Patient and Healthcare Provider Voices, Listening to Improve: Evaluating a Pancreaticobiliary Inflammation and Cancer Program

P. Mathura, E.A. van der Raadt, S. Lalani, I. Hussein, K. Blackie, A. Kwan, M. Timmermans, G. Buchanan, A. Nordin-Garrett, J-E. Nilsson, S. Wasilenko, S. Perryman, S. Veldhuyzen Van Zanten, D. Bigam, J. Shapiro, K. Dajani, B. Anderson, C. Fung, and G. Sandha

Edmonton Zone Medicine Quality Council
Strategic Clinical Improvement Committee
Partnerships in Action

BACKGROUND

- Pancreatic cancer is estimated to become the second-leading cause of cancer death in Canada by 2030[1]
- Nurse Navigator (NN) programs improve patient experience by aligning care with individual needs, providing more timely care access and increase completion rates to cancer care services and patient satisfaction[2]
- Patient navigation has positive effects on patients' quality of life[3].

The EPIC Program

- The EPIC program was launched in July 2023 at the University of Alberta Hospital, Edmonton, AB, to enhance care for pancreatic cancer patients by creating a streamlined, NN-supported pathway from diagnosis to treatment
- Patient feedback can identify gaps in healthcare and communication, leading to more personalized care and better outcomes[3].

★ The purpose of this study was to gather feedback from patients and family members as well as Healthcare providers (HCP) about their involvement with the EPIC program.

OBJECTIVES

1.To examine patients' and HCP perspectives and experiences of being involved in the EPIC program, with particular attention to their interactions with the nurse navigator.

2.To identify perceived strengths of the EPIC program from the patient perspective.

3.To gather patient recommendations for program improvement based on their lived experience.

Research Question:
What are patients' and HCP experiences and perceptions of the EPIC program and their interactions with the nurse navigator, and how do these perspectives inform the strengths and areas for improvement of the program?

METHODOLOGY

- Mixed Methods Study Design - Patient feedback
- Retrospective Cross - section Survey - Healthcare Provider Feedback
- Participants: Purposive data sampling, all patients and family enrolled in the EPIC program eligible to participate. All Healthcare providers directly involved in the EPIC program.

Figure 1. CoACT Survey

Figure 2. Telephone Interview Tool

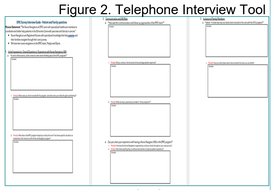
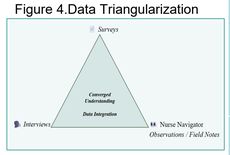


Figure 3. HCP Survey

Figure 4.Data Triangularization



▪ Phase One:
Timeframe: October 2023 to May 2024 (Patient feedback)

CoACT Survey:
1. Collected at 3-6 months
2. NN offered and explained the survey to the patient/family
3. NN entered the results into a Redcap database

Nurse Navigator collected feedback:
(Oct 2023 to June 2025)
★ Thematic analysis and descriptive statistics completed.

▪ Phase Two:
Time frame: July to Aug 2024
Structured 1:1 Telephone Interview:
1. Interview verbal script with consent and 5 questions with prompts informed by phase one data were developed
2.Used the enrolled patient contact list
3. Trialed with 8 patients, minor word changes made, resulting in the final interview questions with prompts
4. Nursing student and the clinic manager conducted calls to patients. The calling protocol involved leaving a voicemail on the first attempt; if there was no response, one follow-up call was made.

HCP Survey:
Time Frame: June 2025 to Sept 2025 (HCP feedback)

1. Collect 24 months after program start
2. Online survey link emailed to HCP from program admin

★ Descriptive statistics were conducted for scaled questions, thematic analysis completed to examine open-ended textual responses.

▪ Integration Phase: Joint Display

RESULTS

Phase One

CoACT Survey Results:

N=41 [46%, 41/90]; 95% patients and 5% family
- Average age: 65 (range 19-62).
- 73% felt involved in their care (n=30).
- Nearly all (97%)could ask questions and understood explanations.
- Courtesy and respect scored high at 85% (n=35), and all respondents' felt care was timely (n=31 always, n=10 usually).

