James Lind Alliance
Priority Setting Partnerships

Appendices to Report of the JLA Community Workshop:

50 Completed Partnerships and Beyond

23.11.17

5. Appendices

5.1 Attendee list
5.2 Slides of presentations
5.3 Posters

5.1 Attendee list

Name	Organisation
Michele Acton	Fight for Sight
Michael Allison	Cambridge University Hospitals NHS Foundation Trust
Sabine Best	Marie Curie
Ellena Badrick	Manchester Cancer Research Centre, University of Manchester
Jennifer Bethell	Dementia and Frailty JLA PSPs
Oliver Boney	National Institute of Academic Anaesthesia
Susan Brunskill	NHS Blood and Transplant (NHSBT)
Helen Bulbeck	Brainstrust
Emily Burns	Diabetes UK
Martin Burton	Cochrane UK
Stephen Campbell	University of Manchester & NIHR Greater Manchester Patient Safety Translational Research Centre
Mariana Campos	Genetic Alliance UK
Iain Chalmers	James Lind Initiative
Eleni Chambers	Freelance survivor researcher (NIHR – NETSCC, INVOLVE; Royal College of Psychiatrists, and others) and PhD student
Tammy Clifford	Canadian Agency for Drugs and Technologies in Health (CADTH)
Lynne Corner	Newcastle University
Matt Costa	University of Oxford
Sally Crowe	Crowe Associates Ltd
James Cusack	Autistica
Ann Daly	Independent
Bridget Davis	Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP RU), Glasgow Caledonian University
Simon Denegri	NIHR
Sophie Dix	MQ: Transforming mental health
Jim Elliott	NETSCC (as a public contributor)
Nick Fahy	University of Oxford
Jeremy Fairbank	NDORMS, University of Oxford
Eric van Furth	GGZ Rivierduinen/ Leiden University Medical Center
Robin Grant	Department of Clinical Neurosciences,Western General Hospital, Edinburgh
Douglas Grindlay	School of Medicine, University of Nottingham
Alyson Huntley	University of Bristol
Stella Huyshe-Shires	Lyme Disease Action
Thomas Kabir	The McPin Foundation
Erika Kennington	Asthma UK
Lynn Kerridge	NETSCC
Andreas Laupacis	St. Michael's Hospital, Toronto, Canada
Terry Lawrence	Patient Representative
Richard Lehman	University of Birmingham
Feng Li	National Cancer Research Institute
Keith Lloyd	Swansea University

Martin Lodemore	INVOLVE Coordinating Centre
Kate Lough	Nursing Midwifery and Allied Health Professions Research Unit
Peter Lovell	NIHR Research Design Service London
Mary Madden	University of Leeds
Jill Manthorpe	Social Care Workforce Research Unit, King's College London
Angela McCullagh	Patient/Carer (advising Marie Curie and others)
Rosie McEachan	The Born in Bradford Research Programme, Bradford Teaching Hospitals NHS Foundation Trust
Richard Morley	Cochrane
Rebecca Morris	NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester
Anne O'Hare	Salvesen Mindroom Research Centre, University of Edinburgh
James Pickett	Alzheimer's Society
Lucy Power	McPin Foundation, Young Persons' Advisory Group
Nicola Rowbotham	University of Nottingham/ Nottingham University Hospitals
Elizabeth Rye	James Lind Alliance PSP
Stephanie Sampson	Member of the Institute of Mental Health, University of Nottingham
Casper Schoemaker	Dutch Juvenile Arthritis Association /Children's Hospital of the University Medical Center Utrecht/National Institute for Public Health and the Environment
Philippa Saunders	The University of Edinburgh
Natalie Shearwood-Porter	National Institute for Health Research
Sarah Sleet	Coeliac UK
Anna-Louise Smith	Parkinson's UK
Alan Smyth	University of Nottingham
Julie Solomon	British Society of Gastroenterology (BSG)
Kristina Staley	TwoCan Associates
Sophie Staniszewska	Warwick Medical School
Syinat Tagaeva	McPin Foundation, Young Persons' Advisory Group
Ruth ten Hove	Chartered Society of Physiotherapy
Kim Thomas	University of Nottingham
Diana Tilston	Patient
Seilin Uhm	Social Science Research Unit, UCL Institute of Education, London
Matt Westmore	Director, Enterprise and Partnerships, Wessex Institute, University of Southampton
Heather Whitehouse	Harrogate and District NHS Foundation Trust
Nic Wray	British Tinnitus Association (BTA)

The James Lind Alliance Advisers

Katherine Cowan	JLA Adviser
Toto Gronlund	JLA Adviser
Tricia Ellis	JLA Adviser
Maryrose Tarpey	JLA Adviser
Catherine White	JLA Adviser

The James Lind Alliance NETSCC team

Steph Garfield- Birkbeck	Assistant Director at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
Beccy Maeso	Senior Research Manager, JLA team
Caroline Whiting	Research Manager, JLA team
Katharine Hanss	Assistant Research Manager, JLA team
Amy Street	Assistant Research Manager, JLA team

5.2 Slides of presentations

5.2.1 Welcome and introduction. The JLA now: Steph Garfield-Birkbeck

JLA COMMUNITY WORKSHOP

WELCOME

#JLA50
@LindAlliance

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Priority Setting Partnerships

JLA COMMUNITY WORKSHOP: Purpose

- Recognise the growth of the JLA
- Consider its current and future context
- Acknowledge the JLA's reach and place in research

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JLA COMMUNITY WORKSHOP: Objectives

- Consider the continued development of the PSP process
- Consider key issues for the JLA including how we define uncertainty
- Share learning from past and present PSPs
- Consider the future of the JLA

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JLA COMMUNITY WORKSHOP: How are we going to do it

- Interactive
- Scene setting:
  - Defining and verifying uncertainty (morning)
  - The future of the JLA (afternoon)
- Short presentations
- Group work
- Reflections from PSPs
- Iain Chalmers' reflections

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5.2.2 Defining and verifying uncertainty: Katherine Cowan

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Defining and verifying uncertainty

Is our approach still appropriate?

Katherine Cowan, Senior Adviser JLA

The current verification process

Cochrane Library

NICE National Institute for Health and Care Excellence

SIGN Scottish Intercollegiate Guidelines Network

Royal College of Nursing

The Royal College of Ophthalmologists

RCGP Royal College of General Practitioners

Royal College of Surgeons
ADVANCING SURGICAL CARE

Royal College of Obstetricians & Gynaecologists

The Royal College of Anaesthetists

Coming up…

- Original definition
- Developments and changes
- Practical implications
- Examples from PSPs
- Over to you
- *A watershed moment…?*

What do we mean by treatment…?

Interventions

The original definition

The current definition

- What are treatment uncertainties?
  - no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exist
  - up-to-date systematic reviews of research evidence show that uncertainty exists

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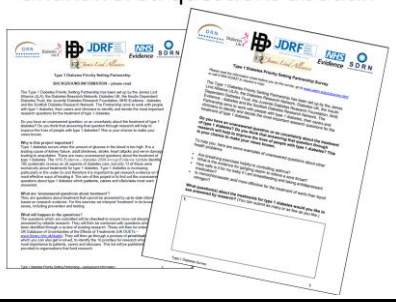
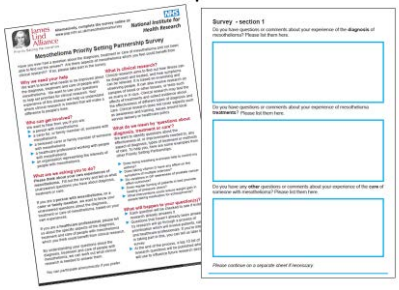
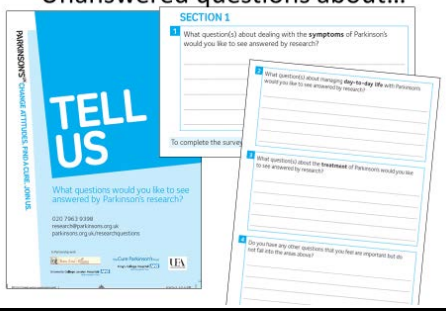
Unanswered questions about…



Unanswered questions about…



Unanswered questions about…



Unanswered questions about…

2. Aims and objectives of the Endometriosis PSP

The aim of the endometriosis PSP is to identify the unanswered questions about endometriosis from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important. The scope of the endometriosis PSP will include cause, diagnostic approaches, treatment options (including lifestyle factors), prevention and awareness.

The objectives of the endometriosis PSP are to:

- work with patients and clinicians to identify uncertainties about endometriosis
- 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.

endo THE JAMES LIND ALLIANCE PRIORITY SETTING PARTNERSHIP FOR ENDOMETRIOSIS

More than treatment uncertainty…?

PSP-led scoping

- Self-funded, self-determined
- Treatment not always the main issue
- From single conditions to broad settings
- Patient/clinician concerns
- Ownership of the outputs

Unanswered questions about…

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

What does this mean in practice?

- Wider scope
  - Communication
  - Volume of data
  - Resource
- Identification of non-RCT questions
- A different verification process
- Engagement with different funders
- JLA definition and guidance obsolete?

Unanswered questions about…

Aims and objectives of the Depression: ARQ

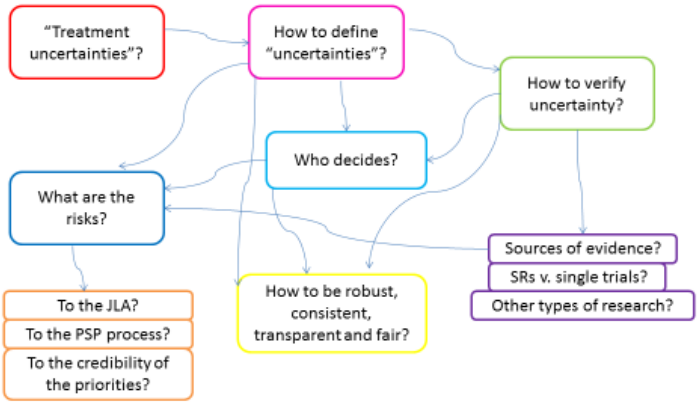
The aim of the Depression: ARQ is to identify the unanswered questions about the cause, diagnosis, treatment, care and prevention of any form of depression (NB bipolar disorder is addressed in a different PSP) from patient and clinical perspectives, and then to prioritise those that patients and clinicians agree are the most important.

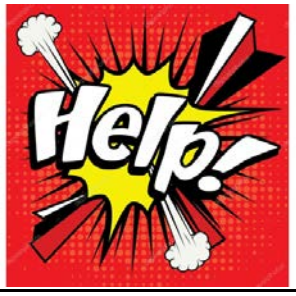
The objectives of the Depression: ARQ are to:

- work with patients, carers and clinicians to identify uncertainties about the cause, diagnosis, treatment, care and prevention of depression
- to agree by consensus at least one prioritised list of those uncertainties, for research
- to ensure information about outcomes important to patients, families and carers are shared with developers of recommended core outcomes for future research in depression
- to publicise the results of the Depression: ARQ and process
- to take the results to research commissioning bodies to be considered for funding

Depression: asking the right questions

What does this mean for the JLA?





Examples of the challenge

- Sabine Best: Palliative & End of Life Care PSP
- Ruth Ten-Hove: Physiotherapy PSP
- Keith Lloyd: Schizophrenia PSP, Depression PSP

5.2.3 Physiotherapy PSP: Ruth ten Hove

CHARTERED SOCIETY OF PHYSIOTHERAPY

What's changing?

