

Global Summit on Autism throughout the Lifespan:

Physical Health & Wellbeing

A collaborative workshop to establish priority research areas to improve the physical health and wellbeing of autistic people, enabling them to live longer, happier, healthier lives.

AUTISTICA

Building brighter futures through autism research

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Why research physical health and wellbeing?

At Autistica our vision is of a world where all autistic people live a long, healthy, happy life. We aim to achieve this by delivering world-class autism research.

With the first children to get a diagnosis of autism reaching old age and adults increasingly being identified as autistic, it is more important than ever to understand autism throughout the lifespan.

Our 2016 report **Personal Tragedies, Public Crisis** highlighted the appalling rates of early death in autistic people relative to the general population. Many serious medical conditions are more common in autistic adults than in the general population, including seizure, stroke, gastro-intestinal disease, immune conditions, sleep disorders and diabetes.¹ What is more, nearly three in four autistic people and families feel that autistic people receive worse healthcare than non-autistic people.²

To date, the number of research studies dedicated to investigating the physical health of autistic adults remains in the low single figures.³



At Autistica we have committed to addressing the global need for increased and improved physical health research in autism to tackle the unacceptable disparity in autistic life expectancy. Research in this area can help us understand health risks in autism, including their trajectory, and develop better primary healthcare services and interventions for autistic people.

Autistica and Newcastle University hosted a two-day Global Summit including world-leading researchers, autistic adults, relatives and professionals to develop world-class research ideas that could improve the health and wellbeing of autistic people.

¹ Croen, L.A. et al. (2015). The health status of adults on the autism spectrum. *Autism*, 19 (7) 814-823.

² The Westminster Commission on Autism (2016). *A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People*.

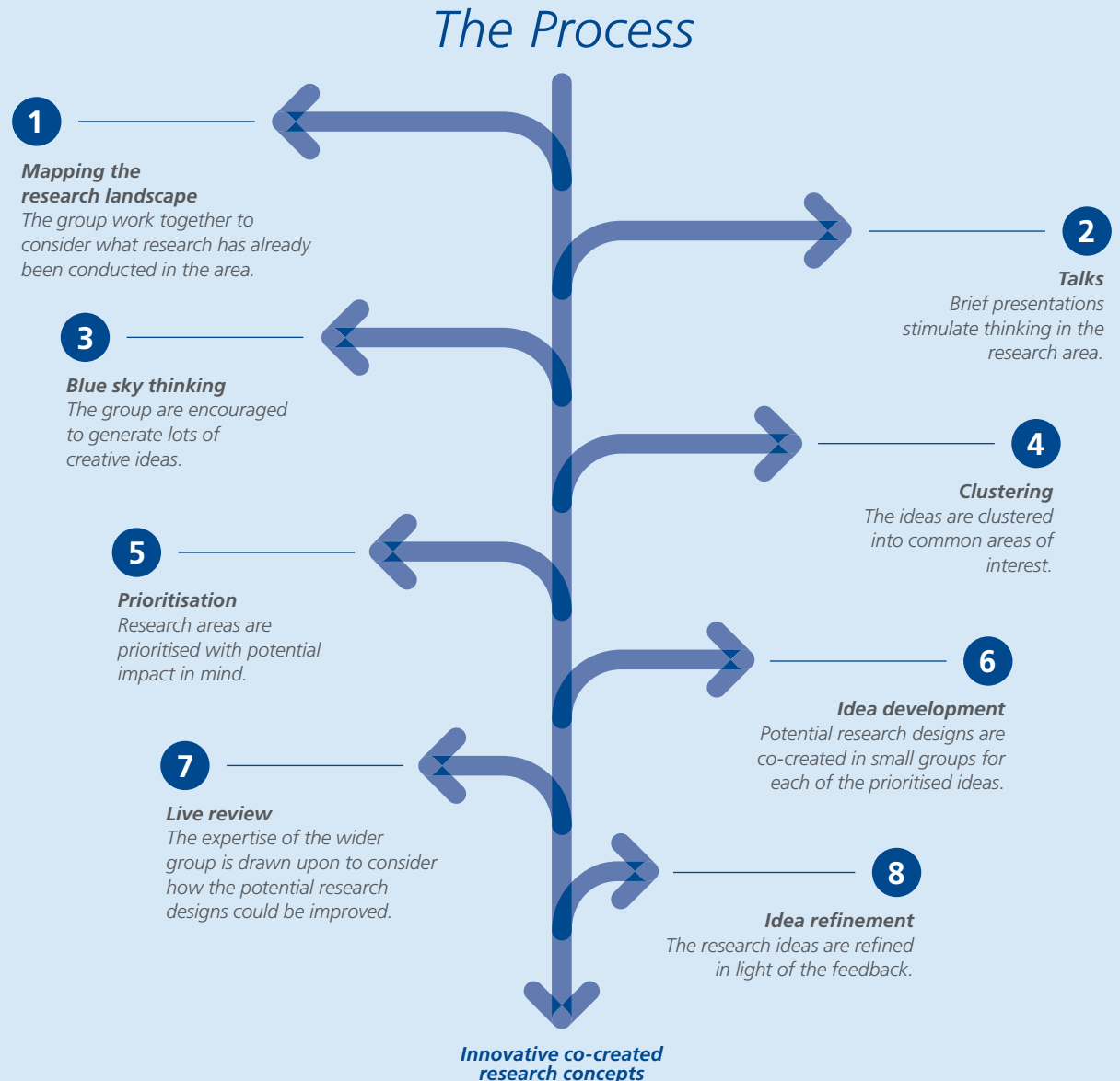
³ Cashin, A. et al. (2016). A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities*, 1744629516665242.

