# Responses to the patient and public involvement question in the ECMC Annual Report Form 2020/21

# Contents

# Background

The Experimental Cancer Medicines 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 £100 million, this infrastructure award supports a network of 18 adult centres of excellence and 11 paediatric locations throughout the UK. By brining together world-class scientific and clinical expertise the ECMC network advances the boundaries of cancer care.

All recipients of 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 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:

| Patient and Public Involvement case study<br>e.g. showcasing patient/public involvement demonstrating the positive impact of involvement improving the quality of research and/or making it more relevant to people's needs. Please outline the value it added to the quality, performance and/or experience of research. INVOLVE definition of what public involvement is/isn't |
|---|

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

# Barts ECMC

PPI Case Study 1: Dr Rowan Miller, in her capacity as a member of the Medical Advisory Board of the Ovacome charity has given several talks over the last year to patients promoting clinical trial research and in particular focusing on the most recent developments in ovarian cancer research and treatment, looking at current focuses and potential future research. Dr Miller's latest talk is available on the Ovacome Charity's YouTube channel (youtu.be/WRwd0o2mI20).

PPI Case Study 2: Prof Powles' The Uromigos podcast continues its success providing scientific updates in the care of patients with genitourinary cancers to patients and healthcare professionals around the world, having reached 66,200 listens. The podcast is available via the Kidney Cancer Association Together Unstoppable page (https://www.kidneycancer.org) with patient representation from all GU cancers (kidney, bladder and renal).

# Belfast ECMC

**The positive impact of the NI Cancer Research Consumer Forum (NICRCF) during the COVID-19 pandemic**

**Background – NICRCF**

The NI Cancer Research Consumer Forum (NICRCF) is a group of around 30 patients/carers affected by cancer. They influence Early Phase Cancer Trials in various ways, working collectively in study review and adoption processes, in advisory sub-groups, or in designated PPI roles across specific studies or research governance e.g., Trial Management Group membership.

Before the COVID-19 pandemic the NICRCF had established quarterly meetings for initiating face-to-face links with researchers as well as conducting other PPI business and training, with further ad hoc meetings with researchers as required alongside on-going e-mail communications.

**Examples of the Positive Impact of the NICRCF**

1. **Advocates for cancer patients' needs when COVID-19 dominated and supporting research activity**

   In March 2020, as the impact of the pandemic became more apparent, Belfast ECMC's Clinical Lead invited NICRCF to give feedback about treatment decisions faced by clinicians and patients. The responses indicated COVID-19 not only raised personal safety concerns but also fears that patients' needs would be side-lined with wider attention on COVID-19 – a scenario the NICRCF considered unacceptable. This advocacy for sustaining cancer services was a message ECMC leadership shared within the region. Concerns were echoed at the first on-line meeting of the NICRCF, July 2020. The call to rapidly address service deficits formed onward communication reinforcing the drive to sustain early phase clinical research activity not only for existing study patients, but to open new studies and swiftly re-open recruitment across the portfolio impacted by the UK-wide pause of recruitment to non-COVID-19 studies. The early phase portfolio started to re-open from June 2020 and patients were keen to take part.

2. **ECMC North Education Event Presentation - Advocates for PPI during the Pandemic**

   The July 2020 NICRCF meeting highlighted how much the process of PPI had changed for members due to the pandemic. Experiences ranged from reduced PPI activity to lots of zoom meetings. These insights triggered the development of the presentation 'Personal Challenges of PPI Reps during COVID times – NI Perspectives' delivered by Margaret Grayson, NICRCF Chair and Ruth Boyd, CRUK Senior Research Nurse/PPI Professional Lead, for the ECMC North Education Event PPI interactive workshop held 19 October 2020. Alongside the presentation and Q&A panel for workshop attendees, a written summary is available on the conference science platform https://osf.io/s5kaf/ .

3. **Sustaining PPI for Early Phase Studies – e.g., SPORT High-Risk Trial**

   The NICRCF and its Prostate Cancer Research PPI Advisory Group have regularly linked with researchers throughout the lifecycle of the SPORT study. During the reporting year members reviewed a Patient Information Sheet designed for existing study patients (now in use) and in March 2020 the Advisory Group (via MS TEAMs)

heard from the Principal Investigator about successful collaboration to develop a national randomised study based on initial results. The enthusiasm and excitement was very evident and both researchers and PPI Representatives are encouraged by these interactions, creating new foundations for future research studies

# Birmingham ECMC

1. The **REPAIR-MDS** phase II trial for low risk myelodysplastic syndrome (MDS) has been developed in active collaboration with patient groups from its initiation. The team worked in partnership with MDS UK (https://mdspatientsupport.org.uk/) who helped to organise patient groups to feedback on the trial design around the country, at the outset of the development of the trial. Sophie Wintrich, CEO of MDS UK, is the PPI representative on the trial monitoring group (TMG) and has been closely involved in producing patient information sheets, reviewing the protocol, preparing for ethics review and helping with patient diaries. She has also been closely involved helping develop quality of life assessments, which are an important part of the end points for the trial.

The study has been developed with the NCRI MDS subgroup of the Haematological Oncology Clinical Studies Group and is funded by Blood Cancer UK. Its Clinical Co-Chief Investigators are ECMC Precision Medicine Lead Dr Manoj Raghavan and Dr Steve Jenkins of the University of Warwick. One of the trial arms (VBaP) has been developed as a result of pre-clinical work by Birmingham researchers Professor Chris Bunce, Dr Farhat Khanim and Professor Mark Drayson. It has now received ethical approval and is opening to recruitment this year.

2. Throughout the last 12 months the ***I***nvolvement and Engagement in ***C***ancer ***R***esearch at ***B***irmingham (ICRB) group has successfully moved to on-line zoom meetings, allowing patients, carers and members of the public to continue to work in collaboration with the Birmingham ECMC. The group have been involved with:

- Discussing the development of a new trial for patients with intracranial germinoma (Dr John Apps) with a CRUK Clinical Trials Fellow at the Cancer Research UK Clinical Trials Unit (CRCTU), University of Birmingham. This involved working with the clinicians to consider views of parents being asked to enter their children into such a trial. Support materials were discussed, along with ways in which to approach this with parents.
- The group worked with the **NOSTRA** trial team to consider ways to present an extra non-therapeutic procedure (study biopsy) within the trial that is currently not recruiting as hoped. Members of the group were able to discuss personal experiences and insights into their decision making process during their cancer journey, to assist the trial management group with considering alternative patient information support material.
- The trial management group for the **De-Iron** trial returned to the group to feedback on the recruitment challenges they encountered, helping to stimulate discussion and learning around trial design. This was an excellent opportunity for both the trial management team and the PPI group to reflect on a clinical trials journey.
- A 1st year Cancer and Genomics PhD student was able to attend the virtual group to ask for insights into a proposed study to ask 'Can we predict which patients with BRAF-mutated colorectal cancer will benefit from the new treatment?'. This proved to be a valuable opportunity for the ICRB group to learn about BRAF mutated cancers and consider wider expectations of patients being offered personalised medicine. However, it was also valuable for the student who had

produced a lay summary and presentation to share with the group and was presented with an opportunity to talk openly to patients and carers about attitudes around experimental cancer trials.

