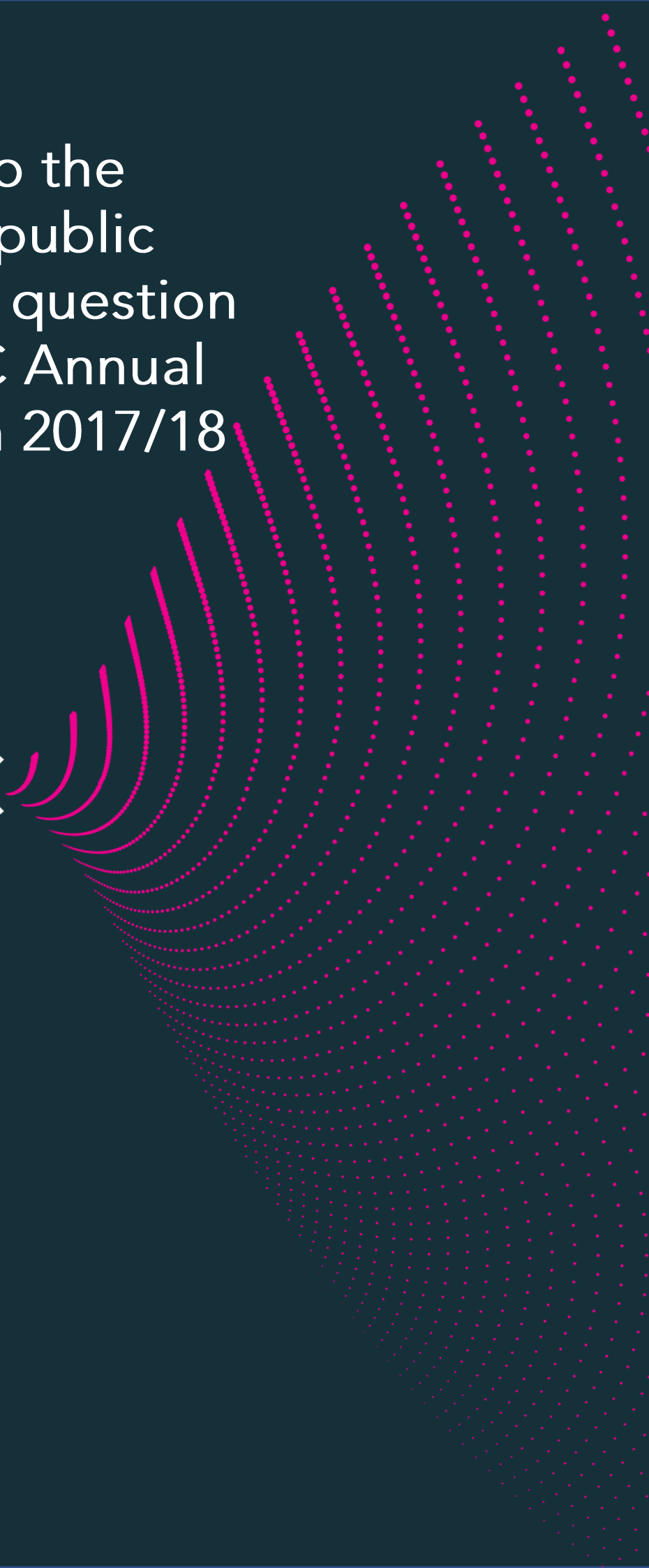


Responses to the patient and public involvement question in the ECMC Annual Report Form 2017/18

ecmc

Experimental
Cancer
Medicine
Centres



Contents

Background.....	2
Summary of responses	3
Barts ECMC.....	4
Belfast ECMC.....	5
Birmingham ECMC	9
Cambridge ECMC.....	11
Cardiff ECMC.....	13
Edinburgh ECMC	15
Glasgow ECMC	17
Imperial ECMC	19
Institute of Cancer Research (ICR) ECMC.....	22
King’s Health Partners (KHP) ECMC	24
Leicester ECMC.....	26
Liverpool ECMC	28
Manchester ECMC	30
Newcastle ECMC.....	33
Oxford ECMC	35
Sheffield ECMC	37
Southampton ECMC.....	39
University College London (UCL) ECMC	41
Acronyms in the document.....	42

Background

The Experimental Cancer Medicine Centres (ECMC) network is an initiative funded in partnership by Cancer Research UK and the four health departments of England, Scotland, Northern Ireland and Wales. Launched in 2007 with a total investment by the funders of over £100million, this infrastructure award supports a network of 18 adult centres of excellence and 11 paediatric locations throughout the UK. By bringing together world-class scientific and clinical expertise the ECMC network advances the boundaries of cancer care.



All recipients of Experimental Cancer Medicine Centre (ECMC) funding provide the ECMC Programme Office (PO) with an annual report detailing activity and progress made in the previous financial year. Annual reports provide valuable information that allows the ECMC PO to review performance, communicate the activities of the ECMC network and respond to requests for information from the ECMC Funders.

There is a patient and public involvement (PPI) question in the annual report that requests the following information:

Please provide a summary of any progress or challenges against the patient and public involvement objectives detailed in the ECMC Review application.

Please consider including in this response any updates to/further information on your objectives, the impact of this activity, any feedback from research partners, any publications/communications from this activity or links to any reports with further information.

[Involve definition of what public involvement is/isn't](#)

You should liaise with your staff representative on the ECMC PPI Group to complete this section

ECMCs could also include an optional PPI case study.

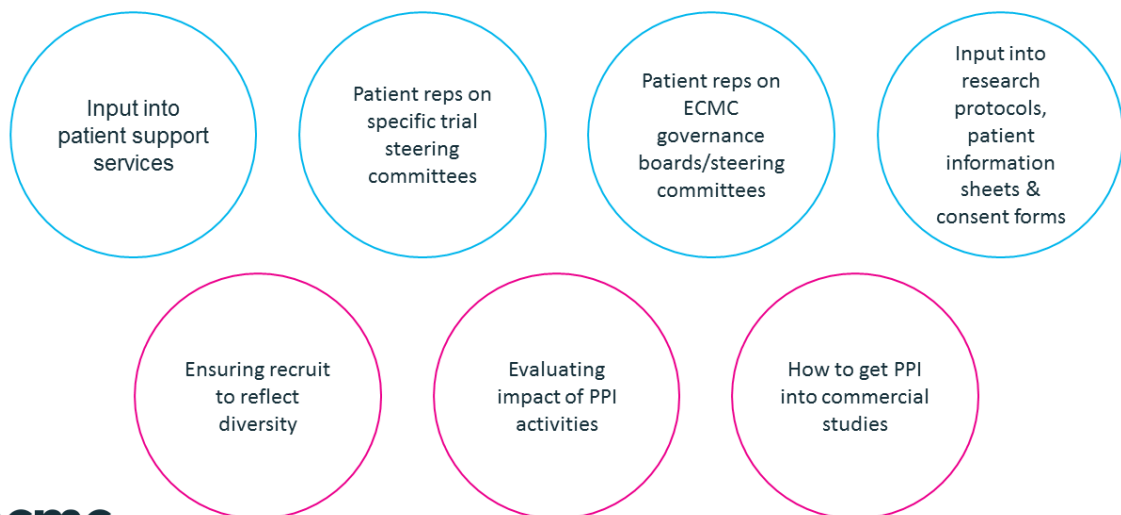
This document contains the responses to the PPI question from the adult ECMCs.

Summary of responses

All ECMCs recognise the importance of involving people affected by cancer in their work and the positive impact it can have on research taking place at their locations. Well established PPI activities taking place across the Network include patient representatives on governance boards and trial specific steering committees, getting patient input into research documents such as protocols and patient sheets. Newer activities that are beginning to be undertaken by ECMCs include measuring the impact of PPI in research, ensuring that patient representatives come from a diverse background and trying to get PPI into commercial studies. Running alongside all of these activities is the need for engagement events, for example symposiums and open days which both raise the profile of research in a location and are a way to recruit members to patient groups or panels.



HOW PPI is being done in the ECMC network



ecmc

Barts ECMC

Barts: response

The Barts ECMC aims to engage with the public at as many opportunities as possible. Over the past year we have continued to be involved in several lab tours where local community have had the opportunity to meet our scientists and clinicians to find out more about the research we conduct. We have also been involved in the International Clinical Trials Day and the annual National Cancer Research Institute Conference to promote and raise awareness of the work that we conduct.

The Centre also participates in the Queen Mary Trial Advisory Group (QMTAG), where we have six public representatives, including cancer patients who have or have not participated in trials, carers as well as members of the public who have no/limited exposure to cancer. The QMTAG have been involved in discussing trial ideas, developing trial designs and producing patient information sheets for upcoming trials. They are also representatives of Trial Steering committees.

