healthwatch

NHS Long Term Plan

Engagement Report

Feedback from patients and the public across Cornwall and the Isles of Scilly

what
would you do?
It's your NHS. Have your say.

Executive summary

Background

The NHS faces a growing demand for its services. More people have long-term conditions for which they need ongoing support. Illnesses linked to inequality and to lifestyle choices are also adding to the pressure on the NHS.

Healthwatch England has been commissioned by NHS England to run a programme of public engagement seeking people's views and ideas to inform the development of local Sustainability and Transformation plans (STPs) supporting local NHS to invest in the right support.

Cornwall and the Isles of Scilly (CIoS) is one of the most popular holiday destinations in the UK with heritage, beaches, wildlife, sailing, surfing and peaceful moorland. But behind this lie large numbers of people living on the edge of poverty. Seventeen Cornish neighbourhoods are in the 10% most deprived in England, with forty four neighbourhoods in the 20% most deprived in England; this has increased in recent years. The proportion of self-employment and the uncertainty and stress that this can bring is 50% higher than the UK average. CIoS is a rural area with poor transport links meaning accessibility, especially for residents of the Isles of Scilly, is a major issue. Added to this, against a backdrop of UK population over 65 being 18%, the over 65s in CIoS total 25% of the population (Office of National Statistics 2016).

Following discussions with Cornwall and the Isles of Scilly's (CIoS) Shaping our Future (SOF) Strategic Transformation Plan programme team, our engagement locally aimed to:

1. Increase feedback from localities where there was either no General Practice Surgery Patient Participation Group or limited public engagement activity
2. Focus on gathering feedback on the specific conditions of
   - Perinatal mental health
   - Cancer

To engage with patients and the public Healthwatch Cornwall and Healthwatch Isles of Scilly promoted a national online survey locally and gathered feedback face to face during public engagement activities at local drop-ins. We then held four focus groups to consider:

- General NHS LTP priorities and local delivery (two groups)

  Asking   "Do you agree with the priorities in the NHS LTP?"
              "What do you feel the priorities for CIoS should be?"

- Perinatal mental health
- Cancer services

  Asking   "Did support meet your needs?"
              "What was your overall experience?"
              "How could it be improved?"

In addition this report contains findings from a brief poll held with visitors to the Royal Cornwall Show in June.

Summary of Findings:

What matters most to people in Cornwall and the Isles of Scilly?

Common themes across all feedback centred on **delivering person-centred care that was respectful of people's views, wishes and time**. There was a call to **improve information sharing between services and patients**, and to **support people in accessing services when and where they needed it, paying particular attention to challenges with travel**.

When looking at local priorities generally, people recognised the need to focus on prevention. This message was particularly extended to the provision of early years services and children's mental health services. There was also a focus on enabling people to manage their own conditions, by ensuring people are sufficiently informed.

People on the IoS were, unsurprisingly, concerned about travel arrangements and access to services on the mainland – something which continues to be a well-recognised issue for residents. However people gave clear indications of their desire to have more technology enabled health interventions, so as to avoid the need to travel. The greater use of technology, to facilitate consultations or support within communities was also welcomed.

What did they tell Healthwatch?

Responses to the general survey showed what people cared most about in order to live a healthy life, was that professionals listened to them and decisions about treatment were taken together, through effective information providing and joint decision making. Secondly, people wanted access to help and treatment when they most needed it and that communication with people was timely.

By far, the greatest proportion of people felt the most important element to leading a healthy, independent life as they age, was that they can remain in their own home for as long as it is safe to do so and are supported as they approach the end of their life. When interacting with the NHS staff and services, the two most important things were that they could speak with their doctor or health professional wherever they are and that the outcomes or results from any consultation about their health are communicated promptly, making the best use of technology to do so where possible.

> *"If I am to increasingly have my health and social care delivered at home I need to know that the staff are available to support me in the way that I would wish - they need the time, the training and also I would want a continuation of the same support team."*

Comments showed many people found the lack of access to doctor's appointments, and to accessing care and support to be a significant concern within the current health and social care climate. Other concerns related to a lack of suitable transport available to get people to their appointments. People reinforced their views about healthcare professionals having adequate time to listen to patients in light of well-recognised time pressures on staff, and to ensuring their views and wishes were well considered.

