Interview series: researchers reflect on their experience of engaging with patients and the public to improve healthcare

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TELL US ABOUT YOUR RESEARCH

My research aims to provide new cell-based therapies to improve function in those that have undergone radiotherapy for head and neck cancer.

TELL US ABOUT YOUR ENGAGEMENT WORK, IN YOUR OWN WORDS

My engagement project involved a focus group of patients that have undergone treatment for head and neck cancer. We explored the impact of the treatments on function, namely, voice, swallowing and breathing. We then discussed what their feelings were over receiving a cell-based therapy. Specifically, we explored whether the use of cells taken from discarded umbilical cord would be a problem. We also discussed opinion over receiving a treatment that isn't established and may never have been given to a human subject before. The project was still in the laboratory experimental phase when these initial discussions took place and therefore the methods were fully adaptable based on patient feedback. This contrasts to later on in the translational process where it becomes very difficult to change protocols or methods based on patient feedback, so it is important to involve patient stakeholders early in the research process.

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HOW DID YOU GET STARTED WITH ENGAGING PATIENTS AND THE PUBLIC IN YOUR WORK?

I discussed my plans with the public and patient involvement and engagement (PPIE) team at UCL and at the National Institute for Health Research (NIHR). They were able to offer guidance on the best way to go about setting up the group and arranged a small fund to cover the costs of travel for the participants.



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WHAT WAS ONE THING YOU WISH YOU'D KNOWN ABOUT WHEN YOU STARTED THE ENGAGEMENT PROJECT?

I was quite keen to provide a small fund to say thank you to the participants for taking part. This was difficult to organise, but I viewed it as important. As it turned out, the patients were happy to take part and contribute to research and development and were reluctant to accept the voucher.

WHAT HAVE BEEN THE KEY ENABLERS OF THIS WORK? WHAT HAVE BEEN THE BARRIERS?

The key enabler was the support I received from Angela Wipperman who was PPIE manager at the UCL Joint Research Office and Derek Stuart who is involved in PPIE via the NIHR and facilitated the group. No barriers were encountered.

WHAT WERE THE KEY IMPROVEMENTS, IMPACTS AND CHANGES TO YOUR RESEARCH BASED ON WHAT YOUR PARTICIPANTS SAID?

It was reassuring to hear that patients are not averse to receiving non-autologous (donor) cell therapies. It was also helpful in further understanding the chronic effects of head and neck cancer treatment on function. I do plan to meet with the group again. This would be at critical translational points such as when I plan an application for a first-in-human study. I will also use the same group to discuss other therapies that are being developed.

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ABOUT THIS RESOURCE

This resource is one of a series of interviews, which aims to highlight different ways that researchers are engaging with patients and the public to improve healthcare. The full interview series is hosted on ACCELERATE Potential - an online, self-paced, short course, which covers an introduction to translational research for researchers. Click <u>here</u> for more information and to sign up for the online course. ACCELERATE Potential is an <u>ACCELERATE</u> initiative.

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