Project title: Developing and implementing a framework for evidence-based practice for technology relevant for autism.

Summary: Autism is characterized by persistent and significant deficits in social communication and interaction accompanied by repetitive and restricted behaviours and interests [1]. Autism is estimated to be diagnosed in just over 1% of the population [2]. The number of individuals with autism is estimated at more than 3.5 million in the United States and more than 600,000 in the UK, with a national cost of supporting people with autism of $236 billion per year in the USA and $47.5 billion per year in the UK [3]. Comparable figures for the European Union as a whole are not available, but a 1% rate would equate to over 5 million people with a diagnosis and 20 million people being directly affected when including families and care-givers¹). In line with the preferences expressed, we use the term autistic community to refer to people who have a diagnosis of autism and autism community, to refer to the broader community affected by autism, such as the families/care-givers [4].

People of all ages within the autistic community can have an affinity for using digital technologies and these can be beneficial in delivering educational and therapeutic content [5,6]. There has been an exponential proliferation in the availability of digital technologies to support the autistic community, with no mechanism by which they, or their care-givers, can easily use evidence to gauge whether such technologies are beneficial, or indeed to assess possible harm. Research shows that digital technologies are used by autistic children around 2-3 hours per day outside of school-time but there are concerns among care-givers about the suitability of these technologies [7,8]. Likewise, practitioners find it difficult to choose the most appropriate piece of technology to support their work. Evidence-based practice (EBP) is central to medical disciplines (see [9]) and has been extended to psycho-behavioural interventions for autism [10]. Digital technologies are relatively new and urgently require their own EBP framework to enable application of the supporting evidence in an accessible manner. With the autistic community, we will co-develop an accessible EBP framework to enable an understanding of the evidence base for digital interventions. To enable the autistic and autism communities to effectively contribute to the co-design of the EBP framework, novel protocols will be developed for online participatory design (using Twitter, Facebook, Skype, Vizzata.com). We will make recommendations for how digital technologies can facilitate inclusion and promote respect for autistic people.

Keywords: Autistic community; Digital technology; Evidence-based practice (EBP).

Type of Disability: Autism

Geographical area of research: UK, France (with Spain and USA)

Project Leads: Dr. Ouriel Grynszpan, Associate Professor, Institut des Systèmes Intelligents et de Robotique (ISIR), Pierre et Marie Curie University, France. Dr. Mark Brosnan, Department of Psychology, University of Bath, Bath, BA2 7AY. UK.

Partners: Dr. Matthew Goodwin; Dr. Sue Fletcher-Watson; Dr. Gerardo Hererra; Patricia Pérez-Fuster; Richard Mills.

¹ See http://www.autism.org.uk/about.aspx
2/ Overall Objective of the project (one page)

Existing models of evidence based practice are not adequate to address the EBP needs of the autistic and autism communities [10]. There are problems with measuring outcomes for an intervention - life satisfaction may be meaningful to the community, but is more difficult to assess than short-term goals that are proximal to the intervention focus. The heterogeneous nature of autism also requires a more personalised methodology. Flexibility is therefore essential, and entails deviation from standard evaluation methods in classical EBP, such as Randomised Control Trial (RCT) methodologies. Mesibov and Shea’s review [10] focuses on educational interventions, but the challenges are intensified when considering the use of digital technologies to deliver benefit. For example, digital technologies offer immense potential to personalise and individualise interventions, in which circumstance a case study approach can be more appropriate than a RCT for evidencing effectiveness of the intervention. Moreover, the rapid rate of development of technologies prevents careful evaluation in RCTs due to a mismatch between the timelines of commercial and academic progress [11]. Nevertheless, it is unacceptable that digital interventions have proliferated for autism with no evidence that they are beneficial. A framework within which EBP can be better defined, specific to digital technologies for autism will not only be beneficial for the autistic community and their care-givers but also for the research community, practitioners and software developers. The EBP framework will provide an explicit structure by which the impact of evidence can be compared and contrasted, as well as setting a roadmap for how the collection of future evidence can be enhanced in the context of rapid technological progress. The majority of digital technologies developed specifically for people with autism are marketed as interventions with the hope of beneficial effects, however there is little or no evidence that this is the case. The next section maps how the project relates to the UN Charter of Rights of People with Disabilities, centering on the harm caused by wasting resources (time, money) on interventions which do not deliver benefit. Understanding the evidence supporting digital technologies will empower the autistic and autism communities to make informed choices and maximise the potential benefits of using digital technologies. The aims of this proposal are: 1) to work with the autistic and autism communities, software developers and researchers to develop an EBP framework for digital-based interventions for the autistic and autism communities; 2) to apply this framework to the technologies listed on popular web sites, specifically the DART website in the UK and the Autism Speaks (USA) and Appy autism (Spain) websites [DART is run by a team member and we have letters of support from Autism Speaks and Appy Autism]; and 3) to develop EBP guidelines for research, software development and an online tutorial for end-users on how to create and evaluate evidence for digital-based interventions for autism. The EBP framework will enable software developers to develop digital technologies that are better informed by the needs of the autistic and autism communities. Our objective is to co-develop the EBP framework with the autistic and autism communities based on participatory design protocols that embrace online communication (social media,
video-conferencing, Vizzata.com) to maximize the inclusion of the autistic and autism communities.

