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Economic and social impact of patient versus clinician travel

An overview of the literature

Paper prepared for a SISSAL project

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Summary

- Specialist services have become increasingly centralised over recent decades in response to evidence of better outcomes for patients treated in hospitals that have high volumes of complex procedures. Although this may be positive overall, there is evidence that centralisation may reduce access to care for people who live far from main centres, and that social and ethnic disparities may be exacerbated.
- An overview of the international literature on patient and clinician travel has been undertaken for information relevant to the fields of specialist oncology, haematology, otolaryngology (ENT), cardiology/cardiac surgery, paediatric surgery, nephrology, and rheumatology services. The volume of literature is small, and much of it is descriptive in nature.
- Studies in England and Scotland have found an association with lower uptake of treatment and late diagnosis for people with breast, colorectal, lung, and prostate cancers that lived furthest from their treatment centre compared to those who lived closer. In New Zealand, poor survival has been associated with longer travel time to a cancer centre for people with breast, colorectal, and prostate cancers, but there was no evidence that people living furthest from a cancer centre were diagnosed at a later stage than those living closer.
- Studies from Canada and the United States suggest that increasing distance of residence from a major centre was associated with factors that could compromise quality of care, such as patients not attending preoperative assessments, and failing to carry out preoperative instructions.
- Patients who live far away from specialised services experience time, financial, and personal barriers to care. They often need an accompanying person, who also experiences the same disadvantages. Impacts include direct costs for transport, accommodation and food, cost of time away from work for patients and accompanying other(s), and child care costs. Other, less measureable barriers include lost productivity, finding substitutes for home or business activities, unfamiliarity with the larger centre, isolation from wider family support, and poor coordination that results in unnecessary travel.
- Maori are already disadvantaged in access to primary health care, so specialist appointments in a more distant location have an even greater impact as they add extra costs for transport, accommodation, and hospital car parking.
- Better coordination of care for patients from outlying areas, and education of staff so that they understand and consider the difficulties for these patients can go some way to minimise inconvenience to patients.
- Outreach clinics where specialists travel from a centralised service to a smaller centre are used both in disadvantaged remote areas as well as in smaller urban centres without specialist tertiary services. Where outreach has been an additional service, it has increased access and patient satisfaction. Patients need fewer trips, or even avoid travel altogether. No studies were found that examined patient outcomes following the replacement of a full service with specialist outreach.

- Little research appears to be available on quality of care which has compared outcomes between patients seen in outreach clinics with patients who have attended fully centralised services.
- The preferences of specialists seem to have also been very little studied.
- The cost of outreach compared to full centralisation depends on what mix of health system and patient costs are taken into account. Centralisation tends to be cheaper for the health service but more expensive for remote patients, while outreach tends to be more expensive for the health service but cheaper for patients. The distances involved and the availability of specialists also affect the feasibility of outreach services.
- Virtual outreach through telemedicine may substitute for some aspects of outreach, particularly initial assessment and follow-up care, if the required expertise is available and the number of consultations warrants the investment in infrastructure.
- Considerations for the SISSAL workshop based on the literature are provided at the end of the report.

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Introduction

Over the past several decades evidence has grown about improved patient outcomes for complex procedures if they are carried out in hospitals with high volumes of such procedures (Stitzenberg et al., 2009). There has been a subsequent trend for specialist services to be centralised in large centres, particularly for advanced surgical and oncology treatments carried out by sub-specialists (Birkmeyer et al., 2003; Patel et al., 2004; Stitzenberg et al., 2009). Other factors that have reinforced the trend to centralisation relate to financial pressures on health systems, mergers within health, and designated providers preferred by medical insurance companies (Stitzenberg et al., 2009). While the impact on patient outcomes may be positive overall, there is concern that increased centralisation creates access problems for people living outside main centres and compounds other social and ethnic disparities. It may also create an overload problem and increased waiting times in the high volume centralised service unless resources are increased (Raval et al., 2010; Stitzenberg et al., 2009).

Literature overview

This overview examines the recent literature that addresses issues of travel for patients and clinicians for specialist services. A search was made of the Medline, Embase, and Web of Science databases for relevant literature in English from the last fifteen years. Systematic reviews and health technology assessments from the Cochrane Library and the Centre for Reviews and Dissemination databases were also examined for any relevant material. References located were manually screened for information relevant to any of the following fields: oncology, haematology, cardiology, cardiac surgery, otolaryngology, nephrology, rheumatology and paediatric surgery. Only articles that were electronically available were obtained in full text; where information was derived from the abstract only, this has been noted. As the search did not produce any information specifically relevant to Maori, subject experts were contacted for their knowledge of research reports and grey literature.

There is not a large literature on issues related to travel by patients or clinicians and the available information is dominated by studies of patients with the most common cancers. This may be because there are more patients receiving treatment for the most common cancers, and because cancer treatment often requires patients and accompanying people to make numerous visits to hospital for surgery, radiotherapy, chemotherapy and follow up. A lesser amount of information was available in all other fields except rheumatology, for which no articles were found.

The following overview is in two sections: the first section examines the negative impact on patients who need to travel long distances to receive assessment and care at large tertiary centres. The second section examines outreach services where clinicians travel to an outlying location, followed by a brief outline of virtual outreach, which may have the potential to offset the negative effects of travel. Finally, some considerations for the SISSAL workshop are made, based on the literature reviewed.

