



Pharmacies and management of medicines – August 2017

Report Summary:

On this consultation Amaze and PaCC asked parent carers in Brighton and Hove about their experience of using pharmacies in relation to receiving general advice around health care and also around prescription and management of medicines.

We found out that **80% of parent carers** who completed the online questionnaire **were happy with explanation of what medicines are for, what they do and possible side effects**. However, considering that many parents and their children take multiple medicines **they would like more information and also to know more about interactions between different medications**.

Parent carers are **confident enough to ask their pharmacist for more information about the medicines**, and **79% of parent carers reported that they can easily find and use an open pharmacy** when they need one. Some parent carers suggest **improving the quality of information and advice from the pharmacy** and **provision of some confidential and private space** where to talk about the medicines.

Most of the people who responded to our on line questionnaire are **aware of the different services that a pharmacy** can provide but only approx.**40% knew that the pharmacist can review and help manage their medications and/or provide health checks**.

Overall the **majority of parent carers, 80% are satisfied with the pharmacy services and some rely on alternative remedies**. However parent carers find the **management of repeated prescriptions very challenging**. **Better communication** between GP and pharmacy, and **coordination** of the different agencies involved could resolve some of those issues.

1. Introduction

1.1 What Amaze does

Amaze is Brighton and Hove 'one stop shop' for parent carers of 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, 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 SEND themselves, up to the age of 25.

1.2 What PaCC does

The PaCC, hosted by Amaze, is a city-wide engagement group with over 320 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has 9 partners, some of them service providers, others community groups formed by parent carers.

PaCC gives a voice to parent carers using different engagement methods as 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.

1.3 Parent Carers' engagement through B&H and local CCG

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Prospectus (TSIP), fund Amaze and PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children (*See Annex 1: How Amaze and PaCC engage with parent carers*). As a result BHCC and B&H CCG are provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local services and how they would like those services to respond to their needs.

In addition BHCC and B&H CCG's understanding of the needs of disabled children and their parent carers is improved, and health and social care services are correspondingly made more responsive and are targeted to actual needs. And finally parent carers feel that their views are valued and that they can influence decision making regarding health and social care services, and help effect change. PaCC and Amaze provide regular feedback and updates on the engagement work to parent carers through their termly newsletter and through social media.

2. Parent carers, medicines and pharmacies

This consultation and resulting report looks into the use of pharmacies, their role around prescription and management of medicines and how parent carers and their children could be more included in this. This consultation was mainly planned around engagement from B&HCCG, however, following a request from B&HCC Health & Adult Social Care who are

undertaking a similar engagement review, three more topics were included, specifically services provided by some pharmacies across the city, use of pharmacies and level of satisfaction.

