Discussions with patients about referral pathways and costs in the diagnosis and treatment of colorectal cancer in Victoria, Australia

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Background and objective
Colorectal cancer (CRC) survival in Australia differs by health insurance status, but why this occurs is uncertain. There are growing concerns about out-of-pocket healthcare costs. We examined patient experiences of referral pathways to diagnosis and treatment of CRC in Victoria, Australia, and discussions about costs, comparing public, private and mixed healthcare system users.

Methods
Semistructured telephone interviews were conducted with 16 purposively sampled, English-speaking patients aged ≥40 years with CRC. Interviews were recorded, transcribed and analysed thematically.

Results
Private patients described greater out-of-pocket expenses balanced by greater choice of provider and access. Public patients perceived limited choice in their diagnostic or treatment provider, although some considered switching systems. Patients trusted their general practitioner or specialist for referrals. Discussions about costs did not meet guideline recommendations.

Discussion
There are limited opportunities for informed decision making about public versus private care for cancer diagnosis and treatment, which could contribute to inequalities in outcomes.

AUSTRALIA has one of the highest incidence rates of colorectal cancer (CRC) in the world.[1] Although CRC survival in Australia compares favourably to other high-income countries,[2] outcomes vary for subpopulations. Health insurance status is one example, with improved survival associated with private insurance compared with public healthcare provision.[3,4] Although quality of care, access to treatment and disease complexity might contribute to insurance-related differences,[5] features of the cancer pathway before initial treatment are also important. For example, delays in primary and secondary care are associated with CRC outcomes;[6] hence, differences in waiting time to access diagnostic tests or commence treatment might contribute to survival variation by insurance status.[7]

Health insurance status is also associated with different costs of care. Cancer patients with private health insurance report higher out-of-pocket expenses compared with those in the public system. If unmanaged, out-of-pocket expenses might cause financial distress and could lead to poorer health outcomes.[8] Being informed about healthcare costs is a key component of high-quality cancer care, empowering patient decision making to mitigate unexpected out-of-pocket costs and limit financial burden. Discussions with clinicians, including general practitioners (GPs), should follow the Australian *Standard for informed financial consent*, whose goal is 'to guide discussions to include cost of care between patients and healthcare professionals to help make informed decisions'.[9]

A better understanding of pathways to CRC diagnosis and treatment through the public and/or private healthcare systems can help identify and address causes of public–private inequities. Although quantitative research measuring the length of pathways is important, understanding why time to care can be prolonged, and how patients make decisions involving cost of care, is best examined with qualitative methods.[6] Previous qualitative studies have found patients report long waiting times in the public system to receive a colonoscopy, the key diagnostic test for CRC, prompting some to switch to a private diagnostic pathway.[10,11] Regarding costs, previous research has found some patients with CRC report unexpected costs[10,12] or no financial discussion at all.[13] To date, there has been limited investigation

into how pathways for patients with CRC might differ by insurance status and the extent to which informed financial consent standards are upheld.[10–15]

The aim of this research is to compare patient experiences of pathways to CRC diagnosis and treatment, focusing on discussions about costs of care and navigating pathways involving private, public and mixed (public–private) healthcare systems, for English-speaking patients aged ≥40 years in Victoria, Australia.

Methods

Design

This was a qualitative, descriptive study involving semistructured telephone interviews with patients diagnosed with CRC.

Methodology

A pragmatic approach was used to interpret meaning and develop themes from telephone interviews with CRC patients.[16] The model of pathways to treatment provided an overarching framework to inform the research, such as interview guide and analysis.[17,18] This model describes intervals from first symptom to treatment and factors influencing timeliness of care, including disease, patient, healthcare provider and health system factors. Reporting follows the consolidated criteria for reporting qualitative research (COREQ) guidelines.[19]

Sampling, recruitment and eligibility

Participants were sampled from respondents of a cross-sectional questionnaire study investigating CRC diagnostic pathways in Victoria, Australia. Respondents were aged ≥40 years and had a primary CRC, and were recruited through the population-based Victorian Cancer Registry. Eligible interview participants were English speakers who expressed interest in participating in further research.

From patients expressing interest, survey responses were reviewed for sociodemographic and clinical information and used for purposive sampling to obtain diverse, rich data from interviews. Characteristics reviewed included age, gender, rural or urban residence, health insurance status and service use.

