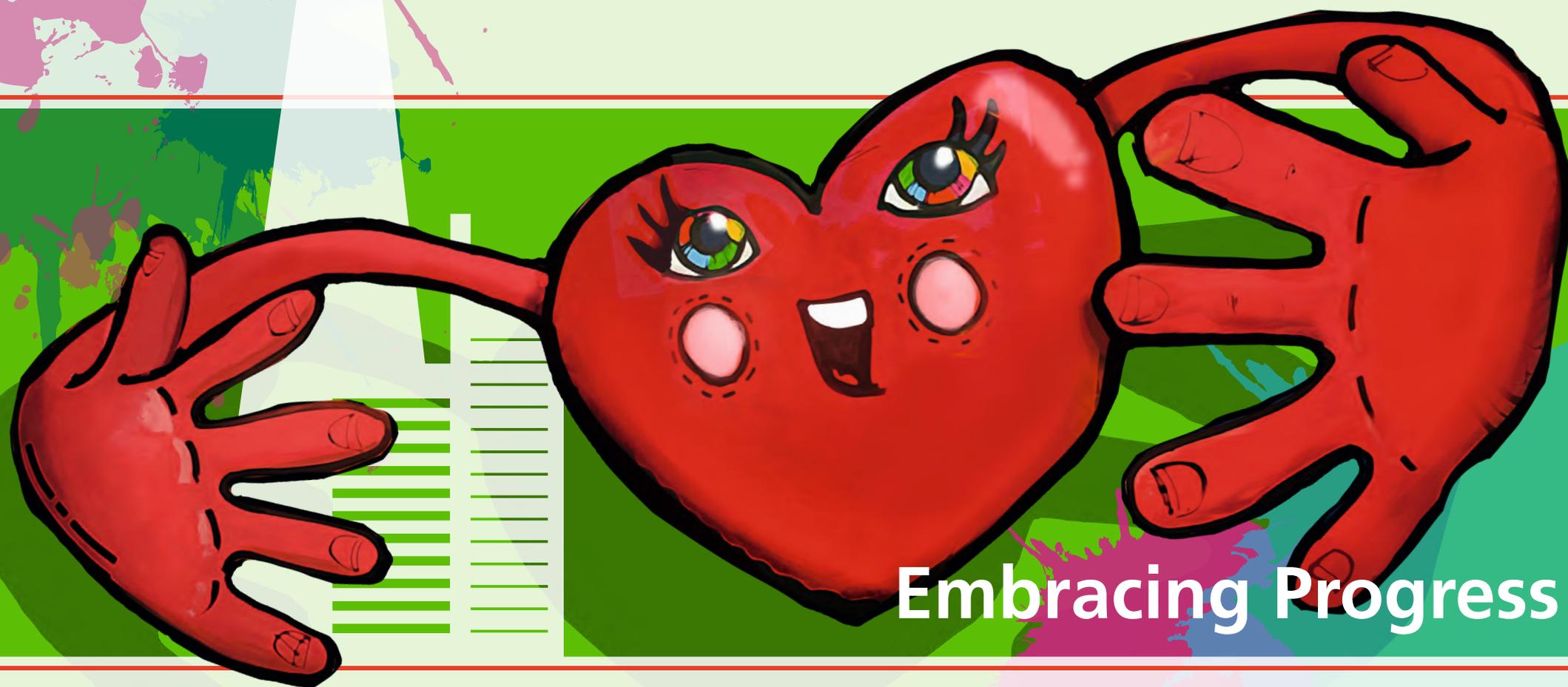


**NHS**

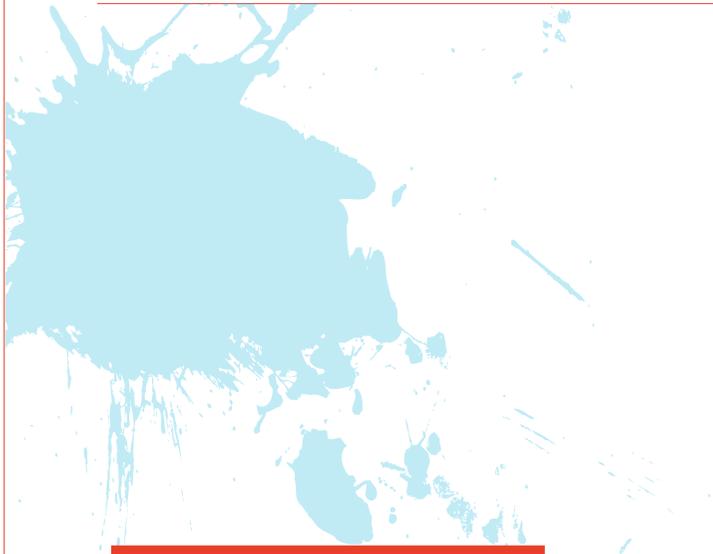
*National Institute for  
Health Research*



**Embracing Progress**

**Biomedical Research Centre**  
At Guy's and St Thomas' NHS Foundation Trust and King's College London

**A BIGGER Picture  
Consultation** 



In partnership with



**Evelina  
London**



## Embracing Progress - A BIGGER Picture Consultation



The Biomedical Research Centre is dedicated to involving its patient advisers and research volunteers in shaping how the service continues to grow and develop. As part of this ongoing commitment, continuous efforts are made to ensure that they can actively participate and have their say.

Stepping outside of traditional methods, children and young people currently involved in medical trials, along with their wider families, were literally given a blank canvas on which they could share their views.

Involving participants from across a wide range of projects, volunteers gave up their Saturday and came together to help 'paint' the 'bigger picture' of what it is like for them being involved in helping pioneer new treatments and interventions.

With support from deadcatdreaming's graphic facilitation service, the attendees were invited to anchor their thoughts and feelings about their involvement, what it means to them, along with suggestions on how their participation in research and that of their peers could be better supported.

## Embracing Progress - A BIGGER Picture Consultation



Graphic facilitation is a unique approach that enables participants to focus and make clear their thoughts and feelings as a series of visual representations. Working collaboratively, the group was encouraged to originate shared metaphors that symbolically reflect their combined viewpoints. These images were expressed in real time as a set of large-scale painted records that participants created for themselves.

In this way, the group clarified and consolidated their opinions, adapting and adjusting their shared representations so that they resonated for the majority. These powerful visual anchors helped keep track of the open conversation, mapping the areas of greatest importance, whilst evidencing that the group had been heard.

The group consisted of children and young people currently taking part in research at Evelina London Children's Hospital, their siblings and parents. The participants were drawn from various research studies across multiple medical specialities. The reflections cover the participants experiences and interaction with all research teams within Evelina London.

