

REPORT ON REGIONAL CONSULTATION

SOUTHERN HEALTH BOARD

Tuesday 30th September 2003 10.30am—3.30pm
Kingsley Hotel, Victoria Cross, Cork

Key Facilitators: Tess O' Donovan and Pat Evans (Health Services National Partnership Forum)

Departmental representative: Martin Kestell

National Traveller Health Advisory Committee representative: Brigid Quirke

Numbers attending: 40

After opening comments and a brief introduction to the study, the meeting split into two preparatory meetings to discuss the questions that had been circulated earlier. These meetings were held concurrently.

1. Traveller/Traveller Organisation Preparatory Meeting

The key points to arise during this discussion were:

- Rural isolation
- The importance of the social determinants of health—education, accommodation, poverty, discrimination/social exclusion, lack of employment, drug and alcohol abuse and erosion of culture.
- Role and attitude of doctors, particularly GP's—refusal to register, operating a quota system, too many prescriptions/medicine, trying to change doctors.
- Health providers need to understand Traveller culture
- Need for intersectoral participation in the study: key agencies such as DoE and councils are the people who need to hear but are not present.
- The need for Travellers to identify themselves, and be identified, regardless of where they live.
- The critical role of primary care projects in the study.
- Some believe it is better Travellers talking to Travellers to collect information; others believe that Travellers would not disclose personal information to another member of their community so a settled person would be better.
- Confidentiality is a key concern
- Need for a good communication strategy to increase and sustain awareness of the study. This could include awareness raising on Traveller culture
- Resources needed include technical support and training, staff time-releases (locums or part-time subs) and finance.
- Impact of legislation on health e.g. Trespass Law
- Traveller involvement and participation is crucial.

The three priority issues identified by this group to be brought back to the Joint Discussion Forum were:

Traveller participation

Additional resources

The social determinants of health to be included in the study

2. Health Services Providers Preparatory Meeting

- While Traveller involvement is crucial the study needs to be more than that so that issues are identified
- The study needs to link into local projects and other agencies e.g. schools and need to link with research already completed.
- A partnership/intersectoral approach is needed to include other departments especially Environment, Housing, Health, Education.
- There is a need to link databases from disability agenda including physical and sensory, physical and intellectual with Travellers.
- The study needs a local Traveller Health research Group with a mix of disciplines.
- Key stakeholders such as Education and Local Authorities, given the impact of accommodation and education on health need to be involved.
- Recognise the existence of Travellers own language CANT and need to take this into account
- All resources for this study should be linked and co-ordinated
- Additional resources are required to cover personnel time
- Developmental work is needed to support representation
- Travellers to have a choice of who interviews them
- Need to recognise the difference between attendance and participation
- A special count on a specific day is needed for this study, as there are anomalies in existing numbers and collection systems.
- Need to ensure that such a count is not seen as a security or tagging issue
- Need for a media campaign to promote positive aspects of revealing Traveller identity.
- Ethnic identifier is needed in all services to gather relevant information.
- Traveller awareness training needs to be offered, and taken up, at all levels
- At local level such training such become an ethos as part of service delivery
- Traveller Health Units and Community Care Services teams have a central role in the research.
- A common IT infrastructure system is needed with appropriate training

The priority areas identified from this discussion to be taken back to the Joint Discussion Forum were:

1. Collaboration and participation between departments—such as Education, environment (Housing)
2. Ethnic identifier
3. Ethos in the Health Board to be inclusive, anti-racism; that there is no exclusion

4. Issue of capturing information regarding disability: intellectual disability, physical and sensory disability, mental health disability.