3/ Originality and innovative nature of the project (one and a half pages)

Our participative approach is both original and innovative in its inclusiveness and in addressing a novel area. The current situation can be characterized as one in which digital technologies with an evidence base to support their efficacy are not commercially available, whereas technologies that are commercially available do not have an evidence base [11,12]. A framework within which EBP can be better defined, specific to digital technologies for autism will not only be beneficial for those on the spectrum and their care-givers but also for the research community, practitioners and software developers. Our project will be innovative in determining whether and how traditional methodologies, such as RCTs, (see [13]) can be applied to the digital intervention context. Single case designs (multiple probe, multiple baseline) will be considered as they could be more relevant depending on the goal of the technological solution and the context of use. Important questions will be addressed concerning the generalisability of evidence (e.g. across contexts, devices, software).

Online social media communication tools (such as Facebook and Twitter) and video-conferencing (such as Skype) are widely and effectively used by the autistic and autism communities [14-19]. Brosnan and Gavin [15] found that people with autism reported preferring online interaction compared to face-to-face interaction as it removed social cues and time pressure to respond. This research highlights that the autistic and autism communities not only actively use online communication but can actually prefer online communication. We will use social media, video-conferencing and Vizzata (a tool especially developed to maximize end-user participation - please see www.vizzata.com for details). The current research team has a great deal of experience in collaborative enquiry with the autistic and autism communities including the development of technologies through participatory design. Some autistic people want to be included within the design process without working in a group. As one autistic person said, ‘not everyone wants to be in a design team, but they do want their voices heard’ [20]. Online communication is ideally suited to enable the autistic and autism communities to co-design the proposed EBP framework with the research team.

Despite the prevalence of Intellectual Disabilities (ID) within the autistic population, the vast majority of research has focused predominantly upon individuals who do not have ID. Mindful of the challenges that can arise from working with groups having autism and ID, an original and innovative aim of our research is to ensure that autistic community members of all cognitive abilities are included throughout the project. Brosnan’s (team member) recent research with people with autism and ID has highlighted how everyone can participate within design and research when the situation is structured appropriately [21]. Where specific individuals are unable to access social media or videoconferencing, we will invite them to join appropriately structured sessions with their parents/ care-givers, to ensure this group is represented within the research. Also original and innovative is the presentation of all the project outputs in a manner and format that is accessible to the autistic and autism communities and a final original and innovative feature of the
The proposed research is the international perspective (integrating experience and expertise from France, Spain, England, Scotland and the USA). In line with the purpose of the UN Convention on the Rights of Persons with Disabilities, this proposal seeks to ensure equality of opportunity for people with Autism (Article 1). This project will produce an EBP framework that will enable politicians, educators and other stakeholders to make "reasonable accommodation" more easily and effectively. In addition, our participatory design methods promote designing with, rather than for, users and this is the best way to promote genuine "Universal Design". The proposal includes the autistic and autism communities throughout, with the aim of enabling accessibility (including access to information), independence and inclusion (Articles 7,9,19,21). Assistive technologies can facilitate opportunities in education, health, employment, habilitation and rehabilitation (Articles 24,25,26,27). Specifically, promoting the availability and use of new technology (incorporating assistive technologies, Article 4g) is central to the current proposal. This will be undertaken in a way that is accessible to the stakeholders (Article 4h) to enable people with autism to participate as fully as possible in all aspects of life (Article 9.1), through promoting appropriate technologies (Article 9.2g). A central output from this project will be the design and development of an EBP framework to enable stakeholders to evaluate the appropriateness of technologies at no financial cost to themselves (Article 9.2h) with the aim of facilitating access to quality assistive technologies (Article 20b). Through engaging with academics and software developers, we are also engaging those who produce assistive technologies and related research to incorporate evidence that is relevant and accessible to stakeholders (Article 20d). All outputs from our project will be available in an accessible manner via free online material (Article 21a). Lastly, although autism appears to be a predominantly male disorders, gender issues will be given special considerations as they could influence preferences towards technology. In accordance with article 26.3, the project will ‘promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation’, with a specific focus upon autism – though we note that the proposed EBP framework can extend to all disabilities. Participation in public life will be facilitated through the use of assistive and new technologies where appropriate (Article 29a,ii), and this will be achieved internationally (Article 32d). The outcomes of this project will enable us to prepare larger projects (submitted to national, EU or international foundations) that will implement the EBP guidelines and follow up on them.
4/ Presentation of research project leaders and partners and their respective roles in the project (one and a half pages)

