



Chair – Leon

Topic: Ambulance Service and
Survey examples

What was talked about?



Saricka came to speak to us about the ambulance service

Saricka spoke about her role to support people who have a learning disability using ambulance services

Saricka asked self-advocates about their experience of using ambulances



Marta shared some examples of GP letters and surveys

Self-advocates said which they liked best and why



Health and Wellbeing Working Group

You Said



- Saricka asked how you feel about your local ambulance service today

You said:

- Strikes are on the news and you felt worried about that
- Ask us, not parents how we feel in an emergency
- Doing a great job, good experience and helpful
- Go slower and explain to help understand was good
- Phoning for friend and words got jumbled, questions can be hard



We Did

We were pleased to hear your comments

We will check with Saricka about a video showing the inside of an ambulance and add this to website

We will invite Saricka to future meetings on self-advocate request





Health and Wellbeing Working Group

You Said



- Marta screen shared some sample GP letters

You said:

- Some still had lots of writing
- Black and white is not good, colour is better
- Photos of real people is important – the person you will meet
- They should have badges on
- Reason why sending letter first
- Space around words, bigger and bolder
- Layout is important



We Did

We will continue to work on this next time and think of survey questions to get feedback from more people

LD clinical lead for Hampshire could be invited to a future meeting and also Beth Lyon





Health and Wellbeing Working Group

You Said



We Did

- Are there any first aid courses at the moment to learn first aid
- Is there any receptionist training as this is a barrier to getting help
- Sharing lived experiences is helpful
- People explaining their jobs is helpful



Marta will check and found an easy read guide and suggested St Johns Ambulance



Marta confirmed her team offer this



There could be ways we can add this into training for staff and others





Chair – Leon

Topic: Ambulance Service and
Survey examples



Health and Wellbeing Working Group

You Said



We talked about communicating with people in health settings

You gave some questions you would like to ask people:

- How are you getting on with your GP?
- Do you get the same GP?
- Do you like to see the same GP
- how do you find your GP
- is it easy to understand them
- do you get easy read letters from your GP
- have you had a health check
- do you go to the dentist
- how helpful is the GP surgery
- do you understand what they say



We Did

Marta found an easy read guide and suggested St Johns Ambulance could come and talk more about services

Marta confirmed her team offer support

There could be ways we can add this into training for staff and others (in 2025 Annual health check video made)





Health and Wellbeing Working Group

You Said



We Did

- how do you get feedback
- do the doctors always listen and talk to you
- share your experience
- LD nurses sometimes do checkups do you find your nurse helpful
- do they treat you with respect
- do you like seeing the nurse
- have you used A and a how was it
- do you have any worries about your health
- do you know your LD nurse
- have you been to hospital and what was it like
- were they communicating with you
- did you understand what the doctor said



Thank you for all the questions we will use these to guide the survey questions





Health and Wellbeing Working Group

You Said



- do you understand the care you've been given
- did you get simple written information on what to do and next steps
- you said pharmacy writing is difficult and you don't like saying your address in front of others
- health checks are not always in person you don't often get an action plan afterwards
- there isn't much support in place and annual health checks are important
- do you get confused by the optician when having an eye test what would help
- Next time you said you would like to talk about:
- Booking an eye test, mental health, experience of going to places like dentists. Hospital passports losing weight and diets, professional support



We Did

Next time we will talk more about attending appointments and how that could be better





Chair – Robert

Topic: Eye Tests and Dentist
experiences



Health and Wellbeing Working Group

You Said



We Did

About Dentist visits:

- You don't mind it
- Depends who it is
- Dentists talk to you more than Doctors, nicer approach
- Need to clean more at back of teeth
- Some have good communication
- Some too quick and its complicated
- Need someone with me
- Can misunderstand what people say
- Ask them to write notes
- Had xrays and teeth out, they explained well
- Held hand to squeeze was ok, explained clearly and no fear
- Not much available in covid
- Need to learn about gum disease



We asked you to think about what would help others based on your experience

Would you like to do a piece of work on this?





Health and Wellbeing Working Group

You Said



We Did

About Eye Tests visits:

- If you want extra tests it costs £25
- Can be good experience
- Sometimes too quick and dizzy
- Hard to see small writing
- Communication cards might help
- Eyelash issue – great experience to fix – not scared
- Asked them to repeat and they said no



We asked you to think about what would help others based on your experience

Would you like to do a piece of work on this?





Health and Wellbeing Working Group

You Said



We Did

About Eye Tests visits:

- We asked **what would help?**
- If they communicate better
- Opticians should slow down
- Back to back patients in and out
- Learn about people who have disabilities
- have training about it
- Explain what they are doing
- Speak slowly and clearly
- Difficult to speak up for myself in these places
- External training how to help us



We asked you to think what you might like to do in this group, about dentist and eye test visits





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You Said



We Did

Future meetings

You said you would like to know more about annual health checks and to invite Beth Lyons

You said you would like to know more about hospital signage

You would like to know about making healthy simple meals

You want to work on questions for a questionnaire

You might like cards to use on GP visits

Next time we will think about the questions for the questionnaire and plan in future meeting topics





Chair – Leon

Topic: Survey questions



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You Said



We Did

We talked about questions for the health questionnaire

You gave ideas:

- Eating healthy
- Annual Health Checks
- Exercise
- Check ups
- How to get appointments
- Letters for appointments
- How do you make appointments?
- Would you like same doctor/nurse?



We will need to choose two questions for the questionnaire





Health and Wellbeing Working Group

You Said



We Did

More questions:

- Do you see same person at appointments?
- Is it important to see same person?
- How do you stay healthy?
- Would you like support on this?
- To have a choice of tick boxes to choose from
- What do you think about your Doctor?
- How do you book your annual health check?
- Are appointments long enough?
- What is your experience of GP services?



We will choose questions that help people cover all that they want to say





Health and Wellbeing Working Group

You Said



We Did

Topics for future meetings:

Katie: Healthy Eating /GP experience

Leon: Cancer Screening /dietitians

Arun: Weight Management /lifestyle choices

James: Health checks



When you chair we will have your chosen topics





Chair – Leon

Topic: Annual Health Checks

Health and Wellbeing (need to choose two next time)

- How to you make appointments?
- Have you had an annual health check?
Tell us about how it was
- How do you stay healthy?
- What is important to you when you attend an appt (eg seeing same Dr, having someone accompany, getting letter in advance)



Health and Wellbeing Working Group

You Said



We Did

You chose the final two questions for the survey

Dr Gemma Langman came to the meeting to talk about annual health checks

You asked questions about health checks and how to get help and support



What helps when you attend an appointment?

How do you stay healthy? Give examples of activities

Dr Gemma said she can help in future if needed and she will attend future meetings when she can





Chair – Fahmina

Topic: Annual Health Check &
Customer Experiences



Health and Wellbeing Working Group

You Said



We Did

Annual Health Checks

You gave an example from a recent health check (own words):

What was good for me – the doctor had a friendly manner, tried to help me understand tricky words. The doctor gave good advice on a personal issue. Did not have to wait long to go into the appointment.

What was negative for me – he didn't introduce himself and his name badge was turned around, I don't know if it was deliberate. Rude about making an autism referral, quite judgy. Not properly listening and did not read the form I filled in. It was mixed.



You wanted to talk about this topic again so we can talk about your experiences of your health checks

We did this today





Health and Wellbeing Working Group

You Said



We Did

You told us about your recent health appointments

You said a physio appointment was cancelled and you wanted to have it

You said you have been to the dentist and had a good experience, but there was a girl there who was scared and she needed extra support, you said she needed to have someone to help her



It is helpful to hear your feedback

We can learn from your experiences and together work out what might have helped





Health and Wellbeing Working Group

You Said



Guest Speaker

Ophelia came along from Solent NHS Trust she told everyone about her role as Experience of Care Lead She wants to know how you find accessing services

Ophelia asked you for questions, you said:

Will there be more NHS strikes?
That your Annual Health Check was cancelled 5 times

You said you would like Ophelia to come to future meetings



We Did

Ophelia would like to gather your feedback at future meetings to help make health services better

There may be more NHS strikes, difficult to know

We can ask for help with annual health checks through Marta and Dr Gemma

Ophelia would love to attend again and we will include her in the invites





Chair – Katie

Topic:
Breast Screening & NHS online forms



Health and Wellbeing Working Group

You Said



Guest Speaker

Jenny and her colleagues came to talk about breast screening

They spoke about the process and asked how to help more people go to the appointments

Jenny and her colleagues were really pleased with the feedback and will use it to make the service better

They will also tell their colleagues in the north of the county



We Did

You said what you think would be helpful

- A sensory bag
- Instructions in easy read
- A video showing the building and machine
- Taking someone for support
- For slow and clear instructions, not rushed





Health and Wellbeing Working Group

You Said



NHS online forms

Ophelia asked for feedback on some new online forms

We looked at them together and you gave feedback on them

We sent the feedback to Ophelia she said it was very good

Ophelia will share your feedback with another team to make changes to the form



We Did

- First page size 14 font is needed
- the sentences need breaking down a bit, paragraphs and full stops
- explain a bit more about what it is a feedback form
- needs to be easy to use
- say - here are the feedback forms first, then put the help information afterwards
- mental health team will do health check pharmacy can do that
- explain what PALs is
- pictures on the paragraph would help (like easy read)
- if not able to add pictures make it shorter
- frequently asked questions page make a bubble like PALs what does faq mean?
- portal the website request portal what is that?
- The anonymous complaint form asks for your email address, does that mean people will make contact with you
- what's the complaint background and information
- find a form that works well and look at that one
- if you can't read it how to submit a complaint?
- change the background color
- what happens for people who need braille?
- is there a phone number option
- suggested using examples from Marta she does good presentations how does she present things





Chair – Arun

Topic:
Future Plans

You said you would like to talk about these topics in future:

1. How to live a healthy life (inc. healthy eating, hygiene, dental care etc)
2. How can health services be more welcoming to people with a learning disability (primary care, hospitals, GPs, dentists, health screening, opticians etc)
3. Wellbeing, Mental Health & Physical Health
4. Other topics related to health and wellbeing / health services

We looked at the overview of the group to decide what to talk about going forwards



What we have talked about:

- Monkey Pox
- Mental Health
- Covid and Vaccinations

- GP letter
- Exercise
- Shapeupforlife

Meets: Monthly

Meets: On Teams

Who can be a member?

8 self-advocates

SHFT representative

CCG representative

Public Health representative

HCC representative + officer to facilitate

Provider rep (tbc)

What should it talk about?

1. How to live a healthy life (inc. healthy eating, hygiene, dental care etc)
2. How can health services be more welcoming to people with a learning disability (primary care, hospitals, GPs, dentists, health screening, opticians etc)
3. Wellbeing, Mental Health & Physical Health
4. Other topics related to health and wellbeing / health services

Possible ideas to talk about

1. LD annual health checks
2. Vaccinations
3. Healthy eating
4. Cancer screening
5. Sexual Health awareness

- Exercise/how to keep fit
- Enjoyable Healthy Eating
- Vaccinations
- Annual Health Checks
- Sexual Health Awareness
- Mental Health
- Monkeypox
- Weight Management
- Dieticians
- Cancer Screening
- Lifestyle/choices
- GP Experience



Chair – Leon

Topic: Mental Health and Job advert for SCAS



Health and Wellbeing Working Group

You Said ?

You looked at the job advert for SCAS and we went through it together

You said you would like this to be shared

You said diabetes is confusing and a film about it would be helpful

You were not all sure if you have a hospital passport and talked about why they might be helpful

You said an easy read for screening tests would help to know what to expect



We Did

This job is to learn about patient experiences

We will share this with contacts

We will look for films on this

We will ask health services about this





Health and Wellbeing Working Group

You Said



We Did

You said services are strained and you are worried about mental health

You said you think wearing lanyards is a good idea as it tells people to be patient and wait a bit

You said you feel more confident wearing it and feel safe – have had bad experiences when not wearing it



We will invite Dionne from VoiceAbility to talk more on this





Chair – James

Topic: Makaton, Forward Plans and updates



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You Said



You said it is difficult with the signage in hospital to get to the right place things would be better in easy read and people should look at hospital passports

Trish asked who knows about Makaton and showed us some

You said you would like to do a word each meeting. Makaton is easier to learn than British sign language



We Did

Ask Lee if he knows of any technology around navigating hospitals

Trish said she will teach a word each meeting





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You Said



We Did

You said what would help to make health information accessible

- photos of workers
- Being person centred
- easy read

For annual reviews/GPs:

- planning and reading of communication
- examples of questions you may want to ask
- explanation of what a review is more information on what is expected of the meeting
- be respectful clear and realistic



Marta and her team are working hard to make more areas of health accessible





Health and Wellbeing Working Group

You Said ?

- feel listened to and informed
- staff induction and staff involved in training
- communication between shifts

feedback on annual reviews

- more time needed speak to us not family
- less jargon
- talk to someone not anyone else
- read notes before the review

Diabetes:

- what can you expect with diabetes
- what is it what have you to do to prevent it
- no idea beforehand, is not easy



We Did

We said tell them if you need more time

We looked at some examples of annual health check letters

L shared that speaking with someone about Mental health has helped to sleep better those nights

We said we will find out if there is easy read information on preventing Diabetes



December

28

No meeting