



Amaze and PaCC Engagement Gateway Report into Urgent Care Services

Sept'13

1. Background

Amaze and the PaCC did a considerable amount of research on the views of parent carers in the writing of our Talk Health report, launched this time in 2012. As such we decided it wouldn't be appropriate to ask parent carers to gather together as focus groups to discuss urgent health care more specifically.

Instead, we decided to widely publicise and promote the completion of the Healthwatch survey to all parent carers we hold details for on the Compass Database. This was promoted via email, via the website and via Facebook and whilst we got a good response rate – 41 parents – we need to be mindful that these are responses only from parents who are 'on-line' and digitally included.

2. Summary of key issues/ideas

Pharmacists:

- Extended opening hours in evenings/Saturdays would be helpful
- Promote the out of hours pharmacies more
- Promote option to talk in private to pharmacist

GPs:

- 30% find (very) difficult to access
- 22% (very) unsatisfied
- Need better system for booking non-urgent appointments, sooner
- Shouldn't rely on the calling at 8.30am system (no good for parents on school run)
- Receptionists are often under so much pressure they can be rude/brash
- GP surgeries need to be fully accessible
- GPs need more training in helping children with learning disabilities and autism in particular as well as Equalities Act and needing to make reasonable adjustments for those with disabilities
- Greater understanding and empathy about pressures on parent carers
- Longer opening hours needed
- Offer of home visits for very sick/disabled children

Brighton Station Health Centre:

- Lack of awareness about this service
- Perception very inaccessible – no cheap or easy parking
- Long waits reported
- Change glass-window rooms
-

Out of Hours GPs:

- 49% said (very) difficult to access
- 36% (very) unsatisfied
- Difficulty finding the building – better signage suggested
- Appointments for children should be with paediatric doctors
- Could there be similar service on West of City?
- Some confusion over this service and NHS 111 service

NHS 111

- Lots of uncertainty about this service
- Reports of very long phone calls with lots of seemingly inappropriate/irrelevant questions
- Several cases where family went to A&E in end anyway

Emergency Dental Service

- Lots of uncertainty about this service – 68% didn't know if accessible and 67% didn't know if satisfied (so may not have used it)
- More promotion needed

A&E

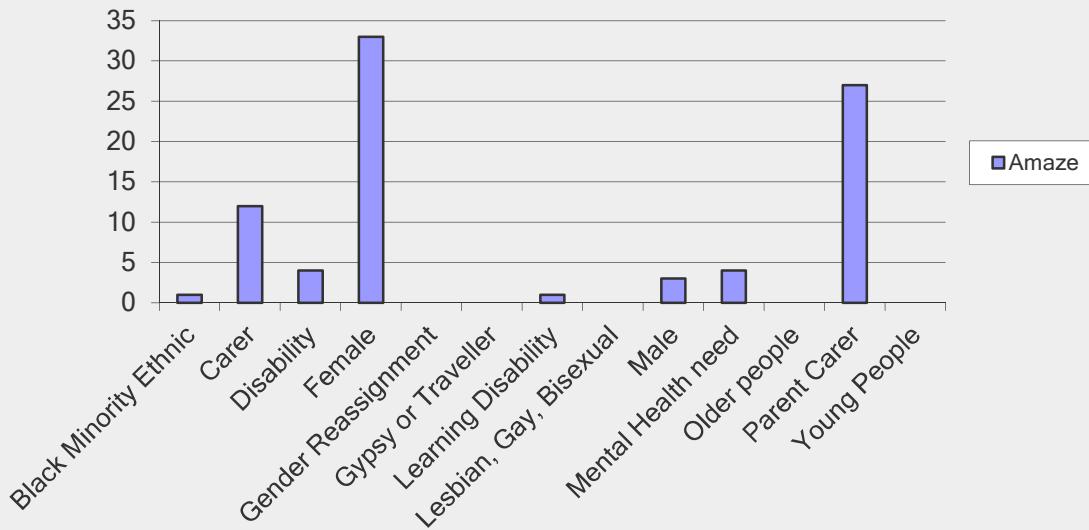
- Lots of praise for good service and staff here
- However still 35% said (very) difficult to access and 26% (very) unsatisfied
- Main concerns about long waiting times and lack of (affordable) car parking spaces
- More training needed for all staff on needs of children with disabilities in particular autism and learning difficulties
- Examples of where parent carer had 'chosen' to attend A&E as felt GP wasn't good enough
- More staff wanted, and reduced waiting times

Children's A&E

- Lots of praise for good service and staff here
- However still 46% said (very) difficult to access – which is higher than for A&E itself so maybe more/better signage required and more drop off parking for dropping off a carer with a child. Need to ensure the new system of prioritising cars with disabled children is working at all times.
- 20% (very) unsatisfied

3. Profile of the respondents

Do you identify with any of the following? (tick all that apply)



33% said they would be interested in completing more surveys on local health care services.

Parent respondents came from across the City:

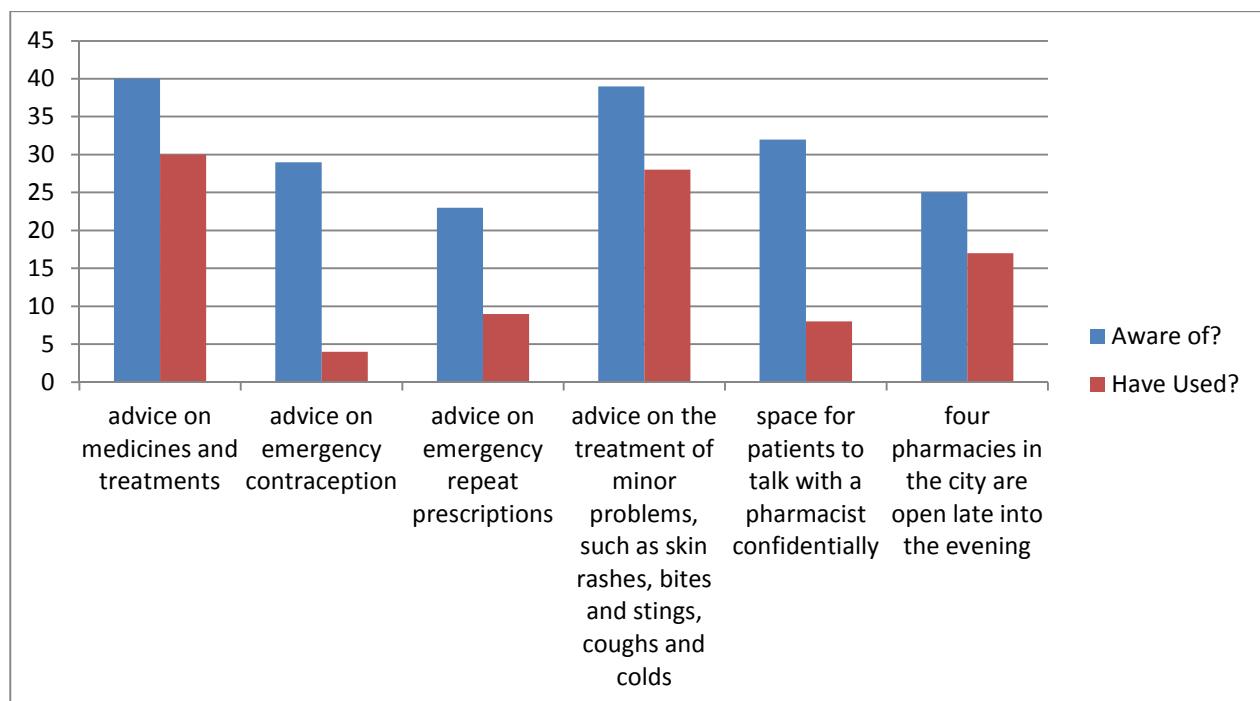
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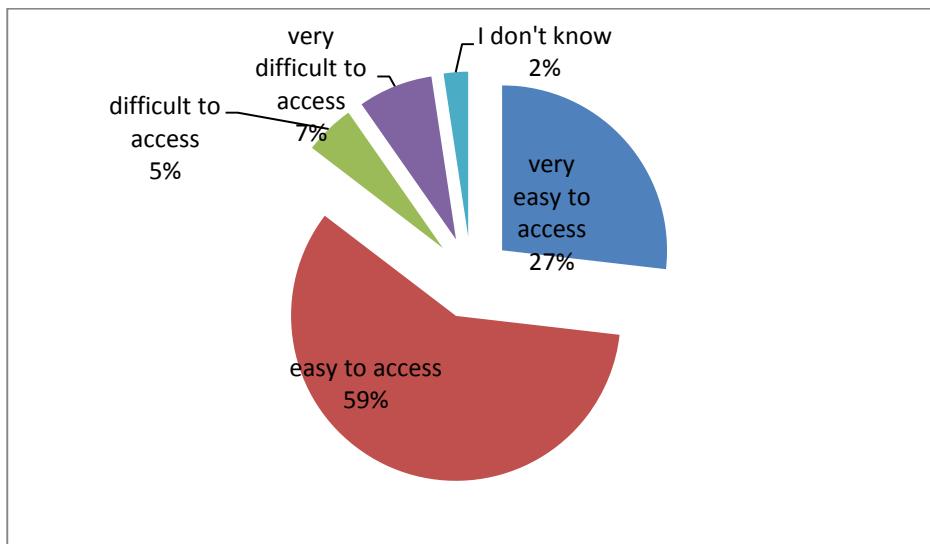
4. Results

3.a. Pharmacies

i. Did Parent Carers know about and had they used?



ii. How accessible is pharmacist?



iii. How satisfied with pharmacist?

iv. Experience willing to share?

39% had an experience they were willing to share from 2013 or 2012, including comments like:

- Just great that the chemist can put my repeat my prescription in and get it and deliver it! Amazing!
- Doctor surgery was supposed to give prescription to adjacent pharmacy. Went to collect items from pharmacy, they didn't have prescription Doctor's reception area had it there for collection, despite me marking it 'send to Lloyds'. Lady in Lloyds went across to doctors, got it and then I had to wait for it to be dispensed.
- Despite my pharmacist providing many repeat prescriptions for my disabled son, he has given me the wrong prescription or dose on several occasions so I have to check them before I leave the pharmacy.
- We have repeat epilepsy medication, and the pharmacist is very helpful and supportive, and has even pointed out when the doctor has prescribed an out of date medicine.
- On several occasions the pharmacy was unable to complete the prescription because either there wasn't product in stock or they didn't have all the required medication. I was advised to come back later or take part of prescription and come back later or go somewhere else .
- I was given the wrong medication as there is another patient with the same name. The address on the drugs was right too but it was the other persons drugs
- My pharmacy, Traherne's, knows myself & understand my daughter's needs. She has recently had severe diarrhoea & they were very helpful with advice. They also rush through prescriptions for me when the GP has been inefficient.
- Weston's - Lewes Rd - always seem open and have the meds there and are pleasant so many thanks to them for staying open so much.
- Always very helpful and knowledgeable.
- A family member is on cd meds my pharmacy has under prescribed and over prescribed on several occasions, i am on sleeping tablets they have also supplied the wrong dose ,as both myself and my partner are disabled and we have a son with special needs it causes extra stress and anxiety
- phoned to say my repeat prescription was in then when I went to collect they said they hadn't received it from the surgery, I had to get the surgery to get my prescription done that evening as I had run out of medication
- Repeat prescriptions for my child with Cystic Fibrosis. I ask for the antibiotics dry so that I can make them up when required as they only have a 7 day shelf life in the fridge. The pharmacist was different to the usual person and question if I knew how to make them up - asked my method. I explained and she was very happy with my response - said would I like a job! She also said to me that I could always bring them back and they would always make it up if needed. I was pleased that they had taken the time to check that I knew what I was doing and it reassured me that I was doing it correctly.
- The system of finding the product on the shelves has not always been very robust. Once they

told us they hadn't received the prescription from the surgery, when it was sitting on the shelf all the time.

