

**Booking Systems for Elective Services in New Zealand:**

**Literature scan to identify any ethical issues  
of national significance**

**A report to the National Ethics Advisory Committee**

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## Preface

This report to the National Ethics Advisory Committee (NEAC) is based on a scan of literature reporting research and developments related to New Zealand's booking system.<sup>1</sup> The purpose is to assist NEAC identify any ethical issues of national significance addressed, or raised, about booking systems for elective services. The focus is on publications reporting research and/or discussing the NZ booking system and accompanying policy. The scanned research projects were variously funded by: the New Zealand Health Research Council, small grants, or the Ministry of Health<sup>2</sup>. The developmental, Continuous Quality Improvement (CQI) work referred to in the report, has been undertaken by members of the Elective Services Group within the Ministry of Health.<sup>3</sup> Because booking system developments are ongoing, conversations with civil servants about current research and policy developments in NZ also inform this report.<sup>4</sup>

An 'elective' (non-urgent) condition has been defined as one 'not requiring immediate treatment, such as a hip replacement or cataract operation' (Elective Services Group 2004). The term 'urgent' (acute) generally refers to conditions that, if left untreated, may result in death or considerable disability (e.g. certain cancers

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<sup>1</sup> Sarah Derrett (SD) is a lecturer in health services research and MBA (Health Executive) programme director at the Centre for Health Planning and Management, University of Keele. She is on the steering group of the NHS Service Delivery and Organisation-funded research project examining the current use and development of GP referral guidelines and practices for elective surgery in the NHS (REFER Research Team 2004). Together with former colleagues (Associate Professor Charlotte Paul, Dr Robin Gauld, Associate Professor Peter Herbison, Dr Jenny Morris and Ms Sue McAllister) from the Department of Preventive and Social Medicine, University of Otago, she has undertaken research evaluating the perceptions, experiences and health status of i) patients on former waiting lists for surgery and ii) patients assessed and prioritised for surgery according to the introduced booking system for elective surgery.

<sup>2</sup> Research undertaken by the NZ CPAC Evaluation Consortium.

<sup>3</sup> The Elective Services Group within the Ministry of Health runs a programme alongside the booking system which "aims to implement a strategy to achieve improved equity of access to treatment, certainty and timeliness...[and] assist in the provision of clear information for patients and their carers regarding their eligibility for publicly funded elective services and to improve the management of waiting times for elective services" (p.3) (Williams and Gandar 2004).

<sup>4</sup> SD is most grateful to Dr Ray Naden, Ms Alison Barber and Mrs Helen Williams (from the Ministry of Health Elective Services Group) for agreeing to speak with her about current developments in New Zealand, and/or providing her with reports, unpublished communication and/or conference presentations at short notice. SD is also very grateful for the helpful comments on earlier versions of this report received from: Dr Andrew Moore (Chairperson of NEAC), Associate Professor Charlotte Paul (NEAC Committee member and formerly fellow-researcher of patients' health status and experiences of waiting lists and booking systems) and Dr Ray Naden. Of course, responsibility for any errors or omissions is SD's.

and cardiac conditions). However, the boundary between elective conditions and urgent conditions is sometimes blurred in relation to elective services' prioritisation. For example, non-urgent conditions may be progressive and ultimately result in an acute health problem. Sometimes the priority tools (Clinical Priority Assessment Criteria – CPAC) prioritise access to treatment across the range of conditions treated within a clinical specialty, including both urgent and elective conditions. Because of difficulties separating elective and urgent conditions, this report sometimes refers to prioritisation for both elective and urgent conditions.<sup>5</sup>

The report contains four sections. Section 1 provides a background to the booking system for elective services – its origins, aims, patients' pathways through the system and a patient-centred framework for considering any ethical issues arising from the system. Section 2 presents the results of the literature scan. Section 3 is a summary and Section 4 contains concluding comments.

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<sup>5</sup> To SD's knowledge, no research has been published reporting on prioritisation for conditions requiring exclusively medical treatments within New Zealand's booking system. Therefore the report often refers to elective surgery rather than elective services. However, any ethical issues raised by the booking system for conditions requiring surgical treatment may well be similar for conditions requiring medical treatment.

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# 1. Background

The NZ booking system origin, aims and functioning are briefly described because they: 1) raise issues of ethical significance through identification of weaknesses associated with the antecedent waiting list system, and 2) influence the nature of research and developmental projects evaluating and appraising the booking system.

## 1.1 Origins of the booking system

NZ is unique in developing explicit prioritisation tools and systems for managing the prioritisation and rationing of access to state-funded elective services.<sup>6</sup> Before the introduction of the booking system, access to surgery was rationed according to waiting time (delay). Patients, placed on waiting lists, were generally not given dates for surgery, but were usually given indications of the possible duration of wait (Fraser, Alley et al. 1993). There was a degree of prioritisation within the waiting list. Patients were allocated an implicitly determined priority ranking by surgeons: A (urgent), B (semi-urgent) or C (routine). Patients with a priority of 'A' were to wait a shorter period of time than patients with a priority of 'C'.<sup>7</sup> Patients also arrived at hospitals acutely (as emergencies) and surgery would usually then be provided within 24 hours (Cranfield and Comber 1989).

Lengthy waiting lists for surgery were identified as a prompt for the NZ health service reforms enacted in the Health and Disability Services Act 1993. A Green and White Paper recommended the formation of an advisory committee to advise the Minister of Health on the allocation of health care resources (Upton 1991). In 1992 the Core Services Committee (CSC) was established. The CSC undertook public

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<sup>6</sup> Other countries have developed, or are developing, systems for prioritising access to treatment but these initiatives do not rely on score thresholds to ration access to services (see 1.3 for discussion of the score threshold). NZ is unusual in making its determinations about which patients will or will not access services on the basis of explicit scoring of those patients' relative priority. Other countries with elective service prioritisation systems also make decisions about which patients will, or will not, gain access to services – but make these rationing decisions implicitly (usually according to clinical judgement) (Derrett, Devlin et al. 2002). In such systems, the prioritisation process is used solely to determine the waiting list 'queue order' or the 'timeliness of access' to treatment.

<sup>7</sup> Anecdotally, a study undertaken with 149 patients on waiting lists for surgery at Dunedin Hospital revealed that many patients had been informed of their priority ranking after the outpatient assessment (Derrett 1997).

consultation exercises and commissioned a report by Fraser et al that summarised some of the problems associated with waiting lists. (Fraser, Alley et al. 1993).

Identified problems with the former NZ-style waiting lists include:

- efforts to reduce the list size being accompanied by paradoxical waiting list increases; inaccuracies in the numbers of patients waiting (Porter 1985; Fraser 1991; Lee, Don et al. 1991; Riley, Grupcheva et al. 2001);
- inappropriate deterrent effects where some patients do not present for surgical assessment because of list size and the perceived duration of wait (Bloom and Fendrick 1987);
- the potential for conflicts of interest where surgeons with long public sector waiting lists may benefit because patients may believe they need to pay for private treatment to receive timely access (see Yates);
- variation between surgeons in implicit decision-making about the indications for surgery and placement of patients on the waiting list (Fraser 1991; Hadorn and Holmes 1997b);<sup>8</sup>
- poor relationships between implicit priority ranking (A, B, C) and health status (Derrett, Paul et al. 1999);
- adverse consequences to patients of lengthy waiting times (Mulgan and Logan 1990; Rigge 1994; Martin, Elliott et al. 1995; Derrett, Paul et al. 1999), and
- little certainty for patients about the duration of wait and poor pathways of access to timely reassessment should patients' conditions deteriorate (Derrett, Paul et al. 1999).

Fraser et al. recommended:

...the present system of hospital waiting lists be abandoned and replaced by a system of 'booked admissions' for non-urgent surgery and medical and diagnostic procedures. Patients should be assessed by defined criteria, according to their need

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<sup>8</sup> To the reviewer's knowledge, the criteria by which clinicians made their decisions about i) access to the waiting list and ii) A,B,C ranked priority within the waiting list have not been explicitly stated or publicly available. Perhaps the historical absence of publicly available decision-making criteria indicates the inevitable complexity of the clinical decision-making. The development work undertaken by the CPAC Consensus Working Groups suggests firstly that some agreement about the key decision-making criteria could be arrived at; and secondly, that universal agreement about the decision-making criteria is problematic. Recently, research undertaken in New Zealand has further indicated the range and quantity of underlying constructs influencing implicit clinical decision-making (MacCormick, A., Macmillan et al. 2004).

and likely benefit (worthwhile health outcome) from the procedure. Patients who satisfy the criteria should be offered a date for surgery within a defined period of time. Patients who do not meet the criteria at the time of their specialist assessment should not be registered with the hospital's booking system (or placed on a 'waiting list'), but should be referred back to their general practitioner for ongoing review (Fraser, Alley et al. 1993)(p.8).

The CSC then facilitated the formation of Consensus Working Groups to develop Clinical Priority Assessment Criteria (CPAC) tools for prioritising patients referred for access to high volume high cost elective procedures (National Advisory Committee on Core Health and Disability Support Services 1993; Hadorn and Holmes 1997a; National Health Committee 2002).

## **1.2 Aims of CPAC prioritisation tools and the booking system**

The CPAC tool development and booking system aimed to:

- Develop a fair and consistent means of defining priority
- Permit assessment and comparison of need, case-mix and severity
- Ensure the inclusion of social values in decision-making
- Allow appropriate and transparent decision-making
- Make possible national studies on health outcomes for patients who do and do not receive surgery
- Ensure that patients with the greatest need and potential to benefit received treatment first
- Provide certainty to patients about the timing of treatment
- And provide nationally consistent access to surgery

(National Advisory Committee on Core Health and Disability Support Services 1995; Shipley 1996; Feek 2000; Ministry of Health 2000).

The next section briefly describes the booking system as it was, and now is, intended to function.



### 1.3 The booking system pathway to elective services

In NZ the 'booking system' refers to the entire process governing access to elective surgery from the time when patients first seek advice about their condition from primary health care professionals (usually GPs) (Gauld and Derrett 2000).<sup>9</sup> The 'booking system' begins with the use of referral guidelines by GPs to determine the appropriateness of referral. The letters of referral are then prioritised at outpatient clinics according to Assessment Criteria for First Specialist Assessment (ACA). ACA guide the speed of access to outpatient appointments with surgical consultants. The next step in the booking system process occurs at the outpatient clinic after the surgical consultant has determined or confirmed the patient's diagnosis and fitness for surgery. Patients are then 'scored' using CPAC to determine whether or not they gain access to surgery, and if so, the speed of access to surgery. It is not until this CPAC scoring has occurred that patients are either 'booked' or 'not booked' for surgery.

The final 'booked' status is dependent on the Treatment Threshold (TT). The TT is the CPAC score at or above which patients are eligible to receive surgery in a state-funded NZ hospital. This is ultimately governed by allocation of funding to services from the funder arm of the District Health Boards (DHBs) to the provider arm. Initially the score threshold determining access to surgery was known as the Financially Sustainable Threshold (FST), and colloquially known as the Financial Threshold. The FST was calculated by 1) estimating the number of anticipated discharges for the coming year (by considering total case-weights purchased by the DHB funders and the numbers of procedures undertaken in the previous year), 2) cumulatively summing the CPAC score profiles for a sample of previous patients and graphing this information, and 3) entering the purchased number of cases and locating the CPAC score on the X-axis of the graph to determine the FST.

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<sup>9</sup> In England, the term 'booking' refers to particular components of the pathway to elective surgery – rather than the overall pathway. The NHS 'booking system project' has focussed on the booking of outpatient appointment slots for patients to be assessed by the surgical consultant (Devlin, Harrison et al. 2002; Ham, Kipping et al. 2002; Kipping, Robert et al. 2002; REFER Research Team 2004), alongside initiatives for greater patient choice. Generally in England, 'booking' does not relate to the use of referral guidelines, ACA or CPAC-type priority scoring tools. Although such tools are being developed and used throughout Primary Care Trusts (PCTs) and Hospital Trusts to guide or even determine access to outpatient appointments and/or surgery; these are the result of local initiatives rather than national policy (Selvachandran, Hodder et al. 2002; Demand Management Team and Orthopaedic Services Collaborative 2003).

More recently, and in an effort to simplify the calculation of the threshold, other terms have been used to describe the CPAC score thresholds determining access to surgery. The Actual Treatment Threshold (aTT) is used to inform one of the Elective Services Performance Indicators (ESPI 3). The aTT is the CPAC score at, or above, which 90% of patients were treated in that local service over the past 12 months, and is argued to be the best indicator of the next years predicted or forecast Treatment Threshold (TT). The aTT is set at the priority score at, or above, which 90% of patients received that elective treatment in the past year to allow for the fact that the threshold will not necessarily be precise over the next 12 months because of unanticipated capacity management issues affecting the provision of elective surgery and also to allow for the "...small number of patients with exceptional circumstances [that] will need to be given higher priority than the CPAC would indicate, or offered surgery even when their relative priority does not reach the normal threshold" (Naden 2003). A further threshold term has also been identified. This is the Commitment Threshold (CT). The CT is the score at which DHBs agree to provide certainty to patients that they will receive elective treatment within the next six months (from the time of their outpatient FSA). The Commitment Threshold is meant to be based closely on the previous year's aTT – although there are reports of some DHBs setting their CTs at much higher levels than their aTT (Naden 2003).

When the booking system was first introduced a Clinical Threshold also accompanied the CPAC tools. This was the CPAC score at which clinicians believed surgery should ideally be provided. In part because of ongoing difficulties removing patients from residual waiting lists, the explicit identification of Clinical Thresholds for each CPAC tool was abandoned and a system of Active Review (AR) was introduced with the aim of addressing the needs of patients clinically in need of surgery but with CPAC scores beneath the TT.

When first introduced in 1996, the booking system required patients with CPAC scores beneath the TT be returned to the care of the primary health care referrer until such time as their condition deteriorated necessitating a re-referral to an outpatient assessment – and re-entry to the referral guidelines/ACA/CPAC assessment pathway. More recently, the Active Review (AR) system has introduced the possibility of hospital-led follow-up for patients with CPAC priority scores falling just beneath the

TT. An AR guidance document produced by the Elective Services Group for the Ministry of Health and District Health Boards (DHBs) states that:

Active Review is for patients for whom elective surgery/treatment is considered to be the best option for their care but

- this service is not currently accessible within the available public funding or provider capacity; and
- there is a realistic probability that the patient's condition may meet the commitment threshold for treatment in the foreseeable future (i.e., the next year)

Please note that Active Review is **not** to be used as a long-term holding place (i.e., greater than six months) for those patients whose priority is so low that they are not likely to get treatment/surgery in the public hospital system (Elective Services Group).<sup>10</sup>

If patients' CPAC priority scores are at, or above, the Commitment Threshold (CT) they are to be 'booked' to receive treatment within six months of the outpatient assessment – or at least given certainty that such treatment will be provided within six months. If they have scores at, or above, the predicted TT, but beneath the CT, they may be placed on the DHB's Active Review list (see below), and/or they may end up receiving surgery – but without the immediate provision of certainty. If they have CPAC priority scores beneath the TT, they are denied access to surgery within six months (unless they rapidly deteriorate and present acutely).

In summary, although the 'booking' of dates for surgery is the one of the final steps in the process of gaining access to elective surgery, the term 'booking system' in NZ refers to access to elective surgery from the point of first referral through to CPAC scoring and eventual receipt (or not) of surgery. The next section presents a framework for considering any ethical issues arising from booking system research and development work.

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<sup>10</sup> Patients with sufficient CPAC priority scores to ensure access to surgery within six months of their outpatient assessment are also placed on the AR list if they have co-existing conditions preventing such prompt provision of surgery (e.g. patients requiring treatment for a urological condition prior to receiving joint replacement, or patients needing to lose weight before they can have surgery), or require staged treatment at particular times (e.g. some paediatric cardiac surgery).

## **1.4 Framework for considering any ethical issues arising from the literature scan**

This report, presenting the results of a rapid literature scan to identify any ethical issues arising from the booking system, does not directly engage with the many philosophical debates about the definitions and contributions of ethics to the understanding of health care systems in general – and prioritisation in particular. However, to provide a structure to the literature scan, a framework for considering any ethical issues has been derived from i) the broad principles, concepts and ethical issues identified by others, and, ii) the previously outlined origin, development and introduction of the booking system.

The booking system, with its CPAC tools of prioritisation and thresholds determining access to publicly funded hospital treatment, immediately calls for consideration of what is ‘fair’. As Evans and Price (1999) observe – determining what is fair in the allocation of resources is a matter of ethical concern. Fairness, justice and equity are sometimes used interchangeably; and equity is often depicted in terms of horizontal and vertical equity – where equals are treated equally and unequals are treated unequally. For example, the CPAC scores could be used to ensure ‘horizontal’ geographical equity of access to treatment such that people with the same score for a hip joint replacement, say 60 points, would receive access to surgery with approximately the same duration of wait regardless of where in NZ they lived. Vertical geographical equity of access could be obtained if patients with higher CPAC scores, say 80 points, received their hip replacements more quickly than patients with 60 points, and again, with a similarly shorter waiting time regardless of where in NZ they lived.

Equity may be viewed horizontally and vertically according to a variety of criteria which can include: timely access, pre-operative need or health status severity, the likely ability to benefit from treatment, post-operative health status severity, clinical symptoms, ethnicity, age, geography etc.<sup>11</sup> Theoretical tensions about equity tend to

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<sup>11</sup> Sometimes horizontal and vertical equity are rather too narrowly defined in relation to the booking system. For example, horizontal equity has been defined as referring to equity across all types of elective conditions – so that a score of 50 on the cataract surgery CPAC tool would equate in terms of severity with a score of 50 on the prostatectomy CPAC tool (Evans and Price 1999; Price 1999). Vertical equity was then viewed as a relative ranking of patients within a single specialty group.

surface in relation to the criteria and measurement strategies used to determine equity (Cooper 1975; Culyer and Wagstaff 1993; Donaldson and Gerard 1993; Bradshaw 1994; Mooney 1998; Daniels 2001; Parfit 2001).

Compared with the earlier waiting list system, the booking system also imposes different qualities (responsibilities and duties) on the relationship between health care professionals and patients (Evans and Price 1999), and which relate to ethical concepts such as autonomy, paternalism, beneficence and non-maleficence (harms) debated in the ethical (and prioritisation) literatures (Gillon 1985; Beauchamp and Childress 1994; Coast 1997; Doyal 1997; Mechanic 1997; Harris 2001; Derrett, Devlin et al. 2002). The nature of the health professional: patient relationship is 'shot through with complex moral dimensions' which we need to try to understand (Zaner 1994). As cited in Guilliford, Figueroa-Muñoz and Morgan (2003), authors of a 1983 report – *Securing Access to Health Care* – commented:

The prevention of death and disability, the relief of pain and suffering, the restoration of functioning: these are the aims of health care. Beyond its tangible benefits, health care touches on countless important and in some ways mysterious aspects of personal life and invest it with significant value as a thing in itself (Gulliford, Figueroa-Muñoz et al. 2003) (p.3) citing (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research 1983).

Beyond possible ethical issues raised by the impact of the booking system on individual patients and health professionals, we should also be alert to the ramifications of the booking system on the wider community and communities within NZ. Mooney observes:

...the nature of the health care system in a society can convey something more than desire to treat sick people. It is a 'performance indicator' of the nature of concerns for equity and caring in a society (Mooney 1998).

The over-arching aims of the booking system were for a fair and consistent system to manage access to elective surgery, and for a system to improve patient certainty (see

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Although this definition highlights an important difficulty with the booking system – that of ensuring equity across (and within) specialties, it has not been adopted in practice. Endeavouring to attain horizontal equity between specialties would raise many problems of service configuration within local DHBs. Secondly, and crucially, the generic (general) tools to evaluate health status and health status outcomes across a wide range of specialties are not yet sufficiently refined to evaluate the attainment of horizontal equity as defined by Evans and Price (Derrett, Devlin et al. 2003). However, there are condition-specific tools that can help evaluate the attainment of equity for particular types of conditions requiring elective treatment – such as cataract removal, prosectomy and hip or knee joint replacement (Derrett, Paul et al. 2002).

1.2). The work of others reveals potential ethical issues related to the nature and measurement of fairness and equity, the nature of the professional: patient relationship, and recognition that provision, denial and process of health care may create benefits and harms for individuals and wider communities beyond the immediate effects resulting from the disease or condition requiring surgical treatment.

The following literature scan, to identify any ethical issues, traces patients' journeys through the booking system:

- referral pathways and processes from primary care to hospital outpatient clinics
- hospital outpatient assessment of referral letters and Assessment Criteria (ACA) for First Specialist Assessment
- use of CPAC tools to determine priority
- CPAC and patient outcomes
- thresholds and use of resources
- and the process of care for patients returned to the care of their GPs following CPAC assessment.

## **2. Literature scan to identify any ethical issues of national significance arising from the booking system**

### **2.1 Referral pathways and processes**

#### **Little known about primary care referral practices**

Within NZ, the CPAC tools have been the focus of research attention. This is in marked contrast with the English NHS where the focus has been on ensuring the timeliness of booked outpatient appointments for First Specialist Assessment (FSA) and more recently on developing referral guidelines to ensure the appropriate and timely referral of patients into the secondary sector from primary care (Ham, Kipping et al. 2002; Kipping, Robert et al. 2002; REFER Research Team 2004). In NZ, very little is known about GP referral practices, yet appropriate and timely referral is the foundation for the booking system.

#### **Shortcuts to the public sector through private outpatient assessment**

McLeod et al undertook 65 interviews with GPs, surgeons and administrators to describe the pathways into the booking system, and attitudes towards it (McLeod, Morgan et al. 2004b). GPs and surgeons raised concern about perceived socio-economic inequities where wealthier patients can afford to pay for consultations and/or surgical treatment in the private sector – or had private insurance to cover such costs. For example, some patients bypass the maximum six-month waiting time for FSA by paying privately for their initial outpatient consultation (FSA) and CPAC scoring at a private hospital and then entering the publicly-funded hospital system to receive elective surgery. Further, the sooner a patient's FSA, the sooner a patient is likely to be booked for surgery. Poorer patients are less able to access such private shortcuts to health care. Evans and Price (1999) raised such shortcuts as an ethical concern in their earlier report, although they were hopeful that the need to be scored using CPAC tools would circumvent quicker access to publicly funded elective surgery and suggested:

Application of the CPAC independently of the referring clinician together with a respect for the integrity of the system [by clinicians] will be important factors in combating shortcutting (p.x) (Evans and Price 1999)

### **Local policy and GP-perceived length of wait**

GPs also reported being influenced in their decision to refer patients by local policy. For example:

GPs reported not referring patients with some conditions to the public system, either because they had been advised not to refer that type of condition or because they perceived the waiting list would be too long (McLeod, Morgan et al. 2004b)

Where local policy about which conditions are eligible for state-funded treatment varies throughout NZ, and where such policy influences the actual referral practice of GPs, then geographical inequities of referral and access to FSA will exist for patients.<sup>12</sup> Similarly, if the GP-perceived 'length of wait' for treatment influences referral (as reported anecdotally), then national equity of access for patients with the same level of need or the same likely ability to benefit from treatment, will remain elusive.<sup>13</sup> Currently, we do not know the extent of regional variation in referral practice.<sup>14</sup>

### **Referral guideline use and GP confidence**

McLeod et al's study did not appear to explore with GPs their views about the referral guidelines, developed for all booking system surgical specialties, and published by the Elective Services Group (Elective Services Group, Ministry of Health 2004). Nor, to the reviewer's knowledge, is there published evidence of specialists' views about the adequacy of the referral guidelines. It may be significant that there were no reported comments from GPs about the guidelines by McLeod et al. (2004b). Indeed:

GPs said that it was not clear to them what to include in a referral letter in order to make a difference to the surgeon's decision to see and/or treat the patient. As one GP reported: 'Well if I knew what the prioritisation system was I could make sure I put down those things' (McLeod, Morgan et al. 2004b).

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<sup>12</sup> McLeod et al (2004b) do not report which elective conditions experience such local variation in accessibility. Historically, the former purchaser-provider split within the NZ health-care system did result in regional differences in access to treatment for varicose vein and benign skin tumour removal (Cumming, J. 1997). Presumably, such local policy variation could exist only for conditions without developed national referral guidelines, ACA and CPAC?

<sup>13</sup> With varying CPAC tools in use and locally-determined Treatment Thresholds, it could also be the case that such nationally varying thresholds also influences GP referral.

<sup>14</sup> The Elective Services Group Elective Services Performance Indicators (ESPIs) provide some indication of delays in accessing surgery for those patients with CPAC scores above the aTT. However, because the aTT is determined locally for each DHB according to the patient profile from the previous 12 months, any historical regional variations in access will not be apparent in indicators such as ESPI 3.



Currently, we do not know if GPs make use of these guidelines, or have confidence in them.

#### **Impact of referral guidelines on joint GP: patient decision-making**

We also lack sufficient knowledge about the nature of the joint GP: patient decision-making around the use of such guidelines in daily practice, and the patient factors influencing their desire for referral to a hospital outpatient clinic for assessment.

To date, only one study has investigated patients' perceptions and experiences of the booking system (Derrett 2001a). This revealed that some patients had desired GP referral to outpatients to seek confirmation of their diagnosis and/or reassurance about the natural history of their condition. For a few patients, the initial GP referral set in motion their pathway through the entire booking system, culminating in surgery, which was not their intention at the time of initial GP referral.<sup>15</sup> Such 'unintended' pathways to surgery can conceivably result in harms to the patient: harms caused by the patient being informed they were sick enough to warrant surgery (when they were seeking information or reassurance); harms as a consequence of any side-effects associated with the surgical procedure itself; harms caused by limitations to the patient's usual activities as a consequence of hospitalisation and the post-operative recovery period, and harms related to any less-than-anticipated improvements in health status following surgery.<sup>16</sup>

#### **GP advocacy**

GPs reported to McLeod et al that they advocated on behalf of their patients by a variety of techniques including: referring patients to specialists with private practices for their initial assessment to bypass the initial waiting time to be seen in a publicly-funded outpatient department; referring patients to private specialists when they had been referred back to the GP after not being prioritised in the public sector to access treatment; highlighting cancer as a possible reason for the referral; approaching individual surgeons personally, and sending patients in to hospital as acute cases (McLeod, Dew et al. 2004).