> *"I am very happy with the care I receive; I am concerned that appointments are not readily available due to the number of patients vs the capacity of staff. This impacts on my and others health. The healthcare professionals I see are always very caring, professional and honest with me. I feel very lucky to have access to the NHS when I need it."*

The majority of survey respondents in the condition specific surveys commented on services for the category of general long term conditions (eg arthritis, diabetes etc), followed by mental health then cancer services. Most people felt their wait to get an initial diagnosis or treatment was either very slow or slow, with little variation if they had multiple conditions. However, people's experiences of waiting to access care or treatment after the initial diagnosis improved somewhat, rating this as either okay or slow.

Respondents mainly described the time they waited to see a specialist as either okay or slow. Just over half of people (57%) reported they were not offered access to further care and support following the initial appointment. Similarly, people felt accessing ongoing support after diagnosis was very difficult. There was a generally held view that people felt the system was under-resourced, they were provided with little ongoing support and more medical staff would lead to an improvement in these experiences.

Cornwall in focus

When we talked to people in more depth during focus groups, there was a strong feeling that the health and social care system should:

- Prioritise funding for less able patients who need more support by encouraging the majority to take more responsibility for their own health and for self-management by supporting people to do so. Focus more on prevention, increase investment in public health and the early developmental stage of life.

- Prioritise resources for child mental health with a particular focus on improving diagnosis.

> *"Having been a cardio rehab nurse I know 95% of the patients in rehab would have been happy to take personal responsibility – they felt they didn't need to be there and could have been supported over the phone"*

Isles of Scilly in focus

We attended a meeting of the Adult Carers group, a peer support group that meet to share experiences and help and support one another. We had wide ranging discussions which highlighted:

- The need for more information/signposting from the IoS Health centre in situations where there was less of a "medical need", such as the promotion of social prescribing, voluntary sector support groups and physical exercise programmes.
- The need to improve the discharge process following hospital admission – greater consideration of transport needs and the ongoing care pathway, particularly for people living on the off islands.
- The need to improve communication - people need to know that their views and concerns are listened to and acted upon

"We have good access to primary care … certainly better than the mainland"

"Discharge happened once with little or no chance of returning (to the islands) on the same day, due to the timings of transport. This necessitated extra cost, complications, and the stress, of finding somewhere to stay overnight"

"Changes must have a positive outcome – not what feels like change for changes sake"

Implementing cancer health and care services

We worked with the C-Siders, a cancer support group on the IoS set up in 2018 with help and guidance from Macmillan Cancer Support. It is important to note that the overall feeling was that the care people received was excellent, and of particular note was the Sunrise Centre at The Royal Cornwall Hospital. The care and treatment received there was universally endorsed as being excellent.

Issues to be considered however focussed on being able to access the treatment, support, and follow up, appropriate to each individual, recognising the common issues around attendance at a mainland clinic. Different diagnoses of cancer require differing treatment regimens which bring with them their own particular problems that are exacerbated by island living; Chemotherapy delivered weekly on the mainland, and the subsequent side effects can significantly affect the ability to travel; Radiotherapy daily for a number of weeks requires stay on the mainland away from normal support networks and at significant extra expense.

Although patients told us the follow up clinics at the Sunrise Centre were well run and efficient, they felt it was not always necessary to travel to the mainland. Travel was both expensive to individuals and to the NHS. It was also inconvenient, requiring a significant time commitment when the appointment would often last only a few minutes.

By far the biggest issue discussed concerned medical travel. There were consistently negative experiences and ALL of those in the focus group had experienced poor service. There was a general consensus that there was a lack of appreciation with regard to the impact of transport difficulties on the patient and those close to them, partly from clinical staff but more specifically from administrative staff.

> *"Travel to the mainland and dealing with the regular delays and disruption can be stressful at the best of times. Undergoing treatment for cancer is far from the best of times. Having that support (an escort) whilst travelling would significantly ease that stress"*

The NHS Kernow CCG Escort Policy and the limitations this placed on people trying to access health services on the mainland was also a significant topic of concern. It was recognised that the policy was strictly enforced in line with national statutory guidance, with exceptions only for maternity 20 week scans and "2 week wait" appointments for symptoms that may include cancer.

Key Findings

The group identified the following ideas as being worthy of consideration in local planning for the Isles of Scilly

- The opportunity for follow up appointments to be carried out remotely using technology – while not always appropriate, patients would like to be offered the choice.

- Offering certain chemotherapy treatments locally on St Mary's – it was understood that not all chemotherapy was suitable to be delivered at remote sites but with suitable staff and training certain treatments could be delivered.

- Extension of 'exceptions' within the escort policy to be afforded to patients who are less physically or mentally able, to enable them to have an NHS funded escort.

Implementing perinatal mental health services

We worked with Kernow Maternity Voices Partnership to speak with women who recently accessed perinatal mental health support. It should be noted that there were some examples of amazing care and support from midwifes and perinatal mental health specialists, along with aspects of care that could be improved.