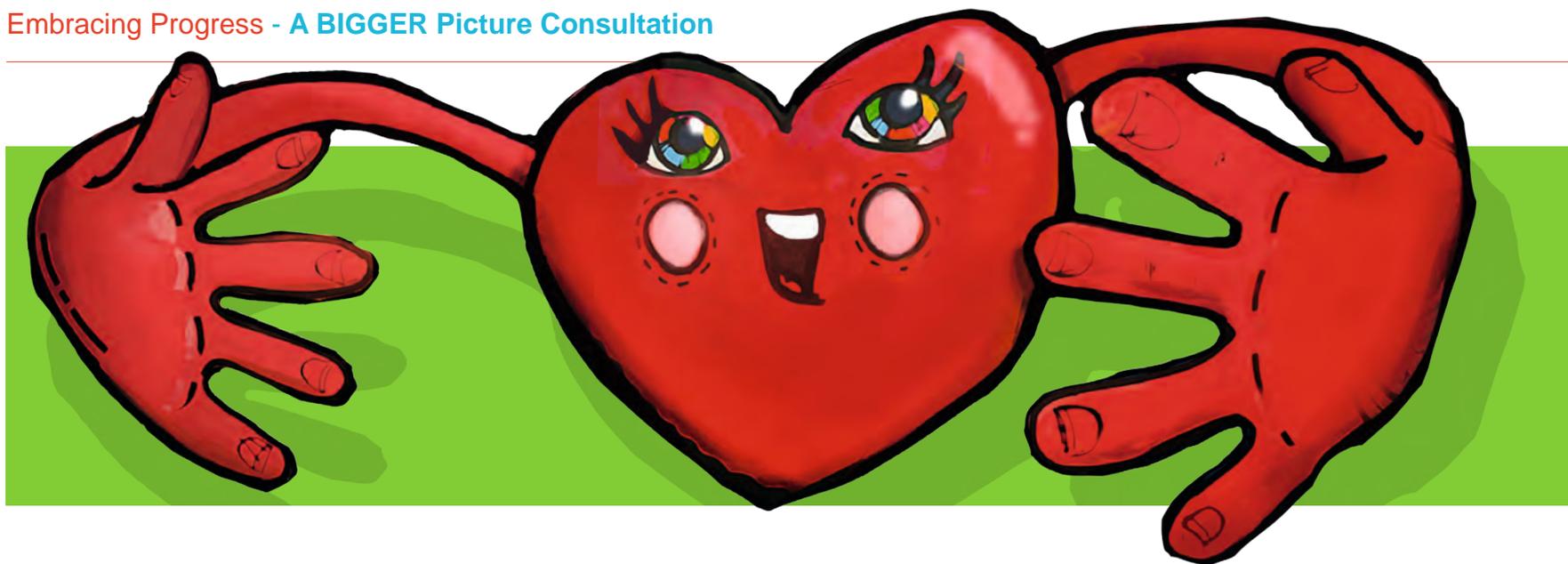
The volunteering participants embraced the process of graphic facilitation wholeheartedly, engaging in a lively and impassioned debate, as well as rolling up their sleeves and rising to the challenge of co-creating the unique artworks.

## Embracing Progress - A BIGGER Picture Consultation



What follows is a brief summary of the evocative images and the significance behind their development.

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The first image on the boards was that of a Warm-hearted Welcome; arms spread wide, this caring motif embodies both the compassionate approach of the dedicated research staff and the sensitive and considered methodology that guides the scientific studies at the heart of the Biomedical Research Centre. Though clinical in nature, what the group valued was the way in which the emotional impact of being part of the study is never excluded or overlooked; instead, they felt that their qualitative thoughts, feelings and wider experiences are given equal significance alongside the quantitative data generated by physical examinations.

“They are very caring and easy to talk to”

The group described how this open and inclusive reach has helped build positive and meaningful relationships between them, the professionals they work with, and the initiative that they are involved in; nurturing a passion and commitment that flows through the whole process. The open arms also illustrate the wrap-around support that makes participation possible. Recognising that no two individuals are the same, this expansive hug is able to stretch to include everyone’s needs, ensuring that a diverse and representative community of volunteers can actively take part.

Deliberately drawn with its eyes wide open, the young people and their families felt that the quality of their experience of being involved in research at Evelina was not by chance and that it was the foresight, expertise and passion of the staff involved that was shaping a new vision for medical research involving children and young people.

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When asked to reflect upon what being part of medical research meant to them personally, the children and young people were quick to rise to the challenge, taking an elevated position that clearly demonstrated that they had already contemplated their individual involvement and where their contribution sat within the wider exploratory landscape.

Research can change the world, it can change the future

Spinning in a new direction, this Accelerating Globe is moving things forward. Seen as potentially world-changing, the group described how although their own involvement in medical research might only appear small, they are inspired to consider that they are part of a global network, adding momentum to a movement that is advancing knowledge and understanding.

The young people ardently acknowledged and accepted that they may never benefit directly from their own involvement and efforts; with the treatments and interventions they receive possibly failing to work as intended. They also understood the importance of control groups and the value of randomisation, confidently explaining the interdependent eco system of modern day research. Whilst they were resigned to the fact that they may never see their own personal health improve, they still felt that research and their involvement as children and young people was making a world of difference, as even knowing the direction 'not' to go in with regards to medication, would always help chart more accurate treatment maps, advancing progress in the right direction.