As part of our initiative to increase the awareness of clinical trials an ECMC Symposium was arranged, a day designated to encourage researchers at the Barts Cancer Institute to engage with the ECMC staff and learn about trials we are currently conducting as well as trials that were initially developed in our labs. As part of the symposium we arranged for a patient representative to present their journey on a clinical trial at Barts, which provided an opportunity for our researchers, both clinical and non-clinical, to have insight into a patient perspective and learn from their experiences.

Belfast ECMC

Belfast: response

Objectives:

1. Promote PPI

The key indicator for this objective was publication of an updated PPI strategy: 'A Strategy for Personal and Public Involvement (PPI) in Cancer Research in NI 2017-2022'. Good progress has been made, most significantly, publication of a regional [cancer research PPI survey](#) to inform the strategy. The survey results were overwhelmingly positive and endorsed the value of PPI and continuation of the NI Cancer Research Consumer Forum (NICRCF). One of the challenges highlighted by the survey was current PPI funding, so as further consultation is required, strategy completion and publication has been delayed. However, an objective to publish in 2018 is on-going. ECMC PPI and PPI training will remain a key element of the new strategy.

The lack of formal administrative support for PPI activity is also a challenge in regard to all aspects of PPI delivery. To help address this NI Cancer Trials Network (NICTN) has submitted an application for support via the HSC Graduate Intern Programme (the outcome of this process will be known in July 2018).

Promoting PPI remains an on-going process. Formal PPI training is available via the HSC R&DD funded/NICTN supported Building Research Partnerships Workshops, which were held 09 May 2017 and 12 October 2017. PPI is embedded in local research process, such as PPI review of study patient documentation pre portfolio adoption. Various approaches in promoting PPI across both researcher and patient/carer communities are utilised – some highlights this year were:

- PPI survey/focus group results were circulated to all cancer researchers in NI and NICRCF members. The result underlined the benefits of PPI and ease and satisfaction with PPI processes
- A PPI 'recognition' event was held 27 March 2018 to acknowledge the work of the NICRCF members and Margaret Grayson, NICRCF chairperson
- Since April 2017 two new members have joined the NICRCF
- The new NICTN website went live in June 2017 and it includes a 'Getting Involved' page which describes information about becoming involved in the NICRCF
- A S:CORT¹ and MErCuRIC² PPI poster was presented at the 1st European Alliance for Personalised Medicine Congress (see case study below) 27-30 November 2017
- Information was displayed and NICRCF members engaged with the public/staff about their PPI role and activities on International Clinical Trials Day celebrated 19 May 2017 in the NI Cancer Centre and during CCRCB Open Day 17 February 2018 (over 300 visitors)
- The ECMC Early Phase Trials Education Booklet was circulated to all NICRCF members for their review/education 20 March 2018

2. Study Quality / Biomarkers and 3. Studies on time and target

Our commitment to sustaining PPI across the research cycle for patient benefit has been on-going. Highlights include:

- NI Biobank (NIB) appointment of a PPI representative, Hazel Fisher (NICRCF member), to membership of the NIB Steering Committee (meetings attended commenced 07 April 2017)
- Approval of Prostate Cancer Immune Gene study amendment including new PIS adopting the Medical Research Council (MRC) alternative PIS format, as recommended by NICRCF members

- Meeting of the NICRCF PPI Prostate Cancer Research Advisory Group – PPI input to SPORT³ protocol amendment, and SPORT, CASPIR⁴ and ADRRAD⁵ on-going progress review
- Hazel Carson (NICRCF member) membership/attendance at CIBRAC⁶ Trial Management Group meetings. Hazel has identified a potential new patient pathway to help address below target recruitment (amendment currently in development)
- Margaret Grayson, MErCuRIC patient representative, has provided input to study co-ordinating site and input to project website, including a video explaining the study for patient/public audiences, currently in development. Through patient networking MErCuRIC gained increased profile in EuropaColon web communications
- On-going NICRCF input to S:CORT project PPI and Engagement Subgroup, including participation in biomarker workshop

4. Effective working across the Network and between Universities and Trusts

- While the position of consumer chairperson of the national ECMC PPI Working Group no longer exists, Geoff Hill continues as Belfast ECMC consumer representative and Ruth Boyd continues in role of Belfast ECMC professional representative
- Ruth Boyd was part of the ECMC PPI Working Group training sub-group, developing the ECMC Early Phase Trials Education Booklet
- Margaret Grayson attended the ECMC North Showcase event in Newcastle, 15 March 2018, networking with ECMC PPI representatives and researchers

Belfast: case study

Case Study in PPI in Colorectal Cancer (CRC)

The NI Cancer Research Consumer Forum (NICRCF) is a PPI partner in both the EU FP7 funded MErCuRIC programme/phase I trial in CRC and S:CORT Stratification in Colorectal Cancer, a MRC/CRUK co-funded Stratified Medicine Consortium. A poster (see below) was devised to demonstrate PPI and successful partnership working (and relevant public engagement) at various stages in the progress of these projects to date. The poster was presented at the 1st European Alliance for Personalised Medicine Congress, held in Belfast 27-30 Nov 2017. The 'Results' presented for each project were:

MErCuRIC

PPI has influenced MErCuRIC at both project and study levels. Margaret Grayson chaired the project public launch event and raises awareness through UK and European networks such as EUPATI and EuropaColon. Input to the website is through liaison with the project administrators Pintail Ltd. Working via e-mail and teleconferences with Jennifer Houlden, Trial Manager in OCTO, enabled changes to the Patient Information Sheet for the MErCuRIC phase I trial, to simplify its text and format, to facilitate patient understanding. Each participating clinical centre has facilitated patient/public awareness of the study, however language differences and the challenge of differing experience/expectations of PPI across a range of European countries has limited the potential for cross-country collective patient involvement. Despite this, MErCuRIC highlights PPI and engagement activities help drive forward a patient focused agenda in the Personalised and Precision Medicine clinical research context.

3. SPORT High-Risk Trial – A Randomised Feasibility Study Evaluating Stereotactic Prostate Radio Therapy In High-Risk Localised Prostate Cancer With Or Without Elective Nodal Irradiation
4. CASPIR – Calcifications as an alternative to surgically implanted fiducial markers for prostate image guided radiotherapy (CASPIR): A prospective feasibility study
5. ADRRAD – Neo-adjuvant **A**ndrogen **D**eprivation Therapy, Pelvic Radiotherapy and **R**ADium-223 for new presentation T1-4 N0/1 M1B adenocarcinoma of prostate
6. CIBRAC – Chemoprevention in BRCA1 Mutation Carriers – a Proof of Concept Study

Birmingham ECMC

Birmingham: response

Patient and Public Involvement (PPI) is a developing area at the Birmingham ECMC. As defined by Involve, the partnership organisation established by the National Institute for Health Research (NIHR), PPI within research is defined as working in partnership 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. The ECMC recognises that involvement of patients and the public is an 'active partnership' process to have a positive impact upon cancer research.

The CRUK Senior Research Nurse and a local PPI representative are members of ECMC PPI steering group and have contributed to the national steering group objectives by:

- Attending annual face to face meetings and teleconferences
- Sharing information amongst colleagues to raise awareness of the ECMC PPI Advisory Service
- Volunteering to assist with a session at the 2018 ECMC Annual Meeting to promote the ECMC PPI Group
- The Birmingham PPI Representative has been a key member of the steering group to develop a booklet which will support people affected by cancer who are taking part in PPI activities in early phase (Phase I and II) cancer research which is now out for consultation

The Birmingham ECMC PPI representative has also been engaged with the development of a PPI plan for a CRUK Grand Challenge application. This has been an exciting opportunity to work with international PPI leaders and representatives.

Over the last 12 months the Birmingham ECMC has developed key collaborations across the Birmingham Health Partners NHS teams linking PPIE leads across these organisations to drive forward PPI activity. In particular the University Hospital Birmingham Trust lead PPI for research has delivered informal sessions on PPI and how to engage and work in partnership on research projects. Sharing best practice at the West Midlands Public Involvement and Lay Accountability in Research group (PILAR) has facilitated the ECMC plans for a PPI group and ensures sharing best practices, keeping up dated on developments in PPI on a national level.

A draft strategy has been developed for Patient and Public involvement & Engagement (PPIE) in Cancer Research at University of Birmingham. The strategy and direction of the group will be developed further by patients and the public following the first meeting in April 2018. The group will be invited to contribute to individual projects, work alongside researchers to prioritise research, offer advice as members of relevant project steering groups and comment on and develop research materials. A key objective will be to involve members of the group with the governance and strategy of the ECMC with a presence on the ECMC executive board in the coming 12 months.

