

**Supplementary Material**

**Experiences and perspectives of colorectal cancer survivors and general practitioners on the delivery of survivorship care in general practice: a mixed methods study**

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## Supplementary Material

Supplementary Appendix A. Themes covered by the colorectal cancer survivor and general practitioner surveys and interviews.

### GP questions covered:

1. Perceptions about the role of GPs in supporting patients and managing sequelae of CRC treatment;
2. How GPs monitor and manage treatment sequelae for CRC survivors;
3. The types of care provided to CRC survivors and how they were supported in managing treatment sequelae;
4. The involvement of GPs in CRC survivorship care and the clinical information the cancer care services provided them;
5. Perceived gaps in care for CRC survivors; and
6. Mechanisms that could better assist GPs in supporting CRC survivors and coordination of care.

### CRC survivor questions covered:

1. Sequelae of treatment experienced by CRC survivors and the extent to which these were discussed with their GP for potential management support;
2. How comfortable CRC survivors felt discussing treatment sequelae they experienced;
3. Types of care provided by GPs to CRC survivors and how they managed sequelae of CRC treatment;
4. CRC survivors' perceptions about the role of GPs in supporting the management of treatment sequelae;
5. Perceived gaps in care in terms of ongoing monitoring and management of acute to long-term sequelae of CRC treatment; and
6. Suggestions to improve care.

Abbreviations: GP General Practitioner, CRC Colorectal.

## Supplementary Appendix B. Summary of colorectal cancer survivor participants' free-text survey responses by theme

Theme	Sub-themes	Example quotes
GP's role in supportive care	The importance of the GP in assessing, monitoring, and managing became more apparent as contact with specialists and hospitals was reduced	<i>It has been great to know my oncologist and cancer nursing team at the hospital are available if I have questions, however, the further away from treatment I move, the more important having a good GP is.</i>  <i>I didn't see her [GP] during my treatment ... but then [she] has been the patient one listening to my challenges and helping me find a new 'normal'</i>
Useful support, services, information sources, or advice	Allied health care and nursing services received	Physiotherapist (n=3), exercise physiologist (n=2), osteopath (n=1), dietitian (n=3), counselling services (n=1), psychologist (n=1), stoma nurse (n=2), district nurse (n=1)
	Talking to other cancer survivors	<i>Talking to other bowel cancer patients is where I've found the most useful advice</i>
	GPs' support for concerns and understanding	<i>She [GP] understood how this is now a total and ongoing life change. Her genuine concern and the time she has to connect and talk [was helpful]. I feel like there aren't any problems she wouldn't help with or get access to if I needed/asked.</i>
	Practical support from the GP	<i>"Telehealth, scripts and referrals", "Running some tests, applying for NDIS", "Referrals to specialists "(n=3)</i>

Ways to ensure adequate patient support and improve ongoing care	GPs scheduling regular appointments and actively asking about problems the patient may experience	<i>GP (or other health care professional) should ask about all areas CRC patients experience, ongoingly - including sexual health, mental health, social wellbeing and financial - and refer for help on these areas, but also follow up and monitor progress.</i>
	More information early on about what to expect long term and strategies to help them manage	<i>I'm almost at 3 years since diagnosis. I didn't ever think three years ago about what life would be like now...I want more stories and information about the longer-term improvements and challenges post-cancer. I want reassurance that I will be able to work full-time again. There must be more strategies out there or things I could have done differently during treatment. I wish someone could have helped me in the early days.</i>
	Self-assessment tools	<i>Have a checklist for symptoms and levels that can be filled out by patient and then a plan in place to assist with living with theses [would be helpful].</i>
	Referral to appropriate services	<i>I would have appreciated some follow-up action on regaining my strength in core muscles etc. A referral to a Physiotherapy program focused on recovery from my specific cancer treatment would have been great. So bring into the team a physiotherapist and perhaps a nutritional expert to guide me through necessary changed eating habits.</i>
	Information about services that were available to them	<i>Maybe a phone call informing me what is there for me rather than asking what I need. You don't know what is out there if you've never experienced this,</i>

