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# A realist synthesis of the evidence on outreach programmes for health improvement of Traveller Communities

# M. Lhussier<sup>1,2</sup>, S.M. Carr<sup>1,2,3</sup>, N. Forster<sup>1,2</sup>

Department of Public Health and Wellbeing, Faculty of Health and Life Sciences, Northumbria University, Coach Lane Campus East (H012), Newcastle upon Tyne NE7 7XA, UK

Address correspondence to M. Lhussier, E-mail: monique.lhussier@northumbria.ac.uk

# **ABSTRACT**

**Background** Improving the health of Traveller Communities is an international public health concern but there is little evidence on effective interventions. This study aimed to explain how, for whom and in what circumstances outreach works in Traveller Communities.

**Methods** A realist synthesis was undertaken. Systematic literature searches were conducted between August and November 2011. Grey literature was sought and key stakeholders were involved throughout the review process. Iterative steps of data extraction, analysis and synthesis, followed by additional searches were undertaken.

**Results** An explanatory framework details how, why and in what circumstances participation, behaviour change or social capital development happened. The trust status of outreach workers is an important context of outreach interventions, in conjunction with their ability to negotiate the intervention focus. The higher the outreach worker's trust status, the lower the imperative that they negotiate the intervention focus. A 'menu' of reasoning mechanisms is presented, leading to key engagement outcomes.

**Conclusions** Adopting a realist analysis, this study offers a framework with explanatory purchase as to the potential of outreach to improve health in marginalized groups.

**Keywords** health promotion, population-based and preventative services, relationships

#### Introduction

There is growing evidence that Traveller Communities (see Box 1)<sup>1</sup> experience: higher mortality rates <sup>1,2</sup>; lower health status <sup>3,4</sup>; increased likelihood of living with long-term conditions <sup>3,4</sup>; higher incidence of measles <sup>5</sup>; higher infant <sup>3,6</sup> and maternal mortality <sup>7</sup>; higher rates of anxiety and depression <sup>4</sup> and increased rates of suicide. <sup>8</sup> They also face barriers to accessing services including discrimination, high levels of illiteracy and mistrust. <sup>9,10</sup> A need for targeted action has been identified internationally, <sup>11–15</sup> but such efforts have been limited by a lack of robust evidence on intervention effectiveness. <sup>1,16,17</sup>

# **Box 1 Terminology**

The term 'Traveller Communities' is used throughout as an overarching term to encompass multiple cultural and ethnic groups with diverse histories and customs, including: Romany Gypsies, Irish Travellers, Welsh Travellers, Scottish Travellers; Roma; New Travellers; Travelling Showpeople; Circus people and boat dwellers.

M. Lhussier, Reader in Public Health Research

S.M. Carr, Professor in Public Health Research

N. Forster, Research Assistant

<sup>&</sup>lt;sup>2</sup>Fuse, the Centre for Translational Research in Public Health, UK

<sup>&</sup>lt;sup>3</sup>Faculty of Health, Federation University, Australia

Although outreach is a promising approach to engaging marginalized groups, <sup>18</sup> it requires greater theoretical development. <sup>18–20</sup> This article reports on a realist synthesis of outreach interventions to improve Traveller Communities health (this was part of a wider study reported elsewhere <sup>21</sup>). This article responds to calls for the maturating of theoretical understandings on outreach and contributes to bridging the gap between knowledge of Traveller Community health needs and the design of interventions. It follows the RAMESES guidelines for reporting of realist syntheses <sup>22</sup> in: methods (rationale for the synthesis; exploratory scoping; literature searches; selection and appraisal; data extraction; analysis and synthesis); results (document flow diagram; documents characteristics, main findings); discussion; conclusions.

#### **Methods**

# Rationale for a realist synthesis

Outreach is a complex intervention<sup>23</sup> as it varies with context and is a function of the relationship between an outreach worker and a target group, which cannot be standardized. Realist synthesis enables 'sensitivity to diversity and change in programme delivery and development'<sup>24</sup> and focuses on the causal links between contexts, intervention mechanisms and observed outcomes. Realist approaches maximize the explanatory potential of even a fragmentary evidence based on an ill-defined intervention. This is achieved by drawing on broader theoretical insights and using evidence to develop and substantiate explanations of how, why, for whom and in what circumstances an intervention may be successful.<sup>25</sup>

# **Exploratory scoping of the literature**

An initial scoping of the literature led to four initial programme theories (Box 2) on outreach for Traveller Communities, which both guided the interrogation of the evidence and were refined through the synthesis process.

