

REPORT ON REGIONAL CONSULTATION

EASTERN REGIONAL HEALTH AUTHORITY

Thursday 11th September at Pavee Point, Dublin.

Numbers attending: 65

DoHC representatives: Anna May Harkin, Hugh Magee, Pauline Ryan

National Travellers Health Advisory Committee members: Brigid Quirke, Kathleen Joyce and Ronnie Fay

Facilitators: Fran Keyes(Independent):Maire O Haire and Seosamh O Maolalai(Health Services National Partnership Forum)

This meeting took place with sequential preparatory meetings for Traveller/Traveller organisations and Health Service providers. After opening comments and an introduction to the study the first preparatory meeting broke into four working groups to consider the preparatory questions (See Appendix 2). The following were the main issues arising from these discussions:

1. Traveller/Traveller organisations preparatory meeting

- There was a significant emphasis on understanding of Traveller culture, racism/discrimination and recognition of the expertise available within the Traveller community and their organisations as the framework for the study.
- Methodology was mentioned on numerous occasions as critical to accessing and utilising information in an ethical manner.
- There was a view expressed that the study should seek to engage with appreciation training i.e. an affirmation of things that are right, not putting the onus on Travellers, not a list of what is wrong and how it could be put right.
- There is an understanding that a holistic view of health will include factors which are both external (and beyond control) and internal (which can be controlled).
- This includes recognition of the experience of being a member of a marginalised community and that this might be set against experiences of illness/depression within minority ethnic groups generally.
- An area of training identified was that of recording information
- The role of the Church and its organisations was considered important in collection of data relating to births and deaths.
- While no view was expressed about a separate census/count it was felt that data collection re a count should take place October/November period.
- Resources required for effective participation including funding, transport, training, and building on what had already been done.
- There needs to be agreement on what the study is trying to achieve
- The study needs to be informed by ethics that cover research—participants need to be actively involved, not be exploited.

- The role and contribution of local voluntary groups in the study needs to be recognised to give ownership of the study at local level
- Traveller men have experienced a loss of traditional and cultural roles that can give rise to a sense of worthlessness and diminish their sense of well being..
- Poor relationship between GP's and Travellers (refusal to take them on, no check-ups, prescriptions and tablets)
- Travel in rural areas within this region
- Need for standards of good practice to include prejudice reduction and anti-racist training
- A complaints system should be built into the study
- Need for a communications strategy as part of the study

Two priority areas were identified by this meeting for consideration at the Joint Forum

1. Definition of Health
2. Process—How and Who? Creative, training and participative for both Travellers and Health Service Providers.

2. Health Service Providers preparatory meeting

There was a brief introduction to the study followed by a question and answer session before the meeting broke into smaller groups to consider the questions previously circulated.

- Dilemma/conflict between specialist services for Travellers and mainstreaming service access. If these are parallel processes then maybe there is too much service provision.
- The degree of stigmatisation associated with some specific health problems, particularly mental health and how this makes it very difficult for marginalised people to engage with that service.
- The issue of attitude/prejudice in society was acknowledged.
- The opportunity for Travellers to participate in the study must be available and time should be spent on qualitative research.
- The study must be inclusive of all groups within the Traveller community and the methodology chosen must be appropriate for the group in question e.g. age, gender.
- There is no effective system of estimating the Traveller population but all existing resources/agencies should be tapped into to disclose information, which can then be collated.
- This study should not put pressure on or upset existing work within either the community or voluntary organisations or statutory agencies and that those appointed as researchers would have to work alongside existing arrangements.
- It should not be left to the health service providers to lead the research up.
- The issue of more and better use of IT equipment and training was essential as an integral part of the study.
- GP's refusal of medical cards
- Lack of understanding from professionals

Four priorities were identified for consideration at the Joint Discussion Forum:

1. Barriers that prevent Travellers using mainstream services—within Traveller community themselves
2. Health care Service providers: values, training, cultural issues and inter-sectoral work
3. Lack of record identifiers
4. How do differences within the Traveller community get included/listened too?

