Autism and Learning Disabilities

Competition for development funding

NHS England NHS Improvement SBRI Healthcare

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The **AHSN**Network



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Executive Summary

Living with autism and a learning disability can be difficult for patients and their families due to significant health inequalities these communities face, including lack of access to sufficient support and care, which are well documented not just in the UK but globally. Despite attempts to tackle these challenges across a range of settings and services, the pressures on healthcare systems continue to grow due to multiple factors. Service activity data and outcomes and research findings show specific issues that need to be addressed. These include: poor identification and diagnosis of autistic people and people with learning disabilities at early stages; lack of access to appropriate care and treatment; long-term evaluation of evidence-based solutions; and a strong need to support patients following diagnosis to maximise independence and minimise secondary consequences.

There are changes occurring from the work done through the 'Transforming Care Programme' that the NHS and other government bodies are doing to help deliver better treatment and care for autistic people and/or people with a learning disability and meet the ambitions set out in the NHS Long Term Plan. However, there still remains room for improvement.

This competition seeks to address three primary issues, taking into account the systemic complexity and recognising some of the key influences on care delivery. The requirement is to find innovative solutions that will tackle challenges associated with:

- 1. Early identification and diagnosis
- 2. Health inequalities and access to care
- 3. Access to effective support and services

Applicants are asked to consider whether their innovation addresses any of the above challenges, the impact of their innovation on the whole system, and to be aware of the competitive environment, even considering working together with other companies and organisations to bring forward solutions that can make a real difference.

Applicants are further asked to consider the impact of their innovation in addressing and/or alleviating variations currently experienced in autism and learning disability care, for example through addressing inequality in access to care, intersectionality (e.g. related to cultural/ethnic minority groups), and geographic disparities.

The COVID-19 emergency has forced changes in healthcare and applicants should consider that the baseline they need to innovate from may be different from that in January 2020. This competition is also open to supporting the further development and evaluation of technologies already introduced during this crisis.

Autism and Learning Disabilities

Background

Autism is a lifelong neurodevelopmental condition that affects how a person communicates with and relates to other people and how they experience the world around them. A learning disability is also a lifelong condition that presents with a significantly reduced ability to understand complex information, learn new skills, and to live autonomously without the need for everyday care support.

It is currently estimated that in the UK about 1.5 million people present some form of learning disability and that about 1 million people have been diagnosed with autism spectrum disorder. While the two are separate conditions and don't necessarily overlap, it is common for autistic people to present with a learning disability as well as other conditions like anxiety, obsessive compulsive disorder (OCD) and depression. Both conditions start in early childhood and the potential impacts of a delayed diagnosis can be wide-ranging, causing undue stress to individuals and families and increased financial costs. These are conservative numbers as many adults have never been diagnosed and it has been proven that autism can present in different ways in females than it does in males, reducing the probability of diagnosis in the former.

Diagnosing co-occurring conditions is a long and complicated process, and while the NHS aims to assess an autism referral between 13 (Northern Ireland) and 26 weeks (Wales), data obtained through a Freedom of Information request by the All Party Parliamentary Group for Autism and Norman Lamb MP in 2018 show these targets are being routinely missed¹. Moreover, the number of referrals requested through the NHS have increased since the beginning of the Covid-19 pandemic and, in November 2020, the NHS reported around 150,000 individuals in contact with learning disabilities and autism services².

Living with autism and a learning disability can be difficult for patients and their families if not provided with the right care at the right time. Delays in care are not only attributed to late identification and diagnosis, but also to health inequalities these communities face.

Autistic people and people with learning disabilities face significant health inequalities and the NHS strongly recognise this. As an example, NHS Digital reported that those with learning disabilities would be between 3.9 – 4.2 times more likely to die prematurely than those with broadly the same characteristics in the general population³. Changes implemented as part of the pandemic exacerbated these inequalities as services were distanced from carers and users, with closures of group care facilities and community-based centres, causing increased risk of mental health deterioration among these people. The Care Quality Commission (CQC) reported a significant increase in deaths among people with a learning disability and autistic people during Covid⁴. Moreover, autistic people from Black, Asian and minority ethnic (BAME) groups have particularly been experiencing challenges getting a diagnosis and access to support services.

