



James
Lind
Alliance

Priority Setting Partnerships

Royal College of
Occupational
Therapists



RCOT/JLA Occupational Therapy Priority Setting Partnership

Launch and Initial Workshop
Monday 4th March 2019

Keep in touch with us



Housekeeping

- Mobiles phones to silent please
- Bathrooms
- Fire alarm and assembly point
- Topping up on refreshments
- #OTResearchPriorities #RCOTresearch

Aims for today

- Raise awareness of the Occupational Therapy PSP
- Begin to explore the scope of the PSP
- Clarify the various options for being involved
- Begin to explore how best to engage various stakeholders
- Harness support to actively promote and progress the PSP

... over to Katherine Cowan

Senior Advisor for the James Lind Alliance



The James Lind Alliance

Setting priorities for health research

Katherine Cowan: Senior Adviser, JLA

@katherine_JLA

What will I cover?

- What is the James Lind Alliance (JLA)?
- What do we do and why do we do it?
- How do we do it?
- What are the outcomes?

What is the JLA?

- Established in 2004
- A new way to set priorities for research
 - Patients / service users
 - Carers / families
 - Health and social care professionals

What is the JLA?

Who normally decides what gets researched?

- Researchers
- Pharmaceutical industry

The priorities of people with conditions and the people who treat and care for them can be very different from those of researchers.

Sir Iain Chalmers

What is the JLA?

Sir Nick Partridge



Dr John Scadding

What is the JLA?

NIHR | National Institute
for Health Research

What do we do?

- Priority Setting Partnerships
 - Patients, carers and clinicians
 - Identifying questions
 - Prioritising them
 - Top 10

Priority Setting Partnerships

- **80** completed
- **24** currently ongoing

Current UK Partnerships

Heart Surgery
Hyperhidrosis
Occupational Therapy
Diabetes and Pregnancy
Detecting Cancer Early
Healthcare Associated Infections
Paediatric Orthopaedic Lower Limb Surgery
Broken Bones of the Upper Limb in People over 50
Nutritional Screening and Malnutrition
Revision Knee Replacement
Hypertension in Pregnancy
Advanced Heart Failure
Vascular Surgery
Foot Health
Exacerbations of COPD



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Priority Setting Partnerships

Completed UK Partnerships



Core values

- Transparency
- Inclusion / exclusion
- Equality
- Evidence

The JLA priority setting process

1. Steering Group
2. Partners
3. Consultation
4. Data analysis
5. Prioritisation
6. Dissemination

The JLA process

steering group



Partners



consultation



Data analysis



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Priority Setting Partnerships

The JLA process



PAGE 3: Selecting priorities for autism research

* 9. Choose up to 10 questions that you most want autism research to answer, based on your personal or professional experience. (tick up to 10 boxes)

<input type="checkbox"/> Classification - Can people with autism be classified into sub-groups such that interventions could be targeted at specific groups?	<input type="checkbox"/> Medical tests - Can brain imaging/other medical tests identify differences and perform more accurate diagnosis and/or identify appropriate treatment?	<input type="checkbox"/> Applied behaviour analysis - Does Applied Behaviour Analysis improve wellbeing/ developmental progress in people with autism?
<input type="checkbox"/> Service delivery - How should service delivery for people with autism be improved and adapted in order to meet needs in terms of co-ordination, location and severity?	<input type="checkbox"/> Sex differences - In what systematic ways do males and females differ in their manifestations of autism and their needs for diagnosis, support and intervention?	<input type="checkbox"/> Mental health problems - What other mental health problems are common in people with autism?
<input type="checkbox"/> Communication - Which interventions are effective in the development of communication/language skills?	<input type="checkbox"/> Sensory processing - Which interventions improve sensory processing disorders in people with autism?	<input type="checkbox"/> Reliable diagnosis - How can autism diagnosis be made more reliable and accurate?
<input type="checkbox"/> Talking therapies - Do talking therapies improve mental health and outcomes for people with autism?	<input type="checkbox"/> Insight - What is the insight living with autism? How is autistic people better and it's like to be autistic? How people better understand	<input type="checkbox"/> Public understanding - How can public understanding and tolerance of autism be improved? And what is the
<input type="checkbox"/> Early intervention - Which early interventions are most effective? And do they lead to better outcomes?	<input type="checkbox"/> Nutrition - Does diet have an effect on the symptoms of autism and	
<input type="checkbox"/> Medications - Which medications (if any) improve the symptoms/ distressing conditions of autism and		

Interim prioritisation - long list to short list

PAGE 4: Ranking your top priorities for autism research

* 10. Now please rank your selected 10 questions in order of priority, 1 being your most important question. (You can drag and drop the questions into order)

