NIHR | Great Ormond Street Hospital Biomedical Research Centre

GOSH DRIVE/GenerationR Health Tech workshop event – 17 April 2019

Young people shaping healthcare technology research

REPORT

NHS Great Ormond Street Hospital for Children Research and Innovation

DRIVE

GenerationR young people improving Research

Contents

1. Introduction

On April 17 2019, 25 children and young people from the GenerationR Alliance Young People's Advisory Groups (YPAG's) travelled to Great Ormond Street Hospital's (GOSH) new digital hub DRIVE unit, an exciting, state-of-the-art technology space. The event was part of GOSH's national Patient and Public Involvement (PPI) programme for paediatric health research supported by the GenerationR Alliance and part of DRIVE's engagement programme with patients and families.

The aim of the day was to ensure future research into new technologies are co-designed specifically for children and young people. During the day the groups took part in four interactive health tech workshops where they met and advised digital researchers and industry colleagues to help them think about how their products could be improved to better meet their needs.

"GOSH patients are a digital native which means they and their families are early adopters of technologies. They will naturally embrace the new devices and apps the unit develops. These young people are our future in so many ways – and of course the future patients of the NHS for the next 50 years."
Dr Shankar Sridharan, Clinical Director of DRIVE

"It's only logical for us to shape the world we live in"
YPAG member

The event was also a great opportunity for the YPAG's to meet each other and recognise that they are all part of the GenerationR Alliance which aims to help improve the health of children and young people through research nationally and internationally.

This report summarises the activities of the day; what health tech kit the YPAG's tested, feedback given and recommendations made. But first a little bit about GenerationR and GOSH DRIVE.

2. About GenerationR

The children and young people attending the event represented seven of the groups who make up the Generation R Alliance, a network of Young People's Advisory Groups (YPAG's) from different centres across the UK.

YPAG's are funded by the National Institute for Health Research (NIHR) and/or NHS organisations through various channels. Groups meet regularly and are actively involved with researchers in the design and delivery of paediatric health research to ensure it is relevant for children, young people and their families.

Currently there are 14 active YPAG's across the country with new groups being mentored and developed.

GenerationR
young people improving Research

3. About GOSH DRIVE

Digital Research, Informatics and Virtual Environments.

October 2018 marked the official launch of GOSH's new digital research and informatics unit DRIVE; the result of a unique partnership between GOSH, University College London (UCL), NHS Digital and leading industry experts in technology, artificial intelligence and digital innovation.

DRIVE has a bold ambition to transform care and improve outcomes and experiences for children by harnessing the power of the latest technologies and digital developments, and rapidly setting them in hospital practice. This is not only for GOSH patients but across the wider NHS. DRIVE has also had support from Great Ormond Street Hospital Children's Charity.

4. Health Tech Workshops

4.1 How the day ran:

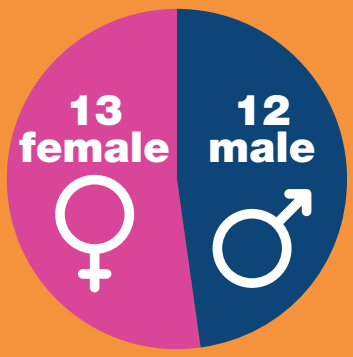
On arrival at DRIVE the YPAG's were issued with different colour coded lanyards. This ensured that the various YPAG's got to meet and mix. Neil Sebire, Managing Director of DRIVE welcomed everyone to the event and gave an overview of DRIVE and its ambitions and explained the importance of working alongside young people to develop future technologies. This was followed by Liverpool YPAG members Adit and Ruby. They introduced everyone to the GenerationR Alliance and stressed the importance of YPAG's working together on national initiatives such as DRIVE and other health research projects, which will ultimately lead to more young people having a say in how their healthcare is designed and delivered.

Keen to get started the groups began their rotation around the interactive Health Tech workshops facilitated by YPAG leads, the DRIVE team, GOSH researchers and industry partners (NTT Data, Microsoft and Samsung). Time was given to demonstrate, test and try the technology with set questions given to focus discussion. Workshops were split -two before and two after lunch with additional time at the end for the groups to come back together and look at common themes emerging.

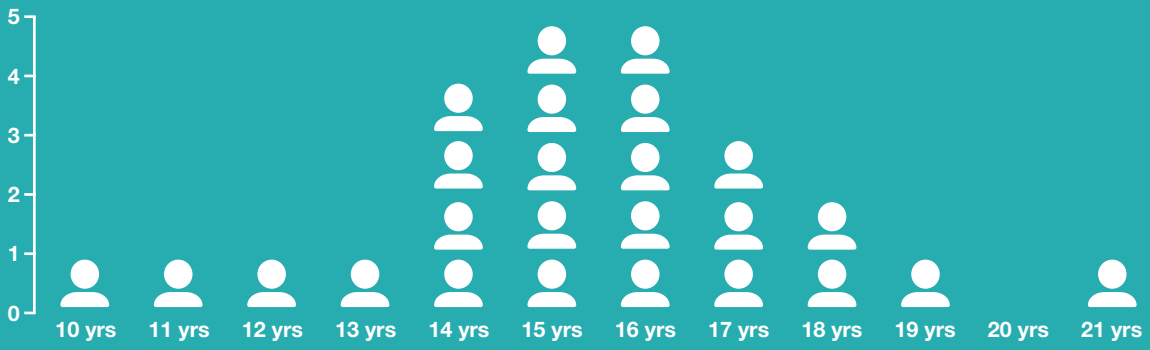
4.2 Which YPAG's were represented?

- KSS (Kent Surrey and Sussex)
- London (GOSH)
- **YPAG Representatives**
- Liverpool
- Scotland Clinical Research Network (CRN)
- Southampton
- West Midlands
- YPAGne (northeast)

4.3 Gender breakdown



4.4 Age breakdown



4.5 Workshops

Workshop	Title	Industry partner/DRIVE	YPAG Leads
A	**Robotics** – Buru-Navi, SOTA & Jibo	NTT Data	Liverpool/West Midlands
B	**Gamification** – Minecraft & Project Fizzyo	DRIVE/Project Fizzyo teams	Kent Surrey & Sussex/ Southampton
C	**Mobile Devices** – Holistic Tablet	Samsung/DRIVE team	West Midlands
D	**Mixed Reality** – Augmented Reality Portal & Virtual Reality Holo-Human	NTT Data & Microsoft	North England/Scotland

5. What Health Tech kit did YPAG's test?

Workshop A: ROBOTICS

Buru-Navi is a haptic (touch based) device that converts directions into vibrations. When you hold it your hand gets the feeling that it's being pulled forwards, left, right or backwards depending on the direction being signalled. **Buru-Navi** could help guide patients with speech and hearing difficulties. It could also be used for virtual reality gaming.

SOTA is a social robot with human like movements. It can be programmed to perform various tasks, through voice commands. The aim is to use **SOTA** to keep children occupied when they are in hospital and at the same time improve their vocabulary. **SOTA** can also connect to a blood pressure meter and other monitoring devices.

Jibo is a social robot who looks, listens and learns. It has a unique 360 degree movement and a personality! Designed to be a helpful part of day-to-day life; **Jibo** experiences the world and reacts with expressive movements and responses. It is powered by advanced Natural Language Understanding (NLU) along with speech and facial recognition technology, so it remembers and builds relationships with the people it interacts with most.

Workshop B: GAMIFICATION

Minecraft is a PC, console and mobile game that allows players to build 3D worlds using many different blocks. The game includes multiple gameplay modes, such as creative mode, in which players have unlimited resources to build with and adventure mode, in which players can explore custom maps created by other players with certain restrictions.

Through partnership with Microsoft, GOSH has been recreated in a **Minecraft** world. The **'GOSH Minecraft'** is available in adventure mode and allows players to virtually explore all areas of the hospital before they come to the hospital and virtually meet and befriend other patients who are there to help improve their patient experience.

Players can interact with entities, such as animals, collect items, craft items and pull levers to move blocks. Future developments to **'GOSH Minecraft'** will include giving players special resources to build with within restricted areas of the hospital site.

Project Fizzyo is a project which has already come through DRIVE and is being used within the hospital to help with patient outcomes and experience. The aims of **Project Fizzyo** are simple – firstly, to make airway clearance treatments more engaging and fun for children with *cystic fibrosis. The hope is that if children start to enjoy doing the routine and burdensome physiotherapy treatments, and do them more regularly, then they will stay well for longer.

Children will be able to use their breath to control computer games: drive a car, play mini golf or collect coins, among many other gaming options being developed! The games use the player's breath to charge firing objects, cause characters to jump/move to avoid obstacles and collect items. Rewards are given for longer breaths. The **Fizzyo** platform also contains a leader board, list of achievements and a summary of the player's breathing exercises and frequency of play. The doctors have access to this information, which helps them check on the player's health remotely. **Project Fizzyo** uses wireless chipped electronic sensors inside airway clearance devices. The sensor detects breathing and converts each breath into an electronic signal, which in turn controls computer games on a tablet.

Secondly, **Project Fizzyo** aims to use data, collected passively via the chipped sensors, to understand more about the relationship between routine airway clearance, exercise behaviours and health outcomes. One of the best things about **Project Fizzyo** is that a lot of useful data can be collected without any extra effort from children with CF and their families.

The **Fizzyo** team has a Vimeo video that shows one of their games.

