healthwatch Tower Hamlets

Patient and User Voice Summary Report

August 2013 - September 2014





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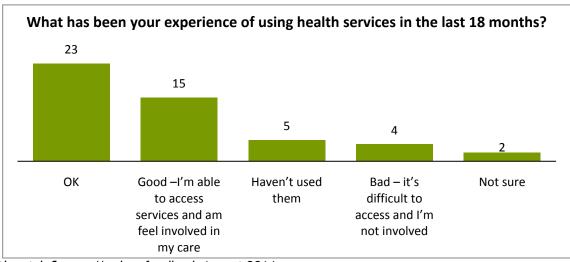
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1. EXECUTIVE SUMMARY

1.1. People in Tower Hamlets are generally satisfied with the services that they receive



Healthwatch Survey Monkey feedback August 2014

- 1.2. Where people were not happy with their care, it generally did not relate to the care itself, but was a frustration with the administration and processes that surrounded the care and/or because of the perceived attitudes of staff.
- 1.3. There seemed to be a multitude of points in their care journey where the system failed patients and users including:
 - accessing a GP appointment
 - getting a referral from the GP to secondary care
 - receiving the correct appointment information at the right time
 - being able to change appointments without being sent back to the GP for rereferral
 - patient transport getting them to their appointment in time so they didn't have to go back to their GP for re referral
 - being able to find the clinic or ward they were attending
 - being seen promptly when they were at their appointment
 - the right medical notes/information/tests being available to clinicians at their appointment
 - actually getting into the operating theatre as operations are being cancelled or postponed at the last minute
 - waiting hours in the discharge lounge for a prescription to be filled after being discharged
 - arriving home again without necessary links to the district nurse, reablement, home adaption's or social care and mental health support packages in place.





1.4. There is a perception in some areas of staff being too few, being unhelpful, uncaring and unwilling to signpost. Some patients feel that staff are equally frustrated with administration problems and are either taking this frustration out on patients or using it as an excuse for a poor patient service. There seems to be a particular issue with receptionists from across providers. The quality and availability of interpreters was also a frequently raised concern which seemed to exacerbate stress and/or medical conditions.

I have been waiting to have a gallstone operation for one year, when I finally got an appointment and booked my place for day surgery, I received a call to say that they needed to change my appointment due to it being double booked. Then when I got the confirmation appointment through the post, it was on a date that I did not agree with when the lady called to cancel. Finally when the surgery day arrived, I got there at 6.30am. At 7am the nurse told me that they cannot find me on the list and therefore I cannot have the surgery as they have too many patients. After two weeks, I got a letter home to say I missed my appointment (which I did not as I didn't receive a letter in the first place) and that they have discharged me to my GP. Now I am waiting again for another referral to be made so I can get my gallstones out and go for the process all over again. I find the process really bad, and I was angry and disappointed, frustrated about the whole thing. (Female, Bangladeshi - Barts Voices, Stifford Centre)

- 1.5. Patient experience also seems to be heavily influenced by expectations and there appeared to be a 'domino' effect in the sense that when one element of care went awry, such as transport services, waiting for appointments or perceived rudeness, then it appeared likely that the whole patient experience became negative. We need to get a better understanding of the process that dictates experiences and the extent to which 'expectations' are dependent on demographic or other factors.
- 1.6. These process issues not only lead to poor patient experience but patients feel they are wasting valuable NHS resources which they are being told are scarce.
- 1.7. There is an evident demand for more 'individualised' care particularly with reference to 'older people' and families with children. This also needs to be linked to better communication both directly to patients but also between primary and secondary care and between different departments.
- 1.8. Clearly we need to see a radical improvement to the administration and appointments systems alongside training/re training of staff on providing a patient focused service. We would also like to see measures in place to monitor whether improvements are having an impact on patient experience outcomes.





- 1.9. More in depth work is required to understand the:
 - patient journey and the nature of the need for 'support' services within provision particularly for the elderly and the young.
 - 'expectations' and the determinants within that including demographic factors
 - 'quality care' among different cohorts of patients and the factors that contribute to 'good' care
 - experiences of those groups who appear underrepresented in our work todate e.g. Eastern European groups and sub-groups, Somali's

2. INTRODUCTION

- 2.1. A core function of Healthwatch Tower Hamlets is to obtain the views of local people about their need for and experience of local care services and make those views known to those involved in the commissioning, provision and scrutiny of care services.
- 2.2. This report summarises key themes that have emerged from the patient and user views gathered by Healthwatch Tower Hamlets during 2013-2014. These views were gathered through the following activities:
- 2.3. Barts Health Patient Voices Project: This project was designed to enable local community groups to collect patient feedback on behalf of Healthwatch. The feedback obtained focused upon the services of the Royal London Hospital, Mile End Hospital, the London Chest Hospital and Community Health Services all of which come within the remit of Barts Health. The Project took place between March and August 2014 and involved the following community groups. Full details are available in the Appendices.
 - Limehouse Welfare Association (LWA)
 - Tower Hamlets Friends and Neighbours (THFN)
 - Collective of Bangladeshi School Governors (CBSG)
 - Stepney Wisdom Group Social Action for Health (SAFH)
 - Globe Wisdom Group Social Action for Health (SAFH)
 - Stifford Centre
 - Deaf Plus
 - East London Vision (ELVIS)
- 2.4. Enter and View visits which have taken place on a regular basis over the past year. Healthwatch Tower Hamlets Board members are responsible for agreeing the Enter and View programme and take into consideration:
 - Concerns raised by patients and the public
 - Areas currently the subject of service redesign or re/de commissioning
 - Joint Strategic Needs Assessment priorities and gaps
 - Services from across the physical and mental health and social services. (full details of each visit can be seen in the Appendices)
- 2.5. General Community Feedback
 - General outreach at community events and gathering points





- Members' feedback via attendance at Advisory Group and other Healthwatch meetings
- Responses to online questionnaires
- People who phone or come into the office for information and signposting to services (a full database of comments collected can be requested from Healthwatch)

Please note that there is a fuller version of this report that includes more detailed user feedback as well as enter and review reports and survey information. Please contact info@healthwatchtowerhamlets if you would like to be sent a copy.

3. KEY THEMES

- 3.1. All comments were collated and explored for key themes and patterns in preparation for this report. It is important to note that the methods of collection and methodology of each piece of work varied. Full details of each source and the methodologies used can be requested from Healthwatch and it would also be possible to browse through the entire comments database if requested.
- 3.2. There were, similar to last year, key themes that emerge from the range of comments across the sources. The data is organised by life-stage and subsequently by themes. Interestingly, almost all of the themes cut across life-stages. Certain issues relating to GPs, Dental Surgeries and services for those with complex needs as well as those with mental health issues have, where appropriate, been discussed separately within the section on Adults

4. UNDER 5s AND CHILDREN

- 4.1. It was clear that at one level there was great appreciation of the services that were received by families.
 - My son is two years old and had been having tonsillitis problems for over a year now. So then he was referred by our GP to the RLH to get his tonsils removed. As we arrived at the children's department for pre admission the receptionist was welcoming and helpful. The environment was very child friendly. We didn't wait long before we were seen by a doctor. After he explained the procedure of the surgery and reassured us that it would be ok and sent home after a few hours. The doctor gave us opportunity to ask questions that was very important for us. We asked is there a possibility anything going wrong. The doctor gave us some leaflets for us to read through. It feels good that we had met the doctor before surgery it is very reassuring and made us feel that our son would be in safe hands. I believe that the children service is at good standard and does not need improvements (Parent of Female, Bangladeshi Barts Voices Project, SAfH)
- 4.2. However, in some cases, the actual care appeared to be questioned;
 The appointment letter came very quickly and she was seen in the Clinic by an Ophthalmologist. Prior to seeing an Ophthalmologist she was seen by Nurses





to have drops in her eyes in order for tests to be carried out. Considering they are working in a Children's Department I expected them to be more understanding and reassuring towards children. My daughter was afraid to have the drops in and they were rushing me to hold her down as there were other patients waiting. They did have to hold her down as the eye drops causes stinging she was struggling to get free. I just feel they could be more welcoming and reassuring towards my daughter so she wouldn't feel afraid, same goes for all children. The tests were done quickly although the waiting is a very long time. The Ophthalmologists are lovely; very welcoming and always spoke to my daughter regarding her care and problems. They do a brilliant job. The nurses could be more considerate and understanding towards my daughter. The waiting is far too long (Parent, Female, Bangladeshi - Barts Voices, Stifford Centre - Opthamology)

4.3. It appeared that a recurrent problem was the lack of information given to patients and poor communication.

The Consultant called us through and I sat and briefly explained the problem. The Consultant very quickly looked down my son's throat and concluded that he will need a tonsillectomy. I was given a leaflet to go home and read about tonsillectomies and the whole consultation lasted for no more than 5 minutes. I was very shocked that the consultant had reached a conclusion without doing any form of examination. Though it is only a tonsillectomy, it is still an operation that carries risks just like any other operation. It seemed strange that the consultant reached such a drastic conclusion without actually examining my son or carrying any other tests to see if there was an alternative that we could try first. So I would like to have seen a thorough investigation on my son before giving the option of an operation. Secondly I feel that the Consultant should have spent a few minutes explaining the procedure and the risks to me and even answer some of the frequently asked questions, rather than just giving me a leaflet to read at home. A tonsillectomy may seem like a trivial thing to a medic but for me and my child it is still a big deal (Parent of Male, Bangladeshi - Barts Voices Project, SAfH)

