

# ASSESSING AND MONITORING WAITING TIMES IN HEALTHCARE: HOW TO PROCEED IN BELGIUM?



# ASSESSING AND MONITORING WAITING TIMES IN HEALTHCARE: HOW TO PROCEED IN BELGIUM?

NADIA BENAHMED, PASCALE JONCKHEER, RENATE ZEEVAERT, BENEDICTE VOS, LAURENCE KOHN



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| Title:                  | Assessing and monitoring waiting times in healthcare: how to proceed in Belgium?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
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Disclaimer:

- The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.,
- Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.,
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## LIST OF ABBREVIATIONS

| ABBREVIATION | DEFINITION                                                                 |
|--------------|----------------------------------------------------------------------------|
| ACS          | Ambulatory consultation with a specialist                                  |
| ANP          | Advanced nurse practitioners                                               |
| AP           | Advanced practitioners                                                     |
| API          | Application programming interface                                          |
| AVI          | Finnish Regional State Administrative Agency                               |
| BCR          | Belgian Cancer Registry                                                    |
| BCSS         | Banque Carrefour de la Sécurité Sociale                                    |
| BMI          | Body mass index                                                            |
| CA           | Canada                                                                     |
| CABG         | Coronary artery bypass grafting                                            |
| CAMHS        | Child and Adolescent Mental Health Services                                |
| CAR          | Centra voor Ambulante Revalidatie (Centres for ambulatory rehabilitation)  |
| CCAA         | Spanish Autonomous regions – comunidades autonomas                         |
| CCN          | Community care networks                                                    |
| CFS          | Rockwood Clinical Frailty scale                                            |
| CGG          | Centra Geestelijke Gezondheidszorg (Centres for Mental Health care)        |
| CIHI         | Canadian Institute for Health Information                                  |
| CNS          | Central Nervous System                                                     |
| COS          | Centra voor ontwikkelingsstoornissen (Centres for developmental disorders) |
| CPAP         | Continuous positive airway pressure                                        |
| CSS          | Cancer-specific survival                                                   |
| CT           | Computed Tomography                                                        |
| DFS          | Disease-free survival                                                      |
| DHCW         | Digital Health and Care Wales                                              |
| DTT          | Decision to treat                                                          |
| ED           | Emergency department                                                       |



|                   |                                                                                                                                                                                                                                    |
|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>EFs</b>        | Evaluations of WT for services to be provided in the future                                                                                                                                                                        |
| <b>EIP</b>        | Early intervention psychosis                                                                                                                                                                                                       |
| <b>EMR</b>        | Electronic medical records                                                                                                                                                                                                         |
| <b>ENT</b>        | Ear Nose Throat                                                                                                                                                                                                                    |
| <b>EPs</b>        | Evaluations of WT for health services provided in the past                                                                                                                                                                         |
| <b>EQ-5D(-3L)</b> | Euroqol - 5 dimensions of health (mobility, self-care, ability to perform usual activities, pain/discomfort, anxiety/depression) – 3 levels of severity (no problems, slight problems, moderate/severe or unable/extreme problems) |
| <b>EQ-VAS</b>     | Euroqol visual analogue scale                                                                                                                                                                                                      |
| <b>ES</b>         | Spain                                                                                                                                                                                                                              |
| <b>FI</b>         | Finland                                                                                                                                                                                                                            |
| <b>FIGO</b>       | International Federation of Gynaecology and Obstetrics                                                                                                                                                                             |
| <b>FOAS</b>       | Foot and ankle outcome score                                                                                                                                                                                                       |
| <b>FOD VVVL</b>   | Federale overheidsdienst volksgezondheid, veiligheid van de voedselketen, leefmilieu                                                                                                                                               |
| <b>FTF</b>        | face-to-face                                                                                                                                                                                                                       |
| <b>GA</b>         | General anaesthetics                                                                                                                                                                                                               |
| <b>GB-ENG</b>     | England                                                                                                                                                                                                                            |
| <b>GB-NIR</b>     | Northern Ireland                                                                                                                                                                                                                   |
| <b>GB-SCL</b>     | Scotland                                                                                                                                                                                                                           |
| <b>GB-WLS</b>     | Wales                                                                                                                                                                                                                              |
| <b>GBO</b>        | Groupeement belge des omnipraticiens                                                                                                                                                                                               |
| <b>GDP</b>        | Gross domestic product                                                                                                                                                                                                             |
| <b>GP</b>         | General practitioner                                                                                                                                                                                                               |
| <b>HBP</b>        | Healthy Budapest programme                                                                                                                                                                                                         |
| <b>HCP</b>        | Healthcare practitioner                                                                                                                                                                                                            |
| <b>HIB</b>        | Hospital Information Branch                                                                                                                                                                                                        |
| <b>HIS</b>        | Health Interview Survey                                                                                                                                                                                                            |



|                 |                                                                                    |
|-----------------|------------------------------------------------------------------------------------|
| <b>HR</b>       | Hazard ratio                                                                       |
| <b>HRQoL</b>    | Health-related quality of life                                                     |
| <b>IBW-IHP</b>  | Initiatieven Beschut Wonen - Initiatives Habitation Protégée                       |
| <b>ICD-9-CM</b> | International Classification of Diseases, Ninth Revision, Clinical Modification    |
| <b>IMA/AMI</b>  | Intermutualistisch agentshap - Agence intermutualiste                              |
| <b>INAMI</b>    | Institut national d'assurance maladie-invalidité                                   |
| <b>iNPH</b>     | Idiopathic normal pressure hydrocephalus                                           |
| <b>KPS</b>      | Karnofsky Performance Scale                                                        |
| <b>KSZ</b>      | Kruispuntbank van de Sociale Zekerheid                                             |
| <b>LHB</b>      | Local health boards                                                                |
| <b>LND</b>      | Lymph node dissection                                                              |
| <b>M-A</b>      | Meta-analysis                                                                      |
| <b>MCID</b>     | Minimal clinically important difference                                            |
| <b>MDT</b>      | Multidisciplinary team                                                             |
| <b>MMSE</b>     | Mini mental state examination                                                      |
| <b>MRI</b>      | Magnetic resonance imaging                                                         |
| <b>MUG</b>      | Mobiele urgentiegroep                                                              |
| <b>MZG</b>      | Minimale Ziekenhuis Gegevens                                                       |
| <b>NCCN</b>     | National Comprehensive Cancer Network                                              |
| <b>NL</b>       | The Netherlands                                                                    |
| <b>NS</b>       | Non-significant difference                                                         |
| <b>OECD</b>     | Organization for Economic Cooperation and Development                              |
| <b>OR</b>       | Operating room                                                                     |
| <b>OS</b>       | Overall Survival                                                                   |
| <b>OWT</b>      | Official Waiting Time                                                              |
| <b>PAAZ</b>     | Psychiatrische Afdeling Algemeen Ziekenhuis – Psychiatric ward in general hospital |
| <b>PAP</b>      | Positive airway pressure                                                           |
| <b>pCR</b>      | pathologic complete response rates                                                 |



|                 |                                                                                 |
|-----------------|---------------------------------------------------------------------------------|
| <b>PCP</b>      | Primary care provider                                                           |
| <b>PDSA</b>     | Plan-Do-Study-Act                                                               |
| <b>PEG</b>      | Pain intensity, interference with enjoyment of life and general instrument      |
| <b>PET</b>      | Positron Emission Tomography                                                    |
| <b>PET-CT</b>   | Positron Emission Tomography – Computed Tomography                              |
| <b>PET-MRI</b>  | Positron Emission Tomography – Magnetic Resonance Imaging                       |
| <b>PHQ-9</b>    | Patient Health Questionnaire-9                                                  |
| <b>PIT</b>      | Paramedical intervention team                                                   |
| <b>PROMs</b>    | Patient-reported outcome measures                                               |
| <b>PTCA</b>     | Percutaneous transluminal coronary angioplasty                                  |
| <b>PZ</b>       | Psychiatrisch Ziekenhuis (Psychiatric Hospital)                                 |
| <b>QoL</b>      | Quality of life                                                                 |
| <b>RAC</b>      | Rapid Access Clinic                                                             |
| <b>RD</b>       | Royal Degree                                                                    |
| <b>RFS</b>      | Recurrence-free survival                                                        |
| <b>RHM</b>      | Résumé Hospitalier Minimum                                                      |
| <b>RIZIV</b>    | Rijksinstituut voor ziekte- en invaliditeitsverzekering                         |
| <b>RNU</b>      | Radical nephroureterectomy                                                      |
| <b>RTT</b>      | Referral to Treatment                                                           |
| <b>SALAR</b>    | Swedish Association of Local Authorities and Regions                            |
| <b>SE</b>       | Sweden                                                                          |
| <b>SES</b>      | Socioeconomic status                                                            |
| <b>SF-36</b>    | 36-item Short Form Survey                                                       |
| <b>SGGG</b>     | Staten Generaal Geestelijke gezondheidszorg - States General Mental Health care |
| <b>SMUR</b>     | Service médical d'urgence                                                       |
| <b>SNS</b>      | Spanish National Health System – Sistema Nacional de la Salud                   |
| <b>SNOT-32</b>  | 22-item Sino-Nasal Outcome Test                                                 |
| <b>SPECT-CT</b> | Single Photon Emission Tomography                                               |



|                   |                                                                                         |
|-------------------|-----------------------------------------------------------------------------------------|
| <b>SPF SPSCAE</b> | Service public fédéral santé publique, sécurité de la chaîne alimentaire, environnement |
| <b>SR</b>         | Systematic review                                                                       |
| <b>STAT</b>       | Specific Timely Assessment for Triage                                                   |
| <b>TAVR</b>       | Transcatheter aortic valve replacement                                                  |
| <b>TEJO</b>       | Therapeuten voor Jongeren (Therapists for Youth)                                        |
| <b>TTD</b>        | Time to diagnosis                                                                       |
| <b>TTG</b>        | Treatment Time Guarantee                                                                |
| <b>TTS</b>        | Time to surgery                                                                         |
| <b>TTT</b>        | Time to treatment                                                                       |
| <b>TUG</b>        | Time Up and Go                                                                          |
| <b>TWT</b>        | Total Waiting Time                                                                      |
| <b>UK</b>         | United Kingdom                                                                          |
| <b>UTUC</b>       | Upper tract urothelial carcinoma                                                        |
| <b>VA</b>         | Veteran Administration                                                                  |
| <b>VRAC</b>       | Virtual rapid access clinic                                                             |
| <b>WL</b>         | Waiting list                                                                            |
| <b>WT</b>         | Waiting time                                                                            |
| <b>WTD</b>        | Worse than death status (i.e. EQ-5D<0)                                                  |
| <b>WTMC</b>       | Waiting Time Monitoring Commission                                                      |



## ■ SCIENTIFIC REPORT

### 1 INTRODUCTION

The performance of a health system is measured along 5 dimensions: quality, efficiency, sustainability, equity, and accessibility. In Belgium, these dimensions are measured by more than a hundred indicators, 18 of which are devoted exclusively to measuring accessibility. Among these, two indicators are used to assess waiting times (WT).<sup>1</sup> These patient-reported indicators are described in detail in section 4.1. WT are used as a key indicator to test the efficiency and affordability of a healthcare system<sup>2</sup> but cannot on their own measure accessibility to care.

Unlike other Organisation for Economic Cooperation and Development (OECD) countries<sup>3</sup>, Belgium does not routinely measure WT for access to health services. As a result, it is considered by the European authorities to have no WT. Based on the principles of free movement of persons within the internal market, all patients are treated equally on the basis of their healthcare needs rather than their Member State of affiliation (European Directive 2011/24/UE). The Directive also mentions that healthcare providers are not obliged to accept elective treatment patients from other Member States or to prioritise them to the detriment of other patients, for example by increasing the waiting time for treatment of other patients. However, the number of patients from the European Union is very small (0.5% of hospital stays in 2013)<sup>4</sup>, but is it true that Belgium has no WT in its healthcare system?

To answer this question, data collection is needed. Therefore, the aim of this report is to assess the feasibility of setting up a system to measure WT for a selected number of health services in Belgium.



## 1.1 Waiting time for healthcare services

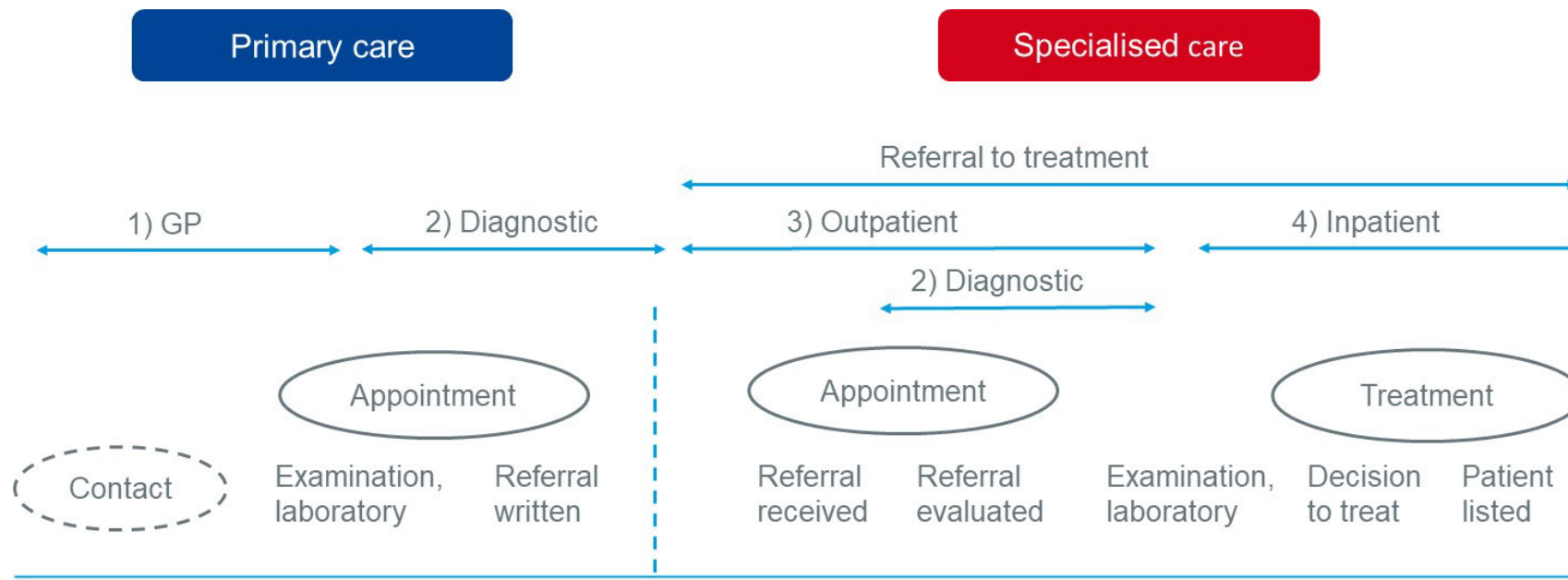
There is no standardised definition of WT.<sup>5</sup> As shown in Figure 1, several WT intervals are acknowledged during the patient's journey leading to the treatment of a health condition. WT are often presented as the result of an imbalance between the demand for and supply of healthcare services.<sup>3</sup> In other words, as explained by the queuing theory (see Box 1), WT occurs when demand exceeds the supply of services at different stages of a patient's journey, starting from the identification of the first symptoms to intervention through diagnosis.<sup>5, 6</sup> This imbalance may be due to various factors, such as capacity constraints, inefficiencies in referral processes or in the delivery health services.<sup>3</sup> WT are assessed quantitatively as the sum of days, weeks, or months between points in time.<sup>5</sup> However, capturing and reporting of WT may vary from between countries, institutions, or levels of urgency ... Therefore, several types of indicators are used to assess WT. They also vary in terms of definition (starting point and end point of measurement see Figure 1) and format (mean or median, number or proportion of patients waiting more than a certain threshold or a certain percentile of the distribution, number of patients or the time spent on a waiting list (WL)). In the literature, the time between the decision to treat and the treatment (also known as the time to treatment TTT) is often reported.<sup>5</sup> Chapter 3 is dedicated to the assessment of WT as described in the recent literature, in Belgium and by health authorities from a number of countries.

### Box 1 –Queueing theory and theory of constraints

**Queueing theory** is the mathematical study of queues in general and can also be applied to healthcare. It originated in the 1900s when A.K. Erling, a Danish engineer, developed the mathematical relationship between customer demand, service rate and customer queue or waiting time to design the capacity of a telephone exchange.<sup>7</sup> Modelling of a queue can be used to quantify appropriate service capacity with acceptable WT for the patients or to analyse the impact of changes in demand or service factors.<sup>7</sup> The demand and service factors that characterise the queue are the arrival process (number of customers and their arrival rate), customer behaviour (e.g. willingness to wait or to leave the queue), service times, service discipline (e.g. first-come-first-served, random order, prioritisation,...), service capacity (number of servers) and waiting room (limits on the number of customers in the system).<sup>8</sup>

**Theory of constraints**, on the other hand, is a holistic management philosophy. Originally developed by Dr Goldratt to solve manufacturing problems, it views any organisation as a system with interacting resources that work together to achieve the goal of the system. The resource that limits the capacity of the whole system is the 'constraint' and is the most important resource because it determines the performance of the whole system. This theory can explain why a particular strategy may not work in all situations because it does not target the bottleneck in the system.<sup>9</sup>

**Figure 1 – Possible waiting times for different health services**



Source: OECD<sup>3</sup>

The issue of WT for health services is multidimensional. It goes far beyond the simple question of measurement. The following paragraphs describe examples of dimensions that need to be considered when addressing the issue of WT.



### Patients' experience of waiting times

Patients' experiences of WT are highly dependent on their condition and the context of care. While waiting can be a positive experience, e.g. for families of patients referred to a gender identity development service<sup>10</sup>, for other patient groups waiting can cause pain, anxiety, frustration, and in some cases can be detrimental to health.<sup>2, 11, 12</sup> Chapter 2 reports on evidence from the literature on the effect of WT on health outcomes. In contrast, short WT may also cause anxiety in cancer patients, as the speed of action may be perceived as a sign of urgency.<sup>13</sup> In addition, the tolerance level regarding WT varies from country to country. For instance, waiting a week to see a (general practitioner) GP for non-acute problems is considered as acceptable by a Finnish patient, whereas any waiting that limits immediate care is perceived negatively in countries such as Hungary, Lithuania and Spain.<sup>14</sup>

Patients often attribute the limited access to primary care providers to the appointment system.<sup>14</sup> Feeling adrift in the healthcare system has also been reported in several studies, particularly among patients seeking pain management services.<sup>12, 15</sup> However, patients with higher income and health literacy appear to navigate the healthcare system more easily<sup>15</sup>, leading to potential inequities in access to care. The emotional, physical and financial burden of waiting has also been highlighted in the literature.<sup>16</sup>

In addition to the effect of waiting for care on the patient's life, it can also affect the lives of their family or relatives.<sup>17</sup> While waiting to see a specialist, patients are keen to seek additional support.<sup>11, 15</sup> Coping strategies consisting of going to A&E and GP are also used to fill the gap created by waiting to see a specialist.<sup>18</sup>

### Professionals' perceptions of waiting times

If patients expect the shortest possible time to see GPs, such high patient expectations can lead to frustration among professionals. There are also differences of opinion between patients and professionals about home visits. Patients expect the possibility of home visits more often than the doctor think it is necessary. For doctors, the preferred place of care is the practice and

out-of-hours services are only considered if needed by the patient.<sup>14</sup> This affects the availability of GPs for out-of-hours services and home visits and increases the WT to receive these services.

In Australia, 134 healthcare professionals specialised in lung cancer (medical oncologists, respiratory physicians, lung cancer care coordinators, and specialist lung cancer nurses) were surveyed about their perceptions of actual and acceptable time to diagnosis (TTD) and time to treatment (TTT).<sup>19</sup> TTD was defined as the time from clinical suspicion of lung cancer to diagnosis and TTT was defined as the time from diagnosis to treatment (chemotherapy, radiotherapy or surgery). Participants estimated that actual TTD to be longer than acceptable TTD more often than TTT. When healthcare professionals estimated actual TTD to be higher than acceptable TTD, delays in diagnosis were attributed by the respondents to (1) clinical factors related to GP triage, lack of local support network of specialists for GPs, GPs' watchful waiting approach or nihilism; (2) system factors (WT to obtain adequate diagnostic tissue samples, lack of referral guidelines for GPs); (3) patient factors (logistical difficulties in attending appointments, comorbidity). When health professionals considered actual TTT to be superior to acceptable TTT, delays in treatment were attributed by the respondents to (1) resource constraints; (2) poor organisation of health system; and (3) patient factors (see above).<sup>19</sup>

### Waiting lists

A waiting list can be defined as a list made up of a group of patients queuing for a health service for which there is a shortage of supply relative to demand.<sup>20-22</sup> The purpose of waiting lists is to organise and coordinate the access to care for people who need a service that is in high demand.<sup>23</sup> Waiting lists can be created at different stages of the patient's journey, but there are two main types of waiting list: a first one to see the specialist who will authorise access to the requested service and a second one to receive the service once the medical need has been established at the previous stage.<sup>21</sup> WL can be assessed by the number of patients on the list or by the time by the patients spend on the list. Both metrics are needed to evaluate the access to care by waiting list. A long waiting list with a short WT is not perceived as a problem for access to care, whereas a waiting list with few



patients and a long WT is of greater concern.<sup>24</sup> Waiting lists are common in countries with universal free health care such as in the United Kingdom, Canada, and Australia.<sup>6</sup>

Managing waiting lists requires setting priorities between patients according to severity, urgency, need, and expected outcomes. Severity refers to the degree, extent or intensity of suffering (e.g. pain, nausea, shortness of breath, depression, anxiety), limitations in daily activities (e.g. ability to work, to meet basic needs), or risk of premature death. Urgency refers to the degree to which immediate clinical action is required.<sup>21</sup> Several actions are identified from the literature to shorten waiting lists such as implementation of a lean-type approach<sup>a</sup>, triage, maximum WT targets, booking strategies, no-show policies, role substitution or task shifting policies<sup>20</sup>, low-intensity treatment<sup>26</sup> ...

Being on a waiting list can be used to set up interventions such as patients with osteoarthritis can use the WT before the appointment with a specialist to try first-line treatment (e.g. physiotherapy sessions and weight-management advice).<sup>27</sup>

### Waiting time threshold or maximum waiting time

We identified two types of WT thresholds, usually, referred to as 'maximum waiting time' but referring to different concepts.

- Maximum waiting time before adverse health events occur.

The maximum WT for a health intervention is defined as the acceptable waiting time that a patient can wait for a health intervention before adverse events occur or before a permanent decline in health occur. Some examples can be found in oncology (see section 4.5) or in other pathologies such as idiopathic scoliosis. Ahn et al. derived the maximum acceptable WT for surgery to treat idiopathic scoliosis from 216 adolescents aged 11 to 17

years.<sup>28</sup> Analysis of the data using the ROC curve revealed that 97 days was the maximum WT to avoid adverse events such as the need for additional surgery, disease progression, worse surgical outcomes, and the need for blood transfusion.

- Maximum waiting time as a target to deliver care.

This type of maximum WT is often set by health authorities for all, or some procedures provided by public and accredited providers. If the care providers are not able to provide care within the maximum time, there are different consequences depending on the country such as penalties for the hospitals that fail to meet the targets for a fixed proportion of patients (e.g. 90% of the patients must be treated within the target), or patients are given the right to consult another healthcare provider<sup>20</sup> (see the international comparison reported in section 3 for more details). In contrast to the 'maximum waiting time before adverse health events' which is based on evidence, these targets are often based only on consensus. This type of threshold is also used for comparisons between healthcare institutions.

### Strategies to reduce waiting times

The main goal of a WT assessment is to reduce the WT if it is considered too long. Different strategies to address the bottlenecks (see Theory of Constraints Box 1) can be implemented at the local level (at provider level), meso (e.g. hospital networks) or macro level (e.g. health authorities). These strategies may include:<sup>29, 30</sup>

- Increasing the supply;
- Increasing productivity by setting a maximum waiting time target linked to economic incentives;

<sup>a</sup> Lean methodology comes from the industry sector. It consists in a set of operating philosophies and methods that help create maximum value for patients by reducing waste and waits. To reach this aim, behaviours and the culture of a healthcare organisation are transformed to use efficiently the

resources in order to create value for the patient (customer). 25. Verolino M, Grassi P, Sosto G, D'Onofrio G, De Simone S, Costagliola C. Lean approach to the management of patients undergoing intravitreal injections during COVID-19 pandemic. *Ther Adv Ophthalmol*. 2021;13:25158414211018893.



- Basing the payment on activity (fee-for-service system);
- Freeing the choice of care provider by the patients waiting above the maximum, including treatment abroad;
- Prioritising the patients to ensure that high severity cases are treated more quickly.

More details on strategies to reduce WT are provided in section 2.5.

## 1.2 Scope of the report

As shown in Figure 1, WT can occur at different stages of the care pathway (e.g. between the symptom onset of and the treatment, between the diagnosis and treatment...) or during the provision of care (e.g. time spent in the practice or emergency department (ED) waiting room, waiting for laboratory results...). This report focuses on the feasibility of an assessment system of WT during the care pathway. WT during the provision of care is out of scope.

During the patient journey, WT can occur for a wide range of health services. In this report, we focus on waiting for an appointment with healthcare professionals or for an scheduled procedure (e.g. scheduled surgery or imaging). Therefore, WT to access residential care, management of WL, watchful waiting strategy in oncology, WT for organ transplantation, and the impact of COVID on WT are not included. In addition, the patient and professional perceptions of WT as such are not covered in this report.

## 1.3 Research objectives and methods

The main objective of this report is to assess **the feasibility of measuring WT** to inform health authorities for planning infrastructure and human resources, international benchmarks, and an *ad hoc* payment system to improve access to care where long WT are identified.

To achieve this objective, a multimodal approach was developed to answer the following research questions:

1. What are the initiatives to assess waiting times for care in Belgium?
2. What are the perceived barriers and facilitators to collecting data on waiting times for:
  - A visit to a legally recognised healthcare professional;
  - An appointment for imaging with a technology that is subject to infrastructure planning (i.e. computed tomography (CT), positron emission tomography-computed tomography (PET-CT), magnetic resonance imaging (MRI), positron emission tomography-magnetic resonance imaging (PET-MRI), single photon emission computed tomography (SPECT-CT));
  - A selection of scheduled surgeries. (Note: in the context of this report, scheduled surgeries are surgeries which could be postponed or not done at all without danger to the patient).
3. How are waiting times for health care assessed internationally?
4. How does waiting time affect health outcomes and costs?
5. What strategies are being used to reduce waiting times for outpatient consultations with healthcare professionals and scheduled procedures?
6. How can data be collected in Belgium on waiting times for outpatient consultations with a healthcare professional, and scheduled procedures?
  - Which health care sectors should be prioritised for the collection of waiting time? Which outpatient consultations, imaging, and scheduled surgery should be assessed?
  - What are the barriers and facilitators to collecting data on waiting times in the hospital and non-hospital sectors?
  - How can data collection be organised?



As agency and government reports and academic studies are the two main sources of information on WT<sup>5</sup>, the multimodal approach combines narrative literature reviews and an international comparison based on data collection from agency and government reports complemented by qualitative data collection. The literature review methodology is described in section 2.1. The other methods used to answer each question are described in dedicated chapters.

### Box 2 – OECD benchmarking of waiting times for selected surgeries

#### OECD reports on waiting times in a set of (scheduled) surgeries:

- Cataract surgery - ICD-9-CM (1996): 13.1--13.8
- Percutaneous transluminal coronary angioplasty (PTCA) - ICD-9-CM (1996): 36.01, 36.02, 36.05
- Coronary bypass - ICD-9-CM (1996): 36.1
- Prostatectomy - ICD-9-CM (1996): 60.2, 60.3--60.6
- Hysterectomy - ICD-9-CM (1996): 68.3--68.7; 68.9
- Hip replacement (total and partial, including the revision of hip replacement) - ICD-9-CM (1996): 81.51-- 81.53
- Knee replacement (including the revision of knee replacement) - ICD-9-CM (1996): 81.54--81.55

#### Two types of waiting times are reported:

- *Waiting times from specialist assessment to treatment* are defined as the time elapsed for patients on the non-emergency (scheduled) surgery waiting list from the date they were added to the waiting list for the procedure (following specialist assessment) to the date they were admitted for treatment.
- *Waiting times of patients on the list* are defined as the time elapsed for patients on the non-emergency (scheduled) surgery waiting list from the date they were added to the waiting list for the procedure (following specialist assessment) to a designated census date.

The WT evaluation does not consider the 'outpatient waiting time' i.e. the time elapsed from the date of the GP referral to the date of specialist assessment.

The metrics used are mean (average), median number of days and percentage of all patients waiting more than three months.

The data are available for all publicly funded patients from 2010 in 16 countries.

ICD-9-CM: *International Classification of Diseases, Ninth Revision, Clinical Modification*

Source: OECD.stat <https://stats.oecd.org/Index.aspx?QueryId=49344>



## 2 A NARRATIVE LITERATURE REVIEW

### Key points

#### Waiting time assessment

- In the narrative review on WT assessment techniques, we included papers in which the main focus was on WT assessment. We found 30 primary studies<sup>31-60</sup> and 1 review<sup>61</sup> describing evaluations of WT for health services provided in the past and evaluations of WT for services to be provided in the future (i.e. the current WT in the health system). The majority of papers retrieved described evaluations of WT for health services provided in the past (24 out of 30 papers).
- The evaluations of WT for health services provided in the past (EPs), i.e. based on retrospective data, assessed WT for an appointment with a care provider, diagnosis (imaging or medical assessment), and surgical or non-surgical treatment. Only one study assessed WT throughout the entire care journey (for patients with prostate cancer). Overall, the evaluations consisted of analysing routine data from pre-existing databases or medical records for secondary use. Only a few studies used data collected specifically to assess WT stemming from hospital care providers, from a survey of a representative sample of the population, or from a waiting time information system. The definition of WT varied widely, depending on the pathology or the service considered.
- In the evaluations of WT for services to be provided in the future (EFs), i.e. based on prospective data, WT was only assessed for an appointment with a care provider in the 6 studies retrieved. The mystery shopper method, also called secret shopper, mystery caller, or mystery client audit, was used: fictitious patients, whose characteristics were described in a detailed clinical vignette, called for an appointment with a care provider or a medical intervention.
- When comparing EP with EF, we found that:

- EP, based on the secondary use of routine data, allows WT to be based on a large number of events across a wide range of health services, as the data collection design used in the EF limits the number of events to be measured and the type of services to those that can be booked by a mystery caller.
- The secondary use of routine data used in EPs saves financial and human resources compared to EFs, which require *de novo* data collection.
- Some EP designs allow WT to be assessed throughout the patient journey, whereas EFs are always limited to a specific event in the patient journey.
- The use of a clinical vignette in EFs allows WT to be assessed in a precise context, whereas EPs may only provide WT adjusted for potential confounders available in the database used for the assessment. This leads to inaccuracies in the value of WT.
- EFs provide an assessment that reflects current WT whereas EPs describe past WT. Using past episodes of care to assess WT may give a biased picture of the current WT because of the possible changes in the organisation of care or developments in medical technology.

#### Effect of waiting times on health outcomes

- We identified 5 reviews<sup>62-66</sup> and 44 primary studies.<sup>67-109</sup> The primary studies focused more on cancer patients (27 papers identified)<sup>67-69, 72, 73, 77, 78, 81, 83, 84, 86-97, 105, 106, 108, 109</sup> than on non-cancer patients (15 studies identified)<sup>70, 71, 74-76, 79, 80, 82, 98-103, 107</sup>. We also found 2 primary studies on mental health.<sup>85, 104</sup> The vast majority of included studies had an observational design. Our literature search for primary studies found only one RCT. The design of observational studies is not suitable for establishing causal relationships between two variables. However, it is ethically questionable to set up an RCT to evaluate WT.



- WT for the care of non-cancer patients:

We divided the interventions for non-cancer patients into 2 groups according to the surgical or non-surgical nature of the intervention. The evidence retrieved for surgical care examined the effect of WT for a wide range of interventions such as aortic valve replacement<sup>75, 98</sup>, hip or knee arthroplasty<sup>71, 99</sup>, hip fracture surgery<sup>80</sup>, anterior cruciate ligament reconstruction<sup>100</sup>, bariatric surgery<sup>76</sup>, hysterectomy for benign gynaecological disease<sup>103</sup>, hallux valgus surgery, endoscopic sinus surgery<sup>107</sup>, shunt surgery for idiopathic normal pressure hydrocephalus.<sup>9</sup> Based on the available evidence, it is not possible to conclude the effect of delayed surgery on health outcomes because the definition of WT and the outcomes considered varied widely between studies. These variations are explained by the variety of pathologies studied. In our literature, WT for non-surgical care was related to consultations with healthcare professionals (i.e. outpatient consultation with a physiotherapist<sup>62, 74</sup> and consultation with an orthopaedic specialist<sup>65</sup>), clinical assessment of epilepsy<sup>82</sup>, initiation of a treatment<sup>102</sup>, or imaging.<sup>79</sup> One study<sup>4</sup> showed no worsening of pain in patients with hip or knee osteoarthritis while waiting for consultation with an orthopaedic specialist. In patients with a single ureteral stone, CT re-evaluation prior to surgery should be offered if WT is  $\geq 60$  days between the diagnostic imaging test and the surgery, as these patients may have already passed the stone and an unnecessary procedure could be avoided.<sup>79</sup> All other studies showed that an increased WT negatively affected the outcomes studied.

- WT for care in mental health care:

Two studies were identified: one on peripartum depression<sup>85</sup> and one on major depressive disorder.<sup>104</sup> Both showed a negative effect of WT on the outcomes studied.

- Time interval in cancer patients:

The evidence on cancer has focused on a wide variety of pathologies: prostate cancer,<sup>77, 83, 96</sup> gynaecological cancers<sup>83, 91, 92, 94, 95</sup>, pancreatic cancer<sup>84, 87, 105</sup>, colo(rectal) cancers<sup>89, 110</sup>, head and neck cancers<sup>90, 109</sup>, paediatric cancers<sup>66</sup>, lung cancer<sup>67, 68, 73</sup>, breast cancer<sup>88, 97</sup>, renal cell carcinoma<sup>81, 108</sup>, upper tract urothelial carcinoma,<sup>64</sup> glioma<sup>72, 93, 106</sup>, gastric cancer,<sup>69</sup> and basal cell carcinoma.<sup>86</sup> A wide range of time intervals was considered. In addition, cancer-specific potential biases were rarely controlled for. An overall conclusion about the effect of delayed treatment in cancer could not be drawn. The effect of delayed cancer treatment on health outcomes should be studied separately by pathology, using an appropriate design that controls for the above biases and other potential confounders. As shown in Chapter 4 on the Belgian experience, the assessment of time intervals plays an important role in the evaluation of quality of care evaluation.

#### Effect of waiting times on costs

Literature on the effect of costs is scarce, probably because of the unclear relationship between WT and health outcomes. Therefore, based on the available evidence<sup>62, 111-113</sup>, no conclusion can be drawn about the relationship between WT and costs from any perspective.

#### Strategies to decrease waiting times

- WT reduction strategies can be studied at the micro, meso and macro levels. They can be classified according to whether they increase supply, reduce demand or combine the two; and according to which dimensions of the people – process – and technology they affect.
- Few studies focus on primary care and the results are mitigated. No real conclusion can be drawn.
- The most studied strategies in specialised care were telemedicine and task shifting.



- Telemedicine used modern technology to reduce face-to-face (FTF) visits and replace them with a possibly more efficient teleconsultation (between providers or between provider(s) and patient) or to improve the efficiency of the referral process.
- Task shifting has involved the delegation of certain tasks, mainly the care for less complicated patients to allied healthcare professionals, nurses or physician assistants, or administrative tasks to non-clinical professionals. Task shifting is often combined with another strategy such as triage, telemedicine or a 'one-stop' clinic, where different investigations are combined with a consultation on the same day.

Results for telemedicine and task shifting, that have been studied at the micro and meso levels have been largely positive, with associations between the strategy and a reduced WT in observational studies<sup>114-124</sup> and a positive effect in two RCTs.<sup>125, 126</sup> Results have sometimes been inconsistent depending on the specialty, the setting and/or the method used to study WT.<sup>126-128</sup>

- The most studied strategy in cancer care was a rapid access clinic, which combined a specific clinical pathway with the reservation of rapid access for those who are most in need of care. This could also be linked to the presence of a maximum WT. This strategy was studied at the micro-meso level and was mostly associated with a reduction in WT, but the result was sometimes inconsistent, depending on the WT interval studied (time to diagnosis or time to treatment), the specialty or the type of therapy.<sup>36, 129-133</sup> In one case, there was an increase in time to treatment combined with a decrease in time to diagnosis, resulting in stable results for the overall WT.<sup>133</sup>
- The most studied strategies in mental health care were complex interventions developed through Plan-Do-Study-Act (PDSA) cycles in a quality improvement project or using lean methods.<sup>134-139</sup> Possible elements of the complex intervention were waiting list updating, administrative efficiency, (guidelines for) triage, a patient

pathway, etc. Complex interventions have been studied at the micro level and have mostly been associated with a reduction in WT<sup>134, 136-138</sup>, while at the meso level, there were associations with reduced WT<sup>135</sup> or stable WT.<sup>139</sup> When complex interventions are used, it is not possible to evaluate the effect of each element that composed the complex intervention, nor the catalyst effect of one intervention on the other.

- Results on other WT reduction strategies studied included:
  - Inconsistent results on specific timely appointments for triage (STAT) including one RCT with reduced WT in primary care<sup>140</sup> and an observational study in specialised care with stable or reduced WT depending on the type of epilepsy consultation<sup>141</sup>. Inconsistent results are also for interventions to improve the efficiency of operating room organisation or to reduce general anaesthesia for surgery or imaging. For each strategy, there were two observational studies with reduced WT<sup>142-145</sup> and one with stable WT<sup>146</sup> or the combination of a stable and a reduced WT interval.<sup>147</sup> The results were also inconsistent for the strategy of maximum waiting time, which was studied in different settings (cancer, mental health), mostly in combination with another strategy, for example, a rapid access clinic or public performance reporting were also inconsistent.<sup>132, 148, 149</sup>
  - Increased WT in observational studies in primary care of community care networks and freedom of choice for GP, as well as pre-referral advanced diagnostic testing in specialised care<sup>150-152</sup>, whereas reduced WT was reported in observational studies in specialised care on increasing capacity, in freedom of choice for specialists and in a 'one-stop' clinic model.<sup>150, 153-157</sup>

Reduced WT have been reported in primary care for funding and open access booking<sup>158, 159</sup>, in specialised care for no-show policy,<sup>160</sup> in cancer for triage, funding, and administrative efficiency<sup>161-164</sup>, and in mental health for administrative efficiency.<sup>165</sup>



### Limitations

We did not perform a systematic quality assessment of the literature using a validated tool. However, due to the large number of observational studies and the small number of available RCTs or meta-analyses, we consider the overall quality of the body of evidence to be low or very low. We also limited our search to the past five years, which includes the COVID-19 period. It is possible that this period may have influenced the nature of the evidence. To reduce the effect of COVID-19, we excluded studies that focused on the association between COVID-19 and WT. However, as WT issues have been studied for many years in some countries, it is possible that we may have missed some evidence by restricting our search to the last five years. Therefore, conclusions based on the evidence described in this chapter must be considered with caution.

Many strategies to reduce WT for consultation, diagnosis and treatment in primary and specialised care have been described, but not all the strategies have been formally evaluated and/or published. There is an under-representation of strategies studied at the macro level and an over-representation of studies with positive results, which may indicate possible publication bias.

## 2.1 Methods

To answer our research questions, we conducted a narrative review to collect and summarise the current evidence on methods used to assess WT, the impact of WT on health outcomes and costs, and the existing strategies to reduce WT. Due to the narrative nature of the review, we did not perform a quality assessment of the included papers.

Our inclusion criteria were based on:

- Languages

Only papers written in English, French, or Dutch were considered for inclusion in the review.

- Countries

Selected countries were countries from (geographical) Europe, North America, Australia, and New Zealand. Countries from the Asian and African continents were excluded.

- Publication date

We included papers published from 2019 to April 2023.

- Design

Systematic reviews and meta-analyses were included. For primary studies, all designs were included in the review.

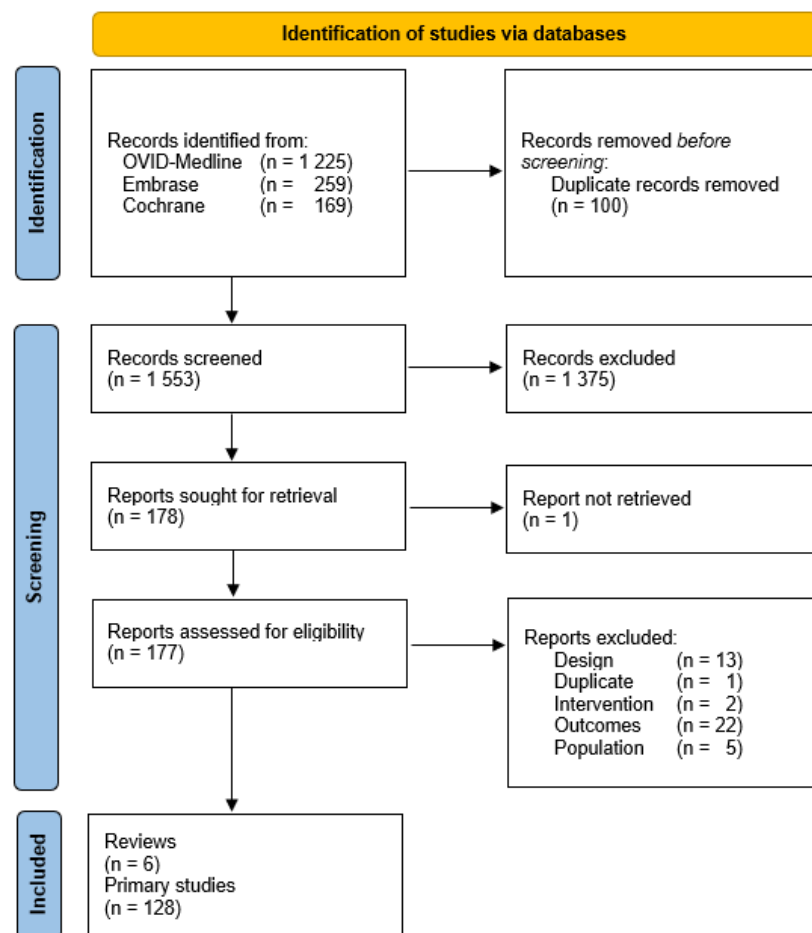
- Topics

Papers regarding methods used to assess WT, the effect of WT on health outcomes and costs, and the existing strategies to reduce WT were included. Papers focusing on waiting lists, emergency care, factors associated with longer WT, and organ transplantation were excluded.

The search strategies used are provided in Appendix I. A total of 1627 papers were retrieved. Two researchers (BV, NB) screened papers on title and abstract. One hundred and forty papers were included to be screened on full text. Finally, 30 primary studies<sup>31-60</sup> and 1 review<sup>61</sup> were included to describe the methods used to assess WT, 5 reviews<sup>62-66</sup> and 44 primary studies<sup>67-109</sup> to provide an overview of the effect of WT on health outcomes, 1 systematic review<sup>62</sup> and 3 primary studies<sup>111-113</sup> for the impact of WT on costs and 55 primary studies for identifying existing strategies to reduce WT.



**Figure 2 – Prisma chart for selection of evidence on assessment methods of WT, the effect of WT on health outcomes and costs, and the strategies to reduce WT.**



## 2.2 Waiting time assessment methods

Based on the evidence published in the last 5 years (see methodology in section 2.1), we identified 2 categories of evaluation methods: (1) evaluation of the WT for services provided in the past, (2) evaluation of the current WT for services to be provided in the future. To establish this classification, we retrieved 30 primary studies<sup>31-60</sup> and 1 review.<sup>61</sup> An overview of the selected studies is provided in Appendix II. The review focused on assessment methods for measuring WT in prostate cancer patients and included primary studies from 2010 to 2019.<sup>61</sup> As no additional designs were reported and more recent evidence was retrieved from our selection of primary studies, the review by Lazzari et al.<sup>61</sup> is not discussed further.

