

REPORT ON REGIONAL CONSULTATION

MID-WESTERN HEALTH BOARD

Thursday 04 September 09.30am ---2.30pm
Ardu Ryan House Hotel, Limerick

Key facilitators: Maire O'Haire and Claire O Reilly (Health Services National Partnership Forum)

Departmental representative: Brendan Ingoldsby
National Travellers Health Advisory Committee members: Brigid Quirke

Numbers attending: 50

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

1. Travellers/Traveller organisations preparatory meeting

After a brief explanation of the questions, the meeting broke into smaller breakout groups to discuss the questions (see Appendix 2)

The key points to arise during this meeting were:

- The need for ongoing consultation,
- A clear local information campaign to explain the study and its importance to Travellers is required
- Language used by researchers etc needs to be understood by Travellers and Traveller organisations
- Health service providers need to be aware of literacy issues
- The study is required to acknowledge accommodations types
- It should take into account the way that nomadism will affect the availability of Travellers to participate
- There is a need to ensure Traveller men engage with the study
- There is a clear desire that the study is undertaken in a partnership arrangement with the health service providers.
- The importance of trust between researchers / Travellers /health service providers for the success of the study.
- This group firmly believed that Travellers should be the people asking the questions
- The need for support for Travellers and their organisations
- A key concern is the amount of time and commitment required from Travellers and their organisations,
- Resources for this study should not be taken from what is already being funded.
- Threats to and difficulties with existing funding arrangements could impact negatively on the study.
- The study needs to be consistent across the island

- Importance to Travellers is required

When the breakout groups came back together the meeting identified three priority issues that they wanted to be discussed at the Joint Discussion Forum. These were:

1. At local level Travellers and the local Traveller community worker involvement needs to be supported
2. Trust: confidentiality and support needs to be a priority and they study needs to look at who best provides this
3. Information campaign aimed at Travellers and the involvement of state agencies, local authorities etc.

2. Health Service Providers preparatory meeting

After a brief explanation of the questions, the meeting broke into smaller breakout groups to discuss the questions. These were different from the ones posed to the Traveller/Traveller organisation meeting (see Appendix 2)

The key points to arise during this meeting were:

- Existing methods of collecting information on Traveller deaths/births were not reliable
- There was strong support for an ethnic identifier to be developed within the health service system. In addressing the issue of asking Travellers to identify ethnicity it was agreed that how the question is asked is crucial
- There is no one source of information and there are gaps in what is available.
- Data Protection issues were important in efforts to get national standardised and consistent information.

The meeting identified three priority issues that they wanted to be discussed at the Joint Discussion Forum. These were:

1. Traveller identification and Traveller involvement in this process: education
2. Raising awareness of Traveller culture and needs for health providers
3. Must be support and training for staff and Travellers to ensure that study is successful

3. Joint Discussion Forum

After lunch Travellers/Traveller organisation representatives and health service providers came together again for a Joint Discussion Forum, Spokespersons for the preparatory meetings summarised the discussion behind the priority issues that their meeting wanted to be discussed in the Joint Forum.

While the two preparatory meeting addressed different questions (see Appendix 2) and their discussions were complementary, there was substantial similarity in the points that came up during the two meeting. Both preparatory

meetings agreed that Travellers must be involved in the study at all levels, that the study should tap into all local sources of knowledge, and that resourcing for both Travellers/Traveller organisations and health service providers. There was a call for language that is easily understood by all.

The Forum then decided on the issues that were to be discussed. These were

1. Support for local Travellers and the Traveller community workers
2. The importance of trust and confidentiality.
3. An information campaign aimed at ensuring Travellers, state agencies, local authorities etc needs to be undertaken.
4. The need for education to ensure Traveller identification and Traveller involvement in that process
5. Raising awareness of Traveller culture and Traveller needs for health service providers
6. Support and training for staff and Travellers

The Forum then split into six small 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 then came back together and a spokesperson from each breakout group summarised their group's discussions. Further discussion involving all the attendees then occurred.

