SUFFOLK for mental wealth
Supporting a positive mental health experience

healthwatch Suffolk

Stepping Forward:
A review of Norfolk and Suffolk NHS Foundation Trust

January 2016

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About Healthwatch and Suffolk User Forum

Healthwatch Suffolk was established by the Health and Social Care Act 2012 to be the "consumer champion" for health and social care services in Suffolk.

It exists to find out what local people think about their health and social care services. It has statutory powers that enable it to use those experiences to influence, shape and improve the services now and for the future.

Healthwatch Suffolk also provides an information and signposting service to help people navigate the health and social care system and understand what to do when things go wrong in services.

Suffolk User Forum (SUF) is a user-led mental health charity. Like Healthwatch, it is dedicated to speaking out for service users and covers a range of services from wellbeing support to inpatient care.

Both organisations inform service users of developments in mental health; improving understanding of what might meet local needs more effectively. Working together, they have been seeking to collate the experiences of mental health service users so that they can make them known for service improvement.

This project is an element of this important work.

1. Introduction

This report summarises the outcome of a joint Healthwatch Suffolk (HWS) and Suffolk User Forum (SUF) initiative carried out during the final quarter of 2015. It's aim was to discover the current views of service users and carers on the Mental Health services in Suffolk provided by Norfolk and Suffolk Foundation Trust (NSFT).

The initiative consisted of two components:

1. a survey asking for service user and carer views on the provision of four key aspects of care by the Trust – Access and Assessment, Care Planning, Care Review and Discharge Planning.
2. a `Stepping Forward` event involving discussion between service users, carers and professionals facilitated by four workshops covering each of the key care aspects as stated in point 1 above.

The survey was distributed as widely as possible by both HWS and SUF and, to an extent, NSFT and ran between October 2015 and December 2015. The Stepping Forward event took place on 18th November and discussions on the workshops were conducted in the light of survey results available at the time of the event.

Although the Stepping Forward event was organised in the first instance by HWS and SUF, discussions with the senior NSFT management prior to the event ensured that the Trust was an equal partner at the Stepping Forward event and able to be a key partner in constructive discussions in the workshops.

Sections 3 of this report focusses on the results of the survey, both quantitative and qualitative. It also provides the outcomes and feedback from the Stepping Forward workshops. The final sections (4 and 5) summarise the overall conclusions and recommendations.

2. Methodology

The questionnaire was designed by a working group comprised of Healthwatch Suffolk and Suffolk User Forum members.

At the time the questionnaire was drafted, the Norfolk and Suffolk NHS Foundation Trust and Healthwatch Suffolk Mental Health Focus Group were invited to comment on the content. This ensured that all parties – stakeholders, service users and carers – had the opportunity to raise any concerns prior to the dissemination of the questionnaire.

The questions within the survey aimed to explore the following themes:

1. Access and assessment
2. Care planning
3. Care review
4. Discharge planning

As four, broad areas of care were covered, the working group thought it best to limit the number of open-ended questions. There was also a consideration that for some

respondents English would not be their first language and open-ended questions would deter them from completing the questionnaire.

The questionnaire was uploaded to Survey Monkey, an online survey service. Hard copies of the questionnaire were also made available and disseminated to all of the relevant organisations in Suffolk.

Dissemination

1,000 questionnaires were printed by Healthwatch Suffolk and delivered to various organisations that had agreed to aid in the dissemination process.

Additionally, the questionnaire was advertised via Healthwatch Suffolk's website, other voluntary organisations throughout Suffolk, Healthwatch Suffolk's Community Development Team, and electronically to Healthwatch Suffolk's existing network of contacts within the community.

The dissemination process was carried out over a four month period (August 2015 to November 2015).

The survey was circulated by the Healthwatch Suffolk Information Team in the following ways:

- An article in the Healthwatch Suffolk quarterly newsletter issued to Friends and Members (the newsletter and biweekly update reach over 3,100 local people who have registered as friends or members of Healthwatch Suffolk);
- Repeated articles in Healthwatch Suffolk electronic fortnightly updates;
- Regular social media updates on Facebook and Twitter; and
- A feature on the Healthwatch Suffolk website including a banner animation with supporting updates on the news, consultation and surveys page.

Healthwatch Suffolk received 119 completed responses.

Although it is acknowledged that this figure is not representative of the Norfolk and Suffolk NHS Foundation Trust's service users, it is comparable to the Care Quality Commission's October 2015 Community Mental Health Services Survey, which received 256 completed responses over both Norfolk and Suffolk. Moreover, the data collected represents a wider discourse within Suffolk and should not be overlooked due to the small number of responses.

3. Findings

The following section presents the data collected from the respondents.

Please note that although 119 people have responded to the survey, not all answered every question.

In light of this, each question will include a figure below which represents the number (out of 119) of respondents who answered the question.

The findings have been separated into the four themes addressed in the questionnaire; access and assessment, care planning, care review, and discharge planning.

Our Stepping Forward Event and Workshops

Stepping Forward events have been used by Suffolk User Forum (SUF) since 2008 when SUF won a national award for this innovative format that enabled the real delivery of co-production.

It is a model that involves workshop discussions with service users, carers and professionals working together as equal partners to discuss experiences of mental health care, identifying best practice needs and recommendations for developing services that better meeting people's needs.

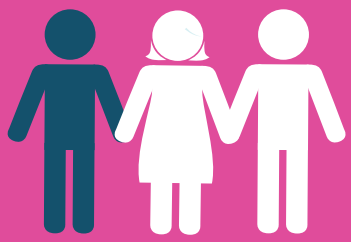
48 service users, carers, and professionals attended the Stepping Forward event. The event began with introductions and a welcoming presentation about the focus of the event and the organisations involved in planning the day and joint survey. Attendees were given an overview of Suffolk User Forum and Healthwatch Suffolk together with information about their shared goal to work to improve mental health services in Suffolk by ensuring the voice of service users, their families and carers is heard and acted upon.

This was followed by a presentation to highlight the findings available to date from the joint survey and an explanation of how feedback from these had been used to identify the four topics for the workshops at the event .

Two workshops were run in the morning session, on access and assessment and care planning. In the afternoon two more workshops covered care review and discharge planning. Each workshop had a facilitator and a scribe.

Each workshop was asked to identify three key issues, where improvements are needed, in relation to each workshop subject area. The key issues identified within the workshops are summarised at the end of the four themed sections (see pages 12, 20, 26 and 32).