Of the 30 primary studies retrieved, only 6 studies evaluated the WT for services to be provided in the future.<sup>39, 40, 46, 50, 58, 60</sup> Most of the 30 studies were conducted in North America (Canada<sup>33, 36, 42, 47, 49, 51, 54-56, 59</sup>; n=10, and US<sup>31, 39, 40, 43, 46, 53, 58, 60</sup>; n=8). In the European Union, studies were conducted in Croatia (n=2)<sup>34, 35</sup>, Hungary (n=2)<sup>38, 57</sup>, Italy (n=1)<sup>37</sup>, The Netherlands (n=1)<sup>41</sup> and Poland (n=1)<sup>52</sup>. The remaining WT assessment studies were conducted in Scotland (n=2)<sup>44, 45</sup>, Australia (n=2)<sup>48, 50</sup>, and New Zealand (n=1)<sup>32</sup>.

### 2.2.1 Finding 1 – Evaluation of the waiting time for health services provided in the past

#### 2.2.1.1 Data sources

Evaluation of WT for a service that has occurred in the past consisted of analysing routine data from pre-existing databases for a secondary use<sup>31-33, 35-37, 41-45, 47-49, 51-57</sup> or data collected for the purpose of WT assessment.<sup>34, 38, 59</sup>

When data were collected specifically to assess WT, data stemmed from hospital care providers<sup>34</sup>, from a representative sample of the population<sup>38</sup> or from a wait time information system.<sup>59</sup> Overall, the data came from a single source such as electronic medical records, registers, surveys... However, 3 studies combined different data sources.<sup>52, 55, 57</sup> Two studies combined primary care data with hospital data<sup>55, 57</sup> and one study combined hospital data with patient interviews.<sup>52</sup>



An overview of the study characteristics is presented in Appendix II.

### 2.2.1.2 Definition of waiting times

The literature presents a variety of definitions for waiting time (WT), which depend on, among other things, the type of care being provided.

#### Waiting time for an appointment with a care provider

Seven studies were found that assessed WT for obtaining a visit with a specialist.<sup>38, 43, 47, 48, 51, 53, 54</sup> Among these, four studies analysed WT in veterans in need of primary, specialised, or mental care<sup>43</sup>, patients in need of any specialised visit<sup>47, 51</sup>, or patients with psoriatic arthritis waiting to see a rheumatologist.<sup>54</sup> Two additional studies focused on children. The first study focused on children with symptoms of isolated daytime urinary incontinence/enuresis or mixed bladder and bowel dysfunction.<sup>48</sup> The second study focused on children waiting for chronic pain clinic evaluation.<sup>53</sup> The last study used patients self-reported WT for outpatient appointments with GPs or specialists.<sup>38</sup> In this study, a representative sample of the population was surveyed online using a standardised set of questions forth by the OECD<sup>166</sup> which was also used in the Health Interview Survey (HIS) study<sup>167</sup> (see section 4.1).

The definition of WT varied across studies. When WT was self-reported<sup>38</sup>, WT was defined as the time taken to get the last appointment with a GP and with a specialist during the preceding 12 months. The results are categorised based on the time it took to receive an appointment such as same day, next day, couple of days, just less than a week, more than a week, more than two weeks, more than one month, more than two months, and more than three months.<sup>38</sup> In five studies<sup>47, 48, 51, 53, 54</sup>, WT was defined as the number of days between referral and specialist appointment. One of these studies<sup>48</sup> incorporated some intermediary measurement points, such as referral received at the hospital, referral acknowledged by the triage nurse, triage nurse, and referral booked. Finally, in another study<sup>43</sup> the WT was defined as the time between the date of approval for veteran care and the appointment date for a new clinical relationship (new patient) in primary

care, specialised care, and mental health (i.e. for a new patient and not for a recurring appointment for a chronic patient).

#### Waiting time for diagnosis

- Imaging

Two studies assessing the WT to get medical imaging were retrieved.<sup>31, 35</sup>

The first study reported on the analysis of data from the Veterans Health Administration in the US to assess the WT between a positive faecal occult blood test and the completion of a colonoscopy.<sup>31</sup> In the second study, the WT for diagnostic imaging (CT scan or MRI regardless of the patient's pathology) was assessed using databases from public hospitals in Croatia; WT was defined as the number of days between the doctor's decision about the need for a scan and the date of imaging.<sup>35</sup>

- Assessment in mental health

Bonati et al. evaluated the time taken to complete the diagnostic pathway in children and adolescents with suspected attention deficit hyperactivity disorder in some Italian reference centres. The time to diagnosis was defined as the time from the request for an initial visit to the date of completion of the diagnostic process.<sup>37</sup>

#### Waiting time for treatment

- Non-surgical treatment

We found one Canadian study in which billing information was used to calculate the WT for the treatment of obstructive sleep apnoea with continuous positive airway pressure (CPAP).<sup>56</sup> The evaluation involved measuring the time from primary care visits to diagnosis by polysomnography and the time from polysomnography to treatment (i.e. initiation of CPAP).<sup>56 44</sup>



- Surgical treatment

- Surgery in cancer patients

Six studies focused on WT for surgery in cancer patients (breast cancer<sup>36</sup>, glioblastoma<sup>41</sup>, non-melanoma skin cancer<sup>42</sup>, colorectal cancer<sup>57</sup>, thyroid cancer<sup>44</sup>, and brain tumour<sup>34</sup>). The earliest starting point for the WT measurement is the date of the first consultation with symptoms leading to further investigations<sup>57</sup>, followed by the date of referral<sup>42, 44</sup> and (the date) of diagnostic imaging.<sup>34, 36, 41</sup> In two studies<sup>41, 42</sup>, WT measurement stopped at the time of surgery. In these two studies<sup>41, 42</sup>, the date of the specialist visit is used as an intermediate measurement point. In contrast, in the breast cancer study, the date of surgery is considered an intermediate point because radiotherapy is the final measurement point.<sup>36</sup> Finally, in three studies<sup>34, 44, 57</sup>, any form of treatment (i.e. surgical treatment, but also oncological treatment, either chemotherapy or radiotherapy or a combination of surgery and other oncological or symptomatic treatment) stopped the WT clock.

Based on a prospectively held database of patients discussed at multidisciplinary team (MDT) meetings, Gardner et al. calculated the time from GP referral to treatment in 62 patients with thyroid cancer. Using the same data, they also measured time from referral to diagnosis.<sup>44</sup>

- Surgery in patients with a non-cancer disease

We identified 6 studies dealing with surgery for non-cancer conditions. Three studies focused on a single intervention: epilepsy surgery<sup>49</sup>, cataract surgery<sup>55</sup>, and surgery for delayed traumatic peripheral nerve injury.<sup>59</sup> The other three studies reported WT measurement for several interventions: total hip or knee arthroplasty<sup>45</sup>, inguinal hernia, cryptorchidism or hypospadias<sup>33</sup>, and surgical or medical treatment of endometrial hyperplasia.<sup>32</sup>

Jabbal et al. did not report a definition of the start and end points for measuring WT in total hip or total knee arthroplasty.<sup>45</sup>

In three studies<sup>32, 55, 59</sup>, the WT quantification started at the date of referral. In two other studies, an earlier starting point was observed: the date of the first medical visit for the symptoms<sup>33</sup> or the date of the diagnosis.<sup>49</sup> Overall, the date of surgery stopped the WT clock, except in the endometrial hyperplasia study<sup>32</sup>, where medical treatment also stopped the WT clock.

### Waiting times through the patient journey

To assess WT throughout the prostate cancer patient journey, Osowiecka et al. combined patient interviews, medical record extracts, and hospital databases from 5 oncologic centres.<sup>52</sup> The starting point for the WT measurement was the cancer suspicion. Cancer suspicion was defined as the date of the first visit to the doctor for a urinary disorder, the date of the prostate-specific antigen (PSA) test in patients without symptoms, or the date of the follow-up visit for the recurrence of a previously treated cancer. The endpoint of the WT evaluation was the start of treatment, i.e. the date of surgery, the date of the first fraction of radiotherapy, and the start of hormone therapy, or chemotherapy. An interim point was considered and defined as the date of receipt of the histopathological results.

#### 2.2.1.3 *Strengths and limitations of methods for the assessment of waiting times for past health services*

The main advantage we have identified in the secondary use of routine data from large datasets e.g. administrative data is the ability to rapidly assess WT for past health services in a large number of patients over a long period (often several years), allowing the analysis of possible seasonal effects on WT without specific data collection on WT. Retrospective data analyses of medical records, on the other hand only allow the analysis of WT in small sample sizes, because data stems from a single centre<sup>32, 42, 53, 168</sup> or is extracted<sup>47</sup> or manually screened<sup>48</sup>. However, this more time-consuming method of data extraction allows more detailed data to be extracted than other retrospective designs in larger datasets.



Despite the above advantages, we have identified several limitations in assessing WT for past services:

- First, the quality of the data depends on the quality of the data coding. Missing data may affect the precision of WT.
- Second, when the WT was measured through the secondary use of routine data, this had several limitations:
  - The use of proxies to determine the starting point and some intermediate points of the WT assessment (e.g. in oncology, the date of imaging was used as the starting point rather than the date of the first consultation with symptoms leading to further investigation).
  - The inability to take into account potential confounders such as the level of urgency of access to care, patient characteristics, healthcare resource characteristics (e.g. staffing, workforce...), availability of the facilities (e.g. number of operating theatres, opening hours of imaging facilities...).
- Finally, the generalisability of the results is limited by the context of care described in the databases. It is therefore not possible to assess the effect on WT of the patients who are still waiting for an intervention (since the intervention is the variable used to select the patients included in the WT assessment) or of patients who received the care they needed in another care setting.

Two studies used patients as a source of information about WT.<sup>38, 52</sup> As these studies involved past health services, we estimate that both studies are subject to recall bias. The study by Brito Fernandes et al. used an online survey to collect data.<sup>38</sup> Therefore, a selection bias is suspected as no paper alternative was proposed for people affected by the digital divide. The use of individual interviews, as suggested by Osowiecka et al.<sup>52</sup>, avoids this type of selection bias but interviews are time-consuming. This limits the number of patients that can be interviewed, as there are significant human and financial costs associated with this type of data collection.

## 2.2.2 Findings 2 – Evaluation of the current waiting time for health services

The evaluation of the current WT for health services requires specific data collection to measure the time (at the time of the data collection) needed to book an appointment or a health procedure.

### 2.2.2.1 Data sources

From the literature of the last 5 years, we found 6 studies using cross-sectional data collection.<sup>39, 40, 46, 50, 58, 60</sup>

Five studies in the US<sup>39, 40, 46, 58, 60</sup> and one in Australia<sup>50</sup>) used the mystery shopper method, also called secret shopper, mystery caller, or mystery client audit. Whatever the name used, this study design involves fictitious patients calling for an appointment with a healthcare provider or a medical procedure. Researchers use precise medical vignettes to describe the clinical situation. The date of the appointment was discussed, but the appointment was not fixed at the end of the call. Some researchers stated that they would call back to confirm the proposed appointment<sup>39, 40, 50, 60</sup> while others stated that the call was part of a study on WT (either directly at the end of the call<sup>46</sup> or by sending a debriefing letter detailing the nature of the study).<sup>58</sup> In one study, the research team asked for consent to participate in the study at the end of the call.<sup>46</sup> With the exception of two studies where the authors estimated that they were exempt from formal approval<sup>46, 60</sup>, all authors sought advice from an ethics committee or an institutional board.<sup>39, 40, 50, 58</sup>

### 2.2.2.2 Definition of waiting times

Overall, WT is defined as the time elapsed between the call and the fictitious appointment made, and the practice was used as the data source to measure WT.<sup>39, 40, 46, 50, 58, 60</sup>



### Appointment with a dermatologist or a GP

Two studies used the mystery shopper design to assess the next available in-person visit with a dermatologist.<sup>39, 40</sup> The first study used a fictitious patient with a new and changing mole asking for an appointment in a dermatology clinic.<sup>40</sup> The second study focused on assessing WT for an appointment for a changing pigmented skin lesion related to a suspicion of melanoma in family medicine and dermatology practices.<sup>39</sup>

### Appointment with a gynaecologist or a urologist

Two studies aimed to assess WT to get an appointment with a gynaecologist or a urologist for a fictitious female patient in two different clinical contexts.<sup>46, 58</sup> The first vignette used by the mystery shopper was a person asking for the earliest available appointment with a urologist or a gynaecologist for her 65-year-old mother, who had recently been diagnosed with uterine prolapse by her gynaecologist.<sup>58</sup> The second mystery shopper's vignette was a new fictional female patient complaining of 'urine leakage' and asking for the earliest available appointment in an academic clinic for female pelvic medicine and reconstructive surgery.<sup>46</sup>

### Appointment in the mental health sector

In an Australian study, a mystery shopper posed as a parent seeking an appointment for their child with anxiety or attention-deficit/hyperactivity disorder in private paediatricians', psychiatric and psychology practices.<sup>50</sup> WT is defined as the number of days between the call and the next available appointment.

Another mystery shopper study in mental health used a vignette reporting an English-speaking 33-year-old woman with a chief complaint of depression without active suicidal ideation seeking for an appointment with a psychiatrist.<sup>60</sup> Two types of WT were assessed: (1) the time elapsed between the call and an in-person appointment and (2) the time elapsed between the call and a telepsychiatry appointment.

### 2.2.2.3 Strengths and limitations of the methods

The mystery shopper method<sup>39, 40, 46, 50, 58, 60</sup> differs from other methods in that it involves collecting data from healthcare providers. We have identified several advantages of using fictitious patients: (1) it allows a clear and similar clinical situation to be defined through the use of a clinical vignette that is used across all calls (2) the clinical vignette also allows different patient characteristics (confounders) to be tested, such as the level of health insurance cover, level of urgency ... This method provides a real-time estimate without the risk of data manipulation from a respondent to a professional survey. However, the method is limited to WT from the call to the appointment date, no other WT during the patient journey can be assessed. To objectify the potential seasonality of WT data, long data collection periods or frequent repetitions of data collection are required.

## 2.3 Effect of waiting time on health outcomes

We identified 5 reviews<sup>62-66</sup> and 44 primary studies.<sup>67-109</sup> Among the primary studies, 27 papers were on cancer patients<sup>67-69, 72, 73, 77, 78, 81, 83, 84, 86-97, 105, 106, 108, 109</sup>, 15 were on non-cancer patients<sup>70, 71, 74-76, 79, 80, 82, 98-103, 107</sup> and 2 were on mental health.<sup>85, 104</sup>

Among the reviews, 3 reviews focused on cancer patients<sup>63, 64, 66</sup>, 1 on hip and knee osteoarthritis<sup>65</sup>, and 1 on musculoskeletal disorders.<sup>62</sup> Three reviews<sup>62-64</sup> were systematic reviews of primary studies and 2 reviews<sup>65, 66</sup> were reviews of systematic reviews and meta-analyses.

For the purposes of this report, we only extracted the data that met our inclusion criteria (see section 2.1). Therefore, the evidence on eye cancer, retrieved by Tope et al.<sup>66</sup> is not discussed further as it focused only on Latin America, a region not included in our inclusion criteria. In addition, Tope et al. included papers in their review that combined different types of cancer. We excluded these papers<sup>169, 170</sup> because of the specific natural history of each cancer.

The evidence is reported narratively in this chapter. Interested readers can find more details about the included studies in the overview tables provided in the supplement (see Appendix II).



### 2.3.1 Finding 1: Waiting time for non-oncological patients

#### 2.3.1.1 Waiting time for surgical care

WT for surgical care were reported in 11 primary studies.<sup>70, 71, 75, 76, 80, 98-101, 103, 107</sup>

#### Waiting time in cardiology

We retrieved 2 studies on transcatheter aortic valve replacement (TAVR).<sup>75, 98</sup>

The first study in Canada focused on 2 170 patients undergoing elective and urgent TAVR whose sociodemographic characteristics and outcomes were reported in the CorHealth Ontario TAVR Registry. Elective patients were defined as patients with a planned TAVR procedure, while urgent patients were those requiring TAVR during a concurrent hospitalisation. After adjusting for urgency status, there was no association between WT and postprocedural outcomes such as 30-day mortality and all-cause readmissions at 30 days.<sup>75</sup>

The second study reported the effect of WT in a cohort of 383 patients undergoing an elective TAVR at a single hospital in France. WT was defined as the number of weeks from the date of referral for valve replacement to the date of the TAVR. The authors found that WT >12 weeks were associated with a 2% per week increase in 1-year mortality after referral. However, there was no association between WT and 30-day mortality, re-hospitalisation for cardiac events or bleeding at 1 year.<sup>98</sup>

#### Waiting time for hip and knee surgery

Note: For more data on quality standards and quality indicators for the care of symptomatic knee osteoarthritis care in Belgium, see KCE report 375.<sup>171</sup>

- Hip or knee arthroplasty

We found two cross-sectional studies, both from the UK.<sup>71, 99</sup>

The first study focused on WT between primary care referral and orthopaedic review and WT between the orthopaedic review and surgery in 1 555 patients undergoing a primary total hip arthroplasty and 1 700 patients undergoing a primary total knee arthroplasty in an orthopaedic teaching hospital.<sup>99</sup> The authors found that patients who reported a state considered to be worse than death (WTD) at 1 year (i.e. EQ-5D<0) had a shorter waiting between primary care referral and orthopaedic review and between orthopaedic review and surgery for primary total hip arthroplasty than those who did not report a WTD (mean (SD) *primary care referral to orthopaedic review* WTD 13.8 weeks (8.1) vs no\_WTD 15.4 weeks (7.5);  $p = 0.018$  / *orthopaedic review and surgery* WTD 12.3 weeks (5.0) vs no\_WTD 13.6 weeks (5.8);  $p = 0.001$ ). These associations were not seen in patients undergoing primary total knee arthroplasty.

The second paper reported the results of a multicentre cross-sectional study involving 326 patients who had undergone a total hip arthroplasty, a total knee arthroplasty, a total knee arthroplasty or partial knee arthroplasty.<sup>71</sup> Patients were contacted by telephone and asked to complete an interviewer-administered verbal questionnaire that included the patient-reported outcome measures (PROMs), i.e. EQ-5D-3L questionnaire, EQ-VAS, CFS (Rockwood Clinical frailty scale). During this telephone call, the patients were asked about the current value of the PROMs and to recall their likely responses six months prior to the call. The authors concluded that patients who waited more than six months for a total hip arthroplasty or knee arthroplasty had a statistically and clinically significant deterioration in their health-related quality of life (HRQoL), increased frailty, and increased risk of WTD.

- Hip fracture

An observational study was conducted in a cohort of 59 675 patients aged 65 years and older with a non-pathological fracture identified in the Swedish Registry for Hip Fracture Patients and Treatment.<sup>80</sup> Patients underwent surgery within 7 days of the hospital admission. WT was defined as the number of hours between the hospital admission and the surgery and divided into two categories  $\leq 24$ h and  $> 24$ h. The authors concluded that there



was no association between WT and 4-month mortality in patients with ASA<sup>b</sup> score 1 or 2. For those with an ASA score of 3 or 4, there was a small increase in the risk of 4-month mortality for those who waited more than 24 hours for surgery. The association was stronger in women than in men (in women, 16% increase in 4-month mortality for those who waited for more than 24h compared with those who waited for a maximum of 24h, whereas in men there was no significant association between WT and 4-month mortality), and in patients >85 years of age (in ASA score 3 or 4, 22% increase in 4-month mortality for those who waited more than 24h compared with those who waited a maximum of 24h).

- Anterior cruciate ligament reconstruction

A single-centre, cross-sectional study in the UK examined the effect of WT for anterior cruciate ligament reconstruction on HRQoL by surveying 67 patients. The authors found that for every 200 days spent on the waiting list for anterior cruciate ligament reconstruction, a patient would experience a clinically significant deterioration in the HRQoL.<sup>100</sup> They also emphasised that the data collection took place during the COVID-19 pandemic. This must be taken into account when interpreting the results.

### Waiting time for other surgeries

- Bariatric surgery

The effect of preoperative WT on weight loss and adverse events was assessed in 415 patients undergoing laparoscopic Roux-en-Y gastric bypass or sleeve gastrectomy in the US. WT was defined as the number of days from the initial consultation to the preoperative visit before surgery. The authors found no association between longer preoperative WT(>3 months) with improved weight loss up to 24 months or reduced adverse events such as complications (anastomotic or staple line leak, gastrointestinal bleeding,

bowel obstruction, myocardial infarction, surgical site infection, and venous thromboembolism) and readmission.<sup>76</sup>

- Hysterectomy for a benign gynaecological condition

A retrospective cohort study using electronic medical records from an academic centre in the US reported results on the association between WT for surgery and clinical outcomes (i.e. complication and readmission rates) and healthcare utilisation in 277 patients undergoing a hysterectomy for benign gynaecological disease. WT was as defined as the number of days between the date of the initial preoperative visit and the date of surgery. Healthcare use during WT referred to telephone calls, messages, emergency room, or office visits. Surgical WT >30 days in patients undergoing a hysterectomy for benign disease was associated with increased intermediate healthcare use. Each additional day of surgical WT, the odds of using healthcare 4 or more interim healthcare use increased by 3%. Patients with a longer surgical WT did not have worse surgical outcomes but were more likely to be readmitted after surgery.<sup>103</sup>

- Hallux valgus surgery

In a prospective single-centre study in Canada, 87 patients undergoing scheduled hallux valgus surgery were surveyed at booking date and 6 months postoperatively.<sup>101</sup> Data were collected using a self-administrated questionnaire that included validated instruments (PHQ-9 (patient health questionnaire-9), PEG (pain intensity (P), interference with enjoyment (E), of life and general (G) instrument), FOAS (foot and ankle outcome score)) to assess depression, pain, other symptoms, function in activities of daily living, function in sports and recreation and foot and ankle-related QoL. No association was found between depression or generic pain scores and WT for surgery. At the 6 months postoperatively, prolonged WT was associated with a smaller reduction in pain and activities of daily living of the foot-specific patient-reported outcomes.

<sup>b</sup> ASA is a physical status classification system developed by the American Society of Anaesthesiologists. The classification is a 6-level scale in which level 1 refers to a healthy patient, level 2 refers to a patient with mild systemic

disease, level 3 refers to a patient with severe systemic disease, level 4 refers to a patient with an incapacitating disease, level 5 refers to a moribund patient with a life expectancy <24h and level 6 refers to a brain dead patient.



- Endoscopic sinus surgery

The effect of WT for endoscopic sinus surgery in 104 patients with medically refractory chronic rhinosinusitis was studied in Canada during a 6-month follow-up using the SNOT-32 (22-item Sino-Nasal Outcome Test).<sup>107</sup> WT was defined as the number of days between the date of consent for endoscopic sinus surgery and the date of surgery. Longer WT may result in less improvement in disease-specific symptoms, but does not appear to worsen psychological or sleep dysfunction. For every 287 days on the waiting list, the postoperative SNOT-22 aggregated score would decrease by the minimal clinically important difference or MCID (8.9 points). For the rhinological, extranasal rhinological and ear/facial subdomains, the WT leading to a postoperative worsening equivalent to the MCID is 452 days (MCID 3.8 points), 421 days (MCID 2.4 points), and 381 days (MCID 3.2 points), respectively.

- Shunt surgery for idiopathic normal pressure hydrocephalus

A retrospective study in 3 007 patients with idiopathic normal pressure hydrocephalus (iNPH) evaluated the effect of WT between the decision to treat and surgery on the score on a modified iNPH scale. (Sweden)<sup>70</sup> This scale combines gait, balance and incontinence outcomes. The difference between the modified iNPH scale scores before surgery, and 3 to 12 months after the surgery was compared between patients with short ( $\leq 3$  months), intermediate (3.1-5.9 months) and long ( $\geq 6$  months) WT. The results showed that shunt surgery in patients with idiopathic normal pressure hydrocephalus should be performed within 3 months of the decision to treat to achieve the best outcomes.

- Ureteroscopy

A retrospective study in Spain focused on the effect of WT on the risk of negative ureteroscopy in 219 patients with a single ureteral stone.<sup>79</sup> In this study, WT was defined as the number of days between the date of the diagnostic imaging test and the date of surgery. The authors found that patients with small (e.g.  $\leq 6$  mm) radiolucent stones and with long WT ( $\geq 60$  days) may be offered CT re-evaluation before surgery as up to 18.7%

of these patients may have already passed the stone and this could avoid an unnecessary procedure.<sup>79</sup>

### 2.3.1.2 Waiting time for non-surgical care

WT in non-surgical care was reported in 2 systematic reviews<sup>62, 65</sup> and 4 primary studies.<sup>74, 79, 82, 102</sup> Of the primary studies, 3 papers<sup>74, 79, 82</sup> had a retrospective design and 1 paper was a secondary analysis of a randomised clinical non-inferiority trial.<sup>102</sup>

#### Musculoskeletal disorders

A systematic review<sup>62</sup> identified 5 RCTs<sup>168, 172-175</sup>, 3 cohort studies<sup>176-178</sup>, and 1 cross-sectional study<sup>179</sup> published between 1990 and 2018 that described the effect of WT for outpatient physiotherapy services in people with musculoskeletal disorders on pain, disability, quality of life (QoL), psychological symptoms, neck or elbow range of motion, and rehabilitation success. The authors found that seven of the nine studies showed a negative effect of WT on at least one clinical outcome. A negative effect of WT was found for QoL and psychological symptoms while an unclear effect of WT (negative to not significant) was found for pain, disability, and range of motion. This review found mixed evidence suggesting a potential detrimental effect of WT on health outcomes, but no studies reported a beneficial effect of WT.<sup>62</sup>

In addition to this review<sup>62</sup>, we also found a primary study of WT for a first visit to a multidisciplinary pain treatment facility in Canada.<sup>74</sup> Data from 3 230 patients referred for a multidisciplinary pain treatment were extracted from the Quebec Pain Registry and retrospectively analysed to assess the effect of WT on health-related quality of life (HRQoL), pain interference and pain intensity. The authors found that longer delays were significantly associated with less improvement in pain interference, pain intensity and HRQoL but these differences were below the minimum clinically important difference. However, a significantly higher proportion of patients achieved clinically significant improvements in the group of patients who waited less than 2 months compared to those who waited  $\geq 2$  months.<sup>74</sup>



### Hip and knee osteoarthritis

Patten et al. conducted a systematic review and a meta-analysis of the effect of WT seeing an orthopaedic specialist on pain in patients with pain due to hip or knee osteoarthritis.<sup>65</sup> Up to 2021, the authors identified 24 RCTs<sup>180-203</sup>, 2 non-randomised controlled trials<sup>204, 205</sup>, and 7 observational studies.<sup>206-212</sup> Of these studies, 15 studies included patients with hip osteoarthritis<sup>181, 186-189, 192, 194, 201, 204-206, 209-212</sup>, 20 studies included patients with knee osteoarthritis<sup>180, 182, 183, 185, 191, 193-195, 197-203, 207-211</sup> and 2 studies mixed indifferently the results of patients with hip and knee osteoarthritis.<sup>184, 196</sup> Based on their meta-analysis, the authors concluded that patients with knee and hip osteoarthritis who were on a waiting list to see an orthopaedic specialist reported no change in pain for up to 1 year.<sup>65</sup>

### Paediatric epilepsy

A retrospective study used chart reviews to assess the effect of the time interval between seizure onset and the first clinical assessment in 197 paediatric patients with suspected epilepsy between 2012 and 2015 at a centre in Canada.<sup>82</sup> The risk of unfavourable outcomes (i.e. patients continuing to have seizures) was assessed at 6, 12 and 18 months. At each time point, a higher risk of unfavourable outcomes was observed with longer WT. This led the authors to conclude that prolonged WT for a paediatric neurological evaluation of children with new-onset epilepsy may increase the risk of poor epilepsy outcomes.

### Severe sleep-disordered breathing

A secondary analysis of a single-centre, randomised, non-inferiority clinical trial of 176 patients with severe sleep-disorder breathing treated with positive airway pressure (PAP) therapy in Canada analysed the effect of WT on two patient-reported outcomes.<sup>102</sup> In this study, WT was defined as the time elapsed between referral and initiation of PAP treatment. The authors found that shorter WT was associated with a greater improvement in somnolence as measured by the Epworth Sleepiness Scale, and a greater satisfaction, as measured by the Visit-Specific Satisfaction Instrument-9.<sup>102</sup>

For more information on the organisation of diagnosis and treatment of obstructive sleep apnoea syndrome in Belgium, see KCE report 330.<sup>213</sup>

### 2.3.2 Finding 2: Waiting time in mental health

Our literature search identified two retrospective studies on depression.

The first study focused on 490 patients with peripartum depression in the US.<sup>85</sup> Longer delays between primary care referral and specialist appointment adversely affected women's mental health, as each week spent waiting for an appointment was associated with a 13% increase in the odds of clinically meaningful worsening of peripartum depression scores (i.e. an increase in the Edinburgh Postnatal Depression Scale score of  $\geq 4$ ) and a 9% increase in the odds of developing new self-harm ideation.<sup>85</sup>

The second study focused on 715 adult outpatients with major depressive disorder in the Netherlands. This multicentre retrospective study analysed data from electronic records and showed an association between longer WT, defined as the interval between diagnostic workup and treatment initiation (pharmacotherapy and/or psychotherapy), and poorer treatment outcome, as assessed by the difference in the score of the Quick Inventory of Depressive Symptomatology self-report at six months follow-up.<sup>104</sup>

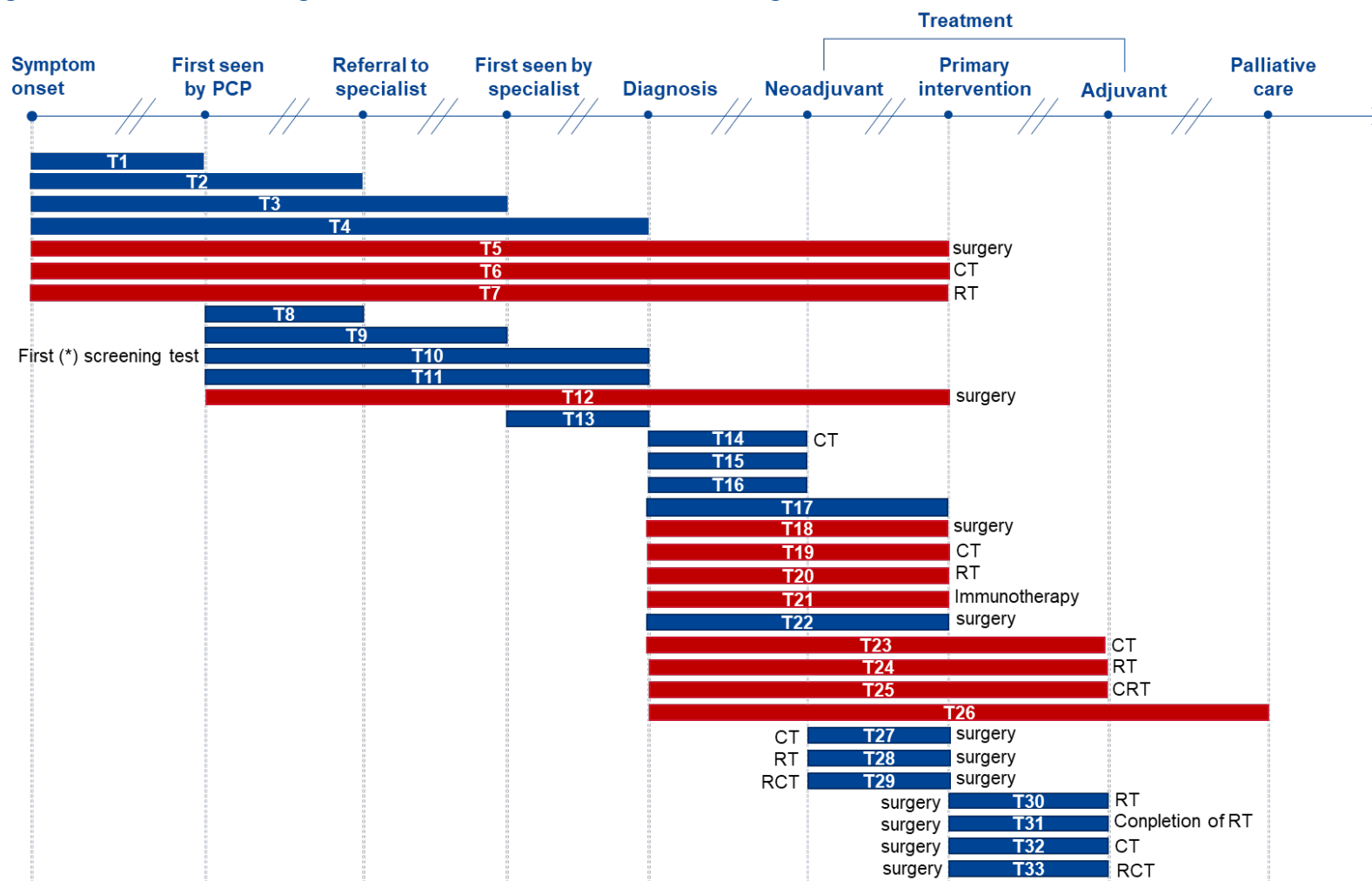
### 2.3.3 Finding 3: Time intervals for care in patients with cancer

#### 2.3.3.1 Preamble

During the COVID-19 pandemic, cancer screening, diagnosis, and treatment were disrupted, resulting in massive reductions in screening, treatment interruptions, or patient prioritisation. In the context of the pandemic, changes in standard protocols for radiological, surgical, and therapeutic interventions have exacerbated delay in cancer care.<sup>66</sup> This has highlighted the effect of time on the health outcomes of cancer patients. Lag times are defined differently in the literature, depending on the start and end points used (see Figure 3).



Figure 3 – Visualisation of lag time intervals used for time to cancer diagnosis and/or treatment

Source: Tope 2023<sup>66</sup>



Despite the variability in the choice of start and end points when assessing time elapsed along cancer care pathways, a number of specific biases have been identified in the cancer literature (see Box 3). The results of literature reported in the following section must be read with these potential biases in mind.

### Box 3 – Sources of potential bias

#### Waiting time paradox

Patients with the most severe/aggressive disease receive earlier care and have worse prognosis.

*Bias direction:* Paradoxical association of longer delays with better outcomes.

#### Lead time bias

Earlier detection of the same cancer results in apparently longer survival, even if the natural history of the tumour is unaltered.

*Bias direction:* Apparently longer survival in patients with earlier diagnosis.

#### Length bias

Patients with the most aggressive disease may die before diagnosis/treatment initiation; hence, they may be underrepresented in cohorts with longer delays.

*Bias direction:* Paradoxical association of longer delays with better outcomes.

#### Confounding

Patients with shorter and longer delays may systematically differ in measurable or unmeasurable confounders. Residual heterogeneity may persist after randomization/matching.

*Bias direction:* Bias may occur in both directions.

#### Adjustment for parameters in the putative causal chain

Adjusting for intermediate outcomes may hide the association with the final outcome.

*Bias direction:* False negative findings on delay-outcome associations.

Source: Luckács 2019<sup>63</sup>

#### 2.3.3.2 Time intervals for care by type of cancer

From our search strategies, we found evidence about time intervals for care by cancer type in three reviews<sup>63, 64, 66</sup> and 27 primary studies.<sup>67-69, 72, 73, 77, 78, 81, 83, 84, 86-97, 105, 106, 108, 109</sup>

One of the retrieved studies reported evidence on multiple cancers<sup>66</sup>, another one on pancreatic cancer<sup>63</sup>, and the last review on urothelial carcinoma of the upper tract.<sup>64</sup> Three primary studies focused on prostate cancer<sup>77, 83, 96</sup>, 5 on gynaecological cancers<sup>83, 91, 92, 94, 95</sup>, 3 on pancreatic cancer<sup>84, 87, 105</sup>, 2 on colo(rectal) cancers<sup>89, 110</sup>, 2 on head and neck cancers<sup>90, 109</sup>, 3 on lung cancer<sup>67, 68, 73</sup>, 2 on breast cancer<sup>88, 97</sup>, 2 on renal cell carcinoma<sup>81, 108</sup>, 3 on glioma<sup>72, 93, 106</sup>, one on gastric cancer,<sup>69</sup> and a last one on basal cell carcinoma.<sup>86</sup>

#### Prostate cancer

Tope et al. published a review of systematic reviews and meta-analyses on the effect of lag time to cancer diagnosis and treatment on clinical outcomes.<sup>66</sup> The authors retrieved papers between 2010 and 2019. Among these papers, one systematic review<sup>214</sup> showed no association between extended time from diagnosis to surgery or to radiotherapy and worse oncological outcomes or overall survival (OS) in patients with low-risk prostate cancer, but some evidence suggests that these associations may be present in patients with moderate- and high-risk prostate cancer.

In addition, we found three primary studies<sup>77, 83, 96</sup> that confirmed the above conclusion. All 3 studies used a retrospective design.



The first study<sup>77</sup>, in 1 466 patients treated for prostate cancer, found no effect of the number of days from the prostate cancer diagnosis by biopsy to the first treatment received (categorised as <90 days and ≥90 days) on QoL and oncological outcomes (upgrading<sup>c</sup>, upstaging<sup>d</sup>, presence of positive surgical margins or PSA level).<sup>77</sup>

A second paper including 2 310 patients with prostate carcinoma found no association between time up to 6 months from biopsy to radical prostatectomy with higher pathological stage, positive margin, lymph node positivity.<sup>96</sup>

A last publication focused on 466 patients with favourable and unfavourable intermediate-risk prostate cancer treated with low-dose brachytherapy.<sup>83</sup> The authors found that increasing time from biopsy to low-dose brachytherapy was associated with an increased risk of recurrence and metastases in patients with intermediate-risk prostate cancer, but no association with OS was found.

### Gynaecological cancers

- Ovarian cancer

In the review performed by Tope et al.<sup>66</sup>, two meta-analyses analysed the effect of time from surgery to adjuvant chemotherapy on mortality. The first meta-analysis found a significantly greater risk of mortality per 1-week increase in time or with longer time between surgery and adjuvant chemotherapy while the second meta-analysis reported no association between time from surgery to adjuvant chemotherapy and odds of 3-year mortality.<sup>215</sup>

Another primary study was found<sup>94</sup>: the authors used a retrospective cohort stemming from the US National Cancer Database, collecting data on patients with International Federation of Gynaecology and Obstetrics (FIGO) stage I epithelial ovarian carcinoma who received multi-agent chemotherapy within 12 weeks of surgery. The authors concluded that delaying the administration of adjuvant chemotherapy between 6 and 12 weeks after

staging surgery may affect the overall survival of patients with FIGO stage I epithelial ovarian cancer, especially for those with high-grade serous histology or stage IC disease.<sup>94</sup>

- Endometrial cancer

Our literature search identified three primary studies.<sup>91, 92, 95</sup> These 3 retrospective studies used either data from a centre<sup>92</sup> or data from administrative databases (one from the Swedish National Cancer Registry<sup>91</sup> and the other from a provincially funded health insurance in Canada<sup>95</sup>).

The first study included 7 366 adult patients with histologically proven primary endometrial cancer and a histology of endometrioid, serous, mucinous, clear cell carcinoma or carcinosarcoma with surgery as primary treatment. Prolonged time (>70 days) from diagnosis to surgery did not appear to have a significant adverse effect on prognosis, as assessed by 5-year relative survival and excess mortality rate.<sup>91</sup>

A second large study, including 3 518 adult women diagnosed with high-grade endometrial cancer who underwent hysterectomy, studied the association between OS and two different delays: (1) from diagnosis based on biopsy to surgery, (2) from gynaecological oncology consultation to surgery.<sup>95</sup> The authors found that patients with a time from diagnosis to hysterectomy of less than 45 days had a higher risk of death than patients with a longer time interval from diagnosis to hysterectomy while patients who underwent surgery more than 45 days after the surgical consultation had a reduced survival.<sup>95</sup>

Finally, Mintrich et al.<sup>92</sup> analysed the survival of 136 patients diagnosed with grade 3 endometrioid endometrial cancer who underwent staging surgery including hysterectomy, bilateral salpingo-oophorectomy, selected omentectomy (for non-endometrioid types), and lymph node staging. In poorly differentiated endometrial cancer, disease-specific survival, OS and progression-free survival were not statistically significantly different between

<sup>c</sup> Upgrading refers to an increase from one prognostic grade group to another.

<sup>d</sup> Upstaging refers to an increase from one stage group to another.



patients who waited  $\leq 12$  weeks between the endometrial biopsy and surgery and those who waited longer than 12 weeks.

- Cervical cancer

We retrieved a retrospective study based on data from the Netherlands Cancer Registry of 4 653 adult women with cervical cancer who underwent surgery or (chemo)radiotherapy with curative intent.<sup>83</sup> The authors reported that a waiting up to 12 weeks from diagnosis to curative treatment in cervical cancer patients did not have negative effect on OS.

### Pancreatic cancer

Luckás et al. performed a systematic review of the potential benefits of timely care in pancreatic cancer.<sup>63</sup> The authors identified 15 retrospective cohort studies<sup>216-230</sup>, 2 prospective studies<sup>231, 232</sup>, and 1 RCT<sup>233</sup> published between 2000 and 2017. These studies considered different time intervals: (1) from the first symptom to the first visit<sup>224, 228, 229, 232</sup>, (2) from the first visit to diagnosis<sup>218, 228, 232</sup>, (3) from the first symptom to the first visit and also from the first visit to diagnosis<sup>220</sup> and (4) from the first cross-sectional imaging to treatment.<sup>216, 217, 221, 227</sup> The authors concluded that, despite the many sources of bias, the majority of studies showed a statistically significant association between shorter delays and better clinical outcomes.<sup>63</sup>

In addition to this review, we found three retrospective primary studies in patients with pancreatic cancer.<sup>84, 87, 105</sup> In 873 patients from the Danish Pancreatic Cancer Database, time to surgery did not affect survival.<sup>84</sup> The other two studies were monocentre studies. In 144 patients from a single tertiary referral centre in Canada<sup>105</sup>, the authors observed an improvement in overall survival and recurrence-free survival in patients who waited more than 12 weeks from imaging diagnosis of ductal adenocarcinoma of the head of the pancreas to surgical resection. According to the authors, the association is likely due to selection bias, as the patients with longer time intervals may have had the least biologically aggressive tumours.<sup>105</sup> After controlling for the lean effect or 'waiting time paradox' in a cohort of 368 patients with resectable pancreatic cancer at a cancer centre in Germany, Kruger et al. observed an absence of a strong adverse effect on OS of

prolonged interval time between the first imaging showing advanced pancreatic cancer and the first receipt of palliative chemotherapy.<sup>87</sup>

### Colo(rectal) cancer

Tope et al. identified 2 systematic reviews and 5 meta-analyses that studied the effect of lag time interval in colorectal cancer on health outcomes.<sup>66</sup> Our literature search identified two additional primary studies.<sup>89, 110</sup>

- Time from neoadjuvant chemoradiotherapy to surgery

One systematic review<sup>234</sup> analysed the effect of the lag time interval between neoadjuvant chemoradiotherapy and surgery on pathological complete response rates (pCR) as an indicator of treatment efficacy in the neoadjuvant setting. The authors showed that a higher pCR was associated with tumour down-staging in patients who waited  $>6-8$  weeks compared with those who waited  $<6-8$  weeks. In addition to this systematic review, three meta-analyses reported that higher pCR rates were associated with a time interval from neoadjuvant chemoradiotherapy to surgery  $>6-8$  weeks<sup>235</sup> or  $>7-8$  weeks<sup>236</sup> or  $\geq 8$  weeks<sup>237</sup>. Two of these meta-analyses found no association with mortality or risk of worse disease-specific survival (DFS) for surgery  $>6-8$  weeks<sup>235</sup> or  $\geq 8$  weeks.<sup>237</sup>

- Time from diagnosis to surgery

A second systematic review<sup>238</sup> identified by Tope et al. found no association between extended time and length of the period from diagnosis to surgery, OS or DFS. Our literature search identified two additional primary studies.<sup>89, 110</sup> The first study is a prospective cohort study from a single Spanish centre including 602 patients who underwent definitive surgery for colorectal cancer without preoperative chemoradiotherapy.<sup>110</sup> The authors also found no association between time from diagnosis to definitive surgery up to 6 weeks with postoperative death, 2-year or 5-year DFS in colorectal cancer patients. The second study is a retrospective cohort study of 187 394 adult patients with stage I, II or III adenocarcinoma of the colon<sup>89</sup>. The authors found that the optimal timing for colon cancer surgery is between 3 and 6 weeks after



diagnosis. Any delay beyond 6 weeks was associated with worse short-term mortality at 1 or 3 months, and 5-year overall survival.<sup>89</sup>

- Time from neoadjuvant radiotherapy to surgery

Tope et al. identified a meta-analysis<sup>239</sup> showing that WT >4 weeks were associated with higher pCR rates, but not with mortality or risk of worse DFS.