The ITASD (Innovative Technologies for Autism Spectrum Disorders) conference in 2014 provided the first panel session on evidence-based practice for digital interventions for autism. The panel consisted of four of the current applicants (Brosnan - England, Grynszpan - France, Goodwin - USA, Pérez-Fuster - Spain). Herrera (Spain) was the Chair of the conference and Fletcher-Watson (Scotland) initiated and chaired the ASDTECH SIG (Special Interest Group) at IMFAR (International Meeting For Autism Research) and is curator of the DART web site (Development Autism Research Technology, www.dart.ed.ac.uk). Richard Mills (UK) is the Director of Research for the Research Autism charitable Trust that is committed to improving the lives of individuals on the autism spectrum through research. He also works in Malta, Greece and Denmark on programme evaluation in conjunction with AT-Autism and will support our recruitment of members of the autistic and autism communities to be research partners and with dissemination. The project will be coordinated by a French-British partnership which includes a team of internationally leading experts who will develop the EBP framework. Members of the autistic and autism communities will be central to the co-ordination, development and evaluation of the project, facilitated by Mills (Research Autism).

**Dr. Mark Brosnan, University of Bath, UK. [M.J.Brosnan@bath.ac.uk](mailto:M.J.Brosnan@bath.ac.uk)**

Dr. Brosnan has published widely in developing protocols to enable the autistic community to contribute to the design of technology. Through participatory design with the autistic community, he has developed both educational software (funded by the EPSRC) as well as psycho-behavioural interventions (funded by The Leverhulme Trust). His role will be to lead on the development of participatory design (incorporating online methods, Phase 2), MOOC development (Phase 4) and overall project co-ordination (focus on UK/USA).

**Dr. Ouriel Grynszpan, Pierre et Marie Curie University, France. [ouriel.grynszpan@upmc.fr](mailto:ouriel.grynszpan@upmc.fr)**

Dr. Grynszpan has been conducting research on adapted technology for the autistic community for the past 14 years. His initial training was in electrical engineering and his current academic position is in neuroscience. His interdisciplinary research is published in journals of psychology, medicine and human-computer interactions. He has led several projects on technology based interventions for autism, using state-of-the-art technology such as virtual reality and eye-tracking, but also more common desktop computers. He coordinated the first meta-analytical review on group designs to assess the efficacy of these interventions. His role in the project will be to coordinate jointly with Dr. Brosnan with a focus on the work that will be carried out in France.

**Richard Mills (Research Director), Research Autism, UK. [richard.mills@researchautism.net](mailto:richard.mills@researchautism.net)**

As Director of Research for a leading autism charity, Richard Mills will lead on the co-ordination of involvement of the autistic community, e.g. for expert groups. Research Autism will also facilitate dissemination.
Dr. Sue Fletcher-Watson, University of Edinburgh, UK. Sue.Fletcher-Watson@ed.ac.uk
Sue Fletcher – Watson is a leading researcher within the field of autism and technology. She has a great deal of experience with participatory and online methods (contributing to Phase 2). She will lead on the co-ordination of assessment of technology with EBP framework and she runs the DART website (Phase 3, UK, DART liaison).

