Review of the National Cancer Patient Experience Survey

A report prepared for NHS England

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Picker

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- Influence policy and practice so that health and social care systems are always centred on people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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Background

Picker, an independent healthcare research charity, was commissioned by NHS England to conduct a full and rapid review of the National Cancer Patient Experience Survey (NCPES). This review sought to understand how well the survey meets stakeholder needs, and to make recommendations for improvements to the current survey design, methodology, and reporting.

Methods

In collaboration with NHS England, Picker identified relevant stakeholders for the NCPES and developed a set of research questions to guide the review. Desk research was conducted to understand how the existing survey materials correspond with best practice in survey design. This included analysis of patterns in responses and missing data, nonresponse, floor and ceiling effects, time lag effects, and inter-item relationships within existing NCPES data.

Stakeholders were consulted and asked to share their views of the NCPES, and how they use the resulting data. Quantitative and qualitative feedback was obtained from stakeholders through an online survey, eighteen interviews, three focus groups, and an online consultation form on the emergent findings.

Qualitative data were analysed inductively using a framework generated in advance, based on the research questions. The coding framework was augmented deductively based on the responses obtained, to identify common themes and patterns within the responses. Numbers and percentages of respondents were tallied and calculated for the online survey.

Key Findings and Recommendations

Overall, the review found that the survey is generally fit for current purpose. Stakeholders appreciated the high response rate; large scale; standardised approach; and access to the data. A national programme was thought to be preferable to regional and local arrangements. Whilst stakeholders supported the NCPES, they offered several suggestions for improvement.

1. The primary purpose of the survey is not understood in a consistent way by all stakeholders. Stakeholders use the survey for different reasons, including policy evaluations, academic research, service improvement, and charity business planning, and therefore have different requirements for the survey results.

   The primary purpose of the survey should be reviewed and defined. The survey should be designed to fulfil this purpose. The impact of the design on secondary uses should be clearly articulated and communicated.

2. Several groups of patients with cancer are currently excluded from the survey. The exclusion affects outpatients, private patients, those with rarer or aggressive cancers, those not receiving active treatment, and those at the end of their lives.

   The survey sampling criteria should be reviewed and where possible the exclusion of these groups of patients should be addressed, to ensure NCPES provides a comprehensive view of care for patients with cancer. However, the potential impact on the cost of survey administration should be considered.

3. There is a time lag between drawing the sample and the survey administration, impacting recall, and excluding patients with poor prognosis. Another time lag exists between the survey administration and reporting, impacting on service improvement.

   Early release of preliminary results to trusts should be considered, to provide them with additional time for action planning prior to the next survey administration. Ideally, it would be desirable to send the survey to patients sooner after their discharge. This would address recall issues; ameliorate stakeholder concerns around the attribution of results to their sites; enable more patients with more aggressive cancers and a poor prognosis to respond; and encourage front-line users to see the results as 'current.' However, such a reduction may prove impractical, principally due to the time taken for Trusts to assemble complete patient records that form the basis of the sample. If this can be resolved a change to the sampling window should nonetheless be approached with caution as our analysis demonstrates that results for a number of items are likely to be impacted by any change, and this will require careful handling in interpreting trend data.

4. Stakeholders highlighted specific issues with survey items, such as double-barrelled questions, overlapping response options, and some topics not being fully explored. There was a consensus that the questionnaire is too long, and repeats questions that are already captured in other national surveys.

   The survey content should be reviewed. The accuracy of descriptions regarding how personal information is handled needs to be improved. Question formats should correspond to best practice. Item correlations and nonresponse should be used to determine question retention. Some terminology requires clarification. However, the impact on comparability and time series should be considered in light of any changes.

5. The survey reporting lacked desired data splits. Stakeholders would like to see results reported by region and with more granularity for tumour groups (some are aggregated on analysis). Trusts feel that they are held accountable for responses relating to other care providers, and would like a mechanism to disaggregate results. In addition, the presentation of the results is not easily understood, and should be more user-friendly.

   The reporting and presentation of results should be reviewed. Ideally, results should include an interactive option that enables stakeholders to access both a 'top-line' report and more granular data (where more than 20 responses are received to protect anonymity). The presentation of results for trusts could be revised to show the

aspects of the care pathway provided by trusts. The remainder of the results should be presented at a regional (e.g. Clinical Commissioning Group, or Local Authority) level to facilitate improvements in primary and social care.

