Author/s:
Bergin, R;Emery, J;Bollard, R;White, V

Title:
How rural and urban patients in Australia with colorectal or breast cancer experience choice of treatment provider: A qualitative study

Date:
2017-11-01

Citation:
Bergin, R., Emery, J., Bollard, R. & White, V. (2017). How rural and urban patients in Australia with colorectal or breast cancer experience choice of treatment provider: A qualitative study. European Journal of Cancer Care, 26 (6), https://doi.org/10.1111/ecc.12646.

Persistent Link:
https://hdl.handle.net/11343/292386

Title page

How rural and urban patients in Australia with colorectal or breast cancer experience choice of treatment provider: a qualitative study.

Authors:

Rebecca Bergin, BA&Sc (Hons), PhD Candidate, rebecca.bergin@cancervic.org.au, phone: +61 3 9514 6467; Centre for Behavioural Research in Cancer, Cancer Council Victoria, 615 St Kilda Rd, Melbourne, Victoria, Australia 3004; and Department of General Practice and Centre for Cancer Research, University of Melbourne, Level 10, Victorian Comprehensive Cancer Centre, Melbourne, Victoria, Australia 3000.

Jon Emery, MBBCh FRACGP MRCGP DPhil, Professor of Primary Care Cancer Research, jon.emery@unimelb.edu.au, phone: +61 3 9035 8018; Department of General Practice and Centre for Cancer Research, University of Melbourne, Level 10, Victorian Comprehensive Cancer Centre, Melbourne, Victoria, Australia 3000.

Ruth Bollard, MBChB, M.Sc, FRCS, FRACS, General and specialist breast surgeon, Ruthbollard64@gmail.com, phone: +61 3 5330 5900; Division of Surgery, Ballarat Health Services, 1 Drummond St, Ballarat, Victoria, Australia 3350.

Victoria White, PhD, Associate Professor and Principal research fellow, Victoria.white@cancervic.org.au, phone: +61 3 9514 6352; Centre for Behavioural Research in Cancer, Cancer Council Victoria, 615 St Kilda Rd, Melbourne, Victoria, Australia 3004.

Corresponding author: Rebecca Bergin, Rebecca.bergin@cancervic.org.au.

Acknowledgements: Funding for Rebecca Bergin's PhD scholarship and the ICBP Module 4 project are supported by the Victorian Government Department of Health. We also wish to thank Professor Sanchia Aranda at Cancer Council Australia for comments on early drafts of this manuscript.

Declaration of Conflicting Interests: The Authors declare that there are no conflicts of interest.

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/ecc.12646

MS. REBECCA BERGIN (Orcid ID : 0000-0003-0448-9125)

Received Date : 09-Jun-2016

Revised Date : 26-Sep-2016

Accepted Date : 01-Dec-2016

Article type : Original Article

Abstract

Modern healthcare systems promote patient choice of cancer treatment provider, but little is known about how place of residence influences decision-making. This research explored how rural and urban patients with breast or colorectal cancer experience choice of cancer treatment provider in Victoria, Australia. Realist thematic analysis of 43 semi-structured telephone interviews identified little active participation in decision-making regardless of area of residence or cancer diagnosis. Perceptions of choice were impacted by urgency for treatment, insurance status and access to providers, a key issue for rural patients. All patients wanted high quality care, but needed to trust health professional's recommendations. Rural patients experienced more complex decision-making, balancing a range of social factors with perceptions about quality of accessible care. Further research into variation of quality of care and complex cancer pathways for rural and urban cancer patients is warranted to inform choices and enhance patient-centred care.

Introduction

There is a global movement toward patient-centred healthcare systems where patient wishes, experiences and priorities are given a central role in the planning and delivery of care (Institute of Medicine 2001). Supporting patient autonomy, including the right to make decisions about the provider of care, is an increasingly common feature of such systems (Vrangbaek *et al.* 2012). Countries such as the UK and the Netherlands have introduced policies and initiatives specifically to support patient choice for healthcare provider (Vrangbaek *et al.* 2012). Cancer care similarly aims to be patient-centred and choice of treatment provider is increasingly important. For example, in Australia, new national recommendations for cancer care (Optimal Care Pathways) state that clinicians should ensure patients "make an informed choice about their care, including the options of referral to other professionals or specialised centres" (Victorian Government 2015). However, to date most research regarding cancer patients' decision-making has focused on choice of treatment rather than provider (Tariman *et al.* 2010).

How cancer patients choose treatment providers could be important for understanding variations in cancer outcomes. In many cases, who or where a patient is treated can impact survival given that timely, appropriate treatment by high quality specialist services is associated with improved cancer outcomes (Neal *et al.* 2015; Archampong *et al.* 2012; Hillner *et al.* 2000). Patients value high quality care (Mohammed *et al.* 2016). If information regarding quality is considered in decisions regarding care provider, patients may choose to be treated by higher quality services, for example, for surgical care (Marang-van de Mheen *et al.* 2011). In a study of American women with breast cancer, women who self-selected their surgeon based on reputation were more likely to be treated by high-volume, and thus experienced, providers or in a specialised cancer centre than those who did not actively choose their treating doctor (Katz *et al.* 2007).

Cancer outcomes are often poorer for people living in rural areas than in major cities (AIHW & AACR 2012; Singh *et al.* 2011). The reasons for rural cancer outcome disparities are complex. Differences may be due, in part, to rural population characteristics associated with poorer cancer outcomes such as lower socio-economic status, ethnicity and poorer health behaviours (Victorian Government 2011; Booth *et al.* 2010). However, health system and patient factors are also important, including quality of care, access to services, and patient preferences and care choices (Heathcote and Armstrong 2007; Singh *et al.* 2011; Ahmed and Shahid 2012). These factors may have variable impacts on rural cancer outcomes, with an Australian study showing that while rural patients with colorectal cancer have worse mortality than urban patients, area of residence has no impact on breast cancer outcomes (Coory *et al.* 2013).