4.4. At times, there was also evidence of poor communication between primary and secondary care:

My son had been complaining of consistent migraines that I had gone and seen my GP about. My GP referred us to the hospital for a CT scan. When we went to the appointment the consultant refused to do a scan on the basis that the GP had failed to provide sufficient information. I had taken my son out of school and felt that the day was a waste of everyone's valuable time. We then had to go back to the GP who wrote another letter explaining in full why my child needed a scan. We then had to wait a fortnight or so for another (Parent of Male, Bangladeshi - Barts Voices Project - SAfH)

4.5. Often, too, a good number of the difficulties families encountered tended to be those that involved administration including the often long waiting times to be seen by a medical professional both in planned and in unplanned care. Further, when there was a hold-up, staff were seen, at times, to be particularly unhelpful:





I was quite disappointed with my appointment as this was the second time they did not have my child's files. We were waiting for over an hour where our appointment was at 9:15 and did not get seen until 10:30 because they could not locate the file. When they finally did see me, there was no apology or anything. If I was late for an appointment, they wouldn't have seen me. Prior to my appointment, the files etc. should have been located and ready for me to be seen on time. In general, the waiting room was tidy and clean. The receptionist could have been friendlier; but that's the usual with hospital receptionists - not approachable and communication skills are poor. (Parent, Bangladeshi - Barts Voices Project, Stifford Centre - ENT Department)

4.6. In addition, staff were also often considered to be unhelpful, particularly when directing patients appropriately:

I received my child's appointment through the post after my GP referred us to the ENT department. My son was suffering from tonsillitis that several doses of antibiotics had not cleared up. Once I got to the RLH I found that the ward was not sign posted and I didn't know which lift to take. So I went to one of the reception desks on the ground floor. I was directed to a lift and told to go to the 6th floor. In order to get to the correct lift I had a long walk with a child that didn't want to come to the hospital and was dragging his heels. When I got to the 6th floor the receptionist told me that I had come to the wrong place. I was then directed to the 7th floor. By then I had a child that was screaming and I found that all of this was very stressful and unnecessary had the place been well signposted (Parent of Male, Bangladeshi - Barts Voices Project, SAFH)

4.7. There were also criticisms of the environment in which families found themselves and the facilities available:

The clinic itself is quite small, not enough seats for so many people who were waiting with their children. There were two or three toys and a TV. The clinic was clean and tidy which I liked... If there aren't enough seats to provide for patients to sit down in the clinic surely something must be wrong; either too many people are booked in or they need a bigger clinic with more doctors (Parent of Female, Bangladeshi - Barts Voices, Stifford Centre - Opthamology)

5. YOUNG PEOPLE

- 5.1. Once people move into the next 'life stage', it appears one of the largest difficulties became waiting for appointments and the long waiting times. A number felt that this was due to inadequate staffing

 The reason they gave me as to why I had to wait very long time that they were understaffed. I was not very happy with the service because I feel due to the shortage of staff there is often a lack of appointment slots available that delay my child's follow up appointments (Male, 16-18, Bangladeshi Barts
- 5.2. More pertinently, long waiting times, not simply for appointments and waiting to be seen but equally for prescriptions, gave the impression of a lack of care for patients

Voices Project, LWA, Orthopaedics, Royal London Hospital)



I found it extremely difficult to get an appointment - I had to wait one month. The doctor explained my current health state to me very well. Staff attitude overall was good but the nurses were a little rude which I recognised when they answered my questions. As a suggestion for an improvement I would say that there should be more appointments available so there would be more convenient dates and nurses need to be given more training on patients' care (Female, 19-21, White British - Enter and View A&E)

- 5.3. This could also be exacerbated by staff who were perceived as being rude and simply uncaring. One mother described how she had gone to A&E with her son who had cut his hand. Her GP's receptionist advised her to go to A&E but, on arrival, the triage nurse had been rude and dismissive assumingly because it was an unnecessary visit. Another young woman described her visit to A&E in the following terms:
 - Staff attitude overall was good, but the nurses were a little rude which I recognised when they answered my questions, when I asked a receptionist when will I be seen by the doctor he replied saying "I do not know, the doctor knows" in a very ignoring manner (Male, 19-21, Bangladeshi Barts Voices Project, CBSG)
- 5.4. Perhaps a more important and underlying issue was that diagnoses appeared to have been slow for a number of patients who had less common conditions. My 15 year old son suffers from a condition known as Overlap Multiple Syndrome. Initially the GP ignored his condition and as a result of poor care he had to go into accident and emergency on several occasions. Then when his health started to further deteriorate and worsen he went into A&E again and was hospitalised for a few months. He had to pass trauma and stress, and mentally suffered. GPs and doctors often initially said his health was nothing of a concern; they didn't really pay much attention to his symptoms I think doctors should be more prompt in getting to the root of the problems, taking full body checks rather than just prescribing medicines and dismissing the conditions, symptoms and patients concerns. I am overall unhappy with overall service my son received as his diagnosis was delayed. The catastrophic journey he passed is unforgettable and we strongly suggest the professional should look into the issue earlier rather later to save patients life (Parent of 13-15 year old, Male, Bangladeshi - Barts Voices Project CBSG)
- 5.5. The issue of interpreters also arose:

I often accompany my son to his appointment as he is under 16 and usually I speak on his behalf regarding his eczema, however as I cannot speak fluent English I require an interpreter but there are usually no interpreters available and this means the quality of the service is poor and the lack of communication with the doctor could affect my son's condition in some ways (Parent of 13-15 year old, Male, Bangladeshi - Barts Voices Project, LWA - Dermatology)

5.6. But for some the care was good:

Access to information regarding treatment is excellent - I can contact my doctor or specialist via phone to ask any questions or discuss any concerns I





have fairly easily (Female, 16-18, Bangladeshi - Barts Voice Project, LWA, Epilepsy Sufferer)

6. ADULTS

6.1. A striking feature of the comments collected with regard to the 'adult' life-stage was that there was a lack of consistency within a patient's journey often leading to unfulfilled expectations and dashed hopes. The following comment refers to a labour experience but it reflects the sense of dissatisfaction, evident in so many experiences and journeys, that appears to have been caused by the lack of consistency in what seems to each individual as 'good care'.

I gave birth at Royal London six months ago. I was very disappointed in the consistency of the care I had throughout my labour. It is worth noting that the rooms and facilities were great and many of the staff were professional and supportive especially the trainees. However, I was truly shocked by some of the staff whose care I was under. I had one midwife who was extremely rude and made my birthing experience become quite negative. She did not introduce herself or ask how I was feeling at any stage. She did not explain why I had to be connected to the monitor for so long (2.5 hours when it should be a half an hour) which prevented me from sleeping. She laughed at my birth plan and when I asked for toilet paper at 2am she said 'That's not my job'. My partner had to source it from another room and leave me during the labour. I asked for paracetemol as pain relief and it wasn't received until after two hours. There was no explanation for this, it was merely placed on the tray. I felt extremely nervous and vulnerable as a new mother once I was in the care of this person. Up until then I was treated very well and felt confident. I broke down in tears when the doctor came in in the morning and explained to them what had happened. She said that she was not surprised to hear that as I wasn't the first woman to complain about her. It really shocked me that someone known amongst their colleagues to be incapable of being a caring professional was working with women in labour. I refused to take a second round of induction gel because I did not trust the woman who made me feel so bad to put her hand inside my body. You might appreciate that this also dragged out my whole labour and subsequently affected my decision making after as I had not slept the whole night in her care.

After the birth I had absolutely no help and was thankful to have my mum and partner there as I had had an emergency c section and was unable to leave the bed. Any time I rang the bell I waited for so long and nobody offered to help. The staff seemed to busy filling out paper work. One nurse even said that she then had to enter the notes into a computer system and was complaining about doubling the work. The advice I was given too with regards feeding my baby and dressing her etc was all conflicting. This advice was also only given when I asked for it having nearly given up on breastfeeding. Some medical professionals should clearly not be working. However, there were some fantastic staff and I had two student midwives who were absolutely lovely and made me feel a lot better than their more experienced colleagues. (Female, 26-30, White Other - Survey Monkey Feedback)





6.2. Further, when patient journeys did not run smoothly, it appeared that the problem was not simply that there was inefficiencies with appointments but that there was a far more systemic issue and the cases below did not appear to be isolated ones

In my experience waiting times have been a nightmare- when arriving early for appointment and still not seen on time especially when being penalised if you're five minutes late you would think they would give you the same courtesy in return. The waiting area is too 'intimate' for my liking and at times stuffy. I don't want to leave with more illnesses than what I first came in for! Accessing interpreting services can be difficult. When getting in touch with the advocacy service it can be a long wait before getting any confirmation. Reception staff to organise advocacy services and should be their doing. They should be more flexible with their time especially when there's a long wait for the next appointment. They need to look at quality of care across the board rather than people feeling like a statistic they need to do away with as soon as they get through the door. Receptionists should be more friendly and be trained to speak to patients in a nicer way as they are the first point of contact whether face to face or over the phone. I've found a lot of the receptionists to be guite cold and patronising especially when speaking with people who don't speak English fluently- talk about the lack of training in taking the non-judgemental approach! (Male, 33-40, Bangladeshi -Barts Voices Project, Stifford Centre - Diabetes Screening)

6.3. It was thus notable for patients when everything appeared to run smoothly as it had for these patients:

I have been registered with this practice for the past twenty-two years and generally very happy with the service and treatment I get here. This is my first visit after a two year absence. I am happy with the way the receptionist spoke to me over the phone and also very happy that I was offered an appointment within two days of making the call. In the past I was always happy with the way the dentist explained the treatments and costs and I hope that this will the same this time around. I find the environment friendly and welcoming and receptionists are also friendly. If I need interpreting support the frontline staff always offer to help. (Female, Bangladeshi - Abbey Dental Practice, Enter and View visit)

