

Young People's Mental Health Priority Setting Partnership

Protocol June 2017

1. Purpose of the PSP and background

The purpose of this protocol is to set out the aims, objectives and commitments of the Young People's Mental Health 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 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) 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.

Over recent years there has been a growing recognition of the importance of young people's mental health. Indeed, the government has established a 'Children and Young People's Mental Health and Wellbeing Taskforce' and agreed to spend "£1.25 billion on improving children's mental health services over the next 5 years". The Mental Health Taskforce [report](#) contains many references and recommendations around children and young peoples (CYP) mental health. It also commissioned a ten year mental health research strategy led by the Department of Health (DH) to be published early next year, within which children and young people's mental health research is a priority area.

In addition, several charities and media campaigns have recently carried out campaigns on children and young people's mental health. The Times newspaper campaigned on young people's mental health over the last year. The Royal family have set up a charity partnership including children's mental health charities – [Heads Together](#).

[MQ](#) are campaigning about the need for more research investment into mental health and have a current public-facing media campaign with a focus on young people's mental health. The Centre for Mental Health recently released a report on existing gaps in services for children and adolescents that received significant media coverage.

There is still relatively little support available for children and young people to get involved in mental health research. As a result of this lack of support children and young people do not have a strong voice in research. A PSP could really increase engagement and involvement of children and young people in mental health research; both in itself, and through providing a high profile example of engagement that can influence others especially those looking to obtain funding for work into any of the priorities that emerge.

The McPin Foundation is well placed to host the PSP given the organisational emphasis on involvement of those with expertise by experience in mental health research, and history of doing this in innovative ways.

We hope that such a PSP would:

- Make a significant difference to mental health research, raising the profile of the mental health of children and young people and unanswered research questions that affect them, their parents and people working with them. The idea is to contribute to a “step change” in understanding and increased focus on needs of young people in relation to mental health.
- Ensure that the voice of young people was much more directly heard in mental health research and increase engagement / involvement of children and young people in mental health research
- Significantly raise the profile and influence of organisations working in the sector

2. Aims and objectives of the young people’s mental health PSP

This PSP will be conducted in a two stage process. The first stage will collect uncertainties broadly about ‘young people’s mental health’. The second stage will focus on a narrower scope to take forward within which to prioritise 10 research questions. Data from the first stage will inform how to focus the scope. See section 5 for more methodological detail.

For the purpose of the broader PSP, the aim of the Young People’s Mental Health PSP is to identify and prioritise the unanswered questions about young people’s mental health.

For the purpose of this PSP, ‘young people’ is defined as people aged 11-25 years inclusive.

Questions that are not specific to any age group, or that are relevant to a wider age group but are also relevant to 11-25 year olds will be included. Questions that are specifically about children younger than 11, or adults older than 25 will be excluded.

We selected this age group for a number of reasons:

1. We need to manage the amount and breadth of data we receive in response to the survey. Using a wider scope (for example 0-25) would potentially attract questions about such a wide variety of topics we could not give everything the focus it needs for a thorough PSP process to take place. For example, we may receive questions about perinatal mental health and newborn development – these areas could justify having their own PSP and top 10 priorities.
2. This age range is a crucial time period for promoting mental health and preventing and treating mental ill health. Half of all lifetime cases of mental ill health begin by age 14 and 75% by age 24¹. Yet 70% of children and young people who have a mental health problem have not received appropriate interventions at an early-enough age². This age range will cover transitions to secondary school, from children’s to adult services and transitions out of care and often into first experiences in the workplace and living independently.
3. We want to ensure good involvement from all stakeholders in line with JLA principles. Involving young children in the process of the PSP is possible, but would take much more time and resource than the project has available in order to do this meaningfully.

We will signpost links to sources of information and support for people who are specifically concerned about the mental health of younger children and older adults.

For the purpose of this PSP, ‘mental health’ is defined as:

¹Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE. (2005). Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62 (6) pp. 593-602. doi:10.1001/archpsyc.62.6.593

² Children’s Society (2008) *The Good Childhood Inquiry: health research evidence*. London: Children’s Society.

‘A state of well-being. Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.’