6. Stakeholders requested more information and clarity regarding the incoming changes to the General Data Protection Regulation and the National Data Guardian review of information security, and how these will affect the NCPES.

   Stakeholders should be provided with guidance regarding the changes to the GDPR, and how this will impact specific surveys; for example, whether the NCPES will be exempt from new rules on consent. Implications for trusts drawing the sample should be detailed, and the impacts of any changes outlined to other stakeholders.

7. The large scale of the survey and high response rate were valued by stakeholders. They recognised that the survey is considered an example of good practice.

   National level data were seen to ensure comparability across the sector, and should be retained.

Acknowledgements

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Background

This report provides a rapid review of the National Cancer Patient Experience Survey (NCPES) in England. It was produced by Picker in consultation with the national Cancer Patient Experience Advisory Group (CPEAG), and several other stakeholder representatives.

Methods

Picker was commissioned by NHS England to conduct a full and rapid review of the National Cancer Patient Experience Survey (NCPES).

Picker sought to understand how well the survey meets stakeholder needs and to develop recommendations for improvements to the current survey approach. It was envisioned that this assessment of the survey and potential improvements could be related to the survey design, methodology, or reporting.

An initial scoping period was agreed to determine the relevant key stakeholders and research questions guiding this work.

This was followed by desk research on the survey itself, and stakeholder engagement activities to evaluate the current NCPES approach. Quantitative and qualitative data were collected and analysed. Informed consent was established in advance of telephone calls, and confirmed at the start of the conversation. Focus group participants were provided with an information sheet and written consent was collected prior to the discussions. An on-line survey was constructed in the survey software SNAP Desktop, and hosted on SNAP Webhost. Survey questions were drafted to address the research questions. These were reviewed in-house at Picker and by NHS England staff, who provided written feedback on a test version of the survey. The questions were adapted based on these reviews.

The findings from this research were triangulated across the multiple data sources; including desk research, focus groups, interviews and an online survey with stakeholders. There was saturation in responses, with common themes emerging. The desk review of the questionnaire did not assess content validity. However, we countered this in focus groups and interviews by asking what is important to patients and other stakeholders around cancer care and treatment. Investigation of the impact of survey mode and subgroup reporting at organisational levels were beyond the scope of this review.

Emerging findings from the research as a whole were synthesised. This synthesis was made available to the wider CPEAG via an online form, hosted on SNAP survey software; this provided an anonymous opportunity for comments on these findings to be sent to Picker, who assembled a final report.

Ethics

The study design was reviewed against the Picker Research Governance Framework, and assessed using the Health Regulatory Authority (HRA) decision tools.[1-2] It was deemed not to need ethical approval.

Results

Twenty-four stakeholders participated in eighteen telephone interviews; thirteen patients and carers with experiences of cancer treatment participated in focus groups; and twelve CPEAG members participated in a further focus group. Stakeholders represented hospital trusts, charitable organisations, national bodies, universities, and patients and carers. The online survey to trust respondents provided 184 responses.

Key Findings

Overall, the review found that the survey is generally fit for current purpose. Stakeholders appreciated the high response rate; large scale; standardised approach; and access to the data. A national programme was thought to be preferable to regional and local arrangements. Whilst stakeholders supported the NCPES, they offered several suggestions for improvement.

"[H]earing the voice of the patient can be really illuminating and it's the thing that also sometimes links together all the different bits of the jigsaw".

Key Finding 1

The primary purpose of the survey is not understood in a consistent way by all stakeholders. Stakeholders use the survey for different reasons; including policy evaluations, academic research, service improvement, and charity business planning, and therefore have different requirements.

Feedback from stakeholders highlighted the diverse uses of the survey data for reporting, improvement, and decision-making. NCPES data are used by academics, charitable organisations, hospital trusts, commissioners and regulatory authorities. The purpose of a survey impacts its design, and consequently the manner in which data are usable. A single design cannot fully satisfy all of the diverse uses; for instance, a national picture of all cancer care requires a different approach to localised improvement efforts. Some participants described a need to conduct additional analyses or to repeat the survey at a local level with a larger sample, duplicating work and placing burden on a busy workforce.

