

**Gypsies and Travellers accessing primary health care:
interactions with health staff and requirements
for 'culturally safe' services.**

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Appendix A

Critical appraisal of methodological quality of reviewed papers on Gypsy and Traveller health

Main themes of Review

The impact of cultural beliefs, attitudes and perceptions about health on the health and health care experience of Gypsy Travellers adults

The impact of cultural beliefs, attitudes and perceptions about health on the health and health care experience of Gypsy Traveller children

The impact of cultural beliefs, attitudes and perceptions about health on Gypsy Traveller's access to health care.

Sources for the Review

Medline

Cinahl

Amed

BNI

Psych Info

IBBS

Assia

Private collections held

Reference citations of existing literature

Search Strategy

Concept 1	Concept 2	Concept 3
Gypsy;Gipsy(ies)	Culture	Health Status
OR	OR	OR
Rom; Roma Romany	Beliefs	Health Outcomes
OR	OR	OR
Travellers	Lifestyle	Health Services Delivery
	OR	OR
	Attitudes to health	Primary care services
	OR	OR
	Health behaviour	Attitude of health personnel

Study inclusion criteria

46 potentially relevant records were originally identified in addition to those already held. These were all saved into the Reference Manager software package (version 10) for future

retrieval and management. Key words were assigned to the different types of paper to facilitate the management.

22 references that were descriptive reviews of personal practice, comments or reviews that were not primary research studies were excluded.

As I was focusing this review question to Gypsy Travellers in the British Isles I had limited to the English language.

I excluded a further 9 papers reporting on studies in Europe and 8 reporting on American Gypsies, for this part of my review. The populations being studied in these papers are quite different, and there appear to be distinctly different cultural influences. The health care systems also differ considerably from the NHS and Irish health care systems, and this limits the extent to which findings can be generalised to factors affecting access to health care and health care experience of Gypsy Travellers in the British Isles.

One further study was excluded because the focus was on the evaluation of a method of service delivery. I also excluded my own paper to avoid bias.

The remaining papers fitted the following inclusion criteria for my review:

- Gypsy Travellers (including Irish Travellers) adults and /or children
- Cultural lifestyle is a considered factor (includes beliefs, attitudes and perceptions)
- Impact on health status or access to health care explored
- Primary research studies
- Publication type- published journal papers.
- Countries – British Isles (England, Wales, Scotland, Northern Ireland, Republic of Ireland)
- Language- limited to English language
- Publication date – limited to post 1966

Number of selected studies that matched these criteria - 7 studies (8 papers)

Although the selected studies do not necessarily examine beliefs, attitudes and perceptions about health specifically, their relevance in relation to cultural lifestyle is implicit either in the hypothesis or the background information.

These remaining selected papers were so few in number that it would have been inappropriate to exclude further in terms of quality, given the difficulties inherent in carrying out methodologically valid studies in this population. The quality of these studies, however, has been considered and is described in the review

Country of origin in the British Isles for selected studies:

England	4
Northern Ireland	1
Ireland	2

The focus for the selected studies was limited to three areas of health outcome:

Child and maternal health (including immunisation status)	– 4 studies
Influence of consanguinity on prevalence of congenital anomalies*	– 2 studies
Dental health, food and hygiene	– 1 study

* this area of focus was also, included in one of the 4 studies of child and maternal health.

Studies concerning determinants of general health of adult Gypsy Travellers were noticeably absent.

Criteria for Methodological Assessment

Six of the seven studies used surveys as the main methodology. Only one study (for which there were two separate papers) also included a qualitative study using in depth unstructured interviews. Qualitative studies, would be the most suitable methodology for the review question, but surveys are the easiest method to employ in researching a 'hard to reach' population. However, methods such as surveys reduce the likelihood of causality being attributed with a high degree of validity and they are low in the hierarchy of quantitative research evidence.

The selected papers were assessed for their methodological quality using a checklist suitable for survey methods. Data was then extracted from the studies using a standard data extraction sheet and the data was collated in a table. Data was collected on study population, study aims and focus, study methodology, outcome measures, results and conclusions. The results were synthesized and entered into a summary table.

The main titles of the seven studies are listed below and are referred to by authors and year in the remainder of the review without additional referencing.