- Time from surgery to adjuvant chemotherapy

Finally, three meta-analyses, identified by Tope et al.<sup>66</sup> evaluated the effect of time between surgery and adjuvant chemotherapy on mortality in patients with colorectal cancer.<sup>240-242</sup> An increased risk of mortality in patients was observed in patients who experimented with a time interval >6-8 weeks<sup>235</sup> or >8 weeks.<sup>241</sup> Similarly, a meta-analysis showed an increased risk of death per 4-week increase in time interval.<sup>240</sup>

### Head and neck cancer

In the review of reviews by Tope et al.<sup>66</sup>, one paper reported the effect of time interval on OS and recurrence-free survival (RFS) in head and neck cancer.<sup>243</sup> The authors reported that extended time from diagnosis to primary intervention was associated with poorer OS, shorter time from surgery to radiotherapy was associated with improved OS and RFS, and prolonged time from surgery to completion of radiotherapy was associated with poorer OS.

We found two additional retrospective studies.<sup>90, 109</sup> The first study<sup>109</sup> included 262 patients, from 2 centres in Slovenia, with oral cavity, oropharyngeal, hypopharyngeal, or laryngeal squamous cell carcinoma who received curative-intent definitive radiotherapy, with or without concurrent chemotherapy. The authors found no statistically significant effect of the time interval between the date of histopathological diagnosis and the first day of the radiotherapy course on disease survival or local recurrence. The second study included 228 patients with oral/oropharyngeal squamous cell carcinoma treated by 3 surgeons in Spain.<sup>90</sup> An AV-shaped association was observed: patients with short intervals from the first specialist visit to the start of treatment and those with long intervals had higher mortality than those

with intermediate intervals. The authors suggested a possible lead-time bias.

### Paediatric cancers

Tope et al.<sup>66</sup> retrieved 3 reviews.<sup>242, 244, 245</sup> These reviews analysed the association between WT, defined as the time from symptom onset to diagnosis, and OS in paediatric cancer patients. While no association was found in paediatric patients with osteosarcoma<sup>244, 245</sup>, longer WT was associated with worse OS in paediatric patients with retinoblastoma.<sup>244</sup> Conflicting evidence was found in paediatric patients with Ewing's sarcoma or central nervous system (CNS) tumours. In Ewing's sarcoma, longer WT was associated with poorer OS.<sup>245</sup> In contrast, in patients with CNS tumours, longer WT was associated with improved OS.<sup>242</sup> The association between WT and OS was not observed for these 2 tumour types in another review.<sup>244</sup> The authors were unable to perform a meta-analysis for methodological reasons.<sup>66</sup>

### Lung cancer

- Small cell and non-small cell lung cancer

A retrospective study of the data from the Quebec Hospitals Cancer Registries followed 1 309 patients with small and non-small cell lung cancer treated with surgery, definitive radiation, definitive chemoradiation or systemic treatment. The authors found that longer WT (>60 days) had a slightly protective to neutral effect on survival, but this was not significant in patients with stage I-II non-small cell lung cancer. In addition, the authors suggested a length bias (a tendency for clinicians to act more quickly in sicker patients) because shorter WT were observed for patients with advanced lung cancer.<sup>73</sup>

- Non-small cell lung cancer

The effect of time in patients with non-small cell lung cancer has been studied in a variety of contexts including a multicentre international<sup>68</sup>, or in a national population-based cohort.<sup>67</sup>



The larger study included 693 554 adult patients with non-small cell lung cancer identified in the National Cancer Data Base from the US.<sup>67</sup> The authors examined the effect of time to treatment, the period between diagnosis and initiation of any first-course treatment, on 5-year OS in three groups of patients: those with early-stage disease, those with locally advanced disease and those with metastatic disease. No adverse effects were observed in patients with longer time to treatment. However, a time to treatment of more than four weeks was associated with a lower risk of death for patients with all stages of cancer, while for early-stage patients who received surgery alone, the results showed that the risk of death was increased by 6% and 17%, respectively, if surgery was performed between 4 and 6 weeks, and after 6 weeks, compared to surgery between 1 day and 4 weeks.

The second study included 181 patients with non-small cell lung cancer who were scheduled to receive curative-intent radiotherapy.<sup>68</sup> These patients were from 5 multicentre prospective cohorts in the US, the Netherlands, Canada and Australia. The time interval studied was the number of weeks elapsed between the diagnostic staging PET/CT scan and the subsequent treatment planning PET/CT scan. The results of the Cox multivariate analyses showed high rates of disease progression in patients with longer intervals. In addition, the highest rates of upstaging were observed in patients with more extensive initial nodal involvement and in those with adenocarcinoma.

### Breast cancer

In 2020, two studies were published on the effect of time intervals during the care pathways in patients with breast cancer.<sup>88, 97</sup>

The first paper reported a monocentric retrospective cohort study in 343 patients with breast cancer who underwent neoadjuvant chemotherapy followed by surgical resection.<sup>88</sup> The time from the date of the last dose of neoadjuvant chemotherapy to the date of the surgery was analysed based on categories (<4 weeks, 4-8 weeks, >8 weeks). Using a multivariable Cox model, the authors found no significant difference in 5-year OS and 5-year DFS between time categories. Therefore, they concluded that patient

outcomes were not meaningfully affected within an 8-week window from the completion of neoadjuvant chemotherapy.

Based on a 25% random sample of all patients with early stage breast cancer (stage I or II) in the province of Ontario who received radiotherapy after lumpectomy, Raphael et al. examined the association between the interval from the date of last surgery or biopsy to the date of first radiotherapy treatment and event-free survival.<sup>97</sup> Time was categorised into two groups: <6 weeks and ≥6 weeks for patients who received chemotherapy and <12 weeks and ≥12 weeks for patients without chemotherapy in their care pathway. Event-free survival was a composite outcome that included no evidence of locoregional recurrence, diagnosis of metastatic disease, or breast cancer-specific mortality. Multivariable Cox proportional hazards modelling showed no association between time and event-free survival in patients who did not receive chemotherapy, but in patients who received chemotherapy, a delay in the initiation of adjuvant radiotherapy after breast-conserving surgery was associated with worse breast cancer survival outcomes.

### Renal cell carcinoma

We identified one study of 22 653 adult patients with pT3 renal cell carcinoma treated with radical and partial nephrectomy and another study of 9 918 patients with non-metastatic renal cell carcinoma at primary diagnosis. Both studies are retrospective cohort studies based on national cancer registries, one in the USA<sup>108</sup> and the other in Sweden.<sup>81</sup>

Based on an extraction of data from the National Cancer Database between 2004 and 2014, Zeng et al.<sup>108</sup> showed that time from date of diagnostic imaging to date of surgery >10 weeks was associated with decreased 5-year OS. The second retrospective cohort study<sup>81</sup>, based on data extracted from the National Swedish Kidney Cancer Register between 2009 and 2021, found that prolonged WT for surgery resulted in a significantly increased risk of early death in patients with renal cell carcinoma. Cox regression analyses showed an increased risk of all-cause mortality as the number of months from the radiological diagnosis to surgery, from radiological diagnosis to treatment decision or from treatment decision to surgery increased.



### Upper tract urothelial carcinoma

A systematic review<sup>64</sup> published in 2002 identified 7 retrospective series<sup>246-252</sup> that reported the effect of WT on CSS, OS and RFS in patients with upper tract urothelial carcinoma who underwent radical nephroureterectomy. The evidence was unclear. While some studies found a positive association with CSS<sup>247, 250, 252</sup>, OS<sup>246, 251, 252</sup> or RFS<sup>247</sup>, others found no effect of delayed surgery on CSS<sup>248, 249</sup>, OS<sup>249</sup> or RFS.<sup>248, 250</sup> However, the authors of the review<sup>64</sup> concluded that a WT longer than 3 months for radical nephroureterectomy after the diagnosis of upper tract urothelial carcinoma could be considered to have a negative effect on CSS, OS or RFS. In high-risk patients or those with ureteral tumour(s) and/or hydronephrosis at the time of diagnosis, the safe delay may be shorter.

### Gastric cancer

In the Netherlands, a retrospective population-based cohort study<sup>69</sup> reported the effect of WT on OS in patients with curable gastric cancer who received neoadjuvant chemotherapy followed by gastrectomy (n=1701) or underwent primary gastrectomy (n=2077). WT, defined as the interval between diagnosis and treatment, was not associated with OS in either patients treated with neoadjuvant chemotherapy followed by a gastrectomy or primary gastrectomy with curative intent.

### Basal cell carcinoma

Kokkinos 2022 et al. analysed the effect of WT between referral and Mohs micrographic surgery on the lesion size in 233 patients with basal cell carcinoma. The authors found a positive correlation between the increase in lesion size and the increase in WT for surgery.<sup>86</sup>

### Glioma

- Glioblastoma

One study<sup>72</sup> retrospectively analysed the data from 4 589 adult patients who underwent a first-time surgery for glioblastoma between 2014 and 2019. Data from 13 hospitals were extracted for patients from the Quality Registry Neuro Surgery, where all patients with glioblastoma in the Netherlands are mandatory registered. The effect of WT between MR scan and surgery and WT between first neurosurgical consultation and surgery on complications, patient functional impairment (KPS score) and survival was assessed. No association was found between WT and outcomes, except for the time from MR scan to surgery and KPS score, and the time from the first neurosurgical consultation to surgery and survival. In fact, less improvement in KPS score was observed in patients who underwent resection after a long time from the MR scan to surgery (i.e.  $\geq 21$  days). Conversely, longer survival was associated with a time from first neurosurgical consultation to surgery of  $\geq 14$  days for all types of surgery.

A retrospective review of electronic medical records of 1 033 patients with a first-time surgery for glioblastoma from 12 neuro-oncology centres in the Netherlands analysed the effect of the time to surgery defined as the number of days between the diagnostic MR scan and surgery. In the context of decision-making for urgent surgery in the Netherlands and surgery typically within 1 month, the authors found that the extent of resection, residual tumour volume, performance change, and patient survival were not associated with time to surgery.<sup>93</sup>

- High-grade glioma

The third study focused on 291 adult patients with high-grade glioma (WHO grade III or IV) patients operated at a hospital in the US.<sup>106</sup> Time from surgery to first date of chemoradiation was not associated with OS.



## 2.4 Effect of waiting time on costs

The literature review on costs is limited and heterogeneous. Four papers were identified: 1 systematic review<sup>62</sup> and 3 primary studies<sup>111-113</sup>. The systematic review examined patient and health system costs of outpatient physiotherapy for patients with musculoskeletal disorders; the definition of costs was reported as it was considered in the primary studies (see Table 5 in Appendix II). The review reported higher costs, lower treatment efficiency and longer sick leaves (in 3 out of 4 primary studies) when physiotherapy was delayed.<sup>62</sup> However, these conclusions were mostly based on the US context (5 out of the 7 primary studies), which limits the generalisation to the Belgian context.

The three primary studies were retrieved from our search strategy: in Canada<sup>111</sup>, Italy<sup>112</sup> and Australia<sup>113</sup>, and each of them related to a different pathology (breast cancer screening, colorectal cancer treatment and cataract surgery). The economic methods used varied between the studies, and none of them performed a sensitivity analysis. They all took the perspective of the health care system (national or provincial, depending on the level of health care organisation). In the analysis of colorectal cancer treatment, health care costs increased with increasing WT (up to a certain very long limit of WT).<sup>111</sup> Reducing WT for cataract surgery would save health care costs<sup>113</sup>. For breast cancer screening, the most cost-effective strategy is the one that halves the WT (from 32 to 16 weeks) and also allows the largest number of patients to be included<sup>112</sup>. However, caution should be exercised in generalising these conclusions to the Belgian healthcare system, as they are based on only three studies, each analysing a specific scope in a specific healthcare context.

## 2.5 Strategies to decrease waiting times

### 2.5.1 Methodology

After the first screening based on title and abstract, full text articles were retrieved for further selection based on in- and exclusion criteria (see section 2.1). In this chapter, we focused on primary studies, both RCTs and observational studies reporting on the actual effect of strategies to reduce WT in primary and specialised care including imaging and (scheduled) surgery. Studies without a comparator or trend were excluded. Observational studies included were (controlled) before-after studies, interrupted time series, prospective or retrospective cohort studies, non-randomised controlled trials and cross-sectional comparisons. Qualitative studies were excluded because they did not report waiting time data, but studies with a mixed design were included if they reported quantitative data on WT. 'Waiting time' refers to all intervals from first symptoms to first consultation, diagnosis or treatment and the intermediate intervals. Intervals beyond (start of) treatment were not taken into consideration, e.g. time to resolution. Systematic reviews were included but other types of reviews were not.

Data extraction included last name of first author and year of publication, setting (country, level, department), design and number of patients included, intervention (strategy to reduce WT), and outcome (effect on WT). After data extraction, the strategies were further classified into larger groups according to the mechanism of the strategy (demand, supply or mixed) and the type of strategy.

Four papers were identified to help the classification process.<sup>20,253-255</sup>

### 2.5.2 Results

After screening 78 full text articles on strategies to reduce WT for in- and exclusion criteria, 55 articles were selected and 23 excluded. Exclusions were based on outcome in 13, design in 6, population in 2 and intervention in 2.

A complete overview of the included articles can be found in the appendix.



### 2.5.2.1 Characteristics of the included studies

About half of the studies we identified were from North America (USA and Canada) (28/55)<sup>36, 114, 115, 117, 119, 121-123, 126-131, 133, 134, 136, 142, 145, 151, 152, 154, 156, 158, 160-162, 256</sup>, about 16% from Australia/New Zealand (9)<sup>118, 120, 124, 140, 141, 149, 157, 159, 257</sup> almost 15% from the UK (8)<sup>135, 137-139, 143, 147, 148, 163</sup> and 18 % from individual European countries (Spain,<sup>125, 150, 153</sup> Norway,<sup>132, 165</sup> from Italy,<sup>144</sup> Denmark,<sup>146</sup> Hungary,<sup>164</sup> Ireland,<sup>116</sup> and the Netherlands).<sup>155</sup> As expected, the majority of studies were observational. Only three studies were cluster RCT's,<sup>125, 126, 140</sup> including one with a stepped wedge design. Another study was a controlled trial with alternate, non-randomised allocation. Most observational studies had a before-after design (n=19)<sup>116, 118, 119, 121, 129, 135, 138, 141-144, 146, 149, 156, 157, 160-163</sup>, a controlled before-after design (n=3)<sup>127, 148, 151</sup>, or an interrupted time series design (n=13)<sup>132, 134, 136, 137, 139, 150, 154, 155, 158, 159, 165, 256, 257</sup>, thus comparing WT in the same hospital, service, region or country, before and after the implementation of a particular strategy. The other studies were prospective or retrospective cohort studies comparing the intervention with a control situation (n=15)<sup>36, 114, 115, 117, 122-124, 130, 131, 133, 145, 147, 152, 153, 164</sup>, and there was one cross-sectional study using a secret shopper methodology collecting information on the next available appointment.<sup>128</sup> About 62% of the interventions were studied or implemented at the hospital or service level (micro) (34/55) and less than 10% at the national level (macro 5/55). The remaining studies concerned interventions that were studied at a regional level (meso), involving at least two different hospitals or services. The setting of the study was mostly specialised care because only a few papers focusing on primary care (9%, 5/55). Seven papers included WT for imaging<sup>130, 145, 154, 156, 160, 164, 257</sup> and nine for surgery.<sup>36, 120, 132, 142-144, 146, 149, 162</sup>

In the following sections, we discuss the different strategies for WT reduction that have recently been studied in the literature for their effect on WT (section 2.3) and the reported effect of the different strategies on WT (section 2.5). We make a distinction between primary and specialised care including WT for consultation, imaging and surgery. As mental health and cancer are important issues in the context of WT, they are discussed separately.

### 2.5.2.2 Different strategies to reduce waiting times

The strategies identified to reduce WT were very diverse and not all of the existing strategies have been formally studied for their effect on WT. Although a main strategy could often be identified, other elements affecting WT were usually implemented at the same time. Sometimes there were two main strategies or there was a complex combination of strategies or elements (complex intervention). When there was a combination of elements/strategies, the effect of individual elements/strategies was not usually investigated. In addition, complex interventions were usually developed in a very specific local context, in a specific hospital or service, which was very different from national initiatives to reduce WT. Although we understand from various reports and publications (e.g. OECD<sup>24</sup>) that many national initiatives have been undertaken, they have often not been formally evaluated in primary studies, or the evaluation results have not been published. The published strategies to reduce WT can be classified in different ways. Amigoni et al.<sup>20</sup> identified 15 separate policies (lean-type approach, rapid access clinics, specific timely appointment for triage (STAT), waiting list update, triage, guidelines for triage, maximum waiting time, no-show policy, task shifting, open access, telemedicine, public-private partnership, freedom of choice, patient-focused booking approach, and patient training programme) and grouped them into three main categories according to whether the strategy generated supply capacity, controlled demand or affected both supply and demand. Amigoni et al. also described whether the strategy was implemented at the local micro level (within a single hospital or clinic), at regional meso level (within a provincial or regional network of hospitals or clinics) or at national macro level.<sup>20</sup> A part from the 15 separate policies, the authors decided to include a macro-policy where there was a combination of at least two of the following interventions: maximum waiting time, waiting list updating, triage, guidelines for triage, no-show policy, and rapid access clinics. These strategies, identified in the context of ambulatory care in a universal, tax-funded, single-payer health care system were not all found in our search of the recent literature, but they were also not sufficient to classify all the strategies that we identified. Additional strategies were drawn from Wennberg's theoretical framework for surgery,<sup>255</sup> which included overlapping and additional policies. Supply can



be affected by funding, increasing capacity through expanding or outsourcing, or optimising capacity including increasing efficiency in the operating room (OR), in administration or in a patient pathway. Demand can be affected by triage, prevention and patient education. The authors also included a performance category with WT monitoring and performance targets.

For each paper, we tried to characterise the interventions described according to one or two main types of strategy. Our classification was based on the classifications proposed by Amigoni et al. and Wennberg et al., but we added three types of strategies: timing of diagnostics, reduction of general anaesthetics and complex interventions. When more than two strategies with equal importance were identified, the strategy was classified as a complex intervention, which usually involves a mix of supply and demand mechanisms to reduce WT.

In total, we identified 16 different main strategies that have been studied individually in the recent literature. In 6 papers, there was a combination of two main strategies<sup>114, 116, 124, 132, 148, 151</sup> and 8 had a complex intervention.<sup>134-139, 256, 257</sup> Seven strategy types were related to supply (task shifting, timing of diagnostic investigations, maximum WT, administrative efficiency, capacity increase operating room organisation and funding), five to demand (triage, STAT, freedom of choice, no-show policy and decrease of general anaesthesia), and 4 to a mix of demand and supply (telemedicine, rapid access clinic, complex intervention and open access). The types of strategy identified are explained in the box below.

#### Box 4 – Possible strategies to deal with WT (a non-exhaustive list)

##### *Explanation of the identified strategy types*

##### **Supply**

- Task shifting: Certain tasks or services, usually performed by physician,s are carried out by allied healthcare professionals, advanced nurse practitioners, advanced practice practitioners or non-clinical staff.<sup>20</sup>
- Timing of diagnostic investigations: Diagnostic procedures can be performed before or after referral<sup>152</sup>, or they can be combined with consultation on the same day in a 'one-stop' clinic'.<sup>116, 130, 153, 154</sup> (new item)
- Maximum WT: The mandatory delivery of services within a certain amount of time may incentivize providers to increase supply to meet the targets. This policy is often coupled with prioritization measures.<sup>20</sup> To meet the targets, other strategies are often implemented like rapid access clinic or public performance reporting. (Wennberg et al. call this strategy 'performance target': a goal to encourage improvements).<sup>255</sup>
- Administrative efficiency: improving efficiency in administration like scheduling or booking.<sup>255</sup>
- Capacity increase: increasing resources either by expansion of the service (staff, space, number of beds) or by outsourcing (e.g. research facilities for MRI or public-private hospital partnership).<sup>255</sup>
- Operating room organisation: improving efficiency in the OR through changes in when, where or how procedures are performed.<sup>255</sup>
- Funding: financial compensation either conditionally based on certain targets or unconditionally, as a one time or as an increase in base funding.<sup>255</sup>



### Demand

- Triage: assessment of patients to ensure their eligibility for certain type of care or prioritization based on patient needs, to filter the demand and provide only necessary services;<sup>20</sup>
- STAT: Specific Timely Appointment for Triage is described as a scheduling model for access and triage, used in Australia for services providing multiple appointments for the same patient.<sup>20</sup>
- Freedom of choice: Patients can choose freely their provider. This can concern access to GPs as well as to specialists, in that case without gatekeeping.<sup>150</sup> This can induce potential competition based on quality and accessibility.<sup>20</sup>
- No-show policy: interventions to decrease the number of patients who fail to keep their appointment; 'No-show' leads to a higher demand (need for a new appointment) and decreased productivity (unutilised time slots).<sup>20</sup> 'No-show' refers to patient failing to attend a scheduled appointment/treatment without prior notice.<sup>258</sup>
- Decrease general anaesthetics (GA): Decreasing the number of procedures under GA will reduce the need for staff, OR space and time, and other resources involved.<sup>143, 145, 147</sup> (new item)

### Mixed

- Telemedicine: Technological innovations including eConsults, eReferrals, tele-consultation and eTriage, can improve efficiency of booking, management and consultation, and can decrease demand for unnecessary treatments.<sup>20</sup>
- RAC: A Rapid Access Clinic is set up in conditions where time to treatment is crucial, in order to reduce waiting time for those at risk. This strategy combines a specific clinical pathway with reserving fast access only to those who need the care the most.<sup>20</sup>

- Complex intervention: a combination of more than 2 strategic interventions including the ones that were used as a main strategy on other publications, but also other elements like waiting list monitoring and update, patient pathways, guidelines for triage, patient education, and prevention;<sup>259</sup> The complex interventions are developed as a quality improvement project with Plan-Do-Study-Act (PDSA) cycles<sup>134, 135, 137-139</sup>, by lean methods,<sup>136, 257</sup> or by process mapping.<sup>256</sup> (new item)
- Open access or 'advanced' access: scheduling approach that promotes patient-driven scheduling in lieu of prearranged appointments, that allows patients to seek and receive health care from their provider at the time of their choosing; All patients receive an appointment on the day they call or the next few days. Triage is minimised because everyone is offered an appointment whether for urgent or routine care.<sup>20, 260</sup>

Table 1 summarises for each type of strategy the level(s) and setting(s) where they have been studied, if they have implications for people, process or technology<sup>254</sup>, the possible subtypes that can be distinguished and the references from the papers where this type of strategy was found. Task shifting, telemedicine and complex interventions were the most frequently studied strategies. Only 6 individual strategies have been implemented/studied at the national level: task shifting, rapid access clinics, funding, maximum waiting time, capacity increase and no-show policy. The latter no-show policy through electronic reminders was only studied individually at the macro level. The other individual strategies were studied at the micro and/or meso level. Seven strategies were studied in cancer (rapid access clinic, OR organisation, timing of diagnostics, maximum waiting time, funding, triage, and administrative efficiency) and 3 in mental health care (complex intervention, maximum waiting time, administrative efficiency). Four strategies were studied individually in primary care (STAT, freedom of choice, task shifting, and funding), and two in combination (increasing capacity and maximum waiting time within a community care



network). Open-access booking was the only strategy that was not studied in specialised care. In total, seven strategies were studied for waiting time until surgery (timing of diagnostics, maximum WT, organisation OR, decrease GA, triage, and rapid access clinic) and seven for imaging (increasing capacity by outsourcing, no-show policy through electronic reminders, decrease GA, funding, complex intervention, rapid access and timing of diagnostics).

For each strategy, we tried to describe whether there was an implication of people, process, or technology, similar to Da Silva et al.<sup>254</sup> who classified actions and recommendations to reduce waiting time in these three dimensions. People do the work and the work is made more efficient by processes, while technology can help to automate the process. The model that evaluates the interaction between people, process and technology is called the PPT model. Balancing the three can improve organisational efficiency.<sup>261</sup> In the strategies identified, we often found changes in all three dimensions. A change in the process is the most likely implicated, followed by people and technology.

**Table 1 – Overview of the studied strategies**

| Type of strategy and mechanism (number of studies) | Level of implementation |      |       | Setting      |                        |             |                   | People<br>process<br>technology | Examples and references                                                                                                                                                                                                                                                                                                                                                                           |
|----------------------------------------------------|-------------------------|------|-------|--------------|------------------------|-------------|-------------------|---------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                    | micro                   | meso | macro | Primary care | Specialized healthcare | Cancer      | Mental healthcare |                                 |                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Task shifting (supply) (n=9)</b>                | X                       | X    | X     |              | X                      |             |                   | People                          | Certain tasks or services usually performed by physician are carried out by a(n):<br>- allied healthcare professionals (dietician, physiotherapist, occupational therapist, audiologist, optometrist) <sup>114, 118, 120, 124</sup><br>- advanced nurse practitioners or advanced practice practitioner <sup>114, 116, 128</sup><br>- non-clinical staff including medical scribes <sup>126</sup> |
| <b>Timing of diagnostics (supply) (n=5)</b>        | X                       |      |       |              | X<br>S                 | X<br>S<br>I |                   | Process                         | Diagnostics and consultation same day, 'single stop clinic' <sup>116, 130, 153, 154</sup><br>Pre-referral advanced diagnostic booking <sup>152</sup>                                                                                                                                                                                                                                              |



|                                                                        |   |   |   |   |  |   |   |   |                                |                                                                                                                                                                                                              |
|------------------------------------------------------------------------|---|---|---|---|--|---|---|---|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Maximum waiting time (supply)</b><br>(n=4)                          | X | X | X | X |  | X | S | X | Process and people             | Within community care networks <sup>151</sup><br>Waiting time targets <sup>148</sup><br>Waiting time targets and public performance reporting <sup>149</sup><br>Within Cancer patient pathway <sup>132</sup> |
| <b>Operating room organization (supply)</b><br>(n=3)                   | X |   |   |   |  | X | S | X | Process, people and technology | Operating swing room <sup>142</sup><br>Separation flow day surgery from ordinary surgery <sup>144</sup><br>Allocating capacity to non-elective patient based on mathematical model <sup>146</sup>            |
| <b>Administrative efficiency (supply)</b><br>(n=2)                     | X |   |   |   |  |   |   | X | Process, people and technology | Reflex testing <sup>161</sup><br>New scheduling policy <sup>165</sup>                                                                                                                                        |
| <b>Capacity increase (supply)</b><br>(n=4)                             | X | X | X |   |  | X | X | I | Process, people and technology | Community care networks <sup>151</sup><br>Service expansion <sup>155</sup><br>Outsourcing to research facility <sup>156</sup> to private service (public private partnership) <sup>157</sup>                 |
| <b>Funding (supply)</b><br>(n=2)                                       | X |   |   | X |  | X |   | X | Process and people             | Healthy Budapest programme funding <sup>164</sup><br>Rural workforce incentives <sup>159</sup>                                                                                                               |
| <b>Decrease GA (demand)</b><br>(n=3)                                   | X |   |   |   |  |   | X | S | Process and people             | Switch from general anaesthesia to general anaesthesia <sup>143, 147</sup><br>MRI without sedation <sup>145</sup>                                                                                            |
| <b>Specific timely appointment for triage (STAT) (demand)</b><br>(n=2) | X | X |   |   |  | X | X |   | Process                        | STAT <sup>140, 141</sup>                                                                                                                                                                                     |
| <b>Triage (demand)</b><br>(n=2)                                        | X |   |   |   |  |   |   | X | Process                        | Centralized intake and triage <sup>162</sup><br>Daily diagnostic multidisciplinary team meeting <sup>163</sup>                                                                                               |
| <b>Freedom of choice (demand)</b><br>(n=1)                             |   |   | X |   |  | X | X |   | Process and people             | Free choice of GP and/or specialist <sup>150</sup>                                                                                                                                                           |
| <b>No-show policy (demand)</b><br>(n=1)                                |   |   |   | X |  |   | X | I | Technology                     | Electronic appointment reminders <sup>160</sup>                                                                                                                                                              |



|                                                          |   |   |   |             |                    |                                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                 |
|----------------------------------------------------------|---|---|---|-------------|--------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|
| Telemedicine (mixed)<br>(n=8)                            | X | X |   | X           | Technology         | Face-to-face visit is replaced by virtual consultation <ul style="list-style-type: none"><li>- between providers e.g. eConsult<sup>115, 119, 122, 123, 127</sup> or eReferral<sup>117</sup></li><li>- C-EYE-C<sup>124</sup></li><li>- between referring PCP, specialist and patient e.g. DETELPROG<sup>125</sup></li><li>- between care team and patient e.g. VRAC<sup>121</sup></li></ul> |                                                                                                                                 |
| Rapid access clinic<br>(mixed)<br>(n=6)                  | X | X | X | X<br>S<br>I | Process and people | DAP for lung cancer <sup>129, 131</sup><br>Breast assessment clinic/sites <sup>133, 262</sup> or Breast health clinic <sup>130</sup><br>Cancer patient pathway <sup>132</sup><br>Mental healthcare EIP <sup>148</sup>                                                                                                                                                                      |                                                                                                                                 |
| Complex combinations<br>or intervention (mixed)<br>(n=8) | X | X |   | X<br>I      | X                  | Process,<br>people and<br>technology                                                                                                                                                                                                                                                                                                                                                       | QI project with PDSA cycles <sup>134, 135, 137-139</sup><br>Lean approach <sup>136, 257</sup><br>Process mapping <sup>256</sup> |
| Open access booking<br>(mixed)<br>(n=1)                  |   | X |   | X           |                    | Process                                                                                                                                                                                                                                                                                                                                                                                    | Physiotherapist <sup>158</sup>                                                                                                  |

*Cancer and mental healthcare are also considered specialised care, however, they are indicated separately in the table*

*EIP early intervention psychosis, C-EYE-C community eye collaboration, DAP diagnostic assessment programme, DETELPROG scheduled telephone referral (Spanish acronym), GP general practitioner, I imaging, MRI magnetic resonance imaging, PDSA plan-do-study-act, QI quality improvement, S surgery, STAT specific timely appointments for tirage.*



### 2.5.2.3 Effect of strategies on waiting time in primary care

The starting point for measuring WT was the authorisation to access community primary care provider (PCP), the date booked, the referral or the first contact (to make an appointment) and the end point was the first appointment. The primary care studied could entail physiotherapists', GPs, or was not further specified.

The different strategies applied were the STAT model, open access booking and freedom of choice at the regional level, and a community care network and rural workforce incentives at a national level in the US and Australia respectively. No strategies were studied at the micro level.

Increased WT (adjusted for confounding) were found in an controlled before-after study after introduction of community care networks (CCNs) in US, but similar for patients within Veteran Administration (VA) facilities with CCNs as for patients in the control group (VA facilities that did not implement CCNs), suggesting an exacerbation of the supply-demand mismatch, probably because of expanded eligibility of veterans for community care and/or underestimation of the (growing) demand for community care.<sup>151</sup> One Spanish study showed an increase of WT after the implementation of freedom of choice. Without freedom of choice, the authors estimated that there would have been no increase in WT, but the data were likely to be biased as they were self-reported data by the population.<sup>150</sup> In contrast, two observational studies showed an association between the implemented strategy (open access booking and rural workforce incentives) and a limited, but significantly reduced waiting time<sup>158, 159</sup> and one RCT with stepped wedge design showed a significant reduction in WT after the introduction of a triage model (STAT) after adjustment for confounding.<sup>140</sup>

A summary of the identified strategies in primary care and their effect on WT can be found in the appendix II (Table 6).

### 2.5.2.4 Effect of strategies on waiting times for specialised healthcare

#### Consultations

There were 23 studies identified regarding strategies to reduce WT for a first visit/consultation with a specialist, not related to cancer or mental health. The level and design, as well as the specialty involved, were very diverse. Specialties involved were rheumatology,<sup>114, 119, 127, 155</sup> orthopaedics,<sup>117, 126</sup> urology,<sup>116, 128, 153</sup> hepatology,<sup>115</sup> ophthalmology,<sup>124</sup> neurology,<sup>121, 141</sup> cardiology,<sup>126</sup> gastroenterology,<sup>118, 157</sup> nephrology,<sup>122, 256</sup> dermatology,<sup>123</sup> and Ear Nose Throat (ENT).<sup>120</sup> Some focused only on children<sup>120, 123</sup> and several focused on specific subspecialties, symptoms or pathologies such as epilepsy,<sup>141</sup> hip and knee musculoskeletal problems,<sup>117</sup> diabetic retinopathy,<sup>124</sup> hand surgery (carpal tunnel syndrome, soft tissue masses and joint pain),<sup>152</sup> positive anti-nuclear antibodies (ANA) referrals,<sup>119</sup> severe lower urinary tract symptoms,<sup>153</sup> or middle ear, hearing and speech concerns.<sup>120</sup> Four studies focused on more than one specialty, for example orthopaedics and cardiology,<sup>126</sup> internal medicine<sup>125</sup> or 'specialists' in general.<sup>150, 160</sup> In contrast to the above mentioned diversity, there was only a limited number of strategy types implemented to reduce WT. The most studied strategy was telemedicine,<sup>115, 117, 119, 121-125, 127</sup> mainly eConsults<sup>115, 119, 122, 123, 127</sup> between providers, followed by task shifting,<sup>114, 118, 120, 124, 126, 128</sup> timing of diagnostics<sup>116, 152, 153</sup> and capacity increase.<sup>155, 157</sup> The other strategies investigated (freedom of choice,<sup>150</sup> no-show policy,<sup>160</sup> STAT,<sup>141</sup> and a complex intervention of new triage and booking system)<sup>256</sup> were the subject of only one paper each.

The WT interval reported as an outcome was relatively consistent, with the starting point being the request<sup>122, 123, 126, 141, 155</sup>, referral<sup>114, 115, 118-125, 127, 256</sup>, appointment made<sup>150, 160</sup> or (first) visit with the referring provider/GP<sup>117, 152, 157</sup>, while the end point was the first visit<sup>114, 115, 117-119, 121-125, 152, 153, 155, 157, 160</sup>, appointment date<sup>126, 127, 256</sup>, first offered appointment<sup>120</sup> or next available appointment<sup>128, 141</sup> with the specialist. There is a possibility of an interval between the booking request and the actual booking of the appointment, also known as 'processing time' which was only explored in Mohammed et al.<sup>117</sup> and Palani et al.<sup>126</sup> A decreased WT can be driven a decrease in this



processing time, probably because the referrals were more complete and legible in the case of electronic referrals<sup>117</sup>, but this was not the case when medical scribes<sup>e</sup> were used.<sup>126</sup> There was a mix of mean and median waiting times reported and no direct comparisons between the two. One study on direct access to diagnostics in an advanced nurse practitioner (ANP)-led clinic, measured the number of patients waiting more than 12 months as a surrogate for WT.<sup>116</sup>

Results were mostly positive (decreased WT)<sup>122-124, 128</sup>, but could also be inconsistent<sup>127, 256</sup>, mixed depending on patient characteristics or (sub)specialty<sup>126, 141</sup> or negative (increased WT).<sup>152</sup> We found only one study where the intervention (pre-referral advanced diagnostic testing) was associated with an increase in WT<sup>152</sup> and one study where there was a decrease in WT for patients who were identified as needing an expedited rheumatology consultation after triage and an increase in WT for those who were not<sup>114</sup>. All other studies did not report increased waiting times. Conclusions about causality were rarely possible, since most studies were observational. In addition, only a minority of studies included adjusted results, to account for possible confounding factors.<sup>126, 127, 160</sup> We will discuss the results by type of strategy.

The **use of an electronic consult** system (eConsults) in the US, which allows rapid communication between providers resulted in fast response times (i.e. the time between the eConsult request and the answer by the specialist), usually within one to two days, which is significantly shorter than the waiting time for a face-to-face visit with a specialist (ranging between 50 and 68d in control).<sup>115, 122, 123</sup> When the waiting time for this face-to-face visit was compared between patients with eConsult and traditional referrals, there was no difference in a controlled before-after study in 8 rheumatology clinics with adjustment for confounding (the strongest design),<sup>127</sup> and moderate reductions between 22% and 31% (11-17d) in two other observational studies, one conducted in 4 nephrology clinics<sup>122</sup> and one in

a paediatric dermatology service.<sup>123</sup> A similar WT for an FTF visit may be appropriate, despite a different mode of referral, if there is the same level of urgency for the patient. The eConsult strategy aims to improve access to specialist care, while reducing the need for FTF visits and reducing the WT for specialist consultations, by helping more patients at primary care level.<sup>115, 122</sup> This strategy involves a triage, as the specialist decides during the process which patients need to be seen FTF and which can be helped at primary care level. However, even if a FTF visit is needed after an eConsult, this visit can be more productive, because work-up is already initiated through eConsult.<sup>119</sup> Three other telemedicine strategies showed significant (between 25% and 66%) reductions in mean or median WT. Firstly, the only RCT identified on telemedicine was a strategy in which patients were present at the primary care practice during phone call with the specialist (DETELPROG, 'Scheduled Telephone Referral', from its acronym in Spanish), and showed a significant reduction in WT for patients in the experimental group, compared with the FTF referral.<sup>125</sup> Secondly, two other observational studies investigated the use of electronic referral compared with paper-based referral.<sup>117, 121</sup> In the first observational study<sup>117</sup>, the use of electronic referral decreased mainly the time between booking request and actual booking, probably because of completeness and legibility of the referrals, while in the second paper, the virtual rapid access clinic (VRAC) between the patient and a neurology care team reduced WT for the patient because of increased workflow efficiency including the presence of multiple practitioners at the same time.<sup>121</sup>

Studies on **task shifting** have involved either an allied healthcare professional, advanced nurse practitioner or advanced practice provider at the micro-meso level, or the use of medical scribes in the VA at the national level. Depending on the specialty, the allied healthcare professional involved may be different, for example a dietician for gastro-enterology,<sup>118</sup> an optometrist for ophthalmology,<sup>124</sup> an audiologist for ENT,<sup>120</sup> etc. We identified studies on task shifting with a second main strategy: virtual

<sup>e</sup> Medical scribes are trained by clinically unlicensed professionals who can assist providers in navigating the electronic health record and entering patient visit information.<sup>126</sup> Palani S, Saeed I, Legler A, Sadej I, MacDonald C, Kirsh

SR, et al. Effect of a National VHA Medical Scribe Pilot on Provider Productivity, Wait Times, and Patient Satisfaction in Cardiology and Orthopedics. *Journal of general internal medicine*. 2023.



consultation between an optometrist and an ophthalmologist<sup>124</sup>, direct access to diagnostics (timing of diagnostics)<sup>116</sup> and triage (performed by an extended role practitioner).<sup>114</sup> Triage is often part of task shifting because there is a selection of eligible patients and can be added to the effect of task shifting.

The observational studies on task shifting at the micro-meso level mostly reported significant reductions in WT for the patients, ranging from 55% and 77% or 65 to 214d.<sup>116, 118, 120, 124</sup> A national RCT on medical scribes, showed significant reductions in WT for orthopaedics, but not for cardiology<sup>126</sup> and a study using a secret shopper approach showed no significant differences between the WT for practices with or without advanced practitioners (APs); however, there was an association with reduced WT if the patient attended a practice with APs if the WT for APs and specialists were compared.<sup>128</sup> Finally, there was an observational study on task shifting and triage which showed an association with reduced WT for expedited patients and an increased WT for non-expedited patients.<sup>114</sup> Similar to eConsult between providers, where more patients are helped at primary care level, the aim of task shifting is to reduce the workload of specialists, so they can spend their time on more complex cases, while at the same time reducing WT for the patients.<sup>118</sup>

The three studies **on the timing of diagnostics** were difficult to compare for different reasons (different outcome measures, in one study there was a combination of two strategies, results depending on the pathology). However, pre-referral advanced diagnostic testing in hand surgery<sup>152</sup> was associated with increased WT, while a single stop clinic combining consultation and diagnostics (after referral) in urology<sup>153</sup> decreased WT, and after referral diagnostics in a single stop. An ANP-led clinic also in urology was associated with a strong reduction in the number of patients waiting more than 12 months,<sup>116</sup> which is in some way consistent with each other.

The other observational studies on strategies to reduce WT were associated with mild to moderate reductions in WT for electronic reminders (no-show policy) in the VA<sup>160</sup>, increasing the capacity of the service either by expanding the service<sup>155</sup> or by outsourcing to a private clinic<sup>157</sup> and free choice of specialist.<sup>150</sup> However, increased capacity led to a higher inflow of

new patients, which may lead to increasing WT if this inflow of new patients is not limited and the effect of free choice had the tendency to wear off, although the difference with a synthetic control remained. The studies on STAT for epilepsy patients<sup>141</sup> and a complex intervention in a nephrology clinic consisting of a new triage and booking system (including admission criteria and triage guidelines, telephone reminders, waiting list review and reduction of follow-up)<sup>256</sup> showed stable WT for respectively first epilepsy consultation and scheduled nephrological categories, but decreased WT for general epilepsy consultation.

A summary of the identified strategies in specialised care consultation and their effect on WT can be found in the Appendix II (Table 7).

## Surgery

This section discusses the different strategies that have been used to reduce the WT for non-cancer surgery. There are strategies specific to surgery such as reducing general anaesthesia, and operating room organisation and non-specific strategies such as task shifting. The latter has already been discussed in the section on consultation in specialised care and the first two will also be discussed in the section on cancer.

The WT interval was the time from referral or date placed on the waiting list to the surgery: insertion of grommets,<sup>120</sup> cataract surgery,<sup>143</sup> or different types of surgery including general, orthopaedics, obstetrics and gynaecology and urology.<sup>144</sup> As the strategies were all different, it is difficult to compare them. There was no increase in WT associated with the strategies. An Italian observational study investigating a multidimensional intervention, including separation of the flow for day surgery and ordinary surgery and a simulator for scheduling, showed mostly an association with significantly reduced WT, except in the highest priority groups (surgery <30d) of all included surgeries (except orthopaedics day care which also had reduced WT). For urology, the results were either not significant or could not be estimated because a small number of observations.<sup>144</sup> An ANP-led clinic was associated with reduced WT for insertion of grommets in a small paediatric study.<sup>120</sup> The results on the effect of decreased general anaesthesia for cataract surgery were described as a 11 week reduction in



WT for surgery without crude data or statistical comparison to verify these results, however only 21 participants were included.<sup>143</sup>

A summary of the identified strategies in specialised healthcare and their effect on waiting times for surgery can be found in the appendix (Table 8).

### Imaging

The waiting time intervals studied for imaging started at the time of the request for the (additional) investigation and ended at the time of the imaging appointment or execution. Only imaging for non-cancer patients is discussed here. Four different strategies were identified: a complex intervention to optimise of MRI capacity,<sup>257</sup> electronic appointment reminders for radiology (no-show policy),<sup>160</sup> increased capacity by outsourcing to a research facility (and combining a clinical and research protocol),<sup>156</sup> and performing MRI without sedation in children (decrease in general anaesthetics).<sup>145</sup> The latter included an intervention with a child life specialist, preparation of the children with videos and pictures, and support for the child and their family. The different strategies were all associated with a reduction in mean WT ranging from 12% to 76%. Only one study showed adjusted results<sup>160</sup>. This was the study with the smallest reductions in waiting time. However, as all studies were observational, no conclusions can be drawn about causality. As all strategies studied were different, no real comparisons between studies can be made.

A summary of the identified strategies in specialised care and their effect on waiting time for imaging can be found in the appendix II (Table 9).

### Cancer

Thirteen studies focused on WT in cancer. More than half of the studies came from Canada<sup>36, 129-131, 133, 142, 154, 162</sup>, and two from the UK.<sup>147, 163</sup> In cancer, many different and overlapping intervals were studied, making comparison of the strategies used to reduce WT even more difficult. The most important intervals are the diagnostic interval (from referral or first visit to diagnosis) and the time to treatment (from diagnosis, but also 'abnormal screening', 'biopsy' or 'date placed on waiting list for surgery' to initial 'treatment', which can be specified surgery, chemotherapy, radiotherapy, or

other). Other intervals studied are the time from referral to first visit, (waiting) time for imaging, time between an (unclear) abnormal result to definitive categorisation, and time from diagnosis to first treatment decision.

