Using urgent and emergency services at times of mental health crisis

Views and experiences of using urgent and emergency health care services in Norfolk during times of mental health crisis: an independent report for the NHS England East Anglian Urgent and Emergency Care Network

Please contact Healthwatch Norfolk if you require an easy read; large print or a translated copy of this report.

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Who we are and what we do

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to under-represented 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 are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

Acknowledgements

We are extremely grateful to the people and organisations who gave their time to us. In particular, we wish to acknowledge the following people and organisations who, in carrying out a range of activities, have made a significant contribution to this work:

- Dr Ben Marshall and staff of Norwich & Central Norfolk MIND
- Zena Aldridge, Dementia Nurse Specialist
- Kevin Vaughan, Feedback Health
- Michael Emeney, Donald Lane and the ‘Experts by Experience’ at City Reach Services
- Dr Deborah Holman and staff of West Norfolk MIND
- Luke Woodley and the team at The Walnut Tree Project
- Declan Geraghty and staff at Access Community Trust
- Ben Margolis at The Grange and Amelie Sells at New Routes
- Debbie Roberts, Graphic Facilitator at Engage Visually

We would also like to thank the local Healthwatches who helped us with queries about models of mental health crisis care and crisis smartphone Apps:

- Healthwatch Cambridgeshire
- Healthwatch Surrey
- Healthwatch Devon
- Healthwatch Cornwall

The East of England Urgent and Emergency Care Network is grateful to Healthwatch Norfolk for the production of this excellent report [July 2017]
Healthwatch Norfolk works with health and social care services in Norfolk to make sure that your views and experiences make a difference to the services we all use.

Your Experiences

We listen

SUPPORT
ADVICE

COMPLAINTS
GUIDANCE

We point you in the right direction

Suggestions
Issues
Feedback
Concerns
Questions

Complaints
Opinions
Compliments
Good Practice

Volunteers are our and

Powerful Voice

We challenge when services need to improve

You make a difference!

Call us on 0808 168 9669
Website: www.healthwatchnorfolk.co.uk Email: enquiries@healthwatchnorfolk.co.uk
Follow us on Twitter: @HwNorfolk Like us on Facebook: facebook.com/healthwatchnorfolk
Summary

Healthwatch Norfolk has done some work for the NHS England East of England Urgent and Emergency Care Network. The work started in December 2016 and finished in May 2017. The aim was to gather together the experiences patients and families of mental health crises care along with the local wisdom of care providers. The focus was to seek out where services are working well and what needs to be improved, so this learning could be shared with others. We had help from a number of community and voluntary organisations, who offered different kinds of support to mental health service users and carers.

We asked people to tell us about their views and experiences of using urgent and emergency services at times of mental health crisis. At least 686 mental health service users and carers shared their stories through:

- 199 survey responses from mental health service users and carers
- An audit of 10,942 calls to a mental health crisis helpline by 498 callers
- Face to face, one to one and paired interviews with 50 mental health service users and carers
- Informal discussion groups comprised of 21 service users and carers
- 33 case stories
- One to one interviews with 18 stakeholders (executives, senior managers, commissioners, service providers, clinicians and practitioners)

The stories came from adults from all walks of life, including for example; veterans, refugees, asylum seekers, people with dementia, depression, anxiety, bi-polar disorder, people recovering from alcohol and drug addiction and people with lived experience of homelessness and rough sleeping. Family members, friends and mental health carers also shared their experiences.

During Mental Health Awareness Week in May 2017, we got together with some of the people who’d helped us and held a workshop. We used this workshop to talk about what we’d found out and how common it was.

Of those who took part in our survey, around 60% were able to plan ahead for times of crisis to some extent but 40% were not. People were using many different services at times of mental health crisis. The pathway to help and support is not always clear. Almost half did not know who to contact in an emergency. Some people who are already receiving mental health treatment and care may have a ‘crisis care plan’ in place (18%) but half (50%) didn’t have a plan but told us that they wanted one. Knowing which service to contact is difficult. People don’t know if they are meant to call NHS 111 or go to A&E.
The lived experience of urgent and emergency mental health crisis services at a time

Context
- Interviews
- Coaches and observers
- Crisis Survey
- Mental Health Act
- Co-production
- Do you have a plan?
- It would be helpful but don’t have one

Evidence
- We have lots of solid evidence
- Does so on a new opportunity to rebuild
to support people to build their resilience

Prevention, escalation & expectation
- The range of human experience
- On the front line
- People’s own journeys
- People’s stories
- Evidence
- Surveys
- Many, many people’s experiences

Reality - lived experience
- The lived experience
- Right - Care - Place - Time
- People’s own potential
- People’s own potential
- Support to develop
- People’s own potential
- Support to develop

Gaps, improvements
- Groups/organisations running on very little or no stable funding
- Don’t do it
- Do it
- Heavy workload
- No one size fits all - take time
- Spend time with me
- Communication is verbal

Whole system - person - life
- People’s own potential
- Support to develop
- People’s own potential
- Support to develop

Cuts
- Services lack of knowledge
- Ad hoc assessment
- When assessment
- Public sector messages
- Services lack of knowledge
- Staff not aware
- People are distressed

Mind, body, brain
- The person often knows
- People network often

Chaos and storm
- Health and care all individuals
- Not the whole picture

Silos
- Organisations
- Health and care

Dementia
- Co-morbidity
- Mental health

Homelessness
- Traumatic identity
- Transient identity
- Lottery

Community
- Peers - support people to build their resilience
- Networks - support people to build their resilience

Do to - Do for - Do with
- Provide their knowledge and skills
- Community
- On the front line
- People’s own potential
- People’s own potential

In the system is currently liminated
- Lots of expressions of views
- People’s own potential
- People’s own potential

www.engagevisually.co.uk
Some people lose the ability to make good decisions when they are in crisis, so getting the right kind of help is important. Carers, family and friends often act as the voice of the service users and support to help them do so is vital. The information we collected gave us a very mixed picture of people’s experiences of services during a mental health crisis. The services that people were most likely to rate as “very good” or “quite good” are GPs (55%), community pharmacies (41%), ambulances and paramedics (34%) and A&E departments (31%). The services people were most likely to rate as “quite poor” or “very poor” are NHS community mental health services (41%) and GPs (24%). A great GP can make a big difference but people said this could “be a bit of a lottery”.

Some people thought there would be, or should be, some kind of ‘fast-track’ into mental health services during a time of crisis. In Norfolk we have a Crisis Resolution Home Treatment team. Mental health professionals told us that there is a 4-hour, 5-day and 28-day response service for people with a mental health problem. People in mental health crisis can get a ‘blue light’ service like an ambulance (999 call), be taken to A&E by ambulance or by someone else and be seen by a mental health specialist within 4 hours. This is no different for a person who has a physical or medical crisis, accident or injury. The idea is that everyone has the same kind of access to emergency services, whether their need is physical or mental. In practice, some mental health service users and carers find this very difficult or they are unhappy because it doesn’t meet their needs. There are mixed messages about going to A&E.

A lot of people are getting help and support from services provided by community and voluntary organisations. This can take the form of mental health telephone helplines, drop-ins, cafes, support groups, counselling and therapies. Many people speak highly of such services but are worried they might be seen as a replacement for good quality NHS mental health care.

This work did not set out to purposely get feedback on the Norfolk & Suffolk Foundation Trust or their mental health crisis services. We often found that people talked about these services as being unresponsive and unsafe. We also heard genuine empathy for front line mental health professionals who are felt to be doing the very best they can. Our conclusion is that mental health crisis services are under-resourced and over-stretched and this issue requires urgent attention. Crisis care plans are important and more people want to have one. Messages on who to contact and where to go in a crisis need to be clear and consistent. Some people and services are especially good at making mental health service users and carers feel safe, welcome and well-cared for and others could learn from them to improve their own services.
1. Why we did this work

1.1 Background to this work

The NHS Midlands and East (East of England) Urgent & Emergency Network has been given a time-limited opportunity to fund pertinent programmes of work which underpin the Network’s key role in the region. Such initiatives must support the Network’s function\(^1\) in the region and add value to the existing knowledge and expertise of the Network’s membership.

1.2 Focus

Healthwatch Norfolk proposed a piece of work which will *add value* and bring *patient and family experiences into the core of service improvement*. We propose that the area of healthcare that we know from our public engagement activity to be of concern to local people is *mental health crises care*\(^2\). The focus will be mental health crises care and interaction with emergency services, for adults in Norfolk aged 18+.

1.3 Rationale for choosing mental health crisis service use

We evidenced the rationale behind our choice of service area in the following ways:

- We know that patient and public behaviours - underpinned by their knowledge, confidence and expectations - creates significant demand for services and has a significant impact upon both urgent and emergency care services in our county

\(^1\) [http://www.nhs.uk/NHSEngland/keogh-review/Documents/Role-Networks-advice-RDs%201.1FV.pdf](http://www.nhs.uk/NHSEngland/keogh-review/Documents/Role-Networks-advice-RDs%201.1FV.pdf)

\(^2\) As set out in the Keogh Review on the role of networks, specifically “the delivery of local mental health crisis care action plans to ensure early and effective intervention to prevent crisis and support people who experience mental health crisis”
In 2014, we spent 150 hours in the waiting room with patients and families at the Accident & Emergency Department of the Queen Elizabeth Hospital in King’s Lynn, we surveyed 550 patients. People told us that A&E can be their preferred port of call for urgent care needs in the absence of alternatives such as a Walk-In Centre.

In 2014, we helped to gather patient experiences of the (then new) Urgent Care Centre at the Norfolk & Norfolk University Hospital where we were told that people feel safe coming to the A&E Department because they know they will be seen by a health professional within four hours. For them, access to a qualified healthcare professional is reason enough to wait up to four hours (or more).

Since 2013, we have been actively engaging with people with dementia, their carers, carers networks and specialist dementia service providers: we know that a crises of care can happen for a person with severe dementia. Such crises impact upon the person with dementia, the wellbeing of their closest carers and families and upon emergency services, at the point when a person may be exhibiting extremely challenging behaviours and a carer is no longer able to cope without immediate help.

Given Norfolk’s demography, the proportion of older and very elderly people and the projected level of unmet dementia care needs point to increasing need for care. The specialist Admiral Nursing Service has been soundly evaluated and shown to demonstrate impact in absorbing and managing crises in dementia care in community settings. The service been held up nationally as an example of good practice, yet Healthwatch Norfolk has learnt that not a single Clinical Commissioning Group in the county will be commissioning this service beyond 2016-2017.

We know from priority projects we have undertaken that people hold their 999 emergency services in high regard but that this service can be perceived as the only route to immediate intervention and support when other community alternatives could better meet mental health and wellbeing needs.

There has been significant local concern and outrage in the reporting of budgetary cuts and constraints placed upon the Norfolk & Suffolk Mental Health Foundation Trust services and in particular, concerns regarding the reduction in the number of acute mental health beds for adults in our local area. Local people perceive - or are led to believe by the media that services are being withdrawn. They feel insecure and let down by this.

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7 http://norfolksuffolkmentalhealthcrisis.org.uk/tag/mental-health-watch/
Our work on adult mental health services\(^8\) has highlighted the importance of *mental health crisis teams* and the role that this service has in providing clinical care at the time it is needed most.

Through engaging with 70+ GPs and practice staff in 43 GP surgeries, and spending 63 hours in waiting rooms surveying 338 patients\(^9\), we know that a primary care referral to the mental health crisis team produces a variable response and one that GPs are frequently dissatisfied with in terms of the quality of response and care provided to patients.

### 1.4 Aims of this work

In conducting this piece of work, Healthwatch Norfolk aimed to bring the patient and family experience of mental health crises care together with the local wisdom of care providers to seek examples of good practice in providing sound community alternatives to acute admissions. The specific objective will be to highlight where local services are working well in preventing or reducing escalation of mental health care crises and to identify how services can be improved.

### 1.5 Population of interest

For the purposes of this project, the population of interest were adults aged 18 years plus and the majority of participants will aged 25 years or over (with no upper age limit). Participants were patients, service users, carers, family members, health care clinicians and practitioners.

### 1.6 What was out of scope?

We did not include mental health service users who are younger than 18 years in our engagement or data gathering. This is not to diminish the experiences of young people and their families who are using mental health and/or urgent and emergency healthcare services but this would increase the complexity of the task at hand and requires a specific\(^10\) focus.

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\(^10\) Healthwatch Norfolk has commissioned work on CAMHs specialist Tier 4 services (UEA, 2014), Tier 3 services (MAP, 2015) and Tiers 1 & 2 (Sounder Lives, 2016)
2. Approach

2.1 Our principles

Our approach to undertaking this piece of work for the UEC Network - as with all our patient and public engagement activity - is a collaborative and emancipatory one. We gather views and experiences from patients, service users, carers and families from those only wishing to give them voluntarily. Similarly, we work hard to engage effectively with health (and social care) providers in our area from the position of wanting only the best possible services for local people; we find that every commissioner, clinician and practitioner also wants the same thing.

In our approach, no one assumes methodological superiority and no one person gets to dictate ‘what counts as evidence’. We strive to conduct our work in an inclusive and robust manner; we have in-built quality controls which are applied to every project we undertake. We are familiar with the evidence base on best practice in community engagement; as an organisation led by and accountable to, local people, we listen and embrace their views on effective ways of working. We do not have, nor do we follow, favourite theories or models choosing instead to select the theories, models and approaches most appropriate to the task at hand.

To achieve this work, we have relied heavily on contributions from a range of community and voluntary organisations in Norfolk and are very grateful for their significant contribution.

2.2 Governance arrangements

The Healthwatch Norfolk Mental Health Sub-Committee will oversee this work. Mr William Armstrong OBE is chair of the Mental Health Sub-Committee (and also the Chair of Healthwatch Norfolk). For matters of quality control and ethical considerations, the advice of the Quality Control Committee will be sought.

2.3 Project team

To deliver this work successfully, a project team was assembled combining and drawing on the expertise of Healthwatch Norfolk projects and engagement teams, volunteers and members. The Executive Lead was Alex Stewart (Healthwatch Norfolk Chief Executive) and the Project Lead was Dr Samantha Revill (Healthwatch Norfolk Projects Manager). In addition, we sought contributions from those organisations with rapport and reach into specific communities of interest across the county.
2.4 Methods

We used a mixed method approach, which included:

- Desk research: contacting other local Healthwatch within the wider Healthwatch network, looking at the local policy and commissioning content
- Stakeholder engagement: through conducting interviews with executives and senior managers, clinicians and practitioners
- Public engagement: through our Engagement Team’s calendar of events and pop-ups across Norfolk from January to May 2017
- Service user and carer survey [online and paper versions]: access, satisfaction, ratings, comments on improving services
- Qualitative interviews and focus groups through partners: creating case stories of the lived experience; patient and carer views and experiences through interviews or holding workshops, café conversations and support groups
- Convening a triangulation/validation workshop to cross-reference key findings

For stakeholders, our key lines of enquiry were:

- What do you consider to be good about services that are meant to help people who are having a mental health crisis?
- Is existing service provision the “right fit”?
- What are the issues that we need to grapple with and what are possible solutions?

For mental health service users and their carers, our questions were:

- What happens when people get the right care, at the right place, at the right time - what works well?
- What sort of services are people using at times of mental health crisis?
- What happens when people don’t get the treatment and care they need?
- What needs to be improved?

2.5 Delivery

In reference to section 2.4. Methods, and as a result of the stipulation on the period of activity, expenditure of funds and completion of the work, we concluded it would be greatly beneficial to work in partnership with others to gather the intelligence needed. In practice, that meant that Healthwatch Norfolk sub-contracted with partner organisations in the VCS to ensure a wider reach of engagement and participation in this project. We were lucky to work collaboratively with many community and voluntary organisations in Norfolk who themselves have expertise in engaging with mental health service users, patients with specific health conditions and complex needs and with carers. Drawing on our relationships with these organisations, we intended to sub-contract approximately 48% of the total value of the funding requested for which we took full contractual responsibility and risk management.
We sought contributions from other providers with expertise in:

- Mental health service user independent voice
- Mental health carer voice
- Dementia care, intensive dementia support
- Mental health crisis support
- Mental health advocacy
- Support for people leading chaotic lives
- Support for users of alcohol or substances
- Providers of key working and housing services for people who are homeless
- Providers of support to victims of domestic violence
- Providers of key working and support to individuals who are; newly arrived in the UK and/or are refugees and/or seeking asylum

2.6 Analysis

We conducted the following analyses:

- Using SurveyMonkey, conduct a simple count and sorting of survey responses and a contents analysis of free text responses to the service user and carer survey
- Using Excel, sum and present data on service experience, sum and present data on trends
- Using NVIVO (and a template or framework analysis) create a conceptual coding model to enable us to categorise and weight recurring themes of service barriers and ideas for service improvements

Please note: When working with VCS and other service providers (see 2.5 Delivery) we did not dictate the manner in which they should collect or analyse information they were gathering on our behalf. We asked them to describe the most useful outputs they could provide us with. For example, we asked a VCS provider to produce a number of case studies of mental health crises but we didn’t dictate how they go about it, believing and trusting them to be the experts in their own field (unless they requested any specific guidance from us).
### 3. What we found out

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3A. Desk research

3A1. Local context: this is what urgent and emergency services look like

The residents of Norfolk have a range of options available to them if they wish to seek urgent medical treatment from our local NHS.

3A1.1 Urgent services

GP services: If a person requires urgent medical treatment, they have the option to contact their GP surgery during the surgery’s opening hours.

Out-of-hours GPs and NHS 111 is the health service for people to use when they need urgent medical care at night, weekends and public holidays. To use the service, people would either telephone their own doctor’s surgery or call 111 and they will either be automatically transferred to Out-of-Hours or advised how to contact them. This service is currently provided in Norfolk by Integrated Care 24 (IC24) and the opening times are Monday to Friday 6.30pm to 8am, Friday 6.30pm to 8am Monday and every public holiday.

The service is provided at the following locations:

- Dereham: Westfield Centre, Dereham Hospital, Cemetery Road, Dereham, NR29 2EX
- Fakenham: Fakenham Medical Centre, Meditrina House, Trinity Road, Fakenham, NR21 8SY
- King’s Lynn: Queen Elizabeth Hospital, King’s Lynn, PE30 4ET
- Long Stratton: Long Stratton Medical Partnership, Swan Lane Surgery, Tharston, NR15 2UY
- North Walsham: Birchwood Medical Practice, Park Lane, North Walsham, NR28 0BQ
- Norwich: Norwich Community Hospital, Bowthorpe Road, Norwich, NR2 3TU
- Thetford: Thetford Community Healthy Living Centre, Croxton Road, Thetford, Norfolk IP24 1JD

There is currently one Walk-In Centre providing urgent primary care and this unit is situated in Rouen Road in Norwich city centre provided by Norwich Practices Health Centre. This is an NHS Walk-In Service and may be accessed, without charge, by anyone entitled to NHS Services whether registered with the practice, another practice or not NHS registered at all. The Walk-In Centre can see and treat Minor Injuries. There is also a Minor Injuries Unit at Cromer Hospital in Mill Road, Cromer and the opening hours are between 8am and 8 pm.

Across Norfolk there are 165 Community Pharmacies\(^{11}\). The majority of pharmacies are standard contractors who open for a minimum of 40 hours a week and there are 20 community pharmacies offering opening hours of 100 hours per week.

3A1.2 Emergency services

In Norfolk, we have three Accident and Emergency departments (sometimes also called ‘A&E’ or ‘ED’). These can be found at the Norfolk and Norwich University Hospital on the

\(^{11}\) These figures are taken from, the Pharmaceutical Needs Assessment for Norfolk, as of 31 July 2014
outskirts of Norwich, the James Paget University Hospital in Gorleston, Great Yarmouth and the Queen Elizabeth Hospital in King’s Lynn.

The East of England Ambulance Service Trust provide Ambulance Services in Norfolk; which provides a 999 call response for ‘life-threatening emergencies’.

3A2. Local context: mental health services

Mental Health Services deal with a very wide range of issues, including, for example:
- Anxiety disorders (e.g. panic attacks and phobias)
- Depression
- Psychosis conditions
- Trauma-related conditions such as post-traumatic stress disorder (PTSD)
- Drugs and alcohol services
- Eating disorders
- Obsessive compulsive disorder
- Autism spectrum conditions and ADHD
- Children’s mental health conditions
- Maternal and peri-natal health conditions including postpartum psychosis
- Mental health conditions related to living with long-term conditions
- Dementia

Mental health services have to be able to provide services for people who come from all walks of life and who may have very different needs. At a local level, mental health services are generally grouped together as follows:
- adult services
- child and adolescent services (CAMHS)
- forensic services
- learning disability services
- older adult’s services
- substance misuse services

How these services are organised in each local area may differ. In any given area, there will be ‘commissioners’ who have a statutory duty to arrange and buy services on behalf of their local population. In Norfolk, mental health services are commissioned by the five Clinical Commissioning Groups in Norfolk. Some are commissioned in partnership with Norfolk County Council and some highly specialised services are commissioned by NHS England. For some mental health service e.g. for a specific group of people who have a mental health need, a range of commissioners come together and may include the local authority, clinical commissioning groups and the police, for example. Community and voluntary sector organisations may also be commissioned to provide a non-statutory mental health service, where it meets a local need.

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12 Our other 999/emergency services include the Norfolk Constabulary (police) and the Norfolk Fire Service.
3A3. Other local priorities for mental health

There is a great deal of focus and activity being devoted to mental health services, wellbeing and prevention across the county. This project set out to look specifically at service use during times of mental health service, so it’s not useful (or even possible) to attempt to describe all the work underway to strengthen and improve mental health services in the county. Strongly associated with the theme of this work, however, is the activity taking place on suicide prevention. In June 2016, Norfolk Public Health carried out an audit\(^\text{13}\) of suicides in the Norfolk population. On average there are 77 suicides in Norfolk every year. A third of people who die by suicide are aged 45-59 years of age. Seventy six percent of people who took their own lives were men. Two thirds of suicides occur in the individuals own home (68%). The audit describes how 90% of people who had died by suicide had seen their GP in the 12 months prior to their death and nearly a quarter of people (23%) had their GP in the week before their death. Forty three percent were known to have had some contact with mental health services and for 33%, this was within the year of their death.

In addition, there is a significant programme of work underway to deliver the Norfolk & Suffolk NHS Foundation Trust (NSFT) Suicide Prevention Strategy 2017-2022\(^\text{14}\) which has been developed in collaboration with multi-agency suicide prevention groups.

Norfolk’s Mental Health Strategic Group have been undertaking a lot of work in accordance to strategy and plan set out in NHS England’s ‘5 Year Forward View’\(^\text{15}\). The plan is that there will be a Psychiatric Liaison Service in A&E 24 hours day, by January 2018 and NHS England are investing £485,000 in that service locally. The plans also include exploring crisis cafes and the use of social prescribing within the mental health crisis pathway on adopting innovative models of care. This includes mental health services for people experiencing a crisis who aren’t already using mental health services or perhaps not yet known (e.g. referred) to mental health services. The work includes a mapping of the crisis care pathway, a cost benefit analysis and a proposal to explore the impact that mental health crisis has upon services.

In November 2016, The Eastern Daily Press\(^\text{16}\) reported that Norfolk was to receive a one-off grant of £394,700 for renovating and expanding “places of safety” in Norwich (at Hellesdon Hospital), King’s Lynn (The Fermoy Unit at the Queen Elizabeth Hospital) and Great Yarmouth (Northgate Hospital). These places of safety are rooms (also known as Section 136 Suites) on NHS premises where people who are experiencing a mental health crisis can be cared for in appropriate environment whilst they are waiting for help.

In April 2017, the Eastern Daily Press ran a report criticising a local idea to explore the use of crisis cafes in helping to support people through a crisis. It was reported that the cafes would “primarily be non-medical” and focus on de-escalation but would “be supported by clinical staff”. Linked to this, The Lowestoft Journal ran an article on 27 April which reported the views of a local campaigning group who said “people in psychiatric crisis...”

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\(^{13}\) Public Health Audit: Suicide in Norfolk. December 2016. Norfolk Public Health: Norfolk County Council
\(^{14}\) NSFT Suicide Prevention Strategy http://nsft.nhs.uk/About-us/PublishingImages/Pages/What-are-our-priorities-and-how-are-we-doing/4622%20-%20Suicide%20strategy_spreads%20110417%2012pp.pdf
needed beds, doctors, nurses, psychologists, social and support works rather than platitudes and cups of tea”.

Healthwatch Norfolk has been involved with the executive body charged with developing the Sustainability and Transformation Plan17 for the Norfolk and Waveney area. We have a role as a local watchdog in seeing how the plan develops and what it delivers for local people, in addition to gathering views on the plan and its proposed impact. Prevention is a key theme within the plan. There is also an emphasis on reducing avoidable admissions to hospital and in seeking new models of care to meet needs in community settings, closer to home. This STP includes a significant programme of work on mental health services and wellbeing. Our other findings on mental health service provision in Norfolk are reflected in our interviews with stakeholders in the county (please see Section 3B2).

3A4. Findings through the local Healthwatch Network

As described in the following pages (Section 3B2), during this work several stakeholders talked about the development of different models of mental health service provision including ‘Crisis Cafes’ and smartphone Apps such as the ‘Stay Alive App’. We were directed to other areas of the country where our stakeholder knew these were being considered or implemented. We took the opportunity to contact other local Healthwatches within our network, to ask if they were aware of any feedback from patients, service users, families and the public on such services and tools.

3A4.1 Crisis Cafes

For feedback on Crisis Cafes, we approached the following and asked if they were aware of any feedback on service experiences - whether positive or negative etc - of using Crisis Cafes:

- Healthwatch Cambridgeshire
- Healthwatch Surrey
- Healthwatch Leeds

Safe Havens

Between December 2016 and February 2017, Healthwatch Surrey visited the 7 Safe Haven cafes in Surrey and North East Hampshire to talk to service users about their experiences of mental health services and reported their findings in their publication “Keeping the Light on”18. There are 5 Adult Safe Havens in Surrey and North East Hampshire and 1 Young Person’s Safe Haven in Aldershot (with one Safe Haven closing recently). Twenty five people between the ages of 14 and 60 shared their experiences with Healthwatch Surrey.

Healthwatch Surrey report that everyone had something positive to say Safe Haven Cafes including that the Cafes had on occasion helped to ‘save their lives’ and had reduced their need for other services. These service users had either mixed or mostly negative

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17 In Good Health http://www.healthwatchnorfolk.co.uk/ingoodhealth/
18 Keeping the Light On: views and experiences of people living with mental ill-health in Surrey” March 2017 www.healthwatchsurrey.co.uk
experiences in A&E (50% had used A&E) and those staying in an in-patient mental health facility reported they were often discharged without a care plan. Many had already accessed other services previously such as their GP, a Community Mental Health & Recovery Service, CAMHS, a crisis helpline (e.g. Samaritans), local charities. One concern raised was the personal safety of service users when visiting one of the locations. Many found the Safe Havens worked for them because they didn’t have ‘flexible professional support’ and Safe Haven met this need.

A key aspect of the Safe Havens is the staff employed and users suggested that there are number of really important questions they would like to be asked or phrases that staff could use to make sure that service users felt more welcomed, valued and respected when accessing services. These were:

- “It’s good to see you”
- “How can I help you today?”
- “How have you been since you were last here?”
- “Are you feeling comfortable here today?”
- “Has anything changed since I saw you last?”
- “Is there anything I can do better in the future?”

Service users had mostly positive things to say about the service although some highlighted their safety concerns:

- “It’s a great service. The availability such as opening hours and location is good. All the staff are great here; there isn’t a bad one. It’s a better option than A&E as it’s a less formal environment, much more comfortable and there’s less pressure to talk and get formal treatment”

- “It’s an amazing service. When I first came the staff were very welcoming. They explained everything about the service and they offered me a hot drink. I speak to the CPD here about what’s happening in my life. She knows me as if she’s my personal CPN which means I don’t need to have one in the community and don’t put pressure on services.”

- “The staff give you the care and attention you need. They give advice on other people and other professionals. You can come to Safe Haven and not be judged. It’s okay not be okay.”

