



# **An analysis of people's views on the future of mental health support in east and west Suffolk**

Executive Summary

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*#AveryDifferentConversation*



# Foreword



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NHS Ipswich and East Suffolk and West Suffolk clinical commissioning groups Clinical commissioning groups (CCGs) are NHS statutory organisations that distribute Department of Health funds to pay for health and other services as described in the Health and Social Care Act 2012. They are membership organisations where the members are the individual GP practices responsible for commissioning most health and care services for patients. These practices, working with other healthcare professionals and in partnership with local communities and local authorities, are responsible for commissioning the majority of NHS services for patients within their local population.

Mental health and emotional wellbeing needs have been unmet for years. Services have been under-resourced and a co-ordinated approach to prioritising need has been lacking. The NHS Ipswich and East Suffolk and NHS West Suffolk CCGs wish to make mental health and emotional wellbeing everybody's business and have identified that a new system-wide approach should

be adopted to start 'a very different conversation'.

The CCGs decided to take a different approach to supporting co-production and hearing what people in Suffolk had to say about mental health and emotional wellbeing. We commissioned Suffolk Family Carers (SFC), Suffolk Parent Carer Network (SPCN), Suffolk User Forum (SUF) and Healthwatch Suffolk (HWS) to co-ordinate an independent listening exercise designed to survey the views of patients, parents, carers and professionals to inform the development of our future model for mental health and emotional wellbeing in Suffolk. We believe this approach is in line with the true meaning of co-production and will provide a rich and wide range of views on how services should look in the future.

We wish to transform services so that physical and mental health issues are increasingly considered together by professionals, patients and parents/carers, for example, with regards to support for patients with long-term conditions. We feel the increased integration of services

in East and West Suffolk will support this agenda and hope to build on existing joint working with our local partners, including the provision of community health services and the work undertaken in the Suffolk Children's Emotional Health and Wellbeing Plan.

We recognise that this is the start of a conversation and that our commitment to honest and meaningful co-production will require us to work in a different way now, and in the future, if we are to better support and care for the mental health and emotional wellbeing needs of our population.

# Executive summary



This report summarises the findings of the mental health engagement carried out by a collaboration of Suffolk User Forum, Suffolk Family Carers, Suffolk Parent Carer Network, Healthwatch Suffolk, Ipswich and East and West Suffolk Clinical Commissioning Groups and Norfolk and Suffolk Foundation Trust for the “A Very Different Conversation” report.

The aim of the engagement and has been to find out what people would like from mental health services. This was achieved using three methods:

1. Suffolk User Forum, Suffolk Parent Carer Network and Suffolk Family Carers collected data from groups, meetings and engagement events across Suffolk. These events collected unstructured data from a diverse range of groups and on a number of different topics and engaged with between 4,000 - 5000 people.
2. Three separate surveys were co-produced by the partnership and distributed online and at engagement events. There was one survey for service users, one for carers and one for professionals. There were 768 responses to the surveys. 444 were from service users and members of the public, 169 were from carers and 155 were from professionals and staff.
3. Data from My Health Our Future, Healthwatch Suffolk’s research with 7,088 young people in schools in Suffolk, aged from 11 to 19 has been included to include young people’s voice in the transformation. This data

is available in a separate section of the full report, and the full standalone MHoF report will be available at the end of 2018.

The large amounts of data generated from the surveys and the summaries of group feedback were thematically analysed by Healthwatch Suffolk. Thematic analysis involves looking through the responses to each survey question or source of data and looking for repeated points or ideas. This was carried out using Nvivo qualitative analysis software.

The themes below appear in multiple sections of the report. The final three themes (digital support and support in schools and transitions to adult services) relate to specific sections of the survey.

1. **Lack of access and unmet needs** - one of the largest and most commonly repeated themes throughout the survey and the group responses. Service users and carers often stated that they received no support for their mental health, that they could not access services, or that there did not appear to be any support available in Suffolk for mental health. Besides general references to a lack of support, service users and carers also reported that their GP was unable to provide them with access to services for their mental health. Many stated that they received no support in a crisis, that there was a lack of support following discharge and that there was no support available in their local community. Lack of access to services was referred to by all three



*I would like to be able to access services. Too ill for well-being service. Don't fit referral criteria for access and assessment....'*

groups in the surveys, however, comments about a lack of access were particularly prominent from service users and carers.

***I would like to be able to access services. Too ill for well-being service. Don't fit referral criteria for access and assessment. Now been off sick for 5 months which need not have happened if I had been able to access services when I knew I needed more help' (Service user or member of the public)***

2. **Access** - Service users and carers also commonly stated that waiting times for services were long or that there was a need for more local services. Waiting times were particularly important in comments about crisis care and were mentioned 142 times in total across all surveys. A number of service users said that that they would like services to be available in their GP surgery or community hub.

***Need young people to have access to services quicker. In the past I was meeting with mental health nurses who came into schools weekly to work with***

***young people. Since the reorganization of CAMHS this has not happened' (Professional)***

3. **Support in the community** - Service users and carers said that the types of services that they would like to receive or find useful were:

- Professional support such as social workers, care- coordinators, community psychiatric nurses, psychiatrists or GP's and;
- Talking therapies, including counsellors, therapists, psychologists and cognitive behavioural therapy;

Qualitative interpretation of mentions of support in the community suggest that people generally find informal support from friends, family and neighbours and voluntary and community sector support useful or important.

***'Shorter Waiting lists. Long term Therapies and Counselling. More CPN Support or Care Co. Ongoing Mental Health Support. The service we have in place is insufficient, temporary and not good enough' (Service user or member of the public)***

4. **Information and signposting** - Service users and carers responses to the questions about the types of information which they found useful or would find most useful were:

- Information about what services are available, how to access services and what sources of

- community support are available;
- Information about their mental health condition or treatment and how to manage or improve their mental health;
  - Professionals, service users and carers all said that professionals need more information about what support is available and how to access it;

***'It would be useful to have a directory of services that could be used and an indication of the type of support each could offer. I expect this exists, but it needs to be updated and realistic' (Professional)***

5. **Continued support** - Service users and carers often said that they would like follow-ups from treatment and more support following a crisis or discharge. Many said that if they had been in recent contact with services, they would like easy access back into services if they had a need. Professionals suggestions for what a good discharge process would look like included:

- A post-discharge plan with details of what to do in a crisis (21);
- Discharge should be co-produced with the patient and family carers (13);
- Discharge should be planned from the start of care (6);



***Follow up appointments to see how they are still doing and perhaps being phased into being discharged to ease them into it' (Professional)***

6. **Listened to and understood** - Service users and carers often said they would like to be listened to and their needs understood in terms of their mental health or mental health care. This is true of both professionals and the wider public. This theme was extremely important for service users in response to the questions about communication, with 119 mentions. Professionals also mentioned the importance of treating service users and carers in this way. Some people also stated that they would like to see the stigma around mental health reduced.

***Lack of understanding about how it affects everyday life especially at school. A teacher commented about 'trying to snap out of it' (Carer)***

7. **Quality of services** - Quality of care was used to refer to a number of themes around the way in which people receive treatment, including from mental health services directly or other health services such as GPs. Service users and carers commonly stated that they wanted mental health treatment to be effective or to alleviate symptoms. They also said that it was important for them to have continuity and consistency in their care, and for their care to be tailored to their personal needs. Some service users and carers also mentioned a desire to be offered treatment other than medication.

***'She feels like whoever she talks to doesn't understand what's going on and they just want to fix her with tablets' (Carer)***

8. **Integrated care** - All three groups, but particularly professionals, commonly mentioned the need for integrated care. For example, in the questions about communication, there were 78 mentions of integrated care by professionals. Key topics within integrated care include the need for mental health services to work more closely together, to work with communities and the voluntary and community sector and the need for a centralised and accessible system for patient records.

***More joined up working and professionals having a better understanding of each other's roles, responsibilities and services' (Professional)***

9. **Resources** - Funding and staff capacity was mentioned by all three groups within the survey responses. This theme was mentioned by service users in response to being asked what they would like from mental health services (48) and in professionals responses to questions about crisis (27) and wait times (31).

***I would like to see more resources being putting into services: staff, quality of training to increase, more support in place for newly qualified staff to provide more opportunity for development and retention of staff; more time being given to complete higher quality assessments and succinct yet detailed information being***



***handed over to ensure needs are met and people do not "slip through the net"  
(Professional)***

10. **Support for carers** - A number of service users who were parents (77) said that they did not receive any support or that there was a lack of support for them to look after their own mental health. 29 respondents to the carers survey also said this. 71 service users who were parents and 41 carers said that there was a lack of support for them to support the person who they cared for. Service users commonly mentioned using or wanting professional support. Carers commonly mentioned using sources of voluntary and community sector support. Throughout the surveys, there were a number of mentions by carers of wanting to be better informed and involved in the care of the person who they care for.

***None. I am a parent of an ASD child who needs mental health support. Years have gone by and he is still waiting for help. I have to support him without support myself  
(Service user or member of***

11. **Digital support** - In response to the questions in the survey about digital support for their mental health or emotional wellbeing, service users and carers most often said that they use or want apps (163), websites (84) and social media (70). The most commonly reported use or desired use for digital support for all three groups was information and signposting (123). Some service users and carers reported using digital technology or wanting more digital support for self-help such as mindfulness (57). 57 said that they used or would like to use digital technologies for peer support, whilst only six mentioned professional support. A minority said that they thought digital support for mental health was ineffective (12), that more human contact was needed (7), or that digital technologies were not accessible to everyone (7).

***'I use the internet to research any changes to my treatment and medication' (Service user or member of the public)***

12. **Schools** - In the surveys, 41 service users and carers mentioned a lack of support in schools or a need for more support for mental health in schools. Service users and carers most commonly mentioned receiving or wanting adjustments such as educational support, safe spaces and time out of lessons (25) to help students with mental health needs. 15 service users and carers and one professional mentioned wanting or finding pastoral care such as school nurses, student support or general pastoral care useful. 15 service users and carers mentioned the provision of talking therapy or counselling in schools. There were 15 mentions of improving teachers training and knowledge about mental health.



***I ended up de-registering my son from school to home educate him due to the lack of help and support from his school at the time. Schools, or these particular schools could have done a lot more to help, but I do feel that all teachers/staff need training in mental health issues in order to be able to better help' (Carer)***

13. **Transitions from child to adult services** - 10 service users and 14 carers mentioned being discharged on transition to adult services or experiencing a lack of support following transition. 22 gave general negative comments about transition, for example ***'Nothing, found the transition really scary and set her back' (Carer)***. 10 mentioned wanting increased continuity of care between the services involved in transition and seven mentioned a need for better integration between services, including communication and better partnership working across services.

***'For transition and adult services to work together' (Service user or member of the public)***

The most common themes reported in the course of this engagement were:

- a) A lack of service or needs not being met, generally across services and in the community.
- b) Delays in access to services including waiting times and the need for more local services.
- c) A desire for more support from

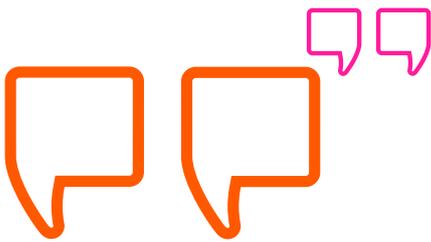
professionals and access to talking therapies in the community and the benefits of support from the wider community including family and friends and the voluntary and community sector.

- d) A need for people to be able to access treatment they feel helps them manage their mental health, including person centered care, continuity and consistency of care.
- e) Service users and carers want to be listened to and have their needs understood.
- f) Service users and carers would like more support following treatment, crisis or discharge. This includes follow up meetings and an easy way back into services if they have a need.
- g) Professionals talked about the need for better integration between the mental health services and communities, schools, local authorities and the voluntary and community sector.
- h) Availability of information was highlighted by all three groups. It is key to providing access to services in an effective manner that ensured continuity for service users across services.
- i) Service users and carers stated that they most often used or would like to use digital support for information and signposting and peer support. Both these groups stated that they

most often used apps over other technologies.

- j) Service users and carers commonly stated that there was a lack of support in schools for mental health. They reported wanting or using educational adjustments, pastoral care, talking therapy in schools. Some felt that there was a need to up-skill teachers with better training and knowledge.
- k) People experiencing a lack of support following a transition from child to adult mental health services or being discharged following a transition.

The themes identified above should provide a focus for the ongoing transformation strategy. More information about all of these themes is available in the full published report of “A Very Different Conversation” available December 2018.



**‘I do feel that all teachers/staff need training in mental health issues in order to be able to better help.’**

