NHS National Services Scotland

Scottish Cancer Network

Pancreatic and Hepatocellular Cancer Pathway Improvement Project (PHCC PIP)

Evaluation

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National Services Directorate (NSD)
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Contents

1. Executive Summary

In December 2020, the Cabinet Secretary for Health and Sport announced the publication of a Cancer Action Plan for Scotland to drive a 'Once for Scotland' approach to cancer services, where this is appropriate. The plan sets out activities to improve equitable access to cancer care and treatment across Scotland.

A Scottish Cancer Network (SCN) was established as a structure to lead and deliver a range of activities within the plan. Developments included the transfer to the SCN of support and governance for three well established National Managed Clinical Networks for cancers, including, the Scottish Hepatobiliary Network (SHPBN).

Evidence from Quality Performance Indicators (QPIs) and a national questionnaire[1] of both patients and healthcare professionals highlighted inequity of access, variation in outcome, delays in treatment, and lack of support for patients. Action 45 of the plan sets out the ambition to improve pathways of less survivable cancers, particularly hepatocellular carcinoma and pancreatic cancer, with a view to shortening the time to staging and agreeing treatment plans. Previous attempts to address this within individual boards had been met with limited success and patients, carers, and charities had advocated for several years for improvements in care and experiences for patients and families.

In support of this ambition Scottish Government funded a proposal through SHPBN for the Pancreatic and Hepatocellular Cancer Pathway Improvement Project (PHCC PIP) to pilot a national delivery model as a test of change to inform a future sustainable service model for a range of tumour sites. The project was scheduled from April 2022 to March 2024.

In April 2023 governance and operational responsibility for the SCN and its constituent components, including PHCC PIP, transferred from NHS National Services Scotland (NSS) Clinical Directorate to National Services Directorate (NSD) who commission national specialist services on behalf of NHS Boards and Scottish Government.

With significant delays to the project timeline due to clinical and IG governance constraints from the outset, the data set available to inform the PHCC PIP evaluation was limited to the period January 2023 to December 2023. The data included 101 patients who were on the Pancreatic Cancer (PC) pathway, (30% of the total eligible), and 103 patients on the Hepatocellular Cancer (HCC) pathway (39% of the total eligible).

Evidence gathered during the project was collated and analysed to assess impact. The evaluation identified significant reduction in the time from referral to treatment and showed improved communication and information sharing for patients and carers. However, the data set was very small, and findings did not evidence

[1] Presented at UK HCC Conference 2019, Ms Anya Adair

improved outcomes for patients who were managed through the national model or its suitability as a sustainable service model.

Based on this evidence, it was agreed through Scottish Cancer Network (SCN) governance that there was insufficient evidence to recommend the model and action initiated to terminate PHCC PIP in line with original project funding and timescales. This was approved by Scottish Government Policy Team.

In March 2024, following a meeting with a patient representative and their clinician the Cabinet Secretary for Health & Sport issued a Ministerial directive that the national model should be supported until 31 March 2025.

With project funding exhausted SCN baseline was used to resource the pathway for an additional 12 months. Work began to establish the necessary information and clinical governance arrangements to mobilise the national model as Scottish Care & Coordination for Hepatobiliary cancers (SCOT HPB). Operational delivery was paused temporarily to allow appropriate risk assessment and mitigation and the national model became fully operational in August 2024 with a slight modification to the clinical rota.

While it has been agreed that this arrangement will continue until 31 March 2025, it is unsustainable for governance reasons and work is underway with stakeholders to appraise longer-term options for the service in line with the 2024-25 commission from SG to NSD to "***develop and agree plans for delivery of similar outcomes for HPB cancers within the wider NHS"*** with a report and recommendations to be submitted for SG consideration by 31 October 2024.

2. Purpose of Document

The purpose of this document is to provide a comprehensive review of the Pancreatic and Hepatocellular Pathway Improvement Project (PHCC PIP) that ran from 1 April 2022 to 31 March 2024.

3. Project Background

The 2020 National Cancer Plan (Recovery and Redesign: An Action Plan for Cancer Services) sets out activities to improve equitable access to cancer care and treatment across Scotland and to drive a 'Once for Scotland' approach to cancer services, where this is appropriate. It includes the establishment of a Scottish Cancer Network (SCN to lead and co-ordinate a range of activities, including the transfer of support and governance for three well established National Managed Clinical Networks for cancers, including the Scottish Hepatobiliary Network (SHPBN).

With evidence from a national questionnaire[2] of both patients and healthcare professionals, along with Quality Performance Indicators (QPIs), of inequity of access, variation in outcome, delays in treatment, and lack of support for patients, with delays often greater for outpatients, Action 45 of the plan sets out the ambition to improve pathways of less survivable cancers, particularly hepatocellular carcinoma and pancreatic cancer with a view to shorten the time to staging and agreeing treatment plans.

Previous attempts to address this within individual boards had met with limited success and patients, carers, and charities had advocated for several years for improvements in care and experiences for patients and families.

In support of this ambition Scottish Government approved a proposal through SHPBN to fund PHCC PIP as a key test of change that aims to test national approaches to care coordination, leading to improved patient outcomes and experience, with the potential to inform future models of care across other tumour groups.

4. Aims and PHCC PIP Pilot Approach

4.1

Scottish Cancer Strategy, 2023-2033[3] Aim
To reduce delays in patient pathways and improve patient outcomes and experience of care.
PHCC PIP Aim
Improving and ensuring quality of care for all patients in Scotland with HCC and PC by reducing delays in patient pathways and improving communication for patients and healthcare professionals.
Approach: • Expediting access to earlier diagnostic investigations, Multi Disciplinary Teams (MDTs) and supportive care for all patients across Scotland with HCC and PC via a complimentary step in the current pathway. • The complimentary step is to send a registration of urgent suspicion of cancer (USC) via radiology reports to the National Cancer Care Team (CCT), hosted by NSD (Appendix A). • The project also includes a signposting service that provides a point of contact for all clinicians and Clinical Nurse Specialists (CNS) in Scotland with HCC and PC patients, in addition to providing support via a national education programme for CNSs who care for HCC patients (Appendix C).
Rationale: • Local governance and responsibility for patient care does not change, however early analysis has shown that the pilot model expedites the current pathways for the patient and improve communication between health professionals. • For PC, there are two routes in for referrals; Pathway A whereby the patient is referred directly via a radiologist and Pathway B, whereby the patient (usually an inpatient) is referred by a consultant who may or may not have HPB experience.

[2] Presented at UK HCC Conference 2019, Ms Anya Adair
[3] Cancer Strategy 2023 to 2033 (June 2023)

- A breakdown of all referrals received by PHCC PIP in 2023 can be seen in Appendix B.

4.2

Realistic Medicine[4] Aim
For people using healthcare services and their families to feel empowered to discuss their treatment fully with healthcare professionals… and all decisions about a person's care should be made jointly between the individual and their healthcare team.
PHCC PIP Aim
Create a care summary for patients which is shared with the patient care 'bubble' (includes all those identified as being involved in the patients care)
Approach: • The CCT creates, and dynamically updates, a care summary for each patient which is sent to all those in the patient's care 'bubble' to ensure they have the most up to date information on the patient. • This ensures that the patient can be fully informed of their care, facilitating better communication between patients, GPs and health professionals in the acute setting.
Rationale: • Following discussions with patients previously diagnosed with PC or HCC, a baseline audit has shown there is variation across boards in relation to the amount of information patients are given to help them make decisions about their care. • The pilot model aims to ensure that all patients are given sufficient information to feel empowered to discuss their treatment fully with decisions made jointly between the patient and the team looking after them.