- “I enjoy the social side. Generally it’s a godsend. I don’t know what we would do without it”

- “They’re really friendly at Safe Haven. You can go in an awful mood and be yourself. At work you have to put on a face and pretend. Before I came to Safe Haven I didn’t know about services I could access in day. Now that I come here I know much more about what options I have, like the Recovery College.”

- “It can get a bit much when people talk about death and depression in the communal areas”

- “When people are blue lighted here or are in full blow crisis you notice the atmosphere changes. Sometimes it causes friction and upsets the balance or the aura. There was an
incident outside a couple of weeks ago where a girl got attached by someone who had been in the Safe Haven the night before.”

**Well-Bean Café - Hope in a Crisis**

Near to St James’s Hospital in Lincoln Green, Leeds is the **Well-Bean Café - Hope in a Crisis** café. The Well Bean Café supports anyone in a crisis, acting as a safe place for people in crisis to and to prevent avoidable attendances at A&E. The café is led by a partnership between the Leeds Survivor Led Crisis Service and Touchstone and is currently being piloted for a period of 20 month. The café is open on Saturday, Sunday and Monday nights from 6pm until midnight.

This service offers a time limited, non-clinical alternative to going to A&E that aims to reduce distress and work with people to resolve or to manage their crisis. The service offers up to two hours of support which includes one hour of one-to-one support and a further hour in the social space where refreshments are available for those needing them.

We contacted Healthwatch Cambridgeshire about the Cambridge Sanctuary which is a service provided by Cambridgeshire, Peterborough and South Lincolnshire MIND. The Sanctuary is funded by Cambridgeshire & Peterborough Clinical Commissioning Group as part of the wider Vanguard First Response approach which aims to offer system wide help to people in mental health crisis “24/7”. The Sanctuary provides a safe place for people who are experiencing an emotional or mental health crisis. It offers “practical and emotional support in a warm, welcoming and friendly environment”. The opening hours are 6pm to 1am, seven days a week and may be used as an alternative to admission to statutory mental health services.

**The Sanctuary**

Healthwatch Cambridgeshire told us that hadn’t received a great deal of feedback on the service directly but told us

“We have heard that the service has been welcomed by service users and families. We understand that there are issues with capacity, and also some concerns that it closes at 1am. Some people would like it to be open for longer”

“The Sanctuaries are run by Mind, but their location is not publicised as people have to be referred by the First Response Service and so cannot just turn up. Generally there is also the issue of access for people living in more rural parts of the county as there is a Sanctuary in Cambridge and one in Peterborough”

“There are also some issues around accessing the First Response Service as you have to telephone and so this can present difficulties for people with hearing loss or who are deaf, as well as people who may find it difficult to communicate during a mental health crisis. Whilst many people have family and friends who can ring on their behalf, this is not true for everyone”.

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19 http://www.cpslmind.org.uk/what-we-do/the-sanctuary/
20 Healthwatch Norfolk will be pursuing a similar line of enquiry with our priority project on people’s experiences of the Out-Of-Hours services in Norfolk.
3A4.2 Suicide Prevention Apps

There are several apps available for smartphones which have been designed to help people plan and manage times of emotional or mental health crisis. During our interviews with stakeholders, several people raised the existence of phone apps and that it was possible some areas in South West had adopted them as part of their local “toolkit”,

One such example is the ‘Stay Alive’ app which has been developed by an organisation called Grass Roots Suicide Prevention.\(^{21}\) This app is described as “A mobile app for those at risk of suicide and people worried about someone”. We approached the following Healthwatches and asked them if they knew about this app and if local commissioners or providers in their area had formally adopted or promoted it:

- Healthwatch Cornwall
- Healthwatch Devon
- Healthwatch Brighton and Hove

Healthwatch Cornwall told us that did not believe the Stay Alive app had been formally adopted locally but they were aware that several local organisations\(^ {22}\) were promoting its use and some had tweeted about it.

Healthwatch Devon told us that one of the Devon Partnership Trusts chosen priority areas for 2016-17 was improving the care and support provided for people in a crisis. The use of apps wasn’t specifically mentioned in their most quality account. Healthwatch Devon said that they had noticed a decline in negative patient experiences when trying to access out of hours support being reported to Healthwatch Devon over the last 12 months and felt that the local focus around the crisis service seemed to have had an impact.

Please see Figure 7 in Section 3L for further views on the use of apps in mental health crisis.

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3B. Stakeholder and public engagement

3B1. Engagement with patients, service users and the public

Our Engagement Team are regularly out and about around the county meeting members of the public and listening to their views and experiences of health and social services. Between January and April 2017 the team had a busy events calendar (as usual). Many individuals approach our team to discuss their mental wellbeing or that of their family members, people they care for or their friends. As part of this project, for example, the engagement went to the event: In Good Company: Loneliness and Mental Health Forum Carers Forum, on March 31st at The Kings Centre, Great Yarmouth (below).

The team also went to Attleborough Library (as pictured above).

When we gather feedback on services from patients, service users and the public, their comments and satisfaction ‘ratings’ of services are fed into our ‘Feedback Centre’.

We use this information to regularly and routinely report on services in the ‘Intelligence Report’ that goes to the Healthwatch Norfolk Board every time they have a meeting. We routinely report on people's satisfaction with GP services, out-of-hours GP services,
community pharmacy, A&E departments in our county’s three hospitals, the ambulance service, hospital in-patients as well as mental health services. We use this feedback to decide on priorities which warrant further investigation. At the meeting held on 17th April 2017, we chose to turn the spotlight onto mental health.

Here are some examples of feedback on service use during times of mental health crisis that have been gathered by our Engagement Team and put into our ‘Feedback Centre’:

People rating their experiences as good or excellent

“My partner was, and still is, being treated by the crisis team and stayed on Thurne Ward. Can’t fault the staff from both departments. Only the doctors messing with long standing pain medication spoiled what we found to be very good care. Overall everyone we had contact with through home to hospital and again home treatment couldn’t have been more supportive to my partner and myself. Massive thank you to all staff working with mental health illness”

“They are always there for my daughter if she’s struggling. Somebody was there within 3 hours when she had an emergency”

People rating their experiences as poor

“...my sister has received excellent first class treatment and support from our GP who is limited as to what they can provide so she then has to have more intensive treatment. The lack of dignity and respect shown from the care team is shocking, I do question whether if these people are in for the care element or just the money?...The lack of communication is a joke and they are very willing to discharge because the patient is conforming and saying the right things, when my sister is unstable the wish and desire to end her life is great. These professionals just take what the patient is saying at that point, no review of past admissions or monitoring of behaviour but no it takes the role of a family member to tell a professional that they are not ready for discharge and if so, who’s responsible for their actions when back in the community mental health team or the family? Well, need I answer that? Yes, official complaints have been logged and yes, CQC has been alerted”

“My daughter had bipolar, she took her life. There was no support for her. Nobody came out to see her in her home, she was isolated”

“My son has mental health issues and has received some support from NSFT and Social Services in the past. Getting the right support is proving very difficult as he is an adult and does not have a physical disability he ‘falls between the cracks’ in terms of support. I am concerned that he will get to crisis point before he gets further support. He wants to get into work but is unable to due to his increasing anxiety.”

“I asked for help as I was in crisis in December but they couldn’t do anything until April.”

“I contacted the Wellbeing Service for help with self-harm, suicidal thoughts and possible psychosis. I was not taken seriously and was told I was not eligible for help as I had not attempted suicide. They also fixated on my being intersex but this was not an issue.”
Feeling desperate and suicidal, I was asked to self-refer via the website. I was offered a session involving about 50 other people which was designed to determine next steps (not good for those with anxiety). All courses on offer were during the day (I wanted to continue working) or evening courses were an hour’s drive away. Very unhelpful.”

“My sister was sectioned a couple of weeks ago she was dumped at my house with no warning by an occupational therapist who had no idea what the medication was or why she was taking it don’t expect any aftercare unless you are prepared to phone constantly and be very firm and don’t believe anything you are told they are doing to do it won’t happen, no communication between family patient and crisis team, absolutely useless”

James Paget Hospital, 17th March

Other comments on mental health services:

“mental health services have been very much depleted”

“the CHRT is not a crisis service because it can take between a week or 8 days to be seen. How is that a crisis service?”

“we need more service user and carer partnership groups”

“You won’t find much in the way of independent, mental health service use voice in Norfolk. It just doesn’t exist, or rather, it does exist of course there are many small groups but it’s not joined up in anyway. That is part of the problem. People often go to the same groups time after time. Also, we need to remember that NSFT’s own service user group are not entirely an “independent Voice”, are they?”

“it’s not their fault. They have had to face so many cuts in funding and then make cuts in staff. You have to remember that front line staff are doing an amazing job, day in, day out”
Case story: “Remember Mid Staffs. It took a long time for people to be listened to”

“As you can imagine, it was a shock when my son died. In the past few years I have been in touch with many people whose relatives have died in similar circumstances. Without exception, they consider NSFT was deficient in its services. I have communicated the views of carers of service users of the Trust who live in the community, both publicly and privately and have informed Healthwatch, the CQC, the CCGs and Norfolk Carers' Council, not only of service user and carer views, but also of the hard facts. Freedom of Information requests reveal that unexpected deaths have risen by 33 per cent between 2015-2016 and 2016-2017.

I have begun to realise that the non-executive directors in the Trust do not understand the extent of the danger those living in the community are in. People are dying for two main reasons: they are served by nurses overwhelmed with unmanageable caseloads, therefore service users do not receive the observation needed to prevent them requiring stabilisation in hospital which is not available anyway due to inadequate provision of beds. Deaths on wards are rare.

We hear from the CEO and the communications department of NSFT about applaudable initiatives like the proposed mother/baby unit which will serve 8 people, but no acknowledgement of the inadequate service available to the majority of people in secondary care living usually alone in miserable conditions in the community...2,000 people are receiving services in the community in the North, South and Central Norfolk area).

...national initiatives to prioritise early intervention have become an excuse to distribute mental health budgets unevenly among service users. I have communicated to the Trust repeatedly that I do not agree with their priorities which do not a mention improving services for community care. There are new initiatives to integrate Central Clusters with primary care, but people like my son continue to fall through the net while NSFT tries another reorganisation of services, with no proof that this will improve services and halt the increase in unexpected deaths.

You may worry about my objectivity, but facts are facts, and it when analysing NSFT's services, it would be good for Healthwatch to have the current statistics of the numbers of people living in the community receiving services in different locations.

There does not seem to be an understanding of the fact that few people recover from schizophrenia, bipolar, autism, personality disorder, dementia and the conditions that secondary mental health care serve because they are lifelong neurological conditions which present specific needs and dangers.

Remember Mid Staffs. It took a long time for people to be listened to”
3B2. Stakeholder interviews

We held face-to-face, one-to-one interviews with executives and senior managers of NSFT, Norfolk Constabulary, the Norfolk and Norwich University Hospital Trust (NNUH), the James Pages University Hospital Trust (JPUH), the Queen Elizabeth Hospital (QEH) and the East of England Ambulance Service Trust (EEAST) and West Norfolk Carers.

**West Norfolk Carers told us:**

The current pathways are too complicated to follow and only provide limited access, due to current funding arrangements. Patients are not being taken seriously and “help” is not available on demand for people in acute crisis. For example, a man aged 24 recognised he was in need of immediate help. He went to the Fermoy Unit in King’s Lynn but was unable to access as a service, as no one answered the door-bell despite the notice saying that it operated a 24hr service. His friends persuaded him to go to A&E but he ran away because he was frightened. There are approximately 200 carers in West Norfolk looking after people with mental health problems. In the local picture in West Norfolk, there are also people living in Cambridgeshire and Lincolnshire needing to access services since the QEH is their nearest provider. Often, the carer of the mental health service user is also unwell and may also have a mental health problem but is helping to provide care around the clock.

From a carers perspective, these challenges could be potentially overcome if there was adequate nursing provision available 24/7, 365 days a year, in order to undertake appropriate triage and then re-direct the person to other services that are available in the community.

**Norfolk & Suffolk Foundation Trust told us:**

It might be obvious but still worth stating that NSFT doesn’t want anyone to have to go to A&E when facing a crisis. The Crisis Home Resolution Team (CHRT) functions well for people who are already in an existing care pathways and helps prevent people having to go to A&E. The Psychiatric Liaison Service operating through the Norfolk and Norwich Hospital is a gold standard commissioned service operating on a 24/7 basis and demonstrating effective outcomes and resolutions for those who have utilised the service.

The CHRT and the Psychiatric Liaison service are good for those than can access them. However, very much a postcode lottery for the latter as only available in Norwich. The 5 year forward view has recognised the need for expanding services and NSFT are currently bidding for monies to enhance and expand existing provision.

Placing greater emphasis on the availability of accessing prevention services would help to ensure that people did not need to go to A&E. Examples being successfully trialled elsewhere include a model of service through a “Crisis Café”. This service offers peer support, community and voluntary sector involvement alongside the ability to access psychiatric services. Whilst being offered in predominantly urban areas, there is no reason why people couldn’t access it from rural communities.

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23 Our previous work “Access to Urgent Care in West Norfolk” published in November 2014 suggested that people are fairly willing to travel – and to drive – to a location such as A&E in order to get help in urgent circumstances.
We were also told that, as part of the Trust’s contribution to the ongoing action plan underpinning the county’s Suicide Prevention Strategy, an in-depth mapping and Root Cause Analysis of deaths and ‘near misses’ was being undertaken along with a map and gap analysis of the Crisis Resolution Home Treatment care pathway and service provision. The scope of this piece of work included an assessment and review of:

- The number and nature of complaints about the CRHT as well as the number and nature of compliments about the service
- The number of referrals received and the appropriateness of referrals
- Access to the service, and discharge from the service
- Exploring how referrals into the service were taken from the NHS 111 route (pathway)
- 24-hour Mental Health Liaison services in our county’s three hospitals, which will enable people to be “fast-tracked” to mental health crisis services
- A focus on each service user having a “Safety Plan” or a crisis plan — which the service user and service both have access to. The Safety Plan will include actions to take when a person feels that their mental health is deteriorating and they are moving towards crisis and includes information on what is most useful to them in times of crisis and what actions make them feel they are taken seriously by staff.

We already know that every person using NHS services should expect to be seen within 4 hours upon attending A&E and that the standard “referral to treatment” for the majority of medical conditions is 18 weeks. Staff at NSFT told us that the Crisis Resolution Home Treatment service is “not a blue light emergency service”: this is not because this is what NSFT or the team has decided themselves, it is because the service has not been designed or commissioned to operate in that fashion. A personal in mental health crisis is likely to be someone who is “floridly psychotic”, deemed to be a “psychiatric emergency at risk of harm to self or others” and is seen as the “psychiatric equivalent of a heart attack”. These individuals may require a blue-light response e.g. dialling 999 for paramedic attendance and being taken to A&E by ambulance (or by family, members, co-workers or other agency workers – as can also happen). On arrival at A&E, the CRHT have a 4-hour window of opportunity to make contact. The CRHT report that 75% of their 4-hour referrals end up not requiring a 4-hour response. This suggests that some clinicians, practitioners etc are less skilled in making a judgement about a person’s mental health crisis needs. It was suggested to us that at time, other clinicians and practitioners may have a consultation with a very distressed person and often family members, carers and friends are also extremely concerned on behalf of their loved one. If an individual is assessed and there is a clinical assessment and judgement made that the person does not require a 4-hour response, that individual may be deemed to be requiring either a 5-day response or a 28-day response.

Essentially, this means the mental health crisis care pathway is the same as the NHS urgent and emergency pathway. Every individual has equity of access to urgent and emergency care whether they have a physical or mental health need:

\[
\text{GP} \xrightarrow{} \text{NHS 111/out-of-hours} \xrightarrow{} \text{A&E} \xrightarrow{} 999 + \text{A&E} \xrightarrow{} \text{specialist treatment}
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24 The NHS Constitution sets out that patients should wait no longer than 18 weeks from GP referral to treatment.
Case example - the ‘Safe Haven Café’

A café in a North East Hampshire ‘Vanguard’ has helped reduce mental health hospital admissions by a third in seven months by providing an alternative solution for patients.

The ‘Safe Haven’ café in Aldershot, on the Surrey and Hampshire border, has been open all year round since 2014 and is an evening drop in where people can go if they need support. NHS workers and third sector partners are on site to provide mental health crisis support which has helped some people avoid the need for NHS care including A&E altogether. Anyone suffering from a mental health problem diagnosed or not, can drop in for a cup of tea and a chat and can request more formal help if needed. Service users say the café has helped them in many ways including preventing some from committing suicide and helping others combat loneliness, homelessness and general crisis.

Dr Andy Whitfield, Clinical Chair, North East Hampshire and Farnham Clinical Commissioning Group (CCG), said: “The café is an excellent example of the Five Year Forward View in action. It shows partners from all sectors working together to provide a service that is close to people’s homes, easy to access at times of need and clearly filling a gap in provision. “We asked service users what they wanted and this was their idea which proves that putting patients at the heart of change is the key to providing the right kind of care and reducing need for costly NHS beds.” The number of attendances to the café each month has jumped from an average of 167 in April to June last year to 415 in the same period in 2015 and 95 per cent of their feedback has been positive.

A separate study carried out for Surrey and Borders Partnership NHS Foundation Trust (SABP) by Mental Health Strategies found that from April to October 2014, the number of admissions to acute in-patient psychiatric beds fell by 33% from within the ‘Safe Haven’ catchment area. The service is de-escalating and preventing crises and avoiding the need for people to present to mainstream services, reducing demand and releasing capacity. Surrey & Borders Partnership NHS Foundation Trust is contracted by the CCG to run the café in partnership with two third sector organisations which provide the staffing. The service has brought partners across the statutory and third sectors together in an innovative way which has been crucial to its success. It provides mental health support in a welcoming environment provided by trained psychiatric nurses and other mental health professionals as well as peer support.

Else, a regular at the café, said: “I’ve never felt so supported, listened to and appropriately cared for. Definitely since I’ve been coming here there are probably six or maybe seven occasions where I’ve come here instead of where I would have gone to A&E or ended up spiraling out of control in this crisis and ended up doing something stupid.”

The café is part of the North East Hampshire and Farnham Vanguard which aims to keep people “Happy, Healthy and at Home” and will support local people to improve their own health and wellbeing or when they are ill or need support, help them receive the best possible joined-up care. The café is funded through NHS North East Hampshire and Farnham CCG and delivered by Surrey and Borders Partnership NHS Foundation Trust, in collaboration with the charities mcch (commissioned by Hampshire County Council and Catalyst).

There is a similar project operating in Norwich, called is the KindaKafe. KindaKafe is a “small and quirky venue that wants you to be Kind to Yourself”. It was suggested that


26 KindaKafe is a non-for-profit social enterprise which is part of the KindaHappy movement http://www.kindakafe.co.uk
using this kind of prevention model, alongside self-help and community support, and with social prescribing support, savings can be made and people living in crisis helped before reaching the ‘point of no return’. This helps to manage demand at an early stage on someone’s health journey thereby preventing the need to access emergency secondary care.

We were told some of the issues to be resolved include:

- Short-termism and the inability to access crisis services unless already known to the system.
- The STP provides a forum by which issues could be addressed from a system wide perspective but opinion is still divided as to its effectiveness.
- By providing alternatives to A&E and associated crisis services, recognising that one size does not fit all, offering options and a “pick and mix” access to early intervention.

Norfolk Constabulary told us:

Services in Norfolk work well together to deal with and support people during times of mental health crisis.

The Norfolk Constabulary has a Mental Health Triage Service comprised of a team of 5 mental health nurses who are based within the Control Centre, operating 7 days a week from 8am-10.00pm (Monday/Friday) and 9-5pm at weekends. This service is currently being reviewed, with a hope to increase the hours as funding has recently been agreed for an extra nurse. The service is currently funded through a partnership arrangement with contributions from a range of agencies including the Office of the Police and Crime Commissioner, Norfolk Constabulary, Norfolk’s CCGs, District Councils, Child & Adolescent Mental Health Services (CAMHS) and NHS England, with NSFT providing the staff. The University of East Anglia conducted an evaluation of the service over a 14 month period. The evaluation showed that between the 31/3/15 and 30/6/16, the team reviewed 40,175 control room incident logs to ascertain whether or not there were any concerns about people’s mental health state and entered comments onto 5478 of these logs. The comments in the logs were used to assist front-line officers plus officers working in specialist departments, to deal with mental health related incidents more effectively.

There is a Liaison and Diversion Service operating in the Constabulary and Magistrates Courts - whereby mental health nurses are employed by NSFT and work in the Custody Suites to assess and provide support to individuals who have been arrested and who may have mental health concerns. There is a Police Mental Health Team, consisting of an Inspector and two Sergeants, who are involved in MDT particularly around discharge from NSFT inpatient acute hospitals. They also attend meetings with Community MH Teams when concerns are raised about service users who have had some involvement with the police and they attend mental health liaison meetings at the NNUH. Partnership working feels “good” and is working due to there being a very dedicated team and extremely responsive mental health trust.
We were told some of the issues to be resolved include:

- Keeping people well in the community - more prevention work is required to prevent crisis happening in the first instance. This needs to be counter-balanced by recognising that crisis can develop very quickly especially in relation to those suffering psychosis as a result of narcotics.
- There is a distinct lack of ability to access crisis care particularly out of hours and the police only have limited powers, e.g., making appropriate use of Section 136 suites. Sometimes the only option for the police is to ensure that a person is taken to A&E.
- “Bed blocking” - sometimes people in crisis are unable to access local acute mental health services when they have been assessed as being in need of admission as no beds are available. Beds are often being ‘blocked’ by people who are ready for discharge but can’t be discharged due to social care issues (e.g. lack of suitable housing to meet their needs in the community). This could potentially be averted through the provision of “step-up and step-down beds/accommodation”.
- CHRT aren’t always able to pick up the phone or provide appropriate support/assistance to police when they need it, as they and are not commissioned to provide services for those who aren’t already active to their service.
- There is inadequate provision for emergency beds linked to “step-up step-down” care.
- EEAST aren’t always able to convey patients who have been detained under Section 135 or Section 136 of the Mental Health Act, in accordance with the timings outlined in the local protocol, which may result in patients being conveyed in police vehicles. There is an excellent working relationship with EEAST and this pressure was recognised as due to demands on the ambulance service.

The East of England Ambulance Service told us:

From the perspectives of the East of England Ambulance Service Trust, there are several issues that are considered to be worth noting:

- Time to assessment in A&E can be lengthy, patients can be kept waiting for long periods of time, partly due to volume of referrals.
- The Assessment Units are inadequately staffed - daytime cover, not always 7 days a week, with little evidence of night cover.
- IT systems used by the different organisations are “not able to speak to each other”. For example, IC24 (who provide the GP Out-of-Hours service in Norfolk) use an IT system which is completely incompatible with EEASTs.
- These IT systems incompatibility is a barrier to timely access to patient records, which would enable some pre-planning for crews prior to attending

These issues can be resolved, potentially using the following approaches:

- Training existing staff to a higher level rather than having specialised training for a small number of staff only.
- Make greater use of “message in a bottle” in people’s homes.
- Expand use of Eclipse Live - a system currently managed by WN CCG and hosted by QEH.
• Make greater use of Cromer Hospital by widening criteria - more patients being seen locally by appropriately trained staff will potentially lead to less clogging up of A&E.

James Paget University Hospital told us:

Some of the issues to be resolved include:

In general, more money needs to be put into the health care system for mental health provision. For example, there is only a limited amount of cover at the JPUH, presently 12 hours each day, with a 4-hour response time. In the event that there is more than one patient presenting in crisis, there are inevitable admissions to hospital beds, which may not be either appropriate or beneficial to the patient’s longer term outcomes in relation to their condition. For example, a patient presenting over the Christmas period who was identified as a severe self-harmer. NSFT recognised need for admission to an acute mental health bed but there wasn’t one available. In order to facilitate the patient’s needs, the JPUH had to clear out a specific area in order to make it safe for that particular patient and provide the correct levels of staffing required for monitoring the patient.

The system could be more innovative and that there are better examples of initiatives being provided elsewhere that could be tested in Norfolk. For example, if greater use were made of Social Enterprises to provide drug and alcohol services, there may be an opportunity to be more flexible as to the hours that provision is provided. An example of current good practice was identified in Lowestoft Rising initiative that is providing support to families who are coping with living with mental health problems and preventing them reaching crisis point. This initiative is also making effective use of social prescribing techniques to support, build and strengthen physical and mental health.

Case example - ‘Lowestoft Rising’

Lowestoft Rising comprises a group of five public sector partners - Suffolk Police, Suffolk Police and Crime Commissioner’s office, Waveney District Council, Suffolk County Council and NHS Great Yarmouth and Waveney Clinical Commissioning Group (known locally as Health East) - which work together in a new and unique way. Its aim is to create a significantly improved quality of life for everybody growing up, living in, working in, visiting and investing in Lowestoft.

Lowestoft Rising is not a project, a scheme or an initiative - it is a radical new approach to delivering public sector services in a specific area and turning Lowestoft into a town where everyone fulfils their true potential. This will be achieved by creating an environment where public sector organisations work together in innovative ways to deliver better services and bring about long-term change for local people.

This demands a new integrated and sustainable approach to service delivery which ensures services are delivered with local people first and foremost; makes more effective use of existing capacity, projects and initiatives; works towards changing the demand for services and investing in services which ensure local people remain independent and are less dependent on costly interventions and make more sense and avoid duplication.

27 Lowestoft Rising http://www.lowestoftrising.co.uk
Norfolk and Norwich University Hospital Trust told us:

From the perspectives of the Norfolk and Norwich University Hospital Trust, this is the issue of most concern:

- There are some issues with the Mental Health Liaison Service. This is a service where the hospital has a 24-hour mental health liaison nursing service provided to cover both the emergency department (A&E) and the wards. It was suggested that the number and professional mix of staff employed are insufficient to provide a service that meets the newly mandated response time for mental health liaison to attend and complete a referral from A&E within 1 hour of the referral being made.

- The Trust has one Consultant Psychiatrist and other hospitals of a similar size have at least 3 or 4. At present, the Mental Health Liaison Service team are saying that they can only agree to see a maximum of 6 patients in a 12-hour shift, as they have to complete and write up each referral on their system for each patient before moving on to the next one (due to clinical governance reasons). They do not seem able to change this process and intimate that the only way to increase capacity and timeliness is with more staff.

- Often patients are referred who are too intoxicated, or recovering from an overdose, and it is not possible for the Mental Health Liaison team to start their assessment within 1 hour of referral. This is where the Clinical Decisions Unit (CDU) helps the NNUH to save ‘breaches’ when it is protected for A&E patients because this cohort of patients go into CDU, are “off the clock” and are seen by the Mental Health Liaison team when sufficiently recovered.

- The data collected on responsiveness is currently collected by NSFT and they report against the currently commissioned target of ‘less than 4 hours from referral to completion’ rather than the Mandated Action target of 1 hour. The emergency department team have been asked to try and work out how to harvest the NNUH data from the Symphony System, so that they can be clear on the response times as recorded by the ED nursing staff. The clinical team are still working out the process to capture the data.

- Due to the capacity of the night team being limited to around 6 patients, the NNUH very often have a number of patients waiting for Mental Health Liaison review in the emergency department in the mornings. The Mental Health Liaison team are based in offices near to Edgefield Ward in the hospital and efforts have been made to move them closer to the emergency department to improve their response times, but the office accommodation found was rejected as unsuitable.

- N&N consider that they need assurance from NSFT staff that they understand and try to work to the 1 hour referral to assessment target, and understand the imperative of the 4 hour standard. At the moment they just say “we have been the patient within 4 hours which is what we are commissioned to do”. The ability to clear the emergency department of Mental Health Liaison patients in the mornings would really help the NNUH with patient flow and would reduce the number of assessment breaches they have early in the day.

This issue can be resolved, potentially using this approach:

- The Trust applied for The System funding, for an additional £1.4m to increase the staff numbers to meet the “Core 24” requirement and the proposal is at the
national stage now but the NNUH don’t expect to hear about the outcome of the bid before the end of March 2017. NSFT have worked out a phased recruitment approach, in case only some of the money is granted. It is not clear what the plan is if they do not receive any extra money.

