

# **Practicalities, challenges and solutions to delivering a national organisational survey of cancer service and processes: lessons from the National Prostate Cancer Audit**

## **Introduction**

Organisational surveys are a critical process to assess the configuration and availability of services within health care systems. This gives an awareness of the current 'landscape' of services on offer for evaluating the provision across a region, to assist patients in their understanding of what services are available at their own local provider and to allow providers to benchmark their own offering.

Organisational surveys relating to the provision of cancer services have been performed internationally to identify important gaps and factors associated with breast cancer care in Europe<sup>1</sup> and across cancer types in The Swedish Cancer Registry<sup>2</sup> and in Australia.<sup>3</sup> In the UK, cancer audits within the National Clinical Audit Programme<sup>4</sup> have carried out surveys to determine the availability and arrangement of prostate,<sup>5</sup> breast,<sup>6</sup> oesophago-gastric<sup>7</sup> and bowel<sup>8</sup> cancer services. Outside of the audit stakeholders, knowledge of the availability of these services is limited and comprehensive system-level data is still difficult to find.

## **Why are organisational surveys important?**

Organisational surveys of cancer services provide an understanding of the structure of care (a key determinant of quality)<sup>9</sup> by detailing the availability of facilities and their geographical organisation. They also can provide information on the processes of care such as the type of image guidance routinely used by a hospital for radiotherapy or the type of surgical technique e.g. robotic or open. This is critical for evaluating the delivery of cancer care services regionally or nationally, and how the availability of services (i.e. its structure) and its configuration can impact on variation in access to care and outcomes of care. Furthermore, the organisational survey provides essential information about patient support services which can be used by organisations and charities to inform patients where particular support services are available.

## **The experience of the NPCA**

### *The NPCA*

The National Prostate Cancer Audit (NPCA) is an audit of all prostate cancer services in England and Wales.<sup>10 11</sup> The audit has been running for 9 years and includes all 138 NHS Hospital Trusts offering diagnostic or treatment services for prostate cancer. The audit uses high quality routine administrative and clinical data sources available in the UK including Cancer Registry data, Hospital Episode Statistics (HES), the Radiotherapy Data Set (RTDS) and the Systemic Anti-Cancer Therapy (SACT) database. These data sources are linked to provide information on the care pathway of patients from the point of initial referral, to treatment and after-care.

Each year the NPCA reports on the variation in the processes and outcomes of care for all patients newly diagnosed with prostate cancer in the England and Wales NHS. Process indicators include the proportion of men receiving transperineal or transrectal biopsies and the proportion of men diagnosed with low risk prostate cancer who receive radical treatment. Outcome indicators routinely reported at the hospital-level includes the proportion of patients who had an emergency readmission within 90 days of radical prostate cancer surgery and the proportion of patients diagnosed with radiation toxicity (gastrointestinal (GI) complication) up to 2 years following radical prostate radiotherapy.

The first NPCA organisational survey was performed in 2014.<sup>12</sup> This survey was essential in providing a contemporary and detailed assessment of the availability of specialist prostate cancer services and workforce in each of the 138 NHS Hospital Trusts in England and Wales which is not available in the routine datasets. For example, the availability of different types of brachytherapy equipment, as well as the number of clinical nurse specialist nurses at each centre with a specialist interest in prostate cancer.

The NPCA makes this information available on our website with an opportunity for providers to 'update' their service provision annually, which ensures that all information is as contemporary as possible.

The survey has provided patients, policy makers and providers with information about disparities in the availability of services nationally. This therefore informs plans for commissioning of specialist services to ensure these gaps do not translate into inequities in access to services and, in turn, impacts on outcomes. In this paper we describe the 2021 NPCA organisational survey and the challenges in conducting a national organisational survey of cancer service and processes.

### *The questionnaire*

The NPCA sent a 'SurveyMonkey' link to an online questionnaire to the prostate cancer clinical leads within each of the 138 NHS providers. Emails included an indication of the time it might take (no more than 15 minutes), the information needed for completion, and a link to our webpage where full instructions and an updated list of respondents was kept. The list of communications, dates and responses are shown below.



At the end of the survey process, we had received 174 responses from 129 providers (more responses than providers due to duplicate responses being submitted), a response rate of 93% (from 138 Trusts). However, this did not come without its challenges.

