



CRUK-KolGo Trg Patient Public Initiative Group Planning



CONTENTS

Introduction

Creating links with Patient and Public

Patient and Public involvement in research- a brief summary

Patient and Public involvement in the research cycle

Appendix

Introduction to PPI





Patient Public Involvement

Patient Public Involvement or PPI(also called lay involvement) is the process of involving the survivors(patients affected with cancer and their relatives) into research for incorporating their ideas and ideals into the development and formation of a research question. Patient involvement is different from Patient participation, since a PPI actively participates in structuring the research and act as co-researchers.

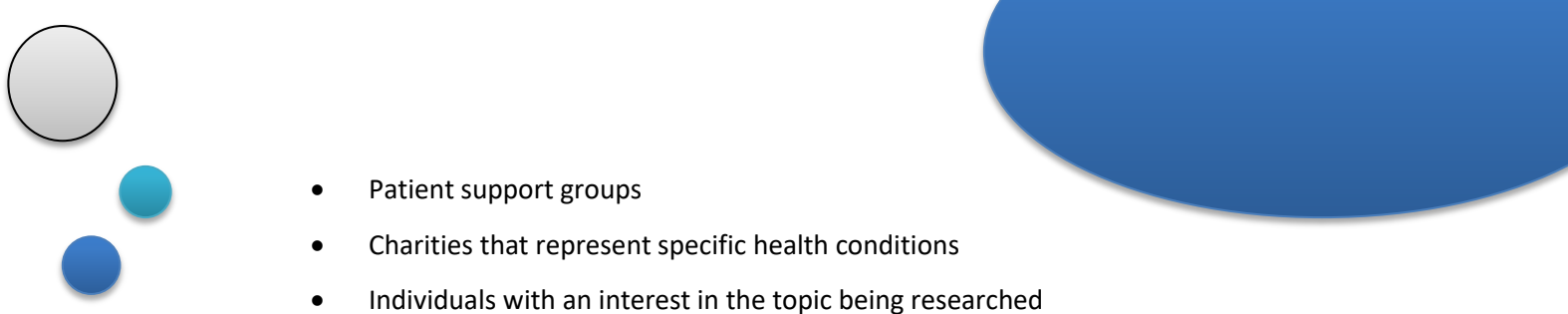
Though researchers are very familiar with disease condition, they need support from patient groups or survivors having wider knowledge about living with the disease and going through the course of treatment. This makes them the ideal person to provide information regarding the possible problems that a researcher can face when dealing with patients, how to deal with such problems and what are the possible alternative strategies. They help to provide information on why and what necessary modifications need to be done from the eyes of a lay person with a history of a disease.

The Patient group works actively with the Research team in the process of :

- Prioritising studies
- Identifying the research question
- Identifying possible changes needed in the study protocol
- Involving more patients into the study
- Assisting in data collection
- Evaluating the results of the study
- Dissemination of the results

Who can be the members of Patient Public Involvement Group?

- Patients affected with or have recovered from cancer.
- Patient carers(unpaid) and family members
- Parents
- Members of the general public
- Organisations who represent patients and users

- 
- Patient support groups
 - Charities that represent specific health conditions
 - Individuals with an interest in the topic being researched

Importance of Patient and Public Involvement

The contribution of the survivors in the research is extremely valuable as it can provide views from a perspective different from the research team. While the research team is more focused on the scientific aspect, the PPI team can provide a wider patient centred perspectives and aspirations which can be extremely useful to identify the real challenges and make necessary amendments which the researchers and health care professionals may not have considered or missed out. This is why most of the International funder organizations focus on PPI activities.

Patient Public involvement in KolGoTrg

KolGo Trg commits to develop the best research studies in India for the benefit of the women affected with cancer in general and the society as a whole. We already have a cancer survivor group called “Sarbojaya” formed of cancer survivors in 2018. Named after Goddess Durga, an epitome of power, strength and women empowerment, the group aims to bring together women cancer survivors in all walks of life for empowering other cancer affected individuals through awareness, survivorship programs and cultural meetings. KolGo Trg is working with support from Cancer Research UK(CRUK) PPI team and has modified CRUK PPI toolkits to develop a stronger PPI group which can be involved in planning, decision making and execution of our upcoming and future studies

Creating links with Patient and Public





How to contact patients to join the PPI group

Since PPI group consist of patients and their relatives involved in research, it is imperative to build rapport with patients and encourage them to join the group.

The patients can be contacted by either the research team, or the healthcare workers at any point of their treatment. Participation by the patient or the relatives is completely voluntary.

Clinics: Patients attending clinics can be asked to participate in the research and join the Patient and Public Involvement group. They can be asked by the research nurses, the clinical doctors or any member of the healthcare team.

Patient groups and charitable organisations: Organisations which deal with women cancers can be linked with and discussed the options of involvement in the PPI group.

Clinical Research Networks: Various national and international research networks aim to help organisations in setting up their PPI groups for the betterment of research. Currently Cancer Research UK is helping us in developing and standardising the PPI group. They have also agreed to advertise for our PPI activities in their bi-weekly newsletters/mails. We expect other world organisations such as World Cancer Coalition to assist us in further standardisation so that our PPI group module can be accepted and implemented in other low middle income countries of the world.

KolGo Trg Website: Our website will host various PPI activities and anyone interested can join the PPI group either through the web portal or by contacting us. Currently we are designing our website and these features will be available soon.

Blogs, community boards and newspapers: Various blogs, community boards and newspapers advertise patients and/or relatives affected with cancer to participate in their patient public involvement activities.

Ethics and Consent

For participating in the Patient Public Involvement group, there is no requirement of consent, as participation is completely voluntary.

● Patient-Public Involvement in research-A brief summary





Method of Patient and Public Involvement

Identify the topic

The first step in involving the PPI is to identify the research question by the research team. The topic of interest in relevance to the study will be identified by the research team and will be conveyed to the CRUK team as well.

Planning the patient involvement

Patient involvement must always be done before starting the group. This helps to deliver a successful and purposeful experience to the research team and the patient volunteers. A worksheet designed by CRUK explaining what problem is being solved, the target audience, method of involvement etc., can help in the planning phase beforehand. (Appendix A)

Aims and objectives:

The aims and objectives of the CRUK-KolGoTrg PPI group initiative will be:

- a) To create a Patient group that will help to clarify and affirm the research question from a patient point of view
- b) review the research question and help in making necessary amendments
- c) Identify any barriers associated with the research proposal.
- d) Plan for future PPI activities.

Our objective is to encourage patients to share views, bounce ideas off each other and engage in constructive conversation/debate. This can uncover perspectives and ideas that may not show up by speaking with patients individually.

To identify the aims and activities of a particular research question, the researcher must ask what is the topic of interest, what are the problems which the researcher is trying to solve, how can patient involvement solve the problem and how will the questions be asked to them.

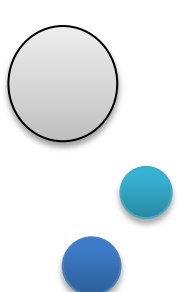
Pre-planning of evaluation

During the planning phase the researcher must plan how will the results of the PPI activity be evaluated. During this time the researcher must also plan regarding how to keep the patient group updated regarding the research results and inform them about the contribution they have made in developing the research.

Choosing the patient involvement method

The researcher chooses the patient involvement method depending on the degree of commitment, type of data and the sample size the researcher wants from the patient and public group.

- a) Identify target audience: Target audience must be identified for joining the PPI group. Identification can be done on the basis of the personal experience, expertise or diverse population.

- 
- b) Budgeting for patient involvement: Budget involvement should be done in accordance to the type of patient group involved, amount of honorarium to be paid, venue hire, transportation costs, foods and so on. Usually Research group has to look forward for the following expenses:

- i) Patient expenses
- ii) Patient payment or honorarium
- iii) Carer costs
- iv) Venue hire
- v) Food
- vi) Cost of an external facilitator
- vii) Training and learning
- viii) Advertising costs

Expenses for the patients can be in the form of:

- i) Rail travel
- ii) Taxis and cars
- iii) Flights
- iv) Office expenses
- v) Overnight accommodation
- vi) Carers

All the survivors are doing this out of goodwill and hence there is no current planning for monetary allowances. They would be invited in our International Research Days and Annual KolGoTrg Meetings.

For calculation of expenses and budgeting the INVOLVE Budget calculator can be used which is available at <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

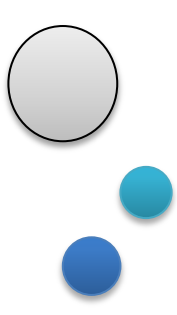
Comparison between different types of patient involvement groups on the basis of sample size, cost effectiveness and type of study are available in Appendix B.

Recruiting Patient Involvement Activity

Patient recruitment should be done to identify which patient involvement group suits best for the particular study. Surveys do not require any interview process to invite maximum number of patients available. For focused groups the patients can register their interest using the Registration form to identify their previous experience of cancer and give them a brief idea about the importance of them participating in the study. An example of the Registration form is given in Appendix C. Patient representative recruitment require an interview similar to a job interview.

The recruitment process should be in the following manner:

- i) Advertise- Advertisement can be done in various communities, blogs, websites, social media or it can be in the form of email newsletters, posters and flyers. . We plan to design our website to add links which will redirect interested patients to access a CRUK-KolGoTrg web portal that will enable them to register their interest for joining PPI groups. There would be brief knowledge provided in the website about the studies in process and the studies currently running.
- ii) Expression of interest: Interested patients can be asked to get in touch where they will be provided their Role Profile depicting their roles with respect to their skills and experiences(Appendix D), and their application form stating they have read their roles and



responsibilities(Appendix E). Patients and/or relatives are supposed to fill up the form and submit online or fillup and return the filled form to the research team directly or via post. Once we receive the requests, the patient groups will be sub classified on the basis of the study design and interest of the candidates in the next steps

- iii) Shortlisting and communicating the shortlisting outcomes: Once the patient list is shortlisted, the results should be communicated to them via mail or a telephonic call. Since the group is on the designing phase, we would like to accept all interested volunteers. Shortlisting will be done at a later stage when the group will be running smoothly and we would have a huge influx of interested participants.
- iv) Interview: An interview can be done after the recruitment to identify whether the selected candidates are perfect for their role. The questionnaire will identify the level of motivation, skills and previous trainings undergone by the patient group. A format of Interview questionnaire is given in Appendix F.
- v) Communicate interview outcomes: The interview outcomes should be given to the patients via telephonic call on information regarding how the induction will take place, when the first meeting will take place, and who will be the key contact person. Regular contact should be maintained till the start of the sessions.

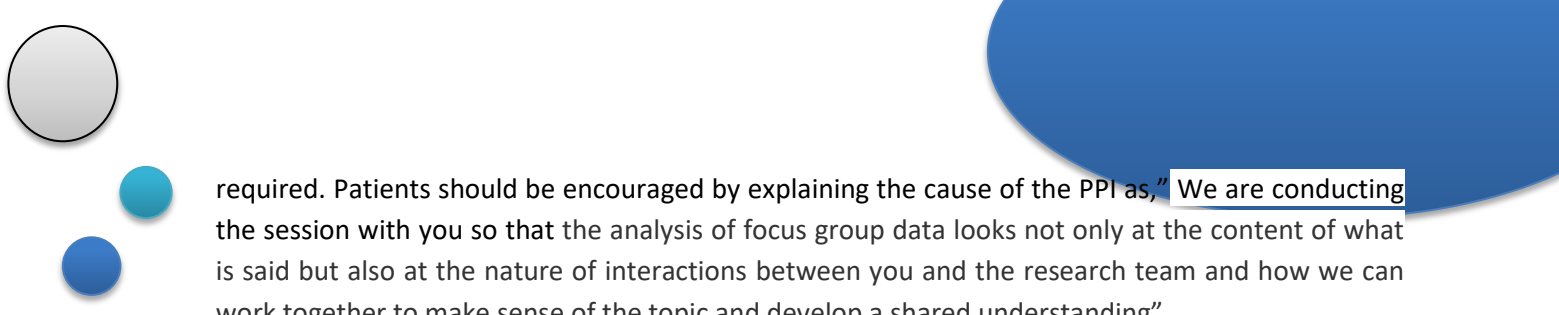
For the preliminary studies we plan to empower the focus group “Sarbojaya”. This group will be the main PPI group which will be sub classified on the basis of on-going studies and the number of patients interested for participating in the studies. One member can join two research group PPIs simultaneously. The meeting days would be different hence there would be no collision of work. Currently we have 5 active patients; hence we would encourage more patients to join through OPD-based awareness on PPI groups and informing them about our advertisement.

Preparing patients for Patient Involvement Activities

Patient groups may or may not require certain training activities to prepare them for their job. Usually Survey groups do not require much education. Interview and focus groups require a pre-read to enable them contribute to the involvement activities; while the Patient representative and the Patient advisory groups should be given an induction and training to meet the expectations such as being professional, asking questions when needed, preparing for meetings beforehand, attending them regularly and so on. The Expectations agreement is given in Appendix G.

The patients can be given a pre-read describing why the patients are being included, the topics that the patients could pre-read and prepare themselves, any questions they want to consider while doing their pre-reads, background information, how their feedback will be used and so on. An example of a Pre-read is given in Appendix H. An induction pack can also be sent with the Pre-reads to describe their role status, a brief about the grant, other links for further knowledge and what other topics that need to be covered in the future meetings. (Appendix I)

Patient induction should be done depending on the number of patients and the role assigned to each of the patients. The induction can take 1-6 hours depending on the degree of discussion



required. Patients should be encouraged by explaining the cause of the PPI as, "We are conducting the session with you so that the analysis of focus group data looks not only at the content of what is said but also at the nature of interactions between you and the research team and how we can work together to make sense of the topic and develop a shared understanding".

A detailed session plan describing how to introduce the topic and group, ice breaking, what activities need to be done and what discussions should be covered, helps to smoothly run an induction process. An example of induction is present in Appendix J.

A preliminary work plan for patient induction will be sent to all the patient participants. They would be given the date, time and venue of induction. The meeting would provide a highlight about the on-going studies and a glimpse of the upcoming studies. We plan to create a job description of the patients and would elect a patient representative who could act as the main spokesperson. The main coordinators of induction would be Dona/ Aparajita and the research team would be there to assist. Delivery of induction would be similar to CRUK, the CRUK team has agreed to assist us regarding planning of the meetings. We are also planning to involve other organisations to assist us in due course of time. We plan to perform this physically but may occur via Zoom in response to the current COVID 19 outbreak.

Delivering Patient Involvement

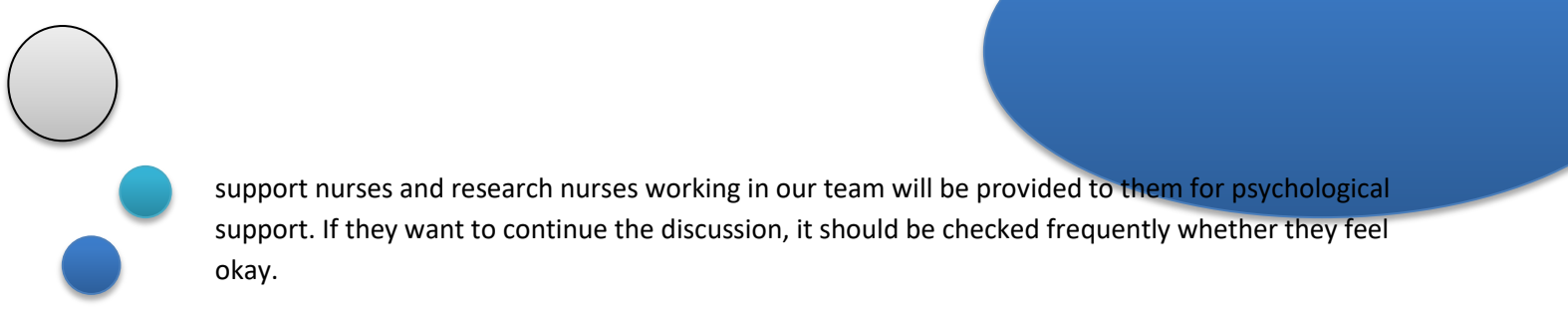
Once inducting the patients is done, Patient involvement meeting needs to be done. Basic preparations like arranging catering services, charts, posters, markers, feedback forms, ny additional paperwork etc. should be done beforehand. The facilitators should be supportive and stimulating, should have capacities of team building and keep the patient group focused while keeping track of time. A warm, non-judgemental approach should be followed, patient's thoughts should be actively listened to and their judgements should be kept in notes.

Open questions should be asked to the public to get wider feedbacks. Car parks and flip charts should be available to the PPI group so that they can make notes of topics they feel to have been missed out during the discussion.

Patients can provide their response through activities like listing, sorting, ranking etc .This kind of activities are more comfortable with those participants who are less comfortable with immediate verbal responses and need extra time for thinking. This will help people to enjoy the sessions rather than feeling bored after a sequence of verbal questions. Activity oriented questions can also be appropriate for talking about sensitive topics, which can be discussed through practical and enjoyable tasks.

The planning for discussion would be done using the CRUK tool. A brief summary of the study will be done by PowerPoint presentation and interactive discussion in local dialect. The meetings would highlight the study in question and the participant's responses and concerns related to the study protocol would be noted by the research team.

Since the discussion can become emotional at times, if a patient feels uncomfortable or breaks down during the discussion, emotional support will be given to them, allowing them to have a moment for themselves or leave if they feel too burdened to stay for long. Contact details of



support nurses and research nurses working in our team will be provided to them for psychological support. If they want to continue the discussion, it should be checked frequently whether they feel okay.

We plan to record the session to revisit any important points we might have missed out. Also, we would be taking notes of all the responses by the participants. There would be car parks on the halls where the participants would write their concerns or feedbacks during breaks or along the discussion.

Final stages of Patient Involvement

After the Patient Involvement activity, patients should be encouraged more for future participation by saying a Thank You to make them feel valued. If the patients are supposed to receive any honorarium or outstanding payment the additional documents should be sent to them. An essential step after patient involvement is keeping them updated about the research by informing them about the research question, the questions asked to them, their feedbacks and how it has helped in restructuring the research protocol.

Improving the outcomes

To improve the patient involvement outcome, a feedback form will be given to the patient group at the end of the discussion session which they can fill and return on the same day or the next day or can email or post us within a stipulated time period. The feedback form would help us understand how well the patient understood, what they felt were more interesting during the discussion and how to improve the activity in the future.(Appendix K)

Assessing if the involvement met the needs

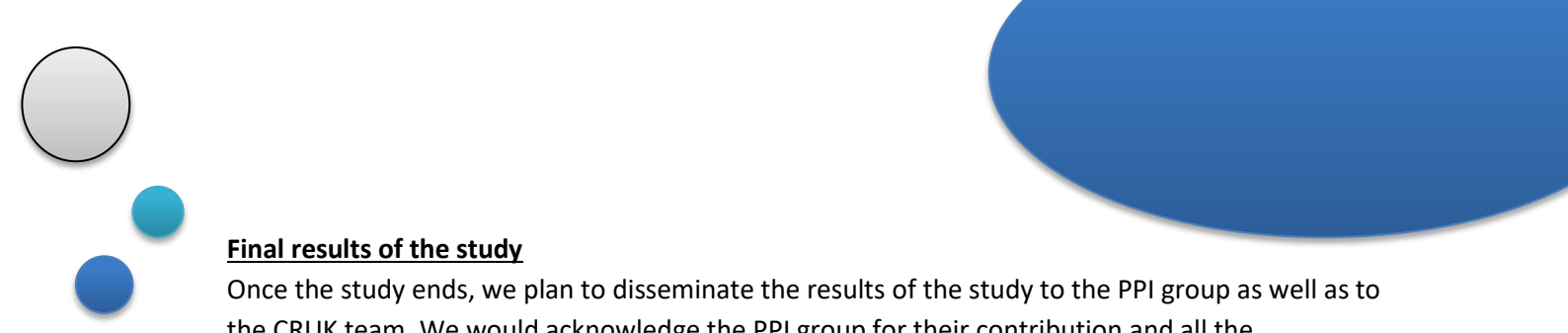
Once we have recorded the participant response, we would hold a research group meeting along with the supporting organisations regarding planning the impact for the research question, prioritising the questions, incorporation into the protocol, methods of acknowledging the patients and feedback on how to improve the next research meeting.

Following discussion, if it is felt that more patient group involvement would suit to address the question better, then further planning for Patient group involvement should be done. More than one type of patient group can be addressed for better clarity in research.

Demonstrate the impact

After completing all the steps, it should be demonstrated how the patient involvement activity helped in shaping the research. The impact can be positive, negative or there can be unplanned events. The involvement may or may not lead to change, but will increase the level of motivation and skill of the researcher, and can bring the researcher and team closer to the cause.

