

# **‘MORE THAN A TOP 10’**

**HOW JAMES LIND ALLIANCE PRIORITY SETTING PARTNERSHIPS’  
TRANSFORM RESEARCH, PEOPLE AND ORGANISATIONS**

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# CONTENT OF THIS PRESENTATION

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- Background to the project and how it was done
- Summary of findings - positive and negative impact patterns
- Limitations of the project
- Our reflections
- 11.15 - 12 – presentation and feedback
- 12.20 – 13.00 facilitated discussion

# BACKGROUND TO THE PROJECT

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- We would describe JLA model as ‘well described but under evaluated’
- Commonly asked question about JLA PSPs is ‘*What is the impact of the priorities on research?*’ – do we know?
- We were curious to know and understand better the impacts of JLA PSPs
- Funded and supported by Trish Greenhalgh NIHR Biomedical Research Centre, Oxford.
- Oxford has a strong history with the origins of the JLA and has hosted many JLA PSPs

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# JAMES LIND ALLIANCE (JLA)

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- Main purpose to agree shared research priorities for research by using a process that is inclusive, equitable, transparent and evidence based
- Conception in 2003 – constant evolution and refinement – move from independent status to part of the Wessex Institute
- @ 2020 over 100 completed Priority Setting Partnerships (PSP)
- Average about 14 completing a year
- International profile (Canada – satellite) Europe, Africa and Australia

# PRIMARY AUDIENCE FOR THE REPORT

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- Main audience for this report is past, present and future PSPs. We hope the lessons learnt will help PSPs with the work that happens after the JLA process has concluded, and could usefully inform future evaluations
- BUT the findings from this project have implications for many other health and research organisations, as impact it is not the sole responsibility of the JLA and PSPs
- Thanks to the Impact Coffee Club for being interested in our work and providing an opportunity to share our findings!

# PROJECT OBJECTIVES

- Identify **examples of success** and develop case studies to explore how researchers and funders were positively influenced in each case
- Identify **challenges and tensions** in the use of JLA PSP priorities by researchers and funders and how these have been addressed
- Explore what **practical approaches** could be taken to maximise the impact of PSPs, both during the process as well as after identifying a Top 10 list of priority topics



# PROJECT METHODS AND APPROACH

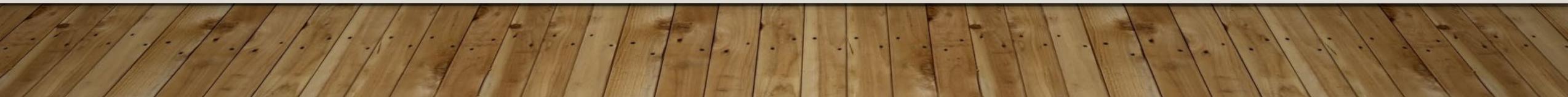


- Convened an Advisory Group (met twice)
- 20 interviews conducted in Spring 2019. Included; PSP leads, a funding manager, researchers & patients. PSP leads reflected different organisations such as charities, universities and patient groups, some of which funded research
- Interviews taped, transcribed and analysed by Kristina and Sally. Findings and themes developed using ‘illuminative evaluation’ approach
- Draft report checked with interviewees, collaborators and funders
- Final report agreed and launched in Sept 2019



# SUMMARY OF FINDINGS

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- Narrative rather than quantitative findings, we tried to avoid notions of ‘success’ and ‘failure’ of JLA PSPs
  - There are PSPs that have real impact on research funding – and there are PSPs that don’t – a mixed picture from our sample.
  - People often assume ‘impact’ is only about getting a prioritised research project funded – we found that this impact takes many forms
  - Impact is also about the people *and* organisations associated with a JLA PSP
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# PATTERNS LINKED WITH POSITIVE IMPACTS ON RESEARCH

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- When the **culture and values** of a **PSP lead organisation** (charities or universities) matched those of the JLA, then they made change happen. For example they:
- integrated PSP priorities into their research strategy - *MS PSP*
- funded projects that addressed Top 10 priorities - *Multiple Sclerosis, Autism, Tinnitus, Palliative and End of Life Care PSPs*
- took ownership of the Top 10, and responsibility for promoting them and tracking progress - *Mild to Moderate Hearing Loss PSP*
- mapped the current research landscape to prioritise amongst the priorities – *Palliative and End of Life Care PSP*

