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The Care of Complex Skin Cancer in Rural New South Wales, Australia – Results of a Pilot Study of Primary Care Physicians

Elizabeth J. Paton[1,#], T. Michael Hughes[2,3], Kavita Enjeti[3], Josie Rutovitz[3,4], Gerald B. Fogarty[1,5,6]

[1] Faculty of Health, University of Technology Sydney, Ultimo 2007, NSW, Australia
[2] Australian National University, Canberra 0200, ACT, Australia
[3] Sydney Adventist Hospital, Wahroonga 2076, NSW, Australia
[4] Northern Haematology and Oncology Group, Wahroonga 2076, NSW, Australia
[5] Icon Cancer Centre, 1-3 Macarthur Avenue, Revesby 2022, NSW, Australia
[6] Sydney Brachytherapy Research Institute, St Leonards 2065, NSW, Australia

Backgrounds: Australia has the highest rates of keratinocyte cancer (KC). This represents a growing burden in the primary-care setting where the bulk of KCs are managed. Recent Complex KC (CKC) specialist treatment advances have led to improved outcomes, and multi-disciplinary team (MDT) case discussion. Do rural General Practitioners (GPs) have a clear pathway of referral so that their CKC patients can benefit? Given the paucity of literature about this we devised a pilot questionnaire and collated results.
Methods: Using a consensus from subject matter experts, a pilot questionnaire was devised to capture a clinician perspective of regionally-based New South Wales (NSW) GPs examining CKC patients and their management. The questionnaire was completed (i) in person at a conference and (ii) via email. Survey Monkey software was used to analyse results, which were reported using descriptive statistics.
Results: 65 people were contacted for this survey: 20 at a conference and 45 by email. The overall response rate was 20%. Eight (62%) respondents indicated that they had no established CKC referral pathway for their patients, patients experienced long waiting times (3 to 6 months) and had a long travel distance for care (200 + kms). Twelve (92%) respondents agreed that their patients did not have timely access to services and indicated their support for CKC MDT participation. There were a number of study limitations.
Conclusion: Despite limited data, there appear to be gaps in rural NSW GP CKC treatment pathways. More research is needed to understand the national landscape.
Keywords: Pilot project; Skin neoplasm; Primary health care; Rural health; Multidisciplinary care team; Australia.

Introduction

Australia has the highest rates of keratinocyte cancers (KCs) in the world, rates are likely higher (given that there are no mandatory KC reporting mechanisms in Australia), increasing with age, and it is a major burden on the health system[1,2]. In Australia, primary care general practitioners (GP) play a central role in the diagnosis and management of KCs[3]. Regional and rural Australian patients have poorer cancer outcomes compared with their metropolitan counterparts[3,4]; this includes a higher incidence of melanoma and rural patients presenting with more advanced KCs[5].

Complex KCs (CKCs) could be defined as lesions that the primary care physician decides that specialist level care is required. In 2017, the Australian government recommended the national need KC multidisciplinary teams (MDTs) to be supported to establish in order to effectively triage and treat complex KC patients to optimise patient outcomes[3]. Many Australian tertiary hospitals now offer a CKC MDT service which facilitates multimodality specialist interaction to discuss treatment considerations for patients[4,6–10]. However, CKC MDTs are not as yet as common place in Australian hospitals as other tumour MDTs[11–15], the reasons for this are unclear. Perhaps it is related to the necessity of many Australian KC patients being seen and definitively treated in the primary care setting[2], disease progression being harder to monitor and follow up, as well as the challenges faced by Australian GPs including to routinely participate in MDTs[16]. Given the volume of KC cases in Australia, an aging population (one third of whom live outside of the metropolitan cities, with a declining number of GPs practicing (including regionally) primary and CKC management remains a national challenge[2,5,17,18].

The authors of this study treat and manage regional patients with CKCs and regularly participate in CKC multi-disciplinary team (MDT) discussions. Many patients who are treated by this team come from regional NSW areas and some patients utilise the subsidised accommodation services to access the care that they need[19]. In order to better explore the KC landscape across

Correspondence: Elizabeth J. Paton. E-mail: Elizabeth.j.paton@student.uts.edu.au. Address: Faculty of Health, University of Technology Sydney, Ultimo 2007, NSW, Australia. ORCID: 0000-0002-7698-3248.
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NSW, the authors considered the various nationally representative membership-based GP networks who support the 40,000 GPs practicing in Australia[20]. Given the experiences of the authors treating patients who come from regional NSW areas, and to address the paucity of literature on this topic, the team designed this pilot questionnaire to better identify the needs of NSW regionally-based clinicians who treat patients with CKC. This study was designed as a pilot study to evaluate participate responses to a questionnaire gathered (i) in person at the NSW chapter of the Rural Doctors Network (RDN) (one of the larger regional membership-based GP networks) annual conference. The RDN supports a national membership of 9,700 members, of these 3,091 were NSW-based in the 2023–2024 year[21] some of whom attend their annual meeting in Coogee, Sydney, NSW, Australia; and (ii) via the team's own regionally-classified GP patient referral database.

Materials and Methods

Drawing on Grounded Theory[22], using a consensus from subject matter experts involved in the research team, a pilot questionnaire was devised which included six main questions (see Supplementary materials). This questionnaire was designed to capture a clinician perspective of rural and regionally-based NSW GPs examining patients with CKCs and their management.

The questionnaire was to be filled out by one of two means:

(1) In person: During an interview to complete the questionnaire that would occur during an annual GP conference hosted by the RDN (NSW Chapter) in Coogee, Sydney, NSW. The senior author was an invited speaker at the conference and there was an information booth promoting the senior author's CKC service. During the 2-day conference, the lead author approached individual conference attendees during the scheduled breaks in the program in the communal break out area in the foyer. The lead author explained the background rationale and invited individuals to participate, provide their consent and complete the questionnaire;

(2) Via email: One co-author (GBF) provided a list of existing referring regionally-based GPs who treat patients with CKC. The lead author contacted each individual GP listed, via direct email. The lead author explained the background rationale and to participate, provide their consent and complete the questionnaire. Participants were provided with a link to an online survey[23].

The participants responses were then collated and analysed the data using the Survey Monkey software[23]. The results were reported using descriptive statistics only, with counts and proportions. The results of the pilot study were intended to inform a larger collaborative study involving other nationally-representative stakeholder groups.

Regionality was confirmed by postcode analysis using the designated postcode tool promoted by the Australian Federal Departments[24,25].

This study was designed as a pilot, conforming with the requirements of a quality improvement project[26].

Results

65 people were contacted for this survey: 20 at the RDN conference and 45 by email. The overall response rate was 20% (13 responses from the RDN conference and 0 responses from email). All participants who responded were working and residents of areas classified as being regional / rural areas in NSW.

The results of the questionnaire revealed eight (62%) respondents indicated that they had no established CKC referral pathway for their patients.

The majority of respondents (7/13) indicated their patients needed to travel greater than 200km for specialist CKC care. The most common category chosen for approximate patient wait time was 1 to 3 months (38%). However, the majority expected their patients to wait for longer than 3 months, with 23% of respondents choosing 3 to 6 months wait and 23% of respondents choosing > 6 months. Seven respondents (54%) reported that they did not think their patients had timely access to CKC specialist care. Twelve respondents (92%) agreed that even more timely access to specialist CKC care was needed and these same people expressed their interest to participate in a CKC MDT service (if the service was made available). All 13 respondents indicated a willingness to receive additional CKC information. There were no negative verbal or written comments about the questionnaire themes. Table 1 describes the results.

Table 1. Pilot questionnaire results.

	Selected Questions (See Supplementary Materials)	Aggregate Responses
1	Is there an established CKC referral pathway?	Yes (5, 38%) No (8, 62%)
2	Distance to specialist care	0–50 km (1, 8%) 50–100 km (3, 23%) 100–200 km (2, 15%) 200 + km (7, 54%)
3	Approximate patient wait time	1 month (2, 15%) 1–3 months (5, 38%) 3–6 months (3, 23%) >6 months (3, 23%)
4	Do your CKC patients have timely access to specialist care?	Yes (3, 23%) No (7, 54%) Other (3, 23%)
5	Is there a need for more timely access to specialist care?	Yes (12, 92%) No (1, 8%)
6	Interest in a CKC MDT service?	Yes (12, 92%) No (1, 8%)

Discussion

What this paper adds

(1) Prior to this study, it was not known if Australian rural GPs had adequate CKC treatment pathways or not.

(2) Despite the study limitations, the pilot questionnaire showed that the majority of rural NSW GPs surveyed had no referral pathway for their CKC patients, patients experience long waiting times and had to travel long distances to access appropriate specialist care.

(3) The pilot questionnaire showed that rural NSW GPs are enthusiastic to receive more CKC treatment information (including about clinical trial opportunities, as well as on MDT services).

What is already known on this subject

(1) Australia has the highest rates KC in the world, it is a significant burden on the Australian health system and incidence is at least 10 times the global age standardised rate and is increasing.

(2) Close to one in three Australians live in regional Australia. There is a higher incidence of melanoma in rural Australia, and rural patients can present with more advanced disease. KC incidence is likely higher than reported, including across rural Australia.

(3) MDTs are common in other cancers and have been shown to improve patient outcomes.

The results of this small pilot study suggest that the pathways to specialist CKC care for rural patients in NSW are not yet ideal. The majority of GPs that we surveyed did not have an established CKC referral pathway available, did not consider that they had timely access to specialist care to ensure that their CKC patients were treated, described that their patients had long waiting times and long travel distances to access specialist CKC care.

What was not surveyed was the appreciation of rural GPs for the rapidly changing landscape of treatment improvement for CKCs, which specialist MDT care delivers for metropolitan-based patients. Rural CKC patients may continue to lag behind and this may hinder patient outcomes. Future research in this area would add depth and nuance which might further enhance the quality of CKC MDT service in Australia and how this could be integrated to improve the participation of GPs practicing outside of the metropolitan centres. What is the way forward?

Electronic or virtual MDTs (eMDTs), made commonplace during the COVID-19 pandemic, may be a way of overcoming the tyranny of distance and the lack of knowledge of new therapies, especially in regional and remote catchments outside of metropolitan cities in Australia. eMDTs are a practical way of including all the relevant specialties in a timely fashion in treatment decisions for individual cases[27]. Previous studies by members of this team have trialled the development of CKC eMDTs in the Australian context[11], but this earlier study was hampered by poor resourcing and competition between stakeholders. Importantly, the participants of both the earlier study and the present study identified that Australian GP participants were enthusiastic to participate in CKC MDTs, advocated for improved access to specialist CKC MDTs and both reported that their regional patients experience longer waiting times and long travel distances to access specialist CKC. These results emphasize the importance of the research question even though both studies were pilot projects with smaller than anticipated sample sizes reducing the impact of any of the findings. Most skin cancers are still managed in the primary care setting in Australia, for patients with progressive, locally advanced or metastatic disease access to experienced MDTs is now becoming critical to ensure adequate care. Given the high volume of KCs in Australia, GP proximity within regional and rural communities (generally beyond the tertiary hospital setting), advances in new CKC therapeutics and technologies[4], and information technology improvements, the roll out of more accessible eMDTs may help engage more GPs earlier and this may help patients sooner.

Consumer engagement is also increasingly important, and rural skin cancer patient advocacy may help[28,29]. Previous research by members of this team and consumer advocates (including in partnership with key Australian KC consumer representatives) have described strategies to improve the treatment of patients diagnosed with CKC in Australia[17]. The consumer voice articulating the needs of patients who live in the country could help shift momentum with a greater focus on addressing the gaps in care, which prevent earlier specialist review and access to treatments.

The Melanoma and Skin Cancer Advocacy Network (MSCAN) is the only skin cancer advocacy organisation in Australia and MSCAN launched in 2019[30,31]. MSCAN are spearheading a targeted national screening program consensus, this is a collaborative venture bringing together various research, treatment, consumer representative. Perhaps this initiative will grow to expand beyond screening and diagnosis to include targeted initiatives to improve CKC patient outcomes for Australians in regional and rural areas[30]. A recent national nursing initiative (developed by Melanoma Institute Australia with the support of a nationally representative group of expert nurse practitioners) was launched in 2025 which will provide up to 30 melanoma nurses throughout Australia who will work alongside MDT teams to care for patients undergoing treatment for high-risk melanoma[32]. However, patients with CKC are not included in this program, the reasons for this are unclear. This may be an area for future research. Future research collaborations involving both GPs and consumer advocates and organisations (with a regional footprint) may help to further highlight the treatment disparity and particular needs of CKC patients (and the families) in regional Australia, and this may help to tailor CKC specialist services for these patients. Effective independent patient advocacy for the needs of CKC patients in regional Australia, may help to improve earlier management which may improve patient outcomes, as well as minimising additional treatment complications and costs. This would be beneficial to individuals and the community overall.

Limitations of our study

There are limitations to our study. The sample size is small and the catchment area is state-specific. The situation may be better in other states of Australia.

This study was developed as a pilot, with the intention of a larger number of responses which may have gone on to inform a larger-scaled project with a national-perspective. The number of participant responses was smaller than expected. The absence of email participant responses highlights the inadequacy of the distribution method. This issue could be addressed by involving the Specialist's involvement to coordinate future email correspondence directly, minimising the possibility that the questionnaire may have been perceived as junk mail. The motivation to undertake this study was intended to enrich the current literature on CKC access for patients; however, given the small sample size this limits the translation of these results into a larger study.

There were also some organisational issues experienced during the in-person data collection at the conference. Some colleagues performing the data collection had less research experience and anecdotally this influenced and reduced their desire to speak with conference participants. This may have led to fewer questionnaires being completed and gathered. Perhaps the provision of additional staff training and education to colleagues performing the data collection (about clinical research[33] and contemporary CKC treatment and care) prior to public events including at conferences may enhance staff confidence to collect more

data. This type of training may boost confidence, enhancing the level of their 'buy-in' to participate in research projects at future events. Since this study was undertaken, the institutional engagement of members of this team have also shifted restricting the ability to design, implement and analyse a larger collaborative study as originally intended and a redesign of the larger project is now underway.

Conclusions

We report on the results of a pilot study that aimed to evaluate a clinician perspective of regionally-based GPs working in NSW who treat patients with CKCs. Despite a limited number of responses, it appears that the current arrangements are not ideal. The majority identified that they did not yet have an established CKC referral pathway available, they did not have timely access to specialist care and described that their patients had long waiting times and long travel distances to access specialist care. In person participation was better than via email. More research is needed to understand and improve the CKC treatment service pathway landscape in Australia.

Abbreviation

CKC, Complex Keratinocyte Cancers; eMDT, Electronic or virtual Multi-Disciplinary Team; GP, General Practitioners; KC, Keratinocyte Cancer; MDT, Multi-Disciplinary Team; N, No; NSW, New South Wales; RDN, Rural Doctors Network; Y, Yes.

Ethics approval and consent to participate

We confirm that this study met with the criteria of Quality Improvement/Assurance activity under the Australian NSW Health policy (linked to the NSW Health, Different of Research, Quality Improvement and Program Evaluation by the Department of Evaluation and Research Services) and therefore did not require full ethical approval. This study was not a clinical trial, was considered as a pilot study, classified as low-risk and non-interventional. The study did not involve vulnerable populations (ie. patients). Written informed consent was obtained from the individual(s) who participated in this study.

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Conflict of interest

Prof. Gerald B. Fogarty OAM is on the advisory boards of Merck Serono Australia Pty Ltd, Sanofi-Aventis Australia Pty Ltd, La Roche Posay (Loreal), Oncobeta GbBH and Atomic Oncology Pty Ltd. He has received industry research grants from Merck Serono Australia Pty Ltd and Sanofi-Aventis Australia Pty Ltd. The other authors declare no conflicts of interest.

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Authors' contributions

EJP, TMH, KE, JR and GBF contributed to study conception and design. EJP and GBF contributed to the project administration, collected and analysed the data and wrote the paper. TMH, KE and JR revised the manuscript. All authors reviewed and approved the final version of the manuscript.

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