

NHS Long Term Plan Engagement with under- represented voices in Cornwall.

A snapshot of young care leaver and Gypsy & Traveller experiences of Health & Social care in Cornwall, during November 2019.

About Us

Healthwatch Cornwall (HC) is an independent, publicly-funded organisation. We have statutory duties and a remit to ensure health and social care services in Cornwall are the best they can be for people, now and in the future.

By listening to your experiences of publicly funded health and social care services we are able to inform decisions made by the commissioners and providers of them. This means your voice is heard by those planning and delivering services and can influence positive outcomes.

Background

Healthwatch Cornwall was asked to oversee and report on Volunteer Cornwall's engagement with young care leavers and Gypsy & Travellers in Cornwall to input into the Long Term Plan. Volunteer Cornwall is a strategic partner on social capital development and voluntary action for the Cornwall & the Isles of Scilly Health & Care partnership. Working with the National Association for Voluntary and Community Action (NAVCA), Volunteer Cornwall was asked to facilitate the engagement of two under-represented communities, young care leavers and Gypsy & Travellers, to feed into the NHS Long-Term Plan.

Volunteer Cornwall planned to work in partnership with other local organisations within the voluntary & community sector:

- To understand what people from the Care Leaver and Gypsy & Traveller communities might want to see included in the Long-Term Plan for Cornwall.
- To test assumptions the Long Term Plan had made about the kind of services it will provide, how & where they are delivered, to ensure they will reach the target communities.
- To identify ways to better engage with communities and include these groups on an ongoing basis, including identifying ways we can support them to play a more active role in looking after their own health and care needs and that of others in the communities around them.

Methodology

Volunteer Cornwall engaged with two local community groups in Cornwall, focusing on the needs of young care leavers and Gypsy & Travellers. Volunteer Cornwall supported CareFree and TravellerSpace to undertake the engagement by providing an outline of the engagement theme and suggestions of how the engagement activities could take place. Each community was given the autonomy to utilise the best approach to collect feedback, based on their knowledge and experience of working with young care leavers and Gypsy & Travellers.

These included:

- Drop in events.
- 1-2-1 interactions.
- Focus group activities.

- A Questionnaire or Survey.
- ‘Piggy-backing’ pre-existing / planned events.

How did Carefree decide to take this engagement forward?

Carefree workers asked 22 young people about their views, using conversation and questioning at a recent public event for care leavers.

The questions asked were:

- How can health services in Cornwall meet the needs of care leavers?
- GP services?
- Hospitals?
- Mental health?
- Sexual health?
- Is there anything that would be a block to you in getting a good service from Cornwall and the Isles of Scilly's health providers?
- What does 'good health' mean to you?

How did TravellerSpace take this engagement forward?

TravellerSpace asked Gypsies & Travellers the following questions at one of their weekly community drop-in groups & on their Facebook page. TravellerSpace workers scribed for those with low levels of literacy and helped to facilitate the discussion, however not everyone wanted to engage with the activity.

The questions asked were:

- What’s your experience of using NHS services - eg doctors, hospital
- Was it a good or bad experience?
- How could it be better?
- Do you have a health need that you can’t get help for? How could the NHS help you to look after you & your family’s health needs better?
- How could the NHS help you to look after you & your family’s health needs better?
- The NHS wants to make sure that Gypsies & Travellers are satisfied with the service they receive - what would be the easiest way for you to them know if you aren’t happy about something?

Key Findings

1. **Relationship- based care** was a strong feedback theme across both communities, which is a primary commitment of the Long-Term Plan. Both communities shared examples of where continuity of carer made a difference to health outcomes for themselves and their wider community. An individual from the Care leaver community spoke highly of the relationship they had with their Children in Care Nurse and another individual shared what a loss that had been at 18 years of age.

“The Teyluva Midwives are brilliant, couldn’t ask for better....The Health Visitor who comes (to the community centre) is fantastic.”

“My Dr changed with placement moves - I would have liked to have seen the same doctor”

“My Children in Care nurse was helpful, they gave me a really useful information folder”

2. **Community- based services** were valued by both Care Leavers and Gypsy & Travellers, as a method of addressing the barriers they face related to the rural environment of Cornwall, limited public transport links and personal finance considerations. The Gypsy & Traveller community expressed particular disappointment at the loss of a number of local services, including local walk-in GP Clinics and sexual health clinics.

“My children’s appointments are always at the hospital and I need someone to take us. My children don’t all fit in one car. Don’t always get the letters with appointments, can’t read the times/dates”

“Carn to Coast (walk-in GP) are excellent recently supporting me with NHS chiropractic, physio and advice for severely painful and debilitating left sided sciatica.”

