

# Developing a *Research Policy and Practice Hub* for Autism Spectrum Disorder:

Evaluation of outcomes and impacts Jan 2013 - July 2014



*Dr. Christopher Ramsden*

## **Project Team**

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## **Section 1: Background**

The project was funded by an award from the ESRC Knowledge Exchange Opportunities scheme, (second call 2011). A primary objective of this scheme was to maximise the impact of social scientific research outside of the field of academia and to promote knowledge exchange, collaboration and engagement activities<sup>1</sup>. The work was match funded by the Welsh Government and ESRC (Ref; ES/J02080X/1) and the grant period was between December 2012 and 31st March, 2014 (24th April, 2014; ESRC).

### 1.2 Overall Research Project Aims and Objectives

The project followed on from a previous ESRC award by the same team: 'Integrating Research and Practice in ASD'. The new objective for the one year knowledge exchange project was to create the first stage of an online Autism Research, Policy, Practice Hub and to provide a mechanism for dialogue between different communities of research, policy and practice, that would create the conditions for the translation and exchange of research knowledge and practice. The project created and launched the Autism Research Policy Practice Hub ([www.autismrpphub.org](http://www.autismrpphub.org)), a coordinated online and offline platform for the collaborative production of knowledge in these three communities. Although the work within this current project has been directed specifically towards research, policy and practice communities. The site is open access and available for everyone to use. A primary goal is to directly and indirectly reach individuals and families affected by autism spectrum disorder.

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<sup>1</sup> <http://www.esrc.ac.uk/collaboration/knowledge-exchange/opportunities/>

### 1.3 Project Management and Performance to Plan

Analysis of project management monitoring data indicates that the project was successful in meeting all of the planned targets for the delivery of activities and outputs across the project lifecycle and main objectives (see original ESRC project grant, ref; ES/J02080X/1 for work-package project plan). The current ESRC award ended in April 2014, however the site continues to be used.

### 1.4 Evaluation Aims and Objectives

In accordance with the project aims and objectives, the project evaluation focussed on evaluating the short term outcomes and impacts of the Autism RPP Hub during the currency of the award, up until the end of award report.

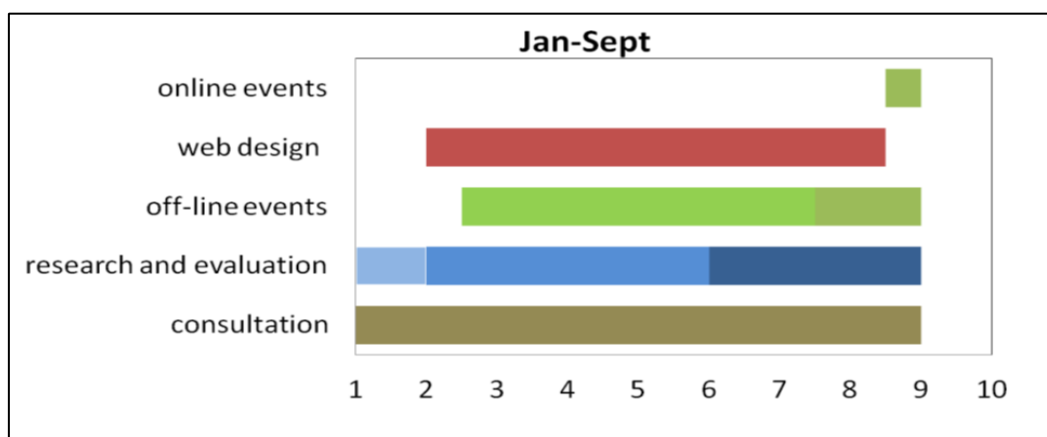
## Section 2: Development Period January 2012 - September 2013

This section outlines the activities during the first stage of the grant, during which time, initial research and consultation was completed and the online web platform the Autism RPP hub was designed and developed.

Main Activities: *Research, Policy and Practice Hub for Autism Spectrum Disorder*

The Autism RPP Hub was launched on Sept 19th by the Deputy Minister for Social Services, Gwenda Thomas, AM. Figure 1 shows the work undertaken across the first nine months of development (January to September 2013).<sup>2</sup>

Figure 1: RPP Hub Development activities over 9 months from Jan 12th to 19<sup>th</sup> Sept 2013



The first nine months of the project involved four main activities; web design (see technical report on p.15), consultation, offline events (see 2.3), research/evaluation (see 2.2). Online events (see section 3) began in October 2013 following the website launch.

<sup>2</sup> This information is also included in the Welsh Government / ESRC matched grant, Autism Hub Progress Report (2014) for this section of the evaluation report.

## 2.1 Consultation

Consultation and stakeholder feedback began in January, 2013. There was an ongoing process of consultation throughout the first 9 months of the project (N.B. Further detailed information, see Appendix 1; p. 15: Autism RPP Website Design and Technical Development).

Consultation was informed by two-day per month policy consultancies from Mr Hugh Morgan, Autism Cymru and Mr Jonathan Morgan, Insight Wales. Further, individual consultation was held with practitioners, researchers and people living with ASD, meetings with National Autistic Society, Research Autism, Welsh Government, Autism Employment Ambassador for Wales, Cardiff University Community Engagement Officer and Research Autism representatives.

Further details of the policy consultancy activity are given on p. 9. As a consequence of the initial consultation work across all stakeholder groups in practice, policy and research, hands-on user trials were also conducted during this period in order to assess the needs and requirements of the stakeholders and the feasibility of the Autism RPP Hub. During this early period the project also engaged up to 16 champions and ambassadors for the Hub, in order to engage users and seed discussions.

## 2.2 Research and Evaluation

Research and formative evaluation began in January 2013 and continued to September 19th, 2013.

(i) *Literature Search/Review and Initial User Trials*: Initially an online comparative analysis of autism and health related websites was undertaken prior to considering the design plans for the Hub in order to address best practices and functionalities for design. An *online literature search; stakeholder interviews, user-trial focus groups* were also conducted to identify stakeholders' needs and requirements. Interview responses directly informed web content and design. Part of this work included 8 qualitative interviews with stakeholders and formed a separate project carried out by Aless Roberts (see p. 14). Thematic analysis identified themes that were used in the questions for a large scale survey (see below).

