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## Urgent Care Services – Parent Carers’ experiences and suggestions

June 2019

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### 1. Executive Summary:

This consultation looks at parent carers’ understanding of urgent care services in Brighton and Hove and their experience of accessing these services for their children and young people (CYP) and for themselves. We also asked parent carers for suggestions and ideas on how urgent care services might be improved.

‘Urgent care’ means any form of medical attention needed on the same day but that is not life-threatening, such as help with a medical condition, injuries, illnesses or other ailments, where the person seeks advice from a health professional such as a GP, pharmacist, NHS 111 or a Walk-in-Centre. Urgent care is different from ‘emergency care’ which is defined as ‘immediate or life threatening conditions, or serious injuries or illnesses’.

Reducing pressure on A&E by better managing demand for urgent care and primary care which responds to patients’ needs is an ongoing challenge for the NHS. Recommendations from this report will be passed on to Brighton & Hove City Council Clinical Commissioning Group (B&H CCG) and inform development of a service specification for a Same Day Urgent Care Service.

We found out that:

1. Parent carers have good awareness of some urgent care services but in spite of CCG efforts to promote urgent care service options, parent carers are less aware of others. Awareness was reported as follows: GPs (89%), NHS 111 (80%), Royal Alexandra Children’s Hospital (65%), Pharmacy (63%) and Walk In Centre (61%). Less well-known urgent care services include NHS Out of Hours (41%), Urgent Care Centre (32%), NHS Dental helpline 111 (30%), Sussex Mental Health line (28%) and Minor Injury Unit (15%)
2. Aside from awareness of urgent care services, the main barrier parents reported from their experience of accessing support is an inflexible system that does not allow them to easily access appointments and does not adequately take into account the needs of SEND families.
3. Parent carers reported that some services are better equipped to provide support for their CYP, for example, the Royal Alexandra Children’s Hospital, including the Paediatric Mental Health Team based there. They explained that this is because they can more reliably access SEND experienced health professionals in this setting.

4. Nearly half of respondents reported they have used an emergency service - ie A&E - instead of urgent care, because they lacked confidence in urgent care services or were not aware of them.
5. Some visits to A&E or urgent care services were a result of a CYP not being seen, or supported, quickly enough by CAMHS.
6. To increase use of urgent care services:
  - a. 46% parent carers said they would need to be more reassured that they will be able to access specialist care from a professional who understands their family's needs
  - b. 32% parent carers said they would want to access a service that addresses their family's needs as quickly as possible / 44% parent carers would like the waiting time to be reduced / 34% parent carers suggested extending opening times and having a better booking system for urgent care services
  - c. 39% parent carers need more information on urgent care services so they are better aware of which service to access and how to find them
7. Most parent carers would like information on urgent care services provided online through a website or an app.
8. Parents reflected that for a publicity campaign to succeed in reducing demand on emergency care by increasing effective use of urgent and primary care services, then parents would have to feel confident that urgent care services have improved and will meet their needs.

### Recommendations:

- **B&H CCG to maintain and develop publicity and promotion of urgent care services. Parents suggested publishing more information online or via an App, and for Amaze and PaCC to share this on social media to increase awareness within the SEND community.**
- **B&H CCG and NHS providers to develop workforce strategies which increase the skills, knowledge and experience of SEND of staff working within urgent care services, eg provide training for all staff around additional needs and disabilities.**
- **B&H CCG to pilot My Medical Passport type initiative to enable parent carers/CYPs to articulate their individual needs to staff within urgent care services. This would help families feel that staff better understand their needs when engaging with health services and increase confidence that the system is responsive and flexible, see e.g. <http://stlawrencesurgery-worthing.nhs.uk/wp-content/uploads/2018/06/My-Medical-Passport-for-Adults-with-Mental-Health-.pdf>**
- **B&H CCG to ensure that Same Day Urgent Care Service includes an improved appointment booking system which take in to consideration needs and demands of caring roles.**

## 2. Report:

### 2.1 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person (CYP), for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with Special Education Needs and Disabilities (SEND) themselves, up to the age of 25.

### 2.2 What PaCC does

The PaCC (Brighton and Hove Parent Carers' Council), hosted by Amaze, is a city-wide engagement group with over 414 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has ten partner organisations, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods, for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and the Carers Centre for Brighton & Hove to gather views and ideas from carers around provision and delivery of health care services. Amaze and PaCC specifically consult parent carers of families with children and young people with additional needs and/or disability – see Amaze and PaCC engagement diagram. Some of these consultations are designed and planned in collaboration with the Carers Centre for Brighton & Hove.



Amaze and PaCC engagement diagram

### 2.3 This consultation

This consultation looks at parent carers' understanding of urgent care services in Brighton and Hove and their experience of accessing these services for their children and young people (CYP) and for themselves. We also asked parent carers for suggestions and ideas on how urgent care services might be improved.

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111 or a Walk-in-Centre. Urgent care is different from 'emergency care' which is defined as 'immediate or life threatening conditions, or serious injuries or illnesses'.

Reducing pressure on A&E by better managing demand for urgent care and primary care which responds to patients' needs is an ongoing challenge for the NHS. Recommendations from this report will be passed on to Brighton & Hove City Council Clinical Commissioning Group (B&H CCG) and inform development of a service specification for a Same Day Urgent Care Service.

### 3. Methodology

To gather data and information for this consultation we used an online questionnaire which was planned in collaboration with Carers Centre Brighton and Hove and designed with support from Amaze's Data and Performance Manager. The questionnaire included a range of questions with 'please select' and 'tick box' options and boxes to provide extra information and comments.



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The questionnaire was sent to 2000+ parent carers in Brighton and Hove on the Compass Register, held by Amaze, and it was promoted via PaCC and PaCC Partners' social media. We received 81 completed questionnaires, which were summarised into a report.

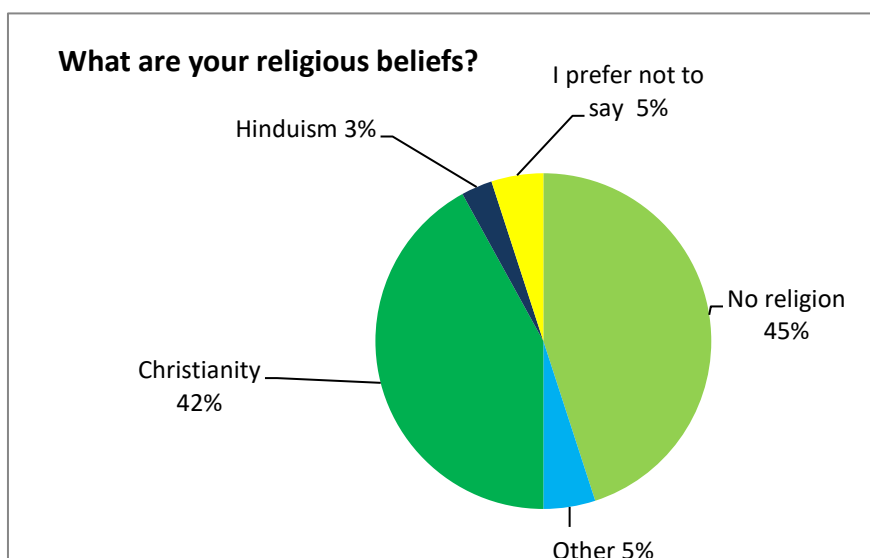
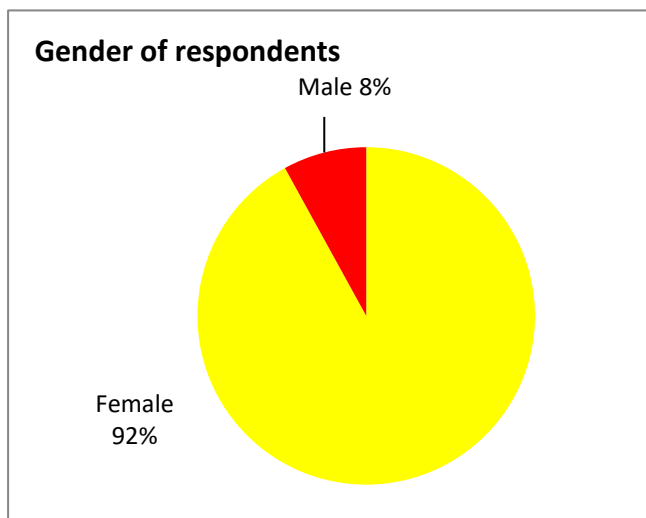
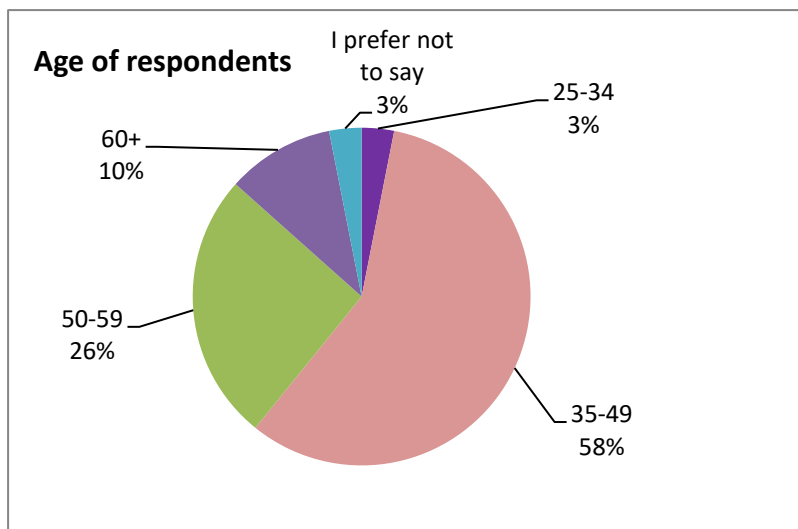