- A member of the ICRB group worked with the CRUK Senior Research Nurse to collaborate with a large international clinical team, to develop an expression of interest for a CRUK Grand Challenge submission. The patient representative was able to provide unique insight and perspective into areas to consider and develop into a larger PPIE plan, should the group be successful moving to the next round.

3. The ECMC is working closely with the CRUK Birmingham Centre and the CRCTU, to develop an ambitious Patient and Public Involvement and Engagement strategy for cancer at Birmingham. A monthly taskforce has been meeting since October 2020 and will continue until summer 2021, to shape the strategy for broader consultation. One of the key aims of this strategy will be to increase the levels of trust with the Birmingham patient and public community with ongoing involvement and engagement.

- This strategy will also link into a broader piece of work related to equality and diversity in trial recruitment. Birmingham and its local region have a broad range of ethnicity and are uniquely placed to answer some of these questions, ultimately looking to ensure that our clinical trials have a breadth of ethnicity that is more representative of our national demographic

# Cambridge ECMC

In the last year, the Cambridge Experimental Cancer Medicine PPI group has maintained its membership at 16 members, has successfully transitioned virtual meetings (due to the COVID pandemic), held six virtual review meetings, and been involved with reviewing nine research projects; including a COVID urgent review project, supported by the CCTU-Cancer Theme. We have promoted the group within the scientific community in Cambridge, this is reflected in the variety of projects that we have received, the increased quantity, and the referrals we have had from one researcher to another.

The Cambridge ECMC where unable to hold their annual ECMC open day in 2020 due to social distancing requirements in the Covid-19 pandemic. For 2021, this event will be held virtually. This will both allow the event to go ahead, and give the opportunity to expand our audience to more than just those who are able to physically attend.

Case study #1: Amongst the reviews carried out by the group this year, there was an approach to the group relating to a study that received initial feedback from the NIHR that the application and study information wasn't sufficiently accessible to patients, and did not adequately include lay explanations.
As a result, the ECMC PPI group was asked to review the patient facing information for this study before re-submission. The group made significant comments on both wording and study procedures. These recommendations were accepted by the study team and were incorporated into the resubmission and trial related materials changed. These resulted in the study being of a better quality and will improve the patient experience.
The ECMC group also went beyond this and suggested that one of them join the Trial Steering Committee (TSC). This offer was welcomed by the investigators, and the TSC now has much stronger patient representation.
This experience has also strengthened processes in the CCTU-Cancer Theme, to ensure PPI review of all study plans/protocols, prior to grant submission and encouragement to Chief Investigators to include PPI representation on TSCs.

Case study #2: A second case relates to the positive impact the Cambridge ECMC PPI group have had through their work on the COMET20 research study. Whilst this was not a study which would normally fall into the remit of our group, when presented with the opportunity they were all incredibly keen to take part. The time sensitive nature of this research meant there was a very short window for PPI involvement, however both the researchers and the group felt that PPI could make a positive impact on study design and patient accessibility.
To ensure we could comply with timelines, we set up a virtual meeting to discuss the study and the group's thoughts on it in real time with the researchers. This was particularly effective, and changes could be discussed and implemented in real time. The researchers fed back that it was incredibly helpful to them to have this kind of patient input, especially when considering a population of patients who might be facing negative outcomes.

# Cardiff ECMC

**Rapid Response Group**
Recruitment of a Rapid Response Group of lay Research Partners who are willing to respond quickly to requests from researchers who need public/patient involvement for funding applications with imminent funding deadlines.

Funders often require evidence of public involvement in the preparation of research bids. Help is available through the Health and Care Research Wales Enabling Involvement Fund but application through the standard process can take several weeks which means that help often cannot be provided quickly enough to meet funding application deadlines.

The PPI team are working together with the Health and Care Research Wales Support Centre and have recruited a group of ten patients/members of the public with experience of cancer who can respond quickly to adverts. The PPI team notify the group as soon as the advert is placed, which enables a very short deadline to be applied, usually a few days. Having such a group increases the support offered to researchers in these situations and also helps to increase the diversity of the help offered both in terms of cancer experience and background of the public involved.

Researchers will benefit in having PPI input at the pre-funded stage which will improve the quality of their funding application, and therefore their chances of success.

This group was set up in March 2021 and has ***already managed to provide help to a researcher with a second stage funding application for an NIHR HTA award*** which had reviewer feedback suggesting that further PPI help was needed. Three expressions of support were obtained from our group within nine days of the request being received.

*The PPI Project Officer, who is part-funded by ECMC, has supported the setting up and running of this service and without them it would not be possible to provide this help for researchers.*

# Edinburgh ECMC

A) Feasibility study of engagement with lung cancer screening

Prof David Weller has secured a CSO Health Improvement, Protection and Services Research Committee Grant to lead a feasibility study into lung cancer screening, exploring how best to select and invite people to screening. Whilst other projects have looked at pilots of deliverability and utility, screening programmes cannot deliver on their potential without ensuring that they engage the 'right' individuals, examining access and rurality, and measuring impact on health disparities. The project is, at its core, one of patient/public involvement in how to most effectively engage those individuals at highest risk, across all social, cultural and geographic group. The design and conduct of the trial is guided by a Patient Advisory Group made up of the SCAN Consumer Group, the Roy Castle Lung Cancer Foundation, and the British Lung Foundation and a major focus is semi-structured interviews with screening invitees on their reasons for responding (or not responding) to the screening call. This integral patient involvement will seek information on identifiable, social, cultural, logistical or other barriers, while also seeking views on the recruitment approach/materials and how they might be improved. The study has received CSO funding and is progressing to set-up.

B) Access to trials

Although not a case study of patient involvement in research conduct and delivery, patient involvement in trial participation raises questions about how to improve equity of access to trials. In Scotland, a key factor is geography, in terms of catchment areas for tertial referral centres as well as which centres run early phase trials.

For the former, Edinburgh, in its role as a South East Scotland Regional Service, has been investing in expansion of trials activity at district general hospitals in Livingston, Dumfries, the Borders and Fife. Livingston has seen the appointment of a dedicated trials nurse and has now been able to open a number of trials, include its first early phase trial.

For the latter, Glasgow and Edinburgh are coordinating a joint service for Phase I trials to serve the whole of Scotland. This is described further in the collaboration case study below. As part of this, patients' referral wishes with respect to other Scottish and UK centres is being explored to understand how we can best offer access to molecularly-selected trials that are not viable to run at every centre.

