

REPORT ON REGIONAL CONSULTATION

NORTH WESTERN HEALTH BOARD

Wednesday 10th September 2003 10.00am—3.00pm

Venue: Allingham Hotel, Bundoran

Key Facilitators: Carol O Reilly and Seosamh O Maolalai (Health Services National Partnership Forum)

Departmental representative: Mary O'Reilly

National Travellers Health Advisory Committee: Brigid Quirke and Missie Collins

Numbers attending: The meeting was attended by 17 North Western Health Board service provider representatives and 13 Travellers/Traveller Organisation representatives. Please see appendix 3 for full list of attendees.

Note: There were no Travellers present from the Sligo area due to a recent bereavement.

The preparatory meetings in this consultation were held sequentially. There were opening comments by Mr Tom Kelly, Assistant Chief Executive Officer, NWHB during which reference was made to the completed questionnaire on the Traveller All-Ireland Health Study which was being submitted to the Institute of Public Health on the day. A copy of a paper by Felim O'Rourke, "Government Policy on the Travelling Community: An examination of Irish Government Policy on the Travelling Community", along with the Board's response to same was also given to the Institute.

Dr Kevin Balanda, Institute of Public Health, provided an introduction to the study to all those present at the start of the meeting. The first preparatory meeting (Health Service Providers) was held in plenary session and considered the questions, which had previously been circulated.

(See Appendix 2)

1. Health Service Providers preparatory meeting

The key points to arise during this meeting were:

- Local variation was identified as a key factor to be reconciled with the need for national monitoring requirements
- There was a strongly expressed view that the study should take a population health approach and not a health service administrative approach. Some believed that existing administrative structures and parameters are part of the problem.
- Problems with the reliability of existing data were identified as:
 - (i) Nomadic population,
 - (ii) The lack of an ethnic identifier and
 - (iii) Fear of self-ascription.
- The group believed that the study should use existing data rather than use study funding for a separate count.
- Concern was expressed about health related behaviours questions being taken out of context, particularly if asked of health service providers. It was agreed that

such issues should be included in the study but great care needed to be taken of the context in which this information was used and interpretation of data must not be quoted out of context.

- Health service areas to be involved in the study were identified as:
 - (i) Primary Care Services e.g. Public Health nurses, GP's, Dentistry, GP Practice Nurses and Voluntary organisations.
 - (ii) General Hospital departments including Social Work
- Key factors influencing health were identified as:
 - (i) Accommodation (and the need to include local accommodation factors);
 - (ii) Discrimination and Racism;
 - (iii) Traveller involvement in the design and delivery of the study;
 - (iv) Culturally appropriate services

The three priority areas identified by this group for discussion at the Joint Forum were

- 1.Primary Care Services
- 2.Womens Health
- 3.General hospital Services

2. Traveller/Traveller organisation preparatory meeting

This meeting had a very brief introduction to the study and then split into four smaller working groups. The key issues raised in these groups were:

- The study must examine the relationship between accommodation and health and racism and health.
- Education and poverty are external factors, which should also be considered.
- Stress and mental health issues including depression and low self-esteem were identified as important health issues
- The manner in which health professionals treat Travellers can cause difficulties with accessing services and a lack of trust between Travellers and professionals.
- The quality of services, including refusal of services (GP, hospital and care) is an issue. Traveller men feel alienated from the system.
- It was believed that Travellers themselves should carry out the study: they will get honest answers and some have experience and knowledge of both research and health issues.
- Training is the key resource needed to enable this to happen.
- Rural isolation and transport is a specific local consideration in this region
- Quality of service and care
- Confidentiality, Trust and ethical methods must be adhered too.

The three priority areas agreed for discussion at the Joint Forum, were:

- 1.Resources and Training
- 2.Targeting people
- 3.Confidentiality and Trust

3. Joint Discussion Forum

After lunch Traveller/Traveller organisation representatives (some of the Traveller representatives had to leave early due to child care arrangements) and health service providers came together for a Joint Discussion Forum. Spokespersons for the preparatory meetings summarised the discussions behind the priority issues that their meeting wanted to be discussed in the Joint Forum.

While the two preparatory meetings addressed slightly different questions (see Appendix 2) and their discussions were complementary there was substantial similarity in the points that came up during the two meetings. There was agreement on the need for Traveller involvement at all levels in the study that rural isolation is a specific factor in this region that cross-border issues need to be considered in the study.