Access and Assessment



Over one in three respondents who had been referred did not receive their first contact from NSFT for over a month.

One in every two respondents did not receive a call from NSFT within four days.

One in every two respondents were not asked about their physical health during their assessment.

> **Since I have a mental health problem everybody I have been in contact with have been excellent. All have explained my problem so I have had no worries regarding it.**

The first part of the questionnaire addressed Access and Assessment. Service users were asked the following questions:

1. Once your GP or healthcare professional had referred you to NSFT (the service), when did the first contact take place?

Question one relates to The National Institute for Health and Care Excellence (NICE) guidelines, entitled service user experience in adult mental health: Improving the experience of care for people using adult NHS mental health services [CG 136], which states that when people are referred to mental health services, it must be ensured that:

- they are given or sent a copy of the referral letter when this is sent to mental health services;
- they are offered a face to face appointment with a professional in mental health services taking place within 3 weeks of referral; and
- they are informed that they can change the date and time of the appointment if they wish.

Question one sought to find out if service users were offered a face to face appointment with a professional in mental health services within three weeks of their referral.

2. If your point of access was A&E, did you receive a courtesy call from NSFT within four days?

The Norfolk and Suffolk NHS Foundation Trust made a commitment to ensure that all patients referred to them for an assessment would receive a courtesy call within four working days. Question two was asked to find out if this has been taking place.

3. If your point of access was A&E or another hospital department, were you held voluntarily or were you detained?

If a service user is deemed a serious risk to themselves or others, they may be detained and treated under the Mental Health Act. Question three was asked to gauge what percentage of service users entering mental health services via A&E or other hospital departments were subject to involuntary detention under the Mental Health Act.

4. Were you asked about your physical health during your assessment?

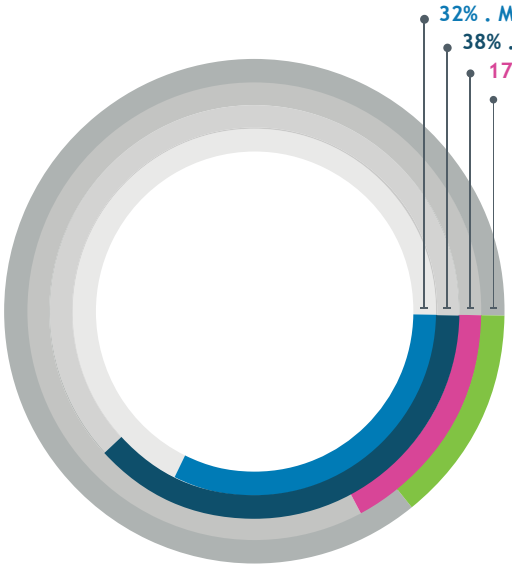
The question regarding physical assessments was asked as poor physical health contributes to 15–20 years loss of life among people with serious mental illness compared to the general population. Inpatient admission offers an invaluable opportunity to monitor and manage the physical health of this patient group.

The Royal College of Psychiatrists standards state that professionals should continuously examine patient notes to make sure that providers are undertaking appropriate assessment and examination of physical health on admission. Where patients refuse, basic signs should still be documented. As seen in the National Institute for Health and Care Excellence's Quality Statement 6: Assessing Physical Health, adults with psychosis or schizophrenia have specific comprehensive physical health assessments that must be administered throughout the care pathway.

1. Once your GP or healthcare professional had referred you to NSFT (the service), when did the first contact take place?

Less than 1 day (24 hours)	14%
More than 1 day but less than 7 days	17%
More than 7 days but less than 1 month	38%
More than 1 month	32%

(101 respondents)

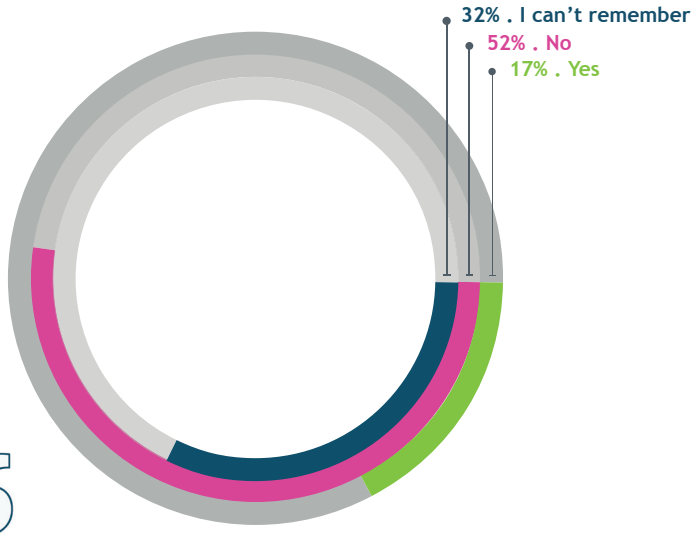


> I am a Young Person (under age 18) who has had a Mental Health Act assessment twice in the last 12 months, once in A&E and once in Custody. I have not received any sort of therapeutic intervention in the 6 years I have been seen by Connect and the Youth Integrated Delivery Team (IDT). My last MHA assessment was 10 days ago and nobody from the Youth IDT has been in touch with me to follow it up or offer me any therapeutic intervention of a "less restrictive option" type than detention.

2. If your point of access was A&E, did you receive a courtesy call from NSFT within four days?

Yes	17%
No	52%
I can't remember	32%

(66 respondents)

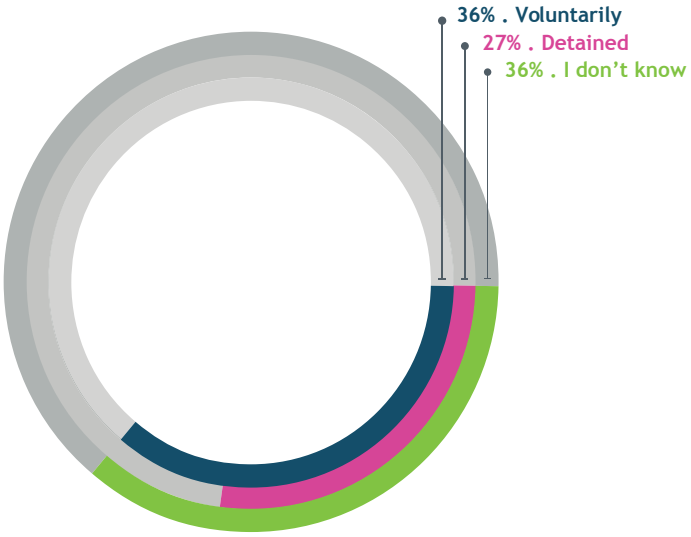


3. If your point of access was A&E or another hospital department, were you held voluntarily or were you detained?

Voluntarilly	36%
Detained	27%
I don’t know	36%

(55 respondents)

> I was taken by ambulance to A&E following overdose. Access and Assessment came to assess me, they were very nice but basically said 'you don't need secondary care' call the wellbeing service. They gave me a leaflet. I was too distressed and drugged up to think clearly. My husband was in despair as he just did not know what to do with me. There was no follow up...I just carried on.



4. Were you asked about your physical health during your assessment?

Yes	42%
No	51%
I can’t remember	7%

(94 respondents)

Access and Assessment Workshop

The three issues identified in this workshop where improvements are needed are as follows:

1. The role of Link workers is essential in the primary sector and must be boosted to ensure widespread availability, referral and recognition within GP practices:

- link workers must be available in all GP practices to ensure referrals can be made quickly when needed and to help determine priorities for admission to NSFT services.
- all GPs and their supporting staff (nurses, receptionists etc.) must be aware of the link worker role and actively involve them in the work of the practice.
- all GP practice websites should provide information about the role of the link worker together with mental health signposting including the information about the Suffolk wellbeing service, SUF and Healthwatch Suffolk.

2. The Access & Assessment service needs to develop a much more person-centred and flexible approach towards service users. The service in particular needs to:

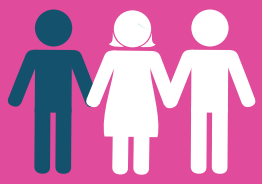
- really listen to service user views and concerns
- think through the communication needs of service users - e.g. what letters or calls are needed to keep people up to speed with what is happening, being clear about the length of time it is likely to take before they can expect to see somebody.
- ensure contact is made with service users in an appropriate way – contact by telephone is not appropriate for some service users, for others a letter will never be opened. Younger people and other service users in particular say that they prefer texts for quick contacts such as appointments.
- take responsibility for ensuring people are referred to other services and signposted to self-help information if admission to NSFT services is not appropriate – this should include maintaining contact until successful handover has actually occurred.
- not just focus on filtering out people that meet internal NSFT service criteria and screen out/abandon the rest

3. Physical Health. Professionals and service users all agreed that this is an essential issue that must be asked about during the access and assessment process since mind and body, thus mental and physical health conditions, are closely interrelated.

- it is worrying that a high proportion of people said they are not to being asked about their physical health during the access and assessment process.

Care Planning

Over one in three respondents did not know or thought that they did not have a care plan.



55% of respondents were not told about the effects of their medication.

One in every five respondents said their care plan did not include a crisis plan.

Help

For 37% of respondents, help may be out of reach. Treatments that could help were discussed with service users but NSFT does not provide them.

> I feel that the Care Plan is about me so I should be a part of it. I am not part of the Care Plan. I am just asked to sign it.

In accordance with the National Institute for Health and Care Excellence's Quality Statement 8: Care Planning, all people using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it. Therefore, two processes should be implemented for all service users:

- Service providers, mental health and social care professionals, and commissioners ensure systems are in place to jointly develop care plans, share copies with services users and agree review dates.

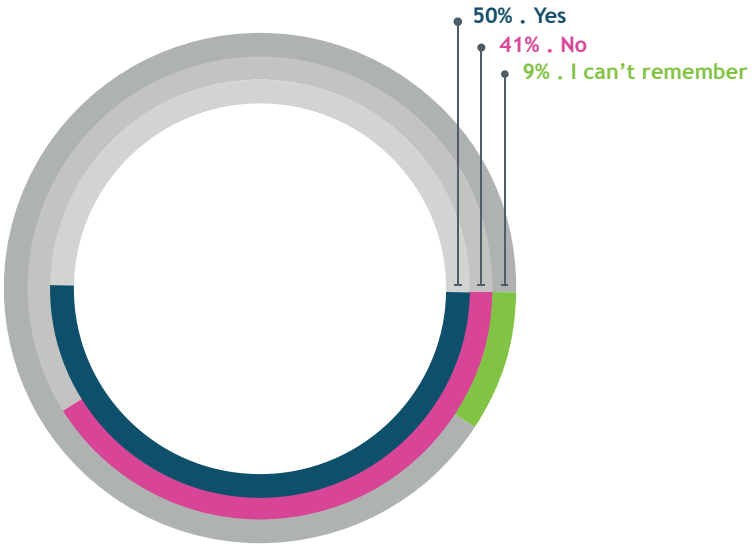
- People using mental health services jointly develop a care plan with mental health and social care professionals, receive a copy of the care plan and agree a date to review it. This should include the needs of the individual service user, activities promoting social inclusion such as education, employment, volunteering and other specified occupations, such as leisure activities and caring for dependants.

The following questions gauge the structure, process and outcomes of respondents' Care Plans.

5. Do you have a document called a 'Care Plan'?

Yes	50%
No	41%
I can't remember	10%

(91 respondents)



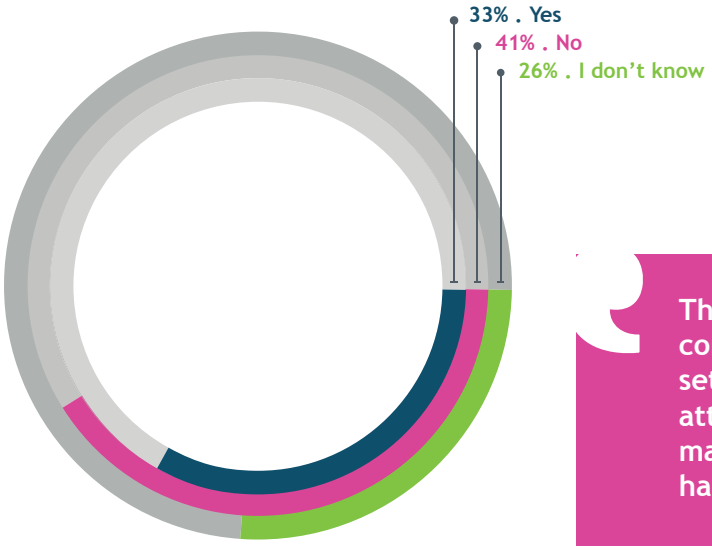
> Care Coordinator very good, but contact very limited considering I had tried to kill myself which was why it was an urgent referral.

> My views don't matter and I have never signed a care plan nor has one ever been discussed with me. When I tell them what I think will help I am just ignored and when my carer tries to tell them he is also ignored. The staff no longer seem to care about me and I am not alone in thinking this.

6. Does your Care Plan include a contingency plan or a crisis plan?

Yes	33%
No	41%
I don't know	26%

(81 respondents)



> This service is dangerous, only contact is weekly by phone and set times despite monthly suicide attempts. No additional contact made after suicide attempt, and had to wait until regular meeting.

7. On a scale of 1 to 5 (1 being extremely dissatisfied and 5 being extremely satisfied), how satisfied are you with your Care Plan?

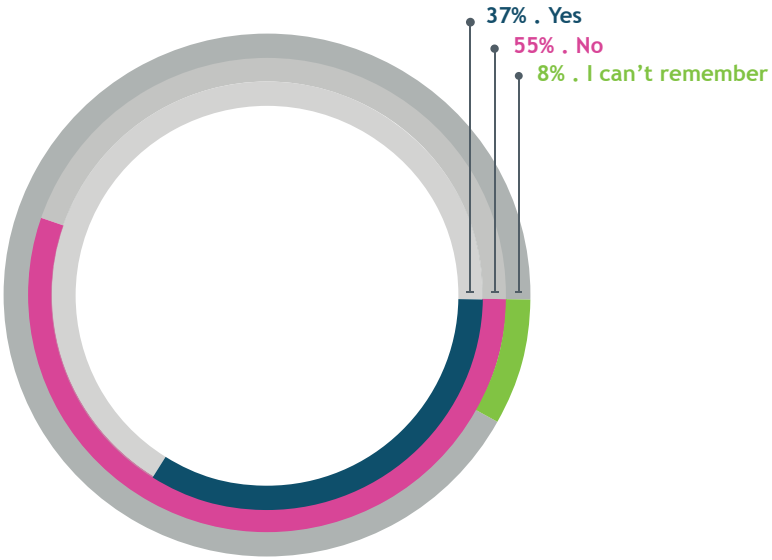
Out of the 119 respondents, 68 answered question seven. On average those who answered rated the satisfaction of their Care Plan as 2.8 out of 5 (56% satisfaction level). In comparison, respondents of the CQC Community Mental Health Services Survey rated the planning of care at 6.7 out of 10 (67% satisfaction level), which is similar to other Trusts in England.

> I have been lucky enough to be able to trust my GP & the Mind charity who have done more to help me than the care Coordinator I was assigned has done.

8. During your appointments, were you told about the effects of your medication? This includes possible side effects.

Yes	37%
No	55%
I don't know	8%

(85 respondents)



9. Have you had a discussion with your Care Co-ordinator about a treatment or therapy that would help you but then been informed that NSFT cannot provide it?

Yes	35%
No	31%
I was not offered a treatment or therapy	6%
I was not offered a treatment or therapy, but I wanted one	8%
I was not offered a treatment or therapy – I was given medication	19%

(83 respondents)

> [There are a] lack of options for people who struggle with talking therapy. Need alternative ways to help address anxiety issues.

> Current lack of support for people with gender identity issues.

10. Please state what treatment or therapy it was in the comment box below.

CBT	26%
Lack of funding	52%
Psychology	11%
Counselling	26%
Waiting list too long	22%
Exceeding my allocation	15%

(27 respondents)

Following on from question nine, those that had a discussion with their Care Co-ordinator about a treatment or therapy that would help them but then had been informed that the Norfolk and Suffolk NHS Foundation Trust could not provide it were asked to comment. The table shown above shows the themes that were extracted from the qualitative responses.

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Care Planning Workshop

The three issues identified in this workshop where improvements are needed, are as follows:

1. Professionals must always enable a meaningful dialogue with service users to produce a care plan that the service user can recognise, understand and that is personal to them. This should include an agreed plan of care for people not on the Care Programme Approach (CPA).

- the care plan (held by the service user) must be up to date and reflect current key care activities and expected outcomes of treatment.

2. Care planning requires that professionals communicate with and involve other people that are relevant to the care of the service user.

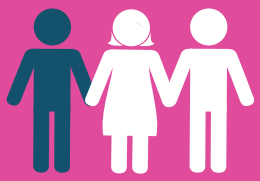
- This should include other significant people including other NSFT professionals, family, carers, close and involved friends and others contributing to the service users support network for their physical and mental health care needs.

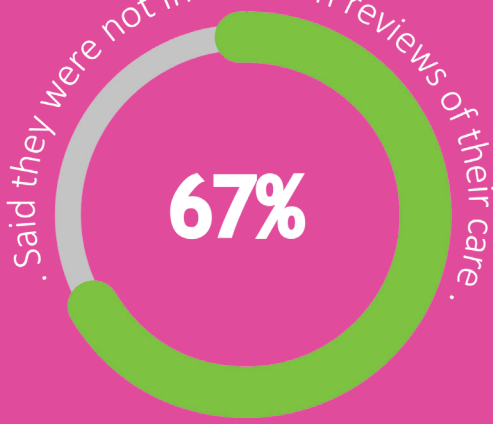
3. Care plans need to identify activities to improve health & well-being and anticipate future contingency needs of the service user

- plans should describe early warning signs of becoming unwell, pre-agreed care/ crisis and risk planning that can be taken to prevent a crisis and contact details of those agreed to respond in an emergency situation.

Care review

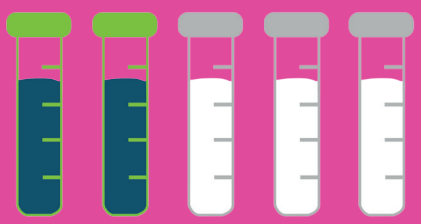
Over one in three respondents said their care plan had never been reviewed. 24% said it had been reviewed several times a year.





Family & Friends

Two in five respondents would have liked their family or friends involved in the review of their care.



Two in five respondents said their blood tests were not reviewed.

The Care Programme Approach (CPA) is a way that services are assessed, planned, coordinated and reviewed for someone with mental health problems or a range of related complex needs.

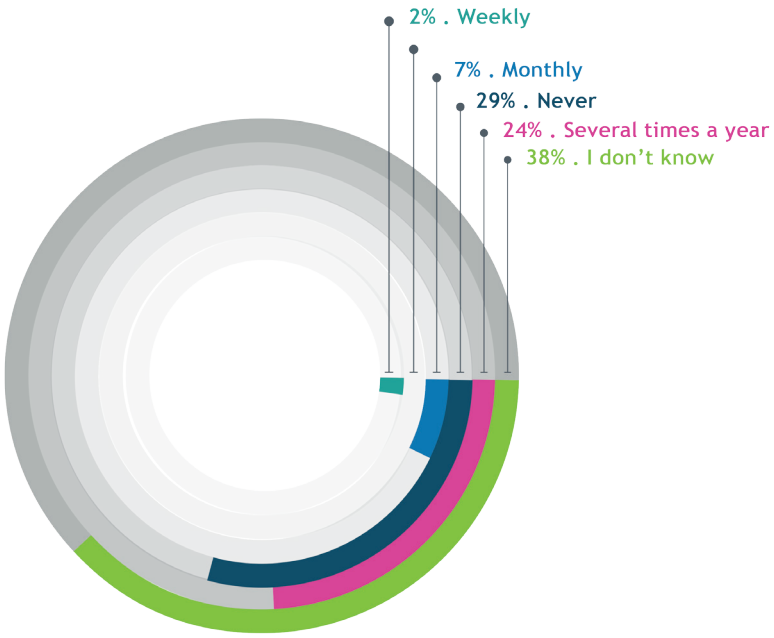
The National Institute for Health and Care Excellence's Quality Statement 8: Care Planning document states that service users should have an agreed date to review their care plan. Moreover, anyone experiencing mental health problems is entitled to an assessment of their needs with a mental healthcare professional, and to have a care plan that's regularly reviewed by that professional. All Care Plans should list the needs of the service user and describe how these needs will be met. Additionally, service users should be involved in making their care plan and should be given a copy.

The following questions address the continued review of a service user's Care Plan and their involvement.

11. How often is your Care Plan reviewed?

Weekly	2%
Every two weeks	0%
Monthly	7%
Several times a year	24%
Never	29%
I don't know	38%

(85 respondents)



12. Are you involved in the review of your Care Plan?

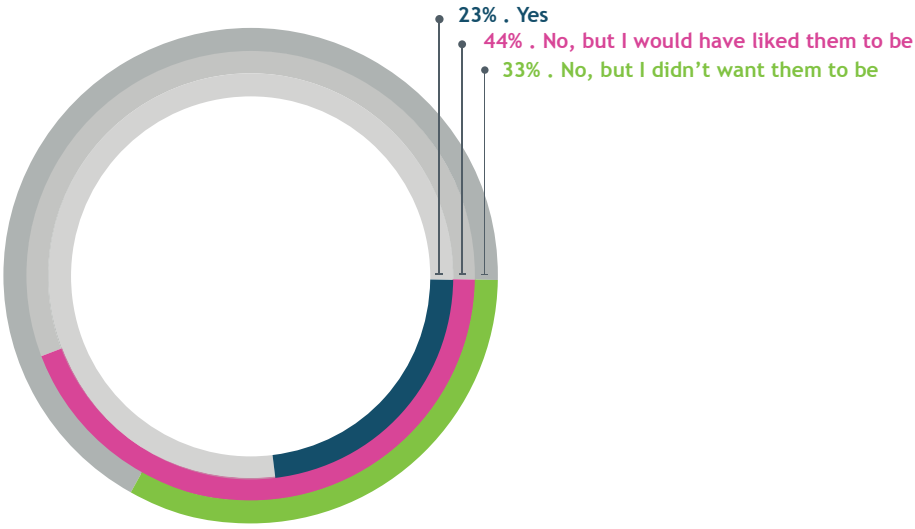
Yes	33%
No	67%

(82 respondents)

13. Were your family or friends involved in the review process?

Yes	23%
No, but I would have liked them to be	44%
No, but I did not want them to be	33%

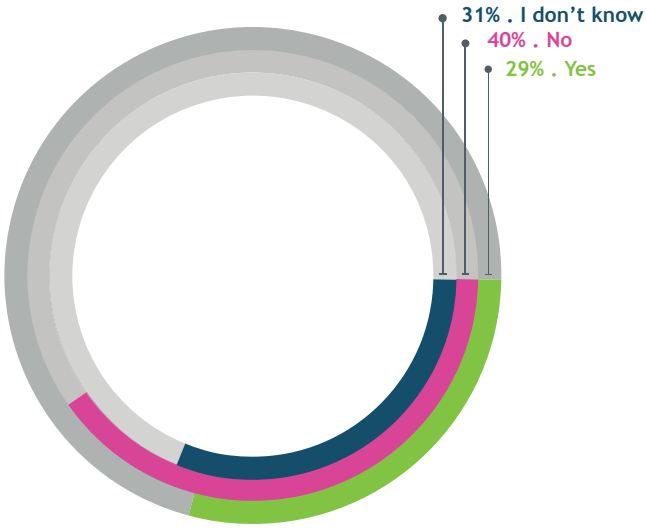
(82 respondents)



14. Were medications requiring a blood test reviewed?

Yes	29%
No	40%
I don't know	31%

(82 respondents)



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Care Review Workshop

The three issues identified in this workshop where improvements are needed are as follows:

1. Professionals need to recognise that the service user, family and/or other carers are the experts in the service users experience and must, unless there is good reason, be part of a care plan review.

- the service user and carer must be active partners at reviews to ensure the real delivery of the triangle of care, carer and service user centred planning and review. This enables inclusion, the right to make choices and active engagement with recovery planning.

2. Care Reviews need to be conducted with all relevant parties present at the same time. This includes the service user and any carers, all relevant staff from NSFT and any other organisations that are involved with the service user.

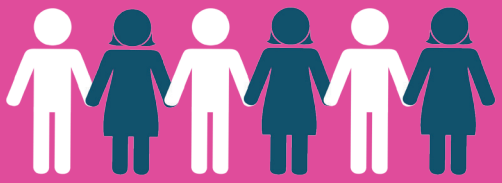
- transitions of care within NSFT, discharge or referral on to other organisations, must be properly planned and discussed with the service user and carer. Reviews must identify where needs cannot be met by the service, so that unmet needs can be reported to service commissioners.