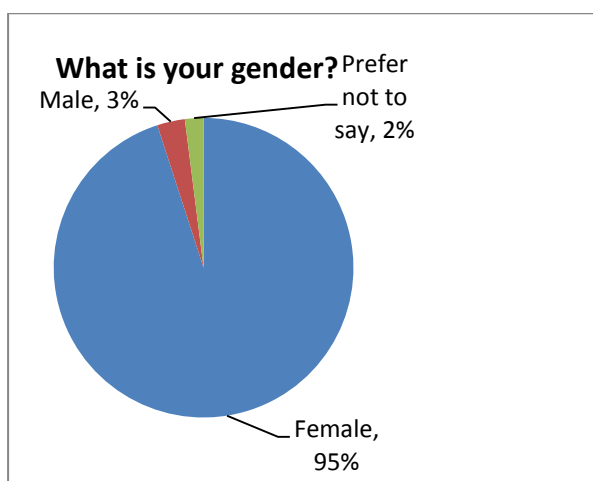
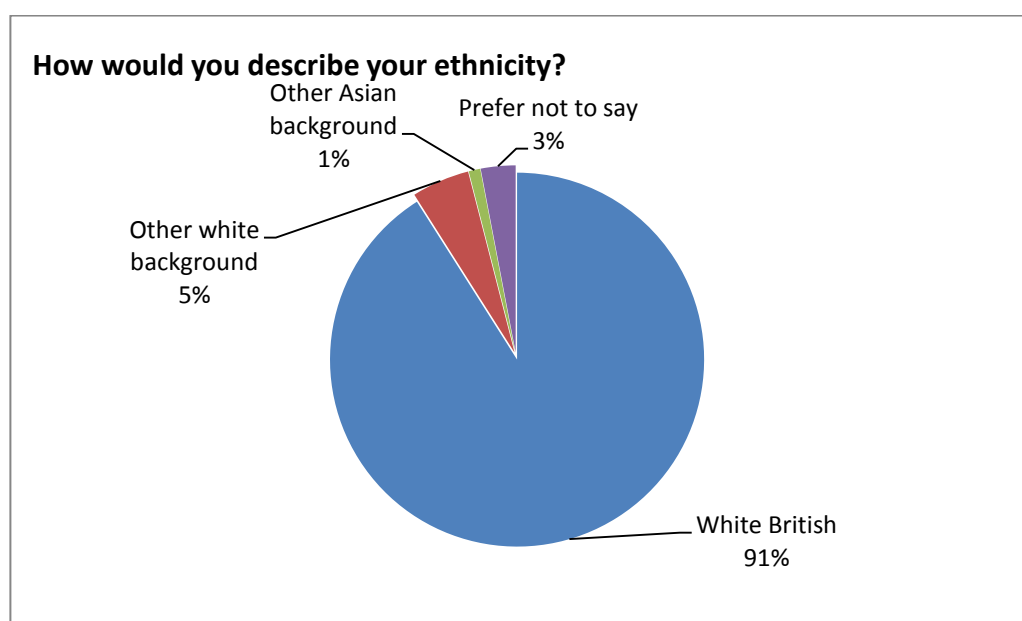
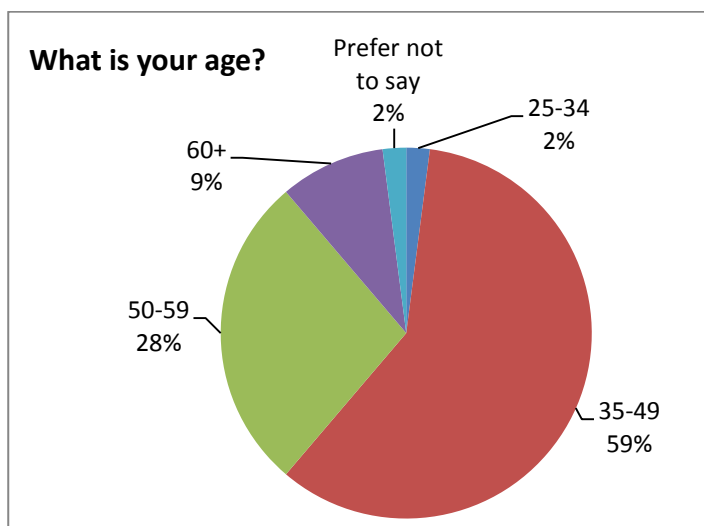
In times of careful management of resources any money saved in the drugs budget is put back into buying other services for patients. *'The CCG has an annual drugs budget of around £39 million and whilst the CCG have a legal and moral responsibility to manage resources wisely to maximise the benefit to the patient it has also a moral responsibility to reduce waste where possible'*. That can be achieved by switching to cheaper drugs as there are many manufacturers and newer less expensive brands, same drug and of the same quality, been created all the time. Other options that parent carers could consider are to ask the pharmacist for advice if there are difficulties on swallowing tablets before buying a liquid medicine, much more expensive, or to buy low cost medicines from the chemist or supermarket rather than asking for a prescription, and to request repeat prescriptions when needed ([See Annex 2: Medicines Optimisation](#)).

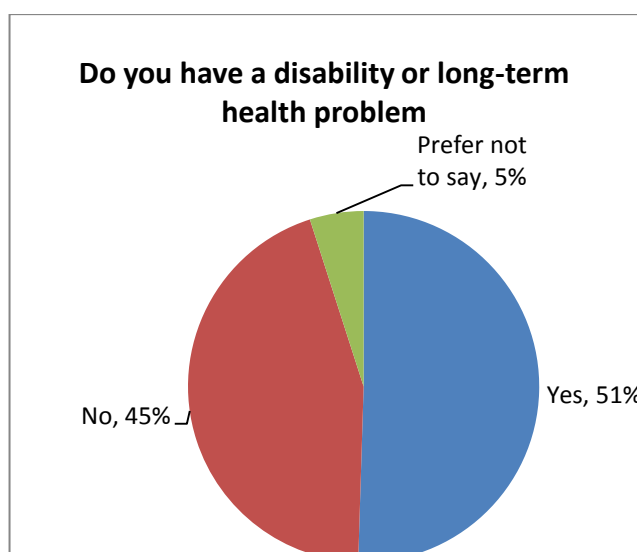
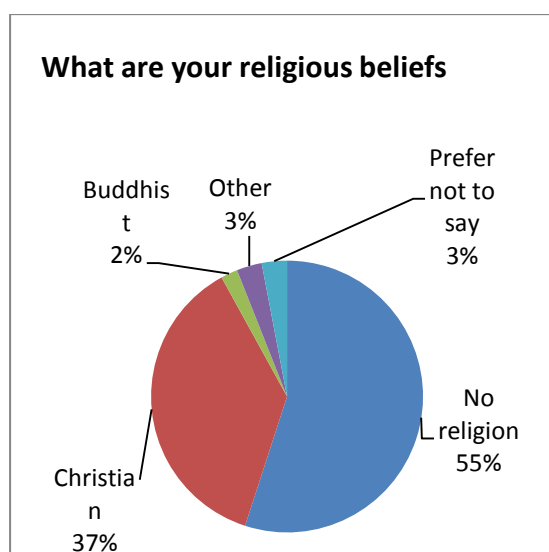
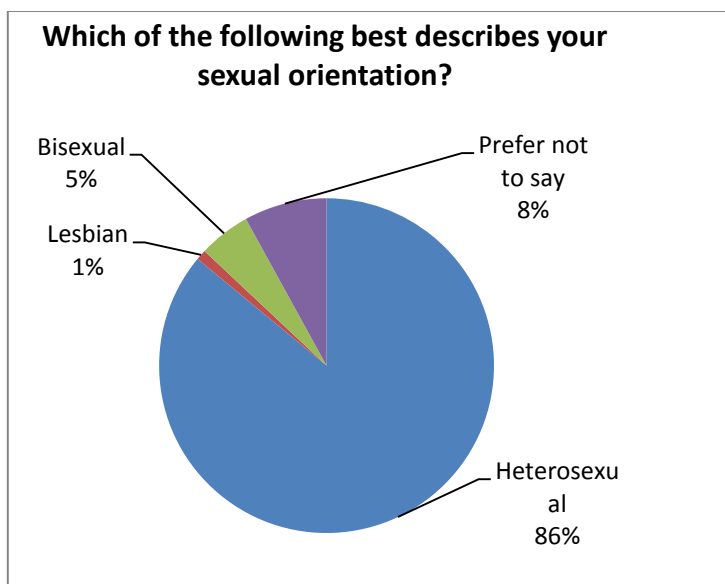
Interestingly a Mencap report - 'Improving pharmacy services for disabled people, their families and carers', found out that *'although negative experiences of pharmacy services are not the norm, a number of barriers exist such as access to information, clear communication, and explanation of the purpose of medicines. The report suggests the use of a wide range of resources that, linked in with important national initiatives, like the NHS Accessible Information Standard, and the rollout of Summary Care Records, could support pharmacists to open up their services to disabled people and improve health outcomes'* ([See Annex 3: Mencap_DP_Pharmacy_resource_v2](#)).

3. Methodology

To gather data and information for this consultation we used an easy to navigate and use online questionnaire which was designed with help from Amaze Database Manager. The online questionnaire had a few questions with 'please select' and 'tick boxes' options and boxes to provide extra information and feedback ([See Annex 4: PaCC_Amaze Survey on Medicines and Pharmacies](#)). The questionnaire was sent to parent carers who are on the Compass Register. We received **67 completed questionnaires** which were collated into a summary ([Annex 5: PaCC_Amaze Survey on Medicines and Pharmacies - Sharedexplore - Public-view](#)) and used to inform this report. Parent carers' contributions to this consultation are reported in verbatim so to better reflect their experiences and comments.

4. Demographics from the online questionnaire



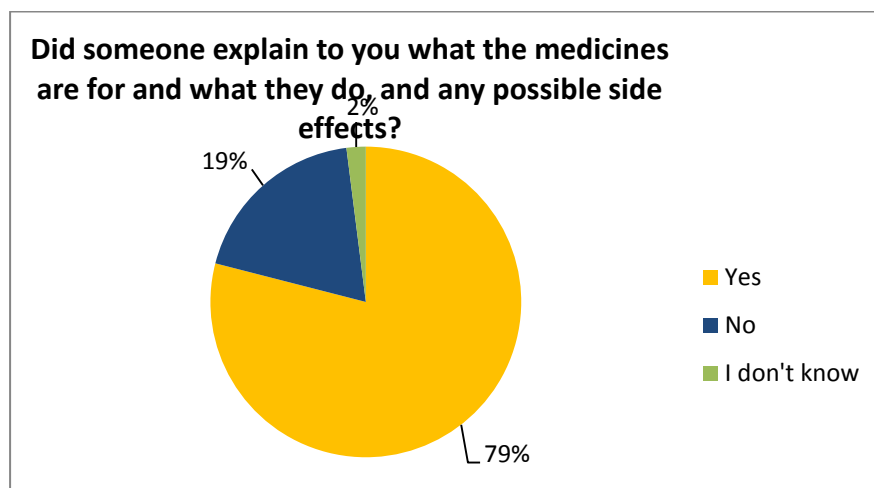


5. Findings from online questionnaire

5.1 Taking medicines

53 respondents to our online questionnaire reported that their child/young person takes medicines while 40 respondents said that they take medicines. Some parents mentioned other relatives who take medicines including eye drops, Sertraline (a medication for thyroid), and Anastrozole and children/young people who take Calpol, contraceptives, Fluoxetine, Celeste and Medikinet.

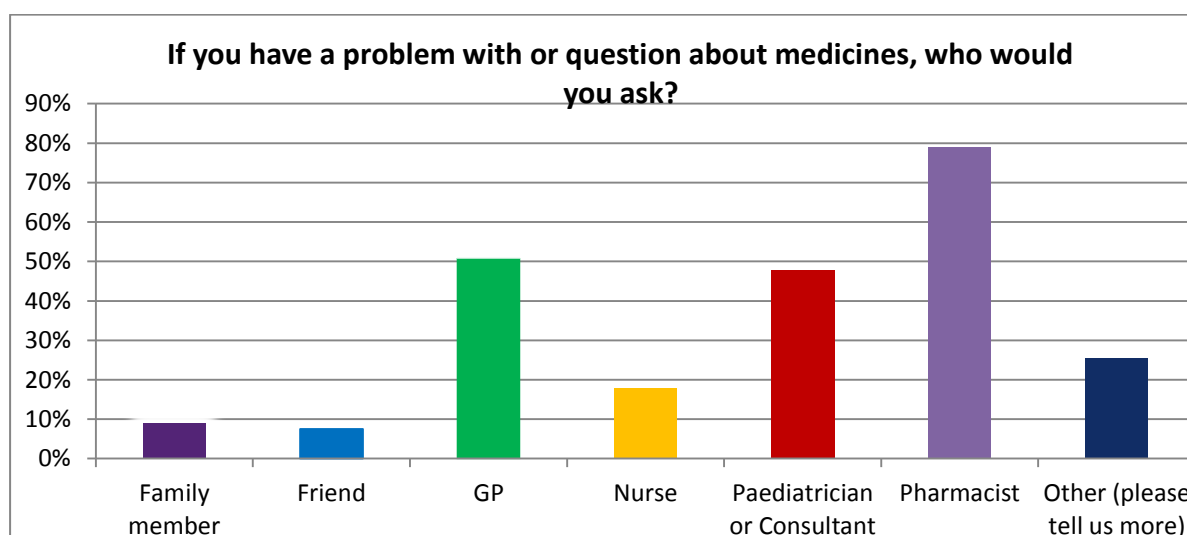
5.2 What medicines are for and side effects



Some parents commented that whilst their prescribing doctor or paediatrician provided information about medicines and side effects they also did some research themselves. Other parents commented that *'some explanations were not made clear'* or *'not all possible side effects though'*. A parent commented *'I have had them explained but not fully and the side effects were minimalised'* and another, who was provided with all explanations, pointed out *'after a very difficult experience regarding a previous medication for our child, and significant side effects, all is now good'*. Some parents and/or their children have complex needs and are on different medications *'It would be good to know when taking multiple medicines which ones interact with others'*.

A respondent commented *'I knew what the medicines were for but no one told me about side effects'* whilst another remarked *'nothing explained'*. One parent reported on the quality of advice received from the pharmacy *'I've had some poor advice from pharmacists and really half-hearted smoking advice, I think leaving private companies to train themselves in medical advice is asking for trouble'*.

5.3 Problems with or questions about medicine

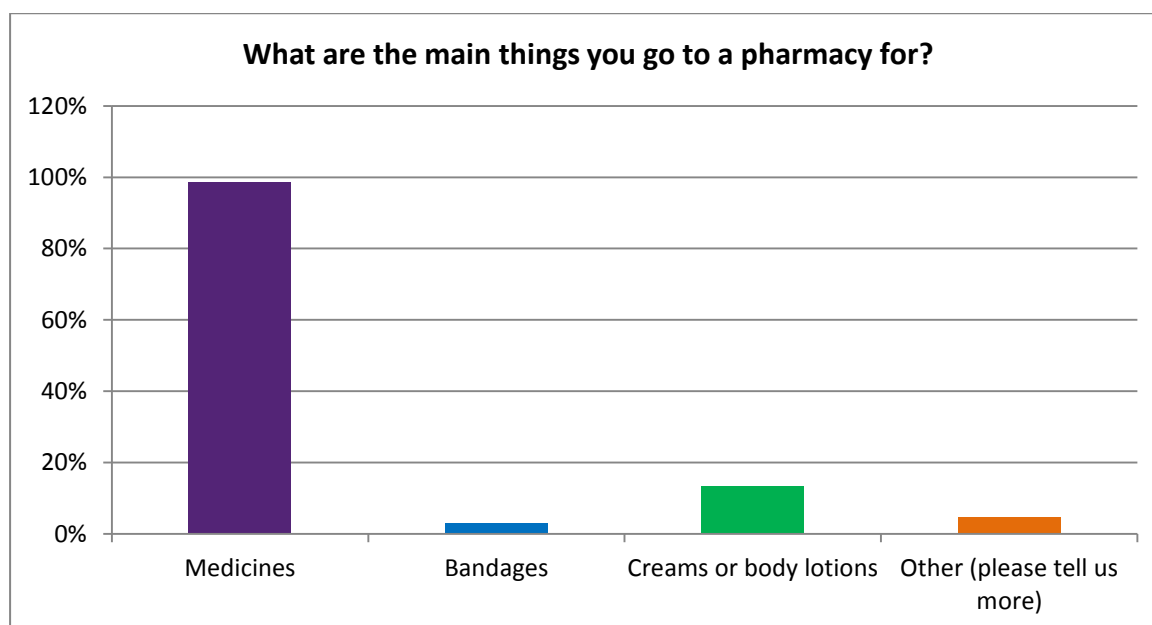


For this question respondents could have chosen more than one person and/or professional. The majority of respondents, **79% felt confident about asking the pharmacist for any additional information about their medicines**. Around 51% of parent carers reported that they would ask their GP but one respondent commented '*Problem often lies with GP - hospital consultant gives details of what needs to be on prescription but GP then does their own review and questions this*'. A similar percentage, 48% would ask their child's paediatrician or consultant.

