


# Involving autistic people and their families in research



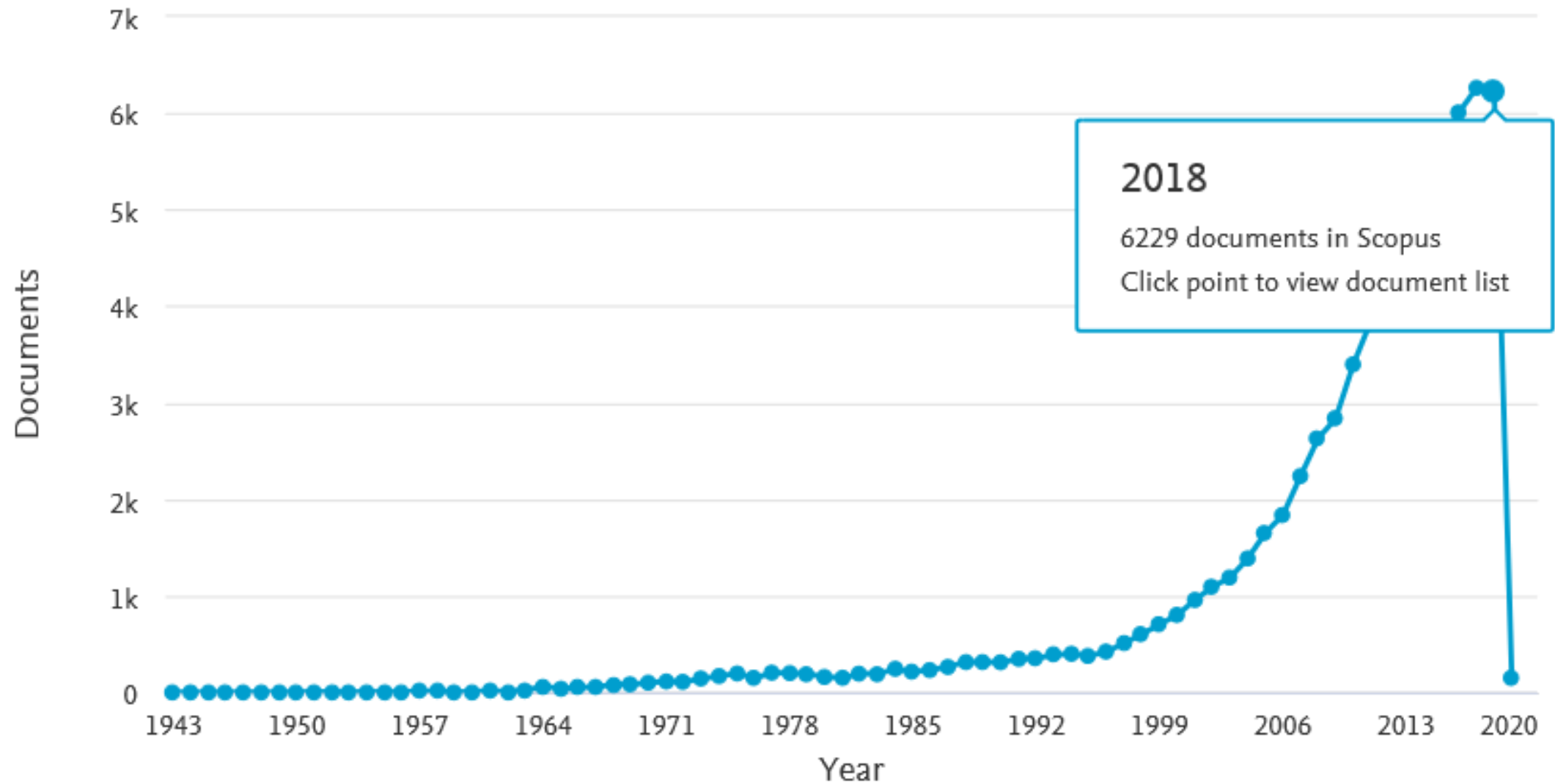
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Discover Lead

