healthwatch Coventry

Views of parents of children with Special Educational Needs and Disability (SEND) about the use of technology in the NHS

Findings from a focused discussion

March 2020

Contents

1 Introduction

Healthwatch Coventry has the role of representing the interests of patients and the public in NHS services by gathering views and feedback on services and taking this information to those who run and plan services.

The Healthwatch Coventry Steering Group added this work to the Healthwatch Coventry work programme as a follow up piece of work to a previous survey gathering views on aims in the NHS Long Term Plan[1].

From October 2019 to 6 January 2020 we ran a public survey and held two focus groups asking questions about:

- How the NHS could use technology to support patients?
- How people would like to communicate with services?
- The extent to which people feel involved in GP services

Our findings are available in the report *Improving patient communication/involvement and the role of technology in local NHS services*.

This report provides further detail of the issues raised by a focused discussion we facilitated with a group of parents of children/young people with Special Educational Needs (SEND). We gathered views on the aim within the NHS Long Term plan to use technology more and to reduce the number of outpatient appointments.

What is meant by Special Educational Needs?

Special Educational Needs and Disability are grouped together under the term SEND. Local authorities and clinical commissioning groups use this terminology when referring to a service user or patient who may have additional learning and access needs for Education, Health and Care.

A child or young person has special educational needs and disabilities if they have a learning difficulty and/or a disability that means they need special health and education support, we shorten this to SEND.

2 Participants

Eight people participated the focus group between 9:30 am and 12:45 pm on Tuesday 28 January 2020.

All participants introduced themselves and their interest in being at the meeting. They were women with sons and daughters who were children or young adults and who had a wide range of experience of local NHS and social care services. They all

[1] https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

kindly provided notes on the challenges they were facing in accessing these services.

Comments were captured on the flipchart and also individual experiences separately on A4 notepaper. This report follows the structure of the discussion questions prepared for the event. Photographs of the flipcharts are included as appendices to this report.

3 Findings

What NHS services do you use and come into contact with and services communicate best with you and why?

Column 1 indicates the 32 NHS services identified. They are listed in no particular order.

(1) Service come into contact with	(2) Communicate well (count)	(3) Mixed experience (Count)
Clinical psychologist	1	
Educational psychologist	3	2
Psychologist	1	1
Psychiatrist		
Gastroenterologist	1	
Ophthalmologist	3	1
MH crisis team		
GP	6	1
Consultant paediatrician		
Community paediatrician	2	
A&E – children and adults		1
Dermatology		1
Occupational Therapy		2
Audiology	2	
Speech and language	2	1
Clinical Commissioning Group transforming care registry		
Ear, Nose & Throat (ENT)		1
Continent service		1
Learning disability nurse		
Cardiology	1	1
Adult MH services		
Neurology		
Neuro surgery		1
Neuro development (Autistic Spectrum Disorders)		
Continuing Health Care		
Genetics	1	
Child, Adolescent Mental Health Services (CAMHS)		

Special needs dentist		
NHS dentist	1	
Eating disorder specialist		
Physio	1	2
Dietician	1	

Column 2 indicates the number of people identifying the services that communicate best. The services coming out most regularly positive were GP, ophthalmologist, educational psychologist, audiologist, and community paediatrician and speech and language specialists.

Column 3 indicates the services where individuals have had a mix of experiences – from the good to the bad. These include Occupational Therapy, educational psychologist, and physio.

The criteria for some services were thought to be an issue or were considered inadequate – for example around age. These include Occupational Therapy, CAMHS, and A&E.

Please note that there is no indication of level of usage of these services by participants.

We also received written comments about experiences of service from group participants. And summary of these is given below:

Child and Adolescent mental health Services (CAMHS)	Daughter had eating disorder and had some involvement with CAMHS previously. She took an overdose at 17 with an intent to end her life. GP was extremely helpful. Suggested taking to A&E to access immediate help. Grey area for 17 year olds - very frustrating. Eventually admitted to children's ward after several hours. Stayed overnight to access CAMHS assessment but then discharged. Promised follow up did not take place. Form did not seem to have correct information. Just tick box, felt like said engagement but no engagement felt. Parent did not sign the forms.
Child and Adolescent mental health Services (CAMHS)	Early diagnosis would help ensure young people are going to the appropriate school e.g. some special schools will not accept a young person without a diagnosis of autism (from personal experience). CAMHS and other professionals must start to listen to patients and believe them. They have been overestimating the patient and that can mean they don't get adequate support in all areas.