> *"My mental health nurse was amazing. I would not have got through it without her."*

Key Findings

The group thought the following ideas were worthy of consideration in local planning:

- Ensure for all mothers and partners, previous traumatic experiences whether through birth, sexual abuse or otherwise should be embedded within care and birth plans and ensure everything is done to minimise those experiences being triggered again. People should only have to tell their story once and the experiences of partners also need to be considered.

- Consider the impact of environments on traumatic experiences and take steps to address this sensitively.

- Ensure women feel well informed and empowered, not pressured into decisions about the care and treatment of themselves and their baby.

- Access to care and care continuity should be improved in order for mums and partners to receive care and support. The use of technology could support this.

- Plans laid out within the NHS LTP were welcomed. Specifically mentioned by this group was the promise:

  - To improve access to and the quality of mental health services for mothers, partners and children, and to extend support from 12 to 24 months post birth.
  - To extend mental health support to partners.
  - To integrate outreach clinics to combine maternity/physical and mental health services.

There was a clear need to ensure previous experiences and current mental health concerns were documented and acted upon by all, then embedded into mutually agreed birth and care plans. This would serve to reduce the number of times they needed to tell their story to different health professionals, as they had found this to be both triggering and traumatic. Environments were also an important factor in causing distress, for example, by supporting people to desensitise them to places or departments which may trigger negative experiences, or avoiding arranging post birth debriefs in the same location as their traumatic experience took place, so to not add to the distress we were told this caused. For some women, with either existing mental health or perinatal mental health conditions, feeling empowered and in control of their body and their care was especially important to them.

> *"I have to keep going back to hospital for therapy, back to where it [started]"*

Unfortunately, we also heard about occasions where senior medical staff/consultants used inconsiderate and inappropriate language which was anxiety-provoking, especially where women may not feel empowered to raise concerns, and especially given their vulnerability. Consent to care and treatment was paramount. Again, we even heard examples of where invasive procedures took place or medicines were administered where people had felt pressured to consent. There was even an example of where a suppository was administered without consent being sought, when in theatre.

"The language they [staff] used was anxiety provoking"

While some felt the 6 sessions of Cognitive Behavioural Therapy they had were helpful, it was also clear that this approach was not suitable for everyone and the duration of support should fit the individual's needs.

Continuity of carer and access to ongoing support when therapy ends one year post birth was raised as a concern. This could leave mums who needed further support waiting to 're-join the queue' to access mental health support again. Therefore, plans to extend the duration of perinatal mental health support from one to two years was incredibly well received, as was the promise of support to be extended to partners. The need for improved communication between teams and service was also evident.

"I don't want to start from scratch every time."

Access to support for mums and partners requires new thinking and greater flexibility. Access was sometimes limited by travel to appointments for a number of reasons including: where childcare was needed for both new baby and siblings, where there is a need to use public transport or travel was a barrier to accessing care and treatment. Digital solutions should be introduced so that consultations could take place from the home or could provide solutions to improving community based support such as receiving a text or a skype call. Women felt the voluntary sector could have a useful role is this.

There was a clear desire to self-manage where ever possible. However, barriers to this included a lack of information and signposting on what services or support is available locally and the inability to take up opportunities for example social prescribing initiatives such as exercise, women often cannot access affordable childcare.

"[Need an] affordable crèche so I can go on a run/walk as I know this will help improve both my mental and physical health."

"Midwifes and GPs, navigating the changing landscape is difficult without support, they just don't talk to each other"

Engaging people in health service delivery

Throughout our discussions with people, the desire to be involved in the development and design of solutions was evident. **People felt strongly that they were prepared to give time and input when they can be confident their input will be respected, listened to and genuinely considered.** The ways in which people's engagement is sought must be mindful of the public's preferences for communication (website, survey, phone, email, face-to-face etc) and should allow sufficient time for people to feed in. Notifying people of the results of engagement was also highlighted as a vital part of the process.

The groups we engaged with as part of this report would all like to be kept informed of developments in the implementation of the NHS LTP locally. This report will be shared with them and both local Healthwatch will continue to share developments and opportunities for engagement as they arise.

NHS Kernow, together with Cornwall Council, have provided seed funding to further develop individual and community involvement in the planning of health and social care services. This will utilise new technology and include tools to extend reach into more diverse communities.

## What people expect during service change and transformation

- People need to know why change is happening, what the outcomes will be and how they will be affected both during and after the change has taken place.

- Communication and information to enable people to make better decisions that affect their health and to make more informed choices.