2 - NHS Digital: https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-services-monthly-

statistics/performance-november-provisional-december-2020 /

^{1 –} Lamb N and All Party Parliamentary Group on Autism (2018) The autism diagnosis crisis. London: All Party Parliamentary Group on Autism.

 $[\]label{eq:2.1} 3 - \text{NHS Digital: https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/standardised-mortality-ratio-indicator$

^{4 -} CQC: https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability

NHS strategy - The NHS Long Term Plan targets

The NHS Long Term Plan (LTP) lists autism and learning disabilities as one of NHS England's top priorities and reports that the "whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing." This recognises that the NHS, in partnership with the wider health, social and third sector system, has a crucial role to play in helping autistic people and people with a learning disability, or both, lead longer happier and healthier lives.

The LTP seeks to:

- Improve community-based support so that people can lead lives of their choosing in homes not hospitals and to reduce waiting times for specialist services.
- Develop a clearer and more widespread focus on the needs of autistic people and their families, starting with autistic children with the most complex needs.
- Make sure that all NHS commissioned services are providing good quality health, care and treatment to people with a learning disability and autistic people and their families.
- Reduce health inequalities, improving uptake of annual health checks, and reducing over-medication and preventable deaths.

Regarding health inequalities, the NHS LTP seeks to address unwanted variation in autism and learning disability care by:

- Providing timely, effective and evidence-based support to autistic people and their families, beyond their diagnosis.
- Keeping people well with proactive care in the community.
- Ensuring that reasonable adjustments are made so that wider NHS services can support, listen to, and help improve the health and wellbeing of autistic people and people with learning disabilities, and their families.
- Ensuring that children with learning disabilities have their needs met by eyesight, hearing and dental services, are included in reviews as part of general screening services and are supported by easily accessible, ongoing care.
- Continuing to improve access to care in the community, so that more people can live in or near to their own homes and families.
- Accelerating the Learning from lives and deaths People with a learning disability and autistic people (LeDeR) initiative to identify common themes and learning points and provide targeted support to local areas.

Furthermore, the NHS strategy also includes ambitions to become the world's first net zero national health service. The "<u>Delivering a Net Zero Health Service</u>" report sets out the ambition and two evidence-based targets, which include:

- To reduce direct emissions (NHS Carbon Footprint) and reach net zero by 2040, with an ambition to reach an 80% reduction by 2028 to 2032;
- To reduce influenced emissions (NHS Carbon Footprint Plus) and reach net zero by 2045, with an ambition to reach an 80% reduction by 2036 to 2039.

Laid out in the NHS LTP, sustainability commitments range from reducing single-use plastics and water consumption, through to improving air quality. The Greener NHS National

Programme exists to drive this transformation while delivering against broader environmental health priorities.

The challenge

Autism and learning disabilities communities are making great strides towards delivering the NHS LTP ambition via a number of national programmes. However, there is recognition that this effort needs to go further faster. Therefore, NHS England and NHS Improvement (NHSEI) are looking for innovations or new approaches that will support these ambitions.

This competition is open to all types of innovations, including but not limited to, medical devices, in vitro diagnostics, digital health solutions, software, artificial intelligence, services or new models of care.

Under the overall theme of "Autism and Learning Disabilities", three categories have been identified via consultation with clinicians and other stakeholders working in provision of care across the spectrum. Applicants are expected to respond to one of the three categories and should consider if their solution is specific to or can be tailored to other categories, whilst being mindful of the broader impact on the autism and learning disabilities care system.

Applications may fit multiple themes, however, you may only select one category on the application portal so please select the most appropriate. Please note that the funding envelope is for the entire competition rather than specifically split between challenges or themes, so there is no advantage or disadvantage to selecting a specific category theme.

Category 1: Early identification and diagnosis

Background

Diagnosis of autism and learning disabilities is often based on observation of atypical behaviours that are difficult to accurately identify. In addition, autistic people are likely to have other cooccurring conditions, e.g. attention deficit hyperactivity disorder (ADHD), which can make it difficult to identify autism. Therefore, many autistic people and/or people with a learning disability are often left unidentified and unsupported, which can be distressing for the undiagnosed person and their family members, resulting in difficult behaviours, the development of long-term mental health issues, and exclusion from opportunities to participate in society.