Assessment processes and CAMHS	We waited 3 years for an (Autism) ASD diagnosis and are now at the start of another wait to be seen by CAHMS for a child assessment. My child this themselves on a daily basis, I have been waiting for help that works, which may mean possible medication but I am facing a possible 2 year wait at CAHMS. I have done all the courses that Neurodevelopmental Team run. Maybe if my child had had a multi-disciplinary assessment then maybe she would not still be hurting herself. The knock on effect on my family is tremendous. I feel I am at crisis point frequently. I suggested a triage system at CAHMS, where you have an initial appointment and maybe that is all you might need. Also multi-disciplinary assessment would meant that child's ASD and Attention Deficit Hyperactivity Disorder (ADHD) assessment could have taken place together. Services seem disjointed.
Occupational Therapy (OT)	NHS OTs and physio don't engage with Education Health Care Plan (EHCP) request or the process which they legally need to. NHS OT referral policy and criteria is discriminatory against children with learning disability. It says you can't be referred in until you are lower than cognitive age. How can you say what is? e.g autism children may have difficulties in some areas and not in others. What is their cognitive age? Children without a learning disability are not discriminated against. If you have a handwriting need and don't have a LD you get seen and get help. No early intervention for children with LD.
Blood taking	Blood taking booking for children - 2 weeks wait when you can go immediately for adults.
Access to services	More notice for appointments - currently letter arrives only a week before the appointment. More guidance in the school selection. Lack of support for families as a whole. Shouldn't have to wait for a referral to another service once already in the system. Social circumstances should not make a case a priority i.e. I was questioned initially if I come from a drug addiction, alcoholic, single parent , abusive relationship, when I answered no I was then not a

	priority or my son was not. Why is he any less important? We have been on numerous courses but there is nothing for the children around understanding their diagnosis.

Other general comments about services include:

- Once in the service it is often OK but the issue is the referral criteria that may bar us from accessing the service
- Comments were made about the poor responsiveness of services – for example CCG transforming care registry.
- Cross border difficulties – when we live somewhere yet go to school in another area.

How do you feel about the use of technology in health care

We asked for people's votes at the beginning of the meeting and at the end.

- At the beginning, people were very reluctant to vote as we were only starting to discuss scope and implications. The key point was …'it depends'.
- At the end, when asked if they were generally positive about the use of technology – **assuming the principles they recommend as given below were adhered to** – they were all positive and raised their hands.

A) What concerns do you have about this?

The following concerns were identified by those who took part:

Security	• Security relating to cybercrime and identity theft. At least one person trusted an 'app' less than the web. • The tampering of details by hackers and by health professionals.
Access	• Difficulties in access. Especially for older people, young people with no technology, and those without the functional skills to operate it. If security processes are too involved and difficult, then people give up. • Doubts whether it will tackle the problems of the poor communications across Trusts. • The fear of losing face-to-face communication especially when access to technology is poor. • Data usage is required (if no Wi-Fi available). People may not have data available to use technology and will be mindful of the cost when on a 'call'.

	• Technology - The devil is in the detail. How appropriate are various services provided this way?
Accuracy of records	• The need to guarantee that records are correct. Given these records are assumed to be a legal record. • The difficulties of a record being in 'dispute'. Should it still be accessible? Are there rules for this? •
Value of face to face	• One advantage of a face-to-face appointment is that it is fixed and we can work round it. Online brings more work and less certainty. • Body language will give information on health and is only available face-to-face or on a video call.
Current issues	• Why are computers not talking to each other? Will this still be a risk and make things worse?
	• Now even GPs cannot share information with each other. They often use GDPR as a reason / excuse. There is a doubt that GDPR is understood commonly in health services.
	• How can technology help with the communications between EHCP (Education, Health and Care Plan) and the NHS – especially when the biggest problem is that NHS staff rarely turn up for meetings? Sometimes the excuse of 'we're not paid for this' is given by community health representatives.
	• I get text messages about appointments but don't know which of my 3 kids and which department or which specialist.
	• Not enough results available such as blood tests, when it does say on GP's online access but isn't offered. Missing ongoing prescriptions.
	• UHCW - I've registered for text alerts for appointments many times but never set up properly so have never had any.
Other	• The difficulties in resolving differences between professionals relating to the care of the patient.
	• When using websites and going from link to link, it is very easy to get confused and to remember how we arrived where we are and how to get back a previous page.
	• The requirements of GDPR – which are still evolving.

