LETTERS TO THE EDITOR

Parent initiated and conventional preschool health surveillance

EDITOR,—I am worried by the article by John Dearlove and Su Illingworth.[1] The topic is interesting for community paediatricians when many believe the routine checks of the child health surveillance (CHS) programme need justification if they are to continue. Good research to answer the question of whether parental concern is as good as regular professional contact in identifying abnormalities is urgently needed.

This study sample of 538 babies is small. Babies were randomised by practice, making this a cluster randomised trial. The sample size needed to give enough power to detect true differences between the groups runs into several thousands. In addition, 234 mothers (43% of the initial sample) were lost by the end of the first year. The numbers randomised to each group at the outset are not given. It is clear however that the study intervention was implemented in only 45 cases, 8% of the original sample.

Neither mothers nor health visitors were keen on mothers making their own appointments. Those mothers who did not comply with the intervention said they found routine appointments more convenient. Anecdotal evidence suggests that health visitors undermined the intervention. It would have been prudent to seek health visitors' views formally as part of the study.

A small study in Northampton (unpublished data) suggests that the CHS programme leads to identification of complex developmental problems in two ways. In a third of cases, the professional alone identifies the abnormality. In another third, the parent identifies it. In half those cases parents used the routine CHS check to raise their concern. In the other half, they raised concern outside the routine programme.

This paper's conclusion is not proven because of small sample size and failure to implement the study intervention. Mothers and health visitors appear to value routine professional contact within a CHS programme. Our local evidence supports that view. More research is needed.

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1 Dearlove J, Illingworth S. A controlled trial of parent initiated and conventional preschool health surveillance using personal child health records. *Arch Dis Child* 1999;**80**:507–10.

Dr Dearlove and Mrs Illingworth comment:

Your correspondent is wrong in thinking that 43% of our sample was lost to follow up. They just did not turn up for their clinic appointments. However, what happened to them is as follows: of the 116 mother/child pairs in our parent initiated surveillance group who did not turn up for their clinic appointments, three possible abnormalities were missed when reviewing their hospital notes at the age of about 3. None of these screening abnormalities needed treatment. In the 118 controls who did not turn up for their appointments, two orthoptic abnormalities were missed (again neither needing treatment).

By the age of 5, two children from each group of non-attenders needed educational psychology involvement at school. This compares to 10 of 163 in the parent initiated group and three of 107 in the control group.

These results suggest that your correspondent is correct in as much as parents voice their concerns to health visitors, not because of a structured child health surveillance programme but probably because the health visitor, speech therapist, or even the occasional GP, are available to listen. As to who identifies complex disabilities, our results[1] are different from those suggested by your correspondent. However the point of our paper was not to deprecate child health surveillance, which may well be very popular with some parents, but rather to illustrate how hard it is to change entrenched views; and secondly to try to measure the value of routine professional contact within the child health surveillance programme. The major effect of the latter was to disempower parents.

1 Dearlove J, Kerney D. How good is general practice developmental screening? *BMJ* 1990; **300**:1177–80.

Covert video surveillance

EDITOR,—Shabde and Craft[1] have misunderstood several issues addressed by Foreman and Farsides.[2] Consequently, they make recommendations that could lead to children being exposed to unnecessary risk.

The biggest ethical difficulty in covert video surveillance (CVS) is not that of breach of trust. It is the risk of harm to the child, who becomes a tethered goat, set to catch a tiger. These risks are not small.[3] This makes CVS an investigation of last resort, as the "double effect" defence preferred by Shabde and Craft implies. Breach of trust is important to the extent that one must have good reason to break trust. Foreman and Farsides first demonstrated that this criterion was effectively the same as the burden of proof for action under The Children Act.[4] Therefore, all cases for which CVS may be justified can also be referred to court. Secondly, medical expertise lies primarily in securing children's health, while children's welfare determines protection issues. So doctors, while being important participants in the process, cannot claim a privileged position in determining the outcome of child protection procedures.

Shabde and Craft recommend that CVS be used to ensure that court action is sufficient to protect the child. The Children Act makes protection of the child of paramount importance to the court. Shabde and Craft do not know whether (a) the court will take the same view as themselves, or (b) whether the court will be incorrect if it takes a different view. Clearly, successful court disposal is safer than CVS, and must be preferred as a first choice. Of course, courts are not always right. Foreman and Farsides agreed that CVS was ethical in restricted circumstances. If there was good reason to think that a court disposal was failing to protect the child, CVS might *then* be ethical to obtain the evidence needed for additional action.