A smaller percentage, 18% are happy to talk to the nurse, whilst a smaller number, 9% would ask a family member or a friend, 8%. One respondent specified CAMHS' psychologist as a point of information. Some parents would prefer to use the internet and do a search online or consulting online support groups '*I would check online first as reaching my doctor is very difficult*' and another parent commented '*usually feels like no one to ask that actually knows the answer*'.

The data above indicates that most of parent carers who took part in to this consultation have a good interaction with their local pharmacy or feel happy and/or confident to ask a pharmacist more information about the medicines. Nearly half of respondents would ask the paediatrician or consultant as many children and young people are referred to/or supported by them, including getting prescriptions.

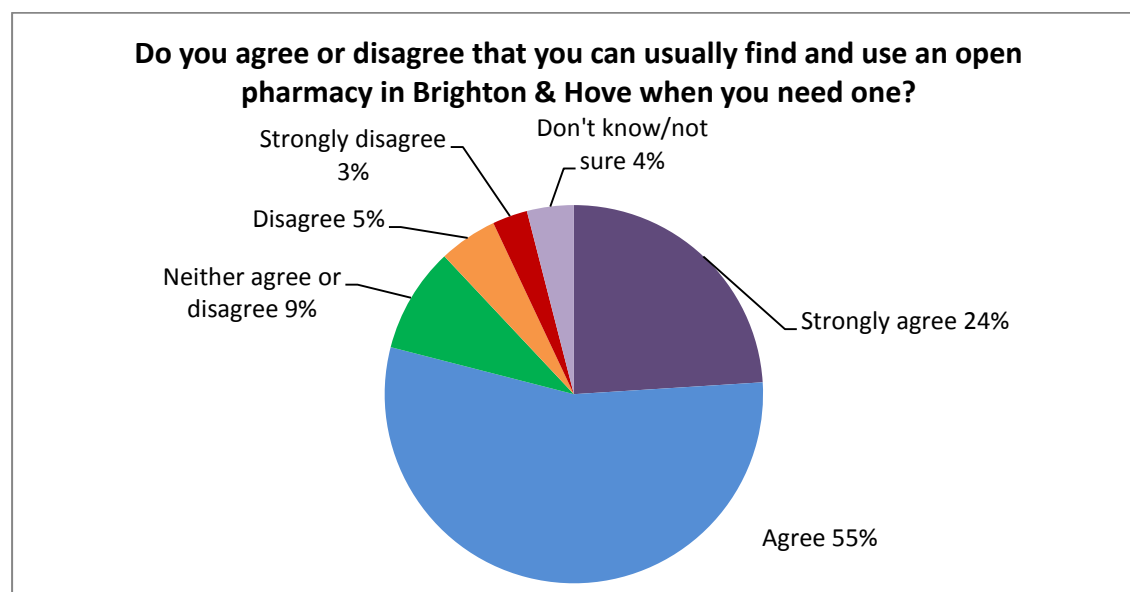
5.4 Using a pharmacy



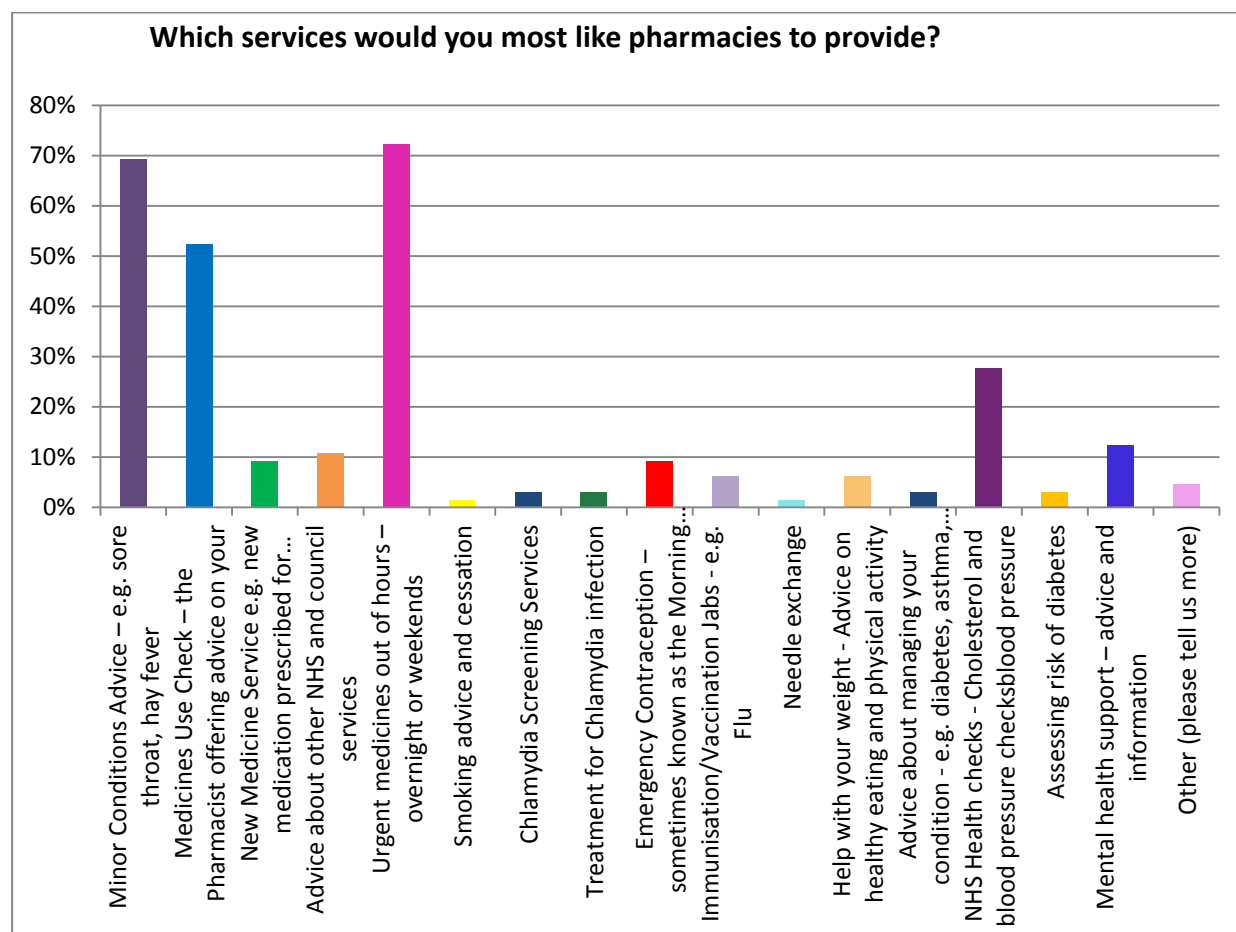
Nearly all respondents to our online questionnaire mainly **use pharmacies to get medicines**. **Only one** parent carer reported to **go to a pharmacy to ask for advice**.

5.5 Access to a pharmacy

The majority of respondents, **79%**, reported that they usually find and use an open pharmacy in the city whilst 8% found difficult to access an open pharmacy.



5.6 Services provided by a pharmacy



