

The Digital Bubbles Questionnaire

Following the seventh, and final, seminar in the ESRC funded seminar series entitled, “Innovative technologies for autism: critical reflections on Digital Bubbles”, the participants at the final seminar (19 in total) were asked to help us develop a “road map” to shape future research in the field of autism and technology.

Using the key themes identified through this initial, open ended, survey, a further questionnaire was developed and sent to everyone who had participated in one (or more) of the Digital Bubbles seminars. This questionnaire aimed to provide a better sense of the extent to which the views expressed in the first survey around autism and technology were shared by a wider audience.

The questionnaire focused on determining future priorities for research in the area of technology and autism, reflecting on the ways in which research in this field should ideally be carried out, and what the research focus should be. Respondents were also asked for their views on future funding priorities.

Overall, 24 people responded. Of these, 2 identified as a parent/carer, 5 as part of a business or organisation, 10 as a related professional, and 11 as an academic, ranging from PhD student to researcher/lecturer (note that the numbers do not add up to 24 as respondents could select more than one choice).

The complete questionnaire can be found in Appendix 1: below we provide a summary of the results obtained.

Question 1A asked respondents to reflect on priorities in research on autism and technology, considering issues of research topic, the research process itself and participation in research. Respondents were asked to rate the importance of eleven issues, identified in the first survey, using a 5 point Likert scale, where 1 = strongly disagree and 5 = strongly agree.

Table 1 shows the results for each of the eleven issues in Question 1A, in order of perceived importance.

Work in autism and technology needs to do more to:	Mean	Std Dev
Include people from across the whole autistic spectrum	4.58	0.65
Include adults with autism	4.50	0.59
Include people with autism who may not communicate verbally	4.50	0.66
Further involve the wider community in making a more autism-friendly world	4.50	0.66
Include stakeholders at earlier stages of design and development	4.46	0.78
Understand what technology is already used	4.46	0.72
Develop better measures of benefits	4.38	0.82
Study longer-term effects rather than short one-off projects	4.29	0.81
Provide resources to help/train stakeholders to participate actively	4.04	1.12
Understand the potential market (the ‘autistic pound’)	3.83	1.01
Look at early intervention	3.79	1.14

Table 1 – Proposed focus of work in the field of autism and technology

As can be seen, although respondents agreed that all issues were worthy of further consideration, the issue of inclusion seemed most important, both in terms of including a much broader range of autistic people in the design of new technologies, but also involving the broader community in creating a more autism friendly world.

Question 1B was phrased as follows:

Imagine you have a pot of resources for work in autism and technology (£100k). Allocate this between these seven project types on technology support (however you like: you don't have to provide support for each one).

Respondents were given six choices, again, derived from the initial survey carried out with participants from the seventh Digital Bubbles seminar (see Table 2 below). Question 1B also included a seventh option, entitled, "Other", where additional project types could be proposed. Note that data from two respondents could not be analysed as it was either missing, or contained examples of projects but no associated funding attribution. This resulted in just over £2 million pounds being allocated to autism research in a hypothetical exercise to see where the money should be spent

Table 2 shows the relative totals for each of the first six options (the seventh is discussed separately below).

Relative distribution of funds across projects:	Total
Adults with autism (e.g. work, independence, relationships)	£381,285 (18%)
People with autism who communicate non-verbally (e.g. communication support)	£360,285 (17%)
School support (e.g. autism friendly environments, staff training)	£328,785 (15%)
Community support (e.g. autism friendly environments, staff/community training)	£297,325 (14%)
Older people with autism (e.g. health and social care)	£264,285 (12%)
Support and training to develop autism-led projects	£175,825 (8%)

Table 2 – Proposed distribution of funds across projects

Again, the data suggest that the greatest proportion of funding should be directed towards autistic adults, and then those who are minimally verbal. Interestingly, funding for older autistic people only ranked fifth out of the six choices.

Of the 24 respondents, 13 specified a further project (or, in some cases, projects) which should also receive funding. These are shown in Table 3.

Additional projects which should be funded:	Amount of funding
Enabling sustained employment	£100,000 (5%)
Bayes factor based meta analysis of existing technology interventions	£70,000 (3%)
Understanding how we actually interact (emotion recognition is easy to measure and teach, but not what we do much of, I think)	£50,000 (2%)
VR for social and emotional skills learning	£40,000 (2%)
Technology for diversity (not just autism)	£30,000 (1%)
Explore novel devices such as robotics, wearables, "smart" environments	£25,000 (1%)

Measuring outcomes of research	£20,000 (1%)
Developing international collaborative long term autism tech projects	£20,000 (1%)
Adolescents with autism	£20,000 (1%)
Creative technology projects	£14,000 (1%)
Early interventions	£10,000 (<1%)
Policy research	£10,000 (<1%)
Women with autism	£5,000 (<1%)
TOTAL FUNDING ALLOCATED (from Tables 2 and 3)	£2,171,790

Table 3 – Additional projects proposed, with amount of funding

The total amount of money allocated in this option exceeds those of the previous six options, which is not surprising given the breadth of projects and priorities which are being proposed under this heading. Interestingly enough, one respondent said that they would allocate their entire budget towards “enabling sustained employment”. To the extent that this could be considered a specific example of the first option “Adults with autism (e.g. work, independence, relationships)” above (as could “Women with autism”), the total budget recommended for this category would be £485,285, which far exceeds the funding allocated to the other categories.

It is also interesting to note that the three issues in Table 3 which received the lowest proposed allocation of funding (early interventions, policy research and women with autism respectively) are currently ‘hot topics’ in the field. In the case of early intervention, it may be that respondents felt that enough money is already being directed at early intervention or, alternatively, that technology is not seen as useful for early intervention. In any case, it would be interesting to explore this issue in more depth.

Question 1C asked respondents to consider how best to measure the success of projects in the area of autism and technology. Respondents were given six choices and asked to rate them using a 5 point Likert scale (where 1 = not at all useful and 5 = very useful). A seventh option allowed respondents to suggest other ways of measuring success.

Appropriate measures of project success:	Mean
In-depth research observing users engaging with resources	4.54
Feedback from stakeholder groups about usefulness and acceptability	4.21
Experimental studies	3.88
Case studies of use of resources	3.75
Structured surveys of views and experiences	3.63
Uptake by people with autism (e.g. number of downloads)	3.17

Table 4 – Ways of measuring project success

It is interesting to note that although experimental studies (in particular, randomised control trials, or RCTs) have typically been considered the “gold standard” in this area, the responses above seem to favour a more holistic and situated approach to evaluation, which engages users more fully and prioritises their perspectives on technology in a broader sense.

In addition to the measures listed in the questionnaire, five respondents provided an additional six measures of project success, shown in Table 5 below.

Additional measures of project success:
Policy and programme analysis
Feedback from parents of people with autism
18 month follow up interviews and observations and progress data downloaded from the tech devices
Holistic, multi-perspective measures of success
Efficacy - as many have said, need more replication, and larger scale RCTs, both in labs and in community setting
Measure professional change management "friction" - how well does this fit into existing financial, pedagogical, scheduling constraints for use in private practice, school, social service agencies, etc.
Policy and programme analysis

Table 5 – Additional ways of measuring project success

Finally, the questionnaire asked respondents about their awareness of the ASCmeI.T. app (<http://ascme-it.org.uk>), an app developed by the Digital Bubbles consortium to provide members of the autism community with a way of suggesting ideas for the technologies that they would find most useful. Of the 24 respondents, 15 (63%) were aware of the ASCmeI.T. app.

Using the premise of the ASCmeI.T. app, respondents were asked for their opinion on the areas in which new apps are needed. Of the three choices provided, 12 respondents choose “Personalised solutions”, 8 selected “Social communication”, while 2 selected “Curriculum subjects”. A further two respondents provided the following additional areas: “Independent living” and “Daily tasks and skills” respectively.

Taken together with the initial survey results, these questionnaire results provide a basis for further discussion around future directions in the area of technology for autism.

Digital Bubbles Survey

Thank you for your participation and interest in the Digital Bubbles seminar series. The series has now finished but we want to continue the work. There were many great ideas and discussions that we had along the way and now we want to develop a roadmap, with your help, that will shape future research in the field of autism and technology.

