

# ***Final Report Executive Summary***



## ***HSC R&D Division Progress Report***

*Reports should be submitted via electronic copy to HSC R&D Division within 6 weeks of the request.  
The report should be completed on the attached form in clear typescript. Please extend boxes as required.  
Please adhere to any word limits. These reports may be subject to external peer review.  
Details from the Report may be placed on the HSC R&D Division website and shared with appropriate key stakeholders or members of the public.*

## HSC R&D Division Award Details

<b>HSC R&amp;D File Reference</b>	STL/5562/19
<b>HSC R&amp;D Funding Scheme</b>	PPI in Research Support: Small Grant Scheme
<b>Project Title</b>	NI Cancer Research Consumer Forum (NICRCF) members, <b>attendance at VOICE 2024 - Vision on Information, Confidence and Engagement Course.</b>
<b>Award Holder Name (Employer)</b>	Ms Ruth Boyd (Belfast Health & Social Care Trust)
<b>Host Research Organisation</b>	Belfast Health & Social Care Trust
<b>Award Duration</b>	1 month
<b>Award Start Date</b>	01.09.24
<b>Award End Date</b>	06.09.24
<b>Name of Lead Supervisor:</b> (only applicable to training awards)	

## Signature

**Award Holder Signature:**



**Date: 14.04.25**

# Evidence Brief

(1 page: which may be used for dissemination by HSC R&D Division)

Why did we start?

(The need for the PPI initiative and/or

Why the work was commissioned/or

Experienced NI Cancer Research Consumer Forum PPI Representatives Ann McBrien and Tim Kerr attended the **VOICE 2024 Course** – bench to bedside science for patient advocates – held at Barts Cancer Institute, London. This Independent Cancer Patients Voice (ICPV) co-designed intensive 5 day residential course offered unique learning opportunities with peers and leading researchers and clinicians including hands-on practical sessions in the laboratory setting. An array of topics in cancer research and cancer care were covered, with the aim of increasing confidence in patient advocacy to enhance effective partnership working in cancer research.

What did we do?

(Methods-Please comment on how your initiative/or attendance at event/conference met any of the UK Public Involvement Standards)

Our week at Barts Cancer Institute was an intense mix of lecture-style presentations and discussions, alongside practical laboratory work, and evening activities, including a session at Centre of the Cell.

In the morning sessions we had the privilege of being guided by some of the country's top scientists, researchers and clinicians through a broad view of cancer biology followed by a series of presentations which focused on different cancer types, their characteristics and the developments in cancer treatments. Recent developments in cancer care with screening, genetic testing and targeted treatments across all tumour groups clearly highlighted the enormous benefits of cancer research which is improving survival statistics and patient outcomes. We also learnt about research terminology and the process for drafting and approval of scientific papers.

The presentations were built around a discussion-style format, rather than 'stand and deliver' and as a result there was much debate and explanation throughout – encouraged and enjoyed by the presenters.

The afternoons were spent in different laboratories with a series of hands-on practical exercises linked to our morning sessions, building up our knowledge over the week. We had the opportunity to work with young researchers and pass on to them the importance of their work from a patients perspective. They said our discussions would motivate them more with their research work as they rarely got to meet cancer patients who have directly benefited from cancer research. They said our discussions made them more resolute to do the best job they could to find a cure for cancer!

What answer did we get?

(Please state the outcome of this initiative/and/or what was/you gained from this event or conference as a PPI representative)

This was one of the most informative and far-reaching courses that we have attended.

The quality of Barts teaching and laboratory staff was outstanding – not only in their presentations, but also in their knowledge and their esteem within their professional fields. They truly cared about patients and clearly wanted to make a real difference to improve patient outcomes. They were willing to listen to patients, take many questions, educate and inform us so we left the course more informed and enthused about cancer research.

Each session was highly relevant and enlightening and as PPI representatives we gained enormous confidence through having built up a strong foundation of knowledge around cancer biology that will enable us both to be more rounded and assured in our research and advocacy roles.

We represented and highlighted the Northern Ireland cancer research community, and PPI therein, and gave interviews which were published in City of London newsletter (attached) and on the Barts Institute website. <https://www.bci.qmul.ac.uk/general-news/2024/10/helping-cancer-patient-advocates-find-their-voice/>

What should be done now?

(Practice/Policy Implications and/or Recommendations for PPI)

We would both would strongly encourage PPI representatives to attend this course – especially if they intend being involved with clinicians and researchers in clinical trials/research projects. It will help enormously in understanding the language, theory and principles of cancer biology and enhance their contribution as a patient advocate.

We understand that plans are afoot to run the VOICE course in Northern Ireland/ Ireland in the coming years and we would very much endorse this move to make its unquestionable value readily available to participating health professionals and PPI representatives.