

repeatability of only one scale point on a range 0-100, which seems unlikely for a score derived from responses to questions concerning subjective symptoms. They say they have used the method of Bland and Altman,² but the results given—the mean difference and the distribution of the differences—are not good measures of reliability. Moreover, Bland and Altman proposed that the limits of agreement should be used to assess repeatability. For example, twice the standard deviation of the differences gives a range within which 95% of the differences will lie.

A mean difference of zero implies that there is no consistent trend affecting test and retest results (all the patients getting better, for example). It does not imply that the measure is reliable. The table gives some hypothetical data to show how you can get a mean difference of 0 and still have widely different test and retest scores, because differences in different directions cancel each other out whatever their absolute size.

Obtaining a mean difference of zero

Subject	Test	Retest	Difference
A	50	80	+30
B	30	20	-10
C	60	40	-20
D	70	70	0
Mean difference			0

Bland and Altman explained that the distribution of the differences can be assumed to be normal because they reflect measurement error rather than variations between subjects. Confirming this has no bearing on the question of reliability.

Brazier and colleagues have not supplied data on the limits of agreement. Thus their conclusion that test-retest reliability was excellent is unsupported. To permit an estimate of the limits of agreement, we would ask the authors to present the standard deviations of the differences and the repeatability coefficients for the six dimensions of the scale along with comparable repeatability data for the Nottingham health profile.

PATRICK GOMPERTZ
ROWAN HARWOOD
SHAH EBRAHIM
EDWARD DICKINSON

Department of Health Care of the Elderly,
Royal London Hospital (Mile End)
London E1 4DG

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AUTHORS' REPLY.—We are glad to be able to clarify the issues raised by Sonja M Hunt and Stephen M McKenna and Patrick Gompertz and colleagues.

Despite the fact that its developers now claim the Nottingham Health Profile to be inappropriate for use in a general population, it is used in this way.^{1,3} Hunt and McKenna have themselves used the profile in community and general practice settings⁴ and have in the past advocated its use in epidemiological studies.⁴ A recently published review of health status measures has suggested that the Nottingham Health Profile is appropriate for use in general populations.⁵ The profile is widely regarded as a well established instrument for the measurement of perceived health status in the United Kingdom and it was the obvious choice of instrument to compare with the SF-36.

Both letters raise important questions concerning test-retest reliability. Our study investigated the performance of the SF-36 in a general population and not at the individual level. For this

purpose the Bland-Altman technique⁷ is an essential addition to correlation coefficients for examining the reliability of an instrument. The Bland-Altman technique looks at the distribution of the differences between the test and retest scores, requiring them to be normally distributed with mean zero. Bland and Altman recommend that the plots of the differences between test and retest scores be visually examined to detect bias. However, there was not sufficient space to present an additional eight figures, and thus we restricted our presentation to the mean differences and their significance for the SF-36 dimensions and the proportion of observations that were within the 95% confidence interval. Our results clearly show that the test-retest score differences of the SF-36 are approximately normally distributed with a mean close to zero, and they indicate that the test and retest score distributions are nearly identical and thus, in conjunction with the correlation coefficients, suggest that the SF-36 reliably measures population scores. Gompertz and colleagues have asked us to present the standard deviations of the differences, and these are presented in the table along with the 95% confidence intervals of the distributions of the differences.

Means, standard deviations, and 95% confidence intervals of distributions of difference in test-retest scores by dimension

Dimension	Mean	Standard deviation	95% Confidence interval
Physical functioning	0.49	4.92	-9.35 to 10.33
Social functioning	0.15	1.47	-2.79 to 3.09
Role limitations (physical)	0.57	3.86	-7.15 to 8.29
Role limitations (emotional)	0.44	2.91	-5.38 to 6.26
Pain	0.39	1.37	-2.35 to 3.13
Mental health	0.70	3.05	-5.40 to 6.80
Vitality	0.71	2.64	-4.57 to 5.99
General health perception	0.40	3.54	-6.68 to 7.48

The socioeconomic gradients we observed are exactly as would be expected, with a consistent contrast between the SF-36 scores for the higher two classes and those for the bottom two groups. The variability observed in the two intermediate classes is similar to that shown across a range of conditions in general practice.⁸ Similarly the high correlation between mental health and vitality scores is entirely consistent with clinical expectations; poor mental health is associated with low vitality. There was no inconsistency between the mean scores in any dimension and the presence or absence of chronic physical problems.

Two papers by the American developers of the SF-36 have recently been published.^{9,10}

We thank Hunt and McKenna for their contribution to the debate regarding the usefulness of the SF-36 but wish to restate that our paper clearly shows acceptable reliability and validity of the SF-36 for primary care and community surveys. It remains necessary to assess its usefulness in a range of clinical settings.