- Frequent updates regarding any planned change to service delivery.

- Better use of technology for access to health care.

- Improved information provision with regard to care services available.

At the Royal Cornwall Show in June we conducted a snap poll asking people to "vote" on the condition they would like to see the NHS prioritise locally.

Our unique voting system attracted attention!

People told us their priorities

- Cancer
- Dementia
- Heart & Lung Disease
- Learning Disabilities
- Mental Health
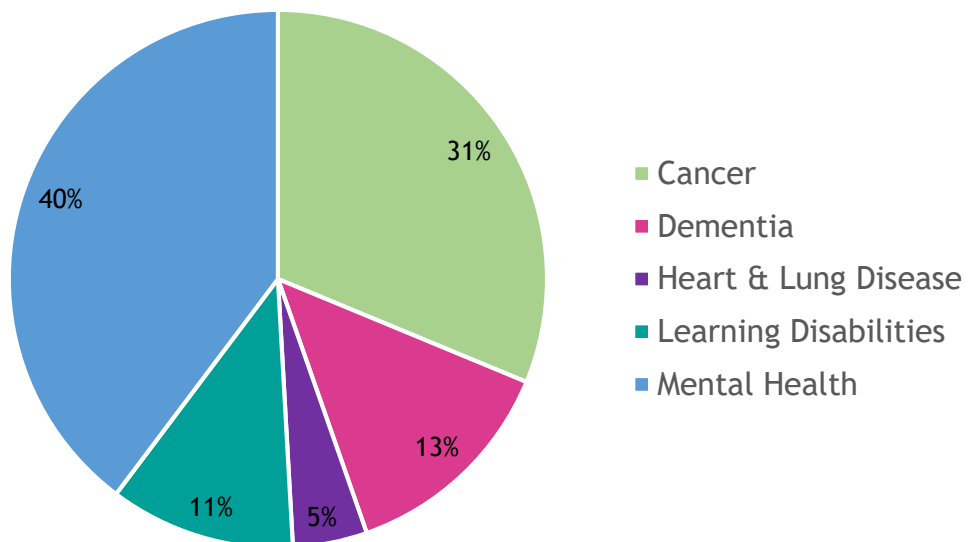
Next steps

It is important that people have meaningful opportunities to comment on, and influence the commissioning of health and care services in CIoS. Cornwall and the Isles of Scilly Health and Care Partnership will be engaging widely over coming months and aligning all engagement to the NHS Long Term Plan.

Ensuring that people have timely access to effective mental health services is one of NHS Kernow's key priorities, and during autumn 2019 they will be giving people the chance to have their say on their draft strategy for adult mental health services. NHS Kernow will be working with Healthwatch Cornwall to build upon the successful discussions that were had at their mental health conference, Together in Mind, held in May 2019, to inform the final strategy.

NHS Kernow will promote the ways people can have their say through established mental health support groups and networks, Healthwatch Cornwall, partners, the media and via social media platforms.

Healthwatch Cornwall will work with NHS Kernow to ensure the views of people contained in this report are combined with their own engagement programme. As part of our normal working processes we will review progress of local plans to deliver the NHS LTP across CIoS.

Methodology

The areas of specific focus chosen were informed through discussion with Shaping our Future leadership and a research plan was then developed using the Healthwatch England quality assurance framework.

The NHS LTP survey developed by Healthwatch England and hosted on their website was promoted via social media across the CIoS footprint for four weeks during April 2019. Written feedback was also invited through face-to-face drop-ins at hospital and community locations across Cornwall and the Isles of Scilly during this period.   The resulting data was analysed and stored in accordance with HC and HIoS Data Policies.

Narrative data was analysed for trends using frequency of key words in feedback and illustrative quotes.

In collaboration with the organisations acknowledged below four focus groups were then held covering the specific topics of

- NHS LTP in general with a focus on local CIoS need (two groups)
- Perinatal mental health
- Cancer services
- Carers perspectives

