

# Outreach programmes for health improvement of Traveller Communities: a synthesis of evidence

Susan M Carr,<sup>1\*</sup> Monique Lhussier,<sup>1</sup> Natalie Forster,<sup>1</sup> Deborah Goodall,<sup>1</sup> Lesley Geddes,<sup>1</sup> Mark Pennington,<sup>2</sup> Angus Bancroft,<sup>3</sup> Jean Adams<sup>4</sup> and Susan Michie<sup>5</sup>

<sup>1</sup>Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, UK

<sup>2</sup>Department of Health Services Research and Policy, London School of Health & Tropical Medicine, London, UK

<sup>3</sup>School of Social and Political Science, University of Edinburgh, Edinburgh, UK

<sup>4</sup>Institute of Health & Society, Newcastle University, Newcastle upon Tyne, UK

<sup>5</sup>Division of Psychology and Language Sciences, University College London, London, UK

\*Corresponding author

**Declared competing interests of authors:** Dr Jean Adams has received funding from NIHR Health Technology Assessment, grants from British Heart Foundation, Cancer Research UK, Economic and Social Research Council, Medical Research Council and the National Institute for Health Research for research activity during the conduct of this study.

Published July 2014

DOI: 10.3310/phr02030

## Scientific summary

### Outreach programmes for health improvement of Traveller Communities

Public Health Research 2014; Vol. 2: No. 3

DOI: 10.3310/phr02030

NIHR Journals Library [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

# Scientific summary

## Background

The term 'Traveller Communities' refers to a complex population group that can be distinguished on multiple dimensions. It encompasses a number of distinct cultural and ethnic groups, including Romani Gypsies, Irish Travellers, Welsh Travellers, Scottish Travellers, Roma, New Travellers, Travelling Showpeople, Circus People and Boat Dwellers. Only estimated figures are available, of between 10 and 12 million Traveller Community members in Europe and between 120,000 and 300,000 in the UK. The lack of reliable demographical data, combined with the mobility of these groups, may lead to their invisibility throughout the planning of health service provision and result in unmet needs. It has also limited the generation of robust evidence on their comparative health status, but points to inequalities across many domains of health. While these groups represent a small proportion of the overall population, they may also share a number of commonalities with a range of socially excluded groups in terms of needs and challenges for service provision. This synthesis of evidence, therefore, contributes to understanding what works to improve the health of Traveller Communities, with the potential to inform understanding of disengaged groups more broadly.

Meeting the multiple and complex needs of excluded groups requires a degree of flexibility and co-ordination across health and social care, which is often unrealised. Outreach has been utilised as a strategy to engage those who, through social exclusion or socioeconomic deprivation, occupy a position on the margins of society. Outreach interventions are often highly individualised, implemented in diverse settings and delivered by a range of people. To date, reports have often described the intervention process and personal qualities of outreach workers, rather than sought to explain how intervention outcomes might occur.

## Review aims and objectives

This research aimed to synthesise the evidence on the effectiveness of outreach programmes to improve the health of Traveller Communities, drawing on scoping, realist and economic review processes.

The review objectives were:

- Scoping: to quantify and classify the available research evidence concerning the health of Traveller Communities. The choice of scoping review (as opposed to meta-analysis or narrative) was dictated by the quality appraisal of data retrieved on the completion of systematic searches.
- Economic: to examine the cost of outreach interventions and determine which approaches might be considered cost-effective.
- Realist: to develop an explanation of how outreach works, for whom and in what circumstances.

## Methods

### *Data sources*

Searches of titles and abstracts were conducted between August 2011 and November 2011 to identify English-language items using the following search strategy: (roma or romanes or romany or gipsy or gypsies or gypsy or gypsies or traveler or traveller or travelers or travellers or "travelling community" or "travelling communities" or "traveling community" or "traveling communities") and (health or outreach).

A number of search strategies were utilised to retrieve grey literature. Websites of organisations that sponsor or conduct relevant research were searched to identify publications of interest. Where the function was available, RSS (Really Simple Syndication) feeds or e-mail alerts were set up in order to keep apprised of new literature.