		<p><i>so the patient doesn't know what to ask for.</i></p> <p><i>There needs to be a clear range of services that GPs can refer patients to if needed. They need to ask about incontinence issues, diet issues, pain and sleep issues as part of ongoing care and have a clear range of services to refer patients on to get help and advice.</i></p>
	Better support for mental health concerns, including acknowledgement of trauma	<p><i>I think there is a lot of focus (and rightly) on physical health and symptoms during and after treatment, but there wasn't necessarily any real follow-up on mental health during and after.</i></p>
Barriers to adequate supportive care in the community	Lack of coordinated care	<p><i>Nobody told me that my GP was my go-to person. Nobody has yet explained to me what I should discuss with the surgeon, the oncologist and my GP respectively... Had I not been proactive, I would have slipped through the cracks totally... Nobody seems to be in overall charge or control. It's all a mish-mash... I don't know how less self-reliant people navigate the process.</i></p>
	Lack of survivorship services	<p><i>I have struggled so much over the last 7 years, and this has impacted all areas of my life. I feel like my GP does not have the time or expert knowledge to help with this... The Colorectal surgeon was awesome... but he is a surgeon, not an aftercare specialist and busy seeing people who need surgery. He gave me 1 diet sheet after my reversal and didn't seem to have any contacts or services to help me ('it will settle down' was a standard answer). I feel that there needs</i></p>

	<i>to be an after-care service for when treatment has finished that patients can contact that addresses specific bowel issues as, at the moment, there is nothing, and patients feel so alone and hopeless.</i>
GPs are time-poor	<i>Making sure a GP has the time to properly treat us [may improve care].</i>
More CRC specific education is needed for health care professionals involved	<i>...Mandatory professional development updates for GPs, surgeons &amp; oncologists so they remain up to date with advances &amp; recommendations in allied health space (especially the benefits of exercise for cancer patients).</i>
<p>Inequity of care</p> <ul style="list-style-type: none"> <li>• Metropolitan vs rural/regional access to services</li> </ul>	<p><i>It's been difficult living regionally. When this game went wrong, I had no one here to see or help me.</i></p> <p><i>Having to go interstate for treatment (due to poor services and long wait lists) has resulted in a big gap in referrals to services in my home state. As many ACT cancer patients do attend interstate services and clinics, this means we are all missing out on knowing what's available. It has taken me 3 years to find some basic services like continence nurse. [CRC survivors in rural and remote area] need to be able to hook into services back home.</i></p>
<ul style="list-style-type: none"> <li>• Some cancers (Breast) have</li> </ul>	<i>Having seen the amazing support that my mother received after her breast</i>

	<p>better access to services</p> <ul style="list-style-type: none"> <li>• Lack of awareness of the needs of younger patients</li> </ul>	<p><i>cancer diagnosis from breast care nurses - there was nothing like this for colon cancer...</i></p> <p><i>When I had breast cancer in 2015, I was inundated with help, trial products etc, and the nurse was so good. I could ask any questions, and she would follow up and refer me. I think Colorectal cancer patients really need this service.</i></p> <p><i>...Equitable access to support services across cancer types! Bowel Cancer patients should have access to a dedicated nurse in the same way breast &amp; prostate cancer does.....</i></p> <p><i>More focus during active treatment on patient quality of life after treatment ends for younger patients... Not everyone has a partner to support them.</i></p>
<p>Ways specialist services could enable GPs to provide better supportive care</p>	<p>Improve communication between specialist services, GPs and patients.</p>	<p><i>One 'handover' meeting between cancer specialists and GP [would be helpful]. So we're all on the same path, and clear lines regarding who to call when.</i></p> <p><i>My GP has played a key role in managing treatment side effects, supporting my mental health &amp; overseeing my return-to-work plan. Better</i></p>

	Setting clearer role expectations	<p><i>communication between GP &amp; cancer team would make this much easier!...I think my GP should be able to access all my scan results etc in real-time! Both during &amp; post-treatment, I frequently go for my check-in with my GP after the latest round of hospital check-ups only to find that NO information has been sent to my GP, so it is up to me as the patient to communicate the update from my cancer specialists.</i></p> <p><i>Inform them (CRC survivors) of whom to turn to for various matters. Keep in touch with them. I've had no formal communications from anyone since I left hospital other than direct contact with my oncologist and GP that I have initiated.</i></p>
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Abbreviations: GP General Practitioner, NDIS National Disability Insurance Scheme, ACT Australian Capital Territory.