In preparation for the PPI Group along with a draft strategy the following important areas have been developed: a role profile for members of the group; an expression of interest form completed by members attending initial meeting and a date set for initial 'get to know you' meeting providing representatives with additional information. Objectives for the first 12 months of the group include: One main group to be made from approx. 10-15 representatives, the main group to be formed and develop Terms of Reference along with main strategy for PPI; 3 subgroups for representatives to be nominated to attend 1)

Cancer Research UK Birmingham Centre 2) ECMC 3) CRUK Clinical Trials Unit; Meet back as one main group 4 times a year, updates and evaluation of activity and impact.

PPI activity forms a regular agenda item on each ECMC Management Committee Meeting and serves as an opportunity to monitor activity and evaluate impact. Each member of the PPI group will be asked to complete an activity record detailing any involvement they have had across the ECMC. This will allow the Birmingham ECMC PPI leads to document and evaluate PPI contributions and importantly focus on impact of PPI locally. It is our ambition to lead and work with the ECMC network to develop PPI skills and partnerships to promote involvement of patients in experimental cancer medicine research.

Birmingham: Case study

High quality Engagement leading to Involvement:

Following on from the success of the first patient and public event, 'The Future of Cancer Treatment' held in March 2017, a second event was held in October 2018. Feedback from the previous event, which gave an overview of the topic highlighted a desire from the audience to learn more about personalised medicine and how it is revolutionising patient care.

This second event allowed the Birmingham ECMC and supporting partners to focus on the opportunities personalised medicine offers patients, understanding 'Big Data', ethical considerations in using genes to improve cancer treatment. A lay member from Cancer Research UK's Stratified Medicine Programme attended to deliver a talk on what personalised medicine may mean for the patient. The event was well attended with over 180 members of the public enjoying lively discussion and a panel debate on how personalised medicine will impact not just cancer patients but also family members who share their genes.

Throughout the evening we were able to highlight the importance of working in partnership with patients, carers and members of the public to ensure the research at the Birmingham ECMC is patient focused and has an emphasis on patient impact. Following the event we were able to invite those who may be interested in finding out more about PPI within the ECMC, the Cancer Research UK Birmingham Centre and the CRCTU to become involved. Many of those who replied are attending the first patient and public involvement and engagement in cancer research at Birmingham meeting in April 2018.

Whilst the ECMC maintains the separate definitions of involvement and engagement, it is recognised that high quality engagement can certainly help to establish involvement in the ECMC. A third event in 'The Future of Cancer Treatment' series is currently being planned for May and will explore advances in surgical cancer care.

Cambridge ECMC

Cambridge: response

In the last year, three meetings have been held with patient representatives, who have provided guidance on a number of aspects relating to setting up a focused early phase and translational cancer research patient and public involvement (PPI) group. The patient representatives are experienced in PPI, and have been advising us regarding a number of aspects relating to PPI groups (including advertising for members, how the memberships and meetings should be managed, training that should be offered to members etc.).

We are now formally recruiting members for our experimental cancer medicine PPI group, and have three confirmed members. We have developed a number of documents for the group, including advertising materials and an in-depth role description, which details responsibilities and expectations. Currently our process is to have an informal meeting with all people who have completed the expression of interest form, in order to ensure they fulfil the requirements as laid out in the role description. We have mandated certain criteria for all members (for example: all members must have a personal experience of cancer or cared for somebody who has had cancer; must have a scientific background, or be willing and able to undergo relevant training).

We are advertising for members in a number of ways, including engaging with our clinicians/research staff and via other patient groups available in the area (including the Cancer Patient Partnership Group [CPPG] and the Addenbrooke's hospital PPI group). We have also discussed the group with the CRUK Cambridge Centre Programme Managers network, all of whom have been requested to liaise with each programme lead to identify additional prospective members and/or ways to promote the group.

In order to ensure the group is representative of the East Anglia region (and does not reflect Cambridge patients and members of the public only), our next strategic move is to promote the group across the region. We are in the process of developing our PPI strategy further, including ways to target patients and members of the public in other Trusts/hospitals within our region (East of England).

At our next meeting in June 2018, investigators and research staff will provide an oversight of the early phase and translational cancer research structure at Cambridge. Additionally, we have invited one of our researchers to present a 'mock' project for the members to 'review'. The aim of this is to ensure all members understand their responsibilities and commitment for these meetings, plus the type of questions and/or research they may be asked to review in later meetings.

Over the last year, we have invested in our PPI activities in order to strengthen the management of the experimental cancer medicine PPI at Cambridge, bringing together the Cambridge CRUK Senior Research Nurse, ECMC senior research nurse, early phase trials team lead/senior research nurse, the ECMC programme manager and the CRUK Cambridge Centre PPI lead. The aim is to ensure that PPI activity across the Centre is approached and delivered in a coordinated way.

A patient- and public-facing Cambridge ECMC Open Day is scheduled for September 2018. The focus of this day is to update on the early phase and translational research being conducted at Cambridge, and to present this to patients and members of the public. We have split the day into five main areas of focus, each will have three ten minute

talks: one of which is to be a presentation by a patient or member of the public in relation to this field. Finally, our experimental cancer medicine PPI group will also have a stand at the Open Day where visitors may find out more generally about PPI, and/or about our group specifically.

Cardiff ECMC

Cardiff: response

Our aim for the last 12 months has been to align the PPI activities within the ECMC with those of the Wales Cancer Partnership (WCP). Public involvement in research is an integral part of our work in both the Wales Cancer Partnership and ECMC and so, consistent with this approach, we have sought feedback from one of our public contributors for this summary.

The originator of the WCP, the Wales Cancer Research Centre (WCRC), has developed a comprehensive Patient and Public Involvement model which includes a suite of documents to support and provide structure for our work. These include a Policy, Terms of Reference, and a Partnership agreement which makes explicit the reasonable mutual expectations between research and public contributors. PPI activities within ECMC are now being aligned with this WCRC model and the WCRC PPI Leadership team are mirrored in the ECMC PPI Group: a Lead Lay Partner, Jim Fitzgibbon, an Academic PPI Lead, Annmarie Nelson and a part-time PPI Officer funded by the ECMC, Kate Cleary.

Key to the success of the PPI model has been the belief that there ought to be PPI representation within all levels of governance and, for this reason, the ECMC Lay Partner, Jim Fitzgibbon, attends all the Cardiff ECMC Senior Staff meetings.

To identify areas of focus and examples of good practice, Jim Fitzgibbon and Kate Cleary are meeting with ECMC colleagues to compile a scoping report. Recommendations highlighted so far include: developing role descriptions; naming a staff lead per focus area; setting PPI objectives; and providing training and formal recruitment.

One identified area of need in our scoping report is measuring impact which has recently been designated as a standard in the national standards for public involvement. Launched at the end of March 2018, these standards are a framework to develop and improve public involvement in research and have been generated by a partnership of organisations across the UK including Health and Care Research Wales and National Institute for Health Research. Recognising the important role that these standards will play, we have created an audit tool to assist organisations or projects to be measured against these standards. Once the audit tool is finalised, we plan to measure the PPI activities in the ECMC against the national standards.

We have firmly established working relationships with ECMC colleagues who actively seek our contribution for bids such as the recent successful Innovate UK bid for Cell and Gene Therapy Treatment Centre.

Cardiff: Case Study

A Patient Sounding Board was created by the ECMC team in Cardiff with 8 patients who meet twice a year or on request when new projects require review. The patients were recruited by Clinicians overseeing their treatment for Haematological malignancies (related to bone marrow transplants) and were able to give their particular viewpoint based on their experience and knowledge. This patient subset has a particularly poor prognosis and represents a key area for developing novel drug design and early phase trials.

The Patient Sounding Board was set up to create stronger communication between the scientists and the patients and public. It allows the patients to contribute their thoughts and feedback on service delivery as well as reviewing research projects, clinical trials, and ethics applications.

The Board now receives comments from a broader spectrum of people involved in cancer care that often sit on funding committees for local and national funding bodies. This input has changed the way Researchers write their research and design their science. Whereas previously the focus may have been on chasing a brand new avenue in science, which would benefit the public in longer term, this Board, is shifting that focus. Researchers are also looking to improve stratification, delivery and monitoring of current treatments, which has more immediate impact on the public and healthcare system and gives hope to those patients currently undergoing cancer therapies.

Edinburgh ECMC

Edinburgh: response

During the time of the last annual update, the Edinburgh Cancer Centre was in the process of setting up a new dedicated PPI group as a joint resource to build new and stronger patient and public involvement initiatives across the Edinburgh ECMC, the Cancer Research UK Edinburgh Centre, NHS Lothian and the South East Scotland Cancer Research Network (SESCRN).

Edinburgh Cancer Centre PPI Group have now been operational since October 2016. We have a small but engaged group of men and women who support our research activity here at the cancer centre. Our group have been highly effective this year, responding to a varied number of requests from our local researchers for patient and public involvement.

