



The OPM Collaboration Project Report



The OPM Collaboration

A research engagement project that aimed to raise the voice of young people with epilepsy, by co-designing key elements of a **new brain scanning technology**.

Through a series of **creative workshops, focus groups and a wider testing phase**, we worked with young people with epilepsy and their parents and guardians to co-design:

Fun and comfortable scanning helmets

Enjoyable activities to do during the scan

Resources to explain the scanning process

This report describes what we did, how and why.

For more information, visit: <https://engagement.fil.ion.ucl.ac.uk/projects/opm-collaboration/>


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Project Overview

About the research

Researchers at UCL's Department of Imaging Neuroscience, alongside partners at Young Epilepsy and others, are developing a new type of wearable brain scanner. It uses technology called **Optically Pumped Magnetoencephalography** or **OPM-MEG**, and works by measuring the tiny magnetic fields produced in the brain. These scans help in the diagnosis and surgical planning for people with epilepsy, by pinpointing areas of the brain causing epileptic seizures.

OPM-MEG has significant potential, particularly for young people with epilepsy, because for the first time, they will be able to benefit from easy access to this non-invasive, powerful technology.



Current scanners require people to stay very still or even be sedated. This can be challenging for young people, particularly those with epilepsy and/or other complex needs. However, this new technology allows young people to continue to play and move during their scan. It is less invasive, less intimidating, provides greater clarity of data and is cheaper to run than current technologies. It will enable clinicians to plan better patient pathways and treatment plans, including surgery, which could have a significant positive impact on health and wellbeing.

Because this new scanning technology is still in development, we had an exciting opportunity to co-design it to meet the needs of the young people who will be scanned. Over two years, a multi-disciplinary team worked with young people with epilepsy, their parents and guardians and wider experts to co-design:

Fun and comfortable scanning helmets

Enjoyable activities to do during the scan

Resources to explain the scanning process

The project had five main phases:

Phase 1: Research and Scoping

We spoke to key experts, including the research team, Young Epilepsy staff, neurophysiologists, play specialists, play therapists, a cognitive neuroscientist and a materials expert. We identified key questions, concerns and challenges related to the technology; learned from current materials and processes, and explored how OPM-MEGs would sit alongside existing technologies. This phase allowed us to define our target groups (including narrowing our focus to 5-8 year olds), align to research and charity aims, and understand the possibilities and limitations of the technology.

Phase 2: Consultation

We then consulted with additional experts to feed into the project design and ensure that we could deliver the project in an engaging, effective way. Due to the Covid-19 pandemic, we also had to move the project online. Therefore, our experts, including a focus group of teachers, a child psychologist and a play specialist, helped us to shape effective methods of collaborating with this group remotely. From these discussions, we co-developed a set of principles, which guided the design of accessible and engaging workshops and materials.

Phase 3: Creative Workshops

Over three weeks, we held online workshops with young people with epilepsy aged 5 – 8, and their parents and guardians in two workstreams: **Helmet** and **Task**. The workshops aimed to explore and co-design key elements of the new technology and the activities that young people could do in the scanning room. A secondary aim embedded across the workshops was to explore the overall **user journey** for young people and parents/guardians, and how to best prepare both groups for a scan. This was explored further in the following two phases.



Helmet



Task



User Journey

Phase 4: Focus Groups

We held two focus groups with parents and guardians who had been involved in the creative workshops. The sessions further explored concerns and questions about the technology, what they would need to know in advance, and how to best prepare their young person for a scan.

Phase 5: Wider Testing

Finally, we ran a wider testing phase with other young people with epilepsy and parents and guardians who hadn't been involved in the project to date. This phase was designed to test the insights collected and to further shape our recommendations.

Partners

The project was delivered by UCL's **Wellcome Centre for Human Neuroimaging**, alongside the charity, **Young Epilepsy** and creative partners, **Hefin Jones** and **Mark Lim from Chalk Studios**.



Hefin Jones



Mark Lim



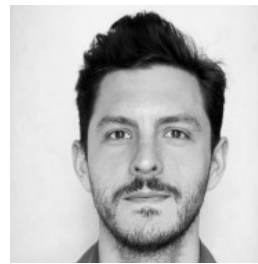
We thank all of the young people, parents, guardians, wider experts and collaborators who contributed throughout this project. You can see their insights, creations and contributions throughout this report.

Please note, due to the extent of the engagement activities in this project, it was designed to involve only a small group of participants. Our insights and recommendations are therefore based on this small group of individuals, and we acknowledge the limitations that this brings.

The Team



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Creative Facilitator



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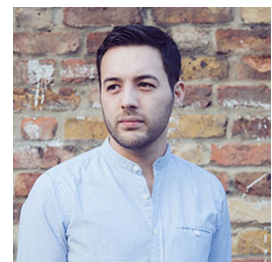
Cassandra Hugill
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Helmet Stream





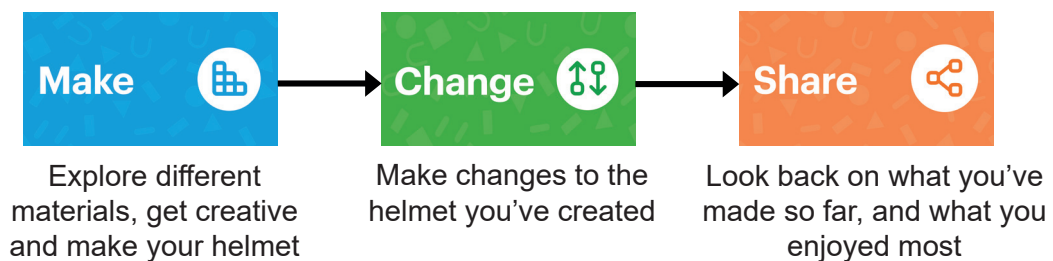
Helmet Stream Overview



Aims: In this stream, we wanted to understand:

- Young people’s preferences for the helmet (such as texture, coverage, look and comfort).
- How young people can build familiarity with the process before a scan.
- What activities are feasible while wearing a helmet.

Young people with epilepsy and their parents and guardians participated in **weekly creative workshops**, over a three week period. Each workshop had a theme: **MAKE, CHANGE** or **SHARE**. Every week, the groups were given a takeaway challenge – to make something which they could share the following week.



The Creative Box

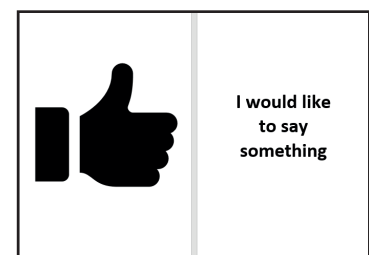
All of the challenges and materials were posted out in a creative box.



The Helmet Kit
(assembled by the young people and parents)



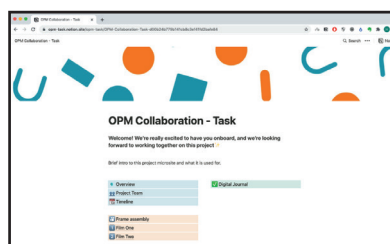
- **Project journal** (for young person)
- **Facilitator’s guide** (for parent)



A5 feedback cards (to support workshop facilitation)



3 ‘Mystery Envelopes’ (to open in the CHANGE stage)



QR codes to a private project website with bespoke introductory films



- **Colouring pens**
- **Child-friendly scissors**
- **Stickers**

Challenge 1: Design and make a helmet that you would like to wear



We wanted to understand young people's preferences of three key helmet elements:

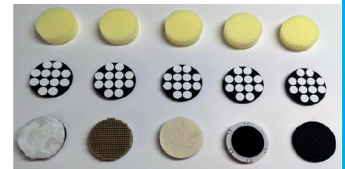
Aesthetic/look

The creative box included cardboard discs and velcro pads that the young people could personalise and add anywhere to the helmet. They could also draw and share their helmet design with us in their personal project journals.



Texture & Feel

The box included different textured discs, which they could select and add to five velcro points inside the helmet. Textures included plastic, foam, faux fur and velvet as well as an adaptable disc.



Coverage

Lastly, the box included a face plate that covered the nose and cheeks. This could be added to the helmet, and cut however they wanted.



Challenge 2: Make changes to the helmet you've created



By introducing three 'mystery envelopes', we brought in new rules which are key to ensuring a good quality scan in the OPM-MEG room. Through this, we could test young people's understanding of the scanning rules, and identify what changes they would make to their helmets, and which activities they would choose to do while wearing it, within these new rules.

Change 1: Heavier helmet

In real life, the helmets are heavier than the cardboard one you have. This is so they can fit the special sensors on. So, we need you to add the heavy bean bag on to the top of your helmet.

Do you need to change anything about your helmet to make it more comfortable now that it has the heavy bean bag on top?

Change 2: Relax!

We want you to be as relaxed as possible whilst wearing your helmet. Being relaxed will make the scan better. What activity do you like to do to relax?

Do you need to change anything about your helmet for you to do your relaxing activity?

Change 3: Do something you enjoy

We want you to be happy during the scan. We hope that if you are doing something you enjoy, you can wear the helmet for longer.

Wearing the helmet longer will make the scan better. What activity do you enjoy doing?

Do you need to change anything about your helmet to do your fun activity?

Challenge 3: Reflect on what you've made and what you enjoyed most



This final session allowed us to evaluate the challenges, workshop design and young people's experience in the project, as well as what aspects of the helmet were most important.



How did you find the Creative Workshops?

Colour in the face that shows how you felt about the workshops.



Key Insights

Customisation



Young people enjoy being creative and want to express their interests

- They were very inventive in how they customised their helmets.
- The workshop process enabled them to share their designs.

Young people may respond better to helmets they can customise and build ownership of

- The majority of young people really liked their own helmets. When asked why, they referred to the elements they had been able to customise.
- Both parents and young people liked the idea of building familiarity with the helmet to improve experiences and reduce anxiety.

Texture & Feel



Young people have different texture preferences, but comfort and softness are key factors in their choices

- They were expressive in describing why they chose to add particular textures to the helmet.
- They may respond differently to decisions about texture due to differing sensory needs.

Adaptable Coverage



Young people's feelings about how much coverage they want on their nose, cheeks and ears are highly varied

- Young people chose to modify the face plate of the helmet in different ways, showing different levels of tolerance to it touching their faces.
- These different preferences may relate to their sensory needs.
- Some issues with the helmet touching specific parts of the face might be rectified if the fit was better.