Currently it is not clear whether and how cancer patients choose treatment providers, and whether this differs for people living in rural compared with urban areas, or by cancer type. Research from general populations has identified that, although patients often do not actively participate in decision-making, a number of factors may moderate choice of healthcare provider (Victoor *et al.* 2012). These include factors with relevance for rural populations where access to specialist services are typically limited, such as availability of provider, and distance or convenience of provider location (Hegney *et al.* 2005). However, other considerations may be equally or more important, such as willingness to travel, social support and waiting times for care (Exworthy and Peckham 2006). In a study examining factors influencing rural patient preferences for a General Practitioner (GP), feeling comfortable with the GP and GP continuity were rated higher than geographic proximity (Humphreys *et al.* 1997). Disease characteristics can also modify choice, with more serious conditions or invasive procedures associated with greater opportunity for and patient willingness to participate in decision-making (Victoor *et al.* 2012; Victoor *et al.* 2014b).

There is limited research into the patient experience and involvement in cancer treatment provider decisions by site of disease and area of residence. Previous work is dominated by European and American perspectives, often focused on general populations with study designs based on hypothetical choice experiments rather than actual choices (Victoor *et al.* 2012). An Australian study investigating rural and urban colorectal cancer patient experiences identified only minimal patient involvement in provider decisions (Pascoe *et al.* 2013). Another Australian study showed that rural patients have 'implicit faith' in the healthcare system and little input into decisions about the location of care (McConigley *et al.* 2011). Work from Canada also suggests that most rural patients with rectal cancer have limited choice of treatment provider, but surgical and hospital service reputation, skill and personal relationships were important in considering treatment location (Nostedt *et al.* 2014). None of these studies explicitly compared rural to urban patient experiences, a common limitation of existing research of the experiences of rural populations (Bettencourt *et al.* 2007; Gessert *et al.* 2015).

The aim of this research was to examine how rural and urban patients experience choice of cancer treatment provider after a diagnosis of colorectal or breast cancer.

Methods

Methods and research team: The study follows guidance for reporting qualitative interview research, the consolidated criteria for reporting qualitative research (COREQ) (Tong *et al.* 2007). The guidelines comprise a 32-item checklist that aims to improve the quality of reporting of qualitative research similar to standards for other study designs, such as CONSORT for randomised controlled trials (Schulz *et al.* 2010).

Semi-structured telephone interviews were conducted with patients within 6 – 9 months of diagnosis in the state of Victoria, Australia. Those with colorectal and breast cancer were chosen as subjects for research. These cancer types are common, high burden diseases (AIHW 2014). By including two cancer populations, we were able to examine whether patient choice experiences differed by cancer type. In addition, we could also contrast experiences between a cancer group with (colorectal) and without (breast) rural-urban outcome disparities (Coory *et al.* 2013).

Author-1 has training in performing qualitative research and is an experienced psychosocial cancer researcher and PhD candidate. Author-1 conducted the interviews. Author-2, Author-3 and Author-4 contributed to the study design, interview guide development and analysis, and have combined expertise in cancer population research, qualitative methodologies and clinical experience in rural cancer care.

Ethics: Ethical approval was obtained from the Cancer Council Victoria's Human Research Ethics Committee (Ref: 1125) and registered at the University of Melbourne (Ref: 1441620).

Research context: Victoria is the second most populous state in Australia with 5.6 million inhabitants, and around one third of residents live in rural areas (ABS 2011). The Australian healthcare system has a complex structure of public and private providers and split state and federal responsibilities for different aspects of health care, with the states responsible for hospital services (OECD 2015). Australians have universal access to primary care and public hospitals. Approximately half the population also purchase private health insurance (OECD 2015). Colorectal and breast cancer control in Australia includes national screening programs established in 2006 and 1991 respectively (AIHW 2014). For symptomatic patients, most present to a GP or hospital Emergency Department. Public patients may choose which public hospital they attend or pay to be treated privately. Those with private health insurance can select both a specialist clinician and private hospital. Both arms of the health system require referral in order to access a cancer specialist. Referral is often mediated by a GP, but hospital clinicians and specialists performing diagnostic tests can also refer patients for cancer care.

Sample, recruitment and data collection: Participants were recruited from the sample of patients participating in the International Cancer Benchmarking Project Module 4 survey (Butler *et al.* 2013). The survey examines presentation mode and time intervals to diagnosis and treatment. For that study, the Victorian Cancer Registry mailed surveys to eligible patients: those over 40yrs of age, within 6 months of breast or colorectal cancer diagnosis. An extra page within the survey invited

patients to express interest in speaking more about their cancer experience. A purposive sample of interested responders was selected for the qualitative study (n=70 from n=132 interested). Potential participants were chosen to capture a range of experiences based on characteristics such as area of residence, age, gender, presentation route (screening or symptomatic presentation) and treatments received (surgery, radiotherapy, chemotherapy). Patients were sent a brief information sheet regarding the study, then telephoned to obtain verbal consent and arrange a time for interview. Reasons for non-participation included: researcher unable to contact patient (n=8), one patient died, five declined due to lack of time/ interest; feeling unwell or preferred not to talk over the phone. Three who had agreed to an interview could not be contacted. Recruitment continued until no new themes were identified in three consecutive interviews.

Interviews: Semi-structured telephone interviews were conducted. Telephone interviews were chosen as this method may encourage more open discussions about sensitive subjects such as an event like cancer or criticism of healthcare professionals, were more convenient for participants and interviewer, and there is no evidence that they produce inferior results (Novick 2008). Main topics explored pathways to diagnosis and treatment using open questions and prompts to explore how and why participants attended particular treatment providers. Interviews were recorded, transcribed, de-identified and data managed using NVivo10.

Methodology and data analysis: Thematic analysis was conducted from a realist paradigm (Braun and Clarke 2006). Realist approaches consider the importance of context in understanding mechanisms for how and why particular outcomes occur (Pawson 2006). Context was considered particularly relevant given the potential impact of physical geography and the Australian healthcare system in modifying choice experiences.

