

**Improving access to primary care for people with learning disabilities**  
Engagement dates: Dec 2014 – April 2015

## **Patient feedback report**



## **Acknowledgements**

NHS Leeds West Clinical Commissioning Group would like to thank all the patients, carers and members of the public who took the time to share their thoughts on this proposal.

We would also like to thank Leeds Involving People for their engagement work and staff at Leeds West GP Practices who assisted us to send surveys out to their patients.

## Executive summary

People with learning disabilities often have more complex health problems and may find it harder than others to access primary care. This may be due to a number of barriers including a lack of accessible information.

National evidence shows people with learning disabilities require better information in different formats to ensure that services are more accessible and health inequalities are reduced. We also know that GPs, practice nurses and other healthcare professionals need specialist skills and especially communication training, which could be provided by service users with learning disabilities.

We worked with CHANGE, a voluntary sector advocacy group who directly employ people with learning disabilities to develop learning disability awareness training which was then offered to all GP practices in NHS Leeds West Clinical Commissioning Group (CCG). Two thirds of practices attended and further training will be offered to the remaining practices

We also developed a survey to understand the needs of people with learning disabilities and how we could improve access to primary care for them. We asked about patient satisfaction with the current service. The survey was shared widely, including with;

- GP practices in Leeds
- Patients in community settings
- Carers using local voluntary services

**232** people responded to the survey. They told us that they were generally happy with the way they were treated by the staff when they attended surgeries. People with learning disabilities said that they wanted to access appointments outside of traditional hours. They also told us that they would like longer appointments as due to their learning disabilities they sometimes needed longer to get their message across. Patients also told us that they wanted to receive information in formats that they could understand such as easy read.

This report makes a series of recommendations to the learning disabilities project team who will use the findings of the engagement to; encourage staff to attend learning disabilities awareness training, look at reviewing the appointments process for patients with learning disabilities and their carer's and look at how information for people with learning disabilities could be provided in more accessible formats such as easy read.

A regular briefing will be produced once the project has begun, to show to what extent the engagement recommendations have been implemented.

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

The report will be shared with those involved in the engagement and the report will also be available on the NHS Leeds West CCG website.

## 1. Background information

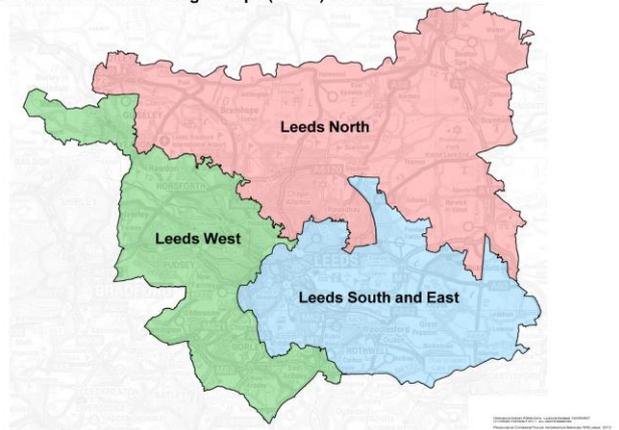
### a. NHS Leeds West Clinical Commissioning Group

There are three clinical commissioning groups (CCGs) in Leeds; NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These organisations are responsible for planning and buying (commissioning) local healthcare services.

The CCG is very different from previous NHS organisations. For the first time, healthcare services will be commissioned by organisations that are led by locally based doctors and nurses, supported by experienced managers.

This means we can have a real, detailed understanding of the health and social care issues there are in our neighbourhoods, and a genuine opportunity to shape health services at a much more local level as well as across the city of Leeds.

Leeds Clinical Commissioning Groups (CCGs) June 2012



NHS Leeds West CCG is made up of 38 GP practices in the west and parts of outer north west and south west Leeds. We are one of three CCGs in Leeds and are the largest, covering a population of around 350,000 people. Our population extends from some of the most affluent neighbourhoods of Leeds to some of the most deprived.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

### b. Leeds Involving People (LIP)

Leeds Involving People is a voluntary organisation that represents the independent voice of people through the promotion of effective involvement. The organisation involves the community in the development of health and social care services by ensuring their opinions and concerns are at the centre of decision making processes. Due to timescales on the project we commissioned LIP to support this engagement.

### c. Detail on health topic/engagement

People with learning disabilities often have more complex health problems and may find it harder than others to access primary care. This may be due to a number of barriers including a lack of accessible information.

National evidence shows people with learning disabilities require better information in different formats to ensure that services are more accessible and health inequalities are reduced.

At NHS Leeds West CCG we want to improve access to primary care for people with learning disabilities and to look at the needs of patients and staff and look at how we can support them to work together to improve the experience.

## 2. How did we identify and engage with patients?

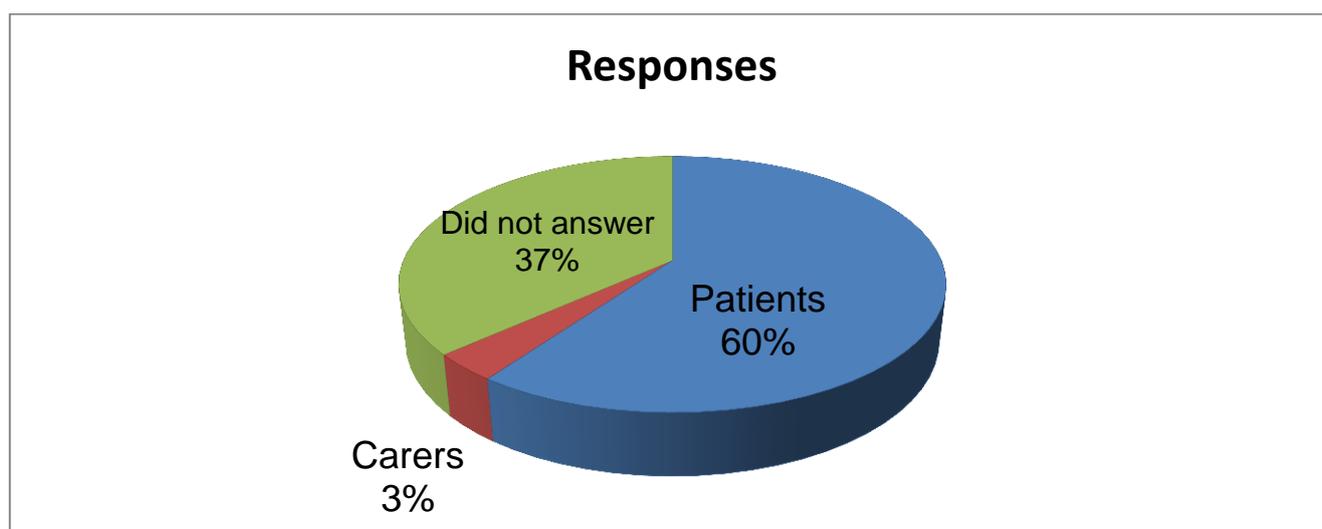
An engagement plan (available on request) was developed by patients, clinicians and commissioners to ensure that the right people are consulted in the right ways. The plan was taken to the NHS Leeds West Clinical Commissioning Group Patient Assurance Group (PAG). This group is made up of patients and assures the CCG's Governing Body that adequate patient involvement has taken place during consultations and engagement. The PAG agreed that the patient groups and engagement methods outlined in the plan were generally appropriate and easy read documents were good ways of communicating.

Group	Who	How
<b>Patients</b>	People who use primary care services	<ul style="list-style-type: none"> <li>Paper copies of survey posted to patients with learning disabilities</li> </ul>
	Local VCF sector organisations who work with people with learning disabilities	<ul style="list-style-type: none"> <li>We sent links to the survey to local VCF organisations asking them to share with their patients, including; <ul style="list-style-type: none"> <li>Tenfold Hamara Centre</li> <li>Mencap</li> <li>Bramley Fulfilling Lives</li> <li>Leeds Involving People who visited people with learning disabilities in the community</li> </ul> </li> </ul>
<b>Carers of people with learning disability</b>	Carers, friends and family	Links to engagement were shared with Carers Leeds
		Link to engagement tweeted to key stakeholders
<b>Public</b>	General public	Shared details of the engagement by social media
		Shared with NHS Leeds West CCG voluntary, community and faith sector network
		Paper copies of the survey sent to GP practices across Leeds West
Group	Who	How
<b>People with protected characteristics as defined by Equality Act 2010</b>	Black and minority ethnic (BME) communities	<ul style="list-style-type: none"> <li>Contacted members of our VCF sector network and informed them of the engagement.</li> </ul>
	Carers	
	Children and young people	<ul style="list-style-type: none"> <li>The survey link was shared on the Doing Good Leeds website</li> </ul>
	Older people	
	People with disabilities	<ul style="list-style-type: none"> <li>The survey link was shared in the LTHT Leeds Health Pathways e-newsletter</li> </ul>
	Users of mental health services	
	Lesbian, gay, bisexual and transgendered people	<ul style="list-style-type: none"> <li>The survey link was shared in Tenfold's newsletter and e-bulletin</li> </ul>
	Gypsies and travellers	
Homeless people		

<b>Partners</b>	Leeds City Council (including public health and adult social care)	Details of the engagement shared through social media.
	Leeds North and Leeds South and East CCGs	<ul style="list-style-type: none"> <li>• Contacted other CCGs with details of the engagement</li> <li>• Engagement added to the CCG websites</li> </ul>
	Healthwatch	<ul style="list-style-type: none"> <li>• Engagement details shared with Healthwatch</li> </ul>
<b>Providers</b>	<ul style="list-style-type: none"> <li>• LTHT, LCH and LYPFT</li> <li>• GP practices</li> <li>• Practice Nurses</li> </ul>	<ul style="list-style-type: none"> <li>• Contacted all key partners with information for them to disseminate using in-house channels such as newsletters, websites and social media</li> </ul>
<b>Media</b>	Local media	Sent out a press release about the engagement and included the media in Twitter and Facebook activity.

### 3. Who replied?

In total **232** people contributed to the engagement. Feedback was received from the following groups;



### 4. What did people tell us?

Leeds West CCG developed a survey to ask people with learning disabilities, their carer's and families what their experiences were around accessing primary care services.

People told us that they were generally happy with the way they were treated by the staff when they attended surgeries. People with learning disabilities said that they wanted to access appointments outside of traditional hours. They also told us that they would like longer appointments as due to their learning disabilities sometimes they needed longer to get their message across. Patients also told us that they wanted to receive information in formats that they could understand such as easy read.

## **What are the key themes from the feedback?**

A number of themes can be identified through the engagement process?

- Patients are generally happy with the service
- Patients want to receive reminders of their appointments in accessible formats
- Patients want it to be easier to make appointments at times that suit their needs
- Information from clinicians was not always clearly explained
- Surgeries running late made patients anxious and stressed
- Wheelchair access into waiting rooms can be a problem
- GPs and staff should have more awareness of the needs of people with learning disabilities
- Some people felt that they were not being listened to
- A number of patients felt that GPs and staff didn't speak to them, but spoke to their carers instead.
- A small number of patients felt that they would be more comfortable in their appointments if they were shown around the surgery.
- A few patients told us that sometimes due to their more complex needs home visits are sometimes more appropriate

## **Recommendations**

Following the engagement the project team are asked to consider ways to:

- Consider making it easier for patients with learning disabilities to make appointments outside of traditional working hours
- Look at ways to provide patients with appointments where waiting times are reduced such as booking on quieter days or early appointments on afternoon surgeries.
- Ensure that waiting areas in practices are wheelchair accessible
- Look at ways to provide patients with appointment reminders and letters in clear accessible information ie easy read, print on yellow paper, large print
- Encourage all primary care staff, especially gatekeepers like receptionists, to attend learning disabilities awareness training
- Consider offering double appointments to patients with learning disabilities to allow better communication with GPs
- Consider offering patients with learning disabilities and their carers the opportunity to become more familiar with the surgery by showing them rooms and equipment they may use
- Consider home visits for patients with learning disabilities who are unable to attend due to their more complex needs such as seizures and may require more privacy
- Give patients an opportunity to routinely feedback their service experience

## Appendix A – What people told us

All comments used in the appendix were written by patients and have been used exactly as originally written.

### What makes you think the doctor is not listening properly?



85% of people who responded to the survey felt that the GP did listen to them.

The remainder of people told us that they felt that one of the reasons GPs don't always listen to them is that their learning disability makes it hard for them to express themselves

*"Because I can't communicate properly with the Dr."*

*"Because I cannot express myself properly".*

*"I cant communicate very clearly".*

*"he or she is not even looking at you, and talking down to you, not on a level"*

Some patients feel that GPs don't understand their disabilities and the needs that they have.

*"I think sometimes the gp dosnt understand me sometime".*

*"I don't feel that they understand my disability. I've been on anti-depressants for a while and they aren't helping. I want to stop taking them, but he won't stop them. He doesn't believe that I'm tired, but this is normal for me due to my disability".*

*"Don't understand me and my needs"*

*"I want help and go see a counsellour. Dr gave me a number which I had to ring myself to set turn down"*

*"Feel that they don't understand my learning disability".*

Some people feel that sometimes GPs don't listen to them and speak to their carers instead

*"Doesn't speak to me"*

*"Not responding to me when I ask a question"*

*"Asking sister in law"*

*"listems to Mum"*

*"Looks at my mum instead of me"*

*"Doesn't look at me, looks at carer"*

## How can the staff at your surgery make it easier for you to attend?



Over two thirds of patients told us that they had problems making appointments that were suitable for them and their carers. They told us that appointments later in the day were preferable

*“Make appointments after 10”*

*“MORE APPOINTMENTS OUTSIDE SCHOOL HOURS”*

*“BY REALISING THAT SOMEONE ELSE HAS TO BRING ME SO THEREFORE APPOINTMENTS NEED TO BE MORE FLEXIBLE”*

*“LATER IN MORNING AS I FIND IT HARDER TO RUSH WHEN I GET UP”*

*“By letting the staff know I have learning difficulties and have epilepsy and not wait for week to get an appointment”.*

Most of the people would like to be reminded of their appointment times. It would help if the staff could ask the patient how they would like to receive reminders.

*“By making sure my appointment are written down so I don't forget”*

*“Sending me a text to my phone to remind me of my appointments”*

*“Remind me of my appointments”*

*“Letter in post reminding of appointment”*

*“Notifying me in ample time about my appointments”*

*“Pictures and photos next to writing”.*

Some patients told us that sometimes doctors and staff didn't explain their treatment. They told us they would also like to see information in formats that were easy to understand such as easy read.

*“More signs”*

*“Most of the people who Easy Read”*

*“Dyslexic friendly item would be good”*

*“Better info with pictures”*

*“Info with pictures”*

*“Accessible info”*

A small number of patients told us that they would prefer to tell staff that they had arrived rather than using the touch screens

*“Just to say "I'm here" rather than tapping the screen”*

A third of patients told us that they become anxious and stressed when they need to visit the surgery for appointments and it would be helpful to have appointments at the start of a surgery or on quieter days.

*“Make sure appointments are on time I get more anxious the more I wait”*

A small number of wheelchair users told us that they have problems accessing the surgery as the doors are not wide enough and they have trouble manoeuvring in the waiting room

*“Easier wheelchair access in the car park would be desirable. On entering the surgery my carers are always having to move the chairs in the waiting area to accommodate my wheelchair. At times people are having to move seats in the waiting area because of my chair - not able to get round or to manoeuvre in the waiting area”*

*“For them to have larger double parking spaces in appropriate places also to have larger waiting area so people in wheelchairs like me can use the space”.*

*“If there is no spaces it would be good if staff offered more support in finding a space and could call me on the phone to tell me when there is available appointments”.*

*“Better wheelchair access ramp is difficult*

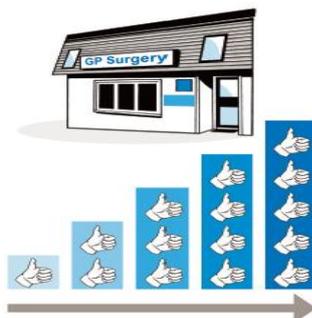
Two carers completed this section and told us that it would make it easier to attend if their relative could sit in a quieter area as they struggled to wait for long periods. They also told us that sometimes home visits would be more appropriate:

*“Sit & wait surgeries are brilliant but my daughter doesn't understand waiting. she needs to be seen within 10 mins - otherwise stress/noise levels go up and there is nothing I can do to help with this”.*

*“With having complex needs it's easier for a home visit for my son, his needs are met better sometimes when he is brewing seizures a visit to GP can be very frustrated with him self-harming, and not a very nice thing for other patients to see, privacy is needed then”*

*“If he is in a happy mood then I take him to the surgery and he can be quite content”.*

## **How can we improve the service from GP surgeries for you and other people with a learning disability?**



85% of people said that they felt the GP listened properly to their answer when he asked them how they were feeling. However 13% of people told us that they didn't listen and felt that GPs and staff should be more aware of their needs

*“Show a little more patience and allow a little more time for frightening things like blood tests”*

*“Have understanding on the phone, would make me feel more comfortable”.*

*“Could explain the ticket order and How it works”*

*“MORE FLEXIBILITY AND MORE UNDERSTANDING OF MY OWN SPECIAL NEEDS”*

*“Give doctors training on disabilities not getting off handed if I do understand anything”.*

*“To be understanding if an appointment needs to be cancelled at short notice due to behaviours”*

*“Maybe use sign language speak to adults with learning disabilities on the same level as them not talk down to them as we are not stupid”.*

*“Explain more what things are if I struggle to understand them”.*

*“have staff at the door and take you where you need to be “*

Over two thirds of people (68%) told us that generally appointments were made at times that were helpful.

30% of people felt that it would be helpful to be able to obtain appointments outside of traditional hours

*“Able to get a appointment”*

*“not closing for lunch hour”*

*“More later opening times through the week as I work till 6pm Monday to Wednesday”*

*“Be able to have more allocated appointments, as sometimes it can be frustrating to wait at the walk-in surgery”.*

Some patients told us that they would like to see information in their surgery available in different formats to allow them to better understand their health concerns

A small number of patients told us that a tour of the surgery would help them to feel more comfortable when attending appointments

*“A hot drink proved, would like a tour of the surgery”.*

*“Would like a tour”*

*“A tour of the doctors”*

A carer completed this section and told us how they felt that services could be improved. They told us a shorter waiting time and a quiet area to wait would be helpful and that better access for wheelchairs would be helpful.

*“Be seen within 10 mins of arrival”.*

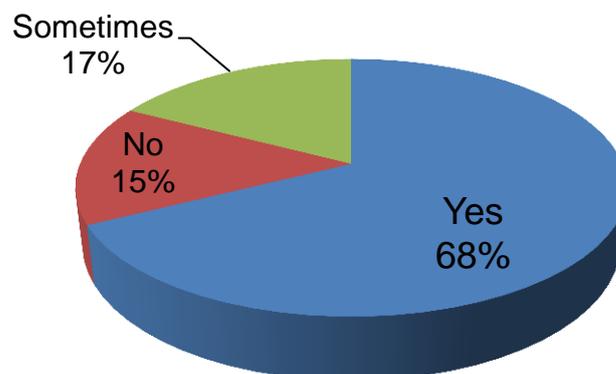
*“A separate “quiet” area available if needed to keep her calm”*

