What have local people told us they would like to see in our five year plan for health and care?

(Interim report – 19 July 2019)

Background

All Sustainability and Transformation Partnerships and Integrated Care Systems are developing five year plans for health and care in their local area, covering the period to 2023/24. These local plans will set out how the national NHS Long Term Plan will be implemented across the country, as well as what health and care partnerships are doing to address specific local issues.

In the spring of 2019, Healthwatch Norfolk conducted some early engagement to help with the development of our five year plan for health and care. They conducted two surveys – one for the general public and one about long-term conditions – as well as six workshops across Norfolk and Waveney. 610 people completed the surveys and 101 people attended the workshops. Thank you to everyone who took part. Read their report – it makes interesting reading and gives us a lot to reflect on.

At the same time, we have also collated this report which summarises the findings from research, engagement and consultation carried out in the past two years by the partner organisations of the Norfolk and Waveney Sustainability and Transformation Partnership, as well as work some of the other engagement that has been done by Healthwatch independently.

This report is structured around the main chapters of the NHS Long Term Plan and it will be used to help inform the development of our local five year plan for Norfolk and Waveney. We're continuing to talk to people about our plan over the summer of 2019. We will be adding further information to this report, including the ideas people put forward via our crowdsourcing site and our face-to-face engagement, before we publish a final version in the autumn.

Please note that in order to make writing this report manageable and readable, it is not exhaustive. The report focuses on research, engagement and consultation that has been conducted across Norfolk and Waveney (at 'system' level) and at CCG or 'place' level. There are lots of insightful and valuable pieces of research and engagement that have been conducted at a more local level, the results of which are being used to improve policy and practice, but for practical reasons they are not included in this report.

Our approach to engagement is to have a continuous and ongoing dialogue with local people and groups. So in addition to formal pieces of research and consultation, there are many conversations which take place in a whole range of forums which also contribute to our understanding and development of health and care services.

A new service model for the 21st century

Our population is growing, people are generally living longer and the type of care that people need is changing. This means that how we look after ourselves, and how health and care services work together to care for people, also needs to change.

Here are the five major changes we will be making to our model of care over the next five years:

1. **People will receive more joined-up and coordinated care, near to where they live, from primary and community health services.**
2. **We will reduce pressure on emergency hospital services.**
3. **People will get more control over their own health, and more personalised care when they need it.**
4. **New technology will modernise our health and care system.**
5. **Local health and care services will work more closely together and use data more effectively to improve people's health and wellbeing.**

Here is a summary of what people have told us about our model of care, what is working and what needs to change:

Primary care

- People have mixed experiences of being able to access primary care – on the whole people can get an appointment in an emergency, but for some people getting more routine appointments is a problem. 46% of patients responding to one of our surveys agreed or strongly agreed that they find it easy to book a routine appointment at a time which suits them.
- A few people have told us they would like to be able to see a named GP, but that that this is not always possible at their surgery. Some people have told us that they think it is particularly important for those with long-term conditions to be able to see the same GP or nurse when they need an appointment.
- Some people have told us they like the idea of outpatient appointments being held at GP surgeries, so that they don't have to travel to hospital.
- People broadly support introducing new roles into primary care, such as pharmacists and physician associates. It's important that we make the best use of nurses who are real specialists in particular conditions and in some cases know more than some GPs. We need to make sure that we don't ask nurses and other professionals to do more than they are capable of or comfortable with though.

Hospital care

- People generally like the current model of local services for simple procedures and treatments and attending specialist centres for complex procedures. For example people currently receive more routine cardiology services at the Queen Elizabeth Hospital, but travel to Papworth Hospital for more specialist treatment.

- People have told us they are worried about transport. They are concerned about services being moved around and having to travel to another hospital that is further away to get the care they need.
- People have different views about whether they would be willing to travel further in order to receive planned surgery or treatment more quickly, some people would readily take-up the offer to be seen more quickly and others would rather wait and be seen at their nearest hospital.

Integrating health and care services

- The majority of people strongly support the idea of more integrated working and what we want to achieve.
- Some people have told us we need to turn talk into action though; saying that integrating health and social care services has been talked about for a long time, but it feels like progress has been slow.
- People have told us that poor communication and coordination between professionals, cultural differences between organisations and using different technology and software are all barriers which are preventing the integration of services.

Sources:

- ‘Summary of the Healthwatch Norfolk events about the Norfolk and Waveney Sustainability and Transformation Partnership’ (December 2017)

  https://www.norfolkandwaveneypartnership.org.uk/publication/previous-engagement-work/13-report-from-taverham,-king-s-lynn-and-great-yarmouth-events-november-december-2017/file

- ‘The future of health and care in Norfolk and Waveney’ (May 2018)

  https://www.norfolkandwaveneypartnership.org.uk/publication/previous-engagement-work/12-report-from-lowestoft-event-april-2018/file

- ‘GP Forward View Improved Access Patient Survey Responses’ (Norfolk and Waveney’s CCGs, December 2017)

  https://www.northnorfolkccg.nhs.uk/sites/default/files/Patient%20Survey%20for%20Stakeholder%20Event.pdf

- ‘An analysis of responses from the public consultation for Norwich Clinical Commissioning Group’s new model of care’ (Healthwatch Norfolk, October 2018)

  https://www.norwichccg.nhs.uk/publications-policies-and-documents/governing-body-papers/governing-body-papers-2019/january-2019/3355-item-20-1-app-a-hwn-final-report-on-the-new-models-of-care-consultation

