A review of the autism research funding landscape in the United Kingdom
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Aims and objectives of the landscape analysis

Autistica’s vision is to build longer, happier, healthier lives for autistic people and their families through world-class science, based on the autism community’s priorities.

To make informed decisions on which research to fund, we need to understand the wider autism research landscape. Although there have been useful reports that take a strategic view of autism research (for example, ‘A Future Made Together: Shaping Autism Research in the UK’1) there has been very little systematic analysis of UK autism research investments to date. New reporting methods that are less reliant on publications alone are starting to change that and should help provide a better developed picture of the funding landscape in future.

This funding landscape analysis aims to highlight gaps in autism research and neglected topics or groups, so in the future we can prioritise underfunded areas and make sure research has a focus on community priorities. Publishing this overview of the current funding landscape will allow autism research funders to be more collaborative and strategic in our thinking. Transparency between funders will get us closer to answering the most important and personal questions faced by the autistic community.

This initial report, primarily focusing on grants awarded in 2016, will provide a springboard to track annual funding trends. By understanding the wider picture of who is being funded, how much they are receiving and where they are located, we can ensure that research achieves greater impact on the lives of autistic people and their families.


KEY OBJECTIVES

1 To provide an overview of the autism research funding landscape
We identify the total amount of UK investment, who is making the investment (sector and organisation) and where the funding is going (by region, institution, and researcher career level).

2 To consider the gaps in autism research that could provide future funding opportunities
We break down grants into research themes, disciplines (e.g. Neuroscience, Genetics, Psychology), areas (e.g. Biology, diagnosis, intervention), methods (e.g. clinical trials, animal studies) and those involved (e.g. age, ability level), we highlight neglected research topics and groups.

3 To consider how far current funding patterns address the priorities of the autism community
We report the level of investment against the autism community’s top ten questions for autism research, as identified by our James Lind Alliance (JLA) Priority Setting Partnership.
Summary of findings

From 2013 – 2016

• The amount of money UK funding organisations invested in autism research tripled, shifting the investment per autistic person from £5 to £15. However, year-on-year investment is erratic, so this may not represent a stable trend.

• It seems the dramatic rise in funding seen in 2016 can be attributed to an increased number of projects exploring autism and co-occurring conditions as well as mechanisms or genes that could be relevant to other conditions.

• The proportion of overall investment made by the charity sector has risen steadily.

• There has been a steady rise in investment in Treatments and Interventions research and a more modest rise in Lifespan Issues research from 2014 onwards and a sharp rise in Biology from 2015 to 2016.

• There has been no research funding identified for effective ways to support or provide social care for autistic adults – the community’s third highest priority.

In 2016

• Although London remained the leading region in terms of the number of grants, the amount of money awarded was highest in Scotland. This was affected by unprecedented large grants being awarded to the University of Edinburgh.

• Funding for autism research was awarded to 17 universities and NHS Trusts across the UK.

• Multi-institutional teams within the UK were only reported for 6 grants.

• 76% of funding was awarded to Senior Leaders.

• The most common research disciplines were Psychology, Neurosciences and Public Health & Services.

• Of the total UK autism research expenditure, 27% was directly spent on the top ten community priorities.

• Just 3% of funding went towards projects recruiting older adults (50 years and over) and 9% for adolescents. The largest proportion was allocated to studies recruiting children (47%), closely followed by adults (41%).

• Animal research represented 44% of total UK autism research funding (7 of 24 grants).

• Opportunities for participation in research projects were highest in Greater London and the North of England.
Method

This report focuses on the funding landscape of UK autism research. Information on UK autism research grants awarded by UK funding organisations was retrieved from the Dimensions database. Supplementary information was collected directly from the institutions for 2016 grants via an online survey.

Many research landscape analyses focus on publications; however, not all research projects result in publication and it can take many years to progress from investment to publication. This report gives a timely indication of the level and nature of investment the UK is making in autism research.

WHAT IS THE DIMENSIONS DATABASE?
Dimensions is a research grant database, developed by UberResearch (uberresearch.com), which covers around 200 funders worldwide. All major UK funding organisations are included in the database (Figure 1), as well as many smaller organisations, such as Autistica.

Search categories can be created in the Dimensions database using key words, boost terms, exclusion terms and by applying a threshold to remove grants that mention the area of interest but are not deemed to have sufficient focus on autism to make it into the final set of grants.

The search expressions are linked to algorithms based on natural language processing and receive scores according to the following rules:

• A specific term scores more than a common term (as determined by the total number of mentions across the whole database).
• A term found in the title scores more than the same term found in the abstract.
• A term found in a short abstract scores more than the same term found in a longer abstract.

Each grant identified in the search receives a total score and are ordered accordingly. A threshold can then be applied to remove the tail of false positives. Boost terms can be used to move relevant grants up the list and enable the threshold to be placed with greater accuracy.

Exclusion terms can be used to remove highly irrelevant search returns and are particularly useful if acronyms are shared across disciplines. This process ensures the best compromise between acceptable recall (finding all relevant grants) and precision (removing false positives). Words used in the original search expression can also be used as boost terms (in isolation or in conjunction with other words) to give them more weight.

Figure 1: Major UK funding organisations

- Arts and Humanities Research Council (AHRC)
- Biotechnology and Biological Sciences Research Council (BBSRC)
- Department for Environment, Food and Rural Affairs (DEFRA)
- Economic and Social Research Council (ESRC)
- Engineering and Physical Sciences Research Council (EPSRC)
- Medical Research Council (MRC)
- Ministry of Defence (MoD)
- National Institute for Health Research (NIHR)
- Natural Environment Research Council (NERC)
- Royal Society
- Science and Technology Facilities Council (STFC)
- Wellcome Trust
SEARCH STRATEGY
Autistica developed a search category to reasonably represent ‘autism research’. The search expression was derived from the description of autism in the Research, Condition, and Disease Categorization (RCDC) thesaurus. Standard Dimensions filters for country (UK), country of funder (UK) and start year were applied. Boost terms were selected based on descriptions of grants returned in the searches across 2013 – 2015 and a threshold score was applied.

The search results were then manually scanned for false positives by two members of the Autistica team. The search category can be applied to future years for a repeatable review based on a consistent approach, enabling the tracking of annual trends in the UK autism research landscape.

LIMITATIONS
The search category used in this landscape analysis provides good representation of UK autism research, with the following caveats:

- Not all UK autism research funding has been captured as some funders, particularly Trust and Foundations, do not currently use the Dimensions database (e.g. Baily Thomas Charitable Fund and Garfield Weston Foundation). Commercial research (e.g. pharmaceutical, diet, software) is not included. International funding of UK research is not included.

- Whilst care was taken in developing a search strategy to reasonably represent ‘autism research’, all subject searches require a degree of subjective decision making - there is no perfect set.

- Grant data is manually inputted by member organisations, meaning grant lists may not be up to date, may have missing data and may have errors. Subjective decisions may be made on which grants to enter onto the database (e.g. some smaller grants, such as seminar grants, may be omitted).

- Partial records (e.g. grants with titles but no abstracts) will result in lower scores, affecting search returns.

- Some grants do not focus solely on autism research but are, for example, investigating other neurodevelopmental disorders as well as autism.

- It is not known whether the grant will be spent as intended. Some budget and/or wider project amendments might take place, including project cancellations.

Autistica tried to address these issues where possible. A list of major UK funding organisations was reviewed against the Dimensions database to ensure their grants were included in the analysis (see Figure 1). Two members of the team worked together cross-checking grant inclusion decisions. Only data up to 2016 was included in the current report, to allow for a time-lag in data entry to the database system. Database analysis was supplemented by direct data collection from the institutions for 2016 project grants (seminar grants were not included) to build a richer picture of the research projects. Responses were not received for four project grants. The Autistica team used available project information to inform the analyses as far as possible.
How much is being invested in UK autism research?

The amount of money UK funding organisations invested in UK autism research tripled from 2013 to 2016 (Figure 2), shifting the investment per autistic person from £5 to £15. Investment almost doubled from 2013 to 2014, there was a decline in 2015, followed by a sharp rise in 2016. Annual trends are heavily influenced by substantial grants of £1 million or above (labelled on Figure 2) given the relatively small amount of overall investment per annum. For instance, two grants of around £2 million in value were awarded in 2014, which together represent nearly two thirds of total investment for that year. Although there has been some fluctuation in the amount invested per annum, the number of investments has steadily increased from 2013 to 2016 (Figure 3).
HOW MUCH OF THE INVESTMENT IS FOCUSING SOLELY ON AUTISM?

When the grants were coded by focus (Figure 4), it seems the dramatic rise in funding seen in 2016 can be attributed to an increased number of projects exploring autism and co-occurring conditions as well as mechanisms or genes that could be relevant to other conditions. This trend could represent a shift in academic and clinical thinking about the relatedness of neurological conditions.

**FIGURE 4. Investment in UK autism research by research focus (2013-2016)**

- **Broad strokes**: These projects are relevant to autism but focus on mechanisms or genes that could be relevant to other conditions.
- **Co-occurring conditions**: These projects focus on autism alongside other specific conditions (e.g., ADHD, schizophrenia). The results will inform our knowledge of autism and other conditions and how the conditions interact. Not all participants are autistic in these studies.
- **Autism focus**: These projects focus on autistic people. This could include a subgroup of the autism community. Co-occurring conditions (e.g., anxiety) are included here as long as all participants are autistic.

How much is being invested in UK autism research? (continued)
Who is funding the research?

SECTORS
In 2016, the greatest investment in UK autism research was made by Research Councils, non-departmental government bodies that receive public funds to invest in research, closely followed by the charity sector (Figure 5). The proportion of overall investment made by the charity sector has risen steadily from 2013 to 2016.

**FIGURE 5. Investment in UK autism research by funding sector (2013 – 2016)**
Who is funding the research? (continued)

**FUNDERS**

In 2016, six funders made investments in UK autism research: Autistica, the Engineering and Physical Sciences Research Council (EPSRC), the Economic and Social Research Council (ESRC), the Medical Research Council (MRC), the National Institute for Health Research (NIHR) and the Wellcome Trust. Funding trends across 2013 to 2016 demonstrate the variability in funding organisations’ annual investments in UK autism research (Figure 6).

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**FIGURE 6. Investment in UK autism research by funding organisation (2013 – 2016)**

- Autistica
- British Academy
- EPSRC
- ESRC
- Innovate UK
- MRC
- NIHR
- Wellcome Trust

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0 £0.5M £1.0M £1.5M £2.0M £2.5M £3.0M £3.5M

2016 2015 2014 2013
Where is the funding going?

**REGIONS**

Historically, the majority of autism research funding has gone to the London region of the UK. Although London remained the leading region in terms of the number of grants, the amount of money awarded was highest in Scotland in 2016.

**Four year (2013-2016) investment map**

Scotland

Northern Ireland 2

North West

West Midlands

Wales

South East

South West

North East

Yorkshire & the Humber

East Midlands

Yorkshire & the Humber

East of England

London

South East

South West

0-25 **Number of grants**

Size of circle indicated amount of money awarded

**FIGURE 7. Investment in UK autism research by Nomenclature of Territorial Units for Statistics (NUTS) region (2016)**
Where is the funding going? (continued)

**INSTITUTIONS**

In 2016, funding for autism research was awarded to 17 universities and NHS Trusts across the UK. The largest amount (£3.9m) was awarded to the University of Edinburgh, which accounted for 37.6% of the total UK autism research funding for the year. Large amounts of funding were also awarded to Central Manchester University Hospitals (£1.7m), Kings College London (£1.2m) and the University of York (£1.0m).

Host institutions for 2016 grants were asked at which other institutions co-investigators were based. Multi-institutional teams within the UK were only reported for 6 grants. An international collaboration was reported for one grant. Figure 8 represents the UK collaboration network for 2016 autism research grants. Institutions that hosted autism research grants in 2016 are listed in pink.

**FIGURE 8. UK institutional autism research collaboration network (2016)**
INDIVIDUALS
For 2016 grants, the host institutions were asked to define the career level of the Principal Investigator at the time the project grant was awarded. Figure 9 indicates the proportion of funding awarded to autism researchers according to their career level. The majority of funding (76%) was awarded to Senior Leaders. Early Career Researchers, for whom the grant was their first award, were the next most funded group (16%), and Lecturers received the smallest amount of funds (8%).

FIGURE 9. Investment in UK autism researchers by career level (2016)
What is being funded and where are the gaps?

**RESEARCH THEMES**

In an effort to describe the UK autism research funded in 2016, a word cloud was generated using the project titles listed on the Dimensions database (Figure 10). The size of each word within the word cloud indicates the frequency of its use in project titles. The word cloud visually portrays the main research themes and topics funded in 2016.

**FIGURE 10.** Word cloud representing themes in 2016 project titles
What is being funded and where are the gaps? (continued)

RESEARCH DISCIPLINES
UK autism research grants awarded in 2016 spanned 12 research disciplines (Figure 11). The most common disciplines were Psychology (13 projects), Public Health and Services (7 projects), and Neurosciences (6 projects).

FIGURE 11. Research disciplines for 2016 grants, using the Australian and New Zealand Standard Research Classification (ANZSRC) framework
RESEARCH AREAS
The research area framework developed by the Interagency Autism Coordinating Committee (IACC) was applied to each grant, according to the main focus of the project (Figure 12). (The research area descriptions are American, taken directly from the IACC framework. The IACC is an advisory committee in the United States, which coordinates federal activities concerning autism. If a grant did not fit any of the seven areas within the framework, it was coded as ‘other’ (indicated by a grey line in Figure 12). Investment in Screening & Diagnosis and Services research peaked in 2014. There has been a steady rise in investment in Treatments & Interventions research, a more modest rise in Lifespan Issues research from 2014 onwards and a sharp rise in Biology from 2015 to 2016.

FIGURE 12. Research areas for 2013-2016 grants, using the Interagency Autism Coordinating Committee (IACC) framework
What is being funded and where are the gaps? (continued)

**COMMUNITY PRIORITIES**

Autistica believe that research should seek to address the priorities of autistic people and their families. To understand what these questions are, we led a James Lind Alliance Priority Setting Partnership, with a number of UK partners including the National Autistic Society, Autism Research Trust and Autism Alliance UK. We asked over 1,000 people for their top questions for autism research. These were then ranked by the community and sorted into a top ten list in a final workshop attended by autistic people, parents and professionals.

**In 2016, 27% of UK autism research funding was spent on the top ten community priorities.**

Figure 13 lists the top ten priority questions and the number of grants awarded from 2013 to 2016 that go some way towards answering the questions. Each grant was only allocated to one priority question according to the main focus of the project. Grants awarded by Autistica are displayed in pink.

Community priorities four and five about anxiety interventions and environmental supports have received the highest number of grants (4 each). No research projects were identified for priority number three about social care for autistic adults.

| **1** | Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people? | 2014 2015 |
| **2** | Which interventions are effective in the development and communication/language skills in autism? | 2016 |
| **3** | What are the most effective ways to support/provide social care for autistic adults? | |
| **5** | Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people? | 2013 2013 2016 2016 |
| **6** | How can parents and family members be supported/educated to care for and better understand and autistic relative? | 2016 2016 |
| **7** | How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed? | 2015 |
| **8** | How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace? | 2016 |
| **9** | How can sensory processing in autism be better understood? | 2014 2015 2016 |
| **10** | How should service delivery for autistic people be improved and adapted in order to meet their needs? | 2013 2013 2014 |

**FIGURE 13.** Investment in UK autism research projects relevant to the Autism James Lind Alliance top ten priorities, with Autistica grants shown in pink
What is being funded and where are the gaps? (continued)

RESEARCH METHODS
A range of research methods were utilised in projects awarded funding in 2016 (Figure 14). The most common methods were literature review, observation and animal studies. ‘Other’ methods included computational modelling, human-robot interaction studies and narratological analysis of texts. Only one full randomised controlled trial was funded, and only one project utilised secondary data.
PARTICIPANTS

Figure 15 indicates participant characteristics for grants awarded in 2016, as defined by the research teams. The proportion of funding spent on participant age ranges is included (indicated by size of circle) - where a project intended to recruit from various age ranges, the grant amount was split evenly among the relevant age categories. The largest proportion of funding was allocated to studies recruiting children (47%), closely followed by adults (41%). Only 9% of funding was allocated to studies recruiting adolescents, and the smallest proportion (3%) went to studies recruiting older adults (50 years and over). Three studies were recruiting people with a learning disability; two were recruiting minimally verbal people. Half of the projects recruiting people (seven projects) were aiming to recruit fewer than 100 participants (each person in the figure represents 25 participants). Seven projects were not recruiting participants, all of which were animal studies. Animal research represented 44% of total UK autism research funding in 2016.

FIGURE 15. Participant characteristics for grants awarded in 2016, as defined by the research teams.
REGIONAL PARTICIPATION OPPORTUNITIES
Different recruitment and data collection strategies can affect regional participation. Some researchers will travel to participants’ homes over a broad regional area, whereas other institutions may require participants on site. Figure 16 indicates the number of opportunities for participating in research regionally. Opportunities for participation in research studies were mostly in Greater London and the North of England for grants made in 2016. Institutional collaborations and remote participation strategies, such as online surveys, allow for research participation beyond the location of the research institution. In 2016, there were three national opportunities for involvement in research studies, and one international opportunity.

FIGURE 16. Map showing opportunities for participation in autism research, from 2016 grants
**WE MUST INVEST MORE IN SCIENCE TO IMPROVE LIVES**

Although autism research remains a grossly underinvested area in the UK, with only £15 spent per autistic person each year, we have seen this figure triple from 2013 to 2016. This indicates we are moving in the right direction. However, year-on-year investment is erratic, so this may not represent a stable trend. With the annual investment in UK autism research being so low, substantial grants of £1 million or above can make a big difference to annual trends. In other words, investment trends are spiky. A good example of a ‘spike’ is the huge investment made in autism Biology research at the University of Edinburgh in 2016. It seems that charitable activity has contributed to the growth in funding, with charitable investment in UK autism research steadily increasing year on year.

**Our plan:** More research into autistic people’s and families’ priorities will improve outcomes. Autistica aims to further increase the UK’s autism research spend to £12 million per year. We will achieve this by:

1. Developing infrastructure like our Discover research network which will increase the feasibility of research.
2. Increasing the quality and potential impact of research proposals by working closely with researchers to address gaps.
3. Working collaboratively and strategically with other funders.
4. Campaigning for an increase in autism research funding by government funders.
5. Working hard to maintain and increase our own spend on autism research.

**WE NEED TO INSPIRE THE NEXT GENERATION OF AUTISM RESEARCHERS**

The majority (76%) of funding awarded in 2016 (i.e. total expenditure) went to senior leaders in autism research. Whilst it is recognised that expertise develops with experience, it is important to maintain a flow of advancement and encourage the next generation of autism research leaders. Establishing career independence in academia is challenging, and many promising scientists are lost to other research disciplines and other careers. That is why we are filling a critical gap in their career development through our annual Future Leader Award.

**Our plan:** Supporting the next generation of leaders in autism research is a key priority for Autistica. We have taken the following steps:

1. Helping researchers to get their first award through our annual Future Leader Award.
2. Developing training and events like our annual Discover conference to support skills development.

**RESEARCHERS CAN DO BIGGER AND BETTER RESEARCH TOGETHER**

With such sparse autism research funding within the UK, it is important to spend every penny in the best possible way. Through taking a more connected approach to autism research, scientific advancement can be accelerated. We can and should do more to share resources and expertise across institutions. We hope to see more multi-institutional teams working on UK autism research grants, with only six reported in 2016. We know the more people involved in studies, the more accurate research outcomes can be and data collected in one study can be helpful in many later studies. However, only one full-sized randomised controlled trial was funded in 2016 and only one project utilised secondary data. By working together, multi-site recruitment could grow trials and improved data sharing could reduce research duplication. Large grants in ‘applied’ research are only possible if people develop big ideas.

**Our plan:** Autistica is leading the way in uniting UK autism research groups and supporting collaboratively:

1. Through Discover - our national autism research network.
2. Our collaborative workshops and grants give researchers, health professionals and the autism community a platform to develop and take forward their ideas, supported by a multidisciplinary resource.
3. Working collaboratively with other funders to leverage our resource and impact.
WE CAN DO MORE TO ALIGN RESEARCH WITH COMMUNITY PRIORITIES

We believe research should answer questions raised by autistic people and their families. The number of treatment and intervention projects, which are welcomed by the community, seems to have steadily increased since 2014. In 2016, 27% of UK autism research funding was spent on the top 10 community priorities. Autistica hope to drive this figure up by directly investing in community priority areas, as well as raising awareness of the priorities among other investors. Autistica is particularly keen to address the neglected priority areas, such as social care for autistic people which appears to have received no direct research funding between 2013 to 2016.

Our plan: Autistica is committed to addressing community priorities, particularly those neglected in the past, through the following steps:

1. Working with government and charity funders to focus on those priority areas.
2. Including community priorities in our research strategy.
3. Funding research on community priorities in areas like mental health and communication and language.
4. Holding workshops and autism study groups which focus on community priorities.
5. Undertaking campaigning, policy and public affairs work on priority areas such as mental health through our #NotOneSize campaign.

WE NEED TO REPRESENT EVERY AUTISTIC PERSON IN RESEARCH

Autism is lifelong but research investment continues to neglect adolescents and older adults, with only 9% and 3% of 2016 funding spent on projects recruiting adolescents and autistic people 50 years or over respectively. Research must broaden across the entire Lifespan and autistic people of all ages should have the opportunity to participate in research. Autistica is committed to funding and campaigning for more autism Lifespan research, alongside more projects serving under-represented groups. Only three projects awarded funding in 2016 were recruiting autistic people with a learning disability.

Our plan: Autistica exists to ensure that every autistic person can live a long, healthy, happy life. To achieve this, we have:

1. Actively prioritised under-represented groups in our research strategy and our involvement promise.
2. Funding a programme of work across the Lifespan focusing on key areas including a cohort, adult diagnosis, anxiety and physical health.
3. Expanding our research database to encompass the full Lifespan.
4. Focusing on language and communication and people with complex needs through the introduction of autism study groups which aim to take strategic action to catalyse research in these areas.

NEXT STEPS

This report provides a springboard to track annual UK autism research funding trends. Collaboration between funders will get us closer to answering the most important and personal questions faced by the autistic community in order to build longer, happier, healthier lives for people on the autism spectrum.

ABOUT AUTISTICA

Autistica is the UK’s autism research charity. We work to transform the lives of autistic people by funding ground-breaking research, stimulating investment in research and campaigning for evidence-based change. We receive no direct funding from government, but work in partnership with statutory and other funders to build autism research capacity in the UK and ensure that work is focused on areas that bring greatest benefit. We work with scientists, health services, autistic people and families across the UK. Together, we can help autistic people live a long, healthy, happy life.

If you share our vision, you can support our work with a one-off or monthly gift at autistica.org.uk/donate

Join our research network Discover to receive research updates and opportunities autistica.org.uk/Discover

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Help us fund the research

Support our groundbreaking research and campaigning around mental and physical health, language and communication and epilepsy.

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