All the care we received in A&E was good. The Doctors were efficient and informed us of what they were doing and if it didn't work what they would do next (Female, 51-59, Bangladeshi - Barts Voices Project, SAfH, Eye Clinic, RLH)

X is my main Consultant. Over the years I have built a good rapport with him. I find that he is welcoming; he always greets me and calls me out by my name. He explains in simple terms what is happening to me and how my treatment is going. My Consultant contacts me directly by phone or email to inform me of test results and any changes in my medication. I feel that he trusts my judgement and is willing to try what I suggest. I have an open relationship with him and feel free to speak my mind (Female, 41-45, Bangladeshi - Barts Voices Project, SAfH, Renal Department)





- 6.4. As with all other categories, the seeming lack of appointments and the long waiting times to be seen were an issue. Low numbers of staff were frequently seen as a key factor.
 - I visited the Bethnal Green chest hospital on the 14th of April due to my heart problem. I did not find booking this appointment very easy and had to wait over two weeks for it. I had to wait very long to be called by the doctor which was very disappointing and I had to go in to work a little late. I booked for interpreting services and was given an interpreter but not all the times are interpreters available (Female, Bangladeshi Barts Voices Project, LWA)
- 6.5. From the present evidence, this seemed to be a particular issue with A&E: My experience at the RLH (A&E) was really outrageous. I went to the emergency department as I had an agonising pain in my fingers. I went in at 9pm and left the department by 3am in the morning. The waiting time was so long I was in pain frustrated then told by the receptionist that there were only two doctors available. I would suggest to have more doctors at night duties or have them on call if it is really busy to reduce waiting time (Male, 31-35, Bangladeshi Barts Voices Project Stifford Centre

I was taken by ambulance to A&E at 11pm and was finally seen by a doctor at roughly 4am. When I asked why there was such a delay the receptionist said that there are many patients to be seen however there were hardly any - only me and another 2 people. There was also only one doctor on shift and I don't know whether this was because it was night but it is truly disappointing as people come to A&E for emergencies and it is not good if there are no medics and doctors to treat them and see to them (Male, 41-45, Bangladeshi - Barts Voices Project, LWA)

- 6.6. Delayed appointments were also perceived to have adverse effects on the patients' health:
 - But to have the tests sometime it was very difficult for me to get an appointment. Due to this many of my appointments were delayed. Also the delay to my diagnosis had adverse effects on my health (Male, 46-50, Bangladeshi Barts Voices Project CBSG)
- 6.7. Not surprisingly, frustration with GP surgeries in trying to obtain appointments was equally common and this seemed to be an issue with most surgeries:

Getting an appointment is difficult; recently they have changed the appointment system, now you have to call the surgery and the reception staff takes your details and then gets a nurse or a GP to call you back, it's a hassle as you have to wait around for a long time before someone calls you back...on the last occasion when the GP called back she decided that I did not have to be seen urgently, however I felt I needed to be seen sooner... the previous 'walkin' system was also not very good as there was long queues that could go outside of the practice and by the time you got to the front of the queue all the appointments would be gone. I would prefer if they just had a traditional appointment system where you just call in and speak to reception staff and they offer you an appointment. Also it takes forever for the surgery to pick up





the phone, on the last occasion it nearly took 25 minutes. Female, 22-25, Bangladeshi - Enter and View visit, Harford Health Centre)

It can be quite difficult to get an appointment here, usually 3-4 days. If it's an emergency, you can request for a telephone consultation and the doctor calls back you to assess if you should be seen and offers an appointment time and date. I called in today and requested an emergency appointment; the doctor called me back within 20 minutes and offered an appointment for today (Male, 31-35, Other - Enter and View visit, Wapping Health Centre)

6.8. Adapting to a new appointment system additionally seemed to cause problems for patients.

I don't like this new triage appointment system, even though I spoke to a nurse on the day I called in, I was offered the appointment two weeks later (which is today), also we had to wait the whole day for the nurse to call back, we would have preferred a time slot for calling back. We would like a normal appointment system where receptionists can offer appointments and also we would like to be seen within 2-3 days. .. My husband waited 1.5 weeks to get an appointment, when he turned up, they told him that there was no rooms available for doctors consultation, although there was a doctor there was no rooms available for him to see patients...how strange...they said he had to make another appointment, but reception staff refused to offer him a new appointment and said my husband had to call back...he was very upset as he had waited a 1.5 weeks to get this appointment and take time off work and through no fault of his own they decide to cancel the appointment, but on top of that they refused to offer a new appointment... after a bit of arguing with the receptionists about all this, the nurse came out and offered him this appointment (Female, 31-35, Bangladeshi - Enter and View visit - Harford Health Centre)

I don't like the new appointment system of calling back; sometimes you can wait for ages before you receive the phone call by the doctor. I prefer the old 'walk in' system; it was much faster in the sense of getting to see a doctor sooner. (Female, 22-25, Bangladeshi - Enter and View visit - Harford Health Centre)

6.9. Some patients related the difficulties with appointments to potentially unnecessary A&E visits

Getting an appointment at this surgery is very difficult, it seems like they are not bothered or care about patient's wellbeing. I don't feel it's right that a doctor should decide whether you should be seen by talking to a patient on the phone, not everyone can explain things properly, then there is also language issues...also it takes a long time to get a call back i.e. 5-6 hours and when they finally call you, they offer you an appointment after two weeks...this is the reason why some patients end up going to hospital or A&E (Male, 31-35, Bangladeshi - Enter and View visit, Harford Health Centre)

6.10. It was also extremely frustrating for patients across the system not to be able to contact the relevant people.





I was referred to the physio department by my GP for my back. The timing of the appointment wasn't suitable, so I called the department. The receptionist stated that if I wanted to reschedule they don't have any appointments till a few months and they are fully booked. She informed me that I wasn't able to book two months in advance anyway. The receptionist also informed me to keep the appointment and phone closer to the time to re-arrange. Furthermore, she added that if I cancel the appointment I will be taken off their system!! Closer to the time of the appointment, I called the department but no one picked up. For that whole week, not one person picked the phone up. I sent an email to address my issues but haven't heard from anyone to hear of rescheduling of the appointment. It's been 6-7 months!!!! I now have to wait to be referred by the GP AGAIN and wait to hear from them Of course!!!!!!! There has to be an efficient and effective service. One should be able to re-arrange their appointment without having to be discharged!! (Female, 31-35, Bangladeshi - Barts Voices Project, Stifford Centre)

6.11. A further view was that text messages were just not appropriate for contacting patients and it was suggested that an appointment system that could be accessed on-line might work well.

I wasn't happy with the text message reminder sent. It has no detail as to where or what department the appointment is for. It also does not state the name of the patient. This is confusing for myself as to whom the appointment is for myself or my children. And also I am under treatment for several appointments so how would I know whether it's for example a physio or dermatology appointment. In order for the text message to be helpful it needs to include; patient's name and department for the appointment as well as times (Female, 31-35, Bangladeshi - Barts Voices Project, Stifford Centre)

6.12. Cancelling, particularly, at short notice could also be highly problematical for patients

I had an appointment before Christmas, and they cancelled this appointment on the day of the appointment, apparently the thing that needed to be placed in my teeth had not been delivered...this late notice was a problem for me as I had taken some time off work to attend the appointment, I feel they could have told me this information the day before and I could have gone to work. Furthermore they did not make me another appointment, I had to chase them up to get this appointment...I feel if they cancel an appointment they should take the initiative to make another appointment for patients. Also staff should look at patient records the day before appointments to make sure everything is in place for the next day, if not, this will give them an opportunity to notify patients earlier about any cancellations... (Male, 31-35, Bangladeshi - Enter and View visit, Abbey Dental Practice)

After a long wait we were given an appointment in May but then we received a letter of cancellation and another giving us an appointment in June. My mum's condition has been unbearable for some time so the change in dates did not help (Female, 51-59, Bangladeshi - Barts Voices Project - Stifford Centre)

6.13. More generally, in direct contrast to patient experiences of obtaining appointments in much of provision, at dental surgeries it was a different





picture. It was interesting to note that obtaining appointments appeared not merely just part of an overall experience but a very critical one:

I've been registered with Abby Dental Practice for seven years now and my experience so far has been positive. I was given a next day appointment as I was in pain and I am very happy about that. The receptionists are very friendly and also very professional over the phone. I think the environment is relaxing, welcoming and safe. I am usually happy with the explanation of the treatment and the service I receive from my dentist, however I last visited the dentist only eight weeks ago and now I am back with severe pain, I feel I should have had an X-ray during my last visit and this would have probably prevented me from coming here again and enduring the pain I am in now. Overall, I am happy with this practice and would happily recommend it to others (Female, 22-25, White/Black Caribbean - Enter and View visit, Abbey Dental Practice)

6.14. Co-ordination of information was an area of concern that arose for patients across provision particularly those with long-term conditions.

I visited a number of different health services throughout last year - 2013, including angiogram, x-ray, ECG, blood test, Accident & Emergency and also optical. I also visited the A&E more recently this year - June 2014. However as improvements to the service I would suggest a coordinated information system to be implemented as I found myself having to repeat myself many times to several doctors, which is exhausting and frustrating (Female, 51-59, Bangladeshi, Barts Voices Project, LWA)

6.15. Communication between departments and different service providers was also frequently seen to be poor.

I have had lower abdomen pains for some time now and after visiting the gynae department I found out that I have ovarian cysts. The cysts are regularly monitored to check they don't grow too big so I go for ultrasound scans on a regular basis. When the letter arrived for my January appointment I noticed something different. This time they wrote in the letter that I have to fast from mid-night and my appointment was late in the afternoon. So I found it strange that they'd never asked me to fast before and why they had given me an afternoon appointment if they require me to fast. The letter also stated this was my final scan. When I arrived for my appointment I went to the reception desk. When I was called through by the sonographer she too was surprised that I had been asked to fast and said this was not necessary. This made me really angry that I had been put through such hardship the whole day on a clerical error. After having the scan, previously I have asked the sonographer for details of the scan and they have always told me that I need to speak with my GP to discuss the results. Also often I wasn't informed that my GP has my scan results but has not called me in to discuss them. Contrary to my previous appointments, this time the sonographer asked me why I had been discharged from the clinic as my cysts had actually started to grow. After informing my GP of this information he has now referred me back to the clinic again. There seems to be little communication between the Gynae Department and my GP. It seems to me that rather than communicating direct that I am





the 'go-between' that is passing information in both direction (Female, 36-40, Bangladeshi - Barts Voices Project, SAfH)

6.16. It was also common to hear requests for continuity of care, especially when pregnant:

I always get to see a different midwife, I would prefer to see the same one, I feel I keep repeating myself, which is frustrating and also due to the changes of midwifes you don't get the opportunity to know someone better or feel comfortable around them (Female, 22-25, Bangladeshi - Enter and View visit - Harford Health Centre)

An integral part of the dissatisfaction reported appeared to be the attitude of staff towards patients particularly those who worked in reception areas. I can only begin with my first impressions of the service I received at reception, which is in my opinion at the forefront of a duty of care. It was my first visit at the hospital, hence I was somewhat worried if I would find my way round. I stopped at the main reception on the ground floor. Assuming that I was at the right place I approached the lady sitting at the desk and informed her I was here for my dermatology appointment. Without a helpful smile or any sense of attention towards me, she vaguely gave some directions. I ended up in the wrong department. I went back to the main reception feeling flustered. The same lady was there and she had the same attitude. She questioned my knowledge of English and was very rude. Without looking up she told me to go back up. At that point I was not feeling calm at her lack of help and went to find the right department myself. The manners and people skills the receptionist lady displayed to me that day was appalling.. (Female, 26-30, Bangladeshi - Barts Voices Project, Stifford Centre)

The receptionist was very rude, and didn't seem to be interested in helping me. There were two at the reception; they spent 10-15 minutes chatting before they acknowledged me (Female, 31-35, Bangladeshi - Barts Voices Project, Stifford Centre, A&E)

6.18. But it was clearly not only reception staff that came in for criticism:

Also the night ward staff especially the nurses behave very rudely, and this needs to be addressed...The nurses need to be appropriately trained. (Male, 26-30, Bangladeshi - Barts Voices Project, CBSG)

Staff in 8B were very rude, did not come when I pressed the buzzer, would not let my husband come and translate for me nor did they give or offer a translator. When I was given IV Fluids, saline, when it ran out the staff were supposed to give me another but when my husband informed them the nurse replied 'don't tell me how to do my job', the staff on this ward were very unprofessional (Female, 26-30, Bangladeshi - Barts Voices Project, Stifford Centre)

I was admitted to the Royal London Hospital, during the night the ward was very short staffed and I had to wait a very long time and ask at least three times for medication. I feel that more staff are needed during the night to





ensure a good level of care for all patients (Female, 41-45, White British - Barts Voices Project, Stifford Centre)

6.19. Those who had experienced the maternity services were often particularly dissatisfied with the way in which they had been treated.

For my first appointment when I became pregnant with my son, I was made to wait for 10 minutes to queue in order to sign in at reception. It was really hot and there was not enough seating for the amount of people that were there. In general, the space was very small and confined. Reception staff were less than helpful and had bad attitude. They were talking amongst themselves whilst being approached by patients. It's very rude not to be acknowledged whilst trying to ask for some help especially if that is the requirement of their job role. Reception staff need to be more helpful and willing to direct assist patients when needed. The air in the waiting area should be more regulated and the seat should be more comfortable and more seats made available to

accommodate for everyone in the waiting area (Female, 22-25, Other - Barts

The experience I had during the birth of my first baby was awful. I never thought anyone could be treated in such a way especially when under such circumstances. The staff nurse I had to unfortunately deal with on my ward during my stay there did not have any customer/patient care skills and found her to be short and abrupt with me whenever I spoke with her to the point where I thought she had an issue with me. I spoke with one of the other new mothers on my ward and soon came to realise that this was just the nurses' nature. I don't understand why people who have no compassion and clearly cannot empathise with their patients/people they are dealing with on a day to day basis; they should not be working as front line staff if they do not have the right attributes for it. They should really look into this before hiring miserable staff! The waiting period when asking for something that was needed I found was quite lengthy and nurses would say they were busy as they had other patients to tend to and would take their sweet time before returning to see what the matter was in the first place. My birth plan was discarded and was not taken into consideration at all. I was a new mother treated very unfairly! (Female, 26-30, Bangladeshi - Barts Voices Project, Stifford Centre)

The first nurse who started the process of inducing me was very unfriendly and showed little emotions towards me. She continued to do her work robotically with a lack of empathy towards me and my hip condition. The second nurse was wonderful. She connected with me and was very empathetic towards me. She continued to ask how I was and whether I needed anything. She also made suggestions as to how I can make myself more comfortable. She went and got me more pillows and would wet my lips with water as I was nil-by-mouth in case I needed a C-section. She asked after me and showed genuine concern for me and my well-being...When I was taken to the post natal ward I was faced yet again by cold, unsympathetic nurses who tried to push me into things without explanation such as giving me medication and just telling me to take them. I need to know what it is I'm taking and why it is that I'm taking it. I didn't appreciate being treated like cattle! They would also do crazy things



Voices Project, Stifford Centre)



like just come without warning and switch the lights off. So I'll be doing something like changing by baby and before I know it we were in darkness. It wouldn't hurt them to be a bit nicer to people (Female, 40-45, Bangladeshi - Barts Voices Project, SAfH, Maternity Ward)

The head nurse was ridiculous, attacking every new mother verbally. The other nurses were very polite and helpful. But they were very under staffed...they need more staff on duty to take care of vulnerable mothers. It is important that mother's needs are met at all times (Female, 26-30, Asian-Barts Voices Project - Stifford Centre, Maternity ward)

6.20. As well as experiencing more negative attitudes, patients also complained of feeling that they were being 'rushed' in and out of appointments and this appeared to be the case both in primary and secondary provision:

Some doctors are ok and give you time, but some always try to get rid of you... (Male, 31-35, Bangladeshi - Enter and View visit, Harford Health Centre)

I thought the doctors were rushing and so therefore didn't explain things to me well or check me thoroughly (Male, 26-30, Bangladeshi - Barts Voices Project, CBSG)

6.21. Perhaps more importantly, was the need to consult patients and to speak to and act towards them with appropriate respect. Thus, for example, using correct nomenclature or asking them whether they minded a student attending the observation <u>before</u> the student comes into the room. And as this young man explained:

For improvements I would suggest staff need to be trained regularly to have better and developed interpersonal skills and empathy so they can relate to the patients and not behave unprofessionally towards them (Male, 22-25, Bangladeshi, Barts Voices Project, CBSG)

My GP referred me to Mile End hospital for an x-ray. I visited the hospital in June this year. The staff I believe were not polite at all, they were too rude to me and their attitude was appalling. The radiographer told me to change into the gown provided. When I had come back the radiographer behaved very rudely towards me. In a very aggressive manner he said "don't you understand what I had told you, you have to remove your vest as well". I replied correcting him that he had not told me to do so, but despite so I went to remove my vest. The radiographer was not very cooperative either. I strongly feel a number of improvements will need to be made to the service so people get better care. Also to treat all patients fairly and not rudely because they may not understand or speak fluent English - they need to be patient and at the same time polite (Male, Bangladeshi - Barts Voices Project, CBSG)

6.22. And this could be especially galling for those with special needs:

I have explained to the receptionist (at Bethnal Green Medical Mission Practice) that I wish to register with the surgery. The receptionist was rather awkward towards me for some reason. I tried to make effort to communicate with receptionist but the receptionist was being difficult. I tried to have eye contact with her but she did not even acknowledge me. The receptionist was



asking for my proof of address so I showed my bank statement with the address to the receptionist. The receptionist was rather rude as she was looking at my balance. I felt offended and I snatched the statement off from her. I decided that I had enough with the receptionist's attitude and walked out from the surgery. I asked the Deaf Plus advocacy to deal with it. The advocacy called the practice for me and explained the situation. The receptionist stereotyped me as deaf and DUMB service user. The advocacy has explained that DUMB term do not exist anymore in modern days (Female, White Other - Barts Voices - Deaf Plus)

I got an appointment with my GP and was expected to have British Sign Language interpreter for the appointment. Unfortunately BSL interpreter failed to turn up and I was stressed about it as I knew that I cannot communicate with GP without BSL interpreter. So the appointment was postponed to another date which it was not helpful at all. I felt that it was not fair...Why should I suffer from this while hearing people easily see GP without any problems? (Female, White British - Barts Voices Project - Deaf Plus)

I am constantly frustrated when arriving at the Royal London to be told that I need to go "that way", when I am carrying a white stick (Barts Voices Project, ELVIS)

There seems to be no mechanism for one department or service that knows I have a sight problem to pass this on to another. This was both the case within different clinics within the hospital and then when I was discharged but needed to see a District Nurse for a while (Barts Voices Project, ELVIS)

I was very concerned when visiting the diabetes clinic at the Mile End hospital. They advised me what I should and shouldn't eat and then gave me a printed sheet of information, which of course I couldn't read. I therefore did my best, but it was guesswork (Barts Voices Project, ELVIS)

- 6.23. From the data, too, it seemed that clear communication between doctor and patient was an essential component of the patient journey.

