30 day mortality rates post SACT

Evaluation survey and next steps

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Summary

In December 2018, the National Cancer Registration and Analysis Service (NCRAS) team at Public Health England (PHE) produced a workbook documenting 30 day mortality rates post systemic anti-cancer therapy (SACT) for 8 patient groups. These rates were calculated for all NHS trusts, cancer alliances and regions in England

The workbook was circulated to all trusts. Recipients at trusts and across a wider group of stakeholders were invited to complete a questionnaire to provide feedback on the workbook. The questionnaire explored how the workbook was used by all recipients. Additionally, participants were asked their preferences concerning potential revisions or alternative formats for 30 day mortality rates post SACT, and what they felt would improve the value and utility of the data in the future.

The feedback was generally positive, and most respondents wanted additional data to be able to use this metric to inform their work further. In addition to requests for the metric to be expanded to cover a larger number of cancer types, respondents were keen to have both more contemporaneous data, as well as case mix adjusted data. These aims cannot be achieved in a single data feed. The following data feeds have been proposed;

Rapid data review – 30 day mortality post SACT patients

For patients dying within 30 days of SACT, we would provide to the treating trust:

- NHS number
- consultant GMC code (provided to SACT dataset)
- cause of death
- place of death

Data would include patients treated over a 3-month period and be circulated 4 months after treatment activity. We would update this data every 3 months.

This data feed is designed to support clinical governance and short-term practice review.

Case mix adjusted 30 day mortality rates post SACT

We would provide case mix adjusted 30 day mortality rate post SACT on patients treated over a 12-month period, circulated 18 months following treatment activity.

This data feed is designed to support comparison of outcomes between trusts.

Background

In 2016, NCRAS published a paper in Lancet Oncology [www.ncbi.nlm.nih.gov/pmc/articles/PMC5027226/] providing 30 day mortality rates post SACT for breast and non-small cell lung cancer (NSCLC). Feedback from NHS trusts, NHS England and the clinical community established that this work had been beneficial in terms of setting a national benchmark, identifying variation between trusts in clinical practice and highlighting areas where patient care could be improved.

NCRAS have developed the current workbook as a follow-up to this publication, considerably extending the number of cancer types included. The workbook was designed as a pilot project, to establish the feasibility, value and effectiveness of an ongoing routine publication of 30 day mortality post SACT.

As part of the evaluation, NCRAS sent a questionnaire to trusts following circulation of the workbook. The questionnaire was designed to establish the most useful format and content for a routine data publication, which would benefit the largest number of stakeholders. Specifically, NCRAS wanted to understand which elements, such as timeliness and /or risk adjustment of the data or breadth of cancer coverage, would be more important to these stakeholders.

Methods

The workbook was sent to a named contact at all NHS trusts, typically the person responsible for uploading SACT data into the SACT portal each month (SACT uploader) and lead cancer pharmacist. Trusts were encouraged to review the data and invited to request the NHS numbers of patients in their trust who had died within 30 days of receiving SACT.

Two weeks later an evaluation questionnaire was sent to the workbook recipients and a wider list of trust stakeholders. The 2-week time delay was designed to give trusts the opportunity to review their data and consider how they may use the information before providing any feedback. This list was collated by the SACT Helpdesk on the basis of previous interactions with trusts and included key target stakeholders for example clinicians, pharmacists, and relevant stakeholders at organisations such as NHS England.

The questionnaire raised awareness of the workbook with a wider audience who may not have received the workbook directly through our initial circulation and had not been made aware of its release via internal trust communication channels. When the questionnaire was sent, recipients were invited to contact the SACT helpdesk if they had not seen the workbook. The SACT helpdesk then directed them to their named trust contact or shared the workbook directly if a valid NHS net email address could be provided.

In total, the questionnaire was sent to 1213 people. The questionnaire was available via an online survey platform hosted by PHE (Select Survey) for 4 weeks. All survey recipients were sent an initial email inviting them to participate and a reminder email 1 week before the survey closed.

In addition to survey responses, NCRAS also collected informal feedback from trusts and NHS England when disseminating the workbook and associated NHS numbers. This feedback has also been incorporated into the following report.

Results

In total, 92 individuals completed the questionnaire, providing a response rate of 7.6%. In many instances respondents gave partial answers only or omitted several questions. We have included the results of these partially answered questionnaires to capture all feedback received. Responses represented 64 different trusts.

The questionnaire contained multiple-choice and free text questions. Response distributions are provided for multiple-choice questions and responses to free text questions are condensed into 'themes'.
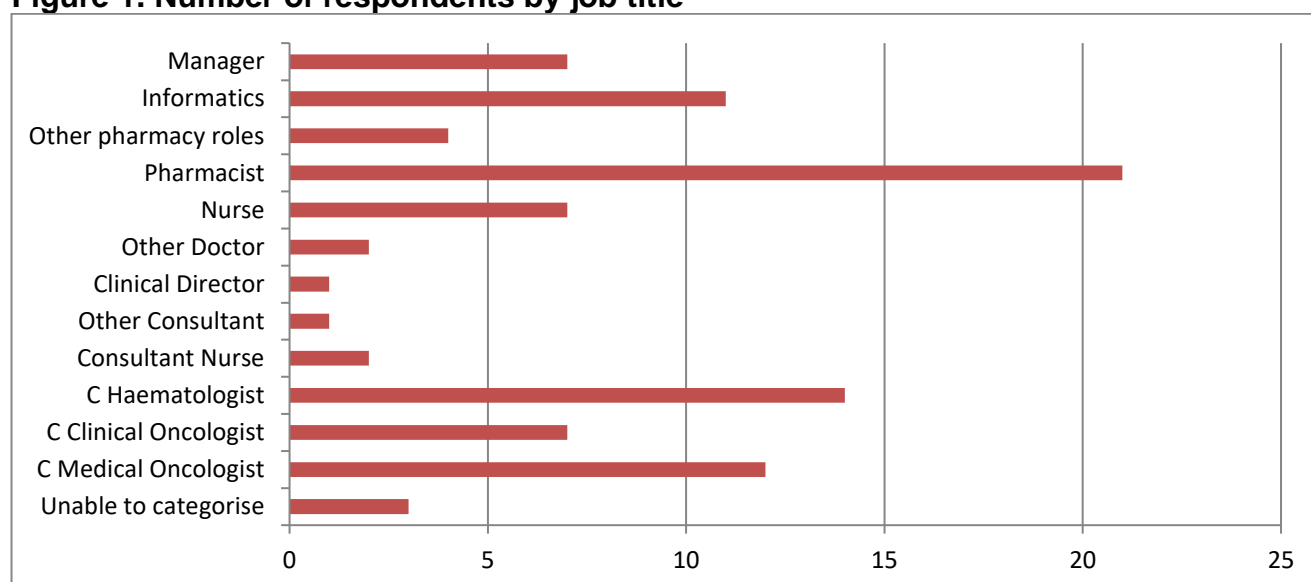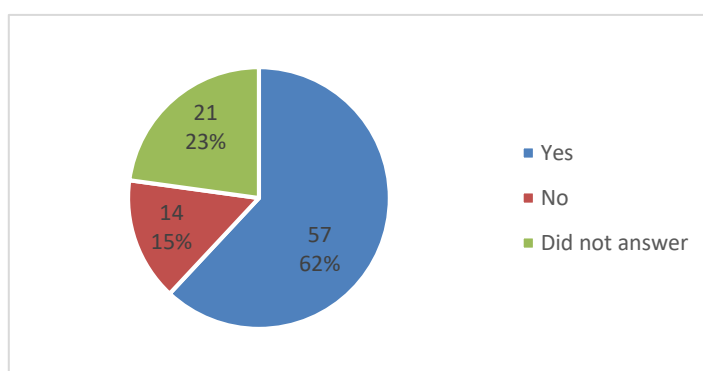
Figure 1. Number of respondents by job title

Figure 2. Proportion of responses to the question 'I accessed the report and viewed its contents'

Respondents who did not access the workbook reported:

- lack of time
- lack of awareness
- poor internal trust communication meant the report was not shared

Figure 3. The proportion of respondents who indicated 'My Trust used / intends to use the information contained within the report'
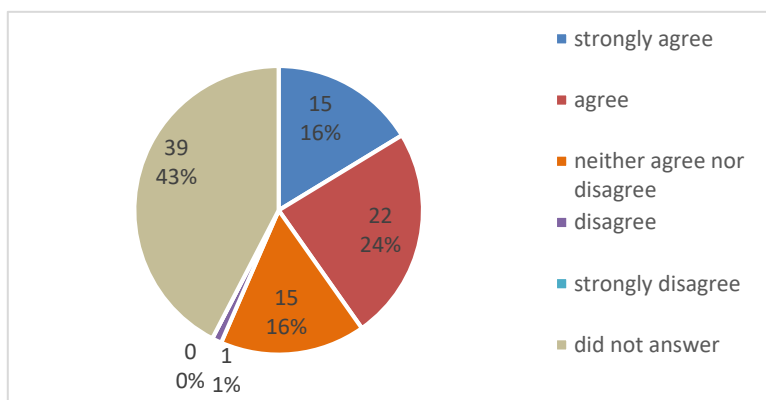
Trusts said they intended to use the information contained within the workbook:

- to inform mortality & morbidity meetings and other trust internal audit/governance meetings
- to appraise consultant performance
- to improve the quality of SACT data submissions, for example improve completeness of 'treatment intent' data
- to inform discussion on provision of workforce and training in relation to patient volume

Figure 4. The proportion of participants who indicated that "the report contained enough information to be useful"
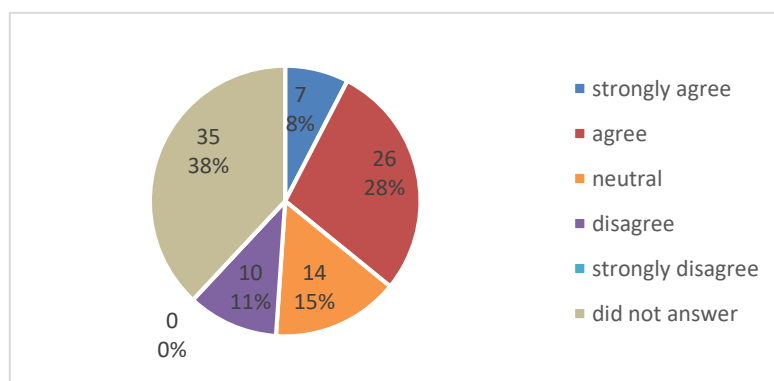
When asked what other information would make the workbook more useful, participants suggested:

- other cancer types
- more recent data
- performance status
- GMC code
- ICD10 code
- whether the patient was prescribed the SACT as part of a clinical trial or not
- height and weight
- line of treatment
- benchmarking (not clarified as to whether this is to national data, or previous performance, or a specific target)
- regimen
- days since death
- deaths grouped by those due to SACT and those due to other causes
- comparison to patients who have not died, to understand what the differences were (not clarified as to whether this was in terms of differences in patient characteristics between these groups, or in the treatment pathways for the patient).
- NCRAS to provide greater insight as to whether 30 day mortality rates post SACT indicate organisational changes are needed to improve service

Some of these requests are beyond scope in terms of the organisational remit of NCRAS and data availability. It is not appropriate for NCRAS to advise on how services should be configured or any specific action that should be taken to improve clinical outcomes.

**Figure 5. The proportion of respondents who indicated that "the impact of the workbook was positive/negative"**
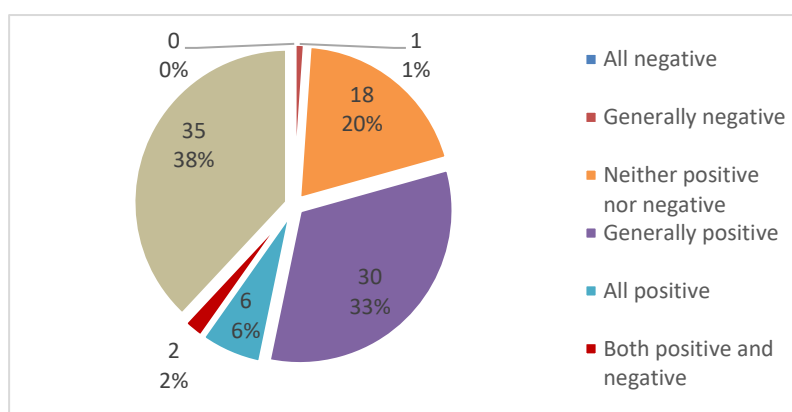
Some respondents were reassured to know their trust's results fell within the confidence limits and that their data was 'statistically normal'. Some trusts reported that the small numbers (presumably of cancers treated at their trust and the associated low number of deaths) limited

the usefulness of this data. Low numbers mean the data does not indicate whether there is a problem or not.