World Health Organisation (2014)

We will accept questions about promoting and managing emotional wellbeing and mental health, and about preventing and treating mental ill health, including behavioural problems. We will exclude questions about developmental disorders (such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD)), acquired brain injury, dementia, developmental delay and learning difficulties. Questions about these will be included only if they relate to co-morbidity with emotional health problems, or the promotion of emotional health amongst these groups. We will include any questions about the mental and emotional health of 11-25 year olds, including questions about the prevention of mental health problems, promotion of mental health, aetiology, diagnosis, treatments and public health interventions.

We are interested in the perspectives of young people aged 11-25, parents/carers of young people aged 11-25, and professionals from across sectors working with young people aged 11-25.

We will include responses from people who do not fall into these categories if they are about the mental health of young people aged 11-25 e.g. somebody aged 30 who has questions about their experience when they were at school, or a parent whose child is now older than 25. ‘Professionals’ will include medical professionals (psychiatrists, psychologists, GPs, nurses, public health professionals), education professionals (teachers, SEN specialists, school support staff), social work professionals, charity sector, youth workers and others who work with young people aged 11-25.

The objectives of the Young People’s Mental Health PSP are to:

- work with young people, parents and professionals to identify uncertainties about young people’s mental health
- 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 Young People’s Mental Health PSP will be led and managed by the following:

Lead organisation:

The McPin Foundation –Vanessa Pinfold (Sponsor), Thomas Kabir (Project Manager), Lauren Evans (Project Coordinator)

Core partners:

MQ – Sophie Dix / Kristen Schmidt

Charlie Waller Memorial Trust – Pooky Knightsmith / Clare Stafford

The Matthew Elvidge Trust – Hamish Elvidge
Mental Health Research UK – Clair Chilvers

Other steering group members:

Minervation – Andre Tomlin
Cochrane – Rachel Churchill
University of Manchester – Steven Pryjmachuk, Professor of Mental Health Nursing Education
Royal College of Psychiatrists – Cornelius Ani
Lambeth Academy – Nick Heard, Vice Principal
British Association of Social Workers - Maris Stratulis, England Manager
Charity Gondwe – Parent
Ruth Atkins - Parent
Representatives from Young People’s Advisory Group (on rotation) X2

The Partnership and the priority setting process will be supported and guided by Maryrose Tarpey of The James Lind Alliance (JLA).

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.

In addition to the steering group, the McPin Foundation will form a Young People’s Advisory Group. This will be made up of 10 young people aged 14-25 both with and without personal experience of mental health problems. The group will meet to discuss decisions influencing the project, and feed in to steering group meetings. This group will be an important part of the PSP process representing a key stakeholder group. The role of the young people’s advisory group is to advise the steering group. The young people that sit on the steering group will be drawn from the Young People’s Advisory Group.

However, decisions about the project will ultimately be taken by the steering group.

As well as face to face meetings of the steering group meetings will also be held by teleconference. If decisions on substantial matters cannot be reached in face to face or teleconference meetings then decisions may be made via email or phone communications with steering group members. In such cases all steering group members will be involved in such conversations. If consensus still cannot be reached, a vote will be taken from the steering group. If this results in a tie, then the McPin Foundation will take the final decision and communicate its reasons for taking that decision with the entire steering group in a clear and transparent manner.

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:

- Young people, including those who have personal experience of mental health problems
- Carers of young people, including carers of young people who have mental health problems
- Medical doctors, nurses and professionals who’s remit covers young people’s mental and emotional health

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.

Supporting partners

These organisations have expressed an interest in the PSP and agreed to support dependent on the final scope that is decided upon (this list is not exhaustive and more partners will be added as the project progresses):

- Anna Freud Centre
- Beat
- Young Minds
- Time to Change
- NSPCC
- Place2be
- IOP, Kings College London
- University of Manchester
- Autistica
- Common Room
- Centre for Mental Health
- Exeter University
- UCL
- Association for young people's health
- Royal College of Psychiatrists
- Action for Children
- Children's society
- Barnardo's
- University of Sheffield
- Unite (to include school nurses)
- National Association of Head teachers (NAHT)
- YMCA
- Mind
- SAPHNA (School and Public Health Nurses Association)
- PSHE Association
- British Association of Music Therapists (BAMT)
- British Association of Art Therapists (BAAT)
- Royal College of Speech and Language Therapists (RCSLT)
- St. Andrew's Healthcare

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 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 Young People's Mental Health PSP.