- There are numerous anecdotal reports of the Mental Health Liaison team refusing to see more patients or to change the way they work in order to provide extra support to the emergency department.
- There is concern that there is no contingency plan for recruit additional staff to the Mental Health Liaison team, if the bid funding is not received. If funding is received, what the expected timescale is for recruitment and implementation of a more timely and improved service.

**Queen Elizabeth Hospital Trust told us:**

Some of the issues to be resolved include:

- Everyone sees A&E as being open 24/7
- CHRT operates in the hospital current and should see people within 4 hours but rarely the case due to demand.
- People in crisis see A&E as way of expediting access to services.
- There are too few acute mental health beds; there is nothing available for older people in crisis (e.g. people with dementia)
- The Trust currently has an in-reach Psychiatrist (0.5 fte) who undertakes ward assessments and this has unmasked an even greater level of need.
- The Trust working to adhere to national standards for in-reach into acute care for the Mental Health Liaison Service and is currently employing 2 mental health nurses, one for older people and one for people with dementia.
- The Liaison Service is provided by NSFT and should be available 24/7 (365 days a year) but the hospital faces issues with both recruiting and retention of staff.
- For families living some distance away, there are numerous unresolved issues surrounding cognitive impairment.
- The hospital faces issues of having to work across 3 mental health trusts, 25% of its patients come from Fenland, 10% from Lincolnshire and 65% from NSFT.

These issues can be resolved, potentially using these approaches

- QE are hoping to become an accredited provider of the Psychiatric Liaison Accreditation Network (PLAN). The Psychiatric Liaison Accreditation Network (PLAN) works with services to assure and improve the quality of psychiatric liaison in hospital settings. PLAN engages staff and patients in a comprehensive process of review, through which good practice and high-quality care are recognised and services are supported to identify and address areas for improvement. Accreditation assures staff, patients and carers, commissioners and regulators of the quality of the service being provided. PLAN includes core areas common for all teams, such as assessment and care planning, but also recognises that some areas
may be outside a team’s remit. This means that a small but well-functioning team can still be accredited in the domains that it is measured against

- Resourcing the Mental Health Liaison Service so it is able to operate 24/7 (365), with appropriate consultant and associated junior cover.
- Building capacity into the existing system for the provision of a “frequent attender clinic” - A&E department are able to identify the frequent attenders.
- Overcoming the barrier of IT systems that cannot share/transfer information, through provision of a patient record system that speaks to other services systems as the hospital is currently unable to access Care Plans.
- Ensure that those who are providing drug/alcohol services have appropriately qualified personnel required to provide a quality service (i.e. people need to be clinically qualified). There is an increased risk and associated drain on acute services as doctors are unwilling to discharge where services are “not fit for purpose” in the community.
- Closer integration with GPs - teams seem to have “retreated” into Chatterton House rather than going directly into GP surgeries - reintroduce CPNs.
- Improve the current A&E Assessment are for mental health patients - the hospital currently doesn’t meet required standards.
- Consistency in staffing (retention of staff) is especially important in management teams.
- Consider the introduction of a Personality Disorder Pathway - the increase in the number of deaths across Norfolk and Suffolk suggest that this is of paramount importance.
- Mandatory GP Training in mental health and increased training for nurses coming out of university training programmes.
- Mental Health Nursing Training needs to go back to learning some basic principles rather than being so theoretical.
- Increase availability of intermediate care beds - Hertfordshire was considered to be operating well in this respect.
- Hypothetical merger of the two community trusts, NSFT and NCH&C
Results of a service user and carer questionnaire

As part of gathering mental health service user and family carer views on crisis service use, Healthwatch Norfolk launched a survey called “Getting the help you need during a mental health crisis” in February 2017. The survey was closed on 17\textsuperscript{th} May 2017 and a total of 161 responses were received; 137 via SurveyMonkey\textregistered{} and 24 paper questionnaires returned using our freepost envelopes. Sixteen respondents had not experienced a crisis within the last two years and therefore their responses were not included in the analysis.

Eighty eight respondents said they were a mental health service user and 57 said they were a carer of a person using mental health services. Fifty three service users were female and 27 were male, the remainder preferred not to disclose their gender. Their ages ranged from 18 to 70 years and their average age was 47.

3C1. Mental health service users views and experiences

All of the mental health service users responding to our survey (100\%, 88 in total) said that they had experienced a crisis in mental health within the last two years. Just over half of them said that they were mostly able to plan ahead for times when their mental health was worse (please see Fig 1 below).

**Fig 1. Response of 83 service users to the question “Are you able to plan ahead for when your mental health gets worse??”**

We asked mental health service users if they had a plan in place to help them (and others) know what to do in a crisis. Slightly less than half responded that they did not have a plan but wanted one (please see Fig 2).
We asked people if they knew who to contact outside of office hours if they had a crisis:

- 30 (34%) said “yes”
- 41 (47%) said “no”
- 17 (19%) said “not sure”

We then asked if people had got the help they needed outside of office hours. The responses of 88 mental health service users are shown in Table 1, showing mixed experiences. Thirty eight (43%) had not tried to contact a service out of office hours whilst 9 couldn’t make contact. Sixteen people (18%) said they did not get the help they needed, 17 (19%) did get help to some extent however only 8 (9%) of service users said they had got the exactly the kind of help they needed.

Table 1. Response of 88 mental health service users to the question “The last time you contacted them, did you get the help you needed?”

<table>
<thead>
<tr>
<th>Answer option</th>
<th>Number (%) of mental health service users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, completely</td>
<td>8</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>17</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
</tr>
<tr>
<td>I could not contact them</td>
<td>9</td>
</tr>
<tr>
<td>Not applicable as I haven’t tried to contact them</td>
<td>38</td>
</tr>
</tbody>
</table>

The kinds of services that people had used during a mental health crisis, along with their view of the treatment and support they received, are shown in Fig 3 overleaf.
Fig 3. Responses of 88 mental health service users to the question “Have you recently received treatment and support for a mental health crisis from any of the services listed below? For each service, please choose the option that best describes the service you received…”
In our sample of respondents, 13 were receiving support from paid carers in their own homes and 5 had lived in residential care within the last two years.

GPs are the professionals that the majority of mental health service users have approached at times of crisis, with over 60% of those using their GP service indicating their treatment and care was quite good (21 people) or very good (27 people). Around 40% of survey respondents - 33 individuals - had used a community pharmacy during a mental health crisis and 28 out of the 33 said their treatment and care there had been either “quite good” or “very good”.

Seventy percent of service users had received treatment and care from community mental health services and 24% from in-patient treatment and care. Sixty six people out the 88 had used community mental health services. Of those 66, 10 said their treatment and care was “quite poor” and 14 said it was “very poor”. Fifteen people said it was “quite good” and 5 said “very good”.

Ambulance services (999 calls) and hospital A&E departments were the two services where mental health service users used more positive ratings describing their treatment and care; no service users rated their experiences as “very poor”.

A fairly small proportion of survey respondents had encountered the police during a mental health crisis; 19 out of 88. Of those 19 people, 12 said their treatment by the police was either “quite poor” (2) or “very poor” (10) however 3 said it was “quite good” and 4 said “very good”.

During a time of mental health crisis, our survey respondents were using their GP, community mental health or community pharmacy services.

3C1.1 What has worked well for mental health service users?

We asked service users to tell us about any service they’d used during a crisis that they found especially good at giving them the help and support they needed. Sixty five people gave us examples. People gave these services between 3 and 5 stars for the quality of service they’d received (with 1 star being poor and 5 stars being excellent). Many gave more than one example of a service that they’d found really supportive.

These are the services that people described [and the number of people describing that particular service is shown in brackets]:

- My own GP [17 people]
- Community, voluntary sector, charitable organisations [23]
- Community mental health teams and professionals [7]
- The Wellbeing Service [5]
- Crisis teams [4]

People had positive comments to make about their experiences with their GP. There was also some indication that whilst a GP could be supportive and attempt to make an appropriate referral, often other services were slow to respond or the response was disappointing.
Here are some examples of what people said:

“My GP. He has been nothing short of spectacular. He has done more for me than the so-called “specialists” at the Wellbeing Service, who have, and I’m being kind here, been dire”

“GP explains well, considers physical alongside mental implications, follow up support”

“GP listened and responded. Kind”

“I tend to see the same GP who knows me and who is supportive. She seems to understand me and works with me”

“NHS doctors surgery, good advice and tried to refer to other services”

“GP always responds well but the problems are with those he then goes to, to get me help”

“My GP was the only person to help because the mental health teams are so backed up it took 8 months before I saw anyone!”

“My doctor as he knows all about my mental health and they are very good treating me”

“My GP is very good and always takes time to listen to me. This is not the case for everyone I know, through listening to other people’s bad experiences”

Some people rated the community mental health teams, the Wellbeing Service and Crisis Teams as very good but a few also highlighted there have been changes to local service provision which they felt had a negative impact on their care:

“NHS Wellbeing courses. Took me a while to book into one that was nearby but was worth the wait. Didn’t realise how much it helped me till after recovery”

“Referred by GP to wellbeing service after admitting I was planning suicide. Wellbeing service chatted with me, listened, ensured I was safe and arranged help for me”

“Crisis Team at Northgate Hospital. Provided regular visits to monitor my manic episodes”

“Crisis Team for King’s Lynn. They just really helped me at the time”

“Crisis Team, they get back to me quickly and listen”

“I used on call at Victoria House in Lowestoft and the psychiatrist”

“the CPN listens to you, are helpful and don’t judge you”

“had a very good CPN (Community Psychiatric Nurse)”

“my Mental Health Support Worker based at Long Stratton, but no longer available due to cuts but with me for years!”
Other services that mental health service users mentioned as being particularly good at providing the right kind of treatment and care were:

- A self-funded, private mental health service [2]
- Social services [2]
- The A&E department at the James Paget University Hospital in Great Yarmouth [1]
- My family and friends [1]
- NHS 111 [1]

Charities were described as providing the right kind of help and support needed during a mental health crisis and the examples given are shown in the list below:

- Norwich & Central Norfolk MIND crisis helpline [5]
- West Norfolk MIND [3]
- Feedback Health, Great Yarmouth & Waveney [3]
- Pathways Care Farm [3]
- Stonham Housing [1]
- Rethink Mental Illness [1]
- Survivors Unite [1]
- Opening Doors [1]
- British Heart Foundation Health Trainers [1]
- Samaritans [1]
- St Barnabas Counselling Service [1]
- Leading Lives [1]
- The Matthew Project [1]
- Together [1]

Here are some of things people said about these charities:

\"the mental health charity MIND. Especially the helpline they run for Norwich and the surrounding area\"

\"mind emergency helpline because they just listened and didn’t ask too many questions and I didn’t feel like they were judging me\"

\"West Norfolk MIND, very friendly staff and open atmosphere\"

\"Samaritans - always available anytime, immediate response, albeit anonymous and distant\"

\"A charity called Opening Doors who have advisors there who have previous social services background who were able to spend time with me and listen to my issues and helped as much as they could for me to come to terms with what was happening at that time\"

\"Pathways Care Farm is very good. I enjoy working with the animals and get on well with everyone it always makes me feel better\"

\"Survivors Unit ring me once a fortnight to see how I’m feeling. Plus I have a group meeting 1st and 3rd Monday of every month\"
“Feedback Health drop-in and peer support”

“Feedback Health group, it helps you to feel less anxious and worried. I can talk to people”

“St Barnabas Counselling Service. My counsellor was consistent and didn’t keep letting me down”

“Matthew Project…acted quickly, worked alongside me...encouraging...workers showed empathy and really listened to my needs. I felt services were tailored for my needs”

In total, 10 service users said all the services they encountered over the last two years had been good and none needed to improve.

3C1.2 What needs to be improved?

Some 57 service users made a variety of comments about services they had used which they felt were poor at giving them the kind of help and support they’d needed during a mental health crisis. These were the sorts of services that people were likely to rate as 1 star - poor - service.

These are aspects of services that people described as needing improvement [and the number of comments describing that particular issue is shown in brackets] which can broadly grouped as following:

- Poor quality of service provision: services not offering the kind of support that people wanted [20]
- Lack of empathy displayed by service professionals and/or practitioners [20]
- Poor communication and/or information [11]
- Long waiting times [7]
- Access barriers [7]
- Medication failures [2]
- Public stigma and assumptions [1]

Some users named specific services they had used and thought could be better:

“Airey Close Assessment Centre, there was no continuity regarding consultants”

“The wellbeing service has been utterly useless....Treatment cancelled on the day it was supposed to start and left with no support from them for 4 months”

“Crisis Line at Carlton Court did not help at all”

“Hellesdon Hospital out-patients with a psychotherapist”

“The Police. They were clueless, did not listen to anything I said and left me alone having poisoned myself with alcohol and prescriptions. They did not even call paramedics to check me out even though I have cancer and a heart condition and had taken 60 pills and drank a large amount of alcohol”

“The Wellbeing Service. Rushed me to answer questions. Finished off my sentences (inaccurately)”
“NSFT. Watching television is not a cure, having no one answer the phone is no help. Mindline, endless time on hold is distressing and they can do nothing. CMHT duty desk, only know what is written, if it’s inaccurate - pointless. They do not act if your worker is away or in meetings, returned calls from CPN come days later. Tell them you are suicidal and they do nothing”

“Crisis team. They need to actually care and give help rather than get back to you days later to check on you, if at all”

“A&E at the N&N was horrendous because it was a weekend and very busy. It was noisy and people were crying and I just couldn’t stay in there and I left before they called me in I was waiting a long time”

“I rang the crisis line but was made to feel I had interrupted their tea”

“NHS Mental Health Team. Failed me for 17 months and still are”

“CRHT…from one meeting assumed I had a diagnosis that I don’t, wrote it in my care records and discussed it with the team”

There were several comments about not being able to get the right help at the right time and the perceived quality and appropriateness of the response. Here are some examples:

“Mental health team, total lack of reliability, don’t do what they say they will and do not coordinate about my care with the other agencies involved”

“I needed and need help desperately when I am suicidal. I get nothing. I tried and tried and gave up in the end as all the refusals of care and broken promises made it worse”

“Now I have been discharged and now I don’t know where to go”

“My problem is static because this Norwich council have not listened to my problems about the noisy neighbour in my block. The end result and resolution is I am going to have to move into sheltered housing in order to protect my physical and mental health”

“No, I have been refused any help by the mental health services”

“Last time I needed a bed in the hospital at Great Yarmouth they told there wasn’t a bed and I didn’t it but my girlfriend was worried about me coming home straight away and she said she couldn’t do everything to look after me”

“Sadly no help”

“I don’t want to contact local NHs services”

“None were any good I gave up in the end and stay alone at home most of the time”

“I once took an overdose 3 years ago because the police kept invading my privacy over a neighbour dispute, and police kept harassing me despite orders...not to do so”

“The wellbeing service based in Cathedral Close, two really good sessions but staff went sick and was never given another appointment/referral”

“Wellbeing workshops on Providence Street were disrupted by a delegate’s uncontrollable 2 year old son. Should have been asked to leave”
“I’ve complained and asked for less bank staff and more full time employees”

“I was not happy with the support I was getting from my GP so I registered with a GP in the same catchment area from where I lived. I discovered that, on telephoning them, that they had taken my name off their books very suddenly without the decency of letting me know, so my new GP has been much better but had there not been another GP in that immediate areas, my subsequent health and care would be substantially jeopardised”

Mental health users described a lack of empathy and understanding displayed by some of the professionals and practitioners that they had encountered when using services:

“I have visited my GP who does not seem to understand my mental health”

“Social services just do not understand people”

“GP and police. Chucked in a cell and left and they turned the bell off”

“GP did not care. Put me on tablets straight away and did not chase up”

“My GP. Tired burnt out uninterested cold rude”

“CRHT didn’t appear to care. Didn’t listen. Didn’t understand my distress. Didn’t attempt to understand my distress. Not empathetic about how distressed I was about my psychotic symptoms. Judged me. Misunderstood me”

“Crisis team, I was told to have a bath when feeling overwhelmingly anxious, which does not help”

“NHS hospital psychologist, they told me they couldn’t help me unless I was slitting my wrists”

“Statutory secondary mental health services. Unresponsive, uncaring, seems as though staff have given up, danger to self not enough to warrant a service, need more staff with much better training. A first class degree does not make a first class nurse. More proper counsellors and psychotherapists and psychologists, not psychiatric trained nurses doing therapy on the cheap without the right training, they don’t have rigorous training and development and operate under different ethical guidelines. Less CBT, it’s not a panacea. Turning someone away when they still have insight, have doubts about their psychotic experiences and are able to ‘engage’ is ridiculous. Waiting until insight is lost means recovery and treatment take much longer”

Some service users highlighted that limited information and poor communication from services as well as between services was something requiring improvement, for example:

“Services chose not to let me know the outcome, repeatedly. Repeat decision: can’t be bothered to help”

“Information about the service has been poor and I need better information”

“Misinformation - told would get treatment then found out on waiting list. Now no contact. Heard nothing - crisis flares getting worse. No one to contact”

“Wellbeing gave wrong information”
The length of time spent waiting to get help and support at times of crisis was another area that service users chose to comment on, for example:

“Chatterton House King’s Lynn I waited almost 20 months for a consultation got a ten minute chat with a ....doctor and nurse present he was in a hurry and I couldn’t understand his accent I have serious mental health issues the service was disgraceful I felt absolutely deflated and helpless I still do”

“The NHS mental health team. Waiting one year for help, but never got any. Referred THREE times in a year by my GP asking for help. Wasn’t until I tried to kill myself they decided I was ill. Had two one hour appointments, then left AGAIN, even after we agreed to meet weekly. It’s an appalling service, not fit for purpose”

“It took 8 months from referral to be seen at Hellesdon and I was meant to have a follow up 3 months later which was meant to be last March (2016) and I’ve still not heard anything from them. I was at crisis point at time of referral!”

Other service users commented on the barriers to accessing services at times of crisis:

“Never able to access anything”

“difficulty in accessing a social worker due to cuts in local government services”

“couldn’t get to see my GP, A&E just wanted to get rid of me”

At the end of the survey, we asked service users if they had any other comments they wanted to make. Forty eight people chose to leave additional comments and the nature of their comments can be broadly grouped together as follows [with the number of comments in brackets]:

- Services are failing people: they are left feeling bad about themselves, they feel let down [18]
- Strongly positive comments about individuals (e.g. staff) who have made a big difference to people’s care and treatment [13]
- Having family, friends, family carers, peer support groups and networks can be really important [10]
- People in front-line services need to have the right personal attributes; to be kind, caring, able to listen and empathise [8]
- Care and treatment needs to holistic and consider a person’s physical and mental wellbeing at the same time [4]

Services are felt to be failing people when they are at the greatest time of need, for example:

“Not listened to when you tell them what you’re going through. Not enough support from care coordinators and doctors at mental health services. No consistency with staff. No one in the job long enough to receive the right support”

“There is no help. I have made detailed plans for suicide. I have no help, no family, nothing. I have been left to sink or swim. It is like there is no NHS at all”
“NSFT make you feel worthless. Samaritans can only listen and that is if you can talk. No hope for those with mental health issues. No contact services for months and now they have changed teams around again. GP is constantly wasting time chasing them. They have failed so many, I wouldn’t have believed the stories if I had not experienced them”

“Would rather cope alone than ever go through wellbeing again caused me and my family so much stress with misinformation”

“Doctors I attend are horrible went there for an emergency due to a break down that was being caused by threatening behaviour doctor told me it was all in my head and basically put up with it and gave me no further help”

“Contact in PALS failed to return my phone call...NHS Mental Health Team the biggest disgrace of them all. 17 months of hell. Referred 3 times by GP, no help until I tried to take my own life. After a further three and half week wait I get a care coordinator. I had two appointments with her and one with a psychiatrist and I’ve not seen anyone since November 2016”

“I’m too ill to keep writing but my experience was dreadful after all the waiting I got almost no help or support and had to squeeze a lifetime of abuse and depression into ten minutes”

“all very poor or non-existent”

Having family, friends or some kind of social or peer support network can be really helpful; in fact some service users rely heavily on their family, friends and support groups to see them through times of crisis. Here are some examples of the comments we received about this kind of support:

“My family especially my wife helps me through the bad days, I have had mental health issues all my life, been on medication through the doctors but it is the family who are there for me”

“I go to the Feedback drop in every month which are very helpful and I enjoy attending”

“The charity Feedback are helpful”

“I am cared for by my son as I suffer from depression”

“Just the mental health drop-ins are really good”

“have never used a crisis team but have heard they are not very supportive and they should do more, maybe a better idea would be an upgrade from peer support to peer mentoring instead of crisis”

“I just wish there was more help for my family as they do not always know what to do when I have a melt down we do not like to ask. If they had some training on what to say to me that would help”

Some people said that using services leads to them feeling bad about themselves and in ways worse than they already feel. Also, it is very important that the people working in
the services have the right kind of personal attributes as well as the right kind of professional expertise and experience:

“I don’t feel the doctors are interested in my mental health”

“Nurses need extra training in confidentiality. Services still too biomedical. All staff on wards need training in active listening and core conditions. Nearly all need to learn common courtesy. Maybe if they had lower caseloads they might be able to care”

“Confusion being passed between teams”

“You have to get to see the right person otherwise they might not take you seriously and they don’t listen properly. Sometimes people don’t even look you in the face when you’re talking to them and it makes you feel like you are nothing to them. Please don’t treat people like that”

The response of services and individuals is extremely important and some mental health service users have given examples of times when services worked well or when one person was particularly receptive, empathetic or effective:

“Senior Practitioner and Carers Lead for NSFT is a good source of support”

“Wellbeing have been fairly supportive”

“the doctor in A&E was very patient and the nurses were nice….especially good to me”

“my nurse in the Crisis Team is great”

“My PA’s are excellent, having PIP allows this and it has probably saved my life on several occasions”

“Consultant Psychiatrist - extremely good”

“Am having CBT at the current time which has proved really useful”
3C2. Mental health carers views and experiences

Fifty seven respondents to our survey said they were a family member, carer or friend of a person who’d experienced a mental health crisis within the last two years. Regarding planning ahead, just over half (53%) said that the person they cared for were not usually able to plan ahead for times when their mental health was worse (please see Fig 4 below) and a quarter (27%) simply said “no”.

![Fig 4](image)

**Fig 4.** Response of 51 service users to the question **“Thinking about the person you care/cared for, are/were they able to plan ahead for when their mental health gets worse?”**

We asked mental health carers if the person they cared for had a plan in place to help them (and others) know what to do in a crisis. Four in ten (39%) responded that their cared-for person did not have a plan but wanted one (Fig 5).

![Fig 5](image)

**Fig 5.** Response of 57 carers to the question **“If you feel that your mental health is getting worse, or a crisis is building up, do you have a plan in place to help you and others know what to do?”**
Nine carers said that their cared-for didn’t have a plan in place but neither did they want a plan. Four carers said that their cared-for had a plan in place for times of crisis and they had used it and 9 said they had a different way of planning ahead.

We asked carers to tell us if they knew who to contact outside of office hours if the person they cared for had a crisis:

- 23 (45%) said “yes”
- 18 (35%) said “no”
- 10 (19%) said “not sure”

Those people saying “yes” were asked to describe who they would contact in an emergency. Here are some examples of what people said [with the number of comments on a similar service or theme in brackets]:

- Mental Health Crisis Team/Crisis home Resolution Team (CHRT) [7]
- Call 999 [4]
- GP [2]
- The Police [2]
- Go to the A&E department [2]
- Telephone the MIND Helpline [1]
- NHS 111 [1]
- Care Agency [1]
- No-one [1]

“GP or 111”
“999 or the Crisis Team”
“CHRT or EDT”
“Crisis team if the service user is on a small list. Police welfare check or ambulance (situation dependent) if not”
“...our GP and the specialist community psychiatric nurse if really needed”
“No point in contacting anybody. A&E makes it worse. We are dealing with every crisis on our own now and have some private support but not in crisis”

We then asked if people had got the help they needed outside of office hours. The responses of 57 mental health carers are shown in Table 2 overleaf, showing mixed experiences. Ten (17%) had not tried to contact a service out of office hours whilst 3 couldn’t make contact. Twenty carers people (35%) said they did not get the help they needed, 19 (33%) did get help to some extent however only 5 (9% of carers) said they had got the exactly the kind of help they needed for the person that they care for.
Table 2. Response of 57 mental health carers to the question “The last time you contacted them, did you get the help you needed for the person that you care/cared for?”

<table>
<thead>
<tr>
<th>Answer option</th>
<th>Number (%) of mental health service users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, completely</td>
<td>5</td>
</tr>
<tr>
<td>Yes, to some extent</td>
<td>19</td>
</tr>
<tr>
<td>No</td>
<td>20</td>
</tr>
<tr>
<td>I could not contact them</td>
<td>3</td>
</tr>
<tr>
<td>Not applicable as I haven’t tried to contact them</td>
<td>10</td>
</tr>
</tbody>
</table>

Carers told us about the kinds of services that those they cared for had used during a mental health crisis, along with their view of the treatment and support that person had received. The responses of 57 carers are shown in Fig 6 overleaf.

In our sample of 57 carers, 9 said the person they cared for were receiving support from paid carers in their own home and 6 said the person they cared had lived in residential care within the last two years.

Cares indicated that GPs are the professionals that the cared-for approaches at times of crisis, with over 43% of carers saying that the GP’s treatment and care was quite good (6 people) or very good (11 people). Unlike the mental health service users responding to our survey, carers find GPs services to be less favourable (i.e. 60% of service users say the GPs treatment and care is quite good or very good as opposed to 43% of carers). Around 50% of carers indicated that the mental health service users they cared for had used a community pharmacy during a mental health crisis and three quarters said the treatment and care received there had been either “quite good” or “very good”.

Next to GP services, carers indicated that mental health service users are receiving treatment and care from NHS mental health services in a community setting. Carers indicated that eighty percent of mental health service users had received treatment and care from and NHS community mental health service and 47% from an NHS in-patient treatment and care. Again, whilst the actual numbers of responses are similar between mental health service users and carers, the percentages are higher, suggesting that carers have a different perspective on mental health services used by those they care for. They are less likely to view the treatment and care of the mental health service user by community services as good. For example, nine carers said the treatment and care of the service users in NHS mental health services in the community was “quite poor” and 15 (35%) said it was “very poor”. Four carers (9%) said it was “quite good” and 4 (9%) said “very good”.

Ambulance services (999 calls), the GP, community pharmacy, the police and hospital A&E departments were the services where carers considered mental health service users had the most positive experiences of care which was quite good or very good.
Fig 6. Responses of 57 mental health carers to the question “Has the person you care/cared for recently received treatment and support for a mental health crisis from any of the services listed below? For each service, please choose the option that best describes the service they received…”
Fifteen carers had encountered the police during a mental health crisis; out of 57 in total. Of those 15 carers, just 1 said the treatment of the mental health service user by the police was “very poor” whilst however 6 said it was “quite good” and 8 said “very good”.

During a time of mental health crisis in the person they are caring for, carers said they were turning to the family GP, community mental health services, A&E and ambulances (999 calls) for treatment and care.

3C2.1 What has worked well for carers of mental health service users?

We asked carers to tell us about any service the mental health service user had accessed during a crisis that they considered especially good at giving them the help and support they needed. Thirty seven carers gave us examples, giving these services between 3 and 5 stars for the quality of service either they or the mental health service user had experience (with 1 star being poor and 5 stars being excellent). Some gave more than one example of a service that they’d found really supportive and some chose to name both services and individuals that they had felt to be very good indeed.

