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

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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?

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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

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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.

What is the JLA?

Sir Iain Chalmers

Sir Nick Partridge

Dr John Scadding

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What is the JLA?

NIHR | National Institute for Health Research

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What do we do?

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

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Priority Setting Partnerships

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

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Current UK Partnerships

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Completed UK Partnerships

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Core values

- Transparency
- Inclusion / exclusion
- Equality
- Evidence

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The JLA priority setting process

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

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The JLA process

Steering group

Partners

Consultation

Data analysis

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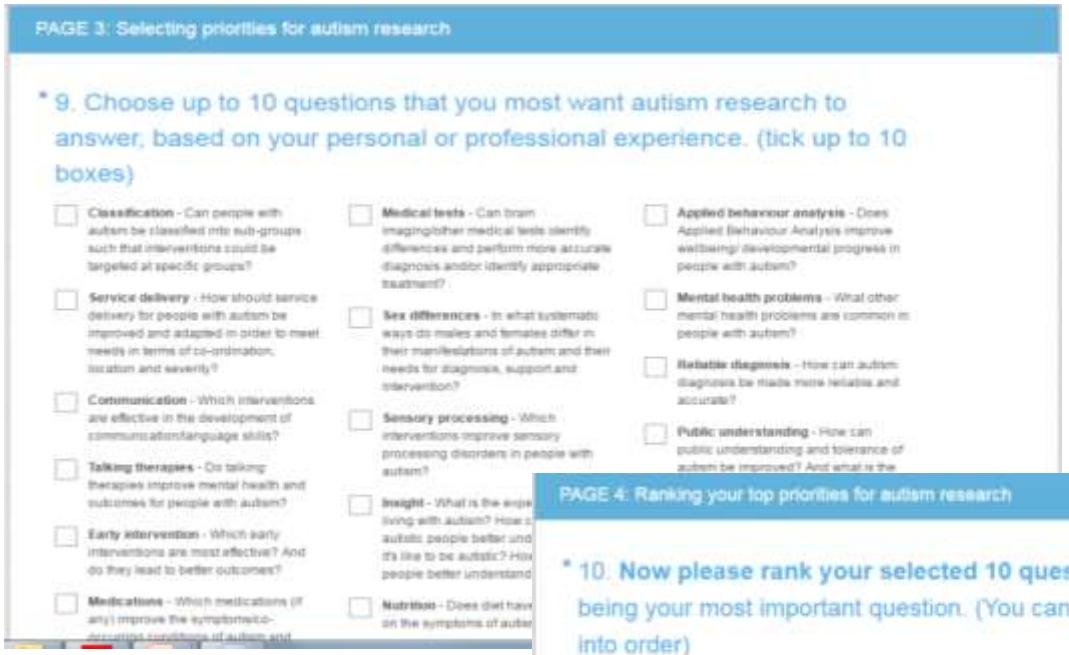
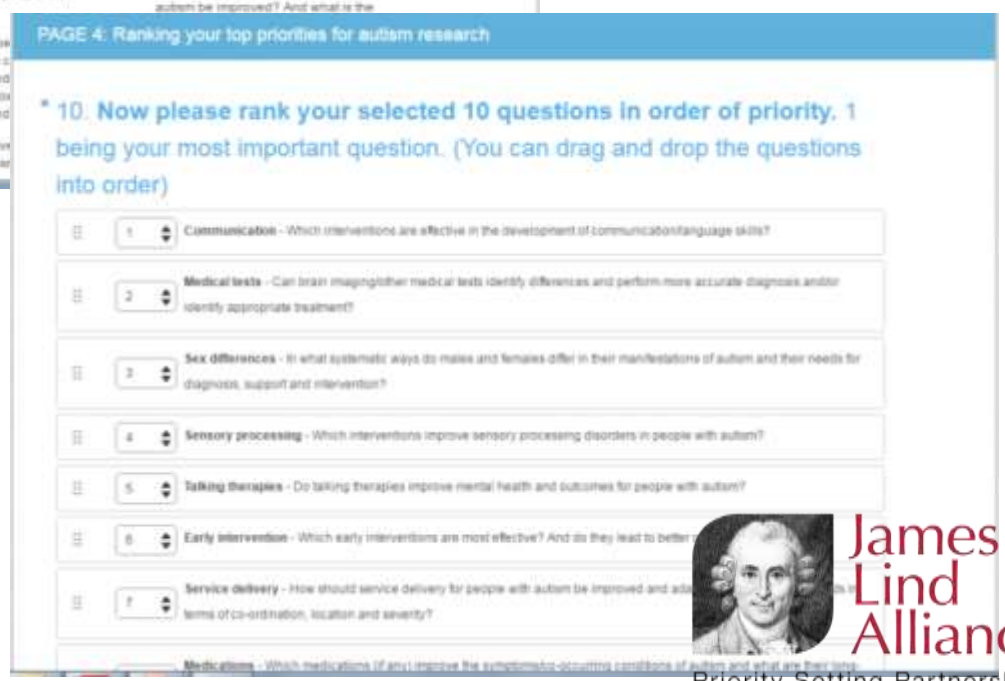
The JLA process





Interim prioritisation – long list to short list

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Final priority setting workshop

The JLA process

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Dissemination and awareness raising

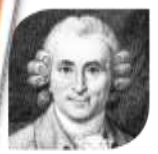
The JLA process

NIHR | National Institute for Health Research

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

THE LANCET

thebmj



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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

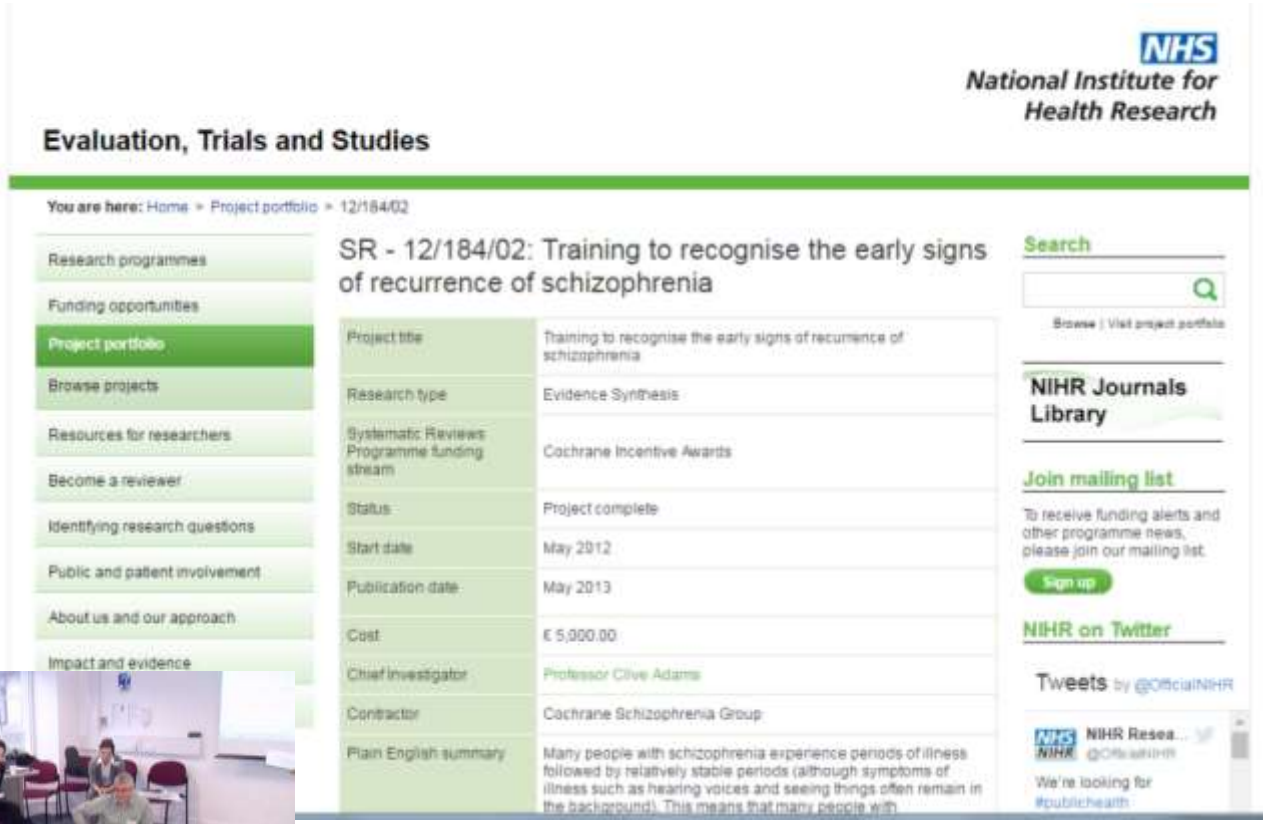
- What is the best way to care for people with **dementia** in a hospital setting when they have acute healthcare needs?
- What are the core **palliative care** services that should be provided no matter what the patients' diagnoses are?
- What approaches are effective for enabling parents, relations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