No restrictions on inclusion were imposed according to type of journal, publication date (up to date of search) or country of research or practice. Foreign-language publications were excluded.

### **Study selection**

The titles and abstracts of identified studies were scanned by two reviewers to make an initial assessment of relevance.

The scoping review included all articles focused on the health of Traveller Communities, in order that the evidence on outreach interventions could be placed in the wider health literature context.

The economic review included any article reporting some measure of resource or effectiveness in the delivery of an outreach intervention.

For the realist synthesis, studies were included if they contributed an understanding to at least one of the following initial explanatory theories:

1. The cultural distinctiveness and particular needs of Traveller Communities mean that outreach forms a key 'bridge' between them and statutory health services.
2. The cultural background of outreach workers (being a peer) is key to the success of their intervention because it enables them to use the right communication tools.
3. The degree of intervention formality and responsiveness to need are key levers for participation.
4. Key aims of outreach are to tackle health inequalities through engagement, advocacy and education.

### **Expert hearing events**

The involvement of key stakeholders, including Traveller Community members, outreach workers and members of Traveller organisations, in a number of expert hearing events formed an important element of the project. They contributed crucial insights into Traveller Community members' decision-making processes around trust and engagement, helping to validate and refine emerging findings.

## **Findings**

### **Scoping review**

Two hundred and seventy-eight articles were included and classified using the following characteristics:

- Date of publication: attention to the health of Traveller Communities is increasing, with approximately 50% of articles on the topic published since 2006.
- Reporting of outreach interventions: approximately 25% of articles on the health of Traveller Communities described the implementation of outreach, the majority being anecdotal accounts rather than reporting research findings.
- Evidence type and study design: the 10 articles reporting research findings on outreach interventions were of poor methodological quality, with only one assessed as of moderate quality. The majority of articles consisted of descriptive accounts.
- Country of publication: the majority of articles were published in the UK and Ireland, suggesting more established programmes of work in these countries. Those published in eastern Europe had a stronger focus on outreach.

- Type of author and outreach worker: studies describing outreach were often written by health service providers and Traveller or third-sector organisations. Almost all outreach interventions were delivered either by members of Traveller Communities or by mainstream health service providers.
- Health focus: approximately 50% of those studies describing outreach focused on improving access to and use of services. Few articles described outreach for children's health, oral and mental health care and none described outreach for cardiovascular disease or cancer.

While much research describes the needs of Traveller Communities, as yet there is a paucity of robust evaluations of outreach interventions. This mapping of the overall evidence base provided a scaffold on which the economic review and realist synthesis could build.

### *Economic review*

Interventions which use mobile clinics to bring health services to Travellers are associated with the highest costs reported, with little confidence that they provide either value for money or an appealing format for Traveller Communities. The employment of full-time outreach workers generates moderate costs, with impacts that may not be primarily improved health. Practice nurses are well placed to facilitate access to primary care and may represent a cost-effective resource. The broader literature suggests that outreach is more effective when delivered by workers who share the ethnicity of the recipients. The training and use of outreach workers from Traveller Communities to promote vaccination and access to antenatal care, in particular, would merit rigorous evaluation.

The implementation of protocol changes, such as texting appointment reminders, is unlikely to be expensive and might be considered the minimum acceptable action to facilitate access to health care by Travellers. Literature examples also suggest that cultural awareness sessions can be delivered successfully by Travellers for modest costs. A recent Department of Health publication suggested an additional payment to general practitioners (GPs) for the registration of Travellers to offset losses in practice income from missed Quality and Outcomes Framework points and to incentivise outreach. Such a funding mechanism would require reliable identification of Travellers, which is an acknowledged issue. In conjunction with the changes outlined above, an appropriate payment for the registration of Traveller Community members by GPs might be effective in improving access to primary health care.

### *Realist review*

An explanatory framework detailing how, for whom and in what circumstances outreach interventions work with Traveller Communities was developed from a combination of synthesising the literature and key existing theoretical constructs. This included a model of person–environment engagement, a typology of individual engagement and a model of trust development. Realist thinking is articulated in the form of Context–Mechanism–Outcome (CMO) configurations.