It is important to note that this is a brief overview rather than an in-depth examination of the topic. It is largely limited to journal publications from major databases. Other

than a paper investigating cancer survival and geographical access to health services in New Zealand (Haynes et al 2008) and the section on impact of travel on Maori, there is little New Zealand information, (which may exist, but would need a subject expert to identify). It should also be noted that there are many other issues related to travel or centralisation that are beyond the scope of this short overview, including workforce availability and distribution, referral guidelines and procedures, resourcing of main and satellite centres, and the approach taken to calculating costs to the health system and to patients.

Section One: the disadvantage of distance for patients

Effects of increased distance from services

Studies are presented below, that demonstrate a reduction in access or the potential to compromise quality of care for patients that live far away from specialised treatment centres. The British, Canadian, and New Zealand studies controlled for factors other than distance, which makes the associations that they reported more likely to have been due to distance rather than any other factors.

Postcode mapping of the residential addresses for 117,097 patients registered in the Northern and Yorkshire Cancer Registry in England, who had primary cancers of the breast, colon, rectum, ovary, prostate, and lung, was used to measure the road travel distance to the nearest cancer centre (Jones et al., 2008). The distances were divided into quartiles (nearest to furthest) from the cancer centre, and each record examined for the treatment received. An inverse association was found with receiving cancer treatment (surgery, radiotherapy, or chemotherapy) for patients whose travel time to hospital was in the most distant quartile compared to those who lived in the quartile with the shortest travel time. The associations remained statistically significant after controlling for known socio-economic influences on treatment uptake including age, sex, deprivation status, stage of disease, pathology of tumour, and nature of the treatment. Patients with lung cancer who lived in the most distant quartile were significantly less likely to receive surgery (odds ratio 0.76, 95% CI 0.68-0.85) compared to those in the nearest quartile, and patients with rectum and lung cancer were less likely to receive chemotherapy (odds ratio for rectum 0.82, (95%CI 0.72-0.96); lung 0.70 (95%CI 0.63-0.79)). Patients with breast, rectum, lung, and prostate cancer were all less likely to receive radiotherapy.¹

An earlier study in Scotland (Campbell et al., 2000) found strong evidence that the further people lived from a cancer centre, the less likely they were to be diagnosed before death compared with those who lived less than 5 kilometres away. The inverse association was particularly strong for colorectal, breast, and stomach cancer, with the odds ratios for remaining undiagnosed in people living more than 38 kilometres away from a centre being 1.78 (95% CI 1.19-2.57) for colorectal cancer, 2.87 (95% CI 1.74-4.74) for breast cancer, and 3.92 (95% CI 2.16-7.08) for stomach cancer. These figures were controlled for age, sex, and size of the township of residence (p. 1864).

¹ Odds ratios breast 0.80 (95%CI 0.73-0.87); rectum 0.64, (95% CI0.57-0.73); lung 0.86 (95%CI 0.80-0.91); prostate 0.88(95%CI 0.79-0.99)

A study of 76,406 cancer registrations and 175,071 hospital discharges for cancer patients in mainland Scotland over a three year period from January 2000 to December 2002 aimed to determine whether there were differences in accessibility of care with respect to travel time from a patient's home (Baird et al., 2008). Travel times were assessed in four categories (less than 1 hour, 1-2 hours, 2-3 hours, and more than 3 hours for a one way trip). Patients living within one hour of a designated cancer centre were twice as likely to be admitted for inpatient specialist cancer care compared to all others, having an average of 2.5 admissions compared to a range of 0.92-1.29 for patients from further away. The standardised discharge rate for patients showed a similar pattern, but the mean number of bed days was only significantly lower for patients living at the greatest distance, who had a mean of 2.5 days fewer bed days overall (p. 5). Additionally, some patients were not referred to the cancer centre nearest to their home and therefore were required to undertake unnecessary travel, and these patients were likely to be the furthest away from any centre and the most disadvantaged in terms of distance. The authors concluded that cancer care in Scotland was an example of the inverse care law whereby the most needy get the least resource, as the most remote patients had to travel furthest and also received less treatment overall.

In New Zealand, a recent study of 99,062 cancer registry records looked at the relationship between cancer survival and ethnicity, deprivation and geographical access to health services (Haynes et al., 2008). While disease extent at diagnosis was strongly related to survival, disease extent at diagnosis was not related to neighbourhood deprivation or travel times. The influence of geographical accessibility to health services depended on cancer site; poorer survival was associated with longer travel time to primary care for prostate cancer (p<0.05) and with longer travel time to a cancer centre for colorectal (p<0.05) and breast (p<0.05) cancers respectively compared to patients who lived in the closest travel quartile to a cancer centre, but no similar effects were found for lung cancer or melanoma (p. 932). These results were controlled for stage of disease at diagnosis. The authors commented that a possible mechanism for some of the disease-specific travel time effects may be the difficulty involved in repeated visits for chemotherapy and radiotherapy treatment.

