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

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michele Acton</td>
<td>Fight for Sight</td>
</tr>
<tr>
<td>Michael Allison</td>
<td>Cambridge University Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>Sabine Best</td>
<td>Marie Curie</td>
</tr>
<tr>
<td>Ellena Badrick</td>
<td>Manchester Cancer Research Centre, University of Manchester</td>
</tr>
<tr>
<td>Jennifer Bethell</td>
<td>Dementia and Frailty JLA PSPs</td>
</tr>
<tr>
<td>Oliver Boney</td>
<td>National Institute of Academic Anaesthesia</td>
</tr>
<tr>
<td>Susan Brunskill</td>
<td>NHS Blood and Transplant (NHSBT)</td>
</tr>
<tr>
<td>Helen Bulbeck</td>
<td>Brainstrust</td>
</tr>
<tr>
<td>Emily Burns</td>
<td>Diabetes UK</td>
</tr>
<tr>
<td>Martin Burton</td>
<td>Cochrane UK</td>
</tr>
<tr>
<td>Stephen Campbell</td>
<td>University of Manchester &amp; NIHR Greater Manchester Patient Safety Translational Research Centre</td>
</tr>
<tr>
<td>Mariana Campos</td>
<td>Genetic Alliance UK</td>
</tr>
<tr>
<td>Iain Chalmers</td>
<td>James Lind Initiative</td>
</tr>
<tr>
<td>Eleni Chambers</td>
<td>Freelance survivor researcher (NIHR – NETSCC, INVOLVE; Royal College of Psychiatrists, and others) and PhD student</td>
</tr>
<tr>
<td>Tammy Clifford</td>
<td>Canadian Agency for Drugs and Technologies in Health (CADTH)</td>
</tr>
<tr>
<td>Lynne Corner</td>
<td>Newcastle University</td>
</tr>
<tr>
<td>Matt Costa</td>
<td>University of Oxford</td>
</tr>
<tr>
<td>Sally Crowe</td>
<td>Crowe Associates Ltd</td>
</tr>
<tr>
<td>James Cusack</td>
<td>Autistica</td>
</tr>
<tr>
<td>Ann Daly</td>
<td>Independent</td>
</tr>
<tr>
<td>Bridget Davis</td>
<td>Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP RU), Glasgow Caledonian University</td>
</tr>
<tr>
<td>Simon Denegri</td>
<td>NIHR</td>
</tr>
<tr>
<td>Sophie Dix</td>
<td>MQ: Transforming mental health</td>
</tr>
<tr>
<td>Jim Elliott</td>
<td>NETSCC (as a public contributor)</td>
</tr>
<tr>
<td>Nick Fahy</td>
<td>University of Oxford</td>
</tr>
<tr>
<td>Jeremy Fairbank</td>
<td>NDORMS, University of Oxford</td>
</tr>
<tr>
<td>Eric van Furth</td>
<td>GGZ Rivierduinen/ Leiden University Medical Center</td>
</tr>
<tr>
<td>Robin Grant</td>
<td>Department of Clinical Neurosciences, Western General Hospital, Edinburgh</td>
</tr>
<tr>
<td>Douglas Grindlay</td>
<td>School of Medicine, University of Nottingham</td>
</tr>
<tr>
<td>Alyson Huntley</td>
<td>University of Bristol</td>
</tr>
<tr>
<td>Stella Huyshe-Shires</td>
<td>Lyme Disease Action</td>
</tr>
<tr>
<td>Thomas Kabir</td>
<td>The McPin Foundation</td>
</tr>
<tr>
<td>Erika Kennington</td>
<td>Asthma UK</td>
</tr>
<tr>
<td>Lynn Kerridge</td>
<td>NETSCC</td>
</tr>
<tr>
<td>Andreas Laupacis</td>
<td>St. Michael’s Hospital, Toronto, Canada</td>
</tr>
<tr>
<td>Terry Lawrence</td>
<td>Patient Representative</td>
</tr>
<tr>
<td>Richard Lehman</td>
<td>University of Birmingham</td>
</tr>
<tr>
<td>Feng Li</td>
<td>National Cancer Research Institute</td>