Contexts form the background from which interventions can lead to favourable outcomes. Outreach workers enter the Community with a trust status, which is linked to their ethnic background, their connections to the Traveller Community and their history of working with them. The more trusted the outreach worker is, the less imperative it is that they negotiate the intervention focus. This inverse role of trust and negotiation forms a key context for outreach.

Mechanisms are the respondents' engagement reasoning that has been triggered in response to the outreach intervention.

Outcomes are the observable and reported results from this engagement process. Outcomes from outreach interventions were grouped in (1) participation, (2) behaviour change or (3) social capital development.

Three sets of CMO configurations offer an explanation of how, for whom and in what circumstances each outcome group is most likely to occur.

The first set of CMO configurations shows how outreach may lead to participation, without this necessarily entailing a depth of questioning of prior attitudes, beliefs or practices. These interventions were implemented in a context where the outreach worker had an initial neutral trust status, which was offset by a variety of negotiation strategies, concurring to explain either participation or non-participation in a programme. For example, a study describing a specialist health visitor from the settled community with prior connections to the Community and a remit broad enough to allow responsiveness to emerging needs (e.g. help with filling in paperwork) is likely to lead to participation. Such interventions have a potential to be used as part of a broader trust-building exercise, thus leading to increased time-effectiveness for subsequent interventions.

The second set of CMO configurations demonstrates how outreach interventions may lead to a change in behaviour. This necessitates the participants to engage with the intervention, a mechanism that was triggered when the outreach worker was highly trusted and sometimes influential within the Community. A study identified individuals well respected within the Community, who were able to initiate conversations to promote safer sex practices. Although the topic of the intervention was not negotiated, the position of the outreach worker meant that individuals in their networks changed behaviour.

The third set of CMO configurations features the impact of organisations that have long-standing relationships with the Communities, and have demonstrated commitment and reliability. Outreach workers come with a 'trusted brand' that facilitates early engagement. Their established links also involve statutory services, funding bodies and educational institutions, and thus offer the opportunity to significantly work towards longer-term goals of social capital development. Typically, these interventions involve the training of outreach workers from the Community, and the purposes of outreach are both broad and responsive to expressed needs.

This analysis has highlighted how outreach interventions, if implemented cognisant of (a) the contextual constraints pertaining to this group and (b) the outcomes that the intervention can reasonably be expected to achieve, have the potential to increase the receptiveness of Traveller Communities to health interventions, and their ability to engage with them.

## Conclusions

The scoping review offered an effective platform from which to engage in the economic evaluation and in realist reviewing. Encouraging the participation of Traveller Community members in research actually shared similar features with outreach. Working with Traveller organisations with established positions of trust to organise expert hearing events proved to be an effective engagement method. Realist synthesis offers great potential in developing the kind of cross-cutting theoretical insights that explain how potentially low-cost interventions such as outreach can work, with whom and in what circumstances.

The inverse role of trust and negotiation identified in this report has, when linked to social network theory, tremendous explanatory potential for why programmes may or may not be successful in engaging other disengaged groups. Capitalising on the inroads into these dense but marginalised social networks offered by community representative organisations is one of the ways in which research effectiveness might be maximised. Other key additions include the need to consider carefully the entry points in a Community, and the potential and realistic impacts of an intervention. The classification developed here around participation, behaviour change and social capital development presents a useful starting point, which will apply in other families of health improvement interventions.

Much of the research endeavour surrounding Traveller Communities has been devoted to better understanding their cultural, historical and ethnic differences. While this is an important research field in its own right, its potential to explain why certain interventions work better than others is limited. We suggest that, instead, patterns of mobility and their consequent impact on access to services should be considered,

but only with an appreciation of the importance of trust and social bonds. The cost-effectiveness of research and practice efforts in implementing group-specific strategies could be greatly improved by pursuing the kinds of theoretical insights developed here.