Edwards and Watts 1996	Diet and Hygiene and Oral health care in the lives of Gypsy Travellers (2 papers)
Pahl and Vaile 1986	Health and health care among Travellers
Feder, Vaclavik, Streetly 1993	Gypsies and childhood immunisation:
Gordon et al 1991	The health of travellers' children in N. Ireland
Flynn M 1986	Mortality, morbidity and marital features of travellers
Barry and Kirke 1997	Congenital anomalies in the Irish Traveller community
Anderson 1997	Health concerns and needs of traveller families

Overall there were serious flaws in methodological quality¹ of most of these papers and this was taken into consideration in discussion of the findings (see Chapter Three) .

1. Crombie I, *The pocket Guide to Critical Appraisal: a handbook for health care Professionals*, BMJ publishing group, London. 1996

Appendix B

Full Research Questions: Phase 1 and Phase 2

Research Questions Phase 1

What are the health beliefs and attitudes of Gypsy Travellers in relation to health service usage and access?

What are Gypsy Travellers' experiences in accessing health care and the cultural appropriateness of services provided?

Research Questions Phase 2

Primary Research Question

- How do Gypsies and Travellers and health staff perceive existing communication barriers?

Secondary Research questions

- Can facilitation of an exchange of views and perceptions between Gypsies and Travellers and health staff lead to modification of perceptions and views on either side?
- Can an exchange of views and perceptions facilitate a collaborative process between the Gypsies and Travellers with the researcher to generate specific resources and methods for improving communication?
- How do participants view the effects of their own involvement in this process of action research, both during the process itself and after completion?

Appendix C
Phase 1 Sampling Grid
and
Characteristics of interviewees

Characteristics	Number from Interviewed sample (n 27)
Gender	
Male	7
Female	20
Age group	
16-25	4
26-45	13
46-65	7
Over 65	3
Accommodation	
Council Site/ Private site	16
Unauthorised roadside site	2
Housed	8
In temporary (homeless)	1
Location	
(pilot) Northampton	2
Bristol	4
Norfolk	3
London	8
Leicester	10

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Appendix E

Study Phase 1 Sample of coded data

HU: DH Traveller project
File: [c:\program files\scientific software\atlasti\textbank\DH
Traveller project April 29th]
Edited by: Super
Date/Time: 12/05/03 11:36:34

222 quotation(s) for code: HEALTH BEHAVIOURS
Quotation-Filter: All

P43: 22 RE.txt - 43:55 (1085:1103) (Super)
Codes: [accommodation factors] [close family living]
[community support or isolation] [depression methods of coping]
[depression/mental health] [family involvement in health
issues] [health behaviours] [lay referral]

And how do you deal with that then, if you do get worried
and you get pressure, what do you do about it? Just like go
for the walk or go and talk to your mum, like say to her,
I'm in a very bad mood today now. Say, what's wrong, she'll
say, like whatever pains or, do you know what I mean? Like
you talk about it. Then when you're around the girls you're
not too bad. Have an old chat, a smoke, a fag, and you have
a good chat with them. And is that more difficult when
you're living in a house, or do you still get to see them?
No it's bad living in a house, love, you can't see nobody.
You do, I go and see them every now and again. On the site?
It's not the same is it? Do you know what I mean? You like
to be staying with them and. You like to be together like

P43: 22 RE.txt - 43:58 (1139:1146) (Super)
Codes: [cleanliness/germs/pollution] [cultural or personal factors]
[health behaviours] [motivation for preventive care]
[self reliance/stoicism]

So what, going back to keeping healthy, is there anything
you do about trying to keep yourself healthy and anything
particularly you do? No, not a lot really. Watch what we're
eating now and In what way? Clean up now and. I don't know,
keep fit, walk around. You know what I mean

P43: 22 RE.txt - 43:60 (1170:1185) (Super)
Codes: [access to health or social care] [health behaviours]
[priority importance of children (and fertility)]

Do you go to the doctor, is that the first person you go
to, if you're not well, the doctor? No we wait for about
four days to see how we get on ourself. If we're getting
worse, have to be dragged out of here. Sometimes we have to
be made to go. Right, but you, would you wait four days
with the children, if they weren't well, to see how they
got on? No. I'd bring them. You'd bring them straight away.
Yeah. If Darren he has a chest infection now I'd drop by
school and bring him straight to the GP at nine o'clock in

the morning. But he always sees the doctor, don't you son?