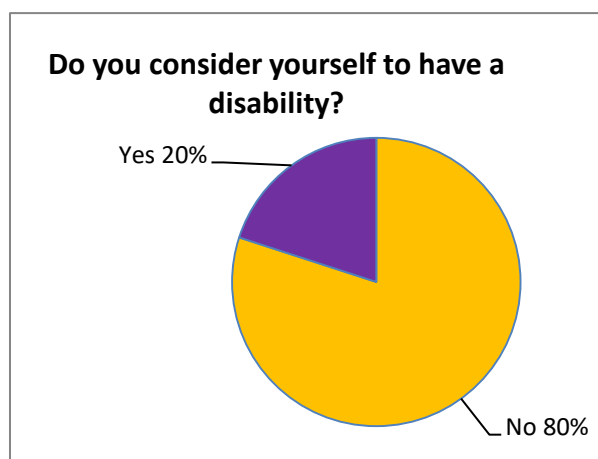
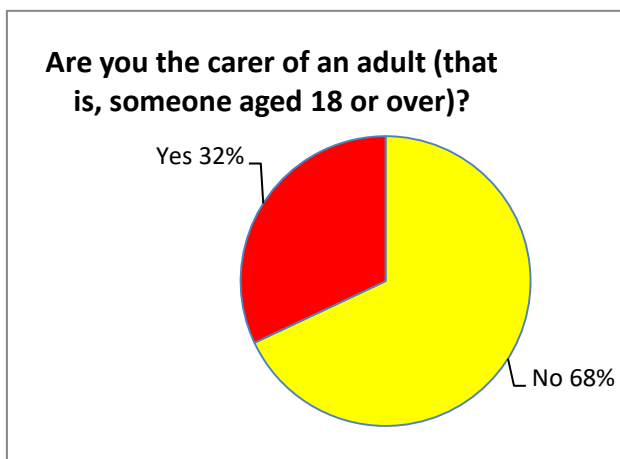
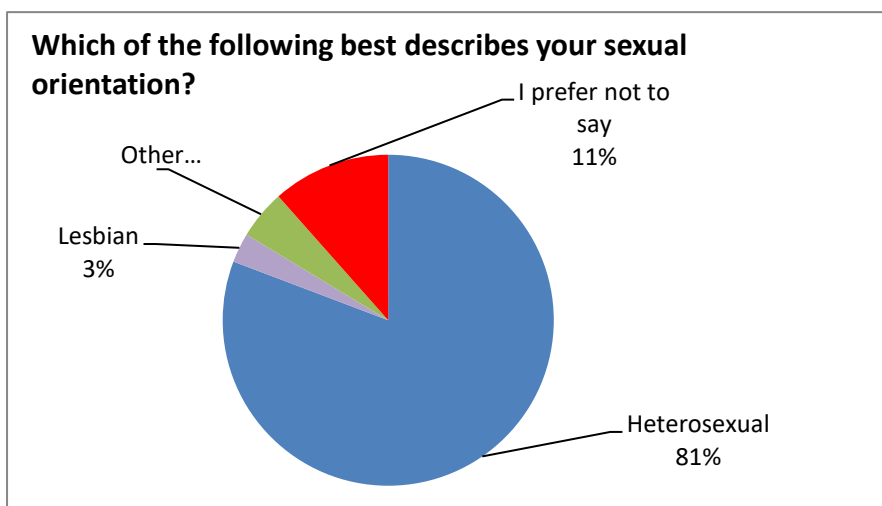
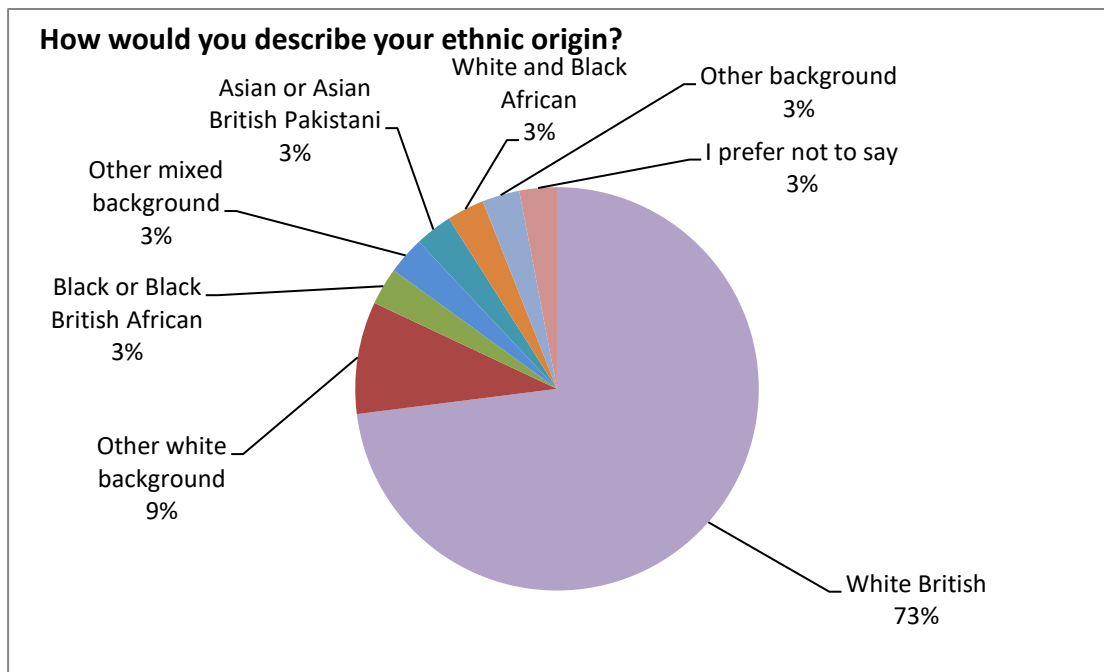
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To complete this consultation, we have also made use of reports from previous consultations around access GPs and pharmacies.

Parent carers' contributions to this consultation are reported in *verbatim* to ensure the detail of their experiences is captured and considered.

