Inquiry into Telehealth Services in Queensland

Health and Community Services Committee

Submission by:

Associate Professor Pam McGrath, Griffith Health Institute, Griffith University

Background to the submission:

The evidence contained in this submission is based on recent (2014) research that examined issues associated with relocation for specialist care for haematology patients in Queensland. The project was funded by the Leukaemia Foundation of Queensland (LFQ) and conducted by Associate Professor Pam McGrath, Senior Research Fellow, Griffith University. The research was based on a descriptive qualitative approach involving open-ended interviews with a purposive sample of forty-five (n=45) haematology patients living in Queensland, Australia. The purposive sample was based on gender, diagnosis, age and geographic location. The sample represented both genders (n=25 females; n=20 males), and adult patients of all ages (18-29 yrs, n=4; 30-39 yrs, n=5; 40-49 yrs, n=12; 50 -59 yrs, n=17; 60-69 yrs, n=5; 70+ yrs, n=2). The purposive sample included a range of haematological diagnostic groups (Hodgkin's Disease, n=3; non-Hodgkins Lymphoma, n=19; Acute Myeloid Leukaemia, n=7; Acute Lymphoblastic Leukaemia, n=1; Acute Promyelocytic Leukaemia, n=4; Chronic Myeloid Leukaemia, n=1;Chronic Lymphocytic Leukaemia, n=1; Myeloma, n=6; Myelodysplastic Syndrome, n=1; Myloproliferative Neoplasm-Essential Thrombocythemia, n=1; Haemolytic anaemia, n=1). The geographic selection of participants included those living within 50km from the primary specialist centres in the metropolitan centres where transplantation is conducted (Metropolitan Treating, n=5), those living within 50 km from regional treatment centres (Secondary Treating, n=16), those living 50km to 300km from treating centres (Regional and Rural, n=14), and those living in remote locations of over 300km from treatment centres (Remote, n= 9) and those living interstate (n=1). All participants in the study were patients cared for by the LFQ during the year 2012.

A caveat to the findings is that the sample is representative of patients supported by LFQ and, to date, research is not available on patients diagnosed with a haematological malignancy who do not access LFQ services.

The research findings have direct relevance for the following topics under consideration by the Health and Community Services Committee inquiry including:

- Models of service delivery
- Patients perceptions and experiences of telehealth
- Quality of patient care
- Access to health services, particularly in rural and remote locations
- The factors that support successful implementation of telehealth services and identify any barriers to successful implementation

Overview of the evidence

> *Telemedicine as a way forward: 'That would be brilliant, marvellous... Oh yeah. I think for our country people that would be a huge help'.*

Travel for specialist care is a major problem, especially for rural and remote patients and their families:

- The treatments can extend over months and require monitoring and further treatment over years
- The major stress is the separation from family and friends
- This stress is exacerbated for many by the fact that the distance home is too lengthy to make any return trips
- This is at a time when the patient usually is dependent on family and friends for practical and emotional support
- The patient can experience loneliness and homesickness
- The separation is stressful for family members, especially if there are children involved
- Considerable stress is placed on family members to cope by themselves, and to maintain the practical concerns of running the home as well as trying to be there for the patient

A major relocation issue is in relation to routine follow-up visits which involve long distances that have to be travelled for short appointments:

- There were extensive examples of patients travelling long distances for check-ups that lasted only minutes (e.g. 6 hour flight each way; 17 hour car trip each way; 8 hour car trip each way; 18 hour bus trip each way; 4 day return trip by car)
- Many were doing the travel under hazardous conditions (e.g. elderly driving at night; driving when unwell after testing; driving in pain; driving causing bleeding from bone marrow aspiration)
- The continuous driving long distances for routine check-up was costly in terms of wear and repair on car, sometimes requiring replacement of car
- Some took their car to avoid cost and confusion of using unfamiliar public transport in metropolitan area
- For some the distances are so great that had to go by flights which has a set of problems (flight schedules do not correspond with appointment times requiring patient to spend days in the metropolitan area for a short appointment; an expensive option; prohibitive for some because of physical conditions such as clotting)
- All the travel was just too physically stressing for some patients to continue
- Often hospitals were not aware that patients were travelling such long distances
- However, there were examples of hospital staff who were aware of the long travel making flexible arrangements for the patient
- Many had to engage in self-advocacy strategies to deal with the situation (such as organising for testing to be done by Royal Flying Doctor Service; engaging the local general practitioner as a go between; sending blood tests down and only agreeing to go to the Brisbane hospital if required for active treatment)