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<sup>15</sup> After surgery some of these patients still reported they wished they had not received surgery because their health had not improved or because they had experienced unpleasant side-effects associated with receipt of treatment.

<sup>16</sup> Of course, there may also be pathways of "unintended *benefits*" for patients who didn't want their GP referral for the purpose of having surgery, but whose referral ultimately led to their receiving surgery, and who were afterwards glad they had received that surgery.

In NZ's health care system GPs act as gatekeepers to the secondary health care providers.<sup>17</sup> If GPs behave differently from one another in advocating (or not) on behalf of their patients, inequities of access to FSA will result. In addition, in studies conducted overseas a variety of sometimes-inappropriate factors have been found to influence GP referral (Joule 1998). When referral is inappropriately influenced by sex, ethnicity, age, socio-economic status or place of residence this is of ethical concern.

Currently, we cannot be certain that such inappropriate bases for referral or differences in GP referral occur, and indeed GPs have reported that factors such as ethnicity do not influence referral (McLeod, Dew et al. 2004). Although one GP said:

I think there is discrimination. I think if they [Maori patients] come from the wrong end of town. If you are an important person in the town you will be seen very quickly, if you are not you won't.

Maori and Pacific people tend to be referred at a later stage in the disease process – when their condition is more severe. Research is required to analyse referral practices from primary to secondary care (Tukuitonga 2002). Research with Maori and Pacific patients, and with other patients presenting to outpatient departments for the first time and receiving high CPAC scores at the FSA, could illuminate patient-experienced and GP-experienced barriers to timely access for these people, and help to develop strategies to overcome such barriers.

#### **GP 'coaching'**

Some GPs reported 'coaching patients to lie and exaggerate conditions' to gain priority for surgery (McLeod, Dew et al. 2004). However, 'coaching' may not always be completely inappropriate. If, for example, a GP is aware of factors caused by their patient's health condition and adversely impacting on the patients' life, and they know such factors are not weighted highly or at all in the hospital CPAC tool, they may feel such 'coaching' is a legitimate strategy to ensure the 'necessary' surgery is provided to benefit the patient.<sup>18</sup> However, in the absence of such

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<sup>17</sup> Occasionally other primary health care professionals also act as gatekeepers – such as optometrists for cataract removal.

<sup>18</sup> It is accepted that if all GPs insisted on following their own 'legitimate' criteria instead of the agreed national referral guidelines the system, fairness (as compared to the former waiting list), is threatened.

'legitimate' motives, harms are also associated with gaming as noted by Evans and Price (1999):

Harms can occur to the patient, other patients, the doctor and society. If the doctor exaggerates their illness patients may be harmed by thinking that they are far sicker than they are. Patients may be harmed in the future due to a stigma of a condition that they never really had. Other patients may be harmed if they miss out on care or treatment because a less needy patient was given priority under false pretences...The physician could be harmed through loss of credibility. Gaming is an affront to veracity and thus undermines the physician's own integrity (p.37).

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Arguably, greater good could be achieved if GPs identifying weaknesses in the system, directly fed back their concerns to the Elective Services Group or took part in the various working parties aimed at improving the various booking system tools (Evans and Price 1999).

## **2.2 Hospital outpatient clinics and Assessment Criteria for First Specialist Assessment (ACA)**

The next stage in the booking system pathway occurs when the letters of referral are received by the outpatient department and prioritised for FSA according to the ACA tools.

### **Standard of GP referral letters**

In McLeod et al's study surgeons criticised the differing quality and content of referral letters from GPs (McLeod, Morgan et al. 2004b). Although the Elective Services Group encourages hospital outpatient departments to provide feedback to GPs on the quality and content of their referral letters, information about the extent to which outpatient departments currently provide such feedback is currently unknown.

Referral letters are used in the hospital outpatient clinics to prioritise access to FSA. Therefore, letters of varying standard may result in varying access and/or timeliness of access to FSA, regardless of the true health needs of the referred patient, and may result in unequal benefits (such as some patients receiving prompt access to assessment, ahead of patients with greater needs) and harms (such as delay in access to assessment and surgery) between patients.

### **Use of ACA**

As with the referral guidelines, research in NZ has not evaluated and explored the use and attitudes towards ACA for FSA. Beyond the unknown extent of inappropriate GP advocacy or gaming, and differences in the standard of referral letter, differences may also occur in the manner such referral letters were managed within hospital outpatient departments. It would be useful to know if the published ACA are routinely used in outpatient departments, if ACA are completed by: outpatient nurses, administrators or clinicians, and, if a single assessor or multiple assessors complete the ACA at each outpatient clinic.

It would also be useful to know the number of patients, if any, returned to the care of their GP without accessing an outpatient appointment. The Elective Services Group has a series of Patient Flow Indicators (Elective Services Performance Indicators –

ESPIs) that are regularly reported on for all DHBs (Elective Services Group 2005). The first ESPI requires that all DHBs advise the patient and their primary care practitioner:

...within 10 days whether or not a first specialist assessment (FSA) is indicated and can be provided (within six months). If an FSA is not offered, advice on alternative care options should be provided if applicable (Elective Services Group 2005).

However, it does not indicate the number or proportion of patients failing to access an FSA.

There is a potential for harm to patients if either the GP referral guidelines (assuming they are used) or the ACA used at outpatients are insufficiently sensitive to detect patients who truly warrant an FSA (Evans and Price 1999). Anecdotally, there are examples of GPs struggling to obtain outpatient appointments for patients, with true needs for specialist consultation, after the patients have been rejected for a FSA outpatient appointment. Just as the CPAC tools used in secondary care are to act as ‘guides to clinical judgement’, there ought to be clear safeguards to allow GPs, uncomfortable about their diagnosis, or, who ‘intuitively feel’ something is amiss with their patients, to ensure such patients can obtain an appointment with a specialist.<sup>19</sup>

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<sup>19</sup> It is accepted by SD that, as indicated by one of this report’s reviewers, problems can also arise when: “...‘implicit’ clinical judgement that might alternatively be used is insufficiently sensitive. And given that FSA too is a key scarce resource, there is also harm of delayed service for *others* arising from tools that are insufficiently specific to detect *only* those patients who truly warrant FSA”.

### 2.3 CPAC tools and prioritisation

CPAC developed, with support from the CSC, were:

- a) to assess patients' relative priority for surgery
- b) to ensure consistency and transparency in the provision of surgical services across New Zealand, and
- c) to provide a basis for describing the kinds of patients who will or will not receive surgery under various possible levels of funding (Hadorn and Holmes 1997a).

Groups of specialists, managers and GPs developed the CPAC for 'large volume/high cost' procedures using the Delphi technique with reference to any existing referral guidelines and best evidence (Hadorn and Holmes 1997a; b). The first CPAC were developed for cataract extraction, coronary artery bypass (CABG) graft surgery, hip and knee joint replacement, cholecystectomy, and surgery for otitis media (Hadorn and Holmes 1997a). The CPAC tools were usually comprised of a mixture of clinical dimensions (e.g. visual acuity, or movement and deformity), patient-experienced dimensions (e.g. extent of loss of visual function) and social factors (e.g. age, impact on work or social activities, threat to independence and time already spent waiting for surgery) (Hadorn and Holmes 1997a). Dimensions within each CPAC were allocated weighted scores summed to a possible total score of 100 points.<sup>20</sup>

The clinical working groups found it difficult to agree on which social factors should be included, and public consultation failed to reach agreement about the social criteria to include in priority tools (National Advisory Committee on Core Health and Disability Support Services 1994). There was also difficulty reaching agreement about the type and weighting of clinical dimensions within the emerging CPAC tools. Halliwell noted that even for cataract disease – a condition believed 'easy' to quantify:

...it proved difficult to obtain consensus amongst ophthalmologists with regard to the assessment criteria and their relative importance (Halliwell 1998).

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<sup>20</sup> The main exception to this style of CPAC was with the Midlands Health Authority where CPAC were comprised of broad category bands. As described later, the more recent move to Integrated Scoring Systems (ISS) instead of CPAC also sees a move away from explicitly weighted score allocation.

Such difficulties contributed to the (unsought) variety of CPAC tools developed for the same surgical procedure, and may also have influenced the reliability of the CPAC scoring process between CPAC assessors.

### **2.3.1 Reliability**

#### **Inter-rater reliability**

Halliwell evaluated the inter-rater CPAC score reliability between two ophthalmology nurses assessing 39 patients on a waiting list for cataract surgery (Halliwell 1998). The cataract CPAC allowed a possible maximum score of 100 points. Scores for the same patients varied between the two assessors by as many as 26 points, leading Halliwell to question the advantages of using CPAC to improve the equity (fairness) of access, particularly when used in conjunction with a Treatment Threshold score to grant (and deny) access to surgery. Unfortunately, Halliwell did not also evaluate inter-rater variation under the former implicit A,B,C waiting list approach to prioritisation. Halliwell wondered what the intra-rater CPAC reliability would be if the same assessor re-assessed the same patient. He also wondered if there would have been greater score reliability if ophthalmologists had undertaken the assessment rather than nurses. The recommendation was that a single assessor ought to use the tools to promote equity among patients assessed for surgery.

#### **Differences in scoring between groups**

In a different study Dennett et al found differences in general surgery CPAC scoring patterns between qualified surgical consultants and surgical registrars (Dennett and Parry 1998). One of the possible explanations for such a difference was ‘gaming’ where the CPAC score was decided by the assessor prior to actually completing the CPAC assessment (see later: 2.3.4).

More recently, linear analogue scale (LAS) scores were found to relate to the surgical team assessing the patients (MacCormick, A., Plank et al. 2002). The researchers wondered if this was an artefact of sub-specialisation, team training and learning or of deliberate ‘gaming’ (inflating the scores of patients beyond the ‘true’ score to ensure access to surgery). As mentioned, concern about such inexplicable variability in priority allocation (A, B or C) between clinicians under the former

waiting list system was one of the prompts for recommending a more explicit approach to prioritising patients.

### **2.3.2 Validity**

Fraser et al had recommended that prioritisation tools should be consistent throughout NZ, with piloted variation being allowed only for the purpose of comparative analysis and tool improvement (Fraser, Alley et al. 1993). However, to promote the shift from waiting lists to booking systems for elective surgery, specialists at different hospitals were permitted to develop and use regional variations of the 'national' CPAC tools (Gauld and Derrett 2000). This was also compatible with the spirit of competitiveness operating within NZ's health sector at the time (Hornblow 1997).

#### **Relationships between CPAC tools and implicit measures of clinical judgement**

Some researchers have evaluated the different CPAC tool criteria and the relationships between CPAC tools and clinical judgement. Dennett et al had compared the scores generated from the general surgery CPAC tool with LAS scores of priority completed by surgeons (a 10cm scale ranging from '0 = offer operation if no resource constraints' to '100 = prompt operation essential')<sup>21</sup>. They found that scores for the same patients, using the two priority tools, were poorly correlated. Additional concerns about validity of the general surgery CPAC were raised when some patients with diagnosed malignant cancers would not have gained access to surgery if the recommended Treatment Threshold had been rigidly applied.

#### **Relationships between generic CPAC tools, condition-specific CPAC tools and implicit measures of clinical judgement**

Another study compared the performance of priority tools for cholecystectomy with 22 patients on a waiting list for cholecystectomy (Dennett, Kipping et al. 1998). They compared: a general surgery CPAC developed by a former Regional Health Authority, the surgeon-completed LAS of priority, and the cholecystectomy-specific CPAC developed by the Consensus Working Party. This study also found little agreement between the two CPAC tools and the surgeons' LAS assessment of priority. Scores for the same patient varied by as many as 30 points depending on the

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<sup>21</sup> Later LAS scores are reported to range from '0=not requiring surgery' to '100=need for expedient elective surgery' (MacCormick, A., Plank et al. 2002)



priority tool used. However, there was a strong correlation between the total scores for the cholecystectomy-specific CPAC and the LAS scores. The distribution of scores also suggested to the researchers that the cholecystectomy-specific CPAC may have been prioritising patients according to need as the specific CPAC had a score distribution with a:

... bimodal distribution which may be closer to clinical reality, the lower peak representing the population at large who need elective surgery and the upper group of patients who need surgery urgently (Dennett, Kipping et al. 1998).

### **CPAC and cancer: tools of diagnosis or prioritisation?**

More recently, MacCormick et al also found the LAS for general surgery was able to differentiate between patients with benign and malignant conditions (MacCormick, A., Plank et al. 2002). However, this does not so much indicate the strength of the LAS (which is a criteria-free 0-10 scale and completed according to the implicit judgement of the individual surgeons) – but the diagnostic ability of the surgeons. When the booking system was introduced, it was stated that CPAC tools were to act as ‘guides to clinical decision-making’. Priority tools were not intended to act as diagnostic tools. Nor do the stated aims of the booking system support such apparent priority of benign conditions over diagnosed or probable malignant conditions – clearly resulting in harms to patients with operable malignant tumours. The use of explicit CPAC tools as rigid arbiters of access to surgery in association with the TT would be harmful.