3. Joint Discussion Forum

After lunch and the conclusion of the Health Service Providers preparatory meeting Travellers/Traveller organisation representatives and Health Service Providers representatives came together. Spokespersons for the preparatory meetings summarised the discussion behind the priority issues that their meeting wanted to be discussed in the Joint Forum. Facilitated discussion took place on the priority issues and it was agreed to discuss the following four:

1. Process—Who and why? Barriers that prevent Travellers using mainstream services.
2. Definition of health
3. Traveller participation
4. Records and identifiers

The Forum the split into four smaller breakout groups, each including some Travellers/Traveller organisation representatives and some health service providers. Each breakout group was allocated one of the issues to discuss in depth.

The breakout groups came back together and a spokesperson from each breakout group summarised their group's discussion. Further discussion involving all the attendees then occurred.

The main points that arose were:

- The more democratic the process the more inclusive it will be.
- Without Traveller participation the study has no meaning, no information and no possibility of success. This participation runs from start to finish: designing questionnaire, to doing survey, analysis of findings and making recommendations.
- The study needs to be integrated with the National Traveller Health Strategy and have visible outcomes.
- The need for this study to connect with the National Health Information Strategy was regarded as crucial.
- There is a need for compatible information systems within the health services
- There is no hard information and data, which allows targets to be set and permits for effective monitoring and evaluation.
- Results should be available on an interim basis and made available and accessible at local and regional level to local groups.
- It is likely that this study could have implications for policies and training for health service providers re anti-racist training/attitudes i.e. that institutional racism might be identified as a significant barrier to participation.

- It was recognised that Traveller culture is itself evolving and that these changes will impact on health, particularly on Traveller men's health.
- The need for simple language was identified as important.
- The study needed to be more than action research: it needs to bring about change for both the Traveller community and the majority community.
- While it was agreed that the self-identifying principle must be respected it was felt that a self-identifier protocol would help Travellers make an informed choice.
- The study needs to acknowledge the range of people and amount of time involved
- The issues of Confidentiality, participation, definition and decision-making are critical at all stages of the study.

4. Outstanding issues to be clarified

- A complaints system as an integral part of the study
- Health is a life time project: how can on-going trends be identified?
- Those who are participating in the research should have choice of researcher but this has resource implications.
- Who owns the information? How do Travellers keep control of information?
- An awareness campaign needs to be undertaken to demonstrate the benefits to the Traveller community of self-identification and participation.
- What is the benefit of participation?

APPENDIX 1
NOTES FROM EASTERN REGIONAL HEALTH AUTHORITY
CONSULTATION

Pavee Point, Dublin Thursday 11th September 2003

The meeting begin slightly behind schedule at 12.10 with approx. 50 people present.

Brigid Quirke welcomed representatives from the Department of Health and children. Kevin Balanda did a brief background to the Institute of Public Health and its role in the design of the study.

Fran facilitated this preparatory meeting with Travellers/Traveller organisations. This group was split into four smaller groups to discuss the preparatory questions (see attached)

These smaller sessions lasted 45 minutes and time constraints meant there was no feedback in the plenary: instead the big group went straight into discussion of priority areas for the Joint Discussion Forum

Traveller/Traveller organisations workgroup discussions on the questions.

(All of the group answers have been amalgamated under each question)

Q1.a) Main factors affecting the health status of Travellers

One group sought a clear definition of what it is trying to achieve Process is very important and ensure full participation Need to work local and national level together Could do a pilot run—use creative methodologies Different methods needed and be inclusive “meet everyone” Look at questions (draw conditions on site{camera})

Careful with methods. Recording

Must listen to consultations, listen to women ideas re survey: training for everyone

Area should be flexible too manage local survey They will know what is best for area Informed by ethics that cover research—actively involved, not exploitative. Ownership: lots of voluntary local groups and value their role. Potential of it.

Inclusive of Traveller men

Not scare people—use appropriate materials –not do act (?) Feedback very important.

Bigger picture:

Discrimination at institutional level

Accommodation, education (lack of literacy) ✓

Lack of health services

Water, sanitation ✓

Dampness

Rats

Work, unemployment ✓

Work environment

Discrimination at different levels: unfriendliness

Lack of awareness of Traveller tradition

Barriers—lack of respect in the treatment of Travellers

2nd class citizens

Travellers experience being bullied, excluded and that others are “not interested” e.g. GP writes a prescription but not really interested.

