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Exploring health stakeholders' views about the prioritisation of patients for the operating theatre

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Declaration

I declare that this document is an original work of my own authorship and that it fulfills all the requirements of the Code of Conduct and Good Practices of the Universidade de Lisboa.

Preface

The work presented in this thesis was performed at Centro de Estudos de Gestão do Instituto Superior Técnico of Universidade de Lisboa (Lisbon, Portugal) during the period February-December 2020. This thesis was supervised at Instituto Superior Técnico by Doctor Klára Dimitrovová and Professor Mónica Duarte Correia de Oliveira.

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Abstract

In healthcare, the distribution of resources may imply strategies which will deny potentially beneficial services to patients, known as rationing. One widely-implemented strategy of rationing are waiting lists for elective surgery. Nevertheless, the criteria which should be used in prioritisation are still not defined. Traditionally, surgeons are responsible for patient prioritisation in SNS, which may bring issues of fairness regarding patient's needs. Demands for a more explicit process, where the criteria are used uniformly in a transparent process, have been increasingly frequent. The work developed in this Master's thesis aims at exploring and modelling health stakeholders' views regarding which dimensions should be considered in the prioritisation of patients in waiting lists. A literature review was carried out with the goal of collecting the criteria suggested for priority setting of patients. Afterwards, the elicitation of the views of surgeons working in SNS about potential criteria was carried out through six semi-structured interviews. These methodological techniques were designed to be followed by a new protocol based on non-numeric judgements to compute the weights of each criteria in an overall prioritisation score, the MACBETH approach. The results showed that the potential criteria which were deemed relevant for use in a PPT were: Severity of Disease, Main Symptoms, Functional Impairment, Probability and degree of improvement of HRQoL, Probability and degree of improvement of severity of disease, Limitation to care for one's dependents, Lifestyle, Limitation in the ability to work, study or seek employment, Waiting Time and Evidence-Based Medicine. The results of the interviews also showed that experts only make use of the criteria defined in Legislation implicitly. Furthermore, the methodology initially proposed must be altered to study what would be the adequate range of applicability of the criteria.

Keywords

Rationing, Patient prioritisation, Waiting lists, Elective surgery, MACBETH method, Delphi

Resumo

A distribuição de recursos em cuidados de saúde pode implicar a negação de serviços médicos potencialmente benéficos a doentes, definido como racionamento. Uma estratégia de racionamento são as listas de espera para cirurgia eletiva, mas existe bastante discussão acerca dos critérios a ser utilizados para definir a prioridade dos pacientes. Tradicionalmente, os cirurgiões têm sido responsáveis pela atribuição de prioridade, o que levanta questões de equidade relativamente às necessidades dos pacientes. Pedidos para um processo mais explícito, em que os critérios são utilizados uniformemente, têm sido frequentes. Esta dissertação visa explorar e modelar as opiniões dos intervenientes nos cuidados de saúde relativamente a que critérios devem ser considerados na priorização de pacientes no SNS. Foi realizada uma revisão bibliográfica com o objectivo de recolher os critérios já sugeridos para o cálculo da prioridade. Posteriormente, a elicitação dos pontos de vista dos cirurgiões foi realizada através de seis entrevistas semi-estruturadas. Estes passos metodológicas foram seguidos por um novo protocolo baseado em julgamentos não numéricos, através da abordagem MACBETH. Os resultados mostraram que os potenciais critérios considerados relevantes foram: Severidade da Doença, Sintomas Principais, Incapacidade Funcional, Probabilidade e grau de melhoria da HRQoL, Probabilidade e grau de melhoria da severidade da doença, Limitações à capacidade de cuidar de dependentes, Estilo de Vida, Limitação à capacidade de trabalhar, estudar ou procurar emprego, Tempo de Espera e Medicina Baseada em Evidência. Os resultados das entrevistas também mostraram que os peritos apenas fazem uso dos critérios presentes na Legislação implicitamente. A metodologia inicialmente proposta deve ser alterada de modo a averiguar qual o alcance ideal da aplicabilidade dos critérios.

Palavras Chave

Racionamento; Priorização de pacientes; Listas de espera; Cirurgia eletiva; Método MACBETH; Delphi

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Acronyms

SNS	Serviço Nacional de Saúde
MACBETH	Measuring attractiveness by a categorical-based evaluation technique
PPT	Patient Prioritisation Tool
PPTs	Patient Prioritisation Tools
GPs	General Practitioners
EF	Ethical Framework
HRQoL	Health Related Quality of Life
CPAC	Clinical Priority Assessment Criteria
URGs	Clinical Urgency-Related Groups
MTBT	Maximum Time Before Treatment
SIGLIC	Sistema Integrado de Gestão da Lista de Inscritos para Cirurgia
LIC	Lista de Inscritos para Cirurgia
MCDA	Multiple Criteria Decision Analysis
LP	Linear programming
FPVs	Fundamental Points of View
FPV	Fundamental Point of View

1

Introduction

Contents

1.1 Motivation

Health has long been acknowledged as one of the essential basic rights of every individual [1, 2]. In an effort to provide the best healthcare possible to every citizen, healthcare spending occupies a significant percentage of the Gross Domestic Product, especially in the case of developed countries [2]. Furthermore, there is a tendency for this percentage to increase in light of the socio-economic situation most developed countries are faced with: the framework of ageing populations, a transition from a high incidence of acute diseases to chronic illnesses, and a massive growth in advances in healthcare technologies, associated with high investment and costly equipment and treatments [2, 3].

Therefore, in order to control the tendency in healthcare spending, it becomes essential to guarantee that healthcare resources are allocated as efficiently as possible, with the goal of maximising population health levels at the minimum cost possible [2, 4]. Inevitably, this distribution of resources will entail implicit or explicit mechanisms that will allow people to go without potentially beneficial services, which is defined in literature as rationing [2, 5]. The process of rationing is especially aggravated in periods of economic recessions and their aftermath, which leads to public spending cuts, as has been observed since the economic crisis of 2008 [2].

Rationing can occur at different levels of the healthcare system and involve different stakeholders [2, 6], as will be explained in the next chapter. These stakeholders could be patients and citizens, representing receivers of healthcare, or physicians and health managers, constituting its providers and regulators. It is generally agreed that despite the stakeholders involved and the level at which ratioting is carried out, more explicit approaches should be adopted, with special emphasis in the process of prioritisation of patients in waiting lists for elective surgery [3].

Surgical care is paramount to the maximization of health benefits, as it is the first (and in many cases the only) option for controlling and treating several health conditions, for example injuries, obstructed labour, malignancy, infections and cardiovascular disease [7]. The number of surgical procedures in both developed and developing countries has increased, as statistics from the World Health Organisation show that the global volume of surgery increased 38.2%, from 226.4 million operations in 2004, compared with 312.9 million in 2012 [7]. Furthermore, surgical care requires a management with a great level of complexity, since the operating theatre relies on a strict coordination of skilled human resources, specialized supplies and equipment [7]. The high number of surgical procedures performed, associated with its complex management, lead to a large portion of healthcare spending being related to hospital care and surgical procedures, as is shown by statistics collected by governments and health organizations around the globe [8].

Despite the large spending in healthcare, the financial and workforce resources are still scarce to meet the demands of every patient. Evidence shows that although there has been investment in expanding the capacity for surgery services, the increase in demand outweighs these efforts in public

healthcare systems [9, 10]. It thus becomes necessary to create a buffer between the demand for elective surgical procedures and the capacity of the health system to provide them [11]. This buffer takes the form of waiting lists for surgery services, which makes it possible to choose which patients should be attended first in a prioritisation process [11].

In fact, there has been extensive research regarding the prioritisation of patients waiting for surgical procedures as a means of rationing [12–18]. Although it is widely agreed that prioritisation of patients through waiting lists is inevitable, the jury is still out as to which criteria should be used to rank patients [2]. Firstly, the different stakeholders mentioned above present different goals as far as healthcare management is concerned, since they assign different purposes to healthcare services as per their roles of receivers, managers or providers. Hence the factors to be prioritised can vary whether the respondent is a citizen, patient, health manager, ethicist or surgeon. Secondly, even within the same group of stakeholders, the moral views may be intrinsically different, leading to a different prioritisation according to efficiency or equity principles. [19].

Prioritising patients for surgical procedures in public healthcare systems remains largely based on a first-come, first-served policy [20, 21]. Demands for a more explicit and non-arbitrary process, where the criteria used for the prioritisation of patients are defined and used uniformly by decision-makers in a transparent process, have been increasingly frequent [1, 3, 6, 22–32]. Although these demands have been noted in several countries and including different types of health systems, special attention will be given to the Portuguese case, where the management of waiting lists is in charge of specialist doctors and surgeons, who often carry out such a task implicitly and in an uncoordinated fashion [3].

Such process can only be achieved if certain measures are taken to ensure its consistency. Firstly, the identification of which criteria are currently used by decision-makers to prioritise patients in waiting lists for elective surgery in the Portuguese public healthcare system must be presented, and whether they are used in an implicit or explicit manner.

Afterwards, consensus should be sought as to whether these criteria considered in current prioritisation processes are indeed adequate for use in a prioritisation scoring model. Furthermore, the strength with which the performance in each criterion contributes to patient prioritisation should be clearly defined and used homogeneously.

Moreover, it must be understood whether criteria are evaluated using generic descriptors of performance or descriptors which are specifically related to the type of surgery speciality.

Finally, the results of this work must be applied in the development of a fair and transparent priority scoring tool, to be implemented in the real-world context of priority setting for elective surgery.

1.2 Objectives

The work developed in this master's thesis aims at exploring and modeling health stakeholders' views regarding which dimensions should be considered in the prioritisation of patients in waiting lists for elective surgery in the Portuguese public healthcare system, *Serviço Nacional de Saúde* (SNS). Methodologically, this thesis is designed to combine literature review, survey design and multi criteria modelling with the goal of generating information about the preferences of health stakeholders. It will contribute to the development of a new patient priority scoring tool to help clinicians, namely surgeons and specialist doctors, in the prioritisation of patients in waiting lists for elective surgery.

To begin with, this thesis will involve the listing of the concepts of health resource allocation, rationing, patient prioritisation and waiting lists. Once these concepts are well understood, a literature review will be carried out to the collect the major theories and criteria used implicitly or explicitly in priority setting of patients waiting for elective surgery in different countries and health systems. Particularly, it is paramount to analyse not only the criteria being used in patient prioritisation instruments, but also how they are defined, and the context in which those instruments are implemented: the specificity or generality of the application of criteria should be registered, as well as the ethical framework used to justify the prioritisation tool. On the other hand, it is expected that a thorough comprehension of quantitative and qualitative methods used to develop those patient prioritisation instruments is acquired.

Once these objectives are achieved, and a list of potential criteria to be used in a patient prioritisation tool for waiting lists is collected, the elicitation of health stakeholders' views on these criteria ensues. A new protocol shall be designed, based on the elicitation of semantic (non-numeric) judgements regarding differences in attractiveness between improvements in the performances of different criteria, through a Measuring attractiveness by a categorical-based evaluation technique (MACBETH) approach incorporated in a Delphi questionnaire. This protocol will result in the assessment of weights for each criterion and ultimately in a numerical scoring scale which will allow precisely the relative prioritisation of the patient by comparing this score to the score of other patients.

Additional to the design of the proposed protocol, it is expected that part of it will be carried out. In order to ensure the reliability of the results of the MACBETH approach, the criteria and the corresponding descriptors of performance, which opeationalise it, will be constructed using information collected from the literature review and from semi-structured interviews with experts in patient prioritisation, namely surgeons, in charge of outpatient consultations in hospitals of the SNS. The remaining steps of the proposed methodology may be carried out in future work, outside the scope of this Master's thesis.

1.3 Document Structure

This master's thesis is organized in seven chapters, starting with an introductory chapter where the motivation and objectives for this work are set.

Furthermore, **Chapter 2** sets the current context on healthcare resource allocation, rationing and prioritisation of patients which justifies this work, whereas **Chapter 3** concerns a literature review on the criteria which may be used to define prioritisation in waiting lists for elective surgical procedures in healthcare systems. Furthermore, examples of methods which allow the development of prioritisation instruments implemented in different public health systems in an international context are given, with a special emphasis on the Portuguese case.

Chapter 4 presents the methodology chosen to elicit relevant stakeholders' attitudes towards patient prioritisation in waiting lists and ultimately to develop a patient prioritisation scoring tool, with a clear definition of the various stages necessary to achieve so. In particular, this chapter will include the description of the methodology used to validate the criteria in semi-structured interviews with the relevant stakeholders, as well as the description of the methodology of the MACBETH approach, which aims at collecting data to elicit those preferences through online tools, both qualitatively and quantitatively.

Chapter 5 presents the results of the data analysis on semi-structured interviews, which lead to the presentation of criteria to be used in the MACBETH approach that aims at defining the weights of these criteria in a patient priority scoring tool. Their comprehensive discussion and interpretation are presented in **Chapter 6**.

Finally, in **Chapter 7**, final thoughts on the work done under the theme of this master thesis are given, along with guidelines for future research on this topic.

2

Context

Contents

This introductory chapter aims at presenting the fundamental concepts and definitions which are paramount to the understanding of the context in which prioritisation may occur in public healthcare systems. Hence, definitions of concepts such as health resource allocation, rationing, and prioritisation of patients are presented. Furthermore, the problem of waiting lists for elective surgery in public healthcare systems is explained, with the aim of presenting prioritisation of patients as a means of rationing at the micro level to improve the management of waiting lists for elective surgery. Finally, different approaches which can be adopted when implementing prioritisation policies are also described.

2.1 Health resource allocation and rationing

Need and demand for healthcare services have outweighted availability of resources since the dawn of the first healthcare systems, hence the problem of resource allocation, which can be defined as the distribution of health-related materials and services among various uses and people [33], has been around for long. Nevertheless, taking into consideration the recent framework of ageing populations, and a transition from a high incidence of acute diseases to chronic illnesses, demand for healthcare has increased even further, together with a massive growth in advances in healthcare technologies, associated with high investment and costly equipment and treatments, healthcare spending has grown more rapidly than overall economic growth [34–36].

This change in healthcare paradigm means that healthcare resource allocation is no longer solely a question of ruling out ineffective treatments and trying to increase production, but rather which optimal package of efficient treatments should be selected to allocate resources from several available [32].

One common consequence of resource allocation strategies is related to the delay or denial of resources to patients in need, so that other patients can be treated. This is known in literature as rationing, that is, any implicit or explicit mechanisms that allow people to go without potentially beneficial services [5, p. 2], based on the grounds of scarcity of a medical resource or excessive cost [37–40].

Although ”rationing” and ”resource allocation” are commonly used interchangeably in literature, it is worth mentioning that the implementation of strategies to target limited healthcare resources does not always result in rationing. For example, opting for a less expensive treatment if it is as effective as a more expensive one, or adopting measures to reduce unnecessary costs are strategies of resource allocation which may not require denying beneficial care to patients, and thus do not imply rationing [39].

Since rationing entails denying potentially beneficial services, rationing strategies must only be carried out when necessary, and must also be ethically justified considering the healthcare context [39]. Nevertheless, many questions are yet to be answered in order to implement legitimate rationing strategies, such as what principles should be used to ethically justify rationing, who should be responsible for defining such principles/ criteria and who would have the authority in implementing them [41].

It is argued in Gordijn, Bert et al, 2013 [23] that this ambiguity is partly due to the complexity that healthcare rationing entails, namely the multitude of levels at which resource allocation, and thus rationing, can take place. Therefore, not only is it important to understand the economical and political context, which is time and country-dependent, but it is also fundamental to define at what level and how resource allocation strategies are implemented [23].

2.1.1 Levels of resource allocation

Healthcare rationing is a controversial and multiplex exercise, and can result from resource allocation happening at three different levels [42–44]:

- **Macroallocation** occurs at the higher level, nationwide and affecting society as a whole. Some examples of macroallocation of resources include governments setting the annual healthcare budget, or healthcare stakeholders defining guiding principles, which will decide what treatments and interventions to include in the healthcare system. [45]
- **Mesoallocation** is usually carried out at the hospital level, and involves hospital providers deciding the budget for each speciality or service, which implicitly gives preference to one service over the other. [45]
- **Microallocation** concerns clinicians making decisions at the individual level, such as resource allocation between different types of interventions for the same patient or between different patients for the same intervention.

Regardless of the level of decision-making, every strategy will eventually have an impact on patients, because the three levels are intrinsically related. Hence, it is argued that these strategies concern every citizen, and not just the clinician or health manager responsible, or the patient directly affected [39, 42].

2.2 Rationing at the micro level

Rationing resulting from resource allocation at the micro level, which is often labelled as bedside rationing, was defined in an article by Peter Ubel and Susan Goold [46] as:

”Withholding by a physician of a medically beneficial service because of that service’s cost to someone other than the patient”

The most common strategies for bedside rationing include:

- Delaying patients from accessing healthcare so that theoretically demand can match supply, through the use of waiting lists [29, 29, 43, 47–50].
- Selectively referring patients who have the highest probability of benefiting from the healthcare service, or set a higher threshold of eligibility for those services [29, 43, 51, 52].

- Diluting the quality of care and services available, but maintaining the healthcare treatments [29, 43].
- Deterring patients by raising barriers to their inclusion in waiting lists [29, 43].
- Deflecting patients to other healthcare institutions or services [29, 43].

Since rationing at the micro level is often carried out implicitly [6], it can become challenging to distinguish between the strategies of rationing mentioned above. For example, rationing by selection at a micro level using a threshold implies that certain patients are denied treatment, and the delaying of patients through waiting lists suggests that one must select which patients must wait. But how can one select which patients should wait longer in a waiting list?

2.3 Waiting Lists as a means of rationing

In countries with centrally organized and publicly funded healthcare systems, waiting lists are frequently perceived as one of the most problematic situations arising unnaturally from a serious imbalance between excessive demand, with the inflow of new patients, and limited capacity or willingness to supply the production of care [9, 13, 21, 28, 50, 53–57].

Although waiting lists are ubiquitous across a wide range of clinical services where issues of access are present, such as expensive medical technologies [58], surgical interventions are perceived as one of the most important activities in hospitals, hence waiting lists for high-demand surgical interventions especially impact the quality of the health service and costs to the healthcare system [20].

It is not uncommon for the topic of waiting lists for access to elective surgery to be subject to political debate and receive extensive negative media attention regarding the growth of waiting lists and their perceived inequitable and inefficient management in public healthcare systems [22, 55, 56, 59]. This can be justified by the lack of opportunity in public health systems to implement strategies that could help regulate supply or demand, for example increasing service provision by extending capacity or charging a higher price for interventions [56]. These restrictions have been particularly evident in light of the recent budget cuts implemented after the economic crisis in European countries [22].

When patients experience excessive waiting times, clinical repercussions may arise, such as deterioration of disease and of quality of life, aggravation of pain and impairment of functional abilities [11, 28, 40, 50, 60, 60–67]. Therefore, efficiently reducing the waiting time of patients in need of elective surgery (i.e., medically necessary but non-emergency [60]) could significantly reduce the overall burden of disease [68].

It is therefore paramount that waiting lists' management strategies are designed with the aim of providing the best possible outcome for patients. Namely, it has been stated that waiting lists policies should be implemented having five potential goals [69]: the reduction of the number of people on waiting

lists, the reduction of the average waiting time [16, 57, 70–72], improving the health status of those on waiting lists, ensuring equal access for those with equal need, and ensuring quickest access for those with greatest need [11, 67, 69]. In order to achieve these five goals in the context of elective surgery in public hospitals, several strategies may be implemented [73]:

- Increased funding and capacity, by hiring more staff or purchasing more equipment [60]. Increased funding leads to increasing capacity, with the aim of treating the prevalent population. Nevertheless, as the subsequent incidence is generally not large enough to fill the created capacity, a cycle may originate, with a tendency for thresholds to be lowered to include states with less obvious needs and declining benefits. Therefore, the waiting lines may remain completely stable [9, 10, 74, 75]. This factor, introduced as supply-induced demand, along with other factors such as exceeding supply, inefficiency, accumulated backlog and the effect of private practice, are responsible for the unavoidability of waiting lists [18, 60] [16, 70–72] [28, 57].
- Setting maximum wait time targets [9, 50, 60, 73, 75–79]. This strategy has been criticized because a conflict often arises between the waiting-time guarantee and the patients' needs [9].
- Development of surgical pathways and restructuring of the referral process, such as the implementation of methods to reduce missed appointments. In countries such as United Kingdom, Canada, Australia, and Norway, there has been a focus on improving the quality of surgical pathways, through strategies such as direct referral, direct access, improved quality and efficiency, and redesign of surgical pathways [73].
- Patient prioritisation Tools (PPTs) can be operationalised in different forms: on the one hand, the healthcare system can make use of less formalized methods, such as two- to four-level classification system ("high priority" and "low priority"), or systems which work informally based on clinical judgment, without the need for an explicit written tool [60]; On the other hand, more formal tools can be implemented, most frequently in the form of priority scoring systems which assign a score to the needs of each patient [11, 50, 60, 67, 73, 80, 81].
- Policies to induce the take-up of private health insurance [73].

The first and second strategies proposed have been criticized for eventually creating hurdles to an efficient waiting list management (either by introducing supply-induced demand, or disregarding the needs of the patients), and the last strategy does not meet the ultimate vision of a public health system. Hence, there exists a need to adopt a management which not only focuses on reducing long waiting lines, but which is also as efficient and fair as possible: a management which ensures that the patients presenting the most urgency are attended to first, and that patients with the same level of need are treated with the same priority [10, 12, 22, 24, 82–85]. In fact, central governments have received criticism regarding their historical approach towards the focus on the total number of patients on waiting lists and

length of time spent waiting. It has been argued that these objectives overshadow the necessity to treat patients according to clinical urgency [18, 24, 83–86].