Finally, Shabde and Craft persist in the error of calling CVS a diagnostic investigation, when in fact it is a forensic investigation used to detect a crime. Doctors merely administer it. This leads them to claim that CVS might be used to "prevent the separation of children from innocent parents". All a negative finding shows is that no offence was recorded while the cameras were running. In these circumstances, CVS may be providing no more than a false sense of security.

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1 Shabde N, Craft A. Covert video surveillance: an important investigative tool or breach of trust? *Arch Dis Child* 1999;**81**:291–4.
2 Foreman D, Farsides C. Ethical use of covert video techniques in detecting Munchausen syndrome by proxy. *BMJ* 1993;**307**:611–13.
3 Southall DP, Plunkett MC, Banks MW, Falkov AF, Samuels MP. Covert video recordings of life-threatening child abuse: lessons for child protection. *Pediatrics* 1997;**100**:735–60.
4 The Children Act. London: HMSO, 1989.

Dr Shabde and Dr Craft comment:

We would like to reply to Dr Foreman's comments. He seems to have misunderstood the thrust of our arguments for and against CVS.

We believe that if operated under a strict and rigorous multiagency protocol, the risk to the child undergoing CVS is minimal. Southall *et al* demonstrated justifiable use of CVS for investigation of an apparent life threatening event in their series where abuse was revealed in 33 with attempted suffocation in 30 patients.

It has been suggested that The Children Act 1989 alone is sufficient to protect children with possible induced illness syndrome. It must be recognised that although there may be enough grounds for legal proceedings, courts may decide to make a supervision order or no order at all, unless an appreciable level of risk is shown and the child may be returned to his or her parents to face the same risk. We do not agree that if there was good reason to think that a court disposal was failing to protect the child, CVS might then be ethical to obtain the evidence needed for additional actions. Surely this is then too late.

Of course a negative finding on CVS shows that no offence was recorded while the camera was running but we strongly contend that CVS needs to be available as an investigative and assessment tool (not merely a diagnostic tool) that can be used for some forms of factitious/induced illness syndrome where there is serious risk of life threatening abuse. We reiterate that it must only be done in the context of adequate child protection procedures which include full child and family assessment, and that staff must be properly trained.

Recommendations for the management of galactosaemia

EDITOR,—Drs Garden and Davidson raise some very important points concerning the best oestrogen preparation for long term replacement in ovarian failure.[1] Their comments are principally directed at oestrogen replacement during adulthood rather than pubertal induction. The latter is most easily effected using ethinyl oestradiol, because suitable low dose preparations are available so that puberty can be induced gradually over several years. The issue of which oestrogen

preparation should be used for long term replacement in patients with hypogonadism is relevant not only to girls with galactosaemia but also to those with Turner's syndrome and hypopituitarism. The recommendation to use a combined oral contraceptive preparation in a young woman who has completed pubertal induction is based on practicality and convenience to the user.

The problem when choosing an oestrogen preparation once full pubertal development has been achieved is that there is a paucity of evidence to inform decision making. Although empirical dose equivalents of ethinyl oestradiol versus conjugated oestrogen or natural oestrogen are available, these values have not necessarily been defined on criteria such as the efficacy in maintaining secondary sexual development or in inducing acquisition of bone mass rather than prevention of osteoporosis. Development of peak bone mass will be very important to women in their late teens or early 20s.

It is clear that randomised studies of different oestrogen preparations in young women who have been induced through puberty are a priority. Until results are available, then either a combined oral contraceptive preparation or a hormone replacement treatment would be acceptable.

1 Garden AS, Davidson DC. Recommendations for the management of galactosaemia [letter]. *Arch Dis Child* 2000;**83**:266.

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Infanticide or SIDS, double jeopardy

A recent article by Meadow[1] documented some clinical features of 81 cases of infanticide in an attempt to identify particular features that might help. Paediatricians differentiate between natural and unnatural infant deaths.[1] In table 1 we have documented the prevalence of some of these features, highlighted by Meadow's study, in a contemporary SIDS database (165 cases of SIDS that occurred in the Republic of Ireland between 1994 and 1997) to give paediatricians, pathologists, and coroners, information to assist them in making a judgment on the likely cause of death.