#### 4. Demographics from the online questionnaire

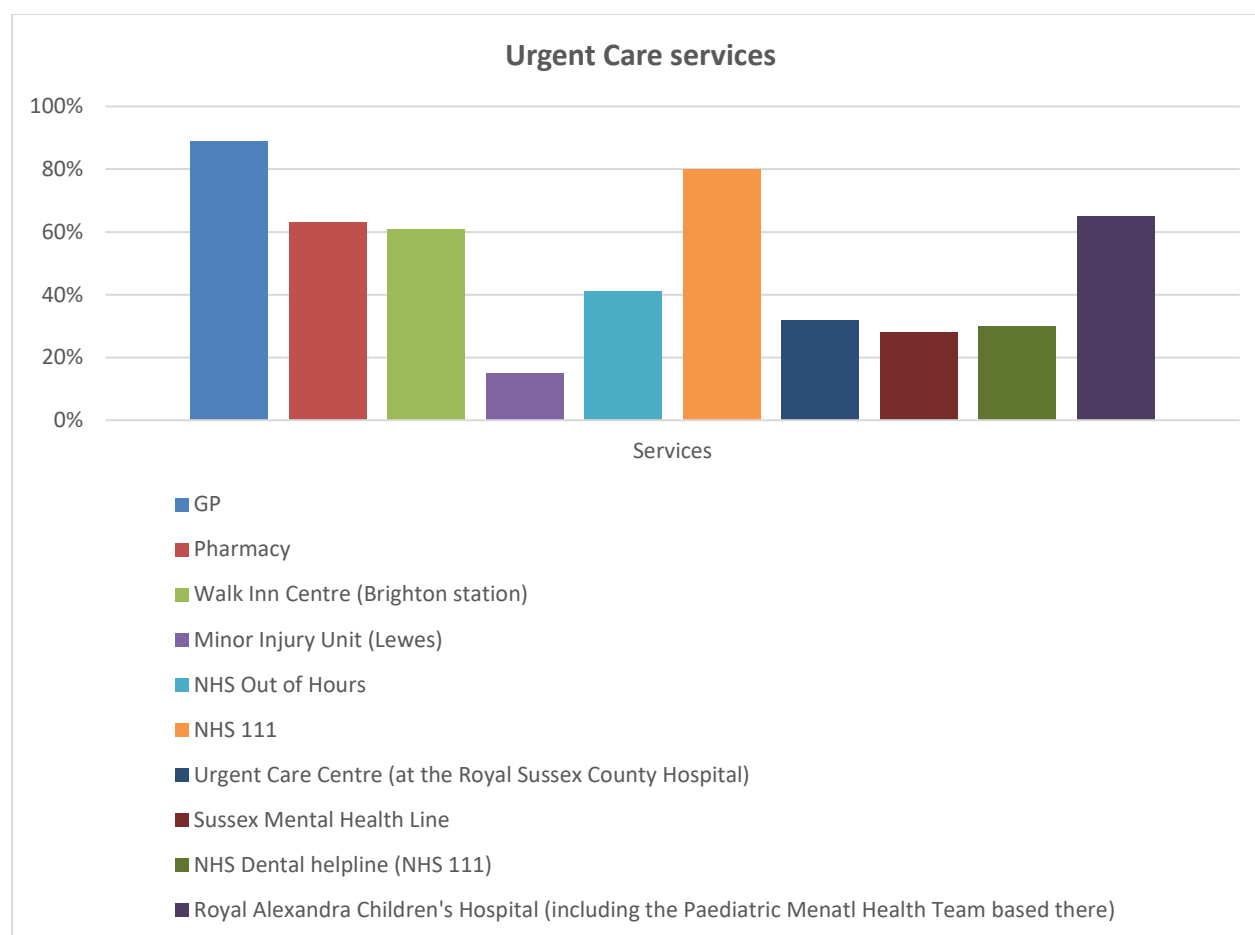




## 5. Findings from online questionnaire – Urgent Care Services for CYP

### 5.1 Parent carers' awareness of urgent care services for the CYP they care for

Parent carers were given a list of all local services that provide urgent care for CYP and were asked to choose the ones of which they were aware:



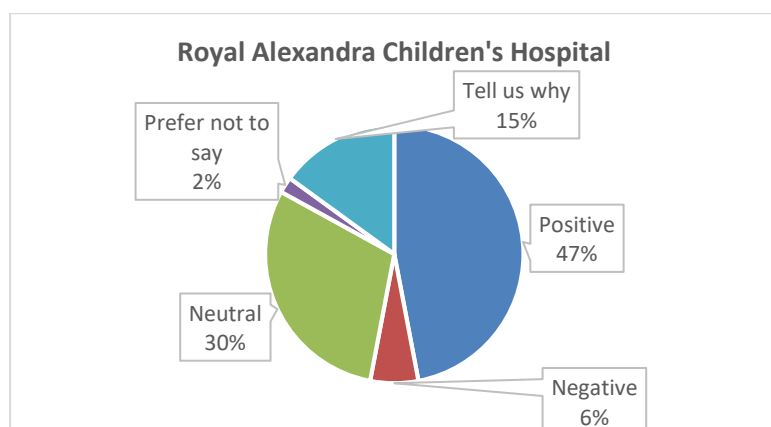
Responses to our online questionnaire clearly highlighted a good **awareness of urgent care services delivered by GPs (89%), NHS 111 (80%), Royal Alexandra Children's Hospital (65%), Pharmacy (63%) and Walk Inn Centre (61%).** Less well-known services included **NHS Out of Hours (41%), Urgent Care Centre (32%), NHS Dental helpline 111 (30%), Sussex Mental Health line (28%) and Minor Injury Unit (15%).**

This suggests that **increased publicity and promotion of urgent care services is needed.**

## 5.2 Parent carers' experience of urgent care services for the CYP they care for

Parent carers were asked to rate their experience of urgent care services and to state which they would prefer to access for their CYP. Respondents were given the option to give 5 stars to the most preferred service and 0 to the least preferred. Services are listed below in order of preference. The 'tell us why' percentage represents those people who provided extra comments.

### A. Royal Alexandra Children's Hospital (including the Paediatric Mental Health Team based there)



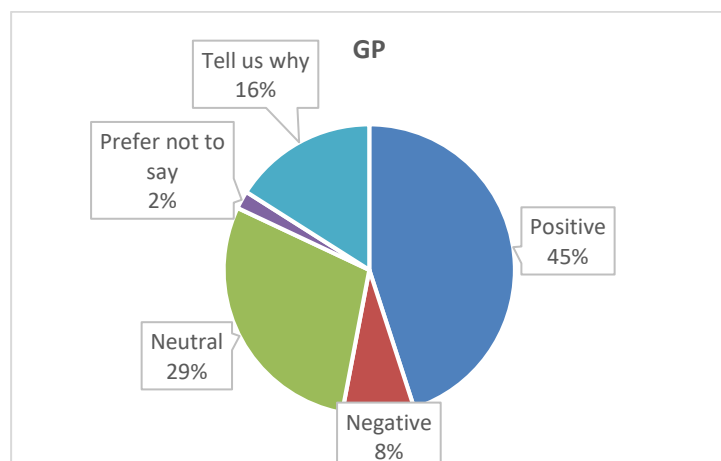
Respondents commented - *'we are well known there and have a care plan in place'* and another noted - *'they are always thorough and excellent staff'*. One parent added - *'seen quickly by understanding and friendly staff. ACORNs are great'* whilst another reported - *'couldn't do enough for my child when I took him there a few times with a mental health problem. Most staff were lovely, patient and listened'*

Many families visit the hospital frequently – *'My daughter is very frightened of hospital and doctors. Royal Alex have been amazing on every occasion (5 times) we have had to visit. Very well trained'* Another respondent to our online questionnaire stated – *'The children's hospital is always the best place. I'd rather turn up there and get a proper examination. By a paediatrician. Even though there can be a long wait'*

Not everyone reported a good experience – *'Nurses were very rough with my child getting blood out at the Alex. Also when my child had a massive meltdown after dental surgery there was no help for me to try and hold him down or to even give him a sedative to calm him down. He freaked out'*



## B. GP



One parent stated - '*amazing GP*' whilst another commented - '*sometimes better than others*'; one parent added - '*sometimes good and sometimes not, GP have a tendency to panic and send us to A&E, getting better now he is older*'.