Early identification and diagnosis of autism and learning disabilities, and effective support pathways can have a significant impact on patients' lives as, once diagnosed, an individual can better understand themselves and their needs and be given access to the right care services. Social care staff and carers/family members play a key role in identifying autism and learning disabilities at early stages, however, they are often not fully equipped or provided with sufficient resources/skills to do so.

Potential solutions

1. Technologies that can improve the identification and diagnosis of autism and learning disabilities across all age groups, including children through early years provision (that includes Health Visitors, School Nurses and educational settings), as well as adults.

2. Innovations to improve awareness/vigilance of signs and symptoms of autism and learning disabilities, including vague symptoms and/or support assessments of complex cases to differentiate autism/learning disabilities from other multiple conditions, e.g. ADHD, dyslexia, executive dysfunction. This can include, but is not limited to, technologies that can risk stratify patients with less severe symptoms of autism and learning disabilities and flag individuals with complex support needs, as well as educational tools for families/carers.

4. Technologies that provide better links and communication channels between stakeholders to support ongoing engagement and completion of diagnostic pathways.

5. Tools to upskill the health and social care workforce, and auxiliary services (e.g. in education settings) and provide them with the knowledge, skills and evidence-based resources to carry out earlier and more effective assessments, including but not limited to enhanced links between social care, primary and secondary care.

6. Technologies that can support a more effective triage for people already in the diagnostic pathway to ensure that they are directed to the most appropriate services.

Category 2: Health inequalities and access to care

Background

Autistic people and people with learning disabilities face significant health inequalities that have created challenges and barriers to accessing care and support services. Furthermore, pressures on specialist services in the NHS are high, creating a back-log of waiting lists and delaying access to care, particularly in light of the Covid-19 pandemic. The lack of sufficient access to care and appropriate support have far-reaching consequences, including deterioration of mental health and rising rates of premature deaths at significantly greater levels than the general population.

Potential solutions

1. Assistive and self-management technologies that can support therapeutic interventions in home and community settings.

2. Technologies that can improve the quality of patient information stored and create meaningful data that can help identify those requiring specialist services, and identify alternative support pathways for those who do not fit the criteria and clinical thresholds.

3. Tools that provide support to patients living in remote and rural settings that may experience reduced access to services in both primary and secondary care, and suffer from poor digital health literacy.

4. Tools that can identify those at risk of experiencing health inequalities, taking into account various factors including age, gender, socioeconomic standings, and ethnic backgrounds.

Category 3: Access to effective support and services

Background

Autism and learning disabilities are lifelong conditions that often require support to improve people's wellbeing, development, and autonomy. In particular, as autistic people and/or people with learning disabilities grow up, the transition from childhood to adulthood can be difficult when they are confronted with everyday life that is constantly changing and challenging, such as the transition from school to employment.

Carers/families often play a key role in supporting autistic people and people with learning disabilities, however, they too experience difficulties in accessing vital information, support and guidance. There is a desperate need to support carers and families to better navigate care pathways and to provide effective managing and adaptive coping strategies and resilience building.

Potential solutions

1. Technologies that can leverage existing services available, such as local community and peer support groups, to help autistic people and people with learning disabilities and carers/families to manage their conditions and support needs by accessing reliable, credible and relevant sources of information about the diagnostic process, support pathways and targeted treatments for related conditions, e.g. communication, anxiety, etc.

2. Technologies that provide information and visibility to support services available, such as financial and housing support, navigating the post-diagnosis landscape, and access to the right services and support that enable autistic people and people with learning disabilities to live longer, healthier and happier lives.

3. Technologies that offer remote care and monitoring of patients to provide continual and effective communication between healthcare professionals and patients and to de-risk the development of life-threatening conditions.

4. Tools that can improve collection of data from Annual Health Checks (learning disability) which would support improvements in planning and decision-making and/or would enhance links between parts of the health and social care system in relation to an individual's needs, treatments etc. with a focus on reducing unnecessary admissions and rapid discharge from secondary care to community settings.

