



Health ambassadors Have your say Southwark event August 2022



**better health and well being
for people with learning disabilities
and autism
in South East London**



We invited people with learning disabilities and autism to come to our event on 4 August and **have their say** about

- making things **accessible**
- **annual health checks**
- Being treated with **respect**
- **black books** and hospital passports
- their **experiences**



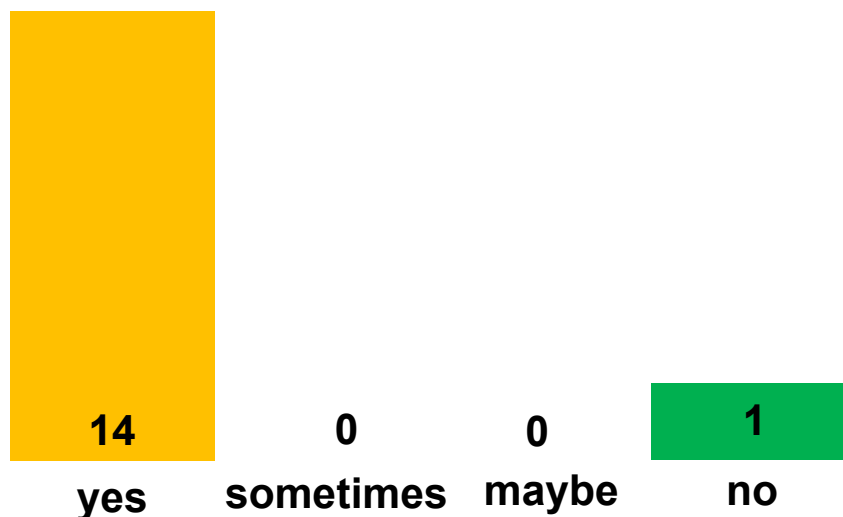
34 people came

- **15 people with learning disabilities**
- **2 people with autism and a learning disabilities**
- **6 support workers**
- **1 health professionals**
- **6 Health Ambassadors**
- **4 project workers**



making things accessible

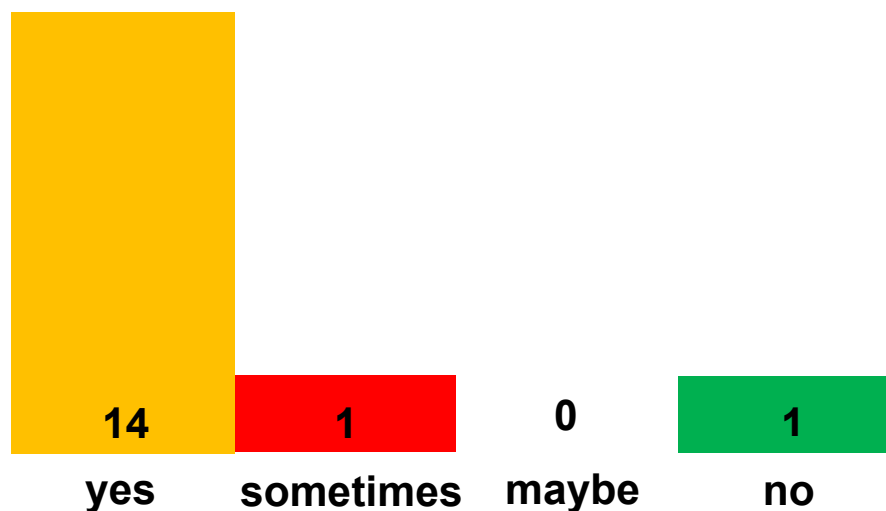
Does your GP or hospital give you information in a way you can understand?



What **helps** you understand?

- If I don't understand, my mother will explain

Are you given extra time for appointments?