B) What are the positives?

The following comments were made by those attending:

• People who do not want to leave their house will appreciate a video call – especially as a follow-up appointment. For example, these people may include those with autism, anxiety, depression, mobility problems, and illness. Some older people and those with 'multi-caring' responsibilities may also appreciate this
• It will assist with higher school attendance rather than taking time to travel to an appointment
• People may not want the emotional stress of seeing more professionals and risk 'bursting into tears'
• A video call is less intimidating than a face-to-face meeting
• Chatboxes allow us to do other things while we are waiting for a response. They can be used for changing appointments, gaining information about the department / venue (for example is it accessible?) and general guidance on what I should I do if…
• Using video links for multi-disciplinary meetings – in which people can call in from their own offices and ensure 'joined up' thinking – could be effective. Could also assist in combining different assessments – for example ASD and ADHD.
• Technology may assist and help develop support groups
• There is an opportunity to use technology to provide information on waiting times. A 'dashboard' could give information on who has been seen, whether information has been received and acted on, and track progress on the stage we are at in the process – therefore managing expectations about what happens next and making people feel that they haven't been forgotten
• Email communications are very useful just to keep people informed
• The technology can be set up to make sure the right people are on the system at the right time – and avoid all the disputes about age that exist now especially in transition periods of child to adult
• There are opportunities to support cross-charging by services to enable prescriptions to be delivered to where it is most convenient for the patient
• Opportunities to support triage – for example at CAMHS

Guiding principles when technology is used for patients to access NHS services

The key principles the group identified were:

- **Choice over use** – i.e. *we should actively 'opt in'*

- **Flexibility**. *For example, there need to be allowances made for essential face-to-face consultations and also we need to be able to choose what information is shared (for example when a comment shows that the child's condition has not been fully understood) and with which service.*

- There must be a **choice of communication medium** to be used. This is because there are various relevant factors which influence a patient's choice – for example noise in background, domestic violence, phone credit, internet access, signal, broadband speed, a child or adult's behaviour, and confidentiality (where there is a need for honesty without fear).

- We need to have a **choice over the security processes used** – for example fingerprint, face recognition or password.

- Need to review rules that are not 'patient-friendly' for example using GDPR as an excuse. Rules need to be much clearer and applied consistently with a **'central place' where permissions to share data are given**.

- **Alerts whenever there is a change to the records.**

- **Right to correct incorrect information** and a clear route to address the issue.

- **Clear recognition of who is managing the patient's care**. For example they may be a nominated carer, deputies, appointees, those with parental responsibility (PR), relevant person's representative (RPR), foster carer, and it must also account for those with powers of attorney and also young adults who deny they face a health issue.

- **Clear procedures for certain situations** (for example where protection is a concern) and where a 'red flag' can be used to ensure alerts go to appropriate individuals and professionals so immediate action or an identified process can be followed.

- **Clear and transparent governance** of the whole system, especially about controlling access and ensuring inclusivity.

- There must be clarity, ruling and **transparency on shared access outside the NHS** for example the police and other services and how this will be controlled.

- There needs to be a robust **contingency for systems failure.**

- It should include a feature of ‘Frequently Asked Questions’.

- It should signpost people to appropriate services that would support the patient, based on the data held.

Appointments such as GP and outpatient

A) Have you had an appointment you did not think was worthwhile?

There were many examples of face-to-face appointments that were not needed for different reasons including not having the right information in advance to be able to make a decision. These are appointments that could be done remotely using technology.

It was very strongly felt that people went to appointments not always because they were worthwhile but that they needed to go in order to stay ‘in the system’. By not going, the fear was that they would be discharged and then have to start again.

