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 purpose of attending event/conference if a PPI representative)

The American Society of Clinical Oncology (ASCO) Annual Meeting is a major international educational event for the oncology community and is attended by UK/NI oncologists. It represents an unparalleled opportunity to network with a large, diverse audience. Results of major cancer clinical trials are announced. An ASCO 'patient advocate' program and bursary supports patients to gain new cancer information, network and explore PPI opportunities. NI Cancer Research Consumer Forum (NICRCF) member, Ashley Hurst, was awarded a bursary (supplemented by the small grant) to attend.

Aim: Learning and networking/PPI opportunity, Ashley would also share new information for the benefit of the NI Cancer Research Consumer Forum (NICRCF) and 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) Ashley Hurst attended the Annual Meeting in June 2022. Networking with fellow Patient Advocates enhanced the understanding of the patient advocate role in other countries. The meeting was navigated and talks, exhibition stands and PPI presentations attended.

Attending this event met the UK Public Involvement Standards:

Inclusive Opportunities – enabling attendance at this international event
Working Together – valuing the PPI role and enabling exploration of PPI roles and
making contacts for future connections

Support and Learning – supporting learning through conference information relating to cancer, research and PPI, thus building skills and confidence

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) On return, Ashley Hurst liaised with the NICRCF PPI Professional Lead about the conference and shared this with the members of the Forum, describing the experience as 'fantastic'. The first face-to-face meeting of the Forum post-COVID is due to take place on 30 March 2023 and Ashley will have a follow-up Q&A session about ASCO as part of the Forum meeting agenda. Ashley highlighted the resources and contact with Rising Tide Foundation. Later in June 2022 an online meeting was held involving a Programme Manager of this Swiss-based organisation, Ashley and the NICRCF PPI Professional Lead. Materials and guidelines the Foundation designed for organisations / patient advocates were noted and relevant for referral as NICRCF develop further induction materials. Ashley reports that she would hope to attend the event in the future.

What should be done now?

(Practice/Policy Implications and/or Recommendations for PPI) Given the vast scale of the event, with 40,000 attendees, in future, in advance of the meeting, the NICRCF PPI Professional Lead (award holder) would, where feasible, facilitate links with the NICRCF member and any other local researcher attendees to promote these connections.

Work developing the training and induction materials for NICRCF PPI representatives is on-going.

Supporting PPI attendance at this and other cancer conferences is a valuable activity for PPI representatives and aligns with UK research standards.