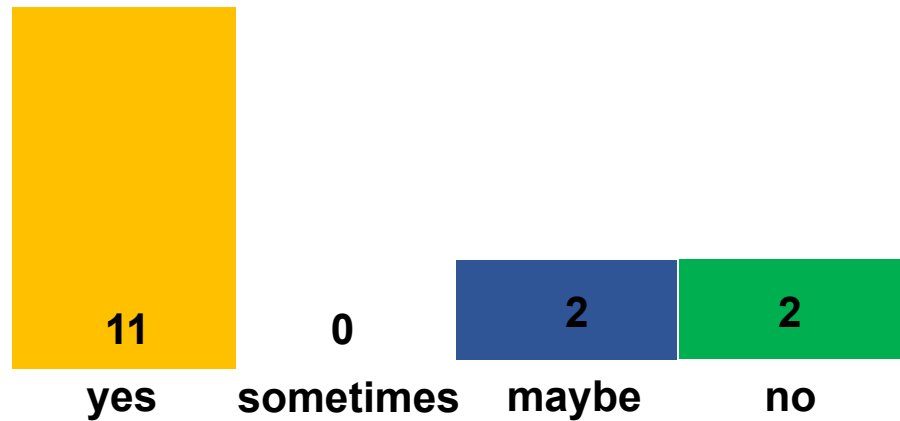
- I have to ask for extra time
- My mum makes the appointment
- I think I have shorter appointments



making things accessible

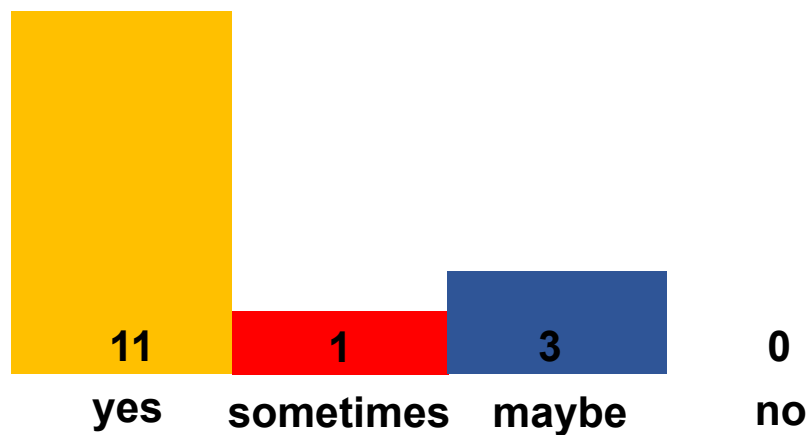


Does your doctor give you time to think and check you understand?



- The doctor just talks to my mum.
- Doctor talks to my sister and they ask me to leave the room.
- The doctor gives letters to my dad

Do people make changes for you because of your learning disability or autism?



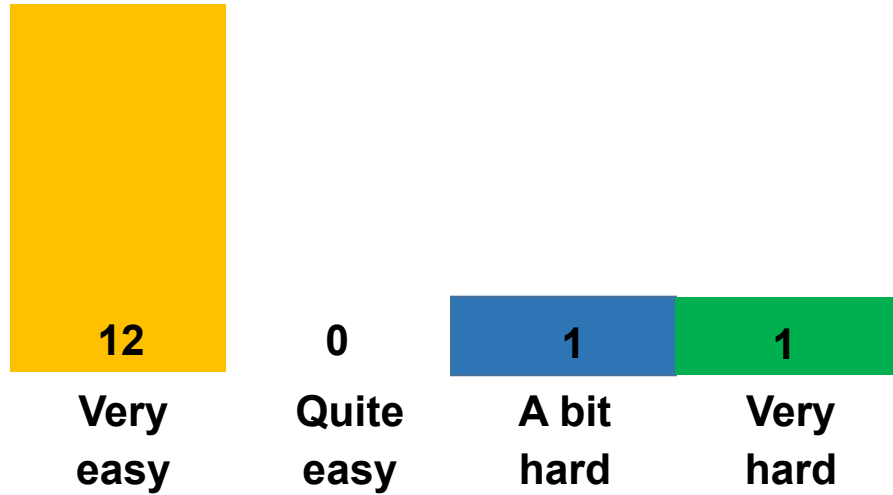
- I can only get an appointment by using the online app and it's too hard for me to use. I would like to be able to call for appointments



making things accessible



How easy is it to get in and around the building?