Cystic Fibrosis (CF) is a life-long disease affecting children from birth that can affect multiple parts of your body, most commonly your lungs. CF patients can experience difficulty in breathing and coughing up mucus. A treatment for CF involves breathing into a device to clear the airway which consists of the tubes in your chest that let air in and out of your lungs so you can breathe. These exercises must be performed daily, but they can be tedious and boring to perform – hence **Project Fizzyo**.

Workshop C: MOBILE DEVICES

Holistic Tablet is a personalised table that contains all of the information patients and families need in one place. It has an app with written information and one with videos guides. It contains a video conferencing app for remote consultation, so patients can see a doctor from home. It has a direct messaging app, so the patients and their families can contact the appropriate team directly. It also has a pain management and meditation app.

At the start of their treatment this personalised **Holistic Tablet** would be given to patients and families and they would use it to assist their care at home. The tablet is a locked down device meaning the use of the tablet is limited to the apps installed in it.

The treatment of some patient's requires their families to have a lot of resources at hand, such as leaflets, videos, websites, etc. that contain information on how to perform certain procedures, how to manage medication, how to deal with pain, who to contact, etc. Having so many resources in a variety of formats causes families to waste time trying to find the piece of information they need. When they don't find it, they call the hospital, which can involve some time waiting in line to be put through to the right team.

Workshop D: MIXED REALITY

Augmented Reality (AR) Portal is a mobile application that can be used to transport the user into a different environment (such as an operating theatre), by just using a mobile phone. The required environment (a different world) can be augmented into the real world and the user can enter through a doorway, making the experience more realistic without using any VR headsets. This is a doorway into a virtual world for use with your tablets or phone!

Virtual Reality (VR) Holo-Human is an interactive 3D anatomy platform application viewable via a head set. It contains over 6,500 individual structures within the following 12 body systems: Skeletal, Connective Tissue, Muscular, Arterial, Venous, Lymphatic, Nervous, Respiratory, Digestive, Endocrine, Urogenital, and Integumentary. This can be used by students or with a teacher speaking to students to help them learn about the body. Through the visor a person can see a skeleton in front of them and can also highlight certain organs onto it. They can even walk through the body to see the inside!

6. Summary Session – common themes arising from feedback in the workshops

Moving back into the main area groups discussed the common themes arising from each of the workshops. A more detailed breakdown of feedback from all the workshops can be found in the Appendices p15-22.

Workshop A: ROBOTICS

Groups enjoyed testing **Buri-Navi** once used to using it and had some excellent feedback on how it could be developed. It could also be useful for people with hearing problems, not just those who are visually impaired. It could help with rehabilitation after a stroke or for physiotherapy after an operation. Why not use it as a call button for your nurse? It could be used in the home too. Health and safety concerns were raised also such as the need for an alert when battery life runs down or the fact that the device cannot detect a spillage on the floor.

The robots were extremely interesting devices that were able to move fluently and talk and respond to your interactions. **Jibo** could take photos and allow you to play games by tracking your movement. Groups discussed their usefulness in relation to keeping people company and entertained and compared them to a more social version of an Alexa. Whilst in this framework it was deemed an exciting prospect, groups also decided that caution must be taken when it comes to younger children as they may become emotionally attached to robots.

Workshop B: GAMIFICATION

Groups gave lots of feedback on how **Minecraft** could be improved and advanced further and how to develop it into a game and to bring people closer together. They thought that **Project Fizzyo** was a clever idea and that it was good that it was tailored to illness as concerns were raised about games tailored to able bodied people which would make unwell people feel bad. Several YPAG members felt that some patients will inevitably be scared, and won't like having their data monitored. But the majority of people were ok with it but that people need to be more informed about what is happening with their data and that they can stop if they want.

Of note also was that developers need to be mindful. With these games, a patient might feel really sad if they are playing a game they would never physically be able to play in real life like running about playing football. Developers need to be sensitive to this.

Workshop C: MOBILE DEVICES

Groups really enjoyed finding out about this project because this tablet will allow its users to access care easier and quicker. Through discussion, they questioned the safety of the data put into the device. Groups all came up with ideas of tackling this issue with facial recognition and Touch ID. The idea of direct messaging and video calling medical professionals was discussed and criticised for its possible misuse and compromise on the time of those answering patients, although its benefits could mean shorter waiting times for patients needing urgent care in the longer run.

Workshop D: MIXED REALITY

Augmented Reality (AR) Portal

An exciting prospect-the gate way into a different room, country or world! This allows patients to not only escape into another place when undergoing stressful or painful procedures but also allows them to preview rooms and wards before getting there, helping predating anxiety. For those who have simply been in the same room for too long, it allows an adventure into the outside once again.

