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Improving the health of older autistic people: tailored healthcare adjustments

Submission date
11/06/2019

Recruitment status
No longer recruiting

Registration date
23/09/2019

Overall study status
Completed

Last Edited
23/09/2019

Condition category
Mental and Behavioural Disorders

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

Plain English summary of protocol

Background and study aims
Autistic people experience different problems when accessing healthcare (for example, finding talking with clinicians challenging, or waiting areas that are full of sensory stimulation). Moreover, autistic people have also been found to die earlier than non-autistic people. So, it is important to make sure that autistic people can access healthcare. The aim of this study is to test the feasibility of an intervention to help older autistic people get better access to healthcare. The researchers will do this by working with autistic people to create individualised ways to overcome problems accessing healthcare.

Who can participate?
Adults aged 50 years old and over who have a diagnosis of autism spectrum disorder and who live in the geographical area covered by the sponsoring NHS Trust. The researchers are working with a range of clinical networks who can refer autistic people to the research team. People who lack capacity to consent can take part, if they have a representative or carer who can act as a consultee to advise on their participation.

What does the study involve?
Once the participant is recruited they will meet with the research clinician to complete a 'Getting to know you' assessment. This is a standardised set of questions to help build rapport between the research clinician and participant. Moreover, this assessment will help identify what the participant's needs are. This will help formulate the intervention for each participant. Once the assessment is completed, the research clinician and participant will identify which healthcare services they require support in accessing. Then the participant and research will agree which adjustments to healthcare are most appropriate for the participant. The clinician then liaises with the GP surgery or other healthcare setting to explore what is feasible to implement. The research clinician and participant will then agree how often to meet and what both parties need to do leading to the development of a personalised plan to overcome barriers to healthcare access.

What are the possible benefits and risks of participating?
This research might lead to an improvement in health services and support for autistic people participating. Also, this may inform clinicians and services about autistic people's experiences of

using healthcare, and what could be improved to help in the future. The intervention could be time-consuming (if the participant has a lot of health needs), health services may not be amenable to adjusting their provision for autistic people, and the participant may come to expect continued support once the study ends. The first risk is minimised as the participant decides on the frequency of the contact with the research clinician. For the second every effort will be made to make adjustments relevant to healthcare providers. The final risk is minimised by explaining to each participant at the beginning of the study, and at debrief, that the researchers can only support the participant for the duration of the study.

Where is the study run from?
1. Northumberland, Tyne and Wear NHS Foundation Trust (UK)
2. Newcastle University (UK)

When is the study starting and how long is it expected to run for?
January 2018 to December 2019

Who is funding the study?
Inge Wakehurst Trust (co: National Autistic Society)

Who is the main contact?
1. Dr Barry Ingham
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2. Prof. Jeremy Parr
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Contact information

Type(s)
Scientific

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
Ingham et al. v1.4

Study information

Scientific Title
Improving the health of older autistic people: tailored healthcare adjustments

Acronym
IHOAP

Study objectives
This is a non-randomised intervention (feasibility pilot) study, with no control group. There is growing evidence that older autistic people experience barriers to accessing healthcare. Barriers reported to date include: sensory issues (i.e. noisy, crowded waiting rooms); difficulties with communication (i.e. literal interpretation of questions, problems describing symptoms); healthcare providers making incorrect assumptions (i.e. about level of functioning, ability to understand communication); cognitive factors (i.e. issues with executive function, memory, and planning).