**AUTISTICA**

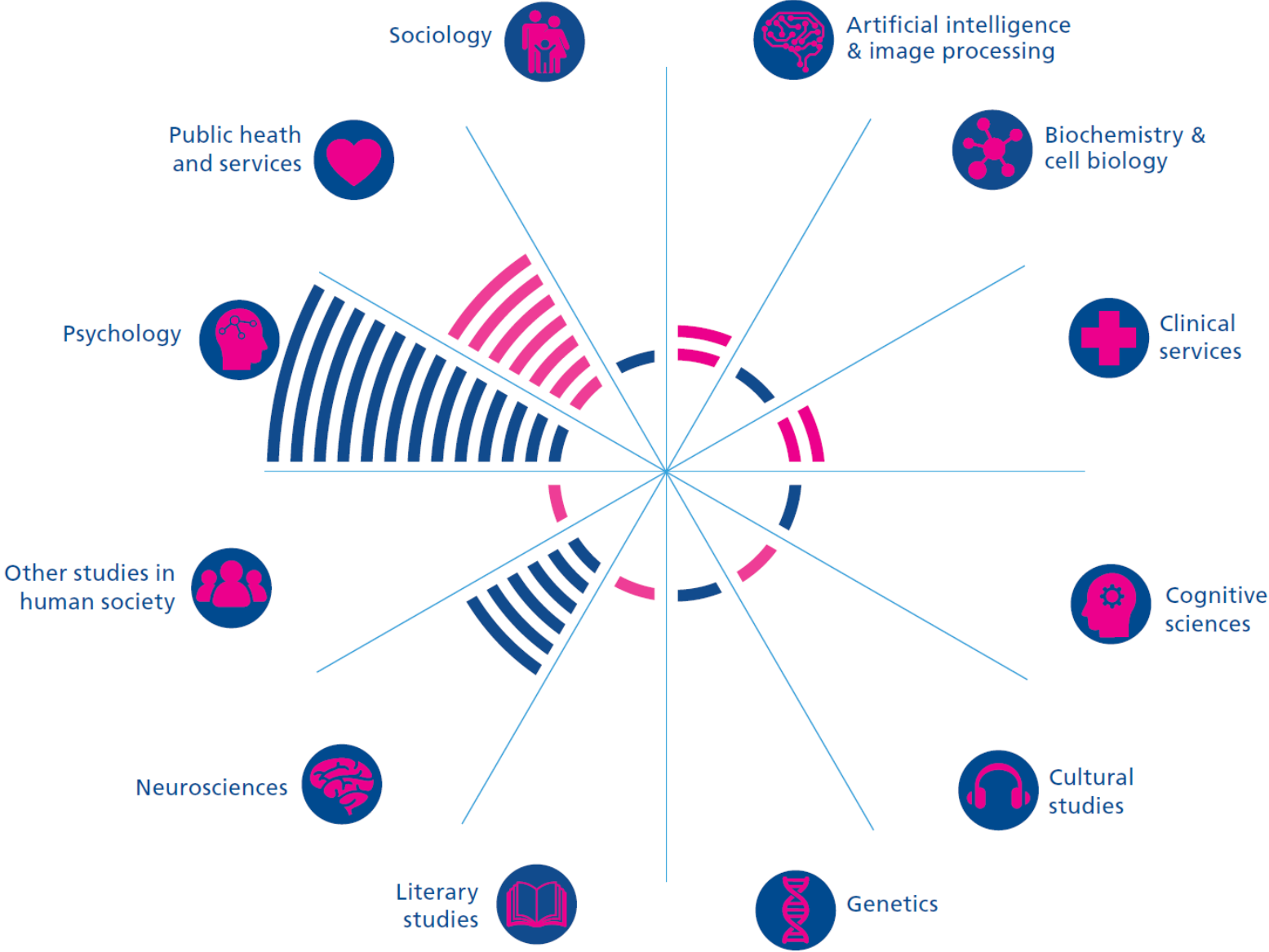
Building brighter futures through autism research

