



# Patient and Public Involvement (PPI) Impact Case Studies 2021-22



Front Cover: Collage created by Suki, GOSH YPAG member as part of the Sensing Spaces of Healthcare creative research workshops

# | Contents

- 1. FRACTURE Study: Update**  
Fast Reporting using Artificial Intelligence (AI) for Children's Traumatic Radiology Examinations
- 2. AI&me**  
Exploring the perceptions amongst children and young people on Artificial Intelligence (AI) in healthcare and medicine
- 3. "Caleb has a Thymus Transplant at Great Ormond Street Hospital"**  
Co-developing a Digital Information Book with patients and their families
- 4. CAR-T cell therapy**  
Families feedback on research priorities and developing the web based CAR-T game for patients
- 5. Using White Blood Cells to fight Leukaemia**  
Patient Information Sheet review
- 6. The Coggi app**  
A Co-design project with GOSH YPAG and GOSH YPF

# 1. FRACTURE Study

## Fast Reporting using Artificial Intelligence (AI) for Children's Traumatic Radiology Examinations

### About the researcher and their research

This Case Study is an update on the PPI work which has been carried out since last year's [PPI Impact Case Study](#)

The researcher is a paediatric radiologist with a background in imaging (looking 'inside' the body), artificial intelligence (AI) and diagnostic accuracy trials.

They are trying to find out whether a computer programme (AI) can help find broken bones on X-rays accurately to prevent fractures being missed on children's X-rays.



### Where in the Research Project Lifecycle did Patient and Public Involvement (PPI) take place?

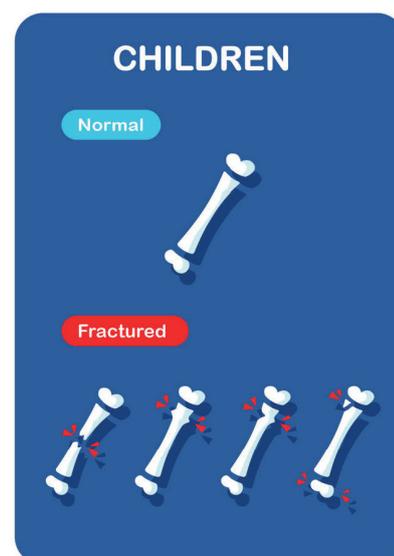
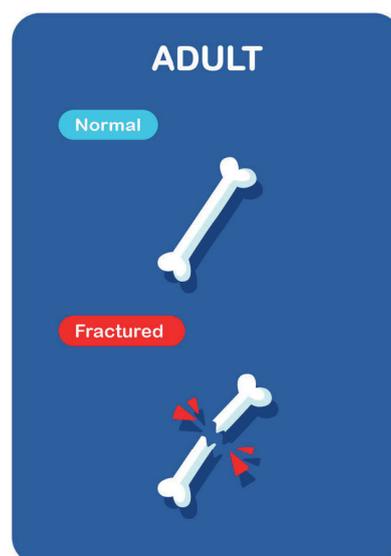
PPI took place at the very early stages of project planning prior to grant application, and PPI continues to help guide the project.

### How does the research benefit patients?

By the end of the project, the researcher expects to have developed the FRACTURE algorithm (a working solution) for accurate and automated children's fracture detection, ready to apply for the next level of regulatory approvals for nationwide usage.

This will mean that hopefully fewer fractures will be missed, children will have the correct treatment first time and avoid repeated visits to hospital and time off school.

Given the growing interest in artificial intelligence in imaging, the researcher will develop into a leading expert in this area and be in a position to guide and help others who are trying to develop similar tools to benefit patient care in a more streamlined and efficient manner.

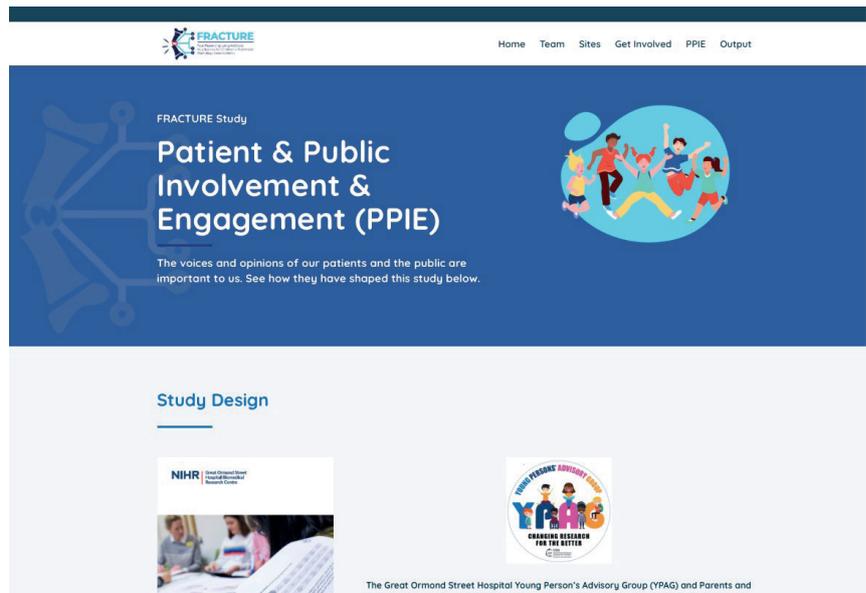




## Who were involved so far this year?

1. The researcher attended a GOSH YPAG meeting in January 2022 with 22 young people to:
  - Feedback on actions taken as a result of their feedback last year
  - Ask for their input into content of PPIE pages and logo design for the [FRACTURE study website](#)

## Content of PPIE pages



- Do you like the way it looks?
- Is it easy to follow and read?
- Do you like the images/cartoons?

*We like the layout of the website and find it professional-looking and we like the images and cartoons used to demonstrate the aims of the research. We think the language used in the website is appropriate and easy to understand.*

## Logo design



- Does the logo reflect the study?
- Which logo is more eye catching to you?
- Is there anything you would change?

*The majority of the group chose the first logo (top image) because they liked how it 'stood out', the use of bold colours and they felt it reflected the point of the study (diagnosis of fracture) whereas the other logo appeared to deal with fracture healing.*

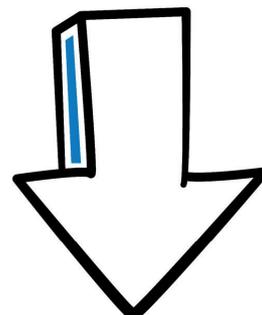
## 2. 'FRACTURE study' PPI Steering Group Committee formed

### Four GOSH YPAG members and three GOSH Parent and Carer Advisory Group representatives

- In the creation of the patient/child and parent survey the PPI Steering Group Committee were involved to make sure that the questions being asked were relevant, understandable and useful in helping researchers design future AI tools that are acceptable and appropriate for clinical use.
- So far two meetings have been held (on 9 October 2021 and 11 February 2022) to test the questions that will be in the final survey.
- Some big changes and suggestions were made since the start of this work based on feedback from the PPI Steering Group Committee. Paper survey forms are now being replaced by online surveys to improve confidentiality, access and privacy; and (given that fractures are very common and affect many children) the survey will now be open to all public members nationwide to get a broader scope of opinions, not just targeted at patients visiting hospital.
- We hope to be able to share this survey and our experiences designing this soon!

*Having seen the wonderful care my daughter received at GOSH, I will take all the opportunities to help improve patient centred care and advances in clinical practice. The FRACTURE study is one of those pieces of innovation that excites me, and I hope to see it showing exciting results!*

Paul, FRACTURE study PPI Steering Committee member



## What Impact has PPI had on the study?

GOSH YPAG made the following **recommendations** which have been taken up by the researcher and updated to the group at their January 2022 meeting. This is a good example of a researcher who maintains contact with GOSH YPAG and keeps them in the research loop.