The most studied types of strategy to reduce WT (and all other intervals) was a Rapid Access Clinic (RAC),<sup>129-133, 262</sup> followed by triage,<sup>162, 163</sup> organisation of the operating room,<sup>142, 146</sup> and timing of diagnostics.<sup>130, 154</sup> For other included types of strategy such as administrative efficiency,<sup>161</sup> decrease GA,<sup>147</sup> and maximum WT with public performance reporting,<sup>149</sup> only one study in cancer patients was identified per strategy. We identified these strategies in different contexts. RACs were studied at micro, meso and macro levels, but the other strategies were only studied at micro level. Again, there is an overlap between the different strategies, elements of RAC could be found in the strategies described by Cha et al.<sup>162</sup>, Gulak et al.<sup>154</sup> and Alvarenga et al.,<sup>161</sup> where the main types of strategy were respectively triage, one-stop clinic (timing of diagnostics) and administrative efficiency.

Most studies on **RAC** reported adjusted results<sup>131, 133, 262</sup> and two of them showed a significant reduction in the time to treatment, one in breast cancer and one in lung cancer.<sup>131, 262</sup> Two other studies from Canada on breast cancer showed different results. The first one, a study on breast assessment sites, showed a small but significant increase (of 4 days) in the time to treatment, but a similar decrease in the diagnostic interval.<sup>133</sup> A possible explanation for this is the shift of staging investigations from the diagnostic interval to the treatment interval.<sup>133</sup> The other study in breast health clinics showed a large reduction in total WT of almost 30 days that was mainly driven by a decreased diagnostic interval, combined with a decreased time to treatment from diagnosis to start initial treatment.<sup>130</sup> The location of the latter study is different (Kamloops, British Columbia versus Ontario) and includes also a triple assessment in one day model, which affects the timing of diagnostics. Two other studies on RAC presented unadjusted results. There was one study on different types of cancer that showed unadjusted results for time to treatment for radiotherapy significantly reduced in colorectal, lung and prostate cancer, but for surgery only in lung and prostate cancer.<sup>132</sup> The final study on RAC was a cancer patient pathway that was combined with a maximum WT. The results showed that a percentage of patients meeting the target for diagnostic interval was almost doubled.<sup>129</sup>



Studies about strategies to reduce WT focusing on triage,<sup>162, 163</sup> administrative efficiency,<sup>161</sup> or timing of diagnostics (navigation day programme one-stop clinic)<sup>154</sup> showed significant reduction in interval times, but all for different intervals, making the results difficult to compare.

Specifically related to surgery are the strategies on surgery room organisation (swing room for immediate reconstruction after mastectomy)<sup>142</sup> and allocation of operating room capacity to non-elective neurosurgical cancer patients based on a mathematical model<sup>146</sup> and the reduction of general anaesthesia<sup>147</sup>, did not always reduce interval times, but non-significant differences may be due to a small sample sizes.<sup>146, 147</sup> A maximum WT target was studied in two large studies in several cancer types, one with performance reporting<sup>149</sup> and one combined with cancer patient pathway.<sup>132</sup> Time to treatment (surgery) was only reduced in specific cancer types, not in the whole group of cancer patients.

Time to imaging for cancer patients was investigated in three studies<sup>130, 154, 164</sup>, but for different imaging techniques: MRI and CT combined, brain MRI, PET-CT and imaging in general. The investigated strategies were two examples of a one-stop clinic (a navigation day programme and a three assessments in one day model (TAM) combined with a RAC<sup>130</sup> and a new type of funding, the Healthy Budapest Programme (HBP)<sup>164</sup> The navigation day programme consisted of nurse-led education, social work, smoking cessation counselling, symptom control and dedicated test slots for PET/CT, pulmonary function tests and brain MRI on the same day. TAM consisted of nurse and physician assessment, breast diagnostic imaging and ultrasound-guided core needle biopsy on the same day. The HBP funding was associated with a shorter maximum WT of 7 days, compared to the National Health Institute funding which was associated with a maximum waiting time of 14 days. All three studies showed a significant reduction in WT for imaging associated with the different strategies.

A summary of the strategies identified in cancer care and their effect on WT can be found in the appendix II (Table 10).

## Mental health

We identified eight studies on strategies to reduce WT in mental healthcare. None of the studies were situated at the macro level. Five studies included children and five focused on another diagnosis or problem such as attention deficit hyperactivity disorder (ADHD),<sup>138</sup> psychosis,<sup>148</sup> substance abuse,<sup>136</sup> memory assessment clinic,<sup>135</sup> learning disability.<sup>137</sup> Three studies focused on more general mental healthcare (neuropsychology or Child and Adolescent Mental Health Services (CAMHS)).<sup>134, 139, 165</sup> Strikingly, in this mental healthcare category, studies were mostly conducted in Europe, five from the UK<sup>135, 137-139, 148</sup> and one from Norway.<sup>165</sup> All were observational studies with (controlled) before-after or interrupted time series design. The strategies were mostly complex interventions, a mix of different elements, often combining administrative and patient pathway efficiency, increasing capacity, no-show through by reminders, triage, triage guidelines, reducing follow-up, monitoring and updating waiting list, etc. The most complex interventions were developed through a quality improvement project using PDSA cycles,<sup>134, 135, 137-139</sup> followed by lean methods.<sup>136</sup> One study reported on the effect of a maximum WT policy. This was studied in England for psychosis by comparing Early Intervention Psychosis (EIP) services to standard care from community healthcare.<sup>148</sup> The last study reported on the effect of a strategy focusing on improving the administrative efficiency developed using mixed methods.<sup>165</sup>

The complex interventions showed a large variation in reducing mean or median interval times, ranging from 3% to 79% or in absolute terms from 2d to 220d, but interval times were not always the same. The interval time could be from referral to intake<sup>134, 139, 165</sup> or from intake to report finalised<sup>135</sup> or from referral to treatment<sup>148</sup> or from referral to assessment completion.<sup>137, 138</sup> It shows that the completion of assessment or report is an important intermediate time point for patients, which can be linked to the possibility of starting treatment (medical or other, sometimes admissions). A significant and moderate decrease in waiting time to intake was associated with a strategy to improve administrative efficiency.<sup>165</sup> The study on early intervention for psychosis linked to maximum waiting time showed no statistical difference compared with standard community care.



There was a reduction in time from referral to treatment before and after implementation but in both the intervention and control groups.<sup>148</sup>

A summary of the mental health strategies identified and their effect on WT can be found in the appendix (Table 11).

#### 2.5.2.5 *Limitations*

It is difficult to draw firm conclusions about the effect of different strategies to reduce WT. Firstly, we only searched the literature from 2019 onwards, which means we will certainly have missed studies that could have provided more useful information. If there are future plans to try a particular strategy, it might be useful to do a more specific literature search on the chosen strategy. Secondly, there is a high risk of publication bias as studies with negative results are less likely to be published. Overall, the retrieved studies showed a stable or positive association between the strategy and WT, which may indicate publication bias. It is also high likely that not all existing strategies have been formally studied.

Most of the identified studies are observational and only a minority adjust for possible confounding by patient or hospital characteristics. Strategies are rarely studied separately, but rather in combination with other strategic elements. When a complex intervention is implemented, the effect of individual elements is not evaluated.

Often the strategy is very specific, developed locally or implemented in a specific patient population within a medical subspecialty or with specific symptoms, which makes it difficult to generalise the results. Sometimes the studies also include a very small number of patients.

Different intervals of the patient pathway are explored, especially for cancer patients and mental health. The use of specific start and end points is important for interpreting and comparing of the results. Sometimes a reduction in one interval may be combined with an increase in another interval of the same pathway, because the pathway is redesigned, e.g. certain investigations are done earlier or later.

Another problem for interpretation of the results is the mixed use of mean and median WT. The median will be less influenced by outliers. Sometimes both are described which can be helpful to get an idea about distribution (mean and median can be similar<sup>149</sup> or very different<sup>162</sup>).



### 3 EXPERIENCE OF WAITING ASSESSMENT FROM ABROAD

#### Key points

- WT are very difficult to compare between countries (and sometimes between regions within a country). There is heterogeneity in what is measured (primary care, outpatient specialised care assessment, treatment, type of disease including cancer or mental health disorders...), how it is measured (retrospective, real-time or prospective data), when it is measured (ongoing or completed waiting), the parameters used (percentages, numbers, median or mean number of days, percentiles 90, 92, 95), when the measurement activity starts (referral from GP, first appointment, decision to treat), and the types of patients and healthcare units to which the data relate. This lack of homogeneity in the measurement and reporting of WT and the risk of misleading interpretation is known for several years.<sup>263</sup>
- The selection of the WT to be assessed is rarely justified in the documents than we found. It may be made in agreement with various stakeholders and regularly revised (NL). WT for mental health (CA, FI, SE, GB-ENG, GB-SCT, GB-WLS) and cancer WT (UK) are sometimes specifically addressed.
- There is an obligation of recording data on WT in many countries, but we found few national legal documents describing the items to be collected, the tools to be used for data transfer... Due to the decentralisation of care in several countries, it is possible that regional laws have been formulated, although we have not identified

them. With or without national legislation, there is heterogeneity in recording between data providers (e.g. regions or Healthcare practitioners (HCPs)) within a same country.

- WT measurement is used at least at two non-exclusive levels: the clinical level to provide services to patients in the best way possible (in particular timely and equitable access) and the policy level for benchmarking between service providers, global planning, and participation in international comparisons.
- Maximum WT are defined in the 9 countries and assessment of exceeding these maxima is usual. They are considered useful for interpreting WT data. However, there are large variations in these maxima between countries and sometimes between regions of the same country. This may be related to the fact that they are mostly often obtained by consensus rather than on the basis of evidence. There is an obligation to respect the maximum WT in 7<sup>f</sup> countries but exceeding WT are rarely (economically) sanctioned. The development of waiting lists, the use of prioritisation criteria, the proposal of alternatives, when there is (a risk of) exceeding WT guarantees, and the importance of informing patients of their rights, are issues highlighted by all countries.
- WT data are often retrospective (giving a picture of the time the patient waited for a service during a predetermined period (e.g. the last month) before the date of the data collection). Prospective data (i.e. the number of calendar days a hypothetical patient would have to wait for an appointment or test on the date of registration) is collected in the Netherlands and in limited cases in Sweden.

<sup>f</sup> It is interesting to mention that a maximum waiting times guarantee for hospital care, considered in 2001, was not introduced in the Netherlands because it would increase bureaucracy and administrative burden and because it would be costly to operationalise.



- In general, data on WT are collected over a full year, except in Canada, where the use of a 6-month period (April 1 – September 30) is considered to be representative of a full year (CA).
- The quality of data on WT is generally monitored either by the national agency gathering WT data (CA, NL), by regions (FI, SE) or HCPs (UK). Guidance is provided to data providers (UK, FI) and discussions with and between data providers are also common (CA, FI, NL). However, data quality is sometimes questioned, especially when there is no independent control of the data quality (ES).
- There is no comprehensive and true picture of the WT experienced by patients.
  - The whole patient pathway (from the first call to have contact in primary care to the first treatment in specialised care, including surgery) is never recorded. The most comprehensive measurement of WT covers the interval between the GP referral and the treatment (UK).
  - The end of the WT is not synonymous of received care service; conversely, some patients are still on the waiting list although they are not waiting.
  - There are clock adjustments or 'clock pauses' meaning that patients may be temporarily removed from the waiting list and that some periods are not counted in the WT calculation (GB-SCL, GB-NIR, ES). Reasons for these adjustments were reported.
  - Data from the private sector are not recorded (ES, CA) or not comprehensive (FI, SE) and the WT for this sector is not appropriately considered.
  - Not all patients waiting for care in the public health care system are in the register of WT. Many 'exceptions' are mentioned in the recording system.
- A risk of falsification of data assessment and reporting of WT according to particular stakeholders' interests is mentioned (ES).
- Data providers themselves sometimes perceive that the reporting system and the output data lack validity and usefulness (which may create a disincentive to report waiting times which in turn reduces the validity and usefulness of the data) (SE).
- Several barriers to WT data recording are mentioned such as technical challenges related to the IT system, administrative burden of the data collection, cognitive barriers to validity (e.g. misinterpretation of how to enter data) or difficulties in choosing time points for measurement.
- There are also elements that can support the WT data recording such as technical facilitators (use of consensus definition, uniformity of ICT system, flexibility in the way to collect data, automatisisation for data extraction, safe portal for data transfer), minimal effort (only necessary items), specific guidance, spot checks or external validity checks, active involvement of stakeholders, access to timely WT data with feedback loops and relative measures (i.e. comparison to own WT in the past), explanations of why WT data collection is important, sharing of experiences between data providers and building progressively the system for WT recording.
- In some countries, there is an obligation to inform patients about the WT (FI, NL, SE). In practice, there are several ways of informing citizens: by the care providers themselves, often on their websites (FI, GB-ENG), by national or regional authorities (CA, ES, FI, NL, GB-SCL, GB-NIR) also on their websites, sometimes with access to interactive and open source data (CA, FI, NL, UK) and additional annual or specific reports (CA, FI, GB-WLS, GB-SCL). Websites are considered as the main place for statistics, as much quicker and with more up-to-date results (SE).



- Even in countries that have been dealing with WT for a long time, there are trends towards an increase in WT, and adaptations are continuous (of what to recorded, which maxima to respect...).
- Possible perverse effects of the WT management system are described on three levels: the risk of inequity for the patients (e.g. by purchasing private health care or by better understanding the system to get faster access to care), the risk of use of WT data by HCPs according to their interests and the risk of statistics misuse by the authorities.
- WT is often perceived negatively. The real meaning of WT is questioned at the medical level (care really needed or not), at the patient level (possible positive experience) and at the management level (need for realistic maximum waiting times compatible with available budgets).
- The selected countries have several similar characteristics to Belgium both in terms of the health status of the population and the healthcare resources. One notable difference is the role of formal gatekeepers for GPs in almost all of them (except in Sweden and Canada).

### 3.1 Methods

As waiting times are a concern shared by countries around the world, for some of them for many years, and as the scientific literature does not provide a detailed picture of how waiting times are assessed in practice, we decided to look more closely at a selection of countries. The **objective** of this chapter is to describe how countries measure waiting times with routine reporting systems and to assess whether the methods used are relevant before the implementation in Belgium. The aim is not only to identify common patterns or differences between countries, but above all to investigate the lessons that can be learnt. The assessment of waiting times through surveys of either patients or health services providers is out-of-scope of this chapter (as mentioned in the introduction to this report).

We limited the scope of our review by focusing on a number of OECD countries that have a system for assessing WT but also a level of resources devoted to healthcare (part of the GDP, density of HCPs) and a status (life expectancy and avoidable mortality rate) similar to those of Belgium. similar to that of Belgium. We therefore selected Finland (FI), Spain (ES), Sweden (SE), the Netherlands (NL), the United Kingdom (UK) and Canada (CA). We followed Viberg et al. (2013)<sup>264</sup> and Lee et al. (2021)<sup>263</sup> by considering England (GB-ENG), Scotland (GB-SCL), Wales (GB-WLS) and Northern Ireland (GB-NIR) as distinct observations.

For each country, we searched the grey literature of administrative material on websites of government institutes and relevant agencies connected with WT reporting. This is similar in strategy to Lee et al. (2021).<sup>263</sup> We also used documents and data from the OECD.

Based on this grey literature, we prepared a document by country describing how the WT is assessed. This document includes the purpose of the WT assessment, the WT definitions used for each measurement and the data collection system. In order to understand the context of each country, we have also gathered information on the healthcare system (e.g. universal coverage, part of public and compulsory financing, health care resources, health status and the legal framework related to waiting times). The characteristic of the nine countries are presented in Box 5. The description of each country follows the same structure: the first part focuses on the healthcare system context; the second one presents a number of items related to the waiting times. The descriptions are available in Appendices II to VIII.

For each country, we contacted at least one representative recognised as a national expert in the field of WT and asked them to answer to a set of pre-established questions and to review the document of their country. We also discussed some issues such as the points of the evaluation of the WT assessment by e-mail, by telephone or online. Some experts supported their comments with scientific publications. Where appropriate, we have referred to these articles in the text. The list of national experts can be found in the colophon.



The transversal description of the nine selected countries presents 15 findings. The country code is inserted at the end of each corresponding example. In the case of the UK, we separate each country (England (GB-ENG), Northern Ireland (GB-NIR), Scotland (GB-SCL), Wales (GB-WLS)), but where the four countries were concerned by the same statement, we use the code UK.

We do not pretend to give a comprehensive picture of the WT recording for all aspects in each country. We present here a collection of information that has been validated by at least one national expert. For each issue described below, we highlight **some country specificities** as examples for feed our reflection. It is possible that the same specificity exists in another country without having been identified as such by our research. Furthermore, the topic of 'measuring waiting times in healthcare' seems to be **constantly evolving**, which has made our descriptive work particularly delicate.

### 3.2 Finding 1 –Assessment and management of waiting times: an old issue for some countries

It has been more than 20 years since countries such as Finland, Sweden or Spain have formally addressed the issue of waiting times in healthcare. For example, Finland has published data on waiting lists since 1993 and Sweden has defined waiting time guarantees since the 1990s.

We found **legal documents** addressing the issue of waiting times in almost every country<sup>9</sup>. However, the majority of these legal texts' focus on the **definition of maximum WT**. Apart from Canada and the Netherlands, these maxima are 'guaranteed' waiting times which means that there is an obligation for the service providers to respect these WT (see section 3.4).

Maximum WT in mental health care are sometimes clearly enacted in a separate law from somatic care (NL), and this may be several years after the somatic care law (GB-ENG, GB-WLS).

Regarding legal documents focusing on the **measurement of waiting times per se**, we found detailed information in three countries (ES, NL, GB-SCL). The Spanish Royal Decree 605/2003 provides a clear description of the data collection (minimum data set, indicators, methods to calculate them) for both specialised ambulatory care and scheduled surgery. One aim of this Royal Decree (RD) is to stimulate regions to provide homogeneous data.<sup>265</sup> In the Netherlands, the 'Regulation on delivery of waiting times' elaborates on which obligations that institutions must fulfil and the methodology they must use to calculate waiting times for specialised medical care.<sup>266</sup> In Scotland, information on how to monitor and record WT is provided in the 'Patients' Rights (Treatment Time Guarantee) (Directions 2022)'.<sup>267</sup>

There is an **obligation of data recording on WT** not only in Spain, the Netherlands and Scotland but also in Sweden, in Finland and the other countries of the UK. However, for these latter countries we did not find any national legal documents on the procedure to be followed for the collection and analysis of WT data. Due to the decentralisation of care in several countries and the resulting regional responsibility for the organisation of WT measurement (CA, SE), it is possible that regional laws have been formulated, although we have not identified them.

Nevertheless, it is interesting to note the involvement of national governments in **plans to reduce waiting times** and in **specific funding** to achieve the objectives of each plan.

According to the OECD, many countries have taken actions to address the backlogs and longer waiting lists for scheduled care caused by the disruption of services during the COVID-19 pandemic (OECD/European Union, 2022[1]). This observation is confirmed in Finland, Canada and Wales. Finland for example decided to allocate in 2023, EUR 110 million for reducing WT, followed by additional funding of EUR 90 million in 2024 and EUR 30 million in 2025. In Canada, the federal government provided an additional funding of CAD 4 billion in 2021 and CAD 2 billion in March 2022

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<sup>9</sup> Sometimes as in Canada is rather Plan with government commitment than legislation.



to support provinces and territories to work through the surgical and diagnostic backlogs caused by the COVID-19 pandemic.<sup>268</sup>

In other countries such as Scotland and Sweden, government plans and actions to reduce WT were already decided before the pandemic.

### 3.3 Finding 2 – Several purposes of waiting time assessment

Waiting time assessment is commonly considered as a measurement of accessibility in the healthcare system.<sup>263</sup> Looking at the different purposes of the WT assessment in the 9 selected countries, we confirm that **monitoring access to care** is an important aim, clearly mentioned by all. There is an emphasis on the **timely** access (GB-SCT, GB-WLS, GB-NIR) but also on an **equitable** access (SE, GB-ENG) to health care.

Like Ebbevi et al.<sup>269</sup>, we consider that there are at least two levels to the purpose of collecting waiting time data. These two levels are not mutually exclusive:

- **The clinical level:** to offer services to patients in the best possible way (transparency towards patients, reorientation when waiting time guarantees are exceeded, local production planning). At this level, providing local accurate information to patients, health care professionals and service providers is paramount. This can facilitate the **patients' choice** of treatment place for non-urgent care (ES, FI, SE, NL). Information can help to reduce patient anxiety and improve patient quality of life or clinical outcomes (GB-SCT). Furthermore, detecting the exceeding of the maximum waiting times allows the health care providers or insurers to assess their own performance (NL, GB-WLS, GB-NIR), offer alternatives to patients (FI, NL) and/or allow patients to claim for alternatives (FI, GB-ENG).
- **The policy level:** for reimbursement, economic sanctions, benchmarking between service providers, global planning and participation in international comparisons. This is a monitoring of the healthcare system performance (CA, ES, NL, UK or FI). Detection of exceeding maximum waiting times allows to provide feedback and sometimes pressure on care providers (FI). Information on WT for

researchers may also be an aim of the WT recording (FI, NL). In Northern Ireland, another specific use of the WT recording is to answer Parliamentary/Assembly questions and *ad hoc* queries each year (GB-NIR).

It is difficult to dissociate WT measurement from predefined maximum WT as they are useful for interpreting WT data. In Canada for example, it is mentioned that since no benchmark has been set for cancer care, if WT increases by 2 to 4 days, it is difficult to conclude whether or not these few days have a significant effect on patient outcomes. (CA)

### 3.4 Finding 3 – Many definitions and application areas of waiting times

As explained in the Chapter 1, a great variability in the definitions of waiting times is observed between countries for many years. This is still the case in 2023 in the 9 countries that we have studied. The recording of data concerns different areas in terms of setting (e.g. primary care or outpatient specialised care or inpatient care), type of care (somatic or mental health care), or steps in the patient pathway (health care professionals appointment, additional investigations, treatment). The start and end points of the WT interval are also extremely variable, both between countries and between types of WT measured in the same country. For example, 'time to referral' can start from either with 'first contact with a healthcare provider' or 'referral by a GP', and end either with 'referral received' or 'referral evaluated'.<sup>263</sup>

The summary of the observations presented below underlines the **wide variability between countries** but also highlights **some common trends**.



### 3.4.1 *Primary care rarely encompassed in the recording system*

Among the 9 countries included in this study, only Finland and Sweden routinely measure the WT in primary care. We do not take into account the WT monitored through the results of national healthcare experience surveys as this is out-of-scope of this report.

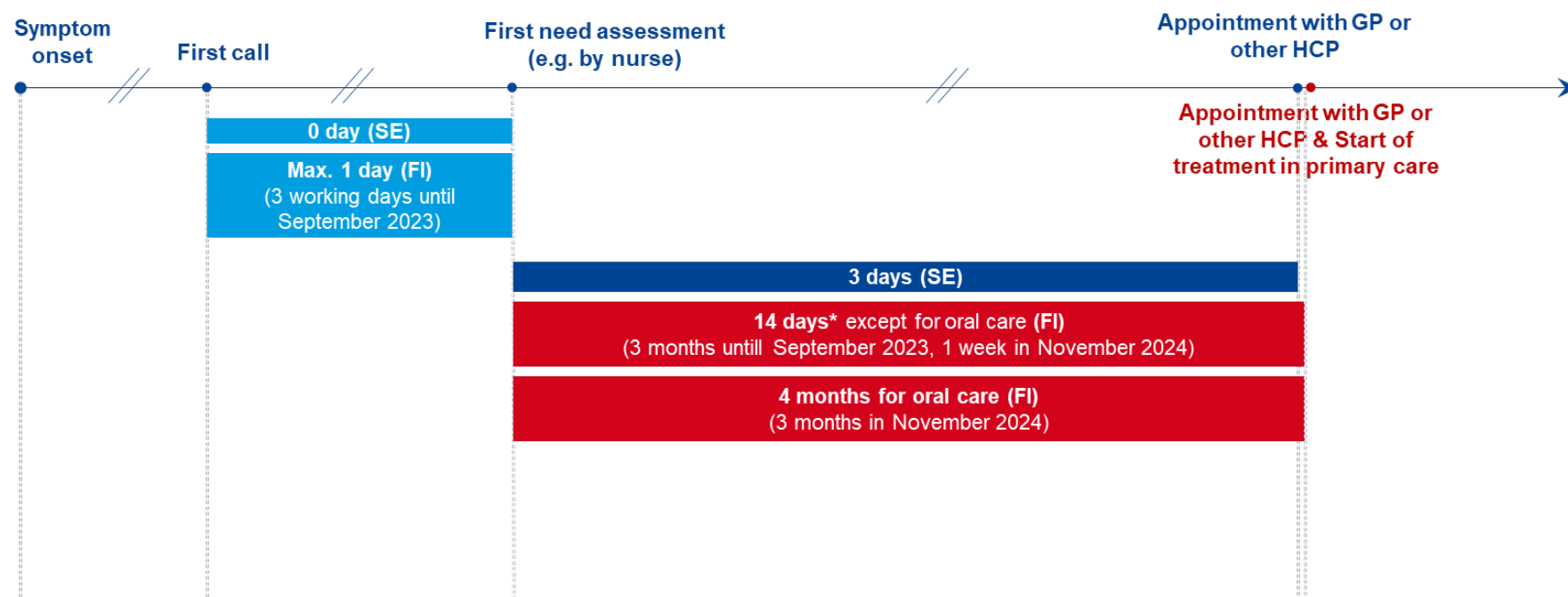
- In Sweden, there are two waiting times recorded in primary care.
  - WT between the patient's first call and the first contact (by telephone, digital channels, or physical visit) with the primary care practice. This contact may provide advice or make an appointment.
  - WT for assessment. This covers the interval between the date of the first contact and the date of assessment by a primary care provider such as GP, occupational therapist, audiologist, midwife, physiotherapist, chiropractor, speech therapist, orthoptist, optician, dietician, psychologist, nurse.
  - There are two maximum WT guarantees as shown in the Figure 4.
  - Every caller should receive a first contact (advice and/or appointment) on the same day. This is the so-called 'rule 0'.
  - The maximum interval between the first contact and the date of assessment is 3 days.

- In Finland, three waiting times are recorded in primary care (including dental care).
  - WT to assess the need for treatment (most often by the nurse).
  - WT to book the appointment with the GP.
  - WT to start the treatment in primary care after assessment of the treatment need.

There is a definition of maximum WT for two of the three indicators as shown in the Figure 4. Since the recent primary care reform, these legal maximum WT are shorter and will be even shorter in 2024. The call should have been made during weekday office hours.



Figure 4 – Start and end points of WT routinely recorded in primary care with the maximum WT allowed in Finland and Sweden



\* If the first visit, to be carried out within 14 days, has taken place with a licensed healthcare professional other than a doctor, a follow-up visit to a doctor that is still found to be necessary must be carried out within seven days (FI).

It is interesting to note that the two countries where WT is routinely recorded in primary care are countries where **access to primary care can start with a nurse consultation** (FI, SE). Furthermore, while GPs have a formal gatekeeper role in almost all the selected countries, this is not the case in Sweden.



### 3.4.2 *Specialised care monitored by all selected countries but in different ways*

Specific areas for WT assessment are defined in all countries with many specialties covered (see Table 2). There are WT for **appointment with specialists** (FI, ES, SE, NL, UK) or with **allied health professionals** (GB-SCT), WT for **imaging** (CA, NL, UK) and other **diagnostic** procedures (NL, UK) and WT for **specialised treatment** including surgery (the 9 countries) or treatment by **allied professionals** (CA, SE, GB-ENG, GB-WLS). WT in emergency care are also measured but it is out-of-scope of this study.

In the UK, **cancer** WT is a specific point of attention with several possible measurements that are not similar across the 4 UK countries such as interval between urgent GP referral for breast cancer and appointment with a breast cancer specialist (GB-NIR), time between GP referral and patient communication of the cancer diagnosis (GB-ENG), or cancer first treatment (UK), interval between decision to treat the cancer and first treatment (GB-ENG, GB-SCT, GB-NIR). In Canada and Spain, cancer surgery was included in the recording of WT. In Sweden (and possibly in other countries), there are regional or specific registries for some diseases such as cancer, with concerns about WT.

**Mental health** is specifically addressed in some countries (CA, FI, SE, GB-ENG, GB-SCT, GB-WLS). This concerns WT for appointment with specialists in adults (CA, NL, GB-ENG, GB-WLS) or in children-young people (SE, FI) and WT for treatment in adults (SE, GB-ENG, GB-SCT, GB-WLS) and in children-young people (FI, SE, GB-SCT).

It is less clear how each country has selected the WT to be assessed. In the Netherlands, the included items were chosen in **agreement with the different stakeholders**: hospitals and independent treatment centres, patient organisations and health insurers. These are either items with long waiting times or of specific interest to the patients. The list of items is **yearly revised** with the stakeholders (NL). In Canada, the 5 priority clinical areas for achieving meaningful reductions in waiting times (i.e. cancer care, cardiac care, diagnostic imaging, joint replacement, and sight restoration) have been agreed by the 13 Premiers (i.e. by the head of government of a province or territory). Since 2004, the provinces have been working together to develop public waiting-time indicators and have agreed by **consensus** on their definition, reporting procedures, standards and benchmarks<sup>h</sup>. The Canadian Institute for Health Information (CIHI) coordinates the discussions with policy-makers and technical representatives from each province or territory.

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<sup>h</sup> Except for hip fracture repair, where the 48-hour benchmark is taken from the literature.


**Table 2 – Waiting times in specialised care assessed in the 9 selected countries by country and kind of service/procedure**

| Countries | Medical or surgical assessment                                                                                                                                      | Diagnosis procedures                                                                                                                                                                                                              | Medical or surgical treatment                                                                                                                                                                                                                                                                                                                                                      | Allied professionals or very specific services                                                                                                                                            |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| CA        |                                                                                                                                                                     | <b>Imaging</b> <ul style="list-style-type: none"> <li>•MRI scan</li> <li>•CT scan</li> </ul>                                                                                                                                      | <b>Surgery</b> <ul style="list-style-type: none"> <li>•Hip replacement, hip fracture repair, Knee replacement</li> <li>•Cataract surgery</li> <li>•</li> <li>•Cancer surgery: Breast, Bladder, Colorectal, Lung, Prostate</li> </ul> <b>Other interventions</b> <ul style="list-style-type: none"> <li>•Coronary artery bypass graft (CABG)</li> <li>•Radiation therapy</li> </ul> | <b>Home care</b> (nurses, physiotherapists, occupational therapists, clinical nutritionists...)<br><br><b>Community mental health counselling (and addiction services in development)</b> |
| FI        | All <b>medical and surgery</b> specialties and specific attention to <b>mental health</b> care for people <23y old (several categories of pathologies)              |                                                                                                                                                                                                                                   | All <b>medical</b> specialties including <b>mental health</b> care for people <23y old (several categories of pathologies)<br><br><b>Elective surgery</b>                                                                                                                                                                                                                          |                                                                                                                                                                                           |
| ES        | 10 <b>medical and surgical</b> specialties (gyneco, ophtalmo, trauma, dermat, neuro, uro, ENT, dig, cardio & surgery)                                               | Not collected although foreseen in the law                                                                                                                                                                                        | 14 <b>surgical specialties</b> (ophtalmo, dermat...)<br><br>15 <b>interventions</b> (cataract, hip and knee prothesis, inguinal hernia, cardiac valve surgery...)                                                                                                                                                                                                                  |                                                                                                                                                                                           |
| SE        | 28 <b>medical and surgical</b> specialties including specialised pain management, dentistry, general <b>psychiatry</b> and <b>child &amp; adolescent psychiatry</b> | In <b>some regions only</b> <ul style="list-style-type: none"> <li>•Imaging (CT, MRI, PET scan, carotid and heart US)</li> <li>•Functional medicine (ECG, spirometry...)</li> <li>•Clinical neurophysiology (EEG, EMG)</li> </ul> | 28 <b>medical and surgical</b> specialties<br><br>Specific registries for some diseases as cancer.                                                                                                                                                                                                                                                                                 | Occupational therapist, audiologist, midwife, physiotherapist, chiropractor, speech therapist, orthoptist, optician, dietician, psychologist, nurse and assistant nurse.                  |
| NL        | 53 <b>medical and surgical</b> specialties including <b>mental health</b>                                                                                           | 15 procedures <ul style="list-style-type: none"> <li>•Imaging (5 MRI, CT, US, X-ray, mammography, DEXA scan)</li> <li>•Gastro- &amp; Colonoscopy</li> <li>•Sleep study &amp; sleep apnoea diagnostic/screening</li> </ul>         | 47 <b>medical &amp; surgical procedures</b> (cataract, hip and knee prothesis, inguinal hernia, angioplasty, male and female sterilization, plastic surgery...)                                                                                                                                                                                                                    |                                                                                                                                                                                           |



|               |                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                           |
|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>GB-ENG</b> | 18 <b>medical and surgical</b> specialties including <b>mental health</b> in adult and pediatric<br><br><b>Cancer</b>                                                                                                                     | 15 procedures<br>•Imaging (MRI, CT, non-obstetric US, barium studies, DEXA scan)<br>•Physiological measurements<br>•Endoscopy                                                                                                                                                                                          | <b>18 consultant specialties</b> (outpatients and in patient admissions) including <b>surgeries</b> and <b>mental health</b> .<br><b>Cancer</b>                                                                                                                                                                                                                                         | Arts therapists, chiropodists/podiatrists, dietitians, occupational therapists, orthoptists, physiotherapists, prosthetists and orthotists, radiographers, speech and language therapists |
| <b>GB-SCT</b> | <b>Medical and surgical</b> specialties, by medical consultants only (e.g. not nurse-led clinics) except MSK service                                                                                                                      | 8 procedures:<br>•CT scan,<br>•MRI scan,<br>•Barium studies,<br>•Non-obstetric ultrasound,<br>•Upper endoscopy,<br>•Lower endoscopy (excluding colonoscopy),<br>•Colonoscopy,<br>•Cystoscopy                                                                                                                           | •Hospital and general <b>medical and surgical</b> specialties (cataract surgery, hip and knee replacement...)<br>•Specific attention for <b>mental health</b> : inpatient and day case in psychiatric hospitals for adults; Child and Adolescent (<18y) Mental Health Services (CAMHS)<br>• <b>Cancer</b><br><br>• <i>Drug and alcohol treatment</i><br>• <i>In vitro fertilization</i> | <b>MSK services</b><br>•Physiotherapy<br>•Occupational Therapy<br>•Chiropody/Podiatry<br>•Orthotics services                                                                              |
| <b>GB-WLS</b> | <b>Mental health</b>                                                                                                                                                                                                                      | •Imaging<br>•Endoscopy<br>•Radiology (consultant referral or GP referral)<br>•Cardiology diagnostic<br>•Neurophysiology<br>•Physiological measurement                                                                                                                                                                  | • <b>Medical and surgical specialties</b> (cardio, gastroenterology, general medicine, gynecology, dermatology, ENT, ophthalmology, pediatrics, dental medicine, palliative medicine, pain management, etc. and all kinds of surgery)<br>• <b>Specifically attention to eye care</b><br>• <b>Mental illness</b> and psychiatry,<br>• <b>Cancer</b>                                      | Arts therapies, audiology –, dietetics, occupational therapy, physiotherapy, podiatry and speech language...                                                                              |
| <b>GB-NIR</b> | • <b>Medical and surgical specialties</b> (cardio, gastroenterology, general medicine, gynecology, dermatology, ENT ophthalmology, gynecology, pediatrics, urology, etc. and all kinds of surgery)<br>• <b>Suspicion of breast cancer</b> | •Imaging tests (MRI, CT, non-obstetric US, barium studies, DEXA scan, radio-nuclide imaging, plain film X-ray)<br>•Physiological Measurement tests (audiometry, echocardiography, perfusion studies, peripheral neurophysiology, sleep studies, urodynamics pressures and flows)<br>•Day Case Endoscopies not included | • <b>Medical and surgical specialties</b> (cardio, gastroenterology, general medicine, gynecology, dermatology, ENT ophthalmology, gynecology, pediatrics, urology, specialists, GPs carrying out inpatient treatment, pain management, etc. and all kinds of surgery)<br>• <b>Cancer</b>                                                                                               |                                                                                                                                                                                           |



For each type of specialised care (appointment, diagnosis, treatment), several WT can be measured. The start and end dates of each WT are described for the 9 selected countries in the Appendices III to VIII and summarized in **the Figure 5**.

The **start** date of the specialised care **appointment** generally depends on the referral from primary care, either the date mentioned on the prescribing doctor's assessment (SE) and/or request (ES) or the reception of the initial referral in the specialised service (CA, FI, NL, UK). The first consultation is defined as a consultation where a patient is to be seen for the first time by a specialist in a particular specialty in relation to a new health problem (ES). The referral can be written by a GP but also by many other HCPs such as nurses, dental practitioners or even by a screening program in case of cancer suspicion (GB-ENG, GB-SCL). In England, a waiting time can also start when the patient books their first appointment online (and when the referral is ratified by a care professional permitted to do so) (GB-ENG). In Sweden also, the patient can self-refer to a specialist and this can start a WT.

The **start** date of treatment in specialised care is the date when the clinician decides to treat (ES, SE) or when the clinician and patient agree on treatment (GB-ENG, GB-SCL, GB-NIR) or when the patient is considered as ready to be treated (CA). For the majority of patients, the treatment agreement is made at an outpatient appointment in, often after reception of the results of diagnostic tests and sometimes after additional time for patient reflection. In this case, the WT are short because all the time a patient may need to undergo diagnostic tests is not taken into account. This observation was also highlighted by Lee et al. in another international comparison.<sup>263</sup> The date of decision to treat can also be used as the end of treatment (see below).

The **end** dates are mostly the first specialist consultation for the assessment or the first treatment including surgery<sup>i</sup> (CA, FI, SE, ES, NL, GB-WLS, GB-SCL). According to Lee et al. the time to treatment (whether from referral or

decision to treat or patient wait-listed) is considered as the most important and the most common measure for determining the accessibility of scheduled care across all international jurisdictions.<sup>263</sup>

However, several considerations have to be highlighted regarding the end date of WT.

Firstly, there are **other possible endpoints under the term 'Time to Treatment'**. In the UK, for example, the Referral to Treatment (RTT) is a standard for assessing WT but in England and Wales it stops not only with treatment but also for reasons other than the start of treatment, i.e. the clinician decides that no treatment (or only active monitoring) is necessary and communicates this decision to the patient (and subsequently their GP and/or other referring practitioner), or the patient decides not to seek treatment (or does not attend the first appointment). In Spain, the end of the waiting times is linked to the departure from the list (because the service is received but also for various other reasons as explained later in this chapter).

Secondly, in some countries, the data collected all the patients who had waited during the period of recording including the patients who are still waiting at the moment of the collection (ES, SE, GB-ENG, GB-WLS, GB-NIR). This means that the assessment concerns **ongoing WT and not completed WT**. In some cases, both ongoing and completed WT are measured and clearly distinguished. In Sweden for example, there are completed WT for patients who have received the service and pending WT calculated from the time the care provider decides to carry out an activity until the time of recording, i.e. the last day of each month. These two different ways of looking at the waiting times are both considered important and complementary (SE). In other countries, it is not so easy to understand if patients are current waiters (GB-NIR, ES, CA). Sometimes, it depends on the type of care. For example, in Canada, the WT for Community Mental Health Counselling starts on the date that the initial referral is received (or at the date of discharge if the patient is in hospital when the referral is

<sup>i</sup> In Scotland, in case of hospital admission, the RTT can stop the day before surgery.



received) and it ends on the date of the first scheduled appointment for ongoing counselling that is offered and accepted by the client, regardless of whether they attend the appointment.

Thirdly, in some countries, there are **clock adjustments or 'clock pauses'** which mean that patients can be temporarily removed from the waiting list and that some periods are not counted in the WT calculation (GB-SCL, GB-NIR, ES). Several reasons may justify these adjustments such as when the patient has given reasonable notice to the Health Board that they will be unable to attend or miss an appointment, or when they refuse a reasonable offer (GB-SCL, GB-NIR); when the patient is suspended for medical or social reasons, such as the patient has another commitment (holiday), the patient needs to consider the proposed treatment, the patient is unavailable for treatment due to another medical condition (GB-NIR). Clock pauses were also used in England, but were abandoned because it was too complicated to manage, and the number of 'pauses' was considered to be relatively low (GB-ENG).

The classification of patients on the waiting list may reflect different situations. For example, in Spain, there are:

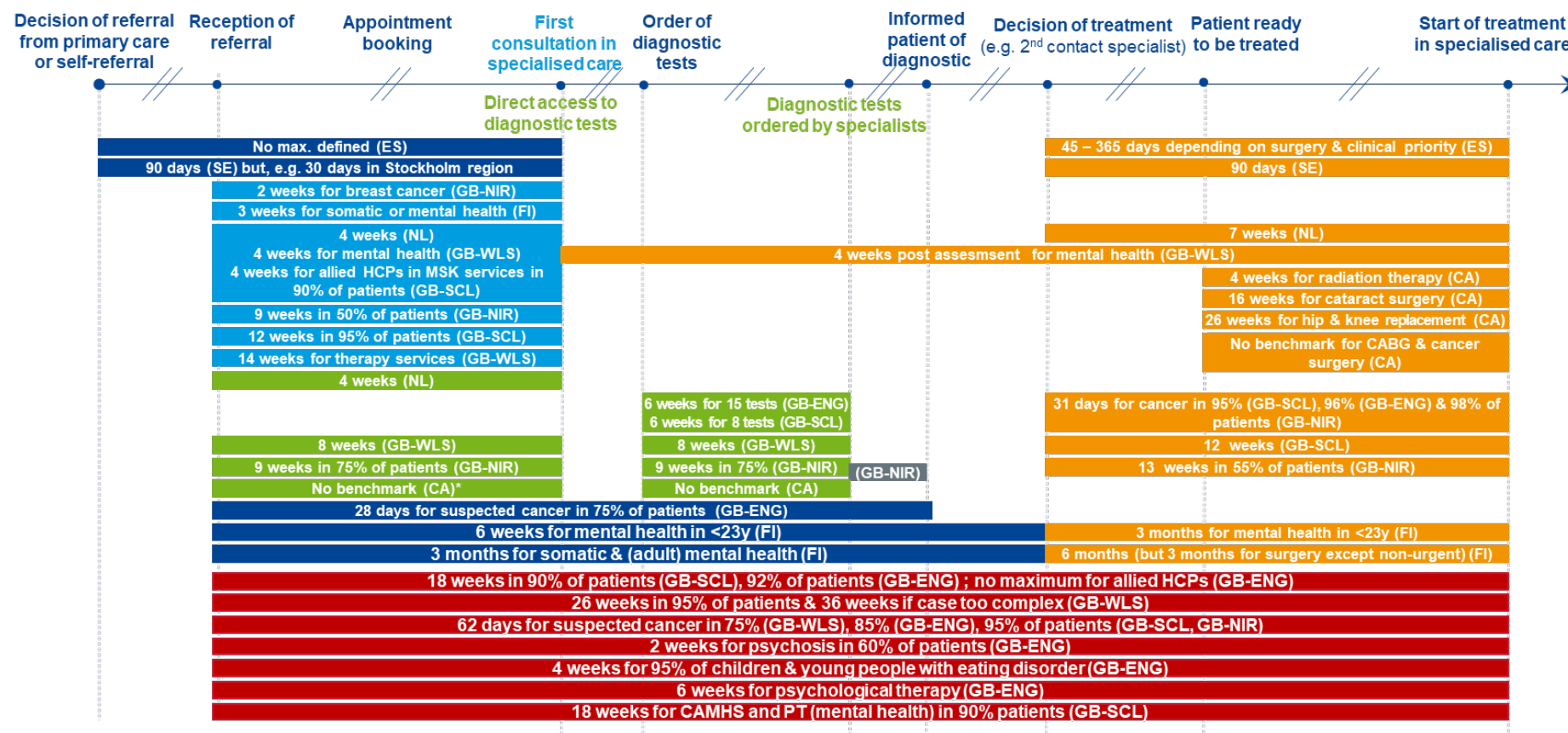
- Patients in structural waiting, i.e. patients whose waiting (for a specialist consultation or surgery) is due to the organisation and availability of resource.
- Patients in non-structural waiting, i.e. patients whose waiting is due to the patients' wishes (personal reasons, work problems...); appointment fixed to a specific date requested by the prescribing doctor.
- Temporarily unprogrammable patients: a patient waiting for surgery whose planning is not possible due to the following reasons:
  - Clinical reasons that contraindicate the procedure or make it temporarily inadvisable.
  - Postponement of the intervention for personal or professional reasons.