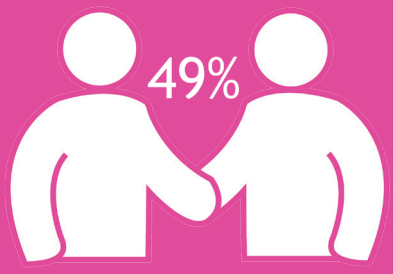
3. Professionals should encourage, where possible, service users to take the lead in initiating care reviews in line with their needs and to help decide the parties that need to be involved.

- where possible the service user should be enabled to trigger the review pro-actively and address consent for care reviews to enable ownership of the process and transparency between different people and/or organisations involved in the Care Plan.

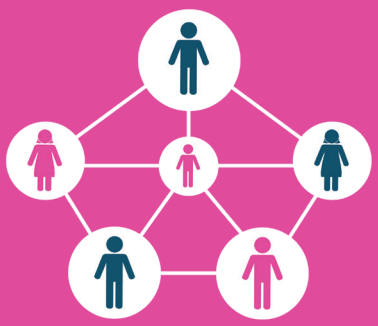
Discharge Planning

One in every two respondents said they didn't think they had a Discharge Plan.





49% said they did not have a person they trust listed on their discharge plan.



Support

One in every two respondents said that their support network was not identified with telephone numbers on their discharge plan.

> When I was discharged I was just left with nothing - no phone numbers or anything. I just felt abandoned.

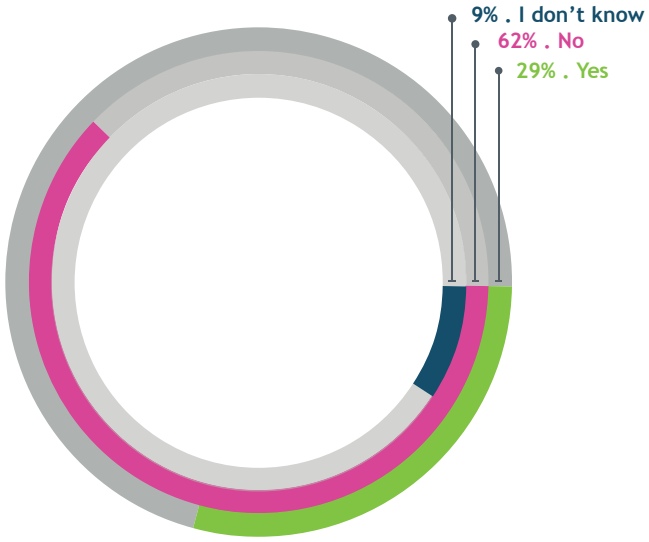
Good practice suggests that when an individual goes into hospital a Care and Treatment Plan is agreed with the service user. It should include what assessment is going to be made and what treatment is considered appropriate. Guidance also suggests that service users should not be discharged from section or from hospital by their responsible clinician until arrangements have been made for continuing care in the community.

The following questions sought to gauge the care and treatment of those discharged by the Norfolk and Suffolk NHS Foundation Trust.

15. Did you receive a document called a 'Discharge Plan'?

Yes	29%
No	62%
I don't know	9%

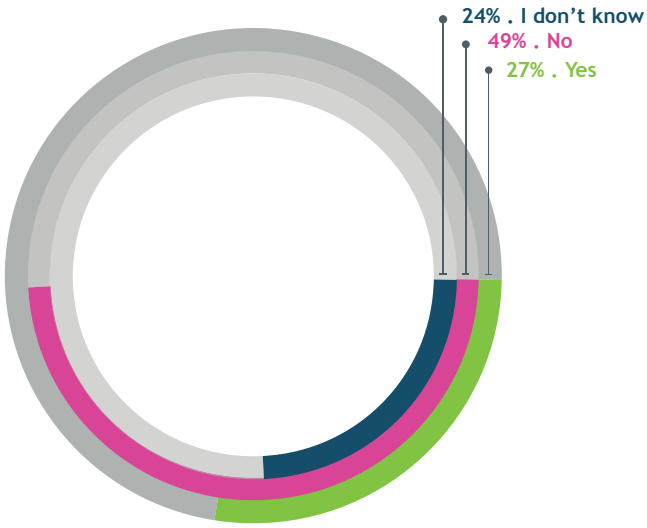
(68 respondents)



16. Is there a person you trust listed on your Discharge Plan?

Yes	24%
No	49%
I don't know	27%

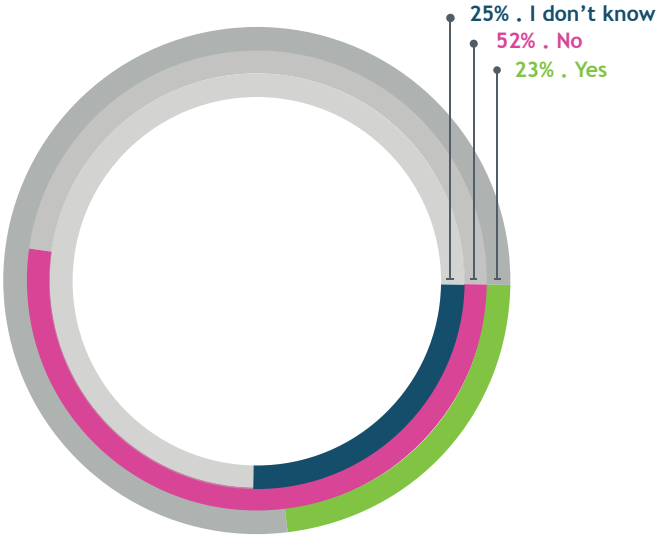
(59 respondents)



17. Was your support network (i.e. family and/or friends) identified with telephone numbers on your Discharge Plan?

Yes	23%
No	52%
I don't know	25%

(64 respondents)



18. If you were not referred to a service, were you told why not?

Yes	26%
No	74%

(54 respondents)

> I asked about a Personal Health Budget because the therapy identified in my discharge and subsequent care plan was not available through NSFT and was told that Suffolk is not doing Personal Health Budgets and they would just remove the therapy from my discharge plan.

19. After discharge, were you able to self-refer yourself to a service you thought you needed? For example, if you thought you needed additional medication, could you access that specific part of the care pathway without having to go through the other steps?

