

AUTISTICA

Building brighter futures through autism research

SHAPe, the Sowerby Health intervention for Autistic People (SHAPe) study: Annual GP health checks for autistic adults to improve primary health access and address mortality and co-morbidities of autistic people.

Research commission: GUIDANCE FOR APPLICANTS

Introduction

Autistica is the UK's national autism research charity. Our vision is a world where all autistic people and their families live a long, healthy, happy life. We aim to achieve this mission by focussing on delivering world-class autism research.

Last year, Autistica launched a report *Personal Tragedies, Public Crisis* to highlight the appalling rates of early death in autistic people relative to the general population. In the report we promised to fund research to address this unacceptable disparity in life expectancy. One method which has shown to be effective for addressing health inequalities in under-served groups is periodic health checks.

The aim of this research commission is to bring the best people together to develop and trial a world-class personalised health checks programme for autistic adults supported by a pre-appointment digital tool, funded thanks to the generosity of the Peter Sowerby Foundation.

Who we need

Work package 1 – Health check

We are looking for a world-class multi-disciplinary research team working across the UK in multiple institutions who are clearly committed and passionate about dramatically improving the health of autistic people. Teams will include:

- Clinical researchers/researchers with clear experience in autism, quantitative research, qualitative research, trial design and research in General Practice medicine.
- General Practitioners and clinical commissioners
- Autistic people
- Parents or caregivers with experience of autism
- Statisticians, researchers with statistical knowledge or access to statistic-based advice
- Health economists

Work package 2 – Pre-health check digital tool

The pre-appointment digital tool will allow autistic adults to read, answer and prepare in advance for questions they may be asked in a health check, and should consider including collecting some biodata through e.g. accelerometers. In addition, information about the autistic person will be fed back to the GP to ensure they are prepared for the appointment.

For the digital tool we therefore require:

- Experience of developing effective, accessible digital assets
- Experience of autism-enabling user design
- Understanding of how digital tools can integrate with existing GP computer systems

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We would like to hear the research team explain how they would develop the digital tool. However, the team may decide to outsource aspects of this work, if it is deemed to be in the best interests of the project.

What we expect

We want the research team to build upon existing tools developed for autism and related areas such as learning disabilities to design a health check which could function effectively within the UK's health systems and work for every autistic adult (WP1). The pre-appointment digital tool will support autistic people and clinicians before, during and after an appointment and will be created by a research team with substantial experience in this area (WP2).

Oversight committee and monitoring

We will convene an oversight committee made up of researchers, autistic individuals, parents and clinicians to guide the project and provide recommendations to the research team, which will meet twice a year. Meetings will take place in September 2018, January 2019, June 2019, January 2020, June 2020 and January 2021.

Project structure

The funded project will be delivered as follows.

Activity	Cost	Start date	End date	Budget	Report to Autistica
Phase 1: Identification (WP1) Qualitative and quantitative research to understand the blockers to General Practice access.	£30,000	2018 Q3	2018 Q4	August 2018 (£30,000)	Report due in January, 2019 GO-NO GO POINT 1 If blockers to GP access are identified, we would proceed to phase 2. If no blockers are identified, we would stop.
Phase 2: Feasibility (WP1) Create an autism-specific physical health checklist, and validate with autism community and GPs. Design an autism-specific health check in consultation with autistic people and test with sample observers.	£30,000 £55,000	2019 Q1 2019 Q2	2019 Q2 2019 Q4	December 2018 (£259,256)	Report due in April 2019 and January 2020. GO-NO GO POINT 2 If the checklist and digital tool are deemed feasible, we will proceed to phase 3. If unfeasible, we would stop.
Digital tool (WP2) Focus groups and analysis to inform content and design.	£22,393	2019 Q1	2019 Q2		

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Development of the tool and testing.	£104,200	2019 Q2	2019 Q4		
Dissemination and launch.	£47,663	2019 Q4	2020 Q2		
Phase 3: Acceptability (WP1) Undertake a pilot trial to understand the acceptability of the health check to GPs and autistic people in GP settings.	£140,000	2019 Q4	2020 Q4	October 2019 (£165,000)	Report due in March 2020, September 2020 and final report in January 2021.
Cost-effectiveness (WP1) Undertake cost-benefit analysis	£25,000	2020 Q4	2020 Q4		GO-NO GO POINT 3 If the health check is deemed acceptable and cost-effective, we would proceed to the second part of phase 4. If not, we would stop.