Dr. Matthew Goodwin, North Eastern University, USA. M.Goodwin@neu.edu
Dr. Matthew Goodwin has a distinguished career working within the field of autism and technology, and has authored a number of books on the topic, highlighting the need for EBP. He will lead on the development of the EBP review (Phase 1) and contribute to the co-ordination of assessment of technology with EBP framework (Phase 3, USA, Autism Speaks liaison).

Dr. Gerardo Herrera, University of Valencia, Spain. Gerardo.Herrera@uv.es
Co-ordination of perspective of groups associated with Intellectual Disability (all phases). He has great experience with online methods with people with autism (Phase 2) and he will also lead on the co-ordination of Spanish translation, and with dissemination (Phase 4).

Patricia Pérez-Fuster, University of Valencia, Spain. Patricia.Perez@autismo.uv.es
The aim of her work has been the implementation of technology-mediated interventions to enhance a wide range of skills in children and adults with ASD and ID, ensuring research rigor and strength, and promoting the establishment of EBP. She has extensive experience with systematic reviews (leading Phase 1). Her role will also be the co-ordination of assessment of technology with EBP framework (Phase 3, Spain, Appy Autism liaison), PD, dissemination.
5/ Methodology and expected outcomes (three pages)

The proposed EBP framework will include detailed processes for managing ethical issues, including checklists for identifying ethical concerns, consent forms and other supporting documents. The proposed EBP Framework will be reviewed and approved by user groups and relevant ethical bodies and committees of participating organisations and countries. The methodology will be based on a thorough review of the EBP, ASD and digital technology literatures and existing software will be used as empirical data during consultation with expert groups. The project will proceed according to the following sequential phases:

- **Phase 1** (months 1-6): Systematic review of current state of evidence supporting digital interventions for ASD. Setup project web site and social media (e.g. Facebook, Twitter). Mobilise existing networks [e.g. the ASDTech network which has over 300 subscribers] to identify expert group and focus group members, for future phases (we have potential participants if funding is successful).

  We will use the Reichow et al. [22] methodology of EBP in autism and apply it to technology-based interventions to develop: (1) rubrics for the evaluation of research report rigor, (2) guidelines for the evaluation of research report strength, and (3) criteria for the determination of EBP [22,23]. Existing APA², NTACT³, NPDC⁴ and NAC⁵ general criteria will be discussed with respect to their applicability to digital technologies and initial categories for framework development (covering Feasibility, Efficacy, Generalizability, Effectiveness, Dissemination). This will be co-developed with two groups of individuals from the autistic community to ensure that all the language is at an accessible level (one in the UK and one in France). The project web site will host an online forum (embracing social media, video-conferencing, Vizzata.com). The online forum will be developed for those who prefer to not meet face-to-face to enable the contributors to see the contributions of the others and to comment upon them. The online forum will enable participants to contribute in the manner they find most amenable. This is a novel methodology for autistic research as it is occurring in an online environment, but will embrace the principles of participatory design that have been successfully employed with autistic people in face-to-face participatory design sessions [24]. The methods for including perspectives from the autistic and autism communities will be developed into a set of recommendations for future research.

**Output 1a**: Systematic review of international evidence for digital interventions for ASD (with reference to presence / absence of ID). Prepared for academic publication (open access).

**Output 1b**: Accessible web document detailing the nature of evidence to support digital interventions for ASD. Developed with the autistic and autism communities.

**Output 1c**: Documentation and questionnaires for consultation (based on Reichow rubric) for the co-development of the EBP framework with expert groups (in Phase 2).

**Output 1d**: Recommendations for facilitating inclusion in co-design through online communication, translated into French, English and Spanish.

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² American Psychological Association http://www.apa.org/practice/resources/evidence/
³ National Technical Assistance Center on Transition http://transitionta.org/effectivepractices
⁴ National Professional Development Center http://autismpdc.fpg.unc.edu/evidence-based-practices
- **Phase 2** (month 7-10): To iteratively refine the recommendations and parameters for the EBP framework over a series of expert surveys using the Delphi study methodology, which is ‘a method for the systematic solicitation and collection of judgements on a particular topic through a set of carefully designed sequential questionnaires interspersed with summarized information and feedback of opinions derived from earlier responses’ [24]. This would be conducted with three distinct expert groups: i. End-users (autistic and autism communities, including those with associated ID); ii. Multidisciplinary researchers (academia, e.g. psychology, computer science, education); iii. Software developers (commerce/industry). Initially we will have 10 members from each expert group, ensuring an international perspective and gender mix.

  We will use a Delphi study methodology which is an ideal technique to extract accurate recommendations on a specific topic from expert panels of respondents. The first round questionnaire will present the EBP questionnaires (output 1c) which will then be refined and modified for the digital-intervention context through a series of iterations with the expert contributors until convergence towards a consensus. Again, Vizzata is ideally suited to supporting the Delphi study methodology as it enables to easily implement its key features (anonymity, structured communication, regular feedback and coordination by a facilitator). This novel methodology therefore allows for the contribution of people from different counties who speak different languages, overcoming many challenges inherent in including the autistic community, who can find travel and groups challenging.

  The questionnaires will be built based on the outcomes yielded by the systematic review performed during phase 1. It will include issues related to usage, context of use (family, school, clinical, independent living ...), end-users’ expectations, social constraints, ethics and prospective evolutions of technology to ensure that the EBP framework can be adapted to emerging and future technological innovations. Regarding the last point, the Delphi methodology was actually initially developed for forecasting in the field of science and technology [26].

  The ‘final draft’ of the EBP framework will then be made available on our online forum for comment from 10 more members of the autistic and autism communities (including those with associated ID and a gender mix) who have not previously taken part in the project, publicized through our international networks and supported by Research Autism. This additional group will be referred to as the focus group. A final iteration of the Delphi study methodology will then be run with the expert groups to integrate these inputs into the final version of the EBP Framework.

  During phase 2, French and English versions of the documents will exist to enable participants to contribute in French or English. Any comments from the English version will be translated and appended to the French version, and vice versa.

  **Output 2a:** An EBP framework, translated in English, French and additionally translated into Spanish

  **Output 2b:** An academic publication relating to the EBP framework (open access), translated

  **Output 2c:** An end-user friendly web document, developed with the autistic and autism communities, translated.
**Phase 3** (month 11-14): Implement the framework on existing international digital technology (including apps) databases (e.g. DART-UK, Autism Speaks-USA, and Appy Autism-Spain: See letters of support), i.e. evaluate existing digital technologies (including apps) using the framework developed in conjunction with members of the autistic and autism communities. This will be undertaken by the team, as well as volunteers from the autistic and autism communities. Research Autism and our existing networks will again advertise the opportunity to apply the EBP framework to digital technologies through their web sites.

In the first instance, we will apply the EBP framework to apps and we have identified web sites in three different countries that provide a list of apps for the autism spectrum and which are free of potential conflict of interests: DART (UK), Autism Speaks (USA), and Appy Autism (Spain). As of June, 602 apps are listed on the Autism Speaks web site. The site identifies whether there is research evidence or not, which is available for 42 (6%) of apps, but not an evaluation of the evidence. The DART website uses a 5-point rating scale to assess the evidence base of 131 apps. Most have 1-star, representing no evidence and only 2 apps have a 5-star rating indicating there is evidence for the intervention generally and/or the app specifically. Thus, good work has started on identifying the presence of evidence (or not) and these web sites are either run by team members or groups who have written letters of support for this proposal. However, evidence cited by app web sites may not relate to the technology but to conventional materials (e.g. studies on the use of visual schedules on laminated paper are relied on to recommend certain visual schedule apps), or app reviews may be cited as evidence, or the data does not relate to autism [25]. This proposal takes evidence based practice to the next stage - developing a framework that will enable the evaluation of not just the presence of evidence but also its quality.

**Output 3a:** An evaluation of existing digital technologies (including apps) using the EBP framework, co-developed with the autistic and autism communities. These will be held on the project webpage and we will work with the existing websites to incorporate the application of the EBP framework too (see letters of support).