Figure 6. The proportion of respondents who indicated that "30 day mortality rate post SACT is the most useful SACT metric to inform my routine work"
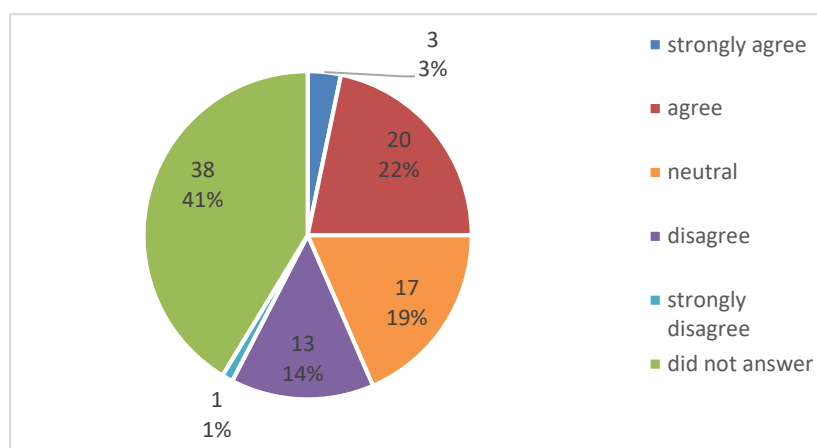
To further clarify responses to the above question (Figure 6) participants were asked 'what other SACT metrics would be more valuable?'. Participants suggested:

- survival (by stage)
- treatment duration (number of cycles)
- 30 day mortality split by cause of death
- 60/90-day mortality (as proxy for 'futile' SACT rather than toxic death)
- comparison of treatments
- split by ethnic background
- Patient Reported Outcome Measures (PROMS)
- recurrence free survival
- case mix adjusted data
- per consultant, with different tumour types merged
- dose reductions, other changes to planned treatment and reasons for change
- treatment outcomes other than death
- treatment wastage data
- compliance with algorithms
- performance status (PS)
- data on those who did not get SACT
- wider health economic variables including mental health and social support
- dose
- more timely provision of NHS numbers to trusts of patients who have died with 30 days of SACT

Although some of these are feasible and have been used to inform our plans, others are beyond the scope of the data currently collected by NCRAS.

Table 1: Participants were asked to rate factors in terms of importance to create the most useful routine mortality feed from 1 most important to 4 least important

Factor	Response total	1	2	3	4	Response average
Time delay following clinical activity	43	30.23% (13)	23.26% (10)	27.91% (12)	18.6% (8)	2.35
Frequency of feed	43	6.98% (3)	30.23% (13)	32.56% (14)	30.23% (13)	2.86
Rates adjusted to take account of case mix (allows more meaningful comparison between Trusts)	44	50% (22)	27.27% (12)	9.09% (4)	13.64% (6)	1.86
Additional data splits to reflect cancer morphologies	48	18.75% (9)	29.17% (14)	27.08% (13)	25% (12)	2.58

Frequency of the feed emerged as the most important factor (response average 2.86). Although responses indicated "Additional data splits to reflect cancer morphologies" would also be valuable (response average 2.58), this may be indicative of the appetite for an expanded range of cancer types. Requests for additional cancer types was reiterated throughout the free text comments. In contrast, none of the free text comments pertained to cancer morphology.

Table 2: Participants were asked to respond to how helpful they would find each of the proposed data feeds.

Data Feed	Not at all Helpful	Slightly Helpful	Moderately Helpful	Very Helpful	Extremely Helpful	Did not answer
1	Patients treated over the latest 12-month period, circulated 6 months after treatment activity, updated every 3 months, Crude mortality rates (not adjusted for case mix)					
	1%	6%	18%	23%	7%	45%
2	Patients treated over the latest 12-month period, circulated 18 months after treatment activity, updated every 12 months, rates adjusted for case mix					
	4%	13%	19%	14%	3%	46%
3	NHS numbers of patients dying within 30 days of SACT provided to trust of diagnosis, includes patients treated over a 3-month period, circulated 4 months after treatment activity, updated every 3 months * Please note NHS numbers only will be provided back to Trusts regarding the affected patients. There will be					

	no ICD-10 diagnosis codes as there is insufficient time lag in this data feed to enable linkage to Cancer Registry data which is required to provide this information					
	4%	8%	16%	19%	8%	45%

Based on the subsequent free-text comments, data feed 3 appeared to be the most divisive. Some respondents were keen for this data feed to start as soon as possible, others were unsure of its purpose, and how they would process this data feed. In general, it was felt that data feed 3:

- does not have a clear purpose, as this information is already considered at mortality & morbidity meetings
- would be a good opportunity to validate the data submitted to SACT against the trust systems
- has the potential to create a large administrative burden, and therefore including consultant GMC code would be important to ensure NHS numbers could be directed to the most relevant person

What was learnt from the feedback

The overall feedback from free text responses, multiple choice questions and additional communications has been summarised into themes below.

Communication

What went well

Many respondents reported that the workbook was well presented, easy to use, and provided all the relevant information.

NCRAS effectively communicated that the data should be used for mortality & morbidity or similar governance meetings, rather than to compare performance between trusts.

What could be improved

The workbook and questionnaire were released over the December holiday period. Whilst there was sufficient time to access the workbook, annual leave and other competing priorities made it challenging to integrate the workbook into normal working practice and governance meetings which were disrupted over the period. Future iterations of the workbook should bear this constraint in mind.

Trust named contacts should be validated via email before sending the workbook. Targeting a larger number of stakeholders in addition to the trust named contacts may be a useful way to facilitate internal trust communications. NCRAS could achieve this through having a wider mailing list to stakeholders whom we email to make aware that the workbook is being released.

Some respondents reported that the workbook is the only recent SACT data which they have seen. This is concerning, as it suggests that trusts are unaware of the activity reporting made available to them via Cancer Stats 2. NCRAS should continue to use the communication channels available to them including the SACT newsletter and the Data Liaison visits to publicise the outputs of the team. We also need to publicise other routes to access NCRAS data such as NCRAS enquiries and the Office for Data Release.

In general, trusts did not realise that they may not know all patients who die within 30 days of receiving SACT at their trust. Specifically, trusts are more likely to be unaware of a death if the patient died at home or in another hospital, or if trust systems do not have a facility for flagging deaths within 30 days of SACT. NCRAS need to better

communicate this issue to trusts and highlight the added value offered by the workbook which leverages data from the Office of National Statistics to provide a complete picture of deaths in a given period. The added value may be further reinforced by releasing additional data items to trusts such as cause of death or place of death alongside the NHS number.

Some trusts felt that limitations in SACT data quality restrict its utility and consequently were not intending to use the workbook to inform a review of care. Given the nature of the dataset, it is unrealistic to expect data quality and completeness to be comparable to a randomised controlled trial. Nevertheless, the dataset is of sufficient quality for many informative analyses, including the current 30 day mortality rates post SACT. NCRAS should provide more information on what the SACT dataset is and is not capable of doing, given the limitations associated with data quality and completeness.

Some respondents reported that the workbook needed to consider additional audiences beyond trusts, despite it being designed as a tool to inform review of practice. NCRAS should engage with stakeholders beyond trusts to better understand what their needs are, and what outputs could be delivered which meet these needs.

NCRAS could better publicise instances of best practice where trusts have used the workbook to review clinical practice and improve processes. It is beyond our remit to advise trusts on any specific actions they should take in response to their data.

NCRAS need to communicate that trusts within the confidence limits may still be able to review and improve their care. Benefits will be provided to the greatest number of patients if the national average 30 day mortality rate post SACT is reduced rather than focussing on a small number of trusts who are outside the confidence limits. However, this objective should not be driven in isolation, as it may lead to risk averse prescribing practices and result in less healthy patients, who may still derive benefit, not receiving SACT. Instead, this should be considered alongside a 'SACT access metric' designed to ensure that all patients who could potentially benefit from receiving SACT are able to do so.

Content

What went well

There was a generally positive reception to the workbook, with many respondents reporting that they were pleased that the previous Lancet Oncology publication was not a 'one-off', and that feedback that a more regular routine feed would be useful was listened to.

It is encouraging that several of the respondents reported that they found the information useful to review practice and inform mortality & morbidity meetings.

Trusts reported using the workbook as a means to demonstrate the importance of SACT data submissions and improve the quality of the data submitted.

What could be improved

There was some concern regarding the timeliness of the data in the workbook, as well as future proposed data feeds. Reassuringly, it was reported that data feed 3 (data presented every 3 months, reflecting treatment activity 4 months in arrears) would be sufficiently timely to support clinical audit.

There was strong advocacy for case mix adjustment, and several participants felt that this was essential for the data to be meaningful.

Throughout the questionnaire, many responses indicated that we should be including a larger number of cancer groups.

Some respondents suggested that low patient numbers at their trust prevented meaningful interpretation of the data. This suggests providing statistical analysis at any finer granularity, for example providing 30 day mortality rates post SACT more regularly to cover shorter periods of treatment activity, would not benefit the recipients of this data. Data based on small numbers does not identify when outcomes do not look normal and there is a risk of falsely reassuring trusts who should be investigating their data further.