"[…] the vast majority of people who actually use NCPES results are lead cancer nurses in hospitals, and they're the policymakers in the charities, they're frontline staff and they're middle managers in NHS Trusts who find all the data quite complex […]And it's just a bit befuddling to people."

[1] HRA: Is my study research? http://www.hra-decisiontools.org.uk/research/
[2] HRA: Do I need NHS REC approval? http://www.hra-decisiontools.org.uk/ethics/

Considerations for the design of the survey should include a determination of whose experiences are being sought, of what, and why. The required granularity of the data on collection and reporting should be defined and the feasibility explored. The benefits for the participation of local sites should be articulated, particularly where small numbers reduce useable outputs. A clarification of whether the survey is concerned with 'the treatment of cancer' (including what constitutes treatment) or 'treatment in the NHS whilst having cancer' should be made. Some stakeholders stated that the survey includes items about care not specific to cancer treatment, favouring the latter interpretation. Further, some patients expressed surprise that they had not been asked to participate in the survey after being hospitalised for infection due to immunosuppression. Trust respondents noted that 'cancer related treatments' was poorly defined.

"We get a big boost in things like breast cancer where those patients have to come in regularly, into hospital so actually they are hitting that survey frame a lot more frequently. […]I think where we would like to see an improvement is probably additional measurements added on top of that, so that we incorporate either community care, or outpatient care."

Data collection and reporting are biased towards more common cancer types (such as breast cancer) and inpatients. Patients with rarer cancers, poor prognoses, not being actively treated, or treated as outpatients are excluded or underrepresented by the current design (See Key Finding 2). In addition, the fixed sampling window (April-June) means that the sample size is directly linked to the organisations' patient volume. Consequently, the current survey method does not capture the experiences of everyone with cancer. Small numbers, arising through rarity of the cancer in general, or at specific hospitals, or through a volumetric effect imposed by the fixed sampling window, are "suppressed" in reports.[3] Thus, the methods impose restrictions on the use of the data for particular cancers, and do not reflect the experiences of everyone with cancer.

The survey is set up as a sampled audit and, amongst other uses, is used as a measure for improvement. However, the receipt of data by trusts comes after the next sample is drawn. This means the data can be used as a measure of past attainment, but not for assisting day-to-day service improvement on an annual cycle. Furthermore, the use of these data as outcome measures are affected by the aforementioned skews on cancer types. Additionally, as the design of the survey captures the full treatment pathway there is a risk of attribution error, in which hospital trusts are held accountable for the entire pathway, even if aspects of care are not provided in that trust. The risk of (real or perceived) misattribution would be reduced with a smaller gap between the sampling window and the survey fieldwork, because concerns arise in part from the idea that people may receive further treatment elsewhere after their qualifying episode but before the survey. Such a change would be unlikely to completely resolve concerns over misattribution:

"[…] it is very difficult to have one lot of data that serves everybody, and everybody's needs, because I know that my needs are profoundly different from those of the cancer charities who are key stakeholders. It is the most important thing that we just focus on the point of it, and that's about improving the experience of care for the people who are using the services."

[3] One stakeholder expressed dissatisfaction with this terminology as it could imply data were masked rather than necessarily protecting the anonymity of people with rare conditions. Analytical phrases, particularly statistical ones, could be reviewed for plain English alternatives.

more use of linked clinical/activity data could help but is likely disproportionate to the benefit achieved.

The national capabilities of the survey were highlighted as a key strength. It was noted that it is difficult to have one data set that serves everybody, and that the survey should retain a primary focus. A review and definition of the primary purpose of and use for the survey should be conducted. Complementing this with a methodological review to ensure this purpose is met, and not consumed by other interests, will be beneficial to increasing the robustness of the data collected. A communications strategy on the components could detail what parts of the survey are useful to whom and for what. Features of the design that impose restrictions on the data would be clearly highlighted.

Stakeholder groups should be facilitated to work together to maximise benefits of the data. For instance, production of data analytics and visualisations that are suitable to mixed needs, and which have a high rigour of result to help reduce the duplication of work. Hospital trusts should be helped to gain the most benefit from their results, and to minimise the burden of collection, especially as this burden is sometimes unrewarded through small numbers resulting in usable reports not being generated. Furthermore, trusts should not be graded or ranked on features of care that they do not provide, with text to that effect placed in reports: Clinical Commissioning Groups (CCGs) are accountable for the system.