Finally, in addition to the WT measured from referral or decision to treat to appointment and/or treatment, there are other specific WT such as the **diagnostic reporting turnaround time**, i.e. the length of time between the diagnostic test being undertaken and the results of that test being verified and dispatched to the referring clinician (GB-NIR).

Figure 5 presents the different steps of a patient pathway for specialised care, including surgery, and the waiting times used by each of the 9 selected countries, together with the associated maximum waiting times where these have been defined (see also section 3.13.1).



Figure 5 – Start and End points of WT routinely recorded in specialised care with the maximum WT allowed in 9 countries



\* No benchmark for community mental health counselling and for home care service (for hospitalised patients, waiting time starts at the time of discharge) (CA)



It is important to note that in some countries (ES, GB-ENG, GB-WLS, GB-SCL) where a patient has more than one referral for unrelated clinical reasons, each referral has its own patient pathway. Some patients are therefore on multiple pathways and results show number of incomplete pathways on waiting list rather than number of individual patients.

### 3.5 Finding 4 – Systems used for the data collection: several examples

It was not so easy to obtain precise information on the data collection for all countries. Furthermore, in some countries such as Canada, the collection system is not designed at a national level as each province or territory has its own way of collecting and reporting retrospective waiting times (which cannot be addressed in this study). Therefore, we do not pretend to be comprehensive, but rather to provide different examples of what is currently done in the 9 selected countries. We distinguish below the WT data collection in primary care and in specialised care (including surgery).

#### 3.5.1 Data collection for primary care

Two of the 9 selected countries have a systematic recording system for WT in primary care. Both have an obligation to record this data.

In Sweden, data is **automatically extracted from electronic records** and are rarely completed manually (for care not linked to maximum waiting times such as when patients actively choose to wait longer). The data are aggregated and sent through an online platform that enables report to be extracted for patients, care providers and other stakeholders. Data on WT in primary care is sent monthly to the Swedish Association of Local Authorities and Regions (SALAR). Data is automatically analysed by a tool called Qlikview.

In Finland, an **automatic extraction is made daily from the information system on patients** owned by service providers and filled in by nurses or GPs. A unique identifier for a visit or episode of care (service transaction), generated in the service provider's own information system, combines the contact date, the assessment of care needs, and the actual visit into a single

service event. The care episode is characterised by the place of care delivery, the profession of the care provider, the waiting times, the degree of urgency, and the reason for the visit. Data is gathered into the Register of Primary Health Care visits called 'Avohilmo'. Some Finnish primary care providers have used prospective data (i.e. the third available date) to measure WT for an appointment with a GP, but this is not legal (FI).

#### 3.5.2 Data collection for specialised care

In general, the recording gathers data on specialised care provided by the **public** health care system (e.g. Medicare in CA, Sistema Nacional de la Salud in ES, NHS in the UK) and private services are not included in the WT recording system. However, in Sweden, in addition to public hospitals, the private hospitals or specialised clinics recognised by each region, report also data on waiting times (but only if conditions to report the requested data are met). In Finland, only some providers from the private sector send information, which means that data collection is not comprehensive. In the Netherlands, there are no publicly owned hospitals but an entirely private hospital landscape that submit their data to the Dutch Healthcare authority.

Data recording is **mandatory** in almost all of the 9 countries (FI, NL, SE, ES, GB-ENG, GB-SCL). However, it is not always clear what happens if the data providers fail to transmit the data. Penalties are possible but rarely applied. In the Netherlands for example, failure to submit waiting times can result in a fine, but in practice, the emphasis is on discussion with the healthcare providers to resolve problems (NL). In Sweden, there are no sanctions if the national waiting time database is not completed by the regions (SE).

In Canada, there is **no obligation to record WT data and no penalties** for the provinces or territories that do not send data to CIHI; the submission of data is based on a long-term collaboration that benefits all partners.

WT data on specialised care are most often **aggregated by the unit/hospital/health care centre** or even by **region** (as provinces and territories or autonomous communities) before being sent to the **national**



**databases** (CA, FI, GB-ENG, GB-SCL<sup>j</sup>, GB-WLS, GB-NIR). In Finland, specialised medical care units collect the data from their own patient information systems themselves and send the aggregated data monthly as separate files to the national Ministry of Health where these files are uploaded to the registry<sup>k</sup> (FI). In Northern Ireland, statistical information is routinely collected from a variety of electronic patient level administrative systems and pre-defined Excel survey return templates (GB-NIR). In Canada, each province and territory is responsible for organising its own data collection system and the provincial ministries and agencies perform all the WT calculations and send the aggregated figures to CIHI (except for hip fracture repair<sup>l</sup>) (CA). In the Netherlands, each institution (hospital or independent treatment centre) has to submit an overview with waiting times for outpatient clinic visit, diagnosis and treatment to the Dutch Healthcare authority (NL).

In Spain, data is collected **individually** and in **real time**. When an indication for a specialised consultation or surgery is filled up in a patient's medical record, the patient is automatically added to the waiting list. It is not aggregated data, since each patient waiting for a first consultation with a specialist in the ambulatory sector or for an scheduled surgery are (and must be entered) on the Patients Register by the regional administration of health (Autonomous Communities, department of health). For each patient on the register, the Autonomous Communities send the data to the National Healthcare System Interterritorial Council. A patient may be on several lists at the same time if she/he has several health problems (ES).

**Prospective data** are sometimes collected in specialised care. This is the case in the Netherlands and in limited cases in Sweden. In the Netherlands, this concerns the waiting times for an outpatient clinic appointment, diagnostic tests and treatment but in different ways. For outpatient clinic appointments and diagnostic tests, the data refer to the number of calendar

days a hypothetical patient would have to wait for an appointment or test on the date of registration (*'peildatum'*). The first appointment considered is actually the third available in the digital booking system, to prevent coincidences influencing a realistic waiting time, for example unexpected cancellation of an appointment.<sup>266</sup> Since 2016, the WT for treatment is no longer the third possible appointment anymore, but the median of all treatment waiting times (between the order date (usually the same as the appointment booking date) and the execution date) for the appointments planned in the next two months (NL).

In Sweden, only in Stockholm, there is a recording system using prospective data (the supply service database that includes clinics' self-reported estimates of short-term future waiting times). The purpose of this database is to provide estimates of future waiting times to refer a patient to specialised care provider (e.g. a median of four-week waiting time for cholecystectomy). The aim is to refer patients to the care unit with the shortest WT, but this is not widely used in practice. Beside this, there is the regional WT registry which gathers retrospective data and sends it to the national WT database (SE).

Several ways are used **to transfer** data from the hospital, centre, unit or region to the national database, such as standard template (GB-SCL), an Excel file (NL, GB-NIR), or an **online platform** (FI, SE, NL, GB-ENG). In the Netherlands, data can be sent to the national authority through the 'Zorgbeeldportal' portal, by application programming interface (API) or by Excel file. The fact that diverse options are possible is considered as a facilitator for data collection (NL) (see section 3.4.2).

<sup>j</sup> except for the General/Acute and Inpatient Day Case where patient-level data are collected in Scotland.

<sup>k</sup> Collection of individual data is foreseen in Finland but the transition to personal data collection will take place in stages, possibly already next year.

<sup>l</sup> CIHI calculates the waiting times for hip fracture repair using the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS).



Data sending is made timely, mostly **monthly** (FI, SE, GB-ENG, GB-SCL<sup>m</sup>, GB-WLS). In the Netherlands, the information is provided by hospitals and independent treatment clinics every 2 weeks (before 2021, it was every month). In Northern Ireland, WT data are reported on a quarterly basis (GB-NIR).

In general, data on WT cover a full year except in Canada for the 5 somatic care priorities<sup>n</sup>, where the patient cohort includes all procedures that were performed between April 1 and September 30, each year. **The use of this 6-month period is intended to improve timeliness and is considered to be representative of the full year** (CA).

**Additional variables** are also included in the recording (FI, ES). For example, in Finland, the reason for waiting is recorded, such as availability of hospital resources, refusal or cancellation of the appointment by the patient, medical reasons, repetition of treatment, or monitoring of the patient at certain intervals (FI).

Data collection may encompass **all patients needing the preselected specialised non-urgent care** or procedure (see Table 2) but few exceptions are described (e.g. WT do not have to be provided when based on fewer than 5 observations in the Netherlands).

### 3.6 Finding 5 – Various measured indicators

Several indicators are used in the same country. We present below the most common ones in the 9 selected countries, and we highlight the differences.

The **number of patients concerned by a waiting time** for care, or a procedure and the **mean/median duration of the WT** are usual indicators presented by the 9 selected countries. Mean WT is used in Spain but median WT (or 50<sup>th</sup> percentile) is preferred in other countries (FI, NL, UK). Canada (depending on the province) and Sweden used both mean and median (SE, CA). Compared to the mean, the median is lower because it minimises the influence of extremes, i.e. outliers patients with very long waiting times.<sup>268</sup>

**Various categories of WT** are used to describe the distribution of patients. These categories differ between countries but also within countries, depending on the procedure or intervention analysed. Where **WT guarantees** exist, they are often used as a **cut-off** for a category. For example, in primary care in Finland, the number and percentage of patients who had waited for their non-urgent visits are categorised as waiting for 0-7 days / 8-14 days / 15-30 days / 31-90 days / or over 90 days. For the assessment of specialised care, the categories are broader: 1-90 days / 91-180 days / more than 180 days for of the need for treatment (FI). In Spain, WT categories for surgery are 1-90 days / 91-180 days / 181-365 days and >365 days.

The WT guarantee can also be used as the **single threshold** for each indicator. For example, in Sweden, the indicators in primary care are the proportion of patients who are contacted on the same day after making a request and the proportion of patients getting an assessment in the 3 days.

<sup>m</sup> With the exception of the General/Acute and Inpatient Day Case, the Waiting Times (Stage of Treatment) and the Mental Health Inpatient and Day Case datasets, which are collected continuously in Scotland.

<sup>n</sup> However for community mental health counselling and home care services in Canada, WT are reported over a 1-year period (fiscal year).



This makes it possible to describe the **number and percentage of patients who not receive care within the WT guarantees**. Even in Canada, where there is no formal WT guarantee, the proportion of patients who received their procedure within the benchmark timeframe (where applicable) is used.

However, according to a Swedish expert, this way of presenting results (numbers and percentages of patients not receiving care within the WT guarantee) is of less value than mean values for waiting times in production planning and auditing.<sup>269</sup> Perhaps this explains why all of 9 countries<sup>o</sup> used different types of indicators (number and/or proportions and median and/or mean).

In most countries, the results show **retrospective data**, i.e. how long patients have already been waiting, most often the month before the monthly data collection (SE, FI, GB-SCL<sup>p</sup>). But as mentioned in the section 3.4, there are completed WT but also pending ones in some cases (such as in CA, SE, ES, GB-ENG, GB-WLS, GB-NIR). In the latter case, the data shows how many patients were still waiting at the time of the data collection. In Northern Ireland, most indicators are reported as the number of patients waiting and the length of time at the end of the quarter surveyed ('current waiters'). In Spain, indicators are computed at two specific points in time called reference dates (i.e. 30 June and 31 December). A study period refers to the 6-month period from 1 January to 30 June, and from 1 July to 31 December. This means that the waiting time for each patient is the difference, in calendar days, between the date of the request of registration and the reference date (30/06 or 31/12). The number of patients waiting for an ambulatory specialist consultation is the total number of patients on the waiting list who are structurally waiting on a given reference date.

The distribution of patients between the pre-defined categories can be presented in **percentiles** as 95<sup>th</sup> percentile (i.e. 1 out of 20 patients has waited longer than this time), 92<sup>nd</sup> percentile or 90<sup>th</sup> percentile (i.e. 1 out of 10 patients has waited this many days or more before receiving care).

This is shown in CA, GB-ENG, GB-SCL, GB-NIR. The 95<sup>th</sup> percentile is used as an indication of the range of current waiting times without being distorted by extreme values or the prioritisation of urgent waits (GB-NIR). Furthermore, the 5% tolerance level (i.e. **95% rather than 100%**) is applied, as for some patients it may not be clinically appropriate to start the treatment within the standard's time (GB-SCL). The percentiles waiting times are also used as they correspond with **certain targets (or operational standards)**. For example, in England, the maximum of 18 weeks from referral to consultant-led treatment should be reached for 92% of patients, while in Wales, the standard is the referral to treatment of 26 weeks in 95% of patients. It should be noted that median and percentile waiting times are calculated from aggregate data, rather than patient-level data, and therefore are only estimates of the position on average WT (GB-ENG).

In Canada, it is also interesting to note that CIHI calculates national estimates for the median and 90th percentile using a **weighted average of provincial submissions** (weights are calculated using provincially reported surgical volumes).

Usually, statistics are shown by (sub)specialities of service and procedures (NL, ES, FI), for the country as a whole, by regions (SE, ES), by type of practice (private versus public) (SE), by type of profession (doctor vs nurse) (FI) or even by health care provider (SE, UK).

Trend analyses are used to monitor annual variations and emerging trends (CA, ES, GB-SCL, GB-NIR).

<sup>o</sup> In the Netherlands, we found mostly the shortest and median WT

<sup>p</sup> with the exception of the General/Acute and Inpatient Day Case, the Waiting Times (Stage of Treatment) and the Mental Health Inpatient and Day Case datasets, which are collected continuously)



### 3.7 Finding 6 – Need of control for quality of data

In general, the quality of data on WT is monitored. This may be more or less rigorous. In some countries, the national agency gathering WT data is responsible for the quality check (CA) while in others it is each region (FI, SE) or health care provider (UK). We provide some examples below.

In Canada, CIHI is a not-for-profit arm's length organisation whose primary purpose is to provide comparable data and information to support improvements in health care and to improve health across Canada by consolidating health data. The **provinces, territories and CIHI** work together to ensure the quality of the data and the accuracy of WT analyses. Methods are standardised across provinces and territories to provide comparable data. CIHI organises regular meetings with representatives from the provinces and territories to discuss the best practice and share experience in the collection of on WT data.

In Finland, the Finnish Institute for Health and Welfare does not carry out a proper quality control. Quality checks are carried out in the regions. Once an error is detected in the care register, efforts are made to correct it in connection with the compilation and maintenance procedures of the register. Data providers themselves are usually asked to correct any errors or deficiencies detected in their data. The rules and procedures for data checks and automatic correction are described in the register (Hilmo) manual, which is published annually. If large discrepancies in the data are detected, for example in comparison with previous months, the Hilmo team asks the regions to check the data (FI).

In the Netherlands, there is a system of automatic reminders and (semi-)automatic quality checks. Institutions are contacted in case of structural problems or illogical waiting times (NL).

In Northern Ireland, following submission, the Hospital Information Branch (HIB) performs a series of checks to verify that information is consistent both within and across returns. Queries arising from validation checks are presented to HSC Trusts for clarification and, if required, returns may be amended and/or resubmitted. Data quality is addressed on an ongoing basis and figures are subject to revision in subsequent publications as hospital

records may not be fully up to date as at the publication date (GB-NIR). In Wales, also Digital Health and Care Wales (DHCW) validates the data in collaboration with local health boards (LHB) before uploading to their national databases. Any anomalies in the data are noted and these are then raised with the LHB, thus enabling LHB to check, correct or comment on their data and to provide contextual information where relevant (GB-WLS).

We found some technical notes and guidance to support the submission of data (FI, UK) and also national reports on the quality of WT data (FI, UK).

Where there is no independent control of the data quality such as in Spain, a lack of rigour in the data persisting over time is mentioned (ES) (see section 3.10.3).

### 3.8 Finding 7 – Publication of waiting times by the care providers and authorities/agencies

In some countries, there is an obligation or at least a strong emphasis on **informing patients** about WT (FI, NL, SE). For example, communication with patients is particularly emphasised in the Scottish legal documents such as the Charter of Patient Rights and Responsibilities,<sup>270</sup> which explains the patient rights to ask questions about WT, to receive clear information, in a format or language that meets their needs, etc. (GB-SCL).

In practice, there are different ways of informing citizens. Sometimes, publications of information by the **care providers themselves are mandatory**, often on their **websites**. For example, the Finnish Health Care Act (1326/2010) requires that public service providers to publish WT for non-urgent care on their websites (FI). In England, the NHS is responsible for publishing waiting times on its website (accessible to everyone), and databases on waiting times are openly available online (GB-ENG). NHS providers and commissioners need to use this information to ensure that they are meeting their patients' legal right to start consultant-led non-emergency treatment and to identify where action is needed to reduce inappropriately long waiting times (GB-ENG).



**National or regional authorities** publish also data on WT on their **websites** (CA, ES, FI, NL, GB-SCL, GB-NIR). In Finland for example, the same information on access to treatment is published by the Finnish Institute for Health and Welfare and by the regions on their own pages. A digital platform (called the cube) gives access to monthly or annual data in primary and specialised care (FI). In Spain, the Ministry of Health, Social Policy and Equality but also each region publish information on waiting times. However, the information published on each official web pages is heterogeneous. In Canada, the CIHI website provides an online reporting tool for the priority clinical areas, as an overview and by province and trends over time (CA). In the UK, most of the data is published in CSV format in order to support secondary analysis but there are also plot interactive charts (GB-ENG, GB-WLS, GB-NIR), read data via API queries (GB-NIR) and open access databases (GB-WLS).

Some **tools for informing individual patients** are available in a few countries (NL, GB-ENG, GB-NIR). In the Netherlands, waiting times for consultations (outpatient clinic visits), diagnostics and treatment in specialised medical care are available for every citizen on [www.zorgkaartnederland.nl](http://www.zorgkaartnederland.nl). The shortest and mean waiting times are given for each (sub)specialty, diagnostic test or treatment and waiting times can be compared between all hospitals and independent treatment centres (NL).<sup>271</sup> In England, if a patient is waiting for a hospital appointment or treatment, they can use the [My Planned Care website](https://www.myplannedcare.nhs.uk/) to check (and compare) the WT by hospital (<https://www.myplannedcare.nhs.uk/>). Patients can and do use this information to inform their choice of where to be referred and also to understand how long they might expect to wait before starting their treatment (GB-ENG).<sup>272</sup> Patients in Northern Ireland have access to a new online system to check how long they have to wait for an outpatient hospital appointment with a specialist in the different clinical specialties in each HSC Trust area. The webpage, known as 'My Waiting Times NI', is available via the HSC NI website (<https://online.hscni.net/my-waiting-times-ni/>). It will be expanded over time to also provide the latest information on WT for procedures, treatments and diagnostics (GB-NIR). In Canada, there is no single way of reporting waiting times, but most of the provinces have set up a user-friendly website to search for waiting times by

selecting a specific procedure, area or hospital (CA). In Spain, some Autonomous Communities such as Valencia, give citizens access to personalised information on the foreseen WT in their care process for surgical interventions, but this is not generalised (ES).

Sometimes, **health care professionals or administrative management** can have **direct access to their own data**. It is described in Sweden where HCPs can request a login to extract data from the national **WT database** concerning their own practice (SE).

There are also **national reports** such as in Finland, where Ministry of Health publishes (in Finnish) twice a year a report on access to primary and dental care at national and provincial level and 3 times a year for specialised care (FI). In Canada, CIHI publishes reports on waiting times for the priority clinical areas comparing all provinces <sup>273</sup>. In Wales, a detailed statistical bulletin is published annually (GB-WLS), and in Scotland, the website of Public Health presents many specific publications on WT such as WT for patients with chronic pain seen at a consultant-led outpatient clinic or findings from the review of adherence to national WT guidance (GB-SCL). However, in Sweden, it is reported that due to the fact that annual reports were quite similar each year – long waiting times and nothing has improved, the website is considered as the main place for the statistics, as it is much quicker and has more up-to-date results (SE).

**The timing of data updates** is not similar across the 9 countries. For example in Spain, information on WT is published by region and by the Ministry of Health every 6 months (ES). In Scotland, Northern Ireland (and England for some cancer indicators), WT are published on a quarterly basis while this is monthly for RTT in England and Wales or 6-Weeks for diagnostic tests WT in England (UK). In Sweden and Finland, statistics on WT are displayed monthly on the dedicated national website (FI, SE).



### 3.9 Finding 8 – Heterogeneity between and within countries

We have mentioned that WT assessment is so different among the 9 selected countries that this hampers a comparison between them. However, in countries where regional entities have latitude to define their own WT assessment, there is an additional source of heterogeneity. This is the case for example in Spain and Canada. Nevertheless, there is a difference between Spain and Canada. In Spain, it is not possible to compare between regions because the data available on the Autonomous Communities websites are not homogeneous despite the standardisation of definitions and legal requirements for the data recording.<sup>274, 275</sup> Conversely, in Canada, there is a standardised policy for measuring WT with a pan-Canadian definition of WT measurement developed in 2005 and adopted by the federal, provincial and territorial ministries. According to some authors, the CIHI publishes WT information that allows useful comparisons between provinces and territories, despite enormous differences in culture and economics that exist across its constituent provinces.<sup>263</sup> However, comparability between Canadian provinces and territories is not perfect.

Results can also vary between regions in Sweden. The 21 Swedish regions (county councils) are responsible for the delivery of health care and have self-autonomy. This means, among a lot of other things, that they have different IT-systems that are not yet interconnected and that a national digital infrastructure is still lacking. In principle, decisions about what must be collected must be taken at national level (all regions together), and then all regions have to figure out how to do that in their own systems. However, in practice, because it depends on what the system allows, so there may be difficulties in finding the same starting points, etc.

### 3.10 Finding 9 – No comprehensive and real picture of the waiting times

Several misinterpretations can emerge from the WT data collection. We have identified issues in the time period really measured, patient identification and data inaccuracy.

#### 3.10.1 *Partial patient pathway*

None of the 9 selected countries provide WT data that cover the whole patient pathway from the first call in primary care to the treatment in specialised care if needed. Data from primary care is rarely recorded in a registry or another systematic measurement<sup>q</sup>. Finland and Sweden collect WT data in primary care, but they report primary and specialised care separately (FI, SE).

In the other countries, most often the WT starts at the moment of the indication of specialised care by the GP or other primary care HCPs (i.e. the referral date mentioned on the prescribing doctor's request or the date of receipt of the referral). But the time taken to access this first step in primary care can be long. For example, in Spain in 2022, the mean time to get an appointment with the GP was 7.81 days.<sup>276</sup> According to Spanish authors, this waiting time should be considered in WT issues which it is currently not the case.<sup>276</sup>

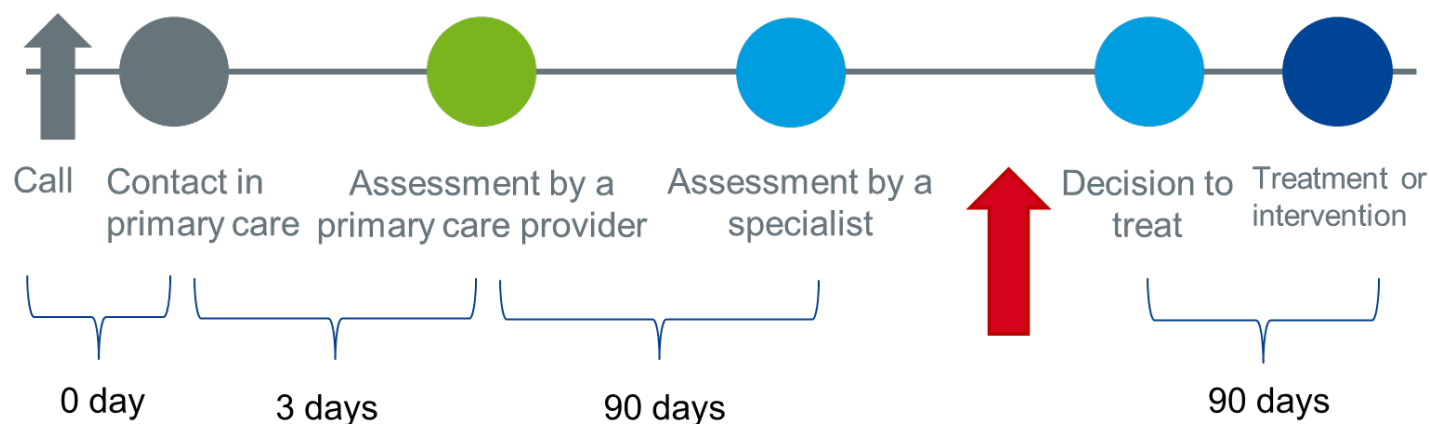
Furthermore, WT in specialised care are also rarely measured in its entirety. In the UK, the referral to treatment covers the whole patient pathway in specialised care, including the diagnostic process but in several other countries, the time required to make the diagnosis in specialised care (i.e. time for imaging and other diagnostic procedures, advice from another specialist, etc.) is not taken into account in the WT measurement (SE, ES) or is measured as a separate indicator (NL, GB-NIR) for a selection of diagnostic procedure (CA). In Spain, for example, the WT for surgery started with the indication for surgery which is made by the specialist physician;

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<sup>q</sup> There are other means as surveys used for measuring WT in primary care.

therefore, this time does not include the previous stages (i.e. the times of the processes since a patient goes to his general practitioner for an ailment, goes to the appointment with a specialist, performs one or several diagnostic tests, consults the general practitioner or specialist again, then meets a surgical specialist and be operated).<sup>274, 277</sup> Similarly, in Sweden, investigations, controls, re-visits, follow-ups are not included in the WT guarantees which create a gap in the pathway. (This is shown by the red arrow in the Figure 6).

**Figure 6 – Waiting times targets in primary and specialised care in Sweden**





Moreover, as mentioned above (see section 3.4.2), there are **ongoing WT** which implies that non completed WT (open or pending pathway) are measured (ES, SE, GB-ENG, GB-WLS, GB-NIR). There are also potential **clock pauses** where patients may be temporarily removed from the waiting list for several reasons (e.g. appointment missed or refused, medical or social problems, etc.) which means that some periods are not counted in the WT calculation (GB-SCL, GB-NIR, ES).

Even when prospective data (third available appointment) is used such as in the Netherlands, the data **does not reflect the real waiting times**. In fact, the real waiting times of a patient can be different from the published WT depending on the complexity of the problem or holiday/absence of a physician (NL).

Thus, the times for the **complete process** are generally **longer in reality** than those presented officially published WT. Some authors have already identified these differences between OWT ('Official Waiting Time') versus TWT ('Total Waiting Time') for certain scheduled procedures, due to gaps of non-recorded time that are nonetheless part of the actual waiting times experienced by patients.<sup>263</sup>

### 3.10.2 Imperfect identification of waiting patients

Another problem with the assessing WT is that the lists of waiting patients are not accurate. In most countries, **data from the private sector** is not recorded (ES, CA, UK) or not comprehensive (FI, SE). In Spain, when patients are referred to the private sector, they are sometimes removed from the list at the time of referral and not when the service is provided (even if there are still waiting for care). If they refuse the referral, the counter is restarted (as if they have not been waiting). In Canada also, the fact that some surgical procedures are outsourced to private clinics (e.g. cataracts) also makes it difficult to have complete data (CA). This is also highlighted for community mental health counselling and for home care services where results are interpreted with caution due to the known differences in definitions among the provincial and territorial systems and the variation in data coverage across Canada, primarily due to missing data by geography or by

type of service (e.g. WT data for publicly funded services that are contracted to third-party organisations is missing for a number of jurisdictions) (CA).

Furthermore, not all patients waiting for care in the public health care system are included in the WT database. There are many 'exceptions' (e.g. the footnotes to the tables of the official statistics). There are also exits from a list without receiving care. According to Lee et al. future studies may fruitfully explore these further to identify areas where officially reported waiting times and waiting list statistics may not match the WT experienced by the patients.<sup>263</sup>

Lack of information about certain care such as mental health care or diseases not included in predefined list is also mentioned.

Furthermore, some patients are still in the lists although they are not waiting. For example, in Spain, it was mentioned that patients who have undergone emergency surgery can be still on the list for scheduled surgery (ES).

### 3.10.3 Lack of confidence in data

We have already mentioned that even in countries where the recording of WT data is mandatory, there is often a lack of sanctions, which hampers assurance of comprehensiveness and accuracy of the data.

In Spain, problems have been reported with the data from Autonomous Communities. Although the collection method has been legally established, it appears that some Autonomous Communities do not follow it or even do not always provide information on WL to the Spanish Ministry of Health central authority. As a consequence, the information available can be considered as a proxy for the challenge posed by WL, but not state of the art or definitive.<sup>275</sup>

Some authors even go so far as to mention that there is a **risk of data falsification in the assessment and reporting of WT** according to particular stakeholders' interest.<sup>263</sup> This risk was reported in a study using



the Newcomb-Benford's Law (NBL)<sup>r</sup>, a mathematical model to test the validity of the WT data in Spain (from December 2003 to December 2015) and in Finland (from December 2007 to December 2012). The findings showed a suspicion of trustworthiness of the Spanish data, but not the Finnish ones.<sup>278</sup> The authors highlighted that *'A deviation from the NBL distribution does not provide conclusive proof of manipulation, just as conformity does not prove the cleanliness of the data. Rather, non-conformity should be seen as a signal flagging up data that need closer inspection and further testing. Benford's Law could thus be used in addition to existing control mechanisms as a first step in checking the possible manipulation of data'*.<sup>[5]</sup> Some reasons for data falsification are presented in the section 3.15.2.

In Stockholm, a survey among administrative management (n=11) and care professionals (n=17) between October 2017 and January 2018, showed that data providers themselves perceived **the validity and usefulness of the WT recor as low**. Several issues with the WT assessment were mentioned by the respondents: slow and insufficient feedback on results, lower value of the findings presented as numbers and percentages of patients not receiving care within the WT guarantee<sup>s</sup>, insufficient granularity of the medical conditions and exception codes...<sup>269</sup> Although Stockholm is not representative of the other 20 regions in Sweden, this is an observation particularly interesting that was translated by Ebbevi et al. in the following affirmation: *'caregivers' perceptions that the reporting system and the output data lacked validity and usefulness created a disincentive to report waiting times which, in turn, decreased the validity and usefulness of data'*.<sup>269</sup>

<sup>r</sup> NBL or Benford's Law or First digit law: the probabilities that the leading digits will be 1, 2 or 3 account for >60% of the total probability distribution. Although this law does not apply to datasets of truly random numbers (e.g. lottery), sequential numbers, assigned numbers (e.g. zip codes) and numerical series with some restrictions, many real world datasets do conform to an NBL first digit distribution.<sup>278</sup> Pinilla J, Lopez-Valcarcel BG, Gonzalez-Martel

### 3.11 Finding 10 – Barriers to the data collection system

Several barriers and challenges to the data collection were reported by the selected countries. Some of them were quoted also by Ebbevi et al. in Sweden (barriers to validity).<sup>269</sup>

- **Technical challenges** such as difficulties with automation in small institutions due to less capacity in their ICT system (e.g. no link between the electronic patient record and the booking system) and heterogeneity of ICT systems between different types of institutions (NL); data collection implies some **adjustments of** the ICT system and time to be ready.
- **Administrative burden** of the data collection (NL).
- **Procedural errors** or errors in the data caused by role divisions between actors and self-perceived/explicit job descriptions.<sup>269</sup>
- **Cognitive barriers** to validity such as misinterpretation of guidelines in terms of how to enter data<sup>t</sup>, situations not covered by guidelines or conscious sidestepping of guidelines such as using medically unnecessary revisit as starting date.<sup>269</sup>
- **Difficulties to choose time points for measurement** of waiting. For instance, current waiting times (i.e. people waiting today) might seem more attractive than retrospective data in terms of timeliness, but cross-sectional WT tend to underestimate the proportion of people with short waiting times when dropout is low, and overestimate it if dropout is high, as compared with retrospective 'true' WT.<sup>269</sup>

C, Peiro S. Pinocchio testing in the forensic analysis of waiting lists: using public waiting list data from Finland and Spain for testing Newcomb-Benford's Law. BMJ Open. 2018;8(5):e022079.

<sup>s</sup> Since then, median and mean are also presented in the WT results.

<sup>t</sup> With sometimes different starting date in treatments used in the same unit (referral date or medical pre-examination instead of the decision date



### 3.12 Finding 11 – Facilitators to the data collection

As for barriers, some countries presented positive experiences and key lessons learned that can provide facilitating elements for setting up a WT measurement system (CA, NL, SE, GB-ENG, GB-NIR). We added the Ebbevi et al.<sup>269</sup> propositions on concrete strategies to address the barriers mentioned above.

- Most of the quoted facilitators are related to the **technical aspects** for gathering the data: the use of **ICD-10 codes and consensus definitions** can contribute to the data quality (CA); **uniformity of the ICT system** (only a few ICT providers) facilitates harmonisation of the data collection (NL); **flexibility in the way** to collect data (e.g. automated or with Excel or manual) allows participation of each institution whatever more or less advanced ICT systems (NL, GB-NIR); **automated system for extraction**, simple and safe **portal for data transfer** facilitate data recording (NL). Automatization to minimise manual data entry but also integration of the existing parallel reporting systems and avoidance of parallel measurement infrastructures is promoted by Ebbevi et al.<sup>269</sup>
- **Minimal effort** by asking for only the necessary information and nothing more is a key element (NL). As Ebbevi et al. mentioned: *'Parsimonious performance indicator systems have a greater chance of delivering high quality data than voluminous systems.'*<sup>269</sup>
- **'Scenario' guidance** is quoted to assist the clinician in completing the form, for example, by proving specialty specific examples of each of the outcome options (GB-ENG). Ebbevi et al. highlighted that passive dissemination of guidelines in terms of how to register data is not sufficient for implementation but rather tailored implementation activities by local care providers based on potential barriers. They

suggested addressing barriers to implementation, monitor implementation and adherence to the guidelines, and alter the strategy if necessary.<sup>269</sup>

- **Spot-checks or external validity checks** are elements that enable quality improvement and can counteract manipulation.<sup>269</sup>
- **Active involvement of all stakeholders** appears to be very positive (CA). This can be useful to ensure that WT data are analysed and presented in a way that meets the needs of care providers and administrative management (not just to demonstrate whether targets are met); it can also allow the development of the IT ontology together with care providers which could ensure ease of use.<sup>269</sup>
- Meetings with data providers (such as the provinces and territories in Canada) to share and discuss practices have enabled mutual learning (CA).
- **Access to timely WT data with feedback loops** is crucial to stimulate the data providers.<sup>269</sup> Old data is of little value and continuous, real-time monitoring of waiting can be used for improvement.<sup>269</sup>
- **Using relative measures** for the WT performance assessment<sup>u</sup> (e.g. current WT compared in one region to their own WT in the same month in the previous year) allows to take into account the different conditions of each region (SE). This can be more stimulating for regions that cannot meet the performance requirement.
- **Umbrella organisations** can help to motivate institutions to provide their data by **explaining why data collection is important** (NL). For example, positive, motivating aspects of WT registration include the possibility of attracting patients by lower WT (NL). In Canada, the umbrella organisation has provided a segment over time, that has been

<sup>u</sup> In the model for the year 2020 in Sweden, the requirement was that at least 85% of the completed medical assessments in primary care should have taken place within three days but the majority of the regions did not meet the

performance requirement in any of the months. The investigation proposes that performance compensation based on a medical assessment within three days remains, but with a requirement that in primarily means an improvement in the region compared to the previous year.



used by the provinces to get a longitudinal perspective, from their data but also from the other provinces, all in the same place (otherwise each provincial website would have to be consulted independently) (CA).

- **Building progressively the system for WT recording is maybe helpful.** In Sweden, the National WT database was started around 2008, in order to be able to monitor and reimburse the performance program and also to be able to follow the adherence to the law. First, the database was very narrow and simple, almost like regions sending in excel files with their information. Step by step, the database has evolved over time, and become much richer with much more data, more details etc. allowing for more analyses (SE).

### 3.13 Finding 12 – Relative effect on timeliness

The aim of WT measurement is for many countries to support timely access to care. This chapter reports our findings on this issue. We mention the maximum WT and targets, the waiting lists and prioritisation system, possible actions for respecting the timeliness and the importance of patient information on this topic.

#### 3.13.1 Definition of maximum waiting times and targets

WT guarantees are a common solution to address excessive WT. These policies state the right of patients to receive care within a certain time and are often formulated as a predetermined maximum WT for patients. The objective of WT guarantees is to provide care on equal terms and within an appropriate time to the population and to ensure that healthcare is accessible to those in need.<sup>279</sup>

Each of the 9 selected countries has defined maximum waiting times. They are **ruled by the law** in 7 of them (FI, SE, ES, 4 countries of the UK). In Canada, each province made a commitment to respect one maximum WT for one priority clinical area but without sanction if not respected. In the Netherlands, the 'Treek norms' or maximum acceptable guarantee serve as a benchmark for evaluation of waiting times and as an informal guideline for doctors. It is interesting to mention that a maximum waiting times guarantee for hospital care, considered in 2001, was not introduced in the Netherlands

because it would increase bureaucracy and administrative burden and because it would be costly to operationalise (NL).

There are no maximum WT for all measured WT as shown in **Figure 5**. The maximum WT depend on the application areas (primary care, specialised care, surgery, mental health care, cancer...) and the type of care (need assessment, diagnosis, treatment...). Figure 5 presented maximum WT as mentioned by the selected countries. Because of the various start and end point of each WT, it is not possible to compare the 9 countries. This **wide variation between countries** was already mentioned in the literature.<sup>263,279</sup> Even within the UK, there are some small differences in the targets such as the 18 weeks for RTT which must be met by 92% of the population in England but 90% in Scotland, or the cancer waiting times for the first definitive treatment which must not exceed 62 days from referral for 85% of the population in England, 95% in Scotland and Northern Ireland, but 75% in Wales. For some authors, the targets that each country has set itself for scheduled care reflect the WT situation *'by necessity, the worse the waiting times, the less ambitious the target'*.<sup>280</sup>

In countries where the organisation of the health care is decentralised, there are sometimes **different maximum WT between regions**. In Sweden, for example, regional healthcare providers can have local policies for shorter waiting times which leads to variation between Swedish regions. This is the case in the Stockholm region where there is a target of a maximum waiting time of 30 days (instead of 90 days) for appointments in specialised care (measured from the decision to refer to a specialist to the first appointment) (SE). In Canada, it is up to each province and territory to decide whether or not to respect the maximum WT, and waiting lists can be established by a practice, a hospital, or a region, on its own initiative.



It was not easy to understand the basis on which the maximum WT were defined. This appears to be mostly **based on consensus** and poorly evidence based. In Spain, the RD 1039/2011 of 29 August 2011<sup>281</sup> proposed a set of **maximum waiting times for surgical interventions, imposed/suggested by the central government and** prepared in 2010 with the **active participation** of the Communities Autonomous, within the Benefits, Insurance and Financing Commission, dependent on the Interterritorial Council of the National Health System. In the processing of this standard, it has also been subject to consultation with the sectors concerned and the Council of Consumers and Users. According to the Royal Decree 1039/2011, the maximum WT should be reviewed periodically to be adapted them, with the prior agreement of the Interterritorial Council of the National Health System, to the health reality of each moment, to the socio-economic situation and the needs of the users of the National Health System. A revision of this list was performed for example in 2015 in Catalonia with the removal of some interventions and the addition of others (ES). In Canada, the WT benchmarks were developed through provincial, territorial and federal collaboration: discussions took place between clinicians and researchers in expert panels. Processes varied by priority clinical area. Benchmarks for hip and knee surgery were derived both from the literature and from a consensus of experts attending to the meetings, who agreed on 'medically acceptable waiting times'; no benchmarks were defined for the imaging procedures due to the heterogeneity of the diseases. No benchmarks were decided for cancer care (CA). In the Netherlands, the maximum acceptable waiting times were agreed upon by healthcare providers and health insurers at a consensus meeting in 2000 at the 'Den Treek' Estate (NL).

There are exceptions to the WT guarantee. For example, in Sweden, exceptions to the maximum target can be made on medical grounds known as medically motivated waiting (e.g. when a complicating co-morbidity temporarily prohibits a planned scheduled treatment) or when patients actively choose to wait longer (e.g. when the patient declines a booking or a certain professional) or when the patient chooses to change care provider for the same health problem. In these cases, the WT episode is given a label known as an exception code. This means that there is no time limit in, or monitoring of, the waiting times.(SE)

In Finland, negative sides of the healthcare guarantee are evoked. For example, the WT guarantee might **not be tolerable for all patients**. The lack of **evidence-based information on appropriate WT** is problematic. Furthermore, a WT guarantee is an ideal that is difficult to achieve at a national level **when the population density is unevenly distributed**.<sup>282</sup>

### 3.13.2 Establishment of waiting list with system of prioritisation

The generally accepted criterion for healthcare waiting times is that patients should be prioritised according to the nature of their clinical condition ensuring that patients with higher severity are treated more quickly, and long waits are concentrated among those who can afford to wait.<sup>30</sup> For example in Spain, beside the maximum WT clearly defined for some surgeries (see section 3.4.2), there is no guarantee for the remaining scheduled surgeries, but there is a maximum reference waiting time 'which is the maximum time that patients should wait given their health characteristics and priority in the list'. This maximum waiting time can be of 90, 180, and 365 days depending on priority criteria (ES).<sup>283</sup>

However, few countries have mentioned the use of a formal prioritisation system to class patients waiting for care (ES, CA, GB-ENG). In Spain, indicators for an **adequate prioritisation** of patients on the National Health System waiting list are defined in the law for non-urgent outpatient consultations, diagnostic/therapeutic tests and scheduled surgical interventions (RD 605/2003). However, in practice it is not used as such. For example, waiting lists for surgery are managed by the specialists who decide whether and when a patient has to be added to the waiting list for surgery. Patients are added to the waiting lists not only based on prioritization criteria such as disease severity, disease progression or limitation of daily life activities but also on non-explicit prioritization criteria, decided by each physician and hospital (ES). In England, there is some guidance on how to prioritise patients for surgical waiting lists within five categories, four related to scheduled care and one to emergency patients).<sup>284</sup>



The fundamental problem mentioned in Sweden and Spain is that it is **difficult to find variables that satisfactorily describe the patient's medical needs**, which is essential information to be able to decide if patients are prioritised according to their needs or on other grounds. For example, the effect on quality of life, the risk of complications during the wait, the clinical effectiveness of the intervention, the use of resources and health care services during the wait are criteria to consider.

### 3.13.3 Possible actions for respecting timeliness

Even in countries where maximum WT are not ruled by the law as in the Netherlands or Canada, patients have a right to a standard of timeliness of care and action can be taken when there is (a risk of) exceeding the WT targets. Several modalities are described for respecting the maximum WT, most often by allowing patients to choose alternate providers.

In several countries, **service providers**<sup>v</sup> such as regions or NHS are directly accountable for providing care within appropriate time limits or propose alternatives to patients (ES, CA, SE, FI, UK). In Sweden for example, the region that does not fulfil the WT guarantee must ensure that the patients receive care from another care provider at no extra cost to the patient. In practice, the way regions work to help patients find another provider varies. In Stockholm for example, services in specialised care that cannot be maintained in the time limits of the waiting times guarantee are reported to the specialist clinic's contract administrator through a computerized system. A specific regional support function (e.g. Region Stockholm's Care Guarantee Office) helps patients change care providers when long waiting times occurred.<sup>279</sup> However, in Sweden, it is also reported that the patients themselves are responsible for finding another care provider.<sup>279</sup>

Alternatives may be sought within the same hospital network, as in Spain, where the Catalan Health Service can transfer patients to other hospitals, while transfer patients to a hospital of another region is very difficult (ES). In Scotland, if treatment has not started within the WT guarantee, the health board responsible for the patient should arrange the treatment, including outside the board's area (GB-SCL).

Alternatives can also be bought by health care providers. In Finland for example, if the health care providers service fails to offer care within the delay fixed in the law, the service must purchase the care in another health care district or in a private health care clinic. Patients waiting for care receive a service voucher<sup>w</sup> and are placed on the waiting list of the specialised care unit of a purchaser. Sometimes the treatment might even be purchased from abroad (FI).