5. Scope of Project

The following activities were agreed by the PHC-PIP Project Team to be in scope:

- Patients referred to the Cancer Care Team with an urgent suspicion of HCC or PC
- The pathway from when a scan is reported to when treatment commences
- Queries from healthcare professionals, working with HPB patients
- SHPBN education sessions provided in collaboration with the HCC Clinical Nurse Specialists

The following were out of scope:

- Other cancers, such as biliary, duodenal and gallbladder
- The pathway for patients with HCC and PC after treatment has commenced
- Radiology reporting outsourced by boards to private providers (however some patients with outsourced reporting may be picked up via Pathway B and benefit from earlier intervention via their CNS due to enhanced communication systems and processes (Appendix A)

[4] Realistic Medicine – Shared decision making, reducing harm, waste and tackling unwarranted variation

During the period that PHCC PIP was running Rapid Cancer Diagnostic Service (RCDS) was also established as a pilot. RCDS provides person-centred fast-track diagnostic pathways to provide primary care professionals with a new route to refer patients with non-specific symptoms that may be suggestive of cancer. Although not in PHC PIP scope Section 10.7 of this evaluation considers the relationship between them as relevant in informing future models to improve early detection, access, outcomes and experience for patients with HPB and other tumour groups.

6. Constraints

Complex governance and IT access arrangements resulted in a nine-month delay to the project, with national roll out commencing at the end of January 2023. The delay limited the opportunity to robustly test a national care coordination approach and collate sufficient data to provide an evidence base by which to evaluate the project. The Covid pandemic also had a significant impact on the project, and the need to fully test the pathway as systems undergo recovery.

The project encountered significant issues around national IT systems and NHS infrastructure. There is little consistency across territorial boards in terms of the processes and structures required to enable remote access to patient systems, and these are long term issues that are embedded within NHS Scotland and cannot be influenced or altered by the project. Further information on IT issues encountered by the project can be found in the IT Access Case Study (Appendix D).

7. Summary of the Project Performance

The project was managed using standard project management approach and tools (Prince 2 and Association for Project Management methodology).

Regular status reporting of progress, risks and issues was in place throughout the project, with high scoring risks escalated to the Portfolio Manager and SCN Steering Group as required.

Project Governance was in place via a Project Team reporting to the SCN Steering Group . (Appendix D).

Clinical and information governance was established prior to commencing rollout of the project (Appendix D).

8. Review of Project Objectives

Objective	Achieved	Status
Develop and operate a national project to test and evaluate the effectiveness	- Cancer Care Team resource recruited	**Complete**, project is fully operational and is in process of transferring to

of improved pathways for patients with suspected HCC or PC	- Consultant of the Day resource recruited from each region - SOPs in place with each board for referrals - Information and Clinical Governance in place - Project operational across all regions / boards - Comprehensive baseline audit completed - 6 and 12 monthly audits of identified KPIs	a service (SCOT HPB) for 2024/25. **To be completed:** initial analysis shows improvement based on the small initial dataset.
Provide a signposting service for all health professionals looking after HCC or PC patients	- Poster circulated to all HPB teams informing them of signposting service - Log maintained of all requests received by CCT - Appropriate responses by CCT to all signposting requests	**Complete,** the CCT operate a service enabling signposting for all health professionals with HPB patients on request
Provide national education via the SHPBN for CNS looking after HCC patients	- Nurse Education Day, 23rd June 2023 well attended - -SHPBN and CNSs provided a national quarterly forum with educational presentations from allied health professionals and specialty consultants - CNS session at SHPBN event, January 2023.	**Ongoing:** Education sessions are established and there has been enthusiasm for them to continue

The outstanding tasks required to carry into BAU are in included in the project plan "post-project closure".

9. Review of Benefits

The Project Team identified a list of anticipated benefits which were reviewed during the project lifecycle. Given the pilot status, analysis was undertaken throughout the project to understand if it had been successful in realising the outlined benefits and showing improvements against Key Performance Indicators (KPIs).

Benefits identified:

- More streamlined pathways for diagnosis and standardised treatment throughout Scotland for those with suspected HCC or PC

- Quicker communication around patient care for both inpatients and outpatients utilising the pathway
- Provision of a key worker to deliver person centred support, earlier initiation of symptom optimisation, prehabilitation treatments and emotional support
- Greater equity of PC and HCC Pathways across Scotland
- Faster route to MDT discussion where patient treatment is determined
- Specialist advice and signposting available for all HCC key workers across Scotland

These 6 benefits were profiled and are included in the Benefits Realisation Report and profiles document.

It has been identified that due to small numbers included in the first year of data, it may be difficult to measure all benefits. These benefits will be reviewed over the course of 2024/25 to understand if they can be realised by SCOT- HPB.

10. Analysis

10.1 Background to analysis

Project scoping anticipated 2 years of data collection by which to assess and evaluate the impact of the project. Due to significant information governance and IT issues, it has only been possible to collect data on patients being managed through the new pathway since the end of January 2023 when the project became fully operational across Scotland. By 31st December 2023, 272 PC patients and 240 HCC patients had been referred to the CCT. Note that the analysis does not include patients who, on completing investigations, were found not to have HCC or PC, or those who were still undergoing their pathway as of 31st December 2023.

10.2 Findings

A comparison of retrospective audit data with prospective data was carried out in both September 2023 and February 2024. The data can be found in Appendix E, along with the Data Specification Document.

The dataset analysis confirms similar themes to those seen in analysis carried out in September 2023 and reinforces the initial significant improvement in objective measures (time) of care.

HCC	Outpatients (median days)	Inpatients (median days)
Reduction in time -GP communication	93% (29 – 2)	75% (16 – 4)
Reduction in time -initiate patients on a treatment path (palliative or curative)	38% (120 –74)	58% (48 - 20)
PC		
Reduction in time -GP communication	75% (8 – 2)	57% (7 – 3)
Reduction in time- initiate patients on a treatment path (palliative or curative)	37% (65 – 41)	50% (46 – 23)

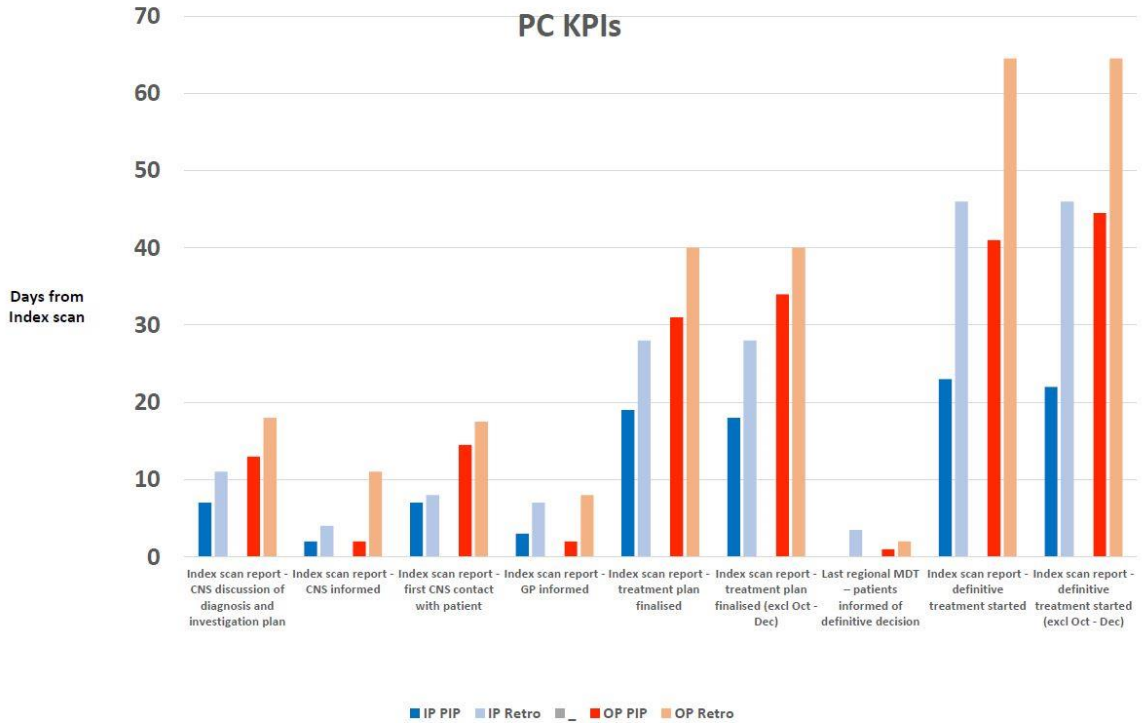
Numbers are small, and differences are more significant in outpatients than inpatients as expected, however both sets of analysis indicate:

- There was a significant reduction in time in communicating findings to relevant health professionals i.e. GP, and MDT team, therefore improving communication relating to the patient's care.
- Streamlining of staging and communications although initial scans for inpatients may be undertaken quickly, pressure on beds often leads to rapid discharge and interval staging investigations.
- opportunity to reduce psychological morbidity through diagnosing benign conditions in a third of patients who are initially suspected as having a cancer
- Reduction in the time taken to start on a treatment path whether this is palliative or curative. This is significant as patients with advanced disease have a survival of less than 6 months and require rapid decisions taking place more quickly than the current 62 day target.
- Fewer than 50% of patients get active treatment with HPB cancers[5] so early holistic intervention by healthcare professionals is essential to ensure that patients receive the support and care that they need as quickly as possible.
- The project has evidenced earlier referral to palliative care, primary care, and charitable services for patients with advanced disease.

10.2.1 Pancreatic Cancer

Results from the analysis indicates decreases in the journey through the pathway for all PC KPI measures for both inpatients and outpatients within the PIP project.

[5] Scottish HepatoPancreatoBiliary Network Audit Report, 2021



For inpatient analysis there was a significant decrease in time from the last MDT to patients being informed of the decision. However, sample sizes for inpatients were very small and data immature.

For outpatients there were significant decreases in time from index scan to:

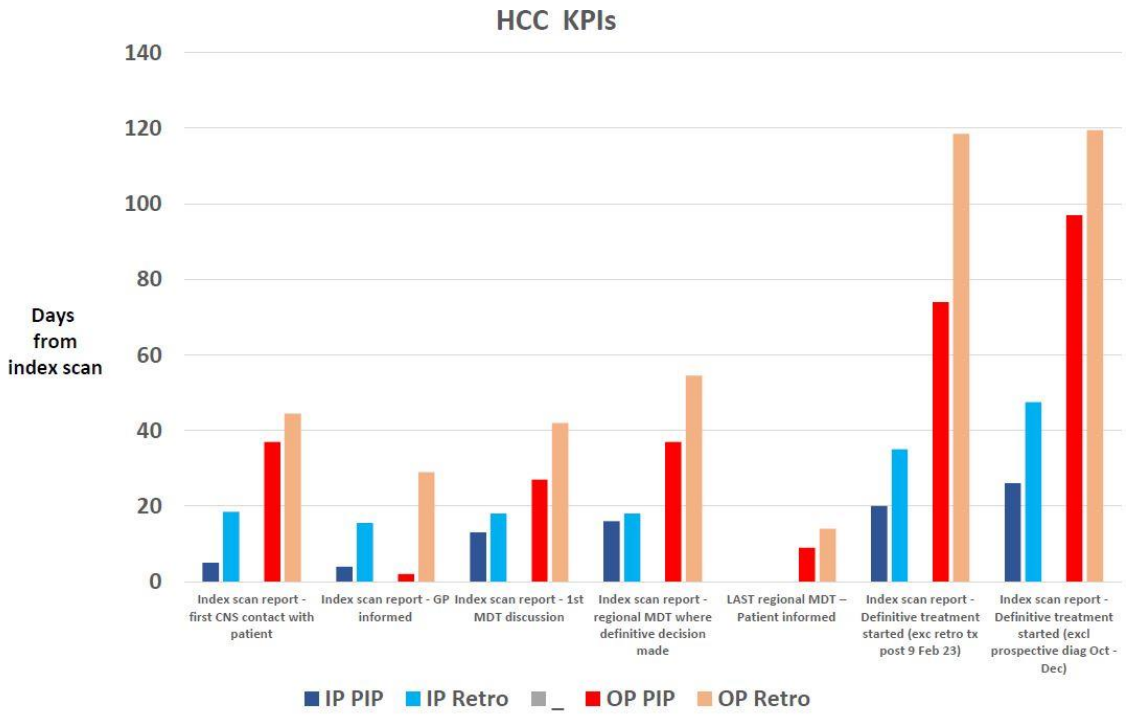
- CNS discussion of the diagnosis and investigation plan (28% decrease)
- CNS informed of patient scan result (82% decrease)
- CNS first discussion with patient (17% decrease)
- GP informed of patient scan result (75% decrease).

The time from the last regional MDT to the patients being informed reduced from a median of 2 days to 1 day.

The entire pathway from reporting of initial investigation to starting definitive treatment decreased significantly from a median of 65 days in the retrospective audit to 41 days for outpatients on Pathway A of the PHCC PIP, a 37% decrease.

10.3 Hepatocellular Cancer

Results indicate decreases in the pathway journey for all KPI measures for both inpatients and outpatients.



For inpatients there were statistically significant decreases in time from index scan to:

- GP being informed (74% decrease)
- Time to first MDT (28% decrease)
- Time to starting definitive treatment (58% decrease)

For outpatients there were statistically significant decreases in index scan to:

- Time to GP being informed (93% decrease),
- 1st MDT discussion (36% decrease)
- MDT where the definitive decision was made (32% decrease).

The entire pathway from diagnosis to starting definitive treatment decreased significantly from a median of 120 days in the retrospective audit to 74 days for outpatients with HCC in PHCC PIP, a 38% decrease.

10.4 Patient Conversations

Conversational-style interviews took place with HCC and PC patients who had completed their pathway. It is important to note that analysis of interviews with pancreatic patients was not possible due to small numbers. Also, the most populous health board (NHS Greater Glasgow and Clyde) currently has no funded HCC CNS and therefore this is likely to impact on communication experienced by HCC patients within this health board.

For HCC, 30 patients participated in the conversational-style interviews in relation to their pathway, with the following broad themes emerging:

- The majority of patients were given leaflets, booklets or were directed to a support website, with 75% of those contacted feeling that they received enough information at the beginning of their pathway.
- Three quarters of patients contacted felt the time allocated for their case discussion at MDT was about right, however communication between health professionals was difficult for some patients whose MDT took place outwith their home health board.
- Some patients reported receiving communication from several different health professionals throughout their pathway and mentioned that the amount of information they received could be overwhelming.

10.5 Signposting

Due to the highly complex nature of treatment for those patients with HCC and PC, a 'signposting' service is provided by the CCT to provide advice on treatment options and information for health professionals, and for any CNS who are new in post. As the service has become more established, the CCT have been able to provide advice and information on where a patient is on the pathway with regards to imaging or staging investigations where required.

All requests for signposting are logged by the CCT, these requests can be reviewed at a later date to understand where the team are adding the most value.

10.6 Potential savings to service

Efficiencies have been achieved via a reduction in 'Consultant of the day costs' from 1PA/day to 0.5PA/day following an evaluation of the time required for consultant input.

The retrospective audit has identified that many patients are discussed at multiple MDTs due to incomplete investigations prior to discussion, and this could result in an avoidable repetition of scans and other investigations, prospective data around the number of MDTs required for a decision on treatment is currently immature and will need to be further analysed when more data is available, to determine cost benefit.

10.7 Rapid Cancer Diagnostic Service (RCDS)

Like PHCC PIP the Rapid Cancer Diagnostic Service (RCDS)[6] was established as a pilot. It provides person-centred fast-track diagnostic pathways which aim to provide primary care professionals with a new route to refer patients with non-specific symptoms that may be suggestive of cancer. The service is currently operating in five boards (NHS Ayrshire & Arran, Borders, Dumfries & Galloway, Fife and Lanarkshire) with funding agreed to September 2024. The service aims to improve the rates of index scan via primary care and tracks the pathway from before the index scan.

