



North East and North Cumbria
Child Health and Wellbeing Network

**Poverty Proofing Health Settings
Report**

February 2021

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Foreword

The Network commissioned Children North East to prepare this report as part of the Poverty Workstream at the end of 2019, to ensure the voices of young people and families were heard, to plan and steer this work. Our priority-setting consultations made it clear that Inequalities and Access were a vital focus to ensure the “*opportunity to flourish and reach their potential*” was available to all, and poverty is a true barrier to that.



The subsequent Covid-response lockdown, very quickly laid out a stark picture for all to see; and calls to address poverty-related inequalities were unavoidable. This work will open our eyes to the most basic challenges our families can have- “..... ***we often don't have enough money for petrol ... the parking is so expensive.***”

This report also lays bare the realities facing our most vulnerable families when it comes to accessing healthcare, and we hope to address the issues and enact recommendations as the project moves into its second phase to implement change in those areas we can address.

We hope these findings also prove useful to member organisations across the region especially those highlighted in appendix C, and that adverse financial impact on our families is considered throughout decision making and planning.

The Network will commit to progress this work and raise these concerns across our region to promote awareness and action; and aim to make things easier for our most vulnerable families.



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Introduction

Initial consultation carried out by the North East and North Cumbria Child Health and Wellbeing Network¹ with professionals, families and young people identified priority areas. Projects within each of these areas have been commissioned. The purpose of this project was to provide young people with the opportunity to develop their own 'Working Together Strategy', to share their thoughts on the ways in which they would like to engage with Network and to suggest ways in which this collaboration could take place.

Children North East collaborated with a number of organisations, schools and youth groups across the region to run focus groups with children and young people, the majority of which were held virtually as a result of the Covid-19 pandemic. In total one hundred and seventeen children and young people took part. The young people were asked to share their views about a range of topics including all of the Network priority areas as well as more general questions about health, health settings and health information. This summary will provide a brief overview firstly of the key themes that emerged across all of the different priority areas, followed by priority area specific feedback and considerations in the table below.

¹ North East and North Cumbria Child Health and Wellbeing network will be referred to as 'the Network' throughout this report

Executive Summary

Children North East was commissioned by the North East and North Cumbria Child Health and Wellbeing Network to scope the financial barriers that exist for children and young people to attend health settings. The consultation was wide, including six types of health setting. A wide range of groups and individuals participated from across the North East and North Cumbria. Covid-19 restricted the number of respondents, as the vast majority of individual and group consultation took place online via surveys and video calls. This inevitably reduced and restricted the number of respondents. Responses were given anonymously.

The following summarises the main findings:

- Transport was the most frequently-reported expense to all settings. Distance to setting, parking costs and difficulties and public transport were most commonly cited.
- Using public transport means it can take substantially longer to get to a setting. Other factors such as using more than one transport provider, length of time taken and travelling with children can lead to increased costs and difficulties. Longer periods of time also lead to other costs such as eating outside the home.
- Appointment times and availability were highlighted as being barriers. Work and childcare considerations are linked to this, such as those with siblings who do not attend school.
- The move to phone and video appointments due to Covid received a mixed response, with some families finding that they removed significant financial barriers and others, who do not have English as a first language, finding them problematic.
- Hospitals were reported to be the most difficult setting to access due to their location and associated travel costs. 35% of survey respondents highlighted parking costs and 25% described them as expensive. One respondent explained that petrol costs were a barrier.
- The cost and availability of food for those who were accompanying their children in hospital was reported, with a minority explaining that they had gone periods of time without eating.
- Those with long term conditions and disabilities expressed the widest range and most frequent potential barriers in accessing health settings.
- Clarity of process and wait times in diagnosis, particularly of ASD, was reported as lacking is potentially more difficult to navigate for those living in poverty.

Many of the key themes are inter-related and, taking into consideration the range of inequalities those living in poverty experience, means that those on low incomes are more likely experience more barriers. These themes are not exhaustive and not every setting will present the same barriers.

Throughout the consultation issues related to communication came up in one form or another with a large number of participants and this is a key lens to look at access through, along with clarity of processes and relationship-building.

Considerations are outlined at the end of each key theme as suggested ways of moving forward, however it is important that the context of each health setting is examined.

There are three main recommendations:

1. Research individual settings be with the [Poverty Proofing](#) participatory approach in order to identify the barriers the current population faces in attending appointments and treatment. This process should highlight current good practice and recommend changes that take into account patients' needs, experiences and suggestions.

2. Use the information gained from Poverty Proofing individual settings to build a picture of what is happening regionally. This will lead to a comprehensive understanding of the myriad of barriers, identify the key themes at regional and local levels, provide a set of guidelines to support health settings and share good practice.
3. Raise staff awareness of the causes and consequences of living in poverty which will increase the potential to improve staff-patient relationships and increase opportunities for signposting to other support services.

Introduction

Children NE is recognised nationally for its ground-breaking *Poverty Proofing the School Day* work, which began in 2011. The aim is to identify and eradicate barriers to learning and engagement in schools by consulting with pupils, families, staff and governors. A written report and action plan are formulated and staff training is an important part of the process.

A 2016 Newcastle University evaluation of the programme outlined many impacts including improved attendance and attainment, greater take up of free school meals, more effective use of pupil premium funding, a less costly school day, and an increase in the uptake of school trips and music tuition by the most disadvantaged pupils.² An evaluation update was undertaken and published in 2020 by the University and case studies released as a result:

‘The case studies were both examples of the ways that Poverty Proofing audits and training continue to offer school leaders a structured approach to tackling the barriers to learning that are caused by the impacts of living in poverty. Poverty Proofing data helped both schools understand the changing demographics of their school communities and discover that poverty is more widespread than school staff had initially thought.’³

In February 2020, Children North East (CNE) was commissioned by the North East and North Cumbria Child Health and Wellbeing Network (NECCHWN) to consult with families about the key issues that are affecting their access to health services.

Specifically the consultation looked at barriers that those living on low incomes face. It is important to note that whilst this work was commissioned before the Covid-19 pandemic, the consultation has taken place during the pandemic, between March and November 2020.