**Our vision** is a world where all autistic people and their families live a **long, healthy, happy life.**

## Documents by year



# What has autism research in the UK focused on?



# Top 10 questions for research

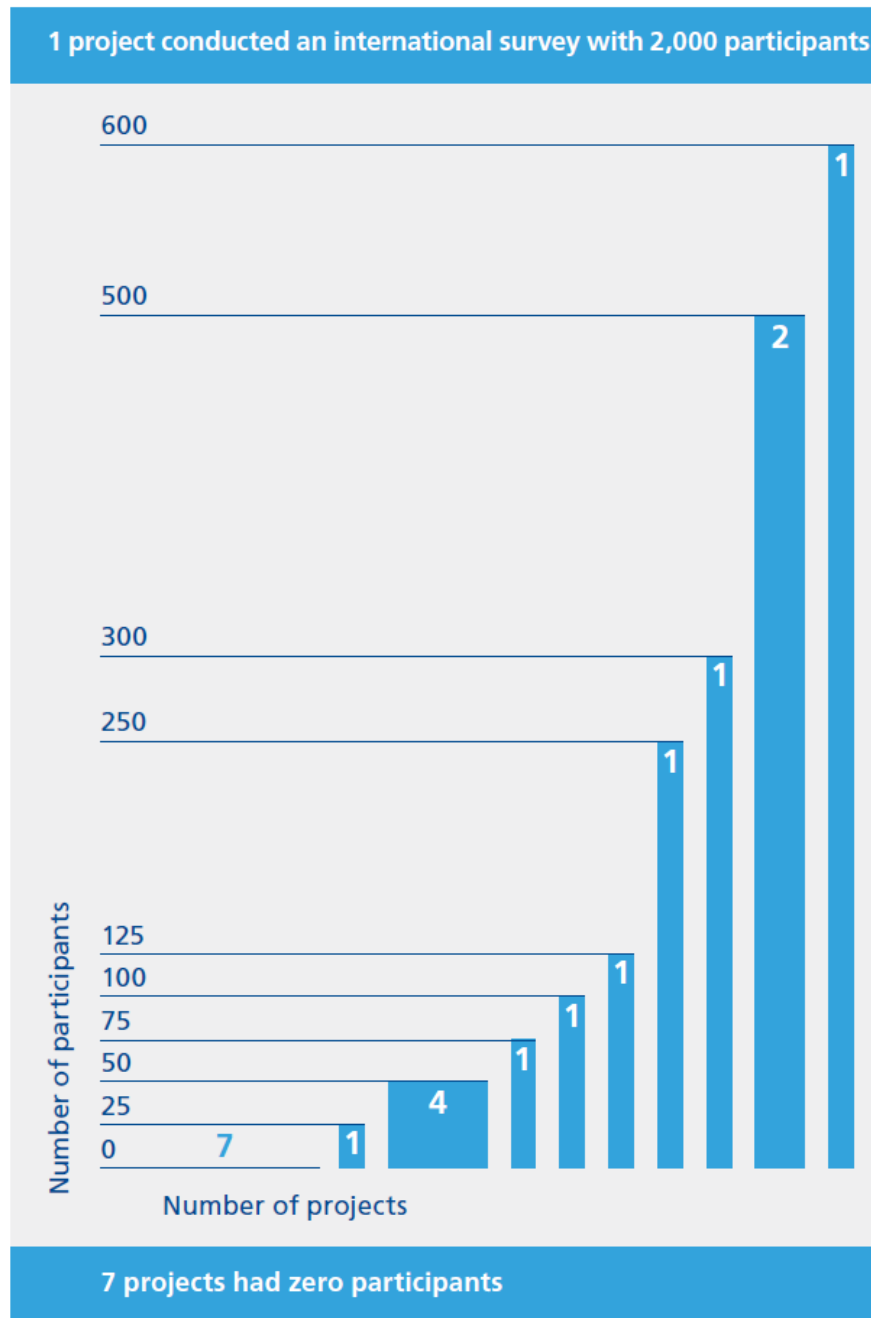


AUTISTICA  
With knowledge comes understanding



- 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?
- 2 Which interventions are effective in the development and communication/language skills in autism?
- 3 What are the most effective ways to support/provide social care for autistic adults?
- 4 Which interventions reduce anxiety in autistic people?
- 5 Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?
- 6 How can parents and family members be supported/educated to care for and better understand and autistic relative?
- 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?
- 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?
- 9 How can sensory processing in autism be better understood?
- 10 How should service delivery for autistic people be improved and adapted in order to meet their needs?