B) Could appointments be done in a different way?

- Face-to-face appointment are very likely to be needed early in diagnosis and then follow-ons could be a mix of remote or face-to-face.
- Follow-ups are critical. FAQs could be used as well as other tools that help patients see and track their progress.
- An appointment should only by triggered if the information required for a decision was available.
- Improvements need to be made around referrals and acknowledgments of these.
- Often referrals are ‘lost’, not only but especially in community-based services.
- Appointment rules are often ‘restrictive’. For example, there may be no appointments left within 2 weeks and we cannot make arrangements after that because our contact has no access to the professional’s diary.
- Referrals do not need paper letters. Texts, emails or telephone will be more effective.

C) How might technology help?

- Technology can offer options that ensure discharge is made at the appropriate point – rather than as a result of missing a face-to-face appointment.
- It can also ensure information / results are available before a follow-up is triggered by the system.
- It will be able to manage the referral process more effectively, giving us information about timing of appointments, allowing us to book / make

changes to these, help us track progress, and reassure us that we are 'in the system'.

4 Conclusions

This was a really interesting discussion with people who have become familiar with many NHS and social care services as well as other services used by those with special educational needs and disability.

It was clear that using so many services can be frustrating and concerns about access to service and how service join up were raised.

There were many comments about communication channels which did not work well as well as processes that could be improved. Whilst technology is unlikely to be the solution to problems in inter agency working, the group clearly identified opportunities to use technology to improve communication and connections between themselves and services. Participants could identify that some face to face appointments were not needed and felt they had to attend them to stay 'in the system'.

There were concerns about data security and management issues as well as concerns about access and that face to face contact was necessary for some people and for some purposes and should not be lost. But the potential of technology to improve record sharing and updating was appreciated and the participants offered very good insight in these area

Overall the group was positive about the use of technology and the experiences and comments they have can be used to help identify how to go about this.

They identified the following principles to guide the consideration of the use of technology:

Key principles for use or technology

- Choice
- Flexibility
- Choice of communication medium
- Choice over the security processes used
- A 'central place' where permissions to share data are given.
- Alerts whenever there is a change to the records.
- Right to correct incorrect information.
- Clear recognition of who is managing the patient's care
- Clear procedures for certain situations
- Clear and transparent governance
- Transparency on shared access outside the NHS
- Contingency for systems failure
- Access to information

This focus groups highlights the usefulness and importance of speaking to those who use services when considering how to do things differently.

