



Friends Families and Travellers

REPORT INFORMATICS

JULY 2014 - SEPTEMBER 2014

Attitudes to medical records sharing in the Gypsy and Traveller community

A summary of the report compiled for Brighton and Hove CCG
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ATTITUDES TO MEDICAL RECORDS SHARING
IN THE GYPSY AND TRAVELLER COMMUNITY

INTRODUCTION

Friends, Families and Travellers (FFT) is a lead organisation seeking to address the problems facing the Gypsy and Traveller communities, providing advice and information along with a wide range of other services. FFT work nationally and for this project work solely with Travellers within Brighton and Hove city, whether residing in or 'resorting' to Brighton.

METHODOLOGY

From July to September 2014, 49 members of the Gypsy and Traveller communities were interviewed on the subject of medical record sharing across service providers, including non-healthcare related services. Due to seasonal traveling, a large proportion of respondents were encamped on unauthorised sites at this time. Reduced capacity at the local transit site also led to a large number of evictions, making it harder to engage with Travellers.

The interviewing was carried out through a combination of:

Bespoke questionnaire.

Telephone interviews/drop-in to office.

1:1 interviews.

Assertive outreach site visits.

Informal Women's Group run by FFT.





DEMOGRAPHIC PROFILE

Of the 49 people interviewed,

29 of them (**59%**) were women, **20** of them (**41%**) men.

The two largest cohorts were Irish Travellers (**37%**) and New Travellers (**35%**).

The two smaller cohorts were Gypsies (**22%**) and Welsh Travellers (**6%**).

47% of respondents lived on unauthorised sites, the largest cohort.

31% lived in bricks-and-mortar accommodation.

14% lived on privately owned sites, with **8%** living on local authority ("council") sites.

WHAT THE RESEARCH UNCOVERED

A large majority of respondents (82%) did not know which agencies currently shared their health information. Following from this, there was a clear and stark hierarchy of trust and distrust of services:

82% were happy for their records to be shared with Accident & Emergency depts.

80% were happy for specialist consultants to have access.

76% were happy for records to be shared from one GP to another.

By contrast,

76% were not happy for their records to be shared with an adult social care team.

90% were not happy for their records to be shared with children's services.

88% did not want their records shared with housing providers/local authority.

COMMENTS FROM RESPONDENTS ON MEDICAL RECORD SHARING

In line with the above results from the survey, there was a marked contrast between the relative trust expressed by most respondents for qualified health care professionals, compared to employees of local authority employees.

“I would not want my records shared with housing or with people who are not medically qualified”, said a 49-year-old New Traveller man. A 23-year-old Gypsy woman said **“My records are confidential - If my records were shared I might not tell my doctor the whole truth.”**

There was concern that sensitive information on health records - for instance, diagnoses of depression or anxiety- combined with the respondents’ status as Travellers could be used against them, i.e by children’s services. The fear of Travellers’ children being removed into care - a common practice in the 1950s and 1960s- was frequently cited.

Past discrimination against Gypsies and Travellers led to worries about record sharing. A 40-year-old Gypsy woman said: **“It is personal between me and my doctor. If there was a war on or concentration camp my community would be the first to be called in.”** A 49-year-old Traveller man said **“I do not trust the local authority as they have discriminated against me and my family in the past with no good reason, other than our traveling lifestyle.”**

Respondents who were relatively happy to have their information shared took a pragmatic stance based on their enhanced needs, or the fact that their children were older and could not be taken away from them. **“If I was younger I may be worried about ... people who were not health people taking my children away”,** said a 47-year-old Irish Traveller woman. A couple of respondents feared that the pooling of information would lead the Department of Work and Pensions to make non-clinical judgments around the issuing of ‘fit notes’.





CONCLUSIONS

A majority of respondents wished to opt in to further record sharing when they felt the time was appropriate. Those who responded positively to record sharing were suffering from long-term health conditions and were already sharing information across services.

Additionally, there was clear ambivalence about the usefulness of online medical services:

49% did not want/trust electronic prescriptions services.

61% wouldn't book appointments online as they "do not or cannot use the internet"

65% wouldn't order repeat prescriptions online for the same reason.

65% wouldn't update their contact details online for the same reason.

65% wouldn't try to access their medical records online for the same reason.

The internet was also distrusted for security and privacy reasons, and it was noted that older people would be more likely to have difficulties using it.

Those who could see themselves using the internet for medical services noted that they would need help getting online if internet access on their site was poor - dongles were cited more than once as a solution.

There was also concern about the effect of poor rates of literacy in the community on accessing services, especially online.

ACTIONABLE RECOMMENDATIONS

1. That surgeries ensure there are available appointments for people who cannot access online facilities.
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2. For surgeries to be clear when registering patients exactly who will share their medical information.
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3. To make opting out of record sharing straightforward at GP surgeries.
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4. To promote cultural competence training at surgeries and within services such as children's services and housing departments.
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5. To work with organisations which support Gypsies and Travellers and commissioning their expertise in training clinical and non-clinical staff, ensuring an ongoing commitment to addressing prejudice, cultural and practical barriers face by Gypsies and Travellers when accessing health services.
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6. To promote and encourage all staff to undertake cultural competency training related to Gypsies and Travellers. Completion of this could result in a standard mark achieved for that surgery or service provider.
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