The main points that arose were:

1. The study must keep participants informed through its duration through a good communications strategy.
2. This strategy needs to positively promote the study in a variety of formats including posters, video materials, local media coverage including radio, intra-net, internet, website and mail shots.
3. It is impossible to overstate the issue of confidentiality and trust.
4. A local mapping exercise at the outset of the study would help to ensure it is as inclusive as possible.
5. While it essential that the study takes a holistic view of health it was needed, it also needed to examine specific health issues including disability, mental health, addiction, dental, domestic violence.
6. The importance of Traveller men participation was emphasised
7. Language must be "user friendly".
8. Commitment to implement the recommendations of the study and resources to do so should become national policy.
9. The study should help support agencies working in partnership.
10. Study data needed to be incorporated into IT systems so that it could be regularly updated and these systems should link with the National Health Information Strategy.
11. Cultural awareness as a two way process: the need for mutual respect between Travellers/Traveller organisations and Health Care Providers.

4. Outstanding issues to be clarified

A number of outstanding issues were identified during the consultation. These included:

1. Will there be a pilot study undertaken?
2. Who is co-ordinating the study?
3. How will it be managed?
4. Who should be the agencies in the local partnership?
5. Is the study going to be random sample or widespread?
6. What is to be done in those areas where there is no Traveller organisation or Primary Health Care programme working with Travellers?

NOTES FROM REGIONAL CONSULTATION MID WESTERN HEALTH BOARD REGION LIMERICK

Thursday 04 September 2003

Facilitators: Maire O Haire and Carol O' Reilly

Notes from Traveller organisation AM preparatory meeting
which was held in small workshop settings.

Question 1:What are the main factors that affect Traveller health?

- Consultation needs to be ongoing
- Support base from bottom up. Local—national
- Consistency—all way through
- Study needs to acknowledge accommodation types

Accommodation is a major factor e.g. R/side

Education Diet and health in general

Nomadism is a major factor especially in summer

- Consultation needs to be on the ground
- Schemes—support base—cut backs
- Trust—sensitive manner

Concern of Study: Time and commitment to be clarified

B) Access and barriers to Travellers participation in health services?

- Local area centre points ---phc etc
- Negative access==barrier
- Appointments etc
- Access needs to be available nationwide
- Medical card difficulties—needs to be nationwide

General point: Use of terminology
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Q.2 Traveller Participation and the Study

Trust at local level with whom they are very familiar with
IPH and local level groups including local community workers (database) who
have direct contact

Education—Local Supports

Suspensions of questionnaires etc and of Health Board

Designing what needs to be asked

Travellers should be the people asking questions

Getting men involved

Literacy issues

Health Service Providers==need to be aware of the literacy issues

Q 3. Resources and Support

Training	Specific in terms of survey Why in depth knowledge
Information	Local and National All Travellers needing to know its happening. Info drive info campaign
Time Constraints & Funding	Development work Schemes etc
Personnel	Good partnership including statutory agency involvement Researchers must do cultural awareness training Resources for this study should not impinge on what is there already

Three priority areas for feedback session

1. Local level Travellers and local Traveller community worker involvement needs to be supported.
2. Trust: confidentiality and support needs to be a priority and study needs to look at who best provides this.
3. Information campaign aimed at Travellers and involvement of State Agencies, local authorities etc

HEALTH SERVICE PROVIDERS PREPARATORY MEETING

Q1. Can public Health nurses identify Traveller births/deaths?

PHN's can do—process—workload heavy
Maternity Hospitals—process—resources are limited
More information needed than NAMES (ethnic identifier?)
Time Factor

Finance available? Possible!!
Depends on amount of info needed!!
Duration: One Year
How will identity be learned in maternity hospitals: Must ask
Are you a Traveller? This will be difficult.
Ethnic identifier being piloted in Tallagh: Results should be available in
Oct/Nov 03
PHN—all mothers are asked if they are Travellers: not 100% identification.
Issues from PHN's Travellers offended by questionnaire
Education needed re way questions are being asked

DEATHS—Sources: GP's
Hospitals
Registration

These are not reliable

Informal Ways

PHN's maybe

Support groups---not widespread

Designated PHNs for Traveller health now in place in MWHB

Some areas nomadic

Q2 Are existing Counts accurate?

2002 Census underestimate

Information from PHN's

GAPS!!!

Local Authority Social Worker—but only if the Traveller needs accommodation

Visiting teacher

County Development Boards

Collating the above

No one person has info

Barriers to agencies releasing information

Data Protection Issues

Travellers who are housed need to be included

Count methodology needs to be consistent nationally

Use existing data versus new count from scratch

Travellers must be involved in process

Data has to identify settled Travellers and Transient Travellers

Is the count one point in time or throughout the year of the study?

Is study going to be random or widespread?

Not known currently.

