

## ORIGINAL RESEARCH

## GOVERNMENT FUNDED TRAVEL AND ACCOMMODATION ASSISTANCE: LEARNING FROM INTER-COUNTRY RESEARCH

PAM MCGRATH<sup>1</sup>, HAMISH HOLEWA<sup>2</sup>, and AMY MUNRO<sup>3</sup>

<sup>1</sup>International Program of Psycho-Social Health Research (IPP-SHR), Centre of National Research on Disability and Rehabilitation Medicine, Griffith Health Institute, Griffith University, Queensland, Australia; <sup>2</sup>Institute of Health and Social Science, Central Queensland University, Brisbane, Queensland, Australia; and <sup>3</sup>Leukaemia & Blood Foundation of New Zealand, Auckland, New Zealand.

Corresponding author: Dr Pam McGrath ([p.mcgrath@griffith.edu.au](mailto:p.mcgrath@griffith.edu.au))

## ABSTRACT

**Objectives:** The paper explores the consumer experience with the New Zealand travel and accommodation assistance scheme, known as the National Travel Assistance (NTA) scheme, as detailed in findings from a recent study on relocation for specialist treatment in haematology. The study is set in the context of the research literature on Australian government travel and accommodation assistance schemes. The findings provide the opportunity for shared, inter-country learning to inform health policy, administration and service delivery. **Methods:** A qualitative methodology was used based on open-ended interviews with participants (n=62) who had relocated for specialist care selected from a database of patients and families maintained by the Leukaemia and Blood Foundation. Criteria included a representation of all major haematological diagnostic groups and location in the corresponding catchment areas of primary specialist haematological centres in New Zealand. The interviews were audio-recorded, transcribed verbatim, coded and thematically analysed. **Results and Conclusions:** In New Zealand there is a high level of satisfaction with the NTA scheme. The process of information giving is active with health professionals, especially hospital social workers, providing the initiative to make sure patients and their carers are well informed and actively supported in relation to the scheme. The majority of New Zealanders interviewed indicated that they found the NTA scheme to be user-friendly with forms easy to fill in and submit, staff available to actively assist with the application process and a clear line of administration for easy approvals. The findings provide useful insights to inform health policy and service delivery in relation to government travel and accommodation schemes in Australian and New Zealand.

**Key Words:** Transport; Accommodation; Relocation; Inter-country comparison; Qualitative research; Regional, rural and remote; New Zealand; Australia.

**SUBMITTED:** 7 July 2011; **ACCEPTED:** 22 August 2011

## INTRODUCTION

*"Effective healthcare depends on access to that care, but the sheer size of Australia precludes easy physical contact between patients living in rural and remote areas and medical specialists, the majority of whom are in urban centres."* (NRHA submission, SCR, 2007)

Advances in medical treatments have been accompanied by a concentration of specialist medical services in the major metropolitan locations. The centralisation of specialist care has led to problems of access and equity for individuals living in regional, rural and remote locations. At a government level the programmatic response to such access and equity issues has been the development of transport and accommodation subsidy schemes to provide financial assistance to those who have to relocate for specialist care. The schemes reflect the social justice notion that healthcare is an important and universal right in modern society and an established feature of Australian society (Theophanous, 1994).

The Australian government travel and accommodation

assistance to patients and carers was originally administered through a national scheme titled the Isolated Patients Travel and Assistance Scheme (IPTAAS). However, since January 1987 the Commonwealth has redirected funds to state authorities to administer the scheme on a local state basis (Brown, 1987). In recent years the problems associated with the varied state administered schemes (McGrath, 2000a) has been recognised as of serious concern resulting in government reviews and eventually in a Senate Inquiry in 2007 (Senate Committee Report, 2007). This is an important health policy topic that requires research to inform solutions.

Although there has been scant academic research on this topic, there is a body of research (McGrath, 1988; 1999a; 1999b; 2000a; 2000b; 2001; McGrath and Seguerria, 2000) on the Queensland travel and accommodation scheme in relation to haematology patients that contributed to the initiation of the Senate Inquiry (SCR, 2007). Recently the researchers who completed this work were funded by Leukaemia & Blood Foundation (LBF) of New Zealand to do an in-depth examination of relocation issues for

haematology patients and their carers in New Zealand, including consumers' experience with the travel and accommodation subsidy scheme. The aim of this study was to extend a program of research that examined issues associated with relocation for specialist treatment to include an understanding of the experience of relocation in relation to patients diagnosed with a haematological malignancy and their carers who reside in New Zealand. This paper not only reports the findings on the New Zealand travel and accommodation assistance scheme, known as the National Travel Assistance (NTA) scheme, but also takes the opportunity provided by inter-country research to reflect on the contribution the findings can make to informing Australian health policy and service delivery issues on the topic. In short, the aim is to provide an opportunity for shared, inter-country learning to inform health policy, administration and service delivery in both countries.