- 1 Communication - Which interventions are effective in the development of communication/language skills?
- 2 Medical tests - Can brain imaging/other medical tests identify differences and perform more accurate diagnosis and/or identify appropriate treatment?
- 3 Sex differences - In what systematic ways do males and females differ in their manifestations of autism and their needs for diagnosis, support and intervention?
- 4 Sensory processing - Which interventions improve sensory processing disorders in people with autism?
- 5 Talking therapies - Do talking therapies improve mental health and outcomes for people with autism?
- 6 Early intervention - Which early interventions are most effective? And do they lead to better outcomes?
- 7 Service delivery - How should service delivery for people with autism be improved and adapted in order to meet needs in terms of co-ordination, location and severity?
- 8 Medications - Which medications (if any) improve the symptoms/ distressing conditions of autism and what are their side effects?
- 9 Public understanding - How can public understanding and tolerance of autism be improved? And what is the impact of public understanding on the lives of autistic people?
- 10 Insight - What is the insight living with autism? How is autistic people better and it's like to be autistic? How people better understand





Final priority setting
workshop

The JLA process





Dissemination and awareness raising

The JLA process



NIHR | National Institute for Health Research

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

THE LANCET



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Examples of priority questions

- Which treatment is more effective for **vitiligo**: steroid creams/ointments or light therapy?
- Does appropriate provision of wheelchairs to enable independent mobility for very young children with **neurodisability** improve their self-efficacy?

Examples of priority questions

- What is the best way to care for people with **dementia** in a hospital setting when they have acute healthcare needs?
- What are the core **palliative care** services that should be provided no matter what the patients' diagnoses are?
- What approaches are effective for enabling parents, relations or carers to support **physiotherapy** treatment or to help patients to manage their own health problem?

Outcomes

Q7. What are the benefits of breathing exercises as a form of physical therapy for **asthma**?

Evaluation, Trials and Studies

You are here: Home > Project portfolio > 09/104/19

- Research programmes
- Funding opportunities
- Project portfolio**
- Browse projects
- Resources for researchers
- Become a reviewer
- Identifying research questions
- Public and patient involvement
- About us and our approach
- Impact and evidence
- News and literature

HTA - 09/104/19: A controlled study of the effectiveness of breathing training exercises taught by a physiotherapist by either instructional videos/DVDs/internet download or by face-to-face sessions in the management of asthma in adults

Notify me when this item is published

Project title	A controlled study of the effectiveness of breathing training exercises taught by a physiotherapist by either instructional videos/DVDs/internet download or by face-to-face sessions in the management of asthma in adults
Research type	Primary Research
Status	Research in progress

THE LANCET Respiratory Medicine

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Volume 6, No. 1, p19-26, January 2018

Physiotherapy breathing retraining for asthma: a randomised controlled trial

Prof Anne Branton, PhD, Prof Amanda Lee, PhD, Prof Lucy Fardley, PhD, Prof James Raftery, PhD, Emily Arden Clark, PhD, Sarah Kelly, PhD, Shihua Zhu, PhD, Manojkumar Thirumangalakudi, MSc, Frances Wilkey, Lyn Taylor, Denise Gibson, Mia, Gaining Yao, PhD, Mark Stafford-William, Jenni Unwin, PhD, Prof Michael Haines, FRCP, Steven George, FRCP, Prof Paul Little, FRCGS, Prof Rishi Jyakeshwar, PhD, Prof David Price, FRCGP, Prof Ian D Paowd, FRCGS, Prof Stephen D Hingle, FRCGS, Prof Mike Thomas, PhD