Respondents to our online questionnaires mention a wide range of services that pharmacies could provide. The most popular services are **urgent medicines out of hours**, including overnight and weekend, **advice about minor conditions**, like sore throat and hay fever, **check and advice on use of medications and NHS health checks**, as for example cholesterol and blood pressure checks. Among the many services mentioned by parent carers are mental health support, including advice and information, and also advice about other NHS and Council services and emergency contraception, known as the morning after pill.

A parent commented *'My use of the pharmacy reflects that my son's condition (epilepsy) is well controlled so our visits are quite routine - prescription drop off and collection. But I like that the pharmacy does other things as listed above.'*

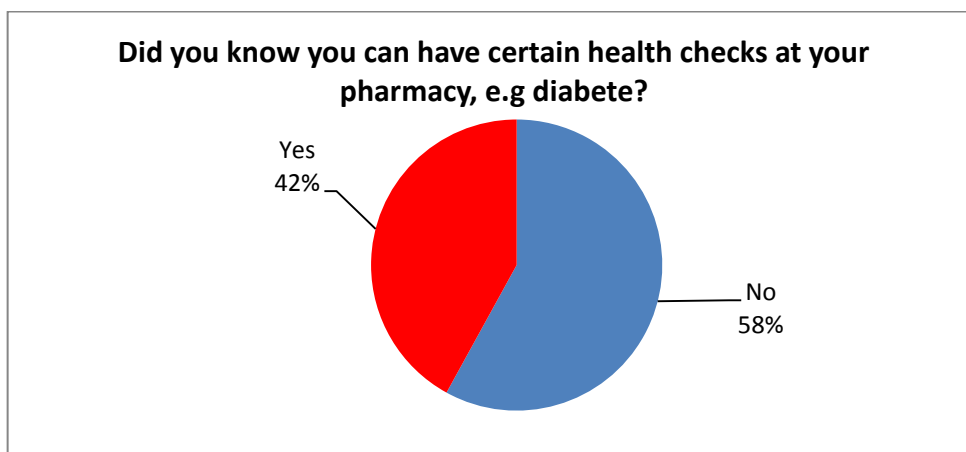
5.7 Pharmacist and review of medicines



The majority of parent carers who participated in our consultation are not aware of the fact that a pharmacist can review and help manage medicines. Within the 60% who responded 'no', there are some contrasting experiences about asking pharmacists to review management of medications, and some confusion. A parent commented *'It seems to depend on the pharmacist how much they want to input when there are medicines queries. Some are really helpful and others just bounce you back to your doctor'* whilst another stated *'I would not feel comfortable taking this advice from a stranger as the pharmacist at my nearest pharmacy changes all the time'* and one added *'not exactly sure what this means or would entail'*.