² Mazzoli Smith, L. and Todd, L. (2016) *Poverty Proofing the School Day: Evaluation & Development Report*. Research Centre for Learning and Teaching, Newcastle University
file:///C:/Users/CNE%20User/Downloads/PovertyProofingReportfinal%20(1).pdf

³ Mazzoli Smith L., Tiplady L., Todd L., and Wysocki L. (2020) *Fighting against poverty: case studies of school action*. Poverty Proofing the School Day evaluation update 2019/20. Newcastle University
<http://www.povertyproofing.co.uk/resources/>

Methodology

CNE gathered data through consultation with children, young people and parents, with contextual input from key health professionals. Families living on low incomes were approached through CNE and NECCHWN networks, although participants were not asked to divulge their household income. Whilst initially face-to-face meetings were planned, for the most part this was not possible due to the pandemic and therefore data collection was largely online. This meant that the collection was primarily dependent on respondents having access to technology and phones and therefore those with no access to technology were unable to participate. Two face-to-face interviews with parents were possible but none with children and young people (CYP) were held. The groups who participated were all well-versed in using video meetings as a means of meeting up. It is recognised that there will be other groups who would have given important information who were unable to participate. Despite these challenges a wide range of people from geographically diverse locations participated. These included new mothers, young carers, children and young people, parents of children with long term conditions, families living in more rural areas, and others living in cities.

Everyone gave their views anonymously. All participants spoke about their own experiences apart from the health and third sector professionals, who shared their work-related experiences.

The following methods were used to explore these initial stages of poverty proofing health settings.

- a) A CNE parent/carer questionnaire was formulated and distributed throughout the region via social media and partner organisations. There were 40 respondents. See Appendix B for an overview of data.
- b) We had two questions included in a Healthwatch Gateshead and Newcastle questionnaire into barriers that affect Young People's access to health settings⁴ with 71 respondents.
- c) Healthwatch collected information from a group of students (Gateshead), 17 young people and 22 parents.
- d) Six focus groups were held: five comprised of young people (Stockton, County Durham, South Tyneside, Newcastle and one mixed Newcastle and Northumberland) one group of parents (Newcastle) and one group of third sector professionals (Northumberland).
- e) Individual phone conversations with 9 parents/carers – 3 of whom are known to have completed the CNE questionnaire (a). This resulted in the richest conversations during the consultation. They were held privately at a convenient time with respondents who were eager to share their experiences.
- f) We consulted with 3 health professionals for their appreciation and experience of barriers children and young people can experience, as well as the barriers that they face as staff in determining need.

A full breakdown of responses by method is provided in Table 1 and Figure 1 on the following page.

⁴ <https://www.healthwatchnewcastle.org.uk/wp-content/uploads/2020/09/Dont-box-me-in-young-people-friendly-services.pdf>

Table 1: Number of responses by method

Method	No. of responses
CNE parent/carer survey	40
CYP focus groups & interviews	40
Parent/carer interviews & groups	34
Health & related professionals	14
Healthwatch CYP Survey	71
Total contacts	199

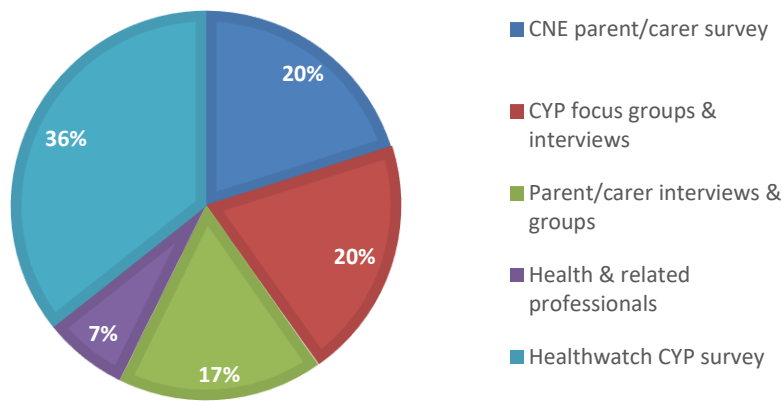


Figure 1: Percentage of responses by method

How to read this report

Participants were asked about their access to health settings, defined as General Practitioners, dentists, opticians, pharmacies, hospitals, and other clinics and mental health services such as Clinics and Mental Health settings (CAMHS) and to outline costs and any cost-related barriers that they have faced in relation to accessing these settings.

Broadly speaking there were two groups of respondents – those who are infrequent users of the NHS and those who need to access appointments and treatment on a regular basis due to long-term conditions, illnesses or disabilities. Within both groups there were respondents who reported having no cost-related barriers in accessing health settings, and those who did. Many of those with children requiring frequent access to health settings not only experience difficulty in accessing settings more often, but also a wider range of them. In this report the terms infrequent and frequent user will be used to specify which group is being referred to where necessary. The section on [Long Term Conditions and Disabilities](#) refers to this in more detail.

Table 2 below shows the vocabulary that will be used throughout the report to indicate an approximate percentage of people to whom we spoke who shared the same experiences and opinions.

Whilst this table is intended to approximate the range and frequency of each issue highlighted by respondents, it is important to note that this will not be an exhaustive list nor necessarily an indication of the extent of the barriers that affect access to individual settings. Not all respondents answered all the questions and we did not discuss all issues with every person. The percentages below refer to the percentage of the number of those who responded to specific questions/themes, not a percentage of *all* of the respondents in the consultation.

Table 2: Frequency of barriers raised

Word	Frequency
Most, the majority, a significant number, in the main, frequently, often	75-100%
Many, a lot of, numerous, generally, regularly	50-75%
Some, sometimes	25-50%
A few, occasionally, a small number	0-25%

An explanatory narrative approach has been taken to highlight how individual contexts interact with the structures and processes of the systems they are navigating. If a small number of respondents have reported barriers, they should absolutely not be disregarded as their health and lives are potentially impacted. Brief case studies (denoted by a boxed text) and quotes (in bold italics) are used throughout the report. Three case studies are included in [Appendix A](#) to illustrate the complexities of people’s lives and to promote a holistic, participatory approach.

Overview of findings per setting

General Practitioners

There were few reported difficulties in accessing GPs. Many said that they could easily get to their doctor's surgery either on foot or by car or public transport. A few mentioned difficulties related to limited parking. A small number expressed difficulty in getting appointments and a few said the timing of appointments was difficult, with time off work being a consideration.

Dentists and Opticians

There were few reported difficulties in accessing dentists and opticians. A small number mentioned limited parking as well as needing to pay for it. A small number reported that they had to travel further than their local dentist in order to be seen as an NHS patient and one said that they are currently receiving private dental treatment as the nearest practice able to offer NHS treatment is too far away.

Not being able to access appointments due to Covid-19 was highlighted by a few, with two respondents concerned about having to wait for dental treatment and leaving full-time education. One of these explained that their dentist was able to see her child for a check-up before leaving full-time education in order to avoid charges. Most students who were interviewed could not remember the last time they visited the dentist, explaining that they would only go if urgent, citing the costs as the barrier.

Pharmacies

Three participants reported travelling to specific pharmacies because of where medication had been prescribed (ie. hospital), because of the relationship with the pharmacy and because they were not aware of pharmacies in their local area. See [Prescriptions](#) for further detail.