More NHS action on prevention and health inequalities

Prevention

Here is a summary of what people have told us about prevention:

- Education and early intervention are vital. It’s important that we teach children and young people more about healthy living. In addition, we also need to encourage and support parents and carers so that they have the right knowledge and understanding about healthy living.
- There needs to be a broad range of activities on offer to keep children healthy and well, including in the school holidays.
- We need to make it easy for people to get the health information they need to make informed choices about their own health and wellbeing.
- Active and involved communities are important and help to keep people healthy and well, and we need to put more focus on helping to build stronger communities.
- It’s important we consider travel and transport to and from formal health services and activities which keep people healthy and well. The rural nature of parts of Norfolk and Waveney, and the cost transport can be barriers to people living healthy lifestyles.
- Working collaboratively in partnership and bringing people together provides an opportunity to strengthen our approach to prevention and should result in better health outcomes.
- Social prescribing can be a good way of providing support to people and helps to tackle some people’s underlying issues, such as loneliness and social isolation. A few people have raised concerns about its effectiveness and whether the voluntary, community and social enterprise sector could cope without additional resources to increase their capacity.
- Some people have told us they are concerned there have been cuts to preventative services over the past few years and/or that we need to invest more in preventative services.
- A few people said that whilst much good work has been done to raise awareness about health prevention, some preventative services do not have enough capacity and there is not always enough information about alternatives for professionals if services are full.
- Investing in primary care services will help to keep people healthy and well. Some people have told us that they are concerned that some GPs are over-stretched and it can be difficult for people to get an appointment with them, so some patients might miss out on being referred to preventative services and end-up at A&E in crisis.
- We need to tackle the wider determinants of health, including housing and poverty.
- We should support community development and the voluntary sector in more deprived areas, where it is more difficult to recruit volunteers.

Source: ‘The future of health and care in Norfolk and Waveney’ (May 2018)

https://www.norfolkandwaveneypartnership.org.uk/publication/previous-engagement-work/12-report-from-lowestoft-event-april-2018/file

A strong start in life for children and young people

Maternity and neonatal services

Results of the national 2018 Maternity Survey

Overall, the maternity services at the Norfolk and Norwich, Queen Elizabeth and James Paget hospitals all received very similar scores to trusts across the country from mothers responding to questions about their care in the Care Quality Commission's 2018 Maternity Survey.

The questionnaire was sent to all women who gave birth in February 2018 (and January 2018 at smaller trusts), and it contains 19 questions covering labour and birth, staffing and care in hospital after birth. When compared with most other trusts from across the country, there were only a few differences:

- The James Paget University Hospitals NHS Foundation Trust scored slightly better for 'Receiving appropriate advice and support at the start of labour', but slightly worse for 'Partners being involved as much as they wanted'.
- The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust scored slightly better for 'If attention was needed during labour and birth, a member of staff helped them within a reasonable amount of time' and 'Being treated with respect and dignity during labour and birth'.
- The Norfolk and Norwich University Hospitals NHS Foundation Trust scored slightly better for 'Being treated with respect and dignity during labour and birth', but slightly worse for 'Feeling the stay in hospital after the birth was the right amount of time' and 'Discharge from hospital being delayed'.

Please note the CQC only provide trust level results for the labour and birth section of the questionnaire. The survey also asked women about their experiences of antenatal and postnatal care to cover the entire pregnancy and birth for completeness. However, some women who gave birth at an acute trust may not have received their antenatal and postnatal care from that same trust. Here are the key findings for England for all aspects of maternity care:

Overall, women reported positive experiences for many areas of their maternity care in 2018, this includes:

- being asked how they feel emotionally during antenatal care
- feeling listened to by midwives during antenatal check-ups
- being spoken to in a way they understood during labour and birth
- having confidence and trust in the staff caring for them
- being treated with respect and dignity
- their partner (or someone else close to them) being involved during labour and birth

However, while there had been small improvements across most questions from 2013 to 2017, very few questions showed this trend continuing between 2017 and 2018, with some questions showing a decline.

This includes women's experiences of:

- being given enough information about emotional changes which may be experienced after giving birth
- being visited by a midwife at home after giving birth
- seeing a midwife often enough at home after giving birth
- staff awareness of the mother and baby's medical history
- being given enough information about their physical recovery after giving birth

Source: 'Maternity Survey 2018' (CQC, January 2019)

www.cqc.org.uk/cqc_survey/5

Findings from our engagement with parents and carers in Norfolk and Waveney

We also conducted some local research into maternity services last year. In 2016 NHS England published 'Better Births: Improving outcomes of maternity services in England'. The report set out NHS England's vision for the planning, design and safe delivery of maternity services; how women, babies and families will be able to get the type of care they want; and how staff will be supported to deliver such care.

To help us implement the recommendations of 'Better Births' in Norfolk and Waveney, we asked parents and carers what they think of local maternity services. We interviewed and surveyed almost 450 parents and carers. Here is a summary of what they told us about local maternity services:

- Overall, mothers and partners were positive about their experience of having a baby in Norfolk and Waveney and the care they received throughout their pregnancy, during labour and after giving birth.
- Many mothers and partners praised the midwives and other health professionals that looked after them for being caring, kind and passionate about doing their job well, particularly those that work at the hospitals and helped to deliver their babies.
- Mothers and partners told us that when they built-up a relationship with a midwife it helped them to feel more comfortable, less worried about things and more trusting of the professional caring for them.
- Mothers and partners who saw quite a lot of different midwives didn't like having to repeat their medical history. For quite a lot of people they saw this is a waste of time, frustrating or "a pain".
- For some people though, such as parents and carers with mental health conditions, it is really difficult having to tell their story to lots of midwives. And at the same time, it is particularly important that each midwife that cares for them truly understands their situation.
- Some parents and carers said that they don't think that having one midwife providing all their care, is particularly practical or realistic. The majority of the parents and carers said that their preference is to either be cared for by a small

team of midwives throughout pregnancy, during birth and after birth, or to have one midwife care for them before and after birth.