# **Box 2 Initial programme theories**

#### CONTEXT

- The cultural distinctiveness and particular needs of Traveller Communities mean that outreach forms a key 'bridge' between them and statutory health services (to whom);
  MECHANISMS
- 2) The cultural background (being a peer) of outreach workers is key to the success of their intervention (by whom);
- 3) Intervention formality and responsiveness to need are key levers for participation (*how*);

# OUTCOMES

4) Key aims of outreach are to tackle health inequalities through engagement, advocacy and education (*what for*).

#### Literature searches

Structured searches were conducted in the following 12 subscription databases: Web of Knowledge, Medline, ZETOC, CINAHL, ASSIA, Social Services Abstracts, British Humanities Index, PsycArticles, AMED, Proquest Nursing and Allied Health Source, IBSS, Sociological Abstracts.

The following search strategy was used between August 2011 and November 2011:

ab,ti(roma or romanies or romany or gipsy or gipsies or gypsy or gypsies or traveler or traveller or travellers or 'travellers or 'travelling communities' or 'traveling communities') and (health or outreach).

Searches were also conducted by two reviewers in Cochrane, Campbell, CRD/DARE and EPI-Centre databases. A number of strategies were undertaken to retrieve grey literature, including searches of the FADE grey literature library for health and social care, open access resources (Directory of Open Access Journals, UK Higher Education Repositories, BioMed Central Open Access, UK theses) and contacting key representatives working with Traveller Communities.

# **Selection and appraisal of documents**

Titles and abstracts were scanned by two reviewers to make an initial assessment of relevance followed by assessment on full text. At both stages, articles which contributed to understanding at least one of the programme theories were included. No restrictions on inclusion were imposed according to journal, publication date (up to the date of searching) or country of research; however, foreign language publications were excluded. Consistent with realist synthesis, no formal quality assessment was undertaken.

#### **Data extraction**

A data extraction sheet was developed, building on the initial theories outlined in Box 2. This was however further refined throughout, with the questions asked of the data changing as theories and understanding developed. Data extraction was undertaken systematically, by two researchers (periodically reviewing one another's extraction sheets) until data saturation was reached.<sup>24,25</sup>

# **Analysis and synthesis processes**

For clarity purposes, the process of analysis is reported step-by-step, although in practice this was a very iterative process.

#### Thematic analysis

The data extracted from each article were categorized according to the four initial theories ('to whom', 'by whom', 'how' and 'what for'), before being collated and thematically analysed. The list of themes were then classified according to whether they described mostly Contexts (C), Mechanisms (M) or Outcomes (O) and were merged into C, M and O files from which we began to formulate potential CMO configurations. This process enabled immersion in the literature, and the search for key terms and hypotheses that could provide explanatory purchase on how outreach might 'work' in Traveller Communities. Detailed data extraction was undertaken for 38 studies selected for their potential to contribute understanding on our initial theories, before data saturation was reached. The net effect of this exercise was thus a 'deconstruction' of the articles along the lines of our initial theories.

# Classifying outcomes

Given the overwhelming accounts of Traveller Communities as a socially excluded group in contemporary society, engagement appeared as a key first step towards health improvement. Three categories of engagement outcomes could be identified:

- Participation in a programme, which is unlikely to generate long-term change, but may be sufficient for immunization or screening for example.
- Engagement in the idea promoted by the programme through explicit questioning of prior knowledge, attitudes, beliefs or behaviours.
- Social capital development, which entailed taking steps to improve conditions for the wider Community.

# Working back from outcomes to generate CMO configurations

Studies were then scrutinized for the mechanisms that might have led to these three categories of outcomes, in particular contexts. CMO configurations were developed, discarded or substantiated through this process and through inclusion of additional literature (see below). The net effect of this stage was thus a 'reconstruction' of meaning from the previously disaggregated pieces of evidence.

