

ECONOMIC AND SOCIAL RESEARCH COUNCIL

KEY FINDINGS REPORT

The Key Findings Report should be completed and submitted using the **grant reference** as the email subject to, reportsofficer@esrc.ac.uk on or before the due date.

Please complete each box as fully as possible, adhering to the word counts, please do not include images within the text. Appendices are not accepted.

Principal Investigators are expected to consult with co-investigators on the content of this report.

Grant Reference:	ES/J02080X/1
Investigator/s:	Principal Investigator: Professor Susan Leekam; Co-Investigator: Dr Dawn Wimpory
Project Title:	Developing a Research-Policy-Practice Hub for Autism Spectrum Disorder

1. Summary of Project Findings (circa 500 words)

Please summarise your main findings from the project. You are also invited to briefly indicate any plans for further research in this, or a related area.

For ESRC Seminar Series and projects under the Research Development Initiative please detail the outcomes of the activities carried out and provide information on the level of demand for participation.

Developing a Research-Policy-Practice Hub for Autism Spectrum Disorder *Funded by ESRC and Welsh Government*

Outcomes and key findings

1. Outcomes from development period (Jan- Sept 2013)

Web development: Outcome: A unique architecture <http://www.autismrpphub.org/> was designed and a *Technical summary* of its development was produced to inform others about the model.

Consultation: Ten initial *meetings* were held with practitioners, researchers and people living with ASD, and meetings were also held with CEOs of 4 charities (National Autistic Society, Research Autism, Autistica, Autism Alliance). A set of *specific user trials* were held. Outcome (1) Stakeholder engagement and consultation views informed the hub design. Outcome (2) User needs matched web technology.

Formal Face-to-Face Events: Six formal conference and seminar presentations were held. (1) Seminars: Local Government Learning Information Network, Welsh Government Assembly Members, UK Autism Alliance, Bristol Autism Research Group (2) Conference presentations: Association of Directors of Social Services, International Meeting for Research in Autism (IMFAR)

Research and evaluation: (1) A series of *qualitative interviews* and a *large scale survey* (N=683) investigated the level of engagement that practitioners currently experience with researchers, and the methods that they use and consider beneficial for increasing research knowledge. Findings showed that non-researchers reported relatively low levels of engagement with researchers. They also had different priorities from researchers about the research information they thought would be beneficial for practice, although their top three priorities were the same. Findings informed the design and content of the final online Autism RPP Hub web-based platform. (2). *Project evaluation:* See section 4: URL for report.

2. Outcomes from operational period (Oct 2013-end March 2014)

General use of the Autism RPP site

Google Analytics data shows that in first month after Hub went online (end of September 2013), there were 10,200 page visits, 1,500 unique visitors with 650 users returning to the Hub site on multiple occasions. From January 1st 2014, to mid-March 2014 there were 3,013 visits, 2,202 unique visitors and 12,466 page visits from people in 10 countries. In total, to July 2014 there have been 45,000 page views and 10,885 users.

Online events (end Oct-Feb)

Diagnostic interview methods: <http://bit.ly/1z1EOKB>

Outcome: The authors of three internationally leading diagnostic methods (ADI-R, DISCO, 3di) created the first opportunity for professionals and public to discuss these methods in an open access forum. It led to raising awareness and understanding of different autism diagnostic techniques and their use. The questions and answers posed for the event have had over 1,000 reads on the RPP hub, with over 3,500 reads on the resources linked to the event.

Employment Hot Topic: <http://bit.ly/1jVa3Du>

Outcome: Many new contacts were made between researchers at universities and non-academic professionals. New reports, information and contact details were extensively shared across communities. One specific outcome was a survey designed for the hub by researcher Dr Lopez, University of Portsmouth that led to key recommendations to local authorities who are basing their proposals on its outcomes and also to three funding bids. 8,800 reads/views.

The Policy Conversation: <http://bit.ly/1rAOo68>

Outcome: This event created the first opportunity for ASD Policy Leads from Wales, Scotland, England and NI, to meet together in a public forum. It directly led to a follow-up meeting in Scotland and a new government-driven exchange on the planned implementation of a particular service model. 4,330 reads/views

Regular Autism RPP Hub features

- (1) *News:* Over 250 news items have been published so far
- (2) *Articles and Resources:* Currently there are 190 articles available.

3. Outcomes since end of grant and plans for further work

Professor Leekam has presented the work of the Autism RPP hub in oral presentations at 5 professional and policy events since March (CEREBRA, Birmingham; Research Autism event, Cardiff; Action on Autism Seminar, Strathclyde; Research Updates Cardiff; Learning Disability and Autism Network, Cardiff. The survey findings have been presented at the *International Meeting for Research on Autism*, Atlanta, May 2014. A peer-reviewed paper on the survey is ready to submit to *Autism: International Journal for Research and Practice*.