Recruitment was conducted from 29 June to 28 July 2020. Potential participants were approached with information about the study by post, telephone or email, with one follow-up for non-responders. An interview was scheduled following consent to participate.

Interviews

Telephone interviews were conducted by an Honours research degree student (AY-DY) who had qualitative interview and research training, supervised by co-authors experienced in qualitative research in oncology. The participants had no prior relationship with the researchers.

Semistructured interviews explored patient experiences of events leading to diagnosis and treatment, discussions with healthcare providers about and experience of out-of-pocket costs, waiting times and accessibility. The interview guide (Appendix 1, available online only) was developed based on previous research and informed by intervals described in the model of pathways to treatment, principally the diagnostic interval (time from first presentation to a healthcare provider to diagnosis) and pretreatment interval (time from diagnosis to commencing treatment).[14,17,18] Interviews averaged 36 minutes (range 22–84 minutes) and were recorded and transcribed intelligent verbatim. Deidentified data were imported to NVivo 10 (QRS International) to support analysis.

Analysis

Thematic content analysis was conducted[20] with comparisons made according to the use of diagnostic (colonoscopy) and treatment services in the public, private or mixed public and private healthcare systems. Coding was largely inductive, with themes generated and organised while collating data, while also drawing on definitions of time intervals and factors affecting timeliness of care as described in the model of pathways to treatment to assist in understanding and coding the data.[17,18] For example, the theme 'perceptions of waiting time' includes patient factors (perceived length of time being acceptable or not), healthcare provider (eg care delayed by GP) and system factors (eg public versus private hospital waiting time). AY-DY led the development of an initial set of codes, then categories, that were iteratively examined to ensure that they were credible and refined. Similar categories were grouped into themes and drafted into a coding framework that was discussed with co-authors during regular meetings to enhance study trustworthiness,[21] with consistency of themes indicating thematic saturation.[22]

Ethics

Ethics approval was obtained from Cancer Council Victoria's Human Research Ethics Committee (Project no. 1802) and registered with The University of Melbourne (Reference: 2057024.1).

Results

Participants

Of 141 patients expressing interest in an interview, 26 were approached and 16 were interviewed. Of the 10 not interviewed, five did not respond and five declined for reasons including a preference for in-person interview or unavailability. Interviews were completed an average 14 months (range 12–16 months) after diagnosis.

Seven participants received diagnostic and treatment services in the private system, five received these services in the public system, and four received these services in both the private and public healthcare systems. Although 11 had some form of private insurance, only seven used this for both colonoscopy and treatment services. One participant without health insurance had a Department of Veterans Affairs Gold Card, which covered all expenses received in private settings. Participant characteristics by healthcare system use are presented in Table 1.

Themes

Four themes, with several subthemes, were identified: (1) experience of out-of-pocket costs and discussions about healthcare costs; (2) perceptions of waiting time; (3) choice of services/care provider; and (4) views of private health insurance and healthcare system choice. Themes and subthemes are described in Tables 2 and 3.

Although participants' experiences were largely similar across public, private and mixed health system use, there were key differences across themes. The findings are summarised below and in matrix displays in Tables 2 and 3, with supporting quotations.

Table 1. Interview participant characteristics

	Healthcare system used[A]		
	Private (n=7)	**Public (n=5)**	**Mixed (n=4)**
Age (years)			
Mean±SD	67.5±10.7	62.0±8.0	75.5±11.4
Range	49–80	52–70	60–84
Sex (n)			
Male	5	3	1
Female	2	2	3
Residence (n)			
Major city	4	3	3
Inner regional	3	0	1
Outer regional	0	2	0
Private health insurance (n)			
None	1	4	0
Yes, hospital cover with or without extras	6	1	4
Diagnostic route (n)			
Symptoms to GP	3	2	0
Emergency department	1	1	0
Screen detected	2	1	2
Investigated for another problem	1	1	0
Other	0	0	2

[A]Public system use was defined as patients having both colonoscopy and treatment in a public setting. Private system use was defined as patients having both colonoscopy and treatment in a private setting. Mixed-system patients were defined as interacting with both systems (ie having a private colonoscopy then being treated at a public hospital or vice versa).

GP, general practitioner; SD, standard deviation.