Virtual Reality (VR) Holo-Human

This was one of the most popular workshops of the day, with the exciting opportunity to use the mixed reality headset – the Holo-lens. Groups were fascinated by the idea of using this to reduce anxiety for patients due to be admitted into hospital – who can prepare by exploring the hospital through the lens. They also discussed other ways this innovative technology could be utilised – in education, leisure and more.

Of note however that was AR/VR could be a scary/ unsettling experience for younger children, would it be disappointing to take off the headset and return to “reality”?

Groups also thought that AR experiences on older phones is generally of poorer quality compared to modern handsets but not all have access to these expensive devices – so the developers need to think about equality of access.

7. Summary Session – Voting

YPAG's voted on their favourite health tech kit and gave reasons why. There were also discussions about how the YPAG's could have future input into DRIVE projects and a real interest in being invited back for future workshops.

7.1 Voting:

7.2 Feedback on voting:

Workshop A: ROBOTICS

- It's real/tangible
- It improves healthcare
- No person needed to be with patient

Workshop B: GAMIFICATION

- Rough around the edges (Minecraft)
- Needs refinement (Minecraft)
- Earlier in development than other technology but has potential (Minecraft)
- Project Fizzyo however shows to have real world benefit to patients and families

Workshop C: MOBILE DEVICES

- Applicable to any patient and really generalisable
- Big potential burden on consultants if patient access via messaging
- Patient expectations need careful management
- Expectation now that responses are immediate
- Benefits for patients

Workshop D: MIXED REALITY

- Teaching patients/students /health professionals
- Escape and entertainment
- Really works, not a prototype, helpful
- Exciting and "wow!" factor
- Talking to a hologram of a real person not physically present would be better than talking to a physically present robot
- Versatility of AR/MR from art to surgery
- Interactive and fun

"My favourite was the virtual reality. It could have lots of different uses like helping junior doctors. I thought it was the technology that was the closest to being ready for use."

GOSH YPAG member Maryam

"It helped me realise the technical advances that are currently happening in medicine and allowed me to have an input (however small) to do with very important new technologies"

Kent Surrey & Sussex YPAG member Kit

"Our app looks a bit like current instant messaging apps but the group suggested that we should inform users of when they can expect a reply if not immediate. We will certainly address this in the ongoing development of the device"

Daiana Bassi, Technical Lead at DRIVE, (who is involved in developing the concept of a personalised device)

"It was fantastic for YPAG's to have the opportunity to see some of the new technology coming onto the scene. It's essential that young people are allowed a voice to determine what they want from their services and I think they are better placed to advise on applicability and user friendliness of these technologies than me or most of my peers! It was a privilege to help facilitate and exciting to see what is around the corner!"

YPAG support staff Kent Surrey & Sussex (KSS)

8. Closing Messages

The DRIVE team and industry partners found the young people's feedback to be constructive and insightful and a positive aide to further development. Industry partners all agreed that the event provided an invaluable opportunity to directly engage with young people and gain new insights into how technology can support patients and families.

DRIVE opened in October 2019 with a commitment to improving the lives of our patients and families through the evaluation and deployment of new technology. We were thrilled to host the Young Persons' Advisory Group's inaugural Tech Workshop event in DRIVE and listen to their unique insights into how the technology on show could be further developed to help support the clinical care of young people both in and outside of hospital.

The hospital's new strategy will be launched later this year with digital innovation one of four themes. We very much look forward to working with YPAG to establish a virtual network which will enable us to keep this invaluable channel of communication 'open'. We need to seize this opportunity to keep the work of DRIVE real, relevant in today's digital word and able to deliver benefits to our young patients and their families.

Our industry and academic partners were impressed by the level of engagement and are looking forward to their next invitation and receiving more words of wisdom about their technology and where further research would be beneficial.

Sue Conner, DRIVE Director of Operations

Children and young people have been involved in improving health research for over 10 years in a well-established network (GenerationR). They have brought clarity and a grounded viewpoint to help researchers, including pharmaceutical companies to develop better medicine studies. When the DRIVE team discussed with us, their idea to link children and young people with their industry partners in technology, it seemed an obvious match for GenerationR. Even then, I was surprised but delighted by the huge commitment from young people volunteering to attend the day, coming from many parts of the country.

Throughout the day I saw and heard real engagement and interest but also direct and informed comment. There was real energy and enthusiasm in the room but also as the day developed, a sense of young people working together to help the partners. Equally the demonstrations and commitment from the industry partners were impressive and appropriate to our young people. This wasn't tokenism, it was real business – hearing and debating feedback to improve the products and services for children.

This report offers reflection and some thoughts on the day. It was the first of, I hope, many more engagements and the model of industry listening to and respecting the young people they strive to help, is inspiring and a great message for the future.