These are the services that people described as providing a particular good service are listed below [along with the number of people describing that particular service is shown in brackets]:

- NHS community mental health teams and professionals [7]
- NHS in-patient mental health services [5]
- Social care services e.g. social workers [5]
- Ambulance (999 calls) and paramedics [5]
- Community, voluntary sector, charitable organisations [5]
- GP [4]
- Crisis team [3]
- Police [2]
- A&E [1]
- Health Visitor [1]
- Care Agency [1]
- Private mental health counselling service [1]

Some carers felt that NHS mental health services were very good at helping during times of mental health crisis in the service user, and gave the following examples of community and in-patient services:

“St Catherine’s Step Up Step Down Unit”

“Northgate Hospital and St Catherine’s”

“Hellesdon”

“We had a good CPN who was marvellous, very understanding and empathetic, helping us to make our own decisions”

“CPN. Got to know him and we had the same lady all the time. Which really helped him move on”

“NSFT Great Yarmouth and Waveney Youth Team”
“The Crisis Team”

“The Crisis Team at Hellesdon, however it can be hit and miss depending who is on shift”

“The local medium secure unit which was extremely caring to the carer as well as client and also support from the consultant”

“Psychiatrist and mental health practitioner had supported my daughter following suicide attempt were person centred and responsive to her needs. Being able to meet where was mentally and literally in the community at home or for a coffee made a massive difference rather than clinic based. They also included family as part of her care plan and we felt more resilience to manage her chronic episodes”

Other NHS services that were considered to be providing the right care included ambulance services and paramedics, GPs and A&E, for example:

“The ambulance service tried everything they could not have to take my mother to A&E as they recognised it was not the right solution for her”

“paramedics outstanding”

“GP who understood the problem”

“GP listens to us and doesn’t use a computer when talking to us, gives us advice”

“GP explored symptoms and gave referral pathways which were helpful, making the person feel like there were options”

“The A and E nurse was brilliant...my girlfriend had taken all her pills, paracetamol and vodka. They knew what to do”

“My wife’s Health Visitor was amazing and put us in touch with the specialist team as soon as I noticed my wife didn’t seem well or usual self after the birth of our son 13 months ago. She had post-natal [depression] quite badly and we never expected that all”

Social care services and professionals were also referenced, for example:

“social worker listened”

“Asperger Service Social worker, although over stretched, gave excellent help and support at times when no one else was able/willing to”

“The Hospital Social Work team were very helpful once I had managed to get my mother’s case referred to them”

Carers also mentioned some charitable organisations were providing the right kind of help and support needed during a mental health crisis and the examples given are shown in the list below:

Julian Support, Ashcroft Residential Unit [1]
3C2.2 What needs to be improved?

Some 48 carers made a variety of comments about services which they felt were poor at giving the kind of help and support a mental health service user needed during a mental health crisis. These were the sorts of services that people were likely to rate as 1 star - poor - service. Most carers chose to comment on more than one kind of service.

The services that carers considered to be providing a poor service can be grouped together as:

- NHS community mental health [25]
- NHS in-patient hospital [10] and the Crisis Team [12]
- GP services [8]
- Social services [4]
- A&E [2]

Some users named specific services they had used and considered to be in need of improvement:

“Wellbeing”

“NHS hospital outpatients. Funding withdrawn so was unable to complete treatment. Absolutely no follow up. We had to manage on our own”

“NSFT, a completely useless service, no help in a crisis. Had to make a formal complaint to NSFT. Private and confidential letter from them sent to the wrong address!”

“In-patients at Carlton Court”

“Mental Health Assessment Team”

“CAMHS service in Great Yarmouth; needs complete overhaul of staff, services and buildings”

“CDHRT have too big a caseload”

“NSFT Crisis service were rubbish”

“I am not impressed with NCC Occupational Therapy”

These are aspects of services that carers described as needing improvement [and the number of comments describing that particular issue is shown in brackets] which can broadly grouped as following:

- Poor quality of NHS mental health service provision [21]
Regarding the quality of mental health service provision, carers had quite a bit to say on this subject. Some made references to the cuts in funding that had been imposed upon local services and expressed their views on the impact of that. Others found fault in specific aspects of the service that meant the person they cared for hadn’t received the best kind of help and support (and oftentimes, neither had they. Here are some examples of comments on the quality of service provision:

“The help afterwards were more or less non-existent”

“Social work department appeared to be lacking in knowledge and confidence”

“Wards are too busy to respond to patient’s needs. Quality of care has dramatically reduced over the past year. CRHT have too big a caseload to be able to respond in a way they wish. Also, not enough mental health beds for crisis”

“Crisis Team, they were supposed to see him in hospital but didn’t turn up”

“The crisis team are great once you are in the service but so poorly resourced meaning they cannot cope with demand, which is of little comfort to those experiencing crisis or caring for them. From experience I believe discharge from in-patients facilities is often too soon resulting in a return of the patient being readmitted only a week later”

“One of my clients was admitted to A&E 3 times over a 24 hour period, including 2 attempts on taking their own life, this resulted in them finally being sectioned and receiving in patient support. This was very effective but was only 48 hour follow and no community support put in place, resulting in re-admission after the referral process starting again a few weeks later. This to me is not cost effective or support enough for these individuals”

Some carers described a lack of empathy displayed by the professionals and practitioners they’d encountered, for example:

“Psychiatrist from Lowestoft was not helpful”

“our GP was mean and harsh”

“The crisis team. Didn’t respond for over a week, despite two calls from GP. Advice given over the phone was ‘Ah bless. Have you tried painting her nails’?”

“GP not at all understanding some just give out pills”

“NSFT - had no time for the person whatsoever”

“GP dismissive. Ambulance service were laughing at person in distress once dropped off at A&E but I over-heard and was in area open to public and staff. Only one nurse (not mental health) was understanding, caring and calmed situation. Other staff managed to escalate distress by interpreting behaviour as aggressive and responding in abrupt and empathetic way”
"The Crisis team may have been very supporting of my husband, but were very dismissive of me, to the point of being rude in making me feel unwelcome in my own home!"

Poor communication was a problem raised as being in need of improvement, for example:

"Communication between the mental health team and GP"

"Services disjointed, poor communication, at some point seemed ‘lost in the system’. Eventually put on a waiting list for ‘fuller assessment’. Has waited almost 12 months, no contact from them, however we kept updating them. Recently out of the blue, with no further discussion an appointment with an EMDR Therapist. Daughter is attending but questioning her diagnosis and whether this is actually the appropriate treatment for her! Things had been settled before NHS appointment was sent. Not so much now. Needless to say, no contact with parents, no introduction as to why and how treatment was chosen...I think everybody has a right to be fully informed and involved in any choices made about their treatment.”

"On admission to hospital the lack of communication and consistency caused a lot of problems"

"Social service Swift team just referred me to the police when I made the emergency call without explanation. Then when police and ambulance came they spent 5 hours trying the necessary information from Social Services to help my mother. Surely once emergency services are involved there should be a fast track system to avoid these overworked people having to make repeated phone calls for up to 5 hours before getting a response, which in any case offered them no support whatsoever, so my mother ended up in A&E”

Others describe a frustrating route and wait before the person they care for could either access or receive the right kind of help:

"We once tried calling our GP one Saturday evening which wasn’t straightforward. I had to speak to many people until someone called us back and asked me lots of questions. They wanted to speak to my wife but she wasn’t up to answering, she was very confused, she wasn’t eating as she was paranoid that someone was trying to poison her and she was having hallucinations about our baby. It was stressful and she was absolutely distraught. Getting hold of the right person during the weekends is probably the most difficult thing. I appreciate that NHS staff need time off too but there are some services which need to operate around the clock - many other businesses and services do as a matter of course and the NHS needs to catch in that respect. We got there in the end and this was never about me because the needs of my wife and our son came first for me but there was no one to give me any advice, help or support although our families stepped in to help after a few days, which made a huge difference. Sometimes different people visited her which seemed to add to her confusion and it didn’t help because she didn’t always trust them.”

"Mental health crisis so bad I and 2 friends took shifts to watch the person so they did no harm to self or others"

At the end of the survey, we asked carers if they had any other comments they wanted to make. Thirty seven people chose to leave additional comments and the nature of their
comments can be broadly grouped together as follows [with the number of comments in brackets]:

- People feel let down by services [23]
- Cuts to the funding of mental health services are having a negative impact upon responsive and the quality of mental health service provision [10]
- A&E departments have a role to play in mental health crisis pathways [4]
- Community and voluntary sector organisations make a valued contribution to the crisis care [4]
- Limited understanding of a carer’s needs

Carers used this opportunity to say that they feel they do not get any help from services at times of mental health crisis in the person they are caring for. They describe feelings of helplessness and isolation. Some carers felt very let down by services and that services had failed people at times of crisis when they were most in need. Here are some examples:

“None, no help, my son was threatening suicide eventually diagnosed with ADHD which he hasn’t got”

“No, it seems as though patients are pushed from pillar to post until someone claims responsibility, resulting in an expensive and often late intervention”

“Awful no help”

“No, service has not been good”

“No help when needed”

“Did not know who to tell this time when the person I care for was unwell”

“More help from all services”

“My mother committed suicide due to the lack of support from her GP and Mental Health Services. As someone with an extensive mental health history she was treated as a nuisance and after trying to commit suicide twice was sent home from hospital with no after care/follow up. No family members were informed of this and we strongly believe that if we had been informed, the outcome would have been different. I also believe that people should not have to be on an average of a 6 month waiting list to be seen by a Mental Health professional. Myself and my family are devastated by the loss of my mother and are appalled at the way she was treated by her GP and Mental Health Services.”

“I could write a book I do not know where to start”

Some carers said they thought that a series of cuts to the amount of funding that services received have put services under pressure which led to a lack of staff, longer waiting times and the ability to deal with only the worst of emergencies:
“I feel NSFT are under a lot of pressure and this shows through the care they are able to provide, this is not to the fault of each individual but as a whole organisation. Because of cut backs, NSFT are not able to provide the quality support to each individual they care for, but instead have to prioritise their time to those who have already reached crisis point instead of preventing and supporting those who are reaching crisis point”

“Statutory crisis provision currently suffers from a lack of adequate funding and preventative reach, meaning safety suffers. It features out medical/business-based models of treatment and in places a lack of evidence-based practice”

“Mental health services seem to be doing their best but there doesn’t seem to be enough staff on every shift to get to people in good time. There is too much waiting involved. We are both well-educated and appreciate there are many other people needing care as well as us, but when you are talking about a new mum and a tiny infant, help is needed fast.”

“The community psychiatric nurse service has been cut, they say I’m doing better but cuts to service. Just as the support is helping me, it is cut. I am a greater risk of a crisis without my CPN or friends”

A small number of carers [4] said that A&E was an important service as that was somewhere that service users could go to for help (although the views on help were mixed):

“A&E staff need mental health training. Peer support workers should be in A&E and all crisis services”

“The person I care for was taken to A&E and left on a trolley for three hours until seen for a mental health assessment. He could have walked out of A&E any time and under a bus, dreadful for someone in acute distress. Though he would have been put in a safe place at A&E not just left in corridor”

Other carers wanted to say how helpful and supportive community and voluntary sector organisations had been, in addition to those providing specific support to carers:

“the MIND helpline people are very kind”

“the carers lead from NSFT and the Great Yarmouth and Waveney MIND carers group are all very positive”

“I like Feedback drop in because it helps to prevent crisis”

3C2.3 Mental health service user and carer service summary

As described, we asked mental health service users and mental health carers to rate their experiences of using services during times of mental health crisis. Their combined responses are shown overleaf in Fig 7. Service users and carers were more likely to rate GPs, community pharmacies, A&E and the ambulance service as “very good” or “quite good”.
Fig 7. Responses of 145 mental health service users and carers to the question “Has the person you care/cared for recently received treatment and support for a mental health crisis from any of the services listed below? For each service, please choose the option that best describes the service they received…”
3D. Norwich and Central Norfolk Mind Mental Health Support Line: Audit of Data on Users, Call Nature, Demand, Resources and Call Outcomes

Produced by Benjamin Marshall, Support Services Manager at Norwich and Central Norfolk Mind for Healthwatch, March 2017.

Executive Summary
This report details the context of the support line project undertaken by Norwich and Central Norfolk (NCN) Mind. After detailing the line’s background and the nature of its service, the report gives statistics regarding the caller base of the service, the nature of calls to the line, patterns in demand, the staffing resource available, and call outcomes and results.

Background
The NCN Mind Support Line was set up in 2015 as a pilot using newly available winter resilience funding from commissioners. After a demonstrably successful six month pilot and considerable service user acclaim, the line was refunded by NSFT for a further six month period. An extensive media and service user campaign followed to have the line reinstated on a more permanent basis, and after negotiation it was agreed that the service would be merged with an existing Wellbeing advice line, extended to all Wellbeing service clients, and run as a single service incorporated into contracts for the Wellbeing service until August 2020.

The support line provides crisis de-escalation, advice and guidance for other services, emotional support, and a regular point of contact if necessary for people dealing with chronic or acute mental health situations, including associated carers or involved individuals. It operates between the hours of 4pm and midnight, with additional 10am-4pm shifts at weekends, in order to provide the best out of hours service possible with the funding granted. The service uses a RAG system to assess and convey the nature of any risks in each call. The operation of this system is detailed under the “nature of calls” subheading.
Service Statistics

Time period in question

This report concerns the service’s statistics from the 1\textsuperscript{st} January 2016 to 31\textsuperscript{st} December 2016. It thus features a sample of 10,942 calls (those for which RAG assessments were possible) from 498 distinct callers.

Users of the service

Despite affected family members and carers being eligible to call the service, alongside professionals where necessary for the coordination of care, it is used overwhelmingly by the service users themselves. Advocates and providers contact the service manager directly when needed, as do care coordinators. Carers tend to use the dedicated carer support service run by NCN Mind and partners and only 10 calls from them were recorded over the studied period.

Many service users find it useful to incorporate regular contact with the line into their routine, and currently no cap is in place on the number of times an individual can call – this is at the service users’ discretion. As such the support line can take on a maintenance role for an individual over time, as well as more “one off” usage for specific information or acute incidents. The table below splits this usage into categories that broadly represent different usage patterns of the line.

Table 1: Usage patterns

<table>
<thead>
<tr>
<th>Once only</th>
<th>Infrequent (2-5 calls)</th>
<th>Bi-monthly to monthly (6-12 calls)</th>
<th>Between monthly and weekly (13-52 calls)</th>
<th>Multiple weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>290</td>
<td>126</td>
<td>21</td>
<td>28</td>
<td>33</td>
</tr>
</tbody>
</table>

Nature of calls

Calls rarely fall into a distinct category and are usually a mix of information and signposting, practical problem solving for events in the caller’s life and emotional support. In terms of risk rating, a RAG (Red-Amber-Green) system is used to designate severity and immediacy of action. An assessment is made at the beginning and end of each call to account broadly for any de-escalation that has occurred, unexpected elements that have caused escalation, or the maintenance of a steady state. Calls that end in a red rating require an immediate response and a prompt handover is conducted to the relevant emergency service. Case studies included in the relevant section below exemplify these in further detail, but red-rated calls tend to feature considerable harm to the caller’s self or another person, or imminent danger of this.
Calls ending in an amber rating feature some risk of harm that is not immediate. They may involve the user having a general inclination towards or thoughts of taking their own life without concrete plans or current will to. Such calls are run past the crisis team in a daily handover telephone call, and notes are added to the caller’s file to ensure that information is available to care coordinators and associated professionals. As an additional precaution, calls can be referred to the line’s manager for follow up the following morning, or a police welfare check arranged via the non-emergency police 101 service for later in the evening.

Calls ending in a green rating require no further response and no significant evidence of threat is deemed to be present. Call notes are simply made on a dedicated database and stored for future reference. No treatment or assessment by other services is deemed necessary. Table 1 below outlines the different risk levels of calls pre-and post-conversation as assessed by operators.

Note that the total number given is for where a full RAG assessment was possible and recorded pre-and post-conversation. It does not include callers who mistook the service for another one and were signposted elsewhere, silent calls, calls in which reception was too poor to allow for comprehensive assessment, and other contact where a RAG assessment was not needed or possible. The call handling software indicates that 13673 calls were handled by the line when such contact is included.

Table 2: Pre- and post-conversation risk status of calls to the support line

<table>
<thead>
<tr>
<th>Risk status of calls</th>
<th>Number of calls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk state maintained (Green to Green)</td>
<td>9227</td>
</tr>
<tr>
<td>Substantial de-escalation of risk</td>
<td>1091</td>
</tr>
<tr>
<td>Amber to Green</td>
<td>1061</td>
</tr>
<tr>
<td>Red to Amber</td>
<td>19</td>
</tr>
<tr>
<td>Red to Green</td>
<td>11</td>
</tr>
<tr>
<td>Sustained level of risk or escalation during call, necessary for handover to other professional.</td>
<td>624</td>
</tr>
<tr>
<td>Red to Red</td>
<td>102</td>
</tr>
<tr>
<td>Amber to Red</td>
<td>59</td>
</tr>
<tr>
<td>Green to Red</td>
<td>12</td>
</tr>
<tr>
<td>Amber to Amber</td>
<td>397</td>
</tr>
<tr>
<td>Green to Amber</td>
<td>54</td>
</tr>
<tr>
<td><strong>Total handled (with full RAG assessment possible)</strong></td>
<td><strong>10942</strong></td>
</tr>
</tbody>
</table>
Demand for the service, time and spread of calls

Demand for the service exceeded capacity over the year in question. The exact ratio of this is difficult to ascertain from the held statistics. Non-handled call rates are inflated by a small subset of regular callers who decline to wait in the queue and instead hang up and repeat call, usually several times per day (a strategic response to this is about to implemented — see the staffing resource selection below). As such number of call presentations is very inflated as an indicator of demand, but statistics indicate 39571 attempted calls to the line.

Demand for the service exhibits a general peak at the 4pm-5pm opening hour. In this the service saw an average of 15.82 calls presenting per day (again a raw figure and not accounting for individuals declining to queue and call back) over the studied period. Further high demand tended to occur over the 8pm to 11pm period, with an average of 11.79 calls per hour presenting over this period.

Staffing resource available

A total staffing resource of 117 hours per week is currently funded. With a half hour unpaid break in 8 hour evening shifts, single staffing on 6 hour weekend 10am-4pm shifts and double staffing at all other times, this results in 68 hours of coverage.

Call handlers spent, on average, 12.85 minutes on each call, although call lengths varied considerably according to circumstance and need. They also made a further 335 callouts, each lasting an average of 10.26 minutes, to relevant professionals or for further checks on particularly vulnerable service users.

Due to demand exceeding capacity, the service manager has been authorised to begin a trial of a supplementary service in which volunteer telephone befrienders do regular callouts to low-risk callers, providing a responsive service to those who use the line for regular maintenance and freeing call-in capacity for optimal urgent responses to acute calls. Recruitment for suitable volunteers has begun, initially to provide a further 36 hours of telephone support time.

Call outcomes and exemplar case studies

Call outcomes vary considerably. As indicated in the RAG system statistics in the relevant preceding section, most calls end with a de-escalated situation/one in which emerging concerns have been placated and wellbeing maintenance conducted. In practice this may be via help navigating a financial concern, signposting to a depression support group, reassurance (but not direct clinical guidance) regarding medication, helping the caller move through a panic-attack or a wide variety of other input. The caller is left more confident in approaching and managing the mental health scenario facing them.

Where the above is not possible, liaison with other services is necessary. To give an indication of this, over the studied period the support line operators made:

- 23 ambulance callouts to individuals who had caused serious physical harm to themselves.
• 46 calls to police, of which there was an even split between emergency calls using the 999 number and requests for welfare checks later in the evening via the 101 non-emergency number.

**Red calls: two typical Examples**

Caller A has taken an overdose of painkillers impulsively and is feeling confused and regretful. The call handler ascertains the amount and nature of what was taken as quickly as possible, advises the caller to unlock their door and stay somewhere warm and secure. They assure the caller they will be taking swift action and offer a check in call from the line manager the following morning. They make an immediate call to the ambulance service and give details, taking the caller’s location from the held information on the system database. They then run this action past the relevant crisis intervention and home treatment team and ask them to update patient notes accordingly so that a care coordinator is aware. A check in call follows to the patient the next day. The caller has been referred to the Mind accident and emergency liaison support service by NSFT nurses, and offered support from NSFT community teams. The line manager encourages them to call the support line as regularly as they need whilst emerging from this crisis situation.

Caller B is suffering from heavy psychotic symptoms with repeated hallucinations urging them to end their life. They reveal that they are under the care of the crisis team and are not taking their medication, and that significant attempts on their own life have happened previously. The call handler tells the caller that they will be getting help and make an immediate handover to the regional crisis team who agree to provide urgent support.

**Amber calls: two typical examples**

Caller A has just lost her mother and this has been involved with an increase in her depressive symptoms. The call handler suggests some counselling for bereavement and provides reassurance that the way the caller is feeling is something that can be addressed with the right support. They look at suitable counselling services with the caller. They also suggest a GP appointment to look at the medication the caller is currently taking, and help the caller make a practical plan for some concerns regarding the funeral. The caller feels more assured but still mentions some unspecific thoughts of ending her life and the general conflict she is having with them. The call handler encourages the caller to call again, and updates a handover report at the end of the call so that the crisis team can update shared NSFT records in the nightly handover, allowing the patient’s care coordinator to be suitably informed. In order to ensure that this happens promptly, the call handler sends an email to the service manager to make care coordinator contact the next day.

Caller B is self-harming with a dedicated razor blade. The call handler helps the caller to bring this to stop with encouragement and suggestions of less harmful techniques using ice cubes and elastic bands. After initial difficulty in getting this established, they create a pause in the harm long enough to get a sterilised strip in place over the wound. There is a small amount of residual bleeding so a visit to a walk in centre is encouraged. The call handler does an internet search for the nearest one and rounds off the call, encouraging the caller to call back once this has been done. On the second call they talk about factors that led to
the self-harm, and agree that the caller will try and record these in a diary to look at patterns in a future call. The call handler notes the increase in harming behaviour on their nightly handover form and records are updated for the care coordinator.

**Green calls: two typical examples**

Caller A is a long-term user of the line and community mental health services. She lives with daily psychotic symptoms from an abusive past, and today needs a check in call to move her attention away from the voices she experiences. She is not acutely distressed by them on this particular occasion, but they are causing discomfort and saying that she is worthless. The call handler assesses standard signs of risk with questions at the start of the call, and ensures that the caller feels comfortable with their medication and general support plan. They have some light chat about the caller’s daily routine, and go over the caller’s plan for the week, ensuring that they have contact with other people to break each day up where possible. They re-cover basics of dealing with voices, and the call handler helps the caller to re-establish her independent view from that of what they are saying, and a rationale for why she is valued and safe. The caller is fine to go about her routine by the end of a twenty minute check in.

Caller B is a new caller experiencing a panic attack. The call handler brings the caller’s focus quickly to regulating his breath, assuring them that other elements can be worked through in due course. Once physical symptoms have dissipated, the caller and call handler look for elements of background stress and anxiety in the caller’s lifestyle and life events. The call handler makes recommendations on sleep, diet and physical activity that may assist with stress levels. The handler also suggests the caller self-refer to the wellbeing service, and signposts to a local anxiety peer-support group. They emphasise that if the attacks continue for the caller, then a GP appointment may be of use to rule out physical causes and discuss any medication that may assist.
3E. Recent Experiences of Mental Health Crisis Services in West Norfolk: a Report for Healthwatch Norfolk

Research conducted by Dr Deborah Holman supported by Richard Irwin, James Sykes and Will Barnes from West Norfolk Mind
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EXECUTIVE SUMMARY

Semi-structured interviews were carried out with thirteen people in King’s Lynn, Heacham and Downham Market, probing people’s experiences with mental health crisis services in West Norfolk. These ranged from 111/101/999 calls, the police, A&E, community mental health services and GPs through to the Crisis Team, and the Fermoy Unit.

Nine interviewees were service users and four were carers. The majority of interviewees were women (eleven) and ages ranged from twenty to seventy-eight. Although the sample size is small, sadly the experiences reported here are familiar to Community Bridge Builders at West Norfolk Mind and to our service users.

Common themes exposed by the interviews were: trust; listening; communication; safety; privacy; dignity; consistency; powerlessness; caring; responsibility; prevention; and, system failure.

Key issues related to first contact in a mental health crisis

- People do not know where to go for help.
- At crisis point, when individuals are very ill and vulnerable, our interviewees felt that the onus is on them to search for the care they need.
- Some interviewees believed they were actively discouraged from accessing crisis services.
- Service users’ impressions are that internal communications between the statutory services, with other mental health services and third sector organisations, is disjointed and, in some cases, there appears to be a lack of understanding of the role and responsibilities of the different services.
- The Fermoy Unit came in for a number of criticisms. Interviewees reported feeling unsafe there, not listened to, left to their own devices, their privacy undermined, and disempowered. This impression was sharpened by the contrast with the Fermoy Unit as it was in its ‘heyday’ and with the level of care in another mental health hospital in Norfolk.
- The Crisis Team were not well regarded by the majority of interviewees who noted: ‘you never saw the same person twice’; ‘having to constantly repeat yourself’; ‘they were patronising’; and, ‘made things worse’. However, one interviewee felt she had a positive relationship with the Crisis Team.
- Accident and Emergency, Queen Elizabeth Hospital, was generally rated as ‘fantastic’, ‘good’, and ‘great’. Three exceptions were the dual use of the assessment/relatives’ room, the practice of leaving an unwell person alone to await their mental health assessment, and some staff members’ lack of understanding of mental illness.
- General Practitioners and the Out of Hours GP Service were generally well-regarded. It was emphasised that seeing one’s own GP was especially appreciated at a time of
There was a perception, however, that the GP’s ability to get the care needed for their mentally ill patients had been circumscribed.

- Police Officers called out to a person in crisis were seen as firm and reassuring by one service user and ‘absolutely useless’ by another.
- Two carers commented on the 111 service which they said was unhelpful. One carer had the same impression of the 999 service.
- Twelve of the thirteen interviewees felt very strongly that service users and carers were not being listened to either at crisis point or during the period of care afterwards.
- Service users and carers felt that they had to ‘fight the system’ or ‘prove themselves to the system’ to get the help they needed, and that so much is ‘down to luck’.
- Interviewees tended to draw a distinction between good staff and a poor system. In all of the mental health crisis services, individuals were singled out for praise, particularly for kindness, care, and respect.
- The majority view is that the system is failing too many people: ‘crisis services are in crisis so how can they help people in crisis?’

**Key issues related to crisis treatment and post-crisis care**

- Consistency of care is undermined by moving patients around on the basis of bed availability, the reduction in staff numbers and high staff turnover, and the number of agencies involved in a person’s care.
- The majority of interviewees felt that communication, whilst in the Fermoy Unit and at discharge, was poor.
- Service users and carers had difficulties reconciling the professionals’ written assessments with their own experience. Consequently, their trust in mental health professionals had weakened.
- People are ‘slipping through the net’ after discharge and left for long periods without any form of support, in two cases resulting in readmissions.
- Carers are not adequately supported and are experiencing very high levels of stress.
- The benefits system – personal budgets, DLA, ESA, PIP - negatively impacts individuals’ mental health and that of carers.
- It takes too long to get support in place after discharge such as care assessments, contact with the community mental health team, a care co-ordinator, and there are long waiting lists for therapeutic support.
- Short-term support doesn’t help: ‘as soon as you get the help, it is taken away’.
- Third sector support services are well regarded: Together UK, West Norfolk Mind, Boudicca Court, and The Matthew Project.
Interviewees’ Recommendations

- Make parity of esteem between mental health and physical health a reality.
- Provide a genuinely person-centred service ... treat us like human beings.
- Take on the responsibility for an individual when they are in crisis for a set period until they are well again.
- Keep us informed: talk to us ... and listen to us.
- Learn lessons from third sector providers.
- After discharge get support in place quickly and for longer, tailored to the service user’s needs.
- Prevention: ‘all this talk of prevention; there is no bloody prevention!’

- A&E, Queen Elizabeth Hospital:
  - Provide a separate mental health assessment room.
  - Provide mental health training for A&E staff.
  - Employ an ‘appropriate adult’ to stay with a patient experiencing a mental health crisis until the assessment team are available.

