**N. Ireland Cancer Registry**

**Implications of Research for Services**

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| **Paper Title** | Systematic review of the use of translated patient reported outcome measures in cancer trials | |
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| **Conclusion** | Patient-reported outcomes (PROs) are used in clinical trials to assess the effectiveness and tolerability of interventions. Inclusion of participants from different ethnic backgrounds is essential for generalisability of cancer trial results. PRO data collection should include appropriately translated patient-reported outcome measures (PROMs) to minimise missing data and sample attrition.  Eighty-four trials met the inclusion criteria, only 14 (17%) (n = 4754) reported ethnic group data, and ethnic group recruitment was low, 611 (13%). Although 8 (57%) studies were multi-centred and multi-national, none reported using translated PROMs, although available for 7 (88%) of the studies. Interviews with 44 international stakeholders identified a number of perceived barriers to ethnically diverse recruitment including diverse participant engagement, relevance of ethnicity to research question, prominence of PROs, and need to minimise investigator burden. Stakeholders had differing opinions on the use of translated PROMs, the impact of trial designs, and recruitment strategies on diverse recruitment. Facilitators of inclusive research were described and examples of good practice identified. | |
| **What this means for the service** | Greater transparency is required when PROs are used as primary or secondary outcomes in clinical trials. Protocols and publications should demonstrate that recruitment was accessible to diverse populations and facilitated by trial design, recruitment strategies, and appropriate PROM usage. The use of translated PROMs should be made explicit when used in cancer clinical trials | |