P43: 22 RE.txt - 43:67 (1474:1487) (Super)

Codes: [access to health or social care] [communication and use of language] [embarrassment/ shame/lack of confidence] [health behaviours]

That's another thing love, feel yourself, it's a bad thing to feel yourself. It always say on the telly you have to look after yourself. Would you do that? Couldn't feel myself the whole time love Because if ** How did you find the lump then? Because I felt. Just washing yourself or something? Yeah. Here. I felt funny then we had to go,

P43: 22 RE.txt - 43:68 (1487:1502) (Super)

Codes: [control over life /choice/self-determination] [family involvement in health issues] [fear of serious/terminal illness/death] [health behaviours] [knowledge .understanding and health awareness]

but there was a woman at the surgery when I was in, she came out and she said, she had a baby with her, his age, a little girl, she said I have, she met her friend, an old lady about 80 years. She said, I have to go to the hospital, she said, I've a lump. I think it's something bad. When I heard her saying that, I said, thinking about her lump about my lump, do you know what I mean. And it's bad though love - lumps. Don't like them things. So you'd talk to your mum, you'd speak to your mum about anything you were worried about? I'd show it to her yeah, I'd show it to her. ** or , I'd have to show it to her. Say what do you think they are? And if she says, ** no harm, but go to the hospital, we listen to that. But then by the time we 're there the sweats falling off us . It's bad to get results like that love. It's not good. I wouldn't like to have results like that.

P43: 22 RE.txt - 43:70 (1522:1531) (Super)

Codes: [access to health or social care] [communication and use of language] [denial] [depression methods of coping] [depression/mental health] [health behaviours] [meaning of health] [self reliance/stoicism]

And how do you go about doing that? How do you do that? Just cool down ourselves and look after ourselves. Do you know what I mean? We get vexed sometimes and what can you do? Not cry or something. You know go crazy like. People who have depression, they sits down , oh God, I'm bad, and I'm going to get worse. Don't think that way. We says like we're feeling bad now, in a bad mood, we thinks it's a bad mood we're in and we try to get out of it ourselves. Try and clean and leave it out of our head. Because if you try to think, turn my depression off, you think If I got depression. I don't need to see the doctors. I don't have depression love , I say , I'm fine.

Appendix F
Action Research Typology

Action research typology (adapted from Hart and Bond by Meyer) ⁴³³					
Action research type: distinguishing criteria	<i>Consensus model of society Rational social management</i>		↔	<i>Conflict model of society Structural change</i>	
	Experimental	Organisational		Professionalising	Empowering
1 Educative base	Re-education	Re-education or training	Reflective practice	Consciousness raising	
	Enhancing social science or administrative control and social change towards consensus	Enhancing managerial control and organisational change towards consensus	Enhancing professional control and individuals' ability to control work situation	Enhancing user control and shifting balance of power; structural change towards pluralism	
2 Individuals in groups	Inferring relationship between behaviour and output; identifying causal factors in group dynamics	Overcoming resistance to change or restructuring balance of power between managers and workers	Empowering professional groups; advocacy on behalf of patients or clients	Empowering oppressed groups	
	Social scientific bias, researcher focused	Managerial bias or client focused	Practitioner focused	User or practitioner focused	
Fixed membership	Closed group, controlled, selection made by researcher for purposes of measurement, inferring relationship between cause and effect	Work groups or mixed groups of managers and workers, or both	Professional(s) or (interdisciplinary) professional group, or negotiated team boundaries	Fluid groupings, self selecting or natural boundary or open/closed by negotiation	
	Fixed membership	Selected membership	Shifting membership	Fluid membership	