FRACTURE Study PPI Steering Committee made the following recommendations which have been taken up by the researcher

### YOU SAID – I DID!

- |          |  |   |  |
|----------|--|---|--|
| <b>1</b> | Computers and humans should work together              | → | This study will make a computer programme that helps doctors, not acting alone       |
| <b>2</b> | Patient views are important and kept centre            | → | Created a website include a patient / parent survey of opinions                      |
| <b>3</b> | The study should focus on how doctors decisions change | → | Added an extra study to my project to see whether AI changes doctors treatment plans |

### PATIENT/ PARENT SURVEY

**AIM:** To find out how parents and children feel about using AI to make medical diagnoses

#### YOU SAID – I DID!

- |          |   |   |   |
|----------|---|---|---|
| <b>1</b> | The wording reads strange to English speaker / 3 <sup>rd</sup> person | → | Reworded and read to be more fluent.<br>Rephrased as 'I feel', 'I think' instead of 'it is important to...' |
| <b>2</b> | Too many questions  | → | Reduced number of questions   |
| <b>3</b> | Tracked changes   | → | I have accepted and merged several questions as suggested   |

## Updates for the FRACTURE Study PPI Steering Committee given by the researcher

### What are the outcomes so far and what's happening in the future?

The researcher was successful in securing an NIHR Advanced Fellowship Application for this study.

- Four GOSH YPAG and three GOSH Parent and Carer Advisory Group members have now formed the PPI FRACTURE Steering Committee and have held two meetings so far.
- A FRACTURE study website to inform other researchers and parents/patients about the progress of the study has been created, with help from the PPI Steering Committee in creating lay summaries for ease of understanding study outcomes. The Steering Committee have also provided their photos and an introduction to themselves for the website. GOSH YPAG have also had input.

### PATIENT/ PARENT SURVEY

#### THINGS I STILL NEED FEEDBACK ON:

- 1** Do you think the survey should be based more on fractures or any medical diagnosis in general?
- 2** What do you think of the new survey? Are there more changes you'd make to this revised version?
- 3** I need to create a child friendly version of the survey. What age child do you think could fill in the same sort of questions as the adult version?

If we wanted to ask a child to do the survey, how many questions and which questions would be most important/interesting for ages 7yrs +?

At the end of the study, a dissemination meeting will be arranged for all GOSH YPAG, Parent and Carer Advisory Group members and affiliated healthcare professionals. The meeting will draw together main findings from the research, thank participants and discuss avenues for dissemination and future research directions. It is intended that one or more presentations will be given by GOSH YPAG members, explaining results in a way that other children and young people can understand.



## 2. AI&me

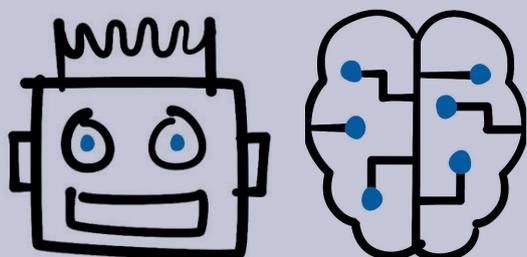
# Exploring the perceptions amongst children and young people on Artificial Intelligence (AI) in healthcare and medicine

### About the researcher and their work

The researcher is developing a framework for the application and evaluation of novel and emerging technologies in healthcare. They are undertaking this research at University College London Interaction Centre (UCLIC) and Great Ormond Street Hospital (GOSH) DRIVE Centre (Digital Research, Innovation and Virtual Environments)

Their work involves:

- Improving the way GOSH introduces novel technologies into healthcare by including a broad spectrum of stakeholders to ensure that no one is left behind as we redesign services
- Working with people who understand the complexities of healthcare interactions including digital natives (children and young people as young patients)
- Preparing those people to use these technologies. The intention to use enabling technologies, data, and analytics to provide safer, smarter, and kinder care.



### About AI

- Originated around 1950's
- Represents simulated intelligence in machines
- Is a sub-set of Data Science
- Aim is to build machines which are capable of thinking like humans



### How does the research benefit patients?

It is acknowledged that a research gap on involving children and young people in developing policies for AI exists. This research aims to transform care and improve outcomes and experiences for children, young people and their families by harnessing the power of the latest technologies and digital developments, and rapidly evaluate them for hospital practice. This is not only for GOSH patients but across the wider NHS.

The team want to ensure future research into new technologies are co-designed specifically for children and young people: “no research about me without me”.

### Where in the research project lifecycle did PPI take place?

The researcher and her team have an ongoing collaboration with GOSH YPAG. They use hypothetical design scenarios to engage with the group and explore their perceptions on the potential for emerging technologies and Artificial Intelligence (AI) in healthcare and medicine. The aim is also to then help shape its' future research direction.

*“It's only logical for us to shape the world we live in”*

GOSH YPAG member

## Who were involved?

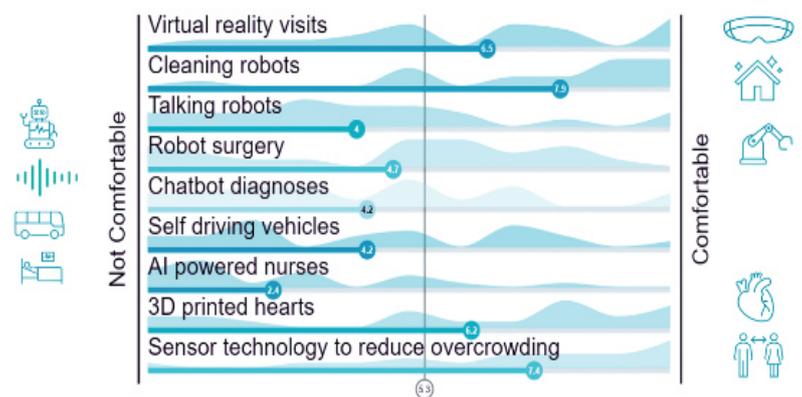
The researcher held an exploratory Patient and Public Involvement and Engagement (PPIE) workshop with 21 members of GOSH YPAG: “Exploring the perceptions amongst children and young people on Artificial Intelligence (AI) in healthcare and medicine”

The workshop used hypothetical design scenarios to engage with the group on the potential for emerging technologies and AI in Medicine in an exploratory way. This was followed by consensus building to identify the most important aspects to test and evaluate mechanisms for involving children and young people in PPI initiatives on emerging technologies in healthcare. The researcher used the audience response system Mentimeter to enable feedback to be captured voluntarily, anonymously and in the group’s own words. It encouraged dialogue and inclusion in the digital space.

## What comes up for you when you think about AI in Healthcare?

*Fair access, Cost, Ethics, Intent, Jobs market, Governance, Human centredness, Trust, Creepiness, Compassion, Control, Emotions, Safety, Education*

## How comfortable do you feel with potential AI-driven scenarios?



## How can healthcare staff communicate effectively with you about the potential for AI?

- “Examples in everyday life”
- “Show positive benefits”
- “Set up workshops to bond trust”
- “Address common worries”
- “Helping humanity (with AI)”
- “Be transparent when it is already being used”

## What was the Impact of Patient and Public Involvement (PPI)?

### 1. Engagement with GOSH staff

The findings of the exploratory PPI workshop held with were selected as an oral presentation at the annual GOSH Staff Conference in November 2021.



### 2. Co-presentation opportunity for GOSH YPAG member

The conference was the basis for developing an opportunity for a GOSH YPAG member to co-present and take live questions from a healthcare audience on the impact of involvement from the PPI workshop.

It enabled the GOSH YPAG member to gain confidence in her public speaking skills and help prepare her for higher education plans and helped build her C.V.

It was also a great opportunity to promote GOSH YPAG and the work they do ensuring the patient voice is at the centre of research at GOSH.