Initial coding was carried out by Author-1 and involved inductive, descriptive analysis of each transcript with categories and themes developed using constant comparative methods. Visual diagrams were used to refine the structure and relationships amongst themes (Miles *et al.* 2014). To improve the rigour of analysis, sample transcripts and diagrams were reviewed and developed in regular meetings between authors.

Reflexivity: The interviewer wrote self-reflective memos during analysis. Some older participants commented on the interviewer's 'young' age. The association with the Cancer Council Victoria organisation, a charity and cancer support service provider, enhanced rapport between interviewer and participant. The interviewer's experience growing up in a regional area of Victoria also aided understanding and rapport-building.

Results

Sample characteristics: Forty-three interviews were completed (61% consent rate: 21 colorectal, 22 breast) with participants from urban (n=17) and rural areas (n=26). Interview length averaged one

hour. Breast participants were younger, were more likely to have presented through screening and received multi-modal therapy than colorectal participants. Rural participants were generally older than urban counterparts, had lower socio-economic status and had travelled around 100km for treatment. Participant characteristics are provided in Table 1.

<insert Table 1>

Themes: Four themes were identified: Perceptions of choice; Trust in health care professionals; Perceptions of quality of care; and Access to healthcare (see Fig. 1). Themes are described with quotations to illustrate findings. Participant cancer type (CRC-colorectal cancer, BC-breast cancer), area of residence (R-rural, U-urban) and gender (F-female, M-male) are provided.

<insert Figure 1>

Perceptions of choice

This theme summarises whether participants were offered options for a treatment provider, how involved they were in decision-making and participants' values about the notion of choice. Sub-themes reflect the large proportion of participants not given options and the range of levels of involvement in decision-making. Being offered a choice of treatment providers was often viewed as something unusual, and a range of opinions about the value of choice were identified. No major differences between rural and urban, and colorectal and breast cancer participants' experiences emerged for this theme.

Most participants were not given explicit options for treatment provider after diagnosis: *"No there wasn't any discussion actually to where I was going. It was just that I was referred to [regional hospital] and that was it." (BC6, R).* Many perceived this to be the normal process, particularly if coming through the public healthcare system. For some colorectal participants who presented to the Emergency Department, choice was not possible as they received surgery before being aware of their diagnosis.

Participants were often unclear regarding reasons for referral to particular places. Some rural participants were confused why they were treated locally when others they knew with cancer had gone to the city. Participants who were given options often perceived this as unusual, *"I thought it was odd when he [GP] asked me" (BC3, R),* though having a choice was a positive, *"it's good that he did because you know some people would have a preference" (BC3, R)*. A few had more negative perceptions about the value of choice, *"I think you can get too many choices." (CRC1, M, R).*

Although many participants had no role in decision-making, others were more active and selected a particular surgeon or hospital, or looked for information about providers before making a decision. A number of elements influenced whether and how participants chose treatment providers. These are described in the following three themes.

Trust in health care professionals

Confidence and trust in health professionals was a key theme threaded throughout discussions of choice of treatment provider. This theme encompasses two main concepts: confidence in a healthcare professionals' skill, ability or inside knowledge of the healthcare system; and participants' lack of knowledge regarding cancer itself and differences between healthcare professionals or services. There were no notable differences by geographic location or cancer type within this theme.

Participants perceived health professionals to be experts with inside knowledge needed to make an appropriate referral. A good relationship between the patient and specialist referred to also helped engender trust and confidence in their skills.

A lack of knowledge about cancer, as well as specialist providers and services, was common: *"Because it's difficult if someone says what breast surgeon do you want? Like most of us don't know any surgeons do we?" (BC3, R)*

This lack of knowledge meant participants relied on the referring clinician – often a GP for breast patients, and GP or endoscopist for colorectal patients – to make an appropriate referral. For some, not having a choice was accepted as part of this knowledge imbalance and not a problem: *"I didn't have any choice there... It was fine. The thing is when you're in this position you do as you're told." (BC18, U).*

Others, such as those who felt they had been involved in making decisions about treatment provider, acknowledged the need to trust the referring clinician to help them make choices. A number of participants directly asked for a recommendation regarding specialist care, often seeking both a professional and personal recommendation: *"He [endoscopist] gave me choices around surgeons, he gave me choices around where I could go, and in the end all I said to him was, 'If you were going to have bowel cancer surgery, who would you choose?'" (CRC12, F, U)*

Participants also expressed how a good relationship or rapport with health professionals (referring doctor or specialist) gave them confidence that they were obtaining an informed, quality referral or skilled treatment: *"I have a really good rapport with my GP so I felt very comfortable with any decisions she was making or helping me make." (BC22, U).* Good doctor-patient communication, an established relationship, or even intuition mediated these perceptions: *"People say I'm not bad at judging and I'm a bit intuitive, yeah, I felt I was in good hands and it proved to be correct." (BC21, U)*

Access to healthcare

In this theme, access was defined in three ways: geographic accessibility, including availability of care and convenience of service access from home or social support; a sense of urgency to access care, which led many to perceive limited or no time for choice; and the impact of private health insurance,

where not having insurance often impaired perceptions of choice. Rural and urban patients differed in the geographic accessibility sub-theme, though there were no differences by cancer type.