Action research type: distinguishing criteria	<i>Consensus model of society</i> <i>Rational social management</i>	↔	<i>Conflict model of society</i> <i>Structural change</i>
	Experimental	Organisational	Professionalising
	Empowering		
3 Problem focus	Problem emerges from the interaction of social science theory and social problems	Problem defined by most powerful group; some negotiation with users	Problem defined by professional in group; some negotiation with users
	Problems relevant for social science or management interests	Problem relevant for management/social science interests	Problem emerges from professional practice or experience
	Success defined in terms of social sciences	Success defined by sponsors	Contested, professionally determined definitions of success
4 Change of intervention	Social science experimental intervention to test theory or generate theory, or both	Top down, directed change towards predetermined aims	Professionally led, predefined, process led
	Problem to be solved in terms of management aims	Problem to be solved in terms of management aims	Problem to be resolved in the interests of resolved in the interests of research based practice and professionalisation
			Problem to be explored as part of the process of change, developing an understanding of meaning of issues in terms of problem and solution

Action research type: distinguishing criteria	<i>Consensus model of society Rational social management</i>		<i>Conflict model of society Structural change</i>	
	Experimental	Organisational	Professionalising	Empowering
5 Improvement	Toward controlled outcome and consensual definition of improvement	Towards tangible outcome and consensus definition of improvement	Towards improvement in practice defined by professionals and on behalf of users	Towards negotiated outcomes and pluralist definitions of improvement: account taken of vested interest
6 Cyclic processes	Research components dominant	Action and research components in tension; action dominated	Research and action components in tension; research dominated	Action components dominant
7 Research relationship, degree of collaboration	Identifies causal processes that can be generalised	Identifies causal processes that are specific to problem context or can be generalised, or both	Identifies causal processes that are specific to problem or can be generalised, or both	Changes course of events; recognition of multiple influences upon change
	Time limited, task focused	Discrete cycle, rationalist, sequential	Spiral of cycles, opportunistic, dynamic	Open ended, process driven
	Experimenter or respondents	Consultant or researcher, respondent or participants	Practitioner, or researcher or collaborators	Practitioner researcher or co-researchers or co-change agents

Appendix G

Phase 2 Reference Group Membership

Lynne Hartwell	Specialist Health visitor for Travelling families in Medham
Val Dumbleton	Specialist Health visitor for Travelling families in Otherton
Sarah Cemlyn	Academic with prior research experience with Gypsy Travellers
Margaret Greenfield	Academic with prior research experience with Gypsy Travellers
Sherry Peck	Manager of Gypsy and Traveller organisation
Siobhan Spencer	Manager of Gypsy and Traveller organisation
Camille Warrington	Researcher with Gypsy and Traveller children
Asma Bhukari	GP

Appendix H Study Phase 2 List of Participants

Gypsy and Traveller participants

Lil Gaskin
 Julie Price
 Charmaine Price
 Neesha Price
 Maggie Smith
 Sherry Bennett
 Tracy O'Neill
 Mary Ann Smith
 Charmaine O'Neill
 Tammy Bennett
 Ann Price
 Violet Tucker
 Eileen Lowther
 Jimmy Lowther
 Tully Lowther
 Kim Maloney
 Ada North

Health Staff

Rowan Surgery
 1 x GP
 1 x Practice Nurse Manager
 3 x Nurses
 1 x Health care assistant
 1x Midwife
 4 x Receptionist

Elm Surgery
 3 x GPs
 2 x Nurses
 1 x Reception manager
 5 x Receptionists

Walk-In Centre
 1 x Nurse leader
 4 x Nurses
 1 x Receptionist

Also
 1x A&E Nurse

Characteristics of Gypsy and Traveller participants

Medham

Ten women in 2 families – covering 3 generations (age range 16 years to over 55 years)
 Living either in houses or on authorised sites
 All married with children except the youngest generation.

