

Traveller Gypsies and childhood immunization: a study in east London

GENE S FEDER

TERESA VACLAVIK

ALLISON STREETLY

SUMMARY. *The immunization status of the children of Traveller Gypsies presenting to two general practices and a paediatric accident and emergency department in east London between July 1988 and February 1990 was compared with that of a control group presenting to the same services. Study of parental reports and other records for 72 Traveller Gypsy children and 106 control children aged 10 months to six years revealed that Traveller Gypsy children had significantly lower completion rates for pertussis, measles, diphtheria/tetanus and poliomyelitis vaccines than the control group. The difference between the uptake of the first and third diphtheria/tetanus, pertussis and poliomyelitis vaccines was significantly greater among the Traveller Gypsy children than among the control group. The low immunization rates are due to poor access to services as well as rejection of certain vaccines by Traveller Gypsies. The 1990 general practitioner contract and reforms to the health service may result in decreased access for Traveller Gypsies unless steps are taken by family health services and district health authorities to meet the health care needs of this group. Possible solutions to this problem include outreach services to caravan sites, opportunistic immunization, better records and targeted health education.*

Keywords: *immunization status; Traveller Gypsies; children and infants; access to health care.*

Introduction

TRAVELLER Gypsies are one of the oldest ethnic minorities in the United Kingdom.¹ Their access to health care and use of preventive services are rarely investigated, but most reports suggest they are poorly served by health authorities and general practitioners.² Only two large surveys of immunization among the children of Traveller Gypsies have been carried out and both have shown low completion rates.^{3,4} Both studies were carried out in rural areas, relied exclusively on parental recall of immunization status and did not include local control groups.⁵ Reasons for low immunization rates among Traveller Gypsies have not been investigated and it cannot be assumed that parental resistance is the most important factor. Barriers to uptake of immunization and other preventive services for Traveller Gypsies include discrimination from doctors, enforced mobility, non-literacy and the absence of postal addresses for recall.⁶

G S Feder, BSc, MRCP, research fellow and T Vaclavik, SEN, research assistant, Academic Department of General Practice and Primary Care, Medical College of St Bartholomew's and the London Hospitals, London. A Streetly, BA, MSc, MB, senior registrar in public health medicine, West Lambeth Health Authority, London.

Submitted: 21 November 1991; accepted: 9 October 1992.

© *British Journal of General Practice*, 1993, 43, 281-284.

This study was part of a larger project to assess the health care of Traveller Gypsies in Hackney, east London. As one measure of preventive health care provision the immunization status of Traveller Gypsy children presenting to primary care services was assessed and compared with that of a control group.

Traveller Gypsies have stopped in Hackney for at least 150 years.⁷ There are no official caravan sites in the borough but there is one 'tolerated site' containing a dozen pitches and many areas of waste ground where Traveller Gypsies stop until a court order moves them on. A specialist health visitor post for Traveller Gypsies was created in 1981⁸ and since 1986 the post-holder's priority has been to encourage Traveller Gypsies to use existing primary care services, rather than providing services such as immunization on caravan sites.⁹ The local settled population from which the control group for this study was drawn is made up of many ethnic groups with a high proportion of low income and single parent families.¹⁰

Method

Consecutive Traveller Gypsy children aged 10 months to six years presenting to the accident and emergency department at the Queen Elizabeth Hospital for Children or to any of the 12 general practitioners working at two practices in Hackney between July 1988 and February 1990 were recruited. A survey of all practices in Hackney and Tower Hamlets¹¹ identified seven which reported seeing at least one Traveller Gypsy patient per week — two of these practices agreed to participate in data collection. The only paediatric accident and emergency department in east London is sited at the Queen Elizabeth Hospital for Children in Hackney. Cases were children whose parents gave a caravan site as a home address or whose notes contained a previous caravan site address or who were known by the receptionists or nurses to be part of a Traveller Gypsy family. Recruitment of controls differed in the two settings. In the accident and emergency department nurses were asked to recruit the next two children who were not Traveller Gypsies seen after a Traveller Gypsy child had been recruited. In the general practices two sex-matched children with the nearest birth date to the Traveller Gypsy child were selected from the practice register. Doctors were asked to take the immunization history from the parents at the next consultation and this was indicated by attaching a data entry card to the front of the notes.

Nursing staff at the accident and emergency department and general practitioners in the participating practices were asked to complete a data entry card with the parental report of the immunization status of the children. Before data were transferred from the data entry cards, the child's name and date of birth were checked against a list of all children recruited from the three centres. Where a child was recruited by two sites only the data from the most recent contact was used. Other records of immunization status were obtained from the health authority computerized records, practice-based child health records and records kept by the specialist health visitor for Traveller Gypsies. If more than one record of immunization status was available that which contained the most recent information was used for comparison with parental recall.

Children were classified as not having had an immunization when they were not immunized one month or more beyond the date recommended in the immunization schedule used in

Hackney during the study period. The three, seven and nine month schedule for the diphtheria, tetanus and pertussis and poliomyelitis vaccines and the 15 month measles schedule were in use at the time of the study. In April 1989 the measles vaccine was replaced with the measles/mumps/rubella vaccine and data on both vaccines were coded together.

Statistical analysis

Differences between groups were assessed using confidence interval and chi square testing using *CIA* (*Confidence interval analysis*) and *SPSS* programmes. A kappa statistic was calculated for Traveller Gypsy and control children as a measure of agreement between parental reports and records. The McNemar test was used to assess whether there was a bias towards 'under reporting' or 'over reporting' from parental or other sources. Neither the kappa statistic nor the McNemar test assumes that the parental or other reports are correct, they simply provide an index of agreement or disagreement.¹²

Results

Immunization status was determined for a total of 72 Traveller Gypsy and 106 control children eligible for completion of the triple antigen plus poliomyelitis vaccines. Of these children 61 and 85, respectively, were also eligible for the measles or measles/mumps/rubella vaccines. The two groups had similar age-sex distributions. In the two general practices 87% of eligible Traveller Gypsy children seen in the study period were recruited, whereas in the hospital only 51% of the eligible Traveller Gypsy children were recruited. In the practice and hospital groups Traveller Gypsy children who were not recruited had similar age-sex distributions to the recruited samples. Seventy per cent of potential controls were recruited in the general practices and 81% in the accident and emergency department.

Validation of parental reports

Using all available sources of data it was possible to assess independently the immunization status of 19 of the 48 Traveller Gypsy children recruited in the general practices (40%) and six of the 24 children recruited in the accident and emergency department (25%). Immunization records were available for 53 of the 67 control children seen in the practices (79%). For the hospital sample information was available on nine of the 39 control children (23%).

The kappa statistic showed substantial agreement (0.6 or greater) between parental recall and immunization records for all immunizations except the first pertussis immunization for Traveller Gypsies where the agreement was fair (0.5) (full table of parental report validation data available from the authors). The McNemar test only produced a significant result for the first pertussis immunization for Traveller Gypsies, where it indicated a bias towards under reporting of the immunization by the parents, or over reporting in the records ($P < 0.05$).

Immunization rates

Table 1 shows that the completion rates for the primary course of all types of immunization were significantly lower among the Traveller Gypsy children than among the control children. A general practitioner's name was given for four of the 24 Traveller Gypsy children recruited in the accident and emergency department (17%) and 35 of the 39 control children (90%). The rates for the completion of the primary course for Traveller Gypsy children recruited to the study in general practice and the accident and emergency department are shown in Table 2. Although absolute completion rates for all components of the primary course were consistently higher in Traveller

Table 1. Percentage of children completing the primary course of immunization (parental reports).

	% of children completing course		
	Traveller Gypsies (n = 72)	Controls (n = 106)	Difference (95% CI)
Pertussis	15	71	56 (44 to 68)***
Diphtheria/tetanus	33	85	52 (39 to 64)***
Poliomyelitis	31	87	56 (44 to 69)***
Measles/MMR ^a	20	71	51 (38 to 65)***

n = total number of children in group. CI = confidence interval. MMR = measles/mumps/rubella. ^an = 61 for Traveller Gypsies, 85 for controls. *** $P < 0.001$ (chi square test, one degree of freedom).

Gypsy children recruited in general practice than in hospital, these differences were not statistically significant. With this sample size a type II error is possible in the sub-group comparison of immunization completion by place of recruitment. For example, a sample of 350 Traveller Gypsy children would have been required to detect a real difference of 15% in poliomyelitis completion rates between children recruited in general practice and the accident and emergency department, with a power of 0.85 at a 0.05 significance level.

Figure 1 shows that the completion rate for the primary tetanus and diphtheria immunization rose throughout the age range studied for Traveller Gypsy children but was static by two and a half years of age for controls (poliomyelitis immunization followed a similar pattern). The completion rate for pertussis immunization was approximately static by two years of age for both groups of children.

Table 3 shows the proportion of Traveller Gypsy and control children who had the first immunization but did not complete the primary course. Both groups have a 'fall-off' between the first and third immunizations for all the components of the primary course, but this was significantly greater for Traveller Gypsy children than for the control group.

Discussion

In this sample of Traveller Gypsy children presenting to primary care services in an inner city area the completion rate for the diphtheria/tetanus and poliomyelitis vaccines was poor, with an even lower rate for the pertussis and measles vaccines. Although the absolute completion rates for all components of the primary immunization course were higher in the Traveller Gypsy children recruited in the two practices than among those recruited in the accident and emergency department, these differences were not significant at the 5% level. It is disappointing that use of a general practice did not result in an increased completion of the primary course of this order. The majority of Traveller Gypsy children recruited in the accident and emergency department did not have enough contact with a general practice for their parents to give the name of a practitioner.

One reason for the low completion rates found in this study may be that the sample was unrepresentative. Two thirds of the sample of Traveller Gypsy children in this study were attending general practice and may not therefore be representative of all Traveller Gypsy children living in Hackney. However, it is unlikely that children who have less contact with primary care services would have a higher uptake of immunization. Another reason for the low rates may be that both parental recall and district child health record systems are unreliable. It cannot be assumed that other records provide a 'gold standard' against which parental recall can be judged.¹³ Nevertheless, concordance

Table 2. Percentage of Traveller Gypsy children completing the primary course of immunization recruited in the two general practices and the hospital accident and emergency department.

	% of Traveller Gypsy children completing course		
	General practice (n = 48) ^a	Hospital (n = 24) ^b	Difference (95% CI)
Pertussis	19	8	10 (-5 to 26)
Diphtheria/tetanus	38	25	13 (-10 to 35)
Poliomyelitis	35	21	15 (-7 to 36)
Measles/MMR	22	15	7 (-13 to 27)

n = total number of children in group. CI = confidence interval. MMR = measles/mumps/rubella. For measles/MMR: ^an = 41; ^bn = 20.

Table 3. Percentage of children having first immunization but not completing primary course of immunization.

	% of children not completing course (total no. having first immunization)		
	Traveller Gypsies	Controls	Difference (95% CI)
Pertussis	42 (19)	12 (85)	32 (7 to 54)**
Diphtheria/tetanus	53 (51)	13 (104)	39 (24 to 55)***
Poliomyelitis	54 (48)	12 (104)	43 (27 to 58)***

CI = confidence interval. **P<0.01; ***P<0.001 (chi square test, one degree of freedom).

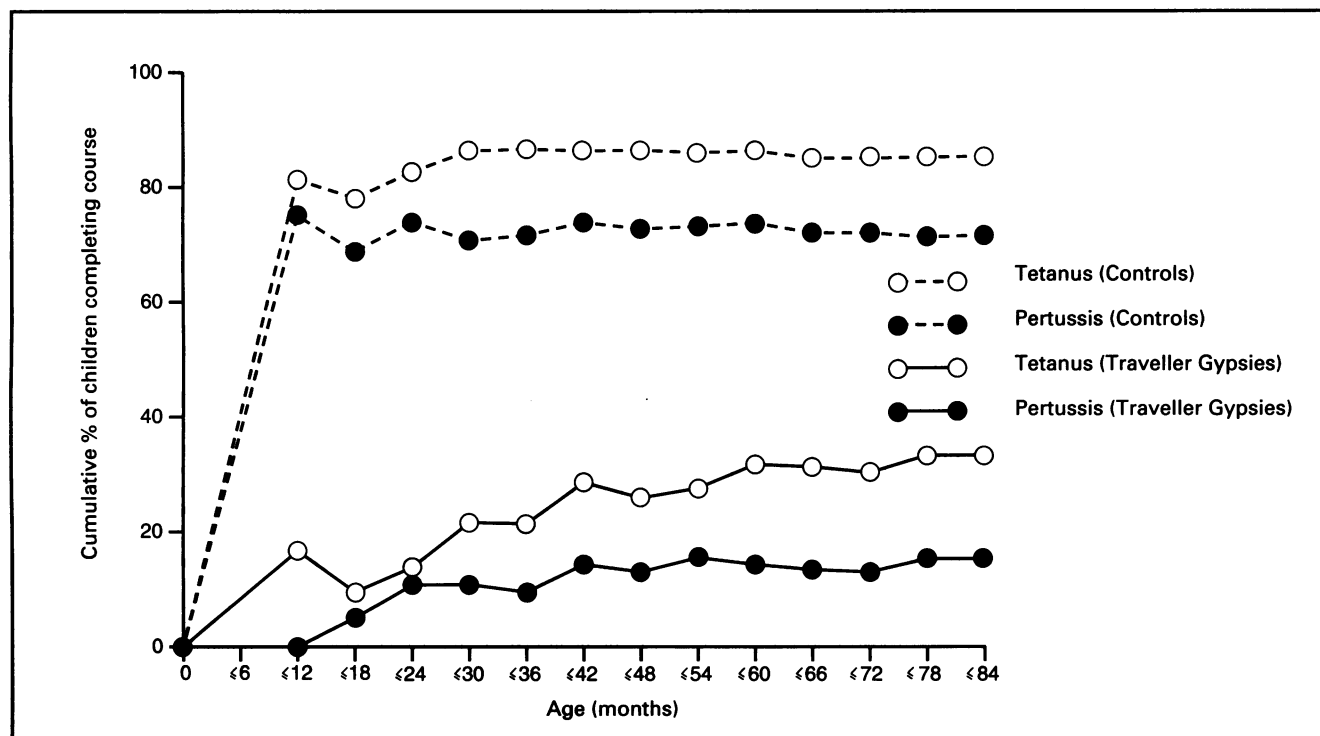
between parental and other reports was good, so it is unlikely that the low completion rates described here are artefactual.

Only 26% of Traveller Gypsy children had their first pertussis immunization and 20% their measles immunization which suggests a larger role for parental choice with these vaccines than with diphtheria/tetanus and poliomyelitis vaccines (71% and

67%, respectively, had first immunization). Subsequent interviews with 28 Traveller Gypsy parents whose children were part of the immunization study suggested that they considered pertussis and measles to be 'normal' or even 'strengthening' for their children, and different from poliomyelitis, tetanus and diphtheria (unpublished data). They also expressed strong views about the pertussis vaccine causing fits and brain damage. While other ethnic minorities may have been shielded from the effects of adverse media publicity by language barriers,¹⁴ television programmes in the 1970s on the putative dangers of pertussis vaccine may have reinforced long held concerns of Traveller Gypsies about the dangers of immunization. The low literacy rate among Traveller Gypsies throughout Europe,¹⁵ suggests that written health education materials will have a negligible impact. Additional support for immunization initiatives may come from local Traveller Gypsy representatives, who have facilitated uptake in the past.¹⁶

Increasing the uptake of pertussis vaccine among Traveller Gypsies could prove difficult, as its rejection may have become part of the symbolic boundary distinguishing Traveller Gypsies and settled people. As described by Okley¹ this boundary consists of pollution taboos and other beliefs which allow Traveller Gypsies to define themselves as separate and different from the dominant society.

In this study over two thirds of Traveller Gypsy children had the first diphtheria/tetanus and poliomyelitis vaccines. Their parents, thus had no objections in principle to these vaccines and therefore the uptake of the first immunization in the course represents a minimum level of completion if access to immunization services were improved. The fact that completion rates for these vaccines continue to rise as Traveller Gypsy children get older supports this hypothesis. Factors which reduce Traveller Gypsies' access to immunizations include involuntary mobility, lack of a general practitioner and lack of information about community health services.^{2,6} These factors are not usually problems for the settled community, where parental attitude is the main determinant of immunization uptake,¹⁷ although they may be

**Figure 1.** Completion of primary tetanus (and diphtheria) and pertussis immunizations for the Traveller Gypsy and control children.

important for homeless families in bed and breakfast accommodation.¹⁸

This study was completed before the imposition of the new general practitioner contract in April 1990. There was already evidence that some general practitioners would not register Traveller Gypsy patients, even as temporary residents,¹¹ and the targets in the contract provide a further disincentive.¹⁹ Another consequence of the new contract is the removal of financial incentives to offer opportunistic immunizations to Traveller Gypsies seen as temporary residents. As a result of this study, the City and East London Family Health Services Authority has introduced an item-of-service payment to general practitioners to encourage the immunization of mobile Traveller Gypsy children who are not registered with practices.

The new structure of the health service may also have unfortunate consequences for Traveller Gypsies. Each purchasing authority is responsible for its resident population and Traveller Gypsies do not easily fit into this category. The size of the Traveller Gypsy community in any area is difficult to determine and its age structure is usually unknown,²⁰ making needs assessment and contracting problematic. The provision of specialist health visitors for Traveller Gypsies is already patchy²¹ and existing posts have already been cut. For example, in April 1992 Bloomsbury and Islington Health Authority in London withdrew its funding for a health visitor for Traveller Gypsies (personal communication).

The following recommendations can be made. Systematic outreach should bring immunization and other preventive services to caravan sites if immunization rates are to improve. Opportunistic immunizations of Traveller Gypsy children presenting to general practitioners and accident and emergency department staff with accidents or non-febrile illnesses, or of siblings accompanying an ill child should be encouraged. Parent-held records should be used to supplement parental recall of immunizations and other child health information. Family health services and district health authorities should encourage practices to register their Traveller Gypsy patients by funding specialist health visitors and compensating for any loss of income resulting from missing immunization targets. Appropriate health education material for Traveller Gypsies should be produced in collaboration with parents who have accepted these immunizations,²² taking account of cultural and literacy barriers. To date there is no appropriate material from the Health Education Authority despite its commitment to ethnic minority needs.²³

In our enthusiasm to give immunizations, we must not lose sight of the right of a parent to refuse specific vaccines for their child. Refusal to have a child immunized may be a rational choice for an individual parent, although not in the interests of Traveller Gypsies as a group.^{24,25} In the last outbreak of paralytic poliomyelitis in England and Wales, 20 of the 26 cases were among people that were not vaccinated and at least six of these were Traveller Gypsies.²⁶

References

- Okley J. *The Traveller-gypsies*. Cambridge University Press, 1983.
- Feder G. Traveller Gypsies and primary care. *J R Coll Gen Pract* 1989; **39**: 425-429.
- Linthwaite P. *Health and health care in Traveller mothers and children*. London: Save the Children Fund, 1983.
- Pahl J, Vaile M. *Health and health care among Travellers*. Canterbury: University of Kent, Health Services Research Unit, 1986.
- Walker PC. The health of Travellers [editorial]. *BMJ* 1986; **293**: 1322.
- Streetly A. Health care for Travellers: one year's experience. *BMJ* 1987; **294**: 492-494.
- Mayall D. *Gypsy-Travellers in nineteenth-century society*. Cambridge University Press, 1988. 8. in east London — adapting health visiting methods to a minority group. *Health Visitor* 1983; **56**: 26-56.
- Dodge L, Miller J, Feder G, Morrison L. *A report on the specialist health visiting service to the travelling families*. London: City and Hackney Health Authority, 1989.
- Jacobsen B, Leahy G. *Health in Hackney 1990: annual public health report on the people of the City and Hackney*. London: Department of Public Health, City and Hackney Health Authority, 1991.
- Feder G, Salkind M, Sweeny O. Traveller Gypsies and general practitioners in east London. *Health Trends* 1989; **21**: 93-94.
- McKinney PA, Alexander FE, Nicholson RA, et al. Mothers' reports of childhood vaccinations and infections and their concordance with general practitioner records. *J Public Health* 1991; **13**: 13-22.
- Scott EA. Low immunisation rates: fact or fiction. *Public Health* 1990; **104**: 275-278.
- Bhopal RS, Samin AK. Immunisation uptake of Glasgow Asian children: paradoxical benefit of communication barriers? *Community Med* 1988; **10**: 215-220.
- Liegeois JP. *School provision for Gypsy and Traveller children*. Luxembourg: Commission for European Communities, 1987.
- Lewis E. Poliomyelitis immunisation of a Gypsy colony. *Communicable Dis Rev* 1982; **18**: 4.
- Peckham C, Bradford H, Senturia Y, Ades A. *National immunisation study: factors influencing immunisation uptake in children*. London: Action Research for the Crippled Child, 1989.
- Conway J (ed). *Prescription for poor health: the health crisis for homeless families*. London: London Food Commission, Maternity Alliance, SAC, Shelter, 1988.
- Anonymous. Gypsy mistrust of jabs hits GP targets. *Guardian* 1990; 2 August.
- Green H. *Counting Gypsies*. London: HMSO, 1991.
- Hussey RM. Travellers and preventive health care. *BMJ* 1988; **296**: 1098.
- McGuire C. Accounting for public perceptions in the development of a childhood immunisation campaign. *Health Educ J* 1990; **49**: 105-107.
- Health Education Authority. *Health Education for the ethnic minorities*. London: HEA, 1990.
- Brock D, Wartman S. When competent patients make irrational choices. *N Engl J Med* 1990; **332**: 1595-1599.
- Anderson RM, Rober RM. Immunisation and herd immunity. *Lancet* 1990; **335**: 641-645.
- Collingham KE, Pollock TM, Roebuck MO. Paralytic poliomyelitis in England and Wales 1976-77. *Lancet* 1978; **1**: 976-977.

Acknowledgements

GF and TV were funded by the North East Thames Regional Health Authority. We thank the general practitioners and practice staff of Lower Clapton and Well Street group practices, the nurses of the Queen Elizabeth Hospital accident and emergency department and the Traveller Gypsies who encouraged us during the study. We are also grateful to Howard Cuckle, Jan Savage, Sue Jenkins and the *Journal's* anonymous statistical referee.

Address for correspondence

Dr G Feder, Academic Department of General Practice and Primary Care, Medical Colleges of St Bartholomew's and the London Hospitals, 2nd Floor New Science Block, Charterhouse Square, London EC1M 6BQ.

RCGP Publications RECENT TITLES

Clinical guidelines: report of a local initiative (Occasional Paper 58)

Extensively revised to make them widely applicable, the Islington Guidelines give 15 sets of guidelines on common medical conditions and preventive care. These will provide a useful starting point and act as a stimulus for the development of clinical protocols in general practice. £11.00

Health checks for people aged 75 and over (Occasional Paper 59)

Starting with a comprehensive introduction, this document presents a practical three-stage approach for primary health care teams offering health checks for people over 75. It represents the latest step in the battle to raise standards of care for one of the most vulnerable age groups in the population. £9.00

The above can be obtained from the Sales Office, Royal College of General Practitioners, 14 Princes Gate, London SW7 1PU. (Enquires, Tel: 071-823 9698)