# PATTERNS LINKED TO POSITIVE IMPACTS ON RESEARCH

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- Where a **culture of collaboration** developed post-PSP (distinct from the usual competition), lead organisations worked together and with international partners to jointly develop research projects and encouraged researchers to do the same. *MS, Autism, Sight Loss and Vision, Type 2 Diabetes PSPs*
- Where a **tight-knit research community** was small, well-networked, communicative and in need of recognition, they respected and responded to JLA PSP priorities. *Stillbirth PSP*
- Where there was a **'champion'** (who had power, influence and skills), they advocated for the Top 10 with researchers and funders - *Tinnitus PSP*

# BROADER POSITIVE IMPACTS - ORGANISATIONS

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- More public involvement in research culture and processes. *Childhood Disability PSP*
- More collaboration within different parts of the same organisation, across organisations in the same field. *Diabetes and MS PSPs*
- Increased profile and credibility of organisations that lead and undertake PSPs. *Lyme Disease PSP*
- Increased profile of the health area. *Stillbirth PSP*



# BROADER POSITIVE IMPACTS - PEOPLE

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## Clinicians

- Change in clinical practice, skills development, informing their own areas of research, career progression, raised profile.

## Patients

- Change in PPI practice, personal empowerment, skills development, restored confidence, further commitment to research.



# PATTERNS LINKED TO NO IMPACT ON RESEARCH

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- Priorities that addressed '**contested areas**' of health research. For example where patients' views of a condition differ from clinical perspectives, or where research is not trusted. *Lyme Disease, Autism PSPs*
- Where there was **limited ownership** of priorities – or the topic didn't 'belong' to anyone/group in particular. *Cellulitis PSP*
- **Lack of dedicated resource** to support follow-up work post PSP e.g. following on from the collaboration led by Parkinson's UK, on the shared priority topic of incontinence.

# PATTERNS LINKED TO NO IMPACT ON RESEARCH

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- Tensions around priorities that do not fit with the **culture and values** of the researchers' or funders' organisations.
- Where JLA PSPs outputs aren't 'innovative', 'new' or 'fashionable'.
- **Limited research capacity** to respond to JLA PSP priorities.

# LIMITATIONS

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- Not a systematic review – we didn't access *all* PSPs, but a selection chosen to reflect the range of different topics and contexts for PSPs
- Unable to answer the extent to which a JLA PSP priority influences funding and researchers decisions, and if so how?
- Unable to answer if the JLA (since its inception) has created an observable change over time in terms of the numbers of projects addressing JLA PSP priorities that are being funded

# OUR REFLECTIONS

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- Kristina and Sally have both invested and benefited professionally and personally from working on, and with the JLA (PSPs). We do this work with commitment to its purpose.
- We conclude that the JLA, which was created to challenge the status quo of research portfolios and to introduce the concept of shared research agendas, has been an impetus to getting more research done in some health areas.

# OUR REFLECTIONS

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- There continues to be tension in who decides what is the ‘right’ question to research, and often trade offs between questions that are relevant and useful to patients and clinicians, and those that are amenable to researching using current methods. The culture of many research institutions tends to prioritise scientific rigor and reliability of evidence over relevance and utility of the findings.
- We believe there must be a continued focus on learning from past and current JLA PSPs about how best to achieve impact and exploration of the wider impacts beyond research, especially as the JLA model itself continues to evolve.





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Tanya Baldwin, Ben Clyde, Jo Crocker ,Russell Dean, Trish Greenhalgh, Caroline Jordan, Polly Kerr, Michele Acton, Katherine Cowan, Bryony Dean Franklin, Simon Denegri, Ed Holloway, Mary Madden, Mark Taylor, Amanda Roberts, Brian Rochford, Roger Wilson, Sabine Best, Jeremy Chataway, James Cusack, Irenie Ekkeshis, Alexander Heazell, Julia Hamer-Hunt, Helen Henshaw, Stella Huyshe-Shires, Lynn Laidlaw, Thomas Kabir, Susan Kohlhaas, Sarah Meaney, Chris Morris, Vanessa Pinfold, Noémi Roy, Kamini Shah, David Stockdale, Kim Thomas, Maryrose Tarpey, Richard Stephens, Beccy Maeso and more anon contributors.

# SOME QUESTIONS TO CONSIDER

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- Who's job is it to work with the JLA priorities?
- What role could your organisation play, if any?
- What would help or hinder this work?

# KEY LESSONS AT THE END OF EACH SECTION

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- **Planning:** preparing for the end at the start
- **Sharing:** disseminating the JLA PSP priorities
- **Influencing:** persuading others to respond to the research priorities
- **Responding:** using JLA PSP priorities to influence strategy and funding decisions
- **Translating:** turning a priority topic into a research project
- **Evaluating:** assessing whether JLA PSPs are making a difference to research
- **Transforming:** changing culture, policy, organisations and people