An ageing population;
rise of long-term conditions
& non-communicable diseases

Increasing focus on public health

Person-centred care: models of co-production, with greater on the whole person & self-management

Rising expectations about accessibility, quality & outcomes of care

Human genome; telecare; health informatics

Increasing financial constraint; imperative to find cost-effective solutions to meeting rising demand

Service commissioning – increasing competition within a growing plurality of providers

Care closer to home

Increasing accountability for care's safety, quality and value for money

Increasing integration of health & social care

More generalist professional roles, less defined by profession and more by competences

5.2.4 The Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (PeolcPSP): Dr Sabine Best, Marie Curie

The Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (PeolcPSP)

23 November 2017
Dr Sabine Best, Marie Curie

https://palliativecarepsp.wordpress.com/

Challenges

Palliative and end of life care Priority Setting Partnership

- We have identified and prioritised **specific research themes**!
- NIHR cannot use top 10 for commissioned research (but can look in the longer list)
- **Difficult health service questions** are prioritised..
- These **need more specific work** to encourage research/ers, an open call is often not enough..
- DUETs?: where to look at the underlying more detailed questions in broad research themes?

What is palliative care?

Palliative and end of life care Priority Setting Partnership

Palliative care

- aims to improve quality of life
- provides relief from pain and other distressing symptoms
- combines psychological, social and spiritual support ('holistic' care)

Scope of the PeolcPSP

- Palliative and end of life care
- Care, support and treatment of adults living with terminal illness (any terminal illness, including cancer and non cancer conditions)

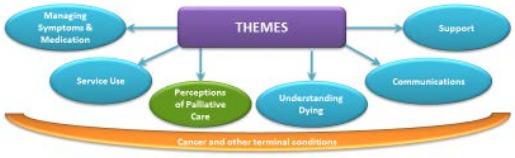
2

Care and support through terminal illness

Further work

Analysis of whole data set, including 'out of scope' data

- Dr Annmarie Nelson, Cardiff University, qualitative researcher
- Thematic analysis: 1/6 themes was not reflected in 'interventional questions'



Care and support through terminal illness

Palliative and end of life care Priority Setting Partnership

PeolcPSP – Identifying 'evidence uncertainties' (or 'research questions')

- **1403** responses to first survey,
- **749** provisional PICO questions identified,
- after de-duplication keywords for **435** questions checked against systematic reviews (mainly Cochrane) and DARE (Database of Abstracts of Reviews of Effects) plus NHS website and charity sites
- No 'unknown knowns' were found (little evidence in peolc)
- Questions were combined to **100, then 83** questions

Palliative and end of life care Priority Setting Partnership

Learnings from PeolcPSP

- Many priorities are **broad** and **in need of further work to define more specific research questions**
- Different questions require **different types of research** as the next step (see MRC Framework for Complex Interventions)
- Many questions will need a concerted effort from a number of research funders and/or other organisations - **collaboration is key!** Example: JLA Shared Learning Group joint workshop on **continence research**
- '**Out of scope' data** can provide useful insights in areas where there is very little evidence to inform possible interventions or where qualitative research might be needed as a first step

Care and support through terminal illness

Palliative and end of life care Priority Setting Partnership

Challenges

Palliative and end of life care Priority Setting Partnership

- Process of **combining large number of (initially PICO) questions** led to a mixture of:
  - ✓ **Broad questions** - from many questions combined in e.g. different conditions / different settings
  - ✓ **Specific PICO questions**, often only mentioned once
- Prioritising mix of broad and specific questions led to:
  - ✓ **Broad questions in the top 10**
  - ✓ **Specific PICO questions in the full list of 83**
- We have identified and prioritised **specific research themes**!

5.2.5 The Future of the JLA: Steph Garfield-Birkbeck

JLA COMMUNITY WORKSHOP AFTERNOON SESSIONS:

- Taking the long view, what are the future needs of the JLA?
- JLA in other contexts
- More than one priority setting partnership
- My JLA
- Iain Chalmers- Reflections

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Key Questions for Discussion

- What does it mean to be a JLA PSP?
- JLA in different contexts
- What does the JLA need around it?
  - Strength
  - Quality assurance
  - Governance and structure
- The JLA in 5,10,15 years' time
- What's the group's top item to feedback?

#JLA50

How we are going to do this

- Presentations to set the scene
  - Andreas Laupacis, Canada
  - Kim Thomas, Nottingham
- Group discussions: The next 50
- JLA conversations: My JLA
  - Terry Lawrence (Surgery for common shoulder problems PSP)
  - Thomas Kabir (Mental Health PSP)
  - Matt Costa (Broken bones in older people PSP)
- Iain Chalmers' reflections

#JLA50

JLA COMMUNITY WORKSHOP:

Thank you

#JLA50

5.2.6 Kim Thomas: Reflections on the value of PSPs from a multiple 'PSPer'

University of Nottingham
UK | CHINA | MALAYSIA

Reflections on the value of PSPs from a multiple 'PSPer'

Professor Kim Thomas

Why do more than one PSP?

- All the same (but different)
- UK Dermatology Clinical Trials Network –
  - Funded some PSPs
  - Provide infrastructure and support

What I will cover

- Why do more than one PSP?
- What does a JLA PSP do for the community of interest?
- Lessons learned

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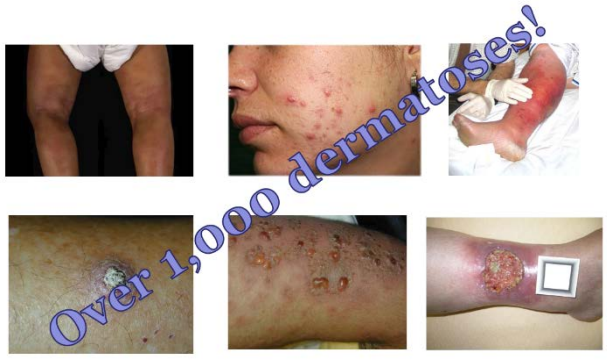
Some reasons to do a JLA PSP?

- Research funding is finite – need to ensure value for money by investigating the most important questions
- Good way to build a network of interested patients and healthcare professionals to develop and deliver studies
- More likely to change practice and have an impact – if research addresses topics of importance to patients and healthcare professionals
- Makes it easier to get funding – particularly for traditionally neglected areas (JLA now embedded in NIHR infrastructure)

Clinical area of interest is skin conditions



It's fun!

- Have led or contributed to four JLA PSPs in:
  - Vitiligo (2010)
  - Eczema (2012)
  - Cellulitis (2017)
  - Lichen sclerosus (ongoing)
- Other PSPs
  - Hidradenitis suppurativa
  - Acne
  - Hair loss
  - Hyperhidrosis
  - Psoriasis
  - Epidermolysis bullosa (Spain)
  - Congenital ichthyosis (Spain)

Who has funded our PSPs?

- Charities / patient support organisations
  - psoriasis, cellulitis, hyperhidrosis, hair loss, acne, hidradenitis suppurativa
- Professional bodies/societies
  - lichen sclerosus
- NIHR Programme Grant
  - eczema, vitiligo

Three benefits of PSPs

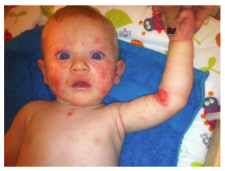
Benefits to community of users:

- Research developed and funded into priority topics
- Network of interested stakeholders established and engaged
- Maps of systematic reviews and overviews of reviews

Benefits to community of users

Research funded!

- Eczema PSP completed in 2012
- 93% of priority topics are now being actively researched (planned, underway or complete).
- 36% of priority topics have been updated in Cochrane Systematic Reviews.
- National Institute for Health Research funding over £8 million.

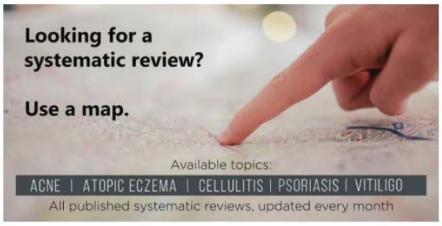


Benefits to community of users

Network of interested stakeholders (including patient partners)

Benefits to community of users

Maps of systematic reviews / overview of reviews



www.nottingham.ac.uk/dermatology

Conclusion

5.3 Posters

5.3.1 JLA Priority Setting Partnership Top 10s 2007-2011

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PSP Top 10s 2007 - 2011

Asthma

Urinary Incontinence

Vitiligo

Prostate Cancer

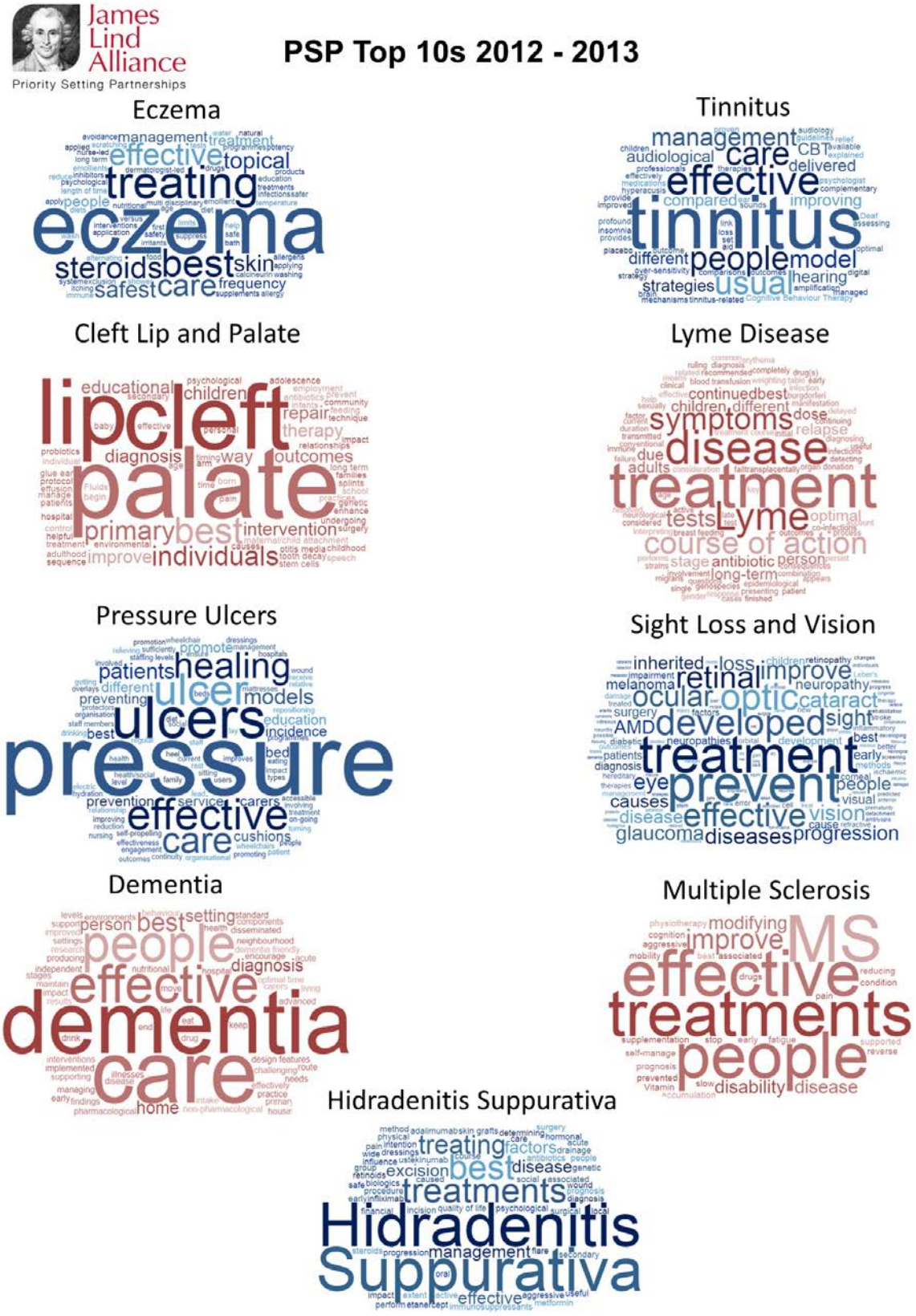
Schizophrenia

Ear, Nose and Throat
- Aspects of Balance

Diabetes (Type 1)