Fit & Comfort



Young people view comfort as one of the most important aspects of their helmet design, perhaps even more so than look

- Comfort was frequently mentioned as a reason for liking or disliking aspects of the helmet, particularly regarding weight, coverage and texture.

Suitable Activities



Young people don't want to be distracted from their chosen activity by helmet stability, fit or comfort

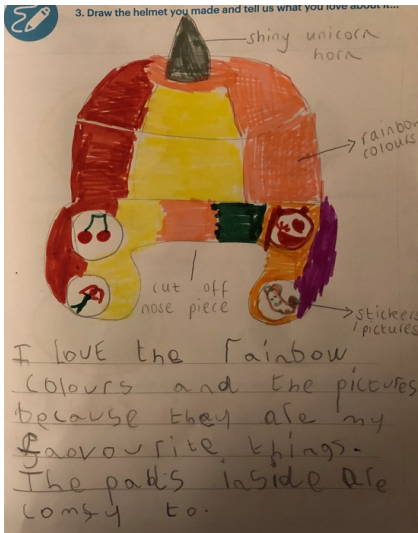
- They found that many of the activities they wanted to do were possible whilst wearing the helmet, particularly once they had adapted it with straps or padding.

Weight

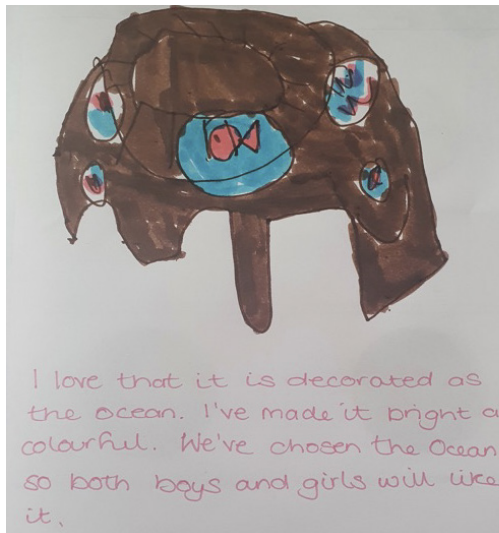


Young people are happy with a heavier helmet as long as it is still comfortable and stable

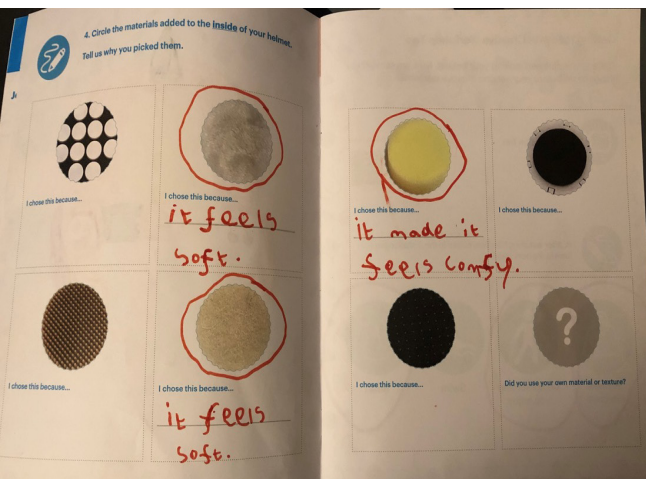
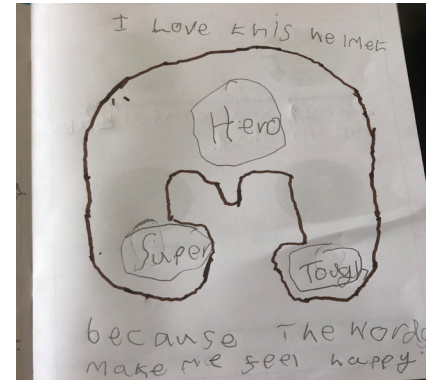
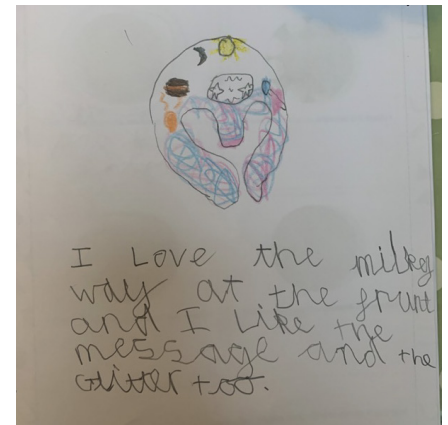
- The added weight was actually preferred by several young people.
- For others, it could be tolerated more if fit and stability were optimised.