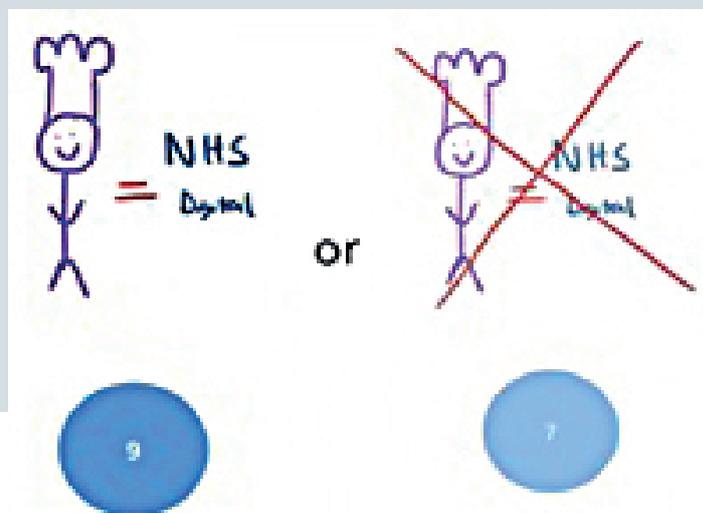
### 3. Follow up workshops on AI with GOSH YPAG

March 2022 - A follow up workshop on the **\*secure multi-party computation data sharing technique**, a new data sharing technique in healthcare with 20 GOSH YPAG and led by a PhD student. It is especially important to understand how children and young people today feel about this topic as they will be in the correct age range to be most impacted by this change if it were to be deployed in the future.

\*Secure means that no information is shared. A party is one of the hospitals and there are multiple of them, thus multi-party. Computation means to compute or learn something.

The workshop used **\*mental models** from Human Computer Interaction (HCI) to explain complex computer science concepts about machine learning and governance into easily understandable analogies to **capture data sharing preferences** and thoughts from GOSH YPAG.

\*A mental model is an explanation of someone's thought process about how something works in the real world.



## What Apps Do You Use?

### Some feedback from GOSH YPAG

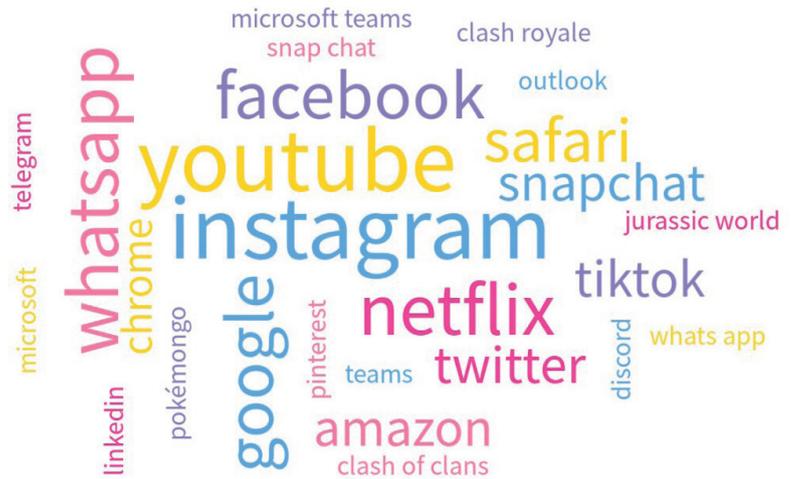
Safety of sharing data should be taught more in schools, especially around ticking 'no' or opting to not share data and taking the time to read these options

Issues with (too much) data sharing:

- Identity fraud
- Exploitation
- Bombarded by companies

Other issues:

- Would want to know how long data is kept for
- Data may be all over the place
- How do we know how things will turn out if they don't know what each other are putting (each being the hospitals sharing the data)
- What would happen if some of the data was long? Or someone managed to find out what data was about you?



### What are the outcomes so far and what's next?

- GOSH YPAG member went on to co-author a peer reviewed paper which was published in April 2022 in a [Nature Portfolio Journal](#)
- AI&me won best Oral presentation at the annual GOSH Conference in November 2021
- Our collaboration will continue in 2022 to find out more from GOSH YPAG members about how they would want to receive data insights about their care and treatment. This will include exploring how best to translate clinical data into meaningful data visualisations and infographics.



# 3. “Caleb has a Thymus Transplant at Great Ormond Street Hospital”

## Co-developing a Digital Information Book with patients and their families

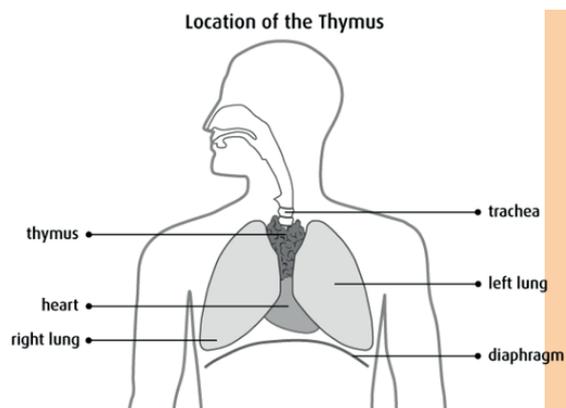
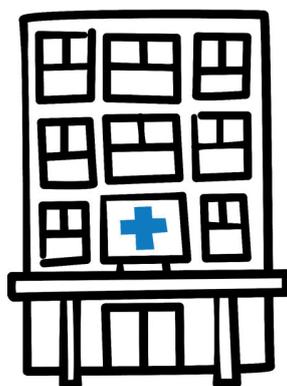
### Who led the Patient and Public Involvement activity?

This Patient and Public Involvement (PPI) activity was carried out by a GOSH Immunology Clinical Nurse Specialist for Thymus Transplantation who is part of the [Thymus Transplantation Translational Research Programme](#).

It was one of the PPI projects funded by the GOSH BRC PPIE 2021 Small Grants Call Award. The project was also supported by Great Ormond Street Hospital Charity, and Immunodeficiency UK.

### How does the research benefit patients?

Families come to Great Ormond Street Hospital (GOSH) from all over Europe for their child to receive Thymus Transplantation. This treatment has been developed to treat children born without a thymus gland (athymia), usually due to a very rare, condition known as Complete DiGeorge Syndrome (cDGS). This has a spectrum of clinical symptoms, of which one of the most severe is athymia. Children with athymia cannot effectively fight viruses and bacteria, leaving them at risk of life-threatening complications from even the most common of infections.



Clinicians and researchers are working together to discover new ways to increase further the number of immune cells produced after the transplantation, and to reduce the chances of complications.

Some patients do develop complications after transplantation as a result of the new T-cells being poorly regulated which can cause some damage to the body's own tissues. These problems are usually treatable, but the research team, based at the [Zayed Centre for Research into Rare Disease in Children at GOSH](#) are working to improve the process and reduce the chance of such complications.

#### Patient Cohort

- Congenital athymia = absence of thymic function
- Treatment = Thymus Transplantation
- Two Centres worldwide
- **GOSH has transplanted 59 children from 27 countries** (since 2009) (Europe and then as far as New Zealand, Australia, Saudi Arabia and recently Israel (since 2009))





## Where in the research lifecycle did PPI take place?

As the Thymus Transplantation service has grown over the last 10+ years, it has become clear that due to the rarity of the condition and its treatment, families have little information available to prepare them for the transplantation journey. This PPI project was developed in response to this need:

- No family focused, written resources available in Europe
- Complex condition and treatment to be explained to non-native English speakers

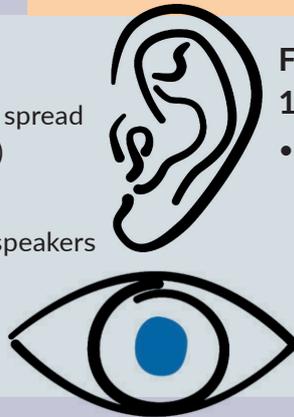
## Who were involved?

**17** families (post-thymus transplantation) participated in **5** interactive PPI Zoom workshops to co-create and co-design a Digital Information Booklet. Its' aim was to explain this complex health condition, treatments and research as well as providing practical advice to help families feel informed.