- We were recognised and our needs were addressed without having to go into masses of detail

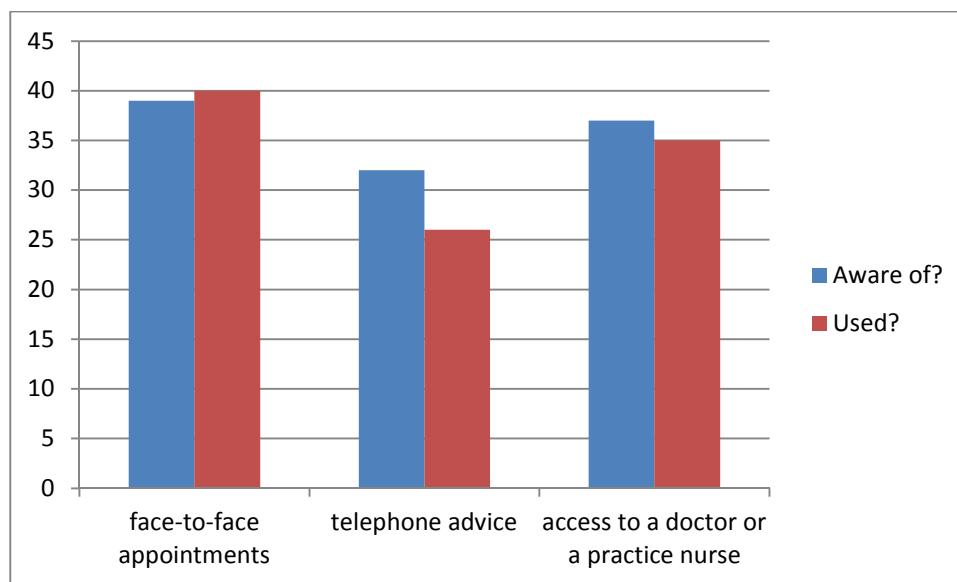
v. Willing to share suggestions?

31% said yes:

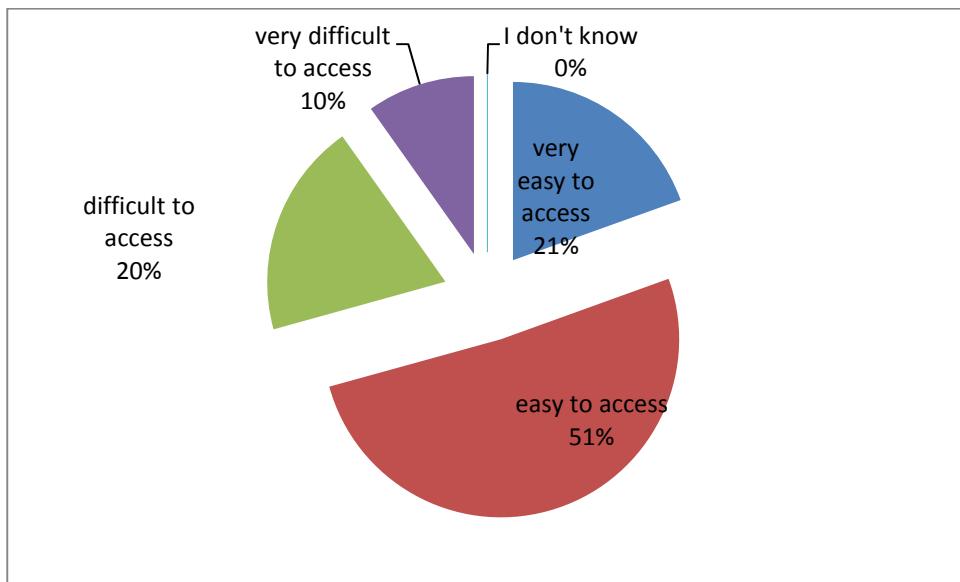
- My local pharmacy is linked to the GP surgery, and so is not open at the weekend. It would be very helpful if it were open until, say, 7pm of an evening and all day on Saturday.
- More than one 24 hour chemist in the city.
- Ticket system so they know who us next in queue and how many people waiting. Pharmacist always available- if they are at lunch, prescriptions have to wait etc.- to help with this, times when pharmacists not around should be stated visibly. Then we could avoid these times.
- Parking needed for easier access
- advice on how to dispose of left-over medicines.
- To ensure that stock is sufficient for customers' needs as this situation has occurred before . This has happened with a variety of medication for adults and children .
- If it provides those other services mentioned above, raise awareness of this.
- Make people aware more clearly that it is possible to talk privately.
- The one at Carden Hill always seems very slow at doing anything - most of time
- Later opening hours in the evening. 6pm is quite early to pick up prescriptions - especially if it is an emergency prescription from the doctors or finishing work,
- They have now improved the system for finding made up prescriptions
- I only know of one out of hour's pharmacy....what are the other 3. This information should be advertised.

3.b. GPs

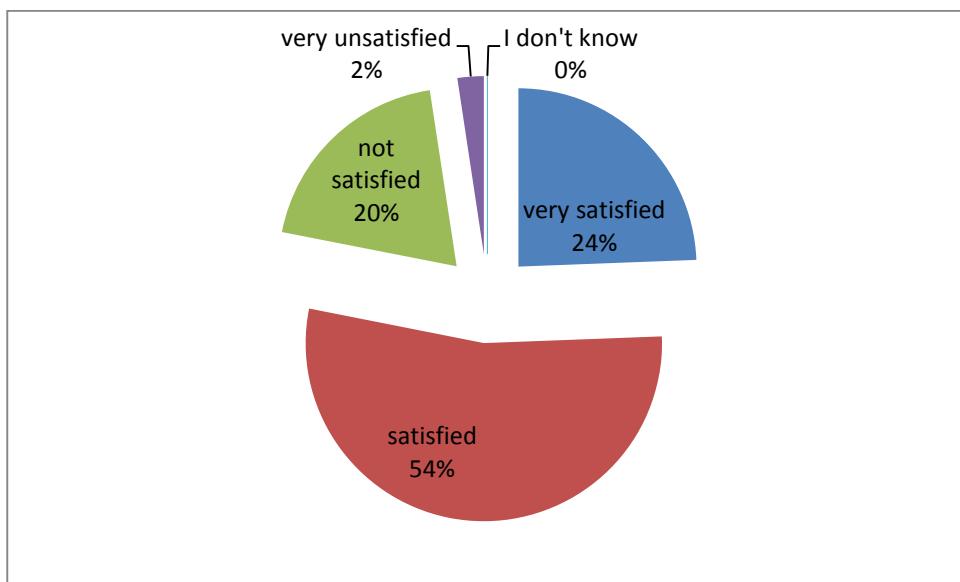
i. Aware of and used before?



ii. Accessible to access GP?



iii. Satisfaction with GPs?



iv. Experience willing to share about GP?

40% said yes and experience was during 2013/2012. Another 6% wanted to share experience prior to 2012:

- I have Asperger's syndrome and my GP is refusing to allow me to use fax and/or email to communicate on occasion. I believe my request is not unreasonable and should be allowed to me as a reasonable adjustment according to the Equality Act 2010 but my GP is still refusing and had said that I can find another surgery if I want. To date, my request for flexibility with appointment times and policy on release of them has also been ignored.
- I have needed urgent care/treatment in the past, at which times I have been seen quite promptly. However, when I have needed a non-urgent appointment, I cannot get access to my GP for over a week - sometimes as much as ten days ahead. .
- Around Nov 2012 I was very depressed & suicidal. I went to GP & had to see a locum. At the time she was hopeless & did & said nothing to help me in the surgery. 2-3 days later I got a call from the Wellbeing team. My experience was, therefore mixed. I would have liked the GP to take control in the appt and tell me she was referring me. (She asked if I wanted to be referred but I did not answer as I could not stop crying & was unable to make even simple decisions at the time). As I said I was suicidal & described how I planned to do it I think I should have been contacted by Wellbeing sooner. However once contacted I was given sessions with a CPN

which were helpful.

- No appointments for TWO weeks!!! Receptionists are under so much pressure but come across rude and brash.
- Child ill, has complex medical history, given antibiotics. Told to come back Fri if no better. Ring for appointment, none available on the Friday. After insisting why I needed an appointment and that GP had told me to come back if no better, receptionist says will ask GP to call me after evening surgery instead. phone call never came so had to visit out of hours doctor at Susx County as a result, who gave different drugs and asked us to go back to GP in few days to check child's chest again. Contacted GP again on Mon, to ask why never called me, she said I wasn't on list!! She apologised. Made appointment to check child on Weds which took place, child sent to Royal Alex with suspected pneumonia.
- I was able to get a same day appointment for my child (on 2 separate occasions) with the Advanced Nurse Practitioner who was able to meet our needs & prescribe. This is an excellent service which adds to the availability of same day appointments in addition to the duty doctor, who was never available.
- I have been asked to call about a prescription review, even though my son has been seen by the specialist recently and had a review. This is duplication of effort.
- previous surgery when we first moved to Brighton, 2012: complete lack of interest in my caring role, despite cards/posters around suggesting otherwise - not as part of the registration process or during GP consultations. The GP sat behind his desk while i struggled to open the consulting room door with my disabled child in his wheelchair and an energetic 3 year old pulling on my arm. We were told that the practice was accessible but i was then asked to leave the wheelchair upstairs and had to carry my nearly 5 year old downstairs (he often bites me) simply to fill in a host of regis. forms; later i was asked to fill them in at home, mainly because the toddler was on the rampage. I moved the family to another practice, where parking is more challenging, even with the blue badge, but the staff are more caring, modern in approach and the surgery is properly accessible for my disabled child.
- The doctor refused to look in my son's ears because he wouldn't keep still, despite the high risk that he had an ear infection.
- When my daughter had severe diarrhoea after surgery they did not think to test for C Dif or MRSA. My dietician suggested it & it turned out my daughter had a positive C Dif result. The GP had prescribed Imodium which she should not have been taking under the circumstances.
- Only one bad experience in recent times - our GP's are all so good normally, dedicated, kind, polite. BUT ; last year I had what I felt were problems with irregular heartbeats.

I would be very aware of it at night. Checks were done and diagnosis was of early beats and not to worry. The problem changed, i would have a sudden very hard beat, a gap and then a hard beat which would throb through my body. I went back to surgery by appointment, this time saw a different GP (female) who told me : "You are just focussing on it"

That was a put - down, did nothing to reassure me, I felt uncomfortable, criticised for having bothered the Dr unnecessarily. i left and have not been back since.

But I worry that something might be wrong or getting worse.