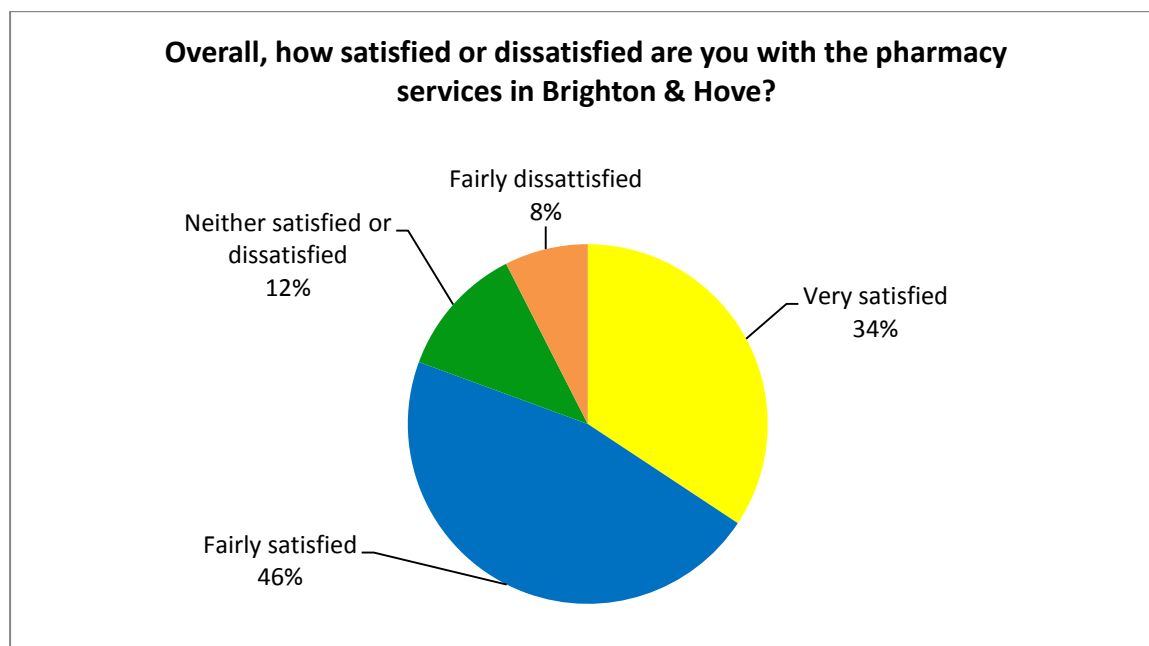
Among respondents who responded 'yes', 40%, one parent commented that *'I usually get told to contact the GP'*, another added *'but in my experience not much help'*. One respondent summarised what probably it is a common situation among parent carers *'I don't ask them as the consultant manages my daughters meds and they are quite an unusual combination. That could put the pharmacist in a difficult position if they have different advice to the treating them'*, a comment reflected by another parent who wasn't aware of possible support from a pharmacist but who also says *'our health conditions are managed by GP or Hospital consultant'*.

5.8 Pharmacy and health checks



Overall the majority of respondents, 58%, were not aware that their pharmacy can provide health checks, a parent commented *'my nearest pharmacy does not make clear what services they offer'*. Among those who responded yes, 42%, one parent carer stated *'I have heard this but not used myself'*. Previous Amaze and PaCC reports have provided recommendations on how health checks should be provided to maximise parent carers and their young adult's attendance. Ideally those recommendations should take in to consideration in relation to pharmacy providing that service (*See Annex 6 Parent carers and Health Checks and Annex 7 Transition - report*).

5.9 Satisfaction with pharmacy services



Whilst the majority of parent carers, 80%, are satisfied with pharmacy services in the city, 8% reported to be fairly dissatisfied. A very satisfied parent carer commented *'Boundary Road Boots are excellent!'*. One respondent was caught with the merging of some GPs *'System works well until there are changes of staff, or, as recently, happened the GP'*

practice merged with another and moved and then chaos with ordering and getting prescriptions ensued!.

5.10 Alternative remedies

7 parent carers out of 67 prefer to take alternative remedies or not to take medicines altogether when they feel ill. Specifically one respondent relies solely on acupuncture, one on doing exercise and restricting sugar whilst another one eats chocolate, cookies, drinks tea and water and uses tissues! Another respondent takes herbal remedies whilst another one takes vitamins and homeopathic remedies. And finally one respondent reported to rely on friends and family.

5.11 How to make the use of medicines more effective

The **management of repeated prescriptions** is one of the main issues facing parent carers either for themselves or for their child if they are taking medicines regularly. A parent observed that *'A lot of the time my local pharmacy do not have my daughter's regular medication. I have to wait days or go around the city looking for the medication. I get a refill every 3 weeks'*.