A related aspect is equity of representation in the research datasets that lead to the development of the next generations of treatments. This is linked with equity of opportunities to participate in such translational research and, as Dr Andy Sims and Dr Jonine Figueroa have demonstrated, the quality and quantity of truly diverse and representative datasets remains limited (https://www.ed.ac.uk/institute-genetics-cancer/news-and-events/news-2020/need-to-derive-more-representative-and-annotated-m).

C) Patient engagement and involvement

Lastly, I wanted to acknowledge that it is not unusual for patient/public representatives to be involved in research themselves and that there is one such researcher who has made a huge contribution in Edinburgh over the last year. Dr Andy Sims sadly passed away of melanoma in May 2021. His own research field was in the bioinformatics of breast cancer (e.g. case study B above) but, throughout the ups and downs of his melanoma treatment, he was also highly engaged in education and research around melanoma, supporting and advising local research and giving a exceptional talk to our research community on world cancer day 4/2/21 where he presented his experiences and perspectives as both a patient as a researcher.

# Glasgow ECMC

The PPI and PPI Oversight Groups are key components of Glasgow's ECMC activity and consumer representatives are involved across our ECMC translational and clinical programmes. All PPI colleagues have membership of the PPI Group which offers support, mentoring, and development programmes. Six colleagues have membership of the PPI Oversight Group,
During the past 12 months a new PPI strategy has been developed and is now being fully implemented in 2021. One of the innovations has been the establishment of the PPI Oversight Group, the purpose of which is to oversee and to ensure the quality of PPI work. This group is led and managed by PPI members.

Our PPI involvement includes representation on:

- The ECMC Steering Committee which has oversight of all of our ECMC activities and strategy [J Fell].
- IHTAB (In-House Trials Advisory Board) which 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). [E Banks, G Dickie, F Milligan]
- CTEC (Clinical Trials Executive Committee) which 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). [E Banks]
- The UTSC (Umbrella Trials Steering Committee) which has oversight of the CR-UK Clinical Trials Unit's studies including many of those within the ECMC Combinations Alliance or other industry collaborations that are led from Glasgow. [E Banks]

Through membership of these committees, our consumers are involved in assessing and developing the ECMC strategy and shaping research questions for specific projects, reviewing clinical and translational research protocols, and reviewing the SOPs of the Clinical Trials Unit and Clinical Research Unit.

PPI members are co-applicants and TMG members in respect of a number of early phase clinical trials both in Glasgow and across the UK and their input at each stage of the trial process is valued and recognised by the various teams.

The skills and experience gained through involvement in the Glasgow ECMC results in many requests from the CRUK Glasgow Centre, other organisations, charities and universities to support clinical trials, CRUK Accelerators, providing insight and experience of the benefits of effective PPI in moving forward. These include CRUK, NCRI, ICPV, etc. These requests range from a CRUK Grand Challenge Initiative, reviewing patient facing documents and supporting PPI Groups elsewhere in the UK. Colleagues have provided

patient/consumer input and review at various UK Guidance Proposal meetings in respect of clinical trials that are at an early stage of development.

In relation to broader ECMC participation, E Banks is the patient representative on the ECMC Network Steering Committee. This role includes providing a lay perspective on operational and strategic issues. She is also a member of the ECMC PPI Steering Group. In addition she has contributed to the Future Network Strategy Insight Gathering Session of the ECMC Network PPI Group and more recently to the ECMC Future Network Strategy Workshop.

A Boyle was invited to speak at the 2021 ECMC Junior Investigator Network Group event.

Case Study 2
Online Course. Research Impact: Making a difference
https://www.futurelearn.com/admin/courses/research-impact/7
The development of this online course was led by University of Glasgow (Institute of Cancer Sciences, including ECMC co-investigators) staff and teaches how to identify and evidence research impact. The course has run 7 times since 2018 (including September 2020) with over 4,000 learners taking part. Learners come from across the globe with around 30% from low & middle-income countries. Our PPI representative Elspeth Banks teaches on this course. This places PPI views and role with equal prominence as all other contributors from industry, NHS, Academia and public sector organizations

# Imperial ECMC

To enable discussions around personalised medicine and what it means to individuals and their care, our CRUK Nurse worked with Imperial Patient Experience Research Centre on a project researching the impact of personalisation on cancer care.

As part of this project, a poetry launch took place on November 11th on Zoom which hosted over eighty participants.

Imperial Science Café: Written Portraits People Like You November 2020
https://www.youtube.com/watch?v=hT-P7Kg9Aws

During this event the process of written portraits was explained, and the experience of patients and staff as 'sitters' was explored. The written portraits have been published in a book of poems. Recordings of all poems can be found on the People Like You website.

People Like You https://peoplelikeyou.ac.uk/

The Imperial Public Involvement Group for Cancer supported over sixty research projects by contributing to grant applications, reviewing lay summaries and trial documentation, participating in focus groups and sitting on study committees.

During Covid, the Imperial Science Cafe was moved online. Five cafes were successfully delivered this year to an audience of 25-80 people. Audiences consisted of patients, members of the public, both NHs and College staff. An evaluation of the Imperial Science Café platform was presented by the CRUK Nurse at UKONS 2020.

Imperial Science Café: Transforming Data, Transforming Care
https://www.youtube.com/watch?v=4XF_SnN8Lsw
Imperial Science Café: Lighting the way to better breast cancer surgery?
https://www.youtube.com/watch?v=2lvIHY3d7cI
Imperial Science Cafe: Functional Outcomes in Breast Surgery
https://www.youtube.com/watch?v=sZBox_0v69Y

Three bespoke Public Involvement teaching workshops were delivered to PhD students which included the CRUK Accelerator Award students as well as Imperial and ICR convergent science students.

A new feedback wall for involving the public during engagement activities was evaluated. The video and blog of the project can be found here:
Video https://www.youtube.com/watch?v=LdxCnQWgwHU
Blog https://blogs.imperial.ac.uk/perc/2020/07/14/feedback-wall-a-patients-question-inspires-art-and-science/

Case study: Our ECMC previously piloted the use of pembrolizumab immunotherapy for gestational trophoblastic cancers and demonstrated that this could save the lives of 75% of patients otherwise expected to die from their disease (Ghorani, Seckl Lancet 2017).