Stroke in Scotland

5.3.2 JLA Priority Setting Partnership Top 10s 2012-2013



5.3.3 JLA Priority Setting Partnership Top 10s 2014

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PSP Top 10s 2014

Acne

Preterm birth

Hip and Knee Replacement for Osteoarthritis

Childhood Disability

Spinal Cord Injury

Intensive Care

Parkinson's

Mesothelioma

5.3.4 JLA Priority Setting Partnership Top 10s 2015

James Lind Alliance
Priority Setting Partnerships

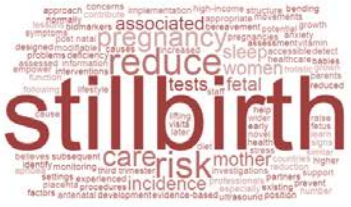
PSP Top 10s 2015

Palliative & End of Life Care

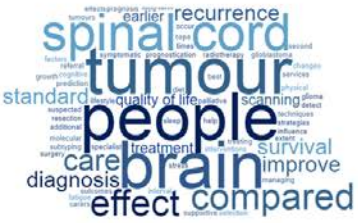
Inflammatory Bowel Disease

Kidney Cancer (Canada)

Stillbirth



Neuro-oncology



Anaesthesia and Perioperative Care

Surgery for Common Shoulder Problems

Mild to Moderate Hearing Loss

Hair Loss

Cavernoma

5.3.5 JLA Priority Setting Partnership Top 10s 2016

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PSP Top 10s 2016

Depression

Kidney Transplant

Autism

Hypertension (Canada)

Eating Disorders (Netherlands)

Early Hip and Knee Osteoarthritis

Bipolar

Womb Cancer

Alcohol-related liver disease

Fibromyalgia (Canada)

5.3.6 JLA Priority Setting Partnership Top 10s 2017 Part 1

James Lind Alliance
Priority Setting Partnerships

PSP Top 10s 2017: Part 1

Cystic Fibrosis

Emergency Medicine

Patient Safety in Primary Care

Contraception

Cellulitis

Endometriosis

5.3.7 JLA Priority Setting Partnership Top 10s 2017 Part 2 so far…

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PSP Top 10s 2017: Part 2 so far…

Dementia (Canada)

Miscarriage

Pessary use for Prolapse

Type 2 Diabetes

Neurodevelopmental Disorders (Canada)

Common conditions affecting the hand and wrist

5.3.8 57 completed JLA Priority Setting Partnerships 2007 – 2017

5.3.9 What you told us about the James Lind Alliance

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What you told us about the James Lind Alliance[1]

What the JLA does well

Why did you choose the James Lind Alliance?
- ✓ Reputation
- ✓ Robust process
- ✓ Previous experience

6 respondents



"It all went extremely smoothly thanks to all the JLA advisers who organised it; lots of disparate viewpoints and agendas, but everyone had ample opportunities to voice their views, and the prioritisation followed a very inclusive, democratic format - aided by some gentle steering by JLA advisers where necessary."

High overall satisfaction with the final priority setting workshop

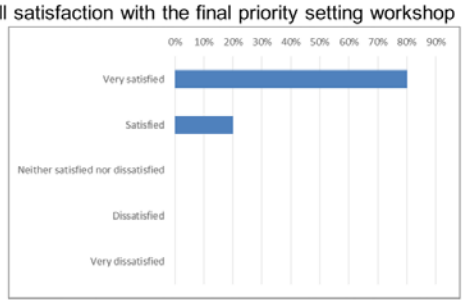


Figure 1: Overall satisfaction with final workshop (20 respondents)

Our skilled & experienced JLA Advisers



Clockwise from top left: Toto Gronlund, Katherine Cowan, Tricia Ellis, Maryrose Tarpey, Sheela Upadhyaya, Catherine White

"....[our adviser] was flexible, supportive and knowledgeable throughout. I found her independent steer invaluable, as did the other members of the Steering Group."

"[The PSP process is an] excellent way of promoting research in neglected areas. Ensures that research conducted is important and wanted by end users."

95% would recommend the PSP process to others

Some of the challenges

"I was not prepared for the huge amount of work that a James Lind Alliance PSP creates - even for a small topic area like [ours]. I think the non-trivial nature of one of these could have been emphasised more."

Resources: time and money

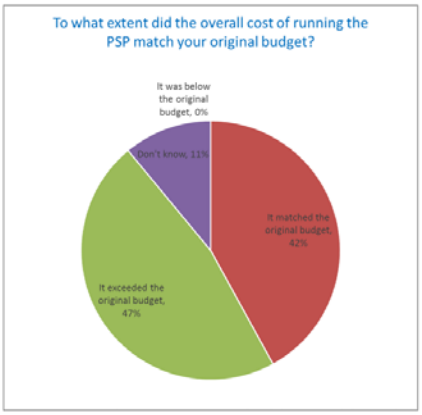


Figure 3: The extent to which the overall cost of running the PSP matched the original budget (19 respondents)

"Classifying the data was actually fairly complicated, as was incorporating all the research suggestions received into a shortlist for prioritisation - but we had enough info and guidance, I think."

Managing the data components of the PSP

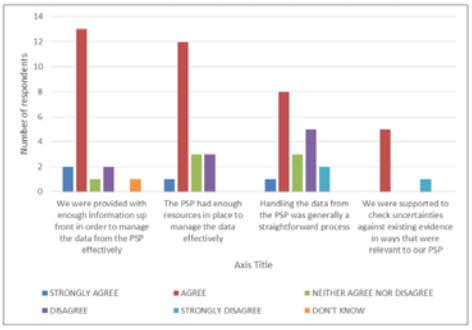


Figure 2: Managing the data components (from 6 to 19 respondents per statement)

What the JLA could do better[2]

"Research planners (myself included) need to have a better understanding of how and when a JLA process will be most useful and appropriate for their organisation before embarking on a programme. Charities, NIHR, and the NHS need to work together to utilise the data obtained even more effectively than has been done to date.....we are really pleased to be a part of this effort!"

"The JLA guideline book is focused almost entirely on treatment questions - while most organisations are interested in a broader range of questions about living with illness. It would be good if the process guidelines were generalised."

- ➢ Greater clarity about time and resources needed
- ➢ Guidebook to reflect wider reach of many PSPs
- ➢ Data management help and detailed examples
- ➢ Shared learning and data use

"I don't recall seeing any practical examples of the process of combining questions to form indicative questions. That would have been helpful. Similarly, practical examples of questions that should be considered out of scope would have been helpful. We had a huge amount of data. Our first attempt involved agonising over which questions could be combined. We were in some difficulty and way behind schedule. The second was conducted by a new data manager and was much quicker."

"...I had enough information but it was overwhelming to digest. The total concept of public patient participation and their active roles in research agenda setting was very new and required some time to fully understand."

[1]Based on 20 final feedback survey responses (from 18 PSPs) between March 2015 and July 2017. Not all respondents answered all questions, especially as some questions were added to the survey recently. Some quotes from 21 respondents to our mid-PSP review survey are also included (February 2017 – August 2017). [2]Themes based on information from 20 respondents.

5.3.10 Exploring the impact of priority setting partnerships in skin disease

Exploring the impact of priority setting partnerships in skin disease

Joanne R. Chalmers, Natasha K. Rogers, Kim S. Thomas
Centre of Evidence Based Dermatology, University of Nottingham
Kim.thomas@nottingham.ac.uk

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Introduction and Aims

- A Priority Setting Partnership (PSP) is a collaboration between healthcare professionals and patients / carers to prioritise research uncertainties for a specific condition.
- The purpose of a PSP is to **reduce research** waste by encouraging subsequent research to answer questions identified as being important to all stakeholders.
- Conducting a PSP requires significant resources, typically costing between £40-£70K, and taking roughly 12 to 18 months to complete, so it is important that impact and value is assessed.
- PSPs are usually conducted using James Lind Alliance methodology; a transparent and standardised process involving surveys to gather and rank uncertainties and a workshop to agree the priorities.[1]

The objective of this study is to assess the impact on the research agenda of PSPs conducted in skin conditions.

Methods

- Search of the relevant databases and websites to identify all skin-related PSPs (published or ongoing).
- Search of trial registries, funder databases, Cochrane Library, and the JLA website to identify ongoing and published research addressing the prioritised uncertainties.

Results

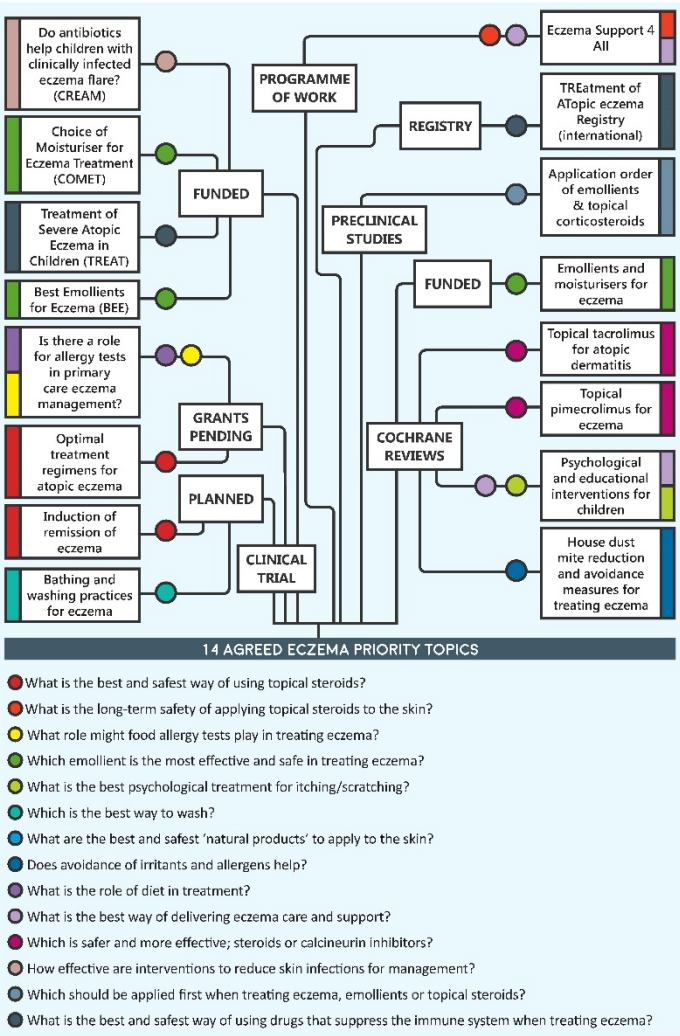
- A total of eight skin-related PSPs were identified as having taken place and published a list of research uncertainties (Table 1).

Skin Condition	Country	Final Workshop
Vitiligo	UK	2010
Eczema	UK	2012
Dystrophic Epidermolysis Bullosa	Spain	2012
Hidradenitis Suppurativa	UK	2013
Congenital Ichthyosis	Spain	2014
Acne	UK	2014
Alopecia Areata	UK	2015
Cellulitis	UK	2017
Psoriasis (due to start)	UK	TBA
Lichen Sclerosis (due to start)	UK	TBA
Hyperhidrosis (ongoing)	UK	TBA

Table 1: Priority setting partnerships in skin disease

- One of the first PSPs to be published in skin disease was in eczema[2] which produced 14 priority topics for research (Figure 1).
- 13/14 (92.9%) of priorities topics are now being actively researched (planned, underway or complete).
- 5/14 (35.7%) of priorities topics have been updated in Cochrane Systematic Reviews.
- **The amount of funding awarded by the National Institute for Health Research (NIHR) addressing these priorities is over £8 million.**

Figure 1: Primary and secondary research currently underway or planned relating to the 14 priority topics identified in the eczema priority setting partnership.



