

## **Detecting Cancer Early Priority Setting Partnership**

### **PROTOCOL September 2018**

## **1. Purpose of the PSP and background**

The purpose of this protocol is to set out the aims, objectives and commitments of the Detecting Cancer Early Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The National Institute for Health Research (NIHR – [www.nihr.ac.uk](http://www.nihr.ac.uk)) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

Detecting cancer earlier is vital because this is when treatment is most likely to be effective. To make sure that research in this area is useful we want to understand what is important to patients, their relatives and the healthcare professionals that look after them. This project will conduct a PSP project (18 months), to determine the research priorities required to improve the early detection of cancer. The central aim is to gather unanswered research questions on early detection, and generate a Top 10 set of research priorities. The outputs of this PSP will be disseminated widely to help inform the research agendas of national and local research funders.

## **2. Aims and objectives of the Detecting Cancer Early PSP**

The aim of the Detecting Cancer Early PSP is to identify the unanswered questions in the early detection of cancer from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important.

The objectives of the Detecting Cancer Early PSP are to:

- work with patients, carers, the public and clinicians to identify potential unanswered research questions about the early detection of cancer.
- to agree by consensus a prioritised list of those uncertainties, for research
- to publicise the results of the PSP and process
- to take the results to research commissioning bodies to be considered for funding.

## **3. The Steering Group**

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this. The Detecting Cancer Early PSP will be led and managed by the following:

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Patient representative/s:

- Lindsey Brown
- Gen Buckley
- David Makin
- Katharine Cresswell (PPIE researcher)

Clinical representative/s:

- Emma Crosbie
- Phil Crosbie
- Clare Dickinson
- Richard Martin
- Helena O'Flynn
- Andrew Renehan

Other members

- Ellena Badrick (Project coordinator)
- James Leighton (networks and Macmillan links)
- Rebecca Morris (prior PSP experience)
- Emma Thorpe (project support and finance)

The PSP will be supported and guided by:

- Tricia Ellis (James Lind Alliance)

## 4. The wider Partners

Organisations and individuals will be invited to be involved with the PSP as partners. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical clinical importance relating to the treatment and management of the health problem in question. Partners represent the following groups:

- people who have had a cancer diagnosis, or experienced symptoms of cancer.
- carers of people who have had a cancer diagnosis
- public participants who may have experience of screening practices, symptoms awareness messages and other educational information.
- medical doctors, nurses and professionals allied to medicine with clinical experience of and aspect of cancer screen, diagnosis or treatment.

We have a communications plan drawn up with the NIHR BRC Manchester communications team, this document includes details of the communications strategy, timelines, potential networks and main contacts. The JLA Adviser will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

### **Exclusion criteria**

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible,

however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

## 5. The methods the PSP will use

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details can be found in the Guidebook section of the JLA website at [www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk) where examples of the work of other JLA PSPs can also be seen.

### Step 1: Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Detecting Cancer Early PSP.

### Step 2: Awareness raising

- to introduce the Detecting Cancer Early PSP to relevant groups across patients, carers, the public and clinical networks
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts

### Step 3: Determining Scope

The scope of this PSP is defined by the steering group as questions that are

1. Not as relating to detection of cancer early in people  $\geq 18$  years,
2. Not about cancer recurrence
3. Can be related to any cancer type
4. Not geographically limited to respondents from the UK.

### Step 4: Identifying treatment uncertainties

A survey to generate the potential research questions relating to Detecting Cancer Early will be conducted. Methods to promote the survey may include membership meetings, email consultation, social media activity and other dissemination platforms (see detailed communications plan). The survey will be open for 3 months and responses to the survey will then be collated.

### Step 5: Refining questions and uncertainties

The JLA will participate in this process as an observer, to ensure accountability and transparency. The screening process will produce "raw" unanswered questions about detecting cancer early. These raw questions will be assembled and categorised and refined by Ellena Badrick into "collated indicative questions" which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews and guidelines will be identified and checked by Ellena Badrick to see to what extent these refined questions have, or have not, been answered by previous research. existing sources of information about treatment uncertainties for patients and clinicians will be searched. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. We will keep a record of these 'answerable questions' and deal with them separately from the 'true uncertainties' considered during the PSP.

Uncertainties which are not adequately addressed by previous research will be collated and recorded by Ellena Badrick. The data will be submitted to the JLA for publication on its website as a longlist of research questions on completion of the PSP in order to ensure that PSP results are publicly available.

**Step 6: Prioritisation – interim and final stages**

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties relating to Detecting Cancer Early. This will be carried out by members of the Steering Group and the wider partnership that represents patients, carers, the public and clinicians.

- The interim stage, to proceed from a long list of uncertainties to a shorter list to be discussed at the final priority setting workshop (e.g. up to 30), may be carried out over email or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. Depending on the length of the long list we will choose the most appropriate method.
- The final stage, to reach, for example, 10 prioritised uncertainties will be conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA Adviser.

The JLA will facilitate this process and ensure transparency, accountability and fairness. Participants will be expected to declare their interests in advance of this meeting.

**6. Dissemination of findings and research**

**Findings and research**

It is anticipated that the findings of the Detecting Cancer Early PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities eg CRUK.

**Publicity**

We will publish the findings of the Detecting Cancer Early PSP using both internal and external communication mechanisms. The Steering Group will capture and publicise the results through descriptive reports of the process itself in Plain English. We will also summarise the process and Top 10 in an Academic paper.

**7. Agreement of the Steering Group**

**Signed by the Steering Group**

The undersigned agree to follow the Detecting Cancer Early Priority Setting Protocol.

Dr Ellena Badrick (on behalf of the steering group)

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Date: .....

[Insert name], The James Lind Alliance

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Date: .....