CORRESPONDENCE

Correspondents are asked to be brief

Confidentiality R. R. L. Pryer, F.R.C.S. 104	Appointment of Preregistration House Officers O. O'Toole 106	Prevention of Pulmonary Embolism D. R. B. Jones, F.R.C.S., and others 109
Ordeal by Investigation D. E. L. Howes, M.B. 104	Infectious Mononucleosis H. Pullen, M.R.C.P.ED. 107	Erythrocyte Sedimentation Rate in Hyperlipidaemia E. N. Wardle, M.R.C.P. 109
Carboxolone Sodium and Deglycyrrhizinated Liquorice in Gastric Ulcer Sir Francis Avery Jones, F.R.C.P. 105	Euglycaemic Diabetic Ketoacidosis J. T. Ireland, F.R.C.P.ED., and W. S. T. Thompson, F.R.C.P.GLASG. 107	Consultant Surgeons and Vasectomy J. J. Hobbs, M.B.; L. N. Jackson, F.R.C.G.P. 109
Higher Specialist Training in General Surgery R. S. Johnson-Gilbert 105	Remission of Hyperthyroidism G. A. MacGregor, M.D. 107	Persistent Fertility after Vasectomy A. Halim, F.R.C.S., and J. P. Blandy, F.R.C.S. 110
Side Effects of the Pill David M. Hall, M.B., and Susan M. Hall, M.B. 105	Sharing the Burden of Certification C. Reisner, M.B., B.CHIR. 108	Ampicillin for Sore Throat E. Joan Stokes, F.R.C.P. 110
Troubles with I.U.C.D.s J. S. Templeton, M.B. 106	Comparison of Co-trimoxazole and Chloramphenicol in Enteric Fever A. Hassan, D.M., and others 108	Intravenous Cordone Bleu C. A. Birch, F.R.C.P. 110
The Problem Oriented Medical Record P. D. Herton 106	Heartburn of Pregnancy R. D. Atlay, M.R.C.O.G. 108	Regulation of the Profession M. Sim, F.R.C.PSYCH.; M. Tcharny 110
Redesign of Medical Records in General Practice T. B. Donnelly, M.B. 106	Vocational Training and the R.C.G.P. S. L. Smith, B.M. 108	Superannuation Surplus W. P. Sweetnam, F.R.C.P. 111
Is Your Pain Really Necessary? G. G. Hill, M.B. 106	Significance of Milk pH in Newborn Babies V. C. Harrison, M.D., and G. Peat, D.M.T. 108	General Practitioners' Superannuation G. D. J. Ball, M.B., and others; W. G. Platt, M.B.; A. M. Duff, M.R.C.G.P. 111
Pruritus Vulvae Rosa Strunin, M.D. 106	Traveller's Ankle H. D. Johnson, F.R.C.S. 109	Women Doctors' Pensions A. Mary Duguid, M.B. 111

Confidentiality

SIR,—The tape-recorded discussion on confidentiality (23 June, p. 700) was both timely and stimulating. One could not fail to be impressed by the enormous gap which appears to exist between the principles governing these matters and the manner in which much of our profession conducts itself.

Recent personal correspondence with the Medical Defence Union reinforces the points made by your contributors: doctors are legally obliged to provide confidentiality for their patients, who are entitled to expect this. We are not obliged to forward confidential information to government departments or their agents, except where a statutory requirement exists or with the patient's consent; and an obligation to our contracts with regional boards is no greater than that to the individual patient. The general principles seem clear: confidential information which identifies the patient should be confined to doctors and the minimum number of people essential to treatment.

If precept is clear, the same cannot be said for practice. Various schemes initiated by the Department of Health and Social Security or regional boards, which seem to be accepted without protest by many doctors, make nonsense of these principles. The Psychiatric Inpatient Survey forwards full identifying details of every psychiatric admission, complete with diagnostic and personal data, to the D.H.S.S. computers. The facts required about every legal abortion and other data collecting schemes now afoot should make any doctor re-examine his concept of confidentiality. Does it embrace, for example, the record linkage system which is now agreed by nearly all hospital groups within the Oxford region? Within this, both clinical data and a detailed personal profile of every hospital admission in the region is automatically sent

to Oxford for computer analysis and storage; it will later involve general practice and other services.

All the schemes require the automatic passage of confidential material to distant departments which are not essential to patient care, without the consent of the patient, without public discussion of the issues, and in the total absence of protective legislation relating to the use and abuse of computer-stored material. How can such systems equate with the confidentiality expected from us? Placing a doctor at the head of groups of computer technologists, clerks, or government departments, with no clinical responsibility, cannot allow them to claim the same right of access to confidential material as the treatment team. I do not believe that we shall return public confidence if we accede to such proposals without protest.

In view of these considerations, the majority of consultant medical staff of the Aylesbury Group of Hospitals felt that it could not agree to transmit identifiable material in present circumstances. They welcome better record systems, with the proper use of computers, and have no hesitation in transmitting non-identifiable data. As a result, the information sheets about cases are completed, but all identifying data are blanked out by the records departments before these leave our hands. Before agreeing to co-operate, we feel that systems which allow patient identity to be retained at the periphery rather than the centre should be reconsidered most carefully. If, however, it can be proved that identification is essential, it should be accepted only when the public are fully conversant with the nature of the scheme, and when patient's notes contain a form for written consent to specific data being utilized for research. This retains the principle of obtaining agreement from the

patient whenever an outside body of a non-clinical nature asks for information. Above all, we ask that parliamentary legislation governing the control and use of data banks should be enacted to protect people from the numerous potential abuses of such systems. If it is ethically questionable to allow confidential material out of our hands, it must be close to foolishness to do so without safeguards and without the knowledge of our patients.

When Aylesbury decided not to co-operate in the present record linkage scheme we found to our surprise that we were the only group of hospitals in the Oxford Region to do so. What happened to everyone else? Some of us still blink to see so much apparent apathy, and so little insistence on fundamental principles or safeguards. At the time of writing neither the D.H.S.S. nor the regional board seem prepared to discuss the issue publicly. Is the problem to remain unresolved until we enter a restructured N.H.S. in 1974, when much lay support will be remote and our representation less? Or may we hope that our profession will join Aylesbury in rejecting the supply of identifiable information until adequate protection of confidentiality exists. If we do not re-examine the basis upon which the doctor-patient relationship largely rests, we should not be surprised if that relationship deteriorates. —I am, etc.,

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Ordeal by Investigation

SIR,—It is a sobering reminder of what is expected of the patient in a modern hospital when, in a recent *B.M.J.* paper, a woman who had submitted to estimation of B.M.R., insulin stimulation test, liver biopsy, E.C.G., E.E.G., skull radiography, lumbar puncture, and air encephalography, as well as the