Published: 11 December 2017

Breathing Freely
Your guide to breathing retraining for asthma

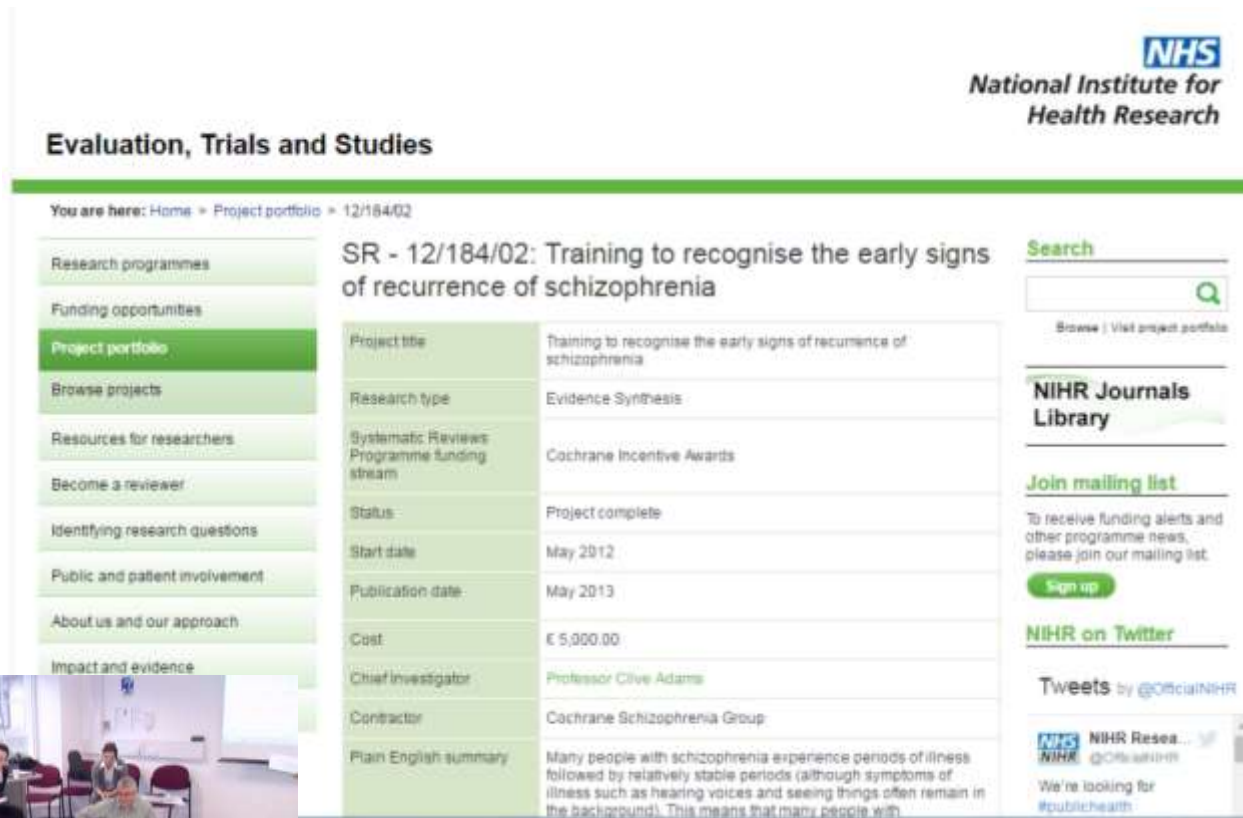
Welcome to the online version of Breathing Freely.
Developed by an experienced team of GPs, physiotherapists, psychologists and patients at the University of Southampton, Breathing Freely was shown to improve the lives of people with asthma, in the Breathe Study. The Breathe Study is now finished but you can try Breathing Freely yourself using the links below - it's completely free.

Get started! Click this button if you want to sign up to the Breathing Freely Programme - it's completely free and you can do it at a time that's convenient for you.

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Outcomes

Q2. What training is needed to recognise the early signs of recurrence of **schizophrenia**?



The screenshot shows the NIHR website interface. At the top right is the NHS logo and 'National Institute for Health Research'. The main heading is 'Evaluation, Trials and Studies'. Below this is a breadcrumb trail: 'You are here: Home > Project portfolio > 12/184/02'. A left-hand navigation menu includes 'Research programmes', 'Funding opportunities', 'Project portfolio' (highlighted), 'Browse projects', 'Resources for researchers', 'Become a reviewer', 'Identifying research questions', 'Public and patient involvement', 'About us and our approach', and 'Impact and evidence'. The main content area displays the project title 'SR - 12/184/02: Training to recognise the early signs of recurrence of schizophrenia'. Below the title is a table with the following details:

Project title	Training to recognise the early signs of recurrence of schizophrenia
Research type	Evidence Synthesis
Systematic Reviews Programme funding stream	Cochrane Incentive Awards
Status	Project complete
Start date	May 2012
Publication date	May 2013
Cost	€ 5,000.00
Chief investigator	Professor Clive Adams
Contractor	Cochrane Schizophrenia Group
Plain English summary	Many people with schizophrenia experience periods of illness followed by relatively stable periods (although symptoms of illness such as hearing voices and seeing things often remain in the background). This means that many people with

On the right side of the page, there is a search bar, a 'NIHR Journals Library' section, a 'Join mailing list' section with a 'Sign up' button, and a 'NIHR on Twitter' section showing a tweet from @ORCAatNIHR: 'We're looking for #publichealth'.