5. Technologies that can ensure access to effective and continued support to hospitalised patients to improve their quality of life and health outcomes.

Useful Information for Applicants

Innovations on the radar



Given the importance and long-term nature of this challenge, there are many products already in the market or in later development. It is important that potential applications for this competition carefully consider the competitive landscape.

It may even be appropriate to consider partnering with another solution provider to generate something even more compelling that addresses the challenge systematically.

The list below illustrates some examples of innovations that have been funded by national programmes with the potential for addressing autism and learning disability issues (it is not intended to be an exhaustive list):

- The NIHR funds large numbers of studies and people to develop evidence to support
 effective changes of practice. Examples include: <u>SoundFields</u> a virtual reality therapeutic
 framework for children with autistic spectrum disorder. SoundFields integrates a range of
 sounds paired with reward during a virtual reality (VR) game. It has previously been used
 by young autistic children and was found to be helpful in reducing sound-associated
 anxieties.
- The NHS Innovation Accelerator has supported innovations such as <u>Brain in Hand</u> a digital self-management support system for people who need help remembering things, making decisions, planning, or managing anxiety, including autistic people. The system is approved by government departments and is in use throughout health, social care and higher education settings across the UK. It has also supported <u>RIX Wiki</u> an accessible multimedia communication, planning and information-sharing tool developed with and for people with learning disabilities alongside their carers, families and professionals. The software enables autistic people and people with learning disabilities to share personal health and care information for effective person-centred support in their communities.

Technologies excluded from this competition

There are a number of technologies or types of solutions which are already available, sometimes from multiple suppliers, these are listed below. Any technologies that negatively impact staff workloads will also be excluded.

- Digital technologies that will not easily integrate or communicate with NHS/community setting systems. Some evidence of interoperability and/or work to assess this will be required.
- Technologies that do not comply with GDPR policies.
- Technologies that will increase health inequalities and inequity of access to care e.g. digital technologies that are inaccessible to certain communities that experience digital poverty.

Innovations that are not co-designed with autistic people and people with learning disabilities.

Eligibility

The competition is open to single organisations (contracts are executed with individual legal entities) based in the UK or EU from the private, public and third sectors, including companies (large corporates and small and medium enterprises), charities, universities and NHS Foundation Trusts, as long as a strong commercial strategy is provided. Organisations based outside the UK or EU with innovations in remit for this call can apply as subcontractors of a lead UK/EU based organisation or via a UK or EU subsidiary.

Collaborations are encouraged in the form of subcontracted services as appropriate.

Allowable costs and duration

The project will be 100% funded up to the value of \pm 100,000 (NET costs, excl. VAT) for a maximum of 6 months. Project costs can include:

- Labour
- Materials
- Capital equipment
- Subcontractor
- Travel & subsistence
- Indirect

Please ensure the proposed project deliverables could be reasonably achieved within the proposed contract duration, and all requested costs are justified and represent fair market value.

Please note that SBRI is a pre-commercial procurement process and the resulting development contract is subject to VAT. VAT is the responsibility of the invoicing business.

Expected exit points

At the end of Phase 1, projects are expected to have established the technical merit, feasibility, and commercial potential of the proposed technology.

Example of exit points include:

- Feasibility technical study
- Market validation
- Business plan developed
- Clinical partners identified
- Evidence generation plan for adoption

- Development of PPIE strategy
- Health inequalities impact assessment

Additional considerations

Those submitting applications are also asked to consider:

- How will the proposed solution impact the care system and how will the system need to be changed (including people, processes and culture) in order to deliver system-wide benefits?
- How will you ensure that the innovation will be acceptable to patients (and their families and wider support network) and to health and social care workers? How could these groups be involved in the design of a solution and its development?
- How will you ensure that the innovation is affordable to the NHS and wider system such as Integrated Care Systems (ICSs) both immediately and throughout the life of the product? What evidence, both health economics and delivery of true impact will the NHS and wider system require before the technology can be adopted?
- How will you ensure that the innovation enhances equity of access (e.g. takes account of underserved ethnic or economic groups) and helps the NHS towards its target to reach net zero carbon?
- For digital innovations, the <u>NICE Digital Health Technology Framework</u> should be consulted and your application should evidence your plan to meet the appropriate evidence guidelines. In addition, please consult the NHSX guidelines for "<u>Designing and building</u> <u>products and services</u>" for the latest links to relevant standards, guidelines and consultations. In addition, universal design principles for accessibility and inclusion should be considered and the following guidelines consulted: <u>European Commission Digital</u> <u>Inclusion Strategy 2022</u>, <u>European Union Rights of Persons with Disabilities 2021-2030</u>, <u>National Autism Strategy</u>.
- Innovators should also demonstrate they are aware of the competitive environment, even considering working together with other companies to bring forward solutions that can make a real difference.
- Applicants should take into account the baseline they need to innovate from, having taken into consideration the forced changes brought by the COVID-19 pandemic.
- Given the rural nature of many places with need, barriers associated with digital interventions requiring wifi connectivity should be comprehensively considered (wifi and phone signals in rural locations may be weak or unreliable).
- Furthermore, consideration should be taken towards the scalability of the technology and the necessary adaptations for different service user groups.

The SBRI Healthcare Programme

A new national Small Business Research Initiative (SBRI) Healthcare competition is being launched by NHS England and NHS Improvement in partnership with the Academic Health Science Networks (AHSNs) to identify innovative new products and services. The projects will be selected primarily on their potential value to the health service and social care system and on the improved outcomes delivered for those in receipt of care.

The competition is open to single companies or organisations from the private, public and third sectors, including charities. The competition runs in two phases (subject to availability of budget in 2022/23):

- Phase 1 is intended to show the technical feasibility of the proposed concept. The development contracts placed will be for a maximum of 6 months and up to £100,000 (NET costs, excl. VAT) per project.
- Phase 2 contracts are intended to develop and evaluate prototypes or demonstration units from the more promising technologies in Phase 1. Only those projects that have completed Phase 1 successfully will be eligible for Phase 2. The number of available Phase 2 awards is subject to budget availability.

Developments will be 100% funded and suppliers for each project will be selected by an open competition process and retain the intellectual property rights (IPR) generated from the project, with certain rights of use retained by the NHS.

The competition opens on Monday 23rd May 2022. The deadline for applications is at 13:00 BST on Wednesday 6th July 2022.

Application process

This competition is part of the Small Business Research Initiative (SBRI) programme which aims to bring novel solutions to Government departments' issues by engaging with innovative companies that would not be reached in other ways:

- It enables Government departments and public sector agencies to procure new technologies faster and with managed risk;
- It provides vital funding for a critical stage of technology development through demonstration and trial especially for early-stage companies.

The SBRI scheme is particularly suited to small and medium-sized businesses, as the contracts are of relatively small value and operate on short timescales for Government departments.

It is an opportunity for new companies to engage in public sector customer pre-procurement. The intellectual property rights are retained by the company, with certain rights of use retained by the NHS and Department of Health. The application process is managed on behalf of NHS England and NHS Improvement by LGC Group. All applications should be made using the application portal which can be accessed through the <u>Research Management System</u>. Applicants are invited to consult the Invitation to Tender and the Portal Guidance; a template Application Form and Frequent Asked Questions are also accessible. All documents are available on the <u>SBRI Healthcare website</u> to help prepare your proposal.

A briefing event for businesses interested in finding out more about this competition will be held on **24th May 2022, 11:00 - 13:00 BST.** An additional webinar event will be organised to respond to potential applicant's questions. Please check the <u>SBRI Healthcare website</u> for confirmation of dates, information on how to register, and details of the challenges that will be presented at the event.

Please complete your application using the <u>online portal</u> and submit all relevant forms by **13:00 BST** on **Wednesday 6th July 2022.**

Key dates

Briefing online event	24 May 2022 (11:00 - 13:00 BST)
Competition launch	23 May 2022
Deadline for applications	06 July 2022 (13:00 BST)
Assessment	July/August 2022
Selection Panels	September 2022
Contracts awarded	October 2022

More information

For more information on this competition, visit: https://sbrihealthcare.co.uk/

For any enquiries e-mail: sbri@LGCGroup.com

For more information about the SBRI programme, visit:

https://www.gov.uk/government/collections/sbri-the-small-business-research-initiative





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