 The doctor was very consistent and thorough in checking me over. She was also very helpful and friendly. The staff were also very informative which I found a delight as I felt I was getting all the right information on my treatment which in turn made me less anxious and confused (Female, 51-59, Bangladeshi Barts Voices Project, CBSG)
- 6.24. Certainly the lack of interpreting facilities was again an issue for many and often exacerbated stress and/or medical conditions.

 My English isn't very good so sometimes I feel I need an interpreter to help me explain my problems well to the GP so that the doctor gets a better understanding of why I came however there are hardly any interpreters available when I call in and ask and they often say the next suitable appointment with where an interpreter will be available is in two weeks or so. This really annoys me because I feel there's no point coming after 2 weeks when I am suffering at the moment. The receptionist also says that if I feel



worse I should go into A&E and this also disappoints me because GPs are supposed to be your first point of contact that you're supposed to be easily accessible to. (Male, 51-59, Bangladeshi - Barts Voices LWA)

I need to highlight this as I feel like it is dangerous practice, when I was taken in for a procedure 'Gastroscopy', they told me in visually and pointing to parts of mouth what they will do, although I can't speak English and I can understand very little, they did not inform my husband nor did they get an interpreter to explain the procedure, they made me sign and did not explain any risks. I'm extremely angry about this. I had another procedure done, I can't remember the name and the same thing, nobody explained what it was and risk involved. This is dangerous practice (Female, 26,30, Bangladeshi-Barts Voices Project, Stifford Centre)

When my daughter spoke to the staff in A&E, they didn't want to explain to her much, but my daughter wanted to know exactly what's going on, the nurse didn't want to explain, I think if your treating a patient who doesn't understand the language then it's vital for the person treating to explain to their next of kin what is going on (Female, 51-59, Bangladeshi - Barts Voices Project, Stifford Centre)

6.25. A substantial amount of spontaneous comments concentrated upon the environment of hospitals and in particular waiting areas. Some complained of the size and the lack of refreshments, seats and of space more generally. Others felt that since they were spending a good deal of time in there with all the endless waiting there could be a good many improvements:

The waiting area in the Renal Department is very small. Many people who are on dialysis are wheelchair bound so sometimes I feel there is no space for everyone in the waiting area. I particularly feel this is the case for people in wheelchairs. I would like to see more health information in the waiting are on how to look after your kidneys, what to eat and what not to. Maybe also some general information, magazines and even a TV to keep us entertained if patients are expected to wait 45 minutes. (Female, 41-45, Bangladeshi - Barts Voices Project - SAfH)

Hot drinks and sandwiches in A&E would also make things easier for patients and those that accompany them (Female, 31-35, Bangladeshi - Barts Voices Project - Stifford Centre)

6.26. Poor signage additionally caused patients consternation

After visiting a friend who has recently given birth, I found making my way to her very difficult and confusing, the halls seem to go on and on, there doesn't seem to be any clear signs directing me to her floor let alone what room she was in, I could not find a member of staff nearby and all the information desks seemed to be empty. After calling her again, she had a nurse who was next to her that was very helpful and was able to give me directions and tell me which lift I needed to get and where from and only then did I finally find her after 30 minutes in the hospital (Female, 26-30, White British - Barts Voices Project, Stifford Centre)





When getting to the hospital I felt very confused I didn't understand any signs. In the old building there was talking signage that was very convenient to use to find where to go in my language. The new building had better facilities but it was like you had to go around the building department seemed very far away. I didn't understand the lifts were very confusing different department different lifts type outside buttons it's just too much changes. Even my daughter who is born in this country found it absolutely horrendous (Female, 51-59, Bangladeshi - Barts Voices Project, Stifford Centre)

However my greatest issues are the lifts, finding my around the hospital I just don't understand it. It makes me really frustrated and angry. I had to take a member of my family with me sometimes it is not convenient for them to come with me so I have to cancel my appointment. There is no support for translation or people to ask to guide or to support me at the hospital (Female 51-59, Bangladeshi - Barts Voices Project - Stifford Centre)

6.27. GPs and Dentists - Specific Issues

- 6.27.1. As has been noted, many of the issues detailed above cut across service provision including GP provision. However, there were one or two issues that appeared to be unique to GPs. In the first place, the fact that GPs were generalists and, for the most part, not specialist, seemed to have had implications for some patients:
 - However I think my GP practice (XX place) is not really fussed about my diabetes...sometimes I feel unwell and it could be diabetes related, but it's so difficult to get an appointment there...the receptionist don't seem to be bothered about the type of illness I have, for them everyone is the same. (Healthwatch signposting phone call)
- 6.27.2. Given this, it is interesting that there was evidence of patients needing services that were more 'holistic', furthering their generalist approach:

 I think they should have one doctor for emergencies only, and also it would be nice to have someone to talk to about general concerns regarding health, like a councillor (Female, 51-59, White British Enter and View visit, Wapping Health Centre)
- 6.27.3. A striking feature of the nature of the comments over the past year was, as has been noted in the Executive Summary, that patients tended not to concentrate on concerns or issues about their care per se. Instead they tended to concentrate on issues surrounding or linked to their care as detailed above. It was notable, therefore, that patients did tend to comment on the care they had received from dentists and, occasionally, GPs:
 - I've been coming here for around 9 years, they offer quick appointments and really look after you...even though I am on benefit, I feel they do not discriminate against me and provide me the best care and service. I have a great relationship with my dentist, she is very friendly and provides good treatment, she even goes the extra mile to keep me happy, for example she cleaned my teeth today, even though I am here for other reasons- which I am really happy about. The people in this dentist are like family, they are all





very warm and friendly (Male, 22-25, Bangladeshi - Enter and View visit - Abbey Dental Practice)

This is my fifth visit to this dentist, today I am here for my six month check up, and I originally came here by family recommendation. The dentist is very good; they explain diagnosis and treatment properly and always answer any questions I have. They also explained the charges properly and I understand what I am entitled to. The staff are friendly and polite and I am very happy with the service I get here. Inside the dentist the surrounding and decoration looks nice and clean (Male, 22-25, Bangladeshi - Enter and View visit - Whitechapel Dental Practice)

6.27.4. Interestingly, in both dental and GP provision, confidentiality seemed to be an issue:

I also feel that there is lack of privacy as the waiting area is small and treatment doors tend to be left open i.e. you can hear conversations and treatments (Female, 41-45, White Other - Enter and View visit, Whitechapel Dental Practice)

I do have issues with some of the reception staff and also the lack of privacy at reception, People behind can hear clearly your discussions with reception staff (Female, 36-40, Bangladeshi - Enter and View visit - Harford Health Centre)

- 6.27.5. In addition, there appeared to be an issue for patients who wished to complain: And also the complaints procedure with the NHS is really complicated, so I didn't bother putting in a complaint about the other practice (Female, 31-35, White British Enter and View visit Wapping Health Centre)
- 6.27.6. Finally, Healthwatch additionally carried out an Enter and View visit to Health E1, a GP practice in Tower Hamlets, that caters for the 'homeless' and often those with complex needs. In this instance, there was, on the whole, praise for the surgery:

I was referred to Health E1 through Dellow Centre. It is easy to get an appointment, I am usually seen on the same day .I think the service is really good and the staff are really good at dealing with problematic patients. I'm usually seen quite quickly, usually within the space of 15 -20 minutes and I am always treated with respect and dignity. Health E1 staff are very good in how they treat their patients. They have a non-judgmental attitude and treat everyone with respect, no matter what the issues is. Overall it is a good service and I have no suggestions to improving this service (Male, 36-40, White British - Enter and View visit, Health E1)

6.27.7. Long waiting times also did not appear to have the impact as they did on patients attending other surgeries:

The hostel I was staying in referred me to Health E1; I have been here 3 times in the last year. The walk in service is very good but it usually takes a long time before you are seen by a doctor; however the doctors are good, so far my experience has been good and I don't have any suggestions for improving the service (Male, 31-35, Bangladeshi - Enter and View visit - Health E1)





It's the only GP practice around here for homeless people, I come here every fortnight to see a GP, and they make regular appointments for me. (XXX) is friendly and helpful, (XXX) is also very good, the doctors and nurses here treat you with dignity and give you respect. Sometimes you have to wait a long time if you use the walk in service, but I am very happy with the service I get here (Enter and View visit - E1 Health Centre)

- 6.27.8. Even for those who had left the borough, it remained the place to go:

 It's a very good service; you can be seen anytime... I have been coming here for
 the past 15 months and I was referred here by the Dellow Centre, one day I
 was not feeling well and asked the staff at the Dellow Centre if anyone could
 help and they told me about this place. When you come in the morning walk in
 sessions you tend to wait a long time, but I don't mind waiting as I always get
 to see a doctor. I have now moved out of this borough, I am now living in
 Newham in sheltered accommodation, but I like this place and still come here
 as I like the doctors because they are caring and friendly and also it's flexible
 as I can see a doctor anytime (Male, 26-30, African Enter and View visit, E1
 Health)
- 6.27.9. There was also a request for greater provision:

 I have one suggestion; I think it would be beneficial to have more afternoon walk in sessions (Male, 26-30, African Enter and View visit, E1 Health)

In terms of improving service I would suggest they have longer walk-in clinic opening times (Male, 36-40, Bangladeshi - Enter and View visit, Health E1)

It would be great if they can open on Saturdays, there is nothing for homeless people in the weekends (Enter and View visit - E1 Health)

- 6.28. Mental Health Provision Specific issues
- 6.28.1. For a number of patients with mental health issues, the process of finding suitable support could be daunting:

 Initially accessing Crisis House was difficult, I had to go to A&E, then hospital, then got discharged and then Home Treatment Team referred me to the Crisis House, I feel this place should be promoted more, its better coming here in the first instance then going through the whole process of being admitted to hospital. When I was admitted to hospital last year I was new to the borough, coming here has allowed me to learn about other services available in this community (Male, 41-45, White British Enter and View visit Crisis House)
- 6.28.2. However, once provided with appropriate support there was often only praise: This place was great for me; it gave me the anchor to move back into the community and believe in myself and helped build my self esteem. It's also a safe place and socialising with other tenants helped me to be relaxed and get support from peers. Staff always take an interest in you and they also did not judge me based on my life history and what I had done. When I came here I felt people believed me and this made a real difference, I felt people trusted me and I could trust people back. Being active was a key part in my recovery,



staff here got me involved with other community groups such as the Bromley by Bow Centre, I got involved with Bromley by Bow Centres time banking and gardening projects. Whilst I was staying here, every third day I would get to see my key worker to review my goals, setting little goals was very good as you felt like you achieved something; this helped to strategise and get back on my feet. Even after being discharged they provided me with on- going support for about two weeks and called me every day to see how I was doing and even after being technically discharged the staff supported me with getting access to see my daughter. Currently I am involved with Look Ahead as a 'peer mentor', I have been involved with the recruitment of staff members (interview panel) and also deliver training to Look Ahead staff on mental health and also delivered presentations to other Crisis Houses in other areas. This place has been like an 'Angel', it has been my saviour (Male, 41-45, White British - Enter and View visit - Crisis House)

6.28.3. Overwhelmingly, however, there appeared to be support for the benefits of social interaction for those with mental health issues:

I like it here you get to socialise with other Bangladeshi people, being here makes me feel happy and I feel that I am not on my own (less isolated), we go to the parks for walk and take part in yoga, also the new 'Fitness Group' is also very good as it helps to keep me healthy (Male, 31-35, Bangladeshi - Enter and View Visit, Pritchard's Row, Day Centre)

Before coming here I use to sit at home and feel angry, agitated and also lonely, since coming here (5 months now) I feel a lot happier mentally because I am able to socialise with other men from my community and also take part in activities. (XXX) is very friendly, he encourages us to take part in activities, organises activities for us and also talks about what is happening around the world (news) (Male, 51-59, Bangladeshi - Enter and View visit - Pritchard's Row Day Centre)

6.28.4. And there was a strong call for more sessions and particularly at times when service users might most need them. Cutbacks too were a concern. There should be a 'drop in' at the weekend for when some of us are unwell and want to socialise with other people. It's somewhere to go and it is better than having to go to A&E. I would like to see more Drop Ins, the compulsory activities are too rigid; can do with more flexibility for when people are unwell. Sometimes feel that I am being forced and pressured to join a group activity when I do not want to. The place keeps people safe. It makes me feels better. Prevention is better that cure. Everyone welcomes you and there is a family feel to it; that is why I have been coming here for last 16 years. The staffs are doing an especially good job. This place provides a safe place for me when I feel frightened of the world (Female, 46-50, White British - Enter and View visit, Pritchard's Row Day Centre)

I like the Somali Group, we make food, eat together have group discussions...it's a nice place, I am very happy and I feel much better coming here. The staff are very caring and very helpful...we are very happy here. I like the new activities; I think this place is better than before... I would like this place to be open in the evenings and also weekends and it would be great if we





can have the Somali group session available more days of the week (Male, 51-59, Somali - Enter and View visit, MIND in Tower Hamlets and Newham)

6.28.5. The classes offered and the benefits accrued also tended to be very much appreciated

I take part in a lot of activities here; I have been to trips and take part in exercise classes. I have also taken a course in basic computing and been a volunteer at the Tea Bar (Male, 31-35, Bangladeshi - Enter and View visit - Pritchard's Row Day Centre)

I like the service here, they always try to help you for example if I am feeling down they arrange a counsellor to see me. Before I use to come here Monday to Friday, now you have to sign up to an activity to attend. I like coming to the groups, I think the activities are good as it gives us options to do things, before we use to do nothing, now they are encouraging us to use our mind (Male, 41-45, Somali - Enter and View visit, MIND in Newham and Tower Hamlets)

6.28.6. But there was some concern that service users were not consulted adequately I have also noticed that a lot of people want to socialise and they like the drop-ins and they don't want to participate in activities, I guess this could be the reason why some people are no longer attending...anyway I think the group activities should be based on what service users want to do, they should be involved in the decision making. In regards to the current activities people were told that they was going to implement the activities and that was that...it would have been useful to ask people what they wanted to do then come up with a activity timetable.. (Female, 22-25, White British - Enter and View visit - MIND in Newham and Tower Hamlets)

I think Mind is very helpful, and the staff are very helpful. I like the Music Therapy Group, it's very good as I find it therapeutic...the new programme is helpful, it would be better if they could ask users what should be included...also I would like more drop-in sessions (Male, 31-35, African - Enter and View visit - MIND in Newham and Tower Hamlets)

6.28.7. However, the majority of comments about the staff were notably complimentary

(XXX) is my key worker, I get to see her at least twice a week, she is very helpful, she helps me with filling up forms, helps with my housing and benefits problems...I like the staff here, they talk to me and give me time (Male, 31-35, Bangladeshi - Enter and View visit, MIND in Tower Hamlets and Newham)

I have been coming here for over 20 years; I was referred by my psychiatrist. I have received excellent support and could not do without my link worker. The present staff are very engaging, they make time for me and everybody, they are the best team that I have come across and they have done more for me than my CPN or Social Worker. Here is the only stable place where I can feel safe, the staff and users make me feel that I belong and am part of a family. I need to go somewhere every day to make friends and socialise and staying home makes me ill. I do not know what I would do if I did not have this place





to come to. I am lucky that I have a partner but most people live on their own. This place is heaven to me. Staff do not force you to do group activity if you feel unwell (Male, 31-35, Bangladeshi - Enter and View visit, Pritchard's Day Centre)

- 6.28.8. And it was noted when staff had made a particular effort

 I feel pressured to join the group activity when I do not want to because I am unwell. It takes the staff a while before they understand what you are going through and then it is fine (Male,51-59, White British Enter and View visit, Pritchard's Row Day Centre)
- 6.28.9. On the other hand, some felt that the support given by the staff was slightly double edged:

I am happy to participate in the group activities but sometimes staff pressure me to take part and I feel like I am in a Nursery. They talk to me like I am a child and I do not like that. It could be thier way of encouragement. I cannot explain. Before I started coming here, I did not want to go out of my home. The one to one support which I received has helped with my recovery. The users and staff are very welcoming (Female, 46-50, White British - Enter and View visit, Pritchard's Row Day Centre)

6.28.10. There appeared to be a further concern about the lack of staff:

I also feel that there is not enough staff to integrate with users and sometimes it can feel there is lack of staff presence...the staff that are here, they always try their best and always try to support you and I feel they represent us well in the service user forum (Female, 51-59, White British - Enter and Visit,

There needs to be more staff to talk to users, general staff engagement with service users is important as they can help service users feel better...just having someone to talk to is important, now you have to make an appointment to talk to someone. I use to like the drop in service, if you feel unwell you can have the opportunity to go somewhere and socialise for a while. I would suggest that we have more drop-in sessions. I groups activities can be great, but they need to have more interaction as sometimes you don't know the people attending the groups. Currently the whole place is dead...some people live a long way and coming down for an hour is not enough, you want to come for at least half a day... also if you participate in activity in the morning and also want to participate in a activity in the afternoon, you are told to come back...this is not possible if you live far away or in the mean time where do you go? It seems unreasonable...I feel there needs to be a balance of both, socialising as well as activities, but they need to be practical about it. Before I use come here almost every day, now it 1 or 2 days, this is making me feel depressed as I am not socialising as much. The current programme does not meet my needs and also it seems they just appeared, there was no engagement with user, I feel staff have not listened to users in this regards and I also feel funders needs don't meet our needs. Evening drop-ins are great, however I feel there needs to be more staff on duty, as currently I feel it is not a safe environment (Male, 41-45, African - Enter and View visit, MIND in Newham and Tower Hamlets)

Pritchard's Row Day Centre)



7. OLDER PEOPLE

7.1. Many of the issues raised by the younger age groups were of course areas of concerns for older people except that they tended to be exacerbated given their stage of life and possible co-morbidities. For these two respondents, for example, the effects of poor communication were unquestionably significant.

I went to Mile End Hospital for my appointment at 9am as my son dropped me off. When I got there I was told that I had come to the wrong hospital and my appointment was for RLH as it had been moved there. I was really angry as the letter did not specify which hospital to go to and I didn't know the eye clinic has been moved. In the future if certain services are being moved I would like to be notified as a pensioner who has been going to a certain service for a long time I assumed it will be at Mile End Hospital (Male, 76-80. Bangladeshi - Barts Voices Project, Stifford Centre)

Recently I received a letter to have my eyes tested, usually it is in Mile End Hospital, I went all the way to the hospital for my 9.30 appointment on a Friday, when I got there they said they cannot see me as it is has moved to London Hospital and I need to go there. They were very were very adamant they cannot see me, so I travelled all the way to London Hospital. When I got there, they saw me but said they could have seen me at Mile End too. In the future when changes are made to departments that patients have been going to for years, they should write to us and inform us that the diabetic eye clinic has moved to Whitechapel so people like me who are not able to read English that well will have taken a note beforehand (Male, 76-80. Bangladeshi - Barts Voices Project, Stifford Centre)

7.2. There was also evidence of a lack of support for the older age group so that when, for example, diagnosis was perceived to be slow, patients could be left feeling particularly distressed

Due to the pain in my chest I went to my local GP several times hoping to understand what is causing it. I was diagnosed with having gallstones. I was told that I will need to undergo an operation to remove the gallstone and I was referred to the hospital where I had my operation. I then started experiencing very strong abdominal pains and went to my GP again. I was told that the gallstone may have still remained and that is what is causing the pain. I was told that I may require further operation. I feel very distressed due to the doctors failing to find what was wrong with me and they were not very certain. Furthermore I I had gone through an endoscopy and various other tests which was also very stressful for me (Female, 71-75, Bangladeshi, Barts Voices Project, LWA)

7.3. In addition, a strong sentiment was expressed that more time should be allocated to older patients almost to counteract the feeling of uncertainty and vulnerability

I feel the doctor doesn't give enough time to patient because of time limit so as a suggestion of area of improvement I think the appointment slots need to





be flexible enough to meet each patient's requirements. Appropriate times with patients will allow sooner diagnoses to be made. Also I have come across the fact that many GPs just simply prescribe medication but they don't explain the disease itself and to how to take the medicine, the side effects and I think it is crucial that the patient knows more about the medication he or she is taking. This should not be left with the pharmacists and the GPs can't be completely certain that the pharmacist will explain to the patient (Male, Bangladeshi - Barts Voices Project, CBSG)

7.4. Again, too, were the difficulties of obtaining appointments, particularly at the London Chest Hospital, as well as the seemingly endless waiting once at the appointment:

Arranging an appointment nowadays is very hard and it often takes two to three months of waiting for the next hospital appointment (Male, Bangladeshi - Barts Voices Project, CBSG)

Around three months ago I was told by the podiatrist at Wapping that I needed to have an assessment at Mile End Hospital and that they would send a letter confirming the appointments, however I never received any letters, so I tried on several occasion to call the foot clinic at Mile End and never managed to get through on the phone, after months of trying I finally managed to get through yesterday and they gave me an appointment for today. I would suggest that they pay a bit more attention to answering phone calls (Male, 80+, White British - Enter and View visit, Foot Health Clinic)

Having been seen by my GP I was referred to the Royal London hospital regarding my heart problem. It was difficult for me to get an appointment and the delayed appointment meant an adverse affect on health. The support I received was not bad but for follow up treatment I found myself having to phone and ask them questions on my medication rather than the doctor calling me (Male, 60-65, Bangladeshi - Barts Voices Project, LWA)

7.5. And delayed appointments were of particular concern

We waited 3 months for the appointment but would have appreciated it sooner as the appointment was for a sensitive issue. My mum was referred by the dentist as the dentist thought it may be mouth cancer. My concern was that if that was the case than she should have been seen sooner rather than later (Female, 60-65. Bangladeshi - Barts Voices Project, SAfH - Dental Hospital)

7.6. Finding their way around the hospital was nigh impossible for some and added to the difficulties encountered:

It's a big hospital and I feel like if I don't take someone with me I can get lost in the big empty corridors. I think more helpers, clear signs and directions should help people who don't always have someone to take them to appointments (Female, 60-65, Bangladeshi - Barts Voices Project, SAfH - Heart Clinic, RLH)





7.7. Certainly the behaviour of the staff for this age group was particularly noticeable and seemed to be an issue across provision.

Some of the nurses are really nice and helpful - I found them to have passion and willingness to 'care' for patients. Whereas other nurses walk around and behave like they are superior to us - majority are the ones with a lead role!!! However, I'd like to say not all nurses are like that!! The nurses are less friendly with people language difficulties too - I found that quite disturbing.... Patients are unable to express their needs anyway and to have nurses who aren't caring or willing to care is hard on top of it. The level of care has gone down compared to a few years ago, and the negligence of nurses is high (Male, 66-70, Bangladeshi - Barts Voice Project - Stifford Centre)

My father-in-law had had several strokes before and when he had his final stroke we took him straight to A&E. All the care we received there was good. The doctors were efficient and informed us of what they were doing and if it didn't work what they would do next. When we went to the Intensive Care unit, the care there was very different. We felt that none of the nurses had time for us. We also found their attitudes to be very rude. We understand that nurses were very limited and are busy but there is absolutely no need to be rude to relatives who are already suffering and grieving. I called nurses several times and they told me to give them a few moments but they disappeared after that. They should have at least come over and listen to what our needs were before deciding to dismiss us as a low priority case. This attitude really got to me and unfortunately I took it all out on the doctors that came to see us during their rounds. But the doctors were very empathetic towards us and showed some emotions to the fact that we had been there with my father-in-law and had spent more than 24 hours. I think that nurses should be given training on manners and how to talk and treat people who are already stressed with their loved ones. Their rudeness and harsh attitudes just add to the problem and further stress people out. If nurses are not committed to their jobs and don't want to be polite to patients they should be forced out as they aren't fulfilling their job roles (Male, 71-75, Bangladeshi - Barts Voices Project, SAfH)

7.8. And many seemed to feel rebuffed by the behaviour of reception staff:

I went to have my first ever breast screen in June 2014. The receptionist looked like she didn't want to be at work, there was no hello, all she said was 'take a seat'. The waiting area was dull, there was no water available. I waited for 40 mins after my appointment time and when I got called, all the nurse said was, 'Take off your upper clothing and come and stand here', no explanation of what was going and what she will do. I had to ask my daughter to ask what are they going to do, even then the nurse said, 'your mother needs to stand here and I will use the machine to screen her breast'. I would like for the waiting area to have water available and for the staff to explain what the procedure and steps are. The receptionist should want to be at work (Female, 60-65, Bangladeshi - Barts Voices Project, Stifford Centre)





7.9. Some, too, appeared to have experienced simple neglect. During the Barts Voices Project, THFN discovered the case of one woman in her seventies who reported that given her incontinence problems she had wet her bed but was left to 'lie in it for ages' and when the staff came to clean her, they scalded her with the hot water. The family have made a formal complaint but have had no reply. Other respondents reported the following

The level of care varies throughout the day - during visiting hours, nurses are on their feet running around trying to tend to every patient. BUT after hours, it's different. My children have often expressed their feelings of sadness and distraught to be witnessing these situations. Patients are left unattended, with their soiled nappies... these patients are calling for assistance, but nurses aren't around. The nurses are less friendly with people language difficulties too - I found that quite disturbing.... Patients are unable to express their needs anyway and to have nurses who aren't caring or willing to care is hard on top of it (Male, 66-70, Bangladeshi - Barts Voices Project - Stifford Centre - Cardio Department)

Once I was admitted into the hospital the care I received I feel was not good. The nurse didn't take good care of me because the saline syringe which was injected in me was kept for 8 days and the nurse forgot to remove it sooner and this led to an infection in my hand. (Male, 80+, Bangladeshi- Barts Voices Project, LWA)

7.10. Key, too, was the clear need for someone to talk to and the loneliness when staff seemed to only 'do their job'. One woman, in her eighties, complained, for example, to THFN that she felt 'sad' that nurses did not wish to speak to her apart from pleasantries. Another interviewee in that project commented as follows:

I get a carer to do my shopping but she buys what she likes not what I wanted. Why they are called 'carers' I do not know. She comes whenever she fancies (Voices of the Housebound, THFN)

7.11. That social and health care were almost inseparable for this age group was also made very clear by this project. The lack of cohesion between services was (and has been a well-researched area of need) a key issue. Many for example had a myriad of regular appointments to attend

I attend a diabetes clinic and go to my GP for my depression; I go to RLH and Barts for my back problems (Voices of the Housebound, THFN)
I have regular hospital visits for eyes, hearing, back pain management, mental health clinic, chiropody clinic, pacemaker clinic. I have problems getting to the services I need (Voices of the Housebound, THFN)

I go to hospital for my problems and the befriender takes me there otherwise I would have to cancel them all (Voices of the Housebound, THFN)

7.12. Further, the attitude of homecare staff tended to be a prominent feature of this. Patients interviewed by THFN complained that carers often only did 'what





they had time for'. Hence for one patient with dementia, they would not always have time to make the breakfast if for example it had taken too long to put on the compression socks

The carers are not caring or understanding; their communication is very poor...they ignore me completely and seem more interested to leave as soon as they walk in. They are not compassionate and they look at it (caring) as a routine. If there were in-house carers from Tower Hamlets it would work better; agencies aren't giving a satisfactory service to vulnerable people (Voices of the Housebound, THFN) I would like my carers to be more talkative (Voices of the Housebound, THFN)

I have had several carers in the last few months and they do this their own way and they shout if I tell them. There have been times when they shout and swear; it frightens me and I get anxious before they come. ...They just come to do their work and then they sit and play games on their mobile phones; (there is) no human contact (Voices of the Housebound, THFN)