Plans: The Autism RPP hub has been unfunded since April 2014. The WG has been unable to consider match fund applications until later this year while preparation of the refreshed ASD Strategic Action Plan is underway. Two unsuccessful single-source grant applications have been made to extend and continue the Autism RPP Hub, (one ESRC responsive mode, one NISCHR). Meetings are being held this month with colleagues at La Trobe University, NISCHR National Mental Health Research Centre and ESRC WISERD Centre, Cardiff University, who have an interest in the model.

2. Exploitation Routes (circa 250 words)

Please describe the process and activities through which you plan to ensure that your findings obtain the maximum potential impact. This can include both scientific impact and economic and societal impact.

Media releases, twitter, Youtube videos, blogs and websites have helped maximise both societal and scientific impact (520 twitter followers, 1100 tweets)

RPP Hub on video at Olga Tennison Autism Research Centre (OTARC), La Trobe University, Australia <http://bit.ly/1rKfhCg>

Autism RPP Hub featured on ASD Mental Health, Government of Canada project, York University, Canada. <http://bit.ly/WCuvi9>

ESRC Features: New hub connecting autism research practice and policy, June 2013 <http://bit.ly/1rsDXQz>

International and national conference presentations have increased scientific impact and impact on social services professionals

Ramsden, C., Roberts, A., Uljarević, U., Carrington, S., White, L., Morgan, L., Wimpory, & Leekam, S., *Closing the gap between research, policy and practice*. Poster presented at the International Meeting for Research in Autism, Atlanta, USA May, 2014.

White, L., Carrington, S., Winn, B., Ramsden, C., Morgan, H., & Leekam, S.R. *Integrating research, policy and practice in ASD*. Poster presented at the International Meeting for Research in Autism, San Sebastian, Spain, May, 2013.

Ramsden, C. *Linking Autism research to better policy decision making and practice*. Oral presentation and plenary at Welsh National Social Services Conference. Llandudno. June 27th, 2013.

A scientific journal article “*Sharing knowledge of autism: how do we do it?*” is to be submitted to *Autism: International Journal for Research and Practice* and will increase scientific impact when published.

Schools and universities are increasing impact: (1) Students at University of Bath completed a coursework exercise supervised by Dr Mark Brosnan using the RPP hub; (2) A teacher at Ashgrove School is an Autism RPP hub champion and leads new parents on a mini-tour of the RPP hub to highlight relevant information when they begin a training programme at the school.

3. Potential use in a non-academic context (circa 250 words)

Please outline any anticipated or potential economic or societal impacts that you believe your project might have in future on the 'user' community.

Potential economic and social benefits may be indirect but are indicated by several examples from the work so far. For **research users**, the Autism RPP Hub has enabled contact with specific people within practice and policy settings who they would not otherwise be able to reach (see Project Evaluation report on website for details). For example, the results of an RPP hub survey by academic researchers at Portsmouth University, led to recommendations being taken up by the local authority to develop services for people with autism, while researchers in Australia used the hub to share findings with a global practitioner audience. There is potential for further opportunities for communication on a UK-wide and international level. A clear future potential exists for developing new research-practice networks that can consolidate resources, save duplication and focus on areas concern to accelerate social and economic benefits for practice and policy. For **policy and practice users**, we now have examples of the RPP hub providing a catalyst for debates on effective service models (The Policy Conversation) and evidence based practice (Diagnostic Methods). There is potential to increase societal and economic benefit by promoting more efficient, research based service models through the hub and ensuring that families and individuals with autism form an active user group. **Outside of the UK** there is the potential for societal and economic impact with linguistic and cultural translation for user communities from low and middle income countries. Charities and centers setting up new services for autism (for example, Latvian Autism Association, Special Education Centre, Palestine Ahliya University) have been using resources from the RPP Hub to guide them (see Project Evaluation report for details).

4. URL

If your project has its own website/web page, please enter the URL here.

Autism Research Policy Practice Hub

<http://www.autismrpphub.org/>

Reports of output can also be found at <http://sites.cardiff.ac.uk/warc/about-us/>

(under Our Progress/ Reports)

5. Sector Coding

Please select the sector(s) from the list that best indicates where the findings of your grant will potentially be of most relevance to (*delete those not applicable*):

Communities

Education

Healthcare

Information and Communication Technologies

Following completion of your report please:

- email your completed report to reportsofficer@esrc.ac.uk ensuring you have adhered to the word count and completed each box as fully as possible.
- ensure you have offered any data arising to the UK Data Service <http://www.esrc.ac.uk/funding-and-guidance/grant-holders/datasets.aspx>
- retain records of any activity, outputs and impacts as these details can be added to the new output system which will replace the Research Outcomes System (ROS) from September 2014.