Geographic accessibility was a particularly strong theme for people from rural areas who mentioned accessibility issues in relation to choice of treatment provider more regularly than urban participants. Participants discussed how they had to attend hospitals with the necessary expertise and equipment to treat their cancer, including centres with ICU units, specialist machinery or expert doctors. For some rural participants, access to these facilities and expertise were not available locally and they were required to travel: *"well we don't have anybody in our town" (BC8, R)*

For rural participants, the concept of choice of treatment provider, particularly at a local level, was seen as somewhat irrelevant: *"I mean you don't have a lot of choice when you're in a regional area." (BC10, R).* When asked whether they considered getting a second opinion, participants acknowledged a lack of options compared to urban residents: *"But there's so many hospitals in Melbourne aren't there. That you could go to one or the other, and see doctors around… But we don't have that capacity" (BC8, R).*

In hindsight however, some noted that they would have chosen care elsewhere if they had had the choice: *"I was just referred to the [regional hospital]. I didn't really get a choice. If I did have a choice I probably would have gone to [urban hospital] as I've heard such good remarks on them." (BC6, F, R)*

For both rural and urban participants who were more active in choosing treatment providers, decisions could be made based on accessibility. This included convenient access to hospital location, or where the specialist practiced: *"… I didn't have any idea about individuals, it was more geographical." (CRC16, M, U).* Rural participants also identified social support as important in moderating perceptions of accessibility of services and decisions regarding which treatment provider to attend:

"I could have chosen to go to [regional hospital], with the pleasure of course, but I have no family or friends in [regional town] so it was better for me to go to Melbourne, stay with the girls and I had their company and their support." (BC2, R)

Perceptions about choice were also influenced by the urgency of care. At diagnosis, most felt a strong desire for rapid access to treatment which was enhanced by perceptions of urgency from the referring clinician: *"So he [GP] said 'I'll make an appointment with you straight away', so he did that there and then, in the surgery he rang up and he said 'tomorrow'…It was very fast." (BC13, R).* This often left no room for patient choice: *"Choices, no. I don't think he [GP] actually had time to discuss the choices." (BC6, R)*

Some clinicians organised referrals to a specialist or hospital even before the participant was aware of their cancer diagnosis. Most were happy about this as they felt it facilitated more rapid, organised access at a stressful time, even though it meant there had been no involvement in that decision: *"Well I actually probably found that [referral to specialist before waking from colonoscopy] probably pretty*

reassuring to be honest because as soon as they said that word, your brain just shut off… so that was probably the best thing that they could have done." (CRC21, F, R)

Whether or not participants had access to the private health system also influenced perceptions of choice, regardless of cancer type or residential location. Few participants in the public health system felt they could choose which hospital or specialist they saw. This perception was firmly held by some, while others were more uncertain:

"Well, basically as a public patient you don't get a hell of a big choice…. You go where you're sent, and you see who you see. You don't have the opportunities to pick and choose." (CRC13, F, R)

"…now I was public not private. So I guess I didn't have a lot of choice…" (BC18, U)

In contrast, participants with private health insurance were often given options for specialist and hospital. Several people commented on choosing a particular hospital around their private health cover: *"No, I wanted a private one. Because I had my health insurance I thought I might as well utilise that..." (BC22, U)* Participants with private insurance could also swap care provider as one participant did after presenting to a public hospital emergency department, then changing on her GPs advice: *"He [GP] just said to me, 'Look if you've got private health insurance, I'd be getting out of there.' " (CRC2, F, U)*

Having private insurance made participants feel they could choose a 'better' specialist and faster access to treatment, linking with the final theme of Perceptions of quality of care: "*I had an appointment by that afternoon. We've got private health insurance so of course that helps in these situations." (BC14, R).*

However, there was often uncertainty regarding quality and waiting-time differences of each system: *"If I didn't have the insurance maybe I'd have to get the general surgeon. I'm not sure" (BC3, R)*

Perceptions of quality of care

This theme encompasses how people assessed quality, including which elements of high quality care, were considered important when making care decisions and how quality is weighed against other factors when making choices. This theme also considers who was more aware or active in assessing quality of care of treatment provider, either for informing decisions or after referral: those with greater health system literacy were most conscious about quality. Comparisons between cancer types and residence areas showed similar experiences, though decision-making could be more complex for rural participants.

Quality of care was important to participants regardless of whether they played an active role in decision-making for treatment provider or not, with many valuing rapid access to treatment and being seen by a 'good' specialist. Specialised cancer care and high volume services were indicators of a

better provider: *"I picked [urban hospital] because I felt confident because that's all they deal in is cancer." (BC1, R).* High ranking clinicians who were up to date with the latest treatments were also important: *"…sort of much the same as going to a hairdresser who keeps up with the coming ways of doing things." (BC8, R)* Participants who had made a choice also mentioned selecting hospitals based on reputation, including safety considerations: *"...I worry about some sort of thing you can catch in hospitals." (CRC03, M, R)*

A number of participants who did not get a choice of specialist sought information about the clinician after they had been referred. Most were seeking reassurance that the specialist was 'good' or skilled. Participants checked quality using social networks, their GP or online information: *"I had a few days to think about it and talk about it with my sister-in-law and to find out about this doctor, that was probably the biggest thing was not knowing if it was a good doctor or not…I just Googled him" (CRC21, F, R).* Participants felt reassured, more confident and informed about the specialist after checking this information. None reported dissatisfaction with information.

While quality of care was important in decision-making, as noted in other themes, a variety of factors also influence choice of treatment provider. For some people, these other factors were more relevant than care quality, such as maintaining privacy or comfortable surrounds: *"I made a choice only because of where the surgery was going to be held, that's all... It wasn't whether he [surgeon] was good or bad or any reason, it was just because I didn't want to have it done at where I work." (BC16, U)* For rural participants in particular, several factors might influence choices. For example, one rural participant weighed the impact of travel burden against perceived lower quality in a public, rural health service. This case demonstrates several linked themes– the impact of geographic access limiting perceptions of choice, health system type and assumptions of quality of care:

"Until I started talking to people and they said 'You'll have to go all the time, you'll be driving up and down all the time and you might be sick' and I thought 'Oh. Yes.' And then people told me good things about [Rural Hospital] but I didn't quite believe that and going public, I didn't think was a good idea, but I really had no choice ..." (BC10, R).