World  
changing





# The route to success

For the group, this image likens their involvement in research as being akin to a journey. From the offset the young people described how they had been given a clear view of what their route through research might be like, the checkpoints and milestones, as well as the possible hazards they may encounter. Armed with accurate up-to-the-minute updates, the group all agreed that the informative guidance they had received so far had been outstanding, bringing them up to speed quickly, helping them to feel confident that they had committed to the right course of action.

You feel you're in control,  
you can stop if you're not  
happy, they listen to you

Deliberately drawn with their hands on the Steering Wheel, the message the young people wanted to share was that they felt empowered and in control, able to direct how their involvement proceeded. The group added to this design a Forking Road to show that they understand they have the option to alter the course of their involvement, or simply stop and move on from the research, if they so choose.

Happy to press on, they also worked in a clear sign of their willingness to help medical research move forward in the form of a Thumbs-up, as a universal endorsement that they 'like' being involved.

Helping fuel this enthusiasm, was the way in which the research staff brought a sense of energy and drive to their interactions with the young people. The group described feeling that their journey is always moving forward and that they are very much aware of the distance they had travelled and the progress that is being made.

# The STAR treatment



The young people went on to explore in more detail how the research staff support their ongoing participation. Alongside practical considerations, such as the staff's ability to adapt to their individual needs, whether that be requirements associated with their medical condition or perhaps other commitments that they as young people might have, such as school; what really shone out for those involved was the way in which their involvement was always valued and appreciated.

Placed inside the supportive embrace of the Caring Heart, this Star embodies the respect and consideration that they feel they are given. Drawn with its Brain exposed, this guiding Star happily shares its knowledge and experience, the real expert in how their condition and treatment is affecting them.

“...everyone is different and unique...  
...you're the star...  
...you're the expert!”

# Extraordinarily ordinary



The Golden Toothbrush was added to the Star design to illustrate the extraordinary way in which the staff quickly made being part of a research project feel very natural and quite ordinary, whilst still making them feel special and important.

They quickly make it feel like it's a normal thing to do

In part, the motif acknowledges the initial feelings of anxiety and uncertainty that inevitably arise in the early stages of becoming involved as a young person in medical research, however it also embodies the refreshing manner in which the researchers build rapport, allay concerns and make the process appear as if it is just a routine part of everyday self care.

For the group, it was this ability to make the research more about them and their responses, rather than the medication and treatment, which makes it easier to smile and feel positive about being involved.

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This joyous 'Leap of Faith' sprang from a conversation about the implications of involving children and young people in medical research. The group were well aware that their altruistic involvement in clinical trials brought with it the potential for associated risks, however they collectively agreed that these dangers were much less significant than those caused by children not being able to receive the best possible medication.

There are unknown possibilities for the difference the research can make

The group went on to work a well positioned Trampoline into their vignette. Symbolising the reassurance they all took from the professionalism of the research team, how well co-ordinated their involvement is and how carefully monitored they all are. The circular design that makes up the flexible fabric of their support, literally makes use of a Target to illustrate a focused and targeted approach. Painted in the colours of the Evelina London logo, the original jumping off point for this particular aspect of their visual metaphor had been a Safety Net, though this was quickly replaced as it was seen as too passive compared to the Biomedical Research Centre's dynamic approach to involving children, young people and their families.

The group chose to depict the Trampoline as if it had just been used to launch another young person's life forward towards improved health. The implication is that this individual is no longer in the frame having exited the research programme, whilst at the same time the next volunteer jumps into action. For the participants this represented the ideal, with a steady stream of children and young people choosing to come forward and help catapult high quality paediatric research to the fore; raising its profile, making sure that children and young people have a say in the treatment they receive and encouraging others to follow suit.





# Shaping better solutions

Literally 'cutting back on paperwork', this image challenges the Biomedical Research Centre to look into crafting new ways of capturing the data it requires from children and young people.

Medical research involving children and young people is all about acknowledging that they are not merely 'cut-down' adults and are in fact made totally differently. With this in mind, this image suggests that it is not only the treatments that need to be altered to better meet the requirements of young patients, but that the actual research approaches also need to be adjusted to provide a better fit.