5. **Mental Health support** was a big concern for both communities, who both had lived experience of trauma and existing mental health considerations. Both communities shared a good understanding of mental health on overall health & wellbeing and were worried about the effects of poor mental health on themselves and their families without clear access to appropriate services.

“I need help to understand my life story....Being able to talk about my experiences.”

“A young man from our site killed himself before he got seen (by mental health services)-He’s not the only one in a bad way.”

“I don’t know where to start-I’m worried that children in care may be struggling with mental health and not getting help.”

6. **Good Communication & Language** is important to Care Leavers and the Gypsy & Traveller communities. Both groups shared experiences where they had been misunderstood or treated unfairly within the Health & Social Care system. This impacted on their confidence to disclose important information about their own health; access certain services or return for ongoing care.

“The NHS needs to understand that the conversations and written letters can be confusing and not all can read or write. We feel it is important to explain in better detail and language what they mean”

“Recently I received a letter charging me £9 for a medicine then £45 on top for fine and threat of £50 more because I mistakenly thought I had free prescriptions as receive tax credits.... I won’t be asking for medicine again plus it freaks me out in case they hit me with a charge.”

Further Thoughts

The Gypsy & Traveller community had many suggestions to improve their health & social care offering and reduce the inequalities they experience. These centred on dental, mental health support for men and language.

“Health check-ups at the (local community centre) for children and parents- we can walk there.”

“No-one can get dentists at all and so many people on site have bad teeth....can we a dentist come to (the community centre)?”

“Equalities training for all NHS staff including receptionists is needed”

“We need more walk in health centres, much easier for Travellers to use, especially if they can carry their own notes around when they move around a lot”

“Fast track counselling services and 1st consultation for teens and young Gypsy men as they are most at risk.”

The care leaver community also had suggestions on how to improve their experience of health & social care. These centred on the transition from teen to adulthood services, addressing childhood trauma through life story work and appropriate advertising of what health & social care services are available to young adults.

“Access to a counsellor to do life story work”

“A drive to make young people aware that they can get help for their needs just like everybody else”

The Engagement Process

By working in partnership with CareFree and TravellerSpace, who both work closely with young care leavers and Gypsy & Travellers, Volunteer Cornwall has been able collect feedback from two under represented communities in Cornwall.

Volunteer Cornwall made simple suggestions as to how the engagement could take place, whilst giving permission for each organisation to work autonomously, in order to personalise the engagement and ensure it was as accessible to each community.

The feedback gathered is raw, honest and impactful; providing clear qualitative feedback on individual experiences of current Health & Social care access in Cornwall. It is important to

note that both of the communities involved in this engagement are often stigmatised and this leads to distrust of healthcare professionals and general disengagement with services.

Suggestions for improvements to services were drawn from both communities and this is a vital part of ensuring that each community receives appropriate care in the future. It is evident that both communities would like to be involved in shaping the care they are offered in the future and people were able to share examples of services that work well for their community.

Analysing both communities feedback together has been challenging for Healthwatch Cornwall, due the significant differences between the chosen methodology and facilitation of the engagement sessions. Despite this there are similarities, in terms of experiences and needs, between both communities as outlined in the Key Findings. The feedback collected reinforces the need for personalised and accessible health & social care, as set out in the Long Term Plan.

Both CareFree and TravellerSpace staff did feed back to HealthWatch Cornwall that the engagement participants had little or no understanding of the Long Term Plan and needed considerable support to participate in the feedback sessions. In the absence of an engagement framework each community group created their own questions/discussion points, which have resulted in discrepancies between the overall feedback collected.

Healthwatch Cornwall also wishes to highlight that the size and demographic of the engaged individuals cannot be viewed as representative of their community as a whole. The majority of the young care leavers engaged with were male and the majority of the Gypsy & Traveller community engaged with were female, which will have affected the feedback themes raised.

Recommendations and considerations for future engagement

For future engagement with under-represented communities Healthwatch Cornwall would recommend that:

1. The facilitator spends time with each group prior to the main engagement event, to establish a level of trust and understanding with each community. This would enable people to feel more confident about participating and the facilitator would gain a better understanding of how to personalise the engagement for each community.
2. The facilitator allots time into the project timeline, to allow for each community to familiarisation with the purpose and content of the engagement.
3. The facilitator provides each community group with a personalised document to introduce the requested engagement, using appropriate language and a mutually agreed set of questions/discussion points that needed to be covered.
4. Consideration should be given to the skills and abilities of the community being consulted with to ensure feedback methods used are most effective.
5. The facilitator may need to reach out to certain demographics in each under-represented community, to enable them to collect more representative feedback.
6. Feedback facilitators could explore creative community engagement methods, such as: graphic facilitation, participatory appraisal, audio recording, music making, lego construction, poster creating or crafting for future projects/events.