- Appointments are mostly available very quickly, i.e. on that day or within 2 days.
- Dr Halford GP appt - listens and responds to questions well - no problems
- always give good telephone advise , especially with regards to my children , my eldest daughter has sld and they are always v helpful
- Although it can be difficult to get an appointment with a GP (and it is extremely difficult to get an appointment with our own GP), I have been satisfied with the treatment when we do go,
- in October 2009 i start with lots of pain and feeling really sick i could not even go to work, gone to see GP a couple times and was told that was a virus or a cold, no tests were done, i new it some was wrong because it was kind of different from others times ,January i was told that i had cancer and it was spread all over ,i am still alive but not thanks to my GP. I was very angry at the time but now i am OK but still no much trust in DOCTORS
- Having a child with CF means that medical attention is required often and quickly. We have so far always seen a doctor on the day required.
- Over all I am happy. The appointments system is overly complicated. I think it must be very difficult for people who work full time to see any health professional at the surgery. The GPs are paid enough to justify opening longer hours and on Saturday mornings for working people. Phoning at 0830am for someone on the school run is difficult too
- It takes far too long to get an appointment with a nurse or gp....about a week

v. Willing to share suggestions?

66% of parent carers were willing to share suggestions:

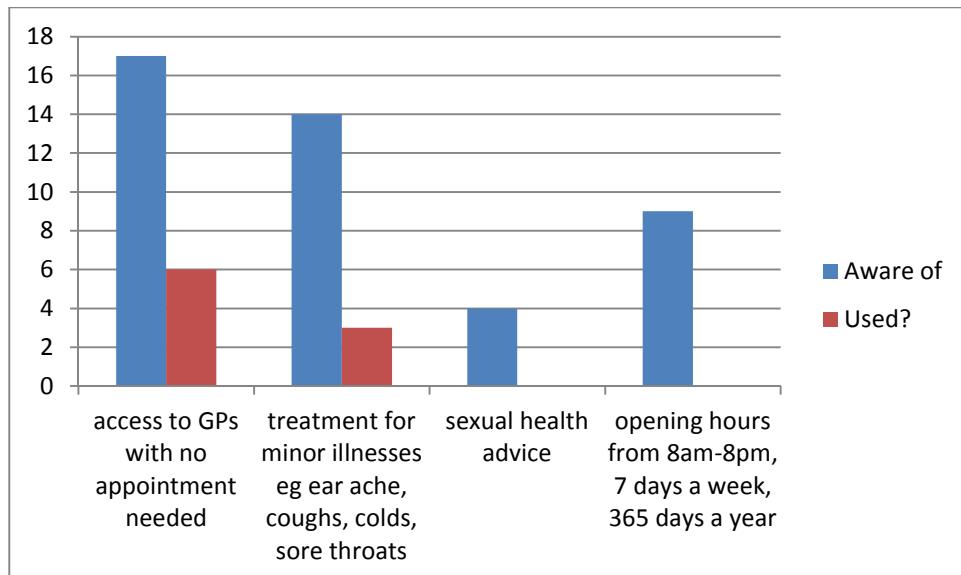
- I have a disable daughter who does not wait very well in the waiting room at the GP surgery. When I take her for an appointment I am very conscious that she is causing a disturbance for other patients and find it difficult to keep her quiet. It would be nice if we could wait in a separate area or I could not have to wait for too long for the appointment. If the receptionist could telephone the GP top let him know we had arrived then we could be given priority over other patients who do not have a disability and have trouble waiting.
- They can be aware of the law and comply with the law regarding reasonable adjustments for people with disabilities and/or mental health issues.
- I find the lengthy wait to see a GP for a non-urgent appointment very frustrating; and the receptionist's advice at the time was to ring and request an urgent appointment - when I would be able to see the gp that day or the next day. It shouldn't necessitate an 'urgent' appointment to be able to see a gp within a 3-4 day period. Perhaps if they made a general appointment available within a 3-4 day period, people wouldn't need to fill 'urgent' appointments unnecessarily.
- My previous surgery has removed all toys & magazines. I assume this is infection thing but it is not in all surgeries. It seems pointless to me & leaves patients with nothing to do. Reduce waiting times. I have had to wait for over an hour recently and was very late to work. Make it easier to get an appointment. In my previous surgery you could not pre-book only call on the day so it was then hard to get through. Also if you work it is easier to be able to prebook. Think about the music that is played and how it affects patients emotionally. Ditto colour or walls etc.
- Better knowledge and interest in areas of health affecting my daughter's medical needs. Separate room where I can wait with my daughter who can struggle with large spaces.
- You have to call 8.30 in the morning to get appointment, and can't always get though , the phone is so busy, and buy the time you do get though you can't always get an appointment that day, something needs to be done, they do a walk in clinic , but it in college time as well, two days a week . Not much gone if only a minor problem.
- Take on more staff. Enable earlier appointments. Offer home visits for the very sick.
- Open for longer hours, and not have to wait so long for an appointment.
- More appointments available sooner. You can't plan a fortnight in advance to be ill! Receptionists unfriendly and condescending. They Never offer you a call back from doctor unless you ask for one, despite explaining the seriousness of the illness
- Train the receptionists to be more aware of my needs regarding my son and not lecture me on being 5 minutes late if I've had to change his pad etc.
- Order repeat prescriptions over the phone.
More toys in waiting area
- The role of the GP in relation to disabled children could be improved. Having a child with complex needs and multiple disabilities takes a lot of persistence, administration and co-ordination. GPs ought to play a central role in ensuring services are being provided to the level and frequency that is commensurate with need. They should also be exploring the needs of other family members too, for example the impact of the caring role. Essentially, making sure all the bits of the jigsaw are linking together. We have only experienced this with one doctor and he wasn't a GP but a consultant neonatal paediatrician who we managed to hang on to for a year in London.
- Provide online services such as appointment booking and repeat prescription ordering etc.
- They need a designated doctor with training and experience of patients with learning difficulties and autism. Every GP my son has seen has never known how to talk to him and we have had inadequate service.
- More training (and somehow more time) for reception/ telephone staff to help patients assess the urgency of their need.
- Older GP's (like the one in 11 above, should have renewed "bedside manner" training after a certain time.
- Keep GP link - allow to have out of hours arranged locally
- Being better at answering phone, too long spent listening to a message or music. Better understanding from receptionist, they don't know everything !
- A greater facility for booking non urgent appointments in advance.
- continuity in the doctor that sees you/ our child especially as we have a daughter with more complex needs and would benefit from her GP having a better understanding of her specifically and being able to give considered advice.
- Friendly reception staff that show some empathy - not everyone is trying to waste their time.

The doctors at our surgery are professional it's just a shame the reception staff aren't.

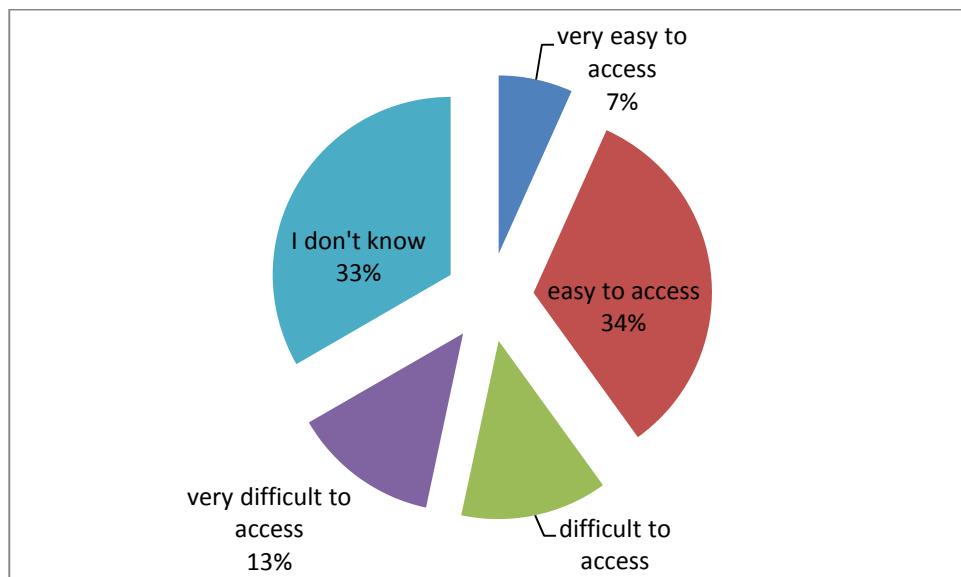
- Extend the opening hours and telephone line. My surgery closes all afternoon including phone line.
- GPs should make home visits out of hours especially if you are housebound or it's a child that is very sick
- An idea of how long you will have to wait to see the GP upon arrival
- Reduction in waiting times when have booked appointment time.

3.c. Brighton Station Health Centre

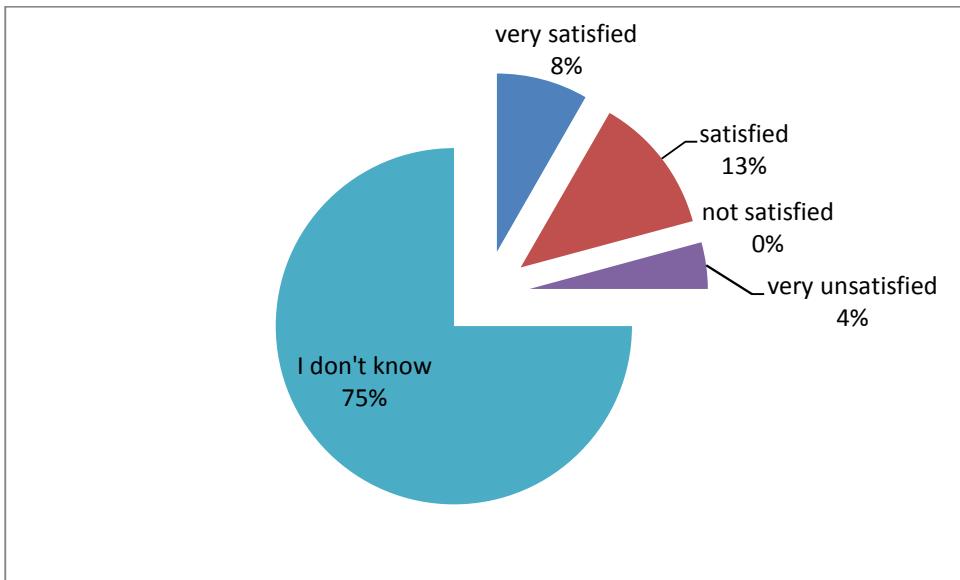
i. Aware of and used before?



ii. Accessible to access Station Health Centre?



iii. Satisfaction with Station Health Centre?



iv. Experience willing to share about Station Health Centre?

Only 5 parents had experiences they were willing to share – 2 of these were before 2012:

- I had previously asked my GP for a referral for help to reduce my alcohol use & was referred to CRI. My first session was at the Health Centre. It is terrible to access due to location. Really busy street. No easy or cheap parking. On arrival I was told the room I was to use was being rebuilt. I would not have wanted to use it anyway. It is a glass room on right as you come in to reception and everyone in the waiting room can see you! No privacy or confidentiality. We used a room at the back but staff kept coming in to get things.
- The waiting time , is terrible, and you don't always get to see a doctor, sometimes only a nurse, for my son with autism, 3and a half hour wait is a complete nightmare.
- Never heard of it
- My youngest child had a few new spots that looked like a recurrence of his recent chicken pox that emerged on a Saturday and i was concerned to get a medical opinion as my other child had an important hospital appointment a few days later, his grommets operation I think, and the pre op info talked about contact with contagious diseases. Can't remember too much detail. I phoned NHS direct and was advised about the Brighton station health centre. We had to wait a long time but were able to sit in a small room away from the main waiting area in case he was contagious. The doctor was helpful and advised me that it was ok to go ahead with the hospital visit.
- it's great to know they're always there
- Referred me to A&E when son hurt his arm. In 2010 I saw GP there and received prescription when feeling quite ill at end of working day (bad cold/flu).

v. Willing to share suggestions?