**A national authority** can be responsible for supervising the timeliness of care. In Finland, the Finnish National Supervisory Authority for Welfare and Health (Valvira) and Regional State Administrative Agencies (AVI) have this mission. When the patient or a next of kin finds that the rights to be seen within the WT guarantee have been violated, the person can file a written objection to the manager in charge of the healthcare centre both in primary care and specialised medical care. The manager has to investigate the case, find a solution to meet the requirements of the law and give a response in about one month. If the person who made the objection is not satisfied with the response, the person can file a complaint with a relevant Regional State Administrative Agency (AVI). In cases of death or severe and permanent injury caused by possible malpractice, a person can file a complaint to the National Supervisory Authority for Welfare and Health (Valvira).

Several countries mentioned **economic sanctions** (such as fines for HCPs not respecting WT) but this appears to be rarely used in practice (SE or FI)<sup>269</sup>

<sup>v</sup> In the Netherlands, this responsibilities is assigned to the health insurers (NL).

<sup>w</sup> A service voucher is a commitment given by the county to the recipient of social and health services to reimburse the cost of the service provided up to a predetermined value.



In Finland, both AVI and Valvira, based on their own findings or a person's complaint, can set an order to the healthcare unit to respect the deadline and also can enhance the order with a **threatened fine**. The authorities can also forbid or interrupt the operation of the healthcare unit.<sup>282</sup> In Sweden, it is up to each region to decide if they want to define a sanction. Some of them, like Stockholm, had this but if sanctions still exist, they are rare. It's more like that the region/county council as a whole receives less money from the government if they do not reach the set limits for waiting times. In England, financial sanctions were defined initially but have been gradually removed from the Standard Contract for waiting time standards (GB-ENG).

In Canada, there are no WT guarantee, and no financial or other penalty is imposed on a jurisdiction if the benchmark is not met, but as noted above, waiting times are publicly reported on the CIHI website which can be a motivation to respect the proposed maximum WT (CA).

**Patients themselves** can ask actions when they consider their waiting time to be too long (FI, NL). In Finland, as mentioned above, patients can file a complaint if they are not satisfied by the WT situation (FI). In the Netherlands, patients considering their waiting time to be too long, can ask their health insurer for 'waiting list mediation' to be helped more quickly in another hospital or ZBC.<sup>271</sup> This works as follows: patients can contact their health insurer by phone or email, who will then investigate the willingness of the patient to travel and check in alternative hospitals or ZBC, capable of providing the appropriate treatment, whether the patient can be treated earlier. Sometimes an appointment is made by the health insurer, but mostly the insurer only informs about the possible alternatives and patients are free to accept (or not) one of the alternatives (NL).

In several countries, patients can also decide to go to the private sector at their own expense (out-of pocket or private health insurances) (see section 3.15.1).

<sup>x</sup> This mechanism has to do with the benefits of a queue for the care provider, as it ensures there will always be patients waiting to be treated and source of

### 3.13.4 Importance of patient information on possible actions

Patients' knowledge of the waiting times guarantee and their right to timeliness access to care imply that patients receive individually adapted information about their rights and how to navigate the health system.<sup>279</sup>

Few countries mention an **obligation for healthcare providers to inform patients on the possibility of waiting time mediation** such as when the Treek norms are exceeded in the Netherlands.

According to Casales Morici et al., it appears that patients are not well informed by care providers about the waiting times guarantee. Known causes are care providers' disincentives to offer information and the inherent methodological difficulties of providing valid and updated information on waiting times in a relevant and understandable format for the patient.<sup>279</sup> This is confirmed in Spain, where the public information available, with some exceptions, is considered as partial, excessively aggregated (no individualized information in real time), and therefore not helpful to the patient (neither to choose center nor to make plans), or even increasing their anxiety (ES).<sup>275</sup> In Sweden too, there have been concerns for several years regarding the degree of patient information and provided support on WT guarantee. Great variation between care providers (with sometimes no information), inconsistent information and support, and information and support not adapted to health literacy or individual patient needs are mentioned.<sup>279</sup> Soft-law regulations and care contracts seem insufficient, and economic mechanisms undermine care providers' willingness to inform patients<sup>x</sup>. There is also a lack of established routine to assist care providers in informing patients.

While **waiting list** statistics help with monitoring health service capacity and are thus often preferred by healthcare providers, from the point of view of the public and prospective patients, **waiting times** statistics give a better indication of the duration people are expected to wait to access treatment.<sup>263</sup> Patients are interested in knowing in real time how many days or weeks they

incomes.<sup>279</sup> Casales Morici B, Augustsson H, Hasson H, Ebbevi D. Information and support to patients when the waiting time guarantee cannot be fulfilled: a qualitative study. *Int J Equity Health*. 2023;22(1):130.



still have to wait. The number of patients in front of them in the queue, their position, is of less interest to them. The indicators 'proportion of patients waiting' is not so interesting (and may be not accurate as mentioned above). Specialties related to frequent pathologies are in greater demand, so they accumulate a greater number of patients.<sup>276</sup> For example, in Spain more than 250 000 MRIs are performed monthly. Having the seemingly huge figure of 75 000 people ahead in the queue would imply a discreet average wait of a week. For obesity surgery, a much shorter queue could mean many months of waiting since they only perform around 5 000 interventions per year (ES).

However, it is not so easy to find the appropriate websites giving information on waiting times and the quality of this information is not always optimal. Sometimes, publishing waiting times was performed to comply with the law rather than provide information to citizens.<sup>285</sup>

### 3.14 Finding 13 – Common evolution over time

According to OECD, the main reason for unmet needs for medical care was typically waiting times, with 1.4% of people reporting this issue in 2021, on average across 26 OECD countries but with more than 4% of the population cited waiting times as a barrier in Finland.<sup>286</sup>

It is not clear if the WT measurement, waiting lists development and maximum WT definition allow to manage the timeliness of access to care. The Finish experience was promising. After the National Health Care Guarantee from 2005, a significant reduction in waiting times was observed for primary and specialised medical care (e.g. for hip and knee replacement and cataract surgery, while the number of surgery increased, the waiting times decreased).<sup>282</sup> It appears that the penalty fine given by the Regional State Administrative Agency had a positive effect on hospital districts where

the maximum waiting times were not respected. However, the improvement was not necessarily long-lasting, and some hospital districts fell back to the same situation with too long waiting times after the threat of getting a penalty fine was lifted. Between 2015 and 2019, waiting times for specialised care were relatively stable (with around 80% of people have WT under 90 days and 1-2% over 180 days).<sup>282</sup> The COVID-19 pandemic changed the trend with an increase of people waiting over 180 days up to 10% in 2022 and consequently the shares of shorter waiting times decreased.<sup>282</sup> Furthermore, there is, between the year 2010 and 2019, a persistent record of more than one percent of patients that waited longer than 6 months (which exceeds the Health Care Act's (1326/2010)), especially in specialised care.<sup>282</sup> A study published in 2014 and quoted by Haiko et al. concluded ineffectiveness of policies such as healthcare guarantee, presenting the decline in patient satisfaction and accessibility between 1988 and 2011.<sup>282</sup> Looking at the other countries, we can notice that WT tends to increase over time, even before the COVID-19 pandemic<sup>y</sup>. It is the case for example in the Netherlands where between 2013 and 2017, the percentage of hospital departments exceeding the WT standards increased (Figure above).<sup>287</sup> In 2023, the waiting lists are so long that the duty of care is considered to be under pressure (NL).<sup>288</sup> In Spain, between 2006 and 2021, the temporal evolution showed a worsening both in the proportion of patients waiting for a first consultation with a specialist and in the duration of waiting times, which has only been exacerbated by the arrival of SARS-CoV-2 (ES).

Even in the case of eventual WT improvement, it is difficult to determine if this is due to systematically improved work or merely the administrative aspect. For example, in Sweden, in the final reporting of the assignment to follow up the care guarantee, the National Board of Health and Welfare stated that the queue billion had been a powerful incentive to get the county councils (currently the regions) to focus on measures against long waiting

<sup>y</sup> In the majority of countries, the COVID-19 pandemic and in particular the backlog caused a worsening situation in waiting times and waiting lists. It is for example noticed in Spain, in Canada.<sup>276</sup> Bernal-Delgado E, López-Valcárcel BE, Peiró S, Pinilla J. Revisitando las listas de espera sanitarias (2): Análisis de los datos. [Web page].2023. Available from:

<https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/revisitando-las-listas-de-espera-sanitarias-2-analisis-de-los-datos>, 277. López-Valcárcel BG, Oliva J, Jiménez JL. Las listas de espera hospitalarias en España. [Web page].2021. Available from: <https://nadaesgratis.es/beatriz-gonzalez-lopez-valcarcel/las-listas-de-espera-hospitalarias-en-espana>



times. The number of patients who were waiting for a visit or a treatment in specialised care decreased between 2009 and 2011, and fewer and fewer of those waiting had a waiting time of more than 90 days. However, it appeared also that this improvement had partly occurred at the expense of other patient groups' waiting times, as a result of changed priorities and referral routines.<sup>289</sup> There is for example the risk of crowding out patients with greater needs and with chronic diseases.

### 3.15 Finding 14 – Potential perverse effects of the waiting time management system

We identified potential perverse effects of the WT management system on three levels: risk of inequity for the patients, risk of use of WT data by HCPs according to their interest and risk of statistics misuse by the authorities. These three kinds of risk are described below not to be comprehensive but for showing the negative side of WT measurement.

#### 3.15.1 Inequity for patients

As shown above, in countries where WT guarantees are defined, it is often expected that health care providers (region, NHS, etc.) propose an alternative to the patients when WT risk to exceed or is exceeding the maximum WT. But there is also the possibility for patients to avoid long WT by opting out of the public health system, purchasing private health insurance or increasing out-of-pocket expenses (ES, UK).<sup>78</sup> More globally, the worsening of waiting times in the public network appears to lead to an increase in private insurance.<sup>290</sup> This can lead to a risk **of inequity** in health care (ES, UK, SE). The probability of voluntarily exiting the waiting list is indeed larger for patients with higher socioeconomic status (SES) compared to lower SES.<sup>283</sup>

However, even within the public system, patients' situation can differ according to their SES. One study based on administrative data 2015-2019 from Catalonia<sup>283</sup> showed that people with medium-high SES (based on co-payment levels for medicines which depend on patient's income) wait less time for some surgeries than those with lower socioeconomic levels, i.e. less by 6.1 days for hysterectomy, by 4.8 days for hip replacement, 2.4 days for

cataract surgery and 0.5 days for breast cancer surgery.<sup>275, 283</sup> This issues has been already mentioned in another Spanish study from Abasolo et al in 2014 who found that individuals with lower education and income levels waited significantly more time than their counterparts for specialised care.<sup>291</sup> A recent study based on the Spanish Health Barometer survey for the year 2010-2019 confirms the presence of a robust SES gradient (mostly on the basis on education) in access to specialised but also primary care.<sup>78</sup> This Socioeconomic inequalities in waiting times for primary care (patients with higher income tending to wait less) was already reported in Canada, Germany, Norway and Sweden across ten OECD countries studied.<sup>292</sup>

In the UK too, research covering the period April 2020 to July 2021 indicated that patients in the most deprived areas were nearly twice as likely to wait more than a year for treatment than those in the least deprived areas.<sup>293</sup>

Inequity can be explained by several factors beside the option to search treatment in private hospitals. According to a UK report published in November 2023, *'there are structural, economic and social factors that can lead to inequalities on elective waiting lists'*.<sup>293</sup> For example patients with a higher SES may have a higher health literacy level, better understanding the situation and being more familiar with the administrative processes to access specialist services, put pressure to the provider through frequent phone calls or rely on informal channels (e.g. knowing someone working at the hospital) or even take more rapidly legal actions if delays become significant.<sup>292</sup> In Sweden, even if it is against local law, it is not uncommon for healthcare providers to make some patients responsible for finding a new provider or arranging a new referral if the waiting time exceeds the guarantee. As finding appropriate information is not easy, even with a digital platform that displays waiting times, this process is seen as a risk of exacerbating inequalities in health care.<sup>279</sup>

Some groups are also less likely or less able to seek healthcare. For such groups, initiatives to reduce demand for scheduled care, in particular a move to require patients themselves to initiate certain types of follow-up appointment, could exacerbate inequalities. Difficulties in attending appointments are also associated with lower SES in the UK. This can be



related to the fact that people with high SES may be more likely to have more flexible jobs.<sup>292</sup>

Patients with high SES may also live in areas where hospitals have higher capacity or higher availability in primary care.<sup>292</sup> Furthermore, as mentioned above, patients with higher SES have a lower probability of having a surgery cancelled for medical reasons, it is also possible that lower SES patients have more delays (by sickness) in their pathway because they have worse health.<sup>283</sup> This is also quoted in UK, where *'people from more deprived areas are more likely to have multiple health conditions, deteriorate more quickly, develop complications while they wait and experience worse health outcomes'*...<sup>293</sup>

### 3.15.2 HCPs interests

Another perverse effect of the waiting lists and the WT guarantees is mentioned in Spain. In some places when a waiting list is too large, physicians are eventually hired to do extra work and are paid by activity performed (fee-for-service). But this solution should even be counterproductive, as has been seen in the past with the so-called 'peonadas' (payments per act to professionals to take care of patients waiting outside their usual hours, which can generate perverse incentives in the distribution of time and intensity of care). The risk is that physicians perform less in the ordinary day to keep the waiting list at levels high enough to maintain the source of additional income.<sup>290</sup>

Furthermore, having a queue can be a way for physician to select the more interesting cases or to be seen by the public as a good doctor. In a context of competition and choice by patients, typical for private systems, waiting list can even be interpreted as a sign of quality or prestige (as is the case with high prices).<sup>275</sup> HCPs could also manipulate data for receiving more or less patients depending of their agenda.<sup>288</sup>

### 3.15.3 Statistics misuse by authorities

Since the COVID-19 pandemic, national authorities are under pressure regarding the topic of WT and waiting lists. In countries with publicly funded National Health Systems, large waiting lists erode the confidence of citizens in the health system, its leaders, and its professionals. As one author evoked: *'As the numbers describing diminishing waiting lists are taken as a noticeable signal of 'success' in healthcare policy, waiting lists management may be more focused on offering appealing short-term 'numbers' than developing coherent long-term solutions consistent with the complex nature of the WL problem.*<sup>z,278</sup>

Therefore, there is a potential temptation for some authorities to play with these numbers. One example is by using administrative updates to present a 'successful' decrease in waiting lists size, without ensuring that the patient no longer requires the intervention he/she was waiting for.<sup>278</sup>

## 3.16 Finding 15 – General consideration of the waiting time as such

One question mentioned by some authors is the **real meaning of WT**. Staying on a waiting list for a few weeks, or a few months, may or may not be a serious problem depending on factors as the severity of the situation (if patients suffer from pain, if it is intense and disabling, if they are in charge of other people, if there is a risk of sequelae or danger to life, etc.), the degree of urgency of the intervention (speed with which it is required) etc.<sup>277</sup> There are lists in which many patients should not be included (because the intervention is no more recommended for their disease, or because more accessible alternatives exist, or because natural evolution is possible).

<sup>z</sup> It is not the aim of this study to provide the solutions to manage this complex topic which encompass an increase of workforce, equipment, facilities, better triage, more efficient scheduling system



It is also important to mention that current information systems are focused on the offer and do not allow monitoring the evolution of the problem from the **patient's experience** throughout its care pathway (through several services successively).

At the management level also, waiting times and waiting lists raise questions. With limited resources, improvement seems difficult to achieve only by controlling demand or increasing productivity. Both strategies are costly for providers. Although governments can ask providers to work more efficiently, this may be counter-productive and come at the cost of lower quality, staff dissatisfaction and low morale. Setting **realistic maximum waiting times** compatible with available budgets is suggested.<sup>30</sup> For some, together with reducing waiting times, it is time to help people understand and manage their conditions, and to feel supported while they are waiting for treatment.

#### Box 5 –Different healthcare systems with some common features

##### Universal health coverage

Universal coverage for a core set of services in healthcare is guaranteed by a large majority of countries in the world.<sup>286</sup> In the 9 selected countries for this study, the percentage of healthcare costs covered by government or compulsory health insurance schemes ranges from 71.6% in Spain to 85.9% in Sweden. This is close to the OECD average of 75.9% published recently and based on data from 2021 in 28 OECD countries.<sup>294</sup> In Belgium, 77.6% of the health expenditures are covered by compulsory health insurance schemes.

##### GDP dedicated to health care

The OECD average part of gross domestic product (GDP) dedicated to health care is estimate at 9.3% in 2022. All of the 9 countries have a higher one with the most important in the UK (11.3%) and Canada<sup>aa</sup> (11.2%).<sup>286</sup> This is also the case in Belgium who spends 10.9% of the GDP to health care.

##### Private insurances

In many countries, voluntary private health insurance is available to provide additional health coverage. The OECD distinguishes between coverage of any cost-sharing remaining after basic coverage (complementary insurance), additional services (supplementary insurance), or faster access or a wider choice of providers (duplicate insurance). The average for the 28 OECD countries in 2021 was 41%.<sup>286</sup>

There is a great variation among countries regarding the proportion of citizen covered by private health insurance. Among the 9 countries, Sweden, UK and Spain show lower private health insurance coverage (respectively 7, 11 and 15%) while Canada and the Netherlands have the highest (respectively 69 and 85% both for supplementary services).

##### Healthcare resources

Density of GPs in 2020/2021 ranges from 0.61/1000 population in Sweden and 1.39/1000 in Finland.<sup>294</sup> There are 1.2 GPs/1000 population in Belgium.

Density of medical specialists in 2020/2021 is around 2/1000 with the lowest in Canada (1.47/1000) and the highest (2.78/1000) in Spain. There are 2 medical specialists/1000 population in Belgium.

<sup>aa</sup> In 2023, health expenditure was projected to account for 12.1% of Canada's GDP. In 2023, health expenditure was projected to account for 12.1% of Canada's GDP (<https://www.cihi.ca/en/national-health-expenditure-trends>)



Among the 9 countries, Spain has the lowest density of nurse with 6.3 practicing nurses for 1000 in 2021 (but also many healthcare assistants) and Finland the highest density with 18.9/1000 in 2020.<sup>286</sup> The definition of practicing nurses focuses on those providing services directly to patients but in some cases those working as managers, educators, researchers or even midwives (e.g. in Spain) are included.<sup>286</sup> The OECD average of practicing nurse in 2021 was 9.2/1000 population. In Belgium, 11.1 practicing nurses/1000 was estimated in 2018.

The number of hospital beds provides an indication of resources available for delivering inpatient services. The OECD statistics include beds in general hospitals, mental health and substance abuse hospitals, and other specialty hospitals. Across the 28 OECD countries, there were on average 4.3 hospital beds per 1 000 people in 2021. Over half of OECD countries reported between 3 and 8 hospital beds per 1 000 people. The density of hospital beds in the 9 countries ranges from 2 to 3/1000 population. Data for some countries do not cover all hospitals. In the United Kingdom, data are restricted to public hospitals and in Sweden, private beds that are privately financed are excluded.<sup>286</sup> In Belgium, the density of hospital beds is 5.5/1000 population.

In the Health at a glance in 2023, the OECD highlights the uneven local distribution of health care resources in Spain and in Finland.<sup>286</sup>

- Primary care role

**GPs** act as gatekeepers in almost all of the 9 countries except in Sweden.

Access to primary care can start by nurse consultation in Finland and Sweden. Nurses are allowed to carry out a first triage in Finland or to perform consultations (with authorisation to prescribe some medicines) in Sweden.

- Specialised care

Most medical specialists work for outpatients and inpatients in hospital (Canada, the Netherlands, the UK). Charges are negotiated and cannot be exceeded (except in Spain where extra can be done in certain conditions).

- Health status indicators

The 9 selected countries have a life expectancy in 2021<sup>bb</sup> exceeding the OECD average of 80.3 years with the highest ones noticed in Spain (83.3y) and Sweden (83.1y).<sup>286</sup> The avoidable mortality rates (from preventable and treatable causes) are lower for the all 9 countries than the OECD average of 237/100 000 in 2021. However, with the exception of Spain, all data are older than 2021 with even data from 2018-2019 in Canada (171/100 000) and in Sweden (150/100 000).<sup>286</sup>

In Belgium, the life expectancy was 81.9 years in 2021 and avoidable mortality in 2018-19 reached 178/100 000.<sup>286</sup>

<sup>bb</sup>Except for UK data, which is from 2020



## 4 WAITING TIME ASSESSMENT IN THE BELGIAN HEALTH SYSTEM

### Key points

#### Time measurement initiatives in Belgium

There have been several time measurement initiatives in the Belgian healthcare system. Nine main experiences are reported. Of these, 4 focused on time to get a consultation with a care provider, 1 reported on time to imaging and 4 dealt with time to treatment (i.e. surgery, radiotherapy or chemotherapy).

#### Time to consultation

Self-reported time to consultation by patients was used in two surveys. The first is a large-scale Health Interview Survey (HIS), which assessed the health of the Belgian population every 4 to 5 years.<sup>295</sup> During the interview, a representative sample of the Belgian population was asked, among other things, about the time it took to consult a GP or a specialist in the previous 12 months. Between 2013 and 2018, the proportion of citizens experiencing WT as a problem increased for both GPs and specialists.<sup>296</sup> The second survey was an one-shot online survey conducted in Flanders among 1 600 healthcare users who had sought help for mental health problems in the previous 2 years, either for themselves or for a child. Reported WT was longer for subsidised ambulatory care compared to residential care and longer for children and adolescents than for adults. During the experienced WT, complaints increased for half of the respondents.<sup>297</sup>

Self-reported time to consultation by healthcare professionals was used in a one-shot survey commissioned by the Federal Health Authorities.<sup>298</sup> Cardiologists, geriatricians, psychiatrists, gynaecologists, radiologists in private practice, and medical directors of hospitals were asked about WT defined as the number of days between the request for an appointment for an initial consultation and the date of the scheduled (non-urgent)

consultation. Participation was voluntary, resulting in a low response rate (23%). The results showed a large variation in WT, depending on the medical specialty and the district considered.

The unique systematic registration of WT took place at the Centra Geestelijke Gezondheidszorg (CGGs, centres for mental health care in Flanders). Two types of WT are measured: WT before a first face-to-face (FTF) interview in a CGG and WT between first FTF contact and treatment. WT before a first FTF contact in a CGG was 50 days during the period 2018-2021 and 41 days in 2022, while WT between first FTF contact and treatment was 53 days in 2018, 58 days in the period 2019-2021 and 48 days in 2022. Average WT for children is generally longer than for adults.<sup>299</sup>

#### Time to diagnostic (or imaging) procedure

The IMA/AMI attempted to estimate the WT for CT, MRI and PET scans using mandatory health insurance billing data from 2010 to 2015.<sup>300</sup> WT was defined as the number of days between the date of the last contact with the prescriber of the procedure and the date of the imaging procedure. When comparing WT between 2010 and 2015 (data as not updated), the results showed an increase in WT regardless of the type of imaging procedure. Variations in WT were found between regions. A significant proportion of WT could not be calculated due to the unscheduled nature of some imaging procedures. It should also be noted that these data do not relate to the quality of the procedures performed and that some PET scans were performed under nomenclature codes other than those listed, so the data may not be complete.

#### Time to cataract surgery

IMA/AMI attempted to estimate the WT for cataract surgery, based on billing data. The WT was defined as the number of days between the date of the decision to treat and the date of surgery.<sup>301</sup> The date of surgery was defined as the date on which one (or two) cataract procedures were recorded in the mandatory health insurance billing databases, and the date of the decision to treat as the date of the last consultation with the



ophthalmologist who performed the cataract surgery. If no such consultation was recorded in the National Health Service billing databases, the date of the last consultation with another ophthalmologist, another specialist or a general practitioner, in order of preference, was used as the date of the decision to treat. In 2015, the mean WT for cataract surgery was 39.7 days (median 27 days, P75 50 days). This WT has remained stable since 2010. It should be noted that, in the case of elective surgery, a long WT is of little value; it is not a minimum WT that should be sought, but a reasonable one. However, it is important to know whether the few really urgent cases are dealt with quickly. The assumption that the most recent date of consultation was the one at which the decision to operate was made, may be a bias.

### Time to treatment

Time to treatment was analysed as a quality indicator in the KCE reports for lung cancer<sup>302</sup>, head and neck cancer<sup>303</sup> and ovarian cancer.<sup>304</sup> Time to treatment was estimated based on mandatory health insurance billing databases. Time to first treatment and time to postoperative treatment were analysed. The proportion of patients treated within the targeted time frame was calculated. Time to first active treatment was defined as the number of days between the date of diagnosis (biopsy or imaging) and the date of initiation of treatment (surgery, chemotherapy, radiotherapy or targeted therapy) with curative or palliative intent. Time to postoperative chemotherapy and/or radiotherapy was defined as the number of days between the date of surgery and the date of initiation of postoperative chemotherapy and/or radiotherapy. The targeted time frames were based on the available evidence, which was discussed with experts.

### Limitations of the time assessment in Belgium

There is only one systematic registration of WT in Belgium. This registration focuses on mental health services in Flanders. The other data collections to assess WT were based on one-shot or repeated surveys, or on billing databases. Several limitations of such approaches have been identified.

Surveys providing self-reported estimates of WT are questionable as they are not based on objective measurements and may be affected by recall bias or low response rate (see time to consultation above). Nevertheless, they can be informative in analysing trends in the data to show deterioration or improvement in the time taken to see a healthcare professional and give information on the patients' perception of the WT.

Three main limitations were identified when using billing data.

- Firstly, the data used were generally old, as it took several years to obtain the full data set and eventually to link with other databases (see examples in oncology where linkage was made with the Belgian Cancer Registry). However, linking billing data with other administrative data increase the opportunities to analyse potential confounding parameters.
- Secondly, the date of the decision to treat is not recorded in the billing data. Therefore, researchers have to use proxies such as the last billed consultation. Without a link to medical records, it is impossible to link the billed consultation to the decision to treat. This can have a large effect on the WT estimate.
- Finally, because there is no link between billing data and medical records, it is also impossible to adjust the WT estimate for potential confounding factors such as the level of urgency, the need to delay the intervention for medical reasons such as the presence of comorbidities, or for practical reasons such as the availability of practitioners, the availability of facilities, the patient's personal or professional preferences.



The Ministry of Health (FOD VVVL/SPF SPSCAE) previously organised data collection regarding the response times of emergency services, i.e. ambulances, emergency mobile service (MUG/SMUR) and paramedical intervention team (PIT). The registration for MUG/SMUR and PIT has been stopped since 2020. The registration was maintained for ambulance. The time is recorded at several intervals to calculate the intervention times of the ambulances and the total duration of their missions.<sup>305</sup> These assessments are not further discussed as WT for the emergency services are out-of-scope of this report.

We have identified several initiatives of WT assessment in Belgium initiated by Sciensano, the Planning Unit for the health professions (FOD VVVL/SPF SPSCAE), IMA/AMI, the mental health sector in Flanders and the oncology care sector. All these initiatives are reported below. In addition, during the interviews (see chapter 0), we identified some local initiatives to evaluate WT in hospitals and in private practices of healthcare professionals. In hospitals, a retrospective analysis of pre-existing databases was used while surveys in healthcare professionals were used for the assessment of WT in a practice or in a specialty. However, these initiatives were not published in reports or peer reviewed journals.

## 4.1 The Health Interview survey (Sciensano)

Since 1997, Sciensano has organised a large-scale Health Interview Survey (HIS) every 4 to 5 years. The most recent retrospective data collection took place in 2023 and the results will be published in 2025.<sup>295</sup> The latest data available are those that report on the situation observed in 2018 and were collected through a survey of approximately 10 000 people in Belgium.<sup>167</sup> The aim of the HIS is to provide an overall picture of the health status of the population in order to inform evidence-based health policies, to reduce health inequalities between the different population groups, and to ensure an accessible and tailored health care system. Based on this information, the decision-makers and the researchers can identify health priorities.<sup>295</sup> As WT is an indicator of access to care, people are asked about the time they had to wait for an appointment with a GP and a specialist. The HIS also reported WT in the waiting room. As WT in the waiting room is out-of-scope in this study, it is not further discussed.

### 4.1.1 *Waiting time for an appointment with a GP*

The 2018 HIS results showed that 6.2% of the respondents consulted a GP without an appointment, while 51.7% had a same-day appointment. These proportions were 12.6% and 57.3% respectively in 2013, showing a deterioration in immediate access to a GP between the two surveys (see Table 3).<sup>296</sup> When focusing on long WT (i.e. WT of one day or more in 2018), there was no effect of gender, income quintile or age category, although two age categories (55-64 and 75+) appeared to be more likely to experience long WT (see Table 4).

Among respondents to the 2018 HIS, 3.9% perceived the WT as problematic compared to 1.4% in 2013.<sup>296</sup> The longer respondents had to wait for an appointment, the higher the proportion who found the delay problematic. In 2018, 5.0% of the respondents who had waited until the next day for a GP appointment, perceived the delay as problematic, while this proportion was 23.8% for those who had waited more than two weeks. The highest proportion (i.e. 26.8%) of respondents who perceived WT as problematic, was observed in the category of respondents who had waiting just under a week. Regional differences were observed in the proportion of patients for whom WT was problematic. The highest percentage was observed in the Brussels-Capital Region (5.2%), while it was 4.1% in Wallonia and 3.1% in Flanders. Compared to 2013, the percentage has increased in the Flemish and Walloon regions but remained stable in the Brussels-Capital Region.

### 4.1.2 *Waiting time for an appointment with a specialist*

According to the 2018 HIS study, less than 1% of respondents consulted a specialist without an appointment while 11.6% had a same-day appointment. Access to a specialist has become longer between the last two data collections. In 2018, 48% of the people who consulted a medical specialist had to wait more than two weeks for an appointment. This was an increase of 10 percentage points (38%) compared to 2013. There was no clear association between WT and gender, income or age. However, the people aged 75 and over were the least likely to experience long WT



(31.8%)<sup>cc</sup>, compared to the other age groups (see Table 4). In 2018, the proportion of patients who had to wait more than two weeks for an appointment with a medical specialist was the highest in Wallonia (56%) and the lowest in Brussels (43%). In Flanders, the proportion of people that had to wait more than two weeks was 46%.<sup>296</sup>

The WT to get an appointment with a specialist was perceived as problematic by 13.5% of the respondents in 2018 compared to only 10.2% in 2013. This increase was also observed in Flanders (8.4% in 2013 vs 11.0% in 2018) and Wallonia (10.0% in 2013 vs 16.3% in 2018) but not in the Brussels-Capital Region, where the proportion of people who perceived WT as problematic decreased between the last two HIS (18.2% in 2013 vs 15.2% in 2018).<sup>296</sup>

**Table 3 – Waiting time to get an appointment with a GP or specialist among respondents aged 15 years and older asking an appointment in previous year (Belgium – 2013/2018) – HIS<sup>295</sup>**

| WT categories*              | GP (%)        |               | Specialists (%) |               |
|-----------------------------|---------------|---------------|-----------------|---------------|
|                             | 2013 (n=4747) | 2018 (n=5322) | 2013 (n=1135)   | 2018 (n=1609) |
| Same day                    | 57.3          | 51.7          | 15.5            | 11.6          |
| Next day                    | 16.5          | 24.0          | 5.2             | 4.7           |
| Couple of days              | 10.6          | 13.5          | 13.3            | 9.5           |
| Just less than a week       | 1.9           | 2.0           | 10.7            | 11.5          |
| Between 1 week and 2 weeks  | 0.5           | 1.2           | 14.5            | 13.5          |
| More than 2 weeks           | 0.6           | 1.4           | 38.4            | 48.4          |
| Did not make an appointment | 12.6          | 6.2           | 2.4             | 0.9           |

\* Definitions of WT categories can be found in the study of Brito-Fernandes 2021<sup>38</sup> in appendix.

<sup>cc</sup> Therefore people aged 75 and more experienced longer WT to see a GP but shorter to see a specialist than other age groups.



**Table 4 – Patients who experienced long WT\* to get an appointment with a GP or a medical specialist among respondents aged 15 years and older asking an appointment in past year – analysis by gender, age category and income quintile (Belgium – 2018) – HIS<sup>295</sup>**

| EU-SILC <sup>dd</sup> |                 | GP<br>% of respondents | Specialists<br>% of respondents |
|-----------------------|-----------------|------------------------|---------------------------------|
| Gender                | Males           | 42.6                   | 49.6                            |
|                       | Females         | 41.7                   | 47.7                            |
| Age category          | 15-24           | 37.9                   | 45                              |
|                       | 25-34           | 36.3                   | 48.7                            |
|                       | 35-44           | 37.9                   | 53                              |
|                       | 45-54           | 42.8                   | 49.7                            |
|                       | 55-64           | 48.4                   | 54.4                            |
|                       | 65-74           | 43.7                   | 45.8                            |
|                       | 75 or over      | 48.0                   | 31.8                            |
| Income levels         | First quintile  | 39.5                   | 53                              |
|                       | Second quintile | 44.2                   | 39.9                            |
|                       | Third quintile  | 46.2                   | 56.4                            |
|                       | Fourth quintile | 39.0                   | 47                              |
|                       | Fifth quintile  | 42.0                   | 47.1                            |

Source: Based on HIS<sup>295</sup> – \*Long WT is defined as a WT longer than 1 day for a consultation with a GP and longer than 2 weeks for a consultation with a specialist

<sup>dd</sup> The EU statistics on income and living conditions (EU-SILC) aim to collect timely and comparable cross-sectional and longitudinal data on income, poverty, social exclusion, and living conditions.



## 4.2 Survey on the balance between supply and demand for doctors by Planning Unit for the health professions (FOD VVVL/SPF SPSCAE)

For several years, the Planning commission and the Planning Unit for the health professions (FOD VVVL/SPF SPSCAE) have been engaged in improving the data, instruments and processes to optimise planning of the healthcare professionals in Belgium. The Planning Unit is analysing the balance between the supply and the demand in each medical discipline subject to workforce planning. WT is one of the balance indicators considered. Therefore, the Planning Unit has organised an online survey to pilot the feasibility of data collection on WT in specialists.<sup>298</sup>

WT is defined as the number of calendar days between the date of the request for an appointment for an initial consultation and the date of the consultation. Follow-up and emergency consultations were excluded. The survey focused on scheduled consultations or technical procedures. Cardiology, geriatrics, psychiatry (adult or child and adolescent), gynaecology and radiology were selected as pilot specialties for the assessment. Medical directors and individual practitioners were surveyed for WT in hospital and in private practice respectively. If doctors worked both in private practice and in hospital, they were asked to answer the question about WT in private practice only. Participation was on a voluntary basis. Table 5 shows WT in the studied medical specialties, by district. As the overall response rate was 23%, the results are difficult to interpret. However, we can conclude that WT varied according to the medical specialty and district (see Table 5).



**Table 5 – Waiting time in calendar days in 6 medical specialties by district in Belgium in 2020 (source: Planning Unit for the health professions – FOD VVVL/SPF SPSCAE)**

| District        | Cardiology |     |                  |     | Geriatrics       |     |                  |     | Gynaecology                     |     |                  |     |
|-----------------|------------|-----|------------------|-----|------------------|-----|------------------|-----|---------------------------------|-----|------------------|-----|
|                 | Hospital   |     | Private practice |     | Hospital         |     | Private practice |     | Hospital                        |     | Private practice |     |
|                 | n          | WT* | n                | WT* | n                | WT* | n                | WT* | n                               | WT* | n                | WT* |
| West-Vlaanderen | 3          | 52  | 2                | 50  | 2                | 7   | -                | -   | 3                               | 27  | 4                | 45  |
| Oost-Vlaanderen | 7          | 23  | 1                | 30  | 6                | 12  | -                | -   | 7                               | 27  | 1                | 34  |
| Antwerpen       | 6          | 16  | 1                | 60  | 5                | 24  | -                | -   | 6                               | 9   | 1                | 44  |
| Limburg         | 2          | 8   | 1                | 7   | 2                | 6   | -                | -   | 2                               | 13  | 6                | 110 |
| Vlaams-Brabant  | 2          | 15  | 1                | 14  | 1                | 2   | -                | -   | 2                               | 8   | 6                | 9   |
| Brussels        | 4          | 23  | 3                | 8   | 3                | 6   | -                | -   | 3                               | 28  | 4                | 37  |
| Brabant Wallon  |            |     |                  |     |                  |     | -                | -   |                                 |     | 1                | 7   |
| Hainaut         | 5          | 50  | 2                | 33  | 5                | 21  | -                | -   | 6                               | 29  | 8                | 34  |
| Namur           | 3          | 42  |                  |     | 2                | 22  | -                | -   | 3                               | 38  | 1                | 42  |
| Liège           | 3          | 19  | 2                | 30  | 3                | 127 | -                | -   | 4                               | 75  | 1                | 20  |
| Luxembourg      | 1          | 30  |                  |     |                  |     | -                | -   | 1                               | 30  | 1                | 10  |
| District        | Radiology  |     |                  |     | Adult psychiatry |     |                  |     | Child and adolescent psychiatry |     |                  |     |
|                 | Hospital   |     | Private practice |     | Hospital         |     | Private practice |     | Hospital                        |     | Private practice |     |
|                 | n          | WT* | n                | WT* | n                | WT* | n                | WT* | n                               | WT* | n                | WT* |
| West-Vlaanderen | 2          | 1   | 1                | 0   | 3                | 31  | 1                | 3   | 1                               | 7   | 3                | 193 |
| Oost-Vlaanderen | 7          | 3   | 3                | 1   | 9                | 55  | 3                | 47  | 4                               | 86  | 5                | 134 |
| Antwerpen       | 3          | 7   | 5                | 3   | 6                | 51  | 6                | 67  | 1                               | 180 | 17               | 179 |
| Limburg         |            |     | 2                | 2   | 2                | 31  | 4                | 28  | 1                               | 40  | 5                | 170 |
| Vlaams-Brabant  | 2          | 1   |                  |     | 5                | 12  | 6                | 51  | 2                               | 16  | 12               | 253 |
| Brussels        |            |     | 4                | 10  | 4                | 23  | 5                | 76  | 3                               | 47  | 2                | 31  |
| Brabant Wallon  |            |     | 2                | 42  |                  |     |                  |     |                                 |     |                  |     |
| Hainaut         | 5          | 13  | 4                | 7   | 6                | 35  | 7                | 98  | 7                               | 82  | 2                | 115 |
| Namur           | 3          | 34  | 1                | 14  | 2                | 88  | 2                | 9   | 2                               | 41  |                  |     |
| Liège           | 3          | 3   | 4                | 193 | 3                | 18  | 2                | 28  | 3                               | 141 |                  |     |
| Luxembourg      | 1          | 7   | 1                | 365 |                  |     |                  |     |                                 |     |                  |     |

Source: Planning Unit for the health professions – FOD VVVL/SPF SPSCAE

\*WT is reported by the participants and is defined as the number of calendar days between the appointment request and the appointment with the doctor.



### 4.3 Waiting time for imaging and cataract surgery (IMA/AMI)

In 2015, the Patient Mobility Observatory (co-created by the RIZIV/INAMI) and the FOD VVVL/SPF SPSCAE to study the cross-border mobility of the patients in the European Union) asked the InterMutual Agency (IMA/AMI) to study the feasibility of measuring WT for patients. The Observatory's request is part of a European request to provide WT for health care. We report here on this attempt to measure WT for healthcare procedures in Belgium based on billing data. Since 2006, the IMA/AMI has been collecting individual data on all services reimbursed by the compulsory health insurance. At the request of the Observatory, billing data were used to calculate WT for medical imaging and cataract surgery.

#### 4.3.1 Imaging<sup>300</sup>

##### Data selection and definition of WT

All beneficiaries who were reimbursed by the compulsory health insurance for a medical imaging procedure (CT scan, MRI or PET scan) performed between 1/1/2010 and 31/12/2015 were selected (i.e. before the implementation of the imaging device registry and the planning of CT, PET, PET-CT, PET-MRI, SPECT-CT, MRI). The authors then checked whether it was possible to trace the (last) contact with the prescriber of the procedure during a period of no more than one year prior to the imaging procedure. Five types of imaging were defined:

- CT scans as part of an oncology care pathway (specifically planned in advance) [CT\_Onco].
- Other CT scans not part of an oncology care pathway [CT\_Other].
- MRI scans [MRI].
- PET scans billed according to the official nomenclature [PET\_Official].
- PET scans that were subject to other nomenclature codes [PET\_Proxy].<sup>300</sup>

### Results<sup>300</sup>

Table 6 presents the WT for different imaging procedures in 2015.

**Table 6 – WT for imaging in Belgium in 2015 (IMA/AMI)**

| WT (calendar days) | Mean  | Median | P <sub>75</sub> |
|--------------------|-------|--------|-----------------|
| CT_Onco            | 54.8  | 28     | 84              |
| CT_Other           | 30.5  | 8      | 25              |
| MRI                | 40.9  | 24     | 44              |
| PET_Official       | 169.1 | 160    | 232             |
| PET_Proxy          | 126.4 | 99     | 209             |

Source: *Intermutualistisch Agentschap – Agence Intermutualiste (IMA-AIM). Rapport de synthèse AIM délais d'attente imagerie médicale 2017.*

When comparing WT between 2010 and 2015, the results show an increase regardless of the type of imaging procedure. A significant proportion of WT could not be calculated for CT (15%), MRI (32%) and PET scan (94%). This can be explained by the unscheduled nature of some imaging procedures. Regional variations were observed. In 2015, the average WT for CT in oncology was shorter in the Brussels-Capital Region (48.0 days) compared to Flanders (57.2 days) and Wallonia (53.9 days). In contrast, the WT for a CT in non-oncology patients was longer in the Brussels-Capital Region (33.9 days) compared to Flanders (30.1 days) and Wallonia (30.0 days). The WT for MRI was shorter in Flanders (37.0 days) than in two other regions (Brussels-Capital Region 43.2 days and Wallonia 48.6 days).



### Limitations<sup>300</sup>

The results in the IMA/AMI reports were reviewed by external experts from the hospital sector. Several reviewers highlighted the following elements to be taken into account for interpretation, as they affect WT for medical imaging:

- the number of machines available in the area (according to official regulations);
- the duration of the procedures (e.g. the number of MRI sequences, which may be related to the pathology of the patients; in this context, it is expected that the reference hospitals will have patients with more complex pathologies, for whom the examinations are longer);
- the different types of imaging procedures, which affect the duration of the procedure (e.g. interventional imaging, under general anaesthesia, with some centres concentrating on less time-consuming procedures);
- the availability of imaging equipment in relation to hospital capacity (e.g. number of beds);
- the need to fit unscheduled priority/emergency procedures into the schedule.

The most important aspect of the methodology is that it measures the time taken to complete imaging. In many situations, imaging is scheduled later than the first available appointment. It would be more accurate to look at the WT between the procedure is actually scheduled and the procedure itself.

Some reviewers also insisted that these data are not related to the quality of the procedures performed. In addition, some PET scans were performed under nomenclature codes other than those listed, so the data may not be complete.

Data are from 2010-2015 and have not been updated.

NB: To improve access to imaging, some Internet websites have been developed that can be accessed by professionals and patients : these platforms show available appointments in the hospitals and centres that agree to share their information. In this way, patients have a global view of

available appointments and providers avoid having free time slots. However, there is no assessment of these platforms on WT.

### 4.3.2 Cataract surgery<sup>301</sup>

#### Data selection and definition of WT<sup>301</sup>

Cataract surgery nomenclature codes were used to identify patients who underwent surgery between 1/1/2010 and 31/12/2015 and their care path was reconstructed to estimate WT. To do this, the researchers identified the date on which one (or two) cataract procedures were documented; then they investigated whether, in the year before the procedure, the patient had any contact with the ophthalmologist who performed the cataract surgery. If no such consultation (with the ophthalmologist who performed the surgery) was recorded in the National Health Service billing databases, the date of the last consultation with another ophthalmologist, another specialist or a general practitioner, in order of preference, was used as the date of the decision to treat. The WT is considered to be the time between the decision to treat and the surgery.

#### Results<sup>301</sup>

In 2015, the mean WT for cataract surgery was 39.7 days (median 27 days, P<sub>75</sub> 50 days). This WT has been stable since 2010. Looking at the regional level in 2015, the longer WT was observed in Wallonia (44.8 days) followed by the Brussels-Capital Region (40.6 days) and Flanders (37.0 days).