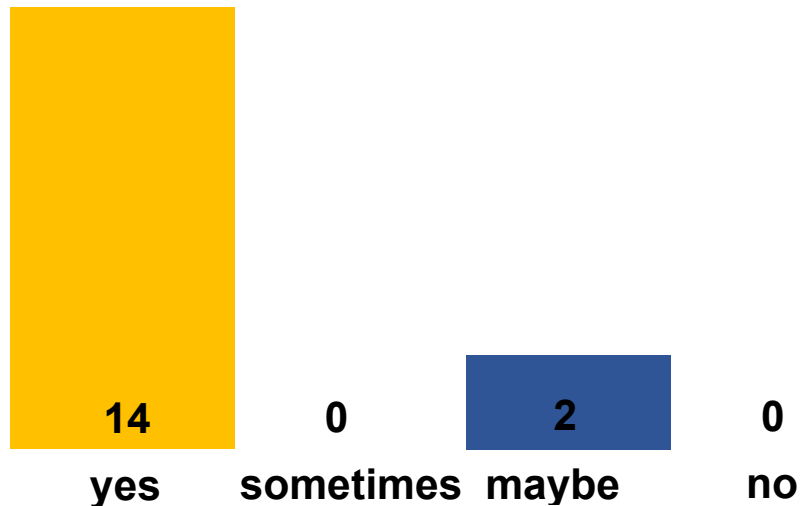
What is easy?

- No Steps at my doctors

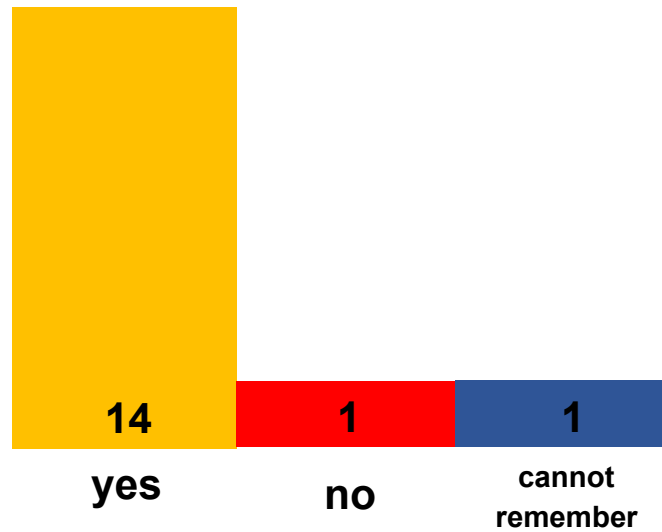
What is hard?

- I can get lost

Are you treated with respect?



Annual health checks



What was good about it?

- I did not feel rushed
- 2 people felt they were listened to
- They explained what they were saying
- 3 people had their blood pressure taken
- It was easy and I felt relaxed
- 2 people said they were told what was going to happen and what was not going to happen to them
- I had my heart checked
- I had my diet checked
- A urine sample was taken
- I had a flu jab
- I had a blood test

Annual health checks

What was bad about it?

- 3 people hadn't had one in the last 2 years
- The Doctor doesn't always tell me what's going to happen
- They took blood
- I don't like my belly touched
- No one asked if I had any worries
- I need to go with a support worker as I use Makaton

What would make it better?

