

Cancer Quality of Life Metric Project

– Lessons learned from an implementation pilot

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NHS England
NHS Improvement

Background

Current national cancer metrics look at survival rates, waiting times for diagnosis and treatment, and overall patient experience. However, there are no national metrics looking at the quality of life of people diagnosed and treated for cancer.

The aim of the Cancer Quality of Life (QoL) Metric project is to collect information that reflects patients' quality of life. This valuable resource can then be used to make changes in care that focus on improving outcomes for patients.

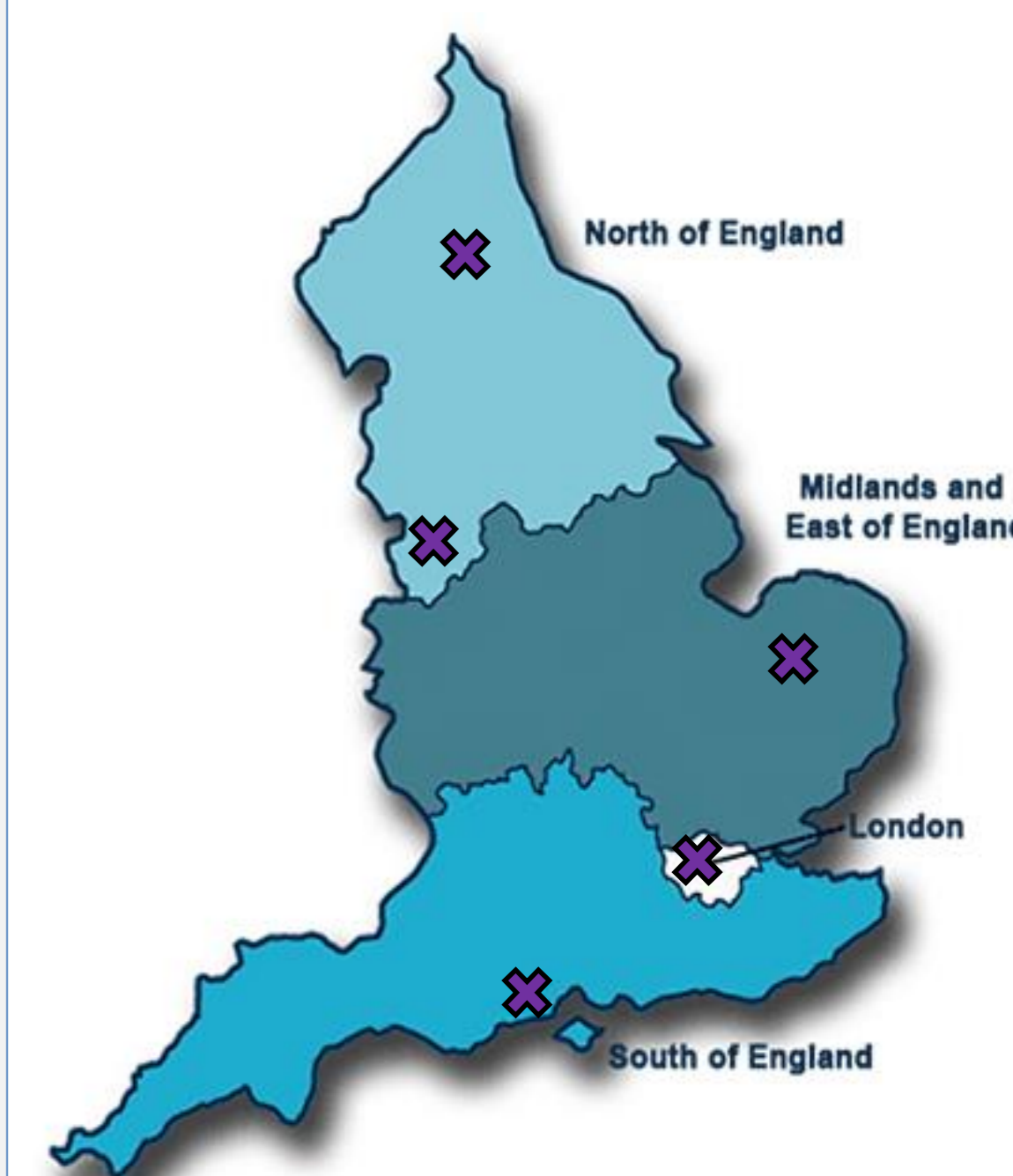
An initial research report produced recommendations on how to collect QoL survey information. These recommendations were reviewed with groups of stakeholders prior to launching a pilot project. The pilot project tested an approach to collecting patient-reported QoL outcomes at the end of breast, prostate or colorectal cancer treatment. Ongoing data analyses are testing the appropriateness of different summary scores for benchmarking of QoL outcomes via reporting systems at national and local levels.