- There was an example of a patient engaging in an active campaign to retain the local haematologist service to ensure local patients did not have to travel

Distance to the metropolitan treating centres presents special problems for farmers and rural property owners (e.g. owner of cattle stations). The difficulties experienced, set in the present context of drought and hardship in the rural section, include:

- The high workload and need for constant care of animals and land, means limited ability to leave the farm or property so relocation is not an option for the carer
- Outsourcing work is either impossible or just too expensive
- Long distances and hours of travel to the metropolitan centre limits or prohibits even short visits by carer
- Most likely scenario is patient has to relocate alone
- The patient will have physical problems maintaining work on the farm because of the illness and treatment which can have financial implications
- The financial strain of diagnosis and treatment and the *irresolvable conflict* between maintaining the farm and attending the metropolitan treatment centre can potentially lead to a *choice* between the property and treatment.
- There were indications that some would stop treatment rather than make the decision to sell the property

A major factor impacting on the experience of relocation was the strong desire to be at home. Described as a 'powerful pull' the longing to be at home has serious ramifications,

- There is a longing for the rural setting when in the metropolitan area
- Relocated individuals can experience a sense of loneliness and home-sickness
- This can be acute for individuals who are sick and coping with treatment and require the comfort of home
- Described as assisting with recovery, being home is both physically and emotionally important for patients
- The practical and emotional consequences of being away from home can be significant for the family left behind especially for children and the elderly
- There are practical considerations in terms of being away from home such as schooling issues, home and lawn maintenance, and keeping up with the mail
- There were examples of individuals travelling long distances and for many hours in order to return home
- Being away from home can be an obstacle for continuing work for both the patient and the carer

There can be relocation problems for those living within the 50km radius of Brisbane including:

- Travelling long distances and taking hours in return trips to hospital
- Living on islands in the Brisbane area where the trip includes water as well as land travel
- Travelling whilst tired and suffering side effects of treatment

- The problems associated with having to pay considerable costs for regular travel on public transport when on the low income provided by a pension without reimbursement from PTSS

In summary, the findings outline the major problems for patients having to relocate to the metropolitan hospitals for specialist treatment and routine follow-up. The long distances to be negotiated, the regularity of travel, the emotional and practical stress of separation from family and the strong desire to stay in the comfort of the home and community, create hardship and stress for those seeking treatment and follow-up from regional, rural and remote areas. Participants described present strategies that were going some way to reducing that stress. Also, the research explored potential directions for the future. *Key strategies* that were seen as assisting to reduce the stress of relocation included haematologist visiting regional centres and the *initial steps in telehealth driven by leading haematologists*. [Note: Research by Wade and Eliott (J Telemed Telecare, 2012,18,8:490-2) refer to such leaders who initiate and promote the uptake of telehealth services as '*champions*' in telehealth service development. 'Champions' are key to initiating and maintaining continued operations of telehealth].

The use of telemedicine documented by the research was limited in number and from a technological perspective would fit into the Inquiry's definition of telehealth as: 'Delivery of health-related services and information via telecommunication technologies, including live audio and/or video interactive links for clinical consultations'. The Australian Medical Association (Australian Medical Association (2013) Technology-based patient consultations. Position Statement, www.ama.com.au/position-statement/technology-based-patient-consultations-2013 Accessed 26th February 2014) refer to such telehealth as 'technology assisted patient consultations' defined as: 'Patient consultations that use any form of technology, including, but not restricted to videoconferencing, internet and telephone, as an alternative to face-to-face consultations'.

The experiences and thoughts about telehealth 'technology assisted consultations' by the patients interviewed included:

- The use of telemedicine for haematology patients in the study is minimal, restricted to teleconferencing, mobile telephone use, texting and Skying
- Few haematologist use these technologies, most technology assisted consultations for participants in the study are provided by one haematologist
- The telehealth is primarily used for follow-up consultations and reviews
- A major benefit is the lengthening of the time between visits to metropolitan centre
- There were examples of self-advocacy where the hardship of lengthy travel motivated a patient to advocate for use of technology assisted consultations
- There is evidence of patients who do not have the availability of technology assisted consultations
- Reasons for not using technology assisted consultations given by participants include the need for face to face contact, desire by patient to go to metropolitan centre for

expertise, and the fact that the slowness of internet interferes with Skype use in some rural areas

