

# **Community Based Mental Health Services in Norfolk and Waveney.**

Year One Community Transformation Steering Group Evaluation  
Summary Report

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# Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

## Summary

Please note, this is a summary version of the Year One Community Transformation Steering Group Evaluation and focusses on the three outcomes that are the most relevant to the public. The full version is available to be viewed or downloaded from the Healthwatch Norfolk Website:

<https://healthwatchnorfolk.co.uk/>

## Glossary

Throughout this report, we have used some terms that are commonly used by members of the Community Transformation Steering Group, and they are explained below.

### Critical Friend

A person or organisation who offers encouragement and support to another person or an organisation, but who also provides honest and often candid feedback that may be uncomfortable or difficult to hear.

### Co-Production

The active involvement of people with lived experience of mental illness in service design to increase the quality and efficiency of services and improve clinical outcomes (McKeown, 2014; Nesta, 2012).

### Community Transformation Steering Group

This group oversees managing the transformation of community based mental health services across Norfolk and Waveney. It is made up of representatives from local health and social care providers, people with lived experience, voluntary and third sector organisations and staff from local mental health services.

### Expert by Experience

A person who represents lived experience in considerations and decisions about how support in community mental health services can be best offered to meet people's needs. This input supports the co-production of personalised and holistic support that improves the experience and quality of treatment and support for service users, carers and families.

### I Statements

Before the community mental health transformation started, eleven I Statements were formed through workshops and focus groups (hosted by Norfolk and Suffolk

Foundation Trust) with adult severely affected by mental illness. These statements focus on their feelings and experiences of community health services and what they would like to see being delivered from the treatment and care they receive.

# Why we looked at this

Healthwatch Norfolk was commissioned by Norfolk and Waveney Integrated Care Board (ICB) to conduct an independent person-centred evaluation of how well the Community Transformation Steering Group delivered their plan to transform community based mental health services in Norfolk and Waveney. Between April 2021 and March 2022 there were approximately 9124 people registered with doctors' surgeries as being severely affected by mental illness (NHS Digital Quality and Outcomes Framework, 2022) who were receiving or waiting for treatment and care in Norfolk and Waveney.

This project is a three-year evaluation, which should be completed by the end of March 2024. The Year One Community Transformation Steering Group Evaluation (of which this is a summary) is an interim report covering the period from June 2021 – June 2022.

Healthwatch Norfolk created an evaluation plan that covered five outcomes and involved engaging with adults severely affected by mental illness, their carers and support networks, Voluntary, Community and Social Enterprise (VCSE) organisations, primary care staff, Rethink Experts by Experience and members of the Community Transformation Steering Group. This report is based on the findings from the Evaluation plan, which can be found as an appendix in the main report.

Due to a delay in rolling out the Rehabilitation Pilot part of the community mental health transformation, Healthwatch Norfolk will be evaluating its progress in year two of our work, after the pilot begins in August 2022.

# How we did this

Healthwatch Norfolk completed this work by using feedback gathered from the public, mental health workforce, primary care workforce and local Voluntary, Community, and Social Enterprise (VCSE) organisations. We hope to provide both Norfolk and Suffolk Foundation Trust (NSFT), NHS England and NHS Improvement assurance that the Community Transformation Steering Group is delivering outcomes for adults severely affected by mental illness and their care networks.

Early in the transformation process eleven “I Statements” were developed by Norfolk and Suffolk Foundation Trust (NSFT) in consultation with service users and carers through a series of engagement events across Norfolk and Waveney. They were created through discussion during the Autumn 2020 and Spring 2021, involving:

- Access Community Trust’s LEAF Group (Lived Experience Advisory Group)
- Carers of adults severely affected by mental illness
- The Community Transformation Steering Group
- Workshops held in January 2021 with adults severely affected by mental illness

The statements were drafted to show the outcomes that people severely affected by mental illness wanted to achieve. The I Statements informed the development of the Community Mental Health Transformation Strategy and we have used them as the basis for our evaluation plan.