This was practice changing both nationally with NHS approved funding and globally. Interestingly, unlike other cancers such as lung and melanoma where pembrolizumab continues for 2 years, we were able to show that just 6 months of immunotherapy was sufficient. This led us to hypothesize that stopping pembrolizumab earlier in lung cancer might also be appropriate saving money, reducing toxicity and improving quality of life. However, a prior underpowered pharma trial of less than 100 patients in each arm suggested that stopping a similar immunotherapy at 1 year increased the risk of relapse and reduced survival. Moreover, our PPI group indicated that patients would not be willing to enter such a trial. Therefore, we developed a reduced frequency study in which after 6 months of standard 6 weekly pembrolizumab, patients would be randomized to continue or receive reduced frequency treatments given 9, 12, 15 or 18 weekly. This was presented to our Science Café where the PPI group felt it was important that patients who progressed on a reduced frequency arm were offered re-escalation to standard 6-weekly dosing. This along with a number of other key PPI-lead suggestions were incorporated into the trial design. PPI also played a central role in the patient information leaflets, our lay abstract and two individuals were appointed to serve on our trial management group. As a consequence of this engagement we have just been awarded £3.15M from NIHR HTA (Seckl) to run this novel phase 3 trial in lung cancer (REFINE-lung). This study will potentially save many tens to hundreds of millions of pounds annually and improve quality of life through reduced hospital visits and toxicity

# Institute of Cancer Research (ICR) ECMC

CASE STUDY 1

Case summary

ECMC funded staff within the DDU have developed a protocol of a randomised control trial which will run concurrently with our early phase clinical trials. This study has received HRA approval and is now open to recruitment. The aim of the study is to compare current standard provision of patient information about the trials with enhanced materials of an extra trial synopsis and ten information videos designed and produced by staff and patients. This research protocol was developed from the findings of the previous years' experience-based co-design project exploring gaps in understanding and provision of information for our patients considering early phase trials.

Level of PPI/E

The foundations of this work and protocol development had a significant amount of patient Involvement and some co-production work with a named patient representative acting as a co-researcher conducting data collection in the forms of interviews. The themes for the videos were developed using patient focus groups and one to one interviews. The focus groups helped to identify where the gaps in understanding were for our patients and what would be useful to have in the form of a video to enhance provision of information. One video is of a patient's experience of a Phase I trial and is written and narrated by a patient.

Impact

The impact of the earlier foundation work was recorded via a researcher impact form. Clear input was visible in terms of patient involvement contribution including development of the themes for the videos, identifying common gaps in understanding for our patients, offering a patient's perspective on the informed consent consultation. These impacts were recorded qualitatively. The impact of this research study will also be demonstrated using the methods used in the data collection; this study utilises a validated quality of informed consent tool to measure improved Phase 1 trial understanding and experience with the enhanced materials. This will provide a quantitative measure of impact of the newly designed information.

*CASE STUDY 2*

Case summary

As part of the programme of research to improve information and the informed consent process a second research study was designed and has been conducted by the staff in this unit. This study again using patient focus groups and interviews to identify unmet information needs within the actual informed consent consultation. Based on this a Phase I specific Question Prompt List (QPL) was developed and piloted in 13 patients, the experience of its use was evaluated via patients interviews and analysis of the narratives.

Level of PPI

PPI was conducted at the design stage of the Question prompt list (QPL). Using the findings from the experience-based co-design project, the questions were developed, and feedback sought from the focus groups on whether they were useful and the likelihood of using the QPL. The study was also presented to the Royal Marsden Patient and Carer Research Review panel for consultation on protocol and all patient facing documents.

Impact

The development of this tool with patient involvement has the potential be significant. This research study's findings showed that people who used the tool in the consultation found it provided added value to the experience in terms of subject understanding of early clinical trials. It also enabled patients to feel empowered to raise concerns with their clinicians. The plan is to further evaluate the use of this tool quantitively. Once the tool is further refined it will be made available to other ECMC centres in the network.

# King's Health Partners (KHP) ECMC

**South East London Consumer Research Panel (SELCRP) for Cancer**
Since the pandemic, the South East London Consumer Research Panel (SELCRP) has continued to meet remotely on a monthly basis, via the Zoom platform. The membership comprises patients, carers, clinical, non-clinical and academic staff (including research nurses), and is co-chaired by two members of the Panel. This continues to work very well and has given our researchers across the KHP Cancer community the opportunity to present and discuss their studies, research proposals, protocols and patient information materialsthroughout the year, prior to the ethics submission.

The overall goal of the Panel is to advocate for reflection of the needs and priorities of the trial participants in all our research. Subjects reviewed in this forum have ranged across a diversity of topics including 'A COVID model to predict healthcare needs and provide additional resources in times of crisis', 'New antibody trials in solid tumour oncology', 'People Living With and Beyond Cancer & the COVID-19 Crisis: Their Contextual and Deeper Experiences (D-CODERS)', and 'Identifying how COVID-19 may affect the treatment of people with cancer and how to best provide guidance and clinical support'.

Several other research groups across King's Health Partners have used SELCRP as an exemplar when planning their own PPI group, utilising the experience and knowledge of the group to support the set-up and management of their group. SELCRP has also been able to advise these newer groups on study design, dissemination strategies, and how best to recruit trial participants.
SELCRP has supported the School for Biomedical Engineering & Imaging Sciences at King's over the past year, by sharing opportunities for online PPI advice with their School Faculty and students. In March 2021, Master's students (5 groups of 3 students) from the School's MSc in Healthcare Technologies course presented their public engagement activity ideas to SELCRP members through bespoke meetings. The meeting was facilitated by our ECMC leadership. The panel provided critical feedback and consultation to ensure the projects reviewed were optimized to benefit those living with cancer. This consultation exercise formed part of the students' formal assessment.

SELCRP has also been a valuable resource to the Translational Oncology and Urology Research (TOUR) team at in our Cancer Centre and to several of their collaborators, including the ReIMAGINE Consortium at University College London. Colleagues have presented to the group on several occasions with various research proposals and the input has been invaluable in providing insight into patient/participant preferences with respect to design and management, data collection, and dissemination of findings. Through SELCRP's participation in interviews and pilot questionnaires the TOUR team has been able to ensure that the needs and priorities of the patients/participants are reflected in their research. In addition to this broader advice, the group have reviewed lay summaries and other patient-facing documents which ensured that information is relevant and accessible.

## Leicester ECMC

Throughout the year, we have continued to work closely with our Patient and Carers' Advisory Group largely by virtual means. The group have contributed significantly to study work-up, assessing study rationale and the suitability of Patient Information Leaflets and Consent forms. The group have fed back to presenting clinicians and researchers enabling them to make more patient-centric REC and local ethics submissions. Over this period, the group has made significant contributions to 6 new studies which have now had the green light to commence.

A further key contribution from the group has been their advice and advocacy around the significant £1.5M capital build expansion of our Hope Clinical Trials Facility. Extensive building and refurbishment works have been ongoing during the course of the pandemic, requiring multiple moves to ensure continuity in patient care. We have worked with the group for their ideas and feedback on how to minimise the effects of disruption for those patients attending in-person visits throughout the pandemic. Introductory welcome packs have been designed for patients, giving extensive signposting around the trials pathway and enabling them to better manage their expectations and understanding.