Dr William Van't Hoff, Director, NIHR GOSH Somers Clinical Research Facility and NIHR GOSH Biomedical Research Centre PPI E Theme Lead

9. Appendices

9.1 What did YPAG's say? Q & A session – Workshop A: ROBOTICS

Thinking about a child/young person being in hospital what do you think Buru-Navi could be useful for?

- good for people with hearing problem as well not just visually impaired
- use in steering wheels in cars? Or for the deaf for directions
- to help in rehabilitation after stroke
- useful at hospital or at home to knew where objects are etc.
- use in VR
- use as nurses call button
- physio /exercise after surgery

What other things do you think would be useful for Buru-Navi to be able to do (new features)?

- link with games - dual functions
- use for training for surgery
- use for keeping elderly active
- a Guide to the hospital ward using Buru-Navi – more personal
- connect to traffic lights, etc. for safety outdoors
- integrate with walking cane?

What concerns might you have using this technology?

- that it would not detect a spill
- might be difficult to use it along with stick – safety concern
- if it ran out of charge after continuous usage
- in crowded places; chances of misinterpretation
- while walking; holding the Buru-Navi down could change the perspective
- if visually impaired has no stick, others will not know about the impairment
- bump into things, extra hazards
- there should be an alert for battery life when it runs down

Other feedback:

- difficult to begin with but is cool once used to it
- would be nice to see hazards
- simple to use
- having a break in between directions might make it easy to understand the directions
- not for everyone
- option to put it around wrist, in case it's dropped
- it takes time to get used to – training time
- certain directions are not prominent
- it has a different sensation – sense of pulling
- can the sensor area be just thumb instead of holding it?
- it's very handy and so can be concealed even when outdoors
- more maps of indoor space will result in more usage
- can it be linked with voice directions
- give notification of arrival beep when arrived, or when half way through
- for small kids it will be too big
- more personal and helps in large hospitals
- can it have a visual arrow? for deaf?
- useful for independence
- can it be incorporated in wrist, ankle, belt, fingers, shoes – to save carrying on hand

Thinking about a child / young person being in hospital what else do you think SOTA and Jibo Robots could be useful for? Do you think they would be popular?

SOTA Robot

- use voice to connect to smart hospital – use to adjust bed for example
- patients at home can give Sota regular updates on how they are feeling. This can be tracked and logged at the hospital and doctors can access this data
- help deal with stress by learning about patients and what they like. Suggesting things that would make them happier/calm them down etc.
- personalisation, sound like a character, information about illness or hospital
- make information child friendly so they can learn about their illness etc.
- Depression helpline with emotion detection

Jibo Robot

- help Doctors learn about symptoms
- useful for appointments and reminders
- home remote monitoring
- call the doctor/nurse
- know the schedule and inform about blood taking, nurses going to come, etc
- tell current oxygen level and what it means

- gives specific information on your illness
- hand gesture to give instructions to Jibo
- rehabilitation yoga and for mindfulness
- could be used to train doctors
- as a receptionist
- faster than waiting in a queue. Interesting for children would calm them down
- give reminders, how much medication to take etc.

What concerns might you have using this technology?

- what happens if the kids are too attached – Jibo as the best friend
- what if it makes a mistake and gives false information
- finding balance between robot and human
- dangerous line to go over on emotional interactions
- problem with accents/foreign language
- could remove face to face interaction with humans
- difficult to have a robot on a ward
- how much data could be stored in Jibo, could it ever compare to the years of knowledge of a doctor?
- might feel uncomfortable talking to a robot (especially old people)
- all information said to Jibo must be relayed to a doctor
- training necessary for home use
- need to be careful about privacy – who is listening, when is it okay to listen? (SOTA)

Other Feedback

SOTA Robot

- less embarrassing to talk to a robot about something than a person – children might find it easier
- help in social care
- patients at home can give SOTA regular updates on how they are feeling. This can be tracked and logged at the hospital and doctors can access this data
- help deal with stress by learning about patients and what they like. Suggesting things that would make them happier/calm them down etc.
- personalisation, sound like a character, information about illness or hospital
- make information child friendly so they can learn about their illness etc.
- depression help line with emotion detection
- emotional support – guided meditation, improve on social skills, information helpline

Jibo Robot

- better talking to a Robot than a Doctor
- robots a regret because hospital is so boring
- less embarrassing talking to Robot
- makes a room more friendly
- like the games
- it feels like an electronic cat, companionship
- like the expression and movement to head – more personal
- fluid movements, cute like a pet
- good for older children – entertainment
- younger people liked it more
- it feels less personal but could be made more personal
- size is big but the movements make up for it
- easier to talk to a robot than a Doctor especially if it is embarrassing
- use in care homes for social interaction
- games are good for children with limited/no movement
- give lonely children company
- getting attached to robot could leave the child sad after
- cute, intuitive

9.2 What did YPAG's say? Q & A session – Workshop B: GAMIFICATION

What do you like about Minecraft?