- **Six** additional post-transplantation parents provided written feedback via email
- Experience ranged from 15 years to 3 months post transplantation
- Two pre-thymus transplantation families provided written feedback via email
- Mothers and fathers contributed alongside one uncle and one grandmother

## Being Seen and Heard

- Zoom was chosen due to the geographical spread of the families (and COVID-19 restrictions)
- A translator known to families attended workshops to support non-native English speakers
- A parent advocate was mentored in preparation to co-facilitate workshops



## Families originated from 19 different countries

- A further meeting was held with five GOSH Parent and Carer Advisory Group for research members



## What Impact has PPI had on the families?

The workshops enabled families/patients to:

- feel empowered as partners in decision-making (which leads to better outcomes)
- make valuable contributions from lived experience
- be recognised for their contribution
- support other families through the transplantation process
- feel listened to in a supportive, safe space

## Parent Feedback

### They said “...”

- How do I immediately protect my child?
- More info on the impact of Hypocalcaemia
- More emphasis on Omens syndrome
- Wounds healing pictures after a few months
- Keep both versions of PIB
- More information about medications
- What are post thymus transplantation complications?
- Make it readily available to clinicians as well as families
- Enjoyment of meeting other families

### I did ...

- Added more information on: Calcium supplementation  
Omens Syndrome  
Medications  
Post transplant complications
- Have Prioritised the interactive storybook
- Asked for more wound healing photos one year +
- Finished booklet be available on the GOSH Intranet
- Plan to arrange Annual Zoom with social and research updates

## What Impact has Patient and Public Involvement (PPI) had?

### Information giving

- Both families and the GOSH Parent and Carer Advisory Group for research felt information on donors in the storybook version needed to be clearer
- Families highlighted the benefit of receiving this information would allow them to retain some level of control over their child's treatment and care options
- Parents were clearly motivated to inform themselves but felt that some websites they had accessed, could be misleading
- Parents felt having access to a booklet created by GOSH, would be viewed as a trustworthy source, providing reassurance. It would reduce the burden on them to search for information, while also helping them explain to their children and extended family.
- While the project was intended to co-develop one booklet, the families were keen to see two versions completed, recognising the different audiences with language and developmental needs, who might benefit from an easier read option and discussed layering of information as parents feel ready to access.

### Knowledge and awareness of clinicians

- Many families had experienced clinicians lacking knowledge due to the rarity of congenital athymia and this had increased their worry and anxiety at the time of diagnosis

## What are the outcomes so far and what's happening in the future?

### Two draft patient information booklets created

- a digital storybook patient journey 'Caleb's story'
- a detailed information version

The digital storybook version is near completion and will aid to increase families' and clinicians knowledge about the novel treatments and research programmes, aiming to achieve improved informed consent for treatment decisions

## Engagement

A **poster** has been submitted for the April 2022 **International Primary Immunodeficiencies Congress Conference** in Portugal as well as a two-minute recorded talk for their website.

The GOSH Immunology Clinical Nurse Specialist for Thymus Transplantation will give an in-person presentation at the conference where there is expected to be lots of parental attendance, including the parent advocate in addition to clinicians from potential referring centres.



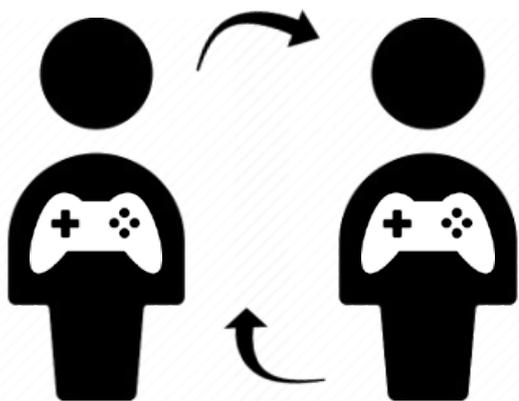
*"I wish I had something like this 8 years ago"*

Parent



## 4. CAR-T CELL THERAPY

Families feedback on research priorities and developing the web based CAR-T game for patients



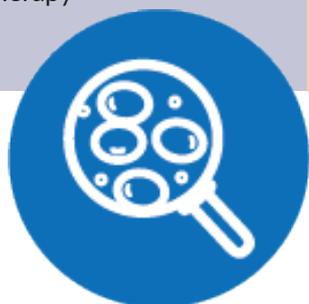
### About the researchers and their research

The Innovative **CAR** Therapy Platform (INCAR) initiative is a new Consortium (group) of world-class centres for CAR-T cell therapy across Europe. They are undertaking state of the art research into **Chimeric Antigen Receptor (CAR)** engineered cellular therapies (SEE CASE STUDY 5. TO LEARN MORE ABOUT CAR)

### How does the research benefit patients?

The common aim of the consortium is to improve patient outcomes by:

- making CAR-T cell therapy more safe
- making CAR-T cell therapy more effective (as a standalone therapy)
- expanding indications for CAR-T cell therapy



### Where in the Research Project Lifecycle did Patient and Public Involvement and Engagement (PPIE) take place?

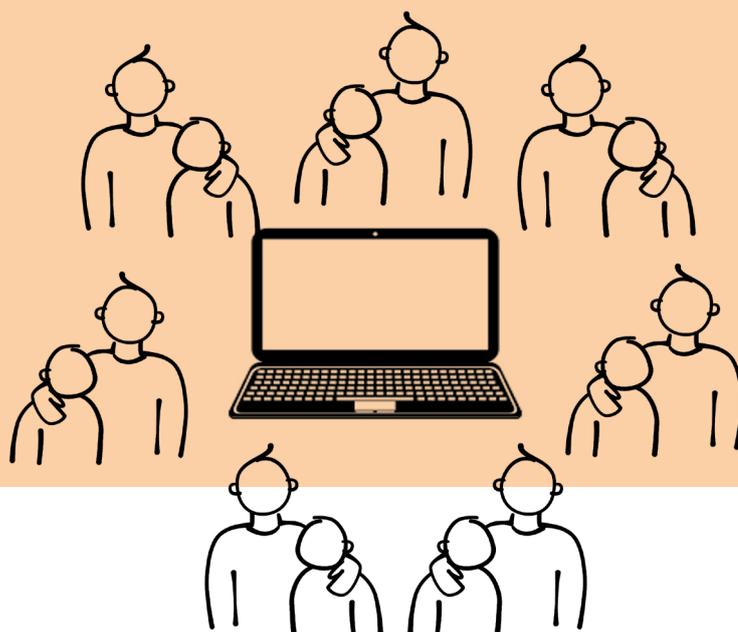
The consortium's PPIE vision is to embed involvement and engagement at the heart of their collaborative, pan-European research programme. Central to this is for interested families to act as informed collaborators.

### Who were involved and what was their input?

The consortium wanted to start some conversations around patient experience of CAR-T cell therapy with families who have mainly had experience of treatment with licensed CAR-T cell therapy, but some who have also been treated on clinical studies.

They wanted to use these meetings as a platform to then discuss research prioritisation and also wanted feedback on the INCAR web-based **game** which has been developed for patients with the aim of developing it further.

Two half day online INCAR Family Meetings were held. At the first meeting a visual scribe captured the key messages in powerful real-time illustrations that gave families a focal point throughout the discussion and a takeaway afterwards.



## What Impact has Patient and Public Involvement (PPI) had

### INCAR Family Meeting 1.

11 September 2021

Six families attended

*An engagement session as families received an update presentation on the consortium's research and research priorities followed by breakout group discussions for involving families:*

### Families were asked: How can we improve the CAR-T web-based game? Families said:

- have the option to choose how the CAR-T looks or what superpowers they can have
- have a marketplace where players can buy different features, using virtual money that they have gained as they play the game
- add more game modes, different sound effects/make it into a story which has different chapters

### Families were asked: Your patient journey: what things stand out? Families said:

- comparing the success rate and long-term toxicity (unwanted side-effects) associated with CAR-T compared to those of other available treatments
- the persistence of CAR-T, what will happen in the longer term?