An unplanned public involvement success has been patients witnessing many of the Hope staff taking part in the Covid Siren study. Patients really supported the commitment of the staff to deliver as well as participate in research. This was well publicised locally and once again raised the profile of taking part in research to the public " "Within an hour, most nurses, who haven't taken a day off during the pandemic, had signed up and half an hour later were taking blood from one another," he said. "The joke going round the ward was 'You know how I feel now'…..They deserve all the praise going. It was quite a humbling experience to see those who are already taking care of people on the front line are also volunteering for the good of the people. It's incredible, it brightened my day." https://www.leicestermercury.co.uk/news/leicester-news/leicester-hospitals-coronavirus-immunity-study-4389893

# Liverpool ECMC

1. Collaboration with VANN – Improving and Enhancing Patient Reported Outcome Measures

Following introduction by the Programme Office, the Liverpool ECMC has entered into a collaboration with VANN, a company focussed on development of digital health technology. VANN was founded by a cancer patient and the technology places the patient journey at the centre of the research.

VANN has previously developed a prototype app to capture data from cancer patients regarding their health in between treatment visits. The aims of this are to improve monitoring of cancer patients, increase communication between patients and clinicians and to capture real world evidence to be used in cancer and drug discovery research.

The Liverpool ECMC team have provided support from both a clinical and operational perspective to develop a local pilot study to trial the app and planned web-based platform. Clinical and scientific insight has been provided by Prof Palmer and Prof Greenhalf to inform decisions on important data to be captured.

Operationally, the study set-up team have provided guidance and expertise on the pilot study design including statistical review and advice for study management including regulatory, legal (e.g. GDPR) and ethical requirements.

VANN have formed part of a collaboration led by the Liverpool ECMC focused on AI-assisted ecosystem modelling of cachexia based on immune response, microbiome, metabolome and metagenomics. Use of technology developed by VANN is proposed to collect self-reported adverse events to therapy, compliance to therapeutic schedules and lifestyle data.

It is envisaged that collaboration on this technology will lead to improved capture of patient reported outcomes in early phase cancer trials.

2. Impact of Follicular Lymphoma Treatment on Response to COVID-19 Vaccines

Patients with follicular lymphoma (FL) have driven the development of a study to investigate how their cancer impacts upon the efficacy and side effects of the COVID-19 vaccines. This is, in general, a significant concern for patients on clinical trials. Two patients in particular have contributed to the design and development of this study and remain active members of the study management team.
New COVID-19 vaccines from Pfizer and Oxford/Astra Zeneca are reporting high immunogenicity and efficacy in clinical trials, but there is a lack of information regarding how well people with different forms of blood cancer respond to these vaccines and to what extent (and for how long) vaccine responses are influenced by specific anti-cancer treatments. This knowledge gap is particularly relevant to people with follicular lymphoma owing to the need to make difficult therapeutic decisions involving drugs that can improve long-term disease control but also induce prolonged immune defects with the potential to impact on COVID-19 outcomes and vaccine responses.

The ongoing NCRI PETReA trial provides a unique and timely opportunity to investigate humoral and cellular immune responses to COVID-19 vaccination in people with FL receiving first-line treatment with drugs that are known to cause prolonged depletion of B cells (rituximab) or T cells (bendamustine) or activate T cells and NK cells (lenalidomide). Specifically, vaccine responses are being compared between patients receiving bendamustine versus other induction regimens, low-risk patients randomised to post-induction rituximab maintenance versus no further treatment, and high-risk patients randomised to rituximab maintenance with or without lenalidomide.
By combining the information from the COVID-19 sub-study with our evolving understanding of which types of vaccine responses are most important in conferring long-term clinical protection against COVID-19, the study should help people with FL to make better informed decisions about induction and maintenance options, while it should give those patients who have already completed treatment a better idea of how much protection to expect and what additional precautions might be required (e.g. preventative pharmacological agents).
Funded by the COVID-19 National Core Studies Immunity programme and Blood Cancer UK, the sub-study is being co-ordinated via the Liverpool ECMC GCPLab Facility and Liverpool Clinical Trials Centre. Sample analysis is being shared between Liverpool (L Turtle, D Naisbitt) and Oxford (S Dunachie, E Barnes, P Klenerman, D Eyres) and aligns with other studies examining COVID-19 vaccine responses in healthy (PITCH) and diseased (OCTAVE) individuals. Clinical oversight is provided by the PETReA Chief Investigator (A Pettitt, Liverpool) as well as two PETReA sub-investigators (T Eyre, Oxford; J Okosun, Barts).

3. <u>Finding My Way UK</u>

The 'Finding My Way' study is a collaboration between the Liverpool Experimental Cancer Medicine Centre and the University of Chester. The study will pilot the use of a web based programme to help patients cope better with the consequences of their cancer treatment, including patients in early phase clinical trials. The online programme is a six week course broken down into 6 modules: (1) treatment and communication with treatment teams; (2) coping with physical symptoms and side effects; (3) managing distress; (4) challenges to identity, body image and sexuality; (5) social and family concerns; and, (6) issues that arise after treatment.
Prior to the study being designed, the Liverpool ECMC facilitated 2 patient workshops to review the intervention and provide input on usability and suggested intervention improvement. These workshops were well attended with >10 patients per session. Significant changes were made to the programme based on the feedback.
Further to the workshops, cancer survivors were directly involved in the development and subsequent improvements to the intervention and adapting the content for use in the UK including video recorded interviewees to generate web-content. The study has established a public engagement arm of the Study Steering Group, which includes cancer survivors, carers and family members who are supporting wider aspects of patient involvement throughout the project and dissemination. This includes input into the quarterly newsletters to participants and collaborators.
The study is open to recruitment and at the time of reporting has 12 patients enrolled.

## Manchester ECMC

**Case study 1. Establishing a Christie early phase trials PPIE group.**

Patient and public involvement and engagement (PPIE) is an integral part of the development of research projects and Manchester ECMC makes continuous efforts to involve people affected by cancer in the design and conduct of their clinical trials. Historically, patient groups were accessed via collaborations with the wider network of patient groups e.g. BRC. However, The Christie Clinical Trials Patient and Public Involvement (PPIE) Group was established in November 2020. This group of patients and carers affected by cancer share the same motivation and belief that cancer research can make a positive difference to patients and their families. The aim is to contribute in the improvement of the quality of research at The Christie and to influence research by making it more relevant to people affected by cancer (patients and carers).

This group of six dedicated PPIE representatives meets monthly via MS Teams. Involving patients and carers in the review of study related documents and engagement strategy has been integral to the early activities of the group. Examples include:

- CONNECT Study - COvid-19 aNd TechNology - thE impact on Clinical Trial patients. The group reviewed the patient questionnaires and patient information sheet and informed consent form for the focus group, for clarity and understanding. The study has now received regulatory approvals. Patient input has ensured documents are accessible, facilitating inclusion into the study as well as a direct impact on the outputs of the study by enabling a better understanding of what patients are being asked for within the questionnaires.
- Review of study questionnaires to be used by the nurses/investigators in assessing dysgeusia. One of the identified adverse events of a drug currently in a phase 1 study is dysgeusia. The group's perspectives helped to ensure the sponsor questionnaire will capture correct information and to improve the quality of research.

