Things I need you to know: a qualitative analysis of advice-giving statements in early-onset colorectal cancer patients’ personal accounts published online

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ABSTRACT

Objective People with early-onset colorectal cancer (EOCRC), defined as colorectal cancer (CRC) before the age of 50, now constitute a significant patient population. In empirical and grey literature EOCRC patients report unsatisfactory experiences of care, especially in relation to protracted intervals from first help-seeking to diagnosis. This study is the first to investigate EOCRC patients’ perspectives on ways to improve experiences of care. The objective is to provide foundational knowledge for the development of EOCRC-specific patient-reported experience measures (PREMs).

Design The study was designed as qualitative Internet Mediated Research, involving a thematic analysis of unsolicited narratives recounting personal experiences of EOCRC care. We examined advice-giving statements in 120 online texts written by EOCRC patients and survivors.

Setting The Internet is the broad research setting. The host websites of three prominent charitable CRC support organisations were selected as specific research sites: Bowel Cancer Australia, Bowel Cancer UK and Bowel Cancer New Zealand.

Results We found that 90% of texts comprised statements of advice to new patients about the importance of self-advocacy in achieving quality care. Four key contexts for self-advocacy were identified: (1) accessing relevant diagnostic services; (2) driving diagnostic investigations when symptoms are not resolved; (3) involvement in treatment decision-making and (4) proactivity about preferred outcomes. Over 30% of advice-giving texts also directed statements of advice to healthcare providers, indicating that their youthfulness had been a barrier to timely diagnosis.

Conclusion Healthcare barriers to, and facilitators of, patient self-advocacy may be indicators of quality EORC care. There is a need for greater awareness of the impact of age bias on the responsiveness of clinicians and healthcare services in EOCRC care. Our findings support the development of EOCRC-specific PREMs that can guide age-appropriate policy and practice for this newly identified patient population.

INTRODUCTION

Colorectal cancer (CRC) is most common in people over the age of 50 however the global incidence of the disease in younger people has been rising since the 1980s.1 People with early-onset colorectal cancer (EOCRC) now constitute a significant patient population12 with epidemiologically, and potentially biologically, distinct characteristics from late onset CRC patients.2–4 EOCRC accounts for 6% of all CRC cases in the UK,5 10.7% of CRC cases in Australia6 7 and 11.5% of CRC cases in New Zealand (NZ).8 As a result of the rising incidence of the disease in young people and static or decreasing CRC incidence in older patients, in higher income countries especially,6 people with EOCRC are becoming a larger proportion of all CRC cases; by one US estimate, for example, early-onset patients will make up 11% of colon cancers and 23% of all rectal cancers by 2030.9

Causes of the rising incidence of CRC in younger people are not yet well established.
Poor diet, decreased physical activity, obesity and overuse of antibiotics, especially in early years of life, are implicated. Further, rising incidence may be part of a trend; early-onset cancers are increasing in prevalence globally. EOCRC patients differ from older people with CRC in their diagnostic trajectories; time to diagnosis can be 60% longer for younger patients with a greater number of missed diagnostic opportunities, and younger people are more likely to be diagnosed in later stages of the disease.

Late stage diagnosis increases the likelihood of aggressive treatment with physical, psychosocial and quality of life outcomes that are uniquely challenging for this patient population. Despite the rising incidence of the disease, health systems are only just over to 45 years and over for average-risk patients; other western countries have yet to revise the guidance on screening age.

Younger people seeking diagnosis are challenged by limited clinical awareness of EOCRC. Few studies have investigated how this newly identified patient population views their healthcare trajectory from help-seeking for symptoms through to treatment outcome and as yet no patient-reported experience measures (PREMs) have been developed specifically targeting EOCRC. We have little empirical data to guide patient-centred best practice in EOCRC care.

CRC support organisations provide online platforms through their websites for CRC patients and survivors to publish accounts of their experiences in the public domain. These platforms present a substantial source of patient-reported, qualitative data on EOCRC care. The unsolicited nature of these data offers researchers a unique opportunity to understand what EOCRC patients want to say about their experiences and to examine the advice these patients offer others. Patient advice is of particular relevance to patient populations that are newly identified; new patients may prioritise the online advice of other patients, especially those whose disease is most personally relevant.

In this paper, we report our investigation of EOCRC patients’ online accounts of diagnosis and treatment. Our study asks: What experiences and perceptions of health services are reflected in the online advice offered by EOCRC patients? The translational aim of this study is to deliver evidentiary support for the development of EOCRC-specific PREMs that can guide healthcare practitioners and policymakers towards best patient-centred EOCRC practice.

**MATERIALS AND METHODS**

This study is reported in accordance with Standards for Reporting Qualitative Research (SRQR items S1-S15) (online supplemental appendix 1).

**Approach and research paradigm**

As yet there is no clear guidance on an appropriate research methodology for online research investigating unsolicited narratives. We devised a method we termed Personal Recollections Organised as Data (PROD). The PROD approach is theoretically constructivist, seeking out the knowledge that materialises as patients recount and reflect on their experiences of healthcare in unsolicited research contexts, such as online environments. The PROD approach is also grounded in pragmatism and framed by complexity science, seeking real world knowledge of healthcare dynamics that can translate to tools for improvement in healthcare quality. Further detail on the analytic methods involved in the PROD approach is available in the protocol for this study.

**Researcher characteristics and reflexivity**

The team was unified in exploring options for data collection, analysis and reporting that would adequately capture and reflect the guidance offered by EOCRC patients in their online narratives. Many of these personal accounts are deeply moving and all represent a challenging time in the life of the patients. In addition to adhering to formal guidelines for the protection of identity the team regularly discussed the authenticity of context in our use of excerpts from the texts and the validity of themes drawn from narrative descriptions.