3. Joint Discussion Forum

The two preparatory meetings then came together to provide feedback to the full group and agree the priority issues for the Joint Discussion Forum. These were agreed as:

1. Participation
2. Resources
3. Culture/cultural awareness
4. Other stakeholders
5. Broader issues effect on health

The meeting broke into five sub-groups to consider each of these topics. The key issues arising from these discussions were:

1. Need to target Travellers not involved on courses or organisation
2. Sufficient support and resources to Traveller organisation to ensure meaningful Traveller participation, including those at 1 above.
3. Traveller involvement in the process includes analysis and recommendations.
4. Public awareness campaign to inform people and organisations what is happening. This might include a road show.
5. This study is needed on an all-Ireland basis
6. Technical resources and support to train Travellers in research skills
7. Denial of identity is a fear of discrimination
8. Need for great sensitivity around disclosure of information: confidentiality
9. A separate census is needed
10. Communication factors can cause mistrust
11. Institutional racism—services have been designed by and for majority population: big challenge to make services appropriate
12. Highest numbers of admission to hospitals caused by non-medication compliance due to not understanding.
13. Involvement of other stakeholders at local and national level is essential.
14. Involvement of National specialist agencies e.g. Combat Poverty
15. Documenting discrimination is not enough

4. Outstanding Issues to be clarified

How do we access the needs of Traveller men: local groups are made up of women?

Query role of local health research team?

Question of corporate commitment to all of this

NOTES FROM SOUTHERN HEALTH BOARD CONSULTATION

Question 1 Main factors affecting the health status of Travellers

Accommodation

Living far from the town/ city for example 4 miles from the car and if she has no car she would have to walk

In Dublin some find that the doctors discriminate against them

In Cork some have found that if they ring for a doctor it might take the doctor three hours to come out, some find that when they live on a halting site that doctors can discriminate against them

Some find that if they are staying in a different places some of the doctors won't see them unless they are their own regardless if they have a medical card or not

Health

They should be told how dangerous certain illnesses are and that they should go to doctors because a lot of illnesses can be saved if they are got in time and have regular check ups.

One woman died of breast cancer in the Dublin group because she bottled everything up and didn't look into it in time

In Dublin she feels that she can't leave one doctor and go to another

Some older travelling people fear going to the doctors and that it's up to us to put our children first

Money is another major problem

Some halting sites are not up to standards; some people have experienced broken glass around trailers to get rid of rats.

In Dublin there are 50 families living in group house in a small area and you were not forced to stay and that you could travel if you wanted to

Education

Some teachers are not helping the travelling students as much as they should

Drugs

Another major problem, more so in some areas

Factors affecting health

- a) Education
- Accommodation
- Poverty
- Discrimination- social exclusion
- Lack of employment
- Drugs and alcohol abuse
- Erosion of culture

- b) Lack of access
Nothing happens/ lack of understanding of how system works?
Literacy: services and information assume literacy
Information not easy to understand
Notices on appointments- can't read
Appointments- too early/ too late
GP's don't examine you
 -too many prescriptions/ medicines
 -refuse to register
 -only one traveller allowed at one time
Non-transfer of medical card
How to explore sensitive issues e.g. miscarriages
 How impact on health and well being of family
 Mental health
- What covered on medical card e.g. smear test
 Not drugs free
- What covered under DTSS
- Access and appropriateness
 Bereavement Counselling services

Education
Environment
Transport
Intersectoral participation

Health board personnel can only treat above

Identifying travellers
Impact is some services on travellers even though living in community

Age precludes accessing respite

Defining the health as all aspects e.g. social

Cultural awareness of giving service e.g. home help service
Unwelcome
Unaware of accessing

Breast cancer
Woman's health

Primary care projects- key to above
Majority settled in areas now

Timing of research- done at optimum time e.g. school holidays

Question 2 Traveller participation in the study

Some people find that since the Primary Health course started a lot of people have let their friends know of their knowledge

They feel it would be better if travellers talked to Travellers, as they would have a better understanding

Travellers wouldn't tell travellers personal information, so it would be better for settled people to find out that information

In Dublin they have a big problem with medical cards some have been mislaid etc.

Some find that surveys should be done to find out how many travellers are in Ireland

Some find that "dates of birth" would be better.

Confidentiality
Protected data
No names

Travellers to participate in study

Traveller organisations to be included in training and research

Need additional resources

Question 3 Methods to record information

More information about travelling people

Focus meeting

They think that people should organise days to go out to the halting site

When people, travelling people find out more information they become more interested.

To find out how many travellers are in Cork- the schools, the halting sites or

Some travellers are married to settled people, some don't recognise that they are travellers.

Some don't want to be classed as travellers

Deaths

Travellers die younger than the settled populations

Travellers have the worst state of health

Depending on "surnames" we would know if they are travellers or not

A lot of people don't have a registration form

Some can't get their birth cert and they have several problems.

Challenge identify travellers

PR company, advertise study

Word of mouth

Births and deaths? through local priest

Informally through Traveller groups- births and deaths

Question 4 Collecting births and deaths data

Accommodation

Discrimination

Education

Health

Very important for doctors, hospitals to recognise that travellers' have their own culture

Some travellers can't read and therefore don't know what tablets they do be taking

Guards make them move because of the Trespass law

Not all travellers in houses can afford some facilities that settled people take for granted.

The three main areas are

1. Health
2. Awareness training
3. Communication
4. Traveller involvement

No one wants to do nothing for nothing, so people should be getting paid, as there would be more involvement.

Question 5 Resources, Training

Resources

Technical support/training

Resources / staffing time- releases

Money

Environment and education

Key issues affecting health of above

Ethnic identifier
System of data collection common to all
Relevant supports i.e. email

Traveller participation the how of doing it

The 3 main things

Traveller involvement is very important and we need communication among Health boards, the settled people and ourselves for example: communication through Traveller awareness

Accommodation, department of the environment and local and county council the people who need to hear are not here and they need to be involved

Education

Discrimination

Priorities

Traveller/ participation

Additional resources

Importance of reflective

The broader causes/factors

Influencing traveller's health

i.e. education
discrimination
accommodation
income/ poverty
employment
social exclusion

In the study

Health Service Providers Preparatory Workshop

Q1 Factors Affecting Traveller health

Bring the study out to the relevant participants
How the questions are asked
Finding appropriate way to capture the information

Travellers talking to travellers but this needs to be broader to identify issues.
Travellers to be involved in the research but other (Traveller Orgs and other Health Board) Comm Dev Workers/ PHN, Welfare, and GP's who know their travellers need to get GP'S involved.

Link into Community Development Projects e.g. Rapid Projects

Identify Providers who have daily contact with Travellers particularly schools.

Need for Partnership approach

(Ethnic identifier) ref Q.3

Many factors are outside the Health Board capacity

Need to link with other Depts e.g. Dept of Education, Housing Dept, and Health/Env

Need for intersectoral approach

Partnership approach with other Dept

Linking Department of Environment, Housing, Health, Education

Capturing information- obtain meaningful consultation with Traveller, How to do this

Linking with research already completed

Access and participation

Issues relating to disability

Literacy

Broader education

National strategy refers to disability. Acknowledges lack of information, included physical and sensory, physical and intellectual

Link two databases- lack of linking with Traveller

Health Status

Who will be on the local Traveller Health Research group?

How do we utilise local talent

How do we ensure a mix of disciplines?

* Noted that housing/ accommodation conditions has a huge bearing in health- key stakeholders missing – Education and Local Authorities

Ripple effect of problems – poor living conditions – ear infections- speech problems

Use of language in the process and in the report very important – traveller language different to language used more widely

Literacy skills relevant

People need to take account of Cant

(Robert Ferry- U.C.C research)

Previous research done by local study group on barriers to accessing services

Traveller awareness programme being developed by SHB

Primary Health Care Projects have an input

Q2 Traveller participation

What form should Traveller participation in the study take locally?

Co-ordinated approach required. Traveller Health Unit (THU) rep from Travellers and Health Service providers provide good representation
Rep from THO & Southern Traveller Org

Covers all those represented and interested

Good lot of resources but need to link

Get broader representation from Services in Education & Environment, Housing
Need all these Depts together
Need reps from T.H.O on Housing, Education, and Environment Dept in linking with key stakeholders

Support for Traveller representation and participation in being a link with key stakeholders

Developmental work provided to support representation

Travellers interviewing travellers – welcome where possible

Recognition that some travellers may not wish to talk to other travellers about personal issues including finance, family planning, sexual health. Some discussion re whether a complete stranger or whether someone known to the travellers would be best as an interviewer

How do we access the needs of travellers men- local traveller groups made up of women?

