

REPORT ON REGIONAL CONSULTATION

NORTH EASTERN HEALTH BOARD

Tuesday 23RD September 2003 10.00am—14.30
Nuremore Hotel, Carrickmacross

Key Facilitator: Mai Kearns O Reilly (Health Services National Partnership Forum)

Departmental representative: Hugh Magee

National Traveller Health Advisory Committee members: Ronnie Fay

Numbers attending: 35

After opening comments and an introduction to the study the meeting split into two preparatory meetings to discuss the questions that were circulated earlier. (See Appendix 2). These meetings were held concurrently.

1. Traveller/Traveller Organisation Preparatory Meeting

After a brief explanation of the questions the meeting split into two groups to consider the questions. The key issues arising from these discussions were:

- Use language we can understand
- Information about the study should become a local discussion via radio, TV and local papers
- Need to get the study known in training centres and beyond
- A holistic view of health is required
- Accommodation (lack of and state of existing) is crucial
- Need to accept that problems do exist in areas of disabilities, mental health, behavioural disorders and speech/vision
- Attitudes of health service providers including GP's, hospitals, nurses, health boards
- Racism
- Cultural cost of Travellers not seeking to use services
- Services "going overboard"---disempowering families instead of supporting them.
- Sterilisation offered to young Traveller women much earlier than offered to settled women.
- Partnership approach should have Travellers playing a large role and settled people a smaller role
- Traveller participants should have a choice in how information is obtained.
- Concerns about the reasons for information being sought reinforce the need for confidentiality and trust
- Travellers should train researchers in Traveller issues and anti-racism.

- Travellers involved as researchers including designing questions and carrying out the study.
- Traveller identity: self-identification and denying identity
- Local population counts are not accurate

The priority areas identified for feedback and further discussion at the Joint Discussion Forum were:

1. The study needs to be implemented and followed through, unlike Task Force report.
2. The identity issue needs to be looked at carefully including the fact that being a Traveller is Who You Are, not where you live.
3. Travellers have to be involved in all parts of this study from the start and at all levels, properly supported, not tokenism.
4. There should be positive outcomes for Travellers. Major inequalities between Travellers and settled people should be tackled and quality of health service for Travellers should be as good as that for settled people.
5. Study results should be compared to those of other minority ethnic groups who face the same inequalities as Travellers.

2. Health Services Providers Preparatory Meeting

This meeting broke into two smaller groups to discuss the questions. The key points to arise from these meetings were:

- A qualitative needs assessment at local level, informed by local knowledge is needed.
- Inclusive approach must extend to agencies beyond the health services.
- There must be good listening so that information provided is not misinterpreted.
- Simple language, good clear communication throughout.
- 2006 Census should have an ethnic identifier question
- Staff will be required to be released from existing work load to participate in study.
- Avoid duplication and ensure co-ordination
- Information Communication Technology (ICT) support and prioritising ICT within the health system is needed

The priority areas identified to be brought back to the plenary sessions for consideration in the Joint Discussion Forum were:

- Equal partnership—how is it going to be done?
- Capacity building for Travellers and health Service Providers
- Involvement of statutory agencies—having an integrated approach
- Communications and Education to build trust and promote awareness
- A guarantee that the study will have positive outcomes for Travellers and that end results are financially resourced
- Data issues

After discussion in full plenary sessions the following four topics were agreed for the Joint Discussion Forum

- 1.Implementation of the findings
- 2.Equality of Partnership
- 3.Training and Information Issues
- 4.Traveller Identity

3. Joint Discussion Forum

The following points were identified during these four workshops as key issues for the study.

- 1.The study has the potential to be long term cost effective and benefit both Travellers Health and help Health Boards fulfil their role.
- 2.An action plan to implement the findings should be developed on an all Ireland basis with specific performance indicators
- 3.Recommendations need to be implemented locally in a partnership arrangement between Health Boards and Traveller Support groups.
- 4.A partnership approach is required at all stages and within that partnership there needs to be continuity and commitment.
- 5.Guarantees of confidentiality need to be given and data provided needs to be treated with sensitivity.
- 6.A training and information programme needs to be set up and properly resourced, managed by a working group with representatives from both voluntary and statutory sector.
- 7.The whole issue of ethnic identity needs to be addressed including the fact of internalised oppression, inferiority complex and denying/disguising identity.
8. Institutional racism needs to be addressed
- 9.There are specific cross-border issues in this region including Nomadism, hand held records/transfer of information and bureaucracy.

4. Outstanding Issues to be clarified

Are there legal problems around collation of existing data collection systems?
There should be a standard or Code of Practice for collecting information.

APPENDIX 1: NOTES FROM NORTHEASTERN REGIONAL CONSULTATION.

NUREMORE HOTEL, CARRICKMACROSS

23RD September 2003

Facilitator: Mai Kearns O Reilly, DoHc rep: Hugh Magee,
IPH rep: Jorun Rugkasa

Morning Session: Traveller/Traveller organisations: Two Groups

General point raised in both workshops:

Basic use of language---language used is not understandable and makes the process impossible---use language we can understand

Q1. How do we make sure we get the right picture with this study?

How information is presented

Trust needs to be developed

Traveller involvement right from the start

Travellers know Travellers

Terminology

Culture

Sensitivity

Health needs to be broken down into all areas (Holistic)

General health

Education—Health

Accommodation ▶ ▶ state of ✓

Mental

Preventative

Men/Women's/Children

Use of services

Psychological health

Environment:

Factories

Mines

Rats

Roads

Refuse

Chemicals

Cultural Aspects

Glasses Dental

Accepting that problems exist---Disabilities

Behavioural disorders

Speech/vision

Attitude changes to problems

You can't see mental health

Cultural Costs----Why people don't get help

Need to look at attitudes of health service providers

GP's, Hospitals, Nurse, health Board

Red tape to actually get info from health Board.

Local GP if family has GP {Work to be undertaken with GP's}
Support for National Forum for Travellers

Q5. Resources, training and support

1. People from research team on the ground and trained in Traveller issues and anti-racism. Travellers to train researchers.
2. Premises made available for group
3. Looking at Travellers and train them and get them to do the study
4. Link into what is already there:

Primary Health Care.

Traveller Women's Group

Get links to Travellers not in a formal system

TARA Workshop and CEC scheme for Travellers not fully informed by people in charge

Study: User friendly

Travellers involved in design of questions

Travellers paid for carrying out the study

Priorities for Joint Discussion

1. This study needs to be implemented and followed through

Task Force was never fully implemented

This is disholysing(? Dishonest, disempowering?)

There needs to be financial commitment

All talk and no action!

2. Identity issue needs to be carefully looked at

3. Travellers have to be involved in all parts of this study and properly supported, not tokenism

4. Proper to carry out funding research

5. Travellers involved from the start at all levels

6. Health study holistic approach:

Accommodation: Traveller specific—nomadic--permanent

Mental

Social

Environmental

Educational

Physical

Mobility

Nomadic way of life facilitated

Traveller is WHO YOU ARE not where you live. These should be included in the study

Outcomes for Travellers and tackle major inequalities between settled and Travellers.

Study needs to highlight:

Culturally appropriate delivery of services

Accommodation

Results of study compared to other ethnic minority, which face the same inequalities as Travellers.

Outcome of quality of health service for Travellers should be the same as settled people.

Morning Session: Health Service Providers: Two Groups

Q1. How do we make sure we get the right picture with this study?

Main Factors

- Qualitative Needs Assessment
- Local Knowledge
- Involvement/inclusion of outside agencies
- Plan/training to be implemented so that the inclusive approach is adopted

The issues

- Good listening and information is not misinterpreted
- Give an equal partnership in the say of things
- Simple language used and good, clear communication throughout all stages of the process
- Concepts of health are clearly defined

Q3. Currents methods of data collection

- Local authorities do head count and include roadside Travellers on an annual basis.
- What is the legal basis around collating this information?
- National Census

Q4. Travellers births and deaths

- Agreement to be made of how this information is to be collated (deaths, births)
- Information gathered now to be included in 2006 census to identify ethnic questions
- PHN's and CWO's records can't identify Travellers
- No Race Relations Act
- Equal Status Act
- Education of Travellers and Service Providers
- Universal and general ethnic identifier
- Standard set on Codes of Practice
- Health reforms to prioritise ICT

Q5. Resources, Support and Training

How is information going to be gathered?

Who will conduct the study?

Release of staff to participate

Publicity and information

Information gathered needs to be co-ordinated

Avoid duplication of information

Targeting

Involvement of other agencies

Training and support of study participants

ICT support

Priority Areas for Joint Discussion Forum:

- Equal partnership: how is it going to be done?
- Capacity building for Travellers and health Service/ Providers

- Build trust on information and communication and promote awareness
- Involvement of statutory agencies—having an integrated approach
- (can't on our own influence the health status of Travellers)
- A guarantee at the end that this will have a positive outcome for Travellers e.g. financial aid (?) study and end results are financially resourced.
- Communication and Education
- Data Issues
- Partnership and Traveller participation

After discussion the following four areas were selected for the Joint Discussion Forum

Group 1. Implementation of the findings

Surveys done and nothing carried out for anyone's benefit

It would be better for health Boards and Travellers

Long term cost effective

For future generations it would shorten gaps (life expectancy)

It would tackle health inequalities

It would be loss of faith if nothing came out of this

It would help the health Boards to fulfil its role

The who and where:

Department of Health

Develop an action plan in relation to the findings of the study (North/South) all-Ireland

Action Plan should have specific performance indicators

Different Government departments (inter-departmentally) to work together

The change of structures in the south might help this

The local health board region's working in partnership with Traveller groups

Regional steering groups (partnership) to implement locally the recommendations of the Action Plan.

Group 2. Equality of partnership

Issue Important

1. Equal benefits for all

a) To know the information we need to ask the right questions in a language understood by all

b) Areas of skill and expertise on all sides; equality of access to services

2. Service providers need to have training in Traveller culture

3. Equal representation for those conducting the survey

4. Regular feedback given to the relevant stakeholders (a feedback mechanism should be built in)

An evaluation should be used hand in hand

5. Costs should be included for community participation (meetings, childcare)

The Who:

Total partnership approach at all stages

Continuity and commitment of those within that partnership

What:

Information and questionnaire. No duplication of information

How:

To be designed and culturally appropriate to the clients (find various forms of communicating this information)

Guarantee of confidentiality be given and treated with sensitivity

Group 3. Training and information issues

Getting the message across i.e.

Information on the study

Reasons behind the study

What will the outcomes be?

Will it benefit Travellers?

How will it benefit Travellers?

How will we overcome the literacy difficulties?

Need for plain language---language as power

Training and information programme needs to be set up **and properly resourced.**

This must be a working group with equal representation from both sectors to ensure there is proper communication on the study and throughout the study.

This 'group' should also be part/inform the design of the study

The participants of the working group should have a genuine interest in and mutual respect for each other.

Why is this issue important?

Exchange information in appropriate manner

Builds trust

Understanding of the need for the study and the benefits

Breakdown of barriers---

Meeting Travellers where they are at

Coming down to ground level

Listening properly and responding appropriately

Locally:

Everyone involved in working group should 'at the start' get out and see what is really happening out there---the reality'walk the walk'

Nationally

The whole area of ethnicity needs to be addressed.

The promotion of ethnicity needs to be on the agenda nationally---for all e.g. White Irish /Black Irish, Traveller etc for all statutory and voluntary services.

Group 4. Traveller identity

Why important:

Hiding identity to be treated equally

Internalised oppression---inferiority complex---effects on mental health

Affect participation in study

Particularly a problem in a rural area/isolated

Travellers' fear of identifying themselves---experience has often been negative

Fear of labelling children---- affects their experience of services

Importance of predevelopment work of study to encourage Traveller participation

Confidentiality/ownership of information—need confidence in the system
Institutional racism, needs to be addressed
Need confidence in results of the study therefore needs to be accurate
Ethnic identifier
Born a Traveller: some Travellers may feel under pressure to deny identity
Self-identification is important
Need to create a situation where people can reclaim their identity

Locally

Target November 2004 Census: concerted /multi-sectoral effort
Use local knowledge to access Travellers
Targeted initiatives to ensure representativeness
Border issues to be addressed:

- Nomadism between Northern Ireland and Republic
- Hand held records/transfer of information
- CWO support
- Bureaucracy

Identity and cultural issues reflected at all levels of study through to analysis and findings
Interim reports/regional foci
Clarity about time frame
On-going briefings
Transport to maternity services—ante natal

Any other key messages for the Advisory Group

Communication, communication, communication: keeping people informed/training.
The study will need to be user friendly language
Use the different media to relay the news about the study to the people
It will need to look at different areas 'needs' and put resources where required
People's fears will have to be rebutted i.e. questions, confidentiality, information not used inappropriately
Really listen to the Traveller community
Feedback given would be delivered on a pilot basis
Study is properly resourced from start to finish
Get it right the first time even if it takes time
Be patient
Involve Travellers from the very beginning
Come down to 'ground level'
Travellers should be involved in 'Data input'
Literacy issues must be addressed from the very beginning
Start at end and work back
Have a 'vision'

APPENDIX 2

QUESTIONS

TRAVELLERS /TRAVELLER ORGANISATIONS PREPARATORY MEETING

1. How do we ensure that the study properly reflects
 - The main factors that affect the health status of Travellers in your local area?
 - The issues in relation to access and participation of Travellers in the health services?
2. What form should Traveller participation in the study take locally?
3. What are the current methods used to record information on Traveller population in your region? Are they effective? If not, how can we improve them?
4. What do you think are the most accurate ways of collecting and collating information on Traveller births and deaths in your area?
5. What resources, training and support does your organisation need to effectively participate in this study?
6. What are the three priority areas to bring to the Joint Discussion Forum?

HEALTH SERVICES PREPARATORY MEETING

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