Hospitals

The majority of all responses of frequent and infrequent users regarding financial difficulties in accessing health settings related to hospitals. Distance to the setting, the cost of travel, including parking charges and difficulty in getting to settings by public transport. Parking charges were described by some as expensive, notable as this was not reported of other settings' parking facilities.

A few respondents explained that the timing and availability of appointments caused difficulties, particularly with reference to childcare and work responsibilities. This is of particular significance for frequent users who see consultants at very specific times/days.

Overnight stays in hospital lead to additional expenses such as food for those accompanying their children. There were a range of experiences reported with some families being offered food at specific times of year, some settings facilitating food being brought in and others not eating for extended periods of time.

Clinics and Mental Health Settings (CAMHs)

The majority of those who answered these questions referred to CAMHs, with a small number referring to CYPS. Some mentioned wait times to get an appointment. Clarity and transparency in diagnosis was referred to by a few young people, parents and carers and professionals working with them. One said that they had paid for a private diagnosis to save time. Lack of consistency in CYPS staff was cited by a few as an important barrier to support their children.

In the Healthwatch *'Don't Box Me In'* survey, mental health services were mentioned by young people as a service they were unable to access. Reasons included the service location being unknown and far to travel to.

Key Themes

Transport

We explored the various ways that participants travel to settings, including walking, cycling, using own or public transport.

Travelling to health settings, specifically hospitals and specialised clinics was the most reported expense and potentially the biggest barrier.

A member of the Great North Children's Hospital clinical staff explained of one active case of a long-stay patient who they had hoped would return home and attend the hospital on a daily basis, however the family did not want that. Upon investigation, they found that the father had recently been furloughed and earning less. The expense of travelling to and from the hospital on a daily basis was too much. In this case they were put in touch with organisations that could help out financially, however they did not qualify for support.

a) **Cost of parking:** for those with their own transport, this was frequently mentioned and some described the experience as stressful, especially at hospitals:

'The absolute care and expertise at RVI is exceptional from the moment you enter the place. Wish the parking was cheaper as I know some of my friends have avoided appointments because they couldn't afford parking.'

'We have to go to Cramlington and we often don't have enough money for petrol. The RVI the parking is so expensive.'

'RVI is stressful. No parking and if by chance you find a space it costs a fortune. NSECH easier to access, but again parking is expensive.'

'Hard. Had appointments at RVI and at Uni Hospital of North Durham and both really expensive car parks. Public transport is too expensive and takes too long.'

'Very difficult! Either expensive bus travel or expensive parking.'

Whilst parking was less of a problem in accessing GPs, dentists and opticians, it still came up in the survey as a potential barrier – see Appendix A. Mention was made of practices that have been put into place to support patients and ideas for solutions too: *'Very easy (to get to GPs) I drive so no problems there. Parking is free with a permit by providing car registration when entering the building. Bus stop on site too.'*

'Both (dentists and opticians) are in walking, scooting distance. No cost, though having somewhere safe to park bikes would be fab.'

b) **Limited parking capacity:** For some hospitals and a few GP, dentist and opticians, the amount of available parking spaces was also referred to. Respondents explained that this adds to appointment time and therefore cost, not only of parking but the related costs including time taken off work.

Some participants explained that because of staying longer due to queuing for parking, consultants being called to emergencies or problems with paying for parking, this has led to increased costs:

‘Car park is always very busy, need to get there at least 20 minutes before appointment to find a space, so need to pay extra for parking. Parking costs get higher, always a machine broken out of use, so everyone needs to use one machine which takes longer...which can make the price of parking higher.’

‘Got 3 parking tickets for overstay. Appointments take longer than estimated.’

c) **Variation in costing structures** was mentioned. Some hospitals charge in one hour units, with no drop-off facilities available, including UHND where the lowest charge is £2.50. One respondent explained that dropping off someone at A&E there also incurs a charge.

The parent of a child with long-term needs explained that when his child was in critical care he had spent a lot of money on parking at the Freeman. The Freeman does offer free parking however he was unaware of this until he had already paid over £20 in car parking charges. Having not kept receipts, he was unable to claim the money back. Once he was alerted to the system it took over 24 hours for the pass to be issued.

d) Distance also creates barriers. One respondent explained: ***‘have had referrals to Darlington which is a really long drive (50 minutes) which isn’t great for a quick appointment with children.’***

Many with cars were mindful of the difficulties afforded by taking public transport: ***‘If you don’t drive, the cost would be extortionate and a lot more time.’ ‘Would be tough without being a car owner.’***

e) **Public transport** brought about a number of barriers related to cost, time and energy for participants. ***‘It’s really tough to get there on public transport.’***

The lack of a fully integrated public transport system increases costs. One parent explained that using 2 buses (Arriva and Go North East) means they would need to pay for two tickets as they are different networks. A health care professional explained that they knew of young people who struggled to access the hospital nearest their homes in Gateshead because it takes two buses to get there rather than taking one bus to Newcastle.

One mother (see [Case Study A](#)) described the additional time and stress for caused by using public transport for her toddler, and highlighted the fact that the Metro costing structure is not integrated with the bus system, creating additional expenditure.

A student highlighted that she used to have to travel on three buses to attend talking therapies and when she was having a bad day she could not bring herself to go which resulted in her being taken off the program and having to reapply.

One young person in the Healthwatch *Don’t Box Me In*’ questionnaire reported that they had cancelled appointments due to not having the bus fare.

Another difficulty cited was the location of bus stops in relation to the entrance of settings: ***'If taking public transport, the walk to out of hours area (when not housed in A&E) is really far from the entrance.'***

The time it takes to get to hospital for emergency care is potentially longer and more expensive for those on lower incomes: ***'I needed an ambulance for my daughter and I was told it would be faster to drive in or get a taxi. I do not have a car so I had to get a taxi which cost £30.'***

'One night, my friend took ill so I called 999... They told me to get a taxi with her which I could not really afford.'

Returning home from A&E is also a consideration when taken there by ambulance. One parent explained the difficulty returning home when, in an emergency, they had not been able to gather everything they needed.

Considerations:

- Charge less / do not charge for parking
- Do not make additional charges if appointments over-run and factor in time it takes to find a parking space
- Offer safe spaces for bicycles to be locked
- Suggestions from respondents of the Healthwatch questionnaire suggested creating young people-friendly maps with directions on how to access the service/clinic/department, such as which door and what stop to get off at on public transport to make it less daunting when new to a setting
- Find out how families will get home if they have arrived to a setting by ambulance
- Campaign for a better integrated public transport system

Appointments

Considerations taken when making and attending appointments were explored with respondents in order to understand factors that hinder access.

a) **Timing and availability:** difficulties expressed here related to the timing and availability of appointments, ***'Getting an appointment in GP has to be on the day and appointments are that day. I work full time so tricky to get the time off.'***

'Sometimes the timing of the appointments, like when I am at college, psychology at the hospital.'