8 parents were:

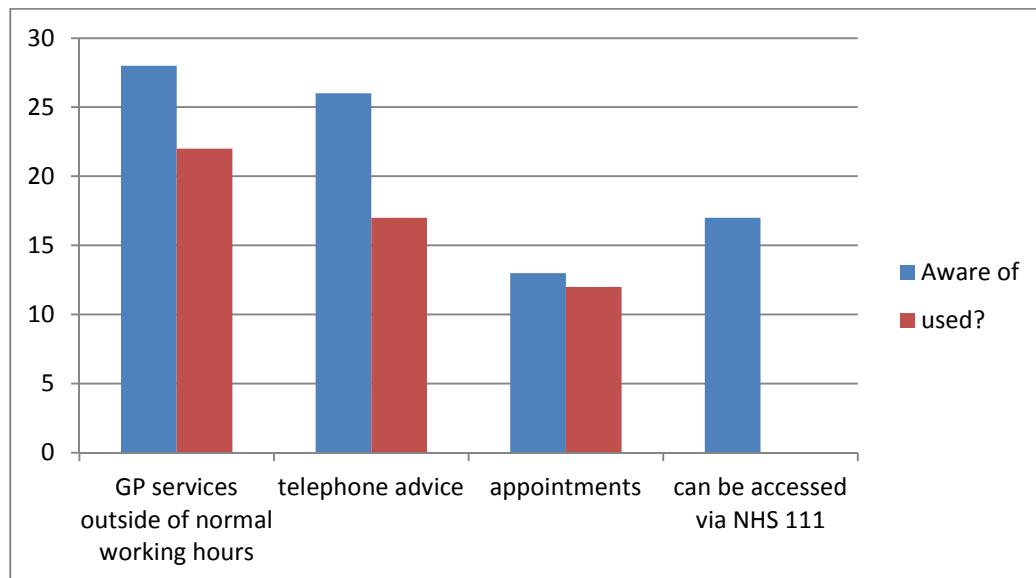
- Providing parking to enable access.
- You should perhaps make people aware that there is actually a Health Centre at Brighton Station. I have always been pointed towards the out of hours doctors at the Royal Sussex County Hospital. I don't know if this is because the Health Centre isn't open late or if it is for a different reason, but I wasn't even aware that it was there and accessible to people.
- No using glass rooms visible to other patients.
A better booking system.
Relocate to somewhere more secluded but with buses and parking.
- Improve waiting time.
- Advertise services more widely
- Didn't have any sense of us being prioritised - even though possible contagious disease, nor

because two small kids - one severely disabled.

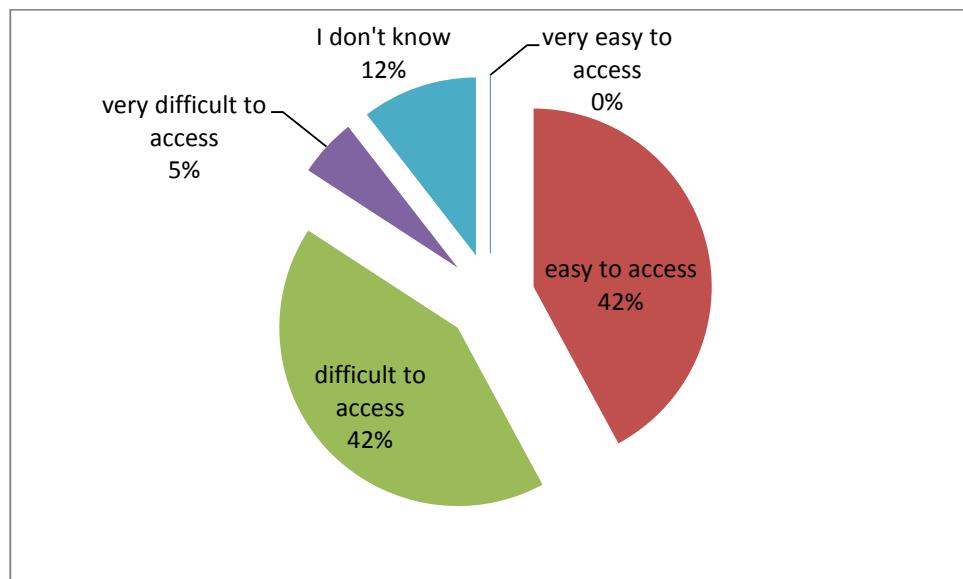
- Disabled parking
- Waiting times are bad. A good two hours. I would attend only if feeling quite unwell or in pain so waiting for long time is not pleasant. Although probably still better than in A&E.
- not sure where it is ????
- I have never heard of it so perhaps a greater media presence.
- Let people know of services available. Location difficult for parking

3.d. GP Out of Hours Service

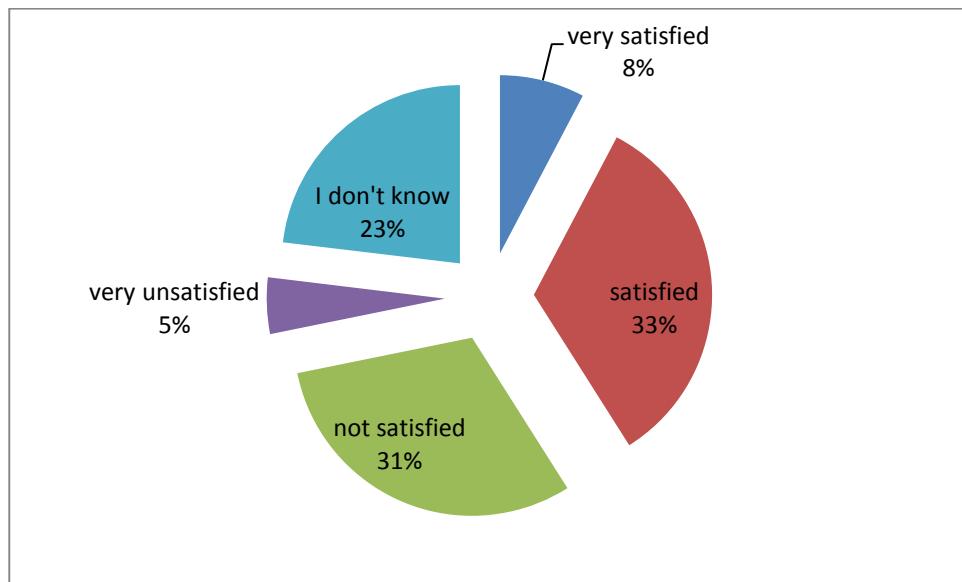
i. Aware of and used before?



ii. Accessible to access GP Out of Hours Service?



iii. Satisfaction with GP Out of Hours Service?



iv. Experience willing to share about GP Out of Hours Service?

13 parents had experiences they were willing to share – 1 of these were before 2012:

- We have used the GP out of hour's service a lot for various ailments over the years but the last time we went to the County Hospital they did see us very quickly and dealt with the problem very efficiently.
- I attended due to a very bad ear infection, and was told that all he could do was offer pain relief as, despite the fact that it should be suctioned as soon as possible, they could no longer access the emergency ENT consultant necessary at the very hospital in which it is situated! I therefore ended up suffering an additional 3 days of severe pain before seeing a consultant at the ENT for suction on the infected ear.
- General advice given regarding my daughter rather than considering her specific medical conditions. Felt they were blasé. Another experience that year was very positive and helpful.
- Lots of silly questions - is patient breathing? When just called to talk about ear ache?! Appointments for children should be offered with paediatric doctors.
- Told to come at specific time, arrived in good time then had to wait over half hour with ill child. Once seen, examination very thorough and he went through all case histories and I was happy with the consultation.
- My 5 week old baby had a high temperature and behaving strangely. Despite my calling twice, no-one came out to see him. In the end I took him to A and E on the advice of a paediatrician friend, and he was kept in hospital for 3 days with suspected meningitis. A baby that small with a high temperature and behaving unusually should always be seen by a doctor immediately.
- wife with problem and self with problem - OK but on seeing GP later they changed some meds
- We got an urgent appointment for our baby son who was very poorly. It was very difficult to find the building as it is not sign-posted but once found they were brilliant
- I called 111 on a Saturday morning as I was concerned that my son was developing a chest infection - he has a tracheostomy and is on a ventilator and has complex medical problems. It took until 6 in the evening for a GP to come out to us (We have two other children so were hoping to get to a pharmacy before bedtime), and I had to ring back to find out what was happening. If the authorities want people to stop using A & E unnecessarily then a viable alternative has to be provided.
- i wasn't sure there was one and i thought it was for real emergencies for advice i.e. really high temperature etc. not for potentially broken limbs
- My daughter, who has on-going health problems, was seen by an out of hour's doctor at the Royal Sussex hospital. The doctor was lovely and gave us a prescription and advice for the future.
- My son has an inborn error of metabolism. If he is unwell we need a prompt response, thankfully they have never let us down
- You need to be able to call the doctor back. If you miss the call e.g. dealing with a child being sick, you want to be able to call them back and you can't. You have to wait for them to call you and then you might miss the call again! Also, I have been so ill that I physically couldn't drive

to the out of hour's gp... what do you do in that case? I didn't want to call an ambulance as I just needed something to stop me being sick....it had been going on for nearly 48hrs. I just had to suffer instead! Poor care

v. Willing to share suggestions?