- The mothers and partners who felt involved in making decisions about their care and felt that their birth plan was followed where possible were more positive about their experience than those who didn't feel listened to or who felt left out of the decision making process.
- Some mothers and partners said that they were left feeling unsupported and confused after receiving conflicting or inadequate advice and guidance, particularly around breast feeding.
- A few mothers who were having their second or third child said that they felt did not receive enough support and that it was assumed they would be ok because they had already had a child.

Source: What did parents and carers think of maternity services in Norfolk and Waveney in 2018? (Norfolk and Waveney STP, June 2018)

Early years and early childhood development

Children's Centre Parental Satisfaction Survey 2017

6,500 parents and carers completed the 2017 survey. Overall there were nearly twice as many respondents to the survey from the most deprived group compared to the least deprived (20% were from the most deprived group, 11% from the least deprived).

Overall four in five people agree to the question "Has your local centre and/or any of its activities/services made a real difference for you and your family?"

81% say 'yes' and 19% 'no'. The proportion saying yes is slightly higher among the most deprived from all parts of group (84%) than the least deprived group (80%). Showing the services are generally equally valued by people Norfolk.

The majority of people attending children's centres do so to attend a group or activity, overall this was 75% of respondents – but 81% of people from the least deprived areas and 72% from the most deprived.

The least deprived group are also slightly more likely to say they have attended the centre to 'obtain information' (31% compared to 28%).

Whereas the most deprived group are more likely to say they have had 1:1 support (19% of the most deprived and only 9% of the least deprived).

So it seems that overall the most intensive support is going to people in the most deprived areas.

The most used services are "family activity including stay and play" (68% used) and "Support and ideas for your child's play, learning and development at home" (65% used).

People from the most deprived areas are far more likely to say that they have used services such as "support to move to school or other early years setting" (43% of most deprived, just 24% of least deprived) and 'family support in the home' (42% of most deprived compared to 31% of least deprived).

People in the least deprived areas report greater use of activities such as “Family activities including stay and play” (74% of least deprived compared to 68% of most deprived) and “Healthy Lifestyle support such as diet, smoking and exercise” (37% of least deprived compared to 30% of most deprived

Satisfaction with these services ranges from 94% satisfied with “Employment support e.g. C.V. writing” to 99% satisfied with “Support and ideas for your child’s play, learning and development at home”. (This is people who answered they found the service satisfactory, good or excellent of all those who had used the service).

It is important to recognise that being in the least deprived group does not mean that a family does not need support from children’s centres, this is a response from a mum living in one of the least deprived areas of Norfolk:

“I have attended several sessions whilst on maternity I would go twice a week. Attending weighing sessions where I was given lots of support with my son not gaining weight. I also went to the signing and play session. The ladies were so lovely and with my son being deaf it was so nice to go to. The Centre kept me going! It got me out of the house and with all the issues with my son it offered me so much support. It was my life-line.”

Source: ‘https://norfolk.citizenspace.com/consultation/childrenscentres-2/supporting_documents/ECFS%20Data%20Pack%20.pdf’ (Norfolk County Council, September 2018)

Early Childhood and Family Service

Norfolk County Council is creating an Early Childhood and Family Service. This will be delivered on an outreach basis within local community venues, such as libraries, village halls and community centres, schools and in families’ homes. The focus of the new service will be to support more vulnerable families, prevent more children aged 0-2 from experiencing neglect or emotional harm and increase social mobility for disadvantaged families with children aged 0-5.

Norfolk County Council consulted people in the development of the new service. There were 1,576 responses, with 1,401 responses from individuals and 175 from respondents affiliated with organisations.

Of the respondents, 68% of residents and 54% of respondents affiliated with organisations disagree or strongly disagree with the proposal, compared to 24% of residents and 35% of respondents affiliated with organisations who agree or strongly agree. Many said that Children's Centres were a familiar, trusted, local hub that are a safe place for families and workers to use and their loss would result in a poorer service.

However, many agreed that the proposed service would provide a better and needed service but wanted them to run alongside the existing Children’s Centres. Respondents affiliated with organisations particularly questioned our thinking behind the proposal, asking whether it is deliverable.

Source: Early Childhood and Family Service Consultation Findings (Norfolk County Council, January 2019)

https://norfolk.citizenspace.com/consultation/childrenscentres-2/0020

Children and young people's mental health services

Feedback on child and adolescent mental health services

In 2017 we asked children and young people, parents and carers and professionals about child and adolescent mental health services. People told us that this is what they would like mental health services for children and young people to be like:

- Children and young people should be able to get the help and support they need quicker and more easily, so that their mental health needs are treated early.
- Mental health services should be person centred, caring and consider the needs of the whole family.
- Services should be delivered locally, close to where people live or in some instances in their home. More services should be provided in schools and colleges.
- Services should be joined-up and integrated.
- Mental health services should be better funded and resourced, with more staff.
- There should be parity of esteem between mental and physical health.