Other than cancer care, two studies examined the association between distance from the hospital and the quality of preoperative care. A Canadian study (Seidel et al., 2006) examined the records of 9, 506 patients who had surgery at the Foothills Hospital in Calgary to determine whether any visit to the preoperative assessment clinic had taken place. It was found that the further patients lived away from the clinic, the less likely they were to attend the preoperative assessment. The "distance decay" effect persisted after adjustment for clinical factors, surgical specialty, urgency of surgery, and whether the surgery was major or minor. Whereas 66% of patients attended the clinic who lived up to 50km distant, there was a further reduction for each 50km needed to travel: 52% attended who lived 50-100km distant, falling further to 39% (101-150km distant), 40% (151-200km distant), 30% (201-250km distant) and 34% (more than 250km distant) (p. 5). Another study in New York looked at the characteristics of 101 patients admitted for laparoscopic renal surgery who were non-compliant with preoperative instructions (Kaye et al., 2010). Of the 24 patients who were non-compliant, "long distance" patients (defined only as compared

to "local" in the article), were nearly five times more likely to be noncompliant with bringing radiographs and completing bowel preparation compared to local patients (p=0.041). Of the long distance patients, six (46.2%) were non-compliant compared to 18 (20.5%) of local patients. This study had some limitations, including the small numbers involved, and a lack of detail about the characteristics of the total sample. Further there were also significant associations shown between non-compliance and non-Caucasian race (p<0.05) and the number of days between consultation and surgical date (p=0.004), but the authors did not comment on whether the associations were independent or may have been due to a combination of factors.

Barriers created by distance

Travelling long distances to treatment centres has time and financial implications for patients, as well as the potential to cause anxiety and stress to patients and their families. Moreover, many patients who need to travel for specialist treatment need an accompanying person on whom further costs may fall, including time off work and child care arrangements. There may also be substitute arrangements to be made for family members or businesses while the patient and others are absent. Studies that have examined barriers for patients have used various approaches including retrospective examination of patient records, surveys or interviews with patients, and modelling of impact based on proposed scenarios. Cancer treatment has been most extensively studied.

A study in the United States (Yabroff et al., 2005) estimated the cost of patient time associated with travelling to and from, waiting for, and receiving care for colorectal cancer based on data from the SEER cancer registry.² These records were compared with a random sample of Medicare enrolees matched to cases by gender, 5-year age strata and SEER registry areas. Time costs were divided into three clinically relevant phases of care - initial, terminal, and continuing care - and the median US wage for 2002 was used to assign a value to patient time. The study found that patient time costs represented an additional 19% of direct medical costs in the initial phase, 16% in the continuing care phase, and 37% in the terminal care phase. The authors commented that their estimates were likely to understate patient time costs for younger patients who would be more likely to be in the workforce and who would also be more likely to seek more aggressive treatment (p. 647). A similar study using data from the same registry (Baldwin et al., 2008) that examined records for 27,143 people aged 66 years and older with colorectal cancer found that a median distance of 47.8 miles (each one way trip) was travelled by more than 50% of rural patients for their care.³

A British study examined the impact that centralisation of cancer services in Britain would have on patients (Patel et al., 2004). The authors used a retrospective audit of 85 patients diagnosed with head and neck cancers that had been treated in the South Devon district hospital to determine the average number of visits that would be needed. It was then calculated how far each of these patients would have needed to

² SEER: Surveillance, Epidemiology and End Results cancer registry. For details of this study design please refer to refer to the full paper as the methods of subject selection and assigning of values to time are complex.

³Information derived from the abstract only.

travel to a centralised service in Bristol during the first six months for treatment, including surgery, radiotherapy, chemotherapy, and palliation. The study found that patients would need to make an average of 28 hospital visits (range 1-78), and that each patient would need to travel on average an extra 5,333 miles [sic] (median 5,658; range 185-13,759). These calculations did not take into account accompanying persons, visits by family or distance travelled by community liaison service providers. The authors also noted that there were resource implications of centralisation both in terms of the available workforce and physical infrastructure of buildings and equipment at the centralised site, and concluded that these factors as well as the additional burden of travel would have a significant impact on patients. The study stopped short of assigning any time or monetary calculations to the distances travelled.

A survey of 484 adults attending cancer clinics in Newfoundland and Labrador between September 2002 and June 2003 was used to identify the importance of personal factors and out-of-pocket costs in patient decisions about cancer care (Mathews et al., 2009). To be eligible for inclusion the participants needed to be resident in either Newfoundland or Labrador, aged 19 years or over and attending the clinic for treatment or follow up for breast, lung, prostate, or colorectal cancer. Clinic staff initially approached the patients about the study, and those who were willing to be included were referred to the researchers. Rural people, (defined as living in communities of 10,000 people or fewer at least 80 km distant from the cancer centre), made up 46.7% (226 patients) of the people surveyed. The remaining people in the sample (53% - 258 patients) were classified as urban. For most patients, regardless of place of residence, the stage of illness and personal feelings (for example, anxiety about their illness) were the most important considerations. However, rural residents were more likely to report that costs were important in decisions about their treatment, with travel costs (odds ratio 1.79, 95%CI 1.21-2.63), drug costs (odds ratio 1.69, 95%) CI 1.13-2.23) and child care costs (odds ratio 2.33, 95% CI 1.09-4.96) all being significantly more important compared to urban residents. The survey did not examine whether actual treatment decisions had been taken based on cost. However, the authors believed that their findings were consistent with previous studies which suggested that patients may forgo or alter care because of costs created by distance from treatment -for example, decisions to choose mastectomy over breast conserving surgery because the latter required more adjuvant therapies, and therefore more trips to large urban centres. (p.57). The authors concluded that policies were needed to address barriers to accessing specialised services for rural residents.

A study from Queensland (Veitch et al., 1996) took a population-based approach to two surveys of households in one remote town (Longreach, 800km west of the nearest large provincial city Rockhampton), and one rural town (Kilcoy, 90km northwest of Brisbane). Random selection was used to select people living both in and outside the township area in each location, and distance stratification was used to ensure that households selected were representative of the range of distance and transport conditions that would be encountered by residents. Altogether 60 households in each area participated in the first survey and 803 in the second survey. Over 90% of the people contacted in both surveys agreed to participate. The results of the second survey are reported in this article, analysed in two categories: firstly the perceived seriousness of issues likely to influence decisions about obtaining urban medical care (measured using an index of seriousness derived by the authors⁴), and secondly, actual problems experienced by people during their most recent trip to an urban centre for medical care. Results showed that the costs of accommodation, food, and transport presented serious difficulties and were rated at 31.7 on the seriousness index by rural and 34.8 by remote area residents. Other issues were isolation from family support (rated 20.2 by rural and 32.1 by remote residents), organising affairs at home, which was a major concern for remote residents (28.9 rural compared to 45.5 remote), as was urgency of the trip (31.3 for rural and 49.9 for remote residents). Difficulties were compounded by broader issues such as unfamiliarity with the city, and services that did not appear to recognise or understand the problems faced by rural and remote area people attending for medical services. Patients from remote areas generally rated the seriousness of concerns more highly than those from the rural township. Some of the problems were compounded by a lack of coordination by urban services in arranging appointments so that patients could have consultations and diagnostic tests done on the one day instead of making repeated trips. Some patients reported that their local GP had tried to organise details before the trip but on arrival the appointed doctor was not available, or that they were not able to be seen and were asked to make another trip. Other problems are records or results were not available and therefore a diagnosis or decision was not able to be made, the appointment had not been recorded, or they had been referred to an inappropriate specialist (p. 107).

Two qualitative studies of patients with colorectal cancer from remote areas of Scotland (Bain and Campbell, 2000; Bain et al., 2002) reported on barriers that these patients had encountered in relation to obtaining care. The studies used focus groups and interviews with patients and their relatives – 32 in the first study, and 95 in the second. In these studies, most problems related to belated recognition of symptoms by primary care doctors, and referral issues caused by poor organisation between primary and secondary care. However, there clearly were difficulties with travelling from remote areas – being caught for hours in snow drifts when suffering from the effects of chemotherapy, and having to stop frequently to find a toilet, for example. Patients' comments showed that they tended to weigh up the benefits and disadvantages between the transport problems and the perception that they would receive better treatment from the specialist centre. In general, though many would have liked services to be closer to them, travelling was largely accepted as an inevitable part of rural life. Some patients stated that they would choose the best quality of care, even if it meant travelling further. On the other hand, distance factors had deterred some patients from seeking advice from their GP, or even refusing to be referred until it was too late, because they did not want to make the trip to the city hospital. The authors noted that expectations of health care and life in general tended to modify decisions to seek care, with people who lived remotely often presenting later and pursuing their care less assiduously than urban residents. This attitude of stoicism, they concluded, might also be a factor in poorer survival of people from more remote areas (Bain et al., 2002, p.273). The findings of studies from focus groups and interviews, while providing important information for the populations in question, need to be caution as they may have limited generalisability to other populations and settings.

⁴ Respondents were asked to rate the seriousness of each problem from 0-4 (with 4 being the most serious). The values assigned to each issue were then summed for all patients and divided by the maximum possible group score, then multiplied by 100 to derive a percentage.

It is interesting to note in the studies above that some barriers for patients from rural and remote areas were created more by poor systems rather than by the travel itself. Poor coordination and scheduling for consultations and diagnostic tests, which may be relatively minor inconveniences for patients who live nearby, create extra expense and distress for patients who travel long distances. The study by Veitch (1996) suggested that specific staff members within centralised facilities should be assigned to smooth the care path and minimise barriers for patients from rural and remote areas so as to ensure that they had as much as possible dealt with in the one trip. Other problems, such as in delays in referral by rural general practitioners, who either did not recognise the symptoms or were reluctant to refer (Bain et al., 2002), are not unique to rural and remote settings but were exacerbated by reluctance of rural people to complain or seek a second opinion when they had few other options for their health care needs.

Offsetting the distance disadvantage: specialist care outside main centres

Outreach services

In outreach services, specialists from centralised services travel to other locations with smaller hospitals, or, in more remote areas, to primary care practices or community health centres. Outreach has obvious advantages in minimising the amount of disruption and inconvenience to patients and their families. Some patients may be treated in the smaller centre, thus saving an unnecessary trip. For other patients who need more specialised treatment, initial assessment and diagnosis may be possible in the outreach clinic, or follow-up and monitoring afterwards. Another potential advantage of outreach is expert support for health professionals in smaller centres, which helps reduce isolation and can support recruitment, retention, and professional development of doctors and nurses in less well served areas. Considerations about outreach also include factors such as infrastructure and workforce availability. The studies outlined below provide some examples of outreach in a variety of contexts. It is important to note that most of these studies appeared to assume that outreach was *additional* to existing services, not a reduction of a full service because of a centralisation process.

A Cochrane systematic review (Gruen et al., 2003) examined the effectiveness of specialist outreach clinics in primary care and rural hospital settings but found that there was not enough evidence available to draw conclusions about whether specialist outreach leads to improved health outcomes and at what cost.⁵ The review was able only to state that outreach had likely benefits in reducing hospital outpatient visits, along with a corresponding reduction in duplicated tests, and an improvement in coordination of care, more on-site procedures, and upskilling of primary care staff (p. 47).

⁵ The review covers specialist clinics in urban GP clinics as well as rural GP and hospital settings. Comments above relate only to those articles that examined services to populations distant from urban centres.

Several studies of specialty outreach oncology in rural hospitals, all in the United States, (Desch et al., 1999; Howe et al., 1997; Smith et al., 1996; Smith et al., 1991), suggested that guideline-consistent specialist care may be improved and delivered safely in rural hospitals without compromising outcomes and at a lower cost to patients. These studies also provided extra training and development opportunities for staff in the rural hospitals.⁶

A cardiothoracic outreach programme from the Medical University of Southern Africa that provided outreach services to disadvantaged rural populations was described by Klein and colleagues (1996). A specialist team of one surgeon, three registrars, two medical officers, six nurses, and four perfusionists, together with all their own equipment travelled to two small rural hospitals where local staff consisted only of non-specialist medical and nurses. Twenty major procedures, mainly heart valve replacements, were carried out at one hospital and 15 at another over the course of five separate outreach visits. There was a low rate of post-operative complications, apart from one patient death two weeks postoperatively. The project was a feasibility study to demonstrate to the South African government and Department of Health that such surgery was possible and would provide a better service to rural communities, and contribute to professional development of staff isolated in rural hospitals. The initiative began in May 1994 and was still ongoing at the time of publication (December 1996). A limitation of this study was the minimal information on how the patients were selected, their demographic details, and their medical conditions.

A second study from South Africa, (Coetzee et al., 1998) examined records from patient visits to haematology outreach clinics held monthly in three provincial hospitals between March 1994 and February 1996. Over the two years that are reported in this study there were 636 patients seen, of whom about one third needed to be referred to the major hospital at Bloemfontein for an intensive diagnostic workup or for treatment of complicated haematological cancers. The remainder were treated successfully in the rural hospitals. The outreach clinics were estimated to have provided significant savings to the patients in transport costs, and health system savings from avoiding unnecessary referrals to the tertiary hospital. There were no transport costs as outreach clinics in other specialties were already running, so that the haematology consultants were able to use the existing transport to get to and from the clinics. The specialists spent around 10% of their time in the outreach clinics, travelled outside of clinic hours, and saw patients who would otherwise have been referred to them in the tertiary hospital, so were considered not to have created additional costs for the health system.

Both these South African studies were done some time ago and are likely to have limited applicability to the New Zealand situation, particularly the cost information (in South African currency), which would now be long out of date. A particular limitation of the study by Coetzee et al (1998) was the inconsistency between, on the one hand stating that no extra workload had been generated, yet also commenting (p. 704), that the clinic at Kimberley was increased to fortnightly in the second year of

⁶ None of these studies was available in full text – comments are based on the article abstracts and conclusions from the Cochrane review

the study because of an increased workload. There was no reference to workforce issues with availability of haematologists.

A more recent Australian study analysed records from 11 years of surgical outreach clinics to three remote, indigenous communities (Gruen et al., 2006). The communities ranged in distance from 260-500km from Darwin, and only one of them had year round road access. The study of records looked at frequency of visits, access provided, referral practices, and patient outcomes. Over the period studied, there were 2,339 surgical problems seen in the clinics in general surgery, ophthalmology, gynaecology, and ear nose and throat surgery. Excluding orthopaedic cases (for which there was no specialist outreach), there were 1878 presentations at the clinics, of which 472 (25%) resulted in emergency referral to hospital. A further 503 (27%) were referred to hospital outpatient clinics. The remainder of the cases were dealt with in the outreach clinics. There were 175 procedures done onsite, including colposcopy, fundoscopy, minor skin incisions, and vasectomy, and most of these patients did not need to travel to Darwin at any time for their treatment. The study found that regular specialist outreach clinics more than twice a year significantly improved access to specialists within 12 months (p=0.003). There was also an increase in referrals being completed in a time proportionate to their urgency (p=0.002), and a 41% improvement in the rate of completed referrals. The outreach clinics saved all patients at least one trip to hospital and in some cases there was no need to travel at all. There were 156 opportunistic attendances at the clinics by patients who had not been referred from primary care and who otherwise would have been unlikely to have sought any care at all. The was no evidence of worse outcomes for those who did not travel to hospital, or evidence of supply-induced demand in increased referrals by primary care practitioners. Patients and staff of the clinics felt that outreach clinics helped specialists to understand the challenges they faced. It was noted that these positive results were achieved in spite of the clinics being irregular at times because of bad weather or staffing or service based limitations. Cost was mentioned only briefly in this study, with the authors reporting only that the cost per patient visit in "the early years" of the service was A\$277 (p. 137), and noting that costs depended on local charges for transport, accommodation, specific equipment, administration costs, and salaries.

Another study of outreach surgery to a remote, but less disadvantaged population from West Australia (Rankin et al., 2001) randomly selected 55 people who had attended a visiting rural surgical service within the previous ten weeks and invited them to participate in a telephone survey. The survey explored patient demographics, mode of transport, distance travelled, occupation, lost income, treatment options and need for an accompanying person. Costs were calculated for travel, and lost income was calculated by multiplying lost work time in hours by the mean hourly wage of the overall sample. Costs were calculated for travel to the visiting service and compared with the cost of travelling to the nearest metropolitan hospital. Patients were asked about their preference for attending a visiting service or going further to the larger hospital. Fifty completed surveys were available for analysis (one patient refused and four surveys were incomplete). Results showed that the comparative mean distances for the round trip were 1,215 km for the metropolitan service and 67.8km for the visiting service. The additional distance was directly proportional to time taken, travel and accommodation expenses, and time off work. Almost half of the patients (46%) needed an accompanying person for the visiting service but a metropolitan

consultation increased this need to 75%, and the accompanying person lost income as well as the patient. The difference in total estimated costs per visit was based on prices at the time of the survey (1999) and calculated to be \$76.85 for the visiting service compared to \$1,154.21 for attending the metropolitan service. Moreover, the waiting times for the visiting service were much shorter than the wait for the metropolitan hospital service, and fewer visits were needed as some consultations and the resulting procedures could be carried out on the same day. Eighty eight percent of the people surveyed preferred a visiting service over attending a larger centre, and 10% of the patients would not have sought treatment if the visiting service had not been available. The limitation of this study for the current review, however, was that the procedures carried out were not highly specialised. Apart from consultations, the procedures were fairly minor such as varicose veins, carpal tunnel, skin excisions and vasectomies. Also, surveying those who had used the visiting service means that there may be potential for bias as it is difficult for people to criticise a service which they have chosen to use.

A comparative study from Canada examined the effect of satellite haemodialysis units (haemodialysis units which are affiliated with, but distant to a main renal centre) on access to renal replacement therapy (Prakash et al., 2007) in two rural regions. Records of patients who were being treated with renal replacement therapy and who were resident in a region that received new satellite units between 1995 and 2002 (the exposure group) were compared to those of patients who lived in a region that already had a satellite unit in 1995 (the control group). The rate of renal replacement therapy in the groups at baseline was 26% higher in the control region (603 vs 506 per million population). By 2002, the difference between the groups had fallen to 13%. Results were adjusted for age, gender, and diabetes but none of these reached statistical significance. Of particular note was the increase in the number of elderly people receiving therapy once local access was provided – the baseline relative difference between elderly in the areas with and without satellite units was 30.6% in 1995, but had decreased to 4.6% by 2002. However, the study was not powered for subgroup analyses and this difference was not statistically significant. The mean distances needed to travel to the nearest unit were reduced significantly for the exposure group from 45.8km in 1995 to 10.7km in 2002 (p<0.0001) and this was likely to have improved access for elderly people and therefore also quality of life (p. 2302). Costs were not included in the analysis.

An older systematic review of cancer treatment programmes in remote and rural areas (Campbell et al., 1999) located fifteen papers that reported on oncology outreach programmes, tele-oncology, and rural hospital initiatives. However, like the Cochrane reviewers, the authors found that conclusions were hampered by studies with methodological limitations, small numbers, and designs vulnerable to bias. They concluded, based on this limited evidence, that shared care between rural practitioners and specialists to take on a proportion of routine monitoring and chemotherapy administration was possible, but had not been shown to give better outcomes for rural people than providing all care in specialist centres. In relation to economic impact, they concluded that both outreach clinics and tele-oncology consultations were more expensive than centralised services, but this conclusion appeared to be derived from only two studies that examined costs, and which, in any case, came to opposite conclusions about the economics of de-centralised programmes.

A cost minimisation study from Canada using a societal perspective (Dunscombe and Roberts, 2001) modelled the economics of three alternative radiotherapy service delivery models in an idealised population living in an area with one larger and one smaller urban centre. The study estimated health system and patient costs, including travel, accommodation and time. Detailed information about how cost estimates were derived is given in the article. The three scenarios that were evaluated were:

- i) a fully centralised comprehensive treatment facility in the larger centre which treated all patients from the entire region and to which patients resident elsewhere in the region had to travel;
- ii) a decentralised model with two independent, fully equipped self-standing treatment facilities which provided each population with their own facility; and
- iii) one fully comprehensive facility located in the larger centre and a smaller satellite facility located in the smaller centre. In this model all planning and activities other than actual treatment for the remote patients were based centrally, and most technical support staff were based centrally and travelled regularly to the satellite.

Results from the modelling exercise showed that the economics of providing each of these scenarios differed depending on whether health system costs alone, patient costs alone, or a societal perspective taking both costs into account was used (p. 32). In the fully centralised scenario, there was considered to be no travel by the staff but an excess of travel by the patients; the model with two self-contained centres was considered to be neutral for both staff and patients as they travelled only to the nearest centre; the third model with the centralised service and a satellite centre was considered to share travel between the staff and patients. The modelling exercise found that the fully centralised service was easily the most economic for the health system, particularly as health system costs were generally easier and less controversial to quantify (p.33). The fully decentralised service, with two independent fully equipped and staffed facilities was more expensive for the health system, because of some under-utilisation of equipment and personnel, but least expensive for the patients. The outreach model was more expensive than the fully centralised service, but less so than the two independent centres. From the patients' point of view, the economics of these three scenarios was reversed (i.e. the two independent facilities model cost them the least, and the fully centralised model the most), with costs rising steeply with increasing distance of residence from the central service. From a societal perspective, taking all costs (including time costs) into account, the outreach model was economically superior for distances between 30km and 170 km, after which the fully decentralised service was superior (p. 34-35). Limitations noted by the authors of this study were the omission of quality of care from their model, uncertainties in assigning costs to time, and the fact that they had used an idealised, rather than actual, population distribution. The authors did not mention workforce availability.

The impact of outreach on clinicians

There was very little evidence found in this overview about the impact of travel on specialists who visit clinics distant from their base hospital. Only one relevant paper was located (Stevenson et al., 2003). This study surveyed 78 health professionals in

the Grampian region (the major hospital based in Aberdeen) for their opinions on priorities in cancer care and the way services should be provided. The survey had 49 items covering quality of care, access to care, feasibility of services, and communication. A rating scale from 1 (total disagreement) to 9 (total agreement) was used to score the various priorities (1-9). Across the group, agreement was defined as over 80% of scores in the 7-9 range; disagreement was defined as 30% or more scoring 7-9 and 30% or more scoring 1-3. Responses to the survey (62 responses, 79% response rate) were received from 26 consultants in a variety of cancer-related specialties, as well as 22 general practitioners, eight district nurses, and a small number of other health professionals. Although there was good consensus on many principles of cancer care, such as rapid diagnosis, access to high-quality treatment, good communication and the importance of team working, the main area of disagreement was the balance between access and quality of care. Whereas primary care practitioners favoured chemotherapy administration at local hospitals (median score 7 on the scale), hospital specialists did not (median score 2 on the scale). A number of specialists commented that local care would be good "in an ideal world" but indicated that feasibility was limited, and that it was not a good use of specialist time, though they were aware that there were practical considerations for patients (p. 826).

The Cochrane review (Gruen et al., 2003) also noted that outreach has potential harms arising from inefficient use of specialists' time away from their main practice, and opportunity costs associated with additional investment that may be necessary in the specialist sector (p. 46). Moreover, the study of outreach services to indigenous Australian communities (Gruen et al., 2006) noted that

"... outreach services to rural, non-indigenous settings depend on whether or not specialists are a scarce resource, and on the presence of a population with unmet needs, substantial access barriers, or both. Successful outreach needs an adequate and motivated specialist base capable of sustaining both local hospital services and outreach services, functioning primary care services, and predictable and responsive visits that integrate with local services" (p. 137)."

This comment may be of particular relevance in the light of a report on workforce requirements for nine surgical specialties prepared for the New Zealand Clinical Training Agency (Health Workforce Information Programme, 2008) that concluded that the combined surgical workforce would need to increase by 50% between 2008 and 2026, at an annual average increase of 2.2% . Concern about workforce shortages in cancer specialties has also been highlighted in the international literature with one commentary stating that rural communities would be likely to face even greater challenges than the present to retain access to qualified oncology specialists (Chang and Collie, 2009).

The impact of travel on Maori

Maori already have difficulties in accessing routine primary care services (Cram et al., 2003; Rameka, 2006). Although the service itself might be free, getting there, particularly in rural areas where public transport is very limited, requires a roadworthy vehicle that is registered and warranted, and money for petrol (Rameka, 2006). Specialist appointments in a more distant location create even more transport

difficulties and add the costs of accommodation, food, and hospital carparking (Jansen et al., 2008). These financial barriers are likely to impact more seriously on Maori because of the lower socioeconomic status of many Maori compared to non-Maori. Rameka (2006) interviewed Maori women in the Wairoa area about their access to health care, including specialist appointments, and found that the biggest barrier was financial poverty. Although many of the costs could eventually be reimbursed by the District Health Board, this sometimes took weeks, and the money had to be found to pay first, which was very difficult for low income families, particularly if the appointment was at short notice and there was not time to save up for it (p. 43). Obtaining entitlements or special needs grants from WINZ could also present a barrier, as cancer was not recognised as a disability by WINZ, the application process was difficult and individual case managers could be unhelpful(p. 47).

A study of access to cancer services for Maori (Cormack et al., 2005) although largely concerned with health system lack of understanding of Maori needs, also considered travel difficulties. A major barrier was the lack of public transport options for accessing cancer services that were several hours away. Some Maori providers and other NGOs indicated that they were providing transport and support services to support their clients but were unable to receive any recognition for doing so in their contracts (p.36). Moreover, there was differential access to entitlements by region because of the differing contracts with District Health Boards; policies outside of the health sector, such as the amount of financial assistance available through WINZ were also noted as barriers for Maori to obtain the financial assistance necessary to access services readily (p. 36). These barriers could influence access to consultations, recommended tests, and the full range of treatment options.

Cormack et al (2005) more generally recommended that "..a clear Maori focus (as opposed to a primarily total population focus) across the cancer continuum [would] be important to improving access..." that would incorporate "..resources that meet the distinctive needs and priorities of Maori... and take into account progress through the service and the quality and timeliness of the process" (p. 44).

Rameka (2006) suggested that DHBs adopt the model used at "Hearty Towers" at Greenlane Hospital for transplant patients, which provides basic food items, accommodation and free parking for long term patients. She indicated that there was a need for Maori liaison officers in DHBs who could advocate for Maori and support them in their dealings with WINZ to access entitlements. She also suggested that WINZ benefits should be increased for families where one member needed hospital care, and that petrol vouchers rather than later reimbursement by the DHB or health providers would be more helpful (p. 51).