(ii) *Large Scale Survey* (N=683). This survey targeted practitioners (in areas of clinical work, education and social care), policy workers (Government and third sector) and researchers internationally. The survey investigated the level of engagement between each professional community, and methods that individuals currently use and consider beneficial for increasing research knowledge. The results have directly informed the formative design and content of the final online version of the RPP Hub web-based platform. The results of the stakeholder survey were presented in May 2014, at an International Meeting for Research in Autism, Atlanta and are being prepared for submission to *Autism: International Journal for Research and Practice*.

## 2.3 Offline Events

The literature search revealed that face-to-face engagement and 'offline' activities are an integral part of the process for the online initiative. Beginning in mid-February 2013, offline events were a key aspect of the overall strategy for achieving project objectives and

formed part of the communications strategy for the Autism RPP Hub. In the first nine months. The events had both a consultation and marketing and promotion function.

Conference presentations, talks and a dedicated launch event gave opportunities for the team to engage formally and informally with stakeholders. Main presentations:

- Presentation, 'Looking Forward to the RPP Hub', Welsh Government 21/01/2013
- Seminar, Local Government Learning Information Network 13/03/13
- Seminar to Welsh Government Assembly Members and Professor Mark Drakeford, AM. 12/03/13
- Presentation to Bristol Autism Research Group (BARG): Ramsden, C. & White, L.J. Developing a Research- Policy-Practice Hub for Autism Spectrum Disorders - Bristol Autism Research Group (BARG). School of Experimental Psychology, Bristol. 9/4/2013
- White, L., Carrington, S., Winn, B., Ramsden, C., Morgan, H., & Leekam, S.R. Integrating research, policy and practice in ASD. May, 2013. Poster presented at the International Meeting for Research in Autism, San Sebastian, Spain. 02/05/2013
- Presentation to Autism Alliance. London (<http://www.autism-alliance.org.uk>) Leekam, S.R. and Ramsden, C. How can research help policy and practice? Autism Alliance UK. London. 12/06/2013
- Presentation National Conference for the Association of Directors of Social Services (Llandudno): Ramsden, C. Linking Autism research to better policy decision making and practice - Welsh National Social Services Conference. Llandudno. 27/06/2013: June 27th, 2013.
- Leekam, S.R. Presentation to Educational Psychology Trainees Cardiff University. 27/06/2013:
- Team presentations to the Autism RPP Launch in September 19<sup>th</sup> 2013:
- Poster Presentation at International Meeting for Research in Autism (IMFAR), (<http://sites.cardiff.ac.uk/warc/files/2013/02/Closing-the-gap-between-research-policy-and-practice.pdf>) 07/05/2014:

### **Section 3: Operational Period October 2013-End March 2014**

This section outline the activities during the second of stage of the project after the online web platform for the Autism RPP hub became operational

*Integration of Autism RPP Hub with Wales Autism Research Centre (WARC) Wordpress Website, Twitter Feed and Facebook Page*

#### **3.1 Twitter ([https://twitter.com/WARC\\_Cardiff](https://twitter.com/WARC_Cardiff)) Statistics**

The project team employed a twitter feed that was synchronously linked to the main WARC website (which has a Wordpress plugin displaying 'tweets' on its front page) after the RPP Hub was launched and used for announcements relating to both general and specific activities, currently or about to occur on the Hub. The twitter feed was also used to announce key articles and resources that had been seeded onto the RPP Hub. Since inception in 2012, the WARC twitter feed tweeted and retweeted approximately 1100 times up until June 2014. The reach of the feed was extensive, to over 520 followers both international and national, and every tweet that was linked to the RPP hub was retweeted between 1 and 4 times by users. All hub content could be retweeted directly from the RPP Hub using the media sharing functionality on each page of the site.

### 3.1.1. WARC Facebook (<https://www.facebook.com/pages/Wales-Autism-Research-Centre-WARC/103033943068748>)

Specifically, announcements and information concerning updates on events on the Autism RPP Hub on twitter were simultaneously shared and broadcast the main WARC Facebook page, which on July 10th had 651 likes.

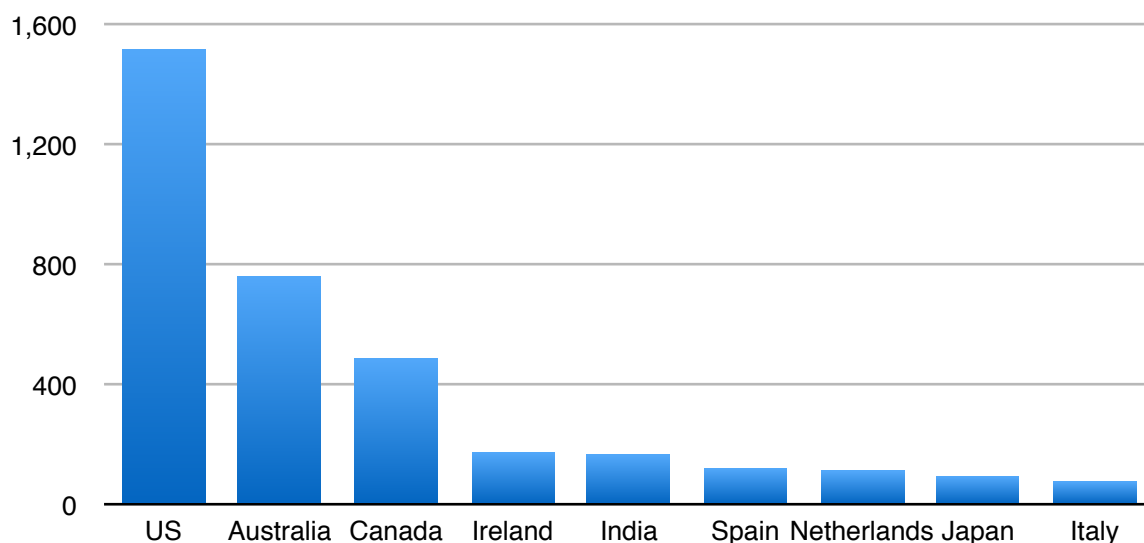
### 3.2 Autism RPP Hub Audience Overview and Website Use Data

Both the main WARC website and the Autism RPP Hub were linked to 'Google Analytics' in order to monitor all traffic through the site. Detailed data gathered from these systems allowed the team to assess the effectiveness of dissemination strategies and the timing for marketing *both* offline and online events. Since the Hub initiative was innovative it is not possible to demonstrate relative or comparative data with similar websites. However, analytics data indicates Autism RPP website has been both extensively and frequently used since its launch on September 19th, 2014. Google Analytics also reported that there have been over 45,000 page views<sup>3</sup> (including repeat viewing) and 10, 885 users (in terms of users who have had at least one engagement with the site and this includes returning users).