One respondent to our online questionnaire pointed out - '*no sense of urgency*' and another observed - '*difficulty accessing an actual doctor, constant issues with my son's essential prescriptions, refusal to attend team meetings... Some individuals are great, but difficult to access them, no continuity of care, lack of understanding of my son's condition*'. A parent highlighted - '*since two surgeries merged there is no knowledge that my child has a morbid fear of doctors and needs to be seen quickly and by the same doctor each time*'

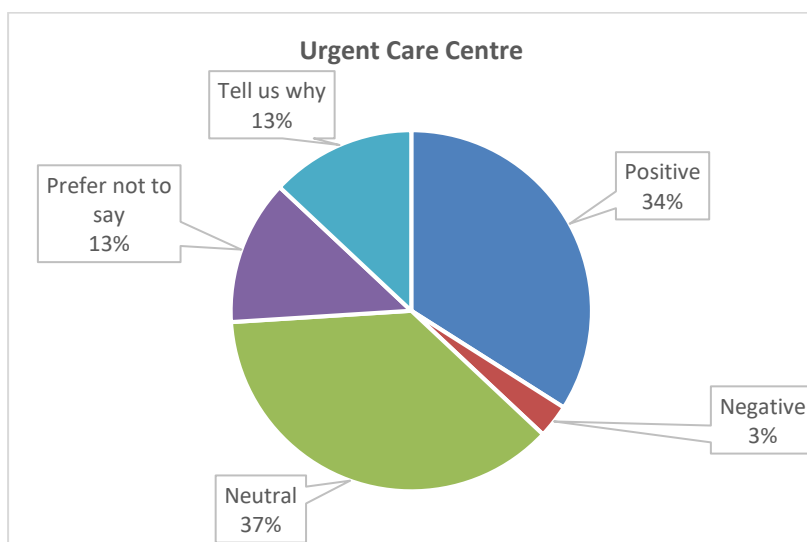
Difficulties on accessing a GP were summarised by one parent - '*I find it ridiculous that it is easier for me to access a consultant neurologist and a specialist paediatrician than it is to access our GP! Inability to provide any continuity of care via the GPs resulted in delays to my son's condition being recognised and referrals being made*'.

A parent suggested - '*Better access to a GP would be really good. A night-time call out nurse would be perfect for us and prevent trips to A&E*'

Some of the findings and comments are very similar to the ones from January 2015 report on accessing GPs, which is disappointing that no more progress has been made in this area.

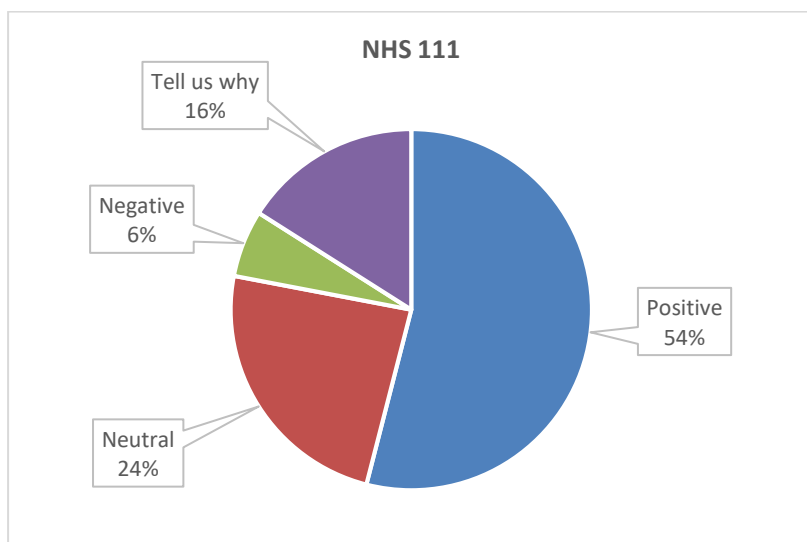


### C. Urgent Care Centre (at the Royal Sussex County Hospital)



One parent commented - '**patient and helpful, feels like doctors have more time than GPs**' whilst another commented '**never heard of it**'.

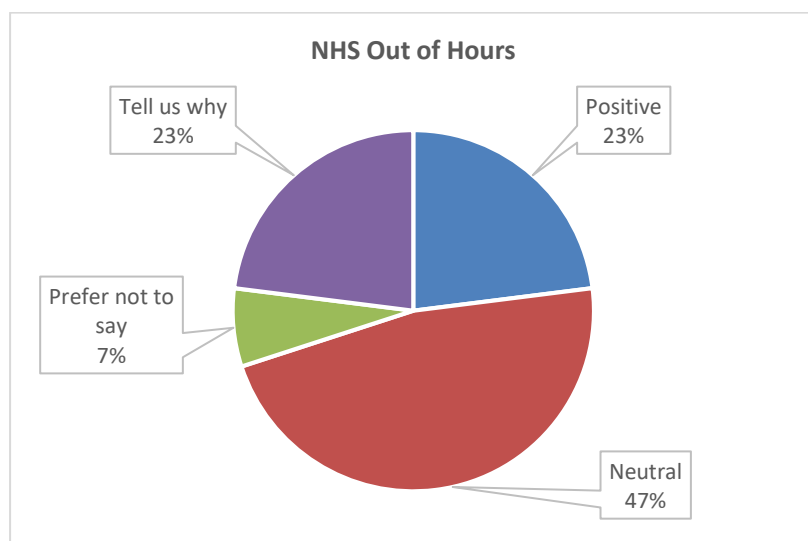
### D. NHS 111



Whilst one respondent reported a good support - '**quick response and supportive**', some others pointed out the long waiting time, as for example - '**ages to answer and very little knowledge, takes a long time to book out of hours appointment**'. A parent reported - '**just told to go to A&E**'.

**One parent wished an easier way to get prescription** - '*On a Sat am it took 3 hours from 8am to 11am to get through to NHS 111 I spoke to 6 different people who passed me onto someone else, i.e. triage. Very protracted process and when at last at 5.30pm we were asked to go to RSCH to see a GP my child refused to go. I had to cancel and said I would contact my GP on Monday. All we needed was a repeat prescription for antibiotic cream. What a waste of resources*'

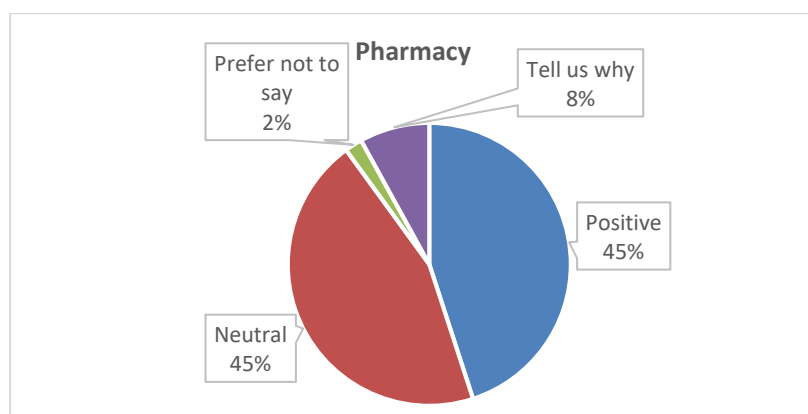
## E. NHS Out of Hours



One parent commented - *'good service but can be a long wait'* and another parent added - *'it takes ages to get a call back when you are obviously worried. That's why you call them'* whilst some respondents underlined **difficulties on getting direct answers from the service** - *'did not want to give an appointment suggested we call A&E or 111'* and another - *'would not answer my enquire about the medication my child was taking and the effect it was having on her. Said I must talk to the doctor who prescribe it. This was a paediatrician whom I could not reach by phone. So ...'*

One parent commented – *'The out of hours doctor was brilliant and very helpful and supportive with my enquiry about my child. However NHS 111 was not; they would not answer my general enquiry about side effect of medication my child was taking'*

## F. Pharmacy



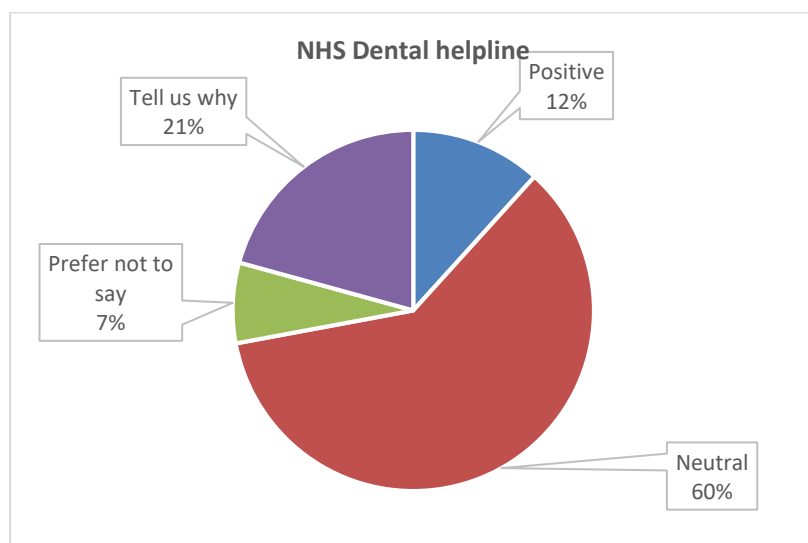
Respondents commented *'good advice but usually need to go on somewhere else'* and *'they have spent a considerable amount of time negotiating with the GP surgery to get urgent prescriptions, have found reliable sources of key medications, are caring and helpful'*

Some of the findings and comments are very similar to the ones from August 2015 report on accessing pharmacies .