Conclusions

- PSPs can greatly influence the funding agenda, as demonstrated by the significant levels of funding investment in eczema priority topics.
- PSP results are increasingly being used by funders such as the NIHR to prioritise research questions and by other groups, such as Cochrane Skin, to prioritise systematic review titles.
- Future work will extend the analysis to other PSPs conducted in skin conditions and assess the wider impact of PSPs such as promotion of ongoing patient involvement in research.

References

1.http://www.jla.nihr.ac.uk/news/latest-version-of-the-james-lind-alliance-guidebook-published/3470

2. Batchelor *et al.* The Eczema Priority Setting Partnership: a collaboration between patients, carers, clinicians and researchers to identify and prioritize important research questions for the treatment of eczema. Br J Dermatol. 2013 Mar;168(3):577-82.

5.3.11 The big questions: guiding future Type 2 diabetes research

The big questions: guiding future Type 2 diabetes research

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

James Lind Alliance
Priority Setting Partnerships

Browne M, Burns E, Cambell-Richards D, Chakera A, Cowan K, Daly A, Farmer A, Finer S, Jenner M, Krakov-Patel D, McCardle P, Metcalfe L, Morris A, O'Neil S, Robb P, Robertson E, Sarda K, Shah K, Stevens J, Whitmarsh A

Why we need research priorities

Almost **3.6 million people** in the UK are diagnosed with diabetes.

90 percent of these have Type 2.

Around **1 million people** are estimated to have undiagnosed diabetes.

11.9 million are at increased risk of getting Type 2.

Type 2 diabetes is **a chronic and complex** condition.

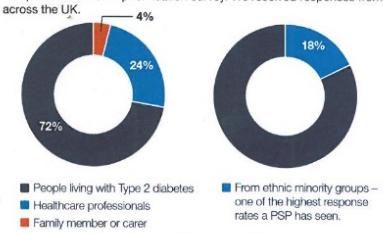
It can lead to **devastating complications**, such as cardiovascular or kidney disease.

It has a **huge cost** to both the individual and the NHS.

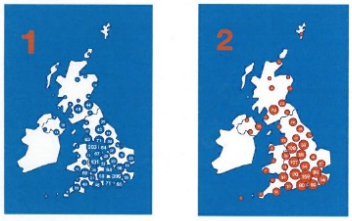
No one understands diabetes better than those who live with it or care for those who do. These priorities will help scientists to take valuable views on board and ensure research makes a real difference to people with Type 2 diabetes.

Our reach

Over **2,500 people** took part in the first survey and over **1,500 people** completed the interim prioritisation survey. We received responses from right across the UK.



Breakdown of first survey participants



Distribution of first (1) and second (2) survey participants

Our process

1 Form a cohesive steering group
People with Type 2 diabetes and healthcare professionals came together in 2016.

2 Build & disseminate first survey
We reached out to over 70,000 people with Type 2 diabetes, carers and healthcare professionals to gather priorities.

3 Analyse & organise responses
We organised over 8,000 ideas: removing answered questions, non-research questions and grouping them together. This created a longlist of 114 research priorities.

4 Interim prioritisation
We asked people with Type 2 diabetes, carers and healthcare professionals to choose and rank their top 10 priorities from the longlist of 114.

5 Narrowing down to a shortlist
The top 10 priorities of people with Type 2 diabetes, healthcare professionals and BAME (Black, Asian and Minority Ethnicity) individuals were all taken forward to the final prioritisation workshop. This resulted in a shortlist of 24 priorities.

6 Identifying the top 10 priorities

A final workshop was facilitated by the James Lind Alliance. It involved a group of people with Type 2 diabetes, carers and healthcare professionals. Over one day, they came to a consensus on the top 10 research priorities together.

Finding the answers

"I hope that researchers and funders will now put patients, who are often the forgotten part of the equation, at the heart of research."
Helen Ogg, living with Type 2 diabetes

"I am optimistic the top 10 priorities will help to create a new sense of direction for research, which will give healthcare professionals and people with Type 2 diabetes the knowledge to best manage the condition and improve outcomes."
Michael Osei Kissi, radiologist and Diabetes UK Clinical Champion

"The top 10 included a really good range of issues – scientific, behavioural, cultural and educational. So I really hope we'll see a variety of new research initiatives that will help those of us with Type 2 today and those at risk of the future."
Liz Montgomery, living with Type 2 diabetes

This year we have established seven **diabetes Clinical Studies Groups**, who will use the Type 1 and Type 2 diabetes top 10 priorities to build their roadmap for the most important future diabetes research.

These groups bring together

• people with diabetes, • leading researchers in key areas, • and healthcare professionals

to create a plan for future research.

We will work with government, industry and other diabetes research funders to ensure greater investments are made in the most vital areas of research.

The top 10 research priorities

1. Can Type 2 diabetes be **cured or reversed**, what is the best way to achieve this and is there a point beyond which the condition can't be reversed?
2. How do we identify people at **high risk** of Type 2 diabetes and help to **prevent** the condition from developing?
3. What is the best way to encourage people with Type 2 diabetes, whoever they are and wherever they live, to **self-manage** their condition, and how should it be delivered?
4. How do **stress and anxiety** influence the management of Type 2 diabetes and does a positive mental wellbeing have an effect?
5. How can people with Type 2 diabetes be supported to make **lifestyle changes** to help them manage their condition, how effective are they and what stops them from working?
6. Why does Type 2 diabetes get **progressively worse** over time, what is the most effective way to slow or prevent progression and how can this be best measured?
7. Should **diet and exercise** be used as an alternative to medications for managing Type 2 diabetes, or alongside them?
8. What causes **nerve damage** in people with Type 2 diabetes, who does it affect most, how can we increase awareness of it and how can it be best prevented and treated?
9. How can **psychological or social support** be best used to help people with, or at risk of, Type 2 diabetes and how should this be delivered to account for individual needs?
10. What role do **fats, carbohydrates and proteins** play in managing Type 2 diabetes, and are there risks and benefits to using particular approaches?

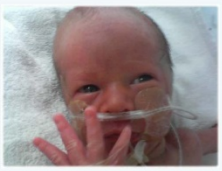
5.3.12 JLA Preterm Birth Priority Setting Partnership

JLA Preterm Birth Priority Setting Partnership

Consensus development for tackling highly technical and emotive challenges

Seilin Uhm (Seilin.uhm.09@ucl.ac.uk, Twitter @psychologyToki)
Prof Sandy Oliver(sandy.oliver@ucl.ac.uk, @profsandyoliver)
Social Science Research Unit, UCL Institute of Education

UCL



31 weeker Ryan at the time of birth

Introducing Preterm Birth PSP

The Preterm Birth PSP was set to provide research priorities about preterm birth. Preterm birth is the single largest direct cause of the world's neonatal deaths(Lawn, Cousens and Zupan, 2005), and increases the risk of dying due to other causes, especially from neonatal infections. Even a minor intervention can have a great impact on the preterm infants, and their families.

The priority setting process took over 3 years (March 2011 to March 2014), which was extended from the original plan (1 year). 26 organisations representing service users' and clinical organisations participated from the UK and Ireland. The PSP had 14 meetings (1 Awareness workshop, 9 face-to-face steering group meetings, 3 steering group teleconferences, and 1 Final Workshop). It was part of a wider NIHR funded research programme.

Lawn, J. E., Cousens, S. and Zupan, J. (2005). '4 million neonatal deaths: when? Where? Why?'. Lancet, 365 (9462), 891-900.

The Prioritisation Process

26 organisations participated, 13 people representing 6 organisations formed steering group

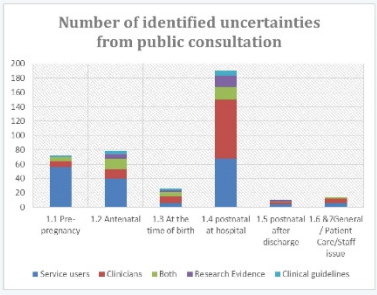
1st stage 386 respondents, 540 systematic reviews searched, 593 research uncertainties

Collated into 104 uncertainties
70 from survey, 28 systematic reviews, 24 from clinical guidelines

537 respondents voted
Top 40 taken to workshop
Top 15 were decided

Priority Gaps between Service Users and Clinicians

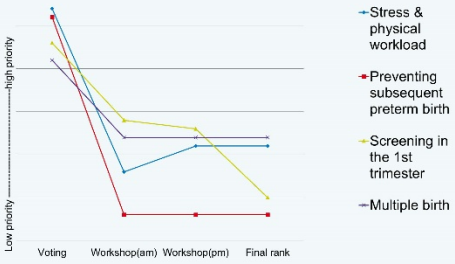
The PSP conducted two major public consultations:
a) identification survey with open questions, and b) a voting stage, selecting 10 priorities from 104 refined questions. The outcomes from both identification and voting stages suggested that there were priority gaps between service users and clinicians.



Lost Priorities during the Final Workshop

Some questions were not prioritised to the top 15 places after the final workshop despite being placed high in the priority after the voting stage. The reasons were: 'it could be included in (or similar to) another question', 'a trial might be in progress somewhere else', 'not a conventional treatment', 'the intervention would not be helpful', 'difficult to define the condition or intervention'.

	Rank (voting)	Final workshop (morning)	Final workshop (afternoon)	Final rank
Stress & physical workload	3	22	19	19
Preventing subsequent preterm birth	4	27	27	27
Screening in the 1st trimester	7	16	17	25
Multiple birth	9	18	18	18



Comparing the PSP to Tuckman's Group Development theory

The SG showed typical stages in group development (forming, storming, norming, performing and adjourning). However, when the new participants were added at the final stage of the decision-making process, the PSP returned to the very beginning stage of the development (forming).

This may explain differences between the public voting, which adapted the Delphi method, and the final workshop, which adapted the Nominal Group technique.

Tuckman (1965). "Developmental sequence in small groups". Psychological Bulletin 63 (6): 384–99.

Tuckman's stages of group development	JLA's 5 stage of partnership working
Forming	Initiation
Storming	Identification
Norming	Summarisation
Performing	Prioritisation
Adjourning	Reporting

Final workshop vs voting

- Often did not match.
- Communication patterns methods to persuade others differed (depending on the stages of the group development). For example, SG used more rational ways than emotive ways compared to new participants.

Royal College of Obstetricians and Gynaecologists
Setting standards to improve women's health

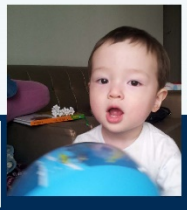
Tiny Life

nct Bliss for babies born too soon, too small, too sick

NOTTINGHAM CLINICAL TRIALS UNIT

SSRU Social Science Research Unit

Ryan at 1 year old



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Improving quality of care and outcome at very preterm birth
NIHR Programme Grant for Applied Research

5.3.13 Palliative and end of life care Priority Setting Partnership (PeolcPSP)

Palliative and end of life care Priority Setting Partnership (PeolcPSP) 63

Current palliative care research neglects out of hours care which is ranked the top end-user research priority

Palliative and end of life care Priority Setting Partnership

Authors: **Florence Todd Fordham**, Sabine Best, Sanjay Thakrar and Bill Noble, Marie Curie

1,403 responses to our initial survey

48% professional; 35% bereaved carers; 13% current carers; 4% patients

From the survey responses, **83** unanswered interventional questions were formulated

PRIORITISATION

The **Top Ten** unanswered questions in palliative and end of life care were published **on 15th January 2015**[1]

TOP PRIORITY

What are the best ways of providing **out of hours palliative care** to avoid crises and help patients to stay in their place of choice?