The potential of virtual outreach

Virtual outreach using telecommunications has been proposed as one solution to overcoming some of the time and cost barriers that occur with increasing centralisation of specialised services. Consultations between specialists at tertiary centres and medical personnel and patients at lower level hospitals, or with general practitioners have substituted for patients travelling to see the specialist in person. Videoconferencing and electronic exchange of x-rays, echocardiographs, and other diagnostic tests have been used in a wide variety of fields to allow both the patient and the specialist to remain in their own centre for preliminary consultations and pre-admission screening, as well as follow-up and monitoring after treatment. The main reported advantages of virtual outreach have been faster diagnosis and access to treatment, less travelling for patients, and continuing education, and professional back-up for health personnel in smaller centres. There is a relatively large literature on telemedicine (as it is commonly referred to), which is somewhat beyond the scope of this review. The following articles are a few representative examples from recent international literature.⁷

- Ferrer-Roca and colleagues (2010) compared a group of patients from an area of rural Spain who had initial referral to a hospital specialist through videoconferencing with a similar number of patients who had attended hospital outpatient clinics in person. This study found no difference in outcomes between the two groups, and improved quality of life for the telemedicine group as they received a fast diagnosis and did not have to travel for the outpatient appointment.
- A series of articles (Smith, 2007; Smith et al., 2007; Xu et al., 2008) reported on a telepaediatric service in Brisbane which analysed records from consultations in sub-specialties including oncology, cardiology and otolaryngology. These articles examined cost factors, and reported on the minimum number of consultations per year that needed to be done to give the cost savings that they achieved.
- Paediatric congenital cardiology consultations between specialists in Toulouse and parents of young children with congenital heart defects and doctors on the island of Réunion were found to be valuable in confirming diagnosis, clarifying treatment options, and encouraging parents to accept surgery (Geoffroy et al., 2008).
- Other applications in cardiology have been reported, including real time echocardiography (Awadallah et al., 2006; Lofgren et al., 2009), remote monitoring and follow up of cardiac implantable devices (Kollmann et al., 2007; Stoepel et al., 2009), and remote assessment of heart sounds through digital recordings (Finley et al., 2006; Gilman et al., 2006).
- Weinerman (2005) reported the use of videoconferencing for patients on Vancouver Island to substitute for difficulties in recruiting an on-site oncologist.
- In New Zealand, a teledermatology service from Waikato hospital has operated in the central North Island (Oakley, 2001; Oakley and Rennie, 2004).

Virtual outreach systems have set-up costs, ongoing operational and maintenance costs, and workforce implications, all of which are context dependent (Smith et al., 2005). Factors to consider are the volume of consultations that are necessary to make investment worthwhile, the level of acceptance by specialists and patients, the availability of staff, training needs, and adequate infrastructure. Most telemedicine involves specialists from centralised services linking up with medical staff and patients in smaller hospitals, rather than use in remote locations where the infrastructure is unlikely to exist (Gruen et al., 2006).

⁷ Information derived from abstract only in this section unless otherwise stated.

Virtual outreach is clearly promising in many specialties and is likely to develop as more technology becomes available. Ideally it can minimise both patient and clinician time and travel and therefore improve access to specialist care. The literature is still largely descriptive and as yet there appear to be few studies comparing outcomes of patients who were diagnosed or followed-up remotely with those who were seen face-to-face. Patients seem to be generally satisfied and pleased to avoid travel, but there is some evidence that clinicians may not find it as satisfactory as face-to-face consultation (Weinerman et al., 2005).

Considerations from the literature for the SISSAL workshop

Economic and social costs of travel by patients

Based on the studies presented, there is fairly strong evidence that increasing distance to specialist services creates significant inconvenience and disruption to patients, and is likely to reduce access to care for those with the fewest resources, thereby exacerbating existing inequalities. Most health systems make some provision for assisting patients from distant areas (for example, accommodation near the hospital or travel allowances), but assistance programmes were barely mentioned in the studies reviewed, and it is not clear how much these programmes offset the barriers encountered.

Economic and social costs of travel by clinicians

There appears to be little available about the impact of travel on clinicians themselves. While their costs would no doubt be met by their health system, there is potential for inconvenience and disruption to the continuity of services where they are based, and to their personal and professional lives. The availability of a sufficient number of specialists willing to maintain an outreach service of sufficient quality and regularity is likely to be a critical factor in its feasibility. Virtual outreach may have potential for the future if it can be used to avoid travel by both patients and clinicians.

Quality of care

Outreach services appear to improve overall quality of care compared with preexisting local services, by improving access for rural and remote patients, and to give good patient satisfaction, particularly where they are additional to existing services. The literature, however, is largely descriptive, with the main emphasis on models of care, access for patients, and some consideration of costs. The advantage of better patient outcomes in high volume hospitals for specialised procedures is one of the key drivers for centralising care, but most of the literature reviewed did not address comparative quality between outreach and central services. Studies that have interviewed patients showed that most patients were generally very satisfied with outreach services but a minority prioritised care quality over increased local access and preferred to travel to a larger centre.

Overall economics of patient compared to specialist clinician travel

If only direct health system costs are taken into account, it is likely to be less costly to provide an outreach service in a smaller centre than have two fully independent services, but more costly than having one centralised service where all travel costs are borne by the patients. However, if social costs are also taken into account, the economics are influenced by the particular context: the demographics and geographical spread of the populations involved, the actual distances needed to travel, time and weather factors, workforce availability, existing infrastructure, and policy decisions about how resources are allocated across the care needs of the population, and the wider political context at the time.

Other relevant factors:

This overview has not examined the impact of centralising specialist services on recruitment and retention of health professionals in the areas where services are reduced, or looked at the flow-on effect of centralisation on waiting times and increased need for resources in the central facility. However, these issues are also relevant and need to be taken into account.

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