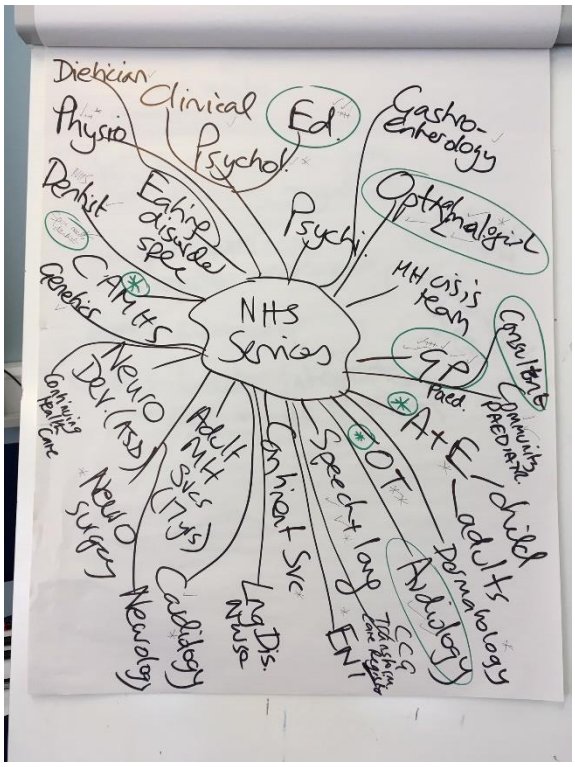
5 Thanks

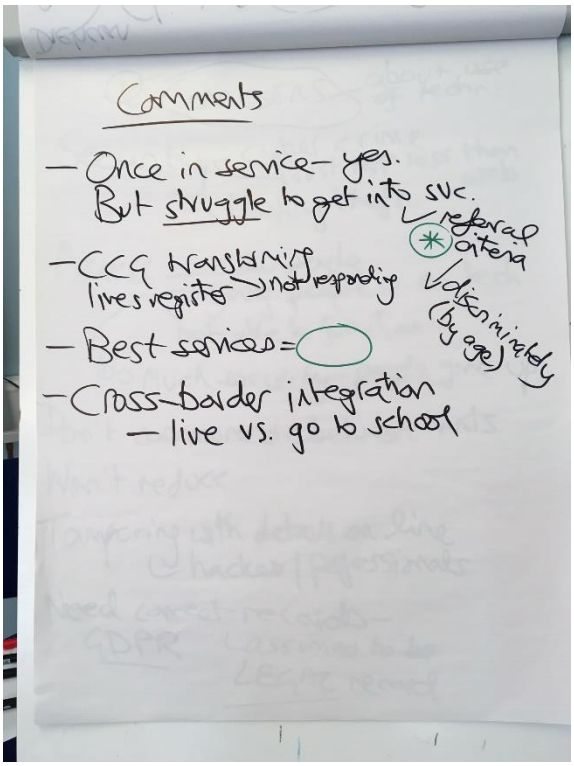
Our thanks to those who took part and the team at SEND for helping to organise this discussion.

6 Copyright

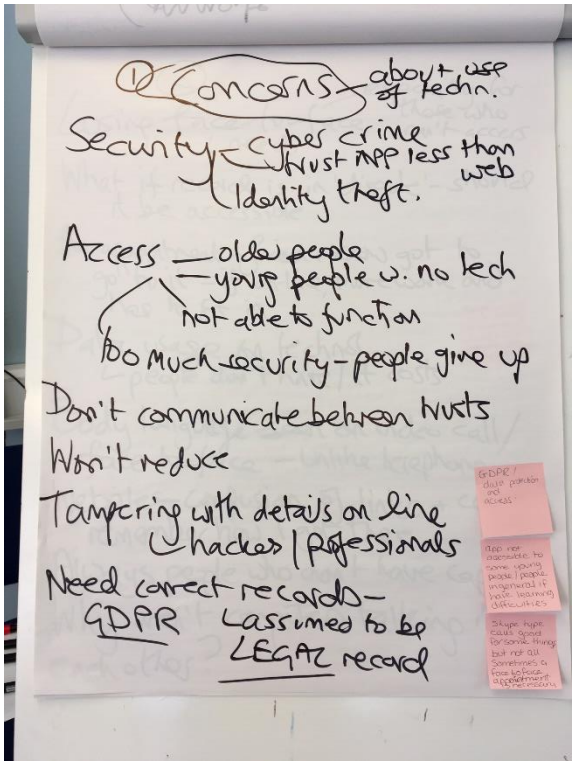
Appendices - photographs of flipcharts

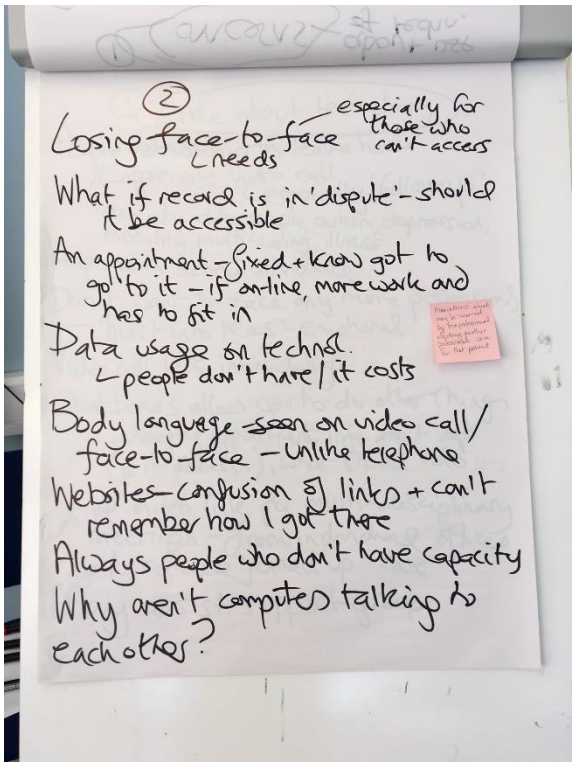
Icebreaker: service used and how are they at communicating

