

# Engagement Report for Specialist Cancer Services (adults), Specialist Hepato-Pancreatic Biliary (HPB) – Pancreatic and Periampullary Cancers Service Specification

27 July 2022, Version 2

## Topic details

<b>Programme of Care</b>	<b>Cancer Programme of Care</b>
<b>Clinical Reference Group</b>	<b>Cancer Clinical Advisory Group</b>
<b>Unique Reference Number (URN)</b>	2325

## 1. Summary

This report summarises the feedback NHS England received from engagement during the development of the Specialist Cancer Services (adults), Specialist Hepato-Pancreatic Biliary (HPB) Pancreatic and Periampullary Cancers Service Specification, and how this feedback has been considered. Two responses were received from stakeholder groups including patient charities and individual patients with knowledge and experience of treatment and care for HPB pancreatic and periampullary cancers.

Feedback was positive overall, with stakeholders registering their broad support for the service specification requirements, standards, and outcomes proposed.

## 2. Background

In 2020, there were 9,368 new diagnoses of pancreatic cancer diagnosed in England, which is an incidence rate of 17.2 per 100,000 (PCUK). Pancreatic cancer is the 10th most common cancer and is the 5th biggest cancer killer in the UK (PCUK). Pancreatic cancer has the lowest survival of all common cancers, with five-year survival less than 7% (PCUK).

The new HPB pancreatic and periampullary cancers service specification has been formed from the current [HPB Service Specification](#) (2013), which covers both benign and malignant disease. There will also be a new service specification covering HPB primary liver, secondary liver, perihilar biliary tract and gallbladder cancers. On approval and publication, the current HPB service specification will be amended to focus solely on benign disease.

The service specification has been developed to set out the must-do requirements for providers and:

- Reflect current care pathways;
- Reference up to date national guidance and guidelines, as well as appropriate national policy, for example Faster Diagnosis and elective recovery;
- Incorporate meaningful quality outcome measures which will support improved outcomes and experiences of care; and
- Avoid duplication with other schedules within the [NHS Standard Contract](#).

It is expected that the new HPB pancreatic and periampullary cancers specification will support Integrated Care Boards (ICBs) to take responsibility for the commissioning of HPB specialist cancer services when delegated.

The new service specification is not expected to change the provider landscape or overall service delivery. As a result, the revised service specification is expected to be cost neutral to NHS England and other parts of the NHS.

In accordance with usual NHSE processes, this service specification was developed with the support and input of a Specification Working Group (SWG), comprising representation from HPB cancer clinical experts and patient and public voice representatives, including Pancreatic Cancer UK.

## 3. Engagement Results

### 3.1 Stakeholder Testing

NHS England has a duty under Section 13Q of the NHS Act 2006 (as amended) to 'make arrangements' to involve the public in commissioning. Full guidance is available in the Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning. In addition, NHS England has a legal duty to promote equality under the Equality Act (2010) and reduce health inequalities under the Health and Social Care Act (2012).

The service specification was sent for stakeholder testing for 2 weeks from 3<sup>rd</sup> July to 17<sup>th</sup> July 2023. Effort was made to review and update the stakeholder engagement list to ensure that relevant professional societies and patient groups were contacted and asked to comment. The feedback received has been reviewed by the Specification Working Group Chair and the Cancer Programme of Care (PoC) to enable consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

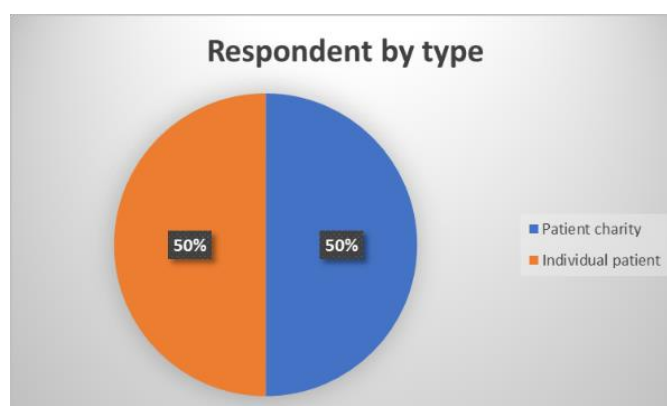
Respondents were asked the following questions:

- The minimum population size in the service specification is based on recommendations made within the National Peer Review Programme HPB Cancer Measures (2013) which recommend an annual team case throughput of at least 80 pancreatic surgical procedures for neoplastic disease or suspected neoplastic disease. The Specification Working Group are considering amending the team case throughput requirement to 60-70 pancreatic resections per year to reflect evidence-based changes to clinical practice and treatment pathways. To what extent would you be in support of this change?
- If the case throughput requirement were set at 60-70, what impact, if any, do you think this would have on standards of care?
- If the case throughput were set at 60-70, what impact, if any, do you think this would have on providers and multi-disciplinary teams?
- Are the service quality outcomes appropriate to the service? If no, what quality outcome measures would you want to see included in the service specification?
- In updating the service specification, we have clarified that HPB Pancreatic and Periampullary Cancers Services must be co-located with interventional radiology services and that there must be 24 hours a day/7days a week access – we have made this change based on clinical advice which also suggests that this wording reflects current provider arrangements and is not a substantive change. To what extent do you support this change?
- If the requirement to have 24 hours a day/7days a week access to interventional radiology services was included in the service specification, what impact, if any, do you think this would have on providers and multi-disciplinary teams?
- The service specification proposes that providers of HPB Pancreatic and Periampullary Cancers Services must be a member of a Cancer Alliance as this reflects the current arrangements for the local coordination of cancer care. Do you support the inclusion of this requirement in the service specification? If no, can you explain why?
- Do you have any comments on the proposal? If yes, please describe below, in no more than 500 words, any comments on the proposal as part of this initial ‘sense check’.
- Do you support the Equality and Health Inequalities Impact Assessment?

## 3.2 Stakeholder testing results and summary of participants

Two responses were received:

- 1 Patient charity
- 1 Individual patient



Overall, the feedback received was positive, with stakeholders registering their broad support for the service specification requirements, standards, and outcomes proposed. Additions to the specification in relation to specialist multi-disciplinary teams to oversee treatment and care not only for patients who are eligible for surgery, but also for those who receive palliative treatment and care were particularly welcomed. Recommendations made across the whole pathway, including for the use of the PACT-UK template for radiology reporting, access to prehabilitation/rehabilitation and a specialist dietitian, ensuring that everyone is prescribed Pancreatic Enzyme Replacement Therapy (PERT), and the requirement for 24/7 specialist consultant cover were also noted as positive elements of the proposal.

In terms of specific questions asked; both respondents strongly supported the clarification in the specification that HPB Pancreatic and Periampullary Cancers Services must be co-located with interventional radiology services and that there must be 24 hours a day/7 days a week access. The impact of this clarification was thought to be minimal owing to this already being considered standard clinical practice. Both respondents also supported the inclusion of the requirement in the specification for providers of HPB Pancreatic and Periampullary Cancers Services to be a member of a Cancer Alliance. Both respondents confirmed their support for the Equality and Health Inequalities Impact Assessment and did not submit further comments on this.

On the question of amending the team case throughput requirement to 60-70 pancreatic resections per year to reflect evidence-based changes to clinical practice and treatment pathways, one respondent somewhat supported the change and one respondent neither opposed nor supported the change. Some feedback on this question surrounded the potential for there to be too few cases to keep the specialist multi-disciplinary team in work for the year and a concern that there would not be enough outputs to keep the specialist multi-disciplinary team viable. Other feedback suggested that further consideration might be given to also setting a minimum number of pancreatic resections

of 12-16 per year per HPB surgeon, as well setting 60-70 pancreatic resections per year per centre, to ensure that individual surgeons are qualified to perform this type of complex surgery. This specific question was included to gauge support for a possible amendment in anticipation of updated guidance being published by the Association of Upper Gastrointestinal Surgeons (AUGIS). It has since been confirmed that the guidance will not be published in time for inclusion in the service specification, however, owing to the support noted for amending the case throughput, NHSE will look to pursue this if/when the updated guidance is published.

Additional feedback on the proposal surrounded a request for the specification to state that the key worker must always be a Clinical Nurse Specialist (CNS) with pancreatic expertise. Finally, although it was recognised that details of the quality metrics dashboard are not included within the service specification itself, there was a request to ensure that each provider has processes in place, alongside capacity and resource, to collect and submit metric data to enable a greater understanding of how care is delivered, and improvements in service delivery and outcomes are made.