Data also indicate that the Hub site had a relatively low overall 'bounce rate' of under 13%. This suggests that the vast majority of users (i.e. 87%) tended to enter via the home page and then transition into the site without immediately leaving. During a single user session an individual user viewed an average of four pages on the RPP site.

Although, users did not have to register to read or download information or resources, users are required to register in order to post comments and discussions. To date there are over 670 actively registered users on the RPP Hub. Google analytics also reveals significant usage spikes both in terms of page views and registered logins during the online seminars and events which were held across several phases between October and February 2014.

■ Graph 1 Showing Total Number of International Sessions Per Country of Origin



<sup>3</sup> Google Analytics data from September 13th to July 10th 2014.

Table 1 Showing the Total Number of User Sessions, New Users and Bounce Rate for Each Country of Origin

<b>RPP Hub User Data</b>			
Country	Sessions	New Users	Bounce Rate
UK	5,986	3,658	15.5700%
US	1,518	1,261	7.5100%
Australia	760	548	11.4500%
Canada	486	383	9.0500%
Ireland	176	132	12.500%
India	164	131	9.1500%
Spain	119	86	15.1300%
Netherlands	114	95	10.5300%
Japan	92	63	16.300%
Italy	81	58	19.7500%
Totals	10,885	7,540	12.800%

There was also increased usage and reach of the RPP Hub across Europe, Asia and Australia across these months attributable to online RPP Hub events. Google analytics data across the site suggests that the Hub contributed to increased access, dissemination and sharing of knowledge and information across the main communities (see Graph 1, previous).

### 3.3 Autism RPP Hub Content Description

#### News

Over 250 news articles have been posted on the Hub since launch. Normally news items were posted daily by a member of the team. In order to facilitate sharing and access across different communities, 'Articles' and 'Resource' items introduced with a summary descriptions: what is this article about? Who should read this document? and Who wrote this document? The items of content were diverse, including links to latest research articles, including diagnosis, theory of mind in autism, employment and updated national guidelines.

#### Articles and Resources

The project broadly distinguished between an *article*: e.g. journal or other peer reviewed materials and a *resource*; e.g. including position papers, government guidelines and links to over 40 autism charities. Populating the Autism RPP Hub with content involved attempting, as much as possible, to ensure that resources and articles were not duplicated from other websites. Over 190 articles and resources were placed on the Hub during the project lifecycle. Articles and resources were read on average on 400 times with certain

key articles read over 2000 times. As well as search functionality the Hub provided a quick select drop down menu which allowed immediate access to articles and resources in the following categories:

- Advisory
- Autism Research Centres and Organisations
- Diagnostic Interview Tools
- Employment Guidelines
- Health and Social Policy
- Lay Summaries and Research Briefings
- Objective Evidence
- Objective Testing
- Other Autism Related Charities and Organisations
- Policy
- Research Articles and Papers

### 3.4 Discussions

Over 100 different discussions have been generated by the team and hub users across research, policy and practice. Group discussions ensued across the main project areas, including diagnosis (11), identification (6) and intervention (25) online conferences, (11) other (42) and social policy (15). Specific discussion topics included government autism strategy, overcoming barriers to employment and online seminars involving guest speakers. A series of international online events were targeted at all communities:

#### 3.4.1. Online Events October-February 2014

- (a) *Diagnostic Interview Methods* Online seminars (three 2-day events October 2013 to February, 2014)
- (b) *Employment Hot Topic* (December 2013 to date)
- (c) *The RPP Hub Policy Conversation* (6<sup>th</sup> November, 2013)
- (d) *Training Event: Autism Diagnostic Observation Schedule (ADOS) Training*

As well as publicising these key events on Twitter, Facebook and the WARC website team employed direct mailing to stakeholders (using multiple lists reaching up to 4000 stakeholders).

3.5 *Diagnostic interview methods*:<http://www.autismrpphub.org/groups/practice/812/diagnostic-methods-online-seminars>

#### Description

In three 2 day seminars, the authors of three internationally leading diagnostic methods gave online seminars. The purpose of these seminars was to help to give more information about these different methods and the research behind them. During October, 2013, January and February 2014, the author of each diagnostic interview tool, David Skuse (3di - Oct), Judith Gould (DISCO - Jan) and Ann LeCouteur (ADI-R - Feb), went online to give answers to questions raised. There was an introduction paper about each diagnostic interview tool to start off the seminar. We also posted a general overview article on the use of interview methods that could be read beforehand. A video was also posted

by the WARC Director, Professor Susan Leekam, which introduced the seminar series: [http://www.youtube.com/watch?v=MCldxe\\_Zxkw](http://www.youtube.com/watch?v=MCldxe_Zxkw).

## Outcome

The online seminars created the first opportunity for professionals and public to discuss these methods in an open access forum. The seminars promoted awareness of the different autism diagnostic techniques and their appropriate use. The questions and answers posed by each conference have had over 1,000 reads on the RPP Hub, and over 3,500 reads on the articles and resource papers associated with the diagnostic tools.

3.6 *Employment Hot Topic*: <http://www.autismrpphub.org/groups/practice/753/hot-topic-overcoming-barriers-employment>

## Description

In December 2013, a discussion was opened on the Autism RPP Hub on employment issues in autism, led by Dr. Beatriz López (University of Portsmouth). A number of people joined the discussion including Robert Lloyd-Griffiths (Wales Autism Employment Ambassador), Dr. Sue Fletcher-Watson (University of Edinburgh), Prof Elizabeth Hill (Goldsmiths College, University of London) and Equalities and Diversity, Cardiff University. People with autism also provided their own experiences. A series of discussions ensued concerning latest research and evaluation on employability programs and postings were contributed by people living with Asperger syndrome and autism, highlighting the psychological challenges faced when living with the condition and attempting to find employment as well as the importance of employer awareness.

## Outcome

A key outcome of the event was to share research findings and evidence across the communities and highlight key areas of priority for further attention. Many new contacts were created for the first time between researchers at universities and non-academic professionals. One specific outcome was a research survey designed for the hub by Dr Beatriz Lopez that led to key recommendations to local authorities who are basing their proposals on the survey's outcomes and also led to three separate funding bids. To date this discussion topic alone has generated over 8,800 reads/views.