How a collaborative workshop is run

Three core values underpin everything Autistica does: our community is involved at all levels; we are confident in our vision and the ability to change lives through autism research; and we collaborate with others. Collaborative workshops are centred on these three values.

The workshops enable autistic people and families to collaborate with multi-disciplinary researchers across institutions and with professionals to co-create prospective research designs to accelerate previously under-investigated research areas. By bringing the leading experts together, including experts by experience, the research area can move forward in an innovative and efficient way.

Collaborative workshop agendas place a strong focus on establishing future research possibilities through group discussion. Workshops are independently facilitated to ensure that everyone in attendance has an equal voice in the process.



Research ideas that came out of the workshop

Research themes generated at the workshop



Health and wellbeing outcomes and measurement



Annual health checks



Social determinants of health



Priority physical health areas



Healthcare self-advocacy



Personalised healthcare (genetics and biology)



Wellbeing in autism



Sexual development



Autism-enabling services



Residential care in older age

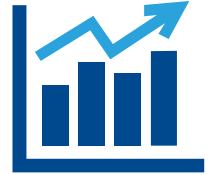


Toolkits to improve health and wellbeing

Other areas of interest discussed at the workshop

- *Common co-occurring conditions e.g. epilepsy*
- *Menopause in autism*
- *Dementia in autism*
- *Sleep management*
- *Immune system function*
- *The role of diagnostic reports in improving access to healthcare*
- *Social value/cost-effectiveness of improved health and wellbeing*
- *How to include autistic people with learning disability in physical health and wellbeing research*

Health and wellbeing outcomes and measurement



Are existing measures of pain valid in autistic people?

How?

Initial thoughts on the research design

- Conduct a large-scale survey to establish levels of perceived pain in autistic adults, focusing initially on osteoarthritis, compared with the general population.
- Use methods such as x-ray imaging to clinically assess pain in the autistic sample, then compare with self-report measures.
- Use the outcomes to potentially inform tailoring existing measures of pain to better suit autistic people.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, third-sector organisations such as Arthritis Research UK, GPs, radiographers, orthopaedic specialists, social care specialists, researchers, epidemiologists and public health specialists.

Why?

Potential impact of the research project

- Earlier and more appropriate intervention to help autistic people with osteoarthritis.
- Improved measurement of self-reported pain in autism.

To consider

Important factors to consider when further refining the research design

- Whether it would be possible to include other conditions similar to osteoarthritis.
- Whether other health factors, such as low muscle tone, hyper-mobility, fibromyalgia, and possible long-term effects of selective serotonin reuptake inhibitors (SSRIs) on bone density, relate to pain in autism.
- The reliability and validity of the refined measures of pain and the applicability of the tools beyond osteoarthritis.
- Who completes the measures and how the research design can be as inclusive as possible.

2 Social determinants of health



Can we agree across studies/countries a core set of socio-economic indicators which can be compared to population data?

How?

Initial thoughts on the research design

- Conduct an international scoping exercise of existing efforts to use the same population level indicators/ measures across autism research groups.
- Organise a collaboration of research groups to establish a core set of demographic, health behaviour and health outcome data.
- Examples of demographic data could include: age, gender, ethnicity, income, education level, employment/occupation, relationship status, living situation, and more specific issues such as loneliness.
- Examples of health behaviour data could include: alcohol consumption, medication use, smoking, sleep quality and exercise.
- Examples of health outcome data could include: physical health and quality of life.
- Assess the reliability and validity of suggested indicators/measures.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, researchers (including specialists in identified areas, e.g. loneliness), health economists, human geographers and epidemiologists in each country.
- It would be important to hold an early stage consultation with organisations that would use the data (e.g. Public Health England) to ensure the outputs would be used and would meet their needs.

Why?

Potential impact of the research project

- High quality data regarding the similarities and differences in terms of social determinants of health in autistic adults compared with the general population.
- Specific data to inform service provision and policy decisions related to the health of autistic people.

To consider

Important factors to consider when further refining the research design

- How to incentivise research groups to join the initiative.
- How to capture important nuances in the factors being measured. For example, 'employment/occupation' should consider employment level comparative to skills and the concept of 'loneliness' might be different for autistic people compared with the general population.

Healthcare self-advocacy

Identifying strategies for healthcare self-advocacy



How?

Initial thoughts on the research design

- Conduct a review of scientific literature and existing good practice, using a broad term such as 'evidence-based healthcare strategies'.
- Use a group communication method called the 'modified Delphi approach' to gather the views of experts in the field to reach a consensus on 'best practice', to improve patient self-advocacy with regard to accessing healthcare.
- Use a qualitative approach (e.g. focus groups or interviews) to consider strategies that have worked or might do so for the majority of autistic adults.
- Develop an exemplar approach for healthcare self-advocacy for autistic people, such as a 'roadmap' – a visual representation that organises and presents important information related to future plans.
- Conduct a feasibility and acceptability trial of the exemplar approach.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, healthcare specialists, public health specialists, qualitative and quantitative researchers and epidemiologists.
- For the qualitative research, a sample of autistic adults aged 40 years and above would initially be targeted, with scope to broaden the age range at a later stage.

Why?

Potential impact of the research project

- Improve autistic people's ability to obtain quality healthcare.
- Improve the health, wellbeing and life expectancy of autistic people.
- Improve self-advocacy in other areas of autistic people's lives.
- Transfer knowledge to other health conditions and populations.

To consider

Important factors to consider when further refining the research design

- Whether 'self-advocacy' is the appropriate term and, if so, how it is defined in this context.
- Examples of good practice from other groups, such as people with dementia.
- How the project can be as inclusive as possible. For example, how can autistic people with a learning disability or those who are less empowered to seek help be included in the research?
- How the exemplar approach can be flexible enough to consider individual experiences, a range of health conditions and different aspects of healthcare (e.g. preventative approaches, access to treatment, and adherence to treatment).

4 Wellbeing

Can we develop a tool to support autistic adults to identify an individual formulation of the factors influencing personal wellbeing?



How?

Initial thoughts on the research design

- Conduct a review of scientific literature and secondary analysis of existing datasets to collate evidence on factors associated with wellbeing in autism.
- Consult with autistic adults regarding the content, formatting and style of a potential wellbeing tool, specifically engaging with autistic adults who are digitally excluded to consider alternative formats for the tool.
- Consult with service providers regarding existing signposting tools and resources, as well as how to design the new wellbeing tool.
- Conduct a small-scale pilot of the tool and use a qualitative approach (e.g. focus groups or interviews) to consider how the tool can be refined and revised.
- Conduct a feasibility and acceptability trial of the wellbeing tool within two local authorities, including an investigation of the economic value of the tool.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, service providers, third-sector organisations, qualitative and quantitative researchers, statisticians and health economists.

Why?

Potential impact of the research project

- Improve autistic people's understanding of their personal wellbeing baseline.
- Improve autistic people's ability to identify ways to improve their personal wellbeing.
- Inform healthcare providers of autistic people's personal wellbeing baseline.
- Enable healthcare providers to develop more focused personal support plans.
- Enable a standardised process for developing care plans and personal budgets.

To consider

Important factors to consider when further refining the research design

- Scope to develop a digital version of the tool (e.g. an app).
- Adaptable and visual models for the tool (e.g. network graphs).
- How to enable the tool to cope with the diversity of autism (e.g. item response theory).
- How gender development might interact with personal wellbeing.
- How a personal wellbeing tool could link to a project on healthcare self-advocacy (see project 3).

5 Autism-enabling services



What does an autism-friendly health service look like?

How?

Initial thoughts on the research design

- Conduct a scoping review to collate evidence on autism-specific accommodations and service design. The review should include learning from wider groups, such as learning disability and dementia.
- Use a group communication method called the 'modified Delphi approach' to gather the views of autistic adults (including under-represented groups), families, service providers and third-sector organisations.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, families, service providers, third-sector organisations and international researchers.

Why?

Potential impact of the research project

- Establish the existing evidence base for good practice regarding autism-specific accommodations and service design.
- Develop a vision for best practice.
- Identify gaps in practitioner knowledge, skills and values.
- Identify strategies to change service models to enable an autism-friendly health service.
- Improve the health, wellbeing and life expectancy of autistic people.

To consider

Important factors to consider when further refining the research design

- Whether 'autism-friendly' is the right term, and how it is defined.
- Whether strategies from education can be applied to the health service.
- How visionary innovation can be encouraged within the project, as well as reviewing existing good practice.
- How to engage those autistic adults who are currently avoiding or otherwise not accessing services.
- How to understand the mechanism that translates an 'autism-friendly' health service into improved health and wellbeing outcomes.
- How learning can be transferred to other populations to improve the health service more widely.

6 Toolkits to improve health and wellbeing



Does a UK-adapted version of the AASPIRE Healthcare Toolkit improve the health and wellbeing of autistic adults?

How?

Initial thoughts on the research design

- Form a UK–US collaboration to adapt the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit⁴ content for use in the UK context.
- Explore which media format(s) the toolkit would be better suited to (e.g. visual, video, audio, app, paper, easy read, British Sign Language, Braille).
- Conduct a feasibility trial of the integration of the toolkit into the National Health Service (NHS), including investigation of the mechanism of action achieved by the toolkit, and explore how to enable ongoing quality improvement of the tool.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, families, physical and mental health service providers, Clinical Commissioning Groups, NHS England and the devolved nations, NHS Digital, Royal Colleges, policy makers and international researchers.

Why?

Potential impact of the research project

- Improve autistic people's ability to obtain quality healthcare.
- Improve experiences of healthcare.
- Improve the health, wellbeing and life expectancy of autistic people.

To consider

Important factors to consider when further refining the research design

- How the toolkit can be made as accessible as possible, including personalisation and assistance for people with learning disabilities and those without English as their first language.
- How the toolkit could be accessed by undiagnosed autistic adults and whether it could support the diagnostic process.
- What an appropriate time scale would be to determine effectiveness and impact.
- Whether different toolkit formats are more appropriate at different life stages.
- Existing websites the toolkit could be integrated with (e.g. National Autistic Society).
- Whether the toolkit can be applied beyond healthcare settings.
- How a UK toolkit could link to a project on annual health checks (see project 7).

⁴Nicolaidis, C. et al. (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their providers. *Journal of General Internal Medicine*. 31:1180-9. DOI: 10.1007/s11606-016-3763-6.

Annual health checks



Do health checks increase access to healthcare? Do health checks improve health-related outcomes?

How?

Initial thoughts on the research design

- Conduct a review of scientific literature to collate evidence on the use of health checks (e.g. learning disability health checks).
- Use a qualitative approach (e.g. focus groups or interviews) to consider the thoughts of autistic adults and healthcare professionals.
- Conduct a national survey to gather a wider perspective.
- Assemble a multi-disciplinary team to create a health check.
- Conduct a feasibility and acceptability trial of the health check, including investigation of training requirements and preferred location for use (e.g. GP practice versus an autism-specific service).

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, caregivers and supporters, healthcare providers, including GPs and nurses, Clinical Commissioning Groups, local authorities, NHS England and the devolved nations, third-sector organisations, researchers and IT specialists.

Why?

Potential impact of the research project

- Increase access to healthcare and offer of healthcare interventions.
- Improve experiences of healthcare.
- Lower the cost of healthcare through preventative action.
- Improve the health, wellbeing and life expectancy of autistic people.

To consider

Important factors to consider when further refining the research design

- Factors affecting identification and uptake of the health checks.
- The age from which the health check would be initiated.
- The level of personalisation required and how this can be achieved.
- Whether the health check should be integrated into clinical training.

8 Priority physical health areas



What are the types of cardiovascular and gut problems that are most prominent in older autistic adults? What are the contributory factors? When and why do they lead to premature death?

How?

Initial thoughts on the research design

- Conduct a review of scientific literature to understand what is known about the prevalence, and effectiveness, of treatments for cardiovascular and gut problems in (i) autistic adults (ii) other neurodevelopmental conditions, and (iii) the general population.
- Conduct an international prevalence study of specific cardiovascular and gut conditions in autistic adults.
- Consult with autistic people and healthcare specialists regarding potential autism-specific contributory factors.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, researchers, statisticians and healthcare specialists, including cardiologists, gut specialists, pharmacologists, geneticists, occupational therapists, dieticians, and sleep consultants.

Why?

Potential impact of the research project

- Improve understanding of the prevalence of cardiovascular and gut problems in autism.
- Improve understanding of autism-specific contributory factors.
- Develop lifestyle and medical interventions to reduce contributory factors.
- Improve the health, wellbeing and life expectancy of autistic people.

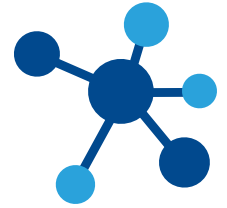
To consider

Important factors to consider when further refining the research design

- Whether there is existing epidemiological data (e.g. Kaiser Permanente data⁵) that is sufficient to answer the question about the comparative prevalence of cardiovascular and gut problems.
- Whether level of exercise and medication use are among the contributory factors to cardiovascular problems in autism.

⁵ Croen, L.A. et al. (2015). The health status of adults on the autism spectrum. *Autism*, 19 (7) 814-823.

Personalised healthcare (genetics and biology)



How can we re-engage autistic people with opportunities to use knowledge about biology to improve health and wellbeing?

How?

Initial thoughts on the research design

- Use a mixed method approach to consult with autistic people regarding opportunities to use knowledge about genetics and biology to improve health and wellbeing – this could include workshops, surveys and qualitative interviews. The discussions would be framed by examples of the application of knowledge from epigenetics and genetics, as well as drug development and personalised treatment.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, families, health service providers (with and without experience of autism), pharmacists, NHS England and the devolved nations, Public Health England, sociologists, ethicists, qualitative and quantitative researchers.

Why?

Potential impact of the research project

- Enable autistic people to re-engage with the opportunities to use knowledge about genetics and biology to improve health and wellbeing.
- A strategy for the development of personalised healthcare and stratified medicine, mutually agreed by autistic people, relatives, clinicians and researchers.

To consider

Important factors to consider when further refining the research design

- How representative views can be captured from across the autistic community.
- How the different aspects of 'genetics and biology' can be presented and discussed.

10 Sexual development

What are the research priorities in sexual development in autism?



How?

Initial thoughts on the research design

- Conduct a review of scientific literature to understand what is known about sexual development in autism and how this may relate to health.
- Use a qualitative approach (e.g. focus groups or interviews) to consider the views of autistic adults.
- Conduct an online content analysis.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, including non-binary and transgender autistic people, qualitative and quantitative researchers, particularly research groups interested in gender and autism.

Why?

Potential impact of the research project

- Improve understanding and awareness of issues related to sexual development among autistic people and health professionals.
- Improve access to relevant services.

To consider

Important factors to consider when further refining the research design

- Whether there is any learning from learning disability research in this area.
- Pathways to questioning sexuality, such as a general feeling of 'not fitting in'.

11 Residential care in older age



What can we learn about the current use of residential facilities by autistic adults?

How?

Initial thoughts on the research design

- Use archival and survey data to calculate general descriptive statistics regarding how many autistic people use residential care facilities for older adults, what type of facilities they are using, and their age and health status.
- Use a qualitative approach (e.g. focus groups or interviews) to consider autistic adults' experiences of residential care for older adults and possible strategies to improve the care experience and support autonomy where possible.

Who?

Likely partnerships and research population

- Partnerships would be formed with autistic people, relatives, staff/ leadership teams of care facilities for older adults, qualitative and quantitative researchers and policy experts.
- For the qualitative research, a sample of autistic adults in residential care for older adults, autistic adults in long-term hospital residence, autistic adults approaching a possible transition into residential care, caregivers, and staff/ leadership teams of care facilities would be targeted.

Why?

Potential impact of the research project

- Inform future interventions, resources and policies to improve the health and wellbeing of autistic adults who may require residential care.