Key Finding 2

Several groups of cancer patients are currently excluded from the survey. These groups comprise outpatients; those with rare or aggressive cancers; those not receiving active treatment; those at the end of their lives; those with low literacy; and private patients.

The sampling frame does not reflect current cancer treatment, which is often delivered in an outpatient setting. To capture feedback from outpatients, the current survey sampling frame should be reviewed or a "bolt-on" option considered.

The current sampling frame uses hospital discharge data to identify adults with a confirmed cancer diagnosis, who have been recently treated as an inpatient or day case for cancer at an NHS trust. From stakeholder interviews and focus groups, there was surprise from some participants that they, or their families had not been invited to take part in the survey, despite being in hospital during the sample window. These exclusions could be due to treatment setting, or a manifestation of coding of admission reasons; e.g. admitted for infection (primary code), as a consequence of immunosuppression through treatment for cancer. This returns to the purpose of the survey; for instance, is the survey about the experience of being treated for cancer or the experience of being treated whilst having cancer? A communications strategy on who is being asked, when, and why, would be beneficial.

Stakeholders repeatedly stated that the inclusion criteria do not reflect current pathways of care, and thereby exclude a significant fraction of cancer patients. This is reflected in only one third of trust respondents stating that the inclusion criteria are fit for purpose. Some groups are over-represented, for

"You've got prostate and significant swathes of lung cancer. We in theory would miss out almost all of lymphoma, because that's delivered as outpatient chemotherapy or radiotherapy."

instance breast cancers and some lymphomas. The following groups were identified by stakeholders as excluded or under-represented:

- Outpatients: cancer treatment, including chemo- and radiotherapy, is increasingly provided in an outpatient setting. Stakeholders suggested that the proportion of patients treated as outpatients is likely to increase in the future.
- Patients with less survivable, or more aggressive cancers: those with poor prognosis may die between sampling and mail out, and are therefore under-represented in the sample. As noted under Key Finding 1, this could be improved through a change to the sampling window, but such a change is unlikely to be straightforward.
- Patients with rare cancers: responses from these patients often need to be suppressed in the reports due to low volume to protect anonymity, or they may not be represented within the sample window.
- In-patients with cancer who are not being treated for cancer, but for a consequence of the cancer treatment; for example, an infection arising from immunosuppression.
- People who are not receiving active treatment, such as those people on "watch and wait" protocols.
- People living with or beyond cancer: those in remission are not included in survey sample. This is a concern for those stakeholders who are keen to understand the whole of the patient journey.
- People at the end of life
- Dissenters: patients who have opted out of the NCPES.
- People with low English language literacy
- People undergoing private treatment

Feedback from stakeholders contends that the omission of outpatients from the NCPES sample is a particular concern. Furthermore, this contributes to underrepresentation of patients with specific cancer types that are more commonly addressed in outpatient settings (for example, prostate cancer).

"A great deal of cancer care is now delivered in outpatient settings and therefore we are failing to capture the experience of huge group of patients."

Addressing the exclusion of outpatients is unlikely to be as simple as revising the survey sample to include people with an eligible inpatient, day case, or outpatient episode within the sampling window. It is likely that the content of the questionnaire would be unsuitable for many people who have predominately received outpatient care. Furthermore, such a change would be expected to impact on overall trends in the survey due to changes in the sample composition. Expansion of the survey to include an overview of the experience of recent outpatients needs to consider:

- How the survey content can be tailored to be suitable for people who are not known to have had a recent inpatient or day case episode.
- How results can be analysed in a way that maintains useful trends for inpatient and day case care, whilst beginning to incorporate this wider group of patients.
- How duplication and unnecessary burden can be avoided, both within NCPES and with other survey collections.

An obvious option is to expand the sampling criteria for the survey and develop a separate questionnaire for use with

"We need to ensure the diversity of the population is reflective of our service users and the concern at present is that it does not capture those diverse groups with different languages."

outpatients. This would, effectively, mean administering two parallel cancer patient surveys, with simultaneous sampling to allow trusts to conduct this as a single exercise. This would minimise added burden for trusts and would avoid duplication of patients across the two collections, whilst allowing tailoring of content for outpatients. A core of questions on common experiences could be included in both surveys to allow development of overall estimates for the population of cancer patients treated in secondary care.

