

The effects of literacy on health in Gypsies, Roma and Travellers (GRT): a systematic review and narrative synthesis

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ABSTRACT

Introduction Gypsies, Roma and Travellers (GRT) frequently experience poorer health outcomes than the general population and represent the most socially and economically disadvantaged individuals in many countries. In general, GRT in OECD (Organisation for Economic Co-operation and Development) countries have lower rates of literacy than the general population. Although 'health literacy' has been examined before, the link between low functional literacy and its effects on health has not yet been explored.

Methods Searches were conducted on five large English-language databases for research papers since 2008. Grey literature was included as the number of eligible papers was small. This was complimented by citation 'chaining'. Study findings of qualitative papers were extracted, codes were devised and then analysed thematically. A narrative synthesis was reported, supplemented by the quantitative findings.

Results 15 studies (and two substudies) were analysed. Four strongly overlapping themes were developed: (1) The context of culturally inadequate healthcare systems, (2) psychological impact and disempowerment, (3) intersectional, contextual factors and the unique needs of GRT and (4) considerations for health information resources for GRT patients with low literacy.

Conclusion Although low literacy in GRT groups is a well-recognised issue, this is the first systematic review to analyse the link between low literacy and its effects on health outcomes for GRT. The wide range of socioeconomic and cultural factors present in GRT communities, combined with low literacy, act synergistically to worsen the physical and mental health of GRT groups in different ways than that seen in members of the general population with similar low literacy levels. National intervention is required to improve the literacy of GRT children and adults. There is a clear need to develop policies and processes that facilitate a better understanding of literacy levels and how they interact with other social determinants of GRT health among healthcare professionals.

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WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Gypsies, Roma and Travellers (GRT) groups experience worse health outcomes than the general population; the life expectancy of European Roma and Travellers at birth is between 9.8 and 10.2 years less than in those in the general population. The life expectancy of Irish Travellers in the UK is between 10 and 12 years less than the general population.
- ⇒ The average illiteracy rate among all GRT groups may be as high as one-third, with a similar proportion never having been enrolled in formal education in some Organisation for Economic Co-operation and Development (OECD) countries. In the general population in OECD countries, individuals with low literacy are 1.5–3 times more likely to experience a given negative health outcome.
- ⇒ The effects of reduced 'health literacy' (the ability to find, understand and use information and services to inform health-related decisions) have been examined before.

WHAT THIS STUDY ADDS

- ⇒ The findings of this review show that the socioeconomic and cultural factors present in GRT communities act synergistically with low literacy to worsen health in different ways than that seen in members of the general population with equivalent literacy levels. The existence of discrimination and perceived stigma alongside low literacy can cause a higher psychological burden on GRT patients that can persist and lead to disengagement with health services. Cultural norms of GRT communities can also affect the interactions with healthcare providers leading to disempowerment of GRT patients. The ability of school-age GRT to maintain adequate levels of school attendance is often hindered by family responsibilities to translate or provide technological assistance. These findings provide a new lens through which to understand the far-reaching impacts of low functional literacy on health in these marginalised communities.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The authors recommend an intensified commitment by national health bodies to implement guidelines on the co-production and collaborative distribution of accessible health information and correspondence in a range of formats, alongside a widened recognition of the impacts of low literacy on health outcomes. Governments must commit to implementing new methods of improving school attendance for GRT children and delivering adult literacy classes acceptable to GRT communities. Further research is needed to validate novel approaches. Research into the effect on the health of improving adult literacy would go further to affirm the findings of this study and establish literacy as a significant social determinant of health in its own right.

INTRODUCTION

Members of Gypsy, Roma and Traveller communities (hereafter referred to as GRT) form a group mainly present in Europe and share the following characteristics: they self-identify as ethnically, culturally or socially belonging to a group considered under the GRT umbrella, traditionally have a culture of nomadism and commonly face social stigma and discrimination.¹ Communities under the GRT umbrella represent a population with diverse backgrounds, ethnicities, cultures and lifestyles but this grouping is consistent with healthcare policy, other research and also by the communities themselves.²⁻⁴ In the UK, Gypsies, Irish Travellers and Roma are recognised ethnic minority groups⁵ protected under the UK Equalities Act 2010.⁶

Difficulty in defining the population is reflected by wide ranges in the estimates of population size.^{7,8} Historical and continued discrimination towards GRT is likely to contribute to estimates of population size being significantly lower than the true number of GRT.⁹ Population estimates by the European Union Agency for Fundamental Rights (FRA) state that the European Union population exceeds 8 million.⁸

This review focused on research in Organisation for Economic Co-operation and Development (OECD) member countries as these closely match the global distribution of GRT and have comparable levels of healthcare coverage¹⁰ and literacy rates.¹¹ Given their relative similarity in socioeconomic and cultural conditions, it seems likely that GRT would face similar healthcare challenges in these countries.

According to a 2020 report by the FRA, which surveyed 4659 Roma and Travellers in six European countries, the life expectancy of Roma and Travellers at birth is between 9.8 and 10.2 years less than in those in the general population.⁸ These health inequities are present in multiple countries and GRT groups. In Ireland, Standardised Mortality Ratios for Irish Travellers are 3.5 times that of the general population.¹² A systematic review of perinatal health outcomes in 13 European countries found that GRT infants had higher rates of preterm birth, growth restriction and mortality and linked poor GRT maternal

outcomes with social determinants of health such as smoking, deprivation and poor nutrition.¹³ In England, GRT are significantly more likely to have a long-term illness or disability which limits daily activities or work and report a higher prevalence of chest pain, respiratory problems and arthritis.¹⁴ GRT have lower rates of immunisation uptake¹⁵ (with associated higher rates of vaccine-preventable diseases¹⁶) and increased rates of suicide.¹⁷ The UK government has recognised that GRT are ‘among the most disadvantaged people in the country and have poor outcomes in key areas such as health and education.’¹⁸

The FRA report also found that approximately one-quarter of GRT children live in a household characterised by severe material deprivation, approximately half of GRT adults had experienced some form of hate-motivated harassment in the past 12 months and between 50% and 85% of adults were not in employment.⁸

Average illiteracy rates among GRT groups may be as low as one-third,⁸ with a similar proportion never having been enrolled in formal education in some countries (eg, UK).⁸ Friends, Families and Travellers, a UK-based GRT charity, has reported that 40% of their beneficiaries report low or no literacy.¹⁹

In the general population in OECD countries, individuals with low literacy are 1.5–4 times as likely to experience a given poor health outcome.^{20,21} They are likely to feel embarrassment over their low literacy,²² are more likely to misunderstand drug warning labels²³ and experience worse physical and mental health.²⁴ The latest data on literacy rates among 25–64 years old ranges from 96.23% to 99.8% in OECD countries.¹¹

There are no published reviews exploring the effects of low functional literacy on health in GRT communities. This systematic review explores the relationship between low literacy and physical and mental health outcomes in GRT individuals. In this way, it considers literacy as a significant social determinant of health.

METHODS

Literature search

Searches were conducted on the following databases in May 2023 and re-run prior to final analysis in July 2024: Embase (via Ovid), MEDLINE (via Ovid), Scopus, Social Policy and Practice (Via Ovid) and The Cochrane Library. Citation chaining of included full texts was performed. For the full search strategies for each database see online supplemental data 1. To specify the desired population, a portion of the search strategy created by McFadden *et al* was adapted.¹ The study was prospectively registered on PROSPERO.²⁵ Grey literature was included.

Eligibility criteria

This review does not aim to assess the impacts of ‘health literacy’ (the ability to find, understand and use information and services to inform health-related decisions²⁶) or ‘digital literacy’ (those capabilities that fit someone for

Table 1 Screening criteria

Stage 1: Title and abstract	
Inclusion criteria	
English language version available	
Research study (ie, not a report/educational paper)	
Research addresses literacy in the target population	
Research addresses health in the target population	
Published from 2008–date (last 15 years)	
Stage 2: full text	
Inclusion criteria	Exclusion criteria
Some or all of the research was performed in an OECD country	Solely examines ‘digital literacy’ or ‘health literacy’ and does not address ‘functional literacy’ (the ability to read and write)
Attempts to relate literacy in the target population to a subjective or demonstrable health impact	Only examines language barriers and not literacy
Described methods and findings	No attempt to relate literacy in the target population to a perceived or demonstrable health impact
OECD, Organisation for Economic Co-operation and Development.	

living, learning, working, participating and thriving in a digital society²⁷) but rather the health impacts of ‘functional literacy’—the ability to read and write the relevant language. Low functional literacy can lead to low health literacy, but the relationship is not always linear. Functional literacy is often overlooked in policies designed to reduce inequitable health outcomes for these groups.

Screening occurred in two stages. The criteria for each stage can be found in [table 1](#).

Selection of studies

The search results were combined, and duplicates detected by EndNote reference management software²⁸ were removed.

Title and abstract screening were completed (MD) with 20% randomly screened (KCD) to ensure consensus. The full-text screening was independently completed by two authors (MD and KCD). Discrepancies were discussed with a third author (EJCT-M).

Data extraction and synthesis

Data were extracted on study type and methods, aims, analysis method used, target population, sample demographics or roles (eg, Traveller or healthcare professional (HCP)), country, outcomes measured, key findings and limitations.

A narrative synthesis was undertaken. First, data was extracted and coded (MD) and then coding was reviewed and developed (MD and KCD). An iterative process was used to develop descriptive themes that grouped the codes (MD and KCD). Researcher triangulation meetings (MD, KCD, EJCT-M and TB) allowed further development of themes, from

descriptive to analytical themes and mechanistic models. An example of this process can be found in online supplemental data 2.

Quantitative data contributed to the triangulation of findings in the narrative synthesis. The heterogeneity in study design and outcomes measured meant a meta-analysis would not have been appropriate.

Critical appraisal

All papers included at the full-text screening stage were critically assessed independently by two authors (MD and KCD) using verified assessment tools. Qualitative papers and systematic reviews were appraised using the corresponding CASP (Critical Appraisal Skills Programme) checklists.²⁹ The AXIS (Appraisal Tool for Cross-Sectional Studies) tool³⁰ was used for the cross-sectional studies. Grey literature papers were also assessed using the ‘best fit’ of these checklist tools. Independent appraisals (MD and KCD) were followed by a discussion to produce a joint ranking of the quality of each study (MD and KCD) (no concerns, mild, moderate or severe level of concern), an approach used in some Cochrane reviews.³¹ The results can be found in [table 2](#).

Patient and public involvement

One of the authors, BC, identifies as a member of the Gypsy, Traveller, Roma, Showmen and Boater community.

RESULTS

The search yielded 1116 results and the re-run yielded a further 150, giving a total of 1266. 817 studies were identified after duplicate removal. In abstract and title screening, 764 papers were excluded, leaving 53 papers. Citation chaining yielded a further eight papers for full-text screening, giving a total of 61 papers. Full-text screening excluded 38 papers (and the full-text English language versions of six could not be accessed), leaving 17 papers for analysis. See [figure 1](#) for the Preferred Reporting Items for Systematic review and Meta-Analysis flowchart and [table 2](#) for a full list of included papers.

One paper³² was a substudy of another included paper,³³ using the same methods but presenting a different subset of the findings, and so was not critically appraised. One other paper³⁴ was an analysis of the data set used in another included paper.³⁵ As it used a different methodology than the main paper, it was critically appraised. During the analytical process, the authors were careful to not give extra weight to concepts that appeared in both halves of each of these ‘paired’ papers, as they relied on the same data. Of the 17 papers included, 15 are therefore considered ‘primary papers’ and two ‘sub-studies’.

Table 2 Included papers' basic information

Citation	Authors	Year	Title	Method	Sample	Country	Other	Quality concern
⁴³	Beirne <i>et al</i>	2019	Culturally sensitive neonatal care provision to infants of parents from the traveller community: A nursing and midwifery perspective	Quali	Midwives	Ireland		Moderate
⁴⁵	Condon <i>et al</i>	2021	Knowledge and experience of cancer prevention and screening among Gypsies, Roma and Travellers: a participatory qualitative study	Quali	GRT of different groups	UK		Mild
⁴¹	Gilhooley <i>et al</i>	2019	Experience of skin disease and relationships with healthcare providers: a qualitative study of Traveller women in Ireland	Quali	Traveller Community Health Workers	Ireland		Mild
³³	Jackson <i>et al</i>	2016	UNderstanding uptake of Immunisations in Travelling aNd Gypsy communities (UNITING): a qualitative interview study*	Quali	Multiple GRT groups and Health Service Providers	England and Scotland		No Concerns
⁴⁰	Jesper <i>et al</i>	2008	A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness	Quali	Romany gypsies	England		Mild
⁴⁴	Keane <i>et al</i>	2022	Identifying barriers to Irish traveller women attending breast screening	Quali	Irish travellers and Health Service Providers	Ireland		Moderate
³⁵	Kelleher <i>et al</i>	2010	All Ireland Traveller Health Study (AITHS): Our Geels: Technical Report 3 Part A**	Quali	Irish travellers and Health Service Providers	NI and ROI	Grey	Mild
³⁶	Marsh	2017	Stories of health and wellness among Romani and traveller communities in Wales	Quali	Romany gypsies	Wales	Grey	Severe
¹	McFadden <i>et al</i>	2018	Gypsy, Roma and Traveller access to and engagement with health services: a systematic review	SR	99 studies	32 different		No Concerns
¹⁹	Mitchell and Garrett	2021	Locked out: a snapshot of access to General Practice for nomadic communities during the COVID-19 pandemic	X-section	GP receptions	England	Grey	Severe
⁴⁶	Neill <i>et al</i>	2015	Parent's information seeking in acute childhood illness: What helps and what hinders decision making?	Quali	GRT parents	England		Mild
⁴⁷	Pappa <i>et al</i>	2015	Health-Related Quality of Life of the Roma in Greece: The Role of Socio-Economic Characteristics and Housing Conditions	X-section	Roma	Greece		Moderate
³⁸	Unwin <i>et al</i>	2023	Inequalities in Mental Healthcare for Gypsy, Roma, and Traveller Communities: Identifying Best Practice	Quali	GRT accessing specific 'case study' services	UK and Ireland	Grey	Moderate
³⁹	Van Hout	2010	Travellers and substance use - Implications for service provision	Quali	Health Service Providers	Ireland		Severe
³⁷	Van Hout and Connor	2008	The normalisation of substance abuse among young travellers in Ireland: implications for practice	Quali	Travellers and Health Service Providers	Ireland		Moderate
³²	Jackson <i>et al</i>	2017	Needles, Jabs and Jags: a qualitative exploration of barriers and facilitators to child and adult immunisation uptake among Gypsies, Travellers and Roma	Quali	Multiple GRT groups and Health Service Providers	England	*Sub-study of UNITING	Not assessed
³⁴	McGorrian <i>et al</i>	2010	Adverse cardiovascular risk profile in a disadvantaged minority community consistent with the thrifty phenotype hypothesis. Findings from the All-Ireland Traveller Health Study	X-section	Irish traveller family units	Ireland	**Uses AITHS data	No Concerns

GP, general practice; GRT, Gypsies, Roma and Travellers; NI, Northern Ireland; Quali, qualitative; SR, systematic review; X-section, cross-sectional.

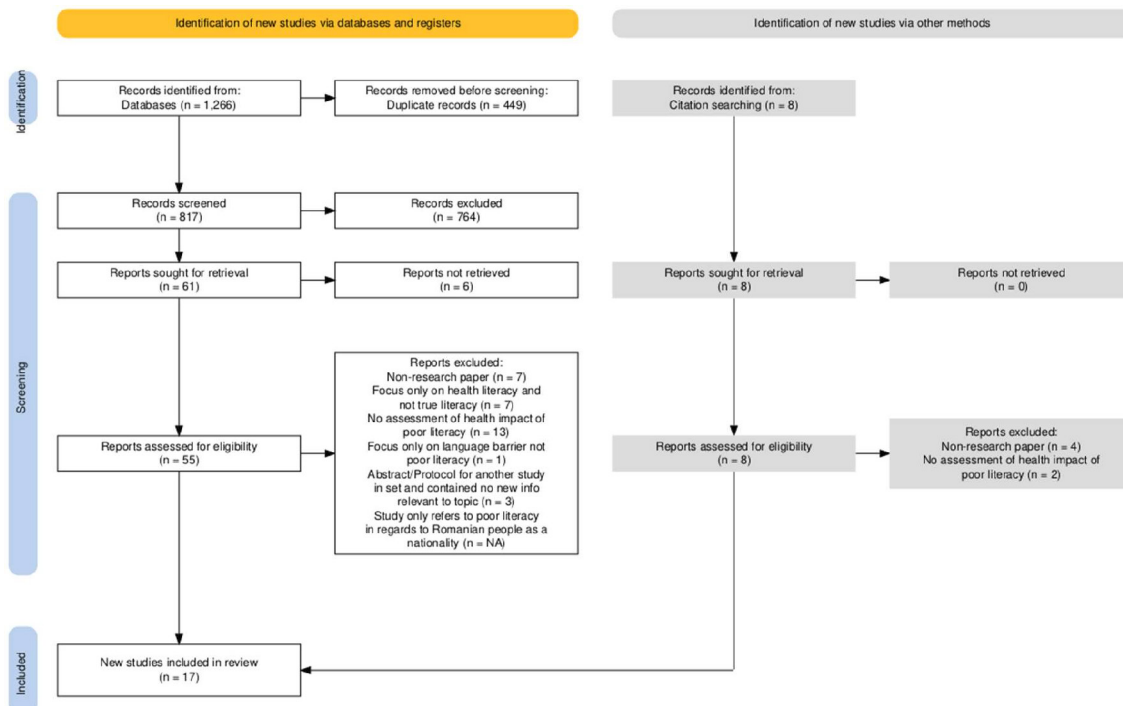


Figure 1 Preferred Reporting Items for Systematic review and Meta-Analysis flow chart.

Range and nature of studies

Study design, participants and settings

Of the 17 papers, 13 were qualitative, three were quantitative (cross-sectional) and one was a systematic review. Four of the 17 papers were classified as ‘grey literature’. All qualitative papers used semi-structured interviews; some also used focus groups, observation, workshops and online forum discussions.

Participants were GRT, HCPs, charity or council service workers and general practice (GP) receptionists. Eight papers used data collected in the UK; eight in the Ireland; one in Northern Ireland and one in Greece. The systematic review¹ included data from 32 different countries but had a UK/Ireland focus.

Study data analysis

12 of the qualitative papers and the systematic review used thematic analysis, with or without the use of frameworks or grounded theory. The remaining paper was a ‘grey’ research paper and used analysis techniques that were not explicit.

Two quantitative papers used regression analysis and the remaining paper was a ‘grey’ paper and used analysis techniques that were not explicit.

Impacts of literacy on health

Four major overlapping themes were developed from the data: (1) The context of culturally inadequate healthcare systems, (2) psychological impact and disempowerment, (3) intersectional, contextual factors and the unique needs of GRT and (4) considerations for health information resources for GRT patients with limited literacy.

Theme 1: the context of culturally inadequate healthcare systems

All the qualitative papers and the systematic review referred to the context of the healthcare systems accessed by GRT. Barriers to accessing healthcare due to low literacy were compounded by deficiencies in healthcare systems. They highlighted how best practice is not achieved when resources such as funding and training are not available.

The healthcare context was considered in two broad categories: logistical and interpersonal. The logistical category refers to ways in which healthcare environments themselves are often poorly geared for reducing health inequity for GRT with low literacy. The interpersonal category refers to how HCPs interact with each other and GRT, in ways that impact either patient voice or patient understanding.

Logistical

One of the most frequently mentioned topics was access to healthcare services. Numerous studies found that having low literacy was associated with difficulty accessing primary care, dentistry and addiction services. This was for a wide range of reasons, including limited patient understanding of healthcare systems such as registration systems and referral pathways.^{1 12 36-38}

One paper used a ‘mystery shopper’ methodology to interview 100 GP receptionists in the UK, posing as a GRT person looking to register for their surgery. Most GP surgeries were unwilling to register a patient without proof of identity and/or proof of fixed address (despite there being no National Health Service (NHS) requirement for these), and of those that were willing to register

the patient (8/100), 2/8 were unwilling to provide help in filling out forms to an illiterate patient.¹⁹

Furthermore, the healthcare environments themselves present barriers to these patients, with illegible signage and inappropriate information formats.^{35 36 39} These issues lead to delays in care provision.³⁹

In relation to the delivery of addiction treatment which commonly involves the use of written informational materials and logbooks, some agency workers commented that they had to read this information to their Traveller clientele and explain in depth, leading to delays in providing addiction counselling.^{–39}

As well as causing delays in care provision, inappropriate information formats can lead to inefficiencies in the healthcare system like missed appointments and multiple appointments for the same issue.^{33 40 41}

"...some people who don't know how to write and read it's difficult and then they don't understand what the letter is about so then they don't turn up for vaccination or they think it's something worse, being scared." BT203a, Romanian Roma, grandfather, Bristol –³³

Aside from issues with access, several papers highlighted issues with poor medication compliance or even overdose as a direct result of impaired ability to read.^{1 35–37 39} One paper suggests that this worse compliance can lead to addiction through accidental overdosing, for which treatment can be complicated by low literacy.³⁹ Some papers also found that young GRT are less likely to engage in drug education and are therefore more likely to engage in risky behaviour.^{37 39} This implies a persistent issue where low literacy increases the risk of sustained addiction in several ways.

Two papers highlighted that public health information is often provided through text-based media and suggested that campaigns planned at the commissioning level often did not consider patients with low literacy.^{1 33}

The uptake of immunisations is known to be lower in GRT communities.⁴² One paper found that poor understanding of immunisations and the resultant hesitancy towards them in this community was directly related to low literacy, and that by improving literacy in younger generations of GRT, vaccine hesitancy could be improved.³³

"A lot of the Travelling community like you saw today are starting to read and write so they'll be able to look and read the leaflets properly... I think it's the old people they don't really understand what injections are for because they probably didn't get their kids done but the younger ones these days what's having kids, they are having them done." LT001a, Irish Traveller, mother, London –³⁵

Interpersonal

Regarding patient voice, diminished opportunity to self-advocate was evident.^{33 35} Some papers asserted that HCPs and GRT charities have a responsibility to empower patients to self-advocate and make informed decisions about their own care and the care of dependents.^{32 36 43}

Regarding informed decision-making, two papers highlighted that low literacy makes consent processes much more difficult and stated that it was not uncommon for GRT to sign consent forms, for example, for childhood vaccinations without an understanding of what they say—or on the other hand, refusing to sign forms for fear of what they are agreeing to.^{33 44}

Low literacy also impairs understanding in healthcare encounters with GRT patients. The issue of the use of medical jargon acting alongside low literacy to limit understanding, recurred in many of the papers.^{1 33 35 36 38 45} Accessing reliable understandable health information is another challenge.^{41 43 45 46}

Frequently, papers indicated that participants felt that HCPs were not doing enough to assess patients' literacy or checking that the information that had been given was understood.^{33 35 36 41}

"It's not being explained; it's just give you the cream, and not all travellers (sic) are good readers and they may not be able to read the instruction (eczema, participant 1, location 3)." –⁴¹

Finally, GRT patients with low literacy must rely on relatives/friends to assist them in reading appointment letters, researching health conditions and advocating for them in healthcare consultations.^{33 35 36 45 46} This creates concerns over privacy and confidentiality.

Healthcare encounters can leave GRT patients feeling lost and this can restrict their ability to advocate for themselves. The idea of feeling unwelcome in, for example, GP surgeries, when information was not accessible³⁵ or HCPs lacked understanding,³³ showed how some patients can be indirectly excluded from receiving services when their needs are not understood. When patients have low levels of literacy, an absence of recognition of their different needs is in itself disempowering. This leads to the discussion of the second theme.

Theme 2: psychological impact and disempowerment

The data from several papers point toward a process of persistent psychological stress exerted on GRT with low literacy. This cycle is strongly tied to other aspects of this review through the ubiquitous theme of disempowerment. **Figure 2** illustrates the mechanistic cycle hypothesised from the data.

Adverse healthcare experiences can lead to embarrassment and shame,^{1 32 33 35 45} which drives patients to avoid seeking healthcare appointments, or to seek appointments with HCPs that recognise their different needs and, for example, avoid the use of 'big words'.³³ Some studies suggested that female GRT were more likely to speak openly about their low literacy with HCPs.^{32 35} One participant suggested that being able to Google things themselves alleviated the need to feel embarrassed—in contrast to those in their community who could not easily Google things.³³ This is a clear example of literacy being empowering to GRT patients.

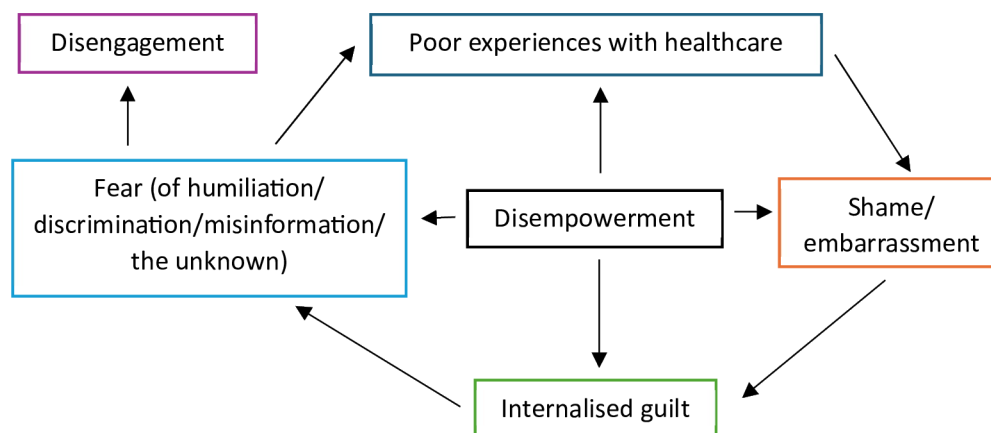


Figure 2 Mechanistic model of psychological impact and disempowerment theme, as experienced by Gypsies, Roma and Travellers with low literacy (MD).

"I would say that if you go in, a man tries to explain himself, doesn't get it quite across to the Dr, or the Dr does not pick up on it, how embarrassed is he coming away from that... People are embarrassed to say they don't understand them" –³⁵

"If someone says a word to me and I think, right I don't want to sound dumb in front of you, but I will Google this when I get home to find out what it means. So the younger generation yes we do like know a lot about the internet and we can all read and write because we have all done our schooling..." –³³

This embarrassment leads to guilt and self-blame about their own literacy level.³⁵ Although several authors of the included papers (and HCP participants) highlighted the need for improved schooling, no GRT participants blamed anyone but themselves for their low literacy. Many adult GRT participants were taking steps to improve their literacy, including through Church-led English courses.³⁶ One paper found that literacy courses (alongside vocational training) can be very empowering to patients and have benefits for patients' mental health.³⁸

Adverse healthcare encounters, shame and guilt result in fear. The perceived stigma that GRT patients experienced resulted in fear of further humiliation,³³ discrimination because of their literacy^{35 40} or misinformation (as they cannot verify the information they are given).^{33 38 45}

Finally, fear of formalised healthcare can lead to disengagement.

The lack of interface with formal medicine because of doctor/patient communication problems, fear in an alienating environment, embarrassment at not understanding, health professional and administrator's lack of understanding or sympathy, or, perceived lack of interest (or discrimination) also meant that Travellers pragmatically resort to informal healing options. The alienating experience of formal medicine makes folk healing an even more important arena for Travellers. –³⁵

This quote clearly demonstrates how the issues mentioned in the healthcare context theme and the mechanism outlined in the psychological theme interact with the disempowerment generated by feelings of

being unwelcome to cause disengagement with formal healthcare.

Theme 3: intersectional, contextual factors and the unique needs of GRT

Although the focus of this study is on the effects of functional literacy on health in GRT and not on the effects of digital literacy, health literacy or primary language difficulties, it is important to recognise the other contextual factors that interact with low literacy to synergistically affect health. GRT communities have a range of socioeconomic and cultural characteristics that differ significantly from the general population. As such, a GRT person with low literacy may experience a different health impact than a non-GRT person with low literacy. This can be understood in terms of sociocultural, educational, and age-related aspects.

Sociocultural

One confounding factor in determining the effects of low literacy is the concept of 'preference for the spoken word' or 'oral culture'. Two papers highlighted this idea, stating that some GRT communities often prefer to hear information in spoken form, whether that be face-to-face or through television advertising.^{33 40} This concept of an 'oral culture' links to traditions of storytelling yet it is unclear how it relates to formal healthcare provision. It also seems that some GRT communities have a different understanding of time than the general population, which also makes booking appointments difficult.³³ It is unclear whether 'oral culture' and differing concepts of time are a result of low literacy, coexisting low numeracy or are distinct cultural phenomena. Regardless, they appear to reduce access.

Appointments within 1 or 2 days of booking are more likely to be attended than appointments booked for a fortnight's time because of some Travellers' broad concepts of time and difficulty with the commitment of a fixed appointment. –³³

One paper expressed that the interactions between social isolation, low literacy and lack of access to a

mobile phone (due to gendered power differentials that may have a cultural influence) could reduce the ability of GRT to access services that help victims of intimate partner violence.³⁵

Educational

It is probable that low literacy impedes the development of health literacy. Several papers mentioned how the two go hand in hand to impair understanding of modern medicine and healthcare systems.^{35–37 45}

Additionally, two papers mentioned the ways in which language barriers and low literacy interact to impair the efficacy of healthcare interventions and make healthcare encounters less productive.^{35 36}

Regarding the education of young GRT, although some HCP participants pointed towards truancy,³⁵ the issue is more complex than this. Bullying and discrimination in school,³⁶ familial illiteracy (see below), perceived lack of cultural appropriateness of the curriculum³⁶ and a reliance on children to help family members in healthcare encounters/with poor digital access^{33 36} may all contribute to lower engagement with school³⁶ or reduced benefit from current education systems.

"... always bad attendance. That is the one issue which it isn't always the case. I mean I know a lot of Travellers that is going to school and is getting trophies or whatever for missing no days and they are still coming out with no education. So there is a problem somewhere" –³⁵

"...I had education, but my parents didn't have education so I was going in there with parents who didn't read and write but the settled community for generations their parents and their grandparents were able to read and write, so we do want to be equal but yet we do have to learnt a different way" –³⁵

One paper confirmed that the education of Irish Travellers in Ireland is much lower than the national average (81.2% received no or only primary education vs 30.4% of the general population when adjusted for low socioeconomic status, age and sex, $p < 0.005$).³⁴ Another paper examining the self-reported health of over 1000 Roma adults living in settlements in Greece found that Roma with higher levels of education (primary vs none and primary vs secondary) reported better physical and mental health, less pain and better social functioning ($p < 0.001$).⁴⁷

Age-related

Some of the data suggested that low literacy was familial—that having parents with low literacy made a GRT person more likely to also have low literacy.^{35 36} However, data from four other papers seemed to contradict this, and instead suggest that literacy is getting better among the younger generation of GRT.^{33 35 36 44} One of these papers suggests that higher rates of literacy among the younger generation lead to better health outcomes, such as greater acceptance of vaccinations.³³

Theme 4: considerations for health information resources for GRT patients with low literacy

This study did not aim to assess the efficacy of different interventions to mitigate the health effects of low literacy, nor ways to improve literacy among this group. However, this section acts as a compilation of aspects that should be considered when developing resources to inform GRT with low literacy on health matters.

Format and content

The most obvious consideration is that of format. Patients with limited reading ability cannot be expected to comprehend lengthy text-based appointment letters or health promotion leaflets.^{33 35 38 46} Several papers mentioned the potential usefulness of audiovisual formats for personal health correspondence or information.^{33 39 43 44 46} Most papers did not give details of potential formats for this information, but one suggested it could take the form of leaflets/letters that could be read aloud by smartphones.⁴⁴ Theme 2 (psychological impact and disempowerment) demonstrated how patients are empowered to take health matters into their own hands by the ability to interpret written information.

The content of health information resources must also be considered. Theme 3 (intersectional factors) showed how health literacy and functional literacy are often interlinked. Beyond this, one paper suggested that a different framing of messages may be helpful for GRT with low literacy—specifically 'shock adverts'.³⁹

Sharing health information

Several papers found that GRT with low literacy may benefit from the use of different avenues of health information, particularly health promotion. Some of the commonly suggested approaches suggested television and social media,^{1 33 35 44 46} likely because of their strong audiovisual elements. One paper recommended the use of information exchange networks, where HCPs/Traveller Health Workers facilitate the translation and sharing of health information.³⁵

Several papers showed that GRT found recall and reminder appointment systems helpful and that opportunistic health appointments could play an important role in treating this group.^{32 33} This relates to the concept of time literacy seen in the Intersectional factors theme.

DISCUSSION

The aim of this review was to explore the effects of low literacy on physical and mental health in GRT communities and is the first systematic review to do so. Reduced literacy has wide-reaching negative impacts on health in the general population and this is exacerbated in GRT due to compounding socioeconomic and cultural factors. This review presents four interconnected themes that relate and provide a narrative for the wide-reaching impacts of low literacy on health among GRT.

1. The context of culturally inadequate healthcare systems.

2. Psychological impact and disempowerment.
3. Intersectional, contextual factors and the unique needs of GRT.
4. Considerations for health information resources for GRT patients with low literacy.

The findings demonstrate that when low literacy interacts with other factors present in GRT communities such as social exclusion, poor socioeconomic status and discrimination, the negative health effects are higher than the effects of poor literacy in the general population.^{20 22–24} The analysis of this review is far-reaching, covering domains of physical and mental health, exploring the perspectives and lived experiences of GRT community members and healthcare/charity professionals, and providing some of the potential considerations for health services that want to create more inclusive health information resources.

The outcomes of this study are likely to be useful in other contexts. UNESCO Institute for Statistics estimates that illiteracy affects 763 million people worldwide, and disproportionately affects residents of lower-income countries, especially school-age and working-age women. This review looked specifically at OECD countries, which are all high or middle-income countries with high literacy rates. The effects of illiteracy in these countries are likely to be quite different from the effects in populations with high levels of illiteracy. Groups that face similar adverse factors (eg, poverty, discrimination and distinct culture/heritage to the majority general population) in OECD countries include but are not restricted to: the Indigenous people of Australia, New Zealand, Canada and the USA, as well as the refugee and homeless populations in many European countries. These groups tend to have lower rates of literacy.^{48–51} They also have been found to have poorer health outcomes in a multitude of metrics when compared with the general population.^{52–55} The impact of literacy on health outcomes in GRT communities may therefore share similarities with other marginalised communities in OECD countries.

Charitable and state-backed interventions to improve literacy often focus on these marginalised groups. For example, in the UK, charities such as Thames Reach and Literacy100 aim to empower homeless people by providing them with the tools to improve their reading and writing skills.^{56 57} In New South Wales, the local Government fund ‘Literacy for Life’ classes for Aboriginal adults across the state. Testimonials from users of the service state things such as ‘Before I did the program ... I was an alcoholic—and now I don't drink anymore’,⁵⁸ and there is limited research suggesting that graduates of these courses make fewer harmful decisions and are better able to manage chronic health conditions.⁵⁹ One of the papers included in this study stated that literacy classes and vocational courses must be recognised as legitimate forms of mental health provision for GRT.³⁸ It is possible that this applies to these other groups.

Strengths and limitations

This review comprehensively assessed all available literature from the last 15 years. The search was broad, including qualitative, quantitative and ‘grey’ literature. The comprehensive search strategy contributes to the validity of the findings, and a variety of methodologies were able to be included to fully capture the effects of low literacy on health. Data extraction was thorough, and researcher triangulation throughout the analysis process allowed for reflexive analysis, considering multiple perspectives when developing themes. Oversight of the manuscript by community members, whose comments were considered and integrated, assists in the alignment of findings with the lived experiences of these community members.

Due to resource constraints, only 20% of the first stage screening (title and abstract) was confirmed by the second author. However, there was consensus with all the papers in this 20% and further papers would have been screened if this was not the case. The findings are limited in their transferability to all OECD countries by the fact that most of the included studies were conducted in the UK and Ireland only. Six papers were not screened at the full-text stage; two were in another language and no English translation existed, four were not accessible in their full-text form. As the review focuses on all OECD countries, the fact that only English language papers were analysed is a limitation.

Implications for clinical practice and policy

This review highlights the need for the incorporation of measures to mitigate the effects of low literacy into national strategies such as the NHS Inclusion Health Strategy.⁶⁰ Such strategies should include the roll-out of more accessible health information resources in a range of formats (including audiovisual) with easily understood language. This applies to letters, health promotion leaflets and prescriptions. Solutions such as NaviLens technology are already being used to help visually impaired people undertake activities such as shopping.⁶¹ In the UK, the NHS application could have a QR code scanning function, paired with QR codes on all NHS communications to provide audiovisual information rather than text-based. This would not tackle issues of digital literacy or exclusion; a range of media formats are needed. This follows the principles of the NHS Accessible Information Standard (2016),⁶² which includes the recommendation that correspondence be made in a format accessible to the user, including audio formats, but which some evidence has shown is not being met.⁶³ Training of dedicated ‘accessibility champions’ in all NHS services that have specific training to assist individuals with a range of access issues including low literacy should also be prioritised.

Allocation of local and national funds to GRT (peer) support groups offering adult literacy and vocational classes is needed to set up new groups where none exist

and to support existing groups, many of which currently operate on a charitable basis.³⁸

Finally, national health bodies should issue guidance to local healthcare services on the appropriate use of ethnicity and illiteracy coding in healthcare settings to facilitate better data collection on health outcomes for GRT groups and to flag patients with low literacy for the healthcare service to offer assistance/different formats of information.

Implications for research

Research assessing the efficacy of different measures to improve school attendance and therefore literacy in GRT children is also needed to improve the literacy of the next generation of GRT. However, improving adult literacy is also a complex issue that needs investigating. Exploratory qualitative research assessing the views of GRT groups on different interventions designed to improve literacy would help understand what approaches are acceptable to GRT communities. Quantitative research comparing health outcomes in literate versus illiterate GRT (thereby alleviating some socioeconomic and cultural confounding factors) would help to validate the findings of this study. Research assessing the efficacy of adult literacy classes in improving health outcomes would validate whether the health disparity linked with low literacy can be overcome in this way. Finally, research on the impacts of low literacy on health in GRT groups in other European countries where GRT groups reside is needed.

CONCLUSION

Although low literacy levels in GRT groups are well recognised, this systematic review is the first to analyse the link between literacy and its effects on health for GRT. Within GRT communities, the detrimental effects of low literacy on health (also seen in illiterate members of the general population) are compounded by a wide range of socioeconomic and cultural factors. These factors, combined with low literacy, broadly worsen the physical and mental health of GRT. National intervention is urgently needed to improve the literacy of GRT children and adults. An intensified commitment to existing accessible information standards and an understanding of the challenges faced by patients with low literacy among healthcare professionals are required. Healthcare professionals must be sensitive to the unique needs of GRT patients, including the impact of literacy levels, in order to support improvements in their health. Above all, literacy must be recognised as a significant social determinant of health.

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