Our objectives are to:

- Be able to offer involvement from suitable patient representatives to our local researchers at any stage of their research project and support meaningful public engagement and involvement.
 - This may for example include review of trial applications, input into study management/governance, review of lay documentation, etc.
- To follow the PPI standards as set out by Involve. <http://www.invo.org.uk/>
- Maintain a robust database, documenting our member's details and subsequent activity.
- To expand the number of representatives and have as broad a range of skill sets as possible.
- Continue to build on the relationships we have developed with our representatives.
- Encourage and support our representatives in being as involved as they can be.

Our activities have included:

- An advisory group for a health economics study.
- An advisory group for a study looking at cardiac complications after chemotherapy.
- A PPI representative to sit on a Steering Group Committee for a study looking at new advances in microscopy technology.
- Document reviews for 2 cancer studies.
- A focus group for one of our Researcher's studies.
- Attendance at 2 cancer conferences.

Other achievements:

- We have ensured our procedures are in line with the Data Protection Act. We have risk assessed the data we are keeping and have our data asset registered with our local Information Governance Department. We have redesigned our Representative Registration Form and Researcher Request Form to be in line with the new Data Protection guidelines.
- We have received positive feedback from our researchers on the help they have received from our group.

- Two of our representatives attended an advisory group for the `Cardiac Care Trial`. Our Representatives said they enjoyed the day, learning about the project and the researcher felt they had given meaningful feedback on the proposed website and other supporting documentation.
- We have supported two, early phase, clinical trials with document review, prior to ethical approval and these studies are now open to recruitment.
- We have a new ECMC staff representative, John Curran who represents Edinburgh at any national PPI, ECMC initiatives. John is a Senior Research Nurse working in our Early Phase Team.
 - Focus on improving the accessibility of information that patients receive before (and after) involvement in trials
 - Education about cancer, treatments and trials for patients, carers, dependents, lay persons and health care professionals
- Feb 2018: Scottish Cancer Prevention Conference. Three of our representatives attended this interesting conference and actively participated in group discussions.
- May 2018: Cancer Research UK Parliamentary Reception. Two of our representatives attended this topical, annual event.

Glasgow ECMC

Glasgow: response

Glasgow has a panel of consumer representatives that are involved in our translational and clinical programmes and who are involved in our ECMC activities. We continue to add new consumers to our group and, led by the CR-UK Lead Research & Information Nurse (grant holder: Evans – ECMC Lead), we continue to review our PPI strategy including developing policies for broader engagement (specifically broadening the tumour types from which our consumer group are currently drawn), and consumers' expenses and honoraria.

ECMC activities include membership of the ECMC Steering Committee which has oversight of all of our ECMC activities and strategy, membership of IHTAB (In-House Trials Advisory Board), CTEC (Clinical Trials Executive Committee), and the Umbrella Trials Steering Group which has oversight of the CR-UK Clinical Trials Unit's studies including many of those within the ECMC Combinations Alliance that are led from Glasgow. The IHTAB committee assesses ideas from researchers and develops these into clinical trial protocols that can be submitted for external funding or support our existing funding (ECMC, Clinical Trials Unit CR-UK Grant). These protocols may involve medicinal products or other therapeutic interventions, or may be entirely translational in nature (e.g. biomarker studies in blood or tumour tissues). CTEC assesses established clinical trial protocols that are brought by investigators, including those developed through the IHTAB route, for consideration of support from our clinical research infrastructure (including from our ECMC funding and resources).

Through membership of these committees, our consumers are involved in assessing and developing the ECMC strategy, and in assessing and developing the research question for specific projects, reviewing clinical and translational research protocols, and reviewing the SOPs of the Clinical Trials Unit and Clinical Research Unit. We have also included consumer representation in our working group to review and develop the clinical research and delivery strategy in the Beatson West of Scotland Cancer Centre. One of our consumer representatives is working with the CR-UK Lead Research and Information Nurse on producing a questionnaire document which is currently undergoing review by the remainder of the Cancer Consumer Group and which will be sent out to patients at the Beatson West of Scotland Cancer Centre to determine their views on research and how it affects them.

Our consumers are also encouraged to attend the NCRI annual conference, the Scottish Cancer Conference (annual), and NHS Research Scotland Conference (annual). We are currently developing a mechanism for members who attend these events to feedback to the wider group.

One of our consumer representatives (Elspeth Banks) and our CR-UK Lead Research & Information Nurse (Laura Rooney) are members of the ECMC Patient and Public Involvement working group, and they have contributed to the PPI Standards Consultation and Kirsteen Jones was part of a smaller staff group to help re-develop the template for reporting on ECMC activity.

We have also involved consumers in our activities including our International Clinical Trials Day symposium, through presentations to the public and to CR-UK fundraisers (through open evenings) and presentations and interviews to the print and broadcast media. These include live interviews (Evans) with STV on clinical trials, and a series of 3 documentaries

(The Cancer Hospital) has been commissioned by BBC Scotland which will be aired in April and May 2018. This includes interviews with ECMC researchers and patients participating in phase I clinical trials.

Imperial ECMC

Imperial: response

Our PPI group is now well established and we have experienced members who are familiar with our researchers as well as our research. Many of them have attended PPI training workshops held by the Patient Experience Research Centre (PERC) which has given them more confidence when feeding back on projects. Going forward we are looking for PPI member to co-chair our PPI meetings, its activities and focus. In addition, we have appointed a PPI representative to the Imperial ECMC Steering Committee to contribute the patient perspective to strategic decisions regarding our research.

Our PPI group is actively involved with many of our projects through grant submissions, review of Patient Information Sheets (PIS), helping to formulate research ideas, dissemination of results and participating in focus groups. This was especially useful in finalising an upcoming healthy volunteer study which will open imminently and grant submission for the Catalyst Award and the CRUK Grand Challenge. We have also PPI representation on many of our clinical trial steering committees, such as REI-EXCISE and Radical.

In the past year we have held four Imperial Science Café events which we host at Maggie's in a patient friendly environment. In February 2017, Professor Coombes spoke about ongoing and new breast translational studies at Imperial and asked PPI group's help to retain patients to specific studies where women are followed up for 4 years. In March 2017, at our PPI group's request Professor Seckl spoke on immunotherapy and in June 2017 Mr Paul Thirulchevam (surgeon) together with Prof James Moore (engineer) spoke on lymphedema. The last café event was in December with the EpiPredict group. Many of our researchers are part of this collaboration and our CRUK Senior Research Nurse, Kelly Gleason arranged a workshop on PPI/PPE for more junior members of the EpiPredict group to learn to engage patients and the public in their research.

We did an outreach project in local schools this year. PhD students went into primary schools with chemotherapy nurses to talk about their respective roles and how research informs care. It was a great exercise allowing PhD students to practice explaining their work in simple ways and it allowed clinical staff to get closer to our research. This project had dual purpose: 1) to give students and staff the opportunity to practice engagement with the public and 2) to bridge the gap between research and NHS service delivery. The children made drawings for our patients, of which nine are framed and exhibited at Charing Cross Hospital in the cancer ward.

Imperial: case study

As mentioned above, one of the Imperial Science Café that we held was with the EpiPredict group and some of the junior researchers in the group had never participated in PPI/PPE work before. As part of special workshop organised by Kelly Gleason, the junior researchers created presentations, wrote blogs and made a video about their work targeting it to a lay audience. In the evening, the researchers presented their work at the Imperial Science Café meeting held at Maggie's, see below slides and photographs taken at the meeting. The presentations and the workshop received very positive feedback from both the PPI members and the researchers and has helped EpiPredict group more aware and involved with various PPI events held by our centre.



Science Cafe poster

Presentation on harnessing epigenetic editing for breast cancer research

Genetics and epigenetics

What is genetics?
- inherited DNA sequence from our parents.
- these DNA codes genes within our DNA controls how our body works.

What is epigenetics?
- study of changes which takes place in a gene which is not seen in the DNA but are said down generations.
- environmental exposure and lifestyle.

Consider these twins:

-twins are young they look the same

-identical twins are clones

As twins get older,

-they have different environmental exposure

Another gene silenced (silence the budget)

Control agency

Epigenetics

Epigenetics

Presentation on metabolic rewiring of endocrine resistant pathways in ER+ breast cancer

Metabolism & Cancer

Why is metabolism so important?

We Are What we Eat!

Cancer cells are different!

What makes them grow so fast?



Understanding the Traffic within the cancer cell



We are Together!



