

REPORT ON NORTHERN IRELAND REGIONAL CONSULTATION

Wednesday 24TH September 2003 10.00am—14.30pm
Loughry College, Cookstown

Key Facilitator: Ann Mc Cready

Departmental representative: Deirdre Kenny, Michael Sweeney

Numbers attending: 90

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

1. Traveller/Traveller Organisation Preparatory Meeting

This meeting was broken into six sub-groups to provide workable and manageable group sizes for the discussion on the questions. The key issues arising from these groups were:

- Traveller involvement at all stages of the process, to be consulted, encouraged, trained and supported.
- Need to ensure all expenses incurred by Traveller participation is covered.
- Find creative ways of collecting and collating information: use audio-visual material, non-threatening methods, combine individual and group approaches, Traveller men to work with Traveller men and same for women, choice of interviewee (settled or Traveller).
- Training for Travellers in facilitation, research, literacy, and health awareness.
- Recognise difficulties nomadic Travellers face in getting registered with GP's and the how health records are kept: idea for a smart card.
- Impact of accommodation (lack or it, quality of it) on health.
- Racism, prejudice and discrimination facing Travellers in reception areas of GP surgeries, hospitals etc.
- Health professionals to be aware of Traveller culture, needs and values.
- Absence of information and education from health providers about health
- Encourage Travellers in their dealings with doctors including how to complain: a code of conduct for how GP's deal with patients.
- No accuracy about number of Travellers.
- Health Visitors, churches, doctors, hospitals, councils and community health workers could all help the accuracy of numbers.
- Collaboration of agencies and not just health: must cover accommodation, education and training bodies.

2. Health Services Providers Preparatory Meeting

- Need to define the priority of health and social care
- Communication difficulties include use of language, postal deliveries and literacy
- Prejudice and lack of understanding of culture
- Health and Social services are poor in responding to specific needs.
- Relationships and Trust are key to improving access and participation: this is a two way process.
- Need to record ethnic origin for statistics
- Study needs to engage with men and women, young and old and guarantee confidentiality and anonymity.
- There are no fully effective existing record keeping systems: large gaps exist.
- Personal records that travel with the individual: a personal identifier is needed
- Dilemmas about sharing data
- Funding, training, cultural awareness needed now to engage Travellers.
- Current system needs to change if this is not to be another study.
- Study implication need to be considered now at interdepartmental level and a commitment given to act on anticipated findings.

The two preparatory meetings ended with a coffee break

3. Joint Discussion Forum

The full plenary session heard feedback from all eight-sub groups including priority issues for the Joint Discussion forum.

| Travellers/Traveller organisations | Health Service Providers |
|---|--|
| Discrimination listening | Parallel process to gain commitment across departments to take action on results |
| Facilities Sites and housing | Full considerations of Travellers views e.g. do Travellers want the study? |
| Education and Awareness | Must be sensitive locally |
| | Lack of local information systems |

After discussion it was agreed that instead of trying to reduce these to three priorities for the Joint Discussion Forum there were sufficient numbers present to enable discussion of six issues in small break out groups after lunch. The topics for the Joint Discussion Forum were agreed as:

1. Discrimination
2. Making sure we get action as a result of the study
3. Facilities: sites and houses
4. Education and Training
5. Need for local information
6. Listening

The key points arising from these breakout discussions were:

1. Racism and racist attitudes by staff at all levels in health facilities/ services is the biggest factor towards exclusion
2. Indirect discrimination is evident as well
3. Travellers must be trained and resourced to be involved in designing questions and carrying out the research
4. Need for easily understood communications about the study
5. Who is accountable if study fails?
6. Health Boards should be required to stick to the study and if it falls off the track funding should be stopped.
7. There should be an Ombudsman for Travellers Health who makes sure standards are set.
8. A focus group should be established to sustain the momentum achieved today.
9. Need a follow day or days like today to keep information on going.
10. Additional support, training and resources are needed for Traveller Support Group workers.
11. It is impossible to overstate the negative impact accommodation conditions have on Travellers health.
12. Travellers' living in houses does not solve all the health problems related to accommodation: they feel unwanted by neighbours and are excluded from their own community.
13. Training and education need to start now if the study fieldwork is to take place next year at the end of the summer.
14. There should some representatives from the Traveller community North and South on the steering group, which oversees the study.

4. Outstanding Issues to be clarified:

Dilemmas about sharing information across agencies: Data protection.
Change need in notification of births and deaths at Registrar General's Office
Will a Focus Group be established in NI to sustain the momentum of today?
Who will resource and provide the training required and requested to maximise Traveller participation in the study?

NORTHERN IRELAND CONSULTATION NOTES

Wednesday 26th September 2003

AM session: Health Service Providers preparatory meeting

Q1. Matters which affect health and access to health services

Define priority of health and social care

Language and understanding

Primary care and determinants

Organisational commitment

Relationships/Trust Building

Identification of target group

Status in society

Physical accommodation and environmental, economic conditions—lack of basic amenity.

Communication difficulties/barriers e.g. postal, literacy.

Prejudice and lack of understanding of culture

H+SS poor in responding to specific needs.

Relationship and trust key to improving access and participation—two-way.

Engage with Travellers

Engage with professionals—health visitors etc who understand Traveller culture

Resources need to be put in place

Build trust with Travellers

Target in priorities for action

GP registration (21 days)

Record ethnic origin for statistics

Q2. How to involve Travellers with the study

One to one engagement ✓

ownership

confidentiality

tailored

peer research (if acceptable)

time

innovation

Participation---extended family, focus groups, one-to-one, engagement of men, participation in health checks.

Interview Travellers.

Financial incentive

Anonymity

Target households

Men and women, young and old, broad participation

Proxy interview?

Q3.Collection of data on Travellers

GP records

Child Health system ✓

Hospital Registration/Admissions

Schools-EWO's

NIHE, DHSS

None of these are fully effective: 'cultural issues'

Personal records that travel—personal identifier

Gaps—large—work needed

Health system, GP's variable, SS-ad hoc, Dilemmas

Local Traveller Support Group

Group Housing Schemes

Q4. Births and deaths notifications

Births---linked to medical card/DHSS etc

Deaths--?

Registrar General---not recorded, change needed

CHS ✓ , CSA

Move to health/morbidity info

Q5. What would assist Travellers have a full say?

Money—training—cultural awareness—brokerage—protocols of engagement.

Unless change current system---big issue that needs to influence info systems. Not another study.

One health service provider group added:

Study implications to be considered now—interdepartmental commitment now to anticipated findings (including councils)

Traveller/Traveller organisation preparatory meeting

AM Session Feedback

Q1: Factors affecting Travellers Health + access to and participation in services

Make creative ways of collating information

Literacy—fear of social workers

fear of statutory sector

Travellers have to be consulted.

Travellers on the ground in each area

Questions to be asked:

Accommodation—conditions—

Nomadic Travellers find it very hard to get registered with doctors, find it very difficult. ✓ ✓ Records being delayed in reaching new doctor.

Travellers from housing accommodation find it easier to access services.

Literacy is a major issue ✓ —can not read letters, miss appointments. Don't value their own health: men, in particular, not the macho thing to do.

Hard to get a doctor

No immediate response to call out

Access to GP's ✓

Conditions on side of road/sites

Environment ✓

Need for Travellers to be qualified medical personnel to enable trust and better communication
Condensation in trailers—effect on children
Need for audio-visual material
Problems experienced at reception sometimes because of attitude towards Travellers.
Problem for Travellers coming into Northern Ireland to get National Insurance numbers, to be able to access GP's
How health records are kept for Travellers—to follow Travellers around—idea for a smart card.
If they had confidence in a Traveller they would give information
Travellers would prefer a settled person going into their own homes and asking questions on their health. They would feel more comfortable with this. The group also stated they would feel more comfortable with part of the research being carried out on a workshop basis with a trained Traveller facilitating it. But more sensitive issues would be better carried out as stated above.
Good sites/bad sites, effect on health
Education for Travellers to access health problems
Doctors not accepting Travellers because of temporary address
Issues—stress causes bad health
Alcohol and smoke
More female doctors—women don't feel comfortable
Men often prefer male talking to male
Doctor for men's health
Embarrassment re: smear test etc
Lack of information from health providers
Lack of education about health
Racism and discrimination in the way they treat Travellers in hospitals, doctors, personnel etc.
Lack of continuous health personal visitors' etc.
Listen to Travellers—involve Travellers at each step of the way
(Note: one of the groups thought questions 1—3 were similar and did not go onto the other questions.)

Q2: Traveller participation in the study

Qualitative research—one to one in a way that is not threatening
Workshops—individual needs for individual areas
A combination of approaches
Travellers and social workers to be involved in asking questions
Issue of confidentiality—(could be better to use outsiders)
Need for Traveller men to work with Traveller men and Traveller women to work with Traveller women
Could give Travellers choice of interview by a Traveller or non-Traveller
A Traveller could facilitate a workshop via a Dictaphone
Get Travellers together more often like today
Expenses should be paid
Meeting place e.g. Citizens Advice Centre
Person from Travellers to conduct study
Support groups within Travellers

Find out more about Travellers culture, values

Voice. Use your voice. Talk to Travellers either one by one or by group discussions. Help them get over their embarrassment.

Offer support to Travellers; build their self-confidence so that they will speak out about their health problems, which they often hide.

Treat each Traveller as an individual, acknowledge their intelligence and don't assume because they can not read and write.

Doctors should take time to listen and do a check of blood pressure, chest etc when they are visiting.

Female doctors for female Travellers

Listen to Travellers

Devise a note for Travellers e.g. telling them what to say to doctors and how to explain their illness and their wants and needs and how to complain and telling them, that they do not have to put up with bad manners e.g. code of conduct.

Travellers need information on how to access services—employment

Travellers often feel they are left to the last voice, again talk to Travellers and use the Travellers to work and assist in surveys etc.

Appears to be a problem in involving Traveller men so work at this and develop their health awareness e.g. sports: football, boxing, swimming.

Traveller young women won't talk in front of their mothers, grandmothers—separate according to ages

Peer education—young women learn from their own age group, not parents

Train Travellers up to be lay health workers

Health professionals must be aware of Traveller culture, needs and values

More female health workers should visit Traveller women in their own homes.

Want action now, been talking for years and health still not improved.

Focus group

One to one interviews

Male/female

Different age groups

Training Travellers how to become more active

Q 3. Current record keeping measures

Census—not accurate

Doctors registers not accurate—nomadic Travellers

No accurate information on Traveller numbers.

All statutory sector registration: registering as Travellers in order to collate information database.

Health visitors in local areas

Could Traveller Support groups keep information ✓ ✓

Should get hospitals to record people's ethnicity

Recorded with local social worker

It is up to every town to keep their own information

Unsure if there is any method

Q4. Accurate ways of collecting information

Births and deaths—church-council-surgeries

Identify Parish Priests who know about births and deaths

If a community health worker had a book they could record births and deaths

Should be an identified health visitor to each area. Not frequent change.

Q5. Resources, training and support to take part

Workers and Travellers employed in each area

Training programme on health for Travellers

Expenses for participation

Collaboration of agencies, not just health: accommodation/ education/ training and employment.

Could tape questions to enable Travellers to ask questions

Training

Payment for doing research

Travellers and non-Travellers to work together on administration

A Traveller trained to collect information, put in computer database

Need Travellers trained up in facilitation

Expenses

Department of health should provide resources

There should be childcare facilities

Education support

Citizens Advice Centre for Travellers

Doctors/ teachers—need to be educated on Traveller rights

Doctors for Travellers, assistants especially.

Funding

When the two groups met in plenary session each sector fed back their identified priorities for the Joint Discussion Forum, to follow after lunch.

These priorities were identified by each sector as follows:

| Travellers/Traveller organisations | Health Service Providers |
|------------------------------------|--|
| Discrimination listening | Parallel process to gain commitment across departments to take action on results |
| Facilities Sites and housing | Full consideration of Travellers views e.g. do Travellers want the study? |
| Education and Awareness | Must be sensitive locally |
| | Lack of local information systems |

After discussion it was agreed that instead of trying to reduce these to three priorities for the Joint Discussion forum the issues were sufficiently important and there were enough people present to discuss six issues in the afternoon.

The six issues chosen were:

1. Discrimination

Racism and racist attitudes by staff at all levels in health facilities/services is biggest factor towards exclusion

Indirect discrimination—literacy e.g. prescriptions

--do not take into consideration needs of Travellers

--do not listen or explain in Traveller terms

Training/Cultural awareness on Travellers culture/ needs and anti-racism
Travellers should be involved in designing questions for the questionnaire
research and in carrying out the research.

Questions should be user friendly

Training provided

Resources

2. Making sure we get action as a result of the study

Starting groups right away from information gathered in the study

Setting up a task force to train Travellers

Travelling people talking on behalf of Travellers

Out of Task Force Travellers who are trained, get them involved, even if it is
only one.

One Traveller, as long as they are motivated, would make all the difference

Team effort required so that progress can be made

A follow up study is vital

Traveller meetings—a spokesperson from the Traveller community at
meetings involving statutory sector

A news letter, not just involving the study, which does not bore people with
jargon. Photos, competitions etc.

One to one meetings are essential with

Who is accountable if study fails?

Someone from all statutory agencies, NIHE, Health and Social Services etc

One big umbrella group in each area

Health Boards stick to study, and if fall off the track, things like funding should
be stopped.

A policy for reminding Travellers about appointments and if Travellers can not
make appointments a telephone calls should be made also.

Ombudsman for Travellers Health---a neutral who makes sure standards are
met.

Respect from the health services for the Traveller community

Less of a clamp down on Travellers lives

Not interfering too much into personal lives

Understanding and respect needed of Travellers culture and traditions

Something for 14 year olds boys e.g. Government training outside of school.

Travellers need to be given the chance to be heard

Everything addressed in order of priority

Financial commitment from the government to ensure study is actioned.

Focus group to keep up the momentum achieved today.

3. Facilities: Sites/houses—thinking about this issue, what does it tell us about
how the study should be done, what info should be collected, who has this
information, who should collect it, how?

There had an earlier discussion on these matters.

Transient sites—bad for health

Stress—no toilets etc

Planning permission applied

Bins emptied for free

Why are there not enough sites?

Why stopped from making sites?

Compare to other countries
Authorities drag heels on site permission
Understand
Only helped minority of Travellers---old NIHE study
Neighbours in housing estates dislike Travellers
Travellers want their own space
Travellers want to keep their own way of life
Travellers are not hippies and vice versa
Travellers have moved with the times
Rubbish collected—water
Travellers want houses at different times
Some Travellers want to travel and have a house
Travellers want to travel no matter what
Not enough sites—need to speak to the authorities and agencies
Not enough houses for Travellers---these need to reflect Traveller requirements---not in the middle of a housing estate where they will feel excluded

4. Education and training---thinking about this issue what does it tell us about how the study should be done, what info should be collected, who has this information, who should collect it, how?

Problem around time frame for the study field work end of summer 04—for 1 year.

Training and Education start now.

Training across different methods, training for workers doing the research

Giving people choice: settled person, Traveller, male/female, choice for Travellers

What Information: Information is in heads of Traveller community

What sort of illnesses people have:

--children—survived and illness

--hospital;

--adult illness, both male and female

--average age

--mental illness

--disability/disabilities

--various services e.g. dentist, doctor

--collect information on accidents due to e.g. site conditions

--health education

--peoples beliefs of their health and how to improve health

--alternative health remedies --understanding of this

--smoking, drinking, eating habits(diet) exercise routine, if any

People need to be trained from now until the end of next summer: needs to happen now

More discussion days, more organised days like this

When will training start???????

Training needs different in different areas. Some Travellers trained while others never had training

If can't connect with Travellers today how are we going to get information next summer?

Need follow up day like today. Support workers may not have time or resources to assist in this study. Therefore support workers need support and training.

Need to know exactly what we want to get out of this study. People in the field need to do this. People high up need to be in touch with people working on the ground with Travellers.

Who knows enough to do education and training---Travellers and settled people working together.

Should be some representatives from North and South Travellers community on steering group which oversees the study.

Anyone involved in training: wages and expenses, travel and childcare

People need long term plan, researchers

What form should questions take e.g. a, b, c, d, e, etc.

Travellers do want to be involved in the study.

Key Points:

Representation of Steering group, sub groups of Travellers

Traveller from each area consultation took place

Different families/different beliefs

More discussion days like this

5. Need for local information---

No feedback or sheets available: *Mary Mc Mahon to check with Derry*

6. Listening ---thinking about this issue how do we ensure that Travellers thoughts/ views/ ideas are included? How can Travellers be involved at every stage of this study—e.g. checking final design, keeping an eye on what's happening, deciding what information means, what needs to be done?

Evidence through action

How to collect views of Travellers women to women

Travellers become part of the study

Resources to support local group

Different issues with gender and age groups within Travellers

Traveller representatives

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

1. How do we ensure that the study properly reflects
 - The main factors that affect the health status of Travellers in your local area?
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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?