## Recommendations for future research

- Testing of the explanatory framework with other disengaged populations would answer questions relating to the engagement of groups with different degrees of connectedness and trust in 'mainstream' institutions.
- Research examining the relationships between trust and belonging to a target group, and the impact of this on outreach effectiveness, has potential to add further depth and nuance to the model developed. Implications could then be drawn on how outreach interventions can best contribute to reducing health inequalities.
- There is a need to put greater focus on theory-informed evaluations, with measurement of intermediate outcomes. Where possible, research on outreach interventions should detail not only the programme strategies employed but also insight into people's reasoning around their engagement decisions.
- Further research is needed evaluating interventions to improve the health of socially excluded groups. In particular, the economic review suggested that the training and use of outreach workers from Traveller Communities to promote vaccination and access to antenatal care is worthy of further research.
- The great emphasis put in research and practice development on implementing group-specific strategies could be greatly improved by pursuing the kinds of theoretical insights developed here. A programme of research is called for, focusing on strategies to initiate and sustain the engagement of socially excluded communities in health improvement initiatives.

## Funding

Funding for this study was provided by the Public Health Research programme of the National Institute for Health Research.

# Public Health Research

ISSN 2050-4381 (Print)

ISSN 2050-439X (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) ([www.publicationethics.org/](http://www.publicationethics.org/)).

Editorial contact: [nhredit@southampton.ac.uk](mailto:nhredit@southampton.ac.uk)

The full PHR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/phr](http://www.journalslibrary.nihr.ac.uk/phr). Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Criteria for inclusion in the *Public Health Research* journal

Reports are published in *Public Health Research* (PHR) if (1) they have resulted from work for the PHR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in *Public Health Research* are termed 'systematic' when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

## PHR programme

The Public Health Research (PHR) programme, part of the National Institute for Health Research (NIHR), evaluates public health interventions, providing new knowledge on the benefits, costs, acceptability and wider impacts of non-NHS interventions intended to improve the health of the public and reduce inequalities in health. The scope of the programme is multi-disciplinary and broad, covering a range of interventions that improve public health. The Public Health Research programme also complements the NIHR Health Technology Assessment programme which has a growing portfolio evaluating NHS public health interventions.

For more information about the PHR programme please visit the website: [www.phr.nihr.ac.uk/](http://www.phr.nihr.ac.uk/)

## This report

The research reported in this issue of the journal was funded by the PHR programme as project number 10/3004/02. The contractual start date was in June 2011. The final report began editorial review in October 2013 and was accepted for publication in March 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PHR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PHR programme or the Department of Health.

**© Queen's Printer and Controller of HMSO 2014. This work was produced by Carr *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.**

Published by the NIHR Journals Library ([www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)), produced by Prepress Projects Ltd, Perth, Scotland ([www.prepress-projects.co.uk](http://www.prepress-projects.co.uk)).

## **Public Health Research Editor-in-Chief**

**Professor Catherine Law** Professor of Public Health and Epidemiology, Unit Head, Centre for Paediatric Epidemiology and Biostatistics, UCL Institute of Child Health, UK

## **NIHR Journals Library Editor-in-Chief**

**Professor Tom Walley** Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

## **NIHR Journals Library Editors**

**Professor Ken Stein** Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

**Professor Andree Le May** Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

**Dr Martin Ashton-Key** Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck** Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

**Professor Aileen Clarke** Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

**Dr Tessa Crilly** Director, Crystal Blue Consulting Ltd, UK

**Dr Peter Davidson** Director of NETSCC, HTA, UK

**Ms Tara Lamont** Scientific Advisor, NETSCC, UK

**Professor Elaine McColl** Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

**Professor William McGuire** Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads** Professor of Health Sciences Research, Faculty of Education, University of Winchester, UK

**Professor Jane Norman** Professor of Maternal and Fetal Health, University of Edinburgh, UK

**Professor John Powell** Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

**Dr Rob Riemsma** Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

**Professor Helen Roberts** Professor of Child Health Research, University College London, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of members of the NIHR Journals Library Board:  
[www.journalslibrary.nihr.ac.uk/about/editors](http://www.journalslibrary.nihr.ac.uk/about/editors)

**Editorial contact:** [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)