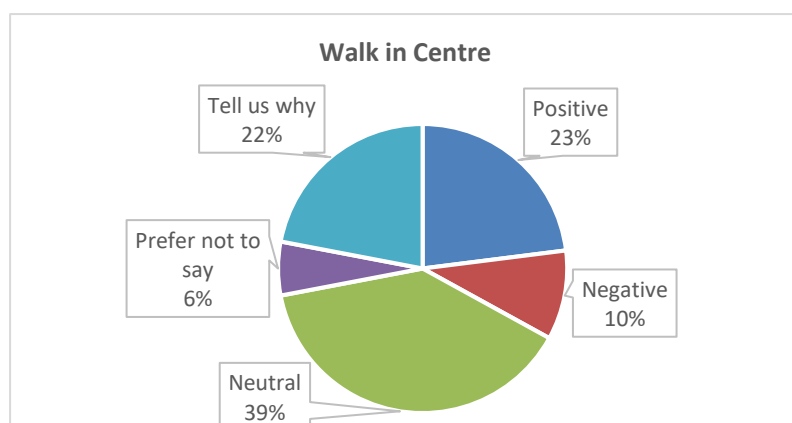
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### G. NHS Dental helpline (NHS 111)



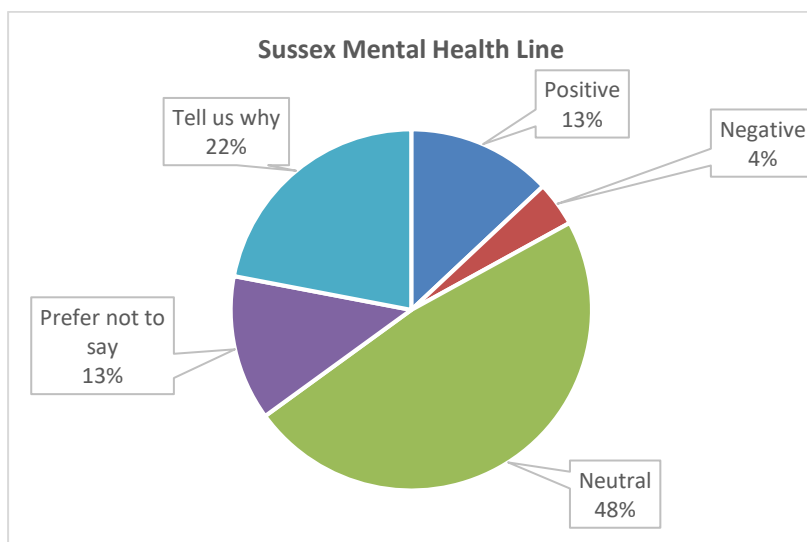
One respondent to our online questionnaire reported that - *'could not arrange any treatment'* and another - *'helpline good, emergency dentist very poor'*

### H. Walk in Centre (Brighton Station)



Most comments point to **waiting times and parking space as issues**, as for example - *'very long wait with a child ...'* A parent observed - *'it's far to go, no parking and probably have to wait'* whilst another stated – *'No awareness of children with severe learning difficulties needing priority even for minor ailments and that a walk in centre is totally inappropriate'*.

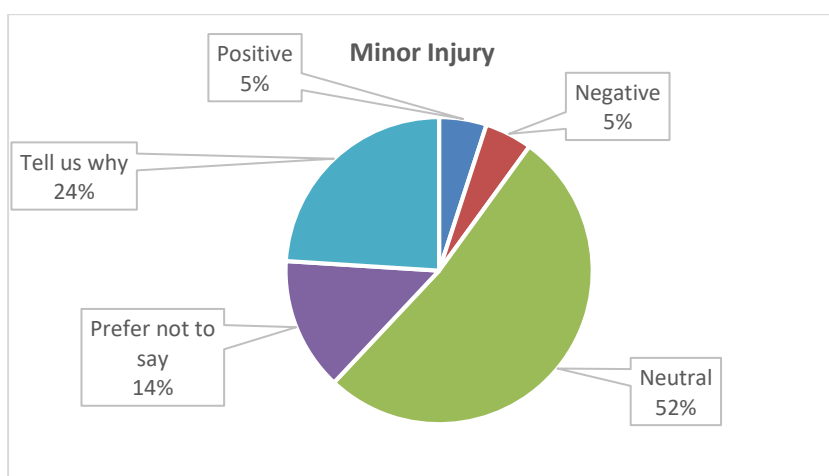
## I. Sussex Mental Health Line



One respondent commented – *'no help available'* and another stated - *'not 24 hours. Indifferent to Autism and totally ineffective'* mirrored by another comment - *'Mental health service not fit for purpose. As soon as they know the young person is autistic they don't want to engage'*

A parent lamented the **scarce follow up** – *'The follow up care for mental health crisis is non-existent and have no government recommendations'*.

## J. Minor Injury Unit (Lewes)



Some parent carers commented that they haven't used this service and one - *'it's far to go, no parking and probably have to wait'*

### 5.3 Additional comments from parent carers in relation to urgent care services for the CYP they care for

Respondents to our online questionnaire provided additional comments and suggestions. One parent highlighted the need for **better joined-up approach** – *‘When in a crisis recently, my child was just left for months in a suicidal state due to the fact numerous referrals to CAMHS by many of these services were rejected.*

Another parent supported the call for a more joined-up approach and **more awareness of additional needs among medical staff** - *‘Generally, most services were unhelpful or aimed at adults and the suggestion was either the child was not "old" enough to have such complex feelings or that parents were overreacting. There was a social services intervention, which stopped as soon as NHS diagnosed autism despite a prior private autism diagnosis. Parents were at fault and causing child's problems by looking for a diagnosis!’*

A point that was echoed by another respondent - *‘A really big problem is that autistic children are more distressed by a health problem and cannot wait and yet are made to wait none the less. Also the lack of training in autism of medics, who don't seem to understand autistics have health issues which affect them more than typical children. If they have mental ill-health it's even worse. I don't think professionals respect parental expertise or voice’*

**Parent's input and ability to navigate the system and be patient** was argued by another respondent – *‘I feel that my mostly positive experiences of urgent care with my son have been mostly safe because of **my own ability as a parent carer to explain my son's complexities and when staff have listened and taken a collaborative approach.** In my experience the mistakes have happened when people have made incorrect assumptions, e.g. assuming my child weighs as much as a 'typical' child of the same age, and then overdosing has occurred’*

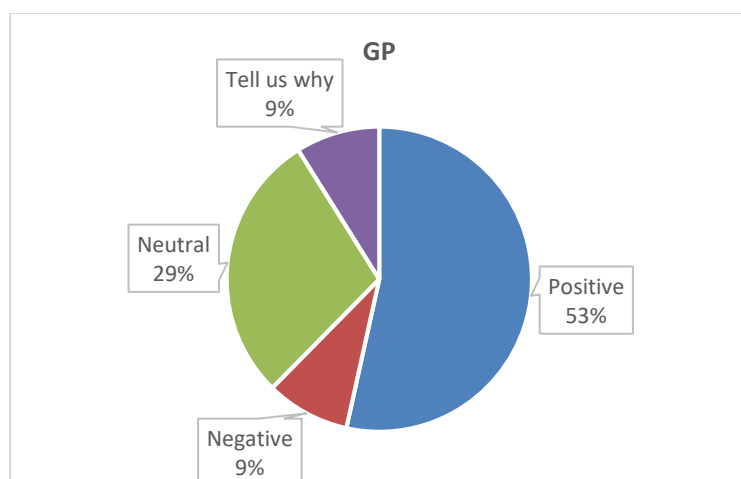
**Other comments recommended to increase workforce** – *‘Should have more people and easy access’* and that *‘young people [get] fast tracked’* whilst another pointed out – *‘felt it was really hard to access urgent care, as what one person thinks is urgent is not what another person sees as urgent’*

## 6. Findings from online questionnaire – Urgent Care Services for Parent Carers

### 6.1 Parent carers' experience of urgent care services for themselves


Parent carers were asked to rate their experience of urgent care services and to state which they would prefer to access for themselves. Respondents were given the option to give 5 stars to the most preferred service and 0 to the least preferred. Services are listed below in order of preference. The 'tell us why' percentage represents those people who provided extra comments.