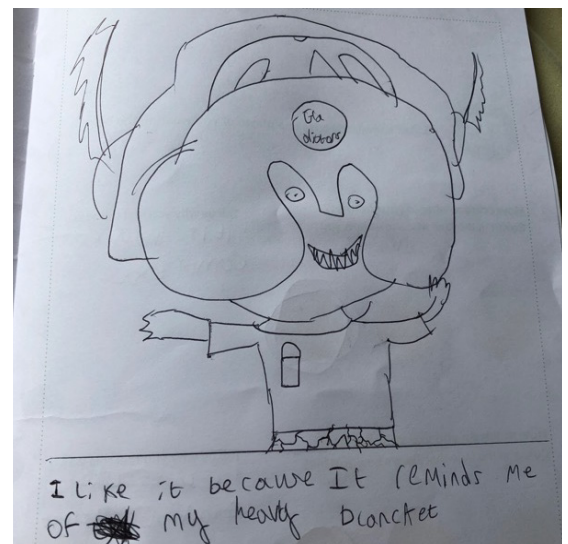
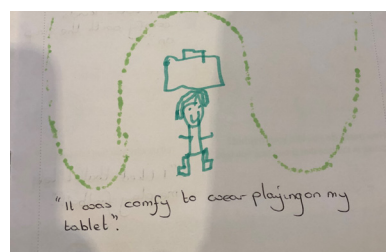
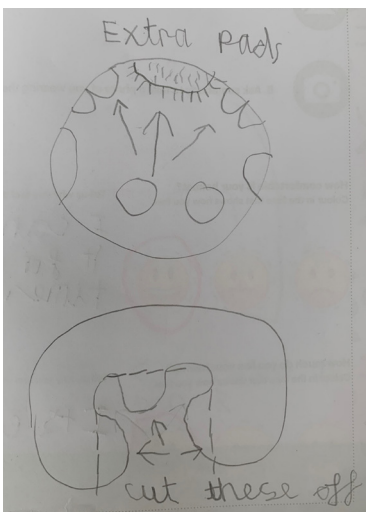
Parent: "[They] said that familiar stickers they could stick on their helmet before the scan would take their mind off the procedure."



Parent: "[They] put inspirational quotes on the helmet. These made him feel happier and braver, eg: Super, Calm, Hero, Happy, Amazing."



"Chose spongy ones for the inside. But by ears, chose soft woolly ones, because they felt comfy. Found it comfy."



Recommendations

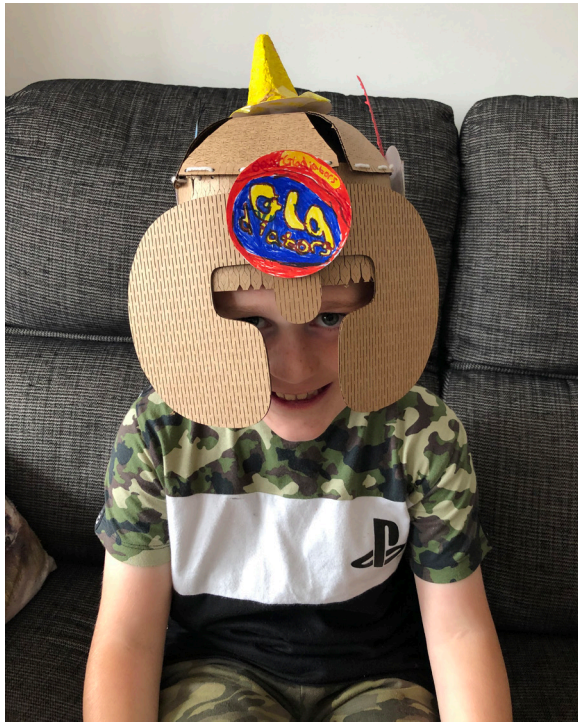
Build in simple ways that young people can customise the helmet to build familiarity and suit their interests and needs

How might we include simple elements that young people could customise and add to the helmet before their scan?

- Could young people create something at home or in the waiting room that could be added to the helmet, to give them ownership and allow them to be expressive?
- Could the customised elements give scanning staff insights into young people's interests and act as an icebreaker?

Prioritise comfort and softness for the helmet interior, allow flexibility in fit and coverage, and be mindful of different sensory needs

- How might we ensure softness (particularly on the helmet interior) to maximise comfort?
- How might we make face coverage removable so that it is adaptable to different needs?
- How might we build in flexibility in fit to adapt to different head shapes and sizes?
- How might we ensure the helmet fit and coverage doesn't distract the young person from doing an activity by feeling unstable, or obscuring their vision?



Task Stream





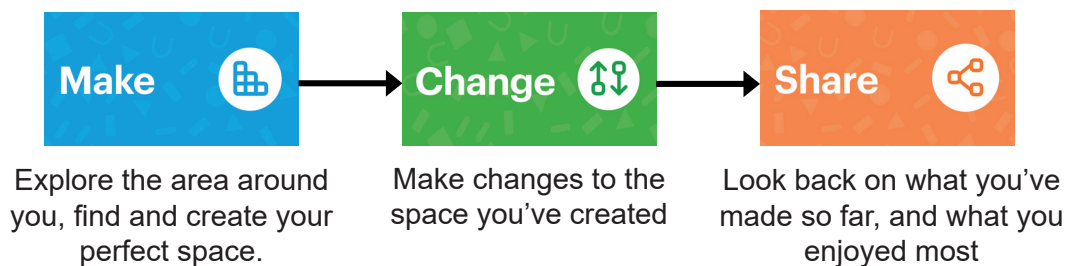
Task Stream Overview



Aims: In this stream, we wanted to understand:

- What activities keep 5 – 8 year olds entertained and relaxed within a small space like the scanning room.
- How young people respond to the technical limitations of the room.