*“More space for wheelchair users”.*

## Appendix B - Detailed analysis of survey findings:

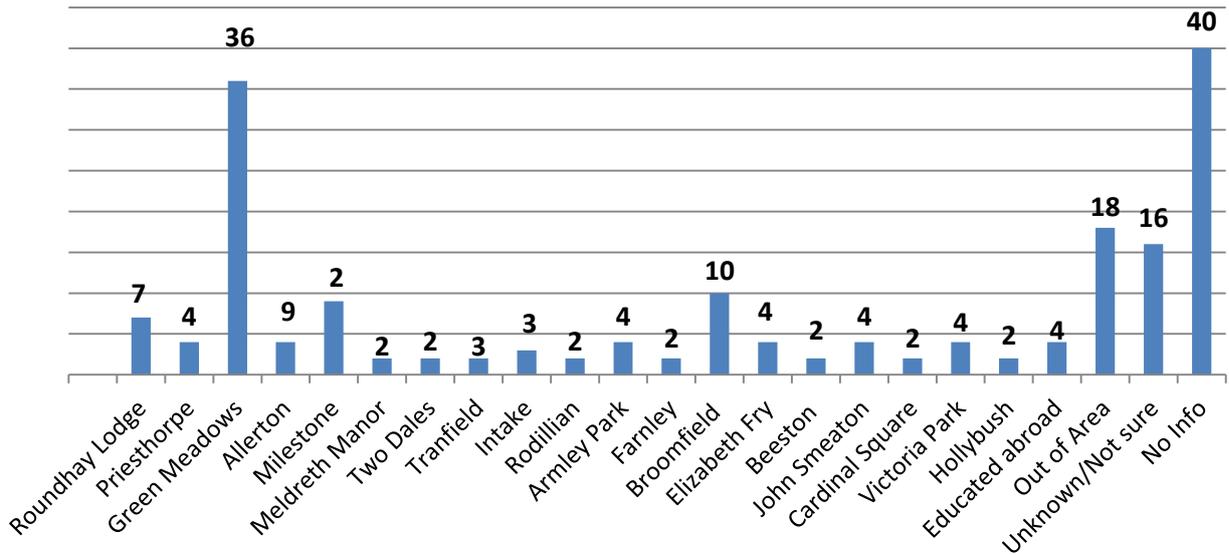


### 1. Do you find reading and writing hard?

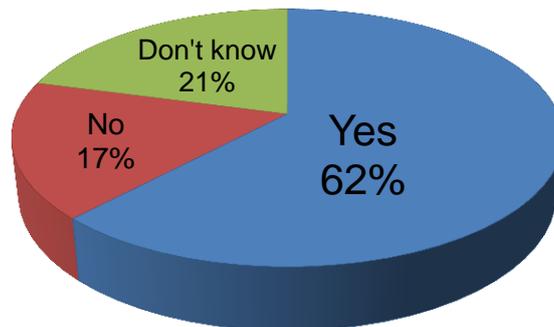




## 2. Which school did you attend?



## 3. Was this a special educational needs school?





#### 4. Did you go to a special education department?

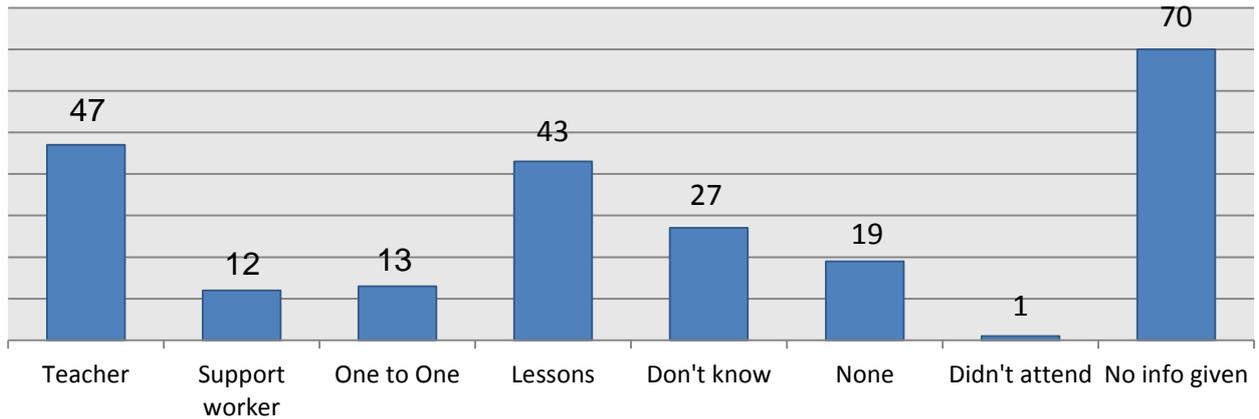


#### 5. Did you have a support worker in the classroom?

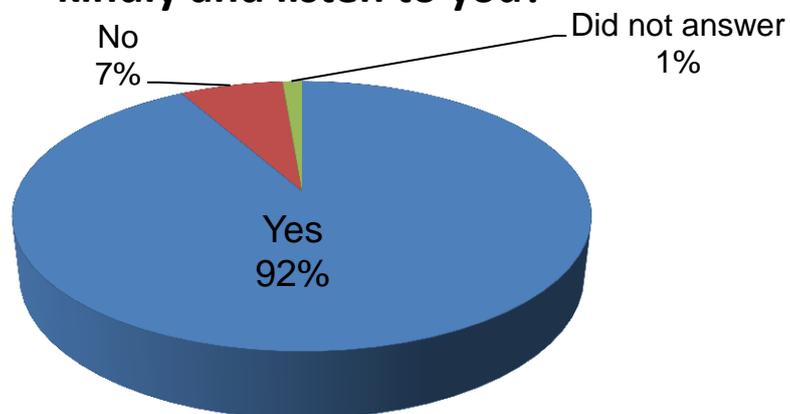




## 6. What support did you get at school?

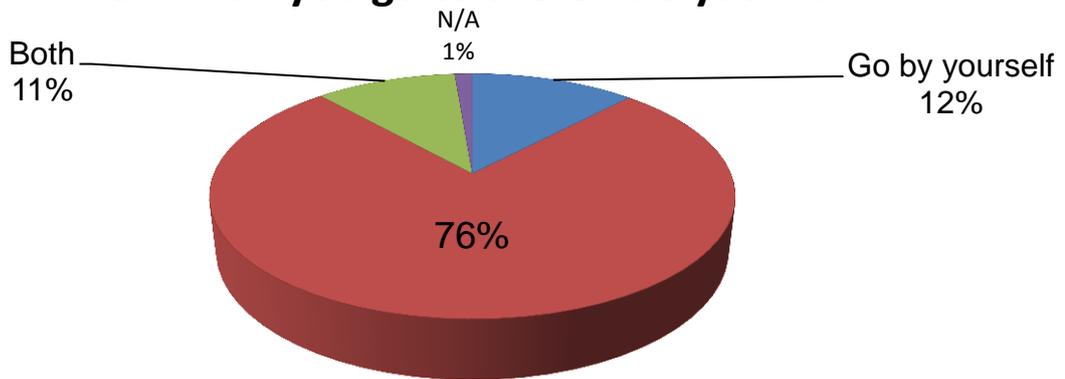


## 7. When you go to your GP do the staff treat you kindly and listen to you?

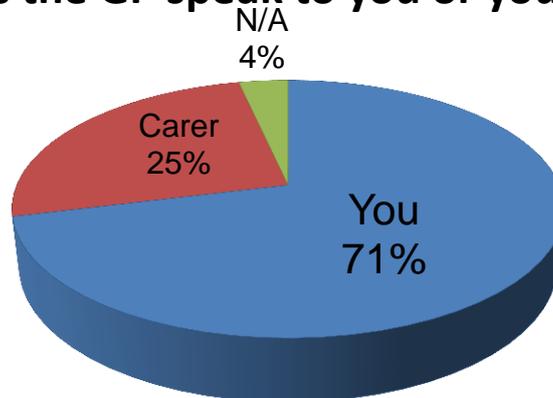




### 8. When you go to the GP do you....?

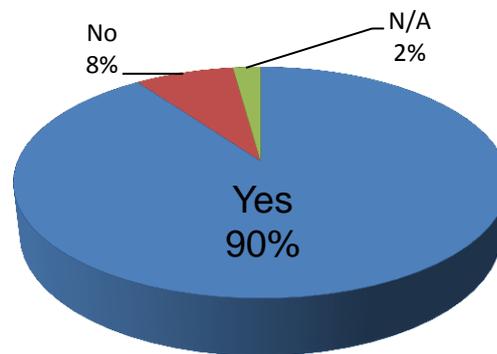


### 9. Does the GP speak to you or your carer?

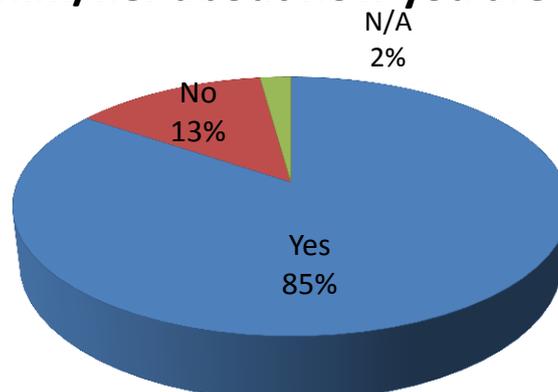




**10. When you visit your GP does he ask how you are feeling?**

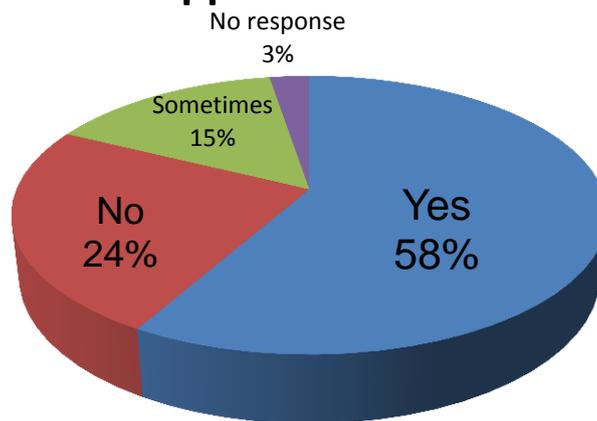


**11. Does your GP listen properly to what you are telling him/her about how you are feeling?**

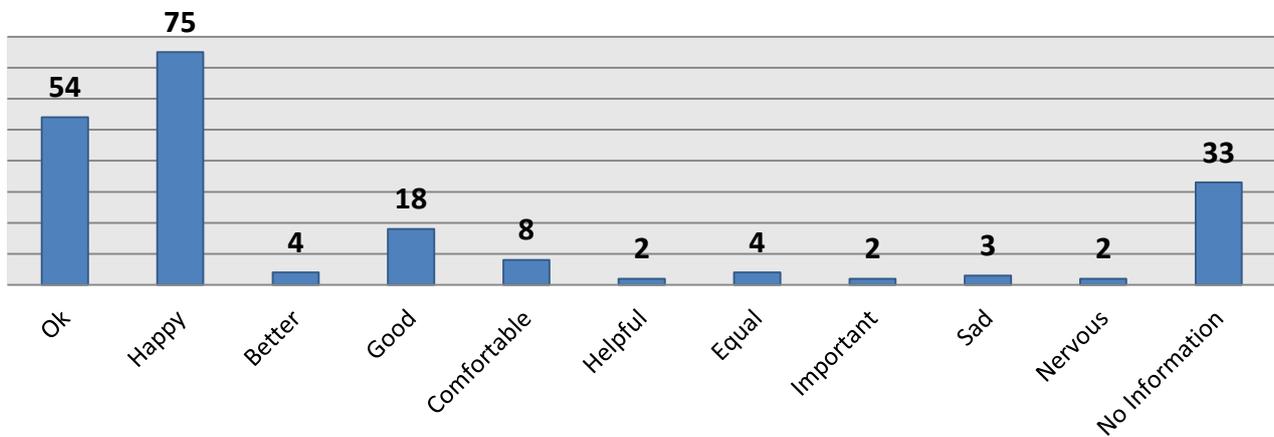




## 12. Do staff at the surgery help you with letters and appointments?

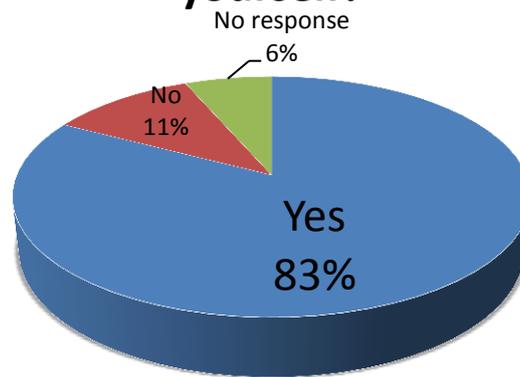


## 13. How do medical staff make you feel?

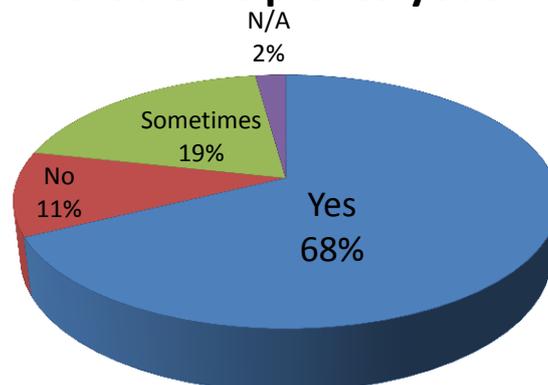




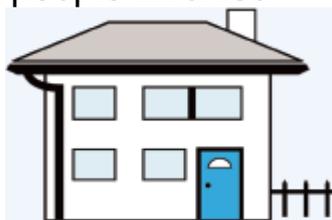
### 14. Do medical people make you feel good about yourself?



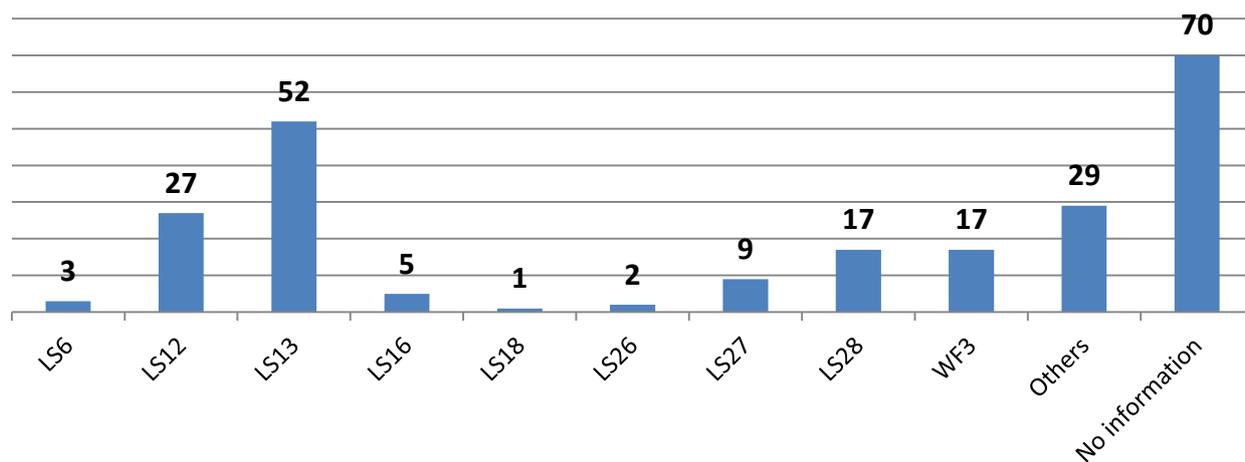
### 15. Do staff help you make appointments at a time that is helpful to you?



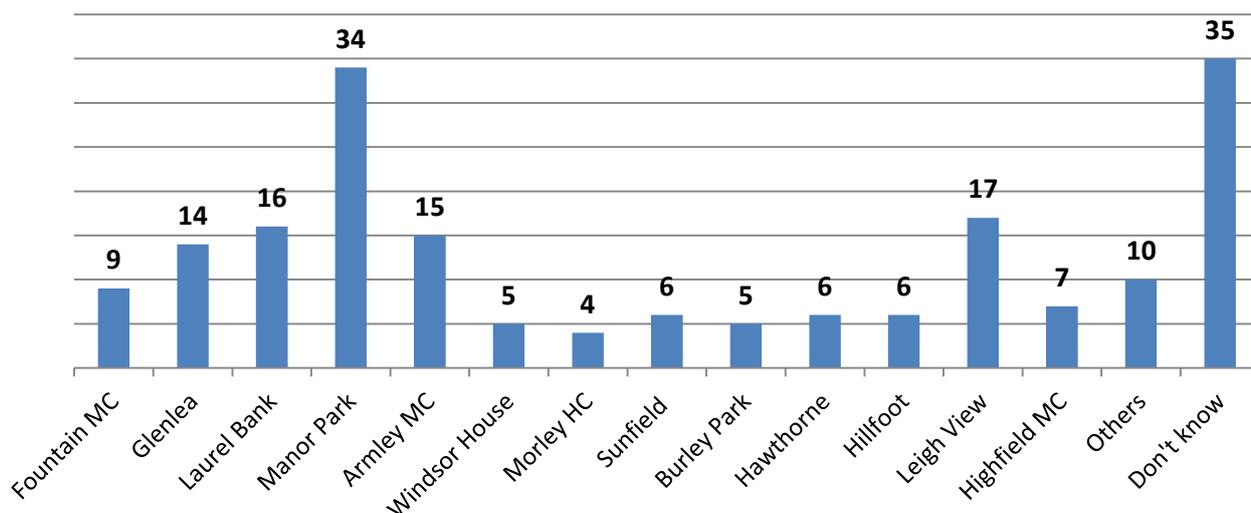
## Appendix C – Detail about the people involved