Littleton

One woman, mother of 2 children
 Living on authorised site

Norville

Five women and one man (age range 25 years to over 70years)
 All married with children except youngest participant
 Living in houses, authorised sites or unauthorised sites

Appendix I

Chronology and Format of the Stages of fieldwork

Date	Group	No	Venue	Purpose and Format
15.6.04	Gypsy and Traveller women's group Medham	7	Health centre	Introductory consultation
13.7.04	Gypsy and Traveller women's group Medham	5	Health centre	Introductory consultation
17.8.04	Reference group	6	Health centre	Consultation
1.11.04	(verbal notification of Research Governance approval)			
4.11.04	Gypsies and Travellers Medham	2	Police HQ Midlands	Attendance at National Forum 'Engaging Gypsies and Travellers in Police Training'
16.11.04	Gypsies and Travellers Medham	3	Health centre	Narratives session
16.11.04	Gypsies and Travellers Littleton	2	Family home	Introductory meeting
14.12. 04	No Meeting – participants unable to attend as planned			
5.1. 05	Gypsies and Travellers (Family A)	3	Health centre	Narratives session
26.1.05	Elm surgery Health staff	9	Staff room	Focus group
27.1.05	Walk-In Centre Health staff	3 + 3	Staff room	Focus groups x 2
28.1.05	Gypsies and Travellers Medham(Family B)	4	Family home	Narratives session
28.1.05	Gypsy Littleton(Family C)	1	Family home	Individual Interview
3.2.05	Gypsies and Travellers Norville	6	G&T support centre	Introductory meeting -Focus group
9.2.05	Gypsies and Travellers Medham (Family A)	3 (+ 1)	Family home	Focus group
15.2.05	Rowan Surgery Health staff	9	Staff room	Focus group

Date	Group	No	Venue	Purpose and Format
18.3.05	Rowan Surgery Health staff	7	Staff room	Narratives session
22.3.05	Elm surgery Health staff	8	Staff room	Narratives session
29.4.05	A&E nurse	1	Health centre	Individual Interview
16.6.05	Gypsies and Travellers Norville	5	G& T centre	Preliminary feedback
22.6.05	Gypsies and Travellers Medham(Family B)	4	Family home	Preliminary feedback
22.10.05	Gypsies and Traveller Medham(Families B& C)	6	Restaurant	Feedback & informal evaluative focus group
12.1 06	Gypsies and Travellers from Medham and Norville	11	G& T centre Norville	Feedback & Evaluative focus group
20.1.06	Elm surgery Health staff	1	GP room	Evaluative meeting
20.1.06	Rowan surgery Health staff	6	Staff room	Feedback &Evaluative focus group

Appendix J

Study Phase 2 Sample of Initial Coding

Document: HS1 005
Created: 09/03/2005 - 16:17:23
Modified: 29/07/2005 - 16:59:19
Description: 1st Focus group with Elm surgery Health staff 26.1.05

Nodes in Set: All Tree Nodes

Node 1 of 95 (11) /Health staff attitudes/stereotyping

Passage 1 of 5 Section 0, Para 56, 57 chars.
Passage 2 of 5 Section 0, Para 60, 46 chars.
Passage 3 of 5 Section 0, Para 74, 33 chars.
Passage 4 of 5 Section 0, Para 90, 37 chars.
Passage 5 of 5 Section 0, Para 106, 28 chars.

Node 2 of 95 (111) /Health staff attitudes/stereotyping/Non compliant compared to 'norm'

Passage 1 of 4 Section 0, Para 116, 159 chars.
Passage 2 of 4 Section 0, Para 270, 93 chars.
Passage 3 of 4 Section 0, Para 492, 78 chars.
Passage 4 of 4 Section 0, Para 496, 158 chars.

Node 3 of 95 (112) /Health staff attitudes/stereotyping/GTs don't compromise

Passage 1 of 2 Section 0, Para 60, 54 chars.
Passage 2 of 2 Section 0, Para 116, 159 chars.

Node 4 of 95 (1 1 3) /Health staff attitudes/stereotyping/generalising language

Passage 1 of 3 Section 0, Para 200, 43 chars.
Passage 2 of 3 Section 0, Paras 218 to 223, 256 chars.
Passage 3 of 3 Section 0, Para 492, 169 chars.

Node 5 of 95 (117) /Health staff attitudes/stereotyping/non-stereotyping or acknowledgement

Passage 1 of 7 Section 0, Para 90, 37 chars.
Passage 2 of 7 Section 0, Para 206, 89 chars.
Passage 3 of 7 Section 0, Para 231, 349 chars.
Passage 4 of 7 Section 0, Para 235, 306 chars.
Passage 5 of 7 Section 0, Para 582, 162 chars.
Passage 6 of 7 Section 0, Para 618, 276 chars.
Passage 7 of 7 Section 0, Paras 618 to 624, 356 chars.