# Validation and refining of theories through Expert Hearings and alternative literature sources

A number of 'Expert Hearings' (EH) with key stakeholders, including Traveller Community members, outreach workers and members of Traveller organizations was organized throughout the synthesis, in order to help develop, refine and validate explanatory theories as they emerged from the analysis. This proved particularly useful to understand potential reasoning pathways of outreach workers and target groups. Access to, and facilitation of, consultation with Traveller Communities was negotiated by those with established relationships with them.

# Complementary literature searches

In realist syntheses, the search process is ongoing<sup>22</sup> and spans the development of research questions, through to refining

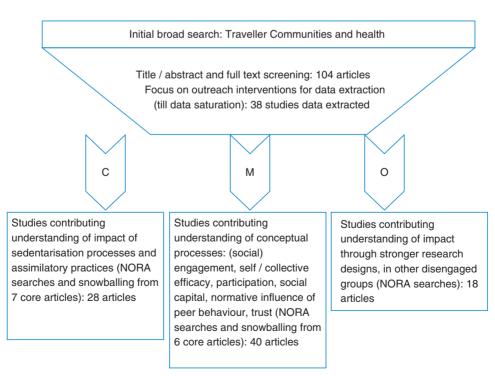


Fig. 1 Complementary literature searches.

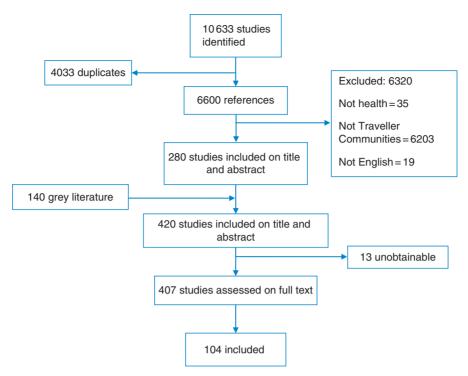


Fig. 2 Studies selection flowchart.

theories.<sup>26</sup> Additional purposive searches were thus undertaken, focusing on commonalities in all Traveller Community subgroups and what distinguishes them and other marginalized groups (C); understanding potential underlying mechanisms (including processes of engagement, participation, social capital, normative influence of peer behaviour and trust) (M) and drawing on stronger research designs than those reported in the literature on Traveller Communities (O) (Fig. 1).

#### **Results**

The searches returned a total of 10 633 studies, 407 were screened on full text and 190 were included in this analysis. Of these, 104 were being specific to Traveller Communities, located through initial broad searches on Traveller Community health (Fig. 2) and 86 were retrieved through complementary searches for theoretical and parallel literature, and used to refine emerging theories (Fig. 1). The strength of the evidence on outreach was poor, including an overwhelming proportion of descriptive and experiential accounts. Overall, there is an increasing interest Traveller Communities health, with half of the studies being published since 2006. Only 25% of the studies focused on outreach, among which only one study could have been scored as of 'moderate' quality<sup>27</sup> using standard quality assessment tools.<sup>28</sup> Fifty per cent of those studies focused on improving access to and use of services.

A process of synthesizing the literature following the steps above, combined with EH consultations, led to the

development of an explanatory framework detailing how, for whom and in what circumstances outreach interventions work with Traveller Communities (Fig. 3).

As in many social programmes, interpersonal relationships between the worker and the Community embody outreach interventions. This takes particular significance in the context of Communities with high level of distrust towards those from outside of the group. Trust is frequently mentioned in the literature on Traveller Communities, and was a key theme throughout EH consultations. In developing our explanatory framework, the trust status of outreach workers thus became an important contextual parameter. Trust is a function of a worker's ethnic background and their connections to, and previous history of, working with the Communities. A second element was the worker's ability to negotiate the focus of the intervention. The more trusted the outreach worker was the lower the imperative for negotiation.

