

RHEUMATOLOGY PATIENTS' KNOWLEDGE ABOUT CLINICAL RESEARCH

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Background: Very little published research has actually explored the patients' knowledge about and willingness to participate in clinical trials and the majority of information is available from cancer studies.

Objectives: We aimed to explore the rheumatology patients' knowledge about clinical trials with a view to improving their involvement in our departmental research projects.

Methods: We conducted a questionnaire-based study, comprising 2 opinion questions about clinical trials knowledge and willingness to take part in research; 18 knowledge questions about the clinical research principles and 4 questions about what could improve patients' understanding and participation in clinical research. The questionnaire was adapted from a recent cancer patients' study (1). Correlation coefficients above 0.6 were considered as strong, as per the accepted cut-off for social science studies.

Results: 85 patients fully completed the questionnaire during their appointments in our rheumatology clinics (63 females, 22 males, mean age 50.9±16.2 years); 25 patients (29.4%) were seen as new patients, and 60 (70.5%) are under regular follow-up for the management of rheumatoid arthritis (45.8%), osteoporosis (24.7%), osteoarthritis (14.1%) and other conditions (median duration of follow-up was 3±0.74 years). Under a quarter (21.1%) of patients had previously participated in clinical research, but 45% of patients considered that they had good understanding about clinical trials, 27% were neutral about this statement and 28% disagreed. The good understanding correlated well with patients' history of participation in research ($r=0.62$, $p<0.05$). Only 12.9% wished to participate in future in clinical trials, while 42.3% patients did not (44.7% were neutral). The biggest consensus was reached on the following points: a clinical trial is a test of an experimental drug (77.6% agreement); statistics help to decide whether an experimental treatment is better than the available treatments (76.5%); proving the efficacy of a drug in vitro is not enough to enable its use in humans (74.2%). Specific questions about definitions of placebo, standard vs. experimental treatment and randomisation generated a significant degree of uncertainty (52.9%, 52.9%, and 50.5% respectively of patients replied "I don't know"). The main incentive for participation in research was the hope for better care and more time with the clinician (45.8%). Only 9.4% would consider this option because of their poor disease control, but this correlated well with patients' previous participation in research ($r=0.71$; $p<0.05$). The lack of understanding of research principles correlated with the lack of willingness to participate in clinical trials ($r=0.72$; $p<0.05$)

Conclusions: The results of our study revealed that patients lack information about clinical trials and have difficulty understanding the principles of medical research. The need for more clinician time was perceived as one of the incentives to enrol in clinical research, showing that research could improve our patients' experience of care.

References:

Cameron P, Pond GR, Xu RY, Ellis PM, Goffin JR. A comparison of patient knowledge of clinical trials and trialist priorities, *Curr Oncol*. 2013 Jun;20(3):e193-205.

Disclosure of Interest: None declared