Question 3 Local sources

PHNs, Maternity hospitals, Local Authorities, Schools , Travellers , Refuges

(Women and children) , GP's, Accident and Emergency, Mental Health

, Disabilities , 'Care group structures', Welfare staff, all community

Quantitative and Qualitative

Question 4: How to measure perceived health and health related behaviours?

Large usage of refuges

Same measure as any other study

Gathering information==needs to be standardised nationally

Stand alone research in various areas

Three priority areas for feedback:

1. Traveller identification and Traveller involvement in same: Education
2. Raising awareness of Traveller culture and needs for health providers

3. Must be support and training for staff and Travellers to ensure that study is successful:

Resourced

Methodology must be consistent with other studies for comparison etc

Other issues arising from health service providers

Funding/commitment

Methodology re child ages for study examinations

Study must be sufficiently Qualitative and not be too focused on Quantitative data

Child health system in mid-Western health board could yield valuable data

Link between poverty in the Traveller community and health status

AFTERNOON BREAK OUT SESSIONS EACH DEALING WITH A SINGLE TOPIC

Workshop 1: Q How can we mainstream the outcome of the study?

Limitations/barriers

Opportunities

Difficult to discuss mainstreaming when we don't know the outcome.

What do we mean by mainstreaming?

Inform people of the results-especially participants

Information campaign soon after the study.

How results can be used

Is there any point to the study if the issue of accommodation is not addressed?

If Travellers don't feel their issues are addressed they may not want to co-operate with the study.

Mainstreaming should be built into the communication strategy around the study.

Relevance of study—if people don't feel it is relevant to them then not willing to take part.

Resources to implement the recommendations

Barriers to accommodation locally

Support workers with Travellers to keep info updated

Bringing the information back through local groups, linking in with Traveller workers locally.

Partnership between health service providers and other agencies e.g. Dept. of Education, County Council etc.

Study should support the agency partnership

Study outcome has to become national policy

Issues that are delayed needlessly need to be addressed nationally.

National Policy recommendations need to come from the study

Accommodation history has to be part of the study

Difficulty of following up when Travellers are not identified

Workshop 2 Q: Identification Process for the study

Who: Travellers be actively involved. Study should be of all areas and all Travellers i.e. settled or those who return (Rathkeal)

How:

1. Clear explanation in "user friendly" language

2. Explained at the start of the process and the reasons as to why it is necessary

3. Traveller representatives to work with e.g. health board staff/PHNs

4. To do this Health board training would be needed---communication/people skills

5. Local knowledge to identify people

6. See above (who)

7. Common approach for all Travellers

8. Trust very important in order for Travellers to provide information

9. Need to positively promote the study---what does it mean? The benefits.

- 10. Need a mix of approaches to research e.g. interviews, focus groups
- 11. Identifying 'contact points' with services that Travellers have and then promoting the study through these 'points'

Why:

- 1. To identify Traveller Health Needs
- 2. To know what services are required, how much is needed.
- 3. What is needed in the future
- 4. How services should be delivered
- 5. To improve Traveller health

Workshop 3: Pat Carroll Cultural awareness and training for the study

Why

- 1. Training and Education is important so that there would be openness and effectiveness of the study
- 2. Travellers to know how the study can be of help to them e.g. help Travellers avail of Health Services.

Who

- 1. Training for Travellers of Health Services
- 2. Training for Service Providers of Traveller issues/culture
- 3. Training for Data collectors of both

How:

- 1. Cultural awareness is long-term and on-going process
- 2. Must be a two-way process
- 3. Through Traveller Support Groups e.g. PHC programme and Traveller Support Groups
- 4. Local information (not regional)

Problems:

How can isolated Travellers be engaged with process around "training"?

Defining culture

Examples of what aware of

Literacy levels, not all Travellers involved.

Motivation of Travellers of benefit of the study

Sub-cultures e.g. some see education important, others not.

Rathkeale

Workshop 4: Confidentiality and Trust

What do we mean? How should it be managed?

Define confidentiality

Information---com. Agreement

Will people be asked to give names –identify?

No means of identification

Not comfortable

Wanted to learn more

There could be difficulties

Trust---TRAINING

Health Providers

How should it be managed?

Local knowledge very important—can't generalise

Training

Younger and older Travellers

Information

Forms should use simple language

Skill up a few men to do the men

Give men the opportunity

Creative ways---views of young Travellers, men's issues.