This approach, whilst straightforward, is not without downsides. Most notably, the cost to NHS England would be significantly increased. However, the overall value for money to trusts may be improved due to the economy of scale inherent in the parallel sampling approach. The biggest cost here would be the marginal costs of printing, posting, and data entering paper questionnaires. A sampling pilot would determine how many people are eligible as outpatients but not inpatients, these data are not otherwise available, and so a precise cost cannot be determined. If outpatients represent the same volume of the patients as inpatients, the marginal costs are thus doubled.

Just over two-thirds of those people drawing the sample had an issue in so doing. The biggest reason is outside of the control of the national NCPES: not enough resources in the trust. Alternative mechanisms could be sought, although would necessarily impact the time-series, thus benefits and risks should be weighed. Several respondents mentioned that cancer registries could be used to improve the diagnosis confirmation, and there could be an advantage of moving the sampling process external to the hospital trusts. Similarly, Hospital Episode Statistics (HES) could be investigated as a data source. Some stakeholders noted a difficulty in establishing what constituted a 'cancer related treatment', thus provision of a determined list of treatments to be included could be beneficial.

Key Finding 3

There are some challenges arising with the administration of the survey. There is a time lag between drawing the sample and the survey administration, impacting recall, and excluding patients with poor prognosis. Another time lag exists between the survey administration and reporting, impacting service improvement.

The desk research identified impacts on the positivity and negativity of responses to different questions. Patients with a longer time period since discharge tended to be more likely to say that they had understood explanations given to them about their cancer; to have been told about possible side effects; to have been given clear information; and to have been content with waiting times. Patients surveyed closer to their discharge are more likely to report having had a conversation about cancer research since their discharge. A similar pattern was observed for questions relating to being told about free prescriptions, suggesting a recall issue: that is, that patients may have forgotten about the relevant discussion by the time of receiving the survey. Adequacy of recall is an issue faced by many surveys, particularly where questions are less salient to respondents. In this case, it should be possible to maintain trends based on the items as, all else being equal, the effect of recall issues should be balanced across years: however, it should be

"Pancreatic cancer hits very quickly and has very poor survival rates, so there are hardly any pancreatic cancer patients in the NCPES data that we get back."

acknowledged that these particular questions do not accurately estimate the concepts they seek to measure.

There was a statistically significant inverse correlation between time-to-respond and survey responses – meaning that later respondents were consistently more negative. This is similar to findings in other surveys. Additionally, due to the lag between drawing the sample and sending out the survey some people could have had additional appointments between the index discharge and the receipt of the survey, with consequent impact on recall. Consideration should be given to adding a 'time since discharge' variable to the standardisation approach for the survey to balance the impact of these differences when comparing organisations. To overcome the under-representation of people with poor prognoses, some stakeholders suggested allowing patients to be notified earlier and provide options for them to complete the survey closer to their discharge.

Stakeholders reported the need to find balance between describing all the stages of the pathway and the impact this has on the timing of the sample, survey, and results (as noted in Key Finding 2). Drawing the sample takes time, and requires resourcing at the hospital trust sites. This resourcing can feel unrewarded as a result of the long time to receive results, often after the next round of sampling has begun. The survey of trusts found that whilst the majority of respondents thought the frequency and scheduling were appropriate, a sizable fraction did not share this view, stating that the delay in receiving data impacted on improvement efforts. There was a dichotomy of opinion between those respondents who advocated increasing frequency, including making the survey near real-time, and those respondents who advocated for a reduction in frequency to give time to action reports. One suggestion was to have early release of preliminary results to trusts to provide a basis for action planning.

"I feel that the time scale from inpatient episode to reporting (over 12 months) does not allow for any action plans to change patent experience."

Stakeholders highlighted a need for a consistent approach to sampling to maintain the quality of the data. They acknowledged that drawing the sample is a time intensive process, requiring adequate time to complete the required steps of identification, cleaning, de-duplication, running deceased checks, and sending out the survey. Stakeholders also thought that the timing of the sample provided patients with time to process and evaluate experiences, which is an important counterpoint to the findings above regarding recall issues in some items. Timing of the survey relative to patients' discharge is not a straightforward decision: although patients may better remember some experiences closer to the event, attempting to survey patients too quickly may cause practical problems for trusts or allow patients insufficient time for reflection.

"To get this kind of national comparable data with such a phenomenally high response rate, it [time] is what it is."