Source: 'Feedback on child and adolescent mental health services' (Norfolk County Council and Norfolk and Waveney's CCGs, November 2017)

Young Shoulders: A window on the emotional and mental wellbeing support of children and young people in Norfolk and Waveney

In autumn 2018, we commissioned RETHINK Partners to review and help progress our approach to transformation of mental health services for children and young people in Norfolk and Waveney. This included looking at aspects of the Local Transformation Plan and wider ambitions for these services including commissioning arrangements, leadership and governance, service models, performance, the provider landscape, and the many interfaces these services have with other parts of the system to truly provide a joined-up service for children, young people and families.

Throughout October and into early November 2018, RETHINK Partners conducted 15 focus groups and 229 conversations / interviews. They spoke with children and young people, professionals (statutory, voluntary sector and volunteers), and parents and carers.

They asked them about the broader system of support for children and young people and their emotional wellbeing. Here is a summary of their findings:

1. Children and young people in Norfolk and Waveney are overwhelmingly contemplating emotional and mental health issues in their daily lives
2. Young people appear to be incredibly resilient on the face of it, but this apparent resilience is dominated by a high propensity to "deal" with issues themselves – in order to avoid "burdening" friends and family
3. Their first line of defence is to internalise and deal with issues and concerns themselves, with family; friends; school and college coming second

4. For young people, there is a lack of awareness of services beyond school and college
5. Professionals trying to support young people are working against a backdrop of confusion over service offers, referral criteria and pathways
6. Schools and medical professionals are constrained by resources and hampered by a complex system that bounces children around, often forcing young people to deteriorate before they get the right support
7. School plays a crucial role as a trusted source of support. It is often the last chance of hope for young people and their families to gain support and advice in the midst of a fragmented and confusing system
8. Schools are commissioning a patchwork of support based on their local connections to compensate for gaps in statutory CAMHS and wellbeing provision
9. There's a dearth of opportunities for young people to discuss emotional wellbeing & build emotional literacy and skills
10. Variation: it's a complex picture of influencing factors on the emotional wellbeing of children and young people - there is no such thing as a universal experience
11. There is a huge appetite from citizens and professionals to influence commissioning decisions but no consistent and inclusive co-production model

Source: 'Young Shoulders: A window on the emotional and mental wellbeing support of children and young people in Norfolk and Waveney' (Irene Carson, RETHINK Partners, December 2018)

Learning disability and autism

Access to health and social care services for Norfolk families with Autism

Healthwatch Norfolk conducted some research to explore families' perspectives and experiences of trying to access help and support for a child with ASD/suspected ASD (0-18 years old), from local health and social care services in October 2018. Here is a summary of their findings:

There were mixed views on accessing health and social care services demonstrating the contrast of experiences across Norfolk. Unfortunately many families had received what they regarded as poor services, and often felt that little had gone well. Despite this, some felt that once you got into 'the system' the service they received was good but there were never enough appointments to allow for timely access to services. The undertaking of this project and further analysis of patient feedback has clearly demonstrated five key findings:

1) This was closely linked to the frustration commonly held amongst parents about the long waits they experienced to access health and social care services including an ASD diagnosis. Many understood services are stretched but recalled the reality of what this meant for their child. This highlighted the need for services to change and improve locally, emphasising the need to listen and engage more with families and service users using the service.

2) Families felt that professionals did not understand what it was like to live with ASD and the effect this has on individual's everyday lives. Physically getting to an appointment could also prove a challenge, especially if it fell outside of the child's usual routine. It was felt that there was lack of understanding of ASD across all health and social care services, to facilitate attendance and effective communication at appointments.

3) Parents stated the need for reasonable adjustments to be made in health and social care services, with particular regard to waiting rooms in clinical settings. Waiting rooms in services were commonly referred to as noisy and unsuitable for children with ASD (who commonly experience sensory overload), especially when they found waiting quite difficult. Small changes to the environments could make a big difference to autistic children and parents felt this needed to be closely considered to improve services.

4) Frequently parents recalled not being aware of the process involved for an NHS ASD diagnosis, due to a lack of information and communication. The pathway process was not explained to them. They stated this needed to be addressed to understand what to expect from the service and to enable them to explain the process to their anxious child. A lack of communication also led to parents often feeling forgotten due to the considerably long waiting times they experienced and not knowing where they were in the process.

5) Many parents identified the lack of support available to the families across Norfolk, especially once the child has received a diagnosis. Many described the continuous fight they had to undertake to get the right support for their child. Some expressed the need for more support to wrap around the wider family unit, including the child's siblings. They believed the siblings received no support and needed help to understand and ensure that all of their children felt supported and comfortable.

Source: 'Access to health and social care services for Norfolk families with Autism' (Steph Tuvey, Healthwatch Norfolk, October 2018)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2019/01/HWN-Final-Full-report-Autism.pdf

Redesigning other health services for children and young people

Dental services for children and young people in West Norfolk

The findings showed a positive overall experience in general, especially praise for staff members. Having said that, there are clear barriers to accessing NHS dental care for children and young people in West Norfolk, stemming from key areas such as, the availability of NHS dental services, in particular services in the local area to where the parents/guardians live, which went hand-in-hand with transport problems for some; the availability of appointments, and more specifically fitting the appointments around school or work hours; cancellations and long waits for appointments and finally, information/advice around taking their children to the dentist and availability of services.