One strategy which particularly ensures a fair management of waiting lists is the use of patient prioritisation tools [87]. Approaches to support the implementation of prioritisation processes for access to elective surgery thus constitute paramount progress in the broader context of health care resource allocation [11]. Several studies in the international context have proven the benefits, at a clinical, social, financial, and legal level [50], of prioritising patients on waiting lists for elective surgery when compared to a system based exclusively on waiting time, using a first-come first-served basis [10, 28, 58, 87–89].

2.4 Prioritisation of patients in waiting lists for elective surgery

The development and implementation of tools to prioritise patients waiting for elective surgery has been far from universal. As a result, prioritisation of patients and patient prioritisation tools have been presented with different definitions in literature [21, 58, 60, 67, 81, 88, 90–92]. In this thesis, the definition presented by Dery et al., 2019 [60] should be considered:

"Prioritisation is a process of ranking referrals in a certain order based on various criteria with the aim of improving fairness and equity in the delivery of care. It is a complex intervention mixing a wide variety of domains, such as engineering, public health, and management."

In this section, patient prioritisation tools will be discussed regarding their classification into implicit or explicit tools, and their range of applicability as far as surgical specialities are concerned. Furthermore, waiting time guarantees, which are common in prioritisation tools will also be discussed, and finally, a subsection on the delegation of responsibility for patient prioritisation will end this chapter.

2.4.1 Implicit and explicit prioritisation tools

In implicit prioritisation tools, society only determines the share of the Gross Domestic Product that is devoted to the healthcare sector, but leaves it to physicians to allocate resources to individual patients, namely in the case of competing needs. In this type of rationing, a common instrument used to allocate resources at a lower level are individual budgets for healthcare providers like hospitals.

On the other hand, explicit strategies are characterized by precise and transparent directives, developed by society, which determine the circumstances under which certain persons are entitled to certain medical services. All services that are claimed must be financed.

Explicit prioritisation tools for patients in waiting lists for elective surgery traditionally implemented in publicly-funded healthcare systems are largely based on waiting time, through a first-come, first-served strategy, despite evidence from various studies that other factors determined by individual physicians may routinely and implicitly influence the waiting period [24, 68, 88, 89, 93–96].

Hence, there has been extensive discussion regarding what would be the adequate level of explicitness of the prioritisation system, and it has been shown that both implicit and explicit processes present advantages and downsides, as shown in Table 2.1 [10, 22, 24, 67, 69, 88, 97].

Table 2.1: Advantages and Downsides of implicit and explicit prioritisation tools.

Prioritisation tools	**Implicit**	**Explicit**
Advantages	Easily applicable	Patients are treated in a more equitable and fair fashion regarding access to surgical procedures; Better information about the size of waiting lists and the duration of waiting times; Characterization of people waiting for services; Greater certainty for patients about their prospects for receiving treatment; Accountability of relevant stakeholders;
Downsides	Generally lack definition	Not unequivocally agreed upon; Often perceived as too inflexible; Impact on doctor–patient relationship;

It has been suggested that the advantages of explicit systems outweigh the advantages of implicit ones, reducing the overall burden of waiting lists for elective surgery by securing equity in prioritisation, according to patients' needs [50]. Consequently, explicit, transparent prioritisation instruments are increasingly being supported and developed [18, 22, 39, 41, 45, 50, 55, 56, 60, 67–69, 88, 98, 98, 99]. Furthermore, the purpose and principles the tool is meant to serve should also be detailed [50].

Notwithstanding, there are still some authors arguing that explicit scoring-based prioritisation tools should be abandoned [69], while others argue that the few prioritisation tools already implemented require reconsideration, as a gold standard method for prioritisation is yet to be defined [9, 55, 69].

Furthermore, as far as the relevant stakeholders are concerned, there are also divergent views: whereas patients, General Practitioners (GPs) and health authority commissioners show a strong preference for the implementation of a prioritisation tool based on nationally agreed criteria, evidence has demonstrated that surgeons are more reluctant towards the process of prioritisation, preferring a prioritisation tool defined more implicitly at the local level [18, 50, 55].

The hesitancy of these stakeholders possibly arises from the lack of consensus regarding the most adequate method for the implementation of priority scoring tools [50], namely what dimensions (clinical, social and/or financial) should be used to determine the priority of patients in waiting lists [18, 100]. Furthermore, there is still ongoing debate on whether those criteria should be generic and used for all surgical specialities, or, on the contrary, should be specific, as well as whether waiting time thresholds should be defined in combination with the prioritisation tool, and finally which stakeholders should be responsible, on the one hand, for deciding the criteria to be included, and on the other hand, for the implementation of the prioritisation tool [18, 50]. These concepts will be discussed in the next subsections.

2.4.2 Generic and specific prioritisation tools

In addition to their classification into implicit or explicit strategies, prioritisation tools can also be divided according to their range of applicability regarding surgical specialities and the type of surgery. There has been significant discussion on whether the criteria used in prioritisation tools should be generic, to be used in all surgical specialities and types of surgery, or specific criteria to be used according to the surgical speciality and type of intervention [50]. Countries such as New Zealand have been implementing condition or specialty-specific prioritisation systems, [18, 101], while generic or non-disease-specific prioritisation systems have been used in the United Kingdom [18, 102, 103].

Whereas generic criteria present the downside of generally being subjective and less evidence-based, these type of criteria are also advantageous as they enable horizontal equity. In other words, establishing generic criteria for all types of surgical procedures might allow for a comparable tool to be used across different procedures [104] [22] [60, 82, 105–107]. On the contrary, specific criteria are more evidence-based, objective and measurable, using indicators such as ejection fraction for cardiac surgery or visual acuity for cataract surgery [60, 61], but may not be suitable for ensuring horizontal equity [17, 50, 108]. Most prioritisation systems developed so far have focused on specific elective interventions, including cataract surgery, hip and knee arthroplasty, cardiac surgery, cholecystectomy and hernia [22, 60, 92].

As far as healthcare stakeholders are concerned, there is a dichotomy regarding preferences of generic or specific prioritisation systems: consultants and health authority commissioners have been more reticent towards generic prioritisation systems than GPs, perhaps as a result of GPs treating routinely a wide spectrum of health problems [18].

2.4.3 Waiting time guarantees

Waiting time is defined in literature as the time, in days, from the day in which the surgeon or a specialist doctor placed a patient on the waiting list to the day in which the surgery was carried out [88]. Traditionally, maximum acceptable waiting times are divided into a small number of levels [69, 88, 104]. For example, in a study by Escobar et al., 2009 [88], three categories were defined, based on maximum acceptable waiting times presented in literature: less than 3 months; 3–6 months and more than 6 months [88]. In a review by MacCormick et al., 2003 [104], the recommended waiting time reported in thirteen studies ranged between 1 and 18 months. Arguments in favour of establishing a maximum waiting time guarantees for patients, dependent on their priority in the waiting list, include the reduction of patient default: if patients are given an estimation of their waiting time for elective surgery, the probability of that patient remaining on the list will be increased [87, 109].

Recommended waiting times have generally been specified for specific interventions, relying on liter-

ature reviews [87, 104]. The Australian and Canadian governments have proposed the establishment of a maximum waiting time according to specific priority scores, instead of a guarantee time for all patients, with the goals of avoiding tampering of registry data and improving healthcare quality [87].

Alternatively, waiting time guarantees could also be applied together with generic criteria, but the literature shows that these thresholds have been externally enforced, which may not necessarily reflect the natural history of different diagnoses and disease progression [104]. Oudhoff et al., 2007 [50] reported significant differences in maximum waiting time guarantees across several priority scoring tools. This could mean that waiting time thresholds are established arbitrarily, which raises the question of whether waiting time thresholds do guarantee high quality health care by ensuring timely access [50,88,104,110]. Supporting this argument, in a study described in Edwards et al., 2003 [18], 56% of GPs, 60% of consultants and 61% of health authority commissioners stated that they did not support current maximum waiting times guarantees [18].

On this topic, it has been noted by Tebe et al., 2015 [87] that the the implementation of a prioritisation system aims at reordering the list so that those patients with a higher priority are operated on earlier [21, 87, 111]. Nevertheless, this measure does not necessarily guarantee an overall reduction in waiting times, once again raising uncertainty about the acceptability of unrealistic waiting time guarantees [87].

2.4.4 Delegation of responsibility of patient prioritisation tools

When discussing the delegation of responsibility for patient prioritisation, it is fundamental to distinguish between the development and the implementation of a prioritisation tool.

The responsibility of the development of a prioritisation tool refers to whose preferences should be elicited when deciding the criteria to be implemented in a prioritisation model for waiting lists. Extensive literature was found on this topic [22, 55, 68, 69, 107, 112].

The responsibility of the implementation of a prioritisation tool refers to which stakeholders should be held accountable for the actual use of the patient prioritisation tool in waiting lists for elective surgery in the context of the public healthcare system. This accountability constitutes one fundamental advantage of explicit prioritisation systems [107].

2.4.4.A Responsibility of the development of patient prioritisation tools

Many researchers argue that the general public, and patients in particular, should be involved in healthcare rationing, including in defining important criteria to be considered in patient prioritisation tools, albeit at different intensities [34, 55, 107, 113–115]. Arvidsson et al., 2012 [116] show that patients want to have some say in healthcare rationing, both at a micro and at a macro level [116]. Arguments in favour of public participation include promoting public confidence in the health system, increasing transparency of patient prioritisation decisions, accountability and legitimacy of rationing decisions and improving the

responsiveness of the health system [107]. Nevertheless, public involvement in deciding criteria for the prioritisation of patients may imply ethical issues regarding biases and the relevance of their opinions. In addition, it raises methodological uncertainty as far as the adequate degree of participation of the general public is concerned (for example, whether it should be purely an advisory-based role or if it should involve direct intervention) [34].

With the aim of studying the agreement regarding the views of different stakeholders (former patients, surgeons, occupational physicians, and physicians) regarding the prioritisation of patients waiting for elective surgery, Oudhoof et al, 2007 [50] developed a study where the respondents' answers were analysed and compared. It was found that since the main role of surgeons concerns restoring the patient's health status, this group of stakeholders holds a bias towards medical criteria. Another study aiming at collecting the views of clinicians regarding the prioritisation of patients found that respondents believed that their clinical judgement was effective in prioritising patients [55]. This preference for individual responsibility is possibly due to concerns regarding misconceptions about the accuracy and sensitivity of systematic priority scoring tools [50, 117, 118].

2.4.4.B Responsibility of the implementation of patient prioritisation tools

Even though consensus has not been achieved on what group of stakeholders should be responsible for implementing patient prioritisation models, clinicians are usually mentioned as the most capable stakeholder group, despite the possibility of holding a bias towards medical criteria, since, on the other hand, they possess a clearer perception of the process and consequences of patient prioritisation. Waiting lists have traditionally been personally maintained by clinicians, namely surgeons and doctors of medical specialities, using a variety of paper-based and electronic records [55, 109].

In addition, it has been shown in Allepuz et al, 2008 [68] that not only is there considerable degree of agreement between clinicians when evaluating different hypothetical scenarios of patient prioritisation, but clinicians were also reflecting patients' perceptions towards patient prioritisation tools. Thus, the same study suggests that delegating both the definition of relevant criteria and the practical implementation of prioritisation instruments to clinicians further contributes to the validation of those prioritisation tools [67, 68].

In this chapter, different patient prioritisation systems have been described, in the context of waiting lists for elective surgery in public healthcare systems. Hence, concepts such as bedside rationing, prioritisation, elective surgery, waiting time guarantees and the categorisation of prioritisation tools regarding implicitness or explicitness, generalisability or specificity have been introduced. These will be fundamental to the comprehension of the results of a literature review presented in the next chapter regarding the criteria used in patient prioritisation instruments and the methodologies used to derive those criteria.

3

Literature Review

Contents

This chapter concerns a literature review carried out with the aim of identifying potential criteria to be incorporated in a patient prioritisation tool in waiting lists for elective surgery in the Portuguese public healthcare system context. Firstly, a description of the methodology used in the literature review is presented. Secondly, studies whose work focuses on the elicitation of stakeholders' preferences regarding these criteria are analysed with the aim of interpreting their context, and presenting precisely those criteria. Thirdly, a detailed description of each criterion mentioned in literature is presented. Furthermore, the methods used for the development of patient prioritisation tools are reported. Finally, some of the patient prioritisation tools implemented in the national and international context are also reported.

3.1 Methodological approach to literature review

A literature review of the published literature was carried out with the goal of identifying scientific papers which describe criteria to be used in prioritisation of patients waiting for elective surgery, and/or which mention an estimation of the relative strength of those criteria [89, 119].

3.1.1 Identification of studies and Search terms

Available published articles in PubMed, the Cochrane Library, Ovid Medline, Embase and Web of Science databases were searched between February 2020 and July 2020. Search terms included "waiting list", "elective surgery", "waiting list prioritisation", "patient prioritisation tools" and various combinations of these terms. In order to identify additional relevant papers, screening for additional studies in the reference lists of articles selected in the review was also performed. Furthermore, gray literature was also considered by citation searches carried out using Google Scholar. Restrictions were used for language (English, Spanish or Portuguese). No restriction was established for the date of publication of papers.

The selection of studies for inclusion in literature review sought the identification of studies which presented criteria to be used in prioritisation of patients waiting for elective surgery, as well as an estimation of relative strength of those criteria. Therefore, papers were selected if they:

- (Mentioned the elicitation of stated preferences of healthcare stakeholders for the provision of health care in a priority-setting for elective surgery context OR
- Mentioned the development of prioritisation tools of patients in waiting lists for elective surgery)
- Reported either original empirical data or presented a review of already existing literature.

Papers where the following conditions are verified were not included:

- Studies targeting strategies/methods for managing waiting lists without using a prioritisation tool or system (see Section 2.3 for other strategies which may be implemented);
- Studies conducted in an emergency context;

- Studies concerning interventions dealing with immediate life-threatening cases (organ transplants).

3.1.2 Information extraction and synthesis

Along with the description of the criteria considered to be relevant and their relative strength, the title of the article, first author's surname, publication year will also be presented. On account of the heterogeneity of contexts in which studies were carried out and the different methodologies adopted for the presentation of criteria in literature, a descriptive reporting approach was deemed appropriate, hence the context of the study is also synthesised in terms of:

- Range of applicability of the patient prioritisation tool (generic or specific). This division was also performed in a review by MacCormick, Andrew et al. (2003), and in this work the analysis of the criteria will be divided according to this range of applicability (resulting in two different analyses for criteria used in a generic or specific context, respectively) [104].
- The ethical framework (EF) used to justify the prioritisation strategy. The category "Ability to benefit" included papers which utilized a measure of the ability of the patient to have their need satisfied as a basis for finding criteria for patient prioritisation. It will be referred as *AB*. The other category "Urgency of need" concerns papers which considered temporal factors when deciding the prioritisation of the patient, and will be referred as *UN* It is of the utmost importance that the ethical framework used in each paper is clearly defined, as different ethical bases may result in different criteria and potentially different patient outcomes [104].
- The method(s) used to derive criteria;
- The existence of waiting time recommendations or guarantees;
- Whether the goal of the study concerned the proposal of a patient prioritisation tool or simply the statement of elicited preferences

Although there was no restriction on the date of publication of papers, all papers were published after the 2000s. The interest in patient prioritisation has been growing, and the number of publications has increased over time. The majority of the papers originated in Europe, Australia and North America [89].

It is important to notice that although an extensive review was carried out, the variability of terms used in literature might bring limitations regarding information extraction. Firstly, since the concept of "tool" is still not agreed upon in the literature, some articles not using this keyword might not have been identified [60]. Secondly, patient prioritisation is a complex strategy, which can be implemented in very distinct shapes, and involves a wide range of domains, such as engineering, public health, and management. Therefore, one can argue that the task of synthesizing data from all these fields is rather challenging. Finally, triage and prioritisation are often interchangeably used in literature, which could hinder the task of identifying adequate articles [60].

All this information is synthesised in Tables 3.1 and 3.2.

Table 3.1: Information regarding **generic** patient prioritisation tools concerning the ethical framework which the tool is based on, the method of derivation of criteria, the existence of waiting time recommendations, and the type of prioritisation tool developed. **Legend**: EF: Ethical Framework; UN: Urgency of Need; AB: Ability to Benefit; Both: EF+AB).

Article	**EF**	**What methods were used to identify the relevant criteria?**	**Are there waiting time recommendations?**	**Prioritisation Tool developed**
McGurran, John et al. (2002) [110]	Both	Multidisciplinary clinical panel	No	Yes
Edwards, Rhiannon et al. (2003) [18]	UN	Literature search and discussions with consultants	No	No. Mean scores in rank order of influence presented using modified Likert scale.
MacCormick, Andrew et al. (2003) [104] (review)	6 articles: AB. 1 article: AB + UN. 15 articles: UN	Consensus methods: 2 articles presenting a generic tool; Qualitative methods: 2 (generic)	In 13 studies (of a total of 50 studies)	**Generic criteria**: 9 utilized the criteria in a tool for prioritising patients. 2 assayed attitudes, 3 did not divulge. Linear analogue scale was used as a global assessment of priority without specified criteria, therefore without subsequent need for summation.
Mullen, Penelope M. et al. (2003) [28] (review)	Both	Not explained	Yes, but in few articles: ranging from less than a month to one year	Score-based prioritisation strategy: many of the more recent formulae for scoring are additive.
Oudhoff, Jurriaan P. et al. (2007) [50]	Both	Focus groups with general public respondents; Criteria selected with experts, using conjoint analysis methodology.	Yes: recommendation of maximum waiting time constraints	No. Elicitation of preferences: multilevel ordered proportional odds regression analysis from mean scale scores on a 5-point scale.
Inza, Fernando et al. (2008) [120]		Literature review in addition to questionnaire to 22 people from management department for validation.	No	Score-based prioritisation strategy.
Testi, Angela et al. (2008) [57]	Both	Formula was developed with surgeons.	Yes, for the ranking system: 8 to 360 days	Ranking patients in urgency groups vs.Score-based prioritisation algorithm: $P_i = 3 \times r_i^2 + a(1 + 0.5p_i^2 + 0.5d_i^2) \times t$
Karlberg, H. I. et al. (2009) [9]	UN	Developed by Swedish parliament	Yes, "1-7-90-90 Rule". Warn that waiting-time guarantee leads to crowding-out effects, overruling ethical principles based on need.	No. Presentation of guidelines supporting practical priority-setting both within specialties and between specialties were developed.

Valente, Roberto et al. (2009) [67]	Both	The scientific committee adopted Italian URGs, based on two implicit semi quantitative criteria	Yes, the MTBT is automatically assigned, according to the selected URG (8 to 360 days)	Score-based prioritisation strategy: $P = (t - t_0) \times ()_v$, where $()_v$ is the urgency score.
Curtis, Andrea J. et al. (2010) [11]	Both	Face-to-face interviews and focus groups; Ranking and rating exercises performed by medical professionals and laypeople using real patient vignettes	Yes: Suggest the development of evidence-based waiting time targets for specific procedures	No. Presentation of consensus guidelines to help determine thresholds for some surgical interventions; Identification of psycho-social characteristics that contribute to patient priority.
Solans-Domènech, Maite et al. (2013) [22]	UN	1- 17 professional profiles participated in a nominal group technique to reach consensus on the relevant criteria. 2- A two round Delphi study was conducted. The panellists individually and anonymously distributed 100 points between the identified criteria in terms of their importance. The mean score for each criterion was calculated. Controlled feedback was provided.	No	Score-based prioritisation algorithm from 0 to 100.
Johar,Meliyanni (2014) [96]	UN	Previous assignment of categories based on clinical need	Yes, from 30 days to 365 days	No. Global guideline to priority categories is presented.
Déry, Julien et al. (2019) [60]	Both			Score-based prioritisation strategy

Table 3.2: Information regarding **specific** patient prioritisation tools concerning the ethical framework which the tool is based on, the method of derivation of criteria, the existence of waiting time recommendations, and the type of prioritisation tool developed. **Legend**: EF: Ethical Framework; UN: Urgency of Need; AB: Ability to Benefit; Both: EF+AB).

Article	**EF**	**What methods were used to identify the relevant criteria?**	**Are there waiting time recommendations?**	**Prioritisation Tool developed**
Bellan, Lorne et al. (2001) [10]	UN	Members of the Department of Ophthalmology plus a medical ethicist	No, but surgeons' mean waiting times are starting to be accounted for	Score-based prioritisation strategy
Derrett, Sarah et al. (2002) [69]	AB	Procedures developed by professional advisory groups	Yes, less than six months.	Score-based prioritisation strategy: Criteria were given points and summed to provide a score, from 0 (least priority) to 100 (greatest priority).
MacCormick, Andrew et al. (2003) [104] (review)	6 articles: AB. 1 article: AB + UN. 15 articles: UN	Consensus methods: 6 articles presenting a specific tool; Multiple regression: 8 (specific); Qualitative methods: 3 (specific)	In 13 studies (of a total of 50 studies)	**Specific criteria**: 14 utilized in a tool for prioritising patients. A weighted linear model was used to sum criteria in 7 papers. 3 preferred a matrix model. The method of summation was not stated in the remaining (5) cases.
Conner-Spady, Barbara L. et al (2005) [24]	Both		No	Score-based prioritisation strategy is the sum of the weighted item responses.
Quintana,José M et al. (2006) [92]	UN	Development of criteria based on RAND appropriateness method: 1- Criteria were developed using a two-phased modified Delphi panel judgment process, with 11 ophthalmologists, as well as a review of the bibliography and the research team's best judgment; 2- Ratings were analysed regarding the level of agreement among panelists. The effect of all variables on the final panel score were presented using general linear and logistic regression models.	No	Continuous score-based prioritisation strategy. Additional classification method into three categories, using ordinal logistic regression.

Allepuz, Alejandro et al. (2008) [68]	UN	4 focus and nominal groups, consisting of general population, patients and close relatives, allied-health professionals and consultants, identified and selected priority criteria. The levels of descriptors were established by the research group. Participants ranked scenarios from the highest to the lowest priority for surgery.	No	Score-based prioritisation strategy: The overall priority score is the sum of the scores in each criterion and it ranges between 0 – the lowest priority- and 100 – the highest priority. The scores for each criteria were obtained from the ranking through a rank-ordered logit model.
Comas, Mercè et al.(2008) [21]	AB	Cojoint analysis technique, involving general population, patients and relatives, clinical specialists and related health professionals.	Yes: Less than 6 months.	Score-based prioritisation strategy using waiting time weighted by priority score.
Witt, Julia et al. (2008) [121]	AB	Evidence from the literature, from focus groups, or including attributes relevant to changes in policies that have not yet been introduced.	No	Score-based prioritisation strategy developed using clinical consensus and Delphi techniques. Urgency scores need to be weighted by the length of time spent on the list.
Escobar, Antonio et al. (2009) [88]	UN	Development of criteria based on RAND appropriateness method: 1- Criteria were developed using focus groups with patients, and through the opinion of 9 orthopaedic surgeons, as well as a literature review; 2- Panellists rated each clinical scenario on a nine-point scale in two rounds using a modified Delphi method. 3- Ratings were analysed regarding the level of agreement among panelists. The effect of all variables on the final panel score were presented using general linear and logistic regression models.	No	Continuous score-based prioritisation strategy. Weights were apportioned among variables so that the scores range from 0 to 100. Development of additional classification method into three categories: urgent, preferent and ordinary.
Comas, Mercè et al.(2010) [58]	UN	Cojoint analysis technique: The general population, patients and relatives, clinical specialists and related health professionals were involved.	Unless supply is increased, an excess waiting time of 3 years would exclude patients from the system.	Score-based prioritisation strategy on waiting time weighted by priority score.

Whitty, Jennifer A. et al. (2015) [107]	UN	Literature review in addition to consultation with research partners and an expert focus group.	No	Score-based prioritisation strategy: 'priority weights' were derived based on the MNL model coefficients. Priority weight for each criterion was estimated by dividing the marginal utility for that criterion level by the marginal utility for effectiveness.
Cristian Tebé et al. (2015) [87]	AB	Not explained	No association was found between priority score and waiting time found.	Score-based prioritisation strategy: sum of points
Kavalieratos, T. et al. (2017) [109]	Both	Not explained	Maximum waiting time guarantee recommended: 2-4 months.	Score-based prioritisation strategy
Arteaga-González, I. J. et al (2018) [40]		Not explained	No	No. Answers question: Are legislation guidelines on waiting time achieved?
Donnan, Jennifer et al. (2020) [122]	AB	Triangulation approach, including a review of the literature, 3 focus groups (using a nominal group technique) with 29 individuals who have had or are awaiting bariatric surgery, and consultation with clinicians.	No	No. Quantify public preferences (essay attitudes)
Silva-Aravena. Fabián et al. (2020) [123]	AB	Literature review plus interview with physicians looking for relevant parameters.	Yes	Score-based prioritisation strategy: each physician quantified each parameter with a score between one and ten, and these answers were averaged to obtain weights.

3.2 Criteria used for prioritisation of patients in waiting lists for elective surgery

As mentioned above, a collection of information on which criteria were introduced in literature for the prioritisation of patients in waiting lists for elective surgery in the context of public healthcare systems was carried out. Similar to what was frequently implemented in literature, five domains of criteria were defined [9, 22, 124]. These domains are: Clinical/Functional Impairment, Expected benefit, Social Role of the patient, Management and Personal factors.

Generally, papers have presented prioritisation tools which reflect a public preference for a combination of distributive assumptions (that is, they involve, at least to some extent, both the frameworks of Ability to Benefit and Urgency of Need, thus several domains are usually represented in prioritisation tools [89, 125, 126]. The results of the literature review, regarding the definition of criteria used in patient prioritisation, are presented in this section, and data collection on the criteria mentioned in each article are presented in Tables B.1, B.2, B.3 and B.4.

3.2.1 Clinical/ Functional Impairment

I **Severity of health condition**

Definition: Extent of organ system derangement or physiologic decompensation of a patient, which are a consequence of the disease in question.

It is usually possible to assess the severity of disease of a patient through clinical examination, additional tests and/or application of existing objective clinical severity scales [22].

The majority of papers including severity of disease as a criterion for prioritisation of patients have found it to be relevant. This finding is in accordance with the Rule of Rescue, which states that out of moral responsibility, one must attend first to those with worst future health prospects if left untreated [89]. Notwithstanding, one paper presented controversial results regarding the importance of severity of illness as a criterion for a generic patient prioritisation tool [126]: not only was this criterion given little importance, but patients with less severity of disease were preferred to patients in severe health condition.

II **Pain**

Definition: Suffering in general or more specifically physical pain, this is, degree of the main symptom (type, intensity or frequency) affecting daily life activities and health related quality of life (HRQoL) [22, 124].

III **Rate of disease progression**

Definition: Risks associated with a postponement in the treatment or surgery, such as risk of death, risk of serious complications, development of co-morbidity and/or worsening the severity of the illness, decrease in the effectiveness of surgery and/or prognosis, past complications, risk of affecting adjacent organs or spread of the disease, and progression that might affect the survival and/or can modify the type of surgery.

Consequently, even in patients with the same condition, the rate of disease progression may vary with their health state, age, and other factors. In one prioritisation score system implemented, a binary variable was introduced with the aim of ensuring domination of the criterion "Rate of deterioration" if there were evidence of or potential for disease progression [57].

IV **Functional impairment**

Definition: Limitation, due to the condition, to undertake daily life activities that were held prior to the disease. These daily life activities should be considered regarding the activities undertaken by a person of similar age and gender and without the disease.

This criterion should not be confused with severity of disease, albeit a correlation or association may exist [22, 58, 60].

V **Psychological distress**

Definition: Emotional suffering typically characterised by symptoms of fear, hopelessness, sadness, anxiety, and frustration.

3.2.2 Patient benefits

I **Probability and degree of improvement**

Definition: Probability and/or degree of improving functionality, pain, claudication, or other characteristics (related to the disease) and overall improvement in health-related quality of life.

One way of measuring this criterion might be through the identification situations (or specific co-morbidities) that have a lower probability of success [22].

The vast majority of studies explicitly considering health benefit as a criterion have clearly referred that an improvement in health or health gain is consistently highly valued by the public in patient prioritisation [89]. Nonetheless, these studies are not homogeneous in their measurement of health gains: whereas some perceive health benefits to involve improvements in life expectancy, others consider quality of life, or even both life expectancy and quality of life in combination as QALYs [89].

On the other hand, some authors have expressed the difficulty in prospectively identifying which patients would benefit the most from a certain intervention, thus raising apprehension about the

adequacy of this criterion [55, 127]. Moreover, it has been argued in literature that patient prioritisation should be based on an ethical principle of distributive justice, that is, on the concept of the distribution of scarce resources in a just manner, considering the rule of rescue. Based on this, the authors have stated that ability to benefit should not be a basis for prioritisation [104].

3.2.3 Social role of patient

In a review of the criteria used in patient prioritisation tools, it was found that when socials factors are included, they generally have a lower weight compared to clinical criteria [101, 128] [22].

I **Being dependent with no caregiver**

Definition: This criterion is in fact two-fold: first, it assesses whether the patient is independent in his daily life; second, in case this is not true, it assesses whether there exists a caregiver or someone who helps with daily life activities [22, 68, 92].

II **Limitation to care for one's dependents**

Definition: Possible limitations to exercise the responsibility of taking care of dependents (i.e. children, elder parents, etc.), due to the condition which could be treated with the programmed surgery [22, 68].

III **Limitation in the ability to work, study or seek employment**

Definition: Limitations to work (in paid or unpaid jobs), which includes limitation for schooling, educational activities and job-seeking as well [22]

3.2.4 Clinical Management

I **Cost-effectiveness of intervention**

Definition: Effectiveness of the surgical intervention for which the patient is being considered for the waiting list, weighted by its cost, when compared with the cost-effectiveness of not performing the surgery of choosing an alternative surgical intervention.

Cost-effectiveness analysis is included in the broader field of Comparative effectiveness research (CER), which can be defined as a method to inform health-care decisions by providing information on the effectiveness, benefits, and harms of different treatment options [129].

II **Economic efficiency**

Definition: Consumption of resources associated with the surgical treatment/ intervention, regardless of the potential effectiveness, benefit or utility associated [22].

Although the acceptance of this criterion is controversial and has been explicitly excluded from prioritisation tools, it has been demonstrated that this criterion is considered in practice, as non-clinical reasons were used to reduce the cost of waiting times [50, 60, 130].

Whereas respondents' willingness to pay for provision of a healthcare intervention has been widely discussed in literature, the impact of the cost of the treatment on prioritisation decisions has been addressed by only a few studies. These studies in turn presented controversial conclusions regarding the importance of this criterion for patient priority setting [89, 131, 132].

III **Waiting time**

Definition: Maximum recommended waiting time that the patient can wait for the surgical intervention, since a longer waiting time is associated with deterioration of condition and smaller clinical benefits while patients wait [40, 88, 133–135].

This criterion has been very often included since the dawn of prioritisation systems in the 1960s/70s, receiving less support nowadays [28]. Although it is especially supported by GPs, consultants and the general public, health authority commissioners have been reticent [18].

This criterion implies an increase of the priority score as a consequence of the increase in the waiting time or the reassessment of patients with low scores after a specified period of time, thus suggesting the existence of a dynamic patient prioritisation system, where scores for a patient who is already in the waiting list can be recalculated.

If waiting time for elective surgery is not considered as a criterion for defining patient scores in a prioritisation tool, other solutions have been proposed to ensure equity and efficiency of waiting lists [22]: the establishment of waiting-time guarantees, which set a maximum waiting time for an intervention, have been implemented in many health systems [40]. In order to satisfy the waiting-time guarantees, it may be necessary to make priority decisions contrary to the ethical principles, by favouring access before needs to keep waiting times within certain limits [9, 22, 24, 60].

3.2.5 Personal factors

I **Age**

Definition: Length of time the patient has lived.

Literature reviews found that although recipient age has been widely discussed as a potential patient prioritisation criterion, it is only a moderately used criterion in patient prioritisation for elective surgery [22, 89]. This is possibly explained by the overall disagreement on whether it is the younger or older individuals who deserve prioritisation.

Preferences for prioritising younger over older patients in waiting lists for elective surgeries might reflect either concerns for efficiency by assuming a larger potential to benefit and a smaller impact in difficulty in doing activities of daily life (utilitarian ageism), or concerns for equalizing age at death (egalitarian ageism, based on the fair-innings theory) [10, 22, 136]. The fair innings theory defends that the youngest have had less of a valuable resource, life years, and therefore should be helped first in order to be given the opportunity to reach a normal-life span. One argument in favour of this criterion concerns the fact that all people age, hence treating people of different ages differently does not mean treating then unequally. Nevertheless, those who argue against it reason with the lack of consideration of prognosis and the categorical exclusion of older people.

Taking into account that it has been reported that respondents feel it would be socially unacceptable to penalize older patients based on a reduced likelihood of benefit [10], and potential benefit and functional impairment have already been considered in a criterion above, in this study the criterion "Age" refers solely to the prioritisation based on the fair innings theory [10, 22, 104].

II **Social Economic Status**

Definition: Measure of the social and economic status of the patient, which tends to be positively correlated with better access to healthcare.

Social and Economic status are often implicitly considered in the prioritisation of patients [22], but there is also evidence of explicit patient prioritisation based on this criterion. In general, studies have found a preference to prioritise patients of lower socioeconomic status [89, 131, 137–139].

It is worth noting that this criterion may play a different role depending on whether the healthcare system is a public or private system: in the case of private health care, it is widely accepted that economic status may avoid long waiting times, as those patients are willing to pay for the treatment [22, 50, 104].

III **Lifestyle**

Definition: Impact of lifestyle or to the potential responsibility of the patient concerning their current health status. It may be argued that self-inflicted conditions, resulting from unhealthy lifestyles, such as smoking, leading an unhealthy diet, or having unprotected sexual intercourse could lower the prioritisation of patients waiting for elective surgery [89, 138].

There have been numerous studies considering lifestyle/ responsibility as a criterion which should be significant in patient prioritisation for waiting lists, although it is also mentioned that it should not be pivotal [89, 140].

3.2.6 Evidence-Based Medicine (EBM)

Definition: "Mathematical estimates of the risk of benefit and harm, derived from high-quality research on population samples, to inform clinical decision-making in the diagnosis, investigation or management of individual patients". Hence, EBM may be regarded as an objective, transparent, and comprehensible foundation for allocation decisions [141], more specifically for prioritisation of patients waiting for elective surgery. The question of whether EBM should be considered a relevant criteria concerns whether scientific proof of effectiveness of a treatment is the benchmark for prioritising the patient benefiting from it or could other criteria also be applied even if the scientific proof is missing [9, 141].

3.3 Methods used for the development of patient prioritisation tools

As far as eliciting which criteria should be used in patient prioritisation tools for waiting lists and their respective strength of preference is concerned, one can conclude by analysing the column "What methods were used to identify the relevant criteria?" in Tables 3.1 and 3.2 that a wide range of methods have been employed. In this subsection, the methods used will be examined further, according to whether these methods were employed for the elicitation of preferences regarding the criteria to be used, or for the summation and weighting of criteria.

3.3.1 Methods used for exploration and elicitation of stakeholders' preferences regarding criteria to be used in patient prioritisation tools

One systematic review from 2019 presented preference exploration (qualitative) and elicitation (quantitative) methods used to gain insights into patients' preferences [142]. The results from this paper can be extended to the exploration and elicitation of health stakeholders' preferences in general. Hence, in Tables 3.3 and 3.4 follows a list of relevant exploration (qualitative) and elicitation (quantitative) methods for gaining insight of stakeholders' preferences regarding criteria to be used in patient prioritisation tools, with special emphasis on methods also described in Tables 3.1 and 3.2.

According to this review, and in accordance with evidence found in the literature review carried out for this thesis, the most frequently cited exploration methods include focus groups and (semi-)structured individual interviews, while most cited elicitation method papers included discrete choice experiments and the visual analog scale.

Table 3.3: Overview of identified qualitative and quantitative methods for exploring health stakeholders' preferences regarding patient prioritisation [142].

Method	Description
Delphi method	Structured, iterative forecasting method involving a panel of experts who provide anonymous responses to questionnaires with the opportunity to revise their responses when the anonymous summary of response from the prior round is revealed.
Focus group	Method that utilizes a group of interacting individuals that provide information about a specific issue to identify how a product, service or opportunity is perceived.
In-depth individual interview	Interview technique that allows for an intensive discussion with one interviewee to explore their perspectives on a topic or theme, to gain a deeper understanding of this particular topic or theme. Often only a limited amount of questions or themes are prepared by the interviewer, and the rest of the questions are based on the response of the interviewee.
Nominal group technique	Method that utilizes a group process that involves making decisions by vote and ranking responses given by members of the group.
(Semi-) structured individual interview	Interview technique that allows new ideas to be brought up during the interview as a result of what the interviewee says in a semi-structured setting, whereas in the structured setting the interviewer strictly sticks to an interview guide and does not ask questions based on the response of the interviewee.

Table 3.4: Overview of identified qualitative and quantitative methods for eliciting health stakeholders' preferences regarding patient prioritisation [142].

Method	Description
Allocation of points	Method that involves asking respondents to rate their conditions on scales, while knowing the weights which they attach to different criteria, indicating the relative importance of particular areas of their lives.
Analytic hierarchy process	Method in which responders assess the relative importance of pairs of attributes (treatment endpoints, properties, criteria, items, objects, etc.) toward achieving a goal, where these responses are used to compute a weight for each attribute.
Best–worst scaling	Involves respondents answering surveys that include lists of attributes or profiles and being asked to indicate the best (or most appealing/important) and the worst (or least appealing/important) of them.
Discrete choice experiment	Method that utilizes an attribute-based measure of benefit, during which individuals are offered a series of hypothetical choice situations (i.e., choice sets), from which they are asked to choose between two or more profiles. There are numerous variants of discrete choice experiments. In contrast to conjoint analysis, this method relies on a theory of the behavior of human preferences [for example random utility theory (RUM)].
Swing weighting	Method for setting the weights in which a decision-relevant range is specified for each attribute, and the impact of 'swinging' the attribute through that entire range of values is assigned a weight relative to the impact of swinging the attribute with the largest weight
Visual analog scale	A self-reporting instrument consisting of a line of predetermined length that separates extreme boundaries of the phenomenon being measured.

3.3.2 Methods used for summation and weighting of criteria

Some methods mentioned in Subsection 3.3.1, which concern the elicitation of preferences regarding patient prioritisation in waiting lists, also allow the derivation of strength of preference associated with each criterion. Therefore, it is possible to derive weights for each criterion, and, taking into account the performance of the patient in each criterion, summation methods can be applied to present an overall prioritisation score.

Although a variety of approaches have been used in literature as far as summation and weighting are concerned, as Table 3.5 shows, there has been a predominance of linear models. Nevertheless, in articles where derivation of weights for criteria were performed, weighting and summation methods were often found to be inconsistent. It has been reported that those methods do not present valid mathematical models supporting their use [89, 104]. Moreover, the impact of those prioritisation algorithms on the actual prioritisation of patients may not have been considered in full depth, as studies of reliability and validity are rarely performed, which results in inconsistencies between clinical judgement and priority scores [104].

On the topic of application of generic or specific criteria, it has been suggested that condition-related criteria generally outperform general health status criteria as far as predicting ability to benefit is concerned. Nevertheless, given the high number of types of elective procedures and specialities, it would be exceedingly challenging to associate appropriate condition-related criteria for all possible interventions. Consequently, the greatest challenge in prioritisation of patients in waiting lists for elective surgery is to develop a tool adequate for prioritising patient across different specialities and types of surgery [69].

It has been noted that in order to assess the adequateness of patient prioritisation tools, it is paramount that the ethical basis of the prioritisation system is first clearly defined, so that the appropriate endpoints can be measured. In addition, identification of waiting times that actually represent the natural history of different conditions could contribute to an improved application of generic criteria in prioritisation tools [104].

Table 3.5: Summation methods used in patient prioritisation scores.

Summation method
Weighted additive linear model
Additive then multiplicative
Non-linear
Matrix
Power Function

3.4 Patient prioritisation tools already implemented in the international context

In a systematic review of 2019 [73] on which countries and health systems have already implemented any type of patient prioritisation tools and waiting time guaranteed, it was found that the Anglo-Saxon and Nordic countries accounted for 84% of the studies, and relevant articles on implementation of prioritisation tool were published only from 2000 onwards. This could imply that although patient prioritisation has been implicitly present for a long time, it has only recently been addressed explicitly [73]. Below follows a list of some countries which have implemented patient prioritisation tools.

3.4.1 United Kingdom

Currently, the public health system of the United Kingdom has a system based on lists with GPs as gate-keepers: patients must join the list of a GP and can only access elective care via a referral by their GP [140]. How the GP prioritises has traditionally been an implicit process [14].

A scoring system for patient prioritisation of elective waiting lists has been proposed, with the aim of uniforming criteria and create an explicit framework. These systems have even been implemented occasionally, for example at Salisbury Health Care NHS Trust hospital [14].

The median time on the inpatient elective admissions waiting list registered in a study was 66 days [140], and waiting times guarantees have been implemented, ranging between three and six months [18, 21, 50, 67, 96, 104, 143].

3.4.2 New Zealand

In 1993, health reforms were implemented, and the current system of prioritisation of patients for elective waiting lists based on three categories of urgency (urgent, semi-urgent or routine) was abolished. Instead, a patient prioritisation tool based on predetermined criteria developed by professional advisory groups was adopted in 1997, known as Clinical priority assessment criteria (CPAC) [55, 69]. The patient prioritisation score consisted of a scale from 0 (least priority) to 100 (greatest priority), where each criteria contributed with a certain number of points to the overall score [69].

This tool has been criticized in literature for its rushed introduction, without the preoccupation of carrying out pilot tests to assess the impacts on patient access and outcomes, and with virtually no evidence to inform its implementation [69].

The criteria combined in this explicit scoring tool include both clinical criteria and social factors understood to contribute to the urgency of treatment, such as the inability to live independently [96]. Although initially clinical criteria included both the level of patient's need and ability to benefit [69], there has been

a shift to the adoption of ability to benefit as the primary rationale [69, 101]. Since then, criteria specific for certain interventions have been developed through literature review and consensus methods. Consequently, multiple tools exist depending on the procedure, and there is no nationally consistent clinical priority access criteria. Waiting times guaranteed have been presented as well, and waiting times must not exceed 3 and 6 months [50], according to the intervention at hand [10, 18, 21, 58, 67, 101, 104].

3.4.3 Australia

Although some articles refer that Australia does not use an explicit tool for prioritising patients [67, 96], specific cases of patient prioritisation tools have been identified: in the State of Victoria, implicit categories of clinical urgency were identified and applied to all elective surgical registrations [67, 144].

3.4.4 Sweden

In 1997, an ethical platform for priority-setting in healthcare was created, which favoured severity of disease before utility and patient benefit. It was determined that cost-effectiveness should only be considered for single patients in the choice of treatment. As far as waiting times are concerned, there is public data on waiting time and waiting lists since 1992, and waiting time guarantees have been implemented (once again, these range between 3 and 6 months) [9, 18, 50, 50, 67, 77, 96].

3.4.5 Canada

This country has also developed explicit patient prioritisation tools, through the use of scoring models which take into account both clinical criteria and social factors. In particular, the Western Canada Waiting List Project (WCWL) has developed five scoring tools with the aim of providing an explicit, transparent, and fair method to rank patients on waiting lists for elective surgery [10, 21, 24, 50, 58, 67, 96, 104, 110, 145].

3.4.6 Italy

In 2001, the Italian Ministry of Health funded the Surgical Waiting List Info System (SWALIS) project, with the goal of creating new methods for effectively managing elective surgery waiting lists. One year later, implicit Urgency-Related Groups (URGs) were defined, each one associated with Maximum Time Before Treatment (MTBT). This urgency was to be measured from the combination of the judgment on three clinical criteria: disease progression, pain or dysfunction and disability [67]. Nevertheless, because urgency was broadly defined, the application of URGs proved difficult and Italian patients are generally admitted on a first-in first-out basis.

3.4.7 Spain

In the district of Catalonia, two scoring systems for the prioritisation of waiting lists for cataract and hip and knee arthroplasty surgery were implemented in pilot tests. The results were encouraging, as it was proven that the prioritisation systems developed constituted a valid and useful instrument to discriminate priorities among patients on waiting lists [21, 58, 87].

In conclusion, although there has been significant progress in many countries regarding patient prioritisation in waiting lists for elective surgery, many of the prioritisation systems implemented have been criticised for being highly subjective and inadequate to assess and compare urgency and case-mix of patients, namely systems based on Clinical Urgency-Related Groups (URGs) and Maximum Time Before Treatment (MTBT) [20].

3.5 Patient prioritisation tools in Portugal

Traditionally, individual surgeons have been responsible for patient prioritisation in waiting lists of the SNS, through personal and private waiting lists. As one would expect, surgeon practices differ between clinical specialities and even between individuals, which may bring issues of equity regarding the prioritisation of patients.

Therefore, certain measures have been implemented to improve the transparency of patient prioritisation at a national level. Political responsibility for the management of waiting lists, which includes controlling the number of patients on waiting lists and the waiting time of patients with different needs, lies within health authorities, namely *Administrações Regionais de Saúde (ARS)*, *Direção Geral de Saúde* (DGS), and *Ministério da Saúde* [146]. A national platform has been developed with the aim of ensuring consistency in the management of patients in any hospital of the SNS: waiting lists have been managed in a continuous and integrated manner with the assistance of an information system, *Sistema Integrado de Gestão da Lista de Inscritos para Cirurgia* (SIGLIC) since 2005.

3.5.1 Patient's inclusion in waiting lists of SNS

After implementation of SIGLIC at the national level, SNS patients may gain access to surgical treatment in hospital care through registration in waiting lists, commonly referred to as *Lista de Inscritos para Cirurgia* (LIC) [147, 148]. This registration is free of charge and can be carried out in an outpatient consultation of the adequate hospital speciality [147, 148].

Upon inclusion of the patient in LIC, an evaluation of the patient's clinical needs, the clinical decision, and the validation of the proposal for completion of the surgical intervention are mandatory, as well as

the patient's consent regarding the surgical intervention. The patient's priority in the waiting list, which is directly translated into a certain maximum waiting time guarantee, depends on the priority category assigned. Priority category is defined in legislation as the class which the patient is assigned, and it is evaluated regarding the disease and associated symptoms and signals, base pathology, disease severity, impact in life expectancy and quality of life of the patient, impact on daily activities, rate of disease progression and time of exposure to the disease [149].

Additionally, the patient's category of prioritisation also determines the maximum deadlines for the patient's transfer to a Destination Hospital in cases where the Source Hospital is not capable of ensuring waiting time guarantees. At any time, patients can choose to be removed from the waiting list and opt for private consultation and procedure, but in this case patients are held responsible for the expenses. The patient's path in LIC until completion of surgical intervention is presented in Figure 3.1 [150, 151].

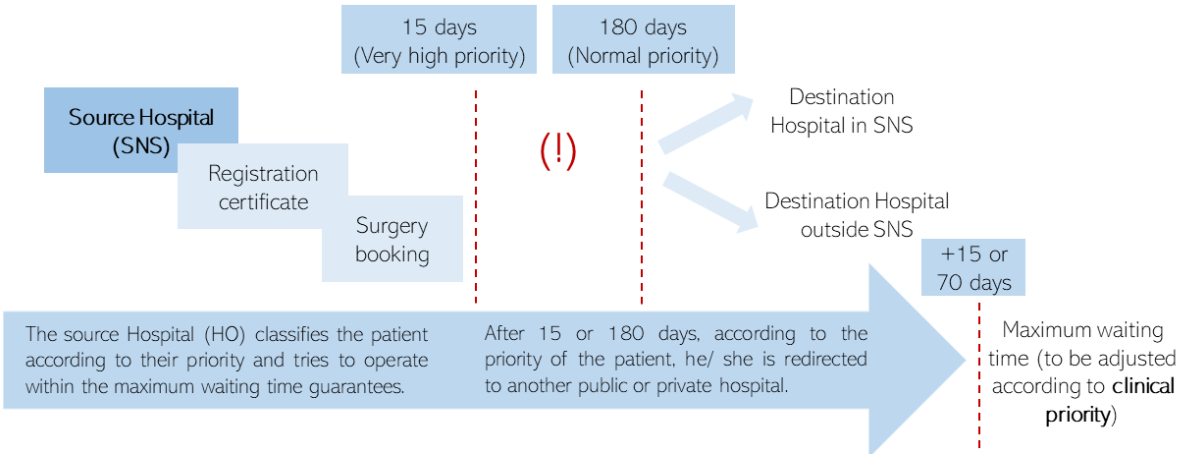

Figure 3.1: Patient's path in LIC until completion of surgical intervention in SNS (Adapted from source: ACSS/ UCGIC) [151].

Elective surgical activity grew 1% in the Portuguese public healthcare system hospitals in 2018, as a result of a similar increase in surgical demand, when compared with the previous year. In absolute numbers, 596 978 patients were subject to surgical interventions in 2018, the highest number ever registered in SNS, as is shown in Figure 3.2 [148]. This increase in the demand and supply of elective surgical activity demonstrates once again that it is paramount that a reliable management system of access to elective surgery is in place.

3.5.2 Waiting time guarantees in SNS

Maximum waiting time guarantees, known as *Tempos máximos de resposta garantidos* (TMRG), were established nationally in the Portuguese legislation, according to priority levels based on the urgency of

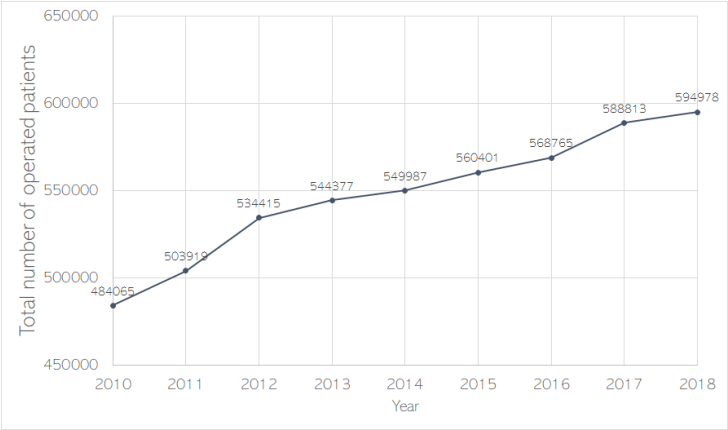

Figure 3.2: Total number of operated patients in SNS hospitals in 2018 [148].

the patient's clinical condition [152].

The maximum waiting time guarantees for each priority level are presented in Table 3.6 [152]. It is evident that when certain surgical specialities are considered more urgent, for example regarding oncological and cardiac diseases, waiting time guarantees are shorter.

Table 3.6: Maximum waiting time guarantees for completion of elective surgical procedures [152].

Completion of elective surgical procedures		**Maximum waiting time guarantees**
Elective surgical procedures	Deferred urgency (level 4)	72 hours following clinical appointment
	Very high priority (level 3)	15 consecutive days after clinical appointment
	High priority (level 2)	60 consecutive days after clinical appointment
	Normal priority (level 1)	180 consecutive days after clinical appointment
Elective surgical procedures related to oncological diseases	Deferred urgency (level 4)	72 hours following clinical appointment
	Very high priority (level 3)	15 consecutive days after clinical appointment
	High priority (level 2)	45 consecutive days after clinical appointment
	Normal priority (level 1)	60 consecutive days after clinical appointment
Elective surgical procedures related to cardiac diseases	Very high priority (level 3)	15 consecutive days after clinical appointment
	High priority (level 2)	45 consecutive days after clinical appointment
	Normal priority (level 1)	90 consecutive days after clinical appointment

Although several measures have been implemented with the aim of achieving a more efficient management, namely through the establishment of waiting time guarantees associated with prioritisation categories, the clarification of the strength of criteria which are used for determining a patient's quantitative prioritisation score is yet to be achieved in Portugal. It thus becomes evident that there is a demand for a prioritisation scoring tool which considers multiple criteria, but is at the same time mathematically consistent and has the potential to be applied in the real context of waiting lists for elective surgery.

4

Methodology

Contents

In the literature review presented in the previous chapter, a comprehensive list of methods used for the development of patient prioritisation tools was presented. Although methods for elicitation of preferences are varied and well studied in literature, scoring and weighting methods, which lead to the development of prioritisation scoring tools, are still not fully described in literature [142]. Most studies incur in what is known in decision-making as the most common critical mistake [153]: by using summing and weighting techniques such as simply summing up ordinal scores on the criteria to reach an overall score, these methods are weighting criteria solely on the basis of importance and ignore the notion of trade-offs underlying additive models, thus originating meaningless scores [153] [154].

In this context, it becomes relevant that a new protocol for the development of a patient prioritisation tool is developed. This prioritisation tool will be based on the elicitation of stakeholders' preferences regarding which criteria should be included in that tool. The modelling approach chosen to elicit stakeholders' preferences and develop a scoring and weighting tool is a multiple criteria decision analysis (MCDA) model.

4.1 Multiple Criteria Decision Analysis Model

An MCDA model is based on the combination of several concerns into a single problem, in a exhaustive and flexible fashion, which in its construction includes different judgements [155] [153]. This type of model allows the deconstruction of a complex problem into several simpler problems, which are analysed independently and then integrated into a global analysis [156]. Hence, this model will allow the evaluation of prioritisation of different patients by evaluating the performance of each patient in each criterion and then performing a weighted sum which represents the overall patient prioritisation score of the patient.

A multiple criteria model is considered to be an adequate approach to the problem of patient prioritisation in waiting lists for elective surgery given that models of this type:

- Are grounded on strong theoretical foundations, thus offering the possibility of overcoming fundamental weaknesses frequent in previous studies. In particular, one weakness is the most common critical mistake incurred in the construction of value functions for criteria, and in the assessment of the weights for the criteria [153];
- Consider the multiple criteria nature inherent to patient prioritisation, as this process presents multiple objectives which may be conflicting sometimes, and concerns diverse stakeholders, whose viewpoints and interests are not homogeneous either [155] [153];
- Favour the development of comprehensive and explicit models, with the same criteria applied to all patients. These models are seen as a tool to overcome flaws in evaluation systems which are considered inequitable and might lead to user dissatisfaction [153].

- Can be designed taking into account their integration in socio-technical processes related with evaluation, and are able to combine advanced metrics with transparent peer review. This is considered a paramount advantage for patient prioritisation methods since these processes account for complex and evolving socio-economic systems, as is the case of waiting lists for elective surgery [153].
- Provide problem structuring methods valuable for the definition of multiple and complex strategic objectives regarding patient prioritisation, which should guide the process of development of patient prioritisation tools [153].

In this chapter, the proposed methodology will be presented. Firstly, an overall view of the methodological design used to reach these objectives is given, and the following sections will explain each methodological step in detail.

4.2 The MACBETH Method

MACBETH is an acknowledged MCDA technique based on paired semantic comparisons between alternatives, and has been appraised for its usefulness both for the construction of cardinal value functions and the calculation of trade-off between criteria. Its mathematical foundations and the model structuring are explained in the next subsections, and are based on the explanations given in Ferreira et al., 2019 [155] and Bana e Costa et al., 2012 [153].

4.2.1 Mathematical explanation of MACBETH

4.2.1.A Construction of Value Functions

MACBETH consists of associating each element of X (where $X = a, b, \ldots, n$ is a finite set of n alternative options) to a value x (resulting from $v(.) : X \rightarrow R$), such that differences such as $v(a)$–$v(b)$ (where a is more attractive than b (i.e., $a\,P\,b$)), are made as compatible as possible with the preferences of the decision-makers. A value function v and thresholds s_k can then be defined according to formula 4.2.1.A:

$$a\,P^{(k)}\,b : s_k < v(a) - v(b) < s_{k+1} \tag{4.1}$$

With the aim of facilitating the practical application of MACBETH, semantic categories of difference of attractiveness were defined. These are presented in Table 4.1. For example, if an action a is considered more attractive than another action b, and if the difference of attractiveness between these two actions is considered extreme, then $(a, b) \in C_6$.

Table 4.1: Semantic categories of difference of attractiveness.

C_0	*No* difference of attractiveness
C_1	*Very weak* difference of attractiveness
C_2	*Weak* difference of attractiveness
C_3	*Moderate* difference of attractiveness
C_4	*Strong* difference of attractiveness
C_5	*Very Strong* difference of attractiveness
C_6	*Extreme* difference of attractiveness

The interactive nature of this step improves learning and allows consensus among the participants to be reached. At this stage, formulas 4.2 and 4.3 should be considered for consistency purposes.

$$\forall\, a, b \in X : v(a) > v(b) \Leftrightarrow a\, P\, b, with\, k, k^* \in 1, 2, 3, 4, 5, 6, \forall\, a, b, c, d \in X\; with\; (a, b) \in C_k \tag{4.2}$$

$$(c, d) \in C_k^* : k \geq k^* + 1 \Rightarrow v(a) - v(b) \geq v(c) - v(d) \tag{4.3}$$

Linear programming (LP) can then be applied according to Equation 4.4, allowing an initial scale to be constructed and presented to decision-makers for validation. In practice, n is the most attractive choice alternative of X, whereas $a_$is the least attractive option, which should be associated to the "zero" of the scale. Technically, the aim of this LP procedure is to minimise the value of n, reducing the length of the basic scale.

(4.4)

$$
\begin{aligned}
&Min\; v(n)\\
&S.T.: \forall a, b \in X{:}aPb \Rightarrow v(a) \geq v(b) + 1\\
&\qquad \forall a, b \in X{:}aIb \Rightarrow v(a) = v(b)\\
&\qquad \forall (a, b), (c, d) \in X,\ \text{if the difference of attractiveness between}\\
&\qquad\qquad a \text{ and } b \text{ is bigger than between } c \text{ and } d, \text{then:}\\
&\qquad\qquad v(a) - v(b) \geq v(c) - v(d) + 1 + \delta(a, b, c, d)\\
&v(a^-) = 0\\
&\text{where:}\\
&n \text{ is an element of } X \text{ so that } \forall a, b, c, \ldots \in X{:}n\ (P \cup I) a, b, c, \ldots\\
&a^- \text{ is an element of } X \text{ so that } \forall a, b, c, \ldots \in X{:}a, b, c, \ldots\ (P \cup I)\ a^-\\
&\delta(a, b, c, d) \text{ is the minimal number of categories of difference of attractiveness}\\
&\qquad \text{between the difference of attractiveness between } a \text{ and } b \text{ and the}\\
&\qquad \text{difference of attractiveness between } c \text{ and } d.
\end{aligned}
$$

This procedure should be repeated until a local performance scale (in other words, a **value scale**)

for each evaluation criterion has been defined and validated by the decision-makers.

4.2.1.B Weighting of Evaluation Criteria and Overall score

If mutual preferential independence among evaluation criteria is guaranteed, a simple additive model can be applied (see Equation 4.5). This allows an overall score for each of the alternatives under evaluation to be obtained.

$$V(a) = \sum_{i=1}^{n} w_i v_i(a) \; with \; \sum_{i=1}^{n} w_i = 1 \; and \; w_i > 0 \quad and \begin{cases} v_i(Best_i) & = 100 \\ v_i(Worst_i) & = 0 \end{cases} \tag{4.5}$$

4.2.1.C Sensitivity and Robustness Analysis

At this stage of the process, sensitivity and robustness analyses are usually carried out to assess the framework's sensitivity to changes in the weights of the evaluation criteria. Recommendations are then made based on the results of the analysis.

How this mathematical explanation relates to the actual steps of the MACBETH approach adopted in this thesis is explained in Subsection 4.2.2.

4.2.2 Model Structuring of MACEBTH

4.2.2.A Variables and Fundamental Points of View

The first phase of the MACBETH consists in the identification of the areas of concern which interfere with the decision-maker's choice. These may take the form of objectives, concerns, indicators, characteristics, attributes or restrictions, and form the basis for the development of criteria. Two types of criteria may be defined: screening (or exclusion) criteria and evaluation criteria, or Fundamental Points of View (FPVs).

- **Screening criteria**

  In MCDA models, screening is performed initially with the aim of reducing a large set of alternatives to a smaller set that most likely contains the best alternatives. There may be criteria in which the options considered cannot be evaluated to have a better or worse performance than the other options, since the decision-maker is not willing to accept a worse performance in this criterion, regardless of how well the option performs in the other criteria. In this case, the decision-maker must define criteria and thresholds related to that criteria which they consider to be fundamental to the viability of the options.

- **Evaluation Criteria**

  As far as criteria which evaluate the performance of options in specific areas of concern are concerned, FPVs are defined. FPVs describe the different independent perspectives that the analyst must consider in order to come up with the best option(s) for the decision-maker.

  Therefore, it is necessary to discuss with the decision-maker, and turn his points of view of what is valuable or not (in the decision context) into an arrangement that would be useful to the evaluation of the options. At this point, a value tree including the set of all criteria to be analyzed is usually designed. In order to ensure the consistency of the analysis of FPVs, these should meet the following conditions:

  1. Complete, which includes all the fundamental aspects to evaluate decision alternatives;
  2. Controllable, to identify the consequences of each alternative and its influence;
  3. Measurable, which defines precise objectives and allows the assignment of values to determine how they can be achieved;
  4. Operational, in order to render the collection of information required for an analysis reasonable considering the time and effort available;
  5. Decomposable, ensuring the independence of the FPVs;
  6. Non-redundant, in order to prevent possible consequences from being considered more than once;
  7. Concise, restricting the number of assumptions to consider to those that are relevant;
  8. Understandable, to facilitate generation and communication of insights guiding the decision-making process.

4.2.2.B Descriptors of Performance

After defining the FPVs which the decision-makers consider relevant, it is necessary to have a descriptor of performance (or descriptor of impacts) so that the FPVs are operational. Each descriptor is an ordered set of plausible performance levels and expresses the fundamental points of view. The descriptors can be characterised in 3 dimensions, namely:

- Quantitative, qualitative or pictorial: a quantitative descriptor relies on the use of numbers in order to create the performance levels; a qualitative one uses semantic expressions and numbers, while a pictorial one uses visual representations.
- Direct, indirect or constructed: direct descriptors directly reflects the associated effects since it is related with the FPV in a natural way; indirect ones indicate causes, as they are not as good to translate the effects associated; constructed ones describe characteristics underlying the criteria.
- Continuous or discrete: continuous descriptors are represented by a continuous function, while discrete are represented by a finite set of levels, as the name states.

Besides defining a descriptor for each FPV, it is also necessary to ask the decision-makers to decide on the reference levels that are necessary for weighting: one level, which corresponds to a **worst** level of attractiveness and another that translates a **best** level of attractiveness. This should be performed before having collected the information for the performance of the options in each FPV, in order to avoid potential bias.

4.2.2.C Value scales

The following steps include the filling of a matrix of judgements of the difference in attractiveness between levels of performance in each FPV, which can be described as very weak, weak, moderate, very strong or extreme. The option of null difference is also allowed. The levels of performance must be the ones defined previously as Best and Worst by the decision-maker(s). Additionally, other levels may be considered, in order to improve the accuracy of the value scale. Therefore, as the number of known points (levels) is increased, the approximation is improved. All levels, including reference levels and other options, must be rank-ordered.

The value scale is obtained from the filling of a judgement matrix of pairwise comparison of options, which evaluate qualitatively their difference in attractiveness using the MACBETH categories in Table 4.1. These pairwise comparisons are performed first between the reference levels Best and Worst, then between each option and each reference, and finally between each two options.

The filling of the judgement matrix results in the presentation of a value scale for each FPV, which must be validated by the decision-makers. The scoring scale is numeric, so that the Best performance level corresponds to 100 and the Worst to 0. Nevertheless, it could happen that there will be negative values and also values above 100, if Best and Worst reference levels are not chosen to be the extreme levels of performance within a certain FPV. The validation of the value scale must be performed regarding the difference in terms of intervals between the scores. Intervals must be considered, as the construction of the scale is based on a linear transformation. If necessary, the scores between certain values may be altered.

Whereas for quantitative descriptors of performance, value scales are presented as a value function, in the case of FPVs with qualitative descriptors only the scale is presented, as the relationship cannot be translated into a numeric function.

4.2.2.D Weighting coefficients

With the aim of obtaining an overall scores which takes into consideration the partial score values of all FPVs, the determination of weights for every FPV must be performed. These weights indicate the extent to which the performance in each FPV contributes to the final overall score.

The method used in the MACBETH approach to calculate these weights is the Swing Weighting method, which relies on the reference values of each FPV defined earlier, Best and Worst. Consequently, the independence of the weights on the options is guaranteed, since all comparisons will be performed on the reference levels, regardless of the performance of the patients. The decision-makers must thus proceed to the filling of a different judgment matrix, for weighting. This process is bound to be challenging since its size varies with the square of the number of FPVs.

In order to fill in the matrix of judgements, the decision-makers must first rank the Worst-Best swings by their overall attractiveness. The decision-makers must be asked successively: "Considering all the criteria at a Worst level, what would be the improvement from that Worst to a Best level that would be most important to you?".

Afterwards, several questions must be posed in order to qualitatively assess, through non-numerical judgements, in the same scale as before, how important a certain swing from Worst to Best is in a certain FPV when compared to another swing in another FPV. These paired comparisons must be carried out for every relationship between two FPVs. Once the matrix is fully filled, the weights are calculated by the software. These weights must be once again validated by decision-makers, and they are usually depicted in terms of percentage of the overall contribution for the decision, visually in form of a histogram.

4.2.2.E Global Score

Once the weights for each FPV have been determined, and the model tested and validated, the patients can finally be assigned a priority score. For this priority score, one must consider both the weights for each FPV and the value of performance of each patient in each FPV.