Haematology patients often have to relocate for specialist treatment for lengthy periods of time and cope with highly invasive and aggressive medical procedures, disruption to work and family life, financial hardship, adjustment to the world of the metropolitan hospital and city living, and the demands of travelling long distances from home (McGrath 1988; 1999a). In both Australia and New Zealand there are major challenges with relocating for haematology patients and their family and support from patient travel and assistance schemes is thus essential (McGrath and Holewa, 2011; McGrath, Holewa, Etcheverry, 2011).

#### **The Queensland Patient Travel Subsidy Scheme (PTSS)**

In Queensland, in order to emphasise the fact that the scheme was about subsidy not full reimbursement, the title has been changed from the Patient Transit Assistance Scheme (PTAS) to the Patient Travel Subsidy Scheme (PTSS). In comparison to New Zealand which has a national scheme, PTSS is administered at state level by Queensland Health through a network of public hospitals (Queensland Government, 2010). The hospitals are in turn responsible to Health Service Districts that are managed by Chief Executive Officers (Queensland Health, 2010).

The state government scheme is designed to assist individuals (state residents with Medicare cards) to access specialist medical services which are considered essential and not available in their local areas (Queensland Government, 2010). Clinical haematology is listed (Schedule 1) as essential specialised medical services. The scheme offers a financial contribution to the cost of transport and accommodation when the specialist services are not available within 50 kilometres of the nearest public hospital (Queensland Government, 2010).

#### **The New Zealand National Travel Assistance Scheme**

The National Travel Assistance Scheme (NTA scheme) is a significant government initiative, providing financial help to patients and their carers who have to relocate for specialist care. The scheme was developed by the Ministry of Health and the District Health Boards to provide some financial assistance to those New Zealanders who may find it difficult to access specialist health and disability services without such assistance. The NTA scheme has many specific

eligibility criteria but, in summary, provides a reimbursement contribution for travel for specialist care as well as, where necessary, part payment for accommodation at the specialist centre (Ministry of Health, 2011a). Eligible distances from specialist centres vary depending on whether the patient is a child or an adult. There is also variance in the amount of support offered depending on frequency of travel (Ministry of Health, 2011a).

#### **METHODS**

This study, conducted by the International Program of Psycho-Social Health Research, was funded by the Leukaemia & Blood Foundation of New Zealand (LBF). This paper reports the sub-set of findings from the study on the government travel and accommodation schemes. Further papers, outlining the same methodology, have been previously published on issues associated with reconceptualising relocation (McGrath and Holewa, 2011) and surviving the crisis of relocation (McGrath, Holewa, and Etcheverry, 2011).

The participants were a purposive sample selected from a database of patients and families maintained by the LBF. The participants were enrolled through two Project Officers for the study who were under contract with the University and thus independent of the LBF. The Project Officers were given a list of names and telephone numbers of haematology patients and their carers who had been in contact with the LBF. The potential participants had all received a letter from the LBF informing them of the study and stating that if the person did not want to participate in the study they could contact the LBF to opt out. Any individual not wanting to be involved in the research was deleted from the list. At this stage the database of patient and family contacts, excluding the details of those who chose to withdraw from the study, was provided to the research program for the selection of participants. Thus, the actual identity of those who did participate remained confidential as the LBF was not provided any detail on the actual selection. The participants were enrolled from a purposive sample from this list, through an initial telephone call, followed by one of the Project Officers providing a written Project Description and inviting voluntary participation in the research. Prior to interviewing, participants were again informed of their ethical rights and individual consent obtained. The University Ethics Committee and the Health Research Council of New Zealand approved the study.

#### **Purposive sample of participants**

A list of potential participants for the study was generated from the LBF list based on a number of criteria including ensuring both a representation of all major haematological diagnostic groups (leukaemia, lymphoma, myeloma) and the corresponding catchment areas of primary specialist haematological centres in New Zealand (Auckland, Christchurch, Dunedin, Hamilton, Palmerston North, Wellington). Once identified, potential participants were consecutively enrolled based upon the declining largest distance between the identified primary specialist treating centre and the client's primary residence. A secondary

subgroup was also chosen to address concerns relating to geographical distances that did not accurately reflect travel time by land, such as participants residing in a location which required travel by ferry to obtain treatment at a primary specialist haematological centre.