We do not know if clinicians have been prioritising patients in such a manner in practice – but if they are unclear about the purpose of the tools, and the role of CPAC as ‘aids to clinical judgement’, then harms to patients may be occurring. It is important, that new medical graduates receive a comprehensive orientation to the purpose and use of CPAC tools and the overall booking system. The evidence that registrars score patients differently to consultants highlights the need for such orientation (Dennett and Parry 1998). However, given the identified differences in scoring between teams of surgeons (MacCormick, A., Plank et al. 2002), any introduced orientation programme would need to be carefully managed in a consistent manner throughout NZ.

### 2.3.3 Implicit and explicit CPAC tools

One of the inherent difficulties associated with LAS priority tools, and the similar Integrated Scoring Systems (ISS) used in orthopaedic surgery,<sup>22</sup> is that the criteria upon which individual clinicians make their decisions are implicit (not transparent or observable)(Derrett 2001b).<sup>23</sup> To understand the differences between clinicians and groups of clinicians, research has identified the criteria used by clinicians when allocating the LAS score (MacCormick, A., Macmillan et al. 2004). Twenty-seven criteria were found to relate to the implicit overall LAS priority decision. The research revealed different decision-making strategies between surgeons. For example, while some surgeons considered the advantages, benefits, or improvements associated with the provision of surgery, this was not consistent and did not necessarily include the capacity of the patient to benefit.

Clinicians considered patient characteristics when deciding priority, including: the age of patients, the biological/physiological age of patients and patient comorbidities. Although such criteria have a place in determining priority of access to certain types of surgery, the use of these, and the other 24, implicit criteria

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<sup>22</sup> ISS priority tools allocate score bands to all the different conditions treated surgically within a single specialty e.g. orthopaedics. Individual clinicians then allocate an 'implicit' priority (from 1 – least priority, to 5 – greatest priority) for patients with particular conditions relative to all other patients they have seen with the same condition. The individual priority score then locates the patient within the possible 'score band' and allows prioritisation of all orthopaedic patients (Derrett 2001b; Elective Services Group, Ministry of Health 2004).

<sup>23</sup> The strengths and weaknesses associated with implicit decision-making have been debated elsewhere (Hunter 1995; Coast 1997; Doyal 1997; Mechanic 1997; Edwards 1999; Derrett, Devlin et al. 2002). Implicit decision-making into three priority groups (A, B and C) under the previous waiting list system – with reported between-clinician and between-region variability – was one of the main prompts for the introduction of the booking system (Fraser, Alley et al. 1993). Briefly, implicit decision-making and prioritisation: do not allow the provision of services according to identified need; may result in unnecessary and/or inappropriate demand or treatment; do not necessarily enhance the information sharing between professionals and patients or increased patient involvement in the decision-making processes, and, as already indicated by NZ research, may contribute to inappropriate gaming whereby clinicians favour 'their' patients over the patients of their colleagues or may favour their patients seen 'today' over their patients seen 'a month ago'.

However, there are also pitfalls associated with explicit decision-making (and strengths associated with implicit rationing). These have been most clearly discussed by Mechanic in relation to rationing, and include: the tendency for developed explicit criteria to become rigid and resistant to change; the potential for the trust-relationship between doctor and patient to be threatened by the use of explicit (technical) approaches; patients have different values, preferences and needs and fixed criteria may not take account of these; explicit criteria may not take account of co-existing disease, and explicit prioritisation may 'fall victim' to politics and may experience ever-increasing calls for more funding to meet the 'measured need' (Mechanic 1997).

inevitably raise questions of equity for patients.<sup>24</sup> For example, does one clinician's judgement of physiological age equate with another clinician's?

The role of comorbidity in prioritising access to surgery is complex, and again, not necessarily uniform among clinicians. If co-existing conditions, such as severe cardiac or respiratory health problems, increase the likelihood of serious risks associated with surgery then this ought to be part of the initial decision-making process between the surgeon and the patient, so the patient can understand the risks and thereby consent (or not) to being prioritised for possible surgery. Co-existing conditions should only be a direct part of the prioritisation decision-making process, when the outcome of surgery is likely to be directly affected by the presence of the co-existing condition itself.<sup>25</sup> If comorbidities are unlikely to influence the risks associated with surgery itself, or the likely benefits associated with the particular type of surgery, the advantages to the patient of receiving surgery may be considerable for the patient who is also burdened with other health problems. For example, a patient with paralysis or a mental health condition may well derive as great a benefit from cholecystectomy, as the patient with no such comorbidity.

There was agreement among participating surgeons about the 27 criteria influencing their decisions about priority – but such broad agreement does not imply consistent use of all 27 criteria in their individual and implicit decision-making. As McLeod et al observe of the more explicit CPAC tools:

Social factors are incorporated in some CPAC, but not as objective measures, leaving potential for variation as a result of the relative weighting placed on different socio-demographic factors (McLeod, Dew et al. 2004).

Research is now required to understand the use of a more detailed seven-criteria likert scale developed to accompany the overall implicit LAS priority score (MacCormick, A., Macmillan et al. 2004). Such research will also need to explore

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<sup>24</sup> Age was initially a consideration in the original CABG CPAC tool as evidence suggested a reduced beneficial outcome from surgery with increased age (over 70 years). Later, this explicit inclusion of age within the CPAC was removed due to concern about perceived discrimination. However, age is again being considered within the CABG CPAC as a predictor of likely benefit from surgery. Where best evidence exists, such inclusion seems appropriate.

<sup>25</sup> A good example of this situation arises in the cataract removal CPAC tool. Initially patients were awarded additional priority points if they had coexisting eye disease. This was then changed to reduce the priority for patients with coexisting eye disease because this was likely to reduce beneficial outcome derived from cataract removal (Mordue and Parkin 1997b), although this has subsequently been questioned (Riley, Grupcheva et al. 2001).

with surgeons the reasons behind their likert scoring to determine whether or not such seven-criteria likert scoring is truly adding to explicit decision-making, or, is simply adding a veneer of explicitness to continued implicit and variable decision-making.

One advantage of explicit CPAC tools, particularly condition-specific CPAC tools (e.g. CPAC for cholecystectomy rather than CPAC for all types of general surgery) (Dennett, Kipping et al. 1998), is the potential to evaluate relationships between the criteria contained within the CPAC and patient health status: at the time of pre-operative assessment, after surgery, and overall improvement. Research evaluating such relationships is presented below (2.3.3: CPAC and patient outcomes).

#### **2.3.4 The CPAC scoring process**

There are other variations in the method of CPAC completion and use that have implications for patient priority and fairness. McLeod et al identified a range of approaches to the process of completing the CPAC (McLeod, Morgan et al. 2004b). For example, one surgeon commented that ‘occasionally and unofficially’ his secretary would complete the CPAC tool:

They shouldn’t but there are some conditions, which are so obvious, and if it’s a pattern that they can score them just as well as I can...[Surgeon] (McLeod, Morgan et al. 2004b).

Interviewed booking system administrators reported receiving incomplete CPAC scores, which they then sometimes completed themselves, and difficulties addressing this with surgeons:

...[surgeons] don’t want to be told what to do by a bit of paper. They decide, if someone needs an operation they think they should have it...I can’t get through to them that it is just as immoral to tell somebody that you are going to be on the waiting list and leave them there for years, as it is to say you are not going to get it [Administrator] (McLeod, Morgan et al. 2004b)

The Dunedin study also revealed different approaches to the process of CPAC scoring (Derrett 2001a; Derrett, Paul et al. 2002). The cataract patients were generally scored by the nursing staff (but sometimes by the ophthalmologist doing the FSA); the prostate patients self-scored a section of the CPAC with the balance

being completed after several clinical tests, and the hip/knee joint patients were scored by the orthopaedic surgeons at the time of their FSA.

Patients reported a lack of understanding about the CPAC, and some did not even realise they were being ‘scored’:

Was sure I would have got more points if I knew what the questions were for. Didn't tell me the questions were the CPAC. It's the moaning people who get surgery...[Cataract patient]

Then lo and behold I got a letter to say I didn't have enough points. How they arrived at the 50 points puzzled me. He [specialist] just talked to me openly and as he was talking he just ticked – he didn't actually question me...I thought it would be a system like going to get a licence...[Hip patient].

Confusion and dissatisfaction was raised by some cataract patients who were scored by the nurses:

Oh well, I'm a bit brassed off. The optician said I needed it and he wouldn't upgrade my glasses. The surgeon said I needed it and the nurses said 'No' – they didn't even use instruments to check your eye at all.

When I first had the booking system thrown at me I was pretty annoyed...The nurse there at the Eye Clinic did the interview with me and asked me a list of questions they ask you. Anyway she turned around and said to me 'I don't allocate the points...it's done by a computer'.

Frustration with the discrepancies between clinical judgement and the CPAC scoring was not restricted to cataract patients:

It's not good enough. Of course, now it's all points. The specialist said I had enough. I don't like it. People shouldn't come down to points – it should be how they feel. You've got to have so many points to get it done, you've almost got to be on your hands and knees [prostate patient].

As identified by Mechanic (Mechanic 1997), the process of ‘scoring’ can harm the health professional: patient relationship. When ophthalmology nurses (or other third parties) do the CPAC scoring harm is caused by removing the decision-making about whether or not to proceed with surgery from the joint doctor: patient relationship. The patient: i) sees the doctor to determine clinical eligibility for surgery, ii) sees the CPAC scoring nurse, and then iii) waits for a fortnight to receive

a letter at home informing them whether or not they received sufficient points to meet the threshold (decided by the computer). Indeed, some patients reported not being informed of the risks of surgery until they attended the pre-operative assessment clinic a few days before the operation. This is an obvious harm, as the information cannot contribute to the patient's decision about whether or not to proceed with surgery in a timely manner<sup>26</sup> – and relates to the ethical concepts of autonomy and informed consent.

Another harm rests in the simple conflict of information received by patients – e.g. where health professionals told patients 'they would operate tomorrow' but 'the computer would need to decide'. Possible benefits associated with structuring the scoring process in such a manner include: avoidance of 'denial disutility' (harm to health professionals caused by having to impart 'bad news' that surgery is not to be provided), or that third party scoring may be believed to be less prone to bias. When scoring is so removed from the doctor: patient relationship and decision-making it seems that the harms expressed by patients may outweigh the potential benefits (which seem to fall mostly to health professionals through avoiding breaking bad news).<sup>27</sup> Some of the possible benefits offered by the more explicit booking system (compared to the former implicit waiting list system) seem to be weakened when scoring is removed from the doctor: patient relationship, thereby removing opportunities for a full discussion of patient preferences and information sharing about the risks and benefits associated with surgery.

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<sup>26</sup> Obviously, when people present acutely or urgently for surgery they may also be informed of the risks and benefits close to the time of surgery. The difference for the elective surgery patients is that they may have been waiting, and 'expecting' surgery, for 6 months or longer before being given the necessary information about risks and benefits. Should the patient change their mind about proceeding with surgery on hearing about the risks, there are harms falling to the hospital in rescheduling theatre sessions.

<sup>27</sup> As mentioned previously, some patients reported receiving surgery when they had initially sought FSA for reassurance or confirmation of their diagnosis – such risks are greater when third parties do the scoring.

### **2.3.5 CPAC and patient outcomes**

#### **CPAC scores and access to surgery**

The aim of CPAC tools was to determine priority – so that patients with higher CPAC scores received surgery more promptly than patients with lower scores (research considering the specific role of the TT in governing the access to surgery is discussed later – 2.4).

The Dunedin study examined the relationships between allocated CPAC score and the actual provision of surgery (Derrett, Paul et al. 2002). For all three surgical conditions evaluated (cataract, prostate and hip/knee joint replacement), surgery was more likely to have been provided to patients with higher CPAC scores. Only 10 of 130 patients with scores above the TT had not received surgery within one year of assessment. Of these, three patients had booked dates for surgery and the remaining seven patients had co-existing illnesses precluding surgery. Conversely, few patients with CPAC scores beneath the TT had received surgery, again suggesting that the CPAC tools were used to ration access to surgery as intended. However, as elaborated in the next section, another study found that other factors (age and sex) could also influence the timeliness of access to surgery (MacCormick, A., Plank et al. 2002).

A poor of relationship between CPAC score and timeliness of treatment has been identified through the continuous quality improvement (CQI) work undertaken collaboratively by the Elective Services Group and clinicians at participating DHBs. Regularly, patients with higher CPAC scores have been found to wait longer for elective surgery than patients with lower CPAC scores – be this for cataract surgery, tonsillectomy, CABG, or hip joint replacement (Barber, Doolan-Noble et al. 2004; Williams and Gandar 2003):

The results indicate a poor correlation between the assigned priority and subsequent treatment offers to patients. Improved equity requires a greater assumption of responsibility on the part of clinicians for ensuring that the priority assigned to a patient is used as the basis for treatment decisions. In turn this raises the requirement for consistency of clinical decision-making, firstly within each clinicians own practice and secondly between clinicians (p.8) (Gandar, Williams et al. 2004).

Where the assigned CPAC score and actual priority of access to treatment are not closely related, it's plausible there's a problem with one or the other, or both.<sup>28</sup>

Qualitative research also supports the mounting evidence for a poor relationship between CPAC scores and the timeliness of access to surgery. In some hospitals theatre lists were compiled by booking system administrators (McLeod, Morgan et al. 2004b). In others, surgeons compiled their own theatre lists. In such cases, some study participants commented that the CPAC scores did not influence priority within the list:

No-one ever asks or seems to take any notice of the scores, as long as there's a score on the form [General surgeon] (McLeod, Morgan et al. 2004b).