Several features highlighted by Meadow's study as possibly raising suspicions of infanticide are either very common in SIDS (death in the first 7 months, 91%) or, while less common in SIDS than infanticide, are sufficiently common to negate their use as markers of infanticide. These include no previous live healthy child (26%), time of death 1100–2200 (22%), an interval of <2 hours from last been seen and found dead (30%). Blood was found in the mouth, nose, or face in 32/122 cases of SIDS. However, the question did not distinguish between blood stained froth or frank blood and needs to be more rigorously framed in future. Death of a previous child and previous apnoeic episodes or apparent life threatening events were uncommon events in the SIDS group. These situations will undoubtably raise concerns in the future.

Although we are unable to address all the issues raised in Meadow's paper we agree that the way forward must be a thorough investigation of all sudden unexpected infant deaths by professionals experienced in this area, including paediatricians and paediatric pathologists. Anything less will allow the present situation of double jeopardy to continue, with cases of infanticide remaining undiagnosed and, increasingly, many newly bereaved SIDS parents wrongly suspected of fatal child abuse.

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1 Meadow R. Unnatural sudden infant death. *Arch Dis Child* 1999;**80**:7–14.

Table 1 A comparison of frequencies of certain features (identified by the Meadow study) in Irish SIDS (1994–1997) versus the Meadow cases

Features identified to help differentiate between natural and unnatural deaths	*SIDS*	*1994–1997*	*Meadow*	*cases*
	%	*No*	*%*	*No*
No previous live child	26	39/150	72	36/50
Death of a previous child	5	6/126	48	24/50
Died in 1st 7 months of life	91	150/165	69	56/81
Time of death 1100–2200	22	27/124	73	55/75
Interval between last seen and found dead (h)				
<2	30	36/121	85	55/65
2–<6	44	53/121	8	5/65
6–12	26	32/121	8	5/65
Blood in mouth, nose, face	26	32/122	39	27/70
Previous apnoeic episodes	4	5/125	61	46/75
Previous ALTEs	2	2/125	36	27/75
Previous hospital admissions mainly due to intercurrent illness	11	14/125	56	43/77

ALTEs = apparent life threatening events.

Vagal nerve stimulation for epilepsy

EDITOR,—It is timely that "Archivist" has taken an interest in vagal nerve stimulation for epilepsy. The comments do not suggest however that Archivist was fully informed.

It is true to say that the mechanism by which the effect is achieved is not known, but there is considerable animal evidence that both serotoninergic and noradrenergic pathways from afferent vagus terminations to the thalamus are involved.[1]

It is also true to say that data on efficacy in children have not been controlled. While one of the multinational trials compared low versus high stimulation,[2–4] it is not possible to design a fully controlled trial for a treatment which involves a surgical procedure and in which the patient is aware of stimulation.

Archivist rightly emphasises that the most important question is whether the children were better off for the intervention. We have attempted to answer this question in a study of children with epileptic encephalopathy in which outcome measures included not only seizure frequency, but also cognitive function and quality of life measures.[5 6] At two years, there was a median seizure reduction of 43% with five of 15 children achieving a more than 60% reduction in seizure frequency and a further three, a 40% to 60% reduction. Adaptive behaviour (a measure of learning) was unchanged, although verbal skills significantly improved in six more able children. Quality of life measures did not improve in most areas except in perceived treatment side effects and general behaviour at one year. All but two families were pleased that the children had had this form of treatment. The reason for this was that all children without exception were more alert, happier, and more interested in interacting.

The three year results are less encouraging with regard to seizure control. The effects on affect and behaviour have been sustained. We are currently investigating the possible causes for relative loss of seizure control. Meanwhile, I would suggest that the subject has evolved considerably further than cerebellar stimulation did some 25 years ago.

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1 Schachter C, Saper CB. Vagus nerve stimulation. *Epilepsia* 1998;**39**:677–86.
2 Ben-Menachem E, Manon-Espaillat R, Ristanovic R, *et al*. Vagus nerve stimulation for treatment of partial seizures: 1. A controlled study of effect on seizures. *Epilepsia* 1994;**35**: 616–26.
3 Ramsay RE, Uthman BM, Augustinsson LE, *et al*. Vagus nerve stimulation for treatment of partial seizures: 2. Safety, side effects, and tolerability. *Epilepsia* 1994;**35**:627–36.
4 George R, Salinsky M, Kuzniecky R, *et al*. Vagus nerve stimulation for treatment of partial seizures: 3. Long term follow up on first sixty seven patients exiting a controlled study. *Epilepsia* 1994;**35**:637–43.
5 Parker APJ, Polkey CE, Binnie CD, *et al*. Vagal nerve stimulation in epileptic encephalopathies. *Pediatrics* 1999;**103**:778–81.
6 Irwin KZ, Rankin P, Parker APJ, *et al*. Vagal nerve stimulation in epileptic encephalopathies: Addendum. *Pediatrics* 1999; **103**:782.

Prognosis for vesicoureteric reflux

EDITOR,—Dr Verrier Jones speaks for all of us in her concluding sentence "The outcome of the systematic review of management of VUR is awaited with interest".[1]

However, while we await the outcome, does she infer that invasive imaging is not indicated in the afebrile child with a first simple UTI after 2 years of age?

Similarly is antibiotic prophylaxis not necessary for these children?

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1 Verrier Jones K. Prognosis for vesicoureteric reflux. *Arch Dis Child* 1999;**81**:287–94.

Dr Verrier Jones comments:

The investigation of children after recovery from the presenting urinary tract infection (UTI) is a form of screening and should therefore be examined according to the WHO criteria for a worthwhile screening programme.[1]

(1) *The condition sought should be an important health hazard*. Recommended imaging tests aim to identify obstruction, vesicoureteric reflux, and renal scarring. All these conditions are potentially serious. *Condition fulfilled.*
(2) *A latent phase of the condition must be recognised by a simple, acceptable test.* While ultrasound can fulfil this requirement, isotope scans are more invasive and less acceptable. Micturating cystography is universally disliked by children[2] and parents and is only acceptable in special, high risk situations. *Condition not fulfilled.*
(3) *The natural history must be understood and beneficial effects of treatment must have been established*. Some children with renal scarring and a few children without scarring will develop new scars if further UTIs develop, particularly if there is a delay in starting treatment, if the child is very young, and if there is high grade reflux. However, neither long term low dose prophylaxis nor surgery have been shown to influence the development of new scars.[3] *Condition not fulfilled.*
(4) *The cost of case finding and treatment must be economically balanced against the expenditure*. Stark has expressed doubt about the cost effectiveness of imaging investigations in children following UTIs in childhood.[4] *Condition not fulfilled.*

Three of the four criteria for a successful screening programme are not fulfilled for vesicoureteric reflux and renal scarring. The natural history of obstruction is for deteriorating renal function and a risk of severe UTIs. Obstruction can be readily identified by ultrasound. Relief of obstruction is an agreed form of treatment. Thus screening for obstruction using ultrasound may fulfil the criteria for screening.

There is evidence that UTIs in children under 2 years of age are under diagnosed in primary care.[5] If we believe that scars are acquired and preventable then it would be better to put more effort into detecting UTIs in children under 2 years and ensuring prompt, appropriate treatment.

Prophylaxis has been shown to decrease the risk of recurrent infection in children with normal urinary tracts.[6] We do not know if prophylaxis is superior to prompt treatment of new infections in the prevention of renal scarring.

1 Wilson JMG, Junger G. *Principles and practice of screening for disease*. Public Health Papers No. 34. Geneva: WHO, 1968.
2 Chambers T. Commentary on article by H Stark. An essay on the consequences of childhood urinary tract infection. *Pediatr Nephrol* 1997;**11**:178–9.
3 Winberg J. Management of primary vesicoureteric reflux in children—operation ineffective in preventing progressive renal damage. *Infection* 1994;**22**:S4–7.
4 Stark H. Urinary tract infections in girls: the cost-effectiveness of currently recommended investigative routines. *Pediatr Nephrol* 1997;**11**:174–7.
5 van der Voort J, Edwards A, Roberts R, Verrier Jones K. The struggle to diagnose UTI in children under two in primary care. *Fam Pract* 1997;**14**:44–8.
6 Smellie JM, Katz G, Gruneberg RN. Controlled trial of prophylactic treatment in childhood urinary tract infection. *Lancet* 1978;**ii**:175–8.

Evidence in favour of NHS Direct

EDITOR,—In his annotation "NHS Direct: here and now",[1] McLellan raises questions about the new service and highlights some of the criticisms levelled against it.[2] We would like to offer some evidence in favour of NHS Direct.

Initial analysis of call volumes and caller awareness for NHS Direct in West Yorkshire reveals an interesting fact. Of the first 27 945 calls received (April to August 1999), 3945 (15%) had heard of NHS Direct from their local Accident and Emergency (A&E) department. Fatovich *et al* have shown that the average time to deal with a telephone call for medical advice to an A&E department is 3.9 minutes (range 0.25–25 minutes).[3] To deal with 3945 such calls would take on average 15 385 minutes (256 hours). Over this five month period, this translates into a potential saving of more than six working weeks (assuming a working week of 40 hours) for A&E services across West Yorkshire. Even though this calculation ignores the time needed to tell a caller to ring NHS Direct, it still represents a substantial time saving.

We wonder what the saving will be nationally as the service grows?

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1 McLellan N. NHS Direct: here and now. *Arch Dis Child* 1999;**81**:376–9.
2 Florin D, Rosen R. Evaluating NHS Direct. Early findings raise questions about expanding the service. *BMJ* 1999;**319**:5–6.
3 Fatovich DM, Jacobs IG, McCance JP, *et al*. Emergency department telephone advice. *Med J Aust* 1998;**169**:143–6.

Children of the 90s

EDITOR,—The review "Children of the 90s II: challenges for the ethics and law committee"[1] states that the study children are reaching an age when their own views and opinions will begin to eclipse those of their parents in importance. It emphasises the need to balance study benefits against research that is acceptable to the community.

Herman-Giddens *et al* have suggested that although the age of menarche has changed little in the last 45 years, the first signs of puberty are occurring earlier.[2] We designed a pilot study to look at the age of pubertal change in the UK population. The study had local research ethics committee approval. A questionnaire was sent to the parents of 160 children aged 8–18 years. Parents were asked to pass the questionnaire to their child if they were happy for them to complete it. The young people were asked to complete the questionnaire themselves to obviate any difficulties that might arise in single parent families where the parent and child were of different sexes. The respondents were asked to assess their pubertal status using a "tick the box" format in relation to line drawings.

Respondents were encouraged to return the questionnaires even if they did not want to complete them. Seventy one per cent of the questionnaires were returned but only 39% were completed overall. Comments made by parents included: "I have been unable to persuade my daughter to take part in your study. She is at an age when she is extremely self-conscious of the rather rapid changes in her body." "I find this all very fascinating and would clearly like my daughter to take part. However she is too embarrassed and refuses."

This study shows that:

- Parents may be happier about completing questionnaires about their children than the children themselves
- Children as young as 8, when given the option, may choose not to take part in a study.

The way we tried to carry out this study was unacceptable to many of our study group. Involving young people at the design stage may increase the acceptability in what is undoubtedly a difficult area to research.

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1 Mumford SE. Children of the 90s II: challenges for the ethics and law committee. *Arch Dis Child Fetal Neonatal Ed* 1999;**81**:F228–31.
2 Herman-Giddens ME, Sloan EJ, Wasserman RC, *et al*. Secondary sexual characteristics and menses in young girls seen in office practice: a study from the paediatric research in office settings network. *Pediatrics* 1997;**99**:505–12.

Economic disadvantages of palivizumab

EDITOR,—We would fully agree with Dr Sanjeev Deshpande's appraisal of the economic disadvantages of palivizumab (*Arch Dis Child* 2000;**82**:88–90) and would also suggest that the financial disincentives are indeed greater than he suggests. He bases his figures on a five month course; however, a review of our figures in Rochdale,[1] shows that there were significant numbers of confirmed cases of respiratory syncytial virus infection as early as September and as late as March in 1999. These results were not considered to be particularly atypical. It would therefore seem likely that to provide realistic "cover" for any baby considered sufficiently at risk, would require immunisations for at least seven months—a cost of £44 800.

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1 Documented cases of RSV January 1999 to January 2000 in Rochdale. Manchester Public Health Laboratory, Withington Hospital, Nell Lane, Withington, Manchester.