Acknowledgements

Healthwatch Cornwall would like to thank the following organisations for their participation in the engagement, on behalf of Volunteer Cornwall:

- CareFree Cornwall
- TravellerSpace

Appendices

TravellerSpace Health Needs Survey- November 2019

We asked Gypsies & Travellers the following questions at a number of drop in groups & on our Facebook page. We scribed for those with low levels of literacy. Not everyone answered all the questions.

One response is reproduced at the end without dividing it into the different questions, as it was a very detailed account of mothers experiences when receiving health care for her terminally ill daughter.

What's your experience of using NHS services - eg doctors, hospital

Can be a real struggle getting an appointment with the doctor, especially in St Day, because you can't get through directly to the surgery

No-one can get dentists at all and so many people on site have bad teeth

Really liked Cardrew, now we just go to A&E instead like before

Such a shame we don't have Cardrew drop-in any more, it made it really easy for Travellers to see the doctor instead of going to A&E

*Since the closure of Cardrew drop in which was excellent as a service and a major blow to our healthcare as since then only I have reregistered at a surgery and thats Carn to Coast by Carn Brea. **Ollie** and **[REDACTED]** (sons) still not registered at a doctors.*

The local surgery to site on Goonhilly is St Keverne and mostly disappointed with this surgery as have had real difficulty registering with them in the past as sites such as Dollys (on the Lizard) weren't recognised as an address, and so only taking temporary patient status. One Dr there was excellent and spotted my ectopic pregnancy symptoms immediately referring me and quite possibly saving my life which was good as a mother of then young children.

Have been in situation when living in Porthtowan and going to Mount Hawk surgery, a Dr snapped the L3 neurolemma when overly palpating for infection of my run over leg. I did not feel that I could challenge him about it as I did not feel he would believe me.

Carn to Coast are excellent recently supporting me with NHS chiropractic, physio and advice for severely painful and debilitating left sided sciatica.

Recently I received a letter charging me £9 for a medicine then £45 on top for fine and threat of £50 more because I mistakingly thought I had free prescriptions as receive tax credits, however this is apparently not the case and so instead of asking me for the 9 quid

they are going in on me and I can tell you now I can't afford this and I might offer them 9 quid plus I won't be asking for medicine again plus it freaks me out in case they hit me with a charge. I find it rude and unprofessional and worries me in case I need their drugs in the future

Was it a good or bad experience?

Good, but scary because of what I was facing with my illness

Outlook SW is really terrible, the waiting times are so long. By the time young men are saying they got a problem, it's already really, really bad. Then they have to wait months. A young man from our site killed himself before he got seen. He's not the only one in a bad way.

The Teyluva Midwives are brilliant, couldn't ask for better.

The Health Visitor [REDACTED] who comes to Teyluva is fantastic.

Dr [REDACTED] in Chacewater is good

Dr [REDACTED] & Dr [REDACTED] in St Day are nice to us, good doctors

[REDACTED] Health Visitor is so kind and lovely

Teyluva Midwives look after us really well

When I was giving birth they were nasty. Asked me to take my daughter out the room and wouldn't tell me anything. So glad we've got the Teyluva midwives now.

Good experience with giving birth to 5 children and one operation. They were kind.

Ambulance called doesn't always turn up

When my baby passed, I felt utterly confused by the diagnosis; I didn't understand it at all.

How could it be better?

Some doctors need to be more culturally sensitive, use simple language and make sure people have understood what they are saying.

Some doctors should take time to listen properly

Local St Keverne surgery need to make appointments more accessible, currently need to phone early in the morning for acute cases, often sitting around for hours whilst waiting to be seen not to mention some (not all) challenging attitudes from receptionists.

Need to be advised that we have to pay for drugs now instead of rinsing people for money they don't have with massive disproportionate fines.

Equalities training for all NHS staff including receptionists is needed.

We need more walk in health centres, much easier for Travellers to use, especially if they can carry their own notes around when they move around a lot

Some health staff need to learn about Traveller culture

Appointments at the Teyluva Centre instead

Appointments all on the same day in the same place for different children in the family would be so much easier

Fast track counselling services and 1st consultation for teens and young Gypsy men as they are most at risk. Appointment needs to be near, use the Teyluva Centre

Can we have a dentist at Teyluva?

Do you have a health need that you can't get help for? How could the NHS help you to look after you & your family's health needs better?