Mechanisms refer to the reasoning of Traveller Community members about their level of engagement in outreach programmes. In order to elicit this, we have drawn a pre-existing typology of individual engagement in:

- Behavioural engagement, which relates to participation in social programmes;
- Cognitive engagement, which relates to the idea of personal investment in an idea or project;
- Emotional engagement, which relates to the creation or modification of ties to individuals or programmes.<sup>31</sup>

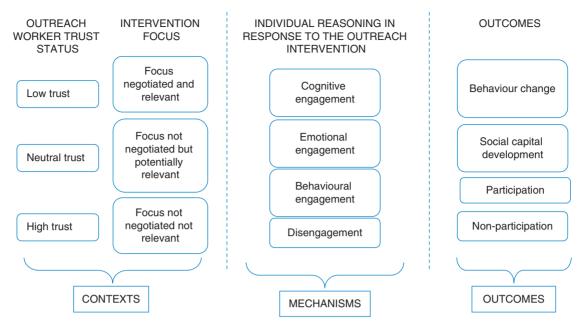


Fig. 3 Overall explanatory framework for outreach interventions in Traveller Communities.

Outcomes are the observable and reported results of this engagement process, grouped into (i) participation, (ii) behaviour change and (iii) social capital development.

Setting aside the 'disengagement' leading to non-participation, three possible sets of configurations could be highlighted within this framework, depending on the engagement outcomes achieved (participation, behaviour change, social capital development).

#### **Participation**

The first set of configurations describes how outreach can lead to participation without necessarily entailing a greater level of engagement. These interventions were most likely to be implemented in a context of neutral or low trust, counterbalanced by negotiation over the focus of the intervention. This triggered the mechanism of behavioural engagement in participants. For example, Streetly<sup>32</sup> described the work of health visitors on a Traveller site delivered out of a 'multipurpose mobile'. Health visitors are likely to have started from a position of neutral trust given that they describe working with teachers on the site in order to gain the acceptance. They describe a process of negotiation which responded to articulated needs. This initially entailed responding to requests related to 'clothing, welfare, and problems with eviction', and once these were addressed, Travellers raised concerns relating to healthcare and services. The article reports acceptance of some preventative services including developmental screening, hearing and vision testing, family planning, dental services, physiotherapy and chiropody.

In contrast, Austerberry *et al.*<sup>33</sup> described an intervention targeting vulnerable young people, which was not very successful in engaging Traveller Communities. In this case outreach workers had a similarly neutral trust status; however, the focus of the intervention was not negotiated. The needs of Traveller were assumed to be similar to that of settled young people and the intervention did not lead to participation.

#### **Behaviour change**

The second set of configurations describes how outreach can lead to behaviour change. Here, outreach workers were highly trusted and often influential within the community, and negotiation over the intervention focus became less important. Instead, the outreach worker's position provided opportunities for social influence, triggering a cognitive engagement leading to behaviour change. For example, Kelly et al.<sup>27</sup> described an intervention aimed at the prevention of HIV and sexually transmitted diseases in Roma men in Bulgaria. The study involved a social network analysis in order to recruit network leaders and trained them on reducing HIV risk behaviour in their network. Outreach workers were highly trusted by the community, and the intervention focus was not negotiated (sexual behaviour is often considered as taboo among Traveller Communities<sup>34,35</sup>). Members of social networks became cognitively engaged with the intervention and report a change in behaviour corroborated by a reduction in the incidence of biologically assessed gonorrhoea. There was a significant reduction in the prevalence of unprotected intercourse (P = 0.01), increased knowledge of the risk of AIDS, positive attitudes to condoms and strength of intentions to reduce risk behaviours in the intervention group. The greater robustness of outcomes reported at 12 months when compared with those at 3 months is attributed to changes in social norms over time. In addition, the success of the intervention may have been helped by the fact that outreach workers and participants were both male.

# Social capital development

The third set of configurations describes outreach interventions that have resulted in social capital development. This was fostered through the work of organizations with longstanding relationships with the Communities, who had demonstrated their commitment and reliability over time and who had established a 'trusted brand' that facilitated early engagement. Their links also involved statutory services, funding bodies and educational institutions, and thus they offered opportunities to work towards longer term goals. A report on Sussex Travellers Health Project<sup>36</sup> suggests that it took around 9 years to establish the project and build the trust and confidence of community members to engage with services. Traveller women felt comfortable discussing health issues such as domestic and mental health problems and requested further information on drug issues, baby massage and reflexology. The project aimed to empower community members to develop their own solutions to health issues and provided opportunities for social engagement. Traveller Community women were supported to share positive representations of their culture with their local community, deliver cultural awareness training to service providers and to take a representative role in communicating with local commissioners.

# **Discussion**

## Main findings of this study

Improving the health of Traveller Communities has been identified as an important public health concern internationally. Through adopting a realist approach to explain patterns of outcomes across interventions, this synthesis has generated insights for designing and implementing outreach interventions.

This study demonstrates the different forms of outreach that can be provided, depending on workers' connections with Communities, in order to achieve different engagement outcomes. If the programme is about promoting attendance to one-off events deemed important, or addressing a need articulated, by the community, outreach workers may not need to have long established relationships of trust. Changing behaviour or developing social capital, on the other hand, requires workers to build explicitly on long established and trusting relationships.

# What is already known on this topic

Mackenzie *et al.*<sup>18</sup> present a 'continuum of complexity' to deconstruct the 'non engagement problems' that outreach seeks to address and the strategies mapping onto these. Realist approaches distinguish between programme strategies and the underlying reasoning of those receiving the programme in response to those (mechanisms). Berkman and Glass<sup>37</sup> have conceptualized a causal pathway between social networks and health, whereby social capital works through mechanisms of social support, social influence or social engagement. Situating the typology offered by Mackenzie alongside this demonstrates how it focuses on resources of social support that can be offered by outreach.

# What this study adds

Our findings highlight how outreach interventions use additional engagement strategies including social influence, whereby outreach workers who are significant within a community offer normative guidance to the group, and social engagement through which potential social ties are converted into action. In addition, the typology of outreach developed by MacKenzie *et al.*<sup>18</sup> was formulated from the perceptions of outreach workers themselves, without incorporating the views of those receiving outreach. This paper therefore builds on the typology to consider the engagement reasoning of participants triggered by different programme strategies, in terms of whether they decide to engage at a behavioural, cognitive, emotional level, or to retreat from the intervention.<sup>31</sup>

Our findings on the need for negotiation support the need for flexibility and adaptability to changing contexts and social dynamics identified in previous conceptualizations of outreach. Additionally, our findings contribute to theoretical developments about peerness in health interventions. We highlight how it is not based solely on fixed characteristics such as belonging to a particular ethnic group, but on the place that outreach workers occupy within the recipients' social networks and the extent to which relationships of trust have been established. In other words, belonging to a particular ethnic group has much less bearing on the success of an intervention than is sometimes assumed.

# Limitations of this study

A limitation of much research involving Traveller Communities, and thus this review, is their well acknowledged reluctance to self-identify. With an increasing proportion of Travellers turning to 'bricks and mortar' accommodation in particular, this poses the issue of the representativeness of research study populations.

The quality of the literature that served as a basis for this review has to be acknowledged as an additional limitation. Adopting a realist approach has enabled us to develop an explanatory framework that offers the most credible account of what works, for whom and in what circumstances.

Both limitations have been mitigated by the use of EH with members of the Community and workers who were well accepted by them. These provided an invaluable source of insider knowledge that helped at all stages of the review, and ensured the strong face validity of the explanatory configurations proposed.

#### **Conclusion**

Returning to our four initial theories, 'To whom' evolved to highlight the importance of mobility, not only as a crude descriptor of a nomadic lifestyle, but also its impact on the formation, development and maintenance of social networks. 'By whom' highlighted the importance of trust. 'How' highlighted the potential of using a model of engagement in order to explain how outreach workers may approach Communities. 'What for' highlighted three levels of individual engagement, which can be considered as intermediate outcomes. Engagement thus emerged as a concept with dual utility in our analysis—it was the process mechanism that could explain most outcomes, but given the lack of trust of Traveller Communities, it was also an important intermediate outcome in its own right. In adopting a realist analysis of outreach interventions for Traveller Communities across disparate contexts, this study offers a framework with explanatory purchase as to the potential of outreach to improve health in these, as well as other marginalized groups.

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