Experience of out-of-pocket costs and discussions about healthcare costs

Out-of-pocket costs were described by over half the participants, most within the private system. The most common out-of-pocket costs were gap fees from specialist services and medication, as well as parking and transport fees, with the latter two more typical among public and mixed service participants. All who experienced out-of-pocket costs, regardless of healthcare system used, reported that these were manageable, with costs for private participants mostly subsidised by their health insurer. However, participants using public and mixed systems commented that costs would have been an issue had they been under different financial circumstances, such as having insufficient savings:

> *I can only imagine what it'd be like to deal with that situation when you get no money. It would be disastrous.* (PP08, male, public system)

Participants in the private system commonly reported being informed of costs, and that costs were transparent, but this was not a 'discussion'. Few participants managed in the public system mentioned that costs were discussed, potentially due to the perception that care is free in the public system. However, one person in the public system was surprised when, after their diagnosis, the surgeon's receptionist informed them of costs for consultations that were not mentioned previously by their referring GP or the specialist:

> *The receptionist … okay that will cost you X amount.* (PP03, female, public system)

Most participants did not discuss costs directly with their GP or specialist. Rather, cost information was provided by other administrative staff prior to procedures:

> (The receptionists) *advise you what the costs would be …* (it) *was quite detailed, but it was through emails.* (PP09, male, private system)

Perceptions of waiting times

Perceptions regarding waiting times were influenced by insurance status. Several participants, both public and privately insured patients, stated that waiting times for colonoscopy and treatment were shorter in the private than public system, an expectation one participant found was supported by their GP:

> *If I went through the public system I would have to wait longer.* (My GP) *told me that … everything would be quicker through the private system.* (PP09, male, private system)

However, there were exceptions relating to the timeliness of treatment once a diagnosis had been made. One mixed system participant reported being surprised by their surgeon who said that, once diagnosed, they would be treated faster if they had the operation in a public hospital due to service availability:

> (Surgeon) *said go public because I got a spot next week … there was a longer wait for private, which I thought would be the other way around.* (PP06, female, mixed system)

Choice of services/care provider

Most private and mixed participants indicated they had choice regarding their diagnosis and treatment providers, whereas only two public participants stated they had the opportunity to choose. Most participants given options

Table 2. Themes and subthemes regarding experience of out-of-pocket costs and perception of waiting time for private, public and mixed (private–public) healthcare system users in the diagnosis and treatment of colorectal cancer

Themes and subthemes	Public	Private	Mixed	Quotations
Experience of out-of-pocket costs and discussions about healthcare costs				
Incurred out-of-pocket expenses	–	++	–	*There was a gap with the surgeon visits, but that was the only costs we paid.* (PP03, female, public system) *We had out-of-pocket-expenses with the physician for the ongoing costs of the thyroid … we didn't have out-of-pocket expenses with the surgeon.* (PP10, male, private system) *I had to pay a substantial amount; I think it was under $1000.* (PP15, male, mixed)
Costs were manageable	–	++	–	*I think I'm in a pretty good spot at the moment, so the money side of it was good … I never worried about it.* (PP08, male, public system) *Well we would have preferred if there wasn't any … it was manageable for us, yep.* (PP13, male, private system) *No, fortunately, I had enough savings … it wasn't thousands of dollars; it was probably hundreds of dollars.* (PP15, male, mixed system)
Private health insurance covered most costs	–	+	None	*Because you use your private health, they have most* (of the) *the excess covered.* (PP11, female, public system) *So, my chemotherapy was all covered by my private health insurance.* (PP13, male, private system)
Cost information provided	–	++	+	*They make you pay beforehand … and they advise you what the costs would be.* (PP09, male, private system) *I was given the doctor's fee … we knew roughly what would be out for the hospital because we pay first.* (PP14, female, mixed) *Yeah, it was all outlined to me … I went through to discuss it with different clinics.* (PP08, male, public system)
Lack of cost discussion	++	–	+	*No, nothing was mentioned … about costs or anything.* (PP03, female, public system) *There wasn't a discussion, but they outlined what the costs were going to be.* (PP12, male, private system) I *don't remember any costs being discussed.* (PP15, male, mixed)
Transparency in costs discussions	–	++	–	*Yeah, it was fine. I actually expected it was gonna cost more than what it has anyway.* (PP08, male, public system) *Yes, they were very honest, yep.* (PP04, male, private system) (Costs) *were explained very clearly … they explained all the money side of it, everything.* (PP06, female, mixed)
Perception of waiting time				
Quick wait times (for diagnosis, treatment or test results)	+	++	++	*Yeah, so that was 4 weeks or so just waiting for the colonoscopy, but again, I didn't feel that was any issue.* (PP03, female, public system) *Well, I understood that he already had a pre-booked holiday or something; that was fine. I still thought it was happening quite quickly and appropriately.* (PP01, female, private system)
				(Waiting time for surgery) *was pretty quick. It was within a month … but it was acceptable, let's put it that way, that I wasn't kept waiting.* (PP15, male, mixed)
Longer waiting times (for diagnosis, treatment or test results) associated with healthcare route or status	–	+	–	*Nah, just the wait time* (prompted considerations to switch to private); *that was all.* (PP02, male, public system) *If I went through the private system, sorry, the public system, I would have to wait longer.* (PP09, male, private system) *So, to the point where I ended up in a public hospital, not a private hospital because that was faster.* (PP06, female, mixed system)
Perceived delays (by patient or clinician)	None	+	–	*So really, if the GP had of done the right thing at the start off, I might've been diagnosed 4 months earlier.* (PP04, male, private system) *The kit did eventually come but … it was definitely delayed for a while.* (PP06, female, mixed system)