The research team will be responsible for modifying, designing and delivering the research in accordance to the feedback from the participants and CRUK team. The Research team would update the CRUK team regarding implementation of the research and any further modifications made. We intend to meet the PPI team quarterly to update them about the on-going research



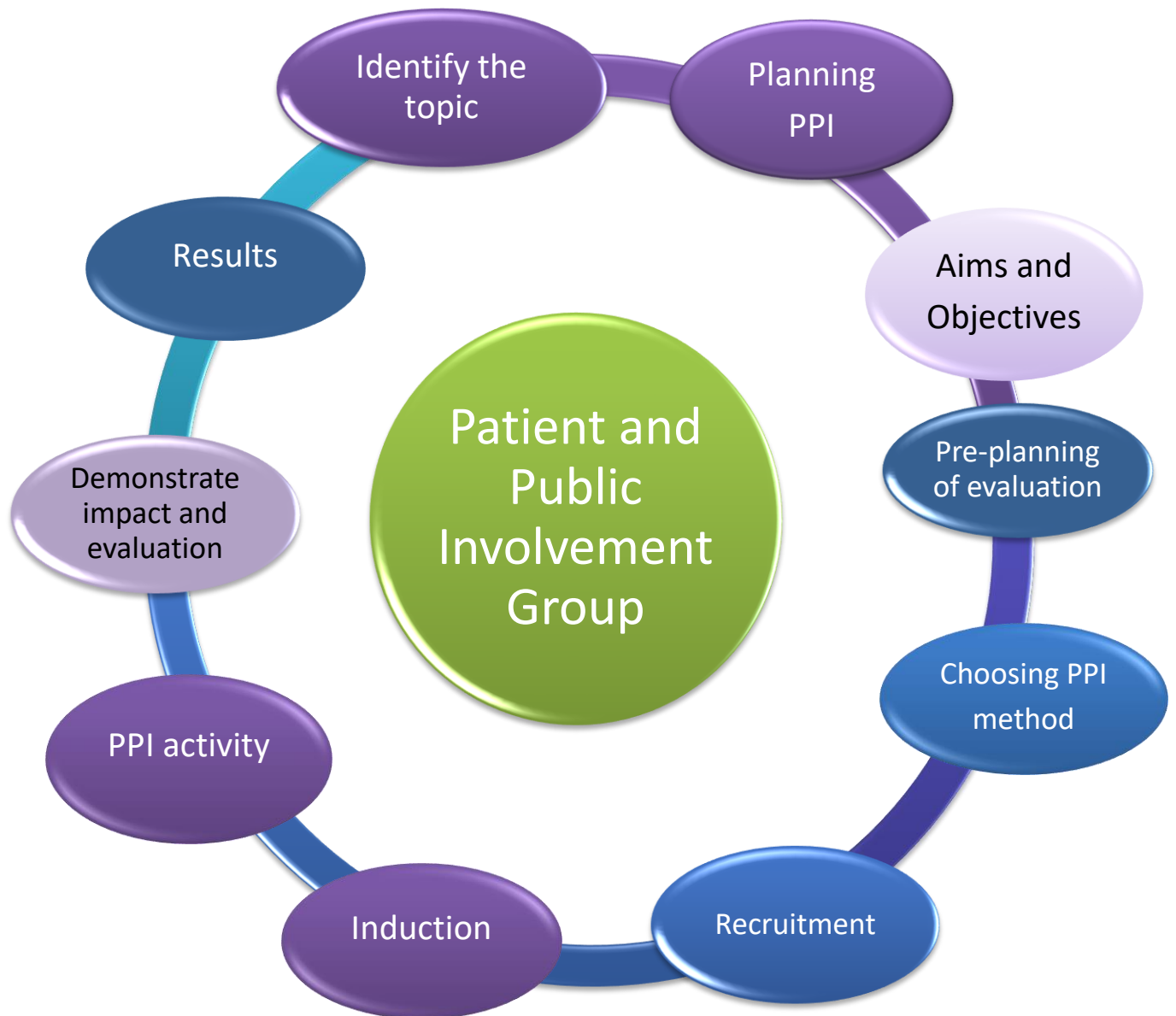
Final results of the study

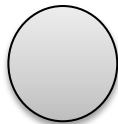
Once the study ends, we plan to disseminate the results of the study to the PPI group as well as to the CRUK team. We would acknowledge the PPI group for their contribution and all the organisations that have helped us in the process of the Patient Public Involvement cycle.

The Patient Public Involvement Cycle

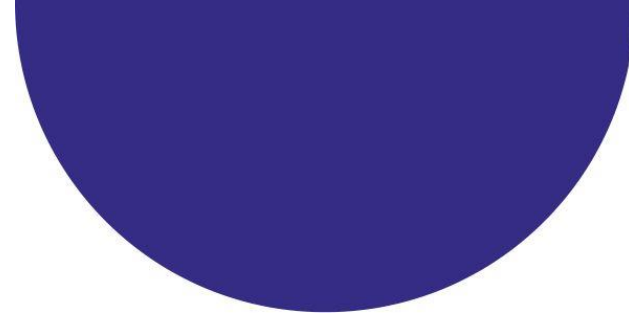


The Patient Public Involvement Cycle is as follows





APPENDIX

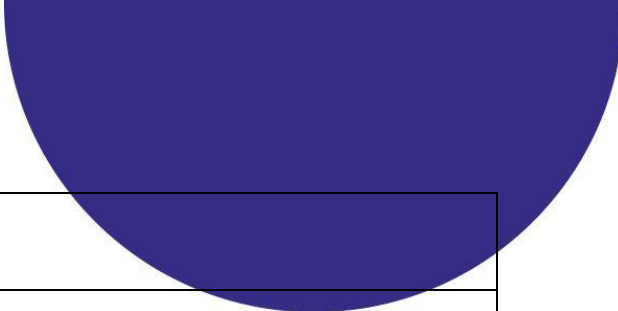


Appendix A.

PLANNING YOUR INVOLVEMENT WORKSHEET

Notes: This worksheet has been developed to help researchers plan their patient involvement activities. You should fill this in once you have read through the Patient Involvement Toolkit for Researchers.

What problem are you trying to solve?
How can insights from patients help you solve this problem?
What questions do you need to ask them to gather this insight?
At what stage/s of your research do you want to involve patients?
Who is your target audience? What experience or skills do they need?
What method/s of involvement will you use?
How will you recruit them?
































What information, training or support will they need?

What do I need to do to successfully deliver the involvement activity?

How will you evaluate the patient involvement?

APPENDIX B

PATIENT INVOLVEMENT METHODS

SURVEYS	INTERVIEWS	FOCUS GROUPS	PATIENT REPRESENTATIVES	PATIENT ADVISORY PANELS
<p>A set of questions designed to gather opinions and perspectives from many people to inform and shape your research project. This should not be confused with conducting a survey as part of your research. They are time efficient and it's rare to offer payment for this.</p> <p>£ £ £     </p> <p>ADVANTAGES:</p> <ul style="list-style-type: none"> • Large sample • Time efficient • Responses can be analysed with quantitative methods • Honest insights <p>DISADVANTAGES:</p> <ul style="list-style-type: none"> • Can't clarify questions or answers • Can't gather in depth insights • Limited on the type and number of questions 	<p>An in-depth conversation that allows you to gather rich information. Interviews can be conducted face to face or over the phone and can be structured, semi-structured or informal. Expenses (if face to face) and an optional payment is provided to patients.</p> <p>£ £ £      </p> <p>ADVANTAGES:</p> <ul style="list-style-type: none"> • Good for complex issues • Can clarify questions or answers • Rich qualitative information • Honest insights <p>DISADVANTAGES:</p> <ul style="list-style-type: none"> • Small sample size • Time consuming 	<p>An event where you bring a group of people together to take part in well planned and facilitated discussions on a topic. You can use different activities and facilitation techniques to gather insights. Focus groups generally run over a half or full day. Expenses and an optional honorarium are paid to patients.</p> <p>£ £ £      </p> <p>ADVANTAGES:</p> <ul style="list-style-type: none"> • Good for complex issues • In depth discussion • Group can bounce ideas off each other • Many techniques for gathering insights <p>DISADVANTAGES:</p> <ul style="list-style-type: none"> • People can be influenced by others' opinions • Time consuming • Higher expenses • Not always accessible to some groups 	<p>Patients that sit on an existing project team or steering group alongside other experts. Ideally there should be at least 2 patient representatives. This provides another patient perspective and peer support. Patients will receive training and an induction. Expenses and an optional honorarium are paid to patients at an equal rate to other steering group members.</p> <p>£ £ £      </p> <p>ADVANTAGES:</p> <ul style="list-style-type: none"> • Expertise increases with time • Keeps research focused on patient benefit • Act as critical friends • Ongoing feedback and discussion throughout your research project <p>DISADVANTAGES:</p> <ul style="list-style-type: none"> • Patients can become experts (so are no longer 'lay') • Can require a lot of support • Limited number of perspectives • Higher expenses 	<p>A group of patients that provide feedback and new perspectives over a longer period. They receive training and an induction. Expenses and an optional honorarium are paid to patients.</p> <p>£ £ £      </p> <p>ADVANTAGES:</p> <ul style="list-style-type: none"> • Can build rapport • Range of skills and experiences • Expertise increases with time <p>DISADVANTAGES:</p> <ul style="list-style-type: none"> • Require a lot of support • Friendships can change group dynamic • Patients can become experts (so are no longer 'lay') • Higher expenses



APPENDIX C

[INSERT NAME OF INVOLVEMENT ACTIVITY] REGISTRATION FORM

***Notes:** This is a template and example of what a registration form for a focus group or other involvement activity could look like. This example is from a focus group held to understand the priorities of patients and the public in early detection research. Please amend to suit your needs.*

Why we need your views:

Spotting and treating cancer in its early stages remains the most powerful way to give patients the best possible chance of surviving the disease. It could also lead to the detection of pre-cancerous stages and interventions that enable people to take action to stop cancer from developing in the first place.

Early detection of cancer is a relatively new and growing field of research. It is important that researchers understand what matters most to patients and the public when undertaking early detection research. We're holding a focus group to hear your views to help ensure that the research we fund is focused on what matters most to patients, the public and people with an increased risk of developing cancer.

You can read more about what early detection research for cancer is on our website here:

<http://scienceblog.cancerresearchuk.org/2016/09/14/strengthening-the-foundations-for-early-detection/>

Who should attend?

