

BMJ Open Patient-centered outcomes for gastrointestinal cancer care: a scoping review protocol

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To cite: Yang J, Barabash T, Rajendran L, *et al*. Patient-centered outcomes for gastrointestinal cancer care: a scoping review protocol. *BMJ Open* 2022;**12**:e061309. doi:10.1136/bmjopen-2022-061309

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-061309>).

Received 23 January 2022
Accepted 26 May 2022



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ABSTRACT

Introduction Following a cancer diagnosis, patients and their caregivers face crucial decisions regarding goals of care and treatment, which have consequences that can persist throughout their cancer journey. To foster informed and value-driven treatment choices, evidence-based information on outcomes relevant to patients is needed. Traditionally, clinical studies have largely focused on a few concrete and easily measurable outcomes such as survival, disease progression and immediate treatment toxicities. These outcomes do not capture other important factors that patients consider when making treatment decisions. Patient-centred outcomes (PCOs) reflect the patients' individual values, preferences, needs and circumstances that are essential to directing meaningful and informed healthcare discussions. Often, however, these outcomes are not included in research protocols in a standardised and practical fashion. This scoping review will summarise the existing literature on PCOs in gastrointestinal (GI) cancer care as well as the tools used to assess these outcomes. A comprehensive list of these PCOs will be generated for future efforts to develop a core outcome set.

Methods and analysis This scoping review will follow Arksey and O'Malley's expanded framework for scoping reviews. We will systematically search Medline, Embase, CINAHL, Cochrane Library and APA PsycINFO databases for studies examining PCOs in the context of GI cancer. We will include studies published in or after the year 2000 up to the date of the final searches, with no language restrictions. Studies involving adult patients with GI cancers and discussion of any PCOs will be included. Opinion pieces, protocols, case reports and abstracts will be excluded. Two authors will independently perform two rounds of screening to select studies for inclusion. The data from full texts will be extracted, charted and summarised both quantitatively and qualitatively.

Ethics and dissemination No ethics approval is required for this scoping review. Results will be disseminated through scientific publication and presentation at relevant conferences.

INTRODUCTION

Cancers of the gastrointestinal (GI) tract represent a leading cause of morbidity and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A broad and comprehensive search of relevant studies will be performed in several academic research databases with the guidance of a health sciences librarian.
- ⇒ Stakeholders including patients with lived experience of cancer will be consulted and engaged with throughout the study process.
- ⇒ As this is a scoping review, quality assessment and grading of articles will not be performed, limiting the ability to provide clinical recommendations.
- ⇒ Studies published in all geographies will be included.

mortality worldwide, with an estimated 4.8 million new cases and 3.4 million deaths in 2018.¹ Management usually requires a multimodal approach and may involve surgery, radiotherapy, chemotherapy, targeted therapy and survivorship care. Each patient trajectory is unique in terms of prognosis, potential complications and choice of therapies. Moreover, the side effects and long-term consequences can vary greatly and impact the patient experience throughout the care continuum. Thus, many complex considerations must be taken into account when making treatment decisions.

Patient-centred care (PCC) is recognised by WHO as a core competency for healthcare providers (HCPs) and a key component of healthcare systems and care quality.² PCC is a model of care in which HCPs are encouraged to partner with patients to codesign and deliver personalised care through shared decision-making.³⁻⁶ Under these tenets, cancer care should address the individual needs, values and preferences of each patient through effective communication and collaboration. These factors determine which outcomes are prioritised when designing treatment plans at each point along the cancer care continuum. This process relies

on both patients and HCPs having accessible and understandable data on care options, evidence and their benefits and harms with regard to relevant patient-centred outcomes (PCOs). However, evidence is often lacking for these outcomes.

PCOs reflect the beliefs, preference and needs of patients.⁷ They are used to amplify patients' voices when assessing the value of healthcare options. PCOs may represent priorities that are less obvious to non-patients when considering treatment choices, such as the impact on function rather than survival. Importantly, PCOs may include, but differ from, patient-reported outcomes, which are measures completed by patients themselves. Traditional clinical trials and studies in cancer care focus on endpoints deemed important by physicians and researchers.⁸ Consequently, available evidence is mostly centred on survival and other clinical events such as recurrence, disease progression and immediate treatment toxicities. While this information is significant for some clinical decisions, they do not capture the personal and social factors that are important to patients when evaluating management options.^{9 10} Overall, little information exists regarding PCOs in the setting of GI cancer care, and patients often feel they do not have a sufficient understanding of their condition, their options and the impact of proposed therapies. Without such information, patients may not be able to meaningfully engage in their care, which can lead to decisional conflict and decision regret.^{11–13} Decision regret is associated with patient dissatisfaction, increased use of health resources and high healthcare cost. Thus, establishing an understanding of the outcomes most relevant to patients is essential to minimise decision regret, improve patient experiences and reduce healthcare costs.