JOHN BRAZIER
ROSEMARY HARPER
NICOLA JONES
KATE THOMAS
LINDA WESTLAKE

Medical Care Research Unit,
Department of Public Health Medicine,
University of Sheffield Medical School,
Sheffield S10 2RX

TIM USHERWOOD

Department of General Practice,
University of Sheffield Medical School,
Sheffield S10 2RX

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Respiratory medicine: the casualties

EDITOR.—As those most directly affected by the Joint Planning Advisory Committee's recent freeze on senior registrar appointments in respiratory medicine we agree with the views expressed in the letter from a group of consultants in respiratory medicine.¹ A group has now been formed to represent career and research registrars in respiratory medicine.

We have conducted a nationwide survey of clinical and research registrars in respiratory medicine; so far we are aware of 53 registrars. This figure is much greater than previously thought. Of these, 41 have completed or are working towards an MD or a PhD in respiratory medicine and half of these have been in the specialty three or more years. Thus an enormous commitment to the specialty has already been made. Most of these registrars are over 30 years old and in the current system have no realistic chance of retraining in another specialty.

As well as the disastrous effect on the people concerned this freeze has catastrophic implications for the future of the specialty. We believe that applying a simple mathematical formula to a complex problem is inappropriate. We have written to the chairman of the Joint Planning Advisory Committee urging that the freeze be lifted immediately pending a comprehensive discussion of the wider issues.

PAUL DILWORTH

Charing Cross Hospital,
London W6 8RF

TIM HOWES
LOUISE RESTRICK

King's College Hospital,
London SE5 9PJ

MIKE IREDALE

Royal Postgraduate Medical School,
London W12 0HS

JEFF MEECHAM-JONES

London Chest Hospital,
London E2 9JX

MARK SANDERSON

Guy's Hospital,
London SE1 9RT

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AIDS and ethics in Birmingham

EDITOR.—The article "AIDS and ethics in Birmingham: a betrayal of trust" by Michael Fitzpatrick categorically asserts that a breach of confidentiality was perpetrated by a "member of the Birmingham AIDS team."¹

There is not a group of individuals so designated, but we believe that the use of this phrase is grossly

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misleading and could only suggest to the reader that the source of the press leak was a member of one or other of our departments, which are regularly responsible for the care of the vast majority of HIV infected individuals in Birmingham. This is simply not true.

Confidentiality is a fundamental tenet of the service we provide for HIV infected individuals and under no circumstances would we divulge a patient's name to the media—certainly not to provide “a focus around which to challenge... mounting complacency about AIDS,” as suggested by Fitzpatrick. The article further implies that we have a “tendency to regard HIV infection as more a moral condition than a disease” and that we judge people with HIV and AIDS “according to the degree of their individual responsibility for their condition.” This does not reflect the attitude of the doctors and other staff dedicated to caring for such people in Birmingham.

M J WOOD
C J ELLIS
J A INNES
S DRAKE

Regional HIV/AIDS Unit,
Directorate of Infectious Diseases,
East Birmingham NHS Trust,
Birmingham B9 5ST

M SHAHMANESH
K RADCLIFFE

Department of Genitourinary Medicine,
General Hospital,
Birmingham

1 Fitzpatrick M. AIDS and ethics in Birmingham: a betrayal of trust. *BMJ* 1992;305:259-60.

AUTHOR'S REPLY.—I am happy to accept that Dr Wood and his colleagues in the regional HIV/AIDS unit and the department of genitourinary medicine were not responsible for the breach of confidentiality that I described in my article. However, somebody with access to detailed clinical information concerning people with HIV/AIDS in Birmingham clearly did leak such information to the press and that remains a matter of concern.

M FITZPATRICK

London N16 9JT

Litigation over illness associated with tryptophan is possible

EDITOR.—The illness associated with tryptophan known as the eosinophilia-myalgia syndrome was newsworthy two years ago. Five Scottish patients were reported on in the correspondence columns of the *BMJ*^{1,2} and the *Lancet*.^{3,4} In the United States around 1500 cases were notified to the Centers for Disease Control, but there may have been 5000-10 000 cases.⁵

Two years on relatively few patients, possibly only 10%, are free of symptoms.⁶ The commonest persisting symptoms are myalgia, fatigue, paraesthesia, muscle cramps, and scleroderma-like skin changes.⁷ A problem for patients with such symptoms is that there is no objective indicator; there is no recurrence of eosinophilia or important increase in the erythrocyte sedimentation rate. Doctors should be alert to the risk of dismissing such symptoms as non-organic. Reports have suggested that the symptoms may slowly improve with time.⁷ Steroids frequently provide symptomatic relief, but there is no convincing evidence of an effect on the duration of the disease.⁷

The legal case is still being argued in the American courts. The cause has not yet been defined, but there is some evidence of an association with some batches of tryptophan made by the Japanese firm Showa Denko. The material was

prepared microbiologically,⁸ and several changes were made in the manufacturing process, including a change in the organism. There may be more than one contaminant.⁹

In the United States numerous support groups for patients with the eosinophilia-myalgia syndrome are well organised into a national network. According to a recent newspaper report in the United States, there are about 1400 plaintiffs with cases against Showa Denko.¹⁰ British sufferers who are generally less litigious, are probably unaware that they could join such action, and the opportunity to do so will soon be time barred. The American patient support groups are willing to guide British sufferers.

If any further information is required I am prepared to respond to any doctor writing to this address on issues affecting individual patients.

A S DOUGLAS

University Department of Medicine and Therapeutics,
University Medical School,
Aberdeen Royal Infirmary,
Aberdeen AB9 2ZD

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HIV infection and certification of death

EDITOR.—John Aldous and colleagues' paper discussing the impact of HIV infection on mortality in young men in a London health authority highlights many of the problems regarding death certification, HIV infection, AIDS, and confidentiality.¹ The authors found that HIV infection was the leading cause of death in 15-44 year old men and emphasise the importance of accuracy in death certification. The fact that HIV infection is the underlying cause of death, however, is not as important as ascertaining the HIV infection status of those who have died.

The actual cause of death may have no immediate or obvious link with HIV infection, but the knowledge that the person was infected could be highly relevant, for example, in cases of suicide. It may also be wrong to assume that HIV infection was the underlying cause of death in people known to be infected but certified as having died of other causes. The most that may be assumed is that HIV infection might have been a contributory cause of death in those who are found to be infected after death.

While the information on death certificates remains non-confidential inaccuracy in certification will occur. The principle must be to maximise the accuracy of the initial certification. Apart from the current facility to offer further information on cause of death, methods should be established for checking the accuracy of death certification and linking with surveillance systems for HIV infection and AIDS. I suggest two possible methods of linkage.

Firstly, people known to be infected with HIV

or to have AIDS could be flagged at the NHS Central Registry as part of the notification system. This would need a level of identifying patients which is available only in some cases. When the flagged patients died the accuracy of their death certificates could be investigated. Secondly, record linkage of surveillance systems for HIV infection and AIDS with death certification data as held at the General Register Office in Scotland is possible. Such record linkages could be performed periodically, and matching cases with the same soundex code and date of birth could be identified and analysed. The advantage of this method would be that an anonymised identification system such as the soundex code could be used and confidentiality preserved.

The second method is also a check on the accuracy of the anonymised data typically held in national and local surveillance systems for HIV infection and AIDS. It could form part of a regular check to validate data held in these surveillance systems.

ANDREW RILEY

Department of Public Health Medicine,
Lothian Health Board,
Edinburgh EH8 9RS

1 Aldous J, Hickman M, Ellum A, Gazzard B, Hargreaves S. Impact of HIV infection on mortality in young men in a London health authority. *BMJ* 1992;305:219-21. (25 July.)

EDITOR.—John Aldous and colleagues, in their study of male residents of Riverside, concluded that HIV infection was the leading cause of death in those aged 15-44 and the third commonest cause of death in those aged 15-64 years.¹ The operational criteria for HIV or AIDS related death in this study is misleading as the diagnosis of HIV infection or AIDS does not necessarily imply a cause of death. On this basis, it is unclear what proportion of deaths was due to common bacterial pathogens or non-HIV related causes in those infected with the virus. McCormick, to whom Aldous and colleagues referred quite extensively, was careful in claiming a cause-effect relation and stated only that the observed increase in mortality is “unattributed to but probably associated with HIV infection.”²

Mientjes *et al* reported a high and rising incidence of bacterial pneumonia among HIV infected intravenous drug users in Amsterdam without a consequential rise in non-AIDS mortality.³ By contrast, an earlier study in New York showed that deaths caused by bacterial pathogens have risen greatly during the AIDS epidemic.⁴ The greater mortality among HIV infected intravenous drug users in New York than in Amsterdam would seem to reflect differences in these two cities in the early detection of bacterial pneumonia among intravenous drug users and accessibility to inpatient and outpatient medical services, both of which are important factors in preventing deaths due to common bacterial pathogens.

Aldous and colleagues did not consider the health consequences of homelessness in their study or the social and psychological deprivations which invariably follow the diagnosis of HIV. Social isolation, a sense of hopelessness and alienation, suicide or accidental drug overdose, and failure of early detection and treatment of bacterial pneumonia in people infected with HIV deserve specific comment in the analysis of data and interpretation of research findings.

Bacterial pneumonia, endocarditis, thromboembolism, and deliberate or accidental self poisoning were major causes of death among intravenous drug users before the advent of HIV and remain largely so. Among single men aged 15-54, HIV arguably has contributed in some degree to increased mortality in the decade 1981-91; that this picture will persist through to the next decade is unlikely, particularly in view of AIDS related self organisation and behaviour change among homosexual groups. We remain vigilant about