Whilst for many having appointments over the phone has increased access to health settings during Covid-19, for those who do not have access to phones or have difficulty in using them, it is more difficult. Respondents who had English as a Second Language all said that they did not feel comfortable with having appointments over the phone. See [Case Study B](#).

A young carer in the Healthwatch *'Don't Box Me In'* questionnaire reported that they found it difficult to find the time to see their GP.

b) **Transport considerations** are a related factor as it can be trickier and more expensive to travel at different times of the day: ***'If I didn't (have a car) couldn't have got to the hospital appointment at the X for 9.30am.'***

c) **Timing of being discharged from hospital** was also highlighted as being difficult by a few participants. [Case Study C](#) features a young person who has had to wait hours to be picked up by family.

d) **Childcare** was referred to by a few respondents who explained the following difficulties ***'I have other children under school age I'm not allowed to take (to hospital appointment) when I attend with my 4 year old. What am I meant to do?'***

'As a single parent accessing hospital could be difficult as I would need someone to look after my other children.'

A few respondents highlighted difficulty in attending related to their children's or own needs for example, not being able to attend because the waiting room was too loud. Whilst not directly related to financial background it is worth highlighting.

Considerations:

- Find ways to offer patients the opportunity to choose the best times for them to attend appointments, and potentially combine appointments per patient or per family
- Include information-gathering about the financial barriers patients face as part of the process of making an appointment, including travel, loss of earnings and childcare
- When being discharged at night, ask how each patient will get home
- Consider using GPs for satellite appointments for those who live far from specialised hospitals
- Consider using phone/video appointments where appropriate whilst giving face-to-face access for those unable to access a phone/internet

Prescriptions

Costs incurred in obtaining prescriptions was investigated with participants.

Two respondents explained that they travel a significant distance to get to their pharmacy. For one it was because they trusted that particular pharmacist, for another it was because they were not aware of pharmacies near to where they live ([see Case Study B](#)).

One participant explained that because a consultant has prescribed for her child, repeat prescriptions come from the hospital and she has not been able to use a local pharmacy for this. There have been times when the hospital pharmacy has not had the medicine in stock and she has had to return another day. She also explained that when her GP has taken over prescribing a medicine, it was in a different form to what the consultant had prescribed: Her 1 year old with reflux had been prescribed liquid medicine by the consultant, however her GP prescribed pills to be ground up, which she felt was less effective. Her GP had cited cost as the reason.

One health-related professional explained that she had worked with young people who had been fined for not completing the prescription exemption form correctly, having ticked the wrong box, resulting in a £100 fine which they then needed to claim back.

Considerations:

- Monitor which pharmacies patients are using, particularly if they move house or change health setting such as GP
- Include questions relating to potential barriers in access when taking on new patients
- Encourage all pharmacies to ensure prescriptions are filled correctly

Food

As part of expenses that can occur when children or young people are hospitalised, access to food if a family member accompanied them was researched.

The mother of a child who is often kept overnight in hospital explained that as parents they eat at the hospital café but are occasionally offered toast at breakfast.

Some outlined when they have had access to refreshments or that they are facilitated such as at the QE special care unit for babies: **'You can have access to tea, coffee'**. The Sunderland Royal was also highlighted: **'Good at taking your own food...can order take outs to room.'**

Mention was also made of particular attention being taken at QE Gateshead: **'Had to go to Paediatrics on Christmas eve, the staff were amazing, we had a long wait as it was really busy, we were given sandwiches and drinks while we waited. My little girl got a box of chocolates and a present. All in all made a horrible situation that much better.'**

One participant made reference to his wife giving birth: **'She gave birth here last month (Sept 2020) and didn't eat anything for 2 days as due to COVID they weren't offering food. She couldn't afford the extortionate prices within the hospital so had to wait until her mam came and gave her food. Not very good after just giving birth.'**

[Case Study B](#) highlights the case of the mother who does not eat when her child is hospitalised because she will not leave her child's side, and this happens on a regular basis.

Considerations:

- Consider how to identify families unable to afford food-related costs within settings and provide them with food
- Monitor the pricing and uptake of food within settings

Staff and Setting Awareness

Staff and setting awareness around individual patients' financial circumstances was explored with health professionals and also highlighted in the voice taken from young people.

A member of the GNCH clinical staff talked about the lack of information that staff have regarding someone's financial background and the awkwardness involved in enquiring about potential financial barriers.

The Healthwatch 'Don't Box me In' survey highlighted the importance of relationships between service-user and staff for young people: ***'When we asked young people what improvements could be made to services, the main themes that emerged were staff and the service environment. Young people told us that services could be more young people-friendly and less intimidating if staff smiled more and if reception staff were friendlier as they are the first point of contact. Respondents also felt that staff needed to speak to them directly to build trusting relationships with them rather than their parent. They suggested staff training on how to communicate with young people and to consider employing younger staff with similar backgrounds to make them more relatable.'***

A few other respondents reported that they felt that staff and settings did not take into account their children's or their own needs.

Considerations:

- Increase staff awareness of the causes and consequences of poverty and their understanding of the lived experience of poverty
- Staff training/coaching on how to handle conversations concerning financial barriers
- Consider asking questions related to financial background when patients attend health settings such as 'How did you get here, how will you get home?' 'When will you eat next?'
- Become more approachable to young people by taking on the suggestions made in the Healthwatch survey: become more young person-friendly and less intimidating by smiling. Speak to young people directly rather than to parents.

Long Term Conditions and Disabilities

We explored the barriers that can exist for children who have long term conditions and disabilities, and their parents.

They reported experiencing more frequent and a wider range of difficulties in accessing health settings than other respondents. Participants with children attending multiple appointments at multiple locations outlined a range of experiences and potential barriers to attending settings. Whilst some of these difficulties are explained in other sections, it is important to feature the experiences gathered during the consultation of this diverse group in one section.

One parent explained that her child has 6 monthly appointments with a range of services to monitor her needs. All appointments occur between 9- 5pm and are dependent on when the consultant is available. One example was the eye consultant only being available on a Thursday morning. She usually takes her child to these appointments, although her husband or the grandmother have attended when she has been unable to. A part time teacher, her workplace pays for a supply teacher to cover her absence and she describes her workplace as being **'very supportive'**; however she explained that it also negatively affects her child's school attendance which is currently 93%, below school and Department of Education expectations.