3.6 *The Policy Conversation*: <http://www.autismrpphub.org/groups/policy/698/four-uk-lead-policy-officials-autism-big-conversation>

## Summary

On 6th November 2013, the RPP Hub hosted the first online discussion of the lead policy officials from Wales (Alistair Davey), England (Michael Swaffield), Scotland (Annette Pye) and Northern Ireland (Maura Briscoe). The discussion revolved around the developments in legislation, funding and strategies for delivering services for people with Autism. In advance of this event we had asked them to consider the six questions. The event was online for one hour and a number of people joined the discussion. A transcript can be found at: <http://www.autismrpphub.org/articles-resources/r/four-uk-policy-lead-officials-conversation-archive-transcript>. There have been over 4330 reads/views of this content item and its associated online documents.



The external policy consultants Hugh Morgan and Jonathan Morgan also created and delivered the following content which is now available in the Articles and Resources area of the Hub (see below). *Documents provided-* Autism Policy in England, Wales, Scotland and Northern Ireland, Autism Policy Initiatives, UK Policy Tables, UK National Autism Strategies and Policies, Who makes Policy Decisions, “Policy” – A small word with a big impact’, ‘How Research and Researchers can shape policy’, ‘Yes Minister! ‘Who takes decisions in Government and how are they made?’

## Outcome

This event created the first opportunity for ASD policy leads from Wales, Scotland, England and Northern Ireland to meet in a public forum. The RPP Hub discussion directly resulted in a joint visit by officials to Scotland which took place on 16<sup>th</sup> January, 2014. The purpose of the visit was to discuss together a service model that had been successful in Scotland. Government officials representing England, Scotland, and Northern Ireland attended and visited “No 6” the One Stop Shop for autism located in the centre of Edinburgh established in 2007 and the One Stop Shop in Dunfermline, which commenced operation in 2013. Formal presentations were held. The visit was hosted by the Scottish Government together with Autism Initiatives (operator of the No 6 One Stop Shop) and Scottish Autism (operator of the Dunfermline One Stop Shop).

## 3.7 Training Event

### *Autism Diagnostic Observation Schedule (ADOS) Training*

ADOS Refresher Training was held in North Wales in November 2013 and January 2014 and a follow up report was provided on the RPP Hub. The ADOS-2 is a standardised diagnostic observation method that includes revised algorithm items for DSM-5 (2013) and extends the age range to include toddlers (Toddler Module: see <http://www.autismrpphub.org/groups/practice/832/ados-2-and-ados-toddler-module-module-t>). The refresher course incorporated the latest ADOS-2. The need for refresher courses had been highlighted by the fact that the numbers of clinicians trained in standardised diagnostic tools far outweigh the numbers of clinicians using them. This gap between training and clinical use is a broader concern that affects all standardised diagnostic methods and has implications for policy. The introduction and documents for this training event have been viewed 880 times.

## **Section 4: Impacts on Stakeholders**

This section provides a summary of the key outcomes and impacts of the project including the specific work of the policy consultants and site visitors.

As part of the evaluation we also asked selected stakeholders: could you please tell us if the Autism RPP hub has had an impact on your work? Have you been able to reach any audiences that you might not have otherwise have reached or make any new contacts (non-researchers or researchers) as a result? This open question was designed to qualitatively evaluate the experiential learning gains, knowledge transfer, sharing and impact of use of the Hub for different stakeholders.

Stakeholder responses revealed a diverse range of outcomes and impacts internationally, including: assisting in dissemination, further developing connections with

others, increase awareness in target audiences, provide a key resource for student learners, parents and teachers, develop the skills of researchers in communicating and monitor latest research developments and bringing together key representatives of the respective nation states in order to share knowledge concerning novel service models. Furthermore, the RPP Hub has had an international impact, contributing to the design and motivation for the creation of a similar Hub in Australia. Examples are shown below.

### *Researchers*

‘I have certainly made contact with other researchers and students through the hub. Our students and researchers have found your materials invaluable. Some of the web chats have been particularly informative - particularly the policy leads and assessment discussions. I think we were able to disseminate some of our research e.g. ‘The Imagining Autism’ work of the University of Kent, to people who may not otherwise have been aware of it.” *Dr. Jill Bradshaw, Lecturer in Learning Disability and Autism RPP Hub Champion, Tizard Centre, University of Kent.*

‘The RPP Hub has allowed me to reach audiences (or specific people/ organisations within audiences) that I couldn’t otherwise reach, particularly those in occupational health aspects of NHS, companies, government, policy makers. It’s also helped develop connections with academics working on autism and employment related matters, thus helping to develop networks which can pool resource (time, data, ideas) together rather than running small, parallel projects.’ *Professor Elisabeth Hill, Professor of Neuro-developmental Disorders, Goldsmiths College.*

‘The Hub has been invaluable in sharing information about employment (i.e. the report from Ruth Townsley on Welsh government). It enabled me to conduct a large survey on barriers to employment for people with autism. I wrote a report with the results of the survey which has been circulated to local authorities (Portsmouth, Hampshire), National Autistic Society and Autism Employment Alliance. The report made two recommendations regarding employment and two local authorities are going to base their bid to the Innovation Fund (from ‘Think Autism’) in this report so they can develop employment services for people with autism. Also, we are preparing three bids based on this survey, one to Peter Cruddas foundation, one to ESRC and one to Big lottery. An academic publication has also been submitted for publication.’ *Dr. Beatriz Lopez, Senior Lecturer in Psychology, University of Portsmouth.*

### *Policy Makers*

‘I was honoured to be invited to act as a Policy Champion for the Autism RPP Hub and that certainly was useful in encouraging a proactive relationship. This was especially so in view of my appointment to Chair the NI Autism Strategy Research Advisory Committee which operates within the NI Autism Strategy and Action Plan which is required by the Autism Act (NI) 2011. The dissemination of the Hub as a unique (thanks to the fact that it is carefully moderated to protect against unsafe research) and useful research and discussion resource has already started in Northern Ireland.

The series of online discussions was a particularly useful tool to Autism NI. The policy discussion brought together the respective government ASD Policy Leads from Wales, Scotland, England and Northern Ireland for the first time ever. Autism NI had identified this need and had encouraged the need for such dialogue for some time through the Celtic Nations Autism Partnership (CNAP) so this RPP Hub initiative was a very

effective and acceptably independent forum to make it happen. The impact has been significant. During this contact an invitation was extended by the Scottish Executive ASD Policy Lead to facilitate visits in Scotland to a service model much debated and misunderstood in Northern Ireland: the one stop shop. In addition, the follow up networking opportunity that this afforded has ensured an ongoing relationship and information exchange that is government driven rather than voluntary sector motivated.' *Dr. Arlene Cassidy, CEO, Autism Northern Ireland.*

#### *Other Visitors*

'I regularly discuss the Hub and its links between research policy and practice to parents and professionals. I have given the details to all members of staff in Ashgrove School and actively encourage them to read or join in group discussions. I also ensure that the parents I meet on EarlyBird training courses know about the Hub and I access the website to give them a little tour to help them find the most relevant information. People are generally very interested in the HUB and the ethos of linking research, policy and practice.' *Eli Carter, Teacher in Charge, Early Intervention Base, Ashgrove School, Penarth.*

'The Autism RPP hub is a valuable resource for all of our target audiences - parents, social services, teachers, universities etc. The most important parts for us I see articles and papers in these categories: advisory, employment and guidelines.' *Liga Berzina, Head of Latvian Autism Association.*

'As an autism research centre in Australia, with a core aim being the translation of research to practice, the RPP hub has been a great way for the Olga Tennison Autism Research Centre (OTARC) to share our findings and knowledge with a global audience. The RPP hub has enabled us to connect with reserachers and clinicians around the world, and has been the impetus for OTARC to create a hub in Australia.' *Wojciech Nadachowski, Senior Advisor: Operations and Projects at Olga Tennison Research Centre, La Trobe University, Australia.*

#### 4.1 Detailed Description of Policy Activities for the RPP Hub/ Outcomes of the Hub

Initially, the policy consultants<sup>4</sup> commenced by mapping which stakeholders were likely to be involved with policy determination in Wales. These were identified as national politicians in the National Assembly for Wales (x60); their researchers (60); special advisors to Ministers (4); Welsh Government officials in the Health and Social Services (x3) and lobbyists from charitable organisations. The consultants then prepared discussion documents for loading onto the 'hub' which offered a background to the context of policy development for autism in Wales, including how policy was initiated and the influences which shaped policy development. This was key in order to explicitly identify the process by which policy for autism had been and was continuing to be developed in Wales and who was involved in its development.

Engagement with senior policy opinion formers was accomplished by holding an information event within the National Assembly for Wales for Assembly Members, staff and

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<sup>4</sup> Although modified in small detail, this subsection was authored by the project policy consultants.

Welsh Government officials. The event, which took place in Cardiff Bay on 12<sup>th</sup> March 2013, was chaired by the chair of the Health committee, Professor Mark Drakeford AM who, following the event was announced as the new Health and Social Services Minister for Wales. Nine Assembly members attended across the political spectrum with two Welsh Government officials. Therefore 1/6<sup>th</sup> of Welsh Assembly Members comprising the National Assembly for Wales contributed to this 'hub' information event. Presentations were given by members of the RPP hub team in order to inform assembly member of key developments as the online platform emerged. The event was followed by regular email updates to Assembly Members, special advisors and civil servants at Welsh Government, and policy officials in local government. This event was fundamental in terms of engaging and raising the awareness of politicians in Wales to the RPP Hub, by giving an authoritative foundation for the RPP Hub, from within the National Assembly for Wales in Cardiff Bay, thereby strengthening its acceptance, uptake and overall message.

On 26<sup>th</sup> June 2013, a similar strategy was also employed to present a public account of progress made by the RPP Hub to the large annual Social Services conference held in Llandudno, North Wales. The event was targeted not just for its large (300+) number of delegates but because of the range of key opinion formers who would be present which included Ministers, Welsh Language Commissioners, all Directors of Social Services for Wales and their deputies, the heads of regulatory bodies (e.g. the Care and Social Services Inspectorate for Wales), with many voluntary organisations contributing exhibition stands and at fringe events. Further, the north-south spread of the RPP hub message was also enhanced through this conference. The first tactic used was a formal presentation given by Hugh Morgan to the main conference on the 'state of play' of autism policy and practice in Wales. In this talk the 'hub' was highlighted and signposted, therefore the second approach, was where Jonathan Morgan and Christopher Ramsden presented the progress made by the 'hub' including a demonstration. The opportunity for shared learning was apparent and delegates were invited to ask questions and to contribute their thoughts to the on-going development. As a model, it was considered by attendees that this was an approach which could be usefully applied to other areas of disability.

The opportunity to use the RPP Hub to bring together autism policy leads in governments was attractive and set as an early objective. We therefore used the 'hub' to construct the basis for dialogue and exchange of ideas between the four governments of the UK. The difficulty from the outset was that had not been attempted or indeed previously achieved. This particular activity was a pioneering undertaking which required a considerable amount of preparation by all members of the RPP Hub team and closer to the day 'hand-holding' so that the officials felt confident in taking part and that the shared environment was 'safe'.

It should be noted that the employment agenda has featured in posts on the 'hub' with several mentions of the need to encourage employers/business to become more open to employ people with autism. One direct consequence of the Nov 6<sup>th</sup> 2013 on-line seminar was the invitation by afforded by the Northern Ireland Government to the Wales Autism Employment Ambassador, Robert Lloyd Griffiths, to speak to a breakfast meeting hosted by the NI Minister for Employment on January 26, 2014 in *Stormont*. This was followed with a debate on autism and employment in NI Assembly held on 10th April, promoted by the NI Assembly's All-Party Group on Autism. In Wales a project funded by the department for the Economy, Science and Transport in Wales has been given the go-ahead to commence in June 2014, whereby Autism Initiatives alongside Autism Cymru and

Admiral Insurance are to pilot the anchor companies autism employment programme, designed to raise the profile and employment opportunities for people with autism throughout the 45 leading 'anchor' companies in Wales. The RPP hub played a significant role in bringing policy makers in UK governments together, for the sharing of knowledge and experiences, and for practice to be influenced as a consequence.

The official launch of the RPP Hub in September 2013 in Cardiff University brought stakeholders together from the research, policy and practice communities and gave a networking opportunity to people from different perspectives. From a policy perspective, the Welsh Government's Deputy Minister for Social Services, Gwenda Thomas AM, launched the hub and reinforced the link between policy development, good practice and academic research. The launch was also an opportunity to link with colleagues from the Celtic Nations Autism Partnership who attended from Scotland and Northern Ireland to share best practice. Once the hub had been launched the Deputy Minister also contributed an article setting out the achievements of the ASD strategic action plan and priorities for the future.

## Section 5: Other Outcomes

In this section, a number of other unexpected and unplanned outcomes<sup>5</sup> are recorded. These included video features, press releases and inclusion of the Hub in a degree curriculum and coursework module.

- A demonstration of the RPP Hub has been given in a recent video episode of 'Inside the Lab' at Olga Tennison Autism Research Centre (OTARC), La Trobe University, Australia <https://www.youtube.com/watch?v=BU6JuPo0zfA&list=PLiyKW2t9WyX4BLRAf6-dwu3NWj9YS-EXS&index=1>
- Autism RPP Hub featured on ASD Mental Health, Government of Canada project, York University, Canada. <http://asdmentalhealth.blog.yorku.ca/2013/10/autism-research-policy-practice-hub/>
- ESRC Features: New hub connecting autism research practice and policy, June 2013. <http://www.esrc.ac.uk/news-and-events/features-casestudies/features/26624/new-hub-connecting-autism-research-practice-and-policy.aspx>
- Press release: Launch of the Autism RPP Hub <http://www.cardiff.ac.uk/news/articles/autism-hub-launches-11776.html>, Sept 2013
- A University summer bursary award to an undergraduate student, Aless Roberts enabled an additional independent project that was related to the aims and objectives of the project. The project results contributed to the large-scale online survey (above)
- Autism RPP Hub was included in a grant proposal to the ESRC (2014)
- Autism RPP Hub was also included in a grant proposal to NISCHR, (National Institute for Social Care and Research) June 2013

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<sup>5</sup> This section is quoted directly from the Welsh Government / ESRC matched grant, Autism Hub Progress Report (2014) for this section of the evaluation report.

- The Autism RPP Hub has featured within a university course designed by Dr Mark Brosnan, University of Bath, 3<sup>rd</sup> Year Psychology undergraduates visited the Autism RPP Hub and complete a coursework exercise involving a search for resources and information from the hub.
- A joint dissemination event with Research Autism and Institutes of Psychiatry and Education, London “A Future Made Together” and “Autism RPP Hub” was held on 3<sup>rd</sup> April and will attract members of charity, parent, practitioner and policy communities.
- RPP Hub has been approached to partner on three international initiatives:
  - (1) *Canada* – The Autism RPP hub is a community partner to a global initiative on early identification and intervention: <http://globalearlyautism.com/>.
  - (2) *Australia*: Autism RPP Hub invited to be an advisor to Australia Olga Tennison Autism Research Centre an advisor for ASD KnowledgeHub
  - (3) *UK/Global*: Prof Leekam invited to be part of the International Society for Autism Research (INSAR) initiative to host global open-access research tools (invitation was a direct result of the RPP initiative to deliver free resources on diagnostic tools on the hub for the online seminar series).

## **Section 6: Discussion and Conclusions**

The project has had a range of short term impacts and outcomes. First, as part the development work for “Developing a Research Policy Practice hub”, the project has contributed to developing knowledge capital, collaborative working and identifying lessons learned. Second, the RPP Hub project in the early months of operation has facilitated knowledge sharing and transfer both internally and externally, at a national and international level and has produced direct policy, research and practice outcomes and new potential identified (e.g. training of students and professional). Medium to long range impacts of the RPP Hub will be addressed in future reporting due to be submitted to the ESRC in July 2015.

# Technical Summary

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## Appendix 1: Autism RPP Website Design

The initial phase of specifying the design, architecture and functionality was conducted in February 2013 until the launch in September 2013. This account of the history of the development of the Autism Research, Policy, Practice is aimed at sharing knowledge and understanding about the actual developmental process and collective thinking that was involved in constructing this unique initiative in the field of ASD in the UK. Additionally, in terms of summative evaluation, the outcomes of mapping this process knowledge are three fold:

- *Knowledge Capital and Lessons Learned*: To contribute to and inform the ESRC concerning the actual processes and activities that were undertaken in order to build an online, knowledge transfer and translation platform. It is hoped that this knowledge will be retained and accessible for use by other projects or programmes who face similar challenges in related and even unrelated fields.
- *Sharing and Dissemination*: To facilitate the sharing of knowledge internally in the School of Psychology, Cardiff University, concerning 'what was done, by who, how and when'. Currently, there is significant interest in the initiative by the internal IT projects officer, since there are other members of the department who wish to undertake similar online projects.
- *Knowledge Exchange*: The experience and knowledge on this project have already contributed to the design inputs of an Australian Autism Hub Project. The team have had a number of Skype-based discussions concerning the issues raised in this document with the Director and Senior Projects Officer at the Olga Tennison Research Centre (OTARC), La Trobe University, Melbourne.

Following a documentary review and qualitative interviews with the project stakeholders, the following summary description reflects a selection of the salient activities and processes carried out to build the Autism RPP Hub:

1. Introduction
2. Designing an Interactive, Community-Based Website
3. Information Structure and Knowledge Architecture
4. Types of Knowledge and Content: The Importance of Knowledge Translation for Knowledge Transfer
5. Summary of Main Menu and Information Page Attributes
6. Content Management System: Drupal Open Source
7. Hosting
8. Domain Names
9. Copyright and IPR
10. Confidentiality and Open Access
11. Content Management and User Administration
12. User Registration and Levels of User Privileges
13. Overall 'Look and Feel' of the RPP Hub Website
14. Google Analytics Accounts





## . Introduction

Building an online community and interactive website as part of a research project was a novel and innovative development for The School of Psychology at the University of Cardiff. This inevitably involved overcoming some organisational as well as technical and developmental challenges.

The grant was originally funded to make use of a pre-existing technology platform (<http://www.awares.org/homepage.asp>). However, it was decided that this site would not be appropriate for the Hub, which required a dynamic and scalable website which would function as a repository and as a space for discussion. The design brief was placed out to tender with three commercial organisations in London, Bristol and Cardiff. Proposals were submitted to develop the site with a budget envelope of approximately 15k<sup>6</sup>. The timescale from formally engaging the developer to completion was approximately six and a half months, between March and September 13th, 2013. An extra three months' work in developing the site from the beginning was met by a no-cost extension from ESRC and WG allowing the project to effectively run until the end of March 2014.

