators and symptoms.”



Healthcare professionals

Figure 17: "I feel informed regarding available service options."



SANE COMMENT

Our findings show that the majority of healthcare professionals have a strong understanding of schizophrenia risk factors and relapse indicators.

However, the recruitment of mental health professionals has become a critical issue. The consequence of this can be found in some of the responses in our survey: primarily not being able to build trust and spend time with patients; the fragmentation of services; and the replacement of teams which stayed with a patient to and from hospital with disparate teams, ranging from home treatment teams to crisis treatment teams who do not liaise with the hospital and community. The problem is that patients are bounced between support services, the hospital and the GP which involves long waits with each referral, often allowing the crisis to escalate and for patients to deteriorate.



"There is not enough choice in accessing community social support."

- Healthcare professional

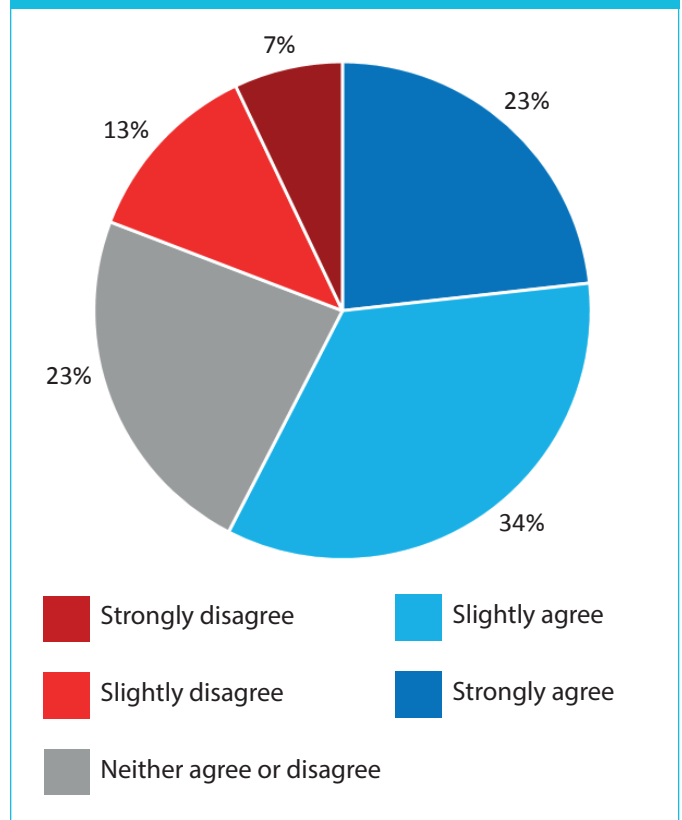
RECOMMENDATIONS

8 'Tube maps' should be devised to clearly inform mental health teams and patients so they are able to navigate the system and know clearly where to go when they need something specific.

9 Training of healthcare professionals should focus on joint-working, shared decision-making and communication skills.

10 Services need to be adequately funded to ensure that the fundamental needs of patients and carers are met.

Figure 18: "I feel supported by healthcare professionals."



References

- 1** The State of the NHS Provider Sector, NHS Providers. www.nhsproviders.org/media/3281/state-of-the-nhs-provider-sector_07-17.pdf
- 2** Schizophrenia, Royal College of Psychiatrists. www.rcpsych.ac.uk/healthadvice/problemsanddisorders/schizophrenia.aspx
- 3** Schizophrenia, World Health Organization. www.who.int/mental_health/management/schizophrenia/en/
- 4** Severe mental illness (psychosis), Royal College of Psychiatrists. www.rcpsych.ac.uk/healthadvice/informationforcarers/severementalillness.aspx
- 5** Picchioni, M.M., Murray, R.M. (2007) Schizophrenia, *British Medical Journal*, 335, 91-95.
- 6** Living with Schizophrenia, SANE. www.sane.org.uk/uploads/living-with-schizophrenia-final-uk_am_0414_0121_vcertainmentation_1-2.pdf
- 7** The State of Care in Mental Health Services 2014 to 2017, Care Quality Commission. www.cqc.org.uk/sites/default/files/20170720_stateofmh_report.pdf
- 8** Better Care In My Hands, Care Quality Commission. www.cqc.org.uk/sites/default/files/20160519_Better_care_in_my_hands_FINAL.pdf
- 9** Gray, R. et al. (2009) Antipsychotic long-acting injections in clinical practice: medication management and patient choice. *British Journal of Psychiatry*, 195: 51-556.
- 10** The Abandoned Illness, Schizophrenia Commission. www.rethink.org/media/514093/TSC_main_report_14_nov.pdf
- 11** Living with Schizophrenia, World Health Organization. www.who.int/mental_health/world-mental-health-day/paper_wfmh.pdf
- 12** Psychosis and schizophrenia in adults: prevention and management, National Institute for Health and Care Excellence. www.nice.org.uk/guidance/cg178/chapter/1-Recommendations#care-across-all-phases
- 13** Report of the second round of the National Audit of Schizophrenia, Royal College of Psychiatrists. www.rcpsych.ac.uk/pdf/FINAL%20report%20for%20the%20second%20round%20of%20the%20National%20Audit%20of%20Schizophrenia%20-%208.10.14v2.pdf
- 14** Stanton, R. and Happell, B. (2014) A systematic review of the aerobic exercise program variables for people with schizophrenia. *Current Sports Medicine Reports*, 13(4), 260–266.
- 15** Key facts about carers and the people they care for, Carers Trust. www.carers.org/key-facts-about-carers-and-people-they-care
- 16** The Triangle of Care: A Guide to Best Practice in Mental Health Care in England, Carers Trust. www.professionals.carers.org/sites/default/files/thetriangleofcare_guidetobestpracticeinmentalhealthcare_england.pdf
- 17** The Five Year Forward View for Mental Health, Mental Health Taskforce. www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf
- 18** Summary of vacancy, shortfall and fill rate data for the clinical workforce, NHS Providers. www.nhsproviders.org/media/3903/summary-of-vacancy-shortfall-and-fill-rate-data-for-the-clinical-workforce.pdf
- 19** Stepping Forward to 2020/21: The Mental Health Workforce Plan for England, Health Education England. www.hee.nhs.uk/sites/default/files/documents/Stepping%20forward%20to%20202021%20-%20The%20mental%20health%20workforce%20plan%20for%20england.pdf
- 20** Progress Report: Five Years On, Schizophrenia Commission. www.rethink.org/media/3190801/the-schizophrenia-commission-progress-report-five-years-on.pdf

Appendix

Figure 8 - Complete results.

Answered by people living with schizophrenia or those who have experienced an episode of psychosis.

1 Having a consistent doctor/nurse/healthcare professional. **60%**

2 Being given tools and information on treatment choices, including medication. **48%**

3 Being given tools and information on managing delusions/hallucinations or voices. **46%**

4 Having shorter wait times to see a healthcare professional or access psychological therapy. **44%**

5 Seeing my healthcare professional (doctor, nurse or social worker) more often. **40%**

6 Being given tools and information on relapsing and relapsing triggers. **39%**

7 Having greater support within the community. **37%**

8 Addressing the stigma that can be associated with schizophrenia. **36%**

9 Being given information to help me better understand schizophrenia. **36%**

10 Being given tools and information on being resilient and having confidence. **31%**

11 Being given tools and information on care planning. **27%**

12 Being given tools and information on dealing with stress. **26%**

13 Having consultations with my doctor that are clearly structured to enable personal progression and achieve certain goals. **25%**

14 Being given tools and information on diet, physical and general health. **23%**

15 Attending talking therapy or a support group. **21%**

16 Attending cognitive behavioural therapy. **21%**

17 Being given tools and information on developing social relationships. **20%**

18= Having more education-focused consultations with my doctor around schizophrenia and treatment options, including medication. **18%**

18= Being given tools and information on managing finances. **18%**

20= Being given tools and information on bills, housing and living independently. **16%**

20= Attending arts therapy. **16%**

22 Being given tools and information on making daily decisions and setting goals. **14%**

23 Being given tools and information on education and employment. **11%**

24 Attending a recovery college. **10%**

25 Being part of a forum or online discussion group. **10%**

26 Attending acceptance and commitment therapy. **9%**

27 Attending dialectical behavioural therapy. **8%**

28= Attending behavioural family therapy. **4%**

28= Other. **4%**

30 None. **1%**

Appendix

Figure 14 - Complete results.
Answered by family members and carers.

1 Having a consistent doctor/nurse/healthcare professional. **65%**

2 Having greater support within the community. **58%**

3 Being given information to help me better understand schizophrenia. **52%**

4 Being given tools and information on treatment choices, including medication. **50%**

5 Having shorter wait times to see a healthcare professional or access psychological therapy. **49%**

6 Having consultations with their doctor that are clearly structured to enable personal progression and achieve certain goals. **47%**

7= Being given tools and information on managing delusions/hallucinations or voices. **46%**

7= Addressing the stigma that can be associated with schizophrenia. **46%**

9 Being given tools and information on relapsing and relapsing triggers. **45%**

10 Seeing their healthcare professional (doctor, nurse or social worker) more often. **43%**

11 Being given tools and information on dealing with stress. **34%**

12 Having more education-focused consultations with my doctor around schizophrenia and treatment options, including medication. **30%**

13 Being given tools and information on being resilient and having confidence. **29%**

14 Being given tools and information on care planning. **28%**

15 Being given tools and information on developing social relationships. **27%**

16 Attending talking therapy or a support group. **26%**

17= Being given tools and information on diet, physical and general health. **25%**

17= Attending talking therapy or a support group. **25%**

19 Being given tools and information on bills, housing and living independently. **24%**

20= Being given tools and information on making daily decisions and setting goals. **23%**

20= Attending a recovery college. **23%**

22 Being given tools and information on education and employment. **20%**

23= Attending behavioural family therapy. **19%**

23= Being given tools and information on managing finances. **19%**

25 Attending arts therapy. **17%**

26 Attending acceptance and commitment therapy. **16%**

27 Attending dialectical behavioural therapy. **15%**

28 Being part of a forum or online discussion group. **11%**

29 Other. **5%**

30 None. **1%**



Registered charity number: 296572

www.sane.org.uk