Responses to the patient and public involvement question in the ECMC Annual Report Form 2019/20

ecmc
Experimental
Cancer
Medicine
Centres

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.

Due to the impact of COVID-19 the ECMC Annual Report Form for 2019/20 was amended to make it easier for ECMCs to complete (abridged form). Please note that some ECMCs returned the original Annual Report Form. Below are the PPI questions in both forms.

Abridged Form:
1. Please provide a minimum of case study under each theme below which best describes the most impactful projects undertaken by your Centre during FY2019-20. Please provide a brief explanation about their impact and provide links to any associated/relevant publications/other resources.
Patient and Public Involvement case study: example 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

Original Form
Please provide a summary of any progress or challenges against the patient and public involvement objectives detailed in the ECMC Review application.
OPTIONAL: Please include a more detailed case study on a specific PPI activity below

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

Barts ECMC

Barts: response

Immunotherapy booklet: Patients receiving chemotherapy at Barts are given a chemotherapy booklet to record hospital appointments and contact details, treatment plans and treatment administration, recent blood and scan results and treatment side effects they experience. These booklets also include information about chemotherapy. Examples of these include the Chemotherapy Record Booklet developed by the former North London and North East London Cancer Networks as well as the 'Your cancer treatment record' developed by Cancer Research UK.

A large proportion of Barts patients receive immunotherapy as part of their participation in a clinical trial, however, there is no equivalent immunotherapy booklet for these patients. One of our bladder cancer patients together with Miss M. Lapuente, our Senior Research Nurse for genitoutinary oncology trials, are developing an immunotherapy specific booklet for Barts patients. Barts Trust has been involved in this project and the first draft is undergoing review. We are hoping this will be available to out-patients in 2021 and will improve the information we provide to our research participants by making it more relevant to their needs.

Supporting ethics committee submissions: At Barts we often participate in complex trials, a recent example being the phase II study looking at the efficacy of a vaccine drug (RO7198457) in combination with immunotherapy in patients with untreated, advanced melanoma. Having recruited patients to the phase I trial with the same molecule, we approached one of our phase I melanoma cohort patients to help us improve the patient information sheet that would be used in the phase II. The patient's review was important in making this complex information easy for patients to understand.

Another example is the review of the ABACUS-2 trial design by one of our genitourinary cancer patients who had previously received immunotherapy. The patient was supportive of the design which they believed would benefit bladder cancer patients and wrote a letter of support that we were able to include in our submission to the ethics committee.

Promoting and improving research: Having an understanding of the difficulties faced by oncology patients and their treatment journeys is an important aspect of developing clinical trial protocols. One of our kidney cancer patients who received immunotherapy as part of a clinical trial gave a talk, together with Prof Powles, to Roche staff on the patient journey and the differences between chemotherapy and immunotherapy in terms of side effects and their effect on a patient's life. The talk was attended by a range of Roche personnel, from medical staff, to clinical trial and marketing teams. This talk gave an insight into the patient's perspective and will hopefully have an impact in future research design.

Belfast ECMC

Belfast: response

PPI in Belfast ECMC continues to focus on the established partnership with the NI Cancer Research Consumer Forum (NICRCF), a group of 30 patients and carers passionate about PPI and cancer research. NICRCF's contribution to Belfast ECMC research continues to be wide ranging. NICRCF representatives actively participate in the following:

- Belfast ECMC Steering Group (G Hill)
- CIBRAC Trial Management Group (H Carson)
- NICRCF Prostate Cancer Research Personal and Public Involvement (PPI) Advisory Group (10 members with focus on ADRRAD, SPORT and ASTRad studies)
- NICRCF involvement through the adoption process for new studies to the ECMC portfolio

NICRCF PPI consistently raises the patient/carer perspective and promotes a driving ambition for rapid research progress, which motivates researchers and enhances process and quality. One development the NICRCF has advocated for, and which became embedded into the Belfast ECMC 2019-2024 PPI strategy, is provision of PPI awareness/education to 'researchers in training including PhD students'. NICRCF members became conscious they were repeatedly giving similar guidance to various researchers and sought to introduce awareness of good PPI practice earlier in research careers, to enhance early understanding of PPI (per INVOLVE definition) in the context of cancer research.

NICRCF Consumer and Professional Leads, M Grayson and R Boyd met with the PGJCCR Scientific Director and Postgraduate Programme Lead resulting in endorsement of the PPI awareness and education objectives and agreement on the introduction of the following plan:

i. PPI awareness session - 1st year PhD induction week
ii. Final year PhD PPI workshop.

During 2019/2020 a successful induction session was delivered by M Grayson and R Boyd 26.09.19. This event led to further links and PPI representation in panel review of 3rd year PhD presentations 28.10.19. PPI workshop plans were put on-hold due to the COVID-19 pandemic; however, PPI awareness induction session will be delivered on-line in October 2020.

Clinical Fellows play an important role in the ECMC local portfolio, thus PPI training in this context has a direct relevance to ECMC study quality. This year Dr Gerard Walls was part of the PhD induction session and also a recipient of a seed-funding award (funded by Queen's University Belfast to support research with line of sight to clinical or translational application as part of our ECMC activity) to (https://ro-journal.biomedcentral.com/articles/10.1186/s13014-020-01583-7), awarded via committee with NICRCF PPI representative G Hill.

Continuous and systematic PPI education is required to achieve a PPI culture change in young researchers; however, this has been a positive new development with potential to increase early and meaningful PPI in ECMC studies of the future.

We are indebted to members of the NICRCF and Margaret Grayson (Chair).

Birmingham ECMC

Birmingham: response

Patient and Public Involvement (PPI) is a key area at the Birmingham ECMC. We recognise that involvement of patients and the public is an 'active partnership' process, to have a positive impact upon cancer research.

i) The **National Lung Matrix Trial** (NLMT) has embraced PPI throughout the research process, embedding PPI into its novel clinical trial design. PPI representatives attend the Trial Management Group and the Trial Steering Committee meetings to provide their perspectives and suggestions. Their involvement has ensured that NLMT has continually focused on improving the quality of the trial, ultimately making it relevant to patients' needs. There has also been partnership with NLMT patients and their families at the Annual Investigator Meeting in April 2019. Involvement entailed an insightful patient experience presentation, and two patients and their families taking part in a PPI workshop alongside site staff. This innovative workshop discussed the impact of PPI on all areas of the research cycle and across all sites. This was a unique opportunity for site staff to share best practice in PPI and fully engage with patients and their families on key issues, such as how best to communicate complex scientific information.