Query role of local health research team

Participation: New forum for participation. Traveller participation vital in research

Broaden the pool of travellers available to provide participation

?? role for males. Men working with men

Going to where travellers meet

? Literacy issues

Feedback from travellers

Confidentiality around travellers collecting info (to be done by Traveller groups)

Flexibility around this

Attendance vs. participation

Q3 Methods to record info at present

Inadequate methods

Recording of information is not adequate

Ethnic identifier

CSO count and Dept of Environment count not accurate- discrepancy

Ethnic identifier: need to be in place in all services to gather the relevant information to identify traveller population in Health Services
Need to do a special count on a particular day
Positive discrimination issue

Media promotion to promote the positive aspects of revealing one's traveller identity

Link with next census for future collection of data on traveller to provide more detailed information so as to record data

Ethnic status needs to be included in forms

Local knowledge by Public Health Nurses

“Definition” of travellers- by mutual consent agreed

Current methods not effective

Hand held records?

PHN- none

PT – none

CWO- halting site versus homeless (side of road)

Stats/ data collection? Duplication

C. W- grant aided

Security and tagging- national issue

Equality authority information- the outcomes

Anomalies in numbers and collection systems

National system

Q4 Most accurate ways of collecting and collating births and deaths

Establishment of an ethnic identifier in hospitals/ community health nurses

If register of birth includes an identifier

Recording of deaths more difficult- signed by doctor

Difficulty

Need for collection for information on ethnic status, at time of birth and death registration

Noted that travellers usually eligible for death grant

National identifier:

Deaths up to individual

A lot of unregistered deaths

? Traveller register

Identification of culture on this
Input of hospital for births
GP's for home births

Q5 What resources do you need?

Resources, Training, Support

- a) Awareness training
Traveller awareness training
- b) Traveller awareness training
Expectation that everyone would be offered and attend
Needs to be at all levels

Education campaign that incorporates Travellers, that people would be aware of all the needs of Travellers

Induction training in the longer term

Done local management team- G Manager
Each head of discipline be responsible for their own team

At local level, become an ethos as part of service delivery
That each individual be aware of the needs of Traveller

Need for extra manpower/ womanpower

THU's seen to have a central role in the research

Community Care Service teams recommended (5)

Include budgeting for some payment to travellers who participate in the study

Secondment to this area
Funding for above linked to THU or CCS or Primary Care

I.T infrastructure (Common system)
Training for above
Clerical support

Question of corporate commitment to all of this

Health Providers Group

Disability
GP's
Acute Hospital
Dental
Comm. Social Worker

Have not participated

Intersectoral

Local res

Team composition

Disability

How participate

Resources

Mechanism for the how

Ethnic i/d on info

Inclusive ethos

Language/ jargon

Culture/ clashes

Gender

Perception

Priority areas to bring to Joint Discussion

1. Collaboration and participation between departments- such as Education, Environment (Housing)
2. Ethnic identifier
3. Ethos in the Health Board to be inclusive, anti racism
That there is no exclusion
4. Issue of capturing information regarding disability. Intellectual disability.
Physical and sensory disability. Mental health disability

And study needs to make recommendations to the national data committee as to how to capture on the disability issues from the Traveller population

Joint Discussion Forum

Participation

Resources

Culture/ culture awareness

Other stakeholders

Broader issues effect on health

Participation

How do we ensure and accommodate active participation by all

Need to target travellers not involved on courses within Traveller orgs e.g. rural

Always same people turning up

Traveller focus groups to stress importance of this study, that its for Travellers benefit

Traveller orgs will need a lot of support and resources to ensure real Traveller participation

Further on focus groups involving HB personnel

Train traveller men and women as spokespeople to raise awareness of study

Door to door research

Public awareness campaign to inform Travellers and Health Board on what's going on

Travellers involved in all aspects of defining their own health issues and in planning to ensure inclusion of areas like disability etc- getting Travellers attitude towards issues.

Recognising the needs and accessing services

Resources

What resources are required to facilitate the study?