We will “introduce an innovative quality of life metric to track and respond to the long-term impact of cancer”.

The NHS England (NHSE) Long Term Plan (LTP)

Method

- Eight pilot hospital trusts from five different Cancer Alliances
- Eligible patients were identified by project coordinators at their hospital trusts, mainly through online medical records systems or cancer registers, and with assistance from clinical teams.
- Breast, colorectal and prostate cancer patients treated with 'curative intent' were invited at three different time points (up to six months post treatment, 12 months post treatment and 13-24 months post treatment) creating three different groups of patients.
- Patients were invited to complete a QoL survey comprising two internationally validated questionnaires (EQ-5D; EORTC QLQ-C30).
- All sites used online platforms for collecting data. Non-responders were sent reminders 2-3 weeks later with an option to use a paper questionnaire.
- A subset of patients were asked to repeat the survey 6-months later.
- Responses were linked to demographic, disease and treatment data held by the National Cancer Registration and Analysis Service at Public Health England.
- A small-scale test providing individual-level feedback to patients and clinicians is included.
- A process evaluation included qualitative interviews and focus groups with administrators, patients and clinicians, as well as quantitative monitoring of coverage and uptake.



Results

An independent process evaluation was carried out by the University of Leeds from September 2017 until April 2019.

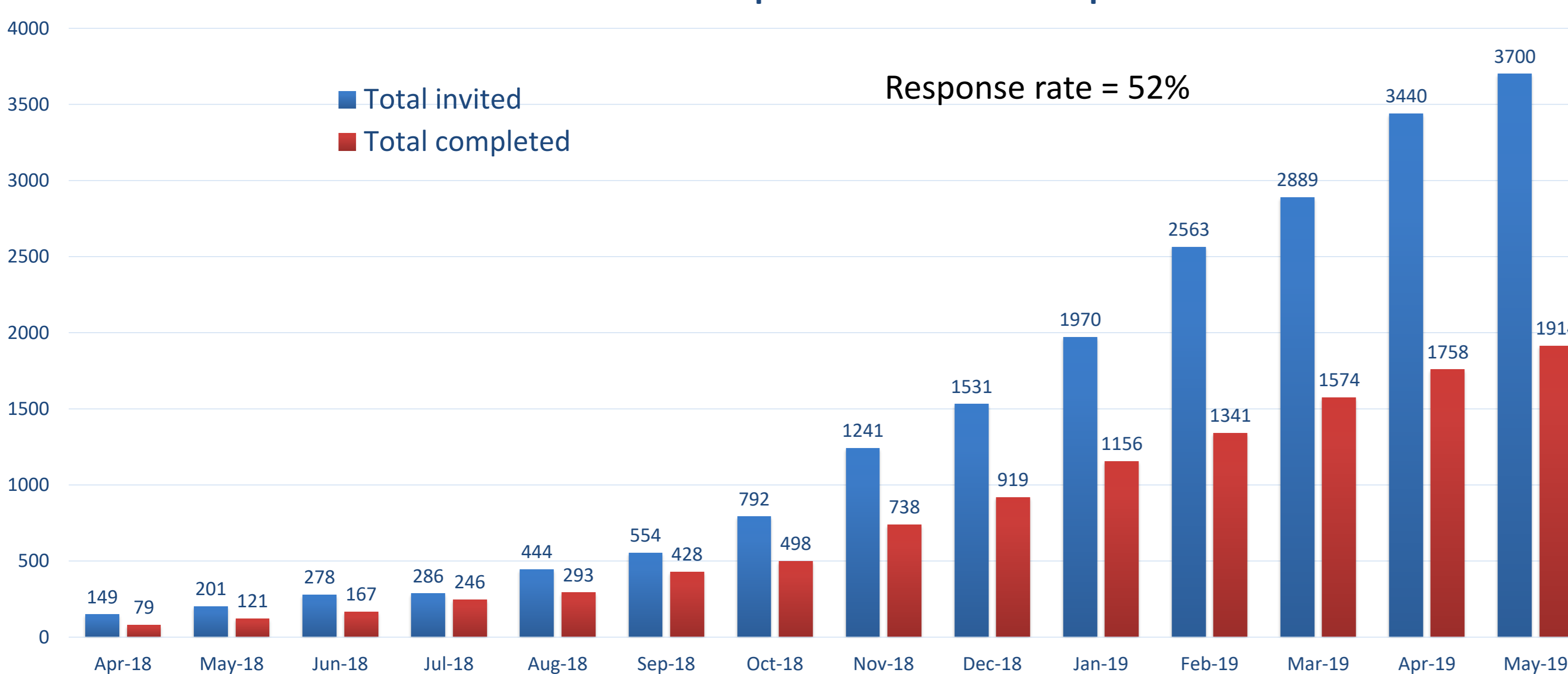
The main challenges identified were:

- Concerns about identifying eligible patients to take part in the pilot. This included problems with finding an 'end of treatment' date because this was not always recorded by trusts or easy to define for patients having multiple treatments.
- Concerns about the amount of administrative time needed to liaise with clinical and IT teams to check that patients were eligible, and processes for contacting patients.
- Issues with establishing IT infrastructure to enable collection of QoL data.
- Difficulties with developing the electronic QoL survey on different online portals.

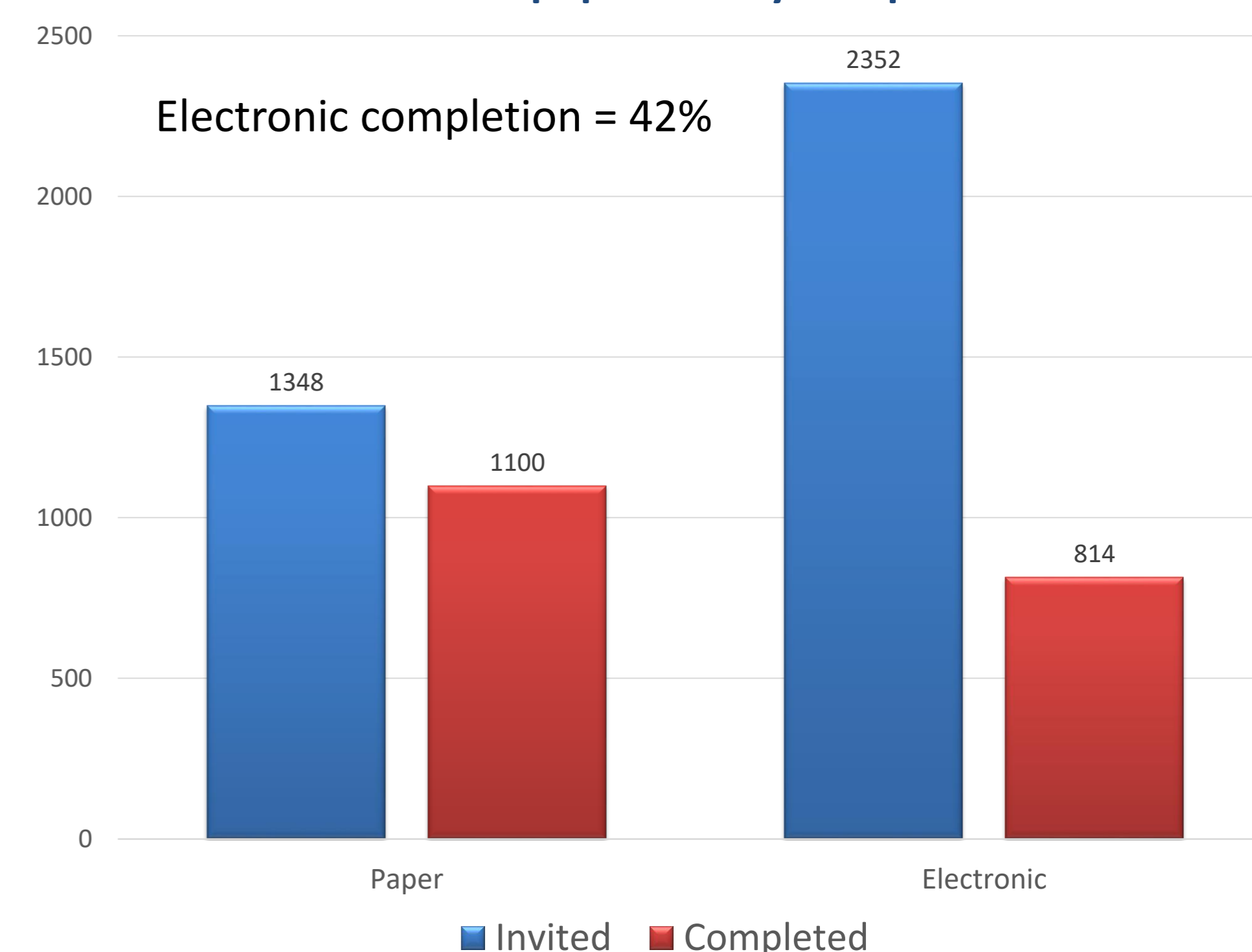
27 patients were interviewed about completing the survey. They told us that:

- Completing the survey was easy and straightforward and there were no technical problems when completing it online.
- They were uncertain about whether they should think about their health more generally when answering the QoL 'cancer' survey as other illnesses also affected their quality of life.
- They could see that the QoL survey captured general basic health but that they expected more cancer-specific questions.
- They were unclear how the results from the QoL survey would be used to benefit patients in the future.

Cumulative number of patient invites and responses



Electronic vs paper survey completions



Recommendations

- Include all cancer patients at all disease stages to support an inclusive approach and allow for a simpler way of identifying patients.
- Change the date patients are invited from 'end of treatment date', which is not routinely collected, to one to two years after the date the patient was informed about their cancer diagnosis using an established recording point, for example, from the Cancer Waiting Times (CWT) system.
- Develop a national communication plan that supports a clear sense of purpose and visual identity for QoL data collection.
- Provide all staff and patients with clear information on how the evidence collected in the survey will be used.
- Revise patient information materials, including the name of the QoL Questionnaire, so that patients understand whether to include other illnesses when answering the questions.
- Continue to give patients the opportunity to complete the survey 'online' in the first instance, but this should always be followed up with a paper survey and a reminder letter to increase uptake rates.
- Source the use of an external supplier to carry out the data collection. This will reduce local administrative burden within hospital trusts. This could also resolve many of the IT issues, ensure consistency across sites in terms of patients' experience and support uniformity in the data collection processes.

Conclusions

The pilot project has shown that a QoL survey in cancer patients assessing the longer-term impact of the illness is feasible to do and acceptable to patients. The project has helped to set the criteria for a national data collection. Initial ambitions to complete the data collection in an entirely electronic format cannot be recommended. Both electronic and paper options for completion are necessary. Locally devolved data collection systems that include the paper survey option are burdensome and should be outsourced to a fieldwork supplier; the overall ambition will be for the QoL data collection system to have as little impact on the delivery of care as possible. Through the collection of national data and appropriate case-mix adjustments, it will be possible to give clear expectations of outcomes for patients with different tumour sites and clinical characteristics.