Step 2: Identifying uncertainties

Each partner will identify a method for soliciting from its member's questions and uncertainties of practical clinical importance relating to young people's mental health. We envisage that uncertainties will be collected between May and early September 2017 although this is subject to change.

The methods may be designed according to the nature and membership of each organisation, but must be as transparent, inclusive and representative as practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, internet message boards and focus group work. We will actively look into the possibility of collecting uncertainties using social media (such as Twitter).

Existing sources of information about treatment uncertainties for patients and clinicians will be searched. These can include question-answering services for patients and carers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: www.evidence.nhs.uk.

Step 3: 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 diagnosis and the effects of treatments. These raw questions will be assembled and themed and refined by McPin Staff, supervised by Andre Tomlin (Minervation Ltd) and Rachel Churchill (Cochrane Collaboration) into "collated indicative questions" which are clear and understandable to all. Similar or duplicate questions will be combined where appropriate.

Step 4: Selecting theme(s) for focus

The indicative questions will be themed and grouped into overarching themes by McPin Staff, supervised by Andre Tomlin (Minervation Ltd) and Rachel Churchill (Cochrane Collaboration). The overarching themes will be agreed with the steering group with advice from the young people's advisory group (YPAG), and based on themes emerging from the data and any existing classification schemes that may be identified.

A theme or themes will then be selected to take forward in the remainder of the process. The decision about which theme(s) to take forward will be made by the steering group. The McPin Foundation will provide both the YPAG and the steering group with information regarding:

- Number of questions submitted that relate to each theme
- Number of respondents who submitted questions about each theme
- A breakdown of the number of responses in each theme from young people, parents, and professionals.
- A breakdown of the number of responses in each theme submitted via the online survey, face to face data collection, social media, or other forms of data collection that may happen.
- An overview of policy relevance for the themes emerging.
- Any evidence available from initial 'light touch' literature searches about the extent of research already conducted related to each theme.

The YPAG can meet to discuss this information and make a recommendation to the steering group about which theme or themes should become the focus for the PSP going forward. The steering group will then consider information provided for each theme, and the recommendation of the YPAG and make a decision about which theme or themes will become the focus of the PSP going forwards.

If no consensus can be met, the process for decision making outlined in the Terms of Reference will take place: initially a vote of the steering group will be held, and if this results in a tie, the McPin Foundation will take a final decision, communicating the reasons for this decision in a transparent manner.

Any potential uncertainties not taken forward at this stage will be made publicly available. These questions will not be checked to see if they have been answered by research. These potential uncertainties will be available either in the form of a searchable database or in Excel spreadsheet format on the McPin website (www.mcpin.org) in the first instance. Uncertainties be listed under their respective theme headings. The uncertainties will also be available to download as a simple list. The McPin Foundation will encourage other organisations and funders of research to take note of this resource.

Step 5: Literature checking

Systematic reviews and guidelines will be identified and checked by Andre Tomlinson (Minervation Ltd) and Rachel Churchill (Cochrane Collaboration) together with McPin Foundation staff 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 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.

A record will be kept of these 'answerable questions' and the questions and answers will be published on the PSP website. The steering group will decide on how any further dissemination of these will be carried out.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a JLA template by Andre Tomlinson (Minervation Ltd) and Rachel Churchill (Cochrane Collaboration) together with McPin Foundation staff. This template will then act as evidence to demonstrate the checking that has been 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 should 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 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 young people's mental health. This will be carried out by members of the Steering Group and the wider partnership that represents patients 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), will be conducted via a second online survey asking participants to select priority questions from a long list. Exactly how this survey will be structured will be decided by the steering group with advice from the young people's advisory group. This stage may also include other methods for engaging stakeholders such as focus groups, online forums and email feedback. The criteria and process for deciding which uncertainties to be taken forward to the interim stage will be decided by the steering group.
- The final stage, to reach 10 prioritised uncertainties, is likely to 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. 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.

6. Dissemination of findings and research

Findings and research

It is anticipated that the findings of the young people's mental health 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 expected 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 young people's mental health 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.

7. Agreement of the Steering Group

Signed by the Steering Group

The undersigned agree to follow the young people's mental health Priority Setting Protocol.

[Insert name and organisation]

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Date:

[Insert name and organisation]

.....

Date:

[Insert name], The James Lind Alliance

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Date: