Outreach programmes for health improvement of Traveller communities: A synthesis of evidence.
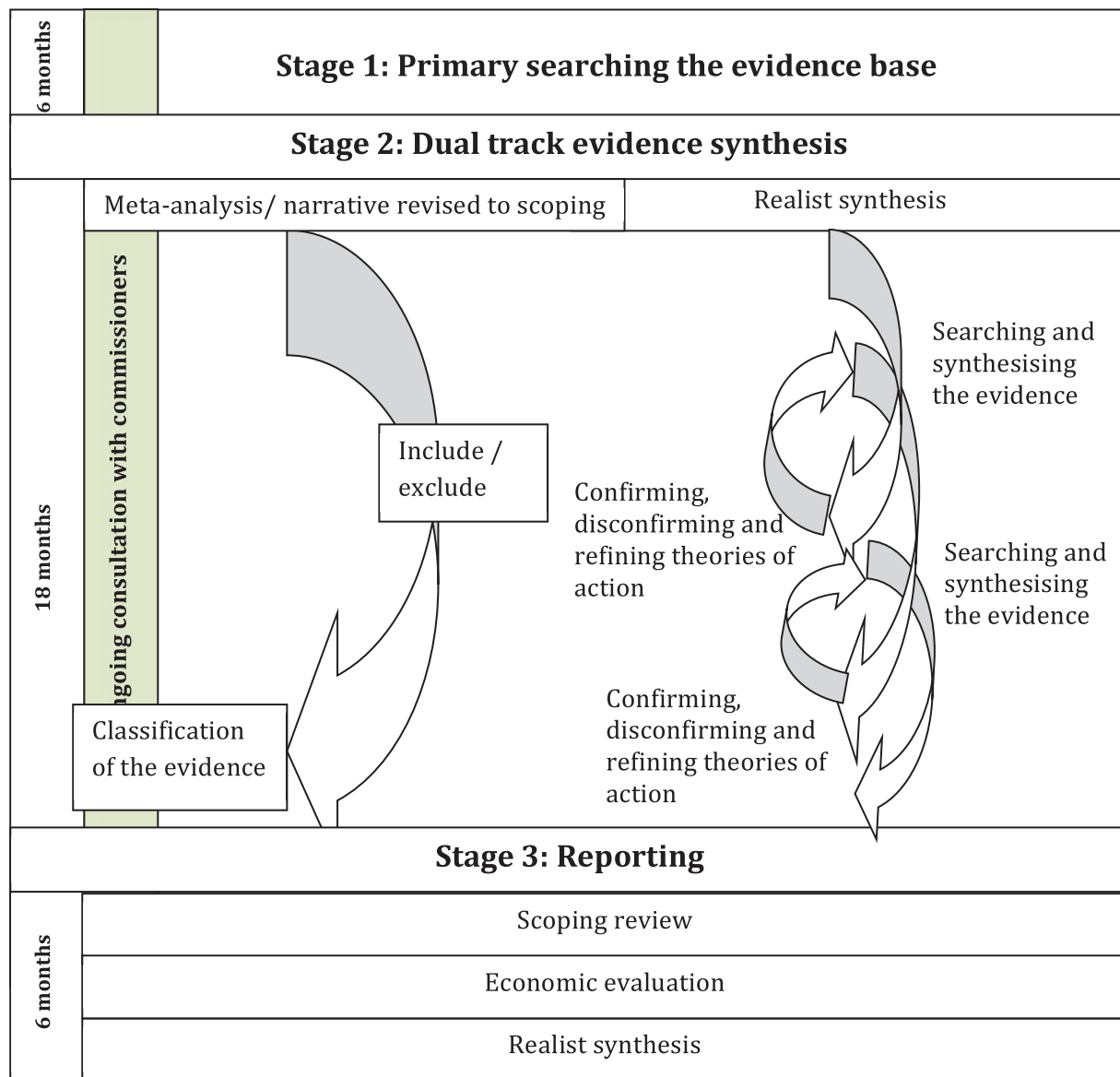
Synthesis strategy

In order to guarantee that maximum utility can be made of the available evidence, we proposed a dual track of evidence synthesis. Such methodological pluralism enables maximum learning to be achieved, regardless of the type and diversity of the evidence accessed.

The review began by a trawl of the literature (search strategy is detailed below). This yielded a literature base from which, after rigorous quality assessment, it was planned to make a decision whether a meta-analysis and cost-effectiveness modelling could be conducted (answering the questions: Are outreach interventions in TC effective? Are they cost effective?), or a narrative synthesis (What intervention modes are in operation? What is their likely effectiveness? Are they likely to be cost effective?). However, the quantity and quality of data retrieved was not appropriate to allow either of these approaches. A revision was negotiated with the funder to undertake a scoping review alongside the economic and realist reviews.

Diagram 1: review phases

1. *Stage 1: searching for evidence*

This stage fed into both types of synthesis, though in slightly different ways. After a short phase of problem definition (2 months), search terms and data sources were finalised (an initial search strategy is however proposed below). A librarian will be involved in the early stages of the process, in order to help with the process of negotiating access to databases. Our approach to the problematic definition phase made most use of the combined experiences of all proposers and project steering group members.

For the realist synthesis, this is a preliminary step providing the reviewers with an initial literature base to populate the pre-established programme theories (theories of underlying mechanisms) detailed in the following section. Pawson et al[36] describe the steps of 'concept mining' (extraction of a theory from the existing literature) and 'theory formalisation' (codification of the theory into a set of explanatory propositions), though this latter element is carried throughout the evidence synthesis phase. The subsequent purpose of the review is to test and refine the theories with emergent evidence.

Searches were made by two reviewers for existing relevant systematic reviews using Cochrane, Campbell, CRD/DARE and EPI-Centre databases, in addition to searches for primary studies. Initial scoping review suggested that the formal literature base (i.e. from peer-reviewed journals) on outreach programmes for TC is relatively small. However, there is a substantial amount of 'grey' literature on this subject which accessed using a variety of search strategies, including:

Searches of electronic databases

Searches were made of relevant electronic databases (Box 1) using various combinations of search terms (see Box 2). These initial search strategies were developed by drawing on the experience of steering group members but then refined and expanded based on emerging evidence. Searches were limited to articles written in English, or for which a translation is readily available.

Searches of the Internet

Searches weremade of the Internet using the Google search engine (**www.google.com**) using the search strategies listed in Box 2. The first 100 results returned by each search strategy were scanned for relevance and those judged to be potentially relevant followed up. If this strategy identifies outreach programmes but little information is available on the Internet, attempts were made to contact programme organisers directly by telephone or e-mail in order to access implementation process detail or potential evaluation results.

Searches of specific websites

A number of specific websites of organisations that sponsor and/or conduct relevant research were searched to identify publications of interest (listed in Box 3). Searches were also be made of various trial and research registers for completed and ongoing research of relevance.

Reference lists of relevant studies

The reference lists of all studies assessed to be relevant were hand-searched to identify additional studies that may be of relevance. Reference lists of previous reviews were also searched to ensure thoroughness.

Searches of the Social Science Citation Index

Citation searches of the Social Science Citation Index were made in order to identify all citations of studies identified as relevant, and therefore identify any further possible relevant studies.

Hand searches of relevant journals

The contents pages of journals considered to be highly relevant (i.e. found to contain a significant number of relevant articles relating to outreach or Traveller communities) were scanned to identify additional relevant publications.

Additional information from authors

When published accounts lack detail or depth of description, publication authors were contacted to gather the full details required for the purpose this review.

Titles of studies identified using the above search strategies were scanned by two reviewers to make an initial assessment of relevance. The PICOS framework[40] (Population, Interventions, Comparators, Outcomes, and Study designs) was used to define inclusion / exclusion criteria (see Table 1) for the meta-analysis/ narrative synthesis. For the realist synthesis, studies were included if they added understanding on at least one element of the analytical framework. In cases where there is any doubt concerning relevance at this stage, abstracts were retrieved in order to make a further judgement. If doubt concerning relevance remained at this stage or no abstract is available, full reports were retrieved for review. Abstracts and relevant articles were reviewed independently by two reviewers based on the inclusion criteria and specified outcomes of interest.

2. Stage 2: Dual track evidence synthesis

Quality appraisal

Meta –analysis / narrative synthesis

The Quality Assessment Tool for Quantitative Studies developed by the Effective Public Health Practice Project, Canada[37] will be used for quantitative studies. The tool assesses: selection bias, study design, confounders, blinding, data collection methods, withdrawals and dropouts, intervention integrity, and statistical analyses.

With respect to qualitative studies, the Critical Appraisal Skills Programme[38] checklist for qualitative research, which is a tool for reviewers recommended by the Cochrane Qualitative Research Methods Group. The checklist comprises ten questions designed to help the reviewer to appraise the report of qualitative research by thinking systematically about the key issues of rigour, credibility and relevance.

Outcome of systematic retrieval and appraisal process

Twelve items were eligible for inclusion after assessment in line with specified criteria. A process of quality assessment categorised two of these items as 'moderate' and ten items as 'weak' using the criteria specified in the project description, ie, with reference to the Quality Assessment Tool for Quantitative Studies (Effective Public Health Practice Project, Canada) for quantitative studies and the Critical Appraisal Skills Programme checklist for qualitative research. The literature base for the narrative review was thus of a limited size

and, when assessed using the above criteria, the overall quality is graded as 'poor'.

Included studies

Linking together multiple reports of the same study reducedthe set of studies to nine, presented in nine project reports and two journal articles. The studies cover nine disparate topics (teenage health, primary health care, community mothers, oral health, Roma drug users, prevention of HIV in Roma, domestic violence, health advocate training, and Romani health); are of varying provenance (nine report studies based in the UK, two report research conducted in Bulgaria, and one report examines policy and programs in Finland, Romania and Bulgaria.

Proposed plans to accommodate quality and quantity of studies retrieved.
This stage therefore marked a change in protocol, negotiated with the funder to undertake a scoping rather than narrative review.
As with a systematic review the research question is identified, relevant studies are found and considered for inclusion/exclusion. However, at this point the criteria are not based on the quality of the studies but on relevance to the topic. Thus it is appropriate for the scoping review to draw from the literature searches undertaken to date. As a broad search strategy was used, it is unlikely that any literature will have been excluded that would be relevant for the scoping review. We propose to include all papers (n = 349) in an alternative quality appraisal process that will refer to the framework for ranking evidence evaluating healthcare interventions developed by Evans (2003) and the quality rating materials developed by Mitton et al (2007) in a study that used grey literature sources to illuminate contextual issues identified from peer-reviewed studies. The appraisal purpose will not aim to 'grade' so as to exclude from any further consideration, but rather to allow inclusion of comment on quantity of material retrieved as well as content, thus ensuring a very transparent audit trail.

References
Evans, D. (2003) Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. Journal of Clinical Nursing, 12, 77-84

Mitton C, Adair CE, McKenzie E, Patten SB, Waye Perry B. Knowledge transfer and exchange: Review and synthesis of the literature. The Milbank quarterly. 2007;85:729-768

Realist synthesis

The quality of studies was assessed using judgement to supplement formal checklists[37,38]. Judgement will in particular focus on whether a study covers the conceptual element under scrutiny, and whether it does so in a methodologically credible manner. Quality appraisal and data extraction steps are thus merged in realist synthesis. Data was extracted from different studies using an iterative and eclectic approach to inform the developing intervention theories.

Data extraction

Scoping review

The studies included in the scoping review were charted according to the 'descriptive analytical' method outlined by Arksey and O'Malley83 whereby 'a common analytical framework' is designed to classify and organise studies according to key issues and themes. The following information was collected from each study and recorded onto a 'data charting form' 83 using NVivo software:

- Date of publication
- Country of publication
- Type of author (e.g. academic, government/local authority, health service providers, Traveller/third sector organisations)
- Evidence type (e.g. research study, anecdotal account, literature review, policy/guidelines for practice, theorerical/opinion paper)
- Study design (e.g. qualitative study, controlled clinical trial, pre and post intervention study, RCT)
- Whether or not outreach is described
- Outreach worker (e.g. Traveller Community member, health visitor)
- Health focus (e.g. Women's health, child health, dental health)

An early case study of using NVivo for a literature review was presented by di Gregorio[91] and whilst a small amount of published material has since developed this process[92-96] the use of such software does not appear to be commonplace. The use of NVivo software for this review facilitated the management and description of the large number of studies, provided a useful operational tool for the manipulation of data during the analysis process, and helped to ensure transparency in the classification of studies.

Realist synthesis

An initial data extraction sheet was adapted from that used by Mc Cormack et al[39] and is presented in Table 2. It has to be noted however, that the data extracted from studies changed as the analysis progressed and the analytical framework refined. The Dahlgren and Whitehead[5] social model of health was used to map intervention outcomes, in order to situate at what level they might be working and therefore their potential effect on health and health inequalities.

Data synthesis

Scoping review

A numerical approach was taken to the collation and presentation of data which examined the distribution of studies according to the characteristics charted and illustrating these graphically, rather than organising the data according to key themes or findings. This approach enabled the presentation of information around how much and what types of evidence is available on the health of Traveller Communities, how much of the overall research evidence on Traveller health reports on the evaluation of outreach interventions, what research designs have been used to do so, who outreach workers are, in which countries are most/least publications being published, and what kind of authors are publishing on the health of and outreach interventions for Traveller Communities.

Realist synthesis

The framework of analysis detailed below (figure 1) was developed on the basis of a realist analysis of evidence on lay health advisor formats in health improvement[30] and consultations with expert members of the project steering group:

   a) By whom?

This conceptual element explored dimensions around the people who are conducting outreach. Elements and concepts of peerness (the extent to which one is perceived to belong to the community in which one conducts outreach activities), cultural awareness and layness (the amount of training one will have had to undertake before being allowed to conduct outreach activities) were explored here.

   b) To whom?

Outreach interventions typically target groups defined as 'at risk' and thus respond to an established need. The extent to which this need was a) formally established and b) perceived by the recipients was explored here.

   c) What for?

This conceptual element explored the explicit, as well as implicit, purposes of outreach activities in Traveller communities. Literature which detailed processes of engagement, advocacy or education for example, was included to explore this dimension. A likely contributor to this element will also be local and national policy directives or financial imperatives. Intervention outcomes were mapped on the Dahlgren and Whitehead[5] diagram of the social model of health, in order to situate intervention effectiveness from a health inequalities aetiology perspective.

   d) How?

This element explored in detail the components intervention techniques of outreach in Traveller communities. This included concepts such as knowledge translation, for example. The theoretical underpinnings (e.g. behaviour change, social learning, communication principles) to outreach interventions were examined, as was their operationalisation. The level of formality, or institutionalisation, of the outreach programme was examined, as were issues such as the remuneration of workers.

This initial theory map was refined in the second stage of the review, through the organisation of Expert Hearings with outreach workers and members of the TC. Such

hearings were organised at regular intervals throughout the realist synthesis phase of the review. In addition, the team accessed a broader range of expertise in TC, through internet postings (see Box 4), through authors of key publications in the field, or through personal contacts of the research team. Such expertise was used to supplement Expert Hearings and steering group meetings when further clarifications will be required.

The analysis in each conceptual element of the framework was related to outcomes relevant to the theory under scrutiny. For example, in conceptual element 3, if an aim of outreach was established to be engagement, then engagement outcomes would be sought, and interventions would be classified as to what were the manifestations of engagement, whether they achieved it, and how, why and in what circumstances they did so.

Figure 1: Proposed analytical framework.
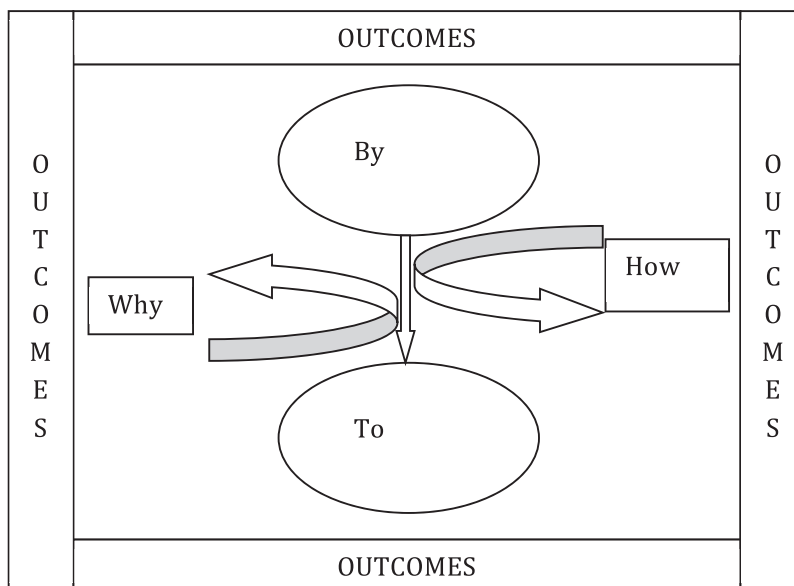
Realist review approaches literature searches in a way that is iterative and responsive to emergent findings, so that programme theories are tested and refined. The aim of the evidence searches being to populate and refine the analytical framework, thresholds were set for the realist synthesis, at which the researchers had reached saturation of evidence on a particular conceptual element, i.e. when the literature retrieved will no longer add to the emerging understanding of the intervention. Such decisions were documented on rigorously kept audit trails.

Box 1 – Electronic databases searched

AMED	IBSS

ASSIA	Medline
British Humanities Index	Proquest Nursing and Allied Health Source
Campbell	PsycArticles
CINAHL	Social Services Abstracts
Cochrane	ZETOC
CRD/DARE	
EPI-Centre databases	

Box 2 – Initial search string

(Outreach OR community intervention OR home-visiting OR community health) AND (hard to reach OR social exclusion OR social capital) AND (nomad$ OR caravan dwelling OR Roma OR Gypsies OR Gipsies OR Travel$ OR Scottish Travellers OR Welsh Travellers OR Irish Travellers OR New Travellers OR Bargees of Boat Travellers OR Showpeople OR circus people) AND (behaviour change OR health promotion/improvement OR disease prevention OR engagement OR empowering OR participation OR advocacy OR self management OR service delivery) AND (inequalitie$ OR unequit$ OR disparit$) AND (local authority OR third sector OR voluntary sector OR private)

Box 3 – Websites hand-searched for relevant publications

Equality and human rights commission	www.equalityhumanrights.com
Friends Families and Travellers	www.gypsy-traveller.org
Intute	www.intute.ac.uk
Irish Traveller Movement in Britain	www.irishtraveller.org.uk
Local Government Improvement and Development	www.idea.gov.uk
NHS Evidence	www.evidence.nhs.uk/
Pavee point (human rights organisation for Irish Travellers in Ireland)	www.paveepoint.ie
Race for Health	www.raceforhealth.org
The Department of Health	www.dh.gov.uk
The Home Office	www.homeoffice.gov.uk
The Joseph Rowntree Foundation	www.jrf.org.uk

The Medical Research Council	www.mrc.ac.uk
The National Audit Office	www.nao.org.uk
The National Federation of Gypsy Liaison Groups	www.nationalgypsytravellerfederation.org
The Office of the Deputy Prime Minister	www.odpm.gov.uk
The Society of Behavioural Medicine	www.sbm.org
The Urban Institute	www.urban.org
Wellcome Trust	www.wellcome.ac.uk

Table 1 – the PICO framework

Include	Exclude
Populations	
Gypsies Roma Gypsies Roma Scottish Travellers Welsh Travellers Irish Travellers New Travellers Bargees or Boat Travellers Showpeople Circus people UK and European countries	Non Gypsy and Traveller communities?
Interventions	
Outreach (interventions which take place beyond usual limits of the delivering organisation) aimed at TC Outreach intervention (e.g. housing related) that have an explicit health improvement aim One to one or group interventions, as long as it involves at least one person going to places where TC live at least once	Interventions without an explicit health improvement focus Interventions that are not outreach Intervention that do not focus on TC Publicity or health promotion campaigns, if delivered through posters or advertisement only
Comparators	
Comparable travelling community, without outreach programme and / or with standard care	Any other community
Outcomes	
Physiological measures of general health Other measures of general health Health behaviour Healthcare beliefs and knowledge: Health care use / uptake of statutory services Effect on socialisation Effects on relatives /carers Adverse outcome e.g. complaints Quality of life Social capital development	
Study designs	
RCT Non-randomised controlled trials Cohort studies	Other evidence / literature reviews