General Survey

There were 118 respondents to the general survey, mainly adults over the age of 35, 58% of whom had a long term condition with a further 21% having more than one long term condition. 36% of respondents would consider themselves to have a disability.
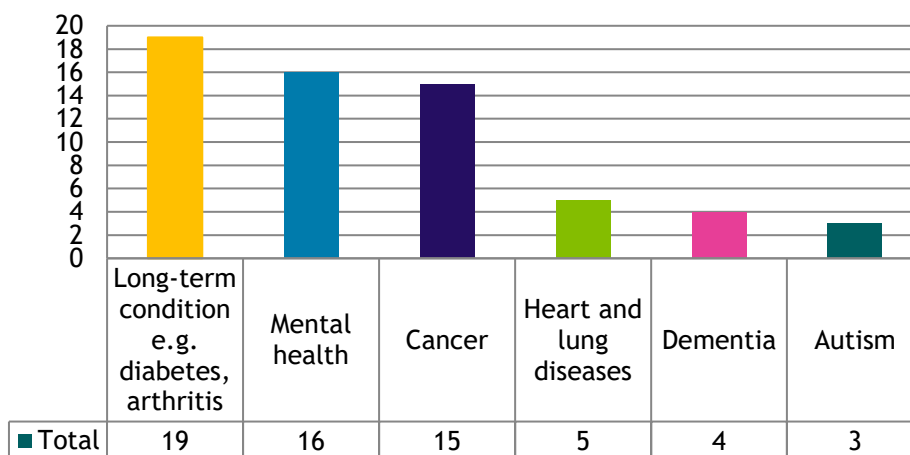
Age

	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75+
■ Total	1	1	1	7	27	32	38	12
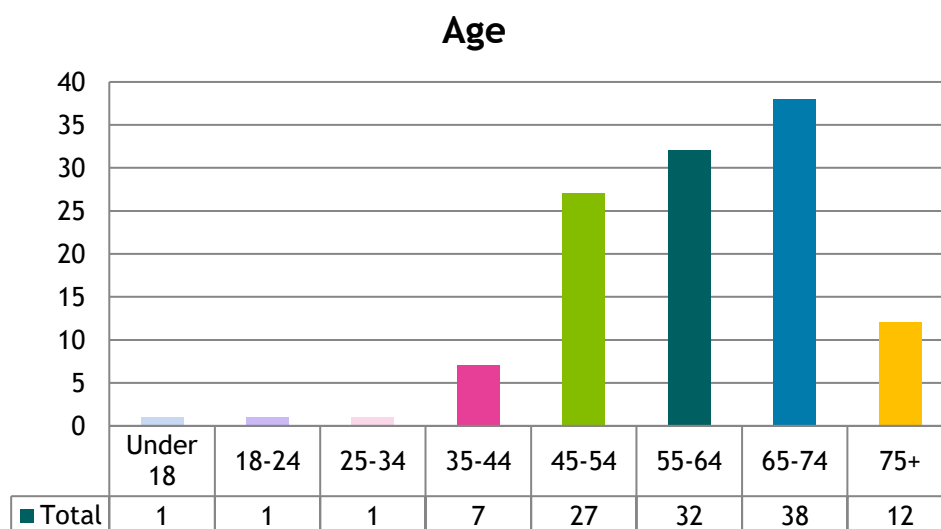
Condition-Specific Survey

There were 63 respondents to the condition specific survey. These respondents were spread more widely in terms of age with 11% under the age of 35.

Age

	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75+
■ Total	1	4	2	3	14	13	17	9
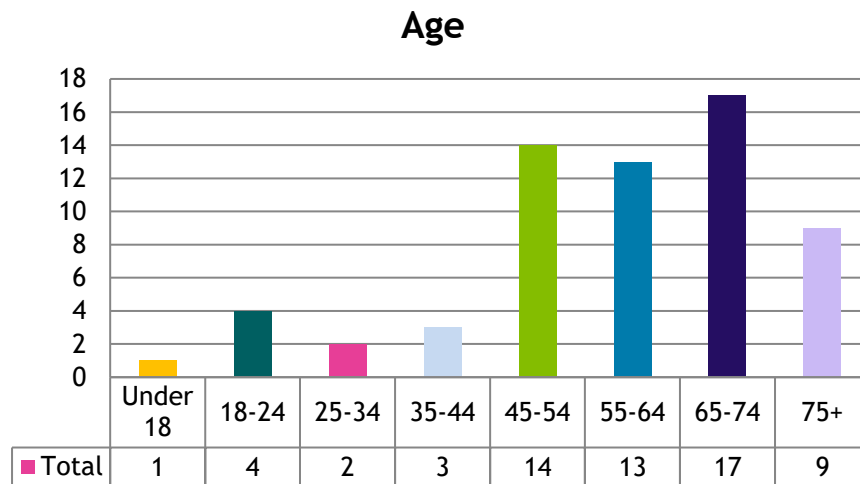
Respondents' conditions were as follows (condition-specific survey)

What is the condition you would like to tell us about?

	Long-term condition e.g. diabetes, arthritis	Mental health	Cancer	Heart and lung diseases	Dementia	Autism
■ Total	19	16	15	5	4	3

Acknowledgements