To consider

Important factors to consider when further refining the research design

- Whether data on autism diagnosis is routinely collected by residential care services.
- Including 'undiagnosed' autistic people in residential care.
- How different forms of residential care may operate differently.
- Whether there are gender differences.
- Any risks associated with pursuing research into residential care, such as implicitly promoting care settings with evidence of poor outcomes.

What's next and how you can get involved



What's next?

These collaborative workshops are only the beginning of the process. Autistica is committed to taking the research concepts forward and developing them into fundable research proposals that will lead to longer, happier and healthier lives for autistic people.

Autistica will:

- Through an open call for proposals, commission a project to develop and trial a world-class and personalised health checks programme for autistic adults, funded thanks to the generosity of the Peter Sowerby Foundation.
- Fund three collaborative grants of £20,000 to enable multi-expertise groups to refine three further ideas presented in this report.
- Work with partner organisations and funders over the coming months to get the remaining questions addressed.

How can you get involved?

Join us on the journey. We'd love to work with you and keep in touch with you.

- Share your experiences of the issues discussed in this report.
- Put us in touch with anyone you think might be interested in supporting our work.
- Follow us on social media for the latest research news and developments on this project.
- **Join our Discover network** for updates.

Who attended the workshop?



Organisers

Dr Georgina Warner – Autistica
Dr Jeremy Parr – Newcastle University
Dr James Cusack – Autistica
Dr Abigail Thompson – Autistica
Jon Spiers – Autistica

Attendees

Debbie Allan – Autistic advocate
Dr Bronia Arnott – NIHR Research Design Service North East
Sir Christopher Ball – Parent of autistic child
Professor Bryony Beresford – University of York
Dr Tom Berney – Newcastle University
Kabie Brook – Autism Rights Group Highland (ARGH) and autistic advocate
Professor Ann Le Couteur – Newcastle University
Dr Lisa Croen – Kaiser Permanente
Dr Catherine Crompton – University of Edinburgh
Dr Susan Daniels – Office of Autism Research Coordination & National Institute of Mental
Dr Ian Davidson – Royal College of Psychiatrists Autism Champion
Dr Richard Evans – Medical Research Council

Deborah Garland – National Autistic Society and parent of autistic child

Professor Hilde Geurts – University of Amsterdam

Dr Barry Ingham – Northumberland Tyne and Wear NHS Foundation Trust & Newcastle University

Sarah Jackson – NHS England

Dr Jan Lecouturier – NIHR Research Design Service North East

Professor Helen McConachie – Newcastle University

Cos Michael – Autistic advocate

Chris Mitchell – Autistic advocate

Professor Christina Nicolaidis – Portland State University

Malcolm Osborne – Autistic advocate

Dr Alexandra Petrou – Newcastle University

Carol Povey – National Autistic Society

Dr Jacqui Rodgers – Newcastle University

Amanda Roestorf – City, University of London

Dr Nikki Rousseau – NIHR Research Design Service North East

Dr Clare Scarlett – Newcastle, Gateshead and North Tyneside Clinical Commissioning Group

Professor Paul Shattuck – Drexel University

Dr Anna Urbanowicz – University of Queensland

Jack Welch – Autistic advocate

Dr Sarah Wigham – Newcastle University

Colin Wilson – Autistic advocate

Dr Marc Woodbury-Smith – Newcastle University

What did people think of the workshop?

“Active consideration of autistic ppls comfort & respectful discourse; wish I could bottle & take these attitudes everywhere.”

@Kabieuk on Twitter (Kabie Brook, autistic advocate)

“Thank you for inviting me to the summit and for how thoughtfully it was organised and run. Talking about improving lives was great. Now it's time to start doing something. International and intra-national communication is needed to ensure limited resources are not wasted in replication. Spread the workload.”

Cos Michael, autistic advocate

“I would like to extend my gratitude to Autistica for a wonderfully hosted summit. I am very grateful for the opportunity to have been involved.”

Amanda Roestorf, UK early career researcher

“I really enjoyed the meeting and am excited about some potential new collaborations! I am so jealous of the UK for having Autistica!”

Christina Nicolaidis, US Professor

Help us fund the research

Now we have research ideas to improve the health and wellbeing outcomes of autistic people, we need to fund the projects. Support Autistica and any partner charities that plan to address these questions so we can maximise the scale and quality of the work we can do together.



Find out more and support us at www.autistica.org.uk

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