They need to be more imaginative  
with how they ask their questions

Though they were extremely positive about their involvement with the research practitioners, the group felt there were times when the updating of information became repetitive and boring. Whilst it was understood that improvements would need to be considered carefully, so as to maintain the Gold Star standards and rigorous underpinnings that medical research demands, they felt there was still plenty of room for creativity.

Shaped by a pair of Listening Scissors, this image suggests developing solutions that respond to the needs and preferences of the individual, producing tailor-made recording tools that listen to and adjust according to previously provided content.

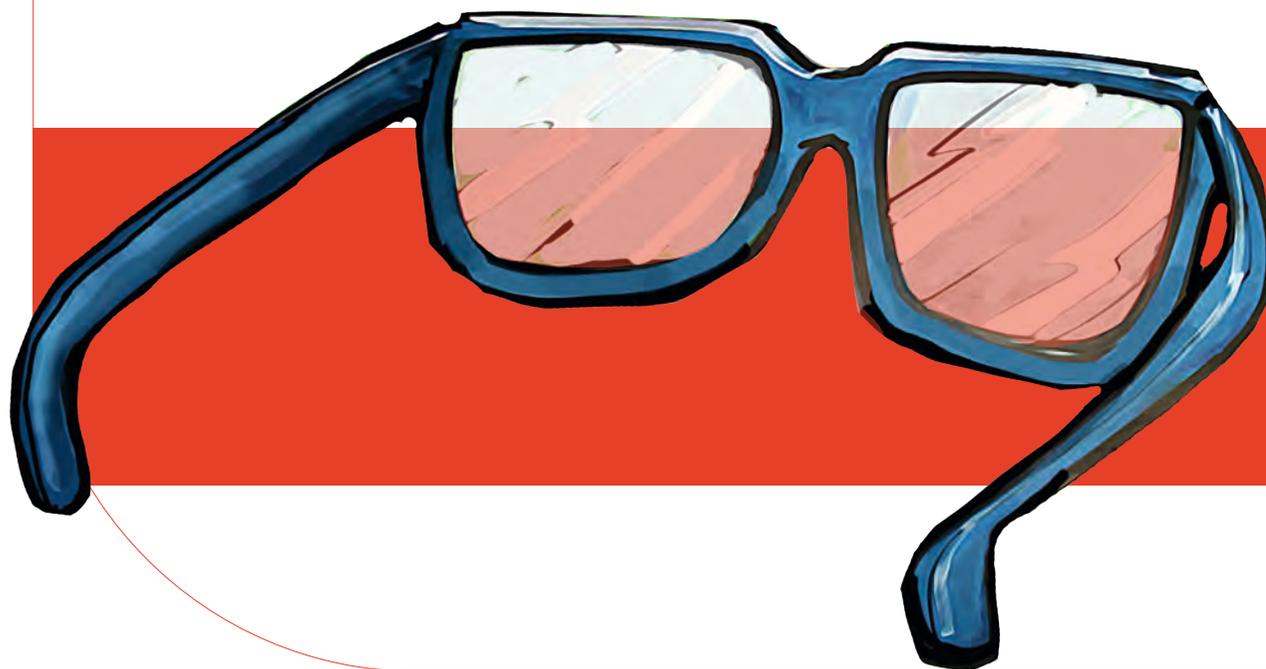
To this end, the young people chose to depict the altered paperwork in their artwork as a Star, echoing the Star motif described earlier in this report.

This metaphor also prompted discussion around better integration of digital technologies, both whilst attending research appointments and remotely via online tools and services.

# A fresh focus

These Oversized Spectacles take a fresh look at how to best help and support participation, maintain engagement and encourage retention for the duration of a young person's research journey. Suddenly popping into existence on the board, their surprise presence brings with it the suggestion that the creation of new tools or activities to help make it easier for young people to share information need not be permanent or routinely used, and instead it is novelty and curiosity that helps stimulate enthusiasm and refocus interest.

This prompted discussion around bringing together focus groups or using other shared activities to help young people see and appreciate the wider benefits of research.



We need everyone to understand what research is trying to do, we need more people involved

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Invited to model what an 'ideal' researcher would look like, the group felt that on the whole they are already well served by those that they work with. Chief amongst their winning attributes is their openness and accessibility, which they depicted as an Unlocked Door.