- The Fermoy Unit:
  - Increase staff numbers at the Fermoy Unit.
  - Provide a structured and safe inpatient environment.
  - Improve patient confidentiality.
  - Improve consistency and levels of care.
  - Keep patients and carers informed.
  - Talk and listen to patients.
  - Provide inpatient therapeutic interventions and teach coping strategies.
  - Do not discharge patients prematurely.

- The Crisis Team:
  - Allot specific team members to work with each service user to improve consistency of care.
  - Improve communication with service users and carers.

Conclusion

- People’s experiences of contact with mental health crisis services are embedded in the larger story of living day to day with a serious mental illness. Contact with crisis services cannot be isolated from that larger story.
Some interviewees felt that their crises could have been prevented had there been sufficient community services in place, and that simple acts or small changes at an earlier stage would have made a significant difference.

Crisis were exacerbated by poor communication, inconsistencies in care, underfunded statutory services and difficulties negotiating the disability benefits regime.

Interviewees came to similar conclusions: no one is listening to us; the system is in chaos; trust in statutory services is eroding; mental health services are underfunded; and, there is no parity of esteem between physical and mental health.

A positive outcome of the research was that people felt listened to and were grateful for the chance to share their experiences.

INTRODUCTION

This research for Healthwatch Norfolk probes people’s experiences as users of mental health crisis services in West Norfolk within the last two years. Three Conversation Cafés (a form of focus group) were planned for King’s Lynn, Heacham and Downham Market. Attendance levels were not as high as expected and so the decision was made to revert to an interview/group interview format. These interviews complemented the four planned semi-structured interviews and, overall, permitted us a greater insight into how contact with a mental health crisis service impacted on people’s lives.

The research was guided by the Statement of Ethical Practice for the British Sociological Association (March 2002). Participants were given an information sheet about the project, the data collection procedures used and who to contact about the project for information (Dr Deborah Holman) or to make a complaint (Eddie West-Burnham, CEO, West Norfolk Mind). The consent forms also included this information. These asked participants to indicate that they had read and understood the information sheet; that they understood their participation was voluntary and they could withdraw at any time; that they agreed to taking part in the study and to written notes being taking during the interviews; and, that they consented to their words being used anonymously in reports. Thank you cards, designed by a West Norfolk Mind service user, containing a £10 Love to Shop voucher and £5 for travel costs, were given to every participant in recognition of their contribution to the study, their time and willingness to travel to speak to us.

The design and conduct of the research was mindful that participants could be particularly vulnerable if, for example, their experience had been recent or involved a hospital admission. At each Cafe session, the interviewer was supported by a note-taker with an additional member of staff managing the catering requirements and ensuring that anyone who became distressed and needed to withdraw had someone to talk to or just to sit with. Preceding each session a briefing was given explaining the information sheet and consent
form, outlining how the session would run and the ‘dos and don’ts’ to be aware of. Questions were encouraged at this point to ensure that everyone was satisfied with the process. At the end of each session participants were debriefed by a counsellor and any further questions participants had were addressed. The four more in-depth interviews were conducted on a one to one basis; each interviewee was briefed at the beginning in line with the Café practice and debriefed at the end by the interviewer.

The research team have appropriate research qualifications and work directly with service users at West Norfolk Mind. They are trained mental health first aiders and have received suicide intervention training. Our counsellor also supported the rest of the research team with a debriefing at the end of each session.

There were some issues we hadn’t anticipated which necessitated some adaptations to the original research design. Briefly, these were recruitment difficulties, refused consent to record the interviews, a higher proportion of female participants, and a greater preference for interviews rather than involvement in group discussions. We were, however, rewarded with especially rich and revealing data.

Thirteen people consented to take part in the study: eleven women and two men. All but one described themselves as White/English/British and ages ranged from 20 years to 78 (with an average age of 50 years). Five people reported contact with multiple crisis services as a result of a single period of mental ill health, six reported contact with two services, and two with one service (a GP). To protect participants’ identities this report will not use names. Instead, each participant will be recorded as F or M along with their age – F24, M20 for example – to distinguish between interviewees. No reference will be made to participants’ diagnoses.

Six aspects of contact with mental health crisis services were used to structure the research and to steer participants through the process, as follows: factual description, feelings then, feelings now, positives of experience, negatives of experience, and recommendations. The analysis of the findings follows this same structure in order to identify common issues occurring at specific points or with specific agencies.

Four case studies are also presented. The case studies contextualize many of the issues raised and highlight that whilst there may be identifiable common issues these are experienced in very different ways by individuals.

The conclusion notes the key issues raised and the overall impression our interviewees have of mental health crisis services.
SIX ASPECTS OF CONTACT WITH MENTAL HEALTH CRISIS SERVICES

What happened?

Right from the start participants’ descriptions of their initial contact with services shows how difficult it is to access help, to get the right kind of help, and to find someone who will listen:

I saw a new GP who didn’t know me... and didn’t know what to do. I should have seen my own GP. [F57]

I completely crashed and knew I needed help quickly. ... My GP’s referral never got anywhere. I ended up spending four days phoning round until someone nice at The Matthew Project got me some help. [F38]

They said on the medical ward that ‘he wasn’t suicidal enough’ to get an admission to the Fermoy Unit. [F78]

For some, help was eventually found after a long trail from one service to another before ending up at A&E.

I rang 111, was told to go to the out of hours GP, I managed to see my own GP, who sent me to Chatterton House who told me to go to A&E. [F72]

I rang 999 ... I rang 111 ... In the end, when I was trying to explain the problem to the receptionist at the surgery, a lady in the queue behind me said to go to A&E, which we did. [M58]

For others, the route was less complex, sometimes explained by the severity of the mental health crisis, sometimes by familiarity with the system as a result of multiple crises, and sometimes because a GP has been able to manage the crisis with the patient.

I was sectioned. [F53]

I was going to jump from a second floor window... They took me to A&E. [F24]

I went to the GP who gave me antidepressants. [F37]

I was admitted through A&E, there was no bed available in the Fermoy so I ended up on a medical ward for over two weeks, then I was sent to Mundesley Hospital for over two weeks and then I was sent to the Fermoy when a bed became available. [F43]

The last quote indicates that the difficulties experienced do not stop at the initial point of contact with a crisis service (see case study 3).
How did you feel?

Interviewees were asked if they could recall their feelings at the point of contact with a crisis service. Understandably, some people were not able to answer this question; those that did reported feeling powerless, confused, frustrated, disbelieved, angry, anxious, and desperate for help.

Before going to the Surgery I felt elated because I had done the right thing: identified my symptoms and made an appointment as soon as possible so that everything could be sorted out before it got too bad like before ... Leaving the Surgery I just felt angry. [F57]

I was feeling very paranoid about the doctor treating me [in A&E] ... I thought he was trying to poison me and I couldn’t find the words to explain that to the nurse as she had been arsy with me for bleeding over the floor. [F24]

I felt really anxious, like people were looking at me with disdain. I didn’t feel listened to at all. I know I am a job to them but can’t they at least listen to me? It was a fight or flight reaction and I ran. [F43]

I felt like someone had dropped me out of an airplane and left me to swim in the sea. [F53]

All I can remember is that after they took him I woke in the night and I cried. Well, that’s it, I just cried. [F74]

I was really distressed at the time, in tears of frustration. Actually listen to me! [F38]

How do you feel about it now?

Asking interviewees to reflect back on their experiences accessing mental health crisis support produced varied responses resulting not only from the severity of the mental health crisis and how well that was managed, but also influenced by the time period between the experience and the interview, where the interviewee currently ‘sits in the system’, and how well they were at the time of interview.

I’ve decided I am not going back to them; I’ll deal with it myself. [F57]

It was an unpleasant experience for all the family. [M59]

I still feel angry and let down. It is good to have a diagnosis and I feel vindicated by that – now they’ll know what to do with me - but I don’t know when I could be shoved off that cliff again. [F43]

I’ve learnt from experience; I keep a notebook documenting everything. [F72]

Getting the help you need depends on luck. [F38]
I feel like I have just been left to get on with it. They think ‘oh, she’s managing. She’s looking after him so she’s okay’. [F74]

It’s very difficult being on your own [in A&E]. ... Trust is really important. [F24]
The message was basically ‘go away and get iller’ before you can get treatment. [F38]

What did the services you were in contact with do well?
Unfortunately, there were very few bright spots for interviewees to recount (which, in part, relates to the self-selecting nature of research participants and the topic area). However, the majority of interviewees distinguished between the failings of the system and the role of individuals working within that system.

The staff are great. The system is not. ... I got the best HCA [healthcare assistant] that night. [F24]

My GP is very good: he really does listen. [F38]

My GP knows me well and has mental health experience. He gets the community team in and knows how to manage my illness when I report my symptoms. [F57]

I thought there was good communication between the psychiatrists and the nurses [in the Fermoy]. [M20]

The police were good. I mean, they talked to me. They said they didn’t know much about mental health ... they were very clear about what they could and couldn’t do ... they were firm. [F24]

What did the services you were in contact with do poorly?
The responses to this question were numerous and wide-ranging, leaping beyond the initial crisis contact to subsequent treatment and the journey from there.

When you’re in crisis don’t say ‘this is your problem’... ... The biggest problem is that the system doesn’t look at your whole history. [F41]

There is only one assessment room in A&E. It is used as a relative’s room too. It is really difficult when I am on my own and other people come in who are upset about a relative. This has happened a lot. [F24]

I don’t think the nurse [in A&E] went into why I refused treatment. I wanted treatment but not by that doctor. I was discharged without seeing any mental health staff even though I had been brought in by the police after an overdose. [F24]
All this is completely new to me. I didn’t know what to do. I rang 999 ... I rang 111 ... I spent ages on the phone. It seemed to me that both services were trying very hard to work out how not to do anything. Both said they could not help. [F58]

The receptionist wanted to know the nature of my illness and I did not want to disclose this to a non-medical member of staff. It’s a small surgery serving a small village. [F57]

She was put on the defensive by them [Crisis Team] and felt they did not listen. [F59]

I went into the Fermoy voluntarily, but they wouldn’t listen or let me go. ... I felt so depressed, disempowered and controlled. ...The hospital put it down that I had psychotic depression. Nobody ever discussed that with me. [F53]

There was no discussion of my diagnosis [in the Fermoy]. I only found out about it when I saw my discharge letter. [F43]

I was very scared on the ward. I remember one night a male patient shook me awake looking for a lighter! ... The safety measures need tightening up. [F53]

The Fermoy doesn’t keep violent and noisy patients away from other patients. Regardless of their diagnosis they are all together. Patients are not safe. [F74]

We all keep notebooks or journals and write everything down. [F74]
Because you just can’t remember everything. [F59]
I’ve got it all written down. [F72]
Well, you have to otherwise they won’t listen to you. [F78]

**What recommendations would you make?**

Interviewees made a number of constructive comments based on their experiences of mental health crisis services. These ranged from the preventative end of the scale, to treatment, inpatient care, outpatient services and communications with carers. Clearly, contact with services at the point of crisis is only one element of people’s long-term and complex experiences of mental ill health.

They ask ‘what do you think would help?’ but I don’t know what help is available, I need someone to talk to me. [F43]

Although I am informed about my condition I don’t always have the capacity to make the right decisions. Having someone to do that for me – someone I can trust – means that, instead of being sectioned, I could be admitted as a voluntary patient and get out much quicker when I am well again. [F24]

[Professionals should] take responsibility away for a set amount of time, while you can’t deal with it, when you’re in crisis. [F41]
There should be an appropriate adult to sit and wait with you [in A&E]. [F41]

Weekly contact with a support worker who will listen and give practical advice and can be available as soon as you are discharged from hospital. [F41]

Peer support ... what would be good would be peer mentoring, someone who has been through it, who can signpost to the help and has experience. [F43]

I was discharged [from the Fermoy] without any coping strategies or anything in place and ended up in crisis again. ... I don’t see why the stuff done at Mundsley [Hospital] isn’t done everywhere. [F43]

I noticed that in the Fermoy when you stand in the corridor you can hear everything that is said in the review rooms. That really needs changing, there’s no privacy ... [F53]

A phone call would help ... so you knew where you were. [F74]

Consistency. [F78]

A quick response. [F72]

Oh, blimey! Where to start?! [F38]
CASE STUDIES

CASE STUDY 1 – The Lucky Service User: ‘When you are at your weakest you need to be the most tenacious to get the support you need ... So much of it comes down to luck.’

F38 has a good insight into her condition and knows what medication works for her and what does not. When we met she was recovering from a recent crisis after almost three years of stability and improvement. She had received an ESA50 form from the DWP which sent her into shock. She had been making good progress; however, having to complete the detailed form meant thinking about her worst days which ‘just brought it all back’. She realised she was heading for a crisis and knew that her condition would mean getting help as quickly as possible: ‘I was desperate.’

Her GP’s referral to a ‘secondary mental health adult team’ was never responded to and she felt that her GP had been left without the support he needed. She ‘decided [she] would have to take things on herself’ and spent four days ringing round every agency she could think of for help. Eventually, she managed to speak to ‘someone nice’ at the Matthew Project who saw her and took her whole history. This was the first time anyone had done this apart from when she joined a new surgery two years before. When this was completed ‘the Matthew Project worker went ‘wow! Has anyone helped you with this?’ The answer was ‘no’.’ Within a week she had been secured an appointment with a psychotherapist via the Norfolk Recovery Partnership.

F38 thought she had been lucky to ‘come across a great person who helped her at the Matthew Project’ though felt that ‘in an ideal world’ she should not have had to phone round services to get the help she needed over four very distressing days. Thinking back on her experience made her feel angry because she was not being listened to ‘and the message was basically ‘go away and get iller’ before you’ll get treatment’: ‘all this talk of prevention; there is no bloody prevention!’

For F38 ‘the system is in chaos’ with ‘ridiculous case loads’ for care co-ordinators, ‘service rationing, and gate-keeping. The failings of the mental health system are ‘related to system failure as much as anything.’
CASE STUDY 2 – The ‘Shunted Around’ Service User: Disrupted Care

A shortage of mental health beds meant that F43, who was sectioned, was first admitted to a medical ward at the Queen Elizabeth Hospital for two weeks and then sent to a private hospital (Mundesley Hospital) for about the same amount of time before being removed from that hospital and sent to the Fermoy Unit for another two to three weeks.

The contrast between Mundesley Hospital and the Fermoy Unit was staggering. At Mundesley ‘they cared’, she ‘felt safe there, from other people and from [herself]’, she felt ‘like a human’. She didn’t feel safe in the Fermoy and noted the low staff levels compared to Mundesley. There wasn’t any interaction with staff or a structure to support inpatients: ‘you’re just supposed to get on with it’. She described a ‘better’ dietary regime in place at Mundesley which was caffeine free, the structured cigarette breaks, and a list of daily activities which you were strongly encouraged to take part in. Inpatients could not leave the grounds and there was graduated access to the grounds, first going out supervised until you could finally go out unsupervised whereas ‘King’s Lynn gave too much freedom.’ Talking with staff was described as ‘more like building a friendship’ and consisted of a 15 minute observation and detailed discussion ‘not like in King’s Lynn where it’s just a head count’. She said: ‘in Lynn there was no chance, no chance, to talk about what was going on with me, no talking therapy and no consistency – you never saw the same person’.

She felt she was making progress at Mundesley and was upset that her stay there ended abruptly when she was ‘shipped off to the Fermoy Unit when a bed became available. Whilst in the Fermoy she was informed by the consultant that she ‘couldn’t hide there’ and ‘needed to go home’. She said ‘I was kicked out before I was ready’ and upset to learn of her diagnosis only when she saw her discharge letter: ‘there was no discussion of my diagnosis’ ... although ‘it’s nice to finally get a diagnosis’.

Since discharge she was used that help have come from my stay in Mundesley, not King’s Lynn’. Post-discharge she received six weeks of support from Mind which was very helpful although, ‘part of the problem is as soon as you get the help it’s taken away’. She was ‘really thankful’ for support from Together UK; particularly, during an assessment where support was described as ‘imperative’. She has been waiting for a personal budget to be put in place since September 2016.
CASE STUDY 3 – The Carer’s Story: ‘I’ve been left alone to cope with it.’

F74 has cared for her husband for many years and also has an adult son with a serious mental health condition. In the past, 2006-2008, he had received ‘marvellous’ care whilst at Cawston Park and had also been admitted to the Fermoy. When she realised he was becoming ill again in 2015, they went to his GP who at first said ‘he was okay’. He wasn’t and when they returned to the GP a referral was made to the crisis team and he was admitted to the Fermoy Unit in 2016. At the time, referring to a previous admission, the comment was made ‘we didn’t do the job properly in the first place!’ She remembers that ‘after they took him [in] I woke in the night and cried ... well, that’s it, I just cried.’

He was discharged in September, 2016 because ‘there was nothing they could do; he is choosing to do this’. Six months later, he still remains in bed, refusing to wash or change his clothing. He has had no follow-up or support since discharge – and neither has she. Recently, she visited her GP to try and get some support. However, she feels she has been left alone to cope and that the attitude of the statutory services is ‘oh, she’s managing; she’s looking after him so she’s okay’.

She attends a carers’ peer support group for two hours a week if she can get away. Pooling their experiences has led to members of the group keeping detailed journals or notebooks documenting everything. They have found that this is the best way to support the people they care for when dealing with professionals.
CONCLUSION

As the case studies illustrate, people’s experiences of contact with mental health crisis services are embedded in the larger story of living day to day with a serious mental illness. Indeed, contact with crisis services cannot be isolated from that larger story; for most of our interviewees, it is a component of their care history and, according to some interviewees, a preventable component - had there been sufficient support available in communities. We felt these issues had to be raised in the report as the connection with a full-blown mental health crisis is clear. Our interviewees highlighted how a crisis could have been avoided - ‘just talk to me before I am in a crisis’; ‘all this talk of prevention; there is no bloody prevention!’

They also highlighted how their crises were exacerbated by poor communication, inconsistencies in care, underfunded statutory services, and the disability benefits regime. It seemed that, in some cases, relatively small changes or simple acts at an earlier stage could have made the difference between a manageable situation and a crisis.

Overall, our interviewees came to similar conclusions: no one is listening to us; the system is in chaos; trust in statutory services is eroding; mental health services are underfunded; and, there is no parity of esteem between physical and mental health.

For participants, a positive outcome of the research was that they felt listened to. Group interviewees in particular expressed gratitude for the chance to share their experiences. For the research team, it was particularly gratifying to learn that West Norfolk Mind and other third sector services are so highly regarded.

Dr Deborah Holman, West Norfolk Mind - 27.3.17
3F. Experiences of veterans accessing mental health crisis support
Conducted by The Walnut Tree Project veterans for Healthwatch Norfolk

February to April 2017
Introduction

We interviewed eight veterans all male as we currently have no female veterans in our service, each were asked the same three questions.

1. When you hit crisis point, who did you turn to?
2. What sort of help and support did you get from the NHS or other services?
3. How was that and could anything have been done better?

The Walnut Tree Health and Wellbeing provides veterans mental health support via our Walnut Tree Project, some of the veterans interviewed are working with a range of forces charities for both welfare and clinical mental health support, others are currently using NHS mental health services.

All veterans volunteered to take part and all gave written consent for us to use the information they provided to form part of this interview process and be submitted to Healthwatch Norfolk and used in the final report.

To protect the identity of the individuals we refer only to the veterans age at time of interview and branch of the forces they served in. All veterans interviewed were resident in the county of Norfolk at the time of the interview.

WARNING! Some obscenities appear in this report, veterans often use such language as part of military culture to make a point or vent frustration. Our role is to report the words of the veterans in a true and honest account.
Army aged 38

When you hit crisis point, who did you turn to?

“At first I tried to soldier on, I thought I could get through it. After a while life just turned to total crap, in the end I went to my GP. No way could I talk to my family, see we have all served grandad, dad and my brother. I was worried they would think I was week!”

What sort of help and support did you get from the NHS or other services?

“My GP was nice but it was clear she didn’t have a bloody clue what to do with me, I was given antidepressants and sent on my way. Couple of weeks later I saw an article on Facebook on a veterans site for Combat Stress. Load of shit to be honest, was told as I didn’t have PTSD I wouldn’t be going to the treatment centre. Gutted wasn’t the word, things went from bad to worse, I went back to the GP and she upped my meds. One day I got up filled with anger, I hated myself and wanted to die. Not going into it you know what happened, well it was the mental health team at the Norfolk and Norwich that called you guys I remember thinking more timewasters who won’t give a shit. When they arrived, and said they were vets who also had mental health conditions I was rather shocked but to be honest after just a short chat I felt they really got me and it felt like they really wanted to help me. “

How was that and what could have been done better for you?

“GP’s really need more mental health training, also most forces organisations only seem to want to know about PTSD and that’s all! Honestly If it wasn’t for the project I wouldn’t have really known how to get help, I mean only cos of the crisis training you gave me do I now know about local mental health services like Wellbeing and how to get referred to services, before I didn’t have a bloody clue it’s like mental health is some secret club that you must be introduced by a member or something. Definitely more information needed on how to get mental health treatment.”

Army aged 28

When you hit crisis point, who did you turn to?

“Honestly the drink, hit the bottle hard just wanted everything in my head to stop. One night I was pissed out my head and got arrested for fighting.”

What sort of help and support did you get from the NHS or other services?

“At the nick, I was interviewed by, I think it was a mental health nurse? Anyway, they said they would refer me to the Wellbeing for mental health support. I had my assessment and they told me about a NHS veteran’s treatment service. I was seen by a psychologist Dr Kingerlee and a veteran from the Walnut Tree Project Luke Woodley. I got help with debt and the project referred me to Outside The Wire veterans drug and alcohol service. I also
went to the drop-in coffee mornings and made new friends, some of them were then on the same Veterans Stabilisation Programme as me.”

How was that and what could have been done better for you?

“For me The Walnut Tree was great mainly because they are vets who have walked the walk, no crap they tell it how it is because they have experienced mental health, also I got to meet others who had been through treatment and were now doing other things like work placements or volunteering and that really gave me hope! I just wish the army had helped me more I got a medical discharge but no treatment or support I was just left to rot.”

Navy aged 54

When you hit crisis point, who did you turn to?

“Well how long have you got! First I went to Combat Stress, they said they couldn’t help and I was referred to Walking With The Wounded, they paid for 12 sessions of private treatment, I got only ten and the counsellor went on holiday and I never got the last two sessions. GP sent me to Wellbeing, for a year I want to all kinds of sessions, each time I was told this won’t work for you but your welcome to stay. December 16, I went into total fucking melt down, GP referred me to CRHT at Hellesdon, they were worse than fucking useless but they said they would refer me to The Walnut Tree Project.”

What sort of help and support did you get from the NHS or other services?

“By late December we had not had any more contact from mental health services or The Walnut Tree Project, my wife called the project and answerphone message said office was closed until 4th Jan 17. My wife sent a Facebook message to The Walnut Tree Project page, they instantly messaged back, seemed CRHT hadn’t referred me to them, still they chased it and within 5 hours of being contacted someone from the VRP team was in my home getting things sorted. Referred for medication review and the Veteran’s Stabilisation Programme, they sorted our welfare problems and even decorated the house as our land lord wanted to inspect it before renewing the tenancy, the place was a bit smashed up as I had taken my anger out punching doors and walls. The VRP cars came out in the early hours to support me and my wife when I was unwell more than once. Honestly the service from you guys has been amazing.”

How was that and what could have been done better for you?

“I feel let down, I was messed about for so long and my condition getting worse this meant I lost my job, then finally I get help from the Walnut Tree Project, they know what they are doing and should be the first point of call for all veteran’s mental health needs. Whilst I am angry that it took so long to get help, when I finally did find it you couldn’t have asked for more. Like I say they should be the only people doing this sort of thing, they understand it, they lived it and know how to help you.”
**RAF aged 62**

**When you hit crisis point, who did you turn to?**

“I had no one to turn to I just tried to keep going, eventually my wife made me go to my GP, it was hard as I didn’t really know what to say or what was the matter with me!“

**What sort of help and support did you get from the NHS or other services?**

“My GP gave me antidepressants and referred me to the Wellbeing Service, I had eight weeks of CBT, and was then referred on to the NHS Veterans Stabilisation Programme, this is run by NSFT in partnership with The Walnut Tree Project.”

**How was that and what could have been done better for you?**

“I didn’t like the Wellbeing Service as I’m sixty odd and having to talk to a young lady who’s twenty something made me very uncomfortable. The Veterans Stabilisation Programme was great, no clinical mumbo jumbo, all straight talking it helped me no end. Overall, I’m lucky I got help and it’s worked!“

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**RAF aged 42**

**When you hit crisis point, who did you turn to?**

“Wasn’t me to be honest, my girlfriend called Combat Stress after seeing a bit in the paper. She knew I was in a bad way I just couldn’t talk about it, not to her or my GP, no one.”

**What sort of help and support did you get from the NHS or other services?**

“I went to the Combat Stress treatment centre for two weeks’ stabilisation, then a couple of months later I did the six-week course and the psychiatrists sorted out my medications. Down side was coming home I struggled and felt I had no Support. Then my girlfriend’s dad was listening to Radio Norfolk and the Walnut Tree Project were talking about the Veterans Response Partnership service, so I called up to find out more. “

**How was that and what could have been done better for you?**

“The Walnut Tree Project signed me up for the Veterans Response partnership, this out of hours’ mental health support really helped me as I felt I was no longer alone. Combat Stress were great but they just need to support veterans more when they go home, currently it’s all about the treatment centres, that’s great being with other vets and that but hits hard when your back home on ya Jack Jones!“

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**Army aged 32**

**When you hit crisis point, who did you turn to?**

“Three years ago, I was seen by the NHS mental health services but I refused treatment, I thought I was ok and could deal with it.”
What sort of help and support did you get from the NHS or other services?

“Obviously, I didn’t deal with it! Got arrested trying to burn my house down, I then tried to hang myself in the police cell, I was remanded in custody at HMP Norwich. When I was being booked in they asked if I was a veteran so I said I was, I was then asked If I had any mental health problems so I told them what I had done in the police cell. The prison called The Walnut Tree Project who came into the prison and worked with the prison mental health team to support me. They worked with defence and prosecution lawyers and probation services and I was given a 18 month mental health treatment order. I have Reiki once a week with the Project and attend the Veterans Stabilisation Programme and have had a medication review. “

How was that and what could have been done better for you?

“How was it, fucking amazing as well as treatment for me the project got the restraining order overturned and have not only worked with me but also my wife and kids, honestly, they saved my marriage and I’m slowly getting my life back. I think the army should do more to support us as they just kick you out the second they know you have a mental health problem no treatment and no support.”

RAF aged 43

When you hit crisis point, who did you turn to?

“Embarrassing really, I took a load of cocaine and tried to throw myself off a carpark, security saw me and called the police. The mental health staff at the police station referred me to the Veterans Stabilisation Programme and NRP for my drinking and drugs. ”

What sort of help and support did you get from the NHS or other services?

“I had my assessment with Norfolk and Suffolk NHS mental health services, at the assessment was Luke Woodley from The Walnut Tree Project. Luke referred me to Outside The Wire a military drink and drugs service, I found this better than the NHS NRP service to be honest they were fucking useless and didn’t really understand my self-medicating to block out what was going on in my head rather than being addicted and needing the drink or drugs, it was more a means to an end if you get what I’m saying? I worked with both Luke and Outside The Wire, I then went on to do the Veterans Stabilisation Programme.”

How was that and what could have been done better for you?

“I found the Veterans Stabilisation Programme difficult at first as it’s a group session, however turned out others had battled on by self-medicating so was good to hear how they had coped. One thing that still upsets me is being put in a police cell, I was in crisis and trying to end my life and was treated like a criminal.”
Army aged 49

When you hit crisis point, who did you turn to?

“I was very ill one night woke up piss wet through with sweat, I couldn’t see at first it was like my eyes couldn’t focus. I knew I was in a bad way and I called the Samaritans.”

What sort of help and support did you get from the NHS or other services?

“The Samaritans were good they just listened to me, I have since spoken to my GP and he referred me to The Walnut Tree Project, I am registered with the Veterans Response Services and have called on the cars28 a couple of time and they are always such a great support, I’m not ready to face treatment yet as my issues are from childhood and even now I don’t feel ready.”