Case control Interrupted time series Ethnographic Phenomenological In depth qualitative evaluations Combined designs Intervention descriptions Evaluations	

Table 2 – Data extraction form

FULL REFERENCE
CONCEPTUAL AREA 1 – BY WHOM
What are the key defining characteristics of outreach workers?
Have outreach workers been trained and to what extent?
What impact has the outreach worker on intervention outcomes?
What type of organisation initiated the outreach programme?
CONCEPTUAL AREA 2 – TO WHOM
On which basis was the target group selected?
Did the intervention have an effect beyond the target group as initially defined?
Was a need assessment conducted prior to the intervention commencing?
What is the target group perception of their own needs?
CONCEPTUAL AREA 3 – WHAT FOR?
What are the explicit aims of the intervention?
Are there any implicit aims?
Has the intervention had unintended consequences / outcomes?
Was the intervention implemented following local or national policy directives?
Mapping outcomes on the Dahlgren and Whitehead (1991) diagram: at what level does the intervention work?
CONCEPTUAL AREA 4 – HOW?
What are the explicit theoretical underpinnings of the intervention?
How are these operationalised?
Are there implicit theories that underpin the intervention?
How are those manifest?
How much total contact time was involved?
What were the methods of intervention administration?
CRITIQUE   (adapted from CASP 2005 – McCormack et al 2006)
Was there a clear statement of the aims of the research?   *Consider:*   *- what the goal of the research was*   *- why it is important*   *- its relevance*
Was the research design appropriate to address the aims of the research?   *Consider:*   - *If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)*
Was the recruitment strategy appropriate to the aims of the research?   *Consider:*   - *If the researcher has explained how the participants were selected*   - *If they explained why the participants they selected were the most*

appropriate to provide access tot eh type of knowledge sought by the study
- *If there are any discussion around recruitment (e.g. why some people chose not to take part)*

Were the data collected in a way that addressed the research issue?

Consider:
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)
- If the methods were modified during the study; if so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recording, video material, notes etc…)
- If the researcher discussed saturation of data

Has the relationship between researcher and participants been adequately considered?

Consider whether it is clear:
- if the researcher critically examined their own role, potential bias and influence during: 1) formulation of research questions; 2) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design?

Have ethical issues been taken into consideration?

Consider:
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent of confidentiality or how they have handled the effects of the study on the participants during and after the study
- If approval has been sought from the ethics committee

Was the data analysis sufficiently rigorous?

Consider:
- if there is an in depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/ themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

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Is there a clear statement of findings

Consider: - If the findings are explicit - If there is adequate discussion of the evidence both for and against the researcher's argument - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) - If the findings are discussed in relation to the original research questions
Write comments here
Would it be useful to get hold of the full report for this study?   Yes   No
References to follow up:

Box 4 – Mailbases information requests

HEALTH-EQUITY-NETWORK@JISCMAIL.AC.UK COMMUNITY-HEALTH@JISCMAIL.AC.UK GP-UK@JISCMAIL.AC.UK GPRD-RESEARCH@JISCMAIL.AC.UK HEALTH-FOR-ALL@JISCMAIL.AC.UK HEALTH-PROMOTION@JISCMAIL.AC.UK HEALTH-SERVICES-RESEARCH@JISCMAIL.AC.UK PUBLIC-HEALTH@JISCMAIL.AC.UK PUBLIC-HEALTH-IN-TRUSTS@JISCMAIL.AC.UK SOCIALWORK-HEALTHINEQUALITIES@JISCMAIL.AC.UK EVIDENCE-BASED-HEALTH@JISCMAIL.AC.UK HEALTH-SECTOR-DEVELOPMENT@JISCMAIL.AC.UK HEALTHFUTURESUK@JISCMAIL.AC.UK APIG@JISCMAIL.AC.UK LEEDSPEERSUPERVISION@JISCMAIL.AC.UK primarycarenursingresearchnetwork@yahoogroups.com evidencenetwork.com click4HP@yorku.ca address_healthcare_disparities@list.ahrq.gov health-disparities@lis.ahrq.gov public-health@latrobe.edu.au SDOH@yorku.ca