Institute of Cancer Research (ICR) ECMC

ICR: response

There is a well-established base of PPI activity that is rooted within the ECMC of the RM/ICR. The PPI activity continues to develop and grow refining current PPI practice with a focus on relevance and impact. There is a joint PPI strategy/steering group that is co-chaired by the DDU ECMC PPI staff representative and the ECMC named patient representative. The aim of this strategy/steering group is to ensure collaboration and cohesion of PPI activities across the organisations of RM, ICR and BRC.

The ECMC staff representative also co-ordinates the Patient and Carer Research Review panel. This is now a well-established PPI group that consists of over 40 PPI colleague members. The PPI Colleagues conduct review via email or more in-depth review at quarterly physical meetings at the RM/ICR ECMC site. All DDU Patient Information Sheets are reviewed via this method prior to REC submission. There is regular attendance from DDU consultants at these meeting who present research ideas for discussion and review as well as offering training in research principles and the science of cancer.

Progress is being made in the measurement of impact. PPI metrics are collected on activity included capturing the suggested and implemented changes. There is a focus to improve researcher feedback as to the impact of PPI and this is currently being collected as a prospective audit.

Our annual public engagement open day has been planned for the 11th May 2018 continuing to unite staff, PPI colleagues as well as patients and public to discuss clinical trials and patient care. Our PPI activity will also be reported in a future edition the Royal Marsden trust magazine that is also accessible online to all patients and staff.

Progress and Challenges in relation to objectives:

- Identifying important research questions and research prioritisation – It remains challenging to have PPI influence on research prioritisation in early trials of novel therapies. However we have been able to include PPI influence in identifying areas to research within the nurse led research programmes. Early input has been given in projects that focus on patient experience issues that arise due to living with the consequences of cancer treatments. A current research study investigating to possible effects on cognitive function in relation to novel targeted therapies has had extensive PPI in developing some of the questions and the direction of the research.
- Improving the design of research protocols, information sheets (PIS) and consent forms (ICF) - Great progress has been with regard to this objective. A change in direction from simply reviewing the finished PIS, ICF has been made toward advising on development at an earlier stage. The PPI group is in the process of updating researcher guidance that is available on the organisation's intranet to advise on correct format and styles of information. There is also a mechanism to have a PPI colleague to help in the writing and development of the document. The aim being that if PPI occurs at this earlier stage by the time it gets to the end review stage it should not need correcting. Post PIS production review is also carried out on all PIS.
- Reviewing patient focused questionnaires and addressing end user needs – Within the ECMC DDU a patient involvement service design project has been conducted to identify any extra needs for patients on Phase I trials. See Q. 1.6a for further details.

- Improving methodologies of data collection and analysis- Complex protocols are discussed at the patient and carer research review panel with discussion surrounding acceptability of number of invasive procedures.

In summary there is a robust PPI structure and level of activity that continues to develop with patient direction at both a strategic and operational level.

ICR: case study

Objective: The overarching aim of this study was to aid development of services for patients with cancer on Phase I trials in terms of support and information. The objectives were to utilise patient experience and involvement to assess the need for any extra support or changes in the delivery of information and plan for improvement of services.

Design: This was a qualitative approach using two focus groups with a loosely designed schedule to prompt discussion the narratives were recorded and analysed.

Settings and Participants: Patients or relatives of patients with advanced cancer on Phase I trials in the Drug Development Unit at the RM/ICR ECMC

Methods: Two, One hour focus groups were digitally audio-recorded. Group 1 consisted of 8 participants and group 2 consisted of 10 participants. The discussions were audio-recorded transcribed verbatim and analysed using a thematic analysis approach.

Results: Four themes emerged from the data that were useful to guide decision making regarding further development of services they were; face to face support, remote support, getting the right information in the right way at the right time and support and relationships with other patients.

Future plans developed from this preliminary work: As a result of ideas and themes raised there are plans to implement a quarterly patient meeting forum that will consist of three sections, trial feedback (information regarding the progress on some of the Phase I trials will be feedback to the patients) well-being session teaching on a particular aspect of well-being for example (eating well when you have cancer) and chat time a time and space for patients to chat and catch up with each other.

King's Health Partners (KHP) ECMC

KHP: response

The South East London Consumer Research Panel (SELCRP) continues to support our researchers with their studies, providing advice on patient information sheets, protocols, and research proposals. Panel members (lay, patient representatives, and active researchers) provide rapid review and feedback to research teams on comprehensibility, terminology used, and patient acceptability of aspects of trial design, and also review draft patient information materials prior to ethics submission.

The group has recognised a need to widen awareness and use of SELCRP by both investigators and the public. As part of the public engagement agenda, members of SELCRP participated in the King's College London K+ programme (<http://kplus.london>). Two panel members took part in a speed science event. The K+ students spoke to panel members including patient representatives about the impact of cancer research on patients, from the patient perspective. The event was extremely successful with 100% positive feedback.

The newly established Biobank Reference Group was set up in February 2018 to support expansion of King's Health Partners Cancer Biobank, and a member of SELCRP is part of this Group. The group includes patients who are or have been treated for cancer, carers, as well as friends and family, with up to 8 members who are representative of the local cancer population. The group provides feedback on biobank operating processes that directly impact patients, they identify and validate mechanisms of improving understanding of biobanking, and they contribute to activities that will raise the profile of the KHP Cancer Biobank. The group meets on a monthly basis with additional information circulated by email.

This year four SELCRP members held a focus group with a number of our clinical trial coordinators and research nurses to explore options around how patients can support other patients who have been offered participation in research/clinical trials. This is a initiative continues to be developed.

- Spicer has continued to support CRUK fundraising, including speaking at meetings of the Catalyst Club and of the Accelerator Club
- The King's ECMC contributed speakers to a CRUK Supporter Event at Guy's Hospital in June 2017
- Karagiannis has been working with the CRUK Philanthropy Team and the Catalyst Club
- The ECMC participated in the KHP Comprehensive Cancer Centre's annual Survivorship celebration in 2017, <https://www.guysandstthomas.nhs.uk/news-and-events/2017-news/june/20170626-fashion-inspires-hope-on-cancer-survivors-day.aspx>
- The ECMC hosted two 6th form students in the Karagiannis laboratory for work experience in June 2017. Plans are underway for the laboratory to host a further student in June 2018
- The Karagiannis laboratory also hosted medical students and clinical fellows in the last year, who subsequently attain clinical academic posts and/or independent funds (e.g. EMBL, BAD, EAACI, ACF, Academic Foundation Programme fellowships)

- Spicer participated in a Crick Chat evening in October 2017 entitled "Cancer: the big picture" <https://soundcloud.com/user-685689991/crick-chat-on-cancer-the-big-picture-20-oct-2017>

Leicester ECMC

Leicester: response

The Leicester Patient Carer Advisory Group (PCAG) continues to extend its remit to review grant applications and study specific related information pertinent to cancer and malignant haematology. The most recent application 'Pre-clinical evaluation of drug efficacy using patient-relevant breast explant models: a bench-to-bedside approach' was successfully awarded a £670K grant from Breast Cancer Now. Whilst a relatively new work stream, the review process was embraced with enthusiasm by all members of the group, thus negating the need to identify a dedicated sub group at the current time. Investigators universally comment on the straightforward requirements in order to seek a review and the value of the feedback they receive. In turn, the requirement of investigators to provide progress updates back to the group is of equal value.

Significant progress has been achieved within the Leicester Mesothelioma Research Programme in developing the world's first molecularly stratified umbrella study, Mesothelioma Stratified Therapy (MisT) is due to open in quarter two of 2018. To date it has been more appropriate to lead PPI via Leicester Meso UK. However, we have been able to contribute by giving advice and sharing the standard operating procedures developed by PCAG that facilitate our robust review process.

All members of the group continue to be supported and encouraged to attend study days.

One patient representative has recently been invited to sit on a Trial Management Group which will inevitably enhance insight of the research process and add value to the group.

Key areas identified as part of the PCAG 17/18 work programme include the development of the Hope Clinical Trials Facility website and the information it provides, particularly with the new patient, their family and friends in mind. Following the successful completion of our 'Coming off Study' leaflet, we are in the midst of producing a suite of documents to provide brief, simple and informative summaries of treatments and how they work.

We continue to conduct an active engagement programme to raise research awareness. Children enjoyed hands on 'cell making' at the City Ride Health and Science Fair. Our ECMC representative is actively involved in CRUK's advertising campaign.

Leicester: case study

Leicester has an ethnically diverse population often including hard to reach groups with language frequently being a barrier. We have successfully made an impact in communicating with both Polish and Afro-Caribbean communities.

An invitation was accepted to provide a research awareness event at the Leicester Polish Centre following Sunday Mass. The parish priest introduced the importance of cancer awareness to his congregation (200 plus) following his own personal experience. Uptake in seeking more information about cancer and research was significant thereafter. Key factors that contributed to the success of the event included the provision of information in polish and the presence of a polish colleague who was able to support communication channels. Hands on activities demonstrating randomisation, targeted therapies and the

'taste test' generated a lot of interest and participants agreed that their knowledge of research was enhanced.

We have successfully developed a partnership with Leicester University's Centre for Black Minority Ethnic (BME) Health. Working collaboratively, this provides easier access to a number of different communities and the opportunity to organise and attend events. A recent 'Play Domino Talk Prostate' event aimed to raise awareness of prostate cancer among African Caribbean men and support those diagnosed with the condition. Seventy men women and children attended and the event was featured on ITV Central News. The opportunity to integrate, provide information and encourage considering research participation as a treatment option was welcomed. The event was deemed a success and attendees have now formed a group that plan to meet regularly. A brief survey conducted indicated that there was little knowledge about research in general. The intention is to return to the group and provide more comprehensive information at a later date.

Liverpool ECMC

Liverpool: response

The LCTU PPI Group continues to mature into a functional and effective team, having been strengthened in this reporting period by the presence of new members, including the appointment of members to the ECMC subgroup.

The ECMC subgroup was established with an introductory meeting to members of the Senior Management Team, where the work of Liverpool ECMC was outlined by the Clinical and Scientific directors. Members of the ECMC subgroup review and provide feedback on trials under consideration, specifically, the burden of the patient pathway, patient facing paperwork (Participant Information Sheets and Informed Consent Forms) and the possible impact of the trial results for patients. Subgroup members have been involved in putting together research proposals and where appropriate have been named as co-applicants.

Our PPI Group Members represent patients and the public on key committees to influence both LCTU and ECMC strategy. These include the LCTU and ECMC Senior Management Teams, Trial Adoption Committee, and Operational Committees, which provide oversight of all activity.

Group members have contributed to the production of the ECMC Early Phase Trials patient information booklet, providing comments and feedback to the Programme Office.

The LECMC team work in partnership with the CRUK Senior Research Nurse to contribute to a diverse range of research engagement events with the University of Liverpool and local NHS Trusts, to raise awareness of clinical trial participation. At Clatterbridge Cancer Centre, the LECMC Team will participate in activities on International Clinical Trials Day, promoting early phase trials to patients and the public, with an interactive and informative programme.

Members of the ECMC team have participated in Cancer Research UK supporter events. A tour of the LECMC GCP Laboratory Facility was organised by the local Cancer Research UK Volunteer Fundraising Manager, who received very positive feedback from the supporters who attended.

Unfortunately our named ECMC Network patient representative has recently had to step down due to poor health. In the coming reporting year we will seek to recruit further members to the LECMC PPI subgroup to both strengthen and broaden their involvement in our research. We will seek to appoint a new network group patient representative for Liverpool, and reach out to the wider cancer community. We have begun this with initial meetings with a local Cancer Survival Service (Sunflowers). Engagement events with this group are planned for the summer.

Liverpool: case study

In preparation for the ECMC application a meeting was held to engage patients and the public with early phase trials & Experimental Cancer Medicines Centres. The meeting was advertised locally and endorsed by clinicians. Of the 30 people who were interested in attending, 20 attended on the day.

There were presentations from the team applying for ECMC status, outlining their plans, and the importance of patient and public involvement in the work of Liverpool ECMC. Presentations were given by Prof Daniel Palmer, Prof Syed Hussain and CRUK Senior Research Nurse, Ruth Stafferton.

Feedback from those attending was positive, with participants stating they would likely attend future events and would recommend the event to someone else. Six participants wanted to be kept up to date with latest innovations and development in cancer research and access to clinical trials.

Since the successful award of the ECMC in Liverpool we have continued to involve patients in the work of the ECMC, forming a subgroup of patients to provide a patient's perspective to our research and the direction of the ECMC in Liverpool

Manchester: response

1. Where Digital Science meets the patient:

- Manchester ECMC have developed an **App** so patients can see where in the queue they are for dispensing their Phase 1 clinical trial medication. Feedback from patients has been universally positive in releasing them to use the waiting time more productively
- We are currently profiling a web-based tool (PROACT) for patients enrolled on ECMC studies to directly (via voice, video or text) feedback on their experiences (safety, efficacy, feasibility, formulation) during their clinical trial. This feedback is then anonymised and summarised to enable sponsors to “hear directly” from the very first patients enrolled into their clinical trial programmes. This enriches the insight beyond that derived from the traditional case report forms
- **The Lymphoma Group launched a website** (<http://www.christie.nhs.uk/services/i-to-q/lymphoma/>) in August 2017 which provides patients, carers and professionals with information about the lymphoma team and clinical trials available at the Christie for patients with lymphoma. Website content is reviewed by a member of the lymphoma team (Ellie White) on a fortnightly basis when newly activated trials are added, closed trials removed and achievements highlighted. Ellie is also in close contact with the Lymphoma Association (UK patient group) and provides this organisation with information about lymphoma trials for their TrialsLink website.

2. Raising awareness of Experimental Cancer Trials

- **Lymphoma patient/carer event at the Christie:** This will feature six short presentations from physicians, nurses and patients describing current and future research, achievements, the patient experience and opportunities to get involved. There will also be a Q&A session and networking over refreshments. A feedback form will be circulated with a view to understanding the appetite for such events and how they might be improved in the future.
- **Jo Taylor** joined Manchester ECMC steering board as a Patient Representative. Jo helped develop our Manchester ECMC "brand" as we refreshed our ECMC website with also the addition of good social media, and has helped to spread the message about what ECMC do to professionals and patients. The steering board meetings are very positive and very well organised with clear actions. As a patient Jo feels comfortable speaking and contributing to the steering board meetings.
- **Norwegian visitors learn from ECMT expertise:** Research staff from a Norwegian teaching hospital were hosted by the Experimental Cancer Medicine Team (ECMT) during February 2018. The two-day visit, by an oncologist and three nurses from the clinical trial unit at Bergen Hospital Trust, gave them an overview of ECMT's and other trust-related operations, such as the clinical research facility and the Manchester Cancer Research Centre. The Scandinavian team are looking to expand their Phase 1 trial capabilities.
- **Christie represented at northern England's first cancer conference:** Two Christie representatives shared their expertise at an event described as the north of England's inaugural cancer conference on Tuesday 27 February 2018. Professor Rob Bristow, Director of MCRC and The Christie's Chief Academic Officer, was the keynote speaker at the event: 'Accelerating Cancer Drug Development – from target to patients'. He was joined on the day by Dr Natalie Cook, Senior Clinical Lecturer in Experimental Cancer Medicine and Honorary Consultant, who co-hosted a session entitled 'Clinical trials and how clinical decisions are made.'

3. Integration with Manchester BRC: The Public Programmes Team at Manchester Universities NHS Foundation Trust, in partnership with The University of Manchester, specialise in Patient and Public Involvement and Engagement (PPIE) and lead (Katherine Cresswell) on the PPIE for the Manchester Biomedical Research Centre (BRC) and Clinical Research Facility (CRF). During the year, this joint enterprise has:

- Set up a Patient and Public Panel, creating a structured way for a diverse mix of the public affected by cancer to become involved in shaping cancer research. To date over 45 people from across Greater Manchester have been recruited to the panel.
- Supported the panel to feedback on at least seven grant applications directly influencing clinical research design and the information provided to patients about the studies supporting researchers to work effectively with the panel.
- Set up a 'Cancer Forum' for key stakeholders within the cancer landscape, such as Cancer Research UK, Manchester Cancer Research Centre and The Christie, to meet on a regular basis to discuss and align PPIE activity across Greater Manchester.
- Collaborated with The Christie on the '100 voices' public engagement project to extend the scope to include research staff, with the aim of highlighting the importance of both the researchers' and the publics' voices within research.
- Scoped out and supported cancer researchers to run and/or contribute to a range of other public engagement opportunities such as the Manchester Science Festival.
- Begun a programme of community-led work aimed at diversifying the types of people involved in cancer research.
- Held a training seminar for BRC and CRF research staff to build PPIE capacity and skills.

Manchester: case study

The importance of patient and public involvement in the work of the Manchester ECMC team continues to be firmly embedded, with examples of PPI involvement at both a study specific level, as well as across disease areas. The latter includes involvement of staff across the multi-disciplinary team being involved, for example, with school student placements and events, to patients supporting development of disease group strategy over the next 3 years. The work of the ECMC Manchester is transforming clinical trial conduct and culture, from the patient as a subject to the patient as a partner and co-scientist. Throughout 2017 we have co-created projects with medical teams, patients, carers, scientists, and clinical trial sponsors to do just this - the PROACT study provides an exemplar as to how the Manchester ECMC values and utilises PPI as a core area for the team.