Eligibility

Applications will only be accepted from principal investigators holding permanent appointments at academic, research or clinical institutions within the United Kingdom. Investigators must be in receipt of salary funding for the duration of the grant requested. Eligibility must be demonstrated with a letter from your institution at the time of submitting the Letter of Intent (LOI).

- a. Applicants who do not meet the eligibility criteria above (e.g., postdoctoral fellows) are eligible to apply only if clear documentation is provided by the host institution stating that the contract is in place throughout the duration of the proposed research.
- b. Proposals may be submitted in partnership with companies. In circumstances where the company receives funds from the grant a clear justification must be given for this at the full proposal stage, as well as a statement on what the company is contributing to the project directly.
- c. Applications will only be accepted from individuals or from companies to support the research and development of products for profit if Autistica are entitled to a share of any such profits to re-invest in our research programme.
- d. Applicants are restricted to one LOI/proposal as Principal Investigator (PI) or Co-PI for this programme.
- e. The bulk of the proposed research must be conducted within the UK, although it is not ruled out that a proportion of the proposed research be conducted as part of an international collaboration.
- f. Applicants should state whether they are applying to work on Work Package 1 and/or 2.

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Award

Autistica will make one award which may be split between Work Packages and institutions. This award is made subject to the go/no-go points described above.

Autistica only pays direct costs (directly charged to a project as money spent and supported by an audit record). Autistica does not pay indirect costs (costs for resources used by a project that are shared by other activities (e.g. proportion of lead investigator or shared technician's time) or directly allocated costs (non-specific costs charged across all projects for underpinning resources (e.g. estates, shared IT and administration)). As we are an AMRC member, Autistica grants are eligible for top-up via the Charity Research Support Fund to cover indirect costs.

Application process

Letter of intent stage

We will review all letters of intent (LOIs). We will invite one research team forward to submit a full application. The method of submission of LOI is through our new grant management system at our [website](#) (we expect our system will accept applications from the 12th January).

The predicted deadline date LOIs is Friday 16th February 2018 (this will be confirmed by the 12th January). All deadlines are at 11:59 PM local UK time. Autistica reserves the right to return without review any LOI found to be not in compliance with the policies, procedures and priorities outlined in the call for proposals.

The LOIs will be reviewed by our Scientific Review Panel. We aim to notify applicants whether they are the chosen research team by Friday 23rd February 2018.

Full application stage

The chosen research team will then be required to submit a full application by Friday 18th May 2018.

The application will be reviewed by external reviewers and our Scientific Review Panel.

Application information and formatting

The LOI should be detailed enough to be screened for scientific merit. It must contain two parts: (i) an outline of the research project, and (ii) a letter from the institution confirming the applicant's eligibility. Please refer to the Eligibility section above.

For the first part you will be expected to give the following information via the online application system:

- A. Project title.
- B. A concise description of the proposed project including the headings: background; specific aims; methods; expected results.
- C. A clear justification of why the project fits the call specification and Autistica's objectives.

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- D. Names, titles and institutional affiliations of active collaborators/co-investigators in addition to and including the PI (excluding consultants, postdoctoral fellows, students and technicians).
- E. Indicative duration and budget of the project should be in keeping with the specification

The content of the first part should equate to three A4 pages (11 point Helvetica/Arial text, single spaced, with 1" margins) or less.

The second part, one page maximum, must be a letter from the institution confirming the applicant's eligibility. Please refer to the Eligibility section above. This letter should be uploaded to the online application system as a PDF file.

Applications with any sections that exceed the page limits will not be reviewed.