We collected feedback through surveys and interviews:

## Surveys

Healthwatch Norfolk compiled two surveys with a series of questions to get feedback from adults severely affected by mental illness and their carers / families. Online surveys were felt to be the best way to collect information to allow a wide reach of people, and to ensure consistency and ease of analysis.

Surveys were co-designed with Rethink Mental Illness and members of their Expert by Experience Reference Group. This was to ensure that we asked the right

type of questions, covered relevant themes and topics and used appropriate language in our surveys.

These surveys were promoted via Healthwatch Norfolk's social media channels (LinkedIn, Facebook, Instagram, and Twitter), Healthwatch Norfolk website and newsletter, via Community Development Officers, through local charities and third sector organisations, the Mental Health Providers Forum and via a survey link on Footfall. The surveys were available to from 1st February to 31st May 2022.

Healthwatch Norfolk and Rethink also co-designed and created an online survey to find out what each of the Experts by Experience thought about:

- their involvement in co-producing the mental health transformation workstreams
- how valued they felt by the Steering Group
- how supported they felt by Rethink in carrying out their role
- any barriers they face to taking part in co-production work

Surveys were posted on SmartSurvey and it was available to the Experts by Experience for six weeks between April and May 2022.

## **Interviews**

Healthwatch Norfolk conducted ten one to one interviews and three one to one interviews, respectively, online via MS Teams and by telephone. Interviewers had a list of broad topic areas and questions that were based on the contents of the online survey to cover during the interview process. Interviews were recorded with the consent of the interviewee.

The interviews allowed us to obtain more in-depth information and opinions regarding the experiences of community based mental health services by adults severely affected by mental illness and their carers / families.

Healthwatch Norfolk conducted one joint interview with two Experts by Experience and one 1:1 interview to explore their experiences of co-production. Participants were asked about their experiences of co-producing the plans for transformation of community based mental health services. The semi-structured interview questions can be found as an appendix in the main report. Both interviews were held online and recorded using a Dictaphone, with prior consent from the participants.



All recordings were deleted once the interview had been transcribed or written up.

## **Involvement and Consent**

Participation in surveys was entirely voluntary and anonymous, however, to complete the survey participants had to give their consent for their answers and feedback to be shared. If participants wanted to leave more in-depth feedback or leave any comments on the survey itself, they were advised to contact Healthwatch Norfolk at: [enquiries@healthwatchnorfolk.co.uk](mailto:enquiries@healthwatchnorfolk.co.uk)

Respondents were also asked if they wished to give their consent for us to contact them for an interview. Healthwatch Norfolk then contacted adults severely affected by mental illness and carers that indicated in the survey that they were willing to be contacted, offering the opportunity to be interviewed.

We ensured that we reached each of the Community Transformation Steering Group's priority cohorts for their year one work (Eating Disorders, Personality Disorders (Complex Emotional Needs) and Rehabilitation) by gathering information about the type of mental illness each survey respondent reported living with, in the demographic section. This information was given voluntarily, and it was not compulsory to fill in this information.

## **Survey Data Analysis**

The surveys included of a range of question types (such as multiple choice, and open ended), which enabled us to get a range of data for analysis, including more in-depth responses. Answers where respondents could type their own comments were analysed thematically in NViVO, by coding them to establish themes, which are reflected in this report.

Comments in this report are direct quotes from survey respondents and interviewees, which have been left unchanged to ensure originality. Percentages in this report are rounded to the nearest whole number. A copy of the survey questions can be found as appendices in the main report.

## **Interview data analysis**

Interview transcripts were analysed using thematic analysis in NViVO and the themes are reported in the 'What we found' section of this report. A copy of interview questions for either outcome can be found as appendices in the main report.

## Limitations

There were some limitations in collecting data and feedback for this evaluation.

Whilst we ensured that our survey was available in paper form, all our responses were received online. This may mean that the results are biased towards members of the public who are more confident with using IT and going online.

Healthwatch Norfolk received a high response from adults severely affected by mental illness wanting to be interviewed about their experiences of community based mental health services. Previous research has shown that people who provide feedback about a service are more likely to leave negative feedback.