**Context**

This study is designed as Internet Mediated Research (IMR). The internet is the broad research setting and the host websites of three key charitable support organisations were selected as specific research settings: Bowel Cancer Australia, Bowel Cancer UK and Bowel Cancer New Zealand. US-based sites were not included because of substantial differences between the US and other care systems; we predicted a heterogeneity of findings that would be a barrier to the translational aims of the research. With permission from the selected organisations and institutional ethics approval we accessed the public domain sections of these websites in which bowel cancer survivors ‘post’ accounts of their experiences, under banners such as ‘real life stories’ or ‘your stories’.

**Population**

The selection of texts was based on the age of the author at date of diagnosis; written accounts were included if an author was aged under 50 at the time of CRC diagnosis. One organisation had stratified the personal accounts on its website that relate to 50 years CRC; the personal accounts published on the other two websites had not been curated according to age, so the texts were screened to identify the ages of the authors. Accounts were excluded from the study if they solely comprised feedback on a medical institution or clinician.

**Data collection and analysis**

All online texts that met the inclusion criteria were downloaded into the NVivo qualitative data analysis
software programme (QSR International Pty Ltd. V.12, 2018), deidentified and assigned a unique participant study number. These accounts were then analysed for advice-giving features,37 which we defined as actionable recommendations for readers.28 Advice-giving features were differentiated from recounting of, and reflections on, personal experiences by the use of second-person grammar in addition to key words such as ‘advice’ or ‘advise’, ‘recommend’, ‘suggest’ and ‘counsel’. Only advice-giving content that focused on health service use was included; this was contrasted with advice-giving text that related to illness mindsets and behaviours.

In line with the PROD method for analysis of unsolicited online narratives, we analysed the advice-giving texts quantitatively to determine the demographic profile of the authors of the texts. We then conducted a thematic analysis to address and explore the research question. The thematic analysis followed the precepts established by Braun and Clarke, originally in their seminal paper in 200638 and described by them more recently in the literature with Terry et al.39 The analysis was inductive and critically realist in its focus on meanings that were semantically explicit in the data.38 39 KL led the thematic analysis with review and consensus from coauthors.

Ethics approval
The selected CRC support organisations consented to the analysis and/or the use of quotes and excerpts from the personal accounts published on their websites and to the dissemination of findings.40 23 Information/data related to the study is stored on password-protected computers and archived on electronic databases on a secure server. In accordance with the Australian National Health and Medical Research Council guidelines for management of data and information in research, the records of this study will be retained for a minimum of 5 years post-study completion or last relevant publication.

Techniques to enhance trustworthiness
To ensure rigour in our investigation, we routinely discussed the criteria for trustworthiness proposed by Lincoln and Guba32 41 and further explored by Morrow,42 involving credibility, dependability, confirmability and transferability. Iterative results were reviewed by a subgroup of study authors and all authors to the study confirmed the results. As noted, the development of themes and the use of excerpts to exemplify themes was a point of regular discussion among study authors; authenticity to the meaning intended by patients43 was confirmed by re-reading the texts. Results were reviewed in relation to extant literature, supporting credibility of consistency between the themes identified as emergent in the data and external evidence.43

Patient and public involvement
No patients and/or public were involved in the design, conduct, reporting or dissemination plans of the research. No patients and/or public were asked to review the findings of the study or to review manuscripts that report the findings. The CRC support organisations that approved data collection from the public domain spaces of their websites were not involved in the design, conduct, reporting or dissemination plans of the research.

Figure 1  Key healthcare advice themes in early-onset colorectal cancer (CRC) patients’ online narratives.
RESULTS
An overview of the results is presented in figure 1.

Demographics
Age and gender demographics of the authors of the accounts were identified either directly through information specified by the writers about themselves or by text analysis of the accounts to identify embedded information. From the three websites, a total of 273 personal accounts were included. Some two-thirds identified as female (n=200, 73.3%) and approximately half were aged 30–39 years (n=131, 48%). Almost half (n=136, 49.8%) were from the UK website, 42.5% (n=116) were from the Australian website and 7.7% (n=21) were from the NZ website.

Of the 273 patient online narratives that met the age and content selection criteria, 44% (n=120) were identified as offering advice about EOCRC-related health services. Of these, 80% identified as females and over half were aged 30–39 years (53%). Just over a third (n=37) were from the UK website, 58% (n=70) were from the Australian website and 11% (n=13) were from the NZ website.

Key themes
Advice-giving discourse across all texts focused on the importance of self-advocacy in managing an EOCRC care trajectory (n=108, 90%). Self-advocacy in cancer care has been defined as ‘the ability of an individual with cancer to overcome challenges in getting their preferences, needs, and values met’44 (see table 1 for key themes and illustrative excerpts). Over a third of the advice-giving texts (n=43, 36%) also recommended greater awareness among healthcare providers of the potential for age bias in EOCRC diagnosis (see table 2 for key themes and illustrative excerpts).

Self-advocacy advice themes
… it is crucial if you have any symptoms at all that you are concerned with, request to have a further investigation and DO NOT let anyone tell you, you are too young to get bowel cancer!

Guidance on self-advocacy in managing an EOCRC healthcare trajectory dominated the advice-giving texts. We identified two broad concerns: self-advocacy during diagnosis; and self-advocacy during treatment and recovery (see Table 1). Advice text related to diagnosis highlighted accessing relevant health services and taking the lead in medical investigations if symptoms persist. Advice text related to treatment and recovery focused on playing an active role in treatment planning and management, and proactivity in maximising personalised outcomes.

Age bias advice themes
No 26-year-old should have to go through what I went through—we need to change the conversation and smash the belief that this is an older person’s disease.