The NLMT has begun to report on results in completed arms. Specific advice was sought from the Involvement and Engagement in Cancer Research at Birmingham (ICRB) group on the effects of drug discontinuation, e.g. when pharmaceutical companies may cease future development of a drug, resulting in early closure of the trial arm. ICRB is a dedicated group of patients, carers and people affected by cancer who are embedded in the research programme in Birmingham, and receive training and support to effectively collaborate with the research community, to add impact and relevance to research. The group helped trial management staff understand the patient and carer perspective on the potential impact of drug discontinuation and fed comments into the patient information sheet. Discussion centred around methods of communicating this to trial patients, and understanding what the potential impacts would be. For example, if the treatment arm is still recruiting new patients, how they may feel entering the trial knowing that the drug will become unavailable in the future. The group's involvement was invaluable to both the research team and to the group members themselves, who had not been aware of this potential issue in early phase trials. Their contribution was acknowledged in the recent NLMT Nature publication (DOI: 10.1038/s41586-020-2481-8).

ii) The NLMT has also explored ways to reach new researchers and practitioners and promote the partnership of PPI in research, really changing the culture and attitudes towards PPI. This is evident in the team's involvement with the **Genomic Medicine MSc course**, which is run by the University of Birmingham. Within the personalised medicine module, there are sessions from the lead clinician and statistician for NLMT and, importantly, from a patient on the trial and a research nurse. This really has allowed the team to promote the high impact of PPI representation and involvement in clinical research, and students are encouraged to explore the role of PPI in their future work, along with the value of hearing the patients' experience.

Cambridge ECMC

[completed the original form]

Cambridge: response

In the last year, Cambridge Experimental Cancer Medicine PPI group has doubled its membership to 16 members, held four group meetings, and reviewed six research projects. The activities of the included:

- Review of two grant applications, both pending outcomes;
- Review of participant-facing information for three experimental cancer trials (including two feasibility studies, all with significant translational aspects);
- Review of project proposal for a junior researcher;
- Engagement with other projects running on the biomedical campus (without formal review by the whole group), for example development of the Cambridge ECMC PPI website.

The members have been involved with remotely reviewing relevant documents and providing comments/suggestions to improve the language, format, and the accessibility of language and scientific concepts for the lay person. There have been an additional eight projects presented at the PPI group meetings. These range from bench scientists presenting ideas and working theories, to collaborations with multi-disciplinary teams across the biomedical campus. The members have questioned the researchers on decisions that have been made and guided research and study structure.

We have continued our focus on group education. This year have been training session on the Cambridge University Hospitals strategy, cancer genetics, what "good" trial evidence is, and cellular therapies. Members of the group have also knowledge with the community, presenting at the Experimental Cancer Medicine Demystified event and supporting promotional stalls at open events.

The CRUK senior research nurse and ECMC programme manager are currently writing a strategy document for the Cambridge PPI group, and we will work in collaboration with the broader ECMC PPI groups to ensure consistency across the Network. There is also ongoing development of a website for the Cambridge group.

Some of the current challenges and ways to address these include:

- Increased size of the group – the group has experienced rapid growth in the last 6 months. Many of the new members have no previous PPI experience. We will need to work on educating these members about the PPI process, and integrating them effectively into the group;
- Increased diversity of the group - whilst the size of the group has increase there is still limited diversity. We will continue liaising with equality & diversity teams at the hospital and the university to identify routes to advertise the groups in areas where we need to improve diversity, as well as taking up all opportunities to meet with new people;
- Continue to promote the group within the scientific community - engage with communications contacts and trial coordination contacts to increase our

engagement with early phase researchers and bench scientist. This will allow us to involve PPI at an earlier stage in the research process.

We held the second annual patient- and public-facing engagement day: Experimental Cancer Medicine Demystified (2019). The aim of the day was to promote the experimental cancer research carried out by Cambridge ECMC and PPI in this area. ~120 attendees came to this free all-day event, a ~50% increase in attendance, compared to the previous year. Topics including: PPI, ovarian cancer, renal cancer, personalised medicine and the Basket of Basket trial, haematological malignancies, immunotherapy, brain cancers and a presentation by a CRUK Grand Challenge winner on STORMING Cancer.

The feedback after the event was extremely positive. 59% of attendees rated the event "excellent" and 41% rated the event "very good". Based on the results from the feedback, we will continue to run this event, we will also try to increase the range of speakers, and give junior researchers the opportunity to present.

Cambridge: case study

As highlighted above we have made a real push to improve and expand our PPI work over the last year. We have become increasingly embedded in the Cambridge Cancer Institute and a recognised as a great place for PPI input. In 2019/20 we have also started to work with SME groups, coming out a spin offs from Cambridge research. One such group is Granta Innovation, a Cambridge based SME focused on artificial intelligence, machine learning and deep learning within Cancer. This company has links with the Cambridge Cancer Centre through their membership in the early detection programme and work with Professor Sala and Dr Tristan Barrett.

Background

The Cambridge ECMC PPI group have an ongoing relationship with Granta Innovation. They have reviewed documents for two different projects, and have provided face to face advise at a group meeting.

The document reviews included a grant application for the use of an AI based diagnostic tool in prostate cancer. The second document review built further on this, providing a lay summary of the prostate diagnostic tool. Finally this idea and proposal was presented to the group in the face to face meeting in February 2020.

Patient and Public Involvement

The Granta Innovation team got involved with the group due to our focus on early development research, the group was recommended to them by other members of the Cambridge Cancer Centre. In the initial document for review, the grant application, members of the group were also provided with background information on the project, some key questions, and an invitation for one member of the group to join the steering committee. This was a brilliant opportunity for the group, on a new type of project, the first AI project. All members were very enthusiastic and provided good feedback and comments. Additionally one member of the group volunteered to be on the trial steering committee.