Elsewhere, and in support of the Elective Services Group CQI results, it was reported that:

Although the prioritization score was rated as a major influence on the selection of patients for surgery by 54.1% ...of surgeons, 87.0% ...reported their clinical judgement as a major influence [in determining the selection of patients for theatre lists] (McLeod, Morgan et al. 2004a).

Such repeated evidence about the variation in use and perceptions of the CPAC scoring process suggests a need to re-visit the purpose, aims and definitions associated with the NZ booking system.

### **CPAC and equity**

Research has highlighted both the presence of different models of CPAC tools, the use of different CPAC for the same surgical procedure throughout NZ (Derrett, Williams et al. 2004), and the different perceptions of clinicians about the aims of prioritisation and use of the CPAC tools. Where different CPAC tools (and thresholds) are used throughout NZ, geographical equity of access (and outcome) will remain elusive:

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<sup>28</sup> There have been concerns that the development of condition-specific CPAC tools, such as those developed for hip or knee joint replacement, may see these conditions given priority over other non-CPAC-scored conditions within the service. Other conditions, such as carpal tunnel surgery or back surgery may then receive an inappropriately small proportion of the specialty's budget. However, similar problems of advantage and disadvantage have also recently been revealed with the ISS approach to prioritisation. A CQI project has found that use of the ISS in orthopaedics has resulted in an undue disadvantage to patients waiting for hip or knee joint replacements compared to other 'less severe' orthopaedic conditions (Gandar, Williams et al. 2004). The Elective Services Group is currently working with clinicians to once again develop hip-specific CPAC to address this inequity.



Regional management of health services, different financial (or resource) thresholds, the socio-demographic and health profiles of the community, and relative demand for acute and elective services were all discussed as influencing elective surgery (McLeod, Dew et al. 2004).

As mentioned previously, geographical variation is not the only starting point for consideration of 'equity'. Other issues of equity such as potential (and inappropriate) influence of age, gender and ethnicity also need to be considered if the booking system is to demonstrate fairness.<sup>29</sup> Agreement about the importance of an equitable and fair system for managing access to elective surgery has been expressed by: groups of the general public (Campbell 1994), patients prioritised for elective surgery (whether they received or did not receive surgery) (Derrett, Paul et al. 2002), academics (Evans and Price 1999), surgeons, clinical directors, GPs and administrators (McLeod, Dew et al. 2004).

Tukuitonga and Bindman analysed the National Minimum Data Set (NMDS) from 1990-1999 to determine the relationships between ethnicity and gender and access to CABG and percutaneous transluminal coronary angioplasty (PCTA), and whether or not the introduction of CPAC tools has influenced rates of access (Tukuitonga 2002). They found:

Compared to other New Zealand men, the mean age-standardised CABG and PCTA intervention rate ratios were 0.64 and 0.25 in Pacific and 0.40 and 0.29 in Maori men respectively. Compared to other New Zealand women, the rate ratios for CABG and PCTA were 0.73 and 0.21 in Pacific and 0.74 and 0.43 in Maori women respectively...despite higher coronary artery disease mortality and morbidity rates [for Maori and Pacific people].

The difference in rates of access between Maori/Pacific people and other ethnic groups was greater in NZ than the differences between minority ethnic groups and others in the US. The researchers raised several hypotheses for such apparently poor access to treatment. These included: ethnic differences in disease prevalence (although this seems an unlikely explanation because of the high mortality rates from heart disease for Maori and Pacific people); lower use of primary health professionals among Maori and Pacific people; lower rates of referral; less timely

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<sup>29</sup> Depending on the agreed definitions of ability to benefit, some patient characteristics – such as age – may have an influence on the potential ability to benefit from certain types of surgery and may appropriately be considered for inclusion within CPAC where these are used as 'aids to clinical decision-making' and permit flexibility of application by clinicians.

access to diagnosis and treatment; the presence of co-existing diseases; a preference for no treatment among Maori and Pacific people; and discrimination. Similar possible reasons for health disparities were offered by clinicians in McLeod et al's study (McLeod, Dew et al. 2004). Tukuitonga and Bindman call for both an increase in the provision of coronary treatments for all New Zealanders, and research evaluating 'referral patterns, patient characteristics and in-hospital process-of-care issues' aimed at understanding the ethnic differences. Similar NMDS evaluation should also be undertaken for other common elective surgical procedures.<sup>30</sup>

A study of patients prioritised for cataract, prostate or hip/knee joint replacement found that CPAC scores were not related to age, socio-economic status or place of residence, and CPAC scores determined the provision (or not) of surgery (Derrett, Paul et al. 2002).<sup>31</sup> Elsewhere, a study of LAS priority scores for patients assessed for general surgery found the scores to be unrelated to age and gender (MacCormick, A., Plank et al. 2002). However, in that study older patients and men waited longer for surgery:

That patient gender and age has an impact on waiting time independent of the priority score is a disturbing finding. At worst, it may indicate institutional bias against these groups (MacCormick, A., Plank et al. 2002).

The possibility of such biases makes all the more urgent the need for clarification of the reasons for the CPAC score *not* reliably determining the timeliness of access to surgery, as revealed by the CQI work. At the moment, research can only hypothesise that ethnicity, age and sex may be inappropriately influencing access to treatment. Determining this ought to be a research priority.

### **CPAC and patient health status**

CPAC tools were not formally evaluated for their ability to prioritise according to patient 'need' or 'ability to benefit' as called for during the early phase of booking system development; only assessed for agreement with clinical judgement.

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<sup>30</sup> CQI work exploring orthopaedic surgery found that Maori and Pacific people above the FT, received access to surgery more quickly than others (Williams and Gandar 2003). Again, research is required to understand the reasons for such differences. One possible explanation could be the greater severity of Maori and Pacific patients at the time of FSA.

<sup>31</sup> Ethnicity was not considered in this study because only 1.5% of the Otago population aged 65 years or more identified as Maori (Statistics New Zealand: Te Tari Tahu 1998).

Exploring the outcomes of prioritising and rationing access to surgery with explicit CPAC provides opportunities for improved decision-making. Although calls for such outcome-based research have been made, only a few studies have evaluated the outcomes for patients prioritised for elective surgery.

A retrospective analysis of 88 patients' medical records on a Christchurch waiting list for CABG found the clinical criteria and the total CPAC score did not predict the risk of readmission to hospital while on the waiting list (Doogue, Brett et al. 1997). Although there was evidence for left ventricular size and function predicting the risk of death or heart attack, these were not included in the original national CPAC tool. The original coronary artery bypass CPAC was modified several times, and later versions did award points for poor left ventricular function.<sup>32</sup>

Another retrospective study of 1422 patients undertaken in Auckland evaluated a later version of the CPAC and found it was also unable to predict readmission to hospital with serious cardiac events (Seddon, French et al. 1999). Worryingly, a Christchurch study also found that patients with CPAC scores beneath the threshold determining access to surgery were 'just as likely to die or suffer a myocardial infarction as those with higher points' (Jackson, Doogue et al. 1999).

A prospective cohort study of patients in Dunedin prioritised for cataract removal, prostatectomy or hip/knee joint replacement, evaluated CPAC scores in relation to patient-experienced health status severity at the time of CPAC assessment (need) and health status improvement following surgery (ability to benefit) (Derrett, Paul et al. 2002). This found that CPAC scores were weakly-to-moderately associated with pre-operative health status (need), but were not associated with the improvement in health status following surgery (ability to benefit). The best predictors of improvement in health status following surgery were the pre-operative measures of health status. Certain criteria within the CPAC tools, such as visual acuity (cataract CPAC), residual urinary volume, and uroflowmetry (prostatectomy CPAC), were not related to patient-experienced improvement following surgery.

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<sup>32</sup> As mentioned, a strength of explicit CPAC tools is the possibility of undertaking research evaluating the relationships between explicit criteria within CPAC tools and such patient outcomes.

The failure of CPAC to prioritise patients according to their experienced ability to benefit suggests that combinations of clinical and patient-experienced criteria should be abandoned in favour of CPAC tools comprised of criteria that relate to the patient's ability to benefit (Derrett, Paul et al. 2002). Throughout the CPAC tool development, there has been a tendency to favour clinical priority criteria that are sometimes viewed as more 'objective' (such as the visual acuity score or the residual urinary volume).<sup>33</sup> Although 70% of clinicians reported a desire for a nationally consistent prioritisation system, the same proportion also reported favouring their clinical judgement as the most effective means of prioritising patients (McLeod, Morgan et al. 2004a). Yet, as McLeod et al note:

Clinical opinion alone will not achieve national consistency in access for elective surgery, as indicated by the substantial body of literature documenting variation in clinical practice (McLeod, Morgan et al. 2004b).

The Dunedin study, and more general studies evaluating predictors of outcome following surgery (Neal, Ramsden et al. 1989; Javitt, Brenner et al. 1993; Schein, Steinberg et al. 1995; Alonso, Espallargues et al. 1997; Hakenberg, Pinnock et al. 1997), suggest that where reliable and valid measures of health status exist, and where these have been found to relate to ability to benefit, these may be the most appropriate criteria to include within CPAC. Others have made similar calls either generally (Troidl, Kusche et al. 1987), or specifically in relation to CPAC:

...the most important criterion for treatment is surely the impact of a condition on a person's lifestyle rather than the simple presence of a symptom, clinical sign, impairment, or disability (Mordue and Parkin 1997a).

Clinical measures of severity may well be necessary to help surgeons make a diagnosis or to decide whether or not they would recommend surgery. However, where such measures do not relate to the desired aim of providing surgery (saving life or improving a patient's health status and quality of life), research indicates that they ought not contribute to CPAC prioritisation tools. Conversely, where clinical measures have been found to predict a desired outcome following surgery, they ought to contribute to CPAC. This means that there may need to be a considerable variation in the types of criteria contained within different CPAC. Where the goal of surgery is

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<sup>33</sup> However, the 'true' objectivity and reliability of such clinical measures has been questioned. Halliwell found considerable variation between assessors in the visual acuity scores for the same patients (Halliwell 1998).

to increase patient-experienced quality of life – then measures to prioritise according to patient-experienced quality of life ought to be included in the CPAC (although as mentioned, these need to be condition-specific or disease-specific rather than generic measures).<sup>34</sup>

Derrett, Paul et al recommended research exploring an alternative to prioritisation according to CPAC scores comprised of a mixture of measures, related and unrelated, to the ability of patients to benefit:

Once specialists have determined that there is a probable clinical benefit in providing surgery, disease-specific health status measures...could inform the process of prioritisation in conjunction with discussion of risks and benefits of surgery (Derrett, Paul et al. 2002).

The crucial step in this approach is the inclusion of patients in the decision-making process. As mentioned, the current CPAC scoring process can preclude the timely discussion between patients and doctors about whether patients really wish to have surgery in full knowledge of the likely risks and benefits.

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<sup>34</sup> Where the goal of surgery is to ‘save’ life as with much cardiac surgery, then CPAC may best contain criteria capable of best predicting lives saved. For certain conditions, such as operable malignant cancers which will inevitably result in death if left untreated, prioritisation according to CPAC tools may not be helpful (and as discussed previously, if clinicians are not clear that the CPAC tools are not to be rigidly applied in such circumstances, CPAC may well result in harms to patients). Perhaps for these types of conditions, prioritisation ought only consider the maximum acceptable waiting time for surgery. Indeed, cardiac specialists may well believe this situation applies to some patients prioritised for cardiac surgery. The difference between malignant cancer and cardiac prioritisation may be the existence of a clinically acceptable threshold effect for surgery. For example, for patients in earlier phases of cardiac disease the risks of surgery may outweigh the likely benefits to the patient – thereby justifying the use of CPAC tools. The author is neither a cardiology nor oncology specialist. However, it seems the first helpful step may be defining and agreeing the goal of surgery. Is the goal to: improve the lives of patients, save their lives – or as is undoubtedly the case in cardiac surgery – a combination of both quality enhancing and life saving? When surgery is directed more to life saving than to life enhancing, does it move from being an issue of prioritising ‘elective’ services to determining access to ‘acute or urgent’ services?

As pointed out by one of this report’s reviewers there are also situations where the condition is urgent, but where the current best evidence suggests there is little likelihood or magnitude of benefit from treatment. It is possible to envisage such situations arising within oncology services. Research publishing the use of CPAC-type tools for such conditions is unknown to SD. It seems that for such conditions the research may best be focussed on developing new and more efficacious treatments rather than developing CPAC tools to prioritise access to treatment of little likely benefit. Perhaps in such situations the decision about whether or not the risks associated with treatment outweigh any likely (small) benefit are best undertaken within the context of the doctor: patient: relationship? Where the benefits of treatment are likely to be minimal it may be that individual patients are more in need of other types of health care – such as pain relief, appropriate palliative care and/or psychological support. Of course, impacting on the decision-making at doctor: patient level will be wider decisions about the opportunity costs associated with the provision of such treatments within the state-funded health sector.