Don't make assumptions

Importance of pilot programme in identifying

Confidentiality should be made clear to all player

Confidentially guidelines should

Mapping exercise to ensure it is as inclusive as possible.

Workshop 5: Information:

Types of information, awareness of study: Local, National:

How to get info out there?

Take account accommodation—roadside, sites, standard housing, private dwellings

Basic—there is a study going on: what is in the study.

Local Strategy:

1.Travellers/ Traveller Groups

Simple explanations where and how

Travellers and HCP—creates transparency

Posters etc—public

Video materials

Local media coverage

Radio

Local info on starting and dates where

2.Health Care Providers

Sessions and Forums on THS

Who gives this to HCP—both Travellers and HCP to do (like C.AT)?

Intra-net//Internet//Website

Mail shot

Specific new PHNs

Local HB innovative programmes

Info needed to be available for study

Breakdown available for local area

Confidentiality policy

Specific health issues: The gaps

Disability issues: Mental Health: Addiction: Dental: Violence against women

Determinants of health: social/cultural/economic

Comments and open ended questions

Info so wheel isn't reinvented

Outside agencies:

VEC, Council, FAS programmes, Schools, buying in

Community groups—A.D.M.; C.D.P.

Who- In partnership?

Need background of info

Cultural awareness

Workshop 6: Resources and Support and Training

Travellers and Health Providers

Identifying what's needed

What's there already—local and National

How should these be managed?

Study Group: What already in existence

Travellers/Traveller Groups/Health Service Providers

Recognition of

Groups at different stages of development

Additional piece of work, in addition to existing workload

Identify good practice, locally, regionally, and nationally

Profiling of Travellers

Working with Travellers

Other agencies stat/vol to 'buy into' study

Resourced at outset

Timeframe—secondment of personnel

IT systems—for this study

---for future information gathering

Supports---Groups not willing to be identified as Travellers

Support, benefits

Not an issue in other areas—proud of culture

Acknowledge diversity of areas/region.

Informal setting v training

Locally: resources/training/supports required

Co-ordinators /trainers

Small geographically areas differ == resources

Not one specific methodology

Gender issues----Involvement of men

How to buy in—creative

Youth

Disability

Additional resources/personnel

IT systems—link with Information strategy

Training—Training for Trainers—data collection

Identified persons/credible persons

Back on stnesm

Facilitation skills

Who is co-ordinating the study?

Regional rep on Health status sub-committee

Sub-committee locally/project manager

Locally through Traveller Health units

Resource dependant.

Concerns/Fears

*Cultural awareness—two-way

All respect one another (Traveller and Health Care Provider)

*Accommodation needs to be included

*Other determinants need to be included as well

*Legitimising the data collector whether they are Health pro or Travellers or both

*Not everywhere has an active Traveller organisation/PHC programme so what do we do?

Appendix 2: Key themes for the Regional Consultation

The following are summaries of the more specific questions that are included in the discussion paper. They will provide some structure to the preparatory meetings and the discussion forum.

TRAVELLERS/TRAVELLER ORGANISATIONS PREPARATORY MEETING

1. How do we ensure that the study properly reflects
 - a. The main factors that affect the health status of Travellers in your local area?
 - b. Access of Travellers to health services and barriers to this?
2. What form should Traveller participation in the study take?
3. What resources, training and support does your organisation require to effectively participate in the study?
4. Identify three priority issues to bring to the Joint Discussion Forum.

HEALTH SERVICES PREPARATORY MEETING

1. Could public health nurses successfully identify all Traveller births and deaths in your local area? If not, what would be the best way of doing this?
2. Are existing counts of the number of Travellers in the health board accurate? If not, what would be the best way to get accurate counts?
3. What local information sources could contribute to the aims of this study? Which health service providers in the local area could provide qualitative/quantitative information that is relevant to this study?
4. Should measures of perceived health and health-related behaviours be a key element of this study? If so, what would be the best way of gathering this information in your local area?
4. Identify three priority issues to bring to the Joint Discussion Forum.

JOINT DISCUSSION FORUM

1. The six priority issues brought by the two preparatory meetings
2. If not already included, the following:
 - 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 managed at the local/regional level, and how should local/regional input into the national study be organised?
- What particular outputs from this study would be most useful at the local/regional level?
- How do we ensure that up-to-date information about the health needs and health status of Travellers becomes part of the mainstream health and health services information?
- How do we promote a broader appreciation of the complementary roles that qualitative and quantitative research methodologies play in the different aspects of the study?