Particular issues noted by the families in RAF Marham in the survey conducted by the Norfolk Armed Forces Covenant Board last year, seemed to be replicated by the families in this survey, but more importantly, there seems to be a wider issue of access in the civilian population of West Norfolk as well as the military families.

Source: ‘Dental services for children and young people in West Norfolk’ (Fennie Gibbs, Healthwatch Norfolk, April 2018)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2016/07/West-Norfolk-Dental-Services-Report-FINAL.pdf

*Commissioned by NHS England

Better care for major health conditions

Cardiovascular disease

Healthwatch Norfolk asked over 800 local people about the non-pharmaceutical interventions they access, or have accessed, in the community to manage the physical lifestyle risk factors associated with long term disease in 2016. Here is a summary of their findings:

NHS Health Checks: Accessibility & Recruitment

- Overall men are reluctant to attend health checks or see their GP
- The average age of a male accessing a health check is older than the average age of a woman accessing a health check
- The majority of men interviewed were confused about what a health check is actually for
- Men told us they are reluctant to book an appointment with their GP.
- Men of working age would like the opportunity to have their health check at a pharmacy but did not seem to be aware this was an option.
- Our findings suggest that the male adults in our sample who accessed health checks lead more active lives and are likely to be more socio-economically advantaged
- Overall, 56% of adults suggested a health check should be available for adults under the age of 40 years
- The average age of an adult in our sample attending a health check was 56 years

Health Checks - Brief advice

- Adults perceived they did not receive enough specific advice about how to reduce the physical risk factors associated with CVD.
- People commented that they did not consider there was room to explore mental health needs during a health check or during a routine visit.
- The immediate changes people made following a check or routine visit to the GP were around diet and exercise but comments suggest these changes were uninformed and unlikely to be sustained.

Community-based Interventions

- Referrals to services that are expert in alleviating single risk factors are consistent; by contrast, referrals to initiatives or programmes that include an exercise component are not. Local evidence we gathered suggests that community based interventions reduce more than one health outcome.
- Community-led services are good at being inclusive and reducing health inequalities.
- Community providers support people to maintain their behaviour changes.

Cardiac Rehabilitation: Phase 3

- Our questionnaire revealed that 97% of patients rated the phase 3 service as excellent and 3% said it was very good; comments suggest this is due to a patient-centred approach

- There were differences in how men and women had experienced physical symptoms leading up to their cardiac event
- There are differences in how men and women cope with the psychological impact post heart attack
- The majority of patients told us they were more confident about how to eat more healthily and the type of exercises they could do
- Survey results strongly indicated that the majority of people did not perceive they would feel confident to exercise in a group that was not led by a specialised instructor
- Over half of respondents indicated their confidence in medication was now lower than what it was when they were first discharged from hospital

Cardiac Rehabilitation: Phase 4

- Participants accessing phase 4 cardiac rehabilitation classes rated the service as excellent
- Patients enjoyed the opportunity to increase their levels of physical activity
- In phase 4, people started to build the resilience they need to re-integrate into the community, returning to work and for some, caring for relatives thus saving money for local services
- Participants told us that having accessed phase 4 classes they were now confident to exercise at home
- Our findings suggest that commissioners have neglected phase 4 cardiac rehabilitation to the point where the programme has become fragile and destabilised

Source: ‘Cardiovascular disease prevention and management in the community’ (Healthwatch Norfolk, 2016)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2016/07/CVD-Executive-Summary-1.pdf

Diabetes

A snapshot of diabetes care in Norfolk

Healthwatch Norfolk gathered some feedback from people with diabetes about their treatment and care in September and October 2018. Here is a summary of the feedback they received:

Most people attended their annual review and a majority could easily recall having tests to check their blood glucose (HbA1c), cholesterol and blood pressure, getting advice on their diet, having a foot check and eye screening carried out. Many had been offered a free flu jab. People were less certain about kidney tests, being able to get care from diabetes specialists and or being offered support to stop smoking. Some people said their annual diabetes review ran like clockwork but a few were vague about any detail and weren’t sure if they even had an annual review or not.

Most people understood the link between their blood glucose levels and the kinds of complications they might face when their blood glucose level was not managed well. A few said they rarely coped well with managing their blood glucose however only a minority spoke about having no complications at all arising from their diabetes. A small number had undergone one or more amputations of their toes or part of their foot. In general, the people in the focus groups with Type One diabetes appeared to be better informed about their blood glucose levels and more confident in managing it.

Regarding foot care, most people could easily recall their most recent foot check, with the majority having this done in their own GP practice with the nurse. Not everyone felt the same about their checking their feet: some did this every day or most days whilst others once a week or month or rarely. Most of those having a foot check gave their foot check service a four- or five-star rating and many could recall specific pieces of advice they'd been given about caring for and checking their feet.

Some had been invited to attend a diabetes education course and found it very useful. Others had not completed the course and some had never attended even though invited. There were mixed views on how the courses could attract better attendance such as organising a rolling programme, giving people more flexible options and lots of notice in advance. Everyone thought 'diabetes prevention courses' were a better idea. Diabetes nurse specialists, consultants and the family carers of people with diabetes were strongly favoured as a good choice for leading education courses. Psychologists or similar who can help to motive people to make changes were seen as very important but often absent. People living with diabetes were seen as the Experts by Experience – especially those with several years' experience – and were strongly favoured as the best messengers, course leaders and advisors for others with the condition.

Source: 'A small snapshot of diabetes care in Norfolk' (Sam Revill, Healthwatch Norfolk, November 2018)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2019/02/HWN-Diabetes-Snapshot-Report.pdf

Adult mental health services

Norfolk and Waveney Adult Mental Health Strategy

Although we have a lot of system data to help us see what is and is not working, nothing is as important as speaking to those people who use local services. This also includes their carers and families as well as health and social staff, people from the voluntary sector and other organisations involved in providing support and care to the population of Norfolk and Waveney.

These real-life experiences paint a very vivid picture of where we are meeting the needs of local people and where we are not. Their perspectives and ideas have strongly shaped this review and helped us write this strategy. Many of these conversations were face to face either at large public events or smaller group meetings. But we also provided people the chance to comment by writing to us or by completing a survey. We also arranged a number of practical working sessions with people from different organisations to ensure a wide and representative group of people were part of the discussions.

A variety of users, health and social care workers and representatives from other organisations and services helped lead the communications and engagement process to ensure it was fair and unbiased.

In total we either held or attended 42 separate events between August and December 2018 of which seven were with people who use mental health services locally, carers and the public. A further 25 were with health and social care staff and 10 were with community and voluntary groups. We also spoke to hundreds of local people online through a discussion on Facebook. Throughout all of this work we were able to gather feedback, viewed and experiences from more than 2,500 local people.

Although the experience of users was highly varied we could see there were a number of consistent themes emerging about the provision of care and services. These were:

- Services were seen as complex, slow and hard to access and navigate, for example, crisis services
- Services were perceived to be poorly integrated between different organisations
- Quality and consistency was perceived to be highly varied (for example waiting times)
- Provision of care seen needed to be more focused on treatment than prevention
- Service users did not feel community care was being fully utilised

Our final strategy has six commitments in it which are based on what people told us:

1. To increase our focus on prevention and wellbeing
2. To make the routes into and through mental health services more clear and easy to understand for everyone
3. To support the management of mental health issues in primary care settings (such as within your GP practice)
4. To provide appropriate support for those people who are in crisis
5. To ensure effective in-patient care for those that need it most (that being beds in hospitals are other care facilities)
6. To ensure the whole system is focused on working in an integrated way to care for patients

Source: Norfolk and Waveney Adult Mental Health Strategy (Norfolk and Waveney STP, March 2019)

www.norfolkandwaveneypartnership.org.uk/test/publications/key-documents/23-norfolk-and-waveney-adult-mental-health-strategy/file.html

Central Norfolk Community Wellbeing Hub

We are developing a Community Wellbeing Hub, based in Norwich and serving people with mental health needs in the populations of South Norfolk, North Norfolk and Norwich. Service users and carers representatives, and stakeholders from the voluntary and community sector, are involved in the monthly steering group meetings that lead the project.

A workshop also took place in October 2018 to co-design the service model for the Wellbeing Hub, and was attended by over 40 service user, carer, health professional, local government and voluntary sector representatives. Here is a summary of the key themes from the event:

Empowering and Enabling

- Help people to decide what outcomes they want to achieve
- Focus on peoples' strengths to support growth
- Connect people to the local community
- Prevent debilitating episodes of crisis
- Always ready to help when someone needs it
- Access to peer supporters who have experience of mental ill-health

Communication and Integration

- Clear and defined pathway
- Strong links to crisis and community mental health services
- Synergy with other services
- Access to a range of advice and support

Safe, Responsive and Accessible

- Strong focus on emotional support
- Robust risk management
- Family and carer friendly
- Non-medical environment

Positive Impact on Community and Wider System

- Promote healthy coping strategies
- Inspire personal development and hope
- Destigmatise mental ill-health and promote understanding and awareness
- Building must be a psychologically informed environment (PIE)

Source: 'Community Wellbeing Hub Engagement Workshop report' (Norfolk and Waveney STP, November 2018)

www.northnorfolkccg.nhs.uk/community-wellbeing-hub-—-central-norfolk

Healthwatch Norfolk has also conducted some research into what people think of urgent and emergency care services for people experiencing a mental health crisis.

Source: ‘Using urgent and emergency services at times of mental health crisis’ (Healthwatch Norfolk, May 2017)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2016/07/Final-Report-Experiences-Urgent-Emergency-Service-Use-at-Times-of-Mental-Health-Crisis-UECN-June-2017.pdf

Dementia

We are currently reviewing dementia support. Over 160 people, including carers and family members directly affected by dementia, people with dementia, and professionals, shared their experience and ideas at six events in Norwich, Beccles, Kings Lynn, and Alysham. We have also conducted an online survey. Here is a summary of what people have told us:

1. Norfolk and Waveney needs to do more to support healthy living for people affected by dementia, or at risk of being affected by dementia.
2. Health services should do more to help people access dementia diagnosis services in settings closer to the places they live, for example in GP practices and through other community health services.
3. When people need support, before or after a dementia diagnosis, this should be from a named individual, they can speak with easily. This support should vary depending on your level of need. Specialist support is also important and valued.
4. Everyone with a diagnosis of dementia should have the opportunity to develop a support plan
5. There should be much better sharing of information between different parts of the health system and social care, so that peoples experience of dementia support improves, and people affected by dementia do not have to tell their story over and over again.
6. We need to do more to promote good quality peer and community support, building on some of the exemplary organisations working in communities across Norfolk and Waveney. We should aim to help everyone, wherever they live, to access the vital support these services, and the wider voluntary sector, can offer.
7. Employers, and the wider community also have an important role to play ensuring society understands and is more responsive to the needs of people affected by dementia.
8. There is a need for much more education and training relating to dementia care and support. Family carers and home support carers play a very significant role, especially in dementia care, and they should be prioritised as groups of people, which long term investment in dementia training targets.

9. We need to recognise that the health and social care system is changing, and there is a new appetite to support GPs and other community health professionals to provide more support, in or close to the communities people live in. Support should be clustered around these communities, and health and social care professionals designing services need to work together to make this happen, more effectively, and in a way that works for everyone, wherever people live in Norfolk and Waveney. There should be no postcode lottery for dementia support.
10. Late stage dementia should be recognised as a terminal illness. Health professionals should be more transparent about this. Everyone should have the opportunity - and access to support and resources necessary - to plan for a good end of life.
11. There should be no difference in support available to someone affected by end of life relating to dementia, and end of life related to other health conditions that can cause early death. For example cancer.

Source: ‘Norfolk and Waveney Dementia Support Review’ (March 2019)

Becoming a dementia friendly GP surgery

This guide outlines five simple steps for making GP practices more dementia friendly. The steps were suggested by local people with dementia and their (family) carers and developed through extensive engagement with primary care staff and other stakeholders. The steps are designed to be low cost, high impact solutions to common challenges experienced by people with dementia and their carers when using primary care services.

1. Supporting your workforce to increase their awareness and knowledge of dementia can be a great way to make your practice more dementia friendly. These opportunities will also contribute to staff personal development and job satisfaction.
2. Dementia is a very complicated condition that changes over time. People with dementia will benefit from seeing the same clinician at each appointment and may need additional support to express their needs.
3. Family carers are often essential partners in a person’s care. Where appropriate (considering any safeguarding concerns), consent should be obtained from people with dementia early on so that their carers can be involved in care planning etc.
4. Providing quality information and signposting early on can make a huge difference to people with dementia and their carers. We expect that the new social prescribing services will play an important role linking people into local advice and support.
5. It can be difficult for people with dementia to find their way around. Small changes to the practice environment can be really helpful, not just for people with dementia but for people with other conditions such as poor eyesight or learning disabilities.

Source: ‘Becoming a dementia friendly GP surgery’ (Healthwatch Norfolk, in partnership with NHS North Norfolk and South Norfolk CCGs, July 2018)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2018/09/HWN-SNNNCCGs-Dementia-Friendly-GP-Guide-July-2018-FINAL.pdf

Learning disability and autism

Learning Disabilities and Transforming Care

People with a lived experience of learning disability services, their families and carers are part of the Norfolk Learning Disabilities Partnership Board, alongside commissioners and providers of health and social care services, advocacy organisations and the voluntary sector.

Norfolk Learning Disabilities Partnership Board plays an important role in making decisions about local services and support for people with learning disabilities and their families. People with learning disabilities and family carers are fully involved in the planning of learning disabilities services.

People with learning disabilities were involved in co-producing ‘My Life, My Ambition, My Future, the Norfolk Learning Disabilities Strategy 2018-2022’, which sets out the vision for shaping and delivering opportunities for people in Norfolk with Learning Disabilities. It explains how we arrived at the vision and how we intend to achieve this vision, through identifying a series of key priorities and actions.

People with learning disabilities have also been at the centre of the Norfolk and Waveney Transforming Care Partnership, aimed at developing the care and support available for people with learning disabilities, autism and challenging behaviour in the area over the next 3 years.

To ensure that the voice of people with learning disabilities is at the core of the Transforming Care Partnership, an 'Experts by Experience' Panel meets monthly to discuss the priorities and progress of Transforming Care, and share experiences of inpatient care and living in the community, and designing how more people with learning disabilities can be involved in the Partnership going forward.

The group is led by people with lived experience of accessing learning disability services, and is supported by Opening Doors, a Norfolk-based advocacy organisation for people with disabilities. The group has led and shaped the development of local iterations of national campaigns and projects, including Stopping over medication of people with a learning disability, autism or both (STOMP): https://www.southnorfolkccg.nhs.uk/services-we-commission/stopping-over-medication-people-learning-disability-autism-or-both-stomp and the national Learning Disability Mortality Review (LeDeR) programme: https://www.southnorfolkccg.nhs.uk/services-we-commission/learning-disabilities-mortality-review-leder-programme

All Age Norfolk Autism Partnership Board

Norfolk County Council, NHS Clinical Commissioning Groups in Norfolk and partners in the wider statutory, independent and voluntary sectors actively work with people with autism and their families to understand their needs, and develop an All-age Autism Strategy for the county.

To enable autistic people and their families and carers to be part of developing this strategy, health and social care commissioners have developed the Norfolk Autism Partnership Group (NAPG), which provides an open forum for autism conversation and wider engagement with the autism community, and a chance to get updates from the Norfolk Autism Partnership Board (NAPB).

The NAPB is inclusive and ensures the active participation of experts by experience, parents and carers. The decision-making board meets four times a year to inform the creation and implementation of an action plan to deliver the national Autism Strategy in Norfolk. The board influences the NHS and local authority commissioners with the aim of developing improved services for children, young people and adults who may have autism. It will raise awareness of autism within the wider community and work to enable people with autism to be fully included in society.

Autistic people have been engaged in the development of the All-age Autism Strategy (currently being finalised), as well as in the design of surveys to help us understand the experience of autistic people of different ages, and the challenges faced by them and their families and carers.

