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Evaluation of a primary care health check for autistic adults

Submission date
14/07/2022

Recruitment status
No longer recruiting

Registration date
20/07/2023

Overall study status
Completed

Last Edited
06/06/2025

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[X] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims
Autistic people are on average more likely to experience poor health than non-autistic people. Some autistic people don't seek healthcare because health professionals and services don't provide the adjustments needed. Health checks identify some important conditions that affect health and wellbeing and are available to some people through the National Health Service (NHS). We have co-designed a primary care health check for autistic adults in partnership with autistic people, carers and supporters, and primary care staff and will now evaluate this health check. The health check aims to improve autistic people's access to and engagement with primary care services and ultimately improve their health, wellbeing, and quality of life. This study aims to test the health check for autistic adults in NHS Primary Care (General Practice) to see if it is acceptable to autistic people, whether it improves the health of autistic people, and whether it is feasible to deliver in the NHS.

Who can participate?
1. Autistic adults (aged 18 years old and over) registered at participating General Practices whose autism diagnosis is known to their GP.
2. Carers and supporters of the autistic adults participating in the study, aged 18 years old or over, if they attend the health check appointment with them
3. Primary care staff involved in delivering the health check

What does the study involve?
General Practices taking part in the study will be randomly allocated to either deliver the health check or continue to provide care as usual. Autistic adults registered at these General Practices who meet the inclusion criteria will be invited to take part in the study. All autistic adults taking part in the study will complete some questionnaires about their health and wellbeing and use of health and social care services at the time of joining the study and at 3, 6, and 9 months. Information on the autistic person's health, social and care needs will be gathered from their GP health record at 9 months.

Autistic adults whose General Practice is delivering the health check will be offered a health check after completing the initial questionnaires. The health check involves completing a questionnaire and attending a health check appointment. The questionnaire asks about the

individual's needs, to inform any adjustments to standard practice that might be needed, and about their general health and wellbeing. The health check appointment covers health promotion, screening, vaccinations, a brief physical assessment, and additional topic areas relevant to an autistic person, such as sleep and mental health. Autistic adults who have a health check, carers and supporters who attend with them, and Primary Care staff delivering the health check, will be asked to complete a brief questionnaire about their experience. Some will also be invited to be interviewed to gather further information about their experience.

What are the possible benefits and risks of participating?
Benefits: The health check might improve the health, wellbeing and quality of life of autistic people. It may also improve the lives of relatives, carers and supporters of autistic people. By taking part, participants will be helping to find out if the health check is acceptable to autistic people and whether it is possible to deliver in NHS services. We will also get information about whether the health check is effective in identifying and meeting autistic people's health needs. Providing training to General Practices delivering the health check during the trial, and those providing care as usual after the trial may also improve Primary Care staff's knowledge of autism, the adjustments that services should consider providing and raise awareness of the health needs of autistic people. This training may be delivered across the UK after the trial.

Risks: Some people find engaging with healthcare services stressful. The questionnaire completed as part of the health check, asks about things that can help the person to attend and engage with the health check appointment and the General Practice will do their best to put in place these adjustments. Completing the questionnaires may take some time which may cause some inconvenience, but we have tried to keep this time to a minimum. We know some autistic people can find being interviewed uncomfortable so we will provide information beforehand so they can prepare their answers if they would like to. We will conduct the interviews at a convenient time and place and offer the choice of the interview being done in person, online, by telephone or by text or email. We will also offer the option to bring a friend, relative, carer or advocate, with them to the interview.

Where is the study run from?
The study is being led by Professor Jeremy Parr and Dr Barry Ingham at Newcastle University (UK) alongside a consortium of autistic people, health professionals, representatives of the National Autistic Society and experienced autism researchers. The study is sponsored by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW).

When is the study starting and how long is it expected to run for?
September 2018 to May 2025

Who is funding the study?
The study is jointly funded by the UK research charity Autistica and National Health Service England (UK)

Who is the main contact?
Professor Jeremy Parr (Newcastle University), Jeremy.Parr@ncl.ac.uk (UK)

Contact information

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Principal investigator

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Scientific

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Additional identifiers

Integrated Research Application System (IRAS)
272808

Central Portfolio Management System (CPMS)
49641

Study information

Scientific Title
Evaluation of the clinical and cost effectiveness of a health check for autistic adults in NHS Primary Care, and the factors important for implementation

Study objectives
Principal research question: Is a primary care health check for autistic adults effective at identifying unmet needs for autistic people when compared with usual care?

Secondary research questions: Is the health check feasible and acceptable to deliver in NHS primary care? Is there evidence of cost-effectiveness?

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 23/06/2021, Wales Research Ethics Committee 5 (Bangor Health and Care Research Wales, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff , CF11 9AB, United Kingdom; +44 (0) 2920 785738 ; Wales.REC5@wales.nhs.uk), ref: 21/WA/0196

Primary study design
Interventional

Study design
Randomized interventional

Study type(s)
Treatment

Health condition(s) or problem(s) studied
Autism spectrum disorder

Interventions
GP practices will be randomised to either a health-check arm (delivering the health check) or a usual-care arm. GP practices in the health check arm will be trained on autism and the delivery of the health check by the research team following randomisation.
The health check comprises two parts:
1. The participant will be asked to complete a pre-appointment questionnaire by their GP practice
2. The participant will be invited to attend a health check appointment by the GP practice
The pre-appointment questionnaire asks about the individual's needs (to inform any

adjustments to standard practice that might be needed to help them attend and engage with the health check) and information about their general health and wellbeing. A summary report of this information will be generated and added to the participant's health records in preparation for review by the clinician prior to their health check appointment. An appropriate clinician will complete the health check using the clinician template and taking into account the information in the pre-appointment questionnaire summary report. GP practices will offer flexibility around how the health check appointment is conducted (e.g. face to face, via video or via telephone) in line with clinician and participant preferences. The health check covers health promotion, screening, vaccinations, a brief physical assessment, and additional topic areas relevant to an autistic person, such as sleep and mental health. We anticipate the health check will take 30-45 minutes. At the end of the health check, the clinician will record the health and social needs identified in a health action plan and offer the participant a written copy. The clinician will also arrange any tests, interventions and onward referrals needed as part of NHS care.