The study also identified advice narratives directed to the medical community regarding age discrimination in the diagnosis of EOCRC. These focused on four key issues: changing the mindset of practitioners towards age-based criteria for CRC investigation; raising awareness of the diagnostic importance of family history of CRC and genetically inherited syndromes; drawing provider attention to broad symptoms that may indicate CRC in younger people and the potential for misdiagnosis; and understanding the importance of person-centred care and listening to patients in EOCRC diagnosis. Table 2 summarises these results with illustrative excerpts.

Singular data points
Six per cent of advice-giving texts (n=7) comprised diverse practical matters, recommending: an infuser port (n=2); choosing one proprietary colonoscopy-preparation treatment over another (n=1); obtaining private health insurance (n=1) and preparedness for long appointment waiting times (n=1). There was also a recommendation for funding of immunotherapy treatment breaks (n=1) and a suggestion that health professionals provide newly diagnosed patients with a list of contacts for cancer support services and early referral to a dietician (n=1). Given the small proportion and heterogenous nature of experiential advice on these matters, we have not investigated these data for themes.

DISCUSSION
Our principal finding is that the EOCRC patients in our study view self-advocacy as an essential resource for ensuring that their clinical and supportive care needs are met by health services. This finding is drawn from self-reported data capturing the experiences and observations that patients prioritise as personally meaningful24 45; it presents a new perspective on EORC patient experience and opens a level of inquiry into how these patients negotiate, adapt to and get best use of the health services and systems available to them.

Self-advocacy is of particular significance for EOCRC patients who face diagnostic challenges. EOCRC diagnostic trajectories commonly involve multiple medical consultations at all levels of care and feature a variety of tests other than colonoscopy over periods from 3 months to 5 years and sometime more.15 17 46 Increasingly disturbing symptoms that significantly impact quality of life13 and eventual late stage diagnosis30 48 can have potentially devastating consequences for this patient population—people who are early to mid-career, just starting or raising families and consolidating their finances.46 47 Self-advocacy may be viewed as the key to maximising the chance of an early diagnosis.

Given the narrative nature of our data, patients recounted the sequence of events from first help-seeking for symptoms to clinical outcome and recovery. Self-advocacy was reported as a vital resource across the entire trajectory of care. Guidance on the
take-up of psycho-emotional support services through treatment and recovery was a prominent aspect of self-advocacy advice; patients spoke of wishing they had used support services or finding support services important to their health status as well as quality of life. The relevance of this patient-to-patient guidance is reflected in a survey of 885 EOCRC patients which found that some 75% had concerns regarding their mental health, and over 60% acknowledged having received support for depression.47

### Table 1

Illustrative excerpts representing themes related to self-advocacy in early-onset colorectal cancer patients’ online narratives

<table>
<thead>
<tr>
<th>Phase</th>
<th>Key self-advocacy themes</th>
<th>Self-advocacy subthemes</th>
<th>Illustrative excerpts</th>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>Obtain access to relevant healthcare</td>
<td>Push past screening guidelines</td>
<td>‘The earlier the diagnosis the better the outcome. Do not allow the free bowel screening age to stop you …’</td>
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<td></td>
<td></td>
<td>Shape GP decision-making</td>
<td>‘My advice to other young people is to please not ignore symptoms, no matter how embarrassing, and even more important, please don’t allow your doctor/s to be complacent about your symptoms’.</td>
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<td></td>
<td>Seek second opinions</td>
<td>‘… if you are not comfortable with your GP’s diagnosis get a second, third or fourth opinion! You are the only one who really knows your body. If I had taken the word of my GP I would not be here today!’</td>
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<td>Drive investigations</td>
<td>Investigate early</td>
<td></td>
<td>‘My advice is to persist and if something feels wrong, please investigate. It often goes unnoticed in younger people until it has advanced in stage, when it is not as easily or as successfully treated’.</td>
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<td></td>
<td>Petition for tests</td>
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<td>‘Don’t be the person worse off, get tests, don’t put it off, seek answers and push, push until you have your answers or resolution, don’t wait, it is your health, it’s your life’.</td>
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<td></td>
<td>Request colonoscopy</td>
<td></td>
<td>‘It was this ownership of my own health, requesting the colonoscopy, going through with the colonoscopy no matter how intrusive it seemed, that has saved my life’.</td>
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<tr>
<td>Treatment and recovery</td>
<td>Play an active role in treatment</td>
<td>Gather personalised information</td>
<td>‘My advice to other women would be to arm yourself with as much information as possible, ask every question that comes to mind even if you think it is stupid’.</td>
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<td></td>
<td>Seek satisfactory interpersonal care</td>
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<td>‘I encourage everyone to find a specialist that they feel comfortable with— you need to be able to discuss confronting subjects with this person. So if possible, try and choose a team you feel comfortable with as it is hard enough dealing with cancer’.</td>
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<tr>
<td></td>
<td>Steer treatment decisions</td>
<td></td>
<td>‘Make sure you have a really good specialist surgeon …. Make sure ALL options are used’.</td>
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<tr>
<td>Be proactive about outcomes</td>
<td>Navigate fertility issues</td>
<td></td>
<td>‘For young women going through radiation, ask about the damage the radiation can do internally, especially if you want kids in the future …. The damage to my uterus and surrounds was too much from the radiation to carry a child’.</td>
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<tr>
<td></td>
<td>Use psycho-social support services</td>
<td></td>
<td>‘You are going to need all your energy, strength and focus during the treatment. Don’t waste energy on other areas. If you don’t know how to do this, see a professional/psychologist. I was provided with one during my treatment and it was very beneficial. I still talk to her to this day’.</td>
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<tr>
<td></td>
<td>Lead post-treatment follow-up</td>
<td></td>
<td>‘I wish I had known, however, that I have to have a loud voice, especially post-surgery. Several issues were identified post-discharge’.</td>
</tr>
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GP, general practitioner.