These weights are used in a simple additive model, as explained in section 4.2.1.B. Not only does this method allow the ranking of patients waiting for elective surgery, but it is also possible to measure the relative difference in attractiveness (in this case, the difference in prioritisation) between patients.

4.3 Methodological Design

The methodological design proposed in this thesis is based on a MACBETH socio-technical approach applied to the problem of prioritisation of patients in waiting lists for elective surgery. It is a MCDA model which involves various progressive steps and makes use of a wide range of techniques and tools. The main steps are presented in Figure 4.1.

This MACBETH socio-technical approach thus combines both technical elements of the MACBETH approach and social elements of participatory methods (such as semi-structured interviews and Delphi processes) to build a multi criteria model. As far as the technical elements are concerned, MACBETH is a non-numerical approach, which allows the quantification of a prioritisation score for each patient

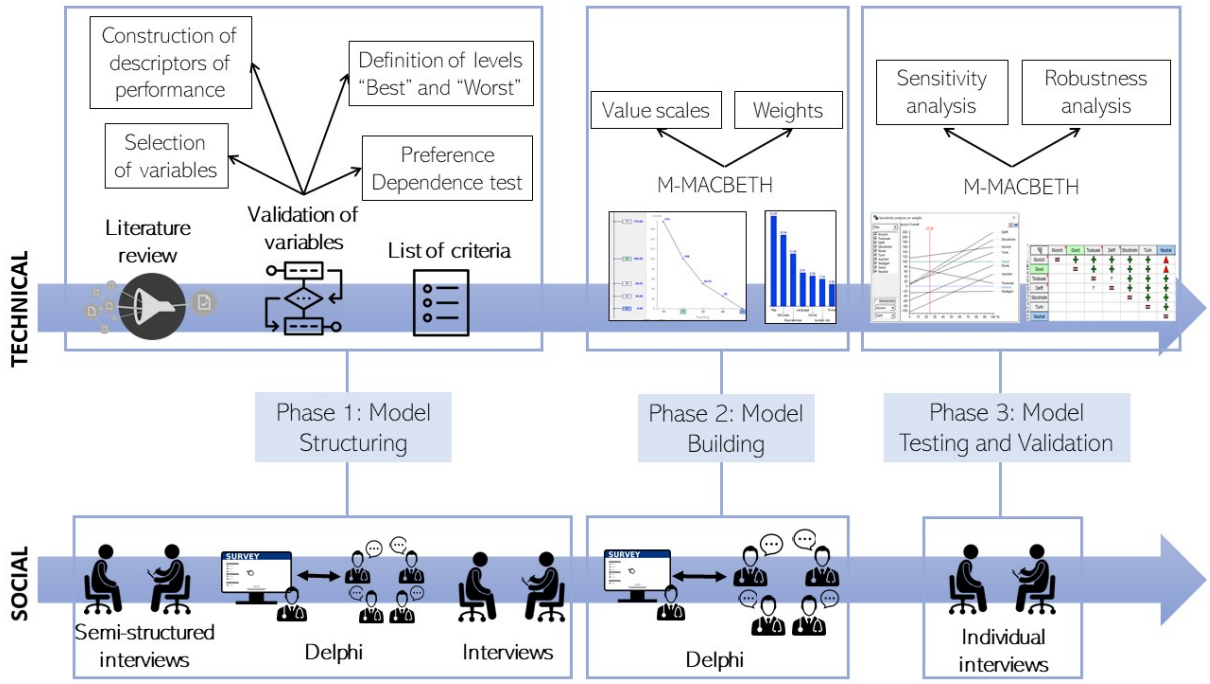

Figure 4.1: Schematic diagram representing the proposed methodology for the construction of a patient prioritisation tool to be used for waiting lists in SNS.

through both scoring and weighting techniques. This technique was chosen precisely because it constitutes a process which is cognitively simpler by using a non-numerical approach. Furthermore, this method is mathematically grounded [155] [153].

Taking into account the different objectives of waiting lists and the stakeholders involved, it is paramount that the problem of prioritisation is looked at from the different perspectives of the different stakeholders, by using both scientific evidence from the literature review already described in Section 3, and the experience of relevant stakeholders and experts, and ultimately reach an efficient and equitable solution for the patient prioritisation problem.

This combination between the technical elements of MCDA, described in Section 4.1, with the social aspects of Decision Conferencing, present in the collection of information from relevant stakeholders, will be referred as a socio-technical approach.

This socio-technical approach will be divided into three phases:

- Phase I: the structuring phase, which consists of the literature review, semi-structured interviews, a Delphi and another round of interviews to obtain and validate with a large group of experts the FPVs, necessary for the prioritisation of patients in waiting lists. Part of this phase, namely the literature review and the semi-structured interviews, will be effectively executed;
- Phase II: the building phase, in which the MACBETH technique should be applied to construct value scales and calculate trade-offs among the FPVs identified in the previous phase;

- Phase III: testing, validation and recommendation phase, in which recommendations are to be formulated based on the analysis of the results.

4.3.1 Phase I

In **Phase I**, which concerns the structuring phase, starts with collection of information with the goal of understanding the problem of patient prioritisation in waiting lists for elective surgery. Specifically, one goal is to acquire knowledge regarding up-to-date literature on the evaluation criteria or FVPs that are currently used in patient prioritisation tools in a national and international context. Moreover, it is also expected that the methods used to elicit stakeholders' preferences and to derive those criteria and their weights are also collected. Since these FVPs have not yet been validated in the context of the patient prioritisation tool to be developed, these should be referred to as variables until such validation occurs.

With the aim of combining additional sources of information, semi-structured interviews will be carried out with a few experts in patient prioritisation, namely surgeons of the SNS. These will provide further knowledge on this topic, particularly how the variables presented in literature are actually carried out in a real-world context. A list of relevant variables mentioned in literature should be reviewed by and possibly altered taking into account the views of experts in these semi-structured interviews.

Once the list of variables and descriptors of performance have been analysed in the semi-structured interviews, this list should serve as the basis for the Delphi that ensues. The aim of the Delphi concerns the validation of the list of variables, hence contributing to the validation of this prioritisation tool, at a national level, since the list of variables is to be presented to a larger sample of experts, geographically distributed. Not only should the variables be validated, but the validation of descriptors of performance and performance levels used for each variable in the MACBETH approach must be carried out as well.

The Delphi method is an iterative and repetitive structured process with controlled opinion feedback. It is understood that with this method a large number of respondents can be enrolled, and a potential influence which the designer of the method might have in the experts' response is eliminated.

Moreover, the Delphi should be carried out online, with the aim of having a sample of geographically distributed experts, as well as potentially increase the response rate to the Delphi.

The development of this online questionnaire is thus a central element in this methodology, and its design will imply a thoughtful decision on the following topics:

- Definition of the layout that will be used to present the different variables, descriptors and levels of performance, and method of evaluation and selection of these.
- Formulation of the questionnaire and presentation of the topics on which information should be collected:
  - Evaluation of the relevance of variables presented as far as patient prioritisation tools for

Table 4.2: Suggested questions and correspondent response scales to be included in the main section of the Delphi questionnaire. ”XXX” should be replaced by each variable or level of performance which is in the process of validation.

Question	**Response scale**
How relevant would you say this variable is in the context of patient prioritisation?	Relevance scale
Do you agree that this descriptor of performance is adequate considering the definition of the variable?	Likert scale
Considering the levels of performance should reflect the most common states of patients when put on a waiting list, do you agree that the level of performance ”Best” is assigned to the level of performance ”XXX” in this descriptor?	Likert scale
Considering the levels of performance should reflect the most common states of patients when put on a waiting list, do you agree that the level of performance ”Worst” is assigned to the level of performance ”XXX” in this descriptor?	Likert scale

waiting lists for elective surgery in the public health system context is concerned. The aim of this evaluation is to validate and potentially exclude variables from the prioritisation tool, but the results of this evaluation will not be used to directly obtain weights for each FPV (this will be done in a later phase with the MACBETH value judgements);

- Evaluation of the adequateness of the descriptors of performance and levels of performance used to operationalise each variable;
- Geographic localization of the respondent and category of the hospital within the SNS in which they are employed;
- Surgical speciality in which the respondent works.

- Choice of the platform on which the questionnaire will be implemented, and elaboration of the said questionnaire taking the measures necessary to ensure randomness and unbiasedness. Special focus should be given on the order of presentation of each section of the questionnaire, presented in the previous item, and the order in which variables will be presented within that section.

  The questionnaire should consist of:

  - An introductory section, where the aim and context of the Delphi are explained;
  - The main section, which aims at collecting the information mentioned in the previous item. Hence, a suggestion of questions that should be answered, as well as of the response scales used to answer these questions are presented in Table 4.2.
  - A final section in which socio-demographic information regarding the respondent is collected, namely their geographic localization, the category of the hospital within the SNS in which they are employed, and their surgical speciality.

- Clarification of the distribution strategy of the questionnaire and the target population.

Finally, the MACBETH approach demands that FVPs are independent, so that the performance of different patients in each FVP can be calculated separately from their performance in other FVPs.

Consequently, it will be necessary to confirm the preference independence of variables in a second round of interviews, and alter them if dependencies are found. In Annex C, an explanation of how these tests should be carried out with the decision-makers is presented. Only then can the variables be adopted as FPVs influencing patient prioritisation.

4.3.2 Phase II

Phase II concerns the building phase, in which a new protocol for the calculation of a priority score for each patient will be presented. This protocol uses the construction of value scales for each FPV and the evaluation of the strength of each FVP in the overall prioritisation of a patient, according to the stakeholders' views.

Because this tool is developed using a MCDA model, these stakeholders, who will participate in the construction of the value scales and weights of each FPV using the MACBETH method, will from now on be named decision-makers, and the designer of the MACBETH model building will be referred to as the facilitator. The elicitation of decision-makers' preferences shall be carried out using a Delphi process, where the MACBETH multi criteria approach will be framed within the Delphi. The advantages of a Delphi method have been referenced before.

In order to achieve an overall priority score for each patient, value functions and weighting coefficients for each FVP must first be defined. In order to compute the value functions, the differences of attractiveness between the levels of performance in each FVP must be computed. In order to compute the weighting coefficients, the differences of attractiveness between the levels of performance in different FVPs must be computed.

Finally, the outputs of this model may be generated, and this model can be used for assigning each patient a prioritisation score: using the respective value functions obtained in the previous step, the performance of a patient in each FVP is converted into a partial value score. The partial value scores are summed to present an overall priority score using the weights for each FVP.

4.3.3 Phase III

Phase III is related to the validation of the prioritisation model using the MACBETH approach. Before the implementation of this model in the SNS context, it is crucial that the sensitivity and robustness of the model be tested, to ensure the reliably of the prioritisation tool.

A sensitivity analysis is needed because the judgments made by the decision-maker are given in a qualitative and a somewhat uncertain way. Therefore, the obtained prioritisation scores for patients may present an associated margin of error that varies between criteria.

This can be analysed by looking at the range of the weight variations, which vary according to the

judgments made. Consequently, we can define the sensitivity analysis on the weight of a criterion as a tool that allows the evaluation of the change in the final results of the constructed model, that is, how much the weight of a certain criterion will influence the prioritisation score, and therefore the ranking of patients if that weight is allowed to change by a certain margin.

After performing sensitivity analysis, which deals with the possible variation of the weight of the different criteria, one should also consider the uncertainty related to any decision-making process: it is a result of a human personal and biased opinion, which can never be perfectly expressed to the analyst. A robust commitment will hold dominance and global preference between options under varying amounts of information.

Both these analyses can be carried out using the M-MACBETH software, possibly in final interviews with experts. It is recommended that individual interviews are performed since these analyses can be quite demanding and are not straightforward for the decision-maker to understand.

4.4 Application of MACEBTH to patient prioritisation

Since this work is part of a master's thesis with a limited time frame to be completed, the focal point will be restricted to the development of part of Phase I of the proposed methodology, that is, the Structuring phase. Hence, the next pages will describe the steps taken to reach a valid list of variables and their respective descriptors and levels of performance. This information may be used for validation in a Delphi, and for the development of the MACBETH model and an overall prioritisation score.

4.4.1 Definition of screening/ exclusion criteria

Considering the scope of this thesis, it was possible to define screening criteria which automatically prevents patients from being inserted in a standard waiting list for elective surgery, and therefore no priority score can be calculated:

- Transplantation of organs: patients who are in need of an organ transplant must be put in a specific waiting list, whose FPVs are not identical to the FPVs identified for waiting lists for elective surgery.

4.4.2 Definition and validation of FPVs and corresponding descriptors and levels of performance

Step 1: Literature Review

The initial step of the MACBETH socio-technical approach was carried out as a literature review. Its aim concerned the creation of a list of FPVs relevant in the context of PPTs, regardless of the context in which each PPT was inserted in. This enabled the construction of a vast and in-depth list.

The potential FPVs, or variables, and their respective definition collected in the literature review were structured according to the dimension of the patient's case to which they referred: Clinical/ Functional Impairment, Patient Benefits, Social Role of the patient, Clinical Management, Personal Factors and Evidence-Based Medicine. The variables and their definition are presented in Chapter 3. Possible descriptors and levels of performance were also taken from the articles mentioned in Chapter 3, and whenever there was not any relevant data, research in other articles was used.

Therefore, Table 4.3 presents the list of variables, together with each descriptor and levels of performance that was presented in semi-structured interviews to surgeons, with the aim of obtaining its validation.

Step 2: Semi-structured interviews

With the aim of validating the variables presented in Table 4.3, it was necessary to contact experts in patient prioritisation in waiting lists for elective surgery.

More specifically, the goals of the semi-structured interview included:

- Defining which variables are indeed relevant for patient prioritisation in waiting lists for elective surgery in the Portuguese public health system context. This includes defining which variables resulting from the literature review should be kept in the list, defining which variables should be excluded from the list, and which variables (if any) should be inserted in the list.
- Validate the definition of relevant variables, with possible alterations resulting from the contribution of the experts.
- Validate the adequateness of the proposed descriptors of performance and performance levels for each variable, with possible alterations resulting from the contribution of the experts.

Although there are various stakeholders whose opinion could prove useful in the development of patient prioritisation tools, it was decided that the contribution of surgeons would bring the most benefit to this work. Surgeons are the stakeholders responsible for outpatient consultations, in which the patients are inserted in waiting lists. They are simultaneously the stakeholders who will ultimately remove the same patients from the waiting list by performing the surgery. Therefore, surgeons have a better perception of the process of decision making concerning prioritisation of patients for elective surgery, and of the health state of the individuals at the time of surgery.

Table 4.3: List of variables, with their respective definition, and suggested descriptors and levels of performance, that was developed as a result of the literature review.

Criterion	Definition of Criterion	Descriptor of Performance)	Levels of performance
CLINICAL/ FUNCTIONAL IMPAIRMENT			
Severity of disease	Extent of organ system derangement or physiologic decompensation of a patient, which are a consequence of the disease in question.	Severity of disease according to American Society of Anesthesiologists (ASA)	Categories I-V
Pain (and other main symptoms)	Pain refers to suffering in general or more specifically about physical pain. It refers to the degree of the main symptom (type, intensity or frequency) affecting daily life activities and health related quality of life (HRQoL).	Numerical Rating Scale	Categories 0-10
Rate of disease progression	Risks associated with a postponement in the surgery, such as risk of death, risk of serious complications, development of co-morbidity and/or worsening the severity of the illness, decrease in the effectiveness of surgery and/or prognosis, past complications, risk of affecting adjacent organs or spread of the disease, and progression that might affect the survival and/or can modify the type of surgery.	Rate of disease progression	Evident fast progression of disease affecting outcome by delay Potential fast progression No fast progression
Functional impairment	Limitation, due to the health condition, to undertake daily life activities that were held prior to the disease.	Ability to carry out daily life activities	Not threatened or difficult Not threatened but more difficult Threatened but not immediately Immediately threatened
Psychological distress	Emotional suffering typically characterised by symptoms of fear, hopelessness, sadness, anxiety, and frustration.	World Health Organization Quality of Life Instruments (WHOQOL-BREF)	Categories 0-20
PATIENT BENEFITS			
Probability and degree of improvement	Probability and/or degree of improving functionality, pain or other characteristics (related to the disease) and overall improvement in health-related quality of life.	Probability of improvement with surgery	0-100% (Continuous numeric descriptor)
SOCIAL ROLE OF PATIENT			
Limitation to being independent	This criterion first assesses whether the patient is independent in his daily life; second, in case this is not true, it assesses whether there exists a caregiver or someone who helps with daily life activities.	Being dependent and having a person to take care of them	The patient has a caregiver or he/she is independent The patient does not have a caregiver and she/he is dependent
Limitation to care for one's dependents	Possible limitations to exercise the responsibility of taking care of dependents (i.e. children, elder parents, etc.), due to the condition which could be treated with the programmed surgery.	Limitation to care for one's dependents (if that be the case)	Without limitations With limitations
Limitat. in the ability to work (..)			Still able to work fully

Limitation in the ability to work, study or seek employment	Limitations to work (in paid or unpaid jobs), including limitation for schooling, educational activities and job-seeking.	Impairments in working	Has to skip work partially Not able to perform job anymore
CLINICAL MANAGEMENT			
Cost-effectiveness	Cost-effectiveness criteria consider the effectiveness of the intervention options, in this case, the surgery for which the patient is being put in the waiting list, weighted by their costs, when compared to the cost-effectiveness of no intervention or an alternative intervention.	Level of cost-effectiveness when compared to an alternative intervention or no intervention	Categories A- E
Economic efficiency	Consumption of resources, regardless of the potential effectiveness, benefit or utility associated with the treatment/ intervention.	Cost of surgical intervention (in €)	0- 50.000+ € (Continuous numeric descriptor)
Waiting time	Time the patient has already spent waiting for surgery, since a longer waiting time is associated with deterioration of condition and smaller clinical benefits while patients wait.	Clinical judgement maximum wait time (in months)	0- 48+ months (Continuous numeric descriptor)
PERSONAL FACTORS			
Age	Length of time that the patient has lived.	Age at time of inclusion on waiting list	Infants (0-2 years old) Children (3-17 years old) Adults (18-64 years old) Seniors (>65 years old)
Socioeconomic Status (SES)	Socioeconomic status is a measure of one's combined economic and social status and tends to be positively associated with better health.	Income	0-3000+ €/month (Continuous numeric descriptor)
Lifestyle	Impact of lifestyle or the potential responsibility of the patient concerning their current health status. This could include self-inflicted conditions, resulting from unhealthy lifestyles, such as smoking, leading an unhealthy diet, or having unprotected sexual.	Impact of lifestyle on patient's condition	The patient's lifestyle did not cause the onset of the condition The patient's lifestyle contributed to the onset of the condition The patient's lifestyle was the main cause of the onset of the condition
EVIDENCE-BASED MEDICINE			
Evidence-Based Medicine (EBM)	Insights and opinions derived from high-quality research on population samples, to inform clinical decision-making in the diagnosis, investigation, management or care of individual patients.	Grading of Recommendations Assessment, Development and Evaluation	High Quality Evidence Moderate Quality Evidence Low Quality Evidence Very Low Quality Evidence

Six surgeons from a Portuguese public hospital were contacted for an individual semi-structured interview, lasting between thirty minutes to one hour. Each surgeon worked in a different surgical speciality: Plastic Surgery, Orthopedic Surgery, Pediatric Surgery, General Surgery, Cardiology and Ophthalmic Surgery. The six interviews were carried out between October and November 2020, in virtual platforms (Zoom, Skype and even Whatsapp). The only facilitator in each interview was the author of this thesis.

These type of interviews are used often in qualitative research and characterized by a mixture of closed- and open-ended questions, often accompanied by follow-up *why* or *how* questions [157].

Whereas with open-ended questions the experts may feel more confident in expressing their points of view, since they can give an explanation for their answers, close-ended questions give some needed structure to allow a potential comparison between answers. Therefore, semi-structured interviews are ideal for discussing a sensitive issue such as patient prioritisation, which could provide a strong foundation for building the methodology and designing the larger-scale survey which ensues.

In order to improve the flow of the interviews and familiarise the six surgeons with the topic in question, a document of preparation was sent attached to the invitation to the semi-structured interview. A copy of this document is presented in Annex A. With the aim of facilitating its interpretation by the experts and adapt the document to a more colloquial language, it was written in Portuguese, and the variables were referred to as criteria, although they had not been validated yet.

The document included an introductory paragraph in which the aim of the interview was clarified within the context of this Master's thesis, and concepts related to patient prioritisation were explained, such as criterion, descriptor of performance, and levels of performance. Table 4.3 was also presented, as well as six questions that were discussed in the interviews (the first question concerned all sixteen variables, whereas the remaining questions applied to each variable individually):

- In your opinion, is there any criterion which should be removed or added to the list of sixteen criteria to be considered in the context of patient prioritisation for elective surgery?
- In your opinion, is the criterion at hand used nowadays in patient prioritisation tools for waiting lists in the context of elective surgery in the SNS?
- Do you agree with the definition of the criterion at hand? In your opinion, is there missing information in the definition of this criterion?
- Do you consider that there exist two or more criteria which evaluate the same dimension of the patient's case, and therefore should be grouped?
- In the table below you may find suggestions of descriptors of performance, mentioned in literature. In your opinion, is there missing information regarding the adequateness of the descriptor?
- In case you agree that the descriptor of performance is adequate for the criterion at hand, in your opinion, are the suggested levels for the classification of patients regarding the descriptor of performance at hand adequate? These levels should reflect the most common states of patients at the time of insertion in the waiting list.

5

Results

Contents

This Chapter presents the results obtained from the first two steps of Phase I of the methodology presented in Chapter 4. As the results of the literature review have already been discussed in Chapter 3, this Chapter will present the results of the semi-structured interviews.

5.1 Semi-structured interviews

5.1.1 Information collected in close-ended questions

The comments of the six experts regarding the relevance of the variables and correspondent descriptors of performance in patient prioritisation for waiting lists are reproduced in Table 5.1.