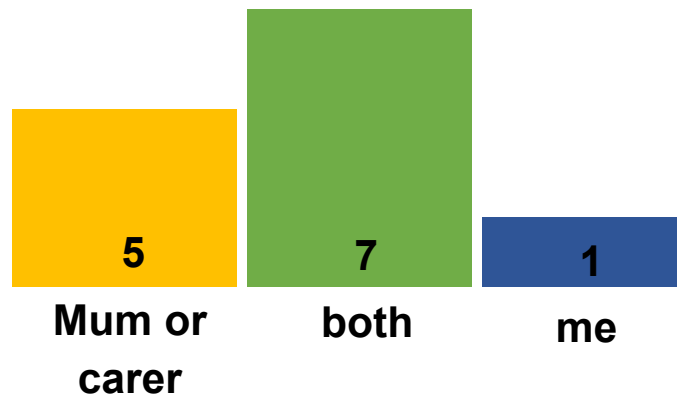
- A quiet waiting room. I don't like busy waiting room, it makes my nerves bad if I have to wait a long time.
- 3 people said - It's hard to get an appointment. I have to go in person to book as I don't use a computer and can't get through on the phone.





respect

Does your doctor speak to you or your carer?



Does your doctor help you choose things?

- Helps me eat healthy and gives me advice.



What's difficult?

- Being on time.
- Cancelled appointments are annoying.
- I waited ages for my injection and it got cancelled. I was annoyed. I got no phone call or letter. I was angry as I spent the whole day staying in. My mum was fed up too.
- I haven't seen my doctor.
- The doctor gives me a short time.
- I don't like going to the doctors



respect



What would make things better?

- Apologise if you cancel something and don't let me know.
- Better support for people with disabilities in MRI scans. I couldn't complete my scan because I was too stressed.
- Explain things better and use pictures
- Print things out for me to help me understand
- Have more time and don't rush
- If you see your doctor face to face, they can see what's wrong
- The doctor should listen to me better
- More time, like a double appointment
- My staff help me read the letters and help me with text
- Good support & more pictures
- If people explain, you don't worry
- Gerry told us there are disability nurses at hospitals to help, call them and tell them you are coming. We need to know more about them

Receptionists

- They are good.
- They smile and make you happy.



Health passports or black books

Who has a health passport or black book?

- 8 people think that having one is a good idea.
- 1 wouldn't mind one.
- 1 doesn't want one.
- 2 people have a hospital passport.
- One has a red book with health information.
- At the day centre we had health passports with info.
- Put information on computer instead.
- Might be more understood if you had a book.
- I have seen a hospital passport
- Too much writing.





Health passports or black books

What sort of information should it have in it?

- Your health - any heart conditions.
- Food I like.
- Something personal about me.
- Family contacts.
- How to communicate with me - Signing.
- All about me.
- Behaviour.
- If I am sick or not.
- A picture of me
- That I don't like smear test - it hurts.
- That I have hearing aids - they need to know about my ears.
- What makes you happy.
- Not to rush me.
- My medication.
- How are you feeling.
- What I am scared of - needles and pain.
- That I have seizures and that I need a carer with me.
- That I hear voices.
- How tense or nervous I get
- How to do things (blood test).
- I want a black book.



Your experiences

Good experiences

- My practice is good.
- They listen to me.

Bad experiences

- I don't like giving blood.
- I can't call as it's only online booking so I have to go in to make an appointment.
- I don't like going to the doctor.
- I find it hard to call the doctors.
- The doctor checks me over and takes my blood pressure.
- I find it hard to answer questions.
- It hurts when I have to get an injection.
- I don't like my blood taken.
- Not getting an appointment.
- I paid for a taxi and my appointment was cancelled.
- The cost of accessing healthcare can be a barrier.



Your experiences

What would make things easier?

- Treat us with respect.
- They need to call out my name as I can't read.
- They need to tell me what is going to happen so I'm not scared
- They need to listen.
- Bigger, better signs with pictures. If I can't find my way, I might be late for my appointment and not everyone can read.





Thank you to everyone who took part in our event.



If you would like **more information** about the Health Ambassadors, please **contact** HA@advocacyingreenwich.org.uk