Another rural participant described how access issues and the costs of care influenced a decision to wait longer for treatment. This case also highlights how perceptions about quality, such as wait time for care, interact with a number of other factors that add complexity to decision-making for those in rural areas:

"I could have gone into a private hospital 10 days earlier, but … it would have cost quite a bit more…Plus the public hospital was in [Suburb 1], and the private hospital was in the middle of the city… Again living in the country often has an influence on your decisions about what hospital to go to and that, because it can be a massive inconvenience to do anything in the middle of Melbourne if you don't have someone in the household who can drive in the city." (BC11, R)

The final sub-theme explored how participants with higher health system literacy were more aware and active in seeking and using quality of care information in decision-making. Those with higher

literacy included participants with experience of the health system through work, health industry contacts or prior illness. This form of health system literacy enabled participants to be more active in requesting particular specialists or services:

"…I said, 'Well, there's a surgeon that I would like a referral to.' The reason for that was that my husband, the previous year …he had hernia surgery with this colorectal surgeon who he was very impressed with, and I asked for a referral to him..." (CRC6, F, U) Familiarity with a hospital was similarly important: *"Knowing a place, going back there: I'd been in it before and I was happy there" (BC9, R)*

Work experience and contacts in the healthcare industry also prompted more active information seeking regarding high quality doctors and requests for referral to particular providers: *"… I used to work in Melbourne, and you work with all the surgeons at the hospital… Then when I came up here I still had a girlfriend who worked in the hospital… so I just rang her straight away and I said all right who is top of the field down there for bowel surgery?" (CRC18, R)*

While higher health system literacy and 'inside' knowledge enhanced participant confidence to request certain specialists, perceptions about skill were largely based on reputation rather than published data or accessible information: *"Yes I did. I'm a nurse and I've worked in the area and you sort of understand when people say, oh so and so is really good." (BC22, U)*

Discussion

This study explored whether and how patients make decisions about who will treat their cancer, and whether there were differences by area of residence and cancer type. We found that most patients perceive little choice, regardless of cancer diagnosis or geography. This finding is consistent with international research in general patient groups (Victoor *et al.* 2014a) and cancer populations (Nostedt *et al.* 2014), and suggests that choice policies or guidelines currently have little impact on patients experiences of choosing a treating clinician or the location of their treatment. A lack of knowledge about cancer and healthcare providers, perceived urgency to act, perceptions about choice in the public health system and access issues acted as barriers to patient involvement in decisions. Such factors have been previously described in mixed samples (Victoor *et al.* 2012) but appear to be particularly important for people newly diagnosed with cancer, and for those in healthcare systems with a public-private design.

Our findings showed that most participants valued the concept of choice, even though many who did not have options presented to them seemed content with their referral and some expressed negative views about choice. Several studies also suggest that not all patients are willing to choose a healthcare provider. For example, a UK report found 11% of surveyed patients felt choice of hospital was 'of little importance' or 'unimportant' and 14% ambivalent (Dixon *et al.* 2010). Support for choice also varies by participant characteristics, for example, older people value having choices (Anell *et al.;*

Dixon *et al.* 2010). However, regardless of whether and why patients prefer to choose or not choose a treatment provider, in a patient-centred healthcare system, patient preferences should be elicited and facilitated where possible.

Rural patients: Despite both urban and rural patients perceiving a lack of choice, there were key differences in factors contributing to this perception. Limited local specialist cancer services impaired perceptions of choice for those in rural areas. Access issues have also been linked to differences in the medical help-seeking behaviour of patients in Scotland, with rural patients less demanding and displaying less 'consumerist' behaviours than urban patients (Farmer *et al.* 2006). In our study, rural patients' perceptions of limited local services included a lack of private providers. In Australia in 2013-14, 22.4% of private hospitals and only 12.7% of private beds available were located in rural areas (ABS 2015). This has implications for rural patient decision-making given our findings that most patients assumed choice was limited in the public hospital system. In Australia, public hospital use is higher and uptake of private insurance lower in rural compared to urban areas (ABS 2015; AIHW 2016). While low uptake of private health insurance may reflect lower average incomes, it may also reflect the lack of access to private services in rural areas (Lokuge *et al.* 2005). Reduced access to a range of local services and greater reliance on the public health system contribute to rural patients' perceptions of a lack of choice of treatment centre and provider.

Our study also identified that greater familiarity and understanding of the health system, a form of health literacy (Paasche-Orlow and Wolf 2007), assisted patients to make more active decisions. Health literacy is an important concept in oncology settings where complex decision-making and understanding may be required across the cancer pathway (Koay *et al.* 2012). Although previous research has not specifically examined health system literacy in rural populations, health literacy more broadly is lower amongst people in country compared to city areas (Zahnd *et al.* 2009; AIHW 2010; Martinez-Donate *et al.* 2013). Overall then, lower health system literacy may contribute to reduced perceptions of choice of cancer treatment provider more so for rural than urban residents.

For those who were actively involved in choosing a treatment location, decision-making was more complex for rural than urban patients. Choices could be based on geographic accessibility, but additional factors such as access to social support, quality and financial considerations were also important. Moreover, trade-offs between these elements were more apparent for those in rural than urban areas. These factors demonstrate common difficulties for rural cancer patients: distance from specialist services, social support and travel burden (Butow *et al.* 2012). Facing access barriers and additional factors to consider in decision-making may mean rural patients have less opportunity to attend high quality providers.

That particular populations can experience reduced perceptions of choice or face more complex decision-making raises equity concerns for countries that promote choice policies (Dixon and Le Grand 2006). In order to support patient choice, targeted assistance for disadvantaged populations, such as help with travel and accommodation, may be required (Fotaki *et al.* 2008; Burchardt *et al.* 2014).

Quality of care and trust: Consistent with international reviews, quality of care was important to both rural and urban participants (Victoor *et al.* 2012; Petersen *et al.* 2015). Despite this, the current study suggests that although some patients sought information about potential providers through online or personal contacts, most relied on advice from their referring clinician regarding the quality of specialists or services referred to. Trust in the referring clinician and specialist's skill was often based on rapport rather than any objective assessment. These results are similar to work from the UK which found that patients have difficulty assessing clinician skill, even though it is considered the most important feature of hospital care (King *et al.* 2015). Patients' assumption that a clinician will refer to a high quality specialist is not supported by current evidence. Recent Australian research showed that communication between the GP and specialist was the most important factor in GPs' referrals for colorectal cancer, rather than clinical skill, multi-disciplinary team access or other quality indicators (Harris *et al.* 2012).