- Telemedicine and/or technology assisted consultations are seen as the '**preferred option**' by many with a desire by those who do not have it for this to be a **future option**
- The perceived benefits included reduced travel, increased opportunity to stay in own home, increased mental health, physical relief from the stress of travel for those who were finding this difficult, and reduced interference of routine follow-up in employment

Examples of participant statements that affirmed the importance of telehealth as a solution to the stresses of relocation include:

- That would be brilliant, marvellous... Oh yeah. I think for our country people that would be a huge help. Myeloma_Remote_48yrs_M
- In: But what I'm hearing from your story is that ... it would help you to keep back on the farm? P: Oh, it (telehealth) would help in lots of ways. But mentally you would do it for your mental health which is a big factor. NHL_RegRural_45yrs_F
- Yeah absolutely and just that ability to cut out that travel for that meeting... Oh yeah. HA_Remote_35yrs_F
- (Telehealth) kept me from having to go down for like every two weeks or whatever. NHL_RegRural_54yrs_M
- Oh, yes, that is a great help every two weeks. Otherwise we would have to go down every 2 weeks. Because we physically couldn't keep up with it. APML_Secondary_54yrs_F
- Int: Was that a help in that it meant you did not have to go down? P: Immensely. Yes, it is such a comfort to be in your own bed, in your own environment. Not 400km away from your support network. It was just great to be at home during treatment. HD_RegRural_32yrs_F

It is important to note that the use of telehealth for haematology patients does not need to involve expensive technology. Because of the advances in medicine and the excellence of clinical care, many haematological malignancies are now chronic, rather than acute, conditions requiring lengthy follow-up over many years. The findings indicate that routine follow-up is practical and cost-effective to handle with telemedicine. At present, the 'champions' in telehealth in haematology engage in a system that involves the patient having blood test completed locally, results forwarded to the specialist haematologist, and the review/follow up conducted via Skype or telephone/teleconference. The use of telehealth this way does not eliminate doctor/patient face to face contact but rather lengthens the time (and reduces the travel) between contacts. The findings resonate with the UK research by Mair and associates (Mair, Whitten, May, Doolittle, J Telemed Telecare 2000; 6,1:36-40) that demonstrates that although all participants in their study all expressed satisfaction with tele-consultations, 50% of respondents had this satisfaction qualified by two factors: seeing the specialist in person on occasions and perceiving the tele-consultation as 'monitoring' or review function. Skype is free and so the savings to the health system are substantial in terms of Patient Travel Subsidy Scheme (PTSS) which has to cover both the travel and the

accommodation (when the patient cannot return the same day). The travel is to the metropolitan centres and, also, to the regional centres that are now increasingly providing haematology clinical services. Table 1 demonstrates a conservative estimation of costs to PTSS for participants in the study travelling to the treatment centres for routine follow-up. The choice of participant is based on PTSS criteria as the person must live over 50km from treating hospital to be listed. Also, the participants had to meet the criteria of travelling for routine follow-up at the time of the interview, not in active treatment or no longer being followed up. Accommodation is factored in if the distance to the specialist centre is further than 200kms as this requires a 5 hour round trip which is the limit of travel that can be accomplished in one day. The costs are based on PTSS payments for 2012 (*PTSS: Patient Travel Subsidy Scheme Information for patients and their carers.* Queensland Government Publication, December 2012) which is the year of the research focus. The estimates are conservative because they do not factor in carer accommodation and are based on the travel at the time of the interview (many participants had travelled more frequently earlier in the year). The costs have been rounded to the nearest dollar.

ID	Appointments • Regularity • No. trips per year	Per Trip: Regional Destination • Kms single (return) • Cost return • Accommodation	Per Trip: Metropolitan Destination • Kms single (return) • Cost return • Accommodation	Total per year
1	Every 8 weeks/n=6		• 290 kms/580 kms • $174 • $60 • Sub- total $234	$1,404
2	Every 2nd month/n=6		• 1,585 kms/3170 kms • (no commercial flights) $951 • $60 • Sub-total $1011	$6,066
3	Every month/n=12		• 1,046 kms/2092kms • $627 • $60 • Sub-total $687	$8,251
4	Every 3 months/n=4		• 137 kms/274 kms • $82 • Sub-total $82	$328
5	Every month/n=12		• 152 kms/304 kms • $91 • Sub-total $91	$1,094
6	Every month/n=12		• 75 kms/150 kms • $45 • Sub-total $45	$540
7	Every three months/n=4		• 80 kms/160 kms • $48 • Sub-total $45	$192
8	Every 6 weeks/n=8	• 277 kms/554 kms • $166 • $60 • Sub-total $226		$1,808
9	Every month/n=12	• 204 kms/408 kms • $122 • $60 • Sub-total $182		$2,184
10	Every 6 months/n=2		• 966kms/1932 kms • $579 • $60 • Sub-total $639	$1,279
11	Every 3 months/n=4		• 521 kms/1042 kms • $312 • $60 • Sub-total $372	$1,490
12	Every 3 months/n=4		• 364 kms/728 kms	$1,113