Men have experienced a loss of traditional and cultural roles that can give rise to a sense of worthlessness and diminish their sense of well being.

Employment, poor income, treated with a lack of respect.

Accommodation: poor accommodation gives rise to poor health ✓ ✓

Lack of understanding 1) By Travellers in relation to medicine (poor literacy)

ii) By Health Providers

There can be difficulty getting a medical card e.g. GP's won't take on

Travellers. ✓ Lack of immunisation information

Lack of user friendly Traveller information

Lack of communication

Problems with Public Health nurses who will not go out onto sites in some areas

Lack of wheel chair access

Traveller people with disability is not tracked

Depression/Fear/ Embarrassment of Traveller

Health professionals not listening

No full check-up, just prescriptions and tablets when Travellers come to GP clinics

Transport to clinic necessary (in rural areas)

Medical information not being co-ordinated (gaps)

Motivation of Travellers to do it for themselves

Incentive for Traveller men to have check-up twice yearly under Health Board

1.b: Access and participation

Information is not Traveller friendly and available

Lack of services and facilities

Discriminatory treatment

Access to childcare (i.e. hospital appointments)

Some GP's do not register Travellers. There are gaps in contact: there is a dilemma as to whether that requires more designated staff or mainstream services.

Workers are times seem uninterested in their client group—carrying over prejudices.

Need for standards of good practice to include prejudice reduction and anti-racist training.

Medical staff ignorant

Travellers are embarrassed because of low literacy levels

Fear of Travellers

Lack of understanding of Travellers

Distance from Health Service

Travellers should be able to use their own local health service

Lack of facilities (such as play room) for mothers with children attending Hospital

Not being listened too

Appointments sent out early with no follow up by health professionals re visits
No postal service in some places
Link between Travellers and health Board not co-ordinated or standardised
Children have dental treatment in school: leave school no tracking or follow-up

Q2. Traveller participation in the study

Travellers involved in developing methodology, carrying out, decision making from beginning to end. Include things external and internal control. Holistic approach==stress/mental health/discrimination/well-being—being a member of marginalised community. Illness/depression in ethnic minorities.
Recognition of its existence.
Looking for models of good practice
Look at the expertise
More training
“Experts” are not objective
Look at methodology—allows for Traveller participation to obtain information or give information.
Confidentiality has to be assured.
Travellers have “knowledge” and it is vital that they participate in the survey
Gathering information: it is important that Travellers are talking to Travellers
There is a challenge to the study team, some of whom may never have visited a site “come and see us”
Travellers should be involved in the interpretation of the data
Local Development and Support groups have a role to play
The study team will maintain links and feedback to the local group is very important.
Religion/spirituality is strong among Travellers. Traditions and traditional ‘cures’ need to be respected.
Induction for the company selected is important to ensure they are “interested” in Travellers and their culture.
What is health—define
Gathering information : objective v subjective
Methodology—manner of research as important as results
Expert committee—Travellers are the real experts: recognise the value of Travellers and their organisations who have already carried out research: add onto this, not lose it.
Question of replication—not really Travellers are not the same in families/areas or regions
Creative way to carry out research—Travellers tired of being researched
Appreciation training---affirming things that are right—not putting onus on the Travellers: not a list of what is wrong and how to make things right.
Local participation:
 what has been done not going to repeat
 Building on what has been done
Information and training—what needs to be done
Traveller organisations + Pavee Point + Health Care Groups
Preparation—what is the study
 Creative ways to do the study

Creative training/trainers
Recording sessions—what has been achieved?
Making study manageable

Question 3 Methods to record information

GP's, health nurses, service providers.
Need ethnic identifier in hospitals, GPs'.
Must be self-identification. CHU's—cross-reference local database that is accurate and able to be updated.
There are discrepancies in data
Trust is a significant factor that will need
---informed choice
---self-identifying principle(re Traveller identity)
---out-reach to marginalised families
Who is asking the question is a significant factor to most Travellers.
Confidentiality is vital
Getting awareness among Travellers in relation to participation, raising trust and identifying concerns is required.
Hospital/Public Health nurses/ Traveller organisations
Local GPS's Traveller link person needed
No co-ordination of information
Ethnicity not considered when forms are designed so tracking does not take place
Training needed by the Traveller organisations in relation to recording information
Confidentiality—how can it be ensured.