To date, patients have not been directly involved in the development of referral guidelines, ACA and CPAC tools. It is possible to imagine patient involvement in the selection of appropriate patient-experienced health status measures for inclusion within CPAC. However, if not carefully managed such involvement could result in mere tokenism.<sup>35</sup> The primary objective, may well be the use (and evaluation) of prioritisation tools placing a greater emphasis on the inclusion of well-validated instruments evaluating patient-experienced need, outcome and ability to benefit where these are known to exist.<sup>36</sup>

Given the historical preference by clinicians to use objective clinical measures in their decision-making (McLeod, Morgan et al. 2004a), the more recent return to implicit prioritisation according to the ISS used in orthopaedics, and the LAS, is of concern where such objective measures are unrelated to patient-experienced outcomes (Derrett 2001b). Research is required to ascertain patient outcomes as a consequence of such LAS and ISS prioritisation.<sup>37</sup> Outcome evaluation is difficult in areas such as general surgery where there may not be 'gold standard' health status measures available to evaluate the outcomes associated with all the different types of general surgical procedures. However an incremental approach could be adopted where the most commonly performed procedures, for which health status measures exist, are first evaluated for outcome.

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<sup>35</sup> Anecdotally, as discussed in 2.3.6, many clinicians seem to hold the view that any increased emphasis on patient-experienced health status within CPAC tools would result in patients 'cheating' to obtain access to treatment. Such a view, while presumably held by a minority, could threaten the quality of direct patient involvement in CPAC design.

<sup>36</sup> Perhaps the involvement of patients would be most appropriate in CPAC development where current 'best available' measures of patient-experienced outcome are lacking. Where well-validated patient-centred instruments are already known to exist for certain conditions the emphasis could then move from including patients in the development of CPAC to ensuring booking system evaluation includes the perspectives of patients?

<sup>37</sup> The ISS facilitates prioritisation across the spectrum of conditions, the prioritisation is entirely implicit and based on the individual clinician's perception of priority relative to all other patients that surgeon has seen. This raises additional ethical concerns (over those raised by the LAS) about the fairness between clinicians and also between regions within NZ. If the severity of referred patients varies between regions of NZ, the priority allocated in one region will necessarily differ from the priority allocated in another, as ISS prioritisation relies on surgeons allocating priority to patients relative to all other patients they have seen with the same condition (Derrett 2001b). Research evaluating the outcomes for patients prioritised with ISS is urgently required. This research needs to consider the relationship between ISS and patient-experienced health status and benefits. As with the LAS prioritisation tool, initial research ought to focus on the most commonly performed orthopaedic procedures for which condition-specific measures of health status exist.

As forewarned by Fraser et al (1993), some researchers have raised the possibility of CPAC score ‘gaming’:

Previous research has shown that the individual clinician has an impact on priority score. It is widely believed that surgeons (deliberately or subconsciously) elevate scores to ensure their patients’ acceptance for elective surgery (MacCormick, A.D., Tan et al. 2004).

Gaming and between-clinician variation detract from the provision of equitable access to elective surgery.

### **2.3.6 CPAC tool use and ‘gaming’**

MacCormick et al analysed 5440 patient priority scores from 16 general surgeons to determine whether or not priority scores were increasing over time independently of any actual increase in patient complexity (MacCormick, A.D., Tan et al. 2004). They found three distinct patterns: 1) no increase in priority score, 2) an increase in priority over time independent of an increase in patient complexity (‘gaming’), and 3) a ‘legitimate’ increase over time reflecting increased patient complexity. It would be interesting to know about any increases in the TT during the course of the study to determine whether such increases influenced the behaviour of the surgeons. It is possible that different definitions accompanying the LAS scale anchor points over time could also have influenced scoring.<sup>38</sup>

Although there were a number of limitations to their study, such as the measures of case-mix complexity possibly being insufficiently sensitive to ‘true’ changes in patients over time; they were able to conclude that although gaming appeared to be happening, it was not occurring to a great extent. Arguably, equally as important as the ‘gaming’ surgeons, is the group of surgeons who did not increase priority when there was an increase in complexity. MacCormick et al call for priority decisions to become part of formal audit and feedback procedures to reduce between-surgeon variation (MacCormick, A.D., Tan et al. 2004). In addition to such calls, it would also be useful to understand the reasons for gaming. Perhaps patient ‘complexity’ was not the most important factor to the surgeons who were ‘gaming’; they may be

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<sup>38</sup> Dennett et al reported the 10cm LAS scale ranged from ‘0=offer operation if no resource constraints’ to ‘100=prompt operation essential’ (Dennett and Parry 1998). Later, the LAS scale is reported as ranging from ‘0=not requiring surgery’ to ‘100=need for expedient elective surgery’ (MacCormick, A., Plank et al. 2002).

‘legitimately’ considering other factors such as ability to benefit or urgency when making their individual implicit priority decisions.

McLeod et al found surgeons clearly reported making their decision about providing surgery or not, and then making the CPAC score match this prior decision. Reasons provided for such a strategy included: concern about the criteria within the CPAC tools, perception of the tools as a management tool only – unrelated to clinical benefit, an inability of CPAC to accommodate situations where patients need staged follow-up surgery, between surgeon variation, different locality profiles influencing access and provision through different score thresholds and population/specialty characteristics (McLeod, Morgan et al. 2004b). Perceived variation in use of the CPAC tools by surgeons sometimes relates to insufficient information about the CPAC tool composition and the purpose of the system.

#### **Patients and ‘gaming’**

When the booking system was first introduced there was a sense that ‘technically rational’ explicit criteria would: lessen the variation between clinicians, reduce the inflation of priority for one patient over another for reasons lacking clinical validity, and reduce the priority afforded to patients more recently seen by clinicians (Cumming, A. 1999). As the system was introduced the emphasis appeared to move from ‘doctors as cheats or gamers’ to ‘patients as potential cheats’ – particularly surrounding the inclusion of patient-experienced criteria within CPAC tools (Derrett 2001a). Anxieties were expressed anecdotally by a number of health professionals involved in prioritising patients that patients may lie or exaggerate their health state to gain access to surgery (Derrett 2001a). Such concerns may cause clinicians to place a greater emphasis on ‘objective’ clinical measures of health status when prioritising patients for elective surgery – despite their sometimes-poor agreement with patient health status or outcome.

Some patients in the Dunedin study also expressed concern that some patients may exaggerate to gain access to surgery. A few assertive patients did gain access to surgery, although quantitative analysis of health status measures and CPAC suggested that patient exaggeration was not a great influence on CPAC scores (Derrett 2001a). The over-riding message from patients was of support for a ‘fair’ system in which patients in greater ‘need’ accessed surgery first – irrespective of



whether or not they themselves were in the groups receiving surgery. Strategies such as ensuring the timely discussion between health professionals and patients about the risks and benefits – including possible patient-experienced health status risks and benefits – may further reduce the temptation of patients to exaggerate their health problems.

If the TT is unduly high there is a likelihood of increased exaggeration by patients and clinicians alike. The next section considers research or publications discussing the TT and the use of resources.

## 2.4 The Treatment Threshold and use of resources

The nature of the health sector reforms in the early 1990s saw the ‘purchasing’ of health services devolved to four regional levels (Ashton 1996). This has contributed in part to regional variation in access to health services generally – and elective surgery in particular. For example, some areas stated that surgery for benign skin tumours and varicose veins were not to be purchased (Cumming, J. 1997). Such local health environments have influenced GP referral practices (McLeod, Dew et al. 2004), but we cannot be sure of the magnitude or extent of such impacts.

During the early phase of the booking system, clinicians expressed anxiety that a high TT would result in reduced access to elective surgery for patients (Seddon, French et al. 1999):

As might be expected, clinicians had mixed views on the project. The most commonly expressed concern was that the government or the regional health authorities would use the criteria to specify arbitrary numerical cut off points below which surgery would not be funded (Hadorn and Holmes 1997b).

Despite such reservations, the system was introduced throughout NZ by the use of strong incentives (Gauld and Derrett 2000), together with a mandatory 1 July 1998 deadline:<sup>39</sup>

The July 1998 deadline for the introduction of the booking system was set by the then Minister of Health, apparently for reasons of political expediency. Little consideration was given to the time required to finalise development and testing of the priority criteria. No guidance was given to hospitals about how to implement and manage the booking systems, or to GPs about how to manage patients who were deemed ineligible for treatment (Howden-Chapman and Ashton 2000).

The explicitness of the booking system did make possible calls for improved patient access and funding based on explicit evidence of a gap between funding and need (Neutze and Haydock 2000). For example, CPAC score profiles of patients could be described to identify the types of patients denied access to surgery because of high TTs. Such an approach was supported by Evans and Price:

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<sup>39</sup> Of course, it is possible, that without such powerful incentives, the former waiting list system would have remained.

...if clinicians just ignore the rules and keep doing their own thing [i.e. 'gaming] when the system *is* unjust they are in a sense tacitly approving of it. The correct thing to do is show how the rules lead to injustice and publicly challenge it. Doctors have considerable standing in the community and carry some responsibility to use it when necessary [And]... Everyone is harmed if the physician just plays along with an apparently unjust system rather than challenging it (p.37) (Evans and Price 1999).

Hadorn and Holmes demonstrated how challenging could be undertaken for CABG surgery (Hadorn and Holmes 1997b). When the national criteria were developed the consensus groups generally agreed a Clinical Threshold. This was the level at which clinicians believed surgery should be funded to.<sup>40</sup> The agreed Clinical Threshold for CABG surgery was 25 points, but:

...preliminary estimates indicate that the current funding levels will permit surgery to be offered to patients scoring at or above 35 points. As such, there is an apparent 10 point gap between what is clinically preferred and what can be afforded. We believe that the ability to quantify this gap, even if imperfectly, represents a major advantage... (Hadorn and Holmes 1997b).

Perhaps because of: the ongoing diversity of CPAC tools and models eventually used within the booking system, a lack of confidence in the tools or process, and an awareness of the local DHB-specific thresholds – calls identifying inappropriate 'gaps' have seldom been made by clinicians. There have been general calls made for improved funding of services, but they do not tend to be CPAC and Treatment Threshold-specific:

...in areas outside of Auckland, such as South Auckland, which have fewer resources and a much larger Maori and Pacific Islander community, patients need a higher score ...before cataract surgery is performed (Piechocki 2004)

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<sup>40</sup> More recently, to address inequities of access for hip patients with the ISS tool, it has been estimated that as much as \$85M would be required to provide sufficient hip replacements to meet the level of available for other orthopaedic procedures (Gandar, Williams et al. 2004). The alternative scenario would see the aTT rise for all other procedures to the extent that few patients with Dupuytren's contracture or carpal tunnel syndrome would gain access to surgery in publicly-funded DHBs. This would also have considerable flow-on effects – "The result of treating in broad priority order with the current prioritisation processes would mean a large increase in the ratio of joints resulting in pressure on limited bed and operating theatre capacity. Addressing this challenge will require rethinking how to utilise capacity across both elective and acute services to maximise the availability of limited resources" (p.14) (Gandar, Williams et al. 2004).

It would be interesting to have an increased understanding of the reasons why improved transparency with the booking system (compared to the former waiting list system) has resulted in few direct calls for increased funding.<sup>41</sup>

Interestingly, the Elective Services Group orthopaedic CQI project found that 71% of clinicians (n=24) were simply unaware of the TT they are working at locally (Derrett, Williams et al. 2004). Further, 50% were unaware of the level of funding provided to their service. Even if they are aware of their local TT, they may be unaware of the extent of regional differences in TT.

The lack of calls addressing funding shortfalls could also mean that clinicians feel anxious that such calls may result in services being further reduced instead of increased. Perhaps clinicians are frustrated to be working within such a technically rational system:

The move towards explicit prioritisation substantially shifts the locus of medical decision-making away from individual practitioners who make judgements about cases on strictly medical/ethical grounds to a context in which decisions are required to reflect explicit principles of prioritisation. Thus the professionalism of medical experts is now constrained. Resource constraints, once considered necessarily outside the ambit of acceptable justifications for clinical decisions is now explicitly factored in...At the level of professional and public discourse...it must be seen as an erosion of discretion and legitimacy (p.433) (Tenbensen 2000).

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<sup>41</sup> The author knows that throughout the course of the booking system many clinicians have written letters of complaint and some have undertaken research aimed at improved understanding and ultimately functioning of the system improve (e.g. Dennett and Parry 1998; Jackson, Doogue et al. 1999; MacCormick, A., Macmillan et al. 2004; McLeod, Morgan et al. 2004; Theis 2004). Indeed, this literature scan was initiated as a result of calls from Canterbury clinicians to revisit the booking system. What appears to be lacking is (visible)'politicisation' that Mechanic feared with explicit prioritisation systems (Mechanic 1997).

There has been one striking example where NZ clinicians called for changes to the system for prioritising access to CABG surgery following the death of a farmer in Southland who had received a high CPAC score – but who had not, at the time of his death, received access to surgery. Concerns were raised about inequitable Treatment Thresholds throughout the country. A review of the CABG system and a report to the Minister of Health noted that: 1) CABG CPAC scoring may not always be undertaken consistently between regions, 2) that media-reported differences in threshold were apparently differences in the Commitment Threshold (i.e. the CPAC score at which patients were given certainty of access to treatment) rather than the aTT (the score at which 90% of patients in the past 12 months gained access to surgery) – and that the aTT score thresholds were much closer between regions than the media-reported Commitment Thresholds, and 3) that treatment was not always delivered according to CPAC score priority order (Ministry of Health 2003; Naden 2004). If the reported differences in CABG CPAC use, Threshold description and priority order also apply to other elective specialties this may explain the relative silence by clinicians in calling for more appropriate funding for services.