INTRODUCTION AND AIM

In 2013/14 the Palliative and end of life care Priority Setting Partnership (PeolcPSP) used the James Lind Alliance (JLA) methodology to establish the top ten list of unanswered questions relating to palliative and end of life care research. These were ranked in accordance with responses from current and bereaved carers, healthcare professionals and people in the last years of life. The JLA methodology identifies questions that are either not answered by a current systematic review or for which no systematic review exists. Nevertheless, there might be current research projects in process which look into the question, either directly or in a way in which the results might be relevant to the question in an indirect way.

This aim of this paper is to review the ways in which current research is addressing the top research priority through a grant mapping exercise.

METHODS

Grant mapping facilitates the visualisation of the current research landscape in palliative and end of life care, highlighting the research questions that are currently being addressed and those where there is less or no attention/funding. To conduct the mapping project, the recently published UKCRC's Health Research Classification System database was used[2]. This dataset, which is composed of £2 billion of UK health relevant research funding for 2014, was analysed for links between the abstracts and the PSP questions.

The following analysis specifically looks at the results relating to the top priority:

Out of hours palliative care.

OUT OF HOURS PALLIATIVE CARE

The out of hours period covers from 18.30 to 08.00 on weekdays, and from 18.30 on a Friday through to 08.00 on a Monday, and on bank and public holidays[3]. Out of hours palliative care is just one component, albeit an important one, of the out of hours services needed by patients in the last years of life living at home.

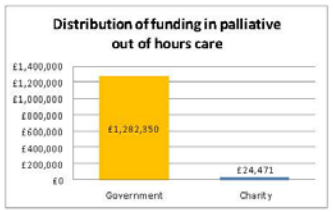
Using keyword searches, the HRCS dataset was searched for relevant grant abstracts. The keywords brought up 4,420 grants of which 594 were manually mapped. The keyword searches that were specific to the out of hours palliative care priority were: palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, working hours, out of hours, out-of-hours, OOH, 24 hour, 24-hour, 24hr, place of choice, famil*, carer.

LIMITATIONS

- Using the HRCS 2014 dataset of health research, this grant mapping process only considered research grants which were active in 2014, so shows a snapshot of the research landscape in palliative and end of life care.
- The dataset looks at £2 billion of project grants. A further £1 billion of infrastructural funding is not included (eg. Marie Curie centres are not included).
- The HRCS 2014 dataset includes most governmental and charitable researcher funders, but not all.

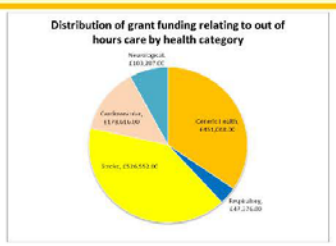
RESULTS AND ANALYSIS

14,934 grant abstracts were searched using keyword searches for all 83 priorities. Of these, only 12 related to the priority on out of hours palliative care. These 12 grants **amount to £1,306,820 of funding, which is 0.06% of the** total health research spend in the 2014 HRCS dataset. The distribution of this funding is displayed in the graph below.



However, of these 12 grants, only 4 are considered "directly" related to the out of hours palliative care priority, with a specific link to 24 hour support for patients at the end of life and their carers and families, reducing the **amount to only £516,924, which is just 0.03% of the health** spend in 2014.

Of this directly related amount, 3.8% comes from Marie Curie (£19,483), and the rest is governmental funding. There only two other funders, direct and indirect, with a combined research funding of £18,932.



As is highlighted above, the **stroke** health category received the highest proportion of the total funding relating to out of hours palliative care.

DISCUSSION

Out of hours palliative care has been identified as the top priority for research by carers, patients and clinicians. The 2014 HRCS research snapshot shows that there is little ongoing research in out of hours palliative care.

In addition, it has been found that the specific need for out of hours palliative care has not been systematically explored in research to date[4]. There is a lack of high quality research evaluating existing out of hour palliative services. High quality implementation and evaluation studies into out of hours palliative care are required to establish national standards.

CONCLUSIONS AND NEXT STEPS

- **Current palliative and end of life care research neglects out of hours palliative care despite it being ranked as the top research priority by carers, patients and clinicians.**
- **To address this unmet need, Marie Curie recently announced its seventh funding call addressing the PeolcPSP priorities. NIHR has recently announced an HS&DR researcher-led funding call with a specific highlight on the PeolcPSP questions.**
- **The Marie Curie conference on 19th October 2016 will look at the issue; conference theme: Round the clock – making 24/7 palliative care a reality.**
- **High quality implementation and evaluation studies into out of hours palliative care are required to establish national standards.**

References

[1] Palliative and end of life care Priority Setting Partnership (PeolcPSP) Final Report, January 15th 2015, http://www.palliativecarepsp.org.uk/finalreport/

[2] "UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015) ISBN 978-0-908730-20-4 http://www.hrcsonline.net/pages/uk-health-research-analysis-2014"

[3] Addington-Hall, J., Gerard, K. Brien, S. B., Braitsford, S., Salisbury, C., Heaney, D., Todd, C., Moore, M., Leydon, G., England, H., Lattimer, V. (2011) Variations in Out of Hours end of life care provisions across primary care organisations in England and Scotland. Final Report. NIHR Service Delivery and Organisation Programme, 2013.

[4] Godwin, M., Anagnostou, D., Morgan, F., Sivell, S., Baillie, J., Byrne, A. and Nelson, A. (2016) Exploring experiences of out of hours palliative and end of life care: a supplementary thematic analysis of the PeolcPSP data, in preparation

5.3.14 JLA PSP for Lyme Disease

JLA PSP for Lyme Disease
Huge challenge, slow progress

Stella Huyshe-Shires
Lyme Disease Action

2003 Starting point

Lyme disease (Lyme borreliosis): an emerging zoonotic disease in the UK, transmitted by the bite of an infected tick. First confirmed UK case 1985.

Limited public awareness
No quality information
Lack of knowledgeable specialists
Little research on tick co-infections
Reliance on serology blood tests
Many documented diagnostic & treatment uncertainties

2003 - 2009 What LDA did

Established a registered charity
Researched the medical literature
Produced information leaflets
Developed a website with carefully researched information
Ran annual conferences
Tried to talk to the Department of Health and doctors
Lobbied MPs

What happened

Zero patient engagement

CMO UPDATE

Those claiming to have 'chronic Lyme disease' or who believe it to be the cause of their chronic condition can be diagnosed definitively through using the HPA's tests.

There is no biological evidence of symptomatic chronic Lyme disease amongst those who have received the recommended treatment regimen.

"I trust the judgements of my colleagues who are experts in this field. I feel there would be no purpose in a meeting at this stage."

Chief Executive, Health Protection Agency

2010-2012 What we did next

Lyme Disease Action achieved accreditation to the Department of Health's Information Standard.

Health & care information you can trust
The Information Standard Certified Member

The public trusted us, but the clinicians ignored us.

So then.. we initiated a JLA PSP

In order to

prove

there *are*

uncertainties.

But this proved very challenging.

We needed a partnership between patients and clinicians.
NHS clinicians, particularly specialists, would not engage with us.

James Lind Alliance
Priority Setting Partnerships

Difficulties we met

The Health Protection Agency refused to engage.

The Department of Health hoped it would "help patients understand more about Lyme disease".

Some patients were ambivalent.

Great resistance among health professionals, causing difficulty in:

- recruiting clinicians to steering group
- persuading clinicians to contribute to the survey.

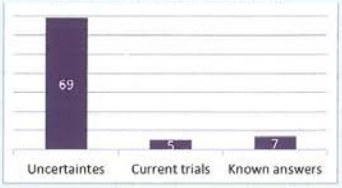
Only 56 NHS health professionals contributed to the survey.

Submission from an infectious diseases consultant who sees 5-10 Lyme disease patients/year

"I have always been able to easily find evidence-based guidelines on how to manage all aspects of Lyme Disease, and am not left with uncertainties about how to prevent, diagnose or manage Lyme Disease."

2013 Survey results

253 respondents
510 questions in scope,
consolidated to give
81 questions



Key uncertainties:

- The best **treatment**, except in early disease
- The best **test** to identify UK infections

2014-2017 Some progress

Public Health England

- Engaged with Lyme Disease Action
- Held 2 conferences
- Some limited guidance for GPs

The Department of Health

- Agreed to meet Lyme Disease Action

..... BUT.....

Professional organisations did **NOT** inform their members of the JLA outcome.

NIHR has **NOT** moved uncertainties onto a research agenda.

A paper, commissioned by the Royal Society for Public Health and relating the JLA outcome, was **rejected** because of comments by one of the reviewers.

Infectious diseases consultants generally still **ONLY** treat if a positive test result.

Doctors **RARELY** re-treat patients when treatment fails.

2018 – where are we now?

No significant research
No experienced clinicians
Many undiagnosed patients
Many under treated patients
Public mistrust & frustration
Sensational, speculative media

Inching forward still !

LDA
Lyme Disease Action
Registered in England & Wales
Registered Charity no. 1100448 Registered Company no. 4839410

Stella Huyshe-Shires, BSc, Chair & CE Lyme Disease Action
Contact: Stella.Huyshe@LymeDiseaseAction.org.uk

www.LymeDiseaseAction.org.uk
@LymeAction

5.3.15 Driving investment in asthma research in Europe

Driving investment in asthma research in Europe: priorities to prevent, cure and manage asthma more effectively

Masefield S[1], Powell P[1], Kennington E[2], Edwards J[2], Cowan K[3], Metcalf L[3], Walker S[2]
[1]European Lung Foundation, Sheffield, [2]Asthma UK, London, [3]James Lind Alliance, Southampton UK

Background

>30 million people live with asthma in the European Union (EU) (10% of the population), which has a great impact on quality of life and an estimated annual cost of >€72.2 billion. It is the most prevalent long-term condition in children (25% of children in some EU countries).

Breakthroughs and technological advances present an opportunity to deliver new diagnostic methods, treatments and self-management tools which could dramatically improve the way asthma is diagnosed, managed and treated.

Here we present priorities for research investment, identified through expert consensus, as part of the FP7-funded European Asthma Research and Innovation Partnership (EARIP). EARIP aims to identify the investment required in different areas to bring about significant improvements in asthma outcomes in Europe.

Methods

Priorities were identified by research gap analysis of overview documents from international and European medical societies, patient organisations and policy makers in the field of asthma

↓

Theses priorities were shortlisted by 1,589 patients and healthcare professionals via a Europe-wide questionnaire exercise

↓

A consensus workshop with 31 individuals (those living with asthma, patient organisation representatives, industry representatives and world-leading asthma clinicians and researchers) worked to rank, validate and contextualise the 15 priorities

Results

The top five priorities were to:

1. Identify, understand and better classify the different forms of asthma, their progression, and effect on airway inflammation and the immune system
2. Assess the effectiveness of patient-professional communication to develop patient-professional partnerships to optimise self-management and adherence
3. Assess the effect of infections in early childhood, the long-term effects of anti-inflammatory treatments, and use of anti-viral drugs and vaccines
4. Assess impact, adoption and transferability of best practice in regional, national and European asthma programmes, care pathways and asthma clinics
5. Develop new treatments for the different types of asthma: treatment-resistant and steroid-resistant asthma, severe asthma, allergic asthma, hyper-responsive asthma

Conclusions

These findings will be used to inform asthma research funding in Europe for the next two decades and have clear value for European and international research bodies, and industry.

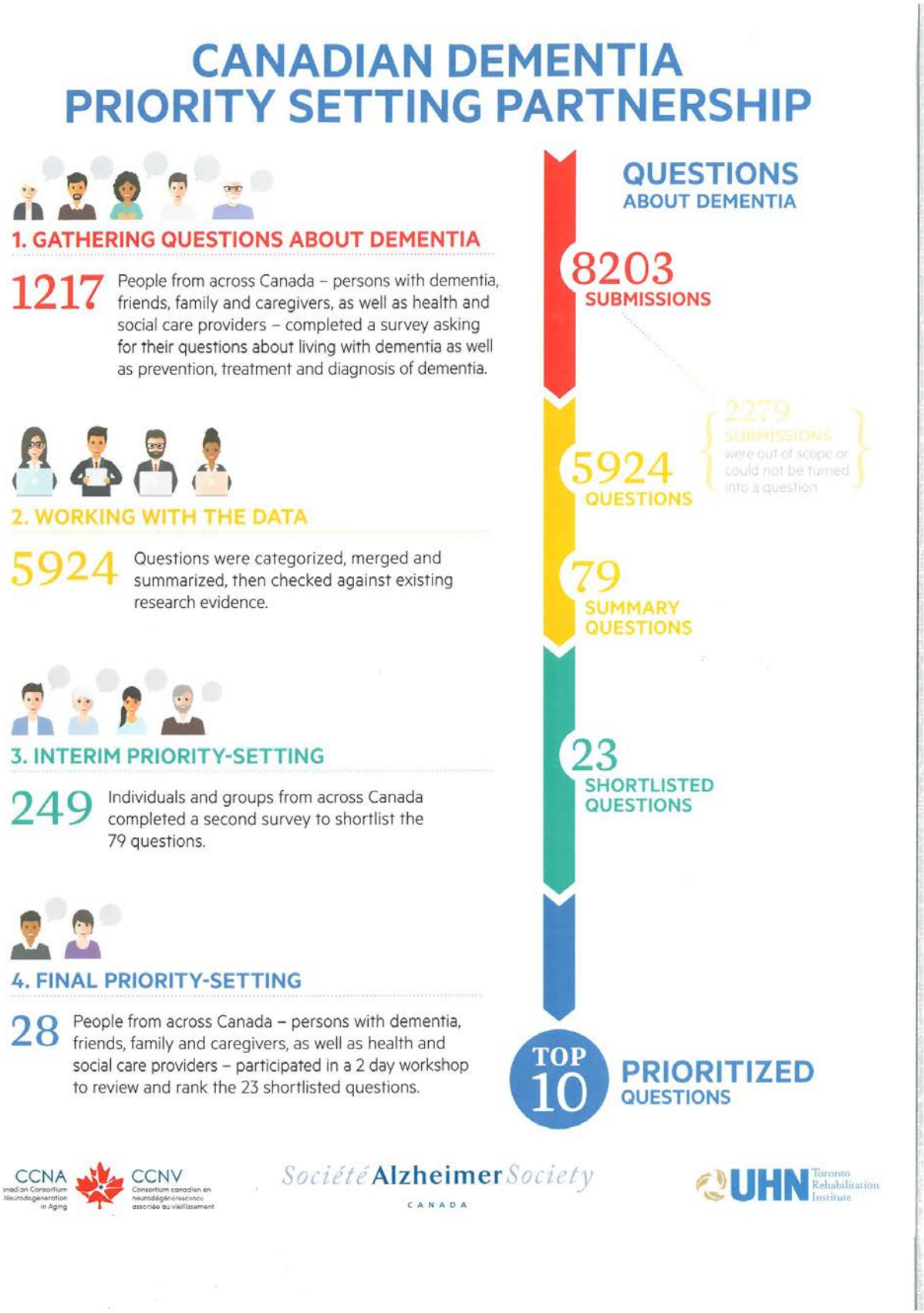
Corresponding author

Sarah Masefield, European Lung Foundation
Patient involvement and engagement,
sarah.masefield@europeanlung.org

In association with

Study funded by the European Commission (GA: 602077)

5.3.16 Canadian Dementia Priority Setting Partnership



CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP

Top 10 Priorities for Dementia Research

1 ADDRESSING STIGMA

What is the impact of stigmas associated with dementia and mental health issues on persons with dementia and their families?

What are effective ways of reducing the stigma experienced by persons with dementia and their friends, family and caregivers/care partners?

2 EMOTIONAL WELLBEING

What can be done to support emotional wellbeing, including maintaining a sense of dignity, for persons with dementia?

3 IMPACT OF EARLY TREATMENT

Among persons with dementia, what is the impact of early treatment on quality of life, disease progression and cognitive symptoms?

4 HEALTH SYSTEM CAPACITY

How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their friend or family caregivers/care partners?

5 CAREGIVER SUPPORT

What services, supports and therapies for friends or family caregivers/care partners of persons with dementia would improve or maintain health, wellbeing and quality of life for persons with dementia and their friends or family caregivers/care partners?

6 ACCESS TO INFORMATION AND SERVICES POST-DIAGNOSIS

After dementia is diagnosed, what would help persons with dementia and their friends, family and caregivers/care partners get the information, treatment, care and services they may need?

7 CARE PROVIDER EDUCATION

What dementia-related skills and knowledge should health and social care providers have? What are effective ways of providing them with these skills and this knowledge?

How can the number of health and social care providers who have these skills and this knowledge be increased?

8 DEMENTIA-FRIENDLY COMMUNITIES

What enables the creation of dementia-friendly communities? What impact do dementia-friendly initiatives have on persons with dementia and their friends, families and caregivers/care partners?

9 IMPLEMENTATION OF BEST PRACTICES FOR CARE

What would ensure implementation and sustainability of best practices for dementia care within and across health care settings, including effective approaches to providing person-centred care?

10 NON-DRUG APPROACHES TO MANAGING SYMPTOMS

Among persons with dementia, what are the effects of non-pharmacological treatments compared to pharmacological treatments on behavioural and psychological symptoms of dementia?

Can non-pharmacological treatments replace, reduce or be used in conjunction with pharmacological treatments for managing behavioural and psychological symptoms of dementia?

5.3.17 Pressure Ulcer Priority Setting Partnership

James Lind Alliance
Priority Setting Partnerships

James Lind Alliance
Priority Setting Partnerships

James Lind Alliance

Using JLAPUP to identify possible areas for further evaluation and reporting across PSPs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Exploring the challenge of health research priority setting in partnership: reflections on the methodology used by the James Lind Alliance Pressure Ulcer Priority Setting Partnership

Mary Madden and Richard Morley

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Background
Conclusion
Declarations
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There is a need to understand and collate formally the range of approaches under the JLA banner and outcomes from PSPs including:

- the theory behind the setting up of PSPs, who set them up, how methods were decided on and used in design and delivery
- the extent to which people understand the process in which they are participating, including 'uncertainty' as the starting point for research
- inclusions and exclusions from and within the partnership, especially its decision-making fora (Steering Groups and the final meeting) and how to engage seldom heard groups, including those with frailty and care home residents, in the process
- ethical considerations, including the necessity and worth of negotiating the NHS ethics framework
- effective survey design for consultation and prioritisation
- interpreting open-ended submissions without 'reading into' them
- whether final priorities are also 'researchable questions' and what to do with submissions not suitable for RCTs
- resources required to adequately check that there is no evidence to answer submitted questions
- the role and responsibility of a PSP in fielding: individual requests for advice about a health condition; offers of resources and involvement from industry (given increasing private involvement in public health and social care provision); and general requests to act as a mouthpiece for a perhaps otherwise poorly represented health condition
- how to promote uncertainties and assess impact when the funding runs out
- lifespans and full costings of PSPs

Broader issues for exploration:

- governance of the JLA and its relationships with stakeholders
- potential for partnerships with evidence synthesis organisations, guideline reviewers, organisations that promote PPI etc.
- the increasing international prevalence of JLA PSPs
- methodological developments in other areas of priority setting that relate to the JLA

Dr. Mary Madden, Lecturer in Applied Health Research, School of Healthcare, Faculty of Medicine and Health, 2.19, Baines Wing, University of Leeds, Leeds, LS2 9JT
Richard Morley, Consumer Coordinator, Cochrane, St Alban's House, 57-59 Haymarket, London SW1Y 4QX

5.3.18 A new PSP for Rare Disease: an umbrella organisation approach

A NEW PSP FOR RARE DISEASE: AN UMBRELLA ORGANISATION APPROACH

Dr Mariana Campos[1] and Dr Amy Hunter[1]

GENETIC ALLIANCE UK

BACKGROUND

There are ~8,000 rare diseases affecting ~3.5M people in the UK. For the majority of rare diseases there is no effective drug treatment. Priority Setting Partnerships are able to highlight where other interventions are most needed to manage symptoms or to improve quality of life.

Conducting a PSP for each individual rare disease would be impractical due to the scale of the task and because the number of patients affected by each disease is small.

Our PSP will therefore encompass a small number of related rare diseases. A similar model is being used for two existing rare disease PSPs, on rare anaemias and rare musculoskeletal conditions, supported by the NIHR Oxford Biomedical Research Centre.

Our PSP is unique in that its scope will be determined democratically by our membership. Genetic Alliance UK is an umbrella organisation representing over 190 diverse patient groups.

PROJECT PLAN

Selecting a topic for our Rare Disease PSP

We will determine the PSP topics through an open call to our members, thereby ensuring that the process is democratic, has the buy-in of our membership and has the best chance of success.

Our expression of interest is open to patient organisations who are members of Genetic Alliance UK. For the exercise to be successful, we will need a number of committed patient groups representing related conditions.

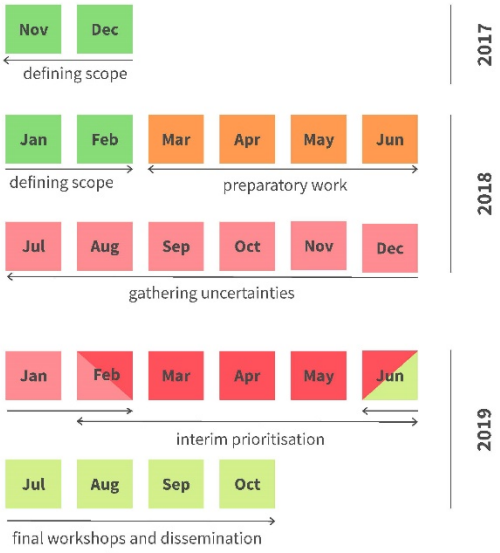
The selection of patient organisations will be informed by answers to a series of questions on the expression of interest form. They include:

1. What would you say are the top three challenges affecting your patients? (That might be answered by research).
2. Who does the condition affect? (select all that apply)
   - Children
   - Young adults
   - Adults
3. How many patients are affected by the condition/conditions you support in the UK?
4. How would you rate access to services for those affected by the condition?
5. If you support a condition that affects children, do you have any experience of how to engage them and their families?
6. Are you in contact with clinicians in the UK who have a clear interest and are engaged with the condition?
7. Are you part of any interest groups or networks where you could secure engagement and disseminate the findings of the project (other than your own members)?
8. Would you be able to provide any resources in kind? You might be able to help develop communications tools, disseminate results, contact patients or do anything else you think might be relevant.

Combining Rare Disease PSP outcomes

Unmet patient needs identified by the rare anaemias and rare musculoskeletal PSPs include some that are 'common' across rare diseases. We aim to add similar findings from our PSPs to this list, thus building a new resource relevant across rare diseases.

Key dates



More information
For more information about this project, please contact Mariana Campos, mariana.campos@geneticalliance.org.uk, visit www.geneticalliance.org.uk or follow us on social media.

GeneticAllianceUK
@GeneticAll_UK
geneticallianceuk

[1]Genetic Alliance UK is an alliance of over 190 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions.

This project is supported by a Wellcome Trust Public Engagement grant.

wellcome

5.3.19 Driving JLA Neuro-Oncology Priority Questions into Clinical Studies

Neuro-Oncology Group
a JLA priority setting partnership

James Lind Alliance
Priority Setting Partnerships

Driving JLA Neuro-Oncology Priority Questions into Clinical Studies

Dr. Robin Grant, Consultant Neurologist, Edinburgh and Dr Helen Bulbeck Director *brainstrust* on behalf of the JLA Neuro-Oncology Group and NCRI brain Clinical Studies Group.

Background

In July 2013 a meeting was held at the Cochrane Editorial Unit, Kings Fund, London to scope out work for a James Lind Alliance – Neuro Oncology Priority Setting Partnership. The scope included adult brain & spine tumours. Funding was secured from brain tumour charities, Cochrane and the Edinburgh Lothian Health Foundation. Agreement to provide facilitation was obtained from the JLA and a JLA Neuro-Oncology Website was developed.

Our aim, following identification of the top 10 Priority Questions, was to:

1. Engage with the clinical research community in Neuro-Oncology;
2. Engage with funding organisations;
3. Progress clinical studies and trials in the JLA priority areas through:
   a. Obtaining the best current evidence through partnership with Cochrane Neuro-Oncology Group,
   b. Agreement with NCRI Brain and CNS Clinical Studies Group to prioritise the JLA questions and develop studies in these areas.

A first survey of the brain tumour community realised > 600 questions which were then categorised, PICO formatted, duplicates combined, questions checked by the stakeholder group. "Out of scope" and already answered questions were removed.

The first stakeholder meeting took forward 95 questions that were asked more than once and stakeholders voted for top 10 questions. We took forward questions voted for by >=4 people (44 questions)

A second public vote on the 44 questions was obtained, by 227 people, equally split between professionals and patients/caregivers. We took forward 25 questions receiving >20% of the total vote.

A final stakeholder meeting (split equally between professionals and patients/caregivers) subsequently identified the **top 10 priority questions (Table 1)**.

Methods

A meeting was held in the Centre for Clinical Practice, NICE Offices, London in June 2015 to discuss developing a strategy to support the JLA questions becoming fundable clinical neuro-oncology research applications.

Attendees included:

- JLA Neuro-Oncology Core Team, Lead for NCRI brain Clinical Studies Group, President of British Neuro-Oncology Society, Leads for Cochrane Neuro Oncology, Director of CCP NICE, Vice Chair for Research Design Service (RDS)/Health Economics.
- Funders – two funding representatives from NIHR, one from Chief Scientist Office (Scotland), one from CRUK. (MRC/Wellcome representatives invited but could not attend) and a scientific/funding representative from each of the main charities: *brainstrust*, International Brain Tumour Alliance (IBTA); the Brain Tumour Charity (TBTC), Brain Tumour Research (BTR) and Children with Cancer (CwC).

The strategy subsequently agreed included:

- Obtaining agreement from the NCRI to use the JLA Neuro-Oncology priority areas to focus Clinical Research applications, led through the NCRI brain CSG Supportive and Pallitaive Care Subgroup.
- Planning "Incubator Days" co-ordinated through NCRI brain CSG, inviting at least three UK centres actively involved in the JLA research topic area to work on a collaborative proposal, a Cochrane Neuro-Oncology Group Co-Fd, a representative from the NIHR Research Design Service and involvement of a UKCRC Clinical Trials Unit and the most appropriate funding partners for the incubating days from the representative charities.

Table 1

Top 10 uncertainties*

1. Do **lifestyle factors** (e.g. sleep, stress, diet) influence tumour growth in people with a brain or spinal cord tumour?
2. What is the effect on prognosis of **interval scanning** to detect tumour recurrence, compared with scanning on symptomatic recurrence, in people with a brain tumour?
3. Does **earlier diagnosis** improve outcomes, compared to standard diagnosis times, in people with a brain or spinal cord tumour?
4. In **second recurrence glioblastoma**, what is the effect of further treatment on survival and quality of life, compared with best supportive care?
5. Does **earlier referral to specialist palliative care services** at diagnosis improve quality of life and survival in people with a brain or spinal cord tumour?
6. Do **molecular subtyping** techniques improve treatment selection, prediction and prognostication in people with a brain or spinal cord tumour?
7. What are the **long-term** physical and cognitive **effects of surgery and/or radiotherapy** when treating people with a brain or spinal cord tumour?
8. What is the effect of interventions to help **carers** cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?
9. What is the effect of additional strategies for managing **fatigue**, compared with standard care, in people with a brain or spinal cord tumour?
10. What is the effect of **extent of resection** on survival in people with a suspected glioma of the brain or spinal cord?

*Uncertainties relate to adults

Strategy meeting to support clinical neuro-oncology research applications, held at the Centre for Clinical Practice, NICE Offices, London.

Results

- Since 2015 the NCRI brain CSG Supportive & Palliative Care Subgroup has held **Incubator Days** on six priority questions 1, 3, 5, 8, 9, 10.
- **Incubator Days** have also been held on Seizure Prophylaxis in Glioma and Cerebellar Cognitive Affective Syndrome.
- **Cochrane Priority Reviews** are underway for reviews in 1, 4, 8, 9, 10.
- **Cochrane Complex Reviews** are planned following a successful NIHR Cochrane Systematic Review Programme Grant for 2, 3, 5, 6, 7.
- **Funding applications** have been submitted to NIHR or charity funders on 1, 5, 8, 9, 10, and Seizure Prophylaxis in Glioma.
- **Successful applications include:**
  - NIHR HTA 16/31/136 – SPRING Seizure Prophylaxis IN Glioma (Multi-Centre RCT).
  - NIHR Cochrane Systematic Review Programme Grant 16/114/18 (NCRI/Cochrane): 8 Complex Systematic Reviews including 7 of the JLA topics 2, 3, 4, 5, 6, 7, 10.
  - TBTC Quality of Life Project Grant – BT LIFE: Brain Tumours – Lifestyle Intervention and Fatigue Evaluation – a multi centre feasibility RCT.
  - A randomised pilot study of Ketogenic Diet (The KEATING trial) (A randomised feasibility trial – Vitaflow International Ltd: NCT03075514).
  - BTR – effect of ketogenic diet on tumour growth – prospective study.
- **Applications submitted/in development:**
  - **Palliative Care Supportive Care Master Protocol** – Prof Robert Hills/Dr Anthony Byrne – Cardiff University (NCRI Haematology Oncology CSG).
  - **Improving support for family caregivers in neuro-oncology** – Dr Florien Boele – Acad. Fellow in Neuro-Psychology, Leeds University.
- **NOCTURN (Neuro-Oncology Clinical Trials UK Research Network) website** was developed out of the Neuro Oncology JLA Website. This is a resource for neuro oncology clinical researchers to obtain all the latest NIHR/CRUK/Wellcome/MRC funding sources and resources to assist application for clinical research funding and to inform the community about the top 10 JLA questions and help that NCRI brain and CNS CSG can give.

Conclusion

Following completion of JLA topics, we recommend active engagement with the evidence synthesis community (e.g. Cochrane), the research community in your specialist area and national and specialty funding sources to actively promote the priority areas.

5.3.20 Identifying the Top 10 research priorities for diagnosis and management of scoliosis – The Scoliosis PSP

Identifying the Top 10 research priorities for diagnosis and management of scoliosis – The Scoliosis PSP

AUTHORS: Jeremy Fairbank MD FRCS, NDORMS, Oxford, and Elizabeth J Holloway BSc (Hons), Medical student (Imperial College London), for the Scoliosis PSP Steering Group
(PSPSG: Pierre Bernard, Young person Carer representative; Stephanie Clark, Scoliosis Association UK; Claire Curley, Scoliosis Association UK; Peter Virley, British Scoliosis Research Foundation; Fraser Old, Adult Carer representative; Katie Henderson, Patient Representative, Ataxia UK; Andrew Clarke, Consultant Orthopaedic Surgeon, Royal Devon and Exeter; Jeremy Fairbank, Consultant Orthopaedic Surgeon, Oxford; Chris Morris, Child Health Group, University of Exeter Medical School; Anne Richard, Paediatric Physiotherapist, formerly of Oxford University Hospitals NHS Foundation Trust; Dominique Rothenfluh, Consultant Spinal Surgeon, Oxford University Hospitals NHS Foundation Trust; Katherine Cowan, The James Lind Alliance)

INTRODUCTION

Do the priorities of patients and researchers when investigating treatment coincide? No!

- There is evidence of a mismatch between priorities of researchers and those with lived experience of a healthcare condition and healthcare professionals who care for these individuals [1]
- The James Lind Alliance (JLA) was set up to address this mismatch [2]
- JLA brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) with the aim of ensuring that those who fund healthcare research are aware of what matters most to users (i.e. those with lived personal experience)

The JLA has facilitated over 50 PSPs in diverse conditions to develop priority lists for future research (http://www.jla.nihr.ac.uk/top-10-priorities/).

Patient and public involvement is effective in:

- identifying user-relevant topics for the research agenda [3]
- improved dissemination of results [3]

Scoliosis has not attracted major research investment, in spite of being a common condition. Examples of treatment/management uncertainties highlighted by patients are:

- Increased frequency and severity of back pain [4]
- More time off school and educational disadvantage
- Diagnostic tests are intrusive and do not always capture all the dimensions of the condition
- Non-operative treatment options can contribute to body image problems and still leave 40% of patients with curves that do not respond and may require surgery.
- Surgery has complications including infection and implant failure, spinal cord damage and paralysis.
- **A research focus on large scale surgery, rather than screening and non-operative management**
- Risks, benefits and costs of screening
- How best to manage small curves, including risk factors for progression and effective interventions
- Uncertainties about long term benefits of scoliosis treatment (especially surgery)
- Long term impact on back pain, employability and lifestyle, as well as when is best to intervene and with what device

The Scoliosis PSP (SPSP) is a first attempt to investigate the priorities for future scoliosis research of those with lived personal and professional experience of scoliosis.

AIMS & OBJECTIVES

- To identify a top 10 list of priorities for future research into scoliosis diagnosis and management
- To publicize the process and results of the Scoliosis PSP
- To encourage the development of these uncertainties into research proposals

METHODS

INITIATION

A Steering Group was set up to facilitate the SPSP aims and objectives.
It includes healthcare professionals, patients and carers as representatives.
Stakeholders were charities and professional groups with an interest in scoliosis.
Steering Group meetings were overseen by an independent JLA advisor.

PROMOTION

Awareness of the Scoliosis PSP was promoted through:
1. Use of Steering Group members' networks and partner organisations representing the interests of patients and clinicians
2. Creation of a designated PSP website
3. Launch of designated social media platforms

UNCERTAINTY GATHERING

The initial 'uncertainty gathering questionnaire' was launched on 27th June 2016 - it was open for 4 months.
Responses were predominantly gathered online, via a link to the questionnaire on Survey Monkey.

PROCESSING

Unique submissions were identified, and similar and duplicate submissions were combined and formatted into summary questions

PRIORITIZATION

The interim survey was launched on 12th April 2017 to narrow down uncertainties
A weighting system was used to ensure equal contribution from patients, carers/relatives and healthcare professionals and to reflect the range of all types of scoliosis.
The final prioritization workshop will take place on Saturday 1st July 2017 and will involve both those with lived personal and professional experience of scoliosis

DISSEMINATION

Results and details of the Scoliosis PSP will be distributed to funders for priority clinical studies

RESULTS

Survey Enrollment
Survey
Participants (n=709)
Uncertainties submitted (n=1692)

Then the following were considered to be out of scope:
114 questions about health services access and quality
195 questions about cause
265 questions asking for information and advice
154 questions which were too broad, unclear or about an unrelated topic

Excluded (n=12)
'Out of scope': 728 questions

Interim prioritization survey
Interim prioritisation survey
Participants: (n=54 patients, parents, carers, clinicians).
Questions: (n=964 questions were categorised into 54 questions)

Top 25 questions
Final prioritization
(give reasons) (n=~25)

Final workshop
Autumn 2017
Q1-25, when the top 10 questions that patients, carers and clinicians want scoliosis research to address will be determined.

CONCLUSIONS

- The main object of the PSP is provide material to guide researchers and research funders where to focus their resources to meet the needs of patients, carers and clinicians to improve the management of scoliosis.
- We have shown we can get engagement from patients and carers, but professionals are sometimes difficult to attract to this process
- There are challenges posed by the diversity of the patient group - we looked at all types of scoliosis and all age groups – to ensure we embraced the wide range of scoliotic conditions

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5.3.21 Top Priority Areas for Improving Everyday Life with Parkinson's

PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

TOP PRIORITY AREAS FOR IMPROVING EVERYDAY LIFE WITH PARKINSON'S

SUMMARY

Parkinson's UK drives better care, treatments and quality of life. Everything we do is shaped by people affected by Parkinson's. Our number one research priority is to develop new and better treatments. We also champion research to improve quality of life.

To help researchers focus on the most important issues, we asked people with direct experience of the condition to tell us their priority areas for improving everyday life. Through this we identified 26 priority areas.

SETTING THE PRIORITIES

Parkinson's UK commissioned a Priority Setting Partnership with the James Lind Alliance. Through an online and paper survey, people living with Parkinson's, carers, family members and health and social care professionals were asked "What questions would you like to see answered by research?" in the areas of symptoms, treatments and day to day life.

- There were more than 4,000 responses from 1,000 participants (60% people with Parkinson's). From this 94 unique unanswered research questions were identified.
- 475 participants (72% people with Parkinson's) prioritised the list producing 26 questions to go forward to the next stage.
- 27 stakeholders (37% people with Parkinson's) came together to prioritise the top 10 priorities from the shortlist of 26 questions.

THE TOP PRIORITY RESEARCH AREAS

1 Balance and falls
2 Stress and anxiety
3 Uncontrolled movements
4 Personalised treatments
5 Dementia
6 Mild thinking and memory
7 Monitoring symptoms
8 Sleep
9 Dexterity
10 Urinary problems
11 On-Off Fluctuations
12 Stage-specific Treatments
13 Fatigue
14 Helping find the right dose
15 Stiffness and Rigidity
16 Physiotherapy and Exercise
17 Freezing and Gait
18 When to choose DBS
19 Bowel problems
20 Hallucinations
21 Helping the carer
22 Fewer Pills
23 Pain in Parkinson's
24 Swallowing
25 Medications on time
26 Tremor

FUNDING

More than £6.7 million was awarded to 12 research projects that addressed the top 26 priorities in 2015 and 2016.

Researchers applying to Parkinson's UK for funding are directed to the research grants pages on our website at **Parkinsons.org.uk/content/research-grants**

We've seen a significant increase in research applications focused on these priorities, with applicants stating how their project addressed unmet needs.

PROGRESS SO FAR:

Balance and Falls

Before the priority setting project, Parkinsons' UK awarded £250,000 to Dr Emily Henderson and her team for their research study looking at whether the commonly prescribed dementia drug Rivastigmine could help prevent falls in people with Parkinson's. This research has found that people who took Riastigmine were 45% less likely to fall than those who took a placebo treatment. The promising results of this trial, coupled with the high priority of balance and falls in the top 26 list, has led Parkinson's UK to extend this study for a further two years.

DEMENTIA

Professor David Burn and his team at Newcastle University are leading a project to predict dementia in people with Parkinson's.

From this study, dementia has been linked to the development of mild memory and thinking problems, particular genetic factors and abnormal levels of certain proteins. These findings could be used to predict which people with Parkinson's are at a greater risk of developing dementia in the future.

The team have also developed two sub-studies on walking and sleep quality in people with Parkinson's. So this one study will help progress research in three of the top 26 priorities.

This priority setting project demonstrates the charities commitment to ensuring that the needs and priorities of people affected by Parkinson's help shape the research agenda.

5.3.22 Tinnitus PSP: "What is the optimal set of guidelines for assessing children with tinnitus?": responding to a research priority

(T)
British Tinnitus Association

"What is the optimal set of guidelines for assessing children with tinnitus?": responding to a research priority

Nic Wray, Communications Manager, British Tinnitus Association

Introduction

Tinnitus is the perception of sound by someone when there is no corresponding external sound. Tinnitus is experienced by around one in ten people on an on-going basis. It can occur in people of all ages, but it occurs more frequently in older people.

It is a commonly held view that tinnitus occurs very rarely in children, but research and clinical experience is showing that is not the case.

The British Tinnitus Association (BTA) undertook a priority setting partnership (PSP) exercise with the James Lind Alliance (JLA) in 2011/2012. One of the priority questions which arose from this exercise was "What is the optimal set of guidelines for assessing children with tinnitus?"

It was hoped that the identification of research priorities would be a catalyst for more research, and encourage funders and researchers alike to rise to the challenge of addressing the selected priorities.

Tinnitus in Children: Practice Guidance

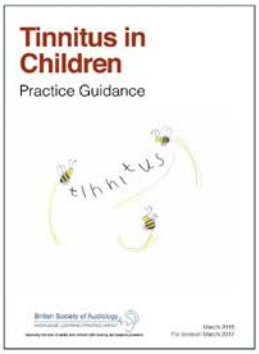


Figure 1: Tinnitus in Children: Practice Guidance

The Paediatric Audiology Interest Group (PAIG) of the British Society of Audiology (BSA) formed a working party of national specialists in paediatric tinnitus in response to the challenge posed by the JLA tinnitus PSP. They published the Tinnitus in Children: Practice Guidance document (Figure 1) in March 2015. The project was supported financially by the BTA.

The practice guidance was written using the available evidence base, and from the clinical experience and practice of the working party members.

The aim of the guidance was that the practical and pragmatic advice offered would enable a wide range of professionals to develop their clinical skills in tinnitus management with children.

It is hoped that in turn this will lead to further clinical developments, research and ultimately a firm evidence base for the management of tinnitus in children.

Assessment and management of tinnitus in children course

A number of the working party who developed the Tinnitus in Children: Practice Guidance then worked with the BTA to devise and deliver a two day residential course for professionals. The course aims to develop a person's clinical skills in the assessment and management of children with tinnitus, exploring in further details areas mentioned in the practice guidance. The first course was delivered in June 2015 and it has run three times since then.

Information and activity booklets

In tandem with the development of the practice guidance, the team at the BTA submitted a proposal to the National Lottery Awards for All fund for a series of children's information leaflets. This bid was successful and work began in May 2015.

Working with a children's author, illustrator/design, our professional advisers, clinicians, users panel, parents and children, the series of three leaflets was launched at the BTA Annual Conference in September 2015.

The leaflets were Highly Commended in the BMA Patient Information Awards in September 2016.

Figure 2: Information booklets for children produced by the BTA

Following the excellent feedback about these booklets, and in response to requests from clinicians, a series of activity books were produced to accompany the information leaflets. Activity books are a familiar concept for children, and the activities within the books aim to help a child come up with a tinnitus management plan for the situations they encounter in an engaging way. The resources won First Prize in the Information for Children award at the 2017 BMA Patient Information Awards.

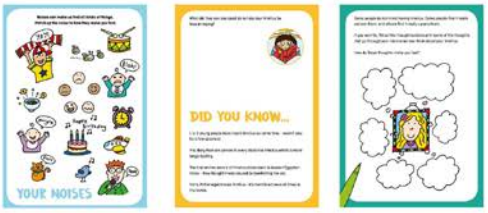


Figure 3: Inside pages from the children's activity books produced by the BTA

Tinnitus Week 2018

Tinnitus Week 2018 will be themed "Kids talk tinnitus". The campaign objectives include raising awareness of the impact of tinnitus on the lives of children, and providing parents and schools with more useful information so they are able to support young people with tinnitus more effectively and make their lives easier.

Results

Over 500 copies of Tinnitus in Children: Practice Guidance have been distributed or downloaded.

84 professionals have attended the Assessment and management of tinnitus in children course.

Over 20 000 copies of the children's information leaflets have been given out to parents and children. The leaflets were highly commended in the 2016 BMA Patient Information Awards.

Approximately 8 000 copies of the children's activity booklets have been distributed. The booklets won First Prize in the Information for Children award at the 2017 BMA Patient Information Awards.

Conclusion

The question raised by the JLA tinnitus PSP did not only stimulate research, it triggered the development of a comprehensive set of resources for supporting those affected by tinnitus in childhood.

These resources have raised awareness of the condition in young people in both the general public and within the health profession. It has led to improved services and support for children with tinnitus.

(T) **British Tinnitus Association, Ground Floor, Unit 5, Acorn Business Park, Woodseats Close, Sheffield, S8 0TB**
Registered charity no: 1011145 Company limited by guarantee no: 2709302 Registered in England

5.3.23 Learning Difficulties PSP: The Challenges

Learning Difficulties Priority Setting Partnership: The Challenges

Professor Anne O'Hare, Dr Sinead Rhodes, Dr Ai Keow Lim, Christine Carlin

1

Terminology and Definitions

The Salvesen Mindroom Centre's definition of learning difficulty:

Any learning or emotional problem that affects, or substantially affects, a person's ability to learn, get along with others and follow convention.

2

Composition of Steering Group

- Parent representatives

Third sector
- Chief Executive of The Salvesen Mindroom Centre
- Chief Executive of Dyslexia Scotland

Education
- Head teacher
- Principal educational psychologist

Health
- Child & adolescent psychiatrist
- Consultant community child health paediatrician
- Consultant paediatrician
- Consultant paediatric neurologist
- Speech & language therapists
- Occupational therapist

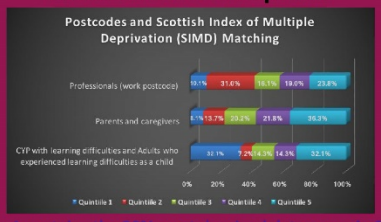
3

Engagement & Contribution

- Children, young people and young adults with learning difficulties
  - Speech & Language Therapists and Occupational Therapists adapted the survey and information sheets to children and young person (CYP) friendly language
- Multidisciplinary professionals, including health, education and third sector staff

4

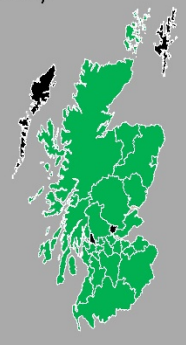
Socio-Economic Spread



Quintile 1 contains the 20% most deprived data zones in Scotland

5 Postcode Data

Postcode data were collected. Respondents from 28 out of 32 Scottish local authorities participated in the first survey.



6 Broad Range of In-Scope Questions

JLA Partnerships	Survey respondents	Submitted Uncertainties	In-scope questions	Target audiences	Demographic makeup
Learning difficulties	367	828	761	Scotland only	3.3% CYP with learning difficulties, 4.9% adults who experienced learning difficulties as a child, 40.0% parents and carers & 51.8% professionals (37% education, 57% health & 7% third sector)
Childhood disability	369	809	356	UK wide	40% non-clinicians & 60% clinicians
Pre-term birth	386	593	555	UK wide	58% people affected by Pre-term Birth (mostly parents), 30% health professionals & 12% both
Autism (including all adults)	1213	3331	Not available	UK wide	23% individuals on autism spectrum or strongly suspect they are on the spectrum, 52% family members and caregivers & 25% clinicians & professionals

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7 8 Themes

Some examples:

Causes
What are the causes of learning difficulties/developmental disabilities/learning disabilities? (parent/carer/professionals)

Identification & diagnosis
What is the best way to screen for learning difficulties? (parent/carer); *There are so many learning difficulties: Can brain scans detect these?* (parent/carer)

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aohare@ed.ac.uk