All patients had to meet the criteria for relocation in that they did not live in the city where the treating centre is located

and for some of their treatment they were forced to live for a period of time away from home at the location of the treating centre. One hundred and forty-two potential participants were contacted to participate in the research with 28 declining to participate and 52 being un-contactable (due to changes in contact details). In total there were 62 participants, of which 46 were patients and 16 were carers. The demographics are outlined in Table 1.

**Table 1:** Demographic characteristics of 62 participants including details of primary treating centres, diagnostic groups, distance travelled and age.

	Distance travelled (km)		Age (years)	
	Mean (SD)*	Range	Mean (SD)	Range
<b>Primary Treating Centres</b>				
Auckland (n=6)	217 (50)	143 -281	50 (9)	35 -60
Christchurch (n=18)	129 (56)	32 -244	58 (9)	40 -68
Dunedin (n=12)	206 (131)	18 -566	46 (14)	23 -63
Hamilton (n=10)	160 (21)	147 -220	45 (11)	23 -61
Palmerston North (n=12)	98 (69)	43 -237	62 (8)	41 -73
Wellington (n=4)	170 (143)	58 -333	63 (2)	61 -65
<b>Diagnostic Groups**</b>				
Leukaemia (n=15)	137 (71)	18 - 281	50 (16)	23 - 73
Lymphoma (n=14)	163 (68)	58 - 249	47 (11)	27 - 65
Myeloma (n=12)	133 (136)	43 - 566	55 (7)	50 - 67
Other (n=5)	179 (109)	85 - 333	55 (9)	42 - 68

\*SD = Standard deviation; \*\*46 patients only.

Note: Some patient needed to relocate to two or more hospitals. Data refers to hospital which patient relocated for the longest period of time. Distance travel determined by straight line. Actual travel distance may be considerably more. Distance travelled excludes duplication of distance by including patient and carer dyads as one entry. Age refers to patients only.

There were significant ethical concerns about avoiding identification of participants as individuals were not only patients and carers known to the LBF, but were also part of a small sub-group of cancers (haematological malignancies which represent five to seven per cent of total cancers) and were treated by a small number of treating centres (n=6) in a country where the research indicates there is a high level of familiarity and interconnectedness in the population. Thus, the consent procedures emphasised confidentiality. For this reason, only broad demographics about the participants are provided. The participants resided in all District Health Boards across New Zealand.

#### Research design

An open-ended, exploratory qualitative design was utilised for the study (Holloway, 2008; Patton, 2002). Qualitative research is important for work with a consumer focus where the intent of the study is to record the experience from the consumers' perspective (Kraithwohl, 1993; Polit and Hungler, 1995). A list of topic areas to explore during the study was developed from the findings of the program's prior Australian research on relocation and included issues that explored the emotional, social, financial and practical aspects of relocation. However, in accordance with the iterative principle of qualitative research (Holloway, 2008) the issues being explored evolved with the study with early insights informing the discussions in subsequent interviews.

#### Interviews

The exploration of the experience of relocation from the consumers' perspective was conducted through an iterative, qualitative research methodology using open-ended interviews conducted by speaker-phone at the time and location of each participant's choice. The initial five interviews were conducted by an experienced psycho-social researcher, the chief investigator for the study, with a background in cross-cultural research employed by the University and thus independent of the LBF. Subsequent interviews were conducted by two project officers who also have extensive experience in conducting qualitative interviews.

The haematology patients and their carers were encouraged to talk about their experience with relocation from the point of diagnosis until the present. The line of questioning included the techniques of probing, clarification, paraphrasing and summarising to explore each participant's experience (Gaskill, Henderson, and Fraser, 1997). Of relevance to this article, it is important to note that all of the participants (n=62) were asked questions about their experience with the National Travel Assistance Scheme. The interviews lasted for approximately one hour and were audio-recorded. The interviews were transcribed verbatim by a research assistant independent of the LBF.

### Analysis

The language texts were then entered into the QSR NVIVO 8 computer program and analysed thematically. All of the participants' comments were coded into 'free nodes' which are category files that have not been pre-organised but are 'freely' created from the data. The list of codes was then transported to Microsoft Word 2007 and organized under thematic headings. The coding was established by an experienced qualitative researcher and completed by one of the Project Officers who has extensive experience with coding qualitative data. There was complete agreement by coder and researcher on the coding and emergent themes. There were 406 free nodes created from the transcriptions. The themes and codes that related to discussions of the National Travel Assistance Scheme (NTA scheme) are presented here.