			• $218 • $60 • Sub-total $278	
13	Every 3 weeks/n=17		• 534 kms/1068 kms • $320 • $60 • Sub-total $380	$6,460
14	Every 2 weeks/n=26		• 218 kms/436 kms • $130 • $60 • Sub-total $190	$4,940
15	Every month/n=12		• 89 kms/178 kms • $53	$640
16	Every 3 months/n=4		• 1,100 kms/2,200 kms • $660 • $60 • Sub-total $720	$2,880
17	Every month/n=12		• 877 kms/1754 kms • $526 • $60 • Sub-total $5862	$7,034
18	Every month/n=12		• 222 kms/444kms • $1332 • $60 • Sub-total $1392	$16,704
19	Every fortnight/n=26		• 636 kms/1272 kms • $381 • $60 • Sub-total $441	$11,481
20	Every 2 months/n=6		• 636 kms/1272 kms • $381 • $60 • Sub-total $441	$2,646
21	Every 3 months/n=4		• 904 kms/1804 kms • $542 • $60 • Sub-total $602	$2,409
22	Every 3 months/n=4		• 225 kms/450 kms • $135 • $60 • Sub-total $195	$780
TOTAL				$81,723

Table 1: Estimate of costs of travel for routine follow-up of participants in the study.

To extrapolate the calculation to all patients cared for by LFQ in 2012, this would be $2,187,546. This is achieved by taking the number of patients followed-up by LFQ in 2012 (n=1203) and divide by the percentage of patients (49%) likely to be on active routine follow-up (n=589) multiplied by an average of the cost of travel and accommodation established in Table 1 (average n=$3714). This a conservative estimate which does not take into account carer travel, the likelihood that a greater percentage would actually be travelling for routine check-ups, and the vast distances many in the rural area would be travelling. However, it does provide a projection of possible cost savings by moving to 'technology assisted patient consultations' as presently used by leading haematologists documented in the research.

Estimates of 2012 cancer incidence for haematological malignancies by the Oncology Analysis System, Queensland Cancer Control Analysis Team (QG, 2012:4) indicate that these diagnostic groups represent the fifth highest incidence with more males (n=1535) than females (n=995) diagnosed. Thus, projecting the above calculations, the saving for all (not just those cared for by LFQ), haematology patients in Queensland in the year of 2012 using

'technology assisted patient consultations' rather than travelling to the specialist centre for follow-up, would be estimated at $4,604,245.

There is the potential to extend the 'technology assisted patient consultations' as an in-part replacement of the requirement to travel for routine follow-up by building on the model developed by the 'champions' of telehealth detailed by the findings from the study. This would not only be of benefit to the patients and their families but would also contribute to cost savings for the Health Department.

The comment in this submission was informed by and restricted to the findings from the study (McGrath P. *The Financial Impact of Relocation for Specialist Treatment: A Pilot Study Focusing on Patients Supported by Leukaemia Foundation of Queensland*. Brisbane, 2014), which indicated the beginnings of telehealth in haematology and the potential to expand the initial efforts of leaders in this field for routine follow-up for the benefit of patients, their families and the health system. The expectation is that telemedicine in haematology also has great potential for treatment, however, as this is outside of the parameter of the study it is not possible to comment on this potentiality. This is an area where there is scant research completed and more work is required on facilitators and barriers, and the haematologists perspectives. From the consumers' perspective the indications are that the increased use of telehealth for haematology patients would be applauded.

Signed:..... Dated 30th April 2014.

Contact details:

Assoc. Professor Pam McGrath, B.Soc.Wk., MA., Ph D

Senior Research Fellow

Population & Social Health Program, Griffith Health Institute

[redacted] Logan Campus, Griffith University

Meadowbrook Qld 4131

Postal Address:

[redacted] Kenmore Qld 4069, Australia

Tel: (07)[redacted] Fax: (07)[redacted]

E-mail:[redacted] or [redacted]