#### Limitations<sup>301</sup>

The results in the IMA/AMI reports were reviewed by external experts from the hospital sector. The reviewers confirmed that the starting point for determining the WT should be a consultation with an ophthalmologist, not another specialist or GP. Furthermore, in the case of scheduled surgery, a long WT is of little value. On the contrary, a short WT may indicate that the surgical indication was made too quickly and the patients did not have enough time to make an informed choice. Therefore, it is not a minimum WT



that should be sought, but a reasonable one. On the other hand, it is important to know whether the few really urgent cases are dealt with quickly.

Data are from 2010-2015 and have not been updated.

In addition, some limitations (confirmed by both the authors and the reviewers) are: the decision to operate can be made at a first consultation, followed by a second consultation for preoperative investigations (in this report, this second date is used for the calculation); in some cases, this second consultation is organised according to the date of the surgery. The results are therefore significantly biased.

#### 4.3.3 Feasibility of waiting time measurement based on billing data

The authors of the reports concluded that billing data can be used to estimate WT for medical imaging and cataract surgery, provided that all the limitations mentioned above are taken into account when interpreting the data. However, this was an estimate because the data were not collected for the purpose of calculating WT. In particular, it is not possible to determine with certainty the time at which the decision to schedule the procedure was made. Certain elements, such as the convenience of the patient in choosing the date (it is not necessarily the first available date that is chosen by the patient), and clinical details or the degree of urgency of the medical procedure, should be included in the measure.<sup>300, 301</sup>

#### 4.4 Waiting time in mental health (Flanders)

In Belgium, there is no systematic registration of WT for mental health care, except in the Centra Geestelijke Gezondheidszorg (CGGs, centres for mental health care). In the period 2018-2021, the mean WT before a first face-to-face (FTF) contact in a CGG was 50 days, while the mean WT between first FTF contact and treatment was 53 days in 2018 and 58 days in the period 2019-2021. In 2022, there was an improvement in mean WT to 41 days before a first FTF contact and 48 days between first FTF contact and treatment. The mean WT for children is generally longer than for adults: 56 days for a first FTF interview and 60 days between first FTF contact and treatment in 2019-2021. In 2022, WT improved to 46 days and 54 days respectively.<sup>299</sup>

In Flanders, a 'WT working group' of the Staten-Generaal Geestelijke Gezondheid (SGGG, States General mental health), an organisation of interested stakeholders in mental health care, collaborated with the Chair 'Public Mental Health' of the University of Antwerp to conduct an online survey among healthcare users in December 2020. They recruited almost 1 600 people who had sought help for mental health problems in the previous 2 years, either for themselves (73%) or for a child up to the age of 18 (27%). Participants were mostly female (83% of those seeking help for themselves and 91% of those seeking help for a child) and their mean age was 40.8 years. The children involved were mostly boys (61.5%) with a mean age of 10.9 years. The main reasons for seeking help were depressive feelings for adults (61%) and social interaction problems for children (47%).<sup>297</sup>

The self-reported WT for different services in mental health for adults and adolescents can be found in Table 7 and for children in Table 8. In general, reported WT were longer for subsidised ambulatory care compared to residential care and longer for children and adolescents than for adults.<sup>297</sup>

**Table 7 – Self-reported waiting times for different services in mental health for adults and adolescents – SGGG-Universiteit Antwerpen**

|                                      | Number of observations | WT    | % At least one month |
|--------------------------------------|------------------------|-------|----------------------|
| <b>Adolescents and adults</b>        |                        |       |                      |
| Admission PZ adolescents (no crisis) | 13                     | 3-6m  | 84.6                 |
| Psychosocial rehabilitation centre   | 40                     | 1-3m  | 77.5                 |
| Assisted living                      | 17                     | 6m-1y | 76.5                 |
| CGG adults                           | 168                    | 1-3m  | 60.1                 |
| CGG adolescents                      | 20                     | 1-3m  | 50.0                 |
| Mobile team long-term care           | 42                     | 2w-1m | 47.6                 |
| Daycare PZ adult                     | 114                    | 2w-1m | 47.4                 |
| Private psychiatrist                 | 377                    | 2w-1m | 46.2                 |
| Admission PZ adult (no crisis)       | 149                    | 2w-1m | 43.6                 |
| Daycare PZ adolescent                | 7                      | 1-2w  | 42.9                 |
| TEJO (adolescents)                   | 11                     | 2w-1m | 36.4                 |
| Centre for addiction                 | 25                     | 2w-1m | 36.0                 |
| Private psychologist                 | 874                    | 2w-1m | 32.8                 |
| Daycare PAAZ                         | 40                     | 2w-1m | 32.5                 |
| Crisis admission PZ adolescent       | 11                     | <1w   | 18.2                 |
| Mobile team crisis adults            | 87                     | <1w   | 13.8                 |
| Crisis admission PZ adults           | 93                     | <1w   | 8.6                  |
| Admission PAAZ                       | 113                    | <1w   | 8.0                  |
| Mobile crisis team adolescents       | 7                      | <1w   | 0.0                  |

Source: Rens E, Glazemakers I, Van den Broeck K, gezondheidszorg. Wg. Wachten op psychische hulp: de lengte en beleving van wachttijden in de Vlaamse geestelijk gezondheidszorg. 2021. Available from: [https://www.statengeneraalggz.be/wp-content/uploads/2021/01/Uitgebreid-rapport-wachttijden\\_Def2.pdf](https://www.statengeneraalggz.be/wp-content/uploads/2021/01/Uitgebreid-rapport-wachttijden_Def2.pdf)

*Assisted living* includes initiatives of sheltered living (residential structures designated for patients with psychiatric problems who have difficulties to live independently) and psychiatric care homes (take care of patients of all ages with a stable psychiatric condition, who need permanent care for a long-term mental health problem and for intellectually disabled persons who need permanent supervision)<sup>306</sup>,

*Mobile team*: psychiatric home care teams care for persons with psychiatric symptoms who are in need of specific care to maintain themselves in their home situation, two types have been created (crisis team and chronic mental health problems)<sup>306</sup>;

CGG centra geestelijke gezondheidszorg (centres for mental health care); m: month(s); PZ psychiatrisch ziekenhuis (psychiatric hospital), PAAZ psychiatrische afdeling algemeen ziekenhuis (psychiatric ward in general hospital) ; TEJO therapeuten voor jongeren (therapists for youth); y: year(s); w: week(s)

**Table 8 – Self-reported waiting times for different services in mental health for children – SGGG-Universiteit Antwerpen**

|                                   | Number of observations | WT    | % At least one month |
|-----------------------------------|------------------------|-------|----------------------|
| <b>Children</b>                   |                        |       |                      |
| <b>CAR</b>                        | 65                     | 1-2y  | 96.9                 |
| <b>COS</b>                        | 42                     | 3-6m  | 90.5                 |
| <b>Home support autism</b>        | 61                     | 6m-1y | 86.9                 |
| <b>CGG</b>                        | 60                     | 3-6m  | 81.7                 |
| <b>Daycare PZ</b>                 | 35                     | 3-6m  | 80.0                 |
| <b>Admission PZ (no crisis)</b>   | 39                     | 3-6m  | 79.5                 |
| <b>Private psychiatrist</b>       | 174                    | 1-3m  | 73.6                 |
| <b>Mobile team long-term care</b> | 8                      | 1-3m  | 63.5                 |
| <b>Private psychologist</b>       | 260                    | 1-3m  | 56.5                 |
| <b>Crisis admission PZ</b>        | 36                     | 2w-1m | 33.3                 |
| <b>Mobile team crisis</b>         | 41                     | 1-2w  | 24.4                 |
| <b>TEJO</b>                       | 19                     | 1-2w  | 21.1                 |

*CAR: centra voor ambulante revalidatie (centres for ambulatory revalidation); CGG centra geestelijke gezondheidszorg (centres for mental health care); m: month(s); PZ psychiatrisch ziekenhuis (psychiatric hospital), ; TEJO therapeuten voor jongeren (therapists for youth); y: year(s); w: week(s)*

During the experienced WT, complaints increased for half of the respondents. The working group emphasized that WT depend on, among other things, the correct indication, treatment turnaround time and the capacity of treatment teams.<sup>297</sup> Subsequently, the SGGG working group on 'WT' conducted a survey of approximately 1300 (1305) healthcare professionals in private practices; mostly females (87%) with a mean age of 40.2 years. Almost 80% of the respondents were clinical psychologists, 7% psychiatrists, 3% educational psychologists and 11% 'other psychotherapists'. Registration stops were common practice: 60.5% of psychiatrists reported that they were not accepting new patients. In addition, 43% of them had a WT of at least 6 months. Of the other healthcare professionals surveyed, half had a WT of less than a month, but about a third reported not accepting new patients. Looking at data from mental

healthcare professionals working with children and adolescents, the WT was less than one month in 36% of cases for children and 42% of cases for adolescents (compared with 53% in adults). About 15% of these respondents had a WT longer than 6 months for children. Almost 40% of the participants noted a large increase in requests related to the coronavirus pandemic.<sup>307</sup>

Finally, in October 2022, the SGGG working group on WT published a report on a short, simple survey of 203 healthcare professionals and adult care organisations regarding their WT policies. Most participants were independent health providers, either in a solo (38%) or in a group practice (35%), others were part of an organisation of subsidised ambulatory care (11%), day and night admissions (7%), primary care (3%) or day care (1%).



In this survey, 9% of respondents reported not taking on new patients while 71 % reported having WT or a WL. Only 5% of the respondents reported being able to answer all questions about care immediately. Actions/strategies that were undertaken during WT included keeping in touch with the client, facilitating contact with others, providing self-help opportunities and offering other interventions. Approximately 71% of participants reported to be active in reducing WT.<sup>308</sup>

#### 4.5 Measurement of time in oncology as an indicator of quality of care (KCE)

Due to the progressive nature of the disease, early treatment of cancer is essential to increase the chances of cure and survival, but also to relieve symptoms as soon as possible. To assess the quality of oncology care, the KCE looked at three types of cancer: lung, ovarian, and head and neck cancer.<sup>302-304</sup> During the process of assessing the quality of care, experts were consulted to select quality indicators based on their expertise and existing clinical evidence. Among the selected indicators were time to treatment (i.e. time between diagnosis and start of treatment with curative intent) and time to postoperative treatment (i.e. time between surgery and the start of chemotherapy or radiology).

The development of these quality indicators required the linkage of several databases i.e. the Belgian Cancer Registry (BCR), health insurance data from IMA/AMI databases, the hospital discharge data from the Minimal Hospital Data ('Minimale Ziekenhuis Gegevens' (MZG)/'Résumé Hospitalier Minimum' (RHM) – FOD VVVL/SPF SPSCAE), and the vital status obtained from the Crossroad Bank of Social Security ('Kruispuntbank van de Sociale Zekerheid' (KSZ)/'Banque Carrefour de la Sécurité Sociale' (BCSS)). The 'optimal' time interval to start a treatment is derived from the available clinical evidence on maximum WT reported in the literature. The maximum WT for a health intervention is defined as the time a patient can wait for a health intervention before an adverse event or decline in health occurs.<sup>28, 309</sup> The starting point for calculating the time interval is the incidence date reported in the BCR. The incidence date is the date of first histopathological confirmation of the tumour. If there is no histopathological confirmation, the

incidence date is the date of the technical procedure or clinical investigation that led to the diagnosis of cancer.

##### 4.5.1 Time assessment in lung cancer

In a report published in 2019, KCE researchers analysed a total of 12 839 tumours in patients with lung cancer diagnosed between 2010 and 2011.<sup>302</sup> They analysed the quality of care provided to this patient population. Among the set of indicators, three of them were related to time assessment.

##### **Time from incidence date to first active treatment (curative intent or palliative intent)**

This indicator reported the median number of days between the incidence date (i.e. date of histologic or imaging diagnosis) and the first day of active treatment. Active treatment was defined as surgery with curative intent, radiotherapy with curative intent, chemotherapy, targeted therapy, or radiotherapy with palliative intent. The indicator was calculated by histological type (non-small cell lung cancer vs small cell lung cancer), clinical stage, treatment modality, and referral status (patients referred to another centre or not). Table 9 presents the values of the indicator.<sup>302</sup>



**Table 9 – Time from incidence date to start of first active treatment by tumour and treatment characteristics, and referral status (Belgium 2010-2011) – BCR-IMA/AMI**

| Characteristic                                     | Median number of days |
|----------------------------------------------------|-----------------------|
| <b>Overall</b>                                     | 20                    |
| <b>Clinical stage</b>                              |                       |
| I                                                  | 32                    |
| II                                                 | 28                    |
| III                                                | 22                    |
| IV                                                 | 16                    |
| X                                                  | 18                    |
| NA                                                 | 33                    |
| <b>Histological type</b>                           |                       |
| Non-small cell lung cancer                         | 22                    |
| Small cell lung cancer                             | 12                    |
| Other specified lung cancer                        | 37                    |
| <b>Treatment modality</b>                          |                       |
| Surgery                                            | 26                    |
| (Chemo)radiotherapy                                | 22                    |
| Chemo-/Targeted therapy                            | 17                    |
| No curative treatment<br>(palliative radiotherapy) | 16                    |
| <b>Referral status</b>                             |                       |
| Not referred to another centre                     | 20                    |
| Referred to another centre                         | 25                    |
| Unknown diagnostic or treatment centre             | 15                    |

Source: BCR-IMA<sup>302</sup>

The proportion of patients that exceeded a threshold of 4 weeks was 32.7%. Median delay increased for the lower stages and for surgical interventions, both may be linked: the lower the stage, the more likely it is that a surgical intervention takes place. Referral to another centre is associated with an increase in median delay of 5 days.<sup>302</sup>

### Time to chemotherapy and radiotherapy

- Small cell lung cancer

The percentage of patients with a pT1-T3 pN1-2 M0 small cell lung cancer receiving an adjuvant chemotherapy after resection was 65.8% while the target was 70%.<sup>302</sup> The targeted proportion of patients with a pIA<sup>ee</sup> small cell lung cancer receiving an adjuvant chemotherapy should be <1% but the authors observed a proportion of 1.2%.

- Non-small cell lung cancer

Two time are measured: time for sequential chemoradiation and time for concurrent chemotherapy. Sequential chemoradiation in cIII<sup>ff</sup> non-small cell lung cancer patients was defined as the start date of chemotherapy and the start date of radiotherapy lying within 120 days of each other, while concurrent chemotherapy was defined as the start date of chemotherapy and RT lying within 30 days of each other. For the period 2010-2011, the authors calculated the proportion of sequential and concurrent chemotherapy to be 51.7% and 29.3% respectively. Adjuvant chemotherapy must occur within 3 months after the date of surgery. Only the half of the patient reached this target.<sup>302</sup>

<sup>ee</sup> Pathological stage IA

<sup>ff</sup> Clinical stage on a stage scale ranging from I to IV



#### 4.5.2 Time assessment in head and neck cancer

In a report published in 2019, KCE researchers analysed a total of 15 339 head and neck cancer patients diagnosed between 2009 and 2014.<sup>303</sup> They analysed the quality of care provided to this patient population. Among a large set of indicators, two of them were related to time assessment.

##### **Timeliness of start of first treatment with curative intent**

The time between diagnosis and treatment of a tumour in patients with head and neck cancer is critical, as the rapid growth rate of this type of tumour is a negative prognostic factor. In fact, an average tumour doubles in size in 96 days to 87 days, or even 30 days for the fastest growing tumours.<sup>303</sup>

The median WT between diagnosis confirmation and the start of treatment for patients with a head and neck squamous cell carcinoma in Belgium was 32 days (IQR: 19-46 days). Patients with oral cavity squamous cell carcinoma were treated more quickly after confirmation of the diagnosis than patients with other head and neck squamous cell carcinoma (median 27 days; IQR: 8-42). When the first treatment was surgery, the median time interval was shorter compared to primary radiotherapy (24 days versus 36 days). Finally, the patients who received their first treatment at the same centre where the diagnosis was confirmed, were treated faster than patients who were referred to another centre (median interval: 26 days vs. 37 days).<sup>303</sup>

##### **Timeliness postoperative radiotherapy**

According to the KCE, guideline postoperative radiotherapy should be started within 6 weeks after surgery.<sup>303</sup> It was considered, by expert consensus that more than 90% of the patients must start postoperative radiotherapy within the recommended timeframe. The authors observed that 48.5% of patients with a head and neck squamous cell carcinoma ended their postoperative radiotherapy within thirteen weeks after surgery, which is much lower than the set target. Indeed, the median interval from surgery to end postoperative radiotherapy was 92 days. Patients who were not referred to another centre for radiotherapy had a higher chance of having

their radiotherapy ended within thirteen weeks after surgery, than their peers who were referred for radiotherapy (51.9% vs. 44.3%).<sup>303</sup>

#### 4.5.3 Time assessment in ovarian cancer

A total of 5 934 tumours of the ovary, fallopian tube and primary peritoneum diagnosed in 2014-2018 were used to assess quality indicators reported in the KCE report 357 published in 2023.<sup>304</sup> Two indicators were related to time assessment.

##### **Time to treatment**

Time to treatment is defined as the period between diagnosis and the start of first treatment (chemotherapy or primary surgery). The date of abdomino-pelvic imaging was used as proxy for the date of diagnosis. The median WT between diagnostic confirmation (by medical imaging) and start of treatment for patients with an epithelial ovarian cancer was 22 days (IQR: 12-37). When surgery was the first treatment performed, the median WT was shorter compared to primary chemotherapy (i.e. 21 days for surgery as first treatment and 25 days for chemotherapy as first treatment).<sup>304</sup>

##### **Time to postoperative chemotherapy**

The administration of adjuvant chemotherapy is suggested to inhibit early tumour growth after surgery in patients with ovarian cancer. In order to balance postoperative recovery and the initiation of chemotherapy, time to chemotherapy is individualised according to, notably, age, performance status, extent of surgery, perioperative complications and patient preference. Clinical experts involved in KCE report 357 chose as a quality indicator a proportion of at least 90% of patients with ovarian cancer receiving the chemotherapy within 42 days after surgery.<sup>304</sup> The median time between surgery and adjuvant chemotherapy observed in operated women with invasive epithelial ovarian cancer who received adjuvant chemotherapy was 33 days (Q1-Q3: 25-43). Of these, 74.9% started chemotherapy within 42 days after surgery, which was below the proposed target.<sup>304</sup>



## 5 MEASURING WAITING TIMES IN BELGIUM –HEALTHCARE PROFESSIONALS' PERSPECTIVE

### Key points

#### Healthcare professionals' perspective

Twenty-four types of stakeholders from different settings, disciplines and regions were interviewed to capture their perceptions of the measurement of WT in Belgium. A qualitative analysis of the notes taken during the interviews showed that:

- The definition and interpretation of WT were questioned

The definition of WT varies widely between disciplines, services or patient's needs (level of urgency, pathology, etc.). There is also the question of what constitutes an (in)appropriate WT, depending on the patient's or HCP's point of view. Furthermore, longer than expected WT does not always imply a lower quality of care. Therefore, having a metric alone is not sufficient and a large amount of data (including HCPs profiles (e.g. subdisciplines), proposed care, patient characteristics...) needs to be collected to avoid subjective or biased interpretation. As the data to be interpreted will depend on the specificity of the (sub)discipline and clinical characteristics, work by (sub)discipline and clinical vignettes should be carried out.

- The relevance of measuring WT was questioned

Two main reasons were given. First, WT is not a problem in all health care sectors. Second, where WT is a known problem, the causes have usually been identified and should be addressed as a priority before measuring WT.

Various strategies have already been put in place to tackle WT, either by HCPs (e.g. cooperation between HCPs in the same discipline and region,

triage, time slots in the agenda for urgent cases, refusal of patients, etc.), by patients (e.g. multiple appointments) or by healthcare facilities (e.g. mobility of staff).

- Defining the objective(s) of measuring WT is crucial

It is particularly important to clarify the purpose of collecting data on WT. Otherwise, stakeholders will not be convinced of the added value of such a task. They need to see some kind of return on their investment of time and additional workload.

The objectives of measuring WT could take into account different perspectives: health authorities, RIZIV/INAMI, hospitals and hospital networks, care providers or patients.

- Acceptance of participating in a data collection on WT was low

Although it is widely recognised that there are problems in certain disciplines or regions, there is low acceptance to participate in a data collection if there is no direct benefit to the HCPs. The resources required (time, human, technical) are expected to be high.

- No clear design for WT data collection can be identified.

Several data sources (patients themselves via surveys, software or medical record extraction...) were described and mentioned as complementary. Prospective WT (third available appointment) is considered as the most relevant and objective measure. The data collection rhythm depends on the objective of the WT measurement, and it is discipline-specific. The use of a representative sample of HCPs in whom WT could be measured is mentioned. Wide access to the results is reported (authorities, NHIDI, hospitals, HCPs, universities...), except for patients, as there is no consensus on whether or not to allow access to results.



- Before starting to collect data on WT, several prerequisites need to be met:
  - Definition of the objective of the WT measure.
  - Selection of health sectors, sub-disciplines, interventions for which WT data is needed.
  - Definition in advance of the data collection process (simple and standardised, such as. automated data extraction), data format (template to be provided), number (appropriate amount) and type of data.
  - Support, whether technical or financial, must be provided.

### Limitations

Given the resources available to the project, the interviews were not fully transcribed, and the analyses were based on the notes taken by an observer during the interviews. The researcher who carried out the analysis generally attended the interviews and relied on the notes. It is possible that certain aspects were not reported as a result of a selection made during the notetaking and that the analysis was influenced by this initial selection. To limit this bias, the researchers who participated in the interviews reviewed and commented on the draft analysis.

## 5.1 Introduction

To understand the perceptions of the healthcare professionals regarding the development of a measurement tool to evaluate WT in their specific discipline and sector, we asked to key stakeholders for their opinions on the definition of WT and an appropriate data collection system.

## 5.2 Methods

### 5.2.1 Design

We have opted for a qualitative approach using explorative group interviews with key stakeholders. We conducted 8 preliminary interviews (4 in Dutch and 4 in French) with representatives of the hospital sector to prepare the interviews with healthcare professionals. Healthcare professionals were selected according to the recruitment criteria detailed in section 5.2.2.

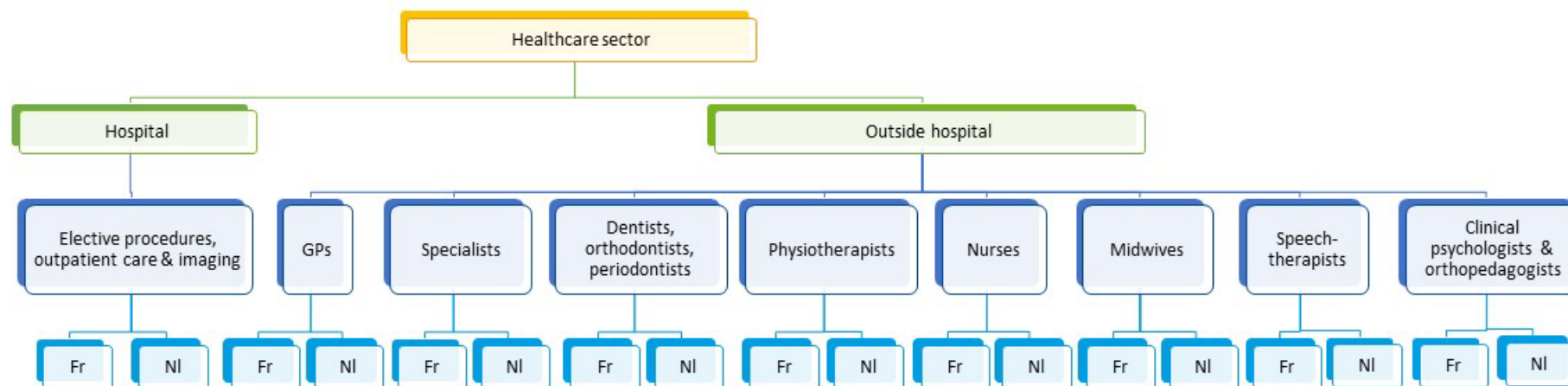
### 5.2.2 Recruitment

Since WT is considered an indicator of access to healthcare<sup>1</sup>, we selected (as participants) healthcare professionals with whom patients can make an appointment and whose numbers are monitored by the Planning Commission, i.e. GPs, specialists, oral and dental healthcare professionals (dentists, orthodontists, periodontists), physiotherapists, nurses, midwives, speech-therapists, clinical psychologists and clinical orthopaedagogues. We excluded paramedics and first-aiders who do not have direct access to patients. As WT for scheduled procedures were included in the scope of this study and professionals may work in- and/or outside the hospital, participants from both settings were selected.

We contacted the different professional organisations to request an interview with their representative(s) with knowledge or experience of (measuring of) WT.



**Figure 7 – Segmentation of the participants**



To cover all these sectors, we planned to conduct interviews with at least one representative in each segment of Figure 7.

### 5.2.3 Data collection process

Interviews were carried out in the native language of the interviewee(s) and the interview moderator (one member of the research team). All interviews were recorded and notes were taken during the interview by another member of the research team (no transcripts). If necessary, the notes were then reviewed, corrected and completed by the moderator.

### 5.2.4 Data collection tool

The topics covered during the interviews were derived from a scoping review on WT measurement carried out in preparation of the project.

The interview guide was first developed in French and was proofread by two members of the KCE qualitative research team (LAK, MAD). Afterwards, it was translated into Dutch by two KCE researchers (GUB, REZ).

A comparison of the two versions was conducted to ensure that both versions were identical in terms of structure and content.

The final interview guides are presented in the appendix. They cover the following topics:

- Identification of recent experience of WT assessment.
- Definition of WT.
- Data collection systems.
- Data format(s).

### 5.2.5 Analysis

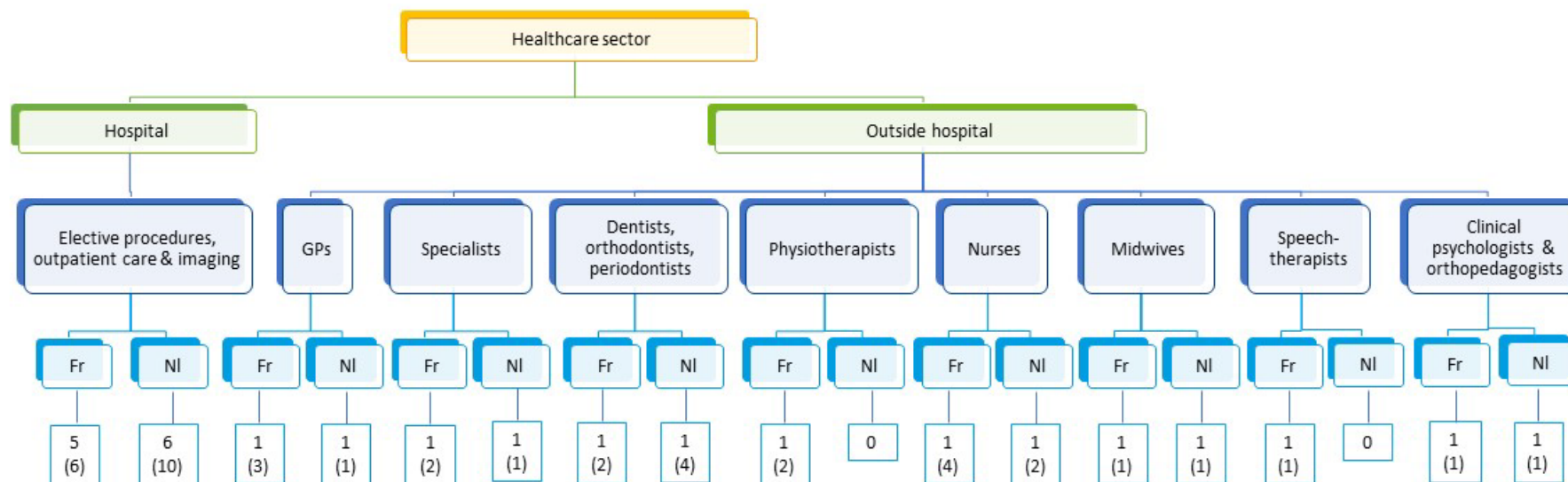
We performed an inductive thematic analysis using Nvivo. Notes from the interviews were coded by one researcher and the themes were further classified into nodes. The coding tree was submitted to the members of the team who participated in the interviews to check for interpretation, accuracy, and completeness.

All the examples of existing measurements were used to inform the findings.



### 5.3 Description of the participants

Figure 8 – Number of interviews conducted in each segment of the participants (number of participants in total)



We conducted 25 interviews in total and met 41 people (1 participant took part in 2 interviews). We covered the following levels of competence: federal, regional, and community. Despite our endeavours, we were not able to find representatives of Flemish speech-therapists and physiotherapists who agreed to participate.



## 5.4 Finding 1 – Definitions of WT and current explanations for them

### 5.4.1 What are 'waiting times'?

Respondents mention several ways in which WT could be understood. It could be the WT perceived by a patient in the emergency unit, to get an opinion, a phone call with a HCP, an appointment, a home visit...

There is also the question of what constitutes an (in)appropriate WT, and the question of whether a difference should be made between emergencies and non-urgent needs. This distinction could be radically different from the healthcare practitioner's point of view compared to that of the patient.

From the quality-of-care perspective, interviewees pointed out that WT are not the only indicator of quality of care and that longer than expected WT does not always mean lower quality of care. WT is a key issue in rapid development diseases such as cancer (see also chapter 3 and 4), while WT can be longer in slow development diseases such as cataracts without jeopardising the patient's health.

### 5.4.2 What are the reasons identified to explain the waiting times?

Whatever the type of WT, it can be explained by several factors:

From the health sector side:

- Supply-related factors:
  - Geographical distribution of the supply, with shortages mainly in the German-speaking region of Belgium.
  - HCPs:
    - Practitioners leaving the profession reduces the supply of services and creates WT for their colleagues. When several healthcare practitioners in a team are absent, the system quickly becomes overloaded. The secretary level is also affected, because these absences will force longer discussions with patients in order to find a new appointment with a colleague. Having a telephone contact becomes more difficult and risks increasing WT.
- Financial aspects:
  - Some HCPs specialise in a specific subspecialty or combine private and hospital practice, in order to achieve more comfort and quality of life. Young speech therapists, for example, prefer to work as employees (e.g. in a school for children with special educational needs) and leave the self-employment sector, or only as a complementary activity. The social security contributions, the people who don't pay, the lack of paid holidays, etc. are too heavy for the self-employed. Managing an independent activity is time-consuming. As a result, it could affect the availability of healthcare professionals for patient contact, which could increase WT.
  - The status of the HCP can affect the WT, especially since specialists in hospital are typically conventioned physicians (i.e. physicians who have agreed to national tariffs). However, they may also have a private practice outside of the hospital [often not conventioned], resulting in different WT for the same specialist. This issue is particularly pressing for the psychologists, who are allowed to work a maximum of 8 hours per week under the conventioned status: a limited number of conventioned hours is then proposed.
  - The financing of procedures influences professionals' willingness to perform them. Home visits require time for travel, distance, search for parking and payment for parking... These travel costs are not appropriately financially valorised, reducing the supply. This is also influenced by the region depending on the parking facilities or the distance.
  - Increasing accessibility may paradoxically affect WT negatively because of a fee-for-service system that encourages activity and ultimately an overload of the system.



- Pathology/care-related factors:
    - For scheduled surgery, WT can be affected by the steps that precede surgery (referral, consultation and diagnostic procedures), as well as by the scheduling of operating theatres (the patients need a place), the number of surgeons and available staff.
    - When the operative programme changes due to an emergency, scheduled surgery may be delayed.
    - Some treatments, such as orthodontics or speech therapy, require numerous and frequent appointments over a considerable duration. Therefore, accepting a new patient means blocking several slots over an extended period. This can vary from 4-6 months (well-organised practices) to as long as 18-24 months before healthcare professionals can see a new patient; for example, in orthodontics, if professionals are overbooked, patients have to wait until another patient has completed treatment before starting his/her own treatment. In speech therapy as well, some treatments require several sessions a week and a long follow-up period. The patient is therefore committed to the HCP for a large number of sessions (e.g. 2 sessions/week for 2 years, or 140 sessions for a child with a language problem who cannot be dropped along the way). Inevitably, if a patient chooses a particular speech and language therapist, he or she may have to wait a certain amount of time for the therapist to be able to integrate him/her as a new patient into the practice.
    - For imaging, priority is given to emergencies and more serious illnesses such as cancer. In addition, the calibration of some equipment and the skills of care providers (technicians and radiologists) are organs-specific and can affect the WT.
    - Seasonal factors: Peaks in demand due to respiratory diseases in winter, back-to-school stress for mental health and back-to-school needs for speech-therapists, or fewer nursing care in the summer due to fewer surgeries...
  - Healthcare system-related:
    - Reimbursement rules can create 'seasonality' with higher peaks in demand. For example, dentists experience more demand at the end of the year due to the reimbursement rules that encourage to have at least one consultation per calendar year. In orthodontics, patients must be seen before their 15<sup>th</sup> birthday, and many patients 'wake up' at the last minute to get an appointment.
- From the patients' side:
- If an HCP is better known, has more experience and more specific knowledge, more patients will want to be treated by that particular HCP and their WT will increase in comparison to choosing the first available HCP.
  - Patients take a long time to decide to make an appointment, not realising that they will have to wait for a certain amount of time.
  - Last-minute cancellations and/or no-shows block availability for other patients.
  - Patients who are not in the right place because they have made a direct appointment with a specialist while a GP could have been useful in redirecting them to a more appropriate specialist regarding their condition. This could be linked to the lack of gatekeeping by GPs.
  - Choice of a particular HCP because of their reputation, flexibility in schedules, fees level (conventioned or not)...
  - Patients favour a home visit for comfort.



## 5.5 Finding 2 – Pertinence and purpose of measuring waiting times

### 5.5.1.1 Pertinence

WT are stated in several domains such as imaging, some specialist consultations, but also in primary care. It is recognised as being a problem:

- for the quality of care, in terms of increasing morbidity, patient suffering, the risk of aggravation of the condition, delay accessing to the treatment, and the use of more expensive and/or irradiating imaging modalities, e.g. if the wait for an ultrasound is too long.
- for the healthcare practitioners, creating mental stress and workload due to overtime work to meet demand or when the GPs have to call to specialists to arrange an urgent or semi-urgent appointments for a patient.
- for the hospitals, as they risk losing patients if they do not respond adequately to patient demand.

Objectifying WT could be informative and help to better target the problems. However, even if it is a real problem in general, measuring WT for the whole healthcare system raised several issues as the aim of such a measurement could be questionable. In fact, WT is not a problem in all healthcare sectors because they are already managed:

- In postnatal care, it is not possible to accept WT and midwives are obliged to take mother and child in charge within a specific delay after birth. Mothers receive an up-to-date list of available midwives during the antenatal care period and after discharge. Once at home, in case of an 'emergency', midwives always succeed in referring their patients to a colleague. They know who are their colleagues and their contact information via their professional association website. The only exception in midwifery is the difficulty of finding a midwife for a home birth.
- In the home nursing care sector, WT are also not frequent. Patients are scheduled for the evening round, the same day or the following

day. After a hospital stay, the hospital may provide the nurse with specific skills (e.g. peripherally inserted central catheter-line). If this is not the case, the patient can search for another nurse and will always find one. All care will be taken in charge over the next 24 hours.

- Ambulatory physiotherapists do not face WT because they refer to a colleague if they are not able to accept a new patient.
- For some diseases: in oncology, every step of the patient journey is considered an emergency and everything is done to get an appointment or access to imaging or surgery as soon as possible.
- For emergencies: HCPs have developed ways to be able to take urgent situations in charge despite potential waiting lists (see section 5.5.2). Nevertheless, the definition of what constitutes an emergency is disputable and differs between the healthcare practitioners and the patients, if there is a definition...

Another reaction from interviewees was that the measure will be so biased that collecting WT will be a huge loss of money and energy, in particular because all of the problems mentioned above have to be resolved first, before measuring WT everywhere. This relativises the pertinence of this measure. Indeed, healthcare practitioners reminded us that they do not need to be confronted with problems, but rather with solutions for improvement. To do that, they said, they need a dialogue between the authorities and the healthcare professionals.

### 5.5.1.2 What is the purpose of measuring waiting times?

During the interviews, several objectives were identified:

- For the Authorities:
  - To manage the flow of new practitioners
  - To geographically better distribute/guarantee supply per province or region



Nevertheless, interviewees noted that an increase in supply will not automatically reduce the WT. An example is the pain clinics: the increasing of resources for the headache clinic has created a buzz, with more patients applying.

- For RIZIV/INAMI
  - To revise reimbursement conditions of some services (e.g. limiting the number of hours for which a clinical psychologist can be accredited creates waiting lists for hours for which the practice is conventioned, while there is still availability for hours for which the practice is not conventioned).
  - To gain a better understanding of the 'services'/procedures' that could be delegated and billed more properly.
- For hospital networks:
  - To better distribute services among their members (what is done better, where).
- For hospitals:
  - To allow managers to identify where human resources are needed to reach a WT target, seen as a quality standard. If undersupply is observed, it can be an objective parameter to negotiate additional human resources financing with the authorities.
  - To compare their accessibility with others (benchmarking).
  - To manage activity at departmental level and optimise patient recruitment.
  - To improve quality of care.
- For the healthcare practitioners:
  - To receive individual feedback and benchmarking.
  - To be more transparent about the opportunities to timely refer to another professional.

- To ensure the quality of care: waiting too long could have both physical and psychological effects. The consequences could be an aggravation of the problem and an increase in the duration of the treatment. In orthodontics, the situation in the mouth could change and therefore affect the length of treatment (when it is initiated).
  - There are some areas where it is possible to say what the acceptable WT is and/or what the recommendations are: perhaps for cancer treatment (the patient must be seen within 15 days), and perhaps for some vascular or cardiac surgeries.
- For the patients:
    - To increase transparency of information.
    - To be better informed in order to allow them to anticipate WT and timely organise their care (empowerment of the patient).
    - To be better informed in order to reassure about their own waiting time compared to the average waiting time.

In the Belgian context, it is important to note that, according to some people we interviewed, there seems to be room to take care of patient urgent needs identified by the HCPs. Consequently, it does not seem appropriate at present to dwell on a WT measure for urgent requests. Nevertheless other stakeholders insist on the fact that only the emergencies deserve to be prioritised, the rest of the demands are less important.

### 5.5.2 How are waiting times currently managed?

**Patients** facing WT tend to find an earlier appointment by making multiple calls. However, in many cases, only people with greater (health) literacy or privileges will succeed, mainly because they are able to pay for a private appointment which is more expensive. WT are often shorter for privileged people. Another way to reduce WT is to use emergency services instead of waiting for an appointment. This is also true for people whose GP has retired or gave up their practice and who have no entitled GP.

We heard from **HCPs** about different strategies to manage the potential WT.



A unanimous point is that emergencies cannot wait and that there are always possibilities to find an appointment for urgent matters. Therefore, the practitioners can either reserve fixed time slots for emergencies in the agenda or force the agenda to intercalate urgent patients, directly or via the secretariat. Some physicians ask, for example, to keep 20% of their consultations free until the last week, for 'last-minute emergency' appointments.

A system of triage allows to identify patients that need a (more) rapid appointment. The secretaries have often developed a clinical sense, as they are the ones who make a first selection and schedule an appointment according to the information provided (and can therefore see how to reduce the delay if necessary). They also have access to the physician if they are not sure of the appropriate delay to consider. For instance, they try to reduce WT as much as possible for oncology patients and to optimise the use of imaging equipment (MRI, scanner, Rx). Some orthodontists use video consultation as a 'pre-consultation' to get a first idea and make a triage of 50% of the patients to assess the emergency level.

For non-urgent cases, if WT are too long or the HCP cannot temporarily accept new patients, the practitioners either put the patients on a waiting list or sometimes give a list of other practitioners.

Some professionals, such as nurses or physiotherapists, have developed a network and are therefore able to refer the patients to another colleague according to their availability and specialisation. Such lists are also considered useful for other professions or for the mental health sector.

GPs are used to calling the specialists they know directly to force the agenda for their patients, by calling directly their personal GSM. However, this seems to be more difficult if the specialist works in a hospital. Nevertheless, when a GP calls, the privileged and human contact (linked to professional collaboration, to the fact that the doctor is calling because he/she has a 'clinical doubt') allows an appointment to be made that the patient would not have had if he/she had called himself/herself.

When patients are in continuous treatment and there is a shortage of available healthcare practitioners, the HCP would decide to spread the treatment, by temporarily reducing the frequency of the visits/consultations, for example once a week instead of two or three times a week.

In orthodontics, because HCPs mainly see patients for a long-term treatment, they either give a first appointment quickly, even if patients have to wait longer for the next steps, i.e. the start of the treatment, or they ask patients to wait longer for their first appointment but once patients are in the system, they will receive their next appointments quickly. In both cases, HCPs will schedule directly their next appointments and as a consequence have a clear view on their agenda for the next 4-6-12 months. This could also be the case for a treatment with a speech therapist.

In **the hospitals**, based on the responses of the people we interviewed, and therefore not covering all specialties and units, we found that:

- Waiting lists are used to manage the occupancy of operating rooms.
- For the follow-up of mothers who have just given birth and their babies, some maternity units provide an up-to-date list of available midwives. This is given to the mothers when they are at discharge.
- Where possible, if there is a shortage in a particular unit, staff will be moved from one unit to another (e.g. midwives from prenatal consultation to the maternity unit) to avoid or reduce WT.
- In some hospitals, there are special 'red lines' reserved for GPs to book appointments for their patients with a specialist with shorter WT. An assistant/post-graduated doctors will then answer the phone, not a secretary. Obviously, this system is not fair and discriminates against patients who do not have entitled GP. In this case, or if a patient tries to make an appointment directly with a specialist consulting in a hospital, if the WT is a too long, the patient may be referred to the private practice of the same physician, or to a 'private' schedule in the hospital, if the physician is not conventioned. Again, there are issues of equity.



However, some HCPs have tried to alleviate the situation by communicating towards patients that they will have to wait a certain amount of time for an appointment. Even if this does not solve the problem, it has the advantage to reducing the patient's anxiety.

The **sickness funds** have a list of nurses available for home visits and have a call centre to organise the visits.

## 5.6 Finding 3 – How could a measurement of the waiting times be set up?

### 5.6.1 Define the objective(s)

It is particularly important to clarify the purpose of collecting data to measure WT. If it is not, stakeholders will not be convinced of the added value of such a task. They need to get a kind of return on their investment of time and additional workload if they are asked to participate in a new data collection, whatever its format. Potential objectives are listed in section 5.5.1.2.

### 5.6.2 Define the data to be collected

Depending on the objective pursued, the data to be collected will be different.

First, the level of the data collection should be defined:

- Per HCP.
- Per setting (practice/hospital).
- Per region.

Secondly, one should define the start and end points of the WT measurement:

The starting point could be:

- The awareness of the first symptom.
- The decision to consult.
- The first phone call to fix an appointment for a consultation or a test.
- The date of prescription, but there is great variability between patients in whether they make an appointment quickly after receiving the prescription.
- The identification of the diagnoses.
- For hospitalisation: the consultation date when the surgeons decide to place a patient on the surgical programme.
- The date of the data collection.

The endpoint could be:

- The first available appointment date, but it will not be illustrative if there are free slots for emergencies.
- The third available appointment date.
- The hospital admission date.
- The contact with an HCP.
- The first contact with the HCP of the patient's choice: this is not as robust because WT may be affected by medical reasons (e.g. the need to have no more baby teeth for orthodontics, etc.).
- The availability of the test result.
- The date of the diagnosis.
- The date of the decision to treat.
- The start of the treatment.



- The WT for a new patient to be added to the patient waiting list in the case of disciplines where there are several sessions (per week) over several weeks/months/years, as for speech therapy, orthodontics or physiotherapy.