Intervention Type
Other

Primary outcome(s)
Incidence of new health needs/conditions detected and met at 9 months measured by gathering relevant information from the participant's GP health records using a Health Records Data Collection Form at 9 months

Key secondary outcome(s)
1. Extent of health monitoring and health promotion needs being met at 9 months measured by gathering relevant information from the participant's GP health records using a Health Records Data Collection Form and a Lifestyle Outcomes Questionnaire at 9 months
2. Incidence of social needs identified at 9 months measured by gathering relevant information from the participant's GP health records using a Health Records Data Collection Form at 9 months
3. Health check acceptance and refusal rates measured by gathering relevant information from GP Practices delivering the health check post-health check
4. Views of autistic people and professionals, and where appropriate carers and supporters, about the acceptability of the health check, its utility, and future use measured using a Health Check Evaluation Questionnaire and semi-structured interviews post-health check
5. Information about the digital version of the pre-appointment questionnaire (e.g. time to complete and whether completed in one visit) measured using a Health Check Evaluation Questionnaire and semi-structured interviews post health check
6. Serious adverse events measured using the Serious Adverse Event form
7. Change in participant or carer-related general health measured using:
7.1 EQ-5D-5L at baseline, 3, 6, and 9 months
2.2 Short-Form Health Survey version 2 (SF-36 v2) at baseline, 3, 6, and 9 months
7.2 Primary Care Outcomes Questionnaire (PCOQ) at baseline, 3, and 9 months
8. Changes in primary and secondary health and social care resource usage and costs measured using a Health Resource Usage Questionnaire at baseline, 3, 6, and 9 months
9. Healthcare costs per participant to the NHS and PSS over 9 months for each area of resource use measured using a Health Resource Usage Questionnaire and Health Check Evaluation Questionnaire at 9 months
10. Participant and care-borne costs at 9 months will be measured using a Time and Travel Questionnaire at 9 months
11. Utility scores derived from response to the EQ-5D-5L and SF-36 v2 questionnaires at

baseline, 3, 6 and 9 months
12. Incremental cost per Quality Adjusted Life Year (QALY) at 9 months
13. Cost-effectiveness acceptability curves (CEACs) to assess the probability of each of the interventions being considered most cost-effective at different willingness to pay (WTP) thresholds for a gained QALY

Completion date
31/05/2025

Eligibility

Key inclusion criteria
1. Autistic adults (aged 18 years old and over) registered at participating general practices, whose formal autism spectrum diagnosis is known to their GP; participants have had an autism diagnosis given by a NHS Multidisciplinary team.
2. Carers and supporters of autistic people
3. GP Practice staff involved in delivering the health check to autistic adults

Participant type(s)
Patient, Health professional, Carer

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Sex
All

Total final enrolment
260

Key exclusion criteria
1. Aged 17 years and under
2. Participants with no formal diagnosis of autism spectrum disorder
3. Attendance at an NHS learning disability health check in the last 12 months or who are anticipated to attend one in the next 3 months
4. Unable to consent and do not have a relative or supporter who can support them or who can answer on their behalf
5. Final stages of a terminal illness
6. GP considers it inappropriate to invite them (e.g. due to family circumstances such as a recent bereavement)

Date of first enrolment
28/02/2023

Date of final enrolment
31/07/2024

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
GP Practices in the North East and North Cumbria regions of the National Institute of Health Research Clinical Research Network
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-
United Kingdom
-

Study participating centre
GP Practices in Yorkshire and Humber regions of the National Institute of Health Research Clinical Research Network
-
-
United Kingdom
-

Study participating centre
GP Practices in North West Coast and Greater Manchester regions of the National Institute of Health Research Clinical Research Network
-
-
United Kingdom
-

Study participating centre
Newcastle University
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Sponsor information

Organisation
Cumbria Northumberland Tyne and Wear NHS Foundation Trust

ROR
https://ror.org/01ajv0n48

Funder(s)

Funder type
Government

Funder Name
Autistica

Alternative Name(s)

Funding Body Type
Private sector organisation

Funding Body Subtype
Other non-profit organizations

Location
United Kingdom

Funder Name
NHS England

Results and Publications

Individual participant data (IPD) sharing plan
The anonymised datasets generated during and/or analysed during the current study will be available upon request from Professor Jeremy Parr, Jeremy.Parr@ncl.ac.uk in line with the study data management plan.

Added 05/02/2024:
Quantitative and qualitative data will become available from June 2026 until 2034. The data will shared with academic and health service professionals for pre-specified analyses through a

contract with Newcastle University as decided by the Chief Investigators and Health Checks for Autistic Adults Consortium. Consent from participants has been obtained and there are no ethical or legal restrictions.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		31/12/2024	02/01/2025	Yes	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes