

## A systematic review of long term health conditions in adults with Autism Spectrum Disorder

Review methods were amended after registration. Please see the revision notes and previous versions for detail.

### Citation

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### Review question

What is the psychological experience of living with a long term health condition from the perspective of an adult with autism?

### Searches

In order to identify relevant publications the following databases indexing scientific studies will be searched: PsycINFO, PubMed, MEDLINE, Scopus, CINAHL, ProQuest, Nursing and Allied Health Source. The search will be supplemented by the following grey literature sources – MEDNAR and Google Scholar.

The search will use key terms related to long term health conditions, autism, participants, and qualitative study designs, these will be adapted for individual databases.

Any research involving patients in a palliative care setting, patients attending cancer screening, research involving children, or adult survivors of paediatric cancer, populations drawn from multiple tumour locations will be excluded.

Language: Any, but must have an English title and abstract. Papers based in the UK will only be used.

Date range: Any paper published after 2003 as this is when cancer was defined as a chronic illness.

The base search terms will include:

Population: "Autism Spectrum Disorder" or "Aspergers" or "Intellectual Disabilities"

Phenomenon of interest: "Chronic Illness" or "Long-term Health Conditions" or "Lifelong Conditions" or "Living with" or "Long-term Implications" or "Chronic Conditions"

Context: "Living with and beyond" or "Living with" or "Experiences" or "Perceptions" or "Lived Experience"

### Types of study to be included

All identified studies which satisfy the following criteria will be included in this systematic review

- Language: Any, but must have an English title and abstract.
- Date range: Any paper published after 2003.
- Type of study: Any qualitative study published in a peer-reviewed journal, government or charity reports.
- Study design: qualitative, or mixed methods study

All identified studies which include the following criteria will be excluded from this systematic review:

- Type of paper: Conference papers, undergraduate or masters dissertations, PhD theses, editorials, books, study protocol.
- Study design: studies using only quantitative methods, systematic reviews, review of reviews, umbrella review, rapid reviews.

### Condition or domain being studied

In the United Kingdom it is estimated that 700, 000 people have a diagnosis of autism spectrum disorder. This is equal to 1.04% of the population. It is estimated that 15 million people in England have a long-term health condition. Recent findings suggest that comorbidity of long term health conditions may be greater in adults with autism than in other populations, these include deafness or partial hearing loss, blindness or partial sight loss, intellectual disabilities, mental health conditions, and physical disabilities.

The aim of the review is to investigate the prevalence of these conditions and how they affect the population in terms of health care, treatment and diagnosis.

### Participants/population

Inclusion: The population being studied in the review is adults over the age of 18 who have a clinical diagnosis of autism spectrum disorder. All participants will also have been diagnosed with a long term health condition or chronic illness. This will include searches that use intellectual disability to group autism spectrum disorder with other intellectual disabilities, these will only be used if the participants include people with autism spectrum disorder.

Exclusion: Research involving patients in a palliative care setting, research involving children.

### Intervention(s), exposure(s)

The focus of the review is to explore what psychological difficulties there can be for adults with a long term health condition and a diagnosis of autism spectrum disorder.

### Comparator(s)/control

Not applicable.

### Main outcome(s)

The review aims to explore what the psychosocial impacts are for an individual diagnosed with autism spectrum disorder who is living with a long term health condition. Due to increased social and sensory issues the review aims to provide an insight into the impact that this may have for a person diagnosed with autism spectrum disorder.

### Measures of effect

Not applicable.

### Additional outcome(s)

None.

### Measures of effect

Not applicable.

### Data extraction (selection and coding) [1 change]

Following completion of the initial searches, all identified papers will be imported into a library on RefWorks, a reference management tool, which will be utilised for sifting. The first stage of the sifting process will involve two independent reviewers. Gemma Brown, will sift the title and abstract of all identified papers against the inclusion criteria. Any papers which are deemed not to have met the inclusion criteria will be excluded at this stage. Following the first sift, and independent reviewer (Stephanie Kilinc) will sift a random 20% of titles and abstracts. Any disagreements between first and second sifters will be resolved by a third reviewer (Judith Eberhardt).

Any disagreements between the first and second sifter will be resolved by a third reviewer (Judith Eberhardt).

A record of included and excluded papers at each stage of the screening process will be recorded using a PRISMA diagram.

A data extraction table will be used in Excel and this will record the specific information for each study including: author, date of publication, study design, sample size and key findings and themes. This will record the specific information needed for analysis.

### Risk of bias (quality) assessment

Included studies will be assessed for methodological quality using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Two independent reviewers will quality assess each included study, with any disagreements resolved by a third reviewer.

### Strategy for data synthesis [1 change]

The findings from the included qualitative studies will be synthesised using methods for the synthesis of qualitative research. Verbatim quotations relevant to the aims of this systematic review will be extracted onto a Microsoft Excel spreadsheet, along with information on the themes, and sub-themes they related to in the original study. The extracted quotations will be coded according to their meaning and context with one reviewer (GB) responsible for coding extracted quotations into overarching themes for the included studies. Two other researchers (SK) and (JE) will check the coding of the themes and sub-themes for consistency.

### Analysis of subgroups or subsets

Not applicable.

### Contact details for further information

Gemma Brown  
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### Organisational affiliation of the review

Teesside University  
<https://www.tees.ac.uk/>

### Review team members and their organisational affiliations [2 changes]

Mrs Gemma Brown. Teesside University  
Dr Stephanie Kilinc. Teesside University  
Dr Judith Eberhardt. Teesside University

Ms Laura Kane. Teesside University

### Type and method of review

Synthesis of qualitative studies, Systematic review

### Anticipated or actual start date [1 change]

11 October 2023

### Anticipated completion date [1 change]

11 October 2024

### Funding sources/sponsors

Not applicable.

### Conflicts of interest

### Language

English

### Country

England

### Stage of review

Review Ongoing

### Subject index terms status

Subject indexing assigned by CRD

### Subject index terms

Adult; Autism Spectrum Disorder; Autistic Disorder; Humans; Surveys and Questionnaires

### Date of registration in PROSPERO

15 November 2022

### Date of first submission

09 November 2022

Stage of review at time of this submission [1 change]

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Revision note

Added another person to the team members.

*The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.*

*The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.*

Versions

15 November 2022

22 September 2023

16 October 2023