A mother of two children with long-term needs spoke about the difficulty of attending multiple appointments at multiple settings both local and further afield. Based in Carlisle, the greatest distance to travel is to two settings in Newcastle and they will often use public transport to do this. This involves a return train journey and return taxis between Newcastle station and the setting/s. Whilst it is possible to book in advance for cheaper train tickets, the price is dependent on the time of day the appointment is. Other expenses include data for devices and food, an estimated £40. Many of the appointments are check-ups involving weighing and measuring and when she has asked if it is absolutely necessary, she reported that she has been told it would be a child protection issue if her child did not attend. She described it as an **'ever-present threat.'** She also described the energy and time required for these appointments as it takes a whole day to attend them. She explained that the video appointments that have been set up because of the pandemic to be a really positive solution.

a) **Wait time** taken to initially access CAMHS services was mentioned a few times, with many of those respondents referring to children and young people with autism:

'Extremely difficult...to try and get a diagnosis and to navigate the mental health system for children.' ***'Once in the CAMHS system, easy to access. Found it a wait to get first appointment.'***

b) **Clarity of process in arriving at a diagnosis** was highlighted by some, with many of these respondents specifying autism. One young person explained that being tested for autism was a **'bit of a nightmare'** with paperwork being a barrier. Once his family realised that they could go via their GP rather than solely the school route, the process became much simpler. One of his reflections was: ***'Can't imagine how a lone parent would go through this.'***

A Youth Worker with many years of experience of working with groups of young people felt that the confidence that families have is also a determinant of how quickly a diagnosis can be reached.

A parent explained that they had paid for an autism diagnosis at a private centre in Warrington because they felt that they had been waiting too long with the NHS. The cost was £1,700 for the diagnosis, and there were associated travel and accommodation costs. They said that her child's school has accepted this diagnosis but, at the time of interview, it had not yet been accepted by the NHS.

c) **Timing and distance travelled to appointments** was also an issue for some.

'CAMHS – was hard to get referred, long waiting list and very little tolerance of my autism. Expensive bus or expensive parking and disjointed appointments. I once had three appointments over two days for various children. Would have been much easier to combine so I only had to take time off work and pay for parking once.'

d) A few also mentioned no longer having treatment due to **non-attendance**: ***'CAMHS, my son missed appointments due to not being able to get there so has been taken off the list. He now just stays at home.'***

One respondent explained that due to Covid-19 access was difficult for their child because: ***'They are not seeing people face-to-face so very hard.'***

e) **Lack of continuity in staff** was specifically mentioned by families who talked about CYPS:

'See a doc from CYPS, constantly changing the names doctor we see - don't even know who our doctor is anymore.'

'The appointments are sporadic and there is no consistency with staff. This is hard for a child with ASD.'

Considerations:

- Ensure all families are aware of the pathways to diagnosis
- Find ways to offer patients the opportunity to choose the best times for them to attend appointments, and potentially combine appointments per patient or per family
- Look at ways to address continuity of staff/ delivery in services
- Examine how missed appointments are dealt with

Covid-19: Maternity and Family Planning

Whilst this information was not part of the initial consultation and therefore there are no suggested considerations, participants shared experiences surrounding access to services related to maternity and family planning, centred on the changes in service delivery due to the pandemic.

The practitioner running a new parents group in Cumbria outlined the difficulties her group were having as they were unable to see a health visitor during the first lockdown. In addition to baby/toddler groups not running it meant that they were unable to share worries such as how much should they eat, sleep and so on. She also talked about the isolation that some were experiencing, with many of them having left work to go onto maternity leave and having no way of meeting other new mums.

A new mum in Newcastle reported that she has been suffering depression. She had not been allocated a health visitor due to lockdown 1 but instead was put into a pool of health visitors. She estimated it took 4 to 5 weeks for her to talk to someone properly about her depression.

Lack of access to family planning during the first lockdown was specifically mentioned by a respondent who wanted access to contraception during the lockdown as they could not afford to have another child.

Conclusion and Recommendations

Poverty and a lack of financial resource is a barrier to children, young people and their families accessing health provision. What the barriers are and the extent to which the barriers limit children's access is yet to be established, but from a small sample we have drawn out a range of areas that present barriers, and these are barriers that have impact across a range of settings.

Health settings are all very different, based on what services they offer, their locations and the people they serve. Those accessing them change with a frequency dependant on those people's lives and the nature of the settings; a GP will have a far more static set of patients that Accident and Emergency. This consultation has highlighted actual and potential barriers that exist for a small, geographically diverse set of respondents with varying needs.

Throughout the consultation issues related to communication came up in one form or another with a large number of participants and this is a key lens to look at access through, along with clarity of processes and relationship-building.

Certain characteristics appear to influence access to health settings due to financial circumstances including having a long term condition or disability, being a lone parent and having an inflexible employer. Understanding the lived experience of poverty will give staff crucial knowledge and confidence when dealing with families living in poverty, and therefore further training in this area would be extremely beneficial.

Children, young people and parents have a lot to say about the challenges they face accessing health settings, and many feel a helplessness as there is nothing they can do about those barriers. By including them in a Poverty Proofing consultation for specific settings and involving them in identifying solutions will allow them to become active participants.

Given the widespread economic effects of the pandemic, it is expected that those already living in poverty are likely to be pushed deeper into it alongside a significant number falling into poverty for the first time. For the first time ever, an October Ipsos MORI poll demonstrated that public concern about poverty has never been so high. This coincided with the House of Commons debate on extending the provision of free school meals into the half term holiday. With more people seeing it as the biggest problem facing the UK, this consultation is timely.⁵

Recommendations

1. The main recommendation is to work in a more specific geographic location and with one or two settings to explore the barriers at a micro level, bringing together the experiences of staff and children, young people and their families to identify barriers and solutions in attendance and engagement with settings. Include staff training within this process.
2. Use the information gained from Poverty Proofing individual settings to build a picture of what is happening regionally. This will lead to a comprehensive understanding of the myriad of barriers, identify the key themes at regional and local levels, provide a set of guidelines to support health settings and share good practice.
3. Raise staff awareness of the causes and consequences of living in poverty which will increase the potential to improve staff-patient relationships and increase opportunities for

⁵ Ipsos MORI October Issues Index October 2020 <https://www.ipsos.com/ipsos-mori/en-uk/ipsos-mori-issues-index-october-2020>

signposting to other support services. This can be seen as stand alone training or, ideally, as part of the process of Poverty Proofing individual settings.

[Appendix C](#) outlines a draft proposal of themes to consider, and includes: transport, timing and availability of appointments, pathways to diagnosis, procedures surrounding admitting and discharging patients, communication relationships with patients and families and staff awareness of poverty. There is already good poverty proofing practice going on, and this process can facilitate a better of view of what that looks like, as well as celebrating and sharing it.

Appendices

Appendix A: Case Studies

Case Study A

A is a lone parent (NE26), mother to a 19-month old child with Down's Syndrome. She has had to give up work for the time being to care for her daughter. With no family living nearby and unable to drive, she uses public transport. She explained that her daughter attended 21 appointments the first week after birth at various hospitals in the region.

When there are no lockdown restrictions, she takes her daughter to four groups each week incurring a monthly cost of £90 for the Metro. One of the sessions is not located near a Metro stop, incurring an additional cost for the bus to attend those sessions. There are other groups and centres she would like to access but cannot. For example, one of the groups is an approximate 45 minute drive away. Other parents have offered to give her a lift but as they often do other things en route such as visiting family, she declines. There are also free groups at the Alan Shearer Centre but this is not easily accessible on public transport for her.

Looking forward to an upcoming appointment at the Freeman Hospital in High Heaton in November 2020, the trip will include one Metro and one bus each way. She explained that this is a lot for her child to experience. The appointment itself is unsettling for her, notwithstanding the journey and potentially bad weather to contend with at that time of year. The letter she received for the upcoming appointment, included information about to contact them if transport to attend is required. However this is for those who are eligible and because she can make it to the appointments, she assumes that she is ineligible.

At birth A was informed that her daughter would be eligible for Disability Living Allowance (DLA) however this was refused twice and it has taken over a year to get. She currently receives the lowest monthly payment of £90 month. Describing the process of applying R explained: ***'Sometimes she's (her daughter) treated as different, she has a disability, but not different enough.'***

When asked what improvements could be made, A explained that she was unaware at the time of birth that her daughter had Down's Syndrome and that the process was extremely difficult for her. She was given a photocopy of a Down's Syndrome Association pamphlet, describing it as having a large logo of the Association on the front, and felt that it was not supportive. She strongly feels that families should receive packs as soon as they find out that includes up-to-date information including facts and support groups. This will help families not to feel alone and also ensure that they are aware of support available. She explained that there is a local group which makes up these kinds of packs, including a book for baby.

She recounted that there is money and information out there that she can access for support but it is difficult to find. When her daughter was born, she spent 5 hours a day, finding out more information about the condition and support available, which would have helped considerably if she had been given this at birth.

She also said that providing taxi service ***'for the likes of me'*** would make a huge difference.

Case Study B

B (NE6) has two children, one of whom has a blood condition and goes to the GP and hospital regularly. B herself has health problems and has frequent medical appointments. She has English as a Second Language and explained that she does not feel confident when speaking and understanding English. B was interviewed in September 2020 and had recently moved to NE6 from another NE postcode in August 2020. She explained that due to mental health problems she is unable to use public transport and so takes a taxi to all medical appointments. It is slightly cheaper for her to get to these now that she has moved and she estimated the following costs (one way and depending on the traffic): GP £6-7 ; Dentist £4 – 5 Hospital £7

The pharmacy she goes to is located in the same building as her GP so collecting a repeat prescription has the same costs of going to the GP. She is not aware of pharmacies near where she now lives.

When asked about the cost of transport she explained: ***'Taxis are a problem for me'....'Difficult for me the life...have less money for food, buy second hand clothes*** (as a result of paying for taxis).'

When her GP has told her at the surgery that she needs to take her child to the hospital due to her blood condition, she has been asked how she is going to get there. She explained that they have called and paid for a taxi rather than them having to wait for an ambulance.

When her daughter needs to stay overnight at hospital, B explained that she does not eat as she will not leave her child on her own to look for food, although sometimes she has been offered milk or juice.

Covid-19 has added some additional challenges with GP appointments being by phone. Seeing a doctor face-to-face makes it easier for her to explain herself and to understand the doctor. She has used interpreter in the past (pre-pandemic) at doctor's appointments but felt that what she had said was lost in the translation.

Case Study C

C is a young person aged 16. They have one parent who works full time:

'I only have one parent, who works full time. I am responsible for taking public transport for going to appointments as well as school. So that can be quite difficult. It would take approximately 45 minutes for me via public transport to get there, to a hospital I mean.

Either the RVI or the UHND - I am in-between both of these so it is a trek for me to make it to either one. It can be quite difficult and daunting to know that I have to rely on public transport for appointments and things.'

C explained that their parent works nightshift and once was kept in the RVI overnight, being discharged around 6.30am and C's parent was not able to pick them up till around 11am. They were offered breakfast before being discharged but otherwise waited until being picked up. They did consider using public transport as they had enough money for it, however stayed until the parent picked them up so that they knew where they were.

Appendix B: CNE Parents & Carers Survey Data

This online survey was promoted throughout the NE and Cumbria between April and October 2020 with 40 responses coming between July and November 2020. The following is a collation of the results.

- 1) Which health settings has your child accessed in the last 12 months? Click only those that apply.

Health setting	Total	Percentage
Doctor's surgery	31	77.5%
Dentist	24	60.0%
Pharmacist	20	50.0%
Optician	19	47.5%
Hospital	18	45.0%
Mental Health Services	8	20.0%
Clinic (unspecified)	7	17.5%

- 2) How easy is to access your local doctor's surgery? Does anything make it difficult to get there? Are there any costs involved to get there or once you are there?

	Total who directly answered	
Easy	11	27.5%
Difficult	4	10.0%

Issues highlighted in comments	Total mentions	
Parking limited/problematic	5	12.5%
Parking costs mentioned	1	2.5%
Getting appointments	3	7.5%
Appointment times	1	2.5%
Time off work to attend appointments	2	5.0%
Having appointment over the telephone and not seeing GP	1	2.5%
No space at local GP so has to travel further	1	2.5%
Child's needs make the experience overwhelming	3	7.5%

- 3) How easy is to access your dentist and optician? Does anything make it difficult to get there? Are there any costs involved to get there or once you are there?

	Total who directly answered	
Easy	16	40.0%
Difficult	2	5.0%

Issues highlighted in comments	Total mentions	
Parking limited/problematic	4	10.0%
Parking costs mentioned	8	20.0%
Getting appointments due to Covid (dentist)	2	5.0%
Difficulty getting appointment (optician)	1	2.5%

Attends as a private patient (dentist as nearest NHS space is approx. 20 miles away, Carlisle – Silloth))	1	2.5%
Takes taxi	1	2.5%

- 4) How easy is to access hospital? Does anything make it difficult to get there? Are there any costs involved to get there or once you are there?

	Total who directly answered this	
Easy	2	2.5%
Difficult	3	7.5%

Issues highlighted in comments	Total mentions	
Parking costs mentioned	14	35.0%
Parking costs referred to as expensive	10	25.0%
Cost of petrol difficult	1	2.5%
Location/ distance from bus stop	2	5.0%
Public transport awkward	1	2.5%
Childcare difficulties (siblings not permitted to attend appointments)	2	5.0%
Getting time off work	1	2.5%

- 5) How easy is to access health clinics or mental health services? Does anything make it difficult to get there? Are there any costs involved to get there or once you are there? Please state which health clinic or mental health service (e.g. CAMHS) you are referring to.