Outcomes

Palliative and End of Life Care PSP



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[Get involved](#)

[Donate](#)



[Researching better care](#) / [Funding for research](#) / [Marie Curie Research Grants Scheme](#) / [2016 call for applications](#)

2016 call for applications

Marie Curie, in partnership with Chief Scientist Office (CSO) and Motor Neurone Disease Association (MND Association), is spending up to £1.425 million this year through the [Marie Curie Research Grants Scheme](#) to fund high quality research.

This research aims to improve the quality of life of people with terminal illnesses and their carers, families and friends by addressing one or more of the research priorities identified by the Palliative and end of life care Priority Setting Partnership (PeolcPSP)



Application process

The application process consists of two stages - the outline application stage and the full application stage.

Marie Curie Research Grants Scheme

[2016 call for applications](#)

[2014 Research Awards](#)

[2013 Research Awards](#)

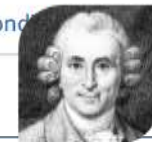
[2012 Research Awards](#)

[2011 Research Awards](#)

[2010 Research Awards](#)

[Previous themes](#)

[Terms and conditions](#)



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Outcomes

Sight Loss and Vision PSP – published May 2013

- Fight for Sight: over £11,000,000 awarded to over 180 projects
- NIHR: £2,000,000 for three clinical trial addressing priorities in cataract, glaucoma and keratoconus
- Macular Society: £700,000 grants for 12 projects
- 2 NIHR horizon scanning reports for new and emerging treatments (corneal disorders and inherited retinal diseases)
- Multi-charity partnership formed to address the top priority in AMD
- www.sightlosspsp.org.uk

For more information...

www.jla.nihr.ac.uk



@LindAlliance

@Katherine_JLA

katherine@katherinecowan.net





Thank you

Katherine Cowan: Senior Adviser, JLA
@katherine_JLA



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Occupational Therapy Research Priority Setting Partnership

The RCOT perspective

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Current (R)COT guidance

White & Creek (2007) *College of Occupational Therapists' Research and Development Strategic Vision and Action Plan: 5-year Review*. *British Journal of Occupational Therapy*, 70(3), 122-128.

College of Occupational Therapists (2007) *Building the Evidence Base: Priorities for Research*. COT: London.

Changing contexts



RCOT R&D Review

Running June 2017- Sept 2019

- Comprehensive review of R&D related activities at RCOT
- Publication of refreshed vision, strategy and action plan
- Support and promote R&D capability and capacity within the profession
- Guide related future activities of RCOT

<http://www.rcot.co.uk/r&dreview>

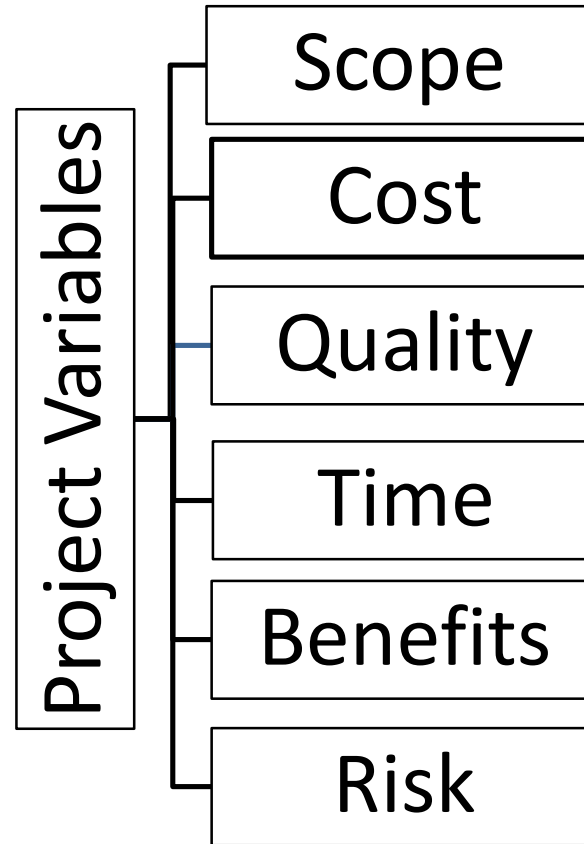
Partnering with the JLA

- Flexible and responsive to particular needs and contexts
- Robust, transparent, inclusive and auditable approach
- Commitment to partnership working between healthcare professionals, service users, carers and the public
- Fits comfortably with the profession's underpinning
- Committed to using and contributing to the evidence base
- Recognised by grant-funding bodies (e.g. the NIHR)

QUESTIONS AND DISCUSSION

Scope of the Occupational Therapy Priority Setting Partnership

Jenny Mac Donnell, Project Lead





The Steering Group defines the scope of the project?

Factors to consider are:

- Capacity in the project team to check the evidence base
- The type of evidence that's available and
- What's important to research funders.



Scope of the Adult Social Work PSP



- Social work - defined in legislation
- Adults – responsibility of the Department for Health and Social Care
- England – Responsibility of the Department for Health and Social Care



Five Key Themes Within the Scope of the Physiotherapy PSP

Promoting patient and
public partnerships

Developing and sharing
models of good practice
for reducing the burden
on secondary care

Putting physiotherapy at
the heart of improving
the health of the
population

Supporting innovative,
effective and
sustainable healthcare

Promoting good
practice in primary care
for people with multiple
morbidities



Two Cross-Cutting Themes Within the Scope of the Physiotherapy PSP

Have your say on the future of physiotherapy

Question 1: What questions do you have about physiotherapy in the workplace and get them to their usual address?

Question 2: What questions do you have about physiotherapy in the workplace to improve their condition/therapies?

Question 3: What questions do you have about physiotherapy in the workplace to improve their health and prevent disease and injury?

Question 4: What questions do you have about how physiotherapy services are accessed and delivered?

- **Implementation Planning; and**
- **Demonstration of impact, outcome and value, including health informatics.**



Group Work

- What should the scope of the Occupational Therapy PSP include and why?
- Can you suggest any questions/uncertainties that might fall into the scope of the OT PSP?
- What topics, issues or areas of occupational therapy might be considered out of scope and why?
- What else should the OT PSP consider when setting out and communicating about its scope?

Getting involved

Occupational Therapy Priority Setting Partnership

Ruth Unstead-Joss, Project Coordinator

What will we cover?

- Steering Group
- Project Partner
- How to sign up
- Group work: How do we involve the right people, in the right way?

Join the Steering Group

- **Role:** Oversee PSP and accountable for key decisions
- **Who:** Service users, carers and occupational therapists
- **Members bring:**
 - Knowledge of occupational therapy practice
 - Understanding of those using services
 - Access to networks and contacts
- **Key responsibilities:**
 - Contribute to each stage of the PSP
 - Listen to, respect and incorporate different perspectives
- **Time commitment:** Monthly teleconference (plus occasional all day face-to-face meetings) and work in between meetings

Become a Project Partner

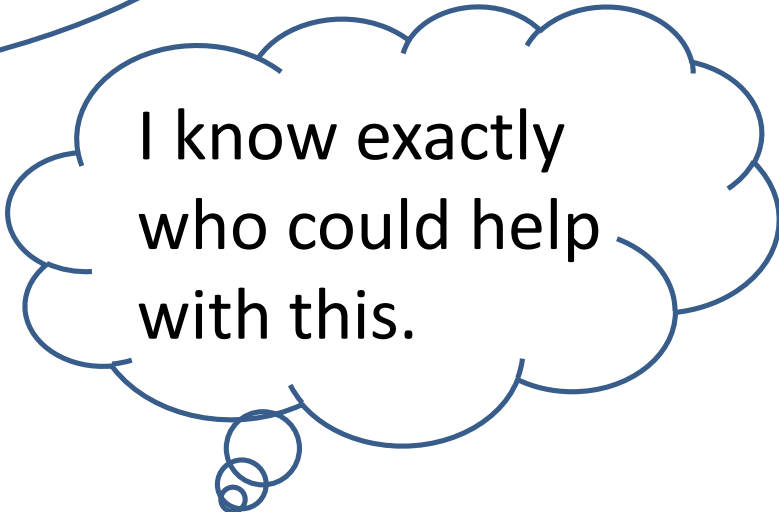
- **Role:** Ensure project is inclusive and reaches as wide a range of people as possible
- **Who:**
Representatives of:
 - Users of occupational therapy services
 - Carers and relatives
 - Health and social care professionals working in occupational therapy services
- **Key responsibilities:**
 - Disseminate information about the project
 - Promote the surveys
 - Encourage networks to participate



I want to join the Steering Group,
and I can commit the time!



I want to sign up as a
Project Partner.



I know exactly
who could help
with this.

Complete Expression of Interest forms:

www.rcot.co.uk/otpsp

Steering Group Deadline 15th March

#OTResearchPriorities

#RCOTResearch

Involving the right people. In the right way.

Stakeholders:

- Occupational therapists, service users, carers and others.
- Seldom heard voices (e.g. BAME, refugees, homeless, living with dementia, etc)

Group work:

- **Who** should be involved?
- **What** do we need to do to ensure their involvement?
- **How** will you help us? (Names!)