### **Challenges of conducting an organisational survey**

There are many challenges to conducting an organisational survey. Although online surveys, rather than paper-based, have become the norm<sup>13</sup> gaining a high completion rate is still difficult, even among professionals<sup>14</sup> and 'survey fatigue' is a recognised problem.<sup>15</sup> A study by Cunningham et al<sup>16</sup> highlighted the difficulties of conducting such a survey. They sent a survey to 904 medical professionals via 'SurveyMonkey' and tried multiple methods to encourage responses including individual personalised email invitations, multiple reminders and a gift draw. Their response rate was 35% with some specialities having higher response rates than others and women being more likely to respond than men. The non-respondents who gave a reason, listed lack of time and survey burden as the main reasons for not responding.

An up to date contact database of key contacts is an important first step. Changes within provider teams may result in 'bounce back' emails and additional time will be required to identify new contacts. Another challenge is the time required to gather responses. We had initially aimed for a two-week window for completing the survey but this was extended to

over two months. This resulted in a delay to the analysis and publication of the results. The NPCA received a very high response rate to the organisational survey because it was an active process from start to finish, with involvement of the senior clinical leads who contacted the healthcare providers who had not submitted a response and encouraged them to do so.

In addition, duplicate responses can be a challenge. We received multiple responses for some providers, meaning that two (or more) different team members filled in the survey independently or, occasionally, the same person filled it in more than once. These responses were examined and the providers were asked to clarify which response they would like to submit as 'final'. If a provider did not respond regarding duplication, then the NPCA team reviewed the data in order to de-duplicate it using a hierarchy based on the provider team member's role and knowledge of the onsite arrangement of services, starting with the clinical leads.

A final challenge is the receipt of conflicting responses from the same provider. To resolve these, we did an online search to determine whether major services were available or not as required. It highlighted that two people working at the same Trust can have very different experience, or awareness, of the services on offer across the whole site. Once the de-duplication process was complete, we sent the results back to all providers to confirm the details were correct before it would be displayed on our website. Box 1 summarises the challenges when conducting an organisational survey.

#### **Box 1: Challenges of conducting organisational surveys**

##### *1. Accuracy*

- It is important to have accurate and up-to-date contact details to ensure the most appropriate member of the MDT is invited to complete the survey.

##### *2. Completion*

- Clinicians are very busy and may struggle to complete the survey by a certain deadline.
- Without contemporary completion, comparability of the results of the survey across providers may be affected.
- Long completion times may delay access to the latest, up to date services information, which is crucial to understand cancer processes and outcomes.

##### *3. Duplicates and discrepancies in responses*

- The provider needs to clarify their response when duplicate responses are submitted.
- Discrepancies in responses from the same provider highlight different people working at the same provider can have very different experience, or awareness, of the services on offer across the whole site.

#### **Suggested solutions for the development of future organisational surveys**

From our experience at the NPCA, there are some suggestions for the practical delivery and development of future organisational surveys, represented in Box 2. It was thanks to the use of many of these strategies, and the engagement of clinicians with the NPCA, that we were able to achieve such a high response rate.

## **Box 2: Suggested solutions for development of future organisational surveys**

1. *Maintain up to date contact lists and encourage our contacts to keep in touch with us with any changes.*
  - This takes significant resource and preferably a dedicated person within the survey team should take responsibility for keeping track of changes.
2. *Clear communication*
  - Ensure that participants are aware of the aims and importance of the survey
  - Circulate a 'save the date' notifying the target audience in advance on the survey rollout
  - Let participants know the time it might take to complete the survey and the information they might need to hand in advance
  - Provide clear instructions for how to complete the survey with links to additional web-based information and survey team contact details
  - Use a range of communication methods – direct communication via email but also newsletters and social media
  - Show participants how similar data has been used in the past and might be useful for them
3. *Design of the survey itself.*
  - Consult with clinical stakeholders and patient representatives in the design of the survey
  - Pilot the survey to test the functionality of the questionnaire, how long it takes to answer the questions and to identify where improvements are needed
  - Limit the number of questions so the time taken is manageable and so response is maximised. Add functionality to the online survey to avoid a Trust being able to submit more than one response.
4. *Suggest that teams complete their organisational survey within an MDT setting*
  - Despite the potential burden that this may place on MDT teams, this would achieve a comprehensive and accurate submission drawing on the understanding of all MDT contributors at one time, potentially a time saving overall.
  - It could also help MDT members to have a better overview of what is on offer where they work.
5. *Support of the professional organisations*
  - Launch data collection during the annual conference of the relevant professional organisation, for example BAUS Oncology, alongside a presentation.