Yes	27%
No	73%

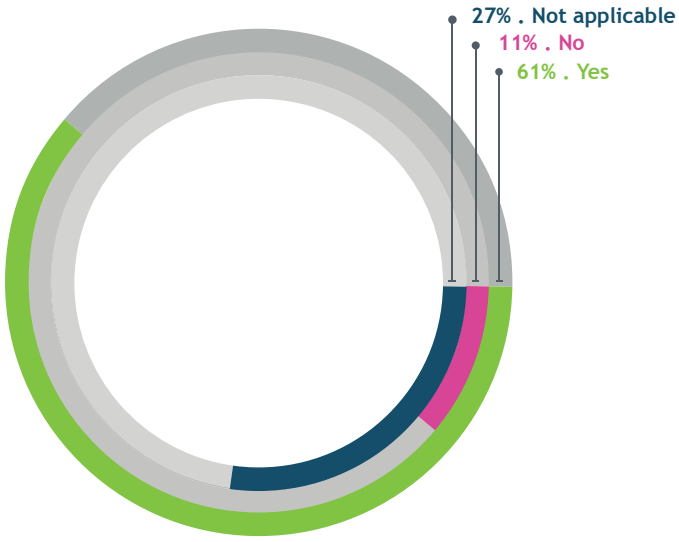
(48 respondents)

> It seems to me that due to cutbacks there isn't the staff available to meet the needs of people. With further cut backs it could implode.

20. Were you able to go to a suitable place of safety after your discharge? For example, did you have suitable accommodation and basic needs such as money and food?

Yes	61%
No	11%
Not applicable	27%

(70 respondents)



Discharge Planning Workshop

The three issues identified in this workshop where improvements are needed are as follows:

1. There is a need for a clear definition of what is meant by a `discharge plan` that has a common understanding between professionals and service users.

- terminology regarding discharge varies between the primary and secondary service sectors which currently creates confusion amongst service users. Within primary care, (GP and Wellbeing Service), when the service user is discharged from part of the service there is currently no discharge plan. In recent feedback secondary care service users have stated that they have been discharged from secondary care without any pre-discussed discharge planning and without a discharge plan.

2. Professionals must understand that service users/patients often fear discharge which can seem an abyss into the unknown where there is no planned or follow on care.

- the importance of this point was particularly stressed by service users present.

3. Discharge, for the service user/patient, is a huge step in their experience of mental health care and recovery. Professionals must take this into account by ensuring appropriate continuity of care by effective discharge planning, including planning to help the service user seek help before any relapse or crisis.

- care planning must begin on admission and continue in active partnership with GPs, and other services where appropriate, through treatment, discharge planning and into continuing community care.
- GPs do not at present seem to be made aware when a service user is to be discharged from a service.
- Some people asked the question whether the term `discharge` plan should be discontinued?
- the service user requires a continually updated and reviewed care plan that crosses organisational boundaries and which tracks changes from inpatient through to community services.

Stepping Forward Workshops
Plenary Session

A plenary session was held to conclude the event where the key issues identified by the workshops were presented and discussed.

Some reservations had been expressed by NSFT during the workshops. The wording of some of the questions was not as clear as they could be. There were concerns that some questions may have been differently understood by service users and/or patients in different service sectors.

It was generally agreed by all however, that these problems did not detract from the overall messages reflected in the survey results or the key issues identified in the workshops.

NSFT had been invited by HWS and SUF to comment on the draft survey questions at an early stage. However it was agreed that, for any future surveys or events, it is important for NSFT to be engaged in greater detail in order to minimise potential problems with question wording.

Whilst this survey was promoted within mental health networks and by SUF, on BBC Radio Suffolk, everyone at the event agreed that any future survey needs an even wider level of publicity in order to encourage larger numbers of survey responses so that results can further reflect the views of the overall population of NSFT service users.

The results however, plausibly reflect the opinions of a significant body of service users within that overall population and must be taken seriously.

Overall, wider discussion of the key issues identified in the workshops led to a view that while many have positive experiences of care provided, NSFT is in financial distress and that some service users and their families had experienced poor continuity of care.

People on the day said that they feel that the Trust is under resourced and over worked, which has led to gaps in the provision of services.

The event concluded with HWS and SUF describing future steps. The survey was to be closed in the near future and a final report including all data, on both the survey and the workshops, was to be produced early in 2016. At this stage it will be shared with the Trust and discussed at a senior management level. It will then be made publicly available.

4. Conclusion

People want many things from mental health care, including continuity of care and smooth transitions. These require planning and co-ordination with the service user.

The findings from the Stepping Forward event highlight that by efficiently deploying multi-professional resources, co-ordinated care systems should be better able to deliver the other things patients require: fast access, effective treatment, respect for their preferences, support for self-care, and the involvement of family and carers. Thus it is no surprise that during the Stepping Forward Event "integration" was repeatedly mentioned by service users, carer and stakeholders alike.

People understand that there are resource limitations for the Norfolk and Suffolk NHS Foundation Trust, Suffolk County Council and the NHS nationally. But they want to know clearly what their entitlements are - not just about care, but support and finance too. Service users that attended the Stepping Forward event want services to agree on these and not to argue between themselves. They want obvious efficiencies to be achieved – not least in use of their own time – for example, by making it possible for multiple appointments to happen on one day.

Divisions into 'primary', 'secondary', 'community' and 'social' care are relatively meaningless to those experiencing declining mental health or those at a point of crisis. The people for whom integration is most relevant, especially those with long term conditions, have said that they are looking for the Norfolk and Suffolk NHS Foundation Trust to combine two things in one place:

- **Knowledge of the service user/carer as a person:** This does not simply refer to the medical need of a service user or carer; a common discourse seen from the Stepping Forward event was that including home circumstances, lifestyle, views and preferences, confidence to care for themselves and manage their condition(s), as well as their health status and symptoms, among others, was a vital mechanism for service user and carer reassurance.

- **Knowledge of the relevant condition(s) and possible pathways:** Service users wanted to be able to clearly see and navigate the mental health services in Suffolk. At present many service users do not know what they are entitled to; it was widely voiced that all options should be presented to a service user at the first point of contact, including a list of all available support services. This report acknowledge that the Norfolk and Suffolk NHS Foundation Trust tries to implement this approach, but all too often service users are 'falling between the cracks'.

Being able to set, and be arbitrated by, patient-focused outcomes was mentioned by many service users and carers during the Stepping Forward event. Although the Norfolk and Suffolk NHS Foundation Trust has continuously worked to achieve this over the last four years with the implementation of reverse commissioning in The Trust Service Strategy 2012-2016, such outcomes are not readily available or quantifiable.