15 parent carers were willing to share these:

- We do have to go all the way across town to the County Hospital. It would be nice to have an out of hour's service on the west of the city.
- Have a doctor at the end of the phone, instead of an operator who takes all the details and asks sometimes silly questions, and then gets the doctor to call you back.
- Enable the GP out of hours service to forward any relevant patients on to the appropriate emergency consultant working at the local hospital so that the patient can get the necessary treatment sooner rather than later; thereby alleviating their pain and discomfort more quickly.
- More local out of hour GP care in local community
- Local people giving local advice- like where to go for appointments etc.
- When doctor calls with advice, you should be offered an appointment if he thinks necessary or if you still feel that you need to actually be seen. Sometimes you feel like you are pleading with them to see you but they fob you off with general advice. If it hasn't been for my sons medical history, he would not have been seen but had a very bad cough which almost turned to pneumonia a few days later, my GP told me.
- There isn't a GP Out of Hours service at my surgery
- Doctors should be more prepared to see patients.
- It is very costly to phone the NHL 111 and can be off putting
- They should bring back home visits
- Let local GPs organise if they want to
- Signpost to where the building is
- The receptionist not very helpful
- be more aware of what we can use it for??? leaflet , card to keep with number on , the same for the health centre , what's the difference???
- When we rang 111 they were very keen to arrange an ambulance to take my daughter to hospital which was not necessary and frightened us. A faster call from a doctor would have been more appropriate.
- Home visits for very sick or children

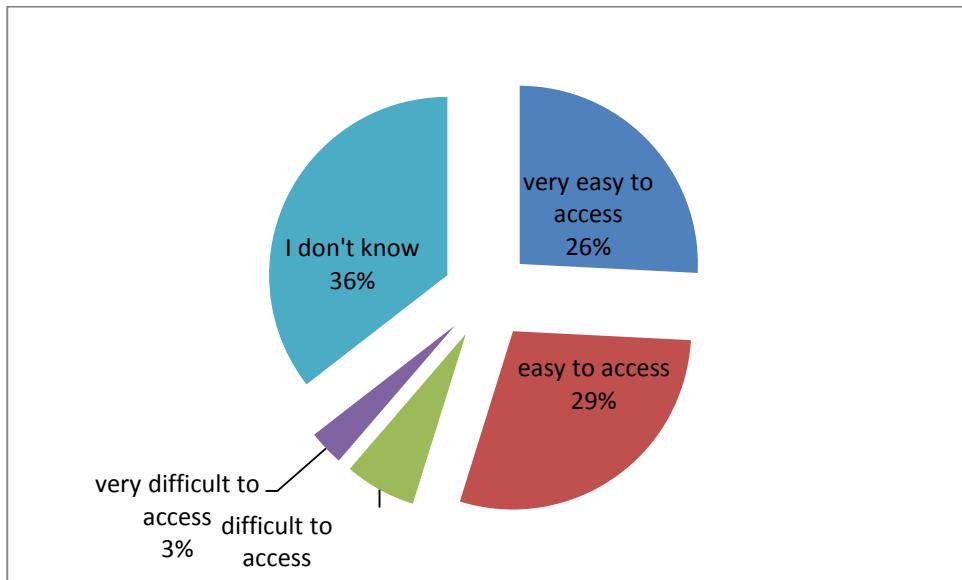
3.e. NHS 111 Service

i. Aware of and used before?

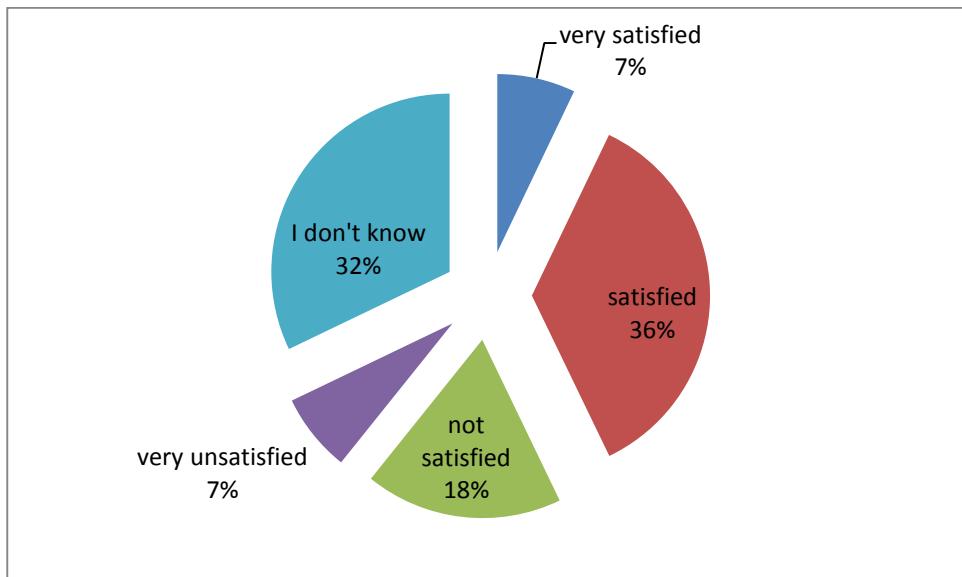
This question had been set up wrong in the survey so it's not been possible to use the data in a graph format. From the 24 parents who chose to answer this question 2 said they hadn't heard of it at all, one had heard of it but forgot what the number was, and one said they were totally confused whether to ring 111, or the GP number or the Brighton Station Health Centre number.

No one said they knew the 111 service could refer to other community based services.

ii. Accessible to access NHS 111 Service?



iii. Satisfaction with NHS 111 Service?



iv. Experience willing to share about NHS 111 Service?

8 Parent carers had experiences they are happy to share:

- I rang because I was in severe pain. After a short delay, I spoke to someone who, after asking questions, said he needed to speak to a colleague and would ring back as his line was engaged. The service rang me back quite quickly and said they'd arranged an immediate appointment for me with the out of hours service so a GP could help me.
- No personally but I have concerns about privatisation, reduction in qualified staff and use of scripts. An elderly neighbour's daughter in law called them recently for advice as my neighbour was ill & the operator spent 209 minutes asking unnecessary Qs whilst my neighbour lay on the floor in pain. Eventually she hung up as the surgery had then opened and called the surgery who dealt with her immediately and expedited a hospital appt.
- Not that helpful, ended up talking him hospital instead.
- I had to wait over an hour for a call back. It seemed that once they had established that i didn't need to call 999 for my child (which i knew!), there was a very long wait. She had a nose bleed which went on for about 20mins and i needed advice on what to do there and then, not to be told I'd be put on a list for a call -by the time the call came, the emergency had passed and the nose bleed had stopped.
- both times used referred to A&E or out of hours GP

- See previous page
- As mentioned before, they wanted to arrange ambulance transfer for my daughter to hospital which was overkill. We really only wanted advice. They did arrange an out of hour's appointment for us though which was very useful.
- Its long winded...if you know you want to see a gp out of hours....you know you want to see a gp! Why all the questions? and why all the questions just because the gp surgery is open!
- Received professional advice swiftly
- by time given information would have been too late if had been emergency. Child swallowed lots of vital c tablets.

v. Willing to share NHS 111 Service suggestions?

5 had suggestions:

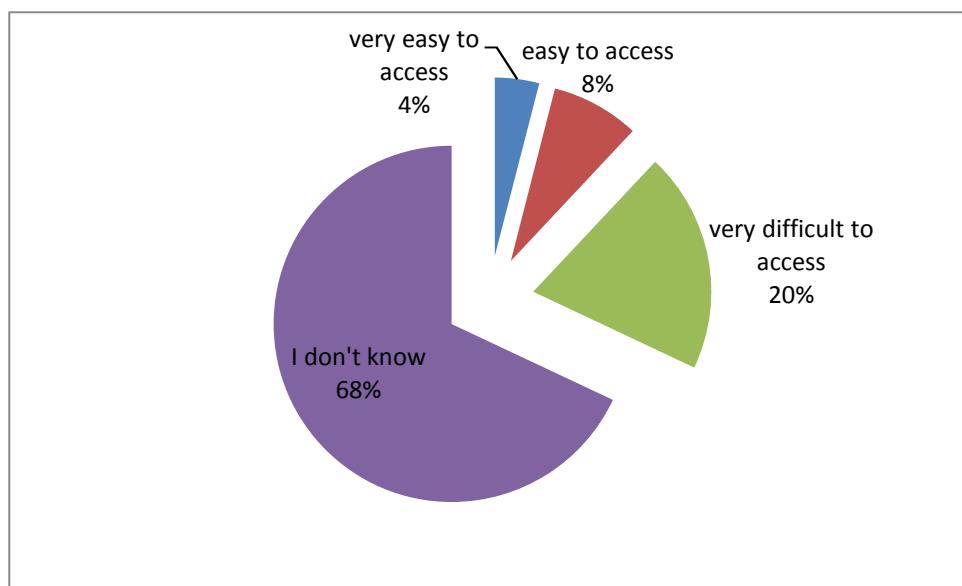
- To have an actual doctor on the end of the phone.
- Trained qualified nurses and doctors based locally answering calls. Return to public sector. Fund it properly
- More available staff, phone lines etc.
- Make it work!
- Just refer, when you are really sick or child really sick, the questions are a nightmare

3.f.Emergency Dental Service

i. Aware of and used before?

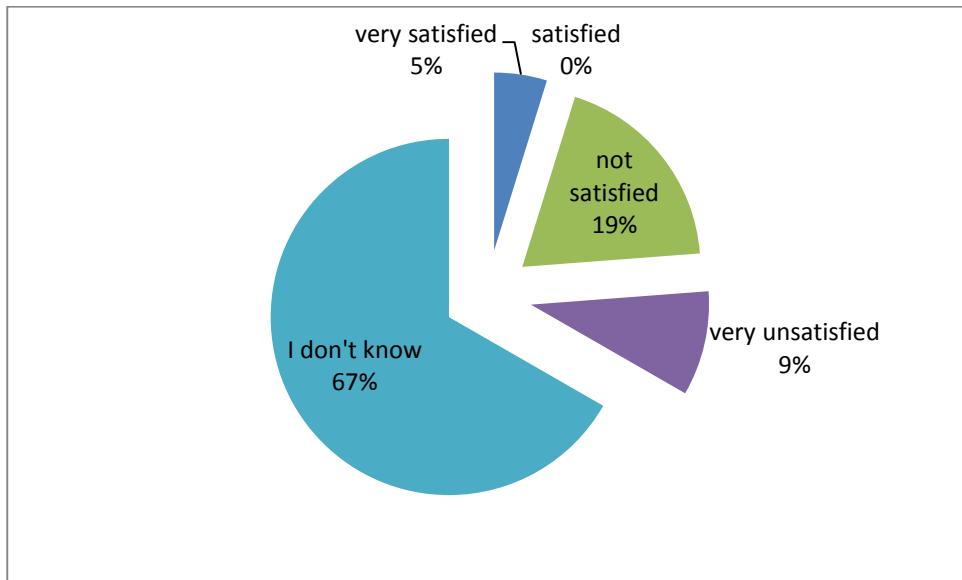
14 parents answered that they did know about this but only 4 had made use of the service. By this point the response rate to the questions had dropped so not sure if this is as valid a response as others.

ii. Accessible to access the Emergency Dental Service?



5 parents said very difficult to access

iii. Satisfaction with Emergency Dental Service?



4 parents were not satisfied and 2 were very unsatisfied.

iv. Experience willing to share about Emergency Dental Service?

3 Parent carers had experiences they are happy to share:

- Desperately tried to get brother advice on awful toothache on a Sunday to no avail!
- Called them but received no reply was unclear on how to access this service
- Daughter fell on her face and knocked out a tooth crooked. A and E recommended out of hours dentist. By the time we were able to see emergency dentist, the next day, it was too late to put tooth back into position. Not so bad as it was a milk tooth.

v. Willing to share Emergency Dental Service suggestions?