After this initial review we received feedback from Granta Innovation that have "feedback from outside our team came up with particularly useful perspectives, highlighting a couple of important points that needed clarifying". They also said that they would be implementing nearly all of the suggested changes. As a result of this positive outcome Granta Innovation also asked if we would be happy to work with them on the next steps of the project.

The next step in our work with Granta Innovation was a review of a lay summary of their proposal for the AI prostate diagnostic tool. The group were all very pleased to continue looking at this work, and commented that it made them feel their input was valued. This time the reviewers felt that some work was needed to make this an acceptable lay summary. Granta Innovation were incredibly receptive to these comments and feedback that they "have completely rewritten the lay summary based on the reviewers' comments. We've adjusted the design to allow the study to show statistically significant benefits, and also adjusted the approach and text about ethics to take into account the concerns they expressed as patients".

This relationship continued to grow when two members of the team from Granta Innovation came to speak to the group at our February 2020 meeting. During this presentation members of the group engaged in active discussion and asked well received questions. These discussions were minuted and then provided to Grana Innovation as part of the feedback from the session.
Going forward a member of the PPI group will be sitting on the trial steering committee, able to provide ongoing input from a PPI perspective. Granta Innovation have also said that they would recommend the group to colleagues, and would be keen to work with us again in the future.

Cardiff ECMC

Cardiff: response

At ECMC Cardiff, we strive to centrally incorporate PPI and, with this in mind, this summary has been written in collaboration with a Lay Partner. We continue to collaborate closely with other research groupings within Cardiff University, particularly Wales Cancer Research Centre (WCRC). Julie Hepburn is Lead Lay Partner in both ECMC and WCRC. Julie attends leadership meetings for both organisations and is centrally involved in decision making process within the centre. She is one of a group of public research partners who are active in assisting with grant applications and research management groups. Their contributions are heard and impact on the study journey. We are to subscribe to fully working in accordance with the recently released UK Standards for Public Involvement (2020).

Wales Cancer Research Centre has recently won a grant for five more years from Health and Care Research Wales funding, starting from April 2020, and the structure of the centre, along with the PPI model, has evolved. As the centres are so closely aligned, the PPI team will continue to look at what areas overlap with the ECMC and what strengths can be brought across.

The PPI Team have built strong links with the research community within Cardiff and beyond and are involved with key developments in the wider research community. As well as adhering to the UK Standards for Public Involvement, the team have attended various Health and Care Research Wales Public Involvement & Engagement workshops where the aim has been to develop a consensus on the most suitable approach to implementing the draft public involvement and engagement Statement of Intent for HCRW.

Work on the Lay Faculty continues with collaboration with the Systems Immunity Research Institute and WCRC, further cementing relationships between the organisations. We now have a committed group of lay members who provide helpful and prompt responses, and therefore our attention has turned to the best way to raise awareness of the Lay faculty within the University. We have secured slots at regularly held lunchtime sessions for Lay faculty members to present to researchers about how PPI can benefit research, using reviewing lay summaries as case studies and running interactive activities looking at use of lay language. We have found the most impactful way to engage with researchers is to include a PPI slot at Divisional meetings: these meetings are well attended and the audience will include researchers who have varied experience of PPI so the message is hitting a wider and a mixed audience. Again, we ensure that the lay members present and have found that this creates a stronger response: following a presentation at the Annual Infection and Immunity Meeting, the Lay Faculty has seen an increase in enquiries from researchers. We have explored various ways to promote the lay faculty within the research community and after receiving positive feedback from people who have used the faculty, a promotional video was created and posted on social media.

Edinburgh ECMC

Edinburgh: response

Dr Peter Hall is leading a patient preference trial, INFO-BC, recently presented as a trial in progress at the UK Interdisciplinary Breast Cancer Symposium 2020 (posters at https://blogs.ed.ac.uk/ectu_ehe/info-bc/info-bc-project-outputs/). This is a study where patient preferences are explored through a survey with a series of hypothetical paired choices between treatments that may differ in terms of specific side effect risks or benefits. The questions were developed after the results of a systematic review of potential treatment attributes were discussed and shortlisted with a patient panel and incorporated into a pilot questionnaire, which could then have a second round of patient testing and review to generate the final survey. For this study of patient preference to be meaningful, it was essential for patient involvement to be core to its design, with the academic team there to provide a systematic structure and a validated survey tool (the discrete choice experiment [DCE] method) to derive the final quantitative results from this patient-driven patient-preference trial.

Impact:

Patient-steered trials of preferences and priorities in their treatment decisions will help clinicians understand the areas of need with current, and future, treatments.

Glasgow ECMC

Glasgow: response

Patient and Public Involvement (PPI) is a key component of Glasgow's ECMC activity and consumer representatives are involved across our ECMC translational and clinical programmes.

This includes PPI representation on:

- The ECMC Steering Committee which has oversight of all of our ECMC activities and strategy.
- 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).
- 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).
- Membership of individual study Trial Management Group, and of the Umbrella Trials Steering Group which has oversight of the CR-UK Clinical Trials Unit's studies including many early phase studies developed through the former ECMC Combinations Alliance or other industry collaborations that are led from Glasgow.

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.

We have developed our PPI representatives through these activities so that, in turn, they have contributed to the wider ECMC Network. For example, Elspeth Banks is a patient representative on the ECMC Network Steering Committee, providing a lay perspective on operational and strategic issues. She is also a member of the ECMC PPI Steering Group and a co-author of 'Early phase cancer research: a reference guide for patient and public involvement contributors' which was presented at the 2019 NCRI Conference.

We have also worked with our PPI in education initiatives, designed to reach broad audiences, including an online course "Research Impact: Making a difference. https://www.futurelearn.com/courses/research-impact/6" . The development of this online course was led by the Institute of Cancer Sciences, University of Glasgow, including ECMC co-investigators and teaches how to identify and evidence research impact. The course has run 5 times since 2018 (twice in April 2019 – March 2020) with over 3,500 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 organisations. By embedding PPI as a core component of the Research Impact MOOC we have generated a platform for awareness and education around PPI in the context of impact.