Some respondents reported **problems and delays with getting prescription from GP to pharmacy**. One parent described *'It is difficult to get repeat prescriptions reliably. Often have a communication breakdown between surgery and pharmacy. Special medicines take ages to order and surgery staff don't always get that you need to order it before it runs out'*. A parent commented *'It is difficult to keep repeat prescriptions going without gaps. Communication between GP surgery and pharmacy is bad, often resulting in a few days without meds. The only way to avoid this is by constantly checking and chasing things up - which is a difficult process to do every month'*.

Many parent carers are disabled themselves and live on low income and managing repeated prescriptions becomes detrimental to their health *'the system of receiving my medications from my nearest pharmacy is problematic although they do a prescription collection service it is not guaranteed to always have my medication ready when I need it and I am often pushed between the pharmacy and the doctors surgery to try and get my medications on time - there has been several occasions where I have been left without vital medication causing my health to suffer and deteriorate - being currently on PIP I have to support my son who has Asperger syndrome while he is in university and paying for medicines when he is ill is a huge strain on my finances yet no one appears to be able to give definitive information as to what financial help might be available for when he does need medicines'*

A parent carer suggests a **better system and improved communication between GP and pharmacy** *'Getting the prescription from the drs to the pharmacy can be tricky - often seems to go 'missing' and I have to chase it and re-request. Would be helpful to be able to get 2mths worth at a time as I have 16 repeats to manage and seem to be constantly at the pharmacy. If the pharmacy request a med from the gp and it is refused for whatever reason,*

*they don't seem to get told, so they tell me to wait another week, and then I discover it's been refused and I need to phone up the drs and find out why, which causes a lot of delay in getting the med. The doctors surgery tells me to allow 2wks to get a repeat, so trying to manage 16 all due at different times gets complicated. The system seems rather ad hoc and I'm surprised we don't run out of meds more often. I have to be constantly on top of it to keep up'. However the idea to get **medicines for long period of time and their disposal** is criticised by another parent 'There is a great wastage of medicines. Often several months of a medicine is initially prescribed. It maybe proves to be unsuitable for one reason or another. When returned to the pharmacy, the unused medicine, even if it is sealed and unopened, is then destroyed'.*

One of the respondents to our consultation reported of their pharmacy is doing a **good coordination of complex prescription management** 'My daughters medication is partly provided by RSCH due to funding changes. This is much more inconvenient to us as we now have to travel further to collect them and there are lots of queues at pharmaceutical at sea. The rest is on repeat. Our GP is quite unhelpful and rigid and we have to coordinate letters ourselves between the hospital and him. Our pharmacist is really helpful in coordinating so this, helping us when we run out and generally trying to make it smooth'.

Quality of information and advice from pharmacy and also **issue or confidentiality and privacy** are highlighted by a parent carers 'pharmacies make too many mistakes and then you end up without meds. Horrible the way you get treated when you go in for ADHD meds. They keep the controlled meds separate and sometimes you end up having to direct younger or newer staff to identify your prescription as "controlled meds" as they don't check. There have been times I have had to shout my condition or medication across the room so everyone hears. They are not confidential about anything. Also you get given the wrong info when you are trying to manage controlled meds. You ask a general question e.g. "can my meds be arranged from my GP by fax?" and they will give you the easy answer (yes no problem) rather than telling you there are certain meds you can't collect in this way and you have to collect the prescription in person from the GP. In fact, some of the staff are not even aware of this and give you completely wrong info'.

A respondent pointed out that 'lots of pharmacies now are only doing branded products and not selling generic products to customer over the counter unless via a prescription'.

6. Recommendations

- **Pharmacies to provide more information and advice about possible side effects due to interaction between different medications**
- **Pharmacies to improve the quality of information and advice about medications, and to also include advice about paying for prescriptions if on a low income/benefits**
- **Pharmacies to provide some sort of confidential and private space and to offer this if a customer seems to have a question**
- **To avoid gaps in repeat prescriptions, pharmacies to stock more supplies of medicines that might be needed regularly or on repeat – or to have a system which can predict when their regular patients' repeat medicines might be needed so these can be in stock when someone needs it**
- **A city wide awareness campaign around services that can be accessed at pharmacies. If this is agreed to ensure to ask a group of patients to help input to the campaign so it is well targeted at users of the service**
- **A better system for the management of repeat prescriptions – can this be better automated somehow? Can patients be provided with medication for a slightly longer period e.g. 6 weeks instead of 3 weeks and offered support to diarise (on their phones for example) when medication should be taken/ when it will run out etc. There are probably some phone 'apps' to help patients manage medications/prescriptions – could pharmacists offer advice/support with using these?**
- **As with most topics, it's clear that communication between the different agencies (Hospital, GP, consultant and pharmacy) can still improve at times.**

7. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: Medicines Optimisation

Annex 3: Mencap_DP_Pharmacy_resource_v2

Annex 4: PaCC_Amaze Survey on Medicines and Pharmacies

Annex 5: PaCC_Amaze Survey on Medicines and Pharmacies - Sharedexplore - Public-view

Annex 6: Parent carers and Health Checks

Annex 7: Transition - report