### RESULTS

As with any publically-funded health scheme, there were a range of both positive and negative factors associated with access and administration. The following discussion of findings will detail the complexity of these factors. However, a caveat to the following discussion is that of the 62 participants only 17 reported any negative comment on the scheme. Overall, there was a high level of satisfaction reported with regards to the NTA scheme.

Note: The identifiers in the brackets in front of quotes refer to whether the individual is patient (Pt) or Carer (Cr),

location (CHC, Christchurch; WLG, Wellington; PN, Palmerston North; HAM, Hamilton; DUN, Dunedin) and disease type (MM, Multiple Myeloma; MF, myelofibrosis; TPLL, T-cell prolymphocytic leukaemia; HL, Hodgkins Lymphoma; CLL, chronic lymphocytic leukaemia; ALL, acute lymphoblastic leukaemia).

#### The positives: Awareness of the scheme

The majority of participants indicated that they were aware of the NTA scheme and the process of administration. There were different points in time that individuals became aware of the scheme, including before the need to relocate arose, at the first point of treatment and as their treatment and relocation experience progressed. Most individuals were informed about the scheme by word of mouth, for example:

- (Pt-HAM-HL) "We did [find out about the scheme] after a short time because someone said you should be able to get reimbursed."

Predominantly people found out about the scheme from the social worker at the hospital who would visit and help fill out the forms. However, as detailed in Table 2, there were a range of individuals, professional and other, who provide direct information on the scheme to patients and their carers who have to relocate. The important point from these findings was that once the patient has to relocate for treatment there were multiple contacts within the hospital system who were likely to ensure that the patient and their carer was aware of the scheme.

Table 2: Person to person information on the New Zealand National Travel Assistance scheme (NTA scheme).

Informant	Participant description of receiving information
Hospital social worker	(Pt-DUN-NHL) Ah it was a social worker at the hospital, that's how I found out about it, yeah she put me onto it.
Transplant Co-ordinator	(Pt-CH- MM) Yes when I was in the hospital the coordinator for the bone marrow unit told me I should fill one out [NTAAS form].
Doctor	(Pt-CH-AML) The specialist was very proactive in helping us with the practical details as well. Yeah she was more than just you know, taking care of my physical health. She actually sent a letter of recommendation for us to relocate. Yeah, she had it sent with the application to, my family to move and receive funding. Yeah she's really tremendous.
Nursing staff	(Cr-HAM- MM) the nursing staff (provided information).
Friends	(Pt-HAM-HD) ... until someone, a friend said you should be able to claim some back, so no one told us straight away. And then I inquired about it and they said: 'you could be doing this'.
Leukaemia & Blood Foundation	(Cr-AUK-NHL) The Leukaemia Foundation ... came and saw her in the hospital while she was having chemotherapy and organised funding for our transport and everything for [participant's wife].
Cancer Society	(Pt-DUN-MM) It was someone from the Cancer Society come round and visited me when I was in hospital and said you can apply for this, and this and that, and that you know.

A central theme associated with the description of being told about the scheme is the expression of appreciation for the information. The participants indicated that without such person-to-person exchange of information it was unlikely they would know about the scheme. It was noted that individuals were so overwhelmed by the diagnosis and treatment situation that that they were not able to access the information themselves, as one participant summed up:

- (Pt-CHC-MM) "No it was wonderful because I had trouble knowing who I was at the time."

#### The positives: A user-friendly scheme

As detailed in Table 3, there were extensive comments describing how user-friendly the scheme was with easy to fill out forms and administrative assistance from health

professionals at the hospital.

The emphasis in the participants' description was on the active supportive process of being given information, of assistance with 'sorting it out', of the required forms being 'filled in' and 'sent away' by those assisting with the scheme. Such active assistance is of particular importance for haematology patients who may be in a state of shock from the diagnosis, weak from the disease and suffering side effects from the treatment, as one participant explained:

- (Pt-CHC-MM) "No it was easy, it was easy. Yes when I was in the hospital the coordinator for the bone marrow unit told me I should fill one out and I thought 'can't be bothered with that' and so she did it all for me."

Table 3: Evidence of user-friendliness of the New Zealand National Travel Assistance scheme (NTA scheme).