The review of stakeholder responses to engagement, and subsequent decisions on whether any changes to the specification might be recommended are outlined in Section 4 below.

A 13Q assessment has been completed following stakeholder testing. The Cancer Programme of Care (PoC) has concluded that the service specification and proposed amendments does not constitute material changes to the way in which services are delivered or the range of services available, therefore further public consultation was not required. This decision has been assured by the Patient Public Voice Advisory Group on 17<sup>th</sup> August 2023.

## 4 How has feedback been considered

Responses to engagement have been reviewed by the Specification Working Group Chair and the Cancer PoC and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the specification and NHS England’s direct commissioning responsibility.

The following themes were raised during engagement:

Respondent category	Key themes in feedback	NHS England Response
	<b>Relevant Evidence</b>	
Patient charity	The service specification must set a minimum number of pancreatic resections per HPB surgeon to ensure that HPB surgeons are qualified to perform this type of complex surgery. Based on the latest evidence (from AUGIS), we believe that the specification must include that each surgeon must be carrying out 12–16 pancreatic resections per year.	Level 2. The recommendations made in relation to minimum volumes have been fully considered by the SWG and proposals to amend numbers by centre reflect current practice and evidence base. Recommendations from relevant professional bodies considered as part of the specification development suggest that a multidisciplinary team approach is essential for the management of these cases, and thus recommendations are not made about the volume of operations for individual surgeons other than to state that surgeons within the same team should be doing an approximately equal number of cases. <b>No change.</b>
	<b>Impact Assessment</b>	
Individual patient	Changing the case throughput requirement will mean there are too few numbers to keep a specialist multi-disciplinary team in work all year and would	Level 2. The amended case throughput requirements were recommended by the SWG as they reflect the evidence-based

	mean there was not enough payment to keep the specialist multi-disciplinary team value up. Training and outputs would not be enough to make the team viable.	changes to clinical practice and treatment pathways. In addition, NHS England have completed an Integrated Impact Assessment which concluded that the adoption of the service specification will be cost neutral to NHS England and other parts of the NHS. <b>No change.</b>
<b>Changes/addition to service specification</b>		
Patient charity	The key worker must always be a Clinical Nurse Specialist (CNS) with pancreatic expertise, i.e. an UGI or HPB CNS.	Level 4. It is not usual for this to be prescribed within a service specification. However, the specification does state that the key worker is normally the Clinical Nurse Specialist (CNS) with expertise in HPB cancers. <b>No change.</b>
<b>Generic feedback/questions</b>		
Patient charity	Although the specification does not provide details on the quality metrics dashboard, each provider must put processes in place so that each HPB centre has the capacity and resource required to collect quality metrics data. Data collection needs to be consistent among all HPB centres to be able to understand how care is delivered and track improvements. To achieve this, data collection, processing and reporting of these data must follow the same process as the cancer registry datasets.	Level 2. Quality metrics are developed by the SWG (which includes PPV representation) and the relevant Clinical Reference Group. Although they do not form part of the service specification, quality metrics will be reviewed and agreed with input from the NHSE Quality and Nursing Team to ensure they are fit for purpose and that robust data can be collected for each metric proposed. <b>No change.</b>



## **5 Has anything changed in the service specification as a result of the stakeholder testing and consultation?**

The feedback received was reviewed by the Specification Working Group Chair and the Cancer Programme of Care (PoC) to enable consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

Based on the engagement responses, no changes were required to the service specification proposal or Equality and Health Inequalities Impact Assessment.

Details of how the feedback has been considered can be seen in the table above.

## **6 Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?**

No changes were required to the service specification as a result of the stakeholder engagement feedback received. There are no remaining concerns outstanding following the consultation that have not been resolved in the final service specification.

The 13Q assessment has been completed following stakeholder testing. The proposal and the 13Q will be reviewed at the PPVAG meeting on 17<sup>th</sup> August 2023.

Confirmation has been received that public consultation is not required.

## **7 What are the next steps including how interested stakeholders will be kept informed of progress?**

A summary of the feedback from stakeholder engagement will be made available to the registered and relevant stakeholders.