They know what you are going through, this makes it easier to open up and talk about your experiences

Enabling a two-way flow, the door also illustrates a thorough and grounded understanding in not only the young person's medical condition, but also their personal narrative.

Described as 'they know what we are going through', it was this personal connection that enables them to feel at home with being part of a research project.

# OPEN DISCUSSION





Humour and positivity were other key facets that the children and young people value in their interactions with staff. This larger than life Sock Puppet covered in a pattern of fun emoji's alludes to a particular doctor (Dr Charlie) that stood out as having an entertaining approach to engagement.

He gives me hope!

This charming example was not about over the top showmanship and stage craft, but rather subtle attempts to lighten the mood and lift spirits. The young person who initiated this conversation described how he drew 'hope' from his appointments even when enduring difficult times due to his condition.

As a result of being added to the graphic, this image also prompted discussion around the role of staff outside of those directly linked to the research teams. What was consistent was the quality of the research thread that seamlessly wove through all aspects of the young people's experience of receiving treatment via Evelina London. Right from the offset, when they were invited to take part in their particular studies, the young people felt that their referring clinician had been well informed about what would be involved; presenting a clear and accurate account of the process.

This level of clarity has continued to be consistent with other medical staff. The young people felt that having a well briefed staff body is important as it fosters a reassuring sense of professionalism and quality, showing research to have a firm footing at Evelina London amidst other medical priorities.

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There was a real sense of pride and belief in the valuable work that the Biomedical Research Centre was developing and the close partnership they have with Evelina London Children's Hospital. The group hoped to see this special relationship continue to grow, encouraging others to value the real and significant benefits to be had by giving children and young people a voice in the design of treatments and interventions that were intended for them and their peers.

With this in mind, this image is about nurturing and sustaining the efforts of everyone involved, and encourages all parties to take time to reflect upon the progress that is constantly being made. Showing multiple faces smiling back, the group went on to perch a Graduation Mortar Board on top of the Mirror's Frame. This academic symbol for knowledge and learning was intended to represent being qualified and capable, an expert in a given field, and was worked into the design by way of an invitation to children and young people and their families to put themselves forward as would-be champions for medical research, helping to raise its profile, dispel myths and encourage others to come forward and make a difference.

Sharing experience to lock our knowledge down, to unlock knowledge for other people

The group spoke at length about who these champions could be and how they might operate; unpacking how different people's experiences could inform their involvement. The conclusion however was that anyone that has been involved in research, whether directly or indirectly, as a parent, carer or sibling, has the potential to be a research champion, as what matters most is that they give an honest and constructive account of their own experience and why they value being involved.



# TIME to CARE

Emerging from a conversation about the most valuable of resources 'time'; the final design on the board is that of a Gold Watch.

In creating the image, the group chose to replace the numbers with much more personalised symbols illustrating care and medical attention.

Emblematic of a reward for commitment and outstanding service, this treasured motif acknowledges the efforts of all those involved in research at Evelina London and the Biomedical Research Centre; from the children, young people and their families, who all contribute their time and energy, to the outstanding researchers and medical staff who work around the clock to achieve the precious progress they are continually making.



The staff, the parent's, the children, everyone's commitment is amazing and should be appreciated



Being part of research  
and getting a new  
treatment might not  
help your child but it  
will always help others...

Parent

**The Research Staff at Evelina London and the Biomedical Research Centre would like to thank** all the children, young people, siblings and parents who generously donated their time to take part in the BIGGER Picture consultation. Your creative ideas, feedback and amazing artwork will help us to explain research to other young people and their families. Your input will shape future research at Evelina London and the Biomedical Research Centre.

**Thank you to the Evelina London and the Biomedical Research Centre staff who planned, designed and ran the project. Your energy and enthusiasm makes us all proud to work in research. Thank you to: Felicity Ballin, Katherine Blackstone, Elizabeth Coombs, Louise Dyer, Claire O'Neill, Ania Rainbird and Ben Sawtell.**

A massive thank you to **deadcatdreaming** whose inventive and engaging approach to consultation has inspired our young people, their families and our staff!

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