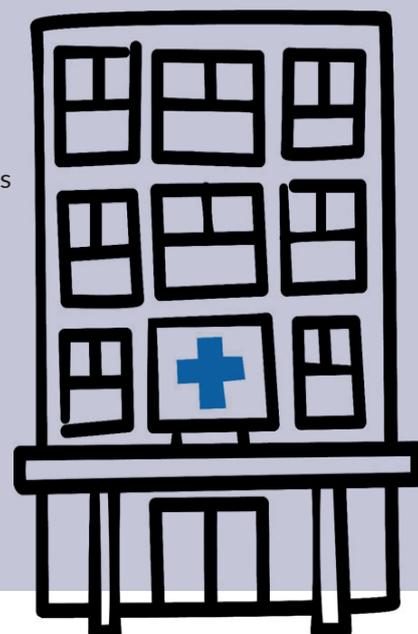
### Families were asked: How can we better keep parents and children informed? Families said:

- create a booklet for parents who are having to make this decision (CAR-T vs Bone Marrow Transplant (BMT)), with feedback from other parents who have gone through the different treatments already
- have more information available in between hospital visits & about the long-term effects of the treatments, so families have a chance to consider all options

### Families were asked: Our research priorities

#### - what do you think of new treatment? Families said:

- I would definitely support these new treatments for other cancers
- despite potential initial toxicities, it should still be offered to patients and families to advance how we treat cancer





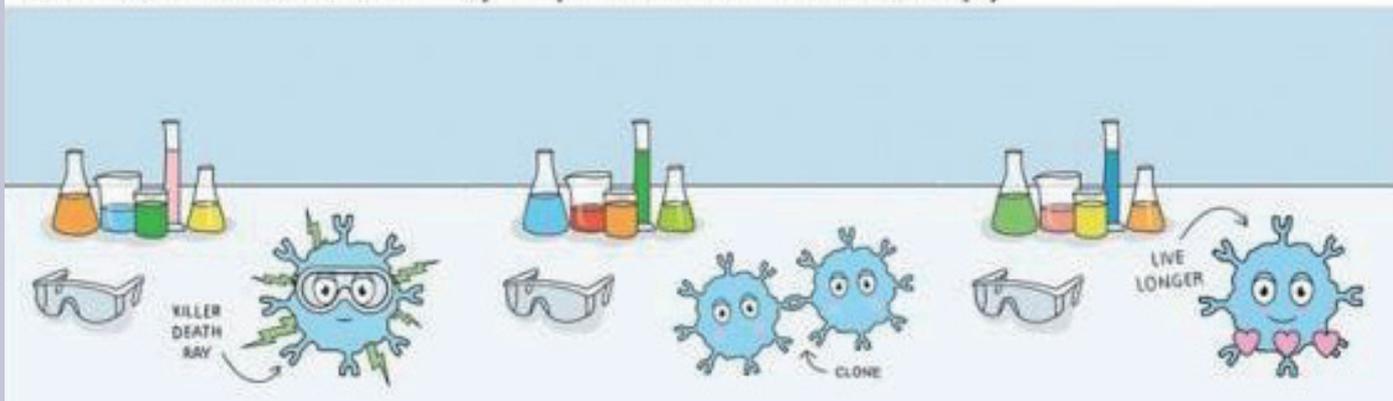
## INCAR Family Meeting 2.

4 December 2021

Six families and two young public representatives attended

Invited the INCAR web-based game developer to look at the feedback given at Meeting 1. on how to improve the web-based game. In the original game the CAR-T cells had superpowers to make them better at fighting cancer cells - they could clone themselves, or live longer, or use a killer death ray.

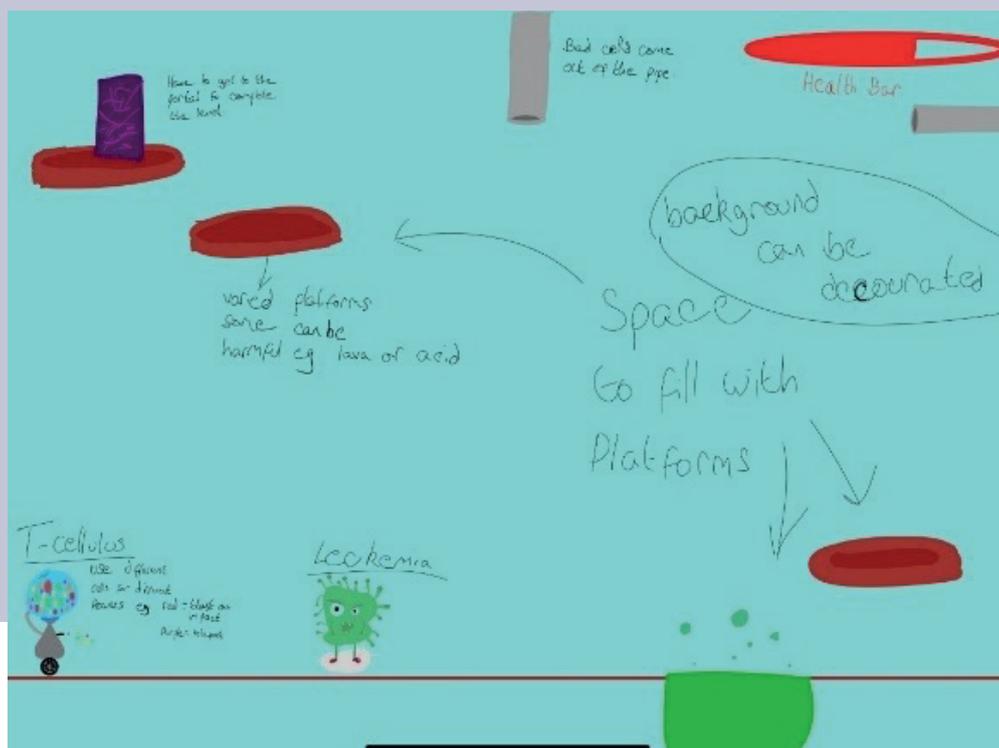
## Illustrations to help children understand our CAR T cell research: Characteristics which may improve CAR T cell therapy

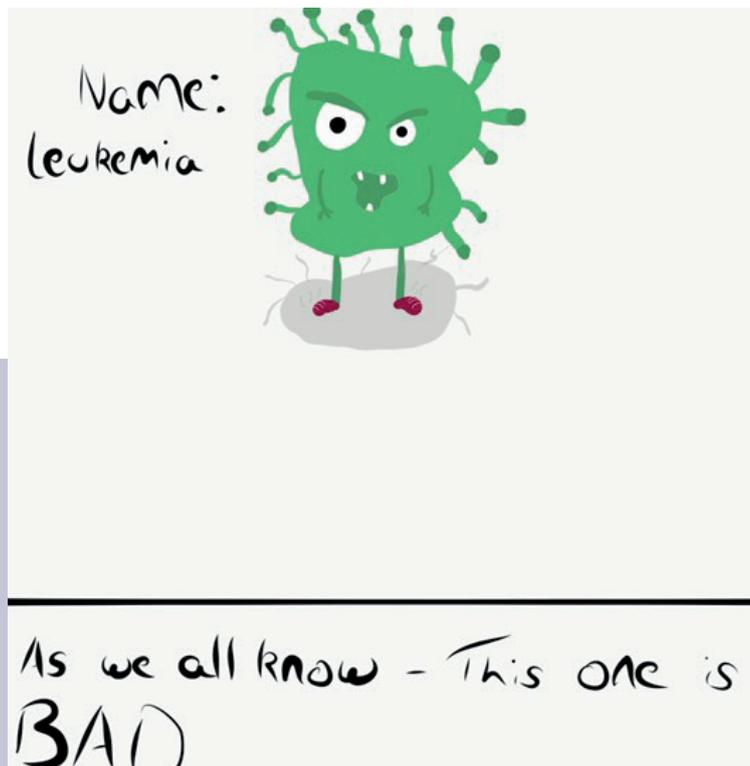


The focus for this meeting was to enable patients, their families, and some young members of the public to work together on ideas for the game moving forward; to give players a bit more control over how your T CELL looks. The group looked at the physical elements of the game, visual style, what they wanted the game to say about their treatment and how they would build their CAR-T cell. Polls were used at the start of the meeting to encourage involvement.

### Families were asked:

helping others understand - what would you like the game to say about your treatment?





### Families said:

- the technical side of things, like lymphocytes and how they are affected during leukaemia
- the fact that these cells were taken out of my child, flown to the US, being worked on in America to make them super cells, flown back and given back to my child is something people find hard to get their head around
- it's important not to bypass the younger children with the information. Still give the option to pass on the information to the younger kids
- age appropriate – have different levels of information or design in a way that it's not essential that you understand all, you can bypass or come back another time
- the idea of losing the game is not appropriate but it doesn't mean the game can't be competitive
- the waiting for test results, and repeated testing

*"I have come up with a very rough and quick sketch on my idea of what the game could be. I am very interested in helping to design the game. Again, this is a flexible sketch so there is a major scope of changing bits and bobs. A quick run through: robot tries to go through the level and get to the portal whilst avoiding the leukaemia cells coming out through the pipes."*

Young patient

### What are the outcomes so far and what's happening in the future?

- Reports from both meetings circulated to our INCAR families and the INCAR Consortium
- PPI presentation made at the INCAR Steering Committee in February 2022
- One patient has now joined the GOSH Young Persons' Advisory Group (YPAG) for research so they can continue to help shape paediatric health research at GOSH
- CAR T patient films are being co-developed with them to support other families and as a way to engage families with the research
- Funding is available to design one more game so we want to run a co-creation session in person in the future. Workshopping some mini game ideas on paper can be a brilliant way of getting children and young people involved in the game making process while also managing expectations around scope/complexity (we have already had some design ideas sent in by one patient)
- We will explore avenues for future peer-to-peer support for families

Illustration on previous page and illustration top right by young person



# 5. Using White Blood Cells to fight Leukaemia

## Patient Information Sheet Review

### About the research

This is a phase 1 clinical trial testing if 'ready-made' CAR-T cells made from healthy donors can treat T- Acute Lymphoblastic Leukaemia (ALL).

### Jargon Buster

#### A phase 1 clinical trial:

Tests the safety, side effects, best dose, and timing of a new treatment

#### Acute Lymphoblastic Leukaemia (ALL):

Is the commonest childhood cancer. Standard treatment is chemotherapy – for up to 3 years and high risk patients may undergo bone marrow transplantation

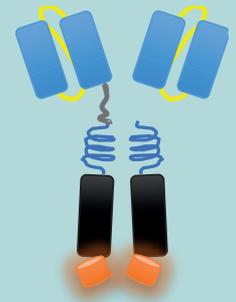
#### What are T cells and what do they do?

- specialised immune cells that patrol our body
- seek and clear up cells that are infected for example with a virus (and other) infections
- we have a thousand billion T cells and each carries a unique recognition molecule to recognise infected cells
- long-lived T cells contribute to life-long immunity from viral infections

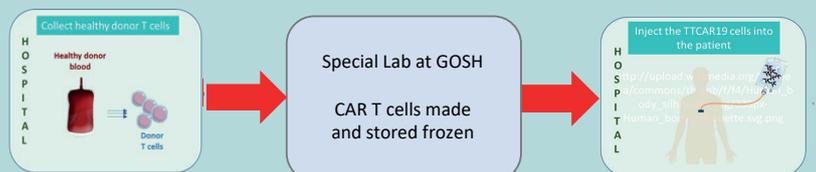
Cancer cells can however go unnoticed as they often look very similar to healthy cells. To use T cells as a cancer treatment researchers can reprogramme them with a cancer 'detector' called chimeric antigen receptor, or CAR for short.

### What is a CAR?

- a Chimeric Antigen Receptor is an artificial recognition molecule
- When the CAR recognises its target on the surface of a cancer cell, it activates T cells to destroy the cancer cell
- CAR's drive T cells to win against cancer



### CAR-T cell therapy in practice



### How does the research benefit patients?

This is a study testing if 'ready-made' CAR-T cells made from healthy donors can treat blood cancers such as T- acute lymphoblastic leukaemia (ALL). It is expected that around 10 children/young people will take part in this study at Great Ormond Street Hospital (GOSH) in the first instance





## Where in the Research Study Lifecycle did Patient and Public Involvement (PPI) take place?

GOSH YPAG members reviewed the Patient Information Sheets (PIS) for recruitment of patients to the study.

A PIS should give a summary of the research project and its aims, clearly outlining the entire research process in a language that a non-expert audience will understand. Sometimes researchers need PPI to help with this. GOSH YPAG are sent out the PIS according to their age group along with a list of questions to answer.

## Who were involved?

7 GOSH YPAG members  
ages 16+

## What Impact has PPI had on the study?

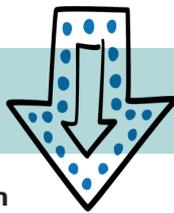
Recommendations made by GOSH YPAG members for changes to the wording and graphics. They also noted typos, spacing and gave comments on overall layout.

*“the sheet is very wordy – this is important in understanding the study but I think that this could be simplified/cut down to be more succinct (or use bullet points) so that the sheet is more engaging and less daunting (this would also have its benefits as the young person would possibly be more likely to take part in the study)”*

## Before and after: ‘Agreeing to take part’ – changing **words** to make them more understandable for patients

### 1. Consent, screening period and study inclusion

You have been considered for the study following a diagnoses of relapsed or refractory T cell malignancy



### 1. Consent, screening period and study inclusion

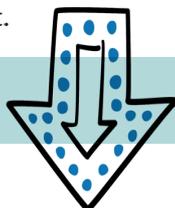
We are testing an experimental medicine for the first time in patients with blood cancer, which has come back (relapsed) or is not responding to chemotherapy (refractory).

GOSH YPAG recommended:  
**change or explain these words -  
‘refractory’ and ‘relapsed’**

## Before and after: 'Taking part'

– changing the **tone** so that patients are put more at ease

2. You have been asked to take part because you have T- ALL and it is proving difficult to treat.



2. You have been asked to take part because you have T- ALL that has not responded to other therapies or has come back.

GOSH YPAG recommended:

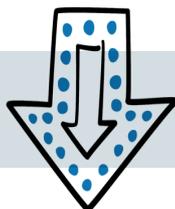
*"it is proving difficult to treat" gives an impression it's the patient's fault/has a tone that conveys a sense of blame. I wonder whether putting a positive spin like "a new more effective method could help you".*

## Before and after: 'The research process'

– changing the **messaging** so that patients are reassured

a. A nurse will thaw the cells and give them through a central line over a few minutes.

b. We will be monitoring you very closely during this study so that we can treat any side effects straight away. Throughout the study, you will need to tell us if you are not feeling very well, so we can help.



a. A specialized nurse will thaw the cells and give them through a central line over a few minutes.

b. We will be monitoring you very closely during this study so that we can treat any side effects straight away. Throughout the study, in case you will not feel very well we will be able to help you and you will receive the best care.

GOSH YPAG recommended:

*a. perhaps mention that a "trained" nurse will thaw cells - I guess the idea that any odd nurse who may not know specifically about this therapy could unthaw them is somewhat unnerving...*

*b. I think providing more reassurance that you will be caring for them and will do your best to make sure they get the best care rather than making it sound like if a child is too shy to speak out and has side effects it is their fault.*



## Equality, Diversity and Inclusion

*The headers in red should be changed to a different colour (potentially blue for example), because red could suggest danger (and for autistic people for example red has negative associations)*

*Perhaps change the subtitle font from red to another colour as some people may not be able to see red!*

**(This feedback was not acted on)**

## What are the outcomes so far and what's happening in the future?

GOSH YPAG continue to support research teams giving online feedback on PIS however the group have recommended the following for future PPI undertaken in this area:

- Develop a 'GOSH YPAG Top Tips' for researchers when devising their PIS to include a list of Equality, Diversity & Inclusion (EDI) recommendations for them to be aware of, for e.g.