- nostalgic, might reduce anxiety, distraction
- would be able to use in different hospital environments, wouldn't matter that the layout is slightly different between different hospitals; your mind isn't looking for the details
- if you are familiar with Minecraft it could be reassuring to walk around or know where you are going
- building blocks, you can create your own world
- space to interact with others
- like the idea of rooms for set conditions
- lets you use your imagination, but this game doesn't allow you to build
- maybe get given tasks to navigate around the hospital to get to know it
- it's creative, like virtual Lego
- it's easy to get lost in it
- minecraft might be good for mental health – people who want safe space – letting them build own safe space and then move out from there into hospital
- group understood concept that it might help people feel prepared
- people like creative aspect of building things in Minecraft

What don't you like about Minecraft?

- still very 'blocky', could make it more realistic
- change the colours, walls and floors are uniform
- if you've not played Minecraft it may not be that helpful
- it's not very realistic so it might be a bit weird if you turn up to the hospital and it doesn't look like it does on minecraft
- the one thing that scares me about hospital is operations. I don't want to know about what they are going to do or where they are going to operate. It would unnerve me to go into a VR operating theatre. Not only do you not want to see it, it just makes you feel more scared to practice it
- it's depressing to learn about your condition
- technology moves so quickly I worry that by the time it's been developed, it's an old game. People might want more realistic VR
- change floors and ceilings because currently same colour
- can you include signs?
- currently quite dark
- can you make the whole area – e.g. local area – before you enter hospital – so the user can familiarise themselves
- was fun to walk around but didn't know where we were

What would you like Minecraft to be able to do/your suggestions on how you could use it?

- add in tasks that are condition specific
- if going for x-ray, task to go to radiology and look at x-rays, spot diagnosis
- could make it slightly more exciting to have games and tasks embedded
- may need to monitor the game otherwise kids may end up exploring unrelated conditions which might cause anxiety
- treasure hunt?
- use rooms for different conditions
- use as a journey of different people they are going to meet
- rewards rather than leader board
- general feeling is we don't like leader board
- might help reduce stress/ anxiety
- good for preparing to go to hospital
- needs to be more exciting
- would be useful for either distracting from the hospital environment or familiarising yourself with the hospital for people with anxiety
- be able to create your own room/build zone to help distract and forget that you are in a hospital environment
- be able to showcase the rooms you've created
- would like to be able to burn it down and cause havoc!
- would like to be able to interact with other users. This would need to be monitored, probably talk to other kids in the hospital
- needs to have other people present
- would be good to map on to own (home) hospital
- set challenges, give rewards so each time you come back you can get more rewards, or get given a secret code which would allow you to access different parts
- live talk to other patients, I think it's important to not feel isolated. It's quite fun trying to find other people
- it needs to show/include other people
- it would be quite good to have your own hospital built, not just GOSH
- you could have different modes to allow people to just want to explore or walk about rather than have to do games, allow different levels of playing
- you could have a live location ('where you are now') which shows you where you are and shows you what is nearby and links to a live map
- none of the doors are labelled; it would be good to label them so you know where you are going

- it would be good to be able to ask the game 'how do I get to….'
- you could make a maze you have to navigate out of
- maybe create a glass roof
- you can also fly in newer versions of Minecraft
- create a quick way out as it can get quite overwhelming
- maybe have a quiz in the game (i.e. how often you need to take your meds, where in the hospital do you need to go)
- it would be good to use it to meet the staff and be introduced to your consultant (i.e. meet a person and then their image comes up and they speak to you)
- if you added a chat element would you restrict and monitor it?
- add challenges: "build the best…" or hide and seek
- allow chat
- would it not be better to have real life images for navigating the hospital- I might find it confusing to navigate with Minecraft?
- it needs some people, it's like a zombie apocalypse, the doors don't open, and it would be good to be able to go through the doors
- good to have interactive arrows and realistic photos of the hospital
- I'd like to be able to blow it all up! it's a great way to vent frustration and anger
- it depends how often you can use it and when. Where would you use it? At home or just in hospital? It would be good to be able to explore it at home
- building and adding to a hospital – playing around
- visits close to what you will be doing – e.g. radiology
- chat room – but who would monitor it?
- informative tour – challenge. e.g. clues and treasure hunt, for example. More fun less harsh and clinical
- different levels and goals? Having targets keeps people coming back
- want to interact other users
- would have to be just patients and staff due to moderation?
- maybe decorate room as you desire or build
- interactive – learning about condition. e.g. Room and visit items. meet different staff
- comments from person who played game
- should know where going, should be a wide map that can orientate you
- would be of benefit if could also learn about condition as some people want to understand why they are at hospital and what the stages are
- could you build in ways to unlock zones?
- where you are now board /map. Map hidden when not explored
- label the doors. We can't work out where people are
- interactive – e.g. quiz integrated in to the game to improve people's understanding of the condition or procedure coming up
- meet the staff element (i.e. meet a nurse and learn what they will help you with
- tasks to find the wards/places they will be visiting
- have both options – to just tour or to play games – to meet different peoples interests
- is there a map of the whole site?
- giving 7 year old whole huge hospital lots but if they can be told how to view the bits they need
- change it to a game
- missions – e.g. your stomach hurts so go do X
- multiplayer – play with other people in hospital with tasks
- put people in it – looks like just after a zombie apocalypse
- doors should open