Outcomes

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



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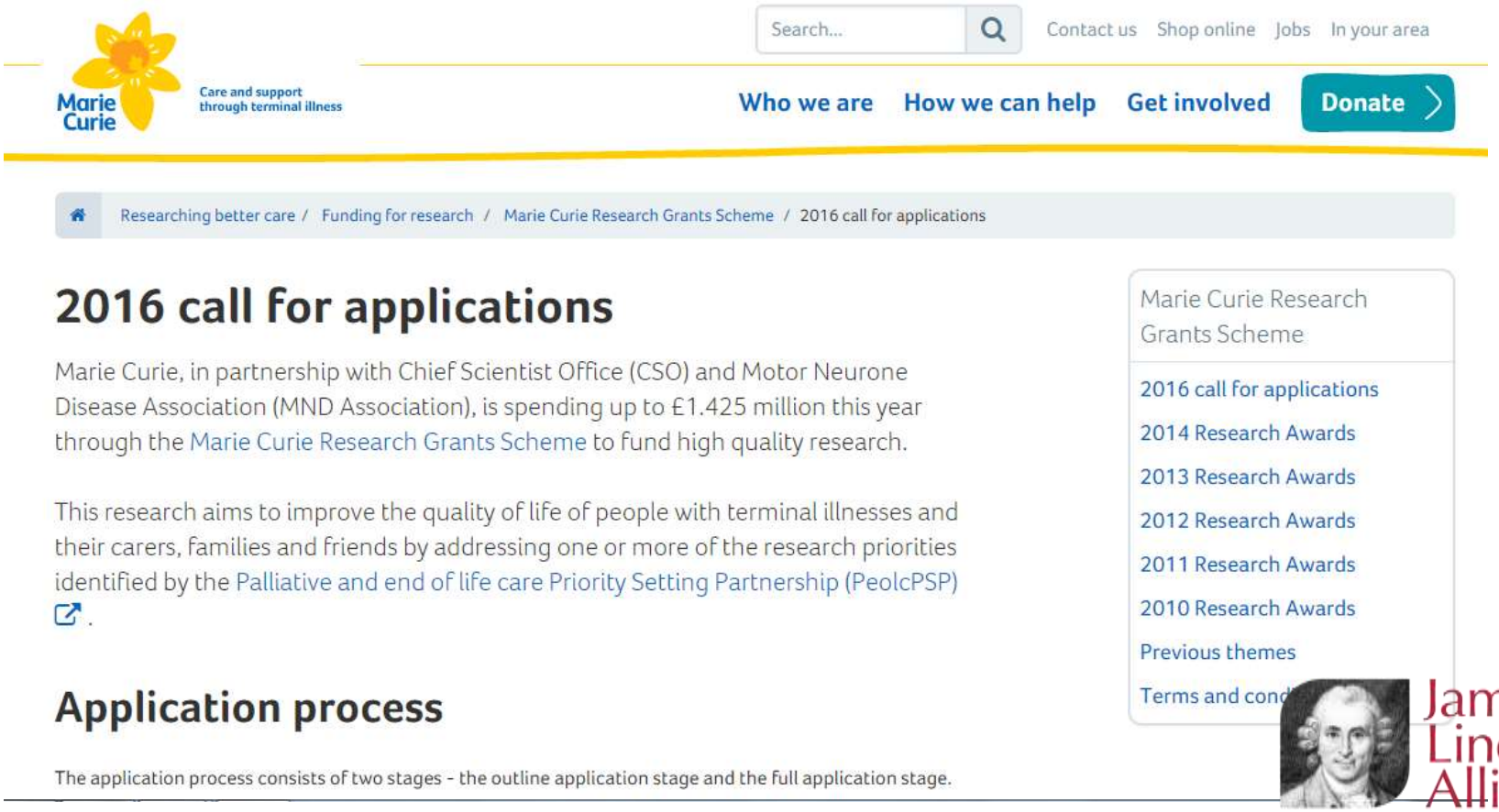
Outcomes

Palliative and End of Life Care PSP



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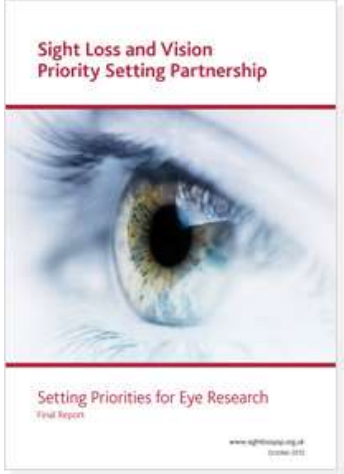
Outcomes



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

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Thank you

Katherine Cowan: Senior Adviser, JLA

@katherine_JLA

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Occupational Therapy Research Priority Setting Partnership

The RCOT perspective

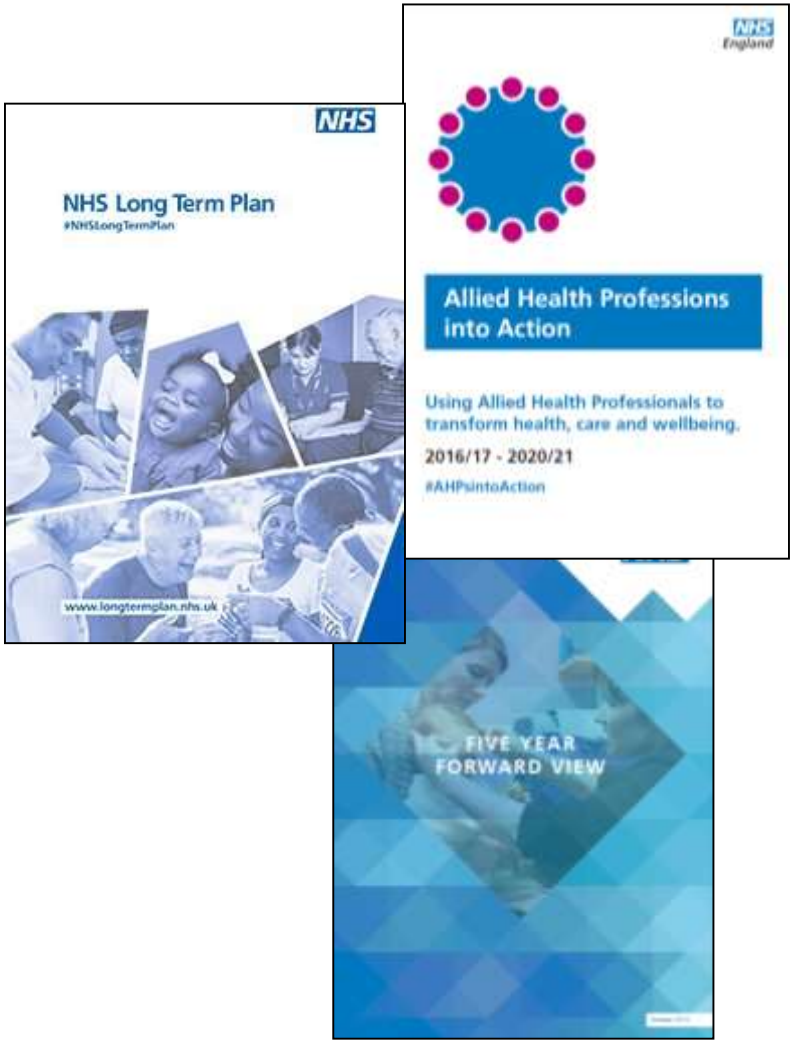
Keep in touch with us

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

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Scope of the Occupational Therapy Priority Setting Partnership

Jenny Mac Donnell, Project Lead

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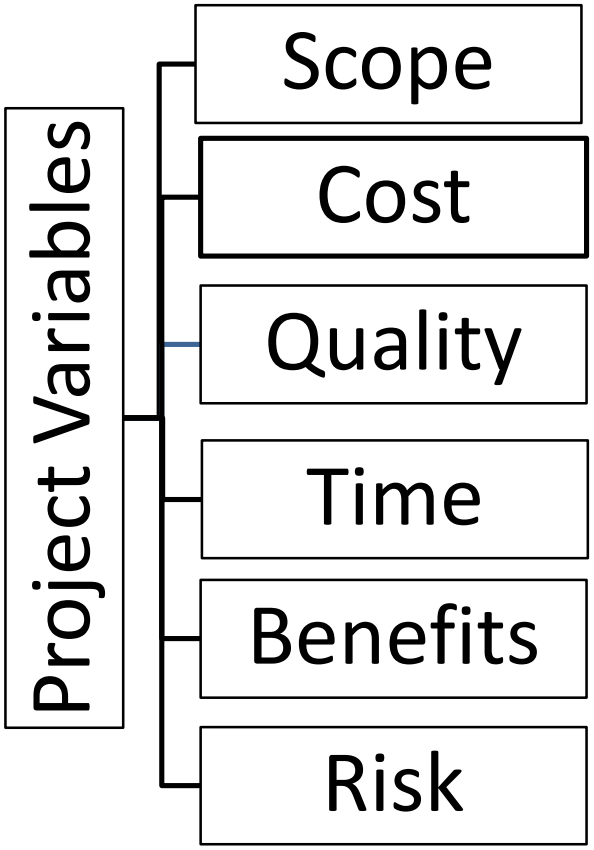

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The Steering Group defines the scope of the project?

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.

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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

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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

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

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

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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?

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Getting involved

Occupational Therapy Priority Setting Partnership

Ruth Unstead-Joss, Project Coordinator

#OTResearchPriorities
#RCOTResearch

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 know exactly who could help with this.

I want to sign up as a Project Partner.

Complete Expression of Interest forms:

www.rcot.co.uk/otpsp

Steering Group Deadline 15th March

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#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!)