This is perhaps unsurprising given the current lack of published quality data available for clinicians to use in referring patients for cancer care. Independent quality information might engage patients and clinicians in more meaningful discussions about cancer treatment provider. However there is uncertainty regarding feasibility of such interventions (Housri *et al.* 2008) and current evidence suggests that even when available, the use of comparative performance information is poor amongst patients and clinicians (Ketelaar *et al.* 2011). Further research is required to identify ways to better inform discussions about referral for cancer care using information that is important to patients.

Pathways to treatment: Understanding cancer pathways through the healthcare system was difficult for both rural and urban patients in this study. There were various clinicians involved in initiating referrals to specialist services and a lack of quality information for public, private, rural and urban services, creating a complex environment for decision-making. This system complexity and the associated difficulties for patient decision-making are also highlighted in a recent OECD report on Australia's healthcare system (OECD 2015). Strategies to define patient pathways, such as the Australian Optimal Care Pathways or New Zealand's National Cancer Standards (Victorian Government 2015; New Zealand Government Ministry of Health 2013), describe the ideal patient journey but provide limited information on the breadth of patient experiences and options for care provider.

As patient-centred care becomes the norm and patients are increasingly involved in choosing care providers (Vrangbæk *et al.* 2007), understanding variation in pathways to treatment and cancer service quality will become increasingly important. Current understanding of rural and urban cancer care pathways in Australia is limited, but such information would be useful at various levels – for patients in choosing treatment providers; clinicians assisting patients to make decisions; and health service managers and policy makers in addressing quality issues at the service and system level.

Strengths and limitations: This was a relatively large qualitative study and interviews continued until saturation of themes was reached. A further strength of the study is its ability to contrast rural and urban experiences of care in two cancer groups, offering novel insights in an under-researched area.

However, unlike larger Australian States, Victoria has fewer areas officially classified as 'remote'. It is possible that patients living in more remote areas may have different decision-making experiences. We would suggest that our findings relating to access and the balance between accessible and perceived quality of care are likely to be even greater for people from remote parts of Australia.

Conclusion

Although patient choice of cancer treatment provider is encouraged, the concept is ill-defined and rarely practised. Rural patients in particular perceive access barriers to making choices and experience more complex decision-making than their urban counterparts. Patient decision-making would be enhanced with evidence-based information about outcomes that matter to patients, such as quality of care. Further research into patients understanding and experience of the cancer care pathways and quality of care in both urban and rural areas is warranted.

References:

ABS (2011) Australian Statistical Geography Standard (ASGS): Volume 5 - Remoteness Structure. ABS, Canberra.

ABS (2015) 4390.0 - Private Hospitals, Australia, 2013-14. In: Private Hospitals, Australia, (ed AUSTRALIAN BUREAU OF STATISTICS). Canberra.

Ahmed S. & Shahid R. K. (2012) Disparity in cancer care: a Canadian perspective. *Current Oncology* **19**, e376-e382.

AIHW (2010) A snapshot of men's health in regional and remote Australia. In: Rural health series. Canberra.

AIHW (2014) Cancer in Australia: an overview 2014. In: Cancer series. Canberra

AIHW (2016) Admitted patient care 2014-15: Australian hospital statistics. Canberra.

AIHW & AACR (2012) Cancer in Australia: an overview 2012. In: Cancer series. Canberra

Anell A., Rosén P. & Hjortsberg C. Choice and participation in the health services: a survey of preferences among swedish residents. *Health Policy* **40**, 157-168.

Archampong D., Borowski D., Wille-Jorgensen P. & Iversen L. (2012) Workload and surgeon's specialty for outcome after colorectal cancer surgery. *Cochrane Database Syst Rev* **3**.

Bettencourt A. B., Schlegel R. J., Talley A. E. & Molix L. A. (2007) The breast cancer experience of rural women: a literature review. *Psycho-Oncology* **16**, 875-887.

Booth C. M., Li G., Zhang-Salomons J. & Mackillop W. J. (2010) The impact of socioeconomic status on stage of cancer at diagnosis and survival: a population-based study in Ontario, Canada. *Cancer* **116**, 4160-4167.

Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative research in psychology* **3**, 77-101.

Burchardt T., Evans M. & Holder H. (2014) Public Policy and Inequalities of Choice and Autonomy. *Social Policy & Administration* n/a-n/a.

Butler J., Foot C., Bomb M., Hiom S., Coleman M., Bryant H., Vedsted P., Hanson J. & Richards M. (2013) The International Cancer Benchmarking Partnership: An international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom. *Health Policy* **112**, 148-155.

Butow P., Phillips F., Schweder J., White K., Underhill C. & Goldstein D. (2012) Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Supportive Care in Cancer* **20**, 1-22.

Coory M. D., Ho T. & Jordan S. J. (2013) Australia is continuing to make progress against cancer, but the regional and remote disadvantage remains. *Medical Journal of Australia* **199**, 605-608.

Dixon A. & Le Grand J. (2006) Is greater patient choice consistent with equity? The case of the English NHS. *Journal of Health Services Research & Policy* **11**, 162-166.

Dixon A., Robertson R., Appleby J., Burge P., Devlin N. & Magee H. (2010) Patient choice: how patients choose and how providers respond.

Exworthy M. & Peckham S. (2006) Access, Choice and Travel: Implications for Health Policy. *Social Policy & Administration* **40**, 267-287.

Farmer J., Iversen L., Campbell N. C., Guest C., Chesson R., Deans G. & MacDonald J. (2006) Rural/urban differences in accounts of patients' initial decisions to consult primary care. *Health & Place* **12**, 210-221.

Fotaki M., Roland M., Boyd A., McDonald R., Scheaff R. & Smith L. (2008) What benefits will choice bring to patients? Literature review and assessment of implications. *Journal of Health Services Research & Policy* **13**, 178-184.