Young people with epilepsy and their parents and guardians participated in **weekly creative workshops**, over a three week period. Each workshop had a theme: **MAKE, CHANGE** or **SHARE**. Every week, the groups were given a takeaway challenge – to make something which they could share the following week.



The Creative Box

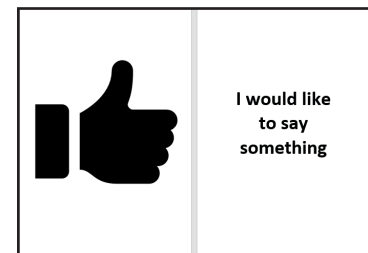
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The Task Kit
(assembled by the young people and parents)



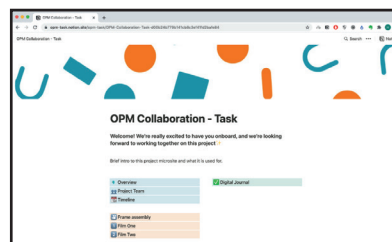
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A5 feedback cards (to support workshop facilitation)



3 'Mystery Envelopes' (to open in the CHANGE stage)



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- **Colouring pens**
- **Stickers**

Challenge 1: Explore the area around you, find and create your perfect space



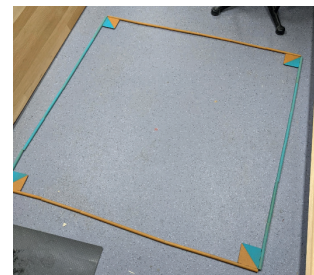
We wanted to understand what would keep young people entertained and relaxed within a small space. The creative boxes included a frame for a 1x1 metre square box. This reflects the space available in the scanning room that enables the best quality data recordings.

We asked the young people to use the frame to create a:

Fun space: Find and create the **most fun** space possible, and spend time having fun in it.

Relaxing space: Find and create the **most relaxing** space possible, and spend time relaxing in it.

Young people could also draw and share designs via their journals.



Challenge 2: Make changes to the space you've created



By introducing three 'mystery envelopes', we brought in new rules which are key to ensuring a good quality scan in the OPM-MEG room. Through this, we could test young people's understanding of the scanning rules, and identify what changes they would make to their spaces, and which activities they would choose to do in the space within these new rules.

Change 1: No metal

The sensors in the helmet are really sensitive. It doesn't take a lot to upset them. If you are near or holding a metal object when you are wearing the helmet, the sensor will detect the metal instead of your brain. So we need to make sure there is no metal inside your frame!

Do you need to change anything about your area to make sure there is no metal inside the frame?

Change 2: Keep your head quite still

Moving around a little bit while wearing the helmet is OK. But if you move too much, the helmet will stop working. This means we can't see what is happening in the brain.

Do you need to change anything about your area to help you to keep your head quite still?

Change 3: Stay for a while

The longer someone wears the helmet, the easier it is for doctors to work out what is going on inside the brain. We want to make sure people are comfortable inside the special scanning room for a little while. We would like you to think about spending 30 minutes inside the space you have created.

Do you need to change anything about your area to be comfortable staying in it for 30 minutes?

Challenge 3: Reflect on what you've made and what you enjoyed most



This final session allowed us to evaluate the challenges, workshop design and young people's experience in the project, as well as what aspects of the activities and space were most important.



How did you find the Creative Workshops?
Colour in the face that shows how you felt about the workshops.



Key Insights

Choice & Variety



Young people are happy and able to share ideas of how to relax and have fun in the space

- They had lots of ideas of how to spend time in the space.
- The workshop process enabled them to share their ideas.

They highly value choice and doing a variety of activities

- They didn't differentiate significantly between what they considered 'fun' or 'relaxing'. However, slightly more active options were chosen as 'fun', compared to more sedentary options for 'relaxing'.

Time



30 minutes is a reasonable amount of time for a young person to be in the restricted space, if they have a range of enjoyable activities to freely move between

- Many were happy to play with their chosen activities for this time period.
- A few young people found the space restrictive, while others didn't comment.

Metal



Young people have a good understanding of what might have metal in it, and are inventive about how to adapt their activities

- Most chosen activities didn't involve metal, even before the 'no metal' rule.
- Some young people were able to describe which objects they thought might include metal. They were inventive about how to continue an activity by removing the metal aspects from the space.