Question 4: Collecting births and deaths data

Count in each area
Crosschecks. Use local groups. Travellers know best. Mark areas clearly for each group to yearly collect data. Work from local to national. Confidential and anonymous information
The role of the Church, Crosscare, Parish of the Travelling People and perhaps local parishes need to be considered
There is the option of developing a database for local groups.
Establish a good time for data collection i.e. October—November.
Co-ordination needed—between groups (Health Boards, Hospitals, Travellers, Public Health nurses)
Standardisation needed for recording purposes
Discrepancies between county and east coast area
Information not recorded accurately
Training needed for Traveller organisations in methods of recording

Question 5: Resources and Training

Training, support, build trust, and need to know what is happening with survey
Funding and support
Build on expertise

Training and Traveller participation in taking survey Locally collate information to use locally, available locally. Is assumption that PHC programme focus of study? Do need reflection of wider groups (i.e. men, young Travellers, old etc) Practical training: who is doing research? Need groups/ tenders who have real experience and knowledge.

Research—educators, psychologists, therapists included.

Body of people.

Pick up institutional racism.

Training of Travellers to be involved in the research

Money ✓

Transport to facilitate participation ✓

Information, media

Link person

Need to “sell the survey” and to keep language simple and accessible

Website for interactive feedback and regular bulletins

Bulletins for local organisations.

A complaints system

It was noted that it would be advantageous to continue the survey so that it is not a “one-off” project and that through on-going study trends can be identified. Health is a life time project.

Basic health care training

Collating data locally

Creative interview methods

Using it locally to extract information

Experienced Traveller researchers to share experiences and training techniques

There was no feedback at end of these workshops the plenary group went straight into identification of the Priority Areas to be fed back for the Joint Discussion Forum

These were identified:

2. PROCESS—HOW AND WHO? Creative, training and participative for both Travellers and Health Service Providers.

1. Definition of Health

Benefits of survey to Travellers—what are they?

Effect on Travellers

Accommodation—dampness Rats

Methodology—Process

Local to Regional

Health service Providers Preparatory Workshop

Q1.a Factors affecting Travellers Health

Accommodation ✓

Education ✓ including education around parenting

Stigmatisation including mental health

Level of information available

Internal and external factors e.g. well-being

Psychological and emotional health
Lack of knowledge
Language of statutory bodies
Discrimination e.g. look at info to settled community.
Society' views e.g. 12 year old child with no knowledge of Traveller culture
Mainstreaming—maybe too much service to them
Participation and mainstreaming
Access locally and within own cultural area
Needs met within mainstream
Setting up specialist groups lets others off the hook
Have to look at mainstream services and patterns of use
Look at statistics re attendance/non-attendance
Need to look at blocks in the study
Attitude—prejudice in society
Living environment—water, rubbish
Poor communication
Cost
View of own health
Health expectation
Keeping appointments
Patriarchal culture
Motivation—priority of health.
Situation has improved—general health
Must define the Traveller
Specialist and mainstream services
Must find out their views
Travellers must be involved thoroughly for study to work
Must link in very closely

Q 1 b Access and participation

Accessing medical cards: GP's refusing medical cards
Refusal—barriers with bureaucracy
Changing addresses
Similarity of names
Suspensions
Lack of understanding from professionals
Not getting mail
Catchment areas
Information filtered—not going to the person
Location of services
Transport

Q2 Traveller participation.

At local level re research and focus groups
Opportunity to participate should be given
Democracy—have different groups within Traveller community
Be aware that Travellers are not homogenous groups and some Travellers are marginalized within Traveller society.
Gender issue to be considered---? For equality. May be need of separate sessions and possibly by age groups e.g. adolescent and older groups.

Inclusion—accessing Travellers who aren't local or involved in an organisation

Why is this study different? What benefit for Travellers?