## 2. Designing and Building the Autism RPP Hub

The early stage website development work involved constructing a dialogue between the different communities, engaging in face-to-face contact and holding a number of large off-line engagement events. As this was the first research-policy-practice hub of its kind internationally, the design and development work revolved around a cyclical and iterative process of identifying user needs through consultation, hands-on user trials, qualitative interviews and surveys. In order to facilitate the initial design process a comparative analysis of similar sites (mainly those providing information and hosting discussions on or around ASD) on the internet and qualitative interviews were conducted with identified stakeholders. The project manager's twenty years experience in undertaking user-focussed evaluations of multi-stakeholder, knowledge based and internet communications technologies also contributed to the preliminary design specification and mark-up requirements.

A number of considerations were taken into account in the design for the RPP Hub:: (i) usability for a wide range of stakeholders; (ii) capability to host large number of out-links to external resources and articles and to host a repository; (iii) the site would be fully scalable and allow flexible control over the interface. It was decided to 'scratch build' a bespoke site which was completely dedicated to the project aims and objectives: to facilitate knowledge translation and transfer across all three communities.

The architecture, structure and functionality of the hub is extensive. The process of design included two cycles of hands-on user trials<sup>7</sup>. During the course of the project up until launch was also over 120 pages of documentation and correspondence between the

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<sup>6</sup> The proposals submitted by two competing, medium-sized web design companies were considerably over the budget. The team selected an independent designer who was able to work closely with the team and was flexible in meeting requirements. This proved crucial to the iterative design of the Hub and meant that there was a single point of contact for the entire duration of the work.

<sup>7</sup> A comprehensive proforma was developed for use in the user trials sessions which included question coverage of five key areas: 'Look and feel' of the site; usability, information layout and structure, content format and relevance and general questions about the site.

project manager and the commercial developer in order to build and optimise the online knowledge Hub.

### **3. Information Structure and Knowledge Architecture**

The Autism RPP Site is predominantly text-based aside from the main branding logo and colour-ways. A multi-colour 'Venn-Diagram' motif was employed to project the sense of crosstalk, interaction and cross-fertilisation of ideas between different communities of practice. The colour-ways in the site are associated with particular groups throughout to assist in identification of information (e.g. blue with research). All pages on the site repeat the primary top level menu structure: Search, Home, Group Discussions, News, Articles and Resources, FAQs, My Account and Logout. The bottom horizontal banner also repeats across the entire site; cookies accept panel, all sponsor logo's and WARC logo, copyright, how to get the most from this site (a comprehensive guide on how to use the site effectively), contact us, site map, privacy policy, terms and conditions. Clicking on the Autism RPP Hub logo will always transition the user back to the home page.

### **4. Types of Knowledge and Content: The Importance of Knowledge Translation for Knowledge Transfer**

An initial needs and requirements analysis indicated that participants from each community of research, policy and practice were interested in asking a diverse range of questions. particularly concerning access to relevant basic research evidence and findings. The design of our content delivery strategy was strongly guided and framed by these knowledge requirements and will address pertinent questions from each community.. Furthermore *all* content delivery and facilitated discussion will be linked to the main objectives and topics of the project grant: *identification, diagnosis and intervention in autistic spectrum conditions*.

In order to help create the conditions for shared understandings and learning between communities through knowledge transfer the team attended to the appropriate translation of knowledge that is made available to each community. In particular a key conversation was to facilitate the effective translation of basic research evidence into a form of knowledge that can be understood by both policy makers and practitioners.

For conceptual and operational purposes the project distinguished between three basic types of knowledge and information-based content in the RPP Hub:

- (i) Informatic knowledge: this type of content is largely static, 'non-commentable', informatic or factually based. This includes but is not limited to: e.g. top-level content such as FAQs, key articles (journal and otherwise) and resources, glossaries, terms and conditions, privacy information, contact details, endorsements, hyperlink referrals (*back and forward*) position papers and think pieces. Other types of media may also be included in this category e.g. audio and video.
- (ii) User generated content and co-constructed knowledge: this category concerns knowledge that is discursively and dynamically constructed by users online e.g. as a consequence of discussions/comments/posts or media that is uploaded by

end-users for viewing and further comment. Note that this category may also include (iii) below.

- (iii) Facilitated, topic-focussed discussion and knowledge creation: content that is strategically positioned in the architecture of the hub in order to facilitate subsequent specific topic focussed discussion.

#### 4.1. Summary of Main Menu and Information Page Attributes

Home/Front page: <http://www.autismrpplib.org> As the main landing page consideration took considerable design effort and modification before the final layout and look and feel were established. Since this is the landing page it was critical that it set the tone of the site and enabled the end-user to transition immediately to information or participate in discussion. A great deal of consideration was involved in constructing a particular 'look and feel' of the front end design/front page of the hub, in order to encourage cross-participation by users in different discussion areas—not simply contributing on the basis of their preexisting professional membership identities (e.g. policy makers discussing policy related issues with other policy makers.) A summary of the site's mission was given and then users were encouraged to 'participate in any discussion'. Up to the top 5 most recent discussion topics were previewed in three boxes on this page. In the lower half of the page, most recent news items and most recent articles and resources were also box-previewed.

*Group Discussion Pages:* <http://www.autismrpplib.org/groups>: Each discussion page (associated with the groups: research, policy and practice) also has a right hand column which displays the latest group discussions occurring on the site. Toggling this column also allows the end user to examine the *most* commented on discussions. Main group discussions are displayed in a scrollable vertical format with no separation. Comments are contextualised directly (vertically) underneath the main discussion group topics. In all main menu items the user is given the opportunity to 'Start a Group Discussion' immediately.

*News:* <http://www.autismrpplib.org/news>: News items were added on an almost daily basis, in order to keep the site dynamic, up-to-date and of interest to a wide range of stakeholder users.

*Articles and Resources:* <http://www.autismrpplib.org/articles-resources>: A basic digest of the article was given and then the abstract and reference. Material was labelled by icon as either Article or Resource. Where applicable a hyperlink was given to the external article/resource or a PDF was downloadable as source. On the right hand menu bar users could also see what latest articles and resources had been added to the repository as well as latest/most commented group discussions. A *QuickSelect Menu* was added to assist users in the rapid access of articles and resources through a single category/subcategory menu.

*FAQs:* <http://www.autismrpplib.org/faq-page> Frequently asked questions. 12 FAQs were added to the site in order to improve access and assist the end-user in using the site.

*Group Notifications:* in order to facilitate information sharing, participation and live updating of information users were able to subscribe to group notifications which would alert them via email to updates to discussions.