At Cancer Research UK we listen to, and work with, people from all backgrounds, cancer experiences and age groups. At this event we would like to hear from people who have cancer, have survived cancer, or who have a high genetic risk of cancer (e.g. BRCA mutation carriers). We also want to hear from members of the public who have not been directly affected by cancer but who are interested in 'early detection' research.

Details of the day:

Please hold the date **Monday 12th March (6-9 pm)**. Attendees will be selected on the week of the **23rd February** and you will be notified of the outcome (this registration form does not guarantee a position at the workshop).

The workshop will be held at the Cambridge University (Cavendish Laboratory, JJ Thomson Ave, Cambridge CB3 0HE). Refreshments will be provided, reasonable travel expenses reimbursed, and we are able to offer an optional £50 honorarium as a thank you for your time.

What to do:

Please fill in the table on the next page and provide back to involvement@cancer.org.uk by **Monday 26th February**.



Why are we asking these questions?

It is really important to Cancer Research UK that we are capturing a wide variety of views and opinions from people from all backgrounds and experiences. As places are limited, the information you provide below will assist us in making sure we have a mix of people in attendance.

Please fill in all the boxes below. If you have any questions, please don't hesitate to contact involvement@cancer.org.uk

Name:	Date of birth:
Address:	
Telephone:	Email:
Experience of cancer:	<input type="checkbox"/> I have/have had cancer <input type="checkbox"/> I have high genetic risk of developing cancer <input type="checkbox"/> Someone I am close to has/had cancer <input type="checkbox"/> No one close to me to has/had cancer
Have you participated in a focus group or consultation with us before?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure



Appendix D

[INSERT NAME OF INVOLVEMENT

ACTIVITY] ROLE PROFILE

Notes: This is an example of what a role profile could look like and the types of information to include. The example used here was for a patient representative on the Cancer Research UK Experimental Cancer Medicine Centres Network Steering Committee. Skills and experiences required here were quite advanced. So not all will be relevant to your involvement opportunity. Please amend to suit your needs.

TYPE OF OPPORTUNITY	TIME COMMITMENT	HONORARIA AND EXPENSES
[e.g. Patient representative]	[e.g. Annual committee meeting 2 year term]	[e.g. Travel expenses and optional £80 honorarium per meeting]

OPPORTUNITY SUMMARY

Summary: Outline briefly **why** you are recruiting people and **what** their role will be. This may include information about the type of involvement, the number of people that you are recruiting, and what sorts of activities they may participate in. For example:

If you're interested in the development of new cancer medicines, we have an exciting opportunity to become a member of a new steering committee. We want to ensure that the patient voice is represented on a new committee for our Experimental Cancer Medicine Centres (ECMC), which aims to speed up the development of new cancer medicine and other interventions to really benefit patients.

The ECMC Network Steering Committee has oversight of the activities of the ECMCs. We are looking for a person affected by cancer who could provide critical and constructive feedback to join the Committee.

You will attend annual meetings and be an active member of the committee, bringing your cancer experience and ensuring that the patient voice is represented and considered as part of our decision making.

Length of role: Two years, with the opportunity to extend. There will be one Network Steering Committee meeting per year in London with approximately 2-3 hours at home pre-reading.

Expenses: We're able to reimburse reasonable travel expenses for travel and subsistence in accordance with our policy. We can also offer an optional honorarium of £80 for attendance and participation in ECMC Network Steering Committee meetings.

YOUR SKILLS AND EXPERIENCES

We are looking for people who...

You will have developed a list of skills and experiences required for this role when identifying your target audience. Refer to the Patient Involvement Toolkit for Researchers for more information on this.

- Have experience of cancer either as a patient, carer, or relative
- Have an understanding or knowledge of the research process for early phase cancer research studies
- Have prior involvement as a lay representative
- Are able to provide critical and constructive feedback
- Have good IT, analytical and networking skills
- Have confidence to voice their own opinions clearly and participate in group discussion
- Have the ability to listen and respect differing opinions
- Have an awareness of equality and diversity

You do not need to have...

- Been on a clinical trial or have a research background

YOUR ROLE

You will be required to...

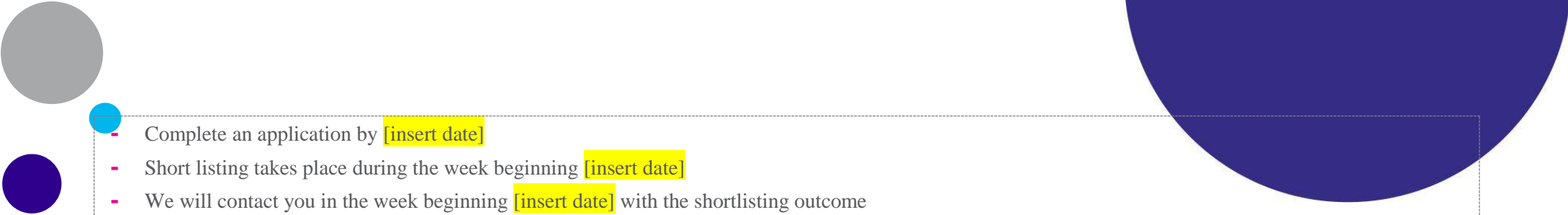
- Attend and take an active part in one ECMC Network Steering Committee meeting per year in London
- Prepare for each meeting by reading any paperwork required
- Share your opinion and give advice
- Ensure that discussions consider how the work fits with our research strategy and is helping to drive patient benefit
- Ensure the network is robust in terms of its objectives, performance measures and research priorities in delivering cancer treatments for people affected by cancer
- Provide a lay perspective on operational and strategic issues
- Provide effective leadership to the ECMC network and deliver the vision in accordance to the values of the ECMC network
- Respect the viewpoints of others in the group

WE WILL SUPPORT YOU BY...

- Providing an induction to the ECMC network and the function of the ECMC Network Steering Committee
- Ongoing support from an ECMC Programme Office member of staff
- Adhoc training as identified by the patient representative and Programme Office
- Inviting you to be an observer on the ECMC Patient and Public Involvement Group

HOW TO APPLY

- Request an application form from [\[insert email\]](#)

- 
- Complete an application by [insert date]
 - Short listing takes place during the week beginning [insert date]
 - We will contact you in the week beginning [insert date] with the shortlisting outcome
 - Interviews take place on week beginning [insert date]
 - The first meeting of [insert opportunity] will take place in [insert date] in [insert location]

ADDITIONAL BACKGROUND INFORMATION

Provide additional background information to give more context to the role and the role of the committee or steering group.



Appendix E

[INSERT NAME OF INVOLVEMENT ACTIVITY] APPLICATION FORM

Notes: This is a template of what an application form could look like for patient representative and patient panel roles. Please amend to suit your needs.

HOW TO APPLY

- We welcome and value the insights and experiences of people from all backgrounds.
- If you need assistance in completing this form or have any questions, please contact [insert email].
- Please complete the application form below and send it to [insert email] by [insert date]
- The information you provide here will assist us shortlist applicants.
- We will let you know if you have been shortlisted in the week beginning [insert date].
- If you are invited to take part in a telephone interview, these will take place in the week beginning [insert date].

Name:		Are you over 18 years old?
Address:		
Telephone:	Email:	
How would you prefer to be contacted (phone / email / text / post)?		

Please tell us why you are interested in [insert opportunity name] (500 words maximum)

(Is there a specific element that you find particularly exciting? Is there something about being involved in [insert opportunity name], that particularly interests you?)

--

Having read the role description and background information, please describe why you would be suited to this opportunity (500 words maximum)

(Please detail relevant skills and experiences, providing examples from your personal life, cancer experience, paid or voluntary work, or training and education).

AVAILABILITY

Interviews for this role are planned to take place in the week beginning [insert date] Are there any dates during the week of [insert date] that you will be unavailable for an interview?



Appendix F

[INSERT NAME OF INVOLVEMENT

ACTIVITY] RECRUITMENT INTERVIEW QUESTIONS

Notes: This is a template of what recruitment interview questions could look like for patient representative and patient panel roles. Please amend to suit your needs.

We recommend having an interview panel of 2 or 3 people. If you are recruiting for an existing patient involvement opportunity we recommend having one of the current or leaving patients sit on the interview panel. Interviews can be face to face or over the phone. If you are doing a telephone interview introduce yourself each time you ask a question, so they know who they are speaking to.

WELCOME AND INTRODUCTIONS

- Thank them for giving up their time to speak with you (make them feel welcomed and valued)
- Everyone to introduce themselves with a short sentence about who they are and what their role is
- The interview format: the interview will last around [insert estimated time], we will give you a quick overview of the role and will take it in turns to ask questions relating to your skills and experiences. There will be time for you to ask questions at the end and it's also an opportunity for you to learn more about whether the role is right for you.
- If at any point you need us to repeat a question, provide more information or ask any questions please feel free to ask.
- If you have a patient on the interview panel it is also worth informing the interviewee that they can ask questions about their experiences of being involved in the role.
- Allow for any questions before you provide a brief overview of the role

OVERVIEW OF THE ROLE

[Insert details about the role – this could be a recap of and in addition to what was provided in the role profile.]

INTERVIEW QUESTIONS AND SCORING FORM

- This form will help you record key details and score each interviewee
- Each panel member should complete one form per interviewee
- Each answer should be given a score using this scale

SCORE SCALE

- 0 = Not met expectations
- 1 = Meets some expectations
- 2 = Meets all expectations
- 3 = Exceeds expectations

NAME OF APPLICANT:

DATE:

PANEL MEMBERS:

MOTIVATION	
1. What was it about the [insert opportunity name] that grabbed your attention and encouraged you to apply?	
<i>We are looking for people to demonstrate in particular: a keen interest in research, a sense of excitement about the role</i>	
<i>Interview notes:</i>	Score [0-3]
2. What is your understanding of the [insert name of committee, organisation or research type]?	
<i>We are looking for some awareness of some of our broad research focuses and research strategy. Note that we will be providing training and induction to patient representative, so we are not expecting applicants to have a lot of knowledge.</i>	
<i>Interview notes:</i>	Score [0-3]

<p>3. Why do you think that people affected by cancer should be involved in discussions with researchers about cancer research? Prompt if required: why not just invite research staff or other healthcare experts?</p> <p><i>We are looking for a recognition that people affected by cancer have valuable experiences to share, that it is important for us to engage and involve people affected by cancer in our work, and an ability to identify opportunities where it would be helpful to gain views of other people affected by cancer.</i></p>	
<p><i>Interview notes:</i></p>	<p>Score [0-3]</p>
<p>SKILLS</p>	
<p>4. What skills and experiences do you feel that you could bring to the role?</p> <p><i>We are looking for an experience of cancer (personally or through being a carer/loved one), experience of taking part in group discussions, skills through employment/work which would be complimentary to our work</i></p>	
<p><i>Interview notes:</i></p>	<p>Score [0-3]</p>
<p>5. [insert opportunity name] members will need to work effectively as a group. Can you tell us about a time where you have had to work as a group, what challenges you faced, and how you overcame them? Prompt if required: Do you think good listening skills are important in this sort of group, and why?</p> <p><i>We are looking for an understanding of diplomacy and tact required in partnership working, ability to understand other people's perspectives/needs, ability to recognise a challenge and ability to work through it.</i></p>	
<p><i>Interview notes:</i></p>	<p>Score [0-3]</p>

<p>6. What patient involvement activities have you been involved in/are currently involved in? Prompt if required: What did you learn from this experience?</p>	
<p><i>Interview notes:</i></p>	<p>Score [0-3]</p>
<p>7. It is important that our patient representative/patient panel are able to draw upon their own experiences, but also to objectively represent the wider views of people affected by cancer. How would you approach this in this role? Prompt if required: For example, how would you seek out the opinions and experience of other people affected by cancer to ensure you are inputting a balanced perspective.</p> <p><i>We are looking for an understanding of the need to represent a range of people affected by cancer and some evidence that applicants have thought about how to do this.</i></p>	
<p><i>Interview notes:</i></p>	<p>Score [0-3]</p>
<p>TRAINING</p>	
<p>8. Are there any aspects of the role that you think will be particularly challenging for you, and how might you overcome these?</p> <p><i>We are looking for people to show that they have considered what the role will involve and have thought about it in relation to their own skills/experiences. Challenges may include representing a range of people affected by cancer, developing specific skills etc.</i></p>	

<i>Interview notes:</i>	Score [0-3]
9. We are committed to supporting you to develop the knowledge and skills you need to do this role well. Is there any additional support or knowledge that you think you might need to help you be an effective [[insert opportunity name]] member?	
<i>Interview notes:</i>	
Final comments:	Total score

OPPORTUNITY FOR INTERVIEWEE TO ASK QUESTIONS

Ensure you have time left for the interviewee to ask questions.

WRAPING UP

- Interviews will be finished by **[[insert date]]**.
- You will be notified of the outcomes shortly after that.
- The induction day will be the week beginning **[[insert date]]**. The specific day will depend on availability of the **patient representatives/patient panel**.
- **[[Insert name]]** is the key contact if you have any questions.
- Thank interviewee for their time.



Appendix G

[INSERT NAME OF INVOLVEMENT

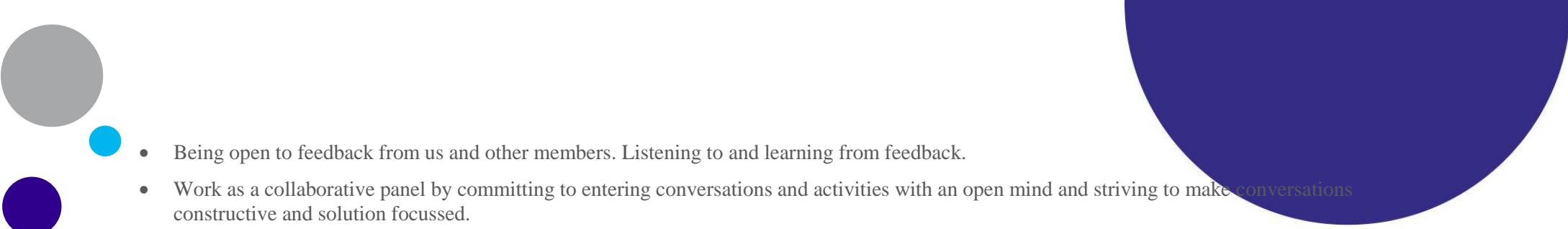
ACTIVITY] EXPECTATIONS AGREEMENT

Notes: This is a template and example of what an expectations agreement could look like for patient representative and patient panel roles. Please amend to suit your needs.

This agreement has been developed with the members of the [insert opportunity name] to enable us all to succeed in our roles. This agreement aims to reflect the commitments that you made to each other, the commitments that [insert your/your organisations name] make to support you and what we ask from you in return.

What is expected of you as a member of [insert opportunity name]:

- Always acting in a professional manner and respect everyone you work with in [insert opportunity name].
- Attending meetings regularly and arriving on time.
- Adequately preparing for meetings, taking the time to read and absorb all pre-read material and emails.
- Asking questions whenever you need clarification.
- Providing responses to input and consultation requests by the due date.
- Contributing constructively at meetings and accommodate for all levels of experience in the room.
- Supporting and listening to your fellow [insert opportunity name] members.
- Co-operating with your key contact and other staff members, being respectful, flexible and mindful of any restraints they are working in.
- Being realistic about what you can achieve and informing us of any change in circumstances and support you may need.
- Giving us plenty of notice if you are unable to attend meetings or meet commitments.
- Promoting a culture of honesty and sharing by raising concerns, issues or suggestions at the time that they arise with your key contact.
- Completing feedback forms when provided and providing ongoing feedback when necessary.

- 
- Being open to feedback from us and other members. Listening to and learning from feedback.
 - Work as a collaborative panel by committing to entering conversations and activities with an open mind and striving to make conversations constructive and solution focussed.
 - We all will foster a pleasant and friendly atmosphere by adhering to the agreed ground rules.

What you can expect from us in return:

- Provision of a key contact to answer questions and support.
- Booking of travel in advance and booking accommodation where necessary.
- Reimbursing any agreed out of pocket expenses within 1 month of receiving your claim.
- Provision of information and support as far in advance as possible, this includes:
 - dates for meetings and involvement activities with agendas and pre-reads.
 - information of additional opportunities as and when they arise via email.
 - a summary of meetings.
- Provide opportunities for feedback through a debrief form and welcoming feedback at any point. We will use this to continually improve the project and how we support you.
- Providing feedback to you when necessary or requested and encouraging two-way communication.
- Providing opportunities to socialise with the group and learn as a team, within the budgetary constraints of the project.
- To be respectful to you, to listen and learn from what you have to say and, where appropriate, feedback on how your views have influenced our work.

I agree to adhere to this expectations agreement.

Name **Signature** **Date.....**

Appendix H.

[INSERT NAME OF INVOLVEMENT ACTIVITY] PRE-READ

Notes: This is an example of what a pre-read (in this case for a focus group) could look like. Include information that is relevant to your session. A good pre-read should provide enough information, so patients can confidently participate, but not too much that it is overwhelming. You should make it as easy as possible for patients to prepare appropriately.

The level of information you need to provide will depend on the topic being explored and your target audience. The target audience for this focus group was patient representatives who sit on Cancer Research UK funding committees. This was because they have a greater understanding of how our funding processes work and could provide relevant insight. Therefore, the level of information was more than what would be provided to patients getting involved with us for the first time on a different topic.

If there is something you would like patients to do to prepare, include instructions here. If there are particular questions you want them to consider while completing their pre-reading, we recommend providing a worksheet with space for them to write their answers.

Use this to get an idea of what a pre-read could look like. Please amend to suit your needs.

We are so excited for you all to join us in [location] on [insert focus group date].

There is a lot to cover so we thank you for taking the time to complete your pre-reading in advance. This pre-read will give you an overview of what we will cover at the [insert name of involvement opportunity] and will prepare you to participate in the activities on the day.

CONTENTS

Topic	Page
Important information	2
What we'll cover during the focus group	3
Pre-read material	4
Shared principles	6

Checklist	7
Contact	7
Guided notes	8

IMPORTANT INFORMATION

DATE AND TIME

24th April 2018

12.30pm (for a 1.00pm start) – 4.00pm

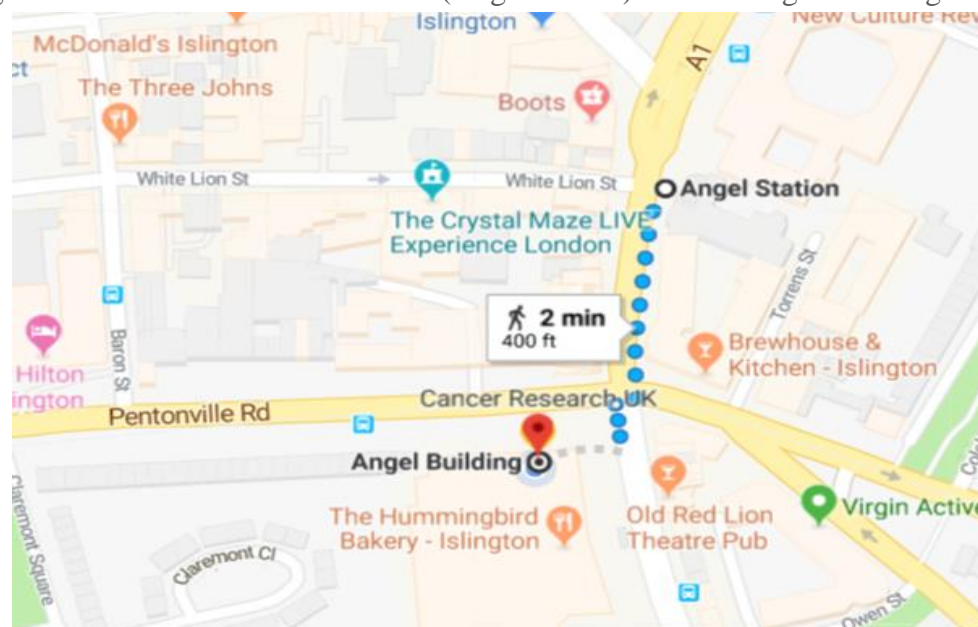
VENUE

Angel Building

407 St John Street

London EC1V 4AD

The map below shows a walking route between the nearest station (Angel station) and the Angel Building.





GETTING THERE

Upon arrival, please check in with the reception desk. [insert name] will then collect you from reception.

Reasonable travel costs will be reimbursed in accordance with our expense policy. We can book your travel for you. If you would like us to do this or have any questions, please email [insert email address].

CONTACT ON THE DAY

If you have any issues or need to contact someone please call on the day of the [insert name of involvement opportunity] please call [insert name] on [insert number]

WHAT WE'LL COVER DURING THE FOCUS GROUP

FOCUS GROUP AIMS

We want to work with you to:

- Identify points in the funding process where patient input could have impact
- Identify which areas of early detection research could benefit from patient and public involvement

We will use the insights from this focus group to inform:

- a) how we include patients and the public in the funding decision process
- b) how researchers applying for funding can meaningfully involve patients and the public.

TOPICS WE'LL COVER

Early detection research

- What is it?
- The Early Detection Research Funding Committee

Patient involvement in early detection research

- What is patient involvement?
- What have we done so far to involve people affected by cancer?

- 
- What is your role in today's focus group?

Applications to the early detection research committee - activity

(make sure you have completed all your pre-reading for this)

- Describe the types of applications that EDx Committee receives
- Discuss where there may be opportunities for patient involvement in the different applications and in their assessment

Funding timelines – activity

- Identify when researcher-led and CRUK-led patient involvement could take place during the funding process
- What are the pros and cons of these models?

Summary discussion

- Discuss key themes and propose recommendations for patient involvement in early detection research and funding process

PRE-READ MATERIAL


ABOUT EARLY DETECTION RESEARCH

Early detection research focuses on detecting cancer as early as possible or even before cancer appears. This allows patients to receive treatment before their cancer has spread or caused serious problems.

Current early detection research seeks to develop simple, non-invasive tests, such as blood and urine tests, that could be used to screen healthy people, aiming to detect as many early cancers as possible. In the future, such tests would be available at GP clinics. New technologies are also expected to accurately calculate a person's risk of getting cancer, allowing people to make informed lifestyle and preventive choices.

The Early Detection Research Committee was launched by CRUK in June 2017 to challenge the research community to focus efforts, drawing together disparate activity across many areas of cancer research from basic science to clinical/population studies and across disciplines – including biomedical sciences, physical sciences, engineering, mathematics and industry – to bring in new thinking and build novel early detection research proposals.

PATIENT INVOLVEMENT IN EARLY DETECTION



CRUK has an ambition of funding research with outcomes that are relevant to cancer patients. The Early Detection Research Committee has a new and potentially unique position regarding the impact of its research on patients and the public. We aim to identify EDx research outcomes that align with the priorities of patients and the public, and to determine how best to involve patients in the EDx grant funding process.

We want our early detection researchers, regardless of what type of research they are doing, to have a ‘line of sight’ to the clinical or population impact of their work. In other words, if a researcher is trying to understand a new biomarker or a new technology, they should also be considering how that marker or device could be implemented to improve cancer detection in patients and/or the public (e.g. for high risk individuals, for the public as part of a screening programme, etc.).

Currently, applications to the Early Detection Research Committee do not include any formal requirements for patient involvement. However, applicants are encouraged to discuss clinical/population impact in their proposals and the Committee does use that as a criterion for evaluation.

So far, we have:

- Consulted with current CRUK Patient Representatives at the training day in September 2017 to gauge interest and assess the necessary supports for involvement in the funding process
- Consulted with people affected by cancer, including members of the public, at a workshop in Cambridge in 2018 about the acceptability of and desired priorities for early detection research that we fund

Based on our workshop with patients and the public, we have written a report describing their views on some aspects of early detection research. These included:

- Overall acceptability of cancer risk tests, if they are accurate and actionable
- Support of earlier detection tests for incurable cancers with the caveat that some individuals may not want to take them
- High accuracy and low invasiveness identified as the most important priorities for new tests; cost and speed were less important factors
- Desire for funding to be directed towards early detection of rarer cancers and cancers with higher mortality rates over those cancers that are currently well funded

We plan to share these outcomes with our Committee and research community. Additionally, your feedback from this focus group session will help us identify key themes and make recommendations for what patient involvement in early detection research and our funding process could look like.

WHAT WE NEED YOU TO DO TO PREPARE FOR THE DAY

To prepare for the session we would like you to read the attached examples of application abstracts. Each abstract is approx. 1 page long and should include information about the background, aims, methods and expected outputs of the proposed research study. We have included abstracts from **10**



projects that were funded in our first application round in January and **7 programmes** that were shortlisted and will be evaluated by the Committee in June.

When reading through the example abstracts, we would like you to think about what the strengths and weaknesses are of involving patient input in both the **study design** and the **evaluation of the application**. We have included a guided notes template to help you shape your responses. Please note that the template is for your preparation for the discussion at the session – we will not be collecting these forms in advance or on the day.

TYPES OF APPLICATIONS WE RECEIVE

Project applications are shorter, hypothesis driven projects that focus on a research question. These are typically 3-4 years and cost up to £500K. Project applications are submitted in full and evaluated by external peer reviewers and our Committee.

Programme applications are larger, integrated research packages that often include a variety of work packages around a cancer question. These are up to 5 years and cost up to £2.5mil. Programme applications are first submitted as an outline, which are shortlisted by our Committee. A full application is then submitted and evaluated by external peer reviewers and our Committee. The applicants also attend an interview.

We consider a range of **research topics** in our applications. Projects tend to focus on a single research topic, while programmes can cover some or even all topics. Some topics may more easily align with patient involvement in the research and/or evaluation. These topics include:

- **Molecular or discovery research**, which would include trying to understand the biology of early cancer or making better models of early stage disease
- **Technology development**, which would include designing new devices or techniques that could help detect cancers earlier
- **Biomarker or preclinical research**, which would include testing new biomarkers for cancer (or other detection signals) on patient samples
- **Clinical implementation**, which would include working directly with patient cohorts, their data and/or samples

SHARED PRINCIPLES

For a smooth session we ask if you can review these shared principles and think of anything else that we should agree at the beginning of the session.

Respect

There aren't any right or wrong answers – just ideas, experiences and opinions that are all valuable.

Confidentiality

Any personal experiences that are shared should be kept confidential.

Speaking in a group



Only one person should talk at a time and contributions must be relevant to the day's objective.

Inclusion

Everyone's ideas and opinions need to be heard. People who are more confident about speaking should remember to hold back at times and give others a chance – this can be difficult when discussing subjects close to people's heart, so we may need to make an effort.

Agree to disagree

It is important for us to hear all sides of an issue. If people have different views it means we are capturing a variety of opinions and experiences.

Disclosure

We can learn a lot from each other by sharing experiences, but no one should feel obliged to disclose anything they don't feel comfortable with.

Stick to the topic

As we may discuss issues that are close to people's heart and experience, it's natural that we will all have lots of things to say. As we only have a limited time we agree to focus on the objective of each session and to park ideas for later discussion.

Jargon

We need to think about the language and acronyms we use to make sure everyone understands. Please ask if anyone uses a term you don't understand.

Time keeping

We have a lot to get through so it's important we all come back on time after breaks.

Mobile phones

Everyone should agree to keep their mobile phones and technology switched off or on silent. If you need to use your phone, please do so outside of the room to avoid distracting anyone.

CHECK LIST

We hope this have been a helpful introduction of what you can expect on the day and we appreciate you taking the time to complete your pre-reading.

Are you ready for the focus group? Don't forget to:

- ✓ Make sure your travel for the focus group is booked
- ✓ Tell **[contact]** if you have any food allergies
- ✓ Read this pre-read document
- ✓ Read the Application Abstracts and use the Guided Notes template to help organise your thoughts for the discussion on the day

CONTACTS



If you have any questions at any point feel free to get in touch. We look forward to seeing you soon!!

[insert contact details]

GUIDED NOTES

For each application, please make some brief notes on the questions below.

From reading the abstract, briefly summarise what you think the proposal is about in a few sentences.

Do you think patients could be involved in the delivery of this research? Please describe the strengths and weaknesses of involving patients in this kind of research.

Do you think patients could be involved in the evaluation of this research to receive CRUK funding? Please describe the strengths and weaknesses of involving patients in evaluating this kind of research.



Appendix I

[INSERT NAME OF INVOLVEMENT

ACTIVITY] INDUCTION PACK

Notes: This intends to give you an idea of what structure and types of things to cover in your induction pack. We recommend including photos and images throughout to break up the text and make it look more inviting. Amend this pack to suit your needs.

CONTENTS

TOPIC	PAGE
Welcome	2
About the Grand Challenge	2
Patient Involvement in Grand Challenge	5
Reviewing expression of interest and applications	6
Important information about your role	6
Your key contacts	6
Glossary acronyms	7
Other useful resources	7



WELCOME!!! [Delete this text and provide your own welcome]

We're absolutely delighted to welcome you as a member of the Challenge Patient Advisory Panel!

At Cancer Research UK we are committed to ensuring people affected by cancer are at the heart of everything we do.

We know that by working together with people affected by cancer, we will increase our understanding of cancer and ensure that our work meets the needs of patients.

Your involvement is vital in ensuring the experience and opinions of people affected by cancer help shape and inform decisions about the research we fund.

ABOUT THE GRAND CHALLENGE [Delete this information and provide context to the patient involvement opportunity]

GRAND CHALLENGE FUNDING SCHEME

Cancer Research UK's Grand Challenge is the most ambitious cancer research grant in the world. The Grand Challenge is a series of £20m awards seeking international, multi-disciplinary teams willing to take on the toughest challenges in cancer - providing the freedom to try novel approaches, at scale, in the pursuit of life changing discoveries. It is intended to drive global collaboration and support research that would not happen without a team approach and funding of this scale.

We define Grand Challenge as:

“An approach to tackle one or more specific barriers that, when removed, would help solve an important problem in cancer research and have significant potential for the benefit of cancer patients.”

In the first round, 9 teams were shortlisted from 56 entries. The generous support of partners and donors enabled 4 of these remarkable Grand Challenge teams to be funded. In the second round, we received an impressive 134 submissions and shortlisted 10.



£20m awards



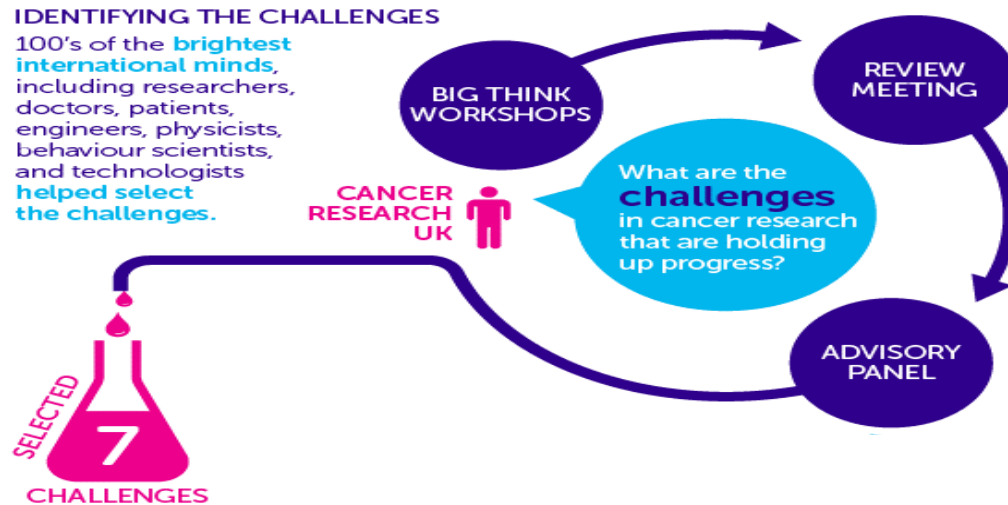
Multidisciplinary



International

GRAND CHALLENGE ADVISORY PANELS

There are two advisory panels that inform the decisions within the Grand Challenge. There is the Patient Advisory Panel and the Scientific (or



Independent) Advisory Panel.

The Patient Advisory Panel

The Patient Advisory Panel represents the views and experiences of people affected by cancer. They do this through ongoing consultation and advice in shaping the scheme, reviewing expression of interests (EOI), full applications and working with funded teams to develop patient involvement elements in their research.

The Scientific (or Independent) Advisory Panel

The Scientific Advisory Panel (sometimes referred to as the Independent Advisory Panel) is made up of world renowned cancer researchers, clinicians, behavioral scientists and a representative from the Patient Advisory Panel. The Scientific Advisory Panel makes the final funding decisions in the Grand Challenge.

SETTING THE CHALLENGES

The challenges were set following consultation with scientists, innovators, thought leaders from across academia and industry and people affected by cancer. Consultation occurred through a series of 'big think' workshops in 2015 to identify barriers to progress. The Scientific Advisory Panel reviewed

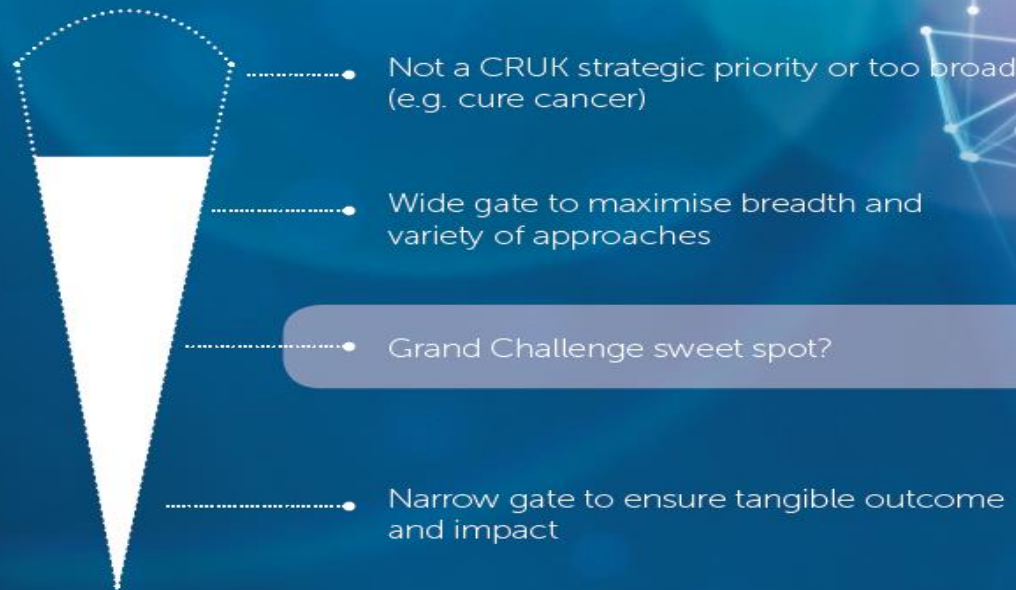
these to determine the Grand Challenges for Grand Challenge 1 and 2. 7 challenges were set for Grand Challenge 1, and 8 challenges were set for Grand Challenge 2.

WHAT MAKES GRAND CHALLENGE DIFFERENT?

Applications to the Grand Challenge can be from any country, any discipline, any academic institution or commercial entity and any career stage. The Grand Challenge sets challenges broad enough to stimulate novel approaches, yet specific enough to be achievable.

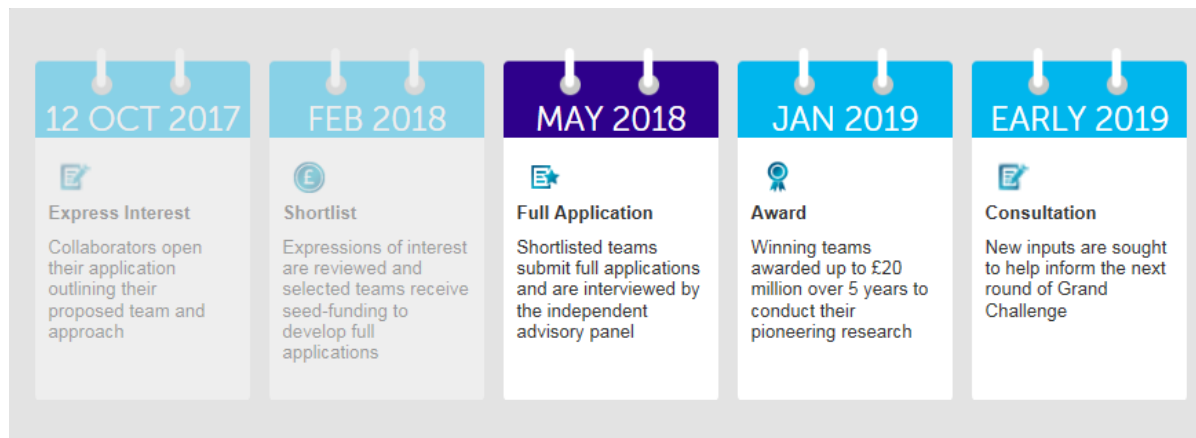
ARTICULATING GRAND CHALLENGE QUESTIONS

We need to set challenges which are broad enough in scope to not limit potential, yet specific enough to drive a critical pathway towards tangible, impactful outcomes



THE GRAND CHALLENGE FUNDING PROCESS

This application process for Grand Challenge 2.



PATIENT INVOLVEMENT IN GRAND CHALLENGE

THE PATIENT ADVISORY PANELS ROLE [provide more information on what their role will be – expand on what was included in the role profile]

Your role is to help us ensure that the research we fund through Grand Challenge has maximum impact for patients. Your experience of cancer can help us understand and communicate the potential impact of the proposed research. You will also help shape clearly defined, innovative patient and public involvement and engagement plans for each project.

You will be reviewing the lay summary, the Patient and Public Involvement plans, the Patient and Public Engagement plans and providing applicants with constructive feedback to help them improve these.

We are looking for high quality, meaningful patient and public involvement and engagement. For some researchers, this might be the first time they are trying to involve patients in their work, so it is important we are providing thoughtful and actionable feedback and support to applicants, so we can see the best outcomes.

In addition to shaping the patient involvement in the shortlisted and funded teams of the Grand Challenge we will be asking you to help shape the Grand Challenge funding scheme itself. So, in addition to the EOI review meeting and full application review meeting we will also come to you from time to time with consultations that you can do from home.

PATIENT INVOLVEMENT IN THE APPLICATIONS

Grand Challenge encourages teams to look for opportunities to build patient involvement into their research. At a minimum, each team is expected to have:

- a lay summary of the research proposal
- patient and public involvement and engagement plans
- a patient representative with a clearly defined role and remit as part of their research steering group

Patient representatives will bring the perspectives of those affected by cancer (e.g. patients, survivors, caregivers) to the work of the Grand Challenge team. They will enable the scientists to see their research through the eyes of the end beneficiary and integrate these perspectives into the direction of their research. Patient representatives would represent patients as a group and not their individual viewpoint or that of any advocacy organisation.

REVIEWING EXPRESSIONS OF INTEREST AND APPLICATIONS

This is the general process for both the expression of interest (EOI) and full application stages:

- 1. You will work in groups of 2-3 to review and discuss EOIs and full applications remotely**
You will need to agree with your partner/s how you will do this.
- 2. One of you will lead in sharing your thoughts on the EOI and full application to the full patient advisory panel**
Once you have discussed and agreed on the scoring and feedback between you and your partner/s, one of you will be asked to share this with the rest of the Patient Advisory Panel. This will happen at the EOI and full application review meetings where the group will discuss and agree on score and feedback to be provided.
- 3. Your group will have the opportunity to work with teams to help them implement your feedback**
As discussed at the induction day, we will be exploring ways for the Patient Advisory Panel to work with applicants and funded teams to help them strengthen their patient and public engagement and involvement plans.

TIME COMMITMENT

[Provide the length of term (e.g. 1 year with the opportunity to extend) and an estimate of length of meetings and time required for preparation]

KEY DATES [Provide a forecast of all upcoming meetings and key dates for them to be aware of]

YOUR KEY CONTACTS

Please do not hesitate to get in touch with your key contact if you have any questions or would like to discuss an element of your role.

KEY CONTACT	CONTACT DETAILS
[Insert contact details]	



GIVING AND RECEIVING FEEDBACK

From time to time we may ask you for feedback about your experience in this role to help improve the way we involve people affected by cancer in our funding committees. You can also get in touch at any point to give us feedback or to suggest changes to be made to the way we involve or support you in this role. We will also provide you with feedback to let you know how things are going and make suggestions about how you can develop in the role. When you first start in the role we will ask you how you would most like to give and receive feedback.

EXPENSES

We can reimburse reasonable expenses for travel, subsistence and overnight accommodation where necessary and agreed in advance and in accordance with our expenses policy. We are also able to book your travel and accommodation in advance if necessary. An optional honorarium is claimable for the EOI review meeting and the full application meeting and then as agreed for any ad hoc events.

WHAT TO DO IF YOU NEED TO TAKE A BREAK FROM THE ROLE

We understand that there may be times when you are not able to attend committee meetings because you or the person you care for needs to attend appointments/treatment or may not be feeling well enough to participate. In these instances, you can take a break from your role on the committee. If you feel able to provide comments over email, we are happy to receive your comments this way, but there is no expectation for you to do this. In some instances, we may invite another patient representative to delegate for you. If you need to take a break from your role on the committee, please contact [\[insert contact details\]](#).