Further, this patient population may deal with different, and potentially more severe, emotional and psychological challenges than are faced by older CRC patients, especially in relation to self-image and sexual functioning. In our study, access to psycho-social or other support services was not noted as an issue; rather the focus of concern was self-advocacy in the take-up of such services. Patients felt guilty about spending time away from family or felt that family and friends were providing all the emotional support needed. Some expressed a perception of being a fraud in the wider cancer patient community if their treatment did not result in a dramatic hair loss or a stoma. Key issues for policy and practice may relate to identifying and recruiting patients to supportive care; young patients may not perceive the need or ‘right’ to access supportive care, particularly if there are no outward aesthetic changes.

In our second set of findings, EOCRC patients directed advice to the medical community and the general public to be aware of age bias in CRC diagnosis. The implications of this advocacy are complex. Previous work by this research team and others has identified a number of current systemic and clinical healthcare-led confounders to diagnosis: lack of experience with EOCRC patients; the broad symptom nature of the disease, especially in its early stages; and barriers to, the enactment of self-advocacy such as physical, psychosocial, cultural or linguistic challenges, could be an intrinsic feature of patient-centred care. Self-advocacy has been recognised as a patient-centred resource that can be formally and informally supported to enhance the quality and safety of care. The current focus of patient-centred care programmes, however, emphasises the interpersonal skills of providers and the development of tools for shared decision-making. Self-advocacy is under-explored in interventions to improve patient-centred care and has not been investigated at all in relation to EOCRC patients. It may be a key topic for inclusion in EOCRC-specific PREMs. Relevant questions may be developed to measure health service facilitators of, and barriers to, the enactment of self-advocacy. The value of these self-identified self-advocacy skills could be validated at population level by cross-checking against time from symptoms to first diagnosis. If validated as effective, patients with lower levels of self-advocacy skills, or who face barriers in enacting self-advocacy such as physical, psychosocial, cultural or linguistic challenges, could be prioritised for patient advocacy support services.

**Limitations**

The strengths of this study in collecting self-determined patient experience data from unsolicited online narratives

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**Table 2** Illustrative excerpts representing themes related to age bias in EOCRC patients’ online narratives

<table>
<thead>
<tr>
<th>Theme</th>
<th>Illustrative excerpts</th>
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<tr>
<td>Shift conventional understanding of colorectal cancer</td>
<td>‘I have been open in sharing my story in the hopes that it helps someone else to recognise the symptoms and to get help. I also share it in the hope that medical professionals will change their mindset and accept that bowel cancer CAN HAPPEN to young people and that you are Never Too Young’.</td>
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<tr>
<td>Raise awareness of family history and inherited syndromes</td>
<td>‘I would strongly encourage all young people to find out about their family bowel cancer history including a history of bowel polyps. You are #Never2Young for bowel cancer and you should not avoid seeking care when things are not right. We also need to change the mindset of healthcare professionals to realise that bowel cancer DOES affect young people’.</td>
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<tr>
<td>Raise awareness of misdiagnosis in EOCRC</td>
<td>‘Many young people end up with advanced bowel cancer. They get misdiagnosed as having dietary intolerances, or worse, their GP believes they are too young to have bowel cancer. My message is that bowel cancer can happen to young, fit people’.</td>
</tr>
<tr>
<td>Importance of person-centred care</td>
<td>‘I feel lucky that my current GP is tenacious and listens! There are many men and women who weren’t so lucky and it’s for them that we, as a community, need to do whatever we can to shift the focus off of cancer discriminating against age. Never too young!!’</td>
</tr>
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</table>

EOCRC, early-onset colorectal cancer.
are mobilised alongside the limitations of a research population whose recollections of events cannot be validated. We had to assume the veracity of the perspectives and opinions presented in the narratives based on the legitimacy of the source websites. Our quantitative demographic analysis of our data made it evident that the perspectives of females are over-represented in our study, in relation to the incidence by gender of EOCRC. Generally, men and women contract EOCRC at similar rates, however, 80% of the advice-giving narratives we analysed were written by women. This limitation reflects the literature indicating higher female participation in online health platforms. Additionally, despite the presence of Indigenous and immigrant populations in the countries of interest, we note a lack of advice-giving data relevant to culturally and linguistically diverse (CALD) EOCRC populations. Linguistic and socio-cultural barriers may preclude CALD populations from sharing healthcare experiences on social media platforms. These limitations impact the transferability of the findings to wider EOCRC populations.

Conclusions
Barriers to and facilitators of patient self-advocacy may be important indicators of quality EOCRC care. Further research on this aspect of EOCRC patient experience may support the development of self-advocacy questions as a component of EOCRC-specific PREMs. Given our findings, self-advocacy as a crucial resource in timely EOCRC diagnosis may be an effective message to embed in public health campaigns targeting consumer-oriented, younger patient populations. On a wider level of cancer care, especially for young people, our finding points to self-advocacy as a mechanism to support patient-centred care.

A growing body of grey and peer-reviewed literature supports EOCRC patients’ concerns with age bias, however, clinical guidelines do not as yet distinguish EOCRC from CRC in older populations and it can be challenging for medical practitioners to identify and screen for EOCRC in average-risk individuals. Researchers, policy makers and healthcare professionals may benefit from engagement with EOCRC patient online communities and consumer advocates to comprehend youthfulness as a barrier to timely diagnosis.

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Contributors KL devised the study and is responsible for the overall content. KL and DF-P undertook the detailed design of the study, in consultation with GA, SSO, BNGE and YT. KL and DF-P prepared the study materials. KL undertook the analysis in consultation with DF-P, SSO and GA. KL wrote the first draft of the manuscript. KL, DF-P, GA, SSO, BNGE, YT, WL and JB contributed to and approved the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Macquarie University Human Research Ethics Committee approved the study (MO HREC Reference ID S20020066115757) and the study has been conducted in accordance with the Australian National Statement on Ethical Conduct in Human Research (2007–updated 2018) and poses no risk of privacy infringement to authors of the texts. The study also adheres to the principles for IMR established by the British Psychological Society. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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Please indicate in which section, figure or table each item has been reported in your manuscript. If you feel that an item does not apply to your manuscript, please enter N/A.

For more information about the SRQR guidelines, please see O’Brien et al., 2014: https://doi.org/10.1097/ACM.0000000000000388

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<td>Title Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</td>
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<td>Introduction Problem formulation Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</td>
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<td>Methods Qualitative approach and research paradigm Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale*</td>
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<td>Researcher characteristics and reflexivity Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</td>
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<td>7</td>
<td>Context Setting/site and salient contextual factors; rationale*</td>
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<td>8</td>
<td>Sampling strategy How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale*</td>
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<td>9</td>
<td>Ethical issues pertaining to human subjects Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</td>
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<td>10</td>
<td>Data collection methods Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale*</td>
<td>p.5-6</td>
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<td>11</td>
<td>Data collection instruments and technologies Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study</td>
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<td>Units of study Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)</td>
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<td>13</td>
<td>Data processing Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts</td>
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<td><strong>Data analysis</strong></td>
<td>Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale*</td>
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<td><strong>Techniques to enhance trustworthiness</strong></td>
<td>Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale*</td>
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<td><strong>Results/findings</strong></td>
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<td><strong>Synthesis and interpretation</strong></td>
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<td><strong>Links to empirical data</strong></td>
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<td><strong>Discussion</strong></td>
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<td><strong>Conflicts of interest</strong></td>
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<td><strong>Funding</strong></td>
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*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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If you would like this checklist to be included alongside your article, we ask that you upload the completed checklist to an online repository and include the guideline type, name of the repository, DOI and license in the Data availability section of your manuscript.

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Personal Accounts of Young-Onset Colorectal Cancer Organized as Patient-Reported Data: Protocol for a Mixed Methods Study

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Abstract

Background: Young-onset colorectal cancer is a contemporary issue in need of substantial research input. The incidence of colorectal cancer in adults younger than 50 years is rising in contrast to the decreasing incidence of this cancer in older adults. People with young-onset colorectal cancer may be at that stage of life in which they are establishing their careers, building relationships with long-term partners, raising children, and assembling a financial base for the future. A qualitative study designed to facilitate triangulation with extant quantitative patient-reported data would contribute the first comprehensive resource for understanding how this distinct patient population experiences health services and the outcomes of care throughout the patient pathway.

Objective: The aim of this study was to undertake a mixed-methods study of qualitative patient-reported data on young-onset colorectal cancer experiences and outcomes.

Methods: This is a study of web-based unsolicited patient stories recounting experiences of health services and clinical outcomes related to young-onset colorectal cancer. Personal Recollections Organized as Data (PROD) is a novel methodology for understanding patients’ health experiences in order to improve care. PROD pivots qualitative data collection and analysis around the validated domains and dimensions measured in patient-reported outcome and patient-reported experience questionnaires. PROD involves 4 processes: (1) classifying attributes of the contributing patients, their disease states, their routes to diagnosis, and the clinical features of their treatment and posttreatment; (2) coding texts into the patient-reported experience and patient-reported outcome domains and dimensions, defined a priori, according to phases of the patient pathway; (3) thematic analysis of content within and across each domain; and (4) quantitative text analysis of the narrative content.

Results: Relevant patient stories have been identified, and permission has been obtained for use of the texts in primary research. The approval for this study was granted by the Macquarie University Human Research Ethics Committee in June 2020. The analytical framework was established in September 2020, and data collection commenced in October 2020. We will complete the analysis in March 2021 and we aim to publish the results in mid-2021.

Conclusions: The findings of this study will identify areas for improvement in the PROD methodology and inform the development of a large-scale study of young-onset colorectal cancer patient narratives. We believe that this will be the first qualitative study to identify and describe the patient pathway from symptom self-identification to help-seeking through to diagnosis, treatment, and to survivorship or palliation for people with young-onset colorectal cancer.

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**Introduction**

Routine systematic collection of patient-reported outcome (PRO) and patient-reported experience (PRE) data is of considerable interest to health systems worldwide and is the subject of ongoing investment [1,2]. Validated instruments—most often in the form of standardized questionnaires—are regularly used to measure patients’ perspectives on the quality of health services and personal outcomes of clinical management care. These data are considered foundational in understanding the effects of health care on patients’ daily lives [3] and for making improvements in health care delivery [4,5]. Mixed-methods approaches [6] are increasingly becoming common in the collection of PRO and PRE data. Measurement instruments are sometimes supplemented with open-ended, free-text questions [7] to capture nuanced and idiosyncratic perspectives [5,8-10]. This descriptive material [7,11] has been shown to contextualize responses to closed questions [12] to provide more detail about the relational aspects of patients’ experiences [11] and to be more specific about the aspects of care that can be improved to promote better outcomes [11-13].

Qualitative researchers investigating patients’ experiences of care and perspectives on outcomes may have opportunities to facilitate mixed-methods approaches [6] for the collection of patient-reported data. In this paper, we present a methodology for producing qualitative data that effectively triangulates [6,14,15] with quantitative colorectal PRO and PRE data [16-19]. The methodology, which we call as Personal Recollections Organized as Data (PROD), pivots data collection and analysis around the validated domains and dimensions measured by PRO and PRE instruments [20-23]. The aim is to facilitate synthesis of patient-reported evidence across research projects. To our knowledge, this is a novel approach to qualitative patient experience data collection.

PROD draws on the “framework method” [24,25], in which free text or narrative data are organized into classifications that have been determined a priori and utilizes thematic/inductive techniques to facilitate the interpretation of emergent PRE and PRO topics [16-19], including qualitative text mining techniques, which are a resource-efficient means of identifying patterns and modelling relationships between topics [12,24,25].

The PROD method will be used to investigate the perspectives of people with young-onset colorectal cancer. The increasing incidence of colorectal cancer in people younger than 50 years over the past 50 years has been described as an alarming phenomenon [26] within the wider population of patients with colorectal cancer [27-32]. The incidence of young-onset colorectal cancer has risen by up to 2% per year worldwide while that of colorectal cancer in older adults is declining by up to 3% per year [26,31,33,34]. Dietary and lifestyle changes framed by shifts in global food chains have been proposed as causes for the rise in young-onset colorectal cancer [35]. Additionally, colorectal cancer awareness campaigns and screening programs are directed at people aged 50 years and older [35]. Patients with colorectal cancer who are younger than 50 years are twice as likely as older patients to experience missed diagnostic opportunities by physicians [36], significantly more likely to be diagnosed at an advanced stage of the disease [30,32], have a greater likelihood of aggressive therapeutic management [32], and will commonly have poorer quality of life outcomes [13,37-39].

We have knowledge of this patient population from age-stratified data of the wider colorectal cancer population; however, there has been limited attention on patients with young-onset colorectal cancer as a specific patient community. Patients younger than 50 years are at that stage of life in which they are establishing careers, building relationships with long-term partners, raising children, and assembling a financial base for the future. Their perspectives on their experiences of health services and outcomes of care may be different from those of older patients with colorectal cancer.

Our study aims to address the gap in qualitative patient-reported data on young-onset colorectal cancer by investigating the personal accounts published online by these patients. Web-based autobiographical accounts of health care experiences and outcomes are emerging sources of qualitative patient-reported data [31,34]. Patient narratives commonly describe the entire health care journey—from initial help-seeking to current survivor or palliative care status [40]—from the patients’ points of view [40]. They feature highly personal perspectives on the performance of health services and physical, emotional, and social outcomes of medical management across the trajectory of care [42]. As sources of patient-reported data, these narratives offer a counterpart to data produced from cross-sectional surveys. They provide significantly more descriptive data than those that can be derived from supplementary free-text questions in PRE and PRO questionnaires. Given that qualitative research by participant interview can be a labor-intensive and time-intensive process, there is an advantage also in the accessibility of patients’ unsolicited narratives with respect to ethical considerations [46]. The PROD methodology, with its clear thematization of coding around existing PRE/PRO dimensions, offers access to rich, longitudinally framed, patient-reported data.

**Methods**

**Design Methodology**

A flowchart of the study design is depicted in Figure 1. This is a study of personal patient stories published on websites hosted by 3 established colorectal disease support organizations: Bowel...
Ethical Considerations
There is no established ethical stance relating specifically to research involving unsolicited web-based narratives. We have obtained permission from each of the organizations to analyze these personal accounts and to use deidentified excerpts and quotes in reports of findings from the study. The organizations that host the websites have agreements with individual patient contributors regarding the use of their information and narrative material. These contributors are not direct participants of our study. However, the study of unsolicited autobiographical narratives is a unique research space with particular ethical issues relating to recruitment [47]. To establish the ethical position of this study, we refer to the Australian National Statement on Ethical Conduct in Human Research (2007-Updated 2018) [48], which indicates that privacy concerns arise when the proposed access to, or use of, the data or information does not match the expectations of the individuals from whom this data or information was obtained or to whom it relates. Therefore, we were granted ethical and scientific approval for this project from the Macquarie University Human Research Ethics Committee (MQ HREC Reference No:52020666115757). In publishing their personal accounts on the selected colorectal support organization websites, these contributors agreed that their stories would be made available for public access and used to raise awareness of young-onset colorectal cancer. This study meets the expectations of the individuals, each story will be deidentified and assigned a unique identifier code. Our framework method for qualitative analysis [47] identifies a priori what features to account for in the public domain sections of these websites in which people post accounts of their experiences under banners such as “real life stories” or “your stories.”

Recruitment
We defined inclusion and exclusion criteria to identify the types of personal accounts published on these sites that would be relevant to the study’s aims. We will include personal accounts that are written by people diagnosed with colorectal cancer (self-reported disease state, including but not limited to cancer of the colon, cancer of the rectosigmoid junction, and cancer of the rectum) [13]; before their 50th birthday; published in the public domain spaces of websites hosted by the 3 prominent colorectal disease support organizations, under agreement for the public dissemination and republication of the material; written by people aged 18 years or older at the time of submitting their personal accounts for publication on the website; and autobiographical, first-person accounts of experiences and outcomes relating to care for colorectal cancer. We will exclude personal accounts from the study if they solely comprise feedback on, or criticism of, a named institution or clinician or substantially describe someone else’s experiences and outcomes relating to care for young-onset colorectal cancer. We are not including serialized narrative material published as ongoing weblogs or blogs. We will take a random sample of 30 personal accounts from the eligible selection of personal stories using the Microsoft Excel (2011) random function, comprising 10 samples from the patient stories published on each of the 3 websites.