Thirdly, additional data are needed to interpret WT correctly and to allow comparisons:

- At the geographical level:
  - The general supply (number of HCP/imaging modalities/laboratories per inhabitant).
  - Data on the services offered in each hospital site: each hospital network operates in its own way, with its own objectives for the distribution of the services across its different sites.
- At the HCP/practice level:
  - Sociodemographic data (gender, age).
  - The specialty of the HCP;
  - The subspecialty of the HCP (e.g. Crohn's disease in gastroenterology). For midwives, those who assist with home births are scarcer.
  - Years of experience.
  - The number of working hours (per day and per week) of the HCP (full-time versus part-time).
  - Employment status (salaried versus self-employed).
  - Percentage of prestation as conventioned tariff: for example, for the first-line psychological consultations, quotas have been set for the number of consultations per psychologist and for the number of psychologists. Some psychologists have to mention that they can see patients, but outside the agreed framework, because the places within the framework are filled.
- The target population (e.g. children).
- The geographical location of the service (i.e. practice, hospital, imaging service, etc.).
- The number of no-shows and last-minute cancellations.
- Information on the proposed care:
  - In terms of length per prestation, number of sessions required, etc.
  - Planned or not.
- At the patient level:
  - Who is referring?
  - The geographical location of the patient.
  - The socio-demographic characteristics of the patient: e.g. the age → need for an appointment outside of school hours, employment status...
  - The type of patient:
    - New or already known by the HCP.
    - New problem or not.
  - The type of demand:
    - The appropriate timing of the demand (i.e. in orthodontics, the age of the patient, the state of the dentition...).
    - The demand for an HCP in general or a specific name or specific subspecialty.
    - The type of care (consultation, diagnostic procedure, treatment) and its complexity. However, for surgery, there is no record of standard labels for interventions at the national level. This list of standard labels should be developed before recording is possible.



- The urgency level of the demand:

As already mentioned, the concept of urgency could be read from different perspectives: the level of urgency perceived by the HCP could diverge from the one perceived by the patient. Indeed, in general, we heard during the interviews that the perception of what is urgent often differs between the patient and the HCP, with the patient being more alarmed than necessary. This sensitivity to the sense of urgency could also be more flexible than in other occupations: for example, an appointment is demanded quickly, but if it is proposed at the same time as a hairdresser's appointment, it could easily be postponed. An urgent need to see an ophthalmologist could be linked to a temporary promotion on glasses. Even for the HCP, the level of can be interpreted in different way: life-threatening condition, risk of sequelae, psychosocial risk (e.g. for treatment of Attention Deficit Hyperactivity Disorder in adults, a cardiac opinion is required for medication; this is not really urgent in general but in this specific situation, given the psychosocial risks (loss of job, relationship, etc.), WT will affect timely treatment).

In specific cases, administrative requirements affect the urgency of having an appointment, e.g. the age of the patient in orthodontics where patients must be seen before their 15<sup>th</sup> birthday in order to submit a file and obtain reimbursement for treatment. If a patient calls at the age of 14 years and 11 months, they need to be seen very quickly, even if it means starting treatment later. The same type of conditions exist for some speech therapy treatments. The level of urgency should then be documented, at least to exclude urgent cases from the measure if it is considered that they are not hampered by long WT (see section 5.5.1.2).

- The reasons for not accepting the first available appointment.
- Qualitative data on patients' wishes, past experiences, etc.: these influence appointments (e.g. to go to private hospitals, you need the money; refusal to go to a hospital even with an early

appointment because of bad experiences; when a patient has a cold, it's acceptable to visit a GP with short appointments (e.g. 10 minutes), otherwise, the patient may choose a GP who spends more time with each patient; etc.).

### 5.6.3 Define the source of the data

Different sources of data were identified by the respondents, but also mentioned as being complementary.

- From the patients: by surveying them about their experiences.
- From the HCP, the healthcare institutions or hospital network.
  - All HCPs: they can be recruited through their professional associations.
  - A specific subset of HCP according to pathology.
  - Representative sampling (practice, solo HCP, sentinel general practices, urban/rural, age...): as not all data are publicly known or centralised somewhere, a preliminary survey would be necessary to identify the characteristics required to draw up a representative sample. Sampling should be random, with a compensation for participation to limit the risk of bias. Otherwise, it is possible that only engaged people and/or people with either long WT (facing the problem) or short WT (having time to respond) would participate in a data collection.
  - Extraction from appointments software:
    - Several software packages are used for making appointments, sometimes combined with a physical secretary, but the coverage is low, especially outside the hospital and varies by type of HCP: practically no midwives, half of the dentists, 10% pf the psychologists use this type of software.
    - In the case of hospitalisation/surgery request, when the doctor sees the patient in consultation, the date of the request is



recorded, and the date of the operation is set. In this case, it is easy to use the agenda system.

- When patients can book an appointment online by themselves, there is no or insufficient information about the nature of the demand. This information is useful for triage (level of urgency or choice of the HCP regarding the pathology) but also for understanding why a particular time slot is chosen by the patient, when it is not the first available. The useful information available is therefore limited.
- Each user can customise the parameters of the software as useful for his/her use. As a result, there is no standardisation.
- Extraction from the EMR when it is available. Not all HCPs have access to their patients' EMR (they need a NIDHI identification code) and not all use it, e.g. some psychologists are reluctant for privacy reasons.
- From the NIDHI:
  - In general, the nomenclature codes have been identified as not usable data because they are not specific enough. Some codes are too general and cover several services with different delivery times. In the case of mental health related codes, they were pointed out as not properly used and thus not explanatory. Only a limited number of midwifery care relating to postnatal care could be extracted.
  - Data on the activity hours of HCPs is available from the NIDHI and could be used in order to interpret WT by practice size.
  - Extraction from billing software: several practice management software ('logiciels métiers' [zakelijke software]) recognised by the RIZIV/INAMI can be used for billing, but they are: not accessible to HCPs without the NIDHI identification code.
- From annual activity reports: for example, mental health services subsidised by the region (e.g. mobile teams) are required to submit annual reports and can therefore submit data.

#### 5.6.4 Define the design of the data collection

It is possible to collect data in order to look backwards or forwards, i.e. if you want to study WT in the past (retrospective) or in the future (prospective). The participants stated that prospective WT are the most relevant and objective and thus probably the most desirable to have. The measurement should assess the first available appointment in the discipline regardless of the professional being considered. In this way, WT should not be affected by the specific work schedule of each professional or by the long-term appointments needed by chronic patients. To avoid the effects of last-minute cancellations, it would be advisable to ask for the third available appointment. This method is suitable for radiology for example, as it does not depend on a specific practitioner.

In the case of postnatal care provided by midwives, it should be possible to collect WT as the starting point is the same for each mother (hospital discharge) and there is a specific protocol of home follow-up. It may be helpful to check that the above requirement (home visit 2 days after discharge) is being met. However, it does not seem to be a priority issue for the reasons mentioned above.

As this question is very methodological, the interviewees were not able to identify precisely the weaknesses of each approach.

#### 5.6.5 Define the data collection tool

Depending on the approach (prospective or retrospective), the interviewees identified useful tools to collect data:

- Specific recording via quantitative survey. Waiting time could be measured using clinical vignettes to take into account the various confounding factors influencing the value of waiting time.
- Specific recording via qualitative data collection.
- Extraction from software. If this solution seems to be the most practical, several issues were pointed out, mainly regarding coverage and standardisation of the tools (see above).



### 5.6.6 Define the rhythm of the data collection

The appropriate rhythm of the data collection depends on the objective of the WT measurement and is discipline related. A 'real-time' information is useful for the speech-therapists for instance because the situation changes rapidly, but requires frequent data collection. For some disciplines, there is some seasonality: the reasons to consult a GP differ in the summer and winter, therefore data collection is needed every 3 months to capture this.

According to participant, the rhythm could also differ according to the data collection objective: If it's for organising care once every quarter, that's fine, just to capture seasonal variations, but if it's for informing patients, you need very regular updates. If it's for infrastructure planning, annual data might be enough.

### 5.6.7 Define the data extraction/transmission mode

It will be necessary to define who will be responsible for the transmission of the data and the format of the extraction. The interviewees did not make concrete proposals, but they stressed that it will require a good ICT support.

### 5.6.8 Analysis of the data

Different levels of analysis have been identified as useful, again depending on the objective of the WT measurement. It could be done:

- per region;
- per care area ('zorgzone'/'bassin de soins');
- per HCP with different approaches, e.g. according to the status of the HCP (conventioned/not conventioned), comparing WT when the patients search for an appointment or if the demand comes from the GP. There are still several issues to be addressed, such as how to

manage the combination of several types of status (combination of hospital and private practice).

- per (sub)- specialty.
- per pathology.
  - according to the recommended maximum time to treatment.
  - according to the availability and capacity to perform the care, examination/imaging (full-body MRI not in every centre), or procedure (complex surgery<sup>99</sup>).
  - according clinical vignettes helping to describe the level of urgency, the need of sub-specialised HCP, the resource needed...
- per line of care: a distinction needs to be made between primary care (first referral-generalist emergencies), secondary care (hospital or outpatient specialists), tertiary care and quaternary care (university-type medicine where a specialist refers a patient to another specialist, e.g. complex cancer, rare diseases).
- Per type of settings: private practice/hospital consultation, university hospital or not...

All the factors influencing WT and the way HCP manages them must be taken in consideration for the analysis (see 5.4.2).

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<sup>99</sup> Transplant are out of scope of the current study



## 5.7 Finding 4 – Barriers to measure waiting times

Acceptability to participate in a data collection on WT is low:

- The objective of the data collection on WT is not clear: what is the personal interest in measuring WT for the HCPs who do not perceive it as a problem. Moreover, some HCPs fear to be obliged to accept new patients if NIDHI uses the WT as a quality control.
- Pertinence to measure WT is questionable, i.e. collecting data on what is not recommended is questionable (e.g. WT for midwives, see 5.5.1.1).
- There are other actions that must be taken first before to collect WT data (see 0), including using already available data to assess the accessibility of care. It would be preferable to work on health targets.
- It requires time and resources that HCPs do not have: Participating in additional data collection is time-consuming in a context where time is lacking. Nobody has the time, so it will be difficult to find volunteers to participate in such data collection.
- Validity and reliability of the collected data is questionable: Bias if data is collected by a survey with an unrepresentative sample.
- It is impossible to control for all the factors that affect the interpretation of WT, such as the presence of chronic patients in the data collection.
- Interpretation of the results is questionable (see 5.4).
- Feasibility is questionable (see 5.6) and mental workload seems to be heavy.
- A core questionnaire will be difficult to build and will require to be adapted for each discipline.
- Problem in mental health because it is spread on different levels of competence.

More generally, the response rate will depend on the expected improvements in the way HCPs work.

## 5.8 Finding 5 – Conditions to start a measurement

During the interviews, the stakeholders mentioned several prerequisites to a new data collection or analysis on WT.

- A list of interventions and essential care should be established in order to identify priorities for WT measurement (cf. COVID list of the group of associations of medical specialists (Groupement des unions professionnelles belges de médecin spécialistes/verbond der Belgische Beroepsverenigingen van Artsen-Specialisten) or OECD surgery list see Box 2).
- An objectivation of the distribution of HCPs across the country would already be useful to identify shortages by region. To do so, HCPs should record data on their practice place(s), what is besides foreseen in the Prosanté/ProGezondheid plan.
- Data on HCPs characteristics have to be collected in order to build a representative sample of the HCPs in which WT could be measured.
- Indicators on the health system performance already exist, but stakeholders complain that debates on them have not been initiated.
- For the data collection itself:
  - The amount of data requested must be reasonable and well selected, otherwise it will not be feasible given the resources available, especially in hospitals.
  - It should require limited human resources or energy, for example by automated data extraction.
  - Financial support will be needed.
  - Data must be solid and easy to collect.
  - A template should be provided for data extraction.
  - Uniformity of the data collection tools is required (including definition).



## 5.9 Finding 6 – Who should have access to the data?

In general, stakeholders would give access to WT data to everyone who can use it to improve the system. They plead for the communication of aggregated data, per network or region.

Stakeholders raised in particular the following future users:

- Authorities (Minister, SPF): to decide on investments. For example, the mental health sector needs more financing. A stakeholder illustrates this 'When you have a broken leg, you receive immediate care, whereas when you have a suicidal child, you are sent home and must wait 6 months for care... and then you no longer have a child! We should invest more in mental health care!'
- NIDHI: The data should be accessible to NIDHI to adjust reimbursement conditions, e.g. for the age of the patients in the case of orthodontic care.
- Hospitals:
  - WT measurement is useful for internal management of the departments.
  - To check their position on the market compared to national means (benchmarking). To let the well-positioned hospitals know it, and to give others the opportunity to improve. Strategically, it's useful to know that some hospitals have well-developed activities with short turnaround times. On the one hand, these activities could be left to the centres that handle them well, so that patients can benefit from them. On the other hand, it can be left to the hospital to use the data for their own purposes.
  - To compare WT between hospital and private practice specialists: It would be interesting for hospitals in terms of medical positioning, to see if there is competition with a well-connected local network, for example. This data would be useful for strategic steering of the hospitals.
- HCPs:

They could also use the figures at a global level to inform the patients on the theoretical delay to get an appointment in certain disciplines, or, if the data are provided at an individual level, as personal feedback or to refer to another HCP (from the same discipline if they are not able to accept new patients, or to a HCP from another discipline to refer timely their patients). For example, dentists/orthodontists (referring for malocclusion or dysphagia), ENT specialists (if there is a vocal cord problem) or internists (once the patients have been discharged from hospital) may be interested in the speech therapists' appointment delays. However, it was related that GPs, for instance, would not appreciate their data being available at an individual level. Instead, the data could be managed by a third party, such as the person of trust in the medical 'circles,' who could look after the population management aspect.
- Universities: Universities must train future colleagues and encourage new professionals (such as physiotherapists) to set up practices where they are needed.
- Sickness funds to inform patients.
- At the 'population' level
- Schools to make referral of children or adolescents with learning disabilities to speech therapists.
- Structures that support patients (social workers, OCMW/CPAS, etc.)
- Patients:

However, there is no consensus on giving access to patients.

  - It can have a negative effect and lead to more medical shopping by patients who want to optimise their WT but forget to cancel appointments that will not be kept.
  - There is a risk of competition between hospitals or HCPs (risk that patients change to another hospital or HCP where there is more rapid availability).



- Privacy of HCPs will be at risk.
- Risk of creating a negative psychological effect because they will realise that they have to wait.
- Risk of commercialisation: the internet website will take advantage of the visibility.

Stakeholders in favour of communicating the WT to the patients pointed out:

- Transparency, but on the condition that only the specialty or domain of expertise is communicated.
- Usefulness of WT visibility to allow patients to plan appointments but no communication on availability of individual HCP.
- Allowing informed decision making by the patients.
- Consideration of the perverse effects of out-of-date WT communication (if the WT has changed in relation to the time originally announced, this can lead to patient dissatisfaction).

### 5.10 Finding 7 – Examples

Interviewees reported examples of measures they (have) used:

- Monitoring of the activity in their own practice.
- Survey among orthodontists at national level.
- Survey among ophthalmologists at national level.
- Survey among psychiatrists, psychologists and financed institutions in the Flemish part.
- In hospital:
  - In hospital A, 3-4 'types of visits' have been identified by department in the IT system. They measure the delay between the date of the prescription for hospitalisation and the date of hospital admission. They have developed indicators at a more precise level

than the specialty. This makes it possible to monitor WT in various specialties.

- In hospital B, they performed a retrospective analysis: measurement of the time between the first demand for an appointment and the delay to get it. Means are reported by WT target (for an appointment in X weeks, in X months/year).

### 5.11 Conclusion

We interviewed twenty-four types of stakeholders from different settings, disciplines, and regions to capture their perception of measuring WT in Belgium.

Listening to their discourses, we can conclude that in general, while it is largely accepted that there are problems in certain disciplines or regions, the acceptability to participate in a data collection is weak when there is no direct benefit for the HCP.

The interviews allowed us to point out that data collection for all HCPs, surgeries, or imaging procedures in all disciplines will be very challenging. The data to be collected will depend on the specificity of the (sub-)disciplines and the characteristic of the patient's demand (level of emergency, need of a sub-specialist, pathology, resource needed): it is impossible to foresee every situation without working further per domain. Moreover, the amount of data to be collected should be huge in order to lead to representativity and a correct interpretation of the results.

All the findings are a rich source to reflect on the relevance of such data collection and precautions for interpretation.



## 6 CONCRETE PROPOSALS FOR ASSESSING WAITING TIMES IN BELGIUM

These proposals should be considered in light of the specificities of the Belgian healthcare context.

- The provision of care in Belgium is based on the principles of independent medical practice, direct access (without gatekeeping), free choice of physicians and healthcare facilities (including hospitals), and predominantly fee-for-service payment.<sup>310</sup>
- Reimbursed healthcare services are provided by both public and private institutions, as well as individual healthcare providers who comply with the same set of rules and offer the same services. Patients have the freedom to choose their healthcare providers and can access most specialized and inpatient care without prior assessment by a general practitioner (GP).<sup>310</sup>
- The available databases are focused on reimbursed care or hospital funding, and do not register referral dates or decision-to-treat dates.

### 6.1 Introduction

In reviewing the experience of measuring WT in the healthcare sector in Belgium, we identified several initiatives related to consultations with a HCP, diagnostic procedures, surgery, and cancer treatment (see Chapter 4). Only one of these is a systematic collection of WT: it concerns WT for mental health care provided in the Centra Geestelijke Gezondheidszorg (CGGs, mental health care centres in Flanders). The other initiatives were based on the National Health Service billing databases or surveys of professionals or patients. With the exception of the patient survey included in the HIS, these initiatives were carried out only once and were therefore could not provide data over time. In this chapter, we describe concrete proposals for the collection of WT in the Belgian healthcare sector in an attempt to avoid the pitfalls of the initiatives identified, namely the production of outdated data,

non-adjustment for confounding factors, recall bias or bias associated with the use of proxies. These proposals aim to meet the specific needs of public health authorities.

The development of these proposals is based on the results of the literature review, the international experiences, and the perspectives of the HCPs interviewed. These proposals were discussed with a group of experts (see colophon) and then revised by the KCE research team. KCE is the solely responsible for the proposals described below.

### 6.2 Health Authorities' needs for waiting time assessment

We interviewed members of the federal health authorities from different departments and members of the federated health authorities of the Walloon Region, the German-speaking community, and the Brussels-Capital Region. The Flemish authorities answered our questions by mails.

#### 6.2.1 Common objectives of data collection regarding by all health authorities

The following objectives of the WT data collection were shared by all healthcare authorities:

- To identify potential **problems with access to healthcare professionals** as part of workforce planning.
- To identify potential **problems with access to healthcare facilities** such as imaging equipment.

#### WT as a shortage indicator for health workforce planning

The aim was not to use the value of WT per se, but to analyse the trend of WT over time to identify potential shortages at country, regional, or local levels. To achieve this goal, WT should be assessed for healthcare professions that are subject to workforce planning, i.e. physicians and dentists. As it is the evolution of WT over the time and not the value that is of interest, it does not seem to measure WT for all professionals concerned.



Consequently, measuring WT in a representative sample of HCPs could provide sufficient information.

### WT as a tool for planning facilities and equipment

Some facilities or equipment are considered to be of particular interest. Because they are subject to infrastructure planning, CT, PET-CT PET-MRI, SPECT-CT, and MRI are imaging devices of interest and WT to get an appointment. To inform the planning, the WT should be assessed in all centres. Data collection is here on a higher level and not at the level of individual healthcare professionals.

The need for WT measurement for access to care provided in mental health facilities has been highlighted by both federal and federated authorities.

#### 6.2.2 Specific considerations of the federal health authorities

Two specific objectives were reported by the federal health authorities:

- To adjust **funding** to improve access to affordable care.
- To participate in **international benchmarking** (e.g. WT for scheduled surgeries at OECD level).

### WT as an indicator for improving equity and ensuring affordable care

The comparison of WT in care provided by 'conventioned' professionals (i.e. healthcare professionals acceding to the agreement on national tariffs) compared to non-conventioned professionals can be used as an indicator of access to care. If disparities are observed between professions depending on their adherence to the tariff agreement, incentives to avoid two-speed medicine can be considered. To achieve this, WT should be assessed in all types of healthcare professions and information on adherence to the tariff agreement should be collected. Again, this objective does not seem to require the measurement of WT in all HCPs, but at least WT in a representative sample.

### WT in international benchmarking

The main international benchmarking of WT takes place at the OECD level.<sup>3</sup> To achieve this objective, WT should focus on the scheduled surgical procedures described in Box 1. Daily data collection in all hospitals does not seem to be necessary. However, as the measurements of WT reported by the different countries are so different, this objective could be achieved by collecting data a once a year in a representative sample of hospitals.

#### 6.2.3 Specific consideration of the federal entities

The federated entities stressed that WT could be used to improve the distribution of professionals on their territory. However, they mentioned that the assessment alone is not sufficient to evaluate access to care or to assess the care needs of the population. WT assessment should be accompanied by the development and implementation of strategies to reduce WT.

## 6.3 Concrete proposals for the evaluation of waiting times in Belgium

#### 6.3.1 Aim of the data collection

The measurement of WT should support the policy-making process at federal and regional level but should not be used at the individual level to inform the population about the availability of individual care providers or facilities.

The measurement of WT should support the policy-making process at federal and regional level with regard to the planning of human resources, the planning of material resources (equipment, devices or facilities), improving the equity, maintaining of affordable care, and participating of international benchmarking on WT.



To meet the objectives of the health authorities, it is not necessary to collect individual data, which can also be very costly. What's more, the interviews revealed that there is very little support for recording data to measure WT, because of the administrative burden involved, and IT infrastructure required. In some professions, WT is not seen as a priority. In addition, there is even a great deal of reluctance to exchange individual data.

In Belgium, private initiatives have been developed online to help people to find an HCP and book an appointment according to their agenda. These initiatives provide an up-to-date view of an HCP's agenda and available slots. Each HCP subscribes to these websites on a voluntary basis in return for payment to the developer under a commercial contract that governs the terms of data exchange. This is out-of-scope the scope of this project.

### 6.3.2 General principles of the waiting time assessment

A generalised and continuous WT assessment system should **not** be considered.

There is no 'one size fits all' data collection system. Most of the countries studied select a set of diseases, procedures and/or interventions, and measure specific WT intervals (e.g. from GP referral to the specialist appointment). The lack of a 'one size fits all' approach is confirmed by the interviews with the Belgian stakeholders who mentioned that the definition of WT varies widely between professions, disciplines (including subspecialties), services, or patient's needs (level of urgency, pathology, etc.) and that the interpretation of data should be done at the level of individual professions.

Furthermore, WT alone is not sufficient to assess access to care. As shown in KCE report 370<sup>1</sup>, access to care is a multidimensional dimension that is currently assessed by 18 indicators covering both geographical and financial access. Although the literature is unclear on the relationship between WT and health outcomes, the choice of priorities should be driven by the burden

of disease and the issues of the availability (accessibility) of the HCP workforce.

During the interviews, professionals reported that they were already aware of problems with WT in several areas of care. Given the limited resources in health care, it is preferable to focus on developing strategies to deal with inappropriate WT<sup>hh</sup>.

According to the experts, a real-time and continuous overview of WT will not add much value to meet the health authorities' objectives. Therefore, it should not be necessary to have an assessment of WT for all services in all professions (exhaustiveness), but a representative picture of WT in specific situations should be sufficiently informative.

### 6.3.3 Characteristics of a data collection adapted to the Belgian healthcare system

A balance should be struck between the value of measuring WT for policy-making and the cost of data collection.

In Belgium, the most appropriate data collection system seems to be based on prospective assessment, for a selection of services, procedures and interventions, and in a representative sample of HCPs and facilities.

The free choice of healthcare provider by patients in Belgium allows direct access to specialised care. As there is no gatekeeping, the characteristics of the referrals are not recorded. Therefore, no existing database can be used to retrospectively assess WT for appointment in specialised care as in other countries with a strong health information system and gatekeeping. Furthermore, experience from other countries has shown that it is impossible to interpret.

<sup>hh</sup> Inappropriate WT is defined below

**Action point:** Organise a prospective assessment of WT.

Several data collection methods were identified through the literature search (see chapter 2), Belgian experience (see chapter 4), and international experiences (see chapter 3). These methods analysed data describing WT observed in the past (retrospective assessment) or current WT for care or health intervention not yet provided (prospective assessment). The data source can be patients, healthcare providers or institutions, or health authorities.

We did not consider using patients as a data source to assess WT because of several disadvantages, including recall bias, a different perception of urgency compared to healthcare providers (HCPs)... Instead, we suggest considering healthcare providers or institutions as potential sources of data. However, the findings in chapter 5 suggest that while they can be a source of data, they should not be responsible for data collection due to the heavy administrative burden that currently exists. Therefore, the burden of data collection should be borne by health authorities, as routine databases cannot accurately describe WT (section 4.3).

A prospective assessment of the WT offers several advantages with regard to the cost of the data collection, and its interpretation. As experience from abroad and attempts in Belgium for imaging and cataract surgery have shown, it is impossible to interpret the absolute value of WT collected retrospectively in administrative databases. Indeed, urgency of care, patient preferences for appointment scheduling, presence of comorbidities that delay care and tariff rules are factors identified in the interviews that may influence access to care. Retrospective data collection can only provide WT adjusted for potential confounders available in the database used for the assessment, and these factors are not always captured. The potential absence of relevant confounders in the database may lead to imprecision about the absolute value of WT. In addition, retrospective data collection describes past WT (see section 2.2): using past episodes of care to assess the value of WT may give a biased picture of current WT due to possible changes in the organisation of care or medical innovations.

In Belgium, attempts to use the National Health Service billing databases for to assess WT for imaging and cataract surgery were unsuccessful because it was not possible to retrieve the information needed to adjust and interpret the WT (see Chapter 1.1). To be able to interpret (routinely) collected data, an access to clinical data would be needed. However, linking between electronic medical records (EMR) and administrative databases to assess WT raises questions about the security of the data process, particularly in a context of the mistrust of EMR data sharing identified during the interviews. The use of EMR to extract WT is also compromised by the lack of systematic and standardised data recording in the EMR (date of diagnosis and decision to treat, service or HCP referred, diagnosis...) and the wide range of medical software with their own databases and processes, as reported during the interviews. As reported during the interviews, the administrative burden of collecting data on WT is perceived as high by HCPs in Belgium. Therefore, the burden of data collection should be borne by the public authorities rather than by professionals.

In the literature, the mystery shopper method is often reported as a prospective data collection design. This study design involves fictitious patients call for an appointment with a care provider or for a medical intervention. Researchers use precise medical vignettes to describe the clinical situation. This method appears to be appropriate for assessing WT for consultations with an HCP or for booking an imaging procedure. Although the studies identified are from the US, the methodology is transferable to the Belgian context, as this type of experiment is not subject to the full force of the law on human experimentation (7 May 2005 MB 18/05/2004). However, the institutions collecting the data should inform the potential participants. The third available slot to receive a service, intervention or procedure may be chosen for outpatient care to eliminate the effect of last-minute cancellations.<sup>311</sup>

The mystery shopper method uses 'clinical vignettes', i.e. a precise scenario framework including a description of symptoms, pathology, characteristics of the patients (age, gender, medical history...), level of urgency. The 'clinical vignettes' are used to standardise each call allowing to assess WT in a specific situation. A prospective cross-sectional data collection based on 'clinical vignettes' by telephone and/or online survey has several



strengths, such as assessing of WT in a precise context, facilitating the interpretation of the data collected, providing WT in real time or reducing the risk of data manipulation, as seen in other countries. According to the experts consulted, prospective data collection could provide a clear picture of WT at a given point in time. If the measurement is carried out on a regular basis, trends in the evolution of WT could be analysed, with a limited number of resources to ensure a balance between the costs and benefits of data collection. Several data collections per year may be necessary to capture seasonal effects. The frequency of data collection may vary according to the discipline concerned.

Although cross-sectional data collection has several advantages, there are several prerequisites for its implementation:

- The scope of the data collection should be well defined:

Data collection on WT should focus on consultations for a new health problem as observed in other countries. As mentioned in the interviews, there is no interest in assessing WT for patients who have started the care pathways, but to focus on the WT experienced by a patient who needs to start the care pathway (e.g. for an orthodontic treatment, care by a speech therapist, diabetic care pathway or renal failure pathway).

For imaging, WT measurement should focus on procedures that can be booked in the outpatient setting. Imaging that is programmed directly by an HCP or performed in an emergency context is less informative for the facility planning.

- The type of data collected should be well defined in order to obtain interpretable data. Clinical vignettes can help to capture the clinical dimensions that influence WT such as pathologies, potential need for specialised care, level of urgency, co-morbidities, referrals from other HCP,... Stakeholders should be involved in the development of the clinical vignettes (see Working Groups below). In addition, the number

of clinical vignettes should be limited to ensure a manageable data collection, but to give a representative picture of possible situations experienced by patients. : '*Parsimonious performance indicator systems have a greater chance of delivering high quality data than voluminous systems.*'<sup>269</sup>

- To capture organisational dimensions affecting WT, data should be collected in different care contexts (academic hospitals<sup>ii</sup>, regional hospitals vs private practices), in different geographical areas (different regions; urban vs rural,...) and in different tariff schemes (conventioned, non-conventioned).
- To build a representative sample, administrative data should be gathered to select the participants (see below).

For the assessment of WT for scheduled surgery, the mystery shopper method is not suitable as the scheduled surgery is planned by the care providers directly in concertation with the patient. Therefore, a specific data collection design should be considered.

**Action point:** Select services, interventions, and procedures for which WT should be assessed.

Based on experience from abroad, even when routine databases are used, the WT recording focuses on a selection of a reasonable number of items to be recorded: type of WT intervals (time to appointment, time to diagnostic procedure, time to treatment) but also specific specialties, procedures or surgeries.

Based on interviews, identified health authority objectives and exchanges with experts, we propose to focus on the following services, procedures, or interventions:

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<sup>ii</sup> In an academic hospital, WT may be affected by their activities that need a high and specific expertise while regional hospitals provide mainly low-variable care.



### Appointment with a healthcare professional

In some professions such as home care nurses, physiotherapists, speech therapists, or midwives, the interviewed practitioners reported that they use an informal network system to avoid WT: patients are referred to other practices in their informal network if there is no place in their own practice.

We therefore propose to focus the assessment of WT on professions where a shortage signal has already been identified and where WT may have a potentially higher direct negative impact on health outcomes, i.e. **GPs, dentists, clinical psychologists** and **specialists**. For the latter, a selection of disciplines to be studied should be defined by a working group on 'Appointment with healthcare professionals' (see below).

Other health professions could eventually also be selected and managed by the *ad hoc* working group including stakeholders from these healthcare professions.

### Imaging

In addition to the imaging provided by equipment/devices subject to planning, it was reported during the interviews that WT should be also considered for high-volume imaging with an already known long WT (e.g. ultrasound). According to experts, a long WT for ultrasound may lead doctors to deviate from the guidelines and good practice by replacing ultrasound with abdominal CT-scan, which has a shorter WT. Interviewees also reported that the WT for an imaging procedure may also depend on the operator or the technical characteristics of the equipment (e.g. MRI should be calibrated by anatomical zones such as abdomen, spine, skull, shoulder, knee, female pelvis, prostate, upper or lower limb joints, arterial vascular system...).

The choice of imaging procedures to be included in WT assessments should be discussed in Working Group – Imaging (see below).

### Surgery

WT should be assessed for a selection of surgeries, at least those used in the OECD assessment (i.e. cataract surgery, percutaneous transluminal

coronary angioplasty (PTCA), coronary artery bypass grafting (CABG), prostatectomy, hysterectomy, hip replacement (total and partial, including the revision of hip replacement), and knee replacement (including the revision of knee replacement)), considered together with other scheduled surgeries (as appropriate) selected by the Working Group – Surgery (see below).

**Action point:** Build a representative sample of healthcare providers and facilities to assess WT.

In order to build a representative sample (at random or with volunteers) and select participants, characteristics of health care providers or facilities should be collected, such as:

- Geographical location of the practice or care facility.
- Type of practice (at hospital or in community).
- Availability of the professionals (e.g. working hours).
- Possible sub-specialisation of the care provider.

Some of these characteristics are available in existing administrative databases, others need to be collected during the WT assessment. In addition, the sample size should be sufficient to ensure the representativeness in all regions.

#### 6.3.4 Organisation of the data collection

If it is decided to collect WT data in Belgium, a systematic involvement of stakeholders is recommended.

International experience has shown that stakeholder involvement is essential to facilitate the acceptance and usefulness of the data collection. Furthermore, as mentioned above, stakeholder involvement is crucial to define the different dimensions needed for the prospective assessment of WT (see above).



**Action point:** Operationalise stakeholder involvement in the form of Working Groups.

Several Working Groups can be set up according to the themes (e.g. access to imaging, surgery, cancer treatment, consultation with a healthcare professional) but also according to sub-themes (e.g. consultation with an ophthalmologist, a gynaecologist, a general dentist, a paediatric dentist, etc.).

As there is no 'one size fits all' data collection system, the Working Groups can provide the necessary input to create a polymorphic system that can adapt the data collection methods to the characteristics of each theme and sub-theme.

**Action point:** Define the missions of the Working Groups including:

- The definition of the **sub-theme(s)** of the WT assessment (e.g. in imaging, focus on already known problem such as MRI and ultrasound or focus on equipment under planning such as PET-San, CT-scan)
- The definition of the **data collection protocol**:
  - Methods to be used (e.g. prospective data collection).
  - Criteria for establishing representative samples of participants, if this option is chosen.
  - Content of the clinical vignettes, if this option is chosen.
  - Practical data collection procedure (e.g. prospective data collection by online survey, by telephone survey...).
  - Data format and type of analysis (e.g. mean, median, proportion of patients waiting longer than a defined period)
- The definition of maximum **WT**, which allows WT to be classified as inappropriate or not.

- The **insight for interpreting** the results of the WT assessments.
- The analyse of **potential strategies** to address inappropriate WT and propose solutions for implementation.
- The provision of **regular feedback** to the concerned authorities.

### Sub-theme(s) of the WT assessment

Based on the interviews, we conclude that working with sub-themes is crucial to have accurate and interpretable data. For example, the Working Groups should consider:

- If WT is to be assessed for an appointment with a specialist, should WT be assessed in all disciplines or only in a subset of disciplines where access problems have already been identified by the field or where the effect of WT on health outcomes is more important...?
- If WT is to be assessed for an oral health appointment, should WT be assessed in general dentistry, paediatric dentistry, orthodontics, or parodontics? If WT is to be assessed for a mental health appointment, should WT be assessed in clinical psychologists, psychiatrists, in which setting (community, hospitals, mental health centres)?
- ...

### Data collection protocol

Depending on the aim of the WT assessment, a data collection protocol is required to ensure that appropriate methods are selected. At present, a prospective data collection appears to be the most efficient method for assessing WT in Belgium but this should be reconsidered as new evidence and/or experience of data collection in Belgium emerges.

If it is confirmed to work with a sample of participants to assess WT (again probably the most efficient method according to the interviews), the Working Groups should identify relevant characteristics of practices and providers in



order to build representative samples with regard to potential confounding factors.

The format of the collection tools and the data collected may vary depending on the theme (e.g. access to imaging, to surgery) or specialty (e.g. appointment with an ophthalmologist, a dentist, etc.) being considered, and should be discussed in each working group based on the available evidence. However, the experts emphasised that the Working Groups should work closely with Waiting Time Monitoring Commission (see below) to apply the same working methodology to ensure consistency in the development of the tool across the specialties and comparability of results.

If the use of vignettes is the chosen option, the content of the clinical vignettes should be defined by the working group.

### **Inappropriate WT**

Inappropriate WT is a WT that may affect patient outcomes, or professional organisation. The assessment of WT per se may be difficult to interpret if no optimal WT is predefined. In other countries, the maximum WT is almost always predefined and used as a threshold to categorise data (e.g. referral to treatment for more or less than 18 weeks).

As far as possible, inappropriate WT should be defined for each proposed WT assessment as observed in other countries. This definition should be based on evidence from the scientific literature or in the absence of evidence, on a formal procedure to find a consensus value that includes also patient representatives.

### **Support for interpretation**

The interpretation of the WT values and their evolution over time need to take into account several factors (e.g. contextual factors affecting access to care). Working Groups should identify these factors and include them in the analysis of the WT values.

### **Strategies to address inappropriate WT**

Working Groups should assess the range of strategies identified in the literature (see section 2.5) as effective for each sub-theme. Strategies can be organised at micro (=at the practice or hospital level), meso (=hospital networks/primary care area) and macro (=regions or Belgium) levels. Incentives to implement these strategies should be discussed and reported in an advice to the authorities concerned.

### **Regular feedback to the relevant authorities**

No WT assessment can be used in isolation. A transversal vision is needed to ensure adequate policies. Regular feedback from the Working Groups to the relevant authorities (see below) is required.

**Action point:** Establish Working Groups with key stakeholders such as representatives of relevant healthcare professionals, representatives of data managers and specific organisations such as Belmip for imaging.

Working Groups should include:

- Representatives of the professions and institutions for which data collection is planned. This includes healthcare providers but also representatives of data managers (both from the authorities (e.g. Health Data Agency, Informatieveiligheids-comité/Comité de sécurité de l'information, RIZV/INAMI, research, development and quality promotion department and data management department of the FOD VVVL/SPF SPSCAE) and people from the data management and ICT field (e.g. for professional software)). According to the experts, the members of Working Groups should include the providers in the focus area, as they are the only ones who can really interpret the data.
- Members of specific organisations working on selected themes such as Belmip for imaging, BCR for cancer WT, etc.
- Representative of the Waiting Time Monitoring Commission (see below) to ensure consistency of approaches across Working Groups.



- Patient representatives.

However, the experts noted that the size of the Working Groups should remain reasonable to ensure efficiency.

In order to be able to analyse trends in WT, a specific structure should be set up within the Ministry in order to make data collection permanent and to avoid one-off measurements.

From the experience from abroad, we have learnt that it may be helpful to build the system for WT recording progressively. To coordinate the development of this system and to monitor the specific problems of WT in Belgium, a specific structure, referred to here as the **Waiting Time Monitoring Commission (WTMC)**, should be established within the Ministry of Health to monitor the problems of WT in Belgium.

Based on the model used for the health workforce planning, policy makers could set up a WTMC to monitor the WT. As for the health workforce planning, the WTM could be supported by a planning cell of the FOD VVVL/SPF SPSCAE. The advisory body, supported by the administration, should be set up not only to assess WT but also to propose strategies to the relevant ministers to tackle inappropriate WT. It is important to work on the synergies between the different administrations (RIZIV/INAMI, FOD VVVL/SPF SPSCAE, KCE, Sciensano, AVIQ in Wallonia, het departement zorg in Flanders...), as each administration can contribute its competences. The creation of an official WTMC will not only give visibility, but also the power to make proposals. Dedicated resources will be needed for the tasks set (see below).

**Action point:** Specify the missions of the WTMC including:

- Definition of the objectives of data collection on WT (see section 1.1).
- Selection and prioritisation of health theme(s) (e.g. access to imaging, to surgery, to cancer treatment, visiting with a healthcare professional) for which WT should be assessed.

- Establishment of specific Working Groups according to the selection of health theme(s) for which WT should be assessed.
- Decisions on the data collection process based on the advice of the Working Groups including the methods to be used, the frequency of the collection, etc.
- Data collection
  - At the care provider level as a form of feedback (for individual (and confidential) benchmarking with global results of all the care providers from the same data collection).
  - At the national level as an indicator of the performance of the Belgian health system.
  - At the international level as a benchmark (e.g. at the OECD level for surgeries).
- Formulation of advises to the Minister of Public Health and the Ministers of Health of the federated entities and the health administrations (such as FOD VVVL/SPF SPSCAE, RIZIV/INAMI, AVIQ, Departement Zorg...) on strategies to tackle inappropriate WT.

### Objectives of the WT assessment

Each working group will be set up by the relevant authority according to pre-established priorities. The objectives of the WT assessment should be clearly defined in order to select the appropriate indicator(s). For example, there may be different levels of purpose for WT assessment: the clinical level (e.g. providing accurate local information to facilitate patient choice of place of treatment) or the policy level (e.g. global planning or international benchmarking). This should be clearly predefined. The objectives described in section 6.3.1 could be a starting point.



### Selection and prioritisation

The selection and prioritisation of the sectors in which WT should be assessed, would be the responsibility of the health authorities to avoid any corporatism or conflict of interest. In addition, the choice should be in line with the political priority of the country and regions.

The setting of priorities in each theme area needs to be discussed in each working group advising the WTM. The selection of priorities should be based on administrative data and experience in the field (e.g. surveys conducted by health professional associations...). The final decision on the priority theme(s) is the responsibility of the WTM.

### Setting up of Working Groups

If the idea of using Working Groups is considered, stakeholder involvement, as observed in other countries, is necessary to ensure compliance with data collection, to support the interpretation of results, and to develop strategies to address inappropriate WT (see above). Depending on the theme chosen, the WTM should establish a specific working group.

### Data collection and reporting

Data collection and reporting should be organised at the level of the health authorities to support the national and international information on access to care in Belgium. However, it is important to remember that WT assessment is part of the evaluation of access to care, but WT alone is not sufficient to assess access to care.

It is very important to set up a clear data collection procedure to ensure good quality of the collected data.

Feedback to data providers can support the organisation of care at the macro level (federal and federated entities), meso (care area, hospital networks) and micro (care providers) levels. Public communication (at least of aggregated data) should be considered. Indeed, access to timely waiting times data with feedback loops is crucial to stimulate the data providers to participate in the data collection.<sup>269</sup>

### Advices to authorities

**Action point:** Integrate the analysis of waiting times into a broader analysis of access to care.

Measuring WT alone is not interesting, but interviewees reminded us that there is a need for strategies to address access to care issues. In addition, as observed in other countries, having a strong information system on WT, supported by WT targets is not enough to reduce WT. Therefore, advising health authorities on strategies for WT reduction should be a core task of the WTM. The conclusions of the WTM should be integrated into an overall strategy for access to care in Belgium.

The WTM could base its advice on pilot studies and implementation research on specific strategies. This type of research can help to further refine the strategy, make it acceptable to all stakeholders, enable a greater uptake and effectiveness. For complex interventions, efforts should be made to evaluate the individual elements of the intervention.

### 6.3.5 Evaluation of the waiting time assessment process

An external evaluation of the data collection process and the quality of the data obtained should be carried out on the basis of predefined indicators.

We have learnt from experience abroad that the assessment of WT can be disappointing because it does not give an accurate picture of how long a patient has to wait in the practice, for example:

- Focus on a particular part of the patient pathway.
- Exclusion of some patients from the record (e.g. appointment cancellation, clock pause...).
- Errors in data collection.
- Risk of data manipulation (e.g. to avoid pressure from the managers, authorities, or medical shopping...).



- ...

Furthermore, experience from abroad has shown that:

- Quality of the data collection process influences the quality of the data and therefore needs to be evaluated.
- Recording data without evaluation of these data can lead to misinterpretation of the reality.
- External evaluation needs to be neutral and independent.
- External validation is a key to the credibility of the process.

Literature showed that external validity checks are elements that enable quality improvement and can counteract manipulation.<sup>269</sup> Therefore, an external evaluation should be set up for Belgium but without making the structure too heavy and too expensive. The « passerelle audit RIZIV/INAMI – FOD VVVL – SPF SPSCAE » to improve of quality of care is an example of such an external evaluation.

### 6.3.6 Research on issues related to the waiting times

Research on the effect of WT on clinical outcomes and costs in the Belgian context should be supported.

Research on the effects of WT is needed to support the work of the WTMC and the Working Groups. It is not obvious from the literature that prolonged WT is always associated with deteriorating health and poor outcomes. The experts consulted suggested that universities could participate and correlate routine indicators such as survival rates and affordability. As there is a cost to collecting and analysing WT data, it is legitimate to know the cost and to ensure that the added value of the information is greater than the cost of producing it.

### 6.3.7 Funding of waiting time assessment

Adequate resources are needed:

- To organise the management, collection, and analysis of the WT data.
- To develop and evaluate strategies for dealing with inappropriate WT.

Organising the management, collection and analysis of WT data requires human and material resources. Adequate resources should therefore be allocated to ensure accurate information that can be used by decision-makers. Assessing WT is not enough, additional resources should be devoted to developing strategies to address inappropriate WT. There is a wide range of strategies available: they may affect the supply of care, the demand for care, or both, and they may target people, processes and/or technologies. Strategies are often complex, combining several elements, making it difficult to interpret their effectiveness. New strategies adapted to the Belgian context require the collaboration of different key stakeholders (Working Groups, WTMC, health authorities and representatives of health professions and sectors, patient representatives). Existing strategies at local level can be a source of information and added value for the development of strategies to tackle WT. The bottom-up approach could support the development of top-down strategies. Implementation may require some adaptations to the local context. Exchange of experiences on strategy development and evaluation are key elements for successful WT management.



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