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Appendix L

Story One in Labov's grid (over 3 pages)

Labov structure	Narrative clauses	Interpretation
Abstract	<p>Question. So do you ever go to a doctor?</p> <p>If I'm ill No. Just if I'm poorly. Physically not mentally.</p>	<p>The Gypsy storyteller would not routinely go to a doctor about mental health issues(implying that this would be inappropriate and a sign of weakness)</p>
Orientation	<p>I was at x town and the children were all small I don't know what was going on. I think there was some people on the site where we were and I think they were all fighting and arguing and [beating] each other up and all things like that and I think it was getting no sleep and being run down and worrying of kids and he couldn't handle money and things was hard. And it was winter and I used to sit and cry and cry and cry. I thought what was wrong with me. There was something wrong with me.</p>	<p>There were many factors contributing to her stress at the time but the depth of her apparent depression confused and worried her</p>

Complicating action	But I did go to the doctor on that occasion and I said I think I'm being paranoid or something because I am continuously miserable	She 'broke' her usual rule and attended the doctor
Resolution	and I sat there and talked to him for a few minutes and he was a nice man and he said well what's your problem. I said I don't know and then he said half a dozen words and in that half a dozen words that he summed up exactly what was wrong... He said, he said, are you sick of your way of life? He was asking questions, he wasn't really telling me anything. And he said, are you sick of your way of life? Are you sick of where you are? And he asked me half a dozen questions and I thought (laugh) yeah. That is it. Spot on. What he was asking me was exactly what the problem was.	The doctor understood her distress and ask revealing questions that helped her to identify the cause of the problem and the appropriate solution
Coda	And he gave me anti-depressant tablets and I said I'm not going to take em and I never took em. I went home. I said to me husband. If it's hard here, it's going to be hard everywhere but the atmosphere was too bad. I said, 'let's go'. And he said, 'no we can't go'. I said, 'we have to go'. And that was the first time I think in a long time I put me foot down. I said we have to go. And we did, we packed up and went and that was about it...And that made it better. And I thought, he's right. Whatever that doctor had said, he was 100% but yeah	She felt didn't need medical treatment once the cause and solution were identified ie if she is able to move / travel according to her cultural practice she would not need medical intervention

<p>Evaluation</p>	<p>I thought it was just me being all misery and grumbling and groaning and kids, but it wasn't. But it took me to sit and talk to a stranger and then in like I say in half a dozen words, he'd hit the nail on the head and he said, 'it's your way of life' And I know. And how he was talking about it. Yeah he was right. That is the total root of the problem"</p>	<p>The doctor was perceptive in being able to validate the cause of her distress as a cultural issue. The real message from the storyteller is that travelling or the ability to travel is a cultural requisite for good emotional and mental health</p>
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Appendix M

Story 2 in Labov's Grid (over 2 pages)

Labov structure	Narrative clauses	Interpretation
Abstract	she wanted a prescription for an antihistamine	Story to follow about Gypsy Travellers attempts to obtain a prescription she required
Orientation	I mean we had a lady, I think it was last week... she tried every desk and there was nothing on the screen. She wasn't on a repeat	The patient came for an prescription that was not authorised for the receptionist to request from GP
Complicating action	and we kept saying you know, I'm sorry we can't just give you them. You've got to see a doctor.	Receptionists vainly attempting to inform patient that she required a GP appointment.
Resolution	And she tried every one and then she'd storm out. 'Oh I can't breathe so if I drop dead will you call an ambulance... Recep B Shrieking and Recep A You know and she didn't get it at one desk.... Anyway in the end I think she, Dr Bennett actually saw her as an urgent	Patient reacted as if receptionist was being deliberately obstructive and started making loud demands at each desk that resulted in her being seen as an urgent appointment

Coda	And she got her antihistamines what she wanted	The patient ' got what she wanted' , but as a result of unreasonable behaviour
Evaluation	What do I do. You know. And she was shouting and every body, you know	Receptionists feel that patient behaviour was manipulative, as they had no choice but to compromise/ concede because of the 'scene' created. GT's getting more than they deserve when they don't follow the 'normal rules'

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