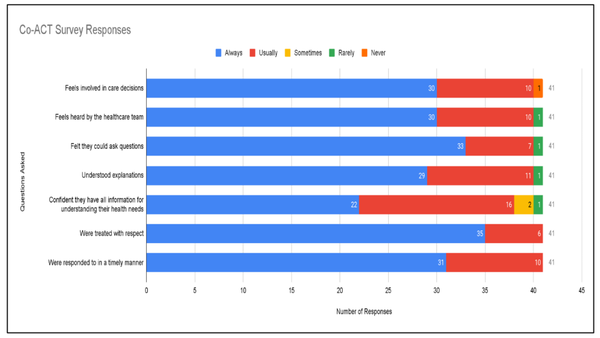


Figure 4. Co-Act Survey Summary of Results

Themes

Satisfaction and Praise (n=10)	○	*"Thank you for your support !! I feel like I am in good hands"*
	○	*"Very very impressed"*
	○	*"Our health care professionals were courteous, kind, and helpful."*
Navigation and Care Coordination (n=3)	○	*"It was wonderful having two nurse navigators with us. I knew there was always someone there to help us and always so quickly."*
	○	*"They've explained things that we didn't understand. They are extremely empathetic and genuinely care about their patients."*
	○	*"Pancreatic cancer nurse team... can't say enough positive about them. We patients NEED this team!"*
Family Engagement (n=1)	○	*"My wife was also treated well, and the team would always talk to her"*
Areas for Improvement (n=5)	○	*"Wish more is done about alternative options" (x2)*
	○	*"Some staff didn't understand how sensitive I was to drugs"*
	○	*"I have left messages with people. No one sometimes gets back to me" (x2)*

* One participant reported no comment.

Figure 5. Summary of Emerged Themes- CoACT Survey Open-Ended Comments

Phase Two

Telephone Interview:

N=63; [53%, 63/119], 92% patients and 8% family
•1023 comments
•8 Themes emerged

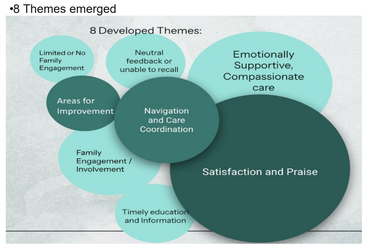


Figure 6. Themes from Telephone Interviews

Telephone Survey Feedback Summary

Satisfaction and Praise:
●**86%** (n=56) reported overall satisfaction with the EPIC program..
●**Most Helpful Aspects: 68%** identified **care coordination** (n=23) and **timely education** (n=22).

" We felt that ofter learning about the program we would no longer be so lost and we had someone to talk to."

Timely Education and Information:
●**Timeliness of Communication: 84%** (n=57) received timely contact.
○**93%** (n=62) defined "timely" as within 2 days

"The [NN's]checked in with me either weekly or biweekly. When I was in the hospital they visited me in person. It was amazing."

Emotionally Supportive Compassionate Care:

●**48%** (n=29): Emotional support & proactive check-ins

"They went above and beyond. They are the "go between" from the hospital to the cross. The EPIC team will always be a resource, and I appreciate how they're dedicated to me as a patient."

Navigation and Care Coordination
●**18%** (n=11): Appointment coordination
●**15%** (n=9): Clear next-step education

Family Engagement / Involvement:

●**65%** (n=37): Family was supportive but not involved in EPIC.
●**58%** (n=36): EPIC team supported their family directly or indirectly
•**Overall, 95%** (n=64)of participants felt supported by the EPIC program

Nurse Navigator Field Notes Summary

N=15, 4 **themes** emerged.

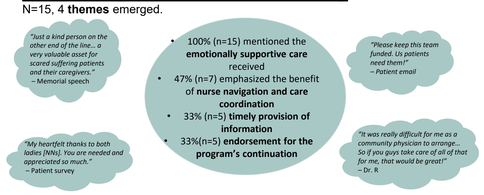


Figure 7. Summary of NN Field Notes

Data Integration Phase

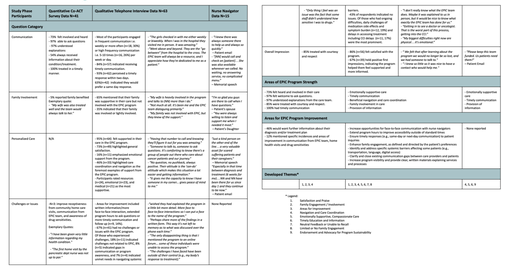


Figure 8. Joint Data Summary of Findings

Healthcare Provider Survey Summary

N=12; [50%, 12/24], 50% physicians, 33% nurses, 17% dieticians.