Data Extraction and Analysis
Narrative accounts will be downloaded from websites and collected and analyzed using the qualitative analysis software NVivo 12 Plus (QSR International) [51]. To avoid identification of individuals, each story will be deidentified and assigned a unique identifier code. Our framework method for qualitative analysis [24] identifies a priori what features to account for in our research reporting [16]. We detail our process for establishing the analytical framework in the following section on PRE and PRO domain coding. The PROD approach involves 4 key steps in creating a new structure for the data, as shown in Figure 2: (1) classifying attributes of the contributors, their
Manual coding and analysis will be undertaken by the process of line-by-line attention to the content in a series of iterative readings. Consistent with the principles of qualitative research, each step of the data extraction and analytical process will be undertaken by at least two researchers [18], as qualitative work with narrative data is interpretive, even when coding to a framework of categories and domains established a priori.

With research questions to guide their choices, 2 researchers working together and constantly comparing their findings can arrive at agreement on the significance of the narrative content and the conclusions that can be drawn from it [18]. The third researcher will validate the findings of the thematic analysis, and the team will collaborate to reach consensus on the significance of the findings in relation to triangulation with extant colorectal PRE and PRO data.

**Attribute Coding**

The first step of the PROD analysis is to identify and classify the key demographic characteristics of the patient contributors, their disease states, the features of their diagnostic pathways, and the clinical features of their treatment and posttreatment phases. We will organize these data in a framework of yes/no and multiple choice categories. The sets of selections are based on conventional research participant attributes and adapted to the level of detail obtainable from unsolicited narratives. In these accounts, attributes such as age, gender, relationship status, and current disease status information may be unknown from the basic information provided in a source website. These characteristics may only be identifiable with close attention to both content and language in a narrative [52], and even then, may only be inferred from implicit clues [40].

**PRE and PRO Domain Coding**

To develop a set of domains and subdomain items for the a priori analytical framework, we reviewed literature on core outcome sets for PRE and PRO measures [2,23,53] and mixed-methods approaches for analyzing PRE and PRO data [12,54-57]. Our conceptual approach to PRE and PRO domain coding is presented in Figure 3. The domains and subdomain items comprised in our analytical framework are presented in Table 1 and also described below.
Table 1. Analysis of personal recollections organized as data using the a priori coding framework.

<table>
<thead>
<tr>
<th>Domains, subdomains</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attribute coding</strong></td>
<td></td>
</tr>
<tr>
<td>Population characteristics</td>
<td>Gender, marital status, children, date of publication</td>
</tr>
<tr>
<td>Disease characteristics and management</td>
<td>Age at diagnosis, current status of disease/diagnosis, stage and type of bowel cancer at diagnosis, type of initial medical consultation for symptoms, family history of CRC, investigation for CRC, time from first consultation for illness symptoms to first diagnosis of CRC, discussion of immunotherapy/precision treatment, clinical trials, biomarker-based approach</td>
</tr>
<tr>
<td>Route to diagnosis</td>
<td>Symptoms prior to first diagnosis, diagnosis received prior to CRC diagnosis, treatments given for diagnosis prior to CRC, investigations undertaken to diagnose CRC, other conditions and genetic syndromes discussed</td>
</tr>
<tr>
<td>Treatment and posttreatment</td>
<td>Treatment received, posttreatment effects</td>
</tr>
<tr>
<td><strong>Domain coding</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Patient-reported experience</strong></td>
<td></td>
</tr>
<tr>
<td>Functional</td>
<td>Financial impact or costs associated with care, physical context (access, cleanliness, and comfort), process (continuity and co-ordination of care, scheduling, and waiting times), quality and efficiency of clinical care</td>
</tr>
<tr>
<td>Relational</td>
<td>Collaborative nature of interactions (provider and admin), informational or educational nature of interactions (clinical and practical information, scheduling and waiting times), interpersonal nature of the interactions (provider and admin)</td>
</tr>
<tr>
<td><strong>Patient-reported outcome</strong></td>
<td></td>
</tr>
<tr>
<td>Everyday living or usual activities</td>
<td>Caring for family or dependents, domestic chores, gastrointestinal function, getting around or mobility, holidays, independence, living conditions and environment, personal or self-care, recreation</td>
</tr>
<tr>
<td>Money matters</td>
<td>Finances or financial services, planning the future, work</td>
</tr>
<tr>
<td>Self and others</td>
<td>Anxiety or depression, body image, existential matters, isolation, pain or discomfort, sexual matters, starting a new family, support and communication</td>
</tr>
<tr>
<td>Additional issues</td>
<td>Others</td>
</tr>
</tbody>
</table>

*CRC: colorectal cancer.

**PRO Domains**

We reviewed general cancer and colorectal-specific PRO instruments [2,23,53,58,59], including the European Quality of Life Questionnaire-5 dimension (EQ-5D) [60], which assesses health outcomes of care across 5 quality of life domains—anxiety/depression, mobility, pain/discomfort, self-care, and usual activities [60]; the European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-29-item colon and rectum cancer-site specific (EORTC-QLQ-CR29), the Medical Outcomes Study 12-Item...
Health Survey, the Functional Assessment of Cancer Therapy-Colorectal (FACT-C), Edmonton Symptom Assessment System, and the Social Difficulties Inventory instrument-21 item (SDI-21), which assesses the impact of cancer on family life, social activities, personal matters, finances, and work. Of these, we selected the SDI-21 and the EQ-5D as being the most relevant to our research interests and for the collection of data from unsolicited free text narratives. We selected these instruments based on the volume of applications in the context of colorectal cancer [12,13,58,61], the applicability of these instruments in people with colorectal cancer across all disease stages and phases of treatment [59,61], and because the domains and items comprised in these instruments offer a balance of broad functional and psychosocial outcomes [13,61-63].

We used 3 core outcome sets from the SDI-21 as the thematic domains for PRO coding: “Everyday Living,” “Money Matters,” and “Self and Others.” We also added a category for “Additional issues” to capture events and perspectives not comprised in these thematic domains. Where possible, we consolidated individual scaled items from SDI-21 outcome sets. For example, in the domain “Money Matters,” we absorbed the items “Welfare benefits,” “Finances,” and “Finance services” into a single item called “Finances or financial services.” Similarly, we synthesized 3 communication and support items into 1 item called “Support and communication.” We also incorporated the SDI-21 single item set into 3 core thematic domains, bringing “Sexual Matters” and “Plans to have a family” into the “Self and others” domain and “Holidays” and “Where you live” into the “Everyday living” domain (Table 1).

While the EQ-5D questionnaire and SDI-21 feature common outcomes, the EQ-5D instrument also accounts for issues relating to pain and discomfort and the psychosocial aspects of everyday life, such as anxiety and depression. We included these items in the framework domain called “Self and others.” To code for issues that are particular to people with colorectal cancer to cover all items included in colorectal cancer-specific PRO questionnaires such as EORTC-QLQ-CR29 and FACT-C [53], we introduced the item, “Gastrointestinal function” into the “Everyday living” domain.

**PRE Domains**

PRE-questionnaires are commonly designed to examine patients’ experiences of particular health organizations, such as the National Health Service National Cancer Patient Experience Survey, or the services offered in certain health settings [64]. The EORTC, for example, publishes PRE-questionnaires specific to inpatients and inpatient experiences, communication with professionals, and information provision. Given that our data set was drawn from websites in 3 countries and that contributors chose the aspects of their experiences that they wished to describe, we required a broad-ranging generic set of PRE domains and subdomain items for our analytical framework [64].

Rather than selecting domains from a particular PRE instrument, we reviewed the literature to identify the core concepts underpinning PRE-questionnaires. We identified that patient experience outcomes are measured broadly for either relational or functional aspects of experience [64-66]. We used these as the 2 PRE domains in our analytical framework. Relational outcomes account for the interpersonal nature of patient-provider communications, patient-provider collaboration, and information provision to patients [65,67]. Functional outcomes account for the organizational and practical aspects of care, environments of care delivery, and the financial impact of care [65,67] (Table 1).

**Patient Pathway Coding**

From patients’ perspectives, experiences of health services and outcomes of care occur as a continuum of patient journey within and across the phases of the patient pathway [40]. We will undertake a patient pathway analysis of the PRE and PRO data by coding for 3 key phases of the patient pathway: diagnosis, treatment, and survivorship/palliative care (Figure 2) [36,68,69].

**Thematic Analysis**

There are 4 steps in our thematic analysis: coding for concepts, categorizing codes into groups, detecting patterns across categories, and interpreting themes within and across these patterns [70]. This process transforms the text into a narrative dataset, moving from highly descriptive findings to highly interpretable findings [16,20].

**Quantitative Analysis**

We will investigate opportunities to interpret the data quantitatively by means of network analysis [71] and quantitative text-based analysis, which uses automated natural language processing to analyze topics across different documents [12] and can measure sentiments within texts. This method may draw out aspects that contextualize other findings [12,13]. Quantitative approaches to analyzing unstructured text are emerging; however, as yet, there is little consensus on optimal strategies [12,46].

**Methodological Limitations**

Our methods will have limitations, including that we will be dealing with text not written for research purposes, not all text will map to our framework, and the data are subjective and will require interpretation. Additionally, data reported in different health systems will need to be seen in the light of those structural and contextual differences. Further, regardless of validity, there are limitations to standardized instruments and these limitations will be reflected in the a priori domains and dimensions that are the foundation of our analytical framework.

**Results**

After searching the 3 colorectal cancer patient support and advocacy websites selected for this study, we found that each featured story meets all the inclusion criteria. All texts were downloaded from the internet into the NVivo analysis software, and analysis commenced in September 2020 on the 30 texts randomly selected for this study. We will complete the analysis in March 2021 and we aim to publish the results in mid-2021.

**Discussion**

The PROD method for systematically extracting relevant patient-reported data from free-text patient stories aims to
maximize the benefits of rich detailed patient-perspective data that can be drawn from patient narratives while framing findings to facilitate data triangulation with patient-reported results from PROs and PREs. Young-onset colorectal cancer is a contemporary issue in need of substantial research input [32-69]. We believe that this will be the first qualitative study to identify and describe the patient pathway from self-symptom identification to help-seeking through diagnosis, treatment, and into survivorship or palliation for people with young-onset colorectal cancer. Unsolicited autobiographical narratives offer a unique opportunity to collect patient-reported data that expose this real-world perspective [40], which is particularly valuable in this age of SARS-COV-2.

Acknowledgments
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Authors’ Contributions
KL devised the study. KL, DFP, and YT undertook the detailed design of the study, in consultation with all authors. KL and DFP prepared the study materials. KL wrote the first draft of the manuscript. All authors contributed to and approved the final manuscript.

Conflicts of Interest
None declared.

References


Abbreviations
EORTC-QLQ-CR29: European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-29-item colon and rectum cancer-site specific
EQ-5D: European Quality of Life Questionnaire-5 dimension
FACT-C: Functional Assessment of Cancer Therapy-Colorectal
PRE: patient-reported experience
PRO: patient-reported outcome
PROD: personal recollections organized as data
SDI-21: Social Difficulties Inventory instrument-21 item
©Klay Lamprell, Diana Fajardo Pulido, Yvonne Tran, Bróna Nic Giolla Easpaig, Winston Liauw, Gaston Arnolda, Jeffrey Braithwaite. Originally published in JMIR Research Protocols (http://www.researchprotocols.org), 26.02.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Research Protocols, is properly cited. The complete bibliographic information, a link to the original publication on http://www.researchprotocols.org, as well as this copyright and license information must be included.