

# Rochdale and District Disability Action Group

RADDAG



Shaping the Future

## **RADDAG Engagement Report**

### **Purpose and overview**

Heywood Middleton and Rochdale Clinical Commissioning Group (HMR CCG) commissioned Rochdale and District Disability Action Group (RADDAG), to deliver a series of engagement activities with people from within the borough of Rochdale, to gather their experiences of local Health Care Services and to encourage them to volunteer with or get involved with the Clinical Commissioning Group. This took place over a period of 6 months starting in May 2017.

This report provides the CCG with an overview of the experiences of local residents when accessing health care services; it highlights good practice whilst also identifying areas that are perceived to require improvement to ensure that the needs of local residents are met. The research data has been gathered through focus groups, online surveys, questionnaires and feedback postcards which have been completed following conversations with respondents at local events. Between May and December 2017 RADDAG engaged with 326 people who provided their experiences of health care services within the Borough.

Throughout the research participants have indicated that they are generally happy with the care received from their GP, dentist and optician's and whilst attending hospital appointments or as an inpatient in hospital, however participants repeatedly highlighted that it was the practicalities of getting appointments, getting to appointments and issues while at hospitals, GP surgeries, Dentist surgeries and opticians that were of concern. Participants felt that the logistics of getting to and attending appointments were more concerning than the actual treatment they were seeking.

## Who we've spoken to

Following feedback from RADDAG members and taking into consideration our knowledge from past research projects, it was decided that to gather experiences from as many different people as possible, we would actually go out, to where people already were, rather than only holding focus groups and expecting participants to attend, we believe that this increased the number of people that we were able to speak to.

We attended 6 events and held conversations about people's experiences of health services with 181 attendees. Conversations were summarised on 'postcards', some of which were completed by the participant, and some of which were completed with assistance.

In order to have a much wider reach and gather experiences from those who don't traditionally engage through face to face focus groups, we utilised an online questionnaire via Survey Monkey, we advertised this questionnaire on Social Media and sent the link to our members. We specifically targeted our members who have identified as LGBT and who have indicated that they would prefer to participate in research online rather than face to face. We asked our members to forward the questionnaire link to their wider social circle of those who also identify as LGBT. This method gathered feedback from 58 participants with 31 participants indicating that they identify as LGBT.

In order to find out about the experiences of people with a Learning Disability, when accessing health care services, we made contact with the PossAbilities Service. Rachel Law, their CEO suggested that we attend their Service User Advisory Group and ask the members whether they thought that PossAbilities service users would be interested in being involved in a number of engagement activities. We produced a draft questionnaire in Easy Read format and sent this to PossAbilities staff, who had agreed to discuss this with Service Users prior to the service user advisory group. This enabled the advisory group to feel comfortable in giving us their comments and suggestions at the meeting. The valuable feedback gathered from the advisory group ensured that our final questionnaire was accessible for people with a learning disability. At the service user advisory group it was suggested that a questionnaire should be written and distributed to PossAbilities Staff, as they support a number of people with a learning disability and therefore have an overview of service provision, examples of good practice and suggestions as to whether there are any gaps in services for people with a learning disability.

## Events attended

17th May – International Day Against Homophobia, Transphobia and Biphobia (IDAHOBIT) at Number One Riverside, Rochdale, 17 feedback postcards were completed following conversations with attendees.

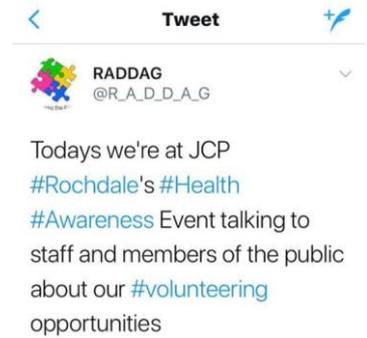


31st May – Volunteer Drop in at Number One Riverside, Rochdale, 23 postcards were completed following conversations with attendees.

5th July – Parent Carer Information day held at Rochdale Cricket and Lacrosse Club, Rochdale between 10am – 7pm organised by RBC Early Help & Schools, 250 people attended over the course of the day and had access to the information stall, 87 feedback postcards were completed following conversations with attendees. Attendees were a mixture of parents, carers, young people and professionals such as social workers, Occupational Therapists and Physiotherapists.



12th July – Health and Wellbeing Awareness Event held at Job Centre Plus Rochdale, attended by people looking to enter the world of work, 34 feedback postcards were completed following conversations with attendees.



27th July - Multi Agency Information Day at St Andrews Church, organised by RBUF – 4 feedback postcards were completed following conversations with attendees.



20<sup>th</sup> October – We held an information stall at the Cherwell Centre, Heywood, 33 service users were assisted in completing feedback postcards following conversations about their experiences of health care services. This is in addition to the Questionnaire and focus groups that we held with PossAbilities Service Users.



## Focus Groups, Drop In sessions and Questionnaires

An online questionnaire using Survey Monkey went live on 7th April 2017, social media was widely utilised on numerous occasions to encourage people to respond, the link was also sent via email to all RADDAG members and an email which specifically targeted our members who identify as LGBT was sent out.



June – Meeting with Rachel Law to arrange engagement activity with PossAbilities Service Users

July – Questionnaire produced in Easy Read format, supported by pictures to ensure that it is accessible to service users of PossAbilities with a learning disability.

July – Pre-Consultation Feedback focus group held with PossAbilities service users and support staff, feedback was received from 26 service users and staff

July – Pre-consultation Meeting with PossAbilities service User Advisory Group to discuss feedback from questionnaire and arrange focus groups. At the Pre-consultation meeting Possibilities service users fed back their thoughts on the questionnaire having had the opportunity to review it prior to the meeting.



August – amendments made to the Easy Read questionnaire as a result of the feedback received at the meeting on 20th July. The PossAbilities Service User Advisory Group suggested that an additional questionnaire should be developed for PossAbilities Staff and carers/PA's to give their feedback/views, to be distributed alongside the easy read version of the questionnaire.

September – Online Survey Closed – 58 online responses received in total

September – Questionnaires distributed to PossAbilities service users and PossAbilities staff, carers/PA's, support was made available to service users at all 6 PossAbilities centres, to complete the questionnaire.

November – 25 Questionnaires completed by PossAbilities service users,

December - 19 Questionnaires completed by PossAbilities staff/carers/PA's.

## **What are the issues?**

This section presents the findings from the **patient experience feedback postcards**, which were completed following conversations with attendees at various events throughout the Borough, the **online questionnaire**, which gathered feedback from those who would like to participate in research, but prefer to do this online rather than face to face, this includes a number of people who identify as **LGBT** and from **consultation events, focus groups and questionnaires** with service users and staff from the **PossAbilities Service**, which is a service for people with a learning disability.

### **Feedback from Patient Experience Postcards**

We attended 6 events and received narrative responses from 181 participants using our feedback postcards, we focused on having conversations with participants and then ensuring that these were summarised either by the participant or by us once the conversation was over. We found that people were much more willing to have a conversation, rather than simply filling in a form, this gathered answers of much greater depth than simply asking participants to write down their experiences or tick boxes. We have analysed the results of the conversations by looking for common themes and using these to categorise the feedback that we received. The full responses from each feedback postcard can be found in the Appendix.

We found during our research that conversation mainly centred on the 'patient journey to and through treatment', the focus of participants conversations was

rarely on the quality of the medical treatment that they received and if they did mention this it was to praise the Doctors, Nurses or Health Care Professionals, that had been involved in their care. 13 participants praised the care that they had received from their doctor, nurse, optician or dentist, with a further 5 identifying that staff at their pharmacy were helpful.

Following analysis of the feedback postcards we found that participants identified issues in the following areas: -

- **Accessibility**

4 participants commented that outside areas of local hospitals were inaccessible to wheelchair users, or those who have difficulty walking, conversations were had around steep ramps and inclines in and around the hospitals.

6 participants said that they hadn't attended or found it difficult to attend a dentist because they couldn't find one that was accessible.

11 participants had a conversation around the inaccessibility of their GP surgery, comments were made about the lack of arms on chairs in the waiting room, which made it difficult for them to get up out of the chair and the lack of space for wheelchair users to wait, which they said made them feel 'in the way'.

1 participants talked about easy read information not being available at their GP surgery.

2 participants were disappointed that diversity was not reflected in the waiting areas of health premises, and commented that posters and leaflets should reflect a wider range of communities and lifestyles.

- **Getting an Appointment**

13 participants talked about issues with booking appointments at their GP surgery, comments were made about the fact that patients had to call the surgery first thing in the morning or wait in line outside until the surgery opened, some people found this difficult. Participants said that they would prefer more appointments available to book in advance and help with booking appointments online.

12 participants said that they had issues getting an appointment, with 3 participants mentioning that they had waited a long time for their appointment to come through when referred to a Consultant.

7 participants commented that they would prefer to have appointments with the same GP each time, however this isn't always possible at their surgery.

Participants suggested that those with long term health conditions spend a significant amount of time during the appointment explaining their health

condition, rather than being able to explain why they've actually made an appointment and so consistency of the GP that they could see would alleviate this issue.

5 participants spoke about waiting times at A&E and the Urgent Care centre being too long.

- **Getting to Appointments**

7 participants thought that car parking at hospitals was too expensive.

12 participants talked about car parking at hospitals, GP surgeries and dentists being unsuitable, comments were made about there not being enough parking, especially accessible parking for blue badge holders and that car parking should be a priority when planning new services or when relocating existing services.

10 participants had an issue with public transport, the volunteer driver scheme or the passenger transport service when attending health related appointments with comments around bus timetables not coinciding with early morning appointments, the criteria for the passenger transport scheme being too strict and the perception that the volunteer drivers may not stay around in order to pick patients up again from appointments.

3 participants said that services such as maternity are too far away from their homes, with the changes that have been made locally.

3 participants commented on the helpfulness of the volunteers at the entrances to hospitals who assist patients in finding their way around.

- **During Appointments with health care professionals**

10 participants specifically mentioned that they were happy with the care that they had received at their appointment with their GP, Dentist, Optician or during a hospital appointment with only 2 participants saying that they were unhappy with the care received.

2 participants suggested that GP appointment should be longer for people who have a long-term health condition, or for those who need extra time to explain the issues to the GP, due to communication difficulties.

4 participants were unhappy at arriving for their hospital appointment to find that it had been cancelled but that no one contacted them to let them know. This caused an issue for those who had to rely on taxis and busses to get to the appointment, with comments around the high cost, further to this cancelled appointments caused an issue for those who have anxiety around attending medical appointments.

4 participants talked about the lack of dignity during their appointments, 2 participants mentioned that the GP insisted on their parents being present during a consultation as they assumed that the patient wouldn't understand without them being there, however this wasn't the case.

8 participants recalled incidents where health care professionals showed a lack of awareness around Gender Identity and issues faced by those who identify as LGBT, such as GP's assuming that Gay men will need to be referred to a sexual health clinic, making assumptions about the gender of patient's partners and issues with patients having to explain their gender identity numerous times, rather than this being in their notes.

9 participants reported that they had issues with interpretation services, that they are either difficult to book, don't turn up or there is a lack of knowledge amongst GP surgery staff as to how to access the service.

5 participants complained that staff didn't speak directly to them, as the patient, during appointments, and instead spoken to the person who was accompanying them to the appointment. Conversations were had around health care professionals assuming that disabled people wouldn't understand and GP's not making any effort to amend their terminology to enable the patient to understand.

2 participants talked about a lack of choice during their Optician appointment, the first issue was around the optician not asking whether the patient was able to read the eye test and not giving the option of a test using pictures, the other comment was around the Opticians pressuring the patient into buying glasses from them, rather than explaining that patients can have their prescription and purchase glasses from anywhere they choose.

- **During a Stay in Hospital**

4 participants talked about the lack of dignity during their hospital stay, with one participant recalling an incident where their wheelchair was moved away from their bedside for no reason other than 'it was in the way'.

1 participant mentioned that the food in hospital was good.

1 participant was impressed with the cleanliness of the ward that they were staying on.

1 participant commented upon the change to visiting times, and that it made it easier now that they could visit patients at all times of the day, rather than restricted hours during the afternoon/evening.

3 participants were unhappy with the cost of the TV's on the wards and thought that they were too expensive, one participant was happy that the TV is now free

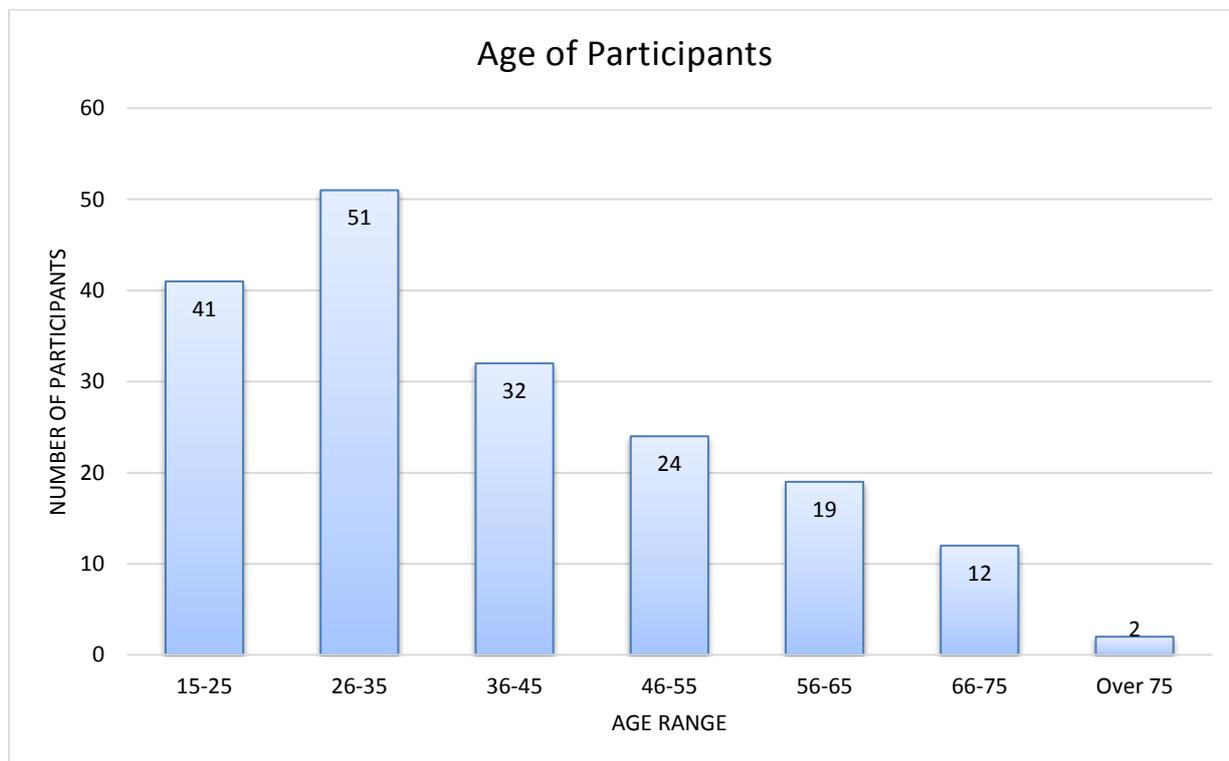
during the day, but commented that patients need the TV's when they're alone at night.

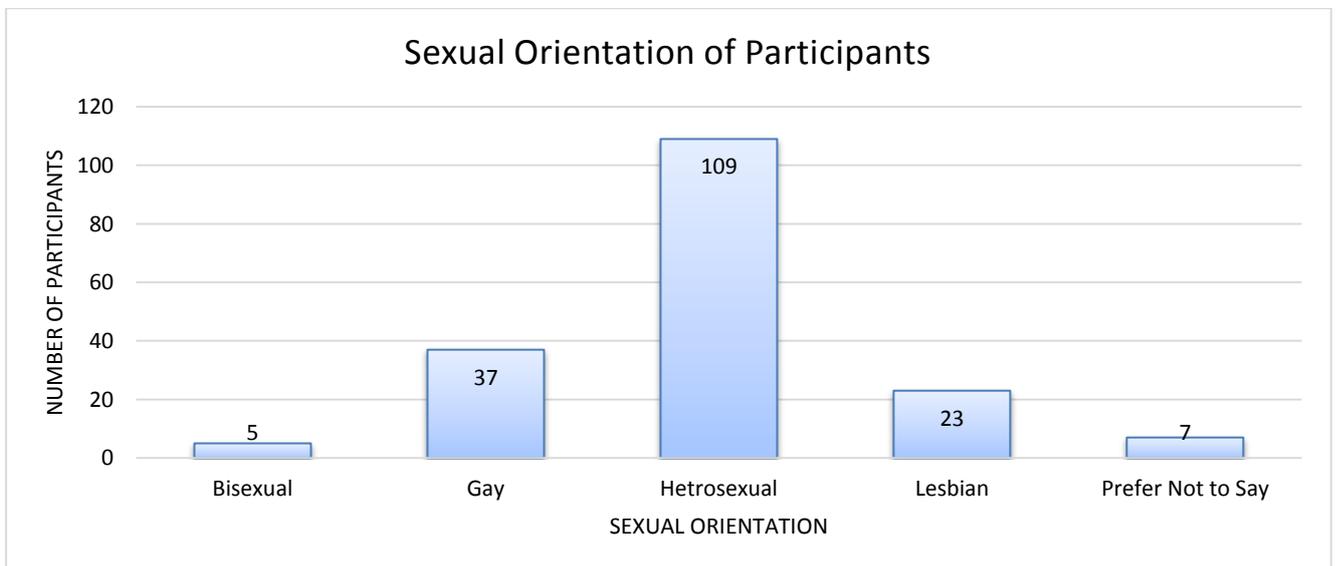
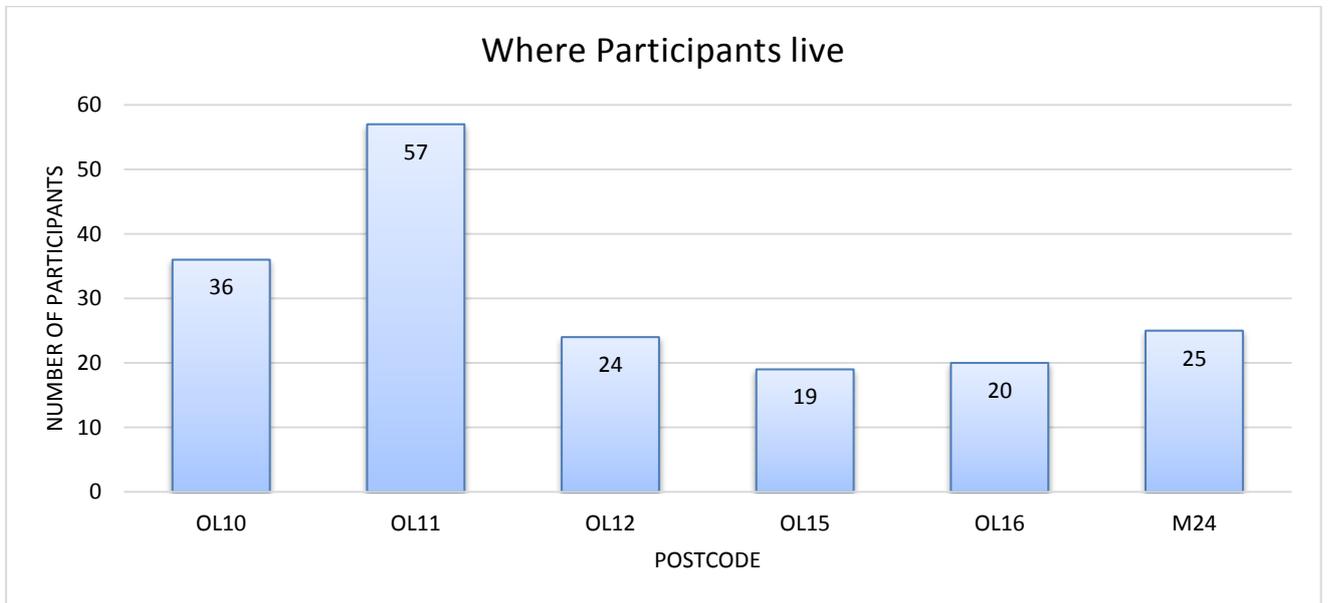
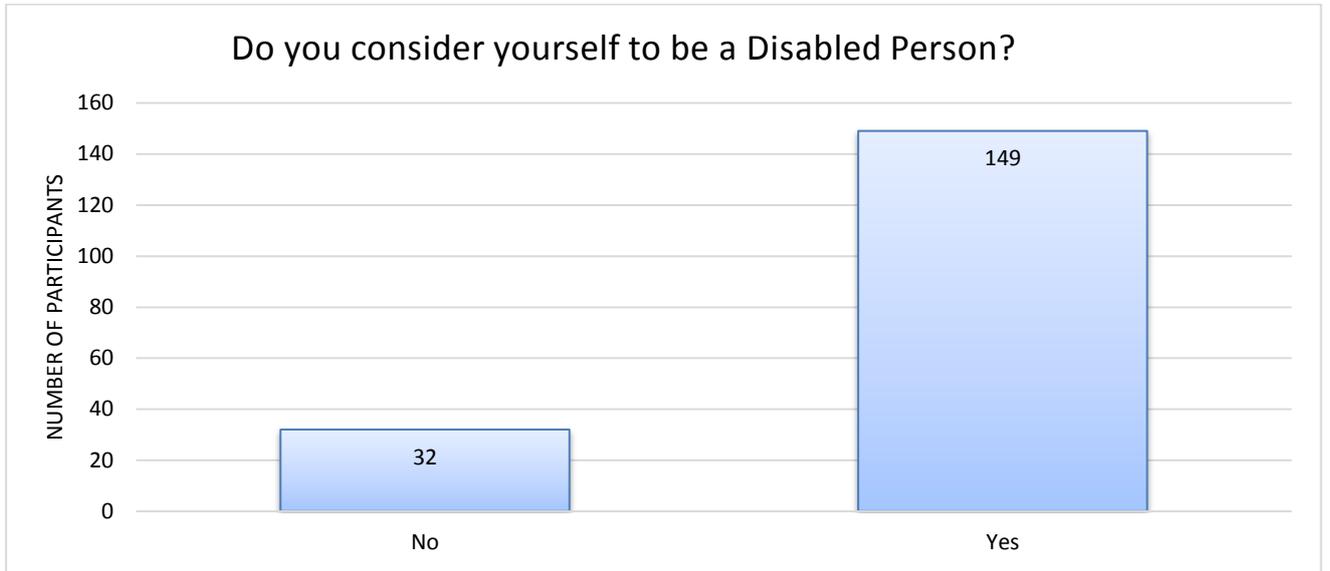
- **Transition from Child to Adult Services**