- 100% agreed EPIC program improved interdisciplinary coordination (n=12).
- 75% observed improved patient experiences (n=9)
- 100% said the program was effective in improving clinical outcomes, with most rating it 'very effective.'
- Satisfaction was also high—92% were very satisfied with their experience.

Recommendations From All Data Sources

Key Strengths: Support & advocacy for program continuation, care coordination, timeliness, emotional support, dedicated person of contact for providers, strong collaboration.

Areas for Improvement:

Patient Feedback	Provider Feedback
• Clearer written program communication and timely callbacks. • More face-to-face contact and extended program hours. • Guidance on care options and medication tolerance. • Consider an online forum for support.	• Streamline referral process. • Expand staffing and increase program awareness. • Add more HPB pathology. • Secure permanent funding for nurse navigators.

Figure 9. Summary of Patient and Provider Areas for Improvement

TAKEAWAYS

Challenge
- Difficult to collect patient and family information due to severity of illness
- Collect within first 3 - 6 months.
- Small HCP sample size

Success
- Patient and HCP insight and feedback provided a perspective and lens to identify program strengths and areas of opportunity.
- Addresses gap regarding limited research on pancreatic NN programs

Lessons
- Seek Patient feedback first. Two feedback tools were not convenient
- Seek HCP feedback more often, use 1:1 interviews or informal feedback approaches (i.e. during program meetings)

Significance
- Improve the feedback tool and process – leverage evidence informed tools and develop a process to ensure patients' voices are heard
- EORTC QLQ C-30 possible validated survey tool to meausre symptom burden and health related quality of life

Limitations
- Quantitative: Surveys lack of depth and context, potential oversimplification of complex phenomena, possible response, reflection and social desirability bias.
- Qualitative: data analysis, time and resource intensive
- Integration: challenging to merge each phase of patient feedback data as were slightly different.

CONCLUSION AND NEXT STEPS

Evidence Informed Patient Survey
- Develop valid questions/ survey grounded in published research
- Consider closed and open-ended questions include consent section
- Pilot the survey, refine as needed

Sustainable prospective (3 - month) data collection
- Select how (online, in-person, phone, paper survey) and with what platform .
- Data storage- Redcap
- Upon enrollment within the welcome package/brochure, add a document about program evaluation, reviewed by NN
- Data collected post 3-months (at minimum) in the program
- Target population will be patients (when possible)

Analysis Plan
- Descriptive statistics and thematic analysis
- Summarize the key points to be shared with program team and supports

REFERENCES

1. Kubiseski, M., Hu, M., & Hajizadeh, M. (2024). Trends in socioeconomic inequalities in pancreatic cancer mortality in Canada: Evidence from the Canadian Vital Statistics Death Database. *Surgical Oncology Insight*, *1*(2), 100051. https://doi.org/10.1016/j.soi.2024.100051
2. Oh, J., & Ahn, S. (2021). Effects of nurse navigators during the transition from cancer screening to the first treatment phase: A systematic review and meta-analysis. *Asian Nursing Research*, *15*(5), 291–302. https://doi.org/10.1016/j.anr.2021.10.001
3. Chan, R. J., Milch, V. E., Crawford-Williams, F., Agbejule, O. A., Joseph, R., Johal, J., Dick, N., Wallen, M. P., Ratcliffe, J., Agarwal, A., Nekhlyudov, L., Tieu, M., Al-Momani, M., Turnbull, S., Sathiaraj, R., Keefe, D., & Hart, N. H. (2023). Patient navigation across the cancer care continuum: An overview of systematic reviews and emerging literature. *CA: A Cancer Journal for Clinicians*, *73*(6), 565–589. https://doi.org/10.3322/caac.21788

ACKNOWLEDGEMENTS

We gratefully acknowledge the patients and HCP who contributed their insights to this evaluation. Your voices inspire change to help improve and sustain the Pancreaticobiliary Inflammation and Cancer Program (EPIC). Special thanks to the University of Alberta nursing students for assisting with the data collection and analysis for this study.