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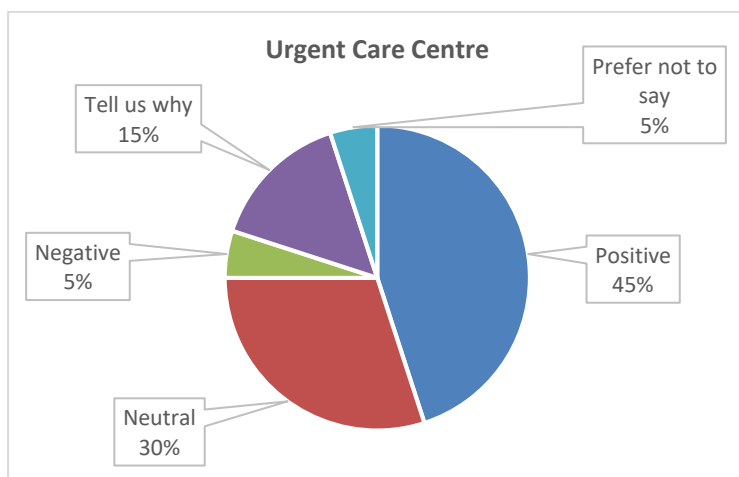


**Getting an appointment seems the main issue**, one respondent commented – *'Inflexibility about when I can see a doctor (I have to arrange care for my son to attend appointments), inability to see same doctor, difficult with calling at the precise moment required to get an appointment'* and another added – *'can never get an appointment'*. Difficulty on get an appointment have an impact on parent carers accessing this service – *'I opt to not go to the doctor rather than deal with the process of getting an appointment and actually getting there'*

One parent felt that – *'I find they don't know very much about my condition'*

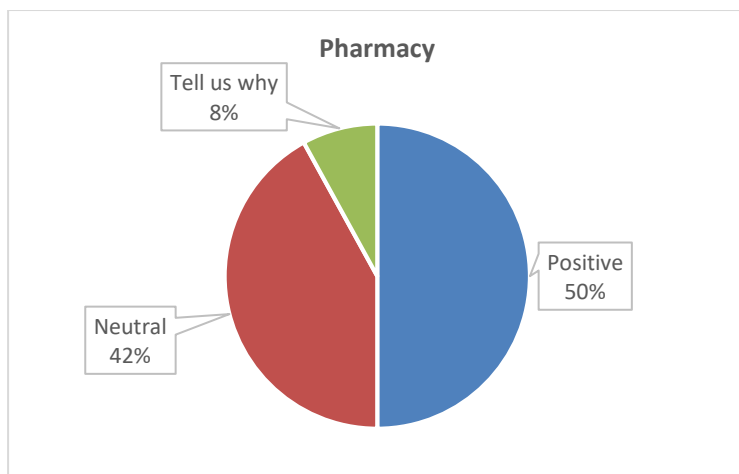
Some of the findings and comments are very similar to the ones from January 2015 report on accessing GPs, which is disappointing that no more progress  has been made in this area.

## B. Urgent Care Centre (at the Royal Sussex County Hospital)



Parent carers reported this as **mostly a good service** – **‘They are always thorough. They don’t just send you away with painkillers’** and **‘sometimes the only way you can see someone’**. One respondent wasn’t happy about the waiting times.

## C. Pharmacy



One parent reported **complete satisfaction with this service** – **‘always helpful’** whilst another reported that **‘I’ve been badly advised in the past regarding an allergy. Which could have been very dangerous’**

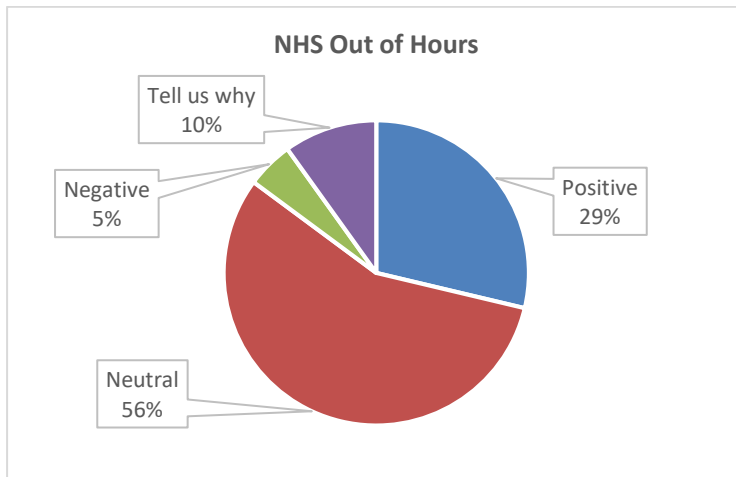
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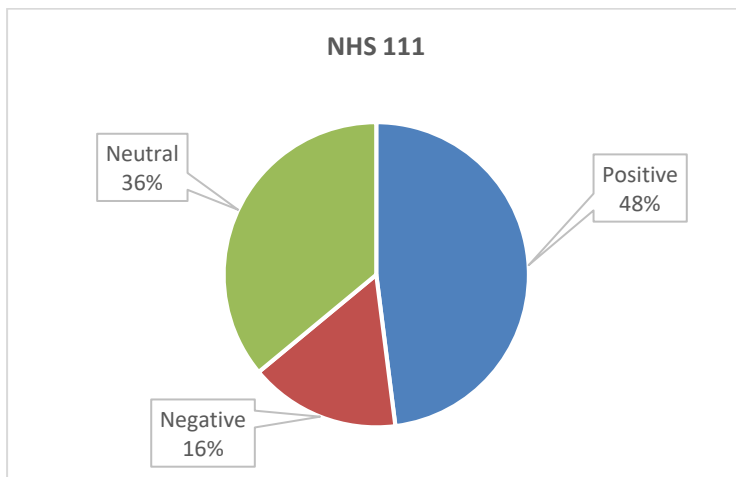
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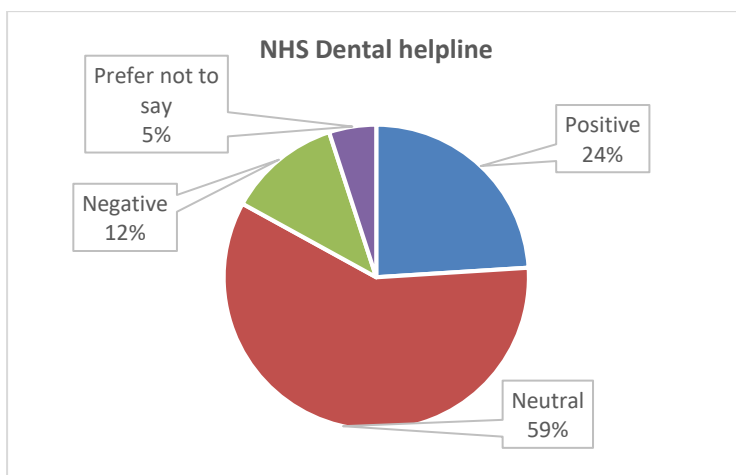
## D. NHS Out of Hours



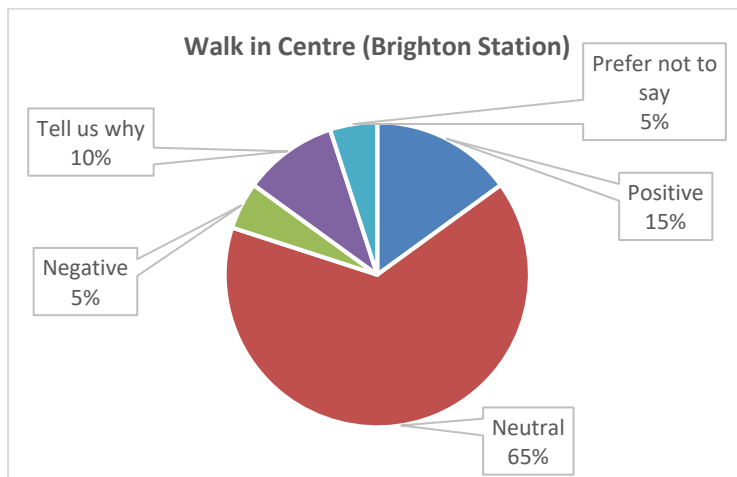
## E. NHS 111



## F. NHS Dental helpline (NHS 111)

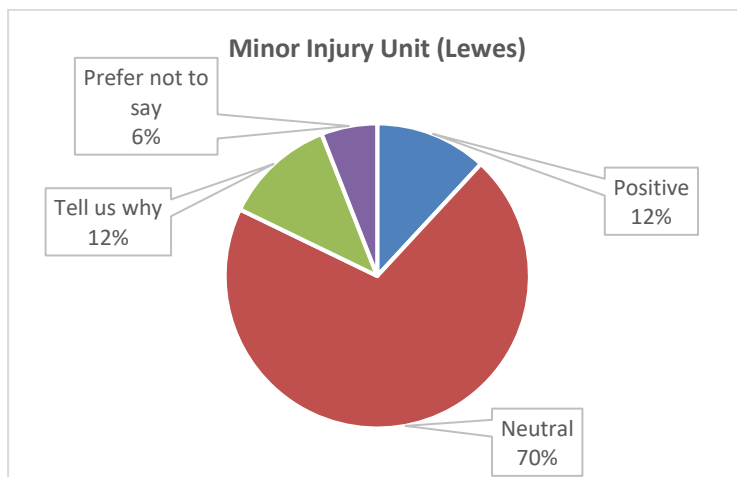


### G. Walk in Centre (Brighton Station)



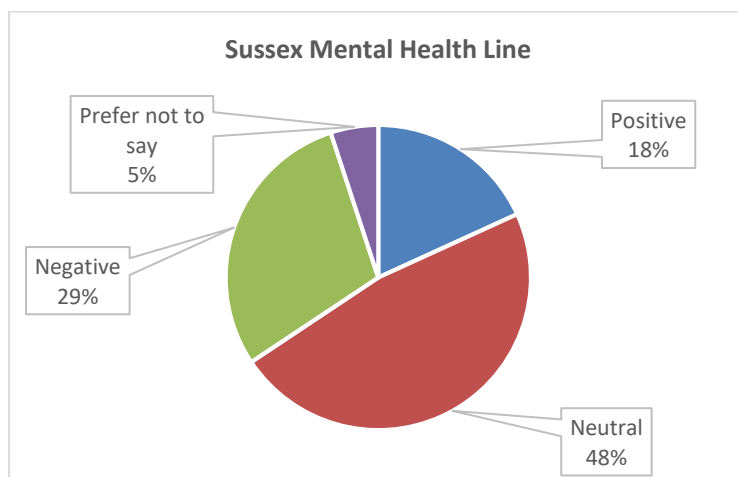
Main issue with Walk in Centre is the waiting time – *'Long wait'* and *'Too busy and over 4hr wait'*

### H. Minor Injury Unit (Lewes)



Respondents to our online questionnaire reported speedy visit – *'Quite quick to be seen'* but also *'not always have appropriate trained staff'*

## I. Sussex Mental Health Line



One respondent to our online questionnaire reported – *'Mental health helpline are great but it doesn't solve the problem. A&E the wait is too long when you are desperate'*

## 7. Additional comments from parent carers in relation to accessing urgent care services for themselves

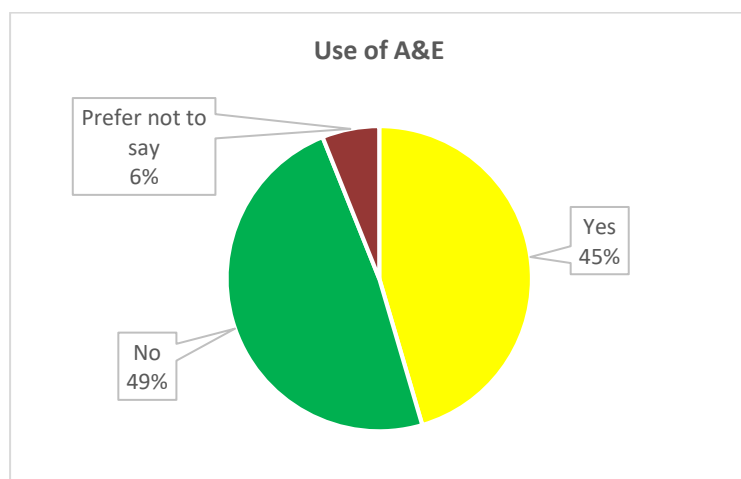
Parents provided additional comments and suggestions about accessing urgent care for themselves. One parent said – *'Services were not available, I was given the idea I was wasting the time of those concerned and no help available. Seemed as though Social Services were suggested as a threat to get me to stop asking for help'*.

A respondent highlighted a recurrent issue – *'There should be some form of additional help for parent carers who may need to urgently attend an appointment and have nobody to look after their disabled children'*

## 8. Parent carers use of A&E and improving access to urgent care services

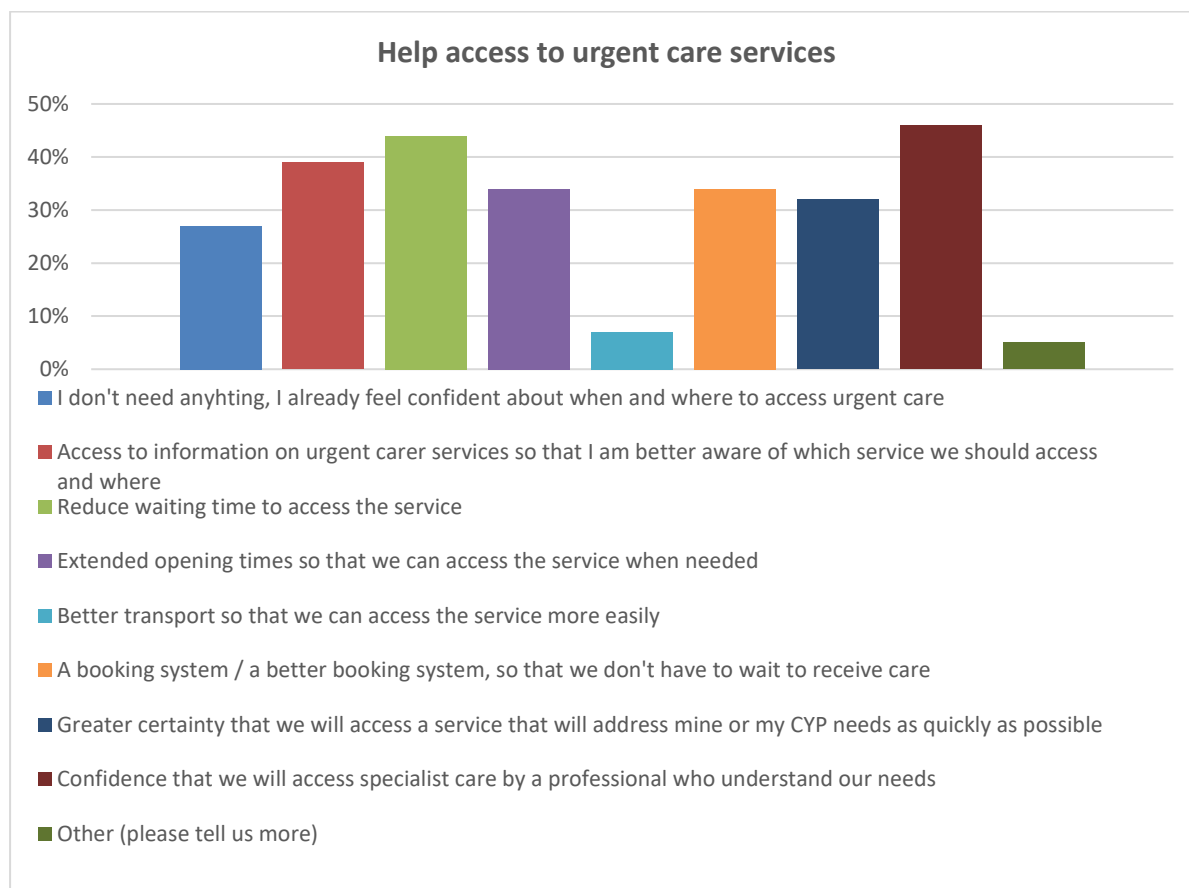
We wanted to understand if SEND families were using A&E instead of urgent care services and why. We also wanted to explore parent carers' ideas for increasing awareness and improving their experiences of services.

To the question, *'I have used A&E for myself or my CYP for urgent care, rather than emergency, because I am not confident or aware of the alternatives'* parents told us:



The chart above clearly indicates that nearly **half of respondents have used emergency service - A&E - because they were not confident on accessing urgent carer services or were not aware of them.**

To the question, 'For you and/or your C, what would help you to access urgent care services and reduce the need for attending A&E / the Royal Alexandra Children's Hospital?' respondents told us:



Among the most chosen suggestions/ideas were '**confidence that we will access specialist care by a professional who understand our needs**', 46%, followed by '**reduce waiting time to access the service**', 44%.

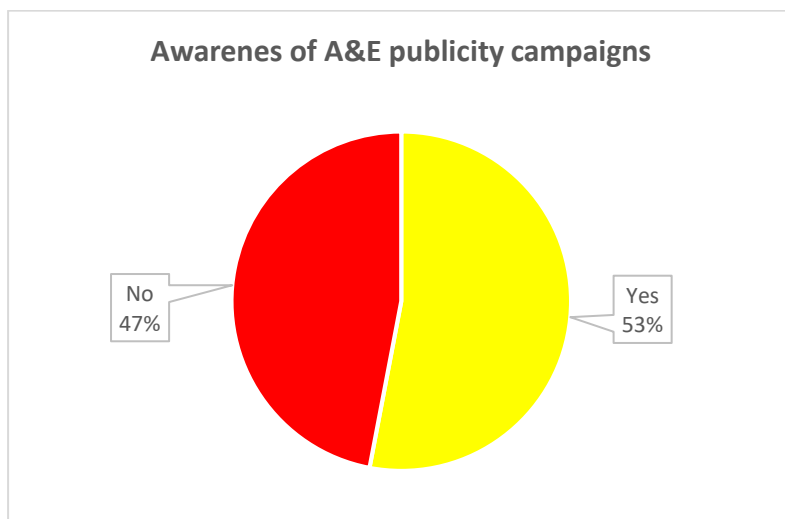
39% of respondents mentioned '**access to information on urgent carer services so that I am better aware of which service we should access and where**'. 34% chose '**extended opening times so that we can access the service when needed**' and '**a booking system / a better booking system, so that we don't have to wait to receive care**'. And finally, 32%, mentioned '**greater certainty that we will access a service that will address mine or my CYP needs as quickly as possible**'

One parent added – '*Despite numerous referrals CAMHs rejected all despite my son being suicidal with severe OCD. This led to having to take him to Royal Alex A&E, which could have been avoided if he was seen more quickly by CAMHS*' and another – '*Poor response to autism*'

To the question '*How would you like to access this information*', **parent carers would like information on urgent care services as online information either through a website or through an app**. A smaller group were happy to get info by phone, email and/or text.

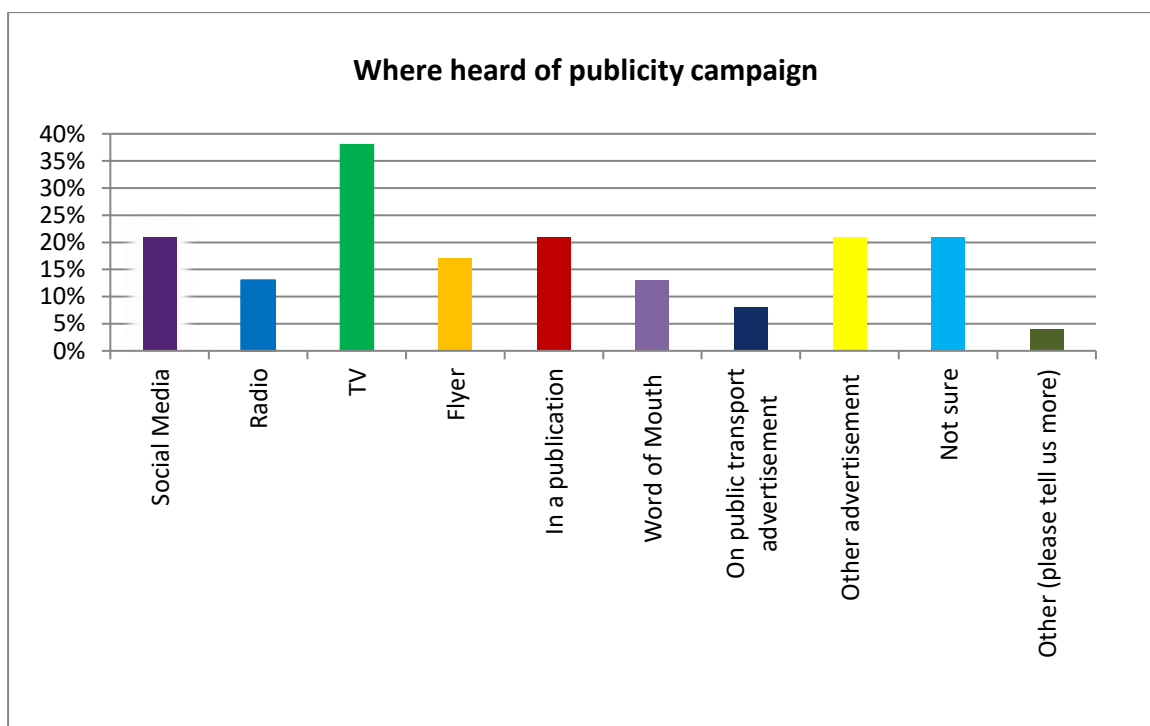
## 9. Awareness of publicity campaign about urgent carer services

One way to inform people about how and when to access A&E is by publicity campaigns. We asked our families, *'Have you heard about any local publicity campaigns about urgent carer services which encourages you not to attend A&E unless you need emergency care?'* respondents told us:



**The majority of parent carers who completed our online questionnaire had heard of a publicity campaign around when and how to access A&E.**

We then asked *'If yes, please tell us where heard about this campaign'* people told us:



Majority of parent carers, **38%**, **heard and/or saw publicity campaign on TV**, whilst an equal number, **21%**, **reported hearing it or seeing it on social media, in a publication and/or in another advertisement**. A smaller percentage, **17%** saw it on a flyer. One parent commented – *'Email from Amaze'*

Finally, we asked *'How could a new publicity campaign encourage you to access urgent care services and reduce pressure on A&E services'*. Parent carers made some suggestions.

**Few respondents commented access to urgent carer services need to improve before a new publicity campaign is launched** - *'I think CAHMS should stop turning high risk children away. That is where the problem lies. As a result, there is no other route other than A&E and more referrals. But being better informed by information on social media, TV, doctors surgeries etc. may be a start'* and another suggested *'make it easier to see a GP. Get out through to someone with medical expertise on 111. Quick way to make an out of hour's appointment, I waited 25mins on 111 last time'*.

Negative experiences from accessing services had an impact on one respondent – *'Nothing would encourage me to use any services again unless either myself or my child were in danger of death. The treatment we have received from professionals health services has caused trauma to the whole family'*

**Some parent carers would prefer information rather than a campaign** – *'Just by informing and educating me on what is available, where and when and when is suitable. Also reassurance that my child needs will be understood and staff are well trained and experienced to assist children with additional needs'* A point mirrored by another comment – *'Clearly laid out leaflet with alternatives to stick up on fridge or pin board'*. One respondent suggested – *'Case studies of typical scenarios'*

## 10. Recommendations

- **B&H CCG to maintain and develop publicity and promotion of urgent care services.** Parents suggested publishing more information online or via an App, and for Amaze and PaCC to share this on social media to increase awareness within the SEND community.
- **B&H CCG and NHS providers to develop workforce strategies which increase the skills, knowledge and experience of SEND of staff working within urgent care services,** eg provide training for all staff around additional needs and disabilities.
- **B&H CCG to pilot My Medical Passport type initiative to enable parent carers/CYPs to articulate their individual needs to staff within urgent care services.** This would help families feel that staff better understand their needs when engaging with health services and increase confidence that the system is responsive and flexible, see eg <http://stlawrencesurgery-worthing.nhs.uk/wp-content/uploads/2018/06/My-Medical-Passport-for-Adults-with-Mental-Health-.pdf>
- **B&H CCG to ensure that Same Day Urgent Care Service includes an improved appointment booking system which take in to consideration needs and demands of caring roles.**