

A systematic review and realist synthesis of Autistic Health Passports

BACKGROUND

Description of the issue

Autism is a normal part of cognitive diversity, resulting in changes in communication style and sensory processing which are often experienced as disabling impairments in a neurotypical world. Autistic people have worse health compared to their neurotypical peers (Bradshaw et al., 2019). This includes significantly worse physical and mental health and a lower life expectancy (Bishop-Fitzpatrick & Kind, 2017). This is associated with systematic stigmatisation (Cage et al., 2018) - including by healthcare professionals (Corden et al., 2021) - and healthcare inaccessibility for Autistic people (Mason et al., 2019). Autistic adult experiences of health and healthcare have been severely under-explored in research to date (Pellicano et al., 2014).

A Health Passport, also known as a hospital passport, is a digital or physical source of information regarding a patient's care (Alshammari, Doody and Richardson., 2020). Health Passports can include information relating to: personal details, contact information, communication needs, personal care and personal preferences (Phillips., 2019), signs of pain and distress, a medical history, plus information on consent and capacity (Northway et al., 2017).

Health Passports are a tool developed to aid information transfer between patients and Healthcare professionals. Health Passports are intended to act as a reasonable adjustment to ensure fair access to healthcare services for those who have alternative communication preferences, such as Autistic individuals (Moloney, Hennessy and Doody, 2021). Some of the Health Passports which have been developed to support Autistic individuals include the Hospital Passport developed by the National Autistic Society (NAS) (Bradshaw et al. 2019); the NHS hospital passport (2021); and the Autism Healthcare Accommodations Tool (AHAT) developed as part of the AASPIRE Healthcare toolkit (Nicholaidis et al. 2016).

It has been argued that the use of Health Passports addresses the differences in communication that may cause misunderstandings between patients and healthcare professionals (Northway et al. 2017). Furthermore, it is suggested that Health Passports may be used to promote person-centered care and/or to improve patient safety (Northway et al. 2017). However, there is no current standardised approach to the development or implementation of Health Passports, although this is sorely needed to provide consistent levels of care (Lunsky, 2018; Northway et al. 2017; McCormick et al. 2020). The importance of Health Passports is often stated without further detailing any empirical evidence for their effectiveness (Bradshaw et al. 2019; Moloney, Hennessy and Doody, 2021; Walsh et al. 2021). Despite literature describing Health Passports as a reasonable adjustment, few literature pieces discuss how this adjustment is implemented in practice (Moloney, Hennessy and Doody, 2021; Hashmi and Davidson, 2021). The key finding within the literature is one of sporadic, varied usage and implementation (Nguyen, Lennox and Ware, 2014). Usage of the Health Passports have been described as "limited" (p.34) and "disappointing" (p.36) by Kelbrick et al. (2013), who compared current clinical practice within the UK with guidelines.

Other literature has identified low use of Health Passports (Sheehan et al. 2016). In addition, Health Passports for children are most frequently discussed within the literature, whilst there is less of a discussion surrounding communication tools for Autistic adolescents and adults (Pratt, Baird and Gringas, 2011; Young et al. 2019).

The need to review the literature

Autism Health Passports (e.g.: National Autistic Society), are cited as an attempt to facilitate better care for Autistic people, but are currently under-theorised and under-evaluated. Following best practice for evaluating interventions (Skivington et al., 2021), this study will review the evidence on Autism Health Passports and attempt to theorise how they work, for whom and in what contexts using realist review methods (Pawson et al., 2005).

RESEARCH TEAM

The team comprises a range of Neurotypes, including Grant, Ellis, Williams, and Morgan who are Autistic. It is important that this research is undertaken sensitively, in light of previous abuse of Autistic people by researchers and health professionals. At least one neurodivergent person will take part in each element of the research.

APPROACH

A realist review approach will be adopted. The use of realist synthesis methods involves using theory to explore the **Context** in which interventions are delivered, including policy, culture, economic conditions, and how they interact with elements within the intervention (ie: **Mechanisms**) and how they combine to create **Outcomes**. These are combined through CMO configurations during the review to understand wider programme theory. Realist reviews traditionally comprise of five steps: We will follow five steps for undertaking the realist review: (1) define the review scope, (2) develop initial programme theories, (3) evidence search, (4) selection and appraisal and (5) data extraction and synthesis.

1. Define the review scope

We will focus on Autism Health Passports in any context for adult healthcare users. Our full scope can be seen below in our Inclusion and Exclusion Criteria.

Aim: To undertake a systematic review and realist synthesis of the literature related to Autistic Health Passports.

2. Initial Programme theory

Our initial programme theory is that the context around Autism Health Passports is inadequate to trigger their intended mechanisms, and therefore there is little to no change in outcome for Autistic people or health care staff.

3. Evidence search strategy: systematic searching

A systematic search will be undertaken within the following databases:

- Medline via Ebscohost
- APA PsycInfo via Ebscohost
- CINAHL via Ebscohost
- Web of Science Core Collection via Clarivate – limited to title, abstract and keywords
- SCOPUS

These databases were identified as the most suitable, due to covering medical, nursing, midwifery, social sciences and psychology literature. Initial scoping through developing the search strategy highlighted a high number of articles which appear in need of full text review.

A search has been developed in Medline, focusing on terms relating to (i) Autism and (ii) Healthcare passports, and is produced below:

Key/Mesh Term:	Alternative Terms:
Autism* (Inclusive of IDD – Intellectual and developmental disabilities).	“Autis*” OR “ASD*” OR “ASC” OR “Asperger*” OR “neurodevelopmental disorder” OR “pervasive developmental disorder” OR “PDD*” OR “IDD*” OR “Intellectual and developmental*”
Healthcare Passport*	"Health Passport*" OR "Hospital passport*" OR "Communication passport*" OR "Patient passport*" OR "Healthcare Passport*" OR "Autism Passport*" OR "Traffic Light Passport*" OR "Traffic-light Passport*" OR "Care Passport*" OR "Bundle Care" OR "Education Health Care Plan*" OR "EHCP*"

RE will undertake all searching. Outside of Medline, the search strategy involves combining all of the synonyms used for the key terms, truncated where appropriate. All synonyms for Autism will be combined on one line using the “OR” Boolean operator. The synonyms for Healthcare Passport will be similarly combined using “OR”. Each overall group of results will then be combined using the “AND” Boolean operator. All searches will be limited to humans from 2010-present.

All citations will be saved into separate Endnote databases relating to each of the five databases to be searched, as per PRISMA guidance, and screened for duplicates.

4. Selection and appraisal

INCLUSION CRITERIA

The PICO approach is viewed as inappropriate for determining inclusion within qualitative studies. Instead, papers will be considered in relation to population, context and phenomenon:

- **Population**
 - Autistic adults (aged 16 years plus)
 - Those who self-identify as Autistic will be included, as well as those with a formal diagnosis
 - Health professionals and others (eg: family/carers) who attempt to facilitate the use of Autism Health Passports, or who have provided their views or experiences of Autism Health Passports

- **Context**
 - Any healthcare setting (ie: excluding social care and education)

- **Phenomenon**
 - Studies and literature with a focus (ie: at least one paragraph of content) on Autism Health Passports
 - Health Passports may focus on health AND other areas (eg: education, social care)
 - Health Passports may be for those who are Autistic AND have an Intellectual Disability/Learning Disability
 - These terms, or terms with similar meanings, must be mentioned in the title and/or aims and objectives and/or main themes of the research article.

Other factors and justifications

Inclusion criteria	Justification
English language	Studies published in languages other than English are unable to be translated and included within the review due to resources.
From 2010	We include literature from the past 11 years, due to the relative lack of literature in this area, and its dearth prior to 2010.
Any research design and grey literature	In order to understand the ways in which Autism Health Passports are utilised, we will not restrict studies based on methodology. Grey literature, including relating to any specialised services will be included.

Full text is unavailable	As we are interested in the detailed accounts of the study population, we will exclude studies for which the full text does not exist, including conference abstracts.
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EXCLUSION CRITERIA

- Not focused on Autism Health Passport. In practice we would expect to see at least one paragraph of content per item included.
- Reports of Autism passports not used in healthcare settings
- Health Passport not used by Autistic people
- Autistic people aged under 16 years
- Published pre 2010
- Full text does not exist (including conference abstracts)
- Full text not available in English language

Selection of studies

Stage 1: title and abstract

All papers will be screened independently by two reviewers (AG & RE) for relevance at the title and abstract stage. If it is not possible to exclude the paper on the basis of failing to meet one or more of the inclusion criteria, the text will proceed to full text review.

Stage 2: Full text

The full text of all papers will be screened independently by two reviewers (AG & RE/one other) for relevance. Any differences in opinion will be resolved by discussion between the two reviewers, with a third reviewer included if consensus cannot be reached. Records will be kept of the reason why papers were excluded, to enable the construction of a PRISMA flow chart.

5. Data extraction and synthesis

Preparation of structured summaries

All papers will be extracted for core factual information by one reviewer (AG or RE).

- Author
- Year
- Funder (to highlight possible Applied Behaviour Analysis industry funding)

- *Country*
- *Setting (eg: primary care, secondary care specialty)*
- *Aims*
- *Methods*
 - *Qualitative /Quantitative /Mixed methods*
 - *Research paradigm*
 - *Theory used in design/development*
- *Autism Health Passport*
 - *Elements within the passport*
- *Approach to Neurodiversity (bio-medical v psycho-social model; identity first v person first language; self-identification v diagnosed only)*
- *Population/sample – size, mean & SD of age, markers of poverty/marginalised group, factors that affect results*
- *Key results*

Extraction of all relevant content

All findings sections (including within abstracts and web-only appendices) which relate to Autism Health Passports will be copied and pasted into the extraction sheets. For analysis, each article or collection of articles relating to a single case study will form a separate 'document' within NVivo.

Realist synthesis

Our realist synthesis will utilise realist synthesis methods (Pawson *et al.*, 2005) to consider the impacts of context on intervention mechanisms (Dalkin *et al.*, 2015) in acknowledgement that interventions will not work in all contexts, and that the 'messy' context of healthcare can be particularly challenging (Shearn *et al.*, 2017). We will utilise the RAMESE II reporting statement in our publication (Wong *et al.*, 2016).

First, we consider each individual intervention, pooling sources which utilise the same intervention into 'case studies'. We will:

- Explore theory used in the development of each intervention
- Explore intervention components in each intervention
- Explore intervention contexts in each report of an intervention

When individual interventions have been considered, we will:

- Explore heterogeneity in settings/context AHPs are used
- Explore the wider elements required for AHPs to 'work' using Context + Mechanism = Outcome (CMO) configurations
 - Consider who AHPs 'work' for – staff, patients, particular sub-groups

Once CMO statements have been agreed, we will:

- Aim to create a list of CMO statements that are required for AHPs to work for particular groups (eg: staff, patients)
- Recommend best practice in the use of AHPs

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