### 16. My postcode is

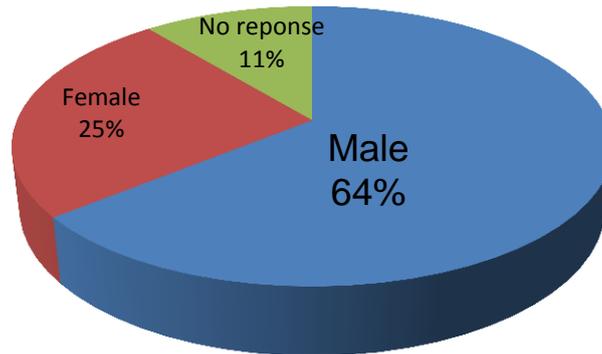


### 17. My GP surgery is

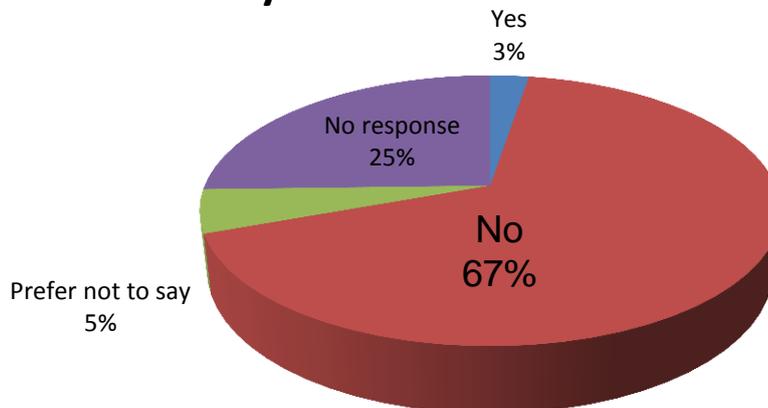




### 18. What gender are you?

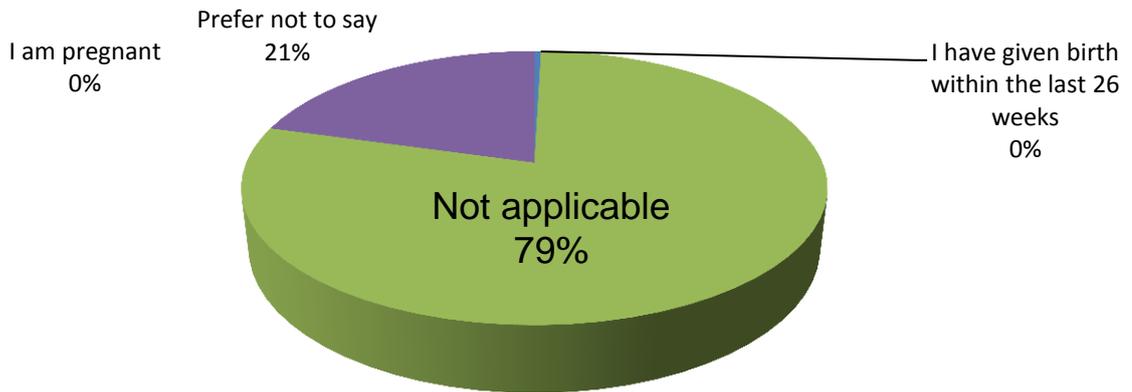


### 19. Transgender - is your gender identity different to the sex you were assumed to be at birth?

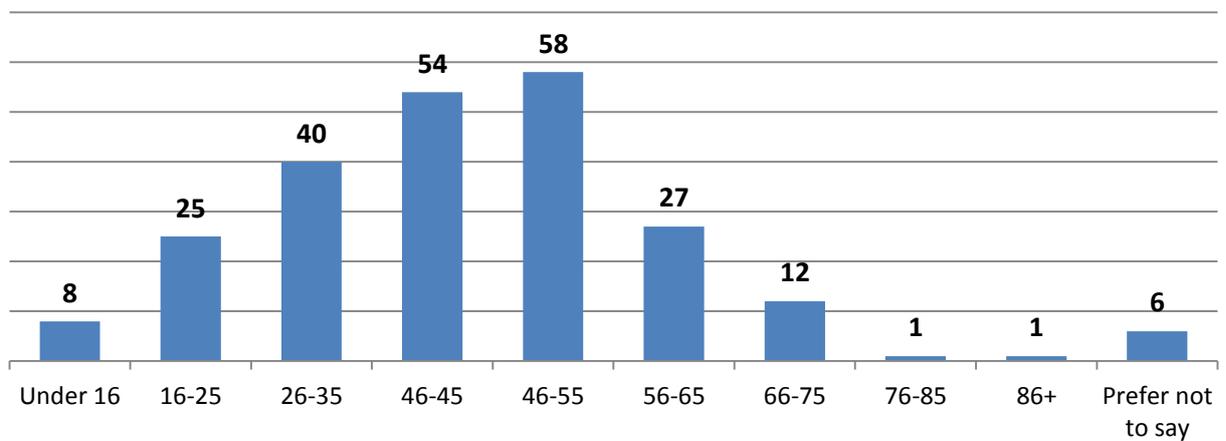




## 20. Pregnancy and Maternity

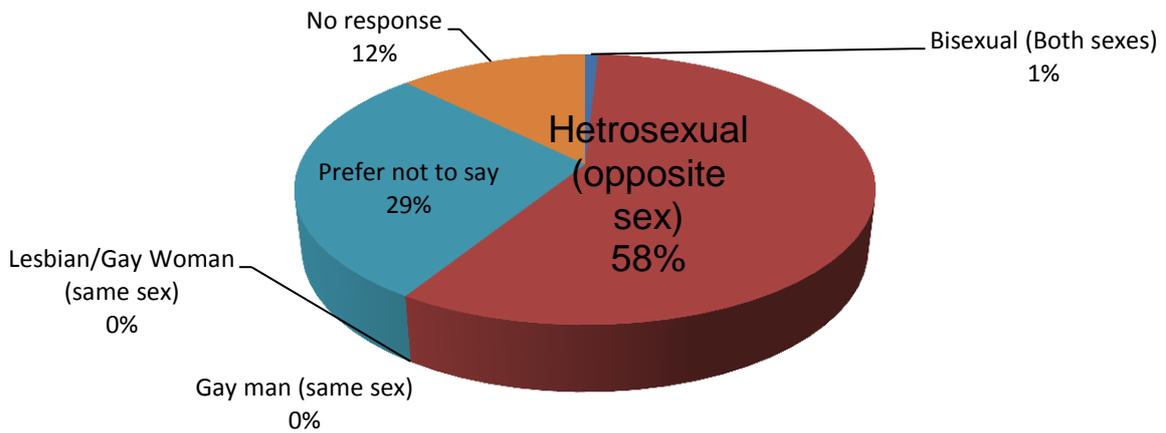


## 21. What is your age?

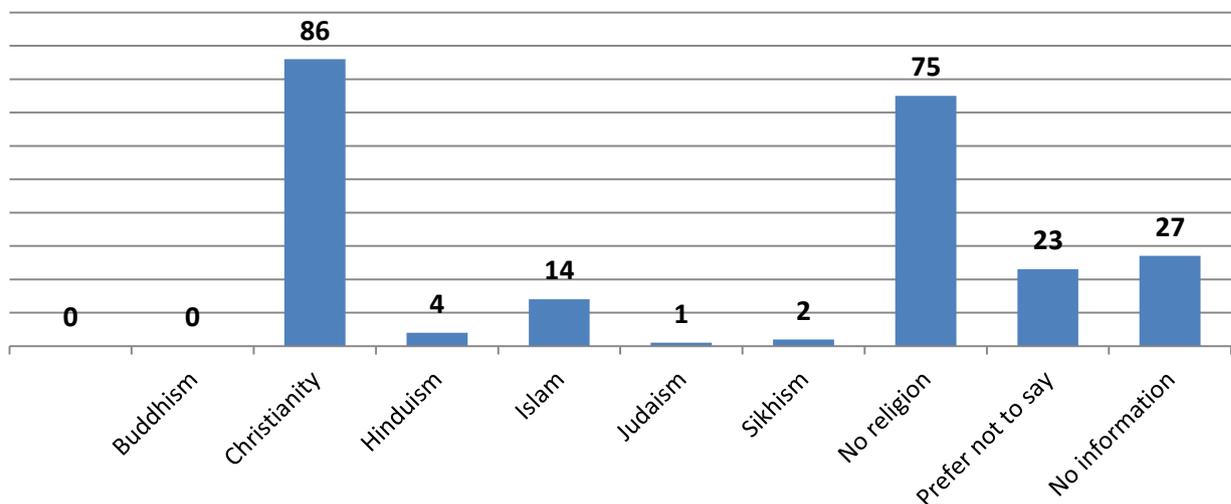




## 22. What is your sexual orientation?

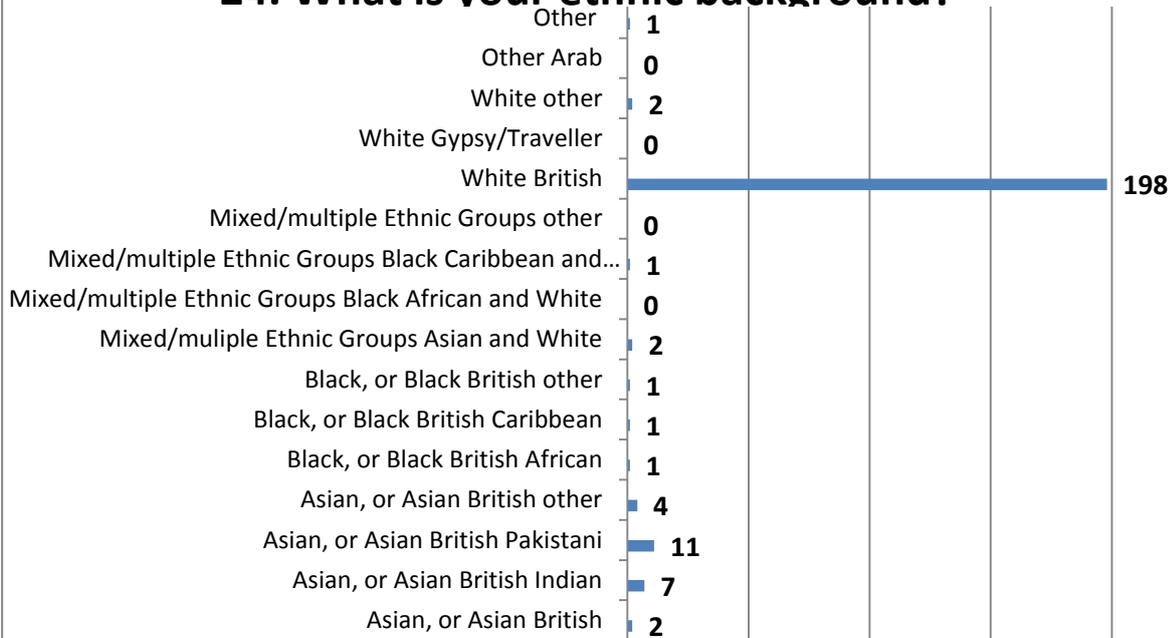


## 23. Do you consider yourself religious?

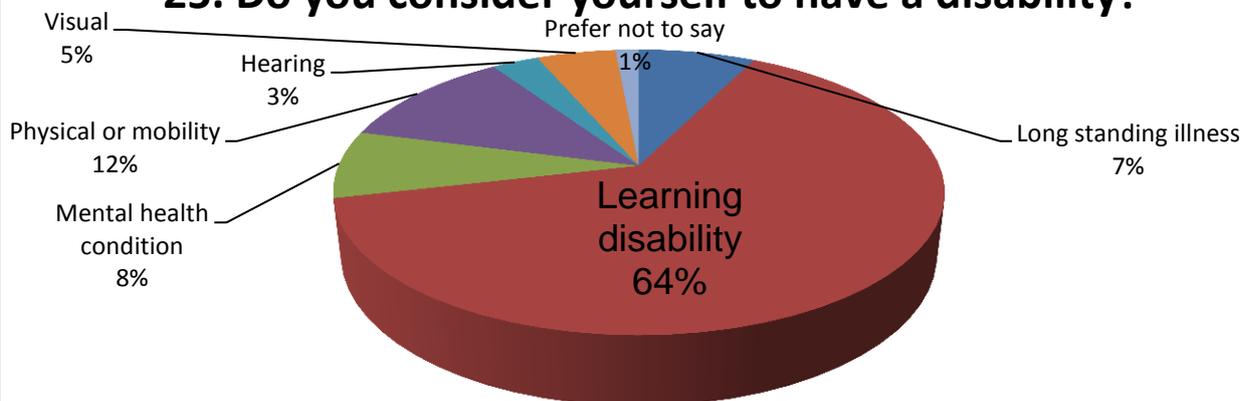


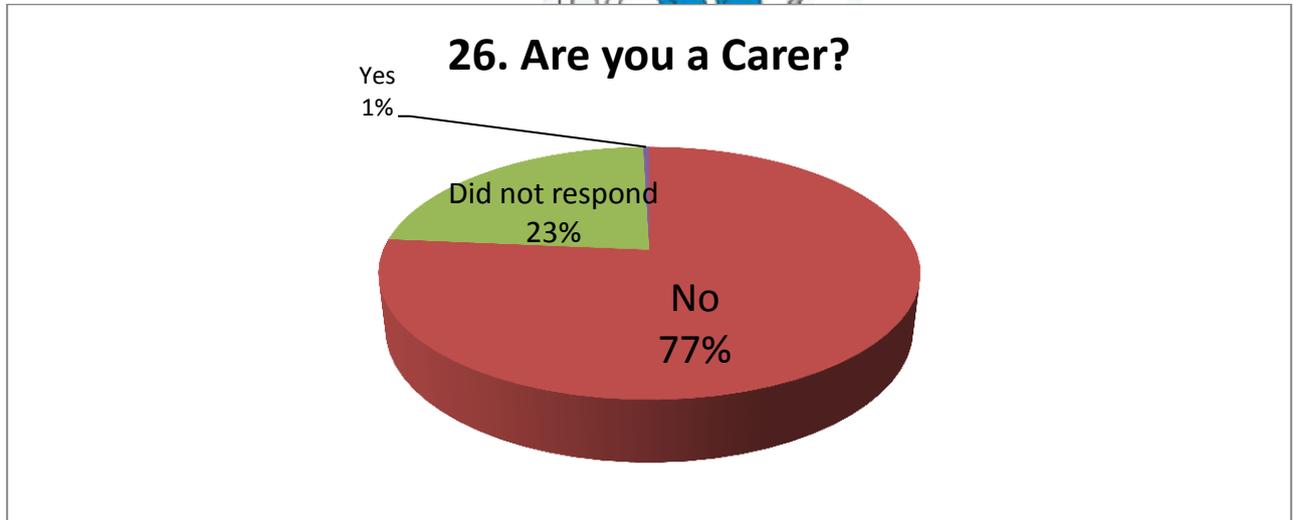


## 24. What is your ethnic background?



## 25. Do you consider yourself to have a disability?





## What will we do with the information?

The report will be shared with all the people involved in the project. The report will also be included in our next e-newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services. The report will also be available on the NHS Leeds West CCG website.

## Appendices

- Appendix A** – What people told us
- Appendix B** – Detailed analysis of survey findings
- Appendix C** – Detail about the people who were involved
- Appendix D** – Glossary of terms

# GLOSSARY

<b>Commissioning</b>	Commissioning is the planning and purchasing of services. The Clinical Commissioning Groups are responsible for commissioning most healthcare services.
<b>Procurement</b>	The acquisition of goods or services.
<b>Provider</b>	Providers are the organisations who deliver healthcare services. GP practices and hospitals are providers of healthcare services.



### Alternative formats

An electronic version of this report is available on our website at [www.leedswestccg.nhs.uk](http://www.leedswestccg.nhs.uk) or please contact us direct if you would like to receive a printed version.

If you need this information in another language or format please contact us by telephone: **0113 84 35470** or by email: [commsleedswestccg@nhs.net](mailto:commsleedswestccg@nhs.net)

'Jeśli w celu zrozumienia tych informacji potrzebuje Pan(i) pomocy w innym języku lub innej formie, prosimy o kontakt pod numerem tel.: **0113 84 35470** lub poprzez email na adres: [commsleedswestccg@nhs.net](mailto:commsleedswestccg@nhs.net)

اگر آپ کو ان معلومات کو سمجھنے کے لیے یہ کسی اور زبان یا صورت میں درکار ہوں تو برائے مہربانی سے اس نمبر پر فون کر کے رابطہ کریں: 0113 8435470 یا اس پتہ پر ای میل لکھیں: [commsleedswestccg@nhs.net](mailto:commsleedswestccg@nhs.net)



### Further information

If you would like any more information about this project or NHS Leeds West Clinical Commissioning Group, or have any questions or comments, please write to:

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