*Social Media Sharing:* All posts, comments, articles and resources had relevant social media buttons associated with their content (i.e. twitter, facebook, google +, email)

*Bookmarking Systems:* items on the site could be stored as book-marked links by registered users in their own personal accounts.

*Main lower banner media links:* Access to the WARC (Wales Autism Research Centre) twitter feed ([https://twitter.com/WARC\\_Cardiff](https://twitter.com/WARC_Cardiff)) and WARC facebook page (<https://www.facebook.com/pages/Wales-Autism-Research-Centre-WARC/103033943068748>) is always available on the lower horizontal banner of the website.

#### 4.2. Content Management System: *Drupal Open Source*

When we originally tendered for the project, Drupal was already being employed by a large commercial company for the development of interactive, community-based websites and we were familiar with its demonstrated capabilities. Although Cardiff University has been employing WordPress as a platform, for the development of some of its internal sites, the team, in negotiation with the developer decided to use Drupal Open Source as a content management and development framework. Drupal is open source and has a massive worldwide community of users and developers. Furthermore, prior to the launch of the website we had no idea of the sheer numbers of potential users and user account registrations we would attract. We considered that the flexibility, scalability, stability and performance of the system, as well as its open source nature would be ideal for the content management framework and back-end of the Autism RPP site (although we also investigated the feasibility of [www.wordpress.com](http://www.wordpress.com) as a platform). Drupal is a core system with thousands of additional modules which can be added to alter and extend its capabilities (see <http://en.wikipedia.org/wiki/Drupal>).

#### 4.3. Hosting

Initially, the site was prototyped and developed by the external developer. Project team members had access to a secure area of the developer's own website ([www.rootsy.co.uk](http://www.rootsy.co.uk)) hosted on a private server. This enabled us to view and interact with a work in progress and discuss future development. However, in the long-term the site needed to be externally hosted since the developer was not an ISP (this is generally the case that a developer will not also be an Internet Service Provider). A number of alternatives were considered but there were considerable concerns over data confidentiality, back-up procedures and security if the site was hosted with a private ISP (e.g. especially if based abroad).

After some negotiation with central IT services at Cardiff University it was decided that a contractual agreement for the site to be hosted on a University Virtual Server would be the most effective and appropriate option; for security, data integrity and confidentiality. In particular, the team considered that this option was best since it allowed us to have direct communications with our host ensuring site maintenance and regular Drupal updating. It should be noted that since the launch of the site the developer has been able to access the site through the university and install regular Drupal updates/administer the site.

The University has a large IT infrastructure and involving the use of appropriate systems and regulations to ensure the security of its online and offline IT systems. We worked with University and departmental IT services to enable a process by which an

external developer ([www.rootsy.co.uk](http://www.rootsy.co.uk)) could access the 'internal server' and undertake administration of the site to a specified level. In particular, this is an important issue which other projects might need to consider. If a commercial ISP is contractually employed, one needs to consider the quality of provision and the level of control one has over that provision. For example, what would happen if the external ISP went out of business? What action can be taken if the site goes down for some reason, who owns the data? In our case we were attracted to the notion that IT services was just a phone call or email away, and that it would be very unlikely, given their data back-up solutions, that a University would go out of business or 'lose' our data.

#### 4.4. Domain Names

To ensure Search Engine Optimisation (SEO) three unique domain names (five years duration) were purchased. The domain names [www.autismrpp.org](http://www.autismrpp.org), [www.autismrpp.co.uk](http://www.autismrpp.co.uk) and [www.autismrpp.com](http://www.autismrpp.com) were all purchased. Currently, the web site resolves to all these addresses.

#### 4.5. Copyright and IPR

Following a discussion with the Cardiff University, a decision was made in the early stages of the design of the Hub that IPR and Copyright issues needed to be carefully attended to in the development and organisation of content. Whilst there are hyperlinks to images, text based articles and resources, movie clips (e.g. youtube) there are also PDF based objects and basic text data (e.g. discussions and comments) stored on the virtual server at Cardiff University. We were mindful only to store only publicly and freely available information on the Hub and not retain copyrighted materials on the Hub itself. Further information on Copyright, Trademark and IPR can be found at: <http://www.autismrpphub.org/content/terms-and-conditions>.

#### 4.6. Confidentiality and Open Access

When undertaking a comparative analysis of other autism and information dissemination based websites, prior to the design of the Hub we decided that the website should be openly accessible to all users. *Any* user arriving at the site can view all the site's content. However, in order to participate in discussions and post comments user must first register on the site. This is a simple process and as long as users have a *bona fidae* email account then they can use any nicknames/names they choose when on the site.

#### 4.7. Content Management and User Administration

Drupal provides the Autism RPP Hub with an extensive 'administration panel', enabling the team to manage all content and to alter the overall structure of content on the website. Only internal team members had user privileges sufficient to enable these changes.

#### 4.8. User Registration and Levels of User Privileges

When a user registers on the site they have a number of privileges, which are designed to control their interaction with the site according to a number of pre-specified rules. Only staff have full access to the administration controls on the control panel. (The developer Rootsy, has 'super-user status' on the site). Users registering on the website are

able to make comments and start a discussion. However, all new contributions go into a moderation queue. Comments are therefore not published immediately but are monitored on a daily basis by the project team and a decision is made to publish the item live on the site (we used a basic set of quality criteria to establish suitability which we also used for the publishing of articles and resources as well as news, including: trustworthiness, authenticity, relevance and appropriateness). A small group of individuals were defined as 'user champions'. This group were given privileges to post content without moderation. Our initial review and research into community based website development indicated that User champions were essential to 'cold start' the process of content uploading onto the hub and seeding the hub with discussions.

#### 4.9. Overall 'Look and Feel' of the RPP Hub website

The project team was fortunate enough to have an employee within the Autism Hub RPP team who was also a parent to a person with autism. Although we considered a range of graphical and colour combinations we decided to make the site as clear as possible and streamlined for purpose. First, as part of the development work for 'Developing the Autism Research, Policy and Practice Hub'. However, we were mindful that end-users may also include people with ASD and their carers (we knew that some professionals were also carers of people with ASD: *the 4th community of the RPP Hub*). Therefore, the use of simple colours and consistency of use of those colours with regards to denoting certain sorts of information and navigation was a conscious design decision which was also explored in the hands-on user trials. The colour ways of the actual website of the RPP logo itself set the standard for designating the information syntax of the site.