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PPPI: The involvement of patients/people in the design and development of clinical trials within Ireland and Europe

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Clinical trials were originally designed and developed with input from various experts, statisticians, clinicians, nurses, etc. Gradually there was a recognition that maybe the patients (or participants) in the actual trial could contribute although at first this was mainly limited to their involvement in the choice of outcome measures. The difficulty of involving patients in clinical trial design was mainly attributed to patients not having sufficient understanding of the trials to be able to make more than simple design changes. However patients' organizations have developed within Ireland and Europe and have become more and more influential at all levels of treatment and health provision. However the patients/organizations still had very little influence over clinical trial design leading to the patients' organizations criticizing the trials when they were taking place or completed. This has led recently to the idea of the 'expert' patient. This is the concept that patients often know quite a lot about their disease so the only thing stopping them from providing useful input into a clinical trial is their comparative lack of knowledge of interpreting the medical literature and/or the design of efficient and valid clinical trials. To address this various programs of education for patients have been devised in Ireland and within Europe training them how to 'read' medical papers and understand clinical trials. This talk provides the history behind these initiatives and the successful results obtained. Now very few trials are planned in Ireland and the EU without some input from patients or patient groups.

Biography

Jean Saunders has completed her CStat and CSci from the Royal Statistical Society, London, UK, running a busy Statistical and Research Methodology Consultancy within the University of Limerick in Ireland. She has particular interests in research ethics and patient participation in medical research. She has been a Board Member for IPPOSI (Irish Platform for Patients' Organizations with Science and Industry) for the last 2 years. She has published over 100 papers in peer-reviewed journals as well as contributing towards many other reports/bulletins. She currently provides statistical consultancy services to the local health executive as well as Pharma.

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