Keeping head relatively still

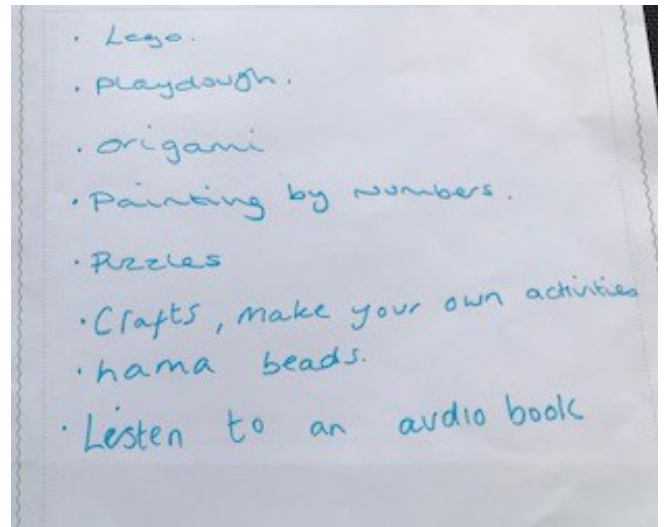
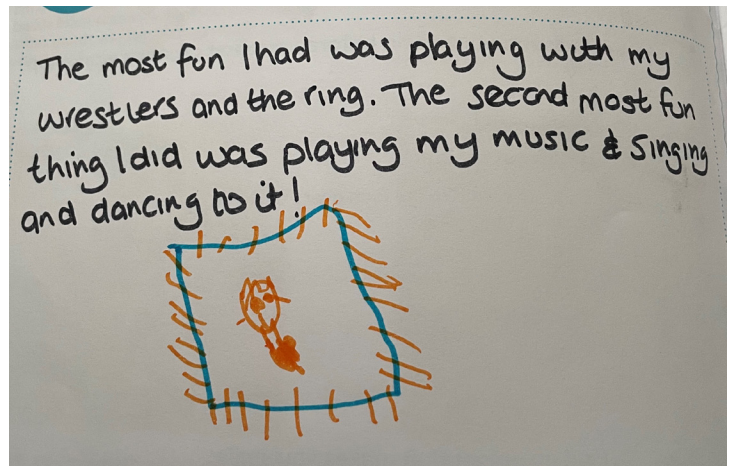
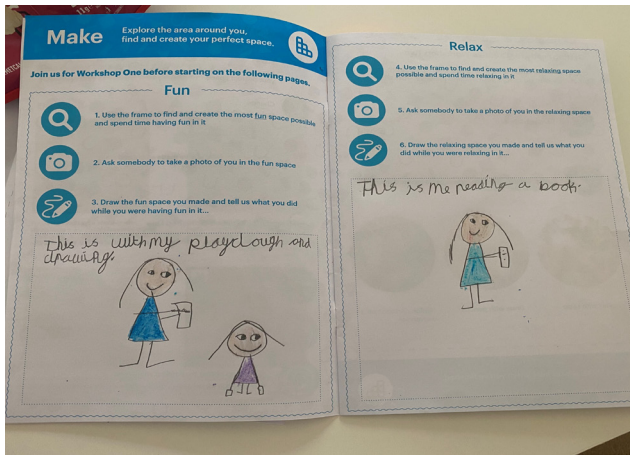


Young people want comfortable seating and surfaces to help them to keep their head relatively still

- Being comfortable was a key element to them being able to stay still and relax.

A calming or focused activity helps with this

- Keeping still was challenging for some young people, but seemed to be easier with certain activities.

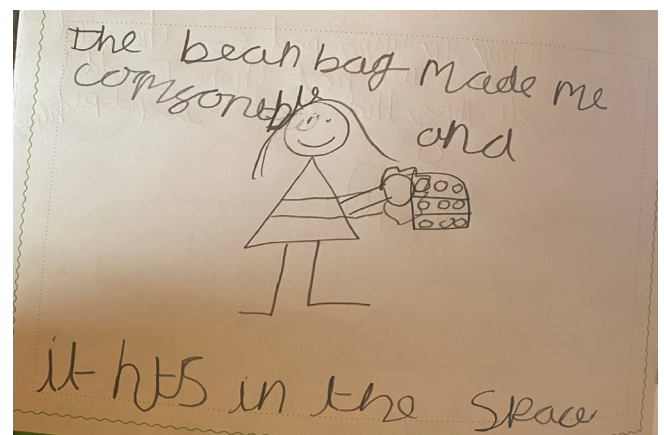
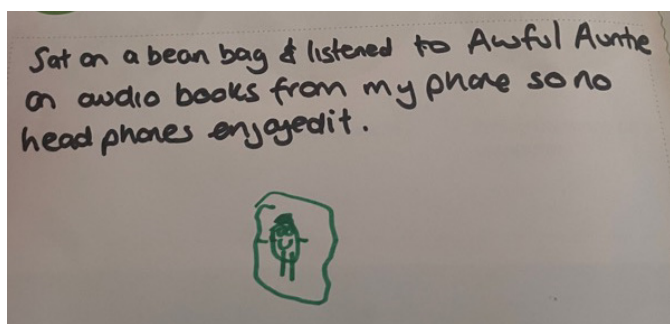


"I had to change my book because all binders were metal. So changed to one that didn't have metal. Some pencils that have rubbers on have metal on the end, so had to change them so I could carry on drawing."

"Playing with dolls and polly pocket in the frame. Shopkins. Painting unicorn.....I think I stayed for like **25 minutes.**"

Facilitator: What made you decide to leave after 25 minutes?

Young person: "Maybe to have a break and go and get new toys"



Recommendations

Ensure young people have choice in and a variety of suitable activities to do in the scanning room

How might young people be involved in planning their scan and activities?

- Can we empower young people by ensuring they know they have a choice in what they do in the scanning room, and can bring different options?
- Can scanning staff use young people's choices as an icebreaker and a means of understanding their needs and interests?

How might we ensure that young people know what activities are suitable for the room?