Future strategy and potential impact:

Going forward, the aim is to welcome new members with representation from different backgrounds including underrepresented Black, Asian and minority ethnic (BAME) groups to support the growing portfolio of research, intensive nature of early phase trials and to promote holistic care to all our trial patients here at The Christie. Opinions back from this group about what is important for them are the following:

- All patients should have equal opportunity to access clinical trials
- Clarity around paper work – patient information sheet and consent forms
- Embrace IT and Innovation

The PPIE representatives' insights on issues such as patient recruitment and safety can be harnessed to influence our development of research design, and user-friendly patient-facing documents. Ultimately, the goal is to improve our approach to treatment and care of cancer patients. This will improve the efficiency of our cancer clinical trial treatment delivery service and identify gaps in access. These changes can stimulate an increase in patient engagement and ultimately participation in clinical trials through increasing accessibly and through removing barriers.

Case study 2. Manchester investigators prioritise patient involvement in the development of new investigator led studies – DETERMINE*, TARGET National** and CUP-COMP*** as exemplars.

The Manchester led **DETERMINE** study will enable patients with rare tumours to access targeted therapies outside of their licence, where they have the specific genetic mutation that particular drug targets. The DETERMINE team has ensured that meaningful involvement of patients take place throughout the whole research cycle, from protocol design to the delivery of the trial and subsequent dissemination of research results.

Various patient groups were run during the early planning phases of the clinical trial, including individual conversations, surveys and focus groups, encompassing teenagers and young adults, ethnic minorities, and parents of children with cancer. Together input from these sessions helped shape the grant application that was presented to, and endorsed by, the CRUK Clinical Research Committee at the beginning of 2021. The organisations that contributed to DETERMINE included Cancer52, Voice up!, Independent Cancer Patient Voice, the Paediatric Oncology Reference team (PORT) and the Black and Minority Ethnic Research Advisory Group (BRAG). Patient feedback, which has been incorporated into the study planning and design, include the development of a study website to disseminate study findings and the creation of a multimedia patient information sheet. Study documentation such as the protocol and the informed consent documents have also been discussed and reviewed by patients to ensure inclusion of appropriate patient reported outcomes and to make sure that information is presented clearly and can be easily understood by every patient.

As with DETERMINE, the Manchester led **TARGET National** study (CI: Krebs; (NCT number: NCT04723316, link) utilised feedback from patients to obtain insight into public views and opinion. The participant information sheet (PIS) based on the original TARGET version was reviewed and commended by Independent Cancer Patient Voice (ICPV). This work has ensured that TARGET National has been developed with the patient perspective firmly in mind. Finally, **CUP-COMP** (CI: Cook; NCT number: NCT04750109, link) involved patient representatives from the CUP Foundation – Jo's Friends in the trial design and documentation review. The development of the research protocol and patient information documents was carried out in collaboration with The CUP Foundation.

PPIE does not stop once a study is approved - two patient representatives have been recruited to the DETERMINE Trial Steering Committee to ensure the participants' experiences, views and preferences are taken into account. A patient representative has been recruited from ICPV who will be involved in any future work on patient facing documentation and will sit on the TARGET National steering board to provide input into important study decisions from a patient perspective.

ECMC support has been instrumental to enable the design and implementation of the PPIE activities outlined above. It is anticipated these will have a substantial impact on the recruitment figures, increasing number of patients who are often underrepresented in clinical research and also on the patient awareness and understanding of this highly challenging precision medicine study.

*Advancing Genomically matched treatments in rare cancers

** Tumour Characterisation to Guide Experimental Targeted Therapy - National Expansion

*** Carcinoma of Unknown Primary (CUP): A comparison across tissue and liquid biomarkers

# Newcastle ECMC

**Electronic Consent to support social distance during the pandemic**

At the start of the first COVID-19 lockdown last year to support social distancing within our research centre and working with our patient and public involvement (PPI) group, the 'Perspectives in Cancer Research', we looked at how we could modify patient visits to reduce the time they needed to be in the clinic. Together we recognised that in some of our research studies patients were coming in to give consent only to allow us access to their tumor blocks; samples that had already been taken and stored within NHS. Gaining access to these samples allows researchers the opportunity to analyse the samples and test them for genetic changes. Importantly we can also use this information to find out if patients are eligible for larger scale clinical trials, which would potentially give them access to additional treatments for their cancer stratified by gene changes found in their cancer cells.

We felt that in the current circumstances we could take this process virtually to improve social distancing in our department and so started a PPI co-designed project. After conducting legal checks with the Health Research Authority, involving ethics committee members in the project, and doing test-runs with our PPI group, we developed a patient centred electronic consent process. The approach to this project ensured that the patient voice was at the centre of this work, as we felt it should be, and allowed patient feedback at every stage of development in this project to produce a new patient friendly method of allowing patients to discuss and consent to taking part in clinical research.

Patient feedback on this project has indicated that this new method of discussion and consent was very user friendly and that it dramatically reduced patient travel time to appointments and increased accessibility. A real positive feature of electronic consent feedback was that patients could invite members of their family from anywhere in the world to take part in these discussions to support them making the decision to participate in research.

This novel method of working is now fully integrated within our translational research work. Going forward we have seen the benefits of utilising this technology and hope to develop a means of merging both face to face research consultations with virtual ones, in order to allow patients to have family members based in other regions of country/world to be part of this process to improve the future informed consent process.

This work is additionally being used to develop a national initiative for cancer centres across the UK through the CRUK Senior Research Nurse and ECMC Nurse steering group networks. Our CRUK senior nurse is submitting a grant application for a nurse-led improvement project in digital health through Burdett Trust for nursing. If successful this will see Newcastle ECMC be the lead site on developing and delivering a national educational conference and e-learning resource built upon this patient co-designed work. This project will share the practices and learning gained from this work nationally, offering resources to other health professional across the ECMC network to support them in delivering electronic consent in their areas of care

# Oxford ECMC

## Oxford: response

**Examples of work that the Oxford Cancer Research Patient and Public advisory group have been involved in and how they have contributed.**

Formed one year ago, a panel consisting of 11 lay members and a senior cancer research nurse, the Oxford Cancer Research Patient and Public advisory group review research projects/summaries/submissions, for clinicians and academics locally and nationally. The group have provided input into projects across a diverse spectrum from small local projects, to participation in national initiatives. Some examples are given below.