Key Finding 4

There are several issues with the survey materials; including ambiguity in covering letters, double-barrelled questions, overlapping response options, and some topics not being adequately explored. Stakeholders felt the questionnaire is too long, and repeats questions that are already captured in other national surveys.

Instructions on how to complete and return the questionnaire are generally clear. However, advice given here on the handling of personal information should be reviewed. In particular, the statement that "*your personal information will be… anonymised after analysis*" appears misleading and contradicts the subsequent statement that "*by completing this questionnaire you are giving your consent for [your personal information] to be … held and used by NHS England and organisations acting under its instruction*". Similarly, the statement that "*names and address information will be destroyed after 3 months of completion of the survey*" is ambiguous, as it is not clear what constitutes completion of the survey: the end of fieldwork or the survey publication would both appear reasonable interpretations, and occur at quite different times. We recommend reviewing and revising the statements around handling of personal information.

Several questions were highlighted for review from design best practice (Q1-3, Q7, Q8-11, Q27-39, Q40, Q54, Q66). Analysis of survey data indicated another set of questions that should be reviewed due to correlations and nonresponse (Q20-23, Q43-45, Q46-48, Q51, Q55). There were several problems with the phrasing of some questions, and response scales. Issues included: double-barrelled questions; overlapping response options; wording of questions; unfamiliar terms or titles for staff groups; difficulties for non-English speakers; and items not set up for people with visual impairments.

"There were a few examples…where the responses that were provided were overlapping. So when we are asking about a timeframe, there were responses that ranged from zero to three months and then the next one was three months to six months, so if there was three months you could answer the first response or second response. So clearly we want to avoid overlapping ranges in response scales as well."

Stakeholders highlighted a lack of questions on screening and diagnosis, especially for under-represented patient groups; and involvement in care and treatment decisions for particular cancer types. The inclusion of additional questions were requested, pertaining to particular treatment types (for instance, stem cell transplantations for blood cancers; involvement with clinical trials, and experiences of different staff groups). The survey's intended purpose should direct whether such detailed questions are necessary in the national survey, or could be better answered through research focussed on specialised interests. The desire for additional questions should be balanced against stakeholders' criticisms of the length of the survey.

"I think it needs to be shorter […]. Substantially shorter. People tell us that it has taken them days over several sittings as it were, to get through the whole survey."

"So one of the failings of the NCPES questionnaire is that it asks… what I describe as kind of transactional stuff about cancer patient experiences…[W]hen you visited your GP, what happened? […] Actually, when you talk to cancer patients, the stuff that most impacts their quality of life and really the impact their experience of what's going on is the emotional support that they get..."

Whilst more detail was sought for some topics, the questionnaire was felt to be too long. There were several suggestions for how to overcome this, with disagreement about the best approach to capture actionable data: more targeted to different groups, or more general to give national comparable results. There were suggestions of a reduced core set of questions, with a rolling programme of more targeted questions. This may be useful in helping to reduce the risk of survey fatigue for the respondent – several stakeholders commented that respondents were asked to complete multiple national surveys each year, many of which contain similar questions. A reduction of repetition through linked responses could be considered, along with removal of overlapping questions across multiple surveys.

"I think there's something to be said about streamlining the process of people, so that when they want to give feedback, they're able to give all the feedback that people want from them, rather than segregating it, as kind of currently happens."

Key Finding 5

The survey reporting lacks granularity. Stakeholders would like to see results reported by region and cancer type. In addition, trusts feel that they are held accountable for responses relating to other care providers and would like a mechanism to disaggregate results. The presentation of the results is not easily understood and should be more user friendly.

Desk research found that the design of the survey reporting was generally attractive with good visual appeal, however some areas for improvement exist, including the creation of an online interface, detail of the statistical tests used, and improvements to data visualisations. Alignment of the bases for appendices and main text should be addressed, and the process for creating the pdf reports should be reviewed to ensure documents produced are of sufficient standard.

"I think what we would really look forward to is having some type of online platform with specific tables or something where we can actually look at the results much more richly than just a PDF report."