++, common theme (≥4 cases); +, occasional theme (3 cases); –, uncommon theme (≤2 cases); GP, general practitioner.

deferred to the recommendation of the referring doctors, often their GP:

> *I would've* (been able to choose) *but I was quite happy to go to the surgeon I was referred to because I knew him well and I've worked with him.* (PP11, female, public system)

In contrast, most public and some private participants perceived having little or no choice for diagnosis or treatment provider. Reasons for lack of choice include limited access to specialists for those living in regional areas, lack of information for decision making and care in the public system:

> *Well, I only had one option, the public because I wasn't in private.* (PP08, male, public system)

Notably, some mixed-route participants were unconcerned about having a choice. Reasons for this included being new to Australia and unfamiliar with the healthcare system, or assumptions about referral based on previous experience:

> *I didn't really care where I went … I* (had) *been to the* (private) *hospital one before so I just assumed that was where I'd get sent again.* (PP06, female, mixed system)

Public participants more commonly reported that they had considered switching healthcare systems. A common reason was perceived shorter waiting times for colonoscopy or treatment in the private sector:

> … *just the wait time* (for colonoscopy). (PP02, male, public system)

Table 3. Themes and subthemes regarding choice of services/care provider and views of private health insurance for private, public and mixed (private–public) healthcare system users in the diagnosis and treatment of colorectal cancer

Themes and subthemes	Public	Private	Mixed	Quotations
Choice of services/care provider				
Choices were provided (by clinician)	–	++	+	*I think* (I had a choice for treatment and colonoscopy referral). *If I wanted to go somewhere else, I wouldn't have had any issues.* (PP08, male, public system) *If I asked my GP and said I wasn't happy with the person I was referred to, she could've referred me to someone else.* (PP05, male, private system) *I thought I just wanted it over and done with, so yeah, I could choose where I wanted to go.* (PP06, female, mixed system)
No or limited choice (for diagnosis or treatment)	++	+	None	*It was arranged and here in* (outer regional) *that would be the only place to go – the next choice would've been an hour and a half away.* (PP03, female, public system) *I didn't have a say, but he was the one I would've chosen anyway. He's the best one in this local area, yes.* (PP04, male, private system)
Lack of care about choice (from patient)	None	None	+	*I didn't mind where I had to go as long as I could have surgery.* (PP06, female, mixed system)
Switched or considered switching health care provider	+	–	–	*So, we had inquired at that point whether it was worth going to private for someone that we knew.* (PP02, male, public system) *I was trying to decide whether to go to the doctor closer where I live or keep up where the medical centre was moving to.* (PP01, female, private system) *He brought it up, the surgeon … asked me if I was willing to go to* (public hospital) *because there's a spot next week, and I said absolutely, I don't have any hesitation.* (PP06, female, mixed system)
Views of private health insurance and healthcare system choice				
Lack of discussion about public or private options (between patients and clinician)	++	++	++	*No, no discussion was mentioned about private healthcare.* (PP03, female, public system) *No, we didn't discuss* (private or public healthcare) *at all.* (PP04, male, private system) *No … there was no discussion we just knew I was going private.* (PP14, female, mixed system)
Assumption of private health insurance status (by clinician or patient)	None	++	+	*Well, he knew that when I was there that I was a private patient.* (PP04, male, private system) *I don't think they even asked me* (about private health insurance). (PP07, female, mixed system)
Positive attitudes towards private health insurance	None	+	–	*And thank Christ I had private health insurance or else I was gonna be put on a waiting list.* (PP04, male, private system) *Well, we've always had private health insurance, and we always go private; then I can have a single room … which means a lot.* (PP14, female, mixed system)

++, common theme (≥4 cases); +, occasional theme (3 cases); –, uncommon theme (≤2 cases); GP, general practitioner.