Action research—local Travellers can do something to change the situation

Use existing research

Public Health nurse, home school liaison teacher/ local Traveller groups

Being involved in doing the research—training the driving force

Have a ?? in the research re language used

Traveller Support groups

In the community

Must use a qualitative research approach and spend time on it

Make more inclusive, involve all age groups

The interviewer must be chosen well, so they can follow on questions

Must consider which methodology to be used first

Qualitative or quantitative

? Focus Groups: informal then formal interviews

Q3: Methods to record info at present

Health board—local initiative CCAG

Age profile is being worked on

Accommodation profile—sites and families

Mobile Unit previously in operation but not currently in use

Most systems do not record

No real effective system of estimating Traveller population

County Council profile sites.

Local Traveller organisation

Public health nurses ✓

County Councils

GP's

Home school liaison

Community welfare services ✓ , not very accurate at present

Social work Information system (children at risk—cant identify Travellers)

Local priest

Not effective—absence of specific ethnic identifiers (PPSN)

Central data system

All meet up together and give information

Triangulation of data

Ethnic identifier on PPS cards. Is being done in UK.

? do new census v triangulation of information

PPS card could be the future for gaining information

No marker or any records to show if Traveller

Q4. Most accurate ways of collecting and collating births + deaths

DoHc working on ethnic identifier

Development at GR office will make tracking of population easier

Rotunda and Tallagh will pilot ethnic identifier. Ethnic ID question is being

develop by DOHC

Confidentiality: needs an ethnic identifier

Public Health Nurse---birth ✓

Priest's/undertaker's ✓ /community welfare worker (death benefit) ✓

GP's

Registration of deaths but not notified
Travellers will know of deaths of Travellers locally
Traveller Support groups

Q5: What resources do you need?

Money

We need to know what the expectations of health care providers are and then meet resources

Need to be conscious of how study would affect relationship on the ground

Not put any local groups or services under pressure or upset status quo.

Possible people (paid) come in and work with those already working on the ground

Needs assessment across the board.

Non-biased people e.g. people researched not already involved e.g. disability but it would cost.

Facilitation. Maybe need to talk to professional groups—key players in different disciplines

But we can't lead it up.

Time limitations

Training on data collection

Training to ensure consistency nation-wide

More IT equipment and training

Clerical assistance

Ethnic Identifier

The feedback session identified four priorities for the Joint Discussion Forum

- Barriers that prevent Travellers using mainstream services—within Traveller community themselves
- Health Care service providers :values, training, cultural issues, inter-sectoral
- Lack of records-identifiers
- How do differences within the Traveller community get included—listened too?

Joint Discussion Forum

This plenary session began by identifying four priorities from the earlier separate preparatory meetings. After facilitated discussion these were agreed and working groups formed to discuss.

Workshop 1. Process: Who and how? Barriers that prevent Travellers using mainstream services.

Why is this issue important?

Process---to be seen as democratic—inclusive

Determine how accurate, more ownership and participative

Structures set up for the study need to link with National Traveller health

Strategy. Visible outcomes

Must be sustainable and integrated with NTHS and existing structures and resources

Action research. Recent research included in the process with interim results and reviews at local and regional level, accessible to the local groups

Process be allowed to effect preset work—progress

Barriers: for Health Service Providers and for Travellers

How should it be dealt with in the study?

Interim reports available

Need for independent researchers

Others not totally involved—taken from their own work—but key participants

How—link is PHC projects that are training—collate information

PHC carry out local research and pass on

Travellers will talk to Travellers—but need training and support

Need for choice of researcher—resource implications

Peer action—research approach—similar to PHC

Barriers: identified by Travellers

Barriers at Health Service Providers and at travellers own level—

literacy etc

Segregated services e.g. Castle Street

Nationally

Interim reports available and reviewed

Research at national level

Census?

Review: policies and training for Health Service Providers re anti-racism training/attitudes. Institutional racism.

Workshop 2: Definition of Health

Is the definition broader than the health sector?

Is a definition Traveller specification?

1. Important to acknowledge the other issues that impact on Travellers health e.g. accommodation, education, discrimination

2. Charity—general perception health==hospital services

3. Different priorities in health

4. Holistic approach

5. Need to involve local authorities, education actively in the study

What should be included in the definition?