**4 year NIHR Project: The aim of the project is to use cancer data and innovative analytical approaches to inform how the National Health Service (NHS) should consider organising specialist surgical, radiotherapy and chemotherapy services. Specifically, to understand the trade-offs between travel time, equity and patient outcomes when considering different designs of the health service.** Following individual applications, two patients from the Oxford PPI group were chosen to sit on the national committee (a total of 8 patient reps were required) and are providing ongoing feedback and support for the duration of the project. A generic invitation received from NIHR project leads to PPI group leads, to seek out interested individuals to give patient perspective. The cancer types for investigation include: Bowel, Breast, Prostate and Oesophageal cancer. From the patients' perspectives, the study will investigate whether specific patient groups (e.g. lower socioeconomic groups) with different types of cancer, and requiring diverse treatments travel further for care than others, and what hospital factors drive this decision. Understanding how different patient groups respond to the current service will inform service re-design to minimise inequalities and improve outcomes.

**Sandie Wellman: Exploring lay opinions on research strategy in Oxford. Presentation to group with feedback given at one of the regular meetings, to inform transformation project.**

Commissioned to explore research delivery for the Oxford Cancer and Haematology directorate, the importance of this project was highlighted due to the Thames Valley and West Midlands research networks currently in last position for numbers of patients recruited to clinical trials compared to the Cancer Research Networks across the country.

Sandie requested views from the group on what should be included, how they would choose what aspects to focus on when there are limited resources available.

The main themes emerging highlighted the importance of "research being seen as part of 'standard care' in an organisation where so much research takes place" and how important it is to "introduce research early to patients and families as part of a comprehensive pathway." Feedback from the PPI group was presented to the transformation committee as part of the final report and will inform on-going strategy in the Trust.

Sandie will to continue to link in with the group as the project progresses to get further input from members. There is currently minimal involvement from PPI in deciding which trials are going to be supported and Sandie has further questions she would like to ask in order to support the strategy going forward.

# Sheffield ECMC

**Overview:** CARBON is a randomised phase IB/IIA study of CApecitabine plus Radium-223 (Xofigo™) in breast cancer patients with BONe metastases (CARBON) conducted under the aegis of Professor Rob Coleman. The patient population is breast cancer patients with bone metastases who have received less than 2 lines of chemotherapy in the metastatic setting. The aim of the initial safety phase of the study is to investigate the side effects of capecitabine when used with Radium-223. The main aim of the following extension phase is to evaluate the frequency of side effects and to investigate whether the treatment causes a reduction in bone resorption (the process of breaking down bone) which is caused by the cancer.

**The study:** In 2015, two PPI members of the Yorkshire and Humber Consumer Research Panel (YHCRP) volunteered to provide PPI. They were involved from the start of the project, and were supplied with agreed terms of reference and description of the role. Both members of the PPI team are members of the TMG and safety committee.

As the trial progressed, the PPI team signed a non-restrictive confidentiality agreement alongside the Terms of Reference, reviewed the protocol, and all patient related documents. The patient information sheet was emailed to all members of YHCRP for comment. Many of the suggested changes were adopted and implemented.

The question of patients being radioactive after being given radium-223 was of particular interest. For example, when travelling, it is possible that highly sensitive security devices could detect the radio-activity and create an alert, leading to a security situation. An agreed protocol was designed for this situation, and the patient-ID card amended for the patient to carry, advising that the patient had radium-223, with contact details of a radio-pharmacist.

The PPI team took the lead on the need to inform patients that there was a possibility that in the case of their demise after receiving radium-223, cremation would need to be delayed. This is to protect workers at crematoria from possible contact with radio-active dust. We found (in 2016) that the UK had no national guidelines for cremation of a person having taken a radio-active drug, whereas Western Australia have very clear instructions. As the possibility of delay could cause distress to relatives, a suitable form of words was agreed and the information put into the PIS.

The radioactivity aspect provides clear examples of how being 'upfront' about a difficult issue would increase a patient's confidence in undertaking a trial.

Recruitment opened in September 2016. As the trial progressed PPI were involved in discussion about 'thank you' cards for participants, and the recruitment of participants using posters and leaflets.

**Dissemination:** The protocol was published in January 2020 (Coleman et al. Trials 2020), and then Covid-19 descended. This curtailed study activities somewhat. However, a poster (which credited PPI and thanked the participants) was created for ASCO using limited data available, and accepted. Unfortunately, the unavailability of bone marker data, due to the pandemic, and tight timescales meant that it needed to be withdrawn. Currently, Professor Coleman is drafting the trial manuscript, and the author list includes both members of the PPI team.

# Southampton ECMC

The Southampton CR UK Clinical Trials Unit (SCTU) currently has 30 PPI representatives sitting on 31 active trials. The ECMC has drawn from this resource, *largely on an ad hoc* basis but given our close integrated working, to provide PPI provisions to ECMC activities

There are 13 PPI reps sitting on 16 different cancer trials (some reps do more than one trial, some trials have 2 reps), as members of the Trial Management Groups, including international trials where the PPI is part of the international TMG. There are 5 cancer trials currently in set-up, and making sure the TMGs for these trials have PPI representation is part of the set-up process. There are 2 PPI reps who sit on SCTU boards (Trial Review Group and Trial Steering Committee). These representatives are integral to these groups and their input helps with decision making around which trials should be supported by SCTU, and making sure that active trials are on-track.

Trials included in this reporting period: Accept, Argo, BL-13, Confirm, Hare-40, iDdx Lung , Maple, P+R-ICE, Procaid, Remodl-A, Remodl-B, RiVa and Spire trials.

For trials in development for grant submission, PPI input has been invaluable. For example, the AURORA trial proposal was developed with substantial input from Action Bladder Cancer UK. The proposal was presented to an ABC,UK PPI focus group by one of Southampton's Junior Investigators, Dr Johnny Martin and a questionnaire was used to gather PPI input to shape the proposal as an output. Key trial documents such as the patient information sheet and consent form were also reviewed by the PPI group and, as stated above, PPI representation will be inherent in the Trial Management Group throughout the lifetime of the project.

The ECMC as part of NCRI infrastructure in Southampton support the Wessex PIN (Patient Involvement Network) which provides an innovative approach to increase the ease and opportunity of involvement in research for the public. This ensures Wessex is an exemplar in effective and appropriate public involvement in research. The Wessex PIN coordinate policies, shares learning, provides people and resources (such as materials and training) so that there is a uniform approach across the region. The result is a thriving PPI community which has remained active throughout the pandemic. Many members of the ECMC have presented their clinical/translation work to the group. The SCTU and ECME has operational representation that ensures we are feeding into the conversations around PPI in local research networks, and our staff and PPI contributors can benefit from the resources and training that the Wessex PIN provides.

