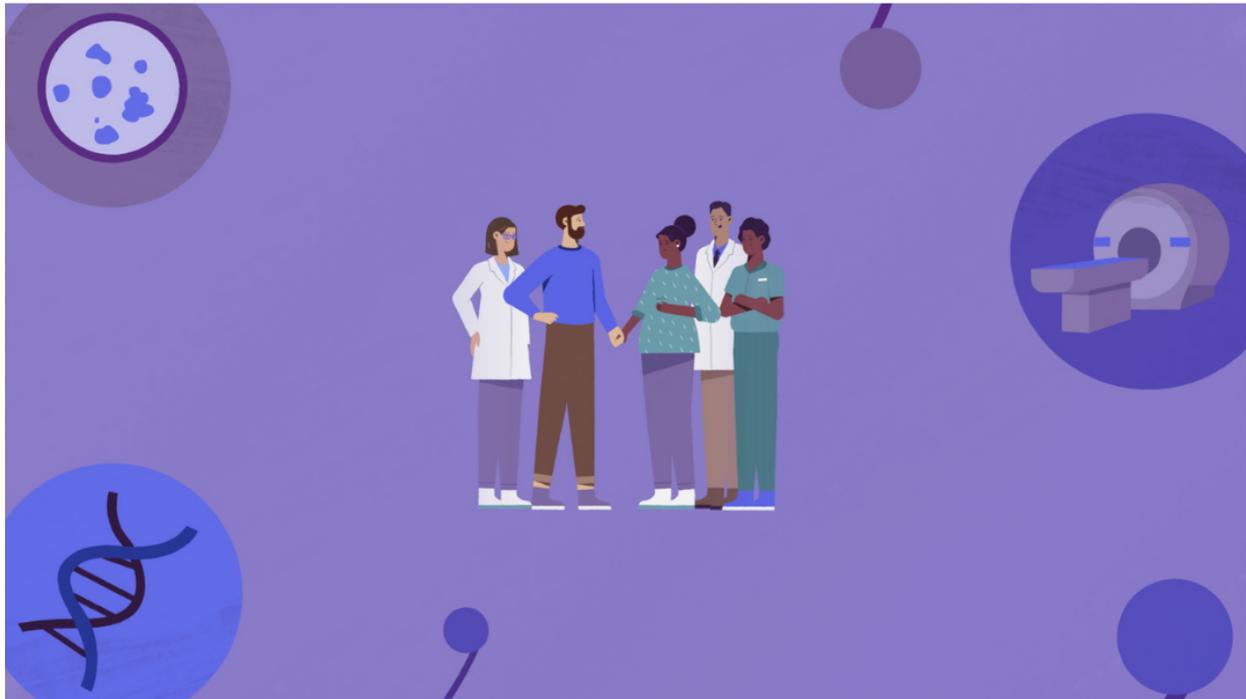


GIFT-Surg and ARC Collaboration- Animation about Charity Involvement in Research

This report includes a summary and review of the collaboration between [GIFT-Surg](#) and [Antenatal Results and Choices \(ARC\)](#) to co-produce a short animation about the charities involvement in research.



Context

ARC is the only national charity helping parents and healthcare professionals through antenatal screening and its consequences. ARC and GIFT-Surg have a long-standing partnership as the charity has been a member of the research groups Public and Patient Advisory Group (PPIAG) since its inception in 2015. In December 2019, ARC approached GIFT-Surg's Public Engagement Officer to explore the possibility of co-developing an animation to showcase the charity's involvement in research, in an accessible way, on their website.

Aims

The aims of this public engagement project were to:

- (i) Develop an accessible animation to showcase ARC's involvement in research to their community and prospective research groups.
- (ii) Provide an opportunity for GIFT-Surg researchers and ARC members to learn from each other's expertise and lived experiences.



(iii) To develop the communication and engagement skills of GIFT-Surg researchers to enable them to engage non-academic audiences with their research.

Animation development

GIFT-Surg researchers contributed towards the development of the animation by (i) providing an overview of ARC's involvement in GIFT-Surg's PPIAG to help inform the script (ii) providing feedback on the script and visual elements during an online workshop with members of the ARC community who had previously experienced a termination of pregnancy for medical reasons.