Gessert C., Waring S., Bailey-Davis L., Conway P., Roberts M. & VanWormer J. (2015) Rural definition of health: a systematic literature review. *BMC Public Health* **15**, 378.

Harris M. F., Pascoe S., Crossland L., Beilby J., Veitch C., Spigelman A. & Weller D. (2012) Patients with colorectal cancer - a qualitative study of referral pathways and continuing care. *Australian Family Physician* **41**, 899-902.

Heathcote K. & Armstrong B. (2007) Disparities in cancer outcomes in regional and rural Australia. *Cancer Forum* **31**, 70-74.

Hegney D., Pearce S., Rogers-Clark C., Martin-Mcdonald K. & Buikstra E. (2005) Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care* **14**, 75-82.

Hillner B. E., Smith T. J. & Desch C. E. (2000) Hospital and Physician Volume or Specialization and Outcomes in Cancer Treatment: Importance in Quality of Cancer Care. *Journal of Clinical Oncology* **18**, 2327-2340.

Housri N., Weil R. J., Shalowitz D. I. & Koniaris L. G. (2008) Should informed consent for cancer treatment include a discussion about hospital outcome disparities? *PLoS Medicine* **5**, 1413-1417.

Humphreys J. S., Mathews-Cowey S. & Weinand H. C. (1997) Factors in accessibility of general practice in rural Australia. *Medical Journal of Australia* **166**, 577-580.

Institute of Medicine (2001) Crossing the Quality Chasm: A new health system for the twenty-first century. Washington

Katz S. J., Hofer T. P., Hawley S., Lantz P. M., Janz N. K., Schwartz K., Liu L., Deapen D. & Morrow M. (2007) Patterns and correlates of patient referral to surgeons for treatment of breast cancer. *Journal of Clinical Oncology* **25**, 271-276.

Ketelaar N., Faber M. J., Flottorp S., Rygh L. H., Deane K. & Eccles M. P. (2011) Public release of performance data in changing the behaviour of healthcare consumers, professionals or organisations. *Cochrane Database of Systematic Reviews* **11**.

King D., Zaman S., Zaman S. S., Kahlon K. G., Naik A., Jessel S. A., Nanavati N., Shah A., Cox B. & Darzi A. (2015) Identifying Quality Indicators Used by Patients to Choose Secondary Health Care Providers: A Mixed Methods Approach. *JMIR mHealth uHealth* **3**, e65.

Koay K., Schofield P. & Jefford M. (2012) Importance of health literacy in oncology. *Asia-Pacific Journal of Clinical Oncology* **8**, 14-23.

Lokuge B., Denniss R. & Faunce T. A. (2005) Private health insurance and regional Australia. *Medical Journal of Australia* **182**, 290-293.

Marang-van de Mheen P. J., Dijs-Elsinga J., Otten W., Versluijs M., Smeets H. J., Vree R., van der Made W. J. & Kievit J. (2011) The relative importance of quality of care information when choosing a hospital for surgical treatment: a hospital choice experiment. *Medical Decision Making* **31**, 816-827.

Martinez-Donate A. P., Halverson J., Simon N.-J., Strickland J. S., Trentham-Dietz A., Smith P. D., Linskens R. & Wang X. (2013) Identifying Health Literacy and Health System Navigation Needs among Rural Cancer Patients: Findings from the Rural Oncology Literacy Enhancement Study (ROLES). *Journal of Cancer Education* 1-9.

McConigley R., Holloway K., Smith J., Halkett G., Keyser J., Aoun S. & Monterosso L. (2011) The diagnosis and treatment decisions of cancer patients in rural Western Australia. *Cancer Nursing* **34**, E1-E9.

Miles M. B., Huberman A. M. & Saldana J. (2014) *Qualitative Data Analysis: a methods sourcebook*, 3rd edition edn, SAGE Publications, Inc, London.

Mohammed K., Nolan M. B., Rajjo T., Shah N. D., Prokop L. J., Varkey P. & Murad M. H. (2016) Creating a patient-centered health care delivery system: A systematic review of health care quality from the patient perspective. *American Journal of Medical Quality* **31**, 12-21.

Neal R. D., Tharmanathan P., France B., Din N. U., Cotton S., Fallon-Ferguson J., Hamilton W., Hendry A., Hendry M., Lewis R., Macleod U., Mitchell E. D., Pickett M., Rai T., Shaw K., Stuart N., Torring M. L., Wilkinson C., Williams B., Williams N. & Emery J. (2015) Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. *British Journal of Cancer*.

New Zealand Government Ministry of Health (2013). National Tumour Standards. (cited 2013).

Nostedt M. C., McKay A. M., Hochman D. J., Wirtzfeld D. A., Yaffe C. S., Yip B., Silverman R. & Park J. (2014) The location of surgical care for rural patients with rectal cancer: patterns of treatment and patient perspectives. *Canadian Journal of Surgery* **57**, 398-404.

Novick G. (2008) Is there a bias against telephone interviews in qualitative research? *Research in Nursing and Health* **31**, 391-398.

OECD (2015) *OECD Reviews of Health Care Quality: Australia 2015: Raising Standards*, OECD Publishing, Paris.

Paasche-Orlow M. K. & Wolf M. S. (2007) The causal pathways linking health literacy to health outcomes. *Am J Health Behav* **31 Suppl 1**, S19-26.

Pascoe S. W., Veitch C., Crossland L. J., Beilby J. J., Spigelman A., Stubbs J. & Harris M. F. (2013) Patients' experiences of referral for colorectal cancer. *BMC Family Practice* **14**.

Pawson R. (2006) *Evidence-based policy: A realist perspective*, Sage.

Petersen G. S., Knudsen J. L. & Vinter M. M. (2015) Cancer patients' preferences of care within hospitals: a systematic literature review. *International Journal for Quality in Health Care* **27**, 1-12.

Schulz K. F., Altman D. G. & Moher D. (2010) CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMC Medicine* **8**, 1-9.