The CRUK Centre/CTU/ECMC are undergoing a refresh of our PPI strategy under the leadership of our Senior CRUK Research Nurse (Kerry Fitzpatrick). The aim is to establish an specialist cancer PPI group integrated across all parts of CRUK infrastructure in Southampton to act as an ad-hoc focus group. It's hoped this will allow researchers and trial managers access to patient representatives earlier in the funding application and trial set-up processes, to get views on trial feasibility, acceptability to patients, etc.

# University College London (UCL) ECMC

Patients have reviewed the ***trial protocol and trial design*** for ProMMise trial - A Platform trial for Relapsed patients to evaluate Ongoing novel therapies in Multiple Myeloma In combination with Standard of care therapies (PI **Dr Rakesh Popat**). PI has held an engagement meeting with the patients to explain the study in detail to ensure patients had a good understanding of the study and its value. Patients also ***reviewed the Patient Information Sheet*** and have been ***involved in the structure of the safety review committee***.

Patients are involved in the ***Trial Management Group*** (TMG) for PlasmaMATCH study - The UK Plasma based Molecular Profiling of Advanced Breast Cancer to inform Therapeutic Choices (plasmaMATCH) Trial: A multi parallel cohort, open-label, multi-centre phase IIa clinical trial aiming to provide proof of principle efficacy for designated targeted therapies in patients with advanced breast cancer where the targetable mutation is identified through ctDNA screening - (PI **Dr Rebecca Roylance**). Patients were also involved in the ***initial study design*** and acceptability of the planned approach. Through their participation in the TMG, patients have been aware of the data.

Patient involvement in various aspects of these studies have been extremely valuable in shaping the design of the studies, improving the relevance of research and selection outcomes for patients.

**Diversity Project** (led by **Dr Rakesh Popat**)
Dr Popat and members of the CRF team (**Clinical Research Fellows**, **Early phase Cancer Research Manager** and **Mekala Gunaratnam**) are part of this project looking at proportions of ethnic groups enrolled into clinical trials in the UK National Health Service (NHS). It also aims to determine differences in patients enrolled into early phase vs late phase trials by ethnicity, sex and age; to assess the ethnic diversity of Multiple Myeloma (MM) patients attending MM clinics and compare if the same diversity was observed in ***clinical trial enrolment;*** to assess the overall survival (OS) of patients enrolled into clinical trials by ethnic group. Since the project started in early 2021, the team was able to access and analyse some initial data for MM patient population. The data shows that the ***proportion of ethnic minorities enrolled into MM clinical trials was lower than expected*** compared to the incidence of MM in the UK. This was ***particularly apparent in Phase I/II clinical trials*** where patients are referred from a wider geographical area. This project highlights an important caveat in early phase cancer research landscape, and we hope that it will be possible for us to expand this project beyond MM and into other types of cancers. Data from the preliminary work will be presented as an abstract at the next European Haematology Association meeting, June 2021 (see under publications).

**Development of Early Phase Cancer Research Webpage**
We are in the process of developing a dedicated website that will showcase our early phase experimental cancer trials at the CRF. This will be an important platform for our patients, clinicians, charities, funders and industry stakeholders to learn about our early phase cancer research and will provide links to other organisations and projects that we collaborate with across UCL and UCLH. Our **Early phase Cancer Research Manager** is critical to this project and will work closely with **Mekala Gunaratnam**. ***PPI*** will be an

important feature of our website and our *PPI members will be leading on the development of the content for this*. We aim to highlight our portfolio of early phase cancer trials as well as bench-to-bedside studies developed at UCL, collaborative studies between UCL and other non-commercial partners and research supported by major pharmaceutical companies.

Early Phase Cancer Newsletter – Monthly and Quarterly Issues
We have re-established our regular Cancer Newsletter to specifically cater for the investigators and patients. The monthly Newsletter features our cancer portfolio studies that are open to recruitment at the CRF and circulated to investigators and clinicians across the wider community. The quarterly newsletter is focused on providing a broader perspective of our work and how we deliver this to our patients. The first edition of the quarterly newsletter was sent out in May 2021 and featured sections on PPI, UCLH Cancer Theme, overview of our current portfolio, a UK recruitment map showing our CRF patient demographic and latest publications and news items on trials. *Our PPI members penned down their experience of being part of our research as well as providing critical review of the newsletter*. This work is coordinated by our Early phase Cancer Research Manager and Mekala Gunaratnam.

Recruitment of Early Phase Cancer Research Manager
We have recently recruited an Early Phase Cancer Research Manager to the CRF. The is a vital post for the *promotion of our PPI/E activities* and, as mentioned above, he is heavily involved in the newsletter and webpage development, as well as the Diversity Project.

# Acronyms in the document

| | |
|---|---|
| BAME | Black, Asian and minority ethnic |
| BRAG | Black and Minority Ethic Research Advisory Group |
| BRC | Biomedical Research Centre |
| CEO | Chief Executive Officer |
| CI | Chief Investigator |
| CRF | Clinical Research Facility |
| CRUK | Cancer Research UK |
| CSO | Chief Scientist Office |
| CTEC | Clinical Trials Executive Committee (Glasgow) |
| CTU | Clinical Trials Unit |
| CUP | Carcinoma of Unknown Primary |
| DDU | Drug Development Unit (Institute of Cancer Research / Royal Marsden Hospital) |
| ECMC | Experimental Cancer Medicine Centre |
| FL | Follicular Lymphoma |
| GCLP | Good Clinical Lab Practice |
| GCP | Good Clinical Practice |
| GDPR | General Data Protection Regulation |
| HTA | Human Tissue Authority |
| ICPV | Independent Cancer Patients' Voice |
| ICR-RM | Institute of Cancer Research – Royal Marsden |
| ICRB | Involvement and Engagement in Cancer Research (Birmingham) |
| IHTAB | In-House Trials Advisory Board (Glasgow) |
| KHP | King's Health Partners |
| MDS | Myelodysplastic Syndrome |
| MM | Multiple Myeloma |
| NCRI | National Cancer Research Institute |
| NHS | National Health Service |
| NICRCF | Northern Ireland Cancer Research Consumer Forum (Belfast) |
| NIHR | National Institute for Health Research |
| OS | Overall Survival |
| PI | Principal Investigator |
| PIS | Patient/Participant Information Sheet |
| PORT | Paediatric Oncology Reference Team |
| PPI/E | Patient and Public Involvement (and) Engagement |
| REC | Research Ethics Committee |
| SELCRP | South East London Consumer Research Panel (King's Health Partners) |
| SOP | Standard Operating Procedure |
| TMG | Trial Management/Monitoring Group |
| TSC | Trial Steering Committee |
| TSG | Trial Steering Group |
| UCL/UCLH | University College London/University College London Hospital |
| UKONS | UK Oncology Nursing Society |
| UTSC | Umbrella Trials Steering Committee (Glasgow) |
| Wessex PIN | Wessex Patient Involvement Network |
| YHCRP | Yorkshire and Humberside Consumer Research Panel (Sheffield) |