

## ESRC End of Award Report

For awards ending on or after 1 November 2009

This End of Award Report should be completed and submitted using the **grant reference** as the email subject, to [reportsofficer@esrc.ac.uk](mailto:reportsofficer@esrc.ac.uk) on or before the due date.

The final instalment of the grant will not be paid until an End of Award Report is completed in full and accepted by ESRC.

Grant holders whose End of Award Report is overdue or incomplete will not be eligible for further ESRC funding until the Report is accepted. We reserve the right to recover a sum of the expenditure incurred on the grant if the End of Award Report is overdue. (Please see the ESRC Research Funding Guide for details.)

Please refer to the Guidance notes when completing this End of Award Report.

<b>Grant Reference</b>	RES-189-25-0275		
<b>Grant Title</b>	Integrating research and practice in autism spectrum disorders		
<b>Grant Start Date</b>	04-07-2011	<b>Total Amount Expended:</b>	£122,853.58
<b>Grant End Date</b>	11-09-2012		
<b>Grant holding Institution</b>	Cardiff University		
<b>Grant Holder</b>	Prof Susan Leekam		
<b>Grant Holder's Contact Details</b>	<b>Address</b>	<b>Email</b>	
	School of Psychology	LeekamSR@cardiff.ac.uk	
		<b>Telephone</b>	
<b>Co-Investigators (as per project application):</b>		<b>Institution</b>	
Dr Sarah Carrington		Cardiff University	

### 1. Non-technical summary

Please provide below a project summary written in non-technical language. The summary may be used by us to publicise your work and should explain the aims and findings of the project. *[Max 250 words]*

Autism spectrum disorders (ASD) are diagnosed when a child or adult has impairments in social interaction, communication and imagination accompanied by a narrow, repetitive pattern of activities and interests. This project was directed towards increasing understanding of scientific research in ASD in non-academic communities. It had three main objectives: (1) to promote knowledge sharing between researchers and practitioners through the

development of a new web-based discussion forum (Project partner- the charity Autism Cymru). (2) to increase research awareness about interventions in practitioners and families through the provision of research-aware leaflets, a research toolkit and workshops (Project partners – charities National Autistic Society and Waterloo Foundation) and (3) to bring the research ‘laboratory’ closer to people's lives, through engagement activities and communication packages. The project directly led to increases in awareness of research and its benefits by families of children with ASD. It also led to increases in the number of professionals who were trained on interventions for ASD and to the award of two directly linked new grants (total value £270,000). This new knowledge exchange work will bring further impacts of enhanced communication with non-academic communities and increased collaboration with charity partners.

## 2. Project overview

### a) Objectives

Please state the aims and objectives of your project as outlined in your proposal to us. *[Max 200 words]*

#### Objectives

(1) to provide new knowledge sharing opportunities for practitioners and researchers in ASD through the development of a new web-based discussion forum for sharing expert knowledge

(2) to increase research awareness in the non-academic community, especially in the areas of intervention and neuroimaging, through the provision of research-aware booklets information booklets, a research toolkit and workshops on intervention

(3). to engage users of future research in consultation and participation, through the provision of engagement activities and improved communication.

### b) Project Changes

Please describe any changes made to the original aims and objectives, and confirm that these were agreed with us. Please also detail any changes to the grant holder's institutional affiliation, project staffing or funding. *[Max 200 words]*

The start date of the grant is shown as 4/7/12 but initial activities began in June 2011 when Professor Rogers began her funded visit as part of the grant.

During the course of the grant, the full-time project manager post was revised to 0.8 and then 0.5 resulting in a three-month extension to the project, which was agreed with the ESRC. Our timetable of work was adjusted accordingly.

## c) Methodology

Please describe the methodology that you employed in the project. Please also note any ethical issues that arose during the course of the work, the effects of this and any action taken. [Max 500 words]

### **Knowledge engagement activities**

Each objective has been met by a different set of knowledge exchange activities

#### Objective 1: Sharing expert knowledge

- *Facilitated discussion*

A small-scale mini-forum was held online with practitioners (Sept 19<sup>th</sup> 2011) enabling first stage evaluation data to be collected to guide the development of a more extensive forum.

- *Web-based discussion forum for practitioners and researchers*

The final AWARES-Talk online forum created a platform to host introductions and discussions between researchers and clinicians. The original proposal plan was to make the forum space available for one month only for a discussion on diagnosis. However, at least 4 topics emerged and developed, and discussion was extended to run between February and June 2012.

#### 2. Objective 2: Increasing research awareness

- *Awareness raising workshops on early intervention:*

Three invited workshops on evidence-based intervention and a keynote lecture were delivered during the international visit by researcher, Prof. Sally Rogers, (MIND Institute, UC Davies, USA). The audience at each venue was predominantly from the practitioner community. At the early intervention workshop in North Wales, presentations were also given by Prof. Green (University of Manchester) and his team (authors of the Preschool Autism Communication Trial; PACT) and by co-organizer, Dr Dawn Wimpory (Music Interaction Therapy; MIT) from Bangor University, and Prof. Leekam.

- *ASD Research Toolkit for evidence evaluation*

A research toolkit was developed in consultation with collaborators at the National Autistic Society (NAS) and The Waterloo Foundation. The toolkit is a resource for non-academics to help them appraise the scientific content of interventions. The toolkit provides an introduction to key technical concepts and explains the reason for particular research procedures.

- *ASD Research Aware booklet*

A booklet was prepared, aimed at helping parents in the task of selecting an intervention for their child with ASD. The goal was to raise awareness of the importance of evidence-based practice, and to communicate why it is important to take account of research. The booklet does not endorse specific interventions but equips to evaluate interventions that are offered. This is done by providing a set of key questions to ask and simple principles to follow.

### 3. Objective 3: Engaging users of future research

- *Family engagement activities: “Researchers on the Road” tour*

A set of “Researcher on the road” meetings with the leaders of parent groups served to provide reciprocal channels of communication on issues important to both parents and researchers. During the meetings some common misconceptions about research were explained and simple research demonstrations were provided.

- *Communication and familiarisation activities: DVD and booklet*

A DVD filmed through the eyes of a person with ASD and a booklet on brain imaging provided a detailed and comprehensible explanation of what to expect when taking part in a brain imaging study with the Wales Autism Research Centre.

#### Dissemination

Two large dissemination events were held (Sept 2011 and Sept 2102) in partnership with NAS’s Cardiff and Vale Parent Group.

There were no ethical issues in this knowledge exchange project.

### **d) Project Findings**

Please summarise the findings of the project, referring where appropriate to outputs recorded on the ESRC website. Any future research plans should also be identified. [Max 500 words]

#### Project Evaluation

Comprehensive evaluation of all outcomes and impact of the project is provided in the **Summative Evaluation Report**. (See: *Research Outcomes System: Consultant Report*).

#### Objective 1

- 171 individuals registered with the AWARES-talk forum, including individuals from UK, Japan, Sweden, and USA. The majority were non-academic clinical or educational professionals who discussed topics including diagnosis, interventions, anxiety and sensory issues, and multi-disciplinary working. The forum was used to coordinate discussion in advance of two international meetings. Qualitative and quantitative evaluation data revealed difficulties in site navigation and greater suitability for more focused discussion topics with clear incentives. The site can still be accessed to view archived discussion <http://awares.org/talk/> (See: *Research Outcomes System: Network*).

#### Objective 2

##### *Early intervention in ASD workshops*

- 400 practitioners and parents attended the keynote lecture given Professor Sally Rogers and more than 100 practitioners attended the workshops. One workshop was expanded to include researchers who lead two UK-based interventions (PACT; Prof. Green and MIT; Dr Wimpory) in addition to Prof Rogers who presented the USA-based intervention -

Early Start Denver Model; Prof. Rogers. (See: *Research Outcomes System: Dissemination/Workshop*).

#### *Research Toolkit:*

- This resource was written by Dr White and Prof. Leekam with collaborators Sarah May (Waterloo Foundation) and Gina Gomez (NAS) as a 10,000 word book and has been submitted for publication to Jessica Kingsley Publishers (submitted 26 Oct) (See: *Research Outcomes System: Manual*).

#### *Research Aware Booklet*

- This booklet was written with guidance from parents and professionals and can be accessed at <https://docs.google.com/file/d/0B3hbI0G072udZUpNYzBzWVNqUWM/edit?pli=1>. 780 Leaflets were distributed. Evaluation data collected in a small scale survey showed that 81% found the booklet useful and the majority (up to 75%) said they would be more likely to ask about research evidence for an intervention after reading the leaflet. (See: *Research Outcomes System: Booklet*).

#### Objective 3

##### *Researchers on the Road' meetings*

- Five meetings were held across Wales with 25 parent group leaders, representing approximately 100 members. Qualitative evaluation data showed two themes: 1) parents wanted more communication from researchers in non-academic language; 2) the need for more communication about research study outcomes. Details of how these themes have been addressed are provided below. (See: *Research Outcomes System: Newspaper*)

##### *Brain imaging DVD and booklet.*

- A DVD was produced to introduce neuroimaging techniques to families. It is now on Youtube (<http://www.youtube.com/watch?v=kTNjsN3DwE4&feature=context-gau> and <http://www.youtube.com/watch?v=WDCjxvAvETQ&feature=g-upl>) and has been viewed by 169. The accompanying booklet has been distributed to 780 and an electronic version is available (<http://psych.cf.ac.uk/warc/docs/warc%20booklet%20cubic2.pdf>). In a small user sample, positive responses were received. Evaluation data showed that watching the video and reading the booklet, changed views in the majority of cases in terms of both increased understanding about the role of neuroimaging and increased interest in potential participation. (See: *Research Outcomes System: DVD, Booklet*).

#### Dissemination Events

- Events held in both 2011 and 2012 attracted 120 people in each year. A short video about the event in September 2012 is available (<http://www.youtube.com/watch?v=RhLgqSfOKLo&feature=youtu.be>). From evaluation questions provided at each event, the numbers participating in research across the year had increased 10%,. A newly produced Newsletter will increase communication with families and will respond to parents' requests for more research information. See *Research Outcomes System: Dissemination, Newsletter*)

### e) Contributions to wider ESRC initiatives (eg Research Programmes or Networks)

If your project was part of a wider ESRC initiative, please describe your contributions to the initiative's objectives and activities and note any effect on your project resulting from participation. [Max. 200 words]

Not part of a wider ESRC programme or network

## 3. Early and anticipated impacts

### a) Summary of Impacts to date

Please summarise any impacts of the project to date, referring where appropriate to associated outputs recorded on the Research Outcomes System (ROS). This should include both scientific impacts (relevant to the academic community) and economic and societal impacts (relevant to broader society). The impact can be relevant to any organisation, community or individual. [Max. 400 words]

#### Objective 1:

- Professional development opportunities were created by meeting researchers online, learning about international research projects and gaining access to written resources stored within the online forum.
- A direct early impact of this work was that the project team applied for and were awarded a new ESRC knowledge exchange grant, "Developing a research-policy-practice Hub (£200,000). This work has been supported by Welsh Government in matched funding. The new grant capitalises directly on the original project. It builds on the team's experience of useability challenges in online contexts and focuses on working across both practitioner and policy communities. The project also consolidates collaborations with charities and with Bangor University and involves policy consultant placement visits at Cardiff University. (See: *Research Outcomes System: Grants*)

#### Objective 2:

- Collaborations were strengthened with two charities (Waterloo Foundation and NAS) who consulted on the Research Toolkit. Practitioners attending workshops were able to learn about state-of-the art research literature.
- Parents benefited from reading our Research Aware booklet (as indicated in evaluation data – see Evaluation Report)
- As a direct impact of learning about early interventions at the Early Intervention workshop in Bangor (June 2011), 23 clinicians obtained new early intervention training. The training was sponsored by the Welsh Government's ASD Strategic Action Plan. This early intervention initiative led to 28 new children and parents obtaining intervention. This intervention programme is now undergoing pilot evaluation at Bangor University.

#### Objective 3:

- Parent group leaders and families benefited from participating in family engagement activities, helping to further their understanding of scientific research (as indicated in evaluation data – see Evaluation Report).
- Feedback from parents about our website during the Researchers on the Road sessions directly led to a small Community Engagement Grant from Cardiff University (£750,

Sept 2012) for the development of a user-friendly family page on our website. The new page has been prepared and will be launched end of Dec 2012). The themes emerging from this objective also resulted in a publication by Dr Louise White and casual researcher Matt Price of a letter entitled “Engaging members of a community in research” in *The Psychologist*, a monthly magazine for professionals.  
(See: *Research Outcomes System: Grants, Newspaper*)

## b) Anticipated/Potential Future Impacts

Please outline any anticipated or potential impacts (scientific or economic and societal) that you believe your project might have in future. [Max. 200 words]

- In the coming year, impacts should reflect a greater awareness of evidence-based diagnostic tools and interventions for ASD and the evidence to support them. This can be monitored for both families and for those in professional communities (e.g. charity, NHS and local authority). Among researchers, we would expect to see greater awareness of non-academic agendas that guide practice and policy in ASD and developments towards research that will make a difference for families. Within our own lab, we would aim to see the impact of our communication activities in terms of increased participation in our research studies, increased attendance by families at WARC events and positive feedback of the experience of engaging in research.
- In the longer term we would be expecting further consolidation and embedding of the impacts above, including (i) more extensive use of research evidence and research methodology in the evaluation of diagnostic tools and intervention programmes, (ii) a greater cultural willingness to incorporate research into practice, so that practitioners and researchers are working together in services for children and/or adults that incorporate research assessments and evidence.

You will be asked to complete an ESRC Impact Report 12 months after the end date of your award. The Impact Report will ask for details of any impacts that have arisen since the completion of the End of Award Report.

## 4. Declarations

Please ensure that sections A, B and C below are completed and signed by the appropriate individuals. The End of Award Report will not be accepted unless all sections are signed. Please note hard copies are **not** required; electronic signatures are accepted and should be used.

**A: To be completed by Grant Holder**

Please read the following statements. Tick **one** statement under ii) and iii), then sign with an electronic signature at the end of the section (this should be an image of your actual signature).

**i) The Project**


This Report is an accurate overview of the project, its findings and impacts. All co-investigators named in the proposal to ESRC or appointed subsequently have seen and approved the Report.	<input checked="" type="checkbox"/>
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**ii) Submissions to the Research Outcomes System (ROS)**

Output and impact information has been submitted to the Research Outcomes System. Details of any future outputs and impacts will be submitted as soon as they become available.	<input checked="" type="checkbox"/>
<b>or</b> This grant has not yet produced any outputs or impacts. Details of any future outputs and impacts will be submitted to the Research Outcomes System as soon as they become available.	

**iii) Submission of Data**

Data arising from this grant have been offered for deposit with the UK Data Service.	<input type="checkbox"/>
<b>or</b> Data that were anticipated in the grant proposal have not been produced and the UK Data Service has been notified.	<input type="checkbox"/>
<b>or</b> No datasets were proposed or produced from this grant.	<input checked="" type="checkbox"/>

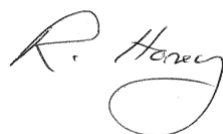
<b>Signature:</b> 
<b>Name:</b> Susan Leekam <b>Date:</b> 07/12/2012



**B: To be completed by Head of Department, School or Faculty**

Please read the statement below then sign with an electronic signature to confirm your agreement.

This Report is an accurate overview of the project, its findings and impacts.



**Signature:**

**Name: Robert C Honey**

**Position: Acting Head**

**Date: 7/12/2012**

**C: To be completed by Finance Officer of Grant-Holding Research Organisation**

Please read the statement below then sign with an electronic signature to confirm your agreement.

ESRC funds have been used in accordance with the ESRC Research Funding Guide. All co-investigators named in the proposal to ESRC or appointed subsequently have seen and approved the Report.

**Signature:**



**Name: Mrs Mina Veillard**

**Position: Research Grants Officer, Post Awards**

**Date: 7/12/12**