The survey was also available as a paper-based version, but all those who wanted to take part in interviews expressed this through the online survey. We were aware that people who are severely affected by mental health issues may struggle to engage. We invited respondents that expressed an interest in talking to us and continued interviewing until we had sufficient feedback.

In outcome three, we had a small sample size. 5 out of 12 Experts by Experience completed our survey, a 42% response rate. Despite the survey being presented to the Reference Group, the small sample size could be due to a number of reasons, for example: people becoming fed up with completing surveys, the nature of the survey (co-producing the transformation of community mental health services) or being too busy. We were able to interview three Experts by Experience (25%). We acknowledge that the themes in this section are based on a small number of participant interviews. The findings may not be representative of the whole Expert by Experience Reference Group.

# What we found out and what this means

You can find the full 'What we found out' (results) section in the main report available on the Healthwatch Norfolk Website:  
<https://healthwatchnorfolk.co.uk/reports/>

## Outcome 1:

### **Adults severely affected by mental illness report improvements in and access to community based services**

It is important to recognise that this is the first year of a three-year evaluation of the Community Mental Health Transformation process and that the transformation is also in its first year. We also know that there are many adults severely affected by mental health illness whose voices we have not been able to capture.

The results of the survey for adults severely affected by mental health illness gives us a baseline and helps to identify areas that can be further improved upon for the Community Transformation Steering Group to ensure that their transformation plans are addressing these issues.

The survey was able to reach those people who are severely affected by a mental health illness. 82% of the respondents to the survey had one of the following identified serious mental health illnesses:

- Severe depression
- Personality disorder
- Bi-polar disorder
- Psychosis
- Eating disorder
- Schizophrenia / schizoaffective disorder

Nearly three-quarters of the people that responded to the survey were women (71%). However, the survey results highlight that there is some disparity in how men and women experience community services:

- Less men than women report feeling included in their care,
- Less men than women believe that their main point of contact understands that their mental health needs affect other areas of their life
- More men than women rate the support they receive from their main point of contact as poor
- More women than men have needed to access the out of hours crisis team
- People who classed themselves as having a disability were more frequently not included in their care, although more likely to have a care plan.

## I Statement Outcomes

Approximately one fifth of survey respondents appear to have the following outcomes:

- They have a care plan in place
- They feel very involved in their care
- They feel that their family are appropriately involved in their care

However, the survey results show that the I-statement outcomes *"I want my care plan to be up to date with my current mental health and my life"*, *"I want to be part of my care"* and *"I want my loved ones and I to have an agreed care plan that is about me"* are not being met for many adults with SMI. 54% of respondents reported that they did not have a care plan, 42% stated that they did not feel involved in their care and 35% said that their family were not involved in their care. Only 35% of respondents reported that there had been a discussion with their main contact about their care plan and how their treatment and care is working.

Person-centred care should treat people with care, dignity and respect and 31% of respondents felt they were always treated in this way, with 41% stating they sometimes were. 76% of respondents said that they had not been asked about their care or how they have been treated. Respondents recognised the pressures that staff were under due to staff shortages and tried to make allowance for this, however unhelpful attitudes and approaches were highlighted by others.

An additional feature of person-centred care is the provision of coordinated care, support and treatment. Over 40% of respondents knew who their main point of contact in community mental health services was, however, 47% of respondents who had a main point of contact felt that the organisation of their treatment and care was bad. This was due to a lack of continuity in care, appointments often being cancelled and poor communication. Individuals also highlighted in the survey and interviews that the professionals they have contact with are "going through a tick-box exercise".

This signifies that there is still progress to be made in respect of the outcome ***“I want to experience person-centred care, wherever I can – with, about and for me”***, which should focus on improving helpful communication and the coordination role of the main contact.

The survey results also identify that when people needed to access the out of hours crisis team, over half of these people (62%) said that the crisis team were not aware of their treatment history or the NHS plan. This identifies that the outcome ***“I want continuity in my care team”*** is not yet fully being met.

In relation to the outcome ***“I expect professional carers to have an understanding of mental health needs”*** the survey results identified that 45% of respondents did not feel that their main contact understood that their mental health needs affected other areas of their life. The follow-up interviews with carers also supported that there is an unrealistic expectation about people who are severely affected by mental illness to keep on top of appointments and follow up with things, especially at time of crisis.

Regarding wider community support and the outcome ***“I want services and support to be well advertised in my local community”*** there was an even mix of awareness about wider support services available with 48% of respondents stating that their awareness of community mental health services available was bad and 52% stating it was good or okay.

### **Are people experiencing positive change?**

We asked respondents what changes they had seen (both good and bad) to community-based services within the last twelve months and the overwhelming response was that people have not experienced any positive changes. We should balance this with the recognition that those people who are more likely to complete a survey like this are people who take the opportunity to express their concerns. However, we cannot ignore the responses from this survey.

The results of the survey and follow-up interviews showed that adults severely affected by mental health issues have not seen changes to their support and that the outcomes that they would like to see around involvement, trust, continuity, up to date care plans, involvement with family / carers and person-centred care are not yet being met.

## Outcome 2

### **Families and carers of adults severely affected by mental illness report improvements in and access to community based services**

Most respondents to the carers survey were women (89%), which is higher than the national statistic: 58% of carers are women (Carers UK, 2019).

Many carers that responded to the survey did not feel involved in discussing the treatment and care of the person they support (66%), how they can help the person they support (70%), nor feel kept up to date about the treatment and care of the person they support nor given enough information about how the mental health of the person they support could change (79%). This lack of involvement of carers suggests that the following outcomes are not likely to be met:

- I want my loved ones and I to have an agreed care plan that is about me
- If I am unable to make my own decisions for myself, my prior wishes, and my family /carer views will be considered

Just over half of carers (51%) reported that they felt that they are often or sometimes treated with kindness and respect, which is less than those people severely affected by a mental health illness. However, this may also reflect the lack of contact that carers have with the community based mental health services.

Two-thirds of carers have needed to find support or help for their own wellbeing, with 32% using their GP for support. People also accessed voluntary and community sector support for carers (17%) and community mental health services (7%) and social services (7%).

#### **Are carers experiencing positive change?**

As with adults severely affected by mental illness, carers also reported a lack of change and expressed frustration about waiting times, having difficulty contacting people and staff changes.

The carers survey and interviews also showed that carers have not seen changes to the support for adults severely affected by mental health issues. A lack of communication with carers makes it difficult for carers to provide appropriate support and adds to the pressure that they are under. Carers also

reported that there is little support available to them, which has an impact on their own mental health.

## Outcome 3

### **The Community Transformation Steering Group can evidence they have made changes that have positively impacted on community mental health provision for adults**

Much of our evidence for this outcome is based on what the Steering Group have told us they have achieved, feedback from the Experts by Experience and feedback from the Voluntary, Community and Social Enterprise (VCSE) sector.

There is clear evidence of involvement throughout the transformation process of Experts by Experience, which has been reported by the Experts by Experience Reference Group. This is also evidenced through the attendance at the Steering Group and the activities the Reference Group have been engaged in. Partners have also been positive about the involvement of Experts by Experience.

The Reference Group supported by Rethink currently consists of ten members and the levels of engagement appear to vary, which is understandable due to people's personal commitments etc. Within the Reference Group there is a smaller cohort who are consistently and enthusiastically engaged with the process and have developed in confidence, have been raising issues to be addressed and putting forward ideas. Whilst the involvement of Experts by Experience has generally been a success, there is a reliance on this small cohort to "speak for" all those who are affected by mental health issues and there is opportunity for wider involvement and engagement through the VCSE sector.

There has been concern raised about how the Community Transformation Steering Group engage with the Experts by Experience Reference Group in their communications, the timings of papers and cancellation of meetings. At present we believe that the Steering Group is involving and engaging Experts by Experience, but there is a long way to go before they have equal partnership in the earliest stages of service design, development and evaluation.

