greater risk of acquiring HIV by sexual activity than by injecting drugs in recent years, even in known drug users, are reported elsewhere.[16]

Cherubin and Sapira's vast review of the (mainly American) published work concludes that the "natural history" of intravenous drug use includes early damaging behaviour followed in the subjects' late 20s and early 30s by attempts to quit drug use and in their late 30s and early 40s by some success in stopping. They also suggested, however, that drug use often continues beyond these decades and that "fifty and sixty year old intravenous drug users" are not rare.[23]

Our data fit in with Cherubin and Sapira's suggested pattern of behaviour and fill in some of the details of behaviour during those long decades of drug taking. They should help those interested in drug use behaviour to understand the complexity of the problem and the consequent problems in treatment and prevention. They should also prepare policy makers for a long haul ahead.[24]

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Variation in coverage by ethnic group of neonatal (Guthrie) screening programme in south London

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Abstract

***Objectives*—To determine whether coverage of the neonatal (Guthrie) screening programme in Britain is different for groups at highest risk of sickle cell disease and to identify possible reasons for incomplete coverage.**

***Design*—Descriptive study of coverage of screening programme and its variation by mobility, district of residence, and ethnic group.**

***Subjects*—1727 infants born between 1 October and 31 December 1991.**

***Setting*—Former West Lambeth and Camberwell District Health Authorities, London.**

***Main outcome measure*—Proportion of infants with an identifiable screening test result.**

***Results*—Screening covered 1663/1727 (96·3%) infants overall (745/786 (94·8%) in West Lambeth; 918/941 (97·6%) in Camberwell). The relative odds ratio of an African infant not having been tested compared with a white infant was 3·05 (95% confidence interval 1·30 to 7·14) (2·08 (0·86 to 5·01) after adjustment for mobility and district of residence). For infants whose families moved into the districts after the birth compared with those born and resident in the districts the relative odds ratio of having been tested was 10·16 (4·85 to 21·29). The odds ratio of locally delivered infants in West Lambeth not having been tested compared with those in Camberwell was 2·12 (1·08 to 4·16) after adjustment for ethnic group.**

***Conclusion*—Coverage of the screening programme is incomplete and poorer in infants of African ethnic group than in white infants. Poorer coverage is also associated with mobility of the family around the time of birth. The findings have implications for using the neonatal programme for testing for sickle cell disease and other disorders. Arrangements for monitoring the existing screening programme are inadequate and an improved system should be established, similar to the scheme that monitors the immunisation programme.**

Introduction

A screening programme to test newborn infants' blood for phenylketonuria (through the use of Guthrie cards) was established in Britain in the 1970s.[1] Testing for congenital hypothyroidism was added to the programme in 1981.[2] In some places tests for other disorders, such as cystic fibrosis and sickle cell disease, have been added. Nationally the programme seems effective in detecting affected infants, and treatment is started early.[3] Recent estimates of coverage range from 93% to 100%.[4-6] Infants at risk of not being tested include those born outside Britain; those living in inner cities; those in special care baby units; and in the United States those born at home, those who are black, those at high risk for HIV, and those with low birth weight.[7-10]

After a pilot study in east Lambeth and south

Southwark, areas covered by the former Camberwell District Health Authority, London, universal screening for sickle cell disease was proposed for the boroughs of Lambeth, Lewisham, and Southwark.[10a] The main aim of the study was to determine whether coverage of the existing programme was different for the groups at highest risk of sickle cell disease—namely, Afro-Caribbeans and Africans—in the areas covered by the former West Lambeth and Camberwell District Health Authorities.

The sample in each district was selected to detect a 5% lower coverage in the combined Afro-Caribbean and African populations if the coverage in the white population was 95% (assuming 95% significance and 90% power). A second aim was to identify possible reasons for incomplete coverage.

Methods

We determined coverage for a cohort of infants born between 1 October and 31 December 1991 who either were resident in the district at birth or had moved into the district before March 1992. We obtained data from three unlinked sources of computerised data (the national child health system, the regional laboratories database, and the EuroKing maternity information system). Information on the data items from each of the three sources of data is available on request.

We matched the first two data sets by using six common items: the infant's surname, forename, date of birth, sex, birthplace, and district of residence. For infants born in local hospitals we then matched records from the maternity information system with those from the national child health system using similar data items, which excluded the infant's surname and forename but included birth weight and the mother's surname.

The ethnic group of the mother was used as a proxy for ethnic group of the infant. The mother's ethnic group was determined by midwives on the basis of country of origin of mother's parents and usually grandparents; the resulting ethnic groups were combined for analysis into African, Afro-Caribbean, white, and other.

We searched for missing results at the other Thames regional laboratories and tried to locate all the infants without a result. For those who were located, health visitors or parents, or both, were asked whether the infant had been screened and about factors that might have affected whether he or she had been tested. Each infant's test status was compared with that recorded on the national child health system. Key staff in the programme were interviewed to identify responsibility for aspects of the service and systems for collecting and monitoring data.

We used EpiInfo for the preliminary analysis[11] and SAS to estimate relative and adjusted odds ratios.[12] The odds ratios were adjusted for confounding factors with a multivariate logistic regression model containing ethnic group, mobility, and district. We calculated the significance levels using the maximum likelihood method.

Relative and adjusted odds ratios (95% confidence intervals) of infants in south London who did not have a test result by mobility, district, ethnic group, and birth weight

	No (%) of infants with no result	Odds ratio	
		Relative	Adjusted†
Mobility:			
Infant born and lives in district	22/1251 (1·8)	1·00	1·00
Family lived and still lives in district, but infant born outside	13/248 (5·2)	3·09 (1·53 to 6·22)	1·73 (0·81 to 3·71)
Family moved into district after infant was born	12/78 (15·4)	10·16 (4·85 to 21·29)	3·98 (1·70 to 9·31)
Family moved out of district after infant was born	17/150 (11·3)	7·14 (3·69 to 13·81)	5·03 (2·50 to 10·13)
Significance		χ^2=51·02*, df=3	χ^2=22·68*, df=3
District:			
Camberwell	23/941 (2·4)	1·00	1·00
West Lambeth	41/786 (5·2)	2·20 (1·31 to 3·70)	1·54 (0·89 to 2·67)
Significance		χ^2=9·23*, df=1	χ^2=2·40, df=1
Ethnic group:			
White	10/675 (1·5)	1·00	1·00
Afro-Caribbean	5/270 (1·9)	1·25 (0·42 to 3·68)	1·26 (0·42 to 3·75)
African	12/274 (4·4)	3·05 (1·30 to 7·14)	2·08 (0·86 to 5·01)
Other	7/244 (2·9)	1·97 (0·74 to 5·25)	1·77 (0·66 to 4·71)
Not known	30/264 (11·4)	8·41 (4·05 to 17·45)	5·02 (2·26 to 11·17)
Significance		χ^2=44·32*, df=4	χ^2=19·20*, df=4
Birth weight:			
Per 100 g	21/1706 (1·2)	0·99 (0·98 to 1·07)	
Significance		χ^2=1·57, df=1	
Total	64/1727 (3·7)		

*P<0·005.
†Adjusted for mobility, district, and ethnic group after birth weight was excluded from the model.

Results

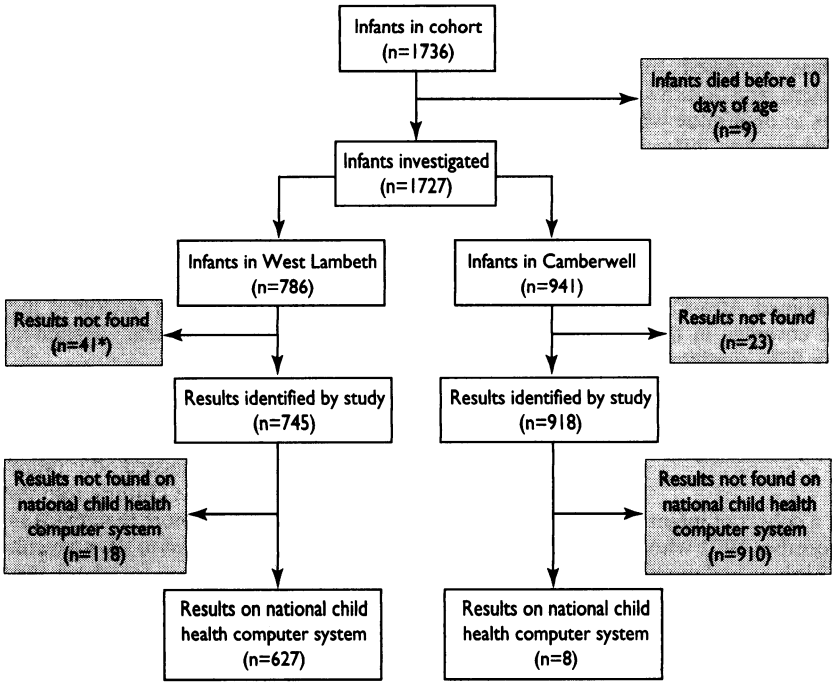
The table shows the relative and adjusted odds ratios of an infant not having a result for the Guthrie test. As infants of African ethnic group were more than twice as likely as the Afro-Caribbean infants not to have a result the relative and adjusted odds ratios for these two groups were estimated separately. Coverage varied with the mobility of the family. After adjustment the odds ratio of an infant not having a result was 3·98 in those moving into the district after birth and 5·03 in those moving out of the district after birth. Overall, the infants in West Lambeth were less likely than the infants in Camberwell to have a result, but after adjustment this difference was not significant. After adjustment for ethnic group, in infants who lived in the district and had been delivered locally the odds ratio of the infants in West Lambeth compared with those in Camberwell not having a result was 2·12 (95% confidence interval 1·08 to 4·16, χ^2=4·98, P<0·05).

Although the African infants were less likely than the infants in other ethnic groups to have a result, the difference was not significant after adjustment for mobility and district. Nine of the 12 African infants who had no result were in families who had moved out of the district after the birth, compared with two of the 10 white and none of the five Afro-Caribbean infants. The highest risk of an infant not having a result was in the infants for whom ethnic group was not known, and this difference remained significant after adjustment for mobility and district. The possible contributory causes for apparent non-testing were identified in 18 cases as mobility of the family around the time of birth (12, including several families living in bed and breakfast accommodation); admission to a special care baby unit (three); twin birth (two); obstetric complications (one); birth abroad (one); and refusal (one, which was also a home birth.) In addition, 10 of the 21 infants with no recorded birth weight had no test result.

The figure shows that the recording of test results on the national child health system was incomplete. Of the 22 infants without a result who were recorded as having been born and living in the district, five were subsequently identified as having moved away, although this was not recorded on the system. Computer data were not used to monitor coverage or to check completeness of data in either district. Checks for results were not made on infants moving into the districts, although midwives in Camberwell operated a separate, manual system to check that infants born in their district had been tested and that results had been received. No single person in either Camberwell or West Lambeth was responsible for the overall running of the programme.

Discussion

Two possible biases should be considered. Firstly, differences between ethnic groups may be overesti-



* 12 Cases had a result recorded on national child health computer system

Information on cohort of infants in survey with respect to recording of results on national child health computer system

mated as ethnic group was not identified for some infants. A review of the names of the infants with no identified ethnic group and no result suggests that if bias exists, it is in underestimating the differences identified. Secondly, coverage may be underestimated as some infants may have been tested even though a result was not found; the effect would be small because in only four of the 32 cases in which no result had been found and health visitors or parents, or both, had been contacted was the infant reported as having been tested.

This study adds to the work on the neonatal screening programme by investigating the variation in coverage by ethnic group and other variables.[5,6] The poorer coverage in infants of African ethnic group indicates that if this programme is used to screen for sickle cell disease about 5% of African infants will not be tested. In the area covered by the study this amounts to about one case of sickle cell disease each year. Also, if incomplete coverage exists among Africans in inner London the anonymous surveillance of maternal HIV infection on the basis of "Guthrie spots" may have underestimated the prevalence of HIV infection in inner London.[13] The fact that coverage of the programme is incomplete and poorer in African infants emphasises the importance of collecting and using data on ethnic origin to monitor the uptake of services.

Infants delivered in Camberwell—the district that checked the receipt of results against a manual register—were more likely to have a result than infants born in West Lambeth. In neither district were the data on the national child health system of a quality or completeness appropriate to use for monitoring. Routinely identifying untested infants has improved coverage but infants moving into an area should also be monitored.[14] Improvements planned in the study districts include monitoring coverage against agreed explicit standards, by a named person, and piloting links between the laboratories database, the maternity information system, and the national child health system, with a unique numbering system to reduce data being entered on computers twice.

Recent developments in genetic technology mean that many more disorders can now be, and in some cases already are, screened for.[15] Policy decisions on neonatal screening should take account of the impact of the test for sickle cell disease on the existing programme.[9] Incomplete coverage reduces the existing programme's cost effectiveness, especially when disorders that are common, as sickle cell disease is in London, are added to the programme.[16,17]

In conclusion, coverage of the neonatal screening programme in south east London is incomplete and poorer in African infants than in white infants and poorer in infants whose families are mobile around the time of birth than in those whose families are not. Also, we identified problems in recording results and monitoring the programme. To address these problems a system for monitoring the coverage of the programme similar to the score that monitors the coverage of the immunisation programme (COVER scheme), based on the national child health system, which includes explicit process standards, is to be established.

Public health implications

- The Guthrie neonatal screening programme which tests infants for phenylketonuria and hypothryroidism can now be used to test for many other disorders, including sickle cell disease
- This study found that in part of inner London coverage of the programme was incomplete
- Infants of African ethnic group were three times as likely as white infants not to have a result
- The poorer coverage of African infants may result in cases of sickle cell disease going undectected
- The system of monitoring coverage of the screening programme should be similar to the scheme that monitors immunisation, and standards for the programme should be agreed

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