The lack of quantifiable outcomes is, in part, due to the current mental health system, and the health and social care systems in England, falling short of "good" integration. The Stepping Forward event provided a discourse of cyclical negativity; not directly focused towards the Norfolk and Suffolk NHS Foundation Trust, but a discourse of negativity towards the

monetary constraints placed upon mental health services nationally by central Government.

In short, those that attended the Stepping Forward event acknowledged that people do not want to fall through gaps, to be forgotten about, to have to explain themselves anew to every professional or service they encounter, and to face the fear of going around in circles when suffering from declining mental health.

Lastly, the Stepping Forward event highlighted that recovery can mean services are withdrawn, leading to a 'fear' of getting better. People are discharged into primary care where the quality of mental health awareness and provision is patchy.

Although their mental health needs may be dealt with, the other needs that underlie their unstable health may not be – including their physical health. Dual diagnosis patients can be excluded from services because of their addiction, and therefore go untreated. Yet, the coping mechanisms of addiction is self medication for the mental illness.

5. Recommendations

Assessment

To improve the continuity of information and record keeping between assessments.

Service users explicitly note that many with mental health conditions face turbulent and often fluctuating periods when in a state of declining mental health. Moreover, individuals' needs escalate and decline at different times, often suddenly and unexpectedly. Fluctuation means some people have more than 8 assessments in a year to access the different services they need for their condition.

There needs to be some continuity of information and record keeping between these assessments:

- a) to avoid having to repeat basic information and case history, (except that information which the patient wishes to control to prevent confidentiality being breached); and;
- b) to provide comparison with past episodes for care planning (for example, knowing what previous drug reactions have been). The care planning and assessment process needs to be continuous.

Mental health and social care

A continued effort to integrate mental health services with social care services.

Integration needs to provide preventive approaches. Social care can be important in supporting someone to recover, or helping someone whose needs have recently increased, to prevent a crisis and hospital treatment. High eligibility criteria for accessing social care can mean this support is only provided at crisis periods. Preventable hospital admissions, which disrupt lives, may be worse for people's health than the initial crisis itself.

Care Coordinators

The Norfolk and Suffolk NHS Foundation Trust should, where possible, assign one, fixed Care Coordinator to each service user.

Co-ordination is key to joining things up for service users. Every integrated care programme must include detailed specification of where, how and by whom the care co-ordination function will be provided for targeted groups of patients - or it will fail. Service users at the Stepping Forward event noted that seeing multiple Care Coordinators often leads to confusion for the service user, carers and care coordination team due to a multitude of disconnected streams of communication.

Care Planning

There needs to be a renewed effort to allow all service users to be a part of their care planning.

Care planning approaches were pioneered in mental health but many service users still report not being fully involved in making and agreeing them. People who most need integrated services also would benefit from regular reviews of their personalised care planning. Undeniably care planning is a major contributor to integrating care for the individual.

Although the Norfolk and Suffolk NHS Foundation Trust have strict policies that professionals should adhere to, the feedback gathered during the Stepping Forward event shows that they are not always followed.

Care plans need regular review but should be actively reviewed and amended with the patient at all points of crisis, uncertainty, transitions or changes in care – or at the service user's request. Access to records and portability of records would also help.

Reviewing Medication

The Norfolk and Suffolk NHS Foundation Trust should ensure that comprehensive medicines reviews need to happen as part of care planning at planned, reoccurring points, and service users enabled to play as full a part as they wish.

Management of medicines is a central and time consuming issue. In all treatment settings many patients say they were prescribed new medicines without being told about the purposes, the potential side effects, or how to use them properly, and without being able to participate as much as they wanted in the choice of medication. Professionals treating patients in single episodes of care will tend to 'prescribe and forget'.

Information

The Norfolk and Suffolk NHS Foundation Trust should create a pathway 'map' for the most common mental health conditions.

Information for patients should be commissioned (not left to 'appear' or not appear through local initiatives, voluntary sector organisations and charities).

A priority should be to commission - for the most common conditions, a clear, easy-read 'map' for each patient of what they should receive and from whom. These should be on National Institute for Health and Care Excellence (NICE) guidelines and standards wherever possible, and commissioners should ensure they are used and promoted.

Information needs along care pathways should be carefully considered and commissioned. Information should not only be medical. It should be holistic and comprehensive (social, emotional, financial effects of conditions; and up to date details of all available services).

Service users and carers should be able to access their information at any time.

Information about service users should accompany them throughout the care pathway. Although there have been County-wide initiatives to tackle this problem, there needs to be an ability for service users and carers to remotely access their information. This will alleviate repetition and help at points of crisis.

Broader service integration

Often left out of the discussion of integration is the joining up of physical and mental health services along with social service and criminal justice services. This is an area that the Norfolk and Suffolk NHS Foundation Trust should continue to tackle.

People with long term conditions, especially those with more than one, often suffer from depression that goes untreated. Conversely, the physical health needs of people with enduring mental health conditions are rarely considered by mental health services, and there may be no assessment of the interaction between physical and mental conditions, nor the interaction of drugs for those different conditions.

New investment in GPs' education and awareness of mental health and its links to physical health would be a major contribution. Additionally, it is widely acknowledged that many people entering the Criminal Justice System suffer from a mental health condition. As with GPs, staff employed by the Criminal Justice System – at all stages, from the police and courts to prison officers and probation officers - would benefit from education and awareness of mental health and its links to physical health.

Longitudinal Evaluation of Service User Satisfaction

A continuous evaluation of service user satisfaction should be implemented and reports delivered on a quarterly basis.

The Norfolk and Suffolk NHS Foundation Trust's Research and Development Department should develop or commission a longitudinal evaluation of service user satisfaction.

Although the Care Quality Commission's Community Survey provides feedback of service user satisfaction, it is not a robust measure and cannot aid in departmental progression.

A refined and robust evaluation measure, which could be sent to service users directly, would allow the Norfolk and Suffolk NHS Foundation Trust to track its own progress in the coming years and allow for proactive, not reactive, measures and policies to be implemented.

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HERE TO HELP...

If you have a query about this report or would like to know more about Healthwatch Suffolk or Suffolk User Forum please contact us as below. We will be happy to help.

You can watch a short video about Healthwatch via the following link:

www.healthwatchsuffolk.co.uk/about-us/

For information about how Healthwatch made a difference in the year 2014/15, please download our annual report from:

http://www.healthwatchsuffolk.co.uk/about-us/annual-reports-and-agm-resources/

You can also contact us for a hard copy (limited availability) or watch our supporting video. Simply search for "Healthwatch Suffolk" on YouTube.

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