

Emergency Medicine Priority Setting Partnership

PROTOCOL (Version 1: 22.10.2015)

Purpose

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

Steering Group

The Emergency Medicine PSP will be led and managed by the following: Patient and carer representatives:

- o Ben McCullough
- Hazel McCullough
- o Douglas Findlay
- Cochrane Group
 - o Ian Roberts

Clinical representatives:

- Royal College of Emergency Medicine
 - o Jason Smith
 - Simon Carley
 - Liza Keating (deputised by Melanie Gager)
 - Lynsey Flowerdew
- Emergency Nursing
 - Rachel O'Brien
 - Miranda Odam
 - o Katharine Wylie

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o Justine Amero

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

- The James Lind Alliance (JLA)
 - o Richard Morley
- Royal College of Emergency Medicine
 - o Sam McIntyre

The Steering Group includes representation of patients, carers and clinicians. 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.

Background to the Emergency Medicine PSP

The JLA is a project which is overseen by the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC). Its aim is to provide an infrastructure and process to help patients and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a "known unknown" – in this case relating to the effects of treatment.

The Emergency Medicine PSP was instigated as a result of an informal priority setting exercise within emergency medicine, and subsequent discussions as to how best approach this issue in the future, ensuing involvement of all the key stakeholders who may have an interest in the future direction of emergency medicine research.

Aims and objectives of the Emergency Medicine PSP

The aim of the Emergency Medicine PSP is to identify the unanswered questions within emergency medicine from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important.

The objectives of the Emergency Medicine PSP are to:

- work with patients and clinicians to identify uncertainties within emergency medicine, covering investigation, diagnosis and management of patients in emergency departments.
- to agree by consensus a prioritised list of those uncertainties, for future research
- to publicise the results of the PSP and process
- to take the results to research commissioning bodies to be considered for funding

Partners

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

- people who have been patients in emergency departments
- carers of people who have been patients in emergency departments James Lind Alliance: Priority Setting Partnership Protocol

 medical doctors, nurses and professionals allied to medicine with clinical experience of working in emergency medicine

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 will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

Organisations wishing to participate in the PSP will be asked to affiliate to the JLA in order to demonstrate their commitment to the aims and values of the JLA. Details on the affiliation procedure can be found at <u>www.lindalliance.org</u>.

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.

A paediatric emergency medicine research prioritisation exercise was recently undertaken by the Paediatric Emergency Research in the UK and Ireland (PERUKI) clinical studies group and published in the Emergency Medicine Journal (Hartshorn S, O'Sullivan R, Maconochie IK, et al. Emerg Med J Published Online First: doi:10.1136/emermed-2014-204484). Paediatric emergency medicine will not therefore be considered during this PSP.

METHODS

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 with be agreed through consultation between the partners, guided by the PSP's aims and objectives. More details and examples can be found at www.JLAguidebook.org.

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 and through the JLA's existing register of affiliates. Potential partners will be contacted and informed of the establishment and aims of the Emergency Medicine PSP and invited to participate.

The Steering Group will draft the invitation specific to potential groups, and the invitation will be distributed through a variety of mechanisms including editorials in relevant journals, newsletters, emails and social media.

2. Initial stakeholder awareness raising

The initial stakeholder awareness raising will have several key objectives:

- to welcome and introduce potential members of the Emergency Medicine PSP
- to present the proposed plan for the PSP
- 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

• 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

3. Identifying treatment uncertainties

Each partner organisation will identify a method for soliciting from its members questions and uncertainties of practical clinical importance relating to the treatment and management of patients within emergency departments. A period of 4 months will be 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. Methods may include membership meetings (such as conferences), email consultation, postal or web-based questionnaires, internet message boards and focus group work.

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: <u>www.evidence.nhs.uk</u>.

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 diagnosis and the effects of treatments. These raw questions will be assembled and categorised and refined by the steering group into "collated indicative questions" which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

The existing literature will be researched by a group of academic emergency medicine trainees, potentially assisted by a data analyst depending on the workload, 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 - ie 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. 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. These answerable questions may form the basis of mini-systemic reviews or Best Evidence Topics (BestBETs) that, if in the appropriate format, could be submitted to the BestBETs database.

Uncertainties which are not adequately addressed by previous research will be collated and prepared for entry into an Emergency Medicine section within the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - <u>www.library.nhs.uk/duets</u>) by Sam McIntyre. This will ensure that the uncertainties have been actually checked to be uncertainties. 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 entered into UK DUETs on completion of the priority setting exercise, in order to ensure any updates or changes to the data have been incorporated beforehand.

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 emergency medicine. 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 (e.g. up to 20), may be carried out over email, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties.

The final stage, to reach, for example, 10 prioritised uncertainties, is likely to be conducted in a faceto-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. 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.

Findings and research

It is anticipated that the findings of the Emergency Medicine PSP will be reported to funding and research agenda setting organisations such as the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), which includes the HTA Programme, and the MRC, as well as 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 Emergency Medicine PSP using both internal and external communication mechanisms. The JLA may also capture and publicise the results, through descriptive reports of the process itself. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. It is intended to submit the findings of the PSP to the Emergency Medicine Journal for publication. However, production of an academic paper should not take precedence over publicising of the final results.

Signed by the Steering Group

The undersigned agree to follow the Emergency Medicine Priority Setting Protocol.

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Dr Jason Smith, Derriford Hospital Date: 17 November 2015

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Richard Morley, The James Lind Alliance Date: 17 November 2015

Sam McIntyre, Royal College of Emergency Medicine Date: 16 November 2015