

Clinical Research Ambassador Group

Since its start in 2012 the **Clinical Research Ambassador Group (CRAG)**, based at Birmingham Heartlands Hospital, has involved patients and the public in countless research projects. Sam Goad from **INVOLVE** met founders Research Manager Teresa Melody and Professor Fang Gao along with group members.



The Clinical Research Ambassador Group (CRAG)

How did the group start?

Teresa Melody: “Back in 2012 we had a project that had been quite difficult to fund and had been rejected by funding bodies. To address this we approached a patient who had a lived experience of the disease that we were studying – chronic pain. I sat with him for about two hours talking to him. For me it became pretty evident the powerful message he was sending over about the impact of the disease.”

“It was truly humbling for me to listen to his story. I don’t think personally I realised the full impact that chronic pain had on an individual. I then looked at the void that we had here in the Trust. It was a void of involving and making patient, public involvement (PPI) in a way that was meaningful and non-tokenistic. So we thought ‘how can we get people involved?’ ”

Professor Fang Gao: “We started with no money but successfully applied to the Research Design Service for sponsorship. Now the group has been growing by various other grants. We have been costing PPI time, activities, travelling and the training which is very important.”

Teresa Melody: “Out of an initial meeting we had about 15 members that wanted to be involved. Over the past five years it has grown and retention has been marvellous, we now have over 50 members. They come because it is a two-way process. We share with them and they share with us, we learn from them and they learn from us.”



Teresa Melody (left)
Chairperson of the
Clinical Research
Ambassador Group,
Professor Fang Gao,
Professor in
Anaesthesia, Critical
Care and Pain

What are the highlights of the CRAG's involvement in research?

Teresa Melody: "There have probably been too many to mention. From just the discussions around the table, that will change the way that the researchers develop their studies. It will change the outcomes of the study."

"I am always impressed by what the group say, and the ideas that they give to us that we haven't even thought about. That to me is the fascination of this group - how they become a true team member embedded with the research."

Professor Fang Gao: "One example is the TOPIC feasibility study which compares interventions to reduce chronic post-thoracotomy pain. The CRAG was involved right from the inception and two representatives with firsthand experience of the surgery, joined the trial management group and gave advice on the running of the study. The proposal was successful in its grant application with the review board highlighting PPI as a strength of the study design."

"The beauty of the CRAG is that it takes patients into the research and involves them in the whole cycle of the research, not just at the beginning."

To find out more contact:

teresa.melody@heartofengland.nhs.uk

www.heartofengland.nhs.uk/research

CRAG Members' views

"I don't think there are many of these projects that have been put in front of this committee that have failed to go forward. They have all benefitted from this group."

Tom Webster



"In my view, the CRAG model is highly effective for all participants. The opportunity to meet with researchers face to face, and discuss their studies, is very powerful and makes the whole process very real and extremely motivating for all involved."

Anne Devrel



"I can offer professionals the thing they don't always think about: the patient's viewpoint."

Gul Man



Top Tips from the CRAG

- Have a clear vision and mission statement. What degree of PPI involvement do you want and what do you want the group to achieve?
- Just start! Whether it is just one or two members to begin with, you have then made a start and it will grow.
- Training is important. Most CRAG members have been on PPI training courses and to the INVOLVE conference.
- The CRAG is now self-sufficient with its funding. It has embedded costs within each of the grants - not only to cover the individual's costs but the CRAG costs as well.

INVOLVE is part of the National Institute for Health Research and supports active public involvement in NHS, public health and social care research.

Tel: 023 8059 5628

Email: involve@nihr.ac.uk

www.involve.nihr.ac.uk