The Forum discussed the priority issues, which had been brought back for consideration and then decided to proceed with four workshops considering the following three themes:

How will the study be conducted and managed in the area? (2 workshops)

How do we count the Traveller population?

Culturally appropriate services—communication and cultural competence

The forum then split into four smaller break out groups each including some Traveller/Traveller organisation representatives and some Health Service Providers. Each group was allocated one of the issues for consideration. The breakout groups then came back together and a spokesperson from each group summarised their group's discussion. Further discussion involving all attendees then occurred.

The main points that arose were:

1. There is a need for a partnership arrangement between Travellers/Traveller projects and Primary Health Care at local level to assist conduct and manage the study.
2. It was strongly felt that neither the Traveller Health Unit or Health Board should have responsibility for management of the study at local level but they need to be kept informed.
3. A Regional Co-ordinator is probably needed for the study in this locality
4. An independent Traveller research would be a valuable link within the region and also assist the motivation of all participants
5. It was considered a matter of ethics that Travellers are involved as researchers
6. The cross border factor is a particular issue in this area and this matter should be considered along with any discussion of the same at the North-Eastern Board Consultation day as well.
7. The all-Ireland dimension to the study makes the count particularly important. It is best to utilise existing, often inadequate and biased data collection methods rather than do a separate count.
8. Language is a problem but the study has to ensure both scientific validity and community participation.

9. Communication is a two-way system and needs time to develop.

10. The study needs a national monitoring group representative of all sectors and Travellers.

11. Questions have to reflect the diversity of the community and the study questionnaires should be culturally proofed and encourage participative and creative methods.

4. Outstanding Issues to be clarified

- Health professionals preferred the use of independent researchers to enable professionals speak openly about their services.
- A suggestion was made for a glossary of terms covering both Traveller language and professional forms.
- Is it a whole population study or a sample, which includes gender, disability and mental health?
- If the study is being done by sample, the sample size should be as big a possible.

APPENDIX 1

NOTES FROM REGIONAL CONSULTATION NORTH WESTERN HEALTH BOARD AREA Bundoran

Wednesday 10th September 2003.

Facilitators: Carol O'Reilly and Seosamh O Maolalai

There were no Travellers present from the Sligo area due a recent bereavement.

Health Service Providers Preparatory meeting was held in plenary session with comments been fed directly onto the flip chart.

Q1. What are the key priority health status and health related areas you feel must be included in this study?

At the outset a question was asked about including other impacts on health such as accommodation. The facilitator reminded those present of the need to prioritise. Local variation was identified as a key factor to be reconciled with the need for national monitoring requirements.

As the discussion moved on the following Health Areas were identified:

❖ Primary Care Services including

- Public Health Nurses
- GP's
- Dental
- GP Practice Nurses
- Voluntary organisation

Children's Health

❖ Women's Health with information available from

- Designated Public health nurses, GP's, Traveller Organisations and Maternity units

Men's Health

Disability Service

❖ General Hospital: all departments including social work

Health promotion

Mental Health and

Health Information: this discussion raised the importance of the ethnic identifier

❖ These three were identified as the priority areas

Key Influencing Factors:

Accommodation—will the study involve local accommodation factors?

Discrimination and Racism

Traveller Involvement in the design and delivery of the study

Culturally appropriate services—communication and cultural competence. There was a discussion about the need to have a population health approach to the study and not a health service administrative approach. The existing administrative structure and parameters are part of the problem.

The Study Group was invited to read the Northwest Health Board's response to the written consultation to ensure we had the full picture.

A question was asked of the DoHC representative about funding for the study. The respondent indicated that the funding for the study will be sought as a separate and additional funding bid; that the difficulty will be with the Department of finance but that the study is an identified Department of Health priority.

A question was posed about Travellers with a disability: As the numbers of Travellers presenting with disability are small are existing services accessible to them? It was decided this was not a priority area.

Q2+3 Population data collection.

It was agreed that there are discrepancies between Traveller Support group figures and Local authority counts and some of the problems in getting an accurate count were identified: Nomadic population, no ethnic identifier, and fear of self-ascription.

Kevin Balanda asked "Are existing sources fairly reliable or are they so disparate that we need a new study count?"

It was unanimously agreed that the study should use existing data rather than use of any of the study funding for a separate count. Existing data should be identified and collated for the study.

On the question of identifying births and deaths during the study period the following sources were identified:

Public health nurses, hospitals and Traveller Support Organisations.

Q4: Priorities from Q1 and perceived health related behaviours

Priorities have been identified in the notes at Q 1(Primary Care, Women's Health and Hospital Services)

Health related behaviours

This discussion was initially very technical re anthropological and ethnographic research methods being used within "systems" as well as with people.

Concern was expressed about health related behaviours questions being taken out of context, particularly if asked of service providers.

It was agreed that interviews with a sample of providers would yield some information.

It was further agreed that issues such as smoking, alcohol, diet etc should be included in the study but great care needed to be taken of the context in which this information was used and interpretation of the data must not be quoted out of place.

Travellers/Traveller organisation preparatory meeting

As we were running behind time Kevin gave a very brief introduction before the preparatory meeting broke up into four small work groups. This represents the collation of all the four group notes.

Accommodation and link to health ✓ ✓ ✓ ✓

-----colds, flu's, bronchitis

sites in rural areas: Finner, Manorhamilton (Leitrim), Lisfarron along the main road—risk of accidents ✓ ✓

No fire precautions

Basic needs: water, toilets

Rural isolation—particularly in Leitrim, access to services by distance

Services and facilities—environmental health factors e.g. rats

Moving on—difficulties—physical attacks (racially motivated)

Living conditions

Racism and Health ✓ ✓ ✓ ✓ ✓ ✓

Stress caused by discrimination, especially among women ✓

Mental Health ✓ ✓

Depression /Low self-esteem

Bullying in schools

Exclusion from bars--- embarrassing

Discrimination (social isolation, racism)

Lack of recognition of culture and way of life

Values and Beliefs

Language

Lack of facilities

Education ✓ ✓

Poverty ✓

Link to women's health

Unemployment

Stress is linked to all the above, too much pressure especially along road

Nomadism in itself, appointments: the way the country is organised by government.

Social Services

No sites.

Relationship between Traveller and social worker

How professionals treat Travellers

Primary Health Care

Asthma, Respiratory disease, vomiting, diahorrea,

Lack of information

More understanding

Literacy

Posters designed by Travellers simply

What are the issues?

1. GP's: Killybegs, Ballyshannon: refusal of service ✓
 - Quality of service
 - Access to doctor
 - Doctors won't come out
2. Hospitals: ✓
 - Letterkenny: maternity services and treatment of women within service
 - Metabolic screening
 - Level of stress
3. Quality of Care
 - Treatment within the system
4. Transport and Rural ✓
 - There is a trust issue with the professionals. ✓
 - There is a lack of understanding of the system
 - Traveller men feeling alienated
 - Hand held records
 - Racism and discrimination
 - Transport
 - Getting GP's out: following up in cases: check up in schools if moved on
 - Some GP's won't take Travellers on
 - PHN should call to all Travellers
 - Literacy
 - Families moving into area
 - Hospital—metabolic disorders: how you are treated
 - No real links between health board and council
 - Health promotion: no inclusion of Travellers and no adaptation of materials
 - Casualty—overused by Travellers because no doctor, then get bullied in/at hospital; leaving before treatment is finished.
 - Health services not suitable
 - Medical Cards need to be made more mobile to Travellers.
 - Doctors and nurses using big words explaining about their medicine

Q2. What form should Traveller participation take?

- Involvement of Travellers from the start is very important
- Primary health Care workers know families well and have built up trust.
- Training and Resourcing of Traveller groups to take part is critical
- Expertise of Traveller organisations should be utilised.
- Use the Primary health Care Programme in Donegal.
- Confidentiality and trust is primary
- Primary Health Care—Local Traveller groups
- Travellers will get honest answers: trust ✓
- Research experience
- Experience of and knowledge about health
- Travellers need some training to deliver.
- If no primary health care project in an area the nearest one should be used as they have the training—family links.
- Resources for training
- Resources for doing research

Children (childcare allowances)
Model like Education Research in Donegal and support
Focus Groups
Travellers going out working with Travellers doing a survey
Travellers would know Travellers in their own area and feel comfortable with them
Confidentiality
Trust
Primary health doing surveys

Q3. What resources training, support do you need to take part?

Transport and childcare ✓
Audit of expertise within different projects
Training: different across the area within NorthWest
Link with PHN's around some of this
Sensitive issues e.g. bereavement; this is especially so for some families.
Training to do research.
Resources needed: childcare, transport, and financial allowance
Training on research needs a co-ordinator at local level
Funding
Training—confidentiality
Transport in rural areas
Professional Guidance
Backing of local Traveller Support Groups
Information to distribute before research
Simple information—we need to all learn that in Primary Health Care—plain English.
Central point in the county—office and computer(s) dedicated to it
Consistency regionally, regional co-ordinator: a person who has worked with families before
Good planning time allocated to it
Priorities:
Resources and Training
Targeting people
Confidentiality and Trust

AFTERNOON SESSION; JOINT DISCUSSION FORUM

Although some of the participants had had to leave at 1.00pm the plenary after lunch broke into four work groups to consider three topics arising from the feedback from the morning sessions.

Two groups considered:

How will the study be conducted and managed in this area?

This study was considered important because it was in the health strategy.
There should be a strong local input preferably through Primary health Care partnership of Travellers and others and/or Traveller project if it exists.
Experience combined with Travellers to build up local capacity
Other Traveller organisations where they exist
Ethical issues—sensitive areas e.g. need for counselling. ✓ Back up services need to be available ✓ .

Local knowledge is important. Medical problems.
Expectation—at individual and general level
Proofing—use of language
Who should ask the questions?
Independent researcher preferred by professionals. Query about the involvement of visiting teachers. Social workers involved in the count. Travellers should be included in the Traveller research. Management is important.
Traveller Health unit involvement—need to keep informed but no active management role.
Community Care structures—need to respect regional structures
Work at Care group structure ✓
Transient families—coming back and forth—cross-border and elsewhere
CAWT—take a role (North-South Health Boards) ✓
Issues of families with members both sides of the border
Liaison with Dental and PHN's
Some issues are only applicable in Northwest and perhaps specific questions need to be added.
Responsibility (for management) lies outside the Board. The Health Board would liaise and co-operate. Independence of the researcher is vital.
Source necessary data etc. from Public Health
Access to data is through HpH, PHN,
Designated PHN holds the register of Births and deaths
Cross-border (?) and how to address
Primary health care projects are key local links
Partnership with the Health Board
Traveller organisations
Regional Co-ordinator/??
Preparation/ Traveller awareness
Simple language
Independent Researcher (Traveller) to link within region and link to motivation
Collect data of Public Health
PHN== Push for a better system
At a National level it was suggested the involvement of visiting teachers and local authority social workers would help in the census (population count) collection.
Resources— Travel, Childcare
Upskilling and Training is important. ✓

How do we count the Traveller population?

Why important:

No counting, no inclusion

Gaps—miss out on families

Nomadism—miss out of families

Facilitate service planning

Data is incomplete to date

Powerful reason for doing it on an all-Ireland basis

Practical question—births and deaths

Planning from the settled perspective—first basis

November census

How should it be dealt with?

At local level County council, CWO's, Traveller organisations, Dept, of Education—
Traveller liaison—National Census—PHN's.

Traveller involvement essential: will give higher accuracy

Identification of Travellers is a difficult issue: some will not identify to services (such
as Dept. of Educ. County council, teachers etc)

Those who do not want to identify to services but will take part in research—is there
a possible role for PHN's: link in with travellers

Schools over count Travellers because of resources

Counting trailers as families

Naming of BIAS within different data collecting systems

Identifying the population:

Death register

PHN's

Skewing results e.g. in relation to those not registered as Travellers at death

Suggestion of blame/responsibility re certain sensitive issues

Ethical considerations---essential that Travellers are involved as researchers

Nationally

Consistency of approach—bought into by all agencies

Across the regions

Need to match the 'top' and 'bottom'

Any other key messages:

Travellers must be involved

Partnership with the other agencies collecting data

Resources of Traveller organisations

Culturally appropriate communication and services

Why this issue is important: How to get the best out of the study.

Language used is a problem even at the consultation process. Communication is a
two-way system

Time to let communication develop

Acknowledge expertise of both sides/groups

Research carried out by Travellers—participation

Planning

Training

Resources

Also mindful that some areas don't have a local group

Scientific validity and community participation

Glossary of terms to explain for everybody: Traveller language and professional
forms

How should it be dealt with?

Locally: Local groups have funding to carry out. Work hand in hand with the
scientific/empirical

What areas need to be researched—service providers

Traveller community

Local working groups, regional structure (management) with agencies {could be sub
group of THU}, national management group—negotiated regionally who, properly
resourced, questionnaires etc: would decide on this.

How to communicate the design of the study: Is it a whole population or sample (gender, disability, and mental health)

Local agencies need to be involved and are critical and nationally.

Build on contacts already created

Literacy issues and full participation

Nationally: national group (monitoring) representative of all sectors and Travellers.

Agencies involved at national level. Recommendations that are fed back need to be implemented. Does the National Traveller health Strategy need to be reviewed?

What is the purpose of the study and will it have benefits? ACTION!!!

Any other key messages:

Representative of population

Large sample as possible

Questions have to reflect the diversity of the community

Questionnaire culturally proofed and participative, creative methods

Confidentiality and Trust and ethical methods

APPENDIX 2

Questions for the Discussion

The following questions will provide some structure to the preparatory meetings and the Joint Discussion Forum.

TRAVELLER /TRAVELLER ORGANISATIONS PREPARATORY MEETING

1. What are the key priority health status and health related areas in this region you feel must be included in this study?
2. What form should Traveller participation in the study take locally?
3. What resources, training and support does your organisation need to effectively participate in this study?
4. What are the three priority areas to bring to the Joint Discussion Forum?

HEALTH SERVICES PREPARATORY MEETING

1. What are the key priority health status and health related area you feel must be included in this study?
2. Are the methods of population data already used credible enough if properly collated? If not, how can we address this?
3. What are the most accurate ways of collating information on Traveller births and deaths?
4. a) Given the key priority health status and health related areas you have discussed above which health service provider in the local area could provide the information relevant to these areas?
b) What would be the best way of gathering the perceived health and health-related behaviours in your local area?
5. What are the three priority areas to bring to the Joint Discussion Forum?

JOINT DISCUSSION FORUM

1. The six priority issues brought forward by the two preparatory meetings. Also, if not already covered,
2. How do we ensure that Travellers, Traveller organisations, health service providers and others in your local area are fully engaged with the study?

3. How should this study be managed at the local/regional level and how should local/regional input into the national study be organised?
4. What particular outputs from this study would be most useful at the local/regional level?
5. How do we ensure that up-to-date information about the health needs and health status of Travellers becomes part of mainstream health and health services information?
6. How do we promote a broader appreciation of the complementary roles that different research methodologies play in the different aspects of the study?

APPENDIX 3

ATTENDANCE RECORD FOR THE CONSULTATION SEMINAR FOR THE NORTH WESTERN HEALTH BOARD ON WEDNESDAY 10TH SEPTEMBER 2003

Tom Kelly, Assistant Chief Executive Officer, NWHB (Chair of Traveller Health Unit)

Dr Kevin Balanda, Institute of Public Health

Mary McMahon, ?Institute of Public Health

Kieran Doherty, General Manager Community Services, NWHB, Donegal

Maire O'Leary, Health and Social Policy Officer, Community Services, NWHB, Donegal

Dr Sheelagh Prosser, Primary Care Research Officer, Public Health Dept., NWHB

Tom Quinn for John Meehan, Director of Nursing, Mental Health Services, NWHB

Mary Heery, Project Officer, National Environmental Health Action Plan NWHB

Caoimhe Gleeson, Equality Officer, NWHB

Des Keaney, Community Worker, Community Services, Sligo/Leitrim NWHB

Liam Breen, Superintendent Community Welfare Officer, Donegal NWHB

Catherine Devaney, Section Officer, Community Services NWHB

Dr Mary Manandhar, Public Health Department, NWHB

Flora Dunne, Designated Public Health Nurse for Traveller Health, Sligo/Leitrim NWHB

Bernadette Reid, Designated Public Health Nurse for Traveller Health, Donegal NWHB

Bernadette Allen, Student Nurse (NWHB)

Kate Meehan for Denise Curran, Physical and Sensory Disability Service Donegal NWHB

Aileen Henry, Public Health Nurse, Donegal Community Services NWHB

Ann Marie Crosse, Asst. Health Promotion Officer, NWHB

Aggie Boyle, Donegal Traveller Project

Mary Quill, Donegal Traveller Project

Mary McGinley, Donegal Traveller Project

Nellie McDermott, Donegal Traveller Project

Annie McGrory, Donegal Traveller Project

Mary Cunningham, Traveller Movement (Northern Ireland)

Maureen Mongan, Primary Health Care Project for Travellers

Denise Delaney, Primary Health Care Project for Travellers

Brid Boland, Sligo Leader Partnership Company

Pat Fitzpatrick, Leitrim Partnership Company

Siobhain McLaughlin, Donegal Traveller Project

Paula Leonard, Primary Health Care Project Co-ordinator

Geraldine McLaughlin, Donegal Traveller Project