*"I see you've included a line in having an interpreter which is great! I wonder whether it would be possible to have these information sheets translated should a patient consent to have a copy. I wonder whether having it written in multiple languages at the beginning : please let us know if you want this in XXX" would be useful/to let the interpreter relay this back to the family?"*

- Request that research teams send the updated PIS back to GOSH YPAG so they can see the impact of their PPI
- Request from researchers for reasons why when they have chosen not to take up GOSH YPAG recommendations (this will help with learning)



# 6. The Coggi App

## A Co-design project with GOSH YPAG and GOSH YPF



Coggi Technologies is a digital health start-up focused on preventative mental health care for children. Coggi have created a mobile application with an augmented reality chameleon that guides and accompanies children through bite-sized exercises to build mental resilience and wellbeing.

Coggi's vision is to deliver evidence-led Positive Psychology wellbeing tools via mobile technology that children and young people (as 'digital natives') want

to use. The aim is to help children and young people manage their own psychological well-being and to prevent mental health problems from occurring or escalating.

As part of an Innovate UK-funded project, Coggi Technologies undertook a six-month (October 2021 to March 2022) **\*feasibility study** with Great Ormond Street Hospital (GOSH) to develop a **minimum viable product** (\*MVP) of an Augmented Reality (AR) solution on mobile technology to prevent unnecessary distress and anxiety for paediatric patients aged 5-12 years old needing MRI scans as a first use case.

**\*A feasibility study** asks whether something can be done, should we go ahead with it, and if so, how.

**\*A minimum viable product (MVP)** is a version of a product with just enough features to be usable by early customers who can then provide feedback for future product development.

Coggi Technologies developed from a research project in 2019 as part of a MSc degree in Applied Positive Psychology and a six-month Research England MedTech Programme led by Imperial College. MedTech SuperConnector is a collaboration of academic institutions with a shared vision to support Early Career Researchers in the development and translation of their early-stage medtech innovations.

## About Coggi and how will it benefit patients?

The Coggi platform consists of simple and fun exercises grounded in the science of Positive Psychology. It can be used to help children and young people understand their strengths and purposeful breathing techniques that can be used at home and under supervision in hospitals and schools to reduce the build up of anxiety.

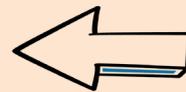
This innovative, user-centred design contains an Augmented Reality (AR) chameleon as the main character (Coggi); an animal that can adapt and change colours depending on their environment.



Helping young people to learn about the science of well-being is also at the heart of what the team are doing so the Coggi tech team also engaged GOSH YPAG and GOSH YPF in a session to learn about the science of positive psychology.

## Where in the Coggi app project lifecycle did Patient and Public Involvement (PPI) take place?

PPI has been central to this project from the very beginning and will continue to be. The Coggi app is at an early stage of development and as it progresses as a patient facing product, feedback from children and young people is essential to its development.



First drawing of Coggi the Chameleon by Libby aged 10, May 2019.



The name Coggi was chosen by the Founder's 10-year-old daughter and came from shortening 'cognition' into a child-friendly, memorable name.

GOSH YPAG and GOSH YPF joined together in November 2021 to meet the Coggi Tech team and give their input on the UI (user interface) and user-led design strategy for Coggi. The meeting was funded by Coggi technologies who sent thank you e-vouchers to all for their involvement.



## How were GOSH YPAG and GOSH YPF involved?

A joint involvement and engagement session was held in November 2021 for 22 children and young people. The group learned about the thinking behind the Coggi app and watched a brief 2-minute video of Coggi's **\*beta version** and Augmented Reality (AR) character.

**\*A beta version** is an early version of a program or application that contains most of the major features, but is not yet complete.

**Breakout room discussions** were held and the following key areas were highlighted as important by the group for the Coggi app to deliver via mobile technology:

1. As an information source in hospital such as MRI specific information
2. As a comfort/reassurance
3. As a distraction/entertainment
4. For communication/connection
5. Access
6. Concerns



The discussions were designed to gather information from GOSH YPAG and GOSH YPF on the following:

**Your views on coming to hospital:** what information you received in advance, what would have helped improve the experience and what you would like to have known in advance.

**Understanding what technology you enjoy using and why** – from a 'digital native' perspective. What level of access do you have to mobile technology.

**Future involvement in Coggi:** Would you be interested in being further involved with Coggi's development within GOSH.

## What did GOSH YPAG and GOSH YPF recommend?

### 1a. Coggi as an information source

Coggi could give more practical information about the hospital/hospital visit/medical procedures/medical equipment in a way that is easier for young patients to understand:

*"Someone who hasn't been to hospital may need to understand what to bring and expect – you could categorise this information into different lengths of stay in the hospital (e.g. information/what to expect going to hospital for 2 days or information/what to expect if you go for longer)".*

### Equality, Diversity and Inclusion

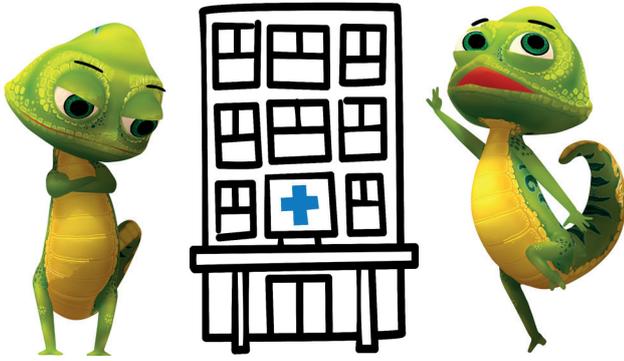
Some young people felt that they hadn't felt suitably prepared before hospital appointments in general and often their parents had been unclear on what to expect too (particularly when English wasn't the first language of the parents).

### 1b. MRI specific information

Coggi could include animated diagrams of a MRI machine, especially as COVID-19 measures have meant that patients are unable to go in and view it in person before the visit:

*"A practice run prior to the real thing as it is daunting (a video of a child or Coggi doing it – if they are doing it then I can do it"*

*"Coggi should say: don't worry it's a little dark you're going to hear some strange noises which might feel strange. It is going to be ok; it does get a little loud, you will feel a weird sensation, but it is part of the test. You're going to watch a movie, so don't worry"*



## 2. Coggi as a comfort/reassurance

The role of Coggi as a friend is an important one; Coggi should be reassuring, say that everything was going to be alright and be “there” for them:

*“I’ve had a few experiences at GOSH since a very young age, I was not prepared as I was very young. It was very scary”*

*“My parents did not know what was happening as not familiar with English (letters, appts. etc.). All they would know is that we would need to go hospital”*

*“Coggi would be a friend to help you along the way, he would be with you in the same environment. I wouldn’t be the only one going through it”*

## 3. Coggi as a distraction/entertainment

This seemed less important to the young people, although still valued.

