INTERACT Summary

Background

Despite increasing recognition of the need to prevent anyone being left behind by research, there are no country-wide datasets available in the UK exploring cancer trial participation and under-representation. Without these data, targeted assessment and validation of interventions to improve representation from underserved groups, cannot be conducted.

Aims

To obtain robust quantitative data on representation of oncology trial participants in comparison to the incident population, assess current data collection standards and foster collaborations with diverse patient and public, NHS and research expert stakeholders.

Objectives

- INTERACT-Retrospective: Characterise inclusivity within our cancer trials, using routinely-collected healthcare data, comparing against the incident population during the equivalent time-period to identify exclusion of any groups.
- INTERACT Prospective: Assess UK-wide NHS practice of recording and auditing patient demographics and trial participation and obtain a snapshot of current practice in trial recruitment at selected NHS sites.
- Building Collaborations: Develop collaborations with diverse patient and public representatives, NHS stakeholders and multidisciplinary researchers for a future programme grant application.

Methods overview

Data held centrally by NHS England will be requested for the approximately 1.2 million people diagnosed with early-stage bladder, breast, head and neck, prostate and testicular cancer between 2007-2021. Approximately 20,100 ICR-CTSU trial participants (representing 44% of those joining similar trials in the same period) will be flagged in the records, accessed for analysis via NHS England's Secure Data Environment. The records will be analysed to identify any groups under-represented amongst trial participants, taking an intersectional perspective.

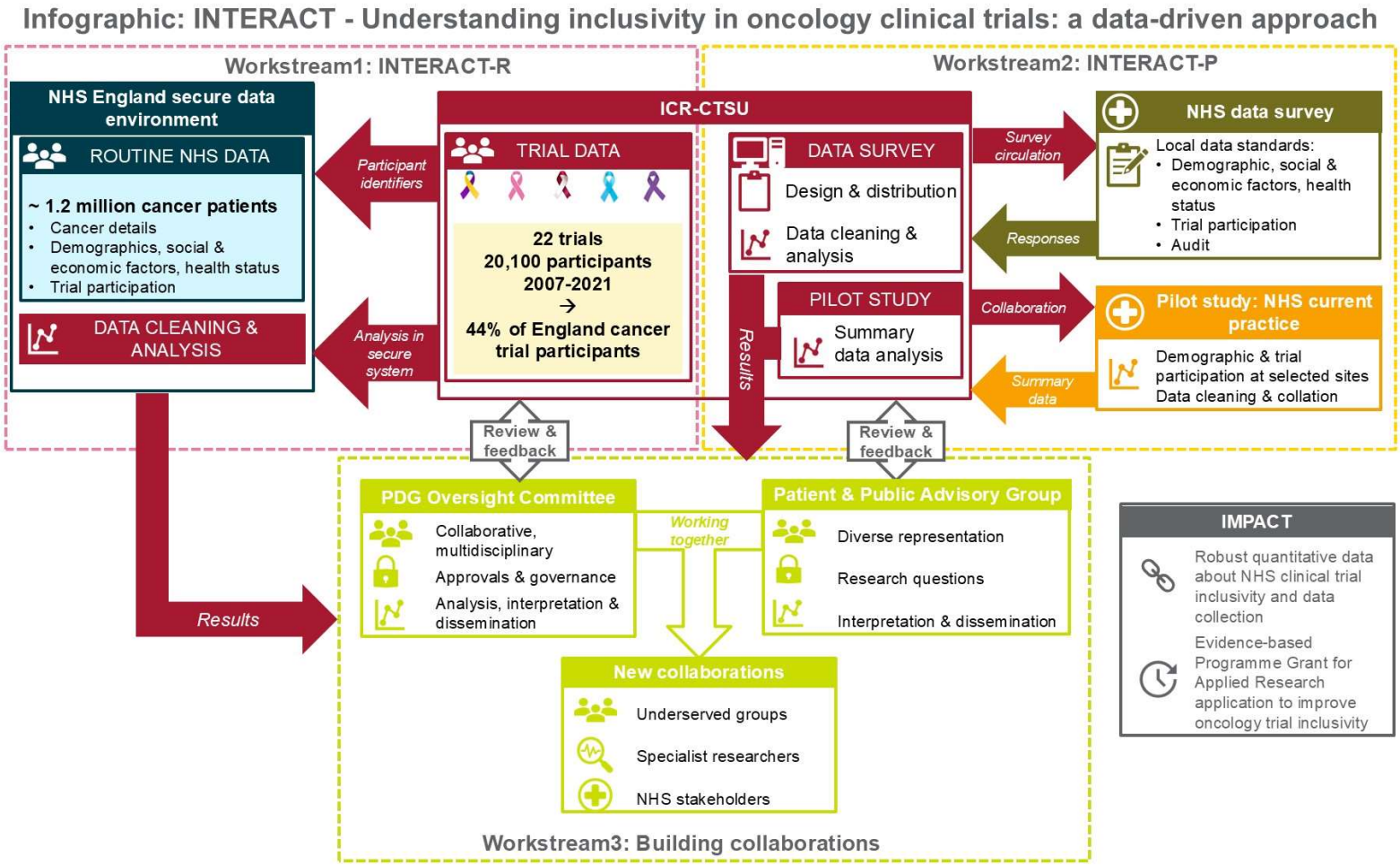
NHS Trusts will be surveyed about current demographic and trial participation data collection. An audit will be conducted at 2-3 NHS Trusts to investigate current practice in oncology trial inclusion, including review of verbatim text in medical records to identify data not captured in standard NHS data fields.

Multidisciplinary collaborations will be built by leveraging our existing links with patient groups, researchers and NHS Trusts across the UK, with targeted outreach to representatives and expert researchers involved with groups confirmed to be underserved by cancer trials.

Study duration: Two years (October 2026).

Next steps

Our results will be presented, published and disseminated via lay summaries and patient and public organisations. We anticipate the results will be valuable to the NHS and UK research community, however our ultimate goal is to use them as a basis to develop a programme grant to develop an evidence base for feasible, effective and value-for-money interventions that improve inclusion from groups confirmed to be underserved, for which there are currently no proven strategies for improvement.


Infographic: INTERACT - Understanding inclusivity in oncology clinical trials: a data-driven approach
Workstream1: INTERACT-R
Workstream2: INTERACT-P
NHS England secure data environment
ROUTINE NHS DATA
~ 1.2 million cancer patients
Cancer details
Demographics, social & economic factors, health status
Trial participation
DATA CLEANING & ANALYSIS
Participant identifiers
Analysis in secure system
ICR-CTSU
TRIAL DATA
22 trials
20,100 participants
2007-2021
→
44% of England cancer trial participants
DATA SURVEY
Design & distribution
Data cleaning & analysis
PILOT STUDY
Summary data analysis
Survey circulation
Responses
Collaboration
Summary data
Results
NHS data survey
Local data standards:
Demographic, social & economic factors, health status
Trial participation
Audit
Pilot study: NHS current practice
Demographic & trial participation at selected sites
Data cleaning & collation
Review & feedback
Review & feedback
Results
PDG Oversight Committee
Collaborative, multidisciplinary
Approvals & governance
Analysis, interpretation & dissemination
Working together
Patient & Public Advisory Group
Diverse representation
Research questions
Interpretation & dissemination
New collaborations
Underserved groups
Specialist researchers
NHS stakeholders
Workstream3: Building collaborations
IMPACT
Robust quantitative data about NHS clinical trial inclusivity and data collection
Evidence-based Programme Grant for Applied Research application to improve oncology trial inclusivity