Or perhaps they simply became disenchanted with the system when clinically unacceptable gaps were identified – and then left unresolved (Hadorn and Holmes 1997b).

In the face of increasing thresholds, the early anxieties held by clinicians may seem visionary. In a Dunedin study, the Treatment Thresholds in all three surgical groups evaluated, increased during the course of the one-year follow-up study (Derrett, Paul et al. 2002).<sup>42</sup>

Such increases in the thresholds resulted in dissatisfaction and uncertainty for patients caught in the gaps between the old threshold and the new higher threshold:<sup>43</sup>

So I was a bit surprised when I first had 55 points and I was over the margin of 50 points and couldn't get it [prostate surgery] done. And now I have 70 points and am just on the margin [TT had increased from 50 to 70 points] and am getting it done. The thing that really upset me was that I was removed from the waiting list and on to the Residual List and nobody told me why. They didn't explain that they had shifted the margin. Although they tell you the truth, they far from tell you the whole truth (Derrett 2001a).

In McLeod et al's qualitative study a clinician expressed acceptance of regional variation in access:

I'm not sure you should have a nationwide threshold because life isn't like that. The example I give you is that if I want to watch the All Blacks, they don't come and play here...Once you require, for instance a secondary service, then you have to do enough work to sustain that service. And because the location of that work may mean that some people get preferential treatment (McLeod, Dew et al. 2004).

Requirements of clinical governance and training will undoubtedly influence the precise configuration of local services. Whether such requirements should

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<sup>42</sup> The Clinical Thresholds were 30, 45 and 40 points for cataract, prostate and hip/knee joint replacement respectively. The initial Treatment Thresholds were: 30, 50 and 55 points; and increased during the study to 38, 70 and 65 points (Derrett, Paul et al. 2002).

<sup>43</sup> This does not indicate a weakness of the booking system approach, compared to any waiting list system. As mentioned, under the waiting list system, patients received 'commitment' – i.e. were told they had been placed on the waiting list for treatment – but then some waited many years without the receipt of treatment (Derrett, Paul et al. 1999). The booking system at least has some account to give of which people were previously amongst those to whom commitment was made and who now have not had that commitment realised. Also, the booking system at least makes research into such matters possible.

necessarily result in postcode surgery within a country with a population as small as New Zealand's is debatable. Strategies for resolving identifiable and unacceptable differences in rates of access to elective services could be explored – for example, mobile treatment units or offering care at other hospitals with capacity to treat to a lower threshold.

Research has found that rising TTs result in uncertainty for patients and health professionals alike. The provision of certainty about whether or not patients were to receive surgery, accompanied by indications of the length of waiting time, was an aim of the NZ booking system seeking to redress the adverse consequences associated with lengthy waiting times for elective surgery. The next section considers the provision of certainty to patients who do not receive sufficient CPAC points to gain access to surgery.

## 2.5 Certainty, re-referral and reassessment

Following the process of FSA at an outpatient clinic and CPAC scoring, patients will either: be booked to receive surgery in the next six months (if they met the CT), be told they are likely to receive surgery within the next six months – but certainty about date cannot be provided until closer to the time of surgery (if they had CPAC scores between the hospital's predicted TT and CT), placed on the AR list for follow-up by the hospital within six months (if they were close to the TT and the specialist was concerned the patient was likely to deteriorate), or returned to the care of their GP (if their CPAC score was low and the specialist did not have immediate concerns about the patient's health status or likely deterioration).

### 2.5.1 Certainty about status

#### Certainty about status within the booking system

As mentioned, to date only one NZ study has elicited views from patient about the booking system (Derrett 2001a; Derrett, Paul et al. 2002). At the initial interview with patients, a greater proportion of patients (70%) who subsequently went on to receive surgery were aware of their status within the booking system than patients who did not eventually receive surgery (16-44%).<sup>44</sup> Conversely, an appreciable minority (10-32%) of the 'No Eventual Surgery' groups were under the misapprehension that they would actually receive surgery.

When people had been led to believe they would receive surgery, or that it would occur within a particular time period and these expectations were not upheld, dissatisfaction was expressed:

[At 1<sup>st</sup> interview]: It's [hip joint surgery] in the offing, I don't know, he wouldn't give me a 'yes' or 'no' or nothing. There is a delay of over two years and he said we only do urgent cases because the government didn't give them enough money. He sort of hinted that there may be an opening in three months time. It's all up in the air. All this carry-on is down to the government apparently.

[2<sup>nd</sup> interview – six months later]: I wished I had had it, it's very painful...I saw my GP the other day and he thinks there is a possibility they might call me soon because I also have another condition.

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<sup>44</sup> The Elective Services Group reports that currently more than 80% of patients assessed are now told whether or not treatment will be available in the next six months (Naden 2004).

[3<sup>rd</sup> interview – another six months later]: I think they can't like me, they don't want me. It does give me quite a bit of trouble...I suffer day and night with it and there's nothing I can do about it. My GP I think has done something and the next time I go to him I'll have to see what he says...I don't feel right the way they're treating me. If it was only a wee bit sore – but it's way worse than that...I was expecting all the time there would be a call from the hospital. That's why I've never talked to my GP again about it.

Such comments clearly indicate harms for patients caused by the ongoing health problems experienced. It is also possible to see resonance between comments such as 'they can't like me' and the President's Commission's observation about the ability of health care (and health systems) to touch people's personal lives in mysterious ways (albeit, in the above instance, adversely) (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research 1983). Of course, such adverse effects associated with such false hopes have also been identified in waiting list systems, and indeed, were one of the prompts for moving to a more explicit booking system (Rigge 1994; Derrett, Paul et al. 1999).

It is quite possible that the increasing TT affected the ability of the hospital to quickly and accurately inform patients in the 'No Eventual Surgery' group about their true status within the booking system. It could also reflect avoidance of 'denial disutility' (being the bearer of bad news) as alluded to previously. The study by McLeod et al found that some surgeons failed to tell patients they did not currently qualify for surgery under the booking system – just as with the previous waiting list system:

I scored him and told him that the score was very low, but I put his name down on the waiting list and said that he's probably going to have a very long wait which is probably a fudge really [orthopaedic surgeon] (McLeod, Morgan et al. 2004b).

Of the 'Eventual Surgery' groups few experienced any postponement or delay to their arranged dates for surgery and most delays resulted from co-existing illnesses or patient preference rather than hospital-initiated causes. This contrasts with reports about high numbers of patients 'dropping out' of former waiting lists.



## **2.5.2 Re-referral and reassessment**

### **Lack of information for patients**

The booking system relies on GPs re-referring patients to hospital outpatient clinics when if the patient's health state worsens. Several problems have been identified with the process of reassessment. Crucially, some patients did not understand that they were to seek re-referral:

I think maybe they should send you something afterwards to know what to do and where to go from there. They told me at the time I didn't have enough points, but that's it...I suppose it's got to get worse and I have to go through the whole thing again to get enough points...It's a black hole, it's nothing. I don't know if I'm supposed to go back to my GP or what [patient assessed for prostate surgery] (Derrett 2001a)(p.331).

The information given to patients about the booking system was incomplete and variable (Derrett, Paul et al. 2002). In systems designed to improve the fairness and consistency of access, the provision of clear, consistent and comprehensible information is crucial.

### **Perceived futility of re-referral**

Sometimes communication between the GP and the hospital appeared to have been mislaid, and sometimes the cost of repeat visits to GPs acted as a deterrent – again raising the question of socio-economic equity. Of particular concern were reports that GPs may feel re-referral to be a futile exercise:

They've [the hospital] wiped me and referred me back to my GP, and he told me it would be a waste of time trying to get back into the system. Because he said if you've had one eye done they won't even look at you [patient assessed for cataract surgery] (Derrett 2001a)(p.331).

### **Lack of information for GPs**

These patient-reported experiences resonate with results from McLeod et al's study where GPs reported a range of strategies for patient advocacy. Variation in the referral patterns of GPs has also been identified elsewhere (Mordue, Parkin et al. 1994; Harrison and New 2000), along with possible (and inappropriate) explanations for varied practice such as differences in the individual values held by GPs (Joule 1998). In NZ additional reasons for the apparent varied approaches to re-referral may

relate to the information and communication between the hospital and the GPs about the CPAC scoring process itself (McLeod, Morgan et al. 2004b).

GPs are often given very little information about patients they have referred to the hospital. For example, they may be told their patient has been assessed and does not have a priority score sufficiently high to be treated (Derrett 2001a). Sometimes they may be told the total CPAC score – but not the points awarded for each of the discrete CPAC criteria. This makes decision-making about the appropriateness of re-referral difficult. When implicit priority tools are used (ISS or LAS) it is likely that transparency of information about the inability to offer access to elective surgery is even more difficult to provide. Some GPs have reported that they are not even clear about the type of priority scoring tool being used at the local DHB:

At the time of the study GPs knew that there had been changes to the way in which patients could access elective surgery but were not able to explain the changes. There was little known about CPAC, with the exception of GPs in one provincial centre who had been personally contacted by a local surgeon who had explained the changes (McLeod, Morgan et al. 2004b).

Although there have undoubtedly been efforts to be more transparent with information about the booking system through websites, true transparency seems elusive both for patients and their GPs. The website contains the national CPAC tools and the ESPI Performance Indicators, but it does not contain information about ongoing regional variations that is known to exist for both the CPAC tools and the TT.

### **Active Review**

Recently, the Active Review (AR) system has patients followed up by the hospital if they had CPAC scores close to, but beneath, the CPAC Treatment Threshold. Even with AR, some patients with low CPAC scores are returned to the care of their GP and require re-referral if their condition deteriorates.

The AR process could in part help remedy uncertainties and variability of re-referral. The Elective Services Group has produced guidelines to help hospitals implement AR. Currently, hospitals adopt a variety of approaches to the review of patients on AR – telephone follow-up, postal follow-up or in-person assessment. Unfortunately, we know that only ~50% of patients under AR are actually receiving regular review

(Naden 2004). As well as increasing this proportion of patients receiving the promised review, research is required to describe the different approaches and outcomes associated with AR follow-up, to ascertain the strengths and weaknesses of the different approaches.

### 3. Literature scan summary

The NZ booking system, with its: GP referral guidelines, ACA, CPAC, aTT, CT, TT and AR, is undoubtedly complex. The following section summarises the key aspects of the system in relation to the ethical issues identified through the literature scan.

#### Referral pathways and processes

- To date, research has focussed on the CPAC tools
- Too little is known about the care pathway prior to First Specialist Assessment (FSA) and CPAC scoring
- The use and perceptions of referral guidelines by GPs is unknown
- Socio-economic inequities of access to FSA have been reported by GPs (where wealthier patients can shortcut the waiting time for FSA by seeing a consultant in the private sector; thereby also reducing the waiting time for elective treatment)
- Perceived regional variation in the provision of services and waiting times affects the national of consistency of GP referral practices
- Currently, we do not know enough about the joint GP: patient decision-making process leading up to referral
- Some patients have reported entering the booking system to seek reassurance or confirmation of their diagnosis, and ending up receiving surgery with possible associated harms
- There is reported variation in GP ‘advocacy’ strategies. If these are inappropriately related to variables such as age, sex, ethnicity or place of residence (e.g. urban vs rural) then this is of ethical concern
- Maori and Pacific people tend to be referred to FSA when their cardiac condition is more serious than others. Research is required to better understand the causes of such differences in access and to implement strategies to remove barriers to access
- Currently, we do not know if differences in access to FSA for Maori and Pacific people apply to all areas of elective surgery – or just to cardiac surgery. Research is required to determine this
- Research is also required to ascertain the reasons for ‘late’ referral for all patients who receive ‘high’ CPAC scores at FSA

- Reports that some GPs ‘lie or exaggerate’ the severity of their patients’ conditions to obtain their access to FSA have become known as ‘gaming’. We need to determine whether such gaming is appropriate or inappropriate. Even where such practice is grounded on ‘legitimate’ concern for a patient’s health state – such behaviour inevitably results in inequities between different GPs (if one GP lies or exaggerates and another GP simply ‘accepts’ delayed access to FSA for their patients). As identified by Evans and Price (1999) a more appropriate response to such reasonable concern would be for GPs to work to improve the booking system tools and processes, and/or, to engage directly with the outpatient specialist to discuss such concerns.