*“Coggi could be like the Apple Siri app. Would be good to be able to ask Coggi for jokes or information. Expand into games or quizzes on medical things. Tells you the right answer and information to learn from”*

*“Have Coggi quizzes. If you get the questions right, you can customise your Coggi more”*

## 4. Coggi for communication/connection

There were several themes around communication and connection both inside and outside the hospital. Some felt Coggi would have been useful for their care in other hospitals before they arrived at GOSH:

*“When I was younger all the people at the hospital were nice and explained everything to my mum and they helped my parents a lot. But then we were moved around different hospitals a lot and we would only see the doctors once. Now at GOSH it’s easier because you see the same doctors every time”*

*“A ‘meet the team’ option would be useful to get to know staff; a picture and a little about them”*

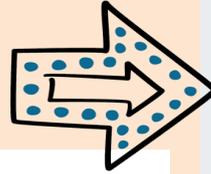
The other areas that children talked about a lot was the feeling of being connected with home, family, friends, school etc. Many commented that they left the preparation to their parent:

*“I wanted the memory of home, being reminded of home would be really useful”*

*“Being far from home is hard”*

## 5. Access to Coggi (as a product for children under 13, parental consent is needed)

Lots of ideas were generated which included:



*"I think if you include it on emails as well to the patients' parents/carers in order to make sure they're aware about the app and can download it for their child."*

*"Sign into the hospital technology with your own Coggi nickname"*

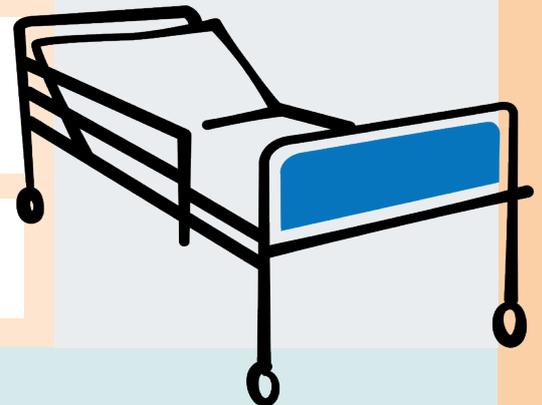
*"I would want to receive Coggi directly, not having to wait for my parents to get around to it"*

There was a general feeling that younger children were more likely to have access to consoles and tablets than phones so Coggi app should be accessible on those:

*"In hospital they had little screens / mini-TV - maybe put the Coggi app onto bedside screens in case parents don't have access to a compatible smartphone"*

*"Coggi app could installed on iPads that patients are able to access when coming into the hospital".*

- Loading Coggi onto the GOSH iPads have a shared login between myGOSH and Coggi
- Parents could give permission first and then it generates the password for the patient.
- Parents to have backup in case patient forgets login details.
- Parents give permission first to activate the app and that is what generates the QR code or link for the patient to access.



## 6. Concerns

Some felt that children could quickly get bored and so the app needs to be dynamic with new content and functions added regularly:

*"I think Coggi is a cool idea. I have seen these reality things before, and it makes me remember it. But you can get bored at it after a while. Especially at the age of 12 years. Will be good for the younger end, but also young people may not have phones".*

One felt that Augmented Reality (AR) : for example using filters/seeing things that aren't there in real life would be scary for younger patients and that it would be good to have options for other animals/people avatars instead:

*"it can be scary to see something on the screen that is not there in real life. Maybe test it first on children"*



## What Impact has Patient and Public Involvement (PPI) had on the research into developing the Coggi App?

- A clear message was that children and young people expect so much from a digital product
- It is critical that the User Experience (UX) and User Involvement (UI) are engaging to ensure adherence as well as gamification and regular updates to keep children and young people from losing interest
- The GOSH YPAG and GOSH YPF discussions also reaffirmed the Coggi technology strategy that whilst clinical validation is essential, the user led design (gamification and making the product fun and engaging) is paramount to the product design

## What are the outcomes so far and what's happening in the future?

The joint GOSH YPAG/YPF session provided important feedback and input and confirmed that Coggi's User Experience (UX) and User Involvement (UI) led design strategy is on the right path with the following areas to be addressed:

### Technical developments

- Low language, High understanding communication
- Slow Delivery, Long retention toolkit
- Emotional projecting onto the character
- Empathy and confidence building tasks
- Digital reduction and parent friendly format

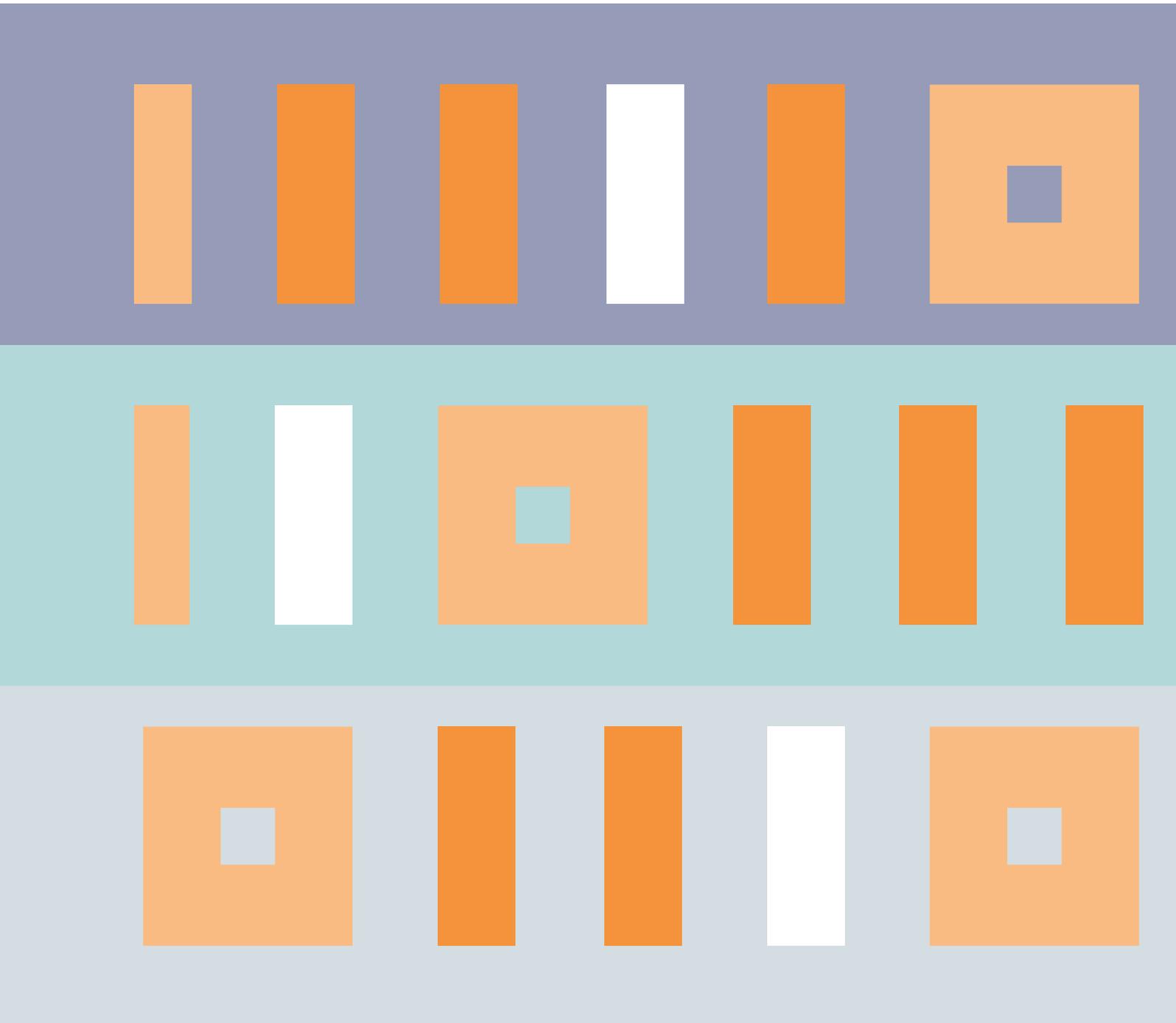
### March 2022 onwards – (with future funding)

- New content/functions to maintain interest
- Continue to aim to make the product both engaging and dynamic
- Coggi is presently more suited to children under 12 years of age and needs more challenging material for older patients
- Ensure Augmented Reality (AR) character is not too scary for the very young
- Huge potential for social aspects/augmenting social connection and communication elements of Coggi within hospital as part of patient wellbeing strategies and outcomes.

### For GOSH YPAG and GOSH YPF

- In March/April 2022 9 GOSH YPAG have tested a beta version of the Coggi app and completed a survey. They received thank you e-vouchers for doing so.
- At the young people's request the developer is in the process of putting an Android testing version together for those GOSH YPAG members to test that don't have Apple devices.
- Future Coggi focus groups will be held.
- Young people will be invited to join the 'Coggi Champions Club', the board of children who advise Coggi Technologies ongoing.







## UK Standards for Public Involvement in Research



## BRC Themes



## GOSH Directorates