- PROACT (Patient Reported Opinions About Clinical Tolerability)

PROACT is a system that is designed to empower patients participating in early clinical studies by giving them a way to directly contribute to drug development that's on their own terms. It gives patients an additional way of contacting their medical team at the clinical trial site between visits. Furthermore, patients have the opportunity to receive study updates from their medical team. As well as strengthening the patient-medical team communication options, PROACT breaks through the traditional concept of a 'communication gap' between patients and the clinical study sponsor. It does this using a 'privacy-by design' approach to maintain the privacy of patients, and the objectiveness of

clinical trial sponsors, whilst providing the patients with the opportunity to share their experiences with those making decisions about the overall drug development program. At all times, patients retain control over their own information and are at complete liberty to decide whether they want to participate, what information they volunteer, and when they do so. This creates the opportunity for clinical researchers to create a truly patient-centred drug program from the start of clinical development, in a way that supports the patient-medical team relationship at the clinical trial site.

PROACT developed in consultation with patients, is a new way of engaging and empowering patients. The study enrolled the first patients in December 2017 with 6 patients enrolled to date. The data and insights gleaned from using real-time technology through PROACT has already provided valuable patient insights for sponsors that could otherwise have impacted on drug development. For example, patient reports via PROACT revealed that a commonly reported side effect associated with one investigational medicine which could have slowed drug development was tolerable and self-limiting.

Newcastle ECMC

Newcastle: response

Perspective in Research PPI group

The 'Perspectives group' patient and public involvement (PPI) group for research continues to develop; through building links with the local 'Cancer Alliance PPI groups' membership of the Perspectives group has increased significantly, we now have 25 active members. These links have additionally offered Perspectives PPI group members the opportunity to attend Cancer Alliance PPI group meetings and support cancer services in the region.

Through engaging with the Northern Centre for Cancer Care (NCCC) at the Freeman Hospital we have, in partnership, initiated NCCCs first PPI group to support service improvement – Perspectives group members will be at heart of this development going forward ensuring that research remains at the on the agenda during discussions of service development and delivery for the regional cancer centre as a whole.

Patient research ambassadors from the group have continued to represent the group at research meetings across the northeast and have been involved in publications such as 'react' science by Newcastle University. The group were recently asked to review a potential major colorectal cancer research UK initiative in the Northeast (COLO-SPEED). The group have subsequently been asked to send representatives to be part be of the NIHR PPI event for the initiative, taking place in Leeds on 23rd April.

Discussions are ongoing with the CRUK Newcastle Research Engagement Manager, CRUK Senior Nurse and ECMC/Centre team to have a "Newcastle" stand at the 2018 NCRI conference and Perspectives group members will also be involved in preparation and, it is hoped, attendance at this national conference

Wider PPI engagement projects

Last year's International clinical trials day open day was a huge success, where 65 members of public attended a first-of-its-kind event and had the opportunity to find out more about the cancer drug trials being undertaken at the Centre, as well as watching laboratory demonstrations and talking directly to researchers and nurses. We are building on this success running another open day on the 19th May, again with committed staff come in on a Saturday so we can open a clinical facility to the public without compromising patient confidentiality and impacting on treatments.

Feedback from the day

'A mind blowing interactive experience which very clearly and positively demonstrated the innovative research being carried out on our doorstep'

'I was grateful for the opportunity to get an insight of the amazing work carried out. Very thought provoking and at times emotional'

'What an amazing experience today, an inspirational unit, finding out more about what goes on behind closed doors; I was amazed, well done. Great idea'

'What a brilliant morning! An excellent opportunity to be educated and gain an understanding of where the money we raise goes. The dedication and enthusiasm of the team is infectious, very inspired to go out and do even more to raise funds so you can continue. Keep up the good work and continue saving lives.'

'As a cancer survivor I found it very educational, patients don't realise what goes on in the background to help us recover and lead a healthy life.'

University engagement

We began a wider engagement project with local universities and colleges, where we gave an insight into the role of a Research Nurse within the clinical trials. At the initial teaching day we illustrated how clinical trials are delivered in the northeast and what the ethics are which govern research clinical trials. So far the project has been delivered to undergraduate nursing students at Sunderland University. Feedback from the event was very positive. Going forward we have an agreement to deliver this project to Teesside University and Newcastle college.

Oxford ECMC

Oxford: response	
<p>What percentage of your research studies have involved patients or public in their development?</p>	<p>Early Phase: All studies that we run have an element of PPI at development, as public representation on ethics committees prior to approval is a prerequisite.</p>
<p>How have you involved patients or the public in the overall priorities for research within the theme?</p>	<p>Patients are approached on an <i>ad hoc</i> basis at request of investigators for involvement in various projects. A panel of lay people (mixture of patients and people affected by cancer) formed to review projects / address requests from other agencies – Oxford Cancer Research (OCR) PPI committee. The OCR PPI committee provided feedback on the design / content of the ECMC PPI handbook.</p> <p>Our PPI representative Nikki Hayward is the Early Phase trials unit committee member on OCTO early phase steering committee. Patient / people affected by cancer asked to attend meeting re CRUK Grand Challenge proposal looking into CRC and microbiome. Examples of the above activity are given below:</p> <ul style="list-style-type: none"> • Two of our CRC patients have agreed to attend meetings to feed into the development of the S:CORT study. We are also • Involved one of the EPCTU PPI committees, helping to shape a project looking at the promise of precision medicine. • Satisfaction survey of EPCTU patients to help us to understand what was important to our patients and improve our service. • A haematology patient from OCR PPI committee is helping the Haematology PPI committee with a research proposal review. • Haematology patients approached to help inform research design for Celgene project, a pharma co. request.

<p>What examples are there that research has been reshaped as a result of patient and public involvement?</p>	<p>Member of PAIR committee which is an overarching PPI group hoping to coordinate and influence PPI across different themes. Direction of this committee is still evolving.</p>
<p>Steps taken to reach out to patients / public to get them involved in your research?</p>	<p>Posters up in public areas to advertise the existence of the OCR PPI committee. Flyers also available on the EPCTU. Emails are sent out to request feedback on projects virtually / sometimes meetings are held if this is more appropriate.</p>

Sheffield ECMC

Sheffield: response

Sheffield ECMC continues its good relationship with the Yorkshire and Humber Consumer Research Panel, a local group of cancer patients and carers who provide expert lay opinion on studies and projects. Sheffield ECMC is very grateful for the added value that PPI input brings. In the previous quinquennium, it was suggested that public engagement be explored and this has included talks from ECMC members to schools (Sarah Danson) and the CRP (Angie Cox and others).

Panel members are trained and participate in a wide range of activities including:

- Membership of the ECMC Executive and Cancer Clinical Trials Executive – Research Governance
- Membership of NCRI Clinical Reference Groups
- Membership of trial development and trial management groups locally, regionally, and nationally
- Membership of NIHR funding review panels
- Membership of HRA and MHRA PPI panels
- Membership of Sheffield and Humber Research Ethics Committee
- Member of the Medical Genetics Clinical Reference Group
- Member of the Cancer and Nutrition Collaboration
- Commenting on patient information sheets and study protocols
- Membership of Sheffield's new Biomedical Research Unit Scientific Advisory Board
- Membership of the Genomics Medicine Centre GeNEQ PPV Panel
- Full details of panel activities can be obtained from <http://www.yhcrp.org.uk>

PPI involvement in the CTE restructure has taken place as planned, and this has resulted in improved commentary on study protocols and patient-facing documentation which is much appreciated by researchers.

Panel members are actively encouraged to apply to attend funded national events and workshops to inform themselves about the research environment and represent the work of CRP nationwide. Opportunities to take part in national panels and studies are circulated as they occur.

Basic training in research methods and associated topics (e.g. ethics) is provided by the Sheffield Hospitals Trust. They are attended by members of the Panel who feel they need to acquire or update their knowledge. More specific training is provided by our local researchers at special events and quarterly CRP meetings. For example, Professor Angie Cox presented a talk about liquid biopsies and their relevance and benefits to cancer patients.

Good practice in PPI and reporting is circulated wherever appropriate. There is active document exchange informing for example about new reporting methods for PPI i.e. GRIPP2, Tips and Tricks for Researchers, and HMRC Guidance on taxation of reward for PPI volunteers. One member gave a talk to NIHR staff about the value of PPI.

A key tenet of good public and patient involvement is to encourage young researchers in their early careers, and opportunities to conduct focus groups and presentations are offered at each quarterly meeting of the Panel. Focus groups and workshops can also be organised outside the meeting schedule. This opportunity has been taken up on

numerous occasions. This year, the CRP also facilitated two meetings on behalf of researchers.

Jacqui Gath remains a patient advocate member of the Sheffield ECMC Executive Committee and the ECMC Network PPI Working Group, which supports and provides advice to the ECMC Secretariat in the development of a PPI Strategy for the ECMC Network. The working group will share best practice and advice on supporting PPI activities in early phase cancer research. The Secretariat has also set up an advisory PPI panel to offer input to members of the network.

