

## Living With and Beyond Cancer Priority Setting Partnership

### PROTOCOL [July 2018]

## 1. Purpose of the PSP and background

The purpose of this protocol is to set out the aims, objectives and commitments of the Living With and Beyond Cancer Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is recommended that the Protocol is reviewed by the Steering Group and updated on at least a quarterly basis.

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<sup>1</sup> 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.

The UK has a growing population of people affected by cancer, yet the level of research to help people living better with and beyond cancer is low compared to other types of cancer research. In 2015 the living with and beyond cancer research spend of the National Cancer Research Institute (NCRI) Partners is only 6% approximately of that of the treatment research taken from the NCRI Cancer Research Database, this level has been fairly consistent in the last 5 years. NCRI has set up an initiative to help increase the level of research in this area and to ultimately improve the quality of life of those affected by cancer.

Undefined research priorities in this broad area has been a barrier to research. The 2015 NHS Independent Cancer Taskforce report also recommends defining research priorities on long-term patient needs and survivorship issues and to identify mechanisms that enable this research to happen. To address this research barrier the NCRI is undertaking a JLA PSP to identify priorities that matter most to people affected by cancer and the health and social care professionals who work with them. We aim for the PSP priorities to direct future research proposals and for the NIHR and other relevant funders to adopt the priorities for funding in the area.

This PSP is funded by the NCRI Partners who want to see improvements in evidence-based interventions relevant to people living with and beyond cancer. The results of the PSP will help direct future research funding by all the Partners and beyond, for the benefit of people affected by cancer.

## 2. Aims and objectives of the Living With and Beyond Cancer PSP

As this is a broad PSP, a meeting of relevant stakeholders took place in February 2017, before the formation of the Steering Group, to provide some advice to the Steering Group on how to define the scope of the PSP. The

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<sup>1</sup> It is recognised that many PSPs now extend their scope beyond identifying and prioritising ‘treatment uncertainties’ and include other health care interventions like prevention, diagnosis, rehabilitation, care, service organisation and service delivery.  
James Lind Alliance: Priority Setting Partnership Protocol – May 2016

Steering Group then agreed on the following scope statement in the first Steering Group meeting held in April 2017.

The aim of the Living With and Beyond Cancer PSP is to identify the unanswered questions about living with and/or beyond cancer from patient, carer and clinical perspectives and then prioritise those that patients, carers and relevant health and social care professionals agree are the most important. This means unanswered questions about all aspects of the living with and/or beyond cancer experience including physical, psychological, social, economic and spiritual aspects. The PSP is looking at interventions, care (including supportive and palliative care), and support across all cancers. The scope of the PSP is limited to any adult were first diagnosed with cancer when aged 16+<sup>2</sup>, carers, health and social care professionals who care for them. The scope does not include new cancer treatment solely aimed to extend life and questions that are only relevant to end of life care.

The objectives of the Living With and Beyond Cancer PSP are to:

- Work with people affected by cancer, health and social care professionals to identify uncertainties about interventions relevant to people living with and beyond cancer.
- Agree by consensus a prioritised list of those uncertainties, for research
- Publicise the results of the PSP and process and to raise awareness of the priorities for research amongst the research community.
- Take the results to research commissioning bodies to be considered for funding and inform research strategies.

### 3. The Steering Group

The Living With and Beyond Cancer PSP will be led and managed by the following:

#### **National Cancer Research Institute**

- Feng Li, Programme Manager, PSP co-Lead
- Ian Lewis - Head of Strategy and Initiatives, PSP co-lead, NCRI (from February 2018)
- Stuart Griffiths, Head of Strategy and Initiatives, PSP co-Lead (February 2017 – January 2018)

#### **Patient and carer representatives:**

#### **National Cancer Research Institute Consumer Forum**

- Richard Stephens, Consumer Lead
- Julia Tugwell (from April 2018)
- Angela McCullagh (from April 2018)

#### **Kirkwood Hospice, Huddersfield**

- Jonathan Tobutt – LGBT Support Worker

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<sup>2</sup> The cancer spectrum, expertise required, service provisions, issues and carer element in living with and beyond are different between children (and adult survivors of childhood cancers) and adults who are diagnosed in adulthood. Adults are the faster growing group with more instances of issues relating to living with and beyond cancer compared to children. Because childhood cancers are rarer than adult cancers, a separate PSP is needed to focus the effort. The ongoing Teenagers and Young Adults PSP (age at diagnosis of 13 – 24 years old and including survivors above 24 years old) has naturally separated the population into 3 groups (children, TYA and adult).

## **Sarcoma UK**

- Lindsey Bennister, Chief Executive (February 2017 – March 2018)

## **Cancer 52**

- Jane Lyons, Chief Executive (from March 2018)

## **Marie Curie**

- Dr Sabine Best, Head of Research

## **Shine Cancer Support**

- Ceinwen Giles, Director of Partnerships and Evaluation

## **Independent Cancer Patients' Voice**

- Dr Adrienne Morgan, Chair
- Jacqui Gath (deputizing Adrienne from April 2018)

## **Macmillan Cancer Support**

- Dr Rebecca Nash, Head of Evidence (February 2017 – February 2018)
- Nicolas Lee, Research Lead (from February 2018)

## **Clinical representatives:**

### **The Royal Marsden NHS Foundation Trust**

- Dr Natalie Doyle, Nurse Consultant – Living With And Beyond Cancer

### **United Lincolnshire Hospitals NHS Trust**

- Dr Jervoise Andreyev, Consultant Gastroenterologist in Pelvic Radiation Disease