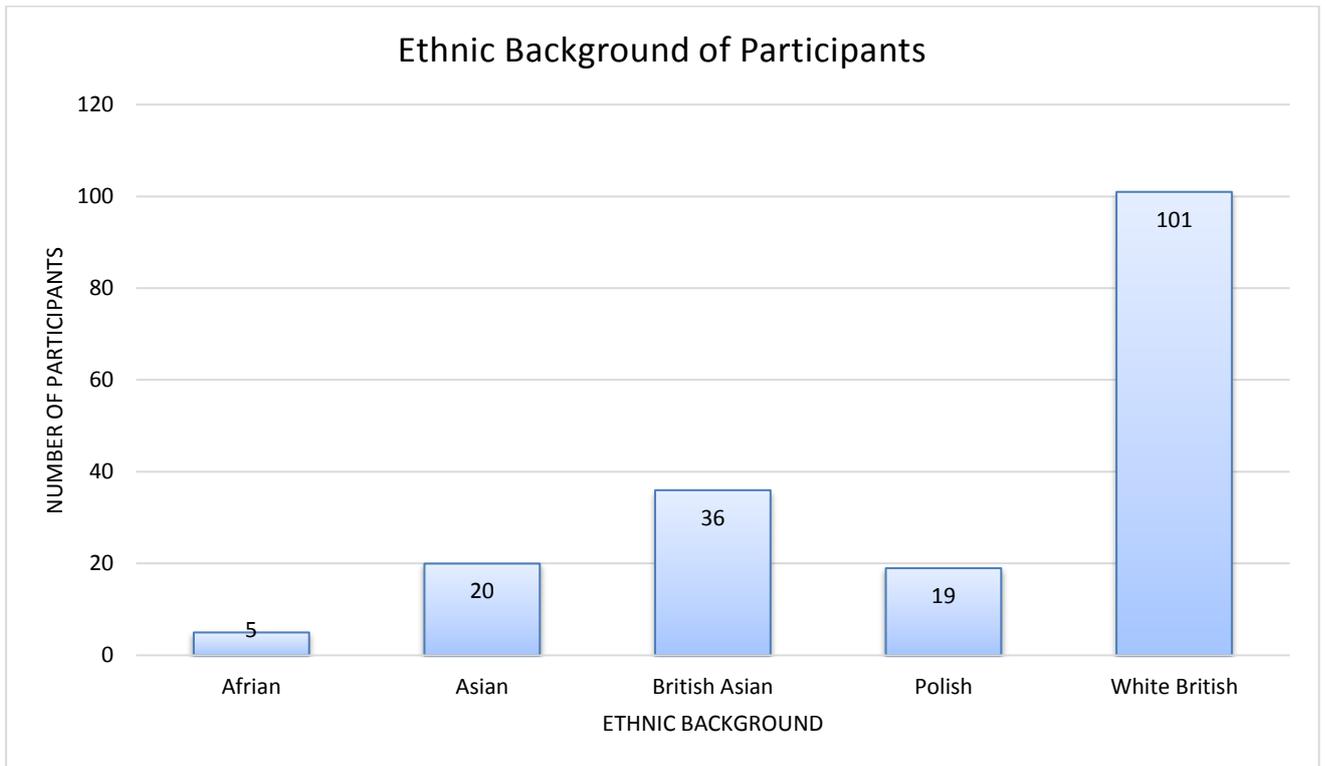
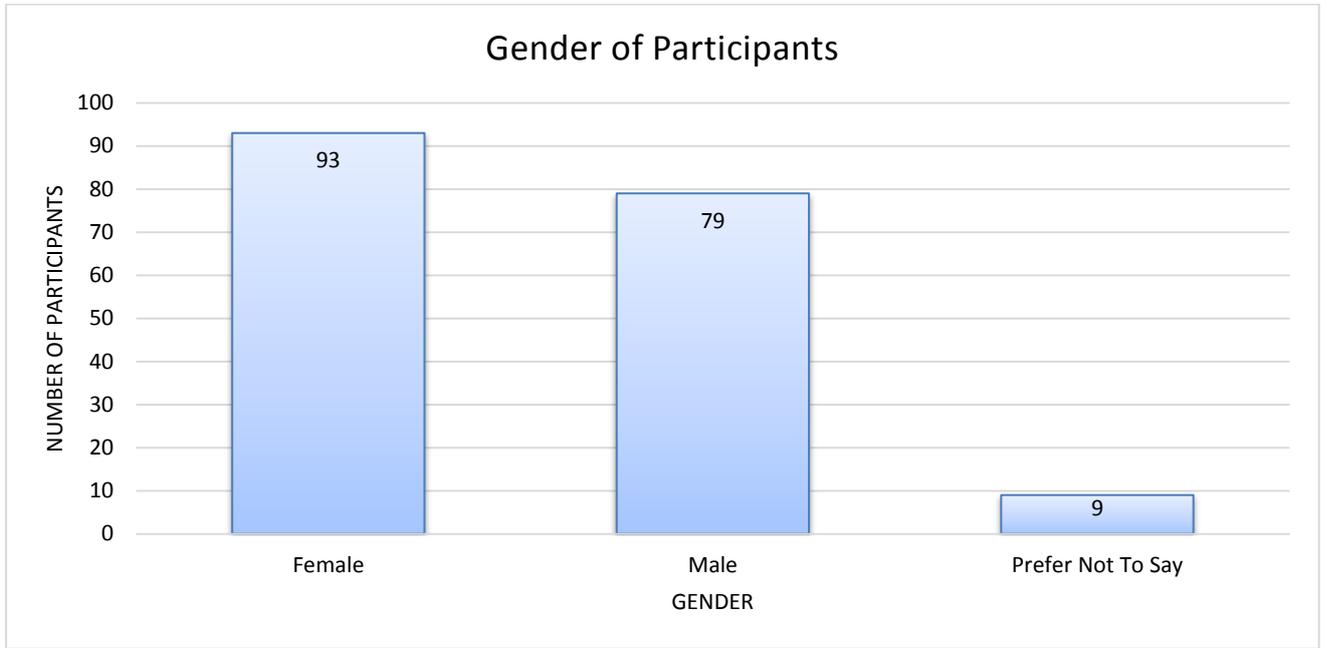
Conversations were had with parents, carers and young people during the Parent Carer Information day, the common theme that arose was around the gap between services for Children and services for Adults, many people that we spoke to said that they felt lost and ignored once they were no longer eligible for Paediatric services. Young people and their parents wanted to be involved in a transition process and believed that planning for this should start at least a year before the transition would take place, ensuring that there were no gaps in treatment, whilst referrals to Adult consultants were made.

12 participants had had issues during the transition from Paediatric services to Adult Services.

## Demographic Data from Feedback Postcards







## Online Questionnaire

The online questionnaire received 58 responses in total, the questionnaire was live from April – September 2017, and was sent via email to all RADDAG members, an email that specifically targeted our members who identify as LGBT was also sent out, and asked members to complete the survey themselves but to also forward the link on to their family, friends and acquaintances from any LGBT support groups that they attend, the questionnaire was also promoted widely on Social Media.

**Participants were asked what they think is good about their GP Surgery, the following summarises the areas covered in the responses received: -**

- Close to where patient live
- Doctors are excellent
- Practice Nurses are helpful
- The surgery and waiting areas are clean
- Staff are friendly
- Minor procedures can be done at some surgeries, meaning that patients didn't have to go to an unfamiliar place

**Participants were asked whether they think there is anything that could be changed at their GP Surgery to improve their experience, the following summarises the areas covered in the responses received:-**

- Appointment System – Can only book on the morning, unsuitable if waiting for carers to arrive and need their assistance, difficult to get through
- Have a named GP at practice – explaining long term conditions or Gender Identity over again to different GP's takes up valuable appointment time
- Car Parking – not enough, especially accessible parking spaces, non-accessible spaces that are there aren't wide enough to get out of the car
- Waiting room call system – Some patients can't see the screen so don't know when it's their appointment
- Waiting Room furniture – chairs are an issue, there needs to be a selection, some with arms and some that are higher from the floor, there also needs to be spaces for wheelchair users to wait without feeling like they are in the way, automated check in systems need to be placed at a height accessible for everyone, but so that the whole waiting room can't see screen
- Seated weighing scales should be more widely available at each GP surgery

- Information displayed in health care settings should represent a wider range of the community
- Better recording of sexual orientation, to avoid having to explain at each appointment
- Further training for staff in Equality and Diversity, highlight the issue of not making assumptions about people.

**Participants were asked to think about when they needed to book an appointment at their GP Surgery, 43 participants responded that booking an appointment was hard, 9 said that it was ok and 6 said that it was easy.**

**Those that felt that booking an appointment was hard, were asked to make suggestions as to what could make their experience easier, they responded: -**

- Have more appointments that can be booked in advance, not just same day
- Have more evening and weekend appointments available as not everyone can make weekdays during the day
- Booking appointments via email
- Make it easier to register for online services, website doesn't always work
- Understand that some people need to book appointments when their carers are available, so same day appointments don't work for everyone and a little flexibility is required, one size does not fit all

**Participants were asked whether their GP and surgery staff were good at communicating with them 43 responded with Yes, however 15 participants responded with No, those who responded gave the following suggestions that could improve communication:-**

- Talk to patient rather than carer/ parent
- Make it easier to book a BSL interpreter for GP appointments
- Make appointments longer, where necessary so that people don't feel rushed and then struggle to communicate.

**34 participants felt that their GP and surgery staff were good at listening to them, however, 24 participants responded that No, they didn't feel that their GP and surgery staff were good at listening to them, the following suggestions were made as to how this could be improved: -**

- More time for appointments, so it isn't rushed
- Listen to patient rather than directing questions at parent or carer

- Discuss all the treatment options available to the patient rather than simply opting for the easiest or cheapest option without listening to the patient's wishes, one size does not fit all
- Understand that patients are often the expert in their own long-term condition and so should be fully involved in all decisions made about their care
- Don't make assumptions

**9 participants thought that it was hard to talk to staff at their GP surgery, 2 participants felt that it was ok, with 47 participants responding that it was easy to talk to staff at their GP Surgery? The following suggestions were made as to how this could be improved:-**

- Reception staff could learn basic BSL
- Loop system doesn't always work, or isn't available, it needs to be checked on a regular basis
- Make it easier to book a BSL interpreter for GP appointments and advertise this
- Ensure that staff avoid making assumptions about people

**19 participants responded that they felt the GP and surgery staff were good at helping them to understand what is happening during and after appointments, 36 said they felt the GP and surgery staff were ok at helping them to understand what is happening during and after appointments, with 3 participants saying that their GP and surgery staff were bad at helping them to understand. Participants were asked to make suggestions as to how this could be improved.**

**Summarising the responses, participants suggested the following improvements:-**

- More time during appointments
- Explain what is happening during an examination before it happens and check that it is okay to proceed
- Write letters in plain English rather than medical speak, include Easy Read documents where needed
- Talk to the patient not the parent or carer

**5 participants thought that they had enough time at their GP appointment, however 53 participants responded to say that they didn't think they had enough time at their GP appointment. Asked how much time they thought they**