An additional initiative is “The Future of Cancer Treatment and Care in Relation to Precision Medicine: A Design Perspective”: http://researchdata.gla.ac.uk/843/ This was jointly conceived by the Innovation School at Glasgow School of Art and the Institute of Cancer Sciences, University of Glasgow (including ECMC co-investigators). Graduating year Product Design students were presented with a challenge-based project to produce a vision of the future based on current trends that relate to Precision Medicine (PM) and Cancer Treatment. This project asked students to consider what will happen in a cancer landscape ten years from now, where PM has evolved to the extent that new forms of medical practice, cancer treatment and care transform how we interact with each other, with professionals and the world around us.

A key component of this project is the bringing together of the students with a range of experts in formal teaching and learning sessions. The invited expert faculty came from industry, innovation offices, University, medical professionals, NHS and patient groups. As part of this innovative teaching we included PPI representation with Elspeth Banks. The outputs of this highly innovative and interactive research-led teaching is captured though a range research, products, services and experiences. The final designs were also presented as public exhibitions in Glasgow and London. Importantly the process and output was captured and archived as a project data collection as an open access resource. All contributors are credited equally and the assignment of a DOI means the project is identifiable and the knowledge and outputs available to all.

This inclusive approach once again places PPI as a driver in the process and with equivalence to all other expert stakeholder input from clinicians, business and NHS.

Imperial ECMC

[completed the original form]

Imperial: response

Imperial hosted eight science cafes this year, which included a six-part series focused on personalisation in cancer care. The science cafes were part of a Wellcome Trust funded research project by the Patient Experience Research Centre. The project involved qualitative interviews of patients and staff and the work of three artists who helped to facilitate discussion around the theme of personalisation.

People Like You https://peoplelikeyou.ac.uk/what-we-do/

At Imperial a poet in residence met with patients and staff to create a written portrait which reflected the personal stories people bring to cancer care. A poetry reading is planned for the Exhibition Road Festival 2020 and a poetry book launch is planned for Maggie's later in 2020.

Written Portraits https://peoplelikeyou.ac.uk/poem/

Our patient group co-led in lay summary writing workshops for Imperial Cancer Frontier students (4th year medical students) with great success. Members of the group also led a panel discussion at a national conference for medical students on March 7th in London.

This year, the Imperial Patient and Public Involvement Group for Cancer supported over sixty projects which included lay summary review, trial documentation review, contributing to grant proposals and taking part in focus groups.

Imperial also worked with Cancer Research UK to pilot PPI training session for fifty Imperial researchers.

Imperial: case study

The Cancer Loyalty Card Study (CLOCS), funded by CRUK, has had numerous patient and public involvement activities over the last year.

- Firstly, we have two ovarian cancer patient advocates as part of the CLOCS team who have over the last year been actively involved in developing the study protocols, ethics applications and reviewing all study documents.
- We have also held our annual meeting for CLOCS on 11th Sept 2019, in which about 50 participants included researchers, research nurses, patient advocates, and members of the public.
- We are currently using social media (twitter and Instagram) to engage with the public and discuss the implications of our research.
- We have also presented the CLOCS study as a case study at a CRUK PPI course
- We have developed an animation and website to promote the study to the public www.clocsproject.org.uk

Institute of Cancer Research (ICR) ECMC

ICR: response

We have established a structure for involving patients and the public in conducting our early clinical trials research conduct within the Drug Development Unit and the ICR-RM ECMC. Over the last year this structure was strengthened with improved governance processes, and an increasing focus on measuring the impact of this involvement and facilitating co-production. This includes working towards purchasing a digital platform for patient and public involvement (PPI). ECMC staff are involved in meetings to set these requirements. One of the capabilities of the platform will be a research prioritization hub where any member of the public can post their suggestions. In DDU it remains challenging to set priorities for Phase I trials. We are in the early stages of a research study aimed at investigating experiences of patients on Phase I trial which is exploring what is important to patients on early clinical trials. We are also working to improve the design of early clinical trial research protocols, information sheets (PIS) and consent forms (ICF) as part of this endeavor. This is building on a project exploring the information needs of patients during the informed consent process. This research is comparing different methods of delivery of information including shorter PISs with links to videos about important aspects of these trials. These videos have already been produced by our ECMC team and include staff explaining procedures and videos of patients explaining their experiences to help new patients understand what being on a clinical trial involves. This project has been developed with PPI integrated into the design process.

Case Study

During 2019 we completed a project investigating informed consent process for patients on Phase I trials on the DDU. This project had patient involvement in terms of patient opinion being sought for assessment of the current service, but was also a co-production PPI project with a specific patient representative acting as a co-researcher on the project who was a named co-author on the disseminated project outputs. This study entitled **" Filling the gaps in informed consent for advanced cancer patients considering Phase I oncology trials: an in-depth qualitative study of key stakeholders in a large Phase I unit"** was conducted over a six-month period. The aim of the study was to describe the elements required for informed consent Phase I key stakeholders. The study used an experience based co-design framework to obtain the opinions of patients who were being treated on Phase I trials and had been through the informed consent process. A series of focus groups and one-to-one interviews took place with patients. These narratives were audio-recorded and transcribed, and the data thematically analysed. Four themes emerged from the data: Theme 1) Patients need to understand key elements of the trial not being the only option, carry uncertainty and have significant time commitment. Theme 2) Current PIS are inaccessible. Theme 3) Consent should be personalised and Theme 4) Summary PIS and Multimedia may be a way forward. The results and discussions from this large project have been used as the basis for a larger research study comparing varying formats of patient information.

This project also had a significant element of co-production. One named patient rep worked as part of the research team. The patient rep attended and helped facilitate the focus groups and conducted most of the one to one interviews. They also helped with some of the thematic analysis.

The output of the study was presented at the European Society of Medical Oncologists in Barcelona in Sept 2019 as a poster abstract. The patient rep was a named co-author.

Conference Presentations where ECMC was acknowledged
Sarah Stapleton, Martin Lee (2019) Collaboratively assessing the impact of patient and public involvement in research – NCRI cancer Conference 2019 Glasgow
Sarah Stapleton, Ann e-Sophie Darlington (2020**) I just can't think straight!" Patient's experience of cognitive function whilst on early clinical trials of novel anti-cancer therapies."** International Cancer and Cognition Task Force Conference Denver _ Colorado

King’s Health Partners (KHP) ECMC

[completed original form]

KHP: response

South East London Consumer Research Panel (SELCRP)

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. They have provided written and face-to-face feedback during this reporting period for around 40 studies. They are an exemplar model supporting our cancer research community and reaching to a diverse range of studies such as Tissue Banking for Imaging Bio-resource research, finding new ways to target pancreatic cancer, predicting treatment response based pathology and radiology image analysis in breast and head-neck cancers, where they have provided valuable insights from the patients’ point of view in terms of study design, as well as dissemination strategies and how best to recruit patients for a study.

The Biobank Reference Group

The Biobank Reference Group continue to meet regularly and during the last year provided significant input into a number of biobank initiatives that are directly relevant to patients. The group has helped to design posters to advertise the KHP Cancer Biobank, which have been printed and also used on electronic boards. They were instrumental in the character design and testing of a digital ‘biobank game’, which informs and tests knowledge of biobanking. The game can be downloaded as an App https://www.khpbiobank.co.uk/biobankgame. Recently, the group designed a generic biobank leaflet that provides a concise overview of participation in biobank activities. The leaflet is now available as a Guy’s and St Thomas Trust information resource https://www.guysandstthomas.nhs.uk/resources/patient-information/cancer/research%20biobanking%20web.pdf. Currently the group are providing input into biobank and research content for information screens located in Guy’s Cancer Centre.

ENGAGEMENT AND OUTREACH ACTIVITIES:

Arnie Purushotham:

- Chair, Cancer Survivors’ Day, Guy’s Cancer Centre, June 2019. Included patient engagement activities by Clinical Trials team

James Spicer:

- Impact of COVID on care and clinical trials, Lung Cancer Canada patient webcast, June 2020

Sophia Karagiannis:

- Oncostars initiative, PanaceaStars and Cancer Research UK, ‘Innovating cancer research: trends, challenges and future perspectives’ November 2019, Francis Crick Institute, London;
- King's Stars 2019 Outreach Programme, July 2019, talk, discussion and hosted laboratory visits for sixth-form students from diverse backgrounds.
- The British Science Festival, September 2019; Panel member and speaker at a Breast Cancer Now-sponsored patient engagement event

Debashis Sarker:

- Patient Education Event for Neuroendocrine Cancer UK Oct 2019

Leicester ECMC

[completed original form]

Leicester: response

The Hope Patient and Carer Advisory Group has continued to thrive throughout the year. With the exception of the last meeting in March (cancelled as a result of the pandemic) they have continued to be well attended. Membership has increased and we have expanded our remit to include representatives on an ad hoc basis to maximise expertise and facilitate certain project activity. Activity has been continued online subsequently to ensure that we maintain engagement.

A key focus of attention has been education. This has resulted in improving knowledge with regard to cancer research activity at a number of levels within the University Hospitals of Leicester NHS Trust.

Opportunities have included:-

- Providing a seminar to a new Royal College of Nursing accredited Cancer Module run via our Cancer Centre for experienced general nurses. Following an overview of the research process, our patient member eloquently described her research journey whilst participating on a Phase 1 trial. This had a significant impact on the group clearly highlighting the importance of early phase research and the significance of participation.
- Contributing to a conference speaking to consultants and managers across the trust highlighting early phase activity and the function of our clinical trials facility.
- In conjunction with the MiST trial, generating a video to demonstrate the value of research and the impact it has had on the participant interviewed.
- At the International Clinical Trials Day in May all inpatients and outpatients within the Cancer Centre received a 'goody bag' containing information about research and how to consider participating.

Community activity has continued. Attendance at a new initiative for cancer patients and their families provided an opportunity for engagement, whilst attendance at the Big Health Connect & Cultural Market enhanced connection with the Black, Asian and minority ethnic communities.

Work that commenced in relation to developing a research project at the end of last year exploring expected versus actual uptake of clinical trials amongst different ethnicities has developed further, leading to the submission of a manuscript to Seminars in Oncology. The Patient and Carer Advisory group played a key part in the direction of this manuscript, recommending that to facilitate trial-related engagement programmes within minority communities, we should first understand what local and UK-wide cancer engagement initiatives have proven successful in increasing engagement with screening and treatment.

An application for funding made jointly with the University of Leicester Centre for Black and Minority Health was unfortunately put on hold as a result of the pandemic. We await outcome in due course

Liverpool ECMC

Liverpool: response

a. **Patient & Public Involvement in Research & Innovation (R&I) Event**

A patient and public engagement event was held on 10th February 2020 at Clatterbridge Cancer Centre (CCC), in advance of the expansion of CCC to the new hospital site in Liverpool. Members of the Liverpool ECMC team sat on the organising committee and participated in the event.

Members of the Liverpool ECMC Operational Group and R&I Senior Management Team opened the event by presenting on current and planned research, covering biobanks, observational studies, sponsorship, R&D visibility and experimental medicine.
Patients and members of the public were then invited to participate in group discussions and provide reflective input on their experience with R&I and potential opportunities associated with the expansion of the centre.

This event was patient focussed and sought to receive feedback on all aspects of patient and public involvement in research including:

- Experience of research participation at the current site.
- Requirements for level and type of information to be made available for potential research participants.
- Considerations on how patients should be approached to take part in early phase trials.
- How to support patients and carers with the increased hospital attendance early phase trials often require.