Table 5.1: Results of the six semi-structured interviews performed: Comments of each respondent regarding the relevance of each variable in the context of patient prioritisation, as well as the adequateness of the suggested descriptors of performance. YES or NO refers to the respondent's opinion on whether the variable at hand SHOULD be considered in patient prioritisation, hence it does not necessarily mean that this variable is used nowadays. The comments which refer specifically to the suggested descriptor of performance are in italic. **Legend: Exp**: Expert

Variable	Exp	Respondents' answers regarding the relevance of the variable
CLINICAL/ FUNCTIONAL IMPAIRMENT		
Severity of disease	A	YES
	B	YES. There are guidelines at the European level for the prioritisation according to the type of surgery.
	C	YES. This variable has consequences in the quality of life of patients. *The performance in this variable can be evaluated by listening to patients.*
	D	YES. This is the criteria to be considered first, hinting that this criteria should have the highest weight. It was stressed that the severity of disease and risk to organ and physiologic decompensation if surgery is delayed must be considered. *NO. ASA measures the risk of surgery, because it measures the comorbidities of the patient. Since it does not measure urgency of need, it is not an adequate descriptor.*
	E	NO. In specialities which do not concern curative surgical interventions, clinical impairment is not taken into account with as much strength as in other specialities.
	F	YES. *NO. ASA does not inform about progression of disease. The systemic sate of the patient coming from diseases that are not the one for which he is being considered for a surgical intervention, should not matter to decide the priority. ASA is mostly used by anaesthetists.*
Pain (and other main symptoms)	A	Difficult to measure, subjective to perception of pain by patient.
	B	YES. Symptoms are fundamental, but pain is not relevant in defining the patient's priority in certain surgical interventions.
	C	Pain is not relevant in defining the patient's priority in certain specialities, for example in plastic surgery and ophthalmology. *Evaluation of pain is highly subjective.*
	D	YES. Nevertheless, this variable is not very important, because it can usually be controlled with drugs.
	E	NO. In specialities which do not concern curative surgical interventions, clinical impairment is not taken into account with as much strength as in other specialities.
	F	YES. *YES. Good choice of descriptor of performance. One weakness of this variable concerns the subjectivity of the pain scale for every patient. Nevertheless, doctors are usually able to evaluate the performance in this variable in spite of the subjectivity of the patient, as they consider more objective factors, such as limitations to the capacity of walking. Dependent on functional impairment.*
Rate of disease progression	A	YES. Used to prioritise patients with the same condition. Deterioration of disease is included in severity of disease. *The performance of the patient on this variable can be evaluated objectively.*
	B	YES. Expert considers how symptoms are evolving over time.
	C	YES. In certain specialities predictions are usually accurate, and there are established criteria that help determine disease progression. Time of exposure to the disease is only important when disease progression is considered. This affects/ is dependent on quality of life and daily living activities.
	D	NO. This variable should only be considered when disease progression implies increase in severity of disease, or pain. Therefore, it can happen that progression of disease does not affect priority of patient.
	E	NO. In specialities which do not concern curative surgical interventions, clinical impairment is not taken into account with as much strength as in other specialities.

	F	This variable does not present a relevant role, except in conditions requiring general surgery and in tumours. It is relatively possible to predict the evolution of disease, but it was stressed that this evolution might differ from patient to patient for the same disease, as it depends on the activity of patient, their daily life, their weight, etc.
Functional impairment	A	It is an objective aspect of Disease progression. On the other hand, the toll it has on the patient is subjective.
	B	YES. Quality of life is very important in patient prioritisation (in some specialities, even more than life expectancy, where it is uncommon for this to be at risk). The autonomy and agility of the patient, and their relationships with the outside world before surgery is paramount in deciding patient prioritisation.
	C	YES. Quality of life is very important in patient prioritisation (in some specialities, even more than life expectancy, where it is uncommon for this to be at risk). The doctors takes into account if there is the possibility of a radical change in economical situation and autonomy/ independence with surgical intervention, assigning a higher priority in that case.
	D	YES.
	E	
	F	YES. This is one of the most relevant variables. *One weakness of this variable concerns the subjectivity of descriptors used nowadays. There are objective descriptors for very specific conditions, but doctors do not have availability to evaluate every patient.*
Psychological distress	A	This variable is considered when doctors consider if the surgical intervention should be performed at all: if the patient is not feeling hopeful, surgery may not have the expected outcome. Comorbidities may affect functional impairment, which affects self-esteem.
	B	YES. Distressed patients might not benefit from surgical intervention, especially when it implies consequences and sequels long after surgery.
	C	YES. *One weakness of this variable concerns the subjectivity of descriptors used nowadays. Since the number of psychologists in SNS is very reduced, doctors usually infer the psychological state of the patient by listening to them.*
	D	YES. *Sometimes feedback about the psychological state of the patient is requested to the psychology team.*
	E	This variable is considered when doctors consider if the surgical intervention should be performed at all. Expert believes that one should try not to value emotional suffering associated to the clinical situation, since this is highly subjective and does not reflect real severity of the condition.
	F	It is difficult to use this variable, but when the performance in this criterion is considered, it is patients with depression or other psychological conditions who have higher priority, when doctor believes that surgery will improve this. *There is no commonly used descriptor, and the performance of the patient in this variable is evaluated subjectively.*
PATIENT BENEFITS		
Probability and degree of improvement	A	
	B	YES
	C	YES. This variable is very important. Doctors often consider if benefits from the intervention include improvements in functional impairment and possibility of living independently. *It is possible to predict if surgery will be successful according to the patient's case, but it is not easy to give a range of percentage of improvement.*
	D	NO. Expert refers that the performance in this variable is relevant mostly in oncological patients.
	E	YES. Expert refers that the performance of the patient in this variable always has to be taken into account in the context of the Portuguese public healthcare system.

Probability and degree of improvement	F	YES *Expert refers that it is possible to evaluate the performance of this variable with the proposed continuous numeric descriptor, but it was highlighted that the performance may not be not the same for every patient having the same condition, therefore implying that the performance in this variable may be dependent on clinical impairment variables.*
SOCIAL ROLE OF PATIENT		
Limitation to being independent	A	YES. This variable is especially important in the Portuguese context because there is no reliable support network for caretakers implemented nationally.
	B	YES. This variable is very important.
	C	YES. This variable is very important, especially in surgical interventions performed in outpatients. It is already currently considered by doctors in patient prioritisation.
	D	YES. This variable is highly dependent of how patient faces the disease, as it was suggested that the level of independence is often defined by the patient. Hence, it was implied that that the performance in this variable is dependent of the variable Psychological distress.
	E	YES. Especially in more complicated surgeries, it was mentioned that if patient is dependent but has no caretaker, the efficacy and duration of results will be compromised. Dependent of probability and extension of benefit.
	F	YES, but it was mentioned that the performance in clinical impairment variables criteria are more important. It was also mentioned that the performance in the three variables in this dimension, Social Role of the Patient, are interdependent.
Limitation to care for one's dependents	A	YES.
	B	
	C	
	D	
	E	
	F	YES, but it was mentioned that the performance in clinical impairment variables should be more valued.
Limitation in the ability to work, study or seek employment	A	
	B	
	C	
	D	YES. Although this variable is not mentioned in legislation, it is considered in patient prioritisation nowadays. Its strength is subjective to the doctor in charge of prioritisation.
	E	YES.
	F	YES, but it was mentioned that the performance in clinical impairment variables should be more valued. The performance in this variable should be considered for patients with the same condition, assigning higher priority to the patient with higher work impairment.
CLINICAL MANAGEMENT		
Cost-effectiveness	A	NO. Expert stated that in their opinion the performance in this variable should not be considered for defining priority of patients, but it should nevertheless be considered at higher levels of resource allocation.
	B	NO. This variable should only be used to decide whether patient should be considered for a certain surgical intervention, but it does not decide level of priority.

Cost-effectiveness	C	NO. Although this variable is currently not considered in the Portuguese public healthcare system context, expert defends that it should be used but only at higher levels of resource allocation. *QALYS are generally not used in the Portuguese healthcare system.*
	D	NO.
	E	
	F	NO. This variable should not be considered in patient prioritisation. *Expert has heard about QALYs but does not use them on a regular basis.*
Economic efficiency	A	NO. This variable is less relevant than the variable cost-effectiveness.
	B	
	C	NO. Although this variable is currently used, the Expert feels that the performance on this variable should not be considered.
	D	NO.
	E	NO. It was stated that decision makers make an effort not to consider the performance of this variable in prioritisation, avoiding the delay of a surgery because of its price.
	F	NO.
Waiting time	A	The relevance of this variable is controversial, unlike variables shown in the beginning of the table. The same disease/ condition might have different maximum recommended waiting times depending on the patient. This variable should also take into account that patients often need psychological preparation and organization for surgical intervention.
	B	YES. This variable is already considered in certain surgical interventions.
	C	
	D	The relevance of this variable is controversial. Maximum waiting times and targets for public hospitals are already defined according to the type of surgical intervention, but these may prejudice longer/ non convenient surgeries.
	E	YES. It was stated that this variable is the most relevant in prioritisation. Regarding time, it was also asserted that duration of surgical intervention is also important.
	F	YES. Nowadays, this variable is already considered, owing to the method of payment to hospitals for performing surgical interventions, which includes sanctions if the hospital is in charge of patients who were not attended to before the recommended maximum waiting time.
PERSONAL FACTORS		
Age	A	
	B	NO. Supported by the fact that this variable is not presented in international guidelines.
	C	NO. Expert stated that what matters is how patient might still live, not how long he has lived.
	D	NO. This variable should only be taken in account in very similar cases.
	E	NO. This variable is especially not relevant in surgical interventions where life expectancy is not at risk owing to the health condition.
	F	YES. It is considered that for a patient who is still working, the consequences of delaying the surgical intervention affects more their daily life than for an older patient.

Socioeconomic Status (SES)	A	YES. It was stated that this should be considered a ”secondary” variable. In SNS, healthcare should be universal, equitable and balanced. Nevertheless, it is necessary to consider if there exists a social support network, which is often dependent of SES.
	B	
	C	YES. In certain specialities, patients are usually elderly people, with low retirement wages. These should be given higher priority because the surgical intervention will bring them a better quality of life, and the ability to live independently. This is crucial in cases when the low wages cannot afford caretakers.
	D	NO.
	E	
	F	NO. The goal of SNS is to treat every citizen, regardless of how much they earn.
Lifestyle	A	NO. The Expert mentioned that the relevance of the performance of this variable is a controversial topic. They agree that lifestyle may be responsible for comorbidities, but they defend that the patient should not be directly blamed, as it is not appropriate ethically, socially, politically. It was mentioned that the lifestyle of the healthcare provider may determine the relevance of the performance of this variable in prioritisation.
	B	YES. It was mentioned that often in patients waiting for surgical intervention,if the lifestyle is not altered, the benefits will be smaller. Therefore, there are already international guidelines that only allow the intervention to be performed if the patient changes their lifestyle, for example, if they quit smoking. It was also mentioned that in certain ethnicities, patients might be reluctant to take drugs, which might affect the outcome of surgery, hence the prioritisation of the patient.
	C	YES. It was stated that this variable should be considered. Surgical interventions usually do not change lifestyle of patients.
	D	YES. It was stated that this variable should be considered because it might influence potential benefits of the surgical intervention.
	E	NO.
	F	YES. It was stated that this variable is relevant. Nevertheless, it was also mentioned that it is not considered nowadays.
EVIDENCE-BASED MEDIDICNE		
Evidence-Based Medicine (EBM)	A	YES. This variable was perceived as relevant, but it was mentioned that many breakthroughs will still be required until a robust and adjustable method is created, since EBM is statistics-based, but medicine must be humanistic. On the other hand, a certain evolution in using EBM in the Portuguese healthcare system was recognized, for example, *DGS* has already created guiding standards for maximum waiting times based on EBM. *It can be evaluated objectively.*
	B	YES. It was stated that the relevance of this variable is greater than the relevance it is given nowadays.
	C	
	D	YES. It was mentioned that the prioritisation of patients already in the list is reviewed every week, using, among other variables, EBM.
	E	YES. Even though it is not used systematically at the moment, Expert suggests that the this variable should be considered.
	F	YES. It was stated that there has been evolution as far as EBM is concerned, since studies nowadays are becoming more organised, which allows doctors to make the right decisions. Medicine is not an exact science, but with more proof it becomes more secure. *Descriptor suggested could be used.*

5.1.2 Information collected in open-ended questions and experts' comments

Apart from the information collected in Table 5.1, it was also possible to gather complementary information regarding the process of patient prioritisation in SNS.

Firstly, it was often referred that it is straightforward to change the priority of a patient in SIGLIC once they have been inserted in LIC, and this is performed often: the priority of a patient may change, not only due to a possible deterioration of the health condition, but also due to a longer waiting time.

Furthermore, several respondents also stressed that in order to accept the significant relevance given to variables concerning the Social Role of Patient, it is fundamental to state the adopted perspective of health when developing this tool, which is highly dependent of the society the health system is inserted in: it depends on its ethics and citizenship moral principles. It was unanimous that a holistic perspective must be adopted, where one should consider a disruption of the well-being, and not only of health.

Although the goals of the interviews did not directly concern the definition of the range of applicability of the proposed prioritisation tool, it was evident from the respondents' answers that some variables should be evaluated according to the surgical speciality. The variables presented in literature, especially those belonging to the clinical dimensions of the patient's case, were criticised for being too general, making the task of deciding who should be prioritised ambiguous. Since nowadays the waiting lists are already managed by surgical speciality, there would be no issue in evaluating patients from different specialities with different descriptors of performance.

Moreover, for some surgical specialities, such as cardiology, international guidelines on which criteria should be used in patient prioritisation have already been adopted in SNS. Since these guidelines may constitute important groundwork for the construction of a prioritisation tool, it must be considered that the implementation of such a tool might be more straightforward in some specialities.

Finally, it was highlighted that research work on patient prioritisation in waiting lists for elective surgery in the context of SNS is fundamental. Nowadays, since criteria are deemed too generic, doctors admitted to prioritise based largely on their own judgement and experience. Nevertheless, it was stated that the principles behind this judgement and experience often coincide with the variables presented in Table 5.1, thus they are used unknowingly. Despite the current implicit use of the variables, respondents defended the development of a prioritisation tool where they would be used explicitly.

5.2 Updated list of variables

After analysing the information about the relevance of each variable in the list presented to the experts, which is presented in Table 5.1, it was evident that this list should be modified to take into account the points of view of these experts in patient prioritisation.

In the first place, it was decided that if a variable was regarded as not relevant by the majority of

experts (i.e. by four or more experts), it should be excluded from the list of variables to be used in the next steps of the methodology. Therefore, three variables were regarded as non-relevant in the context of prioritisation of patients for waiting lists in SNS: **Cost effectiveness**, **Economic efficiency** and **Age**. On the other hand, the variables which were deemed relevant are presented in Table 5.2.

Table 5.2: List of variables which were presented to experts in patient prioritisation in semi-structured interviews and were considered relevant in the context of patient prioritisation.

Relevant variables	
Severity of disease	Limitation to care for one's dependents
Pain (and other main symptoms)	Lifestyle
Rate of disease progression	Limitation in the ability to work, study or seek employment
Functional Impairment	Waiting time
Psychological distress	Socioeconomic Status (SES)
Probability and degree of improvement	Evidence-Based Medicine (EBM)
Limitation to being independent	

Some variables were merged since it was considered that they measure the same aspect of a patient's case. Additionally, the name and definition of some variables were changed as per the experts' comments. To facilitate the comprehension of the modifications made to the list of variables presented to the experts, Figure 5.1 represents a schematic diagram where the colour of each variable in the updated list provides a trace-back of which initial variable(s) were considered to build this new variable. In the following paragraphs, the rationales for the modifications made to the initial list are provided.

Since the variable **Severity of disease** was unanimously stated as relevant, it was kept in the list with changes in its definition. It was decided that **Rate of disease progression** should be merged with this variable since the experts mentioned that the evaluation of the severity of the disease included a prediction of its rate of progression, while others mentioned that a patient would have a worse performance in **Rate of disease progression** only if that rate implied worsening of the severity of disease.

The descriptor of performance for **Severity of disease** is not adequate since several experts defended that severity of disease should be evaluated with specific descriptors of each surgical speciality.

The variable **Pain (and other main symptoms)** was changed to **Main symptoms**, as experts stated that pain can usually be controlled with drugs, hence other symptoms may be more important to consider. This new variable also includes **Rate of disease progression**, as it now includes the rate of progression of symptoms associated with the disease. The descriptor of performance should once again be modified, and adapted taking into account the most recurrent symptoms within each speciality.

It was evident that the variable **Functional Impairment** was regarded differently by the six experts. Whereas one expert associated it with **Severity of disease**, others used the expression "Quality of life" when giving their opinion about this variable, and one other linked this variable to the **Psychological distress** the disease may have on each patient. All opinions considered, it was decided that **Functional**

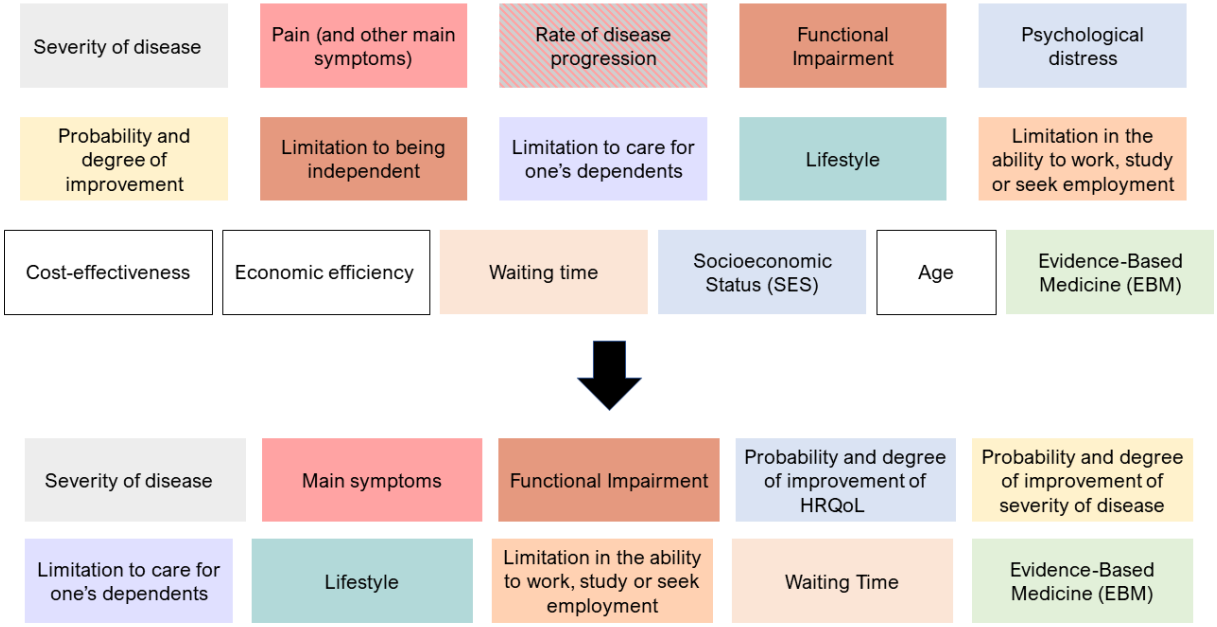

Figure 5.1: Schematic diagram representing the construction of the new list of variables to be used in the Delphi. The construction departed from the initial list of variables collected in the literature review. The color of a variable gives a trace-back of which initial variable(s) were considered to build this new variable.

Impairment can be considered as non-overlapping with **Severity of disease**.

It was also mentioned that **Limitation to being independent** highly overlaps with **Functional Impairment**. Since these variables measure the same aspect of the patient's case, they were aggregated, and the descriptor of performance was modified to include the evaluation of existence of a caretaker.

As far as the variables **Psychological distress** and **Socioeconomic Status** are concerned, the comments from the experts showed that they should be considered in patient prioritisation, but the descriptors were not adequate. For these experts, the potential improvement in the performance of the descriptors related to these variables is more important than the value of the performance *per se* at the time of insertion of the surgery. Moreover, it was hinted that these potential improvements would directly lead to a better quality of life. Therefore it was decided that these variables should be merged, as there is an overlap in what they are truly measuring, which is the improvement in quality of life.

In addition, it was also understood that a potential improvement of the health condition resulting from the surgical intervention for which the patient is being considered to the waiting list is relevant in the context of patient prioritisation. It is important to distinguish between **Rate of disease progression** and **Probability and degree of improvement of severity of disease**: whereas the first measures the evolution of disease if the patient is not operated, the second measures the potential benefits of the operation as far as the health condition of the patient is concerned, that is, it measures the potential halt or regression of disease if the patient is operated.

What is more, owing to an holistic approach to health adopted by most experts, the variables **Limitation to care for one's dependents** and **Limitation in the ability to work, study or seek employment** were considered very important. However, after discussing with the experts, it was suggested that the definitions and descriptors proposed for these variables present a certain degree of overlapping with the new variable **Functional Impairment**. Rather than evaluating if the patient presents limitations to care for their dependents, these variables should only assess if the patient has dependents or is employed.

As far the variable **Lifestyle** is concerned, the opinions were not consensual. Two experts stated that it should be considered for deontological reasons, whereas two other experts mentioned that it should be considered as a potential hurdle to the **Probability and degree of improvement of severity of disease**. The remaining two experts were against the use of this variable in the context of patient prioritisation. Hence, it is suggested that this variable is considered in the next steps, where a larger sample of experts will determine if this variable is indeed important in patient prioritisation.

Waiting time was regarded as one of the most important variables to be considered in patient prioritisation. Although the descriptor suggested, "Clinical judgement maximum waiting time at time of inclusion in waiting list", was built with the aim of evaluating the performance in this variable at the moment of insertion of the patient in the waiting list, after discussion with the experts it was evident that with this descriptor, the variable would be dependent of **Severity of disease**. Instead, these experts suggested including this variable in a dynamic process of prioritisation, where the descriptor of performance would be "Time the patient has already spent waiting". Consequently, the priority of this patient would increase as he spends more time on the waiting list.