</tr>
<tr>
<td>Keith Lloyd</td>
<td>Swansea University</td>
</tr>
<tr>
<td>Name</td>
<td>Organization/Group</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Martin Lodemore</td>
<td>INVOLVE Coordinating Centre</td>
</tr>
<tr>
<td>Kate Lough</td>
<td>Nursing Midwifery and Allied Health Professions Research Unit</td>
</tr>
<tr>
<td>Peter Lovell</td>
<td>NIHR Research Design Service London</td>
</tr>
<tr>
<td>Mary Madden</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Jill Manthorpe</td>
<td>Social Care Workforce Research Unit, King’s College London</td>
</tr>
<tr>
<td>Angela McCullagh</td>
<td>Patient/Carer (advising Marie Curie and others)</td>
</tr>
<tr>
<td>Rosie McEachan</td>
<td>The Born in Bradford Research Programme, Bradford Teaching Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>Richard Morley</td>
<td>Cochrane</td>
</tr>
<tr>
<td>Rebecca Morris</td>
<td>NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester</td>
</tr>
<tr>
<td>Anne O’Hare</td>
<td>Salvesen Mindroom Research Centre, University of Edinburgh</td>
</tr>
<tr>
<td>James Pickett</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Lucy Power</td>
<td>McPin Foundation, Young Persons’ Advisory Group</td>
</tr>
<tr>
<td>Nicola Rowbotham</td>
<td>University of Nottingham/ Nottingham University Hospitals</td>
</tr>
<tr>
<td>Elizabeth Rye</td>
<td>James Lind Alliance PSP</td>
</tr>
<tr>
<td>Stephanie Sampson</td>
<td>Member of the Institute of Mental Health, University of Nottingham</td>
</tr>
<tr>
<td>Casper Schoemaker</td>
<td>Dutch Juvenile Arthritis Association /Children’s Hospital of the University Medical Center Utrecht/National Institute for Public Health and the Environment</td>
</tr>
<tr>
<td>Philippa Saunders</td>
<td>The University of Edinburgh</td>
</tr>
<tr>
<td>Natalie Shearwood-Porter</td>
<td>National Institute for Health Research</td>
</tr>
<tr>
<td>Sarah Sleet</td>
<td>Coeliac UK</td>
</tr>
<tr>
<td>Anna-Louise Smith</td>
<td>Parkinson’s UK</td>
</tr>
<tr>
<td>Alan Smyth</td>
<td>University of Nottingham</td>
</tr>
<tr>
<td>Julie Solomon</td>
<td>British Society of Gastroenterology (BSG)</td>
</tr>
<tr>
<td>Kristina Staley</td>
<td>TwoCan Associates</td>
</tr>
<tr>
<td>Sophie Staniszewska</td>
<td>Warwick Medical School</td>
</tr>
<tr>
<td>Synat Tagaeva</td>
<td>McPin Foundation, Young Persons’ Advisory Group</td>
</tr>
<tr>
<td>Ruth ten Hove</td>
<td>Chartered Society of Physiotherapy</td>
</tr>
<tr>
<td>Kim Thomas</td>
<td>University of Nottingham</td>
</tr>
<tr>
<td>Diana Tilston</td>
<td>Patient</td>
</tr>
<tr>
<td>Seilin Uhm</td>
<td>Social Science Research Unit, UCL Institute of Education, London</td>
</tr>
<tr>
<td>Matt Westmore</td>
<td>Director, Enterprise and Partnerships, Wessex Institute, University of Southampton</td>
</tr>
<tr>
<td>Heather Whitehouse</td>
<td>Harrogate and District NHS Foundation Trust</td>
</tr>
<tr>
<td>Nic Wray</td>
<td>British Tinnitus Association (BTA)</td>
</tr>
</tbody>
</table>

**The James Lind Alliance Advisers**

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katherine Cowan</td>
<td>JLA Adviser</td>
</tr>
<tr>
<td>Toto Gronlund</td>
<td>JLA Adviser</td>
</tr>
<tr>
<td>Tricia Ellis</td>
<td>JLA Adviser</td>
</tr>
<tr>
<td>Maryrose Tarpey</td>
<td>JLA Adviser</td>
</tr>
<tr>
<td>Catherine White</td>
<td>JLA Adviser</td>
</tr>
</tbody>
</table>
The James Lind Alliance NETSCC team

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steph Garfield-Birkbeck</td>
<td>Assistant Director at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)</td>
</tr>
<tr>
<td>Beccy Maeso</td>
<td>Senior Research Manager, JLA team</td>
</tr>
<tr>
<td>Caroline Whiting</td>
<td>Research Manager, JLA team</td>
</tr>
<tr>
<td>Katharine Hanss</td>
<td>Assistant Research Manager, JLA team</td>
</tr>
<tr>
<td>Amy Street</td>
<td>Assistant Research Manager, JLA team</td>
</tr>
</tbody>
</table>
5.2 Slides of presentations

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

JLA COMMUNITY WORKSHOP

WELCOME

#JLA50
@LindAlliance

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

#JLA50

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

#JLA50

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

#JLA50
5.2.2 Defining and verifying uncertainty: Katherine Cowan

Defining and verifying uncertainty
Is our approach still appropriate?
Katherine Cowan, Senior Advisor CCA

Coming up...

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

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

Unanswered questions about...

The current verification process

Cochrane Library
NICE National Institute for Health and Care Excellence
SIGN Scottish Intercollegiate Guidelines Network
RCNi Royal College of Nursing
RCoS Royal College of Surgeons
The Royal College of Anaesthetists

Interventions

What do we mean by treatment...?
Unanswered questions about...

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

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?

What does this mean for the JLA?

**Depression: asking the right questions**
5.2.3 Physiotherapy PSP: Ruth ten Hove

Examples of the challenge

- Sabine Best: Palliative & End of Life Care PSP
- Ruth Ten-Hove: Physiotherapy PSP
- Keith Lloyd: Schizophrenia PSP, Depression PSP
5.2.4 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 2012
Dr Sabine Best, Marie Curie

https://palliativedepsp.wordpress.com/

What is palliative care?

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)

PeolcPSP – Identifying ‘evidence uncertainties’ (or ‘research questions’)
- 1493 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

Challenges
- 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 researchers, an open call is often not enough;
- DUETs?: where to look at the underlying more detailed questions in broad research themes?

Further work
Analysis of whole data set, including ‘out of scope’ data
- Dr Annmarie Nielson, Cardiff University, qualitative researcher
- Thematic analysis: 1/6 themes was not reflected in ‘International questions’

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
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

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?

How we are going to do this

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

JLA COMMUNITY WORKSHOP:

Thank you
5.2.6 Kim Thomas: Reflections on the value of PSPs from a multiple ‘PSPer’

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

Clinical area of interest is skin conditions

- Have led or contributed to four JLA PSPs in:
  - Vitiligo (2010)
  - Eczema (2012)
  - Cellulitis (2017)
  - Lichen sclerosis (ongoing)

- Other PSPs
  - Hidradenitis suppurativa
  - Acne
  - Hair loss
  - Hyperhidrosis
  - Psoriasis
  - Epidermolysis bullosa (Spain)
  - Congenital ichthyosis (Spain)

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)

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

Why do more than one PSP?

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

It’s fun!
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

Looking for a systematic review?

Use a map.

