



Sight Loss and Vision Priority Setting Partnership

Protocol

Purpose

The purpose of this protocol is to set out the aims, objectives and commitments of the Sight Loss and Vision Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. The aim of the PSP is to identify a prioritised list of unanswered questions about sight loss and vision so that research can be targeted accordingly.

Steering Committee

The PSP will be led and managed by the following:

- Fight for Sight. Lead: Michele Acton
- The College of Optometrists. Lead: Michael Bowen
- UK Vision Strategy. Lead: Anita Lightstone
- Mr Richard Wormald, Consultant Ophthalmologist at Moorfields Eye Hospital and co-ordinating editor, Cochrane Eyes and Vision Group

The Partnership and the priority setting process will be supported and guided by Katherine Cowan of The James Lind Alliance (“the JLA”).

The Sight Loss and Vision PSP Steering Committee (“Steering Committee”) has been established to include representatives of patient/service user groups and health care professionals from ophthalmology, optometry, orthoptics, ophthalmic nursing and social care (together “eye health professionals”). Mr Mark Fenton of UK DUETs has agreed to be a member. A researcher will also be represented at this level to advise on the shaping of the process, but will not participate in the prioritisation exercise. This will ensure that the final prioritised unanswered questions are those agreed by patients/service users and eye health professionals only, in line with the JLA’s mission. A list of the members of the Steering Committee is set out in Appendix A.

The Steering Committee will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will be able to advise on this.

Background to the Sight Loss and Vision PSP

The JLA is a project which is funded by the National Institute of Health Research with support from the Medical Research Council. Its aim is to provide an infrastructure and process to help patients and professionals work together to agree which are the most important uncertainties and unanswered questions 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”.

The Vision 2020 UK Eye Research Group was formed to bring together people active in eye health and vision research to help find ways to ensure that research is well targeted and co-ordinated as well as to maximise the case for enhanced funding. This led to the development of proposals for a UK vision research agenda. In 2011, Fight for Sight, the College of Optometry, the UK Vision Strategy and Mr Richard Wormald on behalf of the Vision 2020 UK Eye Research Group asked the JLA to work with them to develop a PSP consulting with all interested organisations in the sector.

Aims and objectives of the PSP

The aim of the PSP is to identify the unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions from the perspectives of patients/service users and eye health professionals and then prioritise those which both groups agree are the most important.

The objectives of the PSP are to:

- work with patients/service users and eye health professionals to identify unanswered questions about the prevention, diagnosis and treatment of sight loss and eye conditions and to agree by consensus a prioritised list of those unanswered questions 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 are, have been or may be affected by sight loss
- carers of people affected by sight loss
- eye health professionals with clinical experience of sight loss

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 advising how the various stakeholder groups are able to participate equally in the process.

Organisations wishing to participate in the PSP will be required 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 www.lindalliance.org. This process is free.

Exclusion criteria

Some organisations may be judged by the JLA or the Steering Committee 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 in the prioritising process. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Committee considers it may be helpful.

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 will be agreed through consultation between the partners, guided by the PSP's aims and objectives.

1. Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Committee members' networks, including Vision 2020 UK and through the JLA's existing register of affiliates. Potential partners will be contacted and informed of the establishment and aims of the PSP and invited to attend and participate in an initial stakeholder meeting.

The JLA can draft the invitation, and an agreement should be reached as to the best organisation to distribute it.

2. Initial stakeholder meeting

The initial stakeholder meeting will have several key objectives:

- to welcome and introduce potential members of the PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- 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

The meeting will be chaired by the JLA in coordination with the administrative process of convening it managed by the Steering Committee in collaboration with the JLA.

Following the meeting, organisations which have decided to participate in the PSP will be asked to complete a declaration of interests, including disclosing relationships with the pharmaceutical industry.

3. Identifying unanswered questions

Each partner will identify a method for soliciting from its members questions and uncertainties of practical clinical importance relating to the prevention, diagnosis and treatment of sight loss and eye conditions. In particular the methodology will enable respondees to answer in relation to one or more specific eye conditions. A period of three 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, email consultation, postal or web-based questionnaires, internet message boards and focus group work.

