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VIII Annual Symposium on Biomedicine, Ethics and Society: "Rethinking Informed Consent: The limits of autonomy"

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Data and samples everywhere – but what about informed consent?

In the last ten years the developments in genomic analysis and computer technology have led to a greater ability to interrogate, share and compare DNA samples and personal data. In the medical context, there is an increase in the number of biobanks; e-science grids are being developed; and there are moves to computerise medical records systems, increasing their attractiveness for research, audit and crime investigation. The standardisation of procedures for the sharing of data and samples between biobanks and researchers in different countries is currently being developed through the P3G network. In such a scenario the principle of informed consent is difficult, if not impossible to implement, as data and samples have the potential to be used for many secondary purposes, by a number of third parties, often unknown at the time of collection. This paper considers the limits of informed consent in this context and asks if it is better to rely on the 'public interest' as justification for not seeking consent. However the concept of the 'public interest' is ill-defined, and as it stands, cannot be relied on as a justification for ignoring individual autonomy in all cases. Therefore in this context alternative methods of protecting autonomy need to be explored.