- Throughout this project, we have collated examples of non-metal, calming activities that are liked by this age group. Can we build these examples into pre-scan resources?
- Young people also tested their knowledge of what contains metal, by watching a short film and doing a quick task in this project. Could a similar creative activity be used to test young people's knowledge before they pick activities to do during the scan?

Ensure young people remain engaged in their activity by providing a comfortable space

How might we prioritise comfort in the room, so that young people can do their chosen activity?

- Can we give young people the opportunity to tell us their needs in terms of seating and equipment?
- Can we include adaptable elements to the room to meet their needs?



User Journey Stream



User Journey Stream Overview



Aims: In this stream, we wanted to understand:

- What questions and concerns parents, guardians and young people have about the scanning process.
- How to effectively communicate the process to young people, parents and guardians.

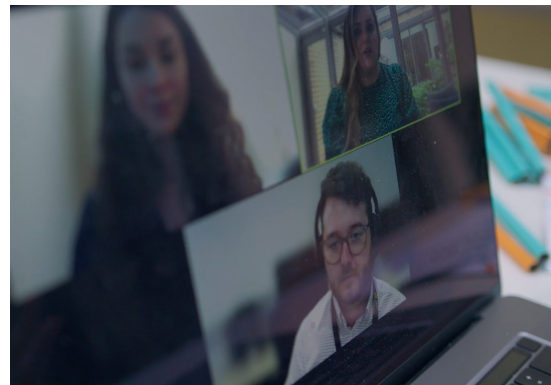
We explored the theme of User Journey throughout three key phases of the project.

Firstly, it was embedded in both the **helmet and task stream workshops**. We collected feedback on overall experiences of scans in the live sessions, as well as in the facilitator guides and young people's journals. This established a rich dataset of thoughts, comments and insights from parents, guardians and young people on the scanning process.

We then held **online focus group sessions** with the parents and guardians who had been involved in our creative workshops, to explore this further. This provided more insight into:

- What questions and concerns they might have about the scanning process
- What information they would need to know, in what format, and when
- Previous experiences of scans (both positive and negative)

These insights were then used to create an **online survey**, as part of our **Wider Testing** phase. We shared the survey with parents and guardians and young people with epilepsy who hadn't been involved in the creative workshops. This final stage tested key materials created, and explored these questions with a broader group.



Key Insights

Voice of young experts

Young people are thoughtful, empathetic and want to support other young people to have a positive experience

- Many thought about how other young people might feel when they were having a scan. They also considered other people's interests when designing their helmet, so that they would like to wear it.

Young people want to be listened to and acknowledged

- They wanted to share their ideas. The icebreaker activities worked well, allowing us to get to know the young people and their interests, and create an environment where they were happy to share with us.

Young people like being referred to as experts, and enjoyed helping the researchers

Preparing parents & guardians for the scan

They have specific needs in terms of the information they get before a scan

- Parents need 'what if' information to prepare them and their young person for the scan. Their priority was for their child to receive appropriately-pitched information; they were more flexible in the delivery of information for themselves. However, timing was very important.

They want to feel listened to, and involved in decision-making during the scanning process

- Several parents shared frustrations about times where they hadn't felt listened to, especially when it came to what might work best for their children.

They have specific needs in terms of the information they get after the scan

- The timeline, clarity of the process, and managing and setting realistic expectations is particularly important.

Creating a good scanning environment

Young people need a scanning environment that is welcoming, well-equipped and child-friendly

- Parents and guardians commented on the importance of the whole experience for young people and parents, not just the scan itself. This includes look and feel of the rooms, uniform of staff and facilities.

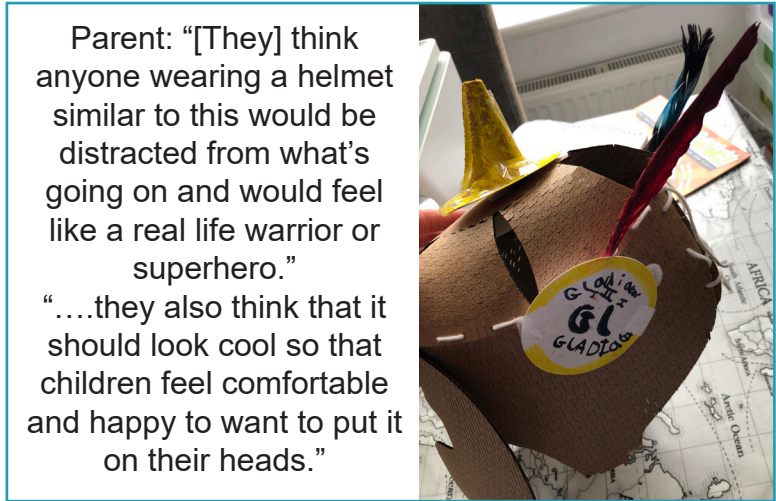
Preparing young people for the scan

Young people have specific needs in terms of information they need to improve their scanning experience

- They need key information in advance, to reduce anxiety and make the scanning process less daunting.
- They also need to know what the scan will not include.
- They need to receive information in a visual, simple, age-appropriate format.
- They liked films as a way of receiving information about the scan.