Singh G. K., Williams S. D., Siahpush M. & Mulhollen A. (2011) Socioeconomic, Rural-Urban, and Racial Inequalities in US Cancer Mortality: Part I;All Cancers and Lung Cancer and Part II;Colorectal, Prostate, Breast, and Cervical Cancers. *Journal of Cancer Epidemiology* **2011**.

Tariman J. D., Berry D. L., Cochrane B., Doorenbos A. & Schepp K. (2010) Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. *Annals of Oncology* **21**, 1145-1151.

Tong A., Sainsbury P. & Craig J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* **19**, 349-357.

Victoor A., Delnoij D., Friele R. & Rademakers J. (2014a) Why patients may not exercise their choice when referred for hospital care. An exploratory study based on interviews with patients. *Health Expectations* n/a-n/a.

Victoor A., Delnoij D. M., Friele R. D. & Rademakers J. J. (2012) Determinants of patient choice of healthcare providers: A scoping review. *BMC Health Services Research* **12**.

Victoor A., Rademakers J., Reitsma-van Rooijen M., De Jong J., Delnoij D. & Friele R. (2014b) The effect of the proximity of patients' nearest alternative hospital on their intention to search for information on hospital quality. *Journal of Health Services Research and Policy* **19**, 4-11.

Victorian Government (2011) Victorian health priorities framework 2012 - 2022: Rural and regional health plan. Victorian Government, Melbourne.

Victorian Government (2015). Optimal Care Pathways. Available from: www.health.vic.gov.au/cancer (cited 2015).

Vrangbæk K., Østergren K., Birk H. O. & Winblad U. (2007) Patient reactions to hospital choice in Norway, Denmark, and Sweden. *Health Economics, Policy and Law* **2**, 125-152.

Vrangbaek K., Robertson R., Winblad U., Van de Bovenkamp H. & Dixon A. (2012) Choice policies in Northern European health systems. *Health Economics, Policy and Law* **7**, 47-71.

Zahnd W. E., Scaife S. L. & Francis M. L. (2009) Health literacy skills in rural and urban populations. *Am J Health Behav* **33**, 550-557.

Table 1: Participant characteristics.

Demographic and clinical characteristics		Colorectal cancer (n=21)		Breast cancer (n=22)	
		Urban (n=8)	Rural (n=13)	Urban (n=9)	Rural (n=13)
Age	Mean (SD)	61.2 (12.7)	66.6 (10.7)	56.8 (11.9)	62.7 (12.1)
	Median (IQR)	60 (24)	67 (14)	57 (23)	61 (20)
	Range	42, 78	48, 87	41, 74	49, 87
Gender	Male	4	7	n/a	n/a
	Female	4	6	9	13
Socio-economic status (IRSD)	0-40% (most disadvantaged)	2	8	3	9
	41-80%	2	2	3	1
	81-100% (least disadvantaged)	4	3	3	2
Patient insurance	Public	2	6	4	5
	Private	6	7	5	8
Hospital attended	Public	2	6	4	6
	Private	6	6	4	3
	Mix public/private	0	1	1	4
Travelled ~100km for treatment	Yes	0	9	0	9
	No	8	4	9	4
Presentation	Symptom	5	9	5	5
	Screening	1	2	4	8
	Emergency	2	2	0	0
Stage at diagnosis (AJCC)	Local (I & II)	4	9	9	10
	Regional (III)	2	4	0	2
	Advanced (IV)	1	0	0	1
	Unable to stage	1	0	0	0
Treatment	Surgery	5	8	0	1
	Surgery & chemo	3	3	1	1
	Surgery & RT	0	0	4	5
	Surgery, chemo & RT	0	1	4	6
	Polyp removal alone	0	1	0	0

Abbreviations: AJCC: American Joint Committee on Cancer (7th Edition); IRSD: Index of Relative Socio-economic Disadvantage; IQR (Inter-quartile range); SD (standard deviation); RT: radiotherapy; Chemo: chemotherapy.

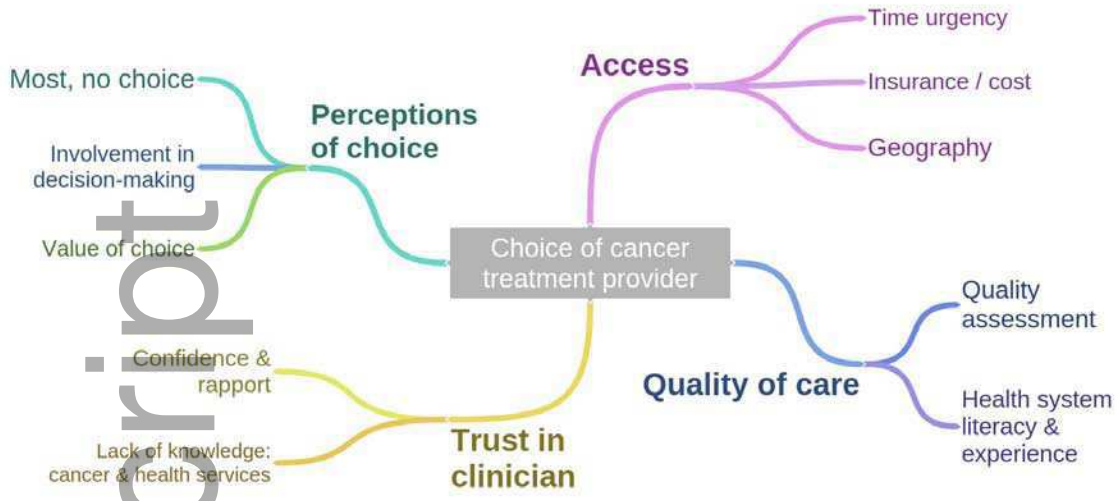

Figure 1 legend: Model of main themes - Four themes and associated sub-themes examining how colorectal and breast cancer patients in rural and urban areas experience choice of cancer treatment provider (Coggle map - Google).