How was that and what could have been done better for you?

“I feel I have more support now especially with the cars out of hours, I feel I’m getting closer to being able to face treatment. Often, I have felt pressured into going for treatment from friends or family and that’s not helpful at all. Now though I feel I’m being supported by the project and I feel more in control as I get to decide when to take the next step.”

28 “the cars” are the vehicles and teams provided by the Veterans Response Partnership. These vehicles provide 24/7 crisis support for veterans registered with the scheme, across Norfolk and Waveney
Mental health crises care and emergency services in Norfolk

A Healthwatch Norfolk Report

Zena Aldridge- Registered Mental Health Nurse Dip He MA
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1. INTRODUCTION
The contents of this report have been gathered for inclusion within a wider project being led by Healthwatch Norfolk.

The project “Mental health crises and emergency care in Norfolk – Experiences of mental health crises upon emergency healthcare service demand in Norfolk and views on ways to improve “ is being carried out and data will be collated and form a report for NHS Midlands & East (East of England) Urgent & Emergency Care Network.

1.1 AIMS
This component of the project work focuses on the experiences of people with dementia and their families / carers in relation to their experience of crises and emergency situations over the past two years in Norfolk.

1.2 PARTICIPANTS AND RECRUITMENT
For the purpose of this report participants were either a person with dementia or their carer and were purposely recruited via established support groups or community groups or other non-statutory organisations offering services to people with dementia. This ensured that the interviewer was able to target the appropriate client group within the timeframe available. This method also facilitated participation across Central Norfolk i.e. people with dementia and their families / carers registered with GP practices in North Norfolk, South Norfolk and Norwich CCG areas.

In total there were 24 participants, some of the information provided by one participant had to be discounted as it was in relation to a historical event outside the two year period identified for his piece of work. Figure 1 illustrates the age of participants.

Of the 24 participants 5 were people diagnosed with dementia and 19 were family members of carers of someone with dementia as seen in Figure 2 below.

Figure 1

Age Of Participants

- <50
- 50-60
- 60-65
- 65-70
- 75-80
- 80-85
7 participants were Male and 17 were Female. From the 24 participants 22 classified themselves as White British and 2 as White European.

1.3 METHOD

The interviewer had planned to carry out a variety of focus groups and 1-1 interviews (either face to face or telephone).

However, it became clear that due to the nature of the content participants found 1-1 interviews preferable, therefore all interviews were 1-1 or 1-2 with the majority, 16, being face to face and further 3 were telephone interviews. Five interviews were paired i.e. the person with dementia and the carer together, 14 interviews were carer only, this was for several reasons including; the person with dementia being unable to recall events, the person with dementia no longer living with the carer or they lived at differing addresses and for two participants the person they cared for had died.

The purpose and nature of the work was explained to participants and with minimal prescription they were invited to share their experiences / stories in relation to the subject content.

At times the conversation needed to be guided and questions pertinent to the experience were asked as appropriate to ensure context and content of the experience was interpreted appropriately.
2. FINDINGS

2.1 WHAT WAS THE CRISIS /EMERGENCY SITUATION?

Participants were asked to identify the crisis/emergency situation, of interest many initially questioned whether they were appropriate to participate as they struggled to identify an ‘emergency/crisis’ situation.

Participants were encouraged to talk through their situation in full, from a point that they wished to commence, the interviewer acknowledged that for many this appeared to be of value and they appeared to benefit from having their story heard, it did not take long before crisis/emergency situation(s) emerged in all cases.

Due to the complex nature of dementia in terms of its impact on mental health, physical health, social care needs, co–morbidities and the intricate relationship between the person with dementia and their carer the emergency/crisis situations varied in presentation and content.

The nature and degree of the incidents differed but is clear that they were experienced as an emergency or crisis situation to the person/people involved. Carers appeared to almost accept such incidents as the norm and this may have been one of the reasons that they struggled to identify such situations initially.

Two distinct groups of incidents reported emerged, incidents relating to the carer (which then often led to critical social care situations in terms of the care and support of the person with dementia) and incidents relating directly to the person with dementia.

2.2 CARER

5 events were reported in relation to the carer and consisted of an injurious fall, mental distress, suicidal ideation and acute medical problems.

One female carer described how she had fallen whilst on a day trip with a friend and fractured her hip resulting in a hospital admission for surgery. Not only did she have to consider her own needs but the complicating factor of managing the care and safety of her husband whilst she was incapacitated who needed 24 hour care.

Many carers spoke of episodes of mental distress which they attributed in part to their caring roles describing situations that had led to the need for seeking urgent support; one explained that she had been suicidal and “felt like jumping off a car park “ and another felt “out of control “. One participant described how she hit a mental brick wall when she realised that her husband could no longer be left alone and the impact his was going to have on her life, becoming acutely distressed and requiring urgent support.

The physical effects of caring were described by one man who advised how he ‘had not felt great’ for a while but not realised how unwell he was and had “ just been trying to keep my head above water trying to care for the wife ….. “, it reached a critical point one evening and he was aware that he needed urgent help he did not know what was wrong with him but knew he was in trouble … his neighbours “ didn’t think I would last the night they took my wife into another room as they thought I might die …”. The neighbours called for an ambulance and he needed urgent treatment, even at this point his primary concern was for his wife and how she would be cared for whilst he was ill.
Another carer spoke of ignoring her high blood pressure to ensure care for her husband was being organised and as a result of not attending to her own health needs experienced a stroke ...however even at this point it took her some time to recognise her symptoms and call for emergency assistance. “I knew I wasn’t feeling right but I thought that I could get home and rest and I would be ok...I realised when I couldn’t speak properly that I was having a stroke ...I hadn’t recognised the symptoms at first...”.

One carer advised how he had to be admitted to hospital for a planned procedure and the relief carer he had arranged for his mother whilst he was in hospital failed to turn up which put her at high risk, as she is unable to be left alone. Therefore although not an emergency in a medical sense it was deemed a crisis situation for the carer who was required to stay in hospital overnight due to the potential of complications following his procedure.

2.3 PERSON WITH DEMENTIA

The situations in relation to the person with dementia were in the majority connected to increased confusional states (often these were not one off incidents and had occurred on more than 1 occasion), often manifesting themselves with increased agitation/aggression and hallucinations. Other events related to falls and infections (again often multiple), or suspected acute cerebral events (Cerebral Vascular Accident CVA, Trans Ischemic Attack TIA). Often the presenting problem was linked to another issue e.g. when diagnosed with an infection or falling whilst confused etc. Many of the incidents were whilst the person was being cared for at home and in several situations it was whilst they were in a 24 hour care setting.

2.4 FALLS

Falls were reported by the majority of participants and again many carers, until given the opportunity had forgotten how frequently such incidents had occurred, some carers were able to link the falls to an acute illness such as a urinary tract infection but many felt they were isolated incidents.

One carer described how his wife had fallen on multiple occasions during the night and he usually picked her up himself, but on one occasion she needed to be taken to hospital at 1am as she had “banged her head quite hard when she fell backwards”. The carer advised that as she had not injured herself previously he had not felt it necessary to seek advice in relation to the falls.

Two carers advised that the person with dementia they cared for had sustained a fractured hip from a fall whilst at home.

Further reports of falls were shared by 6 further carers, mainly believed to be non-injurious but on occasion this could not be ruled out at within the home setting and the carer needed the intervention of paramedics to get the person up from the floor. There were 3 reports of skin tears and wounds that needed treatment following a fall.

Case study

One female carer reported how her husband had fallen out of bed at around 11pm and sustained a laceration to his head, it was not his first fall over recent weeks .She asked her husband if we would like her to get some help as his wife felt he still had capacity to make such decisions with support, he said yes, she called 111 and an ambulance attended quickly.
The carer had hoped that they would dress the wound and leave but the decision was made to take her husband to hospital. The carer had concerns about taking him late at night the ambulance crew felt he needed to be taken to hospital.

The carer tried to contact A&E to see how he was but could get no response so drove to the hospital in excess of 20 miles away a few hours later.

When she arrived at the hospital she found him wandering and distressed and his wound had not been dressed staff reported that he had been agitated overnight.

She was not asked what was normal for him and so was unclear what assessments if any had been done to identify the cause of his increased confusion. There was no discussion about admitting him to hospital. She waited for his wound to be dressed and took him home.

She went to the toilet shortly after arriving home and he wandered off and was found by the neighbours down the road.

Prior to the fall the carer had booked a 2-week period of respite for her husband as they were adapting the home, so he was admitted to respite care at this time. As his condition did not improve this period was extended and he now remains in permanent fulltime care.

The carer continues to question the decision to take him to hospital and feels guilty that she never went with him.

She is clear that “people with dementia should not go to hospital without support.” She also believes that “it was a waste of time and destroyed him.”

2.5 INCREASED CONFUSION

Over half the carers described situations whereby the cared for had become acutely confused on at least one occasion.

Case Study

“Mum had been at my house for Christmas, she lived on her own and went home after Christmas.......3 days later she called me and asked “Are you and the children on their way? I tried to reassure her but she got really upset and said, “Help me! Help me! I have gone mad” when I went over to her house she appeared to be hallucinating and had turned the house upside down...”

After calling 111 a paramedic attended who requested an ambulance and took her to hospital. She was in hospital for 3 weeks “they thought she had a urine infection ...she was moved 4 times in 4 days at one point due to Norovirus, they discharged her with no support.” (This carer subsequently moved her mother into her home to care for her.)

Another carer described how she and her husband had been watching television one evening and without any warning he looked at her and asked; “Who the hell are you??” she responded “I am your wife “ he shouted at her “Where is my stick I am going to whip your head off!” He became increasingly aggressive and she was forced to leave the house fearing for her safety.
One carer advised how she turned up at the care home where her husband was receiving respite to see an ambulance on site. He had allegedly tried to attack staff and was taken to A&E he remained in acute hospital for a week and the decision was made to detain him under the Mental Health Act 2007 and he was transferred to an Older Persons Mental Health Unit for assessment from which he was discharged into full time care.

Another female carer spoke in relation to her mother “I got a call from the care home and they told me she was going mad and they couldn’t cope with her. She was trying to get out and was really angry shouting at the staff...they told me she would have to go.”

11 carers in total described situations were the person with dementia they cared for had displayed symptoms consistent with being acutely confused with varying degrees of intensity and frequency

Symptoms were described as;

Increased confusion, paranoia and accusatory behaviour, visual hallucinations, aggressive mainly verbally to carers but some physical aggression reported by care staff, reduced ability to communicate, agitation and inability to stay still.

When trying to describe the changes in behaviours carers voiced phrases such as;

“Dad had lost the plot.”

“He wouldn’t talk any sense and kept going up and down the stairs in a confused state. I was scared he would fall”

“He was having visual hallucinations and I knew that he could not be left alone...”

“I was frightened and knew I couldn’t look after him properly”

“He was paranoid and accusing me of all sorts...I didn’t know how to handle him.”
Very few of the participants who had experienced caring for someone within the context of an acute confusional state felt that they knew why this had happened. Some felt it was linked to a progression of dementia, others felt that it was linked to an infection, one carer described her husband as appearing delirious, but the diagnosis of Delirium was not used in any cases. One carer said that it “wasn’t a word that had been used at the hospital but a friend who happened to be a dementia specialist said Mum may be experiencing delirium.”

Two carers spoke of Mini-strokes but were not clear on the diagnosis whether this was indeed the correct diagnosis.

2.6 OTHER EXAMPLES OF ACUTE EVENTS

One carer shared how she had alerted care home staff that she felt her husband was not well on the Saturday morning and he was having difficulty breathing but they did not feel there was any need for intervention, she was advised on Sunday that “he is fine” he was taken to hospital overnight without advising his wife. He later passed away in hospital.

The wife of another person with dementia reported multiple incidents of her husband needing urgent support in relation to a suprapubic catheter often out of hours.
2.7 HOW WERE EMERGENCY /CRISIS SERVICES ACCESSED?

OUT OF HOURS

Many of the incidents became critical out of normal working hours and a variety of avenues were utilised but, in the main calling 111 or 999 was the most commonly used method of seeking interventions in the first instance particularly when it was felt to be a medical emergency or a fall.

For those who were in care homes it is unknown as to the exact mechanism for seeking support in a crisis /emergency situation out of hours and it cannot be assumed that these were all managed in the same way as this would be dependent on the nature of the situation, the confidence and competence of staff, whether they were providing nursing care or residential care, and knowledge of local pathways and protocols.

One couple living at home, used the care alarm that they had installed due to their propensity of falls and this alerted family members to attend, they would then make a decision as to whether further assistance was required if they were contactable. When not available paramedics had attended on one occasion.

Very few carers reported that a call handler or GP addressed their concerns but more often escalated to a singular Emergency Care Practitioner /Paramedic or Ambulance crew who were dispatched to assess the situation.

One carer advised how her husband had called the police in a confused state; she was relieved in some ways when they attended. She was struggling to manage his needs following a recent admission to hospital as he had remained confused and paranoid, the police and Dementia Intensive Support Team (DIST) attended as a result.

Only one participant reported accessing support from the DIST as part of an emergency response to a situation relating to increased confusion, increased aggression etc., however 2 other participants reported accessing support from the DIST team as part of a longer term response (i.e. over proceeding days).

One carer stated that she had contacted the Out of Hours GP Service at 8.00pm, a paramedic was sent to attend who stated that a Dr. needed to see the patient as it was a likely infection and the GP arrived at 2pm the following day.

Some carers reported that they had not contacted services when symptoms first appeared as they though it might pass, particularly when it related to increased confusion and agitation.

One carer recalled that her husband had not been himself during the day but not unwell enough to take him to the hospital.

Of concern were those who did experience problems/concerns out of hours but did not try and seek support as they

“Did not want to trouble anyone” or

“Did not know who to ask for help” or,
Were not sure whether their situation warranted an emergency or urgent response.

**Case Studies**

One carer left her home late in the evening as her husband was displaying aggressive behaviour, she was not sure where she should seek help from as it did not meet her understanding of an emergency situation so she moved to an annexe building keeping an eye on the house. She waited until the following morning to contact the GP surgery to ask for help. The GP immediately arranged for an admission to an Acute Hospital, he was later detained under the Mental Health Act 2007 and transferred to an Older Persons Mental Health Unit for assessment.

Another carer reported that his wife fell one evening and sustained a large skin tear, both he and his daughter who supported him with his caring role, felt that they should wait until the following morning to seek help, they had dressings in the house as she had sustained previous skin tears and covered the damaged area overnight. They contacted the local surgery the following morning and when seen by the nurse who told them in no uncertain terms that they should have taken her to Accident and Emergency (A&E) when it happened as the injury was exposing that fatty layer under the skin. The carer advised that he though he was doing the right thing as “they tell you only to go to A&E in an Emergency. I didn’t know that it was an emergency.”

### 2.8 WITHIN NORMAL WORKING HOURS

**999**

For those with a clear injury/ medical emergency during working hours carers felt confident in their knowledge of the right approach to take, 999 was called and an Ambulance attended. I.e. fall with suspected fractured hip, suspected stroke etc.

The daughter of one gentleman with dementia reported that she called 999 as her father collapsed and was experiencing a bleed that clearly needed urgent attention. He was admitted to hospital for surgery.

### 2.9 GP PRACTICE /PRIMARY CARE

For those situations that were seen as urgent but not a cause to contact 999 most participants contacted their GP practice or known health professional to seek advice and/or intervention.

6 carers reported contacting the GP practice when they had concerns about the person they cared or themselves in crisis or presenting with deteriorating health.

One carer reported presenting at the GP surgery as she felt mentally distressed and states she was at risk of harming herself but was unable to get an appointment until the following day and was not offered information regarding alternative support mechanisms.
One carer advised that a family member had contacted the GP practice on her behalf concerning about both her and her husband and in turn the GP had made an urgent referral to Social Services to get them some support.

One carer reported how her mother had 4 acute hospital admissions over a 4 month period and on all occasions the GP had been called in the first instance, however every time this resulted in an admission.

One carer identified that a quick response by a GP when her husband had developed an infection and was becoming delirious saved him from going into hospital as he attended within an hour and commenced antibiotics straight away that enabled full recovery and prevented any further deterioration in his health.

One male carer who has been supporting his mother advised that he had sought advice from an Admiral Nurse in regards to his mothers care when he was in hospital and her privately funded package of care collapsed. She was able to support him in arranging alternative care and ensure his mother was safe whilst he received treatment.

2.10 MINOR INJURIES UNIT

One carer reported that her husband with dementia had fallen outside the home and was seen by neighbours, they managed to get him up but he had several cuts as he had fallen into rose bushes. Both of them described how they had attend the local minor injuries unit and that they had been seen quickly and the wounds were attended to quickly and effectively and follow up care was arranged with their GP practice enabling minimal disruption and coordinated access to the right on-going care and support.

2.11 SOCIAL SERVICES

Two carers had contacted Social Services when a deterioration in their loved ones presentation had led to challenges at their current placement and required either, for them to be moved, or seek further support in managing the care needs of the person with dementia in the current setting.

Some of participants were asked whether they knew about the Swift Service, many carers had the telephone number but were not always clear on what the service provided but felt they may use it in the future following an explanation of the service offered

2.12 IMMEDIATE OUTCOMES OF CRISIS /EMERGENCY SITUATIONS

Following on from the immediate response to the situation some varying outcomes were reported

For “falls” incidents attended by Paramedics the majority of carers reported that the person with dementia was conveyed to A&E to be “checked over ”. Often these incidents were out of hours there appeared to be a fairly even spilt between these that were admitted and those that were discharged after assessment and treatment for wounds etc.

Several falls which did not result in transfer to hospital were self managed by the carers, in one case the GP Practice was contacted the following day to manage a large skin tear.
In the case of increased confusional state the majority of incidents the usual outcome was either conveyance to A&E or direct admission to an acute hospital. Despite the high incidence of confusional states none of the participants reported direct admission to an Older Persons Mental Health Unit and only one person was seen by DIST prior to admission. 3 people with dementia whom had been admitted to an Acute Hospital were transferred to the care of Older Persons Mental Health Services after being detained under Section 2 of the Mental Health Act 2007 one of these patients had to be taken to an Out of Area bed.

One carer followed an ambulance to the hospital at 1am following his wife’s fall to ensure that he could return home when able, it was suggested to him the following morning he could take his wife home, he raised concerns about her presentation but the discharge process continued, as he attempted to transfer her to a wheelchair she collapsed and was treated for an acute illness for the following 10 days in hospital which required surgery.

Another carer advised how her husband was taken to hospital after a prolonged period of declining ill health when he developed a temperature and as a result several health complications were identified and he remained in hospital for over two months. The person with dementia recalls much of the admission and stated “that he thought he was going to die”

2 carers advised that their husbands had been admitted to the Norfolk and Norwich Hospital and later transferred to the Julian Hospital after several days and they felt that they should have gone there in the first instance as they had required 24 hour 1-1 support whilst in the NNUH hospital and this was not always appropriate to be delivered by health staff and on occasion was delivered by security staff. The 3rd carer in a similar situation did not offer an opinion in relation to this.

2.13 SUMMARY OF LONGER TERM OUTCOMES

Overall the outcomes of those who were admitted to hospital were influenced by changes in their care needs, which were often significantly different at the point of discharge and the carer’s ability to manage the needs or the person they care for.

4 of those people with dementia who had been admitted to hospital were placed in care shortly after the admission but after a short period post discharge at their home address.

1 person with dementia was placed in care after a period of 24-hour care in his or her own home due to increased needs.

4 people with dementia were placed in full time care at point of discharge, 1 carer moved her mother into her home offering her 24 hours support after 24 hours post discharge.

3 carers, all offspring of the person with dementia, left work to meet the increasing demands of their parent’s with dementia care needs.

As a result of one male carers admission 2 siblings moved in with their parents to ensure both the person with dementia and the carer receive full support preventing the need for 24 hour residential care for at least one if not both parents.

Many carers continue to display unresolved resentment, anger and indeed guilt associated to the decisions made and the outcomes that in their view had arisen as a result of some of these acute events. For many this had been the first time they had reflected upon such incidents and this often highlighted on-going needs for the carers in such cases they were offered support by the interviewer.
and where appropriate signposted or referred to other services that could continue to offer them support.

2.14 PARTICIPANTS VIEWS OF WHAT WAS POSITIVE AND WHAT REQUIRES IMPROVEMENT.

POSITIVES

Although much of the experiences offered were negative there were some positive messages that did emerge from the interview. Participants expressed some positive views about aspects of care received either at the point of crisis or directly afterwards.

All carers who had been admitted to hospital for their own health issues felt the care they had received had been good and that their needs had been met, for some it had improved their health significantly. This group felt that their situation was made more difficult due to their caring roles and that the crisis not only related to their health but was also a social care crisis in ensuring the safety of the person they cared for whilst they were incapacitated.

3 carers reported that although they did not feel anything was done to change the outcome at for the person they cared for as a result of attending A&E, i.e. no injuries or illness were noted and the person was not admitted to hospital, One carer did feel reassured as a result of the attendance but they were not sure that A&E was the best place for the person with dementia to be especially at night.

2.15 LOCAL SERVICES

One couple advised on how impressed they were with the response that they received from their GP when they were reaching a crisis point and needed referral to other services, They also spoke of their overall satisfaction of their experience of mental health services to date and the “fantastic support they have from the community mental health nurse” (this couple were the only participants in receipt of on-going community mental health nurse support) which was noted to have an on-going benefit in minimising further crisis situations. The husband (person with dementia) stated, “The NHS has been absolutely brilliant and well received.” His wife agreed that although the situation was difficult the response from health services had been good to date.

Support closer to home in the few situations it was accessed was always met with more positive feedback. The Minor Injuries Unit was highly praised by the couple that accessed it for treatment following a fall. Some participants spoke highly of GP’s when the person with dementia had become acutely unwell during working hours but felt that they did not always have the resources and time to prevent deterioration in the situation.

One participant advised that he had been in receipt of support from an Admiral Nurse who he suggests “ offered considerable value to have an on-going contact that can give independent views, or intercede on our behalf if necessary.”
2.16 INDIVIDUALS AND STAFF APPROACHES

Many participants felt that individuals had made a positive difference within a given situation. Individuals were noted to have had significant impact on the experience of services during a crisis or emergency situations.

Reference was made to a call handler in one situation who talked calmly to a carer when her husband who was agitated, she recalled being told,

“Keep on the line. Talk to me and tell me what he is doing now??”

Enabling her to feel that she wasn’t alone and was safe whilst waiting for emergency services to attend.

Other carers noted how the paramedics had responded quickly when called and they used words such as “Amazing’ and ‘Fabulous’ to describe them and their response

A few carers although not satisfied with the provision of services and resources available to people with dementia recognised that many staff did their best with limited resources.

“The hospital was not the place for my husband but I have no complaints about them

...He shouldn’t have been there he should have been receiving specialist care.... “

“The security guards were lovely ......they talked with my husband got to know him a little bit and said to me that my husband was a very interesting man...”

One carer described the team of Dementia Friendly ward staff as “Amazing”

2.17 INFORMAL SUPPORT

Two carers noted that what had enabled their experience to be positive was the fact they could organise and pay for more flexible care that prevented the person with dementia going into hospital or full time care at a critical time when a crisis had occurred and this has significantly impacted positively on the overall experience.

All participants were accessing community support from an individual or support groups and so were able to engage in support enabling some means of sharing some of the concerns that had been raised as a result of a critical situation. The majority valued the moral and peer support that they accessed via the groups and in some cases the practical information they had sourced via the groups especially from other carers who had experienced similar situations.

The response of family members, friends and neighbours was again a source of positive rhetoric. Often making the difference in difficult situations and ensuring that difficult situations did not escalate further. They were often the game – changers and significantly influenced positive outcomes and minimised further deterioration in key situations.
AREAS IDENTIFIED BY PARTICIPANTS FOR IMPROVEMENT

COMMUNICATION

Nearly all participants identified that communication was a key area that needed improving on all levels. Repeatedly they spoke of the lack of communication from hospital staff when an admission had taken place about all aspects of care.

Many carers did not feel that they had been informed fully of the reasons for admission and still do not know of many aspects relating to the admissions and verbalised that there was a lack of engagement with carers when it came to discharging their loved ones. For many the person they cared for is now in care but for those who remain in a caring role they felt that if they had more knowledge and confidence things may have been different e.g. seeking support earlier, challenging or questioning health professionals with regards to decision-making.

Many carers had not been included in discussions about the person with dementia’s care and had not been asked for vital information about the normal baseline functioning of the person. They felt that had they been included and seen more as experts in the person with dementia’s care outcomes may have been different in some cases.

They also felt that when they raised concerns or offered information it was ignored or they were seen as difficult. Many wanted to be included in care planning and discussions about care but often felt they were not included, 2 carers suggested that communication between hospital and GPs could be improved and recommended they had a care plan that everyone knew about.

Carers spoke of how they felt that opinions were formed of their loved ones particularly when they were admitted with increased confusion or conversely they did not realise that the patient had dementia so did not feel staff were fully aware of the needs of the person.

One carer asked a Dr to review her mother’s pain relief the Dr stated that “she was not complaining of pain” but did not seem to realise that she had limited communication and would need support to articulate her pain or it would have to be observed.

Case Study

The female neighbour of one carer who had to be admitted to hospital, not only alerted emergency services to the carers seriously ill health, but when he was taken to hospital stayed with his wife who has dementia and ensured that she was safe until she was able to arrange respite with Social services the following day.

Following his discharge from hospital and his wife’s return from respite it was clear that they would not be able to manage without support. Two of their daughters offered to live in for 6 months of the year each to enable their parents to stay at home together and be supported.

The carer when asked what he thought might have happened without such support was aware that it would have been a very different picture and could not see how the outcome could have been the same without the support he has had from others both initially and on-going.
Another carer had asked on several previous occasions when her husband had been admitted to highlight he had dementia but on a recent admission it had still not been recorded and staff were unaware of his diagnosis.

Case Study

A couple advised on how the person with dementia had been admitted and it was identified he had multiple health problems he was under the care of several specialist teams. However it appeared to them that there was not an allocated lead for his care and the couple were continually getting mixed messages about his care treatment and indeed a prognosis.

The person with dementia advised that he felt that no-one told him anything “I kept asking them what was the matter with me ….it was very frustrating everyone was in a hurry. ...There was nothing else I could do. I thought I was going to die ...”

His wife concurred that no one ever explained anything. She also advised that she felt every decision was a battle made more complex by having so many people involved in his care. She felt that if there were a key person to discuss her husband’s care with that would have been easier and less stressful.

Participants also felt that they needed more information before such crisis occurred to help them reduce the risks but also to have clearer ideas of who to contact and when. Many felt they were muddling through and would have benefitted from better information about dementia and its effects earlier on.

2.19 ALTERNATIVES TO HOSPITAL AND SPECIALIST SUPPORT

The majority of carers felt that admission to hospital for the person with dementia had not been beneficial and in fact many felt it had been detrimental and would have preferred an opportunity for increased support at home, or a more realistic discussion about what the benefits and risks of admission might be to enable them to make informed decisions. Some carers also felt that if more support had been offered they might have tried/been able to keep the person at home.

One carer stated that she had asked paramedics not to convey her husband but they refused to leave him at home but he did not get treated until the morning and was increasingly distressed by the experience.

This carer was not alone in intimating that there should be more positive risk taking, as following conveyance to hospital many patients had experienced long waits in A&E resulting in minimal known intervention, to be discharged only hours later and minimal communication with family to identify baseline functioning of the patient.

Other carers suggested that paramedics should encourage a family member if possible to accompany the person with dementia to improve communication and indeed advocate for the person with dementia and reduce their anxiety and agitation.

Many spoke of the lack of specialist resources to enable them to care for their loved ones, many had been caring for many years and had not been in contact with mental health services since the person...
with dementia had been diagnosed. Others had never been in contact with mental health services as they had been diagnosed when in acute setting.