More information here: https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/all-age-norfolk-autism-partnership-board

Information and support for unpaid carers in Norfolk: feedback from local carers

Healthwatch Norfolk and the Carers Council for Norfolk carried out some research into unpaid carers' experiences of Carers Assessments and information and support in Norfolk. Here is a summary of their findings:

Seventy-three (73) respondents had received a Carers Assessment within the last two years. Their feedback was fairly positive; 56% rated the service as good or very good and staff were particularly praised. Many respondents valued the information and advice they received, but others were concerned that there had been no relevant outcome in terms of practical support or services.

Feedback about Carers Assessments will be shared with Norfolk Older People's Strategic Partnership Board, who requested this information, for them to take forwards as part of the Living Longer Living Well strategy.

Two hundred and fifty-five (255) respondents gave feedback about their experiences of accessing information and support in Norfolk. A significant minority (16%) said they did not currently know where to go for information or advice. More than two in three (68%) respondents felt confident continuing in their caring role but only 37% felt able to manage their health and wellbeing.

When it came to increasing their confidence and health and wellbeing, respondents highlighted the importance of being supported to have a life outside of caring and stated their desire for more planned or unplanned respite care. Many respondents wanted more understanding, recognition and reassurance, and felt that they were currently being left to struggle on alone.

A secondary analysis was undertaken to identify whether respondents' experiences differed according to their age and the number of hours they spent caring. Whilst there were no significant differences, a greater proportion of older carers (65+) felt that they were able to maintain their health and wellbeing. The results of this analysis should be treated with caution due to the size and nature of the sample.

This report makes five main recommendations, which will be taken on by Carers Council for Norfolk as part of their role in the new service 'Carers Matter Norfolk':

1. Respite needs to be recognised to a greater extent in the cared for assessment and personal budget
2. All carers to be supported to have plans for the future and emergencies
3. Working with home care providers to improve outcomes for unpaid carers
4. Carers are supported to manage their health and wellbeing
5. Monitoring and evaluation of outcomes

Source: ‘Information and support for unpaid carers in Norfolk: feedback from local carers’ (Edward Fraser, Healthwatch Norfolk, and Sharon Brooks, Carers Council for Norfolk, January 2018)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2018/02/CCN-HWN-Report-Information-and-Support-for-Carers-in-Norfolk-Jan-18.pdf

Supporting people to age well

End of life care

‘Thinking ahead’ Advance Care Planning

Healthwatch Norfolk conducted some research in to advanced care planning in 2016. Here is a summary of their findings:

Most people surveyed told us they were comfortable talking about death (74%) and most people said they want care to focus on quality of life and being comfortable, even if it means they have a shorter life (72%). Focus groups with black and minority ethnic (BAME) communities also supported findings from our survey, that people less comfortable talking about death are more likely to express a preference for longevity over quality of life.

Whatever their preferences, nearly half of respondents (46%) had not discussed their end of life wishes with anyone else, including their friends and family. We also found that even when people make a Will, it is very rare for them to go on to arrange either a Power of Attorney for Health and Wellbeing (11%) or to complete an Advance Decision to Refuse Treatment – a ‘Living Will’ (5%).

People in Norfolk told us that there are two major prompts to Advance Care Planning, being given a prognosis of a life-limiting illness (51%) and the fear of losing capacity through dementia (62%).

A significant proportion of people surveyed felt it was ‘difficult to know if their wishes would be respected’ (44%) and a further 42% expressed a preference for discussing wishes informally rather than writing them down. Significantly, 29% worried that if they wrote down their wishes, doctors would stop treatment too soon.

Focus group sessions indicated that people with disabilities or long-term conditions were perhaps less likely to engage in ACP, whilst parents of people with learning disabilities appeared the most likely to plan ahead. Local LGBT people also shared concerns in focus groups that their partners would not be recognised as next of kin.

Professionals working with homeless people described the challenges of ACP for vulnerable patients with mental health problems. We also found that whilst end of life care in local prisons was likely to be very good in the dedicated elderly care unit, the processes for ACP were not consistent.

As a result of these key findings, Healthwatch Norfolk make the following recommendations to improve local people’s experience of end of life care in Norfolk:

1. Raise Awareness about the benefits of Advance Care Planning to ensure that everyone with a life-limiting illness has the opportunity, if they wish, to have early and ongoing conversations about end of life care as part of their treatment and care.

2. Assure people that their wishes will be recorded and shared with other health and social care professionals.

3. Ensure professionals caring for people who may be approaching the end of life, have the knowledge, skills and support they need to communicate the benefits of ACP effectively.

4. Access to end of life care services and outcomes for people from different groups should monitored and improved.

Source: ‘‘Thinking ahead’ Advance Care Planning’ (Healthwatch Norfolk, June 2016)

www.healthwatchnorfolk.co.uk/wp-content/uploads/2016/07/Thinking-ahead-Advanced-Care-Planning.pdf

Our staff

This section will be completed shortly. We have just run a big online conversation with people working in health and care – both paid and unpaid – about the future. 3,940 people visited the #WeCareTogether website. We had 117 ideas from our workforce about how we can improve health and care, which generated lots of comments. Plus we have held more than 300 face-to-face conversations too.

We are now reviewing all the contributions, which will help us develop our five year plan for health and care, as well as a new workforce strategy for our partnership. We’ll continue to talk with staff, employers, patients, carers, voluntary and community groups and our wider population.