This variable is considered extremely important in the context of SNS, given how public hospitals are paid according to the surgical interventions performed. In particular, it was mentioned often that the hospital must operate patients within the recommended Maximum Waiting Times established in the Portuguese legislation and mentioned in Chapter 3, after which the hospital is penalized.

Finally, the importance of **Evidence-Based Medicine** was consensual. Although there is still a lot of research to be done in this field in Portugal before it is widely introduced as a reliable tool, all experts stated that this variable would bring much needed objectiveness to the process of patient prioritisation.

The updated list of variables to be used in future steps of the methodology is presented in Table 5.3.

Table 5.3: Results of the six semi-structured interviews performed: relevant variables in the context of patient prioritisation in waiting lists in SNS, and their definition. The descriptors of performance which were accepted are also presented, as well as the levels of performance for each descriptor. **Legend**: **SD**: Severity of disease, **MS**: Main symptoms, **FI**: Functional Impairment, **PHRQoL**: Probability and degree of improvement of HRQoL, **PSD**: Probability and degree of improvement of severity of disease, **LCD**: Limitation to care for one's dependants, **LS**: Lifestyle, **LAW**: Limitation to the ability to work, study or seek employment, **WT**: Waiting time, **EBM**: Evidence-Based Medicine.

VARIAB.	DEFINITION	DESCRIPTOR OF PERFORMANCE	LEVELS OF PERFORMANCE
SD	Extent of organ system derangement or physiologic decompensation of a patient, which are a consequence of the disease in question if surgery is delayed. It must also include the Risks associated with a postponement in the surgery, such as risk of death, risk of serious complications, development of co-morbidity and/or worsening the severity of the illness, past complications, risk of affecting adjacent organs or spread of the disease, and progression that might affect the survival and/or can modify the type of surgery.	[No descriptor suggested. The descriptor of performance must be adapted according to surgical specialities]	
MS	Degree of the main symptoms (type, intensity or frequency) affecting health related quality of life (HRQoL), usually referring but not limited to physical pain. It must also include the risks associated with a postponement in the surgery, such as risk of progression of symptoms.	[No descriptor suggested. The descriptor of performance must be adapted according to surgical specialities]	
FI	First, this variable assesses the impact of the disease in question on health-related quality of life (HRQoL), arising from limitations, due to the health condition, to undertake daily life activities that were held prior to the disease, therefore threatening the level of independence of the patient in his daily life; second, in case there is a significant impact, it assesses whether there exists a caregiver or someone who helps with daily life activities.	Being dependent and having a person to take care of them	The patient has a caregiver or his/her ability to carry out daily life activities is not threatened or more difficult
			The patient does not have a caregiver and his/her ability to carry out daily life activities is not threatened but it is more difficult
			The patient does not have a caregiver and his/her ability to carry out daily life activities is threatened but not immediately
			The patient does not have a caregiver and his/her ability to carry out daily life activities is immediately threatened
PHRQoL	Probability and/or degree of overall improvement in health-related quality of life, through the improvement of functional impairment, main symptoms, socio-economic status, psychological distress or other characteristics related to the disease.	Difference between WHOQOL-BREF before surgery and predicted WHOQOL-BREF after surgery	0-20
PSD	Probability and/or degree of improving the disease condition for which the patient is being considered for insertion in a waiting list.	Probability of improvement with surgery	Low ($<$50%)
			Moderate (50%-70%)

PSD			High (70%-90%)
			Very High (>90%)
LCD	Possible limitations to exercise the responsibility of taking care of dependents (i.e. children, elder parents, etc.), due to the condition which could be treated with the programmed surgery.	Having dependents	The patient has dependents
			The patient does not have dependents
LS	Impact of lifestyle or the potential responsibility of the patient concerning their current health status. This could include self-inflicted conditions, resulting from unhealthy lifestyles, such as smoking, leading an unhealthy diet, or having unprotected sexual.	Impact of lifestyle on patient's condition	The patient's lifestyle did not cause the onset of the condition
			The patient's lifestyle contributed to the onset of the condition
			The patient's lifestyle was the main cause of the onset of the condition
LAW	Possible limitations to work (in paid or unpaid jobs), including limitation for schooling, educational activities and job-seeking, due to the condition which could be treated with the programmed surgery.	Impairments in working	Still able to work fully or the patient has no interest in working
			Has to skip work partially (partially on sick leave)
			Not able to perform job anymore
WT	Time the patient has spent waiting for surgery.	Waiting time (in months)	0-48+ months (continuous numeric descriptor)
EBM	Insights and opinions derived from high-quality research on population samples, to inform clinical decision-making in the diagnosis, investigation, management or care of individual patients.	Grading of Recommendations Assessment, Development and Evaluation	High Quality Evidence [1]
			Moderate Quality Evidence [2]
			Low Quality Evidence [3]
			Very Low Quality Evidence [4]

[1] **High Quality Evidence**: The authors are very confident that the estimate that is presented lies very close to the true value. One could interpret it as "there is very low probability of further research completely changing the presented conclusions.

[2] **Moderate Quality Evidence**: The authors are confident that the presented estimate lies close to the true value, but it is also possible that it may be substantially different. One could also interpret it as: further research may completely change the conclusions.

[3] **Low Quality Evidence**: The authors are not confident in the effect estimate and the true value may be substantially different. One could interpret it as "further research is likely to change the presented conclusions completely.

[4] **Very Low Quality Evidence**: The authors do not have any confidence in the estimate and it is likely that the true value is substantially different from it. One could interpret it as "new research will most probably change the presented conclusions completely.

6

Discussion

Contents

The first steps of the proposed methodology described in Chapter 4 allowed to initiate the development of a new prioritisation tool regarding waiting lists in the context of the SNS. The results of these steps have already been presented, namely the criteria suggested for patient prioritisation collected in a literature review in Chapter 3, and the points of view of six experts from a Portuguese public hospital on the adequateness of a list of variables built based on the literature review, in Chapter 5.

The aim of this Chapter concerns the performance of a critical analysis of the points of view of the six experts presented in the previous Chapter, in light of the objectives initially set and the information provided in Chapters 2 and 3. Finally, some limitations of this methodology will be discussed.

The semi-structured interviews brought important insights to the topic of management of waiting lists in SNS, already discussed in subsection 2.3. Firstly, the strategy which is most widely implemented concerns the establishment of maximum wait time targets. The targets defined in the Portuguese legislation, and mentioned in Table 3.6, were known to the experts and used to define prioritisation of patients.

However, experts also declared that this type of strategy might bring unfairness to the system of patient prioritisation: since the compliance of these maximum waiting targets are associated with funding to hospitals of the SNS, the prioritisation of patients is often adjusted to ensure a correct management of the hospital budget, pushing the needs of the patients into second place.

On the other hand, PPTs have been in place in SNS with a four-level classification system (Deferred urgency, Very high priority, High priority and Normal priority). The classification of patients into the four levels is based on seven criteria defined in the Portuguese legislation, but experts often stated that they were not aware of these criteria. Although after learning of the criteria that should be used in patient prioritisation, the experts would admit to using them at least implicitly, these seven criteria still presented some differences when compared to the variables which were regarded as relevant in the semi-structured interviews. In particular, two dissimilarities should be mentioned.

Firstly, the criteria present in the Portuguese legislation are mainly related to the clinical dimension of the patient's case, whereas the majority of experts defended a holistic approach to health, hence it was argued that other aspects of the patient case should be considered, such as their patient role or the cumulative time the patient has spent waiting for a certain elective surgery.

Secondly, these criteria in Legislation are generic, and no descriptor of performance was presented with the aim of objectively evaluating the level of performance of the patient in each of the dimensions of the patient's case. This lack of objectiveness may favour implicit processes of prioritisation.

Although the strategy currently used towards patient prioritisation takes the form of an implicit tool, it is evident that all six experts were in favour of an explicit prioritisation tool for patients in waiting lists for elective surgery in SNS. The transparency and equity that comes with an explicit tool is thought to out weight its disadvantages. On the other hand, it was mentioned that these type of tools can be too inflexible, since a score is obtained mathematically and cannot account for intricacies that arise from the

humanistic aspect of Medicine. It was suggested that a certain margin must be left for doctors to adjust the prioritisation of a patient if they find it necessary. On the other hand, this may be seen as an obstacle to the transparency associated with explicit prioritisation tools.

This work brings paramount conclusions to the topic of the duality between using general criteria or specific criteria according to the surgical speciality. The six interviews revealed that the variables proposed, which related to the clinical dimension of the patient, would only be approved if they were adapted according to the surgical speciality. It was also implied that the weights given to the performance in each criterion, which are to be determined in a later phase of the methodology, should also be adapted. Hence, it is recommended that the prioritisation tool developed in the context of elective surgery in SNS uses a mixture of general and specific criteria. The use of specific criteria in dimensions of the patient's case where it might be difficult to obtain an objective level of performance with generic descriptors may facilitate the implementation of an explicit prioritisation tool.

This conclusion confirms the information collected in the literature review, where it was evident that the majority of patient prioritisation tools already implemented were tools dedicated to specific conditions or surgical specialities. One could observe that although the number of articles mentioning generic criteria was quite similar to the number of those mentioning specific criteria, when it comes to the implementation of patient prioritisation tools, the adoption of generic criteria may hinder the use of the tool, as it becomes challenging to evaluate the performance of patients in generic descriptors of performance.

When it comes to the ethical framework used to justify the prioritisation tool, hence to justify the variables deemed relevant, there was also a mixture of both frameworks: Ability to Benefit and Urgency of need. Ability to Benefit seems to be considered, not only regarding the health condition in question, but also in non-medical variables, such as Social Economic Status, Functional Impairment and Lifestyle.

6.1 Limitations of the proposed methodology

In this section, some limitations of the proposed methodology are presented. These limitations were identified in the course of the work developed for this thesis, and could be used as recommendations for future work in the proposed methodology.

Firstly, it should be mentioned that the literature review carried out did not take into account the type of health system implemented in the context of the many articles found. Any article or study originating outside the context of SNS could present variables that are inappropriate for this same context.

Moreover, the sample of experts used for the semi-structured interviews was small and geographically concentrated, which could bring some bias to the results presented. The points of view of experts from all specialities and regions of the country must be considered, since the relevance of the variables presented here could vary, especially in regions with higher population density. There, the process of patient prioritisation might not be the responsibility of a single surgeon, but of a management team.

There have also been surgical specialities which have not been covered with the six interviews. Special emphasis should be given to the results presented in this work, which break away from the perception that criteria used in patient prioritisation tools should be generic, and it must be confirmed that the belief that the descriptors of performance should be specific is common across other surgical specialities.

It is then necessary to introduce some changes to the methodology proposed. The next section will explain in detail these changes.

6.2 Necessary changes to the proposed methodology

Since the six experts who participated in the interviews defended that the variables belonging to the clinical dimension should not be generic, but associated with descriptors of performance specific to the surgical speciality at hand, it must be defined which descriptors these are, and if this belief is shared by a large number of experts with different specialities, and in other geographic regions as well.

Therefore, the proposed methodology must be altered to include the results of this work in the prioritisation tool to be developed. The new proposed methodology is presented in Figure 6.1.

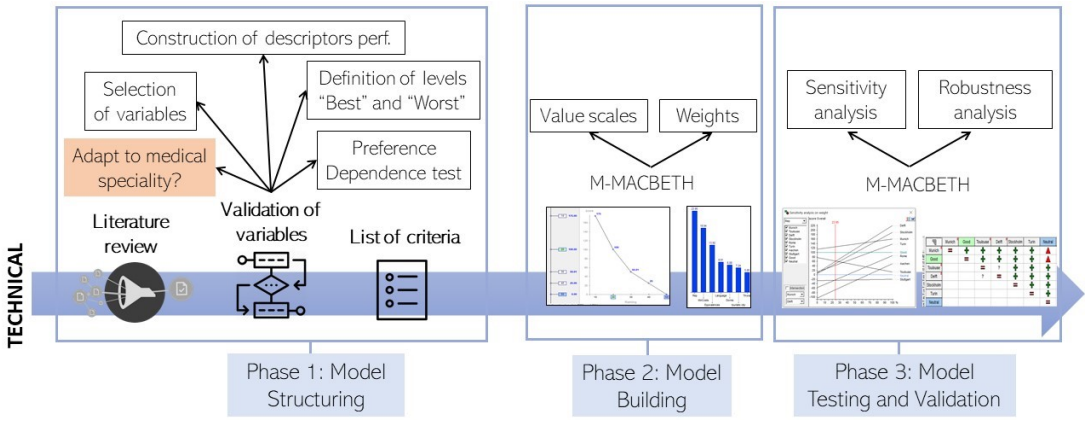

Figure 6.1: Necessary changes to the proposed methodology presented in Chapter 4. The Social component will remain similar, hence it was omitted here. The modification concerns the answer to the question: "Should the criteria used to calculate a patient priority score be adapted to the surgical specialty?".

While the structure of the Delphi must be changed to answer whether the descriptors should be generic or specific, the remaining steps of the methodology should remain as presented earlier, in Chapter 4. It is proposed that this Delphi has three rounds. The first one is an open round to inquire if the variables, in particular those related to the patient's clinical dimension (Severity of Disease and Main Symptoms), should be adapted to the surgical speciality. This could be carried out through a combination of closed-ended and open-ended questions. In this first round, it would also be relevant to collect information on potential descriptors of performance for these two variables. The following rounds could then be dedicated to the validation of the variables presented, as well as their levels and descriptors of performance.

7

Conclusion

The primary goal of this Master's thesis concerned the generation of information about the preferences of heath stakeholders in the context of prioritisation of patients in waiting lists in SNS, as a means to contribute to the development of a new patient priority scoring tool to help clinicians, namely surgeons and specialist doctors in implementing a fair and transparent process.

A methodology which allows the construction of a prioritisation tool was presented. Taking into account the complexity of the problem of patient prioritisation, the socio-technical MACBETH approach was chosen. The proposed methodology brings a fundamental contribution to the field of patient prioritisation.

Firstly, the MACBETH approach has never been used in this context. This is specially relevant since this approach is mathematically grounded, unlike other methods which have been used before in the development of patient prioritisation tools.

Moreover, the non-numeric judgements are an invaluable advantage of this model. Since the problem at hand is very subjective, and the decision-makers are clinicians, namely surgeons, who are not used to the quantification of preferences, the task of assigning strength of preferences to swings between levels of performance is rather challenging. By using non-numeric judgements to reach a quantitative output, in this case a patient priority score, this task becomes more straightforward.

Two steps of the proposed methodology were performed, with a combination of social and technical methods. Firstly, a literature review was performed with the goal of collecting information about which criteria have been suggested for patient prioritisation tools in a national and international context. Besides the variables and their definition, the context in which the prioritisation tool was implemented in each article was also collected, namely the range of applicability of the prioritisation tool, the ethic framework used to justify the same tool, and the existence of waiting time guarantees associated with the tool.

The next step consisted of six semi-structured interviews with experts in patient prioritisation. The experts were surgeons of a Portuguese public hospital, actively involved in defining the priority of patients in waiting lists for elective surgery. The aim of these interviews related to the validation of the list of variables created based on the literature review.

Not only does the proposed methodology make an important contribution, but the information collected is also paramount to the context of patient prioritisation. Very few articles have been published in the Portuguese context about this topic, and the use of the social method adopted, the semi-structured interviews, have allowed those in charge of prioritisation to express their points of view. It was possible to understand both how and with which criteria patients are prioritised currently, and the variables that these experts consider relevant in an ideal patient prioritisation tool.

Maybe even more importantly, the results of the semi-structured interviews showed that the construction of a generic patient prioritisation tool might be inconceivable as a fair process of prioritisation. It was understood that the descriptors of performance of variables associated with the Clinical dimension must

be specific to accurately evaluate the performance of the patient in each variable. Furthermore, it was suggested that in the structuring phase of the MACBETH approach, the calculation of weights to assign each variable should also vary with the surgical speciality.

Nevertheless, the semi-structured interviews take into account only the points of view of six experts from one hospital only. If this tool is to be implemented at a national level, it is paramount that the variables are validated with a larger sample of experts, from different specialties and different geographic regions.

Although the work presented here is just the beginning of a very complex process of development of a prioritisation tool, it was developed with the aim of laying a reliable foundation on which the next steps can be developed.

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A

Document of preparation for the semi-structured interviews

DOCUMENTO DE PREPARAÇÃO PARA UMA ENTREVISTA SEMI-ESTRUTURADA RELATIVA À PRIORIZAÇÃO DE PACIENTES EM LISTAS DE ESPERA PARA CIRURGIA ELETIVA NO SNS

Com vista a identificar os critérios que deveriam ser usados para priorização de pacientes, é apresentada uma **lista de 16 critérios,** que resulta de uma revisão da literatura de artigos publicados em contextos internacionais. A lista de critérios é apresentada na Tabela 1, e os critérios estão organizados de acordo com seis dimensões (incapacidade clínica/ funcional do paciente, benefícios para o paciente, papel social do paciente, gestão clínica, fatores pessoais do paciente, ou medicina baseada em evidência). Cada **critério** é apresentado juntamente com a sua **definição** num contexto de priorização de pacientes em listas de espera para cirurgia eletiva, assim como com um **descritor de desempenho**, e uma recomendação dos **níveis de desempenho** que podem ser usados para classificar o paciente. Um descritor de desempenho é um conjunto ordenado de níveis de desempenho plausíveis, que permite a operacionalização dos critérios, ou seja, permite a avaliação do desempenho de cada paciente relativamente a cada critério.

Convido-o a refletir nas seguintes questões que se referem à informação apresentada na Tabela 1, **tendo sempre em conta o contexto de priorização de pacientes em listas de espera para cirurgia eletiva no SNS**. Enquanto a resposta à primeira pergunta deve ser pensada tendo em conta os 16 critérios descritos na tabela, as questões seguintes devem ser pensadas individualmente para cada critério.

1. Na sua opinião, existe algum critério que deve ser removido ou adicionado à lista dos 16 critérios a ser considerados na priorização de pacientes?
2. Na sua opinião, o critério em questão é usado atualmente em ferramentas de priorização de pacientes em listas de espera para cirurgia eletiva no SNS?
3. Concorda com a definição do critério em questão? Na sua opinião, existe informação em falta na definição do critério?
4. Considera que existem dois ou mais critérios que avaliam um mesmo aspeto do caso do paciente e por isso deveriam ser agrupados?
5. Na tabela encontra sugestões de potenciais descritores de desempenho descritos na literatura, específicos para cada critério. Na sua opinião, existe informação em falta no que toca à adequação do descritor apresentado para o critério em questão?
6. Caso concorde que o descritor de desempenho é apropriado para o critério em questão, na sua opinião, os níveis sugeridos para classificar os pacientes em relação ao descritor de desempenho em questão são adequados? Estes níveis devem refletir os estados mais comuns dos pacientes aquando da sua inserção em listas de espera.

Tabela 1 Resultados da revisão bibliográfica relativa a artigos que avaliaram critérios usados em ferramentas de priorização de pacientes, a sua definição, respetivos descritores de desempenho e/ou níveis.