While the importance of integrating PCOs into cancer care is recognised, the question remains, which PCOs should be focused on and what approaches to measurement of such outcomes should be implemented? Different types of PCOs have been described, each highlighting certain domains of the patient experience. These broad categories include patient satisfaction, decision regret, patient preference and health-related quality of life.¹⁴ PCOs may involve specific long-term complications, adverse events or functional status post-treatment. When incorporating PCOs into cancer research, it is important to remain cognizant of the practical limits of data collection in study designs. A core outcome set (COS) comprised of a short, standardised list of PCOs would be conducive to developing prediction tools and decision aids for systematic use in clinical trials and comparisons of treatments, while minimising the burden of data collection and interpretation on HCPs and researchers.^{15 16}

This study will systematically map and synthesise the evidence on PCOs for GI cancer care. We will outline the existing literature and generate a comprehensive list of previously studied PCOs and their potential measurement strategies to guide the development of a COS, which will be used to direct future research efforts.

METHODS AND ANALYSIS

A scoping review methodology will be used to explore the literature describing the use of PCOs in GI cancer care and research following the expanded Arksey and O'Malley framework for scoping reviews.^{17–19} Reporting will adhere to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews.²⁰

Objectives

The scoping review will answer the following research questions:

1. With a focus on GI cancers, what PCOs have been described to study cancer care interventions or guide treatment decisions?
2. What measures have been described to assess these PCOs in the context of GI cancer research?

Eligibility criteria

Table 1 outlines the inclusion and exclusion criteria. GI cancers will include any solid malignancy of the GI tract, including the oesophagus, stomach, small intestine, colon, rectum, pancreas and biliary system.

Outcome

PCOs are outcomes that are important to the patient and are inclusive of their individual values, preferences, autonomy and needs.^{7 21} While the broad definition overlaps with some elements of traditional clinical research, it also involves unique patient priorities that are often not captured in most conventional cancer studies. Thus, for the purpose of this review, the definition of PCOs will exclude those established endpoints commonly measured in such studies, including survival, progression-free survival, disease recurrence and healthcare cost. We will include all studies that involve measurement of or discussion of any other PCOs.

Exposure

We will consider all cancer interventions for any aspect of the cancer care continuum. This will include interventions for disease treatment, management of cancer-related morbidity and complications, supportive care and cancer survivorship. These interventions must be applicable to any GI cancers specifically or to all solid malignancies.

Population

This review will focus on PCC in adults diagnosed with GI cancer, along the cancer care continuum. Accordingly, any studies with participants under the age of 18 or without a cancer diagnosis will be excluded. Studies involving only participants with any GI cancer will be included. Studies pertaining to solid malignancies inclusive of GI cancers (not site or subtype specific) will also be included. Studies addressing exclusively non-GI cancer (eg, management of breast cancer) will be excluded. Studies involving any haematologic malignancies will be excluded as the approach to management of these cancers is different entirely.

Table 1 Summary of inclusion and exclusion criteria to be applied to citations identified through the literature search