User-friendly aspect of scheme	Participants comment
Easy to fill in forms	(Cr-AUK-NHL) I think the forms for that [are] fairly easy to fill out.
Easy process to submit forms	(Pt-CH-MM) All I had to do was fill in the dates that I'd been up there and I just had to get a print out from the computer and I attached it to it and that was fine, it was really easy.
Accessible staff to process forms	(Pt-HAM-MM) Ah yeah the staff at the haematology clinic, we just filled out the forms and had them stamp those.
Easy administrative process	(Pt-CH-MM) Yes no trouble at all, they just send us a form and we get it signed at the hospital every time we drive through there for the treatment I go, so I go to there once a month and they sign it and then we send it off after every five trips and they pay the money out and then give us another form for the next four weeks. Yeah, works quite well, yes.
Easy approvals	(Cr-AUK-WH-NHL) Oh no trouble at all, [participant's son] was just given a form to fill in and he got it stamped each time and then when it was finally processed there was never any question about anything that he put in for.

#### The positives: Appreciation for level of financial assistance

Many participants successfully accessed both the travel and accommodation assistance provided by the scheme. There was extensive comment, both specific on direct costs and generic on the overall scheme, from participants expressing appreciation for the financial help provided by the scheme. The statements about specific help covered costs such as petrol, for example:

- (Cr-WLG-MF) "Reimbursed me for petrol and that. Yes, it was plenty."

And accommodation assistance, for example:

- (Pt-WLG-TPLL) "Government subsidises the travel and also pays now, used to be 70, now it's a hundred dollars towards motel per day which is great."

Those satisfied understood that the travel assistance was a subsidy not a full payment. In addition, many participants made a range of generic statements about the financial assistance provided by the scheme indicating satisfaction with the level of re-imbursments such as "refunded a good amount" or "I would say we do very well out of it" or "it does help a long way I must admit". A benefit noted is that the NTA scheme covers travel for check-ups not just for treatment.

It is important to note that for some of the participants the financial assistance from the scheme was considered essential, for example:

- (Pt-PN-HL) "... we had to. I mean we just couldn't have afforded the fuel otherwise."

At the other end of the financial continuum, some participants indicated they did not apply as they did not need the assistance from the scheme and believed the funds from the scheme should be used for those in need. There were also examples of individuals making the decision not to claim for travel when they were only away for a few nights so the accommodation centre they were staying at would not miss out on funds.

So far the discussion of findings has focussed on the positive aspects of the scheme, now the discussion will explore participants' concerns about the negative aspects.

#### The negatives: Unmet need

Some of the participants indicated that though they tried to access travel and accommodation funding from the scheme they were not eligible. There were varied reasons noted for ineligibility including not meeting the requirement for distance from the treating centre, not living in the district for the hospital, not reaching the expenditure to claim, and the travel not fitting into the treatment protocol.

#### The negatives: Lack of awareness

There was a minority of participants (n=6) who indicated that they were not aware of the scheme during treatment and a couple of whom only heard about it through the interview. As can be seen by the following example, such individuals slipped through the net of person-to-person information:

- (Pt-PN-CLL) "No, none at all. [Interviewer: No so you've worn all those costs yourself?] Ah yes, yes. No I've never had assistance with that at all."

#### The negatives: Problems interfacing with the scheme

There were some comments that indicated problems with interfacing with the scheme, especially for people who were ill and energy depleted. A major issue, which was only reported with respect to some locations, was of the need to have the NTA scheme form signed off, for example:

- (Pt-HAM-ALL) "You had to fill out forms and then they'd pay you and you'd had to get it stamped by the hospital and I found that quite, just an actual pain actually 'cause you were quite ill and you just did not have the head space to muck around with it."

For some, the difficulty accessing the scheme was exacerbated by the fact of having to do the paperwork without assistance. A few participants mentioned problems with the lengthy time it takes for reimbursement. For those with cash flow problems, having to repay over-payments or finding the travel expense funds up front can be challenging, for example:

- (Pt-DUN-ALL) "But the only problem with that was you've got to have the money to put it in your car in the first place in order to be reimbursed. Well I didn't at the time, no."

There was some concern about carers' travel, especially when there were multiple people providing the caring, as only one nominated person was covered by the scheme.

A major concern was that the financial assistance for travel only partially covered cost. This created hardship for families that had no choice but to travel and who were struggling with the costs, for example:

- (Cr-CHC-MF) "Well they only pay something like fifteen a K [kilometre]. Oh, no wasn't enough."
- (Pt-HAM-HL) "...but we had huge fuel bills ...it was helpful but it was only a tiny bit of ..."