### **The Christie NHS Foundation Trust / University Hospital of South Manchester**

- Dr Laura Cove-Smith, Consultant Medical Oncologist

### **Velindre NHS Trust**

- Dr Anne Johnson, Clinical Psychologist

### **Royal Alexandra Hospital Paisley, NHS Greater Glasgow and Clyde**

- Ms Susan Moug, Consultant colorectal surgeon

### **Transforming Cancer Services Team in London**

- Dr Karen Robb, Macmillan Rehabilitation Clinical lead

### **Brighton and Sussex University Hospital Trust**

- Dr Richard Simcock, Consultant Clinical Oncologist

### **Sheffield Teaching Hospitals NHS Foundation Trust**

- Prof. Diana Greenfield, Macmillan Consultant Nurse

### **Bangor Health Centre, Northern Ireland**

- Dr Graeme Crawford, General Practitioner

## **The Partnership and the priority setting process will be supported and guided by:**

### **The James Lind Alliance (JLA)**

- Sandra Regan (JLA, Chair from November 2016 - May 2017)

James Lind Alliance: Priority Setting Partnership Protocol – May 2016

- Dr Patricia Ellis (JLA, Chair from June 2017)

#### **Information specialist**

- Dr Kristina Staley, TwoCan Associates

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.

## **4. The wider Partners**

Organisations and individuals will be invited to take part in the PSP, which represent the following groups:

- People who have had a diagnosis of cancer.
- Carers, family members and friends of people who have had a diagnosis of cancer.
- Relevant health and social care professionals with experience of working with people living with and/or beyond cancer

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. 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.

#### **Funding Partners:**

The following organisations provided funding for the Living With and Beyond Cancer Priority Setting Partnership, facilitated by the James Lind Alliance (JLA):

- Macmillan Cancer Support
- Department of Health (DH)
- Medical Research Council (MRC)
- Economic and Social Research Council (ESRC)
- Chief Scientist Office (CSO)
- HSC Public Health Agency Research & Development Division (Northern Ireland).

Many other organisations supporting the Living With and Beyond Cancer PSP are not listed here.

## **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: Initial scoping meeting**

The initial stakeholder meeting held on 7<sup>th</sup>, February 2017 had several key objectives:

- to welcome and introduce potential members of the Living With and Beyond Cancer PSP
- to discuss the scope of the PSP and make recommendation to the PSP Steering Group
- to identify those potential organisations which will support the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts

### **Step 2: First Steering Group meeting**

The first Steering Group meeting held on 24<sup>th</sup>, April 2017 had several key objectives:

- to agree scope and methods
- to discuss survey
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to finalise organisations which will support the PSP. These organisations will be contacted and informed of the establishment and aims of the Living With and Beyond Cancer PSP.
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP.

### **Step 3: Identifying uncertainties**

Each partner will identify a method for soliciting from its members questions and uncertainties relating to living with and beyond cancer. A period of 10 weeks was given to complete this exercise.

The methods may be designed according to the nature and membership of each organisation, but must be as transparent, inclusive and representative as practicable. Method used was postal and web-based questionnaires.

### **Step 4: Refining questions and uncertainties**

The Steering Group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions about living with and beyond cancer. These raw questions will be assembled and categorised and refined by a data manager into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate. The information specialist will be supervised by the Steering Group.

Systematic reviews and guidelines will be identified and checked by the Steering Group and the systematic reviewers based at Wales Centre for Evidence Based Care, Cardiff University to see to what extent these refined questions have, or have not, been answered by previous research. Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – i.e. they are "unrecognised knowns" and not uncertainties. If a question 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. Accordingly, the JLA recommends strongly that PSPs keep a record of these 'answerable questions' and deal with them separately from the 'true uncertainties' considered during the research priority setting process.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a template supplied by the JLA) by Dr Kristina Staley. This will demonstrate the checking undertaken to make sure that the uncertainties have not already been answered. This is the responsibility of the Steering Group, which will need to have agreed personnel and resources to carry this accountability. The data will be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

### **Step 5: 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 living with and beyond cancer. This will be carried out by members of the Steering Group and the wider partnership that represents patients, health and social care professional.

- The interim stage, to proceed from a long list (54 questions) of uncertainties to a shorter list to be discussed at the final priority setting workshop (27 questions), was carried out over online, whereby patients, carers and health and social care professionals choose and rank their top 10 most important uncertainties.
- The final stage, to reach, for example, 10 prioritised uncertainties, is conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The methods used for this prioritisation process was determined by consultation with the partner organisations and with the advice of the JLA Adviser. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

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.

Timeline of this PSP:

- |                                      |                           |
|--------------------------------------|---------------------------|
| • First Steering Group meeting       | April 2017                |
| • Gather uncertainties               | September - November 2017 |
| • Categorise and check uncertainties | November - January 2017   |
| • Interim prioritisation             | February - April 2018     |
| • Final prioritisation workshops     | June 2018                 |
| • Publish results                    | November 2018             |

## **6. Dissemination of findings and research**

### **Findings and research**

It is anticipated that the findings of the Living With and Beyond Cancer PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities. Steering Group members and partners are encouraged to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.

### **Publicity**

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Living With and Beyond Cancer PSP using both internal and external communication mechanisms. The Steering Group may capture and publicise the results through descriptive reports of the process itself in Plain English. This exercise will be distinct from the production of an academic paper, which the partners are also

encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

**Out of scope topics/questions**

Topics/questions that are deemed out of scope were reviewed by the Steering Group and a plan of how to address these will be captured in the final report. This may involve passing these questions onto other organisations to address.

## 7. Agreement of the Steering Group

**Signed by the Steering Group**