Available topics:
- ACNE
- ATOPIC DERMATITIS
- ECZEMA
- LUPUS
- MELANOMA

All published systematic reviews, updated every month.

www.nottingham.ac.uk/dermatology
5.3 Posters

5.3.1 JLA Priority Setting Partnership Top 10s 2007-2011

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

PSP Top 10s 2012 - 2013

- Eczema
- Tinnitus
- Cleft Lip and Palate
- Lyme Disease
- Pressure Ulcers
- Sight Loss and Vision
- Dementia
- Multiple Sclerosis
- Hidradenitis Suppurativa
5.3.3 JLA Priority Setting Partnership Top 10s 2014

PSP Top 10s 2014

Acne

Preterm birth

Hip and Knee Replacement for Osteoarthritis

Childhood Disability

Spinal Cord Injury

Intensive Care

Parkinson's

Mesothelioma
PSP Top 10s 2015

1. Palliative & End of Life Care
2. Inflammatory Bowel Disease
3. Kidney Cancer (Canada)
4. Stillbirth
5. Neuro-oncology
6. Anaesthesia and Perioperative Care
7. Surgery for Common Shoulder Problems
8. Mild to Moderate Hearing Loss
9. Hair Loss
10. Cavernoma
5.3.5 JLA Priority Setting Partnership Top 10s 2016

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

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…

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

What the JLA does well

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

It still went extremely smoothly thanks to all the JLA advisors 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 advisors where necessary.

Our skilled & experienced JLA Advisors

95% would recommend the PSP process to others

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

Some of the challenges

Resources: time and money

To what extent did the overall cost of running the PSP match your original budget?

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

Managing the data components of the PSP

What the JLA could do better

“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, NHS, and the NHS need to work together to utilise the data obtained more effectively than has been done to date…we are really pleased to be a part of this effort.”

“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 amalgamating 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 research agenda setting was very new and required some time to fully understand.”

Based on 20 final feedback survey responses (from 19 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 new PSP trial survey are also included (February 2017 – August 2017). Themes based on information from 26 respondents.
5.3.10 Exploring the impact of priority setting partnerships in skin disease

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.

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

Methods

• Search of 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 prioritized uncertainties.

Results

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

Table 1: Priority setting partnerships in skin disease

<table>
<thead>
<tr>
<th>Skin Condition</th>
<th>Country</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitiligo</td>
<td>UK</td>
<td>2010</td>
</tr>
<tr>
<td>Eczema</td>
<td>UK</td>
<td>2012</td>
</tr>
<tr>
<td>Erysipelas Eczema Bullosa</td>
<td>Spain</td>
<td>2012</td>
</tr>
<tr>
<td>Atopic dermatitis</td>
<td>UK</td>
<td>2013</td>
</tr>
<tr>
<td>Congenital keloids</td>
<td>Spain</td>
<td>2014</td>
</tr>
<tr>
<td>Acne</td>
<td>UK</td>
<td>2014</td>
</tr>
<tr>
<td>Alopecia areata</td>
<td>UK</td>
<td>2015</td>
</tr>
<tr>
<td>Celulid</td>
<td>UK</td>
<td>2017</td>
</tr>
<tr>
<td>Psoriasis (due to start)</td>
<td>UK</td>
<td>TBA</td>
</tr>
<tr>
<td>Eczema (due to start)</td>
<td>UK</td>
<td>TBA</td>
</tr>
<tr>
<td>Hypertrophic (ongoing)</td>
<td>UK</td>
<td>TBA</td>
</tr>
</tbody>
</table>

• One of the first PSPs to be published in skin disease was in eczema which produced 14 priority topics for research (Figure 1).

• 1/3 (33.3%) of priorities topics are now being actively researched (planned, underway or completed).

• 1/7 (14.3%) 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.

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.jama.ama-assn.org/content/317/16/1822.full.pdf

5.3.11 The big questions: guiding future Type 2 diabetes research

The big questions: guiding future Type 2 diabetes research


Why we need research priorities

Almost 5.8 million people in the UK undiagnosed with diabetes.
90% of those have Type 2 diabetes.
Around 1 million people are undiagnosed to have undiagnosed diabetes.
1.1 million are at increased risk of getting Type 2 diabetes.

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

Our reach

Our 3,000 people took part in the first survey and over 1,500 people completed the second prioritisation survey. We received responses from right across the UK.

[Graphics showing percentages of people with Type 2 diabetes, healthcare professionals, and family members of people with diabetes.]

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 them 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 and treat 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, how does it affect them, 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?

Finding the answers

"I hope that researchers and funders will now put our ideas, who are often the victims, in charge of the research at the heart of research." - Naka K, living with Type 2 diabetes

"This prioritisation, the top 10 priorities, will help to create a new wave of direction for research, which will lead to healthcare improvements and people with Type 2 diabetes feeling knowledge is being shared and improved.

Richard Duetke, National Diabetes Clinical Champions

"The top 10 included a really good range of issues - socioeconomics, behavioral, cultural and educational. It’s really important we see a priority of research initiatives that will help those of us with Type 2 diabetes and those at risk of the future." - Le Mundamkum, 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 areas diabetes research.

These groups will include:

- People with diabetes
- Leading researchers in key areas
- And healthcare professionals

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

Distribution of first (1) and second (2) survey participants
5.3.12 JLA Preterm Birth Priority Setting Partnership

Consensus development for tackling highly technical and emotive challenges

Solita Uhlm (solita.uhlm.58@ucl.ac.uk) Twitter (@psychologyTohi)
Prof Sandy Oliver (sandy.oliver@ucl.ac.uk, @profSandyJohnson)
Social Science Research Unit, UCL Institute for Education

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, O’Sullivan and Zupan, 2003), and increases the mix of dying due to other causes, especially from neonatal infections. Even a minor intervention can have a significant impact on the preterm infant, 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 NuffR funded research programme.


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.

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 adopted the Nominal Group Technique.


The Prioritisation Process

- 26 organisations participated
- 13 people representing 8 organisations formed the steering group
- 1st stage: 106 respondents, 543 systematic reviews searched, 935 research uncertainties
- Collated into 104 uncertainties
- 70 from survey, 23 systematic reviews, 24 from clinical guidelines
- 631 respondents voted
- Top 40 taken to workshop
- Top 15 were decided

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”.

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.

Part of independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0606-10017). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.
5.3.13 Palliative and end of life care Priority Setting Partnership (PeolcPSP)

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

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

| AUTHOR | Florence Todd-Feeney, Salome Best, Sanjay Theniar and BillNoble, Marie Clarke |

From the survey responses, 83 unanswered Interventional questions were formulated.

The Top Ten unanswered questions in palliative care and end of life care were published on 15th January 2015.

TOP PRIORITIES

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?

OUT-OF-HOURS PALLIATIVE CARE

The end of hours periods from 18:30 to 08:00 on weekdays, and from 15:30 on Fridays through to 08:00 on a Monday, and on bank and public holidays. Out of hours palliative care is not one symptom, albeit an important one, of the end of hours’ services working with patients in the last years of life at home.

Using keyword searches, the HRCs dataset was searched for relevant grant abstracts. The keywords brought up 4,240 grants of which 518 were manually assessed. The keyword searches that were specific to the out of hours palliative care priority were: palliation, end of life, end of life, EOL, terminal, dying, end stage, advanced disease, working hours, out of hours, out of hours, OHM, 24 hour, 24 hour, 24 hr, place of choice, home, home care.

LIMITATIONS

- Using the HRCs 2014 dataset of health research, this grant mapping process only consisted of 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 £2.1 billion of project grants. A further £1.1 billion of institutional funding not included (eg. Marie Curie centres are not included).
- The HRCs 2014 dataset includes non-palliative and charitable research funders, but not all.

RESULTS AND ANALYSIS

14,918 grant abstracts were searched using keyword searches for all 93 priorities. Of these, only 12 related to the priority on out of hours palliative care. These 12 grants amount to £3,208,420 of funding, which is 0.16% of the total health research spend in the HRCs dataset of 2014.

The distribution of this funding is displayed in the graph below.

Distribution of funding in palliative out of hours care

- Government
- Health Service
- Charities

- Of these 12 grants, only 1 is considered “highly” related to the end 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, funding the amount to only £318,654, which is 0.02% of the health spend in 2014.
- Of this directly related amount, £983,060 comes from Marie Curie (12.5%), and the rest is governmental funding. These only two other funders, direct and indirect, with a combined research funding of £3,115,527.

CONCLUSIONS AND NEXT STEPS

- Current palliative care and end of life care research neglects out of hours palliative care which is ranking 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. NHR also recently announced an HSCR researcher-led funding call with a specific highlight on the PeolcPSP questions.
- The Marie Curie conference on 20th October 2016 will look at this issue, conference theme: Erase 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.

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 1988.
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
Run annual conferences
Tried to talk to the Department of Health and doctors
Lobbied MPs

2010-2012
What we did next
Lyme Disease Action achieved accreditation to the Department of Health’s Information Standard.
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.

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......

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 58 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.”

Chief Executive, Health Protection Agency

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!
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


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 and analysis of over 300 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, and 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
Sarah.masefield@europeallung.org

Study funded by the European Commission (GA 602077)
5.3.16 Canadian Dementia Priority Setting Partnership

**CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP**

1. **GATHERING QUESTIONS ABOUT DEMENTIA**
   - **1217** People from across Canada – persons with dementia, friends, family and caregivers, as well as health and social care providers – completed a survey asking for their questions about living with dementia as well as prevention, treatment and diagnosis of dementia.

2. **WORKING WITH THE DATA**
   - **5924** Questions were categorized, merged and summarized, then checked against existing research evidence.

3. **INTERIM PRIORITY-SETTING**
   - **249** Individuals and groups from across Canada completed a second survey to shortlist the 79 questions.

4. **FINAL PRIORITY-SETTING**
   - **28** People from across Canada – persons with dementia, friends, family and caregivers, as well as health and social care providers – participated in a 2 day workshop to review and rank the 23 shortlisted questions.

**QUESTIONS ABOUT DEMENTIA**

- **8203 SUBMISSIONS**
- **2279 SUBMISSIONS were out of scope or could not be turned into a question**
- **5924 QUESTIONS**
- **79 SUMMARY QUESTIONS**
- **23 SHORTLISTED QUESTIONS**
- **TOP 10 PRIORITIZED QUESTIONS**
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

Using JLAPUP to identify possible areas for further evaluation and reporting across PSPs

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 Madeley, Lecturer in Applied Health Research, School of Healthcare, Faculty of Medicine and Health, 2.528 Bohio Wing, University of Leeds, Leeds, LS2 9JT
Rickard Morley, Consumer Co-Ordinator, Cuts Hope, 15 Aldons House, 12-14 Keynsham, London SE9 4SK

30
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 and Dr Amy Hunter

BACKGROUND

There are ~8,000 rare diseases affecting ~2.5 million 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 members, 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

2017

- Nov
- Dec

Defining scope

2018

- Jan
- Feb
- Mar
- Apr
- May
- Jun

Preparing work

- Jul
- Aug
- Sep
- Oct
- Nov
- Dec

Gathering uncertainties

2019

- Jan
- Feb
- Mar
- Apr
- May
- Jun

Interim prioritisation

- Jul
- Aug
- Sep
- Oct

Final workshops and dissemination

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.

1Genetic 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.
5.3.19 Driving JLA Neuro-Oncology Priority Questions into Clinical Studies

Driving JLA Neuro-Oncology Priority Questions into Clinical Studies

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

Background
In July 2011 a meeting was held at the Cochrane Editorial Unit, London to scope out work for a James Lind Alliance – Neuro-Oncology Priority Setting Partnership. This scope included adult brain & spine tumours. Funding was secured from brain tumour charities, Cochrane and the Edinburgh Urban Health Foundation. Agreement to provide funding was obtained from the JLA and a JLA Neuro-Oncology Website was developed.

Our aim, following identification of the top 10 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 most current evidence through partnerships with Cochrane Neuro-Oncology Group
   b. Agreement with NCRI Brain and CNS Clinical Studies Group to promote the JLA questions and develop studies in these areas.

A first survey of the brain tumour community revealed >600 questions which were then categorised, PICO formatted, duplicates removed, 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 added more than once and stakeholders voted for top 10 questions. We took forward questions voted for by >5 people (84 questions).

A second public vote on the 43 questions was obtained by 52 people, equally split between professionals and patient/caregivers. We took forward 23 questions receiving >10% of the total vote.

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 exact progression 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 of care, and in people with a brain or spinal cord tumour?
4. Is 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. Does molecular subtyping techniques improve treatment selection, prediction and prognosis in people with a brain or spinal cord tumour?
7. What are the long term physical and cognitive effects of surgery and radiotherapy when treating people with a brain or spinal cord tumour?
8. What is the value of interventions to help caregivers 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?

Table 1

Results

- Since 2015 the NCRI Brain Tumour Strategic & Palliative Care Subgroup has held Incubator Days to put forward 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 CEU, NICE Vice Chair for Research Design Service (NHS/Health Eeconomics)
  - Funders - two funders representing NIMH, one from Chief Scientist Office (Scotland), one from CRUK (NMC [wellcome] representatives met but could not attend) and a scientific/funding representative from each of the main charities. Involvement, International Brain Tumour Alliance (IBTA), the Brain Tumour Charity (BRC), 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 Tumour Strategic & Palliative Care Subgroup.
- Planning “Incubator Days” (opendate through NCRI Brain TCG, 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-led a representative from the NCRI Research Design Service and involvement of a UNC-RR Clinical Trials Unit and the main appropriate funding partners for the inculcating days from the representative charities.

Successful applications include:
- NHR/HTA/3/01/16-2: SPiRE: Secure Prophylaxis in Glia (Multi-Centre RCT)
- NHR/Cochrane/Synthetic Programme Grant 16/04/19 (NCRI/Cochrane)/J Complex Systematic Reviews, including one of the JLA topics 2.5, 4.5, 6, 15.
- TPC of Quality of Life Project Grant - Brain Tumour - lifestyle intervention and fatigue evaluation – a multi centre feasibility RCT.
- A randomised pilot study of Fatigue in Brain Tumours (The Keeling Trial) (A randomised feasibility trial – Vifetro International Ltd, NCT0375354)
- ETR - effect of fatigue on tumour growth - prospective study.

Applications submitted to date include:
- Palliative Care Supportive Care Master Protocol - Prof Mark Hill (SR Antonio Byrne - Cardiff University (NCR) Haematology and Oncology CS)
- Improving support for family caregivers in neuro-oncology – Dr Florin Boice – Acad Fellow in Neuro-Psychology, Leeds University.
- NOCTURN (Neuro-Oncology Clinical Trials UK Research Network) website was developed out of the JLA neuro-oncology AHaLa. This is a resource for neuro oncology clinical researchers to obtain all the latest NHR/CRUK/MRC funding sources and resources and assist application for clinical research funding and to inform the community about the top 10 JLA questions and help that NCRI brain and CNS TCG are given.

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 external and specialty funding sources to actively promote these priority areas.
5.3.20 Identifying the Top 10 research priorities for diagnosis and management of scoliosis – The Scoliosis PSP

**INTRODUCTION**

The priorities of patients and healthcare workers when investigating treatment options[1] is

- There is a need for a comprehensive overview of the initial and chronic care needs of a patient with scoliosis.
- The nature of the disease makes it difficult to assess the long-term impact of treatment options.
- The nature of scoliosis means that treatment options are often difficult to evaluate.

The Scoliosis PSP was established in 2015 to develop a comprehensive overview of the needs of patients and healthcare workers. The Scoliosis PSP will be used to identify and prioritize research that addresses the needs of patients and healthcare workers.

The Scoliosis PSP (Scoliosis Priority Setting Project) is a systematic approach to identify the priorities for future research needs of those with fixed and progressive scoliosis.

**AIMS & OBJECTIVES**

- To identify a top 10 list of priorities for future research into scoliosis diagnosis and management.
- To communicate the results of the Scoliosis PSP.
- To disseminate the findings of the Scoliosis PSP to promote awareness of the needs of patients and healthcare workers.

**REFERENCES**

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

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 shortest 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 Parkinson.org.uk/content/research-grants.

We’ve seen a significant increase in research applications focused on these priorities, with applicants dealing with the current needs of people with Parkinson’s.

PROGRESS SO FAR:
Balance and falls
Before the priority setting project, Parkinson’s UK awarded £350,000 to Dr Emily Henderson and her team for their research study looking at whether the commonly prescribed medication rasagiline could help prevent falls in people with Parkinson’s. This research has found that people who took rasagiline were 43% 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 charity’s commitment to ensuring that the needs and priorities of people affected by Parkinson’s is the driving force that shapes 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

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 this is not the case.

The British Tinnitus Association (BTA) undertook a priority setting partnership (PSP) exercise with the James Lind Alliance (JLA) in 2015/2016. 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 further research, and encourage funders and researchers alike to rise to the challenge of addressing the selected priorities.

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 2018. The project was supported financially by the BSA.

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 detail areas mentioned in the practice guidance. The course was delivered in June 2018 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 2018.

Working with a children’s author, illustrator/designer, our professional advisers, editors, 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.

Tinnitus Week 2018

Tinnitus Week 2018 will be themed “Talk About 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 can help support young people with tinnitus more effectively and make their lives easier.

Results
Over 5000 copies of Tinnitus in Children: Practice Guidance have been distributed or downloaded.

87 professionals have attended the Assessment and management of Tinnitus in children course.

Over 10,000 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 35,000 copies of the children’s activity booklets have been distributed.

The booklets were Highly Commended in the BMA’s 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 professions. It has fed into improved services and support for children with tinnitus.

British Tinnitus Association, Ground Floor, Unit 5, Acorn Business Park, Woodseats Close, Sheffield, S8 0TB
Registered charity no: 1011418 Company limited by guarantee no: 2708007 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
- Multidisciplinary professionals, including health, education and third sector staff

4. Socio-Economic Spread

Postcode and Scottish Index of Multiple Deprivation (SIMD) Mapping

- SIMD 1: Most Deprived
- SIMD 2: Most Deprived
- SIMD 3: Most Deprived
- SIMD 4: Most Deprived

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

<table>
<thead>
<tr>
<th>In-scope questions</th>
<th>Respondents</th>
<th>Particpants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning difficulties</td>
<td>367</td>
<td>201</td>
</tr>
<tr>
<td>Child health</td>
<td>363</td>
<td>197</td>
</tr>
<tr>
<td>Pre-school</td>
<td>394</td>
<td>219</td>
</tr>
<tr>
<td>Autism (including all adults)</td>
<td>2213</td>
<td>1221</td>
</tr>
</tbody>
</table>

Demographic makeup:
- 3.3% SIMD 1
- 5% SIMD 2
- 10% SIMD 3
- 35% SIMD 4

7. 8 Themes

- Causes
- Co-occurring conditions
- Identification & diagnosis
- What helps
- Evaluation of the availability and quality of provision

8. Examples:

- Causes of learning difficulties:
  - Developmental
  - Learning Disabilities
  - Other

- 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)