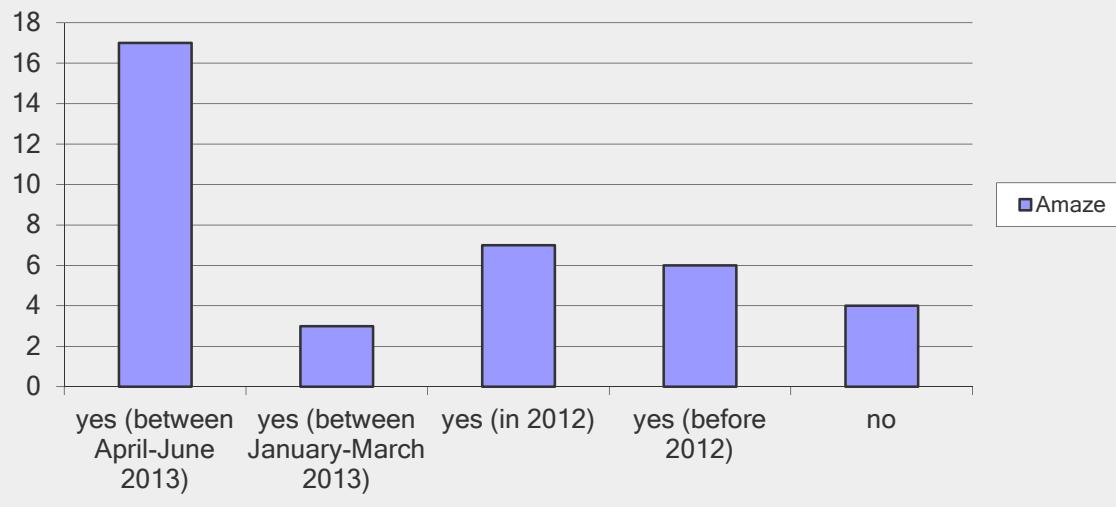
4 parent carers had suggestions:

- Accessible - hospitals and NHS 111 need to be able to pass on the information!
- Advertised more widely
- An immediate contact number for out of hours dental services would be better than the poor recorded message that is confusing and unclear
- Open evenings. Direct access through a and e.
- Haven't heard of emergency dental service. Perhaps greater media presence would help.
- I feel the information on this service is not widely known

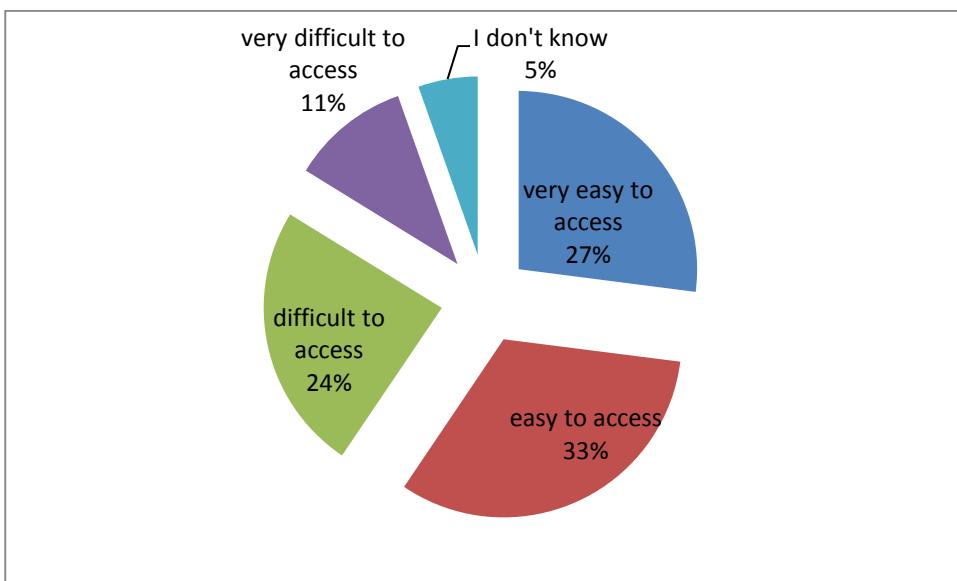
3.g. A&E Department

i. Aware of and used before?

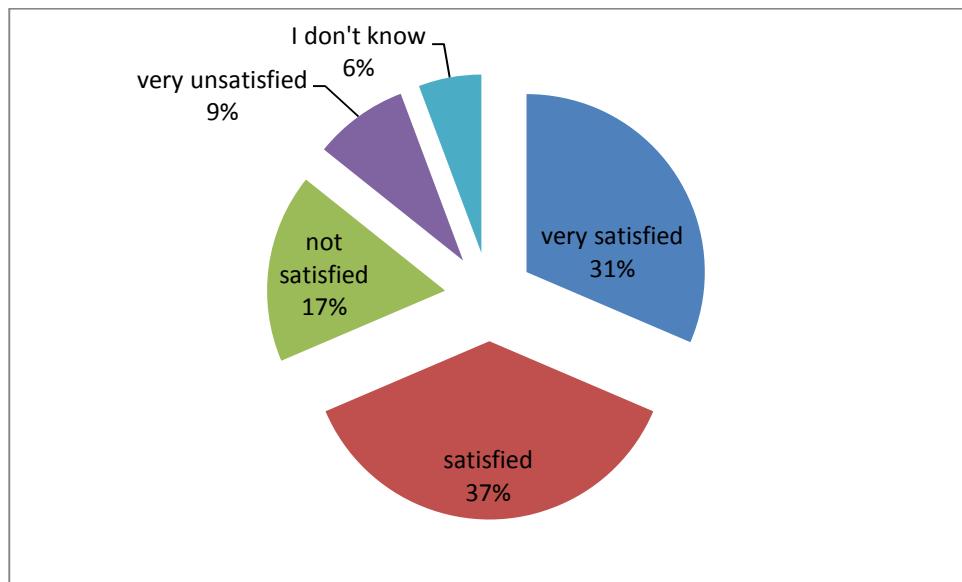
**Have you used Accident and Emergency (A&E) at the hospital in Brighton?
(tick one)**



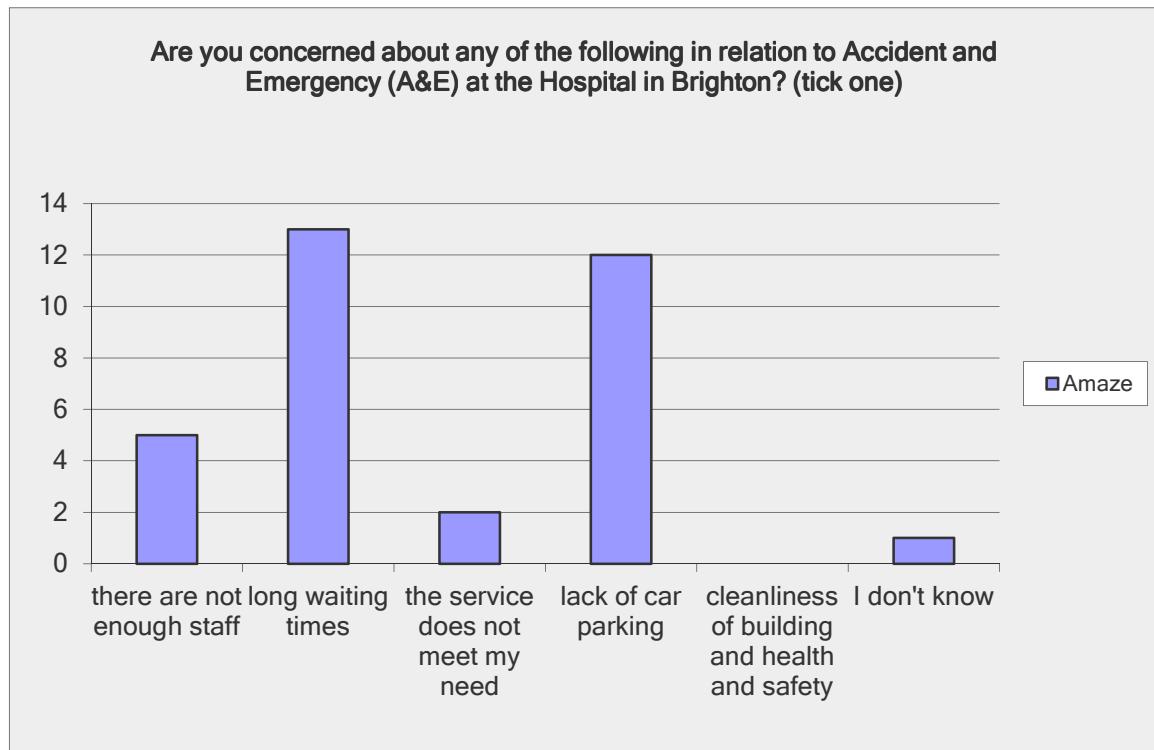
ii. Accessible to access A&E Department?



iii. Satisfaction with A&E Department?



iv. Concerned about any of the following?



- I was admitted to the A&E department after hurting my back at the Children's Hospital. I was attending an appointment with my daughter in the dental department and hurt my back there. I was unable to move at the time and unable to look after my daughter who has learning disabilities. The staff in the department were brilliant at helping me but it became clear that I was not going to be able to go home in a car. They asked for an ambulance to come and pick me up from the A&E department but were told that because I was not on the site they would have to ring for an emergency ambulance. They then rang for an emergency ambulance that refused to come and pick me up because I was on site. In the end after a long time of arguing about who would come and collect me the sorted it out by calling a crash call which was totally unnecessary. However it did get things moving and by this time I was in complete agony and hardly able to stand. I was transported to the A&E department where I was treated but all this could have been easily avoided if they communicated with each other better and worked out a procedure for an accident which may occur in another part of the hospital and what should be done.
- There are not enough staff and when you are seen they treat you as if you shouldn't be there

even though the symptoms you have dictate an A&E visit.

- I am also concerned about the long waiting times and the lack of car parking.
- Long waiting times/dirty/expensive/lack of parking/
- Wasn't told some information , that later found out

v. Willing to share A&E Department experience?

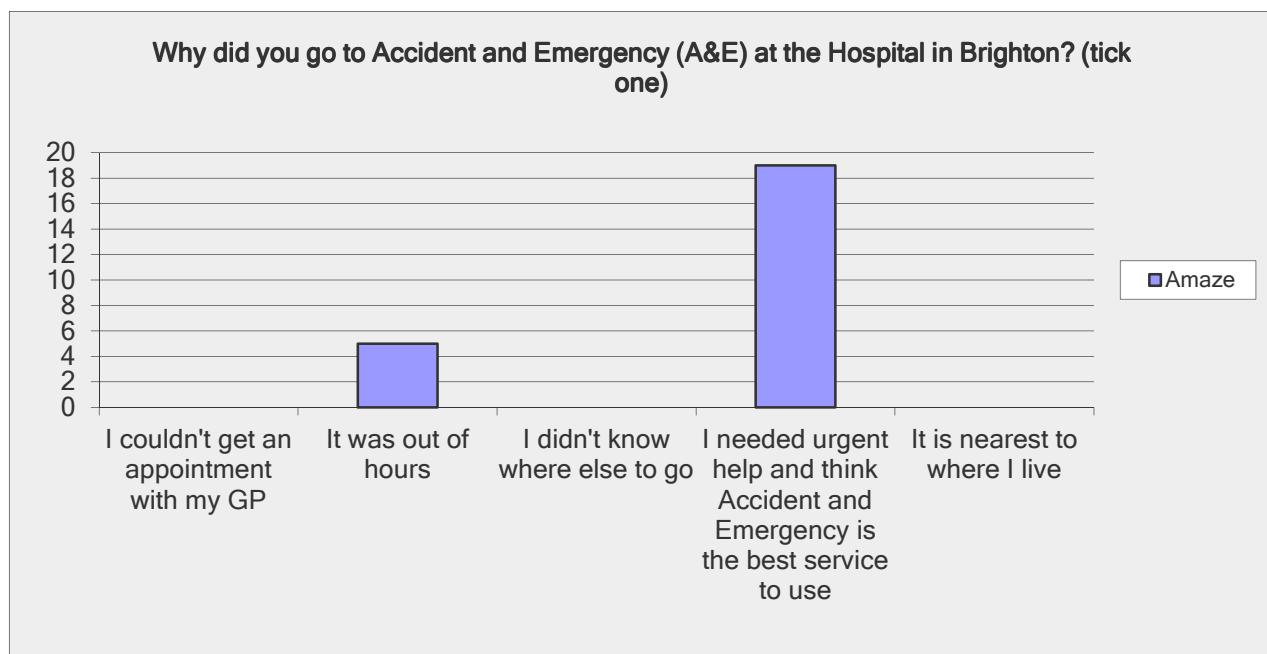
11 parents were willing to share an experience from 2013, 6 from 2012 and 3 from before that:

- I had a severe feeling of chest pressure and high discomfort that I had not had before. I felt very strange and unwell. I had a history of Gerd and possible sliding hiatus hernia but this felt very different. They felt it was related to my GI issues and therefore made me feel as if I should not have attended and should have seen a GP for "chronic symptoms" even though these symptoms were new and different.
- Being diabetic and with other medical problems, including heart problems in the past, I have had several occasions to need the care of the local a&e department. Some of those occasions I arrived on foot, and others in an ambulance. There were long waiting times on all occasions; and on one occasion I even spent the night on a trolley in the corridor because I was not deemed well enough to go home; but there was no room left in the department itself.
- Took my husband up on a Sunday as he had badly cut his thumb on a saw. He was seen and thumb was stitched & he was home within 2 hours. Very good.
- Has to rush my mum up. They were attentive and did a good job despite lack of nurses.
- Very good.
- My step father passed away in A & E after being admitted the evening before with a bad chest infection and problems with breathing. He never left A&E and died on. The trolley the next morning then lost his notes.
- Treated my special needs son with great sensitivity
- My son had a football injury and he was seen quickly and was a good experience
- Children's a&e, very quick friendly service. Only there for a couple of hours.
- I took my son to A and E because I was worried that he had meningitis. My son is autistic and doesn't like his ears touched. The doctor would not look in his ears because he wouldn't keep still. Doctors need more training to deal with children like my son.
- My daughter has a children's passport for the Alex because of her conditions but we still had to go through A&E when she had severe stomach pains & bleeding from her gastrostomy. We were seen by a junior doctor which is annoying as my daughter is complex & you can tell that they haven't got any idea how to deal with the problem. The girl also asked if my 12 year old daughter could be pregnant which made me very angry.
- Foster child, 11 yr. old boy had inserted pencil in body. Staff gave him and us immediate attention, were patient, polite, kind. Spot on attitude to child - not too sympathetic which might have shown encouragement to repeat performance. They kept at problem, were about to do surgery, had "one more try", succeeded. Two amazing, kindly professional young Drs.
- had chest pains and they saw me immediately
- I have A/S and had an iritis attack which I've not had before. Rang 111 Sat morning - saw Eye hospital A&E early afternoon who had some of meds - within 2 hrs. - then got rest from pharmacy. I had a follow up appt scheduled by them the next week which was on time and thorough - not rushed. I would not expect any more and was impressed.
Did go to main A&E by mistake - which was quiet - expect at that time.
- i had two occasions in august 2013 within a week of each other , the staff were amazing , my children ad potentially broken limbs and i wasn't sure who to see
- My daughter has been referred to Accident and Emergency several times this year by her GP. On each occasion the doctor has phoned the hospital to arrange admittance and on each occasion they have not recorded this and we have had to wait a long time. The doctor has also tried contacting the Acute Medical Unit for direct admission but we are always sent back to A&E because they have no knowledge of the call. This means that we have usually had to wait 4 hours before anything happens. Although my daughter is no longer a child and is therefore admitted to adult A&E, My younger child, who is also autistic, often has to accompany us increasing all our stress levels.
- our two year old with a badly split lip could not eat or even drink with it but was made to wait 4 hours before being seen and then told they wouldn't stitch until the following day even though she had not eaten anything since lunch time. She has CP and is severely underweight as it is

so leaving her without any food or drink for nearly 24 hours, in my opinion, is not good practice.

- My son stopped breathing with his first tonic/clonic convulsion. I had to do CPR on him to get him breathing again. The ambulance and Children's A & E were very good
- I can't fault either the children's a&e (ice skating accident - stitches, new-born baby - bowel problems treated with laxatives, skate boarding accident - x-ray) or adult a&e (haemorrhage 8 days after birth). Little or no waiting time and really good care.
The problem is that a&e is so good and gp services very inaccessible - not surprising people are turning away from gp and towards a&e. I don't even bother going to my gp for sexual health issues, wait is too long. I go to Claude Nicol (thrush, bleeding & other problems during pregnancy)
- Son cut head open very deeply down to skull. Eventually required 16 stitches. The individual took over an hour to get anaesthetic into wound prior to stitches. I had to keep my child with poor communication still for this entire painful procedure with very little information. In tears had to ask for different approach to be used as clearly no progress and child in pain.

vi. Why did you go to A&E?



vii. Willing to share A&E Department suggestions?

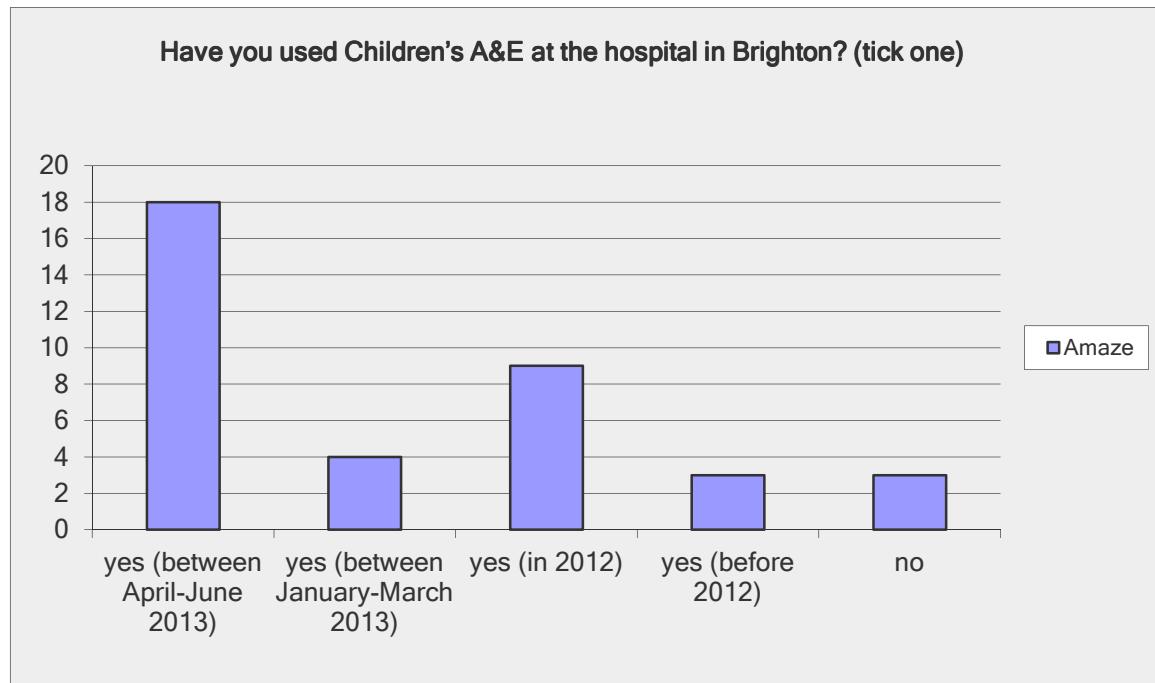
10 parents were willing to share:

- Lessen waiting time, understand patients have a genuine reason they believe they need to be there, when you are not the type of time-waster who attends for a splinter in the finger you don't expect to be treated this way. As I am autistic too I have interoception which means internal discomfort feels worse to me than other people so I have more reason to suspect it's something serious.
- Increase the number of trained staff on duty at any one time, and also maybe increase the size of the a&e department itself as - bearing in mind it covers a fairly large populous area - it is not very big.
- Doctors and nurses need more training on how to deal with patients with learning difficulties
- Do not send junior staff to look at children (& parents) who obviously have spent lots of time in hospital situations. It is just insulting. I have had to explain what a TOF is to juniors in the past because they didn't know. This does not instil confidence in an already stressful situation. I would much rather see a senior nurse if a registrar isn't available.
- Keep staffing within safe limits and have security eject patients who are not compliant.
- More staff the wait is too long
- Obviously, they need more staff but equally obviously, the government are not prepared to pay for this.

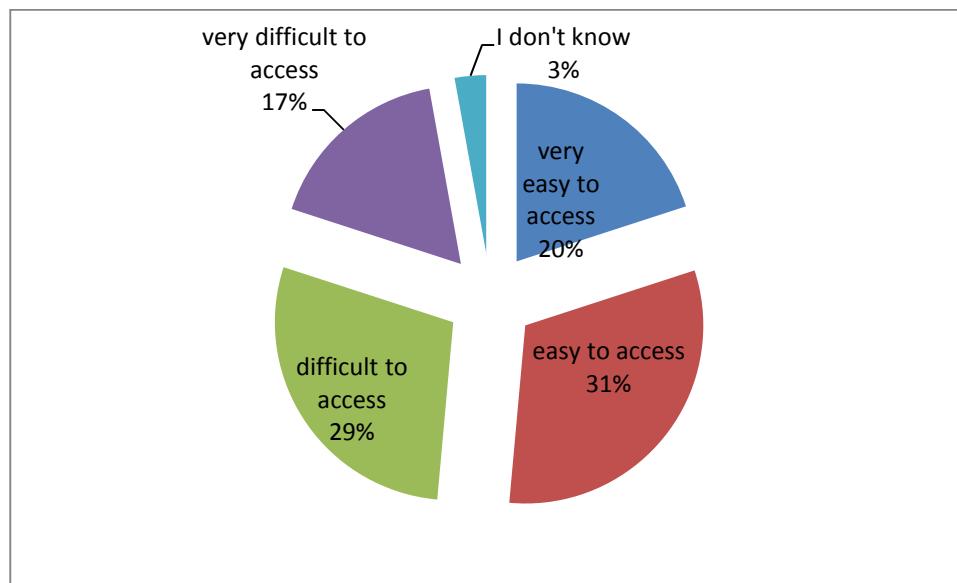
- - There should be an area that you can pull up into to drop off child (with carer) before going to park your car.
- - Generally have more staff
- maybe more staff
- I know from my work as a HV that some people have to wait a long time to see a Doctor
- communicate better with family and patient. Maintain empathy

3.h. Children's A&E Department

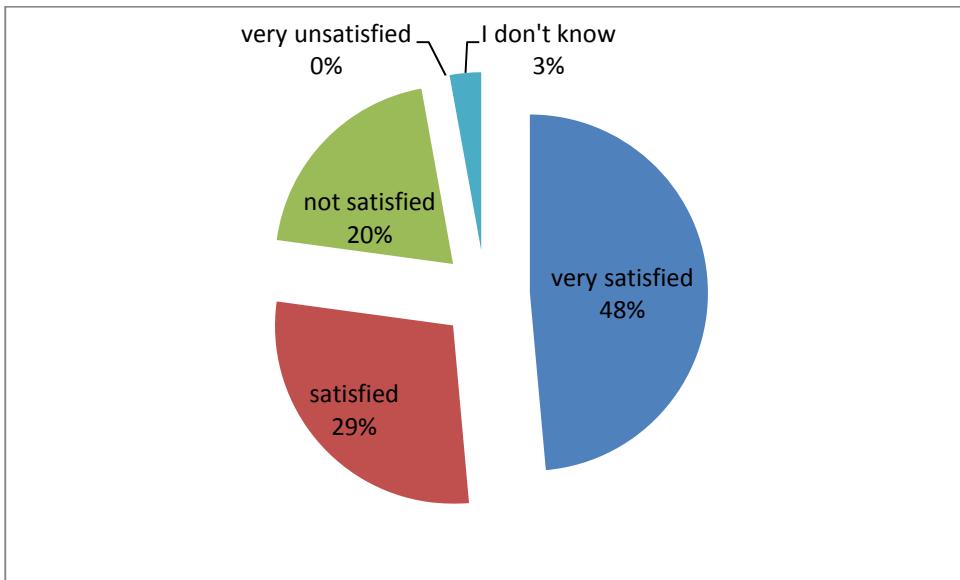
i. Aware of and used before?