Existing sources of information about unanswered questions for patients/service users and clinicians will be searched. These can include question-answering services for patients/service users and carers and for eye health professionals; 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: <http://www.library.nhs.uk/duets/>.

4. Refining questions and uncertainties

The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions. These raw questions will be assembled and categorised and refined into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate. Questions will also be categorised by type of eye condition.

The existing literature will be surveyed to see to what extent these refined questions have, or have not, been answered by previous research. The Steering Committee 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.

Sometimes, unanswered questions are expressed that can in fact be resolved with reference to existing research evidence - ie they are "unrecognised knows" and not uncertainties. If an unanswered 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. Capacity permitting, a record of questions may be maintained by the Steering Committee and partners can advise their membership as appropriate.

Unanswered questions about treatment which are not adequately addressed by previous research will be collated and entered into the Eyes and Vision section within the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). This will ensure that the uncertainties have been actually checked to be uncertainties. This is the responsibility of the Steering Committee, which will need to have agreed personnel and resources to carry this accountability. Unanswered questions about prevention or diagnosis will be managed separately. **This is a key component of the JLA process, and the next stage of prioritisation can only proceed upon its completion.**

5. Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise through consensus the identified unanswered questions relating to the prevention, diagnosis and treatment of sight loss and eye conditions and in particular in relation to different eye conditions. This will be carried out by members of the Steering Committee and the wider partnership that represents patients/service users, carers and eye health professionals.

The interim stage, to proceed from a long list of uncertainties for each eye condition to a shorter list (e.g. up to 20), may be carried out over email or other means, whereby organisations consult their membership and ask them to consider the long list, then rank their top 10 most important unanswered questions. If the long list is deemed too long, and therefore unmanageable, the Steering Committee will need to agree a fair and transparent method for reducing it. The JLA can advise on this process.

The final stage, to prioritise the short listed unanswered questions and agree a top 10 for each eye condition, is likely to be conducted in a series of face-to-face meetings, 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. The Steering Committee will need to agree available resources and support for convening face to face meetings.

Findings and research

It is anticipated that the findings of the PSP will be reported to funding and research agenda setting organisations such as the NIHR HTA Programme and the MRC, as well as the major research funding charities. Steering Committee members and partners are encouraged to develop the prioritised unanswered questions 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 Committee members are encouraged to publish the findings of the PSP using both internal and external communication mechanisms, including raising awareness of the results among the public and scientific audiences. 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. However, production of an academic paper should not take precedence over publicising of the final results. The Partnership is asked to keep the JLA informed of activity undertaken to publicise the results of the priority setting exercise.

Signed by the Steering Committee

The undersigned agree to follow the Sight Loss and Vision Priority Setting Partnership Protocol.

[Insert name and organisation]

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Date:

[Insert name and organisation]

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Date:

[Insert name and organisation]

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Date:

[Insert name], The James Lind Alliance

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Date:

Steering Committee

Katherine Cowan – James Lind Alliance (Chair)

Michele Acton – Fight for Sight

Karen Bonstein – NIHR Biomedical Research Centre for Ophthalmology

Michael Bowen – College of Optometrists

Carol Bronze – Patient representative

Dr Dolores Conroy – Fight for Sight

Kathy Evans – Royal College of Ophthalmologists

Mark Fenton – UK DUETs

Dr Heather Giles – Patient representative

Robert Harper - Optometrist

Simon Labbett – Association of Directors of Adult Social Services

Anita Lightstone – UK Vision Strategy

Dr Fiona Rowe – University of Liverpool (Orthoptics)

Professor Alan Stitt – Queen’s University Belfast (Researcher)

Professor Heather Waterman – University of Manchester (Ophthalmic nursing)

Professor Marcela Votruba – Cardiff University (Ophthalmologist)

Mr Richard Wormald – Cochrane Eyes and Vision Group (Ophthalmologist)