Money- and needs to be capacity awareness and it should include travellers that don't work in T.V.G or in other traveller groups and organisations

It will be a long-term goal

Health board worked should sell the study to their own workers, a lot of studies that have been done which included travellers was never seem

We do need an All-Ireland study on Travellers health, no approach to identify the illness in Traveller's health

The health board feedback that they got back from the study stated that Travellers couldn't access facilities easily

Additional resources

- 1) Awareness of the travellers that's involved in the study and also the rest of the travelling community, awareness among travellers
- 2) Technical resources- access to training helping to train travellers in research skills e.g. focus groups and questionnaires, how to gather information (being involved in the design of questionnaires)
- 3) Make up resources
Who will be the local research team? How local will the people be, the discussion should be friendly (user friendly) and easy to read and understand

Cultural/ gender

Women traditionally responsible for health

Projects for men targeted to the interests of men
How do you do this?

Reluctance of travellers to impart sensitive information to other travellers

Gather information by story telling

Must see the benefit to them- must be set at their pace and include their values

Local knowledge very important

Training of new community workers to talk to men
Older women often more respected and can gather sensitive information

Serious cultural problems for ethnic identifiers.
Data Protection Act states that one must self identify- problem if Traveller does not wish to identify them as a Traveller

Denial of identity- a fear of discrimination

What baseline are we using?

What current information do we have?

To look at pulling together all the different stands

Separate census

Culture/ culture awareness

What key issues will impact the survey

Travellers may have a distinctive way of communicating

Culturally appropriate

Big challenge to make services appropriate

Multicultural/ Intercultural

Institutional racism – services designed for the majority

Education and understanding

Communication factors can often cause the mistrust

Primary health care should address issues

Highest numbers of admission to hospital due to non-medication compliance due to not understanding

Role of other stakeholders

Who?

Dept of Environment

Dept of Education

Traveller liaison teachers/ resource teachers

Health boards

Travellers

County/ City Development Groups

National and local level

Local- THU- National???

THU- given co-ordinating unit

Role of THU – network vehicle of 9 groups and 9 Health Board personnel

Southern Traveller network

Stakeholders have to be approached

How to involve other stakeholders

GP role. Primary Care Unit

Primary Care Manager on THU- defined role

Identifying need

Primary care unit

Effort put into publicity at local and national level

Education to reinforce the strategy

? Road show mechanism

Involving local authority - social inclusion units- Feedback to 7 directorates
(commitment to do same)

Government to fulfil to goals one at a time i.e. inclusion and this strategy

Mechanism for information out and in

Testing of mechanism and process

? Evaluation

Northern Ireland angle. Place it as social inclusion units

Community Service Areas

Community Managers team

Gleaning information locally is the key

? Rapid structure

THU's to do an audit locally of needs

? representative of broad spectrum

Getting to grass roots level

How the broader issues affect this health study

For clarification

Housing/ accommodation

Poverty

What potential things can we do to make sure that their issues are intrinsic to the study

What are the issues?

Education, Housing /accommodation, poverty, discrimination, mental health disability

All of the above impact on health

1) Housing/accommodation

Ensure that the Depts of the Environment, and Education and Justice are involved from the beginning in the design of the study- the planning process from now on should include these people.

2) Poverty- difficult to define poverty- get Combat Poverty involved, us their expertise- their template questionnaire

Look at Traveller participation in local youth groups, community groups etc

- this will effect their health

Focus Group with Travellers to show how discrimination affects their mental health

Some work has been done in SHB on access to services- look at the template for this see can it be used in the broader Travellers Community
Documenting discrimination is not enough

Education- role for home/school liaison officers- Dept of Ed resource teachers for Travellers

Look at literature already there

Lack of education leads to lack of employment- poverty

Mental health

Ensure that the right people are asking the right questions

Travellers' perception of health-ensure that the conclusions drawn are the conclusions meant by the Travellers

Travellers should be involved with the analyses and recommendation.

For clarification

Housing accommodation

Poverty- role of Combat Poverty

Discrimination- access to services- template (through Focus groups)

Mental health

Disability

Steps

1) To make sure all stakeholders are involved from beginning in design

1. How do we ensure that Travellers, Traveller organisations, health service providers and others in your local area are fully engaged with the study?

How should this study be organised, conducted and managed at the local/regional/national level?