The outcome of discussions provided important information to be considered by the ECMC and R&I teams when moving to the new building, ensuring patient voice is embedded into decision making and research delivery in the future. Key suggestions included:

- Development of a framework with patient and public input to outline how public facing information regarding research opportunities should be presented, to ensure clarity and understanding.
- Ensuring a clear dialogue with patients and carers about beliefs and expectations in research is maintained. This should be considered as part of individual patient pathways and include survival, toxicity, impact on hope and living with cancer.
- Models of care based on shared decision-making between health professionals and patients should be enabled through personalised stratified follow up.
- Educating patients about research from the pre-diagnosis stage.
- Improving information presentation and increasing the number of formats to appeal to difference audiences.
- Introduction of research-focused newsletters for patients which include information on the current research portfolio and study results.

- Increasing information provision through the internet, press and social media and increasing visibility in hospital sites.
- Increasing support for early phase trial patients/carers including parking provision, flexible clinic times and opportunities for appointments to take place at local spoke hospitals.

b. Chronic Lymphocytic Leukaemia Patient Support Group

The Haemoto-oncology clinical and research teams have a long and close affiliation with the Chronic Lymphocytic Leukaemia (CLL) patient support group (CLLSA). Biennially a program is put together for CLL and held in Liverpool, that was started by the Liverpool patient chairman of the CLLSA and has continued for the last eight years. The last conference in 2019 was put together by two CCC trial patients along with Jane Tinsley (Lead Haematology Research Nurse).

The program included a joint talk by Jane Tinsley and a trial patient, as well as the main presentation by Prof Andrew Pettitt. All talks are recorded and uploaded to the CLLSA website (www.cllsupport.org.uk). This conference resulted in patients being referred to CCC for treatment after attending the day or watching the talks. Excerpts from the Liverpool 2019 post conference feedback analysis on aspects most liked:

'Excellent main speaker'
'Quality of content from all speakers'
'Information from speakers and meeting fellow people with CLL'
'Opportunity to engage with others' experiencing CLL, my first opportunity. Prof Pettitt presentation was brilliant'
'Meeting like minded people. The talk by Prof Pettitt'
'Meeting others and sharing experiences'
'Group discussion, patient experience presentations, treatment and future by Prof Pettitt, chance for in depth discussion at table and lunch, lots of food for thought'
'Patient stories'
'Very focused event, well presented and informative; you got it right'
'Feel conference was very well organized. Speakers were excellent and very informative'.

The UK CLL Biobank has a local patient and member of CCLSA on the Governance committee who attends and contributes to the annual meetings. The patient was also involved in helping review and amend documents submitted for reapplication for ethical approval for the biobank.

Manchester ECMC

Manchester: response

Patients are at the heart of activities across Manchester ECMC, at the point of setting up a new trial though to the planning and presentation of a major conference with an international audience. Below are three examples;

The IN-Home trial

Manchester ECMC has access to a specifically designed non-clinical space in the experimental cancer medicine research environment, for meeting with patients/carers. The team was able to identify and approach patients about their willingness to contribute to discussions about this technology trial. Through discussions both on a 1:1 basis and in focus groups patients provided a very valuable input and as a result influenced the protocol, to build a more patient acceptable plan as well as a clinically acceptable plan. For a study of this type this was especially important as the patient involvement allowed for the delivery of a higher quality protocol. It is hoped that having taken patient advice the ability to recruit to the trial will be enhanced.

International Phase I Conference

In collaboration with Manchester Cancer Research Centre (MCRC), our ECMC hosted the “Phase I: Where Science Becomes Medicine” conference from 14th-16th of July 2019 in Manchester with a dedicated focus on Phase I cancer trials and an overview of the dynamic landscape of the field. Global experts presented and discussed the key issues facing Phase I clinical triallists. The involvement with patients was a fundamental aspect to the conference. Through video, the first voice heard at the start of every session was that of a patient/carer. These talks detailed first-hand accounts of how cancer and clinical trials affect participating patients and their families provided a constant reminder of the importance of these trials and a focus for each session. Throughout the conference, the involvement from patients was evident and importantly featured heavily as part of the discussion sessions.

PREM-ECM

A key study across Manchester ECMC is the development of PREM-ECM: Patient Reported Experience Measures for Experimental Cancer Medicine. This study has continued throughout 2019 and is on track to complete late 2020. Data from this will support the expanded patient experience theme within the Experimental Cancer Medicine Team, and will be the focus and drive for activities in the next year.

Newcastle ECMC

Newcastle: response

Patient and Public Involvement Development and Adaptation to Pandemic

Our PPI group the 'Perspective in cancer research' celebrated their 5-year anniversary last year and continue to go from strength to strength supporting cancer research in the North East of England.
In the last year we have been able to develop the PPI Group further through involving them in regional educational workshops with Cancer Research UK and local NIHR training programmes to aid researchers' understanding of PPI and how it can support their research.

Pre covid-19 our PPI group reviewed 12 major cancer research projects and, in many cases, group members became co-applicants within reviewed studies to aid their development.

Unfortunately, because of covid-19 face-to-face meetings had to stop in March. We took this as an opportunity to develop a method of keeping our PPI group together and the service they offer through utilising video conferencing. At the end of March, we ran our first PPI meeting via a 'Zoom' meeting and promoting this achievement through Twitter. Thereafter there was a huge amount of interest both locally and nationally from researchers who wanted to present their cancer research ideas to our group for review. Since April, the group have reviewed and given feedback on cancer related research studies at least once a week, and in some cases, up to 5 times in one week. Overall, the group has reviewed and given feedback on a total of 21 studies during this period.

Another positive from this new method of working has been that it has allowed us to join forces with other PPI cancer groups across the region, which would have been unthinkable pre covid-19. Through collaborative working, members of PPI groups from Northumberland and Sunderland have joined our digital forum to review cancer research and give lay member feedback on future research.

In addition to this the group have been a key driver in the development of the social distancing 'virtual clinic' project we have developed in Newcastle. This included supporting its initial concept, aiding its development and being actively involved in practical online pilot sessions to ensure this new method of work is developed with PPI at its core.

Social distancing virtual clinic project

During the pandemic the Newcastle Early Phase PPI group developed a social distancing project to support our research team in the Newcastle ECMC.

Newcastle ECMC is a regional centre and patients in many circumstances have to travel great distances to attend research appointments. Through working with our translational research team, current clinical trial patients and our PPI group, we devised a pilot project to aid social distancing through utilising video conferencing and electronic consent methods. The aim of the project was to reduce patients’ visits to our centre, in particular during the informed consent process of research studies.

