Parents' views of health surveillance

J C Sutton, C Jagger, L K Smith

Abstract

The aim of the study was to discover the views of parents about the 1991 Leicestershire child health surveillance programme, its organisation, and content. The study design was a postal questionnaire survey to parents of a sample of children eligible for the new surveillance programme. One thousand parents received questionnaires, of which 66% (660) were returned.

Poor access for prams and wheelchairs (595 responses) and inadequate general cleanliness (249 responses) caused most criticism of clinic premises. The experiences of parents from ethnic minorities were significantly worse for some professional consultation factors, but they received significantly more health advice than other parents. Parents lacked sufficient information about the surveillance programme and their most frequent reasons for non-attendance were time related factors.

Minimum standards for child health surveillance premises are required. At present, many fail to reach adequate standards of privacy and accessibility. Schemes to ensure an equal partnership in child health surveillance between parents and professionals are essential.

(*Arch Dis Child* 1995; 73: 57-61)

Keywords: parents' views, health surveillance, clinic premises, consultation skills.

During the 1980s, several authors highlighted great diversity in the standards and delivery of child health services throughout the country¹⁻⁴ and, in 1989, a critical review by Butler found no evidence of improvement to the health status of children as a result of existing child health surveillance programmes.⁵ The 1989 report of the joint working party on child health surveillance emphasised the need for a close equal partnership between parents and professionals and recommended a core programme.⁶ It described child health surveillance as having three purposes: (a) the prevention of disease, (b) the early detection of problems affecting growth and development, and (c) the positive promotion of health.

In 1991, Hall's recommendations were incorporated into a new Leicestershire child health surveillance programme.⁷ In 1992, a local multidisciplinary working group was established to evaluate the new programme. Two key factors in the success of a programme are its accessibility and acceptability to users⁸ so this parental survey (which was just one component of a larger evaluation project) was

developed. It aimed to investigate parents' views on the organisation of child health surveillance, the content of the programme, and any reasons for non-attendance. Evaluation of the personal child health record was undertaken as a separate project⁹ and is not therefore reported here.

Methods

PLANNING

Permission was given by the local ethics committee to carry out the study.

SAMPLE

Leicestershire has a population of nearly 900 000 and over 12 000 births annually. Leicester (the city) is the only major urban centre and is surrounded by rural areas, interspersed with market towns (the county). There is a large south Asian minority (77 500 people), 83% of whom live in Leicester. Children between 0 and 5 years (45 595) were registered for the surveillance programme with either general practitioners (GPs) (35 029=77%) or clinical medical officers (CMOs) (10 566=23%) of the Fosse Health Trust (formerly community unit).

A weighted randomised sample of 1000 children was selected in four groups, to ensure adequate representation of the Asian and CMO clinic minorities, while recognising that more than half the 0-5 year age group were registered with 'county' GPs for surveillance (24 053). The sample was: (a) city CMO clinics, 200; (b) county CMO clinics, 200; (c) city GP clinics, 200; (d) county GP clinics, 400. The children were born between 1 April 1991 and 30 September 1991, that is, immediately after the start of the new child health surveillance programme. At the time of the study, they were aged from 18 months to 2 years and had been eligible for surveillance checks at 6 weeks, 8 months, and 18 months of age. Interim health visitor clinics and immunisation visits were also programmed to take place.

DATA COLLECTION

Over simplified satisfaction questions were avoided, due to the problems of definition and measurement of dissatisfaction,¹⁰ the reported high levels of assent,¹¹ and the non-specific nature of the concept of satisfaction.¹²

Questionnaire survey was chosen to maximise the number of potential participants (as compared with interview survey, despite the risk of lower response rates). Postal questionnaire was selected in preference to distribution at child health surveillance clinics so that: (a) non-attenders would not be excluded, (b) the

Department of Public Health Medicine, Leicestershire Health, Gwendolen Road, Leicester LE1 4QF
J C Sutton

Department of Epidemiology and Public Health, Faculty of Medicine, University of Leicester
C Jagger

Department of Ophthalmology, Faculty of Medicine, University of Leicester
L K Smith

Correspondence to: Dr Sutton.

Accepted 14 March 1995

participants could feel less inhibited with their responses at home than in the presence of clinic staff,¹³ and (c) the risk of parents seeking assistance from surveillance staff to complete the questionnaires was reduced.

After a pilot study, all parents participating in the main study received an explanatory letter with the first mail and non-responders were sent up to two reminders. To overcome any language barriers of Asian parents, the reminders included five Asian language invitations to request translated questionnaires, if required.

Results

RESPONSE RATES

The overall response rate was 66% (660 responses) but this was unevenly distributed between city, 55% (221) and county, 73% (439), respondents. Unconditional logistic regression was used to investigate the response rate in 986 children with up to date postcodes. This showed evidence of interaction between deprivation (measured by Townsend deprivation index for enumeration district¹⁴) and race ($p=0.06$). Forename and surname were used to ascribe Asian and non-Asian origin, as recommended by Nicoll *et al.*¹⁵ Among non-Asians there was a significant trend with deprivation, with those from the most deprived areas having a lower response rate (49%) compared with those from the least deprived areas (81%). Asians showed less of a trend with deprivation. They had a similar response rate to non-Asians in the most deprived areas (49%) but in the least deprived areas the response rate was much lower than non-Asians (61%). However, as the Asian groups were smaller (particularly affluent Asians), the rates should be viewed with some caution. After accounting for deprivation and race, there was no significant difference between the four sampled groups.

FAMILY DETAILS

One or both parents completed the questionnaire in 657 cases (99.5%), while three (0.5%) were completed by other carers. Parents self reported ethnic origin (656 responses): 83% were white (543), 15% south Asian (100), and others 2% (13). English was the first language of 87% (573) of respondents.

CLINIC ACCESSIBILITY

From 649 responses, 60% (389) lived within 1 mile of the clinic, 38% (247) lived 1–5 miles away, and 2% (13) lived over 5 miles distant.

Travel to the child health surveillance clinic ($n=656$) often required more than one form of transport and so totals exceed 100%. Most used their own resources: on foot, 52.3% (343), or in their own car, 48.2% (316); a few went by bus, 6.9% (45), had a lift, 2.4% (16), took a taxi, 1.1% (7), or travelled by other means, 1.4% (9).

CLINICAL FACILITIES

Clinic access for prams and wheelchairs was a notable problem for many parents. Our of 618 responses, 17.5% (108) said that clinic entrances were unsuitable. Responses about access within the building ($n=648$) included the comments that prams were not permitted inside, 23.3% (177); there were narrow doorways, 12.5% (81); floors on different levels, 10.5% (68); narrow passages, 6.9% (45); blocked passages, 6.9% (45); and unspecified problems with prams, 11% (71). This totalled 595 complaints about pram and wheelchair access.

Responses about clinic play facilities ($n=589$) were mostly favourable but a minority said that there was no provision (31.9%; 188) or that they were unsafe (7%; 41) – for example, sited at the top of unguarded stairs or near open doorways.

Responses on general clinic hygiene ($n=644$) showed that 38.3% (249) of parents thought cleanliness fell short of 'good' on a four point scale. This was a greater problem at CMO clinics than GP clinics where 50% and 31.8%, respectively were less than good. The difference reached statistical significance (χ^2 , $p<0.000$).

PROFESSIONAL CONSULTATIONS

Parents were asked if provision was made for their privacy during consultations. Sound privacy was better with doctors ($n=631$), as 90% (570) of parents were satisfied, than for health visitors ($n=637$) with 65.5% (417) of parents being satisfied. Similarly, doctors were better equipped in respect of visual privacy in their consulting rooms ($n=620$) with 92.6% (574) of parents satisfied, than health visitors ($n=610$) with 67.2% (410) of parents satisfied. The differences between doctors and health visitors were significant (χ^2 , $p<0.0001$ for both types of privacy). Privacy was more poorly catered for in CMO clinics but was not significantly worse than GP clinics.

The majority of parents thought consultation times were adequate with both doctors (87.6%, that is 553 of 631 responses) and health visitors (88.8%, that is 564 of 635 responses).

Parents were asked about three aspects of their child health surveillance consultations with the doctor and health visitor as: (a) listeners, (b) explainers, and (c) health advisors.

(a) Listeners

Over half the parents reported lack of attention at some time, to their concerns about their

Table 1 Doctors' and health visitors' attention to views and concerns by ethnicity; figures are number (%)

	Doctors		Health visitors	
	Ethnic minority	White population	Ethnic minority	White population
'Should take more notice'				
Always	19 (17.0)	27 (5.1)	28 (24.3)	29 (5.5)
Usually	26 (23.2)	36 (6.9)	22 (19.1)	34 (6.4)
Sometimes	44 (39.3)	219 (42.0)	40 (34.8)	195 (37.1)
Subtotal	89 (79.5)	282 (54.0)	90 (78.2)	258 (49.0)
Never inattentive	23 (20.5)	240 (46.0)	25 (21.8)	268 (51.0)
Total	112 (100)	522 (100)	115 (100)	526 (100)

Table 2 Doctors' and health visitors' explanations about child's progress by ethnicity; figures are number (%)

Explanations unclear	Doctors		Health visitors	
	Ethnic minority	White population	Ethnic minority	White population
Always	5 (4.4)	16 (3.0)	10 (8.8)	15 (2.8)
Usually	7 (6.2)	21 (4.0)	8 (7.1)	24 (4.5)
Sometimes	51 (45.2)	180 (34.2)	43 (38.1)	153 (28.9)
Subtotal	63 (55.8)	217 (41.2)	61 (54.0)	192 (36.2)
Never unclear	50 (44.2)	310 (58.8)	52 (46.0)	338 (63.8)
Total	113 (100)	527 (100)	113 (100)	530 (100)

child both from doctors, 58.5% (371 of 634 responses) and health visitors, 54.3% (348 of 641 responses). However, table 1 shows that the problem was greater for people from ethnic minorities. The differences were statistically highly significant for both doctors and health visitors (χ^2 , $p < 0.00001$ for both groups).

(b) Explainers

Parents were asked if the explanations offered about their child's health and development were ever unclear. Parents' responses about doctors ($n=640$) showed that 43.8% (280) were unhappy with the explanation on some occasion(s). Responses about health visitors' explanations ($n=643$) showed 39.3% (253) were not completely satisfied. Parents from the ethnic minorities experienced greater problems in this respect (table 2). The differences reached significance for the doctors (χ^2 , $p=0.04$) and health visitors (χ^2 , $p=0.0006$).

(c) Health advisors

Respondents were asked whether health promotion and advice had been included in their child health surveillance consultations. Over half, 55.3% (349), of the responses about doctors ($n=631$) and nearly one third, 31.1% (199) of the responses about health visitors ($n=640$) said such advice had never been offered. Parents from the ethnic minorities were offered health advice significantly more often than the white population, both by doctors (χ^2 , $p < 0.0001$) and by health visitors (χ^2 , $p=0.03$) (table 3).

HEALTH LITERATURE AND INFORMATION

A copy of the Leicestershire child health surveillance programme book⁷ is kept in each clinic, primarily for staff reference. As parents were not provided with any information about child health surveillance, they were asked if the surveillance book had been made available, if

Table 4 Benefits to parents of child health surveillance clinics ($n=576$)

	No (%) of responders
Immunisations	437 (75.9)
Discussion with health visitor	392 (68.1)
Doctor examination for anomalies	377 (65.5)
Hearing tests	335 (58.2)
Weight check	304 (52.8)
Eye tests	281 (48.8)
Discussion with doctor	253 (43.9)
Height check	87 (15.1)
Health promotion advice	48 (8.3)
Contact with other children	38 (6.6)
Contact with other parents	38 (6.6)
Health promotion displays	19 (3.3)
Other benefits	26 (4.5)

they wished to see it. Parents' responses ($n=657$) showed that just 3% (20) had been made aware of the book.

Parents' views on health promotion literature in the child health surveillance clinic ($n=585$) were that 79% (462) found it of some help, 17.1% (100) found it little or no help, and 3.9% (23) said none was available. No difference in views, by ethnicity, was found.

CLINIC BENEFITS

Parents were asked to select up to five aspects of child health surveillance, from a list of 13 factors, which they found to be the most beneficial (table 4). The responses of parents who selected more than five options (72 cases) (despite a satisfactory response in the pilot study and clear instructions), were excluded to avoid bias. Most results showed preference for 'measurable' benefits (for example, tests, checks, and immunisations), in preference to the 'unmeasurable' ones (for example, contact with other families and health promotion), although the less quantifiable benefits of professional discussions were also highly valued.

MISSED APPOINTMENTS

Reasons given by parents for 'deliberate' previous child health surveillance non-attendance were divided into four groups: (a) time related factors, (b) financial factors, (c) unsatisfactory surveillance facilities, and (d) staff factors (table 5). Unplanned missed appointments, due to illness, etc, were not included. Some gave several reasons for one missed appointment. The most

Table 5 Reasons given for previous non-attendance (total number of reasons=296)

Reasons	No (%) missed ($n=660$)
Time	
Inconvenient time	88 (13.3)
Long wait in clinic	38 (5.8)
Unspecified delays	27 (4.1)
Journey time	6 (0.9)
Subtotal=159 reasons	
Financial	
Loss of earnings	13 (2.0)
Childminder fees	7 (1.1)
Cost of journey	2 (0.3)
Other expenses	1 (0.2)
Subtotal=23 reasons	
Staff	
Administrative staff	31 (4.7)
Health visitor	29 (4.4)
Doctor	22 (3.3)
Unspecified staff	12 (1.8)
Subtotal=94 reasons	
Facilities	
Unspecified problem	20 (3.0)

Table 3 Doctors' and health visitors' advice to parents by ethnicity; figures are number (%)

Advice given	Doctors		Health visitors	
	Ethnic minority	White population	Ethnic minority	White population
Always	17 (15.0)	29 (5.6)	20 (17.5)	48 (9.1)
Usually	16 (14.2)	37 (7.1)	20 (17.5)	75 (14.3)
Sometimes	33 (29.2)	150 (29.0)	41 (36.0)	237 (45.1)
Subtotal	66 (58.4)	216 (41.7)	81 (71.0)	360 (68.5)
No advice given	47 (41.6)	302 (58.3)	33 (29.0)	166 (31.5)
Total	113 (100)	518 (100)	114 (100)	526 (100)

frequent single reason given for non-attendance was the inconvenient time of the clinic (88 reasons) and time factors together were the most common (159 reasons). Staff factors together accounted for 94 responses.

PARENTS' ADDITIONAL COMMENTS

Finally, some parents offered extra comments, either expanding on previous answers or making new points. Key points are presented in four categories: (a) accessibility, (b) facilities, (c) staff, and (d) child health surveillance programme.

(a) Clinic accessibility (seven comments)

One mother did not attend because, with three young children and no prams allowed in the clinic, it was too great a problem. A disabled mother said that her request for a home surveillance appointment had been denied.

(b) Clinic facilities (61 comments)

Twenty six comments related to prams and wheelchairs in clinic and 10 comments to pram thefts outside the clinic.

(c) Clinic staff (50 comments)

Of 26 comments about individuals, 16 were positive. Other comments included: poor advice (8), absence of doctors (7), kept waiting (7), consultation too short or interrupted (2).

(d) Child health surveillance programme (26 comments)

Of these, 14 were confused about child health surveillance, 11 were negative about it, and one complained about a delayed referral.

In addition, there were approximately 25 telephone messages from parents confused about child health surveillance; they did not know the term child health surveillance, what it involved, and could not complete the questionnaires until more detailed explanations had been given.

Discussion

RESPONSE RATES

Lower response rates were closely related to lower Townsend deprivation scores (than Leicestershire as a whole), which in turn were related to Asian and non-Asian ethnicity. Responses to the survey are therefore biased towards the less deprived population. Cultural factors may have led to some non-response among more affluent Asians. However, language problems probably now play a minor part in Leicester,¹⁶ especially among younger parents, and may be the reason why few requests for translated questionnaires were received.

SURVEILLANCE AMENITIES

Problems of clinic premises and facilities was

particularly noticeable for CMO clinics, possibly related to their part time use as health premises.

Many child health surveillance clinic venues were said to fall short of the standard in the patient's charter,¹⁷ which states that premises should be accessible for use 'by everyone, including children and people with special needs ... by ensuring that buildings can be used by people in wheelchairs'. Also, privacy was inadequate, according to the charter, especially in the case of health visitor consultations. The development of a code of minimum standards for surveillance clinic premises (to include safety, hygiene, and facilities) and enforced in contracts, could help to address these problems.

SURVEILLANCE CONSULTATIONS

Many parents made no negative comments about their child health surveillance consultations. However, parents from ethnic minorities were more affected by poor explanations and inattention than the white majority. Listening skills were particularly poor, which confirmed the results of an earlier study among the parents of preschool children with special needs.¹⁸

Although a large proportion of parents said they had never received advice at the surveillance clinic, the need for such advice and the presentation of such advice, 'disguised' within a wider discussion, could have varied between individual families and professionals. The fact that white parents were given significantly less health advice about their child than ethnic minority parents, should alert staff to the risk of overlooking the needs of those who superficially appear to have less need of support. Relatively few parents selected health promotion issues as offering greater benefits than other components of child health surveillance. This may reflect the low priority given to this by parents themselves or the professionals' own lack of commitment to health promotion matters in child health surveillance. Low response rates from the most deprived areas may have produced an underestimate of some communication problems experienced by parents with professionals, especially when there is a large cultural or social divide between them. Improved training in consultation skills for professionals should be a high priority.

SURVEILLANCE NON-ATTENDANCE

Parents' confusion and lack of knowledge about child health surveillance could have (possibly) contributed to non-response among some parents and non-attendance among others, due to lack of clarity about what was involved. Reasons given by parents for non-attendance at the surveillance clinics indicated that time and staff attitudes were key factor in parents' ability (or wish) to attend. For a few, time and money were linked.

PARENTAL/PROFESSIONAL PARTNERSHIP

To facilitate improvements in the service and

to go beyond the rhetoric of an equal parental/professional partnership in child health surveillance, mechanisms for an exchange of views and information should be developed. Written information on the nature and content of the child health surveillance programme could be included as additional pages in the personal child health record, which could be updated, as necessary. Easily accessible, non-threatening systems should be put in place, to answer queries and to encourage parental feedback on child health surveillance. There are several ways in which this might be achieved. For example, Gillam and Colver advocated regular users' surveys to acknowledge 'parental sovereignty'.¹⁹ There should be at least one parent member on surveillance committees or monitoring groups, according to suitable local selection mechanisms. Contact points (parent and/or provider representative) for information, queries, and feedback should be readily identified in the pages of the personal child health record. It is important that the procedure remains simple and reliable, so that the input of parents does not get lost or neglected.

Conclusion

Although it would be impossible to provide child health surveillance to suit all individuals, most parents invest much energy in ensuring that their child attends surveillance appointments. It is essential that these parents (and those who do not attend but are constantly reminded that they should) should not be persuaded to participate in a scheme that is of little relevance or benefit to them.

There is no evidence in the literature to indicate if, or how, the experiences of Leicestershire parents differ from those of parents elsewhere. However, this study highlights the need for parental input, alongside professionals, if child health surveillance is to achieve its aims. The future service will then be shaped more closely around the

health needs and health gains of tomorrow's adults.

Many colleagues have kindly given their advice and assistance but thanks are particularly due to Dr B Marshall, formerly Medical Director of Fosse Health Trust and chairperson of the Leicestershire Child Health Surveillance Evaluation Group; Dr G Morgan, formerly Director of Public Health, Leicestershire Health; and members of the evaluation group. Material from crown copyright records was made available through the post office and the ESRC data archive.

- 1 World Health Organisation. *Early detection of handicap in children*. Report of a working group. Geneva: WHO, 1981.
- 2 Macfarlane JA, Pillay U. Who does what, and how much in the preschool child health services in England. *BMJ* 1984; **289**: 851-2.
- 3 Colver AF, Steiner H. Health surveillance of preschool children. *BMJ* 1986; **293**: 258-60.
- 4 Stewart-Brown S, Haslum MN. Screening for hearing loss in childhood: a study of national practice. *BMJ* 1987; **294**: 1386-8.
- 5 Butler J. *Child health surveillance in primary care: a critical review*. London: HMSO, 1989.
- 6 Hall DMB, ed. *Health for all children. A programme for child health surveillance*. The report of the joint working party on child health surveillance. 1st Ed. Oxford: Oxford University Press, 1989.
- 7 Leicestershire Health Authority. *Leicestershire Health Authority child health surveillance programme*. Leicester: Leicestershire Health Authority, 1991.
- 8 Carr-Hill RA. The measurement of patient satisfaction. *J Public Health Med* 1992; **14**: 236-49.
- 9 Tamhne R. An audit of the parent held child record in Leicestershire. In: Saffin K, ed. *Where now?—What next? The personal child health record*. (Proceedings of a national meeting, Oxford 14 September 1994.) Oxford: Oxfordshire Community NHS Trust, 1995.
- 10 Locker D, Dunt P. Theoretical and methodological issues in sociological studies of consumer satisfaction with medical care. *Soc Sci Med* 1978; **12**: 283-92.
- 11 Raphael W. *Old people in hospital*. London: King's Fund, 1979.
- 12 Sutherland HK, Lockwood GA, Minkin S, et al. Measuring satisfaction with health care: a comparison of single with paired rating strategies. *Soc Sci Med* 1989; **28**: 53-8.
- 13 Carr-Hill RA, Humphreys KI, McIver S. *Wolverhampton: a picture of health*. York: Centre for Health Economics, 1987 (mimeograph).
- 14 Townsend P, Phillimore P, Beattie A. *Inequality and the north*. London, Croom Helm, 1988.
- 15 Nicholl A, Bassett K, Ulijaszek SJ. What's in a name? Accuracy of using surnames and forenames in ascribing Asian ethnic identity in English populations. *J Epidemiol Community Health* 1986; **40**: 364-8.
- 16 Rashid A, Jagger C. Attitudes to and perceived use of health care services among Asian and non-Asian patients in Leicester. *Br J Gen Pract* 1992; **42** (May): 197-201.
- 17 Department of Health. *The patient's charter*. London: HMSO, 1991.
- 18 Stallard P, Lenton S. How satisfied are parents of preschool children who have special needs with the services they have received? A consumer survey. *Child Care Health Dev* 1992; **18**: 197-305.
- 19 Gillam SJ, Colver AF. Preschool child health surveillance. *Quality in Health Care* 1993; **2**: 129-33.