STUDY PROTOCOL

A protocol for a realist review of the acceptability and implementation of health checks for people with an intellectual disability and for autistic people

[version 1; peer review: awaiting peer review]

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Abstract

Background

Autistic people and/or people with an intellectual disability are more likely to experience health conditions and premature mortality. Regular health checks and assessments are known to be useful for some people with an intellectual disability, but provision is not universal, uptake is lower than expected in some areas, with variable outcomes. Evidence for the effectiveness of health checks for autistic people has been gathered. It is important to understand how the NHS can increase health check provision, uptake, quality, and consistency, and how they should be implemented. Further evidence about how and in what ways health checks work for autistic people and people with an intellectual disability is needed. Health professionals and other stakeholders need to understand how to improve health check provision, uptake, and receipt by making them more accessible. This paper outlines a realist review protocol to explore the variable impacts

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Any reports and responses or comments on the article can be found at the end of the article.

and implementation challenges of health checks for autistic people and people with an intellectual disability.

Methods

This six-staged realist review will include health checks and assessments for people with an intellectual disability and/or autistic people. The review will address what works, how, why, for whom and under what circumstances. The objective is to identify context-sensitive barriers, solutions and their associated outcomes. This will inform the development of an initial programme theory explaining how and why health checks are effective for people with an intellectual disability and autistic people.

Discussion

The programme theories refined and developed through the review will inform subsequent stages of a broader study. A realist evaluation will follow to further develop and test these theories with stakeholder collaboration. The resulting programme theory will then be used to develop practical guidance for policymakers and healthcare staff on how to deliver more impactful health checks across diverse contexts.

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Plain Language summary

People with an intellectual disability and/or autistic people are more likely to have health problems and die earlier than other people. Regular health checks provided by the NHS are one way to try to reduce these unfair differences in the quality of healthcare some people get compared to others. Not everybody with an intellectual disability and/or autistic people are offered a health check. This might depend on where someone lives, for example. People with an intellectual disability, autistic people, their families/supporters, and NHS staff have said there are some problems with health checks that can stop them working well. There are some studies that say health checks help to pick up health problems before they become serious and are worth the money they cost. But there are also some studies that show health checks might not help as much if they are not personalised to people's needs. In this study, we will try to find out how NHS staff can make sure more people with an intellectual disability and/or autistic people are able to have good quality health checks. In this review we will read and learn from what other studies have found about health checks, so we can build on what we know already. We will explore why, how and in what circumstances health checks work well for people with an intellectual disability and for autistic people. We will use what we find to improve the health and wellbeing of people with an intellectual disability and autistic people in future research.

Keywords
autism, intellectual disabilities, physical health, mental health, primary care

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Introduction

People with an intellectual disability and/or autistic people experience higher rates of physical and mental health conditions, significant unmet needs, and preventable health disparities. This leads to increased morbidity, mortality risk, and poorer care provision compared to the general population (Croen et al., 2015; Emerson, 2012; Emerson & Hatton, 2013; Heslop et al., 2013; Hirvikoski et al., 2016; O'Leary et al., 2018; Saqr et al., 2018; White et al., 2024). Additionally, people with an intellectual disability and their family or paid carers are less likely to notice, understand, or communicate the medical significance of symptoms and health changes (Alborz et al., 2005). Those from ethnic minority backgrounds face an even greater risk of premature mortality (Landes et al., 2022). Mason et al. (2019) found that autistic people encounter barriers to accessing healthcare such as patient-provider communication, sensory sensitivities, and executive functioning/planning challenges. In addition, Doherty et al. (2020) conducted an integrative review highlighting the main barriers and solutions in primary care access to UK general practitioners (family doctors or primary care physicians) for people with an intellectual disability and/or autistic people, including more relevant staff training, improved communication, involvement in healthcare decision-making, and longer appointment times. These themes emphasise the need for greater care, dignity, respect, collaborative relationships, and reasonable adjustments. More recently, Wigham et al. (2022) and Mason et al. (2022) replicated these themes when exploring patients, families and health professionals' views on improving primary care access for people with an intellectual disability and autistic people respectively.

In response to the above, primary care health checks have been developed in Australia (Lennox et al., 2007), Scotland (Cooper et al., 2014), Wales (Kerr et al., 2016) and Canada (Sullivan et al., 2018) to detect unmet health needs and facilitate treatment of health conditions. In England, findings from these studies informed the NHS England (NHSE, 2017) template for health checks for people with an intellectual disability.

The effectiveness of primary care health checks for people with an intellectual disability have been evaluated in longitudinal cohort studies and randomised controlled trials (RCTs) indicating improvements in healthcare provision through increased medical investigations, health assessments, identification of common conditions, medication reviews, referrals to secondary care and health promotions (Jones & Kerr, 1997; Lennox et al., 2007 Cooper et al., 2014; Carey et al., 2017; Kennedy et al., 2022). Following implementation of health checks for people with an intellectual disability, there has been significant variation in the proportion of people offered and receiving health checks. General practitioners/primary care practices in England receive payments to conduct health checks for people with an intellectual disability aged 14 years old or over on their intellectual disabilities register. Despite this, the NHS in England (NHS Digital, 2022) reported that 71.8% of people with an intellectual disability had a health check in 2021-22, representing a statistically significant decrease from 75.2% in 2020-21, affecting thousands of NHS patients.

In relation to autism, Nicolaidis et al. (2016) developed the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit to support healthcare access for autistic adults in the USA. Kang et al. (2022) later trialled the toolkit with six autistic adults in Australia. The need for, and development of, health checks for autistic people (with or without an intellectual disability) was identified through a research priority setting exercise (Warner et al., 2018) and cited in the NHSE Long Term Plan (NHS England, 2019). Following this, a research team at Newcastle University developed and evaluated a health check for autistic people to overcome barriers in healthcare access and provide primary care with an opportunity to address healthcare and accessibility needs specific to autistic people (Parr et al., 2024). This health check was co-produced with autistic people and clinicians (Taylor et al., 2022) and builds upon learning from other health checks. The health check aimed to reduce uncertainty by providing an expected appointment to plan around, helping mitigate stress and difficulties in communication during physical or emotional distress. A pre-appointment questionnaire allowed autistic people to report, in advance, about their health and wellbeing, identify concerns and suggest reasonable adjustments for the face-to -face health check appointment (e.g., sensory environment modifications; communication preferences; reducing interaction with unfamiliar people via altered waiting processes). Like health checks for people with an intellectual disability, health checks for autistic people aim to identify unmet health, wellbeing and social needs and establish a health action plan – manuscripts describing the study results are in review. Following the health checks for autistic adults research programme, health checks for autistic people may be offered by the NHS and understanding implementation opportunities is timely which this review will contribute to.

Various factors influence whether health checks are offered and accepted. Societal and environmental factors, such as the COVID-19 pandemic have reduced uptake of health checks for people with an intellectual disability (Taggart et al., 2022). Reasonable adjustments associated with health checks, such as environmental change, are valued and may help uptake (Brice et al., 2021). Delivering health checks for these groups is challenging in primary care, and the current understanding of how health checks work best - why, for whom, and under which circumstances - remains limited. Given inconsistent provision of health checks for people with an intellectual disability within the NHS and emerging delivery of

health checks for autistic people, there is a need to identify how the NHS can increase provision and effectiveness of health checks.

This study is the first stage of a broader research programme on implementation of health checks: "What makes health checks acceptable and implementable in primary care for people with a learning disability and for autistic people?" (https://www.fundingawards.nihr.ac.uk/award/NIHR162051). The aims of the realist review outlined in this protocol are to:

1. Synthesise the wider international literature and explore why, how and in what circumstances, health checks are impactful for people with an intellectual disability and for autistic people.

2. Develop a programme theory (i.e. theoretical explanations and an explanatory model) that will capture how to empower NHS policymakers, managers, and primary care clinicians to deliver more impactful health checks across different contexts for the public (people with lived experience and supporters/carers).

Methods and analysis

A Realist Review approach will be used, following the six stages set out by Pawson (2006) and adhering to the publication and quality standards for realist reviews (Wong et al., 2014) as applied in similar realist review protocols (e.g. Leafe et al., 2024). The review will cover health checks and assessments for people with an intellectual disability and for autistic people, investigating what works, why, how, for whom, and under what circumstances. The goal is to identify context-sensitive active ingredients (e.g., barriers and solutions) and associated outcomes of health checks, leading to the development of an initial rough programme theory (IRPT) explaining how and why health checks are impactful for this broader population. Data will be extracted from the literature to develop and test (confirm, refute, or refine) this IRPT. Where relevant and necessary, behaviour change theories will be applied to explain how health checks may be further enhanced to increase their impact across wider contexts.

In realist reviews, understanding the underlying mechanisms that result in health check outcomes is essential. It is also important to understand the context of health checks and how this context interacts with mechanisms to produce particular outcomes (Hunter et al., 2022). To explain this causation the concepts of contexts (C), mechanisms (M), and outcomes (O) are used and configure into causal explanations taking the form of Context-Mechanism-Outcome Configurations (CMOCs). These CMOCs will be used to build the programme theory of the impacts and implementation of health checks across different contexts.