#### Recommendations

Participants made recommendations to increase the public awareness of the scheme and to streamline the administration so that any patient under a specialist could automatically receive travel assistance, for example:

- (Cr-HAM-MM) "... because you'd think that if they put it under the specialist's name then it would automatically be approved."

It was noted that all social workers need to be informed about the scheme.

#### DISCUSSION

The majority of participants interviewed for the study spoke positively and with enthusiasm about the NTA scheme. Most were aware of the existence of the scheme and the process of administration. Individuals found out about the scheme at several points in time including pre-treatment, beginning treatment and during relocation. In comparison, Queensland research indicated a lack of awareness about the respective scheme with over a quarter of individuals surveyed who had actually travelled for specialist treatment unaware of the travel and accommodation benefits (McGrath and Segueria, 2000). As detailed in the following discussion, insights from the New Zealand experience provide ways to help to improve awareness about travel and accommodation schemes.

The important finding in relation to the high level of satisfaction in New Zealand was that most people found out about the scheme through person-to-person information-giving. There were professionals throughout the health system who actively promoted the NTA scheme and provided patients and their families with information on accessing benefits. The major informant was the hospital social worker, but other key information-givers were the transplant co-ordinator, specialists, nursing staff, friends, support workers from the LBF and Cancer Society. The process of information-giving was active with professionals providing the initiative to make sure relevant individuals were informed. Patients and their carers were highly appreciative of the information and support. The importance of person-to-person information-giving was demonstrated by the fact that the key factor in common of individuals who were not aware of the scheme was that they were not told about it by someone in the health or hospital system.

The person-to-person contact was noted as especially important in consideration of the fact that an individual diagnosed with a haematological malignancy is usually in an overwhelmed state of shock and distress, thus less receptive to independently finding out the required

information. Importantly, social workers and other health and hospital staff provided active person-to-person assistance to patients and carers not just in information-giving but in actually facilitating the processing of the NTA scheme application.

By way of contrast, the emphasis in Australia for the PTSS scheme is on the patient doing the work of application. For example, the booklet on the scheme by Queensland Health (2010, 5) clearly states, "you will take the form to the travel clerk (or other nominated person) at the hospital" and "presenting the form in person will avoid delays that might result from the form being filled out incorrectly". The responsibility for processing is predominantly placed on the individual who may be in shock and overwhelmed from the diagnosis, the treatment and the need to relocate. This is inappropriate, administratively problematic and does not take heed of the major stress that haematology patients and their family are under when needing to access the scheme.

Prior Queensland research emphasised the need for social work responsibility in fostering the administrative process (McGrath, 2000a). The Australian Association of Social Work Code of Ethics clearly states that social justice, including fair access to public services and benefits, is a key value informing the work of the profession (AASW, 2002). However, in contrast to the New Zealand findings, Australian research indicated that the majority of social workers involved with haematology patients did not see they had a role in processing the transport and accommodation scheme (McGrath, 2000a). Nonetheless, social workers were aware of the many problems associated with the scheme including administrative confusion, inconsistent application of criteria, difficult to complete forms, problems with escort approvals, budgetary constraints and poor community awareness of the scheme (McGrath, 2000a). The New Zealand experience would indicate that strong social work involvement in the administration of the scheme is required for improved consumer satisfaction in Queensland.

The majority of New Zealanders interviewed indicated that they found the NTA scheme to be user-friendly. Key factors contributing to the user-friendliness of the administration included the fact that the forms were found easy to fill in and to submit, staff were available to assist with the process and a clear line of administration existed with easy approvals. These findings were in direct contrast to the situation in Australia where both research and presentations to the Senate Inquiry indicated profound consumer and NGO dissatisfaction with the administration. Problems with administration, apart from the sheer complexity of the system, include lack of clarity about administrative processes, poorly defined guidelines and criteria, regional and hospital differences in interpretation of the guidelines that do exist, decision-making based on economic rationalism rather than patient need, problems with retrospective payments, difficult forms to complete and problems with multidisciplinary cooperation (McGrath, 1999b; 2000b). The New Zealand findings highlight the importance and possibility of user-friendly administration.

The findings indicate that most patients were aware that the NTA scheme is about subsidy, not full payment, but were still very appreciative of the financial assistance. For some, the financial impact was profound and the NTA scheme assistance was seen as essential. Similarly, the emphasis for PTSS is on subsidy only, making a contribution that does not cover all costs associated with travel (Queensland Government, 2010). Both schemes are similar in that for private car travel the subsidy is 15 cents per kilometre from the post office nearest the referring hospital to the post office nearest the treating hospital (Queensland Government, 2010; Ministry of Health, 2011b). For accommodation, PTSS provides concession card holders \$30 per person per night and non-card holders the same but with the added requirement that the first four nights accommodation in a financial year must be privately met (Queensland Government, 2010), whilst the NTA scheme provides a daily reimbursement of \$100 in location such as Auckland (Ministry of Health, 2011b).

Queensland research indicated financial hardship associated with relocation expenses for people with haematological malignancies that had to relocate (McGrath, 2001; McGrath and Seguerria, 2000). Most at risk of financial distress were low income earners, the unemployed and pensioners. Like patients in New Zealand, Queensland consumers valued and appreciated the financial support from the travel and accommodation subsidy scheme (McGrath and Seguerria, 2000).

A small group from the New Zealand study had negative experiences with the NTA scheme indicating problems with ineligibility, lack of awareness of the scheme and problems interfacing with the scheme. The problems with process were especially acute for individuals who were ill and energy depleted. The major problem with the NTA scheme was with the process of signing off the application form by relevant hospital specialists. Similarly, this was regarded as a problem with PTSS where the specialist is required to sign off on the application form (Queensland Government, 2010).

The findings indicate that in comparison to those satisfied with the scheme, dissatisfied individuals did not receive person-to-person assistance from staff. For those who were financially stressed by the treatment the rate of reimbursement, upfront payments and delay in reimbursement were factors contributing to lack of satisfaction with the scheme. PTSS has a similar upfront payment before reimbursement and the stated time frame for settlement of accounts and payments made is 30 days (Queensland Government, 2010). The PTSS administration system requires approval before travel. The PTSS form is checked by the travel clerk and reviewed by a medical officer, a process which can take up to two days for clearance before the patient is able to travel (Queensland Government, 2010). The PTSS subsidises transport and accommodation by either booking and paying directly or reimbursing the relevant amount of costs on presentation of receipts (Queensland Government, 2010). Such a process is challenging for those diagnosed with a haematological malignancy where it is well documented that they are usually

required to leave immediately and often in an emergency situation (McGrath, 1988).

There was some concern about the poor rate or lack of reimbursement from the NTA scheme for the travel of carers. PTSS is similarly restrictive with reimbursement for carer travel conditional on the presence of the carer being essential for the physical care of the patient and the need for the carer deemed necessary by the treating specialist (Queensland Government, 2010).

#### Learning from inter-country comparison

The major insight from the New Zealand findings is the significant role that person-to-person information and support plays in ensuring consumer satisfaction with the travel and accommodation subsidy system. The recommendation for the Australian system is for the reversal of the present emphasis on patient-responsibility for initiating and processing the documentation for the scheme and the transfer of that responsibility back to the health care system. The New Zealand experience indicates that social workers within the hospital system, backed up by other treating health professionals, are the ideal contact people in the system to reach out and ensure support for the routine assistance application.

In consideration of the financial hardship associated with relocation, it is informative that the New Zealand daily rate for accommodation is \$100 (Ministry of Health, 2011b), which is over three times that of Queensland's daily allowance of \$30. The inadequacy of the accommodation allowance was a major issue voiced in the Australian Senate Inquiry and continues to be an ongoing concern (SCR, 2007). The recommendation is for an increase in the accommodation allowance not only to bring it in line with standard practice elsewhere but to reflect the high cost of accommodation for those who have to relocate. This resonates with and affirms Recommendation 7 of the Senate Inquiry (SCR, 2007) that the Australian Health Ministers' Advisory Council determine transport and accommodation subsidy rates that better reflect a reasonable proportion of travel costs.

The New Zealand experience also provides insights for addressing the major administration problems encountered in the Australian system. Consumer satisfaction is related to easy to complete forms, staff available to assist with the process, a clear line of administration with easy approvals. This resonates with and affirms Recommendation 6 of the Senate Inquiry (SCR, 2007) to review existing administrative arrangements to make them less complex, including development of a simplified generic application form and revision of authorisation process.

Recommendations in regard to the NTA scheme from participants in the New Zealand study included increasing public awareness, streamlining the administration so that any patient under a specialist automatically receive benefits and making sure all social workers are informed of the scheme. These recommendations resonate with similar issue with regards PTSS voiced by NGOs in the Australian Senate Inquiry.

The hope and expectation is that the findings have provided insights that affirm the way forward and set the Australian concerns in an international context. The Senate Inquiry (SCR, 2007) of 2007 was an important first step in addressing the problems associated with this very important health policy. However, it is essential to maintain the momentum of reform. Hopefully, the information in this article will continue to keep the discussion about this vital government initiative on the Australian policy agenda.

### Conclusion

A valuable outcome of the New Zealand-based study is that it provided the opportunity for shared, inter-country learning on the important topic of governmental provision of travel and accommodation assistance for patients diagnosed with a haematological malignancy who have to relocate for specialist treatment and their carers. The findings provide insights that can be used to inform health policy and service delivery in both Australia and New Zealand.

### ACKNOWLEDGEMENT

The authors would like to thank Nicole Rawson-Huff, Michael Bouwman, Bo McGrath, Anne Wilson, Dr Alison Harrow, the Institute of Health and Social Science, CQU, Pru Etchevery and the staff of Leukaemia and Blood Foundation for their contribution to the study.

### REFERENCES

Australian Association of Social Work (AASW) (2002) AASW Code of Ethics. Cited April 2011:  
<http://www.aasw.asn.au/publications/ethics-and-standards>.

Brown S. (1987) Proposal for a new single transport assistance scheme. *Health Issues* 9: 9-10.

Gaskill, D, Henderson A, Fraser M. (1997) Exploring the everyday world of the patient in isolation. *Oncology Nursing Forum* 24(4):695-700.

Holloway I. (2008) A-Z of qualitative research in healthcare, 2<sup>nd</sup> edn. Blackwell Publishing, Oxford.

Krathwohl D. (1993) *Methods of educational & social science research: An integrated approach*. Longman, New York.

McGrath P, Holewa H, Etchevery P. (2011) *Surviving the crisis of relocation for specialist treatment in haematology: Insights from New Zealand. Illness Crisis and Loss*, In Press.

McGrath P and Holewa H. (2011) *Reconceptualising relocation for specialist treatment: Insights from New Zealand. Supportive Care in Cancer*, in press.

McGrath P, Seguerra J. (2000) The patient transit assistance scheme: A consumer's perspective. *Australian Journal of Rural Health* 8:232-238.

McGrath P. (1988) Relocation for treatment for leukaemia: A description of need. *Australian Health Review* 21(4):143-154.

McGrath P. (1999a) Accommodation for patients and carers during relocation for treatment for leukaemia: A descriptive profile. *Supportive Care in Cancer* 7(1):6-10.

McGrath P. (1999b) The Patient Transit Assistance Scheme: The clerk's perspective. *Australian Journal of Rural Health* 7:140-147.

McGrath P. (2000a) The administration of the Patient Transit Assistance Scheme: Equity and access from the medical superintendents' perspective. *Just Policy* 22:48-55.

McGrath P. (2000b) The Patient Transit Assistance Scheme: A case for social work advocacy! *Australian Social Work* 53(2):13-19.

McGrath P. (2001) 'It's horrendous – but really, what can you do?' Preliminary findings on the financial impact of relocation for specialist treatment. *Australian Health Review* 23(3):94-103.

Ministry of Health, New Zealand. (2011a) *The National Travel Assistance Scheme: Your guide for claiming travel assistance*. Wellington, New Zealand.

Ministry of Health, New Zealand. (2011b) *National Travel Assistance Policy*. Cited June 2011:  
<http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/01665f03b5a4ede2cc257059000b41c8?OpenDocument#1>.

Patton M. (2002) *Qualitative research and evaluation Methods*, 3<sup>rd</sup> rev edn. Sage, Thousand Oaks.

Polit D and Hungler B. (1995) *Nursing research: Principles and methods*, 5<sup>th</sup> edn. Lippincott, Philadelphia.

Queensland Government. (2010) *PTSS: Patient Travel Subsidy Scheme: Information for patients and their carers. Integrated Patient Transport Unit Booklet*, Queensland Health Department, Brisbane.

Queensland Health. (2010) *PTSS: Patient Travel Subsidy Scheme, Pamphlet. Integrated Patient Transport Unit, Brisbane*.

Senate Committee Hansard. (2007) *Senate Standing Committee on Community Affairs: Patient assisted travel schemes*. Commonwealth of Australia, Canberra, ACT.

Senate Committee Report (SCR). (2007) *Highway to health: Better access for rural, regional and remote patients*. AGPS, Legislative and General Purpose Standing Committee, Canberra, ACT.

Theophanous A. (1994) *Understanding social justice: An Australian perspective*, 2<sup>nd</sup> edn. Eilikia Books, Carlton South, Victoria.