PHCC PIP and the RCDS are both aiming to accelerate pathways for less-survivable cancers. The RCDS evaluation report, recently published by the University of Strathclyde, found that HPB cancers are the third most common form of cancer diagnosed by the RCDS

[6] Maguire, Roma and van der Meer, Robert and Egan, Kieren and Thompson, Nathan and Connaghan, John (2024) *Final Report of the Evaluation of Rapid Cancer Diagnostic Services.* University of Strathclyde, Glasgow.

within the five pilot boards. However, the staging pathway for HPB cancers involves several phases, the initial stage being referral for and recognition of a suspicion of an HPB cancer; the RCDS addresses this phase and is evidencing benefit for those patients diagnosed through an outpatient pathway.

The RCDS does not however address the next phase which is negotiating the requirement for further complex patient specific investigations to enable treatment decisions to be made at MDT. The PHCC PIP includes referrals for both inpatients and outpatients, whilst the RCDS only includes those referred by primary care. Analysis has shown that 50% of HPB patients require admission for their index scan and are not referred by primary care and GPs. The PIP has demonstrated improvements for both outpatients and inpatients as it is a reaction to the first Urgent Suspicion of Cancer (USC) scan, whether this arises through primary care, an inpatient or through an RCDS.

The RCDS and PIP interventions are therefore addressing sequential phases of the pathway and are complementary.

10.7 NHS Scotland Infrastructure

The constraints identified during the project in relation to IT and IG are set out in Section 6 and had a significant detrimental impact on project timelines and scope to assess and realise benefits. Any similar project will require a significant amount of scoping to identify and understand the constraints within NHS Scotland infrastructure prior to project initiation.

11.Review of Team Performance

11.1 Cancer Care Team

A virtual Cancer Care Team was in place for the duration of the project. The structure of the team evolved over the course of the project, with the HCC Clinical Nurse Specialists undertaking line-management responsibility for the Care Coordinators. The lessons learned identified that there was limited professional nurse support in place for the HCC Clinical Nurse Specialists and this should be addressed in any future model, to ensure clinical oversight and expertise is in place. The reporting structure for the CCT also altered several times during the project lifecycle due to a change in management and the project transitioning from PgMS to NSD, leading to a lack of continuity for team members.

11.2 Project Team

A Project Team was established comprising clinical leads, CCT, regional cancer managers from across all regions, SHPBN Manager and a dedicated PgMS project manager. Patient/third sector input to the project was through a Patient, Carers and Charities subgroup. The project team met on a fortnightly basis, and latterly weekly, to discuss strategic and operational issues. Involvement from information governance or IT representatives would have also been useful and is recommended going forward. An agenda and action notes were circulated for each of these meetings. For BAU, regular separate meetings could be established for operational and strategic strands, to ensure that relevant representatives are involved.

11.3 Pancreatic Consultants

Service Level Agreements (SLAs) were in place with boards to provide a 'Triage Consultant of the Day'. The requirements of these SLAs were reviewed and a reduction in PAs / week was proposed to increase financial efficiency. While regional services supported PHCC-PIP, with limited evidence of the benefits of the national model evidenced in the project phase modifications were made to the rota within SCOT-HPB.

12. Lessons Learned Report

A team session was held on 1st February 2024 with the purpose of recording and sharing lessons learned to inform and improve future projects. Those who were unable to attend the session in person were also invited to contribute and their views have been captured in this report here.

13. Risks and Issues (as of March 2024)

The table below represents medium / high risks that were recorded as part of this evaluation that relate to the delivery of the SCOT-HPB model. A full list of risks and issues and their status is recorded in the risks and issues register and are managed within SCOT-HPB routine business.

Risk ID	Risk Description	Consequence	Score	Mitigation
R017	There is a risk that the project is unable to recruit to and fill vacant posts	Lack of clinical cover for the project, impacting on patients who are not able to progress on the new pathway	**Medium**	Vacant posts to go through Job Train, promotion of posts to also take place via SHPBN
R24	There is a risk that due to the large number of user IDs / passwords required for system access, the passwords are stored insecurely	Unauthorised access to patient data by individuals not approved for access	**Green**	Use of password manager to store passwords securely, where available.
R27	There is a risk that the CCT will be unable to manage the volume of referrals	Service not able to adhere to 48-hour requirements, lack of clinical cover for the project, both impacting on patients who are not able to progress on the new pathway	**Medium**	CCT to have regular operational meetings to review capacity and inform service management of any issues at earliest opportunity
R28	There is a risk that information governance is not in place and extended prior to April 2024	Service not able to be provided in those boards who have not signed off Caldicotts, impacting on patients who are not able to progress on new pathway	**Green**	CCT to take forward IG requirements at earliest opportunity and ensure activities are prioritized to limit consequences

14. Post-project Plan

Further to the Ministerial directive to continue the national pilot model to 31 March 2025 planning was undertaken to take forward activities to support SCOT-HPB as well as to explore and assess options for a future sustainable service model for tumour groups.

The project plan includes a post-project closure work plan, separated into operational and project tasks. The plan includes the tasks identified as outstanding; however, timelines may be impacted due to resourcing and capacity of the team.

15. Conclusion

This report represents an evaluation of the two year pilot project of the PHCC PIP, the analysis and data trends emerging, and the lessons learned from the project.

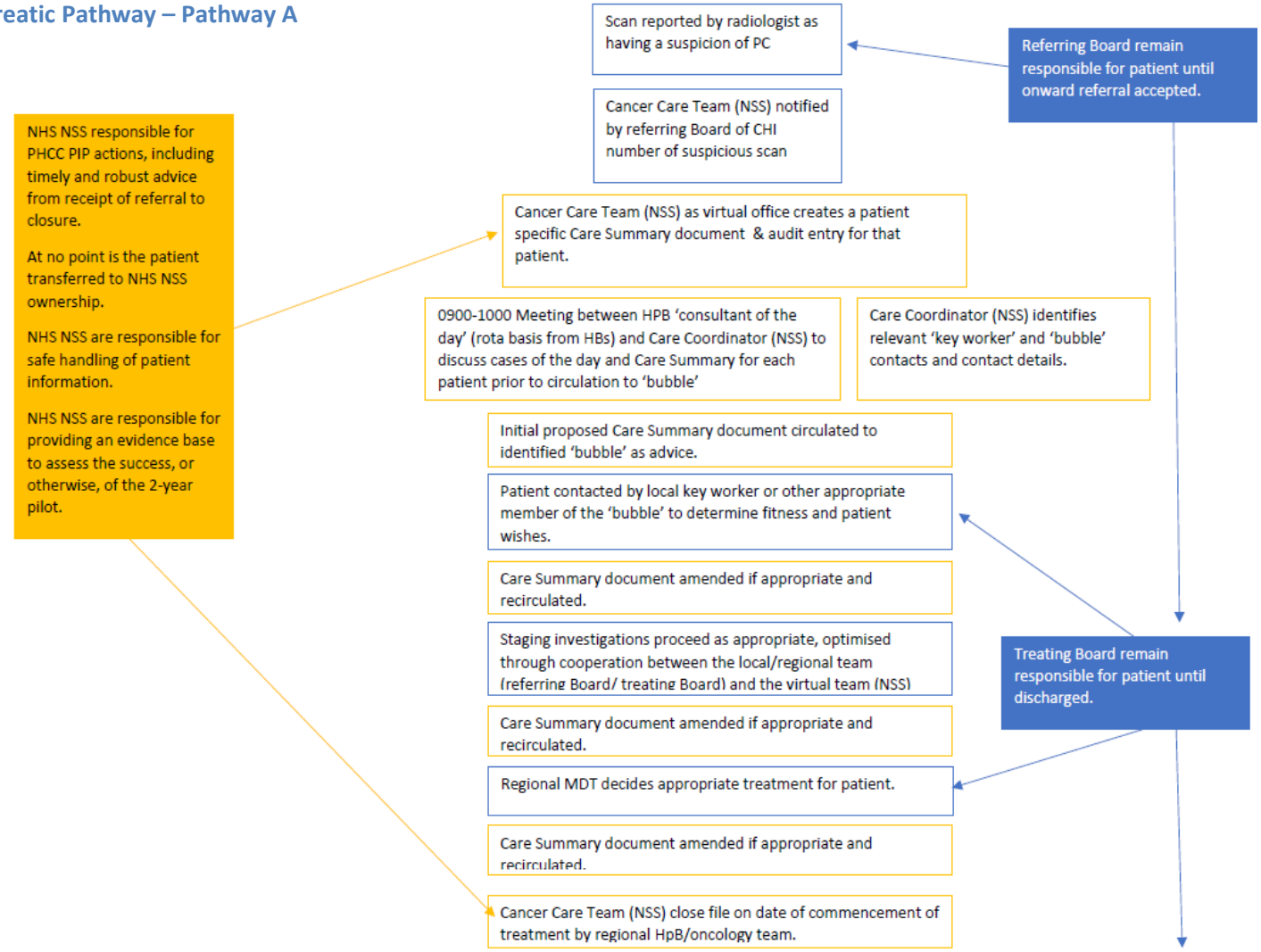
The evaluation has concluded that:

- Improvements have been evidenced against all KPIs for the project, with communication with health professionals and the time from index scan to treatment showing improvements to the process that can infer an improved outcome.
- Lessons learned should be reviewed as the project transitions into SCOT-HPB

Appendices

A) Pancreatic and Hepatocellular Pathways

Pancreatic Pathway – Pathway A



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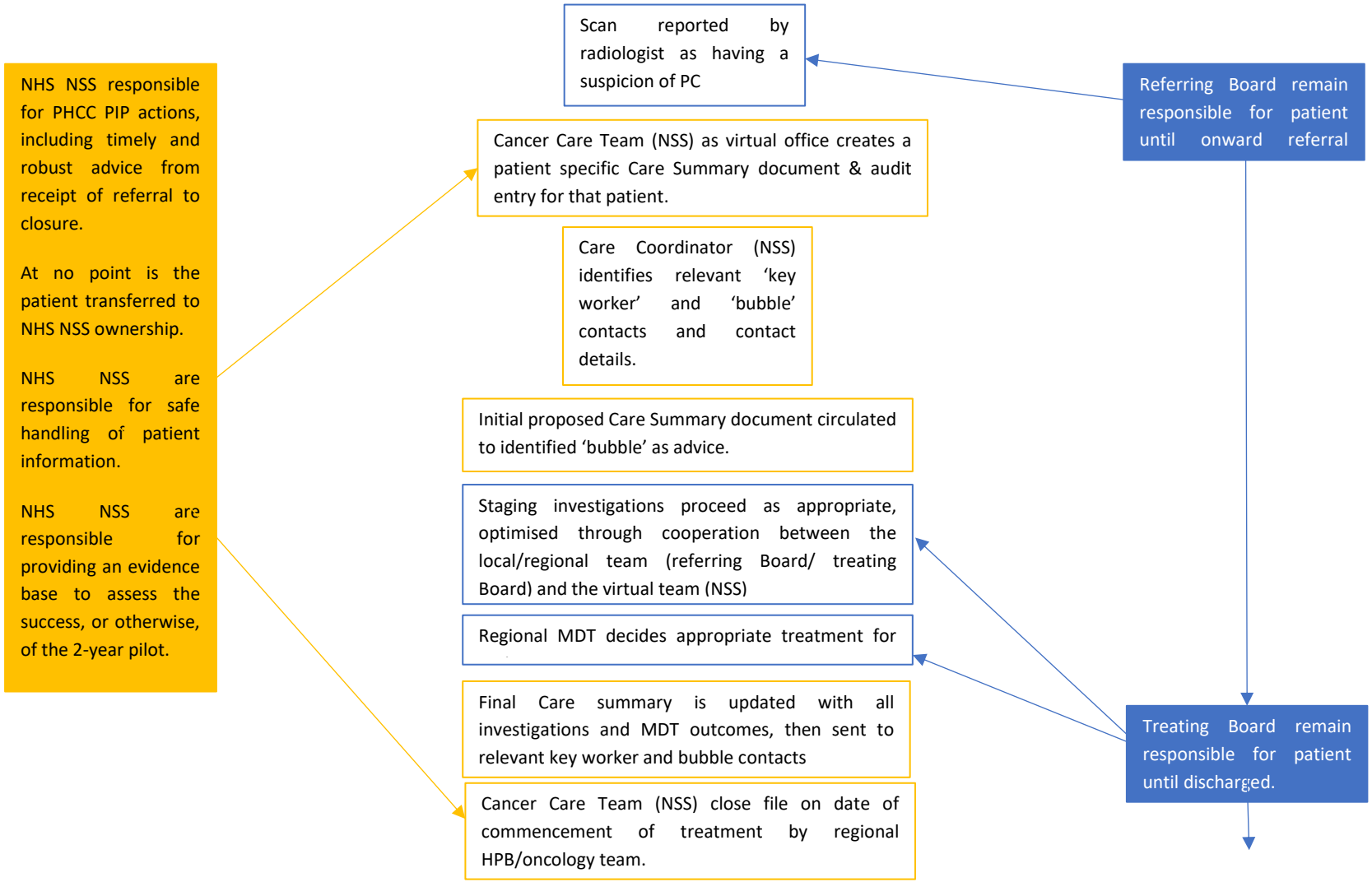
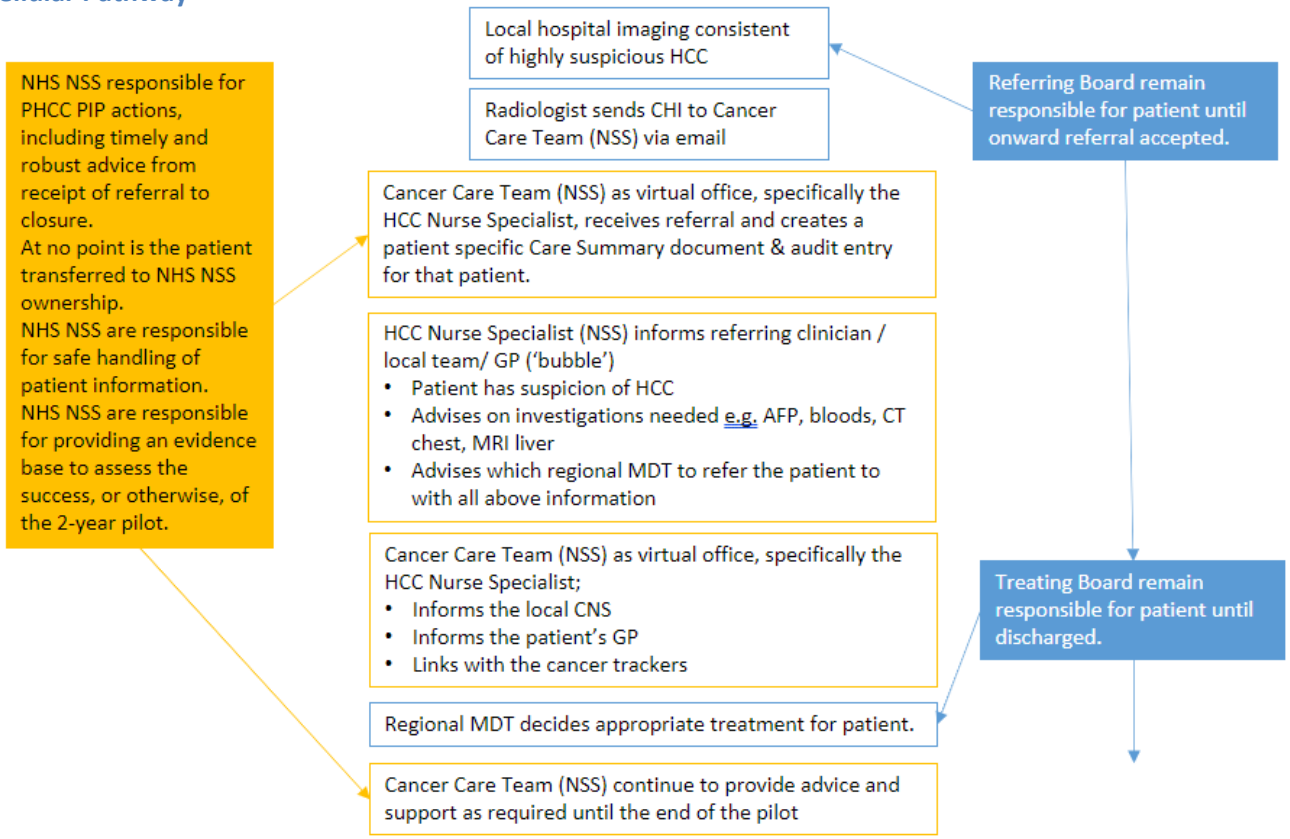
Pancreatic Pathway – Pathway B