Child attends a health clinic/ mental health service		
CAMHS	4	10.0%
Psychologist	2	5.0%
Speech & language / Genetics	1	2.5%
CYPS	2	5.0%
No	24	60.0%

Issues highlighted in comments	Total mentions	
Parking costs mentioned	2	5.0%
Transport costs mentioned	1	2.5%
Timing of appointments	3	7.5%
Difficulty in getting diagnosis	2	5.0%
Wait times	2	5.0%
Paid for a private ASD diagnosis	1	2.5%
Appointment cancelled due to Covid	1	2.5%
Difficulties arising as appointment not face to face	1	2.5%
Lack of consistency CYPs	2	5.0%
Child's needs affect attendance	1	2.5%

Appendix C: Summary of Considerations

Transport	<ol style="list-style-type: none"> 1. Charge less / do not charge for parking 2. Do not make additional charges if appointments over-run and factor in time it takes to find a parking space 3. Offer safe spaces for bicycles to be locked 4. Suggestions from respondents of the Healthwatch questionnaire suggested creating young people-friendly maps with directions on how to access the service/clinic/department, such as which door and what stop to get off at on public transport to make it less daunting when new to a setting 5. Find out how families will get home if they have arrived to a setting by ambulance 6. Campaign for a better integrated public transport system
Appointments	<ol style="list-style-type: none"> 1. Find ways to offer patients the opportunity to choose the best times for them to attend appointments, and potentially combine appointments per patient or per family 2. Include information-gathering about the financial barriers patients face as part of the process of making an appointment, including travel, loss of earnings and childcare 3. When being discharged at night, ask how each patient will get home 4. Consider using GPs for satellite appointments for those who live far from specialised hospitals 5. Consider using phone/video appointments where appropriate whilst giving face-to-face access for those unable to access a phone/internet
Prescriptions	<ol style="list-style-type: none"> 1. Monitor which pharmacies patients are using, particularly if they move house or change health setting such as GP 2. Include questions relating to potential barriers in access when taking on new patients 3. Encourage all pharmacies to ensure prescriptions are filled correctly
Food	<ol style="list-style-type: none"> 1. Consider how to identify families unable to afford food-related costs within settings and provide them with food 2. Monitor the pricing and uptake of food within settings
Staff & Setting Awareness	<ol style="list-style-type: none"> 1. Increase staff awareness of the causes and consequences of poverty and their understanding of the lived experience of poverty 2. Staff training/coaching on how to handle conversations concerning financial barriers 3. Consider asking questions related to financial background when patients attend health settings such as 'How did you get here, how will you get home?' 'When will you eat next?' 4. Become more approachable to young people by taking on the suggestions made in the Healthwatch survey: become more young person-friendly and less intimidating by smiling. Speak to young people directly rather than to parents.
Long Term Conditions and Disabilities	<ol style="list-style-type: none"> 1. Ensure all families are aware of the pathways to diagnosis 2. Find ways to offer patients the opportunity to choose the best times for them to attend appointments, and potentially combine appointments per patient or per family 3. Look at ways to address continuity of staff/ delivery in services 4. Examine how missed appointments are dealt with

Appendix D: Draft Poverty Proofing Health Settings Themes

The delivery of Poverty Proofing Health Settings will centre on the experience of children, young people and their families, and will utilise an exploratory methodology that understands and draws out actual barriers faced by those living poverty. To enable us to have meaningful discussions with patients the consultation process needs a clear structure and, following this scoping exercise, the following themes should be part of that formal structure.

Transport: To include petrol and parking costs, how accessible a setting is to public transport users, how far they are from patient's homes, what is the costing structure (including weekly passes) and how do patients know about potential discounts or exemptions? What happens if a patient has no access to internet or telephone?

Appointments: What is the availability, capacity and timing of them? What happens if an additional member of the family needs to accompany the patient such as a younger sibling? What consideration is/can be given to parents and carers who will lose earnings due to the timings of appointments? What happens if a patient has no access to internet or telephone?

Pathways to diagnosis: The processes and procedures that are in place in order to come to a diagnosis, particularly for illnesses and conditions that take longer to diagnose. How clear and transparent are these processes from the point of view of both patients and staff? How up-to-date is the information and how is it communicated? Are there quicker routes available for those able to pay privately?

Admitting and discharging patients: What support is available such as food for anyone accompanying a child? Is food offered (and eaten) before they leave? What systems are in place if a CYP is picked up late? What happens with those who are being discharged late at night (e.g. A&E)?

Communication: How effective is it? Do patients and their families understand the language / terminology being used? What information is shared between staff?

Relationships with patients and their families: Which staff members do they trust/ find approachable? How much time is available to build up a relationship?

Staff awareness: What is staff's understanding / lived experience of poverty? What indicators of financial difficulty should staff be looking out for? Do staff know where to signpost if someone is experiencing difficulty? Are there other ways of signposting e.g. posters?

Appendix D: Monitoring Information

Postcodes of respondents (where provided)