My children's appointments are always at the hospital and I need someone to take us. My children don't all fit in one car. Don't always get the letters with appointments, can't read the times/dates

Travelling to appointments is difficult when you can't drive/have schoolchildren too.

Outlook appointments take far too long to come round for people in desperate situations

I can't make appointments on time. I don't always get my post so don't know about them. Can't get there without a lift

Young people with depression & anxiety, don't know what to do about it

Dentists

Dentist, can't get one

Dentist

We are with Teyluva Midwives now so it is much better

How could the NHS help you to look after you & your family's health needs better?

Could have health check-ups at the Teyluva Centre for children and parents, we can walk there.

Have groups on at the Teyluva Centre so we can get there

Can't read the letters the hospital send

Be sensitive and understanding

Seeing the same person that you've got a relationship with, like we do with [REDACTED] and the midwives

So many people young people depressed and needing help, young men suicidal seems to be on the rise and don't know where to get help

Understand about Traveller culture, eg women will only see female staff

Appointments too far away we always need lifts

Don't get privatised; really upset to see sexual health clinic at Treliske just got privatised. Likelihood is back street abortions and rise in STD's

The NHS want to make sure that Gypsies & Travellers are satisfied with the service they receive - what would be the easiest way for you to them know if you aren't happy about something?

Phone call

A number to text

Ask the person themselves or the support worker

Call or text

Somewhere you can go online and easily leave feedback, or a number to text

Text to a number

Someone you can text

Phone or email or tell [REDACTED] (Gypsy & Traveller Support Worker)

My name is [REDACTED]. My daughter [REDACTED] was born with brain damage and was terminally ill from birth. Her death was a result of NHS negligence which was proved through an inquest.

The information I am now giving is my experience of the care my daughter and family received.

I have positive memories of her care, but feel that funding and staff was an issue with the deliverance of that care and these are what I am sharing with you now.

I was very involved with the hospital since my daughter's birth. I was given a lot of support by staff, social workers, to understand what was happening and what was going to happen.

I feel that the service and relationship from the doctors and staff changed when my daughter turned from child to Adult. I believe that the hospital did not have the money, resources, or time to provide my daughter and me and my family with the support, advice, guidance and care that was needed.

I believe there should be a trained member of staff that knows the patient and their personal needs, such as language, sign language, lifting moving and administering medication, likes and dislikes, so the patient can receive the best care. I was never comfortable leaving my daughter in the care of the NHS.

I feel the change of staff, doctors, nurses affected my daughters care, and life. I believe the team who supported her as a child should have continued, as they knew her complexities and health complications. I do feel her care diminished when she transferred to adult care. I think, in my experience with terminally ill and complex health issues, that there should be a small team that is aware of all the small complications that will assist the patient and

family and have empathy. For example I had to teach a nurse how to change my daughters nappy whilst in hospital.

The NHS needs to understand that the conversations and written letters can be confusing and not all can read or write. We feel it is important to explain in better detail and language what they mean- as for me (██████) a doctor drew a diagram of what he was he was going to do, which helped me understand and put my mind more at ease.

Summary of Findings - the views of young people in and leaving care on the NHS to inform the Long Term Plan

Context

In October 2019 Volunteer Cornwall asked Carefree to be undertake work with young people with the following remit;

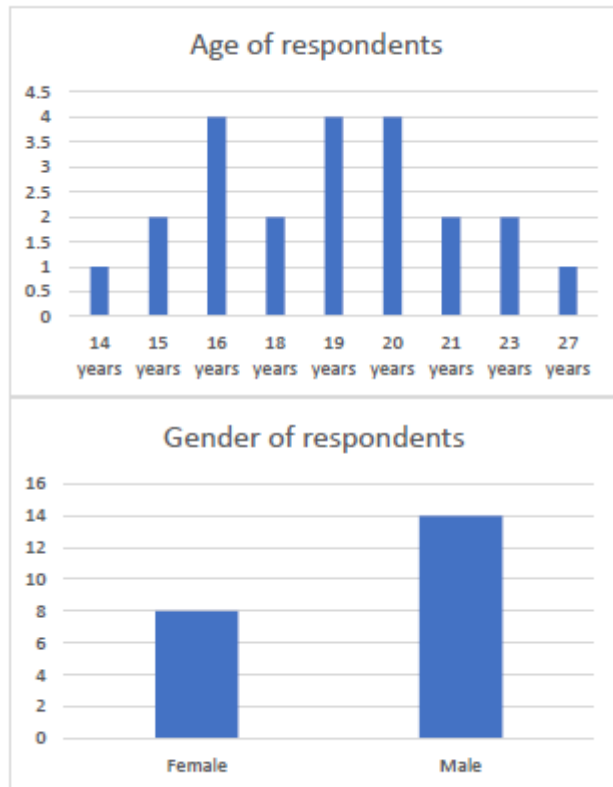
- To understand what people from the traveller and/or care leaver communities might want to see included in the long-term plan for Cornwall & IoS
- To test assumptions the system has made about the kind of services it seeks to provide, and where and how they are delivered, to ensure they will reach the target communities
- To identify ways to better engage and include these groups on an ongoing basis including identifying ways we can support them to play a more active role in looking after their own health and care needs and that of others in the communities around them.

Methodology;

It was agreed that within the timescale provided Carefree would ask 20 young people about their views, using conversation and questioning with the following frameworks as prompts;

- How can health services in Cornwall meet the needs of care leavers?
- GP services?
- Hospitals?
- Mental health?
- Sexual health?
- Is there anything that would be a block to you in getting a good service from Cornwall and the Isles of Scilly's health providers?
- What does 'good health' mean to you?

The questions were asked by 3 researchers (an experienced researcher, a care leaver and a Health professional) engaging with 22 young people. Demographically the young people who responded were as follows;



The broad questions were transcribed and the data was sorted to extract meaningful messages.

Results;

The themes that emerged could be broken down into the following pattern;

Positive feedback
Change and consistency
Importance of relationships
Mental health
Happy
Life story
Sexual health
Availability and accessibility of services
Specific leaving care support
shame/feeling vulnerable
Wider service
Music/arts
Self-care
Healthy eating
Links physical/mental health
Medical model

The 125 separate responses (across 22 respondents) form Appendix 1.

Themes

Positive feedback

There was a general recognition amongst almost all respondents that health services were important and necessary. Several young people simply referred to having a ‘good experience’. Specific praise was offered to specific professions;

My Children in Care nurse was helpful, they gave me a really useful information folder I've had experience of hospital support to help me lose weight and it's been really helpful

Outlook South West men's group really helped me

Other references were to midwifery support and hospital crisis support.

Change and consistency, the importance of relationships.

A very strong theme across all responses was the importance of consistent relationships (18.4% of responses). The feedback included seeing different health professionals, which could be compounded by young people's experience if they moved placement - one young person said *Dr changed with placement moves - I would have liked to have seen the same doctor*

Conversely, a young person in a more stable placement was able to value the consistency that offered;

I've had no trouble getting a dentist, I've had the same one since I was 8 because I've lived in the same placement.

One young person identified that care leavers can be vulnerable once they become young adults; *Lack of support post 18 - I lost my CIC nurse*

Some excellent good practice from health professionals was noted;

My GP is great, helped with my mental health problems and phones me up to check on me

The links between positive relationships and health was recognised on a wider basis by many young people. Several young people mentioned friendship as a positive within health (6.4% of all respondents mentioned friendship, although none of the questions specifically referenced friendship or relationships). Support from carers or former carers was also mentioned.

Mental health, happiness and understanding your own story

19.2% of the responses related to emotional wellbeing and mental health directly - a further proportion referenced the area indirectly. This is consistent with Cornwall's Care for Change

Council's focus on mental health and emotional wellbeing as their top priority in terms of changes to services.

10 of the 22 young people (45%) specifically identified that good health was strongly related to happiness.

Several others specifically related their needs for good health services as relating to the trauma they had experienced as children. For example, one young person correlated good health with having 'no flashbacks'. Another implied the vulnerability of some young people's mental health; they identified that good health was

Good mental health is having a good day and being comfortable in their surroundings. It's a day when they don't feel like it isn't worth it.

Young people had a strong sense that having adverse childhood experiences could make mental health more challenged. One young person said

More support for mental health - I don't know where to start. I'm worried that children in care may be struggling with mental health and not getting help.

There were also several specific references to Life Story work, the process through which children and young people are helped to create a coherent narrative of the trauma they have experienced so that they can find strategies to manage their traumatic experiences rather than being defined by them. Young people said

I need help to understand my life story

Being able to talk about my experiences.

Access to a counsellor to do life story work

Awareness of who you are

Availability and accessibility of services

A very high proportion of responses (27.6%) related to the availability and accessibility of services. A high proportion of respondents made reference to needing extra help to access services which indicated young people's awareness of themselves as more disadvantaged as care leavers. One young person said that there needed to be

A drive to make young people aware that they can get help for their needs just like everybody else

And another said

With all health there should be more information about what's available

Others identified emotional or motivational blocks to accessing services;

I can get free glasses but I'm not motivated to make appointments

Anxiety makes you not want to go to appointments