Through working with our PPI group and current patients we were able to find out if this was a viable idea and how to deliver it in the most patient friendly manner. Thereafter we reviewed the legality and ethics of utilising video conferencing and electronic consent software which allowed us to devise a standard operating procedure for consenting research participants in this novel way.

Subsequently we worked very closely with our PPI group to run mock informed consent sessions in order to develop a robust method for using the system and to ensure that it was patient friendly. The findings from this work were presented to our research and development governance team in June and we were given permission to integrate this new method of consenting patients into our translational studies. In July we were able to gain sponsorship approval to use this novel method within one of our translation research studies.

Newcastle ECMC and CRUK centre resource supports our PPI group in its work, with ECMC staff attending engagement events, in particular on International Clinical Trials Day annually, and our CRUK Senior Nurse Ben Hood, coordinated the group and all the above projects.

Oxford ECMC

Oxford: response

We are currently in process of re-forming the Oxford Cancer PPI panel. Lay representatives on the current committee have reviewed and edited role descriptions to increase relevance to the public. Role description and invitations have now been sent to local patient support groups across all tumour types. A budget has been secured to pay individuals for their time as well as expenses incurred. The aim is to form an advisory panel with representation across different tumour types that is accessible to and useful for all researchers.

Ensure effective joint working across the network, & between universities and trusts:

Presence on BRC PPI Advisory group
Our senior nurse for research and engagement and the patient representative are both members of the Oxford-BRC PPI advisory group (formerly known as PAIR) for the cancer theme. This group has a multi factorial purpose, but fundamentally is advisory in nature. Representation on this overarching committee provides support from the wider research community, and enhanced visibility for our department, which should enable access to resources as well as opportunities to engage with researchers looking for PPI input. The group has discussed undertaking a survey to determine the barriers and challenges researchers face when doing PPI. This would be an opportunity to promote the group's existence, whilst providing information about possible confusion between involvement and engagement. This should also provide an opportunity to emphasise the positives of PPI to achieve a culture of researchers wanting to embrace PPI.

Presence on ECMC PPI Advisory group
Our senior nurse sits on this UK wide group, which provides a resource for sharing opportunities with patients and HCPs to get involved in projects across the UK. The group offer training opportunities periodically across the network and have developed a handbook for lay people aiming to aid understanding of medical terminology and language, to help with review of trial documents, including protocols, PIS/ICF etc. See link: https://www.ecmcnetwork.org.uk/patient-and-public-involvement-ecmc-network
In order to publicise this resource amongst the wider cancer community, the group submitted a poster to the NCRI conference in 2019 and was presented in their "silent theatre".

Patient communication
Films: Our senior nurse for research and engagement worked in collaboration with the trust media and comms. department, the early phase clinical trials team and one of the current patients to make two films aimed at helping patients to make decisions about taking part in a trial. These included the process of giving consent, screening for and taking part in a clinical trial. The films were made in response to a patient survey conducted on the early phase clinical trials unit, indicating that patients needed more information. These films are now available to view on the Oxford centre website – see link https://www.cancercentre.ox.ac.uk/

Challenges

There has been some difficulty in engaging / reaching researchers in order to highlight importance and value of PPI. This has led to only small numbers of requests for feedback/input into research projects. Consequently, and for other reasons such as problems with access to the centre for the public, and a very small committee, PPI activity has been very limited. An example of this was the lack of attendance to a CRUK training event held at the Oxford centre, widely advertised, and aiming to help researchers with different aspects of inclusion of PPI in research design and conduct. Many researchers signed up for the event, but few attended on the day.

Sheffield ECMC
[completed original form]

Sheffield: response
This section was completed by the Sheffield ECMC PPI representative Ms Jacqui Gath.

PPI activities undertaken by the Yorkshire and Humberside Consumer Research Panel (YHCRP) continue. Input is provided to ECMC research studies and many ancillary activities. The importance of use of data is fully understood and conveyed to Panel Members, with two members on the Country Advisory Group of DATA-CAN, the Health Research Hub for cancer.

Involvement opportunities are circulated as they arrive, with information which may be useful to patients such as the Red Flags for Spread of Breast Cancer, and The Decision Aid for Preserving Fertility of young female cancer patients returned to the ECMC.

Panel members work with researchers from both University of Sheffield and Hallam University, and universities nationally. They continue to press nationally for travel expenses to be reimbursed for participants in studies, particularly commercial studies, for the use of comprehensive quality of life measures, and recording of data concerning measures the patient has taken to assist their own recovery. In addition, they have lately taken up the cause for results from research to be disaggregated by natal sex, to discover differences in response to treatment between men and women. It is anticipated that such analyses may highlight further opportunities for research and greater benefit to patients. YHCRP have a good working arrangement with ICPV (Independent Cancer Patients' Voice, which widens access to experienced and trained PPI advocates.

Sheffield: case study
NEPTUNE

Locally, two members have given input to the NEPTUNE study (Enhancement of Immunotherapy, combining Avelumab and repeat doses of Radium-223 in ER+ve, HER2-ve metastatic breast cancer), building on their experience working on the CARBON study. Both studies involve the use of a radioactive drug, Radium-223. Care must therefore be taken in the event of the patient's demise shortly after an infusion so that funerary workers are not exposed to radiation. There was a need to approach difficult issues concerning possible delays to cremation after decease, in the patient information document. This topic was not covered in previous studies as it was felt that patients may be distressed, but collaboration produced a very acceptable form of words which was not challenged by Ethics. Letters of support were provided to the funders and Ethics Committee.
Jacqui Gath is PPI representative on the NEPTUNE Trial Management Group and panel members contribute to study meetings on a regular basis.