The Panel has links to Independent Cancer Patients' Voice, a similar group with similar expertise, based in London. This gives Sheffield ECMC access to a wider range of input than otherwise would be the case.

Members are actively involved in ECMC trials from concept to patient enrolment. For example, the CARBON and ReSoLuCENT trials benefit from consumers sitting on the Trial Management Group, as do many others. They are also involved in national multicentre trials. There are two consumer representatives on the Sheffield Cancer Clinical Trials Executive, which reviews all possible ECMC studies for scientific interest, assesses the logistics of running the studies in our current trial portfolio, and reviews trial paperwork including patient information sheets.

Plans for the coming year:

- Increase recruitment to the Panel (due to the nature of the illness, numbers have reduced).
- Provide more feedback to the Panel on changes made to studies as a result of PPI.
- Develop a strategy to disseminate our work using social media.
- Develop a simple form of evaluation for when someone leaves the study working team.
- Support application for funding the Panel (funding ceased March 2017).

Southampton ECMC

Southampton: response

The CRPG has continued to provide valuable input into cancer research, the group overarches the ECMC & CRUK Centres and members are from across the Wessex region. Participants bring a raft of expertise and experience from various perspectives, not least being different disease sites. In the last year the group has lost several members through death and poor health & we continue to try to recruit new people, which is a challenge. One of our younger members has been able to return to work and so does not attend meetings but contributes via email.

Meetings usually occur quarterly but due to the loss of so many members last year there was a hiatus of meetings, with activity focussed more on email consultation. Lay members also provide support for other involvement activities, such as the CTU trial review group where their input is an important contribution to the meetings, and they sit on specific trial TMGs: POLERISE and PROCAID being two such examples.

The CRPG support and advise on engagement activities and often attend engagement events such as the hospital open day to publicise the useful work of the group. We try and utilise engagement events as an opportunity to recruit new CRPG members. We had some interest at our Research Cafe engagement event at the CRUK Centre & also at a Macmillan Wellbeing event where we had a research clinical trials stand.

The group is involved in a variety of initiatives including advising on PhD and other research projects, representing patients at conferences & local Centre events and reviewing patient documentation: patient information sheets, consent forms and other study documents such as patient diaries.

We endeavour to invite researchers to report feedback on progression of their trial to the group either by presenting at a meeting or providing a written update.

The group are expectant of being involved by researchers at any stage in the trial process from proposal to dissemination. They also feed in to the ECMC national PPI group via the current CRPG chair, currently a health professional, and a lay member. We hope to have a lay member as CRPG chair this year.

Our CRPG strategy was revised this year with the main aim: To deliver meaningful PPI across Wessex/UHS to support the cancer research pathway in a manner responsive to the evolving nature of the clinical trials landscape and broader PPI development.

As part of our ongoing development of the group we have created new links with Wessex PIN (Public Involvement Network), which will be beneficial to achieving our CRPG strategic outputs of:

- PPI will be integrated into local & regional cancer research strategy, management & projects
- Consumers will have a clear pathway for finding out how they can be involved in influencing research
- Researchers will have a clear pathway for accessing PPI
- Consumers will be supported appropriately to maximise the impact of their involvement

- PPI continued learning & development will be supported through regional & national networking

The CRPG have identified evaluating the value of the group as an objective for the coming year and we will be working on measuring the impact of the CRPG's involvement in the research agenda.

University College London (UCL) ECMC

UCL: response

We have established a joint UCL ECMC - Clinical Research Facility (CRF) PPI panel which represents patients from various functions including cancer, general medicine and neurology. We held a tour of the Facilities for the panel on 22nd June 2017 which involved a guided tour of the CRF, meeting various members of the team where patients had the opportunity to ask questions. We have executed Confidentiality Disclosure Agreements between the panel members and the UCLH Trust to enable them to review study related materials. Our PPI panel member has contributed towards protocol review of a commercial phase I study on the PK sampling as well as reviewing Patient Information Sheets for a phase Ib commercial study.

Our PPI panel has quarterly input into the CRF Cancer Newsletter which is circulated to over 1000 recipients across various Trusts, research organisations and Networks.

We also carry out annual patient experience surveys at the CRF and the recent survey was completed in Feb 2018. A total of 68 patients took part in the survey and provided feedback anonymously. 79% were very satisfied with the service provided, 99% either agreed or strongly agreed that they were well informed by a doctor or nurse about their clinical trial treatment journey in the clinical research facility. 100% agreed that they are likely or highly likely to recommend our CRF to friends and family if they needed similar care or treatment. Patients commented on quicker response to medical concerns and also requested TV facility for the lounge area. These have been prioritised and team is working to meet these objectives as soon as possible. These surveys will be ongoing and form part of our continuous improvement plan for patient experience.

Mekala Gunaratnam has been awarded a BRC PPI starter grant which aims to enable researchers to embed PPI at an early stage in their research, promote PPI that has a demonstrable and meaningful impact on research and improve the quality and effectiveness of PPI activities already taking place. The award will support a project looking at 'Mandating PPI in key areas relevant to experimental cancer medicine – Genomics & patient data access, data security and perceptions of risk and benefits'. As a first step towards this project, a PPI focus group has been established which will have its first face to face meeting on 24th Apr 2018. The project will lead to the development of a questionnaire by the panel and we will carry out a patient survey using this questionnaire at our CRF. The survey will be easy to complete, require minimum time and not impose an inconvenience to the participants, but provide researchers all the information they need. Data from this survey will be analysed by the lead member of the panel and the outcome will be implemented via updated patient leaflet to explain the use of genomics, data sharing and risks/benefits of trial participation. The outcome of this project will have direct consequence on how we will consent patients for future trials, not only at the CRF but also at other Cancer centres across UCLH.

Challenges in PPI:

We have made great progress with our PPI work at UCL ECMC but the degree to which our PPI panel can influence the design of commercial studies is limited. However, our investigators are increasingly taking on the role of National Coordinating Investigator and this will allow PPI input into the patient information sheet and consent forms.

Acronyms in the document

ACF	Academic Clinical Fellowship (NIHR)
BAD	British Association of Dermatologists
BRC	Biomedical Research Centre
CCRCB	Centre for Cancer Research and Cell Biology (Belfast)
CPPG	Cancer Patient Partnership Group (Cambridge)
CRCTU	Cancer Research Clinical Trials Unit
CRF	Clinical Research Facility
CRP	Consumer Research Panel (Yorkshire and Humber)
CRPG	Cancer Research Partnership Group (Southampton)
CRUK	Cancer Research UK
CTEC	Clinical Trials Executive Committee (Glasgow)
DDU	Drug Development Unit (ICR)
EAACI	European Academy of Allergy and Clinical Immunology
ECMC	Experimental Cancer Medicine Centre
EMBL	European Molecular Biology Laboratory
EPCTU	Early Phase Clinical Trial Unit (EPCTU)
GCP	Good Clinical Practice
HRA	Health Research Authority
HSC R&DD	Health and Social Care Research & Development Directorate (Northern Ireland)
ICF	Informed Consent Form
ICR	Institute of Cancer Research
IHTAB	In-House Trials Advisory Board (Glasgow)
KHP	Kings Health Partners
LCTU	Liverpool Clinical Trials Unit
MCRC	Manchester Cancer Research Centre
MHRA	Medicines and Healthcare products Regulatory Agency
MisT	Mesothelioma Stratified Therapy
MRC	Medical Research Council
NCCC	Northern Centre for Cancer Care (Newcastle)
NCRI	National Cancer Research Institute
NIB	Northern Ireland Biobank
NICRCF	Northern Ireland Cancer Research Consumer Forum
NICTN	Northern Ireland Cancer Trials Network
NIHR	National Institute for Health Research
OCR	Oxford Cancer Research
OCTO	Oncology Clinical Trials Office (OCTO)
PAIR	Patients Active in Research committee (Oxford)
PCAG	Patient Carer Advisory Group (Leicester)
PERC	Patient Experience Research Centre (Imperial)
PILAR	West Midlands Public Involvement and Lay Accountability in Research Group
PIS	Patient Information Sheet
PPI/E	Public and Patient Involvement and Engagement (in Northern Ireland it is Personal and Public Involvement)
PROACT	Patient Reported Opinions About Clinical Tolerability
QMTAG	Queen Mary Trial Advisory Group (Barts)
REC	Research Ethics Committee
RM	Royal Marsden Hospital
SELCRP	South East London Consumer Research Panel
TMG	Trial Management Group

UCLH University College London Hospital
WCP Wales Cancer Partnership
WCRC Wales Cancer Research Centre