



James
Lind
Alliance

Priority Setting Partnerships

Why set patient-led priorities for eye research?

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Working in partnership with



What I'm going to talk about

- The James Lind Alliance (JLA)
- The Sight Loss and Vision Priority Setting Partnership (SLV PSP)

The James Lind Alliance

- Established in 2004
- To understand what research matters to
 - Patients
 - Carers
 - Clinicians
- Since 2014, coordinated by the National Institute for Health Research

The James Lind Alliance

- Why involve patients in setting priorities for research?
 - Avoid waste
 - Attract funding
 - Be accountable

The James Lind Alliance

- 32 PSPs completed
 - Each have top 10 research priorities
- 28 PSPs currently ongoing
- 88 logged enquiries

The SLV PSP

- Steering Group established
- Followed the JLA process
 - Survey
 - Analysis and evidence checking
 - Prioritisation
 - Promotion

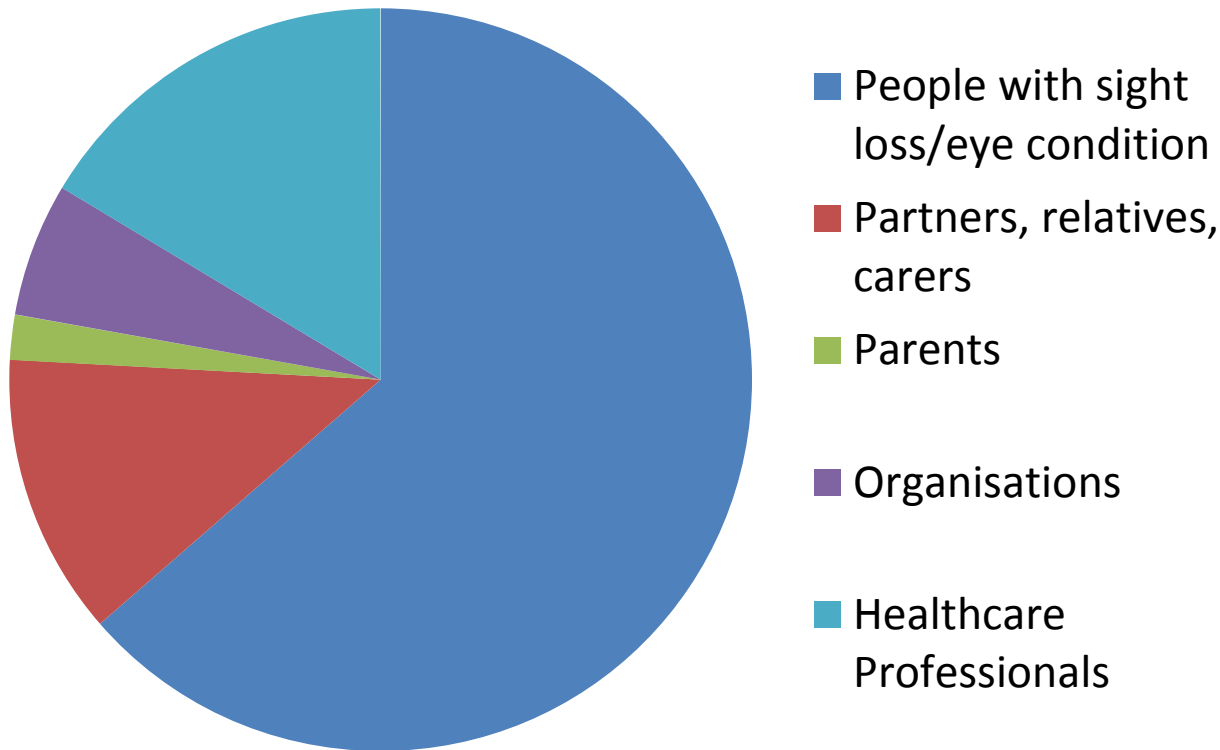
The SLV PSP - survey

- 1 May – 31 July 2012
- Patients, carers, families, eye health professionals

“What question(s) about the prevention, diagnosis and treatment of sight loss and eye conditions would you like to see answered by research?”

The SLV PSP - analysis

- 2200 people responded – 71% patients



The SLV PSP – analysis and checking

- 4461 individual questions suggested
 - 686 unique verified questions
- 12 categories
 - Cataract
 - Ocular Inflammatory
 - Ocular Cancer
 - Glaucoma
 - Corneal and External
 - Refractive Error
 - AMD
 - Inherited Retinal Diseases
 - Childhood-Onset
 - Vitreoretinal and Ocular Trauma
 - Neuro-ophthalmology
 - Retinal Vascular

The SLV PSP – prioritisation

- Interim prioritisation
- Final prioritisation workshops



The SLV PSP

- 12 sets of research priorities
 - 100+ eye conditions
- October 2013: parliamentary reception at the House of Lords



What next?

- A challenge!
- Promotion to
 - Funders
 - Researchers
- Responsibility, accountability and ownership

What next?

- Fight for Sight tracking progress
 - www.fightforsight.org.uk/sightlosspsp
- Today's event
- Learning opportunity for the JLA and PSPs

Thank you



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