Southampton ECMC

Southampton: response

Our PPI modus operandi has changed. The model previously adopted outgrew itself and the UHS NHS Trust has developed a dedicated team for PPI. Whilst this is generic and not cancer specific the lead was previously a researcher at the CRUK Centre & it was deemed by our group to be appropriate to hand over to them. Caroline Barker, PPI lead for the Trust, has confirmed that the contact details of our PPI members have been added to the UHS database. If we are approached for PPI interest, by researchers or patients and public then they are signposted to the UHS PPI team.
Our strategy continues to be:

- 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 strategy continues to be relevant as it fits with our close relationship with the UHS team and complements their mission statement:
University Hospital Southampton R&D Department has a PPI team which exists to support clinicians, researchers and patients/public working across our local infrastructure. Our vision for the next five years is to fully integrate PPI into our work, from identification of research questions, through study design, delivery and dissemination, as well as actively seeking and acting on participant feedback. This team also runs a number of PPI projects/activities including a community outreach project to improve diversity in PPI, research around the impact of PPI and providing training for researchers to support delivery of high-quality PPI.

As an ECMC & CRUK Centre we retain links nationally through the ECMC PPI group & CRUK PPI team. Our local focus is via CTU membership on the Trial Review Group, TMGs & TSGs and we recently had representation on The Oesophageal Consortium.

University College London (UCL) ECMC

[completed the original form]

UCL: response

PPI involvement in the dissemination of project outcome

Mekala Gunaratnam was awarded a BRC grant aimed at addressing **PPI in key areas relevant to experimental cancer medicine** – genomics data, routinely collected data and perceptions of risk and benefits of early phase trials. The project was completed successfully and PPI members interpreted the data and conceived and contributed towards the dissemination of the project outcomes. Findings from this project were disseminated via;

- e-poster presentation at the NCRI conference, Nov 2019, Glasgow
- abstract published in British Journal of Cancer – "Patient Perspective of Experimental Cancer Medicine (PpExCaM Survey) – a Patient-led Initiative to Understand the Views of Participating in Early-Phase Trials", Mekala Gunaratnam, Emma Hainsworth, Terry Emmery, Tim Meyer, BJC, Oct 2019.
- CRUK included this project as a case study to share best practice amongst researchers on how best to do PPI. The case study is used for face to face training, as well as online, on CRUK's Researcher Toolkit. Link to the case study - https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers?_ga=2.57537199.403040431.1567694686-1883953093.1549376490

Patient input into dissemination of rare disease trial launch

Trial patient was interviewed and contributed to the BRC's news launch of the Afatinib trial (A phase 2, single arm, European multi-center trial evaluating the efficacy of afatinib as first line or later line treatment in advanced chordoma) which is run at the UCLH CRF, PI Dr Sandra Strauss. Link to the interview - https://www.uclhospitals.brc.nihr.ac.uk/news/researchers-launch-trial-drug-rare-bone-cancer

PPI in Trial Management Group

Lizzie Lloyd-Dehler is patient representative on the PRIMER1 Trial Management Group (study looking at the efficacy of pembrolizumab combined with lenvatinib with that of pembrolizumab and lenvatinib alone in terms of major pathological response in patients with resectable HCC).

Public Engagements

Patients and their family members were invited to join the experts to learn about the research happening in the field of chordoma, a rare cancer with an unmet need of effective therapies - Meet the Experts, chordoma evening, 24th Jan 2020. Prof Adrienne Flanagan led the meeting and Dr Sandra Strauss, as well as other investigator talked about their latest research developments in chordoma. Following the talks, patients and their families had the opportunity to talk to the investigators and take part in lab tours which showcased the research in action.

UCL ECMC continues to take part in public open days and our GCLP Facility took part in the recent Revealing Research: Pursuit of Personalised Medicine event held in Oct 2019. UCL researchers were involved in the development of the event and facilitated visitors on the day of the event. This event was an immersive lab experience themed around personalised cancer medicine. In total 57 people attended the event and provided exceptional feedback. Since the beginning of the current quinquennium we have hosted two very successful events for the public to showcase and promote cancer research at UCL.

War in the Blood', a film about treating cancer patients with CAR T cell therapy (Jul 2019) - a new BBC film looked at the work of scientists at UCL and clinicians at UCLH working together on ground breaking 'first in-human' immunotherapy trials. The programme highlighted the success of UCL's CAR T-cell research, which receives support from various funding streams, including ECMC. Support from ECMC funds a full time Immunotherapy Technician (Mahnaz Abbasian) who is critical to the programme and leads the manufacturing of CRA T- cells for patients recruited to this portfolio of studies.

Acronyms in the document

AI	Artificial Intelligence
BRC	Biomedical Research Centre
CCC	Clatterbridge Cancer Centre (Liverpool)
CLL	Chronic Lymphocytic Leukaemia
CLLSA	Chronic Lymphocytic Leukaemia Patient Support Group
CLOCS	Cancer Loyalty Card Scheme
CRF	Clinical Research Facility
CRUK	Cancer Research UK
CTEC	Clinical Trials Executive Committee (Glasgow)
CTU	Clinical Trials Unit
DATA-CAN	UK's Health Data Research Hub for Cancer
DDU	Drug Development Unit (Institute of Cancer Research / Royal Marsden Hospital)
ECMC	Experimental Cancer Medicine Centre
GCLP	Good Clinical Lab Practice
HCRW	Health and Care Research Wales
ICF	Informed Consent Form
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
MCRC	Manchester Cancer Research Centre
MOOC	Massive Open Online Course
NCRI	National Cancer Research Institute
NICRCF	Northern Ireland Cancer Research Consumer Forum (Belfast)
NLMT	National Lung Matrix Trial
PGJCCR	Patrick G Johnston Centre for Cancer Research (Belfast)
PI	Principal Investigator
PIS	Patient Information Sheet
PM	Precision Medicine
PPI	Patient and Public Involvement
PREM-ECM	Patient Reported Experience Measures for Experimental Cancer Medicine (Manchester)
R&D	Research and Development
R&I	Research and Innovation
SELCRP	South East London Consumer Research Panel (King's Health Partners)
SME	Small and medium-sized enterprises
SOP	Standard Operating Procedure
TMG	Trial Management Group
TSG	Trial Steering Group
UCL	University College London
WCRC	Wales Cancer Research Centre
YHCRP	Yorkshire and Humberside Consumer Research Panel (Sheffield)