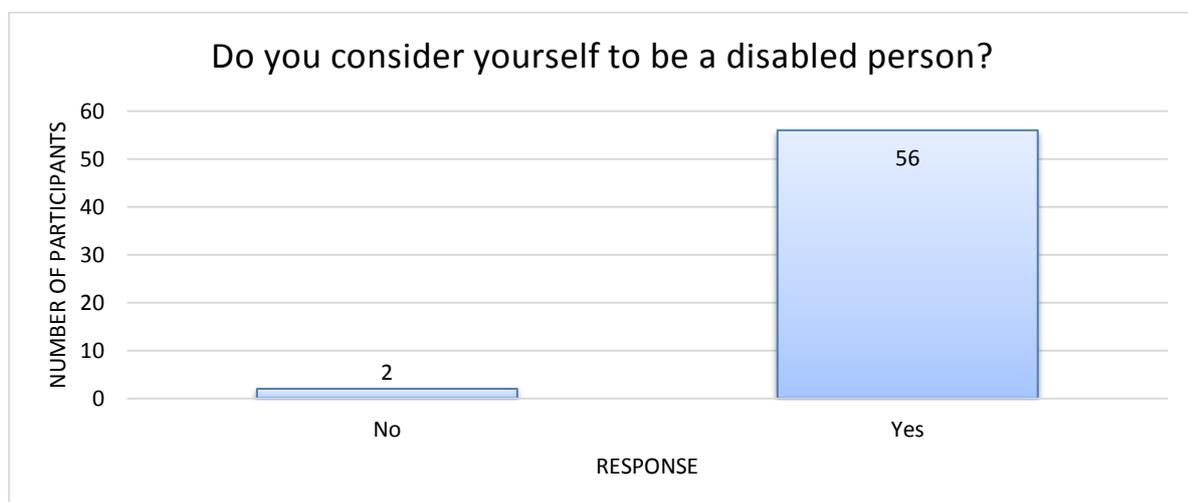
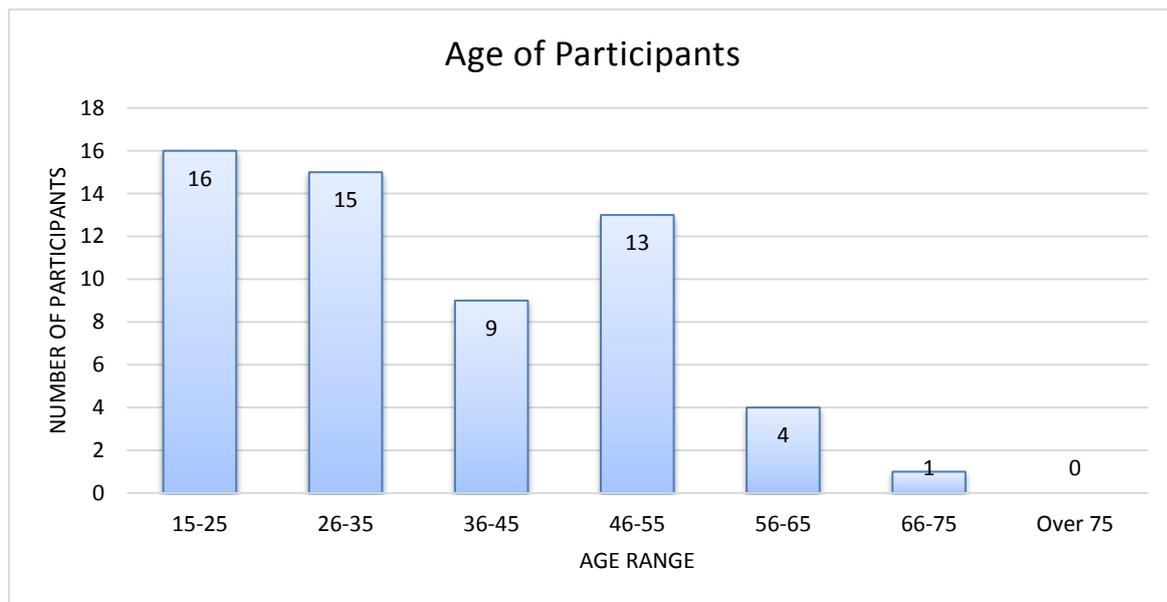
should have for their appointment, from the responses received the following suggestions summarise the responses that were given multiple times:-

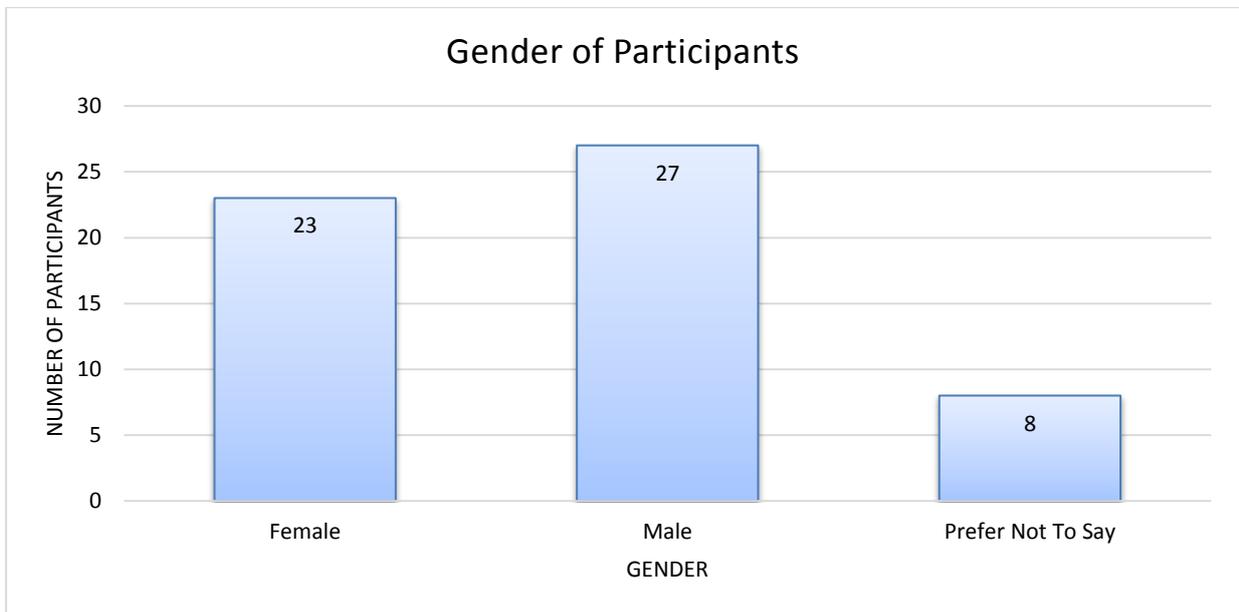
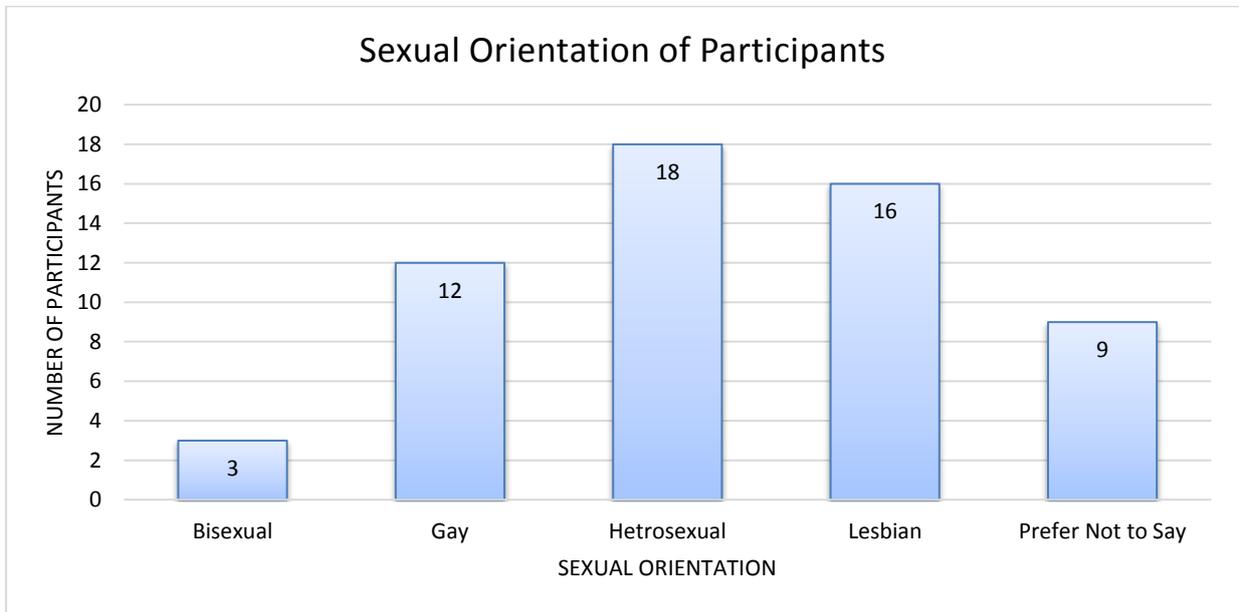
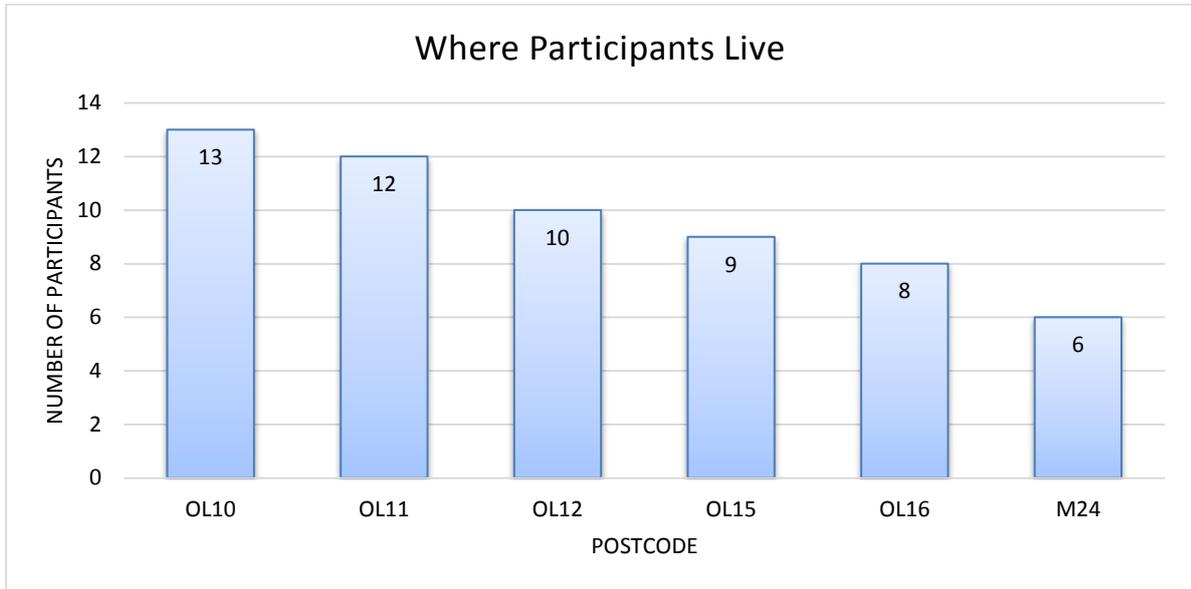
- At least 15 minutes for those with a long term health condition
- 30 minutes for complex cases, even if this means holding a separate clinic after the usual surgery times
- Double appointments. E.g. 20 minutes

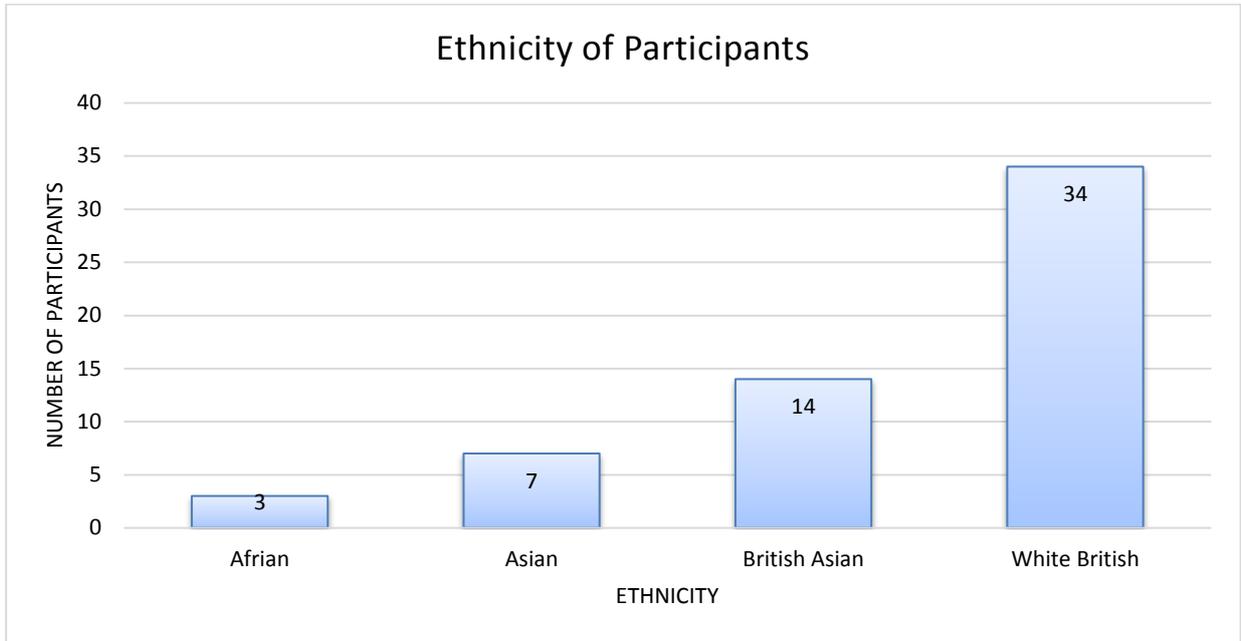
Participants were asked if there was anything else that they would like to tell us about their experience of their GP surgery, in summary those who responded to this question added that:-

- staff are generally excellent, polite and friendly
- the appointment system doesn't work
- GP's don't have enough time to spend with each patient.

### Demographic Data from Questionnaire Respondents







## **Engagement with PossAbilities Service Users**

In order to find out about the experiences of people with a Learning Disability we made contact with the PossAbilities Service. Rachel Law, their CEO suggested that we attend their service user advisory group and ask whether they thought that PossAbilities service users would be interested in being involved in a number of engagement activities. We produced a draft questionnaire in Easy Read format, supported by pictures and sent this to PossAbilities staff to discuss with Service Users prior to the service user advisory group, this enabled them to give us their comments and suggestions at the meeting. This feedback from 26 PossAbilities service users ensured that our final questionnaire was accessible for people with a learning disability. At the service user advisory group, it was suggested that a questionnaire should be written and distributed to PossAbilities Staff, as they support a number of people with a learning disability and therefore have an overview of service provision, examples of good practice and suggestions as to whether there are any gaps in services for people with a learning disability. The service user advisory group requested that a representative from the CCG and RADDAG attend a future meeting of their group, to feedback any changes that have been made to services as a result of their feedback and that they would be more than happy to be involved in any future engagement activity that was planned.

Responses from 25 questionnaires are summarised below, however the full list of responses to these questions can be found in the Appendix.

### **Participants were asked to think about when they make an appointment and visit their Doctors Surgery.**

Participants talked about the surgery being near to their house and therefore easy to access, they also said that staff were respectful, helpful, polite and that the Doctors were kind. In addition they added that they felt listened to and were often seen quickly.

Participants were asked what their Doctors Surgery does well, responses centred around being able to get an appointment easily, looking after patients when poorly, keeping patients healthy, keeping a track of medicines and making patients feel comfortable and therefore confident to go on their own, without support.

Participants were asked whether there is anything that needs to change at their doctor's surgery to make it better, this question generated a mixed response with

half of the respondents commenting that 'no' nothing needed to change. However there were some suggestions of what needed changing at their doctors surgery to make it better, which included having longer appointments and the ability to make appointments in advance rather than just having them available on the day.

Participants were asked whether staff at their Doctors Surgery gave them information about their health condition or treatment in a way that they can easily understand over half of the respondents simply answered yes to this question, with 2 participants suggesting that the doctor does try to help them understand but sometimes their staff or family have to help with this.

### **Participants were asked to think about when they make an appointment and visit their Dentist Practice.**

The first question in this section asked participants what was good about their Dentist Practice. One respondent replied that they didn't go as they had a bad experience in the past, but the remaining participants responded that their Dentist practice explain what treatment is needed, they keep their teeth healthy and clean and they get seen quickly. Participants were happy with the way in which appointments were made, as dentists were more likely to send out appointments in the post, so that patients had a written record of when they needed to attend and a phone call reminder. A number of respondents felt confident enough to attend dentist appointments on their own.

Participants were then asked what their Dentist Practice does well, 3 responses were that 'they treat me well', participants also talked about how their dentist is 'really nice', hygienic, make sure that their teeth are cleaned properly and keep them calm.

Participants were asked if there is anything that needs to change at their Dentist Practice to make it better of those participants who responded to this question 6 said that 'no' there was nothing that needed changing with 1 respondent suggesting that waiting times need to be reduced.

When asked if staff at their Dentist Practice give them information about their treatment in a way that they can easily understand, all participants responded with yes, with the additional information that they tell the patient what they are going to do and ask if it's okay.

**Participants were then asked to think about any appointments that they've had at a hospital, when they've been to Accident and Emergency (A&E) or when they've stayed on a ward**

The first question asked participants what was good about the hospital. Participants talked about staff being polite and caring. They also mentioned food at the hospital being good.

Participants were asked what the hospital staff did well respondents commented that staff were polite, friendly and helpful and this was a comment that was repeated by numerous respondents. The fact that hospital staff kept participants 'safe' and the care was good was again repeated numerous times.

Asked whether anything needed to change at the hospital to make it better waiting times being too long was mentioned, participants thought that hospitals needed better beds and food and that the waiting times for outpatient appointments were too long, respondents thought that there should be more doctors and that they could explain things better to them about their treatment.

The final question about hospital visits and stays asked whether staff at the hospital give participants information about their treatment in a way that they could easily understand. Half of the participants responded that yes they had received information in a way that they could easily understand, however 3 respondents said that they thought the hospitals could explain things better, and that the health care staff should talk to the patient rather than anyone accompanying them.

**Participants were asked to think about any other time that they have received treatment for their health. For example at an Opticians or podiatrist**

The first question asked what was good about when they received treatment other than that already mentioned in the questionnaire. Participants responded with positive replies regarding eye tests that they have attended, with opticians sometimes using pictures and photos for those with a learning disability, some participants said that they felt confident in attending on their own.

Participants were asked as to whether there was anything that needs to change to make things better, not many participants responded to this question, however of those that did 4 participants said that 'no' they didn't think anything needed to change to make things better. However of those that did provide a response they said that the eye test could be difficult in parts and that they think more pictures

would be helpful, so it seems as though not all opticians are offering people with a learning disability the option of an eye test using pictures as oppose to letters.

The final question in the survey asked participants whether they have a general health check, with their Doctor or a nurse, every year. Not all participants responded to this question however of those who did 7 said that they did have an annual general health check, with 2 saying that no they didn't have a health check

### **Demographic Data**

Not all respondents filled in this section of the questionnaire, during the pre-consultation stage working with PossAbilities service users, a number of participants expressed their dislike of the demographic data collection section of the questionnaire, as they felt that it was asking for information that was too personal, especially the question around sexual orientation. Following a discussion at the service user advisory group it was agreed that this section would stay in the questionnaire but it would be made clearer that participants didn't have to fill in this section if they felt uncomfortable. Further works needs to take place with PossAbilities service users to explain why this information is requested, and how it is/ isn't used. As limited responses were received to this question, data is presented below in a narrative format as graphs wouldn't be reflective of all participants who took part.

### **Disability**

9 participants identified as a disabled person, whilst 10 answered that no they would not consider themselves to be a disabled person and 1 participant preferred not to say.

### **Area of the Borough**

Of those Participants who replied to this question 3 were from Heywood and 4 were from Rochdale.

### **Sexual Orientation**

5 participants identified as Heterosexual, 3 as gay, 3 preferred not to say

### **Gender**

7 participants identified as male, with 3 female

### **Ethnic Background**

9 participants identified as White British

## Engagement with PossAbilities staff

The PossAbilities Service user advisory group, at the pre-consultation focus group suggested that staff at the service may have a valuable overview of health care services for people with a learning disability and so a questionnaire was produced and distributed amongst staff. 19 members of staff responded to this and they gave extensive narrative responses, which are summarised below, their full responses have been written up in full and included in the Appendix.

Participants were asked whether they had any suggestions for improving local health care services for people with a learning disability. The following were the key themes identified by PossAbilities staff: -

- Quicker referral times
- Staff given more training to interact with people with a learning disability
- People with a learning disability should not be kept waiting in busy waiting rooms for long periods as they may find this stressful
- More Learning Disability Nurses available in hospital settings
- Treat all individuals equally
- More person-centred care
- Health Care staff to be monitored more closely to ensure best quality support
- Often medical professionals do not know how to speak to people with learning disabilities. They speak to the carers before the person
- Hospitals really poor when it comes to supporting people with a Learning Disability. They leave them alone and often in wet beds, leave food and drinks at side of bed instead of sitting and helping the person.
- Easy read information should be more readily available in all health care settings
- Joint working with provider agencies
- Regular breast and testicular screening for individuals with a learning disability. It would be helpful to have allocated nurses to demonstrate how to check for lumps. It seems that you are only screened once a lump is found
- Being mindful that some individuals with a learning disability find it difficult to have procedures done. It only adds to their anxieties when these are cancelled/rearranged.

**Participants were asked whether they had examples of good practice when people with a learning disability have accessed health care services. The following were the key themes identified by PossAbilities staff:-**

- Talking directly to the individual, being patient and giving individuals the opportunity to express themselves
- One participant highlighted that she supported a lady to attend a GP appointment as she was having 'lady problems'. The nurse was very supportive to this lady and made the experience as stress free as possible for her by explaining everything that they were going to do, they addressed her at all times. The first examination was too distressing for her, so they found a better, less intrusive way to examine her, making the experience less traumatic for her
- The Community Team for learning disabilities have a really good team. Especially Nurse Carol Lonergan who deals with people with a learning disability who have to go into hospital for treatment
- Paul Cheetham's opticians in Rochdale is really good at treating people with a Learning Disability
- The community dental team are very good, very helpful and respectful, with a high standard of work and care
- A participant commented that she had seen plenty of good practice in which staff offer choice and are inclusive. This can be seen when hoisting a person as staff will talk to the person, offer them choices in terms of comfort and where they are being hoisted to
- Treatment support with dental work at Fairfield hospital is good.

**Participants were asked whether they thought there were any gaps in local health care service provision for people with a learning disability. The following were the key themes identified by PossAbilities staff: -**

- One participant responded that more staff training is needed as not all doctors, nurses, medical professionals are trained to care for individuals with a learning disability
- Ensure that health care staff talk to the patient and not around them
- Affording people with a learning disability the same as others without learning disability. RE: investigation, treatment and operations
- There is a real need for more learning disability nurses and staff, especially in hospitals

- More experienced professionals are required when supporting people with a learning disability
- Not reading information that's specific to the person.

**Participants were asked whether they had any other comments. The following suggestions were made by PossAbilities staff:-**

- More services providing home visits for people with a learning disability and autism
- Always talk to the individual
- The traffic light passport was identified as a fantastic idea, however not all hospital staff refer to this, and if used more widely would enable hospital staff to have a better understanding of the individual and provide more tailored care.

### **Summary**

Staff from the PossAbilities service were concerned with the seeming lack of training for health care staff in working with people with a learning disability, they suggested that staff should be given more training to interact with people with a learning disability, especially when it comes to supporting people with a learning disability in Hospitals, so that they are not left alone to eat and drink. Talking directly to the patient was an important point highlighted by PossAbilities staff, rather than talking to any accompanying carer, PA or family member. Having easy read information available was a further suggestion as to how local health care services could be improved.

Staff from the PossAbilities service named specific services who they believe have shown examples of good practice, this included the Community Dental Team, Paul Cheetham's opticians and the community Team for Learning Disability, specifically Nurse Carol Lonergan, who deals with people with a learning disability who have to go into hospital. Staff suggested that these services are very helpful, respectful and show a high standard of work and care.

Staff further suggested that good practice would be to offer people with a learning disability choice and again talk directly to them rather than to whoever was accompanying them.

PossAbilities Staff suggested that there were a number of gaps in local health care service provision for people with a learning disability, the feedback focused on health care staff training, that specifically focuses on supporting people with a

learning disability and ensuring that health care professionals speak directly to the patient rather than people attending to support the patient.

Further comments added by PossAbilities staff focused on more services providing home visits for people who may experience anxiety when attending appointments such as people with a learning disability and those on the Autistic Spectrum. Staff also highlighted once again the importance of talking to the patient rather than those supporting the patient. Finally staff suggested that the traffic light passport is a fantastic idea, however not all hospital staff refer to this, but if they did it would enable staff to have a better understanding of the individual, and therefore provide a better patient experience.

### **Demographic Data**

Not all respondents completed this section and so, data is presented below in a narrative format as graphs wouldn't be reflective of all participants who took part.

#### **Age**

2 participants were aged between 18-29, 3 were aged between 30-39, 2 participants were aged between 40-49, 2 were aged between 50-59.

#### **Disabled Person**

1 participant considered themselves to be a disabled person, whilst 8 did not

#### **Postcode**

3 Participants were from the OL10 postcode, 1 participant was from the OL15 postcode, 2 were from the M24 postcode and 2 participants were from outside of the Rochdale area.

#### **Sexual Orientation**

7 participants identified as Heterosexual and 1 as Gay

#### **Gender**

6 participants were Female and 3 participants were Male

#### **Ethnic Background**

9 participants identified as White British

## Recommendations

Taking into consideration the data received from all engagement activity, patient experience postcards, online questionnaire, focus groups and questionnaires with the PossAbilities service users and staff the following recommendations are made: -

- Additional Training is required for health care staff to ensure that they understand the needs of people with a Learning disability, co-designed with people with a learning disability and their supporters
- Additional training is required for health care staff with a focus on LGBT issues, co-designed with people who identify as LGBT
- Additional Training is required for health care staff to ensure that they understand the needs of all disabled people including how to make their premises, booking process and appointments more accessible, include information on how health care staff can book interpreters
- A campaign should be designed to ensure that health care professionals speak to the patient, where possible, rather than those who have attended the appointment with them.
- Ensure that staff understand not to make assumptions about the ability of patients to understand information
- Ensure that appropriate Easy Read information is readily available in all health care settings
- Ensure that information displayed in health care settings reflects the diversity of the community
- A campaign should be targeted at all health care settings to use the Health Care Passport, which assists with understanding a person with a learning disability
- Ensure that accurate information is sent out with appointment letters that explains parking provision at hospitals and doctor's surgeries and gives details of other services that may be available to assist with patients attending appointments, such as the volunteer drivers service and patient transport.
- When commissioning services consider the cost implications of patients attending the premises in which the service will be delivered, are there appropriate car parking facilities, transport links and are the buildings and surrounding areas accessible for disabled people.

- Work with children who have Long Term Health Conditions, their parents and carers in developing a local pathway for transition from Paediatric to Adult Health and Social Care Service
- A Representative from the CCG and RADDAG attend a future meeting of the PossAbilities service user advisory group to explain what changes have been made to services as a result of their feedback
- Continue to collect service user experiences to inform future service delivery and the commissioning process.

## **Thanks**

We would like to extend our sincere thanks to all participants who took the time to speak to us at an event, attend a focus group or fill in our online questionnaire.

We would especially like to thank the PossAbilities service users and staff who assisted with our pre-consultation focus groups and enabled us to produce an easy read questionnaire, which can now be used as an example of good practice for future engagement activities.

## **Appendix**

### **All Responses from Patient Experience Postcards**

#### **Responses from Feedback Postcards**

Tell us your experiences both positive and negative of local health care services, including your Doctors Surgery, Dentist Practice, Opticians or Hospitals

#### **Issues Raised**

##### **Accessibility**

I have to get someone to ring up for a BSL interpreter every time I have an appointment, I don't see why they can't just have a note on the system and book one for me

I've found a dentist that will treat me even though I struggle with aesthetic because of my condition

Chairs in the waiting room don't have arms, it's really hard to get up

Doctor's surgery has a note on the system that I'm blind, so will ring me rather than sending out letters

My doctor gave me a pot for a sample but I can't open the lid and don't want to ask my family for help, it's embarrassing, no one at the surgery would help me

Car parking at the doctors is terrible, there's never anywhere to park

I was referred to a consultant, but my doctor didn't tell them that I was deaf, I couldn't go to my first appointment as no interpreter was available, surely they could write this on the referral form so they're prepared for when I go to the clinic

Chairs in the waiting room are too low down

There aren't enough car parking spaces

I have to go to hospital to be weighed, they should have sitting down scales at my doctors

It takes me a long time to transfer onto the dentist chair, so they do it while I'm in my chair and it's uncomfy

I need space to wait in my wheelchair, but the waiting rooms are so overcrowded, I feel like I'm in the way

I can't find a dentist that has a downstairs consulting room and a ramp to the entrance, so I haven't registered with any

Dentists are usually in old buildings, I don't think there are any that I can get in

I can't get out of my wheelchair on my own, so I don't go to the dentist, I wouldn't be able to get on their bed, I don't think they'd help me

I'd like to see a dentist but I can't find one that I can get into, they should do a home visiting service

I go to the opticians in town and they see me in a room downstairs because I can't get up the stairs, they're really good

I can't see my name on the screen at the doctors because it's too high up, the doctors don't come out of their room to shout me so I've missed a few appointments

I had to go for a breast screening in a car park, it was a bit worrying at first but the service was excellent

I don't think there's many opticians that I'd be able to go to, I can't transfer out of my wheelchair on my own, so just don't go

My pharmacy explain all the instructions on any new tablets that I get

The volunteers at the hospital entrance are really helpful, they have maps and direct people where to go

My dentist doesn't have a car park, so I have to get a taxi there, it's really expensive

I can't use patient transport, because of their rules, so I have to rely on family but they can't always get time off work to take me

The waiting rooms are too small, so I can't really sit anywhere in my wheelchair without being asked to move

I don't like travelling out of the area for appointments; the hospitals are too big and I don't know my way around

There isn't enough parking at the doctors, if I can't park, I can't go to the doctors, and I've missed appointments because of this

The doctor can't help me onto the bed so I don't have smear tests because I don't want my supporter to come with me

There's too many chairs in the waiting room, so I feel like I'm in the way and having to move

There should be spaces in the waiting room for wheelchairs, I need somewhere to wait

The chairs at the hospital don't have arms, so I struggle to get up when I've been waiting a long time

I struggle to get up off the chairs at my cardiology appointment, they don't have arms and are low down. The chairs at my GP's are much better

I was sent an appointment at Fairfield Hospital at 9am, but the busses don't run that early so I couldn't get there, patient transport won't help and volunteer drivers can't guarantee that they'll wait for you, so I had to cancel the appointment

Patient transport won't take me to hospital because they say I can lift my legs to get in a taxi, but I can't afford a taxi from Littleborough to Fairfield

I would like to book a BSL interpreter for my GP appointments, I don't like my brother having to be at my appointments interpreting for me, but I don't know how to do this and I can't ask the receptionists

Busses don't run at the right times, to make it to appointments

The hearing loop never works in the doctors so I can't use my hearing aid and the receptionist ends up talking loudly so the whole waiting room can hear

My doctor will book an interpreter for me, but sometimes they don't turn up so I struggle at my appointments

My doctors will only take requests for repeat prescriptions over the phone, I can't ring them so I have to go into the doctors every month, it's annoying

I can collect my repeat prescription from the pharmacy, they order everything for me and let me know when it's ready, it's easier now that I don't have to go into the doctors first

Pharmacy is always busy so doesn't take time to explain any new medication to me

I asked my doctors for easy read letters from the surgery, the receptionist said they didn't have any and that my carer should read my letters for me if I don't understand

Amusing questions during a smear test that could have been avoided if nurse had asked my sexual orientation before starting test. Asked If I could be pregnant

LGBT health issues are much more than just sexual health, my GP needs to realise this

My daughter has autism, she was distressed in A&E staff took her through to a private room to wait and saw her as quickly as they could, really impressed

### **Treating Patients as an individual**

My GP talks to my carer or mum rather than me, if they explained things properly then I'd be able to understand

I might be a wheelchair user but I have the ability to understand what's being said to me, my legs might not work but my brain does

My GP needs to be more descriptive when he's doing an examination, I'm visually impaired so can't see properly what's being done, just talking me through it would help

The doctor assumed that I needed to be sent to the sexual health service, just because I told him I was gay, they just make assumptions all the time so it's no wonder people don't tell them

The posters in the surgery should be for everyone and reflect the whole community, not just white British straight families

I need pictures at my opticians appointment, rather than letters as I get them mixed up, just because I don't look disabled the optician assumes that I will be okay with letters, they should ask everyone at the start of the appointment and not make assumptions based on appearance.

Embarrassing situation with GP, asked if I was married, said yes, and automatically assumed that I had a 'husband' because I'm a woman, when in fact I have a wife, don't make assumptions.

Talk to me not my carer, I do understand if things are explained to me in language that I understand

Doctor assumes that because I'm a wheelchair user that I won't understand his questions and always talks to my PA. They shouldn't assume anything and talk to the patient

The Doctors should ask sexual orientation questions at the first appointment and mark it somewhere on the system, it would stop embarrassing questions further down the line

### **Consistency of care**

I can't see the same doctor for every appointment, so I have to explain my long term condition to each new doctor, which takes up a lot of the appointment time, even if they could just read some of my notes before I come in that would help a lot

I moved house, it wasn't far away from my old house, but I had to move doctors, they know me so I wanted to stay there but they wouldn't let me

Physio discharged me after one visit, they used to do lots of appointments

My son's got Autism, so it would really help if we could see the same doctor each time, but it just never works out and we have to see someone different

Discharged from pain clinic after many years due to changes in the service

We see lots of professionals for my daughter, but none of them talk to each other or even read each other's letters, so we have to explain our situation lots of times which takes up valuable appointment time

The criteria to be referred to services seems to be different dependant on your GP, some people get referred but I can't get a referral

Pain clinic won't see me anymore, I've been going for years, but the service has just stopped

Doctor says I can't have injections at the pain clinic anymore, I think it's because of cost, but they say I don't need them anymore, I've been having them for years, so I don't see how they can just stop it

I wish I could see the same doctor each time I go to the surgery, it's tiring having to explain my health conditions every time I go

Different Doctor every time I go to see them

Hard to see a female doctor, even if I try to book in advance

I hate explaining my mental health issues to different doctors, my usual GP understands but I always see different people

I'd prefer to see the same doctor all the time, rather than different ones

### **Appointments**

I can't get an appointment with my doctors, so I just go to urgent care, it's easier

It takes so long to get through to the doctors in a morning, most of the time the appointments are gone, so I have to try again the next day

It's difficult enough getting my carers to come at the times I need them, but then when I need to change things so that they can come to doctor's appointments with me it's even more difficult

Unable to get doctor's appointment in advance, have to call on the same day but appointments are all gone by the time my carers have been and I'm able to get to the phone

My daughter really struggles in crowded places, so the doctors waiting room is a scary place for her, sometimes we have to wait outside and the receptionist comes and gets up

They sent me a letter saying I hadn't attended my appointment, but they hadn't even sent me one, they discharged me because I didn't attend but I didn't even know about it

They keep cancelling my appointments, I think it's to keep waiting times down

It's silly that we have to ring loads of times to get through to the surgery in a morning, it's always worse on a Monday

The referral time for a heart consultant was months, this is for a serious issue, and I think I should be seen sooner

The surgery won't let me have an appointment at a time that my carer can come with me and the care agency won't change the time that my carer comes

Some mornings I've rang the doctors over 100 times before I've got through

I have to wait in a queue outside the doctors at 8am just to get a same day appointment

My consultant appointment keeps getting cancelled

Sometimes it's easier to go to the Urgent Care to be seen, I have to wait a while, but it's better than waiting weeks to see the GP

Apparently there's more appointments online, but I can't get online so I think I'm missing out on appointments

My operation was cancelled days before it should have happened, you build yourself up and then it's cancelled

I can't wait in the waiting room with everyone else because of my anxiety, so the receptionists let me wait in an empty room if they have one and come and get me when it's my appointment

I can't get an appointment with the chiropodist, I used to have one, but they won't see me anymore, they're always moving the goal posts

The out of hours GP appointments are excellent, I work so struggle to go during the day, but I can go at night now

I can only see my doctor for 10 minutes, but I have a few long term health conditions and they will only let me talk about one problem at a time, I can't book a double appointment because there are never any available next to each other

Doctors' appointments are not long enough, I see my consultant and he will take as long as I need, sometimes an hour to listen to me and work out a plan, but my GP doesn't give me enough time

After hours GP provision is great for those of us who work

The receptionist asks why I need an emergency appointment, I don't like telling them, they aren't medically trained so don't need to know

My doctors are really good at offering phone appointments, if I don't need to go to the surgery, it makes it easier for me

Waiting times at the urgent care are ridiculous

I'm so glad I can get my contraceptive implant at my GP surgery, it was embarrassing having to go to the sexual health clinic

Getting an appointment for my son's mental health issues is really difficult

More doctors and nurses should be recruited to fill the spaces

### **Transition from Child to Adult Services**

Issues with getting an appropriate wheelchair for child, wanted one that could be self-propelled but given a pram style chair, not dignified for child

Why do they give out prams for children who could learn to push their own wheelchair, it's as though they think the children should stay dependant on their parents

I wanted my carer to come to my appointments and not my mum, but my mum was insistent that she came with me and the doctor wouldn't tell her to leave the room as he thought I wouldn't understand without her there

I asked our GP what would happen when my son reached 18 and would he need to be transferred to adult services, he said we might have to be re-referred but we've built up a great relationship with our current consultant, who really understands my son's needs, we're worried for his future

It's as though when you reach 18, no one is interested anymore, we don't have help like we did when my granddaughter was younger, we don't have the backup from school anymore and feel lost

Health Care professionals should recognise that the patient and their parents usually know what's best, we should be involved in the transition between child and adult services and be listened to, we've been there for the whole journey and often have a broader knowledge of the situation

Transition to adult services should be planned at least 2 years in advance, so that a smooth hand over can take place, we've been discharged from children's and are still waiting for an appointment with adult provision it isn't good enough, there should be a proper plan

Transition planning is none existent, it's as though it's a surprise when they need adult services

Told to buy large nappies instead of having adult incontinence pads for my daughter, she's only small, but it's a matter of dignity

Services seem to stop when they aren't children anymore, it's so much harder to get adult services

Mental Health services seem to stop when they reach adult age

Services seem to work in isolation, no one talks to each other, I feel like a go between for all my son's doctors

My daughter has lots of hospital appointments, but school always complain that she has to go during the day, I'm not sure what they expect me to do

It feels like a fight for every service my son needs, sometimes I feel like a nuisance but I just want what's best for him

### **Other**

The traffic light passport for people with a learning disabilities is really good, but not all hospitals know what it is, surely they all have the same training.

Opticians spotted abnormality in eyes that A&E missed, very impressed

Waiting times at A&E are too long

Shouldn't have to wait so long at A&E

The wait for wheelchair services is a while, but it's good they assess you and then give you the chair you need, it isn't like that in other areas

Don't agree with not supplying gluten free food on prescription, I hope Rochdale carry on supplying the basics, it's so expensive at a supermarket even just for bread

Urgent Care waiting times are too long, how is it right that ill people have to wait so long to be seen, they need more staff

People just go to Urgent Care because they don't want to wait for a GP appointment, they should tell people who don't need to be there to go home

The ambulance took me to Salford Royal, but my family don't drive so they couldn't visit me

It's okay if you drive, but when you have to get busses and taxis to appointments it's expensive and takes all day

Parking at the hospital should be free, at least for the first hour

I accidently missed an appointment to have my eyes checked by the diabetes nurse, I've tried ringing up for another appointment but they never answer the phone

They should tell you about the volunteers drivers scheme when they send appointment letters, it's a good service, but if people don't know about it, how can they use it

### **Doctor's appointment and visit to a pharmacy**

I had a cold and sore throat last week but couldn't get an appointment at the doctors because they had no appointments. The receptionist told me to go a pharmacy, I went to the one near my house they were very helpful.

When I phone my doctors surgery for an appointment I was told that there wasn't any available for two weeks.

The staff at the chemist shop in Whitworth are always very nice and helpful.

Rochdale should have the A&E back, it's harder to get to Oldham and Bury

My doctors sends my prescription to the pharmacy and then they deliver it to my house, it's great when the system works.

### **Car Parks**

Why is parking at the hospitals so expensive

There's never anywhere to park at Nye Bevan, and you can't park on the streets around, I'm not sure what they expect people to do

They should think about car parking when they build new hospitals, or move more services there, it's a stressful time we shouldn't be having to worry about car parking

There is not enough parking spaces at Fairfield, Oldham or North Manchester hospitals

Why do we have to pay for parking at Whitworth Health Centre

Whenever I go to Rochdale Infirmary I can never get a disabled parking space.

I always struggle to park at Oldham Royal because there is not enough parking spaces.

Croft Shifa never has anywhere to park, the spaces are always full

The ramp from the top car park at Fairfield Hospital near to A&E is too steep to walk down, I don't know how people in wheelchairs manage it

Hospital car parks should be free

It's impossible to park at Fairfield Hospital

I need to park as close as possible to the Hospital, but the blue badge parking is always full

I can't climb up the hills around Fairfield Hospital

Car parking charges have increased massively, they shouldn't be 'taxing' ill people

### **Hospital appointments and visits**

I live in Rochdale and struggle to get to Oldham Royal for hospital appointments because I have walking difficulties and the carpark is too far from the outpatient clinics.

I struggled to visit a relative at North Manchester hospital when they were in hospital because I do not drive and had to travel on buses.

My mum does not speak very good English and needs an interpreter we find it very difficult trying to arrange for an interpreter for hospital appointments. We were told that family members cannot interpret for her but then we have to wait ages for appointments that an interpreter can come to

I wished they had kept the maternity services at Rochdale Infirmary

They need more interpreters; it's difficult to book them for the right date of your appointment

I can get a BSL interpreter easily for my consultant appointments at the hospital, but the receptionist at my surgery tells me I have to bring my own interpreter to see the GP, but it can't be family

### **Stay in hospital**

I recently had to stay in hospital the nurses were very nice and worked very hard.

It's good that you can visit people on wards at any time,

They should enforce the no more than 2 people to a bed rule for everyone

My relatives struggled to visit me when I was in when in hospital because they don't drive and had to travel on buses.

The food isn't amazing, there should be more choice, not everyone wants bland food or spicy curry

Care at Rochdale Infirmary's new facility is excellent

I had a menu with pictures on, so I could choose my own food

The ward was really clean while I was there

My opticians is really good, they offer hearing tests at the same appointment as my eyes

Opticians should tell you that you don't have to buy your glasses from them, I went with my mum and they were pressuring her into buying there and then but I knew she could get them loads cheaper online, it's only because I was there that I knew to ask for her prescription, but they don't tell you that.

Volunteers at the hospital are helpful

When I was in hospital they moved my wheelchair away from the bed, I asked them to move it back, but they said it was in the way, I think I should have my wheelchair with me at all times, it's like taking someone's legs away

Lovely doctors and nurses at the Infirmary, very helpful

The volunteers who help people get around the hospital are a great idea

I have a long term health condition and I am very happy with the health care that I receive.

I was very impressed with the service we received at the X ray department at Manchester Children's Hospital. The staff were very helpful and patient.

Why is the TV system on the wards at the hospitals so expensive to use.

The practice nurse at my GP surgery is very helpful

I wish I could book appointments with my GP Online it would be easier than trying to get through to the surgery via the telephone because it is always engaged.

I do not like going to hospital appointments because I know that I will have to explain my gender identity several times during my appointment and very often staff are not discrete in the ways they ask. I belong to a trans support group and other members of the group have had the same experiences.

I avoid going to my GP's surgery because last time I went I had a very embarrassing experience with the receptionist. She asked rather loudly 'are you a man or a woman?'

Why does it take a long time to get an appointment with the Gender Identity Services?

It is very difficult to access Trans specialist services due to long waiting lists.

Trans people are discriminated against when it comes to cancer screening (cervical, breast or prostate) due to a lack of trans awareness by health service staff.

I am an asylum seeker from South Africa I am having difficulty finding a dr.

I am a refugee from Uganda when I go to hospital appointments I have difficulty getting an interpreter to help me talk to the drs.

TV is too expensive at hospitals

Choose and book service is excellent, I like that I can pick which hospital I go to

It's good that they let you watch TV for free during certain times, but it's at night when you're on your own that you need it most and I can't afford it

I like the more open visiting hours at the hospital, it's so much easier

E-referrals are confusing, got a letter to say I hadn't booked my appointment yet, but didn't have a password, turns out the doctor should have booked the appointment for me there and then but didn't, I had to ring the medical secretary to get it sorted, adding extra time onto my wait

Too ages to get my letter through to see the consultant, then they cancelled my appointment 3 days before I was due to go, I'm still waiting for a new appointment

Got to the hospital to be told my appointment had been cancelled and would have to be rearranged, I'd wasted money on a taxi to get there, they could ring and let people know

They should have more posters and leaflets showing different families, rather than just your typical mum and dad with kids

My dentist is really kind, the nurse holds my hand when I get scared

I get a free teeth clean when I go to my dentist

School complain when I take my son out of school for appointments, but the hospital consultant doesn't offer evening or weekend appointments, so I'm not sure what I'm supposed to do

## **All Responses from PossAbilities Service Users**

**Think about when you make an appointment and visit your Doctors Surgery, sometimes these are called GP practices**

### **What's good about your Doctors Surgery?**

- It's near to my home it has easy access.
- I go with mum, they talk to me and my mum. I have my blood taken
- It's near to my house
- Near by
- They look after me, they are respectful
- Sometimes I get seen quick
- They listen to me
- Very helpful
- Easy to get to
- I go with my carer. She talks on my behalf
- It's not too far away about 10 minutes from my house
- They are polite and discuss things with me
- It's near my house
- The doctor is kind
- The doctor talks explain things to me
- Near me
- I like the Doctor
- They care
- The receptionist is nice
- The receptionist helps me check in for my appointment
- They look after me
- They help me get medicine

### **What does your Doctors Surgery do well?**

- I can get appointments easy
- They have looked after me when I have been poorly
- My doctor will give me medicine to make me better
- Keeps me healthy
- I go with staff sometimes and sometimes on my own, when I go with staff they speak to them not me
- They help me understand

- It's easy to get an appointment, my staff go with me
- They help me to stay healthy, I go with staff
- I can see him quickly
- They keep track of my medicine

**Is there anything that needs to change at your doctor's surgery to make it better?**

- I want to make appointments in advance rather than on the day
- Need to make appointment on the day instead of in advance
- I think it's ok
- Not really
- No
- Short appointments, should be longer
- Shorter waiting times
- I think it's ok
- Sometimes it can be hard to get an appointment
- No
- No
- Appointments are hard to get
- I don't like ringing in the morning
- My carer has to ring in the morning to get an appointment, but it takes ages to get through, so they have less time to get me up
- It takes too long to get an appointment
- They should have easy read and pictures on their leaflets
- Needs to be less people in the waiting room, it's too busy
- No
- Appointment's aren't long enough, it takes me ages to explain things so I need more time, I don't like feeling rushed
- They told me to register online to get an appointment but I don't know how
- They need to talk to me, not my mum

**Do staff at your Doctors Surgery give you information about your health condition or treatment in a way that you can easily understand?**

- Yes
- Yes
- He does with my carers help
- Yes

- Yes they do
- Yes
- Yes
- Yes
- They try to help me understand. I have communication problems, and my staff often need to speak on my behalf
- Yes but my mum helps me
- They explain things to me before doing anything
- They don't talk to me
- They need to talk to me not my staff
- I can't always understand the letters they sent me
- My mum helps me
- The doctor is nice
- The receptionist writes my appointments down for me
- I've got a passport that they fill in when I go to hospital
- They talk to my carer
- They don't talk to me

**Think about when you make an appointment and visit your Dentist Practice.**

What's good about your Dentist Practice?

- I don't go. I had a bad experience in the past
- My dentist sends for me. My mum goes with me
- They keep my teeth healthy and clean
- They explain what treatment I need
- They keep my teeth clean
- My dentist is very good
- I get seen quickly
- They are good at making appointments, they write it down and also leave a message on the phone
- My dentist is alright, I go on my own
- I like going to the dentist, they're kind to me
- The receptionist talks to me before my appointment, so I feel calm
- They're good at explaining what they're going to do, they stop if I don't like it
- The doctor wears gloves, it's very clean
- It smells really clean

- The dentist always wears a mask and gloves
- It's near my house
- They send me appointments and ring me

**What does your Dentist Practice do well?**

- They treat me well, they write to me when I need an appointment, I get my treatment free
- They treat me well. She held my hand because I was scared of having an injection.
- They are hygienic
- My dentist is really nice
- They clean my teeth and tell me what to do
- Make sure my teeth are being cleaned properly
- They treat me well
- They wear gloves and mask
- They tell me when to go and give me a check up
- They treat my teeth and give me fillings
- I don't like it, but they keep me calm
- They tell me what is going to happen
- They look after my teeth
- They clean my teeth and show me how to do it properly
- They keep me calm
- They keep it clean and welcoming
- They have magazines that I can look at in the waiting room, so I keep calm

**Is there anything that needs to change at your Dentist Practice to make it better?**

- No
- Don't know
- Not really
- Waiting times
- No
- No
- No, I think it's good
- No
- No
- It's ok

- Waiting times are sometimes long when you need them to do treatment
- They don't take emergency appointments
- Don't know
- Not sure
- It's fine
- No
- Nope
- Not that I know of
- Better magazines in the waiting room
- The lights are a bit too bright

**Do staff at your Dentist Practice give you information about your treatment in a way that you can easily understand?**

- Yes
- Yes
- They tell me carer as well as me
- They tell me what they are going to do and ask if it's ok
- Yes
- Yes, they explain
- They tell my staff
- Yes
- Yes
- They talk to my PA
- Yes
- They don't do anything until they've asked me if they can
- They give me leaflets that have pictures on
- Yes
- It's easy to look at the leaflets
- I like the leaflets they give me about cleaning my teeth
- Yes
- Yes they're very good
- Yes
- They talk to me
- They don't use big words, I can understand them
- I get leaflets that I understand
- My mum helps me understand

**Think about any appointments that you've had at a hospital, when you've been to Accident and Emergency (A&E) or when you've stayed on a ward**

**What was good about the hospital?**

- People were polite
- It was ok, when I went I was choking on my food, they gave me medicine to drink
- They keep me healthy and safe
- I needed a procedure, and they planned it in advance
- I got my scan really quickly
- Staff were good
- Food was good
- Caring staff
- Caring staff who looked after me
- Food was good
- I have only been as an outpatient, it was good, I was the first person in
- I have only been for appointments
- My GP referred me and they sent me a letter
- Once my staff phoned the hospital and I had to go to A&E with my mum

**What did the hospital staff do well?**

- They were polite
- Friendly and helpful. They told me everything that was going to happen
- They kept me safe and healthy
- Keeping me safe
- The staff were kind and told me what was happening before talking to staff
- Care for you
- Caring and helpful
- They gave me good care
- They were really good
- They cared for me in a good way

**Is there anything that needs to change at the hospital to make it better?**

- No
- Waiting times are too long
- Better beds
- Better food

- No
- Better beds
- Better food
- I had to wait ages to be treated and get on the ward
- Put more doctors on
- Put on more doctors
- They could still explain things a bit better. They only told me what I wanted to know, not what I needed to know
- I had to wait too long to be seen
- My mum couldn't park, she got really stressed
- I don't like waiting for hours when I get there for my appointment on time
- If I'm late I get in trouble, but if they're late with my appointment it's okay
- No
- No
- Maybe better food
- The food isn't amazing

Did staff at the hospital give you information about your treatment in a way that you could easily understand?

- They could still explain things a bit better. They only told me what I wanted to know, not what I needed to know
- They told my mum more than me
- My carer helps
- Yes
- Yes
- Yes
- Yes
- They told me and my mum, so she helped me
- Yes
- Yes
- They showed me what they were going to do
- They gave me a leaflet but it was just words, so I didn't understand
- They don't have pictures on the leaflets
- No, they have too many big words on the leaflets that they give
- Appointment letters are confusing
- My staff help me understand

- They let me ask questions
- I sometimes understand

**Think about any other time that you have received treatment for your health, and answer the questions below.**

**What was good?**

- I have eye tests. I should wear glasses but break them
- My opticians uses photos and pictures
- My feet get looked after and toe nails cut
- I can't read but they (opticians) show me pictures and ask which one I can see the best
- I go to the opticians, they show me letters and I read them out. Then they give me new glasses
- Opticians, it's usually ok but could be better
- I go to the opticians. I go on my own

**Was there anything that needs to change to make things better?**

- No
- No
- More pictures
- No
- The tests can be difficult in parts, I find the letters hard
- They are good and helpful

**Do you have a general health check, with your Doctor or a nurse, every year?**

- Yes
- No
- Yes
- No
- Yes
- Yes
- Yes
- Yes
- Yes

## All Responses from PossAbilities Staff

### Do you have any suggestions for improving local health care services for people with a learning disability?

- Quicker referral times
- Staff given more training to interact with people with learning difficulties
- People with learning difficulties not kept waiting in busy waiting rooms for long periods as they may find this stressful
- More Learning Disability Nurses available in hospital settings
- Hospitals should have more trained staff to understand individuals with a learning disability
- Treat all individuals equal
- More person centred
- Staff to be monitored more closely to ensure best quality support
- Often medical professionals do not know how to speak to people with learning disabilities. They speak to the carers before the person
- Hospitals really poor when it comes to supporting people with a Learning Disability. They leave them alone and often in wet beds, leave food and drinks at side of bed instead of sitting and helping the person.
- All hospitals should have trained staff specifically for people with a learning disability
- Better education RE: Screening and Checks
- Better Education for staff RE learning disabilities
- Streamline Services
- We still get GP's, consultants, nurses etc who have no idea how to engage with our service users (people with a learning disability)
- Improve staff knowledge of supporting individuals with learning disabilities
- Easy read information
- Joint working with provider agencies
- Equal Treatment
- More staff
- More accessible information
- Regular breast and testicular screening for individuals with a learning disability. It would be helpful to have allocated nurses to demonstrate how to check for lumps. It seems that you are only screened once a lump is found.

- Being mindful that some individuals with a learning disability find it difficult to have procedures done. It only adds to their anxieties when these are cancelled/rearranged

**Do you have examples of good practice when people with a learning disability have accessed health care services?**

- Talking directly to the individual
- Being patient and giving individuals the opportunity to express themselves
- Yes, several times with staff having the knowledge sometimes this is based on their own experiences eg. Recently supporting a young man with autism, her son had autism, so this worked well.
- I supported a lady to her GP as she was having 'lady problems'. The nurse was very supportive to this lady and made the experience as stress free as possible for her by explaining everything that they were going to do, they addressed her at all times. The first examination was too distressing for her, so they found a better, less intrusive way to examine her, making the experience less traumatic for her.
- No
- The Community Team for learning disabilities have a really good team. Especially the nurse (Carol Lonergan) who deals with people who have to go into hospital for treatment.
- Paul Cheetham's opticians is really good at treating people with Learning Disability in Rochdale
- The community dental team are very good, very helpful and respectful. High standard of work and care
- I have seen plenty of good practice in which staff offer choice and are inclusive. This can be seen when hoisting a person as staff will talk to the person, offer them choices in terms of comfort and where they are being hoisted to.
- Treatment support with dental work at Fairfield hospital
- When staff have interacted directly with the person rather than just speaking to the accompanying staff member

**Do you think there are any gaps in local health care service provision for people with a learning disability?**

- More staff training as in my opinion not all doctors, nurses, medical professionals are trained to care for individuals with a learning disability.

- Ensure they talk to the patient and not around them
- Possibly in relation to affording people with a learning disability the same as others without learning disability. RE investigation, treatment and operation
- No – From my experience all people supported have had fair access to health services
- There is a real need for more learning disability nurses and staff especially in hospitals
- I think there needs to be more local activities i.e. fun days or organised sports as I feel there isn't enough of this on a regular basis
- More staff who understand individuals with a learning disability
- More experienced professionals are required when supporting people with a learning disability
- Missing information
- Not reading information that's specific to the person
- No

**Do you have any other comments?**

- I would like to see more services providing home visits for people with a learning disability and autism
- Always talk to the individual
- The traffic light passport is a fantastic idea, however not all hospital staff refer to this, this would enable staff to have a better understanding of the individual