



# Your Voice Network Neurodiverse group

Thursday 2<sup>nd</sup> March 2023

## Ice breaker question

Favorite way to relax

People talked about what helps them relax – pets, walks, bath, being in a hot room, going on a cruise, you tube, solitaire apps on phone.

## Main Discussion

Discussion with Mala about NHS App and planning for the next meeting

# Feedback given by the group

Dr Mala Ubhi joined us to get some feedback on the NHS app for her Masters research

- Mala Ubhi is a GP and the lead for Autism in Gloucestershire

She is doing research on the accessibility of the NHS app. The NHS want 75% of people to use it and she is looking at whether this is feasible or possibly ableist. People had the option of leaving and joining a breakout group but nobody chose to. Mala sent through an information sheet and checked whether everyone gave consent to take part and be recorded.

Mala asked if anyone has used the NHS app and what they thought about it:

- Someone said the surgery she uses prefers her to order medication on the app. She likes the biometric log in (fingerprint). Her surgery is not taking part in the messaging service. It would be useful to query something via text even if the response was within 2-3 working days. She doesn't want to take up a spot in the phone queue if she has an important but not urgent query. The messaging service would be good for non urgent queries especially if you might then self-diagnose on the internet
- Someone else said that they have not used the app but they use the online system that his surgery uses. The surgery uses two systems online with different functions. It would be useful for any systems to be able to 'talk' to each other. Services are fragmented with one part using one system and one using another. Things should be joined up. Any system should be really clear and really simple to use.
- Someone has been using the app for a few years. They feel it has a lot of plus points. They can see their own records which is really useful. Being able to see consultation summaries is very helpful because it serves as reminder of what's been said . It helps to make more sense when the GP summarises our conversation. It is important to know how we are being seen by a GP as it causes a huge worry – having transparency about how they view me helps me see if I have been misunderstood or if I have not communicated clearly
- The App allowed some one to see an error an their medical records which they were able to get corrected
- Someone said that being able to communicate through email through the app helped communication as they were able to draft what they wanted to say and then review it before sending .
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- A number of people mentioned that E consult system tried to shoe horn people in to boxes. Which meant they weren't able to describe their needs accurately and or be able to describe long term conditions. One person described it as damaging to their mental health
- Someone had tried request an autism assement through e consult and it returned the option of 'mental health children' only so they had ended up having to put in depression. They also ask what have you tried so far which seems like having to justify why you are bothering them.
- Also e consult is only on when the surgery switches it on which isn't great for people with poor executive function

- Someone said that there's differences between the app interface on the web and on the phone this might cause confusion between the interfaces

- Someone said that they didn't like that the help button meant that you had to jump out of the app to web page. It would be better if it stayed within the app. And there's an abbreviations glossary but this could be improved by just being able to highlight the word and the meaning coming up in the app,

- Someone It would be good to have a section for health passports and these should be available for everyone not just people with learning disabilities and autistic people

- Somebody said it was useful to see medications prescribed and vaccines. It was discussed that it would be useful to have some sort of automatic reordering for prescriptions as many people struggle with executive function, or at least some sort of reminder by text or notification. And text messages about when prescriptions were ready

- A number of people mentioned that were unable to access all the functions of the app as it seemed to be dependent on what individual surgeries allowed. No every one was able to access their medical records or book appointments or message their doctors while others were able to.

- A couple of people mentioned the future of the app and its future capabilities. It would be liberating to be able to self identify as neurodiverse and to be able to access reasonable adjustments etc. being able to opt in and out of things. Would be useful to have community based training videos on the app rather than professional lead training.

- Someone mentioned the accessibility of the app. The interface is very fixed, there is no possibility of changing colours or having less on the screen etc to make it accessible. More icons, less text etc

- Some one mentioned that it would be good to be able to book appointments on like a number of the neurodiverse community find telephone booking systems stressful

- it was mentioned that in a previous meeting that it would be good to have some sort of link to book routine cancer screenings and that it would be good if this could be done through the app

## Planning for the next meeting

The Group were reminded the group that Mark Tucker from the NHS Southwest Learning Disability and Autism Programme Board is coming next month and the group discussed what they would like to talk about with him/ for him to observe.

- It was suggested it might be a good idea to have a few bullet points to talk around such as self-identification, preferring text based communication
- it would be important to talk about the huge variety of difference when people talk to their GPs about being neurodivergent. Some GPs are so dismissive and its damaging.
- how does he see his role in respect to each of the counties because it seems like they run differently.
- Someone said that Mala came along with someone doing the NHS app and they feel like we have been listened to. Maybe the NHS should come along regularly so they can listen to us directly. Maybe they could come quarterly.
- it would be great if they came back and told us about the changes they are going to make, this would close the circle on the coproduction.

## Recommendations

- If multiple apps and interfaces are used across health care the systems should be able to talk to each other
- It would be good if everyone could access the same information on the NHS App it shouldn't be dependent on what the surgery decided

- E consult is not an accessible system for Neurodiverse people and it should be made so that people can talk about long term conditions and not be put in boxes

- It would be good to have an automated system that sent out texts to remind people when their repeat prescriptions need to be ordered or collect them when ready

- A number of people weren't aware of the app or only just become aware of it. If the NHS want 75% people to be using it then there should be some sort of awareness campaign

- Any app should be customisable and accessible to suit different sensory needs

## Next meeting

- Sammy has invited Mark Tucker from the NHS England Learning disability and Autism program to come to the April meeting
- Our April meeting we will talk about barriers to health care and what we want out of good coproduction .

- **Next meeting Thursday 6<sup>th</sup> April 2023**
- **6:00 pm – 7:30pm**