	Inclusion criteria	Exclusion criteria
Outcome	<ul style="list-style-type: none"> ▶ Measurement or discussion of ≥ 1 PCO ▶ Use of validated/existing or original outcome measures ▶ Use of patient-reported outcome measures ▶ Quality of life measures 	<ul style="list-style-type: none"> ▶ No measurement or discussion of specific PCOs ▶ Measurement or discussion of the following outcomes only: <ul style="list-style-type: none"> – Survival – Progression-free survival – Cost to healthcare system
Exposure	<ul style="list-style-type: none"> ▶ Interventions for any aspect(s) of GI cancer care or all solid cancers ▶ Treatment (ie, medical, radiation, surgical) ▶ Supportive care ▶ Cancer-related morbidity and complications ▶ Cancer survivorship 	<ul style="list-style-type: none"> ▶ Interventions outside the context of cancer only ▶ Interventions for non-GI cancer subtypes only (ie, breast, prostate, etc) ▶ Interventions for screening or diagnosis of cancer
Population	<ul style="list-style-type: none"> ▶ Age ≥ 18 years (all participants) ▶ Active or previous diagnosis of solid malignancy (all participants) 	<ul style="list-style-type: none"> ▶ Age < 18 years (any participants) ▶ No cancer diagnosis (any participants) ▶ Non-GI cancer subtypes only ▶ Haematologic malignancies (any participants)
Study details	<ul style="list-style-type: none"> ▶ Randomised and non-randomised interventional trials ▶ Prospective and retrospective observational studies ▶ Reviews and narrative studies ▶ Case series of 10 or more subjects ▶ Qualitative and quantitative studies ▶ Published during or after 2000 ▶ All languages and geographies 	<ul style="list-style-type: none"> ▶ Editorials, opinion pieces, case reports, dissertations, conference abstracts, protocols ▶ Published before 2000

GI, gastrointestinal; PCO, Patient-centred outcome.

Study details

We will include clinical trials, observational studies, reviews, narrative studies, qualitative and quantitative studies and case series of 10 or more subjects published in or after the year 2000, up to the date of the final searches. Those published before the year 2000 will be excluded, as the approach to cancer care and research has since evolved with regard to PCOs. Studies published in all languages will be included; however, search terms will only be executed in English, and no limitations will be placed on the geographic region of the study population.

Search strategy and information sources

The search strategy was developed for Medline with consultation from a health sciences librarian at the University of Toronto and adapted to other search engines including Embase, Cochrane Library, CINAHL and APA PsycINFO. The search will identify studies under the intersection of three search concepts: ‘GI cancer’, ‘patient-centeredness’, and ‘outcome assessment’, through use of relevant MeSH terms and textword searches. The full search strategy for Medline is seen in [table 2](#). The full search strategies for all included databases are shown in online supplemental appendices A–E.

Study selection

We will use a two-stage study selection process. The first stage will be a review of titles and abstracts for inclusion

using the Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia), independently performed by two reviewers. In the second stage, two reviewers will independently conduct a full-text review to determine whether each article meets the inclusion criteria. Disagreements will be resolved with discussion between the two reviewers, and by a third reviewer if necessary to reach consensus. As per recommendations by Levac *et al*, the study selection criteria will be pilot tested with an initial review of a random sample of 25 titles and abstracts.¹⁹ Subsequently, the team will meet to discuss discrepancies and make modifications to the eligibility criteria as needed. Screening will only start once a minimum of 80% agreement is achieved. Moreover, study selection will be an iterative process whereby inclusion and exclusion criteria may evolve as data are retrieved, with meetings between reviewers throughout the process to refine inclusion criteria.

Data items

Key information from the selected studies will be extracted and charted in a form with fields as suggested by Peters *et al*.²¹ A preliminary charting table with included variables to be abstracted is summarised in [table 3](#). This will provide the reader with a logical and descriptive summary of the results that are relevant to the research question as previously described. As per Levac *et al*, data charting will

Table 2 Medline search strategy

#	Searches
1	Neoplasms/
2	exp Digestive System Neoplasms/
3	((anal or bile duct* or biliar* or gastrointestin* or GI or neuroendocrin* or stomach* or gastric* or colon or colorectal or rectal* or rectum* or duoden* or esophag* or gastroesophag* or gallbladder* or liver* or hepat* or pancrea* or bowel* or intestin* or digestive*) adj3 (neoplasm* or adenocarcinoma* or cancer* or tumor* or tumour* or metast* or oncolog*).tw,kf.
4	1 or 2 or 3
5	Patient-Centered Care/
6	Decision Making, Shared/
7	(patient centered or patient centred or person centered or person centred or patient focused or patient oriented).tw,kf.
8	(patient adj3 (priorit* or preference* or value* or expectation* or need* or relevan*).tw,kf.
9	5 or 6 or 7 or 8
10	Outcome Assessment, Health Care/
11	Patient Outcome Assessment/
12	Patient Reported Outcome Measures/
13	(patient outcome* adj3 (measure* or assessment*).tw,kf.
14	((patient centered or patient centred or person centered or person centred or patient focused or patient oriented or patient reported) adj3 outcome*).tw,kf.
15	(core outcome set* or standard set*).tw,kf.
16	10 or 11 or 12 or 13 or 14 or 15
17	4 and 9 and 16
18	limit 17 to yr="2000 -Current"

too be an iterative process, with fields updated as needed as data are abstracted.¹⁹ The form will be pilot tested for the first 10 articles, which will be charted independently by 2 reviewers who will then reconvene with the other authors to ensure that the extracted data are relevant to the research questions.