The lack of specialist support when the person with dementia was admitted to an acute hospital was noted, on 4 occasions carers could recall their loved ones having security guards by their bed due to increased agitation whilst in hospital and rightly identified how this was not the ideal approach for someone who was already feeling scared, confused and vulnerable. One carer reported that her father was cared for in a room with no windows which made it difficult for him to identify day and night which she felt added to his confusion.

One carer advised that “without having a dementia nurse as a friend we would not have known anything as Mum wasn’t seen by mental health services it shouldn’t be like that.”

Carers also identified significant variations in the support they received when mentally distressed themselves, it is important to recognise the need to improve support for carers to include support for their mental, physical health and recognise the risk factors associated with caring for a person with dementia, which can also restrict access to services so these need to be more accessible.

3. CONCLUSION

Although this is a small sample of cases it identifies that there is a high risk of crisis /emergency situations often resulting from an acute change in a chronic presentation.

It also highlights the lack of appropriate specialist provision for this cohort of service users and the gaps in services that limit the effectiveness of interventions in emergency /critical situations as a robust and appropriate alternative admission to hospital cannot be offered within current service structures.

Emergency and crisis situations for people with dementia and their carers often present with complexity due to the physical, mental and social aspects of dementia, very few patients with dementia are case managed and so arguably opportunities to provide early interventions that may minimise the risk of crisis and avoidable emergency admissions for the person with dementia or their carer are often missed.

It is well known that the acute hospital environment is not the best place for a person with dementia and they experience poorer outcomes then those without the condition. This is highlighted in this modest sample of participants in this report whereby 8 people with dementia out of a possible 19 were admitted to 24 hour care either directly from hospital of shortly after discharge or an acute event when carers felt the decline was such that they could no longer cope in their caring role.

It is also known “that people with dementia are sometimes in hospital for condition for which, were it not for the presence of dementia they would not be admitted” (DoH 2015). The interviewer would argue that this too is apparent within this modest sample. Attention needs to be paid to the skill mix within service provision to ensure that the complex needs of this client group are more appropriately managed in all areas of the care pathways within Primary, Secondary and Social care.

It is also clear that this cohort are at risk of multiple admissions as identified within this sample and, on-going support post discharge from an appropriate professional may reduce the risk of further admissions, particularly if carers can be supported to minimise risk factors through education and role modelling. This could also offer opportunities to support more robust care planning and enable difficult discussions around end of life, which are often negated and can lead to crisis situations.
Fox et al (2014) identify that “Dementia is most frequently associated with older people who often present with other medical conditions, known as co-morbidities. Such co-morbidities include diabetes, chronic obstructive pulmonary disorder, musculoskeletal disorders and chronic cardiac failure and are common, 61% of people with dementia are estimated to have three or more comorbid diagnoses.”

There is often poor identification and treatment of these co-morbid conditions which further increases the risk of crisis and emergency situations and indeed a propensity to attribute changes in presentation to the dementia rather than another chronic or emerging health condition or complication resultative from multiple pathologies often referred to as “diagnostic overshadowing”.

Signs and symptoms of delirium include impaired attention, memory disturbance, disorientation and disorganised thinking, altered perceptions (visual hallucinations, illusions, delusions), and emotional disturbance (Manning et al, 2013), it is easy to see why the signs and symptoms are often missed to begin with as they could so easily be attributed to a diagnosis of dementia.

There is a lack of understanding in both family carers and professionals around the impact/causes of delirium and how risks can be identified and reduced and the correlation of increased risk of delirium in patients with dementia.

Whilst carrying out the interviews for this piece of work the interviewer often engaged in general discussion with the participants after the interview about their overall experience of dementia, areas of unmet need were identified in all cases where they were not aware of services that would support them if further incidents occurred, or aids and adaptations / services that could enhance the quality of life for both the carer and the cared for.

In many cases the interviewer was able to identify onward referral to other agencies and or equipment that would improve outcomes both the person with dementia and /or the carer.

4. RECOMMENDATIONS

Caring for someone with dementia is complex and requires specialist support to ensure that the needs of both the carer and the person with dementia are met as effectively as possible and risks to all aspects of health and wellbeing are where possible addressed.

The majority of the experiences offered were via carers and the effects of witnessing such events and the increased stress of decision-making at the time of such events when often the person they cared for lacked capacity to make decisions on their own should not be underestimated. It is essential that their needs are addressed to reduce the long term detrimental effects on their wellbeing and enable appropriate emotional and practical support at such times of transition.

Carers need more help in identifying warning signs earlier and be supported to access preventative support and care where possible rather than wait for a reactive model of care that cannot cope with the demand that is currently being placed upon it.

Careful consideration needs to be given to some of the key messages about trying to reduce healthcare utilisation in Primary and Secondary care as in some instances participants had not accessed medical advice early as they did not wish to burden the system and tried to cope on their own. It is arguable that this may have impacted in the outcomes as a result delays in treatment.

Hence, the importance and value of good quality post diagnostic support for families affected by dementia and improved education and understanding of professionals to reduce the risks and have better understanding of improving patient and carer outcomes.
This is particularly pertinent in dealing with co-morbidities and delirium for example, dementia should be considered in the same manner as of other long-term conditions and where appropriate case management by clinicians with dementia expertise should be offered in complex cases to minimise risks.

Dementia although in the majority diagnosed in mental health services, has significant physical and social and emotional components and services should be designed to fill the gap that exists between primary care, secondary care and social care to meet the needs of the families affected. Currently many services work in silos and this enables gaps in service provision to develop and those who need support slip through the net accessing the most appropriate support for their needs.

There is an urgent requirement to invest in services that support families affected by dementia that are flexible and accessible.

5. REFERENCES

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3H. John Room House Mental Health Survey: A Customer’s Perspective

The basis of this report is a presentation of findings from ACCESS Community Trust customers about their feelings about Mental Health provision and their expectations for future delivery of Mental Health services within their local community.
INTRODUCTION

John Room House is a supported housing scheme providing medium to high support to homeless, vulnerable and socially excluded adults. Our commitment is to helping people turn their lives around by supporting them with over-coming substance misuse and dependency, mental health support and wellbeing enrichment and developing long-term life skills to promote brighter sustainable futures. John Room House comprises of a 10 Bed-Sit accommodation unit and 12 Self-Contained Move-On Flats.

Supported Accommodation Findings

From January 2016 – January 2017 a total of 47 customers accessed our accommodation services; currently 18 customers are still living within our supported housing services. Of the 47 customers that lived within our services 38 have been diagnosed by a health care professional with a mental health condition that effects their lives. The mental health diagnoses vary but depression and anxiety is reported as a factor in all 38 customers; a further 12 of that number are also diagnosed with additional complex mental health conditions. Whilst all mental health conditions and wellbeing factors impact greatly on an individual, for the purposes of this report a complex mental health condition is regarded as any mental health issue that is not solely depression and anxiety. The breakdown of complex mental health issues and the number of customers that they effect is as follows:

- Bi Polar 5
- Borderline Personality Disorder 3
- Self-Harm 3
- Psychosis 2
- PTSD 1
- Schizophrenia 1
- Undergoing a treatment order to remain in the community 1

The overwhelming majority of customers who accessed our services and who have a mental health diagnoses are also struggling to cope with addiction in their lives; with illegal drug use and (or) alcohol dependency being a factor in all but 3 of the 38 customers.
Mental Health Survey.

The John Room House Mental Health Survey was carried out with customers that are still accessing our services, the survey asked about their experiences with mental health treatment delivery, accessing mental health services and what could be improved or enhanced to make mental health delivery more accessible within their community. The survey indicates that whilst customers have a lead doctor within their medical practice they are not always able to see their ‘named’ doctor and this causes perceived gaps in treatment or feelings of being less supported as the doctor they see is unaware of the full extent of their mental and emotional health, customers also highlighted the emotional distress at reliving or repeating issues that these secondary disclosure have upon their wellbeing.

Whilst feedback concerning the Wellbeing Service was generally very positive and the advice and support was found to be helpful and meaningful, there were some recurrent themes in difficulty to access the service. The online referral form was considered hard or difficult to understand and customers found the explanation of their issues difficult. Most customers required the help of a Support Worker to facilitate the completion of the referral and required support in using or accessing IT equipment. Most customers felt that if the GP was suggesting that the Wellbeing Service would be of benefit to them, that the GP practice should have completed this referral form. Customers highlighted that if they were not currently living within a supported housing environment they would have experienced a greater deal of difficulty in accessing services and may have not engaged with the Wellbeing Service. Access to the appropriate wellbeing centre was also highlighted as an issue that prevented customers from engaging with help and support. Customers who were offered places within the Norwich Wellbeing Service were unable to attend due to transport and geographical factors; in these cases their emotional wellbeing was actually further damaged due to feelings of frustration and a sense of being let down by the mental health service in general.

Customers who experienced crisis and required additional support outside of normal working hours reported that the dedicated on call team were extremely hard to contact, they found that the advice given was not suitable and that it was actually the intervention of John Room House Staff that resolved situations or provided the support and nurture that the customers required. Customers felt extremely let down by this service and view it in a negative manner.

John Room House customers feel disconnected from their communities, isolated and vulnerable. They also feel let down by mental health services in general and feel that it is because geographically there is not a consistent mental health approach or enough mental health provision within Thetford that is readily accessible. They feel that more holistic and enrichment programs that provide a meaningful use of time and that would allow them to integrate into their communities would be hugely beneficial. Customers reported that a centre that provided services such as drop-in mornings, workshops and advice would be a positive and valuable asset for the town. Customers stated that they feel comfortable and supported by the role that ACCESS Community Trust has on their lives and that we would be
ideally placed to provide future services; as they state that they can trust and rely on our ongoing support and that we understand their journey and lives.

**Group Discussion.**

The outcome of customer discussion group sessions reinforced the information supplied within the survey. Group discussion took place over several connection activities in a variety of onsite and offsite settings. Customers spoke more freely about their experiences of mental health provision and their feelings of being let down by services and their inability to access appropriate services when they most needed targeted support. They were unanimous in their desire to see an increased mental health footprint within Thetford and identified that the lack of perceived services was creating greater issues in their lives. Customers also voiced concerns that conventional services within the community were unable to offer them assistance due to the chaotic nature of their lives or in some cases the customers being barred from services altogether. There was a sense that other agencies did not understand that for people who are experiencing mental and emotional distress that they needed more support or nurture to facilitate brighter outcomes. Customers were very vocal in voicing their opinions of what additional services and outreach was needed within the town and there were many common themes throughout. The overwhelming response was for a wellbeing style hub that could provide enrichment, employability opportunities and advice and break their feelings of isolation and exclusion. Importantly customers felt that this provision should be staffed and run by professionals that understood their backgrounds, journey and treated them sympathetically without judgement.

**A Personal View 1.**

The following are personal account of ACCESS Community Trust customers who outlines their journeys and the issues they have faced in getting the support and help:

“I have suffered from an early age with my emotional and mental health, I have experienced sexual, physical and domestic abuse throughout my life and I have struggled to cope with the aftermath of these traumatic events. In my teens I really began to go off the rails and found myself running away from home, staying out at night. I did not want to be at home and had a difficult relationship with my mother; who was an alcoholic. It was in my teens that I found myself becoming involved with drugs as a means to escape my life. As my addiction grew deeper and I started to use harder substances, my mother could not cope with the person I had become and I was put into Foster Care. Foster Care was the first real time in my life that I felt safe and happy. After leaving Foster Care I was given a new safe place to live, but my life caught up with me and I could not escape a violent relationship where I once again suffered abuse and trauma. Again I found myself returning to drugs as a means of escape, only this time my addiction was far worse.

Although I am clean now and feel I have finally broken free, I am left to deal with the emotional consequences of my life. I have spoken to my Doctor and he has prescribed me
medication that stabilizes my moods, but I am only ever prescribe medication not real treatment to help me move forward, my medication is on repeat so my Doctor never sees me anyway. Counselling sessions are non-existent within my town and I feel let down at times as I have nowhere to turn and worry for the future. I consider myself lucky to be at John Room House as I have staff that I trust and who look out for me, they understand that I have good and bad days and they look past my mistakes. I wish there were more services within this town where I could turn to for help either now or in the future, a place that was safe and where I could gain skills and the confidence to move on with my life.”

Personal View 2.

“The thing with Mental Health is there are no outward sign of something being wrong; if fact no two days are the same either. I have been under the care of my doctor for nearly a year, I was struggling to cope with daily life and felt I could not face the world or people. I withdrew further into myself and it took support and guidance from my Support Worker to approach my GP. My GP diagnosed me with depression; at first I dismissed their diagnosis as I have always tried to make the best in life. I resolved to try and learn about my condition and looked for ways to try and live my life to the best; when my depression lets me.

I was told that by being more active and enriching my social life can help with feelings of depression. Within the project that I live in there is a large garden and greenhouse. I began doing the odd bit around the garden and spoke to likeminded individuals; as I became more involved around the project, I developed friendships and reduced my anxiety and isolation. I still had ‘darker’ days but I looked forward to the ‘good’ days. I felt I was learning to cope in a safe environment and I was comforted by knowing I had support staff around me; this gave me confidence to test my limits.

I was called forward for a ‘Work Capability Assessment’ to record my suitability for work, I went to the interview and gave an honest account of my life. However, during the assessment no allowance was given as to how my condition effects my daily living outcomes. They met me for less than half an hour and basically disbelieved myself and my GP. They made an assessment that effects my life and finances, without fully understanding me. I tried to improve my life by working with my GP and undertaking meaningful activities following his advice. It turns out the doctor that has known me, understands me, has dealt with me when I have been at my lowest point; actually knows me less than somebody who judged me in 30 minutes.

I believe that I am a statistic, a number and that nobody cares, in truth being judged in this manner has undone all my efforts so far. I feel as if I am being called a ‘liar’ and this upsets me, because you cannot see my depression like you could a broken arm I must be making it up.”
Personal View 3.

“I have been suffering from anxiety and depression since the breakup of a long term relationship seven years ago. At the time I didn’t realise that I could get the support I needed from professionals. I saw my GP but he said it was normal to feel low after a relationship ends. I don’t think he realised how desperately unhappy I was and I felt that I was an inconvenience to him. So I started drinking to numb my feelings of despair. At my lowest point I took some paracetamols and a bottle of vodka. I didn’t want to end my life but I needed somebody to listen and I honestly thought that by taking this action I would end up in hospital and be seen by mental health professionals. Unfortunately, once the hospital were satisfied that I was physically stable, they discharged me. It wasn’t until I moved into supported accommodation that I felt truly heard. I have learnt that it’s ok to talk about my feelings and I have been encouraged into forging a new future for myself, starting with some volunteering in the community. I wish that my GP had originally listened and directed me towards some activities to bring some meaning back into my life.”

Personal View 4.

“I started notice my own wellbeing begin to change and I went to see my GP, who prescribed me some anti-depressants but other than giving me tablets he seemed uninterested. I took the tablets as prescribed but did not feel they were doing any good and because my GP was of little help when I last saw him I did not bother to go back to my surgery either. Over the next 6 years my life slowly fell apart, I sank deeper into a ‘pit’ and I gave up on living. I would of accessed help but because of previous disinterest from medical professionals I thought they would not help. Over those years I attempted to take my life as I did not want to carry on; things got to the point that I was actually helped in crisis by the police who finally managed to get me to be seen by an assessment team. I am now under the care of the community mental health team who provide treatment to allow me to remain in the community, but because of my location the group meetings, trained doctors the ongoing help I need is not provided for in my town. I am lucky that I am in Supported Accommodation I have staff on hand that can support me and I have begun to make connections with people, but if I was on my own I fear to think what would happen to me, I worry about moving back to independence; who will care and look out for me.”
31. Mental Health Snapshot

Produced by Experts by Experience, City Reach Services, Norwich

Mental Health Snapshot

A brief snapshot on Mental-health services, reveals that the Mental-health services are just not up to scratch!

Nor do they scratch the surface of the problems affecting their clients, with funding being reduced the problems will continue to increase!

This increase will lead to people with mental health issues not being taken seriously or even being seen. Ultimately ignored and left in their own misery.

Will lead each individual to try and cope with whatever they can lay their hands on to help forget the endless cycle of, despair?

We cannot allow this to continue, if we claim to be humane!!
Jason, 31yrs

“Suffered from tinnitus from infancy 4/5yrs old and the condition was not discovered until much later in life. This lead to me being prescribed liquid Ritalin (BP) British pharmacy.

A pure amphetamine, which was the first step to my entry to usage of drugs in my life. From my infancy to-date. After being taken off of Ritalin I suffered from withdrawals’ really badly adding to the problem, this lead to ongoing mal-diagnosis and continued increasing, suffering!

My reactions to being withdrawn from caused me agitation on such a scale that I was moved to different schools. This alongside the withdrawals’ I was now about 7-8yrs old I then arose daily, ultra-early and was cleaning the house with products packed with CFC’s these fumes affected me I became a threat to those around me, due to my condition. I was unaware of my actions and the ramifications of what I was doing, and that I could have seriously harm, almost anyone around me especially those close to me.

I was treated with a plethora of drugs in my life, which led me to using street drugs to help me cope with my problems. I believe that instead of Psychoanalyt’s and Psychologist’s trying to guess my issues and prescribing medicines for what they thought the problems were. I wish they had started with a conversation with myself and listened to me before prescribing all of those life damaging drugs! No more guess work! No more Psycho-Babble!

I am now 43 days clean of all substances (congrats), it is scary but I am coping in the main with thing in a day to day basis. By using meditation this helps me, to cope, with the conditions in the Homeless hostel and the other residents who themselves have coping problems and little or no support!”
“Start with having a simple conversation, before prescribing, you may find in some cases that no prescribing is necessary. It all boils down to talking human to human”

“I’ve had mental health problems longer than I have had a drug addiction. I used the drugs to self-medicate my mental health”

“I now need my heroin every 18hrs or I’m bang in the shit my anxieties surround and hound me to score and stop the pain, I see no end”

Harry, mid 40’s

“I was diagnosed in adolescence, as being Bi-polar, I was offered no treatment at that point. At the age 30yrs. I started using heroin as it was helping with my more manic episodes and enabling me to sleep. This situation became worse I started using more and more Heroin as I became a major league addict every day, thus resulting in more severe episodes of mania. When I tried NHS-CBT this guy asked me on a scale of 1-5 did I feel this, did I feel that? This slide rule example happened twice, I had to stop going “I can’t quantify on scale I’m not a f*cking slide rule which in turn increased my usage. Things got increasingly worse for me.

I was never referred to by my G.P. to any mental health therapy, I had to speak to a Psychologist at the Weaver centre a Dr Doesn’t Want-to-Know. When I entered the room to begin the session, he, commented that “I was too well dressed and far too clean to be depressed “Too clean to be seen” that was as far as I got. I basically got up to leave and expressed to the Dr, that he was an ignorant C*nt! Did I have to sleep in a muddy ditch and drag myself backwards
through a hedge in order to comply, and meet his dress code criteria. I’ve never been back to see anyone. At Hellesdon they have drug rehab/recovery. Right next door they have mental health facility, I don’t understand their (ILL-Logic) approach, and I don’t think many do. There is no communication between these buildings!!

At the Weaver centre the main thing is turning in a clean urine sample, if you turn in a dirty they act all surprised, news flash I’m a heroin addict, you have given me no support with my addictions except try and punish me for giving a dirty sample by putting me to the back of the queue, start all over again. I’ve had mental health problems longer than my heroin addiction. I also have people in charge of my care younger than my heroin addiction they haven’t a clue what they are doing and no comprehension that both mental health and addictions are usually intertwined. You should address both the causes of addiction and help with the mental conditions as they arise.

Norwich mental health services are seriously underfunded. Almost non-existent. At the Weavers they are an agency with no clue or medical knowledge although they claim to have medical training they are social workers who are fucking useless! My G.P won’t prescribe my methadone although she has the legal power to she just sends me to an agency that has no interest. The Weaver centre they are just doling out medicine with no other help advice or help available. More support needed!! They have no idea how I live or exist they never ask any questions i.e. what are my living conditions like or my financial situation is, am I on the right benefit do I need any help with anything no questions asked, no information exchange whatsoever, no interest. It’s all about clean samples.

If you produce a dirty sample they punish you by stopping your methadone script and send you back to the beginning. No questions about why you gave a dirty or understanding of my mental health conditions. Then they give you a crappy service as punishment for giving a dirty sample. If you try and access mental health services they just blame the drugs as the cause of your mental state, and are not interested in your mental health, mention drugs and they instantly use that as an excuse not to engage and wash their hands of you and dismiss you summarily. Also, no advice given on my dental problems. A major reason for my relapses. That’s all I can give you today but have many more thoughts on the matters we discussed.”
Mental Health is not an “Indulgence!”

Nor an “Offence!”

“It is misfortune for which no-one should be penalised, and the cost should be shared by the community.”

Andrew, 53yrs

Has suffered mental and physical abuse from childhood and many mental health issues. He used from a very young age, glue, solvents lighter gas, nicotine, alcohol, hashish, acid, skunk, amphetamine, magic mushrooms, ecstasy, cocaine, crack cocaine, heroin salvia-X50. Plus a lot of prescription drugs mainly benzos and sleepers. “Got to sleep sometime!”

“Tried to seek help for my addictions 27yrs ago, obviously didn’t work wasn’t till I was 42yrs I found City Reach. They offered help which I gratefully accepted, took a good 6-7yrs. Trying to detox that was a monumental struggle I don’t intend to repeat. My mental health was the reason for me using substances, I tried CBT, I went to one session the ignorant pr*ck would not even look me in the eye had his back turned to me the entire time after an 1hr of this I persuaded myself not to kick his chair from under him, I decided to leave him in his own personal misery. “What a C*nt!”

My experience with Norfolk NHS mental health was atrocious, would not recommend it to anyone total waste of time and only adds to the frustration. (“26% of NHS patients make their first appointment, the charity practice has a 94% attendance and operates on a human to human basis not “on a scale of 1-10 how much of our bullshit are you prepared to swallow or listen to?”

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George, 30’s

George is a 30 something ex-serviceman who, although now in secured accommodation, which was arrived at via the homeless pathway, is still suffering greatly with his mental health.

George has always been willing to engage with services but feels – “let down horribly”

“The support I’ve had is very little and its a struggle to keep support workers involved”

“I’ve had only 3 appointments from local Mental Health services in 2 years and the communication is crap.”

George says that “this has a detrimental effect on my mental health and wellbeing.”

George has been sober for the last six months and his own perception is that “Because I am now sober I don’t feel I am ‘damaged’ enough to warrant any mental health support. I imagine that services think that I am out of the woods and no further help needed.”

“Lack of support and communication – it just hasn’t worked for me”

“The only real meaningful help I’ve got is from the City Reach GP which has been invaluable and I feel if I hadn’t contacted them I would not be here right now”

“I feel so isolated due to my mental health and lack of support that I feel so vulnerable at times that leaving the house, even to attend a City Reach appointment, takes so much effort and they are the only place I feel has an interest in me as an individual and not a statistic”
3J. Experiences of service users and carers in Great Yarmouth and Waveney

Mental Health Crises and Emergency Care Qualitative Research for Healthwatch Norfolk

May 2017
1. Introduction

Healthwatch Norfolk commissioned Feedback Health to undertake qualitative research on service user and carers lived experience of mental health crisis and emergency care in Norfolk (including those residing in Waveney accessing Norfolk-based services). The findings of this research, along with those from other third sector organisations, will be collated and incorporated within a report from Healthwatch Norfolk to the East of England Urgent & Emergency Care Network (NHS Midlands & East).

1.1 Aims

- Capture qualitative information on the lived experience of people with or caring for someone with a mental health issue which could or did reach crisis point within the last two years
- Identify a) what helps to prevent crisis (b) the routes people choose to manage crisis and (c) gaps in provision for people experiencing mental health crisis (d) examples of good practice

1.2 Participants

In total, there were 18 participants, 10 of whom were recruited from Feedback Health’s Peer Support Groups, 3 via a NSFT Carers Lead and 5 from promotion by Great Yarmouth Library. 5 participants self-identified as carers, 10 as service users (2 of whom were also carers) and 3 preferred not to say. There was one couple who disclosed that they were mutual carers for one another. A second couple self-identified as having lived experience of learning disabilities. Ages were only recorded on the surveys completed (one participant was under 25, all others were aged 40+). 3 participants lived in a rural area. All participants identified their ethnicity as White British; two were living in a local homeless shelter and one was close to homelessness.

All participants voluntarily agreed to take part in the research and gave both verbal and written consent for the information that they shared to be shared with Healthwatch Norfolk and shared in the final report to the East of England Urgent & Emergency Care Network.

1.3 Method

Three focus groups were held between the 18th April – 8th May 2017 and facilitated by Feedback Health’s Development Manager. The purpose and nature of the
research was explained to participants and they were invited to share their lived experience of mental health crisis and accessing services with minimal prescription. The facilitator did, at times, need to guide the conversation within the focus groups and ask targeted questions pertinent to their lived experience of mental health crisis. All participants were offered a £20 involvement fee for taking part in the focus group and completing the Healthwatch Norfolk survey on mental health crisis and emergency care.

2. Findings

The majority of participants reported being able to recognise / self-identify triggers and/or signs of mental health crisis but were unsure where they should go to access appropriate support. Many felt that there were ‘experts by experience’ but that their insight and understanding of their own (or the person they cared-for) health condition was often ignored or not given sufficient ‘weighting’ by professionals. A number of participants expressed anxiety about accessing the wrong service for support during or prior to a crisis; for some, this anxiety resulted in them feeling unable to reach out at time of crisis through fear of being rejected or not receiving the right help.

Several sources of potential support to both prevent and manage crisis were identified:

- GP (Primary Care)
- Crisis Team (NSFT - Secondary Mental Health Services)
- Community Psychiatric Nurse (NSFT)
- Psychiatrist (NSFT)
- Accident and Emergency (A&E – Secondary Acute Services)
- Carers Leads / Assessors
- Friends and Family
- Peer Support Groups (in person or online)
- Salvation Army
- MIND
- Samaritians
- Church (example of Quakers)

In Group 1, people who were current service users accessing secondary mental health services from NSFT said that they were unsure ‘where to go in a crisis:

‘Where do I go: Northgate, James Paget [Hospital] or the Crisis Team?’

Crisis Team

Across all groups there was confusion about the role of the ‘Crisis Team’; one couple (who had self-identified as having learning disabilities) reported that they had been give the number of the Crisis Team but were unclear on when it was appropriate to
call them and what the support offer was. Concerns were also expressed about the capacity of the Crisis Team to respond to requests for support, in particular, visiting people at home. Participants from the rural area felt that there was not equitable access to Crisis Team support; that they were less likely to receive a home visit because of the additional travelling time involved. There was agreement that the Crisis Team needed additional funding to help prevent crises from escalating and keep people from being admitted as an ‘inpatient’ in secondary acute mental health services.

Out of Hours

‘My Mental gets worse after 6pm in the evening’

‘Where is the out of hours crisis line? Does it exist? What’s the number?’

There was a consensus view that out of hours provision was poor (some said ‘non-existent’) but yet this was often the time when people experienced a mental health crisis. Several people across all groups reported that their mental health was often worse and more difficult to manage at weekends and in the evenings. It was felt that services to support people prevent and manage mental health crises were not person-centred; the focus on supplying services during core working hours in the week was given as an example of how current service provision was not person-centred and responsive to the needs of both service users and carers.

Police

Several members of Group 1, including but not limited to those who self-identified as living in a homeless shelter or being close to homelessness, had extensive contact with the police in connection to their mental health. There were strongly held views in the group about the role of the police; there was consensus that the police required further training around mental health, too often people felt treated as criminals when they were unwell and exhibiting behaviours which caused the police concern. Participants felt that they had not seen the benefits ‘on the ground locally’ of mental health nurses working in the police control room at Wymondham; it was felt that nurses should also be co-located in local police stations and provide ongoing training and support to police on patrol and in local custody suites. Two participants reported being arrested multiple times and detained in custody during a mental health crisis; it was felt that police were well placed to refer people into appropriate support if supplied with the necessary training and knowledge of service provision.