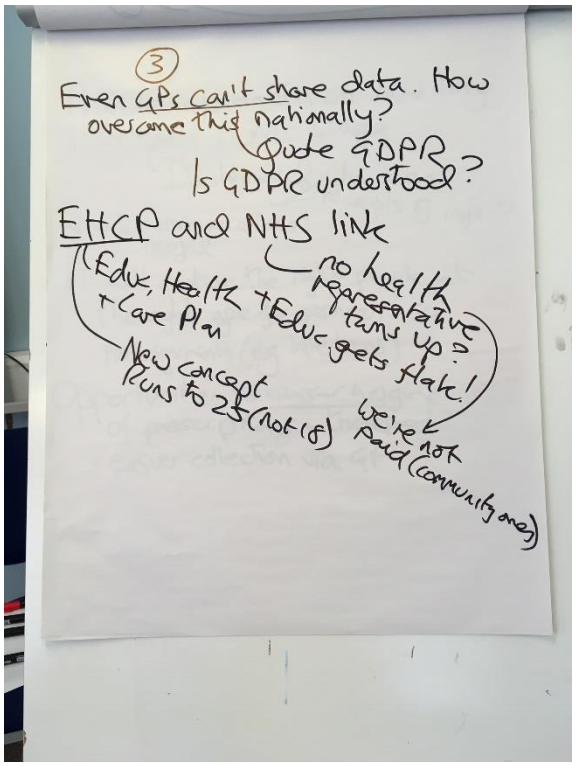




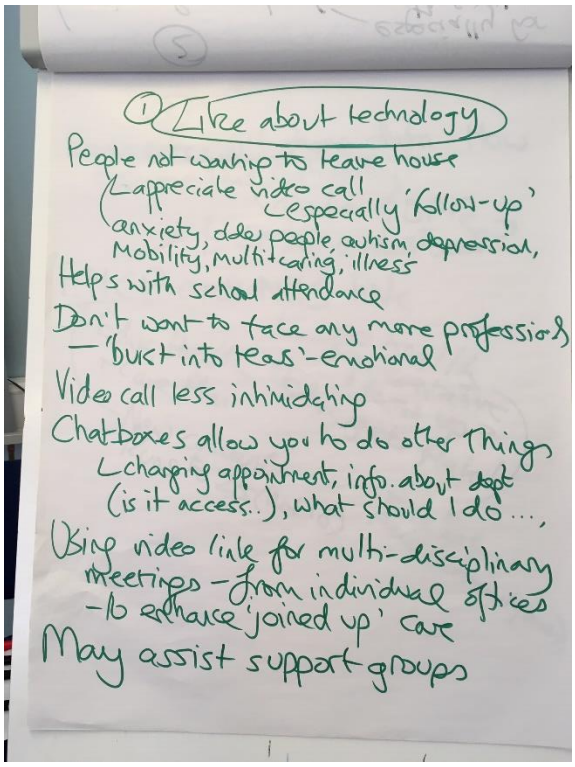
Part 1 – what concerns?

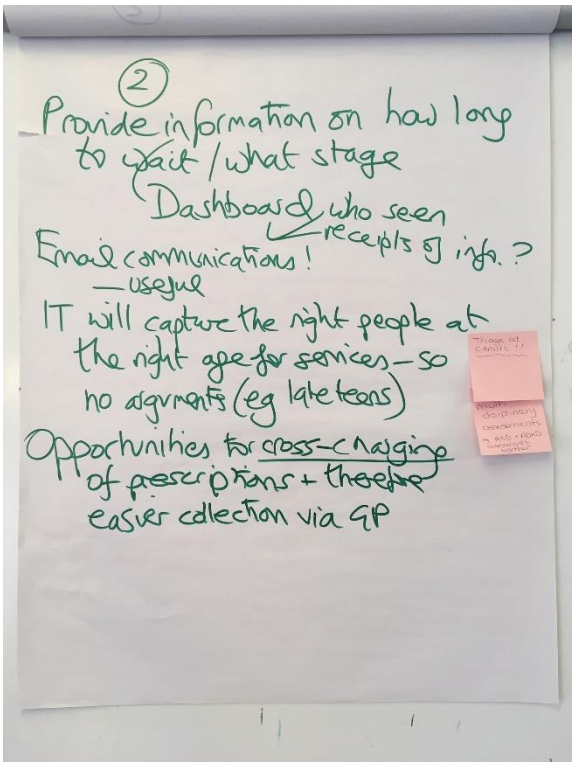




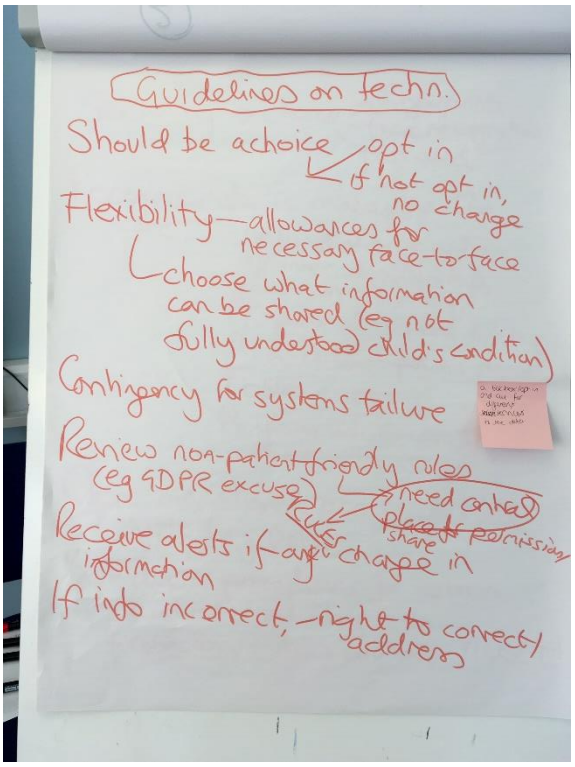


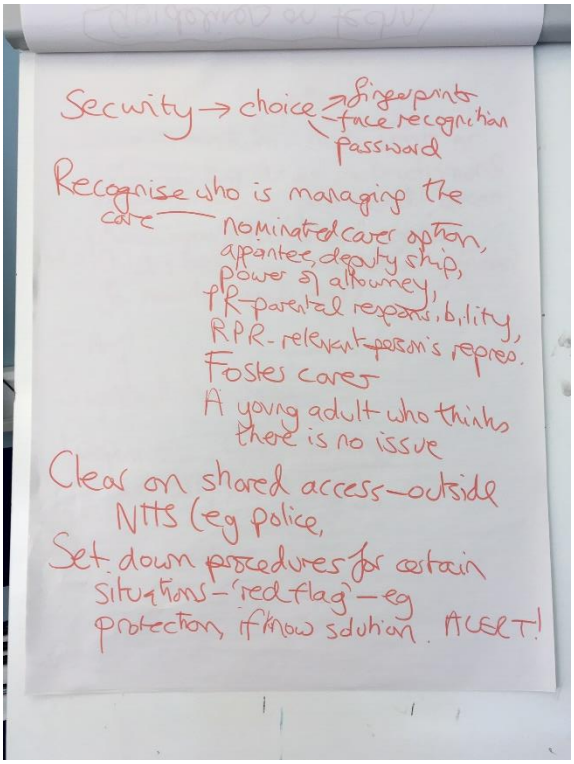
Part 1 - what do you like?