DIMENSÃO	CRITÉRIO	DEFINIÇÃO DO CRITÉRIO	DESCRITOR DE DESEMPENHO	NÍVEIS
INCAPACIDADE CLÍNICA/ FUNCIONAL	Severidade da doença	Extensão da disfunção de um sistema de órgãos ou descompensação fisiológica de um paciente, que sejam uma consequência da doença em questão.	Severidade da doença de acordo com a Sociedade Americana de Anestesistas (ASA) [i]	Categorias I-V
	Dor (e outros sintomas primários)	Sofrimento em geral ou dor física em específico, isto é, grau do sintoma principal (tipo, intensidade ou frequência) que afeta as atividades da vida diária e a qualidade de vida relacionada com saúde (QVRS).	Escala de Avaliação Numérica	Categorias 0-10
	Velocidade de progressão da doença	Riscos associados ao adiamento da cirurgia, tais como risco de morte, risco de complicações graves, desenvolvimento de comorbidades e/ou agravamento da severidade da doença, diminuição da eficácia da cirurgia e/ou prognóstico, complicações passadas, risco de afetação de órgãos adjacentes ou alastramento da doença, e progressão que possa afetar a sobrevivência e/ ou possa modificar o tipo de cirurgia.	Velocidade de progressão da doença	• Evidente progressão rápida da doença, que afeta o resultado da cirurgia se esta for adiada • Potencial progressão rápida • Sem progressão rápida
	Incapacidade funcional	Limitação, devido à condição de saúde, em realizar atividades do dia-a-dia que não apresentavam dificuldade antes do desenvolvimento da doença.	Capacidade de realizar atividades do dia-a-dia	• Não ameaçada ou com dificuldade • Não ameaçada mas com alguma dificuldade • Ameaçada mas não imediatamente • Imediatamente ameaçada
	Distúrbio psicológico	Sofrimento emocional tipicamente caracterizado por sintomas de medo, desespero, tristeza, ansiedade e frustração.	Instrumento de medição da Qualidade de Vida da OMS (WHOQOL-BREF)	Categorias 0-20
BENEFÍCIOS PARA O PACIENTE	Probabilidade e extensão da melhoria	Probabilidade e/ou extensão da melhoria funcional, dor ou outras características (relacionadas com a doença), e melhoria em termos gerais da qualidade de vida relacionada com a saúde do paciente.	Probabilidade de melhoria com a cirurgia	Descritor numérico contínuo (0-100%)

PAPEL SOCIAL DO PACIENTE	Limitações à independência do paciente	Este critério avalia em primeiro lugar se o paciente é independente na sua vida diária; Em caso negativo, avalia também se existe um prestador de cuidados ou alguém capaz de ajudar nas atividades diárias.	Ser dependente e ter alguém capaz de ajudar nas atividades diárias	• O paciente tem um prestador de cuidados ou é independente • O paciente não tem um prestador de cuidados e é dependente
	Limitações à capacidade de cuidar de dependentes	Possíveis limitações ao exercício da responsabilidade de cuidar de dependentes (i.e., crianças, parentes mais velhos), devido à condição que poderia ser tratada com intervenção cirúrgica.	Limitação ao exercício da responsabilidade de cuidar de dependentes (se for o caso)	• Sem limitações (ou não é o caso) • Com limitações
	Limitação à capacidade de trabalhar, estudar ou procurar emprego	Limitações à capacidade de trabalhar (pago ou não pago), incluindo limitações a aceder à educação ou procura de emprego.	Limitações à capacidade de trabalho	• Capaz de trabalhar sem limitações • Precisa de faltar ao trabalho ocasionalmente (baixa médica) • Não é capaz de desempenhar tarefas no seu emprego
GESTÃO CLÍNICA	Custo-efetividade	Efetividade da intervenção cirúrgica para o qual o paciente está a ser colocado na lista de espera, ponderada pelo seu custo, quando comparada com o custo-efetividade de não realizar a intervenção ou uma intervenção alternativa.	Nível de custo-efetividade comparado com a não realização da intervenção ou com uma intervenção alternativa.[ii]	Categorias A- E
	Efetividade económica	Consumo de recursos que a intervenção cirúrgica acarreta, independentemente da sua efetivade, benefício ou utilidade.	Custo da intervenção cirúrgica (em €)	Descritor numérico contínuo (0- 50.000+ €)
	Tempo de espera	Tempo máximo recomendado que o paciente deve esperar pela cirurgia, visto que um tempo de espera prolongado pode estar associado à deterioração da condição e a benefícios clínicos menores.	Opinião clínica quanto ao tempo de espera máximo aquando da inclusão do paciente na lista de espera (em meses)	Descritor numérico contínuo (0- 48+ meses)
FATORES PESSOAIS	Idade	Período de tempo que o paciente já viveu. [iii]	Idade do paciente aquando da inclusão do paciente na lista de espera	• Bebés (0-2 anos) • Crianças (3-17 anos) • Adultos (18-64 anos) • Séniores (>65 anos)
	Estado social e económico (SES)	Medida do estado económico e social do paciente, que tende a estar positivamente relacionado com melhores cuidados de saúde.[iv]	Salário (€/ mês)	Descritor numérico contínuo (0-3000+ €/mês)

	Estilo de vida do paciente	Impacto do estilo de vida ou potencial responsabilidade do paciente relativa ao seu estado de saúde atual. Exemplos: problemas de saúde originários de um estilo de vida não saudável, como fumar, adotar uma dieta não equilibrada ou ter relações sexuais não protegidas.	Impacto do estilo de vida do paciente na sua condição	• O estilo de vida não causou o desenvolvimento da doença • O estilo de vida contribuiu para o desenvolvimento da doença • O estilo de vida foi a principal causa para o desenvolvimento da doença
MEDICINA BASEADA NA EVIDENCIA	Medicina baseada na evidência (EBM)	Conhecimentos e opiniões derivados de investigação de alta qualidade em amostras de população, de modo a informar a tomada de decisão clínica no diagnóstico, gestão e cuidado de pacientes.	Categorias de Avaliação de recomendação, desenvolvimento e avaliação[v]	• Evidência de Alta Qualidade • Evidência de Moderada Qualidade • Evidência de Baixa Qualidade • Evidência de Muito Baixa Qualidade

[i] Severidade da Doença de acordo com a Sociedade Americana de Anestesiologistas (ASA):
I- Paciente saudável; **II-** Paciente com doença sistémica moderada que não implica limites à atividade física; **III-** Paciente com doença sistémica severa que implica limites à atividade física; **IV-** Paciente com doença sistémica moderada que constitui uma ameaça constante à sobrevivência; **V-** Paciente cuja esperança de vida não excede as 24h sem intervenção cirúrgica.

[ii]

	Efetividade	Custo		Efetividade	Custo
Categoria A	Mais efetiva	Inferior	**Categoria D**	Mais efetiva, mais que 100 000€/ QALY	Superior
Categoria B	Mais efetiva, menos de 30 000€/ QALY	Superior	**Categoria E**	Mais efetiva, Efetividade igual ou inferior	Superior
Categoria C	Mais efetiva, 30 000€ a 100 000€/ QALY	Superior	*QALY:* Quality-adjusted life year		

[iii] Preferências para a priorização de pacientes mais novos em listas de espera para cirurgia eletiva podem refletir interesses tanto por efetividade, assumindo-se um maior benefício clínico e um menor impacto na dificuldade em realizar atividades diárias, ou interesses de equalização da idade de óbito, conhecido como a teoria "fair-innings". Esta teoria defende que pacientes mais novos tiveram até ao momento acesso a um recurso valioso- anos de vida-, e portanto devem ter prioridade de modo a lhes ser dada a oportunidade de atingir a esperança média de vida. Neste estudo, o racional que poderá justificar o critério "Idade" deve referir-se apenas à priorização baseada na teoria fair-innings.

[iv] Pensa-se que o SES pode influenciar o estado de saúde através da capacidade de comprar tratamentos e recursos promotores de saúde, além da socialização diferenciada de hábitos de saúde consoante SES.

[v] - **Evidência de Alta Qualidade**: Os autores estão bastante confiantes de que o resultado apresentado é semelhante ao valor/ situação real. Poderá ser interpretado como "Há uma probabilidade muito baixa de que investigações futuras irão refutar completamente estes resultados";
- Evidência de Moderada Qualidade: Os autores estão confiantes de que o resultado apresentado não difere exageradamente do valor/ situação real, mas é possível de que seja substancialmente diferente. Poderá ser interpretado como "Há uma probabilidade de que investigações futuras irão refutar completamente estes resultados";
- Evidência de Baixa Qualidade: Os autores não estão confiantes nos resultados, e o valor/ situação real poderá ser substancialmente diferente. Poderá ser interpretado como "É provável que investigações futuras refutem completamente os resultados apresentados";
– Evidência de Muito Baixa Qualidade: Os autores não têm qualquer confiança nos seus resultados e é expectável que o valor real poderá ser substancialmente diferente. Poderá ser interpretado como "É muito provável que investigações futuras refutem completamente os resultados apresentados".

B

Criteria presented in literature for generic and specific tools

Table B.1: Criteria mentioned in literature as suitable for use in generic prioritisation tools, Part I. **Legend:** ✓✓: criterion mentioned and supported in article; ✓: criterion mentioned but not supported in article; Where there is a description of the criterion used, this criterion was mentioned in the article but under a different name than the name of the criterion adopted (i.e., the name of the column). The symbology of the checkmarks used is the same as without text in the cell.; **CE**: Cost-effectiveness

Article	**Disease Severity**	**Pain (and other symptoms)**	**Rate of Disease progression**	**Functional Impairment**	**Psychological distress**	**Probability and Degree of Improvement**	**EBM**
McGurran et al., 2002 [110]	Duration of illness (✓)	Severity of pain (✓)	Risk of dying; Deterioration of condition without treatment ✓ ✓				
Edwards et al., 2003 [18]	Level of disability (✓ ✓)	Level of pain (✓ ✓)	Rate of deterioration of disease (✓ ✓)		Level of distress (✓ ✓)		
MacCormick et al., 2003 [104]	Disability (✓ ✓)	Pain (✓ ✓)	Deterioration of the condition (✓ ✓)			Ability to benefit (✓ ✓)	
Mullen et al., 2003 [28]	Severity of illness/ disability; Effect of delay on treatment outcome (✓ ✓)	✓ ✓	Deterioration in condition (✓ ✓)	Inability to function normally (✓ ✓)		Capacity to benefit (✓ ✓)	
Oudhoff et al., 2007 [50]	Clinical need (✓ ✓)	Degree of suffering from symptoms (✓ ✓)			✓✓	Ability to benefit (✓)	
Inza et al., 2008 [120]	✓ ✓					Improvement in health (✓)	
Testi et al.,, 2008 [57]	Clinical urgency (✓ ✓)	✓	✓	Disability (✓)			
Karlberg et al., 2009 [9]	✓ ✓					Ability to benefit (✓ ✓)	✓ ✓
Valente et al., 2009 [67]	Clinical Urgency (✓ ✓)	✓✓	Presence of fast disease progression (✓ ✓)	Dysfunction or disability (✓ ✓)			
Curtis et al., 2010 [11]	Need for surgery (✓ ✓)						
Solans-Domenech et al., 2013 [22]	Clinical impairment (✓ ✓)			✓ ✓		Expected benefit (✓ ✓)	
Johar et al., 2014 [96]	Clinical need (✓ ✓)						
Dery et al., 2019 [60]	✓ ✓				Quality of life (✓ ✓)		

Table B.2: Criteria mentioned in literature as suitable for use in generic prioritisation tools, Part II. **Legend** ✓✓: criterion mentioned and supported in article; ✓: criterion mentioned but not supported in article; Where there is a description of the criterion used, this criterion was mentioned in the article but under a different name than the name of the criterion adopted (i.e., the name of the column). The symbology of the checkmarks used is the same as without text in the cell.; **CE**: Cost-effectiveness

Article	**Being dependent with no caregiver**	**Limitation to care for one's dependents**	**Limitations in the ability to work, study or seek employment**	**CE**	**Economic efficiency**	**Waiting time**	**Age**	**Social Economic Status**	**Lifestyle**
McGurran et al., 2002 [110]		✓			Cost to society while waiting (✓)		✓	Ability to pay (✓)	✓
Edwards et al., 2003 [18]		Existence of dependants (✓)		✓	Cost of treatment (✓)		✓	Ability to pay (✓)	Self inflicted health (✓)
MacCormick, 2003 [104]	Social factors (✓ ✓)	Social factors (✓ ✓)	Social factors (✓ ✓)						
Mullen et al., 2003, [28]		✓	✓	✓✓	Resource use (✓ ✓)	✓✓	✓✓	Social status or social merit of the patient (✓ ✓)	
Oudhoff et al., 2007 [50]			✓				✓	Financial status to pay out of pocket (✓); Social limitations (✓)	(✓)
Inza et al., 2008 [120]					Cost of intervention (✓ ✓)	✓✓			
Testi et al., 2008 [57]	✓		✓			✓✓	✓		
Karlberg et al., 2009 [9]				✓ ✓					
Valente et al., 2009 [67]									
Curtis et al., 2010 [11]	Ability to live independently (✓ ✓)	✓✓	✓✓						
Solans-Domenech et al., 2013 [22]	Social role (✓ ✓)	Social role (✓ ✓)	Social role (✓ ✓)						
Johar et al., 2014 [96]								✓	
Dery et al., 2019 [60]			✓✓				✓✓		

Table B.3: Criteria mentioned in literature as suitable for use in specific prioritisation tools, Part I. **Legend:** ✓✓: criterion mentioned and supported in article; ✓: criterion mentioned but not supported in article; Where there is a description of the criterion used, this criterion was mentioned in the article but under a different name than the name of the criterion adopted (i.e., the name of the column). The symbology of the checkmarks used is the same as without text in the cell.; **CE**- Cost-effectiveness

Article	**Disease Severity**	**Pain (and other symptoms)**	**Rate of Disease progression**	**Functional Impairment**	**Psychological distress**	**Probability and Degree of Improvement**	**EBM**
Bellan et al., 2001 [10]				Degree of functional impairment (✓ ✓)			
Derrett et al., 2002 [69] (Cataract procedures)	✓✓			Visual impairment (✓ ✓)			Clinical discretionary points (✓ ✓)
Derrett et al., 2002 [69] (Prostatectomy procedures)	✓✓	Symptoms (✓ ✓)			Quality of life (✓ ✓)		
Derrett et al., 2002 [69] (Hip/ Knee joint procedures)	✓✓	Degree of pain; Pain on examination (✓ ✓)		Functional impairment (✓ ✓)			
MacCormick et al., 2003 [104]	Clinical urgency (✓ ✓)	Pain (✓)				Disease specific outcomes (✓ ✓)	
Conner-Spady et al., 2005 [24]	Clinical need (✓ ✓)			Visual impairment (✓ ✓)		Clinical benefit (✓ ✓)	
Quintana et al., 2006 [92]	Visual acuity; Type of cataract (✓)			Visual function (✓ ✓)		Anticipated postoperative visual acuity (✓ ✓)	
Allepuz et al., 2008 [68]	✓✓	✓✓		Difficulty in doing activities of daily living (✓ ✓)		Probability of recovery (✓ ✓)	
Comas et al., 2008 [21]	Visual impairment (✓ ✓)			✓✓		✓✓	
Witt et al., 2008 [121]		Pain (✓ ✓)			Enjoyment of life (✓ ✓)		

Escobar et al., 2009 [88]	✓✓	Pain on motion; Pain at rest (✓ ✓)		Walking functional limitations; Other functional limitations (✓ ✓)		Existence of other pathologies that could improve with joint replacement; Capacity of benefit (✓ ✓)	
Comas et al., 2010 [58]	✓✓	✓✓		✓✓		Prognosis	
Tebe et al., 2015 [87]	Gravity of illness (✓ ✓)	✓✓		✓✓		Probability of recovery (✓ ✓)	
Whitty et al., 2015 [107]	BMI; Presence of co-morbid conditions (✓ ✓)					Chance of maintaining weight loss after surgery (✓ ✓)	
Kavalier et al., 2017 [109]	Clinical and radiographic criteria (✓ ✓)						
Rahimi et al., 2017 [124]	Disease severity (✓ ✓)	✓✓	Rate of disease progression (✓ ✓)	Difficulty in doing activities (✓ ✓)		Probability and degree of improvement (✓ ✓)	
Arteaga-Gonzalez et al., 2018 [40]	✓✓						
Donnan et al., 2020 [122]	Nb of cardiovascular co-morbidities; Body Mass Index (✓)			✓✓	Impact on mental health (✓)		
Silva-Aravena et al., 2020 [123]	Severity of disease; Urgency; Sleep disorder; Probability of developing co morbidities without surgery; Affected area (✓ ✓)	EVA scale pain (✓ ✓)	Progression of disease (✓ ✓)	Other functional limitations (✓ ✓)		Probability of improvement with surgery (✓ ✓)	

Table B.4: Criteria mentioned in literature as suitable for use in specific prioritisation tools, Part II. **Legend:** ✓✓: criterion mentioned and supported in article; ✓: criterion mentioned but not supported in article; Where there is a description of the criterion used, this criterion was mentioned in the article but under a different name than the name of the criterion adopted (i.e., the name of the column). The symbology of the checkmarks used is the same as without text in the cell.; **CE**: Cost-effectiveness; **SES**: Socio-economic status

Article	**Being dependent with no caregiver**	**Limitation to care for one's dependents**	**Limitations in the ability to work, study or seek employment**	**CE**	**Economic efficiency**	**Waiting time**	**Age**	**Social Economic Status**	**Lifestyle**
Bellan et al., 2001 [10]			Difficulty at work due to visual impairment; Potential loss of one's driver's licence (✓ ✓)			✓✓	✓		
Derrett et al., 2002 [69] (Cataract procedures)	Social factors (✓ ✓)	Social factors (✓ ✓)	Occupational or educational factors (✓ ✓)						
Derrett et al., 2002 [69] (Prostatectomy procedures)						Also on other waiting lists (✓ ✓)			
Derrett et al., 2002 [69] (Hip/ Knee joint procedures)	✓✓	✓✓	✓✓						
MacCormick et al., 2003 [104]	Social factors (✓ ✓)	Social factors (✓ ✓)	Social factors (✓ ✓)						
Conner-Spady et al., 2005 [24]	✓✓	✓✓	✓✓						
Quintana et al., 2006 [92]	Social dependence (✓)	Social dependence (✓)	Social dependence (✓)		Surgical technical complexity (✓ ✓)				
Allepuz et al., 2008 [68]	✓✓	✓✓	✓✓						
Comas et al., 2008 [21]	✓✓	✓✓	✓✓						
Witt et al., 2008 [121]	✓✓	✓✓	✓✓					✓✓	
Escobar et al., 2009 [88]	✓✓	✓✓	✓✓						

Comas et al., 2010 [58]	✓✓	✓✓	✓✓						
Tebe et al., 2015 [87]	Restraints on social criteria	Restraints on social criteria	✓✓			✓		✓✓	
Whitty et al., 2015 [107]				Availability of effective alternatives; CE of treatment (✓ ✓)	Prior medical care; Cost of treatment (✓ ✓)	✓✓	✓	SES; Career status (✓ ✓)	Commitment to lifestyle change; family history (✓ ✓)
Kavalier et al., 2017 [109]	✓✓	✓✓	✓✓						
Rahimi et al., 2017 [124]			✓✓			✓✓			
Arteaga-Gonzalez et al., 2018 [40]						✓✓			
Donnan et al., 2020 [122]									
Silva-Aravena et al., 2020 [123]	✓✓	✓✓	Diminished capacity of study (✓ ✓)			Clinical judgment maximum wait time; Time on the surgical waiting list (✓ ✓)		Family activities (✓ ✓)	

C

Preference Dependence Test

The following pages present an example of how the Preference Dependence Tests could be carried out.

The first section explains why these tests are needed in the development of a patient prioritization tool, and it could be useful to present in a document of preparation to the decision-makers during the second round of interviews (the last step of Phase I).

The second section contains the Preference dependence test itself, with a diagram that can be completed with the levels of performance ”Best” and ”Worst” of criteria i and j to better illustrate how the decision-maker should reason to answer the two questions of the test.

C.1 Introductory explanation

After the proposed criteria have been carefully analyzed in the context of patient prioritization in elective surgery, it is important to discuss whether these criteria are independent. The model that will be used later to determine the weight of each criterion needed for the calculation of patient prioritization demands that these criteria to be independent.

For two criteria to be independent, the impact of the improvement in the performance in one criterion

cannot depend on the performance in the second criterion. For example, a pair of criteria that may hypothetically violate the independence requirement could be the criteria Likelihood and extent of improvement and Severity of disease: the impact of improving the patient's health status gain may depend on their current health status. This dependence would occur if the same improvement has a greater impact (and is therefore more valued) if the patient shows a worrying level of performance in the Severity of Disease criterion. This example is explained in this diagram, so that the decision-maker can have a visual perception of the dependency.

To carry out the preference dependence tests, it is necessary to first define two levels in each criterion with which the impact of the improvement will be assessed. These are two reference levels of performance, one lower and one higher, which will be called ”Worst” and ”Best”: The ”Worst” reference level should correspond to a level where patients are often on the waiting list. The ”Best” reference level could correspond to a level where patients often find themselves after the surgery for which they were put on the waiting list. Going through the list of criteria, you are asked to indicate, for each of these, the two levels you consider to be Worst and Best.

The preference dependence test of the criteria's impact is carried out by asking the experts the following question: ”In your opinion, are there pairs of criteria whose impact of the first may be dependent on the level of performance of the second?”

C.2 Example of dependence of criterion i on criterion j

If the expert mentions a pair of criteria *i* and *j*, the following two questions may be asked to test the preference dependence between those criteria:

1- Considering the categories ”Null”, ”Very Weak”, ”Weak”, ”Moderate”, ”Strong”, ”Very Strong”, ”Extreme”, how do you consider the difference in priority between a patient with performance levels ”Worst” on both criteria i and j, when compared to a patient with performance level ”Worst ”on criterion j but a performance level ”Best” on criterion i?

2- Considering the categories ”Null”, ”Very Weak”, ”Weak”, ”Moderate”, ”Strong”, ”Very Strong”, ”Extreme”, how do you consider the difference in priority between a patient with performance level ”Worst” on criterion i, but a performance level ”Best” on criterion j, when compared to a patient with performance level ”Best ”on both criteria i and j?

These two questions test the independence of criterion i on criterion j, hence the same two questions must be asked (with the necessary modifications) to test the independence of criterion j on criterion i. If the answer to the two questions are the same within both independence tests, it is considered that the pair of criteria i and j are independent.

With the aim of facilitating the understanding of the improvements considered in the preference

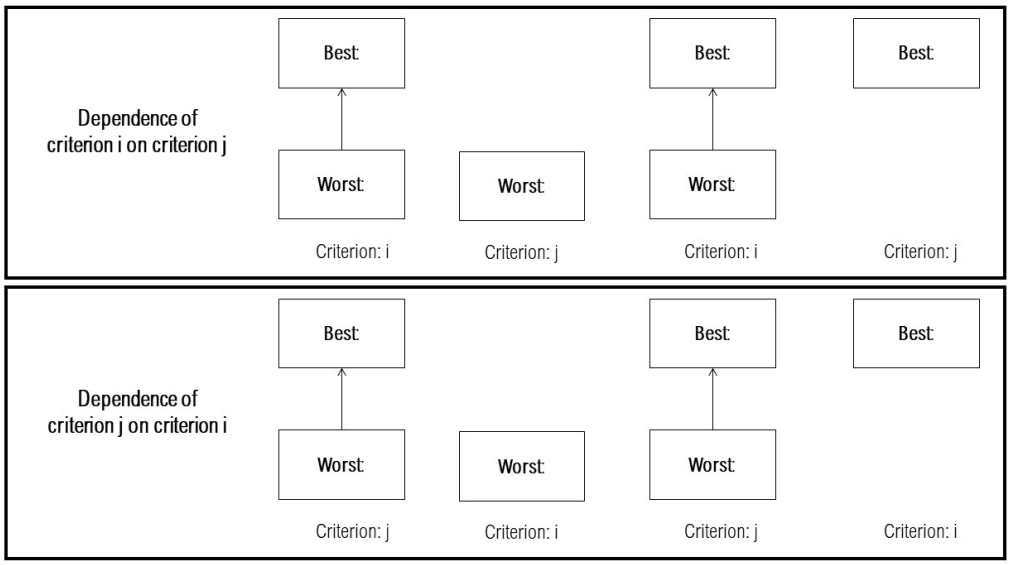

Figure C.1: Diagrams representing the test of preference dependence of two criteria i and j.

dependence test, the two diagrams presented in Figure C.1 may be shown when asking each question.