Those who did switch also reported waiting time as important, as well as the doctor's recommendation, or switching to treatment in the private system simply because they had this option.

Views of private health insurance and healthcare system choice

Most participants, across all healthcare routes, described a lack of discussion about public and private options for diagnostic or treatment services with GPs or other providers:

> *No discussion was made about private* (colonoscopy referral) *... no, nothing was mentioned about private healthcare (treatment referral).* (PP03, female, public system)

Two participants in the private system reported there was some discussion, with one stating that their GP asked them directly:

> *She asked me whether I wanted to go through the public or private system, and I said I had private insurance so I might as well use it.* (PP09, male, private system)

More often, participants reported that their doctor did not enquire about their insurance status or discuss options, and that their insurance status inferred their preferred healthcare route for both colonoscopy and treatment referrals:

> *I think it must've been on the notes or something that we had private health insurance.* (PP01, female, private system)

One private participant found this assumption troubling because his GP was unaware that he had private health insurance despite being a regular patient at the clinic:

> *He* (GP) *felt an urgency, but he was under the impression that I was just a public patient. Which I find it very distressing because I've been at that clinic for at least 30 years.* (PP04, male, private system)

This had implications for cancer outcomes:

> *And thank Christ I had private health insurance or else I was gonna be put on a waiting list to see the surgeon and I wouldn't be here today because my bowel was about to burst.* (PP04, male, private system).

Being mislabelled as 'just a public patient' was highly concerning to the participant, implying that those without cover fare worse than private patients.

This favourable attitude towards private over public care was shared by other private and mixed-system participants, mostly due to perceptions of shorter waiting times. Indeed, one participant described private health insurance as lifesaving:

> *I think without private health insurance I would've been dead ... I was on a wait list ... and then they found I was on private health and then within hours I was on an air ambulance ... which wouldn't have happened of course in the public system.* (PP12, male, private system)

However, one private participant noted that private health insurance provided an illusion of choice because the lack of information about the quality of specialists meant they were unable to make an informed decision:

> *One of the reasons you get private insurance is, supposedly, you got a choice of specialist. Now, how would I know what specialist is good or not?* (PP09, male, private system)

Discussion

The findings from this study indicate that although CRC patient experiences were largely similar across public, private and mixed routes, differences were observed in out-of-pocket costs, perceptions of waiting times, experiences of choice and views of the quality of the healthcare system. Recurring themes for private participants included experiencing out-of-pocket costs but having choice in their healthcare provider during diagnosis and treatment. Public participants perceived little choice of healthcare provider, although were more commonly found to consider switching health systems to a private provider than private participants to a public provider. Mixed-system participants reported caring little about choice of specialists for diagnosis or treatment, switching systems to achieve timely access to treatment and diagnostic tests. Overall, although many participants reported costs to be manageable, financial discussions focused on expected costs and were not always held with clinicians, limiting how cost of care might inform decisions about diagnosis or treatment.

Many participants, regardless of their healthcare route, incurred some form of out-of-pocket costs. This is consistent with research from Western Australia that showed a majority of breast, lung and CRC patients experience both medical and non-medical expenses.[12] However, unlike a previous study that found costs were often not discussed with privately treated patients,[13] most private patients in our study did report being told about expected costs. However, these financial discussions were mostly with administrative staff (eg receptionists) rather than the referring or treating clinician directly, and related to a list of expected costs rather than a discussion about options. This fails to uphold the third principle of the *Standard for informed financial consent*, whereby lead clinicians should be responsible for initiating and guiding these conversations.[9] Guidelines such as the Australian *Optimal care pathways* for cancer also cite the importance of informed financial consent (www.cancer.org.au/health-professionals/optimal-cancer-care-pathways). Discussions about costs are necessary to empower patient decision making, increase access to financial support and help avoid unprecedented financial burden.[12,13] Further awareness and training might be necessary to ensure healthcare professionals and patients engage in cost-related discussions. Resources such as the Department of Health and Aged Care's medical cost finder online tool, which lists median out-of-pocket costs for common specialist medical procedures, could be useful in such discussions (https://medicalcostsfinder.health.gov.au/).