I would like them (social carers) to treat me like a human being- explain what is going on and be helpful towards me.... Nothing is clear (about) what they are supposed to do (Voices of the Housebound, THFN)

7.13. THFN also discovered that many elderly people were confused by the seemingly endless stream of people coming to their home. They described how patients could feel they had lost control of their lives which in turn had, in some cases, led to a mistrust of health and social care professionals:

Everyone comes in and out of my home and no-one asks me if it is all right. I feel have been tricked into given up my keys (Male, 66-70, White British - Barts Voices Project, THFN)

Now I have so many people coming in and out to see me, doctors, nurse, social workers, it is getting confusing - they all just tell me what to do (Female, 80+, White British - Barts Voices Project, THFN)

7.14. This also had to be counterbalanced by the loneliness that could be experienced by this group

It would be nice to have a social club for people who live in the area. I would like a social club for history and literature and other interesting topics not only for a cup of tea and cakes. We might be elderly but a lot of us have tales to tell and have room to learn more and it's better to keep our brain occupied (Voices of the Housebound, THFN)

It would be better to have someone...to help me help myself (Voices of the Housebound, THFN)





7.15. It was also clear that the lack of interpreting services was especially pertinent for this group since it could lead to greater complications

I suffer from bowel cancer. However the doctor doesn't always prescribe medication and advises me to buy them for example vitamins from the local pharmacy. Also I can't speak English very well so I need an interpreter however most of the time interpreter is not available and when I speak to receptionist on the phone they ask me to bring in a family member. This angers me because I cannot take my son or daughter as they as they are not free, and not having an interpreter makes it difficult to communicate and understand the doctors advice (Male, 60-65, Bangladeshi - Barts Voices Project, Stifford Centre)

On my last visit I was seen by an dentist of Indian origin, I could not communicate with her as I speak very little English...this was a problem...luckily for me the dental nurse could speak Hindi, so I communicated with the dentist via her...it would have been useful if I had seen a Bengali dentist, as I could explain myself.. It would be useful if these things could be taken into consideration when booking appointments, especially in the case of elderly non English speaking patients (Male, 60-65, Bangladeshi, Enter and View visit - Abbey Dental Practice)

7.16. This of course was perceived to be a particular issue for those with special needs and having appropriate interpreters was clearly critical.

The patient explained that she was struggling to communicate with nurses and doctors. All the appointments at hospital were never provided with BSL Interpreters and meant her friend had to interpret for her but was not appropriately qualified. She explained that she did not get results about her heart. She was discharged and was given prescription tablets. She was not given an explanation why she was given those tablets. She did ask for BSL interpreter during her stay and the staff took no action on it (Female, 66-70, White British - Barts Voices Project - Deaf Plus)

I was having my cataract operation on 21st March. I was already being provided with British Sign Language Interpreter for the day. I was being prepared to have injections to put me to sleep and I needed assistance from BSL interpreter to explain the situation. But BSL interpreter was being squeamish and left me alone in the operating theatre. I was panicked and the nurse tried to reassure me that it is ok and I was being calm after reassurance. After the operation I woke up and found that the BSL interpreter was not in the same room with her which I was not happy with as I wanted to communicate with the nurse so she had to wait till I was taken back to the resting room. I found the BSL interpreter in the resting room. BSL interpreter explained that she could not cope with things happening in the operation room. I was very angry with her as I felt that she was not fit to be an interpreter (76-80, White British - Barts Voices Project - Deaf Plus)

7.17. The difficulties of getting appropriate equipment and aides often seemed to make a potentially bad situation worse





I urgently need installation of a level access shower. This was approved in 2011 but LBTH has dragged their feet and now in 2014 my grant has expired and they want me to start the process all over again and wait another three years. I need more time on my social care package due to no washing facility but my social worker takes no notice (Voices of the Housebound, THFN) A walk-in shower would definitely change my life and a ground floor flat. I'm waiting to join a social group for outings (Voices of the Housebound, THFN) An electric wheelchair for outdoors and stair lift for indoors: this would help me get around more independently (Voices of the Housebound, THFN) I have a wheelchair and would like someone to wheel me around when I'm lonely and the weather is good. I have asked for this so many times but I have never got it (Voices of the Housebound, THFN)

It is stupid with continence pads, (you've) got to order them three weeks prior to needing them and at this age you forget (Voices of the Housebound, THFN)

7.18. It is further of note that transport provision appeared to remain a large problem

What I do have an issue with is the patient transport system. I know ERS medical have recently taken over so are still a relatively new service but their time keeping is absolutely preposterous. I live in Roman Road so it takes me some time to get to the hospital. If I have an appointment at 10am the transport will arrive ten minutes before my appointment so you can imagine how late I actually arrive. I'm not at all impressed that they tell me to be ready two hours before my appointment time and yet they arrive so late! The main concern for me which I would like to see improvements in would be the patient transport to run more efficiently. I mean, there have been times where I have sat in the discharge lounge for a long time amongst other patients waiting to be taken home and can clearly see a row of patient transport vehicles parked outside for ages and not moving-I spend enough time in hospitals without having to spend any more time than necessary especially when my immune system is very bad so really I should not be exposed to sitting around so many patients with all the various viruses and illnesses (60-65, Bangladeshi - Barts Voices Project, Stifford Centre)

7.19. Indeed, for this group there appeared to be an overall feeling that, given the problems encountered, it led to a perception that they were simply being dismissed. Often, it appeared that no-one was taking the appropriate responsibility as a volunteer befriender noted below:

I am a female aged 65 and suffer from a disability, diabetes and get frequent lung infections. I also have movement restrictions. I regularly visit the Royal London Hospital and my local GP practise due to my health conditions. GP doesn't pay any home visits but advises me to go into walk in centres or A&E. The Doctor often insists I take my medication and to be discharged when I am in hospital- they often claim I have nothing to worry about and will be better in a few days. (Female, 60-65. Asian Other, Barts Voices Project, CBSG)





Years ago THFN could phone the council for social support for someone and they would send a social worker, but that doesn't happen now. And no one is willing to take responsibility - a social worker will say its responsibility of the occupational therapist, who will say it's the social worker, and on and on.... (Voices of the Housebound, THFN)

7.20. Conversely, it was also striking from the evidence that when elderly respondents were pleased with the service, it was the above factors that had made the critical difference, as the following patients made clear:

We got the ambulance here today; they were very quick and got to me within ten minutes of calling- very happy about that. I was at the St Stephens Health Centre when I had a serious heart pain whilst waiting to see a doctor, the doctors checked me straight away and advised I go to A&E and called the ambulance- the staff were great. We got here at 10.15 am and they did tests straight away, I am now waiting for the doctor to give me the results. It's very good here, they are attentive and the staff are all very good, so far I have been very happy (Male, 80+, White British - Enter and View visit, A&E)

We arrived here at 10.30am, got here by an ambulance; ambulance was very quick got to our home with 15 minutes of calling, which we think is great! When we arrived here we got seen by a nurse straight away and also had some tests done...we are just waiting for the test result at moment. They provide a marvellous service here, all the staff are caring and the whole process has been excellent so far (71-75, White British - Enter and View visit, A&E)

When we did get seen the medical staffs were fantastic, they explained everything to us in detail and made sure we were comfortable with everything. She was given a follow-up appointment the following day-fantastic!!! (Female, 60-65, Bangladeshi - Barts Voices Project, Dental Hospital)

8. RECOMMENDATIONS

8.1. General

- 8.1.1. Understand the nature of the need for 'support' services within provision particularly for the elderly and the young
- 8.1.2. Develop an understanding of the processes that might dictate experiences
- 8.1.3. Develop a greater understanding of 'expectations' and the determinants within that including demographic factors
- 8.1.4. Develop a greater understanding of 'quality care' among different cohorts of patients and the factors that contribute to 'good' care
- 8.1.5. Explore and understand the experiences of those groups who appear underrepresented in the work to-date e.g. Eastern European groups and sub-groups, Somali's

8.2. Under 5s and Children





- 8.2.1. Explore how time allocation for appointments could be improved
- 8.2.2. Provide clear directions for patients and families possibly in the form of leaflets and ensure their effective dissemination
- 8.2.3. Explore whether there are adequate more general support services for families where there are ill children or children with severe medical issues and whether there is adequate signposting to those services

8.3. Young People

- 8.3.1. Further understand the difficulties that are encountered in the transition from child to post-18
- 8.3.2. Understand the discrepancies in terms of expectations on the part of both the provider and service users

8.4. Adults

- 8.4.1. Further understand how the 'adult' population breaks down into subgroups in terms of experiences and perceptions of those experiences and in terms of different aspects of the patient journey
- 8.4.2. Explore how different aspects of the patient journey could be improved for the different subgroups

8.5. Older People

- 8.5.1. Ensure that the learning from the provider feedback on 'integrated care' and the Co-ordinated Care Package has been fed back into service provision
- 8.5.2. Ensure feedback is collected from Care Co-ordinators to enable further understanding of the key issues for patients
- 8.5.3. Improve the way in which home visits by health professionals can best be managed for this age group
- 8.5.4. Whether the CCG consider that further staff training across the healthcare system with reference to the treatment of older people would make a marked difference in terms of the perceived lack of time and support, poor communication etc
- 8.5.5. Understand the mechanisms through which the elderly are able to articulate their needs
- 8.5.6. Understand the nature of the key ingredients for 'holistic' and 'patient centred care' to be effective
- 8.5.7. To what extent lessons can be learnt from present work that is looking at the process and implementation of integrated care so that it is applicable across social and health care provision