What do you think about Project Fizzyo?

- clever idea
- good that it's tailored to illness as concerns raised about games tailored to able bodied people which would make unwell people feel bad
- does it have to be on a tablet? People want it on any device
- better to have it on an App

What could we do to improve Project Fizzyo?

- can you alter the leader board so everyone is in the lead when they look
- could have achievements and a board where you can see them
- you could have login bonuses (but there are worries it makes you addicted to the game)
- it would be good to have access to lots of games. Maybe give access to new games once certain targets are reached
- sometimes you just don't want to play a game and just want to do your physio; it becomes distracting
- games often based on able bodied people – this needs to be taken in to account for sick/disabled children
- games need flexibility
- could you have 'random' (unexpected) achievements?
- add in different levels, different difficulties so you are progressing, otherwise the game gets boring and repetitive
- need a variety of games at different ages

What do you think about having your data monitored?

- a group of people will inevitably be scared, don't like having their data monitored but the majority of people are ok with it. People need to be more informed about what is happening with their data and that they can stop if they want
- i think it's a good thing for a serious condition, some people might find it a bit scary or not want their doctor to know they've skipped physio (i.e. don't want the dentist to know I didn't brush my teeth this morning!)
- i don't know, you are already being monitored with the breathing mask; it might be a bit too much monitoring with fit bit as well
- you could just have it monitored for a few hours a day or at least give people choice about being monitored
- some people might change what they do if they know you are watching, they might find ways
- it might make treatment more stressful when you know you are being watched
- could you use the technology with other devices like the shaking vest?
- it's a little invasive but if it stops you dying…
- if you can monitor them remotely and then say you don't need to come in, but then they get ill, it's your fault for telling them not to come in
- people think being monitored is a good thing
- Fitbit – not sure if I would want to be monitored in this way. Quite invasive to be monitored all the time
- would it have to be constant monitoring? Maybe a few hours a day
- wouldn't people change what they do because they wouldn't want people to know what they're doing (or not doing) at home. Is it really what they're normally doing?
- what about monthly feedback to the doctor that I can choose to share

9.3 What did YPAG's say? Q & A session – Workshop C: MOBILE DEVICES

Do you think a personalised tablet, like the Holistic Tablet, could support patients and families? If so, why?

- liked the personalised feature
- not convenient – too big – can we add to iPhone?
- condition updates – clinical trials, diary to trigger messages, pick up on trends
- audit trail/tracker – when did I last speak to my clinician, accountability!
- needs a team or person to manage it – like a service or helpdesk

Can you think of any other apps that could be included in the Holistic Tablet?

- MYGOSH App
- link a smart watch (texting, heart rate, appointment alerts, make calls, games – steps rewards(badges)
- treatment progress tracker
- online medical records- access data through app

If you were to use the Holistic Tablet to message your doctor/care team, would you like the messages to be private, or would you be ok with your family/carer being able to read them?

- should have option to have parents present
- should have parent zone to share information
- encrypted chat with doctor/care team
- option per message to have it private or open
- password access

Can you think of any security issues with the Holistic Tablet, such as confidentiality and security?

- loss of phone or tablet
- what about back up?
- what age should I speak to clinician – early teens?
- reduce tablet theft by finger point and facial recognition
- someone unauthorised sending messages to tablet – concern?
- an App on a phone has less risk compared to banking apps

9.4 What did YPAG's say? Q & A session – Workshop D: MIXED REALITY

Can Mixed Reality be used to educate/support patients / students about their condition, medicines?

- Education of students – "If school could be like this [HoloLens] it would be awesome!"
  - great way to learn Biology/Anatomy/Science
  - interactive
  - get to practice skills in high fidelity
  - fun and engaging
- Education of medical staff (Enhancing Safety & Practical Skills)
  - 3D interactive scans of patients
  - training students/doctors/other healthcare professionals in practical skills
  - MR headset could teach a new skill and prevent user moving on to next step before crucial ground work completed first
  - medical equivalent e.g. cannot take blood until hands washed/ gloves on / skin prepared
  - AR could be used to overlay veins on patient arm in real time (cf Vein Viewer/Finder)
- Education of patients
  - showing them their condition/how their condition affects their body – Transition:
  - could be used to show YP approaching transition to adult services what the adult areas look like (outpatients/wards/ etc.)