Data synthesis

Results will be summarised both quantitatively and qualitatively to provide a description of the collected data. A conceptual framework of PCC will be used to provide an overview of the breadth of the literature.²² We will include both descriptive numerical summary analysis, presented using tables and charts, and qualitative thematic analysis. Descriptive statistics of key outcomes such as frequencies of specific outcomes, outcome measures, cancer types and reported rationales will also be reported. In keeping with scoping review methodology, an evaluation of study quality will not be performed. Finally, a master list of all

Table 3 Summary of charting table fields

(1) Article information	
(a) Author(s)	
(b) Year of publication	
(c) Source origin/country of origin	
(d) Aims/purpose	
(e) Study population and sample size (if applicable)	
(f) Methodology	For example, RCT, cohort study, qualitative, systematic review, etc
(g) Intervention type and comparator (if applicable)	
(h) Duration of the intervention (if applicable)	
(2) Key findings related to scoping review question	
(a) Cancer type(s) and subtype(s)	
(b) Patient-centred outcomes measured	For example, cognitive functioning
(c) How patient-centred outcomes are measured	For example, validated/ existing versus original scoring system; if existing system, state system (ie, EORTC QLQ-C30)
(d) How patient-centred outcomes are collected	For example, clinical (ie, physician report), patient-reported, administrative (ie, death registry)
(e) Times of assessment of patient-centred outcomes	For example, at baseline, during intervention, follow-up
(f) Rationale for measuring specific outcomes	
(g) Study findings on patient-centred outcomes	
EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer quality of life questionnaire; RCT, randomised controlled trial.	

PCOs and their measurement strategies described in the literature for GI cancer care will be reported.

Patient and public involvement

Stakeholder engagement is known to enhance the relevance, validity and quality of research.^{23–25} Following the patient and service users' engagement framework, we will partner with patients, service users, HCPs and health decision-makers to obtain additional sources of information and unique insights into the illness experience to guide research plans and outputs.²⁶ Three patient partners with lived experience of cancer (CL, EK and JD) are members of the research team who have been involved from inception and will participate in all parts of the study

to ensure clinical relevance and applicability. Consultations with stakeholders will also be used to share preliminary findings, validate and identify gaps in our findings, and inform future research efforts.

ETHICS AND DISSEMINATION

This scoping review protocol outlines a method to systematically search and map the literature on PCOs used in GI cancer care and research. Since this review will include only published data, ethics approval will not be sought.

Results of this scoping review will be disseminated through scientific publication and presentation at relevant conferences.

As outlined above, this review will constitute the first stage of the development of a COS for use in GI cancer PCC and research. Following the identification of existing PCOs in the literature, we will conduct semistructured interviews with patients and HCPs. A series of Delphi surveys will be used to prioritise and obtain consensus on the most relevant PCOs for GI cancer care. Ultimately, this COS will support the development of predictive tools and decision aids for personalised GI cancer care delivery. This is necessary to create tools that go beyond typical prognostication and provide patients with a spectrum of information on outcomes they value and that influence decision-making.^{27–30} These aids for shared decision-making will facilitate patient education, improve clinical outcomes and reduce delivery of care that is incongruent with patients' values and wishes.^{31–33} Furthermore, this information can be used by health systems, patient organisations, researchers and HCPs to plan cancer care, guide clinical trials and assess health services by measuring outcomes aligned with the values, needs and priorities of patients and other stakeholders.

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Contributors JY, JH, NGC, TB and LR conceived of the idea, developed the research questions and study methods and contributed to the drafting of the protocol. JY and TB conceived of and executed the search strategy. JH, NGC, ALM, ATH, PDJ, LGC, FCW, CL, EK and JD contributed meaningfully to the editing and critical review of this protocol and approved the final manuscript.

Funding This work was supported by Canadian Health Research Institutes, grant number 459694.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods and analysis section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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