#### **Hospital outpatient clinics and Assessment Criteria for FSA (ACA)**

- Reports of varying standards of GP referral letters suggest that there may be inequities of access to FSA
- The use of ACA by hospital outpatient clinics is unknown
- We do not know the proportion of patients returned to the care of their referring GP without obtaining access to a FSA
- There is a potential harm to patients if the ACA are insensitive to true patient needs for FSA
- GPs may need alternative routes to specialist consultation for their patients if they have ongoing concerns about the lack of access

#### **CPAC tools and prioritisation**

- For the same elective condition – different CPAC tools have been developed and are in use throughout NZ – contrary to the recommendation by Fraser et al (1993). These inconsistent tools have been insufficiently evaluated for their, undoubtedly varying, impact on patient access to surgery and patient outcomes
- Tools vary according to:
  - 1) whether they are explicit (with discrete scoring criteria and points summed to a total CPAC score – usually out of 100) or implicit (where priority is determined according to the ‘unknown’ decisions of individual clinicians and recorded on linear analogue scales of 1-5 or 1-10 as with the LAS tool used in some areas to prioritise patients for general surgery and the ISS used to prioritise patients for orthopaedic surgery)

- 2) whether the tools used locally are the nationally recommended tools (available on the Elective Services website), or regional variations. Local CPAC variations are not posted or defended on the website
  - 3) the CPAC Treatment Thresholds are determined locally within each DHB according to historical workload – thereby varying throughout NZ and perpetuating any former regional inequities of access to treatment
- Such variation in CPAC tool use and thresholds makes national consistency of access unattainable
  - Poor agreement has been found between scores for the same patients obtained from general CPAC (i.e. prioritising all patients assessed for general surgery), condition-specific or disease-specific CPAC (e.g. CPAC prioritising patients assessed for cholecystectomy) and implicit LAS of clinical judgement
  - The use of implicit priority tools – such as the LAS for general surgery and the ISS for orthopaedics – makes evaluating the consistency of relationship between priority and patient outcome difficult
  - Clinicians have agreed about the presence of 27 different criteria that contribute to their implicit priority decisions. We do not know if these 27 criteria are applied consistently between clinicians, or between regions, raising issues of possible inequities of access to surgery if some clinicians focus on inappropriate criteria in making their priority decisions
  - We know CPAC tools are not completed in a uniform manner throughout NZ. CPAC are sometimes completed by medical clinicians, by nurses, by consultants' secretaries and by booking system administrators or clerks
  - When CPAC completion is by third parties, removed from the doctor: patient context, opportunities for joint doctor: patient decision-making about patient preferences for treatment in light of full knowledge of the risks and benefits associated with surgery are removed. This raises issues of patient autonomy and informed consent
  - One study found CPAC scores related to whether or not patients actually received surgery. However, another study found men and older patients waited longer for surgery

- The Elective Services Group has found that allocated priority scores do not relate to the timeliness of access to surgery – and that some patients with higher scores are waiting longer for surgery than patients with lower scores, raising questions about equitable access
- Another study found that half of the participating surgeons reported that the CPAC score influenced their selection of patients for surgery, but nearly 90% favoured their clinical judgement when selecting patients for surgery
- Maori and Pacific people have lower rates of access to cardiac surgery than others. Research is needed to understand the reasons for this and to determine whether such differences also occur in other elective surgical specialties. One project has reported that Maori have quicker access to hip joint replacement than others – but this may reflect a greater actual ‘severity’ at the time of FSA
- Little is known about the relationship between CPAC priority and patient-experienced outcomes
- Studies have found that CPAC scores fail to predict readmission to hospital, myocardial infarction and even death while on waiting lists for cardiac surgery
- A study has also found that CPAC scores at the time of FSA were only weakly-to-moderately correlated with patient-experienced health status, and were not related to patient-experienced health status improvement following cataract, prostate or hip/knee joint surgery
- Certain criteria within the CPAC tools (e.g. visual acuity, residual urinary volume and uroflowmetry) were not related to patient-experienced improvement following surgery. This led to calls to abandon the use of criteria unrelated to patient outcome within CPAC
- Certain clinical criteria undoubtedly relate to outcome – as with the cardiac CABG CPAC currently being improved by the Elective Services team and clinical collaborators
- Where clinicians continue to favour ‘objective’ clinical measures of health status, and where these have been found to be unrelated to patient outcome, it raises concern about the implicit clinical priority scoring approaches
- There is a need to ensure patients desire and consent to surgery in full awareness of the risks and benefits attached to the provision of surgery itself – and in full knowledge (where this is available) of the probable patient-experienced benefits (and lack of benefits) following surgery should it be

provided. Currently, the process of scoring can interrupt the inclusion of patient preferences for treatment

- There is evidence of some priority score ‘gaming’ by clinicians, although this is not extensive. Again, the reasons for gaming need to be understood as some ‘gaming’ may actually be legitimate (although more direct actions could be taken by clinicians to engage with, and improve, the system as outlined by Evans et al)

### **The Treatment Threshold**

- Clinicians’ fears about increasing Treatment Thresholds determining access to surgery have been borne out
- However, calls from clinicians for increased funding to address unmet need (identified through the use of explicit CPAC tools) have been relatively few. Possible reasons for this include: the use of different CPAC tools and thresholds in existence; inconsistent use of CPAC tools thereby preventing the robust identification of insufficient funding to generate an improved allocation of resources; frustration at working within a technically rational system, and/or the lack of clinical champions for booking system improvement throughout NZ
- Patients affected by increasing thresholds experience harm through: a lack of certainty about the provision of surgery, negative health effects resulting from untreated health problems, and even a sense of ‘being uncared for’ – as experienced by patients under the former waiting list system

### **Certainty**

- It appears that greater levels of certainty about access to treatment are being provided under the booking system than was the case under the former waiting list system
- However, patients who are going to receive surgery have greater certainty about their pending treatment than patients who are not going to receive surgery. This may result from the reluctance of health professionals and hospitals to ‘be the bearers of bad news’ or from difficulty managing timely and accurate communication with patients in light of increasing TTs
- We still do not know enough about the care pathways for patients with CPAC scores beneath the TT and denied access to publicly-funded surgery



- Difficulties accessing re-referral to hospital outpatient clinics have been reported by patients
- Crucially, a lack of truly explicit information to GPs (and patients) about the referred patients' inability to obtain sufficient CPAC points to gain access to surgery has been identified. GPs do not appear to receive a detailed breakdown of their patients' CPAC scores. This makes it difficult for GPs and patients alike to know when subsequent re-referral to outpatients would be appropriate (i.e. to know when the patient has deteriorated sufficiently to warrant re-referral). Some GPs do not even know which CPAC tool is being used at their local hospital. The national CPAC tools are posted on the Elective Services website – but not the regional variations in use or the associated TTs
- Active Review (AR) may improve the certainty about treatment pathways provided to patients failing to reach the CPAC score TT. However, only 50% of AR patients are currently being regularly reviewed by hospitals
- Further, we do not know, in sufficient detail, how the AR reviews are conducted by hospitals and what impact the different style of review has on patient outcomes

## 4. Concluding comments

This report has presented a rapid scan of the literature to help identify ethical issues arising from the booking system. However, there is one further issue of definition and understanding arising from the scan that has not been sufficiently elaborated in the report; structured as it has been around the patients' journeys through the booking system.

Precise definitions of the terms 'need' and 'ability to benefit' (and related concepts: 'priority' and 'urgency') were not clearly outlined in the early development of the booking system. Different understandings of these terms have been revealed by the scanned literature. These differences appear to have influenced the development and use of CPAC tools from their inception. Researchers have found little agreement as to the system's purpose, and perhaps consequently, national (and even local) consistency remains elusive.

Research has addressed (in part) the validity and reliability of CPAC tools and reveals widely differing perspectives about the purpose of prioritisation tools – be they implicit LAS or ISS, or explicit CPAC tools. Some of the reported perceptions about the use of tools are at odds with the original aims of the system – and the aims still expressed by the Elective Services Team (Elective Services Group, Ministry of Health 2004). For example, Dennett et al observe that clinicians view equity according to equal access for all patients in need of health care, which implies a lack of agreement with the principle of prioritisation according to ability to benefit. They note that scores on the LAS:

...were positively skewed consistent with the fact that all patients assessed by clinicians warranted treatment because they had symptoms and the observation that healthcare professionals seem to be the most aware of the importance of maintaining equal access for everyone in need of health care (Dennett, Kipping et al. 1998).

In contrast, Doogue et al called for access to treatment to be:

Based on the likely benefits (improved quality and length of life), determined by the evidence from previous trials and clinical audit, weighed against likely costs (operative mortality and morbidity) for each patient (Doogue, Brett et al. 1997).

Similar differences between surgeons were also identified in McLeod et al's study where some surgeons acknowledged their initial reluctance to introduce prioritisation and rationing systems, but believed it to be a more honest approach; and others believed the booking system should not remove people from the waiting list when their CPAC score falls beneath the TT.

The former Health Funding Authority defined 'need' as:

...the capacity, ability, or propensity to benefit from defined health and disability services (Health Funding Authority 1998).

However, such a definition requires elaboration.<sup>45</sup> Ability to benefit could include: potential improvements in 'health status' following surgery, and the benefits of lives saved, or lives extended, in the case of people with malignancies or other life-threatening health conditions. Ability to benefit could allow both the duration and magnitude of anticipated benefit. Ability to benefit could accommodate patients with 'less severe' health problems, if the provision of day case surgery can provide 'ability to benefit' through forgoing the adverse effects of years of slowly degenerating health status until a point of 'severity' is reached. If elective surgery cannot offer a likely ability to benefit for the patient, then it is not elective surgery that is required – but some alternative form of health or social support that can benefit the patient. Ultimately, agreement about the definition and use of 'ability to benefit' will also require a re-evaluation of the importance and nature of socio-economic and socio-demographic variables within CPAC (McLeod, Dew et al. 2004).

However, in the assessment of benefit, it is important that QALY-type instruments (e.g. EQ-5D and HUI) do not become part of the process of *prioritising* patients, as they have not been found to be sufficiently sensitive to patient-experienced health

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<sup>45</sup> As one reviewer commented, and as accepted by SD (Derrett 2001a; Derrett, Paul et al. 2002), there is also the more fundamental point that a very different, and at least equally natural, definition of 'need' is, roughly: 'severity or seriousness of condition'. The fact that 'need' admits these two crucially different understandings makes it an unfortunate term to use in the present setting. It's a fundamental issue whether the point of the service is to reflect patients' presenting seriousness of condition, or instead, to reflect their likely benefit from the service. Only if one decides in favour of the latter do the complexities within the 'benefit' aim even arise. If health professional bodies were to state that prioritisation, and reflection on the basis on which it is to be done, is an important part of professional practice, then the next important issue for such bodies would be *which* broad sort of basis is the most appropriate. The above emphasis on ability to benefit reflects SD's view that health treatments, carrying their inevitable risks, ought to result in an overall likely beneficial outcome to patients. Where such a beneficial outcome is unlikely then SD would argue that some other treatment or service is required to meet the identified 'severity or seriousness' of the patient's condition.

status, or improvements in health status following surgery (Derrett, Paul et al. 2002; Derrett, Devlin et al. 2003). If such QALY-type measures are to be used, it should be for the purpose of academic inquiry only. Similar caveats also need to apply to measures of general health status, such as the SF-36, which by their very nature may reflect health status changes related to co-existing diseases rather than the elective ‘operable’ disease.

In their review of prioritisation systems for elective surgery, MacCormick et al emphasise the importance of agreeing the meanings underlying prioritisation:

The issue of prioritisation and/or rationing is ethically if not politically sensitive. The reporting of the ethical basis that the criteria [e.g. dimensions within CPAC tools] are determined by should be a conscious process in the determination of normative criteria for prioritising patient outcomes. Differing ethical bases may result in different criteria and potentially different patient outcomes (p.641) (MacCormick, A.D., Collecutt et al. 2003).

The current lack of a shared understanding of the terms ‘need’ and ‘ability to benefit’ may explain some of the evident uncertainties and anxieties accompanying the booking system. Indeed, achieving agreement about purpose may help address the current variation in CPAC models and tools:

- Are they rigid tools to ration access to treatment, irrespective of clinical and patient judgements and preferences – or tools to aid clinical judgement within a context of restricted funding?
- Are they tools of diagnosis – or tools to order patients, who meet the diagnostic and surgical eligibility criteria, in a fair and explicit manner?
- Are they tools to prioritise patients according to pre-operative measures of clinical severity – or tools to prioritise patients according to the likely patient-experienced benefits offered by surgery?

The literature describing research and booking system developmental work reveals strengths and weaknesses, benefits and harms, associated with the booking system in practice. It also reveals many gaps in our completed research – gaps, which if filled, would help us to better understand the system and, most importantly, the impact on the system for patients throughout NZ. Conceptually, the booking system promised advantages (national consistency, certainty and equity) for NZ patients over the former waiting list system. To date, the booking system has not functioned in

practice as originally intended. Additional consideration of the reasons for such failure-in-practice and strategies to address any ethical issues raised by the booking system in its current guise is now required.



## List of Abbreviations

ACA	Assessment Criteria for First Specialist Assessment
AR	Active Review
aTT	Actual Treatment Threshold
CABG	Coronary Artery Bypass Graft
CPAC	Clinical Priority Assessment Criteria
CSC	Core Services Committee
CQI	Continuous Quality Improvement
CT	Commitment Threshold
ESPI	Elective Services Performance Indicators
FST	Financially Sustainable Threshold
GPs	General Practitioners
ISS	Integrated Scoring System
LAS	Linear Analogue Scale
NHS	National Health Service
NZ	New Zealand
PCTs	NHS Primary Care Trusts
TT	Treatment threshold (or Predicted Treatment Threshold)

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