Parent: "They added a positive message to make the children wearing it feel happy! They used bright colours and glitter to make the children feel cheerful"



Parent: "[They] think anyone wearing a helmet similar to this would be distracted from what's going on and would feel like a real life warrior or superhero."
 "...they also think that it should look cool so that children feel comfortable and happy to want to put it on their heads."

"Rainbow design of the helmet, good for boys and girls....I like the circles, they are like stickers, so everyone could stick their own things on."



"They enjoyed being a scientist and helping with the research."

"I enjoyed helping!"

"I feel like I've been helpful"



"I got to speak, which I liked. I also liked seeing the other helmets"



"Need to give time to other bits that are just as important as actual scan.... Children remember, so need to make [the whole experience] as positive as possible..."



"The video you provided worked well because it was fun and creative."

"Everyone in the film you provided has a friendly face, and this was important. It was friendly and engaging"

Recommendations

Create visual, engaging resources that clearly explain the scanning process to young people

How might we communicate what the scan does involve, as well as what it does not?

- Can we ensure pre-scan resources explain what will happen step-by-step, and alleviate fears by answering the key questions that were captured in this project?
- Can we ensure that pre-scan resources emphasise that an OPM-MEG scan does not involve glue, loud noises, having anaesthetic or staying very still?
- Can we build in a way that young people can ask face-face questions ahead of the scan?

How might we create different visual resources for young people, to suit different needs?

- Can we adapt project films to better meet the needs of young people, by including footage of people their age, simplifying the language, and showing exactly what will happen in the scan?
- Can we create a version of the film for younger and older age groups?
- Can we create a storyboard or social story based on the film, so that young people can visualise the process step-by-step?

Ensure the voices of young people are included throughout the future development of this technology and its application

How might we continue to involve young people in OPM-MEG to improve user-experience?

- Can we user-test the next stage of the helmet and activities with young people?
- Can we create an ongoing collection of feedback from young people about their scanning experience, so it can be continually evaluated and updated according to their needs?

How might we capitalise on the empathy of young people to help others?

- Can we create a feedback loop so that young people who have a scan can give encouragement and support to others? For example, peer-peer resources for young people to share their experiences?

Create resources that enable parents/guardians to feel well-informed and well-equipped to prepare their young person for the scan.

Provide clarity on what will happen before, during and after the scan

How might we create resources that meet the needs of parents/guardians before a scan?

- Can we ensure pre-scan resources answer the key questions captured in this project?
- Can we create different formats of information to suit different needs?
- Can we have a helpline where parents can ask questions or share concerns in advance?
- Can we create a peer support system where they can connect and share experiences?
- Can we ensure information is received 1–2 months before the scan?

How might we ensure that parents and guardians feel listened to during the scan?

- Can we create an opportunity for them to meet with clinical staff before the scan, to share experiences and input into what might work best for their child related to their seizures?

How might we manage expectations for what happens after the scan?

- Can we ensure there is a clear pathway and timeline for what will happen after the scan?

Ensure that the entire scanning environment meets the needs of young people and parents/guardians

How might we create and maintain a non-clinical, welcoming environment?

- Can we include young people's artwork to decorate scanning spaces?
- Can we ensure staff members' uniforms are non-clinical?
- Can we ensure spaces are well-equipped for both young people and parents/guardians (for example, with toys and coffee machines)?
- Can we learn from other clinical settings? For example, one parent had seen a different service using a "passport-like book", which was used to help staff to get to know a young person's interests and needs, to make them more comfortable.
- Can we create a feedback loop where young people and parents can tell us about their experiences, and improvements can be continually built into the scanning environment?

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“We’re very grateful to the young people and their parents who took part in this project; we were able to learn so much from them, and now we have clear directions both in terms of how we develop the scanning helmets themselves but also how to make the whole experience of being scanned just much more fun and accessible for these young people and their families.”

Professor Gareth Barnes

“Everyone at Young Epilepsy is delighted with the outcome of this work and the insights of the young people and their families who participated. As a result of their enthusiastic engagement, we now have far greater confidence in how we develop this new diagnostic technology to ensure that it not only meets the needs of the clinicians but most importantly of the young people themselves. Having this vital feedback has helped us immensely and we are hugely grateful – Thank you.”

Rosemarie Pardington



“Something that became very clear throughout the process was how much input the young people were able to have into this project. We’ve learned so much from the young people and their parents, and we have been able to develop engaging, meaningful ways to include young people more in research design going forward.”

Joanne Thomas



“We learnt that young people loved being creative and responded well to the helmets that they had been able to customise and build familiarity with. We now need to think about ways to enable the young people to customise the real scanning helmets before they go for a scan. We also learnt comfort was really important to young people, but what made it comfortable was different for everyone. So, we need to think about ways to make the helmets adaptable and flexible to suit different needs.”

Lydia Mardell

“Through the workshops, the young people told us that having a choice in what activities they could do in the scanning space was really important, as was having a few different activities to move between. So we can now think about ways to make sure parents and young people know which activities they are able to bring into the room, communicate really clearly about what will happen, and give them a choice over what they would like to do while they’re being scanned.”



Dr George O'Neill

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To find out more about this technology and opportunities to get involved in future research, please contact: **Lara Carr**, Research Coordinator, Young Epilepsy: lcarr@youngepilepsy.org.uk.