## **Conclusion**

The challenges of conducting an organisational survey include factors ranging from the availability of up-to-date contact information to ensuring that your survey is well designed and relevant. The process highlighted that different members of the MDT may understand the services within their own scope of work but not of all services available within a provider, and that even with careful design, limited time can make surveys feel burdensome to responders.

Despite these challenges, the importance of organisational surveys of cancer services is demonstrated by the better understanding of structure, processes and outcomes of cancer care according to the accessibility of facilities and their geographical organisation. This is essential for evaluating and improving the delivery of cancer care services across a region.

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<sup>1</sup> Joint Research Centre, Institute for Health and Consumer Protection, Villanueva, S., Freeman, C., Nicholson, N., et al., Report of a European survey on the organisation of breast cancer care services : supporting information for the European Commission initiative on breast cancer, Publications Office, 2014,

<sup>2</sup> Ingrid Schmidt, Johan Thor, Thomas Davidson, Fredrik Nilsson, Christina Carlsson, The national program on standardized cancer care pathways in Sweden: Observations and findings half way through, Health Policy, Volume 122, Issue 9, 2018, Pages 945-948, ISSN 0168-8510, <https://doi.org/10.1016/j.healthpol.2018.07.012>.

<sup>3</sup> Hunter, J., Smith, C., Delaney, G.P. et al. Coverage of cancer services in Australia and providers' views on service gaps: findings from a national cross-sectional survey. BMC Cancer 19, 570 (2019). <https://doi.org/10.1186/s12885-019-5649-6>

<sup>4</sup> National Clinical Audit Programme (2022) accessed at <https://www.hqip.org.uk/a-z-of-nca/#.YjMGNpTP02w>

<sup>5</sup> National Prostate Cancer Audit (2022) accessed at <https://www.npca.org.uk/>

<sup>6</sup> The National Audit of Breast Cancer in Older Patients (2022) accessed at <https://www.nabcop.org.uk/>

<sup>7</sup> National Oesophago-Gastric Cancer Audit (2022) accessed at <https://www.nogca.org.uk/>

<sup>8</sup> National Bowel Cancer Audit (2022) accessed at <https://www.nboca.org.uk/>

<sup>9</sup> Berwick D, Fox DM. "Evaluating the Quality of Medical Care": Donabedian's Classic Article 50 Years Later. Milbank Q. 2016; 94(2):237-241. doi:10.1111/1468-0009.12189

<sup>10</sup> NPCA Annual Report 2021 accessed at <https://www.npca.org.uk/reports/npca-annual-report-2021/>

<sup>11</sup> NPCA Annual Report 2020 accessed at <https://www.npca.org.uk/reports/npca-annual-report-2020/>

<sup>12</sup> Aggarwal A, Nossiter J, Cathcart P, van der Meulen J, Rashbass J, Clarke N, Payne H. Organisation of Prostate Cancer Services in the English National Health Service. Clin Oncol (R Coll Radiol). 2016 Aug;28(8):482-489. doi: 10.1016/j.clon.2016.02.004. Epub 2016 Mar 3. PMID: 26947316.

<sup>13</sup> Audibert C., Glass D. & Johnson T.P. (2020). Method and transparency of online physician surveys: an overview Survey Methods: Insights from the Field. Retrieved from <https://surveyinsights.org/?p=12496>

<sup>14</sup> Wiebe ER, Kaczorowski J, MacKay J. Why are response rates in clinician surveys declining? Can Fam Physician. 2012;58(4):e225-e228.

<sup>15</sup> O'Reilly-Shah VN. Factors influencing healthcare provider respondent fatigue answering a globally administered in-app survey. PeerJ. 2017;5:e3785. Published 2017 Sep 12. doi:10.7717/peerj.3785

<sup>16</sup> Cunningham, C.T., Quan, H., Hemmelgarn, B. et al. Exploring physician specialist response rates to web-based surveys. BMC Med Res Methodol 15, 32 (2015). <https://doi.org/10.1186/s12874-015-0016-z>