However, an alternative view said ‘Getting violent helps you get help! Police take us to the S.136 suite’. Some people felt the only effective way to get support was to ‘get violent’ otherwise they were ‘invisible’ to services.
GP (Primary Care)

There were a mixture of both poor and positive experiences across the three groups in accessing GP support in preventing and/or managing a mental health crisis. GP care can be highly effective in preventing crisis – in these cases participants felt ‘listened to as an ‘expert by experience’, supported to self-manage their mental health and wellbeing. They also felt ‘confident’ that their GP understood mental health issues, including depression and anxiety and helped them to develop resilience by drawing on self-managing techniques such as crisis planning. Others reported feeling that difficulties in securing an appointment, short 5-10 minute consultations and attitudes/lack of understanding, prevented them from accessing effective help through primary care.

Recognition of the carer and their own wellbeing needs / mental health, was also seen as a critical factor in effective support from a GP in preventing and/or managing crisis; many participants felt that this didn’t happen in many cases and led to an escalation of crisis for either or both carer and cared-for. Training (e.g. Mental Health First Aid) for GP staff; in particular, reception / telephone staff, was identified as crucial in enabling people to access support from their GP; too often reception / telephone staff were perceived as creating barriers (gatekeeping) through a lack of sensitivity or awareness around mental health and the signs that someone is heading towards or is in crisis. It was suggested that GP surgeries should have access to (either by telephone or located in the surgery) a mental health nurse to support patients and carers.

Information on Services

All participants had found it difficult to find information about support available to them, from both statutory and third sector services. It was felt that service needed to be better and more broadly advertised within local communities; for example, participants asked if was possible for information on mental health services and the crisis pathway to be accessible in public libraries. Stigma was identified as a barrier to people accessing support, in particular, during a crisis, or in the build-up; it was felt that much more exposure in the local and national media was required to help de-stigmatise mental health.

‘Don’t know what Wellbeing is? How do I access it?’, ‘How do we find out information about these services’

Participants felt that there was a lack of coordination and partnership working in distributing information; distribution channels were not ‘close to the ground’ and good at reaching the people who needed it most.
Acute Care / Parity of Esteem

Several participants in Group 2 reported that the James Paget Hospital (A&E in particular) was good at ‘dealing with physical issues [but that] they didn’t want to know about enduring mental health issues’. A number of participants felt that they’d had to wait hours longer in A&E because staff had found it difficult to assess and prioritise mental health issues; perceiving that patients with visible physical conditions were seen quicker irrespective of the severity of the mental health crisis. Participants also felt that when receiving treatment for a physical issue at A&E, no consideration was given to the impact on their mental health (participants who self-disclosed an enduring diagnosed mental health condition), treatment options modified or support offered.

‘JPUH don’t seem to be mental health trained’

Only one participant had been aware of, or had contact with, the mental health liaison nurses at the JPUH. It was noted that this provision is not 24/7 and often crisis happens at times outside of the hours this support is available. Group 2 also reported poor experiences with the JPUH pharmacy:

‘Pharmacy at hospital poor; they accuse you of not taking your meds’

Two people under the care of Northgate Hospital also accessed A&E during a crisis found it difficult to obtain the required prescription from the hospital pharmacy who redirected them to NSFT (Northgate). Group 1 and 2 agreed that delays in receiving meds (from the acute or community pharmacy) contributed to the triggering of crises.

Discharge

All groups raised discharge from services (especially secondary mental health services) as a significant cause for concern on preventing and managing mental health crises. Several participants had been discharged from secondary mental health services months or years prior to the research; some of those had subsequently experienced crisis. Participants reported not being given the information on how and when to re-access services or given the tools to self-manage their mental health & wellbeing.

‘People discharged from services have nowhere to turn to in crisis other than peer support groups like Feedback or their GP’

‘We need proper discharge packages with annual reviews’

Some felt that the pressure on services (both community and acute) to discharge people was so great that opportunities to build resilience and empower services users and carers to self-manage were being lost. Information – key phone number or contact – pathway to access services – was seen as critical to achieving positive outcomes but felt this was lacking at present.
Housing

‘Why are mental health service users being forced out of residential accommodation into older people’s sheltered housing?’

‘Housing issues can cause a mental health crisis’

Some participants felt that they didn’t receive support from housing providers when they experienced mental health crisis but recognised that they were well placed to reduce, prevent and de-escalate crises. Four participants felt negatively about being moved out of a mental housing project into sheltered accommodation (two were under the age of 55). There was consensus that more training for housing staff was required (e.g. mental health first aid) as was greater integration with mental health services. Several participants were anxious that people were being discharged into the community without sufficient report or enough consideration to housing and the role it can play in someone’s mental health and wellbeing.

Carers Leads / Assessors

There was a consensus that Carers Leads in NSFT and Carers Assessors at Norfolk County Council played an invaluable role in preventing and de-escalating crises for both carer and cared-for. Participants reports that the Carers Leads were kind, empathetic, respectful and helped them to plan ahead, giving them tools to develop resilience and self-manage where possible. Two carers stated that they wouldn’t have been able to continue caring if it hadn’t been for the intervention of the Carers Lead from NSFT. A Young Adult Carer (who was also a service user) reported that the NCC Carers Assessor had recognised that he needed support with his own mental health needs and had arranged additional support for his-cared for which helped to reduce pressure on the whole family and enabled him to continue in further education.

Both Carers Groups and education events run by Carers Leads locally were highlighted as helping to develop resilience, self-manage and avoid crisis – both provided a route through back to services (both statutory and third sector). Participants expressed concerns that annual carer reviews were not always being undertaken by the local authority – that these help carers to prevent and manage crisis – sometimes carers are going years in-between assessments.

Peer Support

Peer Support (either from friends and family or through informal and formal groups in person and online) was identified across all three groups as one of the most important sources of support in preventing (and sometimes de-escalating / managing) crises.
'My friends recognise when I’m not well or feeling low; they help lift me up and encourage me to talk to my Lead Care Professional'

‘The Feedback Peer Support Group is part of what keeps me well; it’s an important part of my crisis planning’

Access to peer support was a pre-requisite for self-management for many participants; with support and shared experiences of peers helpful in creating and maintaining motivation. Participants felt that peer support helped them maintain or develop their independence and sometimes gave a reason to ‘get out of bed’ or ‘get out of the house’. Broader local networks, including local shops, community pharmacy, churches and other community groups were also identified as playing a key role in reducing or preventing crises. Connectivity within their local community was very important to most participants – they drew strength from their connections which helped to keep them well.

3. Recommendations

- Better access to information and tools around crisis planning and access to service provision (e.g. Wellbeing and talking therapies).
- Clearer ‘Crisis Pathway’ – who to contact, how and when (clarify role of Crisis Team)
- Review of discharge planning process – better support to enable people to self-manage and build resilience. Include the carer in the discharge planning process.
- Increase access to training for professionals, including GP surgery staff, police and general acute hospital staff and housing providers.
- Develop and increase peer support opportunities and utilisation of local networks (including stronger links between formal services and peer support groups).
- Improve management of co-morbidities; involve experts by experience in training of medical staff to help them better understand the links and interaction between physical and mental health.
3K. Mental health provision for refugees and asylum seekers in Norfolk

Focus group report: Mental health provision for refugees and asylum seekers in Norwich

The Grange and New Routes held a focus group on Monday 22nd May 2017 with three people.

- A is a 27-year-old Iranian man who has been in the UK for four years and is still claiming asylum
- B is a 43-year-old Kurdish woman who has been in the UK for 14 years and has refugee status
- C is a 32-year-old Iraqi man who has been in the UK for 2 years and has refugee status

The focus group was facilitated by Ben Margolis from The Grange and notes were taken by Amelie Sells from New Routes. What follows is a summary of those notes.

Health

The group discussed what they think ‘Health’ is. They raised several areas including food, physical, environment but all strongly agreed that by far the most important is the mind. B said, “If you are not health mind, you can’t use your body.” They all felt that having a health mind is vital and that for almost all the asylum seekers and refugees they know this is a constant challenge.

The group also felt that a healthy environment and community are vital and all feel that Norwich is a good place to be for both of these. It is a quiet city and there are excellent support services with people who really care for them. A said, “In a big city like Birmingham nobody knows who you are or cares. Here people care for you. I recently stayed in my room for 3 weeks and they [staff from New Routes] called me and came to see me and got me out again.”

The group then discussed what they think mental health is. They all felt that British people would probably place physical health before mental health but that they feel it should be the other way round.
Mental health

Words associated with poor mental health in the refugee community include: Angry, stress; nervous, anxiety, worry, scared, headaches, upset, crying, physical pain, unaware of action, not sleeping, lonely.

C said “The solution is that everyone needs a person like a Mum to care for them.” We explored this and all felt that a vital aspect of improving mental health is to have someone to really look out for you and care for you. A noted that under 18 year old asylum seekers (UASC) have a social worker but adults need this as well.

We talked about what happens in their home countries if people have a mental health problem. All felt that everyone in their home countries has some mental health problem due to war, stress and anxiety. It only becomes treated if it is severe. At that stage you would visit a doctor and be prescribed pills. You might then be sent to a mental health hospital and potentially locked up (B talked about a woman who was locked in a room for 4 years).

C then talked about his own experience of seeing a doctor for his mental health. He was prescribed pills and told to come back when they were finished and he could potentially get a higher dose. Within two days, C was very ill and woke up in the toilet now knowing what had happened. His eyes were wide. He found his way back to the GP but passed out outside and claims he was told to go away as they thought he was on (illegal) drugs. He now won’t go back to a GP.

A said that his doctor is a refugee from the same country as him and it is very important your doctor has a cultural understanding of your situation. However, he noted even then his doctor can’t do anything for him. He is currently very depressed and doesn’t know what support he needs.

A said that he always puts on a happy face. He helps friends with their children and goes to groups sometimes and people think he is happy. But in the last year he feels he has fallen apart. “People say to me I am not the person I was a year ago.”
What is needed to support asylum seekers and refugees with mental health challenges?

B has had a lot of 1:1 counselling which she has found useful. We talked about the potential for peer to peer counselling and for some refugees and asylum seekers to be trained to offer this. B said she tried to do a counselling course but couldn’t handle it – you have to be really strong to do the training.

B feels that with 1:1 counselling it needs to be ongoing because it makes ‘everything come out of your body and mind for a little while but after that it just comes back stronger.’

C feels that informal friendship and advice is very important.

The biggest challenges for asylum seekers is the stress of not knowing what the future holds as well as dealing with the trauma from the past. They come here seeking safety but find a lot of anxiety, stress, worry and panic waiting for the letter from the Home Office.

Mentoring and peer support are important. A’s are the support services offered by Red Cross, New Routes, English Plus and others.

For any sort of 1:1 therapy, interpreters would be really important. B feels that a therapy group with a trained psychotherapist could be very helpful. We discussed similar groups in London and agreed they rely on everyone having some level of English.

It is critical to know that people care about you – whoever they are.

Early intervention is vital. ALL asylum seekers have mental health problems but very few get any real support with that.

A feels that a charity like New Routes but with a focus on mental health would be good. He has never heard of MIND or other mental health charities but would try and access them if he know he could and if he got referred.

A has been referred to the wellbeing clinic but has been told there is at least a 2 month wait. He feels he needs help urgently.

It is very important that doctors and others understand what it means to be an asylum seeker.

A said that we must think about the future when there might be far more refugees and asylum seekers in Norwich and how would the services cope then. What services do there need to be to cope with even greater numbers. All felt that peer to peer support is vital perhaps with some training in facilitation for refugees and asylum seekers. All said they are happy and keen to help others in their situation.
3L. A validation workshop

On the 10th May, during Mental Health Awareness Week, representatives from the organisations contributing to this work got together for a validation workshop.

The validation workshop was held so that the recurring themes and key messages arising from the views, experiences and insight drawn from all the organisations could be discussed and weighed up. In qualitative approaches, such as that used mainly to generate the content of this report, this is sometimes called ‘triangulation’. Put simply, this means bringing together key pieces of information from different people and places and collected using different methodologies. The aim was to condense a lot of material down into some key insights about urgent and emergency service use during times of mental health crisis. To give the discussion some structure, a set of initial themes around service use during mental health crisis were drawn out of the eleven components of service user, carer and stakeholder voice, like so:

- Prevention, Escalation, Expectations
- Reality, The Lived Experience
- Right Care, Right Time, Right Place
- Gaps, Improvements

A ‘Graphic Facilitator’ was engaged to capture the content of the conversation during the workshop. The output is shown overleaf in Fig 8. During the discussion, the following points arose:

- **Prevention, Escalation, Expectations**
  - Each individual has a threshold, trigger(s) such as housing, relationship, employment and money worries, addiction
  - To keep people safe, care plans are really important
  - Some people have a network around them, others don’t

- **Reality, the Lived Experience**
  - With so many commissioners there is much fragmentation
  - Not every person has the insight to seek help at times of crisis
  - There needs to be a toolkit for the service user and carer - a ‘menu of options’ for treatment, support and care

- **Right Care, Right Time, Right Place**
  - Accessing services and getting the right help can be a ‘lottery’
  - Messages about which services to contact and which to choose need to be CLEAR and CONSISTENT i.e. telephone your GP, call NHS 111, go to A&E, call the Crisis Team or your care coordinator

- **Gaps, Improvements**
  - Many feel that cuts in budgets have had the greatest impact on mental health services - why is no-one trying to measure the impact?
  - Services need to consider both the ‘mental’ and ‘physical’
Figure 8 Workshop discussion on the lived experience of urgent and emergency services at times of mental health crisis
4. Summary

This work aimed to gather views and experiences of using urgent and emergency services at times of mental health crisis. At least 686 individuals have contributed to the making of this report, with the multiple contributors to the data gathering exercise achieving:

- 199 survey responses from mental health service users and carers
- An audit of 10,942 calls to a mental health crisis helpline by 498 distinct callers
- Face to face, one to one and paired interviews with 50 individuals (service users and carers)
- Informal discussion groups comprised of 21 individuals (mental health service users and mental health carers)
- 33 case stories
- One to one interviews with 18 stakeholders (executives, senior managers, commissioners, service providers, clinicians and practitioners)

One hundred and forty five (145) people out of 161 responding to our survey had experienced a mental health crisis within the last two years, 60% of whom said they were able to plan ahead for times of crisis to some extent. The other 40% were not able to plan for times of crisis; some due to the severity of their mental health condition and others due to the unpredictable nature of their condition or a level of uncertainty, stress or even chaos in their daily lives. Eighteen percent (18%) had a crisis plan in place and had used it, however, half (50%) didn’t have a plan or used to have plan and wanted to have a crisis plan in place now.

Outside of office hours, 35% of mental health service users and carers knew who to contact during a crisis however, 49% did not know who to contact and 16% were unsure. Forty percent of people said they hadn’t needed to contact someone out of office hours, 30% said they had got help from the person or service they’d contacted whilst 30% had not been able to successfully contact a person or a service and had therefore got no help at all.

"Where is the out of hours crisis line? Does it exist? What’s the number?"

Using NHS 111 as an out-of-hours starting point for mental health crisis is not at all widely known or used, although people did report using NHS 111 as part of the process for accessing their GP outside of office hours. Often using NHS 111 led to a person being directed to a GP out of hours location or be redirected to A&E. Demand for the Norwich & Central Norfolk MIND Mental Health Support Line is steadily increasing and demand peaks at 4pm-5pm and again over the period between 8pm and 11pm.

Together, the interviews, focus groups and case studies present a mixed picture of the lived experience of mental health crisis, however, it is quite clear that whilst people and services can come together to provide a person with the right care at the right time, many people’s experiences of trying to getting help and support are unsatisfactory and at times, uncaring, unwelcoming, unsafe and ineffective.
4.1 Use of urgent and emergency services

When using services, all combined survey responses from both mental health service users or carers, indicated the following service experiences were likely to be rated as “very good” or “quite good”:

- GPs - 55%
- Community pharmacy - 41%
- Ambulance service - 34%
- A&E department - 31%

When using services, all combined survey responses from both mental health service users or carers, indicated the following service experiences were likely to be rated as “very poor” or “quite poor”:

- NHS community mental health services - 41%
- GPs - 24%

The picture is most mixed for GPs and this is something that was cross-referenced through our validation workshop. Find a GP with an interest in and supportive attitude towards mental wellbeing can “be a bit of a lottery”.

The stakeholders we spoke to highlighted to us that:

- Demand for NHS services is increasing all the time
- Demand for the Norwich & Central Norfolk MIND Mental Health Support Line is steadily increasing, with peak demands between 4pm-5pm and 8pm and 11pm
- Patient, service user, carer and families expectations of what services can provide and what they will do, are rising
- People’s expectations do not match the reality of service provision
- Frontline service personnel are working very hard, around the clock and want to give the best possible service they can
- Services have finite resources and cannot be all things to all people: there are limitations
- Increasingly, healthcare professionals and services are being expected to provide strategies and solutions for problems which are often outside of their ability to influence e.g. social, financial, housing, employment, relationship problems etc

Throughout many of the conversations, service users and carers described a complete lack of information about services and a struggle to access to services, along with the expectation of some kind of ‘twin-track’ or ‘fast-track’ route into mental health crisis services, which does not actually exist. As it has been described to us, the intensity, distress and confusion of a mental health crisis means people are in an acute and extreme physical, mental and emotional state: the overwhelming feeling is wanting to get help and support as soon as possible. We found however, that the urgent and emergency care pathway is much the same pathway for mental health emergencies as it is for physical health emergencies, unless a person is already known to services, has a crisis care plan in place or is already receiving some kind of treatment, care and support.
We also found that:

- There is a lack of clarity on what service to call out of hours e.g. NHS 111
- People are confused over the messages about when to go to A&E
- Service users don’t always have a Crisis Care Plan in place but they want one

4.2 When services work well

Things go better for mental health service users and their carers when they have access to highly skilled and experienced specialists in mental health crisis care available at times of greatest need. Having their own, tailored, up-to-date ‘Crisis Care Plan’ can make a big difference. Ideally, this crisis care plan should contain information and actions to take, which helps them plan for what they might need to do. This might include specific ‘triggers’ to look out for, setting out clearly who to contact, where to go plus useful tactics and activities to do whilst waiting for help or for distraction.

Many service users and mental health carers referred to the need for a full and thorough assessment to be conducted prior to discharge from any mental health service - in-patient or community based, or when moving between services. This can help prevent crisis and readmission. When this is overlooked at the point of discharge, it is possible for people to fall through some of the gaps in services. When it works well, it means that the receiving service or new clinician or practitioner has the information they need to be able to prepare and to support the individual.

Mental health service users who have family members, friends, carers and co-workers around who are aware of what they need and are able to provide it find that this helps enormously. The exception to this is generally in the case of another person whose attitude, behaviour or treatment of the mental health service user acts a ‘trigger point’ for a crisis. Family members, carers and friends can also act in the critical role of advocate, especially when they are very familiar with the behaviour of the mental health service user and can recognise when that person is saying what the professionals want to hear in order to achieve a particular action or a result.

There are a wealth of services provided the community and voluntary sector - which are often highly tailored and supportive but often over-looked by health professionals and under-valued. These sorts of services enable the service user to develop and maintain social networks and friendships, within communities that are prepared and ready to ‘embrace’ mental health and wellbeing. Such services are often designed to be able to provide more time for listening to a service user and have greater flexibility not only in the physical environment or location but in how the service is shaped. Safe places in calm, welcoming and friendly spaces are highly valued and both service users and carers wish to avoid waiting areas and communal places that are noisy and busy.

Support for mental health carers has been highlighted as essential. When carers have access to good quality information or better yet, education, training and support, they are much better placed to offer support and to identify triggers or specific behaviours which may signal the start of a crisis, then take steps to help prevent the crisis happening.
Services work better for people when they are viewed as being the ‘expert by experience’ in terms of their mental health and wellbeing. The kinds of words and phrases that users and carers used to describe the positive qualities, attributes and behaviours of people and services they encounter included:

“always takes time to listen”
“they get back to me really quickly”
“don’t judge you”
“good communication between the psychiatrists and the nurses”
“knows how to manage my illness when I report my symptoms”
“they were very clear about what they could and couldn’t do. They were firm”
“They have walked the walk, no crap, they tell it how it is because they have experienced mental health”
“I have staff that I trust and who look out for me, they understand that I have good and bad days and they look past my mistakes”
“very patient”
“doesn’t use a computer when talking to us”
“making me feel like there was options”

4.3 How can services be improved?

4.3.1 Increased resourcing of mental health crisis services

Since our inception in April 2013, we have observed that, in general, we receive more negative feedback on services than positive. It is widely acknowledged that when it comes to public services, service users are simply more likely to want to share a negative experience than a positive one. There are many, many positive experiences of health care happening every day yet less is heard about those.

This piece of work did not set out with the purpose of specifically gathering views and experiences on the Norfolk and Suffolk Foundation Trust nor specifically on the mental health crisis services or teams in the county.

Having said that, however, the views and experiences of patients, service users, carers and families of their experiences of mental health services provided by the Norfolk & Suffolk Foundation Trust are at best mixed and at worst poor, unresponsive and unsafe. People have said that community mental health teams can be really supportive and in particular, there have been several references to the value, expertise and care provided by community psychiatric nurses (CPNs). Overall, the feedback we’ve gathered for this piece of work described a consistently unsatisfactory picture of mental health service provision - in particular at times of mental health crisis - in our county.
It is evident from our findings that people want mental health crisis service in Norfolk to not only to improve; but be better funded, better staffed, more responsive and to respond in a manner that does not make service users feel bad about themselves any more than they do already. Mental health carers would also like their knowledge and insight into the needs of the service user heard, considered and valued as useful contribution to the service user’s journey and recovery.

We had many reports of lengthy waiting times for both assessment and for treatment and care. We also heard genuine empathy for front line mental health professionals who are deemed to be doing the best they can with the resources available to them. Many of the participants in this work expressed severe concerns about inadequate resourcing of our mental health services and in particular, mental health crisis services.

Many people wish to see funds allocated to or redirected into mental health services.

4.3.2 Consistency of messages for the public about A&E: to go or not to go?

It is apparent from the feedback and case stories presented here that go to an Accident and Emergency Department (A&E) is an integral part of the mental health crisis care pathway and service experience, just as it is for any other physical health or medical emergency:

*Essentially, this means the mental health crisis care pathway is the same as the NHS urgent and emergency pathway. Every individual has equity of access to urgent and emergency care whether they have a physical or mental health need:*

\[
\text{GP} \Rightarrow \text{NHS 111/out-of-hours} \Rightarrow \text{A&E} \Rightarrow 999 \Rightarrow \text{specialist treatment}
\]

Conversely, the public are frequently told to stay away from A&E unless they absolutely need to go. Whilst offering equity of access to all, the reality is that this pathway *is not perceived as accessible* by some mental health service users, for a number of reasons.

Mental health service users and carers have told us that there are times when they absolutely need to go to A&E to seek urgent treatment and care during a crisis. Mental health service professionals have also told us that for some individuals, when they are very unwell, they lack insight into their state of health and state of mind and thus unable to make a decision about where to go and who to contact. Family members, carers, neighbours and co-workers may be the people who are trying to get hold of urgent help for a person. The confusing nature of mixed messages about going to A&E does not help at all.

We would like the NHS England East of England Urgent and Emergency Care Network to use their influence to make sure there is clarity on whether or not the public should go to A&E.

4.3.3 Appreciate the true value of the community and voluntary sector contribution

Many of the participants in this piece of work told us about a wide variety of services they are using provided by community and voluntary sector organisations, these included; mental health emergency telephone helplines, support groups, carers groups, peer-
support, drop-ins, cafes, support workers, be-frienders, community hubs and many more. The funding of such services can be tenuous but their value in helping to prevent crisis should not be overlooked.

4.3.4 Learning to be gained

Drawing on what people have told us, there are some services and some individuals who are perceived as being particularly good at supporting people in mental health crisis. These people and services may be encountered anywhere along the urgent and emergency care service pathway. We have heard some very positive feedback about paramedics, community pharmacists, community psychiatric nurses and GPs. This can be summarized as:

Whilst it most certainly can “be a bit of a lottery”, when a mental health service user has what they consider to be a good GP it can make a huge difference. We heard some negative things about GPs attitudes to people with mental health problems, however, some individuals spoke highly of their GP and the following qualities are those which elevate a GP to being an especially valued professional; “listening”, “understanding”, helping, not judging and referring people on to services which give the service user the right kind of care when they need it most.

**Paramedics** are trained and experienced in dealing with all manner of emergency situations. Service users and families are very often relieved and reassured when the paramedics arrive to assist a person who is, for example, exhibiting challenging behaviours, experiencing hallucinations or voices and has attempted to, or is deemed to be about to, seriously injure themselves or another person. The paramedic in the green uniform has a solid, professional identity and carries an aura of calm and authority. Some of the words used to describe paramedics were “amazing”, “fabulous” and “outstanding”. Paramedics have the ability to remain unfazed and in control in many situations and send a strong, non-verbal signal that professional help and the individual (and others around them) are no longer alone in a frightening and dangerous scenario. This strongly-held view of the paramedics is something we have found evidence of in our previous work as well²⁹.

**Community pharmacists** are rated very highly by mental health service users and carers and it is their ability to build a longer term relationship with a patient that has been expressed to us as very important. Service users consider community pharmacists to be professional and experts in their own field but they also are appreciative of the pharmacist’s ability to remain non-judgemental - “doesn’t judge me”. Service users have told us that community pharmacists can be seeing a person over a long period of time, for example, during a period of intense substance use, self-medication or self-harming (for needle-exchange services) and throughout a long journey of recovery (for supervised consumption of methadone services). Service users build a relationship with the community pharmacist and going to a high street pharmacy is a “normal” experience for most people, so they don’t feel like they are being singled out as different or ‘second-class’.

We heard a mixed story about attendances to **A&E**. For some this had worked out well as they felt were seen and treated quickly and would have waited longer for help if they had

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gone elsewhere. Some mental health service users and carers describe A&E waiting areas as noisy, confusing and distressing at the best of times and they can be a terrible place for a person in crisis. Some people spoke well of the attitudes of staff in A&E and their ease with dealing with people who may be exhibiting some challenging behaviours. A sense of being judged or mocked by some staff in A&E was reported by some participants in this work, along with some insensitivity in communicating key issues to family members and carers. Whilst the messages are not directly communicated by the A&E departments’ themselves, other organisations are frequently telling the public to ‘stay away’ from A&E, adding to the confusion about whether or not A&E is the appropriate place to go in times of crisis whether or not this is an option in a person’s care plan.

Service users and carers alike spoke highly of the relationship they had developed with their Community Psychiatric Nurse over a period of treatment and care in the community. Service users in particular feel that their CPN knows them very well and they find this reassuring; “We had a good CPN who was marvellous, very understanding and empathetic, helping us to make our own decisions”. Carers spoke about wanting to have one clear point of contact when they sense a crisis could be escalating. Both service users and carers find it upsetting and difficult when staff members leave a team or are replaced by new members they aren’t familiar with.

Whilst not NHS services, we did hear many positive things about a wide range of services provided by the community and voluntary sector. Again, people working in these services have similar qualities and ways of working to health and social care workers, for example, in; listening, not judging, providing information and acting as advisors and advocates. The other - and very important thing - that these services often provide is a place to go, somewhere to be.

4.4 Next steps

Healthwatch Norfolk is keen to share the findings of this work with the people and organisations in the county and region who are responsible for commissioning and providing mental health crisis services. In particular, we wish to highlight:

- Mental health crisis care plans are important - people want them
- Messages on who to contact and where to go in a crisis should be clear and consistent
- Mental health crisis services are under-resourced and this requires an urgent redress
- The community and voluntary already make a substantial contribution to the provision of information, advocacy, support and ‘safe places to be’. Future models of care involving this sector look promising but need to be fully planned and resourced and most importantly, be used to complement, not replace, high quality NHS treat and care

Healthwatch Norfolk would like the NHS England East of England Urgent and Emergency Care Network to publish this report and make it available in Norfolk and to other areas too. We would especially like those people who have contributed and participated and to be able to see and read what others have said and for mental health service users to know that their feedback has been a very important part of helping to improve crisis services for themselves and for others.