Survival data is important to trusts to provide a better understanding of treatment outcomes. NCRAS should consider how it can make more of survival data available to trusts.

There is a demand to understand the causes of death. Respondents requested that deaths were broken down into toxicity, futile chemotherapy and other causes. However, death certificate information is often inaccurate, and would inevitably lead to misclassifications of SACT-related deaths and non-SACT related deaths. Any analysis based on this data is likely to be error prone, and there will be additional issues of even lower numbers associated with each cause of death. These issues would make the data inappropriate for a case mix adjusted analysis. Nevertheless, NCRAS will investigate the Information Governance issues around providing the cause of death information as part of a routine feed of NHS numbers.

Discussion

Whilst a breadth of NHS trusts and professional groups responded to the questionnaire, it is important to remember that the views expressed here represent a small fraction of the wider SACT and cancer community. The response rate was low; however, this is not atypical in situations where no incentive is offered to complete the questionnaire. Results may be biased as people are more likely to complete the questionnaire if they have extreme opinions. For the purposes of this report, this would correspond to either very positive or negative views on the utility of a 30 day mortality metric.

NCRAS has learnt many lessons, particularly around the communication of the workbook. We will implement these when publishing SACT data analysis more broadly. This will help to raise awareness of the capabilities of the database and ensure that the data is communicated and interpreted appropriately.

It is clear from the report that there is an appetite for more frequent data, provided more swiftly following treatment activity, as well as case mix adjusted data to enable comparison between trusts. Unfortunately, these aims are incompatible both from the perspective of statistical feasibility and resourcing. A more frequent data feed would be associated with a shorter reporting period. This will inevitably mean fewer cases, and consequently full statistical adjustment is not an option.

Proposal for future work

Based on the feedback received we propose to provide 2 data feeds to best meet the needs of different stakeholders.

Rapid data review - 30 day mortality post SACT patients

This data feed is designed to support clinical governance and short-term practice review.

To the treating trust for patients dying within 30 days of SACT, we would provide:

- NHS number
- consultant GMC code (provided to SACT dataset)
- cause of death
- place of death

Data would include patients treated over a 3-month period and be circulated 4 months after treatment activity. For example, 30 day deaths for patients treated January to March 2019, would be provided in August 2019. We would update this data every 3 months.

Case mix adjusted 30 day mortality rates post SACT

This data feed is designed to support comparison of outcomes between trusts.

We would provide case mix adjusted 30 day mortality rate post SACT on patients treated over a 12-month period, circulated 18 months following treatment activity. For example, 30 day mortality rate post SACT for patients treated from January 2017 to December 2017, would be available in July 2019.

Time delay

The time delay reflects the need to link SACT data to cancer registry data which is not available for approximately a year post-diagnosis.

Frequency of feed

The frequency of the feed may vary depending on the rarity of the cancer. For less common cancers, it may be more appropriate to pool the data over a longer period in order that there is a sufficient number of cases to complete case mix adjustment.

Tumour group scope

Generating case mix adjusted rates is a resource intensive process, and rates would have to focus on a smaller number of cancers. To meet the demands for a broader range of cancer types, it may be more appropriate to rotate between different cancers every 2-3 years.

Analytical approach

Case mix adjustment

The variables which we would propose to case mix adjust for include:

- performance status
- stage
- co-morbidity status

Missing data

Missing data is a key issue which prevents timely production of case mix adjusted rates, as it is often not straightforward to discern what impact the missing data could have on results. Missing data can lead to bias and the inability to detect true findings which are present in the data.

Trusts who do not meet a required threshold for data completeness for the case mix adjustment variables will not be included in the analysis for the relevant cancer group. In results, trust will be 'not assured' for these groups. A 'missing as category' approach will be taken to handling missing data. This means that all missing data will be assigned a dummy category value, and there will be no attempt to use statistical techniques such as multiple imputation to infer this missing data.

Conclusion

The most recent 30 day mortality post SACT workbook provided more recent data, covering a larger number of cancer sites to NHS trusts throughout England. In addition to highlighting opportunities for clinical audit of patient care, this process engaged many stakeholders and provided an opportunity to collect feedback and establish the most valuable proposals for the future development of this work.

Despite a broad range of requests, the overwhelming themes were that the data needed to be more contemporaneous, and case-mix adjusted to allow fair comparison between trusts. We have proposed 2 complementary data feeds which will address these distinct aims.