Hepatocellular Pathway



For both PC and HCC, CNS input takes place early in the pathway to support patients in parallel to the GP being informed of the patient's imaging findings, in order for them to support and help manage the patient.

Care Summary document amended if appropriate and

B) Referrals

Hepatocellular Referrals

	Jan '23	Feb '23	Mar '23	Apr '23	May '23	Jun '23	Jul '23	Aug '23	Sep '23	Oct '23	Nov '23	Dec '23
Ayrshire & Arran												
Referred	2	2	0	0	2	3	1	1	4	0	1	1
NOT Referred	3	0	5	4	3	1	2	2	5	8	2	3
% not referred	60.0%	0.0%	100.0%	100.0%	60.0%	25.0%	66.7%	66.7%	55.6%	100.0%	66.7%	75.0%
Borders												
Referred	0	1	0	0	0	0	0	0	0	0	0	0
NOT Referred	0	0	1	0	0	1	0	0	0	1	1	1
% not referred	0.0%	0.0%	100.0%	0.0%	0.0%	100.0%	0.0%	0.0%	0.0%	100.0%	100.0%	100.0%
Dumfries & Galloway												
Referred	0	0	0	0	1	3	1	1	0	1	0	0
NOT Referred	0	0	3	1	1	1	0	0	0	0	0	2
% not referred	0.0%	0.0%	100.0%	100.0%	50.0%	25.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%
Fife												
Referred	0	0	1	1	1	2	1	0	1	1	0	0
NOT Referred	0	0	0	5	2	4	2	1	1	4	1	4
% not referred	0.0%	0.0%	0.0%	83.3%	66.7%	66.7%	66.7%	100.0%	50.0%	80.0%	100.0%	100.0%
Forth Valley												
Referred	0	0	0	0	0	0	1	0	2	3	1	3
NOT Referred	0	0	2	3	3	3	4	2	1	2	1	1
% not referred	0.0%	0.0%	100.0%	100.0%	100.0%	100.0%	80.0%	100.0%	33.3%	40.0%	50.0%	25.0%

Greater Glasgow & Clyde												
Referred	0	0	6	7	4	4	2	13	9	7	8	8
NOT Referred	1	7	10	15	14	4	10	11	5	7	8	7
% not referred	100.0%	100.0%	62.5%	68.2%	77.8%	50.0%	83.3%	45.8%	35.7%	50.0%	50.0%	46.7%
Grampian												
Referred	8	1	0	1	3	3	4	4	2	3	0	2
NOT Referred	4	4	5	6	6	5	0	5	4	8	3	3
% not referred	33.3%	80.0%	100.0%	85.7%	66.7%	62.5%	0.0%	55.6%	66.7%	72.7%	100.0%	60.0%
Highland												
Referred	1	0	0	1	0	0	0	0	2	0	2	0
NOT Referred	2	2	3	0	0	0	3	2	2	1	1	0
% not referred	66.7%	100.0%	100.0%	0.0%	0.0%	0.0%	100.0%	100.0%	50.0%	100.0%	33.3%	0.0%
Lanarkshire												
Referred	6	5	2	3	3	4	6	1	3	2	4	3
NOT Referred	2	5	7	4	5	5	1	3	2	2	4	3
% not referred	25.0%	50.0%	77.8%	57.1%	62.5%	55.6%	14.3%	75.0%	40.0%	50.0%	50.0%	50.0%
Lothian												
Referred	1	2	3	1	5	3	0	4	2	3	3	4
NOT Referred	0	1	3	2	2	7	7	5	7	7	1	2
% not referred	0.0%	33.3%	50.0%	66.7%	28.6%	70.0%	100.0%	55.6%	77.8%	70.0%	25.0%	33.3%
Tayside												
Referred	0	0	0	0	1	0	0	0	0	0	1	0
NOT Referred	1	1	2	2	1	2	5	3	0	1	2	2
% not referred	100.0%	100.0%	100.0%	100.0%	50.0%	100.0%	100.0%	100.0%	0.0%	100.0%	66.7%	100.0%

Pancreatic Referrals

	Jan '23	Feb '23	Mar '23	Apr '23	May '23	Jun '23	Jul '23	Aug '23	Sep '23	Oct '23	Nov '23	Dec '23
Ayrshire & Arran												
Referred	0	1	0	0	9	11	4	3	6	5	2	0
NOT Referred	9	5	9	5	10	5	2	2	5	4	1	0
% not referred	100.0%	83.3%	100.0%	100.0%	52.6%	31.3%	33.3%	40.0%	45.5%	44.4%	33.3%	0.0%
Borders												
Referred	0	2	2	0	0	1	1	0	2	0	2	1
NOT Referred	0	0	1	0	0	4	1	0	1	1	3	1
% not referred	0.0%	0.0%	33.3%	0.0%	0.0%	80.0%	50.0%	0.0%	33.3%	100.0%	60.0%	50.0%
Dumfries & Galloway												
Referred	0	0	1	0	2	2	0	2	0	0	1	1
NOT Referred	0	2	3	0	1	2	0	2	0	2	1	1
% not referred	0.0%	100.0%	75.0%	0.0%	33.3%	50.0%	0.0%	50.0%	0.0%	100.0%	50.0%	50.0%
Fife												
Referred	0	0	2	0	1	0	2	4	1	2	0	0
NOT Referred	0	4	1	8	1	4	3	2	2	5	3	2
% not referred	0.0%	100.0%	33.3%	100.0%	50.0%	100.0%	60.0%	33.3%	66.7%	71.4%	100.0%	100.0%
Forth Valley												
Referred	0	0	0	0	3	0	2	2	2	4	5	1
NOT Referred	0	0	2	6	5	3	1	1	3	3	3	3
% not referred	0.0%	0.0%	100.0%	100.0%	62.5%	100.0%	33.3%	33.3%	60.0%	42.9%	37.5%	75.0%
Greater Glasgow & Clyde												
Referred	1	1	1	5	6	7	6	4	6	2	2	3
NOT Referred	0	6	15	23	11	15	2	16	12	12	25	5