GLOSSARY OF ACRONYMS

These are the acronyms you may hear from us. The expressions of interest and applications that you review should have plain English summaries so should not have acronyms without using the full words first.

CRUK – Cancer Research UK

EOI - Expression of Interest

GC – Grand Challenge

PAC – People affected by Cancer

PaP – Patient Advisory Panel

PIC – Patient Involvement and Communications

PPI – Patient and Public Involvement



OTHER USEFUL RESOURCES

PATIENT INVOLVEMENT TOOLKIT FOR RESEARCHERS

While this toolkit has been designed for researchers who are wishing to involve patients and members of the public in their research it will help give you an idea of the advice and guidance that we provide researchers.

<https://tinyurl.com/CRUKPPI>

WHAT'S IT LIKE TO BE INVOLVED IN RESEARCH?

Here are a couple of links to information to help bring to life the experience of patients and carers involved in research:

- Peter talks about his experience as Chair in Grand Challenge on our Impact Page <http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk/impact-of-patient-involvement>
- In 2014, Shirley Harrison, one of our former patient representatives, wrote a blog about her experience as a member of one of our research funding committees. Read it here: <http://scienceblog.cancerresearchuk.org/2014/01/30/helping-to-choose-which-trials-cancer-research-uk-funds-a-patients-perspective/>
- Healthtalk.org have produced a video featuring patients involved in research sharing their experiences. Watch it here: <http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

JARGON BUSTER

INVOLVE have an excellent jargon buster for patients involved in research, which can be found here: <http://www.invo.org.uk/resource-centre/jargon-buster/>

CANCER RESEARCH UPDATES

Our Science Blog is regularly updated with news and analysis about developments in cancer research <http://scienceblog.cancerresearchuk.org/>

YOUR CANCER GUIDE

Our patient information services are there to help answer any questions you may have about cancer. All our information comes direct from cancer experts – from the scientists who study every aspect of cancer, to our team of dedicated specialist nurses.

- Get reliable and easy to understand information on key signs and symptoms, specific cancer types and treatments online here: <http://www.cancerresearchuk.org/your-cancer-guide#CYrBJbwBR8l9kzSI.99>
- Call our information nurses on freephone **0808 800 4040**
- Connect with others affected by cancer and share experiences with our online community.
Read more at <http://www.cancerresearchuk.org/your-cancer-guide#CYrBJbwBR8l9kzSI.99>

Appendix J

[INSERT NAME OF INVOLVEMENT ACTIVITY] SESSION PLAN

Notes: This is an example of what a session plan (in this case for a focus group) could look like. Use this to get an idea of how you can structure your session. Please amend to suit your needs.

The aims of the focus group are to:

- Identify points in the funding process where patient input could have impact
- Identify which areas of early detection research could benefit from patient and public involvement

We will use the insights from this focus group to inform how we include patients and the public in the funding decision process and how researchers applying for funding can meaningfully involve patients and the public.

Time	Session plan	Lead	Materials required
12:00	Set up room <ul style="list-style-type: none">• Cabaret style• Place printed slides, pens, pads and any other handouts on tables• Place water jugs and glasses on tables	Everyone	Pens, water and glasses, printed slides (2 to a page), post it notes or notepads.
12:30	Registration & refreshments Aim: make people feel welcome and comfortable	Everyone	Sandwiches/tea/coffee Name tags Consent forms
13:00	Welcome & housekeeping (5 minutes) Aim: cover logistics and set ground rules for the day <ul style="list-style-type: none">• Facilitators to introduce themselves• Fire alarm and what to do if we hear it• Loo breaks• Ground rules	Alexis	Slides
	Ice breaker Aim: make patients feel comfortable and learn a little bit about why everyone decided to join the focus group In pairs discuss the following questions, then share your partners answers to the group <ul style="list-style-type: none">• What's your name?		

	<ul style="list-style-type: none"> • What CRUK Funding Committee do you sit on? • How long have they been a patient representative? • Why you chose to come today? 		
13:05	<p>Introduction (25 minutes)</p> <p><i>Aim: The patients attending all sit on CRUK Funding Committees so are quite familiar with our grant process, so they won't need much information on this generally.</i></p> <ul style="list-style-type: none"> • Why we are here <ul style="list-style-type: none"> ○ To guide researchers on whether and how to include patient involvement in their proposals ○ To guide our evaluation and funding process • Why early detection is important • Why their input matters • How we'll structure the day <ul style="list-style-type: none"> ○ Activity 1 – research and funding timelines and opportunities for patient input ○ Activity 2 – discuss applications we've received • How we'll use their feedback <ul style="list-style-type: none"> ○ Discussion of recommendations on key themes • Questions? 	Alexis	Slides
13:30	<p>Activity – Research Development/Funding Timelines (50 minutes)</p> <p><i>Aim: Understand where patient involvement would be meaningful and value adding for CRUK, researchers and patients.</i></p> <p>Introduce the types of applications that we see (10 minutes):</p> <ul style="list-style-type: none"> • Projects vs Programmes <p>Two timelines, one for Projects and one for Programmes, will be set up across the room for reps to interact with representing</p> <ul style="list-style-type: none"> • proposal development (researcher-led) • review and funding process (CRUK-led) <p>Timelines will show major events for researchers and CRUK along the way to funding research with <i>researcher-led in blue</i> and <i>CRUK-led in pink</i>.</p> <p>Assign groups to each timeline. Reps will have post-it notes and will have an opportunity to write down ideas for how patients can be involved in the process for that application type. (10 minutes)</p>	<p>1 facilitator per table group</p> <p>-Gemma</p> <p>-Katie-Jane and Lizzie</p> <p>Alexis to float</p> <p>Table facilitators to capture notes</p> <p>Alexis to intro activity and lead closing discussion</p>	<p>Slides</p> <p>Project timeline sheets x 2</p> <p>Programme timeline sheets x 2</p> <p>Post-its</p> <p>Markers</p>

	<p>In their group, they should place their ideas at the points where the involvement could take place. They can discuss with group members and generate/capture new ideas. (10 minutes)</p> <p>After first timeline, groups will switch to the other timeline. Facilitators to put up fresh timelines for groups. Groups will again generate ideas and then add to timeline (20 minutes total)</p> <p>Summarise key take away messages from the discussion. When are the key timepoints to add patient involvement? For researchers? For funders? Are these different for projects vs programmes? (10 minutes)</p>		
14:20	Break (15 minutes)	Everyone	Sandwiches/tea/coffee
14:35	<p>Activity – Types of Early Detection Applications (60 minutes)</p> <p><i>Aim: identify which types of research could meaningfully include patient involvement and what that could look like.</i></p> <p>Introduce the types of applications that we see (10 minutes):</p> <ul style="list-style-type: none"> • Different research themes <ul style="list-style-type: none"> ○ Molecular/Discovery ○ Technology Development ○ Biomarker/Preclinical ○ Clinical implementation <p>In small groups and using their guided notes form, reps will discuss where there are opportunities for patient involvement and what the strengths and weaknesses of these are (40 minutes)</p> <p>Reps can think about differences between research themes and projects vs. programmes. Are there certain types of proposals that make more sense to involve patients?</p> <p>Could be divided into approx. 10 minutes per research theme.</p> <p>Prompt questions:</p> <ul style="list-style-type: none"> • Where can patient insight add value in application development? • Where can patient insight add value in research delivery? • Where can patient insight add value in application assessment and funding processes? 	<p>Table facilitators to capture notes</p> <p>Alexis to intro activity and lead closing discussion</p>	<p>Slides</p> <p>Applications</p> <p>Guided notes</p> <p>Marker pens</p> <p>Flip chart paper</p>

	Summarise key take away messages from the discussion (10 minutes)		
15:35	<p>Discussion – Recommendations (15 minutes)</p> <p><i>Aim: identify the best models of involvement for this committee and funding scheme.</i></p> <p>With the entire group, capture key themes that have emerged from the activities.</p> <p>Identify the top 3 themes or areas and ask reps to brainstorm possible recommendations for patient involvement from both a researcher and a funder (CRUK) perspective, as well as what implementation could look like.</p> <p>We would like to share these with our funding committee and research community, so encourage reps to provide evidence to support their recommendations and justify why patients can add value. We want to drive the best possible applications to our committee, to fund the most outstanding science through a robust and well-rounded application process.</p> <p>Questions to shape the recommendations:</p> <ul style="list-style-type: none"> • What is the potential impact? On research community and research quality? On CRUK? On patients? • What are the limitations of this recommendation? • What are there practicalities that we should consider for implementing this? • Will this recommendation improve the quality of applications that are submitted? Funded? 	<p>Alexis to capture themes and recommendations</p> <p>Table facilitators to capture notes</p>	<p>Flipchart at front of room</p> <p>Markers</p>
15:50	<p>Closing remarks (10 minutes)</p> <p><i>Aim: make patients feel listened to and valued. Provide key reflections and let them know what will happen next.</i></p> <ol style="list-style-type: none"> 1. Key reflections 2. What'll we do with the information 3. When they can expect to receive some feedback 4. Thank them for their time and contribution 5. Ask them to fill in feedback forms 6. Remind them about the expense claim process 	Alexis	<p>Slides</p> <p>Feedback forms</p> <p>Expense claim forms</p>
16:00	Close		
16:15	Break down room	Everyone	

Appendix K

[INSERT NAME OF INVOLVEMENT ACTIVITY] FEEDBACK FORM

***Notes:** We recommend having some introductory text thanking the patients again and explaining what you will do with their feedback. This template has been developed for printing purposes, if you plan on seeking feedback online we recommend using a survey provider rather than sending a word document).*

1. How would you rate your overall experience of being involved in [insert name of involvement activity]? (Please tick one box)

Very good

Good

Neutral

Poor

Very poor

Unsure

☐☐☐☐☐☐

2. Why did you choose to get involved?

3. How did being involved make you feel?

4. I had enough information beforehand to feel prepared to contribute.

Strongly agree

Agree

Disagree

Strongly disagree

Unsure

☐☐☐☐☐

5. Is there any other support or information you would have liked to have?

6. The practical arrangements were suitable (location/venue/catering etc.)

Strongly agree

Agree

Disagree

Strongly disagree

Unsure

☐☐☐☐☐

7. What worked best about the [insert name of involvement activity]?



8. What could have been improved?

9. Please use the space below to share any other feedback or comments:

10. I'd be happy for a member of the team to get in touch to discuss my feedback further

Yes

No

☐☐

If you ticked yes, please let us know your name and the best way to contact you below:

Thank you for attending and sharing your feedback!