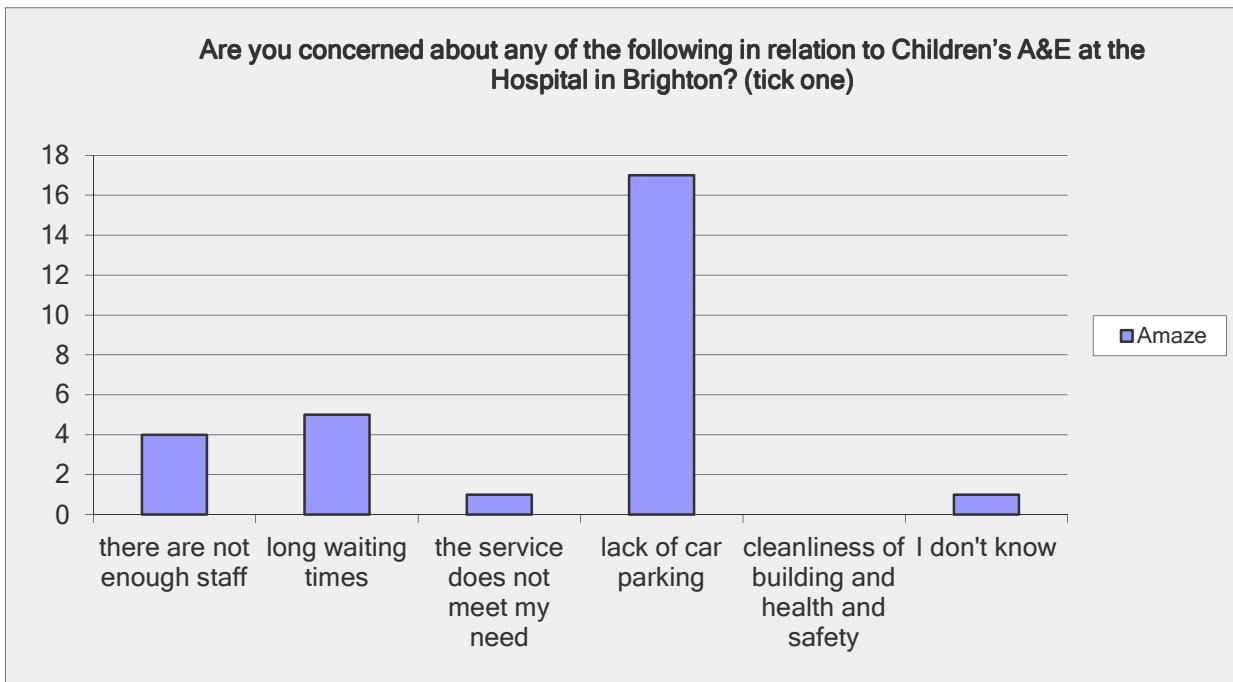
ii. Accessible to access Children's A&E Department?



iii. Satisfaction with Children's A&E Department?



iv. Concerned about any of the following?



- They are not very clued up/supportive about my daughter's conditions.
- Same as a&e
- Need to let taxis know where to collect from.

v. Experience willing to share about Children's A&E Department?

12 parents were willing to share an experience from 2013, 10 from 2012 and 1 from before that:

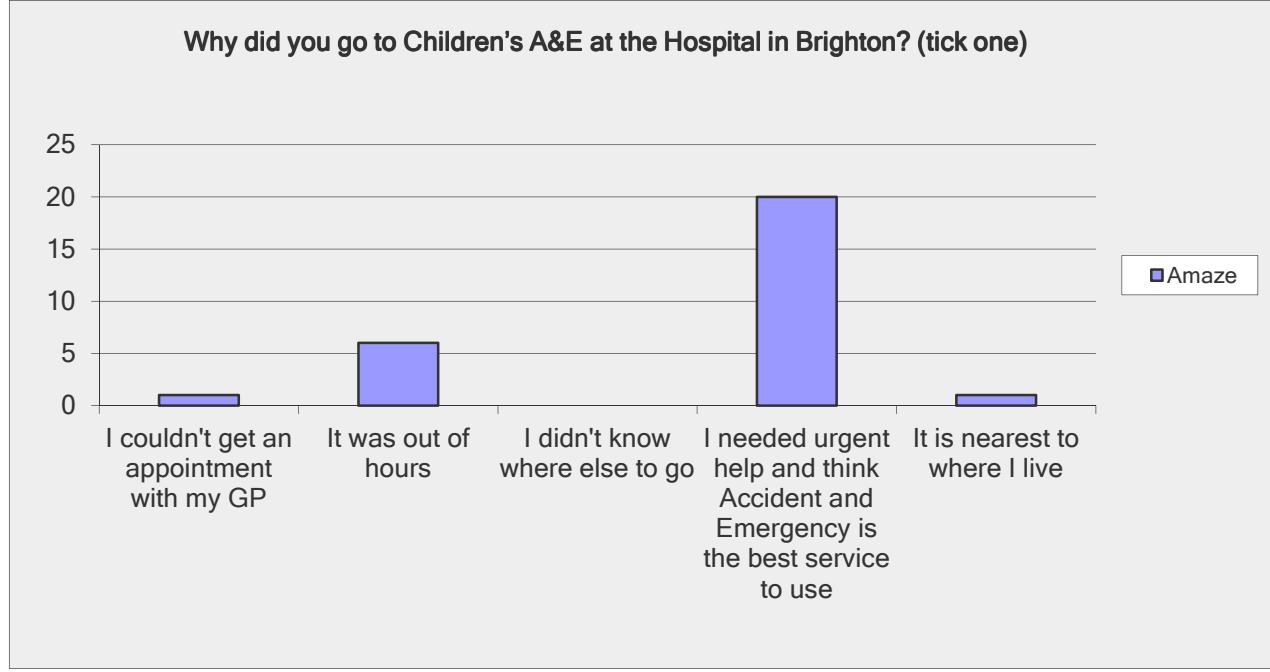
- My daughter fell and smashed her mouth into a stone tiled floor. There was a lot of blood and her mouth swelled up and her teeth were displaced. I had no idea if she had broken any of her jaw as the injury looked very scary. She is autistic too so finds waiting very difficult and despite all of this we had to wait ages.
- My son developed a condition called myositis ossificans, and although it required many tests to enable a definitive diagnosis, the staff at the local children's a&e were brilliant.
- My son fell off his bike a month ago and broke his arm. An ambulance was behind him and he

was taken straight to A&E who referred him on.

- Having to persuade nurses that my daughter was still having a seizure. Felt it was hard to get heard initially.
- Didn't seem like I was time wasting. Staff friendly and helpful.
- Very good saved my babies life
- Despite my son having an emergency passport to the A & E , they had trouble finding his notes and everything took far too long and we had to keep asking nurses to run various tests that needed doing and it took forever for a doctor to arrive.
- My daughter hurt her foot quite badly. We were very well looked after, but the nurse didn't realise how severe the friction burns were, and so we weren't given the appropriate dressing. This meant we had to return to a and e the next day.
- Over 4 hours waiting time in total. We saw triage nurse, a junior doctor, x-rays and orthopaedic doctor, further delay waiting for dressing and drugs to be issued. Child sent for x-rays but hospital number not issued in time - when we got to front of the queue we were sent back to wait another 30 minutes while this was chased up.
- We have used the children's a and e on several occasions and have always received a good service from the dedicated team who have endeavoured to see my child as quickly as possible
- Please see previous page
- Have done so above
- my daughter got good treatment for injured fingers one evening
- We were seen and dealt with very quickly. It has been made a very pleasant environment for the children.
- My son has been admitted via Children's A & E numerous times and we have had a good experience
- my child's had a very bad ear infection with a temperature taken to A&E was seen very quickly and seen by the out of hours doctor but did have to go to a completely different building to see the doctor which was a lot of walking around the hospital at night
- My son had a seizure and he was rushed to children's dept. straight away - ambulance and given help
- Our daughter had badly split her lip open. She couldn't eat or drink anything with the pain and was made to wait 4 hours before being seen. They then said it was too late and she would have to wait until the following day to have stitches. She hadn't eaten since lunch time and then had to go nil by mouth overnight, skip breakfast the following day.
She has CP and is severely underweight as it is. She went nearly 24hours without eating or drinking anything due to the delay in treatment at A&E. In my opinion this is not good practice.
- see previous screen

vi. Why did you go to A&E?

Why did you go to Children's A&E at the Hospital in Brighton? (tick one)



- Was advised to do so by the out of hours gp service because my son's leg was very swollen and still swelling, and he was in a lot of pain.
- Was offered appointment with the out of hours doctor but felt my son needed to see a child doctor as his problems are quite complex.
- Referred by out of hours GP service
- child had tripped over a low wall and toenail was hanging off. GP surgery said they couldn't see him for 3 hours so we thought best to get him to children's a&e in case of infection.
- Sent there by gp
- We were sent there by the Brighton walk in clinic as they thought my son needed X-rays.
- Referred to it by out of hours gp surgery
- CF nurse booked an appointment to have daughter checked over out of hours.
- My son had a fall whilst in leg casts (post op) and we were made to wait a long long time before results were forthcoming

v. Willing to share Children's A&E Department suggestions?

8 parents had suggestions to share:

- Have reasonable adjustments for autistic people, don't fob them off with a nurse when they need a doctor and shorten waiting times.
- Better trained in certain specialisms.
- More staff, children get very distressed waiting especially if in pain
- More staff
- more staff; sandwich vending machine.
waiting with small children awful especially as dinner time came and went - very little food to purchase nearby so we were stuck. We weren't kept informed about what was going on and eventually my other child, who is severely disabled both physically and cognitively, became very distressed.
- Only the car parking which is inadequate it would be a good idea to have a dedicated area of parking for those people bringing children /adults to a and e without the worry of receiving a parking ticket. After all by using a car saves the ambulance service using their resources.
- The staff All need training to deal with patients with learning difficulties
- See previous page
- - There should be an area that you can pull up into to drop off child (with carer) before going to park your car.
- Generally have more staff
- More communication between patient / staff instead of just being able to wait. Most reasonable adults can deal with a wait. Children cannot