Accommodation (and environmental health), Judicial system, Traveller economy, health and safety, mental health, oppression. Education.

Men's health, emotional well being, empowerment for people to take responsibility for their own health. Evolution from Traveller culture and the impact on their health e.g. discrimination.

How should it be dealt with?

Locally:

Primary Health care groups, Travellers: Traveller men and women—different definitions. Language is very important. Visiting teachers, GP's, CWD's, Eho's, Local A+E Departments, PHN's. Primary Care managers
Needs a lot of preparatory work before involving these groups.
Professional Associations. Time constraints—complex
Use the existing structures of THU's—build and expand where needed
Discussion on broadening out to Indicators

Nationally

Involve DoHc/Environment/Justice/Education {visiting teachers}, professional Bodies, Councils, Unions
Existing structures

Workshop 3 Traveller Participation

Why is this issue important?

Without Traveller participation the survey won't be meaningful, informed or successful.

Needs to answer the questions:

1. Why this study—what's wrong with other studies?
2. Clarify what's in this study for me.

If these questions are addressed then Traveller participation will follow. If Travellers do not participate then the study won't work.

Need for this pre-preparation

- i) to be reflected throughout the study consultations.
- ii) to link local, regional, national

Study more than action research. Needs to bring about change to

- i) Traveller community
- ii) Majority community

How should it be dealt with

Locally:

Need to ensure everyone's voice is heard (young, old, women, men, rich, poor)

Variety of approaches used

Acknowledgement of literacy problems

Technology problems

Use local Traveller groups and Health professionals

Travellers talking to Travellers

Acknowledge range of people /amount of time involved

Traveller participation from start to finish:

Design questionnaire; do survey; analysis; make recommendations; findings.

Need to ensure study is accessible to Travellers at the end/checking out feedback

"Traveller proofing" the study

Engagement with Travellers and service providers trying to influence from outset

Workshop 4: Records and Identifiers

Comment: No member of Traveller community in this group, so no direct experience

Why is this issue important?

Dropout of children from school (secondary) gives rise to lack of access to health/dental services

Anecdotal information only and no “hard” information--to set targets, monitor and evaluate value/efficiency.

Data—not collected. Different categories

Need for standard record forms and co-ordination between groups

PPSNo. Has potential but need for confidentiality. An ethnic identifier could be included.

Notifications to Health Board—of births

Self-identifying principle-self-determined, informed choice. Self-identifier protocol required.

PHN receive information from birth notification. Ethical considerations in passing on information.

Incompatible systems in the Health Service Providers are not uncommon locally and perhaps nationally.

How should it be dealt with locally

Training is needed for Travellers and their organisations:

how to fill out records approp.

- involve health workers in that training
- use mobile clinic but realise there have been
- difficulties in accessing information
- PHN's

Potential to use and compare/contrast local information—carry out an audit.

Nationally

National Health Information Strategy e.g. compatible information system.

Consider inclusion of PPSNo and ethical concerns/ethical use of information and identifiers.

Check on records for duplication, human error.

Final plenary session from flip charts

Involvement of Travellers in interpretation of data

Communications strategy

- building links
- challenge to the study team
- consultation in locality

Women already trained in research techniques

Team—to reflect the community—women, men and young people

Influence of judicial system---drugs, depression,

Use of study feedback and local community OWNS the information

Input at beginning, middle, end

Definitions of health

The process of the study—training, resources, **confidentiality**, ✓

Traveller **participation** at all levels

▼
definition ▶ **decision-making**.

Methodology

---creative

---training

Participation Family
Traveller community
Health care Providers

Feedback Respect
“Immediate “response to question(naire)

How do Travellers keep control of information?

What is the benefit of participation?

Psychological aspect of well-being

Holistic view---“definition of health“

Emotional well-being

Include experience of marginalisation

Other Key messages

Awareness raising campaign to demonstrate benefits to the Traveller community in identifying and participating.

Creative in methodology

Qualitative survey of service providers

Process only starts when study finishes

JOINT DISCUSSION FORUM

The priority issues brought forward by the two preparatory meetings. Also, include the following, if not already addressed:

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?