Perceived delays were uncommon among participants in our study, but surprisingly those who did report delays used private or mixed routes.[11] In contrast, other Australian studies have found that individuals in the public systems report longer waiting times to receive treatment or colonoscopy than those in the private system.[10,15,23] This might be explained by subjective perceptions as to what constitutes a delay. For example, one participant stated that there was no delay in their colonoscopy, despite having to wait

three months. This is consistent with findings by Bergin et al, who identified different perceptions and expectations of acceptable diagnostic waiting times among patients with breast and CRC.[15] It might be that public patients are less demanding and have lower expectations of health system waiting times than private patients. Further research is needed to clarify this.

Mixed and private participants typically reported that they had more choice in diagnostic and treatment providers than their public counterparts. This is consistent with findings from a South Australian study, where private patients stated that they had the ability to choose while public patients had limited or no choice.[23,24] These findings accord with public perceptions and the promotion by private health insurance companies that such insurance offers greater choice.[25] However, a lack of knowledge about specific providers hindered a patient's ability to make informed decisions. Further, although private patients might choose a treating specialist, they might not be able to select all clinicians associated with their care (eg the anaesthetist or pathologist associated with surgery). This aligns with research by Pascoe et al, who found that although CRC patients theoretically had the ability to choose their clinician, in reality they lacked information and the opportunity to do so.[10] Also consistent with previous research, we found that limited access to services in rural locations reduced patient choice despite having private health insurance.[14] In addition, although perceived shorter waiting times were a particularly important feature noted by participants for choosing private services, actual wait times are not publicly available to inform decisions and, as one participant experienced, sometimes faster access can be obtained in the public system. Further investigation is needed to determine whether private health insurance provides cancer patients with real choice, or just an illusion of it.

Most in our study reported a lack of discussion about public or private options, with many reporting trust in their GP or other doctor to refer them appropriately, and assumptions made about care preferences based on insurance status. Several other Australian studies have reported that cancer patients rely on a trusted GP or other healthcare professional's recommendation to guide decision making[10,11,13,14] or that insurance influences referrals.[12,13] For example, Slavova-Azmanova et al found that patients with private health insurance expressed disappointment because they were not offered the option to receive treatment as a public patient.[13] Conversations about referral options for diagnosis and treatment that consider both public and private services, as well as discussions about cost, are necessary to empower patients and enable them to make informed decisions. Research into strategies and the implementation of policies to support such decision making in primary and secondary care is required. Possible strategies include individual- and system-level interventions, for instance decision support tools to aid discussions about referral that include costings and links to financial support for people with cancer as required; public reporting of waiting times for diagnostic and treatment services in public and private settings; the reporting of outcomes for clinicians and health services; and average out-of-pocket costs for different procedures in the private system that include the costs of ancillary specialists and services.

Strengths and limitations

This is the first qualitative study to compare private and public patient experiences of CRC diagnosis and treatment. Purposive sampling of patients with diverse sociodemographic and clinical experiences allowed a range of perspectives to be explored, including those using both health systems. Themes were iteratively developed by the research team with thematic saturation improving research rigour. Limitations include a modest sample size of patients diagnosed in one Australian state, most of whom were from major cities and all of whom spoke English. The findings in relation to cancer referral decisions, choice and costs are likely to be even more challenging for rural and non-English-speaking populations. For example, non-English speakers might have different experiences communicating with health professionals, as well as greater difficulty navigating the healthcare system and managing out-of-pocket costs. People living in remote areas might have no local health services and significant out-of-pocket costs associated with the need to travel, which likely poses even greater challenges in the larger, more sparsely populated states, such as Western Australia and Queensland, compared with Victoria. In addition, there might be differences in referrals and costs in other states due to, for example, costs and availability of private colonoscopy and specialist cancer services. A further limitation of the study was that patients completed interviews an average 14 months after diagnosis, which occasionally affected recall of events.

Conclusion

Findings from interviews with English-speaking CRC patients in Victoria highlight the complexity of the Australian healthcare system, with limited opportunities for informed decision making for referral for diagnosis and treatment provider, and suboptimal cost discussions. GPs and other clinicians caring for people with suspected or confirmed cancer should ensure their patients understand both public and private care options, as well as cost implications. Future studies should examine individual and health system-directed strategies to support informed referral and financial decision making.

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