This is also the case with the VCSE sector, who have been positive about the information and updates they receive through the Mental Health Providers Forum but have been clear that they have not played a role in the design or development of the transformation.

Engagement with VCSE organisations tends to be focussed on larger, commissioned organisations, which means that some of input from smaller, but experienced organisations may not get the opportunity to support the transformation plans.

The initial plans for the Community Transformation Steering Group included a focus on outcomes that had been developed by people with lived experience, the "I Statements". We believe that it is important to continue to refer to the outcomes desired by people who have lived experience of mental health issues as a key measure in proving the success of the transformation. These statements are now being refreshed in consultation with the Experts by Experience Reference Group.

The Community Transformation Steering Group have not communicated their plans or successes well, particularly at an operational level, nor how the changes are expected to make a difference to adults severely affected by mental health issues and their carers.

The Rehabilitation Pilot is an excellent example of multi-agency working including the early planning stages. This is a good template for other transformation initiatives.

These findings indicate that the Community Transformation Steering Group have engaged well with Experts by Experience, which has been welcomed as a positive change. They have also provided regular updates to the VCSE sector through updates to the Mental Health Providers Forum, but there is little evidence of coproduction of the transformation plans and the role this sector could play, and the strength of the VCSE sector offer is not fully recognised or understood.

The work to develop the outcomes that adults severely affected by mental health issues wanted for themselves has not stayed at the heart of the transformation plans and the impact of the plans is not measured against these outcomes.

Community Transformation Steering Group have made progress with the Rehabilitation Pilot but have not communicated this success very well.



# Recommendations

## Recommendations for Healthwatch Norfolk

Healthwatch Norfolk will explore other ways of engaging with adults severely affected by mental illness and their carers to get their feedback about community mental health services. This could be achieved by engaging with even more VCSE organisations, attending local Mental Health Hubs in Norfolk and Waveney, and having a presence in the local Mental Health Cafés (for example: the Steam and Rest Cafés). Healthwatch Norfolk will be mindful of engaging those who are part of seldom heard communities (for example: men as 71% of respondents in the adults severely affected by mental illness were women).

## Recommendations for Community Transformation Steering Group

### Outcome One

**The Community Mental Health Service Transformation Steering Group should use the I Statement outcomes as the benchmark for the transformation process.**

- Transformation plans and care pathways should always indicate which of the I statement outcomes will be met as a result of any changes. This will ensure that the needs of adults severely affected by mental illness are always at the heart of any plans.
- The steering group should use the I Statement outcomes as their evaluative framework – the “so what has changed for adults severely affected by mental health illness?” to evidence and measure any change to community mental health services.

### Outcome 2

**Any changes to community based mental health services brought in by the Steering Group should ensure that carers of adults severely affected by mental illness are involved in the care of their loved one, offered support and that the value of their**

**role is recognised. The involvement of carers should be a core focus for each care pathway and priority cohort for the community mental health service transformation.**

- To progress with the plans to develop I-statement outcomes for carers, working with VCSE organisations that work with carers of adults severely affected by mental illness.
- Ensure that transformation plans indicate which of the I-statement outcomes will be met as a result of any change
- Consider forming a Carers Panel or a separate group of Experts by Experience to help co-produce and shape the community mental health service transformation process. This will strengthen the Steering Group's acknowledgment of the importance of families, carers and support networks and treat them as an integral part of their loved one's treatment and care.

## **Outcome 3**

**The Community Transformation Steering Group must ensure that the plans are truly coproduced and that engagement with Experts by Experience and wider stakeholders is not just focussed on getting feedback on plans already made.**

- Continue to develop the role of the Experts by Experience and seek opportunities for full coproduction.
- Seek broader opportunities to engage with wider groups of Experts by Experience through other VCSE partners.
- Review the membership of the Steering Group, Operational Group, and Working Groups to ensure broader VCSE representation.
- Ensure that the I Statements outcomes are at the heart of the evaluation framework for the Community Transformation Steering Group.

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