Stakeholders highlighted the national comparisons as a key strength, and the format overall and the online access were appreciated. However, many stakeholders reported they were conducting additional analyses, and that the reporting is difficult to understand in layman's terms. Summaries and top-line results would be helpful, and a more interactive online platform that allows greater granularity to be achieved was expressed as desirable. Stakeholders wanted to see an increased level of specificity by tumour type, patient group, stage of diagnosis, and treatment region, with linkage and comparisons across data sets. A combination of statistics and stories, to contextualise the results and make use of qualitative data, was suggested, making the narrative comments of NCPES available. It was suggested that the report structures could be aligned to national priorities each year; and that trusts should be searchable by name rather than code to increase usability.

However, the desk research determined, and some stakeholders cautioned, that the use of finer granularity reporting can result in unusable outputs, as low numbers result in the suppression of reports to preserve anonymity.

The aforementioned attribution error of cross-site treatment being allocated to one trust only requires a solution. A potential option is to restructure reports based on the features of care that are provided exclusively by trusts, with the rest of the pathway being reported on at a

regional level within the trust report, placing the onus for change on those aspects on to the CCGs, and primary and social care providers. This would help to align the reports to the provision of cancer care.

Consideration could be given to improving links between academic researchers and charity organisations, to ensure a high degree of rigour in reporting on questions of interest to the community. As many stakeholders are conducting secondary analysis, a review of those analyses should be conducted, with consideration to a supplement to the main analyses if there are considerable overlaps. Any such supplement may need to follow separately from the main publication of the survey to avoid delaying the initial release of findings, but this is likely to mean the additional analyses being available for users more quickly than is currently the case.

"What spoils our sample is the dire experience of their diagnosis and work up in another trust, which is then attributed to ours."

"Patients receive treatment at other hospitals and results/their comments reflect this so results do not accurately portray a trust's position."

Key Finding 6

Stakeholders requested more information and clarity regarding the incoming changes to the General Data Protection Regulation (GDPR), and National Data Guardian review of information security, and how these will affect the NCPES.

There was uncertainty around the potential implications of the National Data Guardian's review of information security and its recommendations on opt-outs from data sharing. Surveying NHS Trusts showed that providers lack consistent and reliable mechanisms to identify patients who have opted-out locally, and the number of reported opt-outs is very low. This means that very few patients are currently excluded from the sample frame due to having expressed their dissent for data sharing; changes that make the option to opt-out of future research more apparent to patients risk increasing this number, and stakeholders anticipated a negative impact on participation in the survey. To defend against this risk a communications strategy is needed to encourage participation, highlighting why this survey is important and the improvements made as a result. This may, however, remain inadequate if patients are making advance decisions to opt out of all research. A better solution would be to seek an exemption from the new opt-out: since this review was undertaken this has been agreed on an initial one-year basis, but stakeholders would benefit from extension of this arrangement.

Similarly, stakeholders indicated a lack of clarity around the GDPR, and wanted to know if existing exemptions for public benefit still apply. There is a risk that differences in how trusts understand the GDPR requirements may affect sample composition for the survey in the future, so guidance should be provided that describes the information governance arrangements for the survey. Meanwhile, the patient information sheet provided with the 2017 survey does not fully meet the requirements of the GDPR, and should be redrafted ahead of future use (see Key Finding 4).

Key Finding 7

The large scale of the survey and high response rate were valued by stakeholders, despite challenges, recognising that the survey is a considered an example of good practice. In general, stakeholders have a positive view of the survey.

Despite concerns the survey is positively perceived, with a number of comments regarding its value, particularly it being drawn together at a national level by a single provider. The national provider was seen to ensure comparability across the sector. Stakeholders expressed concerns of changing the administration approach, for example, moving to in-house survey administration with regards to consistency of approach and anticipated higher costs.

Stakeholders highlighted this survey is looked at by researchers from other countries and those specialising in other diseases as an example of good practice. Strategies to capitalise on the good practice could be made, with dissemination activities to spread knowledge of the survey.

Feedback on this review should be provided to participants in this study, and a communications strategy for sharing key messages with a wider audience could be beneficial for further raising the profile of this survey.

"It's an enormously rich data source that we've been collecting for […] seven or eight years, and a lot of use is made of the data."

"Despite the significant limitations, the NCPES must continue until a robust and systematic solution is found. To be national, this needs to be led and directed nationally. Leaving individual trusts to provide will create inequitable administration of any survey, and non-comparable data - even more unfit for purpose or benefit. Patients are exhausted from being asked to contribute to so many surveys. This all needs joining up at a national level."

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