Can Mixed Reality be used to reduce anxiety? – Yes!

- showing the hospital (and in particular "scary places" within it) to patients before they go there to reduce worry
- distraction from unpleasant experiences (blood samples/needles/ etc.)
- e.g. Google cardboard distraction on IV access
- art as therapy (see entry under Entertainment & Escape)
- Entertainment and Escape
  - the simple freedom of being able to "leave" the hospital room using technology & exploring the hospital – virtual tourism
  - creating your own virtual space to play in without distracting other people
  - if up late at night and can't sleep
  - playing games together in real 3D space
  - multilens (HoloLens) – several users viewing the same experience
- Art Therapy
  - 'Just a Line' and other Apps (up to Tilt Brush VR) to create art
  - for relaxation and fun
  - to publish artworks for others to use in virtual worlds
  - to 3D print
  - decorating their hospital room with virtual pictures/sculptures to personalise

Do you think mixed reality is useful if a patient is bed bound/ you were a patient in a hospital? - Yes

- doctors giving advice and instruction via first responder worn MR headset and can walk through emergency procedures step by step for patients too unstable to move (and no expertise on site to help)
- transfer of patient care information seamlessly from out of hospital to in hospital systems
- interaction with other patients on ward/in hospital when cannot physically meet (infection control/bed-bound/etc.)

Connecting with Others:

- Holographic communication with:
  - friends – meet via holo presence (cf Black Panther communication)
  - family – spending time with family at home whilst in hospital
  - use of 360 degree cameras/telepresence robots at home end and MR headset at hospital
  - could do the same with school to take part in lessons and still be able to take notes in real world (cf VR where could be unable to do this as cannot see through the headset)
  - interestingly not keen for Doctors – felt to be "weird" and intrusive

What are the potential negatives of using Mixed Reality?

- AR/MR could be a scary/unsettling experience for younger children
- the technology [HoloLens] needs to get smaller – ideally the size of a "normal" pair of glasses. Will be achievable eventually
- would it be disappointing to take off the headset and return to "reality"?
- AR experiences on older phones generally of poor quality compared to modern handsets but not all have access to these expensive devices – equality of access?
- are AR/MR experiences really suited to education or will they in fact distract from learning instead?
- privacy concerns if taking photos/using camera based devices on open wards?
- risk of harming self if fully immersed in the experience?
  - Tripping over objects in real world/cables/bumping into people
- do we risk just "pacifying" hospitalised children with a fancy device?

- CF giving a toddler an iPad to keep them quiet

- do we risk reducing real world interaction for hospitalised patients?
  - Impact on mental health of only virtual interaction?

Can you think of any other uses of Mixed Reality across healthcare for e.g. during diagnoses/consultant appointments in inpatients, in outpatients?

- Interactive holographic staff directory
  - imagine if the staff looking after you could be introduced using the sorts of graphics/bios/stats shown about players at the start of football/rugby/etc. matches
  - learn about the people who will be caring for you
  - see what they look like
- Internal hospital "GPS"
  - helps to navigate the hospital in real time using AR real time directions

10. Quotes from the day

The day in general:

"The day at DRIVE provided an incredible insight into the potential for technology in hospitals and patient care and enlightened me to not only technology and ideas I didn't know was out there but also the issues certain patients face when it comes to managing conditions and spending time in hospital. It was great to meet others from around the country and see how they work too"

YPAGne member Nikhita

"I was really excited to get to experience the DRIVE unit at GOSH. Looking at how we can use digital technologies in healthcare enabled me to realise the huge potential this has in transforming healthcare in the future"

Kent Surrey and Sussex
YPAG member Ben

"We got to learn about and experience new technologies and consider their applications in a healthcare context. For us some technologies appeared to be more user friendly and engaging than others, but knowing this might help resources be invested better"

Kent Surrey and Sussex
YPAG members Ed and Ella

What did I like the best?

"I liked Jibo, the robot with the moving head, the best. When I tried it I beat the high score! It's good because you can change its voice to make it sound like someone you know"

London (GOSH) YPAG member Freddie

For more information about how YPAG's are helping shape paediatric research visit:

www.generationr.org.uk

Things I learned from other YPAG members from around the UK:

"Some do not receive the same quantity of feedback we are so good at and getting in Newcastle, however I had the chance to hear about some researchers they've met and they sound equally as interesting as the ones we get the pleasure of meeting with too. The other groups seem to be like minded individuals to us, excited by the prospect of learning about interesting things and giving their views where they can"

YPAGne member Nikhita

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