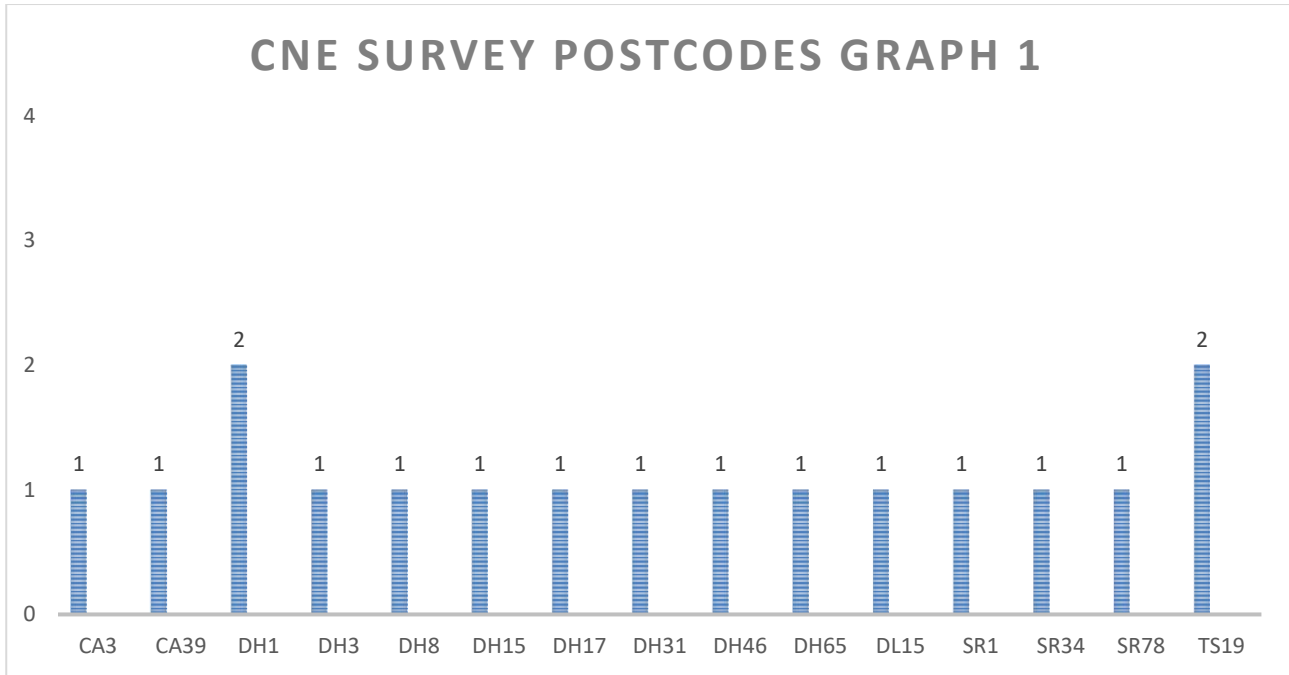


Figure 2: Respondents postcodes (where stated)

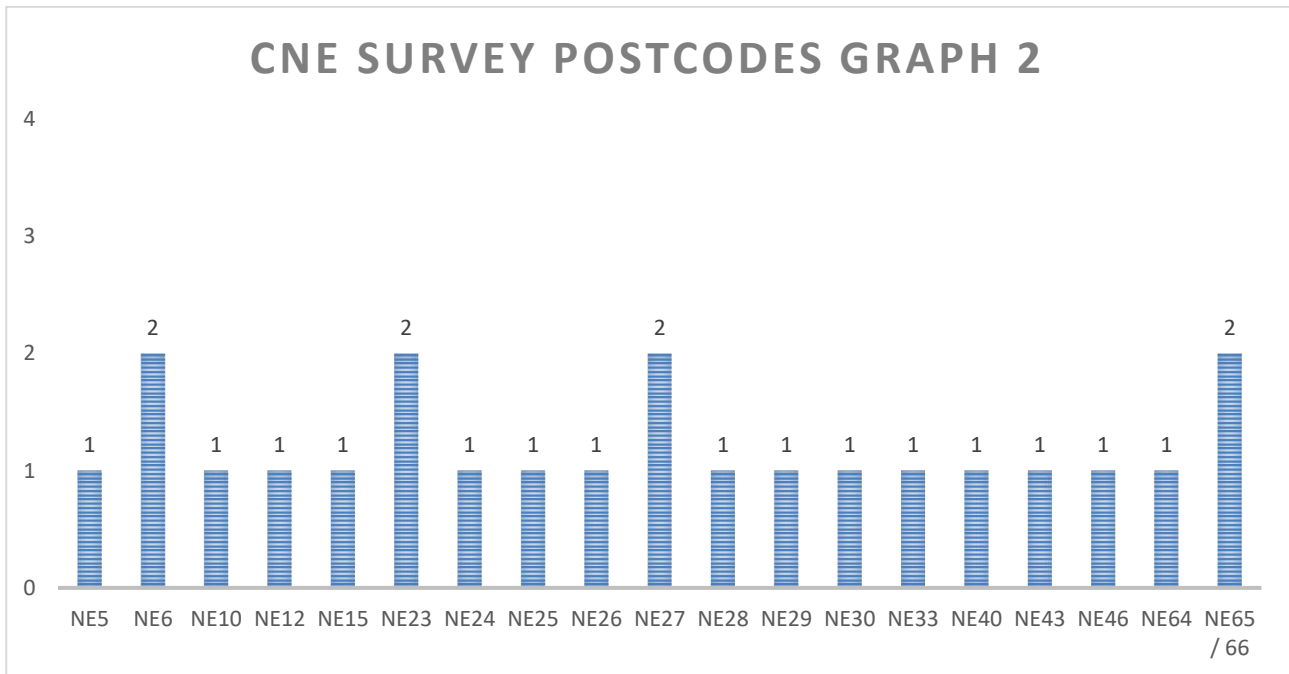


Figure 3: Respondents postcodes (where stated) continued

Gender (where given)

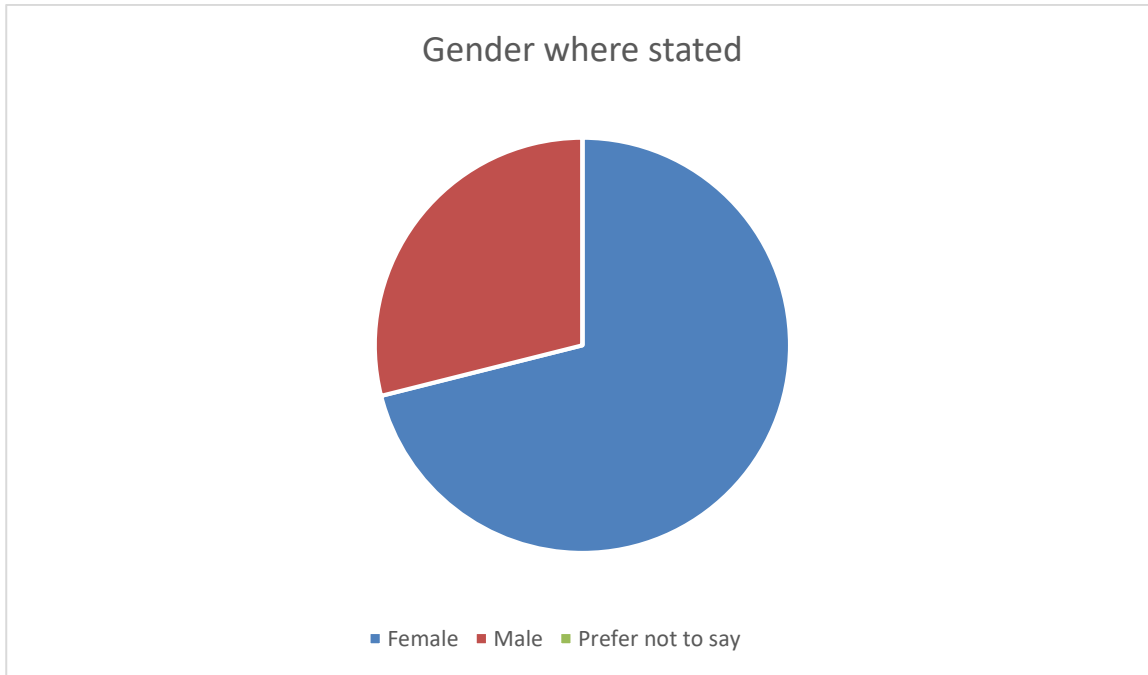


Figure 4: Respondents by gender