% not referred	0.0%	85.7%	93.8%	82.1%	64.7%	68.2%	25.0%	80.0%	66.7%	85.7%	92.6%	62.5%
Grampian												
Referred	0	4	0	1	2	1	2	6	4	5	2	3
NOT Referred	2	7	8	14	15	5	5	4	8	9	4	6
% not referred	100.0%	63.6%	100.0%	93.3%	88.2%	83.3%	71.4%	40.0%	66.7%	64.3%	66.7%	66.7%
Highland												
Referred	0	1	1	0	0	0	0	0	0	0	0	0
NOT Referred	5	2	2	5	1	2	4	3	4	7	2	1
% not referred	100.0%	66.7%	66.7%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Lanarkshire												
Referred	4	2	2	0	4	1	5	2	4	5	6	4
NOT Referred	1	8	9	2	7	11	4	4	2	4	4	1
% not referred	20.0%	80.0%	81.8%	100.0%	63.6%	91.7%	44.4%	66.7%	33.3%	44.4%	40.0%	20.0%
Lothian												
Referred	0	2	4	0	5	7	2	5	3	5	2	7
NOT Referred	0	7	10	9	11	5	5	8	8	11	6	6
% not referred	0.0%	77.8%	71.4%	100.0%	68.8%	41.7%	71.4%	61.5%	72.7%	68.8%	75.0%	46.2%
Tayside												
Referred	0	0	0	0	2	3	4	2	2	1	1	1
NOT Referred	3	2	11	5	3	6	6	4	2	5	3	8
% not referred	100.0%	100.0%	100.0%	100.0%	60.0%	66.7%	60.0%	66.7%	50.0%	83.3%	75.0%	88.9%

C) Patient Signposting, CNS Education and 3rd Sector Support

Patient Signposting

Due to the highly complex nature of treatment for those patients with HCC and PC, a 'signposting' service is provided by the CCT to provide advice on treatment options and information for health professionals with HCC or PC patients and those CNS who are new in post.

A poster has been circulated to HPB teams across Scotland advising them of the 'signposting' service available within the CCT for health professionals who have HCC or PC patients. Members of the team have advised those with HCC patients on where they can see further information on HCC, TACE and ablations as well as sharing patient information sheets and information on where patients can get further information and advice from the third sector. All requests are logged by the CCT and saved in Teams.

Often patients are referred to a regional board MDT and the referring board is not aware of the outcome for the patient. The CCT have access to all the required patient systems for all boards across Scotland and can provide advice and information on where the patient is on the pathway with regards to imaging or staging investigations where required.

Clinical Nurse Specialist (CNS) Education

A national event took place 23rd June, with 38 CNS attending from around Scotland. Speakers provided insight into a variety of topics and there has been lots of positive feedback received. The SHPBN is one of the first networks to provide this type of forum and educational opportunity for their nurses and there has been enthusiasm for further education events in the future.

The CCT have also worked in collaboration with the British Liver Trust on virtual sessions to provide support and information to HCC patients and teams.

Scottish Government and Third Sector Support

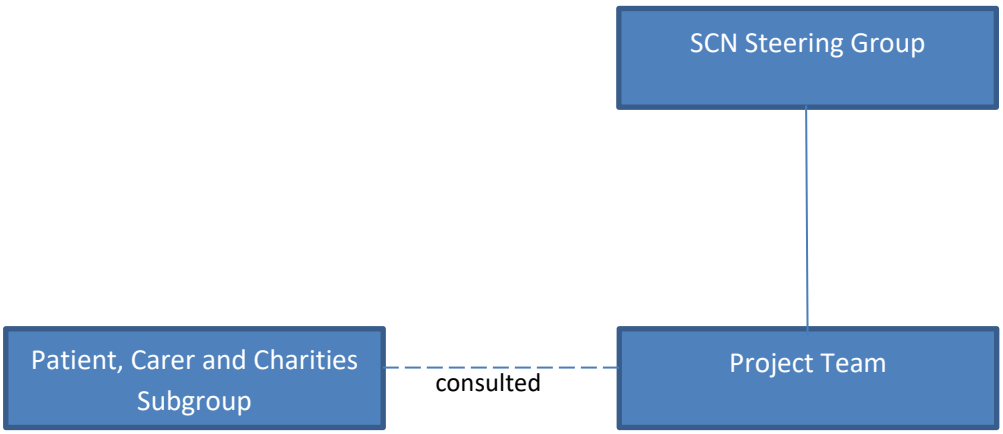
The Cabinet Secretary for Health and Social Care has been supportive, meeting with the Co-Chair of the Patient, Carers and Charities at several stages throughout the project.

Third sector support has been integral, with the Patient, Carers and Charities Subgroup shaping the conversational-style questions that are used with patients for the audit. Support has also included their significant involvement in helping to producing a media release on the project, along with social media engagement from the British Liver Trust, Pancreatic Cancer UK and Pancreatic Cancer Action.

The project was asked to feed into a Scottish Parliament debate in May on liver cancer, and engagement has also taken place with the Less Survivable Cancer Taskforce.

D) Governance

Project Governance



Clinical Governance

The project had clinical oversight from the SHPBN Lead Clinician. Additional clinical governance was in place and is currently under review as the project transitions to a service.

IT and Information Governance

Complex governance and IT access resulted in a significant delay to the project, with national roll out only taking place at the end of January 2023.

NHS Scotland does not have an integrated system in place to enable remote access to all live IT systems and patient data across Scotland. Caldicott approval for access to data and patient systems was initially sought from each of the regional surgical treatment centres:

- North Cancer Alliance (NHS Grampian, Highland and Tayside),
- West of Scotland Cancer Network (NHS Greater Glasgow and Clyde) and
- Southeast Cancer Network (NHS Lothian).

There were significant variations across the boards in the information and assurances required prior to the Caldicott Guardians being content to sign off on the remote access required. Honorary contracts were required in some boards for the CCT prior to Caldicott approval, which took a significant period of time.

Further Caldicott approval was required with each of the outstanding territorial boards to enable remote access to their IT systems. Following Caldicott approval, additional signoff and authorisation was then often required from both IT and system leads within the individual boards.

Standard Operating Procedures (SOPs) were also required from each NHS Board's radiology department to outline how referrals to the national virtual CCT would be carried out. The National IT Access Case Study was presented at the March 2023 SCN Programme Board.

Information governance and IT access for all boards was authorised for the CCT to March 2024 and is currently being extended for the service.

Data Protection Impact Assessment

A Data Protection Impact Assessment (DPIA) has been carried out and is currently being revised for the service going forward.

E) Data Analysis

Retrospective Data

A retrospective audit has taken place to provide a baseline by which to assess the project. Data was collected for patients diagnosed prior to the commencement of the project between October 2021-December 2022.

Findings from the audit data for the months prior to the pilot being launched have indicated that for both HCC and PC:

- Over 40% of patients still require a hospital admission for diagnosis for PC and 35% for HCC
- There are unnecessary delays in requesting the required investigations for patient management decisions
- There are delays in communication and instigating support and early holistic care
- More than a quarter of the patients were exceeding the 62 day cancer pathway targets

Hepatocellular Carcinoma (HCC)

Table 1

Days between day 0 report and … (median)	Inpatient	Outpatient
GP informed	15	28
1st MDT discussion	15	38
MDT decision	15	52
Definitive treatment started	21	111.5
CNS contact	18.4	44
Days between MDT & patient informed of outcome (median)	0	14

Table 2

Number of MDT discussions	Inpatient (%)	Outpatient (%)
1	74	52
2	19	19
3	4	16
4 or more	0	10

Pancreatic Cancer (PC)

Table 3

Days between day 0 report and … (median)	Inpatient	Outpatient
GP informed	7	8
CNS informed	4	11
First CNS contact	8	17.5
CNS discussion of diagnosis and investigation plan	11	18
Treatment plan finalised	28	40
Definitive treatment started	46	64.5
Days between MDT & patient informed of outcome (median)	3.5	2

Table 4

Number of MDT discussions	Inpatient (%)	Outpatient (%)
0	2	0
1	74	52
2	19	19
3	4	16
4 or more	0	10

A retrospective audit also took place around patient, GP and Clinical Nurse Specialist experience. Conversational-style questions, developed by the Patient, Carers and Charities Subgroup were used for discussion with HCC and PC patients who had undergone the pathways. Findings from the audit prior to the project being launched found that:

- A significant proportion of both HCC and PC patients felt that they did not have enough information at the start of their pathway or to make a decision about treatment
- 20% of patients were informed of their diagnosis via phone, Near Me or letter
- 20% of patients felt that the time it took for them to be discussed at MDT was too long

Questionnaires were sent to CNSs throughout Scotland, which highlighted the need for the following:

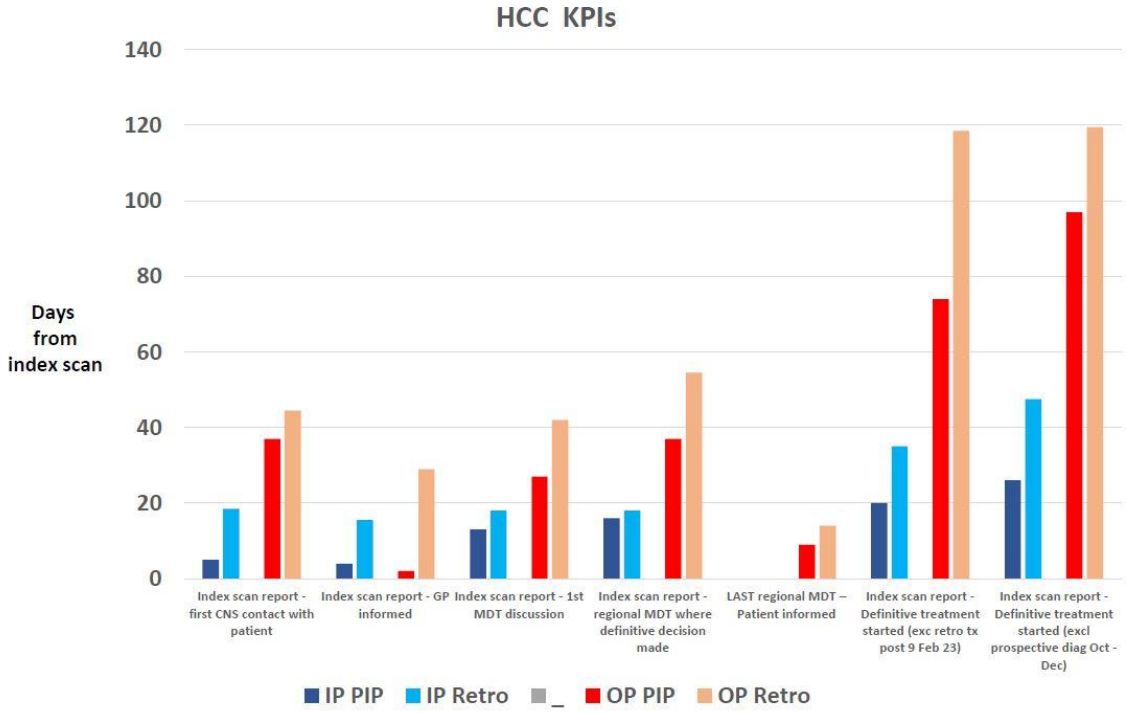
- Real time feedback from MDTs
- Improved communication between regional cancer centres
- Training initiatives for CNS
- Sharing of best practice and documentation

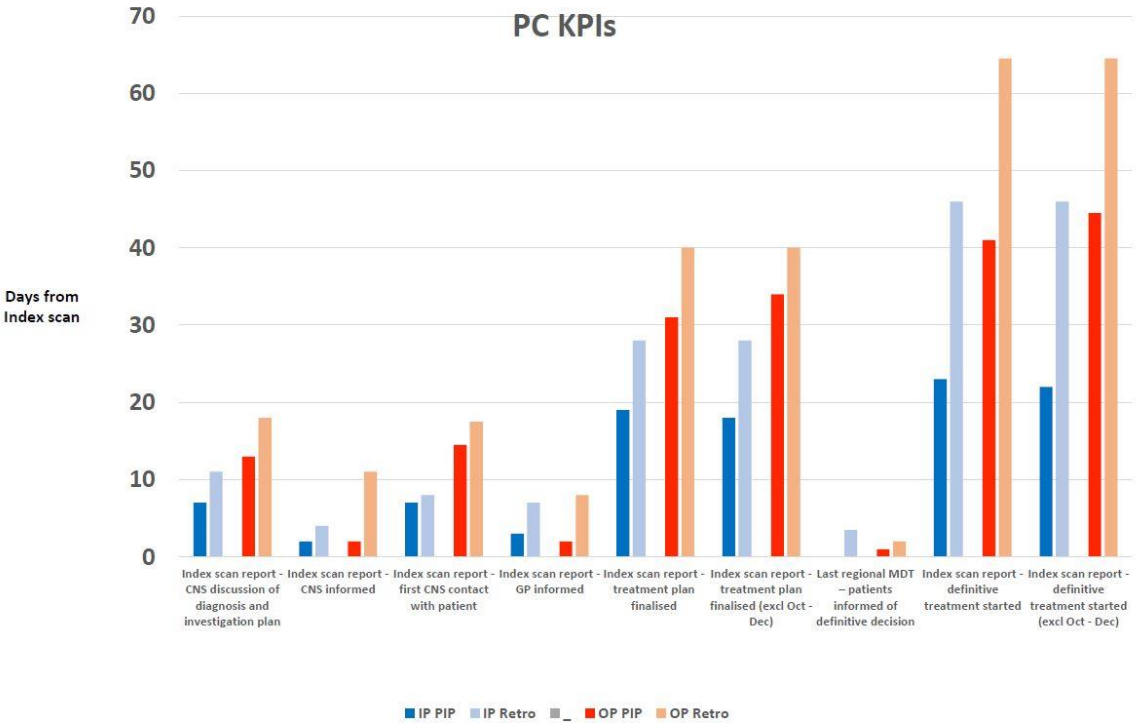
Email questionnaires were also sent to GPs across Scotland who were known to have had a patient diagnosed with HCC or PC. The responses highlighted:

- Less than half of GPs were aware of who to contact for information on patients or for clinical problems
- Only 72% of GPs with HCC patients and 49% of GPs with PC patients agreed that they were provided with sufficient information to allow them to manage their patient from a primary care perspective

- There is a need for better and earlier communication to GPs, to help them manage their patients

A comparison of retrospective audit data with prospective data was carried out in February 2024. Patients included those with hepatocellular carcinoma or pancreatic cancer, who were diagnosed between November 14^{ths} 2022 and December 31st 2023 and had completed their pathway. Data analysis on KPIs for both PC and HCC can be found here with an overview presented in the charts below. The Data Specification document can be found here.




PC KPIs
Days from Index scan
70
60
50
40
30
20
10
0
Index scan report - CNS discussion of diagnosis and investigation plan
Index scan report - CNS informed
Index scan report - first CNS contact with patient
Index scan report - GP informed
Index scan report - treatment plan finalised
Index scan report - treatment plan finalised (excl Oct - Dec)
Last regional MDT – patients informed of definitive decision
Index scan report - definitive treatment started
Index scan report - definitive treatment started (excl Oct - Dec)
IP PIP
IP Retro
_
OP PIP
OP Retro

Document Control Sheet

a. Key Information

Document Status	Draft V0.7
Author	Catriona Johnson, Associate Director

b. Approvals

This document requires the following signed approvals:

Version	Date	Name	Role	Signature
V0.2	27/03/2024	Anya Adair, Ross Carter	Clinical Leads	AA, RC
V0.3	14/04/2024	Roseanne McDonald	Associate Director	
			SCN Steering Group – information only	
V0.6	04/09/2024	Catriona Johnson	Associate Director	CJ
V0.7	18/09/2024	Catriona Johnson	Associate Director, NSD	

c. Distribution

This document has been distributed to:

Version	Date of Issue	Name	Role / Area
			Project Portfolio Manager / PgMS
			SCN Steering Group
			SG Cancer Policy Team