Four GIFT-Surg researchers attended an hour-long online workshop on the 13th May 2021 along with **five ARC members**, two members of the ARC team and two researchers from EXPRESS; another research group associated with ARC.

Workshop Content

The workshop was co-facilitated by GIFT-Surg's Public Engagement Officer Bella Spencer and ARC's Engagement and Development Coordinator, Sara Lykke Madsen. The attendees were split into two groups consisting of both ARC members and GIFT-Surg and Express researchers. The groups gave feedback on the script and style frames, which are still images that represent the content of a scene. Researchers were encouraged to actively listen to the ARC members and to provide comments when specifically prompted. Feedback and questions were captured on [Conceptboard](#), an online whiteboard.

The feedback from this workshop was used to shape the final script and visual elements of the animation.

Evaluation Methods

1. ARC members were asked to share their experience of the workshop in an online survey.
2. Researchers who attended the workshop were asked to share their experience of the workshop in an online survey.

Analysis

ARC member Feedback

All five ARC members who attended the workshop shared feedback. Everyone expressed that their involvement was motivated by the **hope that their personal experiences could help future service users**; *"Basically give back and help create meaning to my loss"*.

All five **ARC members had a positive experience engaging with the researchers**. Two people found it interesting to hear different perspectives and one person appreciated that researchers are involved in such an initiative.

Everyone agreed that their **opinion was listened to and enjoyed during the workshop**; *"Absolutely. Really great facilitation"*. Four ARC members felt they were provided with sufficient information about ARC's involvement in research and the research projects in order to provide informed comments, while one member responded that they were "not sure" if they were appropriately briefed.

Two ARC members commented that their primary take away from the workshop was that **ARC and GIFT-Surg are making a positive contribution to society** *"[there are] a lot of good people trying to help parents."* Two ARC members **learnt about the area of research and ARCs involvement** *"It is nice that research is being done and that ARC is involved in this"*. One member **gained an insight into the process behind the**

animation *“I think really great work in terms of developing the video. Loads of nitty gritty comments which might be very individual – it’s hard to please everyone.”*

Three ARC members said the workshop could be improved by having **more time for discussions**, one member expressed that the Zoom call could have been easier to access and one member would not make any improvements. **All five ARC members would be interested in attending a similar workshop** in the future.

Researcher Feedback

Two of the four GIFT-Surg researchers who attended the workshop gave feedback. One researcher was motivated to attend as the workshop was very relevant to their work in translational medicine, while the other research recognised the **“importance of designing research projects with input from parents”**.

Both researchers found their **interaction with the ARC community a valuable experience**; *“Excellent. Very helpful.”* They both expressed that they **learnt more about the sensitivities around fetal imaging from a parent’s perspective**; *“The [ARC members] provided additional insight in sensitivities, that even after having quite some experience in this field still are relatively new and very important to address”*.

Both researchers felt that the workshop was successful and generated relevant feedback to shape the animation; *“Yes, I **think it is very valuable to design information for parents by the parents**. The input from researchers helped to shape the correct content, while parents helped to shape how and what should be shared.”*

Both researchers felt **the workshop would have been improved by having more time for discussion**; *“More time to discuss the output and ARCs motivation for creating this animation, less time introducing the research projects.”* One researcher also would have valued the involvement and input of Fathers.

Future engagement

The animation will be shared on ARC’s prospective research page on their website. This webpage will showcase research projects that ARC contribute towards, promote opportunities for service users to be involved in research and invite researchers to explore possible collaborations.

The animation is also available on [YouTube](#).

Recommendations for GIFT-Surg

GIFT-Surg should endeavor to continue to engage public and patient groups that are related to GIFT-Surg’s research areas to:

- Ensure the parent perspective shapes how research is developed, designed and disseminated.
- Inform and engage patients and publics with research relating to fetal surgical interventions and innovations.
- Further develop partnerships with relevant charities and community partners.
- Build researchers’ skills and confidence in presenting their research accessibly to non-academic audience.

A news story about the event series was published on the [GIFT-Surg Website](#).