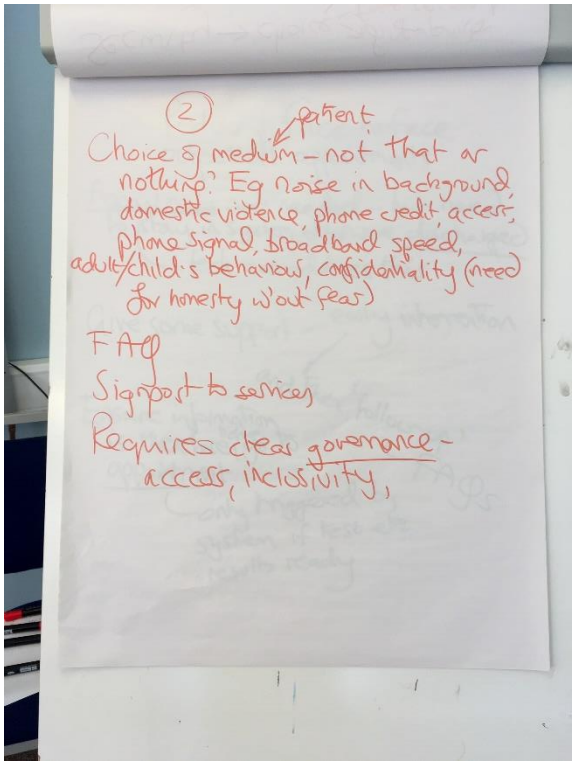




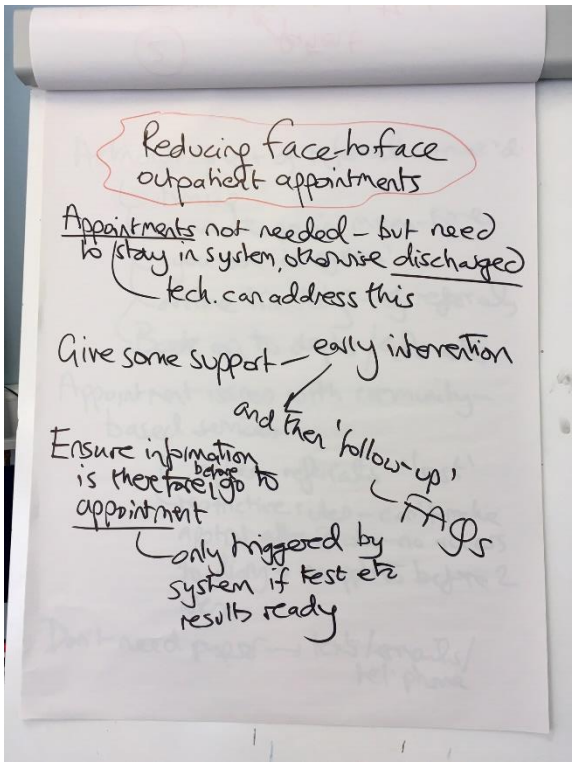
Key principles

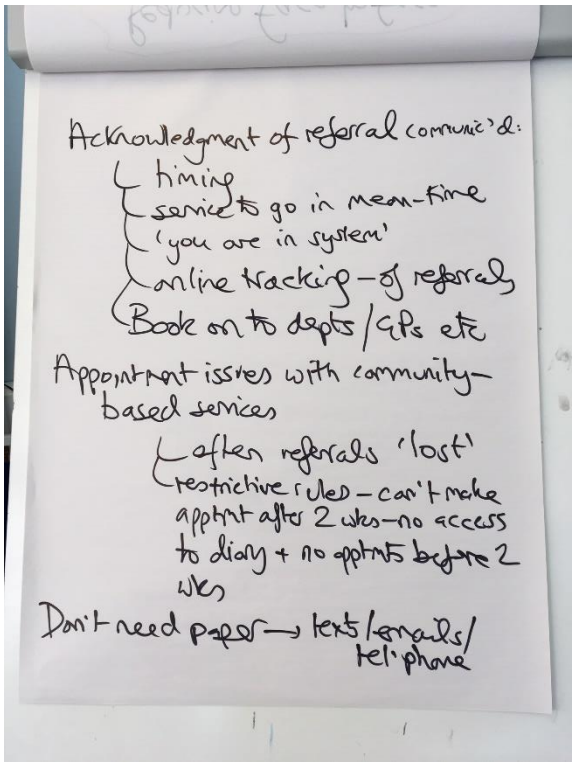






Part 2: appointments





healthwatch Coventry

yoursay@healthwatchcoventry.co.uk

www.healthwatchcoventry.co.uk
@HealthwatchCov

024 7622 0381

Provided by

Voluntary Action Coventry