Autistic people are also more likely to be diagnosed with a range of physical health conditions compared to the general population. Moreover, autistic people are more likely to die compared to age-matched samples of the general population. Thus, it is vital to examine how healthcare access can be improved for older autistic people with a view to improving their health and quality of life.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 26/11/2018, Wales Research Ethics Committee 5 Bangor (Health and Care Research Wales, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB, UK; Tel: +44 (0)7825 244673; Email: WalesREC5@wales.nhs.uk), ref: 18/WA/0397

Study design
Feasibility interventional single-arm non-randomised study

Primary study design
Interventional

Study type(s)
Other

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

Interventions
This study will test the feasibility of tailoring healthcare to support access for older autistic people. As each participant's situation will be unique (i.e. each person's needs, healthcare status, and services that are accessed) the intervention will be co-designed by a research clinician and

the participant. This will involve completing an initial assessment ('Getting to know you') which will identify the participant's preferences and needs. From this, a list of adjustments has been developed (in consultation with autistic people); for instance, assisting with organising travel to, and from, appointments. Once the initial assessment is complete, the participant and research clinician will identify which adjustments will be best suited for overcoming the participants' unique barriers to healthcare access. For example, if the participant struggles with processing conversation in real time the appointment may be audio recorded so the participant can listen to conversation again.

The participant will be a part of the trial for up to 12 weeks (from initial consent and baseline). The duration of the intervention will vary based on the needs of the participant. Those with complex healthcare needs, or those with many barriers to accessing healthcare, will require more meetings with the research clinician. Once the intervention is concluded, there will be a 4-6 week follow-up period wherein participants complete questionnaires and are debriefed.

Intervention Type
Other

Primary outcome(s)
No primary outcome, as this is a feasibility study. We will measure outcomes through a composite score based on two of the study measures: The World Health Organisation Quality of Life Questionnaire (Brief; WHOQoL-BREF) and the Physical Health Indicators in Autism/Learning Disabilities (POMONA). Data will be collected at baseline (when the participant has given consent) and 1 month after the end of the intervention (follow-up).

Feasibility, acceptability, recruitment and retention through the trial:
1. Recruitment rate recorded as the number of eligible participants who consent to participate in the study by 9 months
2. Attrition rate recorded as the number of participants who consent to participate that remain in the study until the end of follow up at 6 weeks post intervention
3. Acceptability of trial procedures and treatment received measured using a bespoke semi-structured interview administered post-intervention

Key secondary outcome(s))
A number of outcome measures related to expected outcomes of the intervention will be tested for feasibility:
1. Adaptive functioning measured by the Waisman Activities of Daily Living Scale – Adaptive (W-ADL) at baseline
2. Quality of life measured by the World Health Organisation Qualify of Life – BREF (WHOQOL-BREF) scale plus the disabilities module and ASD addendum at baseline
3. Physical health measured using the Physical Health Indicators in Autism/Learning Disabilities (POMONA)
Each measure will be administered at baseline, within one week from the end of the intervention, and at follow-up (6 weeks after the end of the intervention)

Completion date
31/12/2019

Eligibility

Key inclusion criteria

1. Adults who are aged 50 or older with a diagnosis of ASD
2. Maybe male, female, or other gender
3. Live in the North East of England
4. Currently have at least two long-term physical health condition for which they may, or may not, be accessing health services

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Senior

Sex
All

Key exclusion criteria
1. An age of less than 50
2. Living outside the specified geographic area
3. Non-English speakers (this is because the researchers do not have the funding, nor the capacity, to accommodate participants who do not speak English)

Date of first enrolment
28/02/2019

Date of final enrolment
30/09/2019

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Newcastle University
Sir James Spence Institute, Level 3
Royal Victoria Infirmary
Queen Victoria Road
Newcastle-upon-Tyne
United Kingdom
NE1 4LP

Study participating centre

Northumberland Tyne and Wear NHS Foundation Trust
Research, Innovation and Clinical Effectiveness Department
St Nicholas Hospital
Gosforth
Newcastle upon Tyne
United Kingdom
NE3 3XT

Sponsor information

Organisation
Northumberland Tyne and Wear NHS Foundation Trust

ROR
https://ror.org/01ajv0n48

Funder(s)

Funder type
Charity

Funder Name
Inge Wakehurst Trust

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request. Anonymised, quantitative data may be made available on request from Dr Barry Ingham (barry.ingham@ntw.nhs.uk). Data will not be available until findings have been published. No identifiable information that may jeopardise the anonymity of participants will be shared beyond the research team.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes