

Clinical trials: do the patients get the thanks they deserve?

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Together, turning vision into reality

Introduction

- Patient-centric initiatives are becoming more common
- On 10 June, 2014, The BMJ launched a new strategy to promote patient partnership
- The BMJ will assess whether patient-dependent articles (i.e., using patient data) address the questions in the Table^{1,2}

Questions asked by *The BMJ* from authors of patientfocused research^{1,2}

- 1. Did you involve patients/service users/carers/lay people in the design of this study?
- 2. Was the development and/or selection of outcome measures informed by patients' priorities and experiences?
- 3. Were patients/service users/carers/lay people involved in developing plans for participant recruitment and study conduct? If so, please specify how?
- 4. Have you planned to disseminate the results of the study to participants? If so, how will this be done?
- 5. Are patients thanked in the contributorship statement or acknowledgements?
- 6. For articles reporting randomised-controlled trials, did you assess the burden of the intervention on patients' quality of life and health? If so, what evaluation method did you use, and what did you find?





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Purpose

To investigate how often patients are thanked in patient-dependent publications in *The BMJ*





Methods

Publications dependent on patient data identified

- We conducted a search in PubMed in August 2014, limited to the journal field for "BMJ"
- The search was ordered by most recent publications first

Publications assessed

- Acknowledgements
 - Thanking patients
 - Thanking others
- Funding source

Further categorization of acknowledgements

- Study design
- Patient population
- Therapeutic area
- Geographical location





Results: patient acknowledgements

- Of 125 articles investigated,
 - 87 (69.6%) were randomised-controlled trials
 - 94 (75.2%) involved adult-only populations and 17 (13.6%) paediatriconly populations

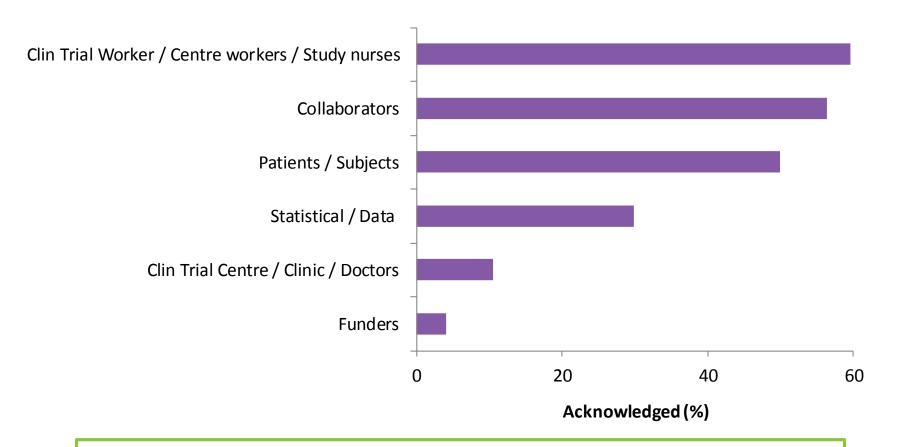
~50% of patient-dependant manuscripts thanked the patients







Results: acknowledgement by group



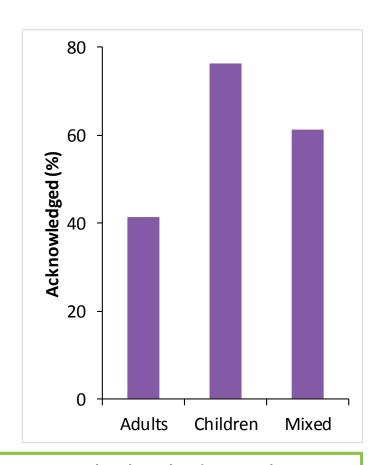
Patients were only the 3rd most commonly thanked group





Results: patient population

- A total of 39/94 (41.5%) adultonly population studies thanked patients
 - Of 17 studies involving only paediatric patients, 13 (76.5%) thanked patients
 - In mixed population studies, 8/14 (57.1%) studies thanked the patient group for their data

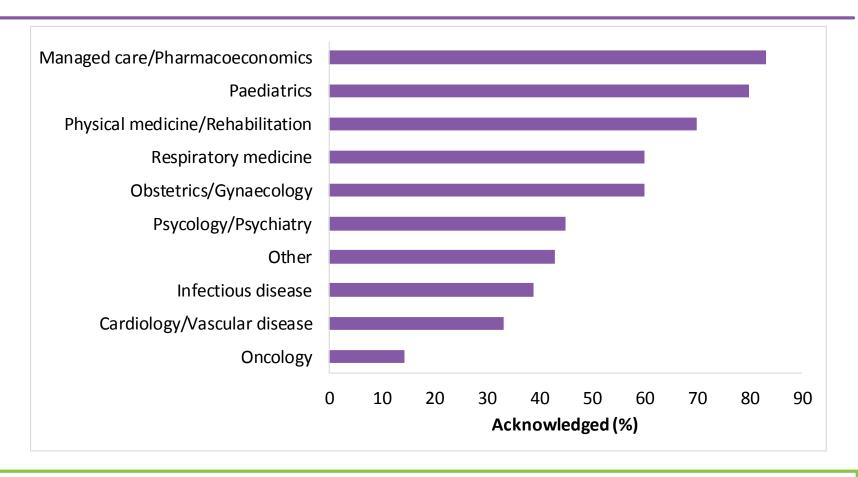


Paediatric patients were the most commonly thanked population





Results: therapeutic area

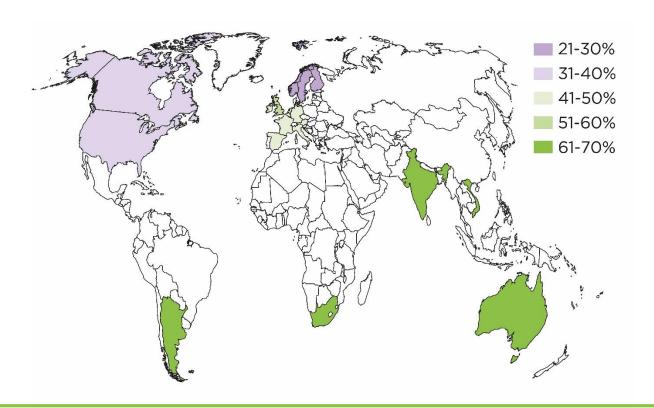


Few papers in the Oncology therapeutic area thanked patients for their data





Results: patient acknowledgement by geographical location



The RoW-based manuscripts most commonly thanked patients





Conclusions

- In patient-focused publications in The BMJ, patients were thanked ~50% of the time
- Publications were more likely to include a thank you to patients if:
 - The study population included paediatric patients
 - If the therapeutic area was Managed care/Pharmacoeconomics or Paediatrics
 - If the corresponding authors was based in the RoW
- Publication professionals could use our results to highlight to authors and sponsors the importance of thanking patients in patient-dependent publications





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