Stage 1: Identifying and developing the research question

The first stage focuses on exploring and defining the topic scope using an informal, non-systematic exploratory review of relevant literature. This includes published research articles, policy documents, case studies, and social media sources. This initial exploration will be used to identify key themes and concepts that will form the review framework. These themes will primarily relate to the delivery and receipt of health checks for autistic people and people with an intellectual disability.

Realist principles using in conjunction with the population, intervention, comparison, and outcome (PICO) framework (see Table 1) will be used to develop and refine the research question. As realist approaches are explanatory, the research question will be shaped through an iterative process and further refined as the review progresses. The PICO framework will support identification of the population of interest and clarification of the primary outcomes associated with the intervention.

During Stage 1, initial programme theories (IRPTs) will be developed through exploratory literature searching, expert knowledge, and discussion within the research team. These IRPTs aim to explain what aspects of health checks work, for whom they work, and how and why they are effective. They will be articulated using "if … then … because …" statements to reflect the underlying explanatory mechanisms. Context will be examined across four levels outlined by Pawson (2006): individual, interpersonal, institutional, and infrastructural. This approach enables consideration of less visible yet influential contextual factors that affect the effective delivery of health checks.

Stage 2: Developing a formal search strategy

A search strategy and sampling framework will be developed in collaboration with an information specialist. Search strategies for identifying studies relating to populations with intellectual disabilities will differ from, but be conducted in parallel with, strategies used to locate relevant literature on autistic populations. Purposive sampling will be employed and will follow an iterative approach, evolving as new theoretical insights emerge from the data.

Table 1. PICO framework.

Population	People aged 14 years and over with an intellectual disability and for autistic people
Interventions	Specialised health checks/assessments for this population
Comparison	No direct comparison
Outcome	Health check provision, uptake, quality and consistency

Table 2. Inclusion/exclusion criteria.

Criteria	Details
Inclusion	
Type of intervention	Health check for people with an intellectual disability and for autistic people
Study Design	All study designs
Types of Settings	Primary care settings providing health checks
Types of Participants	All people with an intellectual disability and/or autistic people and 14 years and over eligible for health check
Outcome Measures	All health check related outcome measures including uptake and identification of health needs
Grey Literature	Including policy and opinion papers related to health checks
Exclusion	
Specific Health Checks	Health checks for specific health conditions or at specific ages

The search process will include systematic exploration of electronic databases (Scopus, PsycInfo, Web of Science, CINAHL, and MEDLINE), forward and backward citation tracking, searches of grey literature sources (such as HMIC), and consultation with experts and study authors. These methods will continue until sufficient evidence has been gathered to test the initial programme theories (IRPTs), in line with the principle of theoretical saturation.

A flow diagram based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) will be used to document and map the evidence identified at each stage of the search process. Exclusion and Inclusion criteria for the initial search will be developed. These criteria will be intentionally broad to capture qualitative, quantitative, and mixed-methods studies, and are detailed in Table 2.

Stage 3 and 4: Selection and quality appraisal of evidence

A structured series of steps will be used to determine whether documents should be included. In keeping with realist review methodology, a wide range of data sources will be considered, and inclusion will not be based solely on study design (for example, restricting inclusion to randomised controlled trials). Instead, decisions will focus on the rigour and relevance of the data within each document. Studies that use methods typically excluded from conventional systematic reviews may be included if they contribute to the development or testing of theoretical explanations of how the intervention works, for whom, and under which circumstances. To operationalise rigour here, once duplicate records have been removed, the literature will be identified, screened, and quality appraised where appropriate. Screening will be conducted in two stages: first by title and abstract, and then by full-text review, undertaken by a research team member. Documents will be assessed for relevance (whether the data can contribute to programme theory development or testing) and rigour (whether credible and trustworthy methods are used to generate relevant data) (Pawson, 2006). It is recognised that some documents meeting the inclusion criteria at the screening stage may not ultimately contain data relevant to programme theory building or refinement.

All documents included following title and abstract screening will be read in full by the screener. A document will be included in the realist analysis if it contains data that can inform any aspect of the programme theory. At the point of inclusion based on relevance, an assessment of rigour will be made. Documents judged as having limited rigour may also be included, as an overall assessment of rigour will also be conducted at the level of programme theory (Wong, 2018). For quality assurance, a random 10% sample of citations at each of the three screening stages will be independently reviewed. Any disagreements regarding inclusion will be resolved through discussion. If consensus cannot be reached, the issue will be referred to the wider project team and resolved by majority decision.

Stage 5: Extracting the data

Data extraction will take place from the included documents to develop and test the initial programme theories (IRPTs) using a bespoke data extraction tool informed by previous realist reviews (Duddy & Wong, 2023). The tool will be applied flexibly, recognising that individual documents may contribute insights to different aspects of the programme. As a result, the type and amount of data extracted will vary across sources. Data extraction will be guided by the IRPTs and will capture information on the intervention, study populations, and conceptual or theoretical explanations relating to contexts and mechanisms, as well as key findings that contribute to theory development. These data will be used to refine explanations of how health checks operate in practice. The process will include abductive reasoning, whereby inferences are made and theories are developed about how an intervention may work, alongside retroductive reasoning, which focuses on identifying and testing underlying mechanisms. Relevant quotations and data excerpts will be extracted to support theory development and ensure transparency in the interpretive process. NVivo will be used to facilitate data extraction from documents. Documents will be read and re-read in detail, with sections relating to how health checks function (or fail to function) highlighted and coded. The coding framework will include both deductive codes linked to the IRPTs and inductive codes that emerge from the data. As theories develop and evolve, documents may be revisited multiple times.

Stage 6: Analysis and synthesis of data

At this stage, the extracted data will be analysed and synthesised using a realist logic of analysis to develop context–mechanism–outcome configurations (CMOCs), as described by Pawson (2006). Previously developed analytic questions will be applied to operationalise the realist approach to analysis (Papoutsi et al., 2018). The CMOCs will articulate inferences related to how health checks are understood to work, and how mechanisms interact with contextual conditions to produce particular outcomes. This will include regular review team discussions where CMOC development will include further analysis of the coded and extracted data will be further analysed, with sub-nodes used to refine theoretical coding into contexts, mechanisms, and outcomes. Analysis will focus on identifying and unpacking patterns in how outcomes occur across different contexts, enabling the testing and refinement of the initial programme theories (IRPTs). The analytic process will be iterative, with CMOCs continually generated and refined through repeated examination of the extracted data. Where gaps in evidence are identified, additional literature searching will be undertaken. Through this process, a set of CMOCs will be developed to address the core research question and inform the refinement of a more coherent and robust programme theory.

Ethics and dissemination

This realist review does not require ethical approval as there will be no primary data collection. The review will rely entirely on existing literature and publicly available documents. The programme theories developed through here will inform the subsequent broader research project stages.

Patient and public involvement

A lived experience advisory group of people with an intellectual disability, autistic people and families/carers will be involved throughout the wider study, to guide the relevance and usefulness of findings. The group will be facilitated by Patient and Public Involvement and Engagement partners (National Development Team for Inclusion, Autistica, and Mencap Northern Ireland). Materials and outputs from the review will be shared with the group in order to gain insights on relevance to lived experience (e.g. helping to refine programme theories, developing literature searches, ensuring written outputs arising from the review are relevant, and helping guide accessible ways of sharing findings with people with an intellectual disability and/or autistic people).

Next steps in the research programme

In the next study phase, a realist evaluation will be conducted to test (confirm, refute or refine) and further develop these theories in collaboration with key stakeholders, including people with lived experience, carers, and healthcare professionals. This iterative process will develop a final programme theory to underpin practical guidance for NHS policymakers, managers, and primary care clinicians. The aim is to enhance the impactful delivery and uptake of health checks in diverse settings and for the benefit of people with an intellectual disability and autistic people.

Professional networks (e.g. Royal College of General Practitioners) will be used to share findings which will also be submitted for peer reviewed publication, ensuring that outcomes are reported in terms which support clinical application and implementation (e.g., factors to support effective health check delivery). Abstracts will be submitted to national and international conferences (International Association for the Scientific Study of Intellectual and Developmental Disabilities; International Society for Autism Research) in order to support further dissemination. The project advisory group, with our Patient and Public Involvement and Engagement partners, will advise and support on accessible ways of sharing information (e.g. animations; infographics) for people with an intellectual disability, autistic people and family/carers. A briefing paper will also be developed to share with healthcare staff, commissioners and policymakers.

Data availability

Underlying data

No underlying data associated with this article.

Extended data

Figshare. A protocol for a realist review of the acceptability and implementation of health checks for people with an intellectual disability and for autistic people. https://doi.org/10.6084/m9.figshare.31343029 (Ingham B. et al. 2026)

This project contains the following underlying data:

- PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol

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