We've divided the questions into four sections. Please do take a few minutes to tell us your thoughts in response. As always, we value and respect the multiple perspectives that you all bring to this. We'll use your responses to create a summary document that we'll post on the Digital Bubbles website. Responses will be fully anonymised unless you tell us that you are happy to be named.

1. What work needs funding in autism and technology?

1A. Work in autism and technology needs to do more to:

1. a) Include adults with autism:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

2. b) Include people with autism who may not communicate verbally:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

3. c) Include people from across the whole autistic spectrum:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

4. d) Include stakeholders at earlier stages of design and development:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

5. e) Understand the potential market (the 'autistic pound'):

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

6. f) Understand what technology is already used:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

7. g) Develop better measures of benefits:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

8. h) Provide resources to help/train stakeholders to participate actively:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

9. i) Study longer-term effects rather than short one-off projects:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

10. j) Look at early intervention:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

11. k) Further involve the wider community in making a more autism-friendly world:

Mark only one oval.

	1	2	3	4	5	
strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	strongly agree

1B. Imagine you have a pot of resources for work in autism and technology (£100k). Allocate this between these seven project types on technology support (however you like: you don't have to provide support for each one)

12. 1) Adults with autism (e.g. work, independence, relationships):

13. 2) Older people with autism (e.g. health and social care):

14. 3) People with autism who communicate non-verbally (e.g. communication support):

15. 4) School support (e.g. autism friendly environments, staff training):

16. 5) Community support (e.g. autism friendly environments, staff/community training):

17. 6) Support and training to develop autism-led projects:

18. 7) Other (add other project types that you think need funding, along with the amounts you would allocate):

Before moving on to the next question, please check your numbers add up to 100.

1C. What are the best ways to measure success of projects in this area?

19. a) Uptake by people with autism (e.g. number of downloads):

Mark only one oval.

1 2 3 4 5

not at all useful very useful

20. b) Case studies of use of resources:

Mark only one oval.

1 2 3 4 5

not at all useful very useful

21. c) Structured surveys of views and experiences:

Mark only one oval.

	1	2	3	4	5	
not at all useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	very useful

22. d) Experimental studies:

Mark only one oval.

	1	2	3	4	5	
not at all useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	very useful

23. e) In-depth research observing users engaging with resources:

Mark only one oval.

	1	2	3	4	5	
not at all useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	very useful

24. f) Feedback from stakeholder groups about usefulness and acceptability:

Mark only one oval.

	1	2	3	4	5	
not at all useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	very useful

25. g) Other (please state):

2. ASCme-IT and new apps for autism

26. I am aware of the ASCmeIT app:

Mark only one oval.

- YES
 NO

The ASCmeIT app (website: <http://ascme-it.org.uk>) asks members of the autism community to suggest ideas for new supportive technology and offers those ideas to tech developers.

27. If there were to be new apps for autism, they would best be in the area of (please choose one):

Mark only one oval.

- curriculum subjects
- social communication
- personalised solutions
- Other: _____

3. What next?

28. I would like to (tick as many as apply):

Check all that apply.

- Remain on the Digital Bubbles mailing list for news and updates (please include your email address in the next section)
- Be involved in possible future projects (please state area of interest below)
- Be involved in linking to other wider groups (e.g. disability forums...)
- Submit a paper to a special issue on Autism and Technology of the journal Research in Autism Spectrum Disorders (website: <http://tinyurl.com/hsgdwdg>)
- Participate in a joint paper in the RASD special issue
- Other (please describe below)

29. Additional information:

4. It would be helpful to know about you

30. I am (choose as many that apply):

Check all that apply.

- On the autism spectrum
- A parent / carer
- A related professional
- A research funder
- A part of a business or organisation
- Other: _____

31. If you would like us to contact you about your answers, please provide your email.

32. We will email out a summary of survey responses. Please tick here if you would not like to receive this.

Check all that apply.

Do not send summary

33. Would you like your name to be included on the summary of responses to these questions?

Check all that apply.

Yes

No

Powered by

 Google Forms