**Output 3b:** Accessible documentation on how to apply the EBP framework to an existing technology, including apps, co-developed with the autistic and autism communities.

**Phase 4** (month 15-16): Dissemination of EBP framework. Co-develop with members of the autistic and autism communities guidelines for research and inclusive software development and an online tutorial for the autistic and autism communities in understanding EBP and integrating evidence into decisions concerning what digital technologies to use (a ‘MOOC’ on the FutureLearn platform).

**Output 4a:** Guidelines for the provision of evidence for research

**Output 4b:** Guidelines for the provision of evidence for software/hardware engineers

**Output 4c:** A MOOC to support the autistic and autism communities evaluate evidence and implement the EBP framework (detailed in output 3b).

Our platform will allow users to apply the EBP framework to any digital technology they wish and to potential future technology. This ongoing activity will be monitored as part of the Centre for Applied Autism research at Bath. All the project outputs will be made available online and free. Please see our letters of support.
6/ Tools produced to disseminate and capitalise on knowledge generated by the research project (and methods for transferring these tools) (one and a half pages)

Throughout the project, the following tools will be produced to disseminate and capitalize on the results of the study:

i) The project web site.
This web site will be created at the onset of the study. It will be hosted by the University of Bath that has the required infrastructure and security settings. Its content will be translated into English and French.
- Phase 1: Once the systematic review of evidence for digital interventions for ASD will be completed, it will be formatted into an accessible web document published on this web site (Output 1a). Recommendations for co-design through online communication will also be published on it (Output 1d).
- Phase 2: The web site will be used to carry out the Delphi study and diffuse its results. After completion of the EBP framework, an end-user friendly web document explaining it will be made available on the web site (Output 2c).
- Phase 3: An accessible documentation on how to apply the EBP framework to existing technology will be published on the web site (Output 3b).
- Phase 4: During the dissemination phase of the project, the web site will be complemented by guidelines for researchers (Output 4a) and software engineers (Output 4b) regarding the provision of evidence. A MOOC will also be created help the autistic and autism community know about the EBP framework (Output 4c).

ii) Existing relevant web sites: During phase 3, the EBP will be implemented on websites that host databases on existing digital technologies for autism, namely DART (UK), Autism Speaks (USA), Appy Autism (Spain). We will also explore the possibility of applying the EBP framework on Applications-autisme.com (France). Websites that implemented the EBP framework will disseminate knowledge about its existence.

iii) Social media: Social media (e.g. Facebook, Twitter) will be used to mobilise the existing networks that are interested by issues related to technology for autism (e.g. ASDTech newsletter). They will also be used to diffuse the end results of the study.

iv) Academic publications and Conference presentations
Our goal is to produce scientific work that is readily available. Hence, we plan to have the outcome of our study published under the open access scheme.
- Output 1a: The systematic review of international evidence for digital interventions in ASD is meant to be published in a scientific journal that has a strong impact in the research community interested in autism.
- Output 1d: The recommendations for inclusion in co-design through online communication will yield a publication in a journal or conference concerned with universal design.
- Output 2b: The EBP framework will be the central publication of the project. We will aim at a journal with a large dissemination power regarding autism.
- Outputs 4a and 4b: The guidelines for provision of evidence will yield publications in journals or conferences concerned with methodology and technological design.

To sum up, dissemination outputs can be categorized according to the specific audiences that needs to be reached:

a) Outputs for researchers:
- Output 1a: Systematic review of evidence for digital interventions for ASD
- Output 1d: The recommendations for inclusion in co-design through online communication
- Output 2b: The EBP framework
- Output 4a: Guidelines on provision of evidence

b) Outputs for software developers
- Output 1d: The recommendations for inclusion in co-design through online communication
- Output 3b: Documentation on how to apply the EBP framework to existing technology
- Output 4b: Guidelines on provision of evidence

c) Autistic, Autism Community and related stakeholders
Output 1b: Accessible web document detailing the nature of evidence to support digital interventions for ASD
Output 2c: An end-user friendly web document explaining the EBP framework developed during the project
Output 3a: An evaluation of existing digital technologies using the EBP framework
Output 3b: Accessible documentation on how to apply the EBP framework to an existing technology
Output 4c: A MOOC to support the autistic and autism communities evaluate evidence and implement the EBP framework.