# Who has been taking part in autism research in the UK?



- Older adults (50+ years)
- Adolescents (14-17 years)
- Adults (18+ years)
- Children (0-13 years)

**44%** of UK autism research funding was spent on animal studies

**3** studies recruited people with a learning disability

**2** included minimally verbal people

Our **community**  
*is involved at all levels*

We are **confident** in our  
*vision and in autism research's  
capacity to change lives*

We **collaborate**  
*with others*

## Recent achievements

2

*Driven a new era of  
adulthood research  
through our pioneering  
programme of work at  
Newcastle.*

4

*Shown that signs of  
autism can be detected  
from six months and  
supported very early  
interventions, which have  
been shown to improve  
social communication.*

1

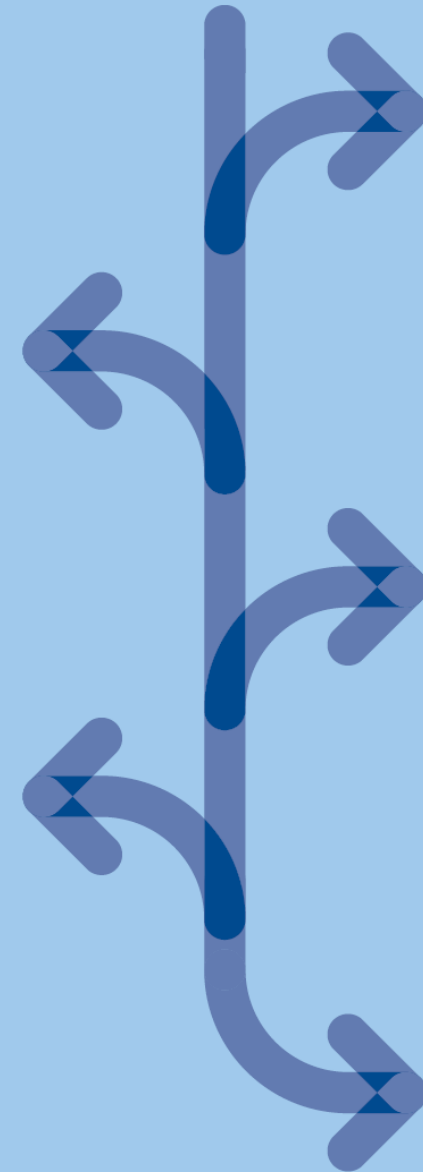
*Highlighted the  
appalling rates of  
premature death in  
autism, kickstarting a  
global response  
to save lives.*

3

*Established crucial  
research infrastructure  
such as the Discover  
autism research network  
and Autism Brain Bank.*

5

*Leveraged millions of pounds  
of further investment from  
other funders to continue our  
innovative early stage projects.*



## Our mission

- To improve outcomes for autistic people of all ages through world-class research.
- To grow autism research in the UK through innovative collaborations with other funders, campaigning for increased state investment and developing capacity and infrastructure within the research community.
- To be the bridge between researchers, policymakers and autistic people, ensuring that services are evidence-based and research responds to the autism community's needs and desires.

## Improving outcomes

We fund the translation of cutting-edge early stage scientific ideas to demonstrate their potential to other, larger funders.



## Breaking new ground

As the autism charity that acts as the bridge between science and autistic people, we make early investments in the most challenging and urgent research areas.

## Supporting people

We support the next generation of leaders in autism science, filling a critical gap in their career development.



## Driving research

We invest in new ways to support everyone working together and make previously impossible research possible. We see research through until it improves lives.



# Our research strategy

## 1 *World-class* **research**

We will launch annual schemes to support the best science and scientists

## 2 *Outstanding* **environment**

We will be a catalyst for world-class science and scientists, leading to a three-fold increase in annual UK autism research spend by 2021

## 3 *Innovative* **involvement**

Autistic people and family members will be at the heart of everything we do, increasing involvement in research through our new involvement strategy

## 4 *Clear* **focus**

We will always focus on the most urgent research priorities



“Active consideration of autistic people’s comfort and respectful discourse; wish I could bottle and take these attitudes everywhere”

Kabie Brooke, autistic advocate  
*Ageing & physical health summit*

**International summits**





## Study Groups



# Participant recruitment





## **Insight Group**



About us

## How we choose partners



**Charles Sharland Autistic Grant Scheme Award**





# AUTISTICA

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